DEBRA

England & Wales · Charity number 1084958

Details

Status	Registered
Legal form	Charitable company
Company number	04118259
Registered	2001-02-09
Register	View on the Charity Commission register

Contact

Address	D E B R A The Capitol Building Oldbury Bracknell RG12 8FZ
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Website	www.debra.org.uk

Activities

Objects: 1) TO PROMOTE RESEARCH FOR THE BENEFIT OF THE PUBLIC INTO THE CAUSE, NATURE, TREATMENT AND CURE OF EPIDERMOLYSIS BULLOSA AND OTHER RELATED MEDICAL CONDITIONS AND TO PUBLISH THE USEFUL RESULTS OF SUCH RESEARCH; AND2) TO RELIEVE PHYSICAL AND MENTAL ILLNESS AND DISTRESS AMONG PERSONS SUFFERING FROM THE SAID CONDITION BY THE PROVISION OF PRACTICAL ADVICE, GUIDANCE AND SUPPORT FOR THE PERSONS RESPONSIBLE FOR THEIR WELFARE AND IN SUCH OTHER WAYS AS THE COMMITTEE SHALL DETERMINE.

Activities: Promote research for the benefit of the public into the cause, nature, treatment and cure of Epidermolysis Bullosa and other related medical conditions.To relieve physical and mental illness and distress among persons suffering from EB by the provision of practical advice, guidance and support for the persons responsible for their welfare

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Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability, Other Charitable Purposes
- **Who:** Children/young People, People With Disabilities

Geography

- **Area of benefit:** NOT DEFINED. IN PRACTICE NATIONAL AND OVERSEAS.
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£18,176,154	£18,557,148	£3,206,258	362
2023-12-31	£18,228,440	£18,891,360	£3,587,252	368
2022-12-31	£16,420,725	£15,968,928	£4,250,172	362
2021-12-31	£13,317,401	£12,500,016	£3,798,375	360
2020-12-31	£11,412,897	£13,783,428	£2,980,990	376

Trustees

Name	Role	Appointed
Carly Fields		2019-05-18
Gareth Jones		2025-02-12
Jaspreet Singh Jhaj		2025-10-20
Katy Hinchcliffe		2025-02-12
Laura Briggs		2025-02-12
MICHAEL PARRY THOMAS		2020-07-01
Rev David Bendor-Samuel		2019-03-12
Sandrine Germaine Miriam Letellier		2025-09-22
Simon Colin Talbot		2021-05-27
Simone Bunting		2021-05-27
Zoe Louise Bailey		2025-11-19

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DEBRA

England & Wales - Charity number 1084958

Accounts

debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

Trustees' Annual Report & Accounts 2024

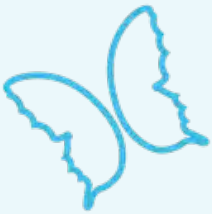
Our vision

A world where no one suffers with epidermolysis bullosa (EB).

Our mission

Provide life-long care, while seeking cures, for all those affected/impacted by living with EB.

Our values



Making a difference

Caring

Inclusive

Respectful

Passionate

Committed

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What is epidermolysis bullosa (EB)?

When the skin is as fragile as a butterfly's wing

Epidermolysis bullosa (EB) is a group of incredibly painful genetic skin conditions that cause the skin to blister and tear at the slightest touch. With skin as fragile as a butterfly's wing, EB is often referred to as 'butterfly skin.'

EB can affect the hands and feet only or in the most severe cases any part of the body, including blistering on the eyes and internal organs.

Genetic condition

People living with EB have a faulty or mutated gene which means the skin cannot bind together and any friction can cause it to tear. Every person has two copies of each gene – one passed on from each parent. EB may be inherited as either dominant (only one copy of the gene is faulty) or recessive (both copies of the gene are faulty). Parents have a 50% chance of passing on a dominant form of EB to their child, whereas the chance of passing on a recessive form of EB drops to 25%. Both parents may carry the gene without knowing and displaying any symptoms.

Types of EB

There are over 30 subtypes of EB, grouped into four main types: EB Simplex (EBS), accounting for around 70% of patients, Dystrophic EB (DEB) 25%, Junctional EB (JEB) 5%, and Kindler EB (KEB) which is rare.

Symptoms and complications

Symptoms vary and range in severity depending on the type of EB. Blisters continuously form and must be drained and dressed daily, a painful process that can take several hours. Internal blisters such as inside the mouth can create difficulty swallowing. There can be narrowing of the oesophagus and airways. The build-up of scar tissue can cause fingers and toes to fuse together, EB can increase the risk of developing skin cancer, and in severe cases it can be fatal.

Treatments

There is currently only one approved EB drug treatment, Filsuvez®, a topical gel that can be used to treat partial thickness wounds associated with DEB and JEB. Other treatments that people living with EB may receive are primarily focused on alleviating the symptoms as much as possible, preventing further damage to the skin, and reducing the risk of complications such as infection. The most common challenge amongst all types of EB is the pain and itching that occurs because of the blistering.

No cures

There are estimated to be at least 5,000 children and adults affected by EB in the UK and 500,000 worldwide. However, these numbers could be much higher as it often goes undiagnosed. Currently there are no cures for EB.

A welcome from our Chair of Trustees and CEO

Thank you for taking the time to read our 2024 annual report and accounts. This report provides an update on the progress we made last year and our financial performance. It also outlines our plans for 2025, across all our directorates.

2024 was another successful year for the charity where the needs of our members remained at the centre of our charitable activities.

During the year we supported more members than ever before; 673 individuals received support from our EB Community Support Team, which was an 8% increase on 2023. We also awarded more member support grants; a total of 552 grants were awarded which was a 30% increase on 2023. These support grants are vitally important and help our members purchase specialist products that can help alleviate their EB symptoms, they support the cost of attending vital EB healthcare appointments and can help fund respite breaks.

More members attended our events and got involved with the charity in 2024; during the year we put on a total of 52 DEBRA events, either in-person or online, which was a 73% increase on 2023. These events are so important in connecting members with each other, with our EB Community Support Team, and with research and healthcare professionals through our new webinar series.

Following our membership recruitment drive we also reached new members of the EB community; our membership comprising people living with EB grew by 7.9% to 2005 members living with EB over the last year, which is really pleasing as we want every one of the estimated 5,000 people living with EB in the UK to benefit from the EB support services we offer. We have commenced projects with NHS England and CPRD (GP) to discover the numbers of patients with EB in England and understand the costs in treating the EB community. These projects we will finalise in 2026.

We took further steps on our journey to securing effective EB drug treatments by awarding £718,000 to EB research projects. This included DEBRA direct funding and £217,000 or external co-funding, which is something we will continue to focus on securing in 2025 to help accelerate our research programme.

A new partnership was established between DEBRA and the NHS National Disease Registration Service that will involve us working together to analyse and study healthcare data from patients living with all types of EB. The objective of this partnership is to improve collective understanding and raise awareness of EB by providing clear facts and figures to GPs, patients, carers, government, and the public. We will also use this information to help garner support for the charity.

The momentum started in 2023 with our 'A Life Free of Pain' appeal, continued throughout 2024 through the 'BE the difference for EB' appeal. Despite our Vice President, Graeme Souness CBE, and the swim team being unable to take on their fundraising challenge, thanks to our many supporters we still managed to raise an impressive £4m. As well as raising this vital funding, the supporting media activity also helped maintain the public profile of both EB and DEBRA and it was particularly pleasing to see strong growth in awareness of 'butterfly skin'.

2024 was however another challenging year for our retail division. Store closures, delays in relocations, increased colleague costs, and external factors like adverse weather in Scotland all negatively impacted trading. There were positive signs though, including sales growth from our Value Stores, online sales, and bought in goods. We also saw volunteer numbers grow and, thanks to the key restructuring efforts and other cost saving initiatives that we undertook, we are now on a solid footing for growth in 2025.

On behalf of the EB community and everyone at DEBRA, we would like to pass on our sincere thanks to everyone who supported the charity last year, we really couldn't do what we do without you. We would also like to congratulate our Vice President, Graeme Souness, who was awarded the CBE in 2024 for his services to football and for the work he has done to support DEBRA and the EB community. We are very grateful to have you on our side, Graeme!

There is much still to do if we are to achieve our vision of a world where no one suffers with EB but together as one – our members; trustees; colleagues; volunteers; our Royal Patron, HRH Duchess of Edinburgh GCVO; our president, Simon Weston CBE; our vice presidents; our ambassadors and independent advisor – we can continue to BE the difference for EB.

Thank you.

Jim Irvine
Chair of Trustees

Tony Byrne
CEO

Our work

Committed to stopping the pain of EB

DEBRA was the world's first EB patient support organisation founded in the UK in 1978 by Phyllis Hilton whose daughter Debra was born with DEB.

When told by medical professionals that she should take her baby home as nothing could be done for her, she set out to find ways to treat Debra's skin herself using cotton dressings. At the age of 15, in 1978, Debra sadly passed away. Later that same year Phyllis met a parent seeking advice for their child with EB and realised that nothing had changed. She decided she had to act and thus organised the first ever meeting for parents of EB, in doing so DEBRA was formed. The charity was established as an association through which help, support, friendship, and a knowledge of EB can flow, and through which improved medical treatment and research into a cure can be worked for.

We have come a long way since then. We have achieved global recognition as a leading authority on EB and made significant progress in advancing diagnosis, treatment, and daily management of the symptoms of all forms of EB.

DEBRA is international in scope with a worldwide network of DEBRA groups, including DEBRA UK, the founding member, sharing information and best practice. We are committed to making sure that people with any form of EB, their families and carers get the vital, wide-ranging care and support they need so that the devastating symptoms can be reduced while we work towards finding effective drug treatments for all forms of EB.

Life-changing EB research

The EB research journey we've been on since 1978 has been remarkable – from gene discovery to cutting-edge trials of therapies that control symptoms and manage complications like cancer. During this time, we have invested over £22m and been responsible for establishing much of what is now known about EB.

We are one of the largest funders of EB research, and we have an ambitious, patient-centred research strategy that drives us to fund science of the highest quality across the world, including prioritising investment in drug repurposing, investing in the next generation of EB researchers to develop a treatment pipeline that will slow or stop the progression of all forms of EB.

Specialist EB healthcare and wellbeing

Throughout our history we have partnered with the NHS and other organisations to ensure that people living with EB in the UK get the specialist healthcare and wellbeing support they need.

In 1987 we funded the first specialist EB nurse, in 2008 we partnered with the NHS to set up the National Specialised Commissioning Group (NSCG) to oversee the provision of specialist EB healthcare, and in 2017 we co-funded the Rare Disease Centre, a first of its kind facility at St Thomas' Hospital in London that provides specialist healthcare support for adults and children with complex rare genetic diseases, including EB. Today the NHS continues to provide a world-class EB healthcare service through four specialist EB healthcare centres of excellence and the Scottish EB health service.

We continue to invest in initiatives that aim to improve patient outcomes for people living with all forms of EB today and in the future. Some examples include establishing specialist podiatry services and developing an accredited podiatry course, co-funding specialist dieticians, clinical and research fellows, partnering with other organisations to provide our members with access to 24/7 online mental health support, and researching product and service ideas that could help alleviate EB symptoms.

Life-long EB community support

The EB community is at the heart of everything we do. We are the only UK EB charity equally focused on today and tomorrow – providing care and support for the EB community today whilst investing in research to secure effective EB drug treatments for tomorrow.

We provide individualised support, information and guidance for people living with EB, their families, and carers – from providing financial support grants and benefits information to bereavement support, social opportunities, holiday home respite, and advocacy. We connect patients with the specialist services they need and provide a support network for the entire UK EB community.

International collaboration to enhance global EB patient care and best practice

We partner and work collaboratively with international organisations and the global DEBRA network to undertake world-class research, coordinate international research grants, support the next generation of EB researchers, and share ideas, expertise, and best practice. As the founding member we continue to invest in DEBRA International, the umbrella organisation which supports more than 50 DEBRA groups worldwide who work together to improve EB patient outcomes. Through DEBRA International we support the development of Clinical Practice Guidelines to increase professional knowledge and best practice for EB patients around the world.

Our year in numbers

£2.7m spent on EB community care and research

3,979 members, +2.6% vs. 2023

2,005 members living with EB, +7.9% vs. 2023

673 individuals supported by the EB Community Support Team, +8.7% vs. 2023

552 support grants awarded, +29.9% vs. 2023

£3.6m raised, thanks to our loyal supporters

£718k awarded to EB research projects*

38% unprompted awareness of butterfly skin, up from 12% in 2023.

**DEBRA direct funding + co-funding*

Achieved together thanks to the support of:

- 362 colleagues.
- 1,180 volunteers who gave 210,799 hours of their time for free, saving the charity over £2.4 million.
- 9 trustees with 5 living with or directly affected by EB.
- 80+ charity shops in England and Scotland.

Research into effective treatments

Our vision

Our vision is a world where no one suffers with epidermolysis bullosa (EB).

We are 100% focused on what matters most to the EB community, which is effective drug treatments that will lessen the day-to-day impact and pain of EB. To achieve this, we continue to fund science of the highest quality, and we play a pivotal role in making EB research a global effort; working with other organisations, but with DEBRA UK at the centre, leading the quest for innovations that will improve quality of life for people living with all forms of EB.

Our objectives

Our Research Strategy and its four overarching research objectives, as detailed below, continued to be the driver for change in 2024:

1. Invest in drug repurposing and develop drug discovery programmes to accelerate securing treatments for all forms of EB.
2. Increase investment in patient-centred research themes.
3. Continue to invest to better understand the causes and progression of EB and the role of the immune system.
4. Invest in the next generation of EB researchers.

Our progress in 2024

In 2024 we continued to make significant progress in line with our research strategy, which guides our efforts toward impactful research that will improve the lives of people living with EB. This included commencing the James Lind Alliance (JLA) priority setting study which aims to identify the top unanswered questions about all types of EB.

This is a global study involving the whole EB community, including some of the international EB community, with a focus on determining the 10 most important questions about EB that could be answered through research. This study will be completed in 2025.

Partnerships

Within the year we extended our partnerships with Fight for Sight, Action Medical Research for Children, and the Medical Research Council.

We increased our focus on securing co-funding from partners to accelerate our research plans and were successful in securing £217k of co-funding within the year.

We also entered a new partnership with the NHS England National Disease Registration Service to analyse EB healthcare data. Through this initiative we aim to increase EB understanding, and we will use the results to help raise awareness by providing clear facts and figures to GPs, patients, carers, government, and the public. The information will also be used to help garner the support we need from policy makers to help improve patient outcomes for the EB community.

Independent advisor

We continued to work with our independent research advisor, Professor Christopher Griffiths OBE, a world-renowned dermatologist, who contributed valuable insights to our research strategy and spoke about the opportunities that drug repurposing creates for the EB community at events including the lunch with our Royal Patron, HRH Duchess of Edinburgh GCVO, at The Beaumont, London in November.

Research grants

Our international research grants call led to the approval of three new PhD studentships supporting our development of future EB researchers.

Scientific Grant Advisory Panel

The panel was expanded to nine members, all of whom are senior experts in their field who contribute their time to ensure we prioritise our research funding for projects that best address the needs of the EB community.

EB lived experience group

The group which comprises 15 DEBRA members, continued to provide essential feedback from the patient perspective during the research review process.

Our plans for 2025

Our research priorities will continue to be shaped by the needs and experiences of the EB community, ensuring that any research investments reflect the real-world impacts on EB patients and families. The emphasis remains on a balance between short-term improvements for people living with all forms of EB and long-term advancements toward effective treatments and potential cures.

Partnerships

We will continue to increase awareness of our research funding schemes and actively seek new partnerships with both EB and non-EB organisations to maximise the impact of our limited resources.

Our partnership with Action Medical Research for Children didn't result in any project funding in 2024 but the partnership has been renewed for 2025, and we will assess all applications to see if they meet our joint research requirements. We will also seek to renew our other partnerships and establish new collaborations with research institutions, pharmaceutical companies, and governmental bodies.

Drug repurposing

We will continue to focus on drug repurposing, leveraging current projects in all EB types to advance towards clinical trials. The development of a new UK drug repurposing platform will be a priority, with the aim of testing multiple potential drug treatments for EB.

Research grants

Our Scientific Grant Advisory Panel, Charitable Purposes Committee, and the EB lived experience group will continue to play a pivotal role in determining which research projects we fund. Their combined expertise, both scientific and experiential, will ensure a robust, patient centred selection process. Special attention will be given to supporting early-career researchers and fostering a new generation of EB-focused scientists.

JLA priority setting study

We will conclude the JLA priority setting study in 2025 which aims to identify the top 10 unanswered questions about all types of EB. The results will help shape our future research strategy and global EB research ensuring that the needs of the EB community are at the centre of our plans. We will also use the results to support our national advocacy and campaigning activities.

Support for clinical trials and treatment approval

We will continue to work closely with the pharmaceutical industry and regulatory bodies such as NICE to push for the approval of effective EB treatments in the UK. Strengthening these relationships and ensuring a clear pathway for drug approval will be key to delivering new therapies for the EB community.

Educational and outreach initiatives

Sharing research updates

We will improve communication within the global EB research community by developing more content including podcasts, blogs, and films to share research updates, insights, and success stories. These efforts will target both the EB community and the wider research ecosystem to raise awareness and drive engagement.

Global conferences and events

We will raise our profile within the global dermatology community and foster vital connections with leading dermatologists, researchers, pharmaceutical companies, healthcare professionals, and other relevant organisations by attending global conferences. This increased visibility will enable us to promote and advance EB research and attract the top-tier research talent and resources that we need to support our cause.

One of the key conferences that we will attend is the European Society of Dermatological Research (ESDR) where we will participate as a sponsored symposium partner.

The increased focus on attending global conferences and events is part of our broader strategy to position EB at the forefront of dermatological research and innovation.

Healthcare data

Our new partnership with the NHS England National Disease Registration Service will continue to develop with a focus on understanding the healthcare landscape for people living with EB. We will work to identify gaps in care, analyse healthcare trends, and deliver actionable insights that can inform future healthcare policies and research agendas for EB. The insights gained from this initiative will also enhance patient-centred research, as the data collected will help address the most pressing concerns of the EB community.

Global EB atlas

Our ambition is to create a global EB atlas which aims to enhance our understanding of EB and its multifaceted impacts on individuals and society. By providing comprehensive, open-access information on the epidemiology of EB across the globe, this initiative will facilitate better research, healthcare strategies, and patient care. This reflects our commitment to driving innovation and collaboration in EB research.

Next generation of researchers

We will continue to invest in the next generation of researchers through our PhD studentships and support for early-career scientists. By fostering these talents, we aim to build a sustainable research community dedicated to finding solutions for EB symptoms. The goal is to empower researchers to set up their own labs, develop innovative research proposals, and pursue novel approaches to tackling EB. By adhering to these strategic priorities, we are well-positioned to accelerate the pace of EB research and deliver meaningful, life-changing solutions for the EB community.

Specialist healthcare and wellbeing support

Working in partnership with the NHS and other organisations to ensure that people with EB in the UK get the healthcare and wellbeing support they need.

Throughout our history we have invested and continue to invest in initiatives with the objective of improving outcomes for people living with all forms of EB. From the establishment of specialist podiatry services and the development of an accredited podiatry course to clinical and research fellows, we continue to explore possibilities and partnerships that will benefit our members and the wider EB community today and in the future.

Our ambition

We are dedicated to ensuring that everyone with any form of EB has access to the best care and specialist EB healthcare expertise and wellbeing support from diagnosis onwards.

Our objectives

1. To connect people living with all forms of EB with the expert, specialist healthcare services they need.
2. To enable and support the development of specialist EB healthcare expertise, services, and multi-disciplinary working.
3. To provide specialist EB healthcare information to the EB community.

Our progress in 2024

Throughout 2024 our EB Community Support Team continued to work with the EB healthcare centres of excellence, as part of the multi-disciplinary team, ensuring people living with EB, their families and carers were able to access the specialist health and social care expertise they needed. The DEBRA team participated in the quarterly EB clinical network meetings which bring together the clinical teams from the four EB centres to share service insights and best practice. Members of the healthcare teams also attended DEBRA events including Members' Weekend, where they had to opportunity to deliver workshops on key EB topics and directly engage with our members.

Our plans for 2025

We will continue to work with the EB healthcare centres, seek further collaboration with outreach and other local clinics and clinicians, and fund training where it is needed to ensure a consistent high level of specialist healthcare is provided to the UK EB community.

Because our members have told us that the current mental health support available to them through the NHS is inadequate*, we will explore initiatives to provide tailored mental health support for the EB community. We will also explore opportunities for enhanced podiatry support locally.

**EB Insights Study 2023*

We are dedicated to ensuring that everyone with EB has access to the best care and specialist expertise from diagnosis onwards.

EB community support

Life-long support, advocacy, and engagement

3,979
DEBRA UK members in 2024

605
members stayed in our holiday homes in 2024

552
support grants awarded in 2024

2.6%
increase in membership vs. 2023

673
members supported by the EB Community Support Team in 2024

52
events (in-person or virtual) in 2024

Our ambition

To provide a comprehensive programme of targeted care and support for the EB community which directly addresses their key needs and maximises every opportunity to make a difference and improve their quality of life.

Our objectives

1. To provide access to support and the specialist health and social care that the EB community needs.
2. To grow our membership, increasing numbers, diversity, and engagement with the wider EB community.
3. To empower our members, ensuring their voice is heard and acted upon and that they have choice and independence throughout their journey of life living with EB.

Our progress in 2024

Membership

Our total membership at the end of 2024 was 3,979, which has grown 2.6% year-on-year. 2,005 (50.4%) of our members are living with EB, which has grown 7.9% year-on-year. These results are very encouraging because it means we have reached new members of the EB community who previously weren't benefiting from the services we offer.

Out of our total members living with EB, 1,298 (65%) have EB Simplex (EBS), which is a 7.8% year-on-year increase reflecting the fact that in 2024 we made a concerted effort to reach members of the EB community with EBS specifically, who weren't already DEBRA members, through activities including publicising the membership drive video and EBS impact report.

Historically we know that some people with EBS have decided against accessing our services as they felt these services should be reserved for people with more severe forms of EB. However, we exist to support anyone in the UK living with any form of EB and so it is very pleasing to see our proportion of EBS members growing and we will continue to actively recruit people with all types of EB, including EBS, throughout 2025.

EB Community Support

With a full-strength DEBRA EB Community Support Team, we were able to support more members in 2024 than ever before. The team supported a total of 673 individuals during the year, which was an increase of 8.7% year-on-year. This included 152 members who were new to the team.

We were also able to offer financial support to more members; we awarded 552 support grants worth £144,654; this was a 29.9% year-on-year increase in the number and a 37.2% increase in the value of support grants awarded.

Member engagement

More members than ever got involved with the charity in 2024; our member involvement network increased to 200 members, which was an 18% year-on-year increase, and over 250 members got involved in projects including enhancing EB information and resources for the new DEBRA website and the JLA research priority setting study. We created many more opportunities to get involved with DEBRA and increased external involvement opportunities which was well received by our members.

Events

The 2024 DEBRA Members' Weekend was a success with 299 members attending.

We also increased the number of in-person and virtual meet-up events; through involvement network/engagement sessions, Members Connect events, and health and research webinars, there were 52 opportunities for members to get involved with DEBRA in 2024, which was a 73% increase year-on-year.

Holiday homes

We opened one new holiday home (Newquay) and one replacement holiday home (Weymouth) within the year. Across our portfolio of six holiday homes, a total of 605 of our members and their guests benefited from a highly discounted holiday break and vital respite in a DEBRA holiday home in 2024; this was up 11.4% on 2023.

Our plans for 2025

In 2025 we will continue to provide excellent care and support to as many members of the UK EB community as possible, maximising every opportunity to make a difference and improve their quality of life.

We will also set aside a fund for new or enhanced care, support, and data collection initiatives. This flexible fund will allow our team to respond quickly to emerging needs or funding requests, ensuring that care and support initiatives can be adapted as priorities change. If necessary, part of this fund may be allocated toward additional staffing, with such decisions pending membership growth and demand.

Membership

We must continue to extend our reach and connect with as many members of the EB community as possible including people who have EB but may not be aware of DEBRA and of the services we offer, so that they can also benefit from what we do. To achieve this, we will continue to raise awareness of EB and of DEBRA and how we support the EB community through the media and a programme of paid digital marketing.

Our objective in 2025 is to increase overall DEBRA membership by 10% with a particular focus on recruiting new members with EBS.

EB Community Support

We will continue to develop a proactive approach to EB community support through the enhanced information and resources that we will signpost members to on the new DEBRA website, through welfare calls, and the EB enquiry support line. These initiatives, alongside the team refining its hybrid model, will ensure we can deliver an efficient and effective support service to our members whilst at the same time having the capacity to respond to changing members' needs and continuing to drive an increase in our membership.

EB specialist healthcare and wellbeing support

We will continue to partner with the UK's four EB healthcare centres and the Scottish EB service and seek further collaboration with outreach and other local clinics and clinicians, funding training where it is needed to ensure a consistently high level of specialist healthcare is provided to the UK EB community.

Because our members have told us that the current mental support available to them through the NHS is inadequate*, we will continue to explore initiatives to provide tailored mental health support for the EB community. We will also explore opportunities for enhanced podiatry support locally.

Information and resources for every stage of life with EB

We will build on the work completed through the Pathways project and continue to enhance the EB information and resources that are available to our members, which includes issuing a new 'Complete guide to DEBRA membership' to all our members. This will summarise all the support services that we offer our members, signpost to EB information and resources on the DEBRA website and provide an overview of all the benefits of DEBRA membership. Additionally, the guide will include a checklist of support that members of the EB community are entitled to receive through the NHS and other organisations, plus resources to raise awareness of EB with healthcare professionals, schools, etc.

Tailored member resources will also be developed for areas where there are currently gaps, including resources for bereaved families and diet and nutrition.

**EB Insights Study 2023*

Awareness and collaboration

We will continue to focus on raising awareness of EB and the support that is available through DEBRA, and other organisations, with GPs, dermatologists, and other healthcare professionals to support diagnosis, specialist healthcare referrals, and our membership drive.

To enhance our EB information and resources we will seek partnerships with other organisations including the Department of Work and Pensions and investigate potential collaboration opportunities with UK children's hospices to enhance local support.

Support grants

We will continue to promote support grants to our members to maximise take-up and ensure that we support as many members as possible. Our support grant funding will be increased to £168k in 2025 and we will continue to seek and secure additional grant funding or co-funding from other organisations.

Member involvement and engagement

To ensure that the needs of the EB community remain at the centre of everything we do, we will broaden our member involvement and engagement opportunities, both in frequency and in the variety of ways we connect with our members. This will include increasing the number of member network groups, publishing insights from key studies, and completing an output and impact study of our key support activities. These actions will also help strengthen our ability to lobby and collaborate with pharmaceutical companies and other key stakeholders to best support the EB community and drive the development of the next DEBRA five-year strategy.

Events

The number of in-person and virtual events will increase further in 2025 to 60 and will include more regional Members Connect events, virtual Member Pitstops, and a full annual programme of Research and Health webinars.

Holiday homes

A replacement holiday home for the current Poole holiday home, in a new location, will be secured in spring 2025.

My EB story – the hidden side of EB

“My EB might not always be visible, but the physical and emotional toll is all too real. I’m not alone in this; my dad, brother and uncle all have EBS too. Symptoms change throughout the year, often worsening when it gets warmer, which makes it hard for others to understand the constant, unpredictable challenges of living with EB.

Living with EB forces you to make sacrifices every day that others don’t even think about. Simple activities like walking, require careful planning because it’s so painful. Say I’d like to go to London for the day with my family, I can’t always walk between tube stops, especially on a warm day. A day on my feet can lead to a prolonged period in a wheelchair and certain shoes aggravate my blisters more. It affects not just me, but my family and friends, who must adjust their plans for me.

I’ve also had to think about this sort of thing when planning holidays like my honeymoon. We’ve had to think about when we can travel, as I can’t go in the summer months as it’s not possible to walk far in the heat.

The constant pain leads to negative thoughts. As a teacher, I can’t afford to develop blisters that make standing or walking nearly impossible, which adds another layer of stress. Excruciating blisters can form and if walked on, they can spread, balloon up and cause huge crevices on my feet which take a long time to heal. You can also end up walking in a funny way to counterbalance this, and I’ve torn tendons from this.

Through DEBRA, I’ve connected with others who have EB which makes me feel less isolated, and I’ve been officially diagnosed with EB, which has been empowering and life changing.

Before DEBRA, I didn’t have the words to explain my condition. Growing up, I constantly thought, “what’s wrong with me,” I felt inadequate, and I thought it was just me and that I wasn’t very good at walking. Now I can say “I have EB” and I have accepted that I cannot do certain things. It’s given me the ability to explain my condition and be kinder to myself.

I’m thankful that my EB is only isolated to my feet, but it’s still frustrating. Blisters on your feet don’t necessarily sound that bad, but now I have my diagnosis, I feel I can be kinder to myself and say, “I can’t do this because of my condition” and people are much more accepting of it.”

Sarah Kay – DEBRA member living with EB Simplex

Our partnerships

160+
research projects worth £22m funded by DEBRA

7
7 current EB PhD studentships

6
health and wellbeing partnerships

27
live research projects

5
research partnerships

20+
corporate partners

Our ambition

We cannot stop the pain of EB on our own which is why we work in partnership with academia, biotechnology and pharmaceutical industries, corporate partners, and other organisations, in the UK and internationally who have an interest in EB or other skin conditions.

The objective of these partnerships is to reach new audiences, raise awareness of EB, share expertise, work together to provide the specialist health and wellbeing services our members need, and drive a programme of world-class research that brings hope and improved outcomes for the global EB community.

Building partnerships to improve patient outcomes

In 2024 we renewed our existing research partnerships and entered a new partnership with NHS England:

Our current research partnerships:

- **Fight for Sight**, partnering to fund EB eye research.
- **Medical Research Council**, partnering to support the next generation of EB researchers.
- **Action Medical Research for Children**, partnering to co-fund an EBS specific research project.
- **Cancer Research UK Scotland Institute**, partnering to develop pre-clinical cancer models that will advance understanding of skin cancer progression in RDEB and enable drugs to be tested prior to patient clinical trials.
- **NHS England National Disease Registration Service**, partnering to analyse EB healthcare data.
- **UK Child Health Research Collaboration (UKCHRC)**, partnering to advance paediatric science and improve the health and wellbeing of children with EB.

Our health and wellbeing partnerships

- **Bullen Healthcare**, partnering to provide DEBRA members with a convenient mail order service for dressings and medication.
- **The Landmark London**, partnering to provide one free hotel stay every month for a DEBRA member and their immediate family, and/or carers.
- **Togetherall**, partnering to provide DEBRA members with access to 24/7 online mental health support.
- **Whizz Kidz,** partnering to co-fund wheelchairs to improve independence for people living with EB.
- **Willow Foundation**, partnering to provide free hampers for EB families.
- **Wood Leisure,** partnering to give EB carers a 10% promotional discount in Wood Leisure's award-winning Scottish holiday parks.

Corporate partners

Our corporate partners including our principal partner, Peninsula Group, play a vital role in raising awareness of EB and DEBRA and support our fundraising campaigns. They also provide in-kind services and help fund EB research, healthcare, and community support activities, and our holiday homes.

We couldn't do what we do without their generous support and commitment to our mission.

Thank you to all our corporate partners who supported us in 2024, including:

The Beaumont Hotel, Mayfair

Centrica

Clifford Chance

DEOS Group

Enterprise

Football Medicine & Performance Association

Gamma

Jaysam

Jamma Fans Association

KBA Financial

Martin Rowley

Molnlycke

Morelli Group

Page Automotive

Pantheon

Paul Glover

Peggs Accident Centre

Peninsula Group

Plenham Ltd (The Bodyshop Magazine)

Sloggett Group

TD Synnex

The Landmark

The Langham

Trek Bicycle Bracknell

Weatherbys

Wyndon Motors

Raising our profile

Engaging communities

+26%
year on year increase in awareness (butterfly skin)**

48%
increase in organic website traffic reflecting our focus on SEO

9.7%
growth in social media following

+33%
increase in email deliveries

and

+28%
increase in email opens

More national media exposure for EB and DEBRA via TV, radio, and press

***YouGov awareness tracking study Sept-24*

Our ambition

Our marketing and communications activity has many objectives and a diverse group of audiences that it needs to reach. We must continue to raise awareness of EB and the impact it has on people's lives, and of DEBRA and the different ways in which we make a difference to the EB community. By making people more aware of the condition we aim to both garner the support we need to help improve quality of life for more people affected by EB and reach more members of the EB community so that they too can benefit from our support services.

Our objectives

1. To raise awareness and understanding of EB and the needs of the EB community particularly with healthcare professionals including GPs.
2. To raise awareness of DEBRA, and how we support our members to drive member recruitment and support for the charity.
3. To drive awareness of our key fundraising initiatives and support our revenue generation activities – fundraising, retail stores, and e-commerce platforms.
4. To connect and build engaged communities for all those living or working with EB, ensuring that the EB community has the support, advocacy and understanding it needs.
5. To lobby government to influence future services and healthcare and wellbeing provision for EB, including garnering support for our drug repurposing programme.

Our progress in 2024

Member resources / new website

Throughout 2024 we focused on reviewing and enhancing all our EB support information and resources through the Pathways project. This involved getting extensive member feedback to ensure the information and resources created met the needs of the EB community. The project culminated in an enhanced package of support information for every form of EB and every life stage made available through the new DEBRA website which launched in October.

Awareness

Despite the DEBRA Challenge 24 swim and cycle fundraising challenge not taking place due to injuries, surgery, and adverse weather conditions, we still managed to generate good national media coverage via the BBC, national and regional radio and press from the campaigns timed to coincide with Rare Disease Week (February), EB Awareness Week (October) and promotion of the challenge prior to it being postponed. This media coverage combined with an increased focus on 'butterfly skin' in our refreshed brand proposition helped deliver a significant increase in unprompted awareness of the term butterfly skin.

Government lobbying

2024 was a time of political change in the UK and due to the July election, we were unable to hold a House of Commons reception as planned. However, post-election we reconfirmed our top five local government asks and shared them with our members, providing them with the content and encouraging them to write to their local politician requesting a meeting to discuss EB which led to several member/MP meetings. We also held a reception at the Scottish parliament in September, which included a speech from Jenni Minto, the Minister for Public Health and Women's Health, and we exhibited and made good connections at the Liberal Democrats autumn conference in Brighton.

Revenue generation

Marketing has a clear role to play in supporting DEBRA's revenue generation and throughout 2024 the marketing team drove awareness of key fundraising initiatives including regular giving, the DEBRA lottery, legacies, and the events programmes. The team also delivered stand-alone initiatives which generated revenue, including the media campaign which underpinned the 2024 challenge and raised over £175,000, the seasonal and mini appeals, which combined raised close to £80,000, and digital fundraising through platforms like Facebook which raised a further £11,500.

The retail marketing team delivered branding solutions and awareness raising activity for all relocated and new stores.

Our plans for 2025

Information and resources for every stage of life with EB

In 2024 our focus was on enhancing all our member support information. In 2025 we will focus on ensuring that these resources are accessed by as many members of the EB community as possible and to achieve this we will regularly promote the new resources and encourage member self-serve as much as possible via the DEBRA website.

We will also issue to all members the brand-new membership guide.

Awareness

We will seek to capitalise on the relationship that we have built with the BBC since 2023 to maximise exposure for the brand and awareness of EB in the build-up and during the rescheduled DEBRA fundraising challenge in May. We will also support the challenge with media interviews, a programme of digital audio advertising, and paid social media.

Later in the year we will use media interviews timed to coincide with EB awareness week to raise awareness of EB and DEBRA and what we do so that we can attract new members, particularly people living with EBS. We will also use the media interviews to help raise awareness of EB and DEBRA with GPs, increasing EB understanding, diagnoses, and referrals to the EB healthcare centres.

Public affairs

We will accelerate our public affairs activities in 2025 leveraging events booked at the Welsh Senedd, the House of Commons, and Scottish Parliament to share new EB patient insight and to clarify the areas in which we need political support most to improve outcomes for the EB community.

We will also look to establish new relationships with key politicians in Northern Ireland and we will continue to ask our members to be part of our campaigning, encouraging them to engage with their local politician and leveraging our stores (where applicable) as opportunities to connect with the EB community in their local area.

Revenue generation

We will continue to support the fundraising and retail functions to maximise revenue generation opportunities in 2025. This will include delivering the seasonal appeals (Spring and Christmas), media campaigns to support the 2025 fundraising challenge, legacy, and lottery direct mail campaigns, plus marketing support for events and challenges, and regular supporter update communications.

In 2025, we will provide tailored marketing support to our stores that need it most, whether that is activity focused on driving footfall/sales, recruiting volunteers, or driving donations.

The focus of our in-store campaigns in the first half of 2025 will be on assets to support in-store sales promotion. Assets to support other retail initiatives including donations and volunteer recruitment, Gift Aid, and new goods, will be available on a store-by-store basis for draw off via our Toolbox platform.

How we raise money

Our ambition

We are committed to raising the funds needed to deliver an enhanced programme of EB community care and support that helps improve quality of life today, and the clinical research that will help us secure effective drug treatments for every form of EB.

Our objectives

1. To grow our core net fundraising income to £3.6m in 2025.
2. To maintain our focus on trusts and grants, corporate and major donors and increasing our fundraising activities in Scotland.
3. To build on the success of 2023 and 2024 and deliver a step up in donations and awareness through the delivery of the 'BE the difference for EB' appeal.

Our progress in 2024

Following the success of the 'A Life Free of Pain' appeal that raised £5m by December 2023, we launched our new campaign, 'BE the difference for EB', in January 2024 which focused on improving quality of life today and creating hope for tomorrow through investment in drug repurposing clinical trials. Thanks to the fantastic support received we achieved just under £4m of the £5m fundraising target by the end of the year and are confident of achieving the full target in 2025.

2024 saw a significant increase in the number of people choosing to support DEBRA, much of this was driven by the PR and media coverage generated from the 2023 English Channel swim challenge. We saw more people take part in individual challenges and fundraising than ever before and we are truly grateful to all our supporters who played their part to be the difference for the EB community.

Relationship development and events

With the support of our Royal Patron, HRH the Duchess of Edinburgh GCVO, our President, Simon Weston CBE, and our Vice Presidents, Frank Warren, Graeme Souness CBE, Lenore England, and Stuart Procter, we have continued to grow the philanthropic interest in supporting the charity. This has led to an increase in the number of personal grants of significant size to DEBRA. We also welcomed a new group of supporters, and new DEBRA ambassadors who help us to grow awareness of the charity, enhance our fundraising capabilities, and enable us to put on some incredible events throughout the year.

Events successfully held in 2024 included royal lunches, sporting lunches, our annual clay pigeon shoot at EJ Churchill, football dinners in London and Glasgow, the Scottish Grand National at Ayr, DEBRA fest, our Great Chefs Dinner, and Fight Night plus our annual calendar of golf days.

Corporate support

We were delighted to have been chosen by Peninsula Group as one of their three designated charity partners for the next three years. Peninsula have committed to raise a minimum of £1m for DEBRA by the end of 2026 and in 2024 we partnered with them on some exciting fundraising initiatives involving their colleagues. They also committed to sponsor the DEBRA 2025 fundraising challenge featuring our Vice President, Graeme Souness CBE.

We were also very grateful to be able to count on the support of several other corporate partners and look forward to developing these partnerships further in 2025.

Our plans for 2025

Trusts and legacies

We have been well supported by charitable trusts, many of whom have made grants to support specific projects, whilst others have made unrestricted grants which are invaluable in supporting our charitable activities. Backed by DEBRA's outcome-focused research strategy, we successfully entered the market for larger restricted grants during 2024 and have obtained six-figure grants for the first time. In 2025 we will continue to apply for grants of this size and above, especially in support of our drug repurposing programme.

We have also been fortunate to have benefitted from several legacies with individual values of over £100,000 over the last three years. As a result, our annual income from gifts in wills increased to over £1.2m in 2024. Much of this has been down to the logjam of those caught up in probate post COVID but also due to the increased value of property. It is anticipated that the wider charitable marketplace will continue to benefit hugely from legacies over the next 5-10 years and thus we will continue to market our free wills scheme to our members, our supporters, our colleagues, and volunteers.

Scotland

Our investment in strengthening the fundraising team in Scotland has helped accelerate our fundraising efforts, bringing in new funding from new events including those at Ayr Racecourse, Loch Lomond Golf Day, DEBRA Fest, and Adana's Golf Day. In 2025 we will add further new events including a Scottish Fight Night, and Celebrity Darts Night.

The team will be boosted with more administrative support following the appointment of a part time administrator. Alongside our fundraising events, we are also increasing our presence in Holyrood to garner support from the Scottish government, and we plan to further raise awareness (and funds) by including our Scottish Ambassadors (Scott Brown and Emma Dodds) in our DEBRA Kilt Walk team.

We will also increase our efforts to identify specific corporates, trusts, and individual supporters who can help make a difference to the EB community in Scotland. Our EB Community Support Team and research commitments in Scotland amount to over £250,000 per year and our aim is to be able to cover this spend with funding raised from within Scotland within the next three years.

Donor development

Following the appointment of a dedicated Individual Giving Manager in 2024 we will execute a data focused individual giving strategy that aims to increase the number of people who regularly support the charity and the amount that they give. The objective will be to significantly grow our existing revenue from £500,000 per annum through individual giving.

Challenge events

As well as promoting our new Kilimanjaro Challenge, we will also drive awareness of the other fundraising challenge opportunities in 2025, including the London Marathon, London Landmarks, and Swim Serpentine, plus the other events in the calendar to maximise the fundraising potential from each.

Graeme Souness CBE and the swim team will be taking on their most difficult challenge yet to raise funds for DEBRA as they plan to swim to France and back in May 2025. We will leverage our relationship with the BBC and utilise other media to maximise the fundraising and awareness raising potential of this challenge.

Major events and golf

Our centrally run fundraising events are now complemented by an ever-growing number of incredibly successful events being organised by people outside of DEBRA. In 2025 we will see repeats of the Spring Ball at St George's and the Morelli led Car Rally in September.

Our DEBRA major events programme will include Great Chefs Dinner at the Langham in September, which celebrates its 10th anniversary, and Fight Night in November, which will celebrate its 20th anniversary.

The DEBRA Golf Programme will run 11 golf days at some of the most prestigious golf courses in the country including St George's Hill, Swinley Forest, Woburn, Royal Birkdale and the JCB Club.

Major donors

To fast-track funding to support our drug repurposing programme we will work collaboratively with partners and major donors to raise £2.5m of incremental funding.

DEBRA retail

Our pre-loved shops and online retail platforms play a vital role in raising the funding we need to be able to support the EB community. They generate much-needed awareness of EB and create opportunities for members of the EB community to connect with each other locally.

Our ambition

To be a destination of choice both on the high street and online for good value, high quality pre-loved clothing, household, shoes, bags, toys, electricals, and furniture.

To have a retail division that is sustainable and resilient enough to withstand the challenging economic conditions.

To count on a highly motivated, knowledgeable, and engaged team of colleagues and volunteers to drive revenue growth.

Our objectives

1. To build a lean, efficient, and sustainable retail function as a basis for expansion.
2. To improve and expand our e-commerce and online sales, reaching a wider audience with a relevant sale offering.
3. To develop a dedicated team of motivated, knowledgeable, and engaged colleagues and volunteers, increasing overall volunteer numbers and ensuring excellence in estate and safety management and compliance.
4. To raise awareness of our cause and build loyalty to our brand within our communities.

Our progress in 2024

2024 was a challenging year marked by store closures, delays in relocations, and external factors like adverse weather in Scotland impacting trading.

We did experience growth in certain areas including our Value Stores, an increase in sales from bought-in-goods, and an increase in sales volume and Gift Aid contribution, but our overall colleague costs increased significantly, whilst overall contribution from retail declined year on year.

Additionally, operational issues, including supply chain disruptions and colleague-related challenges, further contributed to it being a challenging year. Despite these obstacles, key restructuring efforts combined with other cost saving initiatives helped reduce the overall cost base. This and the growth in volunteer numbers signalled positive steps forward and a solid foundation on which to build in 2025 and beyond.

Online

Most of our shops are now selling online to maximise revenue opportunities from higher value donated items. We supported, trained and coached store teams, working with both colleagues and volunteers to ensure we are providing them with easy-to-use systems, including the latest AI product listing tools.

By maximising promotional opportunities online, we have been able to sell more of what we list, increasing our online revenue whilst helping store colleagues to use their time more efficiently.

Our plans for 2025

Cost control

To ensure financial stability across our retail estate we will implement rigorous cost control measures including exiting any store locations that are no longer profitable.

People development

To achieve financial stability and improved sales performance we will upskill colleagues, including improving commercial acumen, through the DEBRA Academy. We will also clarify the expectations of colleagues' individual roles, their responsibilities, and accountabilities, and we will introduce more robust performance management practices to enhance accountability and results.

Revenue generation

We will refocus on all potential revenue streams at store level to ensure consistent contribution and performance, and we will deploy a new portfolio strategy for our stores to strengthen oversight and drive operational excellence.

Online

We will continue to grow online income from stores in 2025 and we will do this by helping our stores to build on their successes; increasing our use of AI supported listing tools to further reduce listing time. As online creates the opportunity for new volunteering roles in retail, from photography to packing, we will aim to recruit and train more volunteers to support us.

Bought-in goods will continue to play an increasing role in our online offering during 2025 as we strive to expand our offer and reach new customers.

Our dedicated volunteers

Our volunteers play an essential role in our retail stores and support our fundraising function and other teams across the charity.

They are an essential part of the team, and we are deeply grateful for their time, their enthusiasm and commitment, and the skills and expertise they bring into the charity. We couldn't do what we do without them.

Our volunteers tell us that volunteering with DEBRA provides them the opportunity to socialise, to learn new skills, and for some, to gain valuable work experience that supports them with their move into paid employment or with college and university applications. We provide a programme of support and development for volunteers across the whole charity that ensures DEBRA is a great place to volunteer and that they are valued, respected, and recognised for the invaluable work they do.

We celebrate National Volunteer Week in June every year, to recognise and thank our inspirational volunteers for the time they give.

We simply couldn't run our retail division without our loyal volunteers. Not only do they enable our stores to function and generate the funds we need to be able to support the EB community, but they also help raise vital awareness of EB. We can count on the support of over 1,100 volunteers giving their time for free, year after year, and we can't thank them enough for their hard work and commitment to DEBRA and the EB community.

Michelle Scott – Head of Retail and Trading

Our people

BEing the difference, every day

Every colleague within Team DEBRA has a part to play in ensuring we make a difference for people living with or directly affected by EB. Whether that's delivering our vital research and health and wellbeing programmes, supporting families and individuals with EB, managing or volunteering in one of our shops, working to raise essential funds, promoting and communicating the work we do, processing income, supporting our cause as an ambassador, or guiding our strategic direction as a trustee or committee member.

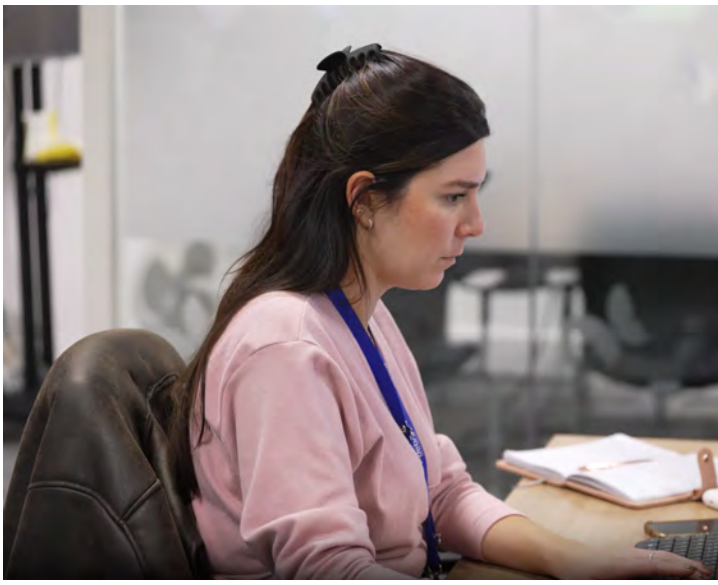
Our ambition

We cannot achieve our vision of a world where no one suffers with EB without our people which is why we aim to create a culture where our colleagues and volunteers can thrive, are valued, where equality and diversity are embedded in our values and actions, and where everyone can develop and enjoy their work, whilst making a positive difference for the EB community.

Our objectives

Our People agenda focuses on three priority areas:

1. To have a resourcing strategy that helps attract, develop, and retain the talent that we need to achieve our objectives, under-pinned by our Equality, Diversity & Inclusion (EDI) practices ensuring our employee demographic represents the EB community we serve.
2. To provide learning and development opportunities that will help ensure our colleagues and volunteers have the skills they need to fulfil their current and future roles.
3. To engage our people by creating a positive working environment, recognising individual and team performance, providing salary and benefits that are competitive within the sector and embedding our values to create a culture where our colleagues can flourish.



Our progress in 2024

Learning & Development

From our colleagues in our offices in Bracknell and Blantyre, to our colleagues and volunteers across the country who work so hard to run our retail shops, our people are our most important assets. This is why in 2024 we invested in people through the introduction of the DEBRA Academy, a tailored development programme aimed at upskilling colleagues in Leadership and Management skills. Over 200 colleagues have progressed through the first phase and the colleague feedback received so far has being overwhelmingly positive.

Colleague benefits

A further commitment to investing in people was the launch of the DEBRA benefits platform and the harmonisation of our colleague benefits package which we undertook to ensure we are competitive with the rest of the sector. As well as supporting our colleagues today and creating a stronger reward culture within the charity, we hope that this will also support us in the long-term with recruiting external talent.

Volunteers

Throughout the year we have been working alongside the National Council for Voluntary Organisations, who have been assessing our volunteering framework to ensure that we are meeting the required high standards. Following this assessment we were delighted to be awarded their Investing in Volunteers accolade, the UK quality standard for good practice in volunteer management.

Safeguarding

Our safeguarding processes and practices are hugely important which is why in January we successfully applied to join the Charity Retail Safeguarding scheme. As part of this scheme, we have assessed our current processes and practices against their robust criteria to ensure said processes are effective in protecting vulnerable individuals from harm. This is part of our ongoing commitment to safeguarding those in need.

Our plans for 2025

Learning and development

We will continue with our commitment to developing our colleagues in 2025 with the roll out of phase two of the DEBRA Academy programme. This will build upon the foundations laid with the Leadership and Management training modules delivered in 2024 and equip our colleagues with the necessary skills and knowledge to lead their teams to perform at their best and deliver the key outputs from the five-year strategy.

Our Environmental, Social, and Governance (ESG) journey

Our ambition

As a charity with over 80 retail stores and over 1,400 colleagues and volunteers, we know we have an impact on the environment and on the communities we work with, which can be positive or negative. We want to be a force for change, reducing the negative impact we have on the environment and on society, ensuring the highest ethical standards, and considering environmental sustainability and social responsibility in all we do.

Our objectives

1. Environmental – To reduce our energy consumption and waste across the organisation.
2. Social – To create a culture that positively impacts the wellbeing of our colleagues, volunteers, members, and the communities we serve.
3. Governance – To maintain a robust and agile structure across the charity.

Our progress in 2024

We have an ESG policy, and an annual action plan to help embed ESG throughout our work and culture.

Environmental

To better manage and reduce our energy consumption across our stores we have moved to smart metering, and we have continued our transition to more energy efficient lighting solutions; gradually replacing existing fluorescent lighting with energy saving LED lighting solutions across the entire retail estate.

To reduce the amount of stock that was going to rag we have implemented sale rails in all our shops, not only has this reduced stock going to landfill but it has also helped generate additional revenue to support the EB community, whilst offering highly affordable pre-loved clothing for the communities we serve. All our shops now have recycling bins to reduce waste going to landfill.

Social

In July, the People Puzzles colleague survey gave us invaluable feedback from our teams across the organisation on what it's like to work at DEBRA. The results demonstrated strong improvements to our culture compared to previous surveys taken in 2020 and 2022 and we have followed this up by investing in the Empowered Engagement platform, which will help us identify any areas that we need to develop to make DEBRA a truly great place to work.

One of our key objectives is to create an inclusive culture at DEBRA, a culture where diversity is valued, and our people feel comfortable to bring their authentic selves to work. To support this, in January, we signed up to become a recognised Disability Committed Employer, where we commit to the core actions of a Disability Confident Employer.

Governance

We strengthened the DEBRA Board of Trustees in 2024, bringing in new Trustees with specific skills and knowledge that will benefit the organisation and how we are governed whilst ensuring we retain at least 50% EB representation, either people living with EB themselves or people with lived experience of EB ensuring that the needs of the EB community remain at the centre of our plans.

Our plans for 2025

Environmental

As part of the Energy Savings Opportunity Scheme (ESOS) we will continue to install LED lighting across the retail estate, and where possible and commercially viable, choose new retail stores that have an EPC rating of C or above to support the Minimum Energy Efficiency Standards. This will help to reduce our energy consumption at source.

We will also introduce wet (food) recycling to ensure no waste goes to landfill.

Social

Understanding DEBRA's current organisational culture and how we can evolve and improve it will be a key focus in 2025. We will utilise the feedback from the 2024 colleague survey and apply the Empowered Engagement tool to help us shape each dimension of the workplace climate, supporting us in our aim of making DEBRA a truly great place to work for all our colleagues and volunteers.

Our Equality, Diversity, and Inclusion (EDI) working group will update the EDI strategy for the charity, reconfirming our commitment to ensuring equality and diversity runs through every aspect of the charity and the work we do.

In 2025 we will aim to publish an Ethnicity Pay Gap report to supplement our existing Gender Pay Gap report to help ensure pay equality across the organisation.

Through our internal colleague and volunteer communications we will celebrate diversity and differences across the organisation.

Governance

Our Board of Trustees will continue to ensure our standards and practices fully embrace the principles of the Charity Commission Charity Governance Code, the Fundraising Regulator and GDPR data protection.

Thank you for BEing the difference for EB

We would like to express our sincere thanks to everyone who supported DEBRA in 2024, whether you donated, took on a fundraising challenge, shared your story to help raise awareness of EB, joined an event, supported our shops, played our lottery, left a gift in your will, or volunteered for us, we couldn't have done it without you.

We are also extremely grateful for the continued support of our Royal Patron, our President, Vice Presidents, Ambassadors, and our Advisor.

Our Patron, President, Vice Presidents

HRH The Duchess of Edinburgh GCVO

Simon Weston CBE

Graeme Souness CBE

Lenore England

Frank Warren

Stuart Procter

Our Ambassadors:

Michel Roux

Emma Dodds

Scott Brown

Steve Rider

John Williams MBE

Dr Anna Martinez

Professor Gareth Inman

Professor John McGrath

Mark Moring

Simon Davies

Jon Isaacs

Laurence Blunt

Lucy Beall

Vie Portland

Fazeel Irfan

Isla Grist

Erin Ward

Kate White

Our independent advisor:

Professor Chris Griffiths OBE

Trusts & foundations

The Ashwater Fund

Bill Brown's 1989 Charitable Trust

Blue Skies Charitable Trust

The Brothers Trust

Buck Family Foundation

The Michael Cornish Charitable Trust

The Dorus Trust

The Dyers Company

Edward Cadbury Charitable Trust

Forest Hill Charitable Trust

Gennets Charitable Trust

Gilbert and Eileen Edgar Foundation

The Hospital Saturday Fund

Innes Family Charitable Trust

John Cowan Foundation

Joseph Strong Frazer Trust

The Christopher Laing Foundation

The Lennox Trust

Mabs Mardulyn Charitable Trust

Manson Family Trust

Marconi (Chelmsford) Employees Fund

The George A Moore Foundation

N Sethia Foundation

Nunes Flavia Chari Nunes Charitable Trust

Riada Trust

The Ripley Trust

Sir Iain Stewart Foundation

Skipasund Foundation

The Verdon-Smith Family Charitable Trust

VTCT Foundation

The Webb Kingpin Foundation

Michael and Anna Wix Trust

Charity overview, objectives & public benefit

Financial review

We spent £3.8m on charitable activities in 2024, compared with £4.4m in 2023, a 13% decrease. New research commitments reduced from £1.6m to £718k, while spend on healthcare, community support and respite remained consistent with the previous year at £1.8m.

There was a net loss from the retail operation of £0.2m (2023: net income of £0.1m). Overall net fundraising income was £3.5m in 2024 (2023: £3.5m).

The deficit for the year was £0.38m, compared with £0.67m in 2023.

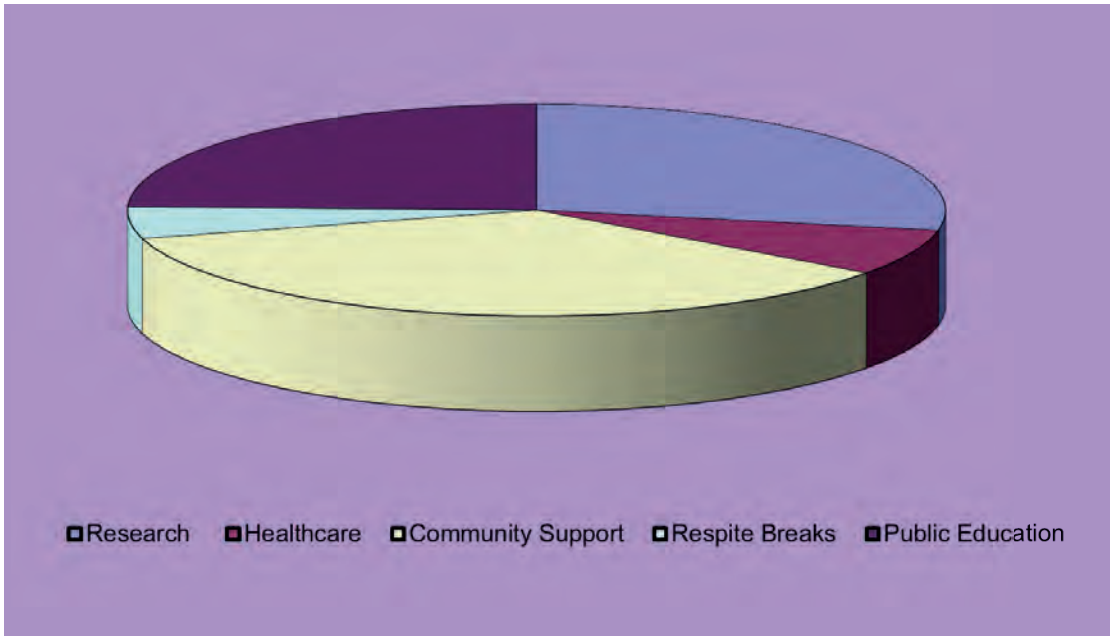
Summary

Table 3 summarises the highlights of our financial performance over the last five years. Gross income was £18.2m in 2024 (2023: £18.2m).

Non-trading gross income was £5.8m, a 2.6% increase from £5.7m in 2023. This includes income from donations, corporate support, trusts and community events.

Total retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops) remained steady at £12.5m.

Charitable expenditure



Charity overview, objectives & public benefit

Table 3: Financial KPI summary

	2024 £'000	2023 £'000	2022 £'000	2021 £'000	2020 £'000
Gross income	18,176	18,228	16,421	13,317	11,413
Non-trading income	5,833	5,681	4,017	4,663	4,387
Net trading income	(1,218)	(758)	(196)	(1,299)	(3,201)
Net retail income including government pandemic support, retail Gift Aid, commission and donations in shops	(189)	107	654	1,689	(673)
Non-trading fundraising costs	882	861	699	662	708
Charitable expenditure	3,843	4,396	2,640	1,885	2,848
Retained surplus/(deficit)	(381)	(663)	452	817	(2,371)
Retained surplus/(deficit) as a % of income	(2)%	(4)%	3%	6%	(21%)
Net current assets	2,622	3,250	3,333	3,124	2,684
Unrestricted reserves	2,822	3,167	3,763	4,050	2,904
Grants payable within 1 year	2,303	1,922	2,019	2,237	2,159

The charity's fixed assets comprise the premises and equipment required to operate trading activities; premises, furniture and equipment required to operate the charity's offices; and seven holiday homes held for the use of those affected by EB. The rest of the charity's assets are held to promote the purposes of the charity through its support services and research programmes.

Reserves policy

DEBRA holds reserves to ensure the charity is able to continue supporting its beneficiaries and as a buffer for short term cash flow needs.

Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be readily mortgaged, thus representing reserves that can be accessed relatively quickly.

The trustees' reserves policy in 2024 was to maintain minimum cash-backed free reserves at £1m, to which the charity adhered. Maintaining the high levels of retail income has been a challenge but this has been offset by a significant increase in fundraising income. The minimum reserves figure is set to cover six month's rent plus one month of other costs. The trustees conducted a thorough review of the reserves policy in 2024, reviewing performance criteria in the light of the economic situation. The trustees' aim is to grow cash-backed free reserves in line with planned growth fundraising and recovery of retail operations.

Charity overview, objectives & public benefit

Funds

The majority of our funds are unrestricted in application and are held in general and designated funds. Where funds are received that are restricted in their application to specific purposes or activities, these are held in a restricted fund. Details of restricted funds and designated funds are set out in Note 18 of the Financial Statements.

Total reserves at the end of 2024 were £3.2m. Cash-backed free reserves after designations were £1m with £1.6m of remaining free reserves giving total general funds of £2.6m. There were £0.2m of designations adding to a total of £2.8m of unrestricted funds.

The trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

Restricted funds

Restricted funds were £375k, including £112k for community support and healthcare activities. Other restricted funds are:

Oliver Thomas Memorial fund

The Oliver Thomas Memorial Fund was established September 2022. The remaining balance is £9,200 for Clinical Best Practice Guidelines.

Research

£75k was donated to fund a research programme at Ninewells Hospital, Dundee.

Respite breaks

Funds were raised to support the purchase of new holiday homes, and the upkeep thereof, giving much needed respite to EB patients and families. One home was purchased in 2022 and another in 2023. The fund balance at the end of 2024 was £224k and will reduce as the homes are depreciated.

Asset cover for funds

Note 19 sets out an analysis of the assets attributable to the various funds. These assets are sufficient to meet the charity's obligations on a fund-by-fund basis.

Investment policy

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit. We aim to apply our income in support of our charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk. £0.5m is held in fixed term deposits with HSBC.

Expenses policy

We have expenses policies for both staff and trustees and a PAYE dispensation in place. Expenses that have necessarily been incurred by staff and trustees in performance of their duties are recoverable from DEBRA. Expenses will only be reimbursed if they meet the following criteria:

- no personal benefit could be derived from the expenditure by the employee concerned;
- the expenditure is reasonable and represents only additional costs to those that would normally arise on a personal basis;
- there is a clear charity justification for the costs; and
- the expenditure does not represent a form of payment to a third party for work undertaken on our behalf.

Any expenses that do not meet the criteria above are regarded as a benefit by HMRC and as a matter of policy we do not reimburse such expenses.

Charity overview, objectives & public benefit

Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2024 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous nonprimary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 12 of the Financial Statements.

Internal audit

RSM are appointed as internal auditors. Audits of Fundraising Compliance, Governance, Gift Aid and Budgeting & Financial Management took place in 2024 and recommended actions are being implemented by management. In 2025 audits of Research, Member Services, Retail, and Financial Controls will take place.

Principal risks and uncertainties

The trustees have established a register for all identified major strategic, business and operational risks identified by them to which the charity is exposed and confirm that these have been reviewed regularly during the year by the Finance, Risk and Audit Committee (as well as annually by the Board of Trustees) and that systems and procedures have been established to manage these risks. The initial responsibility for managing risk lies with the executive, prior to review by the trustees.

A summary extract of the higher risks from our risk register is listed in Table 4 below, including the countermeasures (actions in place to reduce likelihood of the risk) and assurances (how the effectiveness of the countermeasures is determined). DEBRA as an organisation is very proactive in its management of risk, instilling a culture of recognition, ownership and tolerance level for each risk identified.

See Table 4: DEBRA's major risks

Table 4: Summary Extract from DEBRA's Risk Register

Risk	Cause & Effect	Controls
Inability to achieve fundraising goals	Loss of significant amounts of income leading to inability to meet charitable objectives / over-reliance on a small number of donors / supporters for significant funding	▪ Diversity of fundraising activities ▪ Review by Fundraising and Marketing Committee ▪ Regular contact with key supporters ▪ Maintain multiple points of contact ▪ Records of significant communication kept ▪ Regular reporting on key relationships ▪ Robust budgeting process
Failure of retail management to respond to changing face of retail and inability to generate sufficient contribution	Poor trading locations or lack of attention to alternative income streams such as online, leading to loss of significant amounts of income leading to inability to meet charitable objectives	▪ Implement regular strategic reviews to assess progress against key performance indicators (KPIs) ▪ Ensure that any necessary adjustment to business strategies are identified early ▪ Monitor KPIs related to sales growth, customer satisfaction, online engagement, and operational efficiency ▪ Establish benchmarks for the KPIs and implement corrective actions if performance deviates from target ▪ Monitor potential external and internal factors that could impact retail performance

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Major Virus epidemic or pandemic and resulting Government containment actions	Shop closures leading to loss of retail income and staff and potential inability to make payments as they fall due. Could lead to inability to continue meeting charitable objectives and operating as a charity.	▪ Shops Health and Safety file, cleaning (COSHH) and operating procedures set out ▪ News monitoring ▪ Regular updates from charity retail association ▪ Pandemic plan in place
Economy / Inflation	Adverse economic conditions or high inflation impact shop or other income	▪ Retail Committee monthly reports with KPIs, monitoring daily sales/GA report ▪ Performance reviews ▪ Retail Risk Register ▪ Continuous drive to increase retail contribution / enhance pricing
Failure to maintain adequate cash flow	Suppliers not being paid on time, delays in staff expenses reimbursement. Need for overdraft facilities. Ultimately leading to inability to continue to operate.	▪ Cash flow monitoring by Finance Team and reported to FRA quarterly ▪ Annual review by FRA of cash-backed free reserves minimum figure ▪ Monthly monitoring and reporting
Failure to achieve sufficient income to meet commitments	Continuous below budget performance in income generation, leading to declining reserves, inability to provide services to members and potential going concern issues	▪ Reserves target minimum cash backed free undesignated reserves based on formula ▪ Budget monitoring ▪ Research grants and other charitable expenditure committed to only when sufficient reserves held to cover total value of commitment

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Cyber security threats	Cyber-attack from Phishing scams, ransomware, or unauthorised system access leading to loss of data, financial fraud and reputational damage. Data loss could lead to severe GDPR fines and major damage to reputation. Potential impact on DEBRA's ability to continue operating.	▪ End-point detection software / anti-virus on all computers ▪ Cyber insurance policy ▪ MFA/SSO on all IT Infrastructure ▪ Email scanned before reaching DEBRA servers ▪ Remote users hard drives are encrypted ▪ Secured Wi-Fi at Bracknell head office ▪ Remote desktop sessions time out after 20 mins ▪ Back-up daily server images moved to the cloud ▪ File shadow copy active on the server (protects against Malware encryption spyware) ▪ Complex passwords are encouraged ▪ Meraki firewalls in place throughout offices and shops ▪ Anti-virus/spyware solution on all PC based tills ▪ All credit card machines meet PCI compliance standard C ▪ Monitoring of data access ▪ Annual Penetration testing
Recruitment of insufficient and low calibre volunteers	Volunteer numbers and issues involving volunteers are recorded on a monthly basis, so monitoring will highlight potential concerns.	▪ Training focussed on giving Shop Managers the skills to recruit and manage volunteers in Retail ▪ Volunteer Team to develop the volunteer resource in both Retail and EB Community Support ▪ Online training, which has primarily been installed for employees to develop their skills, is also available for up to 500 volunteers

Charity overview, objectives & public benefit

Going concern statement

The Trustees reviewed the charity's budget, cash flows and forecasts for 1 January 2025 – 31 December 2026, which detail the plans for delivering to the EB community during a period of high cost inflation and the cost of living crisis. It is recognised that there are underlying uncertainties, however the Trustees consider the charity can continue its business-critical activities and remain a going concern.

The Trustees consider it is appropriate to prepare the 2024 accounts on a going concern basis on the basis that:

- Fundraising activity is expected to exceed 2024, with a swim event and cultivation of major donors via a specific programme;
- The retail recovery project begun to bear fruit in Q4 2024 and will continue in 2025, proving a greater contribution to reserves;
- The Budget and cash flows for 2025 and 2026 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2025 and 2026 is contingent on achieving fundraising and retail targets.

Structure, governance & management

DEBRA is a company limited by guarantee registered with the Charity Commission in England and Wales (1084958). This means our trustees are also company directors, so subject to company law as well as charity law. We are also registered with the Office of the Scottish Regulator in Scotland.

Board of Trustees

Our Trustee Board has a collective responsibility for everything we do and is responsible for:

- our overall strategic direction including evaluating progress against our strategic plans
- ensuring our financial stability
- acting in the best interests of our organisation
- ensuring that we comply with our governing documents, and any other relevant legislation from our regulators.

New trustees receive the most recent annual report and accounts, copies of previous minutes of the board and committees, and are made aware of the charity's policies including its Scheme of Delegation. Individual inductions from senior trustees as relevant and trustees attend external training courses appropriate to their role on the Board of Trustees. There are four board meetings per year, which the CEO attends and Senior Leadership Team members attend as required.

The Trustees are the sole legal members of the charity.

In 2024

Jo Merchant retired end of third term 10 May 2024. No trustees were appointed in the year. 3 new trustees were appointed in February 2025 – Laura Briggs, Katy Hinchcliffe and Gareth Jones.

Charity overview, objectives & public benefit

Trustee Board Committees

Finance, Risk & Audit Committee ("FRA") – determines and advises the Board of Trustees on matters relating to finance, risk and audit as the Board of Trustees may remit to it, in particular the sound financial management of the charity, its resources and assets.

Charitable Purposes Committee ("CPC") – determines and advises the Board of Trustees on matters relating to strategy in research, healthcare, community support and policy as the Board of Trustees may remit to it.

Nominations & Governance Committee ("N&G") – oversees the structure, composition and effectiveness of the charity's Board of Trustees and its Committees, as well as the appointment process of trustees. The Committee monitors the governance procedures of the charity.

Remuneration Committee – makes recommendation to the Board on a fair remuneration for the Chief Executive and Senior Leadership Team of DEBRA and reviews the Chief Executive's recommendations on the Annual Pay policy for DEBRA.

See Table 5 below – Trustees' membership and attendance.

Board diversity

Our Board of Trustees is made up from a majority of those who have a direct experience of EB, who either have EB themselves or have a close family member with EB, and those who have skills and experience that will add value to the governance and leadership of DEBRA. This ensures a good mix of skills, talents and experience to serve the DEBRA community.

We follow the Equal Opportunities Policy in the selection of Board members, in the same way we do for staff recruitment. Membership of the Board is open to all members of DEBRA, irrespective of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values.

Broader diversity of the Board continues to be reviewed as part of DEBRA's Equality, Diversity & Inclusion policy

Charity governance code

The Board consistently reviews all aspects of DEBRA's governance and ensures that our governance standards and practices fully embrace the principles of the Charity Commission 'Charity Governance Code'.

Succession planning

We have built strength and depth in our Trustee Board, incorporating appropriate succession planning by appointing two Vice Chairs, each for periods of two years with an annual rotation of one of those. Prospective new trustees are often invited to join a committee for a minimum period of 12 months before becoming trustees.

Charity overview, objectives & public benefit

Fundraising standards

Section 162A of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. We do not undertake face-to-face fundraising from the general public. The legislation defines fundraising as 'soliciting or otherwise procuring money or other property for charitable purposes'. Such amounts receivable is presented in the accounts as 'voluntary income' and include legacies and grants.

We make all efforts to train staff and ensure compliance with fundraising standards at all times. Specifically:

- the majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the trustees
- where we work with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met
- there are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc
- where volunteers assist in our fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued
- volunteer fundraisers are managed and supported from the offices in Bracknell and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them
- data protection procedures are in place governing the management of supporter and donor data on our DEBRA database; compliance with GDPR rules continues to be monitored
- we work with vulnerable people, particularly within the EB community, and often they wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly
- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2024

Activities in Scotland

We are active across several areas in Scotland. The primary charitable activities are seen in funding community support and research projects, notably at the Universities of Dundee and Edinburgh and the CRUK Scotland Institute, University of Glasgow. On the income generation side, there were two regional fundraising members of staff and 31 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Blantyre.

Charity overview, objectives & public benefit

Board Attendance Table

Trustee		Board	FRA	N&G	CPC	REMCO
Jim Irvine (Chair)	Chair of Board	4 of 4	3 of 4	4 of 4		1 of 1
David Bendor-Samuel	Chair of N&G	3 of 4		4 of 4		
Simone Bunting	Chair of REMCO	4 of 4				1 of 1
Carly Fields	Vice Chair & Chair of CPC	4 of 4		4 of 4	4 of 4	
Christo Kapourani	Leave of absence					
Debbie Install		4 of 4			3 of 4	
Joanne Merchant	Retired end of third term 10 May 2024	2 of 2	1 of 2			
Dan Mundy	Chair of FRA	4 of 4	4 of 4	4 of 4		1 of 1
Mick Thomas		2 of 4			3 of 4	
Simon Talbot		4 of 4	4 of 4			1 of 1

Auditor

Trustees have taken all reasonable steps to make themselves aware of any information needed by the company's auditor for the purposes of their audit and to establish that the auditor is aware of that information. The trustees are not aware of any relevant audit information of which the auditor is unaware.

Sayer Vincent LLP have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditor 28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

The Trustees' Annual Report, incorporating the Strategic Report, is approved by the Board of Trustees and signed on behalf of the trustees:

Jim Irvine
Chair of Trustees

Trustees' statement of responsibilities

The trustees (who are also directors of DEBRA for the purposes of company law) are responsible for preparing the Trustees' Annual Report including the strategic report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities Statement of Recommended Practice (SORP) make judgements and estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2024 was 9 (2023: 10). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditor's report

Independent auditor's report to the members of DEBRA

Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2024 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2024 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the Financial Reporting Council's Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on DEBRA's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Auditor's report
(continued)

Other Information

The other information comprises the information included in the trustees' annual report, including the strategic report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the trustees' annual report, including the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- The trustees' annual report, including the strategic report, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report, including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Auditor's report
(continued)

Responsibilities of trustees

As explained more fully in the statement of trustees' responsibilities set out in the trustees' annual report, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud are set out below.

Capability of the audit in detecting irregularities

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, our procedures included the following:

- We enquired of management and Finance, Risk and Audit committee, which included obtaining and reviewing supporting documentation, concerning the charity's policies and procedures relating to:
    - identifying, evaluating, and complying with laws and regulations and whether they were aware of any instances of non-compliance;
    - detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud;
    - the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.
- We inspected the minutes of meetings of those charged with governance.
- We obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience.

Auditor's report
(continued)

- We communicated applicable laws and regulations throughout the Audit Team and remained alert to any indications of non-compliance throughout the audit.
- We reviewed any reports made to regulators.
- We reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations.
- We performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud.
- In addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities is available on the Financial Reporting Council's website at: **www.frc.org.uk/auditorsresponsibilities.** This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Fleur Holden
(Senior statutory auditor)

Date: 20 May 2025
for and on behalf of Sayer Vincent LLP, Statutory Auditor

110 Golden Lane, LONDON, EC1Y 0TG

Sayer Vincent LLP is eligible to act as auditor in terms of section 1212 of the Companies Act 2006

Financial statements

For the year ended 31 December 2024

Statement of financial activities

Statement of financial activities including income and expenditure account for the year ended 31 December 2024.

2024					
	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Income from:					
Donations & legacies	2	5,066,898	-	634,553	5,701,451
Charitable activities		31,247	-	-	31,247
Other trading activities	3	12,343,028	-	-	12,343,028
Investments	4	43,478	-	-	43,478
Other		56,950	-	-	56,950
Total income		17,541,601	-	634,553	18,176,154
Expenditure on:					
Raising funds	6	(14,563,773)	(150,000)	-	(14,713,773)
Charitable activities	6	(3,162,822)	-	(680,553)	(3,843,375)
Total expenditure		(17,726,595)	(150,000)	(680,553)	(18,557,148)
Net income / (expenditure)		(184,994)	(150,000)	(46,000)	(380,994)
Transfer between funds		731,397	(731,397)	-	-
Net movement in funds		(546,403)	(881,397)	(46,000)	(380,994)
Reconciliation of funds:					
Total funds brought forward		2,185,187	981,397	420,668	3,587,252
Total funds carried forward		2,731,590	100,000	374,668	3,206,258

Statement of financial activities
(continued)

2023					
	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Income from:					
Donations & legacies	2	4,770,185	-	755,404	5,525,589
Charitable activities		11,834	-	-	11,834
Other trading activities	3	12,544,882	-	-	12,544,882
Investments	4	97,461	-	-	97,461
Other		48,674	-	-	48,674
Total income		17,473,036	-	755,404	18,228,440
Expenditure on:					
Raising funds	6	14,475,656	19,000	-	14,494,656
Charitable activities	6	3,574,457	-	822,247	4,396,704
Total expenditure		18,050,113	19,000	822,247	18,891,360
Net income / (expenditure)		(577,077)	(19,000)	(66,843)	(662,920)
Transfer between funds		-	-	-	-
Net movement in funds		(577,077)	(19,000)	(66,843)	(662,920)
Reconciliation of funds:					
Total funds brought forward		2,762,264	1,000,397	487,511	4,250,172
Total funds carried forward		2,185,187	981,397	420,668	3,587,252

All operations are continuing. The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

The notes on pages 53-72 form part of these financial statements.

Balance sheet

Balance sheet as at 31 December 2024.

	Notes	2024 £	2024 £	2023 £	2023 £
Fixed assets					
Tangible fixed assets	**10**		**1,681,937**		1,437,302
Programme related investment	**11**		**1**		1
Investment in subsidiaries	**12**		**2**		2
			1,681,940		1,437,305
Current assets					
Debtors	**13**	**2,954,873**		2,114,242	
Current asset investment	**14**	**500,000**		2,024,298	
Cash at bank and in hand		**2,795,577**		2,111,857	
		6,250,450		6,250,397	
Creditors: amounts falling due within one year	**15**	**(3,628,830)**		(2,999,964)	
Net current assets			**2,621,620**		3,250,432
Total assets less current liabilities			**4,303,560**		4,687,737
Creditors: amounts falling due after more than one year	**16**		**(694,192)**		(881,673)
Provision for liabilities	**17**		**(403,110)**		(218,812)
Total net assets			**3,206,258**		3,587,252

Balance sheet
(continued)

		2024		2023	
		£	£	£	£
The funds of the charity					
Restricted income funds	**19**	**374,668**			420,668
Unrestricted funds					
Designated funds	**20**	**100,000**		981,397	
General funds	**20**	**2,731,590**		2,185,187	
Total unrestricted funds			**2,831,590**		3,166,584
Total funds			**3,206,258**		3,587,252

Company registration number 4118259

The accounts were approved by the Board on 7 May 2025 and signed on their behalf by:

Jim Irvine
Chair of Trustee Board

Daniel Mundy
Treasurer

Statement of cash flows

Statement of cash flows for the year ended 31 December 2024.

	Notes	2024 £	2024 £	2023 £	2023 £
Cash flows from operating activities					
Net cash (used in) / provided by operating activities	22		**(234,863)**		(698,355)
Cash flows from investing activities					
Dividends, interest and rents from investments		**43,478**		97,461	
Purchase of property, plant and equipment		**(649,193)**		(409,093)	
Proceeds from sale of investments		**2,024,298**		3,000,000	
Purchase of investments		**(500,000)**		(2,024,298)	
Net cash provided by / (used in) investing activities			**918,583**		664,070
Change in cash and cash equivalents in the reporting period			**(683,720)**		(34,285)
Cash and cash equivalents at the beginning of the reporting period			**2,111,857**		2,146,142
Cash and cash equivalents at the end of the reporting period			**2,795,577**		2,111,857

The notes on pages 53-72 form part of these financial statements.

Notes to the financial statements

1 Accounting policies

1.1 Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), Charities SORP (FRS 102), the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and Trustees Investment (Scotland) Act 2005.

1.2 Going concern

The Trustees reviewed the charity's budget and cash flows for 1 January 2025 – 31 December 2026 in November 2024 and consider it is appropriate to prepare the 2024 accounts on a going concern basis on the basis that:

- Fundraising activity is expected to exceed 2024, with a swim/cycle event and cultivation of major donors via a specific programme;
- The retail recovery project begun to bear fruit in Q4 2024 and will continue in 2025, proving a grater contribution to reserves;
- The Budget and cash flows for 2025 and 2026 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2025 and 2026 is contingent on achieving fundraising and retail targets.

1.3 Legal status of charity

The charity is a company limited by Guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

1.4 Judgements and estimates made by management

The financial statements include judgements and estimates as defined by the accounting policies. Legacy income is recognised as probable at probate, using an estimate provided by executors. Premises service charge liabilities are estimated from information supplied by property specialists. The dilapidations provision is reviewed annually on an individual lease basis by a property specialist.

Research grants are recognised in full in the Income and Expenditure Account at the point of commitment in order to ensure no reliance on future fundraising to meet these financial commitments.

Programme related investments are impaired based on a judgement of the intrinsic value of the investment at the balance sheet date, where no market value exists.

The Trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

Notes to the financial statements
(continued)

1.5 Income

Donations and gifts are recognised in full in the Statement of Financial Activities when receivable. Unclaimed gift aid receivable is accrued in the year to which it relates. Legacies receivable are recognised when there is entitlement, probability of receipt and is measurable. Grants are recognised in full when receivable. Gifts in kind are only included in the accounts where the Trustees can ascribe a value in excess of £1,000.

Other trading income is recognised in full when received with the exception of income that is deferred where it represents a payment in advance for a specific event that will not take place until a future accounting period. This exception does not apply to sponsorship for charity challenges taking place in a future accounting period.

Claims made through the UK Government's Coronavirus Job Retention Support Scheme are recognised as income in the period which the associated staff were furloughed. This income is considered to be unrestricted. Small business retail grants have been recognised as unrestricted income in the periods to which they relate.

1.6 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Equipment purchased for use in research is written off as part of the research project costs as incurred. Expenditure on raising funds are those costs incurred in seeking voluntary contributions and running the retail operations. Charitable activities include expenditure associated with the operation of the charity and the provision of its services.

Governance costs comprise the costs relating to the general running of the charity, and include direct items such as external audit, legal advice for trustees, the cost of trustee meetings, and are included in central overhead costs. Central costs are apportioned and allocated between the cost of raising funds and charitable expenditure on the basis of central staff time allocation to the various activities.

1.7 Recognition of grant liabilities

Grants are awarded for research projects over a period of one to five years. All grants provide the right to terminate with up to three months' notice and continuation of funding is dependent on satisfactory progress reporting and review. It is always the intention to honour the funding of all grants awarded and full grant recognition has been incorporated into these accounts as the most appropriate and prudent policy. By adopting this policy, the Trustees ensure the funds for research grants have been raised in full prior to making financial commitments to research institutions.

1.8 Tangible fixed assets and depreciation

Tangible fixed assets with a value in excess of £1,000 are capitalised and stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

Freehold and long leasehold buildings	Over 25 years
Leasehold improvements	Over life of the lease
Mobile homes	Over 10 years
Fixtures, fittings, static equipment	Over 5 years
Software development costs	Over 5 years
Shop equipment	Over 5 years
Mobile equipment	Over 3 years

Notes to the financial statements
(continued)

A review of assets is undertaken annually, and adjustments are made to the expected useful life as required. From 1 January 2009 freehold land and buildings, and long leasehold buildings, are assumed to have a residual value of 50%.

1.9 Programme related investment and impairment

Programme related expenditure with a value in excess of £1,000 is stated at cost less impairment. The investment held was impaired by 99.99% in 2020, with a residual holding value of £1.

1.10 Cash and short-term investments

The charity holds cash requirements for day-to-day activities in current bank accounts with HSBC, Lloyds, Santander and Clydesdale. The deposit account is held with HSBC. Short-term investments are held in money market deposits with HSBC. For the purposes of the cash flow statement, cash equivalents are defined as current asset investments, and short-term deposits with a maturity of less than 3 months, which are readily convertible into known amounts of cash.

1.11 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

1.12 Creditors

Trade creditors and other payables are normally recognised at their settlement amount after allowing for any trade discount due. Payments to suppliers are within standard payment terms of 30 days. Liabilities are recognised when there is a present obligation, as a result of past events, and there is a probable future outflow of resources that can be estimated reliably.

1.13 Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at settlement value.

1.14 Stock

The Trustees do not consider it appropriate to recognise donated goods for resale as stock on the grounds that the cost of obtaining stock information would greatly outweigh any benefit. The costs involved would include the setting up of processes and procedures for a stock count in the large store base, training shop staff and volunteers in the process, software programming, and the checking and analysis of the reports produced.

All other stock is valued at the lower of cost or sales value net of selling costs.

1.15 Accumulated funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the Trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The purposes and uses of the restricted funds and designated funds are set out in Note 19 to the financial statements.

Notes to the financial statements
(continued)

1.16 Consolidated accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the companies' results and the investment the charity holds are shown separately in Note 12 to the financial statements.

1.17 Foreign currency translation

Foreign currency transactions are recorded at the exchange rate at the time of the transaction. Foreign currency assets and liabilities are translated into sterling at the exchange rate ruling at the balance sheet date. Resulting gains or losses on retranslation are included in the statement of financial activities.

1.18 Leases

Operating lease annual rental payments are charged to the statement of financial activities on a straight line basis over the term of the lease.

1.19 Termination payments

Termination payments either by way of redundancy or settlement agreement are recognised at the time of payment. Any payments exceeding the statutory minimum are authorised by the Trustees.

Notes to the financial statements
(continued)

2. Donations and legacies

	Unrestricted funds	Restricted funds	Total 2024	Unrestricted funds	Restricted funds	Total 2023
	£	£	£	£	£	£
Donations & gifts	**3,189,498**	**45,567**	**3,235,065**	4,102,510	223,990	4,326,500
Legacies receivable	**1,245,705**	**41,157**	**1,286,862**	478,276	35,000	513,276
Grants receivable	**631,695**	**547,829**	**1,179,524**	189,399	496,414	685,813
	5,066,898	**634,553**	**5,701,451**	4,770,185	755,404	5,525,589
Donations & gifts:						
Individual donations	**2,414,090**	**31,109**	**2,445,199**	3,698,945	186,271	3,885,216
Corporate donations	**633,598**	**13,000**	**646,598**	365,608	26,473	392,081
International donations	**36,486**	**-**	**36,486**	1,316	-	1,316
Events by individuals	**105,324**	**1,458**	**106,782**	36,641	11,246	39,135
	3,189,498	**45,567**	**3,235,065**	4,102,510	223,990	4,326,500
Grants receivable:						
Charitable trusts	**618,523**	**224,000**	**842,523**	188,168	187,801	375,969
Other grants	**13,172**	**323,829**	**337,001**	1,231	308,613	309,844
	631,695	**547,829**	**1,179,524**	189,399	496,414	685,813

Online adwords received as gifts in kind of £93,927 (2022: £92,969) are included in donations and gifts.

Notes to the financial statements
(continued)

3. Other trading activities

	2024	2023
	£	£
Income	**12,343,028**	12,544,882
Operating expenses	**(13,561,415)**	(13,209,499)
Net expenditure	**(1,218,387)**	(664,617)

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2024 there were 86 shops trading (2023: 92). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net result 2024	Income	Operating expenses	Net result 2023
	£	**£**	**£**	£	£	£
Retail	**11,224,154**	**(12,679,224)**	**(1,455,070)**	11,451,883	(12,440,189)	(988,306)
Fundraising events	**933,887**	**(882,191)**	**51,696**	923,711	(769,310)	154,401
Miscellaneous trading	**184,987**	**-**	**184,987**	169,288	-	169,288
	12,343,028	**(13,561,415)**	**(1,218,387)**	12,544,882	(13,209,499)	(664,617)

Retail income excludes income of £1,265,901 (2023: £1,095,482) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail Gift Aid commission of £65,304 (2023: £91,851) which is recognised in miscellaneous trading. The profit covenanted by DEBRA Trading Limited of £119,683 (2023: £76,787) is recognised in miscellaneous trading.

Notes to the financial statements
(continued)

The table below reflects a true statement of total retail income, including retail Gift Aid, commission and retail donations.

	2024	2023
		£
Income	**12,490,055**	12,547,365
Operating expenses	**(12,679,224)**	(12,440,189)
Net (expenditure)/income	**(189,169)**	107,176

4. Investment income

	2024	2023
	£	£
Interest receivable	**37,055**	93,879
Rent of property	**6,423**	3,582
Total investment income	**43,478**	97,461

Rental income was received from one freehold shop and two flats situated above properties.

Notes to the financial statements
(continued)

5. Grants payable

Expenditure on charitable activities include grants payable to third parties as detailed in Note 24. There were 552 (2023: 424) Community Support grants totalling £144,654 (2023: £144,028) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 24.

Routine Healthcare and Community Support work is considered ongoing and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2024 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,544,889 (2023: £1,724,027) and clinical projects to the sum of £107,997 (2023: £107,997).

The total future commitment is currently committed to be spent as follows:

	2024	2023
	£	£
Within one year	**958,694**	950,341
Within two – three years	**694,192**	881,673
Within four – five years	**-**	-
Provided within the grants payable creditor (notes 15 and 16)	**1,652,886**	1,832,014

Notes to the financial statements
(continued)

6. Expenditure

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2024
	£	£	£	£	£	£
Raising funds						
Donations & legacies	643,005	-	-	311,449	197,904	1,152,358
Other trading activities	7,349,286	-	209,299	448,212	5,554,618	13,561,415
	7,992,291	-	209,299	759,661	5,752,522	14,713,773
Charitable activities						
Research	437,368	534,084	-	87,614	19,875	1,078,941
Healthcare	120,915	3,332	-	47,205	99,014	270,466
Community support	1,102,966	133,311	-	116,555	12,945	1,365,777
Respite breaks	4,933	-	98,301	2,389	79,501	185,124
Public education	646,368	-	-	77,000	219,699	943,067
	2,312,550	670,727	98,301	330,763	431,034	3,843,375
	10,304,841	670,727	307,600	1,090,424	6,183,556	18,557,148

Notes to the financial statements
(continued)

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2023
	£	£	£	£	£	£
Raising funds						
Donations & legacies	660,061	-	-	272,309	352,787	1,285,157
Other trading activities	7,027,568	-	81,677	375,643	5,724,611	13,209,499
	7,687,629	-	81,677	647,952	6,077,398	14,494,656
Charitable activities						
Research	372,808	1,126,651	-	66,354	3,673	1,569,486
Healthcare	112,576	129,273	-	37,223	283,727	562,799
Community support	953,911	144,028	-	108,138	25,706	1,231,783
Respite breaks	-	-	104,378	-	5,278	109,656
Public education	576,201	-	-	61,779	285,000	922,980
	2,015,496	1,399,952	104,378	273,494	603,384	4,396,704
	9,703,125	1,399,952	186,055	921,446	6,680,782	18,891,360

Net income / (expenditure) for the year is stated after charging:

	2024	2023
	£	£
Operating leases		
Land and buildings	**1,909,455**	1,867,741
Equipment	**4,432**	4,432
Auditors' remuneration	**24,000**	22,300
Auditors' remuneration (under accrual in prior year)	**-**	9,000
Non-audit services	**425**	900
Depreciation of tangible fixed assets	**401,429**	281,882
Defined contribution pension costs	**627,207**	407,332
Exchange differences	**(5,988)**	7,911

Notes to the financial statements
(continued)

7. Cost allocation

All central overhead costs are allocated to activities on the basis of staff time, and are detailed below:

	2024	2023
	£	£
Staff costs	**2,251,239**	2,233,530
Overheads		
Office premises rent	**66,014**	62,790
Service charges, utilities & cleaning	**193,620**	61,236
Equipment costs	**344,336**	308,561
Postage, printing, stationery, telephone & fax	**43,038**	67,190
Insurance costs	**185,454**	149,182
Legal, professional & consultancy fees	**93,718**	105,542
Depreciation	**93,829**	75,828
Profit on disposal	**(780)**	-
Irrecoverable VAT	**53,468**	48,952
Bank charges	**2,115**	2,954
Sundry expenses	**(5,988)**	7,911
Governance costs:		
Audit, non-audit and internal audit fees	**24,850**	31,300
	1,090,424	921,445
Total allocation	**3,341,660**	3,154,975

Notes to the financial statements
(continued)

8. Trustees

None of the Trustees received any remuneration from DEBRA during the period, but three of them were reimbursed a total of £310 (2023: one - £58) for travel and accommodation expenses. No Trustees received community grants (2023: £nil), but three family members of Trustee received equipment grants totalling £5,583 in aggregate. This included a specialist wheelchair, dermatherapy bedding and cooling equipment. The aggregate figure for trustee donations in 2024 was £2,384 (2023: £3,135). In addition, many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £4,337 (2023: £5,422), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9. Employees

The average number of employees during the period was:

	2024	**2024**	2023	2023
	No.	**FTE**	No.	FTE
Research	**3**	**2.7**	2	1.7
Healthcare*	**-**	**-**	-	-
Community Support	**19.3**	**18.5**	17	15.7
Fundraising & Comms	**22.2**	**20.1**	23	20.8
Retail	**289.5**	**220**	298	223.8
Management & Administration	**28.3**	**26.2**	28	26.0
	362.3	**287.5**	368	288.0

Notes to the financial statements
(continued)

At the end of the year the number of employees per department was:

	2024 No.	2024 FTE	2023 No.	2023 FTE
Research	**3**	**2.7**	2	1.7
Healthcare*	**-**	**-**	-	-
Community Support	**19**	**18.6**	20	18.1
Fundraising & Comms	**23**	**21.6**	22	20.0
Retail	**277**	**209.2**	290	219.0
Management & Administration	**27**	**24.8**	27	24.9
	349	**276.9**	361	283.7

*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 20. Staff employed by external institutions and funded through research grants are also excluded.

	2024 £	2023 £
Wages & salaries	**8,689,031**	8,134,599
Social security costs	**677,101**	638,017
Pension costs	**501,581**	407,332
Total payroll	**9,867,713**	9,179,948
Other staff costs	**437,128**	523,177
Total allocation	**10,304,841**	9,703,125

Notes to the financial statements
(continued)

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £627,207 (2023: £407,332) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £nil (2023: £nil) unpaid.

There are adequate systems in place to manage expenses and they do not form part of remuneration.

The following members of staff received emoluments above £60,000:

	2024	2023
	No.	No.
Between £60,001 - £70,000	**1**	-
Between £70,001 - £80,000	**5**	4
Between £80,001 - £90,000	**1**	1
Between £90,001 - £100,000	**1**	1
Between £100,001 - £110,000	**-**	-
Between £110,001 - £120,000	**-**	-
Between £120,001 - £130,000	**-**	1
Between £130,001 - £140,000	**2**	-

Redundancy and compensation payments, which were all paid in year, totalled £62,698 (2023: £25,000).

The aggregate pay of key management personnel, including employer's NI and pension contributions was £990,942 (2023: £898,711). The aggregate employer's pension contribution for key management personnel was £75,223 (2023: £75,378).

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £88,817 (2023: £64,176), and there are retirement benefits accruing for ten (2023: seven) employees under a defined contribution scheme.

Notes to the financial statements
(continued)

10. Fixed assets

Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land & buildings	Long leasehold land & buildings	Total
	£	£	£	£	£	£
Cost:						
At 1 January 2024	301,509	844,763	853,017	578,347	82,500	2,660,136
Additions	-	-	649,193	-	-	649,193
Disposals	(183,499)	(28,948)	(76,385)	-	-	(288,832)
At 31 December 2024	**118,010**	**815,815**	**1,425,825**	**578,347**	**82,500**	**3,020,497**
Depreciation:						
At 1 January 2024	255,015	373,663	376,221	193,185	24,750	1,222,834
Charge for the year	19,004	97,578	270,318	12,877	1,650	401,427
Disposals	(183,235)	(28,218)	(74,248)	-	-	(285,701)
At 31 December 2024	**90,784**	**443,023**	**572,291**	**206,062**	**26,400**	**1,338,560**
Net book value:						
1 January 2024	**46,494**	**471,100**	**476,796**	**385,162**	**57,750**	**1,437,302**
31 December 2024	**27,226**	**372,792**	**853,534**	**372,285**	**56,100**	**1,681,937**

The Head Office fit out costs, mobile equipment and software development costs have been included in the fixtures, fittings and equipment category.

Notes to the financial statements
(continued)

11. Programme related investment

	2024	2023
	£	£
Investment in Fibrx Derm Inc		
Net investment value brought forward	**1**	1
Purchase of investment	**-**	-
Impairment charge	**-**	-
Net investment value carried forward	**1**	1

The Trustees invested £190,840 ($250,000) in Fibrx Derm Inc, a US biotech company, purchasing 203,252 series A-2 convertible preferred stock, at a price of $1.23 per share. This investment supported the development of a new treatment to help wound healing in patients suffering from Dystrophic Epidermolysis Bullosa. The purpose of this investment was in furtherance of the charitable objectives of the charity, and no financial return was expected. The value of the investment has been impaired by 99.99% as the most prudent course of action.

12. Investment in subsidiaries

DEBRA had two 100% owned subsidiary companies incorporated in England and Wales at 31 December 2024 (2023: two). These are DEBRA Trading Ltd (company number: 2487114), whose principal activities are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship; and DEBRA Retail Ltd which is dormant.

Financial information for these entities for the year ended 31 December 2024:

	2024		2023	
	DEBRA Trading Ltd	**DEBRA Retail Ltd**	DEBRA Trading Ltd	DEBRA Retail Ltd
	£	**£**	£	£
Turnover	**284,775**	**-**	132,704	-
Total expenses	**161,842**	**-**	56,019	-
Gift aid to DEBRA	**119,683**	**-**	76,685	-
Profit / (loss) for the year	**-**	**-**	-	-
Net assets / (liabilities)	**2**	**1**	2	1
Share capital	**2**	**1**	2	1

Notes to the financial statements
(continued)

13. Debtors

	2024	2023
	£	£
HMRC	**188,123**	276,706
Amounts due from group undertakings	**150,882**	74,255
Other debtors	**528,653**	541,881
Accrued income	**1,339,021**	739,158
Prepayments	**748,194**	482,242
	2,954,873	2,114,242

Amounts due from HMRC are VAT receivable of £188,123 (2023: £276,206). Other debtors includes £442,771 (2023: £269,083) due for shared research grants. Accrued income includes gift aid of 290,403 (2023: £467,366) due from HMRC.

14. Investments in short term deposits

	2024	2023
	£	£
HSBC money market deposits:		
Investments brought forward at 1 January	**2,024,298**	3,000,000
Purchase of investments	**500,000**	2,024,298
Sales of investments	**(2,024,298)**	(3,000,000)
Investments carried forward at 31 December	**500,000**	2,024,298

Notes to the financial statements
(continued)

15. Creditors: amounts falling due within one year

	2024	2023
	£	£
Trade creditors	**375,681**	90,464
Grants payable	**2,302,769**	1,921,526
Other creditors	**300,165**	291,643
Taxation and social security	**155,524**	162,597
Accruals	**424,596**	527,769
Deferred income	**70,095**	5,965
	3,628,830	2,999,965

Grants payable includes £958,693 (2023: £1,724,017) relating to future commitments and £1,344,076 (2023: £971,185) relating to outstanding invoices for work done.

There was deferred income of £70,095 (2023: £5,965), representing income for events which would have to be repaid in the event of cancellation.

16. Creditors: amounts falling due over one year

	2024	2023
	£	£
Grants payable	**694,192**	881,673
	694,192	881,673

17. Provision for liabilities

	2024	2023
	£	£
Dilapidations provision		
Provision brought forward	**218,812**	237,952
Charges	**335,439**	20,560
Release of provision	**(151,141)**	(39,700)
Provision carried forward	**403,110**	218,812

Notes to the financial statements
(continued)

18. Other financial commitments

The following payments are committed to be paid in the future in respect of operating leases:

	2024 Leases of land and buildings	**2024 Other**	2023 Leases of land and buildings	2023 Other
	£	**£**	£	£
Within one year	**865,580**	**3,324**	968,931	4,432
Between one – five years	**1,157,631**	**-**	1,485,626	3,324
After five years	**-**	**-**	13,359	-
	2,023,211	**3,324**	2,467,916	7,756

There were capital commitments of £nil (2023: £nil) at year end, falling due within one year.

19. Analysis of funds: restricted funds

	Balance at 1 January 2024	**Income**	**Expenditure**	**Transfer to general fund**	**Balance at 31 December 2024**
	£	**£**	**£**	**£**	**£**
Oliver Thomas Memorial Fund	**19,200**	**-**	**(10,000)**	**-**	**9,200**
Research	**35,000**	**506,502**	**(466,354)**	**-**	**75,148**
Healthcare	**32,857**	**89**	**(63)**	**-**	**32,883**
Community support	**81,647**	**40,962**	**(88,772)**	**-**	**33,836**
Respite	**251,964**	**87,000**	**(115,363)**	**-**	**223,601**
	420,668	**634,553**	**(680,553)**	**-**	**374,668**

	Balance at 1 January 2023	Income	Expenditure	Transfer to general fund	Balance at 31 December 2023
	£	£	£	£	£
Oliver Thomas Memorial Fund	111,700	-	(92,500)	-	19,200
Research	151,607	467,765	(584,372)	-	35,000
Healthcare	5,600	27,257	-	-	32,857
Community support	85,942	109,236	(113,531)	-	81,647
Respite	132,662	151,145	(31,843)	-	251,964
	487,511	755,403	(822,246)	-	420,668

Notes to the financial statements
(continued)

Restricted funds comprised:	2024	2023
	£	£
Oliver Thomas Memorial Fund[1]	**9,200**	19,200
Research:		
Research Programme Ninewells Hospital Dundee	**75,148**	35,000
Healthcare:		
Birmingham Children's Hospital Specialist Bath	**5,600**	5,600
Catrina Bernardis Fellowship – Hand Surgery	**27,283**	27,257
Community support:		
Community Support team leader	**-**	26,000
Community Support in Berkshire	**2,122**	4,273
Support Grants in Hampshire	**-**	1,552
Support Grants in Somerset	**6,565**	6,914
Support Grants in West Midlands	**-**	581
Support Grants in Buckinghamshire	**22,199**	23,581
Support grants in Cambridgeshire	**1,531**	3,109
Support grants in Midlands	**-**	2,000
Other restricted funds	**1,419**	13,637
Respite breaks:		
Holiday home purchases	**223,601**	251,007
Mobile home appeal	**-**	957
Total	**374,668**	420,668

1. The Oliver Thomas Memorial Fund was established in September 2022. The remaining balance is restricted to £10,000 for an EB weekend get-together and £9,200 for Clinical Best Practice Guidelines.

Notes to the financial statements
(continued)

20. Analysis of funds: unrestricted funds

The Trustees allocated the following amounts as designated funds in 2024:

	Balance at 1 January 2024	Income	Expenditure	Transfers	Balance at 31 December 2024
	£	£	£	£	£
Drug Re-purposing	**481,397**	**-**	**-**	**(481,397)**	**-**
Nursing continuity	**250,000**	**-**	**-**	**(250,000)**	**-**
IT Strategy	**50,000**	**-**	**(50,000)**	**-**	**-**
NHS Digital	**200,000**	**-**	**(100,000)**	**-**	**100,000**
Total designated funds	**981,397**	**-**	**(150,000)**	**(731,397)**	**100,000**
General fund	**2,185,187**	**17,541,601**	**(17,726,595)**	**731,397**	**2,731,590**
Total unrestricted funds	**3,166,584**	**17,541,601**	**(17,876,595)**	**-**	**2,831,590**

	Balance at 1 January 2023	Income	Expenditure	Transfers	Balance at 31 December 2023
	£	£	£	£	£
Drug Re-purposing	481,397	-	-		481,397
Nursing continuity	250,000	-	-	-	250,000
IT Strategy	50,000	-	-	-	50,000
Procurement	19,000	-	(19,000)	-	-
NHS Digital	200,000	-	-	-	200,000
Total designated funds	1,000,397	-	(19,000)	-	981,397
General fund	2,762,264	17,473,036	(18,050,113)	-	2,185,187
Total unrestricted funds	3,762,661	17,473,036	(18,069,113)	-	3,166,584

£481,397 was designated in 2023 to fund drug re-purposing trials. As the specific project envisaged could not go ahead, this amount was transferred to the general fund in 2024 to be used against the research programme overall.

£200,000 was designated in previous year to fund the NHS Digital Data project. This project commenced in 2024 and is due to complete in 2025. At 31 December 2024 £100,000 remained unspent.

The designated fund for nursing continuity had been established in previous years as a contingency for EB nurses in the event of future NHS funding withdrawal. In 2024 it was established that the NHS provide this care under statutory requirements and funding from DEBRA is not required. As a result, the Trustees resolved to undesignate this fund and will consider alternative uses for these reserves in the future.

In 2021 £100,000 was designated to fund future procurement and IT work furthering modernisation of back office practices. The procurement consultancy work was completed in 2023. The IT strategy fund was allocated against CRM development costs in 2024 and the fund has now been fully spent.

Notes to the financial statements
(continued)

21. Analysis of net assets between categories of funds

Fund balances at 31 December 2024 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	**1,681,940**	**-**	**-**	**1,681,940**
Current assets	**5,775,782**	**100,000**	**374,668**	**6,250,450**
Creditors:<1 year	**(3,628,830)**	**-**	**-**	**(3,628,830)**
Creditors:>1 year	**(1,097,302)**	**-**	**-**	**(1,097,302)**
	2,731,590	**100,000**	**374,668**	**3,206,258**

Fund balances at 31 December 2023 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,437,305	-	-	1,437,305
Current assets	4,848,332	981,397	420,668	6,250,397
Creditors:<1 year	(2,999,963)	-	-	(2,999,963)
Creditors:>1 year	(1,100,485)	-	-	(1,100,485)
	2,185,189	981,397	420,668	3,587,254

Notes to the financial statements
(continued)

22. Reconciliation of net income to net cash flow from operating activities

	2024	2023
	£	£
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	**(380,994)**	(662,920)
Depreciation and amortisation charges	**401,427**	261,882
Impairment of programme related investment	**-**	-
Dividends, interest and rents from investments	**(43,478)**	(97,461)
Profit / (loss) on disposal of fixed assets	**3,131**	-
Decrease in stock	**-**	2,063
(Increase) / decrease in debtors	**(840,633)**	(257,561)
(Decrease) / increase in creditors	**625,684**	55,640
Net cash used in operating activities	**(234,863)**	(698,357)

23. Analysis of cash and cash equivalents

	2024	2023
	£	£
Cash at bank and in hand at 1 January	**2,111,857**	2,146,142
Cash flows	**683,720**	34,285
Cash at bank and in hand at 31 December	**2,795,577**	2,111,857

An analysis of changes in net debt note has not been prepared on the basis that DEBRA only has cash and cash equivalents, the movement on which is shown above.

Notes to the financial statements
(continued)

24. Grants to institutions

Research grants:	2024		2023	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
Guy's and St Thomas' Hospital, London				
Improved characterization of chronic wounds in RDEB	**24,888**	**55,388**	23,176	30,500
University of Birmingham				
Clinical Fellowship	**-**	**125,263**	26,359	125,263
Use of highly sensitive and specific gene analytical techniques to identify microorganisms that may play a role in the chronicity of EB wounds	**13,709**	**14,955**	1,246	1,246
High-retention, lubricating eye drops to enhance quality of life in EB patients	**67,529**	**144,569**	77,040	77,040
Instituto Dermopatico deli'Immacolata Rome				
Re histone deacetylase inhibitors for RDEB	**-**	**70,962**	1,928	70,962
King's College London				
PASTE-mediated superexon replacement of COL7A1 as a treatment for DEB	**95,838**	**111,682**	15,844	15,844
Great Ormond Street Institute of Child Health				
Respiratory cell & gene therapy for children with JEB	**-**	**135,338**	16,893	135,338
Bambino Gesù Children's Hospital				
MicroRNAs expression profiling, activity and therapeutic perspectives	**-**	**77,592**	4,408	77,592
University of Edinburgh				
Kindlin-1 loss in squamous cell carcinoma	**-**	**112,834**	22,213	112,834
New York Medical College				
Innate & adaptive immune mechanisms in RDEB	**-**	**207,538**	34,186	207,538

Notes to the financial statements
(continued)

Research grants:	2024		2023	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
CRUK Scotland Institute				
Drug repurposing for the treatment of RDEB squamous cell carcinoma	**26,464**	**96,892**	70,428	70,428
Pre-clinical models of RDEB squamous cell carcinoma	**53,180**	**61,996**	8,816	8,816
Integrated pharmacological and genetic identification of therapeutic targets for RDEB Squamous Cell Carcinoma	**2,917**	**2,917**	-	-
University Salzburg, Austria				
Investigating the potential of repurposing statins for the treatment of highly aggressive RDEB-tumors	**93,168**	**108,864**	15,696	15,696
Cardiff University				
Developing a self-help toolkit for supporting wellbeing in parents of children with EB	**57,274**	**62,000**	4,726	4,726
Queen Mary University, London				
Dissecting the role of inflammatory pathways in JEB	**37,644**	**40,781**	3,137	3,137
Improving skin regeneration in JEB	**34,991**	**37,900**	2,909	2,909
Oral mucosal scarring and resistance to cancer development in RDEB patients	**99,900**	**116,550**	16,650	16,650
Treating JEB with Recombinant Laminin 332	**88,656**	**103,432**	14,776	14,776
Targeting epigenetic gene regulation in EBS	**33,288**	**66,576**	33,288	33,288
Improving the regenerative capacity of Junctional EB skin by re-activating YAP/TAZ signalling	**2,916**	**2,916**		
Fundacion Instituto De Investigation, Madrid				
Non-viral genome editing patching of COL7A1	**13,750**	**15,000**	1,250	1,250
CIEMAT, Madrid				
Novel platform for generation of safer pseudorabies herpesvirus-based vectors for RDEB therapy	**13,750**	**15,000**	1,250	1,250

Notes to the financial statements
(continued)

	2024		2023	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
KK Women's & Children's Hospital, Singapore				
Improving the genetic diagnosis of EB by long-read sequencing	**9,625**	**10,500**	875	875
University of Buenos Aires				
Molecular epidemiology of EB Simplex in Argentina	**13,750**	**15,000**	1,250	1,250
Centre Hospitalier Universitaire de Nice, France				
A 20-Week Multicentre, Open Study Assessing the Efficacy and Safety of Apremilast (Otezla®)	**64,955**	**114,144**	49,189	49,189
University College, London				
Towards cell and gene therapy for JEB airway disease	**6,807**	**6,807**	-	-
Northwestern University, Chicago				
Patient travel support for Dupilumab for itch clinical trial	**4,303**	**4,303**	-	-
Queens University, Belfast				
Development of a Dual Nanogel for JEB	**2,913**	**2,913**	-	-
University of East Anglia, UK				
Epidemiology of Epidermolysis Bullosa in the UK	**13,440**	**13,440**	-	-
Regional Dermatology Training Centre, Moshi, Tanzania				
Establishing an Epidermolysis Bullosa Centre in Africa	**1,666**	**1,666**	-	-
University of Birmingham Dental School & Hospital				
Characterisation of skin microbiome in EB patients	**20,000**	**313,289**	-	293,289
Total	**897,321**	**2,269,007**	447,533	3,039,469

Notes to the financial statements
(continued)

Healthcare projects:	2024	2023
	Total paid in year	Total paid in year
	£	£
Great Ormond Street Hospital for Sick Children		
Clinical nurse specialists in EB	**39,213**	81,540
Guys & St Thomas' Hospital London		
Adult EB support nurses	**(27,380)**	5,572
Birmingham Children's Hospital	**(8,501)**	40,126
	3,332	127,238

Reconciliation of provision:	2024			
	Research grants	**Healthcare grants**	**Community Support grants**	**Total**
	£	**£**	**£**	**£**
Provision brought forward	**1,724,017**	**107,997**	**-**	**1,832,014**
New commitments	**718,193**	**3,332**	**133,311**	**854,836**
Spend in year	**(897,321)**	**(3,332)**	**(133,311)**	**(1,033,964)**
Provision carried forward	**1,544,889**	**107,997**	**-**	**1,652,886**

Reconciliation of provision:	2023			
	Research grants	Healthcare grants	Community Support grants	Total
	£	£	£	£
Provision brought forward	411,167	107,997	-	519,164
New commitments	1,760,383	127,238	144,028	2,031,649
Spend in year	(447,533)	(127,238)	(144,028)	(718,799)
Provision carried forward	1,724,017	107,997	-	1,832,014

25. Related parties

During the year, the charity charged management charges totalling £6,500 including VAT (2023: £6,500) to its subsidiary, DEBRA Trading Limited.

Reference and administrative details

Our Patron, President, Vice Presidents

Royal Patron
HRH The Duchess of Edinburgh GCVO

Life Patron
Philip Evans

President
Simon Weston CBE

Vice Presidents
Graeme Souness CBE
Frank Warren
Lenore England
Stuart Procter

Our Trustees

Jim Irvine (Chair)
Joanne Merchant* (Resigned 10 May 2024)
David Bendor-Samuel (Vice-Chair)
Carly Fields* (Vice-Chair)
Simone Bunting*
Christo Kapourani*
Simon Talbot*
Mick Thomas*
Dan Mundy
Deborah Install*
Laura Briggs (appointed 12 February 2025)*
Katy Hinchcliffe (appointed 12 February 2025)*
Gareth Jones (appointed 12 February 2025)

Additional details

Company secretary
Dawn Jarvis

Registration
Charity Commission Number: 1084958
SCR Number: SC039654
Company Number: 4118259

Registered office & principal address
DEBRA, The Capitol Building, Oldbury, Bracknell, RG12 8FZ

Auditor
Sayer Vincent LLP,
110 Golden Lane, London EC1Y 0TG

Banker
HSBC, Thames Valley Business Banking, Hanborough House, Wallbrook Court, North Hinksey, Oxford, OX2 0QS

Solicitor
Stone King, 91 Charterhouse Street, London, EC1M 6HR

*Members of the Board who have direct experience of EB.

Abbreviations

CPG	Clinical Practice Guidelines
CEO	Chief Executive Officer
CRM	Customer Relationship Management
DEB	Dystrophic Epidermolysis Bullosa
EB	Epidermolysis Bullosa
EBS	Epidermolysis Bullosa Simplex
JEB	Junctional Epidermolysis Bullosa
EDI	Equality, Diversity & Inclusion
EPOS	Electronic Point of Sale
ESG	Environmental, Social, Governance
GDPR	General Data Protection Regulation
HR	Human Resources
k	thousand
LFL	like-for-like
m	million
NHS	National Health Service
pa	per annum
RDEB	Recessive Dystrophic Epidermolysis Bullosa
SGAP	Scientific Grants Advisory Panel
SLT	Senior Leadership Team
y on y	year on year

debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

DEBRA funds pioneering research, specialist healthcare, international best practice and life-long care and support to the EB community. We make a difference today with the aim of a better future for those suffering from the condition.

Together we will #StopThePain.

DEBRA, The Capitol Building, Oldbury, Bracknell, Berkshire, RG12 8FZ

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DEBRA Royal Patron - HRH The Duchess of Edinburgh, GCVO
DEBRA President - Simon Weston CBE

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

A charity registered in England and Wales (1084958D) and Scotland (SC039654).
Company limited by guarantee registered in England and Wales (4118259).
VAT Number 689 2482 79.

Registered with FUNDRAISING REGULATOR

DEBRA

England & Wales - Charity number 1084958

Accounts

debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

Trustees´ Annual Report & Accounts 2023

Our vision

A world where no one suffers with epidermolysis bullosa (EB).

Our mission

Provide life-long care, while seeking cures, for all those affected/impacted by living with EB.

Our values

Making a difference

Caring

Inclusive

Respectful

Passionate

Committed

Contents

The trustees present the annual report (including the strategic report) for the year ended December 2023.

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What is EB

Skin as fragile as a butterfly's wings

Epidermolysis bullosa (EB) is a group of incredibly painful genetic skin conditions that cause the skin to blister and tear at the slightest touch. With skin as fragile as a butterfly's wings, it is often referred to as 'butterfly skin'.

EB can affect the hands and feet only or in the most severe cases any part of the body, including blistering on the eyes and internal organs.

Genetic condition

People living with EB have a faulty or mutated gene which means the skin cannot bind together and any friction can cause it to tear. Every person has two copies of each gene – one passed on from each parent. EB may be inherited as either dominant (only one copy of the gene is faulty) or recessive (both copies of the gene are faulty).

Parents have a 50% chance of passing on a dominant form of EB to their child, whereas the chance of passing on a recessive form of EB drops to 25%. Both parents may carry the gene without knowing or displaying any symptoms.

Types of EB

There are over 30 subtypes of EB, grouped into four main types: EB Simplex (EBS), accounting for around 70% of patients, Dystrophic EB (DEB) 25%, Junctional EB (JEB) 5% and Kindler EB which is rare.

Symptoms and complications

Symptoms vary and range in severity depending on the type of EB. Blisters continuously form and must be drained and dressed daily, a painful process that can take several hours.

Internal blisters such as inside the mouth can create difficulty swallowing. There can be narrowing of the oesophagus and airways. The build-up of scar tissue can cause fingers and toes to fuse together, EB can increase the risk of developing skin cancer, and in severe cases it can be fatal.

Treatments

There is currently only one approved EB drug treatment, Filsuvez®, a topical gel that can be used to treat partial thickness wounds associated with DEB and JEB. This new drug was approved in 2023.

Other treatments that people living with EB may receive are primarily focused on alleviating the symptoms of EB as much as possible, preventing further damage to the skin, and reducing the risk of complications such as infection. The most common challenge amongst all types of EB is the pain and itching that occurs because of the blistering.

No cures

There are an estimated 5,000 people affected by EB in the UK and 500,000 worldwide. However, these numbers could be much higher as it often goes undiagnosed. Currently there are no cures for EB.

A welcome from our Chair of Trustees and CEO

Bringing EB to the public's attention

2023 was a pivotal year for the EB community and for DEBRA UK. Through the A Life Free of Pain appeal and the associated English Channel swimming challenge completed by our Vice President, Graeme Souness, member, Andy Grist, and the team, EB was brought to the public's attention, new supporters and funding was brought into the charity, and members of the EB community who previously weren't aware of DEBRA UK were able to access our support services.

Thanks to donations received through the appeal we also invested in the first of what we hope will be many drug repurposing clinical trials.

2023 saw the UK get its first approved drug (Filsuvez®) for the treatment of partial thickness wounds associated with DEB and JEB. For this we are very thankful to the DEBRA UK members who provided powerful patient testimony, to Amryt Pharma PLC who developed this drug, and to the National Institute for Health Care and Excellence (NICE) who recognised the urgent need for this drug treatment for the UK EB community.

The year wasn't without its challenges though. The external environment and operating conditions for our retail function presented significant challenges in terms of increased costs and revenue generation. These challenges will remain in 2024, however by building a more efficient and lean retail function, using this as a basis for expansion, and ensuring that we have stores in locations that offer the greatest revenue and contribution potential, we are confident that we can overcome these challenges. We will also continue to leverage the opportunity for incremental sales growth and contribution through our online platforms.

In 2024, we need to continue the momentum that we generated in 2023. There is still much to do.

As evidenced in last year's EB insights study, the UK EB community needs more support today whilst we work on securing effective drug treatments for every type of EB for tomorrow. They cannot wait, they need better mental health support, cost-of-living financial support, and more opportunities to connect with each other now.

Our drug repurposing journey has only just started; there are many more repurposed drugs that we need to clinically test. To do this we need our supporters to stay on the journey with us, we need to attract new supporters, and we need financial assistance from the government.

We are delighted that we have funded two non-clinical fellowships commencing in 2024 studying EB and we plan to support more clinical and non-clinical fellowships in the years ahead.

Despite improving awareness of EB and DEBRA in 2023, awareness overall remains low and so we must continue to leverage all the opportunities available to us to raise awareness with the public and to connect with members of the EB community who may not be aware of DEBRA UK so that they can become members and benefit from the support services we offer. We also need more healthcare professionals to be aware of EB and be able to diagnose it so that they can refer patients to the specialist EB healthcare that is already available through the NHS.

There is much to do but together as one – our members; trustees; staff; volunteers; our Royal Patron, HRH Duchess of Edinburgh GCVO; our president, Simon Weston CBE; our vice presidents; our advisors; and our ambassadors – we can BE the difference for EB.

Jim Irvine
Chair of Trustees

Tony Byrne
CEO

Our work

Investing in a future free of EB

DEBRA UK was the world's first EB patient support organisation, founded in 1978 by Phyllis Hilton whose daughter Debra was born in 1963 with Dystrophic EB. When told by medical professionals that she should take her baby home as nothing could be done for her, she set out to find ways to treat Debra's skin herself using cotton dressings.

At the age of 15, in 1978, Debra sadly passed away. Later that same year Phyllis met a parent seeking advice for their child and realised that nothing had changed. She decided to act, organising the first ever meeting for parents of EB and so DEBRA was formed.

We have come a long way since then. We have achieved global recognition as a leading authority on EB and made significant progress in advancing diagnosis, treatment, and daily management of the symptoms of EB. DEBRA is international in scope with a network of DEBRA groups, including DEBRA UK, sharing information and best practice. We are committed to making sure that people with EB and their families and carers get the vital, wide-ranging care and support they need so that the devastating symptoms of EB can be reduced while we work towards finding effective drug treatments for every type of EB.

Life-changing EB research

The research journey for EB over the past 46 years has been remarkable – from gene discovery to cutting-edge trials of therapies that control symptoms and manage complications like cancer. During this time DEBRA UK has invested over £22m and been responsible for establishing much of what is now known about EB. We are the largest UK funder of EB research, and we have an ambitious, patient-centred research strategy that drives us to fund science of the highest quality across the world, including prioritising investment in drug repurposing, to develop a treatment pipeline that will slow or stop the progression of EB.

Specialist healthcare

In 1987 we funded the first specialist EB nurse. We now work in partnership with the NHS to deliver an enhanced EB healthcare service for people with all types of EB in the UK. We have invested in the development of EB centres of excellence, fund clinical best practice guidelines for clinicians and individuals, and connect patients with the expert, specialist services they need across the UK. Our funding has helped establish a model EB diagnostics centre, which makes it possible for parents to receive prenatal diagnostic testing if they are at risk of passing on EB. We are dedicated to ensuring that everyone with EB has access to the best care and expertise from diagnosis onwards.

Life-long community support

The EB community is at the heart of everything we do. We are the only UK EB charity equally focused on today and tomorrow – providing care and support for the EB community today whilst investing in research to secure effective drug treatments for tomorrow.

We provide individualised support, information and guidance for people living with EB and their families and carers – from providing financial grants and benefits information to bereavement support, social opportunities, holiday home respite, and advocacy. We connect patients with the specialist services they need and provide a support network for the entire EB community in the UK. We connect people to help ensure they benefit from peer support.

International collaboration to enhance global EB patient care and best practice

We partner and work collaboratively with international organisations and the global DEBRA network to undertake world-class research, coordinate international research grants, support the next generation of EB researchers, and share ideas, expertise, and best practice.

We are the founding member and continue to invest in DEBRA International, the umbrella organisation which supports close to 50 DEBRA groups worldwide working collaboratively to improve EB patient outcomes. Through DEBRA International we support the development of Clinical Practice Guidelines to increase professional knowledge and best practice for EB patients around the world.

Being the difference for EB

Our impact in 2023

£4.4m spent on research, healthcare, and EB community support.

3877 DEBRA UK members, a +9.5% year on year increase.

£3.7m income raised, thanks to our loyal supporters and customers, which helped ensure we achieved the £5m A Life Free of Pain appeal target.

22 DEBRA UK charity shops re-branded, creating a better retail environment and increasing awareness of EB and our charitable activities.

EB brought to the public's attention through exposure on national media including BBC's The One Show, ITV's This Morning, and national and regional radio.

Unprompted awareness of EB up from **6% to 10%**, and awareness of DEBRA up from 15% to 23%.

Our largest ever EB insight study completed with 200+ members of the EB community and **150** healthcare professionals.

Our first drug repurposing **clinical trial** commissioned.

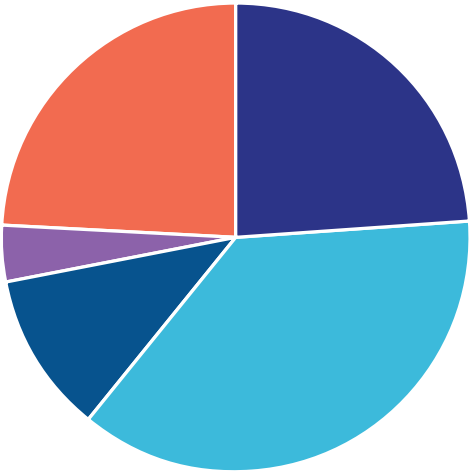
Achieved together thanks to the support of:

- 370 staff.
- 1,065 volunteers who gave 211,132 hours of their time for free, saving the charity over £2.2 million.
- 10 trustees with 7 living with or directly affected by EB.
- 94 DEBRA UK charity shops in England and Scotland.

Committed to the EB community

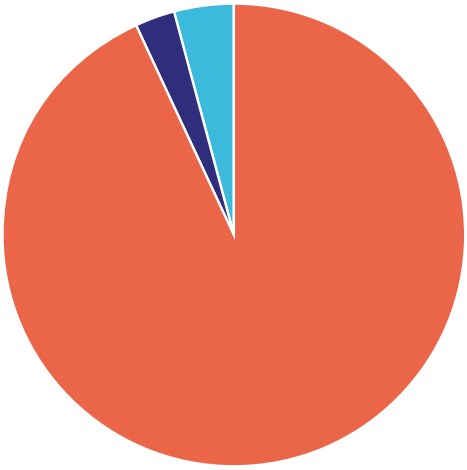
We are committed to ensuring that people with EB in the UK and their families and carers get the essential support they desperately need, supporting specialist healthcare, and investing in life-changing research.

The activities
we spent on in 2023



- Research - £1,569,000
- Community support - £1,232,000
- Healthcare - £563,000
- Respite breaks - £109,000
- Public education - £923,000

How we raised money



- Fundraising
- Retail
- Other

£3,468,000 net fundraising income,
£107,000 net retail income
£146,000 other income

Research into effective treatments for EB

Our vision

Our vision is unchanged: we strive for a world where no one suffers with the pain of EB.

We are 100% focused on what matters most for the EB community, which is effective treatments to lessen the day-to-day impact of EB. To provide this we continue to fund science of the highest quality with the potential to deliver for the EB community, and we play a pivotal role in making EB research a global effort. We work with other organisations, but DEBRA UK is at the centre, leading the quest for innovations to improve quality of life for people living with all types of EB.

Our objectives

Our Research Strategy 2022 to 2026 and its four overarching research objectives, as detailed below, continued to be the driver for change in 2023:

1. Invest in drug repurposing and develop drug discovery programmes to accelerate securing treatments for all types of EB.
2. Increase investment in patient-centred research themes.
3. Continue to invest to better understand the causes and progression of EB and the role of the immune system.
4. Invest in the next generation of EB researchers.

Our progress in 2023

Independent advisor

We were delighted that Professor Chris Griffiths OBE, a world-renowned dermatologist, agreed to become our independent advisor.

Professor Griffiths has provided invaluable advice to support our research programme and has been proactively involved in supporting the charity by speaking at awareness events, including the House of Commons, on the principles of drug repurposing and the potential benefits it offers for people living with EB.

Research grant process

Our first national and international open grant calls were advertised and received 27 applications from EB researchers from 10 different countries. We also recruited two PhD students to our new non-clinical fellowship programme which aims to recruit and support the next generation of EB researchers.

Scientific Grant Advisory Panel

Our Scientific Grant Advisory Panel, which reviews grants on our behalf and makes recommendations to our Charitable Purposes Committee, increased from six to eight members. All members are renowned national and/or international experts in their field and/or EB.

In addition, we now have a lived experience group consisting of 15 members which reviews research applications to ensure the patients' voices are heard, and their feedback helps shape our research plans. The feedback from members has been positive, and the panel is now part of the standard review process.

Drug repurposing programme

We approved our first drug repurposing clinical trial which will see an existing licensed treatment for psoriasis (apremilast) clinically tested on children and adults with severe EBS. The study will be led by Dr Christine Chiaverini, a dermatologist who works at the Centre Hospitalier Universitaire de Nice in France.

Encouraging results published after an initial small trial showed that it appears to reduce blistering and we are now funding a larger trial to measure not only blistering but also whether it could improve quality of life by reducing pain and itch. The clinical trial is set to take two years to complete.

Our plans for 2024

Partnerships

We will continue to seek partnerships with both EB and non-EB organisations to maximise our research funding potential.

We will develop positive relationships with the pharmaceutical industry, the MHRA (Medicines and Healthcare products Regulatory Agency) and NICE to maximise the opportunity to gain UK approval for drugs treatments for all types of EB.

Patient-centricity

EB patients, their family members, and carers through their own experiences are the experts on the impact of EB. Therefore, it is vitally important that the needs of the EB community, those living and working with the condition, help shape the research selection process and drive the future of EB research, balancing short-term patient benefits and support for long-term research into potential treatments. Through forums such as the lived experience group we will continue to ensure that patient voices are heard and help shape our research programme.

Increasing awareness

We will work with both EB and non-EB researchers globally to develop content including podcasts, blogs, and films to raise awareness of EB, and to inform and educate the EB community.

We will attend relevant conferences to raise awareness of EB and of DEBRA UK, our funding schemes and what they entail, with the global research community, pharmaceutical companies, and other organisations.

Specialist healthcare

Working in partnership with the NHS to support over 2,000 EB patients every year.

DEBRA UK works in partnership with the NHS to deliver an enhanced and multi-disciplinary EB healthcare service which is vital for people living with all types of EB. We work with the UK's four designated EB centres of excellence and the Scottish EB service. In 2017 we part-funded the national centre for adults with EB at Guy's and St Thomas' Hospital in London which continues to provide excellent facilities to the EB community.

We continue to fund and promote the clinical best practice guidelines for clinicians and strive to connect EB patients with the expert, specialist healthcare services they need, wherever they live in the UK.

Our ambition

We are dedicated to ensuring that everyone with any type of EB has access to the best care and specialist EB healthcare expertise from diagnosis onwards.

Our objectives

1. To connect patients with all types of EB with the expert, specialist healthcare services they need.
2. To enable and support the development of specialist EB healthcare expertise, services, and multi-disciplinary working.
3. To provide specialist EB healthcare information to the EB community.

Our progress in 2023

In 2023 we continued to part-fund EB healthcare professionals working within the NHS EB healthcare centres of excellence including specialist EB nurses at Great Ormond Street Hospital and Birmingham Women's and Childrens Hospital, and specialist EB dieticians at the Birmingham Children's Hospital. This funding enabled the teams to carry out work that often doesn't fall within the NHS duty of care to provide including additional bereavement home visits. We also provided funding for study and training grants to support their continuous development.

Our Community Support Team continued to work with the EB healthcare centres, as part of the multi-disciplinary team, to ensure people living with EB and their families were able to access the specialist health and social care and expertise they needed. The DEBRA team helped support the quarterly EB clinical network meetings which bring together the clinical teams from the four EB healthcare centres to share experiences and best practice. Members of the healthcare teams also attended DEBRA UK events including Members Weekend where they had to opportunity to deliver workshops on key EB topics and directly engage with members.

Our plans for 2024

We will continue to work with the NHS EB healthcare centres offering funding and other support to enhance services for the EB community.

We will engage with UK podiatry colleges, embed the accredited EB podiatry training course and run a pilot funding programme that will enable members to access expert care locally.

We will continue to work with EB healthcare professionals and the support teams to update and develop new publications and accessible content to educate and inform our members and support them in educating others about EB, including schools, workplaces, GPs, and other people working to support the EB community.

We are dedicated to ensuring that everyone with EB has access to the best care and specialist expertise from diagnosis onwards.

EB community support

Life-long support, advocacy, and engagement

3877
DEBRA UK members (1857 living with EB)

500+
members stayed in our holiday homes in 2023

424
support grants awarded in 2023

9.5%
increase in membership vs. 2022

1621
requests for support from the DEBRA Community Support Team

30
events (in-person or virtual)

Our ambition

To provide a comprehensive programme of targeted care and support for the EB community which directly addresses their key needs and maximises every opportunity to make a difference and improve their quality of life.

Our objectives

1. To build our membership, increasing numbers, diversity, and engagement with the wider EB community.
2. To provide access to support and the specialist health and social care that the EB community needs.
3. To empower our members, ensuring their voice is heard and acted upon and that they have choice and independence throughout their journey of life living with EB.

Our progress in 2023

Membership

Our total membership at the end of 2023 was 3877, 1857 of whom are living with EB. The year-on-year growth in members with EB was 12.6%, which is very encouraging as it means we have reached new members of the EB community who previously weren't benefiting from the services we offer. We also grew the number of members we have with EBS by 13.3%, which is very positive because we know historically some people with EBS have decided against accessing our services as they felt they should be reserved for people with more severe types of EB. DEBRA UK exists to support anyone in the UK living with any type of EB.

Community support

With a full-strength DEBRA Community Support Team, we were able to support more members in 2023, particularly in Scotland where there had previously been a resource shortage. The development of services in this area this year has been very well received by the EB community.

On average we provided community support to 299 members every quarter in 2023, and in the second half of the year we supported 37.5% more members than in the equivalent period in 2022.

Throughout 2023 we supported 619 individual members and conducted 184 home visits.

We were also able to offer financial support to more members in 2023 than in 2022; a total of 424 financial support grants were awarded during the year with a combined value of over £105,000, which was a 14% increase in the total number of grants issued and a 24% increase in total value compared to 2022.

Two new on-line platforms were launched in 2023 to provide additional support for our members; Togetherall, an award winning on-line mental health service which offers safe and confidential peer and community mental health support, and EB Connect, where we set up a UK specific page on this private on-line platform that enables the global EB community to connect with each other to share ideas, experiences, and to create friendships.

Member engagement

Our robust member engagement strategy continued to be embedded across the organisation ensuring that members are always at the centre of our decision-making.

We were very grateful to be able to count on the support of 167 active members of our involvement network in 2023 who supported the charity in many ways including shaping the future of our EB services, deciding what research we'll fund next, defining our holiday home priorities, and enhancing our member events.

In 2023 our members also played a crucial role in both the EB insights study and the NICE approval of Filsuvez®.

The EB insights study was our most comprehensive patient-centric research project to date completed by over 200 members of the EB community, representing all the different types of EB, plus over 100 carers, 50 dermatologists, and 100 GPs. The study provided a baseline of invaluable data from those who know and understand EB best: the EB community, and it highlighted the key issues that need addressing. Without the involvement of the EB community, this study wouldn't have been possible.

DEBRA UK members were also heavily involved with the NICE approval of Filsuvez®, providing powerful patient testimony on the behalf of the EB community which included sharing the daily impact that EB has on their lives and the improvements that a drug such as Filsuvez® could make in terms of quality of life. We are very grateful to our members input which was so integral to securing approval.

Holiday home respite

Ahead of schedule we were pleased to be able to replace an older holiday home in Weymouth and add a second holiday home also in Weymouth and extend our choice of destinations with a new holiday home in Newquay.

In 2023 a total of 500 members benefitted from respite breaks in one of our seven UK holiday homes.

Member events

Throughout 2023 we provided opportunities for our members to connect with each other both virtually and in-person.

We held a total of 9 in-person member events during the year including our annual Members Weekend in May, which was attended by 329 people including 249 members, and our first post pandemic meeting in Scotland, which was attended by 45 members. We also hosted 21 virtual meetings including our series of popular Parent Pitstops.

Our plans for 2024

Membership

We need to extend our reach and connect with more members of the EB community, people who have EB but may not be aware of DEBRA UK and of the services we offer, so that they can also benefit from what we do. To achieve this, we will develop and better communicate our membership offer, and continue to raise awareness of EB, and of our support services. Our objective in 2024 is to increase our overall membership by at least 5%.

Community support

We will work with the EB community to effectively address the key issues that were raised in the 2023 EB insights study.

Many members of the EB community told us that they are being negatively impacted by the cost-of-living crisis, to address this we will increase awareness of both the financial support grants that are available through DEBRA UK, but also the financial assistance and advice that we can offer members to support them with benefit applications and to access other non-DEBRA financial support.

We will continue to offer standardised financial support grants to our members but also expand our offering with a more bespoke package of financial assistance that in conjunction with the support we can offer through the DEBRA Community Support Team will make a tangible difference to our members in times of need.

Our members also told us that the mental health provision available through the NHS for people living with or directly affected by EB is inadequate and better support is needed. In 2023 we partnered with Togetherall, to make available this on-line mental health service to our members, however we need to do more and in 2024 we will trial and review a new face-to-face mental health counselling service for our members.

To deliver an efficient, effective service that supports as many of our members as possible the DEBRA Community Support Team will continue to develop a hybrid way of working with the option of face-to-face or virtual support, depending on the individual needs of the member.

Member engagement

Our members are at the centre of everything we do and in 2024 and beyond we will continue to expand our engagement activities, both in terms of frequency and the ways in which we engage with members, to ensure they continue to play a key role in shaping what we do, and how we do it. This will include increasing member involvement network groups, publishing insights, and assisting in further data collection to assist lobbying and collaboration with the pharmaceutical industry, and other key stakeholders.

Member events

We will continue to develop the range of virtual groups and in-person events we offer throughout the year with more opportunities for the EB community to connect and where presentations are made at events (in-person or virtual), wherever possible we will record and share relevant content via the DEBRA UK website.

For the 2024 Members Weekend we will also create the opportunity for members to join the presentations via live streaming so that anyone unable to physically attend can still feel part of the community and benefit from the content shared on the day.

Any clips that we can get from events where possible we will use as EB teaching aids, to develop publicity for future members' events, and where appropriate to support our fundraising initiatives.

My EB story - Living with EB isn´t easy

“

Throughout my life, I have suffered from a genetic skin condition passed down from my father. Growing up with this condition, it felt like a natural part of my everyday life, and for that reason, I never pursued any medical help or outside help – I essentially used ignorance as a coping mechanism.

At the age of 25, I decided to live my life to the fullest. Having this rare skin condition had made me a hermit, and compared to my peers and friends, my social life was lacking considerably. At this point, I decided to enjoy the usual 20-something activities such as travelling and attending festivals, without really giving much thought to my physical limitations. Before attending events or travelling, the most I would do was purchase a few extra Compeed plasters and moisture-wicking socks. However, I soon found out living life as a ‘normal guy’ in his 20s wasn’t that simple. My travels would usually end up with my feet covered in blisters, which, in turn, made me miserable to myself and to my friends. Likewise with attending festivals. I went to Glastonbury in 2017 and Tomorrowland in Belgium in 2018 – both of which I suffered greatly, and I also missed out on many acts due to being incapable of walking or standing. It was at this precise point that I decided to seek help and try to explore my options.

After a six-month wait, I was referred to St Thomas’ Rare Diseases Centre where my condition of epidermolysis bullosa simplex was confirmed, and I was offered more support. It was also at this moment where I was introduced to DEBRA UK. As a sceptic, I was reluctant to engage with DEBRA UK or any other charity for that matter – you can argue there was some peer pressure involved at the signup; however, this has been one of the best decisions I have ever taken.

Since signing up as a member with DEBRA UK, I have gained important knowledge about the EB community and the support available to us. I was given support with obtaining a Blue Badge; this has been an important inclusion in my everyday life, and I now suffer much less, especially after a bad outbreak of blisters. After obtaining my Blue Badge, I was told about the government support that was available to me, such as Personal Independence Payment. With the support of DEBRA UK through one-to-one appointments, I was able to successfully apply for this, which has given me financial support with some of the costs of bandages and plasters, as well as reapplying for my Blue Badge.

As well as the support and advice given to me, I have also been able to meet some great individuals and characters in the EB community who share my condition. During Covid-19 lockdown, we were able to attend weekly online Zoom events to discuss various aspects of our lives. They provided emotional relief during a difficult period, and it was comforting to know I was not alone with this cruel condition.

As a sufferer of EB simplex, I couldn’t be more thankful for the assistance I have received over the last few years, and I wish I had known about DEBRA UK a long time ago. Living with EB simplex or any other EB condition isn’t easy, but knowing there is support and advice at any given time has been a massive help to my life and situation. Besides their personal help, DEBRA UK also fund research into repurposing medicine and looking at cures. With all that being said, I would urge anyone with EB or as parents of children suffering from EB, to sign up to DEBRA UK.”

DEBRA member living with EBS

”

Our partnerships

We are proud to collaborate and work in partnership with healthcare, research, and corporate partners across the UK and internationally.

150+
research projects worth £22m funded by DEBRA UK

55
DEBRA groups internationally

20+
live research projects

46
years of collaboration

Our ambition

We cannot stop the pain of EB on our own which is why we work in partnership with academia, biotechnology and pharmaceutical industries, corporate partners, and other organisations, both in the UK and internationally who have an interest in EB or other skin conditions.

The objective of these partnerships is to reach new audiences, raise awareness, share expertise, work together to provide the specialist services our members need, and drive a programme of world-class research that brings hope and improved outcomes for people all over the world living with EB.

Building partnerships to improve patient outcomes

As well as renewing our existing partnerships with Fight for Sight, to fund EB eye research, and the Medical Research Council, to support the next generation of EB researchers, we also established three new partnerships in 2023: of world-class research that brings hope and improved outcomes for people all over the world living with EB.

- Action Medical Research for Children to co-fund an EBS research project.
- NHS England to collate EB patient data across NHS departments to better understand the patient journey and bottlenecks within the system, and to help set future research priorities.
- Cancer Research UK Institute (formally known as the Beatson Institute) to develop pre-clinical cancer models to better understand RDEB skin cancer progression and to test drugs prior to patient clinical trials.

Corporate partners

Our corporate partners play a vital role in raising awareness and supporting our campaigns. They also provide in-kind services and help fund research, healthcare, community support activities, and our holiday homes. We couldn't do what we do without their generous support and commitment to our mission, thank you.

Raising awareness

Engaging communities

+8%
increase in awareness of DEBRA

+4%
increase in awareness of EB

210%
increase in emails sent

National media exposure for EB and DEBRA UK

Our ambition

Our marketing and communications activity has many objectives and a diverse group of audiences that it needs to reach.

We must continue to raise awareness of EB and of the impact it has on people's lives. By making people more aware of the condition we aim to garner the support needed to help improve quality of life today and secure effective drug treatments for tomorrow. There are many different audiences that we need to engage including the public, who we want to help spread the word and support our fundraising initiatives, our retail outlets, researchers, the pharmaceutical industry, who we want to use their skills and expertise to help secure effective treatments, and politicians to influence policy change.

It is also vitally important that we engage with healthcare professionals such as nurses, GPs, and dermatologists and make them more aware of EB and its symptoms so that they can effectively diagnose it and ensure that patients are referred to the specialist NHS EB healthcare they are entitled to.

As important is raising awareness of DEBRA UK and the services that we offer to the EB community. We want as many people as possible with EB to become DEBRA UK members so that they can benefit from, and help shape our services, and stay fully informed of the progress we are making against our key objectives.

There is no one audience we are trying to reach; we need as many people as possible as part of Team DEBRA if we are to fulfil our mission.

Our objectives

1. To raise awareness and understanding of EB and the needs of the EB community.
2. To raise awareness of DEBRA UK, the services we offer to the EB community, and our key fundraising initiatives (fundraising and our retail stores and online store).
3. To connect and build engaged communities for all those living or working with EB, ensuring that the EB community has the support, advocacy and understanding it needs.
4. To lobby government to influence future services and provision for EB including securing a funding commitment to support our drug repurposing programme.

Our progress in 2023

Awareness raising

Significant progress was made in 2023 in terms of raising awareness of EB, and of DEBRA UK, and the services we offer.

EB was brought to the public's attention through the media coverage and the paid digital marketing that we commissioned to support the A Life Free of Pain appeal and the associated English Channel swimming challenge.

The media campaign started early in the year with radio and TV interviews to coincide with Rare Disease Day in late February, and continued into the summer with further media interviews, a programme of paid digital advertising, and a direct mail campaign to support the swimming challenge. We rounded off the year with media interviews to coincide with EB Awareness Week in October. The combined media exposure – which included mainstream programmes, such as BBC Breakfast and The One Show, ITV's This Morning, and national radio stations including BBC Radio Five Live and Talksport – helped us reach millions of people across the UK, exposing the charity to a whole new audience, many of whom supported us with donations that helped us achieve our A Life Free of Pain fundraising challenge.

Not only did the media coverage help improve unpromoted awareness of EB, which increased from 6% to 10%, and DEBRA which increased from 15% to 23% year on year, it also helped us reach members of the EB community who previously weren't DEBRA UK members, but who have since joined us and are now benefiting from the services we offer.

Government campaigning

In parallel to the awareness activity supporting the appeal we also made good progress with raising awareness within central government and the devolved nations through our government lobbying campaign. This included an adjournment debate on EB taking place in the House of Commons, an EB debate taking place in the Welsh Senedd, and an EB related parliamentary question being asked of the Scottish government. We were also delighted that health ministers from each of the devolved nations attended our political engagement events. Due to our lobbying activities to date, we are now having direct dialogue with the key politicians that we need to influence. We also have political allies to support our ongoing campaigning activities.

Thank you.

We are very grateful to everyone who played a part in raising awareness of EB and of DEBRA UK and what we do in 2023, including those who participated in the media interviews such as our Trustees, DEBRA President, Simon Weston CBE, and Vice President, Graeme Souness, as well as our members Andy and Isla Grist, and Lucy Beal.

We are also grateful to our members, advisors, ambassadors and to the politicians who supported our political engagement activity in 2023 including Bracknell MP, James Sunderland, MSP for Glasgow Maryhill and Springburn, Bob Dorris, Gareth Bacon MP for Orpington and MS for South Wales Central, Joel James.

Our plans for 2024

We made great progress in 2023 but there is still much more to do. With EB being a rare condition, lack of awareness is always going to be a challenge that we must work hard to overcome.

Awareness

We will continue to invest in awareness activities throughout 2024 including media interviews to coincide with Rare Disease Day and EB Awareness Week to help generate awareness of EB, of DEBRA UK and our support services, and to garner support for our key fundraising initiatives.

Fundraising

We will build on the momentum created by the A Life Free of Pain appeal with a fresh and engaging fundraising proposition (BE the difference for EB) that will be at the centre of all our fundraising marketing plans. BE the difference for EB will continue to position our members at the heart of our storytelling and focus our fundraising asks on the need for enhanced EB care and support for today, and effective drug treatments for all types of EB for tomorrow.

Member recruitment

We will invest in marketing activity to help reach and recruit members of the EB community who are not currently aware of DEBRA UK and of the benefits available to them, so that they become members and eligible for our support.

Healthcare professionals' awareness

To address the issue of lack of awareness / understanding of EB amongst healthcare professionals we will invest in a programme of awareness activity both directly targeting key healthcare professionals such as nurses, GPs, and dermatologists, and indirectly by equipping our members with information and resources (members pack) that they can use to educate healthcare professionals themselves.

Government campaigning

The key focus of our government campaigning in 2024 will be to raise awareness of EB and DEBRA UK with key stakeholders within the opposition parties, to secure meetings with their health spokespersons whilst maintaining dialogue with the in-power health ministers.

To build our profile we will once again aim to hold political engagement events in each of the devolved nations including Northern Ireland, and to amplify our voice we will explore opportunities to collaborate with other rare disease organisations and charities including participation in relevant All-Party Parliamentary Groups.

We will continue to encourage our members to support our campaigning objectives and play their part by creating awareness of EB and the impact it has on them and their families/carers with their local politician.

Building engaged communities

To ensure as many members as possible access the support and resources that are available through DEBRA UK, we will maintain regular communication with our members throughout 2024, leveraging all the platforms available to us. We will increase the frequency of communications centred around financial support and grants, mental health support, and community events, as these were key needs highlighted in the 2023 Insights study.

We will continue to promote all the involvement opportunities that are available to our members, including feedback on our member resources as part of the 'patient pathways' project, to ensure members voices are heard and their feedback and ideas continue to shape what we do and how we do it.

To maximise research grant applications, we will ensure all grant calls are effectively communicated to researchers, and we will provide regular research updates to our members and signpost to clinical trial opportunities.

Retail

We will continue to roll out the refreshed DEBRA UK brand across new and relocated shops in 2024 and deliver an annual programme of in-store and online marketing campaigns to help drive revenue, encourage donations, and recruit new volunteers.

New website / review of member resources

To support the above initiatives and to make it easier for members and healthcare professionals to find EB related resources we will launch a brand-new DEBRA UK website in July 2024 featuring an intelligent AI-based search function and intuitive navigation. As part of the website project, we will review and update member resources ensuring they are PIF Tick compliant and relevant to our members' needs.

How we raise money

The commitment and generosity of existing and new supporters in 2023 enabled us to achieve the £5m A Life Free of Pain fundraising target. This amazing response has enabled the charity to commission its first drug repurposing clinical trial. There is still much to do but we now have a solid foundation upon which to build with improved brand awareness and new supporters brought into the charity.

Our ambition

We are committed to raising the funds needed to invest in enhanced EB community care and support, and research into effective drug treatments for every type of EB. The more money we can raise, the sooner we can improve quality of life for people living with EB.

Our objectives

1. To grow our core net fundraising income to £4m in 2024.
2. To increase our focus on trusts and grants, corporate and major donors and increase our fundraising activities in Scotland.
3. To build on the success of 2023 and deliver a step up in donations and awareness through the delivery of the 'BE the difference for EB' appeal.

Our progress in 2023

A Life Free of Pain / English Channel Swim

2023 was a hugely successful year in terms of fundraising and awareness. The A Life Free of Pain appeal, launched in October 2022, aimed to raise £5 million by December 2023 to fund drug repurposing, life-changing treatments, and care and support for the EB community. Thanks to the fantastic support of our generous supporters, we successfully achieved our target.

The appeal was boosted by the public attention drawn to it by Graeme Souness, Andy Grist, and the team who took on the challenge of swimming the English Channel to raise awareness of EB. To support the challenge, a collaborative relationship was built with the BBC which led to them sharing the challenge exclusively with their BBC Breakfast Show viewers in May. News of the challenge was then shared by other national media, drawing attention to not just the challenge, but also EB and the need for funding.

Due to the emotional engagement shown on camera by Graeme to both Andy and Andy's daughter Isla Grist, who has RDEB, the online fundraising page hosted on the Give As You Live platform attracted a significant number of donations both on the day that the challenge was launched and in the run-up to the swim and beyond. On the evening of Saturday June 17, the team entered the English Channel near Dover and 12 and a half hours later they were in France having completed the challenge.

With Gift Aid included the swimming challenge raised over £1.5m and played a significant part in achieving the overall A Life Free of Pain £5m target.

Over 50 people set up individual fundraising pages on the challenge's Give As You Live page seeking sponsorship for their challenges. These included the fantastic team of EB specialist nurses from Great Ormond Street Hospital, who undertook a skydive for DEBRA UK.

Thank you to everyone who walked, ran, cycled, swam, and flew (!) to raise awareness of EB and donations in support of the A Life Free of Pain appeal.

As well as making a significant contribution to the overall appeal, the English Channel swim and associated media coverage also had a halo effect for our other fundraising activities. We had a combined record attendance of over 5,000 at our 2023 events programme and our contact database grew significantly, which meant we could reach more people through our regular emails and with our Christmas appeal, which raised over £40k.

New team members

In 2023, we also strengthened our Fundraising function with the appointment of a dedicated Deputy Director of Fundraising for Scotland, a new Trusts and Grants Manager, and a Corporate Partnerships Manager.

Our plans for 2024

2023 was a very good year for fundraising but there is still more to do. We must continue that momentum into 2024 with an increased focus on trusts and grants, corporate and major donors, and fundraising in Scotland.

Our budget income for 2024 includes a significant major donor pledge and income from a new major event, there will also be a renewed focus on underlying income streams so that net income levels can be maintained in the absence of short-term events.

Events

We will expand our celebrity event programme with new events creating the opportunity to reach a new audience and thus attract new supporters, and we will improve efficiencies with the introduction of a new web-based event management system.

Corporate fundraising

We will develop existing partnerships and forge new ones with a wide range of companies, with activity focused on fundraising, donating goods, and supporting the work we do through volunteering / team building opportunities.

Trusts and grants

Now that we have dedicated resource and expertise to focus on trust and grants, we will expand the scope and value of our applications to grant making trusts with an increased focus on large three-figure applications whilst also retaining the current smaller grants that we have historically attracted.

Scotland

We will expand our event programme in Scotland in 2024 and increase our focus on Scottish grant-making trusts, placing an emphasis on securing funds that will directly benefit the EB community in Scotland.

Nurturing new supporters

We significantly grew our supporter audience in 2023 but many of these supported Graeme Souness and the challenge he was taking on rather than the charity. This is why it's crucial that we continue to focus on engaging with and converting these new supporters into DEBRA UK supporters, encouraging a longer-term relationship with the charity that extends beyond the swim. We have increased our chances of success by ensuring we have email journeys in place that gradually introduce these supporters to all aspects of the charity, including sharing the key needs of the EB community and the reasons why ongoing support is needed. We will also share examples of where their support has made a difference and provide inspiration for the different ways supporters can get involved with a particular focus on regular giving, legacies, and event attendance.

Digital fundraising

We will continue to leverage the opportunities that exist through digital fundraising including Facebook donations and birthday fundraising, virtual challenges, and text donate.

Thank you

We would like to express our sincere thanks to everyone who supported DEBRA UK in 2023 and helped make it such a successful year. Whether you donated, took on a fundraising challenge, shared your story to help raise awareness of EB, joined an event, played our lottery, left a gift in your Will, or volunteered for us, we couldn't have done it without you.

We are also extremely grateful for the continued support of our Royal Patron HRH Duchess of Edinburgh GCVO; our President Simon Weston CBE; Life Patron Philip Evans; Vice Presidents Lenore England, Stuart Procter, Graeme Souness and Frank Warren; and our ambassadors, Michel Roux and Emma Dodds.

Our Patron, President, Vice Presidents

HRH The Duchess of Edinburgh GCVO

Simon Weston CBE

Lenore England

Graeme Souness

Frank Warren

Stuart Procter

Our Ambassadors:

Michel Roux

Emma Dodds

Steve Rider

John Williams MBE

Dr Anna Martinez

Professor Gareth Inman

Professor John McGrath

Lucy Beal Lott

Vie Portland

Fazeel Irfan

Isla Grist

Our Advisor:

Professor Christopher Griffiths OBE

Trusts & foundations

Bill Brown's 1989 Charitable Trust

The Brothers Trust

C Brewer & Sons Ltd Trust

Calleva Foundation

Enterprise Foundation

The Christopher Laing Foundation

The Clare Foundation

The Corn Mill Trust

The David Laing Foundation

The Donald Ericsson Trust

The Dorus Trust

The Dyers' Company's Charitable Trust

The Field Family Trust

The Forest Hill Charitable Trust

The Fowler, Smith & Jones Charitable Trust

The Gloag Foundation

The Grace Trust

The Headley Trust

The Hospital Saturday Fund

The Hugh Fraser Foundation

J J Fenwick Charitable Trust

The J R Asprey Family Charitable Foundation

James Cowper Kreston

The JC and KC Foundation

The John Cowan Foundation

The Jonathan Cartmel Miller Charitable Trust

The Joseph Strong Frazer Trust

The Klahr Charitable Trust

The Leach Fourteenth Trust

Loftus Charitable Trust

Louis Baylis (Maidenhead Advertiser) Charitable Trust

The Louis Nicholas Residuary Charitable Trust

The Manson Family Charitable Trust

Marconi Charities Trust Fund

The Maud Elkington Charitable Trust

The Michael and Anna Wix Charitable Trust

MJC Stone Charitable Trust

Murphy-Neumann Charity

The Oakgrove Foundation

The P F Charitable Trust

The Raven Charitable Trust

The Riada Trust

The Ripley Trust

The Sir Iain Stewart Foundation

The Squire Patton Boggs Charitable Trust

The Strangward Trust

The Sylvia and Colin Shepherd Charitable Trust

The Verdon-Smith Family Charitable Trust

The Whittington Charitable Trust

The Wixamtree Trust

Our stores

94

UK stores.

45%

increase in online sales year on year.

£100k+

raised to help fund life-changing EB healthcare, community support, and research.

At the heart of our communities

DEBRA UK shops play a vital role in their communities, helping to generate awareness of EB and creating opportunities for the EB community to come together. They also raise the profile of the charity and what we do and generate vital income that helps us fund immediate EB community support and healthcare, and research to find effective drug treatments.

Our ambition

Our aim is to be a destination of choice online and on the high street, reaching a wider audience, commanding higher prices, and ensuring we have a sustainable and resilient approach to enable us to withstand any future economic and environmental challenges.

A motivated, knowledgeable, and engaged team of staff and volunteers is our most essential asset. They will always be at the heart of what we do and are key to our success.

Our objectives

1. To build a more efficient, leaner retail function as a basis for expansion and develop an increased estate of larger format stores by 2026, refurbished to create higher quality, attractive retail environments.
2. To improve and expand our e-commerce and online sales, reaching a wider audience with a relevant sales offering whilst at the same time promoting our cause.
3. To develop our dedicated team of staff and volunteers, increasing overall volunteer numbers and ensuring excellent and consistent health and safety management and compliance.
4. To raise awareness of our cause and build loyalty to our brand within our communities.

Our progress in 2023

Facing the challenge of difficult operating conditions

2023 was a challenging year for our retail division with an additional £1.2m of unplanned costs needing to be absorbed due to increases to the national minimum wage and utility costs. Altogether this accounted for a 16% increase in operational costs year-on-year.

Sales were also negatively impacted due to several of our top five stores unexpectedly being closed for extended periods of the year which highlighted an unhealthy reliance on a small number of stores for a significant proportion of our revenue.

Despite these challenges, year-on-year like-for-like sales were significantly up with store re-profiling and improvements to product pricing structures both directly impacting this positive increase, and retail made a positive net income contribution to support our charitable activities.

Stores

We opened three new stores in 2023 and permanently closed 8, 2 of which were loss making.

The safety and wellbeing of our store communities is integral to everything we do and with the number of new systems and reporting processes implemented during the year, including a new property strategy, overall compliance and property management improved significantly.

Raising awareness and supporting the appeal

During 2023 we successfully re-branded 22 of our stores and maximised the opportunity to raise awareness of EB and DEBRA UK in-store.

Our stores also played their part to support the English Channel swimming challenge, with in-store activity helping to generate awareness of EB and DEBRA UK, and donations in support of the appeal.

Online

We continued to grow our online sales which ended the year +45% up on 2022.

We moved away from a store hub concept to support our eBay business and instead transitioned to all DEBRA UK stores acting as standalone eBay traders. The transition has been successful; however, we must continue to monitor performance to gauge overall impact. As part of this transition, we have also reviewed and streamlined our processes and operations and put in place more accessible and efficient postage solutions, which have been well received by our colleagues.

In September, we also launched our first DEBRA UK online shop through Shopify with Buy It Now items now available for sale through our website.

People

Equipping and developing our store teams was a key focus in 2023. This enabled clear succession planning pathways within teams and has in some areas helped stores to trade more effectively, whilst maximising individuals' potential. We have also created online volunteer opportunities for people who want to support the charity but don't have a store nearby.

Our plans for 2024

Stores

We want a lean, more effective, retail estate to ensure that DEBRA UK retail is operating at maximum efficiency and contribution potential.

The impact felt in 2023 from the unexpected temporary closures of some of our top performing stores showed our reliance on a few stores for a significant proportion of revenue. Therefore, in 2024 there will be a small number of further store closures as we remove underperforming stores, or stores that no longer match our retail business model from our portfolio.

Achieving growth in overall net store numbers will be a key focus for the year, so we will invest further in stores within the estate that match our business model. We will also aim to open 10 new stores within the year in locations that offer the best opportunity for incremental sales growth, including exploring out of town retail opportunities.

Online

We need to continue our online growth in 2024. Key to this is the development of stores as standalone ecommerce traders through training and engagement activity. Ease of listing is essential to maximise listing and sales potential through eBay, and by transitioning to direct listing with despatch via Click & Drop the whole process will be simplified which will drive sales growth.

People

We will continue to focus on equipping and developing our people to maximise their and our potential, both on the high street and online. This will help ensure that our staff and volunteers feel inspired to develop and grow in their abilities, whilst working in a thriving commercial but caring culture. We will continue to work hard to grow our overall volunteer numbers as this is essential to help reduce lone working and maximise our stores sales potential.

Our dedicated volunteers

Our volunteers play an essential role in our retail stores and support our fundraising function and other teams across the charity. They are an essential part of the team, and we are deeply grateful for their time, their enthusiasm and commitment, and the skills and expertise they bring into the charity. We couldn't do what we do without them.

1,065
volunteers

211,232
hours volunteered in 2023

£2.2m
of free labour thanks to our loyal volunteers

"Our volunteers are the lifeblood of our retail organisation; without them we simply couldn't function. I am constantly humbled by their commitment and dedication to our cause and in 2023 we were so grateful to be able to recognise the commitment of a member of the volunteer team, Brian from our store in Send, who has volunteered with us for 25 years! We are honoured to have volunteers like Brian, and we can't thank him and every one of them for their hard work and commitment to DEBRA UK. Thank you"

Mark Francis, DEBRA UK Volunteering Development Manager

Our volunteers tell us that volunteering with DEBRA UK provides them the opportunity to socialise, to learn new skills, and for some, valuable work experience that supports them with their move into paid employment or with college and university applications.

We provide a programme of support and development for volunteers across the whole charity that ensures that DEBRA UK is a great place to volunteer and that they are valued, respected, and recognised for the invaluable work they do.

We celebrated National Volunteer Week in June every year, to recognise and thank our inspirational volunteers for the time they give.

Our people

Making a difference every day

370
permanent members of staff

10
trustees – 7 living with or directly affected by EB

125
hours of training provided

1,065
volunteers

Every person in our charity provides a highly valued contribution towards the services that we provide for the UK EB community, whether that's delivering our vital research and healthcare programmes, supporting families and individuals with EB, managing or volunteering in one of our charity shops, working to raise essential funds, promoting and communicating the work we do, processing income, supporting our cause as an ambassador, or guiding our strategic direction as a trustee or committee member.

Our mission

Our mission is to ensure that in the future no-one suffers with EB. The key to achieving this is our people. We aim to create a culture where our people can thrive, are valued, where equality and diversity are embedded in our values and actions, and where everyone can develop and enjoy their work, whilst making a difference to people living with EB.

Our objectives

Our People agenda focuses on three priority areas:

1. A resourcing strategy to attract, develop and retain the talent that we need to achieve our objectives, under-pinned by our Equality, Diversity & Inclusion (EDI) practices to ensure that our employee demographic represents the EB community we serve.
2. Providing learning and development to ensure employees and volunteers have the skills they need to fulfil their current and future roles.
3. Engaging our people by creating a positive working environment, recognising individual and team performance, providing salary and benefits that are competitive within the charity sector and embedding our values to create a culture where employees can flourish.

Our progress in 2023

Mental health first aiders

In November, we launched a new mental health first aiders (MHFA) initiative with 12 colleagues attending a two-day MHFA course which means they can now fulfil the role of a MHFA to support colleagues across the organisation via a dedicated helpline or individually. MHFA's meet on a weekly basis to review progress and to support each other.

Employee engagement survey

All colleagues were invited to complete our employee engagement survey which focussed on training and development, culture, reward, wellbeing, and communication. 184 colleagues completed the survey, which gave a response rate of 47% which was higher than the expected rate of 40%. Most responses received were positive and either "Strongly Agree" or "Agree". The results have been shared with colleagues and any themes identified will feed into the people plan for 2024.

Employee listening forums

Our first employee listening forum was held in November at the Bracknell office. Each directorate was asked to nominate representatives to gain feedback on certain topics. This forum primarily focussed on the recent results of the employee engagement survey. The forum had a full attendance and discussion points centred around development, culture, engagement, reward, and training. Retail listening forums also took place later in the year and feedback from both will be shared with colleagues and any required actions will feed into the people plan for 2024.

Butterfly Awards

In 2023, we recognised and celebrated 22 colleagues, 21 volunteers, and four separate teams through the Butterfly Awards. In total over 250 colleagues were nominated in the year.

In recognition of the hard work and commitment of our staff and volunteers during the year every member of the team received a gift voucher and a thank you card before Christmas and stores received a small budget per head to recognise and thank our volunteers.

EDI

We are an equal opportunities employer organisation, and we capture the diversity data for our employees, volunteers, and prospective employees. With this data we can identify areas for improvement and put in place any required processes to continue the journey to being an organisation that mirrors the diversity profile of the members and the EB community we serve.

The gender pay gap is a measure of the difference in the average pay of men and women, regardless of the nature of their work, across the entire organisation. Our gender pay gap report for 2023 showed that our mean pay gap was 12.4% in favour of men which is an improvement on the 2022 figure of 16.65%. The mean gap is influenced by a higher proportion of men occupying upper-mid banded roles.

We have made significant progress in recent years; however, we are committed to doing more as part of our EDI and values-driven culture.

The median hourly full pay gap remains 0%.

Training and development

During 2023 we continued with our commitment to develop our people by investing in external face-to-face training courses designed to upskill colleagues in leadership behaviours and project management techniques. Over 50 colleagues attended these training courses. Additionally, we delivered internal training to support colleagues with IT skills, attendance management, performance management, and inclusive recruitment.

Recruitment

We updated our recruitment processes and resources which included embedding our values into job descriptions and interview selection materials.

Our plans for 2024

Employee engagement survey

We are committed to creating a positive working environment for all our colleagues, and to support this we will be conducting another employee engagement survey in 2024, as we did in 2020, 2022, and 2023. This will be complemented with smaller pulse surveys held across a cross selection of colleagues in Q1 and Q4, to ensure that we have an in-depth understanding of the needs and emerging themes from our people. We have also committed to reviewing our current employee reward and benefits to ensure we remain competitive with other charities.

Embedding our values

Although our values were introduced in 2022, we have identified that there is still more work to be done to embed these into our culture. We started this journey by incorporating these into our recruitment process and will continue building on this in 2024, with a specific focus on raising awareness of the values internally.

Training and development

We will continue to focus on the development of our employees by providing continuous. training opportunities through our RISE platform, and through internal training workshops. A key focus in 2024 will be the development of an induction and training programme that supports and provide the tools required for external talent to succeed at DEBRA UK, and we will continue to ensure that we have a robust succession plan in place for key roles.

Our Environmental, Social, and Governance (ESG) journey

Striving to be a force for change environmentally, socially, and governmentally.

100%
of unsaleable clothing recycled rather than sent to landfill.

53%
reduction in paper consumption year on year.

100+
young people volunteered with us through the Duke of Edinburgh scheme in 2023.

Our ambition

As a charity with over 90 stores and 1,400+ staff and volunteers, we know we have an impact on the environment and on the communities, we work with, which can be positive or negative. We want to be a force for change, reducing the negative impact we have on the environment and on society, ensuring the highest ethical standards, and considering environmental sustainability and social responsibility in all we do.

Our objectives

1. To be more sustainable and environmentally friendly in everything we do and with everyone we work with.
2. To create a culture where equality and diversity are embedded in our values and actions, and where staff wellbeing is a priority.
3. To ensure the highest ethical standards, with consideration given to environmental sustainability and social responsibility in all that we do and in all our investment decisions.

Our progress in 2023

We have an ESG policy, and we established an annual action plan to ensure we embed sustainability throughout our work and culture, and regular ESG committee meetings to help measure progress against our ESG objectives.

We set up an internal ESG colleague awards scheme to recognise and encourage good ESG practices. Winners of the award in 2023 included Jonathan Padley, a volunteer from the DEBRA store in Hatfield who for the past four years has been collecting all recyclables from the store twice a week and ensuring that every item is recycled in the town centre recycling bins. Another group of ESG winners were the DEBRA Marketing and Communications team, who had the lowest use of printer / photocopier paper of any function within the Bracknell head office.

An initial internal training workshop was held to upskill colleagues on EDI and unconscious bias. The objective of this training was to help increase diversity and we plan to roll this out more widely to colleagues in 2024.

Environmental

The rollout of recycling facilities and the upgrade to LED lights in all our stores started in 2023. At the end of 2023, 6% of our retail estate had been upgraded with new energy efficient LED lighting. We also sent out energy saving posters to every store to encourage colleagues to switch off lights when not in use, equating the potential cost savings to the support it could fund for the EB community.

We transitioned to FSC approved as a minimum standard for all print procurement across the organisation in 2023, and we continued to monitor internal printer usage with results shared monthly.

Social

We continue to provide an equal opportunity workplace where we invest in professional development and staff and volunteers feel valued, which came through clearly in our 2023 employee engagement study.

We also continue to participate in initiatives such as the Duke of Edinburgh Awards where 100+ young people volunteered in our stores, which not only boosted the charity but also helped develop the individual's confidence and skills such as communication, leadership, and team working.

Governance

Our Trustee Board continue to ensure our standards and practices fully embrace the principles of the Charity Commission Charity Governance Code, the Fundraising Regulator and GDPR data protection. This commitment to strong corporate governance is critical to protect our membership, supporters, employees, and our reputation.

Our plans for 2024

Environmental

We will continue to roll out recycling facilities across our stores ensuring by year-end every DEBRA UK store has adequate facilities to be able to recycle.

The implementation of upgraded LED lighting across the remainder of our retail estate will also be concluded by the end of the year which will result in an annual reduction in CO2 emissions equivalent to 944 tonnes.

We will continue to minimise waste through reduction, re-use, and recycling, and introduce initiatives such as reviewing how we travel by promoting options such as car sharing and hybrid working.

Social

A wider programme of ESG training will be rolled out to colleagues in 2024 and we will continue to work with suppliers and contractors who share our ESG objectives.

We will continue the EDI journey to being an organisation that reflects the diversity profile of the members and communities we serve. We will continue to promote best practice in all our operations and activities, considering environmental protection, public health and safety, human rights, anti-bribery and corruption, and labour and anti-slavery practices.

Governance

Our Trustee Board will continue to ensure our standards and practices fully embrace the principles of the Charity Commission Charity Governance Code, the Fundraising Regulator and GDPR data protection.

> **“We will hold ourselves accountable and measure our progress on our ESG journey, continually seeking to learn and incorporate ESG best practices in all we do.”**
>
> **Tony Byrne, CEO DEBRA UK**

Charity overview, objectives & public benefit

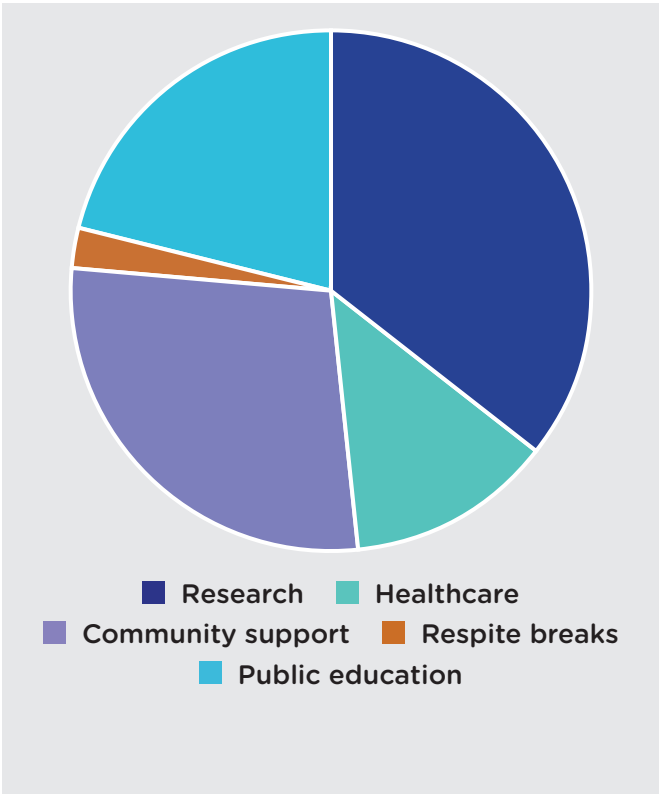
Financial review

We spent £4.4m on charitable activities in 2023, compared with £2.6m in 2022, a 66% increase. Net new research commitments after co-funding and closed project credits soared from £256k in 2022 to £1.1m in 2023. Spend on healthcare, community support and respite amounted to £1.9m, compared to £1.4m in 2022.

Net income from the retail operation was £0.1m (2022: £0.7m). Overall net fundraising income was £3.5m in 2023, compared with £2.3m 2022.

The deficit for the year was £0.66m, compared with a surplus of £0.45m in 2022.

Charitable spend



Summary

Table 3 summarises the highlights of our financial performance over the last five years. Gross income was £18.2m in 2023, an increase of £1.7m (11%) from 2022.

Non-trading gross income was £5.7m, a 40% increase from £4m in 2022. This includes income from donations, corporate support, trusts and community events.

Total retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops) increased by 1% to 12.5m from £12.4m.

Charity overview, objectives & public benefit

Table 3: Financial KPI summary

	2023 £'000	2022 £'000	2021 £'000	2020 £'000	2019 £'000
Gross income	18,228	16,421	13,317	11,413	16,798
Non-trading income	5,681	4,017	4,663	4,387	3,475
Net trading income	(758)	(196)	(1,299)	(3,201)	1,198
Net retail income including government pandemic support, retail gift aid, commission and donations in shops	107	654	1,689	(673)	2,123
Non-trading fundraising costs	861	699	662	708	768
Charitable expenditure	4,396	2,640	1,885	2,848	3,110
Retained surplus/(deficit)	(663)	452	817	(2,371)	795
Retained surplus/(deficit) as a % of income	(4)%	3%	6%	(21%)	5%
Net current assets	3,250	3,333	3,124	2,684	4,878
Unrestricted reserves	3,167	3,763	4,050	2,904	5,138
Grants payable within 1 year	1,922	2,019	2,237	2,159	2,201

The charity's fixed assets comprise the premises and equipment required to operate trading activities; premises, furniture and equipment required to operate the charity's offices; and seven holiday homes held for the use of those affected by EB. The rest of the charity's assets are held to promote the purposes of the charity through its support services and research programmes.

Reserves policy

DEBRA holds reserves to ensure the charity can continue supporting its beneficiaries and as a buffer for short term cash flow needs.

Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be readily mortgaged, thus representing reserves that can be accessed relatively quickly.

The trustees' reserves policy in 2023 was to maintain minimum cash-backed free reserves at £1m, to which the charity adhered. Maintaining the high levels of retail income has been a challenge but this has been offset by a significant increase in fundraising income. The minimum reserves figure is set to cover six month's rent plus one month of other costs. The trustees conducted a thorough review of the reserves policy in 2024, reviewing performance criteria in the light of the economic situation. The trustees' aim is to grow cash-backed free reserves over the next three years to £2m, in line with planned growth in retail and fundraising operations.

Charity overview, objectives & public benefit

Funds

Most of our funds are unrestricted in application and are held in general and designated funds. Where funds are received that are restricted in their application to specific purposes or activities, these are held in a restricted fund. Details of restricted funds and designated funds are set out in Notes 19 and 20 of the Financial Statements.

Total reserves at the end of 2023 were £3.59m. Cash-backed free reserves after designations were £1m with £1.2m of remaining free reserves giving total general funds of £2.2m. There were £1m of designations adding to a total of £3.2m of unrestricted funds.

The trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

Restricted funds

Restricted funds were £421k, including £115k for community support and healthcare activities. Other restricted funds are:

Oliver Thomas Memorial fund

The Oliver Thomas Memorial Fund was established September 2022. The remaining balance is restricted to £10k for an EB weekend get-together and £9.2k for Clinical Best Practice Guidelines.

Research

£35k was donated to fund a research programme at Ninewells Hospital, Dundee.

Respite breaks

A total of £285k was raised following an appeal for new holiday homes giving much needed respite to EB patients and families. One home was purchased in 2022 and another in 2023. The fund balance at the end of 2023 was £252k following depreciation charges.

Asset cover for funds

Note 21 sets out an analysis of the assets attributable to the various funds. These assets are sufficient to meet the charity's obligations on a fund-by-fund basis.

Investment policy

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit. We aim to apply our income in support of our charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk. £2m is held in fixed term deposits with HSBC.

Expenses policy

We have expenses policies for both staff and trustees and a PAYE dispensation in place. Expenses that have necessarily been incurred by staff and trustees in performance of their duties are recoverable from DEBRA. Expenses will only be reimbursed if they meet the following criteria:

- no personal benefit could be derived from the expenditure by the employee concerned;
- the expenditure is reasonable and represents only additional costs to those that would normally arise on a personal basis;
- there is a clear charity justification for the costs; and
- the expenditure does not represent a form of payment to a third party for work undertaken on our behalf.

Any expenses that do not meet the criteria above are regarded as a benefit by HMRC and as a matter of policy we do not reimburse such expenses.

Charity overview, objectives & public benefit

Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2023 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous nonprimary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 12 of the Financial Statements.

Internal audit

RSM are appointed as internal auditors. In 2023 audits of GDPR, Procurement, HR Key Controls and Financial Controls have taken place and recommended actions are being implemented by management.

Principal risks and uncertainties

The trustees have established a register for all identified major strategic, business and operational risks identified by them to which the charity is exposed and confirm that these have been reviewed regularly during the year by the Finance, Risk and Audit Committee (as well as annually by the Board of Trustees) and that systems and procedures have been established to manage these risks. The initial responsibility for managing risk lies with the executive, prior to review by the trustees.

A summary extract of the higher risks from our risk register is listed in Table 4 below, including the countermeasures (actions in place to reduce likelihood of the risk) and assurances (how the effectiveness of the countermeasures is determined). DEBRA as an organisation is very proactive in its management of risk, instilling a culture of recognition, ownership and tolerance level for each risk identified.

See Table 4: DEBRA's major risks.

Table 4: Summary Extract from DEBRA's Risk Register

Risk	Cause & Effect	Controls
Economy / Inflation	Adverse economic conditions or high inflation impact shop or other income	▪ Retail Committee monthly reports with KPIs, monitoring daily sales/GA report ▪ Performance reviews ▪ Retail Risk Register ▪ Continuous drive to increase retail contribution / enhance pricing
Failure to adequately insure	Lack of cover for major event leading to severe financial strain and inability to continue to operate.	▪ Annual insurance review by FD, Finance Manager and relevant SMT members ▪ Insurance Broker researches the market for the best deals to meet DEBRA's needs ▪ FRA periodic insurance review ▪ Tender for insurance brokers every 3 years ▪ Robust risk assessments prior to all DEBRA events
Poor service delivery by third party organisations at DEBRA events	Poor services leading to complaints and damage to DEBRA's reputation. Ultimately leading to loss of donor confidence impacting revenue	▪ Director of Fundraising and Communication reports ▪ Partner only with established reputable sponsors after due diligence ▪ Commercial Participation Agreements

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Non-compliance with H&S or other law	Health and Safety issues not being identified or addressed timely leading to accidents and potential serious injury and legal action. Increase in sickness due to injury caused at work Threat of enforcement actions ('Action Letters') by Local Authorities, Fire and Rescue Services and Environmental Health Departments or the Health and Safety Executive.	▪ Regular reviews of Risk Assessments, version controlled and dated; ▪ Accident and Incident recording and review via Assure software; ▪ Any significant injury or dangerous occurrence will also trigger a review; ▪ Risk Assessments in place for all Regional and National Membership AND Fundraising events; ▪ Staff training and briefing at events; ▪ Event participants are asked about personal history and fitness; ▪ Dedicated Health and Safety Manager has been employed; ▪ Annual Insurance review;
Major Virus epidemic or pandemic and resulting Government containment actions	Shop closures leading to loss of retail income and staff and potential inability to make payments as they fall due. Could lead to inability to continue meeting charitable objectives and operating as a charity.	▪ Shops Health and Safety file, cleaning (COSHH) and operating procedures set out ▪ News monitoring ▪ Regular updates from charity retail association.
Insufficiently robust cyber security	Cyber attack leading to loss of data or financial fraud. Data loss could lead to severe GDPR fines and major damage to reputation. Potential impact on DEBRA's ability to continue operating.	▪ End-point detection software / anti-virus on all computers ▪ Cyber insurance policy ▪ Email scanned before reaching DEBRA servers ▪ Remote user›s hard drives are encrypted ▪ Secured wifi at Bracknell head office ▪ Remote desktop sessions time out after 20 mins ▪ Back-up daily server images moved to the cloud ▪ File shadow copy active on the server (protects against Malware encryption spyware) ▪ Complex passwords required by policy ▪ Meraki firewalls in place throughout offices and shops ▪ Anti-virus/spyware solution on all PC based tills ▪ All credit card machines meet PCI compliance standard C ▪ Monitoring of data access

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Failure to maintain adequate cash flow	Suppliers not being paid on time, delays in staff expenses reimbursement. Need for overdraft facilities. Ultimately leading to inability to continue to operate.	▪ Cash flow monitoring by Finance Team and reported to FRA quarterly ▪ Annual review by FRA of cash-backed free reserves minimum figure ▪ Monthly monitoring and reporting.
Lack of appropriate skills of SLT	Poor performance against budget High number of grievances or staff turnover in a department Whistleblowing	▪ Robust recruitment procedures involving Trustees ▪ Pre employment references ▪ Thorough induction ▪ Budget for L&D for senior managers ▪ Use of 360 input into appraisals
Failure to comply with the requirements to satisfactorily report Safeguarding issues	Any reports or awareness that Safeguarding issues have not been properly reported.	▪ Health & Safety Manager in place (reporting to Director of HR), to specifically lead Safeguarding. ▪ Basic Safeguarding training provided for all staff through eLearning, and additional in-depth training provided for Designated Safeguarding Officers.
Inappropriate Fundraising activities undertaken	Increase in complaints and negative media comment leading to loss of funding. Financial mismanagement leading to audit and investigations. Lack of funds threatens charity existence.	▪ SLT monitoring and CEO reports to Trustees ▪ Fundraising and Communications Committee meetings ▪ Periodic review of Donations Policy ▪ Board approval required for major new initiatives ▪ Donations Policy ▪ Threshold of £10k for confirming donations are from a legitimate source
Board does not have required skills	Lack of specific skills on Board leading to poor strategic direction. Resulting inability to meet charitable objectives and wasted resources.	▪ Recruitment of Trustees with relevant experience and succession planning ▪ Nominations and Governance Committee ▪ Budget in place for trustee training and relevant staff ▪ External advice taken if Board lacks relevant skill ▪ Governance Review ▪ Formalise induction of new trustees

Charity overview, objectives & public benefit

Going concern statement

The Trustees reviewed the charity's budget, cash flows and forecasts for 1 January 2024 – 31 December 2025, which detail the plans for delivering to the EB community during a period of high-cost inflation and the cost-of-living crisis. It is recognised that there are underlying uncertainties, however the Trustees consider the charity can continue its business-critical activities and remain a going concern.

The Trustees consider it is appropriate to prepare the 2023 accounts on a going concern basis on the basis that:

- Fundraising activity is expected to exceed 2023, with large pledges from major donors, and approx. £600k of unbudgeted income already secured for 2024;
- The Budget and cash flows for 2024 and 2025 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2024 and 2025 is contingent on achieving fundraising and retail targets.

Structure, governance & management

DEBRA is a company limited by guarantee registered with the Charity Commission in England and Wales (1084958). This means our trustees are also company directors, so subject to company law as well as charity law. We are also registered with the Scottish Charity Regulator (OSCR).

Board of Trustees

Our Trustee Board has a collective responsibility for everything we do and is responsible for:

- our overall strategic direction including evaluating progress against our strategic plans
- ensuring our financial stability
- acting in the best interests of our organisation
- ensuring that we comply with our governing documents, and any other relevant legislation from our regulators.

New trustees receive the most recent annual report and accounts, copies of previous minutes of the board and committees, and are made aware of the charity's policies including its Scheme of Delegation. Individual inductions from senior trustees as relevant and trustees attend external training courses appropriate to their role on the Board of Trustees. There are four board meetings per year, which the CEO attends and Senior Management Team members attend as required.

The Trustees are the sole legal members of the charity.

In 2023 & 2024 Rebecca Cresswell resigned on 17 May 2023 and Viv Mundy resigned on 7 September 2023. Deborah Install was appointed on 6 December 2023.

Charity overview, objectives & public benefit

Trustee Board Committees

Finance, Risk & Audit Committee ("FRA") – determines and advises the Board of Trustees on matters relating to finance, risk and audit as the Board of Trustees may remit to it, in particular the sound financial management of the charity, its resources and assets.

Charitable Purposes Committee ("CPC") – determines and advises the Board of Trustees on matters relating to strategy in research, healthcare, community support and policy as the Board of Trustees may remit to it.

Nominations & Governance Committee ("N&G") – oversees the structure, composition and effectiveness of the charity's Board of Trustees and its Committees, as well as the appointment process of trustees. The Committee monitors the governance procedures of the charity.

Remuneration Committee – makes recommendation to the Board on a fair remuneration for the Chief Executive and Senior Management Team of DEBRA and reviews the Chief Executive's recommendations on the Annual Pay policy for DEBRA.

See Table 5 below – Trustees' membership and attendance.

Board diversity

Our Board of Trustees is made up from a majority of those who have a direct experience of EB, who either have EB themselves or have a close family member with EB, and those who have skills and experience that will add value to the governance and leadership of DEBRA. This ensures a good mix of skills, talents and experience to serve the DEBRA community.

We follow the Equal Opportunities Policy in the selection of Board members, in the same way we do for staff recruitment. Membership of the Board is open to all members of DEBRA, irrespective of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values.

Broader diversity of the Board continues to be reviewed as part of DEBRA's Equality, Diversity & Inclusion policy.

Charity governance code

The Board consistently reviews all aspects of DEBRA's governance and ensures that our governance standards and practices fully embrace the principles of the Charity Commission 'Charity Governance Code'.

Succession planning

We have built strength and depth in our Trustee Board, incorporating appropriate succession planning by appointing two Vice Chairs, each for periods of two years with an annual rotation of one of those. Prospective new trustees are often invited to join a committee for a minimum period of twelve months before becoming trustees.

Charity overview, objectives & public benefit

Fundraising standards

Section 162a of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. We do not undertake face-to-face fundraising from the general public. The legislation defines fundraising as 'soliciting or otherwise procuring money or other property for charitable purposes'. Such amounts receivable is presented in the accounts as 'voluntary income' and include legacies and grants.

We make all efforts to train staff and ensure compliance with fundraising standards at all times. Specifically:

- the majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the trustees
- where we work with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met
- there are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc
- where volunteers assist in our fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued
- volunteer fundraisers are managed and supported from the offices in Bracknell and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them
- data protection procedures are in place governing the management of supporter and donor data on our DEBRA database; compliance with GDPR rules continues to be monitored
- we work with vulnerable people, particularly within the EB community, and often they wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly
- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2023.

Activities in Scotland

We are active across several areas in Scotland. The primary charitable activities are seen in funding community support and research projects, notably at the Universities of Dundee and Edinburgh and the Cancer Research UK Beatson Institute, University of Glasgow. On the income generation side, there were two regional fundraising members of staff and 24 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Blantyre.

Charity overview, objectives & public benefit

Board Attendance Table

Trustee		Board	FRA	N&G	CAR/CPC	REMCO
Jim Irvine (Chair)	Chair of board	4 of 4	4 of 4	4 of 4		1 of 1
Carly Fields	Vice Chair & Chair of CPC	4 of 4		4 of 4	4 of 4	
David Bendor-Samuel	N&G Chair	4 of 4		4 of 4		
Simone Bunting	REMCO Chair	4 of 4				1 of 1
Joanne Merchant	Chair of FRA	4 of 4	4 of 4	4 of 4		1 of 1
Dan Mundy	Chair of FRA (effective Dec-23)	4 of 4	2 of 4			
Mick Thomas		3 of 4			4 of 4	
Simon Talbot		4 of 4	3 of 4			1 of 1
Christo Kapourani	Leave of absence					
Becky Edwards	Left May 2023	0 of 2				
Viv Mundy	Left May 2023	0 of 1			2 of 4	
Debbie Install	Note: Plus one as observer, appointed as Trustee in Jan-24	1 of 1				

Auditor

Trustees have taken all reasonable steps to make themselves aware of any information needed by the company's auditor for the purposes of their audit and to establish that the auditor is aware of that information. The trustees are not aware of any relevant audit information of which the auditor is unaware.

Sayer Vincent LLP have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditor 28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

The Trustees' Annual Report, incorporating the Strategic Report, is approved by the Board of Trustees and signed on behalf of the trustees:

Jim Irvine
Chair of Trustees
10 May 2024

Trustees´ statement of responsibilities

The trustees (who are also directors of DEBRA for the purposes of company law) are responsible for preparing the Trustees' Annual Report including the strategic report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities Statement of Recommended Practice (SORP) make judgements and estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2023 was 10 (2022: 11). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditor´s report

Auditor's report

Independent auditor's report to the members of DEBRA

Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2023 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at
- 31 December 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the Financial Reporting Council's Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on DEBRA's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Auditor´s report
(continued)

Other Information

The other information comprises the information included in the trustees' annual report, including the strategic report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the trustees' annual report, including the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- The trustees' annual report, including the strategic report, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report, including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Auditor´s report
(continued)

Responsibilities of trustees

As explained more fully in the statement of trustees' responsibilities set out in the trustees' annual report, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud are set out below.

Capability of the audit in detecting irregularities

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, our procedures included the following:

- We enquired of management and Finance, Risk and Audit committee, which included obtaining and reviewing supporting documentation, concerning the charity's policies and procedures relating to:
    - identifying, evaluating, and complying with laws and regulations and whether they were aware of any instances of non-compliance;
    - detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud;
    - the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.
- We inspected the minutes of meetings of those charged with governance.
- We obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience.

Auditor´s report
(continued)

- We communicated applicable laws and regulations throughout the Audit Team and remained alert to any indications of non-compliance throughout the audit.
- We reviewed any reports made to regulators.
- We reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations.
- We performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud.
- In addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities is available on the Financial Reporting Council's website at: **www.frc.org.uk/auditorsresponsibilities.** This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Fleur Holden
(Senior statutory auditor)

Date: 14 June 2024
for and on behalf of Sayer Vincent LLP,
Statutory Auditor

110 Golden Lane, LONDON, EC1Y 0TG

Sayer Vincent LLP is eligible to act as auditor in terms of section 1212 of the Companies Act 2006

Financial statements

For the year ended 31 December 2023

Statement of financial activities

Statement of financial activities including income and expenditure account for the year ended 31 December 2023.

2023					
	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Income from:					
Donations & legacies	2	4,770,185	-	755,404	5,525,589
Charitable activities		11,834	-	-	11,834
Other trading activities	3	12,544,882	-	-	12,544,882
Investments	4	97,461	-	-	97,461
Other		48,674	-	-	48,674
Total income		17,473,036	-	755,404	18,228,440
Expenditure on:					
Raising funds	6	14,475,656	19,000	-	14,494,656
Charitable activities	6	3,574,457	-	822,247	4,396,704
Total expenditure		18,050,113	19,000	822,247	18,891,360
Net income / (expenditure)		(577,077)	(19,000)	(66,843)	(662,920)
Transfer between funds		-	-	-	-
Net movement in funds		(577,077)	(19,000)	(66,843)	(662,920)
Reconciliation of funds:					
Total funds brought forward		2,762,264	1,000,397	487,511	4,250,172
Total funds carried forward		2,185,187	981,397	420,668	3,587,252

Statement of financial activities
(continued)

2022					
	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Income from:					
Donations & legacies	2	2,335,602	481,397	1,194,637	4,011,636
Charitable activities		28,410	-	-	28,410
Other trading activities	3	12,233,823	-	19,511	12,253,334
Investments	4	5,472	-	-	5,472
Other		121,873	-	-	121,873
Total income		14,725,180	481,397	1,214,148	16,420,725
Expenditure on:					
Raising funds	6	13,297,601	31,000	-	13,328,601
Charitable activities	6	2,165,640	-	474,687	2,640,327
Total expenditure		15,463,241	31,000	474,687	15,968,928
Net income / (expenditure)		(738,061)	450,397	739,461	451,797
Transfer between funds		-	-	-	-
Net movement in funds		(738,061)	450,397	739,461	451,797
Reconciliation of funds:					
Total funds brought forward		3,500,325	550,000	(251,950)	3,798,375
Total funds carried forward		2,762,264	1,000,397	487,511	4,250,172

All operations are continuing. The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

The notes on pages 63-89 form part of these financial statements.

Balance sheet

Balance sheet as at 31 December 2023.

	Notes	2023 £	2023 £	2022 £	2022 £
Fixed assets					
Tangible fixed assets	**10**		**1,437,302**		1,290,091
Programme related investment	**11**		**1**		1
Investment in subsidiaries	**12**		**2**		2
			1,437,305		1,290,094
Current assets					
Stocks		**-**		2,063	
Debtors	**13**	**2,114,242**		1,856,681	
Current asset investment	**14**	**2,024,298**		3,000,000	
Cash at bank and in hand		**2,111,857**		2,146,142	
		6,250,397		7,004,886	
Creditors: amounts falling due within one year	**15**	**(2,999,964)**		(3,672,317)	
Net current assets			**3,250,432**		3,332,569
Total assets less current liabilities			**4,687,737**		4,622,663
Creditors: amounts falling due after more than one year	**16**		**(881,673)**		(134,539)
Provision for liabilities	**17**		**(218,812)**		(237,952)
Total net assets			**3,587,252**		4,250,172

Balance sheet
(continued)

		2023		2022	
		£	£	£	£
The funds of the charity					
Restricted income funds	**19**		**420,668**		487,511
Unrestricted funds					
Designated funds	**20**	**981,397**		1,000,397	
General funds	**20**	**2,185,187**		2,762,264	
Total unrestricted funds			**3,166,584**		3,762,661
Total funds			**3,587,252**		4,250,172

Company registration number 4118259

The accounts were approved by the Board on **10 May 2024** and signed on their behalf by:

Jim Irvine
Chair of Trustee Board

Daniel Mundy
Treasurer

Statement of cash flows

Statement of cash flows for the year ended 31 December 2023.

	Notes	2023 £	2023 £	2022 £	2022 £
Cash flows from operating activities					
Net cash (used in) / provided by operating activities	22		**(698,355)**		566,564
Cash flows from investing activities					
Dividends, interest and rents from investments		**97,461**		5,472	
Proceeds from the sale of property, plant and equipment		**-**		92,382	
Purchase of property, plant and equipment		**(409,093)**		(486,086)	
Proceeds from sale of short term investments		**3,000,000**		-	
Purchase of short term investments		**(2,024,298)**		(3,000,000)	
Net cash provided by investing activities			**664,070**		(3,388,232)
Change in cash and cash equivalents in the reporting period			**(34,285)**		(2,821,668)
Cash and cash equivalents at the beginning of the reporting period			**2,146,142**		4,967,810
Cash and cash equivalents at the end of the reporting period			**2,111,857**		2,146,142

The notes on pages **63-89** form part of these financial statements.

Notes to the financial statements

1 Accounting policies

1.1 Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), Charities SORP (FRS 102), the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and Trustees Investment (Scotland) Act 2005.

1.2 Going concern

The Trustees reviewed the charity's budget and cash flows for 1 January 2024 – 31 December 2025 in December 2023 and consider it is appropriate to prepare the 2023 accounts on a going concern basis on the basis that:

- Fundraising activity is expected to exceed 2023, with large pledges from major donors, and approx. £600k of unbudgeted income already secured for 2024;
- The Budget and cash flows for 2024 and 2025 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2024 and 2025 is contingent on achieving fundraising and retail targets.

1.3 Legal status of charity

The charity is a company limited by Guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

1.4 Judgements and estimates made by management

The financial statements include judgements and estimates as defined by the accounting policies. Legacy income is recognised as probable at probate, using an estimate provided by executors. Premises service charge liabilities are estimated from information supplied by property specialists. The dilapidations provision is reviewed annually on an individual lease basis by a property specialist.

Research grants are recognised in full in the Income and Expenditure Account at the point of commitment in order to ensure no reliance on future fundraising to meet these financial commitments.

Programme related investments are impaired based on a judgement of the intrinsic value of the investment at the balance sheet date, where no market value exists.

The Trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

Notes to the financial statements

(continued)

1.5 Income

Donations and gifts are recognised in full in the Statement of Financial Activities when receivable. Unclaimed gift aid receivable is accrued in the year to which it relates. Legacies receivable are recognised when there is entitlement, probability of receipt and is measurable. Grants are recognised in full when receivable. Gifts in kind are only included in the accounts where the Trustees can ascribe a value in excess of £1,000.

Other trading income is recognised in full when received with the exception of income that is deferred where it represents a payment in advance for a specific event that will not take place until a future accounting period. This exception does not apply to sponsorship for charity challenges taking place in a future accounting period.

Claims made through the UK Government's Coronavirus Job Retention Support Scheme are recognised as income in the period which the associated staff were furloughed. This income is considered to be unrestricted. Small business retail grants have been recognised as unrestricted income in the periods to which they relate.

1.6 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Equipment purchased for use in research is written off as part of the research project costs as incurred. Expenditure on raising funds are those costs incurred in seeking voluntary contributions and running the retail operations. Charitable activities include expenditure associated with the operation of the charity and the provision of its services.

Governance costs comprise the costs relating to the general running of the charity, and include direct items such as external audit, legal advice for trustees, the cost of trustee meetings, and are included in central overhead costs. Central costs are apportioned and allocated between the cost of raising funds and charitable expenditure on the basis of central staff time allocation to the various activities.

1.7 Recognition of grant liabilities

Grants are awarded for research projects over a period of one to five years. All grants provide the right to terminate with up to three months' notice and continuation of funding is dependent on satisfactory progress reporting and review. It is always the intention to honour the funding of all grants awarded and full grant recognition has been incorporated into these accounts as the most appropriate and prudent policy. By adopting this policy, the Trustees ensure the funds for research grants have been raised in full prior to making financial commitments to research institutions.

1.8 Tangible fixed assets and depreciation

Tangible fixed assets with a value in excess of £1,000 are capitalised and stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

Freehold and long leasehold buildings	Over 25 years
Leasehold improvements	Over life of the lease
Mobile homes	Over 10 years
Fixtures, fittings, static equipment	Over 5 years
Software development costs	Over 5 years
Shop equipment	Over 5 years
Mobile equipment	Over 3 years

Notes to the financial statements

(continued)

A review of assets is undertaken annually, and adjustments are made to the expected useful life as required. From 1 January 2009 freehold land and buildings, and long leasehold buildings, are assumed to have a residual value of 50%.

1.9 Programme related investment and impairment

Programme related expenditure with a value in excess of £1,000 is stated at cost less impairment. The investment held was impaired by 99.99% in 2020, with a residual holding value of £1.

1.10 Cash and short-term investments

The charity holds cash requirements for day-to-day activities in current bank accounts with HSBC, Lloyds, Santander and Clydesdale. The deposit account is held with HSBC. Short-term investments are held in money market deposits with HSBC. For the purposes of the cash flow statement, cash equivalents are defined as current asset investments, and short-term deposits with a maturity of less than 3 months, which are readily convertible into known amounts of cash.

1.11 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

1.12 Creditors

Trade creditors and other payables are normally recognised at their settlement amount after allowing for any trade discount due. Payments to suppliers are within standard payment terms of 30 days. Liabilities are recognised when there is a present obligation, as a result of past events, and there is a probable future outflow of resources that can be estimated reliably.

1.13 Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at settlement value.

1.14 Stock

The Trustees do not consider it appropriate to recognise donated goods for resale as stock on the grounds that the cost of obtaining stock information would greatly outweigh any benefit. The costs involved would include the setting up of processes and procedures for a stock count in the large store base, training shop staff and volunteers in the process, software programming, and the checking and analysis of the reports produced.

All other stock is valued at the lower of cost or sales value net of selling costs.

1.15 Accumulated funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the Trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The purposes and uses of the restricted funds and designated funds are set out in Note 19 to the financial statements.

Notes to the financial statements

(continued)

1.16 Consolidated accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the companies' results and the investment the charity holds are shown separately in Note 12 to the financial statements.

1.17 Foreign currency translation

Foreign currency transactions are recorded at the exchange rate at the time of the transaction. Foreign currency assets and liabilities are translated into sterling at the exchange rate ruling at the balance sheet date. Resulting gains or losses on retranslation are included in the statement of financial activities.

1.18 Leases

Operating lease annual rental payments are charged to the statement of financial activities on a straight line basis over the term of the lease.

1.19 Termination payments

Termination payments either by way of redundancy or settlement agreement are recognised at the time of payment. Any payments exceeding the statutory minimum are authorised by the Trustees.

Notes to the financial statements

(continued)

2. Donations and legacies

	Unrestricted funds	Restricted funds	Total 2023	Unrestricted funds	Restricted funds	Total 2022
	£	£	£	£	£	£
Donations & gifts	**4,102,510**	**223,990**	**4,326,500**	2,302,674	506,896	2,809,570
Legacies receivable	**478,276**	**35,000**	**513,276**	409,165	500	409,665
Grants receivable	**189,399**	**496,414**	**685,813**	105,160	687,241	792,401
	4,770,185	**755,404**	**5,525,589**	2,816,999	1,194,637	4,011,636
Donations & gifts:						
Individual donations	**3,698,945**	**186,271**	**3,885,216**	2,062,574	426,373	2,488,947
Corporate donations	**365,608**	**26,473**	**392,081**	206,150	79,538	285,688
International donations	**1,316**	**-**	**1,316**	1,321	-	1,321
Events by individuals	**36,641**	**11,246**	**39,135**	32,629	985	33,614
	4,102,510	**223,990**	**4,326,500**	2,302,674	506,896	2,809,570
Grants receivable:						
Charitable trusts	**188,168**	**187,801**	**375,969**	105,160	687,241	792,401
Other grants	**1,231**	**308,613**	**309,844**	-	-	-
	189,399	**496,414**	**685,813**	105,160	687,241	792,401

Online adwords received as gifts in kind of £92,969 (2022: £79,186) are included in donations and gifts.

Notes to the financial statements

(continued)

3. Other trading activities

	2023	2022
	£	£
Income	**12,544,882**	12,253,334
Operating expenses	**(13,209,499)**	(12,449,041)
Net income from fundraising activities	**(664,617)**	(195,707)

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2023 there were 94 shops trading (2022: 102). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2023	Income	Operating expenses	Net income 2022
	£	**£**	**£**	£	£	£
Retail	**11,451,883**	**(12,440,189)**	**(988,306)**	11,204,468	(11,749,690)	(545,222)
Fundraising events	**923,711**	**(769,310)**	**154,401**	841,849	(699,351)	142,498
Miscellaneous trading	**169,288**	**-**	**169,288**	207,017	-	207,017
	12,544,882	**(13,209,499)**	**(664,617)**	12,253,334	(12,449,041)	(195,707)

Retail income excludes income of £1,095,482 (2022: £1,019,370) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail gift aid commission of £91,851 (2022: £163,655) which is recognised in miscellaneous trading. The profit covenanted by DEBRA Trading Limited of £76,787 (2022: £43,362) is recognised in miscellaneous trading.

Notes to the financial statements

(continued)

The table below reflects a true statement of total retail income, including retail Gift Aid, commission and retail donations.

	2023	2022
		£
Income	**12,547,365**	12,403,661
Operating expenses	**(12,440,189)**	(11,749,690)
Net expenditure on fundraising activities	**107,176**	653,971

4. Investment income

	2023	2022
	£	£
Interest receivable	**93,879**	94
Rent of property	**3,582**	4,528
Total investment income	**97,461**	5,472

Rental income was received from one freehold shop and two flats situated above properties, which were acquired in 2009.

Notes to the financial statements

(continued)

5. Grants payable

Expenditure on charitable activities include grants payable to third parties as detailed in Note 23. There were 424 (2022: 354) Community Support grants totalling £105,407 (2022: £85,856) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 23.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2023 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,724,017 (2022: £411,167) and clinical projects to the sum of £107,997 (2022: £107,997).

The total future commitment is currently committed to be spent as follows:

	Total 2023	Total 2022
	£	£
Within one year	**950,341**	384,625
Within two – three years	**881,673**	134,539
Within four – five years	**-**	-
Provided within the grants payable creditor (notes 15 and 16)	**1,832,014**	519,164

Notes to the financial statements

(continued)

6. Expenditure

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2023
	£	£	£	£	£	£
Raising funds						
Donations & legacies	**660,061**	**-**	**-**	**272,309**	**352,787**	**1,285,157**
Other trading activities	**7,027,568**	**-**	**81,677**	**375,643**	**5,724,611**	**13,209,499**
	7,687,629	**-**	**81,677**	**647,952**	**6,077,398**	**14,494,656**
Charitable activities						
Research	**372,808**	**1,126,651**	**-**	**66,354**	**3,673**	**1,569,486**
Healthcare	**112,576**	**129,273**	**-**	**37,223**	**283,727**	**562,799**
Community support	**953,911**	**144,028**	**-**	**108,138**	**25,706**	**1,231,783**
Respite breaks	**-**	**-**	**104,378**	**-**	**5,278**	**109,656**
Public education	**576,201**	**-**	**-**	**61,779**	**285,000**	**922,980**
	2,015,496	**1,399,952**	**104,378**	**273,494**	**603,384**	**4,396,704**
	9,703,125	**1,399,952**	**186,055**	**921,446**	**6,680,782**	**18,891,360**

Notes to the financial statements

(continued)

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2022
	£	£	£	£	£	£
Raising funds						
Donations & legacies	517,816	-	-	213,897	147,995	879,708
Other trading activities	6,672,980	-	63,169	386,748	5,325,996	12,448,893
	7,190,796	-	63,169	600,645	5,473,991	13,328,601
Charitable activities						
Research	294,625	256,461	-	36,430	45,086	632,602
Healthcare	77,018	84,294	-	26,601	107,084	294,997
Community support	780,208	85,856	-	56,327	41,873	964,264
Respite breaks	-	-	57,669	-	62,010	119,679
Public education	418,001	-	-	39,584	171,200	628,785
	1,569,852	426,611	57,669	158,942	427,253	2,640,327
	8,760,648	426,611	120,838	759,587	5,901,244	15,968,928

Net income / (expenditure) for the year is stated after charging:

	2023	2022
	£	£
Operating leases	**1,867,741**	1,796,779
Auditors' remuneration	**22,300**	19,900
Auditors' remuneration: under accrual in prior year	**9000**	-
Non-audit services	**900**	-
Depreciation of tangible fixed assets	**281,882**	180,733
Defined contribution pension costs	**407,332**	381,336
Exchange differences	**7,911**	(46,469)

Notes to the financial statements

(continued)

7. Cost allocation

All central overhead costs are allocated to activities on the basis of staff time, and are detailed below:

	2023	2022
	£	£
Staff costs	**2,233,530**	1,838,856
Overheads		
Office premises rent	**62,790**	55,117
Service charges, utilities & cleaning	**61,236**	50,669
Equipment costs	**308,561**	255,442
Postage, printing, stationery, telephone & fax	**67,190**	72,073
Insurance costs	**149,182**	138,505
Legal, professional & consultancy fees	**105,542**	69,399
Depreciation	**75,828**	51,068
Profit on disposal	**-**	6,319
Irrecoverable VAT	**48,952**	39,840
Bank charges	**2,954**	7,117
Sundry expenses	**7,911**	(26,062)
Governance costs:		
Audit, non-audit and internal audit fees	**31,300**	39,800
Miscellaneous costs	**-**	110
	921,446	759,397
Total allocation	**3,154,975**	2,598,253

Notes to the financial statements

(continued)

8. Trustees

None of the Trustees received any remuneration from DEBRA during the period, but one of them was reimbursed a total of £58 (2022: two - £565) for travel and accommodation expenses. No Trustees received community grants (2022: £nil). The aggregate figure for trustee donations in 2023 was £3,135 (2022: £14,460). In addition, many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £5,422 (2022: £4,375), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9. Employees

The average number of employees during the period was:

	2023	**2023**	2022	2022
	No.	**FTE**	No.	FTE
Research	**2**	**1.7**	2	1.6
Healthcare*	**-**	**-**	-	-
Community Support	**17**	**15.7**	15	13.3
Fundraising & Comms	**23**	**20.8**	22	20.1
Retail	**298**	**223.8**	296	230.4
Management & Administration	**28**	**26.0**	27	25.6
	368	**288.1**	362	291.1

Notes to the financial statements

(continued)

At the end of the year the number of employees per department was:

	2023	2023	2022	2022
	No.	**FTE**	No.	FTE
Research	**2**	**1.7**	2	1.7
Healthcare*	**-**	**-**	-	-
Community Support	**20**	**18.1**	15	13.7
Fundraising & Comms	**22**	**20.0**	20	18.6
Retail	**290**	**219.0**	295	227.3
Management & Administration	**27**	**24.9**	27	25.6
	361	**283.7**	359	286.9

*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 20. Staff employed by external institutions and funded through research grants are also excluded.

	2023	2022
	£	£
Wages & salaries	**8,134,599**	7,467,472
Social security costs	**638,017**	601,090
Pension costs	**407,332**	381,336
Total payroll	**9,179,948**	8,449,898
Other staff costs	**523,177**	310,749
Total allocation	**9,703,125**	8,760,647

Notes to the financial statements

(continued)

The charity does not operate any defined benefit pension scheme. Payments of £407,332 (2022: £381,336) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £nil (2022: £nil) unpaid.

There are adequate systems in place to manage expenses and they do not form part of remuneration.

The following members of staff received emoluments above £60,000:

	2023	2022
	No.	No.
Between £60,001 - £70,000	**-**	-
Between £70,001 - £80,000	**4**	4
Between £80,001 - £90,000	**1**	2
Between £90,001 - £100,000	**1**	-
Between £110,001 - £120,000	**-**	1
Between £120,001 - £130,000	**1**	-

Redundancy and compensation payments, which were all paid in year, totalled £25,000 (2022: £67,528).

The aggregate pay of key management personnel, including employer's NI and pension contributions was £898,711 (2022: £857,698). The aggregate employer's pension contribution for key management personnel was £75,378 (2022: £67,439)

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £64,176 (2022: £59,492), and there are retirement benefits accruing for seven (2022: eight) employees under a defined contribution scheme.

Notes to the financial statements

(continued)

10. Fixed assets

Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land & buildings	Long leasehold land & buildings	Total
	£	£	£	£	£	£
Cost:						
At 1 January 2023	**280,405**	**694,763**	**615,028**	**578,347**	**82,500**	**2,251,043**
Additions	**21,104**	**150,000**	**237,989**	**-**	**-**	**409,093**
At 31 December 2023	**301,509**	**844,763**	**853,017**	**578,347**	**82,500**	**2,660,136**
Depreciation:						
At 1 January 2023	**228,676**	**269,285**	**259,585**	**180,306**	**23,100**	**960,952**
Charge for the year	**26,339**	**104,378**	**116,636**	**12,879**	**1,650**	**261,882**
At 31 December 2023	**255,015**	**373,663**	**376,221**	**193,185**	**24,750**	**1,222,834**
Net book value:						
1 January 2023	**51,729**	**425,478**	**355,443**	**398,041**	**59,400**	**1,290,091**
31 December 2023	**46,494**	**471,100**	**476,796**	**385,162**	**57,750**	**1,437,302**

The Head Office fit out costs, mobile equipment and software development costs have been included in the fixtures, fittings and equipment category.

Notes to the financial statements

(continued)

11. Programme related investment

	2023	2022
	£	£
Investment in Phoenicis Therapeutics, inc		
Net investment value brought forward	**1**	1
Purchase of investment	**-**	-
Impairment charge	**-**	-
Net investment value carried forward	**1**	1

Following a merger In 2023 Fibrx Dem, Inc became Phoenicis Therapeutics, Inc. The Trustees invested £190,840 ($250,000) in Fibrx Derm Inc, a US biotech company, purchasing 203,252 series A-2 convertible preferred stock, at a price of $1.23 per share. This investment supported the development of a new treatment to help wound healing in patients suffering from Dystrophic Epidermolysis Bullosa. The purpose of this investment was in furtherance of the charitable objectives of the charity, and no financial return was expected. The value of the investment has been impaired by 99.99% as the most prudent course of action.

12. Investment in subsidiaries

DEBRA had two 100% owned subsidiary companies incorporated in England and Wales at 31 December 2022 (2021: two). These are DEBRA Trading Ltd (company number: 2487114), whose principal activities are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship; and DEBRA Retail Ltd which is dormant.

Financial information for these entities for the year ended 31 December 2023:

	2023		2022	
	DEBRA Trading Ltd	**DEBRA Retail Ltd**	DEBRA Trading Ltd	DEBRA Retail Ltd
	£	**£**	£	£
Turnover	**132,704**	**-**	90,376	-
Total expenses	**56,019**	**-**	47,014	-
Gift aid to DEBRA	**76,685**	**-**	43,362	-
Profit / (loss) for the year	**-**	**-**	-	-
Net assets / (liabilities)	**2**	**1**	2	1
Share capital	**2**	**1**	2	1

Notes to the financial statements

(continued)

13. Debtors

	2023	2022
	£	£
HMRC	**276,706**	211,221
Amounts due from group undertakings	**74,255**	43,362
Other debtors	**541,881**	544,057
Accrued income	**739,158**	458,491
Prepayments	**482,242**	599,550
	2,114,242	1,856,681

Amounts due from HMRC are VAT receivable of £276,706 (2022: £211,221). Other debtors includes £4,515 (2022: £266,825) due for shared research grants. Accrued income includes gift aid of £467,366 (2022: £289,219) due from HMRC.

14. Investments in short term deposits

	2023	2022
	£	£
HSBC money market deposits:		
Investments brought forward at 1 January 2023	**3,000,000**	-
Purchase of investments	**2,024,298**	3,000,000
Sales of investments	**(3,000,000)**	-
Investments carried forward at 31 December 2023	**2,024,298**	3,000,000

Notes to the financial statements

(continued)

15. Creditors: amounts falling due within one year

	2023	2022
	£	£
Trade creditors	**90,464**	223,903
Grants payable	**1,921,526**	2,019,399
Other creditors	**291,643**	263,332
Taxation and social security	**162,597**	138,323
Accruals	**527,769**	1,013,934
Deferred income	**5,965**	13,426
	2,999,965	3,861,818

Grants payable includes £950,341 (2022: £384,625) relating to future commitments and £971,185 (2022: £1,634,774) relating to amounts owed for invoiced research activity.

Amounts due for future commitments due over one year are detailed in note 16 below.

There was deferred income of £5,965 (2022: £13,426), representing income for events which would have to be repaid in the event of cancellation.

16. Creditors: amounts falling due over one year

	2023	2022
	£	£
Grants payable	**881,673**	134,539
	881,673	134,539

17. Provision for liabilities

	2023	2022
	£	£
Dilapidations provision		
Provision brought forward	**237,952**	187,948
Charges	**20,560**	50,004
Release of provision	**(39,700)**	-
Provision carried forward	**218,812**	237,952

Notes to the financial statements

(continued)

18. Other financial commitments

The following payments are committed to be paid in the future in respect of operating leases:

	2023 Leases of land and buildings	2023 Other	2022 Leases of land and buildings	2022 Other
	£	£	£	£
Within one year	**968,931**	**4,432**	1,019,492	18,747
Between one – five years	**1,485,626**	**3,324**	1,454,360	18,481
After five years	**13,359**	**-**	74,767	-
	2,467,916	**7,756**	2,548,619	37,228

There were capital commitments of £nil (2022: £nil) at year end, falling due within one year.

19. Analysis of funds: restricted funds

	Balance at 1 January 2023	Income	Expenditure	Transfer to general fund	Balance at 31 December 2023
	£	£	£	£	£
Oliver Thomas Memorial Fund	**111,700**	**-**	**(92,500)**	**-**	**19,200**
Research	**151,607**	**467,765**	**(584,372)**	**-**	**35,000**
Healthcare	**5,600**	**27,257**	**-**	**-**	**32,857**
Community support & respite	**85,942**	**109,236**	**(113,531)**	**-**	**81,647**
Respite	**132,662**	**151,145**	**(31,843)**	**-**	**251,964**
	487,511	**755,403**	**(822,246)**	**-**	**420,668**

	Balance at 1 January 2022	Income	Expenditure	Transfer to general fund	Balance at 31 December 2022
	£	£	£	£	£
Oliver Thomas Memorial Fund	-	111,700	-	-	111,700
Research	(350,340)	754,941	(252,994)	-	151,607
Healthcare	20,625	89,048	(104,073)	-	5,600
Community support & respite	77,765	258,459	(117,620)	-	218,604
	(251,950)	1,214,148	(474,687)	-	487,511

Notes to the financial statements

(continued)

Restricted funds comprised:	2023	2022
	£	£
Oliver Thomas Memorial Fund[1]	**19,200**	111,700
Research:		
Apremilast Drug Re-purposing Trial	**-**	151,607
Research Programme Ninewells Hospital Dundee	**35,000**	-
Healthcare:		
Birmingham Children's Hospital Specialist Bath	**5,600**	5,600
Catrina Bernardis Fellowship – Hand Surgery	**27,257**	-
Community support:		
Community Support team leader	**26,000**	-
Community Support Manager for Scotland	**-**	21,542
Community Support in Bedfordshire	**-**	5,121
Community Support in Berkshire	**4,273**	4,273
Support Grants in Hampshire	**1,552**	3,952
Support Grants in Scotland	**-**	66
Support Grants in South Gloucestershire	**-**	1,054
Support Grants in Somerset	**6,914**	6,914
Support Grants in West Midlands	**581**	1,303
Support Grants in Buckinghamshire	**23,581**	13,836
Support Grants in Surrey	**-**	1,674
Support grants in Cambridgeshire	**3,109**	-
Support grants in Midlands	**2,000**	-
Other restricted funds	**13,637**	16,207
Digital Inclusion	**-**	10,000
Respite breaks:		
Holiday home purchases	**251,007**	132,662
Mobile home appeal	**957**	-
Total	**420,668**	487,511

1. The Oliver Thomas Memorial Fund was established in September 2022. The remaining balance is restricted to £10,000 for an EB weekend get-together and £9,200 for Clinical Best Practice Guidelines.

Notes to the financial statements

(continued)

20. Analysis of funds: unrestricted funds

The Trustees allocated the following amounts as designated funds in 2022:

	Balance at 1 January 2023	Income	Expenditure	Transfers	Balance at 31 December 2023
	£	£	£	£	£
Drug Re-purposing	**481,397**	**-**	**-**		**481,397**
Nursing continuity	**250,000**	**-**	**-**	**-**	**250,000**
IT Strategy	**50,000**	**-**	**-**	**-**	**50,000**
Procurement	**19,000**	**-**	**(19,000)**	**-**	**-**
NHS Digital	**200,000**	**-**	**-**	**-**	**200,000**
Total designated funds	**1,000,397**	**-**	**(19,000)**	**-**	**981,397**
General fund	**2,762,264**	**17,473,036**	**(18,050,113)**	**-**	**2,185,187**
Total unrestricted funds	**3,762,661**	**17,473,036**	**(18,069,113)**	**-**	**3,166,584**

	Balance at 1 January 2022	Income	Expenditure	Transfers	Balance at 31 December 2022
	£	£	£	£	£
Drug Re-purposing	-	481,397			481,397
Nursing continuity	250,000	-	-	-	250,000
IT Strategy	50,000	-	-	-	50,000
Procurement	50,000	-	(31,000)	-	19,000
NHS Digital	200,000	-	-	-	200,000
Total designated funds	550,000	481,397	(31,000)	-	1,000,397
General fund	3,500,325	14,725,180	(15,463,241)	-	2,762,264
Total unrestricted funds	4,050,325	15,206,577	(15,494,241)	-	3,762,661

£481,397 (2022: £481,397) has been designated to fund drug re-purposing trials and £200,000 (2022: £200,000) has been designated to fund the NHS Digital Data project. The NHS Digital Data project commenced in 2024, and the drug-repurposing trial is in development.

The designated fund for nursing continuity has been established as a contingency in the event of future NHS funding withdrawal, and the Trustees maintained a balance of £250,000 (2022: £250,000) in this fund.

In 2021 £100,000 was designated to fund future procurement and IT work furthering modernisation of back office practices. The procurement consultancy work was completed in 2023. The IT strategy fund is due to be allocated against CRM development costs in 2024.

Notes to the financial statements

(continued)

21. Analysis of net assets between categories of funds

Fund balances at 31 December 2023 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	**1,437,305**	**-**	**-**	**1,437,305**
Current assets	**4,848,332**	**981,397**	**420,668**	**6,250,397**
Creditors:<1 year	**(2,999,965)**	**-**	**-**	**(2,999,965)**
Creditors:>1 year	**(1,100,485)**	**-**	**-**	**(1,100,485)**
	2,185,187	**981,397**	**420,668**	**3,587,252**

Fund balances at 31 December 2022 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,290,094	-	-	1,290,094
Current assets	5,516,978	981,397	487,511	7,004,886
Creditors:<1 year	(3,672,317)	-	-	(3,672,317)
Creditors:>1 year	(372,491)	-	-	(372,491)
	2,762,264	981,397	487,511	4,250,172

Notes to the financial statements

(continued)

22. Reconciliation of net income to net cash flow from operating activities

	2022	2021
	£	£
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	**(662,920)**	451,797
Depreciation and amortisation charges	**261,882**	180,733
Impairment of programme related investment	**-**	-
Dividends, interest and rents from investments	**(97,461)**	(5,472)
Profit / (loss) on disposal of fixed assets	**-**	6,319
Decrease in stock	**2,063**	(742)
(Increase) / decrease in debtors	**(257,559)**	86,207
(Decrease) / increase in creditors	**55,640**	(152,278)
Net cash used in operating activities	**(698,355)**	566,564

23. Analysis of cash and cash equivalents

	At 1 January 2023	Cash flows	At 31 December 2023
	£	£	£
Cash at bank and in hand	**2,111,857**	**(34,285)**	**2,111,857**
	2,111,857	**(34,285)**	**2,111,857**

An analysis of changes in net debt note has not been prepared on the basis that DEBRA only has cash and cash equivalents, the movement on which is shown above.

Notes to the financial statements

(continued)

24. Grants to institutions

Research grants:	2023		2022	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
University of Dundee				
Clinical fellow funding	**-**	**658,253**	7,664	658,253
Guy's and St Thomas' Hospital, London				
Clinical endpoints study re EB therapy evaluation	**-**	**734,790**	40,233	734,790
Wound care and its complications in patients with EB	**23,176**	**30,500**	7,324	7,324
University of Birmingham				
Gait Analysis in EB Simplex	**-**	**46,032**	30,688	46,032
Clinical Fellowship	**26,359**	**125,263**	33,168	98,904
Novel spray to treat mucosal scarring	**-**	**152,384**	50,777	152,384
Use of highly sensitive and specific gene analytical techniques to identify microorganisms that may play a role in the chronicity of EB wounds	**1,246**	**1,246**	-	-
High-retention, lubricating eye drops to enhance quality of life in EB patients	**77,040**	**77,040**	-	-
University of Cologne				
Immunity in wound healing complications RBEB	**-**	**170,635**	5,929	170,635
Instituto Dermopatico deli'Immacolata Rome				
Re histone deacetylase inhibitors for RDEB	**1,928**	**70,962**	4,627	69,034
King's College London				
Preclinical studies of lentiviral-mediated COL7A1 gene therapy	**-**	**198,978**	10,395	198,978
PASTE-mediated superexon replacement of COL7A1 as a treatment for DEB	**15,844**	**15,844**	-	-
Balance c/fwd	**145,593**	**2,281,927**	190,805	2,136,334

Notes to the financial statements

(continued)

Research grants:	2023		2022	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
Balance b/fwd	**145,593**	**2,281,927**	190,805	2,136,334
Great Ormond Street Institute of Child Health				
Respiratory cell & gene therapy for children with JEB	**16,893**	**70,962**	52,601	118,445
Bambino Gesù Children's Hospital				
MicroRNAs expression profiling, activity and therapeutic perspectives	**4,408**	**77,592**	27,628	73,184
University of Edinburgh				
Kindlin-1 loss in squamous cell carcinoma	**22,213**	**112,834**	38,954	90,621
New York Medical College				
Innate & adaptive immune mechanisms in RDEB	**34,186**	**207,538**	69,120	173,352
The Beatson Institute for Cancer Research				
Drug re-purposing for the treatment of RDEB squamous cell carcinoma	**70,428**	**70,428**	-	-
Pre-clinical models of RDEB squamous cell carcinoma	**8,816**	**8,816**	-	-
University Salzburg, Austria				
Investigating the potential of re-purposing statins for the treatment of highly aggressive RDEB-tumors	**15,696**	**15,696**	-	-
Centre Hospitalier Universitaire de Nice, France				
A 20-Week Multicentre, Open Study Assessing the Efficacy and Safety of Apremilast (Otezla®) in Patients > 6 years of age with EB simplex generalized.	**49,189**	**49,189**	-	-
Balance c/fwd	**669,959**	**5,195,579**	750,554	4,525,620

Notes to the financial statements

(continued)

	2023		2022	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
Balance b/fwd	**669,959**	**5,195,579**	750,554	4,525,620
Queen Mary University, London				
Dissecting the role of inflammatory pathways in JEB	**3,137**	**3,137**	-	-
Improving skin regeneration in JEB by targeting the integrin αvβ6	**2,909**	**2,909**	-	-
Identifying Cellular and molecular mechanisms underlying the oral mucosal scarring and resistance to cancer development in RDEB patients	**16,650**	**16,650**	-	-
Treating JEB with Recombinant Laminin 332	**14,776**	**14,776**	-	-
Targeting epigenetic gene regulation in EBS	**33,288**	**33,288**	-	-
Cardiff University				
Developing a self-help toolkit for supporting wellbeing in parents of children with EB	**4,726**	**4,726**	-	-
Fundacion Instituto De Investigation, Madrid				
Non-viral genome editing patching of COL7A1	**1,250**	**1,250**	-	-
CIEMAT, Madrid				
Novel platform for generation of safer pseudorabies herpesvirus-based vectors for RDEB therapy	**1,250**	**1,250**	-	-
KK Women's & Children's Hospital, Singapore				
Improving the genetic diagnosis of EB by long-read sequencing	**875**	**875**	-	-
University of Buenos Aires				
Molecular epidemiology of EB Simplex in Argentina	**1,250**	**1,250**	-	-
Total	**447,533**	**3,039,469**	379,109	2,591,936

Notes to the financial statements

(continued)

Healthcare projects:	2023	2022
	Total paid in year	Total paid in year
	£	£
Great Ormond Street Hospital for Sick Children		
Clinical nurse specialists in EB	**81,540**	54,681
Guys & St Thomas' Hospital London		
Adult EB support nurses	**5,572**	(26,964)
Birmingham Children's Hospital	**40,126**	56,577
Other	**-**	17,951
	127,238	102,245

Reconciliation of provision:	2023			
	Research grants	**Healthcare grants**	**Community Support grants**	**Total**
	£	**£**	**£**	**£**
Provision brought forward	**411,167**	**107,997**	**-**	**519,164**
New commitments	**1,760,383**	**127,238**	**144,028**	**2,031,649**
Spend in year	**(447,533)**	**(127,238)**	**(144,028)**	**(718,799)**
Provision carried forward	**1,724,017**	**107,997**	**-**	**1,832,014**

Reconciliation of provision:	2022			
	Research grants	Healthcare grants	Community Support grants	Total
	£	£	£	£
Provision brought forward	548,814	125,948	-	674,762
New commitments	256,461	84,294	85,856	426,611
Co-funding contributions	(14,999)	-	-	(14,999)
Spend in year	(379,109)	(102,245)	(85,856)	(567,210)
Provision carried forward	411,167	107,997	-	519,164

25. Related parties

During the year, the charity charged management charges totalling £7,800 including VAT (2022: £11,300) to its subsidiary, DEBRA Trading Limited.

Reference and administrative details

Patrons and ambassadors

Royal Patron
HRH The Duchess of Edinburgh GCVO

Life Patron
Philip Evans

President
Simon Weston CBE

Vice Presidents
Graeme Souness
Frank Warren
Lenore England
Stuart Proctor

Trustees

Jim Irvine (Chair)
Joanne Merchant* (Treasurer)
David Bendor-Samuel (Vice-Chair)
Carly Fields* (Vice-Chair)
Simone Bunting*
Christo Kapourani*
Simon Talbot*
Mick Thomas*
Dan Mundy
Debbie Install*

Additional details

Company secretary
Simon Jones

Registration
Charity Commission Number: 1084958
SCR Number: SC039654
Company Number: 4118259

Registered office & principal address
DEBRA, The Capitol Building, Oldbury, Bracknell, RG12 8FZ

Auditor
Sayer Vincent LLP, Invicta House, 110 Golden Lane, London EC1Y 0TG

Banker
HSBC, Thames Valley Business Banking, Hanborough House, Wallbrook Court, North Hinksey, Oxford, OX2 0QS

Solicitor
Stone King, 91 Charterhouse Street, London, EC1M 6HR

*Members of the Board who have direct experience of EB.

Abbreviations

CPG	Clinical Practice Guidelines
CEO	Chief Executive Officer
CRM	Customer Relationship Management
DEB	Dystrophic Epidermolysis Bullosa
EB	Epidermolysis Bullosa
EBS	Epidermolysis Bullosa Simplex
EDI	Equality, Diversity & Inclusion
EPOS	Electronic Point of Sale
ESG	Environmental, Social, Governance
F&E	Furniture & Electrical retail store
GDPR	General Data Protection Regulation
HR	Human Resources
k	thousand
LFL	like-for-like
m	million
NHS	National Health Service
pa	per annum
RDEB	Recessive Dystrophic Epidermolysis Bullosa
SGAP	Scientific Grants Advisory Panel
SMT	Senior Management Team
Trad	Traditional retail store
y on y	year on year

debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

DEBRA funds pioneering research, specialist healthcare, international best practice and life-long care and support to the EB community. We make a difference today with the aim of a better future for those suffering from the condition.

Together we will #StopThePain.

DEBRA, The Capitol Building, Oldbury, Bracknell, Berkshire, RG12 8FZ

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www.debra.org.uk

/DEBRACharity
@charitydebra
@charitydebra
/company/debra-uk

DEBRA Royal Patron - HRH The Duchess of Edinburgh, GCVO
DEBRA President - Simon Weston CBE

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

FR Registered with FUNDRAISING REGULATOR

A charity registered in England and Wales (1084958D) and Scotland (SC039654).
Company limited by guarantee registered in England and Wales (4118259).
VAT Number 689 2482 79.

DEBRA

England & Wales - Charity number 1084958

Accounts

debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

Trustees´ Annual Report & Accounts 2022

Our vision

A world where no one suffers with epidermolysis bullosa (EB).

Our mission

Provide lifelong care, while seeking cures, for all those affected/impacted by living with EB.

Our values

Making a difference

Caring

Inclusive

Respectful

Passionate

Committed

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What is EB

Skin as fragile as a butterfly wing

EB, epidermolysis bullosa, is a group of extremely painful genetic skin conditions that cause the skin to blister and tear at the slightest touch. With skin so fragile it is often referred to as 'butterfly skin'. EB can affect the hands and feet only or in the most severe cases any part of the body, including blistering on the eyes and internal organs.

Genetic condition

People living with EB have a faulty gene which means the skin cannot bind together so that any friction can cause it to tear apart. Every person has two copies of each gene – one passed on from each parent. EB may be inherited as either dominant (only one copy of the gene is faulty) or recessive (both copies of the gene are faulty). Parents have a 50% chance of passing on a dominant form of EB to their child, whereas the chance of passing on a recessive form of EB drops to 25%. Both parents may carry the gene without knowing or displaying any symptoms.

Types of EB

There are over 30 subtypes of EB, grouped into four main types: EB Simplex (EBS) accounting for around 70% of patients, Dystrophic EB (DEB) 25%, Junctional EB (JEB) 5% and Kindler EB which is rare.

Symptoms and complications

Symptoms vary and range in severity depending on the type of EB. Blisters continuously form and have to be drained and dressed daily, a painful process that can take several hours. Internal blisters such as inside the mouth create difficulty swallowing. There can be narrowing of the oesophagus and airways. The build-up of scar tissue can cause fingers and toes to fuse together. It can mean a higher risk of developing skin cancer. In severe cases it can be fatal.

Treatment

People living with EB may require treatment from a range of medical specialists aimed at symptom relief and to prevent complications such as infection. The most common challenge amongst all types of EB is the pain and itching that occurs as a result of blistering.

No cure

There are an estimated 5,000 people affected by EB in the UK and 500,000 worldwide. It is currently incurable.

Chair of Trustees and CEO introduction and welcome

Last year we announced our ambitious strategic plan to increase the pace and breadth of our work to make our vision of life-changing treatments and, ultimately, cures for EB a reality.

We are enormously proud of the vision of our trustees, strong leadership of our senior management team, the generosity of our supporters and customers, and the determination and commitment of our staff and volunteer teams. At the end of the first year of our five-year plan, together we have brought about a step-change in our approach to funding and delivering our vision that is truly remarkable. It is a journey, but one that we have clearly defined and brought to life, with our values guiding our way.

EB research is essential to the delivery of our ambition. We urgently need to find treatments that will give relief to the devastating symptoms of EB – pain, itch, cancer, wounds, infection. The EB community has driven our commitment to do more to deliver our world-class programme of research and end suffering. We launched a five-year EB research strategy to increase the level of ambition and impact of our EB research. We established a new EB expert advisory panel, increased the involvement of the EB community, launched our first call for applications to support and nurture the next generation of EB researchers and partnered with organisations from the wider medical and scientific community including the Medical Research Council. Our commitment to research will continue with budgeted new research spend of £1.5m for 2023. Most importantly, in addition to funding our active research portfolio this year, we announced funding for drug repurposing to find approved drug treatments for EB faster.

The EB community is at the heart of everything we do. To ensure people with EB and their families were able to access the care and expertise they needed, our Community Support Team worked with healthcare professionals to connect patients with the expert, specialist services across the UK. We supported the development of EB expertise, worked with healthcare professionals to increase the availability of expert information and continued to fund the development of EB best practice guidelines for clinicians and families.

We also worked with an external agency to create the first EB patient insight study, to capture the lived experiences and views that will shape our services and support our lobbying for government funding and support.

We undertook a rebrand to deliver a stronger presence on the high street and, through improved communication and social media, achieved a significant increase in membership numbers and engagement; but central to our ambitious strategic plans is the realisation that increased EB awareness is needed if we are to increase public understanding and government level support to deliver the life-changing improvements to clinical care and treatments we need.

In October we launched our largest appeal yet, A Life Free of Pain, with the support of our President, Simon Weston CBE and Vice Presidents Graeme Souness, Lenore England, Stuart Procter and Frank Warren. The appeal aims to bring considerable attention to improve awareness of EB and to raise £5m to accelerate our research into drug-repurposing, treatments and further support for the EB community. In just a few months the appeal has raised over £1.1m and gives us hope that life-changing treatments to radically improve the quality of life for people living with EB are within reach.

We would like to thank all of our supporters and the customers in our stores and online who shopped with us. Despite the ongoing impact of the pandemic, the war in Ukraine and the cost of living crisis, their commitment and generosity enabled us to achieve a record fundraising income, enabling us to spend over £2.6m on healthcare, support and research, an increase year on year of 40%.

Thank you also to our EB community, the specialist healthcare professionals and researchers we work with, our Patron HRH The Duchess of Edinburgh GCVO, president and vice presidents. It is the commitment and support of you all which has brought us this far and which will enable us, together, to continue on our journey to grow and connect our membership, increase our commitment to EB research and support the development of EB best practice and expertise.

> “Together we will achieve our vision of a world where no one suffers with EB.”

Jim Irvine
Chair of Trustees

Tony Byrne
CEO

Our work

Investing in a future free of EB

DEBRA was the world's first EB patient support organisation, founded in 1978 by Phyllis Hilton whose daughter Debra was born with Dystrophic EB. When told by medical professionals that she should take her baby home as nothing could be done for her, she set out to find ways to treat Debra's skin herself using cotton dressings. Fifteen years later Debra sadly passed away. That year Phyllis met a parent seeking advice and realised that nothing had changed. She decided to take action, organising the first ever meeting for parents of EB and so DEBRA was formed.

We have come a long way since then. We have achieved global recognition as a leading authority on EB and made significant progress in advancing diagnosis, treatment and daily management of EB. DEBRA is now international in scope with a worldwide network of DEBRA groups sharing information and best practice. We are committed to making sure that people with EB and their families and carers get the vital and wide-ranging care and support they need so that the devastating symptoms of EB can be reduced while we work towards finding improved treatments and a cure.

Pioneering EB research

The research journey for EB over the past 44 years has been remarkable – from gene discovery to cutting-edge trials of therapies to control symptoms and manage complications like cancer. During this time we have invested over £20m and been responsible for establishing much of what is now known about EB today. We are the largest UK funder of EB research and we have an ambitious, patient-centred research strategy that drives us to fund science of the highest quality across the world, including prioritising investment in drug re-purposing, to develop a treatment pipeline that will slow, stop and/or reverse EB.

Specialist healthcare

In 1987 we funded the first specialist EB DEBRA nurse. We now work in partnership with the NHS to deliver an enhanced EB healthcare service for people with all types of EB. We have invested in the development of EB centres of excellence, fund clinical best practice guidelines for clinicians and families and connect patients with the expert, specialist services they need across the UK. Our funding has helped establish a model EB diagnostics centre, which makes it possible for parents to receive prenatal diagnostic testing if they are at risk of passing on EB. We are dedicated to ensuring that everyone with EB has access to the best care and expertise from diagnosis onwards.

Lifelong community support

The EB community is at the heart of everything we do. We are the are the only UK charity specifically aimed at continuously supporting the EB community. We provide individualised support, information and guidance for people with EB and their families and carers – from benefits and finance to bereavement support, social opportunities, respite and advocacy, connecting patients with the specialist services they need and a support network across the EB community.

International collaboration and best practice support

We are a founding member of and contribute funding and support for DEBRA International, our umbrella organisation with nearly 50 groups worldwide, sharing information and best practice and working towards improving the lives of those living with EB in their respective countries.

Making a difference

Our impact in 2022

£2.6m spent on EB research, healthcare & support
40% increase year on year

3500+ DEBRA members
17% increase in membership

£1.1m raised towards target £5m by A Life Free of Pain appeal for drug repurposing and EB care and support

Ambitious five year **EB research strategy** launched

First EB **patient insight study** developed to influence EB support, provision and government funding

Rebrand roll out
to deliver a stronger presence on the high street

ESG journey underway with **100%** of waste from our stores diverted from landfill though our waste partner

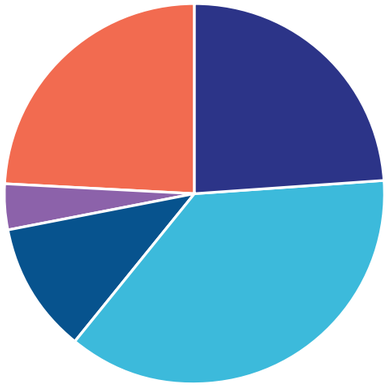
Achieved with help from

- 375 permanent staff
- 1,100 dedicated volunteers giving 230,000 hours of donated time
- 14 trustees, 64% with direct experience of EB
- 102 stores – 8th largest charity retailer in UK
- £2.95m net income raised by our generous supporters and loyal customers

Committed to the EB community

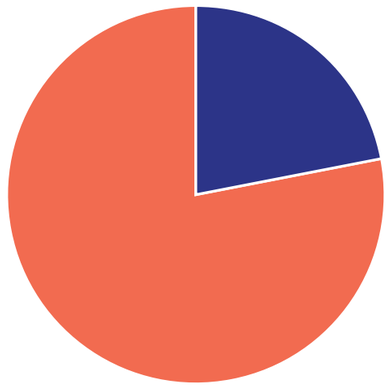
We are committed to making sure that people with EB in the UK and their families and carers get the vital and wide-ranging support they need, supporting specialist healthcare and investing in life-changing research so that the devastating symptoms of EB can be reduced while we work towards a cure.

How we spent our money
£2,640,000 spent on our charitable activities



Research
Community support
Healthcare
Respite breaks
Public education

How we raised our money
£2,950,000 net income raised



Retail
Fundraising

£2,300,00 net fundraising income,
£650,000 net retail income

EB research

Over the past 44 years we have been responsible, through funding pioneering research and working internationally, for establishing much of what is now known about EB. We have invested over £20m in 138 research projects, working with 53 research institutions across 12 countries globally.

We are the largest UK funder of EB research and have been committed to a remarkable research journey for EB, from gene discovery to cutting-edge trials of therapies to control symptoms and manage complications like cancer.

Our ambition

We have a vision of a world where no one suffers from the painful skin condition epidermolysis bullosa. Our ambition focuses on what matters to people living with EB, finding treatments to lessen the day-to-day impact and improve quality of life, and cures to eradicate EB.

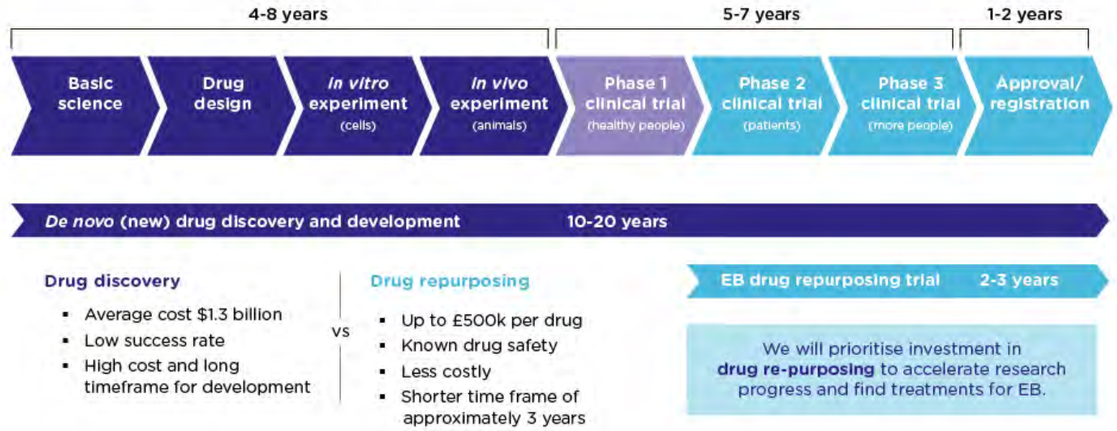
We will fund science of the highest quality that has the potential to deliver for EB patients. We will play a pivotal role in making research into EB a global effort, working with many organisations, but with DEBRA UK front and centre, leading the quest for innovations that improve the lives of people living with EB.

Our objectives

Our four overarching research priorities are those we view as most likely to deliver outputs for people living with EB.

1. Invest in drug repurposing and develop drug discovery programmes to accelerate finding treatments.
2. Increase investment in patient-centred research themes.
3. Continue to invest to increase understanding of the causes and progression of EB and the role of the immune system.
4. Invest heavily in the next generation of EB researchers.

Drug repurposing clinical trials



> "We will invest in drug repurposing and develop drug discovery programmes to accelerate finding treatments that already successfully treat other inflammatory skin conditions such as psoriasis and atopic dermatitis. These drugs are already available within the NHS and we believe they could be effective in slowing, stopping or reversing the progression of EB."
>
> - Dr Sagair Hussain

How we met our objectives in 2022

We introduced a step-change in our approach, with six strategic actions to increase the level of ambition and impact of our EB research.

Set a five year EB research strategy

We launched a five year research strategy which was, and will continue to be, the driver for significant positive changes in our approach to and delivery of EB research.

> **Patients with EB are still suffering from devastating symptoms – pain, itch, cancer and wounds that require hours of dressings and blisters that can lead to infection. Now is the time to accelerate the pace of discovery. We want a future where everyday treatments end the pain and suffering of people with EB and save lives.**

Established a new EB expert panel

We established our own grant making processes in alignment with AMRC (Association of Medical Research Charities) guidance and appointed a Research Grants Administrator.

We set up a Scientific Grant Advisory Panel (SGAP) of renowned national and/or international experts in their field and EB to review grants and make recommendations to the DEBRA Charitable Purposes committee.

Professor Christopher Griffiths OBE was formally appointed as DEBRA's independent research advisor. Professor Griffiths is Foundation Professor of Dermatology at the University of Manchester, President of the European Society for Dermatological Research and a past-President of the British Association of Dermatologists (BAD), EDF, BSID and International Psoriasis Council.

Announced a new partnership with the MRC

Our aim is to develop the next generation of EB researchers, attracting, supporting and developing the brightest researchers at all stages of their careers. We signed an agreement with the MRC (Medical Research Council) and launched our first call for applications for joint DEBRA and MRC funded research with PhD studentships; clinical research training fellowships, clinician scientist fellowships and career development awards.

We also announced a special national and international call for drug repurposing grants to take place in 2023.

Partnered with organisations from the wider medical and scientific community

We engaged with NICE (National Institute for Health & Care Institute), joined the Genetic Alliance and International Alliance of Dermatology Patient Organizations (globalskin) and partnered with Fight for Sight to fund EB eye research relating to vision in EB.

We are in the process of partnering with NHS Digital to collate EB patient data across NHS departments to better understand the patient journey and bottle necks within the system. This will also help set research priorities in the coming years.

Increased involvement with the EB and research communities

We invited our members to get involved in our research decision-making process and set up the first feedback sessions as part of our involvement network. In EB Awareness Week, we ran an online Q&A session, Research Unpacked, to give members the opportunity to learn about our strategy, plans and latest EB research developments. We communicated to UK and international researchers, our members and staff and researchers and developed the research content on our website and social media.

Continued funding EB research programmes

We committed funding of £350,000 in 2022. We approved three new projects in addition to our active research portfolio of 18 projects and our 2022 grant call awarded just over £250,000 to three new projects to start in 2023.

How we will continue to develop in 2023

Our planned new research spend is £1.5m including £500k deferred from 2022.

Our research focus will continue to be guided by what matters to people living with EB. Patients and their family members through their own experiences are the experts on the impact of EB. The key priorities of the EB community, those living and working with the conditions, are essential in shaping the research selection process and driving the future of EB research, balancing short-term benefits for patients and support for long-term research into potential treatments, cure or cures.

Drug repurposing grants of up to £500,000 for up to three years will be available in 2023 and alternate years. These will be promoted through our research calls amongst the global EB research community and awarded to high-quality projects on clinical trials of existing licensed therapeutics repurposed for EB.

We will also promote and offer grant calls for EB research including career development fellowships to support and nurture the next generation of EB researchers.

Partnerships with EB and non-EB organisations will be a strong focus to leverage our funds. We aim to form a new partnership with the British Skin Foundation to co-fund a PhD studentship to encourage new researchers into EB. We will continue to work with the pharmaceutical industry, MHRA and NICE to ensure EB treatments are approved in the UK.

We will continue to **increase involvement with the EB and research communities.** The DEBRA SGAP and involvement network group, consisting of members with lived experience of EB, will be essential in helping us decide which projects to support.

We will continue to work with EB and non-EB researchers globally to develop podcasts, blogs and films to highlight our research and inform and engage the EB community. Attending conferences will be a major endeavour in 2023 to **raise the profile of DEBRA and EB** amongst the research community, pharmaceutical companies and other organisations.

Specialist healthcare

Connecting patients, supporting expertise

Enabling EB healthcare teams to support over 2,000 EB patients each year

Intro

We work in partnership with the NHS to deliver an enhanced EB healthcare service for people with all types of EB. We have invested in the development of EB centres of excellence, and continue to fund clinical best practice guidelines for clinicians and families and connect patients with the expert, specialist services they need across the UK.

Our ambition

We are dedicated to ensuring that everyone with EB has access to the best care and specialist expertise from diagnosis onwards.

Our objectives

1. To connect patients with the expert, specialist services they need for people living with all types of EB across the UK.
2. To enable and support the development of specialist EB expertise, services and multi-disciplinary working.
3. To provide specialist EB healthcare information to the EB community.

How we met our objectives in 2022

Healthcare services continued to be affected by the COVID-19 pandemic, primarily due to the need to address the backlog of core clinical work and resume face to face appointments in clinics and patients' homes. Some of the non-core activities, including publication development and uptake of the podiatry training, also continued to be limited due to core clinical needs taking priority.

Our Community Support Team worked with healthcare professionals and services across the UK to ensure people with EB and their families were able to access the care and expertise they needed.

We remained committed to working with the NHS, funding up to 25% of specialist EB nursing in teams that had the capacity to undertake healthcare activities not funded by the NHS. We provided funding for specialist EB dietitians at Guys & St Thomas' Hospital and Birmingham Children's Hospital one day per week to provide nutritional advice to promote vital health, wellbeing and wound healing.

We supported the development of EB expertise, delivering our EB podiatry training course online, attending EB clinical network meetings, making specialist information and knowledge accessible to podiatrists across the UK, and enabling patients to access vital expert care locally. We provided study grants to professionals and promoted EB specialist training by clinical teams and external organisations.

We worked with healthcare professionals on projects to increase the availability of expert information, including the development of nutritional advice and physiotherapy and movement.

We provided a wide range of healthcare information to our members, communicating through online sessions, newsletters and emails and in-person.

We continued to support and promote the development of clinical best practice guidelines for clinicians and families.

How we will continue to develop in 2023

We will continue to offer funding up to 25% of all existing specialist EB nurses. Additional grants for developing the expertise within clinical teams will be considered along with calls for small project funding that will enhance services. Funding will also be available to continue specialist nutrition services by funding 50% of two EB dietitians.

We will continue to lead the development of an accredited specialist EB podiatry training course and link with undergraduates, aiming to deliver three training courses each year, to make specialist information and support accessible to podiatrists across the UK and access to expert care locally for people with EB. We will also review the development of our short to long term funding of local podiatry.

We will work with healthcare professionals to update and develop new information in multiple formats such as publications and films to inform members, agencies and people working to support the EB Community.

EB community support

Lifelong support, advocacy and engagement

5,000
people with EB in the UK

3,500+
DEBRA members

17%
increase in DEBRA membership

200%
increase in DEBRA grants awarded to the EB community

537
adults & children stayed in our respite holiday homes

The EB community is at the heart of everything we do. Their experiences and views shape our services and drive our commitment to connect patients, families and carers with the specialist services and support they need to improve quality of life today while we work towards a cure.

DEBRA was the world's first EB patient support organisation and we remain the only UK charity specifically aimed at continuously supporting the EB community. We provide practical, financial, emotional support, respite and advocacy for people living with EB and their families, connecting them to specialist services and a support network across the EB community.

Our ambition

To provide excellent care and support to members of the EB community, maximising every opportunity to make a difference and improve quality of life whilst seeking a cure.

Our objectives

1. To build our membership, increasing numbers, diversity and engagement with the EB community.
2. To provide access to support and the specialist health and social care they need.
3. To empower our members, ensuring their voice is heard and acted upon and that they have choice and independence throughout their journey of life living with EB.

Connecting and providing support for people of all ages living with all types of EB, their families, carers and specialists throughout the UK.

How we met our objectives in 2022

We increased team resources, appointing a new role to lead on member engagement and two further support managers to respond to the increase in need for support and access to expert knowledge. We renamed the directorate Member Services to reflect members being central to all of our charitable activity.

Our Community Support Team continued to build on the **successful hybrid working approach** to provide the most accessible and effective service to support people with EB and their families across the UK.

We hosted **virtual and in-person groups and events** throughout the year, sharing expertise and resources and connecting members with others in the EB community. Our annual Members' weekend took place in-person for the first time since the pandemic. Members, their families, staff, volunteers, researchers, healthcare professionals and all involved in the event were pleased to be able to return to having the opportunity to meet and connect as a community, sharing knowledge and experiences, supporting each other and building friendships.

We doubled the number of grants awarded to the EB community and revised our grant decision-making guidance. Grants provided included support grants for items to help daily living, improve health and comfort, assistance to attend clinics, bereavement support and respite holiday homes.

We met the ongoing increase in demand and need for respite, when an opportunity to purchase an additional holiday home earlier than planned, enabled us to purchase one new home and replace an existing one.

We increased communications with members to connect the EB community and provide information on healthcare, research, support, member events and opportunities for involvement. The data cleansing and transformation project was completed, and we moved to a new CRM system.

We set up an involvement network for people in the EB community to encourage members to get involved in research, be a patient representative, play a part in lobbying for EB support and funding, steer our fundraising, review our EB information and communications and influence what we do.

We initiated a number of projects for launch in 2023 including a **quantitative quality of life baseline survey** to inform how we prioritise our activities and introduce new types of support and an independently-assessed quality mark for health information.

One of the highlights of the year was in May when we held our first in person Members' Weekend since 2019. CEO, Tony Byrne summed up the day as a great opportunity to be together again, to share experiences, to learn from one another and have fun. After the past few years, it felt even more special being able to connect as a community.

"When war broke out in Ukraine, my daughter Shybika, age two who has Junctional EB, my son, my partner and me fled the country. We left our home, our country, our lives. Fellow EB parents on social media introduced us to Rowena, our DEBRA Community Support Manager. She helped us to get us financial support to help buy specialist soft clothing and travel expenses to get us to the never-ending medical appointments.

DEBRA also put us in the care of the Rare Diseases Centre at Birmingham Children's Hospital. Shybika has never received this level of care and expertise before. Rowena does more than help solve practical problems, she provides emotional support and comfort. She is one of the greatest gifts my family has ever received."

How we will continue to develop in 2023

We will embark on a new, member-centred journey from 2023 to 2026, which will be underpinned by a new member services strategy.

We will grow and diversify the involvement network, expanding our engagement activities and the opportunities we offer, looking at the journey that our members take with DEBRA and how we can provide more proactive support and information at different times of their life. Additional focus will be given to identifying how we can support those living with less severe EB.

We will reach new members by developing our membership offering, raising awareness of EB, DEBRA and the services and support available, aiming to increase membership by 5% each year.

We will continue working alongside the health and support teams developing up-to-date and accessible information and publications on to help people living and working with EB as well as for schools, GPs and workplaces.

We will continue to develop the virtual groups and in-person events on offer throughout the year. Presentations, information and inspirational stories will be made available in multiple formats to provide a resource that can be easily accessed by members and people working to support the EB Community.

We will increase our grants scheme to make a tangible difference to members in time of need. Requests for funding are often made during the year and sometimes require quick call to action. Funding of £75k for these new or enhanced care and support initiatives will be made available in 2023 and 2024.

The Community Support Team will continue to develop the hybrid way of working ensuring the most efficient and effective service is offered. An additional post in Community Support and two in Membership will be added to manage the additional work in the field attending clinics/ home visits, member events and to support the planned increase in membership, support grant applications and holiday homes and the contribution of the team's expert knowledge to create new resources for the EB community.

Our partnerships

We are proud to collaborate and work in partnership with healthcare, research, and corporate partners across the UK and internationally.

138
research projects across 12 countries at 53 world-class research institutions funded by DEBRA UK

44+ years
of working collaboratively

50
DEBRA International groups

41%
of Clinical Practice Guidelines funded by DEBRA UK in the past 5 years

Our ambition

Central to our ambitious strategic plans is the awareness that a global and collaborative approach is needed if we are to increase the pace and breadth of our work and achieve life-changing improvements to clinical care, treatments and, ultimately, a cure for EB.

Building partnerships, improving outcomes

We work with world-class scientists and clinicians and with national and international partners from academia, biotechnology, pharmaceutical industries, and organisations with a shared interest in EB or other skin conditions. Together, we can reach new audiences, raise awareness, share expertise and work collaboratively to provide the specialist services our members need and drive a programme of world-class research to bring hope and improved outcomes for people worldwide living with EB.

In 2022, we initiated the process of building a partnership with NHS Digital in order to develop a national EB population register to improve clinical practice, support research into EB, inform health service commissioning and evaluate and audit health and social care services for EB patients.

We collaborated with the Medical Research Council to offer jointly funded clinical research training fellowships, Clinician Scientist Fellowships and Career Development Awards to support the next generation of EB researchers.

We are involved in NICE (National Institute for health & Care Excellence) scoping workshops representing the EB voice to evaluate new treatment for EB.

We reviewed the Department of Work and Pensions training module for EB which is used with their benefit assessors to improve understanding of EB.

We are proud members of the Association of Medical Research Charities (AMRC). All projects undergo a thorough application and review process by our Scientific Grants Advisory Panel (SGAP) guaranteeing that we only fund high-quality projects. This process ensures new research projects build on existing knowledge, which helps us to only invest in projects that give the best chance of breakthroughs leading to change.

We collaborated with charity Fight for Sight to set up a partnership to co-fund eye research in EB.

We are working with GlobalSkin, a unique global alliance supporting patient organisations to improve the lives of dermatology patients worldwide. Their work is focused on supporting their members in the fields of research, advocacy, and support. By working with partners such as GlobalSkin we stand a better chance of securing the support we need to ensure that in the future no one has to suffer with the pain of EB.

We are a member of Genetic Alliance UK which will help us in raising awareness and understanding of EB. They are the largest alliance of organisations supporting people with genetic, rare, and undiagnosed conditions in the UK. They provide information and support to families whilst influencing the services they need and add patient voice into debates that matter to the communities they represent.

Enhancing global EB care and best practice

We partner and work collaboratively with international organisations and the global DEBRA network to undertake world-class research, coordinate international research grants, support the next generation of EB researchers, and share ideas, expertise, and best practice.

We are a founding member and continue to invest in DEBRA International, our umbrella organisation, supporting nearly 50 DEBRA groups worldwide working collaboratively for EB.

Through DEBRA International we support the development of Clinical Practice Guidelines to increase professional knowledge and best practice for patients around the world with EB.

Corporate partners

Our many corporate partners play a vital role in helping us raise awareness, supporting our campaigns, providing in-kind services as well as funding for research, healthcare, community support and respite.

Thank you to all our partners for their generous support and commitment to our cause.

> "We are calling on the wider scientific community, other funders and our industry partners to join us on our journey to accelerate EB research innovation."
>
> Dr Sagair Hussain, Director of Research at DEBRA

Raising awareness

Engaging communities

5.5m
people reached on social media

110%
increase in engagement

21%
increase in emails & campaigns

17%
increase in DEBRA membership

Our ambition

Our marketing and communications will focus on empowering and engaging our communities, lobbying government and creating greater awareness of EB to ensure there is understanding for those living with the condition, more widespread EB expertise and funding for essential EB research and care.

Our objectives

1. To raise awareness and understanding of EB, DEBRA's work and the needs of the EB community.
2. To connect and build engaged communities for all those living or working with EB, ensuring that the EB community has the support, advocacy and understanding it needs.
3. To lobby government to influence future services and provision for EB including securing a commitment of £10m to support drug repurposing clinical trials.

How we met our objectives in 2022

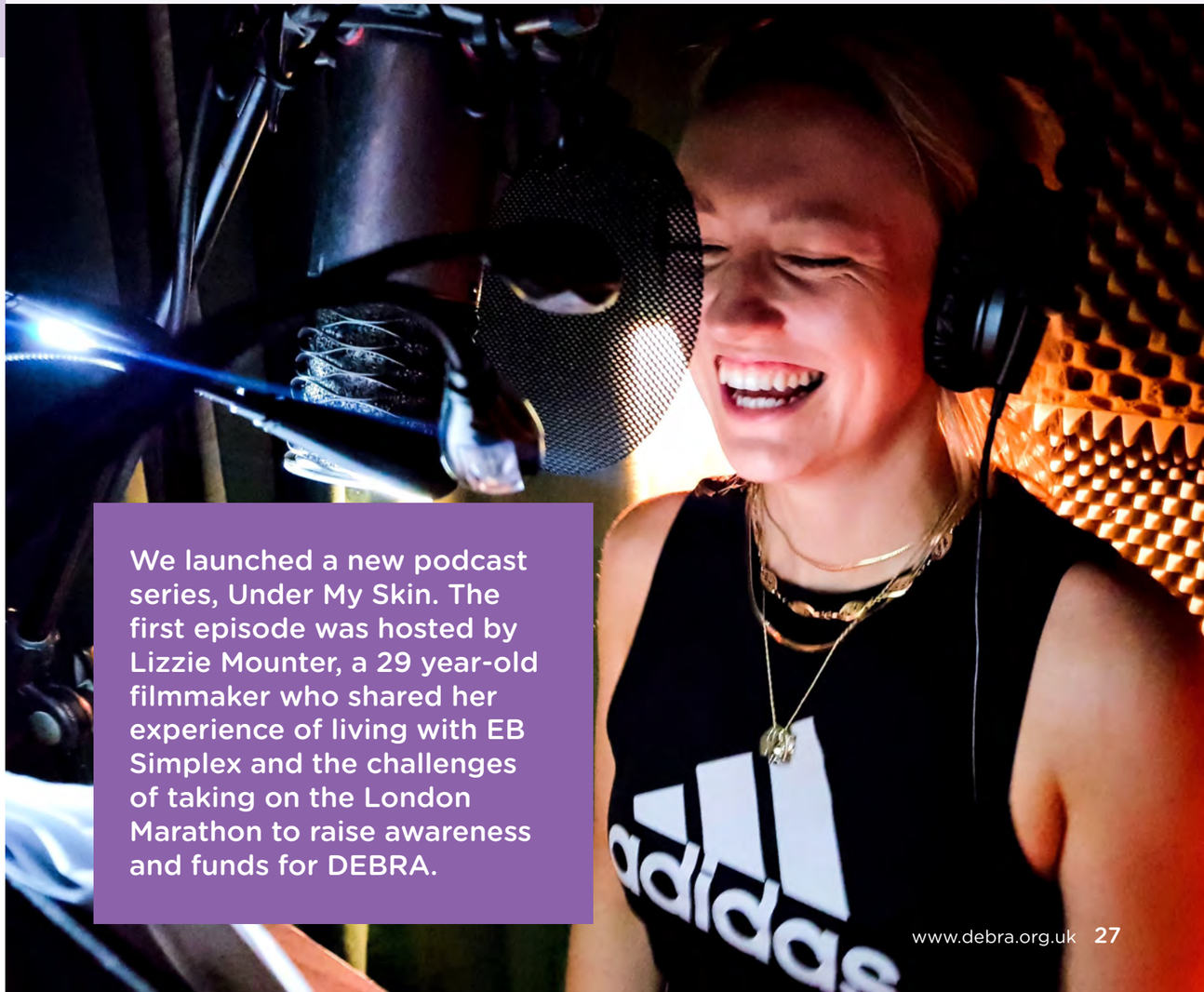
We **built awareness and engagement with our communities** with improved focus and frequency of our communications to supporters, members, staff and volunteers, moved to a new platform with software optimisation to encourage open and click through rates and undertook a data cleansing project to create a better quality, more engaged supporter and membership list.

We **increased the quality and frequency of our social media communications**, leveraging social media to inform and engage our membership. We used organic and paid social media to encourage participation in our fundraising events and support for our appeals through a greater focus on sharing member stories. We also used paid activity to help recruit volunteers and build local awareness of our stores. We established a presence on TikTok and developed our Instagram following as we begin to attract a younger demographic and drive sales through our retail network.

We worked with a specialist external public affairs agency to **accelerate our government lobbying activity** with a letter to the then Health Secretary, Sajid Javid, requesting financial support and a follow-on campaign encouraging staff, volunteers, and members to write to their local MP. This resulted in An Early Day Motion being tabled and offers from MPs to raise our case for support in parliament on our behalf. We have built on this activity with a dedicated public affairs strategy with the objective of building relationships and influence with the key politicians who can help us secure the financial support we need.

We delivered a **refreshed visual brand** that better communicates who we are and what we do and supports our fundraising ambitions. The project involved interviews with key stakeholders across the charity including members and healthcare professionals. We started a phased roll out across digital platforms, publications and marketing collateral with the store roll out planned for improved brand visibility from 2023.

We were delighted to be **awarded the prize from PM Society** – Creativity for Good – and the opportunity to work with a creative agency to deliver the 'DEBRA effect' campaign which was effective in generating awareness across social media and selected retail stores.



We launched a new podcast series, Under My Skin. The first episode was hosted by Lizzie Mounter, a 29 year-old filmmaker who shared her experience of living with EB Simplex and the challenges of taking on the London Marathon to raise awareness and funds for DEBRA.

With the support of members from the EB community, we created a series of hard-hitting images for the A Life Free of Pain appeal that would have emotional impact and help to raise awareness of EB.

How we will continue to develop in 2023

Raise awareness

Awareness of DEBRA and of EB remains low. We need to achieve greater awareness of EB within the healthcare and research communities and the wider public to ensure there is understanding for those living with the condition, more widespread EB expertise and support to enable us to fund vital research and care. We will continue delivering awareness initiatives as part of the 'A Life Free of Pain' throughout 2023 to raise awareness of EB and DEBRA and support our fundraising drive.

Build engaged communities

Members are central to everything we do. We want to ensure that we reach and engage all the individuals and families living with EB and their support network, and provide them with the information, resources and connect the community. We will improve member insight and understanding through the detailed patient insight study and regular feedback mechanisms, set up an online member community network and increase the breadth and quality of health information by working with PIF Tick.

We will seek out and promote EB expertise and developments in research and healthcare to engage our community of researchers & clinicians, develop a core group of specialists, including those within DEBRA, to provide active support as speakers, commentators, and an expert panel to support us in gaining influence with healthcare professionals, central government, corporations, and pharma companies.

We will create compelling communications, illustrating the impact of our work and the inspirational stories from our EB community to connect with our supporters, building a community working towards a shared, urgent goal. We will inform our staff and volunteers about EB, building their knowledge and understanding of our work and their confidence to become advocates of DEBRA and increasing their engagement on social media.

We will build our retail brand to deliver a stronger presence on the high street which will highlight our commitment to our cause and to sustainability and support income generation through our stores and our online shopping platforms.

Lobby government

We will launch our flagship insight study and mental health survey for people living with EB. The findings will shape everything we do at DEBRA, supply vital information to the pharmaceutical industry and play a crucial role in lobbying government for EB support and funding.

How we raise our funds

Together we can transform the lives of people with EB and bring hope for a better future

The commitment and generosity of our supporters in 2022 enabled us to achieve a record fundraising income of £2.3m, despite the ongoing impact of the pandemic and the cost of living crisis. This exceptional response has enabled us to set ambitious targets for the coming years to fund new and effective treatments for EB and deliver the specialist support the EB community needs.

Our ambition

We are committed to raising the funds needed to invest in specialist healthcare and research that will be life-changing for people with EB. The more we can raise, the faster we will beat EB.

Our objectives

1. To grow our core net fundraising income. Our ambitious target for 2023 is to increase this to £3m, representing an increase of 59% over three years.
2. To refocus our fundraising, recognising the short and long-term effects of COVID-19 and the cost of living crisis. We will be less reliant on events and prioritise the development of long term relationships and our major donor, grants, trusts and corporate donations.
3. To drive a substantial increase in donations and awareness about EB through the delivery of the 'A Life Free of Pain' appeal.

How we met our objectives in 2022

Our fundraising was extremely successful in 2022. This was principally due to the development of our major gift programme and the generosity of philanthropist Lenore England, whose donation of £500k for the first of our drug re-purposing projects enabled us to leverage further funds on the back of her support. As a result, we have scaled up our ambitions for fundraising in 2023 and beyond.

The commitment of our supporters enabled us to deliver a varied and successful fundraising events plan, from the traditional DEBRA high-end events such as Fight Night, Great Chefs Dinner to our popular golf programme. We increased the range of events for people to take part in including the 100km challenge and Kiltwalks in Scotland. Thank you to the hundreds of people who have dined, run, walked, cycled and golfed to raise record levels of money to support EB in 2022.

In October 2022 we launched our most ambitious appeal, A Life Free of Pain, with the support of our President, Simon Weston and Vice Presidents Graeme Souness, Stuart Procter, Lenore England and Frank Warren. The appeal will not only raise significant funds, it aims to bring considerable attention to the charity and awareness of EB. A Life Free of Pain aims to raise £5m to accelerate our research into drug repurposing and other life-changing treatments that could radically improve quality of life for people living with EB. At the end of the year, in just a few months, the appeal had raised over £1.1m.

How we will continue to develop in 2023

Relationship development

With the support of our Royal Patron, President and Vice Presidents, we aim to develop new philanthropic support. We will deliver a small number of exclusive events hosted by our Patron, President and Vice-Presidents to build our major donor relationships and commitment.

Grant-making trusts

We will secure at least one major grant (£100k+) from a grant-making trust towards a drug re-purposing project as part of our 'A Life Free of Pain' appeal. We will continue to develop long term relationships with funders that have supported the charity for a number of years or invested heavily in our work.

Corporate support

We will invest in the development of the team, recruiting a corporate partnerships manager to bring in new business along with the stewardship of current corporate supporters. A particular area of interest is the pharmaceutical industries, particularly those with a potential interest or existing interest in EB. We will use the Appeal to encourage engagement with more corporate partners.

Supporter Services

The Supporter Services team will roll out an engaging supporter journey managed within our new CRM system, ensuring that all donors are committed to our vision, feel valued and become regular donors of the future. We will also offer a series of interesting and varied sponsorship events for supporters to get involved with.

Events

Our events introduce over 2,000 new people a year as new and prospective donors as well as welcoming back long-term supporters. These will include the traditional major events in both 2023 and 2024 (the Football Dinner in Glasgow, Great Chefs' Dinner, Fight Night, Shoot at EJ Churchill, Wine Challenge, Sporting Lunch and Kiltwalks.

Gift aid

We will target 50% of income being received under gift aid, which would result in £222k being reclaimed. Of the £4.7m budget, approximately £2m relates to income that may fall within the gift aid scheme.

We subscribe to the Fundraising Regulator and its Code of Fundraising Practice.

Legendary boxing manager and DEBRA Vice-President Frank Warren hosted his 17th DEBRA Fight Night this year, in association with Queensbury Promotions. This was DEBRA's most successful Fight Night in five years raising over £140,000

A Life Free of Pain appeal

On the 20th October, we launched our A Life Free of Pain appeal at The Landmark Hotel in London with DEBRA Vice Presidents Graeme Souness and Lenore England, President Simon Weston CBE, CEO Tony Byrne & Chair of Trustees Jim Irvine and DEBRA members Lucy Beall Lott, Isla Grist and Fazeel Irfan.

> "As a charity we have never before attempted something as big or as ambitious as this. A Life Free of Pain appeal is about changing the everyday lives of people living with the distressing, debilitating and excruciatingly painful condition that is epidermolysis bullosa."
>
> DEBRA President, Simon Weston CBE

Tyson Fury donates £10,000 to DEBRA during interview with Myra Ali

On the same day as the launch of our 'A Life Free of Pain' appeal, Myra Ali, who lives with Recessive Dystrophic EB, interviewed Tyson Fury at the #FuryChisora press conference at Tottenham Hotspurs Stadium. Tyson spoke to Myra about his battle with his mental health and how he deals with physical and mental pain. Tyson had won a £10,000 bet with DEBRA Vice President Frank Warren earlier in the day. During the interview, he took the money from his bag and donated it towards our A Life Free of Pain appeal.

Thank you

We would like to say a heartfelt thank you to everyone who supports us in our fight to end the pain of EB. To all who donated to our cause and the thousands of people who ran, cycled, took up our challenges, volunteered and the many ambassadors who shared their story to help to raise awareness of EB. We are also extremely grateful for the continued support of our Patron HRH The Duchess of Edinburgh GCVO, our President Simon Weston CBE, Life Patron Philip Evans, Vice Presidents Lenore England, Stuart Proctor, Graeme Souness and Frank Warren.

Our Patron, President, Vice Presidents

HRH The Duchess of Edinburgh GCVO
Simon Weston CBE
Lenore England
Stuart Procter
Graeme Souness
Frank Warren

Trusts and foundations

The Oliver Thomas Memorial Fund
The Band Trust
The Brothers Trust
The Souter Charitable Trust
The VTCT Foundation
Bill Brown's Charitable Settlement of 1989
The Dorus Trust
The Kola'a Trust
The Forest Hill Charitable Trust
The Murphy-Neuman Charity
The Dyer's Company
The Edith Murphy Foundation
The John Coates Charitable Trust
The Northwood Charitable Trust The Grace Trust
The Catherine Cookson Charitable Trust
The Peter Harrison Foundation
The DM Charitable Trust
The Fowler Smith and Jones Trust
The Joseph Strong Frazer Trust
The Leach Fourteenth Trust
The Strangward Trust
The GM Morrison Charitable Trust
The Lillie Johnson Charitable Trust
The David Laing Foundation
The Edward Cadbury Trust
The Gilbert and Eileen Edgar Foundation
The Calleva Foundation
The Raven Charitable Trust
The Shanly Foundation
The Tory Family Foundation
The Ammco Trust
The Louis Bayliss Charitable Trust
The Benham Charitable Settlement
The John Cowan Foundation
The William Brake Foundation
The Basil Samuel Charitable Trust
The Childwick Trust
The Verdon-Smith Charitable Trust
The Riply Trust
The Michael and Anna Wix Charitable Trust
The Alice Ellen Cooper Dean Foundation
The Bruce Wake Charity
The February Foundation
The Hugh Fraser Foundation
The QBE Foundation
The Riada Trust
The 29th May Charitable Trust
Marconi Chelmsford Employees Charitable Trust Fund
The Wixamtree Trust
The Mabs Mardulyn Charitable Foundation
Awards for All
The George Stewart Charitable Trust
The Jack Lane Charitable Trust
The Sylvia and Colin Sheppard Charitable Trust
The PF Charitable Trust
The Parry Family Foundation
The Maud Elkington Charitable Trust
The W.E.D Charitable Trust
The George A Moore Foundation
The Hudson Charitable Trust
Baron Davenports Charity
The Hospital Saturday Fund
The Ardwick Trust
The Misses Barrie Charitable Trust
The Eveson Charitable Trust
The James Wise Charitable Trust
The Charles S French Charitable Trust
The Charity Service Fund
The National Lottery Community Fund
The Enid Linder Foundation
The Klahr Charitable Trust
The Manson Family Charitable Trust
The Whittington Charitable Trust
The Barbara and Stanley Fink Foundation
The Simon Gibson Charitable Trust

Our stores

At the heart of our communities

£650,000
raised to fund life-changing EB healthcare, research and support

60%
increase in our online sales

102
stores

8th
largest charity retailer in the UK

800kg+
of unsaleable textile items recycled

Our stores play a vital role in their communities, helping to build awareness of EB, raising the profile of DEBRA and generating vital income to fund our EB research, healthcare and support.

Our ambition

Our aim is to be a destination of choice online and on the high street, reaching a wider audience, commanding higher prices, ensuring we have a sustainable and resilient approach to enable us to withstand any future economic and environmental challenges.

A motivated, knowledgeable and engaged team of staff and volunteers is our most essential asset. They will always be at the heart of what we do and the key to our success.

Our objectives

1. To build a more efficient, leaner retail function as a basis for expansion and developing an increased estate of larger format stores by 2026, refurbished to create higher quality, attractive retail environments.
2. To improve and expand our e-commerce and online sales, reaching a wider audience with a relevant sales offering and promoting our cause.
3. To develop our dedicated team of staff and volunteers, increasing overall volunteer numbers and ensuring excellent and consistent health & safety management and compliance.
4. To raise awareness of our cause and build loyalty to our brand within our communities.

How we met our objectives in 2022

Facing the cost of living pressures

Like many charities we faced considerable inflationary pressures due to energy price rises and national minimum wage increases, resulting in a shortfall in our retail contribution of £0.8m towards our 2022 budget plan. High levels of store closure due to sickness and vacancies also contributed to this loss of sales. Despite this, the development of our dedicated team of volunteers and the loyalty and support of our customers enabled us to achieve £0.65m net retail income to fund life-changing healthcare, research and support for the EB community.

Achieving cost savings and operating efficiencies

As part of our commitment to creating a more efficient and leaner retail function, we started the year with 104 stores and finished with 102, closing five underperforming stores and opening three new stores including two larger stores. These flagship stores led the way as we began a major refurbishment programme to roll out our new branding.

To improve our retail infrastructure and efficiency and ensure we operate in as environmentally friendly manner as possible, we tendered energy, facilities management and waste contracts, reviewed in-store stock processes and procurement, implemented a trial of DEBRA leased vehicles and updated our EPOS system.

Building our online and instore sales

This year has been a challenging but exciting time for DEBRA retail online. We achieved a 70% increase in our online following and 60% growth in like for like online sales, giving a significant boost to our income and diversifying our customer population. We did not meet the growth expectation as originally planned at the beginning of the year, due to the failure of the third party fulfilment agreement we had in place.

Our online and instore brand benefited from the launch of the DEBRA retail social media programme with a new retail-focussed Instagram channel, the development of individual shop Facebook pages, the set-up of online e-commerce hubs, the creation of social media specialists amongst our volunteer team and individual stores posting fashion features and local awareness campaigns to increase footfall and donations.

Developing our dedicated team of staff and volunteers

Internal staff development and progression was a key focus. We also continued to revise and improve staff induction and overall mandatory training and management. This resulted in a significant increase in H&S engagement and compliance and a reduction in the labour turnover ratio.

The improvements in overall instore IT infrastructure, equipment and management systems strengthened our ability to engage, support and communicate with our store teams. We repeated our annual virtual conference for staff and volunteers, providing training as well as key information about EB and our current work in research and community support.

How we will continue to develop in 2023

Our aim is to grow our net income, however we will continue to focus on consolidation with the expectation that the pressure on costs will continue. Good cost control and a review of efficiencies in areas such as energy, transport, waste and facilities management will to be a focus and part of our ongoing ESG commitment.

We will review under-performing stores and anticipate opening a limited number of larger format, high quality stores with strong contribution and stock generation. We will undertake a series of shop refurbishments, optimisation plans and the continued roll out of the new DEBRA branding to ensure attractive retail environments.

We will continue to build our e-commerce and online sales, command higher prices, and grow and diversify our customer population. We aim to align with the growth of online changing consumer shopping habits in the UK, maximise donation potential and expand our overall customer reach.

In addition, we aim to maximise the use of all potential platforms, selling tools, automations, and integrations to increase revenue while streamlining operations. This will enable all stores to achieve their full digital retail potential by maximising engagement and providing appropriate support, allowing us to build donations and ASP via digital sales.

Growing and diversifying our new income streams will play a key feature for the year, with a particular focus on the development of strong corporate stock partnership.

Without the skills and commitment of our retail team of staff and volunteers we could not achieve our plans. We will ensure that we continue to provide support, training and opportunities to develop. We are truly grateful for everything that they do.

Our dedicated volunteers

Our volunteers play an essential role in our retail stores as well as supporting our fundraising and working with teams across the charity. They are an essential part of the DEBRA team. We are deeply grateful for their time, commitment and skills. We couldn't achieve our mission without them.

23%
increase in volunteers in 2022

1,100
volunteers giving 230,000 hours of donated time

£2.2m+
saved for the charity

100+
participants undertaking DofE volunteering through DEBRA stores

180
long service awards presented

Our volunteers report that it is an opportunity to socialise, learn new skills, and gain valuable work experience to move into paid employment. In 2023, we are committed to a programme of support and development for volunteers across the whole charity, ensuring that DEBRA is a great place to volunteer and that they are valued, respected and recognised for the invaluable work they do.

We celebrated National Volunteer Week in June, to recognise and thank our inspirational volunteers for the time they give.

> "Our volunteers are truly remarkable. I am constantly amazed and humbled by their commitment and dedication, so it was lovely to be able to launch long service awards this year as well as recognise some of our hidden heroes."
>
> Mark Francis, Volunteering Development Manager

Our people

Making a difference

We employed over
375
permanent staff

We counted on the support of over
1,100
volunteers

We had 14 trustees,
64%
with direct experience of EB

We provided over
9,000
hours of training for our staff

Every person in our charity provides a highly valued contribution to the service that we provide the EB community, whether delivering our vital research and healthcare programmes, supporting families with EB, managing or volunteering in our charity shops, working to raise essential funds, promoting and communicating the work we do, processing income, providing learning and development, supporting our cause as an ambassador or offering guidance as a trustee.

Our ambition

Our ambition is to lead the fight against EB. To achieve this the key to our success is our people. Our aim is to create a culture where our whole community can thrive, are valued, where equality and diversity are embedded in our values and actions, where everyone has the opportunity to develop, to enjoy their work and to make a difference and ensuring that support operations (Marketing Communications, HR, IT and Finance) are best in class.

Our objectives

Our People agenda focuses on three priority areas:

1. A resourcing strategy to attract, develop and retain the talent that we need in order to achieve our objectives, under-pinned by our Equality, Diversity & Inclusion (EDI) practices to ensure that our employee demographic represents the community we serve.
2. Providing learning and development to ensure employees and volunteers have the skills they need to fulfil their current and future roles.
3. Engaging our people by creating a positive working environment, recognising individual and team performance, providing salary and benefits that are competitive within the charity sector and embedding our values to create a culture where employees can flourish.

How we met our objectives in 2022

Rewarding talent

A talent identification pipeline was undertaken to fill senior positions (historically filled with external candidates) with internal candidates. As a result, a number of key internal promotions have been made. We launched a quarterly employee recognition scheme, the DEBRA Butterfly Awards, to recognise the employees and volunteers who live the DEBRA values.

Skills & resources

Investment in new systems created a major change across DEBRA, revolutionising the way we work. New health & safety, human resources, learning management, payroll and online expenses systems gave employees easy access to self-service and contributed to our ESG targets for reduction of print and paper usage.

The new learning management system, with an extensive library of bought in and internally developed materials, increased mandatory training to over 90%. In addition to online training, face to face training resumed after the pandemic with topics including manual handling, safeguarding, performance management, train the trainer. The key focus has been on health and safety which has resulted in a significant reduction in safety-related incidents and an increased level of reporting.

Building a great place to work

We repeated the employee survey, previously undertaken in 2020. The response rate increased from 30% in 2020 to 59% in 2022. Improvement was noted in all areas with significant improvement for employees' understanding of the charity's vision and strategy, sharing a commitment and passion for the charity's cause, feeling supported by HR and managers and appreciating opportunities for career development.

Safeguarding as a priority

Safeguarding continues to be a priority. In 2022 our focus was on raising awareness of safeguarding amongst our employees and volunteers. In addition to a mandatory online training module, we ran our annual Safeguarding September with a range of materials shared throughout the month including educational videos, case studies, articles, and stories. We also hosted live sessions examining the difference between welfare cases and safeguarding, providing clear guidance on how best to report any concerns that employees or volunteers may have. For our volunteers a new safeguarding booklet was rolled out giving an overview of what safeguarding is along with helpful guidance of what to do if they are concerned for their own or anybody else's wellbeing.

Equality, diversity and inclusion

We are an equal opportunities employer organisation. In 2022 our Equality, Diversity and Inclusion (EDI) workstream moved forward with the capture of diversity data for our employees, volunteers and prospective employees, allowing us to identify areas for improvement and put in place required processes to continue the journey to being an organisation that mirrors the diversity profile of the members and communities we serve. We ran our first EDI January (J-EDI) with the launch of online EDI training, intranet information and personal contributions from staff and volunteers.

Our gender pay gap report for 2022 showed that our mean pay gap was 16.65% in favour of men and our median hourly full pay gap was 0%. The mean gap has been influenced by the increase in man occupying soles in the upper-mid banded roles. This was based on 365 employees (276 female/89 male) on the snapshot date. The gender pay gap is a measure of the difference in the average pay of men and women, regardless of the nature of their work, across the entire organisation. We have made significant progress over the years however we are committed to doing more as part of our EDI and values-driven culture.

How we will continue to develop in 2023

2023 will be a year of consolidation as we embed many of the initiatives and processes launched in 2022 including values, succession planning, manager development, performance management and health and safety best practice. For 2023, our Safeguarding Committee agreed that an internal audit of our safeguarding policy and process should be undertaken to highlight any gaps and support our journey to best practice in this area. The 2023 workplan takes into consideration the employee survey feedback and addresses the areas where improvement is still required. We will move to a new financial reporting system. The succession planning process will be rolled out to all areas of DEBRA.

We will also continue the EDI journey to being an organisation that mirrors the diversity profile of the members and communities we serve.

Our ESG journey

Striving to be a force for change environmentally, socially and governmentally

100%

of waste from our stores diverted from landfill though our waste partner

CO2 emissions saved equivalent to

170*

trees planted

Our ambition

As a charity with over 100 stores and 1400 staff & volunteers, we know we have an impact, on the environment and on the communities we work with, which can be positive. We want to be a force for change, reducing the impact we have on the environment and on society, ensuring the highest ethical standards and considering environmental sustainability and social responsibility in all we do.

Our objectives

1. To be a more sustainable & environment-friendly in everything we do and everyone we work with.
2. To create a culture where equality and diversity are embedded in our values and actions and where staff wellbeing is a priority.
3. To ensure the highest ethical standards, and considering environmental sustainability and social responsibility in all that we do and the impact of our charitable activities and investment decisions on our EB community, our staff, volunteers, supporters, customers and the local economy.

How we met our objectives in 2022

- We created an ESG policy with an annual action plan and set up an ESG committee to monitor progress.
- We put in place ways to measure our carbon footprint and new processes to reduce use of energy, water, paper and other resources including the introduction of new HR, finance and expenses systems removing the need for printed forms and invoices in our offices and our charity shops.
- We continued to provide an equal opportunity workplace where we invest in professional development and staff and volunteers are valued.
- We participated in initiatives such as the Duke of Edinburgh Award with 100 young people volunteering and the Kickstarter Scheme, which provided 15 young people with work placements across our retail stores.
- Our Trustee Board ensured our standards and practices fully embraced the principles of the Charity Commission Charity Governance Code, the Fundraising Regulator and GDPR data protection. This commitment to strong corporate governance is critical to protecting our membership, supporters, employees and our reputation.

*Statistics provided are for six months since measurement began in July 2022 when we changed our waste partner

How we will continue to develop in 2023

- We will continue the EDI journey to being an organisation that mirrors the diversity profile of the members and communities we serve.
- We'll provide training and information to all of our team, work with suppliers and contractors who share our ESG objectives and seek to ensure sustainable investments.
- We'll continue to minimise waste through reduction, re-use and recycling and introduce initiatives such as reviewing how we travel by promoting options such as car sharing and agile working.
- We'll promote best practice in all our operations and activities, considering environmental protection, public health and safety, human rights, anti-bribery and corruption, and labour and anti-slavery practices.
- To engage our staff and volunteers in our ESG commitment, we will introduce bi-annual ESG Champions awards to recognise the actions taken by teams and individuals across the charity and inspire others.
- Our leadership will lead by example both in practice and behaviour.

> "We will hold ourselves accountable and measure our progress on our ESG journey, continually seeking to learn and incorporate ESG best practices in all we do."

Tony Byrne, CEO DEBRA UK

Charity overview, objectives & public benefit

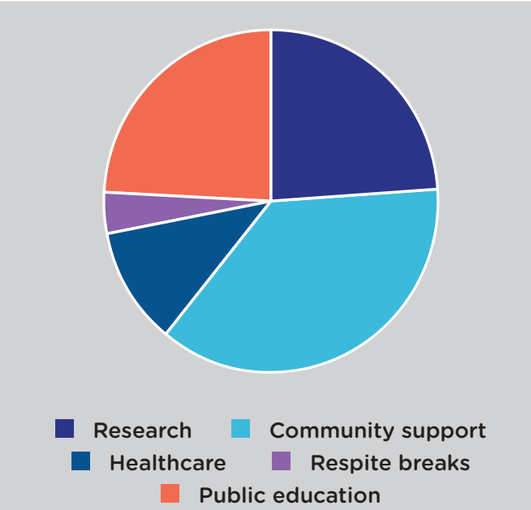
Financial review

We spent £2.6m on charitable activities in 2022, compared with £1.9m in 2021. Whilst new research commitments were limited, spend on healthcare, community support and respite amounted to £1.4m, compared to £1.0m in 2021.

Net income from the retail operation was £0.65m (2021: £1.7m, including government grants of £2.4m). Overall net fundraising income was £2.3m in 2022, compared with £0.96m 2021.

The surplus for the year was £0.5m, compared with £0.8m in 2021.

Charitable spend



Charitable spend was £2.64m in 2022 compared to £1.89m in 2021. All areas of charitable spend increased: Community support up to £0.97m from £0.68m, Research to £0.63m from £0.48m, Healthcare to £0.29m from £0.25m, Respite Breaks to £0.12m from £0.09m and Public Education to £0.63m from £0.36m.

Net assets increased to £4.25m from £3.80m. There was £2.8m in the general fund, £1m in designated funds and £0.49m in restricted funds.

Summary

Table 1 summarises the highlights of our financial performance over the last five years. Gross income was £16.4m in 2022, an increase of £3.1m (23%) from 2021.

Non-trading gross income (not including government retail support) was £4.02m, a 76% increase from £2.29m in 2021. This includes income from donations, corporate support, trusts and community events.

Net retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops, but excluding government support) increased by 43% to £12.4m from £8.7m, following a full year of trading in 2022.

Charity overview, objectives & public benefit

Table 1: Financial KPI summary

	2022 £'000	2021 £'000	2020 £'000	2019 £'000	2018 £'000
Gross income	16,421	13,317	11,413	16,798	16,138
Non-trading income including all government support	4,017	4,663	4,387	3,475	2,979
Net trading income	(196)	(1,299)	(3,201)	1,198	1,193
Net retail income including government pandemic support, retail gift aid, commission and donations in shops	654	1,689	(673)	2,123	2,138
Non-trading fundraising costs	699	662	708	768	727
Charitable expenditure	2,640	1,885	2,848	3,110	2,966
Retained surplus/(deficit)	452	817	(2,371)	795	479
Retained surplus/(deficit) as a % of income	3%	6%	(21%)	5%	3%
Net current assets	3,333	3,124	2,684	4,878	4,394
Unrestricted reserves	3,763	4,050	2,904	5,138	4,420
Grants payable within 1 year	2,019	2,237	2,159	2,201	1,825

The charity's fixed assets comprise the premises and equipment required to operate trading activities; premises, furniture and equipment required to operate the charity's offices; and five holiday homes held for the use of those affected by EB. The rest of the charity's assets are held to promote the purposes of the charity through its support services and research programmes.

Reserves policy

DEBRA holds reserves to ensure the charity is able to continue supporting its beneficiaries and as a buffer for short term cash flow needs.

Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be readily mortgaged, thus representing reserves that can be accessed relatively quickly.

The trustees' reserves policy in 2022 was to maintain minimum cash-backed free reserves at £1.7m, to which the charity adhered. Maintaining the high levels of retail income has been a challenge but this has been offset by a significant increase in fundraising income. The minimum reserves figure is set to cover six month's rent plus one month of other costs. The trustees conducted a thorough review of the reserves policy at the end of 2022, reviewing performance criteria in the light of the economic situation. The trustees' aim is to grow cash-backed free reserves over the next four years to £3m, in line with planned growth in retail and fundraising operations.

Charity overview, objectives & public benefit

Funds

The majority of our funds are unrestricted in application and are held in general and designated funds. Where funds are received that are restricted in their application to specific purposes or activities, these are held in a restricted fund. Details of restricted funds and designated funds are set out in Note 18 of the Financial Statements.

Total reserves at the end of 2022 were £4.25m. Cash-backed free reserves after designations were £1.7m with £1.1m of remaining free reserves giving total general funds of £2.8m. There were £1m of designations adding to a total of £3.8m of unrestricted funds.

The trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

Restricted funds

Restricted funds were £488k, including £86k for community support and healthcare activities. Other restricted funds are:

Oliver Thomas Memorial fund

The Oliver Thomas Memorial Fund was established in September 2022. £85,000 is restricted to a contribution to a Medical Research Council Fellowship, £10,000 for an EB weekend get-together, £9,200 for Clinical Best Practice Guidelines and £7,500 to a contribution to eye research in collaboration with Fight for Sight.

Apremilast Drug Re-purposing

£152k was donated to fund research into re-purposing the psoriasis drug Apremilast for use with EB patients.

Holiday Home Purchase

£135k was raised following an appeal for a new holiday home giving much needed respite to EB patients and families. The home was purchased in 2022 and the fund balance will reduce as the home is depreciated.

Asset cover for funds

Note 19 sets out an analysis of the assets attributable to the various funds. These assets are sufficient to meet the charity's obligations on a fund-by-fund basis.

Investment policy

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit. We aim to apply our income in support of our charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk. £3m is held in fixed term deposits with HSBC.

Expenses policy

We have expenses policies for both staff and trustees and a PAYE dispensation in place. Expenses that have necessarily been incurred by staff and trustees in performance of their duties are recoverable from DEBRA. Expenses will only be reimbursed if they meet the following criteria:

- no personal benefit could be derived from the expenditure by the employee concerned;
- the expenditure is reasonable and represents only additional costs to those that would normally arise on a personal basis;
- there is a clear charity justification for the costs; and
- the expenditure does not represent a form of payment to a third party for work undertaken on our behalf.

Any expenses that do not meet the criteria above are regarded as a benefit by HMRC and as a matter of policy we do not reimburse such expenses.

Charity overview, objectives & public benefit

Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2022 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous nonprimary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 12 of the Financial Statements.

Internal audit

RSM are appointed as internal auditors. Audits of Internal Financial Controls, Cyber Security, Payroll and Fundraising took place in 2022 and recommended actions are being implemented by management. In 2023 audits of GDPR, Procurement, HR Key Controls and Financial Controls will take place.

Principal risks and uncertainties

The trustees have established a register for all identified major strategic, business and operational risks identified by them to which the charity is exposed and confirm that these have been reviewed regularly during the year by the Finance, Risk and Audit Committee (as well as annually by the Board of Trustees) and that systems and procedures have been established to manage these risks. The initial responsibility for managing risk lies with the executive, prior to review by the trustees.

A summary extract of the higher risks from our risk register is listed in Table 4 below, including the countermeasures (actions in place to reduce likelihood of the risk) and assurances (how the effectiveness of the countermeasures is determined). DEBRA as an organisation is very proactive in its management of risk, instilling a culture of recognition, ownership and tolerance level for each risk identified.

See Table 4: DEBRA's major risks.

Table 2: Summary Extract from DEBRA's Risk Register

Risk	Cause & Effect	Controls
Economy / Inflation	Adverse economic conditions or high inflation impact shop or other income	▪ Retail Committee monthly reports with KPIs, monitoring daily sales/GA report ▪ Performance reviews ▪ Retail Risk Register ▪ Continuous drive to increase retail contribution / enhance pricing
Failure to adequately insure	Lack of cover for major event leading to severe financial strain and inability to continue to operate.	▪ Annual insurance review by FD, Finance Manager and relevant SMT members ▪ Insurance Broker researches the market for the best deals to meet DEBRA's needs ▪ FRA periodic insurance review ▪ Tender for insurance brokers every 3 years ▪ Robust risk assessments prior to all DEBRA events
Poor service delivery by third party organisations at DEBRA events	Poor services leading to complaints and damage to DEBRA's reputation. Ultimately leading to loss of donor confidence impacting revenue	▪ Director of Fundraising reports ▪ Partner only with established reputable sponsors after due diligence ▪ Commercial Participation Agreements

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Non-compliance with H&S or other law	Health and Safety issues not being identified or addressed timely leading to accidents and potential serious injury and legal action. Increase in sickness due to injury caused at work Threat of enforcement actions ('Action Letters') by Local Authorities, Fire and Rescue Services and Environmental Health Departments or the Health and Safety Executive.	▪ Regular reviews of Risk Assessments, version controlled and dated; ▪ Accident and Incident recording and review via Assure software; ▪ Any significant injury or dangerous occurrence will also trigger a review; ▪ Risk Assessments in place for all Regional and National Membership AND Fundraising events; ▪ Staff training and briefing at events; ▪ Event participants are asked about personal history and fitness; ▪ Dedicated Health and Safety Manager has been employed; ▪ Annual Insurance review;
Major Virus epidemic or pandemic and resulting Government containment actions	Shop closures leading to loss of retail income and staff and potential inability to make payments as they fall due. Could lead to inability to continue meeting charitable objectives and operating as a charity.	▪ Shops Health and Safety file, cleaning (COSHH) and operating procedures set out ▪ News monitoring ▪ Regular updates from charity retail association.
Insufficiently robust cyber security	Cyber attack leading to loss of data or financial fraud. Data loss could lead to severe GDPR fines and major damage to reputation. Potential impact on DEBRA's ability to continue operating.	▪ End-point detection software / anti-virus on all computers ▪ Cyber insurance policy ▪ Email scanned before reaching DEBRA servers ▪ Remote user's hard drives are encrypted ▪ Secured wifi at Bracknell head office ▪ Remote desktop sessions time out after 20 mins ▪ Back-up daily server images moved to the cloud ▪ File shadow copy active on the server (protects against Malware encryption spyware) ▪ Complex passwords required by policy ▪ Meraki firewalls in place throughout offices and shops ▪ Anti-virus/spyware solution on all PC based tills ▪ All credit card machines meet PCI compliance standard C ▪ Monitoring of data access

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Failure to maintain adequate cash flow	Suppliers not being paid on time, delays in staff expenses reimbursement. Need for overdraft facilities. Ultimately leading to inability to continue to operate.	▪ Cash flow monitoring by Finance Team and reported to FRA quarterly ▪ Annual review by FRA of cash-backed free reserves minimum figure ▪ Monthly monitoring and reporting.
Lack of appropriate skills of SMT	Poor performance against budget High number of grievances or staff turnover in a department Whistleblowing	▪ Robust recruitment procedures involving Trustees ▪ Pre employment references ▪ Thorough induction ▪ Budget for L&D for senior managers ▪ Use of 360 input into appraisals
Failure to comply with the requirements to satisfactorily report Safeguarding issues	Any reports or awareness that Safeguarding issues have not been properly reported.	▪ Health & Safety Manager in place (reporting to Director of HR), to specifically lead Safeguarding. ▪ Basic Safeguarding training provided for all staff through eLearning, and additional in-depth training provided for Designated Safeguarding Officers.
Inappropriate Fundraising activities undertaken	Increase in complaints and negative media comment leading to loss of funding. Financial mismanagement leading to audit and investigations. Lack of funds threatens charity existence.	▪ SMT monitoring and CEO reports to Trustees ▪ Fundraising and Communications Committee meetings ▪ Periodic review of Donations Policy ▪ Board approval required for major new initiatives ▪ Donations Policy ▪ Threshold of £10k for confirming donations are from a legitimate source
Board does not have required skills	Lack of specific skills on Board leading to poor strategic direction. Resulting inability to meet charitable objectives and wasted resources.	▪ Recruitment of Trustees with relevant experience and succession planning ▪ Nominations and Governance Committee ▪ Budget in place for trustee training and relevant staff ▪ External advice taken if Board lacks relevant skill ▪ Governance Review ▪ Formalise induction of new trustees

Charity overview, objectives & public benefit

Going concern statement

The trustees reviewed the charity's budget, cash flows and forecasts for 1 January 2023 – 31 December 2024, which detail the plans for delivering to the EB community during a period of high cost inflation and the cost of living crisis. It is recognised that there are underlying uncertainties, however the trustees consider the charity can continue its business-critical activities and remain a going concern. The retail estate like-for-like sales are now exceeding pre-pandemic level and fundraising income is expected to be significantly higher in 2023 compared to 2022.

The trustees consider it is appropriate to prepare the 2022 accounts on a going concern basis on the basis that:

- Trading in 2023 is exceeding to pre-pandemic levels on a like for like basis;
- There is significant growth in fundraising activity including a major fundraising programme and several key events;
- The Budget and cash flows for 2023 and 2024 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2023 and 2024 is contingent on achieving fundraising and retail targets.

Structure, governance & management

DEBRA is a company limited by guarantee registered with the Charity Commission in England and Wales (1084958). This means our trustees are also company directors, so subject to company law as well as charity law. We are also registered with the Office of the Scottish Regulator in Scotland.

Board of Trustees

Our Trustee Board has a collective responsibility for everything we do and is responsible for:

- our overall strategic direction including evaluating progress against our strategic plans
- ensuring our financial stability
- acting in the best interests of our organisation
- ensuring that we comply with our governing documents, and any other relevant legislation from our regulators.

New trustees receive the most recent annual report and accounts, copies of previous minutes of the board and committees, and are made aware of the charity's policies including its Scheme of Delegation. Individual inductions from senior trustees as relevant and trustees attend external training courses appropriate to their role on the Board of Trustees. There are four board meetings per year, which the CEO attends and Senior Management Team members attend as required.

Charity overview, objectives & public benefit

In 2022

A resolution of directors was passed in July 2022, pursuant to an Extraordinary General Meeting held in April 2022 amending the Articles of Association of the charity, making the trustees of the charity the sole legal members of the charity, increasing the number of trustees with a connection with EB to more than 50% and dispensing with the need to have an Annual General Meeting.

In line with the new articles and as recommended by the Nominations & Governance Committee, the Board of Trustees reappointed David Bendor-Samuel, Carly Fields (previously elected trustee) and Christo Kapourani (previously elected trustee) for a further three-year term. The Board also re-appointed Jim Irvine as the Chair of the Board and Simone Bunting (who had previously served as a trustee, but had taken a year's break as required by DEBRA's articles) for a first term of three years. Simon Talbot was also elected by the members. Dan Mundy was appointed to the Board in November 2022.

Three trustees resigned from the Board during the year – Andy Grist (February 2022), Josie Godfrey (May 2022) and Douglas Rouse (September 2022).

Trustee Board Committees

During the year, the Board convened a Committee Restructure Working Group to evaluate the current Board Committee structure and to make a proposal for restructuring. The main drivers for the proposed restructure were as follows: existing committees had become too operational, duplicating the role of the executive; related to this, there was a threat of a loss of focus on strategy and governance; overlap of content at committees, which can mean that a committee member can hear the same information three or more times; workload for trustees and the threat of 'burnout' with too many committees and recognising the trust the Board has in the Executive.

The outcome of this review was that the Fundraising and Communications Committee and the Retail Committee became executive committees. The current Care and Research Committee was renamed and redirected to become the Charitable Purposes Committee from Jan 1, 2023. In addition, a Remuneration Committee (ad hoc) was set up by the Board.

Charity overview, objectives & public benefit

Finance, Risk & Audit Committee ("FRA") – determines and advises the Board of Trustees on matters relating to finance, risk and audit as the Board of Trustees may remit to it, in particular the sound financial management of the charity, its resources and assets.

Charitable Purposes Committee ("CPC") – determines and advises the Board of Trustees on matters relating to strategy in research, healthcare, community support and policy as the Board of Trustees may remit to it.

Nominations & Governance Committee ("NNG") – oversees the structure, composition and effectiveness of the charity's Board of Trustees and its Committees, as well as the appointment process of trustees. The Committee monitors the governance procedures of the charity.

Remuneration Committee – makes recommendation to the Board on a fair remuneration for the Chief Executive and Senior Management Team of DEBRA and reviews the Chief Executive's recommendations on the Annual Pay policy for DEBRA.

See Table 5 below – Trustees' membership and attendance.

Board diversity

Our Board of Trustees is made up from a majority of those who have a direct experience of EB, who either have EB themselves or have a close family member with EB, and those who have skills and experience that will add value to the governance and leadership of DEBRA. This ensures a good mix of skills, talents and experience to serve the DEBRA community.

We follow the Equal Opportunities Policy in the selection of Board members, in the same way we do for staff recruitment. Membership of the Board is open to all members of DEBRA, irrespective of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values.

Broader diversity of the Board continues to be reviewed as part of DEBRA's Equality, Diversity & Inclusion policy.

Charity governance code

The Board consistently reviews all aspects of DEBRA's governance and ensures that our governance standards and practices fully embrace the principles of the Charity Commission 'Charity Governance Code'.

Succession planning

We have built strength and depth in our Trustee Board, incorporating appropriate succession planning by appointing two Vice Chairs, each for periods of two years with an annual rotation of one of those. Prospective new trustees are often invited to join a committee for a minimum period of twelve months before becoming trustees.

Charity overview, objectives & public benefit

Fundraising standards

Section 162a of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. We do not undertake face-to-face fundraising from the general public. The legislation defines fundraising as 'soliciting or otherwise procuring money or other property for charitable purposes'. Such amounts receivable is presented in the accounts as 'voluntary income' and include legacies and grants.

We make all efforts to train staff and ensure compliance with fundraising standards at all times. Specifically:

- the majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the trustees
- where we work with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met
- there are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc
- where volunteers assist in our fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued
- volunteer fundraisers are managed and supported from the offices in Bracknell and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them
- data protection procedures are in place governing the management of supporter and donor data on our DEBRA database; compliance with GDPR rules continues to be monitored
- we work with vulnerable people, particularly within the EB community, and often they wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly
- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2022.

Activities in Scotland

We are active across several areas in Scotland. The primary charitable activities are seen in funding community support and research projects, notably at the Universities of Dundee and Edinburgh and the Cancer Research UK Beatson Institute, University of Glasgow. On the income generation side, there were two regional fundraising members of staff and 31 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Blantyre.

Charity overview, objectives & public benefit

Board Attendance Table

Trustee		Board	FRA	NNG	CAR/ CPC	Retail	F&C
Jim Irvine (Chair)		5 of 5	5 of 5	5 of 5			
David Bendor-Samuel		5 of 5		5 of 5			
Simone Bunting	Stood down Jun 22 (NNG)	5 of 5		1 of 4		4 of 4	
Rebecca Cresswell		4 of 5					4 of 4
Carly Fields		5 of 5		4 of 5	4 of 4		
Andrew Grist	Stood down 1 Mar 22	0 of 1			1 of 4		
Christo Kapourani		3 of 5			2 of 4		
Joanne Merchant		4 of 5	5 of 5			4 of 4	
Dan Mundy	Appointed 2 Nov 22	1 of 1	1 of 1				
Viv Mundy	Stood down Jun 22 (NNG)	2 of 5		1 of 4	1 of 4		
Douglas Rouse	Stood down 28 Sep 22	2 of 4					2 of 4
Mick Thomas		5 of 5					3 of 4
Simon Talbot		4 of 5	5 of 5				
Josie Godfrey	Stood down 13 May 22	1 of 3			1 of 4		

Auditor

Trustees have taken all reasonable steps to make themselves aware of any information needed by the company's auditor for the purposes of their audit and to establish that the auditor is aware of that information. The trustees are not aware of any relevant audit information of which the auditor is unaware.

Sayer Vincent LLP have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditor 28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

The Trustees' Annual Report, incorporating the Strategic Report, is approved by the Board of Trustees and signed on behalf of the trustees:

Jim Irvine
Chair of Trustees

Date of signing: 17.05.2023

Trustees´ statement of responsibilities

The trustees (who are also directors of DEBRA for the purposes of company law) are responsible for preparing the Trustees' Annual Report including the strategic report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities Statement of Recommended Practice (SORP) make judgements and estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2022 was 15 (2021: 2,343). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditor´s report

Auditor's report

Independent auditor's report to the members of DEBRA

Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2022 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at
- 31 December 2022 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the Financial Reporting Council's Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on DEBRA's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Auditor´s report
(continued)

Other Information

The other information comprises the information included in the trustees' annual report, including the strategic report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the trustees' annual report, including the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- The trustees' annual report, including the strategic report, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report, including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Auditor´s report
(continued)

Responsibilities of trustees

As explained more fully in the statement of trustees' responsibilities set out in the trustees' annual report, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud are set out below.

Capability of the audit in detecting irregularities

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, our procedures included the following:

- We enquired of management and Finance, Risk and Audit committee, which included obtaining and reviewing supporting documentation, concerning the charity's policies and procedures relating to:
  - identifying, evaluating, and complying with laws and regulations and whether they were aware of any instances of non-compliance;
  - detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud;
  - the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.
- We inspected the minutes of meetings of those charged with governance.
- We obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience.

Auditor´s report
(continued)

- We communicated applicable laws and regulations throughout the Audit Team and remained alert to any indications of non-compliance throughout the audit.
- We reviewed any reports made to regulators.
- We reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations.
- We performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud.
- In addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Auditor´s report
(continued)

Use of our report

This report is made solely to the charitable company's members as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Fleur Holden
(Senior statutory auditor)

Date 1 June 2023
for and on behalf of Sayer Vincent LLP,
Statutory Auditor

Invicta House, 108-114 Golden Lane, LONDON, EC1Y 0TL

Sayer Vincent LLP is eligible to act as auditor in terms of section 1212 of the Companies Act 2006

Financial statements

For the year ended 31 December 2022

Statement of financial activities

Statement of financial activities including income and expenditure account for the year ended 31 December 2022.

2022	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Income from:					
Donations & legacies	**2**	**2,335,602**	**481,397**	**1,194,637**	**4,011,636**
Charitable activities		**28,410**	**-**	**-**	**28,410**
Other trading activities	**3**	**12,233,823**	**-**	**19,511**	**12,253,334**
Investments	**4**	**5,472**	**-**	**-**	**5,472**
Other		**121,873**	**-**	**-**	**121,873**
Total income		**14,725,180**	**481,397**	**1,214,148**	**16,420,725**
Expenditure on:					
Raising funds	**6**	**13,297,601**	**31,000**	**-**	**13,328,601**
Charitable activities	**6**	**2,165,640**	**-**	**474,687**	**2,640,327**
Total expenditure		**15,463,241**	**31,000**	**474,687**	**15,968,928**
Net income / (expenditure)		**(738,061)**	**450,397**	**739,461**	**451,797**
Transfer between funds		**-**	**-**	**-**	**-**
Net movement in funds		**(738,061)**	**450,397**	**739,461**	**451,797**
Reconciliation of funds:					
Total funds brought forward		**3,500,325**	**550,000**	**(251,950)**	**3,798,375**
Total funds carried forward		**2,762,264**	**1,000,397**	**487,511**	**4,250,172**

Statement of financial activities
(continued)

2021	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Income from:					
Donations & legacies	2	4,261,175	-	347,477	4,608,652
Charitable activities		20,441	-	-	20,441
Other trading activities	3	8,641,059	-	12,945	8,654,004
Investments	4	14,564	-	-	14,564
Other		19,740	-	-	19,740
Total income		12,956,979	-	360,422	13,317,410
Expenditure on:					
Raising funds	6	10,614,818	-	-	10,614,818
Charitable activities	6	1,604,625	-	280,573	1,885,198
Total expenditure		12,219,443	-	280,573	12,500,016
Net income / (expenditure)		737,536	-	79,849	817,385
Transfer between funds		624,292	(215,950)	(408,342)	-
Net movement in funds		1,361,828	(215,950)	(328,493)	817,385
Reconciliation of funds:					
Total funds brought forward		2,138,497	765,950	76,543	2,980,990
Total funds carried forward		3,500,325	550,000	(251,950)	3,798,375

All operations are continuing. The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

The notes on pages 69-95 form part of these financial statements.

Balance sheet

Balance sheet as at 31 December 2022.

	Notes	2022 £	2022 £	2021 £	2021 £
Fixed assets					
Tangible fixed assets	**10**		**1,290,094**		1,009,272
Programme related investment	**11**		**1**		1
Investment in subsidiaries	**12**		**2**		2
			1,290,091		1,009,275
Current assets					
Fixed assets held for sale		**-**		74,167	
Stocks		**2,063**		1,321	
Debtors	**13**	**1,856,681**		1,942,888	
Current asset investment	**14**	**3,000,000**			
Cash at bank and in hand		**2,146,142**		4,967,810	
				6,986,186	
Creditors: amounts falling due within one year	**15**	**(3,672,317)**		(3,861,818)	
Net current assets			**3,332,569**		3,124,368
Total assets less current liabilities			**4,622,663**		4,133,643
Creditors: amounts falling due after more than one year	**16**		**(134,359)**		(147,320)
Provision for liabilities	**17**		**(237,952)**		(187,948)
Total net assets			**4,250,172**		3,798,375

Balance sheet
(continued)

	Notes	2022 £	2022 £	2021 £	2021 £
The funds of the charity					
Restricted income funds	**19**		**487,511**		(251,950)
Unrestricted funds					
Designated funds	**20**	**1,000,397**		550,000	
General funds	**20**	**2,762,264**		3,500,325	
Total unrestricted funds			**3,762,661**		4,050,325
Total funds			**4,250,172**		3,798,375

Company registration number 4118259

The accounts were approved by the Board on **17.05.2023** and signed on their behalf by:

Jim Irvine
Chair of Trustee Board

Joanne Merchant
Treasurer

Statement of cash flows

Statement of cash flows for the year ended 31 December 2022.

	Notes	2022 £	2022 £	2021 £	2021 £
Cash flows from operating activities					
Net cash provided by (used in) operating activities	22		**566,564**		(270,182)
Cash flows from investing activities					
Dividends, interest and rents from investments		**5,472**		14,564	
Proceeds from the sale of property, plant and equipment		**92,382**		238,649	
Purchase of property, plant and equipment		**(486,086)**		(91,774)	
Proceeds from sale of investments		**-**		-	
Purchase of investments		**(3,000,000)**		-	
Net cash provided by investing activities		**(3,388,232)**		161,439	
Change in cash and cash equivalents in the reporting period		**(2,821,668)**		(108,743)	
Cash and cash equivalents at the beginning of the reporting period		**4,967,810**		5,076,553	
Cash and cash equivalents at the end of the reporting period		**2,146,142**		4,967,810	

The notes on pages 69-95 form part of these financial statements.

Notes to the financial statements

1 Accounting policies

1.1 Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), Charities SORP (FRS 102), the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and trustees Investment (Scotland) Act 2005.

1.2 Going concern

The Trustees reviewed the charity's budget and cash flows for 1 January 2023 – 31 December 2024 in December 2022 and consider it is appropriate to prepare the 2022 accounts on a going concern basis on the basis that:

- Trading in 2023 is exceeding pre-pandemic levels on a like for like basis;
- There is significant growth in fundraising activity including a major fundraising programme and several key events;
- The Budget and cash flows for 2023 and 2024 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2023 and 2024 is contingent on achieving fundraising and retail targets.

1.3 Legal status of charity

The charity is a company limited by Guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

1.4 Judgements and estimates made by management

The financial statements include judgements and estimates as defined by the accounting policies. Legacy income is recognised as probable at probate, using an estimate provided by executors. Premises service charge liabilities are estimated from information supplied by property specialists. The dilapidations provision is reviewed annually on an individual lease basis by a property specialist.

Research grants are recognised in full in the Income and Expenditure Account at the point of commitment in order to ensure no reliance on future fundraising to meet these financial commitments.

Programme related investments are impaired based on a judgement of the intrinsic value of the investment at the balance sheet date, where no market value exists.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

Notes to the financial statements

(continued)

1.5 Income

Donations and gifts are recognised in full in the Statement of Financial Activities when receivable. Unclaimed gift aid receivable is accrued in the year to which it relates. Legacies receivable are recognised when there is entitlement, probability of receipt and is measurable. Grants are recognised in full when receivable. Gifts in kind are only included in the accounts where the Trustees can ascribe a value in excess of £1,000.

Other trading income is recognised in full when received with the exception of income that is deferred where it represents a payment in advance for a specific event that will not take place until a future accounting period. This exception does not apply to sponsorship for charity challenges taking place in a future accounting period.

Claims made through the UK Government's Coronavirus Job Retention Support Scheme are recognised as income in the period which the associated staff were furloughed. This income is considered to be unrestricted. Small business retail grants have been recognised as unrestricted income in the periods to which they relate.

1.6 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Equipment purchased for use in research is written off as part of the research project costs as incurred. Expenditure on raising funds are those costs incurred in seeking voluntary contributions and running the retail operations. Charitable activities include expenditure associated with the operation of the charity and the provision of its services.

Governance costs comprise the costs relating to the general running of the charity, and include direct items such as external audit, legal advice for trustees, the cost of trustee meetings, and are included in central overhead costs. Central costs are apportioned and allocated between the cost of raising funds and charitable expenditure on the basis of central staff time allocation to the various activities.

1.7 Recognition of grant liabilities

Grants are awarded for research projects over a period of one to five years. All grants provide the right to terminate with up to three months' notice and continuation of funding is dependent on satisfactory progress reporting and review. It is always the intention to honour the funding of all grants awarded and full grant recognition has been incorporated into these accounts as the most appropriate and prudent policy. By adopting this policy, the trustees ensure the funds for research grants have been raised in full prior to making financial commitments to research institutions.

1.8 Tangible fixed assets and depreciation

Tangible fixed assets with a value in excess of £1,000 are capitalised and stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

Freehold and long leasehold buildings	Over 25 years
Head office fit out costs	Over life of the lease
Mobile homes	Over 10 years
Fixtures, fittings, static equipment	Over 5 years
Software development costs	Over 5 years
Shop equipment	Over 5 years
Mobile equipment	Over 3 years

Notes to the financial statements

(continued)

A review of assets is undertaken annually, and adjustments are made to the expected useful life as required. From 1 January 2009 freehold land and buildings, and long leasehold buildings, are assumed to have a residual value of 50%.

1.9 Programme related investment and impairment

Programme related expenditure with a value in excess of £1,000 is stated at cost less impairment. The investment held was impaired by 99.99% in 2020, with a residual holding value of £1.

1.10 Cash and short-term investments

The charity holds cash requirements for day-to-day activities in current bank accounts with HSBC, Lloyds, Santander and Clydesdale. The deposit account is held with HSBC. Short-term investments are held in money market deposits with HSBC. For the purposes of the cash flow statement, cash equivalents are defined as current asset investments, and short-term deposits with a maturity of less than 3 months, which are readily convertible into known amounts of cash.

1.11 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

1.12 Creditors

Trade creditors and other payables are normally recognised at their settlement amount after allowing for any trade discount due. Payments to suppliers are within standard payment terms of 30 days. Liabilities are recognised when there is a present obligation, as a result of past events, and there is a probable future outflow of resources that can be estimated reliably.

1.13 Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at settlement value.

1.14 Stock

The trustees do not consider it appropriate to recognise donated goods for resale as stock on the grounds that the cost of obtaining stock information would greatly outweigh any benefit. The costs involved would include the setting up of processes and procedures for a stock count in over 100 shops, training shop staff and volunteers in the process, software programming, and the checking and analysis of the reports produced.

All other stock is valued at the lower of cost or sales value net of selling costs.

1.15 Accumulated funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The exceptional circumstances of 2020 and 2021 resulted in funds being undesignated in order for the charity to continue its charitable objectives. The purposes and uses of the restricted funds and designated funds are set out in Note 19 to the financial statements.

1.16 Consolidated accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the companies' results and the investment the charity holds are shown separately in Note 12 to the financial statements.

1.17 Foreign currency translation

Foreign currency transactions are recorded at the exchange rate at the time of the transaction. Foreign currency assets and liabilities are translated into sterling at the exchange rate ruling at the balance sheet date. Resulting gains or losses on retranslation are included in the statement of financial activities.

1.18 Leases

Operating lease annual rental payments are charged to the statement of financial activities on a straight line basis over the term of the lease.

1.19 Termination payments

Termination payments either by way of redundancy or settlement agreement are recognised at the time of payment. Any payments exceeding the statutory minimum are authorised by the trustees.

Notes to the financial statements
(continued)

2. Donations and legacies

	Unrestricted funds	Restricted funds	Total 2022	Unrestricted funds	Restricted funds	Total 2021
	£	£	£	£	£	£
Donations & gifts	**2,302,674**	**506,896**	**2,809,570**	1,758,535	105,013	1,863,548
Legacies receivable	**409,165**	**500**	**409,665**	8,148	4,431	12,579
Grants receivable	**105,160**	**687,241**	**792,401**	2,494,492	238,033	2,732,525
	2,816,999	**1,194,637**	**4,011,636**	4,261,175	347,477	4,608,652
Donations & gifts:						
Individual donations	**2,062,574**	**426,373**	**2,488,947**	1,469,207	94,482	1,563,689
Corporate donations	**206,150**	**79,538**	**285,688**	253,525	8,025	261,550
International donations	**1,321**	**-**	**1,321**	1,156	-	1,156
Events by individuals	**32,629**	**985**	**33,614**	34,647	2,506	37,153
	2,302,674	**506,896**	**2,809,570**	1,758,535	105,013	1,863,548
Grants receivable:						
Charitable trusts	**105,160**	**687,241**	**792,401**	61,093	238,033	299,126
Government grants				2,433,399	-	2,433,399
	105,160	**687,241**	**792,401**	2,494,492	238,033	2,732,525

Government grants consist of £nil (2021: £809,812) received under the Coronavirus Job Retention Scheme and £nil (2021: £1,623,587) received in local authority grants.

Gifts in kind of £79,186 (2021: £87,206) are included in donations and gifts. This comprises online adwords valued at £79,186 (2021: £67,206) and campaign design and consultancy valued at £nil (2021: £20,000).

Notes to the financial statements
(continued)

3. Other trading activities

	2022	2021
	£	£
Income	**12,253,334**	8,654,004
Operating expenses	**(12,449,041)**	(9,952,625)
Net income from fundraising activities	**(195,707)**	(1,298,621)

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2022 there were 102 shops trading (2021: 105). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2022	Income	Operating expenses	Net income 2021
	£	**£**	**£**	£	£	£
Retail	**11,204,468**	**(11,749,690)**	**(545,222)**	7,911,357	(9,340,096)	(1,428,739)
Fundraising events	**841,849**	**(699,351)**	**142,498**	639,431	(612,529)	26,902
Miscellaneous trading	**207,017**	**-**	**207,017**	103,216	-	103,216
	12,253,334	**(12,449,041)**	**(195,707)**	8,654,004	(9,952,625)	(1,298,621)

Retail income excludes income of £1,019,370 (2021: £732,522) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail gift aid commission of £163,655 (2021: £33,236) which is recognised in miscellaneous trading. In 2021 the COVID-19 pandemic had a significant impact on gross retail income. The profit covenanted by DEBRA Trading Limited of £43,362 (2021: £69,980) is recognised in miscellaneous trading.

Notes to the financial statements
(continued)

The table below reflects a true statement of total retail income, including retail Gift Aid, commission and retail donations.

	2022	2021
		£
Income	**12,403,661**	8,710,081
Operating expenses	**(11,749,690)**	(9,340,096)
Net expenditure on fundraising activities	**653,971**	(630,015)

4. Investment income

	2022	2021
	£	£
Interest receivable	**994**	3
Rent of property	**4,528**	14,561
Total investment income	**5,472**	14,564

Rental income was received from one freehold shop and two flats situated above properties, which were acquired in 2009.

5. Grants payable

Expenditure on charitable activities include grants payable to third parties as detailed in Note 23. There were 354 (2021: 179) Community Support grants totalling £85,856 (2021: £36,752) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 23.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2022 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £411,167 (2021: £548,814) and clinical projects to the sum of £107,997 (2021: £125,948).

The total future commitment is currently committed to be spent as follows:

	Total 2022	Total 2021
	£	£
Within one year	**384,632**	527,442
Within two – three years	**134,532**	147,320
Within four – five years	**-**	-
Provided within the grants payable creditor (notes 15 and 16)	**519,164**	674,762

6. Expenditure

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2022
	£	**£**	**£**	**£**	**£**	**£**
Raising funds						
Donations & legacies	**517,816**	**-**	**-**	**213,897**	**147,995**	**879,708**
Other trading activities	**6,672,980**	**-**	**63,169**	**386,748**	**5,325,996**	**12,448,893**
	7,190,796	**-**	**63,169**	**600,645**	**5,473,991**	**13,328,601**
Charitable activities						
Research	**294,625**	**256,461**	**-**	**36,430**	**45,086**	**632,602**
Healthcare	**77,018**	**84,294**	**-**	**26,601**	**107,084**	**294,997**
Community support	**780,208**	**85,856**	**-**	**56,327**	**41,873**	**964,264**
Respite breaks	**-**	**-**	**57,669**	**-**	**62,010**	**119,679**
Public education	**418,001**	**-**	**-**	**39,584**	**171,200**	**628,785**
	1,569,852	**426,611**	**57,669**	**158,942**	**427,253**	**2,640,327**
	8,760,648	**426,611**	**120,838**	**759,587**	**5,901,244**	**15,968,928**

Notes to the financial statements
(continued)

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2021
	£	£	£	£	£	£
Raising funds						
Donations & legacies	381,817	-	-	164,432	115,943	662,192
Other trading activities	5,338,778	-	61,319	314,047	4,238,482	9,952,626
	5,720,595	-	61,319	478,479	4,354,425	10,614,818
Charitable activities						
Research	274,861	168,806	-	31,262	9,555	484,484
Healthcare	60,235	172,668	-	19,858	-	252,761
Community support	607,601	36,752	-	42,710	-	687,063
Respite breaks	-	-	48,016	-	46,926	94,942
Public education	243,566	-	-	31,934	90,448	365,948
	1,186,263	378,226	48,016	125,764	146,929	1,885,198
	6,906,858	378,226	109,335	604,243	4,501,354	12,500,016

Net income / (expenditure) for the year is stated after charging:

	2022	2021
	£	£
Operating leases	**1,796,779**	1,246,982
Auditors' remuneration	**19,900**	20,000
Non-audit services	**-**	3,600
Depreciation of tangible fixed assets	**180,733**	159,256
Defined contribution pension costs	**381,336**	314,405
Exchange differences	**(46,469)**	27,809

Notes to the financial statements
(continued)

7. Cost allocation

All central overhead costs are allocated to activities on the basis of staff time, and are detailed below:

	2022	2021
	£	£
Staff costs	**1,838,856**	1,403,077
Overheads		
Office premises rent	**55,117**	62,789
Service charges, utilities & cleaning	**50,669**	57,363
Equipment costs	**255,442**	144,088
Postage, printing, stationery, telephone & fax	**72,073**	64,585
Insurance costs	**138,505**	110,401
Legal, professional & consultancy fees	**69,399**	139,356
Depreciation	**51,068**	38,017
Profit on disposal	**6,319**	(143,660)
Irrecoverable VAT	**39,840**	22,348
Bank charges	**7,117**	9,744
Sundry expenses	**(26,062)**	58,201
Governance costs:		
Audit, non-audit and internal audit fees	**39,800**	38,600
Miscellaneous costs	**110**	2,411
	759,397	604,243
Total allocation	**2,598,253**	2,007,320

Notes to the financial statements
(continued)

None of the trustees received any remuneration from DEBRA during the period, but two of them were reimbursed a total of £565 (2021: one - £127) for travel and accommodation expenses. No Trustees received community grants (2021: £nil). The aggregate figure for trustee donations in 2022 was £14,460 (2021: £447). In addition, many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £4,375 (2021: £4,025), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9. Employees

The average number of employees during the period was:

	2022	2022	2021	2021
	No	**FTE**	No.	FTE
Research	**2**	**1.6**	1	1.0
Healthcare*	**-**	**-**	-	-
Community Support	**15**	**13.3**	13	12.3
Fundraising & Comms	**22**	**20.1**	16	15.8
Retail	**296**	**230.4**	299	216.4
Management & Administration	**27**	**25.6**	19	17.6
	362	**291.1**	348	263.1

Notes to the financial statements
(continued)

At the end of the year the number of employees per department was:

	2022	2022	2021	2021
	No	**FTE**	No.	FTE
Research	**2**	**1.7**	1	1.0
Healthcare*	**-**	**-**	-	-
Community Support	**15**	**13.7**	13	12.0
Fundraising & Comms	**20**	**18.6**	16	15.6
Retail	**295**	**227.3**	304	222.2
Management & Administration	**27**	**25.6**	22	19.2
	359	**286.9**	356	270.0

*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 20. Staff employed by external institutions and funded through research grants are also excluded.

	2022	2021
	£	£
Wages & salaries	**7,467,472**	5,960,400
Social security costs	**601,090**	392,291
Pension costs	**381,336**	314,405
Total payroll	**8,449,898**	6,667,096
Other staff costs	**310,749**	239,762
Total allocation	**8,700,647**	6,906,858

Notes to the financial statements
(continued)

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £381,336 (2021: £338,399) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £nil (2021: £nil) unpaid.

There are adequate systems in place to manage expenses and they do not form part of remuneration.

The following members of staff received emoluments above £60,000:

	2021	2020
	No.	No.
Between £60,001 - £70,000	**-**	3
Between £70,001 - £80,000	**4**	1
Between £80,001 - £90,000	**2**	-
Between £110,001 - £120,000	**1**	1

Redundancy and compensation payments, which were all paid in year, totalled £67,528 (2021: £16,739).

The aggregate pay of key management personnel, including employer's NI and pension contributions was £857,698 (2021: £711,022). The aggregate employer's pension contribution for key management personnel was £67,439 (2021: £61,489)

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £59,492 (2021: £59,064), and there are retirement benefits accruing for eight (2021: five) employees under a defined contribution scheme.

Notes to the financial statements
(continued)

10. Fixed assets

Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land & buildings	Long leasehold land & buildings	Total
	£	**£**	**£**	**£**	**£**	**£**
Cost:						
At 1 January 2022	**362,140**	**480,162**	**395,043**	**578,347**	**82,500**	**1,898,192**
Additions	**-**	**248,601**	**237,485**	**-**	**-**	**486,086**
Disposals	**(81,735)**	**(34,000)**	**(17,500)**	**-**	**-**	**(133,235)**
At 31 December 2022	**280,405**	**694,763**	**615,028**	**578,347**	**82,500**	**2,251,043**
Depreciation:						
At 1 January 2022	**253,161**	**245,615**	**201,267**	**167,427**	**21,450**	**888,920**
Charge for the year	**34,074**	**57,670**	**74,460**	**12,879**	**1,650**	**180,733**
Disposals	**(58,559)**	**(34,000)**	**(16,142)**	**-**	**-**	**(108,701)**
At 31 December 2022	**228,676**	**269,285**	**259,585**	**180,306**	**23,100**	**960,952**
Net book value:						
1 January 2022	**108,979**	**234,547**	**193,776**	**410,920**	**61,500**	**1,009,272**
31 December 2022	**51,729**	**425,478**	**355,443**	**398,041**	**59,400**	**1,290,091**

The Head Office fit out costs, mobile equipment and software development costs have been included in the fixtures, fittings and equipment category.

11. Programme related investment

	2022	2021
	£	£
Investment in Fibrx Derm Inc		
Net investment value brought forward	**1**	1
Purchase of investment	**-**	-
Impairment charge	**-**	-
Net investment value carried forward	**1**	1

The trustees invested £190,840 ($250,000) in Fibrx Derm Inc, a US biotech company, purchasing 203,252 series A-2 convertible preferred stock, at a price of $1.23 per share. This investment supported the development of a new treatment to help wound healing in patients suffering from Dystrophic Epidermolysis Bullosa. The purpose of this investment was in furtherance of the charitable objectives of the charity, and no financial return was expected. The value of the investment has been impaired by 99.99% as the most prudent course of action.

12. Investment in subsidiaries

DEBRA had two 100% owned subsidiary companies incorporated in England and Wales at 31 December 2022 (2021: two). These are DEBRA Trading Ltd (company number: 2487114), whose principal activities are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship; and DEBRA Retail Ltd which is dormant.

Financial information for these entities for the year ended 31 December 2022:

	2022		2021	
	DEBRA Trading Ltd	**DEBRA Retail Ltd**	DEBRA Trading Ltd	DEBRA Retail Ltd
	£	**£**	£	£
Turnover	**90,376**	**-**	119,267	-
Total expenses	**47,014**	**-**	49,287	-
Gift aid to DEBRA	**43,362**	**-**	69,980	-
Profit / (loss) for the year	**-**	**-**	-	-
Net assets / (liabilities)	**2**	**1**	2	1
Share capital	**2**	**1**	2	1

13. Debtors

	2022	2021
	£	£
HMRC	**211,221**	174,344
Amounts due from group undertakings	**43,362**	69,980
Other debtors	**544,057**	489,879
Accrued income	**458,491**	681,184
Prepayments	**599,550**	527,501
	1,856,681	1,942,888

Amounts due from HMRC are VAT receivable of £211,221 (2021: £174,344). Other debtors includes £266,825 (2021: £301,908) due for shared research grants. Accrued income includes gift aid of £289,219 (2021: £344,460) due from HMRC.

Total future minimum lease receivable in 2022 was £nil (2021: £nil), in respect of 1 shop.

14. Investments in short term deposits

	2022	2021
	£	£
HSBC money market deposits	**3,000,000**	-
	3,000,000	-

15. Creditors: amounts falling due within one year

	2022	2021
	£	£
Trade creditors	**223,903**	427,092
Grants payable	**2,019,399**	2,236,649
Other creditors	**263,332**	220,134
Taxation and social security	**138,323**	113,353
Accruals	**1,013,934**	845,920
Deferred income	**13,426**	18,670
	3,672,317	3,861,818

Grants payable includes £384,625 (2021: £548,832) relating to future commitments and £1,634,774 (2021: £1,687,817) relating to outstanding invoices for work done.

There was deferred income of £13,426 (2021: £18,670), representing income for events which would have to be repaid in the event of cancellation.

16. Creditors: amounts falling due over one year

	2022	2021
	£	£
Grants payable	**134,539**	147,320
	134,539	147,320

17. Provision for liabilities

	2022	2021
	£	£
Dilapidations provision		
Provision brought forward	**187,948**	181,808
Charges	**50,004**	6,140
Release of provision	**-**	-
Provision carried forward	**237,952**	187,948

18. Other financial commitments

The following payments are committed to be paid in the future in respect of operating leases:

	2022 Leases of land and buildings	2021 Leases of land and buildings	2022 Other	2021 Other
	£	£	**£**	£
Within one year	**1,019,492**	1,233,867	**18,747**	13,115
Between one – five years	**1,454,360**	1,539,926	**18,481**	16,217
After five years	**74,767**	-	**-**	-
	2,548,619	2,773,793	**37,228**	29,332

There were capital commitments of £nil (2021: £nil) at year end, falling due within one year.

19. Analysis of funds: restricted funds

	Balance at 1 January 2022	Income	Expenditure	Transfer to general fund	Balance at 31 December 2022
	£	**£**	**£**	**£**	**£**
Oliver Thomas Memorial Fund	**-**	**111,700**	**-**	**-**	**111,700**
Research	**(350,340)**	**754,941**	**(252,994)**	**-**	**151,607**
Healthcare	**20,625**	**89,048**	**(104,073)**	**-**	**5,600**
Community support & respite	**77,765**	**258,459**	**(117,620)**	**-**	**218,604**
	(251,950)	**1,214,148**	**(474,687)**	**-**	**487,511**

	Balance at 1 January 2021	Income	Expenditure	Transfer to general fund	Balance at 31 December 2021
	£	£	£	£	£
Research	-	176,067	(118,065)	(408,342)	(350,340)
Healthcare	5,600	30,362	(15,337)	-	20,625
Community support & respite	70,943	153,993	(147,171)	-	77,765
	76,543	360,422	(280,573)	(480,342)	(251,950)

Restricted funds comprised:	2022	2021
	£	£
Oliver Thomas Memorial Fund[1]	**111,700**	-
Research – Apremilast Drug Re-purposing Trial	**151,607**	-
Healthcare - EB nurses	**-**	15,025
Healthcare - Birmingham Children's Hospital Specialist Bath	**5,600**	5,600
Community Support – Holiday Home Appeal	**132,662**	-
Community Support - Community Support Manager for Scotland	**21,542**	21,542
Community Support - Community Support in Bedfordshire	**5,121**	5,121
Community Support - Community Support in Berkshire	**4,273**	8,037
Community Support - Support Grants in Hampshire	**3,952**	5,502
Community Support - Support Grants in Scotland	**66**	1,934
Community Support - Support Grants in South East England	**-**	15,851
Community Support - Support Grants in South Gloucestershire	**1,054**	1,054
Community Support - Support Grants in Somerset	**6,914**	-
Community Support - Support Grants in West Midlands	**1,303**	-
Community Support - Support Grants in Buckinghamshire	**13,836**	-
Community Support - Support Grants in Surrey	**1,674**	-
Community Support - other restricted funds	**16,207**	18,724
Digital Inclusion	**10,000**	-
	487,511	98,390
Less:		
Research - COVID Medical Research Charity Support Fund[2]	**-**	(350,340)
Net restricted funds	**487,511**	(251,950)

1. The Oliver Thomas Memorial Fund was established in September 2022. £85,000 is restricted to a contribution to a Medical Research Council Fellowship, £10,000 for an EB weekend get-together, £9,200 for Clinical Best Practice Guidelines and £7,500 to a contribution to eye research in collaboration with Fight for Sight.
2. An agreement was signed with the Medical Research Council who agreed to provide funding for specific research projects already in progress. The funds were received in 2022. The related costs were recognised in the income statement and charged to the general fund on grant award in accordance with DEBRA accounting policies. Therefore, a transfer from restricted funds to general funds was required in 2021 representing spend already incurred.

Notes to the financial statements
(continued)

20. Analysis of funds: unrestricted funds

	Balance at 1 January 2022	Income	Expenditure	Transfers	Balance at 31 December 2022
	£	£	£	£	£
Future research grants	**-**	**-**	**-**	**-**	**-**
Drug Re-purposing	**-**	**481,397**			**481,397**
Nursing continuity	**250,000**	**-**	**-**	**-**	**250,000**
IT Strategy	**50,000**	**-**	**-**	**-**	**50,000**
Procurement	**50,000**	**-**	**(31,000)**	**-**	**19,000**
NHS Digital	**200,000**	**-**	**-**	**-**	**200,000**
	550,000	**481,397**	**(31,000)**	**-**	**1,000,397**
	3,500,325	**14,725,180**	**(15,463,241)**	**-**	**2,762,264**
	4,050,325	**15,206,577**	**(15,494,241)**	**-**	**3,762,661**

	Balance at 1 January 2021	Income	Expenditure	Transfers	Balance at 31 December 2021
	£	£	£	£	£
Future research grants	515,950	-	-	(515,950)	-
Nursing continuity	250,000	-	-	-	250,000
IT Strategy	-	-	-	50,000	50,000
Procurement	-	-	-	50,000	50,000
NHS Digital	-	-	-	200,000	200,000
Total designated funds	765,950	-	-	(215,950)	550,000
General fund	2,138,497	12,956,979	(12,219,443)	624,292	3,500,325
Total unrestricted funds	2,904,447	12,956,979	(12,219,443)	408,342	4,050,325

The future research grants fund was fully un-designated in 2021 in response to the Covid-19 Pandemic and the Trustees resolved that the historical practice of designating all amounts in excess of minimum required cash-backed free reserves for future research would not be re-established. Instead, funds would be designated for specific project opportunities envisaged within the overall Five-Year Strategy. £481,397 (2021: £nil) has been designated to fund drug re-purposing trials and £200,000 (2021: £200,000) has been designated to fund the NHS Digital Data project. These projects are due to commence in 2023.

Notes to the financial statements
(continued)

The designated fund for nursing continuity has been established as a contingency in the event of future NHS funding withdrawal, and the Trustees maintained a balance of £250,000 (2021: £250,000) in this fund.

In 2021 £100,000 was designated to fund future procurement and IT work furthering modernisation of back office practices. £31,000 was spent on procurement consultancy in 2022 leaving a balance of £69,000 as at 31 December 2022. This balance is expected to be used in 2023 for IT and procurement consultancy.

21. Analysis of net assets between categories of funds

Fund balances at 31 December 2022 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	**£**	**£**	**£**
Fixed assets	**1,290,094**	**-**	**-**	**1,290,094**
Current assets	**5,516,978**	**1,000,397**	**487,511**	**7,004,886**
Creditors:<1 year	**(3,672,317)**	**-**	**-**	**(3,672,317)**
Creditors:>1 year	**(372,491)**	**-**	**-**	**(372,491)**
	2,762,264	**1,000,397**	**487,511**	**4,250,172**

Fund balances at 31 December 2021 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,009,275	-	-	1,009,275
Current assets	6,688,136	550,000	(251,952)	6,986,186
Creditors:<1 year	(3,861,810)	-	-	(3,861,818)
Creditors:>1 year	(335,268)	-	-	(335,268)
	3,500,325	550,000	(251,952)	3,798,375

Notes to the financial statements
(continued)

22. Reconciliation of net income to net cash flow from operating activities

	2022	2021
	£	£
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	**451,797**	817,385
Depreciation and amortisation charges	**180,733**	159,256
Impairment of programme related investment	**-**	-
Dividends, interest and rents from investments	**(5,472)**	(14,564)
Profit / (loss) on disposal of fixed assets	**6,319**	(143,663)
Decrease in stock	**(742)**	4,589
(Increase) / decrease in debtors	**86,207**	(326,269)
(Decrease) / increase in creditors	**(152,278)**	(766,914)
Net cash used in operating activities	**566,564**	(270,182)

23. Analysis of cash and cash equivalents

	At 1 January 2022	Cash flows	At 31 December 2022
	£	**£**	**£**
Cash at bank and in hand	**4,967,810**	**(2,821,668)**	**2,146,142**
	4,967,810	**(2,821,668)**	**2,146,142**

An analysis of changes in net debt note has not been prepared on the basis that DEBRA only has cash and cash equivalents, the movement on which is shown above.

24. Grants to institutions

Research grants:	2022		2021	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
University of Dundee				
Clinical fellow funding	**7,664**	**658,253**	146,115	650,589
University of Glasgow				
Re TGF-beta mediated tumour promotion in RDEB		**221,139**	64,001	221,139
Guy's and St Thomas' Hospital, London				
Clinical endpoints study re EB therapy evaluation	**40,233**	**734,790**	160,956	694,557
Stem cell therapy trial re treating debilitating itch	**-**	**497,360**	31,946	497.360
Wound care and its complications in patients with EB	**7,324**	**7,324**	-	-
Thomas Jefferson University, Philadelphia, USA				
Phase 2 clinical trial of Rigosertib for RDEB SCC	**-**	**470,490**	-	470,490
Univ. Birmingham Dental School & Hospital				
Characterisation of skin microbiome in EB patients	**-**	**296,289**	31,359	296,289
Gait Analysis in EB Simplex	**30,688**	**46,032**	15,344	15.344
Clinical Fellowship	**33,168**	**98,904**	30,622	65,736
Novel spray to treat mucosal scarring	**50,777**	**152,384**	76,201	101,607
University of Cologne				
Re immunity in wound healing complications RBEB	**5,929**	**170,635**	23,688	164,706
Universitair Medisch Centrum Groningen				
Re phyto-cannabinoid treatment of pain in EB	**-**	**159,025**	-	159,025
Instituto Dermopatico deli'Immacolata Rome				
Re histone deacetylase inhibitors for RDEB	**4,627**	**69,034**	4,627	64,407
King's College London				
Preclinical studies of lentiviral-mediated COL7A1 gene therapy	**10,395**	**198,978**	43,394	188,583
Great Ormond Street Institute of Child Health				
Respiratory cell & gene therapy for children with JEB	**52,601**	**118,445**	65,844	65,844
Bambino Gesù Children's Hospital				
MicroRNAs expression profiling, activity and therapeutic perspectives	**27,628**	**73,184**	30,876	45,556
University of Edinburgh				
Re Kindlin-1 loss in squamous cell carcinoma	**38,954**	**90,621**	41,379	51,667
New York Medical College				
Re innate & adaptive immune mechanisms in RDEB	**69,120**	**173,352**	69,588	104,232
Total research grants paid in year	**379,109**	**4,236,240**	835,941	3,857,132

Healthcare projects:	2022 Total paid in year	2021 Total paid in year
	£	£
Great Ormond Street Hospital for Sick Children		
Clinical nurse specialists in EB	**54,681**	83,525
Guys & St Thomas' Hospital London		
Adult EB support nurses	**(26,964)**	58,388
Birmingham Children's Hospital	**56,577**	30,755
Other	**17,951**	12,157
	102,245	184,825

Notes to the financial statements
(continued)

Reconciliation of provision: 2022	Research grants	Healthcare grants	Community Support grants	Total
	£	£	£	£
Provision brought forward	**548,814**	**125,948**	**-**	**674,762**
New commitments	**256,461**	**84,294**	**85,856**	**426,611**
Co-funding contributions	**(14,999)**	**-**	**-**	**(14,999)**
Spend in year	**(379,109)**	**(102,245)**	**(85,856)**	**(567,210)**
Provision carried forward	**411,167**	**107,997**	**-**	**519,164**

Reconciliation of provision: 2021	Research grants	Healthcare grants	Community Support grants	Total
	£	£	£	£
Provision brought forward	1,183,468	138,105	-	1,321,573
New commitments	168,806	172,668	36,752	378,226
Co-funding contributions	32,481	-	-	32,481
Spend in year	(835,941)	(184,825)	(36,752)	(1,057,815)
Provision carried forward	548,814	125,948	-	674,762

25. Related parties

During the year, the charity charged management charges totalling £11,300 including VAT (2021: £11,300) to its subsidiary, DEBRA Trading Limited.

Reference and administrative details

Patrons and ambassadors

Royal Patron
HRH The Duchess of Edinburgh GCVO

Life Patron
Philip Evans

President
Simon Weston CBE

Vice Presidents
Graeme Souness
Frank Warren
Stuart Proctor
Lenore England

Trustees

Jim Irvine (Chair)
Joanne Merchant* (Treasurer)
David Bendor-Samuel (Vice-Chair)
Carly Fields* (Vice-Chair)
Simone Bunting*
Becky Edwards*
Josie Godfrey (resigned 13 May 22)
Andrew Grist* (resigned 27 Feb 22)
Christo Kapourani*
Viv Mundy*
Douglas Rouse (resigned 28 Sep 22)
Simon Talbot*
Mick Thomas*
Dan Mundy (appointed 2 Nov 22)

Additional details

Company secretary
Ade Lawal (appointed 26 January 2022)

Registration
Charity Commission Number: 1084958
SCR Number: SC039654
Company Number: 4118259

Registered office & principal address
DEBRA, The Capitol Building, Oldbury, Bracknell, RG12 8FZ

Auditor
Sayer Vincent LLP, Invicta House, 108-114 Golden Lane, London EC1Y 0TL

Banker
HSBC, Thames Valley Business Banking, Hanborough House, Wallbrook Court, North Hinksey, Oxford, OX2 0QS

Solicitor
Stone King, 91 Charterhouse Street, London, EC1M 6HR

*Members of the Board who have direct experience of EB.

Abbreviations

ASP	Average Selling Price
CPG	Clinical Practice Guideline
CEO	Chief Executive Officer
CRM	Customer Relationship Management
DEB	Dystrophic Epidermolysis Bullosa
EB	Epidermolysis Bullosa
EBS	Epidermolysis Bullosa Simplex
EDI	Equality, Diversity & Inclusion
EPOS	Electronic Point of Sale
ESG	Environmental, Social, Governance
GDPR	General Data Protection Regulation
HR	Human Resources
k	thousand
LFL	like-for-like
m	million
NHS	National Health Service
pa	per annum
RDEB	Recessive Dystrophic Epidermolysis Bullosa
SGAP	Scientific Grants Advisory Panel
SMT	Senior Management Team
y on y	year on year

debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

DEBRA funds pioneering research, specialist healthcare, international best practice and life-long care and support to the EB community. We make a difference today with the aim of a better future for those suffering from the condition.

Together we will #StopThePain.

DEBRA, The Capitol Building, Oldbury, Bracknell, Berkshire, RG12 8FZ

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DEBRA Royal Patron - HRH The Duchess of Edinburgh, GCVO
DEBRA President - Simon Weston CBE

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Registered with FUNDRAISING REGULATOR

A charity registered in England and Wales (1084958D) and Scotland (SC039654).
Company limited by guarantee registered in England and Wales (4118259).
VAT Number 689 2482 79.

DEBRA

England & Wales - Charity number 1084958

Accounts

Trustees' Annual Report and Accounts 2021

Company registration number 4118259

Our vision

A world where no one suffers with Epidermolysis Bullosa (EB).

Our mission

Provide lifelong care, while seeking cures, for all those affected/impacted by living with EB.

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The DEBRA effect

At DEBRA, we can't change the future of Epidermolysis Bullosa (EB) in an instant. But we do know that an instant can help change the future of people on a life-long journey with EB.

We believe that anyone can effect change with one small action:

- One interaction with the EB community could bring invaluable insight that…
- Directs our energy and focus onto an essential unmet need which…
- Enables us to tailor our support and services effectively so that…
- Our members feel empowered to take as much control over their lives as possible which…
- Builds our relationships with experts who share our passion for finding life-changing solutions so that…
- Our community becomes more hopeful, connected and mutually supportive and we…
- Strive to make life-long improvements that enable anyone affected to enjoy pain-free, fully-lived lives.

the debra effect

Let us never underestimate the simple things we can do to spread ripples of hope for people living with EB. Let us all take one small action to fight EB so that, one day, EB no longer has any fight left to give.

What is EB

Skin as fragile as a butterfly wing

EB, Epidermolysis Bullosa, is a complex and rare group of genetic skin conditions that cause the skin to tear and blister at the slightest touch. The name comes from 'epiderm' – the outer layer of skin, 'lysis' – the breakdown of cells and 'bullosa' – blisters. EB can impact the external skin and also internal linings e.g. mouth, throat, eyes, anus and organs.

Genetic condition

People living with EB have a faulty gene which means the skin cannot bind together so that any friction causes it to tear apart. Every person has two copies of each gene – one passed on from each parent. EB may be inherited as either dominant (only one copy of the gene is faulty) or recessive (both copies of the gene are faulty). Parents have a 50% chance of passing on a dominant form of EB to their child, whereas the chance of passing on a recessive form of EB drops to 25%. Both parents may carry the gene without knowing or displaying any symptoms.

Types of EB

There are at least 30 genetically distinct forms of EB. The four main types are EB Simplex (EBS) accounting for around 70% of patients, Dystrophic EB (DEB) 25%, Junctional EB (JEB) 5% and other rare types including Kindler Syndrome.

Layers of skin tear and blister

Symptoms vary from mild to severe depending on the type of EB. In its most severe forms, EB is fatal; even in its mildest forms it can cause lifelong disability and pain. Blisters continuously form and have to be drained and dressed daily, a painful process that can take several hours. The build-up of scar tissue can cause fingers and toes to fuse together. It can mean a higher risk of developing skin cancer.

Treatment

People living with EB may require treatment from a range of medical specialists aimed at symptom relief. The most common challenge amongst all types of EB is the pain and itching that occurs as a result of the blistering.

No cure

There are an estimated 5,000 people affected by EB in the UK and 500,000 worldwide. It is currently incurable.

What is EB to me?

Lucy's story

To answer this, I must answer what it was, what it is now, and what it will be.

It was a happy childhood, one that people can't quite believe was as happy as it was. It was an abundance of love pouring over me from my first steps. But it was also bandages from my toes to my fingers. It was my siblings going into the backyard because sometimes, you could hear me scream from every room. It was days and weeks missing school when all I wanted to do was learn.

It was discovering the power of my mind and the power my words could carry. It was writing in the car ride to the children's hospital before surgery the next morning, where I'd start to cry behind an oxygen mask as anaesthetic forced my mind to still. It was saying the name of my condition and finally understanding what it meant.

"It was an abundance of love pouring over me from my first steps. But it was also bandages from my toes to my fingers."

It was a dozen surgeries in less than a decade, and fear, and an understanding that I had to do a lot more than other teenage girls. It was an understanding of society, crying in my car after a woman told me I looked like I'd been mauled by a gorilla. It was friends and my puppy and horse riding. It was pride after I saw my words carry me across countries, with pictures of my scars plastered in the Daily Mail and Huffington Post as I boarded a flight for an education in London.

Now, I am 23 years older than I was meant to be. And here is what it is.

It is my mother and boyfriend fighting back sleep from hospital chairs as they wait to hear if I made it out of the operation. It is watching my scar tissue overtake my fingers, and rites of passage I didn't plan for. It is being interviewed by a Scottish journalist from my hospital bed, an IV dripping pain medicine into my arm and laughing at the ridiculousness of it all.

"It will be possible for me to say, sometime soon, due to the research DEBRA is doing, that I am Lucy, and I HAD EB."

It is pointing and stares and bravery, exhaustion and joy, in the same hour. It's photographers pointing lenses at my scars and resisting the urge to cover myself, hide my soul from them. It is making decisions for the sake of my body with a knowledge that I may be hurting it. It is causing myself pain to heal. It is every ounce of my strength and more, it is words untranslatable, and fear and love and hope.

It is a part of me. It is the force that made me who I am. It's why I sat down to write this for you. My name is Lucy Beall Lott and I have recessive dystrophic Epidermolysis Bullosa. I am a student, an art historian, an archaeologist, a sister, a daughter. And I have EB. I always have. But as we know, many things can change in just a short amount of time.

What will it be? What will I be? I used to think of my future and feel small. But instead of feeling overwhelmed by fear of the future, I am now overwhelmed by the excitement of possibility. There are so many things I now know are possible. It is possible to write a speech for a Ted Talk in bed with wounds across your body, it is possible to write two dissertations while your pinky fuses to your ring finger, it is possible to live not despite your condition but with it.

It is possible to see the beauty in the world, in scars and tears and pain. A future for people with EB is possible. We can see it. It is almost here.

It will be possible for me to say, sometime soon, due to the research DEBRA is doing, that I am Lucy Beall Lott, and I HAD EB.

Lucy Beall Lott

Our work

Investing in a future free of EB

DEBRA UK was the first organisation in the world established to focus on EB. We have a proud history and a dynamic present. We will see our mission to its end – we cannot, and will not, rest until we find the necessary treatments, and ultimately cures, for EB and all those living with it receive the care and support they need.

From discovering the first EB genes to funding the first clinical trial in gene therapy, we have played a pivotal role in EB research globally and been responsible for making significant progress in advancing diagnosis, treatment and daily management of EB.

We are committed to making sure that all of the 5,000 or more people with EB in the UK and their families and carers get the vital and wide-ranging support they need, supporting specialist healthcare and investing in life-changing research so that the devastating symptoms of EB can be reduced while we work towards a cure.

Making a difference in 2021

Working with **4** national EB centres

Collaborating with **60** EB healthcare professionals

19 EB research projects

3,000+ DEBRA members

4,300 support actions, calls, contacts and visits to people living with EB

1,200 volunteers and staff

£1.9 million spent on research, healthcare & support benefiting the EB community

1.2 million kilos of goods recycled in our **105** charity shops

5 million people reached on social media

7th largest charity retailer in UK

An ambitious five-year strategy

Welcome from our Chair of Trustees

The devastating nature of EB continues to drive our determination to achieve our vision and end the suffering that EB brings. This means not only accelerating research to improve quality of life, but challenging ourselves and lobbying others, including Government, to leverage the significant funds that could bring forward the cure that every EB family dreams of.

It means a step-change in our fundraising and our approach to finding individuals, organisations and government bodies to achieve what we have been working towards for over 40 years.

We have developed an ambitious new strategy, with a clear vision for where we want to be in five years. We will return to and surpass pre-pandemic levels of investment and service by making our retail stores more profitable than ever, developing our online sales and building on fundraising and philanthropic opportunities.

> “We want to ensure that DEBRA remains the ‘go to’ place for everything relating to EB. To achieve this, the key to our success is our people.”

We will collaborate with national and international partners to improve delivery of specialist healthcare services and drive a programme of world-class, innovative and collaborative research that will bring hope and improved outcomes for everyone living with all types of EB.

We’ll introduce schemes to nurture the next generation of EB researchers and bring new investment into EB research with a focus on drug repurposing to accelerate research progress.

We will empower and advocate for the EB community, building our knowledge through Quality of Life surveys to increase our engagement with members and help shape our services.

We want to ensure that DEBRA remains the ‘go to’ place for everything relating to EB. To achieve this, the key to our success is our people. We will prioritise learning and development for our staff and volunteers and increase access to specialist EB knowledge and information for all who support people living with EB.

A huge challenge is to make ‘EB’ a term that is understood by the masses and not the few. Achieving such a change will need investment but it will be worth it as the increased awareness will result in a deeper supporter base spreading further awareness and boosting our income along the journey.

Thank you to our EB community, the specialist healthcare professionals and researchers we work with, our customers, supporters, trustees, staff and volunteers. It is your commitment and support which has brought us this far and which will enable us to achieve our ambitious goals.

Jim Irvine
Chair of Trustees

Committed to the EB community

Introduction from our CEO

Despite the challenges of the COVID-19 pandemic and the impact on our finances, we are in a position to exit the crisis strongly as a growing organisation. DEBRA receives no statutory government funding. The income we raise from our retail stores, online sales, from our fundraising activities and the generosity of our supporters is vital to enable us to deliver our charitable objectives – investing in EB research, healthcare and support.

As for so many of us worldwide, the effects of the pandemic over the past 24 months have been significant. Our income-generating potential was put under pressure with fundraising events on hold and our charity shops affected by lock-down closures. However, we have worked hard for many years to raise our levels of reserves and been prudent with our spending. This meant that despite facing highly challenging times this year, we still had the resources needed to deliver vital, front-line services. Our aim for 2022 is to increase our spending on both research and EB support services while we work towards our ambitious vision – ‘a world where no one suffers with Epidermolysis Bullosa (EB).’

> “For over 40 years we have invested in pioneering EB research and healthcare.”

For people with EB, the consequences of COVID-19 are concerning, particularly for those with more severe forms of the condition who may already have fibrosis of the airway tract and be experiencing compromised immunity. We remained committed to supporting the EB enhanced nursing service ensuring that, despite some EB nurses being redeployed, patients continued to receive the vital medical attention they needed. We delivered online training and advice to maintain access to specialist expertise from EB healthcare professionals and our Community Support Team.

For over 40 years we have invested in pioneering EB research and healthcare. Throughout the past year we are proud to have been able to continue building partnerships both in the UK and internationally to further EB research and play a leading role in promoting EB knowledge and best practice for patients around the world.

At the heart of everything we do are the EB families, researchers and healthcare experts we support. I wish to thank our hardworking staff, volunteers,trustees and our supporters, without whom nothing would be possible. In another year of turbulence, your donations made sure people living with EB did not lose vital support at a time when they needed it most.

Tony Byrne
CEO

Growing through challenging times

The COVID-19 pandemic has had a significant impact on our finances, however we are in a position to exit the crisis strongly as a growing organisation.

At the start of 2021 we faced the difficulties experienced by many charities across the country, with our stores closed, the majority of our staff furloughed, fundraising events cancelled and delivery of our services to the EB community restricted to virtual support.

However, despite the challenges created by months of lockdown in 2021, our retail sales were 30% higher overall, with some stores outperforming 2019 sales and we undertook a successful development of online selling initiatives.

We were able to hold events in the second half of the year and support from a number of new major donors enabled us to get our fundraising income back on track.

The income raised through our network of charity shops and fundraising activities enabled us to continue to invest in EB research, specialist healthcare and to provide vital support for the EB community.

- **We continued to support all 19 research projects** with further funding allocated of £168k.

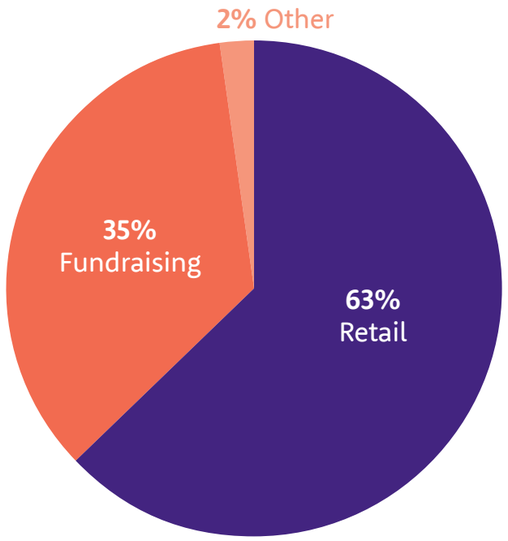
- **We ensured EB patients and families were fully supported by our Community Support Team.** We worked hard to ensure that all who needed our support were able to access us virtually or in person. We broadened the range of online sessions for our members including drop-in groups for parents and for teenagers to build social networks. We ensured access to specialist EB expertise with online sessions from EB dietitians, podiatrists, physiotherapists and other healthcare professionals.

- **We continued to work in partnership with the NHS,** supporting EB services at the four specialist EB centres across the UK, although some of the non-core activities were limited due to the impact of the pandemic on healthcare teams.

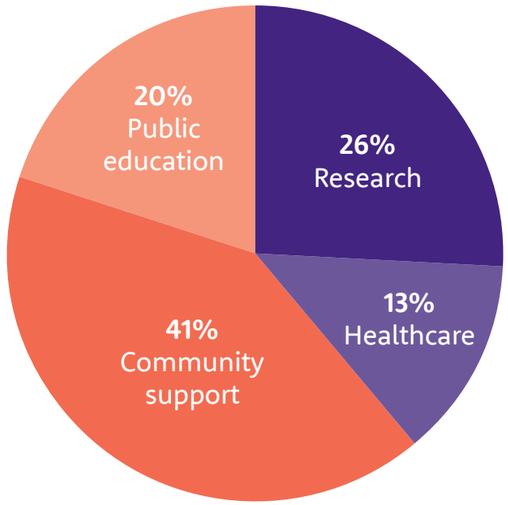
- **Our specialist EB podiatry training course was developed** ready for online delivery to make support accessible to podiatrists across the UK enabling patients to access vital expert care locally.

£1.9m spent on our charitable activities

How we raised our money



How we spent our money



Thank you to our members, community support team, healthcare professionals, researchers, trustees, staff and volunteers, customers, trusts, companies and donors for the continued, committed support you have given to our charity and to the EB community.

We couldn't have survived the past two years without you. Together we have made a difference and will continue to #FightEB until we have achieved our vision of a world where no one suffers with Epidermolysis Bullosa (EB).

EB research

Changing lives

From gene discovery to cutting-edge clinical trials of therapies to control symptoms and manage complications like cancer, the research journey for EB over the past 40 years has been remarkable. During this time, we have invested over £20m and been responsible, through funding world-class, pioneering research and working internationally, for establishing much of what is now known about EB. We are the largest UK funder of EB research and consistently in the top 50 UK funders of research across all diseases and conditions.

Over **£20m** invested

Across **12** countries

In **134** research projects

In **52** research institutions globally

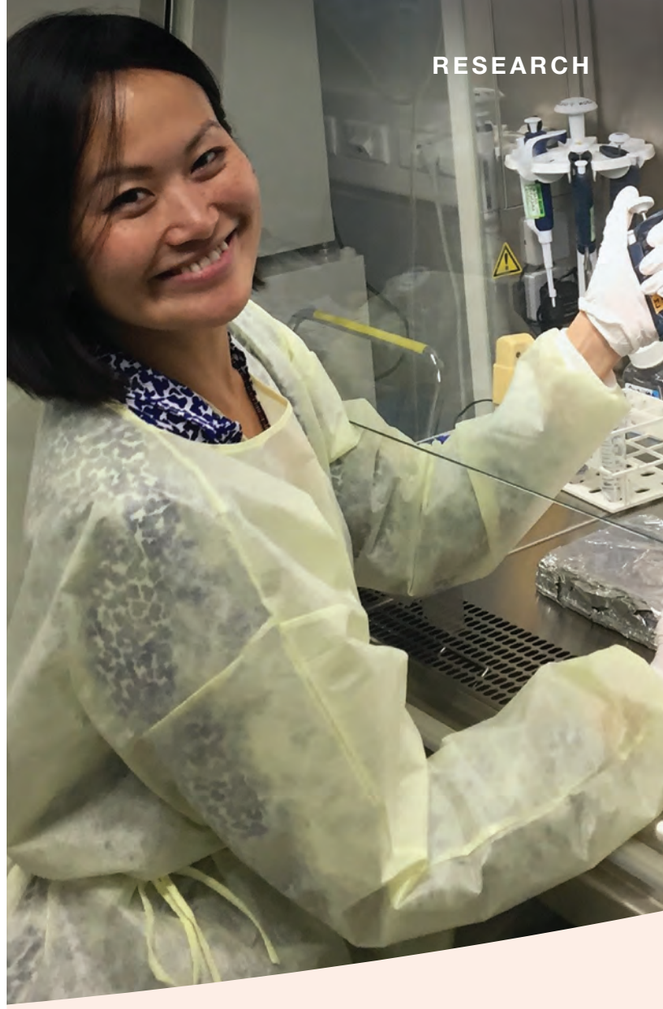
We are proud members of the Association of Medical Research Charities (AMRC). All projects undergo a thorough application and review process by a panel of medical and scientific experts (MSAP) guaranteeing that we only fund high-quality projects. This process ensures new research projects build on existing knowledge, which helps us to only invest in projects that give the best chance of breakthroughs leading to change.

What we did in 2021

The pandemic had a big impact on medical research charities including DEBRA. Some research projects were paused due the need to limit the number of people working in labs, however our commitment to research was unwavering. We continued to support all 19 existing research projects, providing funding of £836k in 2021 and allocated additional funding of £168k to new commitments.

Our grant portfolio, worth around £5m, included research into:

- a revolutionary gene therapy using spray-on cells with a protein that glues the skin together.
- a ground-breaking study into blocking molecule ‘signalling’ to stop cancer growth.
- a skin cream using a human protein that could improve healing and stop wounds scarring. Wounds and pain and the risk of infection they cause, are one of the most debilitating aspects of EB.
- a potential treatment for EB Simplex using gene ‘silencing’ technology to switch off a faulty gene to allow the normal gene to work properly.
- a study into the potential use of cannabinoid-based medicines to manage pain and itch without the side effects of some treatments.
- a cancer treatment drug with the potential to stop the growth of squamous cell carcinoma.
- a project to understand the bacteria which in EB may cause infections, delay wound healing and result in scarring and the potential to re-establish the ‘healthy’ bacteria in the immune system.
- an evaluation into long-term disease progression of RDEB that will inform the use of clinical trials to measure new treatments for all types of EB.
- clinical trials using cell therapy to improve understanding and treatment of severe itch.
- a project investigating inflammation, scarring and wound healing in EB.
- supporting fellowships, to develop and shape researchers and clinical experts for the future.



“Global collaboration is absolutely vital because we have so many experts around the world working on not just EB but other specialities such as oncology and haematology and combining different approaches. Thinking outside the box and working together will speed up the research and the effectiveness of what we can achieve together.”

Dr Su Lwin, Researcher

Andy & Isla's story

"As a parent of a child living with EB, it is incredible to see that research that was science fiction when Isla was born is now part of the solution. Isla has faced many challenges with her pain and she is tired; she wants a cure, as do many others who suffer from this condition. This is an upsetting and painful fight to go through and to watch.

The EB scientific and medical community increasingly believe they can solve the puzzle, that they can and will cure EB. They increasingly know where they need to be heading and are working out how and what they need to get there.

My hope for EB research is to make what was once impossible, possible. I want a brighter future for Isla."

Andy & Isla Grist, DEBRA Members, Scotland

Looking ahead

Where once a parent struggled for information and help, diagnosis, support and information are now widely available and ground-breaking clinical discovery has led to breakthroughs in current and potential treatments and understanding of EB.

But patients with EB are still suffering from devastating symptoms – pain, itch, cancer, wounds that require hours of dressings and blisters that can lead to infection. The EB community is at the heart of all we do. Their voices drive our commitment to do more to increase our programme of world-class research and make what was once impossible, possible. We want a future where everyday treatments end the pain and suffering of people with EB and their children. Now is the time to accelerate the pace of discovery, reduce the pain and challenges of life with EB and save lives.

Breakthrough in research comes from supporting outstanding projects that encourage the best of talented clinicians and scientists. This means increasing our funding and driving a programme of world-class, innovative and collaborative research that will bring hope and improved outcomes for everyone living with EB.

We will increase our funding and drive a programme of world-class, innovative and collaborative research that will bring hope and improved outcomes for everyone living with EB.

Patients and their family members through their own experiences are the experts on the impact of EB. Our new research strategy will be guided by a focus on impact and what matters to people living with EB.

Our ambition

- We want to know what causes EB by better understanding how it affects people living with the condition. We want to develop life-changing treatments to improve the quality of life for EB patients by better managing their symptoms and, ultimately, find a cure or cure(s) for all types of EB.
- We will play a pivotal role in making research into EB a global effort, working with many organisations, but with DEBRA UK front and centre in leading the quest for innovations that improve the lives of people living with EB.

"We are calling on the wider scientific community, other funders and our industry partners to come and join us on this journey to accelerate EB research innovation."

Dr Sagair Hussain, Director of Research, DEBRA UK

How we will achieve it

- Our funding portfolio will be diverse allowing us to seek opportunities to increase our research programmes.
- We will seek opportunities to partner with organisations that have common goals, non-EB funders as well as other DEBRA/EB groups, to bring new investment into EB.
- Partnering with NHS Digital to develop a national EB population register. The data will be a resource to improve clinical practice, support research into EB, inform health service commissioning as well as evaluate and audit health and social care services for EB patients.
- Introduce new schemes including a young leadership/career development fellowship to support and nurture the next generation of EB researchers. This will include providing project and programme grants to support partnerships at key UK universities to create EB Research Hubs, a Young Leadership Programme and New Horizon grants to encourage young researchers and researchers outside EB to bring new expertise into the field.
- A focussed investment in drug repurposing for EB will accelerate research progress where high costs can make traditional drug discovery unviable.

Drug repurposing clinical trials

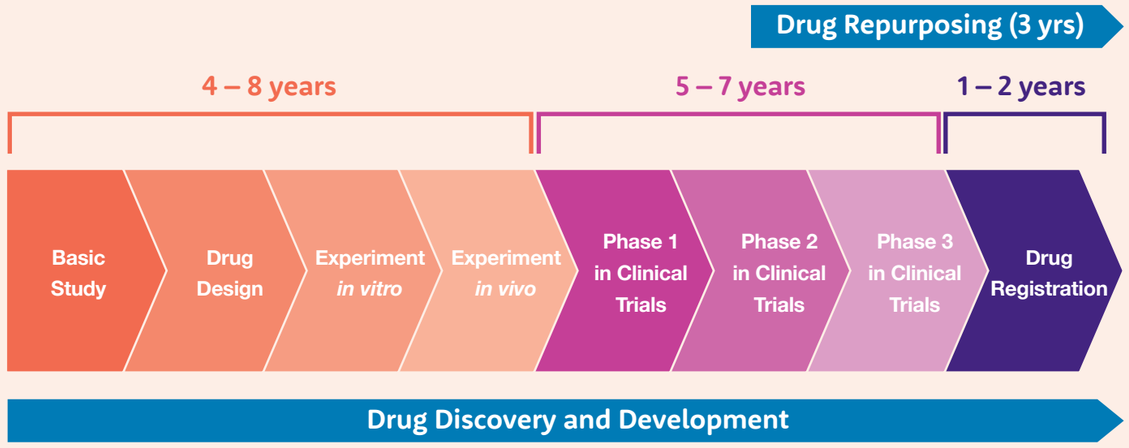
Drug discovery

- Average cost $1.3 billion
- Low success rate
- High cost and long time frame for development

vs

Drug repurposing

- Up to £500k per drug
- Known drug safety
- Less costly
- Shorter time frame of approximately 3 years



We will prioritise investment in drug re-purposing to accelerate research progress and find treatments for EB.

Karen & Simon's story

Laboratory diagnosis is crucial in determining the type of EB and understanding how to treat and manage the condition. Our funding has helped establish a model EB diagnostics centre in London, which has made it possible to receive prenatal diagnostic testing if parents are at risk for passing on EB, ensuring a parental choice.

> "EB is inherited and we were both carriers of the gene. This meant that it was likely our baby would have the same type of EB as Dylan had. Thanks to advances in EB research and funding from DEBRA, we were able to test our baby for EB before she was born. Knowing we would not have to see our new-born go through the same pain and distress Dylan did was a massive relief. Our baby girl was born on 4 November 2018, EB free. We promised Dylan before he passed away that we would always continue to #FightEB. Research into EB is so very important and gives us hope that one day there will be a cure for this devastating condition."

Karen and Simon Talbot, son Dylan and daughter Katie Rose

EB healthcare

Developing specialist services

We work with patients and the NHS to develop specialist EB healthcare services. We are dedicated to ensuring that everyone with EB has access to the best care and expertise from diagnosis onwards.

In 1987 we funded the first specialist EB DEBRA nurse. We now work in partnership with the NHS to deliver an enhanced EB healthcare service for people with all types of EB. We have invested in the development of the EB centres of excellence, fund clinical best practice guidelines and connect patients with the expert, specialist services they need across the UK.

- Providing state of the art facilities and equipment through investment in developments including £250,000 towards the Rare Diseases Centre at St Thomas' Hospital.
- Working in partnership with the NHS funding up to 25% of specialist EB nursing.
- Working with the four centres of excellence to ensure appropriate facilities, equipment and expertise are available for all EB patients.

Enabling EB healthcare teams to support over 2,000 EB patients each year.

- Promoting multi-disciplinary working and the development of EB expertise with support for a range of specialist EB clinicians' work including dietitians, physiotherapy, dentistry and podiatry training, supporting over 2,000 EB individuals each year.

Credit: Nikki Holland Photography

Gemma's story

> "My skin will blister and tear at the slightest touch, and EB causes internal damage too. Repeated blistering and scarring has caused my throat to become as narrow as a straw – I had to have a tracheotomy to help me breathe. The specialist EB Team at Guy's and St Thomas's Hospital, which DEBRA helps to fund, is there to advise me on every aspect of my EB care."
>
> **Gemma Jaega, living with EB**

Our partnership with the NHS gives patients access to specialist EB expertise from healthcare professionals and EB dentistry and podiatry training to bring expert care locally.

What we did in 2021

Throughout the year the pandemic continued to affect healthcare services for EB. From September, our Community Support Team were able to attend clinics at Guys & St Thomas' Hospital and home and school visits where there was a clear need.

- We continued to work in partnership with the NHS, supporting EB services at specialist EB centres although some of the activities were limited due to the impact of the pandemic on healthcare teams.
- We delivered online sessions to provide access to specialist EB expertise from EB dietitians, podiatrists, physiotherapists and other healthcare professionals.
- We provided funding for specialist EB dietitians at Guys & St Thomas' Hospital and Birmingham Children's Hospital one day per week to provide nutritional advice to promote vital health and wellbeing, wound healing and boost immunity.
- Our specialist EB podiatry training course was developed for delivery online, making specialist information and support accessible to podiatrists across the UK, enabling patients to access vital expert care locally.

Jess's story

"I've always suffered with feet that blistered really easily – the skin would tear and it was incredibly painful.

I was in my second year at University studying dance when the problems intensified. My feet would be bloody and my blisters would be infected. I sought a diagnosis and was referred to the specialist EB team at Solihull Hospital (a Centre of Excellence in EB supported by DEBRA). Thanks to the support I have received from the EB team, I'm no longer struggling on my own. I now know how to care for my feet and keep the blistering to a minimum, dramatically reducing the pain I'm in."

Jess Skeith, DEBRA Member

Our ambition

We will establish DEBRA as the 'go to training hub', developing and promoting courses, conferences, and professional networks internationally. An EB podiatry network and accredited course will be established. We will work with external organisations to include EB training at podiatry colleges and as part of dermatology courses. We will provide study grants to more professionals across the UK and support the running of multidisciplinary workshops focused on EB.

How we will achieve it

- Continue funding up to 25% of specialist EB nurses and funding additional grants to develop expertise within the teams as well as small project funding to enhance services.
- Continue to support specialist EB nutrition services, funding 20% of two EB dietitians.
- Continue to lead the development of accredited specialist EB podiatry training and make specialist information and support accessible to podiatrists across the UK enabling people with EB to access expert care locally.
- Work with healthcare professionals to update and develop publications and films that will provide specialist, expert information for people living and working with EB.

Helen's story

"It is such a privilege to work with the healthcare teams to support the EB community. EB is a complex condition – having the dedication and expertise of the specialist multi-disciplinary team is vital. Our members tell us how much difference this expertise makes in their day to day life. Together we are making a difference here and now and for the future."

Helen Weaver, DEBRA EB projects lead, working with healthcare and community support teams for over nine years

Lifelong EB support

Empowering and advocating for the whole EB community

The EB community is at the heart of everything we do. Their lived experiences and views drive our commitment to connect patients, families and carers with the specialist services and support they need to improve quality of life and help us shape our services.

- We provide lifelong support for the families carers and volunteers who provide daily care.
- Our aim is to empower and advocate for people with EB and their families, ensuring they are able to access the full range of vital support, services and care they need.
- We offer a personal, individualised support service, information and guidance to individuals, families and carers – from benefits and finance to bereavement support, social opportunities, respite and advocacy.
- We engage with organisations, from schools to new employers, to ease major life transitions.
- We connect the EB community, creating virtual and in-person opportunities to share experiences and gain peer-to-peer support, access specialist expertise and information and contribute to the development of services for EB.
- We work alongside clinicians and health care professionals to provide complementary social care and emotional support for people living with all types of EB.
- We work with many other DEBRA and EB organisations around the world, many of whom credit us for providing expertise inspiration and guidance.

5,000 people with EB in the UK

3,000+ DEBRA members

7 Community Support Team Managers supporting living with EB virtually and in their homes and advocating on their behalf

5 Membership staff support the wide membership group, connecting and engaging the EB community

470 EB members & families benefiting from respite in our 5 holiday homes

Kanon's story

"DEBRA means a lot to us, they have helped us in so many ways.

Any time I have a problem our Community Support Manager provides expert advice, emotional support and useful practical, and financial information we wouldn't otherwise have access to. She has helped us apply for Disability Living Allowance and Universal Credit and took the time to explain how the process works.

We have taken respite in the DEBRA holiday homes, which has meant we have been able to take Kanon away, something that we wouldn't have been able to afford on our own. On bad days, walking short distances can be impossible for Kanon and cause severe damage to his skin. DEBRA has helped me fund driving lessons so I can now drive Kanon to school and hospital appointments, making daily life more manageable. We want Kanon to lead a happy and most normal life as he can. DEBRA's support makes this possible."

Shalini Thachil, Kanon's mother

Katie's story

"My son Jamie was born with no skin on his feet, knees and hands and even where there was intact skin, it blistered. It was so hard to bond – I didn't hold my baby for the first six months.

He is the first person in my family to have EB so it came as an enormous shock. Jamie has a full skin check every day, which involves me lancing all blisters that have occurred overnight. I dress all the wounds and put protective bandages on before dressing him as well as giving him pain killers. The daily routine is quite structured to ensure he feels safe and secure at all times. He has his large dose of morphine before the evening meal so he's ready for his bath and can cope with more dressing changes. The most difficult thing about EB is seeing your child in pain, knowing that the care you are giving is causing so much distress.

The support I have received from DEBRA has been outstanding and makes a real difference. DEBRA has provided me with a changing table where I keep all the dressings and has signposted me to disability living allowance to help soften the blow of not being able to return to work as I am now a full time carer. The information booklets and website are a good reference to anyone wanting to know more. Meeting others with EB through DEBRA has made my outlook on the future less daunting. Seeing children with EB playing happily and managing daily activities gave me positivity and hope. The DEBRA days give me a boost of mental energy I so often need.

I feel extremely proud and in awe of Jamie, his happiness and joy keeps me motivated to stay strong. I am keeping positive that Jamie will improve with age and become less fragile so his pain levels will reduce."

Katie White, mother of Jamie White

What we did in 2021

Our Community Support and Membership teams worked hard to ensure that all people living with EB and their families who needed our support were able to access us virtually or in person.

- We postponed our Members' Weekend and in-person events due to the difficulties created by the pandemic, however we developed our range of virtual groups and online sessions for members, with drop-in groups for parents and teenagers to build social networks. We ensured access to EB expertise with online sessions from specialist EB dietitians, podiatrists, physiotherapists and other healthcare professionals.
- We provided information and guidance both virtually and through home visits with a successful hybrid approach which worked well, ensuring access for all.
- We connected new EB parents with the services they needed; this was an essential service with double the number of babies referred during the year.
- We enabled families across the UK to take respite breaks in our holiday homes in a year in which demand had never been higher.
- We communicated regularly and connected our community, and began an ambitious data transformation project leading to the introduction of a new database in 2022.
- The increase in requests for grants from members led us to develop our applications and partnership work with other charities and organisation including Children in Need, the Family Fund and Independence at Home to supplement our own grants.

4,300 calls, contacts, visits and a wide range of actions to support people with EB.

Our ambition

We will empower the EB community, ensuring they have a voice and enabling greater choice and independence. We will connect, engage, and grow our membership through communication, understanding their needs, providing support, care, information and advocacy.

How we will achieve it

- Continue to build on the successful hybrid working approach by our Community Support Team to provide the most efficient and effective service to support people with EB and their families across the UK.
- Increase the team resources with the appointment of additional posts to increase member engagement and extend access to expert knowledge and support.
- Provide virtual and, where feasible, in-person groups and events throughout the year, sharing the expertise and resources online to ensure access for members and all within the EB community.

- Expand our membership engagement activities and increase the ways in which members' views are captured and acted upon.
- Launch a quantitative Quality of Life baseline survey to inform how we prioritise our activities and introduce new types of support.
- Undertake a refurbishment plan for our five holiday homes and explore options for new holiday home in 2022 and a replacement home in 2023.
- Relaunch our grants scheme to provide a more targeted service to support members in time of need.
- Review our membership scheme to ensure it meets the current and future needs of all the EB community.
- Work alongside health and support teams to develop up to date and accessible information and publications for those living and working with EB.

DEBRA support

"When I was sixteen, I started developing severe blistering in my throat. Swallowing food can feel like eating razor blades.

DEBRA UK has been my rock. Not only do they help fund EB nurses who make my condition manageable, they have made me realise I can meet and share experiences with other people living with EB. The EB Community is a family. DEBRA UK is like the glue that keeps us together."

DEBRA member

Sabrina's story

"Living with EB can affect people around you including friends, siblings and family members who often provide crucial emotional and physical support.

We helped siblings access emotional support, enabled families to use the DEBRA holiday homes and enhanced the support we offer by undertaking specialist training in listening and counselling skills. We are here to support everyone affected by EB."

Sabrina Khan, Community Support Manager

A global and collaborative approach

Working together for improved outcomes

We are living in an era of enormous scientific and medical innovation. The tremendous effort of researchers looking into treatments, vaccines and cures for COVID-19, has demonstrated that a global and collaborative approach can lead to outstanding results.

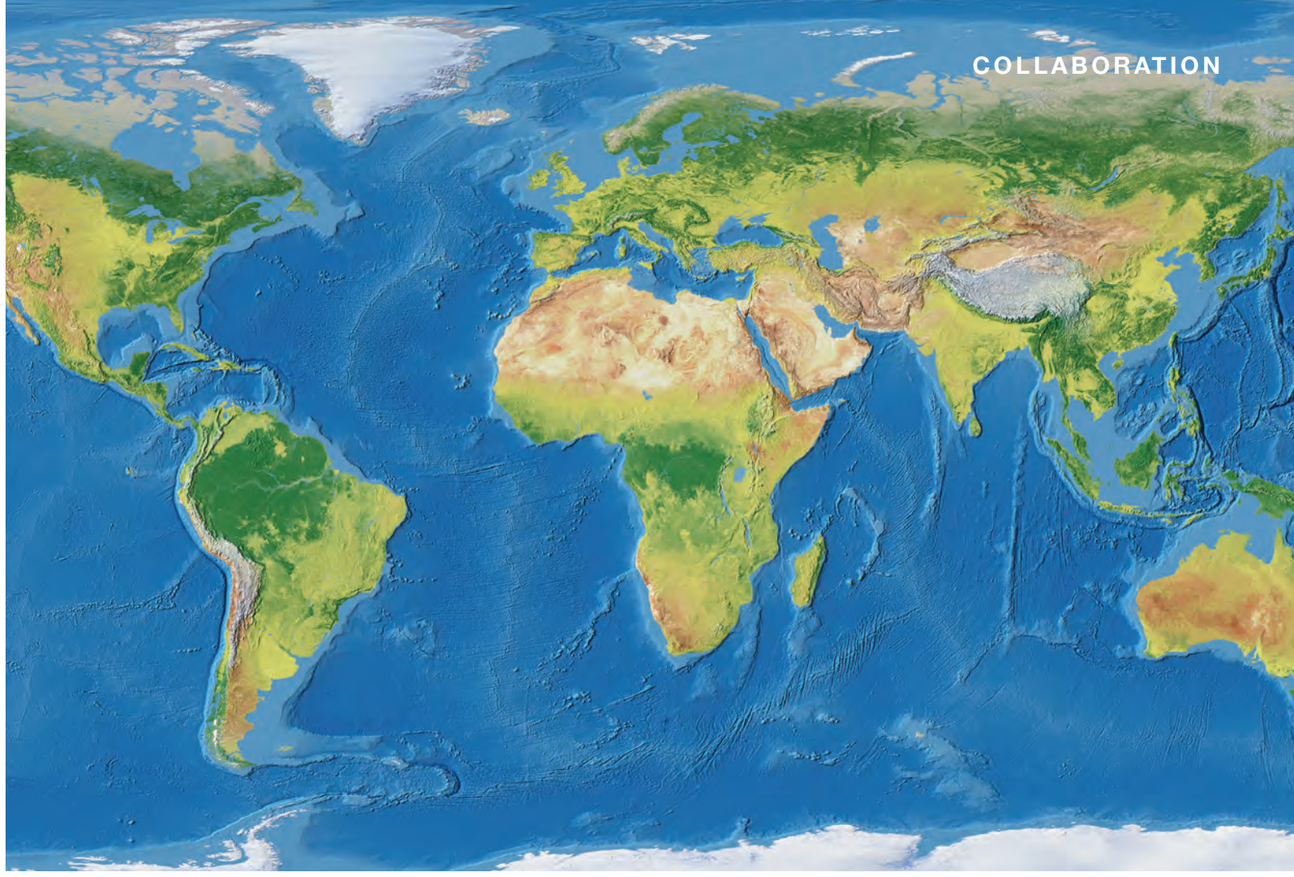
This approach is also the most effective for EB research and healthcare. It is a time of real opportunity, driving a programme of world-class, innovative and collaborative partnerships and healthcare that will bring hope and improved outcomes for everyone living with EB. Together we can achieve this ambitious and essential journey to change lives and end suffering.

40+ years working collaboratively
in EB research, healthcare and support

443 members of the Clinical Practice Guidelines Network

134 research projects across **12** countries and **52** world-class research institutions
funded by DEBRA UK

50 DEBRA international groups
working collaboratively for EB



What we achieved in 2021

- We continued to fund and work in partnership with research institutions across the UK and internationally, driving a programme of world-class research to bring hope and improved outcomes for everyone living with EB.
- We initiated the process of building a partnership with NHS Digital in order to develop a national EB population register.
- We started the process of setting up schemes to nurture the next generation of EB researchers, providing grants to support partnerships at key UK universities to encourage young researchers and researchers outside EB to bring new expertise into the field.
- We continued to invest in DEBRA International and supported the development of Clinical Practice Guidelines to increase professional knowledge and best practice for patients around the world with EB.
- We worked in partnership with the NHS to deliver enhanced EB healthcare services for people with all types of EB.
- We worked with DEBRA Ireland to develop and deliver an accredited mindfulness course for the EB community.
- We collaborated with charity Fight for Sight to set up a partnership to co-fund eye research in EB.

There are an estimated 5,000 people with EB in the UK and 500,000 worldwide.

Enhancing global EB care and best practice

We are a founding member and contribute funding and support for DEBRA International, our umbrella organisation with nearly 50 groups worldwide, all working towards improving the lives of those living with EB in their respective countries.

DEBRA International develops the Clinical Practice Guidelines which, with the help of over 300 clinical and patient volunteers, provide vital, internationally consistent practice information to guide health and social care professionals with patient versions and infographics in a format suitable for a lay audience. DEBRA International also manages EB Without Borders (EBWB) group, a collaborative effort to assist EB patients around the world, particularly in locations without a national DEBRA organisation and little to no clinical knowledge of EB.

41% of Clinical Practice Guidelines (CPGs) funded by DEBRA UK in the past 5 years, with £253,952 funding for 9 CPGs.

Looking ahead

We will continue to work with world-class scientists and clinicians and with national and international partners from academia, biotechnology and pharmaceutical industries and organisations with a shared interest in EB or other skin conditions.

We will also work closely with DEBRA International and DEBRA groups across the world to develop Clinical Practice Guidelines and share knowledge and best practice internationally as well as working with DEBRA International to manage the Research Involvement Network informing members of developments in EB research and promoting its importance and opportunities for patient involvement.

Our ambition

Central to our ambitious strategic plans is the awareness that a global and collaborative approach is needed if we are to increase the pace and breadth of our work and achieve life-changing improvements to clinical care, treatments and, ultimately, a cure for EB.

> "I think of the thriving community that I consider myself very lucky to be part of, the cutting edge research we're undertaking in Birmingham, but also around the world. It truly is a global and collaborative effort to try to improve the quality of life of every individual affected by EB."
>
> **Dr Ajoy Bardhan, University of Birmingham**

> "Tackling the big questions in EB research can only be done through a multidisciplinary collaborative approach. We will continue to work with existing and new partners in all sectors: from universities and NHS to governmental, industry and other charities."
>
> **Tony Byrne, CEO DEBRA UK**

How we will achieve it

- We will create a national EB population register in partnership with NHS Digital. The data will be a resource to improve clinical practice, support research into EB, inform health service commissioning and evaluate and audit health and social care services for EB patients.
- We will continue working with national centres of excellence and partnering with the NHS to provide specialist healthcare services for people with EB.
- We will work with organisations with common or overlapping missions, e.g. British Skin Foundation who share an interest in skin fragility.
- We will develop strong collaborative global relationships with EB organisations, researchers, clinicians, and pharmaceuticals.
- We will share knowledge and work with other DEBRA organisations around the world and participate in the development, funding and promotion of Clinical Practice Guidelines and other international DEBRA initiatives.

EB voices

Raising awareness, engaging communities

As a rare disease, awareness of EB is relatively low. We want to achieve greater awareness of EB within the healthcare and research communities and the wider public to ensure there is understanding for those living with the condition, more widespread EB expertise and support for our income generation through fundraising and our retail stores to enable us to fund essential research and care.

We want to give everyone living with and working with EB a voice. We want to fight EB together.

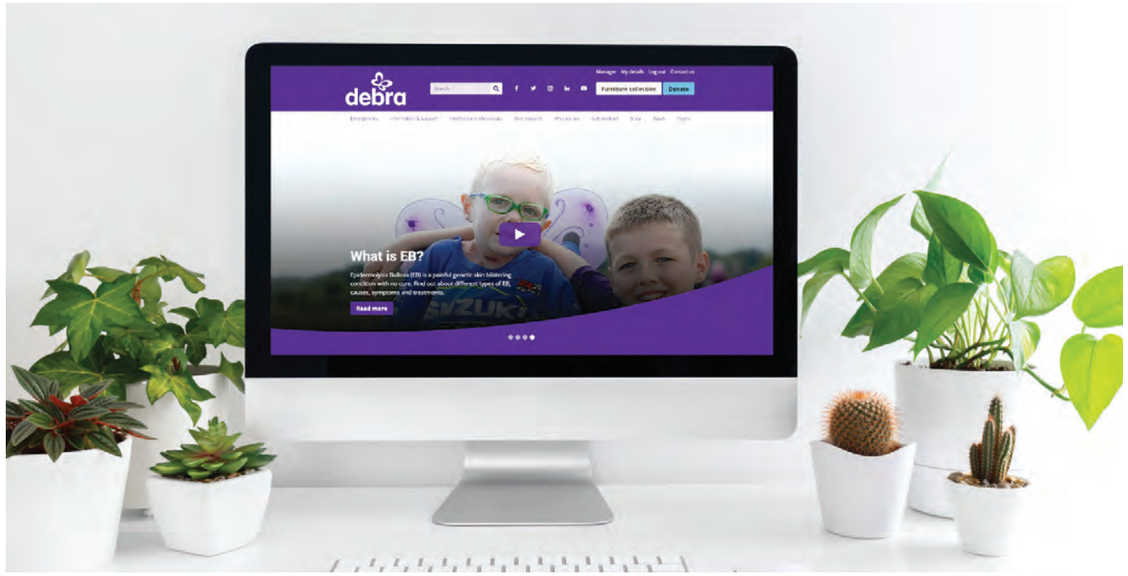
32% of people now aware of EB

5 million people reached on social media

What we achieved in 2021

Due to the continued effects of the pandemic and furloughed staff in the first quarter, we paused some of the projects in our digital transformation roadmap while continuing to support income generation and connecting and engaging our communities with frequent communication.

- As the year progressed, we continued the development of a new website with improved user experience, navigation and accessibility and transferred to a new email marketing communications platform, ready to go live in 2022 along with the new CRM system.
- We continued to build our brand, increasing accessibility, revitalising messaging and promoting our cause throughout our appeals, campaigns, publications, digital communications and signage across the retail stores.
- We prioritised the development of our social media strategy resulting in multi-channel growth.
- To support the growth of our e-commerce and maximise retail donations and footfall we developed our retail social media brand, reviewed use of our Google Ad Grant and increased our targeted digital campaigns. We launched a new initiative with selected stores to promote their goods at a local level, highlighting the key role our store staff and volunteers can play in and connecting with customers and putting the charity shops at the heart of their local community.
- We were delighted to be awarded the prize from PM Society – Creativity for Good – and the opportunity to work with a professional agency, Precision Effect, to promote DEBRA with an awareness campaign which became 'The DEBRA effect' and launched in February 2022.



Our ambition

It's time to transform our brand and empower and engage our communities, so that everyone living with and connected with EB sees us the key source of expertise, support and information on EB and the public recognise and support our cause, engaging with our work and seeking our retail stores as a sustainable destination of choice.

How we will achieve it

To deliver the charity's strategic plan, we will focus on three key areas – raising awareness, being the source of reliable, expert information and engaging our communities.

- To be the 'go to' source of EB expertise, we will review and update the information we provide to enable people with EB and the wider EB community to access reliable, specialist advice on all relevant EB matters including healthcare, latest research, specialist help and support from navigating social care systems; financial and welfare guidance to bereavement support.
- Our information will be available through multiple channels and formats including web, social media, telephone and face-to-face support, in person and online events, communications, video, online and printed materials. We will review and introduce new opportunities such as online forums and live chat.
- We will promote EB expertise and seek out developments in research and healthcare to engage our community of researchers & clinicians, recruiting informed "EB champions" to help us achieve our goals. We will develop a core group of specialists including those within DEBRA, able to provide active support as speakers, commentators and expert panel credibility as we work towards a goal of lobbying healthcare, government and business to influence attitudes, policies and services.

Raising awareness of EB is vital. As a rare disease, public awareness of EB is low, however we are working hard to change this.

A YouGov poll undertaken in March 2022 revealed that 32% of adults surveyed had heard of EB – an increase of 19% since our last poll.[1]

- We will create compelling communications, illustrating the impact of our work and the inspirational stories from our EB community to connect with our supporters, building a community working towards a shared, urgent goal.
- We will continue to develop our core messaging, brand voice and visual identity to improve recognition and understanding. We will build our retail brand to deliver a stronger presence on the high street which will highlight our commitment to our cause and to sustainability and support income generation through our online shopping.
- Our staff and volunteers will be knowledgeable about EB, building their knowledge and understanding of our work and their confidence to become advocates of DEBRA and increasing their engagement on social media.

1 All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2077 adults. Fieldwork was undertaken between 23–24 March 2022. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).

Hiba's story

"The day I was born my mum fainted and my dad was really sad because they didn't expect this to happen to me.

This condition is really hard because it's very painful when my clothes stick, when I change my dressings or when I take a bath. I cry a lot.

My fingers closed and I had an operation on my hands. Four months later they were closed again. I went to school and it was hard to write. Even my feet were swollen. I had an operation on my throat because I couldn't swallow food or water. It was very helpful but it started closing again. I have a gastronomy button now. No one can feel how I feel. The doctors are trying to make things better but EB is really hard for everyone.

When I grow up I want to be a scientist to make new medicines for children that have illnesses like mine. Hopefully I will cure EB. I know it's not impossible. Everything is possible."

Hiba el Mansouri Sghiar

DEBRA's Community Support Team are working with Hiba and her family and have enabled them to move into adapted accommodation and access essential equipment and support. Hiba is keen to be an EB ambassador, sharing her story to increase awareness of EB.

How we raise our funds

Building relationships, creating opportunities

Like many charities, our fundraising has been severely challenged. Having to cancel or postpone our usual programme of events was essential to protect the wellbeing of our staff, volunteers, customers and community.

However, we were innovative in our approach and proactive in building relationships with current and new donors and this, and the response that we had from our supporters, enabled us to get our income back on track.

We want to take this opportunity to say a huge thank you to our community support team, healthcare professionals, researchers, trustees, staff and volunteers, customers, trusts, companies and donors for the continued, committed support you have given to our charity and to the EB community. We couldn't have survived the past two years without you. Together we have made a difference and will continue to #FightEB until we have achieved our vision of a world where no one suffers with EB.

£2.2m raised by our incredible supporters this year.

What we did in 2021

Despite the difficulties of a year where staff were furloughed and events were limited or postponed, we ended the year in a good position with successful events, a number of well-supported appeals and commitment from new major donors including £460,000 towards our first drug repurposing research project.

- We set up and developed an Appeals Group which led to the introduction and support from a number of new major donors.
- We built a case for support focussing on the innovative opportunities that drug repurposing offers for EB, resulting in the commitment of philanthropic support for the first EB drug repurposing research project.
- We invested in the fundraising team to enable income growth through Trusts, Corporate, Events, Digital fundraising and Supporter services.
- We delivered a professional and profitable programme of events and challenges with 69% increase year on year.
- We increased the consistency and impact of our communications and promotion to all audiences, building engagement and reaching new supporters.
- We developed opportunities to build individual and corporate donations, grants, trusts and legacies to mitigate the impact of the pandemic on these areas of giving from our supporters, reducing the overall year on year decline to 18%, in what were very challenging external conditions.

Nurses from Great Ormond Street took part in our 100km Challenge. They make a life-changing difference to children with EB, providing much needed specialist care and support.

> "We are incredibly lucky here at GOSH, to work with an amazing group of children, young people and their families. Their determination and spirit are quite simply inspirational. We wanted to participate in this challenge to acknowledge that living with EB is tough, and to hopefully raise awareness of EB, and support DEBRA in any way that we can."

Our ambition

We have set ourselves an ambitious and challenging target. Our aim is to grow our core net fundraising income from £1.1m in 2021 to £1.6m in 2022 and £1.75m in 2023, an increase of 59%.

Recognising the short and long term impact of COVID-19, we will focus our opportunities for recovery on the development of long term relationships and our major donor, trusts and corporate donations. At the heart of everything we do will be the relationship with our EB Community and our determination to fund specialist healthcare and research that will be life-changing for people with EB.

How we will achieve it

- **Major donors and philanthropic donations:** our aim is to secure six- and seven-figure gifts. We developed a number of significant supporters with close commitments to the charity over the last three years. Working with these key relationships will enable us to leverage support from a number of new philanthropic supporters. Key to this are relationships with our Patron, President, Vice Presidents and members of our Appeals Group whose passion for the charity and our cause is vital in engaging new supporters.
- **Grant making trusts:** we have invested in the Trusts team in order to be able to increase the size of our applications and secure the funding needed for our future research projects as well as applications to fund our core membership and healthcare work.
- **Building our supporter base:** funding comes from people and relationships with people who share our passion for our mission and join us on our journey. We will expand our network of individual donors, major donors, corporate supporters, event attendees, and grant making trusts.
- **Corporate fundraising:** we will develop new corporate partners along with the stewardship of current corporate supporters. A particular area of interest is the pharmaceutical industries, particularly those companies with a potential or existing interest in EB.
- **Digital fundraising:** we have invested in a further team member to deliver our digital fundraising. A particular focus for 2022 will be to work with the marketing team to grow the online supporter base and increase the number of people receiving and engaging with our Appeals over the next three years.
- **Communication:** creating compelling cases for support and messaging based on supporter journeys that will build emotional engagement with potential and existing supporters. This will be supported by the data insights provided by our new CRM database.

Great Chefs Dinner raises £130k

This year's event brings the total raised for DEBRA in the six years Michel Roux Jr has hosted this event, our Great Chefs Dinners, to more than £380,000. We are so grateful to Michel, all the team of incredible chefs and staff at Roux at The Landau, and The Langham who made it all possible.

We are delighted to confirm that, through the generosity and support of major philanthropist, Lenore England, we have secured funding of £460,000 towards our first drug repurposing research project.

Drug repurposing

Drug repurposing has been thrown into the spotlight during the fight against COVID-19 as drugs developed for other conditions have proved highly effective in the treatment of COVID patients.

Drug repurposing is an exciting opportunity for EB and is essential for rare diseases where high costs can make traditional drug discovery unviable.

In 2022, we will be launching a major appeal – the more drugs we can repurpose the greater our chances of making successful, life-changing treatments available.

Thank you

We have been fortunate to be able to count on the continued backing of a number of very generous supporters. To everyone who donated to our cause and to the thousands of people who ran, cycled, took up our 100k challenge, volunteered or supported our appeals. To companies and trustees, the many ambassadors who speak about EB and DEBRA at events and to everyone who shares our story on social media – we would like to say a heartfelt thank you.

We are also extremely grateful to our Patron, HRH The Countess of Wessex, for her continued support throughout 2021 and to our President, Simon Weston CBE and Vice Presidents Frank Warren and Graeme Souness.

Our Patron, President, Vice-Presidents

HRH The Countess of Wessex
Simon Weston CBE
Graeme Souness
Frank Warren

Trusts and foundations

The Band Trust
The Souter Charitable Trust
The VTCT Foundation
Bill Brown's Charitable Settlement of 1989
The Dorus Trust
The Kola'a Trust
The Forest Hill Charitable Trust
The Murphy-Neuman Charity
The Dyer's Company
The Edith Murphy Foundation
The John Coates Charitable Trust
The Northwood Charitable Trust
The Grace Trust
The Hadrian Trust
The Catherine Cookson Charitable Trust
The Peter Harrison Foundation
The DM Charitable Trust
The Fowler Smith and Jones Trust
The Joseph Strong Frazer Trust
The Sir Iain Stewart Foundation
The Co-op Foundation
The Leach Fourteenth Trust
The Strangward Trust
The GM Morrison Charitable Trust
The Lillie Johnson Charitable Trust
The David Laing Foundation
The Edward Cadbury Trust
The Gilbert and Eileen Edgar Foundation
The Calleva Foundation
The Raven Charitable Trust
The Shanly Foundation
The Tory Family Foundation
The Ammco Trust
The Louis Bayliss Charitable Trust
The Benham Charitable Settlement
The John Cowan Foundation
The William Brake Foundation
The Basil Samuel Charitable Trust
The Childwick Trust
The Verdon-Smith Charitable Trust
The Louis Nicholas Residuary Charitable Trust
The Riply Trust
The Michael and Anna Wix Charitable Trust
The Alice Ellen Cooper Dean Foundation
The Bruce Wake Charity
The February Foundation
The Hugh Fraser Foundation
The QBE Foundation
The Riada Trust
The 29th May Charitable Trust
Marconi Chelmsford Employees Charitable Trust Fund
The Wixamtree Trust
The Mabs Mardulyn Charitable Foundation
Awards for All
The George Stewart Charitable Trust
The Jack Lane Charitable Trust
The Sylvia and Colin Sheppard Charitable Trust
The PF Charitable Trust
The Parry Family Foundation
The Maud Elkington Charitable Trust
The W.E.D Charitable Trust
The George A Moore Foundation
The Hudson Charitable Trust
Baron Davenports Charity
The Hospital Saturday Fund
The Brother's Trust
The Ardwick Trust
The Misses Barrie Charitable Trust
The Eveson Charitable Trust
The James Wise Charitable Trust
The Charles S French Charitable Trust
The Charity Service Fund
The National Lottery Community Fund
The Enid Linder Foundation
The Klahr Charitable Trust
The Manson Family Charitable Trust
The Whittington Charitable Trust
The Barbara and Stanley Fink Foundation
The Simon Gibson Charitable Trust

Trusts and grants

In 2021 we were delighted that Lenore England Family Foundation and Philanthropy made a commitment to funding up to £2 million for DEBRA research.

This significant and extremely generous gift represents the biggest single gift we have received and will provide a secure foundation for developing the ambitious programme of world-class, collaborative research we are planning.

Our stores

At the heart of our communities

The support from our customers and the hard work and dedication of our retail staff and volunteers throughout the challenges of the past two years has been vital, keeping our stores at the heart of their communities, helping to build awareness of EB, raising the profile of DEBRA and generating vital income to fund our research, support and healthcare.

What we achieved in 2021

Like many charities, we have been recovering from the impact of the pandemic with our stores closed during successive lockdowns in 2020 and early 2021. However the increase in our online sales, the growing trend towards recycling and the loyalty and support of our customers when we reopened in April with donations and sales enabled us to achieve a healthy growth overall.

- The wellbeing and safety of our staff, volunteers and customers remained a priority. During the national periods of lockdown and restrictions, the majority of the retail team were furloughed and we worked closely with our landlords to negotiate rent reductions. The total number of our stores reduced from 111 to 105 sites.
- We saw some drop off in volunteer numbers as a result of the pandemic and high sickness levels and difficulties in recruiting staff in some areas had an impact on trade.
- The development of our online selling platform initiatives proved very successful with a 30% increase in sales overall.
- The surge in donations in the spring and an increased interest among consumers in recycling and reusing items that contributed to a good cause as well as a desire to hunt out bargains during tougher economic times, meant that overall there was a healthy growth in stores overall, with some stores outperforming 2019 sales.
- Changes and improvements made to the staff induction plans and overall mandatory training management helped to improve Health & Safety engagement and training compliance significantly compared to previous years.
- We held our first virtual retail conference with a wide range of informative and inspiring sessions including presentations on the five year strategy for retail, visual merchandising, research, customer service, EB stories and our first online interactive wellbeing course.
- We introduced a number of new roles – Retail Operations & Compliance, Volunteering Resources and Logistics – to support our work in achieving cost savings and operating efficiencies.

290 dedicated staff in our stores

30% increase in online sales

838 volunteers giving **335,000** hours of donated time

Over **1.2 million** kilos of items recycled

£8.7 million raised by retail

DEBRA is the **7th** largest charity retailer in the UK

Looking ahead

The pandemic has accelerated shifts in consumer behaviour, with the most significant changes taking place in online spending, a greater focus on the community, and a deeper awareness of brand ethics and how our choices impact the environment.

Our stores will play a vital role in their communities, raising awareness of EB and delivering increased income from our online and instore sales to fund life-changing treatments and improved outcomes for everyone living with EB.

Our ambition

We plan to grow our net retail income by 83% over 3 years – from £1.3m in 2021 to £2.1m in 2022 and £2.4m in 2023. This is an ambitious target.

To achieve it, we will need to be the destination of choice online and on the high street, making our retail outlets attractive, pleasant places to work, shop, and volunteer. We will increase our sales and the number and format of our stores, refurbishing them to create higher quality, attractive retail environments. We will also improve our e-commerce and online sales that is more competitive, so that we can reach a wider audience with a relevant sales offering and promote our cause.

Our people are the key to our success. A motivated, knowledgeable and engaged team of staff and volunteers is our most essential asset. They will always be at the heart of what we do. We will work hard to create a stable and well-trained workforce, increasing overall volunteer numbers and ensuring excellent and consistent Health & Safety management and compliance.

Our aim is to reach a wider audience, command higher prices, promote our cause and ensure we have a more resilient approach in the event of any future unforeseen events such as further lockdowns.

£8.7m raised through DEBRA Retail to fund our life-changing healthcare, research and support for the EB community.

David's story

"I joined DEBRA as a volunteer when I was 16. There's a great collaborative atmosphere at DEBRA – I've never worked with a friendlier group of people and we really are invested in the charity and what it stands for.

My first job in retail was won thanks to the experience I got whilst volunteering at the store each week. It taught me so many great lessons that really helped me when I got into paid work.

I've really enjoyed doing work I believe in, from working the till to sorting donations. Because of my background in technology I've ended up becoming a sort of tech expert for the store – I'm always thrilled when we get another interesting bit of tech in a donation for me to work out, and sometimes fix. The environment is so supportive and engaging. Once I started volunteering, I realised I never wanted to stop helping out!

Volunteering at DEBRA opened so much for me. I really feel I'm making a difference here and it's a great way for a young person to develop their skills. I haven't regretted a minute of my time at DEBRA and I encourage anyone to get stuck in and do some work for a good cause!"

David Driver-Gomm, DEBRA Volunteer

Thank you to our amazing volunteers

We are one team. Our volunteers play a crucial role in our retail stores as well as supporting our fundraising and working with teams across the charity. Our volunteers report that it is an opportunity to socialise, learn new skills, and gain valuable work experience to move into paid employment. They are an essential part of the DEBRA team. We are so grateful for their commitment and skills – we couldn't achieve our mission without them.

How we will achieve it

- Open new stores to replace the store closures experienced since 2019 with larger format, high quality stores. The aim is to develop an estate of 130 stores by 2026.
- Build our e-commerce and online sales, reaching a wider audience, commanding higher prices and diversifying our overall customer population.
- Establish stronger brand awareness and community engagement.
- Develop a more efficient and lean retail function as a basis for expansion.
- Improve margin and contribution, by looking at volume, price and gift aid to offset wages inflation.
- Ensure we operate in as environmentally friendly manner as possible. As part of this, continue to implement changes to our logistics infrastructure, including trial of DEBRA leased vehicles and employed drivers.
- Look for cost efficiencies through procurement exercises.
- Increase volunteer numbers and create a motivated and well-trained team of staff and volunteers who are committed to increasing sales and raising awareness.
- Build a robust and well managed induction and training curriculum as part of the measures to improve retention, engagement and efficiency of our staff and volunteers.
- Launch a series of regional training road shows, in addition to the e-learning modules and training support available, with an emphasis on charity engagement, commercial awareness and wellbeing.

Simon's story

"I spent the best part of seven years without skin on my body so I feel relevant to DEBRA.

Babies born with EB can spend the rest of their life in pain, taking pain killers or medications to cure the itch, undergoing dressings that are painful and take hours.

We are trying to help people have improved quality of life. We have to find a cure. Until then we have a real crusade because these incredible people, and these families, don't deserve what they are going through. We need to fund the EB research and healthcare that will bring life-changing improvements to quality of life today and a cure tomorrow."

Simon Weston, President of DEBRA

Our people

Our people are at the heart of everything we do. Whether developing our vital research and healthcare programmes, supporting families with EB, managing or volunteering in our charity shops, working to raise essential funds, promoting and communicating the work we do, processing income, providing learning and development or supporting our cause as a Patron, President or Vice President, every person in our charity provides a highly valued contribution to the service that we provide to EB and our community.

In 2021...

95% of staff furloughed

335,000 hours volunteered in our stores

7,000+ hours of training for staff

We want to say thank you to...

360 employees

840 volunteers

13 trustees

Our commitment to Equality Diversity and Inclusion

"My personal connection to DEBRA and EB is that I am a mum to a daughter with EBS. She is the first in our family to have EB. Now I am involved through the Board of Trustees in order to be front and centre in what is happening with EB.

We started thinking about our Equality Diversity and Inclusion strategy in 2020, to examine ourselves and to ask are we being inclusive enough and ask what more can we do.

We are looking at how we can be more inclusive throughout our charity – board level, staff and volunteers and our members. We also want to improve our diversity through our recruitment and engage better. We know that if you bring your best self to work that we will get the best from you and you will get the best from your working environment so **we want to empower all our employees to feel that DEBRA values them for everything they are.** It is a journey – it can't be achieved overnight but we are striving to be the best we possibly can be."

Carly Fields, Co-Vice Chair of Trustees and Chair Research Care & Research Committee

What we did in 2021

- The effects of the pandemic continued to impact on the charity through most of the year. Our stores were closed until restrictions lifted in April, with retail and many other staff furloughed. The safety and wellbeing of our people remained a priority. Office and administration staff worked from home until the introduction later in the year of a hybrid model.
- Following the appointment of Tony Byrne as CEO in October 2020, there were a number of changes to the senior management team in 2021 with new Directors of Research, People, Finance & IT as well as new retail team appointments including Head of Retail Operations Manager, bringing a renewed focus on developing a robust strategy to deliver on our charitable objectives as well as ensuring good business practice and compliance.
- We launched a new HR self-service software as part of the charity-wide commitment to updating our systems and processes.
- We continued to undertake recruitment campaigns to build our team of dedicated volunteers who are a highly valued resource for us, undertaking vital work in our retail stores and support across many areas of the charity.

> “I consider it a privilege to work for DEBRA. Each day I get to know amazing families who overcome huge challenges. The support we are able to offer makes it a fantastically rewarding role to be in.”
>
> **Amelia,**
> **Community Support Manager**

> “Having worked remotely for over a year now it has been tough to carry out so much work over the telephone. So when I receive a photo of one of the members it can really brighten up my day.”
>
> **DEBRA employee**

> “It is probably one of the most enjoyable and rewarding jobs anyone can do.”
>
> **DEBRA employee**

- We continued to provide learning and development opportunities, ran Safeguarding September and a virtual conference for staff and volunteers.
- As a result of the employee feedback in 2020 and our ambition to be an “Employer of Choice” in the charity sector, we reviewed and updated our company values, created a new Equality, Diversity & Inclusion framework, and initiated a review of our benefits and recognition structure.
- Our Gender Pay Gap report showed that our mean pay gap is 5.86% in favour of men, and our median hourly full pay gap is 0 % compared to a national average of 15.4%. This is based on 324 employees with 76% women, 24% men on the snapshot date. We have made significant progress over the years however we are committed to doing more as part of our EDI and values-driven culture. Visit **www.debra.org.uk/gender-pay-gap** for more details.

Our values

During the year, employees and volunteers participated in a series of values workshops to provide a set of common beliefs, behaviours and understanding to support and enable us to work collectively to achieve our mission. We will build these values into everything that we do – how we interact with each other, training, recruitment, reward and recognition and wellbeing.

Making a difference

We make a positive contribution to the lives of the EB community, our colleagues, and the community we live in through the individual work and activities undertaken by each employee and volunteer.

Inclusive

We value diversity and proactively seek to support, engage and nurture every individual within the DEBRA community.

Respectful

We treat our members, colleagues, volunteers and customers, with respect. We value the views and diversity of others and intervene when those around us do not uphold the high standards we expect.

Passionate

We go the extra mile to achieve individual and collective goals. We do our best every day, so that we can move forward in our quest to improve the quality of life of our members and find a cure for EB.

Caring

We prioritise the needs of others, looking to brighten the day of those around us. Doing a great job really matters whether we are supporting members, serving customers, fundraising or raising awareness of EB. We care for one another.

Committed

We look for solutions, working together to create positive change. We deliver on our promises through hard work, collaboration, and determination.

> “I joined DEBRA as a volunteer to work in my local charity shop.
>
> I had been out of work as I was a stay-at-home mum to my son and also I looked after my mother.
>
> I wanted to start work and applied for many many jobs, but with a gap in my employment history no one would hire me.
>
> Since starting volunteering I have learnt the confidence and skills to sort stock, till training and health and safety. I have made new friends and been a part of the community. I love my job and the fact that I am helping raise awareness and money for EB.”
>
> **DEBRA volunteer**

Our ambition

Our ambition is to lead the fight against EB and be exemplary in all the activities involved in this fight. To achieve this the key to our success is our people. We will prioritise learning and development for our staff, volunteers and others supporting people living with EB, to ensure that they are knowledgeable about EB and up to date in all areas of health and social care. Our aim over the next two years is to focus on becoming a ‘Great Place to Work’. We will support, train and reward our staff for the role they play in delivering our mission ensuring that employees and volunteers have the tools and resources they need to do their job to the best of their ability.

Our People agenda will focus on three priority areas:

1. A resourcing strategy to attract, develop and retain the talent that we need in order to achieve our objectives, under-pinned by our Equality, Diversity & Inclusion (EDI) practices to ensure that our employee demographic represents the community we serve.

2. Providing learning and development to ensure employees and volunteers have the skills they need to fulfil their current and future roles.

3. Engaging our people by creating a positive working environment, recognising individual and team performance, providing salary and benefits that are competitive within the charity sector and embedding our values to create a culture where employees can flourish.

How we will achieve it

- By investing in our people.
- Giving all employees the opportunity to undertake personal development as well mandatory training delivered in a variety of ways, from online courses hosted on our new Learning Management System to face to face training delivered internally by functional experts or accredited external programmes funded by the apprenticeship levy.
- Our aim is to build our volunteer team to over 2,000 volunteers working with us. Recruitment, training, and retention of volunteers is therefore critical to our future success.
- The launch of our Equality, Diversity and Inclusion roadmap will start with an understanding of our current demographic and then put in place a range of initiatives to address any gaps we may have.
- We will ensure that there is the correct governance, fairness, and transparency in relation to all decisions regarding pay and remuneration. As part of a focus on reward and recognition, our retail teams will not only recognise great performance but also celebrate teams and individuals whose behaviours align with our values.
- By investing in technology and support systems we will move from paper-based to digital including the launch of the HR self-serve software and a Learning Management System to give employees and volunteers easy access to engaging learning material for mandatory and personal development.
- To make sure that we are heading in the right direction, we will undertake regular employee surveys and hold focus groups to gain feedback from all our employees, volunteers and members on our journey.

A great place to work

Our aim is to create a culture where our whole community can thrive, are valued, where equality and diversity are embedded in our values and actions and where everyone has the opportunity to develop, to enjoy their work and to make a difference.

Safeguarding

Safeguarding continues to be a priority in DEBRA, in the past 12 months our focus has been on raising awareness of safeguarding amongst our employees and volunteers.

In addition to a mandatory online training module, we ran Safeguarding September where throughout the month a range of materials were shared including educational videos, case studies, articles, and stories. We also hosted live sessions examining the difference between welfare cases and safeguarding, providing clear guidance on how best to report any concerns that employees or volunteers may have.

For our volunteers a new Safeguarding Booklet was rolled out giving an overview of what safeguarding is along with helpful guidance of what to do if they are concerned for their own or anybody else's wellbeing.

Our Safeguarding Committee agreed that an internal audit of our Safeguarding policy and process should be undertaken to highlight any gaps and support our journey to best practice in this area.

Equality, diversity and inclusion

Under the guidance of the Equality, Diversity and Inclusion (EDI) committee there has been significant progress with our EDI agenda in 2021.

An EDI policy and commitments has been created that not only aligns with UK anti discrimination law but also outlines the pro-active steps that DEBRA will take to create a diverse and inclusive community for our members, staff and volunteers. The EDI committee and Senior Management team participated in a one-day EDI training session with all employees being asked to complete an online training module. With a view to ensure participation from all areas of DEBRA an EDI working group has been formed. Their role is to act as champions within their directorate, as well as support the creation and roll out of new EDI initiatives and processes.

With the introduction of new digital databases, we will have visibility of the demographic of our members, staff and volunteers thereby allowing us to tailor our services and policies to meet their needs.

Although we still have a long way to go, we are proud of the steps we have made on the journey so far.

Equal Opportunities Policy Statement

We are an equal opportunities employer organisation. We are committed to ensuring that there will be no discrimination on grounds of race (including colour, nationality, ethnic or national origins), sex or marital status, gender reassignment, sexual orientation, religion or belief, disability, age, or pregnancy/maternity, which is not permitted by law; or on any other grounds, except where this is necessary to ensure that a job is done effectively and safely. This principle will apply to access of services by people whose lives are affected by EB, and to the recruitment, training and promotion of staff, and all other benefits, terms and conditions of employment. All employees and volunteers acting on behalf of DEBRA have a responsibility to apply this principle in practice.

Charity overview, objectives & public benefit

Financial review

The COVID-19 pandemic continued throughout 2021, which began with another lockdown. Shops were closed from January until mid-April. Despite the large drop in income, with good financial planning, we were able to continue serving the EB community. We spent £1.9m on charitable activities in 2021, compared with £2.8m in 2020. Whilst new research commitments were limited, spend on healthcare, community support and respite exceeded £1m, compared to £1.2m in 2020.

The eight months shops were open for trading resulted in net income from the retail operation, including government grants of £1.7m, compared with a deficit of £0.7m in 2020.

Many of our fundraising activities were severely curtailed during the first half of the year. However some major events were pushed back to the autumn and generated positive results. Overall net fundraising income was £0.96m in 2021, compared with £1.05m 2020.

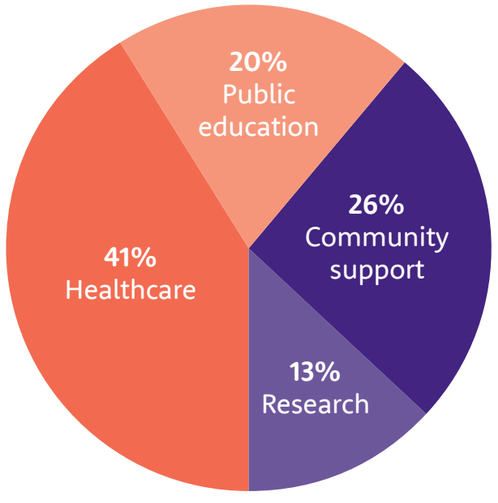
The surplus for the year was £0.8m, compared to a deficit of £2.4m in 2020. DEBRA's reserves built up in prior years have allowed operations to continue and are now being replenished as normal trading resumes.

Charitable spend

Charitable spend was £1.89m in 2021 compared to £2.85m in 2020. The key contribution to this fall was a reduction in research expenditure of £0.70m with £0.48m spent in 2021 compared to £1.18m in 2020. £0.69m (2020: £0.89m) was spent on Community Support initiatives, £0.25m (2020: £0.35m) on Healthcare services and £0.37m (2019: £0.48m) on Public Education.

Net assets increased to £3.80m from £2.98m. There was £3.5m in the general fund, £0.55m in designated funds and a £0.25m deficit in restricted funds.

Chart 1: Charitable Expenditure 2021



Summary

Table 3 summarises the highlights of our financial performance over the last five years. Gross income was £13.3m in 2021, an increase of £1.9m (16%) from 2020.

Non-trading gross income (not including government retail support) was £2.29m, a slight decrease from £2.33m in 2020. This includes income from donations, corporate support, trusts and community events.

Net retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops, but excluding government support) increased by 21% to £8.7m from £7.2m. Although shops numbers reduced by six and were closed for the first four months of 2021 they were less impacted by government action than in 2020.

The pandemic has had a devastating impact on our finances but, due to sound financial management in previous years, the strong reserves base was accessed to maintain close to normal levels of charitable activities.

Table 3: Financial KPI summary

	2021	2020	2019	2018	2017
Gross income	13,317k	11,413k	16,798k	16,138k	16,182k
Non-trading income including all government support	4,663k	4,387k	3,475k	2,979k	3,468k
Net trading income	(1,299k)	(3,201k)	1,198k	1,193k	616k
Net retail income including government pandemic support, retail gift aid, commission and donations in shops	1,689k	(673k)	2,123k	2,138k	1,652k
Non-trading fundraising costs	662k	708k	768k	727k	1,083k
Charitable expenditure	1,885k	2,848k	3,110k	2,966k	3,299k
Retained surplus/(deficit)	817k	(2,371k)	795k	479k	(299k)
Retained surplus/(deficit) as a % of income	6%	(21%)	5%	3%	(1.8%)
Net current assets	3.124k	2,684k	4,878k	4,394k	3,951k
Unrestricted reserves	4,050k	2,904k	5,138k	4,420k	3,997k
Grants payable within 1 year	2,237k	2,159k	2,201k	1,825k	1,156k

The charity's fixed assets comprise the premises and equipment required to operate trading activities; premises, furniture and equipment required to operate the charity's offices; and five holiday homes held for the use of those affected by EB. The rest of the charity's assets are held to promote the purposes of the charity through its support services and research programmes.

Reserves policy

DEBRA holds reserves to ensure the charity is able to continue supporting its beneficiaries and as a buffer for short term cash flow needs.

The trustees' reserves policy in 2021 was to maintain minimum cash-backed free reserves at £1,800k, plus a £250k balance in the designated fund for nursing continuity, to which the charity adhered. We have a high proportion of retail income, which usually provides a stable and reliable income stream. However, this incurs a high cost base, and the minimum reserves figure would cover one month's costs (excluding rent) plus six months' rent.

The trustees conducted a thorough review of the reserves policy at the end of 2021, reviewing performance criteria in the light of the pandemic and the deficit in 2020. The trustees' aim is to grow cash-backed free reserves over the next five years to £3.3m, in line with planned growth in retail and fundraising operations.

Total reserves at the end of 2021 were £3.80m, including a deficit balance of £0.25m in restricted funds. Cash-backed free reserves before designations were £3.28m, of which £0.55m was designated for specific purposes, bringing the total cash-backed free reserves after designations to £2.73m. Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be readily mortgaged, thus representing reserves that can be accessed relatively quickly.

Restricted funds

Restricted funds comprised £98k funds for community support and healthcare activities, and a deficit balance of £350k in respect of Medical Research Council (MRC) funding. An agreement was signed with the MRC who agreed to provide funding for specific research projects already in progress. The funds were received in 2022. The related costs were recognised in the income statement and charged to the general fund on grant award in accordance with DEBRA accounting policies. Therefore, a transfer from restricted funds to general funds is required in 2021 representing spend already incurred.

NHS Digital fund

A total of £200k has been made available in the designated fund for NHS Digital. This balance is sufficient to fund the data project for the fully two-year lifecycle.

Nursing continuity fund

The amount of £250k was made available in the designated fund for nursing continuity. The purpose of this fund is to cover the cost of the continued nursing service to the EB community for six months in the event of the NHS withdrawing current levels of support. It is expected this fund will be spent in the next five to ten years.

General fund

There was £3.50m in the general fund, of which £1.01m can only be realised by disposing of tangible fixed assets. The trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

Investment policy

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit.

We aim to apply our income in support of our charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk.

Prior to the pandemic, the charity took the view that this was best achieved by investing funds not immediately needed in short-term money market deposits through Lloyds Bank Corporate Markets. The investments have been transferred to cash at the current time during this period of uncertainty.

Expenses policy

We have expenses policies for both staff and trustees and a PAYE dispensation in place. Expenses that have necessarily been incurred by staff and trustees in performance of their duties are recoverable from DEBRA. Expenses will only be reimbursed if they meet the following criteria:

- no personal benefit could be derived from the expenditure by the employee concerned
- the expenditure is reasonable and represents only additional costs to those that would normally arise on a personal basis
- there is a clear charity justification for the costs
- the expenditure does not represent a form of payment to a third party for work undertaken on our behalf.

Any expenses that do not meet the criteria above are regarded as a benefit by HMRC and as a matter of policy we do not reimburse such expenses.

Funds

The majority of our funds are unrestricted in application and are held in a general and two designated funds. Where funds are received that are restricted in their application to specific purposes or activities, these are held in a restricted fund. Details of restricted funds and designated funds are set out in Note 17 of the Financial Statements.

Asset cover for funds

Note 18 sets out an analysis of the assets attributable to the various funds. These assets are sufficient to meet the charity's obligations on a fund-by-fund basis.

Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2021 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous non-primary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 22 of the Financial Statements.

Internal audit

The trustees appointed RSM as internal auditors during the year. Audits of Risk Management and Health & Safety were carried out and resulting action plans are being implemented by management. Audits of Internal Financial Controls, Cyber Security, Payroll and Fundraising are planned for 2022.

Principal risks and uncertainties

The trustees have established a register for all identified major strategic, business and operational risks identified by them to which the charity is exposed and confirm that these have been reviewed regularly during the year by the Finance, Risk and Audit Committee (as well as annually by the Board of Trustees) and that systems and procedures have been established to manage these risks. The initial responsibility for managing risk lies with the executive, prior to review by the trustees.

A summary extract of the higher risks from our risk register is listed in Table 4 below, including the countermeasures (actions in place to reduce likelihood of the risk) and assurances (how the effectiveness of the countermeasures is determined). DEBRA as an organisation is very proactive in its management of risk, instilling a culture of recognition, ownership and tolerance level for each risk identified.

See Table 4: DEBRA's top ten risks.

Table 4: Summary Extract from DEBRA's Risk Register

	Risk	Description	Current actions
1	**COVID-19 Pandemic**	Infection rates or government action leads to shop closures understaffing and other business impacts leading to loss of income and reduced ability to meet the needs of the EB community	• COVID-19 Risk Assessment • Training for staff • Covid safe shop layout • PPE and sanitiser supplied • safe working systems • Health and Safety file set to all shops
2	**Compliance with Health and Safety and other laws**	Non-compliance with H&S or other law leads to: • Serious injury / loss of life • fines and legal action against DEBRA and its Trustees / employees • Reputational damage	• Professionally qualified H&S, HR, Finance and compliance personnel • Use of 3rd party consultancy advice • Health & Safety policy and training / IOSH training • Health and Safety Audits • Shops Risk Register
3	**Cyber Security - data breach or loss**	A breach of personal data due to fraud leading to a loss of reputation and GDPR fines System failure leads to critical data loss	• In-house Data Protection Officer supported by External Consultancy • On-going staff training on data protection • Microsoft Authenticator, firewalls, mail scanning and other IT tools • Cyber insurance • IT Backup procedures and use of cloud • Business Continuity plan
4	**Cash**	Failure to maintain adequate cash flows leading to an inability of DEBRA to continue as a going concern	• Treasury management and cash flow forecasting monthly, reported to SMT and FRA (quarterly) • Monitoring by Trustees and FRA of cash-backed free reserves minimum figure
5	**Reputational damage**	Damage to the charity's image leads to loss of support	• Marketing Strategy and PR management • HR Disciplinary Policy • Crisis Communication Plan • Review of complaints and action taken • Pro-active media trawling • Staff induction programme • Social media policy
6	**Safeguarding**	Failure to comply with the requirements to satisfactorily report Safeguarding issues	• H&S and Safeguarding Manager in post • Work with external agencies • Safeguarding training for all staff • Designated Safeguarding Officers in post who undergo further training • Safeguarding Committee meets quarterly
7	**Changing face of retail**	Decline in the high street and growth of online impact of DEBRA's retail income	• Successful trial of Shopiago • Search for new locations
8	**Governance**	Lack of skill and knowledge amongst trustees leads to poor stewardship of DEBRA and non-compliance with laws and regulations, leading to the inability of DEBRA to continue as a going concern	• Up to 50% of trustees appointed based on skills • Trustee induction and training processes
9	**People skills**	Lack of appropriate skills at SMT or wider staff leading to poor business decision making	• Annual CEO appraisal • Recruitment and retention policies • Staff appraisal process
10	**Economy / inflation**	Adverse economic conditions or high inflation impact shop or other income	• Retail Committee monthly reports with KPIs • Performance reviews • Retail Risk Register • Continuous drive to increase retail contribution / enhance pricing

Going concern statement

The trustees have reviewed the financial statements and forecast to the end of 2023, detailing the plans for financial recovery whilst maintaining a first-class service to the EB community. It is recognised that there are underlying uncertainties, however the trustees consider the charity can continue its business-critical activities and remain a going concern. The retail estate re-opened during April 2021 providing a regular income stream of unrestricted funds, plus the suite of fundraising events started up again and there have been no further retail restrictions imposed by the Government since. The trustees consider it is appropriate to prepare the 2021 accounts on a going concern basis on the basis that:

- higher than in 2020, and before the pandemic started, undesignated free reserves at the end of 2021 are higher than in 2019 due to the trustees decision to undesignate the future research fund coupled with the 2021 surplus
- trading in 2021 is back to pre-pandemic levels
- The Budget and cash flows for 2022 and 2023 maintain adequate cash reserves throughout the period; and
- additional research activity programmed in 2022 and 2023 is contingent on achieving fundraising and retail targets. A grant of £500,000 has already been secured in 2022 to support this activity.

Structure, governance & management

DEBRA is a company limited by guarantee registered with the Charity Commission in England and Wales (1084958). This means our trustees are also company directors, so subject to company law as well as charity law. We are also registered with the Office of the Scottish Regulator in Scotland.

Board of Trustees

Our Board of trustees is made up from a majority of those who have a direct experience of EB, who either have EB themselves or have a close family member with EB, and those who have skills and experience that will add value to the governance and leadership of DEBRA. Of the 15 trustees, up to eight are elected by the membership and up to seven appointed by the Board. This ensures a good mix of skills, talents and experience to serve the DEBRA community.

The Board has a collective responsibility for everything we do and is responsible for:

- our overall strategic direction including evaluating progress against our strategic plans
- ensuring our financial stability
- acting in the best interests of our organisation
- ensuring that we comply with our governing documents, and any other relevant legislation from our regulators.

An Annual General Meeting was held via Zoom in May 2021. Three appointed trustees Graham Marsden, Tim Powell and Jo Merchant reached the end of a three-year term. After serving three x three-year terms, Graham retired as required by DEBRA's articles and Tim stepped down after two terms. Both were thanked for their dedication over the years, particularly over the past 12 months.

As recommended by the Nominations & Governance Committee the Board of Trustees re¬appointed Jo Merchant for a third three-year term. The Board also appointed Simone Bunting (who had previously served as a trustee, but had taken a year's break as required by DEBRA's articles) for a first term of three years. Simon Talbot was also elected by the members.

New trustees receive a Trustee Handbook and other relevant publications, individual inductions from senior trustees as relevant and trustees attend external training courses appropriate to their role on the Board of Trustees. There are four board meetings per year, which the CEO attends and Senior Management Team members attend as required.

Trustee Board committees

Finance, Risk & Audit Committee – determines and advises the Board of Trustees on matters relating to finance, risk and audit as the Board of Trustees may remit to it, in particular the sound financial management of the charity, its resources and assets.

Care & Research Committee – determines and advises the Board of Trustees on matters relating to strategy in research, healthcare, community support and policy as the Board of Trustees may remit to it.

Retail Committee – determines and advises the SMT and the Board of Trustees on matters relating to the shops. It utilises specific knowledge of its members to assist the CEO and Director of Retail to manage the shops, deliver operational performance against plan, comply with regulations and promote the cause of the charity.

Fundraising & Communications Committee – oversees the fundraising activities of the SMT on matters relating to the growth of income generation and maximising opportunities within Marketing and PR. The Committee approves and recommends to the Board of Trustees the strategic direction of fundraising and the financial plan. It utilises specific knowledge of its members to challenge and support the Director of Fundraising and Director of Marketing and Communications to deliver against plans, comply with regulations and promote the cause of the charity.

Nominations & Governance Committee – oversees the structure, composition and effectiveness of the charity's Board of Trustees and its Committees, as well as the appointment process of trustees. The Committee monitors the governance procedures of the charity.

Steering Group – this committee was created in light of the pandemic and meets regularly on an 'as needed' basis.

See Table 5 below – Trustees' membership and attendance.

The Trustees plan to undertake a full review of the existing committee structure during 2022.

Board diversity

To ensure that we have a well-balanced board, those with experience of living or working with EB are the majority, together with those trustees who do not have EB experience but possess the relevant skills and knowledge. The Board members come from a variety of backgrounds, in order to bring different perspectives to discussions and enhance the Board's decision-making process.

We follow the Equal Opportunities Policy in the selection of Board members, in the same way we do for staff recruitment. Membership of the Board is open to all members of DEBRA, irrespective of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values. Broader diversity of the Board continues to be reviewed as part of DEBRA's Equality, Diversity & Inclusion project.

Charity governance code

The Board consistently reviews all aspects of DEBRA's governance and ensures that our governance standards and practices fully embrace the principles of the Charity Commission 'Charity Governance Code'. We are currently reviewing the updates to the code in December 2020, which strengthened the Principle of Equality of opportunity, Diversity and Inclusion (EDI) and updated the Integrity Principle.

Succession planning

We have built strength and depth in our Trustee Board, incorporating appropriate succession planning by appointing two Vice Chairs, each for periods of two years with an annual rotation of one of those. Prospective new trustees are often invited to join a committee for a minimum period of twelve months before becoming trustees.

Fundraising standards

Section 162a of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. We do not undertake face-to-face fundraising from the general public. The legislation defines fundraising as 'soliciting or otherwise procuring money or other property for charitable purposes'. Such amounts receivable is presented in the accounts as 'voluntary income' and include legacies and grants.

We make all efforts to train staff and ensure compliance with fundraising standards at all times. Specifically:

- the majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the trustees
- where we work with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met
- there are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc
- where volunteers assist in our fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued
- volunteer fundraisers are managed and supported from the offices in Bracknell and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them
- data protection procedures are in place governing the management of supporter and donor data on our DEBRA database; compliance with the GDPR rules that came into force in May 2018 continues to be monitored
- we work with vulnerable people, particularly within the EB community, and often they wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly
- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2021.

Activities in Scotland

We are active across several areas in Scotland. The primary charitable activities are seen in funding community support and research projects, notably at the Universities of Dundee and Edinburgh and the Cancer Research UK Beatson Institute, University of Glasgow. On the income generation side, there were two regional fundraising members of staff and 37 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Blantyre.

Table 5: Trustees' membership and attendance records as at 31.12.2021.

		Board attendance	Finance, Risk & Audit Committee	Nominations & Governance Committee	Care & Research Committee	Retail Committee	Fundraising & Communications Committee
Jim Irvine	Chair	**4 of 4**	4 of 4	4 of 5			
David Bendor-Samuel		3 of 4		**5 of 5**			
Simone Bunting	Elected May 2021	2 of 2		3 of 5			**4 of 4**
Rebecca Cresswell		1 of 4					4 of 4
Simon Cuzner	Stood down 16.07.2021	2 of 2				**3 of 3**	
Carly Fields		4 of 4		3 of 3	**4 of 4**		2 of 2
Andrew Grist	Stood down 01.03.2022				2 of 4		
Christo Kapourani		2 of 3			3 of 4		
Graham Marsden	Stood down 27.05.2021	2 of 2		3 of 3			
Joanne Merchant		4 of 4	**4 of 4**			4 of 4	
Viv Mundy		2 of 4		3 of 5	3 of 4		
Timothy Powell	Stood down 27.05.2021	2 of 2			**1 of 1**		
Douglas Rouse		3 of 4					3 of 4
Mick Thomas		4 of 4					3 of 4
Simon Talbot		1 of 2	2 of 2				
Josie Godfrey	Co-opted 06.08.2021	1 of 1			0 of 1		

The committee chairs' attendance is highlighted in bold.

Auditor

Trustees have taken all reasonable steps to make themselves aware of any information needed by the company's auditor for the purposes of their audit and to establish that the auditor is aware of that information. The trustees are not aware of any relevant audit information of which the auditor is unaware.

We engaged Sayer Vincent LLP as auditor during 2020 and they have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditor 28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

The Trustees' Annual Report, incorporating the Strategic Report, is approved by the Board of Trustees and signed on behalf of the trustees:

Jim Irvine
Chair of Trustees

Trustees' statement of responsibilities

The trustees (who are also directors of DEBRA for the purposes of company law) are responsible for preparing the Trustees' Annual Report including the strategic report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities Statement of Recommended Practice (SORP) make judgements and estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2021 was 2343 (2020: 3,279). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditor's report

Independent auditor's report to the members of DEBRA.

Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2021 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended.
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice.
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the Financial Reporting Council's Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on DEBRA's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the trustees' annual report, including the strategic report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' annual report, including the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the trustees' annual report, including the strategic report, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report, including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the statement of trustees' responsibilities set out in the trustees' annual report, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud are set out below.

Capability of the audit in detecting irregularities

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, our procedures included the following:

We enquired of management and Finance, Audit and Risk committee, which included obtaining and reviewing supporting documentation, concerning the charity's policies and procedures relating to:

- identifying, evaluating, and complying with laws and regulations and whether they were aware of any instances of non-compliance;
- detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud;
- the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.

We inspected the minutes of meetings of those charged with governance.

We obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience.

We communicated applicable laws and regulations throughout the Audit Team and remained alert to any indications of non-compliance throughout the audit.

We reviewed any reports made to regulators.

We reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations.

We performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud.

In addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities is available on the Financial Reporting Council's website at: **www.frc.org.uk/auditorsresponsibilities.** This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Sayer Vincent LLP

Fleur Holden (Senior Statutory Auditor)

30.05.2022

for and on behalf of Sayer Vincent LLP,
Statutory Auditor

Invicta House, 108-114 Golden Lane,
LONDON, EC1Y 0TL

Sayer Vincent LLP is eligible to act as auditor in terms of section 1212 of the Companies Act 2006.

Financial statements

For the year ended 31 December 2021

Statement of Financial Activities

Statement of Financial Activities including income and expenditure account for the year ended 31 December 2021.

		2021				2020			
		Unrestricted funds	**Designated funds**	**Restricted funds**	**Total**	Unrestricted funds	Designated funds	Restricted funds	Total
	Notes	**£**	**£**	**£**	**£**	£	£	£	£
Income from:									
Donations & legacies	2	**4,261,175**	**-**	**347,477**	**4,608,652**	3,814,335	-	468,926	4,283,261
Charitable activities		**20,441**	**-**	**-**	**20,441**	18,210	-	-	18,210
Other trading activities	3	**8,641,059**	**-**	**12,945**	**8,654,004**	6,903,611	75,771	46,491	7,025,873
Investments	4	**14,564**	**-**	**-**	**14,564**	47,403	-	-	47,403
Other		**19,740**	**-**	**-**	**19,740**	38,150	-	-	38,150
Total income		**12,956,979**	**-**	**360,422**	**13,317,410**	10,820,709	75,771	515,417	11,412,897
Expenditure on:									
Raising funds	6	**10,614,818**	**-**	**-**	**10,614,818**	10,935,662	-	-	10,935,662
Charitable activities	6	**1,604,625**	**-**	**280,573**	**1,885,198**	1,452,433	821,551	573,782	2,847,766
Total expenditure		**12,219,443**	**-**	**280,573**	**12,500,016**	12,388,095	821,551	573,782	13,783,428
Net income / (expenditure)		**737,536**	**-**	**79,849**	**817,385**	(1,566,386)	(745,780)	(58,365)	(2,370,531)
Transfer between funds		**624,292**	**(215,950)**	**(408,342)**	**-**	1,473,695	(1,395,027)	(78,668)	-
Net movement in funds		**1,361,828**	**(215,950)**	**(328,493)**	**817,385**	(92,691)	(2,140,807)	(137,033)	(2,370,531)
Reconciliation of funds:									
Total funds brought forward		**2,138,497**	**765,950**	**76,543**	**2,980,990**	2,231,188	2,906,757	213,576	5,351,521
Total funds carried forward		**3,500,325**	**550,000**	**(251,950)**	**3,798,375**	2,138,497	765,950	76,543	2,980,990

All operations are continuing. The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

The notes on pages 83–109 form part of these financial statements.

Balance sheet

Balance sheet as at 31 December 2021.

	Notes	2021 £	2021 £	2020 £	2020 £
Fixed assets					
Tangible fixed assets	10		**1,009,272**		1,077,946
Programme related investment	11		**1**		1
Investment in subsidiaries	12		**2**		2
			1,009,275		1,077,949
Current assets					
Fixed assets held for sale		**74,167**		167,960	
Stocks		**1,321**		5,910	
Debtors	13	**1,942,888**		1,616,619	
Cash at bank and in hand		**4,967,810**		5,076,553	
		6,986,186		6,867,042	
Creditors: amounts falling due within one year	14	**(3,861,818)**		(4,182,719)	
Net current assets			**3,124,368**		2,684,323
Total assets less current liabilities			**4,133,643**		3,762,272
Creditors: amounts falling due after more than one year	15		**(147,320)**		(599,474)
Provision for liabilities			**(187,948)**		(181,808)
Total net assets			**3,798,375**		2,980,990

		2021	2020
The funds of the charity			
Restricted income funds	17	**(251,950)**	76,543
Unrestricted funds			
Designated funds	18	**550,000**	765,950
General funds	18	**3,500,325**	2,138,497
Total unrestricted funds		**4,050,325**	2,904,447
Total funds		**3,798,375**	2,980,990

Company registration number 4118259

The accounts were approved by the Board on 27.4.2022 and signed on their behalf by:

Jim Irvine
Chair of Trustee Board

Joanne Merchant
Treasurer

Statement of cash flows

Statement of cash flows for the year ended 31 December 2021.

	Notes	2021 £	2021 £	2020 £	2020 £
Cash flows from operating activities					
Net cash used in operating activities	20		**(270,182)**		(1,366,471)
Cash flows from investing activities					
Dividends, interest and rents from investments		**14,564**		47,403	
Proceeds from the sale of property, plant and equipment		**238,649**		7,052	
Purchase of property, plant and equipment		**(91,774)**		(68,791)	
Proceeds from sale of investments		**-**		3,750,000	
Purchase of investments		**-**		(190,840)	
Net cash provided by investing activities			**161,439**		3,544,825
Change in cash and cash equivalents in the reporting period			**(108,743)**		2,178,354
Cash and cash equivalents at the beginning of the reporting period			**5,076,553**		2,898,199
Cash and cash equivalents at the end of the reporting period			**4,967,810**		5,076,553

The notes on pages 83–109 form part of these financial statements.

Notes to the financial statements

1 Accounting policies

1.1 Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), Charities SORP (FRS 102), the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and Trustees Investment (Scotland) Act 2005.

1.2 Going concern

The trustees reviewed the charity's budget and cash flows for 1 January 2022 – 31 December 2023 in December 2021 and consider it is appropriate to prepare the 2021 accounts on a going concern basis on the basis that:

- undesignated free reserves at the end of 2021 are higher than in 2020 and before the COVID-19 pandemic due to the trustees decision to undesignate the future research fund coupled with the 2021 surplus;
- trading in 2021 is back to pre-pandemic levels;
- the Budget and cash flows for 2022 and 2023 maintain adequate cash reserves throughout the period; and
- additional research activity programmed in 2022 and 2023 is contingent on achieving fundraising and retail targets. A grant of £500,000 has already been secured in 2022 to support this activity.

1.3 Legal status of charity

The charity is a company limited by Guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

1.4 Judgements and estimates made by management

The financial statements include judgements and estimates as defined by the accounting policies. Legacy income is recognised as probable at probate, using an estimate provided by executors. Premises service charge liabilities are estimated from information supplied by property specialists. The dilapidations provision is reviewed annually on an individual lease basis by a property specialist.

Research grants are recognised in full in the Income and Expenditure Account at the point of commitment in order to ensure no reliance on future fundraising to meet these financial commitments.

Research grants are recognised in full in the Income and Expenditure Account at the point of commitment in order to ensure no reliance on future fundraising to meet these financial commitments.

Programme related investments are impaired based on a judgement of the intrinsic value of the investment at the balance sheet date, where no market value exists.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

Notes to the financial statements (continued)

1.5 Income

Donations and gifts are recognised in full in the Statement of Financial Activities when receivable. Unclaimed gift aid receivable is accrued in the year to which it relates. Legacies receivable are recognised when there is entitlement, probability of receipt and is measurable. Grants are recognised in full when receivable. Gifts in kind are only included in the accounts where the trustees can ascribe a value in excess of £1,000.

Other trading income is recognised in full when received with the exception of income that is deferred where it represents a payment in advance for a specific event that will not take place until a future accounting period. This exception does not apply to sponsorship for charity challenges taking place in a future accounting period.

Claims made through the UK Government's Coronavirus Job Retention Support Scheme are recognised as income in the period which the associated staff were furloughed. This income is considered to be unrestricted. Small business retail grants have been recognised as unrestricted income in the periods to which they relate.

1.6 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Equipment purchased for use in research is written off as part of the research project costs as incurred. Expenditure on raising funds are those costs incurred in seeking voluntary contributions and running the retail operations. Charitable activities include expenditure associated with the operation of the charity and the provision of its services.

Governance costs comprise the costs relating to the general running of the charity, and include direct items such as external audit, legal advice for trustees, the cost of trustee meetings, and are included in central overhead costs. Central costs are apportioned and allocated between the cost of raising funds and charitable expenditure on the basis of central staff time allocation to the various activities.

1.7 Recognition of grant liabilities

Grants are awarded for research projects over a period of one to five years. All grants provide the right to terminate with up to three months' notice and continuation of funding is dependent on satisfactory progress reporting and review. It is always the intention to honour the funding of all grants awarded and full grant recognition has been incorporated into these accounts as the most appropriate and prudent policy. By adopting this policy, the trustees ensure the funds for research grants have been raised in full prior to making financial commitments to research institutions.

1.8 Tangible fixed assets and depreciation

Tangible fixed assets with a value in excess of £1,000 are capitalised and stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

- Freehold and long leasehold buildings – Over 25 years
- Head office fit out costs – Over life of the lease
- Mobile homes – Over 10 years
- Fixtures, fittings, static equipment – Over 5 years
- Shop equipment – Over 5 years
- Mobile equipment – Over 3 years

A review of assets is undertaken annually, and adjustments are made to the expected useful life as required. From 1 January 2009 freehold land and long leasehold buildings are assumed to have a residual value of 50%.

1.9 Programme related investment and impairment

Programme related expenditure with a value in excess of £1,000 is stated at cost less impairment. The investment held was impaired by 99.99% in 2020, with a residual holding value of £1.

1.10 Cash and short-term investments

The charity holds cash requirements for day-to-day activities in current bank accounts with HSBC, Lloyds, Santander and Clydesdale. The deposit account is held with HSBC. Short-term investments that were held in money market deposits with Lloyds Commercial Banking were redeemed early at the start of the coronavirus pandemic. For the purposes of the cash flow statement, cash equivalents are defined as current asset investments, and short-term deposits with a maturity of less than three months, which are readily convertible into known amounts of cash.

1.11 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

1.12 Creditors

Trade creditors and other payables are normally recognised at their settlement amount after allowing for any trade discount due. Payments to suppliers are within standard payment terms of 30 days. Liabilities are recognised when there is a present obligation, as a result of past events, and there is a probable future outflow of resources that can be estimated reliably.

Notes to the financial statements (continued)

1.13 Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at settlement value.

1.14 Stock

The trustees do not consider it appropriate to recognise donated goods for resale as stock on the grounds that the cost of obtaining stock information would greatly outweigh any benefit. The costs involved would include the setting up of processes and procedures for a stock count in over 100 shops, training shop staff and volunteers in the process, software programming, and the checking and analysis of the reports produced.

All other stock is valued at the lower of cost or sales value net of selling costs.

1.15 Accumulated funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The exceptional circumstances of 2020 and 2021 resulted in funds being undesignated in order for the charity to continue its charitable objectives. The purposes and uses of the restricted funds and designated funds are set out in Note 17 to the financial statements.

1.16 Consolidated accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the companies' results and the investment the charity holds are shown separately in Note 12 to the financial statements.

1.17 Foreign currency translation

Foreign currency transactions are recorded at the exchange rate at the time of the transaction. Foreign currency assets and liabilities are translated into sterling at the exchange rate ruling at the balance sheet date. Resulting gains or losses on retranslation are included in the statement of financial activities.

1.18 Leases

Operating lease annual rental payments are charged to the statement of financial activities on a straight line basis over the term of the lease.

1.19 Termination payments

Termination payments either by way of redundancy or settlement agreement are recognised at the time of payment. Any payments exceeding the statutory minimum are authorised by the trustees.

2. Donations and legacies

	Unrestricted funds	Restricted funds	Total 2021	Unrestricted funds	Restricted funds	Total 2020
	£	£	£	£	£	£
Donations & gifts	1,758,535	105,013	**1,863,548**	1,438,777	157,348	1,596,125
Legacies receivable	8,148	4,431	**12,579**	219,678	37,500	257,178
Grants receivable	2,494,492	238,033	**2,732,525**	2,155,880	274,078	2,429,958
	4,261,175	347,477	**4,608,652**	3,814,335	468,926	4,283,261
Donations & gifts:						
Individual donations	1,469,207	94,482	**1,563,689**	1,189,520	128,112	1,317,632
Corporate donations	253,525	8,025	**261,550**	234,413	26,488	260,901
International donations	1,156	-	**1,156**	496	-	496
Events by individuals	34,647	2,506	**37,153**	14,348	2,748	17,096
	1,758,535	105,013	**1,863,548**	1,438,777	157,348	1,596,125
Grants receivable:						
Charitable trusts	61,093	238,033	**299,126**	82,962	274,078	357,040
Government grants	2,433,399	-	**2,433,399**	2,072,918	-	2,072,918
	2,494,492	238,033	**2,732,525**	2,155,880	274,078	2,429,958

Government grants consist of £809,812 (2020: £1,248,868) received under the Coronavirus Job Retention Scheme and £1,623,587 (2020: 824,050) received in local authority grants.

Gifts in kind of £87,206 (2020: £88,006) are included in donations and gifts. This comprises online adwords valued at £67,206 (2020: £67,206) and campaign design and consultancy valued at £20,000 (2020: £nil). In 2020 gifts in kind also included advertising in a national newspaper valued at £20,800.

Notes to the financial statements (continued)

3. Other trading activities

	2021	2020
	£	£
Income	**8,654,004**	7,025,873
Operating expenses	**(9,952,625)**	(10,227,464)
Net income from fundraising activities	**(1,298,621)**	(3,201,591)

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2021 there were 105 shops trading (2020: 109). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2021	Income	Operating expenses	Net income 2020
	£	**£**	**£**	£	£	£
Retail	7,911,357	(9,340,096)	**(1,428,739)**	6,477,316	(9,757,368)	(3,280,052)
Fundraising events	639,431	(612,529)	**26,902**	429,761	(470,096)	(40,335)
Miscellaneous trading	103,216	-	**103,216**	118,796	-	118,796
	8,654,004	(9,952,625)	**(1,298,621)**	7,025,873	(10,227,464)	(3,201,591)

Retail income excludes income of £732,522 (2020: £606,091) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail gift aid commission of £33,236 (2020: £84,619) which is recognised in miscellaneous trading. In 2020 and 2021 the COVID-19 pandemic had a significant impact on gross retail income. The profit covenanted by DEBRA Trading Limited of £69,980 (2020: £34,176) is recognised in miscellaneous trading.

The table below reflects a true statement of total retail income, including retail Gift Aid, commission and retail donations.

	2021	2020
	£	£
Income	**8,710,081**	7,168,026
Operating expenses	**(9,340,096)**	(9,757,368)
Net expenditure on fundraising activities	**(630,015)**	(2,589,342)

4. Investment income

	2021	2020
	£	£
Interest receivable	**3**	29,940
Rent of property	**14,561**	17,463
Total investment income	**14,564**	47,403

Rental income was received from one freehold shop and two flats situated above properties, which were acquired in 2009.

Notes to the financial statements (continued)

5. Grants payable

Expenditure on charitable activities include grants payable to third parties as detailed in Note 22. There were 179 (2020: 154) Community Support grants totalling £36,752 (2020: £38,071) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 22.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2021 the trustees had authorised a commitment to support research grants over the next three years to the sum of £548,814 (2020: £1,183,468) and clinical projects to the sum of £125,948 (2020: £138,105).

The total future commitment is currently committed to be spent as follows:

	Total 2021	Total 2020
	£	£
Within one year	**527,442**	722,099
Within two – three years	**147,320**	589,406
Within four – five years	**-**	10,068
Provided within the grants payable creditor (notes 14 and 15)	**674,762**	1,321,573

6. Expenditure

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	**Total 2021**
	£	£	£	£	£	**£**
Raising funds						
Donations & legacies	381,817	-	-	164,432	115,943	**662,192**
Other trading activities	5,338,778	-	61,319	314,047	4,238,482	**9,952,626**
	5,720,595	-	61,319	478,478	4,354,425	**10,614,818**
Charitable activities						
Research	274,861	168,806	-	31,262	9,555	**484,484**
Healthcare	60,235	172,668	-	19,858	-	**252,761**
Community support	607,601	36,752	-	42,710	-	**687,063**
Respite breaks	-	-	48,016	-	46,926	**94,942**
Public education	243,566	-	-	31,934	90,448	**365,948**
	1,186,263	378,226	48,016	125,765	146,929	**1,885,198**
	6,906,858	378,226	109,335	604,243	4,501,354	**12,500,016**

Notes to the financial statements (continued)

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	**Total 2020**
	£	£	£	£	£	**£**
Raising funds						
Donations & legacies	415,507	-	-	174,569	118,122	**708,198**
Other trading activities	5,703,336	-	78,022	301,865	4,144,241	**10,227,464**
	6,118,843	-	78,022	476,434	4,262,363	**10,935,662**
Charitable activities						
Research	339,024	572,731	-	38,798	230,545	**1,181,098**
Healthcare	80,880	241,967	-	23,990	-	**346,837**
Community support	651,422	38,072	-	56,432	-	**745,926**
Respite breaks	-	-	48,016	-	45,451	**93,467**
Public education	367,838	-	-	43,441	69,159	**480,438**
	1,439,164	852,770	48,016	162,661	345,155	**2,847,766**
	1,439,164	852,770	126,038	639,095	4,607,518	**13,783,428**

Net income / (expenditure) for the year is stated after charging:

	2021	2020
	£	£
Operating leases	1,246,982	1,279,426
Auditors' remuneration	20,000	19,313
Non-audit services	3,600	-
Depreciation of tangible fixed assets	159,256	158,451
Defined contribution pension costs	314,405	345,016
Exchange differences	27,809	(20,916)

7. Cost allocation

All central overhead costs are allocated to activities on the basis of staff time, and are detailed below:

	2021	2020
	£	£
Staff costs	**1,403,077**	1,521,167
Overheads		
Office premises rent	**62,789**	62,891
Service charges, utilities & cleaning	**57,363**	57,788
Equipment costs	**144,088**	148,634
Postage, printing, stationery, telephone & fax	**64,585**	54,502
Insurance costs	**110,401**	97,435
Legal, professional & consultancy fees	**139,356**	135,198
Depreciation	**38,017**	36,829
Profit on disposal	**(143,660)**	-
Irrecoverable VAT	**22,348**	24,216
Bank charges	**9,744**	6,755
Sundry expenses	**58,201**	(8,681)
Governance costs:		
Audit, non-audit and internal audit fees	**38,600**	19,313
Miscellaneous costs	**2,411**	4,215
	604,243	639,095
Total allocation	**2,007,320**	2,160,262

Notes to the financial statements (continued)

8. Trustees

None of the trustees received any remuneration from DEBRA during the period, but one of them was reimbursed a total of £127 (2020: 9 – £2,259) for travel expenses. No trustees received community grants in 2021 (2020: Andy Grist received £15). The aggregate figure for trustee donations in 2021 was £447 (2020: £2,158). In addition, many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £4,025 (2020: £2,253), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9. Employees

The average number of employees during the period was:

	2021	**2021**	2020	2020
	No.	**FTE**	No.	FTE
Research	**1**	**1.0**	5	2.9
Healthcare*	**-**	**-**	-	-
Community Support	**13**	**12.3**	12	11.2
Fundraising & Comms	**16**	**15.8**	20	18.2
Retail	**299**	**216.4**	321	232.5
Management & Administration	**19**	**17.6**	18	15.7
	348	**263.1**	376	280.5

At the end of the year the number of employees per department was:

	2021	**2021**	2020	2020
	No.	**FTE**	No.	FTE
Research	**1**	**1.0**	4	1.6
Healthcare*	**-**	**-**	-	-
Community Support	**13**	**12.0**	10	9.7
Fundraising & Comms	**16**	**15.6**	19	17.2
Retail	**304**	**222.2**	304	221.6
Management & Administration	**22**	**19.2**	16	14.2
	356	**270.0**	353	264.3

*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 19.

Staff employed by external institutions and funded through research grants are also excluded.

	2021	2020
	£	£
Wages & salaries	**5,960,400**	6,231,757
Social security costs	**392,291**	395,899
Pension costs	**314,405**	312,098
Total allocation	**6,667,096**	6,939,754

Notes to the financial statements (continued)

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £338,399 (2020: £313,959) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £nil (2020: £24,016) unpaid.

There are adequate systems in place to manage expenses and they do not form part of remuneration.

The following members of staff received emoluments above £60,000:

	2021	2020
	No.	No.
Between £60,001 - £70,000	**3**	3
Between £70,001 - £80,000	**1**	-
Between £80,001 - £90,000	**-**	2
Between £110,001 - £120,000	**1**	-
Between £170,001 - £180,000	**-**	1

Redundancy and compensation payments, which were all paid in year, totalled £16,739 (2020: £160,487).

The aggregate pay of key management personnel, including employer's NI and pension contributions was £711,022 (2020: £736,268). The aggregate employer's pension contribution for key management personnel was £61,489 (2020: £59,304)

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £59,064 (2020: £53,246), and there are retirement benefits accruing for five (2020: six) employees under a defined contribution scheme.

10. Fixed assets

Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land & buildings	Long leasehold land & buildings	Total
	£	**£**	**£**	**£**	**£**	**£**
Cost:						
At 1 January 2021	437,742	480,162	321,118	578,347	82,500	1,899,869
Additions	13,858	-	77,916	-	-	91,774
Disposals	(89,460)	-	(3,991)	-	-	(93,451)
At 31 December 2021	**362,140**	**480,162**	**395,043**	**578,347**	**82,500**	**1,898,192**
Depreciation:						
At 1 January 2021	284,949	197,599	165,027	154,548	19,800	821,923
Charge for the year	56,840	48,016	40,231	12,879	1,650	159,256
Disposals	(88,268)	-	(3,991)	-	-	(92,259)
At 31 December 2021	**253,161**	**245,615**	**201,267**	**167,427**	**21,450**	**888,920**
Net book value:						
1 January 2021	152,793	282,563	156,091	423,799	62,700	**1,077,946**
31 December 2021	**108,979**	**234,547**	**193,776**	**410,920**	**61,500**	**1,009,272**

The Head Office fit out costs and mobile equipment have been included in the fixtures, fittings and equipment category.

The trustees agreed to sell one freehold shop during 2019, and a flat above another shop in 2020. These were transferred to current assets in 2020. The flat was sold in October 2021 and the freehold shop was sold in January 2022.

Notes to the financial statements (continued)

11. Programme related investment

	2021	2020
	£	£
Investment in Fibrx Derm Inc		
Net investment value brought forward	**1**	-
Purchase of investment	**-**	190,840
Impairment charge	**-**	(190,839)
Net investment value carried forward	**1**	1

The trustees invested £190,840 ($250,000) in Fibrx Derm Inc, a US biotech company, purchasing 203,252 series A-2 convertible preferred stock, at a price of $1.23 per share. This investment supported the development of a new treatment to help wound healing in patients suffering from Dystrophic Epidermolysis Bullosa. The purpose of this investment was in furtherance of the charitable objectives of the charity, and no financial return was expected. The value of the investment has been impaired by 99.99% as the most prudent course of action.

12. Investment in subsidiaries

DEBRA had two 100% owned subsidiary companies incorporated in England and Wales at 31 December 2021 (2020: two). These are DEBRA Trading Ltd (company number: 2487114), whose principal activities are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship; and DEBRA Retail Ltd which is dormant.

Financial information for these entities for the year ended 31 December 2021:

	2021		2020	
	DEBRA Trading Ltd	**DEBRA Retail Ltd**	DEBRA Trading Ltd	DEBRA Retail Ltd
	£	**£**	£	£
Share capital	**2**	**1**	2	1
Turnover	**119,267**	**-**	96,247	-
Total expenses	**49,287**	**-**	62,070	-
Gift aid to DEBRA	**69,980**	**-**	34,176	-
Profit / (loss) for the year	**-**	**-**	-	-
Net assets / (liabilities)	**2**	**1**	2	1

13. Debtors

	2021	2020
	£	£
HMRC	**174,344**	281,158
Amounts due from group undertakings	**69,980**	34,176
Other debtors	**489,879**	402,321
Accrued income	**681,184**	363,233
Prepayments	**527,501**	535,731
	1,942,888	1,616,619

Amounts due from HMRC are VAT receivable of £174,344 (2020: £216,811), plus £nil (2020: £64,347) from the Coronavirus Job Retention Scheme. Other debtors includes £301,908 (2020: £266,825) due for shared research grants. Accrued income includes gift aid of £344,460 (2020: £147,660) due from HMRC.

Total future minimum lease receivable in 2021 was £nil (2020: £3,413), in respect of one shop and one flat above a shop.

14. Creditors: amounts falling due within one year

	2021	2020
	£	£
Trade creditors	**427,092**	678,754
Grants payable	**2,236,649**	2,158,657
Other creditors	**220,134**	308,617
Taxation and social security	**113,353**	92,476
Accruals	**845,920**	917,315
Deferred income	**18,670**	26,900
	3,861,818	4,182,719

Grants payable includes £548,832 (2020: £790,811) relating to future commitments and £1,687,817 (2020: £1,436,558) relating to outstanding invoices for work done.

There was deferred income in 2021 of £18,670 (2020: £26,900), representing income for events which would have to be repaid in the event of cancellation.

Notes to the financial statements (continued)

15. Creditors: amounts falling due over one year

	2021	2020
	£	£
Grants payable	**147,320**	599,474
	147,320	599,474

	2021	2020
	£	£
Dilapidations provision		
Provision brought forward	**181,808**	241,812
Charges	**6,140**	21,420
Release of provision	**-**	(81,422)
Provision carried forward	**187,948**	181,808

16. Other financial commitments

The following payments are committed to be paid in the future in respect of operating leases:

	2021	2020	2021	2020
	Leases of land and buildings	Leases of land and buildings	**Other**	Other
	£	£	**£**	£
Within one year	**1,233,867**	1,264,152	**13,115**	15,274
Between one – five years	**1,539,926**	1,170,587	**16,217**	29,332
After five years	**-**	5,250	**-**	-
	2,773,793	2,439,989	**29,332**	44,606

There were capital commitments of £nil (2020: £1,200) at year end, falling due within one year.

17. Analysis of funds: restricted funds

	Balance at 1 January 2021	Income	Expenditure	Transfer to general fund	**Balance at 31 December 2021**
	£	£	£	£	**£**
Research	-	176,067	(118,065)	(408,342)	**(350,340)**
Healthcare	5,600	30,362	(15,337)	-	**20,625**
Community support & respite	70,943	153,993	(147,171)	-	**77,765**
Public Education	-	-	-	-	**-**
	76,543	360,422	(280,573)	(480,342)	**(251,950)**

	Balance at 1 January 2020	Income	Expenditure	Transfer to general fund	**Balance at 31 December 2020**
	£	£	£	£	**£**
Research	-	182,771	(104,103)	(78,668)	**-**
Healthcare	79,477	26,223	(100,100)	-	**5,600**
Community support & respite	134,099	292,599	(355,755)	-	**70,943**
Public Education	-	13,824	(13,824)	-	**-**
	213,576	515,417	(573,782)	(78,668)	**76,543**

Notes to the financial statements (continued)

Restricted funds comprised:

	2021	2020
	£	£
Healthcare - EB nurses	**15,025**	-
Healthcare - Birmingham Children's Hospital Specialist Bath	**5,600**	5,600
Community Support - Community Support Manager for Scotland	**21,542**	37,259
Community Support - Community Support Manager Post	**-**	10,496
Community Support - Community Support in Bedfordshire	**5,121**	-
Community Support - Community Support in Berkshire	**8,037**	8,048
Community Support - Support Grants in Hampshire	**5,502**	5,502
Community Support - Support Grants in Northamptonshire	**-**	962
Community Support - Support Grants in Scotland	**1,934**	1,934
Community Support - Support Grants in South East England	**15,851**	-
Community Support - Support Grants in South Gloucestershire	**1,054**	1,356
Community Support - other restricted funds	**18,724**	5,386
	98,390	76,543
Less:		
Research - COVID Medical Research Charity Support Fund*	**(350,340)**	-
Net restricted funds	**(251,950)**	76,543

*An agreement was signed with the Medical Research Council who agreed to provide funding for specific research projects already in progress. The funds were received in 2022. The related costs were recognised in the income statement and charged to the general fund on grant award in accordance with DEBRA accounting policies. Therefore, a transfer from restricted funds to general funds is required in 2021 representing spend already incurred.

18. Analysis of funds: unrestricted funds

	Balance at 1 January 2021	Income	Expenditure	Transfers	**Balance at 31 December 2021**
	£	£	£	£	**£**
Future research grants	515,950	-	-	(515,950)	**-**
Nursing continuity	250,000	-	-	-	**250,000**
IT Strategy	-	-	-	50,000	**50,000**
Procurement	-	-	-	50,000	**50,000**
NHS Digital	-	-	-	200,000	**200,000**
Total designated funds	765,950	-	-	(215,950)	**550,000**
General fund	2,138,497	12,956,979	(12,219,443)	624,292	**3,500,325**
Total unrestricted funds	2,904,447	12,956,979	(12,219,443)	408,342	**4,050,325**

	Balance at 1 January 2020	Income	Expenditure	Transfers	**Balance at 31 December 2020**
	£	£	£	£	**£**
Future research grants	2,618,290	-	(763,340)	(1,339,000)	**515,950**
Nursing continuity	250,000	-	-	-	**250,000**
EB:2021 Conference	38,467	75,771	(58,211)	(56,027)	**-**
Total designated funds	2,906,757	75,771	(821,551)	(1,395,027)	**765,950**
General fund	2,231,188	10,821,809	(12,388,095)	1,473,695	**2,138,497**
Total unrestricted funds	5,137,945	10,897,480	(13,209,646)	78,668	**2,904,447**

The future research grants fund was fully un-designated in 2021 in response to the COVID-19 Pandemic. The trustees resolved in October 2021 that the historical practice of designating all amounts in excess of minimum required cash-backed free reserves for future research would not be re-established. Instead, funds would be designated for specific project opportunities envisaged within the overall Five-Year Strategy. In 2021 £200,000 (2020: £nil) has been designated to fund the NHS Digital Data project for two years.

Notes to the financial statements (continued)

The designated fund for nursing continuity has been established as a contingency in the event of future NHS funding withdrawal, and the Trustees maintained a balance of £250,000 in this fund in 2021.

Two amounts of £50,000 (2020: £nil) was designated in 2021 to fund procurement and IT work furthering modernisation of back office practices as set out in the Two-Year Business Plan.

19. Analysis of net assets between categories of funds

Fund balances at 31 December 2021 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	**Total**
	£	**£**	**£**	**£**
Fixed assets	1,009,275	-	-	**1,009,275**
Current assets	6,688,136	550,000	(251,952)	**6,986,186**
Creditors:<1 year	(3,861,810)	-	-	**(3,861,818)**
Creditors:>1 year	(335,268)	-	-	**(335,268)**
	3,500,325	550,000	(251,952)	**3,798,375**

Fund balances at 31 December 2020 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	**Total**
	£	£	£	**£**
Fixed assets	1,077,949	-	-	**1,077,949**
Current assets	6,024,549	765,950	76,543	**6,867,042**
Creditors:<1 year	(4,182,719)	-	-	**(4,182,719)**
Creditors:>1 year	(781,282)	-	-	**(781,282)**
	2,138,497	765,950	76,543	**2,980,990**

20. Reconciliation of net income to net cash flow from operating activities

	2021	2020
	£	£
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	**817,385**	(2,370,531)
Depreciation and amortisation charges	**159,256**	162,872
Impairment of programme related investment	**-**	190,839
Dividends, interest and rents from investments	**(14,564)**	(47,403)
Profit / (loss) on disposal of fixed assets	**(143,663)**	(6,777)
Decrease in stock	**4,589**	390
(Increase) / decrease in debtors	**(326,269)**	310,082
(Decrease) / increase in creditors	**(766,914)**	394,057
Net cash used in operating activities	**(270,182)**	(1,366,471)

20 Analysis of cash and cash equivalents

	At 1 January 2021	Cash flows	**At 31 December 2021**
	£	£	**£**
Cash at bank and in hand	5,076,553	(108,743)	**4,967,810**
	5,076,553	(108,743)	**4,967,810**

An analysis of changes in net debt note has not been prepared on the basis that DEBRA only has cash and cash equivalents, the movement on which is shown above.

Notes to the financial statements (continued)

22. Grants to institutions

Research grants:

	2021		2020	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
University of Dundee				
Clinical fellow funding	146,115	650,589	89,572	504,474
University of Glasgow				
Re TGF-beta mediated tumour promotion in RDEB	64,001	221,139	78,525	157,138
Guy's and St Thomas' Hospital, London				
Clinical endpoints study re EB therapy evaluation	160,956	694,557	120,717	533,601
Stem cell therapy trial re treating debilitating itch	31,946	497.360	113,262	465,414
Wound care and its complications in patients with EB	-	-	-	-
	192,902	1,191,917	233,979	999,015
Thomas Jefferson University, Philadelphia, USA				
Phase 2 clinical trial of Rigosertib for RDEB SCC	-	470,490	40,984	470,490
Univ. Birmingham Dental School & Hospital				
Characterisation of skin microbiome in EB patients	31,359	296,289	113,500	264,930
Gait Analysis in EB Simplex	15,344	15.344	(11,508)	-
Clinical Fellowship	30,622	65,736	35,114	35,114
Novel spray to treat mucosal scarring	76,201	101,607	25,406	25,406
	153,526	478,976	162,512	325,450
University of Cologne				
Re immunity in wound healing complications RBEB	23,688	164,706	57,462	141,018

Grants to institutions continued:

	2021		2020	
	Total paid in year	**Total paid to date**	Total paid in year	Total paid to date
	£	**£**	£	£
Universitair Medisch Centrum Groningen				
Re phyto-cannabinoid treatment of pain in EB	-	159,025	47,300	159,025
Instituto Dermopatico deli'Immacolata Rome				
Re histone deacetylase inhibitors for RDEB	4,627	64,407	32,739	59,780
King's College London				
Preclinical studies of lentiviral-mediated COL7A1 gene therapy	43,394	188,583	84,044	145,189
Great Ormond Street Institute of Child Health				
Respiratory cell & gene therapy for children with JEB	65,844	65,844	-	-
Bambino Gesù Children's Hospital				
MicroRNAs expression profiling, activity and therapeutic perspectives	30,876	45,556	14,680	14,680
University of Edinburgh				
Re Kindlin-1 loss in squamous cell carcinoma	41,379	51,667	10,288	10,288
New York Medical College				
Re innate & adaptive immune mechanisms in RDEB	69,588	104,232	34,644	34,644
Total research grants paid in year	835,941	3,857,132	886,719	3,021,191

Notes to the financial statements (continued)

Healthcare projects:

	2021 Total paid in year	2020 Total paid in year
	£	£
Great Ormond Street Hospital for Sick Children		
Clinical nurse specialists in EB	83,525	66,176
Guys & St Thomas' Hospital London		
Adult EB support nurses	58,388	79,647
Clinical best practice guidelines on parenteral and enteral feeding	-	39,996
Birmingham Children's Hospital	30,755	56,148
Other	12,157	48,108
	184,825	290,075

Reconciliation of provision:

	2021			
	Research grants	Healthcare grants	Community Support grants	Total
	£	£	£	£
Provision brought forward	1,183,468	138,105	-	1,321,573
New commitments	168,806	172,668	(36,752)	378,226
Co-funding contributions	32,481	-	-	32,481
Spend in year	(835,941)	(184,825)	(36,752)	(1,057,815)
Provision carried forward	548,814	125,948	-	674,762

Reconciliation of provision continued:

	2020			
	Research grants	Healthcare grants	Community Support grants	Total
	£	£	£	£
Provision brought forward	1,428,243	186,213	-	1,614,456
New commitments	572,731	241,967	(38,072)	852,770
Co-funding contributions	69,213	-	-	69,213
Spend in year	(886,719)	(290,075)	(38,072)	(1,214,866)
Provision carried forward	1,183,468	138,105	-	1,321,573

23. Related parties

During the year, the charity charged management charges totalling £11,300 including VAT (2020: £7,200) to its subsidiary, DEBRA Trading Limited.

Reference and administrative details

Patrons and ambassadors

Royal Patron
HRH The Countess of Wessex

Life Patron
Philip Evans

President
Simon Weston CBE

Vice Presidents
Graeme Souness, Frank Warren

Trustees

Chair
Jim Irvine

Treasurer
Joanne Merchant

Vice-Chairs
David Bendor-Samuel (from 29.04.2021),
Carly Fields
Graham Marsden (until 29.04.2021)

Trustees
Simone Bunting (from 27.05.2021)
Rebecca Cresswell
Simon Cuzner (until 27.05.2021
Josie Godfrey (from 08.08.2021)
Andrew Grist (until 01.03.2022)
Christo Kapourani
Vivien Mundy
Timothy Powell (until 27.05.2021)
Douglas Rouse
Simon Talbot (from 27.05.2021)
Michael Thomas

Additional details

Charity Commission Number
1084958

OSCR Number
SC039654

Company Number
4118259

Registered office & principal address
DEBRA, The Capitol Building, Oldbury, Bracknell, RG12 8FZ

Auditor
Sayer Vincent LLP, Invicta House, 108-114 Golden Lane, London EC1Y 0TL

Banker
HSBC, Thames Valley Business Banking, Hanborough House, Wallbrook Court, North Hinksey, Oxford, OX2 0QS

Solicitor
Stone King, 91 Charterhouse Street, London, EC1M 6HR

Abbreviations

CPG	Clinical Practice Guideline
CEO	Chief Executive Officer
EB	Epidermolysis Bullosa
EDI	Equality, Diversity & Inclusion
F&E	Furniture & Electrical retail store
GDPR	General Data Protection Regulation
HMRC	HM Revenue and Customs
HR	Human Resources
H&S	Health & Safety
IOSH	Institute of Occupational Safety and Health
IT	Information Technology
k	thousand
m	million
NHS	National Health Service
pa	per annum
SMT	Senior Management Team
SOFA	Statement of Financial Activities
y on y	year on year

DEBRA funds pioneering research, specialist healthcare, international best practice and lifelong care and support to the EB Community.

Our vision is a world where no one suffers with Epidermolysis Bullosa (EB).

Together we #FightEB.

www.debra.org.uk

Patron: HRH The Countess of Wessex GCVO

01344 771961 | debra@debra.org.uk | DEBRA, The Capitol Building, Oldbury, Bracknell, Berkshire RG12 8FZ

Registered with FUNDRAISING REGULATOR

amrc ASSOCIATION OF MEDICAL RESEARCH CHARITIES

DEBRA A charity registered in England and Wales (1084958) and Scotland (SC039654)
Company limited by guarantee registered in England (4118259). VAT Number 689 2482 79

DEBRA

England & Wales - Charity number 1084958

Accounts

Trustees' Annual Report and Accounts 2020

Company limited by guarantee registered in England and Wales (4118259).

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Our vision

A world where no one suffers from the painful skin condition Epidermolysis Bullosa (EB)

Our mission

Provide lifelong care and support to everyone in the UK affected by EB

Our aims

Fund pioneering research for symptom alleviation and ultimately a cure

Provide care and support to the entire EB community

Together we #FightEB

Investing in a future free of EB

DEBRA UK funds:

- Specialist healthcare
- Pioneering research
- Community support
- International best practice

What we do

DEBRA is the national charity supporting those living with or directly affected by EB. We have achieved global recognition as a leader on EB and are the only UK charity specifically aimed at continuously supporting the EB community.

Phyllis Hilton, whose daughter Debra had EB, set up the charity in 1978 as the world's first EB patient support group. We have come a long way since then, working internationally through a network of nearly 50 DEBRA groups to share information and best practice.

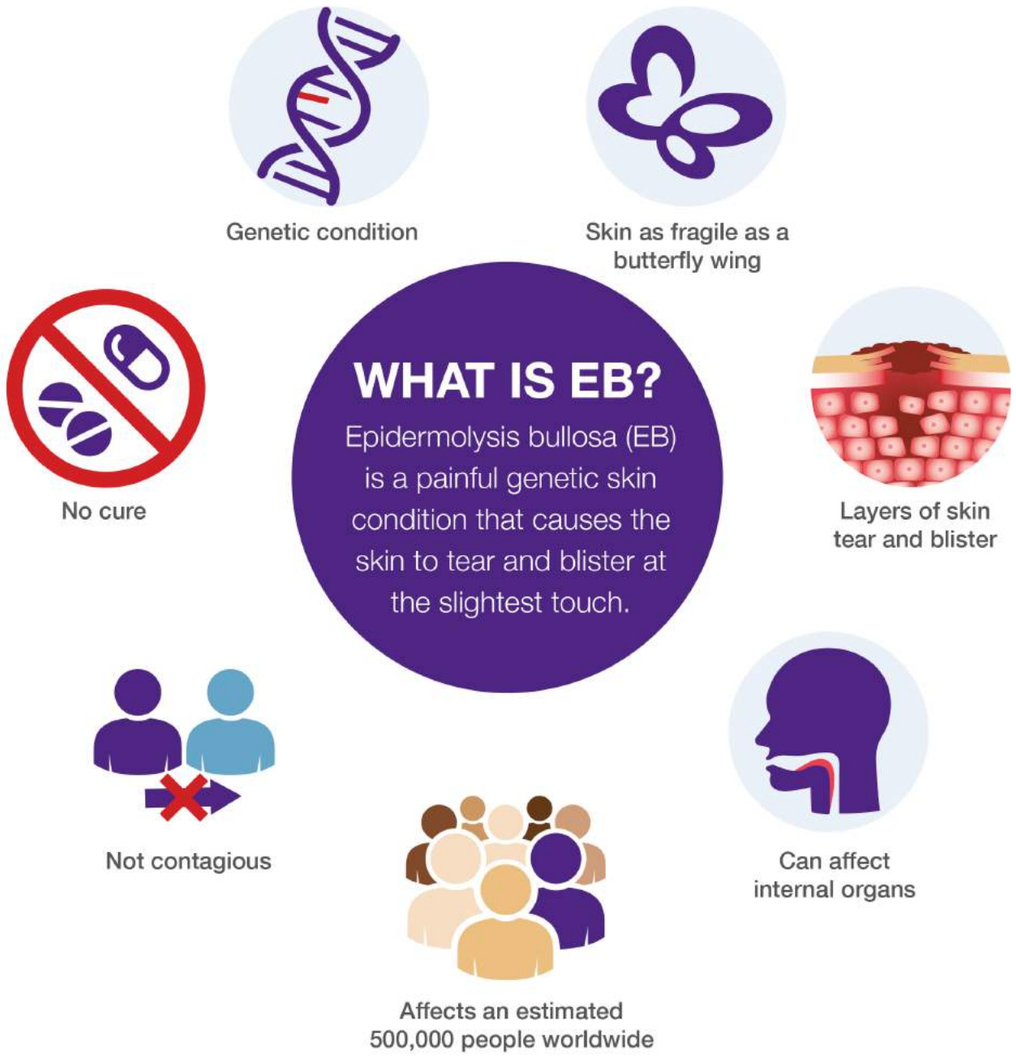
We fund pioneering research, provide specialist healthcare, promote best practice and deliver lifelong support to individuals, families and the entire EB community. Our support includes:

- providing practical, financial and emotional support and advocacy for people with EB and their families
- partnering with the NHS to provide specialist care and clinical care guidelines
- working with researchers to find a cure(s) and alleviate the debilitating effects of living with EB
- investing in our Community Support Team to allow us to share knowledge, skills and experience to empower and enable achievements within the EB community
- expanding and strengthening family health and community support networks to improve quality of care.

Supporting DEBRA – through fundraising activities, direct donations, purchasing items in the retail shops or offering time as a volunteer – has a direct impact on the support we offer the EB community.

While our vision is for a future where no one suffers from EB, until that day arrives we work tirelessly to improve quality of life for the entire EB community.

What is EB?



EB is a potentially fatal skin condition that causes constant pain due to continuous internal and external blistering. With EB, skin is so fragile that it can tear at the slightest touch and for this reason it is sometimes called ‘butterfly skin’. There are an estimated 5,000 people affected by EB in the UK and 500,000 worldwide.

In its most severe forms, EB is fatal; even in its mildest forms it can cause lifelong disability and pain. Blisters continuously form and have to be drained and dressed daily, a painful process that can take several hours. Repeated blistering results in the build-up of scar tissue which can cause fingers and toes to fuse together and can mean a higher risk of developing skin cancer. The debilitating effects of EB inevitably impact the mind as well, leading to psychological challenges. EB is currently incurable.

Strategic report

Highlights of DEBRA’s services and income generation activities in 2020 and an overview of future plans

Welcome from our Chair

When I was preparing my statement for last year's (2019) Annual Report we were in the early days of coping with the coronavirus pandemic and had just entered the first UK national lockdown. I said then that "the outcomes are currently uncertain and they will ultimately shape our ambitions for the years ahead" and "we are financially strong and fully expect to come through the crisis fully intact". None of us had any real idea back then about how big an impact COVID-19 would, and continues to, have but twelve months on we can start to have a level of optimism that the worst might well be behind us, allowing us to focus on the future once more.

I am delighted to report that, despite a significant hit to our financial strength during 2020, our objectives are unchanged. DEBRA continues to focus on improving the quality of life for those living with all types of EB as we invest in world-leading research towards finding cures.

Our financial strength allowed us to meet our existing research commitments and during the year we approved a further spend of £764,000 on some exciting new projects including investing £191,000 into the biopharmaceutical company FIBRX Derm Inc. Meanwhile, our wonderful Community Support Team had to adapt and learn almost overnight how to provide care remotely. Retail income took a hammering and, with over 300 retail staff and significant lease commitments to meet, we were hugely grateful for the various levels of government support that allowed us to keep our portfolio intact. Fundraising from events had a great start to the year and despite being seriously curtailed from March still managed some real successes. We made real progress in legacies with growth from £185,000 in 2019 to £257,000 in 2020.

I was hugely disappointed that we had to cancel our Members' Weekend in 2020 but the safety of our community dictated that we had no option. We are committed to restarting that event, and others, when it is safe to do so but in the meantime we will continue to embrace technology that allows us to engage remotely with our community.

The year had started in spectacular fashion with the EB 2020 World Congress, hosted and primarily funded by DEBRA, in London during January. With 730 delegates representing 215 organisations from 54 countries, it was by far the largest gathering of EB community, professionals and bio-pharma companies that has ever taken place. The conference was a huge success and it is worth reflecting on just how far DEBRA has come since being established as a parent support group in 1978. Under the guidance and governance of our Trustees and with the leadership of our new CEO, Tony Byrne, we are all committed to playing a leading role in collaborating internationally to #Fight EB.

My closing words from last year's statement reflected on the fantastic support we receive from our army of volunteers and the resilience and strength of character of the entire EB community. Those words resonate as loudly today as they did then as we seek to find our 'new normal' and continue to fight, and ultimately beat, EB.

Jim Irvine
Chair of Trustees

Welcome from our CEO

I was delighted to join DEBRA in October 2020, an 'interesting' time to join any organisation. The UK had already undergone one major lockdown and many of DEBRA's team members were working from home or furloughed. In November and then at the end of December we entered the second and third lockdowns, however I was still able to meet team members and the EB community during this time. Most, if not all, meetings have been conducted virtually and I have been impressed by how DEBRA and our members have utilised technology, adapted and met the challenges of the pandemic.

The year has been difficult for our members, colleagues, volunteers and supporters. It has been financially challenging, with our sources of income severely curtailed from the closure of our retail stores and the cancellation and postponement of our fundraising events.

We have been grateful for the continued support of our donors, the support of our fundraisers and the donations received from the limited events we have been able to run in a Covid-safe manner. The DEBRA team have risen to the challenge, with at times over 90% of the team furloughed either full or part-time. They have in these uncertain times worked tirelessly for the benefit of our members.

Our priority focus has always been to support those affected by EB.

Our Community Support Team have reached out to our members through individual phone calls, and virtually via online platforms and through social media, ensuring information and support is always available. We continued to invest £839,000 in membership and community support activities in 2020.

We continued our support for EB nurses with up to 25% of their costs being met by DEBRA and supporting healthcare with a further investment of £347,000.

Our funding of research into cure and care did not cease in 2020: we invested £1.181m in our continued search for answers to cure this terrible condition.

As we look to the future, we have introduced a Management and Performance (MAP) process which aligns our objectives to our business plan and gives clarity and focus on what and how we are delivering against our goals.

We are undertaking a review of our IT systems, our policies and procedures and the way we support and listen to our members and our teams. Our aim is to learn from the pandemic, understanding how it affected the way we work. We will apply this learning to improve our ways of working, to improve how we support our members, colleagues, volunteers and supporters, to help us find better treatments for the care of our members and, ultimately, to find the cure our members need to #FightEB.

Finally, we look back with gratitude. We are so proud of how our staff and volunteers worked together throughout 2020. Our heartfelt thanks go to them, to the extraordinary generosity and commitment of our supporters, the brilliant community of EB specialists and healthcare professionals and, above all, the individuals and families living with EB. Thank you.

Together we will continue to #FightEB in 2021.

Tony Byrne
CEO

Charity overview

DEBRA is the national charity (incorporated in the UK) supporting everyone in the UK affected by EB. We are registered with the Charity Commission for England and Wales, as well as the Office of the Scottish Charity Regulator (OSCR) in support of our Scottish activities that continue to form an important part of DEBRA's UK strategy. The financial statements comply with current statutory requirements, the memorandum and articles of association, the requirements of a directors' report as required under company law, and the Statement of Recommended Practice - Accounting and Reporting by Charities: SORP applicable to charities preparing their accounts in accordance with FRS 102.

Like many charities, our income from our retail shops, fundraising and Gift Aid was affected by the pandemic. Despite this, throughout the year our amazing supporters, volunteers and staff gave us unwavering support. We receive no statutory government funding, but we were able to take full advantage of government incentives such as the Coronavirus Job Retention Scheme.

Our objectives

The 2021-22 Business Plan sets DEBRA's course for the next two years, ensuring it remains on a solid financial footing. In parallel, the Trustee Board and Senior Management Team are charting an ambitious five-year strategy to deliver some significant goals by 2026 including:

- playing a pivotal role in coordinating research into EB, a global exercise with DEBRA front and central in leading the quest for a cure
- reconfiguring how we will care for our members, ensuring they are centremost in our long-term plans
- refocusing our fundraising efforts, recognising that the short and long-term effects of the pandemic mean that there will be less reliance on events and more reliance on building long-term relationships
- building a more efficient and leaner retail function
- increasing brand awareness across all of our audiences
- continuing to develop the skills and knowledge of our people
- ensuring that our operations, governance and risk management are best in class.

Public benefit

DEBRA meets the definition of a public benefit entity under FRS102, s17 of the Charities Act 2011 and Charity Commission and OSCR guidelines. We provide support to people across the UK living with any type of EB, as well as family members and carers of someone who has EB and those working within the EB community in a professional capacity.

Members affected by EB are encouraged to engage with us to further develop our services and the support available. This includes through taking part in satisfaction and service development surveys, group discussions as well as the DEBRA patient panel made up of members of the EB community who help review research projects.

Our Care & Research Committee makes strategic and fundamental recommendations on the charitable activities undertaken by DEBRA for the benefit of sufferers of any type of EB.

The Trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning its future activities. In particular, the Trustees consider how planned activities will contribute to the aims and objectives that have been set.

"My son Jamie has generalised severe EB. He was born with no skin on his feet, knees and hands and even where there was intact skin, it blistered. It was so hard to bond - I didn't hold my baby for the first six months. He is the first person in my family to have EB so it came as an enormous shock.

The most difficult thing about EB is seeing your child in pain, knowing that the care you are giving is causing so much distress. The community support I have received from DEBRA has been outstanding and makes a real difference."

Katie White, mother of Jamie White living with EB

In 2017 Simon and Karen Talbot lost their son Dylan to Junctional EB aged 3 months and 1 day.

“In 2018, we learnt Karen was pregnant. EB is inherited and we were both carriers of the gene and this meant it was likely our baby would have the same type of EB Dylan had. Thanks to advances in EB research and funding from DEBRA, we were able to test our baby for EB before she was born. Knowing we would not have to see our new-born go through the same pain and distress Dylan did was a massive relief. Our baby girl was born on 4 November 2018, EB free. We named her Katie Rose Talbot after the EB Nurse Specialist at Great Ormond Street Hospital – Katie Plevey. She was such a big part of family life with Dylan that we wanted her to be forever part of our family. Rose is also Dylan’s birth month flower, so her name is very special.”

Simon & Karen Talbot, EB parents

Pioneering research

Despite concerns surrounding the pandemic, we were able to approve a total of £764,000 for research projects in 2020, spending £573,000 on new research projects and investing £191,000 into the biopharmaceutical company FIBRX Derm Inc., which is researching an EB therapy.

We continue to be strategically focused on investing in pioneering research to find cures and treatments for EB that will significantly improve quality of life.

Research strategy

Our research strategy of striving to achieve cures, manage symptoms and improve quality of life has been maintained within the expanding global focus on EB research. We continue to invest in research into clinical, scientific and pharmacoeconomic endpoints that will support the regulatory pathways for treatment approvals in the future.

The current portfolio of research projects includes pre-clinical laboratory work, research into gene and cell therapies and drug re-purposing, as well as projects driving a change in symptom relief for wound healing and cancer therapy. It is critical to ensure there is a balance of research into all types of EB represented in our community. We also support fellowships, helping to develop and shape our researchers and clinical experts for the future.

Key areas

Developing a novel gene technology for EBS treatment

We are proud to continue funding the ongoing work by researchers at the University of Dundee, including a DEBRA Clinical Research Fellow. This pre-clinical study aims to develop methods for using gene silencing technology as a therapeutic option in clinic for people with Epidermolysis Bullosa Simplex (EBS). There are also hopes for wider application for other types of EB.

Defining relevant clinical endpoints

Since 2013, we have committed £735,000 to a project that aims to better understand the progression of Recessive Dystrophic EB (RDEB) by identifying and defining relevant clinical endpoints that could be measurable target outcomes for EB clinical trials. This work is ongoing, and it is hoped that it will ultimately help future clinical trials for all types of EB.

Investing in industry for potential treatments

In 2020, we made our first investment into a biotechnology firm, FIBRX Derm Inc. in support of a study that aims to continue research (originally funded by DEBRA) investigating a naturally occurring protein that may serve as a viable anti-scarring therapy for people living with DEB (Dystrophic EB) and which could be administered topically. The company has received financial support from the US Department of

Defense and multiple EB groups across the world, supporting our desire to take the lead in international collaboration.

Understanding immunity and fibrosis

DEBRA UK and DEBRA Ireland have committed to co-funding research to evaluate the inflammatory response in people living with RDEB. This study is investigating the sequence of immune responses to understand how chronic inflammation and fibrosis develop with the aim of identifying potential treatment options.

Understanding cell behaviour to help determine potential therapies

Ongoing research funded by DEBRA UK aims to understand the mechanism of how TGF-ß (protein) signalling can lead to cancer migration, invasion and tumour growth, as well as identify how the molecular characteristics (biomarkers) of TGF-ß behave in RDEB skin cancer, both of which may help to determine potential therapies.

Driving research globally

The EB World Congress, the flagship global conference on EB, was organised and majority funded by DEBRA UK with contributions from other EB groups. It was held in London at the end of January 2020 and attended by more than 700 individuals including key stakeholders from industry, researchers, clinicians, patients and EB groups. The inaugural Congress was more than double the size of any previous international EB research/care conference. The data presented represented the latest in research and clinical management. All other EB research funding bodies participated and over 20 biotechnology companies sponsored and attended the meeting, all with a focus on cures, treatment and management strategies for the EB community.

We welcome partnerships and collaboration with other EB organisations under the mutual aims of finding cures for the EB community. Communication and coordination are critical to the success of continued international research projects, both in direction and funding.

2020 Research by numbers

- £573,000 committed to new research projects
- £608,000 spent on other research activities
- £191,000 invested in a biotech company
- 19 ongoing research projects funded by DEBRA UK
- £8.1m spent on research grants over the last 10 years
- 7 projects co-funded with other DEBRA groups and one with a pharmaceutical company

Looking to the future

We recognise that the support of a wide range of research into cures and treatment is critical to achieving our aims. As such, we will continue to use expert summits to identify new research opportunities. Due to the pandemic, we were unable to participate in the autumn 2020 grant round for funding EB research projects; however, we plan to continue proactively identifying projects and developing and enhancing our funding strategies for the future.
Working hand in hand with industry and academia is key to bringing research developments into routine clinical practice, paving the way for health and technology assessments.

Our research aims for 2021

- Invest circa £250,000 in research projects in 2021 to help maintain our ongoing project portfolio, with a view to increasing investments where possible.
- Focus on the translation of pre-clinical research into early phase patient studies identifying suitable treatments for cures and control of EB, as well as symptom relief and treatments that will impact positively on quality of life.
- Link our research strategy of striving to achieve cures, manage symptoms and improve quality of life with DEBRA International's research strategy.
- Continue to proactively identify core areas for research and enhance the EB clinical and research community.
- Champion communication, co-ordination and collaboration to ensure a coherent approach to EB research globally.
- Work with other EB groups to co-fund future research that provides continuity for currently funded research.

"I was first introduced to the traumatic plight of EB sufferers several years ago and I felt compelled to contribute to the global research effort dedicated to developing treatments for patients ever since. EB is an excruciatingly painful skin blistering disorder that is inherited and affects children from birth. The more aggressive forms of EB are further complicated by the onset of dangerous life-threatening skin cancers which are very difficult to effectively treat.

It is vital that we raise both awareness of EB and funds to develop new treatments to alleviate the suffering that both patients and their families currently have to bear."

Professor Gareth Inman, CI UK Beatson Institute, University of Glasgow

International collaboration and best practice

EB is a condition that can affect anyone in any part of the world. Therefore, international collaboration and coordination of research and projects are vital in developing effective treatments and potential cures for EB. We work closely with other national DEBRAs as well as with external groups to ensure our research efforts are effectively coordinated and best practice information is shared with all relevant parties – including researchers, clinicians, other charities, pharmaceutical companies and biotechnology organisations.

Collaborating at the international level

Our strategy for international collaboration is to:

- build on the success of the flagship conference, EB 2020 World Congress
- improve international clinical care practices by developing and maintaining an up-to-date multi-lingual library reviewing all existing literature and detailing current best practice treatment and care for all aspects of EB
- improve clinical care through developing clinical networks, sharing knowledge and training
- raise awareness of EB and the care required by advocating on behalf of the UK EB community and membership
- ensure that all DEBRA funded research is peer reviewed by the DEBRA Medical & Scientific Research Panel
- improve joint working on communication, campaigns and projects
- review possible partnerships with promising biotech start-ups on a case-by-case basis.

Key areas

Coordinating international research projects

DEBRA UK is a founding member of DEBRA International, our umbrella organisation with nearly 50 members groups in other countries that aims to ensure all EB research and care activities are coordinated worldwide where possible. We work alongside DEBRA International to manage the Research Involvement Network, which aims to inform members of developments in EB research and promote its importance and opportunities for patient involvement.

Enhancing global EB care and best practice

Alongside other members of DEBRA International, we assist in the development of an international EB Patient Registry and Clinical Practice Guidelines (CPGs). Aimed at clinicians, these guidelines are often citable articles published in professional journals. Most guidelines are now also available as patient versions, which are written to help people living with EB to understand and implement the guidance and

advice, and some have been translated into other languages. In 2020, we committed funding to three new CPGs – CAIMS (Complementary & Integrated Medicines), Palliative Care and Neonatal Care.

Raising EB awareness around the world

Working with DEBRA International groups, we aim to raise the profile of EB significantly in the coming years through integrated and coordinated awareness campaigns. As an example, in 2020, in collaboration with DEBRA International, we developed a simplified 'What is EB' infographic that was shared with and used by other national DEBRA groups during the global 2020 EB Awareness Week campaign.

Enhancing clinical and research knowledge

We annually fund training grants through the Professor Robin Eady Grant fund to assist clinicians and researchers in furthering their professional development and their interest in the field of EB. The pandemic prevented us from awarding the grant in 2020 due to global travel restrictions and constraints on clinicians' time, which meant that professionals were unable to attend in-person meetings and training events. In 2021 we plan to support more virtual international training events and meetings.

Significant partnerships

We support a small number of international projects and contribute to the running costs of DEBRA International through a subscription as well as giving time and expertise to support DEBRA International. DEBRA UK ensures good value is received from DEBRA International's activities with progress reports outlining delivery of DEBRA UK-funded projects.

DEBRA International coordinates the CPG programme and manages the EB Without Borders (EBWB) group, a collaborative effort to assist EB sufferers in need around the world, particularly in locations that do not have a national DEBRA organisation. DEBRA UK and UK clinicians work closely with the EBWB Team on a referral basis.

International by numbers

- Some 50 national DEBRA groups established around the world
- 420 Members of the Clinical Practice Guidelines Network
- 602 individuals in the DEBRA International Research Involvement Network
- 8 international CPGs funded by DEBRA UK
- 17 global EB research sites funded by DEBRA UK
- 3 national DEBRA groups co-funding research with DEBRA UK

Looking to the future

Working with DEBRA International, DEBRA UK plans to bolster its activities through further funding of services, particularly with the development of international CPGs and the international EB Patient Registry.

Our international collaboration aims for 2021

- Continue joint funding the development of international CPGs.
- Participate in the development of international research strategy and discussion with all EB charities.
- Improve joint working on communication, campaigns and projects that can be of benefit to the global DEBRA community.
- Work with other research groups to ensure information sharing and to prevent duplication.
- Ensure information on research is easily available to members, professionals and industry.
- Consider plans for the next EB World Congress event.

“EB certainly runs in my family. My dad was in the army but got a medical discharge during the war due to EB. My brother has EB as does his daughter and her three children. And my daughter also has it. Back then EB was just called blisters. My symptoms were the same as my dad’s and when it got bad dad would use a needle and wool to burst the blisters on my hands and drain them. The treatments for EB have really improved over the years. When I was younger, my feet were saturated in blisters and the podiatrist used a rough scrubber to remove the skin. He had no idea what EB was. Today of course we have specialist bandages and creams to ease the pain. I was introduced to DEBRA by one of my doctors at St Thomas’ Hospital. DEBRA has really helped me. I finally had some support and I got to meet and speak to people who knew about my condition and what I was going through. People ask me how I have coped with such a painful condition, but you just get on with it. You can’t let anything beat you.”

Terry Cook, living with EBS

Specialist healthcare

We provide funding to deliver a UK-wide specialist healthcare service for people living with any type of EB. This service is provided in partnership with NHS England’s Specialised Services Commissioning Team and NHS Scotland who fund the core (NHS duty of care) clinical service.

EB Centres of Excellence

There are four designated EB Centres of Excellence in the UK based at hospitals in Birmingham and London: Birmingham Women’s and Children’s Hospital, Solihull Hospital, Great Ormond Street Children’s Hospital and St Thomas’ Hospital.

Multidisciplinary teams consisting of DEBRA Community Support Managers, consultants, EB nurses and other specialist healthcare professionals meet at these centres to provide the high levels of expertise required to care for people living with EB.

Key areas

Podiatry

Even in its milder form, EB affects the hands and feet of most sufferers, yet there is very little awareness among the podiatric community about the condition. To address this, in 2017 we committed £105,000 over three years to fund the development of an accredited EB podiatry training course, as well as a full training programme across the UK, enabling people suffering from EB to receive more expert care and improve their quality of life. In 2019, the first training course took place in London and the EB podiatry network was established. However, due to the coronavirus pandemic, further training and development of the network has been on hold but will restart in 2021.

Clinical teams

The pandemic placed enormous pressures on all clinicians across the UK in 2020. Yet the teams worked immensely hard to ensure a specialist EB service remained accessible, even when those teams were on standby or were redeployed to help the fight against the pandemic. A combination of virtual and in-person clinics and care were offered and teams continued to provide specialist EB training to enable professional development, and knowledge and experience in the field of EB, to be maintained at the highest standard within the wider healthcare practice.

Nursing

Our funding of the two paediatric designated Centres of Excellence continued in 2020 with the funding of an additional two-year fixed-term nursing post at each location. Following multiple retirements and vacancies, this funding will support the establishment of the new teams and ensure that they have the time to undertake the required clinical specialist training. These posts have also assisted with providing care to an increasing number of patients at each centre.

Rare Diseases Centre

The Rare Diseases Centre at St Thomas' Hospital (supported by £250,000 of DEBRA funding) continues to greatly enhance the clinical facilities available to the EB community and enable the development of multi-disciplinary working. These facilities have enabled the operation of virtual clinics and have reduced movement across clinical settings as the centre has multiple facilities including a small skin surgery room. We continue to support all the UK's EB Centres of Excellence through lobbying and/or funding to ensure that the appropriate facilities and equipment are available for all EB patients.

Healthcare by numbers

- 2,000 patients supported by EB specialists
- 100 days of specialist dietitian services
- 10 clinical supervision workshops
- Up to 25% of specialist EB nurses' costs covered by DEBRA
- £347,000 spent on healthcare
- 18 different TV grants covering 141 inpatient days
- 14 specialist EB training days

Looking to the future

We will continue to review our support plans to meet the changing needs of the EB community and to address the uncertainty caused by the pandemic.

Our healthcare aims for 2021

- Encourage and support innovative clinical practice and service developments that will enhance the lives of those affected by EB.
- Update and enhance the range of information and publications and improve the accessibility of information available to members and healthcare professionals.

At the start of the coronavirus pandemic, our Community Support Team arranged immediate delivery of a free emergency food parcel and found a supplier able to provide Scott with regular food delivery slots. They investigated local sources of PPE for his carers and had a delivery confirmed for him within 48 hours. They also asked him if he would work with DEBRA to create a motivational video showing other EB sufferers how to cope with isolation, and help Scott himself feel more connected.

“I am in self-isolation, in fact strict “shielding” and can’t leave my home because of my condition, EB. Without DEBRA’s emergency food package I would be without food. They helped to set me up with a local food service long term and arranged a food package immediately to stop me from going hungry before this service was in place. I cannot thank them enough.”

Scott O’Sullivan, living with RDEB

Lifelong community support

We provide membership and specialist community support services to people across the UK. Liaising directly with members of the EB community is vital to understanding the needs of EB sufferers and those impacted by the condition.

Engaging with the EB community

We consistently request and review feedback from our members through surveys, focus groups and general meetings. Some of the topics include programme requests for member events, new projects and publications. The 2020 virtual member groups identified that members like what we are currently doing but would like us to increase or improve peer support, sharing of research updates, printed materials and website content and functionality. These requests are all within our plans for improvement.

Key areas

Information and liaison support

We are committed to delivering support to improve quality of life for the EB community.

We offer a range of benefits to our members and support from a dedicated, expert team which can advocate and advise on topics from welfare rights reform, housing and employment to education and independent living. These services are provided based on feedback received from the EB community. We continue to focus on contacting people suffering from EB who are not taking advantage of the services to enable them to do so.

When the pandemic started early in 2020, the planned development of the Community Support Team and additional activities were postponed in order to focus on supporting members’ immediate needs within the funding available. Members with severe EB received a well-being call and all members received an email or letter to ensure they had the support they required as we entered lockdowns at the start and end of the year. Throughout the remainder of 2020 the team continued to offer a service across the UK, predominantly remotely but where necessary in person. At times, a number of team members were working reduced weekly hours and were placed on flexi-furlough but all urgent and essential requests for support were fulfilled.

Support grants

We provide support grants to members for emerging needs and to assist in covering costs for basic quality of life improvements, such as white goods and new-born baby goods. In addition to DEBRA support grants, the Community Support Team have successfully helped members of the EB community to access financial support from other sources.

Community events

Instances of members of the EB community feeling isolated and alone increased in 2020 due to the impact of the pandemic. We responded by providing opportunities across the UK for our members to meet, share experiences and learn how others manage the condition. As all in-person events were cancelled, a range of virtual groups were quickly set up to facilitate peer support, share insights and information and engage with members. This helped us to gain an understanding of current needs and prioritise the work of the charity. The virtual meetings were well received. In some cases, they helped develop IT skills and confidence to use technology for keeping in touch with family/friends and on-line shopping which was important due to the restrictions caused by the pandemic.

Respite care

Having the opportunity to go on holiday may be out of reach for many people within the EB community because of cost or lack of adequate specialised facilities. At times during 2020, all of our holiday homes were closed in line with government rules. Some members were apprehensive about travelling and the uncertainty of the situation. However, despite this, 71 weeks of holiday were taken by 478 members in 2020 in the six DEBRA holiday homes. In September one of the holiday homes at Weymouth was sold for trade use as it had reached its maximum age. Feedback from members continues to be very positive about all homes, the range of locations and their facilities.

Significant partnerships

We work with, and are members of, other organisations – including DEBRA International, Disability Rights UK and Carers UK – to enhance the services available to the EB community.

Community support by numbers

- 1,195 individuals accessed the DEBRA Community Support service
- 1,078 Covid well-being calls made to members
- 154 support grants awarded to value of £24,000
- 76 virtual members groups held
- £839,000 spent on membership and community support activities
- 3,279 individuals in the free DEBRA membership scheme
- 71 weeks booked and enjoyed by 478 members in DEBRA's six holiday homes

Looking to the future

We will continue to review plans postponed from 2020 and the changing needs of the EB community caused by the pandemic. We plan to increase engagement with our members. This will help shape care and support service developments and improve membership benefits with more regional/local events (virtual and hopefully in-person towards the second half of the year) providing greater opportunities for peer support and sharing information.

We will review and develop our publications and the use of multimedia to improve the sharing of information. We plan to develop a more detailed understanding of the EB community to help achieve a more proactive service and to maintain the aspects of the remote service that have worked well for members and the team, alongside in-person activity.

The search for a new holiday home for 2023 will begin. We will continue to deliver a support and membership service with the current team, prioritising urgent and essential support if the membership grows or if the demand for support increases.

Our community support aims for 2021

- Provide a professional membership and community support service to members of the EB community across the UK.
- Develop the Membership and Community Support Teams to meet current and future needs that may arise as a result of the coronavirus pandemic – for example if unemployment rises the need for support regarding benefits is likely to increase.
- Ensure that sufficient funds remain available within the support grant budget allowing for the projected rise in applications for urgent and essential goods and services.
- Encourage and support innovative research projects and service developments that will enhance the lives of those affected by EB.
- Review the membership model, increase membership numbers, diversity and engagement of members and undertake a survey of service satisfaction.
- Facilitate an enhanced range of virtual peer support and membership activities including virtual member events and AGM.
- Explore the opportunities available to set up a volunteer befriending network.
- Publish a report on the achievements and support available for the EBS community.
- Publish a report on the non-medical achievements and support available to members of the EB community, positioning us as the go-to EB charity and engaging new and current audiences.

> "Life came to an abrupt end for me because of the virus. One day I was working, the next I was not able to go out due to my EB. I struggled to get food and my income suddenly stopped. I was scared and didn't know what to do until Amelia called. Her support meant everything. She arranged a food parcel and helped me get financial support, I now feel mentally and physically much better."

Inderjeet, DEBRA Member

The first Covid-19 lockdown left Sharon needing a new focus, so she decided to give some of her time to volunteer at our store in Winstanley.

“During the Covid-19 lockdown I was unable to work as a freelance children’s entertainer, actor and music researcher. I needed to do something productive and confidence boosting so, as soon as my favourite local DEBRA shop reopened, I signed up as a volunteer. I have learned many new skills, made new friends and enjoy serving customers. I like to get creative with shop displays. I get a real sense of achievement from volunteering.”

Sharon Lowe, Volunteer DEBRA Winstanley

Our retail stores

Our retail stores transform unwanted goods into funds for life-changing support and research to help our commitment to fighting EB. The pandemic had an enormous impact on our retail income in 2020. However, despite the challenging conditions faced by retailers in 2020, our sales performance after lockdown was more resilient than we expected, both in terms of sales and stock generation.

From a business perspective, the pandemic has been hugely disruptive, but there has been much to learn from the experience. The unexpected slowdown in our operations has given us the time and the motivation to accelerate our efforts to strengthen our portfolio, people and infrastructure, creating new opportunities and efficiencies in a rapidly changing world.

Key areas

Impact of the pandemic

As the scale of the COVID-19 outbreak became clear early in the financial year, we took the difficult but necessary decision to close all our retail outlets as of 22nd March 2020. Many of our colleagues, volunteers and supporters are in the high-risk category, and the safety of our people will always come first. With no retail income coming into the business due to successive lockdowns and to protect jobs in the long term, over 95% of retail colleagues were furloughed. Despite the welcome financial support from the UK Government, with a phased reopening of our shops and our small online operations starting in June, retail profit for 2020 was severely impacted. Gross retail income, including donations received in our stores and income from the Coronavirus Job Retention Scheme, decreased by £4.5m.

Restructure

The additional pressures on retail caused by the pandemic have meant that reducing operational overheads where possible has never been more important. As part of an internal review of operations, a limited restructure of the Retail Department was undertaken to merge the management structures of Traditional and Furniture & Electrical (F&E) stores. We have numerous examples of F&E stores being successfully managed through the Traditional management structure at DEBRA. The restructure gave us the opportunity to balance the workload across management teams, create greater service flexibility and align operational areas to maximise present and future efficiency. The restructure has proven extremely beneficial for the Retail Department and in support of our work.

Sustainability

We are working hard to develop a long-term sustainability plan and to significantly lower our carbon footprint. Our 109 charity shops help to prevent tonnes of textiles and furniture going to landfill each year. Alternatives to plastic for carriers are being trialled to reduce the number of single use plastic bags across our retail outlets.

Estate

At the end of 2020, our portfolio consisted of 109 stores. The current portfolio is made up of four freeholds, 91 leaseholds and 14 temporary shops.

Significant partnerships

This year we have continued to grow our existing partnerships while trialling new partnerships and finding innovative ways of working with other brands. Moving forward, we plan to expand our online partnerships by working with various online pre-loved platforms to test selling our items to a younger audience, who are already engaged with shopping second-hand.

There will be a continued focus on developing our engagement and relationships with both corporate and local supporters to enhance the performance of DEBRA Retail and overall charity awareness.

Retail by numbers

- 109 shops at year end
- £553,000 received through the Retail Gift Aid Scheme
- Approximately 800 volunteers with almost 200 new volunteers signed up

Retail Gift Aid Scheme

In addition to the impact on trade this year, shop closures, social distancing and the need for contactless donations have also greatly impacted Gift Aid capture within stores across the country. Together with retail donations, this represented a total income of £606,000.

Our team

We continue to recognise the vital requirement for dedicated volunteers and staff and understand that our retail chain would not succeed without this support. We are continually looking to improve the experience of working and volunteering in our stores.

We know that in order to fight EB, we need a talented and ambitious community of people working in our stores and are focusing on key areas to make this happen. These areas include unlocking our people's full potential, ensuring the provision of excellent training and induction programmes and a safe and trusted environment for all.

Our average volunteer numbers within Retail remain significantly lower than the sector average. The success of our stores depends greatly on our volunteers. Therefore in 2021 we will continue to place a strong emphasis on volunteer recruitment for our stores. We want to encourage people, with a diverse range of skills and backgrounds, to consider volunteering for us.

Looking to the future

The existing and unpredictable trading conditions have highlighted the need to maximise our organisational flexibility and to respond effectively and positively to changing circumstances.

We will continue to review our operating model and central costs to permit a more effective and efficient management of the Retail department, enabling us to focus on areas that generate the greatest level of contribution.

The lack of a mature e-Commerce operation is viewed as one of the key components affecting income performance when benchmarked with the sector.

Our retail aims for 2021

- Continue the significant improvements in margin and contribution made before the pandemic with a strong focus on existing store optimisation and profitability.
- Continue with the planned series of refurbishment projects within stores that we put on hold during 2020.
- Ensure we have a stable and well-trained workforce and increase overall volunteer numbers.
- Continue to invest in training for our shop teams, focusing on product and productivity while continuing to provide training and resource to ensure a safe retail environment for all staff and volunteers.
- Deliver enhanced and structured training and induction programmes throughout all areas and consistent Health & Safety management and compliance across all stores.
- Continue to identify and pursue cost savings which support bottom line growth, looking in particular at lease negotiations, distribution costs and facilities management.
- Continue to work towards reducing the requirement for single-use plastic within our shops.

September 2020

DEBRA Patron HRH The Countess of Wessex volunteered at our newly opened store in Martins Heron, Bracknell, Berkshire to support the individuals and families living with EB.

The Countess volunteered alongside DEBRA volunteers and staff, and had a busy morning sorting donations, pricing stock and helping to serve customers.

Graeme Souness, our Vice President, united Scottish sports personalities under one roof for the Old Firm United to Fight EB event in March and helped to raise over £112,000 for vital research funding.

“I am delighted to be Vice President because I am in a position to bring this charity to the attention of a number of people who will be able to make a real difference. I was appalled at just how cruel and painful the condition is – more people need to know about EB. If I can generate the sort of passion that I feel for this cause from a few people that I know then we could make a huge impact on the research into EB – research that not only will help those living with this now but could even lead to a cure.”

Graeme Souness, DEBRA Vice President

How we raise our funds

Supporting the EB community

As a charity we are reliant upon our fundraising activities to deliver our charitable objectives. Everything people do to help support us – from hosting a fundraising event to donating directly – positively impacts the EB community. Our Fundraising Team strives to raise as much money as possible to help support our work and to fight EB. Those funds support our commitment to making a difference today through our healthcare and EB Community Support services, as well as working towards a better future through international collaboration and funding of pioneering research projects.

Our fundraising mission

Our traditional fundraising efforts include hosting a portfolio of high-quality major events as well as supporting individual fundraisers, applying to major trusts and grants and partnering with businesses for charity of the year status.

In 2020 we were unable to do much of what we had intended as our events programme was effectively put on hold by the pandemic in March. We are very thankful to our loyal supporters who responded to a series of appeals throughout the year to raise funds in support of our continued services to members.

Key areas

Trusts

We are grateful to the many grant making trusts that have supported us in 2020. These include the Patricia G. and Jonathan S. England Fund which has made a long term support commitment to DEBRA; the Peter Harrison Trust which has made a three-year commitment to supporting children with EB in the South East of England; the VTCT Foundation which has funded the changes to our website; the National Lottery Community Fund which funded all of our community support for three months during the height of the pandemic; and the Robert Luff Foundation which made a donation to support our research projects. There are many more whose support has been vital.

Major events

Thanks to the generosity of Michel Roux Jnr and the team at The Langham Hotel we were able to stage a successful Great Chefs Dinner in February. This was followed by a very successful Old Firm Dinner in March in Glasgow, with the generous support of our Vice President, Graeme Souness. Despite the difficult circumstances, our Events Team were able to run one more event, a Covid-secure shoot at E.J. Churchill Shooting Grounds in September.

Fundraising with the EB Community

We are very grateful to the number of people who took part in various challenges during the first lockdown of 2020 to raise funds for people with EB. Many of the EB community undertook their

own activities to raise money including sporting, walking and cycling challenges, while there was overwhelming support for the 2.6 Challenge that finished in May.

The DEBRA Golf Society

The Golf Team worked hard to ensure we were able to re-schedule and run 14 Covid-secure golf days in 2020. Numbers were limited due to social distancing and club restrictions but to realise a net income of over £77,000 was very impressive.

Appeals and legacies

The continued support of all who responded to our various appeals throughout the year was very positive. With so much of our fundraising being postponed we were reliant on donations. These included the Coronavirus Emergency Appeal in May, The Big Give and the Christmas Appeal featuring baby Ray in December. We also received multiple donations after a re-showing of the powerful documentary 'The Boy Whose Skin Fell Off' on Channel 4. We were also very fortunate to receive the support of a number of people who were kind enough to remember DEBRA in their wills.

Significant partnerships

We are extremely grateful to our Patron, HRH The Countess of Wessex, for her continued support throughout 2020 and to our President, Simon Weston CBE and Vice Presidents Frank Warren and Graeme Souness. We have also been fortunate to be able to count on the continued backing of a number of very generous supporters during these challenging times.

Fundraising by numbers

- £77,000 net income from the DEBRA Golf Society
- £267,000 net income from individual donors
- £444,000 net income from legacy and trust donations
- £946,000 overall net fundraising income in 2020, compared with £1,671,000 in 2019

Looking to the future

The pandemic will continue to have a significant effect upon income generated for the charity in 2021. However, our experiences in 2020 have shown us that with a 'can do' attitude we can progress with events such as golf and shooting. We hope fundraising dinners will return in the last quarter and we have plans to put on some exciting events – especially with the support of our Vice Presidents. We have made considerable efforts to manage relations with key supporters closely over the last four years and this will stand us in good stead to recover from the lasting effects of the pandemic. We will continue to rely on the support and goodwill of our many supporters to help us get through this uncertain time.

Our fundraising aims for 2021

- Deliver a professional and profitable programme of events when it is safe to do so.
- Utilise the events programme to progress relationships with major supporters, current corporate supporters and sponsors.
- Work with our major supporters to leverage funds from their pledged support.
- Empower people to continue to raise money for us and support those with a close connection to EB to raise funds in their local communities.
- Raise awareness of the importance of legacies and the difference they make to enable us to support the EB community.
- Invest in our Trust Application Team.

100km challengers

Amy Coote has EB Simplex and challenged herself to cycle 100 miles a day around Lincolnshire after the 2020 RideLondon event was cancelled due to COVID-19.

"I have loved training to complete the event for DEBRA UK, even though the main RideLondon was cancelled. Cycling has now become a passion of mine for sure and it hasn't affected my EB Simplex once."

Hannah West, who took on the 100km challenge went the extra mile and dyed her hair purple in support of DEBRA.

"EB has a huge impact on my family. My eldest daughter Charlotte has the condition and not a day goes by when she doesn't have a new injury to her skin which is really debilitating. The support DEBRA offers our family is outstanding. Through DEBRA, Charlotte has met other children with EB and has made some firm friends who understand what she is experiencing day to day. We were really excited to participate as a family in the #FightEB 100km challenge. It's wonderful to be able to show our appreciation to DEBRA and to raise awareness of this awful condition."

“The worst thing about EB is the pain. The pain is incredible. I have to take so many painkillers every day – sometimes paracetamol and ibuprofen, sometimes the medication is so extreme it puts me to sleep. Then there’s the itch. Some days there is no itch at all and sometimes I have days where I just can’t stop itching. And there is normal stuff like eating. I can’t eat hard foods, like crisps, because that creates blisters in my mouth. The EB nurses are amazing. They know everything – without them, I probably wouldn’t know what to do with all the creams and dressings I have to put on every day to protect my skin. My skin scarring, the fusion of my fingers and the depletion of my skin tissue all increase as I get older which will make life even trickier for me.

I want to find a cure for EB if DEBRA hasn’t found one by the time I’m old enough to be a doctor. I have big plans. I want everyone to understand what having EB really means. We all need to be better educated.”

Fazeel Irfan, living with RDEB

Raising awareness

Public awareness of EB is low when benchmarked against conditions that have a similar number of people affected. A YouGov poll undertaken for DEBRA UK in 2020 revealed that 10% of UK adults surveyed had heard of EB. The level of awareness rose to 13% when given a description of EB. Conditions with similar numbers in the UK such as Motor Neurone Disease had a significantly higher level of awareness at 91%[1].

Raising the awareness of EB, the profile of DEBRA and the work of the charity is a strategic priority within our five-year plan. We need to ensure all families living with EB have access to information, advice, support, advocacy, latest news and best practice. We need to ensure that the public are informed and engaged, creating greater understanding for those living with the condition, more widespread EB expertise and support for our income generation to enable us to fund vital research and care.

Key areas

Engagement

Our priority during the pandemic was to continue to connect with our community providing frequent information, advice and support and to support income generation to engage with our current supporter base and raise awareness for the gradual reopening of our retail stores.

Communication with our audiences quadrupled and media activity increased with the introduction of a new PR & Content role. We achieved a significant increase year on year in reach and engagement on social media and website traffic through additional digital expertise, more engaging content, focused messaging and specific campaigns targeting the EB community, healthcare, volunteers, retail and the general public.

We introduced new online campaigns to recruit volunteers, reach supporters and generate an increase in stock donations for the charity shops. The trial of a new digital initiative was launched to build a community of brand advocates, connecting with customers on local social media and putting the charity shops at the heart of their local community.

Raising awareness would not be possible without the help of the EB community and supporters who share their experiences of living with EB. Our EB Awareness Week campaign in October focused on a ‘back to basics’ approach with infographics and communications to explain ‘What is EB’ and sharing the emotive and inspirational personal illustrations of our EB ambassadors through ‘What is EB to me’ videos, blogs and social media posts. We reached over 1.1m people on social media through this effective, low-cost campaign.

Digital and brand development

Through grant funding we were able to begin the development of a new website in quarter three – a critical factor in improving the positioning of the charity and the effectiveness of its online communications. Progress was delayed during lockdown while staff were on furlough.

A planned brand review project was also paused, but in the interim, we took the design refresh in-house, standardising branding and tone of voice throughout our publications and digital communications and revitalising messaging and signage across the retail stores.

Looking to the future

Since the charity was set up in 1978 it has become known for its commitment to investing in EB research, healthcare, support and best practice.

Our aim is to ensure we are recognised as the authority on EB knowledge and expertise and the source of information, advice, support, advocacy, latest news and best practice. We also want to achieve greater public awareness of EB to ensure there is understanding for those living with the condition, more widespread EB expertise and support for our income generation through fundraising and our retail stores to enable us to fund vital research and care. We need to ensure that we are a charity of choice for funders and that the public are informed and engaged enough to want to support us.

Awareness & engagement by numbers

- Website: 1.2m page views, +20% year on year
- Social Media: 5.2m organic reach, +295% year on year
- DEBRA PR potential reach: 151.6m people
- EB Awareness Week: 1.1m reach, +451% compared with weekly average

Our marketing aims for 2021

- To raise awareness of EB and DEBRA, building a brand that is recognised by the EB community as the ‘go to’ source of support, expertise and information on EB and that resonates with the public as a charity of choice for funders and supporters.
- Support income generation through increased awareness and engagement.
- Increase understanding of EB and the specialist services and information DEBRA provides.
- Improve access to information via multi-channel communications for all audiences at all touchpoints.
- Create a digital-first offering for all external and internal audiences.
- Build an engaged social community and an online presence that has credibility, is informative, provides access to expertise and latest knowledge and that is centred around the needs of the EB community.

[1]All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2,057 adults. Fieldwork was undertaken between 10th - 11th November 2020. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+)

Our people

From its origins, over 40 years ago, as a small support group for parents affected by EB, we have grown significantly – in income and personnel. At the end of 2020, DEBRA employed 360 staff and engaged approximately 800 volunteers. The range of jobs is broad, from managing a charity shop and organising fundraising events to processing income and supporting members with home visits, but each contributes significantly to the service that we provide to our membership.

Employees

The effects of the pandemic on our working practices were significant. The majority of office and administration staff worked from home, many staff were furloughed during the year and the safety and well-being of all of our people was more important than ever.

Communication during the pandemic was a priority. We communicated frequently with our staff and volunteers. This included regular e-newsletters, emails with updates about COVID-19, changes to working patterns such as furlough and a wide range of information about matters that affected them individually or as a whole.

During the year we worked with an external consultancy, People Puzzles, to consult with our employees and ensure their views were heard and incorporated into our strategic planning. The review included individual meetings, focus groups and surveys to understand our organisational culture and gain feedback on what working at DEBRA is like in difficult and turbulent times as well as taking the opportunity to drill down into specifics such as the onboarding process for our retail employees.

As a result of the employee feedback, we have launched some proactive projects that will underpin our ambition to be an “Employer of Choice” in the charity sector. These include a review of our benefits and recognition structure, updating our company values and launching a new Equality, Diversity & Inclusion framework.

Volunteers are a significant and highly valued resource for us. We rely on their commitment and dedication to enable us to undertake the work of our retail stores and support across many areas of the charity. Our Volunteer Manager worked closely with the Retail and Community Support Teams in 2020 to increase volunteer resources in these areas. The ‘EB Connections’ initiative, developed in 2019 and envisaging the development of Practical Community Volunteers (PCVs) to support members in their homes, was placed on hold due to the pandemic.

Learning and development

All members of staff are encouraged to continually develop their skills and the eLearning platform

first introduced in 2017 continues to prove useful, particularly in delivering mandatory training in Safeguarding, Equal Opportunities and GDPR.

In line with our Equal Opportunities policy, we take full and fair consideration of applications for employment made by disabled persons and their aptitude and abilities and encourage training, career development and promotion within our organisation.

Reflecting the increasing requirements to develop the skills of staff, and to develop bespoke training using technology such as eLearning modules, we recruited a dedicated Learning & Development Manager in February 2020. During the pandemic, bespoke training modules were developed for employees to complete while furloughed including training on the Retail Gift Aid Scheme.

Pay policy

Rates of pay and salaries within DEBRA are set at a level that are legally compliant and proportionate to the requirements of each role within the sector to attract and retain the best employees for each position. We benchmark key management and all pay rates to ensure we are competitive within the charity sector and in line with other trusted sources.

In January 2020, the annual pay review awarded a pay increase of 2% for all staff.
In accordance with the Charity Statement of Recommended Practice, DEBRA discloses:

- all payments to Trustees (no Trustees are paid) and reimbursed expenses
- SMT (Senior Management Team) reimbursed expenses
- the number of staff in receipt of £60,000 pa and above (in bands of £10,000)
- employer pension contributions.

All aspects of pay – including rates, salary levels, reviews, incentive schemes and termination costs – were considered by the Quarterly Pay Review Committee, which reports to the Board of Trustees. In October 2020 QPRC was dissolved and has not been replaced. In order to maintain the required level of governance in relation to pay, a new process has been introduced whereby a business case must be put forward to the CEO for consideration before any kind of pay increase or change to incentives can be actioned. Where required Board approval will also be sought.

During March, April and May 2020, all of our employees were paid at 100% of their normal monthly salary. If employees were furloughed in these months, we topped up their furlough pay by 20%, i.e. from 80% to 100%, utilising the Government's Coronavirus Job Retention Scheme. In June and July 2020, we enabled furloughed employees to take a week of annual leave at 100% pay to increase their monthly income. Between August and December 2020, we reduced furloughed employee pay to 80% with no top up.

Gender pay gap

A gender pay gap is a measure of the difference in the average pay of men and women, regardless of the nature of their work, across an entire organisation, business sector or the economy as a whole. Our mean hourly full pay gap is 2.61% in favour of males. As a comparison, our mean gender pay gap for 2019 was 4.9%.

The median hourly full pay gap is -2.39% in favour of the female workforce. The hourly pay analysis is based on 376 relevant full pay employees. The mean bonus pay gap is 4.92% in favour of females and the median bonus pay gap is -14.92% in favour of females. Bonus payment calculations relate to payments made to all eligible employees in the 12 months preceding the snapshot date.

The full Gender Pay Gap Report is available on our website.

Table 1: Summary Gender Pay Gap Report
Pay – hourly rate: the difference between men and women

	Mean	Median
All	11.31	8.98
Female	11.23	8.98
Male	11.53	8.77
Pay Gap	2.61	-2.39

Table 2: Summary Gender Pay Gap Report

	Mean bonus	Median bonus	Number receiving a bonus	% Bonus distribution
Female	497.60	312.00	156	56.52
Male	474.25	271.50	46	46.00
Pay Gap	-4.92	-14.92	-	-

As part of our strategy to address the gender pay gap, we will be further developing our remuneration and benchmarking policies to move towards a more transparent and experience-based pay structure. In addition, we will continue to focus on the broader Equality, Diversity & Inclusion (EDI) agenda which will incorporate the activities and processes required to close our gender pay gap.

The coronavirus pandemic

Following the temporary closure of our charity shops in March 2020 and the postponement or cancellation of fundraising events, 85% of employees were furloughed in the same month. The remaining staff continued to work in their existing jobs or were redeployed to support DEBRA members, doing so from their homes. Since March, a further 8% of the workforce were furloughed. Supporting and maintaining regular communication with both these groups of employees became the focus for our Human Resources Team.

A phased opening of our charity shops started on 15th June 2020. Full PPE was provided to all stores and staff and all relevant government guidelines and measures were put in place for the safety of our staff, volunteers and customers. By late September 2020 all stores were open after a successful, phased re-opening. On 31st October 2020 the Government announced a second national lockdown resulting in the closure of all of our stores on 5th November 2020. We re-opened them on Wednesday 2nd December 2020. On 21st December 2020, the Government's Tier System was introduced. Our shops were subsequently closed in the period leading up to Christmas and into early 2021.

Equal opportunities

We are at the beginning of creating an EDI strategy and development programme to make DEBRA a place where everyone is welcome and supported to achieve their potential. We are committed to developing a positive working environment that is not only free from discrimination, victimisation and harassment but is also one where people treat each other with mutual respect regardless of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values. The benefits that derive from having a diverse workforce are highly valued. In particular, the involvement of people affected by EB is actively sought in all aspects of the charity's work.

Safeguarding and reporting of concerns

Safeguarding remains a priority within DEBRA, ensuring that any vulnerable person who comes into contact with DEBRA is adequately protected. All staff undertake mandatory training in safeguarding and in 2020 'Safeguarding September' was introduced to maintain a high awareness of safeguarding among staff. 'Safeguarding September' also reminded employees and volunteers that any concern could be reported internally in confidence. Updated posters and alert cards were issued during this month. The Safeguarding Review group met quarterly in 2020 to review the safeguarding alerts that had been internally reported and to ensure that the appropriate action had been taken in each case.

The Designated Safeguarding Lead receives annual updated training via an accredited external training provider and attends an annual safeguarding conference. Other staff receive safeguarding training appropriate to their role. Policies and procedures relating to safeguarding are reviewed and, if necessary, updated at three monthly intervals. The governance of the safeguarding provision is overseen by an experienced Trustee.

The Community Support Team received enhanced training in Level 2 Safeguarding and works closely with other agencies to ensure our members are safe and supported appropriately. Some members of the Community Support Team received further training in 2020 to take on the roles of 'Designated Safeguarding Officers' that report directly to the Safeguarding Lead in the organisation, with several safeguarding cases having been supported in the last 12 months.

In our retail stores, we are committed to creating a safe and rewarding environment in which all our people can work with a robust safeguarding policy to ensure everyone is treated properly. We also have a whistle blowing policy to ensure our staff can raise any concerns confidentially to a dedicated email address or by leaving a confidential message via a secure messaging facility.

All retail staff receive regular safeguarding training online and work closely with the designated Safeguarding Lead Officer to ensure that all staff, volunteers and customers are safe and supported appropriately. To ensure we are continually maintaining the highest standards of safeguarding, guidance from the Government, the Charity Commission and the Charity Retail Association on procedures and protocols for Safeguarding are monitored regularly. In the last 12 months, there have been several examples of robust action being taken to prevent harm to vulnerable people.

Working from home

In March 2020 our office-based employees had to adjust to new ways of working, which meant working from home due to office closures. Our management teams across the organisation established structured check-ins with the affected staff, provided several different types of communication technology including Zoom and Microsoft Teams, offered opportunities for remote social interaction within the team, developed resources for and awareness of the importance of mental health and well-being and provided encouragement and emotional support.

Financial review

Our accounts show the financial affairs of the charity for the year ended 31st December 2020. Net income after accounting for the costs of raising funds was £477k, dropping significantly from £3,905k achieved in 2019. Net income includes £1,249k received from the Coronavirus Job Retention Scheme and £824k from COVID-related local authority grants.

We entered the pandemic with strong reserves which enabled us to continue, enhance and adapt our charitable activities at this particularly difficult time for the EB community, despite the huge drop in income. We spent £2,848k on charitable activities in 2020, compared with £3,110k in 2019.

We have a large suite of charity shops which meant the pandemic hit us particularly hard. All shops were shut for four to six months of the year, which, despite government support, resulted in a deficit from the retail operation of (£673k), compared with £2,123k surplus achieved in 2019.

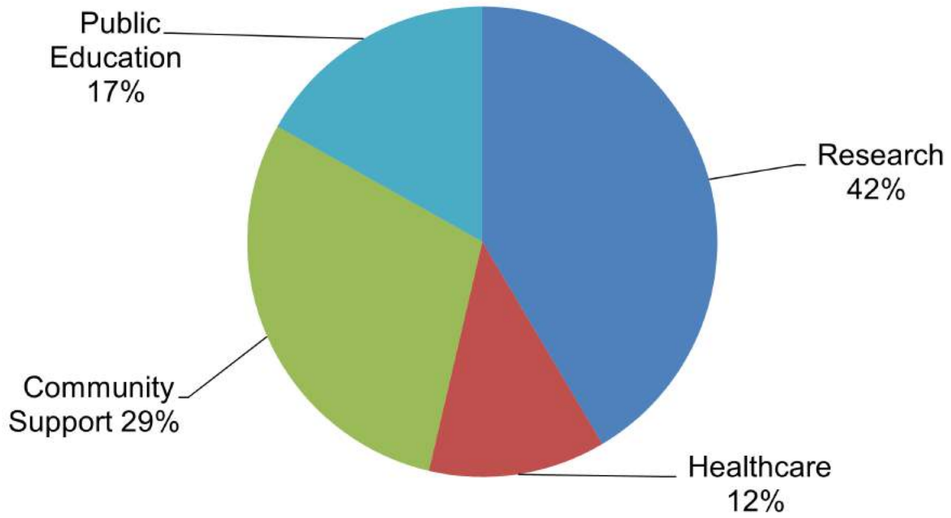
Many of our fundraising activities were severely curtailed during the year. Encouragingly our donor development programmes produced significant growth in this area. Overall net fundraising income was £946k in 2020, compared with £1,671k in 2019.

The deficit in the year was (£2,371k), funded by the historic build-up of reserves.

Charitable spend

Charitable spend in 2020 fell by just 8% over 2019. Research spend during 2020 was £1,181k (2019: £1,496k), whereas £839k (2019: £925k) was spent on Community Support initiatives, £347k (2019: £357k) on Healthcare services and £480k (2019: £333k) on Public Education.

Chart 1: Charitable Expenditure 2020



The deficit in the year led to a decrease in net assets from £5,352k to £2,981k. There was £2,138k in the general fund, £766k in designated funds and £77k in restricted funds.

Summary

Table 3 summarises the highlights of our financial performance over the last five years. Gross income was £11,413k in 2020, a decline of £5,385k (32%) from 2019. Excluding government support of £2,073k the decline was £7,458k (44%).

Non-trading gross income was £4,387k, an increase of £912k over 2019, but excluding government financial support of £2,073k the figure would be £2,314k, a drop of £1,161k (33%) as a result of reduced corporate support and trust donations, and a significantly reduced calendar of community events,

Net retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops) had grown dramatically between 2016 and 2019 from £1,318k to £2,123k. Despite government support of £1,916k attributable to retail, this fell to (£673k) in 2020.

See next page for Table 3 Financial Summary.

Table 3 Financial Summary £'000

	2020	2019	2018	2017	2016
Gross income	11,413	16,798	16,138	16,182	14,136
Non-trading income including all government support	4,387	3,475	2,979	3,468	2,832
Net trading income	(3,201)	1,198	1,193	616	330
Net retail income including government pandemic support, retail gift aid, commission and donations in shops	(673)	2,123	2,138	1,652	1,318
Non-trading fundraising costs	708	768	727	1,083	819
Charitable expenditure	2,848	3,110	2,966	3,299	1,715
Retained surplus/(deficit)	(2,371)	795	479	(299)	628
Retained surplus/(deficit) as a % of income	(21%)	5%	3%	(1.8%)	4.4%
Net current assets	2,684	4,878	4,394	3,951	3,340
Unrestricted reserves	2,904	5,138	4,420	3,997	4,301
Grants payable within 1 year	2,159	2,201	1,825	1,156	1,519

The pandemic has had a devastating impact on our finances but, due to sound financial management in previous years, the strong reserves base was accessed to maintain close to normal levels of charitable activities.

The charity's fixed assets comprise the premises and equipment required to operate trading activities; premises, furniture and equipment required to operate the charity's offices; and five holiday homes held for the use of those affected by EB. The rest of the charity's assets are held to promote the purposes of the charity through its support services and research programmes.

Reserves policy

DEBRA holds reserves to ensure the charity is able to continue supporting its beneficiaries and as a buffer for short term cash flow needs.

The Trustees' reserves policy in 2020 was to maintain minimum cash-backed free undesignated reserves at £1,300k, plus a £250k balance in the designated fund for nursing continuity, to which the charity adhered. We have a high proportion of retail income, which usually provides a stable and reliable income stream. However, this incurs a high cost base, and the minimum reserves figure would cover one month's costs (excluding rent) plus six months' rent.

In a normal year, the charity's income is to some extent dependent on a few large fundraising events at specific times in the financial year, as well as seasonal variations in the trading performance of the shops.

The Trustees conducted a thorough review of the reserves policy at the end of 2020, reviewing performance criteria in the light of the pandemic. Recognising the impact of a large drop in income as we experienced in 2020, the aim is to grow accessible reserves over the next 5 years to £3m. This would be sufficient to ensure a continuation of care services for at least 3 years.

Total reserves at the end of 2020 were £2,981k, including £77k in restricted funds. Cash-backed free reserves before designations were £2,066k, of which £766k was designated for specific purposes, bringing the total cash-backed free reserves after designations to £1,300k. Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be readily mortgaged, thus representing reserves that can be accessed relatively quickly.

Future Research Fund

A total of £516k was available in the designated fund for future research, which is in line with the charitable objectives of DEBRA and is anticipated to be spent or undesignated in the next year.

Nursing Continuity Fund

The amount of £250k was made available in the designated fund for nursing continuity. The purpose of this fund is to cover the cost of the continued nursing service to the EB community for six months in the event of the NHS withdrawing current levels of support. It is expected this fund will be spent in the next 5-10 years.

EB2020 Fund

The Trustees established a designated fund for the EB2020 World Congress which was hosted by DEBRA in January 2020 in London. There was a balance of £38k in this fund at the beginning of 2020, which has now been spent.

General Fund

There was £2,138k in the general fund, of which £1,078k can only be realised by disposing of tangible fixed assets. The Trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

Investment policy

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit.

We aim to apply our income in support of our charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk.

Prior to the pandemic, the charity took the view that this was best achieved by investing funds not immediately needed in short-term money market deposits through Lloyds Bank Corporate Markets. The investments have been transferred to cash at the current time during this period of uncertainty.

Programme related investment

The Trustees invested $250k (£191k) in the US biotech, FIBRX Derm, Inc, purchasing 203,252 series A-2 convertible preferred stock at a price of $1.23 per share. The purpose of this investment was in furtherance of the charitable objectives of the charity and no financial return is expected. The investment was made as part of our policy to invest in top quality, world class research. This will further our charitable objectives by supporting the development of a new treatment to help wound healing in patients suffering from Dystrophic EB.

The Trustees agreed to prudently impair this programme related investment by 99.99% in 2020 because the project has progressed well and the funds have substantially been spent. To all intents and purposes this investment was a research grant and the high impairment in the year reflects this fact.

Expenses policy

We have expenses policies for both staff and Trustees and a PAYE dispensation in place. Expenses that have necessarily been incurred by staff and Trustees in performance of their duties are recoverable from DEBRA. Expenses will only be reimbursed if they meet the following criteria:

- no personal benefit could be derived from the expenditure by the employee concerned
- the expenditure is reasonable and represents only additional costs to those that would normally arise on a personal basis
- there is a clear charity justification for the costs
- the expenditure does not represent a form of payment to a third party for work undertaken on our behalf.

Any expenses that do not meet the criteria above are regarded as a benefit by HMRC and as a matter of policy we do not reimburse such expenses.

Funds

The majority of our funds are unrestricted in application and are held in a general and two designated funds. Where funds are received that are restricted in their application to specific purposes or activities, these are held in a restricted fund. Details of restricted funds and designated funds are set out in Note 17 of the Financial Statements.

Asset cover for funds

Note 18 sets out an analysis of the assets attributable to the various funds. These assets are sufficient to meet the charity's obligations on a fund-by-fund basis.

Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2020 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous non-primary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 22 of the Financial Statements.

Internal financial controls

The Trustees have conducted a review of the effectiveness of the charity's internal financial controls in 2020, using the Charity Commission financial controls checklist. This review concludes that the controls are relevant, appropriate to DEBRA and are not too onerous or disproportionate.

"The physical symptoms of EB are obvious to people but the emotional and psychological trauma you feel are just as painful. The constant itch drives me mad, and in my sleep I would tear and blister my skin constantly. My skin feels like it's always on fire.

I was introduced to DEBRA in 1996 after I had been referred to the St Thomas specialist EB unit. The support DEBRA has given me has changed my life. I am now in regular contact with other people who have EB and I receive so much information and support to help with my everyday life. I should have asked for help a lot sooner but I thought I could cope on my own and I wasn't aware of the support services available to the EB community. I have recently been given a care package and I now have a dedicated carer who visits me twice a day to do my dressings. I'm not suffering in silence anymore. When I speed off on the bike it's like I leave EB in the gutter. After I have a day on my bike I need several to help my skin recover. But it is worth it. Life with EB is an unimaginable roller coaster and it has had a profound and devastating impact on my life. But I will not let EB beat me."

Les Paine, living with Dystrophic EB (DEB)

Principal risks and uncertainties

The Trustees have established a register for all identified major strategic, business and operational risks identified by them to which the charity is exposed and confirm that these have been reviewed regularly during the year by the Finance, Risk and Audit Committee (as well as annually by the Board of Trustees) and that systems and procedures have been established to manage these risks. The initial responsibility for managing risk lies with the executive, prior to review by the Trustees.

A summary extract of the higher risks from our risk register is listed in Table 4 below, including the countermeasures (actions in place to reduce likelihood of the risk) and assurances (how the effectiveness of the countermeasures is determined). DEBRA as an organisation is very proactive in its management of risk, instilling a culture of recognition, ownership and tolerance level for each risk identified.

See next page for Table 4: Summary Extract from DEBRA's Risk Register

Table 4: Summary Extract from DEBRA's Risk Register

Identified Risk Factor	Countermeasure	Assurance
Global pandemic causes UK-wide lock-down, threatening the going concern of the charity	Access all forms of government funding, Coronavirus Job Retention Scheme, local authority retail grants, and the National Lottery Community Fund Cancel future expenditure commitments Home working to facilitate social distancing Risk assessments in shops Home working risk assessments Health and safety shop re-opening procedures	Weekly Trustee Steering Group meeting Weekly Senior Management Team meetings Regular executive reporting to trustees Clear roles and responsibilities of trustees and staff identified Appropriate reporting lines established Reverse stress testing to estimate when liquidity would break Financial forecasting including recovery planning following the COVID-19 pandemic through to end 2022
Charity image damaged	Marketing and PR strategy Disciplinary policy Crisis communications plan Review of any complaints received Extensive social media policy for staff	Media monitoring Annual staff appraisals Register of crises Investigation of occurrences
Insufficiently robust cyber security	Anti-virus software Cyber insurance policy Encryption of hard drives Secured Wi-Fi connection Daily backups stored in the cloud Upgrade of firewalls PCI compliance Use of complex passwords	Anti-virus tool displays Monthly reports Firewall logs checked regularly Daily logs of server activity
Misuse of data and failure to comply with Data Protection legislation	In-house Data Protection Officer External data protection consultancy Data protection policy Regular data protection training	Data protection working party Regular reporting GDPR eLearning module
Loss of major source of income	Diversity of fundraising activities Regular contact with key supporters Review of management information	Regular reporting Review of key relationships Development of CRM database

Going concern statement

The Trustees have reviewed the financial statements and forecast to the end of 2022, detailing the plans for financial recovery whilst maintaining a first-class service to the EB community. It is recognised that there are underlying uncertainties, however the Trustees consider the charity can continue its business-critical activities and remain a going concern. The retail estate re-opened during April 2021 providing a regular income stream of unrestricted funds, plus the suite of fundraising events started up again. An analysis of risks and opportunities relating to the forecast resulted in net opportunities exceeding £400k, therefore uncertainties are expected to be managed and not be material to our ability to continue operating.

During the first few months of 2021 the third national lockdown impacted DEBRA's financial situation, resulting in an estimated £2.1m reduction in total income following three-four further months of shop closures in early 2021. In addition, lockdown prevented face-to-face fundraising events taking place. The economic fallout of lockdown and the uncertainty it generated impaired the ability of individuals, corporate and trusts to make donations.

The Trustees therefore decided to carry out some cost reductions to mitigate this impact with further cost saving levers that could be pulled if required. This included the furlough of staff who are not involved in business-critical work, recruitment freeze and limited new research commitments. This has produced savings of £1.7m in 2021 compared with the original budget.

Before the pandemic struck DEBRA had financial strength with high cash balances which have provided a buffer to weather the storm. All applicable sources of government financial aid have been accessed. Given DEBRA's financial strength at the outset of the pandemic, whilst uncertainty continues to exist, this does not pose a material uncertainty that would cast doubt on the charity's ability to continue as a going concern. As the country emerges from lockdown, the financial plan demonstrates DEBRA will pull through this crisis and the Trustees consider it is still appropriate to prepare the 2020 accounts on a going concern basis.

Structure, governance & management

DEBRA (Company Limited by Guarantee) is a membership organisation and governed by its Articles of Association, which state that the Board of Trustees shall comprise of up to 15 Trustees, with no less than 50% of the Trustees having direct experience of EB management.

DEBRA Trustees

Our Board of Trustees is made up from a majority of those who have a direct experience of EB, who either have EB themselves or have a close family member with EB, and those who have skills and experience that will add value to the governance and leadership of DEBRA. Of the 15 Trustees, up to eight are elected by the membership and up to seven appointed by the Board. This ensures a good mix of skills, talents and experience to serve the DEBRA community.

No Annual General Meeting was held during 2020 due to the pandemic. The Board of Trustees re-appointed Simon Cuzner for a further three-year term. The Board also co-opted Becky Edwards and Vivien Mundy who are both Elected Trustees for a second three-year term.

Two new candidates, Douglas Rouse and Michael Thomas, were also co-opted by the Board as Elected Trustees. James Hinchcliffe and Simone Bunting reached the end of their third term, so stepped down and David Wilkinson retired at the start of the year. The Trustees thank them for their valuable contribution to DEBRA over the last nine years. Following this, a postal vote of members took place which confirmed the co-opted appointments as Elected Trustees.

New Trustees receive a Trustee Handbook and other relevant publications, individual inductions from senior Trustees as relevant and Trustees attend external training courses appropriate to their role on the Board of Trustees. There are four board meetings per year, which the CEO attends and Senior Management Team members attend as required.

Trustee Board committees

Finance, Risk & Audit Committee – determines and advises the Board of Trustees on matters relating to finance, risk and audit as the Board of Trustees may remit to it, in particular the sound financial management of the charity, its resources and assets.

Care & Research Committee – determines and advises the Board of Trustees on matters relating to strategy in research, healthcare, community support and policy as the Board of Trustees may remit to it.

Retail Committee – determines and advises the SMT and the Board of Trustees on matters relating to the shops. It utilises specific knowledge of its members to assist the CEO and Director of Retail to manage the shops, deliver operational performance against plan, comply with regulations and promote the cause of the charity.

Fundraising & Communications Committee – oversees the fundraising activities of the SMT on matters relating to the growth of income generation and maximising opportunities within Marketing and PR. The Committee approves and recommends to the Board of Trustees the strategic direction of fundraising and the financial plan. It utilises specific knowledge of its members to challenge and support the Director of Fundraising and Communications and the Marketing and PR Team to deliver against plans, comply with regulations and promote the cause of the charity.

DEBRA UK International Committee – determines and advises the Board of Trustees on matters relating to international strategy in research, healthcare, community support and international policy as the Board of Trustees may remit to it. In addition, the international Medical and Scientific Advisory Panel makes recommendations for research projects to DEBRA International which may be considered by the DEBRA UK International Committee.

Nominations & Governance Committee – oversees the structure, composition and effectiveness of the charity's Board of Trustees and its Committees, as well as the appointment process of trustees. The Committee monitors the governance procedures of the charity.

Steering Group – this committee was created in light of the pandemic and meets regularly on an 'as needed' basis.

See Table 5 below – Trustees' membership and attendance.

The Trustees plan to undertake a full review of the existing committee structure during 2021.

Board diversity

To ensure that we have a well-balanced board, those with experience of living or working with EB are the majority, together with those Trustees who do not have EB experience but possess the relevant skills and knowledge. The Board members come from a variety of backgrounds, in order to bring different perspectives to discussions and enhance the Board's decision-making process.

We follow the Equal Opportunities Policy in the selection of Board members, in the same way we do for staff recruitment. Membership of the Board is open to all members of DEBRA, irrespective of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values. Broader diversity of the Board will be reviewed in 2021 as part of DEBRA's Equality, Diversity & Inclusion project.

Charity governance code

The Board consistently reviews all aspects of DEBRA's governance and ensures that our governance standards and practices fully embrace the principles of the Charity Commission 'Charity Governance Code'. We are currently reviewing the updates to the code in December 2020, which strengthened the Principle of Equality of opportunity, Diversity and Inclusion (EDI) and updated the Integrity Principle.

Succession planning

We have built strength and depth in our Trustee Board, incorporating appropriate succession planning by appointing two Vice Chairs, each for periods of two years with an annual rotation of one of those. Prospective new trustees are often invited to join a committee for a minimum period of twelve months before becoming trustees.

Fundraising standards

Section 162a of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. We do not undertake face-to-face fundraising from the general public. The legislation defines fundraising as 'soliciting or otherwise procuring money or other property for charitable purposes'. Such amounts receivable is presented in the accounts as 'voluntary income' and include legacies and grants.

We make all efforts to train staff and ensure compliance with fundraising standards at all times. Specifically:

- the majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the Trustees
- where we work with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met
- there are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc
- where volunteers assist in our fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued
- volunteer fundraisers are managed and supported from the offices in Bracknell and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them
- data protection procedures are in place governing the management of supporter and donor data on our DEBRA database; compliance with the GDPR rules that came into force in May 2018 continues to be monitored
- we work with vulnerable people, particularly within the EB community, and often they wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly
- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2020. We received 73 compliments in 2020 for either the service we provide to the EB Community or through liaising with the general public in DEBRA shops.

Activities in Scotland

We are active across several areas in Scotland. The primary charitable activities are seen in funding community support and research projects, notably at the Universities of Dundee and Edinburgh and the Cancer Research UK Beatson Institute, University of Glasgow. On the income generation side, there were two regional fundraising members of staff and 37 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Blantyre.

Table 5: Trustees' membership and attendance records as at 31.12.2020.

Name	Notes	Board Attendance	Finance, Risk & Audit Committee	Nominations & Governance Committee	Care & Research Committee	Retail Committee	Fundraising & Communications Committee	DEBRA UK International Committee
Jim Irvine	Chair	**7 of 7**	5 of 5	5 of 5				
David Bendor-Samuel		6 of 7		**5 of 5**				
Simone Bunting	stood down 22.07.2020	2 of 3		4 of 5			**6 of 6**	
Rebecca Cresswell		4 of 7					5 of 6	
Simon Cuzner		5 of 7	3 of 5			**5 of 5**		
Carly Fields		7 of 7			3 of 3		5 of 6	
Andrew Grist	on leave of absence	1 of 7		1 of 5	1 of 2			
James Hinchcliffe	stood down 26.06.2020	leave of absence						
Christo Kapourani		4 of 7			1 of 3			
Graham Marsden		5 of 7		5 of 5				**1 of 1**
Joanne Merchant	Treasurer	7 of 7	**5 of 5**			5 of 5		1 of 1
Vivien Mundy		6 of 7			2 of 3			1 of 1
Timothy Powell		5 of 7			**3 of 3**			
Douglas Rouse	elected 01.07.2020	3 of 4					5 of 5	1 of 1
Michael Thomas	elected 01.07.2020	3 of 4					2 of 3	
David Wilkinson	stood down 23.01.2020	0 of 1						

The committee chairs' attendance is highlighted in bold.

Auditor

Trustees have taken all reasonable steps to make themselves aware of any information needed by the company's auditor for the purposes of their audit and to establish that the auditor is aware of that information. The Trustees are not aware of any relevant audit information of which the auditor is unaware.

We engaged Sayer Vincent LLP as auditor during 2020 and they have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditor 28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

The Trustees' Annual Report, incorporating the Strategic Report, is approved by the Board of Trustees and signed on behalf of the Trustees:

Jim Irvine

Chair of Trustees

29th April 2021

Trustees' statement of responsibilities

The Trustees (who are also directors of DEBRA for the purposes of company law) are responsible for preparing the Trustees' Annual Report including the strategic report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities Statement of Recommended Practice (SORP)
- make judgements and estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2020 was 3,279 (2019: 3,111). The Trustees are members of the charity but this entitles them only to voting rights. The Trustees have no beneficial interest in the charity.

Auditor's report

Independent auditor's report to the members of DEBRA.

Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2020 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2020 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the Financial Reporting Council's Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on DEBRA's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the Trustees' Annual Report, including the strategic report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Annual Report, including the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Annual Report, including the strategic report, has been prepared in accordance with applicable legal requirements

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report, including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the statement of Trustees' responsibilities set out in the Trustees' Annual Report, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud are set out below.

Capability of the audit in detecting irregularities

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, our procedures included the following:

- we enquired of management and Finance, Audit and Risk committee, which included obtaining and reviewing supporting documentation, concerning the charity's policies and procedures relating to:
    - identifying, evaluating, and complying with laws and regulations and whether they were aware of any instances of non-compliance
    - detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud
    - the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.
- we inspected the minutes of meetings of those charged with governance
- we obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience
- we communicated applicable laws and regulations throughout the Audit Team and remained alert to any indications of non-compliance throughout the audit
- we reviewed any reports made to regulators
- we reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations
- we performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud
- in addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to

anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Fleur Holden (Senior Statutory Auditor)
Date: 6 May 2021
for and on behalf of Sayer Vincent LLP, Statutory Auditor
Invicta House, 108-114 Golden Lane, LONDON, EC1Y 0TL

Sayer Vincent LLP is eligible to act as auditor in terms of section 1212 of the Companies Act 2006

Financial statements

For the year ended 31 December 2020

Statement of Financial Activities

Statement of Financial Activities including income and expenditure account for the year ended 31 December 2020.

	Notes	2020 Unrestricted funds £	2020 Designated funds £	2020 Restricted funds £	2020 Total £	2019 Unrestricted funds £	2019 Designated funds £	2019 Restricted funds £	2019 Total £
Income and endowments from:									
Donations and legacies	2	**3,814,335**	**-**	**468,926**	**4,283,261**	2,790,693	-	573,611	3,364,304
Charitable activities		**18,210**	**-**	**-**	**18,210**	20,299	-	-	20,299
Other trading activities	3	**6,903,611**	**75,771**	**46,491**	**7,025,873**	12,845,645	264,717	211,958	13,322,320
Investments	4	**47,403**	**-**	**-**	**47,403**	56,544	-	-	56,544
Other		**38,150**	**-**	**-**	**38,150**	34,432	-	-	34,432
Total		**10,821,709**	**75,771**	**515,417**	**11,412,897**	15,747,613	264,717	785,569	16,797,899
Expenditure on:									
Raising funds	6	**10,935,662**	**-**	**-**	**10,935,662**	12,891,642	-	1,000	12,892,642
Charitable activities	6	**1,452,433**	**821,551**	**573,782**	**2,847,766**	1,446,033	1,141,627	522,388	3,110,048
Total		**12,388,095**	**821,551**	**573,782**	**13,783,428**	14,337,675	1,141,627	523,388	16,002,690
Net income/(expenditure)		**(1,566,386)**	**(745,780)**	**(58,365)**	**(2,370,531)**	1,409,938	(876,910)	262,181	795,209
Transfer between funds		**1,473,695**	**(1,395,027)**	**(78,668)**	**-**	(1,170,160)	1,355,000	(184,840)	-
Net movement in funds		**(92,691)**	**(2,140,807)**	**(137,033)**	**(2,370,531)**	**239,778**	**478,090**	**77,341**	**795,209**
Reconciliation of funds:									
Total funds brought forward		**2,231,188**	**2,906,757**	**213,576**	**5,351,521**	1,991,410	2,428,667	136,235	4,556,312
Total funds carried forward		**2,138,497**	**765,950**	**76,543**	**2,980,990**	2,231,188	2,906,757	213,576	5,351,521

All operations are continuing. The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

The notes on pages 79-106 form part of these financial statements.

Balance sheet

Balance sheet as at 31 December 2020.

	Notes	£	2020 £	£	2019 £
Fixed assets					
Tangible assets	10		**1,077,946**		1,262,260
Programme related investment	11		**1**		-
Investment in DEBRA Trading Ltd	22		**2**		2
			1,077,949		1,262,262
Current assets					
Current asset investment	12	**-**		3,750,000	
Stocks		**5,910**		6,300	
Debtors	13	**1,616,619**		1,926,703	
Cash at bank and in hand		**5,076,553**		2,898,199	
Fixed assets held for sale		**167,960**		78,000	
		6,867,042		8,659,202	
Creditors: amounts falling due within one year	14	**(4,182,719)**		(3,781,180)	
Net current assets			**2,684,323**		4,878,022
Total assets less current liabilities			**3,762,272**		6,140,284
Creditors: amounts falling due over one year	14		**(599,474)**		(546,951)
Provisions for liabilities			**(181,808)**		(241,812)
Total net assets			**2,980,990**		5,351,521

The funds of the charity

Restricted income funds	16	**76,543**	213,576
Unrestricted funds	17	**2,904,447**	5,137,945
Total charity funds		**2,980,990**	5,351,521
Unrestricted funds			
- Designated	17	**765,950**	2,906,757
- General		**2,138,497**	2,231,188
		2,904,447	5,137,945
Restricted funds	16	**76,543**	213,576
Total charity funds		**2,980,990**	5,351,521

Company registration number 4118259

The accounts were approved by the Board on 29th April 2021 and signed on their behalf by:

J Irvine

Jim Irvine
Chair of Trustee Board

Joanne Merchant
Treasurer

Cash flow statement

	Notes	2020 £	2020 £	2019 £	2019 £
Cashflows from operating activities:					
Net cash provided by operating activities	17		**(1,366,471)**		1,580,543
Cashflows from investing activities:					
Dividends, interest and rents from investments		**47,403**		56,544	
Proceeds from the sale of property, plant and equipment		**7,052**		-	
Purchase of property, plant and equipment		**(68,791)**		(383,314)	
Proceeds from sale of investments		**3,750,000**		-	
Purchase of investments		**(190,840)**		(1,000,000)	
Net cash (used in) / provided by investing activities			**3,544,825**		(1,326,770)
Change in cash and cash equivalents in the reporting period			**2,178,354**		253,773
Cash and cash equivalents at the beginning of the reporting period			**2,898,199**		2,644,426
Cash and cash equivalents at the end of the reporting period			**5,076,553**		2,898,199

The notes on pages 79 to 106 form part of these financial statements.

Notes to the accounts

1 Accounting policies

1.1 Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015), Charities SORP (FRS 102) (second edition - October 2019), the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and Trustees Investment (Scotland) Act 2005.

1.2 Going concern

The Trustees reviewed the charity's budget in December 2020 and were content that these plans were affordable and that the accounts should be prepared on going concern basis. However the continuing impact of the coronavirus pandemic and its effect has meant that the Senior Management Team and Trustees have been reviewing financial plans for the next 12 months to ensure the charity can continue its business-critical activities and remain a going concern.

The Government decision to impose a third national lockdown has had an effect on DEBRA's financial situation, resulting in an estimated £2.1m reduction in total income following three-four further months of shop closures in 2021. In addition, on-going social distancing measures present challenges to running fundraising events. The economic fallout of lockdown and the uncertainty it generates impairs the ability of individuals, corporate and trusts to make donations.

The Trustees have, therefore, decided to carry out some cost reductions to mitigate this impact with further cost saving levers which can be pulled should it be required. This includes the furlough of staff who are not involved in business-critical work, recruitment freeze and limited new research commitments. This has produced savings of £1.7m in 2021 compared with the original budget. Before the pandemic struck DEBRA had financial strength with high cash balances which have provided a buffer to weather the storm. All applicable sources of government financial aid have been accessed.

Taking into account the measures announced by the government in the March 2021 budget, a financial forecast has been prepared to the end of 2022, detailing the plans for financial recovery whilst maintaining a first-class service to the EB community.

Given DEBRA's financial strength at the outset of the pandemic, whilst uncertainty continues to exist, this does not pose a material uncertainty that would cast doubt on the charity's ability to continue as

a going concern. As the country emerges from lockdown, the financial plan demonstrates DEBRA will pull through this crisis and the Trustees consider it is still appropriate to prepare the 2020 accounts on a going concern basis.

1.3 Legal status of charity

The charity is a company limited by Guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

1.4 Judgements and estimates made by management

The financial statements include judgements and estimates as defined by the accounting policies. Legacy income is recognised as probable at probate, using an estimate provided by executors. Premises service charge liabilities are estimated from information supplied by property specialists. The dilapidations provision is reviewed annually on an individual lease basis by a property specialist. Research grants are recognised in full in the Income and Expenditure Account at the point of commitment in order to ensure no reliance on future fundraising to meet these financial commitments. Programme related investments are impaired based on a judgement of the intrinsic value of the investment at the balance sheet date, where no market value exists.

The Trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

1.5 Income

Donations and gifts are recognised in full in the Statement of Financial Activities when received. Unclaimed gift aid receivable is accrued in the year to which it relates. Legacies receivable are recognised when there is entitlement, probability of receipt and is measurable. Grants are recognised in full when received. Gifts in kind are only included in the accounts where the Trustees can ascribe a value in excess of £1,000.

Landlord concessions received during the COVID-19 pandemic have not been treated as gifts in kind because the Trustees considered due to the extent of the concessions as a result of the generosity of the landlords, it would significantly distort the accounts for the reader, therefore rent concessions are reflected as reductions in rent costs in the year.

Trading income is recognised in full when received with the exception of income that is deferred where it represents a payment in advance for a specific event that will not take place until a future accounting period. This exception does not apply to sponsorship for charity challenges taking place in a future accounting period.

Claims made through the UK Government's Coronavirus Job Retention Support Scheme are recognised as income in the period which the associated staff were furloughed. This income is considered to be unrestricted. Small business retail grants have been recognised as unrestricted income in the periods to which they relate.

1.6 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Equipment purchased for use in research is written off as part of the research project costs as incurred. Expenditure on raising funds are those costs incurred in seeking voluntary contributions and running the retail operations. Charitable activities include expenditure associated with the operation of the charity and the provision of its services. Governance costs comprise the costs relating to the general running of the charity, and include direct items such as external audit, legal advice for trustees, the cost of trustee meetings, and are included in central overhead costs. Central costs are apportioned and allocated between the cost of raising funds and charitable expenditure on the basis of central staff time allocation to the various activities.

1.7 Recognition of grant liabilities

Grants are awarded for research projects over a period of one to five years. All grants provide the right to terminate with up to three months' notice and continuation of funding is dependent on satisfactory progress reporting and review. It is always the intention to honour the funding of all grants awarded and full grant recognition has been incorporated into these accounts as the most appropriate and prudent policy. By adopting this policy, the Trustees ensure the funds for research grants have been raised in full prior to making financial commitments to research institutions.

1.8 Tangible fixed assets and depreciation

Tangible fixed assets with a value in excess of £1,000 are capitalised and stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

Freehold and long leasehold buildings	Over 25 years
Head office fit out costs	Over life of the lease
Mobile homes	Over 10 years
Fixtures, fittings, static equipment	Over 5 years
Shop equipment	Over 5 years
Motor vehicles	Over 4 years
Mobile equipment	Over 3 years

A review of assets is undertaken annually, and adjustments are made to the expected useful life as required. From 1 January 2009 freehold land and buildings are assumed to have a residual value of 50%.

1.9 Sale and leaseback

In 2017 the charity sold office premises originally purchased in 2004. These premises were leased back at market rent, until January 2020.

1.10 Programme related investment and impairment

Programme related expenditure with a value in excess of £1,000 is stated at cost less impairment. The investment held in 2020 has been impaired by 99.99% in year one, with a residual holding value of £1.

1.11 Cash and short-term investments

The charity holds cash requirements for day-to-day activities in current bank accounts with HSBC, Lloyds, Santander and Clydesdale. The deposit account is held with HSBC. Short-term investments that were held in money market deposits with Lloyds Commercial Banking were redeemed early at the start of the coronavirus pandemic. For the purposes of the cash flow statement, cash equivalents are defined as current asset investments, and short-term deposits with a maturity of less than 3 months, which are readily convertible into known amounts of cash.

1.12 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

1.13 Creditors

Trade creditors and other payables are normally recognised at their settlement amount after allowing for any trade discount due. Payments to suppliers are within standard payment terms of 30 days. Liabilities are recognised when there is a present obligation, as a result of past events, and there is a probable future outflow of resources that can be estimated reliably.

1.14 Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at settlement value.

1.15 Stock

The Trustees do not consider it appropriate to recognise donated goods for resale as stock on the grounds that the cost of obtaining stock information would greatly outweigh any benefit. The costs involved would include the setting up of processes and procedures for a stock count in over 100 shops, training shop staff and volunteers in the process, software programming, and the checking and analysis of the reports produced.

All other stock is valued at the lower of cost or net realisable value.

1.16 Accumulated funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the Trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The exceptional circumstances of 2020 resulted in funds being undesignated in order for the charity to continue its charitable objectives. The purposes and uses of the restricted funds and designated funds are set out in Note 17 to the financial statements.

1.17 Consolidated accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the company's results and the investment the charity holds in DEBRA Trading Limited are shown separately in Note 22 to the financial statements.

1.18 Foreign currency translation

Foreign currency transactions are recorded at the exchange rate at the time of the transaction. Foreign currency assets and liabilities are translated into sterling at the exchange rate ruling at the balance sheet date. Resulting gains or losses on retranslation are included in the statement of financial activities.

1.19. Leases

Operating lease annual rental payments are charged to the statement of financial activities on a straight line basis over the term of the lease.

1.20. Termination payments

Termination payments either by way of redundancy or settlement agreement are recognised at the time of payment. Any payments exceeding the statutory minimum are authorised by the Trustees.

2 Donations and legacies

	Unrestricted funds	Restricted funds	**Total 2020**	Total 2019
	£	£	**£**	£
Donations & gifts	1,438,777	157,348	**1,596,125**	2,671,296
Legacies receivable	219,678	37,500	**257,178**	184,761
Grants receivable	2,155,880	274,078	**2,429,958**	508,247
	3,814,335	468,926	**4,283,261**	3,364,304
Donations & gifts:				
Individual donations	1,189,520	128,112	**1,317,632**	2,012,963
Corporate donations	234,413	26,488	**260,901**	590,001
International donations	496	-	**496**	524
Events by individuals	14,348	2,748	**17,096**	67,808
	1,438,777	157,348	**1,596,125**	2,671,296
Grants receivable:				
Charitable trusts	82,962	274,078	**357,040**	508,247
Government grants	2,072,918	-	**2,072,918**	-
	2,155,880	274,078	**2,429,958**	508,247

Government grants consist of £1,248,868 (2019: 0) received under the Coronavirus Job Retention Scheme and £824,050 (2019: 0) received in local authority grants.

Gifts in kind of £88,006 (2019: £100,454) are included in donations and gifts. These include the ongoing advertising in a national newspaper valued at £20,800 (2019: £20,800) and online AdWords valued at £67,206 (2019: £70,308).

3 Other trading activities

	Total 2020	Total 2019
	£	£
Income	**7,025,873**	13,322,320
Operating expenses	**(10,227,464)**	(12,124,386)
Net income from fundraising activities	**(3,201,591)**	1,197,934

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2020 there were 109 shops trading (2019:121). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	**Net income 2020**	Net income 2019
	£	£	**£**	£
Retail	6,477,316	(9,757,368)	**(3,280,052)**	751,975
Fundraising events	429,761	(470,096)	**(40,335)**	84,552
Miscellaneous trading	118,796	-	**118,796**	361,407
	7,025,873	(10,227,464)	**(3,201,591)**	1,197,934

Retail income excludes income of £606,091 (2019: £1,226,225) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail gift aid commission of £84,619 (2019: £144,523) which is recognised in miscellaneous trading. In 2020 the COVID-19 pandemic had a significant impact on gross retail income, dropping by 47%. There was also a drop of 12 in the number of shops trading. The profit covenanted by DEBRA Trading Limited of £34,176 (2019: £216,884) is recognised in miscellaneous trading.

The table below reflects a true statement of total retail income, including retail Gift Aid, commission and retail donations.

	2020	2019
	£	£
Retail income	**7,168,026**	13,609,304
Retail expenditure	**(9,757,368)**	(11,486,581)
Retail net income	**(2,589,342)**	2,122,723

Investment income	**Total Unrestricted 2020**	Total 2019
	£	£
Interest receivable	**29,940**	29,766
Rent of property	**17,463**	26,778
Total investment income	**47,403**	56,544

Rental income was received from one freehold shop and two flats situated above properties, which were acquired.

4 Investment income

	Total Unrestricted 2020	Total 2019
	£	£
Interest receivable	**29,940**	29,766
Rent of property	**17,463**	26,778
Total investment income	**47,403**	56,544

Rental income was received from one freehold shop and two flats situated above properties, which were acquired in 2009.

5 Grants payable

Expenditure on charitable activities include grants payable to third parties as detailed in Note 21. There were 154 (2019: 334) Community Support grants totalling £38,071 (2019: £85,117) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 21.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2020 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,183,468 (2019: £1,428,243) and clinical projects to the sum of £138,105 (2019: £186,213).

The total future commitment is currently committed to be spent as follows:

	Total 2020	Total 2019
	£	£
Within 1 year	**722,099**	1,067,505
Within 2-3 years	**589,406**	489,658
Within 4-5 years	**10,068**	57,293
	1,321,573	1,614,456
Provided within the grants payable creditor (note 14)	**1,321,573**	1,614,456

6 Expenditure

	Staff costs	Grants payable	Other costs	**Total 2020**	Total 2019
	£	£	£	**£**	£
Raising funds:					
Donations and legacies	415,507	-	292,691	**708,198**	768,256
Other trading activities	5,703,336	-	4,524,128	**10,227,464**	12,124,386
	6,118,843	-	4,816,819	**10,935,662**	12,892,642
Charitable activities:					
Research	339,024	572,731	269,343	**1,181,098**	1,495,647
Healthcare	80,880	241,967	23,990	**346,837**	357,350
Community support	651,422	38,072	56,432	**745,926**	824,070
Respite breaks	-	-	93,467	**93,467**	100,434
Public education	367,838	-	112,600	**480,438**	332,547
	1,439,164	852,770	555,832	**2,847,766**	3,110,048
	7,558,007	852,770	5,372,651	**13,783,428**	16,002,690

	Staff costs	Grants payable	Other costs	**Total 2019**	Total 2018
	£	£	£	**£**	£
Raising funds:					
Donations and legacies	373,590	-	394,666	**768,256**	727,350
Other trading activities	5,778,241	-	6,346,145	**12,124,386**	11,966,308
	6,151,831	-	6,740,811	**12,892,642**	12,693,658
Charitable activities:					
Research	315,029	685,893	494,725	**1,495,647**	1,366,338
Healthcare	103,825	224,194	29,331	**357,350**	472,066
Community support	680,069	85,117	58,884	**824,070**	781,204
Respite breaks	-	-	100,434	**100,434**	84,674
Public education	224,927	-	107,620	**332,547**	261,382
	1,323,850	995,204	790,994	**3,110,048**	2,965,664
	7,475,681	995,204	7,531,805	**16,002,690**	15,659,322

Other costs

	Depreciation and amortisation	Overhead allocation	Miscellaneous costs	**Total 2020**	Total 2019
	£	£	£	**£**	£
Raising funds:					
Donations and legacies	-	174,569	118,122	**292,691**	394,666
Other trading activities	78,022	301,865	4,144,241	**4,524,128**	6,346,145
	78,022	476,434	4,262,363	**4,816,819**	6,740,811
Charitable activities:					
Research	-	38,798	230,545	**269,343**	494,725
Healthcare	-	23,990	-	**23,990**	29,331
Community support	-	56,432	-	**56,432**	58,884
Respite breaks	48,016	-	45,451	**93,467**	100,434
Public education	-	43,441	69,159	**112,600**	107,620
	48,016	162,661	345,155	**555,832**	790,994
	126,038	639,095	4,607,518	**5,372,651**	7,531,805

	Depreciation and amortisation	Overhead allocation	Miscellaneous costs	**Total 2019**	Total 2018
	£	£	£	£	£
Raising funds:					
Donations and legacies	-	178,750	215,916	**394,666**	383,899
Other trading activities	83,116	292,446	5,970,583	**6,346,145**	6,347,696
	83,116	471,196	6,186,499	**6,740,811**	6,731,595
Charitable activities:					
Research	-	33,553	461,172	**494,725**	93,104
Healthcare	-	29,331	-	**29,331**	25,026
Community support	-	52,439	6,445	**58,884**	51,556
Respite breaks	35,613	-	64,821	**100,434**	84,674
Public education	-	107,620	-	**107,620**	79,191
	35,613	222,943	532,438	**790,994**	333,551
	118,729	694,139	6,718,937	**7,531,805**	7,065,146

Net income / (expenditure) for the year is stated after charging:

	2020	2019
	£	£
Operating leases	**1,279,426**	1,639,888
Auditors remuneration	**19,313**	20,420
Non-audit services	**-**	24,773
Depreciation of tangible fixed assets	**158,451**	138,758
Defined contribution pension costs	**345,016**	312,098
Exchange differences	**(20,916)**	34,441

7 Cost allocation

All central overhead costs are allocated to activities on the basis of staff time, and are detailed below:

		2020	2019
		£	£
Staff costs:		1,521,167	1,450,761
Overheads:			
Office premises rent		62,891	58,640
Service charges, utilities & cleaning		57,788	54,644
Equipment costs		148,634	142,517
Postage, printing, stationary, telephone & fax		54,502	82,430
Insurance costs		97,435	92,458
Legal, professional & consultancy fees		135,198	50,278
Depreciation		36,829	22,653
Irrecoverable VAT		24,216	52,988
Bank charges		6,755	15,081
Sundry expenses	-	8,681	87,224
Governance costs:			
Audit fees		19,313	20,420
Miscellaneous costs		4,215	14,806
		639,095	694,139
Total Allocation		2,160,262	2,144,900

8. Trustees

None of the Trustees received any remuneration from DEBRA during the period, but nine of them were reimbursed a total of £2,259 (2019: 6 - £3,871) for travel, subsistence and training expenses.

Tim Powell's wife received £600 (£2019: £1,400) for administrative services at EB2020. James Hinchcliffe received a community support grant totalling £0 (2019: £720). Andy Grist received community grants totalling £15 (2019: £528). The aggregate figure for trustee donations in 2020 was £2,158 (2019: £726). In addition many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £2,253 (2019: £1,883), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9 Employees

The average number of employees during the period was:

	2020 Full time equiv	2020 Number	2019 Number
Research	2.9	5	5
Healthcare*	-	-	1
Community Support	11.2	12	15
Fundraising & Comms	18.2	20	14
Retail	232.5	321	331
Management & Administration	15.7	18	19
	280.5	376	385

At the end of the year the number of employees per department was:	2020 Full time equiv	2020 Number	2019 Number
Research	1.6	4	5
Healthcare*	-	-	1
Community Support	9.7	10	17
Fundraising & Comms	17.2	19	14
Retail	221.6	304	332
Management & Administration	14.2	16	19
	264.3	353	388

*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 19. Staff employed by external institutions and funded through research grants are also excluded.

Employment costs

	Total 2020	Total 2019
	£	£
Wages & salaries	6,484,221	6,231,757
Social security costs	432,918	395,899
Pension costs	345,016	312,098
	7,262,155	6,939,754

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £313,959 (2019: £309,502) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £24,016 (2019: £5,917) unpaid.

During the year the CEO and SMT were paid relevant business expenses totalling £13,028 (2019: £37,237).

The following members of staff received emoluments above £60,000:

	2020	2019
Between £60,001 - £70,000	**3**	2
Between £80,001 - £90,000	**2**	2
Between £100,000 - £110,000	**1**	-
Between £140,001 - £150,000	**-**	1

The figures above exclude a compensation payment made to the ex-CEO of the charity. If this compensation figure is included there would be one member of staff who received emoluments between £170,000 and £180,000.

Redundancy and compensation payments totalled £124,289 in 2020 (2019: £12,195), which were all paid in 2020.

The aggregate pay of key management personnel, including employer's NI and pension contributions was £736,268 (2019: £678,512). The aggregate employer's pension contribution for key management personnel was £59,304 (2019: £70,856)

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £53,426 (2019: £62,666), and there are retirement benefits accruing for six (2019: five) employees under a defined contribution scheme.

10 Fixed assets

Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land and buildings	Long leasehold land and buildings	Total
	£	£	£	£	£	£
Cost:						
At 1 January 2020	403,961	547,162	325,614	699,347	82,500	2,058,584
Transfer to current assets				(121,000)		(121,000)
Additions	36,245	-	32,546	-	-	68,791
Disposals	(2,464)	(67,000)	(37,042)	-	-	(106,506)
At 31 December 2020	**437,742**	**480,162**	**321,118**	**578,347**	**82,500**	**1,899,869**
Depreciation:						
At 1 January 2020	228,065	216,582	165,240	168,287	18,150	796,324
Transfer to current assets				(26,620)		(26,620)
Charge for the year	59,075	48,017	36,829	12,881	1,650	158,452
Disposals	(2,191)	(67,000)	(37,042)	-	-	(106,233)
At 31 December 2020	**284,949**	**197,599**	**165,027**	**154,548**	**19,800**	**821,923**
Net Book Value:						
Brought forward	175,896	330,580	160,374	531,060	64,350	1,262,260
At 31 December 2020	**152,793**	**282,563**	**156,091**	**423,799**	**62,700**	**1,077,946**

The Head Office fit out costs have been included in the fixtures, fittings and equipment category.

The Trustees agreed to sell one freehold shop during 2019, and a flat above another shop in 2020, both of which remained unsold at 31st December 2020 and are held for sale within current assets on the balance sheet.

11 Programme related investment

	2020	2019
	£	£
Investment in Fibrx Derm Inc	**190,840**	-
Impairment	**(190,839)**	-
Net Investment Value	**1**	-

The Trustees invested £190,840 ($250,000) in Fibrx Derm Inc, a US biotech company, purchasing 203,252 series A-2 convertible preferred stock, at a price of $1.23 per share. This investment supported the development of a new treatment to help wound healing in patients suffering from Dystrophic Epidermolysis Bullosa. The purpose of this investment was in furtherance of the charitable objectives of the charity, and no financial return was expected. The value of the investment has been impaired by 99.99% as the most prudent course of action.

12 Investment in short term deposits

	2020	2019
	£	£
Lloyds money market deposits	**-**	3,750,000
	-	3,750,000

13 Debtors

	2020	2019
	£	£
HMRC	**281,158**	259,632
Misc debtors	**387,844**	210,306
Other debtors	**48,653**	295,263
Accrued income	**363,233**	550,443
Prepayments	**535,731**	611,059
	1,616,619	1,926,703

Payments due from HMRC are VAT payable of £216,811 (2019: £259,632), plus £64,347 (2019: 0) from the Coronavirus Job Retention Scheme. Miscellaneous debtors includes £266,825 (2019: £197,612) due for shared research grants. Other debtors includes £34,176 (2019: £216,884) profit due from the trading subsidiary. Accrued income includes gift aid of £147,660 (2019: £278,092) due from HMRC.

Total future minimum lease receivable was £3,413 in 2020 (2019: £3,388), in respect of one shop and one flat above a shop.

14 Creditors: amounts falling due within one year

	2020	2019
	£	£
Trade creditors	**678,754**	669,803
Grants payable	**2,158,657**	2,201,344
Other creditors	**308,617**	6,226
Taxation and social security	**92,476**	96,107
Accruals	**917,315**	692,069
Deferred income	**26,900**	115,631
	4,182,719	3,781,180

Grants payable includes £790,811 (2019: £875,173) relating to future commitment and £1,436,558 (2019: £1,320,047) relating to outstanding invoices for work done.

There was deferred income of £26,900 in 2020 (2019: £115,631), representing income for events which would have to be repaid in the event of cancellation.

During the year we discovered that certain employee benefits had historically been mis-categorised as expenses resulting in an underpayment of income tax and national insurance. We also discovered that in 2019 and 2020 we had over-recovered VAT. We voluntarily reported both matters to HMRC during 2020 and paid a total sum of £64,341 in 2021 in settlement of these disclosures. This figure is included in other creditors. In voluntarily reporting these matters, we avoided having any penalties applied.

Creditors: amounts falling due over one year

	2020	2019
	£	£
Grants payable	**599,474**	546,951
	599,474	546,951

There was a dilapidations provision of £181,810 (2019: £241,812). In the year £81,422 was released from the provision and a further £21,420 was charged. It is uncertain when this provision will be spent.

15 Other financial commitments

The following payments are committed to be paid in the future in respect of operating leases:

	2020	2019	2020	2019
	Leases of land and buildings	Leases of land and buildings	**Other**	Other
	£	£	**£**	£
Within 1 year	**1,264,152**	1,617,494	**15,274**	22,394
Within 2-5 years	**1,170,587**	1,421,057	**29,332**	5,283
After 5 years	**5,250**	58,029	**-**	-
	2,439,989	3,096,580	**44,606**	27,677

There were capital commitments of £1,200 (2019: £0) at year end, falling due within one year.

16 Analysis of funds

Restricted funds

	Balance at 31 Dec 2019	Income	Expenditure	Transfer to General Fund	**Balance at 31 Dec 2020**
	£	£	£	£	**£**
Research	-	182,771	(104,103)	(78,668)	**-**
Healthcare	79,477	26,223	(100,100)	-	**5,600**
Community Support & Respite	134,099	292,599	(355,755)	-	**70,943**
Public Education	-	13,824	(13,824)	-	**-**
	213,576	515,417	(573,782)	(78,668)	**76,543**

Transfers to the general fund occurred following restricted income received in the current year for projects fully committed in the accounts in a prior year.

	Balance at 31 Dec 2018	Income	Expenditure	Transfer to General Fund	**Balance at 31 Dec 2019**
	£	£	£	£	**£**
Research	300	150,551	(123,851)	(27,000)	**-**
Healthcare	39,245	268,951	(228,719)	-	**79,477**
Community Support & Respite	96,690	366,067	(170,818)	(157,840)	**134,099**
	136,235	785,569	(523,388)	(184,840)	**213,576**

Restricted funds comprised:

	2020	2019
	£	£
Healthcare - EB Nurses		73,877
Healthcare - Birmingham Children's Hospital Specialist Bath	**5,600**	5,600
Community Support - Community Suppport Manager for Scotland	**37,259**	60,000
Community Support - Community Support Manager Post	**10,496**	56,167
Community Support - Community Support in Berkshire	**8,048**	8,476
Community Support - Support Grants in Northamptonshire	**962**	2,400
Community Support - Support Grants in Hampshire	**5,502**	1,550
Community Support - Support Grants in Scotland	**1,934**	-
Community Support - Support Grants in South Gloucestershire	**1,356**	-
Community Support - other restricted funds	**5,386**	5,506
	76,543	213,576

17 Analysis of funds

Unrestricted funds

The Trustees have transferred the following amounts into designated funds during 2020:

	Balance at 31 Dec 2019	Transfers	Income	Expenditure	**Balance at 31 Dec 2020**
	£	£	£	£	**£**
Future research grants	2,618,290	(1,339,000)	-	(763,340)	**515,950**
Nursing Continuity	250,000	-	-	-	**250,000**
EB2020 conference	38,467	(56,027)	75,771	(58,211)	**-**
Total designated funds	2,906,757	(1,395,027)	75,771	(821,551)	**765,950**
General fund	2,231,188	1,473,695	10,821,709	(12,388,095)	**2,138,497**
Total unrestricted funds	5,137,945	78,668	10,897,480	(13,209,646)	**2,904,447**

	Balance at 31 Dec 2018	Transfers	Income	Expenditure	**Balance at 31 Dec 2019**
	£	£	£	£	**£**
Future research grants	1,948,840	1,355,000	-	(685,550)	**2,618,290**
Nursing Continuity	250,000	-	-	-	**250,000**
EB2020 conference	229,827	-	264,717	(456,077)	**38,467**
Total designated funds	2,428,667	1,355,000	264,717	(1,141,627)	**2,906,757**
General fund	1,991,410	(1,170,160)	15,747,613	(14,337,687)	**2,231,188**
Total unrestricted funds	4,420,077	184,840	16,012,330	(15,479,314)	**5,137,945**

The funds held in excess of the minimum cash-backed reserves as stated in the Reserves Policy have been designated by the Trustees to be expended on future research grants in line with the charitable objectives of the charity. In the light of the coronavirus pandemic the Trustees undesignated £1,397,000 from this fund to the general fund to contribute towards the running costs of the charity. It is anticipated this fund will be spent in the next year.

The designated fund for nursing continuity has been established as a contingency in the event of future

NHS funding withdrawal, and the Trustees maintained a balance of £250,000 in this fund in 2020.

In 2018 the Trustees established a designated fund for the EB2020 conference, which was hosted by DEBRA in the UK in January 2020. £300,000 was designated to this fund in 2017 and 2018. During 2020 income of £75,771 was added to this fund and £58,211 was spent. The balance of £56,027 in this fund was transferred to the designated fund for future research.

18 Analysis of net assets between categories of funds

	Unrestricted funds	Restricted funds	**Total 2020**	Total 2019
	£	£	**£**	£
Fund balances at 31 December 2020 are represented by:				
Fixed assets	1,077,949	-	**1,077,949**	1,262,262
Current assets	6,790,499	76,543	**6,867,042**	8,659,202
Creditors: amounts falling due within one year	(4,182,719)	-	**(4,182,719)**	(3,781,180)
Creditors: amounts falling due over one year	(781,282)	-	**(781,282)**	(788,763)
	2,904,447	76,543	**2,980,990**	5,351,521

	Unrestricted funds	Restricted funds	**Total 2019**	Total 2018
	£	£	**£**	£
Fund balances at 31 December 2019 are represented by:				
Fixed assets	1,262,262	-	**1,262,262**	1,099,016
Current assets	8,445,626	213,576	**8,659,202**	7,617,553
Creditors: amounts falling due within one year	(3,781,180)	-	**(3,781,180)**	(3,223,805)
Creditors: amounts falling due over one year	(788,763)	-	**(788,763)**	(936,452)
	5,137,945	213,576	**5,351,521**	4,556,312

19 Reconciliation of net income to net cash flow from operating activities

	2020	2019
	£	£
Net income for the reporting period (as per the statement of financial activities)	**(2,370,531)**	795,209
Depreciation and amortisation charges	**162,872**	138,758
Impairment of programme related investment	**190,839**	-
Dividends, interest and rents from investments	**(47,403)**	(56,544)
Profit on disposal of fixed assets	**(6,777)**	3,313
Decrease in stock	**390**	11,838
Decrease in debtors	**310,084**	278,285
Increase in creditors	**394,057**	409,684
	(1,366,471)	1,580,543

20 Analysis of cash and cash equivalents

	As at 1 Jan 2020	Cash Flows	**As at 31 Dec 2020**
	£	£	**£**
Cash at bank and in hand	2,898,199	2,178,354	**5,076,553**
Total	2,898,199	2,178,354	**5,076,553**

An analysis of changes in net debt note has not been prepared on the basis that DEBRA only has cash and cash equivalents, the movement on which is shown above.

21 Grants to institutions

	Total paid in 2020	Total paid to date	Total committed project cost
	£	£	£
Research projects:			
University of Dundee			
1. Clinical fellow funding	**89,572**	504,474	504,474
University of Glasgow			
1. Mechanisms of TGF-beta mediated tumour protectin in RDEB	**78,525**	157,138	157,138
Guy's and St Thomas' Hospital, London			
1. Validated clinical endpoints study re EB therapy evaluation	**120,717**	533,601	734,790
2. Stem cell therapy trial to investigate treating debilitating itch	**113,262**	465,414	497,360
3. Wound care and its complications in patients with EB	**-**	-	112,500
	233,979	999,015	1,344,650
Thomas Jefferson University, Philadelphia, USA			
2. Phase 2 clinical trial of Rigosertib for RDEB SCC	**40,984**	470,490	470,490
University of Birmingham Dental School & Hospital			
1. Characterisation of skin microbiome in EB patients	**113,500**	264,930	296,289
2. Gait Analysis in EB Simplex	**-**	-	46,030
3. Clinical Fellowship	**35,114**	35,114	125,263
4. Novel spray to treat mucosal scarring	**25,406**	25,406	152,385
	174,020	325,450	619,967
University of Cologne			
1. Exploring immunity in wound healing complications in RBEB	**57,462**	141,018	170,635

Universitair Medisch Centrum Groningen			
1. Effectiveness of phyto-cannabinoid treatment of pain in EB	**47,300**	159,025	159,025
Instituto Dermopatico deli'Immacolata Rome			
1. Anti-fibrotic potential of histone deacetylase inhibitors for RDEB	**32,729**	59,780	70,963
King's College London			
1. Preclinical studies of lentiviral-mediated COL7A1 gene therapy	**84,044**	145,189	174,023
Great Ormond Street Institute of Child Health			
1. Respiratory cell and gene therapy for children with junctional EB	**-**	-	135,338
Bambino Gesù Children's Hospital			
1. MicroRNAs expression profiling, activity and therapeutic perspectives	**14,680**	14,680	77,592
University of Edinburgh			
1. Understanding role of Kindlin-1 loss in squamous cell carcinoma	**10,288**	10,288	112,833
New York Medical College			
1. Identifying innate and adaptive immune mechanisms in RDEB	**34,644**	34,644	207,538
Other			
Decrease in research provision	**(244,775)**	-	-
Grants written off at end of project		-	-
Total research grants	**653,452**	3,021,191	4,204,666
Research project expenditure by category:			
Pre-clinical development	**182,575**		1,555,381
Clinical investigation	**269,331**		1,202,372
Patient treatment study	**201,546**		1,126,875
	653,452		3,884,628

	Total paid in 2020	Total project cost
Healthcare projects:	**£**	£
Great Ormond Street Hospital for Sick Children		
Clinical nurse specialists in EB	**66,176**	66,176
Guys & St Thomas' Hospital London		
Adult EB support nurses	**79,647**	80,288
Clinical best practice guidelines on parenteral and enteral feeding	**39,996**	38,000
Other		
Birmingham Children's Hospital	**56,148**	56,394
Miscellaneous	**-**	22,891
Total Healthcare Team grants	**241,967**	263,748

22 Related parties

The principal activities of DEBRA Trading Ltd (company number: 2487114), a company incorporated in England and Wales, are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship. DEBRA has a beneficial interest in 100% of the company's issued share capital of £2.

	2020	2019
	£	£
Turnover	**96,247**	307,231
Net profit gift aided to DEBRA	**34,176**	216,884
Net assets	**2**	2

During the year, the charity charged management charges totalling £7,200 including VAT (2019: £7,200) to its subsidiary, DEBRA Trading Limited.

Louise Bellaers Photography

Reference and administrative details

Patrons and Ambassadors

Royal Patron
HRH The Countess of Wessex

Life Patron
Philip Evans

President
Simon Weston

Vice Presidents
Graeme Souness, Frank Warren

Trustees

Chair
Jim Irvine

Treasurer
Joanne Merchant

Vice-Chairs
Graham Marsden & Carly Fields (from 13.02.20)

Trustees
David Bendor-Samuel
Simone Bunting (until 22.07.2020)
Rebecca Cresswell
Simon Cuzner
Andrew Grist
James Hinchcliffe (until 26.06.2020)
Christo Kapourani
Vivien Mundy
Timothy Powell
Douglas Rouse (from 01.07.2020)
Michael Thomas (from 01.07.2020)
David Wilkinson (until 23.01.2020)

Senior Management Team

Chief Executive
Ben Merrett (until 30.06.20)
Tony Byrne (from 12.10.2020)

Director of Research
Caroline Collins (until 27.11.2020)

Director of Healthcare, Membership & Community Support
Claire Mather

Director of Retail
Chantelle Milne

Director of Fundraising & Communications
Hugh Thompson

Director of Human Resources
Louise Westphalen

Director of Finance
Carol Harris

Company Secretary
Dawn Jarvis

Additional details

Charity Commission Number
1084958

OSCR Number
SC039654

Company Number
4118259

Registered office & principal address
DEBRA, The Capitol Building, Oldbury, Bracknell, RG12 8FZ

Auditor
Sayer Vincent LLP, Invicta House, 108-114 Golden Lane, London EC1Y 0TL

Banker
HSBC, Thames Valley Business Banking, Hanborough House, Wallbrook Court, North Hinskey, Oxford, OX2 0QS

Solicitor
Stone King, 91, Charterhouse Street, London, EC1M 6HR

Abbreviations

CPG	Clinical Practice Guideline
CEO	Chief Executive Officer
DEB	Dystrophic Epidermolysis Bullosa
EB	Epidermolysis Bullosa
EBS	Epidermolysis Bullosa Simplex
EDI	Equality, Diversity & Inclusion
F&E	Furniture & Electrical retail store
GDPR	General Data Protection Regulation
HR	Human Resources
k	thousand
LFL	like-for-like
m	million
NHS	National Health Service
pa	per annum
RDEB	Recessive Dystrophic Epidermolysis Bullosa
SMT	Senior Management Team
Temporary shop	any shop that has a notice period of one year or less, where notice can be served by the landlord and has a tenure of: holding over (England), holding over by licence, lease with rolling break, licence, licence with rolling break, tacit relocation, tenancy at will.
y on y	year on year
PPE	Personal Protective Equipment
HMRC	HM Revenue and Customs

DEBRA funds pioneering research, specialist healthcare, international best practice and lifelong care and support to the EB Community.

We make a difference today with the aim of a better future for those suffering from the condition.

Together we #FightEB.

Facebook: /DEBRACharity
Twitter: @charitydebra
Instagram: @charitydebra

Registered with FUNDRAISING REGULATOR

www.debra.org.uk | 01344 771961 | debra@debra.org.uk

DEBRA, The Capitol Building, Oldbury, Bracknell, Berkshire RG12 8FZ

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Signable

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Parties involved with this document

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Thu, 29th Apr 2021 12:21:33 BST	Jim Irvine - Signer (c70f668949a3c5c2660a9d3079e0e655)
Thu, 29th Apr 2021 12:22:30 BST	Joanne Merchant - Signer (ee649f8c9454a28654f97e55ad2e2db4)

Audit history log

Date	Action
Thu, 29th Apr 2021 12:22:30 BST	The envelope has been signed by all parties. (31.53.64.153)
Thu, 29th Apr 2021 12:22:30 BST	Joanne Merchant signed the envelope. (31.53.64.153)
Thu, 29th Apr 2021 12:21:56 BST	Joanne Merchant viewed the envelope. (31.53.64.153)
Thu, 29th Apr 2021 12:21:49 BST	Joanne Merchant opened the document email. (31.53.64.153)
Thu, 29th Apr 2021 12:21:34 BST	Document emailed to joanne.merchant@debra.org.uk (18.132.9.15)
Thu, 29th Apr 2021 12:21:33 BST	Sent the envelope to Joanne Merchant (joanne.merchant@debra.org.uk) for signing. (185.164.181.131)
Thu, 29th Apr 2021 12:21:33 BST	Jim Irvine signed the envelope. (185.164.181.131)
Thu, 29th Apr 2021 12:18:25 BST	Jim Irvine viewed the envelope. (185.164.181.131)
Thu, 29th Apr 2021 9:48:30 BST	Document emailed to jim.irvine@debra.org.uk (3.8.19.21)
Thu, 29th Apr 2021 9:48:30 BST	Sent the envelope to Jim Irvine (jim.irvine@debra.org.uk) for signing. (81.156.41.172)
Thu, 29th Apr 2021 9:48:30 BST	Carol Harris signed the envelope. (81.156.41.172)
Thu, 29th Apr 2021 9:47:42 BST	Carol Harris viewed the envelope. (81.156.41.172)
Thu, 29th Apr 2021 9:47:12 BST	Document emailed to carol.harris@debra.org.uk (18.130.127.192)
Thu, 29th Apr 2021 9:47:11 BST	Sent the envelope to Carol Harris (carol.harris@debra.org.uk) for signing. (81.156.41.172)
Thu, 29th Apr 2021 9:46:36 BST	Joanne Merchant has been assigned to this envelope (81.156.41.172)
Thu, 29th Apr 2021 9:46:36 BST	Jim Irvine has been assigned to this envelope (81.156.41.172)

Thu, 29th Apr 2021 9:46:36 BST	Carol Harris has been assigned to this envelope (81.156.41.172)
Thu, 29th Apr 2021 9:44:53 BST	Document generated with fingerprint bf8d4c3d3754c40cd089850be38ddb42 (81.156.41.172)
Thu, 29th Apr 2021 9:44:46 BST	Envelope generated by Carol Harris (81.156.41.172)