

Trustees' Annual Report & Accounts 2024



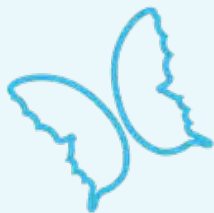
Our vision

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.

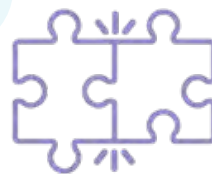
Our values



Making a difference



Caring



Inclusive



Respectful



Passionate



Committed

Contents

The trustees present the annual report (including the strategic report) for the year ended December 2024.

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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 of 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.





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 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 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 the 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 been 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 GCMG
Simon Weston CBE
Graeme Souness CBE
Lenore England
Frank Warren
Stuart Procter

Our Ambassadors:

Michel Roux	Simon Davies
Emma Dodds	Jon Isaacs
Scott Brown	Laurence Blunt
Steve Rider	Lucy Beall
John Williams MBE	Vie Portland
Dr Anna Martinez	Fazeel Irfan
Professor Gareth Inman	Isla Grist
Professor John McGrath	Erin Ward
Mark Moring	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.

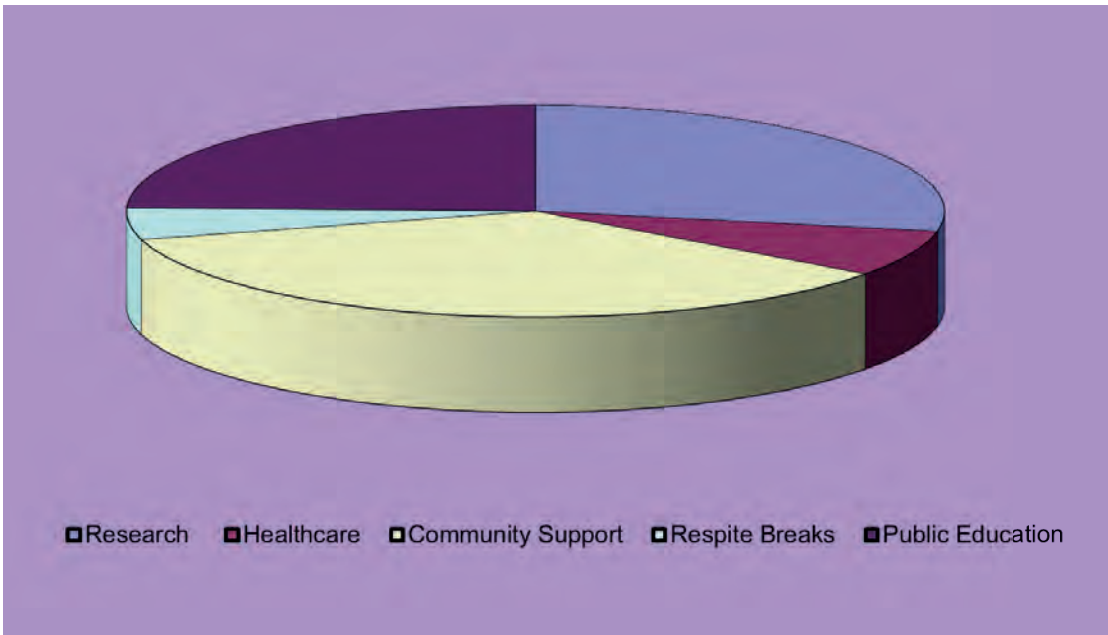
Summary

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	<ul style="list-style-type: none">■ 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	<ul style="list-style-type: none">■ 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.	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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.	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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.	<ul style="list-style-type: none"> ■ 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.	<ul style="list-style-type: none"> ■ 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					
		Unrestricted funds	Designated funds	Restricted funds	Total
	Notes	£	£	£	£
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					
		Unrestricted funds	Designated funds	Restricted funds	Total
	Notes	£	£	£	£
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.

		2024		2023	
	Notes	£	£	£	£
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.

		2024	2024	2023	2023
	Notes	£	£	£	£
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 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.

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
	<u>5,066,898</u>	<u>634,553</u>	<u>5,701,451</u>	<u>4,770,185</u>	<u>755,404</u>	<u>5,525,589</u>
	<u><u>5,066,898</u></u>	<u><u>634,553</u></u>	<u><u>5,701,451</u></u>	<u><u>4,770,185</u></u>	<u><u>755,404</u></u>	<u><u>5,525,589</u></u>
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
	<u>3,189,498</u>	<u>45,567</u>	<u>3,235,065</u>	<u>4,102,510</u>	<u>223,990</u>	<u>4,326,500</u>
	<u><u>3,189,498</u></u>	<u><u>45,567</u></u>	<u><u>3,235,065</u></u>	<u><u>4,102,510</u></u>	<u><u>223,990</u></u>	<u><u>4,326,500</u></u>
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
	<u>631,695</u>	<u>547,829</u>	<u>1,179,524</u>	<u>189,399</u>	<u>496,414</u>	<u>685,813</u>
	<u><u>631,695</u></u>	<u><u>547,829</u></u>	<u><u>1,179,524</u></u>	<u><u>189,399</u></u>	<u><u>496,414</u></u>	<u><u>685,813</u></u>

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
	<u>7,992,291</u>	<u>-</u>	<u>209,299</u>	<u>759,661</u>	<u>5,752,522</u>	<u>14,713,773</u>
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
	<u>2,312,550</u>	<u>670,727</u>	<u>98,301</u>	<u>330,763</u>	<u>431,034</u>	<u>3,843,375</u>
	<u>10,304,841</u>	<u>670,727</u>	<u>307,600</u>	<u>1,090,424</u>	<u>6,183,556</u>	<u>18,557,148</u>

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
	<u>7,687,629</u>	<u>-</u>	<u>81,677</u>	<u>647,952</u>	<u>6,077,398</u>	<u>14,494,656</u>
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
	<u>2,015,496</u>	<u>1,399,952</u>	<u>104,378</u>	<u>273,494</u>	<u>603,384</u>	<u>4,396,704</u>
	<u>9,703,125</u>	<u>1,399,952</u>	<u>186,055</u>	<u>921,446</u>	<u>6,680,782</u>	<u>18,891,360</u>

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
<u>Governance costs:</u>		
Audit, non-audit and internal audit fees	24,850	31,300
	<u>1,090,424</u>	<u>921,445</u>
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, dermatotherapy 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
	<u>362.3</u>	<u>287.5</u>	<u>368</u>	<u>288.0</u>

Notes to the financial statements

(continued)

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

	2024	2024	2023	2023
	No.	FTE	No.	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	-	-
	<u> </u>	<u> </u>
Net investment value carried forward	<u>1</u>	<u>1</u>

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
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

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)
	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
	<u>3,628,830</u>	<u>2,999,965</u>

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
	<u>694,192</u>	<u>881,673</u>

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)
	<u>403,110</u>	<u>218,812</u>

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	-
	<u>2,023,211</u>	<u>3,324</u>	<u>2,467,916</u>	<u>7,756</u>

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
	<u>420,668</u>	<u>634,553</u>	<u>(680,553)</u>	<u>-</u>	<u>374,668</u>

	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
	<u>487,511</u>	<u>755,403</u>	<u>(822,246)</u>	<u>-</u>	<u>420,668</u>

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)
	<u>2,731,590</u>	<u>100,000</u>	<u>374,668</u>	<u>3,206,258</u>

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)
	<u>2,185,189</u>	<u>981,397</u>	<u>420,668</u>	<u>3,587,254</u>

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
	<hr/>	<hr/>
Net cash used in operating activities	(234,863)	(698,357)
	<hr/>	<hr/>

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
	<hr/>	<hr/>
Cash at bank and in hand at 31 December	2,795,577	2,111,857
	<hr/>	<hr/>

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 del'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
	<u>3,332</u>	<u>127,238</u>

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	<u>1,544,889</u>	<u>107,997</u>	<u>-</u>	<u>1,652,886</u>

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	<u>1,724,017</u>	<u>107,997</u>	<u>-</u>	<u>1,832,014</u>

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 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.

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

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