

Trustees' Annual Report & Accounts 2023



Our vision

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

Our mission

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

Our values



Making a difference



Caring



Inclusive



Respectful



Passionate



Committed

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

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What is EB

Skin as fragile as a butterfly's wings

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

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

Genetic condition

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

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

Types of EB

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

Symptoms and complications

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

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

Treatments

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

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

No cures

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

A welcome from our Chair of Trustees and CEO

Bringing EB to the public's attention

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

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

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

The year wasn't without its challenges though. The external environment and operating conditions for our retail function presented significant challenges in terms of increased costs

and revenue generation. These challenges will remain in 2024, however by building a more efficient and lean retail function, using this as a basis for expansion, and ensuring that we have stores in locations that offer the greatest revenue and contribution potential, we are confident that we can overcome these challenges. We will also continue to leverage the opportunity for incremental sales growth and contribution through our online platforms.

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

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

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

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

Despite improving awareness of EB and DEBRA in 2023, awareness overall remains low and so we must continue to leverage all the opportunities available to us to raise awareness with the public and to connect with members of the EB community who may not be aware of DEBRA UK so that they can become members and benefit from the support services we offer. We also need

more healthcare professionals to be aware of EB and be able to diagnose it so that they can refer patients to the specialist EB healthcare that is already available through the NHS.

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





Our work

Investing in a future free of EB

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

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

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

Life-changing EB research

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

Specialist healthcare

In 1987 we funded the first specialist EB nurse. We now work in partnership with the NHS to deliver an enhanced EB healthcare service for people with all types of EB in the UK. We have

invested in the development of EB centres of excellence, fund clinical best practice guidelines for clinicians and individuals, and connect patients with the expert, specialist services they need across the UK. Our funding has helped establish a model EB diagnostics centre, which makes it possible for parents to receive prenatal diagnostic testing if they are at risk of passing on EB. We are dedicated to ensuring that everyone with EB has access to the best care and expertise from diagnosis onwards.

Life-long community support

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

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

International collaboration to enhance global EB patient care and best practice

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

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

Being the difference for EB

Our impact in 2023



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



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



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



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



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



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



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



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

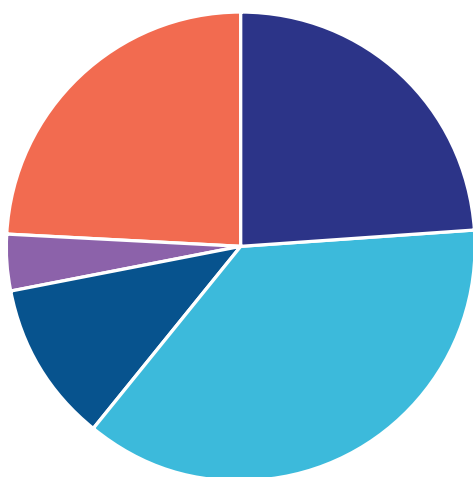
Achieved together thanks to the support of:

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

Committed to the EB community

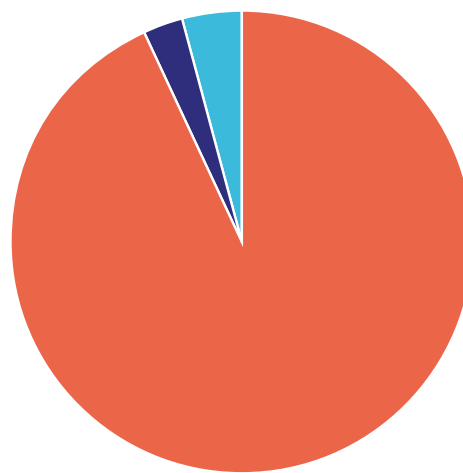
We are committed to ensuring that people with EB in the UK and their families and carers get the essential support they desperately need, supporting specialist healthcare, and investing in life-changing research.

The activities
we spent on in 2023



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

How we raised money



- Fundraising £3,468,000 net fundraising income,
- Retail £107,000 net retail income
- Other £146,000 other income

Research into effective treatments for EB

Our vision

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

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

Our objectives

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

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

Our progress in 2023

Independent advisor

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

Professor Griffiths has provided invaluable advice to support our research programme and has been proactively involved in supporting the charity

by speaking at awareness events, including the House of Commons, on the principles of drug repurposing and the potential benefits it offers for people living with EB.

Research grant process

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

Scientific Grant Advisory Panel

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

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

Drug repurposing programme

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

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

Our plans for 2024

Partnerships

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

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

Patient-centricity

EB patients, their family members, and carers through their own experiences are the experts on the impact of EB. Therefore, it is vitally important that the needs of the EB community, those living

and working with the condition, help shape the research selection process and drive the future of EB research, balancing short-term patient benefits and support for long-term research into potential treatments. Through forums such as the lived experience group we will continue to ensure that patient voices are heard and help shape our research programme.

Increasing awareness

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

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



Specialist healthcare

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

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

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

Our ambition

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

Our objectives

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

Our progress in 2023

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

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



Our plans for 2024

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

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

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



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

EB community support

Life-long support, advocacy, and engagement

3877

DEBRA UK members
(1857 living with EB)

500+

members stayed in our
holiday homes in 2023

424

support grants
awarded in 2023

9.5%

increase in
membership vs. 2022

1621

requests for support from
the DEBRA Community
Support Team

30

events (in-person
or virtual)

Our ambition

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

Our objectives

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

Our progress in 2023

Membership

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

Community support

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

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

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

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

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

Member engagement

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

We were very grateful to be able to count on the support of 167 active

members of our involvement network in 2023 who supported the charity in many ways including shaping the future of our EB services, deciding what research we'll fund next, defining our holiday home priorities, and enhancing our member events.

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

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

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



Holiday home respite

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

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

Member events

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

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

Our plans for 2024

Membership

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

Community support

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

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

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

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

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



Member engagement

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

Member events

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

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

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



My EB story - Living with EB isn't easy

“

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

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

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

Since signing up as a member with DEBRA UK, I have gained important knowledge about the EB community and the support available to us. I was given support with obtaining a Blue Badge; this has been an important inclusion in my everyday life, and I now suffer much less, especially after a bad outbreak of blisters. After obtaining my Blue Badge, I was told about the government support

that was available to me, such as Personal Independence Payment. With the support of DEBRA UK through one-to-one appointments, I was able to successfully apply for this, which has given me financial support with some of the costs of bandages and plasters, as well as reapplying for my Blue Badge.

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

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

DEBRA member living with EBS

”



Our partnerships

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

150+

research projects worth
£22m funded by DEBRA UK

55

DEBRA groups internationally

20+

live research projects

46

years of collaboration

Our ambition

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

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

Building partnerships to improve patient outcomes

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

- Action Medical Research for Children to co-fund an EBS research project.
- NHS England to collate EB patient data across NHS departments to better

understand the patient journey and bottlenecks within the system, and to help set future research priorities.

- Cancer Research UK Institute (formally known as the Beatson Institute) to develop pre-clinical cancer models to better understand RDEB skin cancer progression and to test drugs prior to patient clinical trials.

Corporate partners

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



Raising awareness

Engaging communities

+8%

increase in awareness
of DEBRA

+4%

increase in
awareness of EB

210%

increase in
emails sent



National media exposure
for EB and DEBRA UK

Our ambition

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

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

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

As important is raising awareness of DEBRA UK and the services that we offer to the EB community. We want as many people as possible

with EB to become DEBRA UK members so that they can benefit from, and help shape our services, and stay fully informed of the progress we are making against our key objectives.

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

Our objectives

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

Our progress in 2023

Awareness raising

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

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

The media campaign started early in the year with radio and TV interviews to coincide with Rare Disease Day in late February, and continued into the summer with further media interviews, a programme of paid digital advertising, and a direct mail campaign to support the swimming

challenge. We rounded off the year with media interviews to coincide with EB Awareness Week in October. The combined media exposure – which included mainstream programmes, such as BBC Breakfast and The One Show, ITV's This Morning, and national radio stations including BBC Radio Five Live and Talksport – helped us reach millions of people across the UK, exposing the charity to a whole new audience, many of whom supported us with donations that helped us achieve our A Life Free of Pain fundraising challenge.

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



Government campaigning

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

Thank you.

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

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

Our plans for 2024

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

Awareness

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

Fundraising

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

Member recruitment

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

Healthcare professionals' awareness

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



Government campaigning

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

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

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

Building engaged communities

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

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

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

Retail

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

New website / review of member resources

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

How we raise money

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

Our ambition

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

Our objectives

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

Our progress in 2023

A Life Free of Pain / English Channel Swim

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

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

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

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

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

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

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

New team members

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

Our plans for 2024

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

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

Events

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





Corporate fundraising

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

Trusts and grants

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

Scotland

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

Nurturing new supporters

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

Digital fundraising

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



Thank you

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

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

Our Patron, President, Vice Presidents

HRH The Duchess of Edinburgh GCVO
Simon Weston CBE
Lenore England
Graeme Souness
Frank Warren
Stuart Procter

Our Ambassadors:

Michel Roux
Emma Dodds
Steve Rider
John Williams MBE
Dr Anna Martinez
Professor Gareth Inman
Professor John McGrath
Lucy Beal Lott
Vie Portland
Fazeel Irfan
Isla Grist

Our Advisor:

Professor Christopher
Griffiths OBE



Trusts & foundations

Bill Brown's 1989 Charitable Trust
The Brothers Trust
C Brewer & Sons Ltd Trust
Calleva Foundation
Enterprise Foundation
The Christopher Laing Foundation
The Clare Foundation
The Corn Mill Trust
The David Laing Foundation
The Donald Ericsson Trust
The Dorus Trust
The Dyers' Company's Charitable Trust
The Field Family Trust
The Forest Hill Charitable Trust
The Fowler, Smith & Jones Charitable Trust
The Gloag Foundation
The Grace Trust
The Headley Trust
The Hospital Saturday Fund
The Hugh Fraser Foundation
J J Fenwick Charitable Trust
The J R Asprey Family Charitable Foundation
James Cowper Kreston
The JC and KC Foundation
The John Cowan Foundation
The Jonathan Cartmel Miller Charitable Trust

The Joseph Strong Frazer Trust
The Klahr Charitable Trust
The Leach Fourteenth Trust
Loftus Charitable Trust
Louis Baylis (Maidenhead Advertiser) Charitable Trust
The Louis Nicholas Residuary Charitable Trust
The Manson Family Charitable Trust
Marconi Charities Trust Fund
The Maud Elkington Charitable Trust
The Michael and Anna Wix Charitable Trust
MJC Stone Charitable Trust
Murphy-Neumann Charity
The Oakgrove Foundation
The P F Charitable Trust
The Raven Charitable Trust
The Riada Trust
The Ripley Trust
The Sir Iain Stewart Foundation
The Squire Patton Boggs Charitable Trust
The Strangward Trust
The Sylvia and Colin Shepherd Charitable Trust
The Verdon-Smith Family Charitable Trust
The Whittington Charitable Trust
The Wixamtree Trust

Our stores

94

UK stores.

45%

increase in online sales
year on year.

£100k+

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

At the heart of our communities

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

Our ambition

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

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

Our objectives

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

Our progress in 2023

Facing the challenge of difficult operating conditions

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

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

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

Stores

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

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

Raising awareness and supporting the appeal

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

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

Online

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

We moved away from a store hub concept to support our eBay business and instead

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

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

People

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



Our plans for 2024

Stores

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

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

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

Online

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

People

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



Our dedicated volunteers

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

1,065

volunteers

211,232

hours volunteered in 2023

£2.2m

of free labour thanks to
our loyal volunteers

“

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

”

Mark Francis, DEBRA UK
Volunteering Development
Manager

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

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

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

Our people

Making a difference every day

370

permanent
members of staff

10

trustees - 7 living with or
directly affected by EB

125

hours of training provided

1,065

volunteers

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

Our mission

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

Our objectives

Our People agenda focuses on three priority areas:

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

Our progress in 2023

Mental health first aiders

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

Employee engagement survey

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

Employee listening forums

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

Butterfly Awards

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

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



EDI

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

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

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

The median hourly full pay gap remains 0%.

Training and development

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

Recruitment

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

Our plans for 2024

Employee engagement survey

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

Embedding our values

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

Training and development

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

Our Environmental, Social, and Governance (ESG) journey

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

100%

of unsaleable clothing recycled rather than sent to landfill.

53%

reduction in paper consumption year on year.

100+

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

Our ambition

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

Our objectives

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

Our progress in 2023

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

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

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

Environmental

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

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

Social

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

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

Governance

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

Our plans for 2024

Environmental

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

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

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



Social

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

We will continue the EDI journey to being an organisation that reflects the diversity profile of the members and communities we serve. We will continue to promote best practice in all our operations and activities, considering

environmental protection, public health and safety, human rights, anti-bribery and corruption, and labour and anti-slavery practices.

Governance

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

“

We will hold ourselves accountable and measure our progress on our ESG journey, continually seeking to learn and incorporate ESG best practices in all we do.

”

Tony Byrne, CEO DEBRA UK



Charity overview, objectives & public benefit

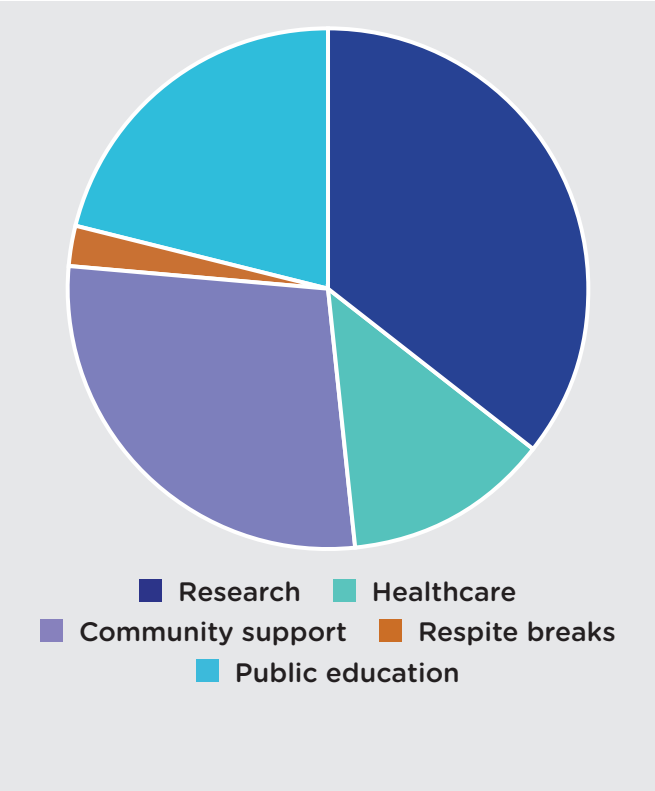
Financial review

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

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

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

Charitable spend



Summary

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

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

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

Charity overview, objectives & public benefit

Table 3: Financial KPI summary

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

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

Reserves policy

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

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

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

Charity overview, objectives & public benefit

Funds

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

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

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

Restricted funds

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

Oliver Thomas Memorial fund

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

Research

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

Respite breaks

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

Asset cover for funds

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

Investment policy

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

Expenses policy

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

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

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

Charity overview, objectives & public benefit

Related parties

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

Internal audit

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

Principal risks and uncertainties

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

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

See Table 4: DEBRA's major risks.

Table 4: Summary Extract from DEBRA's Risk Register

Risk	Cause & Effect	Controls
Economy / Inflation	Adverse economic conditions or high inflation impact shop or other income	<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 adequately insure	Lack of cover for major event leading to severe financial strain and inability to continue to operate.	<ul style="list-style-type: none">■ Annual insurance review by FD, Finance Manager and relevant SMT members■ Insurance Broker researches the market for the best deals to meet DEBRA's needs■ FRA periodic insurance review■ Tender for insurance brokers every 3 years■ Robust risk assessments prior to all DEBRA events
Poor service delivery by third party organisations at DEBRA events	Poor services leading to complaints and damage to DEBRA's reputation. Ultimately leading to loss of donor confidence impacting revenue	<ul style="list-style-type: none">■ Director of Fundraising and Communication reports■ Partner only with established reputable sponsors after due diligence■ Commercial Participation Agreements

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Non-compliance with H&S or other law	<p>Health and Safety issues not being identified or addressed timely leading to accidents and potential serious injury and legal action. Increase in sickness due to injury caused at work</p> <p>Threat of enforcement actions ('Action Letters') by Local Authorities, Fire and Rescue Services and Environmental Health Departments or the Health and Safety Executive.</p>	<ul style="list-style-type: none"> Regular reviews of Risk Assessments, version controlled and dated; Accident and Incident recording and review via Assure software; Any significant injury or dangerous occurrence will also trigger a review; Risk Assessments in place for all Regional and National Membership AND Fundraising events; Staff training and briefing at events; Event participants are asked about personal history and fitness; Dedicated Health and Safety Manager has been employed; Annual Insurance review;
Major Virus epidemic or pandemic and resulting Government containment actions	Shop closures leading to loss of retail income and staff and potential inability to make payments as they fall due. Could lead to inability to continue meeting charitable objectives and operating as a charity.	<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.
Insufficiently robust cyber security	Cyber attack leading to loss of data or financial fraud. Data loss could lead to severe GDPR fines and major damage to reputation. Potential impact on DEBRA's ability to continue operating.	<ul style="list-style-type: none"> End-point detection software / anti-virus on all computers Cyber insurance policy Email scanned before reaching DEBRA servers Remote users hard drives are encrypted Secured wifi at Bracknell head office Remote desktop sessions time out after 20 mins Back-up daily server images moved to the cloud File shadow copy active on the server (protects against Malware encryption spyware) Complex passwords required by policy Meraki firewalls in place throughout offices and shops Anti-virus/spyware solution on all PC based tills All credit card machines meet PCI compliance standard C Monitoring of data access

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Failure to maintain adequate cash flow	Suppliers not being paid on time, delays in staff expenses reimbursement. Need for overdraft facilities. Ultimately leading to inability to continue to operate.	<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.
Lack of appropriate skills of SLT	<p>Poor performance against budget</p> <p>High number of grievances or staff turnover in a department</p> <p>Whistleblowing</p>	<ul style="list-style-type: none"> ■ Robust recruitment procedures involving Trustees ■ Pre employment references ■ Thorough induction ■ Budget for L&D for senior managers ■ Use of 360 input into appraisals
Failure to comply with the requirements to satisfactorily report Safeguarding issues	Any reports or awareness that Safeguarding issues have not been properly reported.	<ul style="list-style-type: none"> ■ Health & Safety Manager in place (reporting to Director of HR), to specifically lead Safeguarding. ■ Basic Safeguarding training provided for all staff through eLearning, and additional in-depth training provided for Designated Safeguarding Officers.
Inappropriate Fundraising activities undertaken	Increase in complaints and negative media comment leading to loss of funding. Financial mismanagement leading to audit and investigations. Lack of funds threatens charity existence.	<ul style="list-style-type: none"> ■ SLT monitoring and CEO reports to Trustees ■ Fundraising and Communications Committee meetings ■ Periodic review of Donations Policy ■ Board approval required for major new initiatives ■ Donations Policy ■ Threshold of £10k for confirming donations are from a legitimate source
Board does not have required skills	Lack of specific skills on Board leading to poor strategic direction. Resulting inability to meet charitable objectives and wasted resources.	<ul style="list-style-type: none"> ■ Recruitment of Trustees with relevant experience and succession planning ■ Nominations and Governance Committee ■ Budget in place for trustee training and relevant staff ■ External advice taken if Board lacks relevant skill ■ Governance Review ■ Formalise induction of new trustees

Charity overview, objectives & public benefit

Going concern statement

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

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

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

Structure, governance & management

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

Board of Trustees

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

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

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

The Trustees are the sole legal members of the charity.

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

Charity overview, objectives & public benefit

Trustee Board Committees

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

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

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

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

See Table 5 below – Trustees’ membership and attendance.

Board diversity

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

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

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

Charity governance code

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

Succession planning

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

Charity overview, objectives & public benefit

Fundraising standards

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

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

- the majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the trustees
- where we work with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met
- there are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc
- where volunteers assist in our fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued

- volunteer fundraisers are managed and supported from the offices in Bracknell and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them
- data protection procedures are in place governing the management of supporter and donor data on our DEBRA database; compliance with GDPR rules continues to be monitored
- we work with vulnerable people, particularly within the EB community, and often they wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly
- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2023.

Activities in Scotland

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

Charity overview, objectives & public benefit

Board Attendance Table

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

Auditor

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

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

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

Jim Irvine
Chair of Trustees
10 May 2024

Trustees' statement of responsibilities

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

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

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

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

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

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

Auditor's report

Auditor's report

Independent auditor's report to the members of DEBRA

Opinion

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

In our opinion, the financial statements:

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

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Auditor's report

(continued)

Other Information

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

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Auditor's report

(continued)

Responsibilities of trustees

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

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

Auditor's responsibilities for the audit of the financial statements

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

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

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

Capability of the audit in detecting irregularities

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

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

Auditor's report

(continued)

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

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

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

Use of our report

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

Fleur Holden

(Senior statutory auditor)

Date: 14 June 2024

for and on behalf of Sayer Vincent LLP,
Statutory Auditor

110 Golden Lane, LONDON, EC1Y 0TG

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

Financial statements

For the year ended 31 December 2023



Statement of financial activities

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

2023					
		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

Statement of financial activities

(continued)

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

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

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

Balance sheet

Balance sheet as at 31 December 2023.

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

Balance sheet

(continued)

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

Company registration number 4118259

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

Jim Irvine

Chair of Trustee Board

Daniel Mundy

Treasurer

Statement of cash flows

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

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

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

Notes to the financial statements

1 Accounting policies

1.1 Basis of preparation

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

1.2 Going concern

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

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

1.3 Legal status of charity

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

1.4 Judgements and estimates made by management

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

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

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

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

Notes to the financial statements

(continued)

1.5 Income

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

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

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

1.6 Expenditure

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

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

1.7 Recognition of grant liabilities

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

1.8 Tangible fixed assets and depreciation

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

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

Notes to the financial statements

(continued)

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

1.9 Programme related investment and impairment

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

1.10 Cash and short-term investments

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

1.11 Debtors

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

1.12 Creditors

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

1.13 Financial instruments

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

1.14 Stock

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

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

1.15 Accumulated funds

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

Notes to the financial statements

(continued)

1.16 Consolidated accounts

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

1.17 Foreign currency translation

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

1.18 Leases

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

1.19 Termination payments

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

Notes to the financial statements

(continued)

2. Donations and legacies

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

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

Notes to the financial statements

(continued)

3. Other trading activities

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

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

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

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

Notes to the financial statements

(continued)

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

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

4. Investment income

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

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

Notes to the financial statements

(continued)

5. Grants payable

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

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

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

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

Notes to the financial statements

(continued)

6. Expenditure

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2023
	£	£	£	£	£	£
Raising funds						
Donations & legacies	660,061	-	-	272,309	352,787	1,285,157
Other trading activities	7,027,568	-	81,677	375,643	5,724,611	13,209,499
	<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>

Notes to the financial statements

(continued)

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

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

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

Notes to the financial statements

(continued)

7. Cost allocation

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

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

Notes to the financial statements

(continued)

8. Trustees

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

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

9. Employees

The average number of employees during the period was:

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

Notes to the financial statements

(continued)

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

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

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

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

Notes to the financial statements

(continued)

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

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

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

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

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

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

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

Notes to the financial statements

(continued)

10. Fixed assets

Tangible fixed assets

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

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

Notes to the financial statements

(continued)

11. Programme related investment

	2023	2022
	£	£
Investment in Phoenicis Therapeutics, inc		
Net investment value brought forward	1	1
Purchase of investment	-	-
Impairment charge	-	-
	<u> </u>	<u> </u>
Net investment value carried forward	<u>1</u>	<u>1</u>

Following a merger In 2023 Fibrx Dem, Inc became Phoenicis Therapeutics, Inc. The Trustees invested £190,840 (\$250,000) in Fibrx Derm Inc, a US biotech company, purchasing 203,252 series A-2 convertible preferred stock, at a price of \$1.23 per share. This investment supported the development of a new treatment to help wound healing in patients suffering from Dystrophic Epidermolysis Bullosa. The purpose of this investment was in furtherance of the charitable objectives of the charity, and no financial return was expected. The value of the investment has been impaired by 99.99% as the most prudent course of action.

12. Investment in subsidiaries

DEBRA had two 100% owned subsidiary companies incorporated in England and Wales at 31 December 2022 (2021: two). These are DEBRA Trading Ltd (company number: 2487114), whose principal activities are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship; and DEBRA Retail Ltd which is dormant.

Financial information for these entities for the year ended 31 December 2023:

	2023		2022	
	DEBRA Trading Ltd	DEBRA Retail Ltd	DEBRA Trading Ltd	DEBRA Retail Ltd
	£	£	£	£
Turnover	132,704	-	90,376	-
Total expenses	56,019	-	47,014	-
Gift aid to DEBRA	76,685	-	43,362	-
Profit / (loss) for the year	-	-	-	-
Net assets / (liabilities)	2	1	2	1
Share capital	2	1	2	1
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

Notes to the financial statements

(continued)

13. Debtors

	2023	2022
	£	£
HMRC	276,706	211,221
Amounts due from group undertakings	74,255	43,362
Other debtors	541,881	544,057
Accrued income	739,158	458,491
Prepayments	482,242	599,550
	2,114,242	1,856,681

Amounts due from HMRC are VAT receivable of £276,706 (2022: £211,221). Other debtors includes £4,515 (2022: £266,825) due for shared research grants. Accrued income includes gift aid of £467,366 (2022: £289,219) due from HMRC.

14. Investments in short term deposits

	2023	2022
	£	£
HSBC money market deposits:		
Investments brought forward at 1 January 2023	3,000,000	-
Purchase of investments	2,024,298	3,000,000
Sales of investments	(3,000,000)	-
Investments carried forward at 31 December 2023	2,024,298	3,000,000

Notes to the financial statements

(continued)

15. Creditors: amounts falling due within one year

	2023	2022
	£	£
Trade creditors	90,464	223,903
Grants payable	1,921,526	2,019,399
Other creditors	291,643	263,332
Taxation and social security	162,597	138,323
Accruals	527,769	1,013,934
Deferred income	5,965	13,426
	<u>2,999,965</u>	<u>3,861,818</u>

Grants payable includes £950,341 (2022: £384,625) relating to future commitments and £971,185 (2022: £1,634,774) relating to amounts owed for invoiced research activity.

Amounts due for future commitments due over one year are detailed in note 16 below.

There was deferred income of £5,965 (2022: £13,426), representing income for events which would have to be repaid in the event of cancellation.

16. Creditors: amounts falling due over one year

	2023	2022
	£	£
Grants payable	881,673	134,539
	<u>881,673</u>	<u>134,539</u>

17. Provision for liabilities

	2023	2022
	£	£
Dilapidations provision		
Provision brought forward	237,952	187,948
Charges	20,560	50,004
Release of provision	(39,700)	-
	<u>218,812</u>	<u>237,952</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:

	2023	2023	2022	2022
	Leases of land and buildings	Other	Leases of land and buildings	Other
	£	£	£	£
Within one year	968,931	4,432	1,019,492	18,747
Between one - five years	1,485,626	3,324	1,454,360	18,481
After five years	13,359	-	74,767	-
	<u>2,467,916</u>	<u>7,756</u>	<u>2,548,619</u>	<u>37,228</u>

There were capital commitments of £nil (2022: £nil) at year end, falling due within one year.

19. Analysis of funds: restricted funds

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

	Balance at 1 January 2022	Income	Expenditure	Transfer to general fund	Balance at 31 December 2022
	£	£	£	£	£
Oliver Thomas Memorial Fund	-	111,700	-	-	111,700
Research	(350,340)	754,941	(252,994)	-	151,607
Healthcare	20,625	89,048	(104,073)	-	5,600
Community support & respite	77,765	258,459	(117,620)	-	218,604
	<u>(251,950)</u>	<u>1,214,148</u>	<u>(474,687)</u>	<u>-</u>	<u>487,511</u>

Notes to the financial statements

(continued)

Restricted funds comprised:	2023	2022
	£	£
Oliver Thomas Memorial Fund ¹	19,200	111,700
Research:		
Apremilast Drug Re-purposing Trial	-	151,607
Research Programme Ninewells Hospital Dundee	35,000	-
Healthcare:		
Birmingham Children's Hospital Specialist Bath	5,600	5,600
Catrina Bernardis Fellowship – Hand Surgery	27,257	-
Community support:		
Community Support team leader	26,000	-
Community Support Manager for Scotland	-	21,542
Community Support in Bedfordshire	-	5,121
Community Support in Berkshire	4,273	4,273
Support Grants in Hampshire	1,552	3,952
Support Grants in Scotland	-	66
Support Grants in South Gloucestershire	-	1,054
Support Grants in Somerset	6,914	6,914
Support Grants in West Midlands	581	1,303
Support Grants in Buckinghamshire	23,581	13,836
Support Grants in Surrey	-	1,674
Support grants in Cambridgeshire	3,109	-
Support grants in Midlands	2,000	-
Other restricted funds	13,637	16,207
Digital Inclusion	-	10,000
Respite breaks:		
Holiday home purchases	251,007	132,662
Mobile home appeal	957	-
Total	420,668	487,511

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

Notes to the financial statements

(continued)

20. Analysis of funds: unrestricted funds

The Trustees allocated the following amounts as designated funds in 2022:

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

	Balance at 1 January 2022	Income	Expenditure	Transfers	Balance at 31 December 2022
	£	£	£	£	£
Drug Re-purposing	-	481,397			481,397
Nursing continuity	250,000	-	-	-	250,000
IT Strategy	50,000	-	-	-	50,000
Procurement	50,000	-	(31,000)	-	19,000
NHS Digital	200,000	-	-	-	200,000
Total designated funds	550,000	481,397	(31,000)	-	1,000,397
General fund	3,500,325	14,725,180	(15,463,241)	-	2,762,264
Total unrestricted funds	4,050,325	15,206,577	(15,494,241)	-	3,762,661

£481,397 (2022: £481,397) has been designated to fund drug re-purposing trials and £200,000 (2022: £200,000) has been designated to fund the NHS Digital Data project. The NHS Digital Data project commenced in 2024, and the drug-repurposing trial is in development.

The designated fund for nursing continuity has been established as a contingency in the event of future NHS funding withdrawal, and the Trustees maintained a balance of £250,000 (2022: £250,000) in this fund.

In 2021 £100,000 was designated to fund future procurement and IT work furthering modernisation of back office practices. The procurement consultancy work was completed in 2023. The IT strategy fund is due to be allocated against CRM development costs in 2024.

Notes to the financial statements

(continued)

21. Analysis of net assets between categories of funds

Fund balances at 31 December 2023 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,437,305	-	-	1,437,305
Current assets	4,848,332	981,397	420,668	6,250,397
Creditors:<1 year	(2,999,965)	-	-	(2,999,965)
Creditors:>1 year	(1,100,485)	-	-	(1,100,485)
	<u>2,185,187</u>	<u>981,397</u>	<u>420,668</u>	<u>3,587,252</u>

Fund balances at 31 December 2022 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,290,094	-	-	1,290,094
Current assets	5,516,978	981,397	487,511	7,004,886
Creditors:<1 year	(3,672,317)	-	-	(3,672,317)
Creditors:>1 year	(372,491)	-	-	(372,491)
	<u>2,762,264</u>	<u>981,397</u>	<u>487,511</u>	<u>4,250,172</u>

Notes to the financial statements

(continued)

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

	2022	2021
	£	£
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	(662,920)	451,797
Depreciation and amortisation charges	261,882	180,733
Impairment of programme related investment	-	-
Dividends, interest and rents from investments	(97,461)	(5,472)
Profit / (loss) on disposal of fixed assets	-	6,319
Decrease in stock	2,063	(742)
(Increase) / decrease in debtors	(257,559)	86,207
(Decrease) / increase in creditors	55,640	(152,278)
Net cash used in operating activities	(698,355)	566,564

23. Analysis of cash and cash equivalents

	At 1 January 2023	Cash flows	At 31 December 2023
	£	£	£
Cash at bank and in hand	2,111,857	(34,285)	2,111,857
	2,111,857	(34,285)	2,111,857

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

Notes to the financial statements

(continued)

24. Grants to institutions

Research grants:	2023		2022	
	Total paid in year £	Total paid to date £	Total paid in year £	Total paid to date £
University of Dundee				
Clinical fellow funding	-	658,253	7,664	658,253
Guy's and St Thomas' Hospital, London				
Clinical endpoints study re EB therapy evaluation	-	734,790	40,233	734,790
Wound care and its complications in patients with EB	23,176	30,500	7,324	7,324
University of Birmingham				
Gait Analysis in EB Simplex	-	46,032	30,688	46,032
Clinical Fellowship	26,359	125,263	33,168	98,904
Novel spray to treat mucosal scarring	-	152,384	50,777	152,384
Use of highly sensitive and specific gene analytical techniques to identify microorganisms that may play a role in the chronicity of EB wounds	1,246	1,246	-	-
High-retention, lubricating eye drops to enhance quality of life in EB patients	77,040	77,040	-	-
University of Cologne				
Immunity in wound healing complications RBEB	-	170,635	5,929	170,635
Instituto Dermopatico del'Immacolata Rome				
Re histone deacetylase inhibitors for RDEB	1,928	70,962	4,627	69,034
King's College London				
Preclinical studies of lentiviral-mediated COL7A1 gene therapy	-	198,978	10,395	198,978
PASTE-mediated superexon replacement of COL7A1 as a treatment for DEB	15,844	15,844	-	-
Balance c/fwd	145,593	2,281,927	190,805	2,136,334

Notes to the financial statements

(continued)

Research grants:	2023		2022	
	Total paid in year £	Total paid to date £	Total paid in year £	Total paid to date £
Balance b/fwd	145,593	2,281,927	190,805	2,136,334
Great Ormond Street Institute of Child Health				
Respiratory cell & gene therapy for children with JEB	16,893	70,962	52,601	118,445
Bambino Gesù Children's Hospital				
MicroRNAs expression profiling, activity and therapeutic perspectives	4,408	77,592	27,628	73,184
University of Edinburgh				
Kindlin-1 loss in squamous cell carcinoma	22,213	112,834	38,954	90,621
New York Medical College				
Innate & adaptive immune mechanisms in RDEB	34,186	207,538	69,120	173,352
The Beatson Institute for Cancer Research				
Drug re-purposing for the treatment of RDEB squamous cell carcinoma	70,428	70,428	-	-
Pre-clinical models of RDEB squamous cell carcinoma	8,816	8,816	-	-
University Salzburg, Austria				
Investigating the potential of re-purposing statins for the treatment of highly aggressive RDEB-tumors	15,696	15,696	-	-
Centre Hospitalier Universitaire de Nice, France				
A 20-Week Multicentre, Open Study Assessing the Efficacy and Safety of Apremilast (Otezla®) in Patients > 6 years of age with EB simplex generalized.	49,189	49,189	-	-
Balance c/fwd	669,959	5,195,579	750,554	4,525,620

Notes to the financial statements

(continued)

	2023		2022	
	Total paid in year £	Total paid to date £	Total paid in year £	Total paid to date £
Balance b/fwd	669,959	5,195,579	750,554	4,525,620
Queen Mary University, London				
Dissecting the role of inflammatory pathways in JEB	3,137	3,137	-	-
Improving skin regeneration in JEB by targeting the integrin $\alpha\text{v}\beta 6$	2,909	2,909	-	-
Identifying Cellular and molecular mechanisms underlying the oral mucosal scarring and resistance to cancer development in RDEB patients	16,650	16,650	-	-
Treating JEB with Recombinant Laminin 332	14,776	14,776	-	-
Targeting epigenetic gene regulation in EBS	33,288	33,288	-	-
Cardiff University				
Developing a self-help toolkit for supporting wellbeing in parents of children with EB	4,726	4,726	-	-
Fundacion Instituto De Investigation, Madrid				
Non-viral genome editing patching of COL7A1	1,250	1,250	-	-
CIEMAT, Madrid				
Novel platform for generation of safer pseudorabies herpesvirus-based vectors for RDEB therapy	1,250	1,250	-	-
KK Women's & Children's Hospital, Singapore				
Improving the genetic diagnosis of EB by long-read sequencing	875	875	-	-
University of Buenos Aires				
Molecular epidemiology of EB Simplex in Argentina	1,250	1,250	-	-
Total	447,533	3,039,469	379,109	2,591,936

Notes to the financial statements

(continued)

Healthcare projects:	2023	2022
	Total paid in year £	Total paid in year £
Great Ormond Street Hospital for Sick Children		
Clinical nurse specialists in EB	81,540	54,681
Guys & St Thomas' Hospital London		
Adult EB support nurses	5,572	(26,964)
Birmingham Children's Hospital	40,126	56,577
Other	-	17,951
	<u>127,238</u>	<u>102,245</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>

Reconciliation of provision:	2022			
	Research grants £	Healthcare grants £	Community Support grants £	Total £
Provision brought forward	548,814	125,948	-	674,762
New commitments	256,461	84,294	85,856	426,611
Co-funding contributions	(14,999)	-	-	(14,999)
Spend in year	(379,109)	(102,245)	(85,856)	(567,210)
Provision carried forward	<u>411,167</u>	<u>107,997</u>	<u>-</u>	<u>519,164</u>

25. Related parties

During the year, the charity charged management charges totalling £7,800 including VAT (2022: £11,300) to its subsidiary, DEBRA Trading Limited.

Reference and administrative details

Patrons and ambassadors

Royal Patron

HRH The Duchess of Edinburgh GCVO

Life Patron

Philip Evans

President

Simon Weston CBE

Vice Presidents

Graeme Souness

Frank Warren

Lenore England

Stuart Proctor

Trustees

Jim Irvine (Chair)

Joanne Merchant* (Treasurer)

David Bendor-Samuel (Vice-Chair)

Carly Fields* (Vice-Chair)

Simone Bunting*

Christo Kapourani*

Simon Talbot*

Mick Thomas*

Dan Mundy

Debbie Install*

Additional details

Company secretary

Simon Jones

Registration

Charity Commission Number: 1084958

SCR Number: SC039654

Company Number: 4118259

Registered office & principal address

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

Auditor

Sayer Vincent LLP, Invicta House,
110 Golden Lane, London EC1Y 0TG

Banker

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

Solicitor

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

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

Abbreviations

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



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

Together we will #StopThePain.

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

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

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