

Trustees' Annual Report & Accounts 2022



Our vision

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

Our mission

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

Our values



Making a difference



Caring



Inclusive



Respectful



Passionate



Committed

Contents

The trustees present the annual report (including the strategic report) for the year ended 31 December 2022.

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What is EB

Skin as fragile as a butterfly wing

EB, epidermolysis bullosa, is a group of extremely painful genetic skin conditions that cause the skin to blister and tear at the slightest touch. With skin so fragile it is often referred to as 'butterfly skin'. EB can affect the hands and feet only or in the most severe cases any part of the body, including blistering on the eyes and internal organs.

Genetic condition

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

Types of EB

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

Symptoms and complications

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

Treatment

People living with EB may require treatment from a range of medical specialists aimed at symptom relief and to prevent complications such as infection. The most common challenge amongst all types of EB is the pain and itching that occurs as a result of blistering.

No cure

There are an estimated 5,000 people affected by EB in the UK and 500,000 worldwide. It is currently incurable.

Chair of Trustees and CEO introduction and welcome

Last year we announced our ambitious strategic plan to increase the pace and breadth of our work to make our vision of life-changing treatments and, ultimately, cures for EB a reality.

We are enormously proud of the vision of our trustees, strong leadership of our senior management team, the generosity of our supporters and customers, and the determination and commitment of our staff and volunteer teams. At the end of the first year of our five-year plan, together we have brought about a step-change in our approach to funding and delivering our vision that is truly remarkable. It is a journey, but one that we have clearly defined and brought to life, with our values guiding our way.

EB research is essential to the delivery of our ambition. We urgently need to find treatments that will give relief to the devastating symptoms of EB – pain, itch, cancer, wounds, infection. The EB community has driven our commitment to do more to deliver our world-class programme of research and end suffering. We launched a five-year EB research strategy to increase the level of ambition and impact of our EB research. We established a new EB expert advisory panel, increased the involvement of the EB community, launched our first call for applications to support and nurture the next generation of EB researchers and partnered with organisations from the wider medical and scientific community including the Medical Research Council. Our commitment to research will continue with budgeted new research spend of £1.5m for 2023. Most importantly, in addition to funding our active research portfolio this year, we announced funding for drug repurposing to find approved drug treatments for EB faster.

The EB community is at the heart of everything we do. To ensure people with EB and their families were able to access the care and expertise they needed, our Community Support Team worked with healthcare professionals to connect patients with the expert, specialist services across the UK. We supported the development of EB expertise, worked with healthcare professionals to increase the availability of expert information and continued to fund the development of EB best practice guidelines for clinicians and families.

We also worked with an external agency to create the first EB patient insight study, to capture the lived experiences and views that will shape our services and support our lobbying for government funding and support.

We undertook a rebrand to deliver a stronger presence on the high street and, through improved communication and social media, achieved a significant increase in membership numbers and engagement; but central to our ambitious strategic plans is the realisation that increased EB awareness is needed if we are to increase public understanding and government level support to deliver the life-changing improvements to clinical care and treatments we need.

In October we launched our largest appeal yet, A Life Free of Pain, with the support of our President, Simon Weston CBE and Vice Presidents Graeme Souness, Lenore England, Stuart Procter and Frank Warren. The appeal aims to bring considerable attention to improve awareness of EB and to raise £5m to accelerate our research into drug-repurposing, treatments and further support for the EB community. In just a few months the appeal has raised over £1.1m and gives us hope that life-changing treatments to radically improve the quality of life for people living with EB are within reach.

We would like to thank all of our supporters and the customers in our stores and online who shopped with us. Despite the ongoing impact of the pandemic, the war in Ukraine and the cost of living crisis, their commitment and generosity enabled us to achieve a record fundraising income, enabling us to spend over £2.6m on healthcare, support and research, an increase year on year of 40%.

Thank you also to our EB community, the specialist healthcare professionals and researchers we work with, our Patron HRH The Duchess of Edinburgh GCVO, president and vice presidents. It is the commitment and support of you all which has brought us this far and which will enable us, together, to continue on our journey to grow and connect our membership, increase our commitment to EB research and support the development of EB best practice and expertise.

“ Together we will achieve our vision of a world where no one suffers with EB. ”



Jim Irvine
Chair of Trustees



Tony Byrne
CEO



Our work

Investing in a future free of EB

DEBRA was the world's first EB patient support organisation, founded in 1978 by Phyllis Hilton whose daughter Debra was born with Dystrophic EB. When told by medical professionals that she should take her baby home as nothing could be done for her, she set out to find ways to treat Debra's skin herself using cotton dressings. Fifteen years later Debra sadly passed away. That year Phyllis met a parent seeking advice and realised that nothing had changed. She decided to take action, organising the first ever meeting for parents of EB and so DEBRA was formed.

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

Pioneering EB research

The research journey for EB over the past 44 years has been remarkable – from gene discovery to cutting-edge trials of therapies to control symptoms and manage complications like cancer. During this time we have invested over £20m and been responsible for establishing much of what is now known about EB today. We are the largest UK funder of EB research and we have an ambitious, patient-centred research strategy that drives us to fund science of the highest quality across the world, including prioritising investment in drug re-purposing, to develop a treatment pipeline that will slow, stop and/or reverse EB.

Specialist healthcare

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

Lifelong community support

The EB community is at the heart of everything we do. We are the only UK charity specifically aimed at continuously supporting the EB community. We provide individualised support, information and guidance for people with EB and their families and carers – from benefits and finance to bereavement support, social opportunities, respite and advocacy, connecting patients with the specialist services they need and a support network across the EB community.

International collaboration and best practice support

We are a founding member of and contribute funding and support for DEBRA International, our umbrella organisation with nearly 50 groups worldwide, sharing information and best practice and working towards improving the lives of those living with EB in their respective countries.

Making a difference

Our impact in 2022



£2.6m spent on EB research, healthcare & support
40% increase year on year



3500+ DEBRA members
17% increase in membership



£1.1m raised towards target £5m by A Life Free of Pain appeal for drug repurposing and EB care and support



Ambitious five year **EB research strategy** launched



First EB **patient insight study** developed to influence EB support, provision and government funding



Rebrand roll out
to deliver a stronger presence on the high street



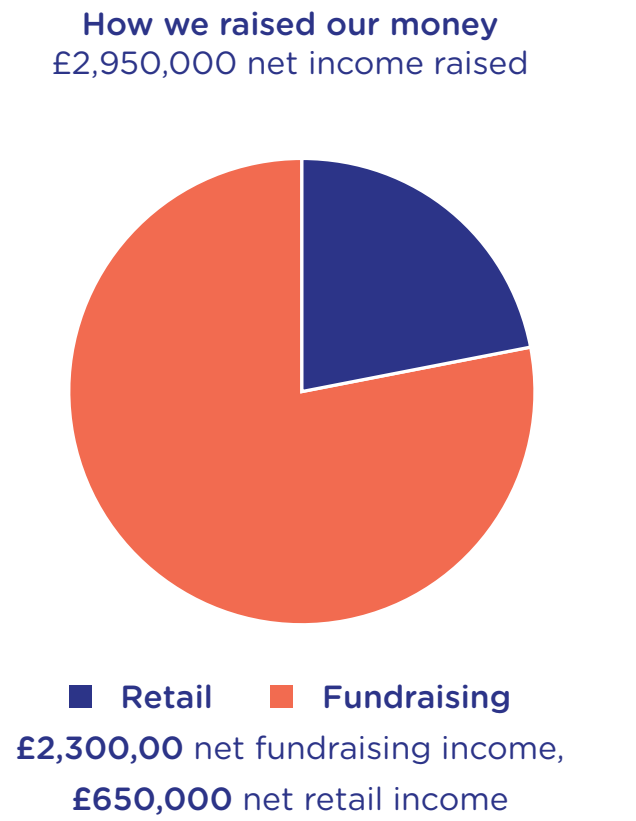
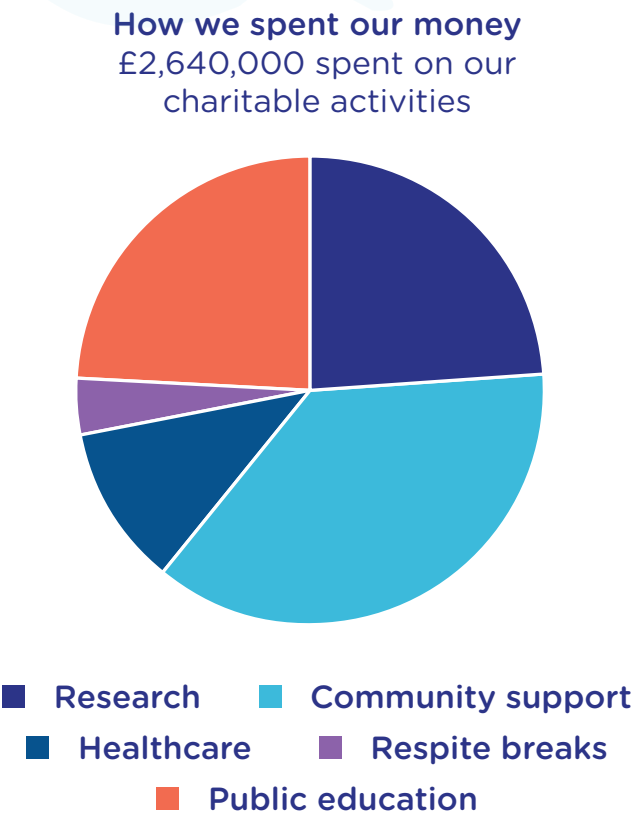
ESG journey underway with **100%** of waste from our stores diverted from landfill through our waste partner

Achieved with help from

- 375 permanent staff
- 1,100 dedicated volunteers giving 230,000 hours of donated time
- 14 trustees, 64% with direct experience of EB
- 102 stores – 8th largest charity retailer in UK
- £2.95m net income raised by our generous supporters and loyal customers

Committed to the EB community

We are committed to making sure that people with EB in the UK and their families and carers get the vital and wide-ranging support they need, supporting specialist healthcare and investing in life-changing research so that the devastating symptoms of EB can be reduced while we work towards a cure.



EB research

Over the past 44 years we have been responsible, through funding pioneering research and working internationally, for establishing much of what is now known about EB. We have invested over £20m in 138 research projects, working with 53 research institutions across 12 countries globally.

We are the largest UK funder of EB research and have been committed to a remarkable research journey for EB, from gene discovery to cutting-edge trials of therapies to control symptoms and manage complications like cancer.

Our ambition

We have a vision of a world where no one suffers from the painful skin condition epidermolysis bullosa. Our ambition focuses on what matters to people living with EB, finding treatments to lessen the day-to-day impact and improve quality of life, and cures to eradicate EB.

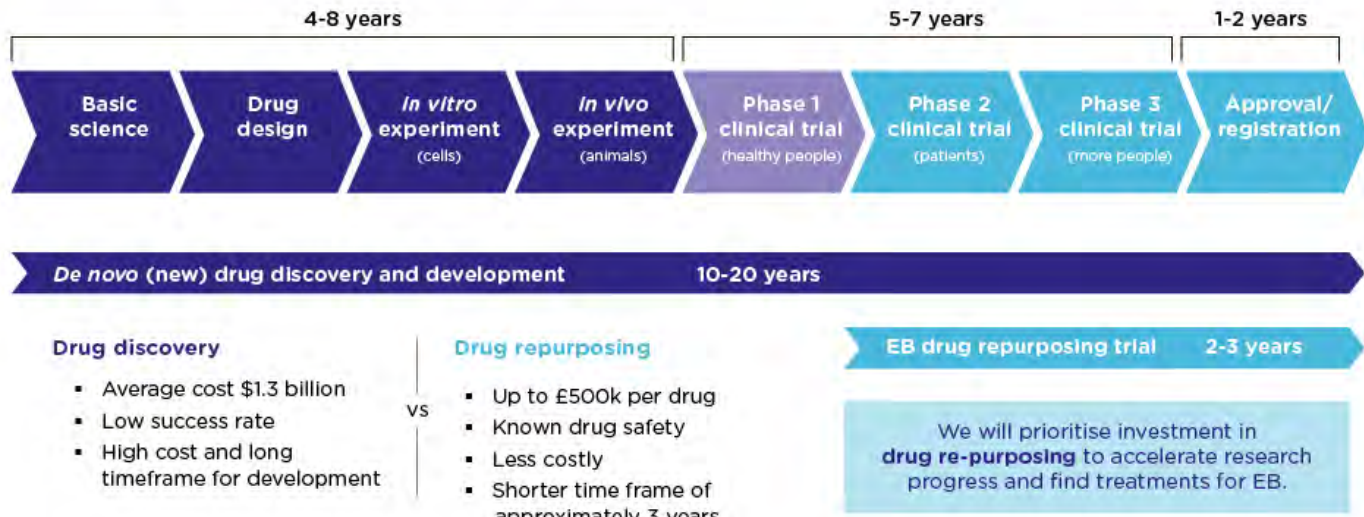
We will fund science of the highest quality that has the potential to deliver for EB patients. We will play a pivotal role in making research into EB a global effort, working with many organisations, but with DEBRA UK front and centre, leading the quest for innovations that improve the lives of people living with EB.

Our objectives

Our four overarching research priorities are those we view as most likely to deliver outputs for people living with EB.

1. Invest in drug repurposing and develop drug discovery programmes to accelerate finding treatments.
2. Increase investment in patient-centred research themes.
3. Continue to invest to increase understanding of the causes and progression of EB and the role of the immune system.
4. Invest heavily in the next generation of EB researchers.

Drug repurposing clinical trials



“ We will invest in drug repurposing and develop drug discovery programmes to accelerate finding treatments that already successfully treat other inflammatory skin conditions such as psoriasis and atopic dermatitis. These drugs are already available within the NHS and we believe they could be effective in slowing, stopping or reversing the progression of EB. ”

- Dr Sagair Hussain



How we met our objectives in 2022

We introduced a step-change in our approach, with six strategic actions to increase the level of ambition and impact of our EB research.

Set a five year EB research strategy

We launched a five year research strategy which was, and will continue to be, the driver for significant positive changes in our approach to and delivery of EB research.

Patients with EB are still suffering from devastating symptoms – pain, itch, cancer and wounds that require hours of dressings and blisters that can lead to infection. Now is the time to accelerate the pace of discovery. We want a future where everyday treatments end the pain and suffering of people with EB and save lives.

Established a new EB expert panel

We established our own grant making processes in alignment with AMRC (Association of Medical Research Charities) guidance and appointed a Research Grants Administrator.

We set up a Scientific Grant Advisory Panel (SGAP) of renowned national and/or international experts in their field and EB to review grants and make recommendations to the DEBRA Charitable Purposes committee.

Professor Christopher Griffiths OBE was formally appointed as DEBRA's independent research advisor. Professor Griffiths is Foundation Professor of Dermatology at the University of Manchester, President of the European Society for Dermatological Research and a past-President of the British Association of Dermatologists (BAD), EDF, BSID and International Psoriasis Council.

Announced a new partnership with the MRC

Our aim is to develop the next generation of EB researchers, attracting, supporting and developing the brightest researchers at all stages of their careers. We signed an agreement with the MRC (Medical Research Council) and launched our first call for applications for joint DEBRA and MRC funded research with PhD studentships; clinical research training fellowships, clinician scientist fellowships and career development awards.

We also announced a special national and international call for drug repurposing grants to take place in 2023.

Partnered with organisations from the wider medical and scientific community

We engaged with NICE (National Institute for Health & Care Institute), joined the Genetic Alliance and International Alliance of Dermatology Patient Organizations (globalskin) and partnered with Fight for Sight to fund EB eye research relating to vision in EB.

We are in the process of partnering with NHS Digital to collate EB patient data across NHS departments to better understand the patient journey and bottle necks within the system. This will also help set research priorities in the coming years.

Increased involvement with the EB and research communities

We invited our members to get involved in our research decision-making process and set up the first feedback sessions as part of our involvement network. In EB Awareness Week, we ran an online Q&A session, Research Unpacked, to give members the opportunity to learn about our strategy, plans and latest EB research developments. We communicated to UK and international researchers, our members and staff and researchers and developed the research content on our website and social media.

Continued funding EB research programmes

We committed funding of £350,000 in 2022. We approved three new projects in addition to our active research portfolio of 18 projects and our 2022 grant call awarded just over £250,000 to three new projects to start in 2023.

How we will continue to develop in 2023

Our planned new research spend is £1.5m including £500k deferred from 2022.

Our research focus will continue to be guided by what matters to people living with EB. Patients and their family members through their own experiences are the experts on the impact of EB. The key priorities of the EB community, those living and working with the conditions, are essential in shaping the research selection process and driving the future of EB research, balancing short-term benefits for patients and support for long-term research into potential treatments, cure or cures.

Drug repurposing grants of up to £500,000 for up to three years will be available in 2023 and alternate years. These will be promoted through our research calls amongst the global EB research community and awarded to high-quality projects on clinical trials of existing licensed therapeutics repurposed for EB.

We will also promote and offer grant calls for EB research including career development fellowships to support and nurture the next generation of EB researchers.

Partnerships with EB and non-EB organisations will be a strong focus to leverage our funds. We aim to form a new partnership with the British Skin Foundation to co-fund a PhD studentship to encourage new researchers into EB. We will continue to work with the pharmaceutical industry, MHRA and NICE to ensure EB treatments are approved in the UK.

We will continue to **increase involvement with the EB and research communities**. The DEBRA SGAP and involvement network group, consisting of members with lived experience of EB, will be essential in helping us decide which projects to support.

We will continue to work with EB and non-EB researchers globally to develop podcasts, blogs and films to highlight our research and inform and engage the EB community. Attending conferences will be a major endeavour in 2023 to **raise the profile of DEBRA and EB** amongst the research community, pharmaceutical companies and other organisations.

Specialist healthcare

Connecting patients, supporting expertise

Enabling EB healthcare teams to support over 2,000 EB patients each year

Intro

We work in partnership with the NHS to deliver an enhanced EB healthcare service for people with all types of EB. We have invested in the development of EB centres of excellence, and continue to fund clinical best practice guidelines for clinicians and families and connect patients with the expert, specialist services they need across the UK.

Our ambition

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

Our objectives

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

How we met our objectives in 2022

Healthcare services continued to be affected by the COVID-19 pandemic, primarily due to the need to address the backlog of core clinical work and resume face to face appointments in clinics and patients' homes. Some of the non-core activities, including publication development and uptake of the podiatry training, also continued to be limited due to core clinical needs taking priority.

Our Community Support Team worked with healthcare professionals and services across the UK to ensure people with EB and their families were able to access the care and expertise they needed.

We remained committed to working with the NHS, funding up to 25% of specialist EB nursing in teams that had the capacity to undertake healthcare activities not funded by the NHS. We provided funding for specialist EB dietitians at Guys & St Thomas' Hospital and Birmingham Children's Hospital one day per week to provide nutritional advice to promote vital health, wellbeing and wound healing.

We supported the development of EB expertise, delivering our EB podiatry training course online, attending EB clinical network meetings, making specialist information and knowledge accessible to podiatrists across the UK, and enabling patients to access vital expert care locally. We provided study grants to professionals and promoted EB specialist training by clinical teams and external organisations.

We worked with healthcare professionals on projects to increase the availability of expert information, including the development of nutritional advice and physiotherapy and movement.

We provided a wide range of healthcare information to our members, communicating through online sessions, newsletters and emails and in-person.

We continued to support and promote the development of clinical best practice guidelines for clinicians and families.

How we will continue to develop in 2023

We will continue to offer funding up to 25% of all existing specialist EB nurses. Additional grants for developing the expertise within clinical teams will be considered along with calls for small project funding that will enhance services. Funding will also be available to continue specialist nutrition services by funding 50% of two EB dietitians.

We will continue to lead the development of an accredited specialist EB podiatry training course and link with undergraduates, aiming to deliver three training courses each year, to make

specialist information and support accessible to podiatrists across the UK and access to expert care locally for people with EB. We will also review the development of our short to long term funding of local podiatry.

We will work with healthcare professionals to update and develop new information in multiple formats such as publications and films to inform members, agencies and people working to support the EB Community.



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

EB community support

Lifelong support, advocacy and engagement

5,000

people with
EB in the UK

3,500+

DEBRA
members

17%

increase in DEBRA
membership

200%

increase in DEBRA
grants awarded to the
EB community

537

adults & children
stayed in our respite
holiday homes

The EB community is at the heart of everything we do. Their experiences and views shape our services and drive our commitment to connect patients, families and carers with the specialist services and support they need to improve quality of life today while we work towards a cure.

DEBRA was the world's first EB patient support organisation and we remain the only UK charity specifically aimed at continuously supporting the EB community. We provide practical, financial, emotional support, respite and advocacy for people living with EB and their families, connecting them to specialist services and a support network across the EB community.

Our ambition

To provide excellent care and support to members of the EB community, maximising every opportunity to make a difference and improve quality of life whilst seeking a cure.

Our objectives

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

Connecting and providing support for people of all ages living with all types of EB, their families, carers and specialists throughout the UK.

How we met our objectives in 2022

We increased team resources, appointing a new role to lead on member engagement and two further support managers to respond to the increase in need for support and access to expert knowledge. We renamed the directorate Member Services to reflect members being central to all of our charitable activity.

Our Community Support Team continued to build on the **successful hybrid working approach** to provide the most accessible and effective service to support people with EB and their families across the UK.

We hosted **virtual and in-person groups and events** throughout the year, sharing expertise and resources and connecting members with others in the EB community. Our annual Members' weekend took place in-person for the first time since the pandemic. Members, their families, staff, volunteers, researchers, healthcare professionals and all involved in the event were pleased to be able to return to having the opportunity to meet and connect as a community, sharing knowledge and experiences, supporting each other and building friendships.

We doubled the number of grants awarded to the EB community and revised our grant decision-making guidance. Grants provided included support grants for items to help daily living, improve health and comfort, assistance to attend clinics, bereavement support and respite holiday homes.

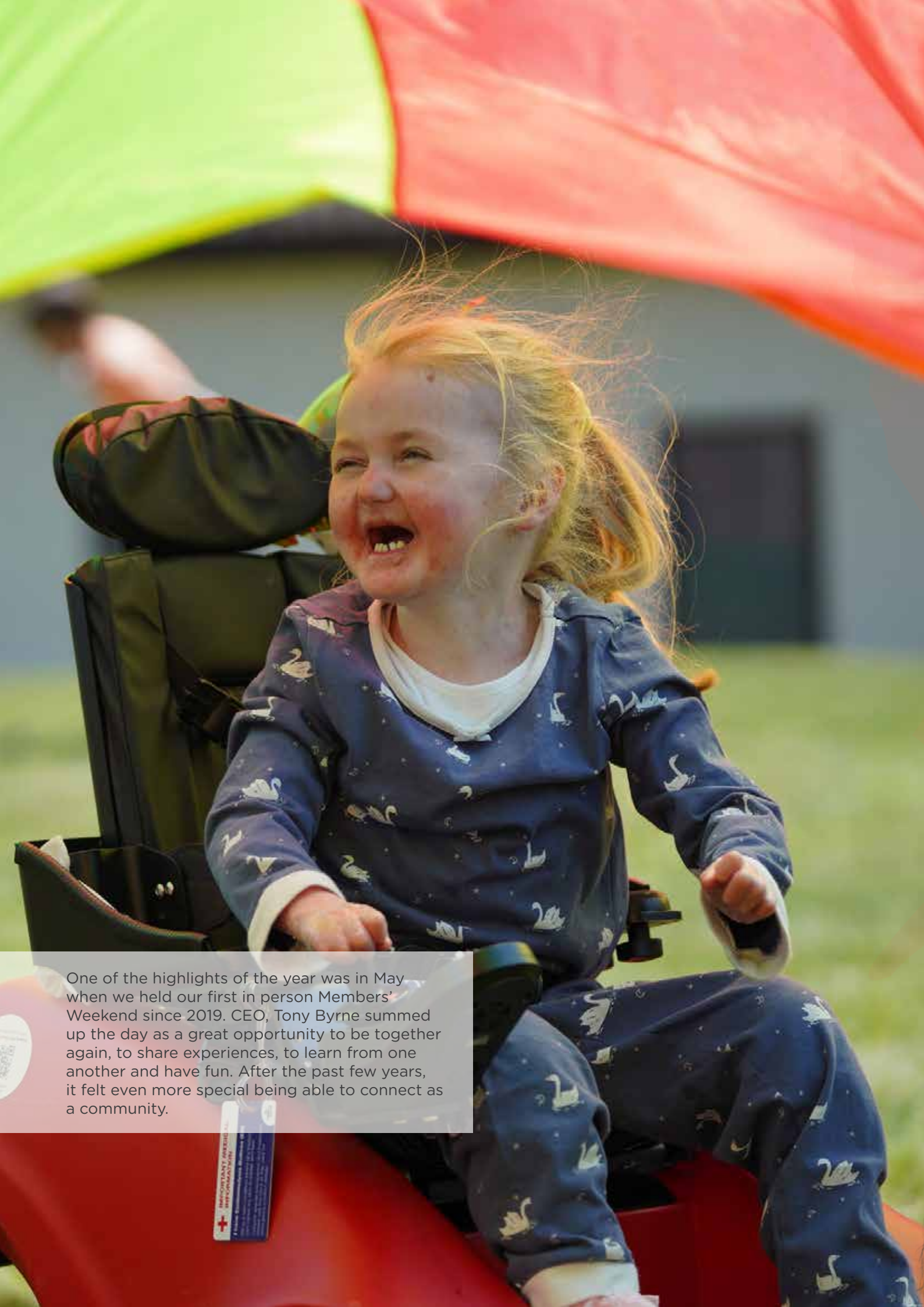
We met the ongoing increase in demand and need for respite, when an opportunity to purchase an additional holiday home earlier than planned, enabled us to purchase one new home and replace an existing one.

We increased communications with members to connect the EB community and provide information on healthcare, research, support, member events and opportunities for involvement. The data cleansing and transformation project was completed, and we moved to a new CRM system.

We set up an involvement network for people in the EB community to encourage members to get involved in research, be a patient representative, play a part in lobbying for EB support and funding, steer our fundraising, review our EB information and communications and influence what we do.

We initiated a number of projects for launch in 2023 including a **quantitative quality of life baseline survey** to inform how we prioritise our activities and introduce new types of support and an independently-assessed quality mark for health information.





One of the highlights of the year was in May when we held our first in person Members' Weekend since 2019. CEO, Tony Byrne summed up the day as a great opportunity to be together again, to share experiences, to learn from one another and have fun. After the past few years, it felt even more special being able to connect as a community.

“

When war broke out in Ukraine, my daughter Shybika, age two who has Junctional EB, my son, my partner and me fled the country. We left our home, our country, our lives. Fellow EB parents on social media introduced us to Rowena, our DEBRA Community Support Manager. She helped us to get us financial support to help buy specialist soft clothing and travel expenses to get us to the never-ending medical appointments.

DEBRA also put us in the care of the Rare Diseases Centre at Birmingham Children's Hospital. Shybika has never received this level of care and expertise before. Rowena does more than help solve practical problems, she provides emotional support and comfort. She is one of the greatest gifts my family has ever received.

”



How we will continue to develop in 2023

We will embark on a new, member-centred journey from 2023 to 2026, which will be underpinned by a new member services strategy.

We will grow and diversify the involvement network, expanding our engagement activities and the opportunities we offer, looking at the journey that our members take with DEBRA and how we can provide more proactive support and information at different times of their life. Additional focus will be given to identifying how we can support those living with less severe EB.

We will reach new members by developing our membership offering, raising awareness of EB, DEBRA and the services and support available, aiming to increase membership by 5% each year.

We will continue working alongside the health and support teams developing up-to-date and accessible information and publications on to help people living and working with EB as well as for schools, GPs and workplaces.

We will continue to develop the virtual groups and in-person events on offer throughout the year. Presentations, information and inspirational stories will be made available in multiple formats to provide a resource that can be easily accessed by members and people working to support the EB Community.

We will increase our grants scheme to make a tangible difference to members in time of need. Requests for funding are often made during the year and sometimes require quick call to action. Funding of £75k for these new or enhanced care and support initiatives will be made available in 2023 and 2024.

The Community Support Team will continue to develop the hybrid way of working ensuring the most efficient and effective service is offered. An additional post in Community Support and two in Membership will be added to manage the additional work in the field attending clinics/home visits, member events and to support the planned increase in membership, support grant applications and holiday homes and the contribution of the team's expert knowledge to create new resources for the EB community.



Our partnerships

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

138

research projects across 12 countries at 53 world-class research institutions funded by DEBRA UK

44+ years

of working collaboratively

50

DEBRA International groups

41%

of Clinical Practice Guidelines funded by DEBRA UK in the past 5 years

Our ambition

Central to our ambitious strategic plans is the awareness that a global and collaborative approach is needed if we are to increase the pace and breadth of our work and achieve life-changing improvements to clinical care, treatments and, ultimately, a cure for EB.

Building partnerships, improving outcomes

We work with world-class scientists and clinicians and with national and international partners from academia, biotechnology, pharmaceutical industries, and organisations with a shared interest in EB or other skin conditions. Together, we can reach new audiences, raise awareness, share expertise and work collaboratively to provide the specialist services our members need and drive a programme of world-class research to bring hope and improved outcomes for people worldwide living with EB.

In 2022, we initiated the process of building a partnership with NHS Digital in order to develop a national EB population register to improve clinical practice, support research into EB, inform health service commissioning and evaluate and audit health and social care services for EB patients.

We collaborated with the Medical Research Council to offer jointly funded clinical research training fellowships, Clinician Scientist Fellowships and Career Development Awards to support the next generation of EB researchers.

We are involved in NICE (National Institute for health & Care Excellence) scoping workshops representing the EB voice to evaluate new treatment for EB.

We reviewed the Department of Work and Pensions training module for EB which is used with their benefit assessors to improve understanding of EB.

We are proud members of the Association of Medical Research Charities (AMRC). All projects undergo a thorough application and review process by our Scientific Grants Advisory Panel (SGAP) guaranteeing that we only fund high-quality projects. This process ensures new research projects build on existing knowledge, which helps us to only invest in projects that give the best chance of breakthroughs leading to change.

We collaborated with charity Fight for Sight to set up a partnership to co-fund eye research in EB.



We are working with GlobalSkin, a unique global alliance supporting patient organisations to improve the lives of dermatology patients worldwide. Their work is focused on supporting their members in the fields of research, advocacy, and support. By working with partners such as GlobalSkin we stand a better chance of securing the support we need to ensure that in the future no one has to suffer with the pain of EB.

We are a member of Genetic Alliance UK which will help us in raising awareness and understanding of EB. They are the largest alliance of organisations supporting people with genetic, rare, and undiagnosed conditions in the UK. They provide information and support to families whilst influencing the services they need and add patient voice into debates that matter to the communities they represent.

Enhancing global EB care and best practice

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

We are a founding member and continue to invest in DEBRA International, our umbrella organisation, supporting nearly 50 DEBRA groups worldwide working collaboratively for EB.

Through DEBRA International we support the development of Clinical Practice Guidelines to increase professional knowledge and best practice for patients around the world with EB.

Corporate partners

Our many corporate partners play a vital role in helping us raise awareness, supporting our campaigns, providing in-kind services as well as funding for research, healthcare, community support and respite.

Thank you to all our partners for their generous support and commitment to our cause.

“We are calling on the wider scientific community, other funders and our industry partners to join us on our journey to accelerate EB research innovation.”

”

Dr Sagair Hussain,
Director of Research
at DEBRA

Raising awareness

Engaging communities

5.5m

people reached on
social media

110%

increase in
engagement

21%

increase in emails
& campaigns

17%

increase in DEBRA
membership

Our ambition

Our marketing and communications will focus on empowering and engaging our communities, lobbying government and creating greater awareness of EB to ensure there is understanding for those living with the condition, more widespread EB expertise and funding for essential EB research and care.

Our objectives

1. To raise awareness and understanding of EB, DEBRA's work and the needs of the EB community.
2. To connect and build engaged communities for all those living or working with EB, ensuring that the EB community has the support, advocacy and understanding it needs.
3. To lobby government to influence future services and provision for EB including securing a commitment of £10m to support drug repurposing clinical trials.

How we met our objectives in 2022

We **built awareness and engagement with our communities** with improved focus and frequency of our communications to supporters, members, staff and volunteers, moved to a new platform with software optimisation to encourage open and click through rates and undertook a data cleansing project to create a better quality, more engaged supporter and membership list.


We **increased the quality and frequency of our social media communications**, leveraging social media to inform and engage our membership. We used organic and paid social media to encourage participation in our fundraising events and support for our appeals through a greater focus on sharing member stories. We also used paid activity to help recruit volunteers and build local awareness of our stores. We established a presence on TikTok and developed our Instagram following as we begin to attract a younger demographic and drive sales through our retail network.

We worked with a specialist external public affairs agency to **accelerate our government lobbying activity** with a letter to the then Health Secretary, Sajid Javid, requesting financial support and a follow-on campaign encouraging staff, volunteers, and members to write to their local MP. This resulted in An Early Day Motion being tabled and offers from MPs to raise our case for support in parliament on our behalf. We have built on this activity with a dedicated public affairs strategy with the objective of building relationships and influence with the key politicians who can help us secure the financial support we need.

We delivered a **refreshed visual brand** that better communicates who we are and what we do and supports our fundraising ambitions. The project involved interviews with key stakeholders across the charity including members and healthcare professionals. We started a phased roll out across digital platforms, publications and marketing collateral with the store roll out planned for improved brand visibility from 2023.

We were delighted to be **awarded the prize from PM Society** – Creativity for Good – and the opportunity to work with a creative agency to deliver the 'DEBRA effect' campaign which was effective in generating awareness across social media and selected retail stores.

We launched a new podcast series, Under My Skin. The first episode was hosted by Lizzie Mounter, a 29 year-old filmmaker who shared her experience of living with EB Simplex and the challenges of taking on the London Marathon to raise awareness and funds for DEBRA.



With the support of members from the EB community, we created a series of hard-hitting images for the A Life Free of Pain appeal that would have emotional impact and help to raise awareness of EB.

How we will continue to develop in 2023

Raise awareness

Awareness of DEBRA and of EB remains low. We need to achieve greater awareness of EB within the healthcare and research communities and the wider public to ensure there is understanding for those living with the condition, more widespread EB expertise and support to enable us to fund vital research and care. We will continue delivering awareness initiatives as part of the 'A Life Free of Pain' throughout 2023 to raise awareness of EB and DEBRA and support our fundraising drive.

Build engaged communities

Members are central to everything we do. We want to ensure that we reach and engage all the individuals and families living with EB and their support network, and provide them with the information, resources and connect the community. We will improve member insight and understanding through the detailed patient insight study and regular feedback mechanisms, set up an online member community network and increase the breadth and quality of health information by working with PIF Tick.

We will seek out and promote EB expertise and developments in research and healthcare to engage our community of researchers & clinicians, develop a core group of specialists, including those within DEBRA, to provide active support as speakers, commentators, and an expert panel to support us in gaining influence with healthcare professionals, central government, corporations, and pharma companies.

We will create compelling communications, illustrating the impact of our work and the inspirational stories from our EB community to connect with our supporters, building a community working towards a shared, urgent goal. We will inform our staff and volunteers about EB, building their knowledge and understanding of our work and their confidence to become advocates of DEBRA and increasing their engagement on social media.

We will build our retail brand to deliver a stronger presence on the high street which will highlight our commitment to our cause and to sustainability and support income generation through our stores and our online shopping platforms.

Lobby government

We will launch our flagship insight study and mental health survey for people living with EB. The findings will shape everything we do at DEBRA, supply vital information to the pharmaceutical industry and play a crucial role in lobbying government for EB support and funding.

How we raise our funds

Together we can transform the lives of people with EB and bring hope for a better future

The commitment and generosity of our supporters in 2022 enabled us to achieve a record fundraising income of £2.3m, despite the ongoing impact of the pandemic and the cost of living crisis. This exceptional response has enabled us to set ambitious targets for the coming years to fund new and effective treatments for EB and deliver the specialist support the EB community needs.

Our ambition

We are committed to raising the funds needed to invest in specialist healthcare and research that will be life-changing for people with EB. The more we can raise, the faster we will beat EB.

Our objectives

1. To grow our core net fundraising income. Our ambitious target for 2023 is to increase this to £3m, representing an increase of 59% over three years.
2. To refocus our fundraising, recognising the short and long-term effects of COVID-19 and the cost of living crisis. We will be less reliant on events and prioritise the development of long term relationships and our major donor, grants, trusts and corporate donations.
3. To drive a substantial increase in donations and awareness about EB through the delivery of the 'A Life Free of Pain' appeal.

How we met our objectives in 2022

Our fundraising was extremely successful in 2022. This was principally due to the development of our major gift programme and the generosity of philanthropist Lenore England, whose donation of £500k for the first of our drug re-purposing projects enabled us to leverage further funds on the back of her support. As a result, we have scaled up our ambitions for fundraising in 2023 and beyond.

The commitment of our supporters enabled us to deliver a varied and successful fundraising events plan, from the traditional DEBRA high-end events such as Fight Night, Great Chefs Dinner to our popular golf programme. We increased the range of events for people to take part in including the 100km challenge and Kiltwalks in Scotland. Thank you to the hundreds of people who have dined, run, walked, cycled and golfed to raise record levels of money to support EB in 2022.

In October 2022 we launched our most ambitious appeal, A Life Free of Pain, with the support of our President, Simon Weston and Vice Presidents Graeme Souness, Stuart Procter, Lenore England and Frank Warren. The appeal will not only raise significant funds, it aims to bring considerable attention to the charity and awareness of EB. A Life Free of Pain aims to raise £5m to accelerate our research into drug repurposing and other life-changing treatments that could radically improve quality of life for people living with EB. At the end of the year, in just a few months, the appeal had raised over £1.1m.



How we will continue to develop in 2023

Relationship development

With the support of our Royal Patron, President and Vice Presidents, we aim to develop new philanthropic support. We will deliver a small number of exclusive events hosted by our Patron, President and Vice-Presidents to build our major donor relationships and commitment.

Grant-making trusts

We will secure at least one major grant (£100k+) from a grant-making trust towards a drug re-purposing project as part of our 'A Life Free of Pain' appeal. We will continue to develop long term relationships with funders that have supported the charity for a number of years or invested heavily in our work.

Corporate support

We will invest in the development of the team, recruiting a corporate partnerships manager to bring in new business along with the stewardship of current corporate supporters. A particular area of interest is the pharmaceutical industries, particularly those with a potential interest or existing interest in EB. We will use the Appeal to encourage engagement with more corporate partners.

Supporter Services

The Supporter Services team will roll out an engaging supporter journey managed within our new CRM system, ensuring that all donors are committed to our vision, feel valued and become regular donors of the future. We will also offer a series of interesting and varied sponsorship events for supporters to get involved with.

Events

Our events introduce over 2,000 new people a year as new and prospective donors as well as welcoming back long-term supporters. These will include the traditional major events in both 2023 and 2024 (the Football Dinner in Glasgow, Great Chefs' Dinner, Fight Night, Shoot at EJ Churchill, Wine Challenge, Sporting Lunch and Kiltwalks).

Gift aid

We will target 50% of income being received under gift aid, which would result in £222k being reclaimed. Of the £4.7m budget, approximately £2m relates to income that may fall within the gift aid scheme.

We subscribe to the Fundraising Regulator and its Code of Fundraising Practice.



Legendary boxing manager and DEBRA Vice-President Frank Warren hosted his 17th DEBRA Fight Night this year, in association with Queensbury Promotions. This was DEBRA's most successful Fight Night in five years raising over £140,000



A Life Free of Pain appeal

On the 20th October, we launched our A Life Free of Pain appeal at The Landmark Hotel in London with DEBRA Vice Presidents Graeme Souness and Lenore England, President Simon Weston CBE, CEO Tony Byrne & Chair of Trustees Jim Irvine and DEBRA members Lucy Beall Lott, Isla Grist and Fazeel Irfan.

“As a charity we have never before attempted something as big or as ambitious as this. A Life Free of Pain appeal is about changing the everyday lives of people living with the distressing, debilitating and excruciatingly painful condition that is epidermolysis bullosa.”

DEBRA President,
Simon Weston CBE

Tyson Fury donates £10,000 to DEBRA during interview with Myra Ali

On the same day as the launch of our 'A Life Free of Pain' appeal, Myra Ali, who lives with Recessive Dystrophic EB, interviewed Tyson Fury at the #FuryChisora press conference at Tottenham Hotspurs Stadium. Tyson spoke to Myra about his battle with his mental health and how he deals with physical and mental pain. Tyson had won a £10,000 bet with DEBRA Vice President Frank Warren earlier in the day. During the interview, he took the money from his bag and donated it towards our A Life Free of Pain appeal.

Thank you

We would like to say a heartfelt thank you to everyone who supports us in our fight to end the pain of EB. To all who donated to our cause and the thousands of people who ran, cycled, took up our challenges, volunteered and the many ambassadors who shared their story to help to raise awareness of EB. We are also extremely grateful for the continued support of our Patron HRH The Duchess of Edinburgh GCVO, our President Simon Weston CBE, Life Patron Philip Evans, Vice Presidents Lenore England, Stuart Procter, Graeme Souness and Frank Warren.



Our Patron, President, Vice Presidents

HRH The Duchess of Edinburgh GCVO
Simon Weston CBE
Lenore England

Stuart Procter
Graeme Souness
Frank Warren

Trusts and foundations

The Oliver Thomas Memorial Fund
The Band Trust
The Brothers Trust
The Souter Charitable Trust
The VTCT Foundation

Bill Brown's Charitable Settlement of 1989
The Dorus Trust
The Kola'a Trust
The Forest Hill Charitable Trust
The Murphy-Neuman Charity

The Dyer's Company
The Edith Murphy Foundation
The John Coates Charitable Trust
The Northwood Charitable Trust The Grace Trust
The Catherine Cookson Charitable Trust
The Peter Harrison Foundation
The DM Charitable Trust
The Fowler Smith and Jones Trust
The Joseph Strong Frazer Trust
The Leach Fourteenth Trust
The Strangward Trust
The GM Morrison Charitable Trust
The Lillie Johnson Charitable Trust
The David Laing Foundation
The Edward Cadbury Trust
The Gilbert and Eileen Edgar Foundation
The Calleva Foundation
The Raven Charitable Trust
The Shanly Foundation
The Tory Family Foundation
The Ammco Trust
The Louis Bayliss Charitable Trust
The Benham Charitable Settlement
The John Cowan Foundation
The William Brake Foundation
The Basil Samuel Charitable Trust
The Childwick Trust
The Verdon-Smith Charitable Trust
The Riply Trust
The Michael and Anna Wix Charitable Trust
The Alice Ellen Cooper Dean Foundation
The Bruce Wake Charity
The February Foundation

The Hugh Fraser Foundation
The QBE Foundation
The Riada Trust
The 29th May Charitable Trust
Marconi Chelmsford Employees Charitable Trust Fund
The Wixamtree Trust
The Mabs Mardulyn Charitable Foundation
Awards for All
The George Stewart Charitable Trust
The Jack Lane Charitable Trust
The Sylvia and Colin Sheppard Charitable Trust
The PF Charitable Trust
The Parry Family Foundation
The Maud Elkington Charitable Trust
The W.E.D Charitable Trust
The George A Moore Foundation
The Hudson Charitable Trust
Baron Davenports Charity
The Hospital Saturday Fund
The Ardwick Trust
The Misses Barrie Charitable Trust
The Eveson Charitable Trust
The James Wise Charitable Trust
The Charles S French Charitable Trust
The Charity Service Fund
The National Lottery Community Fund
The Enid Linder Foundation
The Klahr Charitable Trust
The Manson Family Charitable Trust
The Whittington Charitable Trust
The Barbara and Stanley Fink Foundation
The Simon Gibson Charitable Trust

Our stores

At the heart of our communities

£650,000

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

60%

increase in our
online sales

102

stores

8th

largest charity
retailer in the UK

800kg+

of unsaleable textile
items recycled

Our stores play a vital role in their communities, helping to build awareness of EB, raising the profile of DEBRA and generating vital income to fund our EB research, healthcare and support.

Our ambition

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

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

Our objectives

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

How we met our objectives in 2022

Facing the cost of living pressures

Like many charities we faced considerable inflationary pressures due to energy price rises and national minimum wage increases, resulting in a shortfall in our retail contribution of £0.8m towards our 2022 budget plan. High levels of store closure due to sickness and vacancies also contributed to this loss of sales. Despite this, the development of our dedicated team of volunteers and the loyalty and support of our customers enabled us to achieve £0.65m net retail income to fund life-changing healthcare, research and support for the EB community.

Achieving cost savings and operating efficiencies

As part of our commitment to creating a more efficient and leaner retail function, we started the year with 104 stores and finished with 102, closing five underperforming stores and opening three new stores including two larger stores. These flagship stores led the way as we began a major refurbishment programme to roll out our new branding.

To improve our retail infrastructure and efficiency and ensure we operate in as environmentally friendly manner as possible, we tendered energy, facilities management and waste contracts, reviewed in-store stock processes and procurement, implemented a trial of DEBRA leased vehicles and updated our EPOS system.

Building our online and instore sales

This year has been a challenging but exciting time for DEBRA retail online. We achieved a 70% increase in our online following and 60% growth in like for like online sales, giving a significant boost to our income and diversifying our customer population. We did not meet the growth expectation as originally planned at the beginning of the year, due to the failure of the third party fulfilment agreement we had in place.

Our online and instore brand benefited from the launch of the DEBRA retail social media programme with a new retail-focussed Instagram channel, the development of individual shop Facebook pages, the set-up of online e-commerce hubs, the creation of social media specialists amongst our volunteer team and individual stores posting fashion features and local awareness campaigns to increase footfall and donations.

Developing our dedicated team of staff and volunteers

Internal staff development and progression was a key focus. We also continued to revise and improve staff induction and overall mandatory training and management. This resulted in a significant increase in H&S engagement and compliance and a reduction in the labour turnover ratio.

The improvements in overall instore IT infrastructure, equipment and management systems strengthened our ability to engage, support and communicate with our store teams. We repeated our annual virtual conference for staff and volunteers, providing training as well as key information about EB and our current work in research and community support.



How we will continue to develop in 2023

Our aim is to grow our net income, however we will continue to focus on consolidation with the expectation that the pressure on costs will continue. Good cost control and a review of efficiencies in areas such as energy, transport, waste and facilities management will be a focus and part of our ongoing ESG commitment.

We will review under-performing stores and anticipate opening a limited number of larger format, high quality stores with strong contribution and stock generation. We will undertake a series of shop refurbishments, optimisation plans and the continued roll out of the new DEBRA branding to ensure attractive retail environments.

We will continue to build our e-commerce and online sales, command higher prices, and grow and diversify our customer population. We aim to align with the growth of online changing consumer shopping habits in the UK, maximise donation potential and expand our overall customer reach.

In addition, we aim to maximise the use of all potential platforms, selling tools, automations, and integrations to increase revenue while streamlining operations. This will enable all stores to achieve their full digital retail potential by maximising engagement and providing appropriate support, allowing us to build donations and ASP via digital sales.

Growing and diversifying our new income streams will play a key feature for the year, with a particular focus on the development of strong corporate stock partnership.

Without the skills and commitment of our retail team of staff and volunteers we could not achieve our plans. We will ensure that we continue to provide support, training and opportunities to develop. We are truly grateful for everything that they do.

Our dedicated volunteers

Our volunteers play an essential role in our retail stores as well as supporting our fundraising and working with teams across the charity. They are an essential part of the DEBRA team. We are deeply grateful for their time, commitment and skills. We couldn't achieve our mission without them.

23%

increase in volunteers
in 2022

1,100

volunteers giving
230,000 hours of
donated time

£2.2m+

saved for the charity

100+

participants undertaking DofE
volunteering through DEBRA stores

180

long service awards
presented



Our volunteers report that it is an opportunity to socialise, learn new skills, and gain valuable work experience to move into paid employment. In 2023, we are committed to a programme of support and development for volunteers across the whole charity, ensuring that DEBRA is a great place to volunteer and that they are valued, respected and recognised for the invaluable work they do.

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

“Our volunteers are truly remarkable. I am constantly amazed and humbled by their commitment and dedication, so it was lovely to be able to launch long service awards this year as well as recognise some of our hidden heroes.”

Mark Francis, Volunteering
Development Manager

Our people

Making a difference

We employed over

375

permanent staff

We had 14 trustees,

64%

with direct experience of EB

We counted on the support of over

1,100

volunteers

We provided over

9,000

hours of training for our staff

Every person in our charity provides a highly valued contribution to the service that we provide the EB community, whether delivering our vital research and healthcare programmes, supporting families with EB, managing or volunteering in our charity shops, working to raise essential funds, promoting and communicating the work we do, processing income, providing learning and development, supporting our cause as an ambassador or offering guidance as a trustee.

Our ambition

Our ambition is to lead the fight against EB. To achieve this the key to our success is our people. Our aim is to create a culture where our whole community can thrive, are valued, where equality and diversity are embedded in our values and actions, where everyone has the opportunity to develop, to enjoy their work and to make a difference and ensuring that support operations (Marketing Communications, HR, IT and Finance) are best in class.

Our objectives

Our People agenda focuses on three priority areas:

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



How we met our objectives in 2022

Rewarding talent

A talent identification pipeline was undertaken to fill senior positions (historically filled with external candidates) with internal candidates. As a result, a number of key internal promotions have been made. We launched a quarterly employee recognition scheme, the DEBRA Butterfly Awards, to recognise the employees and volunteers who live the DEBRA values.

Skills & resources

Investment in new systems created a major change across DEBRA, revolutionising the way we work. New health & safety, human resources, learning management, payroll and online expenses systems gave employees easy access to self-service and contributed to our ESG targets for reduction of print and paper usage.

The new learning management system, with an extensive library of bought in and internally developed materials, increased mandatory training to over 90%. In addition to online training, face to face training resumed after the pandemic with topics including manual handling, safeguarding, performance management, train the trainer. The key focus has been on health and safety which has resulted in a significant reduction in safety-related incidents and an increased level of reporting.

Building a great place to work

We repeated the employee survey, previously undertaken in 2020. The response rate increased from 30% in 2020 to 59% in 2022. Improvement was noted in all areas with significant improvement for employees' understanding of the charity's vision and strategy, sharing a commitment and passion for the charity's cause, feeling supported by HR and managers and appreciating opportunities for career development.

Safeguarding as a priority

Safeguarding continues to be a priority. In 2022 our focus was on raising awareness of safeguarding amongst our employees and volunteers. In addition to a mandatory online training module, we ran our annual Safeguarding September with a range of materials shared throughout the month including educational videos, case studies, articles, and stories. We also hosted live sessions examining the difference between welfare cases and safeguarding, providing clear guidance on how best to report any concerns that employees or volunteers may have. For our volunteers a new safeguarding booklet was rolled out giving an overview of what safeguarding is along with helpful guidance of what to do if they are concerned for their own or anybody else's wellbeing.

Equality, diversity and inclusion

We are an equal opportunities employer organisation. In 2022 our Equality, Diversity and Inclusion (EDI) workstream moved forward with the capture of diversity data for our employees, volunteers and prospective employees, allowing us to identify areas for improvement and put in place required processes to continue the journey to being an organisation that mirrors the diversity profile of the members and communities we serve. We ran our first EDI January (J-EDI) with the launch of online EDI training, intranet information and personal contributions from staff and volunteers.

Our gender pay gap report for 2022 showed that our mean pay gap was 16.65% in favour of men and our median hourly full pay gap was 0%. The mean gap has been influenced by the increase in men occupying roles in the upper-mid banded roles. This was based on 365 employees (276 female/89 male) on the snapshot date. The gender pay gap is a measure of the difference in the average pay of men and women, regardless of the nature of their work, across the entire organisation. We have made significant progress over the years however we are committed to doing more as part of our EDI and values-driven culture.

How we will continue to develop in 2023

2023 will be a year of consolidation as we embed many of the initiatives and processes launched in 2022 including values, succession planning, manager development, performance management and health and safety best practice. For 2023, our Safeguarding Committee agreed that an internal audit of our safeguarding policy and process should be undertaken to highlight any gaps and support our journey to best practice in this area. The 2023 workplan takes into consideration the employee survey feedback and addresses the areas where improvement is still required. We will move to a new financial reporting system. The succession planning process will be rolled out to all areas of DEBRA.

We will also continue the EDI journey to being an organisation that mirrors the diversity profile of the members and communities we serve.



Our ESG journey

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

100%

of waste from our stores diverted from landfill through our waste partner

CO2 emissions saved equivalent to

170*

trees planted

Our ambition

As a charity with over 100 stores and 1400 staff & volunteers, we know we have an impact, on the environment and on the communities we work with, which can be positive. We want to be a force for change, reducing the impact we have on the environment and on society, ensuring the highest ethical standards and considering environmental sustainability and social responsibility in all we do.

Our objectives

1. To be a more sustainable & environment-friendly in everything we do and everyone we work with.
2. To create a culture where equality and diversity are embedded in our values and actions and where staff wellbeing is a priority.
3. To ensure the highest ethical standards, and considering environmental sustainability and social responsibility in all that we do and the impact of our charitable activities and investment decisions on our EB community, our staff, volunteers, supporters, customers and the local economy.

How we met our objectives in 2022

- We created an ESG policy with an annual action plan and set up an ESG committee to monitor progress.
- We put in place ways to measure our carbon footprint and new processes to reduce use of energy, water, paper and other resources including the introduction of new HR, finance and expenses systems removing the need for printed forms and invoices in our offices and our charity shops.
- We continued to provide an equal opportunity workplace where we invest in professional development and staff and volunteers are valued.
- We participated in initiatives such as the Duke of Edinburgh Award with 100 young people volunteering and the Kickstarter Scheme, which provided 15 young people with work placements across our retail stores.
- Our Trustee Board ensured our standards and practices fully embraced the principles of the Charity Commission Charity Governance Code, the Fundraising Regulator and GDPR data protection. This commitment to strong corporate governance is critical to protecting our membership, supporters, employees and our reputation.

How we will continue to develop in 2023

- We will continue the EDI journey to being an organisation that mirrors the diversity profile of the members and communities we serve.
- We'll provide training and information to all of our team, work with suppliers and contractors who share our ESG objectives and seek to ensure sustainable investments.
- We'll continue to minimise waste through reduction, re-use and recycling and introduce initiatives such as reviewing how we travel by promoting options such as car sharing and agile working.
- We'll promote best practice in all our operations and activities, considering environmental protection, public health and safety, human rights, anti-bribery and corruption, and labour and anti-slavery practices.
- To engage our staff and volunteers in our ESG commitment, we will introduce bi-annual ESG Champions awards to recognise the actions taken by teams and individuals across the charity and inspire others.
- Our leadership will lead by example both in practice and behaviour.

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

Tony Byrne, CEO DEBRA UK



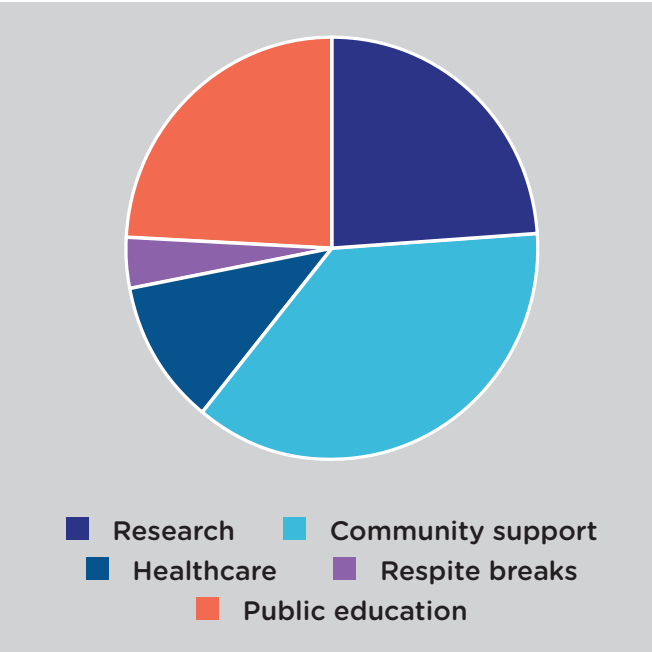
*Statistics provided are for six months since measurement began in July 2022 when we changed our waste partner

Charity overview, objectives & public benefit

Financial review

We spent £2.6m on charitable activities in 2022, compared with £1.9m in 2021. Whilst new research commitments were limited, spend on healthcare, community support and respite amounted to £1.4m, compared to £1.0m in 2021.

Charitable spend



Charitable spend was £2.64m in 2022 compared to £1.89m in 2021. All areas of charitable spend increased: Community support up to £0.97m from £0.68m, Research to £0.63m from £0.48m, Healthcare to £0.29m from £0.25m, Respite Breaks to £0.12m from £0.09m and Public Education to £0.63m from £0.36m.

Net assets increased to £4.25m from £3.80m. There was £2.8m in the general fund, £1m in designated funds and £0.49m in restricted funds.

Net income from the retail operation was £0.65m (2021: £1.7m, including government grants of £2.4m). Overall net fundraising income was £2.3m in 2022, compared with £0.96m 2021.

The surplus for the year was £0.5m, compared with £0.8m in 2021.

Summary

Table 1 summarises the highlights of our financial performance over the last five years. Gross income was £16.4m in 2022, an increase of £3.1m (23%) from 2021.

Non-trading gross income (not including government retail support) was £4.02m, a 76% increase from £2.29m in 2021. This includes income from donations, corporate support, trusts and community events.

Net retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops, but excluding government support) increased by 43% to £12.4m from £8.7m, following a full year of trading in 2022.

Charity overview, objectives & public benefit

Table 1: Financial KPI summary

	2022 £'000	2021 £'000	2020 £'000	2019 £'000	2018 £'000
Gross income	16,421	13,317	11,413	16,798	16,138
Non-trading income including all government support	4,017	4,663	4,387	3,475	2,979
Net trading income	(196)	(1,299)	(3,201)	1,198	1,193
Net retail income including government pandemic support, retail gift aid, commission and donations in shops	654	1,689	(673)	2,123	2,138
Non-trading fundraising costs	699	662	708	768	727
Charitable expenditure	2,640	1,885	2,848	3,110	2,966
Retained surplus/(deficit)	452	817	(2,371)	795	479
Retained surplus/(deficit) as a % of income	3%	6%	(21%)	5%	3%
Net current assets	3,333	3,124	2,684	4,878	4,394
Unrestricted reserves	3,763	4,050	2,904	5,138	4,420
Grants payable within 1 year	2,019	2,237	2,159	2,201	1,825

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

Reserves policy

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

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

The trustees’ reserves policy in 2022 was to maintain minimum cash-backed free reserves at £1.7m, to which the charity adhered. Maintaining the high levels of retail income has been a challenge but this has been offset by a significant increase in fundraising income. The minimum reserves figure is set to cover six month’s rent plus one month of other costs. The trustees conducted a thorough review of the reserves policy at the end of 2022, reviewing performance criteria in the light of the economic situation. The trustees’ aim is to grow cash-backed free reserves over the next four years to £3m, in line with planned growth in retail and fundraising operations.

Charity overview, objectives & public benefit

Funds

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

Total reserves at the end of 2022 were £4.25m. Cash-backed free reserves after designations were £1.7m with £1.1m of remaining free reserves giving total general funds of £2.8m. There were £1m of designations adding to a total of £3.8m of unrestricted funds.

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

Restricted funds

Restricted funds were £488k, including £86k for community support and healthcare activities. Other restricted funds are:

Oliver Thomas Memorial fund

The Oliver Thomas Memorial Fund was established in September 2022. £85,000 is restricted to a contribution to a Medical Research Council Fellowship, £10,000 for an EB weekend get-together, £9,200 for Clinical Best Practice Guidelines and £7,500 to a contribution to eye research in collaboration with Fight for Sight.

Apremilast Drug Re-purposing

£152k was donated to fund research into re-purposing the psoriasis drug Apremilast for use with EB patients.

Holiday Home Purchase

£135k was raised following an appeal for a new holiday home giving much needed respite to EB patients and families. The home was purchased in 2022 and the fund balance will reduce as the home is depreciated.

Asset cover for funds

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

Investment policy

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit. We aim to apply our income in support of our charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk. £3m is held in fixed term deposits with HSBC.

Expenses policy

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

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

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

Charity overview, objectives & public benefit

Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2022 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous nonprimary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 12 of the Financial Statements.

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.

Internal audit

RSM are appointed as internal auditors. Audits of Internal Financial Controls, Cyber Security, Payroll and Fundraising took place in 2022 and recommended actions are being implemented by management. In 2023 audits of GDPR, Procurement, HR Key Controls and Financial Controls will take place.

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

See Table 4: DEBRA's major risks.

Table 2: Summary Extract from DEBRA's Risk Register

Risk	Cause & Effect	Controls
Economy / Inflation	Adverse economic conditions or high inflation impact shop or other income	<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 reports■ Partner only with established reputable sponsors after due diligence■ Commercial Participation Agreements

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Non-compliance with H&S or other law	Health and Safety issues not being identified or addressed timely leading to accidents and potential serious injury and legal action. Increase in sickness due to injury caused at work Threat of enforcement actions ('Action Letters') by Local Authorities, Fire and Rescue Services and Environmental Health Departments or the Health and Safety Executive.	<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 user's hard drives are encrypted Secured wifi at Bracknell head office Remote desktop sessions time out after 20 mins Back-up daily server images moved to the cloud File shadow copy active on the server (protects against Malware encryption spyware) Complex passwords required by policy Meraki firewalls in place throughout offices and shops Anti-virus/spyware solution on all PC based tills All credit card machines meet PCI compliance standard C Monitoring of data access

Charity overview, objectives & public benefit

Risk	Cause & Effect	Controls
Failure to maintain adequate cash flow	Suppliers not being paid on time, delays in staff expenses reimbursement. Need for overdraft facilities. Ultimately leading to inability to continue to operate.	<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 SMT	Poor performance against budget High number of grievances or staff turnover in a department Whistleblowing	<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"> SMT monitoring and CEO reports to Trustees Fundraising and Communications Committee meetings Periodic review of Donations Policy Board approval required for major new initiatives Donations Policy Threshold of £10k for confirming donations are from a legitimate source
Board does not have required skills	Lack of specific skills on Board leading to poor strategic direction. Resulting inability to meet charitable objectives and wasted resources.	<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 2023 – 31 December 2024, which detail the plans for delivering to the EB community during a period of high cost inflation and the cost of living crisis. It is recognised that there are underlying uncertainties, however the trustees consider the charity can continue its business-critical activities and remain a going concern. The retail estate like-for-like sales are now exceeding pre-pandemic level and fundraising income is expected to be significantly higher in 2023 compared to 2022.

The trustees consider it is appropriate to prepare the 2022 accounts on a going concern basis on the basis that:

- Trading in 2023 is exceeding to pre-pandemic levels on a like for like basis;
- There is significant growth in fundraising activity including a major fundraising programme and several key events;
- The Budget and cash flows for 2023 and 2024 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2023 and 2024 is contingent on achieving fundraising and retail targets.

Structure, governance & management

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

Board of Trustees

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

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

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

Charity overview, objectives & public benefit

In 2022

A resolution of directors was passed in July 2022, pursuant to an Extraordinary General Meeting held in April 2022 amending the Articles of Association of the charity, making the trustees of the charity the sole legal members of the charity, increasing the number of trustees with a connection with EB to more than 50% and dispensing with the need to have an Annual General Meeting.

In line with the new articles and as recommended by the Nominations & Governance Committee, the Board of Trustees reappointed David Bendor-Samuel, Carly Fields (previously elected trustee) and Christo Kapourani (previously elected trustee) for a further three-year term. The Board also re-appointed Jim Irvine as the Chair of the Board and Simone Bunting (who had previously served as a trustee, but had taken a year’s break as required by DEBRA’s articles) for a first term of three years. Simon Talbot was also elected by the members. Dan Mundy was appointed to the Board in November 2022.

Three trustees resigned from the Board during the year – Andy Grist (February 2022), Josie Godfrey (May 2022) and Douglas Rouse (September 2022).

Trustee Board Committees

During the year, the Board convened a Committee Restructure Working Group to evaluate the current Board Committee structure and to make a proposal for restructuring. The main drivers for the proposed restructure were as follows: existing committees had become too operational, duplicating the role of the executive; related to this, there was a threat of a loss of focus on strategy and governance; overlap of content at committees, which can mean that a committee member can hear the same information three or more times; workload for trustees and the threat of ‘burnout’ with too many committees and recognising the trust the Board has in the Executive.

The outcome of this review was that the Fundraising and Communications Committee and the Retail Committee became executive committees. The current Care and Research Committee was renamed and redirected to become the Charitable Purposes Committee from Jan 1, 2023. In addition, a Remuneration Committee (ad hoc) was set up by the Board.

Charity overview, objectives & public benefit

Finance, Risk & Audit Committee (“FRA”) –

determines and advises the Board of Trustees on matters relating to finance, risk and audit as the Board of Trustees may remit to it, in particular the sound financial management of the charity, its resources and assets.

Charitable Purposes Committee (“CPC”) –

determines and advises the Board of Trustees on matters relating to strategy in research, healthcare, community support and policy as the Board of Trustees may remit to it.

Nominations & Governance Committee (“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 2022.

Activities in Scotland

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

Charity overview, objectives & public benefit

Board Attendance Table

Trustee		Board	FRA	N&G	CAR/ CPC	Retail	F&C
Jim Irvine (Chair)		5 of 5	5 of 5	5 of 5			
David Bendor-Samuel		5 of 5		5 of 5			
Simone Bunting	Stood down Jun 22 (N&G)	5 of 5		1 of 4		4 of 4	
Rebecca Cresswell		4 of 5					4 of 4
Carly Fields		5 of 5		4 of 5	4 of 4		
Andrew Grist	Stood down 1 Mar 22	0 of 1			1 of 4		
Christo Kapourani		3 of 5			2 of 4		
Joanne Merchant		4 of 5	5 of 5			4 of 4	
Dan Mundy	Appointed 2 Nov 22	1 of 1	1 of 1				
Viv Mundy	Stood down Jun 22 (N&G)	2 of 5		1 of 4	1 of 4		
Douglas Rouse	Stood down 28 Sep 22	2 of 4					2 of 4
Mick Thomas		5 of 5					3 of 4
Simon Talbot		4 of 5	5 of 5				
Josie Godfrey	Stood down 13 May 22	1 of 3			1 of 4		

Auditor

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

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

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

Jim Irvine
Chair of Trustees

Trustees’ statement of responsibilities

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

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

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

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

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

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company’s website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2022 was 15 (2021: 2,343). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditor's report

Auditor's report

Independent auditor's report to the members of DEBRA

Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2022 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at
- 31 December 2022 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Auditor's report (continued)

Other Information

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

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Auditor's report

(continued)

Responsibilities of trustees

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

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

Auditor's responsibilities for the audit of the financial statements

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

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

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

Capability of the audit in detecting irregularities

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

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

Auditor's report

(continued)

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

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

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

Auditor's report

(continued)

Use of our report

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



Fleur Holden

(Senior statutory auditor)

Date 1 June 2023

for and on behalf of Sayer Vincent LLP,
Statutory Auditor

Invicta House, 108-114 Golden Lane, LONDON,
EC1Y 0TL

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

Financial statements

For the year ended 31 December 2022

Statement of financial activities

Statement of financial activities including income and expenditure account for the year ended 31 December 2022.

2022					
		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
Total income		14,725,180	481,397	1,214,148	16,420,725
Expenditure on:					
Raising funds	6	13,297,601	31,000	-	13,328,601
Charitable activities	6	2,165,640	-	474,687	2,640,327
Total expenditure		15,463,241	31,000	474,687	15,968,928
Net income / (expenditure)		(738,061)	450,397	739,461	451,797
Transfer between funds		-	-	-	-
Net movement in funds		(738,061)	450,397	739,461	451,797
Reconciliation of funds:					
Total funds brought forward		3,500,325	550,000	(251,950)	3,798,375
Total funds carried forward		2,762,264	1,000,397	487,511	4,250,172

Statement of financial activities

(continued)

2021					
		Unrestricted funds	Designated funds	Restricted funds	Total
	Notes	£	£	£	£
Income from:					
Donations & legacies	2	4,261,175	-	347,477	4,608,652
Charitable activities		20,441	-	-	20,441
Other trading activities	3	8,641,059	-	12,945	8,654,004
Investments	4	14,564	-	-	14,564
Other		19,740	-	-	19,740
Total income		12,956,979	-	360,422	13,317,410
Expenditure on:					
Raising funds	6	10,614,818	-	-	10,614,818
Charitable activities	6	1,604,625	-	280,573	1,885,198
Total expenditure		12,219,443	-	280,573	12,500,016
Net income / (expenditure)		737,536	-	79,849	817,385
Transfer between funds		624,292	(215,950)	(408,342)	-
Net movement in funds		1,361,828	(215,950)	(328,493)	817,385
Reconciliation of funds:					
Total funds brought forward		2,138,497	765,950	76,543	2,980,990
Total funds carried forward		3,500,325	550,000	(251,950)	3,798,375

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

The notes on pages 69-95 form part of these financial statements.

Balance sheet

Balance sheet as at 31 December 2022.

		2022	2021
	Notes	£	£
Fixed assets			
Tangible fixed assets	10	1,290,091	1,009,272
Programme related investment	11	1	1
Investment in subsidiaries	12	2	2
		<u>1,290,094</u>	<u>1,009,275</u>
Current assets			
Fixed assets held for sale		-	74,167
Stocks		2,063	1,321
Debtors	13	1,856,681	1,942,888
Current asset investment	14	3,000,000	
Cash at bank and in hand		<u>2,146,142</u>	<u>4,967,810</u>
			6,986,186
Creditors: amounts falling due within one year	15	<u>(3,672,317)</u>	<u>(3,861,818)</u>
Net current assets		<u>3,332,569</u>	<u>3,124,368</u>
Total assets less current liabilities		4,622,663	4,133,643
Creditors: amounts falling due after more than one year	16	(134,359)	(147,320)
Provision for liabilities	17	<u>(237,952)</u>	<u>(187,948)</u>
Total net assets		<u>4,250,172</u>	<u>3,798,375</u>

Balance sheet

(continued)

		2022	2021
		£	£
The funds of the charity			
Restricted income funds	19	487,511	(251,950)
Unrestricted funds			
Designated funds	20	1,000,397	550,000
General funds	20	<u>2,762,264</u>	<u>3,500,325</u>
Total unrestricted funds		<u>3,762,661</u>	<u>4,050,325</u>
Total funds		<u>4,250,172</u>	<u>3,798,375</u>

Company registration number 4118259

The accounts were approved by the Board on **17.05.2023** and signed on their behalf by:

Jim Irvine

Chair of Trustee Board

Joanne Merchant

Treasurer

Statement of cash flows

Statement of cash flows for the year ended 31 December 2022.

		2022	2022	2021	2021
	Notes	£	£	£	£
Cash flows from operating activities					
Net cash provided by (used in) operating activities	22		566,564		(270,182)
Cash flows from investing activities					
Dividends, interest and rents from investments		5,472		14,564	
Proceeds from the sale of property, plant and equipment		92,382		238,649	
Purchase of property, plant and equipment		(486,086)		(91,774)	
Proceeds from sale of investments		-		-	
Purchase of investments		(3,000,000)		-	
Net cash provided by investing activities			(3,388,232)		161,439
Change in cash and cash equivalents in the reporting period			(2,821,668)		(108,743)
Cash and cash equivalents at the beginning of the reporting period			4,967,810		5,076,553
Cash and cash equivalents at the end of the reporting period			2,146,142		4,967,810

The notes on pages 69-95 form part of these financial statements.

Notes to the financial statements

1 Accounting policies

1.1 Basis of preparation

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

1.2 Going concern

The Trustees reviewed the charity's budget and cash flows for 1 January 2023 – 31 December 2024 in December 2022 and consider it is appropriate to prepare the 2022 accounts on a going concern basis on the basis that:

- Trading in 2023 is exceeding pre-pandemic levels on a like for like basis;
- There is significant growth in fundraising activity including a major fundraising programme and several key events;
- The Budget and cash flows for 2023 and 2024 maintain adequate cash reserves throughout the period; and
- Research activity programmed in 2023 and 2024 is contingent on achieving fundraising and retail targets.

1.3 Legal status of charity

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

1.4 Judgements and estimates made by management

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

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

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

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

Notes to the financial statements

(continued)

1.5 Income

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

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

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

1.6 Expenditure

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

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

1.7 Recognition of grant liabilities

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

1.8 Tangible fixed assets and depreciation

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

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

Notes to the financial statements

(continued)

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

1.9 Programme related investment and impairment

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

1.10 Cash and short-term investments

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

1.11 Debtors

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

1.12 Creditors

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

1.13 Financial instruments

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

1.14 Stock

The trustees do not consider it appropriate to recognise donated goods for resale as stock on the grounds that the cost of obtaining stock information would greatly outweigh any benefit. The costs involved would include the setting up of processes and procedures for a stock count in over 100 shops, training shop staff and volunteers in the process, software programming, and the checking and analysis of the reports produced.

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

1.15 Accumulated funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The exceptional circumstances of 2020 and 2021 resulted in funds being undesignated in order for the charity to continue its charitable objectives. The purposes and uses of the restricted funds and designated funds are set out in Note 19 to the financial statements.

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 2022	Unrestricted funds	Restricted funds	Total 2021
	£	£	£	£	£	£
Donations & gifts	2,302,674	506,896	2,809,570	1,758,535	105,013	1,863,548
Legacies receivable	409,165	500	409,665	8,148	4,431	12,579
Grants receivable	105,160	687,241	792,401	2,494,492	238,033	2,732,525
	2,816,999	1,194,637	4,011,636	4,261,175	347,477	4,608,652
Donations & gifts:						
Individual donations	2,062,574	426,373	2,488,947	1,469,207	94,482	1,563,689
Corporate donations	206,150	79,538	285,688	253,525	8,025	261,550
International donations	1,321	-	1,321	1,156	-	1,156
Events by individuals	32,629	985	33,614	34,647	2,506	37,153
	2,302,674	506,896	2,809,570	1,758,535	105,013	1,863,548
Grants receivable:						
Charitable trusts	105,160	687,241	792,401	61,093	238,033	299,126
Government grants				2,433,399	-	2,433,399
	105,160	687,241	792,401	2,494,492	238,033	2,732,525

Government grants consist of £nil (2021: £809,812) received under the Coronavirus Job Retention Scheme and £nil (2021: £1,623,587) received in local authority grants.

Gifts in kind of £79,186 (2021: £87,206) are included in donations and gifts. This comprises online adwords valued at £79,186 (2021: £67,206) and campaign design and consultancy valued at £nil (2021: £20,000).

Notes to the financial statements

(continued)

3. Other trading activities

	2022	2021
	£	£
Income	12,253,334	8,654,004
Operating expenses	(12,449,041)	(9,952,625)
Net income from fundraising activities	(195,707)	(1,298,621)

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2022 there were 102 shops trading (2021: 105). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2022	Income	Operating expenses	Net income 2021
	£	£	£	£	£	£
Retail	11,204,468	(11,749,690)	(545,222)	7,911,357	(9,340,096)	(1,428,739)
Fundraising events	841,849	(699,351)	142,498	639,431	(612,529)	26,902
Miscellaneous trading	207,017	-	207,017	103,216	-	103,216
	12,253,334	(12,449,041)	(195,707)	8,654,004	(9,952,625)	(1,298,621)

Retail income excludes income of £1,019,370 (2021: £732,522) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail gift aid commission of £163,655 (2021: £33,236) which is recognised in miscellaneous trading. In 2021 the COVID-19 pandemic had a significant impact on gross retail income. The profit covenanted by DEBRA Trading Limited of £43,362 (2021: £69,980) is recognised in miscellaneous trading.

Notes to the financial statements

(continued)

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

	2022	2021
	£	£
Income	12,403,661	8,710,081
Operating expenses	(11,749,690)	(9,340,096)
Net expenditure on fundraising activities	653,971	(630,015)

4. Investment income

	2022	2021
	£	£
Interest receivable	994	3
Rent of property	4,528	14,561
Total investment income	5,472	14,564

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

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 354 (2021: 179) Community Support grants totalling £85,856 (2021: £36,752) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 23.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2022 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £411,167 (2021: £548,814) and clinical projects to the sum of £107,997 (2021: £125,948).

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

	Total 2022	Total 2021
	£	£
Within one year	384,632	527,442
Within two – three years	134,532	147,320
Within four – five years	-	-
Provided within the grants payable creditor (notes 15 and 16)	519,164	674,762

Notes to the financial statements

(continued)

6. Expenditure

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

Notes to the financial statements

(continued)

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2021
	£	£	£	£	£	£
Raising funds						
Donations & legacies	381,817	-	-	164,432	115,943	662,192
Other trading activities	5,338,778	-	61,319	314,047	4,238,482	9,952,626
	<u>5,720,595</u>	<u>-</u>	<u>61,319</u>	<u>478,479</u>	<u>4,354,425</u>	<u>10,614,818</u>
Charitable activities						
Research	274,861	168,806	-	31,262	9,555	484,484
Healthcare	60,235	172,668	-	19,858	-	252,761
Community support	607,601	36,752	-	42,710	-	687,063
Respite breaks	-	-	48,016	-	46,926	94,942
Public education	243,566	-	-	31,934	90,448	365,948
	<u>1,186,263</u>	<u>378,226</u>	<u>48,016</u>	<u>125,764</u>	<u>146,929</u>	<u>1,885,198</u>
	<u>6,906,858</u>	<u>378,226</u>	<u>109,335</u>	<u>604,243</u>	<u>4,501,354</u>	<u>12,500,016</u>

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

	2022	2021
	£	£
Operating leases	1,796,779	1,246,982
Auditors' remuneration	19,900	20,000
Non-audit services	-	3,600
Depreciation of tangible fixed assets	180,733	159,256
Defined contribution pension costs	381,336	314,405
Exchange differences	(46,469)	27,809

Notes to the financial statements

(continued)

7. Cost allocation

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

	2022	2021
	£	£
Staff costs	1,838,856	1,403,077
Overheads		
Office premises rent	55,117	62,789
Service charges, utilities & cleaning	50,669	57,363
Equipment costs	255,442	144,088
Postage, printing, stationery, telephone & fax	72,073	64,585
Insurance costs	138,505	110,401
Legal, professional & consultancy fees	69,399	139,356
Depreciation	51,068	38,017
Profit on disposal	6,319	(143,660)
Irrecoverable VAT	39,840	22,348
Bank charges	7,117	9,744
Sundry expenses	(26,062)	58,201
<u>Governance costs:</u>		
Audit, non-audit and internal audit fees	39,800	38,600
Miscellaneous costs	110	2,411
	<u>759,397</u>	<u>604,243</u>
Total allocation	2,598,253	2,007,320

Notes to the financial statements

(continued)

None of the trustees received any remuneration from DEBRA during the period, but two of them were reimbursed a total of £565 (2021: one - £127) for travel and accommodation expenses. No Trustees received community grants (2021: £nil). The aggregate figure for trustee donations in 2022 was £14,460 (2021: £447). In addition, many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £4,375 (2021: £4,025), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9. Employees

The average number of employees during the period was:

	2022	2022	2021	2021
	No	FTE	No.	FTE
Research	2	1.6	1	1.0
Healthcare*	-	-	-	-
Community Support	15	13.3	13	12.3
Fundraising & Comms	22	20.1	16	15.8
Retail	296	230.4	299	216.4
Management & Administration	27	25.6	19	17.6
	362	291.1	348	263.1

Notes to the financial statements

(continued)

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

	2022	2022	2021	2021
	No	FTE	No.	FTE
Research	2	1.7	1	1.0
Healthcare*	-	-	-	-
Community Support	15	13.7	13	12.0
Fundraising & Comms	20	18.6	16	15.6
Retail	295	227.3	304	222.2
Management & Administration	27	25.6	22	19.2
	359	286.9	356	270.0

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

	2022	2021
	£	£
Wages & salaries	7,467,472	5,960,400
Social security costs	601,090	392,291
Pension costs	381,336	314,405
Total payroll	8,449,898	6,667,096
Other staff costs	310,749	239,762
Total allocation	8,700,647	6,906,858

Notes to the financial statements

(continued)

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees’ personal pension plans. Payments of £381,336 (2021: £338,399) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £nil (2021: £nil) unpaid.

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

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

	2021	2020
	No.	No.
Between £60,001 - £70,000	-	3
Between £70,001 - £80,000	4	1
Between £80,001 - £90,000	2	-
Between £110,001 - £120,000	1	1

Redundancy and compensation payments, which were all paid in year, totalled £67,528 (2021: £16,739).

The aggregate pay of key management personnel, including employer’s NI and pension contributions was £857,698 (2021: £711,022). The aggregate employer’s pension contribution for key management personnel was £67,439 (2021: £61,489)

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £59,492 (2021: £59,064), and there are retirement benefits accruing for eight (2021: five) employees under a defined contribution scheme.

Notes to the financial statements

(continued)

10. Fixed assets

Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land & buildings	Long leasehold land & buildings	Total
	£	£	£	£	£	£
Cost:						
At 1 January 2022	362,140	480,162	395,043	578,347	82,500	1,898,192
Additions	-	248,601	237,485	-	-	486,086
Disposals	(81,735)	(34,000)	(17,500)	-	-	(133,235)
At 31 December 2022	280,405	694,763	615,028	578,347	82,500	2,251,043
Depreciation:						
At 1 January 2022	253,161	245,615	201,267	167,427	21,450	888,920
Charge for the year	34,074	57,670	74,460	12,879	1,650	180,733
Disposals	(58,559)	(34,000)	(16,142)	-	-	(108,701)
At 31 December 2022	228,676	269,285	259,585	180,306	23,100	960,952
Net book value:						
1 January 2022	108,979	234,547	193,776	410,920	61,500	1,009,272
31 December 2022	51,729	425,478	355,443	398,041	59,400	1,290,091

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

Notes to the financial statements

(continued)

11. Programme related investment

	2022	2021
	£	£
Investment in Fibrx Derm Inc		
Net investment value brought forward	1	1
Purchase of investment	-	-
Impairment charge	-	-
	<u> </u>	<u> </u>
Net investment value carried forward	<u>1</u>	<u>1</u>

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

12. Investment in subsidiaries

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

Financial information for these entities for the year ended 31 December 2022:

	2022		2021	
	DEBRA Trading Ltd	DEBRA Retail Ltd	DEBRA Trading Ltd	DEBRA Retail Ltd
	£	£	£	£
Turnover	90,376	-	119,267	-
Total expenses	47,014	-	49,287	-
Gift aid to DEBRA	43,362	-	69,980	-
Profit / (loss) for the year	-	-	-	-
Net assets / (liabilities)	2	1	2	1
Share capital	2	1	2	1

Notes to the financial statements

(continued)

13. Debtors

	2022	2021
	£	£
HMRC	211,221	174,344
Amounts due from group undertakings	43,362	69,980
Other debtors	544,057	489,879
Accrued income	458,491	681,184
Prepayments	599,550	527,501
	<u> </u>	<u> </u>
	<u>1,856,681</u>	<u>1,942,888</u>

Amounts due from HMRC are VAT receivable of £211,221 (2021: £174,344). Other debtors includes £266,825 (2021: £301,908) due for shared research grants. Accrued income includes gift aid of £289,219 (2021: £344,460) due from HMRC.

Total future minimum lease receivable in 2022 was £nil (2021: £nil), in respect of 1 shop.

14. Investments in short term deposits

	2022	2021
	£	£
HSBC money market deposits	3,000,000	-
	<u> </u>	<u> </u>
	<u>3,000,000</u>	<u>-</u>

Notes to the financial statements

(continued)

15. Creditors: amounts falling due within one year

	2022	2021
	£	£
Trade creditors	223,903	427,092
Grants payable	2,019,399	2,236,649
Other creditors	263,332	220,134
Taxation and social security	138,323	113,353
Accruals	1,013,934	845,920
Deferred income	13,426	18,670
	3,672,317	3,861,818

Grants payable includes £384,625 (2021: £548,832) relating to future commitments and £1,634,774 (2021: £1,687,817) relating to outstanding invoices for work done.

There was deferred income of £13,426 (2021: £18,670), representing income for events which would have to be repaid in the event of cancellation.

16. Creditors: amounts falling due over one year

	2022	2021
	£	£
Grants payable	134,539	147,320
	134,539	147,320

17. Provision for liabilities

	2022	2021
	£	£
Dilapidations provision		
Provision brought forward	187,948	181,808
Charges	50,004	6,140
Release of provision	-	-
	237,952	187,948

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:

	2022	2021	2022	2021
	Leases of land and buildings	Leases of land and buildings	Other	Other
	£	£	£	£
Within one year	1,019,492	1,233,867	18,747	13,115
Between one – five years	1,454,360	1,539,926	18,481	16,217
After five years	74,767	-	-	-
	2,548,619	2,773,793	37,228	29,332

There were capital commitments of £nil (2021: £nil) at year end, falling due within one year.

19. Analysis of funds: restricted funds

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

	Balance at 1 January 2021	Income	Expenditure	Transfer to general fund	Balance at 31 December 2021
	£	£	£	£	£
Research	-	176,067	(118,065)	(408,342)	(350,340)
Healthcare	5,600	30,362	(15,337)	-	20,625
Community support & respite	70,943	153,993	(147,171)	-	77,765
	76,543	360,422	(280,573)	(480,342)	(251,950)

Notes to the financial statements

(continued)

Restricted funds comprised:	2022	2021
	£	£
Oliver Thomas Memorial Fund ¹	111,700	-
Research - Apremilast Drug Re-purposing Trial	151,607	-
Healthcare - EB nurses	-	15,025
Healthcare - Birmingham Children's Hospital Specialist Bath	5,600	5,600
Community Support - Holiday Home Appeal	132,662	-
Community Support - Community Support Manager for Scotland	21,542	21,542
Community Support - Community Support in Bedfordshire	5,121	5,121
Community Support - Community Support in Berkshire	4,273	8,037
Community Support - Support Grants in Hampshire	3,952	5,502
Community Support - Support Grants in Scotland	66	1,934
Community Support - Support Grants in South East England	-	15,851
Community Support - Support Grants in South Gloucestershire	1,054	1,054
Community Support - Support Grants in Somerset	6,914	-
Community Support - Support Grants in West Midlands	1,303	-
Community Support - Support Grants in Buckinghamshire	13,836	-
Community Support - Support Grants in Surrey	1,674	-
Community Support - other restricted funds	16,207	18,724
Digital Inclusion	10,000	-
	487,511	98,390
Less:		
Research - COVID Medical Research Charity Support Fund ²	-	(350,340)
	487,511	(251,950)

1. The Oliver Thomas Memorial Fund was established in September 2022. £85,000 is restricted to a contribution to a Medical Research Council Fellowship, £10,000 for an EB weekend get-together, £9,200 for Clinical Best Practice Guidelines and £7,500 to a contribution to eye research in collaboration with Fight for Sight.

2. An agreement was signed with the Medical Research Council who agreed to provide funding for specific research projects already in progress. The funds were received in 2022. The related costs were recognised in the income statement and charged to the general fund on grant award in accordance with DEBRA accounting policies. Therefore, a transfer from restricted funds to general funds was required in 2021 representing spend already incurred.

Notes to the financial statements

(continued)

20. Analysis of funds: unrestricted funds

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

	Balance at 1 January 2021	Income	Expenditure	Transfers	Balance at 31 December 2021
	£	£	£	£	£
Future research grants	515,950	-	-	(515,950)	-
Nursing continuity	250,000	-	-	-	250,000
IT Strategy	-	-	-	50,000	50,000
Procurement	-	-	-	50,000	50,000
NHS Digital	-	-	-	200,000	200,000
Total designated funds	765,950	-	-	(215,950)	550,000
General fund	2,138,497	12,956,979	(12,219,443)	624,292	3,500,325
Total unrestricted funds	2,904,447	12,956,979	(12,219,443)	408,342	4,050,325

The future research grants fund was fully un-designated in 2021 in response to the Covid-19 Pandemic and the Trustees resolved that the historical practice of designating all amounts in excess of minimum required cash-backed free reserves for future research would not be re-established. Instead, funds would be designated for specific project opportunities envisaged within the overall Five-Year Strategy. £481,397 (2021: £nil) has been designated to fund drug re-purposing trials and £200,000 (2021: £200,000) has been designated to fund the NHS Digital Data project. These projects are due to commence in 2023.

Notes to the financial statements

(continued)

The designated fund for nursing continuity has been established as a contingency in the event of future NHS funding withdrawal, and the Trustees maintained a balance of £250,000 (2021: £250,000) in this fund.

In 2021 £100,000 was designated to fund future procurement and IT work furthering modernisation of back office practices. £31,000 was spent on procurement consultancy in 2022 leaving a balance of £69,000 as at 31 December 2022. This balance is expected to be used in 2023 for IT and procurement consultancy.

21. Analysis of net assets between categories of funds

Fund balances at 31 December 2022 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,290,094	-	-	1,290,094
Current assets	5,516,978	1,000,397	487,511	7,004,886
Creditors:<1 year	(3,672,317)	-	-	(3,672,317)
Creditors:>1 year	(372,491)	-	-	(372,491)
	<u>2,762,264</u>	<u>1,000,397</u>	<u>487,511</u>	<u>4,250,172</u>

Fund balances at 31 December 2021 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,009,275	-	-	1,009,275
Current assets	6,688,136	550,000	(251,952)	6,986,186
Creditors:<1 year	(3,861,810)	-	-	(3,861,818)
Creditors:>1 year	(335,268)	-	-	(335,268)
	<u>3,500,325</u>	<u>550,000</u>	<u>(251,952)</u>	<u>3,798,375</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)	451,797	817,385
Depreciation and amortisation charges	180,733	159,256
Impairment of programme related investment	-	-
Dividends, interest and rents from investments	(5,472)	(14,564)
Profit / (loss) on disposal of fixed assets	6,319	(143,663)
Decrease in stock	(742)	4,589
(Increase) / decrease in debtors	86,207	(326,269)
(Decrease) / increase in creditors	(152,278)	(766,914)
Net cash used in operating activities	<u>566,564</u>	<u>(270,182)</u>

23. Analysis of cash and cash equivalents

	At 1 January 2022	Cash flows	At 31 December 2022
	£	£	£
Cash at bank and in hand	4,967,810	(2,821,668)	2,146,142
	<u>4,967,810</u>	<u>(2,821,668)</u>	<u>2,146,142</u>

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:	2022		2021	
	Total paid in year £	Total paid to date £	Total paid in year £	Total paid to date £
University of Dundee				
Clinical fellow funding	7,664	658,253	146,115	650,589
University of Glasgow				
Re TGF-beta mediated tumour promotion in RDEB		221,139	64,001	221,139
Guy's and St Thomas' Hospital, London				
Clinical endpoints study re EB therapy evaluation	40,233	734,790	160,956	694,557
Stem cell therapy trial re treating debilitating itch	-	497,360	31,946	497,360
Wound care and its complications in patients with EB	7,324	7,324	-	-
Thomas Jefferson University, Philadelphia, USA				
Phase 2 clinical trial of Rigosertib for RDEB SCC	-	470,490	-	470,490
Univ. Birmingham Dental School & Hospital				
Characterisation of skin microbiome in EB patients	-	296,289	31,359	296,289
Gait Analysis in EB Simplex	30,688	46,032	15,344	15,344
Clinical Fellowship	33,168	98,904	30,622	65,736
Novel spray to treat mucosal scarring	50,777	152,384	76,201	101,607
University of Cologne				
Re immunity in wound healing complications RBEB	5,929	170,635	23,688	164,706

Notes to the financial statements

(continued)

Research grants:	2022		2021	
	Total paid in year £	Total paid to date £	Total paid in year £	Total paid to date £
Universitair Medisch Centrum Groningen				
Re phyto-cannabinoid treatment of pain in EB	-	159,025	-	159,025
Instituto Dermopatico del'Immacolata Rome				
Re histone deacetylase inhibitors for RDEB	4,627	69,034	4,627	64,407
King's College London				
Preclinical studies of lentiviral-mediated COL7A1 gene therapy	10,395	198,978	43,394	188,583
Great Ormond Street Institute of Child Health				
Respiratory cell & gene therapy for children with JEB	52,601	118,445	65,844	65,844
Bambino Gesù Children's Hospital				
MicroRNAs expression profiling, activity and therapeutic perspectives	27,628	73,184	30,876	45,556
University of Edinburgh				
Re Kindlin-1 loss in squamous cell carcinoma	38,954	90,621	41,379	51,667
New York Medical College				
Re innate & adaptive immune mechanisms in RDEB	69,120	173,352	69,588	104,232
Total research grants paid in year	379,109	4,236,240	835,941	3,857,132

Notes to the financial statements

(continued)

Healthcare projects:	2022	2021
	Total paid in year £	Total paid in year £
Great Ormond Street Hospital for Sick Children Clinical nurse specialists in EB	54,681	83,525
Guys & St Thomas' Hospital London Adult EB support nurses	(26,964)	58,388
Birmingham Children's Hospital	56,577	30,755
Other	17,951	12,157
	102,245	184,825

Notes to the financial statements

(continued)

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

Reconciliation of provision:	2021			
	Research grants £	Healthcare grants £	Community Support grants £	Total £
Provision brought forward	1,183,468	138,105	-	1,321,573
New commitments	168,806	172,668	36,752	378,226
Co-funding contributions	32,481	-	-	32,481
Spend in year	(835,941)	(184,825)	(36,752)	(1,057,815)
Provision carried forward	548,814	125,948	-	674,762

25. Related parties

During the year, the charity charged management charges totalling £11,300 including VAT (2021: £11,300) to its subsidiary, DEBRA Trading Limited.

Reference and administrative details

Patrons and ambassadors

- Royal Patron**
HRH The Duchess of Edinburgh GCVO
- Life Patron**
Philip Evans
- President**
Simon Weston CBE
- Vice Presidents**
Graeme Souness
Frank Warren
Stuart Procter
Lenore England

Trustees

- Jim Irvine (Chair)
Joanne Merchant* (Treasurer)
David Bendor-Samuel (Vice-Chair)
Carly Fields* (Vice-Chair)
Simone Bunting*
Becky Edwards*
Josie Godfrey (resigned 13 May 22)
Andrew Grist* (resigned 27 Feb 22)
Christo Kapourani*
Viv Mundy*
Douglas Rouse (resigned 28 Sep 22)
Simon Talbot*
Mick Thomas*
Dan Mundy (appointed 2 Nov 22)

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

Additional details

- Company secretary**
Ade Lawal (appointed 26 January 2022)
- Registration**
Charity Commission Number: 1084958
SCR Number: SC039654
Company Number: 4118259
- Registered office & principal address**
DEBRA, The Capitol Building, Oldbury,
Bracknell, RG12 8FZ
- Auditor**
Sayer Vincent LLP, Invicta House,
108-114 Golden Lane, London EC1Y 0TL
- Banker**
HSBC, Thames Valley Business Banking,
Hanborough House, Wallbrook Court,
North Hinksey, Oxford, OX2 0QS
- Solicitor**
Stone King, 91 Charterhouse Street,
London, EC1M 6HR

Abbreviations

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



DEBRA 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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Company limited by guarantee registered in England and Wales (4118259).
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