

# Trustees' Annual Report and Accounts 2021



# Our vision

A world where no one suffers with Epidermolysis Bullosa (EB).

# Our mission

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

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# The DEBRA effect

At DEBRA, we can't change the future of Epidermolysis Bullosa (EB) in an instant. But we do know that an instant can help change the future of people on a life-long journey with EB.

**We believe that anyone can effect change with one small action:**

- One interaction with the EB community could bring invaluable insight that...
- Directs our energy and focus onto an essential unmet need which...
- Enables us to tailor our support and services effectively so that...
- Our members feel empowered to take as much control over their lives as possible which...
- Builds our relationships with experts who share our passion for finding life-changing solutions so that...
- Our community becomes more hopeful, connected and mutually supportive and we...
- Strive to make life-long improvements that enable anyone affected to enjoy pain-free, fully-lived lives.



Let us never underestimate the simple things we can do to spread ripples of hope for people living with EB. Let us all take one small action to fight EB so that, one day, EB no longer has any fight left to give.

# What is EB



## Skin as fragile as a butterfly wing

EB, Epidermolysis Bullosa, is a complex and rare group of genetic skin conditions that cause the skin to tear and blister at the slightest touch. The name comes from 'epiderm' – the outer layer of skin, 'lysis' – the breakdown of cells and 'bullosa' – blisters. EB can impact the external skin and also internal linings e.g. mouth, throat, eyes, anus and organs.



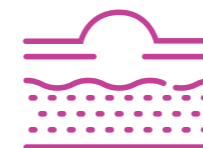
## Genetic condition

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



## Types of EB

There are at least 30 genetically distinct forms of EB. The four main types are EB Simplex (EBS) accounting for around 70% of patients, Dystrophic EB (DEB) 25%, Junctional EB (JEB) 5% and other rare types including Kindler Syndrome.



## Layers of skin tear and blister

Symptoms vary from mild to severe depending on the type of EB. In its most severe forms, EB is fatal; even in its mildest forms it can cause lifelong disability and pain. Blisters continuously form and have to be drained and dressed daily, a painful process that can take several hours. The build-up of scar tissue can cause fingers and toes to fuse together. It can mean a higher risk of developing skin cancer.



## Treatment

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



## No cure

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

# What is EB to me?

## Lucy's story

To answer this, I must answer what it was, what it is now, and what it will be.

It was a happy childhood, one that people can't quite believe was as happy as it was. It was an abundance of love pouring over me from my first steps. But it was also bandages from my toes to my fingers. It was my siblings going into the backyard because sometimes, you could hear me scream from every room. It was days and weeks missing school when all I wanted to do was learn.

It was discovering the power of my mind and the power my words could carry. It was writing in the car ride to the children's hospital before surgery the next morning, where I'd start to cry behind an oxygen mask as anaesthetic forced my mind to still. It was saying the name of my condition and finally understanding what it meant.



“ It was an abundance of love pouring over me from my first steps. But it was also bandages from my toes to my fingers. ”

It was a dozen surgeries in less than a decade, and fear, and an understanding that I had to do a lot more than other teenage girls. It was an understanding of society, crying in my car after a woman told me I looked like I'd been mauled by a gorilla. It was friends and my puppy and horse riding. It was pride after I saw my words carry me across countries, with pictures of my scars plastered in the Daily Mail and Huffington Post as I boarded a flight for an education in London.

Now, I am 23 years older than I was meant to be. And here is what it is.

It is my mother and boyfriend fighting back sleep from hospital chairs as they wait to hear if I made it out of the operation. It is watching my scar tissue overtake my fingers, and rites of passage I didn't plan for. It is being interviewed by a Scottish journalist from my hospital bed, an IV dripping pain medicine into my arm and laughing at the ridiculousness of it all.

“ It will be possible for me to say, sometime soon, due to the research DEBRA is doing, that I am Lucy, and I HAD EB. ”

It is pointing and stares and bravery, exhaustion and joy, in the same hour. It's photographers pointing lenses at my scars and resisting the urge to cover myself, hide my soul from them. It is making decisions for the sake of my body with a knowledge that I may be hurting it. It is causing myself pain to heal. It is every ounce of my strength and more, it is words untranslatable, and fear and love and hope.



It is a part of me. It is the force that made me who I am. It's why I sat down to write this for you. My name is Lucy Beall Lott and I have recessive dystrophic Epidermolysis Bullosa. I am a student, an art historian, an archaeologist, a sister, a daughter. And I have EB. I always have. But as we know, many things can change in just a short amount of time.

What will it be? What will I be? I used to think of my future and feel small. But instead of feeling overwhelmed by fear of the future, I am now overwhelmed by the excitement of possibility. There are so many things I now know are possible. It is possible to write a speech for a Ted Talk in bed with wounds across your body, it is possible to write two dissertations while your pinky fuses to your ring finger, it is possible to live not despite your condition but with it.

It is possible to see the beauty in the world, in scars and tears and pain. A future for people with EB is possible. We can see it. It is almost here.

It will be possible for me to say, sometime soon, due to the research DEBRA is doing, that I am Lucy Beall Lott, and I HAD EB.

Lucy Beall Lott

# Our work

## *Investing in a future free of EB*

DEBRA UK was the first organisation in the world established to focus on EB. We have a proud history and a dynamic present. We will see our mission to its end – we cannot, and will not, rest until we find the necessary treatments, and ultimately cures, for EB and all those living with it receive the care and support they need.

From discovering the first EB genes to funding the first clinical trial in gene therapy, we have played a pivotal role in EB research globally and been responsible for making significant progress in advancing diagnosis, treatment and daily management of EB.

We are committed to making sure that all of the 5,000 or more people with EB in the UK and their families and carers get the vital and wide-ranging support they need, supporting specialist healthcare and investing in life-changing research so that the devastating symptoms of EB can be reduced while we work towards a cure.



## Making a difference in 2021

Working with  
**4**  
national EB centres

Collaborating with  
**60**  
EB healthcare professionals

**19**  
EB research projects

**3,000+**  
DEBRA members

**4,300**  
support actions, calls, contacts  
and visits to people living with EB

**1,200**  
volunteers and staff

**£1.9 million**  
spent on research, healthcare &  
support benefiting the EB community

1.2 million  
kilos of goods  
recycled in our **105** charity shops

**5 million**  
people reached on social media



**7th**  
largest charity  
retailer in UK

# An ambitious five-year strategy

## Welcome from our Chair of Trustees

The devastating nature of EB continues to drive our determination to achieve our vision and end the suffering that EB brings. This means not only accelerating research to improve quality of life, but challenging ourselves and lobbying others, including Government, to leverage the significant funds that could bring forward the cure that every EB family dreams of.



It means a step-change in our fundraising and our approach to finding individuals, organisations and government bodies to achieve what we have been working towards for over 40 years.

We have developed an ambitious new strategy, with a clear vision for where we want to be in five years. We will return to and surpass pre-pandemic levels of investment and service by making our retail stores more profitable than ever, developing our online sales and building on fundraising and philanthropic opportunities.

“ We want to ensure that DEBRA remains the ‘go to’ place for everything relating to EB. To achieve this, the key to our success is our people. ”

We will collaborate with national and international partners to improve delivery of specialist healthcare services and drive a programme of world-class, innovative and collaborative research that will bring hope and improved outcomes for everyone living with all types of EB.

We’ll introduce schemes to nurture the next generation of EB researchers and bring new investment into EB research with a focus on drug repurposing to accelerate research progress.

We will empower and advocate for the EB community, building our knowledge through Quality of Life surveys to increase our engagement with members and help shape our services.

We want to ensure that DEBRA remains the ‘go to’ place for everything relating to EB. To achieve this, the key to our success is our people. We will prioritise learning and development for our staff and volunteers and increase access to specialist EB knowledge and information for all who support people living with EB.

A huge challenge is to make ‘EB’ a term that is understood by the masses and not the few. Achieving such a change will need investment but it will be worth it as the increased awareness will result in a deeper supporter base spreading further awareness and boosting our income along the journey.

Thank you to our EB community, the specialist healthcare professionals and researchers we work with, our customers, supporters, trustees, staff and volunteers. It is your commitment and support which has brought us this far and which will enable us to achieve our ambitious goals.

**Jim Irvine**  
Chair of Trustees

# Committed to the EB community

## Introduction from our CEO

Despite the challenges of the COVID-19 pandemic and the impact on our finances, we are in a position to exit the crisis strongly as a growing organisation. DEBRA receives no statutory government funding. The income we raise from our retail stores, online sales, from our fundraising activities and the generosity of our supporters is vital to enable us to deliver our charitable objectives – investing in EB research, healthcare and support.



As for so many of us worldwide, the effects of the pandemic over the past 24 months have been significant. Our income-generating potential was put under pressure with fundraising events on hold and our charity shops affected by lock-down closures. However, we have worked hard for many years to raise our levels of reserves and been prudent with our spending. This meant that despite facing highly challenging times this year, we still had the resources needed to deliver vital, front-line services. Our aim for 2022 is to increase our spending on both research and EB support services while we work towards our ambitious vision – ‘a world where no one suffers with Epidermolysis Bullosa (EB).’

“ For over 40 years we have invested in pioneering EB research and healthcare. ”

For people with EB, the consequences of COVID-19 are concerning, particularly for those with more severe forms of the condition who may already have fibrosis of the airway tract and be experiencing compromised immunity. We remained committed to supporting the EB

enhanced nursing service ensuring that, despite some EB nurses being redeployed, patients continued to receive the vital medical attention they needed. We delivered online training and advice to maintain access to specialist expertise from EB healthcare professionals and our Community Support Team.

For over 40 years we have invested in pioneering EB research and healthcare. Throughout the past year we are proud to have been able to continue building partnerships both in the UK and internationally to further EB research and play a leading role in promoting EB knowledge and best practice for patients around the world.

At the heart of everything we do are the EB families, researchers and healthcare experts we support. I wish to thank our hardworking staff, volunteers, trustees and our supporters, without whom nothing would be possible. In another year of turbulence, your donations made sure people living with EB did not lose vital support at a time when they needed it most.

**Tony Byrne**  
CEO

# Growing through challenging times

The COVID-19 pandemic has had a significant impact on our finances, however we are in a position to exit the crisis strongly as a growing organisation.

At the start of 2021 we faced the difficulties experienced by many charities across the country, with our stores closed, the majority of our staff furloughed, fundraising events cancelled and delivery of our services to the EB community restricted to virtual support.

However, despite the challenges created by months of lockdown in 2021, our retail sales were 30% higher overall, with some stores outperforming 2019 sales and we undertook a successful development of online selling initiatives.

We were able to hold events in the second half of the year and support from a number of new major donors enabled us to get our fundraising income back on track.

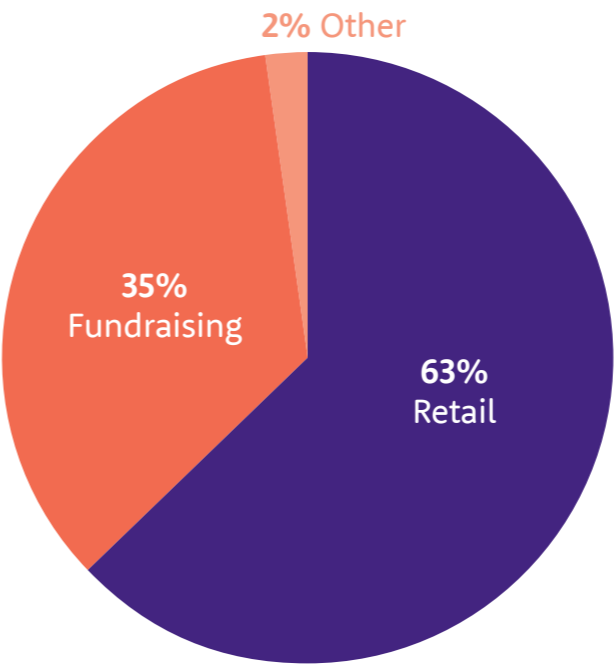


The income raised through our network of charity shops and fundraising activities enabled us to continue to invest in EB research, specialist healthcare and to provide vital support for the EB community.

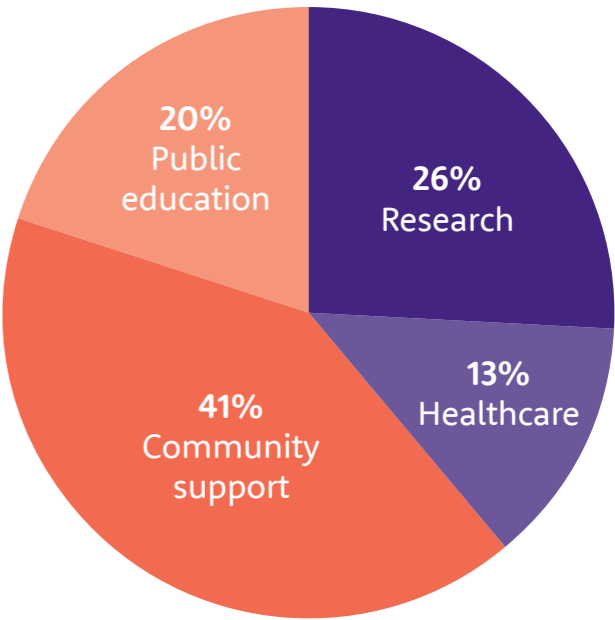
- **We continued to support all 19 research projects** with further funding allocated of £168k.
- **We ensured EB patients and families were fully supported by our Community Support Team.** We worked hard to ensure that all who needed our support were able to access us virtually or in person. We broadened the range of online sessions for our members including drop-in groups for parents and for teenagers to build social networks. We ensured access to specialist EB expertise with online sessions from EB dietitians, podiatrists, physiotherapists and other healthcare professionals.
- **We continued to work in partnership with the NHS,** supporting EB services at the four specialist EB centres across the UK, although some of the non-core activities were limited due to the impact of the pandemic on healthcare teams.
- **Our specialist EB podiatry training course was developed** ready for online delivery to make support accessible to podiatrists across the UK enabling patients to access vital expert care locally.

# £1.9m spent on our charitable activities

How we raised our money



How we spent our money



Thank you to our members, community support team, healthcare professionals, researchers, trustees, staff and volunteers, customers, trusts, companies and donors for the continued, committed support you have given to our charity and to the EB community.

We couldn't have survived the past two years without you. Together we have made a difference and will continue to #FightEB until we have achieved our vision of a world where no one suffers with Epidermolysis Bullosa (EB).

# EB research

## Changing lives

From gene discovery to cutting-edge clinical trials of therapies to control symptoms and manage complications like cancer, the research journey for EB over the past 40 years has been remarkable. During this time, we have invested over £20m and been responsible, through funding world-class, pioneering research and working internationally, for establishing much of what is now known about EB. We are the largest UK funder of EB research and consistently in the top 50 UK funders of research across all diseases and conditions.



Over **£20m** invested



Across **12** countries



In **134** research projects



In **52** research institutions globally

### What we did in 2021

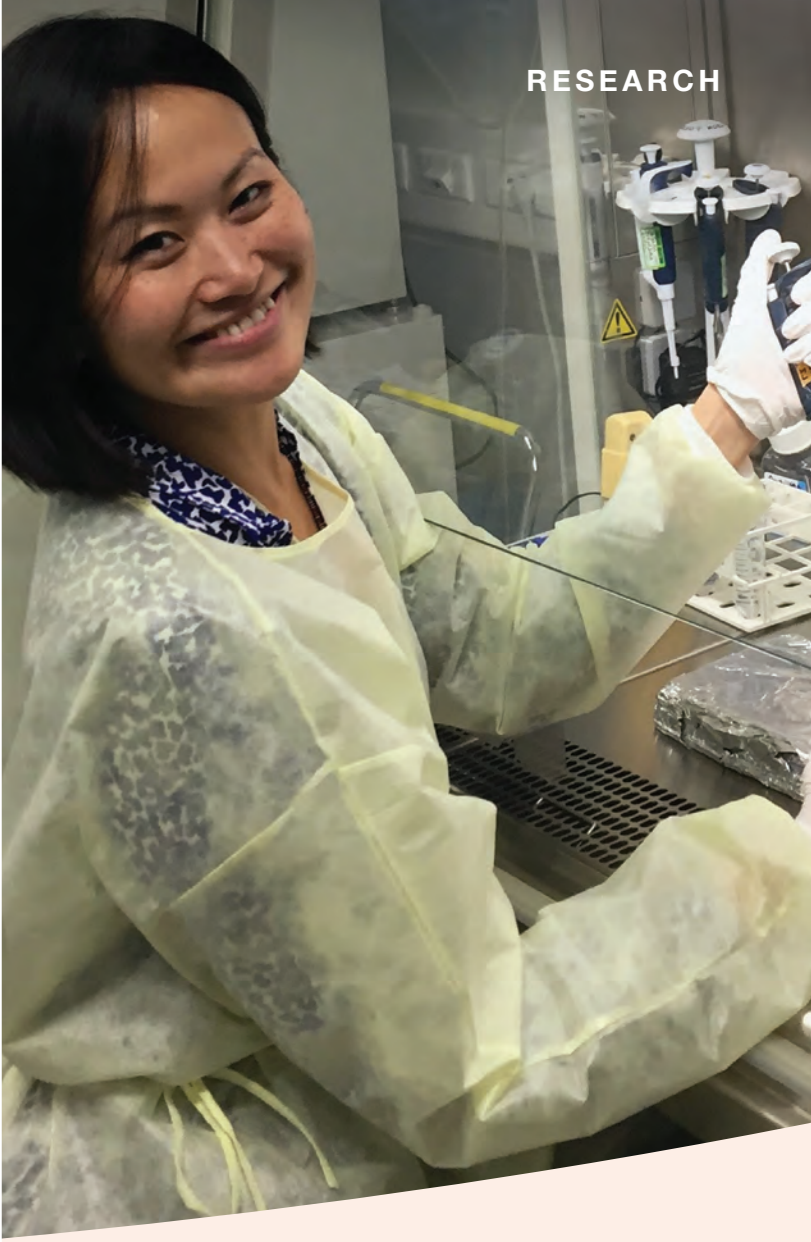
The pandemic had a big impact on medical research charities including DEBRA. Some research projects were paused due the need to limit the number of people working in labs, however our commitment to research was unwavering. We continued to support all 19 existing research projects, providing funding of £836k in 2021 and allocated additional funding of £168k to new commitments.

Our grant portfolio, worth around £5m, included research into:

- a revolutionary gene therapy using spray-on cells with a protein that glues the skin together.
- a ground-breaking study into blocking molecule ‘signalling’ to stop cancer growth.
- a skin cream using a human protein that could improve healing and stop wounds scarring. Wounds and pain and the risk of infection they cause, are one of the most debilitating aspects of EB.
- a potential treatment for EB Simplex using gene ‘silencing’ technology to switch off a faulty gene to allow the normal gene to work properly.
- a study into the potential use of cannabinoid-based medicines to manage pain and itch without the side effects of some treatments.
- a cancer treatment drug with the potential to stop the growth of squamous cell carcinoma.

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

- a project to understand the bacteria which in EB may cause infections, delay wound healing and result in scarring and the potential to re-establish the ‘healthy’ bacteria in the immune system.
- an evaluation into long-term disease progression of RDEB that will inform the use of clinical trials to measure new treatments for all types of EB.
- clinical trials using cell therapy to improve understanding and treatment of severe itch.
- a project investigating inflammation, scarring and wound healing in EB.
- supporting fellowships, to develop and shape researchers and clinical experts for the future.



“ Global collaboration is absolutely vital because we have so many experts around the world working on not just EB but other specialities such as oncology and haematology and combining different approaches. Thinking outside the box and working together will speed up the research and the effectiveness of what we can achieve together. ”

Dr Su Lwin, Researcher



## Andy & Isla's story

“ As a parent of a child living with EB, it is incredible to see that research that was science fiction when Isla was born is now part of the solution. Isla has faced many challenges with her pain and she is tired; she wants a cure, as do many others who suffer from this condition. This is an upsetting and painful fight to go through and to watch.

The EB scientific and medical community increasingly believe they can solve the puzzle, that they can and will cure EB. They increasingly know where they need to be heading and are working out how and what they need to get there.

My hope for EB research is to make what was once impossible, possible. ”

**Andy & Isla Grist, DEBRA Members, Scotland**

## Looking ahead

Where once a parent struggled for information and help, diagnosis, support and information are now widely available and ground-breaking clinical discovery has led to breakthroughs in current and potential treatments and understanding of EB.

But patients with EB are still suffering from devastating symptoms – pain, itch, cancer, wounds that require hours of dressings and blisters that can lead to infection. The EB community is at the heart of all we do. Their voices drive our commitment to do more to increase our programme of world-class research and make what was once impossible, possible. We want a future where everyday treatments end the pain and suffering of people with EB and their children. Now is the time to accelerate the pace of discovery, reduce the pain and challenges of life with EB and save lives.

Breakthrough in research comes from supporting outstanding projects that encourage the best of talented clinicians and scientists. This means increasing our funding and driving a programme of world-class, innovative and collaborative research that will bring hope and improved outcomes for everyone living with EB.



We will increase our funding and drive a programme of world-class, innovative and collaborative research that will bring hope and improved outcomes for everyone living with EB.

Patients and their family members through their own experiences are the experts on the impact of EB. Our new research strategy will be guided by a focus on impact and what matters to people living with EB.

## Our ambition

- We want to know what causes EB by better understanding how it affects people living with the condition. We want to develop life-changing treatments to improve the quality of life for EB patients by better managing their symptoms and, ultimately, find a cure or cure(s) for all types of EB.
- We will play a pivotal role in making research into EB a global effort, working with many organisations, but with DEBRA UK front and centre in leading the quest for innovations that improve the lives of people living with EB.



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

**Dr Sagair Hussain, Director of Research, DEBRA UK**

How we will achieve it

- Our funding portfolio will be diverse allowing us to seek opportunities to increase our research programmes.
- We will seek opportunities to partner with organisations that have common goals, non-EB funders as well as other DEBRA/EB groups, to bring new investment into EB.
- Partnering with NHS Digital to develop a national EB population register. The data will be a resource to improve clinical practice, support research into EB, inform health service commissioning as well as evaluate and audit health and social care services for EB patients.
- Introduce new schemes including a young leadership/career development fellowship to support and nurture the next generation of EB researchers. This will include providing project and programme grants to support partnerships at key UK universities to create EB Research Hubs, a Young Leadership Programme and New Horizon grants to encourage young researchers and researchers outside EB to bring new expertise into the field.
- A focussed investment in drug repurposing for EB will accelerate research progress where high costs can make traditional drug discovery unviable.

Drug repurposing clinical trials

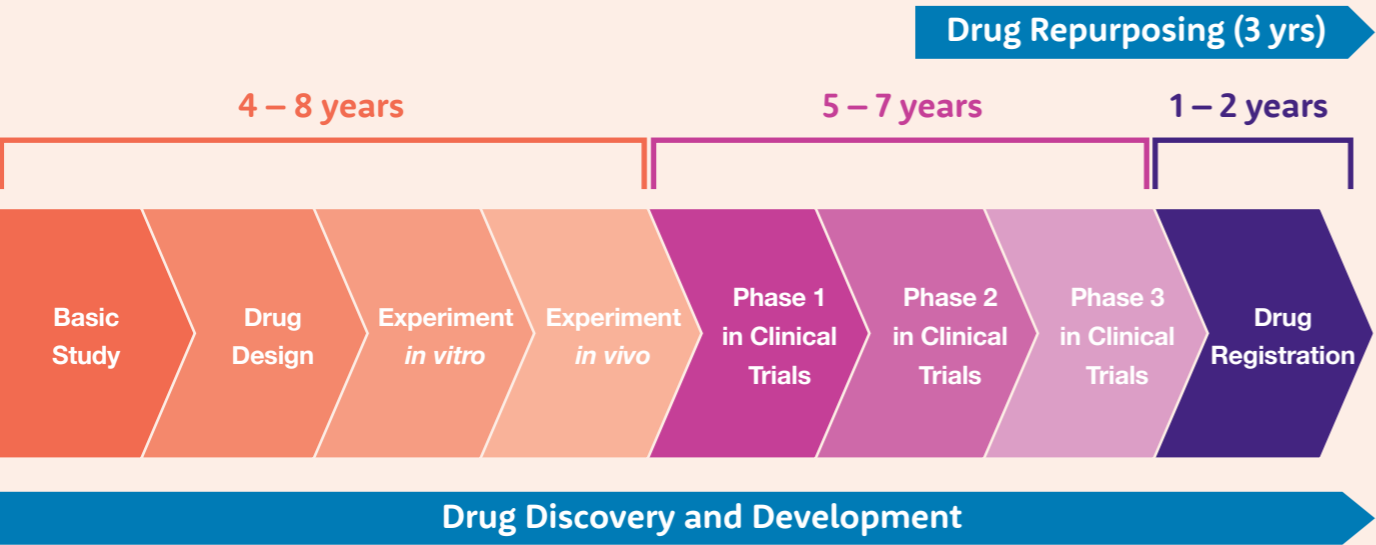
Drug discovery

- Average cost \$1.3 billion
- Low success rate
- High cost and long time frame for development

vs

Drug repurposing

- Up to £500k per drug
- Known drug safety
- Less costly
- Shorter time frame of approximately 3 years



We will prioritise investment in drug re-purposing to accelerate research progress and find treatments for EB.



Karen & Simon's story

Laboratory diagnosis is crucial in determining the type of EB and understanding how to treat and manage the condition. Our funding has helped establish a model EB diagnostics centre in London, which has made it possible to receive prenatal diagnostic testing if parents are at risk for passing on EB, ensuring a parental choice.

“ EB is inherited and we were both carriers of the gene. This meant that it was likely our baby would have the same type of EB as Dylan had. Thanks to advances in EB research and funding from DEBRA, we were able to test our baby for EB before she was born. Knowing we would not have to see our new-born go through the same pain and distress Dylan did was a massive relief. Our baby girl was born on 4 November 2018, EB free. We promised Dylan before he passed away that we would always continue to #FightEB. Research into EB is so very important and gives us hope that one day there will be a cure for this devastating condition. ”

Karen and Simon Talbot, son Dylan and daughter Katie Rose

# EB healthcare

## *Developing specialist services*

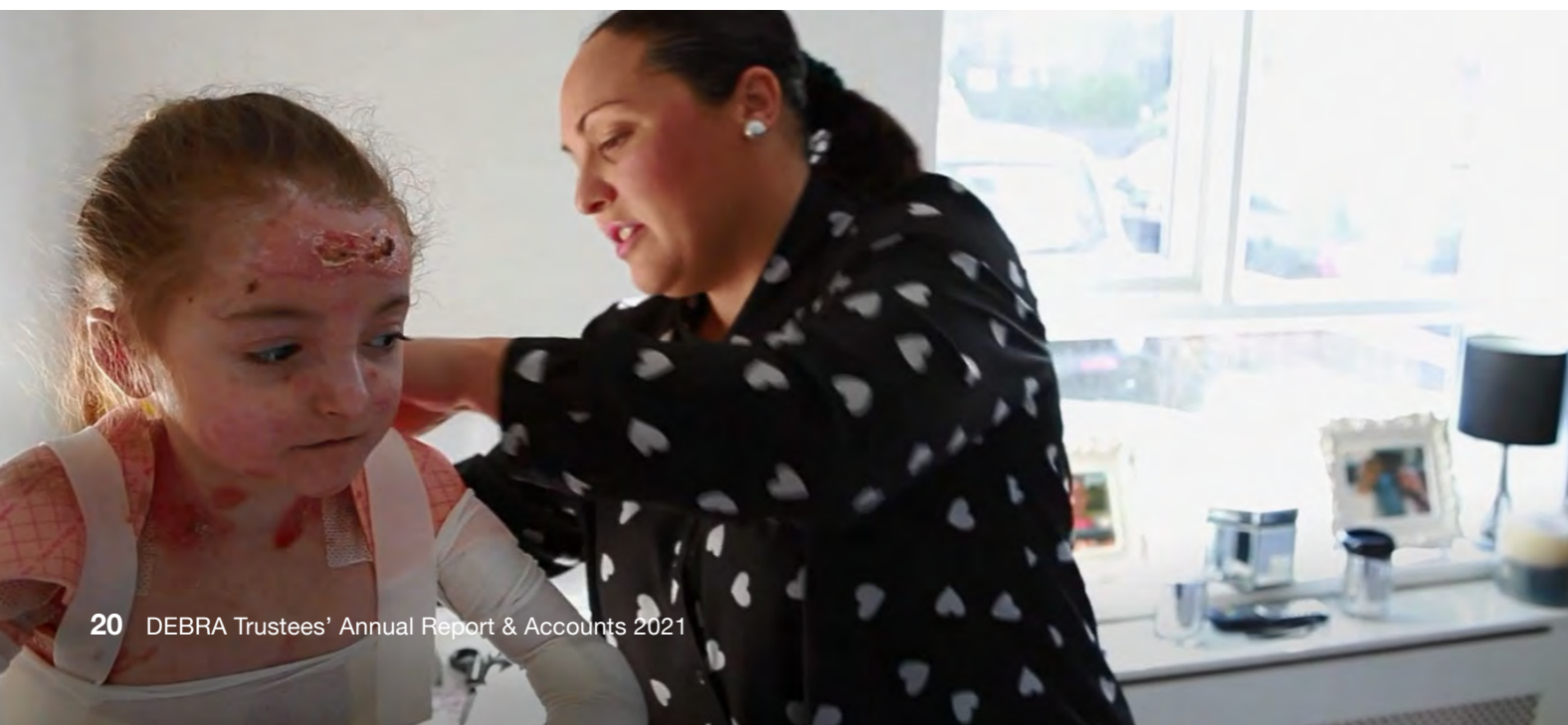
We work with patients and the NHS to develop specialist EB healthcare services. We are dedicated to ensuring that everyone with EB has access to the best care and expertise from diagnosis onwards.

In 1987 we funded the first specialist EB DEBRA nurse. We now work in partnership with the NHS to deliver an enhanced EB healthcare service for people with all types of EB. We have invested in the development of the EB centres of excellence, fund clinical best practice guidelines and connect patients with the expert, specialist services they need across the UK.



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

- Providing state of the art facilities and equipment through investment in developments including £250,000 towards the Rare Diseases Centre at St Thomas' Hospital.
- Working in partnership with the NHS funding up to 25% of specialist EB nursing.
- Working with the four centres of excellence to ensure appropriate facilities, equipment and expertise are available for all EB patients.
- Promoting multi-disciplinary working and the development of EB expertise with support for a range of specialist EB clinicians' work including dietitians, physiotherapy, dentistry and podiatry training, supporting over 2,000 EB individuals each year.



Credit: Nikki Holland Photography

## Gemma's story

“ My skin will blister and tear at the slightest touch, and EB causes internal damage too. Repeated blistering and scarring has caused my throat to become as narrow as a straw – I had to have a tracheotomy to help me breathe. The specialist EB Team at Guy's and St Thomas's Hospital, which DEBRA helps to fund, is there to advise me on every aspect of my EB care. ”

**Gemma Jaega, living with EB**

Our partnership with the NHS gives patients access to specialist EB expertise from healthcare professionals and EB dentistry and podiatry training to bring expert care locally.

What we did in 2021

Throughout the year the pandemic continued to affect healthcare services for EB. From September, our Community Support Team were able to attend clinics at Guys & St Thomas’ Hospital and home and school visits where there was a clear need.

- We continued to work in partnership with the NHS, supporting EB services at specialist EB centres although some of the activities were limited due to the impact of the pandemic on healthcare teams.

- We delivered online sessions to provide access to specialist EB expertise from EB dietitians, podiatrists, physiotherapists and other healthcare professionals.
- We provided funding for specialist EB dietitians at Guys & St Thomas’ Hospital and Birmingham Children’s Hospital one day per week to provide nutritional advice to promote vital health and wellbeing, wound healing and boost immunity.
- Our specialist EB podiatry training course was developed for delivery online, making specialist information and support accessible to podiatrists across the UK, enabling patients to access vital expert care locally.

Jess’s story

“ I’ve always suffered with feet that blistered really easily – the skin would tear and it was incredibly painful.

I was in my second year at University studying dance when the problems intensified. My feet would be bloody and my blisters would be infected. I sought a diagnosis and was referred to the specialist EB team at Solihull Hospital (a Centre of Excellence in EB supported by DEBRA). Thanks to the support I have received from the EB team, I’m no longer struggling on my own. I now know how to care for my feet and keep the blistering to a minimum, dramatically reducing the pain I’m in. ”

Jess Skeith, DEBRA Member

Our ambition

We will establish DEBRA as the ‘go to training hub’, developing and promoting courses, conferences, and professional networks internationally. An EB podiatry network and accredited course will be established. We will work with external organisations to include EB training at podiatry colleges and as part of dermatology courses. We will provide study grants to more professionals across the UK and support the running of multidisciplinary workshops focused on EB.

How we will achieve it

- Continue funding up to 25% of specialist EB nurses and funding additional grants to develop expertise within the teams as well as small project funding to enhance services.
- Continue to support specialist EB nutrition services, funding 20% of two EB dietitians.
- Continue to lead the development of accredited specialist EB podiatry training and make specialist information and support accessible to podiatrists across the UK enabling people with EB to access expert care locally.
- Work with healthcare professionals to update and develop publications and films that will provide specialist, expert information for people living and working with EB.



Helen’s story

“ It is such a privilege to work with the healthcare teams to support the EB community. EB is a complex condition – having the dedication and expertise of the specialist multi-disciplinary team is vital. Our members tell us how much difference this expertise makes in their day to day life. Together we are making a difference here and now and for the future. ”

Helen Weaver, DEBRA EB projects lead, working with healthcare and community support teams for over nine years

# Lifelong EB support

## Empowering and advocating for the whole EB community

The EB community is at the heart of everything we do. Their lived experiences and views drive our commitment to connect patients, families and carers with the specialist services and support they need to improve quality of life and help us shape our services.

- We provide lifelong support for the families carers and volunteers who provide daily care.
- Our aim is to empower and advocate for people with EB and their families, ensuring they are able to access the full range of vital support, services and care they need.
- We offer a personal, individualised support service, information and guidance to individuals, families and carers – from benefits and finance to bereavement support, social opportunities, respite and advocacy.
- We engage with organisations, from schools to new employers, to ease major life transitions.
- We connect the EB community, creating virtual and in-person opportunities to share experiences and gain peer-to-peer support, access specialist expertise and information and contribute to the development of services for EB.
- We work alongside clinicians and health care professionals to provide complementary social care and emotional support for people living with all types of EB.
- We work with many other DEBRA and EB organisations around the world, many of whom credit us for providing expertise inspiration and guidance.



5,000 people with EB in the UK



3,000+ DEBRA members



7 Community Support Team Managers supporting living with EB virtually and in their homes and advocating on their behalf



5 Membership staff support the wide membership group, connecting and engaging the EB community



470 EB members & families benefiting from respite in our 5 holiday homes



### Kanon's story

“ DEBRA means a lot to us, they have helped us in so many ways.

Any time I have a problem our Community Support Manager provides expert advice, emotional support and useful practical, and financial information we wouldn't otherwise have access to. She has helped us apply for Disability Living Allowance and Universal Credit and took the time to explain how the process works.

We have taken respite in the DEBRA holiday homes, which has meant we have been able to take Kanon away, something that we wouldn't have been able to afford on our own. On bad days, walking short distances can be impossible for Kanon and cause severe damage to his skin. DEBRA has helped me fund driving lessons so I can now drive Kanon to school and hospital appointments, making daily life more manageable. We want Kanon to lead a happy and most normal life as he can. DEBRA's support makes this possible. ”

Shalini Thachil, Kanon's mother

## Katie's story

“ My son Jamie was born with no skin on his feet, knees and hands and even where there was intact skin, it blistered. It was so hard to bond – I didn't hold my baby for the first six months.



He is the first person in my family to have EB so it came as an enormous shock. Jamie has a full skin check every day, which involves me lancing all blisters that have occurred overnight. I dress all the wounds and put protective bandages on before dressing him as well as giving him pain killers. The daily routine is quite structured to ensure he feels safe and secure at all times. He has his large dose of morphine before the evening meal so he's ready for his bath and can cope with more dressing changes. The most difficult thing about EB is seeing your child in pain, knowing that the care you are giving is causing so much distress.

The support I have received from DEBRA has been outstanding and makes a real difference. DEBRA has provided me with a changing table where I keep all the dressings and has signposted me to disability living allowance to help soften the blow of not being able to return to work as I am now a full time carer. The information booklets and website are a good reference to anyone wanting to know more. Meeting others with EB through DEBRA has made my outlook on the future less daunting. Seeing children with EB playing happily and managing daily activities gave me positivity and hope. The DEBRA days give me a boost of mental energy I so often need.



I feel extremely proud and in awe of Jamie, his happiness and joy keeps me motivated to stay strong. I am keeping positive that Jamie will improve with age and become less fragile so his pain levels will reduce.

**Katie White, mother of Jamie White**

## What we did in 2021

Our Community Support and Membership teams worked hard to ensure that all people living with EB and their families who needed our support were able to access us virtually or in person.

- We postponed our Members' Weekend and in-person events due to the difficulties created by the pandemic, however we developed our range of virtual groups and online sessions for members, with drop-in groups for parents and teenagers to build social networks. We ensured access to EB expertise with online sessions from specialist EB dietitians, podiatrists, physiotherapists and other healthcare professionals.
- We provided information and guidance both virtually and through home visits with a successful hybrid approach which worked well, ensuring access for all.
- We connected new EB parents with the services they needed; this was an essential service with double the number of babies referred during the year.

- We enabled families across the UK to take respite breaks in our holiday homes in a year in which demand had never been higher.
- We communicated regularly and connected our community, and began an ambitious data transformation project leading to the introduction of a new database in 2022.
- The increase in requests for grants from members led us to develop our applications and partnership work with other charities and organisation including Children in Need, the Family Fund and Independence at Home to supplement our own grants.



4,300 calls, contacts, visits and a wide range of actions to support people with EB.



Our ambition

We will empower the EB community, ensuring they have a voice and enabling greater choice and independence. We will connect, engage, and grow our membership through communication, understanding their needs, providing support, care, information and advocacy.

How we will achieve it

- Continue to build on the successful hybrid working approach by our Community Support Team to provide the most efficient and effective service to support people with EB and their families across the UK.
- Increase the team resources with the appointment of additional posts to increase member engagement and extend access to expert knowledge and support.
- Provide virtual and, where feasible, in-person groups and events throughout the year, sharing the expertise and resources online to ensure access for members and all within the EB community.



- Expand our membership engagement activities and increase the ways in which members' views are captured and acted upon.
- Launch a quantitative Quality of Life baseline survey to inform how we prioritise our activities and introduce new types of support.
- Undertake a refurbishment plan for our five holiday homes and explore options for new holiday home in 2022 and a replacement home in 2023.
- Relaunch our grants scheme to provide a more targeted service to support members in time of need.
- Review our membership scheme to ensure it meets the current and future needs of all the EB community.
- Work alongside health and support teams to develop up to date and accessible information and publications for those living and working with EB.

DEBRA support

“ When I was sixteen, I started developing severe blistering in my throat. Swallowing food can feel like eating razor blades.

DEBRA UK has been my rock. Not only do they help fund EB nurses who make my condition manageable, they have made me realise I can meet and share experiences with other people living with EB. The EB Community is a family. DEBRA UK is like the glue that keeps us together. ”

DEBRA member



Sabrina's story

“ Living with EB can affect people around you including friends, siblings and family members who often provide crucial emotional and physical support.

We helped siblings access emotional support, enabled families to use the DEBRA holiday homes and enhanced the support we offer by undertaking specialist training in listening and counselling skills. We are here to support everyone affected by EB. ”

Sabrina Khan, Community Support Manager

# A global and collaborative approach

## Working together for improved outcomes

We are living in an era of enormous scientific and medical innovation. The tremendous effort of researchers looking into treatments, vaccines and cures for COVID-19, has demonstrated that a global and collaborative approach can lead to outstanding results.

This approach is also the most effective for EB research and healthcare. It is a time of real opportunity, driving a programme of world-class, innovative and collaborative partnerships and healthcare that will bring hope and improved outcomes for everyone living with EB. Together we can achieve this ambitious and essential journey to change lives and end suffering.



**40+ years working collaboratively**  
in EB research, healthcare and support



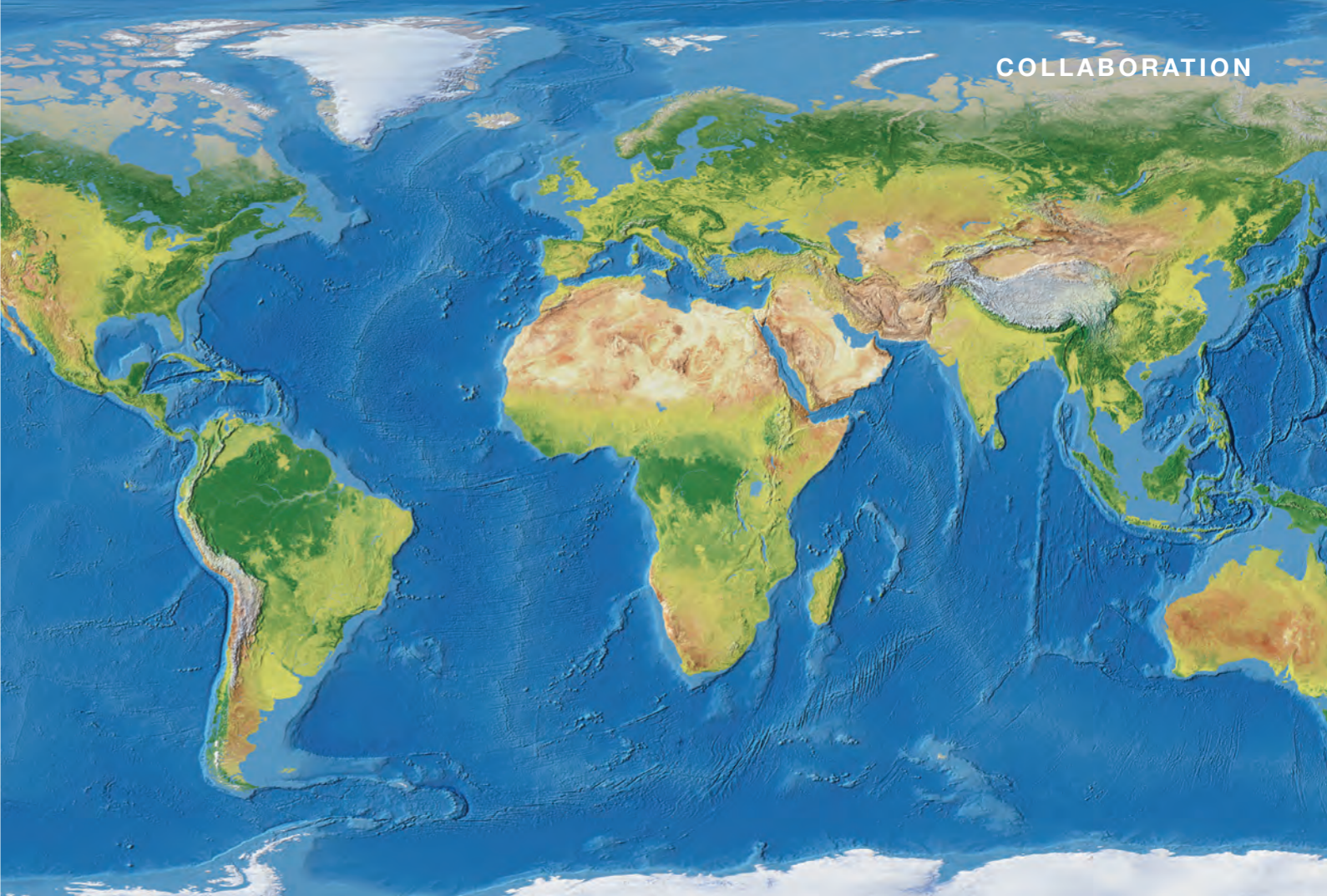
**443 members of the Clinical Practice Guidelines Network**



**134 research projects across 12 countries and 52 world-class research institutions**  
funded by DEBRA UK



**50 DEBRA international groups working collaboratively for EB**



### What we achieved in 2021

- We continued to fund and work in partnership with research institutions across the UK and internationally, driving a programme of world-class research to bring hope and improved outcomes for everyone living with EB.
- We initiated the process of building a partnership with NHS Digital in order to develop a national EB population register.
- We started the process of setting up schemes to nurture the next generation of EB researchers, providing grants to support partnerships at key UK universities to encourage young researchers and researchers outside EB to bring new expertise into the field.
- We continued to invest in DEBRA International and supported the development of Clinical Practice Guidelines to increase professional knowledge and best practice for patients around the world with EB.
- We worked in partnership with the NHS to deliver enhanced EB healthcare services for people with all types of EB.
- We worked with DEBRA Ireland to develop and deliver an accredited mindfulness course for the EB community.
- We collaborated with charity Fight for Sight to set up a partnership to co-fund eye research in EB.



There are an estimated 5,000 people with EB in the UK and 500,000 worldwide.



## Enhancing global EB care and best practice

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

DEBRA International develops the Clinical Practice Guidelines which, with the help of over 300 clinical and patient volunteers, provide vital, internationally consistent practice information to guide health and social care professionals with patient versions and infographics in a format suitable for a lay audience. DEBRA International also manages EB Without Borders (EBWB) group, a collaborative effort to assist EB patients around the world, particularly in locations without a national DEBRA organisation and little to no clinical knowledge of EB.



41% of Clinical Practice Guidelines (CPGs) funded by DEBRA UK in the past 5 years, with £253,952 funding for 9 CPGs.

### Looking ahead

We will continue to work with world-class scientists and clinicians and with national and international partners from academia, biotechnology and pharmaceutical industries and organisations with a shared interest in EB or other skin conditions.

We will also work closely with DEBRA International and DEBRA groups across the world to develop Clinical Practice Guidelines and share knowledge and best practice internationally as well as working with DEBRA International to manage the Research Involvement Network informing members of developments in EB research and promoting its importance and opportunities for patient involvement.

### Our ambition

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

“ I think of the thriving community that I consider myself very lucky to be part of, the cutting edge research we’re undertaking in Birmingham, but also around the world. It truly is a global and collaborative effort to try to improve the quality of life of every individual affected by EB. ”

Dr Ajoy Bardhan,  
University of Birmingham

### How we will achieve it

- We will create a national EB population register in partnership with NHS Digital. The data will be a resource to improve clinical practice, support research into EB, inform health service commissioning and evaluate and audit health and social care services for EB patients.
- We will continue working with national centres of excellence and partnering with the NHS to provide specialist healthcare services for people with EB.
- We will work with organisations with common or overlapping missions, e.g. British Skin Foundation who share an interest in skin fragility.
- We will develop strong collaborative global relationships with EB organisations, researchers, clinicians, and pharmaceuticals.
- We will share knowledge and work with other DEBRA organisations around the world and participate in the development, funding and promotion of Clinical Practice Guidelines and other international DEBRA initiatives.

“ Tackling the big questions in EB research can only be done through a multidisciplinary collaborative approach. We will continue to work with existing and new partners in all sectors: from universities and NHS to governmental, industry and other charities. ”

Tony Byrne, CEO DEBRA UK

# EB voices

## Raising awareness, engaging communities

As a rare disease, awareness of EB is relatively low. We want to achieve greater awareness of EB within the healthcare and research communities and the wider public to ensure there is understanding for those living with the condition, more widespread EB expertise and support for our income generation through fundraising and our retail stores to enable us to fund essential research and care.

We want to give everyone living with and working with EB a voice. We want to fight EB together.



32% of people  
now aware of EB



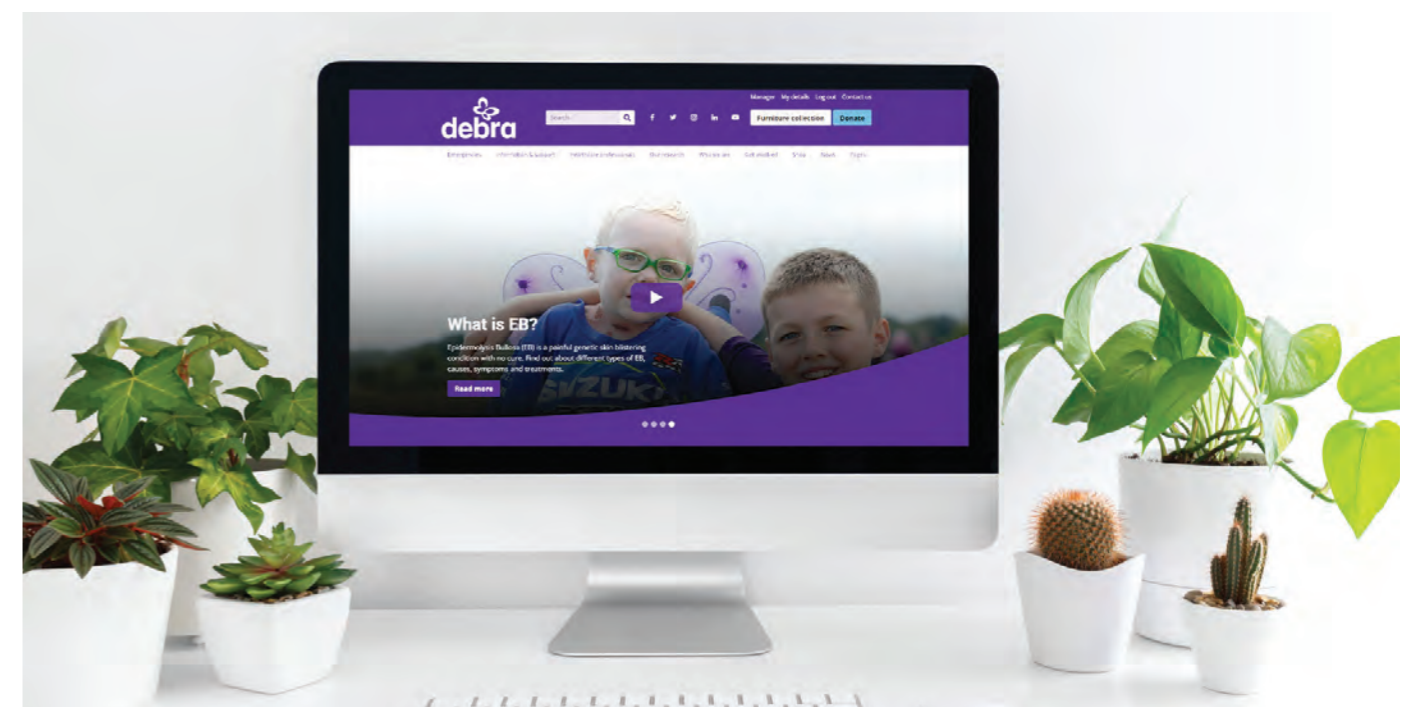
5 million people  
reached on  
social media

### What we achieved in 2021

Due to the continued effects of the pandemic and furloughed staff in the first quarter, we paused some of the projects in our digital transformation roadmap while continuing to support income generation and connecting and engaging our communities with frequent communication.

- As the year progressed, we continued the development of a new website with improved user experience, navigation and accessibility and transferred to a new email marketing communications platform, ready to go live in 2022 along with the new CRM system.
- We continued to build our brand, increasing accessibility, revitalising messaging and promoting our cause throughout our appeals, campaigns, publications, digital communications and signage across the retail stores.

- We prioritised the development of our social media strategy resulting in multi-channel growth.
- To support the growth of our e-commerce and maximise retail donations and footfall we developed our retail social media brand, reviewed use of our Google Ad Grant and increased our targeted digital campaigns. We launched a new initiative with selected stores to promote their goods at a local level, highlighting the key role our store staff and volunteers can play in and connecting with customers and putting the charity shops at the heart of their local community.
- We were delighted to be awarded the prize from PM Society – Creativity for Good – and the opportunity to work with a professional agency, Precision Effect, to promote DEBRA with an awareness campaign which became 'The DEBRA effect' and launched in February 2022.



## Our ambition

It's time to transform our brand and empower and engage our communities, so that everyone living with and connected with EB sees us the key source of expertise, support and information on EB and the public recognise and support our cause, engaging with our work and seeking our retail stores as a sustainable destination of choice.

## How we will achieve it

To deliver the charity's strategic plan, we will focus on three key areas – raising awareness, being the source of reliable, expert information and engaging our communities.

- To be the 'go to' source of EB expertise, we will review and update the information we provide to enable people with EB and the wider EB community to access reliable, specialist advice on all relevant EB matters including healthcare, latest research, specialist help and support from navigating social care systems; financial and welfare guidance to bereavement support.
- Our information will be available through multiple channels and formats including web, social media, telephone and face-to-face support, in person and online events, communications, video, online and printed materials. We will review and introduce new opportunities such as online forums and live chat.
- We will promote EB expertise and seek out developments in research and healthcare to engage our community of researchers & clinicians, recruiting informed "EB champions" to help us achieve our goals. We will develop a core group of specialists including those within DEBRA, able to provide active support as speakers, commentators and expert panel credibility as we work towards a goal of lobbying healthcare, government and business to influence attitudes, policies and services.
- We will create compelling communications, illustrating the impact of our work and the inspirational stories from our EB community to connect with our supporters, building a community working towards a shared, urgent goal.
- We will continue to develop our core messaging, brand voice and visual identity to improve recognition and understanding. We will build our retail brand to deliver a stronger presence on the high street which will highlight our commitment to our cause and to sustainability and support income generation through our online shopping.
- Our staff and volunteers will be knowledgeable about EB, building their knowledge and understanding of our work and their confidence to become advocates of DEBRA and increasing their engagement on social media.

Raising awareness of EB is vital. As a rare disease, public awareness of EB is low, however we are working hard to change this.

A YouGov poll undertaken in March 2022 revealed that 32% of adults surveyed had heard of EB – an increase of 19% since our last poll.<sup>1</sup>

<sup>1</sup> All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2077 adults. Fieldwork was undertaken between 23–24 March 2022. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).



## Hiba's story

“ The day I was born my mum fainted and my dad was really sad because they didn't expect this to happen to me.

This condition is really hard because it's very painful when my clothes stick, when I change my dressings or when I take a bath. I cry a lot.

My fingers closed and I had an operation on my hands. Four months later they were closed again. I went to school and it was hard to write. Even my feet were swollen. I had an operation on my throat because I couldn't swallow food or water. It was very helpful but it started closing again. I have a gastronomy button now. No one can feel how I feel. The doctors are trying to make things better but EB is really hard for everyone.

When I grow up I want to be a scientist to make new medicines for children that have illnesses like mine. Hopefully I will cure EB. I know it's not impossible. Everything is possible. ”

**Hiba el Mansouri Sghiar**

DEBRA's Community Support Team are working with Hiba and her family and have enabled them to move into adapted accommodation and access essential equipment and support. Hiba is keen to be an EB ambassador, sharing her story to increase awareness of EB.

# How we raise our funds

## *Building relationships, creating opportunities*

Like many charities, our fundraising has been severely challenged. Having to cancel or postpone our usual programme of events was essential to protect the wellbeing of our staff, volunteers, customers and community.

However, we were innovative in our approach and proactive in building relationships with current and new donors and this, and the response that we had from our supporters, enabled us to get our income back on track.

We want to take this opportunity to say a huge thank you to our community support team, healthcare professionals, researchers, trustees, staff and volunteers, customers, trusts, companies and donors for the continued, committed support you have given to our charity and to the EB community. We couldn't have survived the past two years without you. Together we have made a difference and will continue to #FightEB until we have achieved our vision of a world where no one suffers with EB.



**£2.2m** raised by our incredible supporters this year.



### What we did in 2021

Despite the difficulties of a year where staff were furloughed and events were limited or postponed, we ended the year in a good position with successful events, a number of well-supported appeals and commitment from new major donors including £460,000 towards our first drug repurposing research project.

- We set up and developed an Appeals Group which led to the introduction and support from a number of new major donors.
- We built a case for support focussing on the innovative opportunities that drug repurposing offers for EB, resulting in the commitment of philanthropic support for the first EB drug repurposing research project.
- We invested in the fundraising team to enable income growth through Trusts, Corporate, Events, Digital fundraising and Supporter services.
- We delivered a professional and profitable programme of events and challenges with 69% increase year on year.
- We increased the consistency and impact of our communications and promotion to all audiences, building engagement and reaching new supporters.

- We developed opportunities to build individual and corporate donations, grants, trusts and legacies to mitigate the impact of the pandemic on these areas of giving from our supporters, reducing the overall year on year decline to 18%, in what were very challenging external conditions.

Nurses from Great Ormond Street took part in our 100km Challenge. They make a life-changing difference to children with EB, providing much needed specialist care and support.

“ We are incredibly lucky here at GOSH, to work with an amazing group of children, young people and their families. Their determination and spirit are quite simply inspirational. We wanted to participate in this challenge to acknowledge that living with EB is tough, and to hopefully raise awareness of EB, and support DEBRA in any way that we can. ”



Our ambition

We have set ourselves an ambitious and challenging target. Our aim is to grow our core net fundraising income from £1.1m in 2021 to £1.6m in 2022 and £1.75m in 2023, an increase of 59%.

Recognising the short and long term impact of COVID-19, we will focus our opportunities for recovery on the development of long term relationships and our major donor, trusts and corporate donations. At the heart of everything we do will be the relationship with our EB Community and our determination to fund specialist healthcare and research that will be life-changing for people with EB.

How we will achieve it

- **Major donors and philanthropic donations:** our aim is to secure six- and seven-figure gifts. We developed a number of significant supporters with close commitments to the charity over the last three years. Working with these key relationships will enable us to leverage support from a number of new philanthropic supporters. Key to this are relationships with our Patron, President, Vice Presidents and members of our Appeals Group whose passion for the charity and our cause is vital in engaging new supporters.
- **Grant making trusts:** we have invested in the Trusts team in order to be able to increase the size of our applications and secure the funding needed for our future research projects as well as applications to fund our core membership and healthcare work.



Great Chefs Dinner raises £130k

This year’s event brings the total raised for DEBRA in the six years Michel Roux Jr has hosted this event, our Great Chefs Dinners, to more than £380,000. We are so grateful to Michel, all the team of incredible chefs and staff at Roux at The Landau, and The Langham who made it all possible.

- **Building our supporter base:** funding comes from people and relationships with people who share our passion for our mission and join us on our journey. We will expand our network of individual donors, major donors, corporate supporters, event attendees, and grant making trusts.
- **Corporate fundraising:** we will develop new corporate partners along with the stewardship of current corporate supporters. A particular area of interest is the pharmaceutical industries, particularly those companies with a potential or existing interest in EB.
- **Digital fundraising:** we have invested in a further team member to deliver our digital fundraising. A particular focus for 2022 will be to work with the marketing team to grow the online supporter base and increase the number of people receiving and engaging with our Appeals over the next three years.
- **Communication:** creating compelling cases for support and messaging based on supporter journeys that will build emotional engagement with potential and existing supporters. This will be supported by the data insights provided by our new CRM database.

We are delighted to confirm that, through the generosity and support of major philanthropist, Lenore England, we have secured funding of £460,000 towards our first drug repurposing research project.



Drug repurposing

Drug repurposing has been thrown into the spotlight during the fight against COVID-19 as drugs developed for other conditions have proved highly effective in the treatment of COVID patients.

Drug repurposing is an exciting opportunity for EB and is essential for rare diseases where high costs can make traditional drug discovery unviable.

In 2022, we will be launching a major appeal – the more drugs we can repurpose the greater our chances of making successful, life-changing treatments available.

# Thank you

We have been fortunate to be able to count on the continued backing of a number of very generous supporters. To everyone who donated to our cause and to the thousands of people who ran, cycled, took up our 100k challenge, volunteered or supported our appeals. To companies and trustees, the many ambassadors who speak about EB and DEBRA at events and to everyone who shares our story on social media – we would like to say a heartfelt thank you.

We are also extremely grateful to our Patron, HRH The Countess of Wessex, for her continued support throughout 2021 and to our President, Simon Weston CBE and Vice Presidents Frank Warren and Graeme Souness.

## Our Patron, President, Vice-Presidents

HRH The Countess of Wessex

Simon Weston CBE

Graeme Souness

Frank Warren

## Trusts and foundations

The Band Trust

The Souter Charitable Trust

The VTCT Foundation

Bill Brown's Charitable Settlement of 1989

The Dorus Trust

The Kola'a Trust

The Forest Hill Charitable Trust

The Murphy-Neuman Charity

The Dyer's Company

The Edith Murphy Foundation

The John Coates Charitable Trust

The Northwood Charitable Trust

The Grace Trust

The Hadrian Trust

The Catherine Cookson Charitable Trust

The Peter Harrison Foundation

The DM Charitable Trust

The Fowler Smith and Jones Trust

The Joseph Strong Frazer Trust

The Sir Iain Stewart Foundation

The Co-op Foundation

The Leach Fourteenth Trust

The Strangward Trust

The GM Morrison Charitable Trust

The Lillie Johnson Charitable Trust

The David Laing Foundation

The Edward Cadbury Trust

The Gilbert and Eileen Edgar Foundation

The Calleva Foundation

The Raven Charitable Trust

The Shanly Foundation

The Tory Family Foundation

The Ammco Trust

The Louis Bayliss Charitable Trust

The Benham Charitable Settlement

The John Cowan Foundation

The William Brake Foundation

The Basil Samuel Charitable Trust

The Childwick Trust

The Verdon-Smith Charitable Trust

The Louis Nicholas Residuary Charitable Trust

The Riply Trust

The Michael and Anna Wix Charitable Trust

The Alice Ellen Cooper Dean Foundation

The Bruce Wake Charity

The February Foundation

The Hugh Fraser Foundation

The QBE Foundation

The Riada Trust

The 29th May Charitable Trust

Marconi Chelmsford Employees Charitable Trust Fund

The Wixamtree Trust

The Mabs Mardulyn Charitable Foundation

Awards for All

The George Stewart Charitable Trust

The Jack Lane Charitable Trust

The Sylvia and Colin Sheppard Charitable Trust

The PF Charitable Trust

The Parry Family Foundation

The Maud Elkington Charitable Trust

The W.E.D Charitable Trust

The George A Moore Foundation

The Hudson Charitable Trust

Baron Davenports Charity

The Hospital Saturday Fund

The Brother's Trust

The Ardwick Trust

The Misses Barrie Charitable Trust

The Eveson Charitable Trust

The James Wise Charitable Trust

The Charles S French Charitable Trust

The Charity Service Fund

The National Lottery Community Fund

The Enid Linder Foundation

The Klahr Charitable Trust

The Manson Family Charitable Trust

The Whittington Charitable Trust

The Barbara and Stanley Fink Foundation

The Simon Gibson Charitable Trust

## Trusts and grants

In 2021 we were delighted that Lenore England Family Foundation and Philanthropy made a commitment to funding up to £2 million for DEBRA research.

This significant and extremely generous gift represents the biggest single gift we have received and will provide a secure foundation for developing the ambitious programme of world-class, collaborative research we are planning.

# Our stores

## At the heart of our communities

The support from our customers and the hard work and dedication of our retail staff and volunteers throughout the challenges of the past two years has been vital, keeping our stores at the heart of their communities, helping to build awareness of EB, raising the profile of DEBRA and generating vital income to fund our research, support and healthcare.



### What we achieved in 2021

Like many charities, we have been recovering from the impact of the pandemic with our stores closed during successive lockdowns in 2020 and early 2021. However the increase in our online sales, the growing trend towards recycling and the loyalty and support of our customers when we reopened in April with donations and sales enabled us to achieve a healthy growth overall.

- The wellbeing and safety of our staff, volunteers and customers remained a priority. During the national periods of lockdown and restrictions, the majority of the retail team were furloughed and we worked closely with our landlords to negotiate rent reductions. The total number of our stores reduced from 111 to 105 sites.
- We saw some drop off in volunteer numbers as a result of the pandemic and high sickness levels and difficulties in recruiting staff in some areas had an impact on trade.
- The development of our online selling platform initiatives proved very successful with a 30% increase in sales overall.

- The surge in donations in the spring and an increased interest among consumers in recycling and reusing items that contributed to a good cause as well as a desire to hunt out bargains during tougher economic times, meant that overall there was a healthy growth in stores overall, with some stores outperforming 2019 sales.
- Changes and improvements made to the staff induction plans and overall mandatory training management helped to improve Health & Safety engagement and training compliance significantly compared to previous years.
- We held our first virtual retail conference with a wide range of informative and inspiring sessions including presentations on the five year strategy for retail, visual merchandising, research, customer service, EB stories and our first online interactive wellbeing course.
- We introduced a number of new roles – Retail Operations & Compliance, Volunteering Resources and Logistics – to support our work in achieving cost savings and operating efficiencies.



**290 dedicated staff**  
in our stores



**30% increase in**  
online sales



**838 volunteers**  
giving **335,000** hours  
of donated time



**Over 1.2 million kilos**  
of items recycled



**£8.7 million** raised  
by retail



DEBRA is the **7th** largest  
charity retailer in the UK

Looking ahead

The pandemic has accelerated shifts in consumer behaviour, with the most significant changes taking place in online spending, a greater focus on the community, and a deeper awareness of brand ethics and how our choices impact the environment.

Our stores will play a vital role in their communities, raising awareness of EB and delivering increased income from our online and instore sales to fund life-changing treatments and improved outcomes for everyone living with EB.

Our ambition

We plan to grow our net retail income by 83% over 3 years – from £1.3m in 2021 to £2.1m in 2022 and £2.4m in 2023. This is an ambitious target.

To achieve it, we will need to be the destination of choice online and on the high street, making our retail outlets attractive, pleasant places to work, shop, and volunteer. We will increase our sales and the number and format of our stores, refurbishing them to create higher quality, attractive retail environments. We will also improve our e-commerce and online sales that is more competitive, so that we can reach a wider audience with a relevant sales offering and promote our cause.

Our people are the key to our success. A motivated, knowledgeable and engaged team of staff and volunteers is our most essential asset. They will always be at the heart of what we do. We will work hard to create a stable and well-trained workforce, increasing overall volunteer numbers and ensuring excellent and consistent Health & Safety management and compliance.

Our aim is to reach a wider audience, command higher prices, promote our cause and ensure we have a more resilient approach in the event of any future unforeseen events such as further lockdowns.



David's story

“ I joined DEBRA as a volunteer when I was 16. There’s a great collaborative atmosphere at DEBRA – I’ve never worked with a friendlier group of people and we really are invested in the charity and what it stands for.

My first job in retail was won thanks to the experience I got whilst volunteering at the store each week. It taught me so many great lessons that really helped me when I got into paid work.

I’ve really enjoyed doing work I believe in, from working the till to sorting donations. Because of my background in technology I’ve ended up becoming a sort of tech expert for the store –

I’m always thrilled when we get another interesting bit of tech in a donation for me to work out, and sometimes fix. The environment is so supportive and engaging. Once I started volunteering, I realised I never wanted to stop helping out!

Volunteering at DEBRA opened so much for me. I really feel I’m making a difference here and it’s a great way for a young person to develop their skills. I haven’t regretted a minute of my time at DEBRA and I encourage anyone to get stuck in and do some work for a good cause!

David Driver-Gomm,  
DEBRA Volunteer



## Thank you to our amazing volunteers

We are one team. Our volunteers play a crucial role in our retail stores as well as supporting our fundraising and working with teams across the charity. Our volunteers report that it is an opportunity to socialise, learn new skills, and gain valuable work experience to move into paid employment. They are an essential part of the DEBRA team. We are so grateful for their commitment and skills – we couldn't achieve our mission without them.

### How we will achieve it

- Open new stores to replace the store closures experienced since 2019 with larger format, high quality stores. The aim is to develop an estate of 130 stores by 2026.
- Build our e-commerce and online sales, reaching a wider audience, commanding higher prices and diversifying our overall customer population.
- Establish stronger brand awareness and community engagement.
- Develop a more efficient and lean retail function as a basis for expansion.
- Improve margin and contribution, by looking at volume, price and gift aid to offset wages inflation.
- Ensure we operate in as environmentally friendly manner as possible. As part of this, continue to implement changes to our logistics infrastructure, including trial of DEBRA leased vehicles and employed drivers.
- Look for cost efficiencies through procurement exercises.
- Increase volunteer numbers and create a motivated and well-trained team of staff and volunteers who are committed to increasing sales and raising awareness.
- Build a robust and well managed induction and training curriculum as part of the measures to improve retention, engagement and efficiency of our staff and volunteers.
- Launch a series of regional training road shows, in addition to the e-learning modules and training support available, with an emphasis on charity engagement, commercial awareness and wellbeing.



## Simon's story

“ I spent the best part of seven years without skin on my body so I feel relevant to DEBRA.

Babies born with EB can spend the rest of their life in pain, taking pain killers or medications to cure the itch, undergoing dressings that are painful and take hours.

We are trying to help people have improved quality of life. We have to find a cure. Until then we have a real crusade because these incredible people, and these families, don't deserve what they are going through. We need to fund the EB research and healthcare that will bring life-changing improvements to quality of life today and a cure tomorrow. ”

**Simon Weston, President of DEBRA**

# Our people

Our people are at the heart of everything we do. Whether developing our vital research and healthcare programmes, supporting families with EB, managing or volunteering in our charity shops, working to raise essential funds, promoting and communicating the work we do, processing income, providing learning and development or supporting our cause as a Patron, President or Vice President, every person in our charity provides a highly valued contribution to the service that we provide to EB and our community.

In 2021...

 **95%** of staff furloughed

 **335,000** hours volunteered in our stores

 **7,000+** hours of training for staff

We want to say thank you to...

 **360** employees

 **840** volunteers

 **13** trustees



## Our commitment to Equality Diversity and Inclusion

“ My personal connection to DEBRA and EB is that I am a mum to a daughter with EBS. She is the first in our family to have EB. Now I am involved through the Board of Trustees in order to be front and centre in what is happening with EB.

We started thinking about our Equality Diversity and Inclusion strategy in 2020, to examine ourselves and to ask are we being inclusive enough and ask what more can we do.

We are looking at how we can be more inclusive throughout our charity – board level, staff and volunteers and our members. We also want to improve our diversity through our recruitment and engage better. We know that if you bring your best self to work that we will get the best from you and you will get the best from your working environment so **we want to empower all our employees to feel that DEBRA values them for everything they are.** It is a journey – it can't be achieved overnight but we are striving to be the best we possibly can be. ”

**Carly Fields, Co-Vice Chair of Trustees and Chair Research Care & Research Committee**

What we did in 2021

- The effects of the pandemic continued to impact on the charity through most of the year. Our stores were closed until restrictions lifted in April, with retail and many other staff furloughed. The safety and wellbeing of our people remained a priority. Office and administration staff worked from home until the introduction later in the year of a hybrid model.
- Following the appointment of Tony Byrne as CEO in October 2020, there were a number of changes to the senior management team in 2021 with new Directors of Research, People, Finance & IT as well as new retail team appointments including Head of Retail Operations Manager, bringing a renewed focus on developing a robust strategy to deliver on our charitable objectives as well as ensuring good business practice and compliance.
- We launched a new HR self-service software as part of the charity-wide commitment to updating our systems and processes.
- We continued to undertake recruitment campaigns to build our team of dedicated volunteers who are a highly valued resource for us, undertaking vital work in our retail stores and support across many areas of the charity.

“ I consider it a privilege to work for DEBRA. Each day I get to know amazing families who overcome huge challenges. The support we are able to offer makes it a fantastically rewarding role to be in. ”

Amelia,  
Community Support Manager

“ Having worked remotely for over a year now it has been tough to carry out so much work over the telephone. So when I receive a photo of one of the members it can really brighten up my day. ”

DEBRA employee

“ It is probably one of the most enjoyable and rewarding jobs anyone can do. ”

DEBRA employee

- We continued to provide learning and development opportunities, ran Safeguarding September and a virtual conference for staff and volunteers.
- As a result of the employee feedback in 2020 and our ambition to be an “Employer of Choice” in the charity sector, we reviewed and updated our company values, created a new Equality, Diversity & Inclusion framework, and initiated a review of our benefits and recognition structure.
- Our Gender Pay Gap report showed that our mean pay gap is 5.86% in favour of men, and our median hourly full pay gap is 0 % compared to a national average of 15.4%. This is based on 324 employees with 76% women, 24% men on the snapshot date. We have made significant progress over the years however we are committed to doing more as part of our EDI and values-driven culture. Visit [www.debra.org.uk/gender-pay-gap](http://www.debra.org.uk/gender-pay-gap) for more details.

Our values

During the year, employees and volunteers participated in a series of values workshops to provide a set of common beliefs, behaviours and understanding to support and enable us to work collectively to achieve our mission. We will build these values into everything that we do – how we interact with each other, training, recruitment, reward and recognition and wellbeing.



Making a difference

We make a positive contribution to the lives of the EB community, our colleagues, and the community we live in through the individual work and activities undertaken by each employee and volunteer.



Inclusive

We value diversity and proactively seek to support, engage and nurture every individual within the DEBRA community.



Respectful

We treat our members, colleagues, volunteers and customers, with respect. We value the views and diversity of others and intervene when those around us do not uphold the high standards we expect.



Passionate

We go the extra mile to achieve individual and collective goals. We do our best every day, so that we can move forward in our quest to improve the quality of life of our members and find a cure for EB.



Caring

We prioritise the needs of others, looking to brighten the day of those around us. Doing a great job really matters whether we are supporting members, serving customers, fundraising or raising awareness of EB. We care for one another.



Committed

We look for solutions, working together to create positive change. We deliver on our promises through hard work, collaboration, and determination.



“ I joined DEBRA as a volunteer to work in my local charity shop.

I had been out of work as I was a stay-at-home mum to my son and also I looked after my mother.

I wanted to start work and applied for many many jobs, but with a gap in my employment history no one would hire me.

Since starting volunteering I have learnt the confidence and skills to sort stock, till training and health and safety. I have made new friends and been a part of the community. I love my job and the fact that I am helping raise awareness and money for EB. ”

DEBRA volunteer

Our ambition

Our ambition is to lead the fight against EB and be exemplary in all the activities involved in this fight. To achieve this the key to our success is our people. We will prioritise learning and development for our staff, volunteers and others supporting people living with EB, to ensure that they are knowledgeable about EB and up to date in all areas of health and social care. **Our aim over the next two years is to focus on becoming a ‘Great Place to Work’.** We will support, train and reward our staff for the role they play in delivering our mission ensuring that employees and volunteers have the tools and resources they need to do their job to the best of their ability.

Our People agenda will focus on three priority areas:

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

How we will achieve it

- By investing in our people.
- Giving all employees the opportunity to undertake personal development as well mandatory training delivered in a variety of ways, from online courses hosted on our new Learning Management System to face to face training delivered internally by functional experts or accredited external programmes funded by the apprenticeship levy.
- Our aim is to build our volunteer team to over 2,000 volunteers working with us. Recruitment, training, and retention of volunteers is therefore critical to our future success.
- The launch of our Equality, Diversity and Inclusion roadmap will start with an understanding of our current demographic and then put in place a range of initiatives to address any gaps we may have.
- We will ensure that there is the correct governance, fairness, and transparency in relation to all decisions regarding pay and remuneration. As part of a focus on reward and recognition, our retail teams will not only recognise great performance but also celebrate teams and individuals whose behaviours align with our values.
- By investing in technology and support systems we will move from paper-based to digital including the launch of the HR self-serve software and a Learning Management System to give employees and volunteers easy access to engaging learning material for mandatory and personal development.
- To make sure that we are heading in the right direction, we will undertake regular employee surveys and hold focus groups to gain feedback from all our employees, volunteers and members on our journey.

A great place to work

Our aim is to create a culture where our whole community can thrive, are valued, where equality and diversity are embedded in our values and actions and where everyone has the opportunity to develop, to enjoy their work and to make a difference.



## Safeguarding

Safeguarding continues to be a priority in DEBRA, in the past 12 months our focus has been on raising awareness of safeguarding amongst our employees and volunteers.

In addition to a mandatory online training module, we ran Safeguarding September where throughout the month a range of materials were shared including educational videos, case studies, articles, and stories. We also hosted live sessions examining the difference between welfare cases and safeguarding, providing clear

guidance on how best to report any concerns that employees or volunteers may have.

For our volunteers a new Safeguarding Booklet was rolled out giving an overview of what safeguarding is along with helpful guidance of what to do if they are concerned for their own or anybody else's wellbeing.

Our Safeguarding Committee agreed that an internal audit of our Safeguarding policy and process should be undertaken to highlight any gaps and support our journey to best practice in this area.

## Equality, diversity and inclusion

Under the guidance of the Equality, Diversity and Inclusion (EDI) committee there has been significant progress with our EDI agenda in 2021.

An EDI policy and commitments has been created that not only aligns with UK anti discrimination law but also outlines the pro-active steps that DEBRA will take to create a diverse and inclusive community for our members, staff and volunteers. The EDI committee and Senior Management team participated in a one-day EDI training session with all employees being asked to complete an online training module. With a view to ensure participation from all areas of DEBRA an EDI working group has been formed. Their role is to act as champions within their directorate, as well as support the creation and roll out of new EDI initiatives and processes.

With the introduction of new digital databases, we will have visibility of the demographic of our members, staff and volunteers thereby allowing us to tailor our services and policies to meet their needs.

Although we still have a long way to go, we are proud of the steps we have made on the journey so far.

### Equal Opportunities Policy Statement

We are an equal opportunities employer organisation. We are committed to ensuring that there will be no discrimination on grounds of race (including colour, nationality, ethnic or national origins), sex or marital status, gender reassignment, sexual orientation, religion or belief, disability, age, or pregnancy/maternity, which is not permitted by law; or on any other grounds, except where this is necessary to ensure that a job is done effectively and safely. This principle will apply to access of services by people whose lives are affected by EB, and to the recruitment, training and promotion of staff, and all other benefits, terms and conditions of employment. All employees and volunteers acting on behalf of DEBRA have a responsibility to apply this principle in practice.

# Charity overview, objectives & public benefit

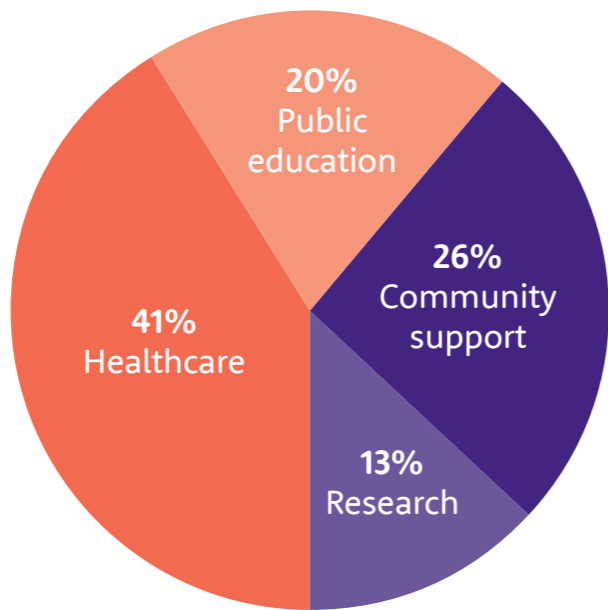
# Financial review

The COVID-19 pandemic continued throughout 2021, which began with another lockdown. Shops were closed from January until mid-April. Despite the large drop in income, with good financial planning, we were able to continue serving the EB community. We spent £1.9m on charitable activities in 2021, compared with £2.8m in 2020. Whilst new research commitments were limited, spend on healthcare, community support and respite exceeded £1m, compared to £1.2m in 2020.

The eight months shops were open for trading resulted in net income from the retail operation, including government grants of £1.7m, compared with a deficit of £0.7m in 2020.

Many of our fundraising activities were severely curtailed during the first half of the year. However some major events were pushed back to the autumn and generated positive results. Overall net fundraising income was £0.96m in 2021, compared with £1.05m 2020.

Chart 1: Charitable Expenditure 2021



The surplus for the year was £0.8m, compared to a deficit of £2.4m in 2020. DEBRA’s reserves built up in prior years have allowed operations to continue and are now being replenished as normal trading resumes.

## Charitable spend

Charitable spend was £1.89m in 2021 compared to £2.85m in 2020. The key contribution to this fall was a reduction in research expenditure of £0.70m with £0.48m spent in 2021 compared to £1.18m in 2020. £0.69m (2020: £0.89m) was spent on Community Support initiatives, £0.25m (2020: £0.35m) on Healthcare services and £0.37m (2019: £0.48m) on Public Education.

Net assets increased to £3.80m from £2.98m. There was £3.5m in the general fund, £0.55m in designated funds and a £0.25m deficit in restricted funds.

## Summary

Table 3 summarises the highlights of our financial performance over the last five years. Gross income was £13.3m in 2021, an increase of £1.9m (16%) from 2020.

Non-trading gross income (not including government retail support) was £2.29m, a slight decrease from £2.33m in 2020. This includes income from donations, corporate support, trusts and community events.

Net retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops, but excluding government support) increased by 21% to £8.7m from £7.2m. Although shops numbers reduced by six and were closed for the first four months of 2021 they were less impacted by government action than in 2020.

The pandemic has had a devastating impact on our finances but, due to sound financial management in previous years, the strong reserves base was accessed to maintain close to normal levels of charitable activities.

Table 3: Financial KPI summary

	2021	2020	2019	2018	2017
Gross income	13,317k	11,413k	16,798k	16,138k	16,182k
Non-trading income including all government support	4,663k	4,387k	3,475k	2,979k	3,468k
Net trading income	(1,299k)	(3,201k)	1,198k	1,193k	616k
Net retail income including government pandemic support, retail gift aid, commission and donations in shops	1,689k	(673k)	2,123k	2,138k	1,652k
Non-trading fundraising costs	662k	708k	768k	727k	1,083k
Charitable expenditure	1,885k	2,848k	3,110k	2,966k	3,299k
Retained surplus/(deficit)	817k	(2,371k)	795k	479k	(299k)
Retained surplus/(deficit) as a % of income	6%	(21%)	5%	3%	(1.8%)
Net current assets	3,124k	2,684k	4,878k	4,394k	3,951k
Unrestricted reserves	4,050k	2,904k	5,138k	4,420k	3,997k
Grants payable within 1 year	2,237k	2,159k	2,201k	1,825k	1,156k

The charity’s fixed assets comprise the premises and equipment required to operate trading activities; premises, furniture and equipment required to operate the charity’s offices; and five holiday homes held for the

use of those affected by EB. The rest of the charity’s assets are held to promote the purposes of the charity through its support services and research programmes.

## Reserves policy

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

The trustees' reserves policy in 2021 was to maintain minimum cash-backed free reserves at £1,800k, plus a £250k balance in the designated fund for nursing continuity, to which the charity adhered. We have a high proportion of retail income, which usually provides a stable and reliable income stream. However, this incurs a high cost base, and the minimum reserves figure would cover one month's costs (excluding rent) plus six months' rent.

The trustees conducted a thorough review of the reserves policy at the end of 2021, reviewing performance criteria in the light of the pandemic and the deficit in 2020. The trustees' aim is to grow cash-backed free reserves over the next five years to £3.3m, in line with planned growth in retail and fundraising operations.

Total reserves at the end of 2021 were £3.80m, including a deficit balance of £0.25m in restricted funds. Cash-backed free reserves before designations were £3.28m, of which £0.55m was designated for specific purposes, bringing the total cash-backed free reserves after designations to £2.73m. Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be readily mortgaged, thus representing reserves that can be accessed relatively quickly.

## Restricted funds

Restricted funds comprised £98k funds for community support and healthcare activities, and a deficit balance of £350k in respect of Medical Research Council (MRC) funding. An agreement was signed with the MRC who agreed to provide funding for specific research projects already in progress. The funds were received in 2022. The related costs were recognised in the income statement and charged to the general fund on grant award in accordance with DEBRA accounting policies. Therefore, a transfer from restricted funds to general funds is required in 2021 representing spend already incurred.

### NHS Digital fund

A total of £200k has been made available in the designated fund for NHS Digital. This balance is sufficient to fund the data project for the fully two-year lifecycle.

### Nursing continuity fund

The amount of £250k was made available in the designated fund for nursing continuity. The purpose of this fund is to cover the cost of the continued nursing service to the EB community for six months in the event of the NHS withdrawing current levels of support. It is expected this fund will be spent in the next five to ten years.

### General fund

There was £3.50m in the general fund, of which £1.01m can only be realised by disposing of tangible fixed assets. The trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

## Investment policy

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit.

We aim to apply our income in support of our charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk.

Prior to the pandemic, the charity took the view that this was best achieved by investing funds not immediately needed in short-term money market deposits through Lloyds Bank Corporate Markets. The investments have been transferred to cash at the current time during this period of uncertainty.

## Expenses policy

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

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

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

## Funds

The majority of our funds are unrestricted in application and are held in a general and two designated funds. Where funds are received that are restricted in their application to specific purposes or activities, these are held in a restricted fund. Details of restricted funds and designated funds are set out in Note 17 of the Financial Statements.

### Asset cover for funds

Note 18 sets out an analysis of the assets attributable to the various funds. These assets are sufficient to meet the charity's obligations on a fund-by-fund basis.

## Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2021 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous non-primary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 22 of the Financial Statements.

## Internal audit

The trustees appointed RSM as internal auditors during the year. Audits of Risk Management and Health & Safety were carried out and resulting action plans are being implemented by management. Audits of Internal Financial Controls, Cyber Security, Payroll and Fundraising are planned for 2022.

# Principal risks and uncertainties

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

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

See Table 4: DEBRA's top ten risks.

**Table 4: Summary Extract from DEBRA's Risk Register**

Risk	Description	Current actions
<b>1 COVID-19 Pandemic</b>	Infection rates or government action leads to shop closures understaffing and other business impacts leading to loss of income and reduced ability to meet the needs of the EB community	<ul style="list-style-type: none"> <li>• COVID-19 Risk Assessment</li> <li>• Training for staff</li> <li>• Covid safe shop layout</li> <li>• PPE and sanitiser supplied</li> <li>• safe working systems</li> <li>• Health and Safety file set to all shops</li> </ul>
<b>2 Compliance with Health and Safety and other laws</b>	Non-compliance with H&S or other law leads to: <ul style="list-style-type: none"> <li>• Serious injury / loss of life</li> <li>• fines and legal action against DEBRA and its Trustees / employees</li> <li>• Reputational damage</li> </ul>	<ul style="list-style-type: none"> <li>• Professionally qualified H&amp;S, HR, Finance and compliance personnel</li> <li>• Use of 3rd party consultancy advice</li> <li>• Health &amp; Safety policy and training / IOSH training</li> <li>• Health and Safety Audits</li> <li>• Shops Risk Register</li> </ul>
<b>3 Cyber Security - data breach or loss</b>	<p>A breach of personal data due to fraud leading to a loss of reputation and GDPR fines</p> <p>System failure leads to critical data loss</p>	<ul style="list-style-type: none"> <li>• In-house Data Protection Officer supported by External Consultancy</li> <li>• On-going staff training on data protection</li> <li>• Microsoft Authenticator, firewalls, mail scanning and other IT tools</li> <li>• Cyber insurance</li> <li>• IT Backup procedures and use of cloud</li> <li>• Business Continuity plan</li> </ul>

Risk	Description	Current actions
<b>4 Cash</b>	Failure to maintain adequate cash flows leading to an inability of DEBRA to continue as a going concern	<ul style="list-style-type: none"> <li>• Treasury management and cash flow forecasting monthly, reported to SMT and FRA (quarterly)</li> <li>• Monitoring by Trustees and FRA of cash-backed free reserves minimum figure</li> </ul>
<b>5 Reputational damage</b>	Damage to the charity's image leads to loss of support	<ul style="list-style-type: none"> <li>• Marketing Strategy and PR management</li> <li>• HR Disciplinary Policy</li> <li>• Crisis Communication Plan</li> <li>• Review of complaints and action taken</li> <li>• Pro-active media trawling</li> <li>• Staff induction programme</li> <li>• Social media policy</li> </ul>
<b>6 Safeguarding</b>	Failure to comply with the requirements to satisfactorily report Safeguarding issues	<ul style="list-style-type: none"> <li>• H&amp;S and Safeguarding Manager in post</li> <li>• Work with external agencies</li> <li>• Safeguarding training for all staff</li> <li>• Designated Safeguarding Officers in post who undergo further training</li> <li>• Safeguarding Committee meets quarterly</li> </ul>
<b>7 Changing face of retail</b>	Decline in the high street and growth of online impact of DEBRA's retail income	<ul style="list-style-type: none"> <li>• Successful trial of Shopiagio</li> <li>• Search for new locations</li> </ul>
<b>8 Governance</b>	Lack of skill and knowledge amongst trustees leads to poor stewardship of DEBRA and non-compliance with laws and regulations, leading to the inability of DEBRA to continue as a going concern	<ul style="list-style-type: none"> <li>• Up to 50% of trustees appointed based on skills</li> <li>• Trustee induction and training processes</li> </ul>
<b>9 People skills</b>	Lack of appropriate skills at SMT or wider staff leading to poor business decision making	<ul style="list-style-type: none"> <li>• Annual CEO appraisal</li> <li>• Recruitment and retention policies</li> <li>• Staff appraisal process</li> </ul>
<b>10 Economy / inflation</b>	Adverse economic conditions or high inflation impact shop or other income	<ul style="list-style-type: none"> <li>• Retail Committee monthly reports with KPIs</li> <li>• Performance reviews</li> <li>• Retail Risk Register</li> <li>• Continuous drive to increase retail contribution / enhance pricing</li> </ul>

# Going concern statement

The trustees have reviewed the financial statements and forecast to the end of 2023, detailing the plans for financial recovery whilst maintaining a first-class service to the EB community. It is recognised that there are underlying uncertainties, however the trustees consider the charity can continue its business-critical activities and remain a going concern. The retail estate re-opened during April 2021 providing a regular income stream of unrestricted funds, plus the suite of fundraising events started up again and there have been no further retail restrictions imposed by the Government since. The trustees consider it is appropriate to prepare the 2021 accounts on a going concern basis on the basis that:

- higher than in 2020, and before the pandemic started, undesignated free reserves at the end of 2021 are higher than in 2019 due to the trustees decision to undesignate the future research fund coupled with the 2021 surplus
- trading in 2021 is back to pre-pandemic levels
- The Budget and cash flows for 2022 and 2023 maintain adequate cash reserves throughout the period; and
- additional research activity programmed in 2022 and 2023 is contingent on achieving fundraising and retail targets. A grant of £500,000 has already been secured in 2022 to support this activity.

## Structure, governance & management

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

### Board of Trustees

Our Board of trustees is made up from a majority of those who have a direct experience of EB, who either have EB themselves or have a close family member with EB, and those who have skills and experience that will add value to the governance and leadership of DEBRA. Of the 15 trustees, up to eight are elected by the membership and up to seven appointed by the Board. This ensures a good mix of skills, talents and experience to serve the DEBRA community.

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

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

An Annual General Meeting was held via Zoom in May 2021. Three appointed trustees Graham Marsden, Tim Powell and Jo Merchant reached the end of a three-year term. After serving three x three-year terms, Graham retired as required by DEBRA's articles and Tim stepped down after two terms. Both were

thanked for their dedication over the years, particularly over the past 12 months.

As recommended by the Nominations & Governance Committee the Board of Trustees re-appointed Jo Merchant for a third three-year term. The Board also appointed Simone Bunting (who had previously served as a trustee, but had taken a year's break as required by DEBRA's articles) for a first term of three years. Simon Talbot was also elected by the members.

New trustees receive a Trustee Handbook and other relevant publications, individual inductions from senior trustees as relevant and trustees attend external training courses appropriate to their role on the Board of Trustees. There are four board meetings per year, which the CEO attends and Senior Management Team members attend as required.

### Trustee Board committees

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

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

**Retail Committee** – determines and advises the SMT and the Board of Trustees on matters relating to the shops. It utilises specific knowledge of its members to assist the CEO and Director of Retail to manage the shops, deliver operational performance against plan, comply with regulations and promote the cause of the charity.

### Fundraising & Communications Committee

– oversees the fundraising activities of the SMT on matters relating to the growth of income generation and maximising opportunities within Marketing and PR. The Committee approves and recommends to the Board of Trustees the strategic direction of fundraising and the financial plan. It utilises specific knowledge of its members to challenge and support the Director of Fundraising and Director of Marketing and Communications to deliver against plans, comply with regulations and promote the cause of the charity.

### Nominations & Governance Committee

– oversees the structure, composition and effectiveness of the charity's Board of Trustees and its Committees, as well as the appointment process of trustees. The Committee monitors the governance procedures of the charity.

**Steering Group** – this committee was created in light of the pandemic and meets regularly on an 'as needed' basis.

See Table 5 below – Trustees' membership and attendance.

The Trustees plan to undertake a full review of the existing committee structure during 2022.

## Board diversity

To ensure that we have a well-balanced board, those with experience of living or working with EB are the majority, together with those trustees who do not have EB experience but possess the relevant skills and knowledge. The Board members come from a variety of backgrounds, in order to bring different perspectives to discussions and enhance the Board's decision-making process.

We follow the Equal Opportunities Policy in the selection of Board members, in the same way we do for staff recruitment. Membership of the Board is open to all members of DEBRA, irrespective of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values. Broader diversity of the Board continues to be reviewed as part of DEBRA's Equality, Diversity & Inclusion project.

## Charity governance code

The Board consistently reviews all aspects of DEBRA's governance and ensures that our governance standards and practices fully embrace the principles of the Charity Commission 'Charity Governance Code'. We are currently reviewing the updates to the code in December 2020, which strengthened the Principle of Equality of opportunity, Diversity and Inclusion (EDI) and updated the Integrity Principle.

## Succession planning

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

## Fundraising standards

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

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

- the majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the trustees
- where we work with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met
- there are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc
- where volunteers assist in our fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued
- volunteer fundraisers are managed and supported from the offices in Bracknell and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them
- data protection procedures are in place governing the management of supporter and donor data on our DEBRA database; compliance with the GDPR rules that came into force in May 2018 continues to be monitored

- we work with vulnerable people, particularly within the EB community, and often they wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly
- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2021.

## Activities in Scotland

We are active across several areas in Scotland. The primary charitable activities are seen in funding community support and research projects, notably at the Universities of Dundee and Edinburgh and the Cancer Research UK Beatson Institute, University of Glasgow. On the income generation side, there were two regional fundraising members of staff and 37 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Blantyre.

Table 5: Trustees' membership and attendance records as at 31.12.2021.

		Board attendance	Finance, Risk & Audit Committee	Nominations & Governance Committee	Care & Research Committee	Retail Committee	Fundraising & Communications Committee
Jim Irvine	Chair	<b>4 of 4</b>	4 of 4	4 of 5			
David Bendor-Samuel		3 of 4		<b>5 of 5</b>			
Simone Bunting	Elected May 2021	2 of 2		3 of 5			<b>4 of 4</b>
Rebecca Cresswell		1 of 4					4 of 4
Simon Cuzner	Stood down 16.07.2021	2 of 2				<b>3 of 3</b>	
Carly Fields		4 of 4		3 of 3	<b>4 of 4</b>		2 of 2
Andrew Grist	Stood down 01.03.2022				2 of 4		
Christo Kapourani		2 of 3			3 of 4		
Graham Marsden	Stood down 27.05.2021	2 of 2		3 of 3			
Joanne Merchant		4 of 4	<b>4 of 4</b>			4 of 4	
Viv Mundy		2 of 4		3 of 5	3 of 4		
Timothy Powell	Stood down 27.05.2021	2 of 2			<b>1 of 1</b>		
Douglas Rouse		3 of 4					3 of 4
Mick Thomas		4 of 4					3 of 4
Simon Talbot		1 of 2	2 of 2				
Josie Godfrey	Co-opted 06.08.2021	1 of 1			0 of 1		

The committee chairs' attendance is highlighted in bold.

# Auditor

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

We engaged Sayer Vincent LLP as auditor during 2020 and they have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditor

28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

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

Jim Irvine  
**Chair of Trustees**

## Trustees' statement of responsibilities

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

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

- select suitable accounting policies and then apply them consistently

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

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for

safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

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

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2021 was 2343 (2020: 3,279). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

## Auditor's report

Independent auditor's report to the members of DEBRA.

### Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2021 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended.
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice.
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

## Basis for opinion

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

## Conclusions relating to going concern

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

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

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

## Other information

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

We have nothing to report in this regard.

## Opinions on other matters prescribed by the Companies Act 2006

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

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

## Matters on which we are required to report by exception

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

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

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

## Responsibilities of trustees

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

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

## Auditor's responsibilities for the audit of the financial statements

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

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

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

Capability of the audit in detecting irregularities

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

We enquired of management and Finance, Audit and Risk committee, which included obtaining and reviewing supporting documentation, concerning the charity’s policies and procedures relating to:

- identifying, evaluating, and complying with laws and regulations and whether they were aware of any instances of non-compliance;
- detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud;
- the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.

We inspected the minutes of meetings of those charged with governance.

We obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience.

We communicated applicable laws and regulations throughout the Audit Team and remained alert to any indications of non-compliance throughout the audit.

We reviewed any reports made to regulators.

We reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations.

We performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud.

In addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

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

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

Use of our report

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

Sayer Vincent LLP

Fleur Holden (Senior Statutory Auditor)

30.05.2022

for and on behalf of Sayer Vincent LLP,  
Statutory Auditor

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

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

# Financial statements

For the year ended 31 December 2021

# Statement of Financial Activities

Statement of Financial Activities including income and expenditure account  
for the year ended 31 December 2021.

2021						2020			
		Unrestricted funds	Designated funds	Restricted funds	Total	Unrestricted funds	Designated funds	Restricted funds	Total
	Notes	£	£	£	£	£	£	£	£
Income from:									
Donations & legacies	2	4,261,175	-	347,477	4,608,652	3,814,335	-	468,926	4,283,261
Charitable activities		20,441	-	-	20,441	18,210	-	-	18,210
Other trading activities	3	8,641,059	-	12,945	8,654,004	6,903,611	75,771	46,491	7,025,873
Investments	4	14,564	-	-	14,564	47,403	-	-	47,403
Other		19,740	-	-	19,740	38,150	-	-	38,150
Total income		12,956,979	-	360,422	13,317,410	10,820,709	75,771	515,417	11,412,897
Expenditure on:									
Raising funds	6	10,614,818	-	-	10,614,818	10,935,662	-	-	10,935,662
Charitable activities	6	1,604,625	-	280,573	1,885,198	1,452,433	821,551	573,782	2,847,766
Total expenditure		12,219,443	-	280,573	12,500,016	12,388,095	821,551	573,782	13,783,428
Net income / (expenditure)		737,536	-	79,849	817,385	(1,566,386)	(745,780)	(58,365)	(2,370,531)
Transfer between funds		624,292	(215,950)	(408,342)	-	1,473,695	(1,395,027)	(78,668)	-
Net movement in funds		1,361,828	(215,950)	(328,493)	817,385	(92,691)	(2,140,807)	(137,033)	(2,370,531)
Reconciliation of funds:									
Total funds brought forward		2,138,497	765,950	76,543	2,980,990	2,231,188	2,906,757	213,576	5,351,521
Total funds carried forward		3,500,325	550,000	(251,950)	3,798,375	2,138,497	765,950	76,543	2,980,990

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

The notes on pages 83–109 form part of these financial statements.

# Balance sheet

Balance sheet as at 31 December 2021.

		2021	2020
	Notes	£	£
<b>Fixed assets</b>			
Tangible fixed assets	10	1,009,272	1,077,946
Programme related investment	11	1	1
Investment in subsidiaries	12	2	2
		<u>1,009,275</u>	<u>1,077,949</u>
<b>Current assets</b>			
Fixed assets held for sale		74,167	167,960
Stocks		1,321	5,910
Debtors	13	1,942,888	1,616,619
Cash at bank and in hand		4,967,810	5,076,553
		<u>6,986,186</u>	<u>6,867,042</u>
<b>Creditors: amounts falling due within one year</b>	14	<u>(3,861,818)</u>	<u>(4,182,719)</u>
<b>Net current assets</b>		<u>3,124,368</u>	<u>2,684,323</u>
<b>Total assets less current liabilities</b>		<u>4,133,643</u>	<u>3,762,272</u>
<b>Creditors: amounts falling due after more than one year</b>	15	(147,320)	(599,474)
<b>Provision for liabilities</b>		<u>(187,948)</u>	<u>(181,808)</u>
<b>Total net assets</b>		<u><u>3,798,375</u></u>	<u><u>2,980,990</u></u>

		2021	2020
<b>The funds of the charity</b>			
<b>Restricted income funds</b>	17	(251,950)	76,543
<b>Unrestricted funds</b>			
Designated funds	18	550,000	765,950
General funds	18	3,500,325	2,138,497
		<u>4,050,325</u>	<u>2,904,447</u>
<b>Total unrestricted funds</b>		<u>4,050,325</u>	<u>2,904,447</u>
<b>Total funds</b>		<u><u>3,798,375</u></u>	<u><u>2,980,990</u></u>

Company registration number 4118259

The accounts were approved by the Board on 27.4.2022 and signed on their behalf by:

Jim Irvine

**Chair of Trustee Board**

Joanne Merchant

**Treasurer**

# Statement of cash flows

Statement of cash flows for the year ended 31 December 2021.

		2021	2021	2020	2020
	Notes	£	£	£	£
<b>Cash flows from operating activities</b>					
Net cash used in operating activities	20		(270,182)		(1,366,471)
<b>Cash flows from investing activities</b>					
Dividends, interest and rents from investments		14,564		47,403	
Proceeds from the sale of property, plant and equipment		238,649		7,052	
Purchase of property, plant and equipment		(91,774)		(68,791)	
Proceeds from sale of investments		-		3,750,000	
Purchase of investments		-		(190,840)	
<b>Net cash provided by investing activities</b>			161,439		3,544,825
<b>Change in cash and cash equivalents in the reporting period</b>			(108,743)		2,178,354
<b>Cash and cash equivalents at the beginning of the reporting period</b>			5,076,553		2,898,199
<b>Cash and cash equivalents at the end of the reporting period</b>			4,967,810		5,076,553

The notes on pages 83–109 form part of these financial statements.

# Notes to the financial statements

## 1 Accounting policies

### 1.1 Basis of preparation

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

### 1.2 Going concern

The trustees reviewed the charity’s budget and cash flows for 1 January 2022 – 31 December 2023 in December 2021 and consider it is appropriate to prepare the 2021 accounts on a going concern basis on the basis that:

- undesignated free reserves at the end of 2021 are higher than in 2020 and before the COVID-19 pandemic due to the trustees decision to undesignate the future research fund coupled with the 2021 surplus;
- trading in 2021 is back to pre-pandemic levels;
- the Budget and cash flows for 2022 and 2023 maintain adequate cash reserves throughout the period; and
- additional research activity programmed in 2022 and 2023 is contingent on achieving fundraising and retail targets. A grant of £500,000 has already been secured in 2022 to support this activity.

### 1.3 Legal status of charity

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

### 1.4 Judgements and estimates made by management

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

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

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

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

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

# Notes to the financial statements (continued)

## 1.5 Income

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

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

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

## 1.6 Expenditure

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

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

## 1.7 Recognition of grant liabilities

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

## 1.8 Tangible fixed assets and depreciation

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

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

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

## 1.9 Programme related investment and impairment

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

## 1.10 Cash and short-term investments

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

## 1.11 Debtors

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

## 1.12 Creditors

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

# Notes to the financial statements (continued)

## 1.13 Financial instruments

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

## 1.14 Stock

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

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

## 1.15 Accumulated funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The exceptional circumstances of 2020 and 2021 resulted in funds being undesignated in order for the charity to continue its charitable objectives. The purposes and uses of the restricted funds and designated funds are set out in Note 17 to the financial statements.

## 1.16 Consolidated accounts

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

## 1.17 Foreign currency translation

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

## 1.18 Leases

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

## 1.19 Termination payments

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

## 2. Donations and legacies

	Unrestricted funds	Restricted funds	Total 2021	Unrestricted funds	Restricted funds	Total 2020
	£	£	£	£	£	£
Donations & gifts	1,758,535	105,013	<b>1,863,548</b>	1,438,777	157,348	1,596,125
Legacies receivable	8,148	4,431	<b>12,579</b>	219,678	37,500	257,178
Grants receivable	2,494,492	238,033	<b>2,732,525</b>	2,155,880	274,078	2,429,958
	<u>4,261,175</u>	<u>347,477</u>	<u><b>4,608,652</b></u>	<u>3,814,335</u>	<u>468,926</u>	<u>4,283,261</u>
<b>Donations &amp; gifts:</b>						
Individual donations	1,469,207	94,482	<b>1,563,689</b>	1,189,520	128,112	1,317,632
Corporate donations	253,525	8,025	<b>261,550</b>	234,413	26,488	260,901
International donations	1,156	-	<b>1,156</b>	496	-	496
Events by individuals	34,647	2,506	<b>37,153</b>	14,348	2,748	17,096
	<u>1,758,535</u>	<u>105,013</u>	<u><b>1,863,548</b></u>	<u>1,438,777</u>	<u>157,348</u>	<u>1,596,125</u>
<b>Grants receivable:</b>						
Charitable trusts	61,093	238,033	<b>299,126</b>	82,962	274,078	357,040
Government grants	2,433,399	-	<b>2,433,399</b>	2,072,918	-	2,072,918
	<u>2,494,492</u>	<u>238,033</u>	<u><b>2,732,525</b></u>	<u>2,155,880</u>	<u>274,078</u>	<u>2,429,958</u>

Government grants consist of £809,812 (2020: £1,248,868) received under the Coronavirus Job Retention Scheme and £1,623,587 (2020: 824,050) received in local authority grants.

Gifts in kind of £87,206 (2020: £88,006) are included in donations and gifts. This comprises online adwords valued at £67,206 (2020: £67,206) and campaign design and consultancy valued at £20,000 (2020: £nil). In 2020 gifts in kind also included advertising in a national newspaper valued at £20,800.

# Notes to the financial statements (continued)

## 3. Other trading activities

	2021	2020
	£	£
Income	<b>8,654,004</b>	7,025,873
Operating expenses	<b>(9,952,625)</b>	(10,227,464)
Net income from fundraising activities	<b>(1,298,621)</b>	(3,201,591)

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2021 there were 105 shops trading (2020: 109). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2021	Income	Operating expenses	Net income 2020
	£	£	£	£	£	£
Retail	7,911,357	(9,340,096)	<b>(1,428,739)</b>	6,477,316	(9,757,368)	(3,280,052)
Fundraising events	639,431	(612,529)	<b>26,902</b>	429,761	(470,096)	(40,335)
Miscellaneous trading	103,216	-	<b>103,216</b>	118,796	-	118,796
	<b>8,654,004</b>	<b>(9,952,625)</b>	<b>(1,298,621)</b>	<b>7,025,873</b>	<b>(10,227,464)</b>	<b>(3,201,591)</b>

Retail income excludes income of £732,522 (2020: £606,091) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail gift aid commission of £33,236 (2020: £84,619) which is recognised in miscellaneous trading. In 2020 and 2021 the COVID-19 pandemic had a significant impact on gross retail income. The profit covenanted by DEBRA Trading Limited of £69,980 (2020: £34,176) is recognised in miscellaneous trading.

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

	2021	2020
	£	£
Income	<b>8,710,081</b>	7,168,026
Operating expenses	<b>(9,340,096)</b>	(9,757,368)
Net expenditure on fundraising activities	<b>(630,015)</b>	(2,589,342)

## 4. Investment income

	2021	2020
	£	£
Interest receivable	<b>3</b>	29,940
Rent of property	<b>14,561</b>	17,463
Total investment income	<b>14,564</b>	47,403

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

# Notes to the financial statements (continued)

## 5. Grants payable

Expenditure on charitable activities include grants payable to third parties as detailed in Note 22. There were 179 (2020: 154) Community Support grants totalling £36,752 (2020: £38,071) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 22.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2021 the trustees had authorised a commitment to support research grants over the next three years to the sum of £548,814 (2020: £1,183,468) and clinical projects to the sum of £125,948 (2020: £138,105).

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

	Total 2021	Total 2020
	£	£
Within one year	<b>527,442</b>	722,099
Within two – three years	<b>147,320</b>	589,406
Within four – five years	-	10,068
Provided within the grants payable creditor (notes 14 and 15)	<b>674,762</b>	1,321,573

## 6. Expenditure

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2021
	£	£	£	£	£	£
<b>Raising funds</b>						
Donations & legacies	381,817	-	-	164,432	115,943	<b>662,192</b>
Other trading activities	5,338,778	-	61,319	314,047	4,238,482	<b>9,952,626</b>
	<u>5,720,595</u>	<u>-</u>	<u>61,319</u>	<u>478,478</u>	<u>4,354,425</u>	<u><b>10,614,818</b></u>
<b>Charitable activities</b>						
Research	274,861	168,806	-	31,262	9,555	<b>484,484</b>
Healthcare	60,235	172,668	-	19,858	-	<b>252,761</b>
Community support	607,601	36,752	-	42,710	-	<b>687,063</b>
Respite breaks	-	-	48,016	-	46,926	<b>94,942</b>
Public education	243,566	-	-	31,934	90,448	<b>365,948</b>
	<u>1,186,263</u>	<u>378,226</u>	<u>48,016</u>	<u>125,765</u>	<u>146,929</u>	<u><b>1,885,198</b></u>
	<u>6,906,858</u>	<u>378,226</u>	<u>109,335</u>	<u>604,243</u>	<u>4,501,354</u>	<u><b>12,500,016</b></u>

# Notes to the financial statements (continued)

	Staff costs	Grants payable	Dep'n & amort'n	Overhead allocation	Other costs	Total 2020
	£	£	£	£	£	£
<b>Raising funds</b>						
Donations & legacies	415,507	-	-	174,569	118,122	<b>708,198</b>
Other trading activities	5,703,336	-	78,022	301,865	4,144,241	<b>10,227,464</b>
	<u>6,118,843</u>	<u>-</u>	<u>78,022</u>	<u>476,434</u>	<u>4,262,363</u>	<u><b>10,935,662</b></u>
<b>Charitable activities</b>						
Research	339,024	572,731	-	38,798	230,545	<b>1,181,098</b>
Healthcare	80,880	241,967	-	23,990	-	<b>346,837</b>
Community support	651,422	38,072	-	56,432	-	<b>745,926</b>
Respite breaks	-	-	48,016	-	45,451	<b>93,467</b>
Public education	367,838	-	-	43,441	69,159	<b>480,438</b>
	<u>1,439,164</u>	<u>852,770</u>	<u>48,016</u>	<u>162,661</u>	<u>345,155</u>	<u><b>2,847,766</b></u>
	<u>1,439,164</u>	<u>852,770</u>	<u>126,038</u>	<u>639,095</u>	<u>4,607,518</u>	<u><b>13,783,428</b></u>

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

	2021	2020
	£	£
Operating leases	1,246,982	1,279,426
Auditors' remuneration	20,000	19,313
Non-audit services	3,600	-
Depreciation of tangible fixed assets	159,256	158,451
Defined contribution pension costs	314,405	345,016
Exchange differences	27,809	(20,916)
	<u>1,771,052</u>	<u>1,881,330</u>

## 7. Cost allocation

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

	2021	2020
	£	£
<b>Staff costs</b>	<b>1,403,077</b>	1,521,167
<b>Overheads</b>		
Office premises rent	<b>62,789</b>	62,891
Service charges, utilities & cleaning	<b>57,363</b>	57,788
Equipment costs	<b>144,088</b>	148,634
Postage, printing, stationery, telephone & fax	<b>64,585</b>	54,502
Insurance costs	<b>110,401</b>	97,435
Legal, professional & consultancy fees	<b>139,356</b>	135,198
Depreciation	<b>38,017</b>	36,829
Profit on disposal	<b>(143,660)</b>	-
Irrecoverable VAT	<b>22,348</b>	24,216
Bank charges	<b>9,744</b>	6,755
Sundry expenses	<b>58,201</b>	(8,681)
<u>Governance costs:</u>		
Audit, non-audit and internal audit fees	<b>38,600</b>	19,313
Miscellaneous costs	<b>2,411</b>	4,215
	<u><b>604,243</b></u>	<u>639,095</u>
<b>Total allocation</b>	<b>2,007,320</b>	2,160,262

# Notes to the financial statements (continued)

## 8. Trustees

None of the trustees received any remuneration from DEBRA during the period, but one of them was reimbursed a total of £127 (2020: 9 – £2,259) for travel expenses. No trustees received community grants in 2021 (2020: Andy Grist received £15). The aggregate figure for trustee donations in 2021 was £447 (2020: £2,158). In addition, many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £4,025 (2020: £2,253), as allowed under section 4.3.3 in DEBRA's Articles of Association.

## 9. Employees

The average number of employees during the period was:

	2021	2021	2020	2020
	No.	FTE	No.	FTE
Research	1	1.0	5	2.9
Healthcare*	-	-	-	-
Community Support	13	12.3	12	11.2
Fundraising & Comms	16	15.8	20	18.2
Retail	299	216.4	321	232.5
Management & Administration	19	17.6	18	15.7
	<b>348</b>	<b>263.1</b>	<b>376</b>	<b>280.5</b>

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

	2021	2021	2020	2020
	No.	FTE	No.	FTE
Research	1	1.0	4	1.6
Healthcare*	-	-	-	-
Community Support	13	12.0	10	9.7
Fundraising & Comms	16	15.6	19	17.2
Retail	304	222.2	304	221.6
Management & Administration	22	19.2	16	14.2
	<b>356</b>	<b>270.0</b>	<b>353</b>	<b>264.3</b>

\*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 19.

Staff employed by external institutions and funded through research grants are also excluded.

	2021	2020
	£	£
Wages & salaries	5,960,400	6,231,757
Social security costs	392,291	395,899
Pension costs	314,405	312,098
<b>Total allocation</b>	<b>6,667,096</b>	<b>6,939,754</b>

# Notes to the financial statements (continued)

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £338,399 (2020: £313,959) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £nil (2020: £24,016) unpaid.

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

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

	2021	2020
	No.	No.
Between £60,001 - £70,000	3	3
Between £70,001 - £80,000	1	-
Between £80,001 - £90,000	-	2
Between £110,001 - £120,000	1	-
Between £170,001 - £180,000	-	1

Redundancy and compensation payments, which were all paid in year, totalled £16,739 (2020: £160,487).

The aggregate pay of key management personnel, including employer's NI and pension contributions was £711,022 (2020: £736,268). The aggregate employer's pension contribution for key management personnel was £61,489 (2020: £59,304)

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £59,064 (2020: £53,246), and there are retirement benefits accruing for five (2020: six) employees under a defined contribution scheme.

## 10. Fixed assets

### Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land & buildings	Long leasehold land & buildings	Total
	£	£	£	£	£	£
<b>Cost:</b>						
At 1 January 2021	437,742	480,162	321,118	578,347	82,500	1,899,869
Additions	13,858	-	77,916	-	-	91,774
Disposals	(89,460)	-	(3,991)	-	-	(93,451)
<b>At 31 December 2021</b>	<b>362,140</b>	<b>480,162</b>	<b>395,043</b>	<b>578,347</b>	<b>82,500</b>	<b>1,898,192</b>
<b>Depreciation:</b>						
At 1 January 2021	284,949	197,599	165,027	154,548	19,800	821,923
Charge for the year	56,840	48,016	40,231	12,879	1,650	159,256
Disposals	(88,268)	-	(3,991)	-	-	(92,259)
<b>At 31 December 2021</b>	<b>253,161</b>	<b>245,615</b>	<b>201,267</b>	<b>167,427</b>	<b>21,450</b>	<b>888,920</b>
<b>Net book value:</b>						
1 January 2021	152,793	282,563	156,091	423,799	62,700	1,077,946
<b>31 December 2021</b>	<b>108,979</b>	<b>234,547</b>	<b>193,776</b>	<b>410,920</b>	<b>61,500</b>	<b>1,009,272</b>

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

The trustees agreed to sell one freehold shop during 2019, and a flat above another shop in 2020. These were transferred to current assets in 2020. The flat was sold in October 2021 and the freehold shop was sold in January 2022.

# Notes to the financial statements (continued)

## 11. Programme related investment

	2021	2020
	£	£
<b>Investment in Fibrx Derm Inc</b>		
Net investment value brought forward	1	-
Purchase of investment	-	190,840
Impairment charge	-	(190,839)
	<u>1</u>	<u>1</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 2021 (2020: two). These are DEBRA Trading Ltd (company number: 2487114), whose principal activities are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship; and DEBRA Retail Ltd which is dormant.

Financial information for these entities for the year ended 31 December 2021:

	2021		2020	
	DEBRA Trading Ltd	DEBRA Retail Ltd	DEBRA Trading Ltd	DEBRA Retail Ltd
	£	£	£	£
Share capital	2	1	2	1
Turnover	119,267	-	96,247	-
Total expenses	49,287	-	62,070	-
Gift aid to DEBRA	69,980	-	34,176	-
Profit / (loss) for the year	-	-	-	-
Net assets / (liabilities)	<u>2</u>	<u>1</u>	<u>2</u>	<u>1</u>

## 13. Debtors

	2021	2020
	£	£
HMRC	174,344	281,158
Amounts due from group undertakings	69,980	34,176
Other debtors	489,879	402,321
Accrued income	681,184	363,233
Prepayments	527,501	535,731
	<u>1,942,888</u>	<u>1,616,619</u>

Amounts due from HMRC are VAT receivable of £174,344 (2020: £216,811), plus £nil (2020: £64,347) from the Coronavirus Job Retention Scheme. Other debtors includes £301,908 (2020: £266,825) due for shared research grants. Accrued income includes gift aid of £344,460 (2020: £147,660) due from HMRC.

Total future minimum lease receivable in 2021 was £nil (2020: £3,413), in respect of one shop and one flat above a shop.

## 14. Creditors: amounts falling due within one year

	2021	2020
	£	£
Trade creditors	427,092	678,754
Grants payable	2,236,649	2,158,657
Other creditors	220,134	308,617
Taxation and social security	113,353	92,476
Accruals	845,920	917,315
Deferred income	18,670	26,900
	<u>3,861,818</u>	<u>4,182,719</u>

Grants payable includes £548,832 (2020: £790,811) relating to future commitments and £1,687,817 (2020: £1,436,558) relating to outstanding invoices for work done.

There was deferred income in 2021 of £18,670 (2020: £26,900), representing income for events which would have to be repaid in the event of cancellation.

## Notes to the financial statements (continued)

### 15. Creditors: amounts falling due over one year

	2021	2020
	£	£
Grants payable	147,320	599,474
	<u>147,320</u>	<u>599,474</u>
	<u><u>147,320</u></u>	<u><u>599,474</u></u>

	2021	2020
	£	£
<b>Dilapidations provision</b>		
Provision brought forward	181,808	241,812
Charges	6,140	21,420
Release of provision	-	(81,422)
	<u>187,948</u>	<u>181,808</u>
Provision carried forward	187,948	181,808

## 16. Other financial commitments

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

	2021	2020	2021	2020
	Leases of land and buildings £	Leases of land and buildings £	Other £	Other £
Within one year	1,233,867	1,264,152	13,115	15,274
Between one – five years	1,539,926	1,170,587	16,217	29,332
After five years	-	5,250	-	-
	<u>2,773,793</u>	<u>2,439,989</u>	<u>29,332</u>	<u>44,606</u>

There were capital commitments of £nil (2020: £1,200) at year end, falling due within one year.

## 17. Analysis of funds: restricted funds

	Balance at 1 January 2021	Income	Expenditure	Transfer to general fund	Balance at 31 December 2021
	£	£	£	£	£
Research	-	176,067	(118,065)	(408,342)	<b>(350,340)</b>
Healthcare	5,600	30,362	(15,337)	-	<b>20,625</b>
Community support & respite	70,943	153,993	(147,171)	-	<b>77,765</b>
Public Education	-	-	-	-	-
	<u>76,543</u>	<u>360,422</u>	<u>(280,573)</u>	<u>(480,342)</u>	<u><b>(251,950)</b></u>
	<u><u>76,543</u></u>	<u><u>360,422</u></u>	<u><u>(280,573)</u></u>	<u><u>(480,342)</u></u>	<u><u><b>(251,950)</b></u></u>
	Balance at 1 January 2020	Income	Expenditure	Transfer to general fund	Balance at 31 December 2020
	£	£	£	£	£
Research	-	182,771	(104,103)	(78,668)	-
Healthcare	79,477	26,223	(100,100)	-	<b>5,600</b>
Community support & respite	134,099	292,599	(355,755)	-	<b>70,943</b>
Public Education	-	13,824	(13,824)	-	-
	<u>213,576</u>	<u>515,417</u>	<u>(573,782)</u>	<u>(78,668)</u>	<u><b>76,543</b></u>
	<u><u>213,576</u></u>	<u><u>515,417</u></u>	<u><u>(573,782)</u></u>	<u><u>(78,668)</u></u>	<u><u><b>76,543</b></u></u>

# Notes to the financial statements (continued)

## Restricted funds comprised:

	2021	2020
	£	£
Healthcare - EB nurses	15,025	-
Healthcare - Birmingham Children's Hospital Specialist Bath	5,600	5,600
Community Support - Community Support Manager for Scotland	21,542	37,259
Community Support - Community Support Manager Post	-	10,496
Community Support - Community Support in Bedfordshire	5,121	-
Community Support - Community Support in Berkshire	8,037	8,048
Community Support - Support Grants in Hampshire	5,502	5,502
Community Support - Support Grants in Northamptonshire	-	962
Community Support - Support Grants in Scotland	1,934	1,934
Community Support - Support Grants in South East England	15,851	-
Community Support - Support Grants in South Gloucestershire	1,054	1,356
Community Support - other restricted funds	18,724	5,386
	<b>98,390</b>	<b>76,543</b>
Less:		
Research - COVID Medical Research Charity Support Fund*	(350,340)	-
	<b>(251,950)</b>	<b>76,543</b>

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

## 18. Analysis of funds: unrestricted funds

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

	Balance at 1 January 2020	Income	Expenditure	Transfers	Balance at 31 December 2020
	£	£	£	£	£
Future research grants	2,618,290	-	(763,340)	(1,339,000)	515,950
Nursing continuity	250,000	-	-	-	250,000
EB:2021 Conference	38,467	75,771	(58,211)	(56,027)	-
Total designated funds	2,906,757	75,771	(821,551)	(1,395,027)	765,950
General fund	2,231,188	10,821,809	(12,388,095)	1,473,695	2,138,497
Total unrestricted funds	5,137,945	10,897,480	(13,209,646)	78,668	2,904,447

The future research grants fund was fully un-designated in 2021 in response to the COVID-19 Pandemic. The trustees resolved in October 2021 that the historical practice of designating all amounts in excess of minimum required cash-backed free reserves for future research would not be re-established. Instead, funds would be designated for specific project opportunities envisaged within the overall Five-Year Strategy. In 2021 £200,000 (2020: £nil) has been designated to fund the NHS Digital Data project for two years.

# Notes to the financial statements (continued)

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

Two amounts of £50,000 (2020: £nil) was designated in 2021 to fund procurement and IT work furthering modernisation of back office practices as set out in the Two-Year Business Plan.

## 19. Analysis of net assets between categories of funds

Fund balances at 31 December 2021 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,009,275	-	-	<b>1,009,275</b>
Current assets	6,688,136	550,000	(251,952)	<b>6,986,186</b>
Creditors:<1 year	(3,861,810)	-	-	<b>(3,861,818)</b>
Creditors:>1 year	(335,268)	-	-	<b>(335,268)</b>
	<u>3,500,325</u>	<u>550,000</u>	<u>(251,952)</u>	<u><b>3,798,375</b></u>

Fund balances at 31 December 2020 are represented by:

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fixed assets	1,077,949	-	-	<b>1,077,949</b>
Current assets	6,024,549	765,950	76,543	<b>6,867,042</b>
Creditors:<1 year	(4,182,719)	-	-	<b>(4,182,719)</b>
Creditors:>1 year	(781,282)	-	-	<b>(781,282)</b>
	<u>2,138,497</u>	<u>765,950</u>	<u>76,543</u>	<u><b>2,980,990</b></u>

## 20. Reconciliation of net income to net cash flow from operating activities

	2021	2020
	£	£
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	<b>817,385</b>	(2,370,531)
Depreciation and amortisation charges	<b>159,256</b>	162,872
Impairment of programme related investment	-	190,839
Dividends, interest and rents from investments	<b>(14,564)</b>	(47,403)
Profit / (loss) on disposal of fixed assets	<b>(143,663)</b>	(6,777)
Decrease in stock	<b>4,589</b>	390
(Increase) / decrease in debtors	<b>(326,269)</b>	310,082
(Decrease) / increase in creditors	<b>(766,914)</b>	394,057
Net cash used in operating activities	<u><b>(270,182)</b></u>	<u>(1,366,471)</u>

## 20 Analysis of cash and cash equivalents

	At 1 January 2021	Cash flows	At 31 December 2021
	£	£	£
Cash at bank and in hand	5,076,553	(108,743)	<b>4,967,810</b>
	<u>5,076,553</u>	<u>(108,743)</u>	<u><b>4,967,810</b></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)

## 22. Grants to institutions

Research grants:

	2021		2020	
	Total paid in year £	Total paid to date £	Total paid in year £	Total paid to date £
<b>University of Dundee</b>				
Clinical fellow funding	146,115	650,589	89,572	504,474
<b>University of Glasgow</b>				
Re TGF-beta mediated tumour promotion in RDEB	64,001	221,139	78,525	157,138
<b>Guy's and St Thomas' Hospital, London</b>				
Clinical endpoints study re EB therapy evaluation	160,956	694,557	120,717	533,601
Stem cell therapy trial re treating debilitating itch	31,946	497,360	113,262	465,414
Wound care and its complications in patients with EB	-	-	-	-
	<u>192,902</u>	<u>1,191,917</u>	<u>233,979</u>	<u>999,015</u>
<b>Thomas Jefferson University, Philadelphia, USA</b>				
Phase 2 clinical trial of Rigosertib for RDEB SCC	-	470,490	40,984	470,490
<b>Univ. Birmingham Dental School &amp; Hospital</b>				
Characterisation of skin microbiome in EB patients	31,359	296,289	113,500	264,930
Gait Analysis in EB Simplex	15,344	15,344	(11,508)	-
Clinical Fellowship	30,622	65,736	35,114	35,114
Novel spray to treat mucosal scarring	76,201	101,607	25,406	25,406
	<u>153,526</u>	<u>478,976</u>	<u>162,512</u>	<u>325,450</u>
<b>University of Cologne</b>				
Re immunity in wound healing complications RBEB	23,688	164,706	57,462	141,018

Grants to institutions continued:

	2021		2020	
	Total paid in year £	Total paid to date £	Total paid in year £	Total paid to date £
<b>Universitair Medisch Centrum Groningen</b>				
Re phyto-cannabinoid treatment of pain in EB	-	159,025	47,300	159,025
<b>Instituto Dermopatico del'Immacolata Rome</b>				
Re histone deacetylase inhibitors for RDEB	4,627	64,407	32,739	59,780
<b>King's College London</b>				
Preclinical studies of lentiviral-mediated COL7A1 gene therapy	43,394	188,583	84,044	145,189
<b>Great Ormond Street Institute of Child Health</b>				
Respiratory cell & gene therapy for children with JEB	65,844	65,844	-	-
<b>Bambino Gesù Children's Hospital</b>				
MicroRNAs expression profiling, activity and therapeutic perspectives	30,876	45,556	14,680	14,680
<b>University of Edinburgh</b>				
Re Kindlin-1 loss in squamous cell carcinoma	41,379	51,667	10,288	10,288
<b>New York Medical College</b>				
Re innate & adaptive immune mechanisms in RDEB	69,588	104,232	34,644	34,644
Total research grants paid in year	<u>835,941</u>	<u>3,857,132</u>	<u>886,719</u>	<u>3,021,191</u>

# Notes to the financial statements (continued)

## Healthcare projects:

	2021	2020
	Total paid in year £	Total paid in year £
<b>Great Ormond Street Hospital for Sick Children</b>		
Clinical nurse specialists in EB	83,525	66,176
<b>Guys &amp; St Thomas' Hospital London</b>		
Adult EB support nurses	58,388	79,647
Clinical best practice guidelines on parenteral and enteral feeding	-	39,996
<b>Birmingham Children's Hospital</b>	30,755	56,148
<b>Other</b>	12,157	48,108
	<u>184,825</u>	<u>290,075</u>

## 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	<u>548,814</u>	<u>125,948</u>	<u>-</u>	<u>674,762</u>

## Reconciliation of provision continued:

	2020			
	Research grants £	Healthcare grants £	Community Support grants £	Total £
Provision brought forward	1,428,243	186,213	-	1,614,456
New commitments	572,731	241,967	(38,072)	852,770
Co-funding contributions	69,213	-	-	69,213
Spend in year	(886,719)	(290,075)	(38,072)	(1,214,866)
Provision carried forward	<u>1,183,468</u>	<u>138,105</u>	<u>-</u>	<u>1,321,573</u>

## 23. Related parties

During the year, the charity charged management charges totalling £11,300 including VAT (2020: £7,200) to its subsidiary, DEBRA Trading Limited.

# Reference and administrative details

## Patrons and ambassadors

**Royal Patron**  
HRH The Countess of Wessex

**Life Patron**  
Philip Evans

**President**  
Simon Weston CBE

**Vice Presidents**  
Graeme Souness, Frank Warren

## Trustees

**Chair**  
Jim Irvine

**Treasurer**  
Joanne Merchant

**Vice-Chairs**  
David Bendor-Samuel (from 29.04.2021),  
Carly Fields  
Graham Marsden (until 29.04.2021)

**Trustees**  
Simone Bunting (from 27.05.2021)  
Rebecca Cresswell  
Simon Cuzner (until 27.05.2021)  
Josie Godfrey (from 08.08.2021)  
Andrew Grist (until 01.03.2022)  
Christo Kapourani  
Vivien Mundy  
Timothy Powell (until 27.05.2021)  
Douglas Rouse  
Simon Talbot (from 27.05.2021)  
Michael Thomas

## Additional details

**Charity Commission Number**  
1084958

**OSCR Number**  
SC039654

**Company Number**  
4118259

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

**Auditor**  
Sayer Vincent LLP, Invicta House,  
108-114 Golden Lane, London EC1Y 0TL

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

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

# Abbreviations

CPG	Clinical Practice Guideline
CEO	Chief Executive Officer
EB	Epidermolysis Bullosa
EDI	Equality, Diversity & Inclusion
F&E	Furniture & Electrical retail store
GDPR	General Data Protection Regulation
HMRC	HM Revenue and Customs
HR	Human Resources
H&S	Health & Safety
IOSH	Institute of Occupational Safety and Health
IT	Information Technology
k	thousand
m	million
NHS	National Health Service
pa	per annum
SMT	Senior Management Team
SOFA	Statement of Financial Activities
y on y	year on year



DEBRA funds pioneering research,  
specialist healthcare, international best  
practice and lifelong care and support  
to the EB Community.

Our vision is a world where no one  
suffers with Epidermolysis Bullosa (EB).

**Together we #FightEB.**

[www.debra.org.uk](http://www.debra.org.uk)



Patron: HRH The Countess of Wessex GCVO

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