



Trustees' Annual Report and Accounts 2020

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Our vision

A world where no one suffers from the painful skin condition Epidermolysis Bullosa (EB)

Our mission

Provide lifelong care and support to everyone in the UK affected by EB

Our aims

Fund pioneering research for symptom alleviation and ultimately a cure

Provide care and support to the entire EB community

Together we #FightEB



Investing in a future free of EB

DEBRA UK funds:

- Specialist healthcare
- Pioneering research
- Community support
- International best practice

What we do

DEBRA is the national charity supporting those living with or directly affected by EB. We have achieved global recognition as a leader on EB and are the only UK charity specifically aimed at continuously supporting the EB community.

Phyllis Hilton, whose daughter Debra had EB, set up the charity in 1978 as the world's first EB patient support group. We have come a long way since then, working internationally through a network of nearly 50 DEBRA groups to share information and best practice.

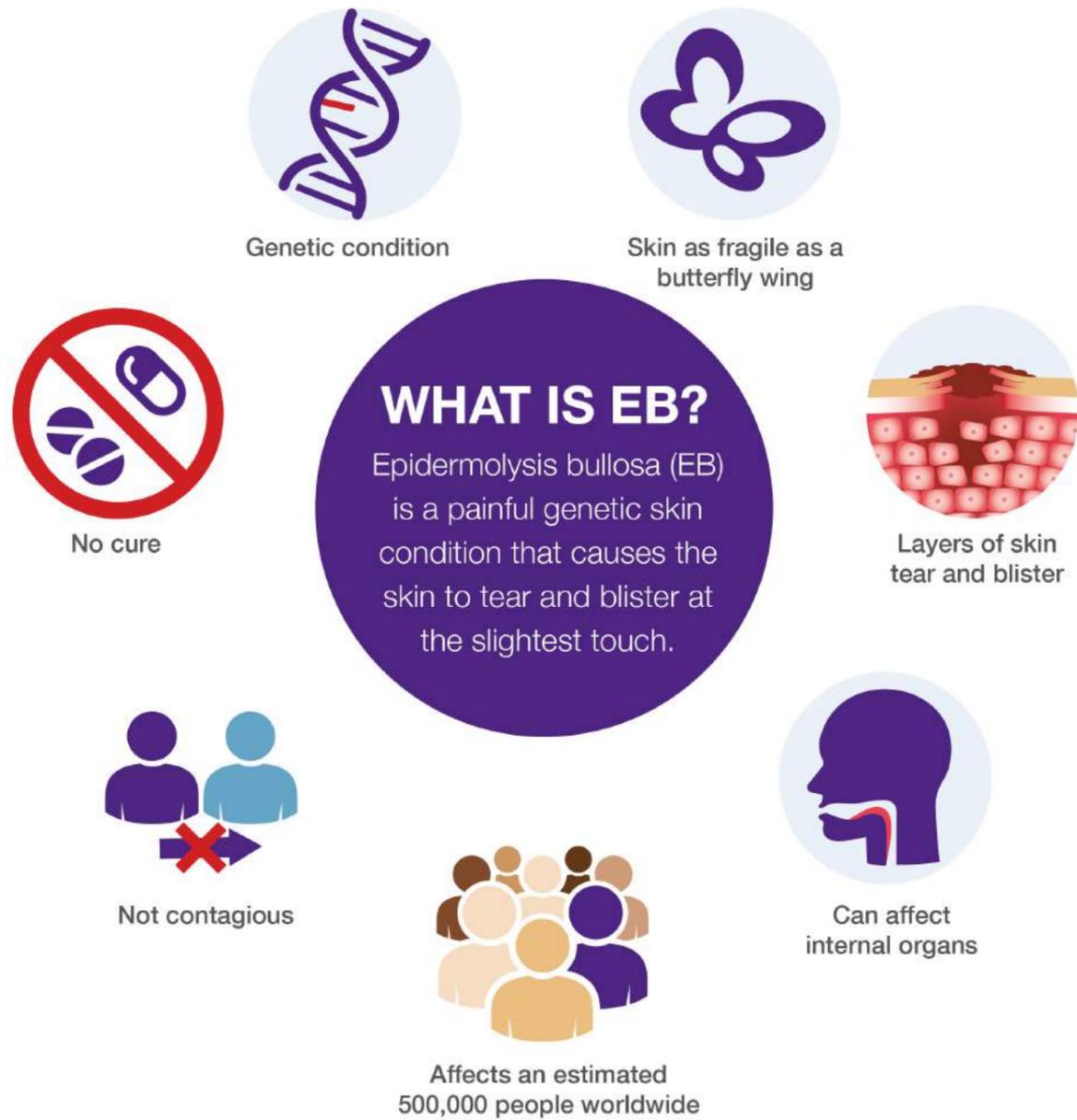
We fund pioneering research, provide specialist healthcare, promote best practice and deliver lifelong support to individuals, families and the entire EB community. Our support includes:

- providing practical, financial and emotional support and advocacy for people with EB and their families
- partnering with the NHS to provide specialist care and clinical care guidelines
- working with researchers to find a cure(s) and alleviate the debilitating effects of living with EB
- investing in our Community Support Team to allow us to share knowledge, skills and experience to empower and enable achievements within the EB community
- expanding and strengthening family health and community support networks to improve quality of care.

Supporting DEBRA – through fundraising activities, direct donations, purchasing items in the retail shops or offering time as a volunteer – has a direct impact on the support we offer the EB community.

While our vision is for a future where no one suffers from EB, until that day arrives we work tirelessly to improve quality of life for the entire EB community.

What is EB?



EB is a potentially fatal skin condition that causes constant pain due to continuous internal and external blistering. With EB, skin is so fragile that it can tear at the slightest touch and for this reason it is sometimes called 'butterfly skin'. There are an estimated 5,000 people affected by EB in the UK and 500,000 worldwide.

In its most severe forms, EB is fatal; even in its mildest forms it can cause lifelong disability and pain. Blisters continuously form and have to be drained and dressed daily, a painful process that can take several hours. Repeated blistering results in the build-up of scar tissue which can cause fingers and toes to fuse together and can mean a higher risk of developing skin cancer. The debilitating effects of EB inevitably impact the mind as well, leading to psychological challenges. EB is currently incurable.



Louise Bellaers Photography

Strategic report

Highlights of DEBRA's services and income generation activities in 2020 and an overview of future plans

Welcome from our Chair



When I was preparing my statement for last year's (2019) Annual Report we were in the early days of coping with the coronavirus pandemic and had just entered the first UK national lockdown. I said then that "the outcomes are currently uncertain and they will ultimately shape our ambitions for the years ahead" and "we are financially strong and fully expect to come through the crisis fully intact". None of us had any real idea back then about how big an impact COVID-19 would, and continues to, have but twelve months on we can start to have a level of optimism that the worst might well be behind us, allowing us to focus on the future once more.

I am delighted to report that, despite a significant hit to our financial strength during 2020, our objectives are unchanged. DEBRA continues to focus on improving the quality of life for those living with all types of EB as we invest in world-leading research towards finding cures.

Our financial strength allowed us to meet our existing research commitments and during the year we approved a further spend of £764,000 on some exciting new projects including investing £191,000 into the biopharmaceutical company FIBRX Derm Inc. Meanwhile, our wonderful Community Support Team had to adapt and learn almost overnight how to provide care remotely. Retail income took a hammering and, with over 300 retail staff and significant lease commitments to meet, we were hugely grateful for the various levels of government support that allowed us to keep our portfolio intact. Fundraising from events had a great start to the year and despite being seriously curtailed from March still managed some real successes. We made real progress in legacies with growth from £185,000 in 2019 to £257,000 in 2020.

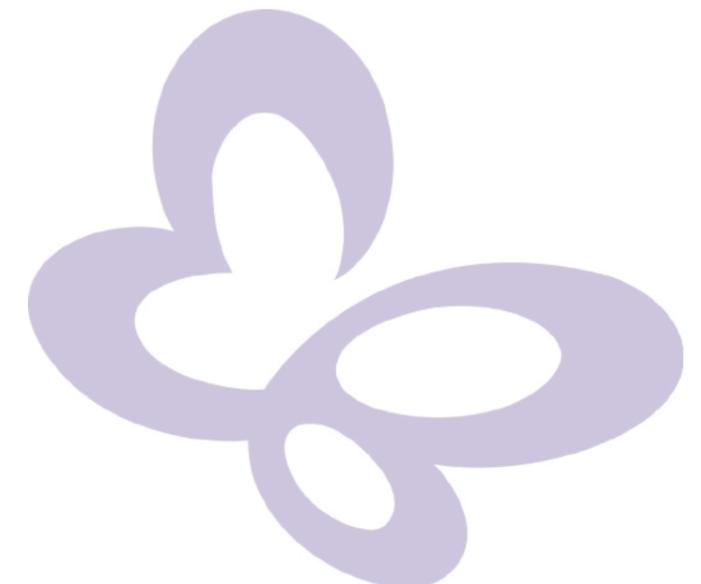
I was hugely disappointed that we had to cancel our Members' Weekend in 2020 but the safety of our community dictated that we had no option. We are committed to restarting that event, and others, when it is safe to do so but in the meantime we will continue to embrace technology that allows us to engage remotely with our community.

The year had started in spectacular fashion with the EB 2020 World Congress, hosted and primarily funded by DEBRA, in London during

January. With 730 delegates representing 215 organisations from 54 countries, it was by far the largest gathering of EB community, professionals and bio-pharma companies that has ever taken place. The conference was a huge success and it is worth reflecting on just how far DEBRA has come since being established as a parent support group in 1978. Under the guidance and governance of our Trustees and with the leadership of our new CEO, Tony Byrne, we are all committed to playing a leading role in collaborating internationally to #Fight EB.

My closing words from last year's statement reflected on the fantastic support we receive from our army of volunteers and the resilience and strength of character of the entire EB community. Those words resonate as loudly today as they did then as we seek to find our 'new normal' and continue to fight, and ultimately beat, EB.

Jim Irvine
Chair of Trustees



Welcome from our CEO



I was delighted to join DEBRA in October 2020, an 'interesting' time to join any organisation. The UK had already undergone one major lockdown and many of DEBRA's team members were working from home or furloughed. In November and then at the end of December we entered the second and third lockdowns, however I was still able to meet team members and the EB community during this time. Most, if not all, meetings have been conducted virtually and I have been impressed by how DEBRA and our members have utilised technology, adapted and met the challenges of the pandemic.

The year has been difficult for our members, colleagues, volunteers and supporters. It has been financially challenging, with our sources of income severely curtailed from the closure of our retail stores and the cancellation and postponement of our fundraising events.

We have been grateful for the continued support of our donors, the support of our fundraisers and the donations received from the limited events we have been able to run in a Covid-safe manner. The DEBRA team have risen to the challenge, with at times over 90% of the team furloughed either full or part-time. They have in these uncertain times worked tirelessly for the benefit of our members.

Our priority focus has always been to support those affected by EB.

Our Community Support Team have reached out to our members through individual phone calls, and virtually via online platforms and through social media, ensuring information and support is always available. We continued to invest £839,000 in membership and community support activities in 2020.

We continued our support for EB nurses with up to 25% of their costs being met by DEBRA and supporting healthcare with a further investment of £347,000.

Our funding of research into cure and care did not cease in 2020: we invested £1.181m in our continued search for answers to cure this terrible condition.

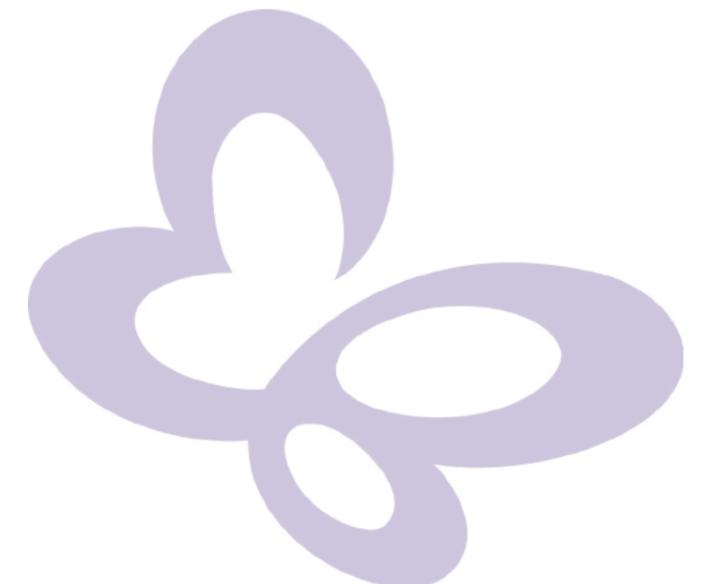
As we look to the future, we have introduced a Management and Performance (MAP) process which aligns our objectives to our business plan and gives clarity and focus on what and how we are delivering against our goals.

We are undertaking a review of our IT systems, our policies and procedures and the way we support and listen to our members and our teams. Our aim is to learn from the pandemic, understanding how it affected the way we work. We will apply this learning to improve our ways of working, to improve how we support our members, colleagues, volunteers and supporters, to help us find better treatments for the care of our members and, ultimately, to find the cure our members need to #FightEB.

Finally, we look back with gratitude. We are so proud of how our staff and volunteers worked together throughout 2020. Our heartfelt thanks go to them, to the extraordinary generosity and commitment of our supporters, the brilliant community of EB specialists and healthcare professionals and, above all, the individuals and families living with EB. Thank you.

Together we will continue to #FightEB in 2021.

Tony Byrne
CEO



Charity overview

DEBRA is the national charity (incorporated in the UK) supporting everyone in the UK affected by EB. We are registered with the Charity Commission for England and Wales, as well as the Office of the Scottish Charity Regulator (OSCR) in support of our Scottish activities that continue to form an important part of DEBRA's UK strategy. The financial statements comply with current statutory requirements, the memorandum and articles of association, the requirements of a directors' report as required under company law, and the Statement of Recommended Practice - Accounting and Reporting by Charities: SORP applicable to charities preparing their accounts in accordance with FRS 102.

Like many charities, our income from our retail shops, fundraising and Gift Aid was affected by the pandemic. Despite this, throughout the year our amazing supporters, volunteers and staff gave us unwavering support. We receive no statutory government funding, but we were able to take full advantage of government incentives such as the Coronavirus Job Retention Scheme.

Our objectives

The 2021-22 Business Plan sets DEBRA's course for the next two years, ensuring it remains on a solid financial footing. In parallel, the Trustee Board and Senior Management Team are charting an ambitious five-year strategy to deliver some significant goals by 2026 including:

- playing a pivotal role in coordinating research into EB, a global exercise with DEBRA front and central in leading the quest for a cure
- reconfiguring how we will care for our members, ensuring they are centremost in our long-term plans
- refocusing our fundraising efforts, recognising that the short and long-term effects of the pandemic mean that there will be less reliance on events and more reliance on building long-term relationships
- building a more efficient and leaner retail function
- increasing brand awareness across all of our audiences
- continuing to develop the skills and knowledge of our people
- ensuring that our operations, governance and risk management are best in class.

Public benefit

DEBRA meets the definition of a public benefit entity under FRS102, s17 of the Charities Act 2011 and Charity Commission and OSCR guidelines. We provide support to people across the UK living with any type of EB, as well as family members and carers of someone who has EB and those working within the EB community in a professional capacity.

Members affected by EB are encouraged to engage with us to further develop our services and the

support available. This includes through taking part in satisfaction and service development surveys, group discussions as well as the DEBRA patient panel made up of members of the EB community who help review research projects.

Our Care & Research Committee makes strategic and fundamental recommendations on the charitable activities undertaken by DEBRA for the benefit of sufferers of any type of EB.

The Trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning its future activities. In particular, the Trustees consider how planned activities will contribute to the aims and objectives that have been set.

“ My son Jamie has generalised severe EB. He was born with no skin on his feet, knees and hands and even where there was intact skin, it blistered. It was so hard to bond - I didn't hold my baby for the first six months. He is the first person in my family to have EB so it came as an enormous shock.



The most difficult thing about EB is seeing your child in pain, knowing that the care you are giving is causing so much distress. The community support I have received from DEBRA has been outstanding and makes a real difference. ”

Katie White, mother of Jamie White living with EB



In 2017 Simon and Karen Talbot lost their son Dylan to Junctional EB aged 3 months and 1 day.

“ In 2018, we learnt Karen was pregnant. EB is inherited and we were both carriers of the gene and this meant it was likely our baby would have the same type of EB Dylan had. Thanks to advances in EB research and funding from DEBRA, we were able to test our baby for EB before she was born. Knowing we would not have to see our new-born go through the same pain and distress Dylan did was a massive relief. Our baby girl was born on 4 November 2018, EB free. We named her Katie Rose Talbot after the EB Nurse Specialist at Great Ormond Street Hospital – Katie Plevy. She was such a big part of family life with Dylan that we wanted her to be forever part of our family. Rose is also Dylan’s birth month flower, so her name is very special. ”

Simon & Karen Talbot, EB parents

Pioneering research

Despite concerns surrounding the pandemic, we were able to approve a total of £764,000 for research projects in 2020, spending £573,000 on new research projects and investing £191,000 into the biopharmaceutical company FIBRX Derm Inc., which is researching an EB therapy.

We continue to be strategically focused on investing in pioneering research to find cures and treatments for EB that will significantly improve quality of life.

Research strategy

Our research strategy of striving to achieve cures, manage symptoms and improve quality of life has been maintained within the expanding global focus on EB research. We continue to invest in research into clinical, scientific and pharmacoeconomic endpoints that will support the regulatory pathways for treatment approvals in the future.

The current portfolio of research projects includes pre-clinical laboratory work, research into gene and cell therapies and drug re-purposing, as well as projects driving a change in symptom relief for wound healing and cancer therapy. It is critical to ensure there is a balance of research into all types of EB represented in our community. We also support fellowships, helping to develop and shape our researchers and clinical experts for the future.

Key areas

Developing a novel gene technology for EBS treatment

We are proud to continue funding the ongoing work by researchers at the University of Dundee, including a DEBRA Clinical Research Fellow. This pre-clinical study aims to develop methods for using gene silencing technology as a therapeutic option in clinic for people with Epidermolysis Bullosa Simplex (EBS). There are also hopes for wider application for other types of EB.

Defining relevant clinical endpoints

Since 2013, we have committed £735,000 to a project that aims to better understand the progression of Recessive Dystrophic EB (RDEB) by identifying and defining relevant clinical endpoints that could be measurable target outcomes for EB clinical trials. This work is ongoing, and it is hoped that it will ultimately help future clinical trials for all types of EB.

Investing in industry for potential treatments

In 2020, we made our first investment into a biotechnology firm, FIBRX Derm Inc. in support of a study that aims to continue research (originally funded by DEBRA) investigating a naturally occurring protein that may serve as a viable anti-scarring therapy for people living with DEB (Dystrophic EB) and which could be administered topically. The company has received financial support from the US Department of

Defense and multiple EB groups across the world, supporting our desire to take the lead in international collaboration.

Understanding immunity and fibrosis

DEBRA UK and DEBRA Ireland have committed to co-funding research to evaluate the inflammatory response in people living with RDEB. This study is investigating the sequence of immune responses to understand how chronic inflammation and fibrosis develop with the aim of identifying potential treatment options.

Understanding cell behaviour to help determine potential therapies

Ongoing research funded by DEBRA UK aims to understand the mechanism of how TGF- β (protein) signalling can lead to cancer migration, invasion and tumour growth, as well as identify how the molecular characteristics (biomarkers) of TGF- β behave in RDEB skin cancer, both of which may help to determine potential therapies.

Driving research globally

The EB World Congress, the flagship global conference on EB, was organised and majority funded by DEBRA UK with contributions from other EB groups. It was held in London at the end of January 2020 and attended by more than 700 individuals including key stakeholders from industry, researchers, clinicians, patients and EB groups. The inaugural Congress was more than double the size of any previous international EB research/care conference. The data presented represented the latest in research and clinical management. All other EB research funding bodies participated and over 20 biotechnology companies sponsored and attended the meeting, all with a focus on cures, treatment and management strategies for the EB community.

We welcome partnerships and collaboration with other EB organisations under the mutual aims of finding cures for the EB community. Communication and coordination are critical to the success of continued international research projects, both in direction and funding.

2020 Research by numbers

- £573,000 committed to new research projects
- £608,000 spent on other research activities
- £191,000 invested in a biotech company
- 19 ongoing research projects funded by DEBRA UK
- £8.1m spent on research grants over the last 10 years
- 7 projects co-funded with other DEBRA groups and one with a pharmaceutical company

Looking to the future

We recognise that the support of a wide range of research into cures and treatment is critical to achieving our aims. As such, we will continue to use expert summits to identify new research opportunities. Due to the pandemic, we were unable to participate in the autumn 2020 grant round for funding EB research projects; however, we plan to continue proactively identifying projects and developing and enhancing our funding strategies for the future.

Working hand in hand with industry and academia is key to bringing research developments into routine clinical practice, paving the way for health and technology assessments.

Our research aims for 2021

- Invest circa £250,000 in research projects in 2021 to help maintain our ongoing project portfolio, with a view to increasing investments where possible.
- Focus on the translation of pre-clinical research into early phase patient studies identifying suitable treatments for cures and control of EB, as well as symptom relief and treatments that will impact positively on quality of life.
- Link our research strategy of striving to achieve cures, manage symptoms and improve quality of life with DEBRA International's research strategy.
- Continue to proactively identify core areas for research and enhance the EB clinical and research community.
- Champion communication, co-ordination and collaboration to ensure a coherent approach to EB research globally.
- Work with other EB groups to co-fund future research that provides continuity for currently funded research.

“ I was first introduced to the traumatic plight of EB sufferers several years ago and I felt compelled to contribute to the global research effort dedicated to developing treatments for patients ever since. EB is an excruciatingly painful skin blistering disorder that is inherited and affects children from birth. The more aggressive forms of EB are further complicated by the onset of dangerous life-threatening skin cancers which are very difficult to effectively treat.



It is vital that we raise both awareness of EB and funds to develop new treatments to alleviate the suffering that both patients and their families currently have to bear. ”

Professor Gareth Inman, CI UK Beatson Institute, University of Glasgow



International collaboration and best practice

EB is a condition that can affect anyone in any part of the world. Therefore, international collaboration and coordination of research and projects are vital in developing effective treatments and potential cures for EB. We work closely with other national DEBRAs as well as with external groups to ensure our research efforts are effectively coordinated and best practice information is shared with all relevant parties – including researchers, clinicians, other charities, pharmaceutical companies and biotechnology organisations.

Collaborating at the international level

Our strategy for international collaboration is to:

- build on the success of the flagship conference, EB 2020 World Congress
- improve international clinical care practices by developing and maintaining an up-to-date multi-lingual library reviewing all existing literature and detailing current best practice treatment and care for all aspects of EB
- improve clinical care through developing clinical networks, sharing knowledge and training
- raise awareness of EB and the care required by advocating on behalf of the UK EB community and membership
- ensure that all DEBRA funded research is peer reviewed by the DEBRA Medical & Scientific Research Panel
- improve joint working on communication, campaigns and projects
- review possible partnerships with promising biotech start-ups on a case-by-case basis.

Key areas

Coordinating international research projects

DEBRA UK is a founding member of DEBRA International, our umbrella organisation with nearly 50 members groups in other countries that aims to ensure all EB research and care activities are coordinated worldwide where possible. We work alongside DEBRA International to manage the Research Involvement Network, which aims to inform members of developments in EB research and promote its importance and opportunities for patient involvement.

Enhancing global EB care and best practice

Alongside other members of DEBRA International, we assist in the development of an international EB Patient Registry and Clinical Practice Guidelines (CPGs). Aimed at clinicians, these guidelines are often citable articles published in professional journals. Most guidelines are now also available as patient versions, which are written to help people living with EB to understand and implement the guidance and

advice, and some have been translated into other languages. In 2020, we committed funding to three new CPGs – CAIMS (Complementary & Integrated Medicines), Palliative Care and Neonatal Care.

Raising EB awareness around the world

Working with DEBRA International groups, we aim to raise the profile of EB significantly in the coming years through integrated and coordinated awareness campaigns. As an example, in 2020, in collaboration with DEBRA International, we developed a simplified 'What is EB' infographic that was shared with and used by other national DEBRA groups during the global 2020 EB Awareness Week campaign.

Enhancing clinical and research knowledge

We annually fund training grants through the Professor Robin Eady Grant fund to assist clinicians and researchers in furthering their professional development and their interest in the field of EB. The pandemic prevented us from awarding the grant in 2020 due to global travel restrictions and constraints on clinicians' time, which meant that professionals were unable to attend in-person meetings and training events. In 2021 we plan to support more virtual international training events and meetings.

Significant partnerships

We support a small number of international projects and contribute to the running costs of DEBRA International through a subscription as well as giving time and expertise to support DEBRA International. DEBRA UK ensures good value is received from DEBRA International's activities with progress reports outlining delivery of DEBRA UK-funded projects.

DEBRA International coordinates the CPG programme and manages the EB Without Borders (EBWB) group, a collaborative effort to assist EB sufferers in need around the world, particularly in locations that do not have a national DEBRA organisation. DEBRA UK and UK clinicians work closely with the EBWB Team on a referral basis.

International by numbers

- Some 50 national DEBRA groups established around the world
- 420 Members of the Clinical Practice Guidelines Network
- 602 individuals in the DEBRA International Research Involvement Network
- 8 international CPGs funded by DEBRA UK
- 17 global EB research sites funded by DEBRA UK
- 3 national DEBRA groups co-funding research with DEBRA UK

Looking to the future

Working with DEBRA International, DEBRA UK plans to bolster its activities through further funding of services, particularly with the development of international CPGs and the international EB Patient Registry.

Our international collaboration aims for 2021

- Continue joint funding the development of international CPGs.
- Participate in the development of international research strategy and discussion with all EB charities.
- Improve joint working on communication, campaigns and projects that can be of benefit to the global DEBRA community.
- Work with other research groups to ensure information sharing and to prevent duplication.
- Ensure information on research is easily available to members, professionals and industry.
- Consider plans for the next EB World Congress event.



Specialist healthcare

We provide funding to deliver a UK-wide specialist healthcare service for people living with any type of EB. This service is provided in partnership with NHS England's Specialised Services Commissioning Team and NHS Scotland who fund the core (NHS duty of care) clinical service.

EB Centres of Excellence

There are four designated EB Centres of Excellence in the UK based at hospitals in Birmingham and London: Birmingham Women's and Children's Hospital, Solihull Hospital, Great Ormond Street Children's Hospital and St Thomas' Hospital.

Multidisciplinary teams consisting of DEBRA Community Support Managers, consultants, EB nurses and other specialist healthcare professionals meet at these centres to provide the high levels of expertise required to care for people living with EB.

Key areas

Podiatry

Even in its milder form, EB affects the hands and feet of most sufferers, yet there is very little awareness among the podiatric community about the condition. To address this, in 2017 we committed £105,000 over three years to fund the development of an accredited EB podiatry training course, as well as a full training programme across the UK, enabling people suffering from EB to receive more expert care and improve their quality of life. In 2019, the first training course took place in London and the EB podiatry network was established. However, due to the coronavirus pandemic, further training and development of the network has been on hold but will restart in 2021.

Clinical teams

The pandemic placed enormous pressures on all clinicians across the UK in 2020. Yet the teams worked immensely hard to ensure a specialist EB service remained accessible, even when those teams were on standby or were redeployed to help the fight against the pandemic. A combination of virtual and in-person clinics and care were offered and teams continued to provide specialist EB training to enable professional development, and knowledge and experience in the field of EB, to be maintained at the highest standard within the wider healthcare practice.

Nursing

Our funding of the two paediatric designated Centres of Excellence continued in 2020 with the funding of an additional two-year fixed-term nursing post at each location. Following multiple retirements and vacancies, this funding will support the establishment of the new teams and ensure that they have the time to undertake the required clinical specialist training. These posts have also assisted with providing care to an increasing number of patients at each centre.

“ EB certainly runs in my family. My dad was in the army but got a medical discharge during the war due to EB. My brother has EB as does his daughter and her three children. And my daughter also has it. Back then EB was just called blisters. My symptoms were the same as my dad's and when it got bad dad would use a needle and wool to burst the blisters on my hands and drain them. The treatments for EB have really improved over the years. When I was younger, my feet were saturated in blisters and the podiatrist used a rough scrubber to remove the skin. He had no idea what EB was. Today of course we have specialist bandages and creams to ease the pain. I was introduced to DEBRA by one of my doctors at St Thomas' Hospital. DEBRA has really helped me. I finally had some support and I got to meet and speak to people who knew about my condition and what I was going through. People ask me how I have coped with such a painful condition, but you just get on with it. You can't let anything beat you. ”

Terry Cook, living with EBS

Rare Diseases Centre

The Rare Diseases Centre at St Thomas' Hospital (supported by £250,000 of DEBRA funding) continues to greatly enhance the clinical facilities available to the EB community and enable the development of multi-disciplinary working. These facilities have enabled the operation of virtual clinics and have reduced movement across clinical settings as the centre has multiple facilities including a small skin surgery room. We continue to support all the UK's EB Centres of Excellence through lobbying and/or funding to ensure that the appropriate facilities and equipment are available for all EB patients.

Healthcare by numbers

- 2,000 patients supported by EB specialists
- 100 days of specialist dietitian services
- 10 clinical supervision workshops
- Up to 25% of specialist EB nurses' costs covered by DEBRA
- £347,000 spent on healthcare
- 18 different TV grants covering 141 inpatient days
- 14 specialist EB training days

Looking to the future

We will continue to review our support plans to meet the changing needs of the EB community and to address the uncertainty caused by the pandemic.

Our healthcare aims for 2021

- Encourage and support innovative clinical practice and service developments that will enhance the lives of those affected by EB.
- Update and enhance the range of information and publications and improve the accessibility of information available to members and healthcare professionals.





At the start of the coronavirus pandemic, our Community Support Team arranged immediate delivery of a free emergency food parcel and found a supplier able to provide Scott with regular food delivery slots. They investigated local sources of PPE for his carers and had a delivery confirmed for him within 48 hours. They also asked him if he would work with DEBRA to create a motivational video showing other EB sufferers how to cope with isolation, and help Scott himself feel more connected.

“ I am in self-isolation, in fact strict “shielding” and can’t leave my home because of my condition, EB. Without DEBRA’s emergency food package I would be without food. They helped to set me up with a local food service long term and arranged a food package immediately to stop me from going hungry before this service was in place. I cannot thank them enough. ”

Scott O’Sullivan, living with RDEB

Lifelong community support

We provide membership and specialist community support services to people across the UK. Liaising directly with members of the EB community is vital to understanding the needs of EB sufferers and those impacted by the condition.

Engaging with the EB community

We consistently request and review feedback from our members through surveys, focus groups and general meetings. Some of the topics include programme requests for member events, new projects and publications. The 2020 virtual member groups identified that members like what we are currently doing but would like us to increase or improve peer support, sharing of research updates, printed materials and website content and functionality. These requests are all within our plans for improvement.

Key areas

Information and liaison support

We are committed to delivering support to improve quality of life for the EB community.

We offer a range of benefits to our members and support from a dedicated, expert team which can advocate and advise on topics from welfare rights reform, housing and employment to education and independent living. These services are provided based on feedback received from the EB community. We continue to focus on contacting people suffering from EB who are not taking advantage of the services to enable them to do so.

When the pandemic started early in 2020, the planned development of the Community Support Team and additional activities were postponed in order to focus on supporting members’ immediate needs within the funding available. Members with severe EB received a well-being call and all members received an email or letter to ensure they had the support they required as we entered lockdowns at the start and end of the year. Throughout the remainder of 2020 the team continued to offer a service across the UK, predominantly remotely but where necessary in person. At times, a number of team members were working reduced weekly hours and were placed on flexi-furlough but all urgent and essential requests for support were fulfilled.

Support grants

We provide support grants to members for emerging needs and to assist in covering costs for basic quality of life improvements, such as white goods and new-born baby goods. In addition to DEBRA support grants, the Community Support Team have successfully helped members of the EB community to access financial support from other sources.

Community events

Instances of members of the EB community feeling isolated and alone increased in 2020 due to the impact of the pandemic. We responded by providing opportunities across the UK for our members to meet, share experiences and learn how others manage the condition. As all in-person events were cancelled, a range of virtual groups were quickly set up to facilitate peer support, share insights and information and engage with members. This helped us to gain an understanding of current needs and prioritise the work of the charity. The virtual meetings were well received. In some cases, they helped develop IT skills and confidence to use technology for keeping in touch with family/friends and on-line shopping which was important due to the restrictions caused by the pandemic.

Respite care

Having the opportunity to go on holiday may be out of reach for many people within the EB community because of cost or lack of adequate specialised facilities. At times during 2020, all of our holiday homes were closed in line with government rules. Some members were apprehensive about travelling and the uncertainty of the situation. However, despite this, 71 weeks of holiday were taken by 478 members in 2020 in the six DEBRA holiday homes. In September one of the holiday homes at Weymouth was sold for trade use as it had reached its maximum age. Feedback from members continues to be very positive about all homes, the range of locations and their facilities.

Significant partnerships

We work with, and are members of, other organisations – including DEBRA International, Disability Rights UK and Carers UK – to enhance the services available to the EB community.

Community support by numbers

- 1,195 individuals accessed the DEBRA Community Support service
- 1,078 Covid well-being calls made to members
- 154 support grants awarded to value of £24,000
- 76 virtual members groups held
- £839,000 spent on membership and community support activities
- 3,279 individuals in the free DEBRA membership scheme
- 71 weeks booked and enjoyed by 478 members in DEBRA's six holiday homes

Looking to the future

We will continue to review plans postponed from 2020 and the changing needs of the EB community caused by the pandemic. We plan to increase engagement with our members. This will help shape care and support service developments and improve membership benefits with more regional/local events (virtual and hopefully in-person towards the second half of the year) providing greater opportunities for peer support and sharing information.

We will review and develop our publications and the use of multimedia to improve the sharing of information. We plan to develop a more detailed understanding of the EB community to help achieve a more proactive service and to maintain the aspects of the remote service that have worked well for members and the team, alongside in-person activity.

The search for a new holiday home for 2023 will begin. We will continue to deliver a support and membership service with the current team, prioritising urgent and essential support if the membership grows or if the demand for support increases.

Our community support aims for 2021

- Provide a professional membership and community support service to members of the EB community across the UK.
- Develop the Membership and Community Support Teams to meet current and future needs that may arise as a result of the coronavirus pandemic – for example if unemployment rises the need for support regarding benefits is likely to increase.
- Ensure that sufficient funds remain available within the support grant budget allowing for the projected rise in applications for urgent and essential goods and services.
- Encourage and support innovative research projects and service developments that will enhance the lives of those affected by EB.
- Review the membership model, increase membership numbers, diversity and engagement of members and undertake a survey of service satisfaction.
- Facilitate an enhanced range of virtual peer support and membership activities including virtual member events and AGM.
- Explore the opportunities available to set up a volunteer befriending network.
- Publish a report on the achievements and support available for the EBS community.
- Publish a report on the non-medical achievements and support available to members of the EB community, positioning us as the go-to EB charity and engaging new and current audiences.

“ Life came to an abrupt end for me because of the virus. One day I was working, the next I was not able to go out due to my EB. I struggled to get food and my income suddenly stopped. I was scared and didn't know what to do until Amelia called. Her support meant everything. She arranged a food parcel and helped me get financial support, I now feel mentally and physically much better. ”

Inderjeet, DEBRA Member



The first Covid-19 lockdown left Sharon needing a new focus, so she decided to give some of her time to volunteer at our store in Winstanley.

“ During the Covid-19 lockdown I was unable to work as a freelance children’s entertainer, actor and music researcher. I needed to do something productive and confidence boosting so, as soon as my favourite local DEBRA shop reopened, I signed up as a volunteer. I have learned many new skills, made new friends and enjoy serving customers. I like to get creative with shop displays. I get a real sense of achievement from volunteering. ”

Sharon Lowe, Volunteer DEBRA Winstanley

Our retail stores

Our retail stores transform unwanted goods into funds for life-changing support and research to help our commitment to fighting EB. The pandemic had an enormous impact on our retail income in 2020. However, despite the challenging conditions faced by retailers in 2020, our sales performance after lockdown was more resilient than we expected, both in terms of sales and stock generation.

From a business perspective, the pandemic has been hugely disruptive, but there has been much to learn from the experience. The unexpected slowdown in our operations has given us the time and the motivation to accelerate our efforts to strengthen our portfolio, people and infrastructure, creating new opportunities and efficiencies in a rapidly changing world.

Key areas

Impact of the pandemic

As the scale of the COVID-19 outbreak became clear early in the financial year, we took the difficult but necessary decision to close all our retail outlets as of 22nd March 2020. Many of our colleagues, volunteers and supporters are in the high-risk category, and the safety of our people will always come first. With no retail income coming into the business due to successive lockdowns and to protect jobs in the long term, over 95% of retail colleagues were furloughed. Despite the welcome financial support from the UK Government, with a phased reopening of our shops and our small online operations starting in June, retail profit for 2020 was severely impacted. Gross retail income, including donations received in our stores and income from the Coronavirus Job Retention Scheme, decreased by £4.5m.

Restructure

The additional pressures on retail caused by the pandemic have meant that reducing operational overheads where possible has never been more important. As part of an internal review of operations, a limited restructure of the Retail Department was undertaken to merge the management structures of Traditional and Furniture & Electrical (F&E) stores. We have numerous examples of F&E stores being successfully managed through the Traditional management structure at DEBRA. The restructure gave us the opportunity to balance the workload across management teams, create greater service flexibility and align operational areas to maximise present and future efficiency. The restructure has proven extremely beneficial for the Retail Department and in support of our work.

Sustainability

We are working hard to develop a long-term sustainability plan and to significantly lower our carbon footprint. Our 109 charity shops help to prevent tonnes of textiles and furniture going to landfill each year. Alternatives to plastic for carriers are being trialled to reduce the number of single use plastic bags across our retail outlets.

Estate

At the end of 2020, our portfolio consisted of 109 stores. The current portfolio is made up of four freeholds, 91 leaseholds and 14 temporary shops.

Significant partnerships

This year we have continued to grow our existing partnerships while trialling new partnerships and finding innovative ways of working with other brands. Moving forward, we plan to expand our online partnerships by working with various online pre-loved platforms to test selling our items to a younger audience, who are already engaged with shopping second-hand.

There will be a continued focus on developing our engagement and relationships with both corporate and local supporters to enhance the performance of DEBRA Retail and overall charity awareness.

Retail by numbers

- 109 shops at year end
- £553,000 received through the Retail Gift Aid Scheme
- Approximately 800 volunteers with almost 200 new volunteers signed up

Retail Gift Aid Scheme

In addition to the impact on trade this year, shop closures, social distancing and the need for contactless donations have also greatly impacted Gift Aid capture within stores across the country. Together with retail donations, this represented a total income of £606,000.

Our team

We continue to recognise the vital requirement for dedicated volunteers and staff and understand that our retail chain would not succeed without this support. We are continually looking to improve the experience of working and volunteering in our stores.

We know that in order to fight EB, we need a talented and ambitious community of people working in our stores and are focusing on key areas to make this happen. These areas include unlocking our people's full potential, ensuring the provision of excellent training and induction programmes and a safe and trusted environment for all.

Our average volunteer numbers within Retail remain significantly lower than the sector average. The success of our stores depends greatly on our volunteers. Therefore in 2021 we will continue to place a strong emphasis on volunteer recruitment for our stores. We want to encourage people, with a diverse range of skills and backgrounds, to consider volunteering for us.

Looking to the future

The existing and unpredictable trading conditions have highlighted the need to maximise our organisational flexibility and to respond effectively and positively to changing circumstances.

We will continue to review our operating model and central costs to permit a more effective and efficient management of the Retail department, enabling us to focus on areas that generate the greatest level of contribution.

The lack of a mature e-Commerce operation is viewed as one of the key components affecting income performance when benchmarked with the sector.

Our retail aims for 2021

- Continue the significant improvements in margin and contribution made before the pandemic with a strong focus on existing store optimisation and profitability.
- Continue with the planned series of refurbishment projects within stores that we put on hold during 2020.
- Ensure we have a stable and well-trained workforce and increase overall volunteer numbers.
- Continue to invest in training for our shop teams, focusing on product and productivity while continuing to provide training and resource to ensure a safe retail environment for all staff and volunteers.
- Deliver enhanced and structured training and induction programmes throughout all areas and consistent Health & Safety management and compliance across all stores.
- Continue to identify and pursue cost savings which support bottom line growth, looking in particular at lease negotiations, distribution costs and facilities management.
- Continue to work towards reducing the requirement for single-use plastic within our shops.

September 2020

DEBRA Patron HRH The Countess of Wessex volunteered at our newly opened store in Martins Heron, Bracknell, Berkshire to support the individuals and families living with EB.

The Countess volunteered alongside DEBRA volunteers and staff, and had a busy morning sorting donations, pricing stock and helping to serve customers.





How we raise our funds

Supporting the EB community

As a charity we are reliant upon our fundraising activities to deliver our charitable objectives. Everything people do to help support us – from hosting a fundraising event to donating directly – positively impacts the EB community. Our Fundraising Team strives to raise as much money as possible to help support our work and to fight EB. Those funds support our commitment to making a difference today through our healthcare and EB Community Support services, as well as working towards a better future through international collaboration and funding of pioneering research projects.

Our fundraising mission

Our traditional fundraising efforts include hosting a portfolio of high-quality major events as well as supporting individual fundraisers, applying to major trusts and grants and partnering with businesses for charity of the year status.

In 2020 we were unable to do much of what we had intended as our events programme was effectively put on hold by the pandemic in March. We are very thankful to our loyal supporters who responded to a series of appeals throughout the year to raise funds in support of our continued services to members.

Key areas

Trusts

We are grateful to the many grant making trusts that have supported us in 2020. These include the Patricia G. and Jonathan S. England Fund which has made a long term support commitment to DEBRA; the Peter Harrison Trust which has made a three-year commitment to supporting children with EB in the South East of England; the VTCT Foundation which has funded the changes to our website; the National Lottery Community Fund which funded all of our community support for three months during the height of the pandemic; and the Robert Luff Foundation which made a donation to support our research projects. There are many more whose support has been vital.

Major events

Thanks to the generosity of Michel Roux Jnr and the team at The Langham Hotel we were able to stage a successful Great Chefs Dinner in February. This was followed by a very successful Old Firm Dinner in March in Glasgow, with the generous support of our Vice President, Graeme Souness. Despite the difficult circumstances, our Events Team were able to run one more event, a Covid-secure shoot at E.J. Churchill Shooting Grounds in September.

Fundraising with the EB Community

We are very grateful to the number of people who took part in various challenges during the first lockdown of 2020 to raise funds for people with EB. Many of the EB community undertook their

Graeme Souness, our Vice President, united Scottish sports personalities under one roof for the Old Firm United to Fight EB event in March and helped to raise over £112,000 for vital research funding.

“ I am delighted to be Vice President because I am in a position to bring this charity to the attention of a number of people who will be able to make a real difference. I was appalled at just how cruel and painful the condition is – more people need to know about EB. If I can generate the sort of passion that I feel for this cause from a few people that I know then we could make a huge impact on the research into EB – research that not only will help those living with this now but could even lead to a cure. ”

Graeme Souness, DEBRA Vice President

own activities to raise money including sporting, walking and cycling challenges, while there was overwhelming support for the 2.6 Challenge that finished in May.

The DEBRA Golf Society

The Golf Team worked hard to ensure we were able to re-schedule and run 14 Covid-secure golf days in 2020. Numbers were limited due to social distancing and club restrictions but to realise a net income of over £77,000 was very impressive.

Appeals and legacies

The continued support of all who responded to our various appeals throughout the year was very positive. With so much of our fundraising being postponed we were reliant on donations. These included the Coronavirus Emergency Appeal in May, The Big Give and the Christmas Appeal featuring baby Ray in December. We also received multiple donations after a re-showing of the powerful documentary ‘The Boy Whose Skin Fell Off’ on Channel 4. We were also very fortunate to receive the support of a number of people who were kind enough to remember DEBRA in their wills.

Significant partnerships

We are extremely grateful to our Patron, HRH The Countess of Wessex, for her continued support throughout 2020 and to our President, Simon Weston CBE and Vice Presidents Frank Warren and Graeme Souness. We have also been fortunate to be able to count on the continued backing of a number of very generous supporters during these challenging times.

Fundraising by numbers

- £77,000 net income from the DEBRA Golf Society
- £267,000 net income from individual donors
- £444,000 net income from legacy and trust donations
- £946,000 overall net fundraising income in 2020, compared with £1,671,000 in 2019

Looking to the future

The pandemic will continue to have a significant effect upon income generated for the charity in 2021. However, our experiences in 2020 have shown us that with a ‘can do’ attitude we can progress with events such as golf and shooting. We hope fundraising dinners will return in the last quarter and we have plans to put on some exciting events – especially with the support of our Vice Presidents. We have made considerable efforts to manage relations with key supporters closely over the last four years and this will stand us in good stead to recover from the lasting effects of the pandemic. We will continue to rely on the support and goodwill of our many supporters to help us get through this uncertain time.

Our fundraising aims for 2021

- Deliver a professional and profitable programme of events when it is safe to do so.
- Utilise the events programme to progress relationships with major supporters, current corporate supporters and sponsors.
- Work with our major supporters to leverage funds from their pledged support.
- Empower people to continue to raise money for us and support those with a close connection to EB to raise funds in their local communities.
- Raise awareness of the importance of legacies and the difference they make to enable us to support the EB community.
- Invest in our Trust Application Team.

100km challengers

Amy Coote has EB Simplex and challenged herself to cycle 100 miles a day around Lincolnshire after the 2020 RideLondon event was cancelled due to COVID-19.



“ I have loved training to complete the event for DEBRA UK, even though the main RideLondon was cancelled. Cycling has now become a passion of mine for sure and it hasn’t affected my EB Simplex once. ”

Hannah West, who took on the 100km challenge went the extra mile and dyed her hair purple in support of DEBRA.



“ EB has a huge impact on my family. My eldest daughter Charlotte has the condition and not a day goes by when she doesn’t have a new injury to her skin which is really debilitating. The support DEBRA offers our family is outstanding. Through DEBRA, Charlotte has met other children with EB and has made some firm friends who understand what she is experiencing day to day. We were really excited to participate as a family in the #FightEB 100km challenge. It’s wonderful to be able to show our appreciation to DEBRA and to raise awareness of this awful condition. ”



Raising awareness

Public awareness of EB is low when benchmarked against conditions that have a similar number of people affected. A YouGov poll undertaken for DEBRA UK in 2020 revealed that 10% of UK adults surveyed had heard of EB. The level of awareness rose to 13% when given a description of EB. Conditions with similar numbers in the UK such as Motor Neurone Disease had a significantly higher level of awareness at 91%¹.

Raising the awareness of EB, the profile of DEBRA and the work of the charity is a strategic priority within our five-year plan. We need to ensure all families living with EB have access to information, advice, support, advocacy, latest news and best practice. We need to ensure that the public are informed and engaged, creating greater understanding for those living with the condition, more widespread EB expertise and support for our income generation to enable us to fund vital research and care.

Key areas

Engagement

Our priority during the pandemic was to continue to connect with our community providing frequent information, advice and support and to support income generation to engage with our current supporter base and raise awareness for the gradual reopening of our retail stores.

Communication with our audiences quadrupled and media activity increased with the introduction of a new PR & Content role. We achieved a significant increase year on year in reach and engagement on social media and website traffic through additional digital expertise, more engaging content, focused messaging and specific campaigns targeting the EB community, healthcare, volunteers, retail and the general public.

We introduced new online campaigns to recruit volunteers, reach supporters and generate an increase in stock donations for the charity shops. The trial of a new digital initiative was launched to build a community of brand advocates, connecting with customers on local social media and putting the charity shops at the heart of their local community.

Raising awareness would not be possible without the help of the EB community and supporters who share their experiences of living with EB. Our EB Awareness Week campaign in October focused on a 'back to basics' approach with infographics and communications to explain 'What is EB' and sharing the emotive and inspirational personal illustrations of our EB ambassadors through 'What is EB to me' videos, blogs and social media posts. We reached over 1.1m people on social media through this effective, low-cost campaign.

“ The worst thing about EB is the pain. The pain is incredible. I have to take so many painkillers every day – sometimes paracetamol and ibuprofen, sometimes the medication is so extreme it puts me to sleep. Then there's the itch. Some days there is no itch at all and sometimes I have days where I just can't stop itching. And there is normal stuff like eating. I can't eat hard foods, like crisps, because that creates blisters in my mouth. The EB nurses are amazing. They know everything – without them, I probably wouldn't know what to do with all the creams and dressings I have to put on every day to protect my skin. My skin scarring, the fusion of my fingers and the depletion of my skin tissue all increase as I get older which will make life even trickier for me.

I want to find a cure for EB if DEBRA hasn't found one by the time I'm old enough to be a doctor. I have big plans. I want everyone to understand what having EB really means. We all need to be better educated. ”

Fazeel Irfan, living with RDEB

Digital and brand development

Through grant funding we were able to begin the development of a new website in quarter three – a critical factor in improving the positioning of the charity and the effectiveness of its online communications. Progress was delayed during lockdown while staff were on furlough.

A planned brand review project was also paused, but in the interim, we took the design refresh in-house, standardising branding and tone of voice throughout our publications and digital communications and revitalising messaging and signage across the retail stores.

Looking to the future

Since the charity was set up in 1978 it has become known for its commitment to investing in EB research, healthcare, support and best practice.

Our aim is to ensure we are recognised as the authority on EB knowledge and expertise and the source of information, advice, support, advocacy, latest news and best practice. We also want to achieve greater public awareness of EB to ensure there is understanding for those living with the condition, more widespread EB expertise and support for our income generation through fundraising and our retail stores to enable us to fund vital research and care. We need to ensure that we are a charity of choice for funders and that the public are informed and engaged enough to want to support us.

Awareness & engagement by numbers

- Website: 1.2m page views, +20% year on year
- Social Media: 5.2m organic reach, +295% year on year
- DEBRA PR potential reach: 151.6m people
- EB Awareness Week: 1.1m reach, +451% compared with weekly average

Our marketing aims for 2021

- To raise awareness of EB and DEBRA, building a brand that is recognised by the EB community as the 'go to' source of support, expertise and information on EB and that resonates with the public as a charity of choice for funders and supporters.
- Support income generation through increased awareness and engagement.
- Increase understanding of EB and the specialist services and information DEBRA provides.
- Improve access to information via multi-channel communications for all audiences at all touchpoints.
- Create a digital-first offering for all external and internal audiences.
- Build an engaged social community and an online presence that has credibility, is informative, provides access to expertise and latest knowledge and that is centred around the needs of the EB community.

¹All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2,057 adults. Fieldwork was undertaken between 10th - 11th November 2020. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+)





Our people

From its origins, over 40 years ago, as a small support group for parents affected by EB, we have grown significantly – in income and personnel. At the end of 2020, DEBRA employed 360 staff and engaged approximately 800 volunteers. The range of jobs is broad, from managing a charity shop and organising fundraising events to processing income and supporting members with home visits, but each contributes significantly to the service that we provide to our membership.

Employees

The effects of the pandemic on our working practices were significant. The majority of office and administration staff worked from home, many staff were furloughed during the year and the safety and well-being of all of our people was more important than ever.

Communication during the pandemic was a priority. We communicated frequently with our staff and volunteers. This included regular e-newsletters, emails with updates about COVID-19, changes to working patterns such as furlough and a wide range of information about matters that affected them individually or as a whole.

During the year we worked with an external consultancy, People Puzzles, to consult with our employees and ensure their views were heard and incorporated into our strategic planning. The review included individual meetings, focus groups and surveys to understand our organisational culture and gain feedback on what working at DEBRA is like in difficult and turbulent times as well as taking the opportunity to drill down into specifics such as the onboarding process for our retail employees.

As a result of the employee feedback, we have launched some proactive projects that will underpin our ambition to be an “Employer of Choice” in the charity sector. These include a review of our benefits and recognition structure, updating our company values and launching a new Equality, Diversity & Inclusion framework.

Volunteers are a significant and highly valued resource for us. We rely on their commitment and dedication to enable us to undertake the work of our retail stores and support across many areas of the charity. Our Volunteer Manager worked closely with the Retail and Community Support Teams in 2020 to increase volunteer resources in these areas. The ‘EB Connections’ initiative, developed in 2019 and envisaging the development of Practical Community Volunteers (PCVs) to support members in their homes, was placed on hold due to the pandemic.

Learning and development

All members of staff are encouraged to continually develop their skills and the eLearning platform

first introduced in 2017 continues to prove useful, particularly in delivering mandatory training in Safeguarding, Equal Opportunities and GDPR.

In line with our Equal Opportunities policy, we take full and fair consideration of applications for employment made by disabled persons and their aptitude and abilities and encourage training, career development and promotion within our organisation.

Reflecting the increasing requirements to develop the skills of staff, and to develop bespoke training using technology such as eLearning modules, we recruited a dedicated Learning & Development Manager in February 2020. During the pandemic, bespoke training modules were developed for employees to complete while furloughed including training on the Retail Gift Aid Scheme.

Pay policy

Rates of pay and salaries within DEBRA are set at a level that are legally compliant and proportionate to the requirements of each role within the sector to attract and retain the best employees for each position. We benchmark key management and all pay rates to ensure we are competitive within the charity sector and in line with other trusted sources.

In January 2020, the annual pay review awarded a pay increase of 2% for all staff.

In accordance with the Charity Statement of Recommended Practice, DEBRA discloses:

- all payments to Trustees (no Trustees are paid) and reimbursed expenses
- SMT (Senior Management Team) reimbursed expenses
- the number of staff in receipt of £60,000 pa and above (in bands of £10,000)
- employer pension contributions.

All aspects of pay – including rates, salary levels, reviews, incentive schemes and termination costs – were considered by the Quarterly Pay Review Committee, which reports to the Board of Trustees. In October 2020 QPRC was dissolved and has not been replaced. In order to maintain the required level of governance in relation to pay, a new process has been introduced whereby a business case must be put forward to the CEO for consideration before any kind of pay increase or change to incentives can be actioned. Where required Board approval will also be sought.

During March, April and May 2020, all of our employees were paid at 100% of their normal monthly salary. If employees were furloughed in these months, we topped up their furlough pay by 20%, i.e. from 80% to 100%, utilising the Government’s Coronavirus Job Retention Scheme. In June and July 2020, we enabled furloughed employees to take a week of annual leave at 100% pay to increase their monthly income. Between August and December 2020, we reduced furloughed employee pay to 80% with no top up.

Gender pay gap

A gender pay gap is a measure of the difference in the average pay of men and women, regardless of the nature of their work, across an entire organisation, business sector or the economy as a whole. Our mean hourly full pay gap is 2.61% in favour of males. As a comparison, our mean gender pay gap for 2019 was 4.9%.

The median hourly full pay gap is -2.39% in favour of the female workforce. The hourly pay analysis is based on 376 relevant full pay employees. The mean bonus pay gap is 4.92% in favour of females and the median bonus pay gap is -14.92% in favour of females. Bonus payment calculations relate to payments made to all eligible employees in the 12 months preceding the snapshot date.

The full Gender Pay Gap Report is available on our website.

Table 1: Summary Gender Pay Gap Report
Pay – hourly rate: the difference between men and women

	Mean	Median
All	11.31	8.98
Female	11.23	8.98
Male	11.53	8.77
Pay Gap	2.61	-2.39

Table 2: Summary Gender Pay Gap Report

	Mean bonus	Median bonus	Number receiving a bonus	% Bonus distribution
Female	497.60	312.00	156	56.52
Male	474.25	271.50	46	46.00
Pay Gap	-4.92	-14.92	-	-

As part of our strategy to address the gender pay gap, we will be further developing our remuneration and benchmarking policies to move towards a more transparent and experience-based pay structure. In addition, we will continue to focus on the broader Equality, Diversity & Inclusion (EDI) agenda which will incorporate the activities and processes required to close our gender pay gap.

The coronavirus pandemic

Following the temporary closure of our charity shops in March 2020 and the postponement or cancellation of fundraising events, 85% of employees were furloughed in the same month. The remaining staff continued to work in their existing jobs or were redeployed to support DEBRA members, doing so from their homes. Since March, a further 8% of the workforce were furloughed. Supporting and maintaining regular communication with both these groups of employees became the focus for our Human Resources Team.

A phased opening of our charity shops started on 15th June 2020. Full PPE was provided to all stores and staff and all relevant government guidelines and measures were put in place for the safety of our staff, volunteers and customers. By late September 2020 all stores were open after a successful, phased re-opening. On 31st October 2020 the Government announced a second national lockdown resulting in the closure of all of our stores on 5th November 2020. We re-opened them on Wednesday 2nd December 2020. On 21st December 2020, the Government's Tier System was introduced. Our shops were subsequently closed in the period leading up to Christmas and into early 2021.

Equal opportunities

We are at the beginning of creating an EDI strategy and development programme to make DEBRA a place where everyone is welcome and supported to achieve their potential. We are committed to developing a positive working environment that is not only free from discrimination, victimisation and harassment but is also one where people treat each other with mutual respect regardless of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values. The benefits that derive from having a diverse workforce are highly valued. In particular, the involvement of people affected by EB is actively sought in all aspects of the charity's work.

Safeguarding and reporting of concerns

Safeguarding remains a priority within DEBRA, ensuring that any vulnerable person who comes into contact with DEBRA is adequately protected. All staff undertake mandatory training in safeguarding and in 2020 'Safeguarding September' was introduced to maintain a high awareness of safeguarding among staff. 'Safeguarding September' also reminded employees and volunteers that any concern could be reported internally in confidence. Updated posters and alert cards were issued during this month. The Safeguarding Review group met quarterly in 2020 to review the safeguarding alerts that had been internally reported and to ensure that the appropriate action had been taken in each case.

The Designated Safeguarding Lead receives annual updated training via an accredited external training provider and attends an annual safeguarding conference. Other staff receive safeguarding training appropriate to their role. Policies and procedures relating to safeguarding are reviewed and, if necessary,

updated at three monthly intervals. The governance of the safeguarding provision is overseen by an experienced Trustee.

The Community Support Team received enhanced training in Level 2 Safeguarding and works closely with other agencies to ensure our members are safe and supported appropriately. Some members of the Community Support Team received further training in 2020 to take on the roles of 'Designated Safeguarding Officers' that report directly to the Safeguarding Lead in the organisation, with several safeguarding cases having been supported in the last 12 months.

In our retail stores, we are committed to creating a safe and rewarding environment in which all our people can work with a robust safeguarding policy to ensure everyone is treated properly. We also have a whistle blowing policy to ensure our staff can raise any concerns confidentially to a dedicated email address or by leaving a confidential message via a secure messaging facility.

All retail staff receive regular safeguarding training online and work closely with the designated Safeguarding Lead Officer to ensure that all staff, volunteers and customers are safe and supported appropriately. To ensure we are continually maintaining the highest standards of safeguarding, guidance from the Government, the Charity Commission and the Charity Retail Association on procedures and protocols for Safeguarding are monitored regularly. In the last 12 months, there have been several examples of robust action being taken to prevent harm to vulnerable people.

Working from home

In March 2020 our office-based employees had to adjust to new ways of working, which meant working from home due to office closures. Our management teams across the organisation established structured check-ins with the affected staff, provided several different types of communication technology including Zoom and Microsoft Teams, offered opportunities for remote social interaction within the team, developed resources for and awareness of the importance of mental health and well-being and provided encouragement and emotional support.



Financial review

Our accounts show the financial affairs of the charity for the year ended 31st December 2020. Net income after accounting for the costs of raising funds was £477k, dropping significantly from £3,905k achieved in 2019. Net income includes £1,249k received from the Coronavirus Job Retention Scheme and £824k from COVID-related local authority grants.

We entered the pandemic with strong reserves which enabled us to continue, enhance and adapt our charitable activities at this particularly difficult time for the EB community, despite the huge drop in income. We spent £2,848k on charitable activities in 2020, compared with £3,110k in 2019.

We have a large suite of charity shops which meant the pandemic hit us particularly hard. All shops were shut for four to six months of the year, which, despite government support, resulted in a deficit from the retail operation of (£673k), compared with £2,123k surplus achieved in 2019.

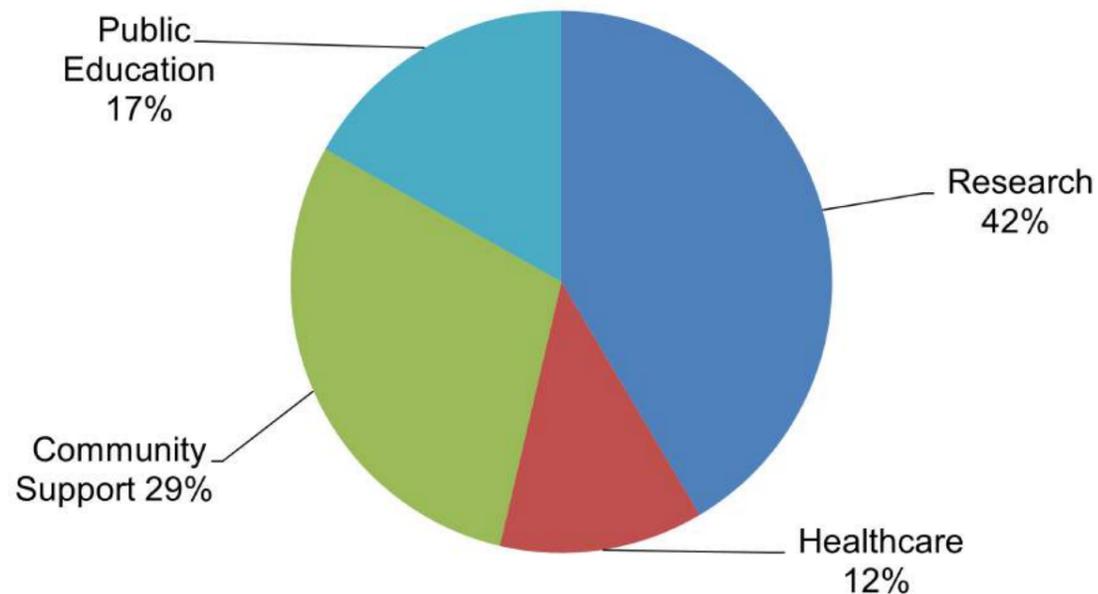
Many of our fundraising activities were severely curtailed during the year. Encouragingly our donor development programmes produced significant growth in this area. Overall net fundraising income was £946k in 2020, compared with £1,671k in 2019.

The deficit in the year was (£2,371k), funded by the historic build-up of reserves.

Charitable spend

Charitable spend in 2020 fell by just 8% over 2019. Research spend during 2020 was £1,181k (2019: £1,496k), whereas £839k (2019: £925k) was spent on Community Support initiatives, £347k (2019: £357k) on Healthcare services and £480k (2019: £333k) on Public Education.

Chart 1: Charitable Expenditure 2020



The deficit in the year led to a decrease in net assets from £5,352k to £2,981k. There was £2,138k in the general fund, £766k in designated funds and £77k in restricted funds.

Summary

Table 3 summarises the highlights of our financial performance over the last five years. Gross income was £11,413k in 2020, a decline of £5,385k (32%) from 2019. Excluding government support of £2,073k the decline was £7,458k (44%).

Non-trading gross income was £4,387k, an increase of £912k over 2019, but excluding government financial support of £2,073k the figure would be £2,314k, a drop of £1,161k (33%) as a result of reduced corporate support and trust donations, and a significantly reduced calendar of community events,

Net retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops) had grown dramatically between 2016 and 2019 from £1,318k to £2,123k. Despite government support of £1,916k attributable to retail, this fell to (£673k) in 2020.

See next page for Table 3 Financial Summary.

Table 3 Financial Summary £'000

	2020	2019	2018	2017	2016
Gross income	11,413	16,798	16,138	16,182	14,136
Non-trading income including all government support	4,387	3,475	2,979	3,468	2,832
Net trading income	(3,201)	1,198	1,193	616	330
Net retail income including government pandemic support, retail gift aid, commission and donations in shops	(673)	2,123	2,138	1,652	1,318
Non-trading fundraising costs	708	768	727	1,083	819
Charitable expenditure	2,848	3,110	2,966	3,299	1,715
Retained surplus/(deficit)	(2,371)	795	479	(299)	628
Retained surplus/(deficit) as a % of income	(21%)	5%	3%	(1.8%)	4.4%
Net current assets	2,684	4,878	4,394	3,951	3,340
Unrestricted reserves	2,904	5,138	4,420	3,997	4,301
Grants payable within 1 year	2,159	2,201	1,825	1,156	1,519

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

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

Reserves policy

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

The Trustees' reserves policy in 2020 was to maintain minimum cash-backed free undesignated reserves at £1,300k, plus a £250k balance in the designated fund for nursing continuity, to which the charity adhered. We have a high proportion of retail income, which usually provides a stable and reliable income stream. However, this incurs a high cost base, and the minimum reserves figure would cover one month's costs (excluding rent) plus six months' rent.

In a normal year, the charity's income is to some extent dependent on a few large fundraising events at specific times in the financial year, as well as seasonal variations in the trading performance of the shops.

The Trustees conducted a thorough review of the reserves policy at the end of 2020, reviewing performance criteria in the light of the pandemic. Recognising the impact of a large drop in income as we experienced in 2020, the aim is to grow accessible reserves over the next 5 years to £3m. This would be sufficient to ensure a continuation of care services for at least 3 years.

Total reserves at the end of 2020 were £2,981k, including £77k in restricted funds. Cash-backed free reserves before designations were £2,066k, of which £766k was designated for specific purposes, bringing the total cash-backed free reserves after designations to £1,300k. Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be readily mortgaged, thus representing reserves that can be accessed relatively quickly.

Future Research Fund

A total of £516k was available in the designated fund for future research, which is in line with the charitable objectives of DEBRA and is anticipated to be spent or undesignated in the next year.

Nursing Continuity Fund

The amount of £250k was made available in the designated fund for nursing continuity. The purpose of this fund is to cover the cost of the continued nursing service to the EB community for six months in the event of the NHS withdrawing current levels of support. It is expected this fund will be spent in the next 5-10 years.

EB2020 Fund

The Trustees established a designated fund for the EB2020 World Congress which was hosted by DEBRA in January 2020 in London. There was a balance of £38k in this fund at the beginning of 2020, which has now been spent.

General Fund

There was £2,138k in the general fund, of which £1,078k can only be realised by disposing of tangible fixed assets. The Trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

Investment policy

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

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

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

Programme related investment

The Trustees invested \$250k (£191k) in the US biotech, FIBRX Derm, Inc, purchasing 203,252 series A-2 convertible preferred stock at a price of \$1.23 per share. The purpose of this investment was in furtherance of the charitable objectives of the charity and no financial return is expected. The investment was made as part of our policy to invest in top quality, world class research. This will further our charitable objectives by supporting the development of a new treatment to help wound healing in patients suffering from Dystrophic EB.

The Trustees agreed to prudently impair this programme related investment by 99.99% in 2020 because the project has progressed well and the funds have substantially been spent. To all intents and purposes this investment was a research grant and the high impairment in the year reflects this fact.

Expenses policy

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

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

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

Funds

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

Asset cover for funds

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

Related parties

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activities in 2020 were a house clearance service and sales of new goods in our charity shops. Other activities include miscellaneous non-primary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 22 of the Financial Statements.

Internal financial controls

The Trustees have conducted a review of the effectiveness of the charity's internal financial controls in 2020, using the Charity Commission financial controls checklist. This review concludes that the controls are relevant, appropriate to DEBRA and are not too onerous or disproportionate.



“ The physical symptoms of EB are obvious to people but the emotional and psychological trauma you feel are just as painful. The constant itch drives me mad, and in my sleep I would tear and blister my skin constantly. My skin feels like it's always on fire.

I was introduced to DEBRA in 1996 after I had been referred to the St Thomas specialist EB unit. The support DEBRA has given me has changed my life. I am now in regular contact with other people who have EB and I receive so much information and support to help with my everyday life. I should have asked for help a lot sooner but I thought I could cope on my own and I wasn't aware of the support services available to the EB community. I have recently been given a care package and I now have a dedicated carer who visits me twice a day to do my dressings. I'm not suffering in silence anymore. When I speed off on the bike it's like I leave EB in the gutter. After I have a day on my bike I need several to help my skin recover. But it is worth it. Life with EB is an unimaginable roller coaster and it has had a profound and devastating impact on my life. But I will not let EB beat me. ”

Les Paine, living with Dystrophic EB (DEB)

Principal risks and uncertainties

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

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

See next page for Table 4: Summary Extract from DEBRA's Risk Register

Table 4: Summary Extract from DEBRA's Risk Register

Identified Risk Factor	Countermeasure	Assurance
Global pandemic causes UK-wide lock-down, threatening the going concern of the charity	<ul style="list-style-type: none"> Access all forms of government funding, Coronavirus Job Retention Scheme, local authority retail grants, and the National Lottery Community Fund Cancel future expenditure commitments Home working to facilitate social distancing Risk assessments in shops Home working risk assessments Health and safety shop re-opening procedures 	<ul style="list-style-type: none"> Weekly Trustee Steering Group meeting Weekly Senior Management Team meetings Regular executive reporting to trustees Clear roles and responsibilities of trustees and staff identified Appropriate reporting lines established Reverse stress testing to estimate when liquidity would break Financial forecasting including recovery planning following the COVID-19 pandemic through to end 2022
Charity image damaged	<ul style="list-style-type: none"> Marketing and PR strategy Disciplinary policy Crisis communications plan Review of any complaints received Extensive social media policy for staff 	<ul style="list-style-type: none"> Media monitoring Annual staff appraisals Register of crises Investigation of occurrences
Insufficiently robust cyber security	<ul style="list-style-type: none"> Anti-virus software Cyber insurance policy Encryption of hard drives Secured Wi-Fi connection Daily backups stored in the cloud Upgrade of firewalls PCI compliance Use of complex passwords 	<ul style="list-style-type: none"> Anti-virus tool displays Monthly reports Firewall logs checked regularly Daily logs of server activity
Misuse of data and failure to comply with Data Protection legislation	<ul style="list-style-type: none"> In-house Data Protection Officer External data protection consultancy Data protection policy Regular data protection training 	<ul style="list-style-type: none"> Data protection working party Regular reporting GDPR eLearning module
Loss of major source of income	<ul style="list-style-type: none"> Diversity of fundraising activities Regular contact with key supporters Review of management information 	<ul style="list-style-type: none"> Regular reporting Review of key relationships Development of CRM database

Going concern statement

The Trustees have reviewed the financial statements and forecast to the end of 2022, detailing the plans for financial recovery whilst maintaining a first-class service to the EB community. It is recognised that there are underlying uncertainties, however the Trustees consider the charity can continue its business-critical activities and remain a going concern. The retail estate re-opened during April 2021 providing a regular income stream of unrestricted funds, plus the suite of fundraising events started up again. An analysis of risks and opportunities relating to the forecast resulted in net opportunities exceeding £400k, therefore uncertainties are expected to be managed and not be material to our ability to continue operating.

During the first few months of 2021 the third national lockdown impacted DEBRA's financial situation, resulting in an estimated £2.1m reduction in total income following three-four further months of shop closures in early 2021. In addition, lockdown prevented face-to-face fundraising events taking place. The economic fallout of lockdown and the uncertainty it generated impaired the ability of individuals, corporate and trusts to make donations.

The Trustees therefore decided to carry out some cost reductions to mitigate this impact with further cost saving levers that could be pulled if required. This included the furlough of staff who are not involved in business-critical work, recruitment freeze and limited new research commitments. This has produced savings of £1.7m in 2021 compared with the original budget.

Before the pandemic struck DEBRA had financial strength with high cash balances which have provided a buffer to weather the storm. All applicable sources of government financial aid have been accessed. Given DEBRA's financial strength at the outset of the pandemic, whilst uncertainty continues to exist, this does not pose a material uncertainty that would cast doubt on the charity's ability to continue as a going concern. As the country emerges from lockdown, the financial plan demonstrates DEBRA will pull through this crisis and the Trustees consider it is still appropriate to prepare the 2020 accounts on a going concern basis.



Structure, governance & management

DEBRA (Company Limited by Guarantee) is a membership organisation and governed by its Articles of Association, which state that the Board of Trustees shall comprise of up to 15 Trustees, with no less than 50% of the Trustees having direct experience of EB management.

DEBRA Trustees

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

No Annual General Meeting was held during 2020 due to the pandemic. The Board of Trustees re-appointed Simon Cuzner for a further three-year term. The Board also co-opted Becky Edwards and Vivien Mundy who are both Elected Trustees for a second three-year term.

Two new candidates, Douglas Rouse and Michael Thomas, were also co-opted by the Board as Elected Trustees. James Hinchcliffe and Simone Bunting reached the end of their third term, so stepped down and David Wilkinson retired at the start of the year. The Trustees thank them for their valuable contribution to DEBRA over the last nine years. Following this, a postal vote of members took place which confirmed the co-opted appointments as Elected Trustees.

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

Trustee Board committees

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

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

Retail Committee – determines and advises the SMT and the Board of Trustees on matters relating to the shops. It utilises specific knowledge of its members to assist the CEO and Director of Retail to

manage the shops, deliver operational performance against plan, comply with regulations and promote the cause of the charity.

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

DEBRA UK International Committee – determines and advises the Board of Trustees on matters relating to international strategy in research, healthcare, community support and international policy as the Board of Trustees may remit to it. In addition, the international Medical and Scientific Advisory Panel makes recommendations for research projects to DEBRA International which may be considered by the DEBRA UK International Committee.

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

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

See Table 5 below – Trustees' membership and attendance.

The Trustees plan to undertake a full review of the existing committee structure during 2021.

Board diversity

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

We follow the Equal Opportunities Policy in the selection of Board members, in the same way we do for staff recruitment. Membership of the Board is open to all members of DEBRA, irrespective of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependents, economic status or political values. Broader diversity of the Board will be reviewed in 2021 as part of DEBRA's Equality, Diversity & Inclusion project.

Charity governance code

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

Succession planning

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

Fundraising standards

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

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

Specifically:

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

- we are a member of the Fundraising Regulator and comply with the relevant codes of practice
- we received no fundraising complaints in 2020. We received 73 compliments in 2020 for either the service we provide to the EB Community or through liaising with the general public in DEBRA shops.

Activities in Scotland

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

Table 5: Trustees' membership and attendance records as at 31.12.2020.

Name	Notes	Board Attendance	Finance, Risk & Audit Committee	Nominations & Governance Committee	Care & Research Committee	Retail Committee	Fundraising & Communications Committee	DEBRA UK International Committee
Jim Irvine	Chair	7 of 7	5 of 5	5 of 5				
David Bendor-Samuel		6 of 7		5 of 5				
Simone Bunting	stood down 22.07.2020	2 of 3		4 of 5			6 of 6	
Rebecca Cresswell		4 of 7					5 of 6	
Simon Cuzner		5 of 7	3 of 5			5 of 5		
Carly Fields		7 of 7			3 of 3		5 of 6	
Andrew Grist	on leave of absence	1 of 7		1 of 5	1 of 2			
James Hinchcliffe	stood down 26.06.2020	leave of absence						
Christo Kapourani		4 of 7			1 of 3			
Graham Marsden		5 of 7		5 of 5				1 of 1
Joanne Merchant	Treasurer	7 of 7	5 of 5			5 of 5		1 of 1
Vivien Mundy		6 of 7			2 of 3			1 of 1
Timothy Powell		5 of 7			3 of 3			
Douglas Rouse	elected 01.07.2020	3 of 4					5 of 5	1 of 1
Michael Thomas	elected 01.07.2020	3 of 4					2 of 3	
David Wilkinson	stood down 23.01.2020	0 of 1						

The committee chairs' attendance is highlighted in bold.

Auditor

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

We engaged Sayer Vincent LLP as auditor during 2020 and they have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditor 28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

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

Jim Irvine

Chair of Trustees

29th April 2021

Trustees' statement of responsibilities

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

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

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

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

In so far as the Trustees are aware:

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

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions. Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2020 was 3,279 (2019: 3,111). The Trustees are members of the charity but this entitles them only to voting rights. The Trustees have no beneficial interest in the charity.

Auditor's report

Independent auditor's report to the members of DEBRA.

Opinion

We have audited the financial statements of DEBRA (the 'charitable company') for the year ended 31 December 2020 which comprise the Statement of Financial Activities, balance sheet, statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2020 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

The other information comprises the information included in the Trustees' Annual Report, including the strategic report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Responsibilities of Trustees

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

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

Auditor's responsibilities for the audit of the financial statements

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

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

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

Capability of the audit in detecting irregularities

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

- we enquired of management and Finance, Audit and Risk committee, which included obtaining and reviewing supporting documentation, concerning the charity's policies and procedures relating to:
 - identifying, evaluating, and complying with laws and regulations and whether they were aware

of any instances of non-compliance

- detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud
- the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.
- we inspected the minutes of meetings of those charged with governance
- we obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience
- we communicated applicable laws and regulations throughout the Audit Team and remained alert to any indications of non-compliance throughout the audit
- we reviewed any reports made to regulators
- we reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations
- we performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud
- in addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

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

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

Use of our report

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

anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Fleur Holden (Senior Statutory Auditor)

Date: 6 May 2021

for and on behalf of Sayer Vincent LLP, Statutory Auditor

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

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



Financial statements

For the year ended 31 December 2020

Statement of Financial Activities

Statement of Financial Activities including income and expenditure account for the year ended 31 December 2020.

		2020	2020	2020	2020	2019	2019	2019	2019
	Notes	Unrestricted funds	Designated funds	Restricted funds	Total	Unrestricted funds	Designated funds	Restricted funds	Total
		£	£	£	£	£	£	£	£
Income and endowments from:									
Donations and legacies	2	3,814,335	-	468,926	4,283,261	2,790,693	-	573,611	3,364,304
Charitable activities		18,210	-	-	18,210	20,299	-	-	20,299
Other trading activities	3	6,903,611	75,771	46,491	7,025,873	12,845,645	264,717	211,958	13,322,320
Investments	4	47,403	-	-	47,403	56,544	-	-	56,544
Other		38,150	-	-	38,150	34,432	-	-	34,432
Total		10,821,709	75,771	515,417	11,412,897	15,747,613	264,717	785,569	16,797,899
Expenditure on:									
Raising funds	6	10,935,662	-	-	10,935,662	12,891,642	-	1,000	12,892,642
Charitable activities	6	1,452,433	821,551	573,782	2,847,766	1,446,033	1,141,627	522,388	3,110,048
Total		12,388,095	821,551	573,782	13,783,428	14,337,675	1,141,627	523,388	16,002,690
Net income/(expenditure)		(1,566,386)	(745,780)	(58,365)	(2,370,531)	1,409,938	(876,910)	262,181	795,209
Transfer between funds		1,473,695	(1,395,027)	(78,668)	-	(1,170,160)	1,355,000	(184,840)	-
Net movement in funds		(92,691)	(2,140,807)	(137,033)	(2,370,531)	239,778	478,090	77,341	795,209
Reconciliation of funds:									
Total funds brought forward		2,231,188	2,906,757	213,576	5,351,521	1,991,410	2,428,667	136,235	4,556,312
Total funds carried forward		2,138,497	765,950	76,543	2,980,990	2,231,188	2,906,757	213,576	5,351,521

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

The notes on pages 79-106 form part of these financial statements.

Balance sheet

Balance sheet as at 31 December 2020.

		2020		2019	
	Notes	£	£	£	£
Fixed assets					
Tangible assets	10	1,077,946		1,262,260	
Programme related investment	11	1		-	
Investment in DEBRA Trading Ltd	22	2		2	
		<u>1,077,949</u>		<u>1,262,262</u>	
Current assets					
Current asset investment	12	-	3,750,000		
Stocks		5,910	6,300		
Debtors	13	1,616,619	1,926,703		
Cash at bank and in hand		5,076,553	2,898,199		
Fixed assets held for sale		167,960	78,000		
		<u>6,867,042</u>	<u>8,659,202</u>		
Creditors: amounts falling due within one year	14	<u>(4,182,719)</u>	<u>(3,781,180)</u>		
Net current assets		<u>2,684,323</u>	<u>4,878,022</u>		
Total assets less current liabilities		<u>3,762,272</u>	<u>6,140,284</u>		
Creditors: amounts falling due over one year	14	(599,474)	(546,951)		
Provisions for liabilities		(181,808)	(241,812)		
Total net assets		<u>2,980,990</u>	<u>5,351,521</u>		

The funds of the charity

Restricted income funds	16	76,543	213,576
Unrestricted funds	17	2,904,447	5,137,945
Total charity funds		<u>2,980,990</u>	<u>5,351,521</u>
Unrestricted funds			
- Designated	17	765,950	2,906,757
- General		2,138,497	2,231,188
		<u>2,904,447</u>	<u>5,137,945</u>
Restricted funds	16	76,543	213,576
Total charity funds		<u>2,980,990</u>	<u>5,351,521</u>

Company registration number 4118259

The accounts were approved by the Board on 29th April 2021 and signed on their behalf by:

Jim Irvine
Chair of Trustee Board

Joanne Merchant
Treasurer

Cash flow statement

		2020		2019	
	Notes	£	£	£	£
Cashflows from operating activities:					
Net cash provided by operating activities	17	(1,366,471)		1,580,543	
Cashflows from investing activities:					
Dividends, interest and rents from investments		47,403	56,544		
Proceeds from the sale of property, plant and equipment		7,052	-		
Purchase of property, plant and equipment		(68,791)	(383,314)		
Proceeds from sale of investments		3,750,000	-		
Purchase of investments		(190,840)	(1,000,000)		
Net cash (used in) / provided by investing activities		3,544,825		(1,326,770)	
Change in cash and cash equivalents in the reporting period		2,178,354		253,773	
Cash and cash equivalents at the beginning of the reporting period		2,898,199		2,644,426	
Cash and cash equivalents at the end of the reporting period		5,076,553		2,898,199	

The notes on pages 79 to 106 form part of these financial statements.

Notes to the accounts

1 Accounting policies

1.1 Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015), Charities SORP (FRS 102) (second edition - October 2019), the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and Trustees Investment (Scotland) Act 2005.

1.2 Going concern

The Trustees reviewed the charity's budget in December 2020 and were content that these plans were affordable and that the accounts should be prepared on going concern basis. However the continuing impact of the coronavirus pandemic and its effect has meant that the Senior Management Team and Trustees have been reviewing financial plans for the next 12 months to ensure the charity can continue its business-critical activities and remain a going concern.

The Government decision to impose a third national lockdown has had an effect on DEBRA's financial situation, resulting in an estimated £2.1m reduction in total income following three-four further months of shop closures in 2021. In addition, on-going social distancing measures present challenges to running fundraising events. The economic fallout of lockdown and the uncertainty it generates impairs the ability of individuals, corporate and trusts to make donations.

The Trustees have, therefore, decided to carry out some cost reductions to mitigate this impact with further cost saving levers which can be pulled should it be required. This includes the furlough of staff who are not involved in business-critical work, recruitment freeze and limited new research commitments. This has produced savings of £1.7m in 2021 compared with the original budget. Before the pandemic struck DEBRA had financial strength with high cash balances which have provided a buffer to weather the storm. All applicable sources of government financial aid have been accessed.

Taking into account the measures announced by the government in the March 2021 budget, a financial forecast has been prepared to the end of 2022, detailing the plans for financial recovery whilst maintaining a first-class service to the EB community.

Given DEBRA's financial strength at the outset of the pandemic, whilst uncertainty continues to exist, this does not pose a material uncertainty that would cast doubt on the charity's ability to continue as

a going concern. As the country emerges from lockdown, the financial plan demonstrates DEBRA will pull through this crisis and the Trustees consider it is still appropriate to prepare the 2020 accounts on a going concern basis.

1.3 Legal status of charity

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

1.4 Judgements and estimates made by management

The financial statements include judgements and estimates as defined by the accounting policies.

Legacy income is recognised as probable at probate, using an estimate provided by executors.

Premises service charge liabilities are estimated from information supplied by property specialists. The dilapidations provision is reviewed annually on an individual lease basis by a property specialist.

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

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

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

1.5 Income

Donations and gifts are recognised in full in the Statement of Financial Activities when received.

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

Landlord concessions received during the COVID-19 pandemic have not been treated as gifts in kind because the Trustees considered due to the extent of the concessions as a result of the generosity of the landlords, it would significantly distort the accounts for the reader, therefore rent concessions are reflected as reductions in rent costs in the year.

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

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

1.6 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Equipment purchased for use in research is written off as part of the research project costs as incurred. Expenditure on raising funds are those costs incurred in seeking voluntary contributions and running the retail operations. Charitable activities include expenditure associated with the operation of the charity and the provision of its services. Governance costs comprise the costs relating to the general running of the charity, and include direct items such as external audit, legal advice for trustees, the cost of trustee meetings, and are included in central overhead costs. Central costs are apportioned and allocated between the cost of raising funds and charitable expenditure on the basis of central staff time allocation to the various activities.

1.7 Recognition of grant liabilities

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

1.8 Tangible fixed assets and depreciation

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

Freehold and long leasehold buildings	Over 25 years
Head office fit out costs	Over life of the lease
Mobile homes	Over 10 years
Fixtures, fittings, static equipment	Over 5 years
Shop equipment	Over 5 years
Motor vehicles	Over 4 years
Mobile equipment	Over 3 years

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

1.9 Sale and leaseback

In 2017 the charity sold office premises originally purchased in 2004. These premises were leased back at market rent, until January 2020.

1.10 Programme related investment and impairment

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

1.11 Cash and short-term investments

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

1.12 Debtors

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

1.13 Creditors

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

1.14 Financial instruments

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

1.15 Stock

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

All other stock is valued at the lower of cost or net realisable value.

1.16 Accumulated funds

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

1.17 Consolidated accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the company's results and the investment the charity holds in DEBRA Trading Limited are shown separately in Note 22 to the financial statements.

1.18 Foreign currency translation

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

1.19. Leases

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

1.20. Termination payments

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

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total 2020	Total 2019
	£	£	£	£
Donations & gifts	1,438,777	157,348	1,596,125	2,671,296
Legacies receivable	219,678	37,500	257,178	184,761
Grants receivable	2,155,880	274,078	2,429,958	508,247
	3,814,335	468,926	4,283,261	3,364,304
Donations & gifts:				
Individual donations	1,189,520	128,112	1,317,632	2,012,963
Corporate donations	234,413	26,488	260,901	590,001
International donations	496	-	496	524
Events by individuals	14,348	2,748	17,096	67,808
	1,438,777	157,348	1,596,125	2,671,296
Grants receivable:				
Charitable trusts	82,962	274,078	357,040	508,247
Government grants	2,072,918	-	2,072,918	-
	2,155,880	274,078	2,429,958	508,247

Government grants consist of £1,248,868 (2019: 0) received under the Coronavirus Job Retention Scheme and £824,050 (2019: 0) received in local authority grants.

Gifts in kind of £88,006 (2019: £100,454) are included in donations and gifts. These include the ongoing advertising in a national newspaper valued at £20,800 (2019: £20,800) and online AdWords valued at £67,206 (2019: £70,308).

3 Other trading activities

	Total 2020	Total 2019
	£	£
Income	7,025,873	13,322,320
Operating expenses	(10,227,464)	(12,124,386)
Net income from fundraising activities	(3,201,591)	1,197,934

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2020 there were 109 shops trading (2019:121). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2020	Net income 2019
	£	£	£	£
Retail	6,477,316	(9,757,368)	(3,280,052)	751,975
Fundraising events	429,761	(470,096)	(40,335)	84,552
Miscellaneous trading	118,796	-	118,796	361,407
	7,025,873	(10,227,464)	(3,201,591)	1,197,934

Retail income excludes income of £606,091 (2019: £1,226,225) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. Retail income also excludes retail gift aid commission of £84,619 (2019: £144,523) which is recognised in miscellaneous trading. In 2020 the COVID-19 pandemic had a significant impact on gross retail income, dropping by 47%. There was also a drop of 12 in the number of shops trading. The profit covenanted by DEBRA Trading Limited of £34,176 (2019: £216,884) is recognised in miscellaneous trading.

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

	2020	2019
	£	£
Retail income	7,168,026	13,609,304
Retail expenditure	(9,757,368)	(11,486,581)
Retail net income	(2,589,342)	2,122,723
Investment income	Total Unrestricted	Total
	2020	2019
	£	£
Interest receivable	29,940	29,766
Rent of property	17,463	26,778
Total investment income	47,403	56,544

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

4 Investment income

	Total Unrestricted 2020	Total 2019
	£	£
Interest receivable	29,940	29,766
Rent of property	17,463	26,778
Total investment income	47,403	56,544

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

5 Grants payable

Expenditure on charitable activities include grants payable to third parties as detailed in Note 21. There were 154 (2019: 334) Community Support grants totalling £38,071 (2019: £85,117) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 21.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2020 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,183,468 (2019: £1,428,243) and clinical projects to the sum of £138,105 (2019: £186,213).

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

	Total 2020	Total 2019
	£	£
Within 1 year	722,099	1,067,505
Within 2-3 years	589,406	489,658
Within 4-5 years	10,068	57,293
	1,321,573	1,614,456
Provided within the grants payable creditor (note 14)	1,321,573	1,614,456

6 Expenditure

	Staff costs	Grants payable	Other costs	Total 2020	Total 2019
	£	£	£	£	£
Raising funds:					
Donations and legacies	415,507	-	292,691	708,198	768,256
Other trading activities	5,703,336	-	4,524,128	10,227,464	12,124,386
	6,118,843	-	4,816,819	10,935,662	12,892,642
Charitable activities:					
Research	339,024	572,731	269,343	1,181,098	1,495,647
Healthcare	80,880	241,967	23,990	346,837	357,350
Community support	651,422	38,072	56,432	745,926	824,070
Respite breaks	-	-	93,467	93,467	100,434
Public education	367,838	-	112,600	480,438	332,547
	1,439,164	852,770	555,832	2,847,766	3,110,048
	7,558,007	852,770	5,372,651	13,783,428	16,002,690

	Staff costs	Grants payable	Other costs	Total 2019	Total 2018
	£	£	£	£	£
Raising funds:					
Donations and legacies	373,590	-	394,666	768,256	727,350
Other trading activities	5,778,241	-	6,346,145	12,124,386	11,966,308
	6,151,831	-	6,740,811	12,892,642	12,693,658
Charitable activities:					
Research	315,029	685,893	494,725	1,495,647	1,366,338
Healthcare	103,825	224,194	29,331	357,350	472,066
Community support	680,069	85,117	58,884	824,070	781,204
Respite breaks	-	-	100,434	100,434	84,674
Public education	224,927	-	107,620	332,547	261,382
	1,323,850	995,204	790,994	3,110,048	2,965,664
	7,475,681	995,204	7,531,805	16,002,690	15,659,322

Other costs

	Depreciation and amortisation	Overhead allocation	Miscellaneous costs	Total 2020	Total 2019
	£	£	£	£	£
Raising funds:					
Donations and legacies	-	174,569	118,122	292,691	394,666
Other trading activities	78,022	301,865	4,144,241	4,524,128	6,346,145
	<u>78,022</u>	<u>476,434</u>	<u>4,262,363</u>	<u>4,816,819</u>	<u>6,740,811</u>
Charitable activities:					
Research	-	38,798	230,545	269,343	494,725
Healthcare	-	23,990	-	23,990	29,331
Community support	-	56,432	-	56,432	58,884
Respite breaks	48,016	-	45,451	93,467	100,434
Public education	-	43,441	69,159	112,600	107,620
	<u>48,016</u>	<u>162,661</u>	<u>345,155</u>	<u>555,832</u>	<u>790,994</u>
	<u>126,038</u>	<u>639,095</u>	<u>4,607,518</u>	<u>5,372,651</u>	<u>7,531,805</u>

	Depreciation and amortisation	Overhead allocation	Miscellaneous costs	Total 2019	Total 2018
	£	£	£	£	£
Raising funds:					
Donations and legacies	-	178,750	215,916	394,666	383,899
Other trading activities	83,116	292,446	5,970,583	6,346,145	6,347,696
	<u>83,116</u>	<u>471,196</u>	<u>6,186,499</u>	<u>6,740,811</u>	<u>6,731,595</u>
Charitable activities:					
Research	-	33,553	461,172	494,725	93,104
Healthcare	-	29,331	-	29,331	25,026
Community support	-	52,439	6,445	58,884	51,556
Respite breaks	35,613	-	64,821	100,434	84,674
Public education	-	107,620	-	107,620	79,191
	<u>35,613</u>	<u>222,943</u>	<u>532,438</u>	<u>790,994</u>	<u>333,551</u>
	<u>118,729</u>	<u>694,139</u>	<u>6,718,937</u>	<u>7,531,805</u>	<u>7,065,146</u>

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

	2020	2019
	£	£
Operating leases	1,279,426	1,639,888
Auditors remuneration	19,313	20,420
Non-audit services	-	24,773
Depreciation of tangible fixed assets	158,451	138,758
Defined contribution pension costs	345,016	312,098
Exchange differences	(20,916)	34,441

7 Cost allocation

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

	2020	2019
	£	£
Staff costs:	1,521,167	1,450,761
Overheads:		
Office premises rent	62,891	58,640
Service charges, utilities & cleaning	57,788	54,644
Equipment costs	148,634	142,517
Postage, printing, stationary, telephone & fax	54,502	82,430
Insurance costs	97,435	92,458
Legal, professional & consultancy fees	135,198	50,278
Depreciation	36,829	22,653
Irrecoverable VAT	24,216	52,988
Bank charges	6,755	15,081
Sundry expenses	- 8,681	87,224
Governance costs:		
Audit fees	19,313	20,420
Miscellaneous costs	4,215	14,806
	639,095	694,139
Total Allocation	2,160,262	2,144,900

8. Trustees

None of the Trustees received any remuneration from DEBRA during the period, but nine of them were reimbursed a total of £2,259 (2019: 6 - £3,871) for travel, subsistence and training expenses.

Tim Powell's wife received £600 (£2019: £1,400) for administrative services at EB2020. James Hinchcliffe received a community support grant totalling £0 (2019: £720). Andy Grist received community grants totalling £15 (2019: £528). The aggregate figure for trustee donations in 2020 was £2,158 (2019: £726). In addition many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £2,253 (2019: £1,883), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9 Employees

The average number of employees during the period was:

	2020	2020	2019
	Full time equiv	Number	Number
Research	2.9	5	5
Healthcare*	-	-	1
Community Support	11.2	12	15
Fundraising & Comms	18.2	20	14
Retail	232.5	321	331
Management & Administration	15.7	18	19
	280.5	376	385

	2020	2020	2019
	Full time equiv	Number	Number
At the end of the year the number of employees per department was:			
Research	1.6	4	5
Healthcare*	-	-	1
Community Support	9.7	10	17
Fundraising & Comms	17.2	19	14
Retail	221.6	304	332
Management & Administration	14.2	16	19
	264.3	353	388

*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 19. Staff employed by external institutions and funded through research grants are also excluded.

Employment costs

	Total	Total
	2020	2019
	£	£
Wages & salaries	6,484,221	6,231,757
Social security costs	432,918	395,899
Pension costs	345,016	312,098
	7,262,155	6,939,754

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £313,959 (2019: £309,502) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £24,016 (2019: £5,917) unpaid.

During the year the CEO and SMT were paid relevant business expenses totalling £13,028 (2019: £37,237).

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

	2020	2019
Between £60,001 - £70,000	3	2
Between £80,001 - £90,000	2	2
Between £100,000 - £110,000	1	-
Between £140,001 - £150,000	-	1

The figures above exclude a compensation payment made to the ex-CEO of the charity. If this compensation figure is included there would be one member of staff who received emoluments between £170,000 and £180,000.

Redundancy and compensation payments totalled £124,289 in 2020 (2019: £12,195), which were all paid in 2020.

The aggregate pay of key management personnel, including employer's NI and pension contributions was £736,268 (2019: £678,512). The aggregate employer's pension contribution for key management personnel was £59,304 (2019: £70,856)

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £53,426 (2019: £62,666), and there are retirement benefits accruing for six (2019: five) employees under a defined contribution scheme.

10 Fixed assets

Tangible fixed assets

	Shop equipment	Mobile homes	Fixtures, fittings & equipment	Freehold land and buildings	Long leasehold land and buildings	Total
	£	£	£	£	£	£
Cost:						
At 1 January 2020	403,961	547,162	325,614	699,347	82,500	2,058,584
Transfer to current assets				(121,000)		(121,000)
Additions	36,245	-	32,546	-	-	68,791
Disposals	(2,464)	(67,000)	(37,042)	-	-	(106,506)
At 31 December 2020	437,742	480,162	321,118	578,347	82,500	1,899,869
Depreciation:						
At 1 January 2020	228,065	216,582	165,240	168,287	18,150	796,324
Transfer to current assets				(26,620)		(26,620)
Charge for the year	59,075	48,017	36,829	12,881	1,650	158,452
Disposals	(2,191)	(67,000)	(37,042)	-	-	(106,233)
At 31 December 2020	284,949	197,599	165,027	154,548	19,800	821,923
Net Book Value:						
Brought forward	175,896	330,580	160,374	531,060	64,350	1,262,260
At 31 December 2020	152,793	282,563	156,091	423,799	62,700	1,077,946

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

The Trustees agreed to sell one freehold shop during 2019, and a flat above another shop in 2020, both of which remained unsold at 31st December 2020 and are held for sale within current assets on the balance sheet.

11 Programme related investment

	2020	2019
	£	£
Investment in Fibrx Derm Inc	190,840	-
Impairment	(190,839)	-
Net Investment Value	<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 short term deposits

	2020	2019
	£	£
Lloyds money market deposits	-	3,750,000
	<u>-</u>	<u>3,750,000</u>

13 Debtors

	2020	2019
	£	£
HMRC	281,158	259,632
Misc debtors	387,844	210,306
Other debtors	48,653	295,263
Accrued income	363,233	550,443
Prepayments	535,731	611,059
	<u>1,616,619</u>	<u>1,926,703</u>

Payments due from HMRC are VAT payable of £216,811 (2019: £259,632), plus £64,347 (2019: 0) from the Coronavirus Job Retention Scheme. Miscellaneous debtors includes £266,825 (2019: £197,612) due for shared research grants. Other debtors includes £34,176 (2019: £216,884) profit due from the trading subsidiary. Accrued income includes gift aid of £147,660 (2019: £278,092) due from HMRC.

Total future minimum lease receivable was £3,413 in 2020 (2019: £3,388), in respect of one shop and one flat above a shop.

14 Creditors: amounts falling due within one year

	2020	2019
	£	£
Trade creditors	678,754	669,803
Grants payable	2,158,657	2,201,344
Other creditors	308,617	6,226
Taxation and social security	92,476	96,107
Accruals	917,315	692,069
Deferred income	26,900	115,631
	<u>4,182,719</u>	<u>3,781,180</u>

Grants payable includes £790,811 (2019: £875,173) relating to future commitment and £1,436,558 (2019: £1,320,047) relating to outstanding invoices for work done.

There was deferred income of £26,900 in 2020 (2019: £115,631), representing income for events which would have to be repaid in the event of cancellation.

During the year we discovered that certain employee benefits had historically been mis-categorised as expenses resulting in an underpayment of income tax and national insurance. We also discovered that in 2019 and 2020 we had over-recovered VAT. We voluntarily reported both matters to HMRC during 2020 and paid a total sum of £64,341 in 2021 in settlement of these disclosures. This figure is included in other creditors. In voluntarily reporting these matters, we avoided having any penalties applied.

Creditors: amounts falling due over one year

	2020	2019
	£	£
Grants payable	599,474	546,951
	<u>599,474</u>	<u>546,951</u>

There was a dilapidations provision of £181,810 (2019: £241,812). In the year £81,422 was released from the provision and a further £21,420 was charged. It is uncertain when this provision will be spent.

15 Other financial commitments

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

	2020	2019	2020	2019
	Leases of land and buildings	Leases of land and buildings	Other	Other
	£	£	£	£
Within 1 year	1,264,152	1,617,494	15,274	22,394
Within 2-5 years	1,170,587	1,421,057	29,332	5,283
After 5 years	5,250	58,029	-	-
	2,439,989	3,096,580	44,606	27,677

There were capital commitments of £1,200 (2019: £0) at year end, falling due within one year.

16 Analysis of funds

Restricted funds

	Balance at 31 Dec 2019	Income	Expenditure	Transfer to General Fund	Balance at 31 Dec 2020
	£	£	£	£	£
Research	-	182,771	(104,103)	(78,668)	-
Healthcare	79,477	26,223	(100,100)	-	5,600
Community Support & Respite	134,099	292,599	(355,755)	-	70,943
Public Education	-	13,824	(13,824)	-	-
	213,576	515,417	(573,782)	(78,668)	76,543

Transfers to the general fund occurred following restricted income received in the current year for projects fully committed in the accounts in a prior year.

	Balance at 31 Dec 2018	Income	Expenditure	Transfer to General Fund	Balance at 31 Dec 2019
	£	£	£	£	£
Research	300	150,551	(123,851)	(27,000)	-
Healthcare	39,245	268,951	(228,719)	-	79,477
Community Support & Respite	96,690	366,067	(170,818)	(157,840)	134,099
	136,235	785,569	(523,388)	(184,840)	213,576

Restricted funds comprised:

	2020	2019
	£	£
Healthcare - EB Nurses		73,877
Healthcare - Birmingham Children's Hospital Specialist Bath	5,600	5,600
Community Support - Community Support Manager for Scotland	37,259	60,000
Community Support - Community Support Manager Post	10,496	56,167
Community Support - Community Support in Berkshire	8,048	8,476
Community Support - Support Grants in Northamptonshire	962	2,400
Community Support - Support Grants in Hampshire	5,502	1,550
Community Support - Support Grants in Scotland	1,934	-
Community Support - Support Grants in South Gloucestershire	1,356	-
Community Support - other restricted funds	5,386	5,506
	76,543	213,576

17 Analysis of funds

Unrestricted funds

The Trustees have transferred the following amounts into designated funds during 2020:

	Balance at 31 Dec 2019	Transfers	Income	Expenditure	Balance at 31 Dec 2020
	£	£	£	£	£
Future research grants	2,618,290	(1,339,000)	-	(763,340)	515,950
Nursing Continuity	250,000	-	-	-	250,000
EB2020 conference	38,467	(56,027)	75,771	(58,211)	-
Total designated funds	2,906,757	(1,395,027)	75,771	(821,551)	765,950
General fund	2,231,188	1,473,695	10,821,709	(12,388,095)	2,138,497
Total unrestricted funds	5,137,945	78,668	10,897,480	(13,209,646)	2,904,447

	Balance at 31 Dec 2018	Transfers	Income	Expenditure	Balance at 31 Dec 2019
	£	£	£	£	£
Future research grants	1,948,840	1,355,000	-	(685,550)	2,618,290
Nursing Continuity	250,000	-	-	-	250,000
EB2020 conference	229,827	-	264,717	(456,077)	38,467
Total designated funds	2,428,667	1,355,000	264,717	(1,141,627)	2,906,757
General fund	1,991,410	(1,170,160)	15,747,613	(14,337,687)	2,231,188
Total unrestricted funds	4,420,077	184,840	16,012,330	(15,479,314)	5,137,945

The funds held in excess of the minimum cash-backed reserves as stated in the Reserves Policy have been designated by the Trustees to be expended on future research grants in line with the charitable objectives of the charity. In the light of the coronavirus pandemic the Trustees undesignated £1,397,000 from this fund to the general fund to contribute towards the running costs of the charity. It is anticipated this fund will be spent in the next year.

The designated fund for nursing continuity has been established as a contingency in the event of future

NHS funding withdrawal, and the Trustees maintained a balance of £250,000 in this fund in 2020.

In 2018 the Trustees established a designated fund for the EB2020 conference, which was hosted by DEBRA in the UK in January 2020. £300,000 was designated to this fund in 2017 and 2018. During 2020 income of £75,771 was added to this fund and £58,211 was spent. The balance of £56,027 in this fund was transferred to the designated fund for future research.

18 Analysis of net assets between categories of funds

	Unrestricted funds	Restricted funds	Total 2020	Total 2019
	£	£	£	£
Fund balances at 31 December 2020 are represented by:				
Fixed assets	1,077,949	-	1,077,949	1,262,262
Current assets	6,790,499	76,543	6,867,042	8,659,202
Creditors: amounts falling due within one year	(4,182,719)	-	(4,182,719)	(3,781,180)
Creditors: amounts falling due over one year	(781,282)	-	(781,282)	(788,763)
	<u>2,904,447</u>	<u>76,543</u>	<u>2,980,990</u>	<u>5,351,521</u>

	Unrestricted funds	Restricted funds	Total 2019	Total 2018
	£	£	£	£
Fund balances at 31 December 2019 are represented by:				
Fixed assets	1,262,262	-	1,262,262	1,099,016
Current assets	8,445,626	213,576	8,659,202	7,617,553
Creditors: amounts falling due within one year	(3,781,180)	-	(3,781,180)	(3,223,805)
Creditors: amounts falling due over one year	(788,763)	-	(788,763)	(936,452)
	<u>5,137,945</u>	<u>213,576</u>	<u>5,351,521</u>	<u>4,556,312</u>

19 Reconciliation of net income to net cash flow from operating activities

	2020	2019
	£	£
Net income for the reporting period (as per the statement of financial activities)	(2,370,531)	795,209
Depreciation and amortisation charges	162,872	138,758
Impairment of programme related investment	190,839	-
Dividends, interest and rents from investments	(47,403)	(56,544)
Profit on disposal of fixed assets	(6,777)	3,313
Decrease in stock	390	11,838
Decrease in debtors	310,084	278,285
Increase in creditors	394,057	409,684
	<u>(1,366,471)</u>	<u>1,580,543</u>

20 Analysis of cash and cash equivalents

	As at 1 Jan 2020	Cash Flows	As at 31 Dec 2020
	£	£	£
Cash at bank and in hand	<u>2,898,199</u>	<u>2,178,354</u>	<u>5,076,553</u>
Total	<u>2,898,199</u>	<u>2,178,354</u>	<u>5,076,553</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.

21 Grants to institutions

	Total paid in 2020	Total paid to date	Total committed project cost
	£	£	£
Research projects:			
University of Dundee			
1. Clinical fellow funding	89,572	504,474	504,474
University of Glasgow			
1. Mechanisms of TGF-beta mediated tumour protectin in RDEB	78,525	157,138	157,138
Guy's and St Thomas' Hospital, London			
1. Validated clinical endpoints study re EB therapy evaluation	120,717	533,601	734,790
2. Stem cell therapy trial to investigate treating debilitating itch	113,262	465,414	497,360
3. Wound care and its complications in patients with EB	-	-	112,500
	233,979	999,015	1,344,650
Thomas Jefferson University, Philadelphia, USA			
2. Phase 2 clinical trial of Rigosertib for RDEB SCC	40,984	470,490	470,490
University of Birmingham Dental School & Hospital			
1. Characterisation of skin microbiome in EB patients	113,500	264,930	296,289
2. Gait Analysis in EB Simplex	-	-	46,030
3. Clinical Fellowship	35,114	35,114	125,263
4. Novel spray to treat mucosal scarring	25,406	25,406	152,385
	174,020	325,450	619,967
University of Cologne			
1. Exploring immunity in wound healing complications in RBEB	57,462	141,018	170,635

Grants to institutions continued

Universitair Medisch Centrum Groningen

1. Effectiveness of phyto-cannabinoid treatment of pain in EB	47,300	159,025	159,025
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Instituto Dermopatico deli'Immacolata Rome

1. Anti-fibrotic potential of histone deacetylase inhibitors for RDEB	32,729	59,780	70,963
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King's College London

1. Preclinical studies of lentiviral-mediated COL7A1 gene therapy	84,044	145,189	174,023
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Great Ormond Street Institute of Child Health

1. Respiratory cell and gene therapy for children with junctional EB	-	-	135,338
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Bambino Gesù Children's Hospital

1. MicroRNAs expression profiling, activity and therapeutic perspectives	14,680	14,680	77,592
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University of Edinburgh

1. Understanding role of Kindlin-1 loss in squamous cell carcinoma	10,288	10,288	112,833
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New York Medical College

1. Identifying innate and adaptive immune mechanisms in RDEB	34,644	34,644	207,538
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Other

Decrease in research provision	(244,775)	-	-
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Grants written off at end of project	-	-	-
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Total research grants

	653,452	3,021,191	4,204,666
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Research project expenditure by category:

Pre-clinical development	182,575		1,555,381
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Clinical investigation	269,331		1,202,372
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Patient treatment study	201,546		1,126,875
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	653,452		3,884,628
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	Total paid in 2020	Total project cost
Healthcare projects:	£	£
Great Ormond Street Hospital for Sick Children		
Clinical nurse specialists in EB	66,176	66,176
Guys & St Thomas' Hospital London		
Adult EB support nurses	79,647	80,288
Clinical best practice guidelines on parenteral and enteral feeding	39,996	38,000
Other		
Birmingham Children's Hospital	56,148	56,394
Miscellaneous	-	22,891
Total Healthcare Team grants	241,967	263,748

22 Related parties

The principal activities of DEBRA Trading Ltd (company number: 2487114), a company incorporated in England and Wales, are the sale of promotional items on behalf of DEBRA, a house clearance service and corporate sponsorship. DEBRA has a beneficial interest in 100% of the company's issued share capital of £2.

	2020	2019
	£	£
Turnover	96,247	307,231
Net profit gift aided to DEBRA	34,176	216,884
Net assets	2	2

During the year, the charity charged management charges totalling £7,200 including VAT (2019: £7,200) to its subsidiary, DEBRA Trading Limited.



Reference and administrative details

Patrons and Ambassadors

Royal Patron HRH The Countess of Wessex	Life Patron Philip Evans	President Simon Weston	Vice Presidents Graeme Souness, Frank Warren
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Trustees

Chair Jim Irvine	Treasurer Joanne Merchant
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Vice-Chairs
Graham Marsden & Carly Fields (from 13.02.20)

Trustees
David Bendor-Samuel
Simone Bunting (until 22.07.2020)
Rebecca Cresswell
Simon Cuzner
Andrew Grist
James Hinchcliffe (until 26.06.2020)

Christo Kapourani
Vivien Mundy
Timothy Powell
Douglas Rouse (from 01.07.2020)
Michael Thomas (from 01.07.2020)
David Wilkinson (until 23.01.2020)

Senior Management Team

Chief Executive
Ben Merrett (until 30.06.20)
Tony Byrne (from 12.10.2020)

Director of Fundraising & Communications
Hugh Thompson

Director of Research
Caroline Collins (until 27.11.2020)

Director of Human Resources
Louise Westphalen

Director of Healthcare, Membership & Community Support
Claire Mather

Director of Finance
Carol Harris

Director of Retail
Chantelle Milne

Company Secretary
Dawn Jarvis

Additional details

Charity Commission Number
1084958

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

OSCR Number
SC039654

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

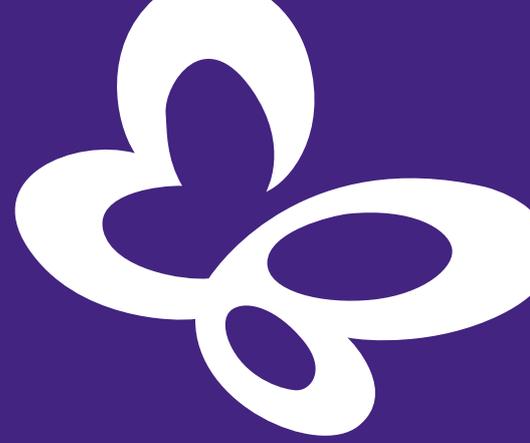
Company Number
4118259

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

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

Abbreviations

CPG	Clinical Practice Guideline
CEO	Chief Executive Officer
DEB	Dystrophic Epidermolysis Bullosa
EB	Epidermolysis Bullosa
EBS	Epidermolysis Bullosa Simplex
EDI	Equality, Diversity & Inclusion
F&E	Furniture & Electrical retail store
GDPR	General Data Protection Regulation
HR	Human Resources
k	thousand
LFL	like-for-like
m	million
NHS	National Health Service
pa	per annum
RDEB	Recessive Dystrophic Epidermolysis Bullosa
SMT	Senior Management Team
Temporary shop	any shop that has a notice period of one year or less, where notice can be served by the landlord and has a tenure of: holding over (England), holding over by licence, lease with rolling break, licence, licence with rolling break, tacit relocation, tenancy at will.
y on y	year on year
PPE	Personal Protective Equipment
HMRC	HM Revenue and Customs



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

We make a difference today with the aim of a better future for those suffering from the condition.

Together we #FightEB.

Facebook: /DEBRACHarity
Twitter: @charitydebra
Instagram: @charitydebra



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www.debra.org.uk | 01344 771961 | debra@debra.org.uk

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

DEBRA

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