

“Imagine being too  
fragile to hug.”

Help Mason #FightEB

# Trustees' Annual Report & Accounts

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# 2019



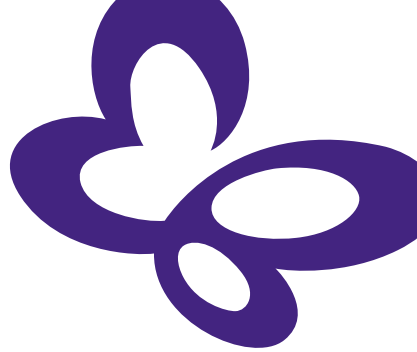
# DEBRA 2019

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Trustees' Annual  
Report & Accounts

Together we #FightEB





## What does DEBRA do?

DEBRA is the national charity supporting those directly affected by, and working with, EB (Epidermolysis Bullosa) – providing lifelong support to the entire EB Community.

Working as a team to understand the needs of the entire EB Community underpins DEBRA's core strategy. DEBRA offers practical, financial and emotional support to, and advocates for, EB sufferers; partners with the NHS to provide specialist care and internationally-recognised clinical care guidelines; and works with researchers investigating alleviation for the debilitating effects of living with EB.

DEBRA has achieved global recognition as a leader on EB, and is the only charity specifically aimed at continuously supporting the EB Community. Investing more funds and increasing the number of dedicated people in our Community Support Team allows DEBRA 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 is vital to DEBRA's work.

Supporting DEBRA – be it through fundraising efforts, direct donations, purchasing items in the retail shops or offering time as a volunteer – has a direct impact on helping the EB Community.

DEBRA envisages a future when no one suffers from EB. Until then, DEBRA strives to improve the quality of life for the EB Community.

## Investing in a future free of EB

### DEBRA UK funds:

- Specialist Healthcare
- Pioneering Research
- Community Support
- International Best Practice

## What is EB?

EB is a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering.

There are an estimated 500,000 people suffering from EB worldwide, and one in 227 of us carry a defective gene that could cause the condition.

In its most severe forms, EB is fatal; even in its mildest forms it can still cause lifelong disability and pain. Blisters continuously form and have to be drained and dressed daily, which is a painful process that can take several hours.

The building up of scar tissue from repeated blistering can cause fingers and toes to fuse together, which can also lead to an aggressive form of skin cancer. The overall impact of EB affects the whole body and psychological challenges are inevitable.

EB is currently incurable.



## Living with Recessive Dystrophic EB

“I was born on the 17th May 2008. My mum had a normal pregnancy like most women. But when I arrived everyone was surprised. My Mum fainted and my dad just cried. No one could prepare us for what lay ahead. I lived in an incubator for the first two months of my life and soon after I was diagnosed with Recessive Dystrophic Epidermolysis Bullosa (RDEB). This means my body is covered in blisters and some of my skin is missing. The doctors told my parents that I would die so they should try not to get too attached to me. But a year later I was still alive.

Growing up with EB is a constant mental and physical battle. Life was lonely. When I went to a park everyone would move away from me and look scared. My first few years were spent in Spain but the heat and insect bites made my daily life unbearable. I was always in hospital because I had high temperatures. My clothes would stick to my skin and it would be impossible to take off my clothes without the skin coming off too. Despite doctors saying I would not walk or talk my mum taught me how to do both. I was determined from day one – I am going to survive this.

There are many health complications with EB. The wounds which appear on my skin cause my muscles and tendons to shorten and harden which makes the joints in my bones rigid and deformed. So I've had my hands operated on a number of times as they keep fusing together. This is sometimes successful but not always. And it doesn't stop there. The lining of my mouth and oesophagus (swallowing tube) are also fragile. I can't swallow and eat like normal people. I have a gastrostomy button – a tube attached to my stomach which provides me with food and drink through a syringe. As well as being in constant pain my feet get very swollen too. Luckily I have a wheelchair which helps me get about.

On doctors' orders my family moved to the UK in 2017 as the climate is better suited to my EB. It took 9 months for me to be accepted at a local school. Given the complexity of my condition I need 1-1 classroom support. I am happiest when I'm at school and I feel lucky because my teachers have helped me and my family.

DEBRA UK have supported me and my family though some very tricky times. I am so grateful. My DEBRA Community Support Worker attends medical visits and hospital appointments with me and recently organised a translator to visit us for a meeting with my social worker. Sometimes my clothes have to be cut off me because the blistering on my skin is so bad. DEBRA gives me clothes from the local charity shop to wear otherwise I wouldn't have any. I have a mobile phone now and can use it to keep in touch with my school friends thanks to DEBRA and help from a charity called Brighter Side of Life so I do not feel alone anymore.

Sometimes I feel like I am going to die. I cry a lot. But I must keep going. When I grow up I want to study to become a scientist to make new medicines for children like me – with EB. I believe anything is possible”.

Hiba, aged 11



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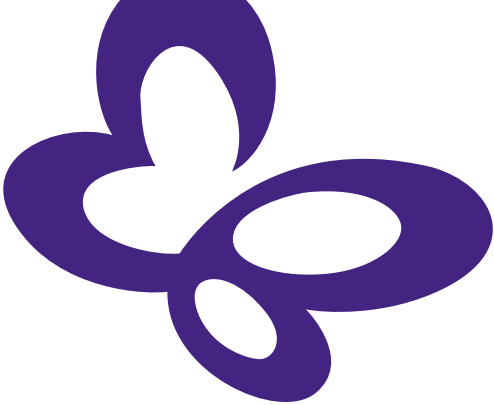
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# #FightEB

# Our Strategy



## 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

# Our Work In 2019



For every £1 raised 84p spent on charitable activities or designated for future charitable spend



£3.11m spent on charitable activities in 2019



£2.12m raised in DEBRA shops and £1.67m by DEBRA fundraisers



A further £500k approved for charitable spend on two new research projects



Total net income £3.9m, an increase of 13% over 2018



Over 60,000 registered Gift Aid donors

### Research

16 ongoing research projects facilitated in the UK

£686k committed to new research projects

£810k spent on other research activities

### Healthcare

2,000 patients supported by EB specialists

17 specialist EB training grants

Up to 25% of specialist EB nurses, costs covered by DEBRA

### Community Support

3,111 DEBRA Members of whom 503 accessed DEBRA's Community Support service

327 home visits took place and 334 support grants awarded

755 holiday days taken in DEBRA's six holiday homes

### International

48 DEBRA groups worldwide

8 international clinical best practice guidelines, funded by the UK

17 global EB research sites funded in 2019





## Katie and Jamie's Story



### Living with Generalised Severe EB

"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.

Jamie has a full skin check every day, which involves me lancing all blisters that have occurred overnight. I dress all the wounds and put protective bandages on before dressing him as well as giving him pain killers. The daily routine is quite structured to ensure he feels safe and secure at all times. He has his large dose of morphine before the evening meal so he's ready for his bath and can cope with more dressing changes.

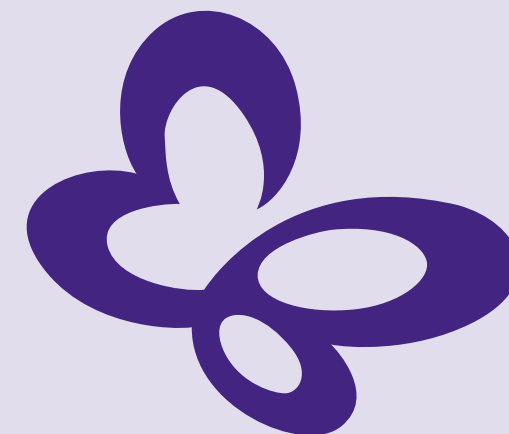
I thought that being a nurse would make caring for Jamie easier. The most difficult thing about EB is seeing your child in pain, knowing that the care you are giving is causing so much distress. The Community support I have received from DEBRA has been outstanding and makes a real difference.

DEBRA has provided me with a changing table where I keep all the dressings and has signposted me to disability living allowance to help soften the blow of not being able to return to work as I am now a full time carer. The information booklets and website are a good reference to anyone wanting to know more.

Meeting others with EB through DEBRA has made my outlook on the future less daunting. Seeing children with EB playing happily and managing daily activities gave me positivity and hope. The DEBRA days give me a boost of mental energy I so often need.

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

**Katie White, Mother of Jamie White**



# Strategic Report

Highlights DEBRA's services and income generation activities in 2019 and an overview of future plans.

# A Message from our Chairman & CEO

Our role as governors of the charity is to ensure that we work continuously toward our strategic goals of improving the quality of life for the EB Community whilst searching for cures. We’re delighted to report that 2019 saw some significant developments towards both.

At the time of writing this report we find ourselves in the midst of having to ‘fast forward’ from reflecting on the successes of 2019 to facing the stark reality of the challenges that COVID-19 brings us in 2020. The outcomes are currently uncertain and they will ultimately shape our ambitions for the years ahead but, for now, it’s only right that the annual report should focus on the year on which it reports (2019).

DEBRA UK has always been central to collaboration with other DEBRAs globally and with other EB charitable organisations. Last year saw us take that collaboration further and led to us taking a bold new step towards making our first investment in a Biotech project (FIBRX Derm) alongside four other parties.

2020 will see us developing these partnerships and we are delighted to have been the driving force, and primary financier, of EB2020 - a flagship world congress on EB which was held in London in January 2020. The event was twice the size of any previous EB Research/Care conference, with over 700 attendees from 50 countries. We gathered the world’s greatest minds in EB research and clinical management for four days and gave them a platform to share their thoughts and the opportunity to collaborate with peers. Twenty different Biotech companies were present, all focusing their efforts in the direction of cures, treatment and management strategies for the EB Community. And we also managed to attract all other worldwide EB research funding bodies. We are hugely excited by the potential outcomes of EB2020 and are big supporters of seeing the event repeated.

2019 saw the needs of the EB Community continue to grow and we committed to a significant expansion of our Community Support Team as well as investing in a further holiday home for the EB Community, based in Norfolk.

Despite a recent survey informing us that some 10m people in the UK are aware of DEBRA, we decided to invest in our Public Relations and Communications team as part of our overall brand development and to further drive awareness of and education about EB.

We are clearly dependent on having the finance to make any investment and we are delighted to say that 2019 saw significant net income generation and growth of 13%, allowing the above and much more to happen. Shops, Fundraising, Major Events and Trust income was excellent across the board with many success stories you can read about later in this report. This financially strong position is vital as we face the expected decline in income at the start of the outbreak of COVID-19 in 2020.

Our Retail operation provides us with the added benefit derived from being a charity with one of the highest retail gift aid conversion rates in the country. It also creates an environmental benefit via the recycling of clothing and everyday products through our shops.

Over the last decade we have grown our organisation threefold, forcing us to say goodbye in 2019 to our original head office in Crowthorne. Our new premises in Bracknell will help us to recruit and retain the highest quality members of staff.

DEBRA is hugely dependent on, and is profoundly grateful to, its army of around 1,000 volunteers who are spread widely across the UK. They are a hugely diverse group of individuals and families who share our goals of improving the quality of life for the EB Community and supporting the charity in a variety of ways, from raising funds using their local networks and providing assistance to our paid staff in our 120 shops to participating in a variety of challenges. We would both like to say a huge ‘thank you’ to each and every volunteer.

We are financially strong and fully expect to come through the Covid-19 crisis intact. As the UK gradually comes out of lockdown, we will be more dependent than ever on each and every one of our community to pull together to get us back to ‘normal’ (whatever that looks like). We thank you in advance for your support to that end and look forward to delivering you a healthy annual report for 2020.

Let’s look forward positively and together continue to #FightEB.

**Jim Irvine**  
Chair of Trustees

**Ben Merrett**  
Chief Executive Officer

# Overview

DEBRA is the national charity (incorporated in the UK) supporting people suffering from Epidermolysis Bullosa (EB), a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering.

DEBRA is registered with the Charity Commission for England and Wales, as well as the Office of the Scottish Charity Regulator (OSCR), the latter required because of DEBRA’s Scottish activities that continue to form an important part of DEBRA’s UK strategy.

Receiving no direct government funding, the charity relies solely on the generosity of the public to carry out its vital work. DEBRA does take full advantage of generic government incentives (e.g. Gift Aid), which have become very important.

Envisioning a world where no one suffers from EB, the charity continues to provide specialist care to those who need it, support to people and families affected by the condition and hope for the future through funding research that could one day lead to effective treatments and a cure for EB.

## Objectives

- Enhance the quality of life for people affected by EB
- Provide continuing services and support to the EB Community
- Develop effective treatments through funding research into EB
- Advocate for the well-being of those affected by EB, and facilitate their full integration into society
- Promote best current practice in treatments for EB
- Increase professional and public knowledge of EB
- Encourage the development of global EB support groups and foster coordination between these groups and other EB related organisations to achieve our common aims
- Raise sufficient funds to achieve these objectives

In fulfilling these objectives, DEBRA encourages members of the EB Community to get involved with the charity and raise awareness of the condition.

## 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. DEBRA provides 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.

All people affected by the condition are encouraged to engage with DEBRA to further develop the services and support available through taking part in satisfaction and service development surveys, group discussions and the DEBRA patient panel made up of the EB Community who review research projects.

DEBRA’s Care & Research Committee makes strategic and fundamental recommendations on the charitable activities undertaken by DEBRA for the benefit of present and future people with any type of EB.



# Research

DEBRA continues to be strategically focused on investing in pioneering research to find cures and treatments for EB that will have a significant impact on improving quality of life. DEBRA was able to invest £686k on new research projects in 2019 aimed at developing new treatments and delivery of technology for all types of EB.

## Research Strategy

DEBRA's research strategy of cure(s), control and quality of life has, and will be, maintained within the expanding global focus on EB research. DEBRA will 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 editing methodology; small early phase clinical studies and drug re-purposing as well as projects driving a change in symptom relief – both for wound healing and cancer therapy. Critical is the balance of research into all types of EB which are represented in our community.

DEBRA is supporting a number of fellowships, helping to develop and shape our researchers and clinical experts for the future.

## Key Areas

### Academic and Industry Partnership for EBS and other types of EB

The needs of all the EB Community remain central to our research and development plan. The work at Dundee University with Dr Peter van den Akker and his team, initially looking at gene technology for treating EBS, has wider implications for research into cures for more than one type of EB and remains ongoing.

### Gene Therapy that may lead to “Spray on Skin” for RDEB

Patient-friendly effective therapies for RDEB are desperately needed. Dr Su Lwin and her collaborators at King’s College, London, propose to address this challenge by developing a spray-on gene therapy for RDEB designed for longer-lasting therapeutic benefit including prevention of scarring.

### Gene Therapy for JEB

A recently funded project on combined respiratory epithelial cell and gene therapy for improvement in respiratory symptoms in children with junctional epidermolysis bullosa aims to discover whether a gene based therapy may help with correcting the lining of the airway that is affected by EB. DEBRA welcomes another new researcher, Dr. Colin Butler from Great Ormond Street Institute of Child Health, London, and is pleased to be co-funding this project with DEBRA Austria.

### Quality of Life Improvements from New Delivery Methods

Professor Liam Grover, Professor of Biomaterials Science at the University of Birmingham, and his collaborative group are working towards the development of a new spray delivery system as both a treatment and preventive strategy for scarring that affects the mucosa or membranes in the body which characterises EB.

### Biotechnology Partnerships – Driving a Change for the Future

As well as investing in a range of academic research projects across all EB types. DEBRA has selected its first Biotech project (FIBRX Derm) – a follow on investment from a number of years ago, when a protein was identified that may have significant impact on severity and wound healing in Dystrophic Epidermolysis Bullosa (DEB). DEBRA has joined many other EB funding organisations in this particular endeavour and strongly favour this collaborative direction.

## Driving Research Globally

EB2020, a flagship world congress on EB, organised and for the most part funded by DEBRA UK, was held in London at the end of January 2020, which was double the size of any previous EB Research/Care conferences. The data presented represented the latest in research and clinical management along with presentations and participation from all other EB research funding bodies. Over 20 biotechnology companies sponsored and attended the meeting, all focusing their efforts in the direction of cures, treatment and management strategies for the EB Community.

DEBRA welcomes partnership and collaboration with other EB research organisations and welcomes the mutual aims of finding cures for the EB Community. Communication and coordination is critical to the success of continued international research projects, both in direction and funding.

## Research by Numbers

|       |   |       |   |
|-------|---|-------|---|
| £686k | committed to new research projects              | 17    | researchers funded by DEBRA UK in 2019          |
| £810k | on additional research expenditure              | 25    | research groups funded in the past five years   |
| 16    | ongoing EB research projects funded by DEBRA UK | £7.7m | spent on research grants over the last 10 years |

## Looking to the Future

Breadth of research and exploring all avenues towards cures and treatment remains important not least to ensure that no stone remains unturned.

DEBRA will continue to use expert summits to identify new research opportunities. We will also continue with our strategy of funding projects through our reactive grant rounds and move increasingly towards proactive identification of projects and look to develop and enhance our funding strategies.

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

## Aims for 2020

- Invest c£600k on research projects in 2020, curtailed from the original plan of £1m as a result of the impact of COVID-19 on income generation
- 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 the quality of life
- Proactively identify core areas for research and enhance the EB clinical and research community
- Champion communication, coordination and collaboration to ensure a coherent approach to EB research globally



# Community Support

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

## Engaging with the EB Community

DEBRA consistently requests and reviews feedback from its Members through the use of surveys, focus groups and general meetings. Some of the topics include programme requests for Member events, new projects and publications. The 2019 National Member Survey received a high response rate and in summary identified that Members would like more of what DEBRA is currently doing, with specific focus on peer support and enhancing printed materials and website content/functionality.

## Key Areas

### Information and Liaison Support

The quality of life for the EB Community continues to be enhanced by DEBRA's support. Areas identified needing assistance with particular issues include: welfare rights reform, housing, employment, education and independent living.

DEBRA offers a range of benefits to its Members, which is why a continued area of focus remains on contacting people suffering from EB who are not taking advantage of the services. These services are provided based on feedback received from the EB Community and are advantageous to those impacted by the condition. In 2019 the Community Support Team started a process of growth and restructure, which will allow more support to be offered across the UK in an attempt to meet the increasing demand and complexities of support needed by the EB Community. It is predicted that the increase will continue as membership increases and as other agencies continue to cut back their services.

### Support Grants

DEBRA provides support grants to Members for emerging needs and to assist in covering costs for basic quality of life improvements, such as white goods. In 2019 a new grant fund was made available to Members to promote independence through technology. In addition to DEBRA's support grants, the Community Support Team successfully helped members of the EB Community in accessing financial support from other sources.

### Community Events

There are many stories of Members of the EB Community feeling isolated and alone. It is important for DEBRA to provide opportunities across the UK where DEBRA Members can meet, share stories and learn more about how others manage the condition. DEBRA provides the EB Community with a UK-wide EB Get Together event known as Members' Weekend. This event provides an excellent opportunity for members of the EB Community to meet with other Members and professionals, as well as to learn more about research and living with EB. For many people this has become an annual two-day event to maximise opportunities for meeting others living with EB.

In addition to the annual event, DEBRA also hosted three regional Member events, as well as one long weekend away trip in 2019. The latter event provided the opportunity for respite, peer group support and developing independence, and was highly rated by attendees.

### Respite Care

Having the opportunity to go on holiday is often out of reach for many people within the EB Community, often because of cost or inadequate facilities. 110 holidays were taken by Members in 2019 in DEBRA holiday homes. In September 2019 a new holiday home was purchased in Norfolk. DEBRA now own six holiday homes at five locations across the UK, which were booked to full capacity over the peak seasons.

## Significant Partnerships

DEBRA works with, and is a member of, other organisations – including Disability Rights UK, and Carers UK, to enhance the services available to the EB Community.

## Community Support by Numbers

|     |  |       |  |
|-----|--|-------|--|
| 503 | individuals accessed the DEBRA Community Support service | £925k | spent on Membership and Community Support activities |
| 334 | support grants awarded to value of £85k                  | 3,111 | individuals in the free DEBRA membership scheme      |
| 369 | people attended Members' Day                             | 755   | holiday days taken in DEBRA's six holiday homes      |
|     |  | 327   | home visits took place                               |

## Looking to the Future

To best meet the needs of the EB Community, DEBRA plans to increase engagement with its Members. This will in turn help shape and focus care and support service developments and improve Membership benefits, including more regional/local events.

Publications and the use of multimedia will be reviewed and developed to ease the sharing of information. Development of a more detailed understanding of the EB Community is planned to help achieve a more proactive service.

A new or replacement holiday home is planned in 2021, and funds will be utilised to expand the team in order to deliver support to a growing number of Members and undertake new initiatives or enhance existing ones.

## Aims for 2020

- 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 needs and increasing demand that is likely post COVID-19 – for example if unemployment increases the need for support with benefits is likely to increase
- Ensure 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
- Increase Membership and engagement of Members, including a survey of service satisfaction
- Review and promote support grants available to Members
- Introduce a number of local and smaller member events across the UK – these may be virtual events depending on the longevity of the pandemic
- Update and enhance the range of information and publications, and improve the accessibility of information available to Members and healthcare professionals
- Explore the opportunities available to establish a volunteer support network
- Maintain membership of external organisations (such as Disability Rights UK), facilitating DEBRA's ability to campaign for the EB Community
- Publish a report on the achievements and support available for the EBS Community

# Healthcare

DEBRA provides 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 both 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 amongst the podiatric community about the condition. In order to strengthen this service, in 2017 DEBRA committed £105k 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. The first training course took place in London, November 2019 and the EB podiatry network has been established.

### Clinical Teams

With limited numbers of specially trained EB clinical professionals, DEBRA provided 38 study grants to support the designated national EB team including doctors, nurses and dietitians to enable professional development, knowledge and experience in the field of EB to be maintained at the highest standard.

DEBRA also provided 17 study grants to other health professionals including school nurses and ward staff to gain knowledge and experience of EB to help provide the best care to the community across the health and care services.

### Nursing

Recognising the need to provide further support to existing nursing teams at the two paediatric designated Centres of Excellence, DEBRA continued to fund an additional two-year fixed-term nursing post at each location. This ensures the new teams (following multiple retirements and vacancies) become well established and 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.

### Rare Diseases Centre

The Rare Diseases Centre at St Thomas’ Hospital (supported by £250k DEBRA funding in 2017) continues to greatly enhance the clinical facilities available to the EB Community and further enables the development of multi-disciplinary working. DEBRA continues to support all Centres of Excellence in EB, through lobbying or funding to ensure appropriate facilities and equipment is available for EB patients.

## Significant Partnerships

Collaboration with leading healthcare organisations is vital in providing appropriate care and support to the EB Community. The partnership between DEBRA and the NHS has a direct impact on increased quality of life for EB sufferers through greater access to specialist care (e.g. home visits, outreach clinics and bereavement support).

In addition, DEBRA has funded small pieces of equipment, inpatient grants and inpatient TV viewing during hospital stays, as well as some travel and accommodation to enable individuals and carers to attend appointments. DEBRA has helped facilitate clinical best practice guideline development by working closely with the clinical network and DEBRA International and has supported the team with funding for clinical supervision.

## Healthcare by Numbers

|           |   |       |                                |
|-----------|---|-------|--------------------------------|
| 2,000     | patients supported by EB specialists            | £357k | spent on Healthcare activities |
| 100       | days of specialist dietician services           | 235   | hospital inpatient TV grants   |
| 16        | clinical supervision workshops                  | 17    | specialist EB training grants  |
| Up to 25% | of specialist EB nurses’ costs covered by DEBRA |       |                                |

## Looking to the future

The EB Community is at the core of DEBRA’s work, so future plans include identifying clinical need and research that aims to improve the quality of life for people living with EB today.

Ongoing partnership work with the EB Centres of Excellence, specialist clinical teams and commissioners will continue to be developed to ensure the level of care required is met.

## Aims for 2020

- It is recognised that some nurses will be redeployed during the pandemic. However, DEBRA remains committed to supporting the EB health service and will continue funding up to 25% of each specialist EB nurse in the UK carrying out charitable activity, plus final year 100% funding for two short term posts to support newly formed teams
- Promote training opportunities and study grant availability to enhance best clinical practice
- Encourage innovative projects and service developments that will enhance the lives of people living with EB
- Implement the DEBRA UK Clinical Research Strategy – encouraging and offering financial support in developing best practice research that will enhance the quality of life of people living with EB
- Identify the areas of clinical priority, and provide funding towards the development of EB clinical best practice guidelines within the identified areas



# DEBRA – UK & International

International collaboration and coordination is vital in developing effective treatments and a potential cure(s) for EB. DEBRA works closely with other DEBRAs globally and external groups to ensure work is not duplicated and best practice information is shared with all relevant parties – including researchers, clinicians, charities, pharmaceutical and biotechnology organisations.

## Collaborating at the International Level

The UK's strategy for international collaboration remains consistent with the following key objectives:

- Improve clinical care through developing clinical networks, sharing knowledge and developing clinical practice guidelines
- Raise awareness of EB and the care required by advocating on behalf of the UK Membership
- Improve joint working on communication, campaigns and projects

## Key Areas

### Coordinating International Research Projects

DEBRA UK is a founding member of DEBRA International (DI), an umbrella organisation with around 50 members in other countries that aims to ensure all EB research activity is coordinated worldwide.

### Enhancing Global EB Care and Best Practice

Alongside other DI members, DEBRA UK is assisting the development of an International EB Patient Registry and Clinical Best Practice Guidelines (CPGs).

### Raising EB Awareness around the World

Awareness of the condition with the general public is poor and DEBRA UK aims to raise its profile significantly in the coming years through integrated, coordinated awareness campaigns together with other DI groups.

### Enhancing Clinical and Research Knowledge

DEBRA UK funded four training grants (Professor Robin Eady Grant fund) to assist clinicians and researchers further their professional development and interest in the field of EB.

DEBRA UK produced a report on the global impact of EB research highlighting the achievements to date and current projects in lay terms, accessible to all key stakeholders.

## Significant Partnerships

DEBRA UK supports a small number of international projects and makes a contribution to the running costs of DI through its subscription as well as giving time and expertise to support DI. DEBRA UK ensures good value is received from DI's activities.

DI coordinated the clinical practice guideline programme and also manages the EB Without Borders (EBWB) group in a collaborative effort to assist EB sufferers in need around the world, particularly in those locations where a leading DEBRA organisation is not present.

## International by Numbers

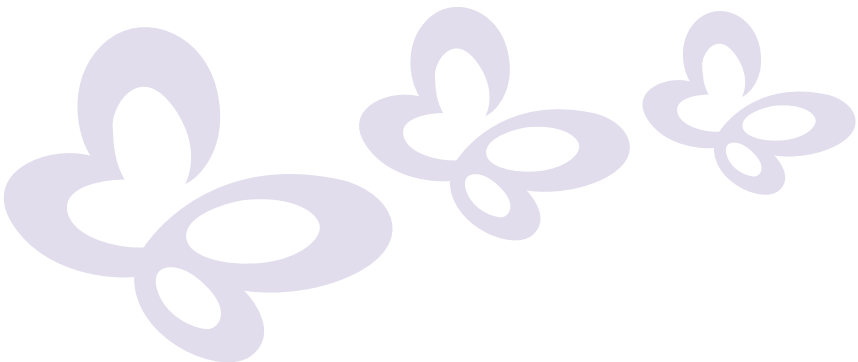
|     |   |    |  |
|-----|---|----|--|
| 48  | DEBRA groups worldwide  | 10 | CPGs in development around the world with four published |
| 333 | Members of Clinical Best Practice Guidelines network – all continents represented | 8  | International CPGs funded by DEBRA UK                    |
| 364 | Individuals taking part in the DI Research Involvement Network                    | 1  | Robin Eady training grants funded by DEBRA UK            |
|     |   | 7  | Robin Eady course/conference grants funded by DEBRA UK   |

## Looking to the Future

Working with the aims of DI, DEBRA UK plans to bolster its activities through further funding of services, (particularly in the development of international Clinical Best Practice Guidelines and the international EB patient registry).

## Aims for 2020

- Provide funding for the development of international Clinical Best Practice Guidelines
- Coordinate international research grant rounds
- Work with other research groups to ensure information sharing and to prevent duplication
- Assist DI in the development of international strategy
- Ensure information on research is made easily available to Members, professionals and industry
- Having delivered the flagship EB World Congress in January 2020 in London we believe we have identified opportunities and set out a blue-print for further world congresses





## Pioneering Research

“We are dedicated to funding research projects to find cures and improve the quality of life for people suffering from EB. We are making significant progress in the ongoing EB research projects which include research into gene editing, EB cancer, wound healing and alleviating the debilitating symptoms of pain and itch. By gathering the scientific evidence needed, we hope effective treatments can become widely available for the EB Community.”

**Caroline Collins, Director of Research**



## Specialist Healthcare

“DEBRA’s investment into EB Podiatry care has enabled us to increase awareness of EB in the medical industry and help improve the quality of care to the EB Community nationally. The EB Skills in Podiatry training course and Podiatry Clinical Best Practice Guideline (CPG) launched in 2019 has increased medical understanding of the condition and helped raise awareness in the healthcare industry. A patient version of the CPG was also published for the EB Community and provides advice on all types of EB to help people in the UK and around the world with managing their everyday EB footcare problems in the most beneficial way.”

**Dr Tariq Khan, Consultant Podiatrist & DEBRA Podiatry Lead**



## International Collaboration

“From gene discovery to cutting edge clinical trials, vital research into controlling symptoms, and finding better ways to manage devastating complications like cancer, the multimillion Euro investment from DEBRA to the international EB research community has been a remarkable journey. Striving to find a cure, better ways to treat symptoms and prevent complications however still requires further work. With DEBRA’s strength behind the international collaborative effort, the future looks assured, and progress will continue and reach fruition.”

**Professor Jemima Mellerio, Consultant Dermatologist & Head of the Rare Diseases Centre**



## Lifelong Care & Support

“EB can be an extremely isolating condition. The Community Support Team is driven to help the EB Community and improve their quality of life, by providing support, enabling them to access relevant services and providing information around issues including, but not limited to, benefits, finance, housing, education, employment and well-being. As the National Community Support Manager, I aim to further develop the national EB Community support service by delivering a robust and professional support and advocacy service to the entire EB Community.”

**Sabrina Khan, National EB Community Support Team Manager**





# Public Engagement Raising Awareness

Public awareness of EB (Epidermolysis Bullosa) and the work of the charity is relatively low, when benchmarked against conditions that have a similar number of sufferers as EB. A YouGov poll undertaken for DEBRA UK in 2019 revealed that 9% of UK adults were aware of EB. The level of awareness rose to 12% when given a description of the condition and to 15% for the charity name DEBRA. Conditions with similar numbers in the UK such as Motor Neurone Disease had a significantly higher level of awareness at 92%. Raising awareness of EB and the charity is a priority for 2020.<sup>[1]</sup>

## #FightEB Campaign

As part of national EB Awareness Week in October, the second #FightEB campaign was launched on social media to raise awareness of the condition. The campaign’s headline messages focussed on the devastating impact of the fragility of the skin as a result of EB. Influencers within the DEBRA Community and leading EB experts helped create compelling video content and encouraged social sharing of comment and stories from those living with EB. The campaign increased the charity’s reach on social media platforms by 327% from 301,000 to 1,287,095 with engagement up by 105%. Fundraising linked to the campaign for research and treatments to help alleviate pain, itch, wounds and mental health was boosted. This was in part due to the commitment and generosity of Tom Holland and the Brothers Trust, with the sales of limited edition #FightEB t-shirts.

DEBRA continued to focus on developing its online presence with strategies to increase its following on social media platforms, introduced a number of new online campaigns to recruit volunteers and generated an increase in stock donations for the charity shops. In October 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 the profile of EB and the work of the charity relies on our ability to reach a wider audience with compelling stories and up to date information that will engage the EB Community, healthcare, researchers, supporters and the public. During 2019 a review was undertaken of communications and the resources needed to drive global awareness of EB and increase funding for research, healthcare and support. The outcome was a commitment to achieve a digital first approach and the development of the Marketing and Communications function to increase expertise and capacity in digital, PR and content generation.

The work of DEBRA would not be possible without the help of the EB Community and supporters who share their experiences and enable us to tell their inspirational stories.


## Significant Partnerships

The #FightEB campaign was heavily promoted using social media, as well as in the traditional press, having reached a pinnacle with the involvement of Tom Holland and the Brothers Trust, especially through the sales of the #FightEB t-shirts.


<sup>[1]</sup> All figures, unless otherwise stated, are from YouGov Plc. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+). Total sample size was 2,153 adults in fieldwork undertaken between 27th-28th August 2019 and 2109 adults for fieldwork 16th-17th October 2019.




“Imagine having skin too fragile to touch.”  
Help Maya #FightEB




“Imagine being too fragile to hug.”  
Help Mason #FightEB




“Together we will fight EB, together we can beat EB.”  
Help Matthew #FightEB



“Imagine having skin too painful to walk.”  
Help Gemma #FightEB



“Imagine having skin too fragile to blink.”  
Help Qassim #FightEB



“Imagine having skin as fragile as paper.”  
Help Myra #FightEB

## Public Engagement by Numbers

- 2,800k

reached on social media in 2019
- 33%

increase in social and media exposure since 2018
- 14%

increase in social media engagement since 2018
- 16%

increase in traffic to the DEBRA UK website since 2018

## Looking to the Future

The key areas of focus for 2020 will be to increase the PR, Content and Digital expertise enabling the Marketing team to develop a digital-first approach, ensure the voice of the EB community is heard and connect and engage with supporters and influencers to increase awareness of EB and highlight the work of the charity.





## Claire and Matthew's Story



**debra**  
for people whose  
skin doesn't work  
we do

“Imagine living in  
constant pain.”

### The Physical and Mental battle of living with EB

“16 years ago I didn't expect to have a 'different' child and didn't know anything was wrong for the first few weeks. The DEBRA EB nurses said this crazy name to me, 'Epidermolysis Bullosa' (EB). I couldn't even pronounce it but knew my world had changed. The EB nurses helped me to manage and understand my Matthew's condition. I was suddenly being taught to lance blisters, drain them, dress them, administer pain killers and ensure a constant supply of dressings.

Matthew is currently studying for his GCSEs so my role is more complicated and diverse than ever. The battle with EB is a constant, relentless, uphill climb and the top of the mountain always seems just out of sight. I think I'm getting somewhere with the challenge and then something new jumps up to surprise us; new open wounds, new vitamin deficiencies, new psychological problems. He's finding things really hard, as am I.

My son is remarkable and my inspiration. His resilience, bravery and determination in the face of endless pain is incomprehensible to me, I am permanently in awe of him. Life is currently a constant, relentless round of medication, dressings, appointments and pain. He is an amazing boy who puts up with it. He has his moments but considering the permanent pain that he is in, he is my hero!

We decided to share our EB story and get involved in the #FightEB Campaign in order to raise awareness of the condition and help raise funds to advance research into finding effective treatments and a cure(s) for EB. DEBRA is investing in an innovative research trial that pilots a new pain relief medicine, one that could give Matthew relief. The pioneering research projects DEBRA funds gives us hope that in the near future, new treatments and a cure will become widely available to the EB Community to improve their quality of life by dramatically reducing the physical pain whilst helping with psychological battles both the EB patient and their family face.”

**Claire Smith, Matthew's Mum**



## The Talbot's Story

### Fighting EB in memory of Dylan

“When our beautiful baby Dylan was born in 2017, he was rushed off to the Special Care Baby Unit where we were told he had Epidermolysis Bullosa (EB). He was taken for a skin biopsy to find out what type of EB he had; we then had an agonising 2 week wait for the results.

When the EB nurse from Great Ormond Street said they were doing a home visit that day, we knew something wasn't right. That was the day our worlds fell apart. Dylan was given the terminal diagnosis of Junctional Generalised Severe EB. The body needs a certain amount of protein to heal, and Dylan had none. His blisters were not just on the skin, but internal too. 90% of babies with this type of EB don't live to see their first birthday. After a healthy and normal pregnancy we were both in shock and completely heartbroken.



My wife and I had to make some difficult decisions about end of life care as well as managing his deteriorating condition. This involved the loss of skin, managing open wounds and pain medication. DEBRA helped us so much through such a difficult time. Our DEBRA Community Support Manager offered emotional support for us as a family and during medical appointments. DEBRA also sourced and helped fund medical equipment (specialised nappies, EB friendly baby clothes and air cushions) which took away from additional stress and meant we could spend precious time with our son.

Despite the pain he was in, Dylan was an amazingly calm and happy baby and brought so much joy to our lives. He was with us for 3 months and 1 day before he passed away. DEBRA continues to support us today; after Dylan passed away we were offered bereavement counselling and have taken respite in a DEBRA funded holiday home.

In 2018, we learnt Karen was pregnant. EB is inherited and we knew both myself and Karen were carriers of the gene which meant it was likely our baby would have the same type of EB Dylan had. Thanks to advances in EB research and the funding from DEBRA, we were able to test our baby for EB before she was born. Knowing we would not have to see our newborn go through the same pain and distress Dylan did was a massive relief. Our baby girl was born on 4th November 2018 EB free; we named her Katie Rose Talbot after the EB Specialist nurse at Great Ormond Street. Katie was such a big part of family life with Dylan, we wanted her to be forever part of our family.



We promised Dylan before he passed away that we would always continue to #FightEB so we do all we can to support DEBRA. We will always remember Dylan and treasure the memories we had with him. Dylan has inspired us and so many wonderful people to fundraise by taking on personal challenges to raise awareness and funds. I am also extremely lucky to have had the support of my work behind me, and my colleagues voted for DEBRA to become Charity of the Year in 2019, smashing their annual fundraising goal and set a new record by raising a fantastic £281k to #FightEB.

Research into EB is so very important and gives us hope that one day there will be a cure into this devastating condition”.

**Simon Talbot, Dylan's Dad**



# Fundraising

## Supporting the EB Community

As a charity, DEBRA is reliant upon its fundraising activities to deliver its charitable objectives. Everything people do to help support DEBRA – from hosting a fundraising event to donating directly – impacts the EB Community. EB is such a cruel condition and affects not just those with the condition but their whole family.

### Fundraising Mission

The Fundraising Team strives to raise as much money as possible to help support the work of the charity. DEBRA is committed to making a difference today (Healthcare and EB Community Support services), as well as working towards a better future (working internationally and funding pioneering research projects).

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

2019 was an exceptional year for Fundraising with net income of well over £1 million against a budget of £855k which was an increase of 46% from 2018. Thanks goes to everyone who helped achieve this.

### Key Areas

- Major Events**  
Thanks to the incredible generosity of Michel Roux Jnr and the team at the Langham Hotel DEBRA was able to stage a very successful Great Chefs Dinner. The Butterfly Ball in June was a success thanks to the support of David Wilkinson and friends. Fight Night achieved record income in recent years thanks to the efforts of Mark Moring and the Warren family. In total over £200k net came from these amazing events.
- Friends Groups**  
Working with the EB Community is key to DEBRA's fundraising success. In 2019 Friends Groups were launched by the White family in Bournemouth, the Faiers family in South East Kent and the Townley family in North Staffordshire. Friends Groups are instrumental in raising awareness about EB in the local community.
- The DEBRA Golf Society**  
Over £90k was raised by the DEBRA Golf Society and the Race For Mauritius was won by the Chevening Financial Team.

#### Significant Supporters

- **The Access Group:** the company chose DEBRA as their charity of the year because one of their employees tragically lost a baby to EB (the Tablot family featured on page 27). The group raised a total of £281k – a simply phenomenal sum.
- **EB2020 Sponsors:** £186k has been realised from 20 corporate sponsors of this event.
- **The Band Trust:** the new holiday home in Norfolk was kindly funded by the trust with their very generous donation of £150k.
- **The Brothers Trust:** the Holland family continued their fantastic support for DEBRA by donating over £50k and by inviting a number of children with EB to special screenings of 'Spiderman Far From Home' and 'Spies In Disguise'. The #FightEB campaign was re-launched as part of EB Awareness Week in October. Thanks to the support of the Brothers Trust, the campaign was seen by thousands of people.

### Significant Partnerships

DEBRA is extremely grateful to its Patron, HRH The Countess of Wessex, for her continued support. She was joined by DEBRA President, Simon Weston CBE, at the Patron's lunch at the Stafford Hotel in November. DEBRA is also very grateful to its Vice Presidents, Frank Warren and Graeme Souness, for their fantastic support.

### Fundraising by Numbers

|       |  |      |  |
|-------|--|------|--|
| £217k | net income from the DEBRA Major Events     | £90k | net income from the DEBRA Golf Society     |
| £162k | net income from individual donors          | £52k | net income from the major challenge events |
| £566k | net income from legacy and trust donations |      |  |

### Looking into the Future

The COVID-19 pandemic will have a significant effect upon income generated for the charity through fundraising. All events planned for the period from 15 March to the end of June 2020 have been cancelled or postponed. Almost all community fundraising and corporate support will be significantly reduced. Applications to grant making Trusts will continue but this will be a more crowded environment.

DEBRA will schedule as many events as possible in the latter half of the year including our Golf Days and Sporting Lunch. We hope our two big events in November, the Prestonfield Lunch and Fight Night will still go ahead. Corporate support for our events programme is likely to be affected due to the economic downturn in the longer term.

DEBRA has made considerable efforts to closely manage relations with key supporters over the last three years. This stands us in good stead to recover from the lasting effects of the pandemic. We will have to rely on the support and goodwill of our key supporters to help us get through this uncertain time.

### Aims for 2020

- Deliver the fantastic programme of events when it is safe to do so to the highest expectation and greatest return to the charity
- Utilise the events programme to progress relationships with major supporters, current corporate supporters and sponsors
- Identify new corporates and major supporters
- Empower people raising money for DEBRA, particularly those with a close connection to EB, to raise significant sums from their own local communities
- Raise awareness of the importance of legacies and the difference they make to enable DEBRA to support the EB Community

# Retail

## DEBRA on the High Street

DEBRA retail shops and stores transform unwanted goods into life-changing support and research to help #FightEB. Despite the challenging conditions faced by high street retailers in 2019, DEBRA's Retail chain achieved the charity's most successful trading year yet. This is both in terms of overall profit margin and like-for-like (LFL) sales growth, generating a total profit of £2,123k to fund our work.

DEBRA's Retail division continues to raise awareness of our charity's work in local communities and offers supporters the opportunity to offer practical help by donating goods or volunteering. None of this would have been possible without our extraordinary volunteers and staff, who work tirelessly every day to raise vital funds.

### Key Areas

#### Traditional Shops

The plan of consolidation was continued throughout 2019. Following a detailed analysis of underperforming shops, decisions have been made to either break or not renew shop leases. This approach will continue as necessary, with any shop contributing less than £8k pa closed at the earliest opportunity. Early intervention to avoid unnecessary shop closures remains a priority, in order to maximise income potential and maintain DEBRA's profile nationally. Whilst expansion within traditional retail was not a focus for 2019, DEBRA continues to consider new retail opportunities, predominantly in the South of England, where trading has proved particularly successful.

#### Furniture and Electrical

An early closure of one underperforming shop eliminated a loss maker within the chain, replaced later in the year by the new Croydon shop which saw record-breaking first day sales of £12.7k. This shop has continued to perform above the business case projections, and is expected to be a top performer in 2020. Building on the success of the existing F&E portfolio, there is planned expansion in this area with new openings planned post pandemic. The F&E portfolio suffered the relative loss of corporate stock compared to 2018, impacting LFL results.

#### Sustainability

DEBRA is working hard to develop a long term sustainability plan and to significantly lower our carbon footprint. DEBRA's 121 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 2019, DEBRA's portfolio consisted of 121; 103 Traditional and 18 Furniture and Electrical shops (11 in England and 7 in Scotland). The current portfolio is made up of 4 freeholds, 101 leaseholds and 16 temporary shops.

#### Retail Gift Aid Scheme

The result of higher trading profitability has meant that the charity's dependence on Gift Aid has reduced further. Together with retail donations, this represented a total net income of £1,169k, which is a notable achievement at a time when evidence shows that a record number of adults are paying no income tax.

#### Volunteering

DEBRA recognises the vital requirement for dedicated volunteers and understands that its retail chain would not succeed without this support. Despite the increase in overall volunteer numbers for retail in 2019, the level of volunteer contribution remains below that of comparative sized chains, and recruitment of volunteers will continue to be a primary focus in 2020.

## Significant Partnerships

Developing relationships with corporate supporters can only enhance the performance of DEBRA Retail. Initiatives in place for 2020 for partnerships include:

- A purchase agreement for Dormeo mattresses
- Donation partnerships with Barclaycard, Emma mattresses, and other organisations
- Developing relationships with Corporate Companies/Sponsors for 'Retail Challenge' team building days

## Retail by Numbers

|         |   |      |   |
|---------|---|------|---|
| 16%     | margin achieved                             | 4.7% | growth in LFL sales   |
| £1,169k | received through the Retail Gift Aid Scheme | 121  | shops at year end, 103 traditional and 18 Furniture and Electrical shops (inc. in Scotland) |

## Looking to the Future

The unprecedented circumstances created by COVID-19 have led to considerable uncertainty in the retail sector, and presented unforeseen challenges as well as the potential for new opportunities. Low volunteer numbers and the likely need to continue social distancing will be two of the challenges we will need to overcome.

The key aims for DEBRA Retail are to continue improving margin and contribution, but the way in which this will be delivered will be dependent on responding to prevailing conditions. There will be a strong focus on price optimisation within all shops in order to maximise the potential of all donations. To ensure that the highest possible standards are achieved and to maximise the effective merchandising of our shops, a series of refurbishment projects are to be carried out in some of the traditional stores.

DEBRA continues to invest in training for our shop teams, focusing on product and productivity whilst continuing to ensure that adequate training and resource is provided to ensure a safe retail environment for all staff and volunteers. Enhanced and structured training and induction programmes will be delivered through area meetings and regular shop visits. Electronic communication will be dramatically improved with the roll-out of computers to all shops in 2020.

From an environmental point of view, DEBRA is proud to be a national charity re-use retailer, and will strive to reduce the requirement for single use plastic within our shops.

A strong emphasis on the recruitment of volunteers will continue to be a key focus in shops for 2020. A revised structure in Retail Senior Management has been proposed in order to effectively and successfully deliver all key objectives.

## Aims for 2020

- Continue to consolidate the portfolio if a reasonable return cannot be made from underperforming shops
- Improve margin through price optimisation and enhance standards of visual merchandising
- Improve volunteer contribution to a level of 10–20 volunteers per shop (depending on shop size)
- Encourage members of the EB Community and their extended circle to volunteer in their local shop
- Effect greater shop social media exposure and engagement



# Our People

From its origins, over 40 years ago, as a small support group for parents affected by EB, DEBRA has grown significantly – in income and personnel - and at the end of 2019, DEBRA employed 380 employees 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 DEBRA can provide to its membership.

## Employees

### Volunteers

Volunteers continue to be a significant resource to DEBRA, and the Volunteer Manager worked closely with the Retail and Community Support teams in 2019 to develop volunteer resources in these areas.

The ‘EB Connections’ initiative, which had been introduced in 2018, developed in 2019 to successfully match a handful of Practical Community Volunteers (PCVs) with DEBRA Members to individually support them in their homes. Before the service expands, a full evaluation and review of the processes involved in supporting a member in this way, is being undertaken to ensure the safeguarding of all personnel involved.

## Learning and Development

All members of staff are encouraged to continually develop their skills and the eLearning platform that was introduced in 2017, continues to prove useful, particularly in delivering mandatory training in Safeguarding, Equal Opportunities and GDPR.

The All Staff Conference in April brought together a high proportion of staff and trustees, to share knowledge, promote internal communication, provide opportunities to recognise and reward achievement, and inspire continued engagement. The 2019 event, spanning two days, was held in Nottingham and several members from the EB Community also attended to give an insight into how the condition affects their day-to-day life.

Reflecting the increasing requirements to develop the skills of staff, and to develop bespoke training using technology such as eLearning modules, the decision was made at the end of 2019 to recruit a dedicated Learning & Development Manager.

## Pay Policy

Rates of pay and salaries within DEBRA are set at a level that are legally compliant, proportionate to the requirements of each role and sufficiently competitive within the charity sector to attract and retain the best employees for each position.

All aspects of pay – including rates, salary levels, reviews, incentive schemes and termination costs – are considered by the Quarterly Pay Review Committee, which reports to the Board of Trustees. In January 2019, 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
- The number of staff in receipt of £60k pa and above (in bands of £10k)
- Employer pension contribution

## Gender Pay Gap

DEBRA's mean gender pay gap for 2019 is 4.9%, which tells us that, on average, the hourly rate of pay that female employees receive is 4.9% lower than the rate male employees receive, which equates to a difference of £0.52 ph in monetary terms. Comparing this year's mean gender pay gap figure to that for April 2018, there has been a decrease of 0.4%, continuing the trend of a decrease each year since reporting started.

This is below the figure of 5.6% recorded for organisations within the charity sector. Whilst being a charity, for the purposes of gender pay reporting, DEBRA is designated as working within the ‘human health and social work’ arena, and within this category, the average mean gender pay gap is 23.4%, so again, DEBRA's figure of 4.9% compares very favourably.

The full Gender Pay Gap Report is available on DEBRA's website.

Table 1: Summary Gender Pay Gap Report

| Description   | Gender Pay Gap |
|---|----------------|
| Difference in hourly rate of pay – mean                 | 4.9%           |
| Difference in hourly rate of pay – median               | 0.0%           |
| Difference in bonus pay - mean                          | 43.7%          |
| Difference in bonus pay - median                        | 28.9%          |
| Percentage of employees who received bonus pay - male   | 42.9%          |
| Percentage of employees who received bonus pay - female | 52.3%          |

| Band | Description  | Males | Females |
|------|--|-------|---------|
| A    | Includes all employees whose standard hourly rate places them at or below the lower quartile.                      | 29.2% | 70.8%   |
| B    | Includes all employees whose standard hourly rate places them above the lower quartile but at or below the median. | 21.3% | 78.7%   |
| C    | Includes all employees whose standard hourly rate places them above the median but at or below the upper quartile. | 21.3% | 78.7%   |
| D    | Includes all employees whose standard hourly rate places them above the upper quartile.                            | 24.7% | 75.3%   |

## COVID-19

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 members, but they did so from their homes. Since March a further 8% of the workforce has been furloughed. Supporting and maintaining regular communication with both these groups of employees became the focus for HR.

# Our People

## Equal Opportunities

DEBRA is 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 adult or young person who comes into contact with DEBRA is adequately protected. All staff undertake mandatory training in Safeguarding and in 2019 'Safeguarding September' was introduced to maintain a high awareness of Safeguarding amongst 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. DEBRA introduced a dedicated email address for making confidential safeguarding referrals. The Safeguarding Review group met quarterly in 2019 to review the few 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.

### Community Support Team

The Community Support Team receive enhanced training in Level 2 Safeguarding and work closely with other agencies to ensure our members of the EB Community are safe and supported appropriately. Some members of the Community Support Team received further training 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.

### Retail

We are committed to creating a safe and rewarding environment for all of our people to work and volunteer in our shops. This means we have a robust Safeguarding policy to ensure everyone is treated properly and a whistle blowing service to ensure people 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 working closely with the designated Safeguarding Lead Officer to ensure that all staff, volunteers and customers are safe and supported appropriately. To ensure DEBRA is continually maintaining the highest standards of safeguarding, guidance from 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 where DEBRA has taken robust action to prevent harm coming to vulnerable people.

## Head Office Relocation

DEBRA's Head Office relocated at the end of 2019 to Bracknell from Crowthorne, where it had been for over twenty years. The new office, which accommodates personnel for Finance, Fundraising, Communications, Community Support, HR, IT, Research and DEBRA International, provides 50% more floor space and is a modern, open-plan, accessible, working environment in a fully serviced office building, close to good road and public transport networks.

The costs of relocating were kept to a minimum by securing a very competitive rental rate for the office and by fitting it out with donated furniture, free of charge, kindly donated by the Financial Ombudsman's Office.

# Financial Review

## Overview

DEBRA's accounts show the financial affairs of the charity for the year ended 31 December 2019. The charity's net income after accounting for the costs of raising funds was £3,905k, growing by 13% from £3,445k achieved in 2018.

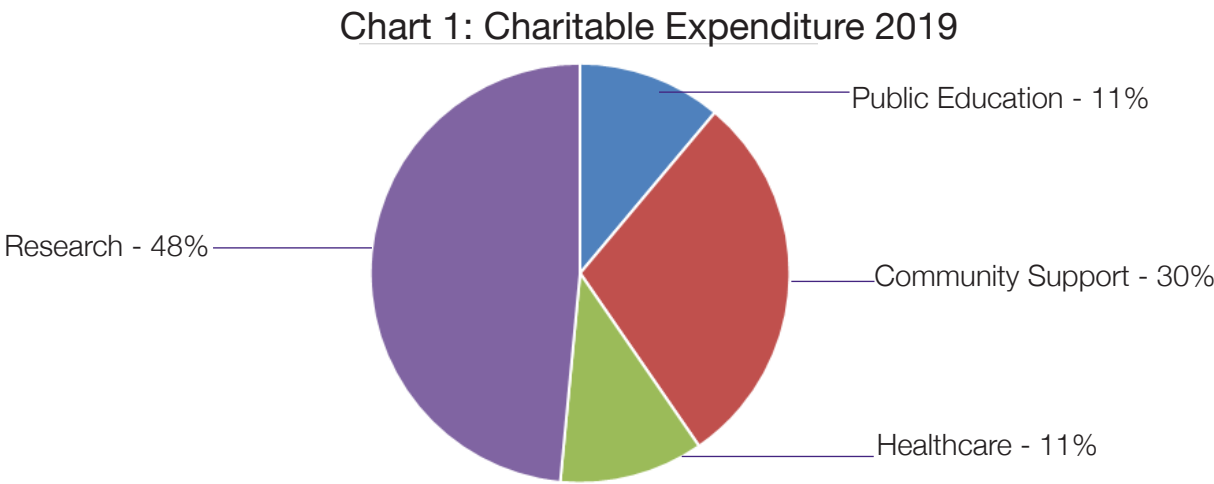
Non-Retail fundraising achieved strong growth during 2019, with particular support from The Access Group and The Band Trust.

Following on from 2018, Retail had a further year of consolidation during 2019, rather than expansion in shop numbers. Net retail income was £2,123k, which covered all overhead costs of the charity for the second year in succession.

Expenditure on charitable activities was £3,110k, resulting in a surplus of £795k for the year. For every £1 of net contribution in 2019, 84p was spent on charitable activities or designated for future charitable spend.

## Charitable spend

Charitable spend in 2019 grew by 5% over 2018. Research spend during 2019 was £1,496k (2018: £1,366k), whereas £925k (2018: £866k) was spent on Community Support initiatives, £357k (2018: £472k) on Healthcare services and £333k (2018: £261k) on Public Education.



There are plans to increase charitable spend in future periods, demonstrated by the trustees' decision to designate £2,618k to future research projects, as significant sums will be needed in the near future to continue funding expensive clinical and other trials, in both academic institutions and biotech companies.

The surplus in the year led to an increase in net assets from £4,556k to £5,352k. There was £2,231k in the general fund, £2,907k in designated funds and £214k in restricted funds. In the light of the COVID-19 pandemic, the trustees may consider un-designating funds if appropriate.



# Financial Review

## Summary

Table 2 summarises the highlights of DEBRA’s financial performance over the last five years. Net retail income achieved through the shops (including Retail Gift Aid, commission and donations received in the shops) has grown dramatically in this time from £833k to £2,123k. Net retail income before allocation of central overheads was £2,706k, which covers all DEBRA’s central overheads, plus the direct costs of raising voluntary income and all DEBRA’s fundraising events. Non-trading gross income increased from £2,979k in 2018 to £3,475k in 2019 as a result of significantly increased donations from corporates and trusts.

Table 2: Financial Summary  
£’000

|   | 2019   | 2018   | 2017   | 2016   | 2015   |
|---|--------|--------|--------|--------|--------|
| Total income  | 16,798 | 16,138 | 16,182 | 14,136 | 12,501 |
| Non-trading income  | 3,475  | 2,979  | 3,468  | 2,832  | 2,768  |
| Net trading income  | 1,198  | 1,193  | 616    | 330    | 34     |
| Net retail income including retail gift aid, commission and donations in shops* | 2,123  | 2,138  | 1,652  | 1,318  | 833    |
| Non-trading fundraising costs   | 768    | 727    | 1,083  | 819    | 763    |
| Charitable expenditure  | 3,110  | 2,966  | 3,299  | 1,715  | 2,524  |
| Retained surplus/(deficit)  | 795    | 479    | (299)  | 628    | (486)  |
| Retained surplus/(deficit) as a % of income                                     | 5%     | 3%     | (1.8%) | 4.4%   | (3.9%) |
| Net current assets  | 4,878  | 4,394  | 3,951  | 3,340  | 2,905  |
| Unrestricted reserves   | 5,138  | 4,420  | 3,997  | 4,301  | 3,732  |
| Grants payable within 1 year  | 2,201  | 1,825  | 1,156  | 1,519  | 1,694  |

\* Comparative figures have been adjusted to include retail gift aid commission to ensure consistent presentation.

In 2019 for every £1 of net contribution 84p (2018: 83p) was either spent on, or designated for future charitable activities. Cost to income ratios for charity shops are high throughout the charity sector, which impacts significantly on fundraising efficiency statistics. In addition, DEBRA has a very high proportion of income generated through its retail activities that compounds the problem in calculating a meaningful ratio. However, if income from trading activities is considered net of running costs instead of using gross trading income, this more realistic ratio is generated. This differs greatly to the fundraising efficiency ratio published on the Charity Commission website, which takes no account of the overhead costs incurred in running, in DEBRA’s case, proportionately a very large, retail operation.

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 six 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 2019 was to maintain minimum cash-backed free undesignated reserves at £1,300k, to which the charity adhered. DEBRA has a high proportion of retail income, which provides a stable and reliable income stream. However, this incurs a high cost base, and the minimum reserves figure would cover one month’s costs (excluding rent) plus six months’ rent.

The 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.

Total reserves at the end of 2019 were £5,352k, including £214k in restricted funds. Cash-backed free reserves before designations were £4,206k, of which £2,906k 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 £2,618k 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 1-2 years.

### 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. This fund will be spent, or undesignated, 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 end of 2019 which will be spent in the next year.

### General Fund

There was £2,231k in the general fund, of which £1,340k 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.

DEBRA aims to apply its income in support of its 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.

During 2019, the charity took the view that this was best achieved by investing funds not immediately needed in short-term money market deposits through Lloyds Corporate Markets.

# Financial Review

## Expenses Policy

DEBRA has expenses policies for both staff and trustees and also has 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 DEBRA's behalf

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

## Funds

The majority of DEBRA's funds are unrestricted in application and are held in a general and three 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 15 of the Financial Statements.

## Asset Cover for Funds

Note 16 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 are a house clearance service, sales of new goods in DEBRA's charity shops and sponsorship of EB2020, a conference hosted by the charity in January 2020. Other activities include miscellaneous non-primary purpose trading undertaken by the charity. For information, the company's results are shown separately in Note 20 of the Financial Statements.

## Internal Financial Controls

The trustees have conducted a review of the effectiveness of the charity's internal financial controls in 2019, 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.

# 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 DEBRA's risk register is listed in Table 3 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.

Table 3: 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 | Access all forms of government funding, Job Retention Scheme, Local Authority Retail Grants, CBILS loan and the National Lottery Community Fund<br>Cancel future expenditure commitments<br>Home working to facilitate social distancing<br>Risk assessments in shops<br>Home working risk assessments | Weekly Trustee Steering Group meeting<br>Twice weekly Operational Pandemic Planning Group meeting<br>Twice weekly Senior Management Team meetings<br>Regular executive reporting to trustees<br>Clear roles and responsibilities of trustees and staff identified<br>Appropriate reporting lines established<br>Reverse stress testing to estimate when liquidity would break<br>Financial forecasting including recovery planning following the COVID-19 pandemic through to end 2021 |
| Charity image damaged  | Marketing and PR strategy<br>Disciplinary policy<br>Crisis communications plan<br>Review of any complaints received<br>Extensive social media policy for staff   | Media monitoring<br>Annual staff appraisals<br>Register of crises<br>Investigation of occurrences  |
| Insufficiently robust cyber security   | Anti-virus software<br>Cyber insurance policy<br>Encryption of hard drives<br>Secured wifi connection<br>Off-site backup three times weekly<br>Use of firewalls<br>PCI compliance  | Anti-virus tool displays<br>Monthly reports<br>Firewall logs checked regularly<br>Daily logs of server activity  |
| Misuse of data and failure to comply with Data Protection legislation                  | In-house Data Protection Officer<br>External data protection consultancy<br>Data protection policy<br>Regular data protection training   | Data protection working party<br>Regular reporting<br>GDPR e-learning module   |
| Failure to ensure safeguarding of vulnerable adults and children                       | In-house Safeguarding Officer<br>Staff training  | Activity reports<br>Register of complaints and incidents   |



# Structure, Governance & Management

DEBRA (a 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 Members having direct experience of EB.

## DEBRA Trustees

DEBRA Members elect up to 8 of the trustees (the majority), and the Nominations & Governance Committee is responsible for proposing up to a further 7 with relevant skills to be appointed by the trustees themselves. At the Annual General Meeting in 2019, as recommended by the Nominations & Governance Committee, 2 trustees – Andy Grist and David Wilkinson – were re-elected for a further three-year term and two new trustees – Carly Fields and Christo Kapourani – were elected by the Members for their first term of three years. David Bendor-Samuel was also appointed by the board, as recommended by the Nominations & Governance Committee for a first term of 3 years, increasing the number of trustees to 14.

After the loss of DEBRA's Chair of Trustees Mike Jaega early in 2019, Jim Irvine became Acting Chair and was appointed by the board as Chair of Trustees in October 2019. Joanne Merchant was also appointed as Treasurer. New trustees receive a Trustee Handbook and other relevant publications, individual inductions from senior staff and trustee training as required. There are four board meetings per year, which the CEO and Senior Management Team (SMT) attend. DEBRA carries out regular governance reviews and during 2019 a new trustee was appointed as Chair of the Nominations & Governance Committee and tasked with completing the review of the feedback after the external governance review, carried out in 2017 and make recommendations to the board. Trustees and the Senior Management Team attended a strategy day in November 2019 which will be followed up by implementing a 3 to 5 year-plan as soon as possible once the immediate pandemic crisis has passed. Trustees attend external training courses appropriate to their role on the Board of Trustees.

## Trustee 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.

**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.

**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 management team to deliver against plans, comply with regulations and promote the cause of the charity.

## Trustee Committees (Continued)

**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.

## Board Diversity

To ensure that DEBRA has 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 give different perspectives to discussions and enhance the board's decision making process.

DEBRA follows the Equal Opportunities Policy in the selection of board members, in the same way it does 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.

## 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 Governance Code.

# Structure, Governance & Management

Table 4: Trustees’ Membership and Attendance Records as at 31.12.2019

| Board of Trustees           |                     |                     | Committees            |                          |                 |               |                              |                        |
|-----------------------------|---------------------|---------------------|-----------------------|--------------------------|-----------------|---------------|------------------------------|------------------------|
| Trustee                     | Year of Appointment | Board Meetings      | Finance, Risk & Audit | Nominations & Governance | Care & Research | Retail        | Fundraising & Communications | DEBRA UK International |
| Jim Irvine - Chair          | 2012                | <b>4 of 4</b>       | 4 of 4                | 2 of 2                   | -               | 2 of 2        | -                            | -                      |
| David Bendor-Samuel         | 2019                | 2 of 3              | -                     | <b>4 of 4</b>            | -               | -             | -                            | -                      |
| Simone Bunting              | 2011                | 3 of 4              | -                     | 4 of 5                   | -               | -             | <b>3 of 4</b>                | -                      |
| Rebecca Cresswell           | 2017                | 4 of 4              | -                     | -                        | -               | -             | 4 of 4                       | -                      |
| Simon Cuzner                | 2014                | 2 of 4              | 2 of 4                | -                        | -               | <b>4 of 4</b> | -                            | -                      |
| Carly Fields                | 2019                | 2 of 2              | -                     | -                        | 1 of 1          | -             | 2 of 2                       | -                      |
| Andrew Grist                | 2016                | 3 of 4              | -                     | 1 of 5                   | 1 of 4          | -             | -                            | 0 of 1                 |
| James Hinchcliffe           | 2011                | on leave of absence | on leave of absence   | -                        | -               | -             | -                            | -                      |
| Christo Kapourani           | 2019                | 0 of 2              | -                     | -                        | 1 of 2          | -             | -                            | -                      |
| Graham Marsden              | 2012                | 4 of 4              | -                     | 5 of 5                   | -               | -             | -                            | <b>1 of 1</b>          |
| Joanne Merchant - Treasurer | 2015                | 3 of 4              | <b>4 of 4</b>         | -                        | -               | 2 of 2        | -                            | 1 of 1                 |
| Vivien Mundy                | 2017                | 3 of 4              | -                     | -                        | 4 of 4          | -             | -                            | 1 of 1                 |
| Timothy Powell              | 2015                | 3 of 4              | -                     | -                        | <b>4 of 4</b>   | -             | -                            | -                      |
| David Wilkinson             | 2016                | 4 of 4              | -                     | -                        | -               | -             | -                            | -                      |

The committee chairs’ attendance is highlighted in bold.

## Succession Planning

DEBRA has built strength and depth in its trustee board, incorporating appropriate succession planning by appointing two Vice Chairs – Graham Marsden and Carly Fields – and each of the DEBRA Committees aims to have a Vice Chair.

## Fundraising Standards

Section 162a of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. DEBRA does 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 are presented in the accounts as ‘voluntary income’ and include legacies and grants. DEBRA makes all efforts to train staff and ensure compliance to 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 DEBRA works 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 DEBRA’s 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 DEBRA’s database; Compliance with the GDPR rules that came into force in May 2018 continues to be monitored
- DEBRA does work with vulnerable people, particularly within the EB Community, and often they do 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
- DEBRA is a member of the Fundraising Regulator and complies with the relevant codes of practice
- DEBRA received 1 fundraising complaint in 2019, which was registered, satisfactorily resolved and recorded
- DEBRA received 66 compliments in 2019 for either the service they provide to the EB Community or through liaising with the general public in DEBRA shops

## Activities in Scotland

DEBRA is 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.

On the income generation side, there were 2 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.



# Auditors

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

In addition to the audit work, BDO LLP provided a variety of non-audit services throughout the year, as disclosed in Note 6 to the Financial Statements.

BDO LLP have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditors 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  
26 June 2020



# Trustees' Statement of Responsibilities

The trustees are responsible for preparing the Strategic Report, the Trustees' Annual Report and the Financial Statements in accordance with applicable law and regulations.

Company law requires the trustees to prepare Financial Statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law the trustees must not approve the Financial Statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period.

In preparing these Financial Statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Make judgements and accounting estimates that are reasonably prudent
- State whether applicable UK Accounting Standards 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 business

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity 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 charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Financial Statements are published on the charity's website in accordance with legislation in the United Kingdom governing the preparation and dissemination of Financial Statements, which may vary from legislation in other jurisdictions. The maintenance and integrity of the charity's website is the responsibility of the trustees. The trustees' responsibility also extends to the ongoing integrity of the Financial Statements contained therein.

# Auditor’s Report

## Independent Auditor’s Report to the Members and Trustees of DEBRA

### Opinion

We have audited the Financial Statements of DEBRA (‘the Charitable Company’) for the year ended 31 December 2019 which comprise the statement of financial activities, the balance sheet, the cash flow statement and notes to the Financial Statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 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 2019 and of its incoming resources and application of resources 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 in 2010

### 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 relevant to our audit of the Financial Statements in the UK, including the FRC’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 Related to Going Concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- The trustees’ use of the going concern basis of accounting in the preparation of the Financial Statements is not appropriate; or
- The trustees have not disclosed in the Financial Statements any identified material uncertainties that may cast significant doubt about the Charitable Company’s ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the Financial Statements are authorised for issue

### Other Information

The other information comprises the information included in the Annual Report, other than the Financial Statements and our Auditor’s Report thereon. The other information comprises: the Chairman and CEO statement and the Strategic Report. The trustees are responsible for the other information.

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.

In connection with our audit of the Financial Statements, 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 audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the Financial Statements or a material misstatement of the other information. 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’ Report, which includes the Directors’ Report and the Strategic Report prepared for the purposes of Company Law, for the financial year for which the Financial Statements are prepared is consistent with the Financial Statements
- The Strategic Report and the Directors’ Report, which are included in the Trustees’ Report, have 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 misstatement in the Strategic Report or the Trustees’ Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 requires us to report to you if, in our opinion:

- Proper and 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 directors’ remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit



# Auditor's Report

## Responsibilities of Trustees

As explained more fully in the trustees' statement of responsibilities, 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 determines 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 the Acts and relevant regulations made or having effect thereunder.

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.

A further description of our responsibilities for the audit of the Financial Statements is located at the Financial Reporting Council's ('FRC's') website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.


## Use of 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 to the Charitable Company's trustees, as a body, in accordance with 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 and trustees 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, the Charitable Company's members as a body and the Charitable Company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



*BDO LLP*

Kyla Bellingall (Senior Statutory Auditor)  
For and on behalf of BDO LLP, statutory auditor  
Birmingham  
Date: 3 July 2020

BDO LLP is a limited liability partnership registered in England and Wales (with registered number OC305127).



# Tom's Story



## Raising Awareness of EB Simplex

"I was born with Epidermolysis Bullosa Simplex (EB), a hereditary condition which causes the skin to blister and tear at the slightest touch. My parents first noticed something was wrong as my feet started to blister when I learned to walk. Soon after I was diagnosed with EB Simplex, the more common type of EB (Junctional and Dystrophic being the more severe forms).

I've always been active since I was a child so participating in sports activities whilst being in constant pain is something I've learned to live with.

The condition affects my feet when walking or running in warm weather. The trigger point for this is around 18°C plus, but my skin will start blistering if I'm active in cooler conditions. The blisters are likened to third degree burns by health experts and can form anywhere on my feet, in between my toes and under my toe nails.

The majority of people love warm weather but my feet are a ticking time bomb when the sun comes out. The most effective short term relief for me is to put my feet under the cold water tap. To stop the blisters from growing I cut them with surgical scissors and press them. This is excruciating but a necessity to prevent the pain from worsening.

EB isn't just a physical condition, it's all consuming and mentally draining. My feet are often covered so on the face of it nothing appears to be wrong with me as my symptoms aren't visible. I share this condition with my mum and I've embedded certain coping mechanisms into my daily lifestyle. We have both tried every treatment available from Botox injections to soaking my feet in formaldehyde. All have had varying degrees of success but nothing resembling pain relief or a cure.

It's difficult living with EB as the majority of society are virtually unaware it exists. I hope to raise awareness of Epidermolysis Bullosa Simplex on a global level by sharing my story and believe the international collaboration work DEBRA is funding is vital to finding effective treatments and a cure(s) for the condition to benefit of the 500,000 sufferers worldwide".

**Tom Ridley**



# Financial Statements

For the year ended  
31 December 2019

## Statement of Financial Activities

Statement of financial activities including income and expenditure account for the year ended 31 December 2019

|                                    |       | 2019<br>Unrestricted<br>funds | 2019<br>Designated<br>funds | 2019<br>Restricted<br>funds | 2019<br>Total     | 2018<br>Unrestricted<br>funds | 2018<br>Designated<br>funds | 2018<br>Restricted<br>funds | 2018<br>Total     |
|------------------------------------|-------|-------------------------------|-----------------------------|-----------------------------|-------------------|-------------------------------|-----------------------------|-----------------------------|-------------------|
|                                    | Notes | £                             | £                           | £                           | £                 | £                             | £                           | £                           | £                 |
| <b>Income and endowments from:</b> |       |                               |                             |                             |                   |                               |                             |                             |                   |
| Donations and legacies             | 2     | 2,790,693                     | -                           | 573,611                     | 3,364,304         | 2,557,209                     | -                           | 261,229                     | 2,818,438         |
| Charitable activities              |       | 20,299                        | -                           | -                           | 20,299            | 19,700                        | -                           | -                           | 19,700            |
| Other trading activities           | 3     | 12,845,645                    | 264,717                     | 211,958                     | 13,322,320        | 13,025,419                    | -                           | 134,072                     | 13,159,491        |
| Investments                        | 4     | 56,544                        | -                           | -                           | 56,544            | 47,362                        | -                           | -                           | 47,362            |
| Other                              |       | 34,432                        | -                           | -                           | 34,432            | 93,291                        | -                           | -                           | 93,291            |
| <b>Total</b>                       |       | <b>15,747,613</b>             | <b>264,717</b>              | <b>785,569</b>              | <b>16,797,899</b> | <b>15,742,981</b>             | <b>-</b>                    | <b>395,301</b>              | <b>16,138,282</b> |
| <b>Expenditure on:</b>             |       |                               |                             |                             |                   |                               |                             |                             |                   |
| Raising funds                      | 6     | 12,891,642                    | -                           | 1,000                       | 12,892,642        | 12,692,533                    | -                           | 1,125                       | 12,693,658        |
| Charitable activities              | 6     | 1,446,033                     | 1,141,627                   | 522,388                     | 3,110,048         | 1,675,187                     | 1,031,119                   | 259,358                     | 2,965,664         |
| <b>Total</b>                       |       | <b>14,337,675</b>             | <b>1,141,627</b>            | <b>523,388</b>              | <b>16,002,690</b> | <b>14,367,720</b>             | <b>1,031,119</b>            | <b>260,483</b>              | <b>15,659,322</b> |
| <b>Net income/ (expenditure)</b>   |       | <b>1,409,938</b>              | <b>(876,910)</b>            | <b>262,181</b>              | <b>795,209</b>    | <b>1,375,261</b>              | <b>(1,031,119)</b>          | <b>134,818</b>              | <b>478,960</b>    |
| Transfer between funds             |       | (1,170,160)                   | 1,355,000                   | (184,840)                   | -                 | (1,432,941)                   | 1,512,000                   | (79,059)                    | -                 |
| <b>Net movement in funds</b>       |       | <b>239,778</b>                | <b>478,090</b>              | <b>77,341</b>               | <b>795,209</b>    | <b>(57,680)</b>               | <b>480,881</b>              | <b>55,759</b>               | <b>478,960</b>    |
| <b>Reconciliation of funds:</b>    |       |                               |                             |                             |                   |                               |                             |                             |                   |
| Total funds brought forward        |       | 1,991,410                     | 2,428,667                   | 136,235                     | 4,556,312         | 2,049,090                     | 1,947,786                   | 80,476                      | 4,077,352         |
| <b>Total funds carried forward</b> |       | <b>2,231,188</b>              | <b>2,906,757</b>            | <b>213,576</b>              | <b>5,351,521</b>  | <b>1,991,410</b>              | <b>2,428,667</b>            | <b>136,235</b>              | <b>4,556,312</b>  |

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 54 to 70 form part of these financial statements.



# Balance Sheet

## Balance sheet as at 31 December 2019

Company registration number: 4118259

|  |       | 2019               |                    | 2018             |
|--|-------|--------------------|--------------------|------------------|
|  | Notes | £                  | £                  | £                |
| <b>Fixed assets</b>                                    |       |                    |                    |                  |
| Tangible assets  | 10    | 1,262,260          |                    | 1,099,014        |
| Investment in DEBRA Trading Ltd                        | 20    | 2                  |                    | 2                |
|  |       | <u>1,262,262</u>   |                    | <u>1,099,016</u> |
| <b>Current assets</b>                                  |       |                    |                    |                  |
| Current asset investment                               | 11    | 3,750,000          | 2,750,000          |                  |
| Stocks   |       | 6,300              | 18,139             |                  |
| Debtors  | 12    | 1,926,703          | 2,204,988          |                  |
| Cash at bank and in hand                               |       | 2,898,199          | 2,644,426          |                  |
| Fixed asset held for sale                              |       | 78,000             | -                  |                  |
|  |       | <u>8,659,202</u>   | <u>7,617,553</u>   |                  |
| <b>Creditors: Amounts falling due within one year:</b> |       |                    |                    |                  |
|  | 13    | <u>(3,781,180)</u> | <u>(3,223,805)</u> |                  |
| <b>Net current assets</b>                              |       |                    |                    |                  |
|  |       | <u>4,878,022</u>   |                    | <u>4,393,748</u> |
| <b>Total assets less current liabilities</b>           |       |                    |                    |                  |
|  |       | <u>6,140,284</u>   |                    | <u>5,492,764</u> |
| <b>Creditors: Amounts falling due over one year:</b>   |       |                    |                    |                  |
|  | 13    | <u>(546,951)</u>   |                    | <u>(663,975)</u> |
| <b>Provisions for liabilities</b>                      |       |                    |                    |                  |
|  | 13    | <u>(241,812)</u>   |                    | <u>(272,477)</u> |
| <b>Total net assets</b>                                |       |                    |                    |                  |
|  |       | <u>5,351,521</u>   |                    | <u>4,556,312</u> |
| <b>The funds of the charity</b>                        |       |                    |                    |                  |
| Restricted income funds                                | 15    | 213,576            |                    | 136,235          |
| Unrestricted funds                                     | 15    | 5,137,945          |                    | 4,420,077        |
| Total charity funds                                    |       | <u>5,351,521</u>   |                    | <u>4,556,312</u> |
| <b>Unrestricted funds</b>                              |       |                    |                    |                  |
| - Designated   | 15    | 2,906,757          |                    | 2,428,667        |
| - General  |       | <u>2,231,188</u>   |                    | <u>1,991,410</u> |
|  |       | <u>5,137,945</u>   |                    | <u>4,420,077</u> |
| Restricted funds                                       | 15    | 213,576            |                    | 136,235          |
| Total charity funds                                    |       | <u>5,351,521</u>   |                    | <u>4,556,312</u> |

The notes on pages 54 to 70 form part of these financial statements..

The accounts were approved by the Board on 26 June 2020 and signed on their behalf by:

Jim Irvine  
Chair of Trustees

Joanne Merchant  
Treasurer

# Cash Flow Statement

## Cash Flow Statement for the year ended 31 December 2019

|   |       | 2019               |   | 2018             |
|---|-------|--------------------|---|------------------|
|   | Notes | £                  | £ | £                |
| <b>Cash-flows from operating activities</b>                               |       |                    |   |                  |
| Net cash provided by operating activities                                 | 17    | 1,580,543          |   | 406,565          |
| <b>Cash-flows from investing activities:</b>                              |       |                    |   |                  |
| Dividends, interest and rents from investments                            |       | 56,544             |   | 47,362           |
| Purchase of property, plant and equipment                                 |       | (383,314)          |   | (67,331)         |
| - Purchase of investments   |       | (1,000,000)        |   | (950,000)        |
| Net cash (used in) investing activities                                   |       | <u>(1,326,770)</u> |   | <u>(969,969)</u> |
| <b>Change in cash and cash equivalents in the reporting period</b>        |       |                    |   |                  |
|   |       | <u>253,773</u>     |   | <u>(563,404)</u> |
| <b>Cash and cash equivalents at the beginning of the reporting period</b> |       |                    |   |                  |
|   |       | <u>2,644,426</u>   |   | <u>3,207,830</u> |
| <b>Cash and cash equivalents at the end of the reporting period</b>       |       |                    |   |                  |
|   |       | <u>2,898,199</u>   |   | <u>2,644,426</u> |

The notes on pages 54 to 70 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 January 2020 and were content that these plans were affordable and that the accounts should be prepared on a going concern basis. However, the impact of the recent Covid-19 outbreak and its financial 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's decisions on social distancing is expected to have an effect on DEBRA's financial situation and an estimated £5.6m reduction in total income following several month of shop closures. In addition on-going social distancing measures present challenges to running fundraising events. The economic fallout of the lockdown will impair the ability of individuals, corporates 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 no new research commitments. This has produced savings of £4.5m in 2020.

Before the pandemic struck, DEBRA had financial strength with high cash balances and short term deposits which have provided a buffer to weather the storm. All applicable sources of government financial aid have been accessed, and a reverse stress test indicated liquidity would not break until November 2021.

The length of the Covid-19 outbreak and the measures taken by the Government to contain this are not known and outside of our control but we have put processes in place to manage cash flow on a monthly basis and review financial stability as matters progress. A cautious financial forecast has been prepared to the end of 2021, detailing the plans for financial recovery whilst maintaining a first rate service to the EB community.

Given DEBRA's financial strength at the outset of the pandemic, whilst uncertainty exists, this does not pose a material uncertainty that would cast doubt on the charity's ability to continue as a going concern. As both the reverse stress test and the financial plan have demonstrated, DEBRA will pull through this crisis and the trustees consider it is still appropriate to prepare the 2019 accounts on a going concern basis.

The potential effect on the balance sheet for 2020 is explained further in Note 21.

### 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.

## Accounting Policies (Continued)

### 1.4 Judgements and Estimates Made by Management (Continued)

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. 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. 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.

### 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 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 land and buildings | Over 25 years          |
| Head office fit out costs                      | Over life of the lease |
| Holiday 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.



# Notes to the Accounts

## Accounting Policies (Continued)

### 1.10 Cash and Short-Term Investments

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

### 1.11 Debtors

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

### 1.12 Creditors

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

### 1.13 Financial Instruments

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

### 1.14 Stock

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

### 1.15 Accumulated Funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The purposes and uses of the restricted funds and designated funds are set out in Note 15 to the financial statements.

### 1.16 Consolidated Accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the company’s results and the investment the charity holds in DEBRA Trading Limited are shown separately in Note 20 to the financial statements.

### 1.17 Foreign Currency Translation

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

### 1.18 Leases

Operating lease annual rental payments are charged to the Statement of Financial Activities (SOFA) on a straight line basis over the term of the lease.

### 1.19 Termination Payments

Termination payments either by way of redundancy, settlement agreement or ‘gardening leave’ 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 2019 | Total 2018 |
|-------------------------|--------------------|------------------|------------|------------|
|                         | £                  | £                | £          | £          |
| Donations & gifts       | 2,541,845          | 129,451          | 2,671,296  | 2,382,844  |
| Legacies receivable     | 184,761            | -                | 184,761    | 179,433    |
| Grants receivable       | 64,087             | 444,160          | 508,247    | 256,161    |
|                         | 2,790,693          | 573,611          | 3,364,304  | 2,818,438  |
|                         |                    |                  |            |            |
| Donations & gifts:      |                    |                  |            |            |
| Individual donations    | 1,958,660          | 54,303           | 2,012,963  | 1,852,215  |
| Corporate donations     | 519,062            | 70,939           | 590,001    | 437,535    |
| International donations | 524                | -                | 524        | 1,235      |
| Events by individuals   | 63,599             | 4,209            | 67,808     | 91,859     |
|                         | 2,541,845          | 129,451          | 2,671,296  | 2,382,844  |
|                         |                    |                  |            |            |
| Grants receivable:      |                    |                  |            |            |
| Charitable trusts       | 64,087             | 444,160          | 508,247    | 256,161    |
|                         | 64,087             | 444,160          | 508,247    | 256,161    |

Gifts in kind of £100,454 (2018: £145,150) are included in donations and gifts. These include the ongoing advertising in a national newspaper valued at £20,800 (2018: £20,800) and online ad-words valued at £70,308 (2018: £93,750).

## 3. Other Trading Activities

|  | Total 2019   | Total 2018   |
|--|--------------|--------------|
|  | £            | £            |
| Income                                 | 13,322,320   | 13,159,491   |
| Operating expenses                     | (12,124,386) | (11,966,305) |
| Net income from fundraising activities | 1,197,934    | 1,193,186    |

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2019 there were 121 shops trading (2018:125). The major categories of income and expenditure are summarised below:

|                       | Income     | Operating Expense | Net Income 2019 | Net Income 2018 |
|-----------------------|------------|-------------------|-----------------|-----------------|
|                       | £          | £                 | £               | £               |
| Retail                | 12,238,556 | (11,486,581)      | 751,975         | 835,815         |
| Fundraising events    | 722,357    | (637,805)         | 84,552          | 183,208         |
| Miscellaneous trading | 361,407    | -                 | 361,407         | 174,163         |
|                       | 13,322,320 | (12,124,386)      | 1,197,934       | 1,193,186       |

# Notes to the Accounts

## 3. Other Trading Activities (Continued)

Retail income excludes income of £1,226,225 (2018: £1,165,168) 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 £144,523 (2018: £137,113) which is recognised in miscellaneous trading. In 2019 there was strong like for like growth in retail and a drop of 4 in the number of shops. The profit covenanted by DEBRA Trading Limited of £216,884 (2018: £37,050) is recognised in miscellaneous trading.

The table below reflects a true statement of total retail income, including retail Gift Aid, commission and retail donations. The 2018 figure has been adjusted to include retail Gift Aid commission to ensure a consistent presentation

|                    | Total<br>2019 | Total<br>2018 |
|--------------------|---------------|---------------|
|                    | £             | £             |
| Retail income      | 13,609,304    | 13,404,466    |
| Retail expenditure | (11,486,581)  | (11,266,370)  |
| Retail net income  | 2,122,723     | 2,138,096     |

## 4. Investments

|                         | Total Unrestricted<br>2019 | Total Unrestricted<br>2018 |
|-------------------------|----------------------------|----------------------------|
|                         | £                          | £                          |
| Interest receivable     | 29,766                     | 19,672                     |
| Rent of property        | 26,778                     | 27,690                     |
| Total investment income | 56,544                     | 47,362                     |

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 19. There were 334 (2018: 273) Community Support grants totalling £85,117 (2018: £61,951) made through the Community Support programme. All other grants were payable to institutions as detailed in Note 19.

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 2019 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,428,243 (2018: £1,488,759) and clinical projects to the sum of £186,213 (2018: £240,985).

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

|   | Total<br>2019 | Total<br>2018 |
|---|---------------|---------------|
|   | £             | £             |
| Within 1 year   | 1,067,505     | 1,065,769     |
| Within 2-3 years                                      | 489,658       | 663,975       |
| Within 4-5 years                                      | 57,293        | -             |
|   | 1,614,456     | 1,729,744     |
| Provided within the grants payable creditor (note 13) | 1,614,456     | 1,729,744     |

## 6. Expenditure

|                          | Staff<br>Costs | Grants<br>Payable | Other<br>Costs | Total<br>2019 | Total<br>2018 |
|--------------------------|----------------|-------------------|----------------|---------------|---------------|
|                          | £              | £                 | £              | £             | £             |
| Raising funds:           |                | -                 |                |               |               |
| Voluntary income         | 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 &<br>Amortisation | Overhead<br>Allocation | Miscellaneous<br>Costs | Total<br>2019 | Total<br>2018 |
|--------------------------|--------------------------------|------------------------|------------------------|---------------|---------------|
|                          | £                              | £                      | £                      | £             | £             |
| Raising funds            |                                |                        |                        |               |               |
| Voluntary income         | -                              | 178,750                | 215,916                | 394,666       | 383,899       |
| Other trading activities | 83,116                         | 292,446                | 5,970,583              | 6,346,145     | 6,347,696     |
|                          | 83,116                         | 471,196                | 6,186,499              | 6,740,811     | 6,731,595     |

|                        |         |         |           |           |           |
|------------------------|---------|---------|-----------|-----------|-----------|
| 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    |
|                        | 35,613  | 222,943 | 532,438   | 790,994   | 333,551   |
|                        | 118,729 | 694,139 | 6,718,937 | 7,531,805 | 7,065,146 |

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

|                                       | Total<br>2019 | Total<br>2018 |
|---------------------------------------|---------------|---------------|
|                                       | £             | £             |
| Operating leases                      | 1,639,888     | 1,593,680     |
| Auditors remuneration                 | 20,420        | 19,825        |
| Non-audit services                    | 24,773        | 16,287        |
| Depreciation of tangible fixed assets | 138,758       | 125,370       |
| Defined contribution pension costs    | 312,098       | 269,886       |
| Exchange differences                  | 34,441        | (23,669)      |



# Notes to the Accounts

## 7. Cost Allocation

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

|  | 2019      | 2018      |
|--|-----------|-----------|
|  | £         | £         |
| Staff costs:                                   | 1,450,761 | 1,325,104 |
| Overheads:                                     |           |           |
| Office premises rent                           | 58,640    | 40,500    |
| Service charges, utilities & cleaning          | 54,644    | 36,661    |
| Equipment costs                                | 142,517   | 142,224   |
| Postage, printing, stationery, telephone & fax | 82,430    | 87,159    |
| Insurance costs                                | 92,458    | 85,284    |
| Legal, professional & consultancy fees         | 50,278    | 58,080    |
| Depreciation                                   | 22,653    | 18,068    |
| Irrecoverable VAT                              | 52,988    | 52,375    |
| Bank charges                                   | 15,081    | 11,794    |
| Sundry expenses                                | 87,224    | 14,178    |
| Governance costs:                              |           |           |
| Audit fees                                     | 20,420    | 19,555    |
| Miscellaneous costs                            | 14,806    | 10,091    |
|  | 694,139   | 575,969   |
| Total Allocation                               | 2,144,900 | 1,901,073 |

The trustees held a strategic planning day in November 2019 which led to an increase in Governance costs over 2018.

## 8. Trustees

None of the trustees received any remuneration from DEBRA during the period, but 6 of them were reimbursed a total of £3,871 (2018: 10 - £5,611) for travel and subsistence expenses.

Tim Powell’s wife received £1,400 (£2018: £0) for professional services at EB2020.

James Hinchcliffe received a community support grant in 2019 totalling £720 (2018: £150).

Andy Grist received community grants totalling £528 (2018: £0).

Michael Jaega received no community support grants in 2019 totalling £0 (2018: £1,255).

The aggregate figure for trustee donations in 2019 was £991 (2018: £3,466).

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 £1,883 (2018: £1,705), as allowed under section 4.3.3 in DEBRA’s Articles of Association.

## 9. Employees

The average number of employees during the period was:

|                             | 2019 Full Time Equivalent | 2019 Number | 2018 Number |
|-----------------------------|---------------------------|-------------|-------------|
| Research                    | 3.3                       | 5           | 5           |
| Healthcare*                 | 1.0                       | 1           | 1           |
| Community Support           | 13.7                      | 15          | 13          |
| Fundraising                 | 12.6                      | 14          | 14          |
| Retail                      | 241.8                     | 331         | 328         |
| Management & Administration | 15.8                      | 19          | 18          |
|                             | 288.2                     | 385         | 379         |

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

|                             | 2019 Full Time Equivalent | 2019 Number | 2018 Number |
|-----------------------------|---------------------------|-------------|-------------|
| Research                    | 3.3                       | 5           | 5           |
| Healthcare*                 | 1.0                       | 1           | 1           |
| Community Support           | 15.3                      | 17          | 14          |
| Fundraising                 | 13.1                      | 14          | 13          |
| Retail                      | 236.1                     | 332         | 331         |
| Management & Administration | 15.5                      | 19          | 19          |
|                             | 284.3                     | 388         | 383         |

\*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 2019 | Total 2018 |
|-----------------------|------------|------------|
|                       | £          | £          |
| Wages & salaries      | 6,231,757  | 6,054,739  |
| Social security costs | 395,899    | 395,891    |
| Pension costs         | 312,098    | 269,886    |
|                       | 6,939,754  | 6,720,516  |

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees’ personal pension plans. Payments of £309,502 (2018: £285,512) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £5,917 (2018: £3,320) unpaid.

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

# Notes to the Accounts

## 9. Employees (Continued)

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

|                             | 2019 | 2018 |
|-----------------------------|------|------|
| Between £60,001 - £70,000   | 2    | 3    |
| Between £70,001 - £80,000   | 2    | 1    |
| Between £130,001 - £140,000 | -    | 1    |
| Between £140,001 - £150,000 | 1    | -    |

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £62,666 (2018: £57,689), and there are retirement benefits accruing for five (2018: five) employees under a defined contribution scheme.

The aggregate pay of key management personnel, including employer's NI and pension contributions was £678,512 (2018: £618,520). The aggregate employer's pension contribution for key management personnel was £70,856 (2018: £63,151).

Redundancy and compensation payments totalled £12,195 in 2019 (2018: £18,964).

## 10.Fixed Assets

### Tangible Fixed Assets

|                     | Shop<br>Equipment | Holiday Homes | Fixtures, Fittings<br>& Equipment | Freehold Land &<br>Buildings | Long<br>Leasehold Land<br>& Buildings | Total     |
|---------------------|-------------------|---------------|-----------------------------------|------------------------------|---------------------------------------|-----------|
|                     | £                 | £             | £                                 | £                            | £                                     | £         |
| Cost:               |                   |               |                                   |                              |                                       |           |
| At 1 January 2019   | 395,210           | 398,322       | 202,943                           | 799,347                      | 82,500                                | 1,878,322 |
| Additions           | 83,747            | 148,840       | 150,727                           | -                            | -                                     | 383,314   |
| Disposals           | (74,996)          | -             | (28,056)                          | (100,000)                    | -                                     | (203,052) |
| At 31 December 2019 | 403,961           | 547,162       | 325,614                           | 699,347                      | 82,500                                | 2,058,584 |
| Depreciation:       |                   |               |                                   |                              |                                       |           |
| At 1 January 2019   | 241,196           | 180,969       | 167,652                           | 172,988                      | 16,500                                | 779,305   |
| Charge for the year | 61,543            | 35,613        | 22,653                            | 17,299                       | 1,650                                 | 138,758   |
| Disposals           | (74,674)          | -             | (25,065)                          | (22,000)                     | -                                     | (121,739) |
| At 31 December 2019 | 228,065           | 216,582       | 165,240                           | 168,287                      | 18,150                                | 796,324   |
| Net Book Value:     |                   |               |                                   |                              |                                       |           |
| Brought forward     | 154,014           | 217,353       | 35,291                            | 626,359                      | 66,000                                | 1,099,017 |
| At 31 December 2019 | 175,896           | 330,580       | 160,374                           | 531,060                      | 64,350                                | 1,262,260 |

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, which remained unsold at 31st December 2019 and is held for sale within current assets on the balance sheet.

## 11. Investment in Short Term Deposits

|                              | 2019      | 2018      |
|------------------------------|-----------|-----------|
|                              | £         | £         |
| Lloyds money market deposits | 3,750,000 | 2,750,000 |
|                              | 3,750,000 | 2,750,000 |

## 12. Debtors

|                       | 2019      | 2018      |
|-----------------------|-----------|-----------|
|                       | £         | £         |
| HMRC                  | 259,632   | 237,922   |
| Miscellaneous debtors | 210,306   | 79,429    |
| Other debtors         | 295,263   | 82,914    |
| Accrued income        | 550,443   | 1,012,576 |
| Prepayments           | 611,059   | 792,147   |
|                       | 1,926,703 | 2,204,988 |

VAT repayment of £259,632 (2018: £237,922) is due from HMRC. Miscellaneous debtors includes £197,612 (2018: £0) due for shared research grants. Other debtors includes £216,884 (2018: £37,050) profit due from the trading subsidiary. Accrued income includes gift aid of £278,092 (2018: £744,425) due from HMRC.

Total future minimum lease receivable was £3,388 in 2019 (2018: £10,528), in respect of 1 shop and 1 flat above a shop in 2019, and 1 shop and 2 flats in 2018.

## 13.Creditors

### Amounts Falling Due Within One Year

|                              | 2019      | 2018      |
|------------------------------|-----------|-----------|
|                              | £         | £         |
| Trade creditors              | 669,803   | 680,113   |
| Grants payable               | 2,201,344 | 1,824,913 |
| Other creditors              | 6,226     | 1,644     |
| Taxation and social security | 96,107    | 100,760   |
| Accruals                     | 692,069   | 589,475   |
| Deferred income              | 115,631   | 26,900    |
|                              | 3,781,180 | 3,223,805 |

Grants payable includes £875,173 (2018: £1,065,769) relating to future commitment and £1,320,047 (2018: £759,144) relating to outstanding invoices for work done.

There was deferred income of £115,631 in 2019 (2018: £26,900), representing income for events which would have to be repaid in the event of cancellation.



# Notes to the Accounts

## 13.Creditors (Continued)

### Amounts Falling Due Over One Year

|                | 2019    | 2018    |
|----------------|---------|---------|
|                | £       | £       |
| Grants payable | 546,951 | 663,975 |
|                | 546,951 | 663,975 |

There was a dilapidations provision of £241,812 (2018: £272,477). In the year £52,665 was released from the provision and a further £21,000 was charged. It is uncertain when this provision will be spent.

## 14. Other Financial Commitments

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

|                  | 2019<br>Leases of<br>Land &<br>Buildings | 2018<br>Leases of<br>Land &<br>Buildings | 2019<br>Other | 2018<br>Other |
|------------------|--|--|---------------|---------------|
|                  | £  | £  | £             | £             |
| Within 1 year    | 1,617,494                                | 1,571,286                                | 22,394        | 22,394        |
| Within 2-5 years | 1,421,057                                | 1,271,991                                | 5,283         | 27,677        |
| After 5 years    | 58,029                                   | -  | -             | -             |
|                  | 3,096,580                                | 2,843,277                                | 27,677        | 50,071        |

## 15.Analysis of Funds

### Restricted Funds

|                             | Balance at<br>31 Dec 2018 | Income  | Expenditure | Transfer to<br>General Fund | Balance at<br>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                   |

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, and purchases of fixed assets fully discharging the restriction on donations.

|                             | Balance at<br>31 Dec 2017 | Income  | Expenditure | Transfer to<br>General Fund | Balance at<br>31 Dec 2018 |
|-----------------------------|---------------------------|---------|-------------|-----------------------------|---------------------------|
|                             | £                         | £       | £           | £                           | £                         |
| Research                    | 5,500                     | 159,163 | (89,154)    | (75,209)                    | 300                       |
| Healthcare                  | 54,922                    | 94,071  | (105,898)   | (3,850)                     | 39,245                    |
| Community Support & Respite | 20,054                    | 142,067 | (65,431)    | -                           | 96,690                    |
|                             | 80,476                    | 395,301 | (260,483)   | (79,059)                    | 136,235                   |
|                             |                           |         |             | -                           |                           |
|                             |                           |         |             | -                           |                           |
|                             |                           |         |             | -                           |                           |
|                             |                           |         |             | -                           |                           |

### Restricted Funds Comprised:

|   | 2019    | 2018    |
|---|---------|---------|
|   | £       | £       |
| Research -CureEB (Sohana Research Fund)                     | -       | 300     |
| Healthcare -EB Nurses                                       | 73,877  | -       |
| Healthcare - EB Nurse Leadership                            | -       | 33,645  |
| Healthcare - Birmingham Children's Hospital Specialist Bath | 5,600   | 5,600   |
| Community Support - Community Support Manager for Scotland  | 60,000  | -       |
| Community Support - Community Support Manager Post          | 56,167  | 32,680  |
| Community Support - Early Intervention Project              | -       | 25,000  |
| Community Support - Youth Project                           | -       | 9,497   |
| Community Support - Community Support in Berkshire          | 8,476   | 8,915   |
| Community Support - Support Grants in Northamptonshire      | 2,400   | 2,058   |
| Community Support - Support Grants in Hampshire             | 1,550   | 3,320   |
| Community Support - Volunteer Co-ordinator                  | -       | 6,961   |
| Community Support - Holiday Home                            | -       | 4,830   |
| Community Support - other restricted funds                  | 5,506   | 3,429   |
|   | 213,576 | 136,235 |

# Notes to the Accounts

## 15. Analysis of Funds (Continued)

### Unrestricted Funds

The trustees have transferred the following amounts into designated funds during 2019:

|                          | Balance at<br>31 Dec 2018 | Transfers   | Income     | Expenditure  | Balance at<br>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 | (14,337,675) | 2,231,188                 |
| Total unrestricted funds | 4,420,077                 | 184,840     | 16,012,330 | (15,479,302) | 5,137,945                 |

|                          | Balance at<br>31 Dec 2017 | Transfers   | Income     | Expenditure  | Balance at<br>31 Dec 2018 |
|--------------------------|---------------------------|-------------|------------|--------------|---------------------------|
|                          | £                         | £           | £          | £            | £                         |
| Future research grants   | 1,697,786                 | 1,212,000   | -          | (960,946)    | 1,948,840                 |
| Nursing Continuity       | 200,000                   | 50,000      | -          | -            | 250,000                   |
| EB2020 conference        | 50,000                    | 250,000     | -          | (70,173)     | 229,827                   |
| Total designated funds   | 1,947,786                 | 1,512,000   | -          | (1,031,119)  | 2,428,667                 |
| General fund             | 2,049,090                 | (1,432,941) | 15,742,981 | (14,367,720) | 1,991,410                 |
| Total unrestricted funds | 3,996,876                 | 79,059      | 15,742,981 | (15,398,839) | 4,420,077                 |

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. There were transfers totalling £1,355,000 into this fund in 2019. It is anticipated this fund will be spent, or undesignated, in the next 1-5 years.

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 2019.

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 2019 £264,717 income was added to this fund and £456,077 was spent. This fund will be spent in the next year.

## 16. Analysis of Net Assets Between Categories of Funds

|   | Unrestricted<br>Funds | Restricted<br>Funds | Total<br>2018 | Total<br>2017 |
|---|-----------------------|---------------------|---------------|---------------|
|   | £                     | £                   | £             | £             |
| 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)     |
|   | 5,137,945             | 213,576             | 5,351,521     | 4,556,312     |

|   | Unrestricted<br>Funds | Restricted<br>Funds | Total<br>2018 | Total<br>2017 |
|---|-----------------------|---------------------|---------------|---------------|
|   | £                     | £                   | £             | £             |
| Fund balances at 31 December 2018 are represented by: |                       |                     |               |               |
| Fixed assets  | 1,099,016             | -                   | 1,099,016     | 1,157,055     |
| Current assets  | 7,481,318             | 136,235             | 7,617,553     | 6,570,064     |
| Creditors: amounts falling due within one year        | (3,223,805)           | -                   | (3,223,805)   | (2,619,271)   |
| Creditors: amounts falling due over one year          | (936,452)             | -                   | (936,452)     | (1,030,496)   |
|   | 4,420,077             | 136,235             | 4,556,312     | 4,077,352     |

## 17. Reconciliation of Net Income to Net Cash Flow From Operating Activities

|  | 2019      | 2018      |
|--|-----------|-----------|
|  | £         | £         |
| Net income for the reporting period (as per the statement of financial activities) | 795,209   | 478,960   |
| Depreciation and amortisation charges  | 138,758   | 125,370   |
| Dividends, interest and rents from investments                                     | (56,544)  | (47,362)  |
| Loss on disposal of fixed assets   | 3,313     | -         |
| Decrease in stock  | 11,838    | 1,121     |
| Decrease / (Increase) in debtors   | 278,285   | (662,014) |
| Increase in creditors  | 409,684   | 510,490   |
|  | 1,580,543 | 406,565   |

## 18. Analysis of Cash and Cash Equivalents

|                          | As at<br>1 Jan 2019 | Cash<br>Flows | As at<br>31 Dec 2019 |
|--------------------------|---------------------|---------------|----------------------|
|                          | £                   | £             | £                    |
| Cash at bank and in hand | 2,644,426           | 253,773       | 2,898,199            |
|                          | 2,644,426           | 253,773       | 2,898,199            |

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.



19. Grants to Institutions

|  | Total Paid 2019 | Total to Date | Total Committed Project Cost |
|--|-----------------|---------------|------------------------------|
|  | £               | £             | £                            |
| Research Projects  |                 |               |                              |
| University of Dundee   |                 |               |                              |
| 1. Clinical fellow funding   | 101,194         | 414,902       | 504,472                      |
| University of Glasgow  |                 |               |                              |
| 1. Mechanisms of TGF-beta mediated tumour protecting in RDEB             | 78,613          | 78,613        | 157,138                      |
| Guy's and St Thomas' Hospital, London                                    |                 |               |                              |
| 1. Validated clinical endpoints study re EB therapy evaluation           | 45,638          | 412,884       | 412,884                      |
| 2. Stem cell therapy trial to investigate treating debilitating itch     | 200,248         | 352,152       | 497,360                      |
|  | 245,886         | 765,036       | 910,244                      |
| Thomas Jefferson University, Philadelphia, USA                           |                 |               |                              |
| 2. Phase 2 clinical trial of Rigosertib for RDEB SCC                     | 163,746         | 429,506       | 470,490                      |
| University of Birmingham Dental School & Hospital                        |                 |               |                              |
| 1. Characterisation of skin microbiome in EB patients                    | 119,944         | 151,430       | 296,289                      |
| 2. Gait Analysis in EB Simplex   | 11,508          | 11,508        | 46,030                       |
| 3. Clinical Fellowship   | -               | -             | 125,263                      |
| 4. Novel spray to treat mucosal scarring                                 | -               | -             | 152,385                      |
|  | 131,452         | 162,938       | 619,967                      |
| University of Cologne  |                 |               |                              |
| 1. Exploring immunity in wound healing complications in RBEB             | 55,704          | 83,556        | 170,635                      |
| Universitair Medisch Centrum Groningen                                   |                 |               |                              |
| 1. Effectiveness of phyto-cannabinoid treatment of pain in EB            | 79,250          | 111,725       | 159,025                      |
| Instituto Dermopatico deli'Immacolata Rome                               |                 |               |                              |
| 1. Anti-fibrotic potential of histone deacetylase inhibitors for RDEB    | 25,037          | 27,051        | 70,963                       |
| King's College London  |                 |               |                              |
| 1. Preclinical studies of lentiviral-mediated COL7A1 gene therapy        | 61,145          | 61,145        | 174,023                      |
| Great Ormond Street Institute of Child Health                            |                 |               |                              |
| 1. Respiratory cell and gene therapy for children with Junctional EB     | -               | -             | 135,338                      |
| Bambino Gesù Children's Hospital   |                 |               |                              |
| 1. MicroRNAs expression profiling, activity and therapeutic perspectives | -               | -             | 77,592                       |
| University of Edinburgh  |                 |               |                              |
| 1. Understanding role of Kindlin-1 loss in squamous cell carcinoma       | -               | -             | 112,833                      |
| Other  |                 |               |                              |
| Decrease in research provision   | (60,511)        | -             | -                            |
| Grants written off at end of project                                     | 1,989           | -             | -                            |
| Total research grants  | 883,505         | 2,134,472     | 3,562,720                    |
| Research project expenditure by category:                                |                 |               |                              |
| Pre-clinical development   | 263,171         |               | 1,555,379                    |
| Clinical investigation   | 177,090         |               | 880,466                      |
| Patient treatment study  | 443,244         |               | 1,126,875                    |
|  | 883,505         |               | 3,562,720                    |

19. Grants to Institutions (Continued)

|   | Total Paid 2019 | Total Committed Project Cost |
|---|-----------------|------------------------------|
|   | £               | £                            |
| Healthcare Projects   |                 |                              |
| Great Ormond Street Hospital for Sick Children                      |                 |                              |
| Clinical nurse specialists in EB                                    | 81,963          | 81,963                       |
| Guys & St Thomas' Hospital London                                   |                 |                              |
| Adult EB support nurses   | 89,745          | 93,193                       |
| Clinical best practice guidelines on parenteral and enteral feeding | 38,000          | 38,000                       |
| Other   |                 |                              |
| Birmingham Children's Hospital                                      | 20,129          | 20,129                       |
| Miscellaneous   | (5,643)         | 33,434                       |
| Total Healthcare Team grants  | 224,194         | 266,719                      |

20. Related Parties

DEBRA Trading Ltd

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

The company's results for the year were as follows:

|                                | 2019    | 2018    |
|--------------------------------|---------|---------|
|                                | £       | £       |
| Turnover                       | 307,231 | 152,733 |
| Net profit gift aided to DEBRA | 216,884 | 37,050  |
| Net assets                     | 2       | 2       |

During the year, the charity charged management charges totalling £7,200 including VAT (2018: £11,476) to its subsidiary, DEBRA Trading Limited.

21. Post Balance Sheet Event

Since 31 December 2019 to the date of signing these financial statements the outbreak of the pandemic, COVID-19, has had an economic effect across all sectors and DEBRA has considered the effect on the charity as a going concern, its resilience through this period and the effect on the assets and funds of the charity. The trustees have reviewed the revised financial plans and agreed a series of activities that should ensure financial stability in these difficult times.

The trustees consider the COVID-19 pandemic as a non-adjusting post balance sheet event. Before the pandemic struck the charity had significant financial strength and high cash balances which, together with short-term deposits redeemed early, provided a buffer to weather such a storm. All applicable sources of government funding have been considered: the Job Retention Scheme, Local Authority Retail Grants, The National Lottery Community Fund and a Coronavirus Business Interruption Loan. A reverse stress test has been performed, indicating liquidity would not break until November 2021.

A detailed financial forecast through to the end of 2021 has been produced, providing a roadmap for DEBRA's recovery following the lockdown. The estimated financial effect is mainly seen in an estimated £5.6m reduction in income, with a planned £4.5m reduction in expenditure to mitigate the effect and ensure that this does not affect business-critical activities. The cautious re-opening of shops from period 7 2020 has been assumed, together with an expectation of further regional lockdowns in the event of a 2nd, or even a 3rd wave of infection. The challenges of running fundraising events whilst social distancing remain in place have been recognised, together with a drastic fall in expected income

# Notes to the Accounts

## 21. Post Balance Sheet Event (Continued)

from donations from individuals, corporates and trusts. Legacies receivable of £154k may also be affected as property prices and stock markets fall.

A gradual recovery during 2021 has been assumed, with EB community events re-commencing in the second half of 2021. Despite these financial challenges, DEBRA's cash-backed free reserves remain above the Reserves Policy recommended minimum of £1,300k at the end of 2020, and fall just below this figure, to £1,164k, by June 2021. To achieve this the trustees will need to utilise designated reserves previously designated for research and healthcare projects.

The short and medium term risks posed to the charity have been discussed by the trustees and the risk register updated to include a new risk 'global pandemic causes UK-wide lockdown, threatening the going concern of the charity'. The countermeasures and assurances associated with this risk are include in the summary extract from DEBRA's risk register detailed on page 39.

# Reference and Administrative Details

## Patrons and Ambassadors

|   |                                    |                                  |  |
|---|------------------------------------|----------------------------------|--|
| <b>Royal Patron</b><br>HRH The Countess of Wessex | <b>Life Patron</b><br>Philip Evans | <b>President</b><br>Simon Weston | <b>Vice Presidents</b><br>Graeme Souness, Frank Warren |
|---|------------------------------------|----------------------------------|--|

## Trustees

|  |   |
|--|---|
| Chair:                                   | Jim Irvine (Interim from 25.4.19 - Chair from 24.10.19)<br>Michael Jaega (19.05.18 to 06.02.19) |
| Vice Chair:                              | Andrew Grist (from 19.05.18 to 01.03.19)<br>Graham Marsden & Carly Fields (from 13.02.20)       |
| Treasurer:                               | Joanne Merchant (from 24.10.19, Acting Treasurer from 25.04.19)<br>Jim Irvine (until 25.04.19)  |
| David Bendor-Samuel (appointed 12.03.19) |   |
| Simone Bunting                           |   |
| Rebecca Cresswell                        |   |
| Simon Cuzner                             |   |
| Christo Kapourani (appointed 18.05.19)   |   |
| James Hinchcliffe                        |   |
| Graham Marsden                           |   |
| Vivien Mundy                             |   |
| Carly Fields (appointed 18.05.19)        |   |
| Timothy Powell                           |   |
| David Wilkinson                          |   |

## Senior Management Team

|  |  |
|--|--|
| <b>Chief Executive</b><br>Ben Merrett (resigned 30.06.20)                          | <b>Director of Fundraising &amp; Communications</b><br>Hugh Thompson |
| <b>Director of Research</b><br>Caroline Collins                                    | <b>Director of Human Resources</b><br>Louise Westphalen              |
| <b>Director of Healthcare, Membership &amp; Community Support</b><br>Claire Mather | <b>Director of Finance</b><br>Carol Harris                           |
| <b>Director of Retail</b><br>Chantelle Milne (from 01.12.19)                       | <b>Company Secretary</b><br>Dawn Jarvis                              |

## Additional Details

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| <b>Charity Commission Number</b><br>1084958  | <b>Auditors</b><br>BDO LLP, 2 Snow Hill, Queensway,<br>Birmingham, B4 6GA  |
| <b>OSCR Number</b><br>SC039654   | <b>Bankers</b><br>HSBC, Thames Valley Business Banking,<br>Hanborough House, Wallbrook Court, North Hinskey Lane,<br>Oxford, OX2 0QS |
| <b>Company Number</b><br>4118259   | <b>Solicitors</b><br>Stone King, 91, Charterhouse Street,<br>London, EC1M 6HR  |
| <b>Registered office &amp; principal address</b><br>DEBRA, The Capitol Building, Oldbury,<br>Bracknell, RG12 8FZ |  |



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.

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[www.debra.org.uk](http://www.debra.org.uk) | 01344 771961 | [debra@debra.org.uk](mailto:debra@debra.org.uk)

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

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