



Trustees' Annual Report & Accounts

2018

debra
for people whose
skin doesn't work
we do



DEBRA

2018

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Report & Accounts

Together, we #FightEB



Maya's Story

My dream of improving itch and pain management...

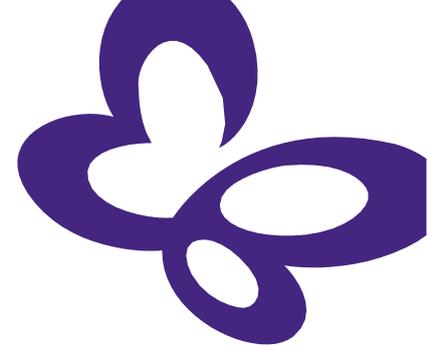
Maya is a freelance model and an advocate for EB. She suffers from EB and spends her time using her modelling and social media platform to spread awareness and educate people about EB.

EB affects Maya's everyday life in many ways. Recently the condition of her skin deteriorated so much that she had to give up her job as a Retail Assistant. For Maya, one of the most frustrating side-effects of EB is itch.

"It's like my whole body is on fire and I have ants crawling all over me. It's so overwhelming and no one without EB can understand how bad the itch actually is. I think the lack of awareness has always been a big difficulty for me because I hate having to explain to every single person who sees my skin what EB is. It means I hide my skin as best as possible in most situations to avoid being questioned," she says.

Maya decided to get involved in fundraising for DEBRA and raising awareness of EB to prevent future EB sufferers from dealing with the same struggles as she is.

Maya says: "I'm particularly interested in EB research. This is important to me because I think the quality of life for EB sufferers could be greatly improved if there was more help for itch and pain management. Donating to DEBRA can help to achieve this."



WHAT DOES DEBRA DO?

DEBRA is the national charity supporting people suffering from Epidermolysis Bullosa (EB) – a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering. 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 life changing specialist care and produce internationally recognised clinical care guidelines; and works with researchers investigating effective treatments to relieve the symptoms of EB and ultimately find a cure.

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 people dedicated to specialising in EB 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 the quality of life is vital to DEBRA's work.

Supporting DEBRA – be it through fundraising efforts, direct donations, purchasing items in the charity shops or offering your 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.

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 5,000 people suffering from EB in the UK and 500,000 people suffering from EB worldwide.

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.



Danish's Story

Advocating for the EB Community...

Danish is 30 years old and until recently he was living at home, sharing a room with his brother.

"We get on well, but because of my EB the situation was really difficult. The heat in the room was a terrible problem – I need it quite cool so that it won't exacerbate my blistering, but my brother likes it warmer than me, and this really damages my skin. I also need to rest a lot, so I like to turn out the lights and have some quiet. It just wasn't working," he says.

In 2014 Danish applied to be on the local authority housing list and had been on the waiting list for nearly four years. That all changed when he met Sabrina Khan, his Community Support Manager from DEBRA. Sabrina asked the council to reassess Danish's case and see if he could be given a higher priority for housing on medical grounds.

"I had told the housing authority that I have EB but I find it difficult to articulate the problems it causes, and also sometimes it's quite embarrassing to explain the same things over and over again," he says.

The housing authority agreed to re-prioritise Danish's case and now, with help from Sabrina Khan in DEBRA's Community Support Team, he has a place of his own.

Sabrina's work with Danish is ongoing. She has helped him apply for Universal Credit, including housing benefit, as well as council tax support, so he can start to pay for rent, bills and food. Last year, his Personal Independence Payments (PIP) were stopped. Danish appealed the decision and he is waiting for a tribunal date. Sabrina will be on hand to support him through that too.

Photo: DEBRA EB Community Support Manager Sabrina Khan (pictured right) with Hazel Ewens, Membership Manager
Cover photo: Lackshhya Jaisswar and parents Kamleash Jaisswar and Upender Kishore

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#FightEB



Fazeel's Story

My mission to cure EB...

Fazeel is 12 years old and has EB. He loves playing games with his brothers and his sister, seeing his friends, going on the trampoline, doing karate and playing on his games console.

“The worst thing about EB is the pain. The pain is incredible. I have to take so many painkillers every day – sometimes paracetamol and ibuprofen, sometimes ones so extreme they put you to sleep,” he says.

EB also causes chronic itch for Fazeel and affects his eating. Any hard food, such as crisps, would create blisters in his mouth and throat, and he also finds it difficult to eat large portions as this would also cause blistering.

“I can't play roughly, like other people,” he adds. “Although I go on the trampoline, I don't do any tricks. When you have EB, a lot of things are restricted. You have to think about every single thing you do. Other children don't have to do that.

That's why I want to find a cure for EB, if DEBRA hasn't found one by the time I'm old enough to be a doctor.”

OUR WORK IN 2018



For every £1 of net contribution 83p was spent on charitable activities, or designated for future charitable spend



£2.97m spent on charitable activities in 2018



£2m raised in DEBRA shops and £1.28m by DEBRA fundraisers



Over 50,000 active registered Gift Aid donors

Research

14 ongoing research projects were facilitated in the UK

£958k committed to new research projects

£408k spent on additional research activities

Healthcare

1,630 EB patients supported in England and Wales

28 specialist EB training grants

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

Community Support

2,892 DEBRA Members; 578 of which accessed DEBRA's Community Support service

472 home visits took place; 103 EB hospital clinics attended; and 273 support grants were awarded

770 holiday days taken in DEBRA's five holiday homes

International

51 DEBRA groups worldwide

2 international clinical best practice guidelines, funded by the UK

19 global EB research sites funded by the UK in the last 5 years



What DEBRA brings to us

Isla (10) and her sister Emily (13), go to school, have their friends round and like to play on the trampoline whenever they get the chance.

When Isla came into this world, parents, Rachel and Andy knew immediately something was wrong. She was missing skin on her hands and feet, and was immediately rushed to hospital. Doctors confirmed that Isla had EB. For the first six months of her life, they carried Isla around on a pillow as the slightest knock or rub could tear her skin and they had no idea how to look after her.

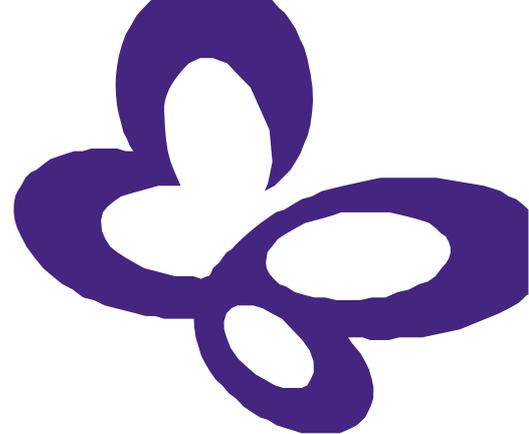
An EB nurse, part funded by DEBRA, showed them how to look after Isla's skin. With support, they grew more confident. Spending hours applying dressings to protect her delicate skin and administering morphine for the pain – is now just part of the family's daily routine.

"EB stops me from having a normal life, and that is what I want," Isla says.

"DEBRA brings a lot to our family – as part of DEBRA, we feel part of a bigger community working to help us, to help Isla. And the more we meet other people facing EB – at DEBRA's Members' Day and Get-Togethers – the more we realise that normal is a difficult concept to define. Life with EB is not an abnormal life, it's just a different life.

DEBRA is funding pioneering research into effective treatments and a cure for EB. We're fundraising for DEBRA to make this happen and help give Isla the pain-free life she so desperately wants.

In the meantime, our normal is about making the most of life. That's exactly what Isla is doing," say Rachel and Andy.



Our Vision

A WORLD WHERE NO ONE
SUFFERS FROM THE PAINFUL SKIN
CONDITION EPIDERMOLYSIS BULLOSA

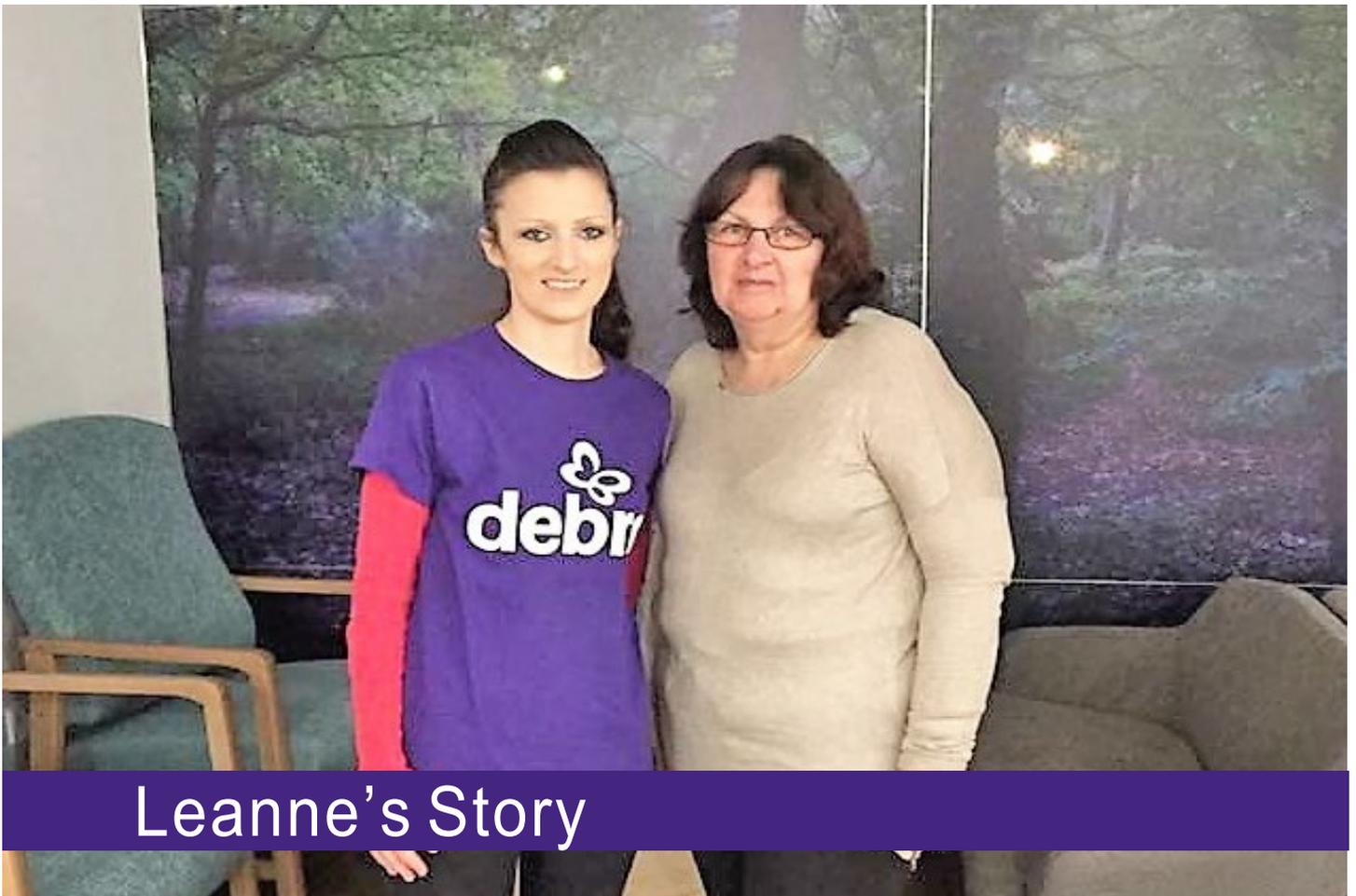
Our Mission

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 EB COMMUNITY



Leanne's Story

DEBRA makes a difference...

For Leanne, even swallowing food can feel like eating razor blades, but that's not her biggest problem. Leanne's EB is invisible to the naked eye but can cause life-threatening internal damage.

When she was 16, Leanne developed blistering in her throat and also has a restricted oesophagus, which causes extreme difficulties with drinking and eating, and a constant risk of choking. She needs surgery to widen her throat every six months to a year.

Low bone density, and bone weakness caused by her EB causes so much pain in her knees, ankles, hips and wrists that she struggles with walking or even sitting for any length of time.

However, what she finds most difficult is making people understand that she has a disability.

She says: "I have a blue badge and have to use the priority seats on the bus when I travel to hospital. I always get really horrible looks from people."

DEBRA works in partnership with the NHS to provide life changing care and support to the EB Community. Leanne regularly attends clinic at the new Rare Diseases Centre at St Thomas' Hospital. DEBRA contributed £250k to this £2.1 million pound project, which brings together all the specialist services needed to help adults with EB like Leanne stay as healthy as possible, including specialist dentists and dietitians.

Leanne remains upbeat. She says: "DEBRA has been my rock. DEBRA has helped me realise I am not on my own. The EB Community is a family! The charity DEBRA is like the glue that keeps us together, they arrange events and days out where we don't have to feel different, but know we are a strong unit!"



STRATEGIC REPORT

Highlights and
breakdown of
DEBRA's services
and income
generation
activities in 2018
and an overview
of future plans.

A MESSAGE FROM OUR INTERIM CHAIRMAN & OUR CEO

Once again, 2018 saw us significantly grow the levels of income generation in nearly all of our operations and we are now able to support more members of the EB Community than ever before. The growth of our Fundraising was assisted by the launch of our #FightEB campaign; Retail hit new heights; and the £2m attained retail surplus is worthy of particular praise.

This success enables us to search for more research projects and provide higher levels of care for the EB community. As well as our own fully-funded quality of life clinical trials, we are closely monitoring the growth of biotech companies who are seeking funding for emerging treatments. We will always raise money before spending it and have about £2m ready to invest when the right projects are available.

Effective treatment development is a worldwide task and we are very actively supporting DEBRA International to help with this. The Board has approved a significant budget that allows us to host EB2020, the first EB World Congress in London in January 2020, which will include the best researchers, clinicians and world leaders in EB as well as representation from the pharmaceutical companies.

We commissioned an independent review of our governance and received a detailed set of recommendations to consider. There are 190,000 registered charities in the UK and DEBRA now ranks in the top 1,000. As we grow, we continue to aspire to the standards set out in the Charity Governance Code. Each year the Board agrees a rolling 3 year strategic plan with the executive and sets growth targets to facilitate increased spending on research and care. Later this year we plan to have a joint trustee/executive meeting "offsite" to review progress of the plan and assess the longer-term needs of the EB community. We adopt a philosophy of continually investing in training for all trustees.

Finding the right balance in levels of remuneration to attract and retain staff at all levels of the charity is an ongoing challenge. Bonus payments in the sector are the exception, not the norm. That said, in Retail, we actively promote a culture of financially incentivising our staff and believe that's been a key factor in the long-term growth that we have achieved. We no longer pay bonuses to senior management and the Board is grateful to Ben and his team for accepting that fact so readily.

DEBRA is an equal opportunity employer and prides itself in the diversity of its staff across the country. We are delighted to report a strong improvement in our gender pay gap which is significantly under the sector average. Having reached the end of our lease at the Crowthorne head office, we decided that a relocation to a more modern facility is warranted and are in the midst of finalising plans to move during 2019.

Our ability to have an impact is attributable to our donors, staff, volunteers and trustees, all of whom we remain very grateful to. We recently had the opportunity to spend time with many of those at our Staff & Volunteer Conference and look forward to seeing many of the EB community at our upcoming Members Day.

After a period of reflection since losing our Chair of Trustees Mike Jaega, we have commenced a restructuring of our governance structure starting with the appointment of an Interim Chairman. We now have a variety of different Trustees working closely with the executive and overseeing major projects including EB2020, Head Office relocation and the implementation of the independent external governance review. A search for a permanent Chair is underway. Mike achieved so much in his life and he never allowed his EB to stand in his way. We were delighted to see him be appointed Chairman of DEBRA and President of DEBRA International. He was instrumental in creating and delivering the impact that DEBRA has on the EB community over a prolonged period and we continue to walk along the path he created. Mike's journey started with his presence at our founding meetings 40 years ago and will continue in his memory until we achieve our vision of a world where no one suffers from EB. RIP Mike, *"You'll Never Walk Alone"*.

Jim Irvine
Interim 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 due to 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. Satisfaction and service development surveys and group discussions take place and DEBRA has a patient panel made up of the EB Community, to review research projects.

DEBRA's Care & Research Committee, which is led by a trustee who is a parent of a child living with EB, 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

RESEARCH STRATEGY

DEBRA remains strategically focussed on funding pioneering research to find cure(s) for EB and having an ongoing major impact on improving the quality of life. Having invested £7.1m on research grants over the last decade, DEBRA was able to fund 14 ongoing projects worldwide in 2018, supporting a global expansion in EB research.

The breadth and depth of research remains important and is vital to DEBRA's research strategy of cure(s), control and quality of life. DEBRA continues to support research into clinical and scientific endpoints that will support the regulatory pathways for approval of treatments in the future. The current portfolio of research projects includes pre-clinical exploratory work; small early phase clinical studies in drug repurposing as well as projects driving a change in symptom relief. Scientific peer review and grant management with a clear reporting structure ensures scientific rigour.

KEY AREAS

Gene Technology

The needs of all the EB Community remain central to our research and development plan. A clearer focus on EB Simplex (EBS) has been identified; the work at Dundee University, initially looking at gene technology for treating EBS, has wider implications for research into cure(s) of more than one type of EB and remains ongoing.

Cancer Therapy

DEBRA funding is focussed on pre-clinical and clinical projects supporting Professor Gareth Inman, who has been newly appointed as Director of Research Strategy and Professor of Cell Signalling at the Beatson Institute, Glasgow. DEBRA also has ongoing work with Professors Andrew South, Johann Bauer and Jemima Mellerio, investigating 'targeted' cancer therapy working closely with Onconova Therapeutics.

Wound Healing

Following a successful summit in late 2017 in London, two new researchers were funded, fuelling both the strategy of bringing new academicians into the field of EB as well as driving projects to understand and develop treatments for wound management. Professor Ian Chapple in Birmingham, UK, and Dr Sabine Eming in Cologne, Germany, will investigate the mechanisms of immune function and infection in EB wounds. A clearer understanding of healing pathways will facilitate development of effective treatment options for wound healing in people with EB in the future.

Quality of Life

DEBRA is committed to continue work with London based Professors John McGrath and Jemima Mellerio to investigate the specific role stem cell therapy has on itch. A very timely project exploring cannabinoid medicines to treat pain and itch in adults with EB has been started with the team in Gröningen, led by Nicholas Schröder.

A GATHERING OF LEADING EXPERTS

A summit of the world's top experts in EB, along with recognised experts in chronic inflammation, fibrosis and cancer in other disciplines, was held in Vienna in May 2018. A grant round followed and as a result, a number of high quality applications for funding are being reviewed. This model of gap analysis, expert summit and grant round is yielding valuable projects and drawing new researchers into the field of EB.

SIGNIFICANT PARTNERSHIPS

DEBRA welcomes the partnerships developed with other research organisations and respects the mutual aims of providing support for the EB Community. Communication, coordination and collaboration with organisations (including other DEBRAs and EB organisations) is critical to the success of continued international research projects, both in direction and funding. In this spirit, DEBRA continued to administer one project for Cure EB (formerly 'The Sohana Research Fund').

In January 2020, DEBRA UK will host the first global EB conference in London which will bring together research, clinical aspects of EB (with EB-CLINET) and a community focus with DEBRA International.

RESEARCH BY NUMBERS

£958k	committed to new research projects	24	researchers funded by DEBRA UK in 2018
£408k	on additional research expenditure	£7.1m	spent on research grants over the last 10 years
14	ongoing EB research projects funded by DEBRA UK		

LOOKING TO THE FUTURE

There is still some way to go to find a cure(s) for EB. Because of this, DEBRA will use expert summits to identify new research opportunities and draw in relevant expertise outside the field of EB; continue funding projects which add to knowledge on the natural history or treatment of EB; and build on results obtained from ongoing projects and translating clinical findings into meaningful treatments.

AIMS FOR 2019

- Fund up to £1m on research projects in 2019 with an estimated spend of £3.4m on total research over the next 3 years
- Focus on the translation of pre-clinical research into early phase patient studies identifying suitable treatments for cure(s) and control of EB, as well as symptom relief and treatments that will impact positively on the quality of life
- Continue to identify core areas for research and drawing experts from other fields into the EB research community
- Champion communication, coordination, and collaboration to ensure a coherent approach to EB research, within the UK and worldwide
- Work to develop, build and fund the flagship EB World Congress in January 2020

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.

In 2018 DEBRA invested £472k to enhance the core service through funding increased hours for specialist nurses and dietitians, as well as supporting initiatives such as the multi-disciplinary outreach clinics and training.

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, 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 improving the quality of life.

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 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. A contribution was made to further develop the national clinical database for EB.

HEALTHCARE BY NUMBERS

1,630	patients supported in England and Wales	£472k	spent on Healthcare activities
100	days of specialist dietitian services	192	hospital inpatient TV grants
69	hours of clinical supervision	28	specialist EB training grants
Up to 25%	specialist EB nurses' ongoing 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 2019

- Continue funding up to 25% of each ongoing specialist EB nurse in the UK, 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 for the development of EB clinical best practice guidelines within the identified areas
- Develop strategies for managing increasing patient caseload

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 continued to provide membership and specialist community support services to people suffering from EB and their families across the UK.

ENGAGING WITH THE EB COMMUNITY

DEBRA consistently requests and reviews feedback provided 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 review of existing printed materials and website content continues with updates being actioned accordingly. However, further development is still required.

KEY AREAS

Information and Liaison Support

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

Support Grants

DEBRA provides support grants to Members for emergent needs and to assist in covering costs for basic quality of life improvements, such as white goods. In 2018 two new grant funds were made available to Members to promote independence through travel, and education and learning. Over the year, there was a 17% increase in the number of support grant applications when compared with 2017, which is most likely a result of increased awareness of funds available. In addition to DEBRA's support grants, the Community Support Team successfully aided members of the EB Community in accessing financial support from other sources.

Community Events

There are many stories of EB Community members feeling isolated and alone. It is important for DEBRA to provide opportunities across the UK where 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 four regional Member events, as well as two long weekend away trips. 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, either due to cost or inadequate facilities. 110 holidays were taken by Members in 2018 in DEBRA holiday homes. The Lake District holiday home, purchased in 2017, is the most popular choice. DEBRA now owns five holiday homes, which were booked to full capacity over the peak seasons. Work is underway to develop initiatives to increase low season usage.

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

578	individuals accessed the DEBRA Community Support service	£866k	spent on Membership and Community Support activities
273	support grants were awarded to value of £62k	2,892	individuals in the free DEBRA Membership scheme
103	EB hospital clinics attended	770	holiday days taken in DEBRA's five holiday homes
295	people attended Members' Day	472	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 to help shape and focus care and support service developments and improved Membership benefits, including more regional and 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 2019, 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 2019

- Provide a professional Membership and Community Support service to members of the EB Community across the UK
- Expand and develop the Membership and Community Support Teams to meet current needs and increasing demand
- 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
- Introduce a technology support grant fund for Members to develop skills and independence
- Introduce a number of local and smaller member events across the UK
- Update and enhance the range of publications and improve the accessibility of information available to Members and healthcare professionals
- Maintain membership of external organisations (such as Disability Rights UK) facilitating DEBRA's ability to campaign for the EB Community

DEBRA - UK & INTERNATIONAL

International collaboration and coordination is vital in developing effective treatments and a potential cure(s) for EB. DEBRA UK 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 and pharmaceutical and biotechnology organisations.

COLLABORATING AT THE INTERNATIONAL LEVEL

DEBRA 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 DEBRA 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 over 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 (CPG).

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 (Prof Robin Eady Grant fund) to assist clinicians and researchers further their professional development and interest in the field of EB.

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.

DEBRA UK INTERNATIONAL & DI BY NUMBERS

51	DEBRA groups worldwide	7	CPG in development around the world, with 4 completed
276	Members of clinical practice guideline network – all continents represented	4	Robin Eady international training grants funded by the UK
227	Individuals taking part in the DI Research Involvement Network	2	International clinical practice guidelines funded by the UK
19	EB research groups worldwide have received UK funding over the last five years		

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) and assistance from personnel where required.

AIMS FOR 2019

- 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
- Produce a global EB research impact report
- Ensure information on research is made easily available to Members, professionals and industry
- Work towards hosting EB2020, the first EB World Congress in London in January 2020



PUBLIC ENGAGEMENT

RAISING AWARENESS

The #FightEB campaign ran through to the end of February 2018. Publicity surrounding the campaign frontman James Dunn led to coverage on both BBC Breakfast and Good Morning Britain. The campaign, which ran from October 2017 realised over £319k in associated gifts and helped raise a significant amount of awareness about EB. The #FightEB branding has now been integrated into the DEBRA brand and we plan to re-launch the campaign digitally in 2019.

Very sadly James passed away in April 2018. His death prompted a large number of tributes that were testament to the incredible charisma and fortitude that were so apparent in him.

KEY AREAS

There are many platforms from which DEBRA can engage with the public. In 2018, our media monitoring service recorded 741 media mentions of "Epidermolysis Bullosa" and/or "DEBRA" in the media, including magazines, newspapers radio and television broadcasts.

These included the screening of 'The Boys with No Skin' on Channel 5 and the remarkable story of the Syrian refugee in Germany, Hassan, whose skin graft and subsequent operation was featured on the BBC News. These two stories give an immense amount of hope to all of the EB Community in the progression of treatments as well as raising awareness amongst the public.

On 25 September, 2018, DEBRA's Royal Patron, the Countess of Wessex, opened the Rare Diseases Centre at St Thomas' Hospital, London. The Centre was funded by DEBRA and a number of other charities and its importance is already apparent. Adults with EB now have a 'one stop shop' within the hospital for their consultation and treatment. EB Consultant Prof Jemma Mellerio and her team are delighted to be able to provide their services from one place and the positive impact upon patients is clear.

In November 2018 DEBRA celebrated its 40th Anniversary with a 'Butterfly Release' at a reception held at Bank of America, Merrill Lynch. Nearly 250 people from all parts of the EB Community came together to celebrate the achievements of the charity and to hear the strategic intent for the years ahead. At the event, DEBRA welcomed an address by the charity's new President, Simon Weston CBE.

Simon spoke about the impact of the prolonged use of opiates to relieve pain and how this has affected him over the past 40 years. DEBRA is funding a clinical trial to assess the potential use of cannabinoid oil instead of opiates to relieve pain in people with EB. This story was then released into the media and picked up by national and local press and radio.

Digital Engagement

In efforts to further develop DEBRA's digital presence, a more focused communication was introduced on social media platforms with regular EB community-focused content. To support content generation, a new area, 'EB Corner', dedicated to Member-focused content, has been introduced on the website.

Digital public engagement was measured throughout 2018. There were a total of 287,115 people who visited DEBRA's website – compared with 254,346 in 2017.

Social media also saw an increase in reach and engagement compared to 2017:

- Facebook – 8% more likes on the page
- Twitter – 11% increase in the number of followers
- Instagram – 180% increase in the number of followers

SIGNIFICANT PARTNERSHIPS

DEBRA's #FightEB Campaign came to an end in February 2018. Over the course of 6 months the campaign realised over £319k in associated donations and fundraising. More importantly, thousands of people were inspired by the campaign's frontman James Dunn. James appeared on both BBC Breakfast and ITV Good Morning shows talking about life with EB and the importance of getting behind the charity DEBRA. He was an inspirational ambassador for the EB Community.

The Automobile Association helped to raise awareness of EB by highlighting DEBRA's cause on the AA route planner website. Over the course of six months hundreds of thousands of people were exposed to the DEBRA brand.

In November DEBRA were the chosen charity for the BBC Radio 4 Appeal. DEBRA Golf Society President Steve Rider fronted the Appeal that realised over £15,000 of income.

PUBLIC ENGAGEMENT BY NUMBERS

410k emails were sent to DEBRA Members and supporters

20k copies printed of DEBRA's Member and supporter magazines

287,115 people visited the DEBRA website

8,600+ likes on Facebook

4,600+ followers on Twitter

1,258 followers on Instagram, tripled since 2017

LOOKING TO THE FUTURE

In 2019 DEBRA is investing in its internal Communications Team by creating a new senior role of Head of Communications. This role will head up a proactive approach to engage with the wider EB Community – going beyond those with EB – to directly link healthcare workers, researchers, pharmaceutical companies, DI and all interested EB parties to harness their activities to promote the work of the charity.

AIMS FOR 2019

- Engage with the wider EB Community, including healthcare workers, researchers, pharmaceutical companies, DI and all interested EB parties
- Unify organic, beneficiary-generated social media activity within the DEBRA brand
- Adopt a proactive approach to PR to ensure that DEBRA is associated with all appropriate EB stories.
- Re-launch DEBRA's #FightEB Campaign to raise awareness and engage with the EB Community





Myra's Story

Empowering others...

31 year-old Myra is a motivational speaker and advocate for EB. Although EB has caused visible scarring to her skin and irreparable damage to her hands, she is determined to use her story to empower others.

Raising awareness of EB and promoting body-positivity are of high importance to Myra and she has been inspiring thousands of people through her Instagram channel.

"You never want people to see you as a victim. You never want people to feel sorry for you because you are suffering. You have to empower people to feel inspired by you," she says

Myra doesn't let her EB define or restrict her. She works part-time as a translator – speaking Urdu and Punjabi – at Birmingham Women's and Children's NHS Trust, which is a Centre of Excellence in EB, and has ambitions to be a television presenter in future.

"It's important to raise awareness of EB. Everyone needs to know about it. Everyone needs to be educated about this painful condition."

FUNDRAISING

SUPPORTING THE EB COMMUNITY

As a charity, DEBRA is reliant upon its fundraising activities to deliver its charitable objectives. Everything people do to support DEBRA – from hosting a fundraising event to giving directly – has a positive impact on the EB Community.

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 by providing Healthcare and EB Community Support services, as well as working towards a better future through funding pioneering research projects.

DEBRA's fundraising efforts include hosting 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.

Combined income from both fundraising and retail has grown significantly in both 2017 and now in 2018 despite the ongoing wider political and economic uncertainty. This has enabled the charity to do more for the EB Community and to commit more funds to research projects.

KEY AREAS

Major Events

DEBRA's Major Events programme was successful once again in 2018. Of particular note were the Great Chefs Dinner with Michel Roux in February, the 40th Anniversary Dinner and Ball at the Savoy in June and the 14th Fight Night with Frank Warren in November. The DEBRA Golf Society had a record return in recent years under the captaincy of Tony Lewis.

Corporate Partnerships

DEBRA is committed to building meaningful partnerships with companies based on mutual goals. We offer a range of innovative ways to engage staff with the cause and help ensure that the partnership makes a really positive impact to the company. This year has seen many companies come on board to support DEBRA and #FightEB together. We would like to thank all of the companies who have made donations, the thousands of staff who have raised money for DEBRA and everyone who has taken part in the 'Retail Challenge' which was officially launched in 2018. Corporate giving increased by 72% (net) from 2017 to 2018 and we look forward to building more partnerships in 2019.

Sports and Challenges

The 2018 London Marathon was a record for DEBRA in terms of the amount of money raised by the charity's participants. It is perhaps no surprise though, as more than two thirds of DEBRA's runners had a direct link to EB in their own family, that in total, 30 runners raised an incredible £130k.

Individual Giving

In 2018 DEBRA was one of the beneficiaries of the BBC Radio 4 Appeal. The programme, presented by Steve Rider sports presenter and supporter of the DEBRA Golf Society, was aired in November. This realised income of over £15k for the charity as well as raising much needed awareness.

Grant Making Trusts

In 2018 DEBRA was fortunate enough to enjoy the support of many grant making trusts and foundations, including The Brother's Trust, The Dyers' Company's Charitable Trust, The People's Postcode Trust, The Childwick Trust, The Garfield Weston Foundation, QBE Foundation, The Co-op Foundation, British Association of Dermatologists, Bill Brown's Charitable Settlement, Genetic Disorders UK, Berkshire Community Foundation, The Lowde Music Trust, O'Sullivan Family Trust and The G F Eyre Charitable Trust.

SIGNIFICANT PARTNERSHIPS

DEBRA was once again indebted to its Patron, HRH The Countess of Wessex, for her wonderful support. In September she officially opened the Rare Diseases Centre in St Thomas Hospital. Few will forget her incredible invitation to James Dunn to come to Buckingham Palace in February 2018 to take her portrait.

In 2018 DEBRA worked with a greater number of companies both in terms of directly helping the charity through corporate support or by helping the events programme through sponsorship. The DEBRA Networking Meetings were launched in early 2018 and provide a good opportunity for businesses involved with DEBRA to get together. Companies involved directly include Morelli, Constance Hotels and Resorts, Golf Breaks, Chapel Down, EJ Churchill, Holland and Holland and Switzerland Travel Centre.

FUNDRAISING BY NUMBERS

£210k	net income from the DEBRA Major Events	£110k	net income from the DEBRA Golf Society
£207k	net income from individual donors	£118k	net income from the major challenge events
£318k	net income from the legacy and trust donations		

LOOKING TO THE FUTURE

The team restructure that was put in place in 2017 is now directly positively impacting levels of income generation and efficiencies within the Fundraising and Communications Team. The challenge for 2019 is to continue the growth in income that has been seen in 2017 and 2018. This growth is anticipated to come from corporate giving, major donors and grant making trusts whilst still delivering an excellent events programme. Relationship development is key across all income streams and this is where focus will continue.

Working directly with the EB Community is also key and in 2019 a new initiative, known as Friends' Groups, will be introduced – designed to empower families to raise awareness of EB and to raise money from their own local community. DEBRA's first fundraising event directly involving the EB Community will also be held in July 2019 – the charity's inaugural Butterfly Walk.

RETAIL

DEBRA ON THE HIGH STREET

Retail continues to be a significant income generator for DEBRA. In 2018, DEBRA's Retail chain of both traditional and furniture and electrical (F&E) shops produced the charity's most successful trading year. This is in terms of both improved margin and like-for-like sales, with growth across the chain being well above the sector average. DEBRA's visible presence on the high street cannot fail to raise public awareness about those affected by EB and the work of DEBRA.

RETAIL STRATEGY

Since the appointments of a new Director and Deputy Director of Retail early in 2018 several strategic areas have been reviewed. Amongst them was improving margin, incorporating optimum pricing, and improving standards with the launching of a revised Shops Operations Manual. The retail bonus scheme has been revamped and there has been a full transport review. The end of 2018 and beginning of 2019 will see the roll out of computers across the chain.

KEY AREAS

Traditional Shops

The theme of consolidation was continued throughout 2018. A detailed analysis of under-performing shops has been undertaken, and where appropriate decisions have been made to break or not renew leases. As a result, DEBRA has seen a higher margin/contribution attained with fewer shops. Further contraction is planned for the Traditional chain, in that any shop with a contribution of less than £8k pa will be closed at the earliest opportunity. Early intervention to avoid this situation arising will be a priority, in order to protect jobs and maintain DEBRA's profile in the community. Whilst not actively planning expansion in traditional retail, DEBRA remains opportunistic and sensible to new prospects, predominantly within the M4 corridor/Thames Valley.

Furniture and Electrical

There has been one closure (Hemel Hempstead) in 2018 due to poor performance. Other under-performing F&E shops will be reviewed as and when lease breaks occur. However, building on the success of the existing F&E portfolio there is planned expansion in this area with two new openings early in 2019, and further expansion at a rate of two a year in subsequent years.

Estate

At the end of 2018, DEBRA's shop portfolio spanned 125 locations: 107 Traditional shops and 18 F&E (11 in England and seven in Scotland). The current portfolio is made up of four freeholds, 103 leaseholds and 18 temporary shops.

Retail Gift Aid Scheme

Retail Gift Aid training has been conducted across all the shops in the chain by the Finance Department. DEBRA's standards of compliance are high. The result of higher trading profitability has meant that the charity's dependence on Gift Aid has lessened. Together with retail donations, this represented a total net income of £1,165k (2017: £1,258k), which is 58% of total retail net income (2017: 80%).

Volunteering

DEBRA recognises that its retail chain wouldn't be successful without the help of its dedicated band of volunteers. It is recognised that the level of volunteer contribution falls short of similar sized chains. Recruitment of volunteers will be a primary focus in 2019.

SIGNIFICANT PARTNERSHIPS

Developing relationships with corporate supporters can only enhance the performance of DEBRA Retail. The charity has focussed on two main areas in 2018 and will further develop these in 2019:

- Donations of furniture such as Nectar Sleep and Emma Mattresses, and Accor Hotel chain furniture
- Developing relationships with Corporate Companies for 'Retail Challenge' team building days

RETAIL BY NUMBERS

15%	margin achieved	5.3%	growth in like-for-like sales
£1,105k	received through the Retail Gift Aid Scheme	125	shops at year end, 107 traditional and 18 F&E (inc. in Scotland)
c6,000	volunteer hours contributed weekly		

LOOKING TO THE FUTURE

DEBRA's key aims for Retail are primarily the continued improvement of margin and contribution. There will be a strong focus on standards of visual merchandising and great emphasis will be placed on the recruitment of volunteers.

Enhanced and structured training and induction programmes will be delivered, including appraisals, Area Meetings and regular one-to-one meetings at all levels. Communication will be dramatically improved with the roll-out of computers to all shops. The 2019 Staff Conference will provide a focal point to the year, increasing motivation and engagement.

DEBRA's Retail division brings recognition to the public of the charity's work and offers its supporters the opportunity to offer practical help by donating goods or their time, rather than direct monetary support.

AIMS FOR 2019

- Consolidate the portfolio if a reasonable return cannot be made from underperforming shops
- Improve margin through price optimisation and enhancing standards of visual merchandising
- Grow like-for-like sales income by a further 2.5%
- 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

OUR PEOPLE

From its origins 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 2018, DEBRA employed just over 380 employees, and engaged approximately 800 volunteers. The range of jobs is broad, from managing charity shops 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.

VOLUNTEERS

Volunteers continue to be a significant resource to DEBRA, and the new post of Volunteer Manager was created in 2018 to develop volunteer resources across the organisation, focusing particularly on Retail and EB Community Support. The Volunteer Manager is working in conjunction with Retail management and is prioritising support for the shops which currently have insufficient volunteers.

A new initiative was introduced mid-way through the year – EB Connections – which will match Practical Community Volunteers (PCVs) with Members to support them in their own homes in whatever way suits them best, e.g. spending time with a sibling of a child with EB, possibly helping with shopping or gardening. The foundations for this project were laid in 2018, after surveying a selection of Members to establish that there was a need and to identify the nature of what practical help would be useful. It is anticipated that up to ten PCVs will have been appointed and matched with families by the end of 2019.

LEARNING & DEVELOPMENT

All members of staff are encouraged to continually develop their skills, and the e-learning platform that was introduced in 2017 proved useful in 2018 as a means to efficiently deliver modules on Safeguarding 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 2018 event was held in Nottingham and spanned two days. Several members from the EB Community also attended to give an insight into how the condition affects their day-to-day life.

SAFEGUARDING

‘Say something’ was the message of the Safeguarding campaign that was launched within DEBRA in 2018. As media coverage early in the year highlighted the particular challenges of ensuring safeguarding in the charity sector, DEBRA reviewed its policy and committed to ensuring that every member of staff was adequately trained and informed, through a combination of e-learning modules, a presentation at the All Staff Conference in April, increased visibility of the policy and procedures through posters in every DEBRA workplace (offices and shops), and advanced external training for Designated Safeguarding Officers. The Health & Safety Manager, a member of the HR Team, assumed responsibility for safeguarding in 2018 and leads a Safeguarding Committee which meets quarterly to ensure that DEBRA continues to practise effective safeguarding and that safeguarding remains a priority within the organisation.

APPRENTICESHIPS

From April 2017, DEBRA started making payments in respect of the apprenticeship levy. Based on a contribution of 0.5% of the annual wage bill (with a standard allowance of £15k), funds are accumulating in a specific levy account, from which payment can be made towards training for existing members of staff or for the training of new employees who are recruited as apprentices.

Funds which are drawn from the levy cannot be used to contribute to the wages of an apprentice, and this is one of the reasons that there has been resistance to recruit apprentices, who need to be supported by existing staff. Employees have been encouraged to develop their skills by undertaking apprenticeship schemes, but this too, in practice, has seemed to hold little appeal.

DEBRA is not alone as an organisation finding it difficult to use the levy, and it was widely reported in 2018 that the government's initial target in 2015 of seeing three million people start apprenticeships by 2020 will fall short. Nevertheless, within DEBRA the apprenticeship scheme will continue to be promoted throughout 2019 to both employees and volunteers.

PAY POLICY

Rates of pay and salaries within DEBRA are set at a level that is 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.

In accordance with the Equality Act 2010 (Gender Pay Gap Information) Regulations 2017, DEBRA has reported pay data for the 'snapshot' date of 5th April 2018.

DEBRA's mean gender pay gap is 5.3%, which tells us that, on average, the hourly rate of pay that female employees receive is 5.3% lower than the rate male employees receive, which equates to a difference of £0.56 ph in monetary terms. Comparing this year's mean gender pay gap figure to that for April 2017, there has been a decrease of 6.1%.

This is significantly below the figure of 11.3%, 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 25.0%, so again, DEBRA's figure of 5.3% compares very favourably. The full Gender Pay Gap Report 2018 is available on DEBRA's website.

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 2018, 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

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.



Jess' Story

Expert care changed my life

22 year-old Jess loves to dance. But every step causes her excruciating pain – Jess' EB affects her hands and feet.

Specialist foot care and support from DEBRA has enabled Jess to achieve her ambitions.

"I'd always suffered with feet that blistered really easily – the skin would tear and it was incredibly painful," Jess says. "I pushed myself harder to do the things I wanted, although my feet would be bloody and the blisters infected. The problems intensified in my second year of uni, where I was studying dance – the pain was so bad I hobbled around on crutches, going beyond endurance to keep up with the pace of the course."

"I sought a diagnosis and I was referred to the specialist EB team at Solihull Hospital, which I found out was a Centre of Excellence in EB supported by DEBRA. The EB team has helped me understand my condition and control it. I'm no longer struggling on my own. I now have the knowledge and access to proper dressings and sterile needles so I can care for my feet – I get far fewer infections now."

"This support has changed my life – I now know how to care for my feet and minimise blistering, dramatically reducing the pain I'm in. I'm now able to do my dream job, dancing and coordinating children's activities on a Disney Cruise Liner."

DEBRA provides care and support to EB sufferers and funds research into effective treatments and a cure.

DEBRA is currently funding the development of a full podiatry training programme across the UK, enabling more people like Jess to have access to expert foot care, raising awareness of EB in the medical community and improving the quality of life for thousands of people with EB.

FINANCIAL REVIEW

OVERVIEW

DEBRA's accounts show the financial affairs of the charity for the year ended 31 December 2018. The charity's net income after accounting for the costs of raising funds (principally charity shop trading costs) was £3,445k, growing by 15% from £3,000k achieved in 2017.

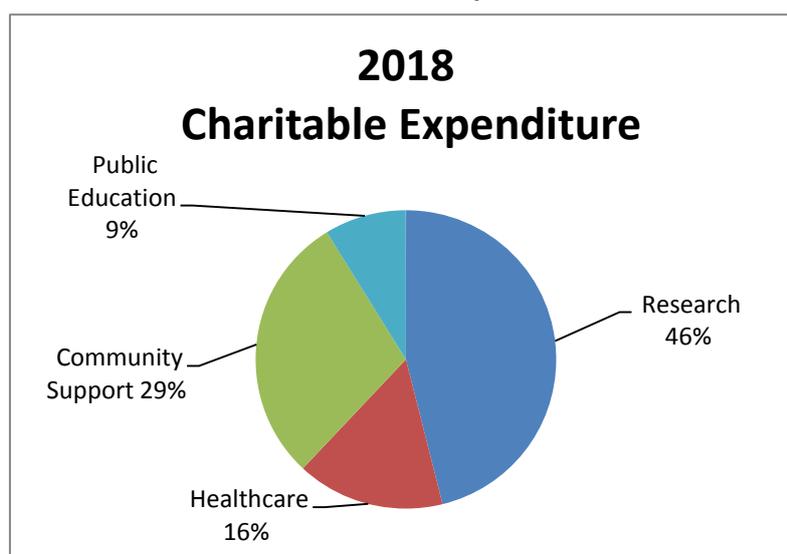
Retail enjoyed the financial benefits of a year of consolidation, rather than expansion in shop numbers, with net retail income growing by 27% over 2017 to £2,001k. This covers all overhead costs of the charity.

Expenditure on charitable activities was £2,966k, leaving a surplus of £479k for the year. For every £ of net contribution in 2018, 83p was spent on charitable activities or designated for future charitable spend.

CHARITABLE SPEND

Charitable spend in 2018 was less than in 2017, due mainly to two large projects committed to in 2017. A contribution of £250k to the St Thomas' Hospital Rare Diseases Centre was made in February 2017, as well as commitment of £463k to a pioneering cancer trial. The charity continued to invest in Research during 2018, costing £1,366k (2017: £1,561k), whereas £866k (2017: £772k) was spent on Community Support initiatives, £472k (2017: £715k) on Healthcare services and £261k (2017: £252k) on Public Education.

Chart 1: Charitable Expenditure 2018



There are plans to increase charitable spend in future periods, demonstrated by the trustees' decision to designate £1,949k for future research projects, as significant sums will be needed in the near future to continue funding expensive clinical and other trials.

The surplus in the year led to an increase in net assets from £4,077k to £4,556k. There was £1,991k in the general fund, £2,429k in designated funds and £136k in restricted funds.

FINANCIAL REVIEW

SUMMARY

Table 2 summarises the highlights of DEBRA's financial performance over the last five years. Net trading income achieved through the shops (including Retail Gift Aid and donations received in the shops) and fundraising events increased from £1,874k to £2,358k between 2017 and 2018. Net retail income before allocation of central overheads was £2,537k, 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 fell from £3,468k in 2017 to £2,979k in 2018 because significantly more legacy income was received in 2017, plus large trust donations came in towards the Rare Diseases Centre at St Thomas' Hospital.

Table 2: Financial Summary

£'000

	2018	2017	2016	2015	2014
Total income	16,138	16,182	14,136	12,501	11,881
Non-trading income	2,979	3,468	2,832	2,768	2,938
Net trading income	1,193	616	330	34	639
Net trading income including retail gift aid and donations in shops	2,358	1,874	1,517	1,035	1,541
Non-trading fundraising costs	727	1,083	819	763	736
Charitable expenditure	2,966	3,299	1,715	2,524	3,266
Retained surplus/(deficit)	479	(299)	628	(486)	(425)
Retained surplus/(deficit) as a % of income	3%	(1.8%)	4.4%	(3.9%)	(3.6%)
Net current assets	4,394	3,951	3,340	2,905	4,034
Unrestricted reserves	4,420	3,997	4,301	3,732	3,650
Grants payable within 1 year	1,825	1,156	1,519	1,694	1,490

In 2018 for every £1 of net contribution 83p (2017: 74p) 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. 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 five holiday homes held for the use of those affected by EB. The rest of the charity's assets are held to promote the purposes of the charity through its support services and research programmes.

RESERVES POLICY

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

The trustees' reserves policy in 2018 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 2018 were £4,556k, including £136k in restricted funds. Cash-backed free reserves before designations were £3,729k, of which £2,429k 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 mortgaged at short notice, thus representing reserves that can be accessed immediately.

Future Research Fund

A total of £1,949k 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 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. It is anticipated this fund will be spent in the next 5-10 years.

EB2020 Fund

The trustees have established a designated fund for the 2020 EB Conferences to be held in London and hosted by DEBRA. There was a balance of £230k in this fund at the end of 2018. It is anticipated this fund will be spent in the next 1-2 years.

General Fund

There was £1,991k in the general fund, of which £1,099k 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 2018, 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 activity is the sale of promotional items on behalf of the charity, plus other non-primary purpose trading. 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 2018, 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 are 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
Charity image damaged	Marketing and PR strategy Disciplinary policy Crisis communication plan Review of any complaints received Extensive social media policy for staff	Media monitoring Annual staff appraisals Register of crises Investigation of occurrences
Insufficiently robust cyber security	Anti-virus software Cyber insurance policy Encryption of hard drives Secured wifi connection Offsite backup three times weekly Use of firewalls PCI compliance	Anti-virus tool displays Monthly reports Firewall logs checked regularly Daily logs of server activity
Misuse of data and failure to comply with Data Protection legislation	In-house Data Protection Officer Data protection policy Regular data protection training	Data protection working party Regular reporting GDPR e-learning module
Loss of major source of fundraising income	Diversity of fundraising activities Regular contact with supporters	Quarterly fundraising and communications meetings with trustees Performance against budget
Decline in retail contribution	Monthly detailed shops reporting Separate retail risk register Continuous drive to grow contribution	Quarterly Retail Committee meetings with trustees Performance against budget

STRUCTURE, GOVERNANCE AND MANAGEMENT

DEBRA (a Company Limited by Guarantee) is a membership organisation and governed by its Articles of Association, which state that the board 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 eight of the trustees (the majority), and the Nominations & Governance Committee is responsible for proposing up to a further seven with relevant skills to be appointed by the trustees themselves.

At the Annual General Meeting in 2018, as recommended by the Nominations & Governance Committee, four trustees – Jim Irvine, Graham Marsden, Joanne Merchant and Tim Powell – were re-appointed for a further three-year term by the board. The Chair, David Spence retired, leaving DEBRA with 12 trustees on the board as at 31 December 2018. The board agreed to reduce the number of trustees for the time being in line with current recommendations for charities to have a smaller board. The Vice Chair, Mike Jaega was appointed as the new Chair and Andy Grist became Vice Chair. Sadly, Mike Jaega passed away in February 2019 and Jim Irvine was appointed as Interim Chair and Joanne Merchant as Acting Treasurer on 25 April 2019.

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 2018 the external governance review report – carried out in 2017 – was considered and a temporary sub-governance group was set up to review the feedback and make recommendations to the board.

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

TRUSTEE COMMITTEES cont.

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.

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 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.

CHARITY GOVERNANCE CODE

The board are considering the new Charity Governance Code as a guide to good governance practice going forward.

Table 4: Trustees' Membership and Attendance Records

Board of Trustees			Committees					
Trustee	Year of Appointment	Board Meetings	Finance, Risk & Audit	Nominations & Governance	Charitable Activities	Retail	Fundraising & Communications	DEBRA UK International
David Spence – Chair	2009	1 of 2	1 of 2	2 of 3	-	1 of 2	-	-
Michael Jaega – Vice Chair/Chair	2013	4 of 4	3 of 5	5 of 5	3 of 3	-	-	1 of 3
Jim Irvine – Treasurer	2012	4 of 4	5 of 5	-	-	4 of 5	-	-
Simone Bunting	2011	4 of 4	-	3 of 5	-	-	4 of 4	-
Rebecca Cresswell	2017	3 of 4	-	-	-	-	4 of 4	-
Simon Cuzner	2014	3 of 4	3 of 5	-	-	5 of 5	-	-
Andrew Grist – Vice Chair	2016	4 of 4	-	1 of 2	4 of 5	-	-	3 of 3
James Hinchcliffe	2011	On leave of absence	On leave of absence	-	-	-	-	-
Graham Marsden	2012	3 of 4	-	5 of 5	-	-	-	3 of 3
Joanne Merchant	2015	4 of 4	5 of 5	-	-	-	-	0 of 3
Vivien Mundy	2017	3 of 4	-	-	4 of 5	-	-	2 of 3
Timothy Powell	2015	3 of 4	-	-	3 of 5	-	-	-
David Wilkinson	2016	4 of 4	-	-	-	-	1 of 2	-

*Records in **bold** indicates Committee Chair

SUCCESSION PLANNING

DEBRA has built strength and depth in its Board of Trustees, incorporating appropriate succession planning and each of the DEBRA committees has a Vice Chair.

STRUCTURE, GOVERNANCE AND MANAGEMENT

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 Crowthorne 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 two fundraising complaints in 2018, both of which were registered, satisfactorily resolved and recorded
- DEBRA received 128 compliments in 2018 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 38 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
Interim Chair of Trustees

2 May 2019



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 2018 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 2018 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; and
- 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

AUDITOR'S REPORT

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 Interim Chair 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; and
- 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

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 OUR REPORT

This report is made solely to the Charitable Company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and 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.

Julia Poulter (Senior Statutory Auditor)
For and on behalf of BDO LLP, statutory auditor
Gatwick, West Sussex
Date:

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



Freddie's Story

Providing lifelong support...

When Jenna and Nick's son Freddie was born with EB, he had no skin on his hands and feet. Freddie was rushed to intensive care. Doctors later diagnosed him with EB.

Specialist EB nurses, part funded by DEBRA, were called in straight away and showed Jenna and Nick how to care for Freddie's skin.

Freddie's EB meant that he will need constant care and Jenna had to give up work to look after him. His parents struggled with his diagnosis and worried about how they would cope financially. They felt completely overwhelmed.

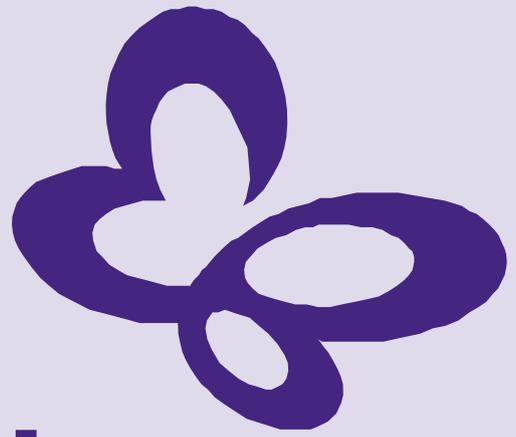
Thankfully, DEBRA was able to help. A Community Support Manager from DEBRA was assigned to Freddie and his family, and provided practical, financial and emotional assistance.

DEBRA also provided a support grant to buy a soft carpet for their living room so that Freddie wouldn't tear his skin on the hard floor as he learned to crawl – a simple thing that made a big difference.

As Freddie prepared to start school last year, DEBRA worked with teaching staff, making sure they understood the impact of EB and were ready to provide the support Freddie needs, like making sure he can use his wheelchair when he needs to – to minimise damage to his feet.

Freddie is now five and enjoying life. His parents feel confident knowing they can call DEBRA whenever they need support.

"Without DEBRA we'd have been lost," says Jenna. "They helped us when we had nothing to help Freddie and they are always on the other end of the phone if I need someone to talk to. DEBRA are always there for us."



FINANCIAL STATEMENTS

For the year ended
31 December 2018

STATEMENT OF FINANCIAL ACTIVITIES

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2018

		2018	2018	2018	2018	2017	2017	2017	2017
	Notes	Unrestricted funds	Designated funds	Restricted funds	Total	Unrestricted funds	Designated funds	Restricted funds	Total
		£	£	£	£	£	£	£	£
INCOME AND ENDOWMENTS FROM:									
Donations and legacies	2	2,557,209	-	261,229	2,818,438	2,985,017	-	376,384	3,361,401
Charitable activities		19,700	-	-	19,700	17,150	-	-	17,150
Other trading activities	3	13,025,419	-	134,072	13,159,491	10,110,557	2,429,929	173,967	12,714,453
Investments	4	47,362	-	-	47,362	40,253	-	-	40,253
Other		93,291	-	-	93,291	48,985	-	-	48,985
Total		15,742,981	-	395,301	16,138,282	13,201,962	2,429,929	550,351	16,182,242
EXPENDITURE ON:									
Raising funds	6	12,692,533	-	1,125	12,693,658	11,154,010	2,027,970	-	13,181,980
Charitable activities	6	1,675,187	1,031,119	259,358	2,965,664	957,471	1,796,593	545,428	3,299,492
Total		14,367,720	1,031,119	260,483	15,659,322	12,111,481	3,824,563	545,428	16,481,472
Net income/(expenditure)		1,375,261	(1,031,119)	134,818	478,960	1,090,481	(1,394,634)	4,923	(299,230)
Transfer between funds		(1,432,941)	1,512,000	(79,059)	-	(1,067,617)	1,067,617	-	-
Net movement in funds		(57,680)	480,881	55,759	478,960	22,864	(327,017)	4,923	(299,230)
Reconciliation of funds:									
Total funds brought forward		2,049,090	1,947,786	80,476	4,077,352	2,026,226	2,274,803	75,553	4,376,582
Total funds carried forward		1,991,410	2,428,667	136,235	4,556,312	2,049,090	1,947,786	80,476	4,077,352

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 2018

Company registration number: 04118259

		2018		2017	
	Notes	£	£	£	£
Fixed assets					
Tangible assets	10		1,099,014		1,157,053
Investment in DEBRA Trading Ltd	20		2		2
			<hr/> 1,099,016		<hr/> 1,157,055
Current assets					
Current asset investment	11	2,750,000		1,800,000	
Stocks		18,139		19,260	
Debtors	12	2,204,988		1,542,974	
Cash at bank and in hand		2,644,426		3,207,830	
		<hr/> 7,617,553		<hr/> 6,570,064	
Creditors: amounts falling due within one year	13	<hr/> (3,223,805)		<hr/> (2,619,271)	
Net current assets			4,393,748		3,950,793
Total assets less current liabilities			<hr/> 5,492,764		<hr/> 5,107,848
Creditors: amounts falling due over one year	13		(663,975)		(820,496)
Provisions for liabilities			(272,477)		(210,000)
Total net assets			<hr/> 4,556,312		<hr/> 4,077,352
The funds of the charity					
Restricted income funds	15		136,235		80,476
Unrestricted funds	15		4,420,077		3,996,876
Total charity funds			<hr/> 4,556,312		<hr/> 4,077,352
Unrestricted funds					
- Designated	15		2,428,667		1,947,786
- General			1,991,410		2,049,090
			<hr/> 4,420,077		<hr/> 3,996,876
Restricted funds	15		136,235		80,476
			<hr/> 4,556,312		<hr/> 4,077,352

The notes on pages 54 to 70 form part of these Financial Statements.

The accounts were approved by the board on 2nd May 2019 and signed on their behalf by:

Jim Irvine
Interim Chair of Trustees

Joanne Merchant
Acting Treasurer

CASH FLOW STATEMENT

CASH FLOW STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2018

		2018		2017	
	Notes	£	£	£	£
CASHFLOWS FROM OPERATING ACTIVITIES:					
Net cash provided by operating activities	17		406,565		491,664
CASHFLOWS FROM INVESTING ACTIVITIES:					
Dividends, interest and rents from investments		47,362		40,253	
Proceeds from the sale of property, plant and equipment		-		221,550	
Purchase of property, plant and equipment		(67,331)		(245,068)	
Net cash (used in) / provided by investing activities			(19,969)		16,735
Change in cash and cash equivalents in the reporting period			386,596		508,399
Cash and cash equivalents at the beginning of the reporting period			5,007,830		4,499,431
Cash and cash equivalents at the end of the reporting period			5,394,426		5,007,830

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), 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 conclude that the charity is a going concern because of the continuing financial strength of the balance sheet underpinned by a robust reserves policy, and the anticipated ongoing income streams generated by fundraising and retail activities.

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. 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

General donations and trading income 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 and grants receivable are recognised when the amount due is probable. Income is deferred where it represents a payment in advance for a specific event that will not take place until a future accounting period, except for sponsorship for charity challenges. Gifts in kind are only included in the accounts where the trustees can ascribe a value in excess of £1,000.

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. Full grant recognition has been incorporated into these accounts as the most prudent policy.

1.8 Tangible Fixed Assets and Depreciation

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

Freehold and long leasehold buildings	Over 25 years
Mobile homes	Over 10 years
Fixtures, fittings, static equipment	Over 5 years
Shop tills	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 have been leased back at market rent, for a term of 5 years.

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, 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.

NOTES TO THE ACCOUNTS (CONTINUED)

2. DONATIONS AND LEGACIES

	Unrestricted Funds	Restricted Funds	Total 2018	Total 2017
	£	£	£	£
Donations & gifts	2,330,101	52,743	2,382,844	2,722,194
Legacies receivable	179,433	-	179,433	281,676
Grants receivable	47,675	208,486	256,161	357,531
	<u>2,557,209</u>	<u>261,229</u>	<u>2,818,438</u>	<u>3,361,401</u>
Donations & gifts:				
Individual donations	1,808,997	43,218	1,852,215	1,924,223
Corporate donations	430,058	7,477	437,535	710,330
International donations	1,235	-	1,235	602
Events by individuals	89,811	2,048	91,859	87,039
	<u>2,330,101</u>	<u>52,743</u>	<u>2,382,844</u>	<u>2,722,194</u>
Grants receivable:				
Charitable trusts	47,675	208,486	256,161	357,531
	<u>47,675</u>	<u>208,486</u>	<u>256,161</u>	<u>357,531</u>

Gifts in kind of £145,150 (2017: £430,000) are included in donations and gifts. These include the ongoing advertising in a national newspaper valued at £20,800 (2017: £147,072) and online AdWords valued at £93,750 (2017: £92,300).

3. OTHER TRADING ACTIVITIES

	Total 2018	Total 2017
	£	£
Income	13,159,491	12,714,453
Operating expenses	(11,966,305)	(12,098,920)
Net income from fundraising activities	<u>1,193,186</u>	<u>615,533</u>

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2018 there were 125 shops trading (2017:131). The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2018	Net income 2017
	£	£	£	£
Retail	12,102,185	(11,266,370)	835,815	312,095
Fundraising events	883,143	(699,935)	183,208	203,937
Miscellaneous trading	174,163	-	174,163	99,501
	<u>13,159,491</u>	<u>(11,966,305)</u>	<u>1,193,186</u>	<u>615,533</u>

The net income incurred by retail excludes £1,165,168 (2017: £1,257,562) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. In 2018 there was strong like-for-like growth in retail and a slow down in new shop openings. The profit covenanted by DEBRA Trading Limited of £37,050 (2017: £15,860) is included in miscellaneous trading.

Total retail income, including retail Gift Aid and retail donations, was as follows:

	2018	2017
	£	£
Retail income	13,267,353	13,059,477
Retail expenditure	<u>(11,266,370)</u>	<u>(11,489,820)</u>
Retail net income	<u>2,000,983</u>	<u>1,569,657</u>

4. INVESTMENT INCOME

	Total Unrestricted 2018	Total Unrestricted 2017
	£	£
Interest receivable	19,672	15,240
Rent of property	<u>27,690</u>	<u>25,013</u>
Total investment income	<u>47,362</u>	<u>40,253</u>

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 273 (2017: 233) Community Support grants totalling £61,951 (2017: £63,369) 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 ongoing and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2018 the trustees had authorised and communicated a commitment to support research grants over the next three years to the sum of £1,488,759 (2017: £1,218,000) and clinical projects to the sum of £240,985 (2017: £141,666).

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

	Total 2018	Total 2017
	£	£
Within 1 year	1,065,769	539,170
Within 2-3 years	<u>663,975</u>	<u>820,496</u>
	<u>1,729,744</u>	<u>1,359,666</u>
Provided within the grants payable creditor (note 13)	<u>1,729,744</u>	<u>1,359,666</u>

6. EXPENDITURE

	Staff costs	Grants payable	Other costs	Total 2018	Total 2017
	£	£	£	£	£
Raising funds:					
Voluntary income	343,451	-	383,899	727,350	1,083,060
Other trading activities	5,618,612	-	6,347,696	11,966,308	12,098,920
	<u>5,962,063</u>	<u>-</u>	<u>6,731,595</u>	<u>12,693,658</u>	<u>13,181,980</u>
Charitable activities:					
Research	315,130	958,104	93,104	1,366,338	1,560,707
Healthcare	101,820	345,220	25,026	472,066	715,055
Community support	667,697	61,951	51,556	781,204	707,396
Respite breaks	-	-	84,674	84,674	64,626
Public education	182,191	-	79,191	261,382	251,708
	<u>1,266,838</u>	<u>1,365,275</u>	<u>333,551</u>	<u>2,965,664</u>	<u>3,299,492</u>
	<u>7,228,901</u>	<u>1,365,275</u>	<u>7,065,146</u>	<u>15,659,322</u>	<u>16,481,472</u>

Other costs

	Depreciation	Overhead allocation	Miscellaneous costs	Total 2018	Total 2017
	£	£	£	£	£
Raising funds:					
Voluntary income	-	149,285	234,614	383,899	695,138
Other trading activities	76,905	251,599	6,019,192	6,347,696	6,422,278
	<u>76,905</u>	<u>400,884</u>	<u>6,253,806</u>	<u>6,731,595</u>	<u>7,117,416</u>
Charitable activities:					
Research	-	26,518	66,586	93,104	26,019
Healthcare	-	25,026	-	25,026	25,382
Community support	-	44,351	7,205	51,556	44,289
Respite breaks	33,021	-	51,653	84,674	64,626
Public education	-	79,191	-	79,191	75,079
	<u>33,021</u>	<u>175,086</u>	<u>125,444</u>	<u>333,551</u>	<u>235,395</u>
	<u>109,926</u>	<u>575,970</u>	<u>6,379,250</u>	<u>7,065,146</u>	<u>7,352,811</u>

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

	2018	2017
	£	£
Hire of plant and machinery – operating leases	22,395	30,815
Auditors remuneration	19,825	19,860
Non-audit services	16,287	11,326
Depreciation of tangible fixed assets	125,370	126,147
Defined contribution pension costs	269,886	233,133
Exchange differences	(23,669)	44,780

7. COST ALLOCATION

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

	2018	2017
	£	£
Staff costs:	1,325,104	1,329,980
Overheads:		
Office premises rent	40,500	4,385
Service charges, utilities & cleaning	36,661	32,943
Equipment costs	142,224	142,972
Postage, printing, stationery, telephone & fax	87,159	84,386
Insurance costs	85,284	70,238
Legal, professional & consultancy fees	58,080	72,103
Depreciation	18,068	24,604
Irrecoverable VAT	52,375	46,141
Bank charges	11,794	8,622
Sundry expenses	14,178	52,611
Governance costs:		
Audit fees	19,555	19,860
Miscellaneous costs	10,091	6,470
	575,969	565,335
Total Allocation	1,901,073	1,895,315

8. TRUSTEES

None of the trustees received any remuneration from DEBRA during the period, but 10 of them were reimbursed a total of £5,611 (2017: £4,276) for travel and subsistence expenses.

Michael Jaega received community support grants in 2018 totalling £1,255 (2017: £637).

James Hinchcliffe received a community support grant in 2018 totalling £150 (2017: £nil).

Scott O'Sullivan received a community support grant in 2018 totalling £nil (2017: £25).

The aggregate figure for trustee donations in 2018 was £3,466 (2017: £11,185).

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 £1,705 (2017: £2,433), as allowed under section 4.3.3 in DEBRA's Articles of Association.

9. EMPLOYEES

The average number of employees during the period was:

	2018 full time equiv	2018 Number	2017 Number
Research	3.1	5	5
Healthcare*	1.0	1	1
Community Support	12.3	13	11
Fundraising	12.4	14	14
Retail	248.7	328	336
Management & Administration	14.0	18	16
	<u>291.5</u>	<u>379</u>	<u>383</u>

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

	2018 full time equiv	2018 Number	2017 Number
Research	3.1	5	5
Healthcare*	1.0	1	1
Community Support	13.3	14	13
Fundraising	12.1	13	13
Retail	242.2	331	335
Management & administration	14.6	19	17
	<u>286.3</u>	<u>383</u>	<u>384</u>

*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 2018	Total 2017
	£	£
Wages & salaries	6,054,739	6,061,935
Social security costs	395,891	401,912
Pension costs	269,886	233,133
	<u>6,720,516</u>	<u>6,696,980</u>

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £285,512 (2017: £215,586) were made in the year and charged to the SOFA in the period they were due. At the year-end there remained £3,320 (2017: £18,947) unpaid.

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

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

	2018	2017
Between £60,001 - £70,000	3	1
Between £70,001 - £80,000	1	2
Between £130,001 - £140,000	1	-
Between £150,001 - £160,000	-	1

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £57,689 (2017: £48,438), and there are retirement benefits accruing for five (2017: four) employees under a defined contribution scheme.

The aggregate pay of key management personnel, including employer's NI and pension contributions was £618,520 (2017: £639,295). The aggregate employer's pension contribution for key management personnel was £63,151 (2017: £60,440).

Redundancy and compensation payments totalled £18,964 in 2018 (2017: £14,400).

10. FIXED ASSETS

Tangible fixed assets

	Shop fittings	Mobile homes	Fixtures, fittings & equipment	Freehold land & buildings	Long leasehold land & buildings	Total
	£	£	£	£	£	£
Cost:						
At 1 January 2018	358,908	391,652	199,734	799,347	82,500	1,832,141
Additions	57,452	6,670	3,209	-	-	67,331
Disposals	(21,150)	-	-	-	-	(21,150)
At 31 December 2018	395,210	398,322	202,943	799,347	82,500	1,878,322
Depreciation:						
At 1 January 2018	207,016	147,948	149,584	155,690	14,850	675,088
Charge for the year	55,332	33,021	18,068	17,299	1,650	125,370
Disposals	(21,150)	-	-	-	-	(21,150)
At 31 December 2018	241,198	180,969	167,652	172,989	16,500	779,308
Net Book Value:						
Brought forward	151,892	243,704	50,150	643,657	67,650	1,157,053
At 31 December 2018	154,012	217,354	35,290	626,358	66,000	1,099,014

11. INVESTMENT IN SHORT TERM DEPOSITS

	2018	2017
	£	£
Lloyds money market deposits	2,750,000	1,800,000
	2,750,000	1,800,000

12. DEBTORS

	2018	2017
	£	£
HMRC	237,922	217,022
Misc debtors	79,429	18,849
Other debtors	82,914	10,023
Accrued income	1,012,576	654,036
Prepayments	792,147	643,044
	2,204,988	1,542,974

VAT repayment of £237,922 (2017: £217,022) is due from HMRC. Accrued income includes gift aid of £744,425 (2017: £306,050) due for 2018.

Total future minimum lease receivable was £10,528 in 2018 (2017: £24,111), in respect of one shop and two flats above shops.

13. CREDITORS

Amounts Falling Due Within One Year

	2018	2017
	£	£
Trade creditors	680,113	571,467
Grants payable	1,824,913	1,155,836
Other creditors	1,644	19,340
Taxation and social security	100,760	95,772
Accruals	589,475	743,666
Deferred income	26,900	33,190
	3,223,805	2,619,271

Grants payable includes £1,065,769 (2017: £539,170) relating to future commitment and £759,144 (2017: £616,666) relating to outstanding invoices for work done.

There was deferred income of £26,900 in 2018 (2017: £33,190), representing income for events which would have to be repaid in the event of cancellation.

Amounts Falling Due Over One Year

	2018	2017
	£	£
Grants payable	663,975	820,496
	663,975	820,496

There was a dilapidations provision of £272,477 (2017: £210,000). In the year £13,313 was released from the provision and a further £75,790 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:

	2018	2017	2018	2017
	Leases of land and buildings	Leases of land and buildings	Other	Other
	£	£	£	£
Within 1 year	1,571,286	1,821,982	22,394	19,860
Within 2-5 years	1,271,991	1,545,206	27,677	36,358
	<u>2,843,277</u>	<u>3,367,188</u>	<u>50,071</u>	<u>56,218</u>

There were capital commitments of £nil at year end, falling due within one year (2017: £8,301).



15. ANALYSIS OF FUNDS

Restricted funds

	Balance at 31 Dec 2017	Income	Expenditure	Transfer to General Fund*	Balance at 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

	Balance at 31 Dec 2016	Income	Expenditure	Transfer to General Fund*	Balance at 31 Dec 2017
	£	£	£	£	£
Research	24,531	220,831	(239,862)	-	5,500
Healthcare	34,728	251,233	(231,039)	-	54,922
Community Support & Respite	16,294	78,287	(74,527)	-	20,054
	75,553	550,351	(545,428)	-	80,476

Restricted funds comprised:

	2018	2017
	£	£
Research – Dundee Project	-	5,500
Research – Cure EB	300	-
Healthcare – EB Nurse Leadership	33,645	45,409
Healthcare – Birmingham Children's Hospital Specialist Bath	5,600	5,600
Healthcare – Podiatry Clinics	-	3,850
Healthcare – other restricted funds	-	63
Community Support – Community Support Manager Post	32,680	-
Community Support – Early Intervention Project	25,000	-
Community Support – Youth Project	9,497	-
Community Support – Community Support in Berkshire	8,915	-
Community Support – Support Grants in Northamptonshire	2,058	4,256
Community Support – Support Grants in Hampshire	3,320	3,164
Community Support – Support Grants in London	-	2,832
Community Support – Volunteer Co-ordinator	6,961	-
Community Support – Holiday Home	4,830	6,000
Community Support – other restricted funds	3,429	3,802
	136,235	80,476

*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.

15. ANALYSIS OF FUNDS (CONTINUED)

Unrestricted Funds

The trustees have transferred the following amounts into designated funds during 2018:

	Balance at 31 Dec 2017 £	Transfers £	Income £	Expenditure £	Balance at 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
EB 2020 World Congress	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

	Balance at 31 Dec 2016 £	Transfers £	Income £	Expenditure £	Balance at 31 Dec 2017 £
Future research grants	1,031,906	1,904,910	-	(1,239,030)	1,697,786
Nursing continuity	491,073	201,365	-	(492,438)	200,000
Furniture and electrical shops	456,225	(858,184)	2,429,929	(2,027,970)	-
Special projects fund	230,474	(230,474)	-	-	-
GSTT Rare Diseases Centre	65,125	-	-	(65,125)	-
EB 2020 World Congress	-	50,000	-	-	50,000
Total designated funds	2,274,803	1,067,617	2,429,929	(3,824,563)	1,947,786
General fund	2,026,226	(1,067,617)	13,201,962	(12,111,480)	2,049,090
Total unrestricted funds	4,301,029	-	15,631,891	(15,936,043)	3,996,876

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 £1,212,000 into this fund in 2018. It is anticipated this fund will be spent 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 transferred a further £50,000 to this fund in 2018.

The trustees established a designated fund for the EB2020 conference, which will be hosted by DEBRA in the UK in January 2020. £50,000 was designated to this fund in 2017 and a further £250,000 was designated during 2018. This fund will be spent in the next 1-2 years.

16. ANALYSIS OF NET ASSETS BETWEEN CATEGORIES OF FUNDS

	Unrestricted funds £	Restricted funds £	Total 2018 £	Total 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)
	<u>4,420,077</u>	<u>136,235</u>	<u>4,556,312</u>	<u>4,077,352</u>
	Unrestricted funds £	Restricted funds £	Total 2017 £	Total 2016 £
Fund balances at 31 December 2017 are represented by:				
Fixed assets	1,157,055	-	1,157,055	1,249,230
Current assets	6,489,588	80,476	6,570,064	6,093,195
Creditors: amounts falling due within one year	(2,619,271)	-	(2,619,271)	(2,933,384)
Creditors: amounts falling due over one year	(1,030,496)	-	(1,030,496)	(32,459)
	<u>3,996,876</u>	<u>80,476</u>	<u>4,077,352</u>	<u>4,376,582</u>

17. RECONCILIATION OF NET INCOME (EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2018 £	2017 £
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	478,960	(299,230)
Depreciation and amortisation charges	125,370	126,147
Dividends, interest and rents from investments	(47,362)	(40,253)
Loss / (profit) on disposal of fixed assets	-	(10,454)
Decrease in stock	1,121	5,806
(Increase) / Decrease in debtors	(662,014)	25,724
Increase in creditors	510,490	683,924
	<u>406,565</u>	<u>491,664</u>

18. ANALYSIS OF CASH AND CASH EQUIVALENTS

	As at 1 Jan 2018 £	Cash Flows £	As at 31 Dec 2018 £
Cash at bank and in hand	3,207,830	(563,404)	2,644,426
Short term deposits	1,800,000	950,000	2,750,000
Total	5,007,830	386,596	5,394,426

19. GRANTS TO INSTITUTIONS

	Total paid in 2018 £	Total paid to date £	Total committed project cost £
RESEARCH PROJECTS			
University of Dundee			
1. TGF β signalling in Recessive Dystrophic EB	24,044	190,284	190,284
2. Clinical fellow funding	111,627	313,708	350,922
3. EBS Genotyping	4,000	24,000	24,000
4. Delivery of Antisense Oligonucleotides to the Basal Layer	8,500	8,500	8,500
	148,171	536,492	573,706
University of Glasgow			
1. Mechanisms of TGF- β mediated tumour protecting in RDEB	-	-	78,613
Guy's and St Thomas' Hospital, London			
1. Validated clinical endpoints study re EB therapy evaluation	129,134	367,246	412,884
2. Phase 1 study of the lentiviral-mediated COL7A1, funded by Cure EB	4,415	499,320	499,320
3. Stem cell therapy trial to investigate treating debilitating itch	151,904	151,904	497,360
	285,453	1,018,470	1,409,564
Thomas Jefferson University, Philadelphia, USA			
2. Phase 2 clinical trial of Rigosertib for RDEB SCC	164,526	265,760	470,490
Birmingham Dental School & Hospital			
1. Characterisation of skin microbiome in EB patients	31,486	31,486	296,289
University of Cologne			
1. Exploring immunity in wound healing complications in RBEB	27,852	27,852	170,635

GRANTS TO INSTITUTIONS (CONTINUED)

	Total paid in 2018	Total paid to date	Total committed project cost
	£	£	£
Universitair Medisch Centrum Groningen			
1. Effectiveness of phyto-cannabinoid treatment of pain in EB	32,475	32,475	159,025
Instituto Dermopatico del'Immacolata			
1. Anti-fibrotic potential of histone deacetylase inhibitors for RDEB	2,014	2,014	70,963
King's College London			
1. Preclinical studies of lentiviral-mediated COL7A1 gene therapy	-	-	174,023
Other			
Increase in research provision	270,755	-	-
Grants written back at end of project	(4,628)	-	-
Total research grants	958,104	1,914,549	3,403,308
Research project expenditure by category:			
Pre-clinical development	436,292		1,035,440
Genetic investigation	4,000		24,000
Clinical investigation	169,120		717,673
Patient treatment study	348,692		1,626,195
	958,104		3,403,308
HEALTHCARE PROJECTS			
Total paid in 2018			
Total committed project cost			
£			
£			
Great Ormond Street Hospital for Sick Children			
Clinical nurse specialists in EB		34,109	34,758
Guys & St Thomas' Hospital London			
Adult EB support nurses		84,693	87,198
Clinical best practice guidelines on pregnancy and childbirth		31,000	31,000
Other			
Birmingham Children's Hospital		89,222	88,685
Clinical best practice guidelines on oral health		30,012	30,012
Hand therapy evaluation		69,785	69,785
Miscellaneous		6,400	48,025
Total Healthcare Team grants		345,220	389,462

20. RELATED PARTIES

DEBRA Trading Ltd

The principal activity of DEBRA Trading Ltd (company number: 02487114), a company incorporated in England and Wales, is the sale of promotional items on behalf of DEBRA. DEBRA has a beneficial interest in 100% of the company's issued share capital of £2.

The company's results for the period under review were as follows:

	2018	2017
	£	£
Turnover	152,733	46,020
Net profit gift aided to DEBRA	37,050	15,860
Net assets	2	2

During the year, the charity charged management charges totalling £11,476 including VAT (2017: £6,933) to its subsidiary, DEBRA Trading Limited.

REFERENCE AND ADMINISTRATIVE DETAILS

PATRONS AND AMBASSADORS

Royal Patron

HRH The Countess of Wessex

Life Patron

Philip Evans

President

Simon Weston

TRUSTEES

Chair: Jim Irvine (Interim from 25.4.19)
Michael Jaega (19.5.18 to 6.2.19)
Andrew Grist Vice Chair (from 19.5.18 to 1.3.19)
David Spence (until 19.5.18)
Vice Chair: Michael Jaega (until 19.5.18)
Treasurer: Joanne Merchant (Acting Treasurer from 25.4.19)
Jim Irvine (until 25.4.19)

Simone Bunting
Rebecca Cresswell
Simon Cuzner
James Hinchcliffe

Graham Marsden
Vivien Mundy
Timothy Powell
David Wilkinson

No trustee has any beneficial interest in the company. All trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

SENIOR MANAGEMENT TEAM

Chief Executive

Ben Merrett

Director of Fundraising & Communications

Hugh Thompson

Director of Research

Caroline Collins

Director of Human Resources

Louise Westphalen

Director of Healthcare, Membership & Community Support

Claire Mather

Director of Finance

Carol Harris

Director of Retail

Lesley Gorton (from 26 Feb 2018)

Company Secretary

Dawn Jarvis

ADDITIONAL DETAILS

Charity Commission Number

1084958

Auditors

BDO LLP, 2 City Place, Beehive Ring Road
Gatwick, West Sussex, RH6 0PA

OSCR Number

SC039654

Bankers

HSBC, High Street
Crowthorne, Berks, RG45 7AD

Company Number

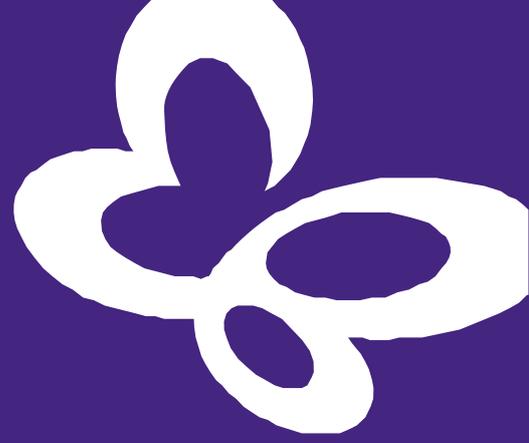
04118259

Solicitors

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

Registered office & principal address

DEBRA House, 13 Wellington Business Park
Dukes Ride, Crowthorne, Berks, RG45 6LS



DEBRA provides life
changing 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, together we will beat EB.

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



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

DEBRA House, 13 Wellington Business Park, Dukes Ride, Crowthorne, Berkshire, RG45 6LS

DEBRA | A charity registered in England and Wales (1084958) and Scotland (SC039654).
Company limited by guarantee registered in England (04118259). VAT Number 689 2482 79.