

# Trustees' Annual Report & Accounts 2016



I Fight EB,

with

# Our purpose

**We have a vision of a world where no one suffers from the painful genetic skin condition Epidermolysis Bullosa (EB).**

Until that day, we offer specialist care to those who need it.

We give support to people and families affected.

And we provide real hope for the future by funding pioneering research to one day find a cure.

It is this vision and purpose that drives our plans and our people.

# Our values

By working with, and for, DEBRA we aim to:

- make a positive difference for people with EB
- work together to attain our vision of curing EB and providing care
- strive for excellence in all our activities
- be passionate about all we do

A close-up photograph of a baby sitting on a brown carpet. The baby has visible scarring on their face, particularly around the eyes and nose. They are wearing a white long-sleeved shirt with teal accents and white leggings. A yellow and blue toy is visible in the background.

“DEBRA’s EB Community Support Manager has been my lifeline and was absolutely amazing when I moved into my new home; we wouldn’t have been able to cope without her and DEBRA.”

**Jenna, Mum to Freddie who is living with EB Simplex Dowling-Meara (EBS-DM)**

# 2016 Key Facts Summary

13 research projects were managed, leading to a better understanding of EB

1,850 patients accessed the EB healthcare service, which is part-funded by DEBRA

2,554 DEBRA members within the EB community of whom 234 attended the Annual Members' Day

464 mentions of DEBRA and EB in the media, reaching over 60 million people

4.7% increase in like-for-like sales in the DEBRA charity shops

15% growth to £2,343k in net income available for charitable activities

£4,377k total reserves of which £2,350k were restricted or designated for future expenditure



# DEBRA

## REFERENCE & ADMINISTRATIVE INFORMATION

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### Trustees

|                   |                                    |
|-------------------|------------------------------------|
| David Spence      | Chair                              |
| Michael Jaega     | Vice Chair                         |
| James Irvine      | Treasurer                          |
| Simone Bunting    |                                    |
| Simon Cuzner      |                                    |
| Rhian Edwards     | until 12 January 2017              |
| Jon Field         | until 14 April 2016                |
| Andrew Grist      | from 14 May 2016                   |
| James Hinchcliffe |                                    |
| Christo Kapourani | until 14 May 2016                  |
| Graham Marsden    |                                    |
| Joanne Merchant   |                                    |
| Scott O'Sullivan  | until 12 January 2017              |
| John Parker       | from 14 May 2016 until 22 Feb 2017 |
| Timothy Powell    |                                    |
| Amy Price         | until 14 May 2016                  |
| John Tough        | until 14 May 2016                  |
| David Wilkinson   | from 14 May 2016                   |

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.

Royal Patron  
Life Patron  
Retail Ambassador  
Social Media Ambassador

HRH The Countess of Wessex  
Philip Evans  
Scott O'Sullivan  
Rhian Edwards

### Senior Staff

|                   |  |
|-------------------|--|
| Ben Merrett       | Chief Executive<br>Acting Director of Fundraising & Communications<br>from 1 June 2016 |
| Caroline Collins  | Director of Research   |
| Carol Harris      | Director of Finance  |
| Claire Mather     | Director of Healthcare, Membership &<br>Community Support                              |
| Paul Guest        | Director of Retail from 22 February 2016   |
| Louise Westphalen | Director of HR   |
| Dawn Jarvis       | Company Secretary  |

Charity Commission Number

1084958

OSCR Number

SC039654

Company Number

4118259

Registered office &  
principal address

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

Auditors

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

Bankers

HSBC, High Street, Crowthorne,  
Berks, RG45 7AD

Solicitors

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

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# 1 Introduction from Chair and Chief Executive

The Trustees' and Strategic Reports provide a comprehensive review of DEBRA, our 2016 activities, and plans for future years. The Board of Trustees are very aware of the enormous efforts made by DEBRA's staff, volunteers, shoppers, and donors to generate income for continued research into cures for the terrible EB (Epidermolysis Bullosa) conditions, as well as to improve the quality of life for those affected by the disease and their families.

The EB community is at the core of DEBRA's charitable activities. Future plans include increased engagement initiatives that can help shape and focus care and support service developments, as well as improved membership benefits. Publications and the use of multimedia will be reviewed and developed to ease the sharing of information and increase engagement within the EB community. Further development of community support profiling anticipates a more proactive service. Key support is given through podiatry clinics, specialist EB nurses in the UK, occupational therapies, dietician services, and the development of clinical best practice guidelines.

The breadth of research remains important. Research projects include pre-clinical and laboratory work, early phase clinical studies in small numbers of patients, as well as symptom relief. A clearer focus on the EB Simplex condition is emerging with a commitment to on-going and future projects involving more of the community. Drug repurposing may be a viable option in some of the genetic 'mistakes' found in EB. In December 2016, the world's top experts in EB and wound healing in other disciplines joined together to review clinical data and identify priorities and opportunities in EB.

DEBRA has been working with St Thomas' Hospital and EB members to develop the exciting, new £2.1m Rare Disease Centre, planned to open in the latter part of 2017. The charity has contributed £250k<sup>1</sup> to this vital development, which will greatly improve the facilities where top-class EB specialist clinics are held.

During 2016, we made significant financial recovery from the disappointing income generation experienced in 2015. We have maintained our reserves at a prudent level given the risk associated with our large workforce and retail property leases. Having the appropriate level of reserves is important to DEBRA and needs to reflect our particular mix of operations.

**David Spence**  
**Chair of Trustees**

**Ben Merrett**  
**Chief Executive Officer**

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<sup>1</sup> Guys and St Thomas' Charity NHS Foundation Trust press release, <http://www.guysandstthomas.nhs.uk/news-and-events/2017-news/january/20170127-centre-transform-care-rare-diseases.aspx>

# 2 Trustees' Annual Report

## Overview of DEBRA

DEBRA is registered with the Charity Commission for England and Wales and the Office of the Scottish Charity Regulator (OSCR), the latter required due to DEBRA's Scottish activities, which continue to form an important part of DEBRA's national strategy.

DEBRA is the national charity (incorporated in the UK) supporting individuals and families affected by EB – a group of genetic skin conditions that cause the skin to blister and tear at the slightest touch. Blistering can also affect inner body linings, such as the mouth and throat. Tragically, certain types of EB can be fatal in infancy and others are severely life-limiting. It is estimated that there are at least 5,000<sup>2</sup> people living with EB in the UK, and 500,000 worldwide.

DEBRA provides an enhanced healthcare service, in partnership with the NHS, as well as a dedicated Community Support Team who offer help and advice directly to the EB Community. The charity also commissions world-leading research into the condition with the aim of finding effective treatments and, ultimately, a cure for EB.

DEBRA receives no direct government funding. While 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; indicators show these will stay in place for the foreseeable future.

## Aims and Objectives

DEBRA has a vision of a world where no one suffers from the painful genetic skin condition, EB. Until that day, the charity provides specialist care to those who need it, support to people and families affected, and real hope for the future by funding pioneering research to one day find a cure.

The charity's primary objectives are to:

- enhance the quality of life for people affected by EB
- provide continuing services and support to the EB community
- develop effective treatments by funding research into EB conditions
- promote best current practice in treatments for EB
- promote the well-being of people with EB and their families, and facilitate their full integration into society
- promote professional and public knowledge of EB
- encourage the development of global EB support groups and foster coordination

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<sup>2</sup> Data compiled by Director of Research, Caroline Collins, in the report "The Epidemiology of Epidermolysis Bullosa", specifically with reference to a study by Browne F, Heagerty AHM, and Martinez A "The epidemiology of epidermolysis bullosa in the UK: a 9-year study"; British Journal of Dermatology, 2011; 165 (suppl s1) 8-11

- raise sufficient funds to achieve these objectives

In fulfilling these objectives, DEBRA encourages contributions from the EB community to the charity and to the public.

## Structure, Governance, and Management

DEBRA (a Company Limited by Guarantee) is 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 Members elect the majority of eight of the trustees and the Nominations and Governance Committee is responsible for proposing a further seven with relevant skills to be appointed by the trustees themselves. At the Annual General Meeting in 2016, the Vice-Chair was re-appointed as recommended by the Nominations & Governance Committee and four candidates stood for election. Three trustees were elected while outgoing members (i.e. John Tough, Amy Price, Christo Kapourani, and Jon Field) were thanked for their valuable contribution as trustees. A casual vacancy for an appointed trustee had therefore become available, so DEBRA had 14 trustees on the board as at 31 December 2016.

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) members attend, and an evaluation of board and committee effectiveness is performed annually.

Committees support trustees in the following areas:

- Finance, Risk and Audit Committee – determines and advises the Trustee Board on matters relating to finance, risk and audit as the Trustee Board may remit to it, in particular the sound financial management of the Charity, its resources, and assets.
- Nominations and 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.
- Charitable Activities Committee – determines and advises the Trustee Board on matters relating to strategy in research, health and community support, and policy as the Trustee Board 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 and Communications Committee – oversees the fundraising activities of the SMT on matters relating to the growth of income generation and maximising opportunities within Marketing and PR. The Committee approves and recommends to the Board of Trustees the strategic direction of fundraising and the financial plan. It utilises specific knowledge of its members to challenge and support the Director of Fundraising and Communications and 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 Trustee Board on matters relating to international strategy in research, health and community support, and international policy as the Trustee Board may remit to it.

In addition, the international Medical and Scientific Advisory Panel makes recommendations for research projects.

**Table 1: Trustees' Membership and Attendance Records**

|                   |   | Trustee Board | Finance, Risk and Audit Committee | Nominations and Governance Committee | Charitable Activities Committee | Retail Committee | Fundraising and Communications Committee | DEBRA UK International Committee |
|-------------------|---|---------------|-----------------------------------|--------------------------------------|---------------------------------|------------------|--|----------------------------------|
| David Spence      | Chair                                   | 4 of 4        | 7 of 7                            | 4 of 4                               |                                 | 4 of 4           |  |                                  |
| Michael Jaega     | Vice Chair                              | 4 of 4        | 6 of 7                            | 4 of 4                               | 3 of 3                          |                  |  | 3 of 3                           |
| James Irvine      | Treasurer                               | 3 of 4        | 7 of 7                            |                                      |                                 | 3 of 4           |  |                                  |
| Simone Bunting    |   | 3 of 4        |                                   | 3 of 4                               |                                 | 2 of 3           | 1 of 2                                   |                                  |
| Simon Cuzner      |   | 3 of 4        |                                   |                                      |                                 | 3 of 4           |  |                                  |
| Rhian Edwards     | until 12 January 2017                   | 0 of 4        |                                   |                                      | 0 of 3                          |                  |  |                                  |
| Jon Field         | Resigned 14 April 2016                  | 0 of 1        |                                   |                                      |                                 |                  |  |                                  |
| Andrew Grist      | from 14 May 2016                        | 2 of 2        |                                   |                                      |                                 |                  |  | 0 of 1                           |
| James Hinchcliffe |   | 3 of 4        | 5 of 7                            |                                      |                                 |                  |  |                                  |
| Christo Kapourani | until 14 May 2016                       | 0 of 2        |                                   |                                      | 2 of 2                          |                  |  |                                  |
| Graham Marsden    |   | 4 of 4        |                                   | 4 of 4                               |                                 |                  |  | 3 of 3                           |
| Joanne Merchant   | from 14 May 2016                        | 3 of 4        | 6 of 7                            |                                      |                                 |                  |  | 0 of 1                           |
| Scott O'Sullivan  | until 12 January 2017                   | 1 of 4        |                                   | 0 of 1                               |                                 | 0 of 1           |  |                                  |
| John Parker       | from 14 May 2016 until 22 February 2017 | 1 of 2        | 0 of 4                            |                                      | 2 of 2                          |                  | 3 of 4                                   |                                  |
| Timothy Powell    |   | 3 of 4        |                                   |                                      |                                 |                  |  |                                  |
| Amy Price         | until 14 May 2016                       | 1 of 2        |                                   |                                      |                                 |                  |  | 0 of 1                           |
| John Tough        | until 14 May 2016                       | 2 of 2        |                                   |                                      |                                 | 2 of 2           |  |                                  |
| David Wilkinson   | from 14 May 2016                        | 2 of 2        |                                   |                                      |                                 |                  | 4 of 4                                   |                                  |

## 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. All people living with EB are encouraged to join DEBRA as a member. Both the charity and the specialist EB clinical teams encourage people living with EB to engage with DEBRA to further develop the services and support available. A number of satisfaction and service development surveys and group discussions have taken place during 2016, including discussions on the facilities required in the Rare Disease Centre at St Thomas' Hospital, as well as the location and facilities for a new DEBRA holiday home in the UK.

The DEBRA Charitable Activities Committee, led by a trustee living with EB, makes strategic and fundamental decisions on the charitable activities undertaken by DEBRA for the benefit of present and future people with any kind of EB.

## Employees

DEBRA recognises that organisations succeed by realising the potential of their people. The charity was proud to achieve the 'Investors in People' accreditation in April 2016, which acknowledges this responsibility, and more importantly, provides a framework for on-going improvement. Effective consultation and communication between senior management and their teams is key to determining the improvements that should be considered, and employees were invited to share their opinions in this respect via regular staff satisfaction surveys through the year.

Employees have always been encouraged to develop their skills by taking the training opportunities available to them. To make these more accessible and cost effective, DEBRA invested in online learning in 2016 to enable all employees and volunteers to access e-courses across a broad range of subjects from early 2017.

The year ended with a team day for the administrative and management employees, which provided an opportunity for staff to share the progress in their work with colleagues, as well as hear from an external speaker about the stages of developing drugs for rare conditions, such as EB. The event included an Awards Dinner to celebrate individual and team achievements.

## Remuneration Policy

DEBRA's Pay Policy states that it is the organisation's intention to pay employees a salary/rate of pay that is fair and 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. The policy is also to reward high performance, respect equality in the workplace, and recognise the charitable status of the organisation.

All aspects of pay, including rates of pay, levels of salaries, reviews, incentive schemes and termination payments are reviewed by the Quarterly Pay Review Committee, which reports to the Board of Trustees. The Chair, Vice Chair and Treasurer determine the remuneration of the CEO.

In 2016, the annual pay review did not result in a 'cost of living' pay increase being awarded.

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 £60,000 pa and above (in bands of £10,000)
- 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 dependants, 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.

## Volunteers

In addition to the 1,000+ valued volunteers who worked in DEBRA's shops during 2016, contributing 250,000 hours over the year (the equivalent of nearly 150 full-time members of staff), a significant number of volunteers also generously participated in Regional Fundraising events, helping to raise awareness of EB in the community and generate income.

Following the appointment of an additional team member in HR, the administration of volunteers transferred in 2016 from the Retail Administration function to HR. For the first time, a survey was carried out to better understand volunteers' experiences and identify how these could be improved. The results encouragingly suggested that over 90% of volunteers would specifically recommend DEBRA to a friend who wanted to volunteer at a charity. DEBRA will focus on improving and developing all aspects of volunteering in 2017.

## 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 two regional fundraising members of staff and 36 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Hamilton.

## DEBRA International

DEBRA is a founder member of DEBRA International, which currently has over 50 members in other countries.

DEBRA International ensures all EB research activity is coordinated worldwide. Other important initiatives include the development of global Clinical Best Practice guidelines and EB Without Borders (EBWB), the collaborative effort to assist EB sufferers in need around the world.

DEBRA makes a modest contribution to the running costs of DEBRA International; however, its volunteers also make a significant contribution. DEBRA's Vice-Chair, Mike Jaega, is currently President of DEBRA International and leading the development of its important activities. DEBRA ensures good value is received from DEBRA International's activities.



## DEBRA Staff

Employees at DEBRA actively volunteer time outside their standard working hours to attend EB community events and fundraising activities, recruit additional volunteers for the cause, as well as participate in awareness campaigns.

# 3 Strategic Report

## 3.1 Achievements and Performance

### Research

#### 2016 Summary

Over the last 10 years DEBRA has invested £10m on research and 13 on-going or new research projects were supported throughout 2016. The breadth of this research remains important. Research projects include pre-clinical and laboratory work, early phase clinical studies in small numbers of patients, as well as symptom relief. DEBRA continues the investigation into meaningful endpoints for research that will smooth the regulatory path.

A clearer focus on EB Simplex is emerging with a commitment to on-going and future projects that will involve more of the EB community. 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. This study also supports the strategy for involving newer members of the EB research community and industry.

On-going results from Philadelphia suggest that drug repurposing may be a viable option for correcting some of the genetic 'mistakes' found in EB.

Traditionally, few research projects have been applied for in wound care. However, in London in December 2016, a summit of the world's top experts in EB, along with recognised experts from wound healing in other disciplines, came together to review clinical data and identify priorities and opportunities in EB. The proceedings will be published and applications taken in 2017 for a specific grant round.

DEBRA continues to administer projects for the Sohana Research Fund and this critical communication, coordination, and collaboration is important between all organisations funding EB research – both charitable and commercial.

#### 2016 In Numbers

- £1,008k cash outlay on research grants, £774k of which was committed in prior years
- £234k committed to new research projects
- £275k on additional research expenditure

## Aims for 2017

- Funding up to a total of £460k into a specific cancer trial to start in 2017
- Focus on the translation of pre-clinical research into:
  - patient studies identifying suitable treatments for cure and control of EB
  - symptom relief and clinical care programmes that will impact positively on quality of life
- Champion communication, coordination, and collaboration to ensure a coherent and coordinated approach to EB research, within the UK and worldwide

## Plans for Future Periods

Strategy for future periods will include coordination of research with other DEBRAs and EB organisations globally to focus both direction and funding. Further advisory boards (along the lines of the 2016 wound healing meeting) will be used to identify research opportunities and draw in relevant expertise outside the field of EB. Projects will continue to be funded that add to knowledge on the natural history or treatment of EB.



“We have been working on synthetic molecules that switch off an abnormal gene in EB Simplex, an approach which may allow the good copy of the gene to work normally and to stop the skin from blistering. We have also developed a genetic test that can be used to assess which patients may be suitable.”

**Dr Peter van den Akker**  
**Dundee Clinical Fellow, 2015 - 2017**

Work is now continuing to understand how to get these molecules into the skin to allow them to be used as potential treatments. This DEBRA-funded research will have implications for other types of EB, if successful.

# Healthcare

## 2016 Summary

DEBRA continued to assist with the funding of a UK-wide specialist healthcare service for people living with any type of EB. This service is provided in partnership with the NHS England's Specialised Services Commissioning team and NHS Scotland who fund the core (NHS duty of care) clinical service. DEBRA enhances the core service through funding increased hours for specialist nurses, dieticians, a podiatrist, as well as supporting initiatives such as the multi-disciplinary outreach clinics. DEBRA, EB nurses and other specialist healthcare professionals work together as multi-disciplinary teams within the UK's four designated EB Centres of Excellence. These teams provide the high levels of expertise required to care for people living with EB.

DEBRA had been funding a clinical fellow and additional nursing hours and was successful in helping demonstrate the benefit of these initiatives to the NHS. These are now funded by the NHS long-term.

The development of a Rare Disease Centre at St Thomas' Hospital, which will greatly enhance the clinical facilities available to the EB community and enable further development of multidisciplinary working, remained in the planning phase for longer than anticipated. DEBRA's charitable donation of £250k, which was expected to be made in 2016, was not required until 2017. The new facility is planned to be opened in the latter part of 2017.

The NHS and DEBRA partnership had a direct impact on increased quality of life through greater access to specialist care such as home visits, outreach clinics, and bereavement support. In addition, DEBRA funded small pieces of equipment, in-patient grants, in-patient TV viewing, and some travel and accommodation to enable individuals and carers to attend appointments and hospital stays.

In total, DEBRA funded £267k healthcare activities in 2016.

## 2016 In Numbers

- 1,850 patients were provided with support
- 25% of specialist EB nurses costs covered by DEBRA - enabling the core NHS service to be enhanced with activities (e.g. additional bereavement visits, product evaluation, assistance with research projects, education days, and nursing care for patient weekends away)
- 100 days per annum of specialist dietician services
- 24 specialist EB podiatry clinics
- 18 clinical supervision workshops
- 11 specialist EB training grants
- 2 contributions to regional multi-disciplinary clinics, affiliated to Great Ormond Street and St Thomas' Hospitals, giving patients the opportunity to receive care closer to their home

## Aims for 2017

- Fund 24 podiatry clinics and the development of the podiatry clinical best practice guideline
- Fund up to 25% of all specialist EB nurses in the UK
- Fund enhanced occupational therapy, dietician services, and the development of clinical best practice guidelines
- Support 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 someone 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
- Contribute £250k and work with St Thomas' Hospital team and EB members to develop the new £2.1m Rare Disease Centre

## Plans for Future Periods

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

On-going partnership work with the designated EB Centres of Excellence and specialist clinical teams and commissioners will continue to be developed to ensure the provision of care required is met. In addition, an increase in the development of international clinical best practice guideline work is planned.

# Real Life Story

Imagine your family's medical appointments regularly taking up two whole days of your time.



**Nathan (first on the left) and Adam (second from the right) both have EB.**

Natalie and two of her four children, Nathan (15) and Adam (1), have Epidermolysis Bullosa Simplex.

“How do you explain to your employer that you need to take two days off work for a medical appointment and tell the children's schools that you need to take them out for two days?” said Natalie.

“I suffered particularly badly as a teenager with the blisters which form every day on my hands, feet and in my mouth, making every aspect of life difficult. They can be

caused by the most basic everyday activities, like walking or even writing. I've found shoes have always given me the worst problem but recent developments in dressings and specialist socks, which DEBRA provide me with, have made a big difference to my quality of life. But even so, navigating around London with two children with fragile skin and overnight bags is extremely wearing and painful.”

These two-day trips to the specialist EB clinics at two separate London hospitals all changed when funding from DEBRA made specialist multi-disciplinary clinics for people living with EB possible. “The DEBRA-funded multi-disciplinary clinic has had a huge impact on our lives. We've been to about three now in Exeter which is a lot more local for us. A massive advantage is that we can see the full specialist EB team in one place. After a couple of hours seeing the various specialists we have a break. DEBRA provides refreshments and a separate room to relax in, which makes the whole process less stressful. While I'm there I'm also able to meet with my DEBRA EB Community Support Manager to talk about any issues we have or support we need.

“The multi-disciplinary clinics are also an opportunity to chat to other parents of children with EB, which is as important to me as the clinical care. I can talk to local families about things that are worrying me. It can be very isolating living with a rare condition like EB, so having the chance to share experiences is a real blessing. It would be terrible if DEBRA isn't able to fund future multi-disciplinary clinics.”

# Community Support and Membership

## 2016 Summary

DEBRA spent £691k providing membership and specialist community support services to people living with EB across the UK. There continued to be an increase in demand for services, particularly following on-going welfare reforms.

Funds from the Health and Community Support Designated Fund continued to support growth within the team and support services available.

Access to the support grant budget was less than anticipated, predominantly due to the Community Support Team successfully aiding the EB community in accessing financial support from other sources.

The quality of life for members of the EB community was enhanced by the support provided by DEBRA through helping individuals and families with particular issues - e.g. welfare rights, education, housing, employment, and independent living; contacting people with EB who are not currently using the DEBRA services; identifying and improving (in partnership with the EB community) service developments; and providing accommodation for respite breaks.

DEBRA owns four holiday homes, which were booked to full capacity over the peak season. Additionally, the Annual DEBRA Members' Day was, for the second time due to previous success and requests of members, held over two days. This event provided an excellent opportunity for the EB community to meet other members and professionals, as well as learn more about research and living with EB. To enhance membership engagement, two additional regional members' events were held in York and Birmingham.

A number of surveys and meetings were conducted throughout the year to ascertain members' views on issues such as facilities and accommodation at members' events and location of an additional holiday home. Some literature and web information was reviewed and updated, but further development is required in this area.

DEBRA became a member of Disability Rights UK at the end of 2016.

## 2016 In Numbers

- 452 individuals accessed the DEBRA community support service, an 18% increase over 2015
- 188 support grants were awarded
- 2,554 individuals in the DEBRA membership scheme of whom 234 attended the annual Members' Day event
- 98 EB hospital clinics were attended by a member of the Community Support Team, offering support
- 82 weeks of holidays were taken in a DEBRA holiday home by families living with EB, providing them with much needed respite

- 341 Community Support home visits were carried out
- Specific publications and communications were sent regularly to all members, healthcare teams, and healthcare companies providing information on DEBRA services, EB research, and events

## Aims for 2017

- Provide a professional community support and membership service to EB families across the UK
- Expand and develop the team 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
- 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 Genetic Alliance and Disability Rights UK, facilitating DEBRA's ability to campaign for the EB community

## Plans for Future Periods

The EB community is at the core of DEBRA's charitable activities. Future plans include increased engagement initiatives that can help shape and focus care and support service developments and improved membership benefits (including more regional events).

Publications and the use of multimedia will be reviewed and developed to ease the sharing of information and increase engagement; the development of community support profiling to achieve a more proactive service is anticipated.



**Tia with her mum,  
Anne Marie.**

## Real Life Story

**Tia is three years old and has Junctional EB generalised intermediate.**

Anne Marie, Tia's Mum, said: "DEBRA's EB Community Support Manager has been my rock at difficult times. She is like a best friend to me with a wealth of knowledge on EB. She is always on the end of the phone if I need some advice or just a chat with someone who understands what I'm going through. She has also assisted us in accessing alternative sources of funding for essential household goods which make our daily life with Tia easier."

# Public Education

## 2016 Summary

EB is relatively unknown, so raising awareness of the condition is vital in order to attract more support and funding for the services DEBRA provides.

Reaching over approximately 60 million people DEBRA and EB were referenced 464 times in the press excluding advertisements (national, regional, consumer and online).. Unlike in the previous two years, DEBRA was unable to benefit from media appeals, which meant significantly less national and regional coverage. The BBC Lifeline appeal allows applications every three years, which means DEBRA can re-apply in 2017 to become a beneficiary of the initiative in 2018.

In 2016, DEBRA continued benefitting from The Times' pro-bono advertisement placements. As these adverts are used as 'filler ads', records are not kept about how many times and in which issues the DEBRA ads appeared. These free adverts raised over £8,500 in 2016 for DEBRA.

The #ShowYourSeams campaign was repeated during EB Awareness Week in October with celebrities Kelvin Fletcher, Adam Fielding, and Brian McFadden taking part, as well as DEBRA groups internationally. This campaign resulted in increased social media interaction reaching 20,000 people on Facebook and achieving over 100,000 impressions on Twitter. The campaign contributed to a successful year on social media. The DEBRA Facebook page has over 7,000 likes (2015: 6,200) and the DEBRA Twitter feed has nearly 3,500 followers (2015: 2,700). More importantly, the average post on Facebook reached over 3,800 people (2015: 2,323) helping to increase awareness of DEBRA and EB across the social media site.

The DEBRA website (debra.org.uk) had 199,387 visitors (2015: 166,414). The website has seen further improvements with the integration of the Recrutive software that streamlines and automates the online recruitment process; a system to enable furniture collection bookings online was also introduced.

A total of 768 donations were made via the website during 2016 (2015: 500) amounting to nearly £36,000 (2015: £27,500). The average time spent on the website remains high at just under two minutes.

DEBRA's profile was also raised by Nadia Sawalha who appeared on *'Tipping Point: Lucky Stars Series 3'* and won £2,300 for DEBRA, as well as by James Dunn's appearance in the BBC programme *The Big Life Fix*; over 1,000 people visited the DEBRA website during or straight after the programme.

## 2016 In Numbers

- £36k generated through 768 donations on the DEBRA website
- 10,500 people engaged on DEBRA social media pages
- 464 mentions of DEBRA and EB in the media

## Aims for 2017

- Review the DEBRA brand by improving the strapline and how DEBRA represents itself to the general public - visually and through the tone of voice
- Further develop the charity's 'brand guidelines' document outlining how each marketing material (leaflets, posters, shop signs, etc.) and publications should look and read, including consistency in the style of font, headings, photographs, illustrations, icons, and the tone of voice used
- Achieve consistency in DEBRA's communication to help people easily recognise the charity, which is crucial to help DEBRA stand out in the crowded charity market
- Raise much needed awareness of DEBRA and EB through the creation of communications strategies for each area of the charity
- Improve the process of reaching journalists
- Further develop DEBRA's digital spaces (website, social media and digital marketing) to reach new audiences and evaluate how DEBRA can enhance those spaces through digital marketing techniques
- Collaborate with other teams to ensure communication is smooth and to develop reciprocal relationships that benefit all parties
- Develop the newly created Social Media Ambassador roles initially taken up by ex-trustee Rhian Edwards

## Plans for Future Periods

Digital will continue to play a major role in raising awareness of DEBRA and EB as more people embrace digital platforms. In addition to maximising the reach of the digital assets that are available to DEBRA free of charge, such as the website and the network of followers on social media platforms, testing of paid-for initiatives is also essential to improve the charity's online presence. Additionally, a comprehensive review of the DEBRA website will be performed.

Lack of awareness of DEBRA and EB remains a challenge, particularly for the fundraising team. Therefore, refreshing the brand, to explain the impact of DEBRA's work, is paramount. DEBRA will invest in working with a professional branding agency to create an engaging and appealing brand for the charity. To ensure that the charity will reach more people with its refreshed brand, DEBRA will also work with a national PR agency in 2017.

## Royal Patronage

DEBRA's Royal Patron, The Countess of Wessex, GCVO, has continued to show a keen interest in the charity's work. She provides considerable support to the charity, through attending events, which make a significant contribution to their success and DEBRA's public profile. She has committed to involvement with two fundraising events in 2017 as well as to creating a one- minute promotional video for the charity.

## Fundraising

### 2016 Summary

When compared with 2015, 2016 was a much improved year for income generation. Core fundraising events (e.g. golf days and clay pigeon shoots) performed well, and the annual Fight Night exceeded budget. Challenge and sporting events continued to make major contributions having exceeded targets in 2016, as did regional support from corporate and community activities throughout the UK.

It was the addition of some new and re-introduced events that made the main difference. Following the previous support of the Roux family with successful Great Chefs Dinners at The Waterside Inn, a Great Chefs Dinner was held at the Landau at the Langham London, this time hosted by Michel Roux Jr, which alone resulted in £52k net income raised. This format will be repeated annually. A fundraising lunch for major donors and long term supporters with DEBRA's Royal Patron, HRH Countess of Wessex at Mosimann's Restaurant raised £65k, and a Wine Challenge hosted by Norton Rose was also very successful. The introduction of Sporting Lunches with celebrity sports personalities has proved popular with supporters.

DEBRA's contribution towards the new Rare Disease Centre at St Thomas' Hospital has provided a valuable fundraising target and £170k had already been raised or pledged in 2016 through trust applications and appeals at events specifically for this purpose. The balance required for the project was raised during January and February 2017.

The services of an external fundraising consultant were engaged during the year which helped DEBRA re-assess its strategy.

### 2016 In Numbers

- £198k net income raised from shooting and other major events
- £192k net income raised from individual donors
- £163k net income raised from legacy and trust donations
- £128k net income raised from regional fundraising
- £93k net income raised from DEBRA Golf Society
- £84k net income raised from the 12th DEBRA Fight Night event
- £78k net income raised from major challenge events

## Aims for 2017

- Grow 'major giving' via on-going relations with key supporters
- Build on success of fundraising events – improve supporter experience by revisiting formats and auction lots, as well as introducing new venues
- Re-introduce an annual national gala event with a view to engaging new supporters
- Grow regional corporate partnerships throughout the UK
- Grow trust donations by making applications that better match DEBRA's charitable activities to the charitable interests of individual trusts
- Target new celebrity supporters, build on existing relationships and expand celebrity focused resources (e.g. video messages)
- Appoint a new director of Fundraising and Communications (completed in March 2017)

## Plans for Future Periods

Whilst maintaining the target of increased major gifts, the Fundraising and Communications Team will continue to build on the successful formula of events and challenge and sporting activities. The Regional Fundraising Team, covering England and Wales, has undergone a consolidation and will have a primary focus on corporate partnerships and the education sector whilst also growing relationships with the EB community. In Scotland, the main objectives will be to grow existing charity partnerships and to seek new corporate relationships.

## Fundraising Standards

Section 162a of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. Although DEBRA does not undertake widespread fundraising from the general public, the legislation defines fund raising 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 fund-raisers. 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 high fundraising standards are met
- Where volunteers assist in DEBRA's fundraising activities, they are briefed verbally and/or in writing on the process and best practices, as appropriate
- The charity is not bound by any regulatory scheme; however, DEBRA is a member of the Fundraising Regulator and complies with the relevant codes of practice
- DEBRA received five fundraising complaints in 2016, all of which were registered, satisfactorily resolved and recorded

# Retail

## 2016 Summary

Overall, DEBRA retail made a good recovery in 2016 when compared with 2015 results.

The charity embarked on a new retail strategy in 2016, focussing on opening new 'community' stores, which are local stores that benefit both the local community and the charity. In addition, poor performing stores were transformed into discount stores and trading hours have also been extended. Improved management information required to drive the business forward is progressing well and puts DEBRA in a very good position for the future.

Furniture and Electrical (F&E) shops saw a rapid expansion in 2016, doubling the existing portfolio with the doors opening at six new locations. The most recent and largest store at Ashford continued the trend of grand openings in F&E, setting a record of £9,149 sales of donated goods in a single day. Setting up so many shops is not without cost, and it is with this in mind that there will be a year of consolidation for F&E in 2017.

The 2015 aim of expanding the traditional charity shop retail chain by acquiring 10 additional shops was achieved, and DEBRA's first two donation centres have opened in Scotland, providing unique drop off points for donations.

Retail Gift Aid was buoyant in the year, which, together with retail donations, represented a significant proportion of total net income at £1,187k (2015: £1,001k).

There were 130 shops at year end, 118 traditional and 12 F&E. During the year, 13 traditional shops were opened, two of which were relocations and six F&E shops were opened. The current portfolio is made up of four Freeholds, 107 leaseholds and 19 temporary shops.

The success of the on-going volunteer recruitment drive is measured quarterly through growth in volunteer hours and sales at store level. This initiative will be built on to maintain high levels of volunteer support; DEBRA shops offer volunteers a rewarding experience that boosts confidence in the workplace and helps to develop new skills whilst providing demonstrable experience and references if needed.

The 'Meeting the Challenge' DEBRA Conference took place in March and included breakout sessions to share best practice, remind staff of DEBRA's purpose, relay key messages, and celebrate achievements.

## 2016 In Numbers

- 4.7% growth in like-for-like sales
- 135,000 Gift Aid donors were registered at the end of 2016 and the proportion of sales that were gift aided was 46%
- 130 shops at year end – 118 traditional and 12 F&E
- 19 shops opened including two relocations – 13 traditional and 6 F&E
- 1,000+ shop volunteers actively supported DEBRA

## Aims for 2017

- Grow net income by acquiring up to 20 additional traditional charity shops
- Open another donation centre to maximise stock and introduce extra deliveries to drive sales
- Pause the expansion of F&E to cover the investment made and re-direct funds back into charitable activities
- Grow like-for-like sales income by 2.5% – improved data analysis will help drive this
- Focus on finding community stores that are convenient for both customers and donors
- Introduce seven-day trading throughout the chain
- Develop the newly created Retail Ambassador role, taken on by ex-trustee Scott O'Sullivan

## Plans for Future Periods

DEBRA's key aim for Retail is to improve on current margins, with a goal of 20%. The three year plan objective targets the margin growing to 18% by 2019, a vast improvement on the 11% achieved in 2016. To create additional income, the retail chain will be expanded by acquiring up to 20 new traditional shops per annum, including four further donation centres in 2018, plus four or five new F&E shops in each of 2018 and 2019. Underperforming shops will be trialled as a discount store before any consideration of closure. Provision has been made in the plan for temporary shops that are forced to close at short notice. Where viable, attempts will be made to secure a lease to maintain tenancy in temporary shops threatened with closure.

Engagement and efficiency of existing staff and volunteers will continue to play an important role in 2017:

- Structured training and induction programmes will be delivered, and communication to all staff and volunteers will be improved by having annual appraisals, six managers' meetings, and regular one-to-one meetings
- The success of the volunteer recruitment drive will be built on to maintain high levels of volunteer support

- An annual conference to motivate staff, share best practice, and deliver key messages will be held; reward, recognition, and achievements will be an integral part of the annual conference dinner

In addition, it should not be forgotten that continued growth in this area brings greater recognition of DEBRA's work and provides opportunities for friends of DEBRA to help in a practical way by donating goods, working at one of the shops, or volunteering time.

## DEBRA Shop Volunteer

**Volunteering boosts your confidence according to one DEBRA shop volunteer.**



What originally began as an opportunity to boost his CV, Brian Stalley has now been a loyal DEBRA volunteer for nearly two decades.

Brian has a visual impairment and volunteers at one of the DEBRA shops together with his faithful pooch, his guidedog, Justin. Brian and Justin work side-by-side 3 days a week at their local DEBRA shop.

Brian credits working in a DEBRA shop to helping gain confidence in social situations – through interacting with both the staff and customers. He has also learned to adapt to his surroundings and overcome any challenges that come his way.

For anyone considering a volunteer position with DEBRA, Brian recommends to: “Give it a go, as you don’t have anything to lose. If anything, you have lots to gain. Volunteering boosts your confidence.

If I can volunteer with my visual impairment, then anyone can do it!”

## 3.2 Financial Review

### Overview

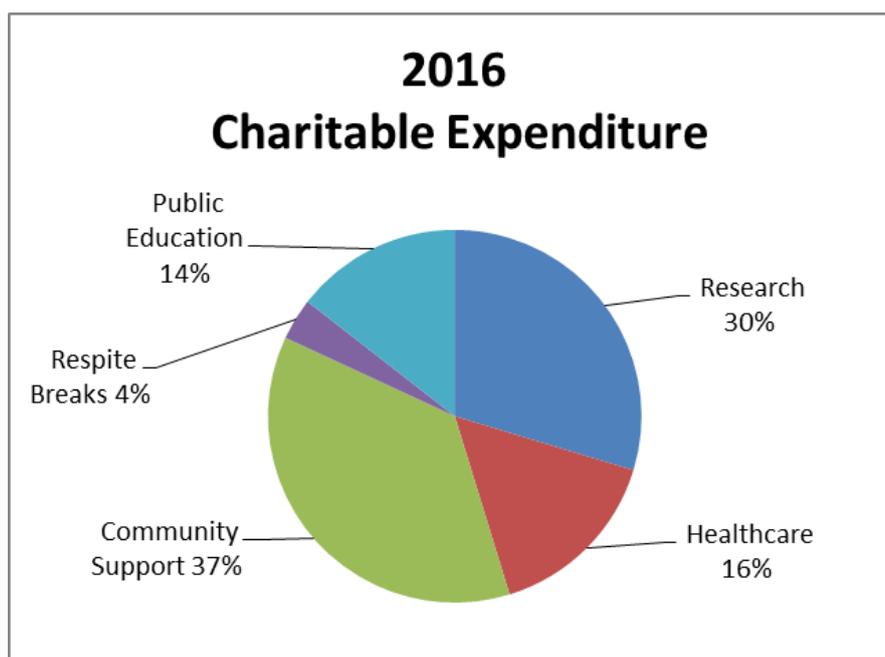
The accounts show the financial affairs of the charity for the year ended 31 December 2016. The charity's net income after accounting for the costs of raising funds (principally, charity shop trading costs) was £2,343k. Expenditure on charitable activities was £1,715k, leaving a surplus of £628k for the year.

Gross income during the year was £14,136k, a growth of 13.1% compared with 2015, resulting primarily from the increase in the number of charity shops from 122 to 130. There was a significant improvement in fundraising performance, aided by the specific capital fundraising project for the Rare Disease Centre at St Thomas' Hospital. Net income available for charitable spend grew by 15% from £2,038k in 2015 to £2,343k in 2016.

### Charitable Spend

Charitable spend in 2016 was significantly below 2015 and what had been planned because commitment to two large projects slipped into 2017. A contribution of £250k to the St Thomas' Hospital Rare Disease Centre was made in February 2017, as well as commitment of £330k out of a total of £460k to a pioneering cancer trial. The charity continued to invest in the Community Support Team during 2016, costing £691k (2015: £706k), whereas £509k (2015: £1,150k) was spent on research, £267k (2015: £375k) was spent on healthcare, and £248k (2015: £293k) on public education.

**Chart 1: Charitable Expenditure in 2016**



This pie chart shows the split between the major categories of charitable expenditure.

There are plans to grow charitable spend in future periods, not only from the two large projects described, but also demonstrated by the trustees' decision to designate funds for specific charitable projects.

The trustees have designated £1,032k for future research projects, as significant sums will be needed in the near future to continue funding expensive clinical and other trials.

There is £491k designated for new health and community support projects. The increased funding secured in 2011 from the NHS for EB nurses has led to savings of £334k each year, and the trustees are committed to ploughing these savings back into new health and community support initiatives, including a contingency of £150k in the event of future withdrawal of funding. A designated fund has been set up for this purpose.

The trustees established a new designated fund for special charitable projects during 2016 as a result of increased funds made available following the disposal of two freehold shops. There was a balance of £230k in this fund at the end of 2016.

Funds raised at a fundraising event attended by the Countess of Wessex have been specifically designated for the GSTT project, totalling £65k.

The surplus in the year led to an increase in net assets from £3,749k to £4,377k. There was £2,026k in the general fund, £2,275k in designated funds, and £76k in restricted funds.

## Summary

Table 2 summarises the highlights of DEBRA's financial performance over the last five years. Net trading income achieved through the shops and fundraising events increased significantly from £34k to £330k between 2015 and 2016. These figures exclude retail gift aid and donations received in the shops, which totalled £1,187k in 2016. A prudent accounting policy is followed, whereby the majority of set-up costs incurred for the new shop openings are expensed in the period they are incurred, with only true tangible assets capitalised.

There was no benefit to net trading income from negative goodwill amortisation in 2015, which averaged (£236k) in the other four years.

**Table 2: Financial Summary****£'000**

|   | <b>2016</b> | <b>2015</b> | <b>2014</b> | <b>2013</b> | <b>2012</b> |
|---|-------------|-------------|-------------|-------------|-------------|
| Total income  | 14,136      | 12,501      | 11,881      | 11,360      | 11,044      |
| Non trading income  | 2,832       | 2,768       | 2,938       | 2,968       | 2,845       |
| Net trading income  | 330         | 34          | 639         | 504         | 390         |
| Net trading income including retail gift aid and donations in shops | 1,517       | 1,035       | 1,541       | 1,325       | 1,128       |
| Non trading fundraising costs                                       | 819         | 763         | 736         | 564         | 576         |
| Charitable expenditure  | 1,715       | 2,524       | 3,266       | 2,187       | 1,960       |
| Retained surplus/(deficit)  | 628         | (486)       | (425)       | 720         | 699         |
| Retained surplus/(deficit) as a % of income                         | 4.4%        | (3.9%)      | (3.6%)      | 6.3%        | 6.3%        |
| Net current assets  | 3,340       | 2,905       | 4,034       | 3,991       | 3,167       |
| Unrestricted reserves   | 4,301       | 3,732       | 3,650       | 3,253       | 3,132       |
| Grants payable within 1 year  | 1,519       | 1,694       | 1,490       | 1,202       | 1,302       |

In 2016 for every £ raised 74p (2015: 73p) was either spent on or allocated to 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.

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 four 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

The trustees' reserves policy in 2016 was to maintain minimum cash-backed free reserves at £1,300k, to which the charity adhered. DEBRA has a high proportion of retail income, which incurs a high cost base and has continued to increase with the growth in shops. The minimum reserves figure is calculated as one month's costs (excluding rent) plus six months' rent. Reserves are held as a buffer for short-term cash flow needs because the charity's income is to some extent dependent on a few large fundraising events at specific times in the financial year. Also, there are seasonal variations in the trading performance of the shops. Total reserves at the end of 2016 were £4,377k, including £76k in restricted funds. Cash-backed free reserves before designations were £3,575k, of which £2,275k was designated for specific purposes. 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 which can be accessed immediately.

There was £1,032k 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.

There was £491k in the designated fund for new health and community support projects. The NHS increased funding for EB nurses in 2011, which made it possible for all savings from these arrangements to be re-invested into new projects for the benefit of the EB community. It is anticipated this fund will be spent in the next 1-2 years.

There was £456k in the designated fund for F&E shops. The trustees designated £700k in 2011 to fund the setup of a number of large F&E shops. It is expected that this fund will be spent or undesignated in the next 1-2 years.

There was £230k in the designated fund for special projects, set up by the trustees following the sale of two freehold properties, and it is anticipated this fund will be spent in the next 1-5 years.

There was £65k in the designated fund for the GSTT project, the contract for which was signed in February 2017.

There was £1,249k in the general fund that 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 while minimising risk. During 2016, 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 and a deposit account with NatWest.

## Expenses Policy

DEBRA has expenses policies for both employees 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 fund and five 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. For information, the company's results are shown separately in Note 21 of the financial statements.

A donation of £10k was received from Powell Gilbert LLP, of which trustee Timothy Powell is a partner.

## Internal Financial Controls

The trustees have conducted a review of the effectiveness of the charity's internal financial controls. This review concludes that the controls are relevant, appropriate to DEBRA and are not too onerous or disproportionate.

### 3.3 Principal Risks and Uncertainties

The trustees have established a register for all 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 and annually by the Trustee Board, 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 the table below, including the countermeasures (actions in place to reduce likelihood of the risk) and assurances (how the effectiveness of the countermeasures is determined).

**Table 3: Summary Extract from DEBRA’s Risk Register**

| <b>Identified Risk Factor</b>   | <b>Countermeasure</b>  | <b>Assurance</b>  |
|---|--|---|
| Charity image damaged   | Marketing and PR strategy<br>Disciplinary policy<br>Crisis communication plan<br>Review of any complaints received                                     | Media monitoring<br>Annual staff appraisals<br>Register of crises<br>Investigation of occurrences               |
| Insufficiently robust cyber security                                  | Anti-virus software<br>Encryption of hard drives<br>Secured wifi connection<br>Offsite backup three times weekly<br>Use of firewalls<br>PCI compliance | Anti-virus tool displays<br>Monthly reports<br>Firewall logs checked regularly<br>Daily logs of server activity |
| Misuse of data and failure to comply with Data Protection legislation | In-house Data Protection Officer<br>Data protection policy<br>Regular data protection training   | Data protection working party<br>Regular reporting  |
| Loss of key staff and knowledge                                       | Job and knowledge sharing<br>Procedure documentation<br>Succession planning<br>Attractive terms of employment  | Annual appraisals<br>Exit interviews  |
| Incompetent senior managers   | Robust recruitment procedure<br>Pre-employment references<br>Induction and training  | Performance against budget<br>Annual appraisal and regular reviews<br>Staff satisfaction survey                 |
| Loss of major source of fundraising income                            | Diversity of fundraising activities<br>Regular contact with supporters   | Quarterly fundraising and communications meetings with trustees<br>Performance against budget                   |
| Decline in retail contribution  | Monthly detailed shops reporting<br>Separate retail risk register<br>Continuous drive to grow contribution   | Quarterly Retail Committee meetings with trustees<br>Performance against budget                                 |
| Failure to ensure safeguarding of vulnerable adults and children      | In-house Safeguarding Officer<br>Staff training  | Activity reports<br>Register of complaints and incidents  |

## Auditors

The trustees on the Finance, Risk and Audit Committee, on behalf of all trustees, have taken all reasonable steps that they ought to have taken 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.

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:

**David Spence**  
**Chair of Trustees**  
**27 April 2017**

## 4 Statement of Trustees' 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 on-going integrity of the financial statements contained therein.

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

We have audited the financial statements of DEBRA for the year ended 31 December 2016 which comprise the statement of financial activities, the balance sheet, the cash flow statement and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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

## Respective Responsibilities of Trustees and Auditors

As explained more fully in the statement of trustees' 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. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Financial Reporting Council's (FRC's) Ethical Standards for Auditors.

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

## Scope of the Audit of the Financial Statements

A description of the scope of an audit of financial statements is provided on the FRC's website at [www.frc.org.uk/auditscopeukprivate](http://www.frc.org.uk/auditscopeukprivate).

## Opinion on Financial Statements

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2016 and of the charity's incoming resources and application of resources, including the income and expenditure, 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).

## Opinion on Other Matters Prescribed by the Companies Act 2006

In our opinion the information given in the trustees' annual report, which includes the strategic report for the financial year for which the financial statements are prepared, is consistent with the financial statements and the strategic report and the trustees' annual report have been prepared in accordance with applicable legal requirements.

Based on our knowledge and understanding of the charity and its environment obtained during the course of the audit, we have identified no material misstatements in the strategic report and trustees' annual report.

## Matters on which we are required to Report by Exception

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

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

**Don Bawtree (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).

# 6 Statement of Financial Activities

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2016

|                                    | 2016         | 2016              | 2016             | 2016           | 2015              | 2015              | 2015             | 2015             |                   |
|------------------------------------|--------------|-------------------|------------------|----------------|-------------------|-------------------|------------------|------------------|-------------------|
|                                    | Unrestricted | Designated        | Restricted       | Total          | Unrestricted      | Designated        | Restricted       | Total            |                   |
|                                    | funds        | funds             | funds            |                | funds             | funds             | funds            |                  |                   |
| Notes                              | £            | £                 | £                | £              | £                 | £                 | £                | £                |                   |
| <b>INCOME AND ENDOWMENTS FROM:</b> |              |                   |                  |                |                   |                   |                  |                  |                   |
| Donations and legacies             | 2            | 2,181,611         | 65,125           | 333,360        | 2,580,096         | 2,368,019         | -                | 242,834          | 2,610,853         |
| Charitable activities              |              | 14,483            | -                | -              | 14,483            | 14,304            | -                | -                | 14,304            |
| Other trading activities           | 3            | 8,833,920         | 2,374,029        | 96,231         | 11,304,180        | 8,673,146         | 1,023,772        | 36,439           | 9,733,357         |
| Investments                        | 4            | 39,587            | -                | -              | 39,587            | 67,785            | -                | -                | 67,785            |
| Other                              |              | 197,997           | -                | -              | 197,997           | 75,186            | -                | -                | 75,186            |
| <b>Total</b>                       |              | <b>11,267,598</b> | <b>2,439,154</b> | <b>429,591</b> | <b>14,136,343</b> | <b>11,198,440</b> | <b>1,023,772</b> | <b>279,273</b>   | <b>12,501,485</b> |
| <b>EXPENDITURE ON:</b>             |              |                   |                  |                |                   |                   |                  |                  |                   |
| Raising funds                      | 6            | 9,614,405         | 2,179,261        | -              | 11,793,666        | 9,308,435         | 1,154,735        | -                | 10,463,170        |
| Charitable activities              | 6            | 863,367           | 501,870          | 349,524        | 1,714,761         | 1,107,010         | 570,030          | 847,029          | 2,524,069         |
| <b>Total</b>                       |              | <b>10,477,772</b> | <b>2,681,131</b> | <b>349,524</b> | <b>13,508,427</b> | <b>10,415,445</b> | <b>1,724,765</b> | <b>847,029</b>   | <b>12,987,239</b> |
| <b>Net income/(expenditure)</b>    |              | <b>789,826</b>    | <b>(241,977)</b> | <b>80,067</b>  | <b>627,916</b>    | <b>782,995</b>    | <b>(700,993)</b> | <b>(567,756)</b> | <b>(485,754)</b>  |
| Transfer between funds             |              | (827,288)         | 848,588          | (21,300)       | -                 | (331,584)         | 331,584          | -                | -                 |
| <b>Net movement in funds</b>       |              | <b>(37,462)</b>   | <b>606,611</b>   | <b>58,767</b>  | <b>627,916</b>    | <b>451,411</b>    | <b>(369,409)</b> | <b>(567,756)</b> | <b>(485,754)</b>  |
| <b>Reconciliation of funds:</b>    |              |                   |                  |                |                   |                   |                  |                  |                   |
| Total funds brought forward        |              | 2,063,688         | 1,668,192        | 16,786         | 3,748,666         | 1,612,277         | 2,037,601        | 584,542          | 4,234,420         |
| <b>Total funds carried forward</b> |              | <b>2,026,226</b>  | <b>2,274,803</b> | <b>75,553</b>  | <b>4,376,582</b>  | <b>2,063,688</b>  | <b>1,668,192</b> | <b>16,786</b>    | <b>3,748,666</b>  |

All operations are continuing.

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

The notes on pages 41 to 53 form part of these Financial Statements.

# 7 Balance Sheet

## BALANCE SHEET AS AT 31 DECEMBER 2016

|  |       | Company registration<br>number |                         |
|--|-------|--------------------------------|-------------------------|
|  |       |                                | 4118259                 |
|  | Notes | 2016<br>£                      | 2015<br>£               |
| <b>Fixed assets</b>                                    |       |                                |                         |
| Tangible assets  | 10    | 1,249,228                      | 1,488,289               |
| Intangible assets                                      | 10    | -                              | (230,098)               |
| Investment in DEBRA Trading Ltd                        |       | 2                              | 2                       |
|  |       | <u>1,249,230</u>               | <u>1,258,193</u>        |
| <b>Current assets</b>                                  |       |                                |                         |
| Current asset investment                               | 11    | 1,400,000                      | 2,000,000               |
| Stocks   |       | 25,066                         | 11,007                  |
| Debtors  | 12    | 1,568,698                      | 1,521,443               |
| Cash at bank and in hand                               |       | <u>3,099,431</u>               | <u>2,108,395</u>        |
|  |       | 6,093,195                      | 5,640,845               |
| <b>Creditors: amounts falling due within one year:</b> | 13    | <u>(2,753,384)</u>             | <u>(2,735,595)</u>      |
| <b>Net current assets</b>                              |       | <u>3,339,811</u>               | <u>2,905,250</u>        |
| <b>Total assets less current liabilities</b>           |       | <u>4,589,041</u>               | <u>4,163,443</u>        |
| <b>Creditors: amounts falling due over one year:</b>   | 13    | (32,459)                       | (267,277)               |
| Provisions for liabilities                             | 13    | <u>(180,000)</u>               | <u>(147,500)</u>        |
| <b>Total net assets</b>                                |       | <u><u>4,376,582</u></u>        | <u><u>3,748,666</u></u> |
| <b>The funds of the charity</b>                        |       |                                |                         |
| Restricted income funds                                | 15    | 75,553                         | 16,786                  |
| Unrestricted funds                                     | 15    | 4,301,029                      | 3,731,880               |
| Total charity funds                                    |       | <u><u>4,376,582</u></u>        | <u><u>3,748,666</u></u> |

The notes on pages 41 to 53 form part of these Financial Statements.

The accounts were approved by the Board on 27 April 2017 and signed on their behalf by:

**David Spence**  
Chair of Trustee Board

**Joanne Merchant**  
Vice Chair of the Finance, Risk and Audit Committee

## 8 Cash Flow Statement

### CASH FLOW STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2016

|   | Notes | £               | 2016<br>£        | £        | 2015<br>£        |
|---|-------|-----------------|------------------|----------|------------------|
| <b>CASHFLOWS FROM OPERATING ACTIVITIES:</b>                               |       |                 |                  |          |                  |
| <b>Net cash provided by (used in) operating activities</b>                | 17    |                 | <b>57,433</b>    |          | <b>(821,671)</b> |
| <b>CASHFLOWS FROM INVESTING ACTIVITIES:</b>                               |       |                 |                  |          |                  |
| Dividends, interest and rents from investments                            |       | <b>39,587</b>   |                  | 67,785   |                  |
| Proceeds from the sale of property, plant and equipment                   |       | <b>350,001</b>  |                  | -        |                  |
| Purchase of property, plant and equipment                                 |       | <b>(55,985)</b> |                  | (93,735) |                  |
| <b>Net cash provided by (used in) investing activities</b>                |       |                 | <b>333,603</b>   |          | <b>(25,950)</b>  |
| <b>Change in cash and cash equivalents in the reporting period</b>        |       |                 | <b>391,036</b>   |          | <b>(847,623)</b> |
| <b>Cash and cash equivalents at the beginning of the reporting period</b> |       |                 | <b>4,108,395</b> |          | <b>4,956,018</b> |
| <b>Cash and cash equivalents at the end of the reporting period</b>       |       |                 | <b>4,499,431</b> |          | <b>4,108,395</b> |

The notes on pages 41 to 53 form part of these Financial Statements.

# 9 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 on-going 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 Income resources

Income is accounted for on an accruals basis where practicable to do so. Gifts in kind are only included in the accounts where the trustees can ascribe a value in excess of £1,000. 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.

### 1.5 Resources expended

Expenditure is accounted for on an accruals basis where practicable to do so, 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 costs of generating funds and charitable expenditure on the basis of central staff time allocation to the various activities.

### 1.6 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.

#### 1.7 Tangible fixed assets and depreciation

Tangible fixed assets with a value in excess of £1,000 are capitalised and stated at cost less depreciation. On all assets purchased since 1 January 2002, depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

|  |               |
|--|---------------|
| Freehold and long leasehold land and buildings | Over 25 years |
| 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%.

All set up costs for new shops, with the exception of tills, are expensed as incurred.

#### 1.8 Intangible fixed assets and amortisation

The charity acquired ten freehold properties from another charity in September 2009. The difference between the market value and the price paid is recognised as negative goodwill. This is amortised in line with a reducing guarantor liability on the assets, which commenced in 2010 and runs for six years.

#### 1.9 Cash and short-term investments

The charity holds cash requirements for day-to-day activities in current bank accounts with HSBC, Lloyds, Santander, Clydesdale, and Nat West. Deposit accounts are held with HSBC and Nat West. 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.

#### 1.10 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.

#### 1.11 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.

1.12 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 is included in other trading activities. DEBRA Retail 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 21 to the financial statements.

1.13 Foreign currency translation

Foreign currency is translated into sterling at the current exchange rate at the date of the transaction.

1.14 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.

1.15 Judgements and estimates made by management

Legacy income is recognised as probable at probate. 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. As noted in the going concern policy above, the trustees consider the charity is a going concern because financial strength is maintained. 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.

1.16 Termination payments

The various constituents of termination payments, i.e. redundancy, compensation or 'pay in lieu of notice' are recognised at the time of payment. Any payment exceeding the statutory minimum is authorised by the trustees.

## 2 Donations and Legacies

|                               | Unrestricted funds | Restricted funds | Total 2016              | Total 2015       |
|-------------------------------|--------------------|------------------|-------------------------|------------------|
|                               | £                  | £                | £                       | £                |
| Donations & gifts             | 2,103,422          | 167,079          | <b>2,270,501</b>        | 2,354,312        |
| Legacies receivable           | 58,612             | 8,614            | <b>67,226</b>           | 106,295          |
| Grants receivable             | 84,702             | 157,667          | <b>242,369</b>          | 150,246          |
|                               | <u>2,246,736</u>   | <u>333,360</u>   | <u><b>2,580,096</b></u> | <u>2,610,853</u> |
| <b>Donations &amp; gifts:</b> |                    |                  |                         |                  |
| Individual donations          | 1,824,324          | 117,345          | <b>1,941,669</b>        | 1,688,472        |
| Corporate donations           | 184,809            | 47,379           | <b>232,188</b>          | 540,973          |
| International donations       | 1,090              | -                | <b>1,090</b>            | 1,350            |
| Events by individuals         | 93,199             | 2,355            | <b>95,554</b>           | 123,517          |
|                               | <u>2,103,422</u>   | <u>167,079</u>   | <u><b>2,270,501</b></u> | <u>2,354,312</u> |
| <b>Grants receivable:</b>     |                    |                  |                         |                  |
| Charitable trusts             | 84,702             | 157,667          | <b>242,369</b>          | 150,246          |
|                               | <u>84,702</u>      | <u>157,667</u>   | <u><b>242,369</b></u>   | <u>150,246</u>   |

### 3 Other trading activities

|  | <b>Total<br/>2016</b> | Total<br>2015 |
|--|-----------------------|---------------|
|  | £                     | £             |
| Income                                 | <b>11,304,180</b>     | 9,733,357     |
| Operating expenses                     | <b>( 10,974,267)</b>  | ( 9,699,750)  |
| Net income from fundraising activities | <b><u>329,913</u></b> | <u>33,607</u> |

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2016 there were 130 shops trading (2015:122). The major categories of income and expenditure are summarised below:

|                       | Income            | Operating<br>expenses | <b>Net income<br/>2016</b> | Net income<br>2015 |
|-----------------------|-------------------|-----------------------|----------------------------|--------------------|
|                       | £                 | £                     | £                          | £                  |
| Retail                | 10,471,299        | (10,387,270)          | <b>84,029</b>              | (231,173)          |
| Fundraising events    | 766,603           | (587,011)             | <b>179,592</b>             | 191,226            |
| Miscellaneous trading | 66,278            | 14                    | <b>66,292</b>              | 73,554             |
|                       | <u>11,304,180</u> | <u>(10,974,267)</u>   | <b><u>329,913</u></b>      | <u>33,607</u>      |

The net income incurred by retail excludes income of £1,187,243 (£2015: £1,001,489) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. There was significant investment in retail during 2016 in new shop openings, where set up costs were written off as incurred and not depreciated over the life of the lease. There is amortisation of negative goodwill of (£230,097) (2015: £0). The profit covenanted by DEBRA Trading Limited of £15,703 (£2015: £7,629) is included in miscellaneous trading.

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

|                    | <b>2016</b>             | 2015           |
|--------------------|-------------------------|----------------|
|                    | £                       | £              |
| Retail income      | <b>11,658,542</b>       | 9,991,527      |
| Retail expenditure | <b>(10,387,270)</b>     | (9,221,211)    |
| Retail net income  | <b><u>1,271,272</u></b> | <u>770,316</u> |

### 4 Investments

|                         | Unrestricted<br>funds | <b>Total<br/>2016</b> | Total<br>2015 |
|-------------------------|-----------------------|-----------------------|---------------|
|                         | £                     | £                     | £             |
| Interest receivable     | 16,082                | <b>16,082</b>         | 43,174        |
| Rent of property        | 23,505                | <b>23,505</b>         | 24,611        |
| Total investment income | <u>39,587</u>         | <b><u>39,587</u></b>  | <u>67,785</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 includes grants payable to third parties as detailed in Note 20. There were 192 Community Support grants totalling £41,933 made through the Community Support programme. All other grants were payable to institutions as detailed in Note 20.

Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research projects have a finite life and at 31 December 2016 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £381,145 (2015: £1,101,111).

The total commitment is currently budgeted to be spent as follows:

|   | <b>Total<br/>2016</b> | Total<br>2015 |
|---|-----------------------|---------------|
|   | £                     | £             |
| Within 1 year                               | <b>348,686</b>        | 833,834       |
| Within 2-3 years                            | <b>32,459</b>         | 267,277       |
|   | <b>381,145</b>        | 1,101,111     |
| Provided within the grants payable creditor | <b>381,145</b>        | 1,101,111     |

## 6 Expenditure

|                          | Staff costs<br>£ | Grants payable<br>£ | Other costs<br>£ | <b>Total<br/>2016</b><br>£ | Total<br>2015<br>£ |
|--------------------------|------------------|---------------------|------------------|----------------------------|--------------------|
| <b>Raising funds:</b>    |                  |                     |                  |                            |                    |
| Voluntary income         | 481,212          | -                   | 338,187          | <b>819,399</b>             | 763,421            |
| Other trading activities | 5,380,347        | -                   | 5,593,920        | <b>10,974,267</b>          | 9,699,749          |
|                          | <b>5,861,559</b> | -                   | 5,932,107        | <b>11,793,666</b>          | 10,463,170         |

### Charitable activities:

|                   |                  |         |           |                   |            |
|-------------------|------------------|---------|-----------|-------------------|------------|
| Research          | 245,017          | 234,384 | 29,219    | <b>508,620</b>    | 1,149,598  |
| Healthcare        | 110,681          | 134,692 | 21,825    | <b>267,198</b>    | 375,120    |
| Community support | 542,074          | 41,933  | 44,569    | <b>628,576</b>    | 650,944    |
| Respite breaks    | -                | -       | 62,069    | <b>62,069</b>     | 55,336     |
| Public education  | 176,728          | -       | 71,570    | <b>248,298</b>    | 293,071    |
|                   | <b>1,074,500</b> | 411,009 | 229,252   | <b>1,714,761</b>  | 2,524,069  |
|                   | <b>6,936,059</b> | 411,009 | 6,161,359 | <b>13,508,427</b> | 12,987,239 |

| <b>Other costs</b>            | Depreciation and<br>amortisation<br>£ | Overhead<br>allocation<br>£ | Miscellaneous<br>costs<br>£ | <b>Total<br/>2016</b><br>£ | Total<br>2015<br>£ |
|-------------------------------|---------------------------------------|-----------------------------|-----------------------------|----------------------------|--------------------|
| <b>Raising funds:</b>         |                                       |                             |                             |                            |                    |
| Voluntary income              | -                                     | 194,875                     | 143,312                     | <b>338,187</b>             | 289,862            |
| Other trading activities      | ( 161,976)                            | 194,866                     | 5,561,030                   | <b>5,593,920</b>           | 4,843,471          |
|                               | <b>( 161,976)</b>                     | 389,741                     | 5,704,342                   | <b>5,932,107</b>           | 5,133,333          |
| <b>Charitable activities:</b> |                                       |                             |                             |                            |                    |
| Research                      | -                                     | 29,219                      | -                           | <b>29,219</b>              | 30,831             |
| Healthcare                    | -                                     | 21,825                      | -                           | <b>21,825</b>              | 22,775             |
| Community Support             | -                                     | 35,589                      | 8,980                       | <b>44,569</b>              | 49,182             |
| Respite breaks                | 25,669                                | -                           | 36,400                      | <b>62,069</b>              | 55,336             |
| Public education              | -                                     | 71,570                      | -                           | <b>71,570</b>              | 72,659             |
|                               | <b>25,669</b>                         | 158,203                     | 45,380                      | <b>229,252</b>             | 230,783            |
|                               | <b>( 136,307)</b>                     | 547,944                     | 5,749,722                   | <b>6,161,359</b>           | 5,364,116          |

## Expenditure (continued)

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

|  | 2016    | 2015    |
|--|---------|---------|
|  | £       | £       |
| Hire of plant and machinery - operating leases | 29,834  | 30,736  |
| Auditors remuneration                          | 18,550  | 21,200  |
| Non-audit services                             | 15,174  | 12,718  |
| Depreciation of tangible fixed assets          | 119,363 | 112,684 |
| Defined contribution pension costs             | 234,116 | 233,326 |

## 7 Cost allocation

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

|  | 2016             | 2015      |
|--|------------------|-----------|
|  | £                | £         |
| <b>Staff costs:</b>                            | <b>1,353,053</b> | 1,537,195 |
| <b>Overheads:</b>                              |                  |           |
| Office premises rent                           | 36,173           | 50,939    |
| Service charges, utilities & cleaning          | 39,033           | 35,830    |
| Equipment costs                                | 141,468          | 132,574   |
| Postage, printing, stationery, telephone & fax | 88,702           | 91,247    |
| Insurance costs                                | 59,107           | 50,283    |
| Legal, professional & consultancy fees         | 56,164           | 23,718    |
| Depreciation                                   | 25,574           | 26,660    |
| Irrecoverable VAT                              | 40,976           | 43,482    |
| Bank charges                                   | 10,987           | 11,067    |
| Sundry expenses                                | 24,067           | 11,714    |
| Governance costs:                              |                  |           |
| Audit fees                                     | 18,550           | 21,200    |
| Miscellaneous costs                            | 7,142            | 8,018     |
|  | <b>547,943</b>   | 506,732   |
| <b>Total Allocation</b>                        | <b>1,900,996</b> | 2,043,927 |

Non-audit payments made to BDO totalled £15,174 in 2016 (2015: £12,718).

## 8 Trustees

None of the trustees received any remuneration from DEBRA during the period, but 10 of them were reimbursed a total of £5,443 (2015: £8,095) for travel and subsistence expenses.

Rhian Edwards received community support grants in 2016 totalling £25 (2015: £444).

Michael Jaega received community support grants in 2016 totalling £1,000 (2015: £1,537).

Christo Kapourani received a community support grant of £314 (2015: £25).

Scott O'Sullivan received community support grants in 2016 totalling £0 (2015: £45).

Amy Price received community support grants in 2016 totalling £0 (2015: £43).

A close family member of a DEBRA trustee received a community support grant of £26 (2015: £0).

The aggregate figure for trustee donations in 2016 was £11,970 (2015: £1,015).

In addition many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £2,379 (2015: £2,304), as allowed under section 4.3.3 in DEBRA's Articles of Association.

## 9 Employees

| The average number of employees during the period was: | 2016 full time<br>equiv | 2016<br>Number | 2015<br>Number |
|--|-------------------------|----------------|----------------|
| Research   | 2.9                     | 4              | 3              |
| Healthcare <sup>3</sup>                                | 0.5                     | 1              | 1              |
| Community Support                                      | 10.3                    | 11             | 11             |
| Fundraising  | 15.1                    | 17             | 19             |
| Retail   | 250.8                   | 311            | 277            |
| Management & Administration                            | 12.6                    | 16             | 19             |
|  | <u>292</u>              | <u>360</u>     | <u>330</u>     |

| At the end of the year the number of employees per department was: | 2016 full time<br>equiv | 2016<br>Number | 2015<br>Number |
|--|-------------------------|----------------|----------------|
| Research   | 3.5                     | 5              | 3              |
| Healthcare <sup>3</sup>  | 0.3                     | 1              | 1              |
| Community Support  | 9.7                     | 11             | 11             |
| Fundraising  | 14.1                    | 16             | 18             |
| Retail   | 255.5                   | 322            | 293            |
| Management & Administration  | 13.0                    | 17             | 19             |
|  | <u>296</u>              | <u>372</u>     | <u>345</u>     |

### EMPLOYMENT COSTS

|                       | Total<br>2016<br>£ | Total<br>2015<br>£ |
|-----------------------|--------------------|--------------------|
| Wages & salaries      | 5,840,791          | 5,396,292          |
| Social security costs | 385,086            | 369,083            |
| Pension costs         | 234,116            | 233,326            |
|                       | <u>6,459,993</u>   | <u>5,998,701</u>   |

The charity makes payments to a variety of employees' personal pension plans. Total pension payments of £242,303 (2015: £230,565) were made in the year and charged to the SOFA (Statement of Financial Activities) in the period they were due. At the year-end there remained £1,400 (2015: £9,588) 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: | 2016 | 2015 |
|---|------|------|
| Between £60,001 - £70,000   | -    | 1    |
| Between £70,001 - £80,000   | 2    | 2    |
| Between £80,001 - £90,000   | 1    | -    |
| Between £160,001 - £170,000                                       | 1    | -    |
| Between £170,001 - £180,000                                       | -    | 1    |

<sup>3</sup> These numbers exclude healthcare staff funded through grants to external organisations and detailed in Note 20. Staff employed by external institutions and funded through research grants are also excluded.

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £45,477 (2015: £49,250), and there are retirement benefits accruing for four (2015: four) employees under a defined contribution scheme.

The aggregate pay of key management personnel, including employer's NI and pension contributions was £676,360 (2015: £693,331). The aggregate employer's pension contribution for key management personnel was £61,472 (2015: £67,608). Redundancy and compensation payments totalled £68,984 in 2016 (2015: £4,409).

## 10 Fixed assets

| Tangible fixed assets      | Shop fittings  | Mobile homes   | Fixtures, fittings & equipment | Freehold land and buildings | Long leasehold land and buildings | Total            |
|----------------------------|----------------|----------------|--------------------------------|-----------------------------|-----------------------------------|------------------|
|                            | £              | £              | £                              | £                           | £                                 | £                |
| <b>Cost:</b>               |                |                |                                |                             |                                   |                  |
| At 1 January 2016          | 295,452        | 256,687        | 201,509                        | 1,329,961                   | 82,500                            | 2,166,109        |
| Additions                  | 41,505         | -              | 14,480                         | -                           | -                                 | 55,985           |
| Disposals                  | -              | -              | (12,825)                       | (207,500)                   | -                                 | (220,325)        |
| <b>At 31 December 2016</b> | <b>336,957</b> | <b>256,687</b> | <b>203,164</b>                 | <b>1,122,461</b>            | <b>82,500</b>                     | <b>2,001,769</b> |
| <b>Depreciation:</b>       |                |                |                                |                             |                                   |                  |
| At 1 January 2016          | 167,696        | 99,936         | 151,506                        | 247,132                     | 11,550                            | 677,820          |
| Charge for the year        | 46,405         | 25,669         | 17,249                         | 28,390                      | 1,650                             | 119,363          |
| Disposals                  | -              | -              | (12,825)                       | (31,817)                    | -                                 | (44,642)         |
| <b>At 31 December 2016</b> | <b>214,101</b> | <b>125,605</b> | <b>155,930</b>                 | <b>243,705</b>              | <b>13,200</b>                     | <b>752,541</b>   |
| <b>Net Book Value:</b>     |                |                |                                |                             |                                   |                  |
| Brought forward            | 127,756        | 156,751        | 50,003                         | 1,082,829                   | 70,950                            | 1,488,289        |
| <b>At 31 December 2016</b> | <b>122,856</b> | <b>131,082</b> | <b>47,234</b>                  | <b>878,756</b>              | <b>69,300</b>                     | <b>1,249,228</b> |

| Intangible fixed assets                       | Acquisition goodwill |
|---|----------------------|
|   | £                    |
| <b>Cost</b>                                   |                      |
| <b>At 1 January 2016 and 31 December 2016</b> | <b>(1,318,750)</b>   |
| <b>Amortisation:</b>                          |                      |
| At 1 January 2016                             | 1,088,652            |
| Charge for year                               | 230,098              |
| <b>At 31 December 2016</b>                    | <b>1,318,750</b>     |
| <b>Net Book Value:</b>                        |                      |
| Brought forward                               | (230,098)            |
| <b>At 31 December 2016</b>                    | <b>-</b>             |

The charity acquired 10 freehold properties from Action for Children in September 2009, valued at £1,518,750. The difference between the market value and the price paid of £200,000 is recognised as negative goodwill. There has been a reducing balance guarantor liability on these assets restricting their sale. The release of these assets from the restriction has been as follows:

| Date     | Released in year | Cumulative |
|----------|------------------|------------|
| Mar 2010 | 115,000          | 115,000    |
| Mar 2011 | 380,000          | 495,000    |
| Mar 2012 | 290,000          | 785,000    |
| Mar 2013 | 275,000          | 1,060,000  |
| Mar 2014 | 193,750          | 1,253,750  |
| Mar 2016 | 265,000          | 1,518,750  |

This negative goodwill is being amortised in line with the reducing guarantor liability.

## 11 Investment in short term deposits

|                              | 2016             | 2015             |
|------------------------------|------------------|------------------|
|                              | £                | £                |
| Lloyds money market deposits | <u>1,400,000</u> | <u>2,000,000</u> |
|                              | <u>1,400,000</u> | <u>2,000,000</u> |

## 12 Debtors

|                | 2016             | 2015             |
|----------------|------------------|------------------|
|                | £                | £                |
| HMRC           | 206,345          | 122,893          |
| Misc debtors   | 51,183           | 61,720           |
| Other debtors  | 7,458            | 16,373           |
| Accrued income | 752,818          | 821,647          |
| Prepayments    | <u>550,894</u>   | <u>498,810</u>   |
|                | <u>1,568,698</u> | <u>1,521,443</u> |

VAT repayment of £206,345 is due from HMRC. Accrued income includes gift aid of £665,036 due for 2016.

Total future minimum lease receivable was £31,981 in 2016 (2015:£10,767), in respect of 1 shop and 2 flats above shops.

## 13 Creditors: amounts falling due within one year

| CREDITORS: amounts falling due within one year | 2016             | 2015             |
|--|------------------|------------------|
|  | £                | £                |
| Trade creditors                                | 387,962          | 213,687          |
| Grants payable                                 | 1,518,716        | 1,693,668        |
| Other creditors                                | 557              | 9,588            |
| Taxation and social security                   | 104,921          | 93,319           |
| Accruals                                       | 717,078          | 713,983          |
| Deferred income                                | 24,150           | 11,350           |
|  | <u>2,753,384</u> | <u>2,735,595</u> |

There was deferred income of £24,150 in the year (2015: £11,350), representing income for events which would have to be repaid in the event of cancellation.

| CREDITORS: amounts falling due over one year | 2016          | 2015           |
|--|---------------|----------------|
|  | £             | £              |
| Grants payable                               | <u>32,459</u> | <u>267,277</u> |
|  | <u>32,459</u> | <u>267,277</u> |

There was a dilapidations provision of £180,000 (2015: £147,500). In the year £10,203 was released from the provision and a further £42,703 was charged.

## 14 Other financial commitments

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

|                           | 2016<br>Leases of land and<br>buildings<br>£ | 2015<br>Leases of land and<br>buildings<br>£ | 2016<br>Other<br>£ | 2015<br>Other<br>£ |
|---------------------------|--|--|--------------------|--------------------|
| Expiring within 1 year    | 1,807,158                                    | 1,622,566                                    | 28,846             | 29,350             |
| Expiring within 2-5 years | 2,005,421                                    | 2,131,129                                    | 10,111             | 29,705             |
| Expiring after 5 years    | 10,134                                       | 28,836                                       | 952                | -                  |
|                           | <u>3,822,713</u>                             | <u>3,782,531</u>                             | <u>39,909</u>      | <u>59,055</u>      |

There are capital commitments of £2,767 at year end, falling due within one year (2015: £2,767).

## 15 Analysis of funds

| Restricted funds            | Balance at<br>31 Dec |                |                   | Transfer to General<br>Fund | Balance at<br>31 Dec<br>2016 |
|-----------------------------|----------------------|----------------|-------------------|-----------------------------|------------------------------|
|                             | 2015<br>£            | Income<br>£    | Expenditure<br>£  |                             |                              |
| Research                    | 980                  | 145,618        | (100,767)         | ( 21,300)                   | 24,531                       |
| Healthcare                  | 6,972                | 51,066         | (23,325)          | -                           | 34,713                       |
| Community Support & Respite | 8,834                | 232,907        | (225,432)         | -                           | 16,309                       |
|                             | <u>16,786</u>        | <u>429,591</u> | <u>( 349,524)</u> | <u>( 21,300)</u>            | <u>75,553</u>                |

### Analysis of funds (continued)

Restricted funds at 31 December 2016 comprise:

|   |               |
|---|---------------|
| Research - Itch Project                                     | £ 21,228      |
| Research - Clinical Trials                                  | 1,974         |
| Research - Sohana Research Fund                             | 1,329         |
| Healthcare - GSTT Rare Disease Centre                       | 28,389        |
| Healthcare - Birmingham Children's Hospital Specialist Bath | 5,600         |
| Healthcare - other restricted funds                         | 724           |
| Community Support - Support Grants in Hampshire             | 3,164         |
| Community Support - Support Grants in North West            | 2,249         |
| Community Support - Holiday Home                            | 2,086         |
| Community Support - other restricted funds                  | 8,810         |
|   | <u>75,553</u> |

The transfer of £21,300 from the research restricted fund into the general fund represents restricted funding received for research projects fully committed and recognised in the general fund in a prior year, but not paid for until 2016.

### Unrestricted funds

The trustees have transferred the following amounts into designated funds during 2016:

|   | Balance at<br>31 Dec 2015<br>£ | Transfers<br>£   | Income<br>£       | Expenditure<br>£    | Balance at<br>31 Dec<br>2016<br>£ |
|---|--------------------------------|------------------|-------------------|---------------------|-----------------------------------|
| Future research grants                    | 784,896                        | 514,712          | -                 | ( 267,702)          | 1,031,906                         |
| New health and community support projects | 391,365                        | 333,876          | -                 | (234,168)           | 491,073                           |
| Furniture and electrical shops            | 491,931                        | -                | 2,143,555         | (2,179,261)         | 456,225                           |
| Special projects fund                     | -                              | -                | 230,474           | -                   | 230,474                           |
| GSTT Rare Disease Centre                  | -                              | -                | 65,125            | -                   | 65,125                            |
| Total designated funds                    | <u>1,668,192</u>               | <u>848,588</u>   | <u>2,439,154</u>  | <u>(2,681,131)</u>  | <u>2,274,803</u>                  |
| General fund                              | <u>2,063,688</u>               | <u>(827,288)</u> | <u>11,267,598</u> | <u>(10,477,772)</u> | <u>2,026,226</u>                  |
| Total unrestricted funds                  | <u>3,731,880</u>               | <u>21,300</u>    | <u>13,706,752</u> | <u>(13,158,903)</u> | <u>4,301,029</u>                  |

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 in line

with the charitable objectives of the charity. There were transfers totalling £514,712 from the general fund into this fund in 2016. It is anticipated this fund will be spent in the next 1-5 years.

The trustees designated £700,000 in 2011 to fund the set-up of a number of large Furniture and Electrical Shops. It is anticipated this fund will be spent or undesignated during the next 1-2 years.

DEBRA saved £333,876 during 2016 (2015: £333,876) from the increased funding for healthcare of EB patients by the NHS, this amount being transferred from the general fund into the health and community support designated fund in 2016. This designated fund was established in 2011 to demonstrate the trustees' commitment to ploughing back all these savings into new health and community support projects.

On-going savings continue to be added to the fund and a £150,000 contingency is held in the event of future funding withdrawal. Expenditure from this fund on new projects totalled £234,168 in 2016 (2015: £315,967). It is anticipated this fund will be spent in the next 1-5 years.

A new designated fund for special projects was established in 2016 following the increase in funds of £230,474 available for charitable spend from the disposal of two freehold assets. It is anticipated this fund will be spent in the next 1-5 years. The trustees designated £65,125 for the GSTT Rare Disease Centre, following a successful fundraising lunch. This fund was spent in February 2017.

## 16 Analysis of net assets between categories of funds

|  | Unrestricted funds<br>£ | Restricted funds<br>£ | Total<br>2016<br>£      | Total<br>2015<br>£ |
|--|-------------------------|-----------------------|-------------------------|--------------------|
| <b>Fund balances at 31 December 2016 are represented by:</b> |                         |                       |                         |                    |
| Fixed assets   | 1,249,230               | -                     | <b>1,249,230</b>        | 1,258,193          |
| Current assets   | 6,017,642               | 75,553                | <b>6,093,195</b>        | 5,640,845          |
| Creditors: amounts falling due within one year               | (2,933,384)             | -                     | <b>( 2,933,384)</b>     | ( 2,883,095)       |
| Creditors: amounts falling due over one year                 | (32,459)                | -                     | <b>( 32,459)</b>        | ( 267,277)         |
|  | <u>4,301,029</u>        | <u>75,553</u>         | <u><b>4,376,582</b></u> | <u>3,748,666</u>   |

## 17 Reconciliation of net income (expenditure) to net cash flow from operating activities

|  | 2016<br>£            | 2015<br>£         |
|--|----------------------|-------------------|
| Net income / (expenditure) for the reporting period (as per the statement of financial activities) | <b>627,916</b>       | ( 485,754)        |
| Depreciation and (amortisation) charges  | <b>( 110,735)</b>    | 112,684           |
| Dividends, interest and rents from investments   | <b>( 39,587)</b>     | ( 67,785)         |
| Loss / (profit) on disposal of fixed assets  | <b>( 174,319)</b>    | -                 |
| (Increase) / decrease in stock   | <b>( 14,059)</b>     | 10,782            |
| (Increase) / decrease in debtors   | <b>( 47,255)</b>     | 2,663             |
| Increase / (decrease) in creditors   | <b>( 184,528)</b>    | ( 394,263)        |
|  | <u><b>57,433</b></u> | <u>( 821,673)</u> |

## 18 Reconciliation of net cash flow to movement in net funds

|  | 2016<br>£               | 2015<br>£        |
|--|-------------------------|------------------|
| Increase in cash                               | <b>991,036</b>          | 402,377          |
| Cash outflow from increase in liquid resources | <b>( 600,000)</b>       | ( 1,250,000)     |
| Net funds brought forward                      | <b>4,108,395</b>        | 4,956,018        |
| Net funds carried forward                      | <u><b>4,499,431</b></u> | <u>4,108,395</u> |

## 19 Analysis of cash and cash equivalents

|                          | As at 1 Jan 2016<br>£ | Cash Flows<br>£ | As at 31 Dec 2016<br>£  |
|--------------------------|-----------------------|-----------------|-------------------------|
| Cash at bank and in hand | 2,108,395             | 991,036         | <b>3,099,431</b>        |
| Short term deposits      | 2,000,000             | ( 600,000)      | <b>1,400,000</b>        |
| Total                    | <u>4,108,395</u>      | <u>391,036</u>  | <u><b>4,499,431</b></u> |

## 20 Grants to institutions

|  | Total<br>2016<br>£    | Total<br>to date<br>£   | Total<br>project cost<br>£ |
|--|-----------------------|-------------------------|----------------------------|
| <b>Research Projects:</b>                                      |                       |                         |                            |
| <b>University of Dundee</b>                                    |                       |                         |                            |
| 1. TGFβ signalling in Recessive Dystrophic EB                  | 59,428                | 98,076                  | 190,284                    |
| 2. Skin fragility assessment tool grant                        | 25,485                | 38,225                  | 38,225                     |
| 3. Clinical fellow funding                                     | 91,648                | 112,213                 | 202,081                    |
| 4. EBS Genotyping  | -                     | -                       | 24,000                     |
|  | <u>176,561</u>        | <u>248,514</u>          | <u>454,590</u>             |
| <b>University of Edinburgh</b>                                 |                       |                         |                            |
| 1. Defining the role of Kindlin1                               | <u>64,086</u>         | <u>137,202</u>          | <u>191,838</u>             |
| <b>Guy's and St Thomas' Hospital, London</b>                   |                       |                         |                            |
| 1. Validated clinical endpoints study re EB therapy evaluation | 50,681                | 177,736                 | 177,736                    |
| 2. Mesenchymal stem-cell therapy clinical trial                | 205,120               | 432,496                 | 432,496                    |
| 3. Phase 1 study of the lentiviral-mediated COL7A1             | 234,954               | 426,431                 | 499,320                    |
|  | <u>490,755</u>        | <u>1,036,663</u>        | <u>1,109,552</u>           |
| <b>University College Dublin</b>                               |                       |                         |                            |
| Studies about the problem of Puritis in EB patients            | <u>35,171</u>         | <u>66,449</u>           | <u>66,449</u>              |
| <b>University of Salzburg</b>                                  |                       |                         |                            |
| Combining gene-therapy and stem-cell-therapy for JEB           | <u>22,121</u>         | <u>219,187</u>          | <u>219,187</u>             |
| <b>University of Minnesota</b>                                 |                       |                         |                            |
| Limbal stem cells for treatment of corneal wounds in EB        | <u>51,201</u>         | <u>175,709</u>          | <u>175,709</u>             |
| <b>The Jackson Laboratory, Maine, USA</b>                      |                       |                         |                            |
| Modelling EB genetics in mice                                  | <u>56,116</u>         | <u>203,563</u>          | <u>203,563</u>             |
| <b>Thomas Jefferson University, Philadelphia, USA</b>          |                       |                         |                            |
| Read-through of nonsense mutations in COL7A1                   | <u>111,526</u>        | <u>186,799</u>          | <u>234,344</u>             |
| Other  |                       |                         |                            |
|  |                       | (719,966)               |                            |
|  |                       | ( 53,187)               |                            |
| <b>Total research grants</b>                                   | <u><b>234,384</b></u> | <u><b>2,274,086</b></u> | <u><b>2,655,232</b></u>    |
| <b>Research project expenditure by category:</b>               |                       |                         |                            |
| Genetic research   | 231,728               |                         | 653,745                    |
| Therapies  | 2,656                 |                         | 2,001,487                  |
|  | <u>234,384</u>        |                         | <u>2,655,232</u>           |

## Grants to institutions (continued)

| Healthcare Team projects:                             | Total<br>2016<br>£ | Total<br>project cost<br>£ |
|---|--------------------|----------------------------|
| <b>Great Ormond Street Hospital for Sick Children</b> |                    |                            |
| Clinical nurse specialists in EB                      | 26,566             | 26,635                     |
| <b>Guys &amp; St Thomas' Hospital London</b>          |                    |                            |
| Adult EB support nurses                               | 71,952             | 71,952                     |
| <b>Other</b> Miscellaneous healthcare grants          | 4,260              | 59,053                     |
| Birmingham Children's Hospital                        | 31,914             | 33,843                     |
| <b>Total Healthcare Team grants</b>                   | <u>134,692</u>     | <u>191,483</u>             |

## 21 Related parties

### DEBRA Trading Ltd

The principal activity of DEBRA Trading Ltd (company number: 2487114), 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:

|                                | 2016<br>£     | 2015<br>£    |
|--------------------------------|---------------|--------------|
| Turnover                       | 36,087        | 32,491       |
| Net profit gift aided to DEBRA | <u>15,702</u> | <u>7,629</u> |
| Net assets                     | <u>2</u>      | <u>2</u>     |

During the year, the charity charged management charges totalling (£5,182) including VAT (2015: £11,618) to its subsidiary DEBRA Trading Limited.