

# Trustees' Report & Accounts 2015



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

A charity registered in England and Wales (1084958) and Scotland (SC039654)  
Company limited by guarantee registered in England and Wales (4118259)

# 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 with DEBRA





“Life is a roller-coaster for us and I have very mixed emotions; one minute I’m able to just get on with it and the next I find myself crying and thinking ‘why my daughter, why us’.”

**Anne Marie, Mum to Tia who is living with Junctional EB generalised intermediate**



# 2015 Highlights

12 research projects were managed during the year leading to a better understanding of EB

1,800 patients accessed the EB healthcare service – a service part-funded by DEBRA

333 people attended the DEBRA Annual Members' Event making it the biggest event to date

There were 1,041 mentions of DEBRA and EB in the media raising much needed awareness

The DEBRA Golf Society raised over £100k net income

Like for like sales in the DEBRA charity shops increased by 2.2%



## DEBRA

### REFERENCE & ADMINISTRATIVE INFORMATION

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#### Trustees

David Spence*	Chair from 30 <sup>th</sup> April 2015
Simone Bunting	
James Hinchcliffe*	
James Irvine*	Treasurer
Michael Jaega*	Vice Chair from 30 <sup>th</sup> April 2015
Christo Kapourani	
Graham Marsden	
Amy Price	
Melissa Smith	until 16 <sup>th</sup> May 2015
John Tough	
Jon Field	until 14 <sup>th</sup> April 2016
Scott O'Sullivan	
Simon Cuzner	
Rhian Edwards	from 16 <sup>th</sup> May 2015
Joanne Merchant*	from 16 <sup>th</sup> May 2015
Timothy Powell	from 16 <sup>th</sup> May 2015

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. \* Members of Finance, Risk & Audit Committee

#### Royal Patron

HRH The Countess of Wessex

#### Life Patron

Philip Evans

#### President

Michael Portillo

#### Senior Staff

Ben Merrett	Chief Executive
Mike Bartlett	Director of Fundraising & Communication
Caroline Collins	Research Lead
Carol Harris	Director of Finance
Claire Mather	Director of Healthcare, Membership & Community Support
Maureen Nickson	Director of Retail
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

After a difficult year for our income generation teams it was uplifting to commit to a clinical study at the end of the year that, for the first time in EB, will use a drug to hopefully control the growth of an aggressive skin cancer to which EB patients are susceptible. This research project follows on from earlier work that we commissioned in the UK and supports a researcher who has moved to the USA. We always invest our hard-earned money in the best research projects, irrespective of geography, and we are hopeful that as well as patients from Austria the necessary hospital permission will be granted in the UK, enabling some British patients to be part of this study.

We have also been able to pledge a significant sum to help one of the EB UK centres of clinical excellence, who are working in partnership with a number of charities to raise the £2m needed to develop a rare disease centre. This necessary commitment is indicative of the financial challenges that the NHS face. The support of the hospital is essential and they are just as keen as us to complement the excellent staff, that we help fund, with world class physical facilities.

EB needs long-term recurring income streams and 2015 has been a testing year for us. Our chain of charity shops represent continuity, but as they involve heavy investment and commitment we expand with caution. To support fundraising, defined cases for support will be developed to help donors understand the difference their generosity can make.

The development of DEBRA International is important as our challenge is a global one – we received considerable praise for hosting a highly successful DEBRA International conference in London last September.

2015 was a tough year for the charity sector with trust dropping drastically thanks to a host of issues which were highlighted by negative press. We are pleased to report that we do not engage in the activities that have damaged the reputation of other charities.

**David Spence**  
Chair of Trustees

**Ben Merrett**  
Chief Executive Officer

# 2

## Trustees Report

DEBRA is the national charity (incorporated in the UK) that supports individuals and families affected by Epidermolysis Bullosa (EB) – a group of genetic skin conditions which cause the skin to blister and tear at the slightest touch. Tragically, certain types of EB can be fatal in infancy and others are severely life-limiting. It is estimated that there are more than 5,000 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 that 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 and therefore relies on the generosity of the public to carry out its vital work. DEBRA does however take full advantage of generic government incentives, such as Gift Aid, which have become very important, and the indicators are that these will stay in place for the foreseeable future.

### 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 not less than 50% of the members having direct experience of EB. DEBRA Members elect the majority of eight of the trustees and the Nominations & Governance Committee is responsible for proposing a further seven with relevant skills, who will then be appointed by the trustees themselves. In 2015 due to the transitional provision in the Articles, all vacancies on the Board were deemed to be for “Appointed Trustees” until the numbers concurred. This meant there was no requirement to hold an election and the Board appointed five trustees recommended by the Nominations & Governance Committee at the AGM. Melissa Smith was thanked by the board for her very valuable contribution as a trustee.

David Spence became Chair and Michael Jaega was appointed as Vice Chair by the Board on 30 April 2015.

New trustees receive a Trustee Handbook and 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 attend.

Trustees are supported by committees and advisory groups in the following areas of interest: finance, risk and audit; charitable activities; international; retail; fundraising and communications; and nominations and governance. In addition, the international



Medical and Scientific Advisory Panel gives expert advice on research priorities and quality.

DEBRA's President, Michael Portillo, and DEBRA's Royal Patron, The Countess of Wessex, continue to give considerable support and guidance to the charity, graciously attending events on behalf of the charity which make a considerable contribution to their success and DEBRA's public profile.

DEBRA is registered with the Office of the Scottish Charity Regulator, as required due to DEBRA's Scottish activities, which continue to form an important part of DEBRA's national strategy.

## Public Benefit

DEBRA exists to meet the public benefit of the advancement of the health of people with EB and related diseases. DEBRA meets the definition of a public benefit entity under FRS102.

## Objectives and Activities

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, gives support to people and families affected and provides real hope for the future by funding pioneering research to one day find a cure.

DEBRA aims to enhance the quality of life of people who are affected by EB by every means possible. The primary objectives are:

- To provide continuing services and support to people whose lives are affected by EB
- To develop effective treatments for EB through funding of research into the condition
- To promote best current practice in treatment
- To promote the well-being of people with EB and their families, and to maintain their full integration into society
- To promote professional and public knowledge of EB
- To encourage the development of EB support groups around the world and to foster co-operation and liaison
- To raise sufficient funds to make achievement of these objectives possible

During 2015 the new DEBRA UK research strategy was implemented. A two stage process was put in place for reviewing projects and a patient panel was included for the first time.

## Volunteers

A significant amount of DEBRA's work is undertaken by volunteers. In 2015 the charity had 1,107 volunteers (139 Full Time Equivalent - FTE) working in the charity's shops carrying out a variety of retail tasks. The head office had four volunteers (0.08 FTE) performing clerical duties. Additionally, there were a significant number of fundraising volunteers active in the community, assisting with income generation and raising awareness of the charity.

## Employees

Annual appraisals and reviews (quarterly and probationary) are carried out to ensure that all employees have the opportunity to reflect on their performance, plan their development and agree objectives for the forthcoming period. During an appraisal, line managers share information about DEBRA's projected performance and discussions provide an opportunity to re-iterate the charity's purpose, vision and values. Appraisals importantly promote two-way communication giving employees the chance to air concerns and explore solutions, suggest ideas and request training.

DEBRA's performance is dependent on the skills of the workforce and employees are encouraged to share and develop their skills by taking the training opportunities available to them.

Two successful Team/Leadership Development Days for administrative and management employees were held in 2015, the second of which included an Awards Dinner to recognise individual and team achievements.

In 2015, DEBRA committed to working with 'Investors In People' and accreditation was achieved in April 2016.

## Management Remuneration Policy

Salary rates for key management personnel are determined with reference to current market rates; information is gathered from relevant salary surveys specific to the sector, such as those carried out by the Charity Retail Association and Agenda Consulting, as well as more generic salary surveys, and advice is sought from recruitment consultants. The charity adopts a 'performance related' approach to determine an individual's on-going salary, evaluating performance against objectives which reflect the strategy set out in the 3 Year Plan.

Salaries are reviewed by an internal committee, which meets quarterly to ensure that all employees are paid a fair salary for their responsibilities, and that pay parity is maintained across the organisation.

Following the annual review of salaries, any recommendation for a cost of living increase is proposed by senior management and subject to approval by the board of trustees.

## Employment of Disabled Persons

As a disability charity, DEBRA is positively committed to providing employment opportunities to those with a disability or chronic medical condition. DEBRA also aims to increase the involvement of people with EB in all aspects of the charity's work. It is recognised that ensuring equal opportunities for disabled people may involve adjustments being made to the working environment or other employment arrangements. These adjustments will be made wherever reasonable and within a reasonable time frame.



# 3

## Strategic Report

### 3.1 Achievements and performance

#### Research

##### 2015 Summary

DEBRA UK has continued to support 12 ongoing research projects through 2015 along with a commitment to 3 new projects. The breadth of this research is important and it spans the natural history of EB through to investigations into gene therapy and stem cell transplantation.

The projects include pre-clinical and laboratory work through to early phase clinical studies in small numbers of patients as well as symptom relief. As research moves into the clinic, continued investigation into meaningful endpoints for research will be increasingly important and is part of the overall focus.

We have also been able to fund dedicated research personnel, bringing a wealth of experience into the UK with Dr Peter van den Akker, a Clinical Geneticist spending a year in Dundee to focus on EBS.

Coordination of approach has enabled research into mechanisms and treatment of itch to start in Dublin alongside DEBRA Ireland, and the first results and ongoing new research into stem cell infusions at Guys and St Thomas' Hospital in London with the Sohana Research Fund. Early results from this work suggest a role for stem cells providing short term improvements in RDEB patients.

##### 2015 In Numbers

- Expenditure on research grants in 2015 was £782k and of this £624k was designated for RDEB research and funded by the Sohana Research Fund
- The remaining £158k was spent on 3 new small grant applications
- In addition there were 12 ongoing studies, 3 of which are funded by the Sohana Research Fund and administrated by DEBRA UK and along with 1 other project are taking treatments into the clinic for further evaluation

## Aims for 2016

- Focus on the translation of pre-clinical research into
  - Patient studies to identify suitable treatments
  - Symptom relief and clinical care programmes
- Support the research community in communication and education and the development of new researchers in the field
- Communication and coordination with other DEBRAs and organisations funding research into EB to ensure a coherent and coordinated approach

### Case Study



**“This DEBRA funded research means that for the first time we can get a detailed look at all aspects of living with Recessive Dystrophic Epidermolysis Bullosa (RDEB). This will help us identify what is meaningful in terms of outcome measures for future clinical trials.” Dr Jemima Mellerio**

A systematic review of data relating to the natural history of RDEB was undertaken prior to the start of a prospective longitudinal study that includes assessment of laboratory, clinical, quality of life and socioeconomic parameters associated with RDEB. The funding has enabled development of an electronic based questionnaire to capture all aspects of each patient visit. The data so far have provided a framework to help further map the natural history of the disease and care requirements.

# Healthcare

## 2015 Summary

During 2015 DEBRA continued to assist with the funding of a specialist healthcare service for people living with any type of EB across the UK. This service is provided in partnership with NHS England's Specialised Services Commissioning team and NHS Scotland who fund the core (NHS duty of care) clinical service. DEBRA enhances the core service by increasing the hours of specialist nurses, dieticians, podiatrist, a clinical fellow and supporting initiatives such as multi-disciplinary out-reach 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 level of expertise required to care for people living with EB.

The NHS and DEBRA partnership had a direct impact on increased quality of life through greater access to specialist care such as home visits, out-reach clinics and bereavement support. In addition, DEBRA funded hospital visits, in-patient stays, as well as patient and carer travel costs.

In total DEBRA funded £375k of healthcare related activities in 2015.

## 2015 In Numbers

DEBRA funded:

- Approximately 25% of the cost of specialist EB nurses, enabling the core NHS service to be enhanced with activities such as additional bereavement visits, product evaluation, assistance with research projects, education days and nursing care for patient weekends away. Approximately 1,800 patients were supported during the year
- 2 days per week of specialist dieticians
- 24 specialist EB podiatry clinics
- 1 Clinical Fellow post supporting the clinical team
- A contribution to 3 additional multi-disciplinary clinics, giving patients the opportunity to receive care closer to their home

## Aims for 2016

- Continue to fund 24 podiatry clinics
- Continue to fund up to 25% of all specialist EB nurses in the UK



- Continue to fund enhanced occupational therapy and 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 research strategy, by encouraging and offering financial support in developing best practice research that will enhance the quality of life of someone living with EB
- Provide funding for the development of EB clinical best practice guidelines

## Plans for Future Periods

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

Ongoing 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, and an increase in the development of international clinical best practice guideline work is planned.



## Case Study

**Corben is seven years old and has Dominant Dystrophic Epidermolysis Bullosa (DDEB). His sister, Serin, also has the same type of EB.**

Both children rely on a soft, easily digestible diet because they are prone to gastro-oesophageal reflux (acid reflux). This is where food, drink and acid travels back up the windpipe causing irritation and, in Corben's case,

makes swallowing very painful. Corben's had six dilations, to stretch his throat, in two years. Corben and Serin both see the EB specialist dietitian at Great Ormond Street Hospital.

# Community Support and Membership

## 2015 Summary

DEBRA spent £706k during 2015 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, so the Community Support team expanded to ensure the support that the EB community received remained consistently high. Funds from the Health and Community Support Designated Fund were used for this purpose.

The quality of life for members of the EB community was enhanced by the support provided which included helping individuals and families with particular issues, such as 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 people living and working with EB) service developments; and providing accommodation for respite breaks.

All 4 holidays homes were booked to full capacity over the peak season and the Annual DEBRA Members' Event was, for the first time, held over two days providing an excellent opportunity to meet other members and professionals. An EBS meeting was also held at Dundee and a transition gathering was held at Birmingham Children's Hospital.

## 2015 In Numbers

- 383 individuals accessed the DEBRA community support service
- 192 support grants were awarded
- There were 2,052 individuals in the DEBRA membership scheme, of whom 333 attended the annual Members Day
- 188 EB hospital clinics were attended by a member of the Community Support team to offer support
- 80 weeks of holidays were taken in a DEBRA holiday home by families living with EB, providing them with much needed respite
- 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 2016

- Continue to provide a professional community support and membership service to EB families across the UK

- Expand the team to try and meet the current and increasing demand
- Increase 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 people living with EB
- Increase membership and engagement of members

## 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, and the development of community support profiling to achieve a more proactive service is anticipated.



### Case Study

**“My wife and I had never heard of EB before our son Rafay was born. Now it’s at the centre of our lives.**

“Rafay was born at Manchester General Hospital and very quickly diagnosed with RDEB...but understanding what EB would mean for us wasn't easy.

“Thankfully, Zainib Hussain, our DEBRA EB Community Support Manager and Victoria Warren, our Specialist EB Nurse (who DEBRA part-funds) at Birmingham Children's Hospital were able to work very closely together and help us. Zainib has attended hospital appointments and even home visits where she has been able to translate for us. We have faced many difficulties but Zainib has helped us cope with a big one – the language barrier has been lifted.” **Hayee, Rafay's daddy**



# Public Education

## 2015 Summary

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

DEBRA and EB were referenced 1,041 times in the press (national, regional, consumer and online) during 2015 (2014: 601) reaching over 91 million people. This coverage would have cost the charity £2.3 million to buy at commercial rates. National radio coverage was also achieved following a successful pitch to Global Radio's charity – Global's Make Some Noise. Interviews with Ben Merrett and a number of families living with EB were secured across Global's network, but with particularly prominence on LBC and Heart.

In August, DEBRA's first television advert aired. The one-minute advert was viewed by at least 4 million people and 10,000 people visited the DEBRA website during the period that the advert aired. 200 new donors were recruited and the advert is expected to break even in two or three years.

The launch of #ShowYourSeams during October (to raise awareness of EB in conjunction with EB Awareness Week) resulted in a large increase in social interaction as well as local press coverage – the campaign reached 69,000 people on social media and 26 news articles appeared in local newspapers. The campaign helped contribute to a highly successful year on social media – the DEBRA Facebook page now has 6,252 likes (2014: 5,500) and the DEBRA Twitter feed has 2,779 followers (2014: 2,100). More importantly, each post on Facebook reached an average of 2,323 people helping to increase awareness of EB and DEBRA across the social media site. The six regional Facebook pages continued to grow and provide a good platform for the promotion of local fundraising events.

The DEBRA website (debra.org.uk) continues to go from strength to strength. Having launched late 2014, this year saw further developments to the website to drive donations including appeal modules, the ability to make a donation when buying items from the shop (ie. Christmas cards) and reminder pop-ups if a visitor started the donation process then dropped out. Almost 500 donations were made via the website during 2015 amounting to over £27,500. The average time spent on the website remains high at just over two minutes.

DEBRA's profile was also raised by actor Kelvin Fletcher who appeared on *All Star Mr and Mrs* in October and presenter Nadia Sawalha who appeared on *The Chase Celebrity Special* and won £25k; 2,500 people visited the DEBRA website during Nadia's appearance.

## 2015 In Numbers

- £27,500 donations on the DEBRA website
- 9,031 people engaged on the DEBRA social media pages
- 1,041 mentions of DEBRA and EB in the media

## Aims for 2016

- Continue to raise much needed awareness of DEBRA and EB, making [debra.org.uk](http://debra.org.uk) the go to site for EB information
- Review the DEBRA brand to improve awareness and to help us stand out in the crowded charity market
- Develop DEBRA's digital spaces (website, social media and eMarketing) to reach new audiences and look at ways we can make the most of those spaces through digital marketing techniques
- Work in partnership with other teams to ensure communication is smooth and to develop reciprocal relationships that benefit all parties

## Plans for Future Periods

Online and digital will continue to play a major role in the marketing mix for DEBRA particularly as the overall economic climate suggests marketing within limited budgets is likely to continue, and more and more people are embracing digital platforms and outputs.

Awareness of EB and DEBRA remains a difficulty, particularly for the fundraising team, so a strong brand will remain a priority beyond 2016.

## Royal Patronage

Her Royal Highness The Countess of Wessex, GCVO has continued to show a keen interest in DEBRA's work. Her Royal Highness' written support for DEBRA was utilised in several key DEBRA publications during 2015.

# Fundraising

## 2015 Summary

2015 was a difficult year for fundraising; a combination of factors led to a 'perfect storm' to counter DEBRA's efforts to generate voluntary income. Some of these were within the charity's control, many were not. This led to a poor return despite some event highlights.

Several of the negative factors were one-offs, such as the delays in a hospital clinic project for which trust applications and major donor asks were held back, and a change in the management of the Kiltwalk in Scotland which led to a change in grant issuing criteria. Other areas below budget, corporate partnerships, legacy gifts and some areas of regional fundraising, reflected an ongoing trend.

In addition, wider sector issues affected many charities including damaging press coverage about charity fundraising, an increasingly restrictive data protection act, a decline in average donations, fewer participants in challenge events, increasing donor choice and more strategic charity partner choices by companies.

As it became clear that there was a significant downward trend in 2015 DEBRA undertook a thorough review of all fundraising activities and action was taken to ensure that 2016 puts fundraising back on a growth path. This included a limited restructure resulting in a couple of redundancies.

On the positive side, both the DEBRA Golf Society and DEBRA Fight Night were ahead of target, several new corporate partnerships were secured and a Great Chefs Dinner held in February 2016 had sold out by the end of 2015.

An emerging major donor programme developed during the year with the development of a stewardship programme for the top 80 donor prospects, individual meetings with donors, a new research case for support and the launch of a major donor programme in Scotland with a dinner at Gleneagles.

## 2015 In Numbers

- £335k total fundraising team net income
- £106k raised from legacy donations
- £161k net income raised from regional fundraising
- £90k net income raised from the 11<sup>th</sup> DEBRA Fight Night event
- £106k net income raised from DEBRA Golf Society

- £69k net income raised from major challenge events
- £231k raised from individual donors

## Aims for 2016

- Achieve growth in major giving
- Match up projects to specific donor interests
- Focus trust applications on capital projects and healthcare
- Expand events calendar, including dinners and sporting events
- Engage more supporters through events
- Secure regional corporate partnerships
- Engage new supporters with guidance from a pro-bono partnership with a media agency

## Plans for Future Periods

With a leaner fundraising team in 2016 focused on major donor income, sporting events and project funding, net income is expected to increase towards pre-2015 levels. More tailored communications to existing supporters will ensure that donor interests are met and that the right level of ask is being made. In addition, guidance on how to market the charity will be sought, to attract new supporters to DEBRA. The charity does not engage in any unsolicited fundraising techniques, either directly or through a third party.



# Retail

## 2015 Summary

Overall 2015 was a very challenging year and the aim of expanding the retail chain by acquiring 18 additional shops proved problematic. New shops opened more slowly than expected resulting in slower growth in sales of donated goods. The fall in rag sales due to the volatility of the market, the drop in Gift Aid sales, and higher than budgeted IT costs, set up costs, maintenance and repairs resulted in a decline in net trading income.

Retail Gift Aid year to date sales were 44.6% for traditional and 60.4% for Furniture and Electrical (F&E). Gift Aid peaked at 49% in April following training at the DEBRA Conference but lost some momentum. Following retraining for all staff in the autumn, Gift Aid improved and the year ended at 46%.

Property ended the year with 122 shops – 116 traditional and 6 F&E. During the year 14 traditional shops were opened, three of which were relocations, the Hyde shop closed (which we are aiming to relocate) and three F&E shops opened. The current portfolio is made up of six freeholds, 95 leaseholds and 21 temps.

Volunteers continued to be extremely valuable to the charity, supporting shops throughout the UK. DEBRA shops offer volunteers a fun, positive experience that boosts confidence in the work place and helps to develop new skills whilst providing demonstrable experience and references if needed.

The 'Make a Difference' DEBRA Conference took place in April and included breakout sessions to share best practice, remind staff of DEBRA's purpose, relay key messages and celebrate achievements.

## 2015 In Numbers

- 2.2% growth in like for like sales
- 22,500 Gift Aid donors registered – the proportion of sales that were Gift Aided was 46%, representing £954k reclaimed from HMRC
- 14 shops opened, including 3 relocations
- 1,107 shop volunteers actively supported DEBRA

## Aims for 2016

- Grow like for like sales income by 2.5%

- Open 10 additional traditional shops and four F&E shops. There will be a focus on finding better located, larger square footage premises to enable a higher percentage of furniture sales
- Online auction sales will be expanded via click and collect shops
- Shop teams will be encouraged to achieve a high level of valid Gift Aid declarations

## Plans for Future Periods

The three year plan objective to create new income, by growing the retail chain, is now in progress. The retail chain will be expanded by acquiring 10 additional traditional shops and four F&E shops per annum. The assumption is that if shops are underperforming they will close at the earliest break and that 10% of the temporary shops will be forced to close each year. Where viable, temporary shops threatened with closure will be relocated. Disposal of the freehold properties will be considered by the trustees. Four shops would be sold with vacant possession, two properties sold and leased back and another shop sold tenanted. The increase in cash-backed free reserves as a result of these disposals would be designated by the trustees for charitable expenditure in a new Special Projects Designated Fund.

Engagement and efficiency of existing staff and volunteers will play an important role in 2016:

- Structured training and induction programs will be delivered and communication to all staff and volunteers will be improved by having annual appraisals, quarterly manager 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
- Annual conference to motivate staff, share best practice and deliver key messages will be held – reward, recognition and achievement are an integral part of the annual conference dinner

## Scotland

DEBRA is active in Scotland in several areas. Charitable activities include funding community support and research projects, notably at the Universities of Dundee and Edinburgh.

On the income generation side there were two regional fundraising heads and 31 charity shops. Both of these activities are supported by an active volunteer network. The office for retail administration for the entire charity is also based in Hamilton.

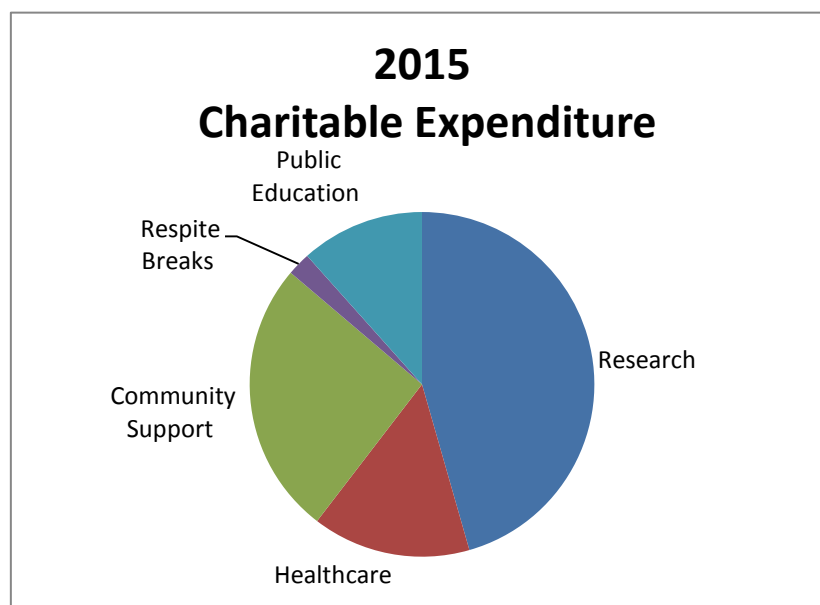
## 3.2 Financial Review

The accounts show the financial affairs of the charity for the year ended 31 December 2015. The charity's net income after taking due account of the costs of raising funds (principally charity shop trading costs) was £2,031k. Expenditure on charitable activities was £2,524k, creating a deficit for the year of (£493k). Net income showed a significant decline compared with the 2014 figure of £2,832k.

Gross income was £12,494k, a growth of 5.2% compared with 2014, resulting from the increase in the number of charity shops from 109 to 122 during the year.

Fundraising experienced a disappointing year in a challenging environment and the costs of running the retail arm of the organisation grew significantly in the setting up of new, smarter shops. All set up costs are expensed as incurred, except for the till. Restricted income declined from £587k to £279k because the majority of donations to the Sohana Research Fund are now going directly to a new charity, and there was no specific capital project for restricted trust or major donor fundraising in 2015.

With strong reserves the charity has been able to continue investment in the Community Support team during 2015, costing £706k (2014: £631k). In addition £375k (2014: £352k) was spent on healthcare and £293k (2014: £293k) was spent on public education. Research expenditure was £1,150k, down from £1,990k spent in 2014 because restricted expenditure from the Sohana Research Fund dropped by £458k and the timing of trustee approval for the major grant round slipped into January 2016.



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

Despite the income generation challenges in 2015, there are plans to grow charitable spend in future periods, demonstrated by the trustees' decision in 2015 to designate £785k to future research projects. This has been done because very significant sums will be needed soon to continue the funding of expensive clinical and other trials. The increased funding secured in 2011 from the NHS for EB nurses has led to savings of £334k during 2015 and the trustees are committed to ploughing these savings back into new health and community support initiatives. A designated fund has been set up for this purpose, in which there was a balance of £391k at the end of 2015. There was expenditure of £317k from this fund during the year.

The deficit in the year led to a decline in net assets from £4,234k to £3,749k. However, the excess of expenditure over income was from restricted funds brought forward, and unrestricted reserves grew from £3,650k to £3,732k during 2015. There was £2,064k in the general fund, £785k in the designated fund for future research, £492k in the designated fund for F&E shops and £391k in the designated fund for nursing and community support new projects.

The table overleaf summarises the highlights of DEBRA's financial performance over the last five years. Net trading income achieved through the shops and fundraising events fell dramatically from £630k to £26k between 2014 and 2015. These figures exclude retail gift aid and donations received in the shops, which totalled £1,001k in 2015. Increased retail costs arose from an active refurbishment programme and significant set up costs. 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. Other significant areas of expenditure growth were in IT support, higher rents from new larger premises and increased stock generation costs. There was also no benefit from negative goodwill amortisation in the year. Fundraising efficiency continues to fall following the change in status of the Sohana Research Fund.



**£'000**

	<b>2015</b>	<b>2014</b>	<b>2013</b>	<b>2012</b>	<b>2011</b>
Total income	12,494	11,872	11,360	11,044	11,979
Non trading income	2,768	2,938	2,968	2,845	3,371
Net trading income	26	630	504	390	1,036
Net trading income including retail gift aid and donations in shops	1,027	1,541	1,325	1,128	1,774
Non trading fundraising costs	763	736	564	576	499
Charitable expenditure	2,524	3,266	2,187	1,960	2,010
Fundraising efficiency: Non trading income less non trading expenditure, divided by non trading income	72.4%	74.9%	81.0%	79.8%	85.2%
Retained surplus/(deficit)	(486)	(425)	720	699	1,898
Retained surplus/(deficit) as a % of income	(3.9%)	(3.6%)	6.3%	6.3%	15.8%
Net current assets	2,758	4,034	3,991	3,167	2,656
Unrestricted reserves	3,732	3,650	3,253	3,132	2,657
Grants payable within 1 year	1,694	1,490	1,202	1,302	1,288

Cost to income ratios for charity shops are high throughout the charity sector which impacts significantly on overall ratios. However, if trading activities are considered net of running costs a more realistic ratio is generated. Using this method, in 2015 for every £ raised 90p (2014: 91p) was spent on charitable activities.

The charity's fixed assets comprise the premises and equipment required to operate trading activities, premises, furniture and equipment required to operate the charity's offices, and four holiday homes held for the use of people with EB and their families. The rest of the charity's assets are held to promote the purposes of the charity through its research programmes and support services.

## Reserves Policy

The trustees' reserves policy in 2015 was to increase minimum cash-backed free reserves from £900k to £1,300k, which the charity adhered to. The charity has a high proportion of retail income, which incurs a high cost base and with the growth in shops this has continued to increase. The minimum reserves figure is calculated as one month's costs (excluding rent) plus 6 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 2015 were £3,749k, including £17k in restricted funds. Cash-backed free reserves before designations were £2,968k, of which £1,668k were

designated for specific purposes. Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold property. This is the value that could be mortgaged at short notice, thus representing reserves which can be accessed immediately.

There was £785k 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 1-5 years.

There was £492k 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 during 2016.

There was £391k in the designated fund for new health and community support projects. This fund was established in 2011 following increased funding for EB nurses by the NHS so that all savings made by DEBRA from these arrangements would be ploughed back 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 £1,488k 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 2015, the trustees 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 which 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
- Under no circumstances will DEBRA reimburse alcohol costs

Any expenses which 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 three designated funds. Where funds are received which 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 to the financial statements, and consolidated statements are included in this report.

DEBRA received a donation from Clinisupplies in the year. Michael Jaega, a trustee, received remuneration from Clinisupplies in his role as Patient Representative. Payment was made to QSUK Ltd, of which Louise Westphalen, director of HR is company secretary, for the provision of Health and Safety and other miscellaneous services. Full details are in Note 21 to the financial statements.

## 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. The potential financial impact of these risks would be mitigated by delaying new research commitment.

Summary extracts of the key risks from the risk register are listed in the table below, demonstrating the management and monitoring of these risks.

Identified Risk Factor	Risk Control	Monitoring
Charity image damaged	Marketing and PR strategy Disciplinary policy Crisis communication plan	Media monitoring Annual staff appraisals Register of crises
Decline in retail activity	Monthly detailed shops reporting Separate retail risk register	Retail Committee meetings
Failure to protect against fraud	Financial regulations Whistleblowing policy Segregation of duties	Finance, Risk and Audit Committee meetings
Loss of key staff and knowledge	Job and knowledge sharing Procedure documentation Succession planning	Annual executive review
Failure to maintain satisfactory links with key partners	Liaison and review meetings	Trustee Board meetings
Funding poor quality research projects	Medical and Scientific Panel review and scoring system	Trustee Board meetings
Relationships with other DEBRAs	Declarations of conflict of interest Collaboration and resource sharing	International Committee meetings Trustee Board meetings
3 <sup>rd</sup> party involvement in DEBRA events	Director of Fundraising reports	Finance, Risk and Audit Committee meetings
Board does not have required skills	Recruitment of trustees with relevant experience Nominations Committee	Trustee Board meetings
Senior management recruitment	Recruitment procedures References taken up Panel interviews	Trustee Board meetings



Unfortunately during 2015 there have been two cases of alleged fraud (which the trustees believe to be connected). Although the amounts concerned are not material to the financial statements, the trustees have taken a firm stance with their policy of zero tolerance in such matters. Lawyers have been engaged and the police are involved.

## 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' Report, incorporating the Strategic Report, is approved by the board of trustees and signed on behalf of the trustees:

**David Spence**

**Chair of Trustees**

**28<sup>th</sup> April 2016**

# 4

## Statement of Trustees Responsibilities

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

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

In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Make judgements and accounting estimates that are reasonably prudent
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

# 5

## Independent Auditors' Report to the Trustees and Members of DEBRA

We have audited the financial statements of DEBRA for the year ended 31 December 2015 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 auditor

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.

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

Our 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.

### 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 charitable company's affairs as at

31 December 2015 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;

- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; 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.

## 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:

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

### **Donald Bawtree, Senior Statutory Auditor**

for and on behalf of BDO LLP, Statutory Auditor

Gatwick, West Sussex

United Kingdom

Date:

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

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 2015

		2015	2015	2015	2015	2014	2014	2014	2014
		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	2,034,143	333,876	242,834	2,610,853	1,209,268	1,081,862	493,709	2,784,839
Charitable activities		14,304	-	-	14,304	13,538	-	-	13,538
Other trading activities	3	8,673,146	1,023,772	36,439	9,733,357	8,165,026	699,198	79,235	8,943,459
Investments	4	67,785	-	-	67,785	50,596	-	14,000	64,596
Other		75,186	-	-	75,186	75,042	-	-	75,042
<b>Total</b>		<b>10,864,564</b>	<b>1,357,648</b>	<b>279,273</b>	<b>12,501,485</b>	<b>9,513,470</b>	<b>1,781,060</b>	<b>586,944</b>	<b>11,881,474</b>
<b>EXPENDITURE ON:</b>									
Raising funds	6	9,308,435	1,154,735	-	10,463,170	8,472,863	548,701	19,012	9,040,576
Charitable activities	6	1,107,010	570,030	847,029	2,524,069	1,057,033	860,300	1,348,987	3,266,320
<b>Total</b>		<b>10,415,445</b>	<b>1,724,765</b>	<b>847,029</b>	<b>12,987,239</b>	<b>9,529,896</b>	<b>1,409,001</b>	<b>1,367,999</b>	<b>12,306,896</b>
<b>Net income/(expenditure)</b>		<b>449,119</b>	<b>( 367,117)</b>	<b>( 567,756)</b>	<b>( 485,754)</b>	<b>( 16,426)</b>	<b>372,059</b>	<b>( 781,055)</b>	<b>( 425,422)</b>
Transfer between funds		2,292	( 2,292)	-	-	110,066	( 68,395)	( 41,671)	-
<b>Net movement in funds</b>		<b>451,411</b>	<b>( 369,409)</b>	<b>( 567,756)</b>	<b>( 485,754)</b>	<b>93,640</b>	<b>303,664</b>	<b>( 822,726)</b>	<b>( 425,422)</b>
<b>Reconciliation of funds:</b>									
Total funds brought forward		1,612,277	2,037,601	584,542	4,234,420	1,518,637	1,733,937	1,407,268	4,659,842
Total funds carried forward		2,063,688	1,668,192	16,786	3,748,666	1,612,277	2,037,601	584,542	4,234,420

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.

# 7

## Balance Sheet

### BALANCE SHEET AS AT 31 DECEMBER 2015

		Company registration number		4118259	
	Notes	£	2015 £	£	2014 £
<b>Fixed assets</b>					
Tangible assets	10		1,488,289		1,507,238
Intangible assets	10		( 230,098)		( 230,098)
Investment in DEBRA Trading Ltd			2		2
			<u>1,258,193</u>		<u>1,277,142</u>
<b>Current assets</b>					
Current asset investment	11	2,000,000		3,250,000	
Stocks		11,007		21,789	
Debtors	12	1,521,443		1,524,105	
Cash at bank and in hand		<u>2,108,395</u>		<u>1,706,018</u>	
		5,640,845		6,501,912	
<b>Creditors: amounts falling due within one year:</b>	13	<u>( 2,883,095)</u>		<u>( 2,468,003)</u>	
<b>Net current assets</b>			<u>2,757,750</u>		<u>4,033,909</u>
<b>Total assets less current liabilities</b>			<u>4,015,943</u>		<u>5,311,051</u>
<b>Creditors: amounts falling due over one year:</b>	13		<u>( 267,277)</u>		<u>( 1,076,631)</u>
<b>Total net assets</b>			<u><u>3,748,666</u></u>		<u><u>4,234,420</u></u>
<b>The funds of the charity</b>					
Restricted income funds	15		16,786		584,542
Unrestricted funds	15		<u>3,731,880</u>		<u>3,649,878</u>
<b>Total charity funds</b>			<u><u>3,748,666</u></u>		<u><u>4,234,420</u></u>

The accounts were approved by the Board on 28th April 2016 and signed on their behalf by:

David Spence  
Chair of Trustee Board

James Irvine  
Treasurer

# 8

## Cash Flow Statement

### CASH FLOW STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2015

	Notes	£	2015 £	£	2014 £
<b>CASHFLOWS FROM OPERATING ACTIVITIES</b>					
Net cash provided by (used in) operating activities	17		( 821,673)		194,684
<b>CASHFLOWS FROM INVESTING ACTIVITIES</b>					
Dividends, interest and rents from investments			67,785		64,596
Purchase of property, plant and equipment			( 93,735)		(184,842)
Net cash provided by (used in) investing activities			(25,950)		(120,246)
<b>CASHFLOWS FROM FINANCING ACTIVITIES</b>					
Repayments of borrowing			-		(24,553)
Net cash provided by (used in) financial activities			-		(24,553)
Change in cash and cash equivalents in the reporting period			( 847,623)		49,885
Cash and cash equivalents at the beginning of the reporting period			4,956,018		4,906,133
Cash and cash equivalents at the end of the reporting period			<u>4,108,395</u>		<u>4,956,018</u>

# 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 *Reconciliation with previous Generally Accepted Accounting Practice*

In preparing the accounts the trustees have considered whether in updating the accounting policies required by FRS102 and the Charities SORP (FRS 102), the restatement of comparative items was required. At the date of transition a restatement was required to reflect the savings from variable rent agreements, which under FRS 102 are required to be amortised over the life of the lease, rather than to the first break point as was previously the case. Governance costs have been reallocated as support costs.

In accordance with FRS102 and the Charities SORP 2015, 2014 financial statements have been restated and are reconciled below.

	2014
	£
Total funds under UK GAAP at 31/12/2014	4,301,780
Restatement of variable rent accrual	(67,362)
Total funds under FRS102 AT 01/01/2015	<u>4,234,418</u>
Reconciliation of 2014 deficit from UK GAAP to FRS102	
2014 deficit under UK GAAP	(358,063)
Restatement of variable rent accrual	(67,362)
2014 deficit under FRS102	<u>(425,425)</u>

#### 1.3 *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 activities and the activities in the shops.

#### 1.4 *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.

#### 1.5 *Incoming 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 which will not take place until a future accounting period, except for sponsorship for charity challenges.

#### 1.6 *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.

#### 1.7 *Recognition of grant liabilities*

Grants are awarded for research projects over a period of one to five years. All grants provide the right to terminate with three months notice and continuation of funding is dependent on satisfactory progress reporting and review. Full grant recognition has been incorporated into these accounts as the most prudent policy.

# **ACCOUNTING POLICIES** **(continued)**

## **1.8 Tangible fixed assets and depreciation**

Tangible fixed assets with a value in excess of £1,000 are capitalised, and are 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

Assets transferred from Dystrophic Epidermolysis Bullosa Research Association (unincorporated) as at 1 January 2002 have continued to be depreciated as in the previous charity.

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 tills, are expensed as incurred.

## **1.9 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.

## **1.10 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.

## **1.11 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.

## **1.12 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.

## **1.13 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 Ltd are shown separately in note 21 to the financial statements.

## **1.14 Foreign currency translation**

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

## **1.15 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.

## **1.16 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 estimated by finance as 5% of the cost of lease to the first break point, spread over the term of the lease to the first break point, and reviewed 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.



## 2 DONATIONS AND LEGACIES

	Unrestricted funds	Restricted funds	Total 2015	Total 2014
	£	£	£	£
Donations & gifts	2,207,661	146,651	2,354,312	2,257,815
Legacies receivable	101,295	5,000	106,295	329,185
Grants receivable	59,063	91,183	150,246	197,839
	<u>2,368,019</u>	<u>242,834</u>	<u>2,610,853</u>	<u>2,784,839</u>
<b>Donations &amp; gifts</b>				
Individual donations	1,604,296	84,176	1,688,472	1,879,007
Corporate donations	481,140	59,833	540,973	238,487
International donations	1,350	-	1,350	867
Events by individuals	120,875	2,642	123,517	139,454
	<u>2,207,661</u>	<u>146,651</u>	<u>2,354,312</u>	<u>2,257,815</u>
<b>Grants receivable</b>				
Charitable trusts	59,063	91,183	150,246	197,839
	<u>59,063</u>	<u>91,183</u>	<u>150,246</u>	<u>197,839</u>

## 3 OTHER TRADING ACTIVITIES

	Total 2015	Total 2014
	£	£
Income	9,733,357	8,943,459
Operating expenses	( 9,699,750)	( 8,304,114)
Net income from fundraising activities	<u>33,607</u>	<u>639,345</u>

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2015 there were 122 shops trading compared with 109 at 31 December 2014. The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2015	Net income 2014
	£	£	£	£
Retail	8,990,038	( 9,221,211)	( 231,173)	448,310
Fundraising events	669,547	( 478,321)	191,226	162,241
Miscellaneous trading	73,772	( 218)	73,554	28,794
	<u>9,733,357</u>	<u>( 9,699,750)</u>	<u>33,607</u>	<u>639,345</u>

The net deficit incurred by retail excludes income of £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 also significant investment in retail during 2015, in new shop openings and shop refurbishments. Other areas of expenditure growth were in IT support, stock generation and higher rents resulting from new larger premises. Set up costs were written off as incurred and not amortised over the life of the lease. In addition there was no amortisation of negative goodwill in the year. There was a temporary growth in miscellaneous trading due to a catch up in retail gift aid commission that related to the previous year.

## 4 INVESTMENTS

	Unrestricted funds	Total 2015	Total 2014
	£	£	£
Interest receivable	43,174	43,174	38,813
Rent of property	24,611	24,611	25,783
Total investment income	<u>67,785</u>	<u>67,785</u>	<u>64,596</u>

Rental income was received from 1 freehold shop and two flats situated above properties, which were acquired in 2009.

## 5 GRANTS PAYABLE

Expenditure on charitable activities include grants payable to third parties as detailed in Note 20. 192 Community Support grants totalling £55,161 were 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 no future commitment is provided for. Research projects have a finite life and at 31 December 2015 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,101,111 (2014: £1,951,468).

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

	<b>Total 2015</b>	Total 2014
	£	£
Within 1 year	<b>833,834</b>	874,837
Within 2-3 years	<b>267,277</b>	1,050,081
Within 4-5 years	-	26,550
	<b><u>1,101,111</u></b>	<b><u>1,951,468</u></b>
Provided within the grants payable creditor	<b>1,101,111</b>	1,951,468
	<b><u>1,101,111</u></b>	<b><u>1,951,468</u></b>

## 6 EXPENDITURE

	Staff costs	Grants payable	Other costs	<b>Total 2015</b>	Total 2014
	£	£	£	£	£
<b>Raising funds</b>					
Voluntary income	473,559	-	289,862	<b>763,421</b>	736,462
Other trading activities	4,856,278	-	4,843,471	<b>9,699,749</b>	8,304,114
	<b><u>5,329,837</u></b>	<b><u>-</u></b>	<b><u>5,133,333</u></b>	<b><u>10,463,170</u></b>	<b><u>9,040,576</u></b>

### Charitable activities:

Research	337,107	781,660	30,831	<b>1,149,598</b>	1,990,188
Healthcare	147,808	204,537	22,775	<b>375,120</b>	352,598
Community support	546,601	55,161	49,182	<b>650,944</b>	580,841
Respite breaks	-	-	55,336	<b>55,336</b>	50,050
Public education	220,412	-	72,659	<b>293,071</b>	292,643
	<b><u>1,251,928</u></b>	<b><u>1,041,358</u></b>	<b><u>230,783</u></b>	<b><u>2,524,069</u></b>	<b><u>3,266,320</u></b>
	<b><u>6,581,765</u></b>	<b><u>1,041,358</u></b>	<b><u>5,364,116</u></b>	<b><u>12,987,239</u></b>	<b><u>12,306,896</u></b>

### Other costs

	Depreciation and amortisation	Overhead allocation	Miscellaneous costs	<b>Total 2015</b>	Total 2014
	£	£	£	£	£
<b>Raising funds</b>					
Voluntary income	-	156,108	133,754	<b>289,862</b>	280,228
Other trading activities	60,839	185,901	4,596,731	<b>4,843,471</b>	3,990,786
	<b><u>60,839</u></b>	<b><u>342,009</u></b>	<b><u>4,730,485</u></b>	<b><u>5,133,333</u></b>	<b><u>4,271,014</u></b>

### Charitable activities:

Research	-	30,831	-	<b>30,831</b>	30,815
Healthcare	-	22,775	-	<b>22,775</b>	18,958
Community Support	-	38,458	10,724	<b>49,182</b>	42,878
Respite breaks	25,186	-	30,150	<b>55,336</b>	50,050
Public education	-	72,659	-	<b>72,659</b>	70,455
	<b><u>25,186</u></b>	<b><u>164,723</u></b>	<b><u>40,874</u></b>	<b><u>230,783</u></b>	<b><u>213,156</u></b>
	<b><u>86,025</u></b>	<b><u>506,732</u></b>	<b><u>4,771,359</u></b>	<b><u>5,364,116</u></b>	<b><u>4,484,170</u></b>

## 6 EXPENDITURE (continued)

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

	2015	2014
	£	£
Hire of plant and machinery - operating leases	30,736	30,736
Hire of other assets - operating leases	-	1,412,469
Auditors remuneration	21,200	16,000
Non-audit services	12,718	4,484
Depreciation of tangible fixed assets	112,684	92,138
Defined contribution pension costs	233,326	201,327
	<u>233,326</u>	<u>201,327</u>

## 7 COST ALLOCATION

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

	2015	2014
	£	£
<b>Staff costs</b>	<b>1,537,195</b>	<b>1,467,369</b>
<b>Overheads</b>		
Office premises rent	50,939	26,967
Service charges, utilities & cleaning	35,830	35,754
Equipment costs	132,574	126,456
Postage, printing, stationery, telephone & fax	91,247	98,535
Insurance costs	50,283	45,625
Legal, professional & consultancy fees	23,718	23,674
Depreciation	26,660	22,024
Irrecoverable VAT	43,482	41,129
Bank charges	11,067	19,369
Sundry expenses	11,714	12,814
Governance costs:		
Audit fees	21,200	16,000
Miscellaneous costs	8,018	11,562
	<u>506,732</u>	<u>479,909</u>
<b>Total Allocation</b>	<b><u>2,043,927</u></b>	<b><u>1,947,278</u></b>

Non-audit payments made to BDO totalled £12,718 in 2015 (2014: £4,484).

## 8 TRUSTEES

None of the trustees received any remuneration from DEBRA during the period, but 10 of them were reimbursed a total of £8,095 (2014: 8,367) for travel and subsistence expenses.

Rhian Edwards received community support grants in 2015 totalling £444 (2014: £0).

Michael Jaega received community support grants in 2015 totalling £1,537 (2014: £1,671).

Christo Kapourani received a community support grant of £25 (2014: £0).

Scott O'Sullivan received community support grants in 2015 totalling £45 (2014: £561).

Amy Price received community support grants in 2015 totalling £43 (2014: £644).

The aggregate figure for trustee donations in 2015 was £1,015 (2014: £1,605).

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 £2,304 (2014: £2,092), as allowed under section 4.3.3 in DEBRA's Articles of Association.

## 9 EMPLOYEES

The average number of employees during the period was:

	2015 full time equiv	2015 Number	2014 Number
Research	1.9	3	3
Healthcare*	1.0	1	1
Community support	9.8	11	9
Fundraising	16.8	19	19
Shops	227.5	277	256
Management & administration	14.3	19	17
	<b>271</b>	<b>330</b>	<b>305</b>

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

	2015 full time equiv	2015 Number	2014 Number
Research	1.7	3	3
Healthcare*	1.0	1	1
Community support	10.7	11	11
Fundraising	15.9	18	19
Shops	234.3	293	275
Management & Administration	14.5	19	16
	<b>278</b>	<b>345</b>	<b>325</b>

\*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.

### EMPLOYMENT COSTS

	Total 2015	Total 2014
	£	£
Wages & salaries	5,396,292	4,833,666
Social security costs	369,083	332,073
Pension costs	233,326	201,327
	<b>5,998,701</b>	<b>5,367,066</b>

The charity does not operate any charity pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £230,565 (2014: £198,511) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £9,588 (2014: £2,226) unpaid. In addition, £0 (2014: £4,601) has been provided to cover new employees because auto-enrolment has commenced.

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:	2015	2014
Between £60,001 - £70,000	1	1
Between £70,001 - £80,000	2	2
Between £160,001 - £170,000	-	1
Between £170,001 - £180,000	1	-

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £49,250 (2014: £43,453) and there are retirement benefits accruing for four (2014: four) employees under a defined contribution scheme.

The aggregate pay of key management personnel, including employer's NI and pension contributions was £693,331 (2014: £717,756). The aggregate employer's pension contribution for key management personnel was £67,608 (2014: £65,577).

Redundancy payments totalled £4,409 in 2015 (2014: £15,093)

# 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 2015	378,312	254,395	190,687	1,329,961	82,500	2,235,855
Additions	63,641	2,292	27,802	-		93,735
Disposals	( 146,501)	-	( 16,980)	-		( 163,481)
<b>At 31 December 2015</b>	<b>295,452</b>	<b>256,687</b>	<b>201,509</b>	<b>1,329,961</b>	<b>82,500</b>	<b>2,166,109</b>
<b>Depreciation</b>						
At 1 January 2015	276,457	74,750	150,151	217,359	9,900	728,617
Charge for the year	37,740	25,186	18,335	29,773	1,650	112,684
Disposals	( 146,501)	-	( 16,980)	-		( 163,481)
<b>At 31 December 2015</b>	<b>167,696</b>	<b>99,936</b>	<b>151,506</b>	<b>247,132</b>	<b>11,550</b>	<b>677,820</b>
<b>Net Book Value</b>						
Brought forward	101,855	179,645	40,536	1,112,602	72,600	1,507,238
At 31 December 2015	<b>127,756</b>	<b>156,751</b>	<b>50,003</b>	<b>1,082,829</b>	<b>70,950</b>	<b>1,488,289</b>

## Intangible fixed assets

	Acquisition goodwill £
<b>Cost</b>	
At 1 January 2015 and 31 December 2015	( 1,318,750)
<b>Amortisation</b>	
At 1 January 2015 and 31 December 2015	1,088,652
<b>Net Book Value</b>	<b>( 230,098)</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 is a reducing balance guarantor liability on these assets restricting their sale. The release of these assets from the restriction is 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

	2015 £	2014 £
Lloyds money market deposits	2,000,000	3,250,000
	<b>2,000,000</b>	<b>3,250,000</b>

# 12 DEBTORS

	2015 £	2014 £
HMRC	122,893	153,959
Misc debtors	61,720	47,776
Other debtors	16,373	23,132
Accrued income	821,647	866,695
Prepayments	498,810	432,543
	<b>1,521,443</b>	<b>1,524,105</b>

VAT repayment of £122,893 is due from HMRC. Accrued income includes gift aid of £576,290 due for 2015.

Total future minimum lease receivable was £10,767 in 2015 (2014:£23,200), in respect of 1 shop and 2 flats above shops.

13	<b>CREDITORS: amounts falling due within one year</b>	<b>2015</b>	<b>2014</b>
		<b>£</b>	<b>£</b>
	Trade creditors	<b>213,687</b>	181,920
	Grants payable	<b>1,693,668</b>	1,490,455
	Other creditors	<b>157,088</b>	127,404
	Taxation and social security	<b>93,319</b>	115,461
	Accruals	<b>713,983</b>	542,355
	Deferred Income	<b>11,350</b>	10,408
		<b><u>2,883,095</u></b>	<b><u>2,468,003</u></b>

There is a dilapidations provision of £147,500 (2014: £120,000) accounted for under other creditors. In the year £32,859 was released from the provision and a further £60,359 was charged.

There was deferred income of £11,350 in the year (2014: £10,408), representing income for events which would have to be repaid in the event of cancellation.

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
<b>CREDITORS: amounts falling due over one year</b>		
Grants payable	<b>267,277</b>	1,076,631
	<b><u>267,277</u></b>	<b><u>1,076,631</u></b>

#### 14 OTHER FINANCIAL COMMITMENTS

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

	<b>2015</b>	<b>2014</b>	<b>2015</b>	<b>2014</b>
	<b>Leases of land and buildings £</b>	<b>Leases of land and buildings £</b>	<b>Other £</b>	<b>Other £</b>
Expiring within 1 year	<b>356,093</b>	198,498	<b>2,175</b>	-
Expiring within 2-5 years	<b>3,008,423</b>	2,579,595	<b>56,880</b>	<b>88,848</b>
Expiring after 5 years	<b>418,015</b>	403,750	-	-
	<b><u>3,782,531</u></b>	<b><u>3,181,843</u></b>	<b><u>59,055</u></b>	<b><u>88,848</u></b>

There are capital commitments of £2,767 at year end, falling due within one year (2014: £11,068).

#### 15 ANALYSIS OF FUNDS

<b>Restricted funds</b>	<b>Balance at 31 Dec 2014 £</b>	<b>Income £</b>	<b>Expenditure £</b>	<b>Balance at 31 Dec 2015 £</b>
Research	571,942	151,790	722,752	<b>980</b>
Healthcare	6,772	44,100	43,900	<b>6,972</b>
Community Support & Respite	5,828	83,383	80,377	<b>8,834</b>
	<b><u>584,542</u></b>	<b><u>279,273</u></b>	<b><u>847,029</u></b>	<b><u>16,786</u></b>

**Restricted funds at 31 December 2015  
comprise:**

	<b>£</b>
Research - Sohana Research Fund	<b>980</b>
Healthcare - Birmingham Children's Hospital Specialist Bath	<b>5,600</b>
Healthcare - other restricted funds	<b>1,372</b>
Community Support - Support Grants in Hampshire	<b>3,165</b>
Community Support - Support Grants in North West	<b>2,617</b>
Community Support - work in Nottinghamshire	<b>1,334</b>
Community Support - other restricted funds	<b>1,718</b>
	<b><u>16,786</u></b>

The Sohana Research Fund was created to raise funds restricted to Recessive Dystrophic EB research and clinical trials. The fund has received total net income of £52,789 in 2015 (2014: £240,616) and £623,751 was transferred to the new Sohana Research Fund charity in 2015, which has aims similar to DEBRA.



**15 ANALYSIS OF FUNDS (continued)**  
**Unrestricted funds**

The trustees have transferred the following amounts into designated funds during 2015:

	Balance at 31 Dec 2014	Movement between funds	Income	Expenditure	Balance at 31 Dec 2015
Future research grants	1,041,250			256,354	<b>784,896</b>
New health and community support projects	373,457	( 2,292)	333,876	313,676	<b>391,365</b>
Furniture and electrical shops	562,894		948,772	1,019,735	<b>491,931</b>
Shop refurbishment fund	60,000		75,000	135,000	<b>-</b>
Total designated funds	2,037,601	( 2,292)	1,357,648	1,724,765	<b>1,668,192</b>
General fund	1,612,277	2,292	10,864,564	10,415,445	<b>2,063,688</b>
Total unrestricted funds	3,649,878	-	12,222,212	12,140,210	<b>3,731,880</b>

The trustees designated £700,000 in 2011 to fund the setup of a number of large Furniture and Electrical Shops. It is anticipated this fund will be spent or undesignated during 2016.

DEBRA has saved £333,876 during 2015 (2014: £333,876) from the increased funding for healthcare of EB patients from the NHS. A designated fund was established in 2011 to demonstrate the trustees' commitment to ploughing back all these savings into new health and community support projects. Ongoing 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 £315,967 in 2015 (2014: £361,691). It is anticipated this fund will be spent during 2016.

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. It is anticipated this fund will be spent in the next 1-5 years.

**16 ANALYSIS OF NET ASSETS BETWEEN CATEGORIES OF FUNDS**

	Unrestricted funds	Restricted funds	Total 2015	Total 2014
	£	£	£	£
Fund balances at 31 December 2015 are represented by:				
Fixed assets	1,258,193	-	<b>1,258,193</b>	1,277,142
Current assets	5,624,059	16,786	<b>5,640,845</b>	6,501,912
Creditors: amounts falling due within one year	(2,883,095)	-	<b>( 2,883,095)</b>	( 2,468,003)
Creditors: amounts falling due over one year	(267,277)	-	<b>( 267,277)</b>	( 1,076,631)
	<b>3,731,880</b>	<b>16,786</b>	<b>3,748,666</b>	<b>4,234,420</b>

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

	2015 £	2014 £
Net income / (expenditure) for the reporting period (as per the statement of financial activities)		
	<b>( 485,754)</b>	( 425,422)
Depreciation charges	<b>112,684</b>	( 76,100)
Dividends, interest and rents from investments	<b>( 67,785)</b>	( 60,191)
Loss / (profit) on disposal of fixed assets	-	-
(Increase) / decrease in stock	<b>10,782</b>	566
(Increase) / decrease in debtors	<b>2,663</b>	( 364,042)
Increase / (decrease) in creditors	<b>( 394,263)</b>	1,119,873
	<b>( 821,673)</b>	<b>194,684</b>

**18 RECONCILIATION OF NET CASH FLOW TO MOVEMENT IN NET FUNDS**

	2015 £	2014 £
(Decrease) in cash	<b>402,377</b>	( 500,115)
Cash outflow from increase in liquid resources	<b>( 1,250,000)</b>	550,000
Net funds brought forward	<b>4,956,018</b>	4,906,133
Net funds carried forward	<b>4,108,395</b>	<b>4,956,018</b>

## 19 ANALYSIS OF CASH AND CASH EQUIVALENTS

	As at 1 Jan 2015	Cash Flows	As at 31 Dec 2015
Cash at bank and in hand	1,706,018	402,377	<b>2,108,395</b>
Short term deposits	3,250,000	( 1,250,000)	<b>2,000,000</b>
Total	<u>4,956,018</u>	<u>( 847,623)</u>	<u><b>4,108,395</b></u>

## 20 GRANTS TO INSTITUTIONS

	Total 2015 £	Total to date £	Total project cost £
<b>Research Projects</b>			
<b>University of Dundee</b>			
1. TGFβ signalling in Recessive Dystrophic EB	33,817	38,648	190,284
2. Skin fragility assessment tool grant	12,740	12,740	38,225
3. Clinical fellow funding	20,565	20,565	82,258
	<u>67,122</u>	<u>71,953</u>	<u>310,767</u>
<b>University of Edinburgh</b>			
1. Defining the role of Kindlin1	<u>62,702</u>	<u>73,116</u>	<u>191,838</u>
<b>Guy's and St Thomas' Hospital, London</b>			
1. Mesenchymal stem-cell therapy clinical trial	40,235	477,872	477,872
2. Validated clinical endpoints study re EB therapy evaluation	35,924	127,055	127,055
3. Mesenchymal stem-cell therapy clinical trial	187,626	227,376	432,496
4. Phase 1 study of the lentiviral-mediated COL7A1	191,477	191,477	499,320
5. Study on bone health in adults with RDEB	12,000	12,000	12,000
	<u>467,262</u>	<u>1,035,780</u>	<u>1,548,743</u>
<b>University College Dublin</b>			
1. Studies about the problem of Puritis in EB patients	<u>31,278</u>	<u>31,278</u>	<u>62,555</u>
<b>University of Salzburg</b>			
1. Combining gene-therapy and stem-cell-therapy for JEB	<u>89,700</u>	<u>197,066</u>	<u>212,004</u>
<b>University of Minnesota</b>			
1. Limbal stem cells for treatment of corneal wounds in EB	<u>87,280</u>	<u>124,508</u>	<u>150,163</u>
<b>Association Developpement des Sciences Medicales, Nice</b>			
1. Validation of drug for EB dermal fibrosis and tumour invasion	<u>74,464</u>	<u>198,559</u>	<u>198,559</u>
<b>The Jackson Laboratory, Maine, USA</b>			
1. Modelling EB genetics in mice	<u>65,532</u>	<u>147,447</u>	<u>196,581</u>
<b>Thomas Jefferson University, Philadelphia, USA</b>			
1. Read-through of nonsense mutations in COL7A1	<u>60,306</u>	<u>75,273</u>	<u>184,882</u>
<b>Other</b>			
- Transfers to Sohana Research Fund charity	778,303		
- Decrease in research provision	(850,357)		
- Grants written back at end of project	( 151,932)		
<b>Total research grants</b>	<u><b>781,660</b></u>	<u><b>1,954,980</b></u>	<u><b>3,056,092</b></u>
<b>Research project expenditure by category:</b>			
- Genetic research	188,540		573,301
- Therapies	593,120		2,482,791
	<u>781,660</u>		<u><b>3,056,092</b></u>

20 GRANTS TO INSTITUTIONS (continued)

	Total 2015	Total project cost
	£	£
<b>Healthcare Team projects</b>		
<b>Great Ormond Street Hospital for Sick Children</b> Clinical nurse specialists in EB	59,407	59,604
<b>Guys &amp; St Thomas' Hospital London</b> Adult EB support nurses	76,295	76,807
<b>Other</b>		
- Miscellaneous healthcare grants	44,280	120,479
- Birmingham Children's Hospital	24,555	26,368
<b>Total Healthcare Team grants</b>	<u>204,537</u>	<u>283,258</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:

	<b>2,015</b>	2014
	£	£
Turnover	<b>32,491</b>	29,201
Net profit gift aided to DEBRA	<b>7,629</b>	9,381
Net assets	<u><b>2</b></u>	<u><b>2</b></u>

During the year, the charity charged management charges totalling £11,618.40 including VAT (2014: £8,400) to its subsidiary DEBRA Trading Limited.

**Other Related Parties**

DEBRA received donations totalling £47,759 (2014: £12,500) from Clini Supplies Ltd. Michael Jaega, a trustee of DEBRA received £250 (2014: £200) in remuneration from Clini Supplies Ltd for his role as a Patient Representative.

Gifts in kind to the value of £8,010 (2014: £0) were received by DEBRA from Powell Gilbert LLP during 2015, of which trustee Timothy Powell is a partner, for the provision of legal services.

Payment of £717 (2014: £180) was made to QSUK Ltd, of which senior staff member Louise Westphalen is company secretary, for the provision of Health and Safety services for the DEBRA Members Day and other miscellaneous services.