

# Trustees' Report & Accounts 2014



# 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

A photograph of a baby with light brown hair and blue eyes, wearing a white cable-knit sweater and maroon pants. The baby is sitting on a dark wooden floor, looking up at the camera with a slight smile. On the baby's forehead, there is a visible, slightly raised, reddish-brown injury. The baby's hands are resting on a colorful, green and yellow plastic toy with various buttons and rings. A semi-transparent text box is overlaid on the lower half of the image.

“DEBRA’s EB Community Support Manager, Miranda, has been my lifeline and was absolutely amazing when I moved into my new home, providing white goods and soft carpet which wouldn’t chafe Freddie’s delicate skin. Her visits are always welcome and we wouldn’t have been able to cope without her and DEBRA.”

**Jenna, Mum to Freddie who is living with EB Simplex generalised severe**



## 2014 Highlights

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

24 EB foot clinics were run helping patients with specialist knowledge to care for blisters on their feet

231 support grants were given to help families pay for urgent and essential goods and services

87 weeks of holidays were taken in a DEBRA holiday home giving families some much needed respite

400,000 people watched the DEBRA BBC Lifeline Appeal improving awareness of EB

Over £120k net income was raised from DEBRA's flagship gala event – Fight Night

Gift aided sales in the DEBRA charity shops achieved 48%

1,250 volunteers gave up their time to support the DEBRA charity shops and help at fundraising events

## DEBRA

### REFERENCE & ADMINISTRATIVE INFORMATION

Trustees	Robin Hood*	Chair until 17 <sup>th</sup> April 2014
	David Spence*	Treasurer until 30 <sup>th</sup> July 2014 Vice Chair & Acting Chair from 30 <sup>th</sup> April 2014, and Chair from 30 <sup>th</sup> April 2015
	Simone Bunting	
	James Hinchcliffe	
	James Irvine*	Treasurer from 30 <sup>th</sup> July 2014
	Michael Jaega*	Vice Chair form April 30 <sup>th</sup> 2015
	Christo Kapourani	
	Amy Livesey	until 16 <sup>th</sup> March 2014
	Irene Leigh	until 5 <sup>th</sup> August 2014
	Graham Marsden	
	Amy Price	
	Melissa Smith	
	Anthony Tomei	until 5 <sup>th</sup> August 2014
	John Tough	
	Jon Field	from 17 <sup>th</sup> May 2014
	Scott O'Sullivan	from 17 <sup>th</sup> May 2014
	Simon Cuzner	from 30 <sup>th</sup> July 2014

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 from 10 <sup>th</sup> November 2014
	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	Tim Marsden Norton Rose LLP, 3 More London Riverside London SE1 2AQ	

# Contents

	Page
<b>1</b> Introduction	7
<b>2</b> Trustees Report	8
<b>3</b> Strategic Report	12
<b>3.1</b> Achievements and performance	12
<b>3.2</b> Financial Review	24
<b>3.3</b> Principal Risks and Uncertainties	28
<b>4</b> Statement of Trustees Responsibilities	30
<b>5</b> Auditors Report	31
<b>6</b> Statement of Financial Activities	34
<b>7</b> Balance Sheet	35
<b>8</b> Cash Flow Statement	36
<b>9</b> Notes to the Accounts	37

# 1

## Introduction from Chair and Chief Executive

DEBRA's quest to understand and find effective treatments for EB has developed greatly during 2014, with updated recommendations on diagnosis being published in a prominent scientific journal and the funding of a number of new research projects. In 2015 we look to further extend this work with a focus on small scale patient trials, translating previous medical advances into practice, as well as supporting specific symptom relief research such as understanding the mechanism and impact of persistent and debilitating 'itch' – a serious and painful issue many people with EB have to face. On the care side we have expanded our community support team to ensure patients receive the help they need, particularly in light of recent government cuts to benefits.

We exist to help the UK EB community and have not forgotten our roots as a self-help group of parents who started to meet 37 years ago over a cup of tea in a kitchen. That initial drive to gain a better understanding of EB has led to us being able to identify the genetic defect in more than eight out of ten patients. This information is key to developing better and more personalised therapies for people living with EB. That said, the shock of having a new born baby who is in unremitting pain and profoundly disfigured still happens, but the excellent EB nurses, part funded by DEBRA, quickly step in to give essential information and hope.

As an organisation we have transformed ourselves from a network of parents to a charity with 150,000 registered gift aiders, 1,250 volunteers, a diversified network of donors, 300 dedicated members of staff and a vibrant board of trustees.

A special thank you goes to the fundraising effort over the last 4 years by Sharmila Nikapota and James Collins on behalf of the Sohana Research Fund, which is a restricted fund within DEBRA for Recessive Dystrophic EB. The fund had grown to such an extent they were big enough to form their own charity during 2014. We wish them every success with their on-going fundraising activities and we look forward to the continuation of the excellent working relationship between the two EB charities for the benefit of the EB community as a whole.

The awareness of just how devastating EB is remains low, but we will not rest until this painful and debilitating condition is beaten.



**David Spence**  
Chair of Trustees



**Ben Merrett**  
Chief Executive Officer

# 2

## Trustees Report

DEBRA is the national charity 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. We estimate 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 is governed by its Articles of Association which were amended in 2014 to simplify and modernise the provisions regarding the composition of the board and their appointment, to suit the demands of the charity whilst retaining not less than 50% with direct experience of EB. The members continue to elect the majority of eight of the trustees and the Nominations & Governance Committee are responsible for proposing a further seven who will then be appointed by the trustees themselves. In 2014 this Committee had originally recommended six candidates who were approved by the board but the Chair resigned, leaving only five who were elected at the AGM. The sixth vacancy was filled at the next trustee board meeting. David Spence became Acting Chair and Michael Jaega was appointed as Acting Vice Chair. David also stepped down from the post of Treasurer and James Irvine was appointed to this role. Irene Leigh and Anthony Tomei both resigned as trustees in August and the board would like to thank them for their valued contribution to DEBRA.

Sadly in September 2014 Amy Livesey, who had been a DEBRA Trustee until March 2014, passed away; she is greatly missed. Amy was always prepared to make the long journey, which was not easy, to attend the board meetings. This was really appreciated by the board because it is very important that DEBRA continues to have a majority representation of trustees who have experience of EB and her contribution was invaluable.

Robin Hood, who resigned as Chair during the year, has continued his devoted and untiring work on behalf of his late daughter, Alex, who died in 2008 after a lifelong battle with EB. During 2015 he is planning to walk the length of Scotland promoting awareness of EB. His achievements over many years for DEBRA are greatly appreciated.

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 Managers attend.

Trustees are supported by committees and advisory groups in the following areas of interest; finance, risk and audit; charitable activities; international; retail 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.

## 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 2014 the DEBRA UK research strategy was reviewed. The conclusion was that the focus will be on patient trials emerging in a range of countries that try to create quality of life improvements, to achieve clinical best practice understanding that improves quality of care and to fund basic research that represents innovation and is unlikely to be funded from other sources.

## Volunteers

A significant amount of DEBRA's work is undertaken by volunteers. In 2014 the charity had an average of 1,181 volunteers (147.4 Full Time Equivalent - FTE) working in the charity's shops which valued at the pay rate of shop assistants would be an equivalent of £1,692k in donated time. The head office had two volunteers (0.08 FTE) which valued at the pay rate of administration staff would be an equivalent of £1.3k in donated time. Additionally, there were 68 fundraising volunteers (10.1 FTE) which valued at the rate of fundraising assistants would be an equivalent of £202k in donated time.

## 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 2014, the second of which included an Awards Dinner to recognise individual and team achievements. Additionally in 2014 a talent management initiative, '*Rising Stars*', was introduced.

## 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

##### 2014 Summary

DEBRA funding during 2014 enabled some of the world's EB experts to identify and take forward laboratory findings which with further scientific investigation, could provide therapy options in the future.

DEBRA supported 16 research projects in 2014, seven of which were newly committed during the year. Some of these projects started up to three years ago and are now proving fruitful in terms of new information and knowledge. The projects span early stage clinical studies in patients, symptom relief research and pre-clinical "discovery" work in the laboratory or in suitable models. DEBRA funds research based on quality and innovation, feasibility and value and, critically, patient benefit.

In 2014, the first result of a powerful new tool that improves our ability to sequence human genes was published in The British Journal of Dermatology. This new technique called 'whole exome sequencing' will improve genetic diagnosis and in the long-term contribute to translational research that is looking for a treatment for EB. Professor John McGrath and his team published this work and commented on the value of the results: "Making quick and accurate diagnoses is very important for people with EB. This information is vital in planning optimal healthcare and future treatments."

##### 2014 In Numbers

- Expenditure on new research grants in 2014 was £1.7m
  - Of this £1.08m was restricted to projects within the Sohana Research Fund
- 16 projects were completed, ongoing, or newly approved during the year
  - 4 projects delivered results and final reports are yielding new scientific information
  - Of the 7 newly approved projects, 3 will take treatments into clinical studies

## Aims for 2015

- Improve DEBRA's understanding of EB to create new concepts for treatment through 'discovery and therapeutic-concept' research
- Develop disease-modifying therapies
- Improve clinical-care through research by expanding the evidence-base
- Develop the future EB research community
- Foster partnerships to develop and deliver treatments



### Case Study

**“This DEBRA funded research has enabled us to identify potential lead compounds for the treatment of EB associated cancer” Dr Andrew South**

People with Recessive Dystrophic Epidermolysis Bullosa (RDEB) often develop a type of skin cancer called squamous cell carcinoma. An important driver, causing cells to multiply, in several types of cancer is a molecule called Polo-Like Kinase 1 (PLK1). Dr Andrew South and his group have shown that inhibiting the action of PLK1 kills the carcinoma cells. Many compounds work in the laboratory but the challenge is to identify effective and safe compounds for patient use. The study identified two potential compounds which may be taken forward into clinical testing in the future.

# Healthcare

## 2014 Summary

During 2014 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, 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 DEBRA partnership had a direct impact of an 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 and patient and carer travel costs.

In total DEBRA funded £345k of healthcare related activities in 2014. This sum was lower than 2013 due to vacancies within the team, including the clinical fellow post, and a late start to new best practice guideline work.

## 2014 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
- 2 days per week of specialist dieticians
- 24 specialist EB foot 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 2015

- Continue to offer funding for a one-year EB Clinical Fellow post
- 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
- Host the EB Clinet 2015 conference in London

## 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

**Josh is eleven years old and has RDEB. The condition not only affects his skin but also his internal linings, including his mouth, throat and oesophagus.**

Josh is scared of eating after a piece of food caught on the lining of his oesophagus causing him to choke; a terrifying experience that Josh has never forgotten and from which he has had to be coaxed back into eating again. Josh's Specialist Paediatric Dietitian at Birmingham Children's Hospital, Rosie Jones, with the help of Liz Lawson, Play Specialist at Warwickshire Community Children's Nursing Team, has encouraged him to re-engage with food again through an enjoyment of cooking, baking and tasting. Josh has since produced 'Josh's Easy Bites' a recipe book of his favourite foods, mainly soft and easy to swallow, which has helped him to enjoy food again.

# Community Support and Membership

## 2014 Summary

DEBRA spent £567k during 2014 providing membership and specialist community support services to people living with EB across the UK. There was an increased demand for services, particularly following 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 a replacement home at Poole with more modern and comfortable facilities was purchased.

## 2014 In Numbers

- 350 individuals accessed support
- 231 support grants were awarded
- At least 3 times a year specific publications and communications were sent to all members, healthcare teams and healthcare companies providing information on DEBRA services, EB research and events
- There were 1,247 individuals in the DEBRA membership scheme, of whom 269 attended the annual Members Day
- 170 EB hospital clinics were attended by a member of the Community Support team to offer support
- 87 weeks of holidays were taken in a DEBRA holiday home by families living with EB, providing them with much needed respite

## Aims for 2015

- Continue to provide a professional community support and membership service
- Have a period of consolidation allowing the newly formed team to focus and execute planned service developments

- Increase the support grant budget allowing for the projected rise in applications for urgent and essential goods and services, and allow funding for attending events and grants from the Wakefield EB Community Enablement Fund
- 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
- Host the DEBRA International 2015 conference in London

## 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

**Leanne is 26 and was diagnosed with RDEB when she was born – there was no skin on her right foot and ankle where a large blister had burst.**

DEBRA has been able to support Leanne in a number of ways: "DEBRA has been amazing over the years. I have been lucky enough to use the DEBRA holiday homes and attend the DEBRA weekend away and meet some inspirational people who also have EB. My DEBRA EB Community Support Manager was a tremendous help when I lost my job, due to the amount of time I need to recover in between operations, and is helping me to return to work which is my ultimate goal! My family has also been fantastic, along with my partner who has always stuck by me through it all, even when it gets tough."

# Public Education

## 2014 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.

In July 2014 DEBRA was given the opportunity to feature on BBC Lifeline Appeal which aired to an audience of 400,000. The outcome of the appeal was £23k in donations, 2,000 hits on our website (four times our usual daily traffic), press coverage in the Daily Mail and three regional newspapers, and 250 new followers / likes on Twitter and Facebook. The impact of the appeal was huge in terms of awareness which has resulted in new supporters being engaged with DEBRA's cause.

During 2014 [debra.org.uk](http://debra.org.uk) was re-developed, and was launched on 17 October. On average, the number of pages being viewed on the new site versus last year was up by 43% and the number of people exiting the site after reaching it was down by 16%. This is fantastic as it means more engaged visitors which in turn will lead to more people supporting the cause or more people using DEBRA's services. New visitor rates remained high at 73.9% (2013: 75%) and the average time spent on the website was just over two minutes (above the national average).

Social media continued to be a great avenue to educate the public on DEBRA and EB. The DEBRA Facebook page now has 5,500 likes (2013: 4,200) and the DEBRA Twitter feed has 2,100 followers (2013:1,300). The six regional Facebook pages continued to flourish.

DEBRA and EB were referenced 601 times in the press (national, regional, consumer and online) during 2014 reaching over 53 million people. This coverage would have cost the charity £1.4 million to buy at commercial rates.

## 2014 In Numbers

- 400,000 people watched the DEBRA BBC Lifeline Appeal
- 7,600 people engaged on the DEBRA social media pages
- 601 mentions of DEBRA and EB in the media

## Aims for 2015

- 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
- Better communicate outputs and outcomes of DEBRA's work – in particular the pioneering research DEBRA has funded

- Coordinate communications across DEBRA to ensure messaging is consistent and the DEBRA brand is maintained
- Develop DEBRA's digital spaces (website and social media) to reach new audiences

## Plans for Future Periods

Online and digital will continue to play a major role in the marketing mix for DEBRA. Beyond 2015 these avenues will need to be further researched and developed to keep up with the fast and changing pace of the digital landscape.

Within DEBRA, communication needs to become much more integrated and streamlined to maintain a tight brand. Steps will need to be taken in 2015 to assist with this.

## Royal Patronage

Her Royal Highness The Countess of Wessex, GCVO has continued to show a keen interest in DEBRA's work. In February 2014, Her Royal Highness attended an EB clinic at Guys and St Thomas' Hospital where she met adults living with EB and the EB healthcare team working at the hospital. Her Royal Highness also attended two fundraising events in 2014 – a reception held at Buckingham Palace for major donors and DEBRA's flagship gala event, Fight Night.

# Fundraising

## 2014 Summary

2014 was a consolidation year for the fundraising team, with new specialist positions in donor marketing, major donor fundraising, challenge events and corporate fundraising. Regional fundraising was also revised geographically in order to focus on more dense population areas and locations of EB families.

Total net incoming resources attributable to the fundraising team grew by 15% to £806k in 2014. This was in part due to two significant legacy donations of £92k and £74k respectively. The new fundraising posts have developed structures and leads in order to build a more sustainable income mix.

Highlights were the tenth anniversary Fight Night event, the Hourglass Appeal (designed to raise money from major donors for research) which raised £86k, and the DEBRA Golf Society which generated over £100k in net income.

Corporate income was disappointing overall though medium-level partnerships were account managed successfully with several extending their support into 2015 and beyond. Sponsorship was achieved for the DEBRA Golf Society leading to record entries and excellent results. Applications for large Charity of the Year partnerships were made but were unsuccessful due to a range of factors including total income levels and public awareness of DEBRA and EB.

Regional fundraising was mixed with the Midlands and Scotland exceeding target whilst other areas were below budget. This was due to a mixture of staff changes, cancellation of donor events and competition with other charities. Scotland income benefitted from the start of a three-year partnership with the regional Kiltwalk events.

## 2014 In Numbers

- £806k total fundraising team net income
- £329k raised from legacy donations
- £295k net income raised from regional fundraising
- £120k net income raised from 10<sup>th</sup> anniversary Fight Night event
- £103k net income raised from DEBRA Golf Society
- £100k net income raised from major challenge events
- £63k raised from Kiltwalk Challenges in Scotland

## Aims for 2015

- Achieve growth in areas of major giving, corporate income and individual donations
- Recruit at least one new significant corporate partnership
- Secure major individual gifts for ongoing research projects
- Expand DEBRA Golf Society geographically
- Restore regional fundraising income levels to pre-2014 levels
- Utilise new website and online media to generate donations and fundraising support

## Plans for Future Periods

With a full team in place at the end of 2014 there is potential to stabilise and grow income steadily over the coming years, with the additional possibility of a step-change in corporate partnerships, large individual gifts and legacies.

Greater clarity on research and non-research funding needs will help appeals and generate stronger cases for support to larger funders. Partnerships with research institutions, fellow medical research charities and NHS facilities will be vital in communicating clear need to supporters.

# Retail

## 2014 Summary

Overall 2014 was a very successful year placing retail growth back on a firm footing. A 10% price increase was implemented in April which enabled sustainability in underlying sales.

Gift Aid outperformed against expectations, hovering around 48% for most of the year, enabling stable guaranteed income.

During the year nine shops closed, seven of which were on a temporary license, and 13 shops opened, ending the year with 109 shops. Four new shops were also acquired to be opened in 2015. Alongside this, to strengthen the current income stream, a rolling programme of shop refurbishments continued and refits were carried out to incorporate new signage and key messaging, improve sales, and create a better customer experience and working environment for staff and volunteers.

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

The 'We can do it!' 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.

Despite the drop in rag price on clothing and books, due to volatility of the market, retail income continued to grow and now represents 75% of the charity's total gross income.

## 2014 In Numbers

- 6.2% growth in like for like sales
- 25,000 Gift Aid donors registered and the proportion of sales that were gift aided was 48% (£857k)
- £9,215k total income including Gift Aid and a net contribution of £1,578k
- 13 shops opened, 13 refits carried out and nine shops closed
- 1,181 shop volunteers actively supported DEBRA

## Aims for 2015

- Grow like for like sales income by 3%

- Open 18 new traditional shops and six Furniture and Electrical (F&E) shops
- Expand online auction sales via eBay and Amazon
- Implement cost management solutions to reduce costs

## Plans for Future Periods

A plan is in place to expand the retail chain and raise more net income by acquiring 18 additional traditional charity shops and six F&E shops each year. A planned restructure of the areas will enable faster development in Scotland, the Midlands and the South areas and additional resource has been invested in the property team to support the acquisition growth.

Strengthening the current income stream by growing like for like sales, through optimum pricing, shop refits, stock acquisition, training and merchandising, will remain a priority. Similarly, Gift Aid sales will grow through training and campaigns.

Online sales will expand through click and collect at selected stores and there will be a focus on boosting the engagement and efficiency of existing volunteers, through the delivery of structured training and inductions.

## 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.

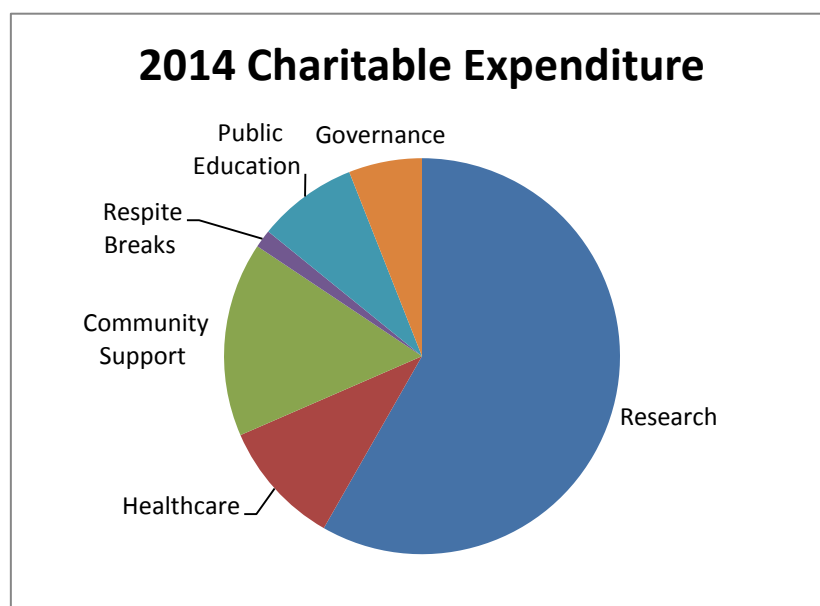
On the income generation side there were two regional fundraising heads and 29 charity shops. Both of these activities are supported by an active volunteer network. The office for retail administration for the entire charity is based in Hamilton.

## 3.2 Financial Review

The accounts show the financial affairs of the charity for the year ended 31 December 2014. The charity's net incoming resources after taking due account of the costs of generating funds (principally charity shop trading costs) was £3,022k. Expenditure on charitable activities was £3,380k, creating a deficit for the year of (£358k).

Gross incoming resources were £11,881k, a growth of 4.6% compared with 2013. Unrestricted net incoming resources grew by 19% from £2,063k to £2,454k as a result of a strong performance in legacy income and growth in retail income, both in sales of donated goods and the Retail Gift Aid Scheme. Restricted net incoming resources declined from £845k to £568k primarily because the majority of donations to the Sohana Research Fund are now going directly to a new charity.

As stated in the 2013 Trustees' Report and Accounts, there were plans to significantly increase expenditure on charitable activities in future periods. This commenced in 2014 with charitable expenditure growing by 55% from £2,187k to £3,380k. £1,969k was spent on research, £537k on community support and £345k on healthcare. The remaining £529k was spent on public education, governance and respite breaks.



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

There are plans to maintain this increased level of charitable spend in future periods, demonstrated by the trustees' decision in 2014 to designate £1,041k to future research projects. This has been done because very significant sums will be needed soon to continue the funding of what will be expensive clinical and other trials. In addition, there was a balance of £572k restricted income in the Sohana Research Fund for Recessive Dystrophic EB research and clinical trials. The increased funding

secured in 2011 from the NHS for EB nurses has led to savings of £334k during 2014 and the trustees are committed to ploughing back all these savings into new health and community support initiatives. A designated fund has been set up for this purpose, in which there was a balance of £373k at the end of 2014. There was expenditure of £362k from this fund during the year, £68k of which was capital expenditure towards two new holiday homes.

The deficit in the year led to a decline in net assets from £4,660k to £4,302k. However, the excess of expenditure over income was from restricted funds brought forward, and unrestricted reserves grew from £3,253k to £3,717k during 2014. There was £1,680k in the general fund, £1,041k in the designated fund for future research, £563k in the designated fund for F&E shops, £373k in the designated fund for nursing and community support new projects, £60k in the designated fund for shop refurbishments and £585k in restricted funds.

The table below summarises the highlights of DEBRA's financial performance over the last five years. Net trading income achieved through the shops and fundraising events grew from £504k to £782k between 2013 and 2014. 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. Fundraising efficiency has fallen slightly following the change in status of the Sohana Research Fund.

	<b>£k</b>				
	<b>2014</b>	<b>2013</b>	<b>2012</b>	<b>2011</b>	<b>2010</b>
Total incoming resources	11,881	11,360	11,044	11,979	10,435
Non trading income	2,938	2,968	2,845	3,371	2,506
Net trading income	782	504	390	1,036	760
Non trading fundraising costs	698	564	576	499	527
Charitable expenditure	3,380	2,187	1,960	2,010	1,994
Fundraising efficiency: Non trading income less non trading expenditure, divided by non trading income	76.2%	81.0%	79.8%	85.2%	79.0%
Retained surplus/(deficit)	(£358)	720	699	1,898	746
Retained surplus/(deficit) as a % of income	(3.0%)	6.3%	6.3%	15.8%	7.2%
Net current assets	4,101	3,991	3,167	2,656	850
Unrestricted reserves	3,717	3,253	3,132	2,657	1,300
Grants payable within 1 year	1,490	1,202	1,302	1,288	948

Cost to income ratios for charity shops are high throughout the sector which impacts significantly on overall ratios.

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 mobile 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 2014 has been to maintain cash-backed free undesignated reserves at £900k. 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 2014 were £4,302k and cash-backed free reserves were £2,938k, of which £2,038k 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. 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 Constitution 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 2014, 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

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 four 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 14 of the financial statements.

## Asset Cover for Funds

Note 15 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. In accordance with SORP 2005 paragraph 383 c, the accounts of DEBRA Trading Limited have not been incorporated into these accounts on the grounds that the results are not material. For information, the company's results are shown separately in Note 20 to the financial statements.

Payment was made by DEBRA in the year to Katherine Marsden, daughter of trustee Graham Marsden.

DEBRA received a donation from Clini Supplies in the year. Michael Jaega, a trustee, received remuneration from Clini Supplies in his role as Patient Representative. Full details are in Note 20 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, 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 potential 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.

<b>Risk Factor</b>	<b>Risk Control</b>	<b>Monitoring</b>
Charity image damaged	Marketing and PR strategy Disciplinary policy	On-going media monitoring Annual staff appraisals
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	Trustee Board meetings
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
3 <sup>rd</sup> party involvement in DEBRA events	Director of Fundraising reports	Senior Management Team 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

## Auditors

All of the current trustees have taken all the 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:

A handwritten signature in black ink, appearing to read 'David Spence', written over a horizontal line.

**David Spence**

**Chair of Trustees**

**30<sup>th</sup> April 2015**

# 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 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 2014 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 2014 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: 5 May 2015

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 2014

	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total 2014 £	Total 2013 £
<b>INCOMING RESOURCES</b>						
<b>Incoming resources from generated funds</b>						
Voluntary income	2	1,209,268	1,081,862	493,709	<b>2,784,839</b>	2,813,031
Activities for generating funds	3	8,165,025	699,198	79,235	<b>8,943,458</b>	8,391,294
Investment income	4	50,596	-	14,000	<b>64,596</b>	73,365
<b>Incoming resources from charitable activities</b>						
Respite breaks		13,538	-	-	<b>13,538</b>	9,931
<b>Other incoming resources</b>		<b>75,042</b>	<b>-</b>	<b>-</b>	<b>75,042</b>	71,992
<b>Total incoming resources</b>		<b>9,513,469</b>	<b>1,781,060</b>	<b>586,944</b>	<b>11,881,473</b>	11,359,613
<b>RESOURCES EXPENDED</b>						
<b>Costs of generating funds</b>						
Costs of generating voluntary income	6	678,951	-	19,012	<b>697,963</b>	564,310
Fundraising trading: cost of goods sold and other costs	6	7,612,388	548,701	-	<b>8,161,089</b>	7,887,780
<b>Total costs of generating funds</b>		<b>8,291,339</b>	<b>548,701</b>	<b>19,012</b>	<b>8,859,052</b>	8,452,090
<b>Net incoming resources</b>		<b>1,222,130</b>	<b>1,232,359</b>	<b>567,932</b>	<b>3,022,421</b>	2,907,523
<b>Charitable activities</b>						
Research	6	141,353	567,004	1,261,072	<b>1,969,429</b>	855,380
Healthcare	6	140,504	173,007	31,803	<b>345,314</b>	371,478
Community support	6	360,784	120,289	56,112	<b>537,185</b>	510,022
Respite breaks	6	50,050	-	-	<b>50,050</b>	43,511
Public education	6	276,006	-	-	<b>276,006</b>	237,665
<b>Governance costs</b>	6	<b>202,500</b>	<b>-</b>	<b>-</b>	<b>202,500</b>	169,236
<b>Total charitable expenditure</b>		<b>1,171,197</b>	<b>860,300</b>	<b>1,348,987</b>	<b>3,380,484</b>	2,187,292
<b>Total resources expended</b>	6	<b>9,462,536</b>	<b>1,409,001</b>	<b>1,367,999</b>	<b>12,239,536</b>	10,639,382
<b>Net income/(expenditure) for the year</b>		<b>50,933</b>	<b>372,059</b>	<b>( 781,055)</b>	<b>( 358,063)</b>	720,231
<b>Total funds brought forward</b>		<b>1,518,636</b>	<b>1,733,937</b>	<b>1,407,268</b>	<b>4,659,841</b>	3,939,610
Transfer between funds		110,066	( 68,395)	( 41,671)	-	-
<b>Total funds carried forward</b>		<b>1,679,635</b>	<b>2,037,601</b>	<b>584,542</b>	<b>4,301,778</b>	4,659,841

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 2014

		Company registration number		4118259	
				Restated 2013	
	Notes	£	2014 £	£	£
<b>Fixed assets</b>					
Tangible assets	10		1,507,238		1,414,534
Intangible assets	10		( 230,098)		( 398,336)
			<u>1,277,140</u>		<u>1,016,198</u>
<b>Current assets</b>					
Current asset investment	11		3,250,000		2,700,000
Stocks			21,790		22,355
Debtors	12		1,524,105		1,160,063
Cash at bank and in hand			<u>1,706,018</u>		<u>2,206,133</u>
			6,501,913		6,088,551
<b>Creditors: amounts falling due within one year:</b>	13		<u>( 2,400,644)</u>		<u>( 2,097,787)</u>
<b>Net current assets</b>			4,101,269		3,990,764
<b>Total assets less current liabilities</b>			<u>5,378,409</u>		<u>5,006,962</u>
<b>Creditors: amounts falling due over one year:</b>	13		( 1,076,631)		( 347,121)
<b>Net assets</b>			<u>4,301,778</u>		<u>4,659,841</u>
<b>Funds</b>					
Unrestricted funds					
- Designated	15		2,037,601		1,733,937
- General			<u>1,679,635</u>		<u>1,518,636</u>
			3,717,236		3,252,573
Restricted funds	15		584,542		1,407,268
			<u>4,301,778</u>		<u>4,659,841</u>

The accounts were approved by the Board on 30th April 2015 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 2014

	Notes	£	2014 £	Restated 2013 £
<b>Net cash inflow from operating activities</b>	17		<b>194,684</b>	344,300
<b>Returns on investments and servicing of finance</b>				
Sale of current asset investment		-	-	43,584
Interest and rent received		64,596	64,596	73,365
Interest element of finance lease rental payments		(4,405)	(4,405)	(7,550)
<b>Net cash inflow from returns on investments and servicing of interest</b>			<b>60,191</b>	109,399
<b>Capital expenditure</b>				
Payments to acquire tangible fixed assets and investments		(184,842)	(184,842)	(104,445)
<b>Net cash outflow from capital expenditure</b>			<b>(184,842)</b>	(104,445)
<b>Management of Liquid Resources</b>				
(Increase) / decrease in short term deposits			(550,000)	(2,700,000)
<b>Financing</b>				
Capital element of finance lease rental payments			(20,148)	(34,540)
<b>(Decrease) in cash</b>	18		<b>(500,115)</b>	<b>(2,385,286)</b>

# 9

## Notes to the Accounts

### 1 ACCOUNTING POLICIES

#### 1.1 *Basis of preparation*

The accounts are prepared under the historical cost convention, and are in accordance with the Charities Act 2011, the Companies Act 2006, the Statement of Recommended Practice "Accounting and Reporting by Charities" (March 2005), the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and Trustees Investment (Scotland) Act 2005. Prior year grant liabilities have been restated to reflect a more appropriate classification of costs.

#### 1.2 *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 not recognised until there is certainty of timing and amount. 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.

#### 1.3 *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. Costs of generating 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, together with an allocation of staff costs and general overheads attributable to the support of governance activities. 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.

#### 1.4 *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.

#### 1.5 *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
Mobile equipment	Over 3 years
Motor vehicles	Over 4 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%.

#### 1.6 *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 will run for six years.

#### 1.7 *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, liquid resources are defined as current asset investments and short term deposits which are readily convertible into known amounts of cash.

#### 1.8 *Stock*

Stock is valued at the lower of cost and net realisable value.

#### 1.9 *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 14 to the financial statements.

## 1 ACCOUNTING POLICIES (continued)

### 1.10 Consolidated accounts

In accordance with SORP 2005 paragraph 384 (c), the accounts of DEBRA Trading Ltd and DEBRA Retail Ltd 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 activities for generating funds. DEBRA Retail Ltd 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 19 to the financial statements.

### 1.11 Foreign currency translation

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

### 1.12 Leases

Operating lease annual rental payments are charged to the SOFA on a straight line basis over the term of the lease. Assets financed by finance leases have been capitalised at present values and are depreciated in line with the depreciation policy. The interest element of the lease payments is charged to the SOFA over the period of the lease.

2 VOLUNTARY INCOME	Unrestricted funds	Restricted funds	Total 2014	Total 2013
	£	£	£	£
Donations & gifts	1,901,290	356,525	2,257,815	2,533,363
Legacies receivable	329,185	-	329,185	164,783
Grants receivable	60,655	137,184	197,839	114,885
	<u>2,291,130</u>	<u>493,709</u>	<u>2,784,839</u>	<u>2,813,031</u>
<b>Donations &amp; gifts</b>				
Individual donations	1,625,343	253,664	1,879,007	1,828,855
Corporate donations	158,385	80,102	238,487	548,301
International donations	817	50	867	1,126
Events by individuals	116,745	22,709	139,454	155,081
	<u>1,901,290</u>	<u>356,525</u>	<u>2,257,815</u>	<u>2,533,363</u>
<b>Grants receivable</b>				
Charitable trusts	60,655	137,184	197,839	107,785
Scottish Executive	-	-	-	7,100
	<u>60,655</u>	<u>137,184</u>	<u>197,839</u>	<u>114,885</u>

3 ACTIVITIES FOR GENERATING FUNDS	Total 2014	Total 2013
	£	£
Income	8,943,458	8,391,294
Operating expenses	( 8,161,086)	( 7,887,780)
Net income from fundraising activities	<u>782,372</u>	<u>503,514</u>

The greatest income from activities for generating funds is derived from the operation of charity shops selling donated goods. As at 31 December 2014 there were 109 shops trading compared with 105 at 31 December 2013. The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2014	Net income 2013
	£	£	£	£
Retail	8,211,070	( 7,622,737)	588,333	211,860
Fundraising events	703,716	( 538,469)	165,247	249,546
Miscellaneous trading	28,672	120	28,792	42,108
	<u>8,943,458</u>	<u>( 8,161,086)</u>	<u>782,372</u>	<u>503,514</u>

Retail showed a notable improvement in 2014 over the previous year due to pricing initiatives and shop refurbishments.

<b>4 INVESTMENT INCOME</b>	Unrestricted funds	Restricted funds	<b>Total 2014</b>	Total 2013
	£	£	£	£
Interest receivable	24,813	14,000	38,813	58,429
Rent of property	25,783	-	25,783	14,936
Total investment income	<u>50,596</u>	<u>14,000</u>	<u>64,596</u>	<u>73,365</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 6. 249 Community Support grants totalling £65,002 were made through the Community Support programme. All other grants were payable to institutions as detailed in Note 18.

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 2014 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,951,468 (£887,679 at 31 December 2013).

The total commitment is currently budgeted to be spent as follows:	<b>Total 2014</b>	Total 2013
	£	£
Within 1 year	<b>874,837</b>	540,558
Within 2-3 years	<b>1,050,081</b>	347,121
Within 4-5 years	<b>26,550</b>	-
	<u><b>1,951,468</b></u>	<u>887,679</u>
Provided within the grants payable creditor	<b>1,951,468</b>	887,679
	<u><b>1,951,468</b></u>	<u>887,679</u>

As disclosed in the accounting policies, there is no contingent liability as full grant recognition is incorporated into these accounts.

<b>6 RESOURCES EXPENDED</b>	Staff costs	Grants payable	Other costs	<b>Total 2014</b>	Total 2013
	£	£	£	£	£
<b>Costs of generating funds</b>					
Voluntary income	429,885	-	268,078	<b>697,963</b>	564,310
Activities for generating funds	4,259,007	-	3,902,082	<b>8,161,089</b>	7,887,780
	<u>4,688,892</u>	<u>-</u>	<u>4,170,160</u>	<u><b>8,859,052</b></u>	<u>8,452,090</u>
<b>Charitable expenditure:</b>					
Research	244,145	1,700,017	25,267	<b>1,969,429</b>	855,380
Healthcare	134,901	193,574	16,839	<b>345,314</b>	371,478
Community support	440,418	65,002	31,765	<b>537,185</b>	510,022
Respite breaks	-	-	50,050	<b>50,050</b>	43,511
Public education	210,970	-	65,036	<b>276,006</b>	237,665
	<u>1,030,434</u>	<u>1,958,593</u>	<u>188,957</u>	<u><b>3,177,984</b></u>	<u>2,018,056</u>
<b>Governance costs</b>	133,717	-	68,783	<b>202,500</b>	169,236
	<u>5,853,043</u>	<u>1,958,593</u>	<u>4,427,900</u>	<u><b>12,239,536</b></u>	<u>10,639,382</u>

## 6 RESOURCES EXPENDED (continued)

	Depreciation and amortisation £	Overhead allocation £	Miscellaneous costs £	Total 2014 £	Total 2013 £
<b>Other costs</b>					
<b>Costs of generating funds</b>					
Voluntary income	-	132,521	135,557	<b>268,078</b>	194,458
Activities for generating funds	( 119,742)	143,743	3,878,081	<b>3,902,082</b>	3,637,702
	( 119,742)	276,264	4,013,638	<b>4,170,160</b>	3,832,160
<b>Charitable expenditure</b>					
Research	-	25,267	-	<b>25,267</b>	48,090
Healthcare	-	16,839	-	<b>16,839</b>	16,430
Community Support	-	27,720	4,045	<b>31,765</b>	38,555
Respite breaks	21,618	-	28,432	<b>50,050</b>	43,511
Public education	-	65,036	-	<b>65,036</b>	58,638
	21,618	134,862	32,477	<b>188,957</b>	205,224
<b>Governance costs</b>					
Auditors remuneration	-	-	16,000	<b>16,000</b>	16,000
Non-audit services	-	-	470	<b>470</b>	3,891
Other costs	-	41,221	11,092	<b>52,313</b>	43,109
	-	41,221	27,562	<b>68,783</b>	63,000
	( 98,124)	452,347	4,073,677	<b>4,427,900</b>	4,100,384

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

	2014 £	2013 £
Hire of plant and machinery - operating leases	<b>30,736</b>	38,307
Hire of other assets - operating leases	<b>1,345,107</b>	1,271,409
Auditors remuneration	<b>16,000</b>	16,000
Non-audit services	<b>470</b>	3,891
Depreciation of tangible fixed assets	<b>92,138</b>	118,048
Defined contribution pension costs	<b>201,327</b>	157,057

## 7 COST ALLOCATION

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

	2014 £	2013 £
<b>Staff costs</b>	<b>1,467,369</b>	1,376,254
<b>Overheads</b>		
Office premises rent	<b>26,967</b>	33,540
Service charges, utilities & cleaning	<b>35,754</b>	28,887
Equipment costs	<b>126,456</b>	128,649
Postage, printing, stationery, telephone & fax	<b>98,535</b>	97,014
Insurance costs	<b>45,625</b>	45,641
Legal, professional & consultancy fees	<b>23,674</b>	13,331
Depreciation	<b>22,024</b>	23,523
Irrecoverable VAT	<b>41,129</b>	30,500
Bank charges	<b>19,369</b>	8,392
Sundry expenses	<b>12,814</b>	41,291
	<b>452,347</b>	450,768
<b>Total Allocation</b>	<b>1,919,716</b>	1,827,022

## 8 TRUSTEES

None of the trustees received any remuneration from DEBRA during the period, but 7 of them were reimbursed a total of £8,367 for travel and subsistence expenses.

Scott O'Sullivan received community support grants in 2014 totalling £561.

Amy Price received a community support grant in 2014 of £644.

Michael Jaega received community support grants in 2014 totalling £1,671.

Insurance has been purchased to protect DEBRA from losses arising from wrongful acts committed by trustees or employees at a cost of £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:

	2014 full time equiv	2014 Number	2013 Number
Research	2.3	3	3
Healthcare*	1.0	1	1
Community support	8.1	9	9
Fundraising	16.3	19	18
Shops	204.7	256	247
Management & administration	13.6	17	17
	246	305	295

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

	2014 full time equiv	2014 Number	2013 Number
Research	2.0	3	3
Healthcare*	1.0	1	1
Community support	9.9	11	7
Fundraising	17.3	19	17
Shops	219.1	275	244
Management & Administration	13.4	16	16
	263	325	288

\*These numbers exclude healthcare staff funded through grants to external organisations and detailed in Note 18.

Staff employed by external institutions and funded through research grants are also excluded.

### EMPLOYMENT COSTS

	Total 2014 £	Total 2013 £
Wages & salaries	4,833,666	4,784,248
Social security costs	332,073	327,759
Pension costs	201,327	157,057
	5,367,066	5,269,064

The charity does not operate any charity pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £198,511 (2013: £192,595) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £2,226 (2013: £2,556) unpaid. In addition, £4,601 (2013: £1,456) has been provided to cover new employees who will have the opportunity to join the scheme after three months employment, backdated to the date of commencement of employment.

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:

	2014	2013
Between £60,001 - £70,000	1	2
Between £70,001 - £80,000	2	1
Between £150,001 - £160,000	-	1
Between £160,001 - £170,000	1	-

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £43,453 (2013: £40,438) and there are retirement benefits accruing for four (2013: three) employees under a defined contribution scheme.

## 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 2014	339,594	131,000	176,696	1,329,961	82,500	2,059,751
Additions	38,718	123,395	22,729	-	-	184,842
Disposals	-	-	( 8,738)	-	-	( 8,738)
<b>At 31 December 2014</b>	<b>378,312</b>	<b>254,395</b>	<b>190,687</b>	<b>1,329,961</b>	<b>82,500</b>	<b>2,235,855</b>
<b>Depreciation</b>						
At 1 January 2014	251,058	53,133	145,190	187,586	8,250	645,217
Charge for the year	25,399	21,617	13,699	29,773	1,650	92,138
Disposals	-	-	( 8,738)	-	-	( 8,738)
<b>At 31 December 2014</b>	<b>276,457</b>	<b>74,750</b>	<b>150,151</b>	<b>217,359</b>	<b>9,900</b>	<b>728,617</b>
<b>Net Book Value</b>						
Brought forward	88,536	77,867	31,506	1,142,375	74,250	1,414,534
At 31 December 2014	<b>101,855</b>	<b>179,645</b>	<b>40,536</b>	<b>1,112,602</b>	<b>72,600</b>	<b>1,507,238</b>

### Intangible fixed assets

	Acquisition goodwill £
<b>Cost</b>	
At 1 January 2014 and 31 December 2014	( 1,318,750)
<b>Amortisation</b>	
At 1 January 2014 and 31 December 2014	920,414
Charge for the year	168,238
<b>At 31 December 2014</b>	<b>1,088,652</b>
<b>Net Book Value</b>	
Brought forward	( 398,336)
At 31 December 2014	<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

	2014	2013
Lloyds money market deposits	3,250,000	2,700,000
	<b>3,250,000</b>	<b>2,700,000</b>

## 12 DEBTORS

	2014	2013
	£	£
HMRC	153,959	126,389
Misc debtors	47,776	55,308
Other debtors	23,132	25,995
Accrued income	866,695	562,232
Prepayments	432,543	390,139
	<b>1,524,105</b>	<b>1,160,063</b>

VAT repayment of £153,959 is due from HMRC. Accrued income includes gift aid of £825,901 due for 2014.

13	CREDITORS: amounts falling due within one year	2014	Restated 2013
		£	£
	Trade creditors	181,920	165,392
	Grants payable	1,490,455	1,202,386
	Other creditors	127,404	274,161
	Taxation and social security	115,461	91,972
	Accruals	474,996	358,876
	Deferred Income	10,408	5,000
		<b>2,400,644</b>	<b>2,097,787</b>

There is a dilapidations provision of £120,000 (2013: £250,000) accounted for under other creditors. In the year £201,335 was released from the provision and a further £71,335 was charged.

There was deferred income of £10,408 in the year (2013: £5,000), representing income for events which would have to be repaid in the event of cancellation.

14	CREDITORS: amounts falling due over one year	2014	Restated 2013
		£	£
	Grants payable	1,076,631	347,121
		<b>1,076,631</b>	<b>347,121</b>

#### 14 OTHER FINANCIAL COMMITMENTS

The following payments are committed to be paid during the next year in respect of operating leases:

	2014	2013	2014	2013
	Leases of land and buildings £	Leases of land and buildings £	Other £	Other £
Expiring within 1 year	255,995	130,680	-	-
Expiring within 2-5 years	1,014,647	894,194	30,430	30,736
Expiring after 5 years	67,500	91,500	-	-
	<b>1,338,142</b>	<b>1,116,374</b>	<b>30,430</b>	<b>30,736</b>

There are capital commitments of £11,068 at year end, falling due within one year (2013: £92,747).

#### 15 ANALYSIS OF FUNDS

	Balance at 31 Dec 2013	Movement between funds	Incoming resources	Resources expended	Balance at 31 Dec 2014
Restricted funds	£	£	£	£	£
Research	1,399,975	13,329	419,710	1,261,072	571,942
Healthcare	3,303	-	35,272	31,803	6,772
Community Support & Respite	3,990	( 55,000)	112,950	56,112	5,828
Fundraising	-	-	19,012	19,012	-
	<b>1,407,268</b>	<b>( 41,671)</b>	<b>586,944</b>	<b>1,367,999</b>	<b>584,542</b>

##### Restricted funds at 31 December 2014 comprise:

	£
Research - Sohana Research Fund	571,942
Healthcare - Birmingham Children's Hospital Specialist Bath	5,600
Healthcare - Dressings	1,172
Community Support - Support Grants in Hampshire	2,589
Community Support - work in Nottinghamshire	1,334
Community Support - other restricted funds	1,905
	<b>584,542</b>

The Sohana Research Fund has been created to raise funds for Recessive Dystrophic EB research and clinical trials, initially restricted to the area surrounding stem cell therapy. The fund has received total net income of £240,616 in 2014 (2013: £743,799) of which £1,081,979 was committed in 2014 to developing individualised therapies for children with EB, focusing on Recessive Dystrophic EB. The balance held in the fund will be used to finance new Recessive Dystrophic EB research projects and clinical trials.

Restricted income includes a £30,000 grant from The Clothworkers Foundation and a £20,000 grant from the Garfield Weston Foundation towards the purchase of a new holiday home in North Wales, for use by families with EB.

## 15 ANALYSIS OF FUNDS (continued)

### Unrestricted funds

The trustees have transferred the following amounts into designated funds during 2014:

	Balance at 31 Dec 2013	Movement between funds	Incoming resources	Resources expended	Balance at 31 Dec 2014
Future research grants	860,268	-	747,986	567,004	<b>1,041,250</b>
New health and community support projects	401,272	( 68,395)	333,876	293,296	<b>373,457</b>
Furniture and Electrical shops	472,397	-	639,198	548,701	<b>562,894</b>
Shop Refurbishment Fund	-	-	60,000	-	<b>60,000</b>
Total designated funds	1,733,937	( 68,395)	1,781,060	1,409,001	<b>2,037,601</b>
General fund	1,518,636	110,066	9,513,469	9,462,536	<b>1,679,635</b>
Total unrestricted funds	<u>3,252,573</u>	<u>41,671</u>	<u>11,294,529</u>	<u>10,871,537</u>	<b><u>3,717,236</u></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 2015 and 2016.

DEBRA has saved £333,876 during 2014 (2012: £305,676) 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 £361,691 in 2014 (2013: £236,660). It is anticipated this fund will be spent in the period 2015-2016.

The funds held in excess of the stated cash backed 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 FUNDS

	Unrestricted funds £	Restricted funds £	Total 2014 £	Total 2013 £
Fund balances at 31 December 2014 are represented by:				
Fixed assets	1,277,140	-	<b>1,277,140</b>	1,016,198
Current assets	5,917,371	584,542	<b>6,501,913</b>	6,088,551
Creditors: amounts falling due within one year	( 2,400,644)	-	<b>( 2,400,644)</b>	( 2,444,908)
Creditors: amounts falling due over one year	( 1,076,631)	-	<b>( 1,076,631)</b>	-
	<u>3,717,236</u>	<u>584,542</u>	<b><u>4,301,778</u></b>	<u>4,659,841</u>

## 17 NET CASH INFLOW FROM OPERATING ACTIVITIES

	2014 £	2013 £
Reconciliation of changes in resources:		
Changes in resources	<b>( 358,063)</b>	720,231
(Profit)/loss on disposal of fixed assets	-	1,421
Amortisation and depreciation of fixed assets	<b>( 76,100)</b>	( 120,740)
Decrease / (increase) in stock	<b>565</b>	( 2,473)
Decrease / (increase) in debtors	<b>( 364,042)</b>	( 184,580)
(Decrease) / increase in creditors	<b>1,052,515</b>	( 3,744)
Investment income receivable	<b>( 64,596)</b>	( 73,365)
Interest element of finance lease rental payments	<b>4,405</b>	7,550
	<b><u>194,684</u></b>	<u>344,300</u>

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

	2014 £	Restated 2013 £
(Decrease) in cash	<b>( 500,115)</b>	( 2,385,286)
Cash outflow from increase in liquid resources	<b>550,000</b>	2,700,000
Net funds b/f	<b><u>4,906,133</u></b>	<u>4,591,419</u>
Net funds c/f	<b><u>4,956,018</u></b>	<u>4,906,133</u>

## 19 ANALYSIS OF NET FUNDS

	As at 1 Jan 2014	Cash Flows	As at 31 Dec 2014
Cash at bank and in hand	2,206,133	( 500,115)	<b>1,706,018</b>
Short term deposits	2,700,000	550,000	<b>3,250,000</b>
Total	<u>4,906,133</u>	<u>49,885</u>	<u><b>4,956,018</b></u>

## 20 GRANTS TO INSTITUTIONS

	Total 2014	Total to date	Total project cost
<b>Research Projects</b>			
<b>University of Dundee</b>			
1. Pre-clinical trials re application of siRNA therapy in EB Simple:	5,355	192,804	192,804
2. TGFβ signalling in Recessive Dystrophic EB	4,831	4,831	190,284
	<u>10,186</u>	<u>197,635</u>	<u>383,088</u>
<b>University of Edinburgh</b>			
1. Defining the role of Kindlin1	<u>10,414</u>	<u>10,414</u>	<u>191,838</u>
<b>Blizard Institute of Cell and Molecular Science, London</b>			
1. Dissecting the role of basement membrane components	<u>14,727</u>	<u>173,877</u>	<u>173,877</u>
<b>Guy's Hospital, London</b>			
1. Determining the molecular basis of EB	5,503	87,792	87,792
2. Mesenchymal stem-cell therapy clinical trial	204,780	437,637	477,872
3. Validated clinical endpoints study re EB therapy evaluation	52,314	91,131	104,249
4. Mesenchymal stem-cell therapy clinical trial	39,750	39,750	432,496
5. Phase 1 study of the lentiviral-mediated COL7A1			499,320
	<u>302,347</u>	<u>656,310</u>	<u>1,601,729</u>
<b>University College Dublin</b>			
1. Studies about the problem of Puritis in EB patients			<u>62,555</u>
<b>University of Salzburg</b>			
1. Combining gene-therapy and stem-cell-therapy for JEB	<u>80,186</u>	<u>107,366</u>	<u>212,004</u>
<b>University of Minnesota</b>			
1. Developing individualised therapies for children with EB	12,885	154,625	154,625
2. Limbal stem cells for treatment of corneal wounds in EB	37,228	37,228	150,163
	<u>50,113</u>	<u>191,853</u>	<u>304,788</u>
<b>Association Developpement des Sciences Medicales, Nice</b>			
1. Validation of drug for EB dermal fibrosis and tumour invasion	<u>99,276</u>	<u>124,095</u>	<u>198,559</u>
<b>The Jackson Laboratory, Maine, USA</b>			
1. Modelling EB genetics in mice	<u>65,532</u>	<u>81,915</u>	<u>196,581</u>
<b>Thomas Jefferson University, Philadelphia, USA</b>			
1. Read-through of nonsense mutations in COL7A1	<u>14,967</u>	<u>14,967</u>	<u>184,882</u>
<b>Other</b>			
-Increase in research provision	1,063,790		
-Grants written back at end of project	( 11,521)		
<b>Total research grants</b>	<u><b>1,700,017</b></u>	<u><b>1,558,432</b></u>	<u><b>3,509,901</b></u>
<b>Research project expenditure by category:</b>			
- Genetic research		96,416	661,093
- Cancer research		19,558	364,161
- Therapies		1,584,043	2,484,647
		<u>1,700,017</u>	<u><b>3,509,901</b></u>

## 20 GRANTS TO INSTITUTIONS (continued)

	<b>Total 2014</b>	<b>Total</b>
	<b>£</b>	<b>project cost</b>
		<b>£</b>
<b>Healthcare Team projects</b>		
<b>Great Ormond Street Hospital for Sick Children</b>		
Clinical nurse specialists in EB	39,649	40,302
<b>Guys &amp; St Thomas' Hospital London</b>		
Adult EB support nurses	86,507	87,844
<b>Other</b>		
- Miscellaneous healthcare grants	43,726	121,138
- Birmingham Children's Hospital	23,691	24,567
<b>Total Healthcare Team grants</b>	<b>193,574</b>	<b>273,851</b>

## 21 DEBRA Trading Ltd

The principal activity of DEBRA Trading Ltd, 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>Total 2014</b>	2013
	<b>£</b>	<b>£</b>
Turnover	<b>29,201</b>	32,639
Net profit transferred to DEBRA	<b>9,381</b>	11,314
Net assets	<b>2</b>	-

During the year, the charity charged management charges totalling £8,400 including VAT (2013: £4,800) to its subsidiary DEBRA Trading Limited.

### Other Related Parties

Payment of £553.86 was made by DEBRA to Katherine Marsden, daughter of trustee Graham Marsden, for 2 weeks employment during which time she undertook a specific project.

DEBRA received a donation of £12,500 from Clini Supplies Ltd. Michael Jaega, a trustee of DEBRA received £200 in remuneration from Clini Supplies Ltd for his role as a Patient Representative.