



DEBRA

TRUSTEES' REPORT & ACCOUNTS

**FOR THE YEAR ENDED
31 DECEMBER 2012**

A charity registered in England and Wales (1084958) and Scotland (SC039654)
Company Registration No 4118259 (England and Wales)

DEBRA**REFERENCE & ADMINISTRATIVE INFORMATION**

Trustees	Roger Wakefield*	Chair
	Robin Hood*	Vice-Chair since 2 September 2012, Acting Chair from 21 Nov 2012 due to Chair's ill health
	David Spence*	Treasurer
	Scott O'Sullivan	Secretary
	David Bendor-Samuel *	
	Simone Bunting	
	Robin Eady	until 19 May 2012
	Philip Evans	until 19 May 2012
	James Hinchcliffe	
	James Irvine*	from 19 May 2012
	Amy Livesey	
	Irene Leigh	from 19 May 2012
	Graham Marsden	from 19 May 2012
	Amy Price	
	Melissa Smith	
	Anthony Tomei	co-opted from 23 October 2012
	John Tough	
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
	John Dart	Director of Research & International, Company Secretary and Seconded Chief Operating Officer of DEBRA International
	Carol Harris	Director of Finance
	Claire Mather	Director of Nursing & Social Care
	Maureen Nickson	Director of Retail
	Louise Tait	Director of Fundraising & Communication
	Louise Westphalen	Director of HR
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	
Medical & Scientific Adviser	Professor John McGrath	

DEBRA

CONTENTS

	Page
Trustees' Report	1-25
Statement of Trustees' responsibilities	26
Auditor's Report	27-28
Statement of Financial Activities	29
Balance Sheet	30
Cash Flow Statement	31
Notes to the Accounts	32-40

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

INTRODUCTION

DEBRA is the national charity that supports individuals and families affected by Epidermolysis Bullosa (EB) – a rare genetic condition which causes the skin to blister and shear at the slightest friction, or even spontaneously. There are at least 5,000 people living with this devastating condition in the UK and 500,000 worldwide.

EB has a number of distinct forms: in the least severe form, blistering is confined to the hands and feet. In more severe cases, the whole body is affected and wounds heal very slowly, giving rise to scarring, physical deformity and significant disability. Blistering can also affect inner body linings, such as the mouth and throat and, in its most advanced form, EB is fatal in infancy.

DEBRA was founded in 1978 as an unincorporated charity, subsequently incorporated, and provides funding for an expert team of nurses and social care staff to work directly with families affected by EB. 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, improving lives and giving hope. DEBRA does however take full advantage of generic government incentives which have become very important and all the indicators are that these will stay in place for the foreseeable future. It is expected that promising therapeutic approaches, currently at late preclinical or early clinical trial stages, will require very significant investment by the charity within 18-24 months to take them further towards use in the clinic. Consequently, a substantial designated research fund has been established to start to provide the extensive capital required to address this anticipated need.

STRUCTURE, GOVERNANCE AND MANAGEMENT

The trustees incorporated DEBRA, a charitable company limited by guarantee, on 1 December 2000, and on 1 January 2002 it assumed responsibility for the activities of the unincorporated Dystrophic Epidermolysis Bullosa Research Association. The incorporated charity is governed by its Memorandum and Articles of Association.

Trustees are elected by members at each AGM to serve for a period of three years. During 2012 the Articles of Association were amended, following advice from specialist charity solicitors, to create a Nominations Committee to provide a more sophisticated means of ensuring that trustees have the balance of skills and experience needed by a growing charity whilst retaining the requirement that at least 51% of the Trustee Board has personal experience of living with EB. Responsibility for the appointment of the Officers was transferred to the Board, rather than by direct election at the AGM as was previously the case. Nine of the fourteen current Board members either have EB themselves or are the parent of a child with EB. New trustees receive individual induction from senior staff and advisers, and trustee training is regularly discussed at trustee meetings.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

Trustees received relevant publications, such as "Governance" magazine, and briefings by external advisers.

Trustees are supported by a number of committees and advisory groups to provide expertise in specific areas of the charity's work. The committees, chaired by a trustee, advise the Trustee Board on their respective areas of interest which, in 2012, were finance, risk and audit; charitable activities, international; retail and nominations. In addition, the international Medical and Scientific Advisory Panel gives expert advice on research priorities and quality and a Translational Research Advisory Panel provides advice on developmental issues in bringing therapy from the laboratory and into the clinic.

DEBRA is very fortunate to have the support of organisations such as Bank of America Merrill Lynch, Henderson Global Investors, Charles Stanley and Publicis who offer facilities for committee meetings free of charge.

DEBRA's President, Michael Portillo, continued to give considerable support and guidance to the charity throughout the year. DEBRA's Patron, the Countess of Wessex, graciously attended several events on behalf of the charity which made a considerable contribution to their success and DEBRA's public profile.

Professional staff are employed, under the direction of the Chief Executive, to carry out the activities determined by the trustees and to support the many volunteers who undertake work on behalf of the charity. DEBRA is an active member, and funder, of DEBRA International and is represented on that organisation's Executive Committee by a trustee. In addition, the Director of Research & International is seconded for 60% of his time to serve as the Chief Operating Officer of DEBRA International. He also serves on the Board of Directors of EURORDIS and, in 2012, was appointed as that organisation's Deputy General Secretary.

DEBRA is registered with the Office of the Scottish Charity Regulator, as required due to DEBRA's Scottish activities. The income and public profile derived from the Scottish shops, fundraising, healthcare and social care teams continue to form an important part of DEBRA's national strategy.

PUBLIC BENEFIT

DEBRA exists to meet the public benefit of the advancement of health, specifically to take action to advance the health of people with EB and related diseases. Our main activities are described below. All activities are undertaken to further our charitable purposes for the public benefit, and we have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing our aims and objectives, and in planning our future activities. The trustees are confident that DEBRA meets the public benefit test.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

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 which will one day find a cure.

DEBRA is the representative voice of people whose lives are affected by EB. It is an association of people with EB, their carers, families, friends and supporters (both lay and professional), dedicated to eradicating the condition and helping people with the condition to exercise their rights to full citizenship. 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.

In fulfilling these objectives, DEBRA encourages the contribution that people with EB and their families make to the charity and to the life of the community in general.

DEBRA has continued its core work of funding research and providing services and support to people whose lives are affected by EB in the UK and abroad. In pursuance of these objectives in 2012, DEBRA maintained and increased its existing medical research programme and continued to consolidate its health and social care provision with an increased collaboration with statutory services. During the year, successful negotiations took place with the National Health Service to achieve greater consistency in contractual and financial arrangements relating to the specialist EB nursing teams.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

Grant Making Policy

DEBRA is a member of the Association of Medical Research Charities (AMRC), abides by its recommendations on best practice in the award of medical research grants, and holds the AMRC certificate for best practice in Medical and Health Research Peer Review. When renewed in 2011, the AMRC review panel commented that 'DEBRA is working to a good standard. The panel felt this demonstrated that good quality peer review could be carried out in organisations regardless of size or rarity of condition.'

All DEBRA research grant applications are independently peer reviewed by at least two, and usually three, external reviewers and by DEBRA International's independent Medical and Scientific Advisory Panel. This Panel, whose members are all eminent scientists and clinicians in relevant fields, has members from six different countries. The Medical and Scientific Advisory Panel is tasked to review all research grant applications received by member groups of DEBRA International, so that available funding can be properly targeted and unknowing duplication avoided. This International peer review process is managed by the DEBRA International Research Manager and the Chief Operating Officer who are funded, either in part or in whole, by DEBRA. Any grant recommendations made by the panel for funding by DEBRA UK are reviewed by the senior executives for commercial assessment.

Volunteers

A significant amount of the charity's work is undertaken by members and supporters. In 2012, the charity had an average of 1,222 volunteers (176 Full Time Equivalent - FTE) working in the charity's shops, which valued at the pay rate of shop assistants would be an equivalent of £1,921k in donated time. The head office had a total of 3 volunteers (0.25 FTE) which valued at the pay rate of administration staff would be an equivalent of £4.7k in donated time. Additionally, there are 1,293 fundraising volunteers (8.5 FTE), which valued at the rate of fundraising assistants, would be an equivalent of £171k in donated time.

Employees

Annual appraisals and reviews (quarterly and probationary) are carried out to ensure that all employees have the opportunity to review their performance and agree objectives for the forthcoming period.

During an appraisal, line managers share information about the charity's performance, and discuss the financial and economic factors affecting DEBRA. The discussions provide an opportunity to re-iterate the charity's purpose, vision and values that are introduced to employees during the recruitment, selection and induction processes.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

Appraisals importantly promote two-way communication, giving employees the chance to air concerns and explore solutions, suggest ideas, and request training.

To improve communication and consultation at all levels across the organisation, a staff consultation group, 'Voice', was introduced in 2012.

Additionally, each month an internal newsletter is distributed from Fundraising, Retail or HR in turn, to inform all staff about the charity's performance and share news.

The charity's performance is dependent on the skills of the workforce, and there is an ongoing programme of learning and development to ensure that employees are continually progressing. In addition to the training programme which provides essential training to staff, specific training initiatives have been introduced to enhance the skills of managers (Leadership Days), and share knowledge (Spotlight Sessions).

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, and aims to increase the involvement of people with EB in particular 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.

ACHIEVEMENTS AND PERFORMANCE

DEBRA is registered as a national and international charity with the Charity Commission and as a charity registered in Scotland by the Office of the Scottish Charity Regulator and exists to provide services and support to people living with EB and to facilitate the development of lasting and effective treatments for the condition through research.

The primary focus is on the estimated minimum of 5,000 people with EB in the UK. The EB population is heterogeneous with varying needs depending on the type of EB, age and family circumstances. DEBRA aims to address the needs of all people with EB, without favouring any one type of the condition. The condition affects all ethnic groups and DEBRA aims to provide equal access to services without impediment.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

Research

DEBRA has a long history of working internationally in EB research and aims to fund the best research worldwide, not just in the UK. As stated earlier in this report, DEBRA works closely with other DEBRAs worldwide who wish to fund research to agree priorities, coordinate grant making and to promote collaboration between researchers. This is achieved by a centralised peer-review system, managed from the UK, which is used by the DEBRAs able to make a significant contribution to research funding. In addition, the scientific management of DEBRA-funded research is undertaken from the UK by the DEBRA International Research Manager, whose post is principally funded by DEBRA UK.

During 2012, one 'normal' research grant round was held, managed from the UK and funded by DEBRA UK. DEBRA UK funded two new research projects and one extension of a pre-existing project, with a total commitment of £368k, the details of which can be found in the audited accounts. Two of these projects are being undertaken in the UK, whilst the other originates from the USA. In addition, DEBRA Austria funded five new projects, following a special call for collaborative research projects, at a cost of £1,605k; the scientific management for all of these will be provided from the UK.

In addition to the above rounds, DEBRA was able to allocate an additional £155k from the Sohana Research Fund to finance an innovative research project to be undertaken by the team responsible for the bone marrow transplant trials in Minnesota. This Fund consists of money raised through the efforts of a member family specifically for Recessive Dystrophic EB research and clinical trials; who restricted the use of part of the Fund's resources for this project. Additional funds raised for the Sohana Research Fund are being held by DEBRA in a restricted fund for allocation in 2013. Full details are in note 14 to the accounts on page 38.

As indicated in the 2011 report, the need to focus on translating the results of research in the laboratory into treatments available in the clinic increases in importance year on year as more interventions move into early stage clinical trials, e.g. in 2012 EBSTEM and the continuing fibroblast trial. Advice from the Translational Research Advisory Panel and contacts with industry indicates clearly that the involvement of external public and private partners will be essential in bringing therapies to market. DEBRA's research strategy, shared with DEBRA International, was revised at the end of 2011 to provide a stronger focus on translational research. During 2012 a number of activities were undertaken to help the charity become 'partnership ready' by developing the data that external funders, regulators and reimbursement agencies (the NHS in the case of the UK) will need in order to take promising therapies through the development process. Funding was provided for a project (included in the report above) to understand better the natural history of different types of EB and meetings were organised and funded to support the development of suitable measures of severity and quality of life. The impact of this work will be to enable clinical trials to be more robust and, therefore, more likely to be accepted by regulators and potential partners.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

DEBRA staff, particularly the International Research Manager, played a leading role in the scientific organisation of EB2012, the triennial planning conference attended by virtually all of the key players in EB therapy development, held in Spain in November 2012. This meeting identified the opportunities and challenges that we face in taking current therapy initiatives forward into the clinic and the outcomes will be published in a respected international journal in 2013. The high costs of taking therapies through the science and regulatory processes were underlined again, and industry representatives highlighted that, in general, pharmaceutical and biotechnology companies will want potential therapies for EB to be much further along the development pathway in terms of clinical trials than DEBRA has been accustomed to funding before they are prepared to invest significantly in bringing to market. This further justifies DEBRA's decision to create a substantial designated research fund to help to bridge the funding gap before external funding can take over.

Healthcare

One of DEBRA's core objectives is to assist with the provision of specialist, dedicated healthcare services for people living with any type of EB across the UK. This work is carried out in partnership with local statutory providers, all of whom are responsive to the needs of the EB community. This is particularly necessary since EB is a rare condition about which few health professionals will have any knowledge or expertise. DEBRA and the specialist nursing teams work closely with the designated four EB centres of excellence (Great Ormond Street Hospital for Children, St Thomas' Hospital, Birmingham Children's Hospital and Heartlands and Solihull Hospital) and NHS colleagues to provide the high level of expertise needed to care adequately for people living with EB both directly and via shared care with local health professionals.

Due to the rarity of EB and the specialist care required, national funding towards the clinical service is provided by NSCT (National Specialised Commissioning Team) and is enhanced by DEBRA funding. In 2012 DEBRA funded £463k of healthcare activities which included enhancing the nursing service provision, 24 specialist EB foot clinics, and funding for supervision, enhanced specialist study and research projects.

Following on from the work carried out in 2011, DEBRA continued to secure extra funding for the National EB Nursing service. Working on behalf of the EB community as the National EB Patient Support Group, DEBRA worked hard in partnership with the NHS National Commissioners, Clinical EB teams and hospitals to assist in developing 'The National EB Nursing Service Principles'. In 2012 the EB community continued to have a set of principles that clearly outline the care that someone living with EB can expect from both the NHS and DEBRA, and the enhanced funding and partnership working will develop this further.

In general 75% of each specialist EB nurse carries out what is deemed to be 'core' NHS activity and as a result the NHS now provides full funding for all core work. DEBRA will continue to enhance the NHS service by continuing to fund work such as additional bereavement visits,

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

research, and charitable activities including nursing care for patient weekends away. This continues to be a long term arrangement and a significant achievement making a positive difference all round. It continues to allow DEBRA to make even greater enhancements to the charitable health, social care and membership activities provision to meet the expanding and developing needs of the EB community and highly specialist teams. As agreed with the Trustee Board, during 2012 £243k was transferred (from the savings for DEBRA following the increased NHS funding for the EB service) to the Nursing and Social Care Designated Fund. £79k from the fund has been spent during the year to provide additional services / benefits including: additional nursing hours, an increase in support grant provision, a national EB Simplex conference, support for the Birmingham Children's Hospital nursing team, an increase in Social Care Managers, service engagement initiatives with the EB community and improved communication activities.

The on-going closer partnership working with the NHS continues to support and bring EB to the attention of healthcare providers, and recognise the need for NHS funding provision for all core activities and care that the NHS has a duty of care to provide. DEBRA greatly values the collaboration between the NHS centres, National Commissioners and the charity and continues to promote a unified service. As part of this effort, DEBRA maintained its support for the clinical network group comprising the four hospitals, national clinical teams and DEBRA, and actively engaged in activities across the four centres. Work continues with the Scottish NHS and commissioners to help ensure the best possible EB nursing service is provided in Scotland. From December 2012 the Scottish NHS/commissioners funded and undertook the management of the full adult EB nursing service supporting the fully enhanced nursing model, releasing additional funding back to DEBRA to be reinvested in health, social and membership activities. This Scottish transfer to the NHS was later than anticipated and to date does not include the transfer of the paediatric post as planned.

Significant efforts continue to be made by the EB nursing teams, in conjunction with colleagues, in clinical research, particularly in the fields of wound care and treatment trials. Links continue to be forged with academic centres and industry in pursuit of this. In addition, the EB nurses and other members of the multidisciplinary clinical teams remained in high demand to speak at external conferences and events, both in the UK and abroad.

Social Care and Membership

DEBRA's objective is to provide specialist social care services for people with EB across the UK, which are responsive to the wishes of the EB community. During 2012 there was been a clear increase in the work for the team following the announcement of the welfare reform by the government. Many of the individuals and families supported by DEBRA were heavily affected by the reforms and the social care team predicts the increase in demand for their support service will continue into 2013. To reflect this increase, during the course of the year, the social care team was

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

enhanced by the appointment of two regional social care managers covering the UK, and an increase in the area social care manager's hours for the South and Scotland. In total 50% additional hours have been committed to the service.

The Social Care Team has three main priorities:

- to provide a casework service to families and individuals to help with particular issues, such as welfare rights, education, housing, employment, etc
- to make contact whenever possible with people with EB who are not currently using services
- to identify, in conjunction with people with EB, the need for new services or means of support.

The development and implementation of the DEBRA Social Care Team database during 2012 enables all records to be held electronically and centrally, but also will enable activity reporting that can be used to assess and develop future social care service provision.

A successful annual conference was held in May 2012 and a number of smaller meetings, or opportunities for people with EB to meet, as well as a weekend away for adults, were organised and funded. All main EB hospital clinics were also attended by a member of the social care team.

Respite Breaks

One of DEBRA's objectives is to enable individuals and families living with EB to have breaks away from home in accommodation that has been specially chosen to meet their needs. The three holiday homes in England and Scotland were maintained and offered a very popular service to people with EB during 2012, with bookings to near full capacity during peak times already in place for 2013. One of the older holiday homes, in Weymouth, was replaced due to an exceptionally good offer but the replacement of the Scottish holiday home was postponed to 2013 whilst a new site/ accommodation is being sourced.

Public Education

Because Epidermolysis Bullosa is rare, raising public awareness of the condition is vital to DEBRA's work as awareness of EB attracts more support and funding for the services and research we provide.

In 2012, DEBRA launched its first ever digital awareness campaign, "Peel Here". This interactive campaign was devised and delivered, on a pro bono basis, by top advertising and PR company Publicis and was launched to mark International EB Awareness Week in late October.

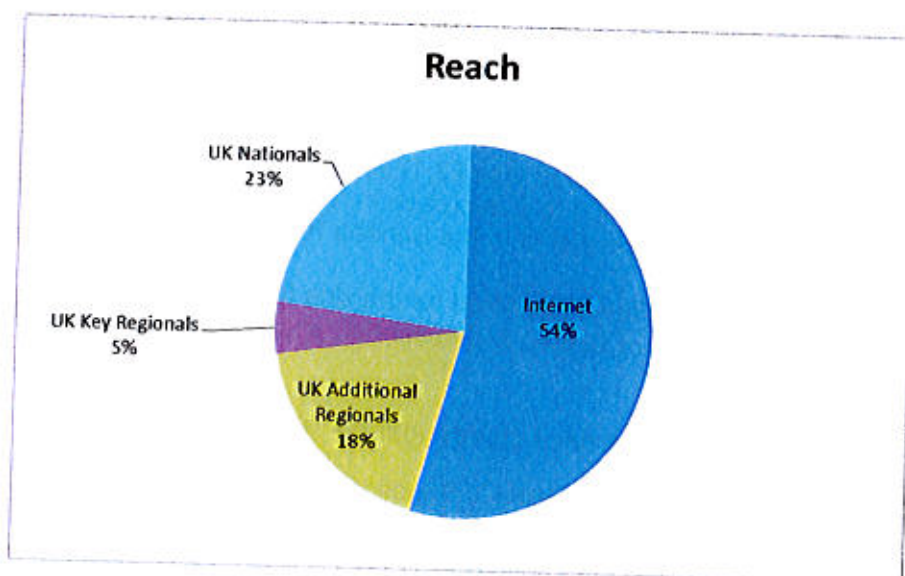
DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

The campaign resulted in a big spike in DEBRA's social media activity, mainly on Facebook but also on Twitter. On the day the campaign was launched, DEBRA's website received the highest number of visitors ever recorded: 978 unique visitors in one day. The lasting impact of the campaign continues to be seen in the increased number of visitors to our website on a daily basis.

With the help of this campaign, DEBRA has been proactive in developing its digital media profile and now has in excess of 3,200 direct followers on Facebook, a sizeable increase on 2011 when we had 1,770. During 2012 we also consolidated our Twitter presence and now have over 580 followers.

We plan to continue to grow our Facebook presence as this will, in time, allow us to target the information we share according to supporters' interests.



This pie chart shows the percentage of news coverage about EB and DEBRA in different publication types.

During 2012, DEBRA and EB were referenced 952 times in the national press, local press and online (2011:743). There was prominent national coverage in The Sunday Times, The Guardian, ITV, BBC and The Sun. Most of this coverage centred on families with EB, highlighting the condition and the gruelling day-to-day routines families face when caring for a child with a severe form of EB. This coverage would have cost the charity over £1m to buy at commercial rates.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

Royal Patronage

HRH The Countess of Wessex was particularly supportive through 2012. An informal visit to the DEBRA Head Office in May to meet staff was followed by dropping into a DEBRA Shop and meeting shop volunteers and manager. At the shop Her Royal Highness was presented with a silver DEBRA butterfly necklace by a child with EB Acquisita. DEBRA staff and volunteers found this hugely encouraging of their work.

In July Her Royal Highness attended the Bearwood Lakes Golf Day on behalf of DEBRA and our partnering charity for the day, International Golf for Youth. The Countess took time to talk to all the golfers in turn and met with an EB family, she then spoke eloquently about EB and DEBRA's services and activities.

The Countess also attended a "Great Chefs" evening in September and represented DEBRA and the Sohana Research Fund at the ICAP Charity Day in December 2012.

Fundraising

Net voluntary income achieved in 2012 was £2,123k, a drop of 21% on the 2011 figure of £2,692k. This decline was predominantly due to a decrease in restricted net voluntary income from £871k to £437k, the majority of which is restricted to the Sohana Research Fund.

The 2012 figure includes continued restricted fundraising for Recessive Dystrophic EB research via the Sohana Research Fund of £386k, a substantial legacy of £337k plus a one off donation of shares of £43k.

Core fundraising net income remained steady year on year from 2011 to 2012.

Major Giving, which comprises of DEBRA's Shooting & Golf Societies, high level sporting challenges (e.g. Virgin London Marathon, the Hot Chillee London to Paris cycle), corporate activity and gala events (e.g. Annual Celebration Dinner, Fight Night, Great Chefs), saw overall growth of 33% compared with 2011.

DEBRA has focussed on increasing efficiency from existing successful activities and continued to expand its range of fundraising income streams, this year adding a new cycle ride – the DEBRA Surrey Cycle. Following a successful pilot in 2012 this event will become an annual activity.

Other notable areas of success in 2012 were DEBRA's Golfing Society which saw net fundraising income grow by 117% against 2011. The Hot Chillee London to Paris cycle ride raised £62k net and saw a DEBRA rider win the coveted purple jersey for top fundraiser; the second year in a row a DEBRA rider has achieved this accolade. DEBRA's Shooting Society had its best year ever, we therefore plan to add an event to the Shooting Calendar for 2013, and the Appeals Council has grown by 15 as new members continue to hear about and be moved to support the EB community and DEBRA.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

Generous support, ably led by DEBRA's Appeals Council, continues to be maintained for our gala events with Fight Night 2012 achieving a net income of £80k and this year's Great Chefs evening achieving its best ever result.

Net income from community fundraising grew by 4% compared with 2011 as planned events came to fruition at the end of the year. Long term well established regions in Greater London and the North continue to perform amazingly well, whilst the South, Midlands and Scotland are reaching maturity. It is widely accepted in the sector that Community Fundraising takes 3 years to reach its peak.

Expansion of volunteer led support speakers, groups and committees remained a core growth strategy in achieving the budgeted target income and growing and developing the community team, including working together with EB families and the DEBRA shops.

The annual Big Breakfast event, supported by a national chain, raised £26k which was an eightfold increase over 2011. There will be a continued focus on improving this event for further growth. Partnerships with local businesses supporting DEBRA as Charity of the Year proved to be an excellent way to encompass community, volunteering and retail, offering more scope for support.

As traditional methods of communications continue to change, with online interaction becoming even more significant with the rise of tablet and mobile users leading the charge, the general public are more inclined to respond to personal recommendations rather than general advertising. With this in mind the Community Team developed a Social Media Strategy and each region established its own Facebook page which has been actively promoting community fundraising. In addition, a new regionalised e-newsletter was created.

Income from regular gifts was £138k in 2012, a decline of 3% compared with 2011. This is encouraging when compared with levels of giving to charities nationwide which have fallen by 20% in real terms between 2011 and 2012.

Retail

The overall assessment is that 2012 has been a year of consolidation while the charity migrated away from temporary shops. This has provided the opportunity to develop the portfolio and bring together a new professionalism within the shops, through learning and development and focus on figures and customer care. There has been a robust policy in closing underperforming shops and non-profit making temporary shops, and like for like sales have improved through pricing and stock generation. Gift aid sales conversions have plateaued at 40%.

A new induction process for staff and volunteers has been introduced, with regular appraisals and reviews. New interior and exterior signage has been rolled out, new broadband based tills have been installed in both new and lease renewal shops and there is music in store. Continual

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

improvements have been made in health and safety compliance and risk management through internal audits and shop visits. All shops are issued with an operations manual which is reviewed annually and updated on a regular basis as procedures change. Charity retail will continue to be highly competitive and DEBRA shops will strive to present themselves in a professional way, equally, as a destination charity and an employer.

In line with other retailers, the charity retail sector had a tough year. The current traditional shops portfolio consists of 103 shops, 64 leaseholds, 7 freeholds and 32 temporary shops. In 2012 11 shops were opened (10 leaseholds and 1 temporary), and 24 shops were closed (19 temporary and 5 leaseholds). The retail gift aid scheme continues to be a key area of steady growth, the charity having attained a 40% conversion of donated items being gift aided, resulting in a reclaim of £670k from HMRC. This gift aid figure is included in voluntary income on the Statement of Financial Activities. The retail division continues to be resilient, able to innovate and adapt to the changing environment.

Following the trustees' decision to proceed with a new initiative to venture into the rapidly growing Furniture and Electrical segment of the Charity Retail market, two large shops were opened in the south of the UK. It is still early days for this initiative and, as expected, there has been a steep learning curve in developing the best operational way of managing these stores.

The third annual DEBRA Shops Conference, 'Be Inspired', took place in January 2012 at Keele University. A two day varied and interesting programme of speakers and presentations was put together, including an awards dinner celebrating achievements, making the conference both inspiring and worthwhile. The annual conference has proved to be a great motivator, an opportunity to network, raise EB and research awareness, share best practice and in particular for DEBRA to get across key messages. DEBRA President Michael Portillo attended as a keynote speaker.

Home Delivery Service - Bullen Healthcare Distribution Agreement

Income received from the distribution agreement with Bullen Healthcare was £12k in 2012. Bullen Healthcare remains committed to providing a dressing and pharmacy service which continues to be well received by the EB community for home delivery of dressings and medications. Bullen Healthcare also made a generous charitable donation again in 2012 supporting the replacement holiday home in Weymouth.

Scotland

DEBRA is active in Scotland in several areas. Charitable activities include funding nursing care, social care support and research projects, notably at the University of Dundee.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

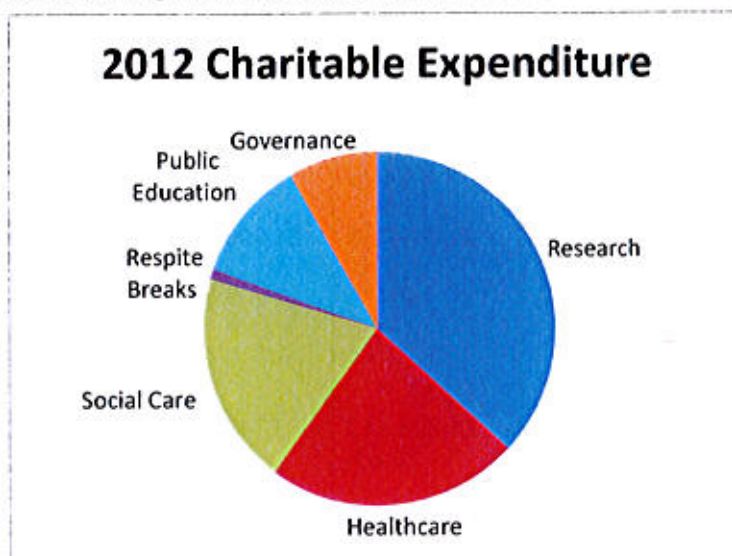
On the income generation side there are two regional fundraising heads and 25 charity shops. Both of these activities are supported by an active volunteer network. The office for retail administration for the entire charity is based in Hamilton.

FINANCIAL REVIEW

The accounts show the financial affairs of the charity for the year ended 31 December 2012. The charity's net incoming resources after taking due account of the costs of generating funds (principally charity shop trading costs) was £2,659k. Expenditure on charitable activities was £1,960k, creating a surplus for the year of £699k. The trustees decided that the unrestricted surplus of £475k is to be retained in the charity, contributing to the new designated fund for future research.

Gross incoming resources were £11,044k, a decline of 8% compared with 2011. Strategic investment in both fundraising and retail during 2012 resulted in net incoming resources falling by 32% year on year. The decline in net unrestricted incoming resources was less pronounced at 22%. Restricted net incoming resources fell by 56% largely because fundraising for the Sohana Research Fund, although still very successful in 2012, didn't emulate the extraordinary success of 2011.

Expenditure on charitable activities was £1,960k, a decline of 2% compared with 2011. Research accounted for 37% of this figure, healthcare 24% and social care 19%. The remaining 20% was spent on public education, governance and respite breaks.



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

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

There are plans to significantly increase charitable spend in future periods. This is demonstrated by the trustees' decision in 2012 to designate £951k to future research projects. There is a balance of £786k restricted income in the Sohana Research Fund, and ambitious fundraising plans are in place to increase the fund still further 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 £243k during 2012 and the trustees are committed to ploughing back all these savings into new health and social care activities. A designated fund has been set up for this purpose from which there was expenditure of £79k in 2012, which will increase in future periods as new projects are developed.

The surplus in the year led to a strengthening of the balance sheet during 2012 with net assets growing from £3,241k to £3,954k. There is £1,432k in the general fund, £951k in the designated fund for future research, £417k in the designated fund for Furniture and Electrical shops, £332k in the designated fund for nursing and social care new projects, and £807k in restricted funds.

The table below summarises the highlights of DEBRA's financial performance over the last five years. Non-trading Income fell during 2012 from the decline in fundraising for the Sohana Research Fund, legacies and grants. Net trading income achieved through the shops and fundraising events fell from £1,036k to £390k between 2011 and 2012 as a result of investment in retail operations in moving from temp to leased properties, and the Furniture and Electrical project. 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.

£

	2012	2011	2010	2009	2008
Total incoming resources	£11,044,405	£11,978,996	£10,435,462	£7,711,999	£6,997,515
Non trading income	£2,844,933	£3,371,127	£2,508,488	£1,869,031	£1,979,244
Net trading income	£390,062	£1,035,804	£760,493	£683,051	£699,850
Non trading fundraising costs	£675,945	£499,028	£526,627	£488,449	£578,249
Charitable expenditure	£1,959,941	£2,009,763	£1,993,962	£1,719,548	£2,343,273
Fundraising efficiency: Non trading income less non trading expenditure, divided by non trading income	79.8%	85.2%	79.0%	73.9%	70.8%
Retained (deficit)/surplus	£699,109	£1,898,140	£746,392	£344,063	£(242,428)
Retained surplus as a % of income	6.3%	15.8%	7.2%	4.5%	(3.5%)
Net current assets/(liabilities)	£3,167,323	£2,656,202	£850,369	£86,449	£(116,324)
Unrestricted reserves	£3,132,175	£2,656,840	£1,300,109	£549,367	£218,499
Grants payable within 1 year	£605,166	£574,663	£267,917	£179,446	£697,328

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

Cost to income ratios for charity shops are high throughout the sector which impacts significantly on overall ratios. In addition, ratios have been impacted by significant investment in trading activities in 2012.

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 three 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 2012 has been to maintain cash-backed free undesignated reserves of £900k. This was increased from the 2011 figure of £700k in recognition of the growing expenditure base and lease liability of the charity. 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 2012 were £3,940k and cash-backed free reserves were £2,600k, of which £1,700k 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 2012, 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 Nat West.

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

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

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 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 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 the company 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 19 to the financial statements.

RISK STATEMENT

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 during

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

the year by the Finance, Risk and Audit Committee and the Trustee Board, and that systems and procedures have been established to manage those 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.

Risk factor	Risk Control	Monitoring
Decline in retail activity	Monthly detailed shops reporting	Retail Committee meetings
Failure to monitor Furniture and Electrical operation	Monthly management information	Retail Committee meetings
Failure to protect against fraud	Regular review of Financial Regulations, whistle-blowing policy and segregation of duties	Finance, Risk and Audit Committee meetings
Loss of key staff and knowledge	Job and knowledge sharing and procedure documentation	Trustee Board meetings and succession planning
Failure to meet Health and Safety requirements	Health and Safety policy and training	Retail Committee meetings
Inappropriate activities undertaken	Fundraising and marketing policy	Trustee Board meetings
Charity image damaged	Marketing and PR strategy and media monitoring	Trustee Board meetings

There has been a major investment in developing Furniture and Electrical shops in 2012 and the trustees considered the potential failure to monitor the performance of this operation to be a new key risk. The HR department was strengthened during 2011 so the trustees considered the risk of failure to comply with current employment law is decreasing in 2012 and no longer a key risk.

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.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

PLANS FOR FUTURE PERIODS

Research

This is an exciting time for EB research and therapy development with a number of therapeutic approaches either in clinical trial or on the horizon. At the same time, more fundamental research is still needed to bring the knowledge base to a point where potentially more far reaching treatments can be developed. DEBRA will seek to balance its efforts and expenditure between research with nearer and longer term benefits to people living with EB.

The outcome of the special call for research proposals funded by DEBRA Austria gave DEBRA a great opportunity to collate the views of the world EB research community on where they saw the major opportunities for developing effective treatment to be. Excellent applications were submitted from virtually all of the leading research teams across gene, cell, protein and small molecule therapies. The intention had been to invest up to £3 million in one or two large scale projects to bring a particular therapy closer to the clinic. However, our expert advisers believed that, although all of the different therapeutic approaches were important and should be supported, none had yet reached the point where very large scale investment should be made and, instead, recommended 4-5 grants of approximately £500k each to move each area forward to the point where their potential for clinical application could be more effectively evaluated in approximately two years' time. It was believed that, at this point, there would be a need for very high levels of investment from DEBRA into several therapy types.

Consequently, DEBRA's strategy in 2013 will be to continue to support high quality research through its normal research grant rounds and also to build up a designated fund for future research, capable of making this significant investment. A special call for large scale programme grant applications is scheduled for mid-2014 to take those therapies where the capacity of clinical application has been demonstrated forward to the point where external partners have the confidence to invest in taking them to market. As previously indicated, considerable investment from DEBRA and our partners in DEBRA International will be needed and the designated research fund created in 2012 is an essential element of our forward strategy.

As therapies become ever closer, DEBRA recognises that it will need partners to bring those therapies into the clinic, since the costs and range of skills needed to bring products to market are beyond the capacity of a medical research charity on its own. As indicated above, DEBRA will drive the development of therapies as far as it can from its own resources, whilst seeking to form partnerships with public and private external funders. The capacity for translation to the clinic will continue to form an important part of the review process of applications for the allocation of DEBRA funds.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

In the short-term, DEBRA will continue to support existing early stage clinical trials that are already DEBRA-funded, including the mesenchymal stem cell trials in London, and seek opportunities to facilitate new, high quality trials, wherever they are happening in the world.

DEBRA will also seek to collaborate with investigators and institutions undertaking promising work with non-DEBRA funding. The trend for EB research starting to attract significant external funding is likely to continue and we will work as closely as we can with these investors, such as Lotus Tissue Repair in the development of protein therapy for Dystrophic EB.

DEBRA recognises that, in order to be attractive to external partners, there needs to be a clear business, as well as scientific, case for their involvement. Funders need to have confidence that enough is known about the normal course of the different types of EB to be able to have measures of whether a trial has been successful that are robust enough to satisfy the regulators in Europe, the USA and elsewhere that determine whether an eventual therapy can be authorised. Investors also need confidence that the payers for treatments, the NHS in the case of the UK, will be prepared to fund new treatments. As previously described, DEBRA commenced work to provide this data during 2012 and this will be extended in 2013, specifically in the areas of protection of intellectual property and in the identification of suitable business models that take into account the complexities and economic realities of rare disease therapy development.

DEBRA's focus will continue to be international, both in the research supported and in collaboration between the national DEBRAs on funding. The resources available from DEBRA UK for research are detailed in the Three Year Plan, which forecasts a significant and sustainable increase in research funding from 2014 to reflect the likely considerable demand for therapy development funding that is predicted.

Healthcare

The plan for 2013 is to continue the joint partnership working with the NHS and the immediate focus for DEBRA to work with the National EB centres to ensure the best possible service is offered to all people living with any type of EB across the UK, whilst ensuring all 'core NHS work' is fully funded by the NHS accordingly. Any money released by national funding will be used to develop the health, social care and membership services further by enabling DEBRA to supplement the core service with additional care benefits outside the reach of the NHS.

DEBRA's aims for 2013 include:

- to deliver and develop the nursing service resulting in an increase in care provision through provision of an equitable and easy to access holistic nursing service, and ensuring knowledge is transferred effectively with new resources developed for both healthcare professionals and people living with EB

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

- to develop further the EB foot clinic service that will directly help people with EB Simplex across the UK, and develop a mobile multidisciplinary clinic
- to develop a closer NHS partnership nursing service in Scotland for people living with EB and for local hospitals and clinicians
- to support the London based clinical teams with the provision of a Clinical Fellow (Doctor)
- to develop and enhance the specialist EB Dietetic services
- to further develop expertise within the nursing teams to carry out research in the clinical setting. With research coming ever closer to identifying effective treatments for EB it is vital that we have the skills necessary to translate these directly into patient care.

Social Care and Membership

The increased allocation of funds for the social care team and service provision in 2013 will make an immense and much needed difference to the service available for people living with EB across the UK and enable the team to be best equipped to support people through the welfare reform. Provision will be made for succession planning to ensure knowledge transfer and excellent practice continues for future years.

The development and re-launch of the DEBRA Membership scheme and database aims to promote our support services, provide access to information and enhance communication with the EB community.

Further review and development of DEBRA health, social and membership publications and media platforms is hoped to provide better access to and up to date content of publications and self-help directories.

DEBRA will also continue to provide and enhance the range of activities that people with EB have come to expect. This will include an increase in the number of people benefiting from the weekends away or outings/networking opportunities for adults, teenagers and children, an increase to the number of home visits where necessary, and assistance to enable more people to attend the annual conference which will again be made into an opportunity for a day out as well as a conference. An increase in DEBRA support grants to meet instances of individual or family hardship will continue to be made as an increase in demand is anticipated due to government cutbacks. The holiday home provision will increase to 4 and the replacement of the holiday home in Scotland will occur during the year, and enquiries will be made into a permanent or all year round accessible home.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

International

As has been previously mentioned in this report, DEBRA sees international collaboration as being a very important element of its mission, particularly in therapy development. This involves both bilateral contacts at national level and, through DEBRA International, collective activity at the international level. In support of this work, DEBRA seconds staff to undertake leadership roles in DEBRA International and encourages trustees to participate in international events. The importance of this area of work was recognised during 2012 by the creation of the DEBRA UK International Committee, chaired by a trustee, to oversee the charity's international activities and to recommend how the UK can best support them.

The International Medical and Scientific Advisory Panel, managed from the UK, will continue to play the pivotal role in providing peer review for all research grant applications received by DEBRAs worldwide and in helping to guide research strategy.

DEBRA International has a number of programmes in place that are of benefit to people with EB in the UK and DEBRA will continue to provide support, both financial and in kind, to their further development. These include the international Clinical Practice Guidelines with three expected to be published in 2013, the professional training initiatives to give clinicians access to gold standard care, the increase in emphasis on the provision of high quality information to both the lay and professional audiences, and supporting the growth of new DEBRAs around the world.

Through their roles in DEBRA International, seconded DEBRA staff will continue active contact with key international opinion formers and decision makers, including EURORDIS and the European Medicines Agency, amongst others.

Fundraising

2013 is expected to be a time of continued growth and consolidation. We will continue to focus on:

- continued growth, support of and development of the DEBRA Appeals Council and ambassadors to enable DEBRA to unlock individual, corporate, trust and foundation income and attract major gifts
- DEBRA's Golf Society, Shooting Society, special events and challenge portfolios which will continue to play an important part in the success of the charity's Fundraising Strategy with focus on developing each event to maximise potential
- DEBRA's Communications Strategy which will aim to drive increased reach for the charity, through the core channels of the shop network, digital social media, local PR, national PR, e-communications, word of mouth and events

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

- producing articulate case plans, for presentation to Trusts, Foundations and corporates, that eloquently describe the various services and research projects which DEBRA has identified as vital for funding
- expansion of volunteer led support (speakers, groups and committees) remains a core growth strategy in achieving target income levels, and growing and developing the community team including collaborating with EB families and DEBRA shops.

DEBRA's fundraising success would not be possible without the tremendous support it receives from the Appeals Council, Golfing and Shooting Societies, other donors and the large number of volunteers who help extensively on behalf of the charity. The generosity of time and effort given freely to us is both encouraging and greatly appreciated.

Retail

The planned three key drivers of growth in 2013 are:

- Net growth of leasehold shops.

The underlying assumption is that 25% of the current portfolio of temporary shops will close in the year. The aim is to replace these with leasehold shops across all areas.

- Like-for-like sales growth.

Average weekly sales are planned to increase by monitoring stock density through space management, pricing and promoting proactive stock initiatives throughout the year. There will be collaboration with local businesses to encourage stock donation. Leasehold shops will be opened in areas where the public can drop off direct to the shop, therefore reducing transport costs.

Following the opening of the e-Shop, a 3862 sq ft warehouse unit in Normanton, Leeds, increasing online sales will be developed through eBay and Amazon. This service currently operates in the north only and will be extended to the other regions.

- Increase sales of gift aided items.

Gift aid represents 8% of gross shops income and is therefore a major contributor, a key driver that the charity is dependent on and must maintain. Following the success of attaining 40% of sales being gift aided, the target is to grow this further, particularly on donated furniture goods. Culled rotated stock will keep the Gift Aid Identification and the possibility of gift aid on recycled rag will be explored.

There are now over 60,000 address records of those who have donated stock to our UK shops and 8,500 email addresses, and these are still growing significantly. The implication appears to be that

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

there will be a continual stream of new donors. In 2013 opportunities will be explored to invest in donor development to build relationships with these donors.

Alongside these key performance indicators are other improvement programmes that will continue to improve shop management professionalism through learning and development and a recruitment and retention programme for staff and volunteers. There will also be a rolling programme of shop improvements, including new signage and marketing materials plus refurbishment of leasehold shops at lease renewal.

Another key planned change will be the gradual migration from paid assistant managers to volunteer assistant managers. The intention is to recruit volunteer manager support where viable for the traditional charity shops and one mobile manager per area will be employed to support this. The charity currently employs 86 assistant managers. Other charities have been running this concept successfully for years with the most profitable shops directly linked to those who have the highest average number of volunteers.

During 2013 good performance will be attained at the two initial sites before expanding the Furniture and Electrical operation. The good news is that even where there are competing charities in specific locations good quality stock has been acquired. Just like the traditional shops, the overall market dynamics for charity retailing in Furniture and Electrical remain very compelling. In times of austerity, increasing demand is perhaps not a surprise and when the high street is really struggling, this part of the market has been obtaining 3% growth. So the industry trends of increasing sales, central government incentives and consumer demand for good quality second hand goods remain very encouraging. Perhaps, as the tough times continue, people will hold onto potential donated items for longer. As well as actively participating with the Charity Retail Association, which gives us an industry perspective, the performance of these shops will be tightly monitored because charity retail is a very important income stream for the charity. There is a very conservative accounting policy for shops where there have been set up costs with almost all these costs written off in the year they are incurred. The performance in both the traditional and the Furniture and Electrical shops needs to be viewed with this in mind.

The fourth retail annual conference 'Plan for Success' was extended to include head office and fundraising staff and was held at Keele University in April 2013. Once again it was over 2 days and included a celebration awards dinner. The conference proves to be a great motivator and the opportunity is taken to raise more awareness of EB, research and fundraising, as well as thanking staff for the good work they do, which enables DEBRA to continue to provide specialist care and vital research.

DEBRA

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

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.

SIGNATURE FOR TRUSTEES' REPORT AND ACCOUNTS

The Chairman, Roger Wakefield, is unable to sign the 2012 Trustees' Report and Accounts due to ill health. The trustee board authorised Robin Hood, in his role as Acting Chairman, to sign the documents in the Chairman's absence.

The Chairman has been instrumental, with the Trustee Board, in ensuring all the required systems and procedures are in place, enabling the charity to maintain all of its commitments and obligations during this time.

By order of the board:



Robin Hood

Acting Chair

24th April 2013

DEBRA

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees are responsible for preparing the annual report and the financial statements in accordance with Companies Act 2006 and for being satisfied that the financial statements give a true and fair view. The trustees are also responsible for preparing the financial statements in accordance with United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charity and of the incoming resources and application of resources for 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 estimates that are reasonable and prudent
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on a 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 show and explain the charity's transactions, 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 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 group's website is the responsibility of the trustees. The trustees' responsibility also extends to the ongoing integrity of the financial statements contained therein.

DEBRA

INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES AND MEMBERS OF DEBRA

We have audited the financial statements of DEBRA for the year ended 31 December 2012 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and the related Notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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

RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND AUDITORS

As explained more fully in the Trustees' Responsibilities Statement (set out on page 22), 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 Auditing Practices Board's (APB'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 APB's website at www.frc.org.uk/apb/scope/private.cfm.

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 2012 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;

DEBRA

INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES AND MEMBERS OF DEBRA

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

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

Gatwick

West Sussex

United Kingdom

Date:

1 May 2015

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

**STATEMENT OF FINANCIAL ACTIVITIES
INCLUDING INCOME AND EXPENDITURE ACCOUNT
FOR THE YEAR ENDED 31 DECEMBER 2012**

	Notes	Unrestricted funds £	Designated funds £	Restricted funds £	Total 2012 £	Total 2011 £
INCOMING RESOURCES						
Incoming resources from generated funds						
Voluntary income	2	1,063,070	1,193,440	442,579	2,699,089	3,190,993
Activities for generating funds	3	8,010,873	125,216	83,383	8,199,472	8,607,869
Investment income	4	44,882	-	-	44,882	55,747
Incoming resources from charitable activities						
Respite breaks		7,246	-	-	7,246	5,818
Other incoming resources		93,716	-	-	93,716	118,569
Total incoming resources		9,218,787	1,318,656	526,962	11,044,405	11,978,888
RESOURCES EXPENDED						
Costs of generating funds						
Costs of generating voluntary income	6	570,243	-	5,702	575,945	499,028
Fundraising trading: cost of goods sold and other costs	6	7,409,288	400,124	-	7,809,410	7,572,065
Total costs of generating funds		7,979,529	400,124	5,702	8,385,355	8,071,093
Net incoming resources		1,240,258	918,532	500,260	2,659,050	3,907,903
Charitable activities						
Research	6	442,917	113,834	161,203	717,954	882,200
Healthcare	6	383,428	9,210	70,229	462,867	489,839
Social care	6	268,282	69,388	45,054	382,704	271,979
Respite breaks	6	18,819	-	-	18,819	30,639
Public education	6	218,822	-	-	218,822	189,192
Governance costs	6	158,775	-	-	158,775	145,914
Total charitable expenditure		1,491,043	192,412	276,486	1,959,941	2,009,763
Total resources expended	6	9,470,572	592,536	282,188	10,345,296	10,080,856
Net income/(expenditure) for the year		(250,785)	726,120	223,774	699,109	1,898,140
Total funds brought forward		1,683,218	973,622	583,881	3,240,501	1,342,381
Transfer between funds		-	-	-	-	-
Total funds carried forward		1,432,433	1,699,742	807,435	3,939,610	3,240,501

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.

BALANCE SHEET
AS AT 31 DECEMBER 2012


Company registration number 4118259

	Notes	£	2012 £	£	2011 £
Fixed assets					
Tangible assets	10		1,429,558		1,577,922
Intangible assets	10		(637,124)		(888,935)
			<u>792,434</u>		<u>688,987</u>
Current assets					
Current asset investment	10		43,584		-
Stocks			19,883	14,405	
Debtors	11		978,483	722,428	
Cash at bank and in hand			<u>4,581,419</u>	<u>4,078,185</u>	
			5,630,369	4,815,018	
Creditors: amounts falling due within one year:	12		<u>(2,463,046)</u>	<u>(2,158,816)</u>	
Net current assets			3,167,323		2,656,202
Total assets less current liabilities			<u>3,959,757</u>		<u>3,345,189</u>
Creditors: amounts falling due over one year:	12		(20,147)		(104,888)
Net assets			<u><u>3,939,610</u></u>		<u><u>3,240,501</u></u>
Funds					
Unrestricted funds					
- Designated	14		1,699,742		973,622
- General			<u>1,432,433</u>		<u>1,683,218</u>
			3,132,175		2,656,840
Restricted funds	14		807,435		583,661
			<u><u>3,939,610</u></u>		<u><u>3,240,501</u></u>

The accounts were approved by the Board on 24th April 2013 and signed on their behalf by:



Robin Hood
Acting Chairman



David Spence
Treasurer

**CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 DECEMBER 2012**

	Notes	£	2012 £	£	2011 £
Net cash inflow from operating activities	16		453,770		1,607,924
Returns on investments and servicing of finance					
Interest and rent received		44,862		55,747	
Interest element of finance lease rental payments		(7,550)		(7,550)	
Net cash outflow from returns on investments and servicing of interest			37,332		48,197
Capital expenditure					
Payments to acquire tangible fixed assets and investments		(93,328)		(22,959)	
Receipts from sales of tangible fixed assets		150,000		270,100	
Net cash outflow from capital expenditure			66,672		247,141
Financing					
Capital element of finance lease rental payments		(34,641)		(34,541)	
Increase in cash	17		513,233		1,868,721

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

1.0 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) and the Charities and Trustees Investment (Scotland) Act 2005. Prior year governance costs 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. 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. The threshold for capitalisation was raised from £500 on 1 January 2009. 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 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 Stock

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

1.8 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.

1.9 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.

1.10 Foreign currency translation

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

1.11 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.

1.12 Governance costs

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.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

2	VOLUNTARY INCOME	Unrestricted funds	Restricted funds	Total 2012	Total 2011
		£	£	£	£
	Donations & gifts	1,715,183	352,184	2,067,347	2,436,888
	Legacies receivable	481,889	-	481,889	566,015
	Grants receivable	79,458	90,415	169,873	188,089
		<u>2,258,510</u>	<u>442,579</u>	<u>2,699,089</u>	<u>3,190,993</u>
	Donations & gifts				
	Individual donations	1,471,115	130,432	1,601,547	1,707,381
	Corporate donations	123,424	168,276	291,700	619,257
	International donations	963	40	1,023	1,048
	Events by individuals	119,661	63,418	173,077	109,195
		<u>1,715,183</u>	<u>352,184</u>	<u>2,067,347</u>	<u>2,436,889</u>
	Grants receivable				
	Charitable trusts	79,458	84,265	163,723	179,889
	Scottish Executive	-	6,150	6,150	8,200
		<u>79,458</u>	<u>90,415</u>	<u>169,873</u>	<u>188,089</u>

3	ACTIVITIES FOR GENERATING FUNDS	Total 2012	Total 2011
		£	£
	Income	8,199,472	8,607,889
	Operating expenses	(7,809,410)	(7,572,065)
	Net income from fundraising activities	<u>390,062</u>	<u>1,035,804</u>

The greatest income from activities for generating funds is derived from the operation of charity shops selling donated goods. As at 31 December 2012 there were 105 shops trading compared with 118 at 31 December 2011. The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2012	Net income 2011
	£	£	£	£
Retail	7,381,003	(7,306,913)	74,090	601,320
Fundraising events	789,764	(500,891)	288,873	399,222
Miscellaneous trading	48,705	(1,606)	47,099	35,262
	<u>8,199,472</u>	<u>(7,809,410)</u>	<u>390,062</u>	<u>1,035,804</u>

Shops showed a significant decline over the previous year because there has been significant investment in new leased properties, including 2 large furniture and electrical shops in 2012. Set-up costs of £180,795 were written off as incurred and further investment of £184,338 was made in the Furniture and Electrical project during the year. The contribution achieved by the shops was also adversely affected by a decline in the amortisation of negative goodwill and fewer shops in the portfolio. The decline in income from fundraising events has been because the Silver Butterfly dinner which raised a total of £119,806 in 2011 restricted to the Sohana Research Fund, was not repeated in 2012.

4	INVESTMENT INCOME	Total 2012	Total 2011
		£	£
	Interest receivable	38,687	28,939
	Rent of flats	8,195	26,808
	Total investment income	<u>44,882</u>	<u>55,747</u>

Rental income was received from two flats, which are situated above properties acquired in 2009.

5 GRANTS PAYABLE

Expenditure on charitable activities include grants payable to third parties as detailed in Note 6. 127 Social Care grants totalling £59,628 were made through the Social Care programme. All other grants were payable to institutions as detailed in Note 18.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

5 GRANTS PAYABLE (continued)

Healthcare and Social Care work is considered on-going and no future commitment is provided for. Research projects have a finite life and at 31 December 2012 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,022,227 (£983,753 at 31 December 2011).

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

	Total 2012	Total 2011
	£	£
Within 1 year	606,166	574,883
Within 2-3 years	417,081	408,090
Within 4-5 years	-	-
	1,022,227	983,753
Provided within the grants payable creditor	1,022,227	983,753
Contingent liability	-	-
	1,022,227	983,753

As disclosed in the accounting policies, there is no contingent liability as full grant recognition is accounted for from the 2009 Accounts onwards.

6 RESOURCES EXPENDED

	Staff costs £	Grants payable £	Other costs £	Total 2012 £	Total 2011 £
Costs of generating funds					
Voluntary income	347,875	-	228,271	575,946	499,028
Activities for generating funds	4,285,315	-	3,514,095	7,809,410	7,572,085
	4,642,990	-	3,742,366	8,385,356	8,071,093
Charitable expenditure:					
Research	281,754	417,206	38,994	717,954	882,200
Healthcare	285,288	181,783	15,818	452,869	489,839
Social care	288,989	59,528	34,207	382,704	271,979
Respite breaks	-	-	18,819	18,819	30,839
Public education	188,590	-	50,232	218,822	189,192
	984,599	658,497	168,070	1,801,166	1,883,849
Governance costs	108,508	-	50,267	158,775	145,914
	5,738,097	658,497	3,960,703	10,345,297	10,080,856

Prior year governance figures have been restated to reflect a more appropriate classification of costs.

	Depreciation and amortisation £	Overhead allocation £	Miscellaneous costs £	Total 2012 £	Total 2011 £
Other costs					
Costs of generating funds					
Voluntary income	-	103,589	124,882	228,271	221,107
Activities for generating funds	(174,629)	146,213	3,542,511	3,514,095	3,308,162
	(174,629)	249,802	3,667,193	3,742,366	3,527,269
Charitable expenditure					
Research	-	38,994	-	38,994	42,500
Healthcare	-	15,818	-	15,818	22,844
Social care	-	23,573	10,834	34,207	38,829
Respite breaks	10,338	-	8,481	18,819	30,839
Public education	-	50,232	-	50,232	47,347
	10,338	128,617	19,115	158,070	181,959
Governance costs	-	32,330	17,937	50,267	53,350
	(164,291)	410,749	3,704,245	3,950,703	3,762,578

Operating lease costs of £1,251,133 are included in miscellaneous costs and relate to rental of premises (£1,214,395), equipment hire (£16,925) and vehicles (£19,813).

Auditor's remuneration for the year was £16,000 (2011: £16,000).

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

7 COST ALLOCATION

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

	2012 £	2011 £
Staff costs	1,378,587	1,184,518
Overheads		
Office premises rent	33,630	31,272
Service charges, utilities & cleaning	31,499	29,229
Equipment costs	112,180	100,145
Postage, printing, stationery, telephone & fax	107,700	101,908
Insurance costs	41,749	41,595
Legal, professional & consultancy fees	17,806	34,050
Depreciation	20,508	19,810
Irrecoverable VAT	27,018	23,870
Bank charges	9,365	12,555
Sundry expenses	9,295	947
	410,747	395,382
Total Allocation	1,789,334	1,579,900

8 TRUSTEES

None of the trustees (or any person connected with them) received any remuneration during the period, but 7 of them were reimbursed a total of £10,042 for travel and subsistence expenses.

Amy Livesey received social care grants in 2012 totalling £755.

John Tough received a payments totalling £1,861 in 2012 for his work as a Charity Shop Consultant and Scott O'Sullivan received £1,480 for his work as a Living with EB Consultant. Authority for these payments is provided in the charity's constitution.

£26,430 was paid to DEBRA Ireland for the employment of Robin Hood as a fundraiser. This was arranged on an arms length basis and was agreed by the trustees in a meeting where Robin was absent. Authority for these payments is provided in the charity's constitution.

Insurance has been purchased to protect DEBRA from losses arising from wrongful acts committed by trustees or employees at a cost of £2,067

9 EMPLOYEES

The average number of employees during the period was:

	2012 full time equiv	2012 Number	2011 Number
Research	1.5	2	2
Healthcare*	4.0	6	5
Social care	4.7	6	5
Fundraising	15.0	17	14
Shops	211.4	284	281
Management & administration	15.6	19	17
	252	312	324

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

	2012 full time equiv	2012 Number	2011 Number
Research	1.5	2	2
Healthcare*	3.7	4	5
Social Care	5.4	6	5
Fundraising	16.6	19	14
Shops	206.6	254	275
Management & Administration	14.7	18	20
	249	303	321

*These numbers exclude the eight 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.

9 EMPLOYMENT COSTS

	Total 2012 £	Total 2011 £
Wages & salaries	4,727,032	4,804,391
Social security costs	341,801	324,789
Pension costs	171,364	130,583
	5,239,897	5,059,723

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

9 EMPLOYMENT COSTS (continued)

The charity does not operate any charity pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £157,441 were made in the year and charged to the SOFA in the period they were due. At the year end there remained £21,413 unpaid. In addition, £18,137 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:

	2012	2011
Between £60,001 - £70,000	2	2
Between £160,001 - £160,000	-	1
Between £180,001 - £170,000	1	-

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £28,307 and there are retirement benefits accruing for three employees under a defined contribution scheme.

10 FIXED ASSETS**Tangible fixed assets**

	Shop fittings	Mobile homes	Fixtures, fittings & equipment	Freehold and long leasehold land and buildings	Total
	£	£	£	£	£
Cost					
At 1 January 2012	243,881	125,757	258,134	1,539,572	2,167,344
Additions	43,190	34,000	18,138	-	95,328
Disposals	-	(48,272)	(71,718)	(135,000)	(254,988)
At 31 December 2012	287,071	111,485	202,559	1,404,572	2,005,684
Depreciation					
At 1 January 2012	142,588	82,802	222,814	141,438	589,422
Charge for the year	51,809	10,338	12,496	33,583	108,026
Disposals	-	(39,422)	(71,325)	(10,575)	(121,322)
At 31 December 2012	194,177	53,518	163,985	164,446	576,126
Net Book Value					
Brought forward	101,313	43,155	35,320	1,398,134	1,577,922
At 31 December 2012	92,894	57,967	38,574	1,240,126	1,429,558

The net book value of fixtures, fittings and equipment includes an amount of £34,541 (2011: £69,081) in respect of assets held under finance leases and hire purchase contracts. The related depreciation charge on these assets for the year was £34,541 (2011: £34,541).

Intangible fixed assets

	Acquisition goodwill £
Cost	
At 1 January 2012	(1,318,750)
Additions	-
Disposals	-
At 31 December 2012	(1,318,750)
Amortisation	
At 1 January 2012	429,815
Charge for the year	251,811
Disposals	-
At 31 December 2012	681,626
Net Book Value	
Brought forward	(888,935)
At 31 December 2012	(637,124)

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.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

10 CURRENT ASSET INVESTMENT

Included in current asset investments is £43,684 in respect of listed investments.

11 DEBTORS

	2012 £	2011 £
HMRC	146,211	98,965
Misc debtors	17,969	27,259
Other debtors	50,266	74,650
Accrued income	390,691	201,350
Prepayments	370,368	322,204
	<u>876,483</u>	<u>722,428</u>

VAT refund of £146,211 is due from HMRC. Accrued income includes gift aid of £365,627 due for quarter 3 and 4 of 2012.

12 CREDITORS: amounts falling due within one year

	2012 £	2011 £
Trade creditors	237,610	172,380
Grants payable	1,302,088	1,267,806
Other creditors	398,842	432,710
Taxation and social security	115,342	(333)
Accruals	404,688	244,844
Deferred income	5,496	21,600
	<u>2,463,046</u>	<u>2,158,816</u>

The charity installed the EPOS system during 2009 to facilitate the reclaim of gift under the retail gift aid scheme. Part of this investment is financed by lease financing over a five year period. £34,641 in finance lease payments are due within one year.

There is a dilapidations provision of £272,751 (2011: £317,312) accounted for under other creditors. In the year £198,311 was released from the provision and a further £153,750 was charged.

There was deferred income of £5,496 in the year (2011: £21,600), representing the drop in the year in income for events which would have to be repaid in the event of cancellation.

CREDITORS: amounts falling due over one year

	2012 £	2011 £
Finance leases	20,147	54,688
Acquisition creditor	-	50,000
	<u>20,147</u>	<u>104,688</u>

The terms of the acquisition of the Action for Children shops allow for the payment to be spread over four annual payments, commencing in 2010.

13 OTHER FINANCIAL COMMITMENTS

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

	2012	2011	2012	2011
	Leases of land and buildings £	Leases of land and buildings £	Other £	Other £
Expiring within 1 year	239,398	394,470	11,686	10,473
Expiring within 2-5 years	599,400	519,251	23,163	24,477
Expiring after 5 years	111,698	163,752	-	-
	<u>850,398</u>	<u>1,077,473</u>	<u>34,749</u>	<u>34,950</u>

The following payments are committed to be paid in respect of finance leases:

	2012 Epos equipment £	2011 Epos equipment £
Payable in 1-2 years	20,148	34,641
Payable in 2-5 years	-	20,147
Payable after 5 years	-	-
	<u>20,148</u>	<u>54,688</u>

There were capital commitments of £13,941 at the year end. (2011: £2,510)

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

14 ANALYSIS OF FUNDS

	Balance at 31 Dec 2011	Movement between funds	Incoming resources	Resources expended	Balance at 31 Dec 2012
	£	£	£	£	£
Restricted funds					
Research	542,706	-	404,375	161,203	785,878
Healthcare	6,540	24,909	53,204	70,229	14,424
Social care	34,415	(24,909)	42,681	45,054	7,133
Fundraising	-	-	5,702	5,702	-
	<u>583,661</u>	<u>-</u>	<u>505,962</u>	<u>282,188</u>	<u>807,435</u>

Restricted funds at 31 December 2012 comprise:

	£
Research - Sohana Research Fund	785,878
Healthcare - India fund	6,250
Healthcare - Dressings	5,608
Healthcare - nurses study leave fund	2,566
Social Care - Churchill family	1,930
Social Care - work in Nottinghamshire	1,705
Social Care - holiday and travel costs Manchester families	1,420
Social Care - sports	523
Social Care - work in Islay	420
Social Care - West Lancashire	370
Social Care - work in Kingston	363
Social Care - David Green garden	200
Social Care - work for Tameside families	187
Social Care - work in Wimbourne and Ferndown	15
	<u>807,435</u>

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 £385,967 in 2012 (2011: £942,706) of which £154,625 was committed in 2012 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.

No funders have asked for specific disclosure of their grants in the accounts.

Unrestricted funds

The trustees have transferred the following amounts into designated funds during 2012:

	Balance at 31 Dec 2011	Movement between funds	Incoming resources	Resources expended	Balance at 31 Dec 2012
Furniture and Electrical shops	691,682	-	125,216	400,124	416,774
New health and social care projects	168,106	-	242,728	78,578	332,256
Research grant round in 2012	113,834	-	-	113,834	-
Future research grants	-	-	950,712	-	950,712
Total designated funds	<u>973,622</u>	<u>-</u>	<u>1,318,656</u>	<u>582,536</u>	<u>1,689,742</u>
General fund	1,683,218	-	9,219,787	9,470,572	1,432,433
Total unrestricted funds	<u>2,656,840</u>	<u>-</u>	<u>10,538,443</u>	<u>10,053,108</u>	<u>3,132,175</u>

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 during 2013 and 2014.

DEBRA has saved £242,728 during 2012 (2011: £168,106) 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 social care 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 health and social care projects totalled £78,578 in 2012. It is anticipated this fund will be spent in the period 2013-2015.

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 1-3 years.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

15 ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds £	Restricted funds £	2012 Total £	2011 Total £
Fund balances at 31 December 2012 are represented by:				
Fixed assets	792,434	-	792,434	666,987
Current assets	4,822,934	807,435	5,630,369	4,815,018
Creditors: amounts falling due within one year	(2,463,048)	-	(2,463,048)	(2,158,816)
Long term creditors	(20,147)	-	(20,147)	(104,888)
	<u>3,132,175</u>	<u>807,435</u>	<u>3,939,610</u>	<u>3,240,501</u>

16 NET CASH INFLOW FROM OPERATING ACTIVITIES

	2012 £	2011 £
Reconciliation of changes in resources:		
Changes in resources	699,109	1,898,140
(Profit)/loss on disposal of fixed assets	(16,334)	(33,622)
Amortisation and depreciation of fixed assets	(143,786)	(221,285)
Decrease / (increase) in current asset investments	(43,694)	-
Decrease / (increase) in stock	(5,478)	(8,950)
Decrease / (increase) in debtors	(263,055)	(23,462)
(Decrease) / increase in creditors	284,229	45,301
Investment income receivable	(44,882)	(55,747)
Interest element of finance lease rental payments	7,660	7,550
	<u>453,770</u>	<u>1,607,624</u>

17 RECONCILIATION OF NET CASH FLOW TO MOVEMENT IN NET FUNDS

	2012 £	2011 £
Increase in cash	513,234	1,868,721
Net funds b/f	4,078,185	2,209,464
Net funds c/f	<u>4,591,419</u>	<u>4,078,185</u>

18 GRANTS TO INSTITUTIONS

	Total 2012	Total to date	Total project cost
Research Projects			
University of Dundee			
Pre-clinical trials re application of siRNA therapy in EB Simplex	64,715	123,103	192,605
Establishment of an EB keratinocyte collection	55,839	67,007	67,007
Pre-clinical assessment of PLK1 inhibitors	30,450	35,306	66,138
	<u>151,004</u>	<u>225,418</u>	<u>325,950</u>
Netherlands Cancer Institute			
Studying Kindler Syndrome in an <i>in vivo</i> model system	50,732	59,164	101,997
King's College London			
Developing refined stem-cell therapies for RDEB	62,204	148,530	148,530
Bilzard Institute of Cell and Molecular Science, London			
Dissecting the role of basement membrane components	57,460	110,173	173,877
Istituto Dermatologico dell'Immacolata, Roma			
Modifying genes in phenotypically discordant siblings with RDEB	43,710	76,407	87,344
University of Santiago, Chile			
Increasing research capacity	3,337	40,000	40,000
Great Ormond Street Hospital, London			
Review of pain perception and management	1,400	4,200	4,200
Guy's Hospital, London			
Determining the molecular basis of EB	54,826	65,792	65,792
Mesenchymal stem-cell therapy clinical trial	48,081	48,081	388,171
Validated clinical endpoints study re EB therapy evaluation	-	-	97,600
	<u>102,907</u>	<u>113,873</u>	<u>551,463</u>

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2012

18	GRANTS TO INSTITUTIONS (Continued)	Total 2012	Total to date	Total project cost
	University of Salzburg			
	Combining gene-therapy and stem-cell-therapy for JEB	-	-	212,004
	University of Minnesota			
	Developing individualised therapies for children with EB	-	-	154,825
	Other	38,474		
	- Increase in research provision	(94,012)		
	- Grant underspends			
	- Unused grants written back at end of project	(55,538)	-	-
	Total research grants	417,206	777,763	1,799,890
	Research project expenditure by category:			
	- Genetic research	177,188		288,837
	- Cancer research	3,642		240,015
	- Clinical research	(8,888)		24,200
	- Therapies	243,082		1,247,138
		417,206		1,799,890
		Total		Total
		2012		project cost
		£		£
	Healthcare Team projects			
	Great Ormond Street Hospital for Sick Children			
	Three clinical nurse specialists in EB	43,514		54,042
	Guys & St Thomas' Hospital London			
	Five adult support nurses	130,358		161,143
	Other	3,155		88,683
	- Miscellaneous healthcare grants	1,383		88,717
	- Scotland	3,374		3,374
	- Birmingham Children's Hospital			
	Total Healthcare Team grants	181,784		393,959

19 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:

	2012	2011
	£	£
Turnover	27,081	28,595
Net Profit transferred to DEBRA	2,706	955
Net assets	-	-

During the year, the charity charged management charges totalling £7,200 including VAT (2011: £7,200) to its subsidiary DEBRA Trading Limited.

Other Related Parties

£220,850 was payable to DEBRA's medical advisor Professor John McGrath during the year, in respect of four research projects approved by the trustees, with a further provision of £340,090 as at 31 December 2012.

Payments were made to two DEBRA trustees, John Tough and Scott O'Sullivan, for their professional services. See note 8 for details.

Payment was made to DEBRA Ireland during the year for the employment of Robin Hood, a DEBRA trustee, as a fundraiser. This was arranged on an arms length basis and agreed by the trustees in a meeting where Robin was absent. See note 8 for details.

