



## **DEBRA**

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### **TRUSTEES' REPORT & ACCOUNTS**

**FOR THE YEAR ENDED  
31 DECEMBER 2011**

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

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**DEBRA****REFERENCE & ADMINISTRATIVE INFORMATION**

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Trustees	Roger Wakefield*	Chair from 21 May 2011
	Vacancy	Vice-Chair since 21 May 2011
	David Spence*	Treasurer
	Scott O'Sullivan	Secretary
	David Bendor-Samuel *	
	Clinton Budd	until 21 May 2011
	Simone Bunting	from 21 May 2011
	Robin Eady	
	Philip Evans*	Chair until 21 May 2011
	James Hinchcliffe	from 21 May 2011
	Robin Hood	from 21 May 2011
	James Irvine*	co-opted from 9 September 2011
	Amy Livesey	from 21 May 2011
	Graham Marsden*	until 21 May 2011
	Heather Mills	until 21 May 2011
	Gillian Pigott	until 10 January 2011
	Amy Price	from 21 May 2011
	Simon Rothwell	until 21 May 2011
	Melissa Smith	
	Michael Thomas	until 21 May 2011
	John Tough	
	Patrick Turnbull	until 21 May 2011
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 Subcommittee		
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	Head of Retail
	Louise Tait	Director of Fundraising & Communication
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 Emerald House, East Street Epsom, Surrey, KT17 1HS	
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	

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## **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011**

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### **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.

### **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 2011 the Articles of Association were amended to limit the number of terms that a trustee could serve without a break of at least one year. Consequently, four long-standing trustees stood down and a further two resigned for other reasons. Four new trustees were elected and a further trustee was co-opted to fill a vacancy caused by resignation. 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. Trustees received relevant publications, such as "Governance" magazine, and briefings by external advisers.

Trustees are supported by a number of subcommittees 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 2011, were finance, risk and audit; charitable activities and fundraising. In addition, the international Medical and Scientific Advisory Panel gives expert advice on research priorities and quality and a Translational Research

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Advisory Panel has been recruited to provide advice on developmental issues in bringing therapy from the laboratory and into the clinic. During late 2011, it was decided to seek legal advice on what amendments to the Articles of Association and changes in procedures would be needed to ensure a balance of skills and expertise on the Trustee Board to manage a complex and growing organisation, whilst retaining strong representation of people with personal experience of living with the condition. Solicitors with expertise in charity law were instructed in December 2011 and it is anticipated that the membership will vote on the proposed changes at the Annual General Meeting in May 2012.

DEBRA's President, Michael Portillo, continued to give considerable support and guidance to the charity throughout the year. The trustees were also delighted that the Countess of Wessex accepted their invitation to become DEBRA's Patron.

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.

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.

### **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.

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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 2011, DEBRA aimed to maintain and increase its existing medical research programme and 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; with some changes implemented during 2011 with the remainder scheduled for 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, which was 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.'

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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 all the 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 2011, the charity had an average of 1,432 volunteers (175 Full Time Equivalent - FTE) working in the charity's shops, which valued at the pay rate of shop assistants would be an equivalent of £1,907,312 in donated time. The head office had a total of 4 volunteers (0.8 FTE) which valued at the pay rate of administration staff would be an equivalent of £14,490 in donated time. Additionally, there are several hundred volunteers undertaking occasional fundraising activities.

#### ***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

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one type of the condition. The condition affects all ethnic groups and DEBRA aims to provide equal access to services without impediment.

### ***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 2011, two 'normal' research grant rounds were held, both managed from the UK. DEBRA took responsibility for funding one of those rounds, with DEBRA Austria taking responsibility for the other. DEBRA (UK) funded four new research projects, with a total commitment of £301k, the details of which can be found in the audited accounts. Three of these projects are being undertaken in the UK, whilst the fourth originates in The Netherlands. DEBRA Austria funded five new projects, at a cost of €760,000, in Austria, Germany, Singapore and the USA (2); the scientific management for all of these will be provided from the UK.

In addition to the 'normal' rounds, DEBRA was able to allocate an additional £400,000 from the Sohana Research Fund to finance EBSTEM, which is research and a clinical trial into mesenchymal stem cell therapy in London. This Fund consists of money raised through the efforts of a member family specifically for Recessive Dystrophic EB research and clinical trials; it included a significant donation from Goldman Sachs which was restricted to the project that was funded. Additional funds raised for the Sohana Research Fund are being held by DEBRA in a restricted fund to finance further phases of this work.

Although the grants are not financed by DEBRA UK, the charity funds the staff who have taken a leading role in the management of a special programme grant round for collaborative research, focused on therapy development. At the end of the year, nine proposals ranging from €1-3 million each were being assessed and funds will be allocated in April 2012. It is anticipated that there will be more high quality research recommended for approval than the funding available of €3 million and the challenge during 2012 will be to find alternative means of enabling this work to take place.

As indicated in the 2010 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. EBSTEM and the continuing fibroblast



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trial. The meeting of the Translational Research Advisory Panel in 2011 was very helpful in identifying both the challenges and opportunities facing the charity in therapy development, where the involvement of external public and private partners will be essential in bringing therapies to market. DEBRA's research strategy, shared with DEBRA International, has been revised to incorporate these new elements. In addition, agreement was reached during 2011 to commit up to £50,000 at the beginning of 2012 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. DEBRA staff has also 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, to be held in Spain in November 2012.

### ***Healthcare***

One of DEBRA's main 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 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 specialist care required, some national funding for the clinical service is provided by NSCT (National Specialised Commissioning Team). Since DEBRA first helped to set up the nursing teams based in London and Scotland over 30 years ago it has continued over the years to fund in excess of 83% of the service costs, whilst the more recently established teams at Birmingham Children's Hospital and Solihull Hospital have been funded by the NHS.

2011 was a remarkable year for the EB nursing service and DEBRA with the charity helping to secure extra funding for the National EB Nursing service and being a key player in helping develop 'The National EB Nursing Service Principles'. 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 EB nursing service principles. For the first time the EB community now have a set of principles that clearly outline the care that someone living with EB can expect from both the NHS and DEBRA.

In general 75% of each 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 fund all non-core NHS work including additional bereavement visits, research, and charitable activities

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including nursing care for patient weekends away. This is a long term arrangement and is a significant achievement making a positive difference all round. It allows DEBRA to make even greater enhancements to the charitable health and social care activities provision to meet the expanding and developing needs of the EB community and highly specialist teams. In addition DEBRA is able to offer the EB teams in the Midlands funding to undertake non-core activities.

This closer partnership working with the NHS is the culmination of a lengthy process to 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/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 engaging in activities across the four centres.

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 remained in demand to speak at external conferences, both in the UK and abroad.

#### ***Social Care***

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. Following the retirement of the social care manager in the north of England and Scotland a replacement was recruited to cover the north of England 3 days per week leaving a vacancy to cover the Scottish work (one day per week) which is to be enhanced into a greater role in 2012. There has been a clear increase in the work for the team following the announcement of the welfare reform by the government with many of the individuals and families DEBRA support being heavily affected by the reforms.

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.

Given the reduction in the size of the team due to the temporary charitable expenditure cuts in 2009 and the vacancy in Scotland, priority continued to be given to enabling individuals and families to access services to meet current and often urgent difficulties. There is the recognition

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by the EB community that DEBRA funding had been cut back and that there is a strong desire to use available funds to continue to rebuild the team in 2012.

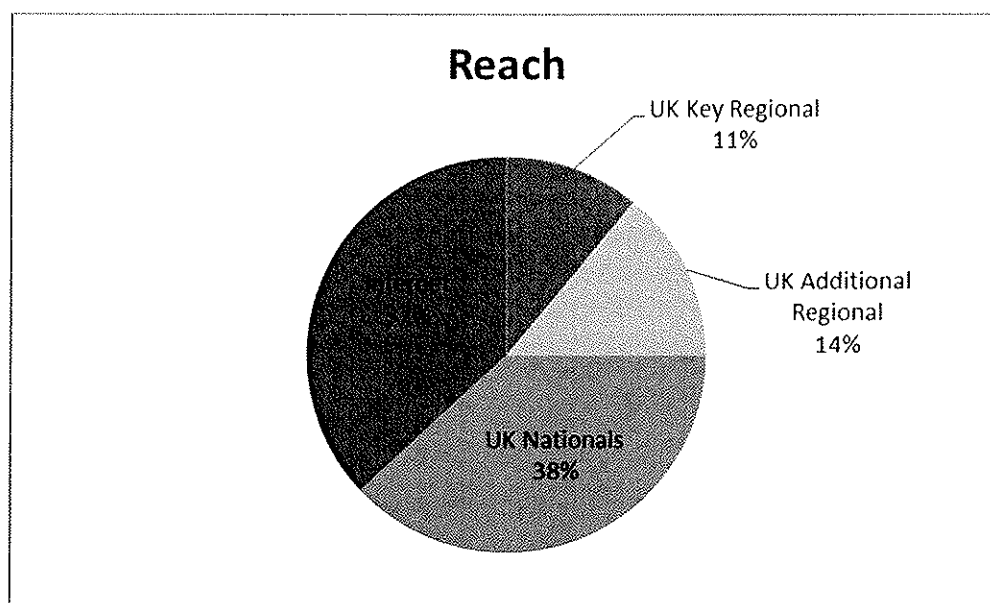
A successful annual conference was held in May 2011 and a number of smaller meetings, or opportunities for people with EB to meet, were organised and funded. All main EB hospital clinics were also attended by a member of the team.

### ***Respite Breaks***

DEBRA's objective is to enable 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 2011, and bookings to near full capacity are already in place for 2012.

### ***Public Education***

Raising public awareness of Epidermolysis Bullosa is key to DEBRA's work. The BBC Three documentary, *Stormchaser: The Butterfly and The Tornado*, was broadcast in the UK at the end of October.



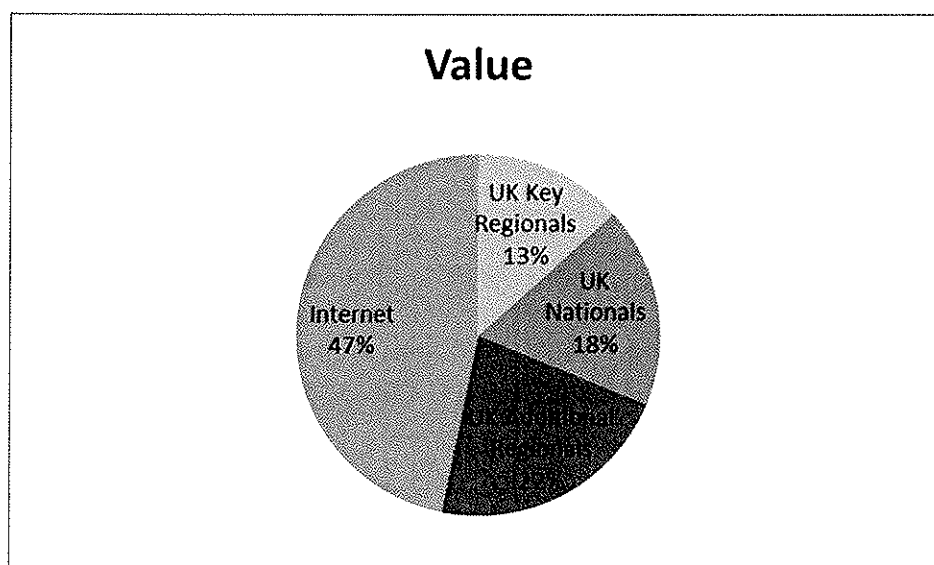
DEBRA continues to be proactive in developing its digital media profile and has in excess of 1,770 direct followers on Facebook, with an extended network of 557,000. We also have three Regional Community Fundraising pages for Community Fundraising Groups to communicate together and advertise activities and events.

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During 2011 DEBRA was referenced 998 times in the national press, local press and online which reached an audience of around 2.9 million people.



This coverage would have cost the charity over £1m to buy at commercial rates.

DEBRA is also active on Twitter.

The DEBRA Fight Night in September was broadcast live by Sky Sports and, for the first time, DEBRA was widely featured throughout the programming, including interviews with the CEO and with a person who has EB. The programme was watched by over 90,000 viewers.

DEBRA's new logo and strapline is in the process of being rolled out across the organisation. In order to save costs this has been done on an "as need" basis. Our Sporting activities campaign "Get a Blister" was trialled in 2011. DEBRA continues to benefit from the support of a leading brand agency, Publicis, which provided pro bono expertise and resource for this work.

#### ***Royal Patronage***

HRH The Countess of Wessex undertook her first official engagement for DEBRA, attending the annual dinner - "DEBRA at the Savoy" – where she met individuals with EB, clinicians and researchers, and key supporters.

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#### ***Fundraising***

Net voluntary income grew by 49% in 2011 over 2010 and net fundraising event income grew by 135%.

In part this success was due to substantial legacy giving of £566,015. Previous levels of legacy giving at DEBRA have been low at around £50,000 per annum and, as a result of this year's outcome, DEBRA will look to promote legacy gifts as an area of increased emphasis.

A tremendously successful initiative in 2011 was the Sohana Research Fund. The fund took on the immense challenge of raising restricted funding for Recessive Dystrophic EB research utilising mesenchymal stem cells, led by Professor McGrath.

Rallying parents from Sohana's school, friends, family and colleagues alike and working in close partnership with DEBRA, the Sohana Research Fund raised over £926,000 in 2011 including £410,000 from the partner funded Goldman Sachs Gives programme.

Because of the drive and dedication of those who are involved with the Sohana Research Fund DEBRA was able to commit £400,000 at the end of 2011 to finance EBSTEM, which is research and a clinical trial into mesenchymal stem cell therapy. The trial, which will involve up to 20 children with Recessive Dystrophic EB, is already in the early pre-clinical stages of preparation.

DEBRA has expanded its range of fundraising income streams. During 2011, increased emphasis was placed on challenge and sporting events and regional fundraising as reliable, steady income streams in difficult economic conditions.

Particularly successful was a new City Challenge Shooting Society event which raised net income of £60,000, and will now become an annual event. DEBRA's relationship with the iconic Hot Chillee L2P 450 person cycle challenge continues to grow. In 2011 DEBRA had 10 riders which raised net income of £25,000 with one of DEBRA's riders winning the coveted purple jersey for top fundraiser – proving once again how compelling our cause is.

An International EB Awareness Day, originating in the USA, was adopted by the UK this year. Activities and events were focused around this

DEBRA at the Savoy saw the return of DEBRA's Annual Dinner in a new format. Attended by HRH The Countess of Wessex in her first official activity as DEBRA's Royal Patron, the dinner achieved a net income of £48,000, a growth of 182% over the previous dinner in 2009.

Community Fundraising performed over expectations; the increased emphasis on this area of fundraising saw the coming together of groups of supporters from all walks of life. Bringing together families living with EB, the general public, DEBRA Charity shop clients and workers and long term supporters of DEBRA's work this area of fundraising continues to develop. There were 9 brand new community groups created in 2011.

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Income from regular gifts remained steady at £130,000 demonstrating high levels of retention and supporter loyalty. One-off gift income was boosted by a Christmas Appeal as well as our regular DEBRA News appeal.

#### ***Retail***

Retail ended a very challenging year with a net income from activities for generating funds of £597,000, a 6.9% growth over 2010. Average weekly sales of donated goods (including rags) peaked in November at £1,397, though the overall average throughout the year was £1,220. A better than hoped for December closed a tough year for retail and 2012 is expected to be an equally challenging year. Encouragingly, like for like sales grew by 2.36% for the whole year and gift aided sales hovered at 39%, but fell slightly in December to 37.1%, the total year figure being 36.7%. As a result DEBRA was able to reclaim £662,000 from HMRC, an extra £116,000 over 2010 (£546,000). This gift aid figure is included in voluntary income on the Statement of Financial Activities. During the year we attracted 31,000 new Gift Aid donors, an increase of 14.3% on 2010.

We started the year with 118 shops but by the close of 2011 this had dropped to 116. During the year we opened 28 temporary shops and closed 30 shops, which highlighted the fact that the temporary shops model had run its course. This was not a growth strategy for DEBRA, so we took a new direction in deciding not to enter into any more temporary agreements or licenses without first trying to secure them for at least six months. In addition, an active search for leasehold properties commenced.

During the year we completed a strategic review of our Retail operation. The unanimous Trustee decision was to invest in our current estate and also create a new focus with large Furniture and Electrical Shops. This initiative will be led by the CEO and it is anticipated that these larger stores will create a bedrock of recurring unrestricted income streams that will help fund the development of clinical trials over the next decade.

The retail management structure has been enhanced with the appointments of Head of Retail, Head of Property, Living with EB Consultant and Learning and Development Manager, whilst continuing to focus on Health & Safety, to ensure compliance with its statutory duties under Health & Safety law.

The second annual DEBRA Shops Conference 'Celebrating Success' took place in January 2011 at Keele University. The invitation was extended to assistant managers as well as shop managers. A full programme of speakers for the day was both informative and entertaining, resulting in another extremely successful day with presentations about nursing, research and social care as well as retailing, focussing on price optimisation and the benefits of gift aid. Awards were presented for long service, increase in like for like sales and attaining 50% gift aid conversion.

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#### ***Home Delivery Service - Bullen Healthcare Distribution Agreement***

This year has seen a dramatic change in the prescription reimbursement system in England resulting in marked decrease in the income that is received from the distribution agreement with Bullen Healthcare, a well known UK based appliance and EB dressing distributor, and EB pharmacy service. Bullen Healthcare remain committed to providing the dressing and pharmacy service which continues to be well received by the EB community for home delivery of dressings and medications.

#### **FINANCIAL REVIEW**

The accounts show the financial affairs of the charity for the year ended 31 December 2011. The charity's net incoming resources after taking due account of the costs of generating funds (principally charity shop trading costs) was £3,898,519. Expenditure on charitable activities was £2,000,379, creating a surplus for the year of £1,898,140. The trustees decided that the unrestricted surplus of £1,372,880 is to be retained in the charity with £691,682 designated for the Furniture and Electrical Shops project, £168,106 designated for new health and social care expenditure and £113,834 designated for new research grants.

Net incoming resources grew by 42% over 2010, largely accounted for by the extraordinary success of fundraising for the Sohana Research Fund which brought in £926,557 net income and the receipt of three substantial legacies totalling £503,985. Net income from retail activities grew by 6.9% to £597,270, with additional voluntary income of £738,377 raised through the shops network, of which £661,942 was from the retail gift aid scheme.

Expenditure on charitable activities was static compared to 2010 at £2,000,379 but there are plans to significantly increase charitable spend in future periods. There is a total balance of £542,706 restricted income in the Sohana Research Fund, plus further ambitious fundraising plans are in place to increase the fund still further for Recessive Dystrophic EB research and clinical trials. A write back of unspent research grants of £113,834 in 2011 has been designated for research expenditure in 2012. Another reason why charitable spend is comparatively low in such a successful year from an income generation point of view is the increased funding secured from the NHS for some EB nurses. This has led to savings of £168,106 during 2011 and the trustees are committed to ploughing back all these savings each year into new health and social care activities. A designated fund has been set up for this purpose.

The surplus in the year led to a significant strengthening of the balance sheet during 2011 with net assets growing from £1,342,361 to £3,240,501.

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## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011

The table below summarises the key highlights of DEBRA's financial performance over the last five years. Non-trading income grew dramatically during 2011 largely from the success of the fundraising for the Sohana Research Fund and the three substantial legacies. Net trading income achieved through the shops and fundraising events grew from £760,493 to £1,030,174 between 2010 and 2011. A significant new fundraising event organised to raise funds for the Sohana Research Fund raised a net income of £228,081; the remainder of the growth in net trading income was achieved largely through retail.

	2011	2010	2009	2008	2007
Total incoming resources	£11,978,996	£10,435,462	£7,711,999	£6,997,515	£6,792,985
Non trading income	£3,371,127	£2,506,488	£1,869,031	£1,979,244	£2,152,916
Net trading income	£1,030,174	£760,493	£683,051	£699,850	£953,429
Non trading fundraising costs	£502,782	£526,627	£488,449	£578,249	£809,197
Charitable expenditure	£2,000,379	£1,993,962	£1,719,548	£2,343,273	£2,685,327
Fundraising efficiency: non trading income less non trading expenditure, divided by non trading income	85.1%	79.0%	73.9%	70.8%	62.4%
Retained (deficit)/surplus	£1,898,140	£746,392	£344,083	£(242,428)	£(308,181)
Retained surplus as a % of income	15.8%	7.2%	4.5%	(3.5%)	(5.7%)
Net current assets	£2,656,202	£850,369	£86,449	£(116,324)	£70,272
Unrestricted reserves	£2,656,840	£1,300,109	£549,367	£218,499	£392,774
Grants payable within 12 months -SOFA	£574,663	£267,917	£179,446	£697,328	£882,913

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 a continued investment in trading activities.

The charity's fixed assets comprise the premises, equipment and vehicles 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.



## **DEBRA**

### **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011**

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#### ***Reserves Policy***

The trustees' reserves policy in 2011 has been to maintain cash-backed free reserves of £700,000. This was increased from the 2010 figure of £500,000 in recognition of the growing expenditure base 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 2011 are £3,240,501 and cash-backed free reserves are £2,082,853. 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.

The charity successfully rebuilt reserves during 2010 and invested £500,000 cash-backed reserves in a two year breakable bond with Nat West earning 2.7% interest. 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 2011, 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 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 business justification for the costs

## **DEBRA**

### **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011**

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- 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. 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 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 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.

## DEBRA

### TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011

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Risk factor	Risk Control	Monitoring
Decline in retail activity	Monthly detailed shops reporting	Shops Board meetings
Failure to protect against fraud	Regular review of Financial Regulations, whistle-blowing policy and segregation of duties	Finance, Risk and Audit Sub-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	Shops Board meetings
Failure to comply with current employment law	Employment law advice service	Trustee Board meetings
Inappropriate activities undertaken	Fundraising and marketing policy	Trustee Board meetings
Charity image damaged	Marketing and PR strategy and media monitoring	Trustee Board meetings

As a result of increasing diversity in fundraising activities during 2011 the trustees considered the risk disclosed in 2010 of loss of major source of fundraising income is decreasing and no longer significant. The HR department has been strengthened during 2011 so whilst the risk of failure to comply with current employment law is still significant, it is considered to be decreasing.

### 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 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.

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. 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

## **DEBRA**

### **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011**

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continue to form an important part of the review process of applications for the allocation of DEBRA funds.

In the short-term, DEBRA will support existing early stage clinical trials that are already DEBRA-funded, including the fibroblast and 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. DEBRA will commence work to provide this data during 2012 and this is already attracting the interest of other patient groups who feel that our work may develop into a useful model for rare diseases as a whole.

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 2012 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 and social care services further by enabling DEBRA to supplement the core service with additional care benefits outside the reach of the NHS.

DEBRA's aims for 2012 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

## **DEBRA**

### **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011**

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knowledge is transferred effectively with new resources developed for both healthcare professionals and people living with EB

- to develop further the EB foot clinic service that will directly help people with EB Simplex across the UK
- to develop a closer NHS partnership nursing service in Scotland for people living with EB and for local hospitals and clinicians
- 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***

The allocation of funds for recruiting a new social care team member to complement the team in England and provide a service in Scotland will make an immense and much needed difference to the service available for people living with EB across the UK. The aim is for the new post holders to start work in April 2012.

DEBRA will 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 for adults, teenagers and children, an increase to the number of home visits where necessary, and assistance to more people to attend the annual 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. DEBRA aims to update and increase the range of patient information materials published. The three mobile homes will continue to be available and further funding for new replacement holiday homes in Weymouth and Scotland will be sought as well as funding for a fourth holiday home to be located in the Midlands/North of the country.

#### ***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.

## DEBRA

### TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011

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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.

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***

2012 is expected to be a time of growth with strategies embarked upon in 2011 expected to show positive results in the latter end of the year. Continuous improvement of the strategy has resulted in the following areas of emphasis in five broad areas:

- growth, support of and development of the DEBRA Appeals Council and ambassadors will allow DEBRA to unlock individual, corporate, trust and foundation income and attract transformational and philanthropic major gifts
- growth, management and support of DEBRA's volunteer network to raise awareness of EB and of DEBRA's work allowing incremental development of community and volunteer-led fundraising throughout the UK. Fundraising "Products" such as the Big Breakfast, DEBRA Lottery and London Bridges Walk, piloted in 2011 will continue in 2012 with additional products created including the Surrey Cycle
- DEBRA will actively promote Legacy Giving. We will measure success for this long term strategy in terms of pledges made
- DEBRA's Communications Strategy will aim to significantly increase the charity's reach, through the core channels of the shop network, digital social media, local PR, national PR, e-communications, word of mouth and events
- DEBRA's Golf Society, Shooting Society, special events and challenge and sporting portfolios will continue to play a key part in the success of the charity's Fundraising Strategy with focus on growing each event to maximise potential.

DEBRA's fundraising success would not be possible without the tremendous support it receives from the Appeals Council, other donors and the large number of volunteers who help extensively on behalf of the charity. This effort is both encouraging and greatly appreciated.

# DEBRA

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011

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### ***Shops***

The three key drivers of growth in 2012 are:

- 3% like for like sales growth
- 40% Gift Aid conversion
- Opening new leasehold shops.

Alongside these key performance indicators are improvement programmes including a new pricing matrix to develop price optimisation, weekly sales targets, improvement of shop management professionalism through learning and development, new induction programme for staff and volunteers and a rolling programme of shop improvements, including a new fascia and marketing materials.

During 2012 we intend to open 3 large Furniture and Electrical Shops within a 50 mile radius of our head office in Crowthorne. We have already surveyed 40 sites and are discussing terms with a number of landlords. The business model depends on a well implemented retail offering with good quality, gift aided donations that are presented in a good shopping environment. We intend to define our operations and high standards with these initial shops that will become a repeatable format once these concepts have been proven.

The third annual retail conference 'Be Inspired' was held at Keele University on 21st & 22nd January 2012. This two day programme which was very informative, motivating and inspiring, included keynote speaker Michael Portillo, President of DEBRA. His motivating presentation, together with a warm welcome message from our Royal Patron the Countess of Wessex, got the conference off to a good start. A celebratory awards dinner, including special recognition awards was held in the evening.

## **DEBRA**

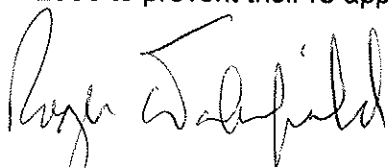
### **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2011**

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#### **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.



**Roger Wakefield**

Chair

25<sup>th</sup> April 2012



## DEBRA

### STATEMENT OF TRUSTEES' RESPONSIBILITIES

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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.

## **DEBRA**

### **INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES AND MEMBERS OF DEBRA**

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We have audited the financial statements of DEBRA for the year ended 31 December 2011 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](http://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 2011 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**

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- 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

Epsom

United Kingdom

Date: 30 April 2012

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 2011**

	Notes	Unrestricted funds £	Restricted funds £	Total 2011 £	Total 2010 £
<b>INCOMING RESOURCES</b>					
<b>Incoming resources from generated funds</b>					
Voluntary income	2	2,269,770	921,223	3,190,993	2,331,212
Activities for generating funds	3	8,332,184	275,685	8,607,869	7,928,974
Investment income	4	55,747	-	55,747	30,670
<b>Incoming resources from charitable activities</b>					
Respite breaks		5,818	-	5,818	7,130
<b>Other incoming resources</b>		118,569	-	118,569	137,476
<b>Total incoming resources</b>		<b>10,782,088</b>	<b>1,196,908</b>	<b>11,978,996</b>	<b>10,435,462</b>
<b>RESOURCES EXPENDED</b>					
<b>Costs of generating funds</b>					
Costs of generating voluntary income	6	452,864	49,918	502,782	526,627
Fundraising trading: cost of goods sold and other costs	6	7,577,695	-	7,577,695	7,168,481
<b>Total costs of generating funds</b>		<b>8,030,559</b>	<b>49,918</b>	<b>8,080,477</b>	<b>7,695,108</b>
<b>Net incoming resources</b>		<b>2,751,529</b>	<b>1,146,990</b>	<b>3,898,519</b>	<b>2,740,354</b>
<b>Charitable activities</b>					
Research	6	414,991	468,928	883,919	756,367
Healthcare	6	393,214	97,541	490,755	690,739
Social care	6	223,533	49,261	272,794	229,134
Respite breaks	6	24,639	6,000	30,639	31,656
Public education	6	191,108	-	191,108	160,436
<b>Governance costs</b>	6	131,164	-	131,164	125,630
<b>Total charitable expenditure</b>		<b>1,378,649</b>	<b>621,730</b>	<b>2,000,379</b>	<b>1,993,962</b>
<b>Total resources expended</b>	6	<b>9,409,208</b>	<b>671,648</b>	<b>10,080,856</b>	<b>9,689,070</b>
<b>Net income for the year and net movement in funds</b>		<b>1,372,880</b>	<b>525,260</b>	<b>1,898,140</b>	<b>746,392</b>
<b>Total funds brought forward</b>		<b>1,300,109</b>	<b>42,252</b>	<b>1,342,361</b>	<b>595,969</b>
Transfer between funds		( 16,149)	16,149	-	-
<b>Total funds carried forward</b>		<b>2,656,840</b>	<b>583,661</b>	<b>3,240,501</b>	<b>1,342,361</b>

All operations are continuing.

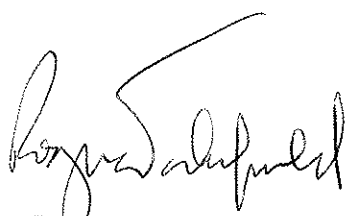
The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.


**BALANCE SHEET  
AS AT 31 DECEMBER 2011**

Company registration number 4118259

	Notes	£	2011 £	£	2010 £
<b>Fixed assets</b>					
Tangible assets	10		1,577,922		1,900,115
Intangible assets	10		( 888,935)		( 1,218,894)
			<u>688,987</u>		<u>681,221</u>
<b>Current assets</b>					
Stocks			14,405	5,455	
Debtors	11		722,428	698,966	
Cash at bank and in hand			<u>4,078,185</u>	<u>2,209,464</u>	
			4,815,018	2,913,885	
<b>Creditors: amounts falling due within one year:</b>	12		<u>( 2,158,816)</u>	<u>( 2,063,516)</u>	
<b>Net current assets</b>			2,656,202		850,369
<b>Total assets less current liabilities</b>			<u>3,345,189</u>		<u>1,531,590</u>
<b>Creditors: amounts falling due over one year:</b>	12		( 104,688)		( 189,229)
<b>Net assets</b>			<u><u>3,240,501</u></u>		<u><u>1,342,361</u></u>
<b>Funds</b>					
Unrestricted funds					
- Designated	14		973,622		-
- General			<u>1,683,218</u>		<u>1,300,109</u>
			2,656,840		1,300,109
Restricted funds	14		583,661		42,252
			<u><u>3,240,501</u></u>		<u><u>1,342,361</u></u>

The accounts were approved by the Board on 25th April 2012 and signed on their behalf by:

  
 Roger Wakefield  
 Chairman

  
 David Spence  
 Treasurer

**CASH FLOW STATEMENT  
FOR THE YEAR ENDED 31 DECEMBER 2011**

	Notes	£	2011 £	£	2010 £
<b>Net cash inflow from operating activities</b>	16		<b>1,835,933</b>		<b>552,208</b>
<b>Returns on investments and servicing of finance</b>					
Interest and rent received			<b>55,747</b>		<b>30,670</b>
<b>Capital expenditure</b>					
Payments to acquire tangible fixed assets and investments		( 22,959)		( 21,084)	
Disposal of investments		-		83,000	
<b>Net cash outflow from capital expenditure</b>			<b>( 22,959)</b>		<b>61,916</b>
<b>Increase in cash</b>	17		<b>1,868,721</b>		<b>644,794</b>

## NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2011

**1.0 ACCOUNTING POLICIES****1.1 Basis of preparation**

The accounts are prepared under the historical cost convention, and are in accordance with 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.

**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. Equipment purchased for use in research is written off as part of the research project costs as incurred. 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 2011

<b>2 VOLUNTARY INCOME</b>	Unrestricted funds	Restricted funds	Total 2011	Total 2010
	£	£	£	£
Donations & gifts	1,626,276	810,613	2,436,889	1,883,426
Legacies receivable	564,015	2,000	566,015	51,295
Grants receivable	79,479	108,610	188,089	396,491
	<u>2,269,770</u>	<u>921,223</u>	<u>3,190,993</u>	<u>2,331,212</u>
<b>Donations &amp; gifts</b>				
Individual donations	1,391,343	316,048	1,707,391	1,402,373
Corporate donations	145,385	473,872	619,257	328,729
International donations	1,046	-	1,046	28,954
Events by Individuals	88,502	20,693	109,195	123,370
	<u>1,626,276</u>	<u>810,613</u>	<u>2,436,889</u>	<u>1,883,426</u>
<b>Grants receivable</b>				
Charitable trusts	79,479	100,410	179,889	382,141
Scottish Executive		8,200	8,200	14,350
	<u>79,479</u>	<u>108,610</u>	<u>188,089</u>	<u>396,491</u>

<b>3 ACTIVITIES FOR GENERATING FUNDS</b>	Total 2011	Total 2010
	£	£
Income	8,607,869	7,928,974
Operating expenses	(7,577,695)	(7,168,481)
Net income from fundraising activities	<u>1,030,174</u>	<u>760,493</u>

The greatest income from activities for generating funds is derived from the operation of charity shops selling donated goods. As at 31 December 2011 there were 116 shops trading compared to 118 at 31 December 2010. The major categories of income and expenditure are summarised below:

	Income	Operating expenses	Net income 2011	Net income 2010
	£	£	£	£
Retail	7,696,891	(7,099,621)	597,270	558,797
Fundraising events	874,925	(477,275)	397,650	169,233
Miscellaneous trading	36,053	(799)	35,254	32,463
	<u>8,607,869</u>	<u>(7,577,695)</u>	<u>1,030,174</u>	<u>760,493</u>

Shops continue to show a good rate of growth over the previous year. The growth in income from fundraising events has been outstanding during 2011, despite the difficult economic circumstances this year. Of particular note is the success of the Silver Butterfly dinner which raised a total of £120k, restricted to the Sohana Research Fund. This event also raised £108k in donations recognised in voluntary income above.

<b>4 INVESTMENT INCOME</b>	Total 2011	Total 2010
	£	£
Interest receivable	28,939	13,250
Rent of flats	26,808	17,420
Total investment income	<u>55,747</u>	<u>30,670</u>

Rental income was received from four flats, situated above properties acquired in 2009, two of which were disposed of during 2011.

**5 GRANTS PAYABLE**

Expenditure on charitable activities include grants payable to third parties as detailed in Note 6. 143 Social Care grants totalling £32,418 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 2011

**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 2011 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £983,753 (£571,324 at 31 December 2010).

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

	Total 2011 £	Total 2010 £
Within 1 year	574,663	267,917
Within 2-3 years	409,090	303,407
Within 4-5 years	-	-
	<b>983,753</b>	<b>571,324</b>
Provided within the grants payable creditor	983,753	571,324
Contingent liability	-	-
	<b>983,753</b>	<b>571,324</b>

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 2011 £	Total 2010 £
<b>Costs of generating funds</b>					
Voluntary income	277,921	-	224,861	502,782	526,627
Activities for generating funds	4,265,905	-	3,311,790	7,577,695	7,168,481
	4,543,826	-	3,536,651	8,080,477	7,695,108
<b>Charitable expenditure:</b>					
Research	233,398	606,301	44,220	883,919	756,367
Healthcare	274,223	192,972	23,560	490,755	690,739
Social care	200,732	32,418	39,644	272,794	229,134
Respite breaks	-	-	30,639	30,639	31,656
Public education	141,845	-	49,263	191,108	160,436
	850,198	831,691	187,326	1,869,215	1,868,332
<b>Governance costs</b>	92,564	-	38,600	131,164	125,630
	5,486,588	831,691	3,762,577	10,080,856	9,689,070
<b>Other costs</b>	Depreciation and amortisation £	Overhead allocation £	Miscellaneous costs £	Total 2011 £	Total 2010 £
<b>Costs of generating funds</b>					
Voluntary income	-	96,521	128,340	224,861	232,882
Activities for generating funds	(252,623)	144,711	3,419,702	3,311,790	3,342,549
	(252,623)	241,232	3,548,042	3,536,651	3,575,431
<b>Charitable expenditure</b>					
Research	-	44,220	-	44,220	26,372
Healthcare	-	23,560	-	23,560	17,887
Social care	-	20,960	18,684	39,644	28,388
Respite breaks	11,527	-	19,112	30,639	31,656
Public education	-	49,263	-	49,263	33,360
	11,527	138,003	37,796	187,326	137,663
<b>Governance costs</b>	-	32,147	6,453	38,600	26,340
	(241,096)	411,382	3,592,291	3,762,577	3,739,434

Operating lease costs of £1,206,478 are included in miscellaneous costs and relate to rental of premises (£1,172,329), equipment hire (£16,619) and vehicles (£17,455).

## NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2011

**7 COST ALLOCATION**

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

	2011 £	2010 £
<b>Staff costs</b>	<b>1,184,518</b>	<b>1,190,689</b>
<b>Overheads</b>		
Office premises rent	31,272	35,195
Service charges, utilities & cleaning	29,229	25,938
Equipment costs	100,145	78,684
Postage, printing, stationery, telephone & fax	101,908	96,914
Insurance costs	41,595	37,811
Legal, professional & consultancy fees	34,050	24,288
Bad debt write off	-	-
Auditor's remuneration (audit services)	16,000	16,957
Depreciation	19,810	18,518
Irrecoverable VAT	23,870	- 44,733
Bank charges	12,556	8,922
Sundry expenses	947	14,089
	<b>411,382</b>	<b>312,583</b>
<b>Total Allocation</b>	<b>1,595,900</b>	<b>1,503,272</b>

**8 TRUSTEES**

None of the trustees (or any person connected with them) received any remuneration during the period, but six of them were reimbursed a total of £4,757 for travel and subsistence expenses.

Scott O'Sullivan received welfare grants during the year totalling £245. Amy Livesey received one grant of £54 and Melissa Smith received one grant of £2,543.

John Tough received a payment of £400 in 2011 for his work as a Charity Shop Consultant and Scott O'Sullivan received £1,038 for his work as a Living with EB Consultant. 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:

	2011 full time equiv	2011 Number	2010 Number
Research	1.5	2	2
Healthcare*	3.7	5	5
Social care	3.2	5	3
Fundraising	12.4	14	17
Shops	224.7	281	262
Management & administration	14.8	17	13
	<b>260</b>	<b>324</b>	<b>302</b>

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

	2011 full time equiv	2011 Number	2010 Number
Research	1.5	2	2
Healthcare*	3.7	5	4
Welfare	3.5	5	3
Fundraising	12.6	14	18
Shops	215.3	275	285
Management & Administration	17.7	20	14
	<b>254</b>	<b>321</b>	<b>326</b>

\*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 2011 £	Total 2010 £
Wages & salaries	4,604,391	4,143,237
Social security costs	324,769	307,745
Pension costs	130,563	118,537
	<b>5,059,723</b>	<b>4,569,519</b>

## NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2011

**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 £100,883 were made in the year and charged to the SOFA in the period they were due. At the year end there remained £25,637 unpaid. In addition, £5,159 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:

	2011	2010
Between £60,001 - £70,000	2	2
Between £120,001 - £130,000	-	-
Between £150,001 - £160,000	1	1

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £25,613 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	Motor vehicles	Freehold land and buildings	Total
	£	£	£	£	£	£
<b>Cost</b>						
At 1 January 2011	236,101	125,757	242,956	10,717	1,784,572	2,400,103
Additions	7,780		15,178			22,958
Disposals				(9,375)	(245,000)	(254,375)
<b>At 31 December 2011</b>	<b>243,881</b>	<b>125,757</b>	<b>258,134</b>	<b>1,342</b>	<b>1,539,572</b>	<b>2,168,686</b>
<b>Depreciation</b>						
At 1 January 2011	94,440	71,075	211,013	6,030	117,430	499,988
Charge for the year	48,128	11,527	11,801	1,367	35,850	108,673
Disposals				(6,055)	(11,842)	(17,897)
<b>At 31 December 2011</b>	<b>142,568</b>	<b>82,602</b>	<b>222,814</b>	<b>1,342</b>	<b>141,438</b>	<b>590,764</b>
<b>Net Book Value</b>						
Brought forward	141,661	54,682	31,943	4,687	1,667,142	1,900,115
<b>At 31 December 2011</b>	<b>101,313</b>	<b>43,155</b>	<b>35,320</b>	<b>-</b>	<b>1,398,134</b>	<b>1,577,922</b>

The net book value of fixtures, fittings and equipment includes an amount of £69,081 (2010: £103,622) 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 (2010: £34,541).

**Intangible fixed assets**

	Acquisition goodwill
	£
<b>Cost</b>	
At 1 January 2011	(1,318,750)
Additions	-
Disposals	-
<b>At 31 December 2011</b>	<b>(1,318,750)</b>
<b>Amortisation</b>	
At 1 January 2011	99,856
Charge for the year	329,959
Disposals	-
<b>At 31 December 2011</b>	<b>429,815</b>
<b>Net Book Value</b>	
Brought forward	(1,218,894)
<b>At 31 December 2011</b>	<b>(888,935)</b>

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

Date	Released in year	Cumulative
Mar 2010	115,000	115,000
Mar 2011	380,000	495,000
Mar 2012	355,000	850,000
Mar 2013	275,000	1,125,000
Mar 2014	193,750	1,318,750
Mar 2015	200,000	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 2011

11	DEBTORS	2011	2010
		£	£
	HMRC/Misc Debtors	124,224	90,105
	Other debtors	74,650	64,353
	Accrued income	201,350	239,698
	Prepayments	322,204	304,810
		<u>722,428</u>	<u>698,966</u>

HMRC/Misc Debtors includes quarter 4 2011 VAT refund due of £96,965. Accrued income includes gift aid of £183,649 due for quarter 4 2011.

12	CREDITORS: amounts falling due within one year	2011	2010
		£	£
	Trade creditors	172,390	196,865
	Grants payable	1,287,605	947,697
	Other creditors	432,710	367,859
	Taxation and social security	- 333	113,238
	Accruals	244,844	435,457
	Deferred Income	21,600	2,400
		<u>2,158,816</u>	<u>2,063,516</u>

The charity has 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. £34,541 in finance lease payments are due within one year.

There is a dilapidations provision of £317,612 (2010: £256,934) accounted for under other creditors.

	CREDITORS: amounts falling due over one year	2011	2010
		£	£
	Finance leases	54,688	89,229
	Acquisition creditor	50,000	100,000
		<u>104,688</u>	<u>189,229</u>

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

## 13 OTHER FINANCIAL COMMITMENTS

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

	Premises rent £	Equipment hire £	Van hire £
Expiring within 1 year	394,470		10,473
Expiring within 2-5 years	519,251	16,619	7,858
Expiring after 5 years	163,752		
	<u>1,077,473</u>	<u>16,619</u>	<u>18,331</u>

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

	Epos equipment £
Payable in 1-2 years	34,541
Payable in 2-5 years	20,147
Payable after 5 years	-
	<u>54,688</u>

There was a capital commitment of £2,510 at the year end.

## NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2011

## 14 ANALYSIS OF FUNDS

	Balance at 31 Dec 2010	Movement between funds	Incoming resources	Resources expended	Balance at 31 Dec 2011
	£	£	£	£	£
<b>Restricted funds</b>					
Research	-	16,149	995,485	468,928	542,706
Healthcare	16,196	-	87,885	97,541	6,540
Social care	26,056	-	63,620	55,261	34,415
Fundraising	-	-	49,918	49,918	-
	<u>42,252</u>	<u>16,149</u>	<u>1,196,908</u>	<u>671,648</u>	<u>583,661</u>

**Restricted funds at 31 December 2011 comprise:**

	£
Research - Sohana Research Fund	542,706
Healthcare - dressings	8,253
Healthcare - India fund	6,250
Healthcare - nurses study leave fund	2,507
Healthcare - dietician fund	333
Healthcare - nursing equipment	177
Social Care - work in Dundee or Tayside	13,930
Social Care - work in West Lancashire	3,884
Social Care - work in Nottinghamshire	1,705
Social Care - holiday and travel costs Manchester families	1,420
Social Care - work in Liverpool	1,000
Social Care - work in Kingston	463
Social Care - work near Halifax	426
Social Care - work in Islay	420
Social Care - work for Tameside families	187
	<u>583,661</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 £942,706, of which £400,000 was committed in 2011 to the project EBSTEM. This project is based in London and is in the early pre-clinical stages of preparation for a mesenchymal stem cell clinical trial, involving up to 20 children with Recessive Dystrophic EB. The balance held in the fund will be used to finance new Recessive Dystrophic EB research projects and clinical trials, including further development of the EBSTEM project.

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 2011:

	Balance at 31 Dec 2010	Movement between funds	Incoming resources	Resources expended	Balance at 31 Dec 2011
	£	£	£	£	£
Furniture and Electrical shops	-	-	700,000	8,318	691,682
New health and social care projects	-	-	168,106	-	168,106
Research grant round in 2012	-	-	113,834	-	113,834
Total designated funds		-	981,940	8,318	973,622
General fund	1,300,109	( 16,149)	9,800,148	9,400,890	1,683,218
Total unrestricted funds	<u>1,300,109</u>	<u>( 16,149)</u>	<u>10,782,088</u>	<u>9,409,208</u>	<u>2,656,840</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 2012 and 2013.

DEBRA has saved £168,106 during 2011 from the increased funding for healthcare of EB patients from the NHS. A designated fund has been established to demonstrate the trustees' commitment to ploughing back all these savings into new health and social care projects, which will commence in 2012. Ongoing savings will be added to the fund and a £150,000 contingency will be held in the event of future funding withdrawal.

There was a writeback of £113,834 of unspent research grants in 2011, which has been designated by the trustees for expenditure on new research grants in 2012.

## 15 ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds £	Restricted funds £	2011 Total £	2010 Total £
Fund balances at 31 December 2011 are represented by:				
Fixed assets	688,987	-	688,987	681,221
Current assets	4,231,357	583,661	4,815,018	2,913,885
Creditors: amounts falling due within one year	( 2,158,816)	-	( 2,158,816)	( 2,063,516)
Long term creditors	( 104,688)	-	( 104,688)	( 189,229)
	<u>2,656,840</u>	<u>583,661</u>	<u>3,240,501</u>	<u>1,342,361</u>

## NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2011

16	NET CASH INFLOW FROM OPERATING ACTIVITIES	2011	2010	
		£	£	
	Reconciliation of changes in resources:			
	Changes in resources	1,898,140	746,392	
	(Profit)/loss on disposal of fixed assets	236,478	111,742	
	Depreciation of fixed assets	( 221,286)	11,411	
	Decrease / (increase) in stock	( 8,950)	5,585	
	Decrease / (increase) in debtors	( 23,462)	( 74,436)	
	(Decrease) / increase in creditors	10,760	( 217,816)	
	Investment income receivable	( 55,747)	( 30,670)	
		<u>1,835,933</u>	<u>552,208</u>	
17	RECONCILIATION OF NET CASH FLOW TO MOVEMENT IN NET FUNDS	2011	2010	
		£	£	
	Increase in cash	1,868,721	644,794	
	Net funds b/f	2,209,464	1,564,670	
	Net funds c/f	<u>4,078,185</u>	<u>2,209,464</u>	
18	GRANTS TO INSTITUTIONS	Total	Total	
		2011	to date	
		£	£	
	Research Projects		Total	
			project cost	
			£	
	University of Dundee			
	Pre-clinical trials re application of siRNA therapy in EB Simplex	58,388	58,388	192,804
	Establishment of an EB keratinocyte collection	11,168	11,168	67,007
	Pre-clinical assessment of PLK1 inhibitors	4,856	4,856	66,138
		<u>74,412</u>	<u>74,412</u>	<u>325,949</u>
	Netherlands Cancer institute			
	Studying Kindler Syndrome in an <i>in vivo</i> model system	8,432	8,432	101,997
	King's College London			
	Developing refined stem-cell therapies for RDEB	74,012	86,326	148,530
	Blizard Institute of Cell and Molecular Science, London			
	Dissecting the role of basement membrane components	52,723	52,723	114,960
	Istituto Dermatopatico dell'Immacolata, Rome			
	Modifying genes in phenotypically discordant siblings with RDEB	32,697	32,697	87,344
	University of Santiago, Chile			
	Increasing research capacity	36,663	36,663	40,000
	Clinical guidelines for dental care in EB patients	15,000	15,000	15,000
		<u>51,663</u>	<u>51,663</u>	<u>55,000</u>
	Great Ormond Street Hospital, London			
	Review of pain perception and management	2,800	2,800	4,200
	Guy's Hospital, London			
	Determining the molecular basis of EB	10,966	10,966	65,792
	Mesenchymal stem-cell therapy clinical trial	-	-	400,000
		<u>10,966</u>	<u>10,966</u>	<u>465,792</u>
	Other			
	- Increase in research provision	412,430		
	- Grant underspends	(113,834)		
	-Unused grants written back at end of project			
		<u>298,596</u>	<u>-</u>	<u>-</u>
	Total research grants	<u>606,301</u>	<u>320,019</u>	<u>1,303,772</u>
		Total £		Total £
		2011		project cost
	Research project expenditure by category:			
	- Genetic research	( 7,999)		288,637
	- Cancer research	9,423		181,098
	- Clinical research	36,132		39,200
	- Therapies	568,746		794,837
		<u>606,301</u>		<u>1,303,772</u>

# DEBRA

## NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2011

### 18 GRANTS TO INSTITUTIONS (continued)

	Total 2011 £	Total project cost £
<b>Healthcare Team projects</b>		
<b>Great Ormond Street Hospital for Sick Children</b>		
Three clinical nurse specialists in EB	48,884	62,977
<b>Guys &amp; St Thomas' Hospital London</b>		
Five adult support nurses	141,389	217,390
<b>Other</b>		
- Miscellaneous healthcare grants	2,148	12,908
- Scotland	551	106,082
<b>Total Healthcare Team grants</b>	<u><u>192,972</u></u>	<u><u>399,357</u></u>

### 19 RELATED PARTIES

#### 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:

	2011 £	2010 £
Turnover	28,595	24,822
Net Profit transferred to DEBRA	<u><u>955</u></u>	<u><u>8,431</u></u>
Net assets	<u><u>-</u></u>	<u><u>-</u></u>

During the year, the charity charged management charges totalling £7,200 including VAT (2010 - £5,875) to its subsidiary DEBRA Trading Limited.

#### Other Related Parties

£96,146 was payable to DEBRA's medical advisor Professor John McGrath during the year, in respect of two research projects approved by the trustees, with a further provision of £572,869 as at 31 December 2011.

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

