



About DEBRA

DEBRA is the national charity that supports individuals and families affected by Epidermolysis Bullosa (EB) – a genetic condition which causes the skin to blister and shear at the slightest friction, or even spontaneously.

DEBRA was founded in 1978 and provides 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 relies on the generosity of the public to carry out its vital work, improving lives and giving hope.

For more information on DEBRA visit www.debra.org.uk.

About EB

- EB is a currently incurable genetic skin condition.
- There are three main types of EB varying in severity – Simplex, Dystrophic and Junctional.
- In its most severe forms, EB is fatal in infancy and can cause fatal skin cancer in young adults, However, in its mildest forms it can cause lifelong disability and pain.
- EB causes a breakdown in the natural proteins that hold the skin and internal membranes, causing blistering and sores at the slightest touch – or even spontaneously.
- Skin blisters have to be lanced and dressed every day – a painful procedure, taking up to 3 hours.
- Excessive blistering creates scar tissue which can cause toes and fingers to fuse together. Scar tissue can also cause the oesophagus to narrow, making eating difficult.
- People with EB are often fighting infection, both internally and externally.
- One in 227 of us carry the recessive EB gene.
- There are at least 5,000 people living with EB in the UK and about 500,000 worldwide. This means that one in 17,000 births are affected by EB.

Our purpose:

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

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

We give support to people and families affected.

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

Our values:

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

Make a positive difference to people living with EB.

Work together to achieve our purpose of providing care and curing EB.

Strive for excellence in all our activities.

Be passionate about all we do with DEBRA.

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Introductions



During 2010 DEBRA continued to raise money to support EB sufferers, their families and nurses; and to fund research into the causes of EB and into possible treatments. Given the economic environment, the charity performed well, shifting the emphasis of its fundraising in response to the new

conditions. I pay tribute to the staff who enabled DEBRA to weather the storm.

I am always struck by the enormous courage of EB sufferers who volunteer to take part in clinical trials, and who appear on public platforms or on the media to spread knowledge and understanding of EB and to inspire others, perhaps younger sufferers. They are exceptional people who make a vital contribution to this charity.

Another group of people impresses me deeply: the medical teams who care for EB patients and who conduct the research. Their skill and commitment are breath-taking. Their willingness to appear in public and speak in layman's terms about EB helps to spread awareness of the condition and to raise the money that will enable their work to make further progress.

Michael Portillo, DEBRA President



The charity entered 2010 conscious of the likely continuing adverse effects of the international economic downturn, but with growing confidence in the sustainability of income from our ever-growing network of shops.

This sustained income and continuing improvement

throughout the year allowed the trustees to sponsor a research grant round during the second half of the year and to approve funding of nearly half a million pounds in December 2010 for four new projects.

The board of Trustees also continue to maintain their commitment to DEBRA's nursing and social care teams, whose roles are pivotal in the care of people with EB.

I feel very privileged to have been the Chair of DEBRA for 23 years and I am proud of the advances that trustees, staff and people living with EB have made over this period of time in making DEBRA the force for good that it has become in all aspects of our work.

Philip Evans, Chairman



This has been a very good year for our charity as we have very quickly created our financial strength during a very difficult period for many competing causes. Perhaps the best moment for me was when we immediately stepped in and supported one of our nurses as soon as we learnt

that a cut in funding would have resulted in our nursing capability being reduced.

Expanding the welfare team and a significant fresh commitment to new research at the end of the year also created a feel good impact for all of us. Money talks! Our research grants have a new focus on searching for clinical trials that make a real difference to the community as well as basic research to develop core genetic understanding. At a time when we are working hard to turn around our fundraising we should give a big thanks to our Retail team. Our profit from the shops has tripled over the last few years and we are starting to benefit from the sale of freehold properties that we acquired for no cost as part of our acquisition in 2009.

It remains a privilege and a challenge to be the CEO at DEBRA. The fight against EB is clearly a long term endeavour and it is only with team work that we are able to raise money, spend it as effectively as possible and make transformational steps in genetic understanding as well as giving the best level of care that we can afford. Your team at DEBRA exists for you and I would like to give a particular thank you to the members of the community who often inspire us with their fortitude.

Ben Merrett, CEO

How we help

Research

This is an exciting time for EB research. There are now a number of potential therapeutic approaches in late preclinical stages or early-stage clinical trials for different types of EB which we expect to see develop further over the coming years. Increasingly, DEBRA pump-priming of research is attracting major follow-on funding for therapy development from other organisations, including large UK medical charities, EU government, and biopharma-company partnering.

One of these trials, undertaken in the UK by Prof. McGrath, involves the injection of fibroblasts into the skin of people with severe EB whose wounds often take a long time to heal, or do not heal at all. Initial results from a small group of patients showed evidence of significantly improved wound healing and increased skin stability. During 2010, with funding from DEBRA and a small biotech company providing the fibroblasts, the data obtained so far were evaluated and the infrastructure for a Phase II trial put in place. Recruitment for the Phase II trial started at the end of 2010 and the trial will start in early 2011.

Whilst there are many challenges to be overcome in basic research and in therapy development, there has never been a time when so many opportunities existed and DEBRA has committed itself to doing all it can to make sure that the necessary work is undertaken to take them forward.

The charity entered 2010 conscious of the need for prudence in the light of the international economic downturn but with growing confidence in the sustainability of income from charity shops. Consequently, with existing substantial commitments to ongoing research projects, trustees took the view early in 2010 that commitments to fund new research, with the exception of the fibroblast trial mentioned above, should be delayed until the end of 2010 by which time the robustness of the charity's financial position could be more accurately assessed. However, the continuing improvement during the year in income and the strength of the reserves did in fact allow the trustees to sponsor a research grant round during the second half of the year: in December 2010, trustees approved funding of £435,000 on four new projects with the potential to advance the development of therapies for EB and its complications.

Research expenditure during the year was £756,367 and the trustees are confident that research expenditure can safely be budgeted to grow over the next three years. December 2010 saw successful completion of DEBRA first two major programme

grants, each budgeted at £1M+, over five years, one targeting cancer in severe RDEB, the other, topical drug development for EB Simplex. Both projects have led to further large-scale external funds and industry collaborations to take research forward to the clinic, as well as giving DEBRA confidence in the added value of the synergy of big collaborative grants.

DEBRA has a long history of working internationally in EB research, so it was also possible for a research grant application round, financed by DEBRA Austria (with a contribution from DEBRA of America), to be launched in the first half of 2010. DEBRA International research is managed by the mainly UK funded DEBRA International research staff. Two research projects from this round were recommended for funding. One of the successful applicants was subsequently awarded nearly €5M from the European Union to fund preclinical research and an eventual Phase I clinical trial for gene therapy in Recessive Dystrophic EB, abrogating the need for DEBRA funding, so these funds were reallocated to future research. DEBRA International is a partner in this EU grant.

As a result of the increased stability and predictability of income achieved during 2010, DEBRA can look forward confidently to increasing its impact year-on-year in the development of treatments for EB. Combining resources with other DEBRAs and working to common goals and priorities, sufficient funding will be available for two research grant rounds during 2011, with DEBRA contributing £500,000 for new research.

Equal priority will be given to research with either nearer-term, or longer-term, benefits for people living with EB. The objective is to balance work to create improvements in quality of life by symptom relief, with more complex and fundamental research to create lasting and effective treatments and cures. In parallel, there will be an increasing focus on the logistics and funding of therapy development and delivery, utilising the new Translational Research Advisory Panel to identify areas where DEBRA needs to commission ancillary projects to drive clinical application of research outputs and adoption of novel therapies by the NHS and other healthcare providers. A budget of £100,000 has been allocated to this work in 2011.

Overall, DEBRA can look back of 2010 as a year when it was, once again, able to take a leading role in the facilitation and funding of EB research and can look forward, with confidence, to increasing that impact in 2011 and beyond.



DEBRA Health and Social Care Services

One of DEBRA's primary objectives is to provide specialist, dedicated healthcare services for people with EB, both directly and indirectly in conjunction with local statutory providers, which are responsive to the wishes of the EB community across the UK. This is particularly necessary since EB is a rare condition about which few health professionals will have any knowledge and for which no local or regional health care provider will establish a specialist service. The DEBRA Healthcare Team, and their NHS colleagues, bridges that gap by providing the high level of expertise needed to care adequately for people living with EB both directly and via shared care with local health professionals.

The team currently consists of 11 nurses employed through a combination of being employed directly or via DEBRA healthcare grants. DEBRA also funds the EB podiatry service at St Thomas Hospital. In 2010, the DEBRA healthcare team increased the number of nurse-led clinics and outreach work in order to support the diverse and dynamic needs of people living with and accessing the EB services. The team were also heavily involved in research projects, product development, evaluations and establishing best practice care guidelines to support people living and working with EB.

DEBRA continued to work closely with the four EB hospital centres of excellence based at St Thomas, Great Ormond St, Solihull and Birmingham Children's hospitals. DEBRA have supported both national and international EB conferences, study/ training days as well as poster and article publications all of which have helped share knowledge of EB and specialised care practices.

DEBRA Social Care

In 2010, DEBRA remained dedicated to its objective of providing specialist social care services for people living with EB, which is responsive to the wishes of the EB community, and allocated additional funding to the team to increase the number of team members and the availability of support grant funds.

During 2010 the social care team priorities continued to be:

- 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.



DEBRA's social care managers can visit clients in their homes or whilst they are in clinic.

- to identify, in conjunction with people with EB the need for new services and means of support.

The change in social reform, particularly with regard to benefits towards the end of 2010 has already resulted in an increase demand on the DEBRA social care team. During 2010 many DEBRA support grants were awarded to individuals and families making a real difference to the quality of life, from specialist bed mattresses at home to funding other essential or emergency items.

A successful DEBRA 2010 members' day conference was held in Manchester and a number of smaller meetings and opportunities for people living and working with EB to meet, were organised and funded.

Respite breaks and weekends away

DEBRA's objective is to enable people living with EB to have breaks away from home in accommodation that has been specifically chosen to meet their needs. The three mobile homes, located in Weymouth (Dorset) and in Brighthouse Bay (Dumfries & Galloway) continued to be very popular throughout 2010 for individuals and families living with EB, and bookings for 2011 are near to full capacity.

DEBRA's objective to provide an opportunity for adults with EB to have a weekend away, fully supported with all of the necessary care, not only provides a great opportunity for people to



DEBRA members enjoying the glamorous Manchester Ball as part of their weekend away.

socialise and have fun, but also offers some carers respite. In 2010, people from across the UK had a fantastic break away in Manchester which included attending a Butterfly Ball, a private fashion show at one of the world's prestigious stores and many opportunities to socialise and explore Manchester.

Fundraising and awareness



Mason White, who featured in the BBC Lifeline programme alongside Sohana Collins and Melissa Smith

BBC Lifeline Appeal

DEBRA featured as the nominated charity on November's BBC Lifeline television programme. Hosted by DEBRA President Michael Portillo it is estimated that 1m people will have seen this 9 minute film profiling families living with EB and the work of DEBRA. In addition to increased public awareness the programme raised £27,000 in 2010 with further amounts continuing to come in. At almost three times the average reported amount for the lifeline appeals in 2009-2010, this serves to underline once again the compelling nature of DEBRA's work and the cause of the EB community in the public's perception.

Changing the way we communicate

DEBRA has been proactive in developing its digital media profile and has in excess of 1,400 followers on Facebook with whom we can quickly and inexpensively communicate. DEBRA began trials of specialist email service providers, to allow a greater reach on our core messages and provide detailed analysis on the effectiveness of the charity's e-communications.

Work commenced on a comprehensive review of the charity's Communications Strategy to allow DEBRA in the UK to reflect the international branding being formally adopted across many DEBRAs worldwide. As a part of this strategy a new logo and strapline were approved by the Trustees in the latter part of 2010, along with new vision and purpose definitions. DEBRA benefited from the support of a leading brand agency, Publicis, which provided pro bono expertise and resource for this work.



DEBRA supporters Frank Warren and Jim Rosenthal with DEBRA member Dean Anderson at the charity's flagship Fight Night event.

Key Events

DEBRA runners in the Virgin London Marathon (VLM) were particularly successful, raising a total of £119,000 (including gift aid). The average amount raised per DEBRA Gold Bond runner was £4,600, which is nearly double the average amount raised by runners in the VLM.

The DEBRA Fight Night achieved a net income of £87,000, a growth of 50% over 2009. This success was underpinned by increased levels of attendance, with over 400 guests, and a reduction in operating costs. The Fight Night Committee, made up of volunteers from DEBRA's "Appeals Council" of senior supporters, continued to give support and guidance to DEBRA, actively assisting with table sales and attracting high value auction items.

Community Fundraising

Community fundraising performed broadly in line with expectations. DEBRA has some excellent small groups and individuals who are actively organising and running localised events and activities with minimal direct DEBRA input: e.g. a significant contribution was made by a passionate supporter undertaking a car rally, raising £58,000 for DEBRA. This model of fundraising "in aid of DEBRA" continued to be a robust income stream, even through the period of recession, and is an area for future development.



DEBRA supporters Simon McKenzie-Smith and Rupert Marks embarked on the journey of a lifetime by driving a 1929 Model A Ford over 14,000 kilometres from Peking to Paris.

Shops

DEBRA has a network of 120 shops across the UK and enjoyed another strong year in 2010 with 40% gross income growth. In addition, the retail gift aid scheme has grown from £138,000 in 2009 to £546,000 in 2010. This was a key area of growth identified in the 2009 Report and Accounts. At the end of 2010 30% of sales were gift aided, with plans in place to increase this important source of income. This year benefitted particularly from the full year effect of the 34 shops acquired in the latter part of 2009. This acquisition included £1.5m of freehold property which, as a charge on these properties is reduced, will significantly strengthen the financial position of the charity. Strong like for like performance and new pricing initiatives also contributed to this growth.



Treasurer's Report

DEBRA had a successful year financially in 2010, a £746,000 operating surplus resulting in a significant strengthening of the balance sheet. The financial objective for the year was primarily to rebuild reserves to the policy level of £500,000 cash-backed free reserves. This was achieved alongside a 16% increase in charitable expenditure over 2009. Outlined below is a table showing the last 6 years results, showing the movement in DEBRA's financial position over this period.

	2010	2009	2008	2007	2006	2005
Surplus/ (Deficit)	£746,392	£344,083	£(242,428)	£(388,181)	£(182,249)	£25,880
Unrestricted Reserves	£1,300,109	£549,367	£218,499	£392,774	£765,597	£988,906

The surplus during 2010 and the resulting growth in reserves is a commendable achievement by the charity during a period of economic recession. The charity is financially strong and can make new commitments to charitable expenditure in 2011 with confidence. The most significant area of income growth has been the dramatic increase in the retail gift aid scheme, growing from £138,000 in 2009 to £546,000 in 2010, with further growth budgeted for 2011.

Despite the economic recession most areas of fundraising grew in 2010 compared to 2009 with gross income exceeding £10 million, a 35% increase. In addition to the gift aid mentioned above, particular successes during 2010 were the £119,000 raised from the London Marathon and a net profit of £87,000 from DEBRA's annual Fight Night held in association with Frank Warren. To mitigate any potential negative impact of the economic recession DEBRA invested significantly in trading activities in 2009 with the introduction of EPOS tills to facilitate gift aid commencing in quarter 3 and an acquisition of 34 shops in quarter 4. The full year effect of these acquired shops contributed to the 40% growth in shops gross income from £5,167,000 to £7,208,000. At the end of 2010 there were 120 shops compared to 118 at the end of 2009 and plans are in place to increase this portfolio during 2011.

In addition to supplementing the reliable income stream of trading activities, the acquisition included 10 freehold properties valued at £1.5m which will notably strengthen the

balance sheet over the next few years as legal charges over them are removed. To assist in increasing DEBRA's cash reserves one of these properties was sold in 2010 and two more will be sold early in 2011.

The support from the Appeals Council and DEBRA's President Michael Portillo during 2010 has once again been invaluable. In particular Michael Portillo spearheaded the DEBRA BBC Lifeline appeal, broadcast in November 2010. This appeal raised £27,000 in 2010, and with further donations coming in during 2011 the total amount raised is expected to be £40,000. This was by far the largest amount raised by a Lifeline appeal in 2010, demonstrating the captivating nature of DEBRA's cause.

Expenditure on charitable activities was £1,994,000, which was up from £1,720,000 in 2009. This increase was due largely to increased expenditure on the nursing team, some of which was as a result of the withdrawal of national funding. DEBRA's research programme benefitted from £435,000 of new commitment in December 2010, and now reserves have been successfully rebuilt, this is an area that is anticipated to grow significantly in 2011.

Unrestricted Reserves have increased from £549,000 at the end of 2009 to £1,300,000 at the end of 2010. Cash-backed free reserves are £619,000, comfortably over the policy level of £500,000. Cash-backed free reserves are unrestricted reserves minus fixed assets (excluding investments) and represent the level of reserves the charity can access immediately.

Summary accounts are shown on the next page. These have been prepared from the full financial statements of DEBRA, on which the auditors expressed an unqualified opinion, and which will be put to the members for approval at the AGM on 21st May 2011. The full financial statements are filed each year with the Charity Commission and the Registrar of Companies. The summarised financial accounts shown here are not the company's statutory accounts and may not contain enough information to allow for a full understanding of the financial affairs of DEBRA. For further information, the full financial statements should be consulted, copies of which will be available on request from the DEBRA office.

David Spence

Auditors' Statement to the Trustees of DEBRA

We have examined the summarised financial statements of DEBRA.

Respective responsibilities of trustees and auditors: The trustees are responsible for preparing the summarised annual report in accordance with applicable law. Our responsibility is to report to you our opinion on the consistency of the summarised financial statements within the summarised annual report with the full financial statements and Trustees' Report. We also read the other information contained in the summarised annual report and consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the summarised financial statements.

Our report has been prepared pursuant to the requirements of the Companies Act 2006 and for no other purpose. No person is entitled to rely on this report unless such a person is a person entitled to rely upon this report by virtue of and for the purpose of

the Companies Act 2006 or has been expressly authorised to do so by our prior written consent. Save as above, we do not accept responsibility for this report to any other person or for any other purpose and we hereby expressly disclaim any and all such liability.

Basis of opinion: We conducted our work in accordance with Bulletin 1999/6 'The auditors' statement on the summary financial statement' issued by the Auditing Practices Board for use in the United Kingdom.

Opinion: In our opinion the summarised financial statements are consistent with the full financial statements and trustees' report of DEBRA for the year ending 31 December 2010.

Auditors: BDO LLP, Registered Auditors, Reading

27 April 2011

Financial Overview

Summary Statement of Financial Affairs at 31 December 2010

	2010 £	2009 £
Income		
Voluntary	1,525,743	1,126,762
Corporate	328,729	378,426
International	28,954	956
Charitable Trusts	396,491	236,096
Legacies	51,295	94,678
Trading - Shops	7,208,382	5,167,089
Trading - Events	720,592	675,880
Other Income	144,606	23,641
Bank Interest	30,670	8,471
Total	10,435,462	7,711,999
Costs of Generating Funds		
Fundraising Activities - Shops	6,649,585	4,660,790
Fundraising Activities - Events	518,896	499,130
General Fundraising & Publicity	526,627	488,449
Total	7,695,108	5,648,369
Net incoming resources available	2,740,354	2,063,630
Charitable Expenditure		
Research Grants	756,367	721,351
Healthcare	690,739	545,076
Social Care	229,134	207,746
Respite Breaks	31,656	28,819
Public Education	160,436	116,684
Governance Costs	125,630	99,871
Total	1,993,962	1,719,547
Net Income	£746,392	£344,083
Fund balances b/f	£595,969	£251,886
Fund balances c/f	£1,342,361	£595,969

Summary Balance Sheet at 31 December 2010

	2010 £	2009 £
Fixed Assets	1,181,221	866,290
Current Assets	2,413,885	2,200,240
Creditors	(2,063,516)	(2,113,791)
Net Current Assets/(Liabilities)	350,369	86,449
Long Term Creditors	(189,229)	(356,770)
Total assets less liabilities	1,342,361	595,969
Represented by:		
Restricted Funds	42,252	46,602
Unrestricted Funds	1,300,109	549,367
Total	1,342,361	595,969

Performance Indicators

	2010	2009
Charitable spend per £ raised (including net trading activities)	61p	67.4p
Fundraising efficiency (excluding trading activities)	79.0%	73.9p
Retained Surplus as a % of income	7.2%	4.5%

Charitable Expenditure



Trusts & Foundations

The support that DEBRA receives from charitable trusts and foundations continues to play a vital role in ensuring that people living with the daily challenges of EB receive specialist care and support, along with helping us in our quest to find new treatments for this devastating condition.

Our gratitude goes to each and every one of the charitable trusts who have given so generously towards our work during 2010. The following are just a few of our many trust supporters that we would like to thank in particular:

The BAND Trust

The William Brake Charitable Trust

The Louis Baylis (Maidenhead Advertiser) Charitable Trust

Bill Brown's Charitable Settlement of 1989

The Calleva Foundation

The Childwick Trust

The John Coates Charitable Trust

Baron Davenport's Charity

The Dorus Trust

The John Ellerman Foundation

The Eveson Charitable Trust

The Thomas Farr Charity

The Forest Hill Charitable Trust

The Donald Forrester Trust

The Joseph Strong Frazer Trust

The Gannochy Trust

The Gloag Foundation

The Hargreaves Beare Charity

The Hilton in the Community Foundation

The Klahr Charitable Trust

The Mickel Fund

The William and Mabel Morris Charitable Trust

The Murphy-Neumann Charity Company Limited

The Northwood Charitable Trust

The Norton Rose Charitable Foundation

The Austin and Hope Pilkington Trust

The Rank Foundation

The Riada Trust

The Sir James Roll Charitable Trust

The Coral Samuel Charitable Trust

The Sovereign Health Care Charitable Trust

The Thornton Foundation

The UPS Foundation

William Grant & Sons Ltd

Key Personnel

Key personnel

President: Michael Portillo

CEO: Ben Merrett

Director of Research & International: John Dart

Director of Finance: Carol Harris

Director of Nursing & Social Care:

Claire Mather (from 1 April 2010)

Director of Fundraising & Communication:

Gareth Simpson (from 19 April 2010)

EB Nurse Consultant (Children):

Jacqueline Denyer

EB Nurse Consultant (Adults):

Elizabeth Pillay

Trustees

Chair: Philip Evans

Vice-Chair: Michael Thomas

Treasurer: David Spence

Secretary: Scott O'Sullivan

David Bendor-Samuel, Clinton Budd, Robin Eady, Graham Marsden, Heather Mills, Gillian Pigott, Simon Rothwell, Melissa Smith, John Tough (from 22 May 2010), Patrick Turnbull, Roger Wakefield (from 22 May 2010)

International Medical and Scientific Advisory Panel

DEBRA manages the peer review system for all member groups of DEBRA International. We are grateful to the distinguished members of the International Medical and Scientific Advisory Panel for their advice and support.

Chair: Prof. Jo-David Fine (USA)

Vice Chair: Prof. Leena Bruckner-Tuderman (Germany)

Members: Prof. Robin Eady (UK), Dr Adrian Heagerty (UK), Prof. Helmut Hintner (Austria), Prof. Peter Humphries (Ireland), Prof. Thomas Magin (Germany), Dr John Marshall (UK), Prof. Jouni Uitto (USA), Prof. Giovanna Zambruno (Italy) and Dr Jemma Mellerio (UK).

DEBRA UK Medical & Scientific Adviser:

Prof. John McGrath





For further information please call 01344 771961

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A charity registered in England and Wales (1084958) and Scotland (SC039654)