



**EURORDIS**  
Rare Diseases Europe

**Making a difference today:  
Specialised healthcare and Community Support  
for people living with EB**

***Claire Mather – DEBRA UK***  
**Director of Healthcare and Community Support**



# Background information



- > DEBRA UK is a national charity supporting people living and working with EB
- > Epidermolysis Bullosa (EB) is a rare genetic skin condition which causes the skin to blister and shear at the slightest friction, or even spontaneously
- > The severity of blistering and life expectancy depends on the type of EB
- > There are four main types of EB and currently no cure for any type of EB
- > Estimated 5000 people living with EB in UK, and 500,000 Worldwide
- > DEBRA UK supports 'CURE' and 'CARE' initiatives.  
50% charitable expenditure is spent on research and 50% in making a difference to people 'today' through the healthcare and community support initiatives

# GENERAL INFORMATION ON THE SERVICE



**Name of Service:** > **EB Specialist Nursing and Healthcare in association with DEBRA**  
> **DEBRA EB Community Support**

**Country:** **UK**

**Type of Service:** 1 > **In partnership with the NHS enhancing the healthcare provision for people living with EB: inc. Nursing, Podiatry, Dietetic services, Multidisciplinary team initiatives**

2 > **Providing community / social care support, advice, advocacy and liaison services for individuals and families living and working with all types of EB**

**Type of institution:** **Registered National Charity**

**Origins of funding:** **Charitable funding from individual donors, charity retail, corporates, grants for trusts/foundations and TAX relief initiatives /'Gift Aid'**

**Cost for beneficiaries:** **Nil**

**Dates/Times of the Year:** **Continuous**

**Target Population:** **5000+ people living with EB and their families, carers, in addition to people working to support people with EB inc. Health & social Care professionals, Education for support workers etc.**

**Age-Groups:** **Any Age**

**Countries of Origin:** **UK- England, Northern Ireland, Scotland and Wales**

**Webpage:** **[www.debra.org.uk](http://www.debra.org.uk)**

# MAIN FIGURES

## EB Community Support And Enhanced Healthcare



**Total Budget/Year:**  
**c£1 Million DEBRA funding**

**Total Nr. of Beneficiaries/Year:**  
**c1200 people living with EB  
access support each year**

**Total Nr. of Permanent Staff:**  
**Employed by DEBRA: 10**  
**In Partnership with NHS: 18**

**Total Nr. of Intermittent Staff:**  
**Nil**

**Nr. of Volunteers/year:**  
**Nil**

# BRIEF HISTORY

DEBRA UK Established: **1978**

Created by: **Phyllis Hilton and families affected by EB**

Short History- Key mile stones:

**Specialist EB Healthcare and Community Support:**

- 1987- 1<sup>st</sup> TV appeal raised awareness and £500,000  
1<sup>st</sup> Specialist paediatric EB nurse employed  
Consultant Dermatology interest in developing EB service  
National Paediatric centre started to develop at GOSH London.
- 1989- 1<sup>st</sup> Specialist Adult EB nurse  
1<sup>st</sup> DEBRA Social Care Manger  
National Adult centre started to develop at GSTT London
- The Nursing and Community Support (previously Social Care) teams expanded over the years in response to the number of people accessing support, and continue to do so.
- Service developments funded by DEBRA including EB Podiatry service, nurse led clinics, clinical supervision, specialised EB training courses, patient network meetings and members groups/outings/events, out reach satellite clinics and regional social care posts established over the years




# Brief History cont.



**Celebrating 25 years of specialist EB nursing**

DEBRA and NHS working together and committed to the future

[www.debra.org.uk](http://www.debra.org.uk) 

A charity registered in England and Wales (1004900) and Scotland (SC021624)

- 2002- National Specialised Commissioning funds and designation of 4 national centres in UK (London and Midlands)
- 2011 > NHS partnership principle formally established  
> National EB Nursing Service Principles developed (DEBRA, NHS Commissioners and Clinical Teams)
- 2013- All Specialist EB Nurses in UK now employed by the NHS and supported up to 25% by DEBRA to carry out charitable activities along side core NHS work
- 2013- Dieticians also funded in partnership with NHS  
- Clinical fellow to be appointed for 1 year
- 2013- Welfare reforms initiated- Increase in demand for support resulting in growth of team
- Social Media, WEB, Healthcare shop, Asian Worker, Multi lingual and multi audience publications

# BRIEF HISTORY



**Were patients involved in the creation process? Yes, Patients of all ages, families, carers and people working with EB**

**The people DEBRA work to support are at the centre of what we do and how we do it**



**£381,000**

Healthcare



- Nursing
- Dieticians
- EB Clinical Fellow
- Podiatry
- Best Practice Guidelines
- Publications, Conferences, Training



**£216,000 EB Community Support Team**

***EB Community Support Team:  
Understanding the issues  
and seeking the solutions.  
A support, advice, advocacy  
and liaison service for  
individuals and families***

- **Promote & enable independent living**  
Benefits, Housing, Equipment
- **Emotional Support**  
Giving time to listen, whether its everyday problems or life changing events: Bereavement
- **Leisure** Advice and support, networking, weekend away
- **Education, work**  
Offering information and support
- **Support Grants**  
providing essential & emergency items and services

**£321,000**  
Activities

Membership



- In-Touch Newsletters
- Holiday Homes
- Members meetings
- Weekend Away
- Publications
- Communications
- Support Grants/ supply of goods
- Members Day
- Membership Data base

# GOVERNANCE AND MANAGEMENT



Currently managed by: **DEBRA UK**

Funded by: **Charitable funding**

**Governance structure: (nr of people and general profiles of board members and members of advisory committee if there is one)**

**DEBRA as an organisation including Retail, Fundraising, Research, Finance, HR, Health and Com Support:**

**Trustee Board of 15 members**

**1 CEO, 6 Directors (Senior Management Team)**

**Various committees:**

**Charitable Activities Committee works with SMT, reports to Board**

**Are patients/patient representatives involved in the governance process? And How Many?**

**Yes: 11 of the 15 Trustees either have EB or are closely related. 2 people living with EB are members of the Charitable Activities Committee**

**What is their role and their scope of action?**

**Quarterly board meetings and CAC meetings. Information/discussion about the economic numbers, Information about the developments in the charity as a whole and specifically charitable activities/service developments**



# QUALITY ASSESSEMENT

**Are patients evaluating the service after attending?**

Throughout the year the EB community are encouraged to participate in evaluations of all aspects of the services offered /Supported.

Focus Group meetings and Face Book are also used to gather feedback.

**Is the service accredited by any authority performing quality control?**

The nursing is regulated by The Care Quality Commission

**Is the service connected to a Centre of Expertise/Hospital?**

Yes, there are 4 national centres of excellence for EB within the UK:

Guys and St Thomas Hospital-	London- Adult
Heart of England Hospital-	Solihull- Adult
Birmingham Children's Hospital-	Birmingham – Paediatric
Great Ormond Street Hospital-	London – Paediatric



# Why have specialist EB services?

- Simple things can be expensive, both quality of life and financially
- Few people know about rare conditions
- Act as a resource for patients, families, carers and other professionals
- Sharing knowledge and skills is vital
- Work together to develop MDT approach to providing holistic care



# Why have specialist EB services?



# Summary



- **Specialist services make a huge difference to quality of life, and efficiency and effectiveness of care provision**
- **Always keep the people you are trying to support at the centre of what you do**
- **Patient groups can play a vital role in helping establish specialised services**
- **Don't reinvent the wheel- look at what others are doing and share experiences**
- **Partner with other organisations/ professionals**
- **Beware of regulations**
- **Think strategically – Big Picture**
- **Team members are key to success**
- **Share knowledge and expertise**

For more information



[www.debra.org.uk](http://www.debra.org.uk)

[www.debra-international.org](http://www.debra-international.org)

Thank you