



debra International

debra International is a worldwide network of patient support groups working on behalf of those affected by Epidermolysis Bullosa (EB)

An introduction to debra International

The first **debra** was set up in 1978 in the UK, we now have over 40 groups worldwide and are continually growing

- **debra** International is an umbrella group whose members are the national associations representing people affected by Epidermolysis Bullosa (EB). It was established in 2008 as an international not-for-profit organisation with offices in Austria and the UK.
- **debra** International is committed to working with and on behalf of member groups to provide essential patient support services and to fund research into the development of an effective treatment for EB.
- **debra** is the only international patient support group and medical research charity working on behalf of people living with EB.
- **debra** groups in Europe, North America and Australia are well represented and we have a growing membership in Central and South America, Asia and, to a lesser extent, Africa.
- **debra** relies entirely on voluntary donations.

Our mission

To work with, and on behalf of, national **debra** groups in the development of treatments and cures for all forms of Epidermolysis Bullosa, and to do all in its power to alleviate the suffering caused by EB worldwide

Our goals

- Promoting and stimulating collaboration and exchange between people with EB and organizations which support people with EB
- Collaborating with national governments and national and international organizations which defend the interests and needs of people with EB.
- Research into the causes of EB and stimulating and funding clinical, scientific, and pharmacological research in the field of EB with the clear aim of finding approaches to curing and developing therapies and palliative treatments,
- Collaborating with healthcare professionals and scientists to find the best treatment and eventual cure for EB
- Providing services which are directly or indirectly to the benefit of people with EB (medical care, social assistance, advice and information, etc.)
- Raising awareness for the needs of people with EB, promoting a positive attitude of the broad public towards people with EB and strengthening the self-confidence of all those directly or indirectly affected by EB

National Conferences

Our national conferences are the forums for everyone (member groups and healthcare professionals involved in the management of EB) to come together for an update on the latest developments in clinical care and research.

About EB

Epidermolysis bullosa (EB) is the name of a group of genetic conditions where the skin breaks at the slightest touch, causing painful, open blisters and wounds. EB can mean a life of extreme pain, disability and, at its worst it is fatal in infancy. People with severe EB are likely to contract a fatal skin cancer.

The youngest sufferers are sometimes described as butterfly children because their skin is as fragile as a butterfly's wing.



Our Achievements:

Developing national groups

All **debra** groups share the same history of starting a national group with no funds and no resources. **debra** International may not have money at its disposal, but it is generous with its experience, information and guidance regarding how to grow these fledgling organizations into strong, independent groups.

Patient Support

Where national groups have not yet been established, we provide information and guidance regarding access to treatment and current clinical care.

Our international conferences provide sessions on particular relevance to those living with EB.

debra provides information and support to those living with EB in publications, on the web and increasingly in dedicated patient's forums.

Clinical

We support the development of best practice in clinical care for people with EB through, for example, the production and dissemination of best-practice guidelines and quality and standards of care protocols to medical professionals, organization of clinical symposia and conferences, and the provision of training support and observation visits.

We provide assistance to associations in less favoured countries in the development of their nursing services.

debra has taken a lead role in the development of national and regional centres of clinical excellence in the treatment of EB.

Research

Current research priorities are to:

1. Work towards the development of gene-, cell- and small-molecule therapies.
2. Prevent cancer in Dystrophic EB
3. Improve wound healing in EB
4. Improve the management of EB through clinical research

Whilst we are still a long way from the development of permanent cures for EB, there are significant advances in our understanding of the causes of EB, and hence identification of targets for therapeutic intervention; some potential treatments are at an advanced stage of development and now undergoing clinical trials and, if successful, will help to improve the quality of life of those affected by some forms of EB. **debra** ensures that only the best research is funded, through a rigorous peer-review procedure overseen by **debra's** international Medical and Scientific Advisory Panel of leading EB researchers. Our research portfolio is managed by a dedicated Research Manager who works to ensure our research goals and targets are achieved. **debra** plays the lead role in the organization of international EB research conferences on EB for all senior EB researchers worldwide on a triannual basis.

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debra International is a registered charity: ZVR 932762489

