

AN INTRODUCTION TO DEBRA INTERNATIONAL, AN ASSOCIATION WORKING WITH EPIDERMOLYSIS BULLOSA (EB)

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Introduction: Debra International is a worldwide network of patient support groups whose collective goal is to help people with Epidermolysis bullosa (EB).

Aim: To promote improvements in the quality of life of people with EB, including the development of improved treatments.

Methods: EB patient support groups in Europe have been working together since 1992. In May 2008 DEBRA International was established as an international non-profit organisation with offices in Austria and the UK. Current Board members represent Europe, North America, South America and Australia / Asia.

Results: Current activities include:

- Establishment of an international Medical and Scientific Advisory Panel to peer review research grant applications by all of the member groups
- Employment of a Research Manager
- Management of the International EB Forum for professionals
- Organisation of clinical and research conferences
- Specialist working group to collate best clinical practice in the treatment of EB
- Website www.debra-international.org
- Assistance in establishing new groups

Discussion: Whilst relatively young, DEBRA International has a growing portfolio of activities with new initiatives planned including major gift fundraising for research and an international public awareness campaign.