

## Who is DEBRA Austria?

DEBRA Austria was founded in 1995 as a support group for those suffering from Epidermolysis Bullosa (short: EB), their families and carers. Today DEBRA Austria offers help, counselling and information to those, whose quality of life is significantly limited by this rare disease that has serious consequences and is often very painful.

### Butterfly Children

The youngest EB-patients are often called "butterfly children" because of their highly sensitive skin which is as fragile as the wings of a butterfly. The congenital (inborn), rare, and at time incurable skin disease EB affects approximately 500 people in Austria and about 30.000 persons in the EU. EB is a so called rare (orphan) disease. On European level there are some initiatives for these rare diseases. At the moment medical care and scientific research as well as the running costs for the world's first EB clinic (the so called EB-Haus Austria) are covered completely by private donations.



### Clinical Picture

Even with the slightest friction this disease can cause painful blisters on the entire body: both externally (skin, eyes, etc.) and internally (such as inside the mouth or in the gastro-intestinal tract). Those with EB are living with permanent pain and undergo daily difficult wound treatment. In addition to the skin problems there are often troubles with hair loss, nail and tooth decay, deformation of the fingers and toes, as well as dietary and digestion problems.

Someone who suffers from EB has a most difficult and painful life that – in some cases – is threatened by aggressive skin tumours and thereby a shortened life expectancy.



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