

[www.eb-handbook.org](http://www.eb-handbook.org)

At present, the EB Handbook is available in German, English and Italian and is continuously revised. Please do not hesitate to contact the outpatient team of the EB-Haus if you have important questions.

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**Your contribution makes a big difference.**

Donations for the „butterfly children“ can be made at:

DEBRA Austria: PSK Bank, IBAN: AT22 6000 0000 9000 0041 BIC: OPSKATWW

**Thank you!**

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# This is how life feels to people with EB.

They have Epidermolysis Bullosa, a painful and currently incurable skin blistering condition. Let us tell you about the EB Handbook and how it will help people with EB.

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 **ebHandbook**





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## As fragile as a butterfly

DEBRA International is an umbrella organisation with more than 50 national DEBRA members and supports people who live with Epidermolysis Bullosa (EB). People are born with EB, and it is a lifelong condition: we call affected children „butterfly children“ because their skin is as fragile as the wings of a butterfly.

EB causes the skin to develop blisters or to tear with the slightest mechanical friction, or even spontaneously. Wounds can also appear on the linings of the mouth, eyes, oesophagus and gastro-intestinal tract.

With severe forms of EB, life expectancy is shortened. Living with EB is an immense challenge for those affected and their relatives.



## Everyday life and EB

Living with EB means accepting particular challenges on the one hand and on the other, leading a life with highs and lows as well as longings and desires. Slowly but surely, a routine does set in although there are many special aspects. To call attention to how daily life with EB can best succeed, how those affected by EB are able to design the world around them and gauge their possibilities are concerns of DEBRA Austria and the EB House Austria.

## EB Handbook

The EB Handbook represents the desire to support those affected by EB and their relatives in their daily lives. It is meant to offer useful information to „butterfly children“ and their families and strengthen them in this way to accept and overcome the diverse challenges.

The basis for this online reference book is the expertise accumulated over many years of EB doctors, nurses and therapists, as well as relevant studies and practical experiences made by and with affected families. The EB Handbook offers the following content:

- Explanations of the various forms of Epidermolysis bullosa
- Medical information about essential topics like, for instance: care, pain, itching, nutrition, movement and sport
- Coping with everyday life
- Useful literature

The format of the online handbook makes it possible for affected families to construct their own individual handbook and print it out.

**Note:** The EB Handbook does not replace professional care by the doctor!

