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## Give the butterfly children hope and confidence

Closely linked and encircling the globe, EB-CLINET partners all have a common mission: to further develop specialised medical care for people with EB and to ensure that they have the best possible quality of life.

For more information see:

- [www.eb-clinet.org](http://www.eb-clinet.org)
- [www.eb-handbook.org](http://www.eb-handbook.org)
- [www.eb-haus.org](http://www.eb-haus.org)
- [www.debra-international.org](http://www.debra-international.org)

### Your contribution makes a big difference.

Donations to DEBRA Austria:

IBAN: AT02 2011 1800 8018 1100, BIC: GIBAATWWXXX

Donations to DEBRA International:

IBAN: AT65 6000 0005 1004 5254, BIC: BAWAATWW

### Thank you!



[www.facebook.com/schmetterlingskinder](https://www.facebook.com/schmetterlingskinder)  
[www.facebook.com/DebraInternational](https://www.facebook.com/DebraInternational)



[www.youtube.com/user/DEBRAustria](https://www.youtube.com/user/DEBRAustria)  
[www.youtube.com/user/DEBRAinternational](https://www.youtube.com/user/DEBRAinternational)

### EB House Austria, EB Academy, University Clinic of Dermatology

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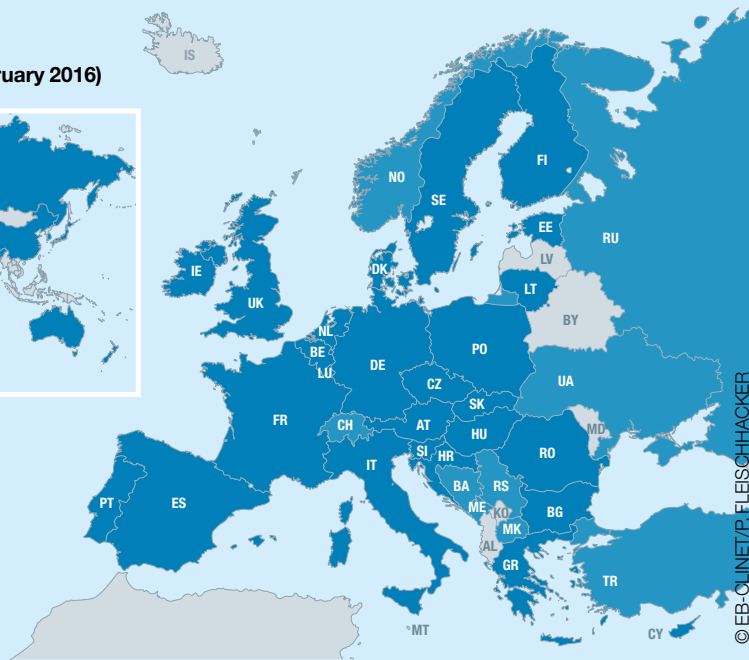
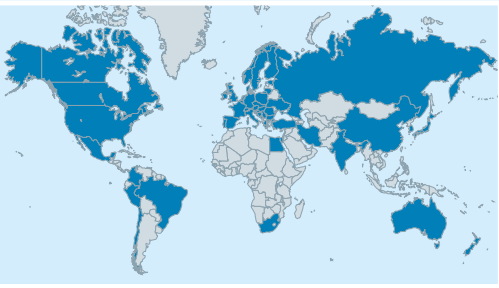
# This is how life feels to people with EB.

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



LOWE GGK

## EB-CLINET partners (February 2016)



## 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.



## EB House Austria

The EB House Austria has existed since 2005 as an international centre of expertise at the Salzburg University Clinic. It consists of three units:

- the EB Outpatient Unit, where specially trained doctors, nurses and therapists work, providing medical care for the „butterfly children“ and adults with EB;
- the EB Research Unit, where research into clinical care for symptom-relief, and treatments to heal the skin, is carried out; and
- the EB Academy, where training and further education for patients, medical staff and scientists is organised, and which is also responsible for international networking between EB health care professionals and scientists.

## EB-CLINET - Linking clinical expertise in EB

A rare disease like EB requires the pooling of expertise and experience. EB-CLINET, the Clinical Network of EB Centres and Experts, aims at:

- strengthening the collaboration between medical institutions worldwide already providing specialised medical care for people with EB;
- finding „partner centres“ for health care in the field of EB, both within and beyond Europe, and building up EB-relevant knowledge within such centres of EB expertise; and
- setting up an online community and an online database for best practice medical care in EB.

In cooperation with well over 80 partners, EB-CLINET is working on these projects:

- training programmes for EB health care professionals and scientists;
- clinical practice guidelines for EB therapy with global availability;
- international EB patient registry for clinical studies and treatment; and an
- online directory of all centres of expertise, laboratories and biobanks in the field of EB.

