

Epidermolysis Bullosa

**This is how life feels
to people with EB.**



What is Epidermolysis Bullosa?

Epidermolysis bullosa (EB) is a congenital, serious and currently incurable skin disease. It is also a rare disease. There are about 500 people with EB in Austria and around 30,000 in Europe. Those affected are called “butterfly children” because their skin is as vulnerable as the wings of a butterfly.



The clinical characteristics

EB causes the skin to blister or crack, even under the slightest amount of stress. Wounds also occur on mucous membranes, in the mouth, eyes, esophagus and in the stomach-intestine tract. EB is a multisystemic disease, which, depending on its severity, can affect many other organs as well as the skin. The life expectancy of patients who have severe forms of EB is significantly shortened. Living with EB is a major challenge for those affected and for their families.

Medical care

Despite some promising approaches in research, Epidermolysis bullosa (EB) is still incurable. On the initiative of DEBRA Austria, the world’s first special clinic for “butterfly children” was opened at the University Hospital Salzburg in 2005. The EB House Austria consists of four units: In the EB Outpatient Clinic, the “butterfly children” receive medical care from two specially-trained physicians and two nurses. The EB Research Unit develops methods of alleviating and healing the disease. The EB Academy is responsible for the networking of patients, physicians and researchers – and also provides training and further education for the medical staff and those affected by the disease. The EB Study Centre team is totally committed to determining the effectiveness, tolerability and safety of new therapeutic approaches to EB.

DEBRA Austria

The public health system is neither prepared nor equipped to deal with the specific challenges of a disease like Epidermolysis bullosa (EB). This is why medical care, research and individual support for the “butterfly children” can only be continued with the help of donations. Founded in 1995, the patient organisation DEBRA Austria helps people who must live with EB. DEBRA Austria receives neither grants nor subsidies from the public sector – and the EB House can only continue its good work if caring people are kind enough to donate whatever they can.



Please give the “butterfly children” hope for the future by donating at schmetterlingskinder.at/spenden or by using the IBAN: AT02 2011 1800 8018 1100.