

# Epidermolysis bullosa (EB)

BUTTERFLY CHILDREN - THIS TERM HAS BECOME ESTABLISHED FOR CHILDREN AND ADULTS WITH EPIDERMOLYSIS BULLOSA, BECAUSE THEIR SKIN IS AS VULNERABLE AS THE WINGS OF A BUTTERFLY.



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## WHAT IS EPIDERMOLYSIS BULLOSA?

Epidermolysis bullosa (EB for short) is a congenital, serious and currently incurable skin disease. EB is one of the rare diseases. There are about 500 people living with EB in Austria and about 30,000 in Europe.

## THE CLINICAL CHARACTERISTICS

EB causes the skin to blister or crack even under the slightest stress. Sores also occur on mucous membranes, in the mouth, eyes, esophagus and gastrointestinal tract. EB is a multisystem disease, which means that, depending on the severity of the disease, many other organs may be affected in addition to the skin. In severe forms of EB, life expectancy is shortened. Living with EB is a great challenge for those affected and their relatives.

## MEDICAL CARE

Epidermolysis bullosa (EB) is - despite promising approaches in research - still not curable today. On the initiative of DEBRA Austria, the world's first special clinic for "butterfly children" was opened at Salzburg University Hospital in 2005. The EB House Austria consists of four units: In the EB outpatient clinic, the "butterfly children" are medically cared for by specially trained doctors and certified nurses. In the EB Research Unit, alleviative and curative methods are developed. The EB Academy is responsible for the education and further training of affected persons and medical personnel as well as the networking of patients, doctors and researchers. The EB Study Center team is intensively involved in determining the efficacy, tolerability and safety of new therapeutic approaches for EB.

## DEBRA AUSTRIA

The public health system is not prepared for the special challenges of such a disease. Therefore, medical care, research and individual support for the "butterfly children" are currently only possible with donations. The patient organization DEBRA Austria was founded in 1995 and helps people living with epidermolysis bullosa (EB). DEBRA Austria does not receive any benefits or subsidies from the public sector - even the operation of the EB House Austria is only possible with donations.



Please give hope and confidence to the "butterfly children" and donate at [www.schmetterlingskinder.at](http://www.schmetterlingskinder.at) or AT02 2011 1800 8018 1100!

