

About EB

Epidermolysis bullosa (EB) is a group of incredibly painful genetic skin conditions that cause the skin to blister and tear at the slightest touch. People living with EB have skin as fragile as a butterfly's wing, for this reason it is also commonly known as butterfly skin.

EB can affect the feet only or any part of the body including blistering on the eyes and on internal organs including the throat. In every form, EB causes life-long pain and the most severe forms have a high death rate.



Genetic condition



Skin as fragile as a butterfly wing



Layers of skin tear and blister



Can affect internal organs



Affects an estimated 500,000 people worldwide



Not contagious



No cure

About DEBRA UK

DEBRA UK is a national medical research charity and the patient support organisation for people living with or directly affected by all forms of EB.

Providing care and support for people living with EB, while funding pioneering research to find effective treatments and ultimately cures for EB.



With your support we can fund:



Specialist healthcare

We work in partnership with the NHS and other organisations to ensure that people with EB in the UK get the healthcare and wellbeing support they need.



Member services

The DEBRA EB community support team works with the EB community, healthcare, and other professionals to improve quality of life for people living with EB. They offer support, advocacy, information, and practical help at every stage of life. The DEBRA UK membership scheme includes holiday home respite, grants, and bespoke events to support people living with EB.



Pioneering research to find effective treatments

DEBRA UK supports research programmes that aim to find treatments that will slow or stop the progression of EB. Repurposing drugs that are already available and successful in treating other inflammatory skin conditions are a key part of the research programme.