debra International

inside out

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debra.org.au/insideout

What is EB?

Epidermolysis bullosa (EB) is a painful and incurable condition that makes skin as fragile as a butterfly's wing. Even a hug or clothing can cause blisters and wounds.

- Affects 1 in 30,000 people (500,000 worldwide)
- Affects all genders and ethnicities equally

EB is complex

Classified into 4 main types:

- EB simplex (EBS)
- Dystrophic EB (DEB)
- Junctional EB (JEB)
- Kindler Syndrome

30 different clinical subtypes

Characteristics and symptom severity vary widely depending on the type of EB.

Everyday life with EB

EB affects almost every part of daily life, not just physically, but emotionally too.

- Getting dressed can take hours.
- Eating can hurt, even with soft food.
- Children often miss out on play, school and friendships.
- Adults face constant pain, fatigue and isolation.
- The condition is lifelong — and currently, there is no cure.

Awareness, funding and research

Awareness helps the public, healthcare workers and policymakers understand EB, leading to better support and inclusion.

Funding means families can get practical help, advice and access to life-changing support.

Research brings us closer to new treatments, better care, and one day, a cure.