

Epidermolysis Bullosa (EB)

Epidermolysis Bullosa (EB) is the name for a group of painful genetic skin conditions that cause the skin to tear and blister at the slightest touch.

The name comes from 'epiderm' - the outer layer of skin, 'lysis' - the breakdown of cells and 'bullosa' - blisters.

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Types

- The type and/or subtype is characterized by varying degrees of severity, and minor trauma or friction can cause painful blisters which results in open wounds and scarring.
- EB can also affect internal linings, mucous membranes, and organs.

Causes

All forms of EB are genetic in origin and the genes responsible for several different sub-types of the condition are now known. However, not all genes have been identified yet.

Impact on the Patient's Quality of Life

Prevalence rate in Canada - approximately 1 in 30,000-50,000 children are born with EB. It affects every racial/ethnic group and affects both genders equally.

- EB is not contagious (it is genetic) and does not affect intelligence
- Simple movements like crawling, walking, sitting, rolling over in bed can cause blisters and open wounds
- Those born with EB are called Butterfly Children – as their skin is as delicate as a butterfly's wing
- Parents spend an average of 2 hours a day changing dressings

Treatment and Care of Condition

- There is no cure at present.
- There is on-going research for effective treatments and a cure.
- Daily wound care, pain management and protective bandaging are currently the only treatment options available.



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