

Epidermolysis Bullosa (EB)

Fact Sheet

What Is EB?

Epidermolysis Bullosa (EB) is a genetic condition where the skin breaks at the slightest touch, causing painful, open blisters and wounds. EB can mean a life of extreme pain, disability and, at its worst, it is fatal in infancy. People with severe EB are likely to contract a fatal skin cancer.

What Does The Name Mean?

The skin is made up of a number of different layers. The outer is called the epidermis; the inner layers are the dermis. "Bullosa" is simply the name for a blister and "lysis" means breakdown. Hence, Epidermolysis Bullosa means the breakdown and blistering of the epidermis.

What Causes EB?

All forms of EB are genetic in origin and the genes responsible for most of the sub-types of the condition are now known. Some still await identification. There are three major types of EB; Simplex, Dystrophic and Junctional. These vary from relatively mild to incapacitating, crippling, and sometimes fatal disorders. Within these there are over twenty different sub types of EB, each with their own characteristic symptoms.

What Are Butterfly Children?

The youngest sufferers are called butterfly children because their skin is as fragile as a butterfly's wing.

Is Epidermolysis Bullosa Infectious or Contagious?

Definitely not, however, the blisters themselves can easily become infected by germs. This causes further pain and delays healing.

More severe types are transmitted in an indirect form known as recessive inheritance; that is, both parents carry the gene for the disorder but are not themselves affected by it. An average of one in four of their children will be born with the disease but, as nature is capricious, some families have the terrible misfortune to have most, or even all, of their children affected.

Approximately two of the four children will carry the gene but, like their parents, will not be affected by it. The disease will re-surface if they marry another such carrier. The engaged couple are usually totally unaware that they carry the gene.

Fresh mutations of the gene take place from time to time. This is rare – but it could happen.

Does the disorder impair mental health?

Not at all. Despite the considerable disfigurement the disease can cause, the mental health of all the sufferers is normal. Indeed the above-average intelligence of many of the sufferers means that they find their physical limitations very hard to come to terms with. They are more than ever aware of the restrictions placed on them and many of their hopes and ambitions cannot be fulfilled.

Is there a cure?

EB is currently an incurable condition. There is no effective treatment for EB. The most extreme type of the disease can be fatal. Infants can be born with areas of the skin completely missing and the blisters do not heal.

How Can I Help/Learn More?

More information and donations are accepted through the DEBRA Canada website at:
www.debracanada.org

To speak with a representative of DEBRA Canada call 1-800-313-3012, or email:

Gena Brumitt (President/Director of Awareness and Education) at gena@debracanada.org
Rocky Tesa (Vice President) at rtesa@debracanada.org
Erin Hoyos (Administration) at ehoyos@debracanada.org

###