

What is EB



Outer Skin Breakdown Blister Epidermolysis Bullosa

- RARE**
1 : 17,000
One in seventeen thousand live births affected.
- GENETIC**
Hereditary, but parents may not know they are carriers.
- ANYONE**
Equally affects Both Genders and Every Ethnic Group.
- NOT CONTAGIOUS**
Being genetic, there is no risk of 'catching' EB.
- NO CURE**
yet ! But Research is hopeful. Current treatment is based on Wound Care and Pain Management.

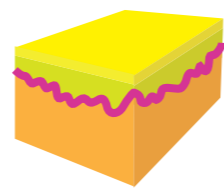
A CONDITION THAT MAKES SKIN FRAGILE.
Gentle skin contact causes blistering, open wounds, sores.

How is it passed on?



Why?

Any one of 16 EB proteins that bind the layers of skin is defective. Layer of blistering determines the Type of EB.



Diagnosis

Skin biopsy (examining a small skin sample under a microscope). Dermatologist identifies where skin separation occurs.

Treatment

Blisters - have to be punctured, drained and dressed.
Bandaging - to protect skin from friction and infection. In severe cases daily bandaging takes hours and is very painful.
Oral Care - done meticulously by hand as oral cavities can be smaller than normal with blistering and fusing of internal skin.

Dominant
50% Chance of passing on
One parent carries the gene for EB and is affected by the condition themselves.

Recessive
25% Chance of passing on
Both parents carry the gene but unaffected and usually don't know.

Spontaneous Mutation
Neither parent carries EB. Gene mutates spontaneously in either the sperm or the egg before conception.

3 MAIN TYPES

SYMPTOMS

Wide range of severity within different types of EB. More than 30 variants are known.

Simplex

Blistering on Hands and Feet.
Blistering all over body.

With good wound and pain management, many EB sufferers lead fulfilling and reasonably unrestricted lives.

Dystrophic

Contraction of joints
Fusion of fingers and toes
Contraction of mouth membranes
Narrowing of oesophagus.
Possibility of skin cancer.

Possibility to develop Squamous cell carcinoma (Aggressive Skin Cancer) before age 35yrs.

Junctional

Marking and damage to skin on face
Internal blistering of oral tracts.
Extensive blistering over the body.
Blistering of membranes of internal organs
Severe complications can often kill.



Children with severe forms of Junctional EB can die within the first 2 years due to malnutrition and anaemia caused by blistering of pharynx and oesophagus.

How can I help?



Spread the awareness of EB within your social groups.

SUPPORT RESEARCH

Research and clinical trials have achieved major advances in the understanding and treatment of EB. Eventual cures based on procedures such as Stem-cell or Gene Therapy seem promising but require ongoing funding. Rare diseases are low priority for Governments and pharmaceutical companies so research relies heavily on charitable fund-raising.

Learn , get involved in local initiatives and make donations at:
www.debra.org.uk/



70% EB Types as frequency of overall EB 25% 5%

This is an overview of EB, not to be used as a means of diagnosis. Severity and treatment options vary widely in individual cases. Contact your local health professionals if you suspect your child has EB. Designed by FIENDISH.com for DEBRA-UK. Licensed under creative commons 2013 Free to print, distribute and display.

