

EB

is Epidermolysis Bullosa

'Hard to say. Hell to live with'

FRAGILE SKIN CONDITION Friction causes blistering, skin loss, open wounds, sores and can lead to skin cancer

WHY

Skin proteins that 'glue' skin layers together are defective or missing



1 in 227 of us carry a defective gene that causes EB **Affects 500,000 people worldwide**

ANYBODY Equally affects males and females across every ethnic group

GENETIC Inherited, though a small number may be acquired

NOT CONTAGIOUS You cannot 'catch' EB as it is genetic

NO TREATMENT NO CURE yet! But Research is progressing fast

DIAGNOSIS Microscopic evaluation of a skin biopsy to see which layer is affected

SKIN

TYPES OF EB

The layer of blistering determines the type of EB:

EPIDERMIS

SIMPLEX Mildly affected may have blistering on hands and feet. In more severe cases, whole body blistering can be extensive. Whilst painful and debilitating the majority lead long lives

BASEMENT LAYER

JUNCTIONAL Blistering can be extensive over the whole body and internal organs such as mouth, oesophagus and trachea. Herlitz Junctional is rapidly fatal with 87% dying in the first year of life. It is extremely painful due to extensive internal blistering to mouth, nasal passages, trachea, oesophagus, stomach, intestine, making even breathing very painful

DERMIS

DYSTROPHIC Deep wounds leading to scarring and contractures around joints. Mitten deformities of fingers and toes, contracture of mouth, narrowing of oesophagus and corneal abrasions, severe pain and increasing disability leading to malignant aggressive skin cancer (squamous cell carcinoma) in early adulthood

KINDLER SYNDROME Multi-layered blistering affecting skin, mouth, intestine and eyes

HOW



RECESSIVE

Both parents carry the gene but unaffected and usually don't know **25% chance of child having it**



SPONTANEOUS MUTATION

Neither parent carries EB. The gene mutates spontaneously in either the sperm or egg before conception



DOMINANT

One parent carries the gene for EB and is affected by the condition themselves **50% chance of passing on**

DAILY MANAGEMENT

BLISTERS Have to be popped with a needle and dressed

BANDAGING To cover open wounds to prevent infection and protect skin from further friction
Daily bandaging can take hours and is very painful

NUTRITION Small mouth opening due to blistering and scarring. Swallowing impaired from narrowing and pain
Stomach tube and supplements often needed

EYE CARE Regular eye ointments to prevent corneal abrasions which are extremely painful



HELP

FIGHT FOR A LIFE FREE OF PAIN. TO END EB. RESEARCH THE CURE

Research is being translated into clinical trials. Gene modification and gene correction technologies make cures a realistic possibility. The challenge is bringing forward effective treatments for all types of EB. **PLEASE DONATE**

#cureEB

100% OF DONATIONS GO TO FUND RESEARCH

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This is a generalisation of the four main types of EB. For accurate diagnosis, if you suspect your child may have EB please contact your local doctor. Cure EB is a charity registered in the England & Wales 1158672



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