What is EB?

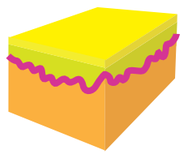
A CONDITION THAT MAKES SKIN FRAGILE.

Gentle skin contact causes blistering, open wounds, sores.

Outer Skin **Epidermolysis** Breakdown **Bullosa** Blister

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

Why?



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

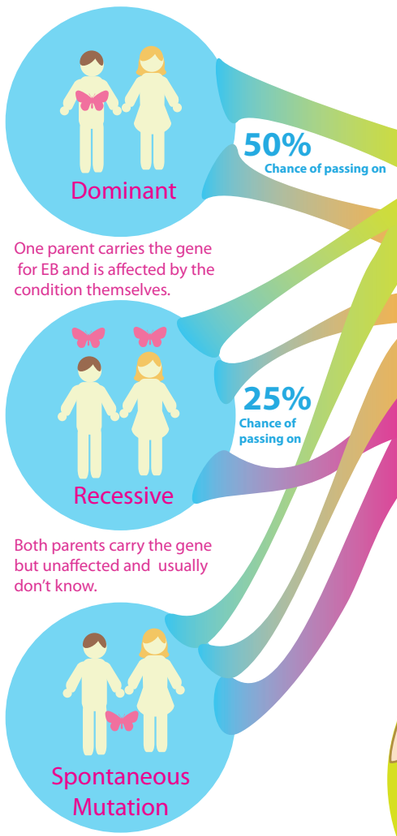
Diagnosis

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.

How is it passed on?



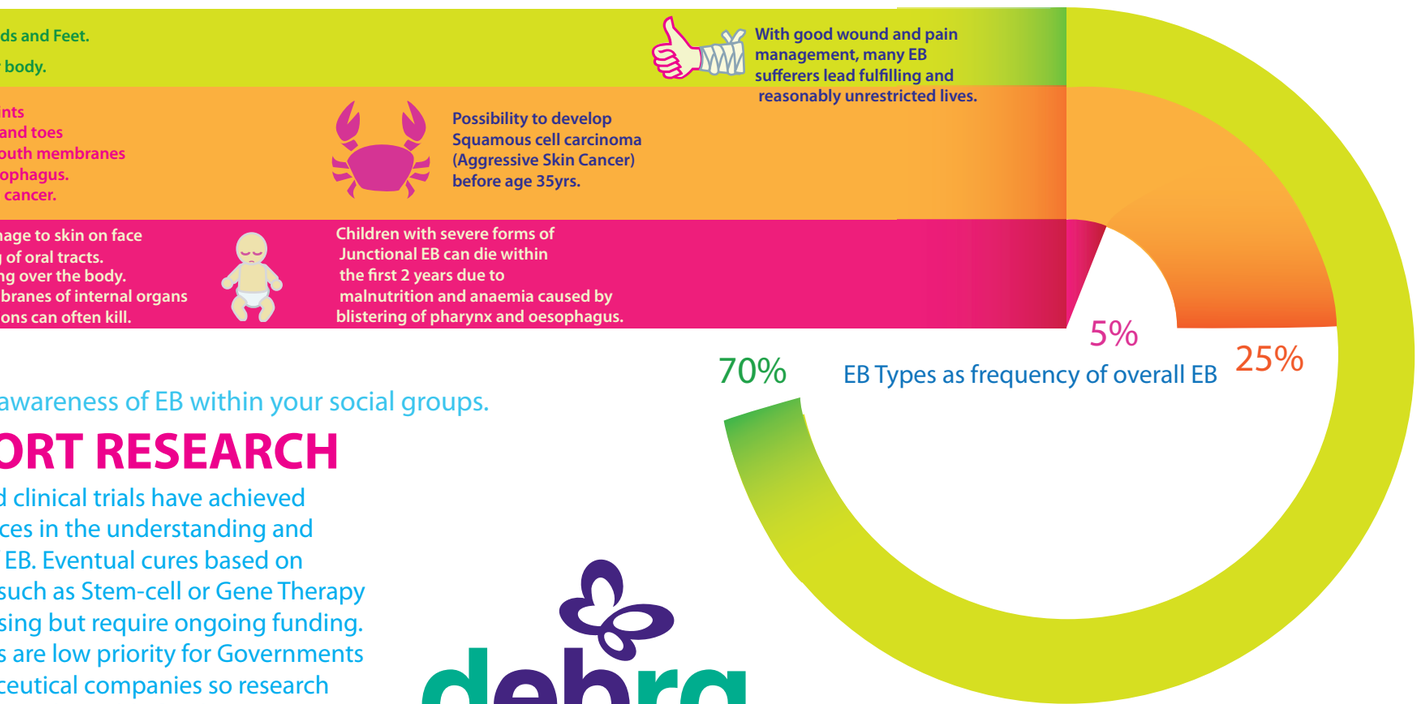
One parent carries the gene for EB and is affected by the condition themselves.

Both parents carry the gene but unaffected and usually don't know.

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.



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/

debra
for people whose skin doesn't work we do

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.
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