



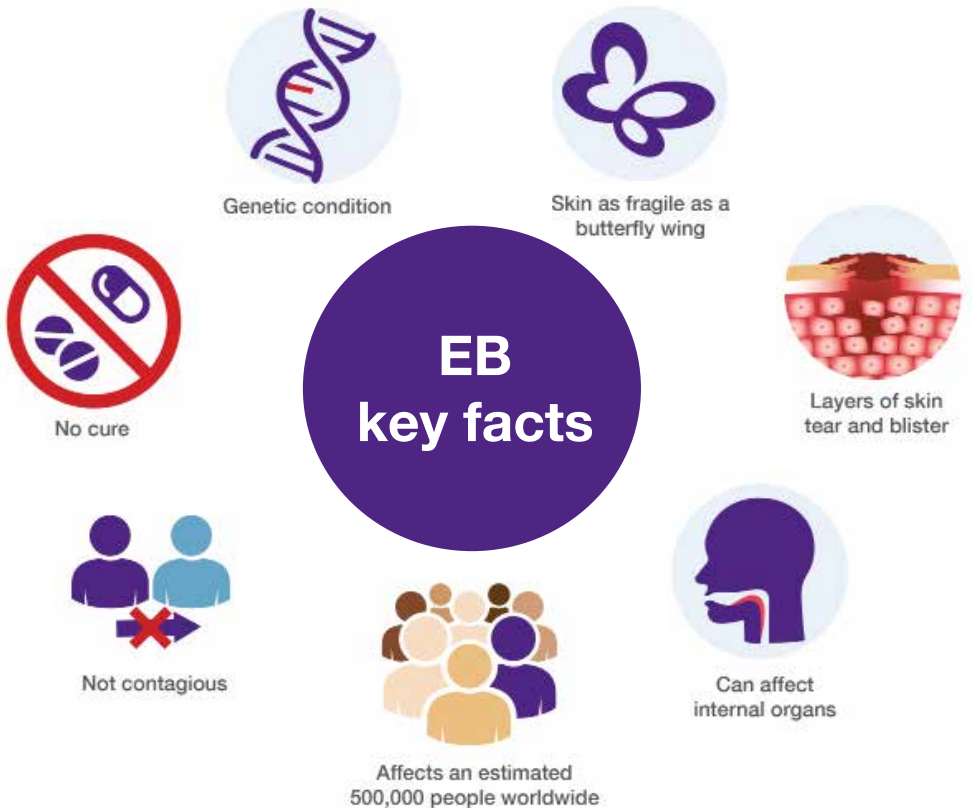
What is EB?

Information about Epidermolysis Bullosa
and DEBRA UK


debra
for people whose
skin doesn't work
we do

What is EB?

- ✈ Epidermolysis Bullosa (EB) is a group of painful genetic skin conditions that cause the skin to tear and blister at the slightest touch and for this reason it is sometimes called 'butterfly skin'.
- ✈ People with EB have a faulty gene, meaning the skin cannot bind together, so any trauma or friction can cause painful blisters, open wounds and scarring. It can also affect internal linings and organs.
- ✈ The name comes from 'epiderm' - the outer layer of skin, 'lysis' - the breakdown of cells and 'bullosa' - blisters.
- ✈ There are many different types of EB, ranging from the mildest, in which only the feet are affected, to the most severe, which can have a devastating effect on any part of the body, causing lifelong disability and pain, and in some cases is fatal.





“ The worst thing about EB is the pain. The pain is incredible. I have to take so many painkillers every day. Then there’s the itch. Some days there is no itch at all and sometimes I have days where I just can’t stop itching. My skin scarring, the fusion of my fingers and the depletion of my skin tissue all increase as I get older which will make life even trickier for me.

That’s why I want to find a cure for EB if DEBRA hasn’t found one by the time I’m old enough to be a doctor. I want everyone to understand what having EB really means. ”

Fazeel living with Recessive Dystrophic EB



“ Our son Dylan was born in June 2017 and was immediately rushed off to the Special Care Baby Unit. We were told he had EB and that we couldn't hold him in case we caused his skin to blister. DEBRA introduced us to a Community Support Manager who provided us with vital emotional support. She made detailed notes during medical appointments so we could just listen to how we could care best for Dylan before he sadly passed away. DEBRA also sourced and helped fund medical equipment (specialised nappies, EB friendly baby clothes and air cushions) which took away the additional stress and meant we could spend precious time with our son. ”

Simon & Karen Talbot

How we #FightEB

There are an estimated **5,000 people** affected by EB in the UK and **500,000 worldwide**. DEBRA is the national charity supporting those living with or directly affected by EB. DEBRA does not receive any statutory funding and is therefore reliant on voluntary and charitable donations in order to continue to support the EB Community.

Thanks to generous supporters like you, we are able to fund:



Specialist healthcare

We deliver an enhanced EB healthcare service in partnership with the NHS through EB clinical and multi-disciplinary teams and provide training and funding for medical professionals.



Community support

We aim to connect people living with EB and their families with the services they need. We offer information, financial help, emotional support, respite breaks, events and more to the EB Community.



Pioneering research

We strive to find effective treatments and cures for the EB Community to improve their quality of life. From discovering the first EB genes to funding the first clinical trial in gene therapy, we have made significant progress in advancing diagnosis, treatment and daily management of EB.



International collaboration

International collaboration and coordination is vital for sharing expertise and developing effective treatments and potential cures for EB. It allows us to coordinate research grants, fund international training and share expertise and best practice.

**We have a vision of a world where no one suffers from EB.
Together we #FightEB, together we will beat EB.**



“ I was appalled at just how cruel and painful the condition is - more people need to know about EB. If I can generate the sort of passion that I feel for this cause from a few people that I know then we could make a huge impact on the research into EB – research that not only will help those living with this now but could even lead to a cure. ”

Graeme Souness, DEBRA Vice President

How you can get involved

Your support is vital to help us **#FightEB** and there are lots of ways to get involved:



Make a donation

Help us continue our work by becoming a regular supporter, giving a one-off donation or donating in memory of a loved one.



Fundraise for us

Become a fundraising hero and take on one of our challenge events, like the iconic London Marathon or choose your challenge and do something you love and turn it into a fundraiser.



Get your company involved

Partnering with DEBRA can make a big difference to our cause. Just as importantly, it can have a positive impact on your company too. From match funding to corporate advertisement, there are a range of opportunities to get involved.



Leave a gift in your Will

Include a gift to DEBRA in your Will and your legacy will enable DEBRA to provide support and care to those living with EB, and fund EB research projects.



Shop with us

Visit your local DEBRA store and donate your items to keep our stores stocked with quality pre-loved, clothing, furniture, homeware and more. You can also join our team and volunteer in-store.



Join an event

Join us and enjoy a fantastic day at one of our popular fundraising events including golf days at prestigious venues, clay pigeon shooting days and dining events.

For full details of how you can **#FightEB** visit www.debra.org.uk/getinvolved



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Contact the DEBRA Fundraising Team:

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