

A photograph of a family of three outdoors. A man with short dark hair, wearing a blue and white striped shirt, is carrying a young boy on his shoulders. The boy has blonde hair and is wearing a blue jacket over a patterned shirt. A woman with long blonde hair, wearing a grey patterned top, is standing to the right, looking up and smiling. The background is a lush green garden with trees and a stone wall.

Your guide to

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**EB and DEBRA**

# Who is DEBRA and what is EB?

DEBRA is the national charity supporting those directly affected by, and working with, Epidermolysis Bullosa (EB) – a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering.



EB is a genetic condition that affects around 5,000 people in the UK and 500,000 worldwide



1 in 227 of us carry a defective gene that can cause EB



The whole body can be affected by EB and psychological challenges are common



There is no cure



## How does DEBRA help?

DEBRA provides lifelong support to the EB Community by working with our Members to meet their needs in care, treatment and research.

We offer practical, financial and emotional support for those living with EB, partner with the NHS to provide specialist care, or fund researchers to investigate alleviation for the effects of the condition.

DEBRA hopes for a future where no one suffers from EB.

# Your support helps change lives

With your support we can continue to make a real difference by funding important services and research which has a real impact on everyone living with EB.

## Research



Finding a cure



Improving quality of life



Identifying new treatments

## Healthcare



Delivering enhanced nursing care



Developing specialist EB services



Promoting clinical awareness

## Community Support



Funding urgent and essential grants



Offering support to the EB Community



Holding EB Member events and activities

## International



Developing international best practice guidelines



Hosting EB expert conferences



Fostering global collaboration



“For me, having EB Simplex, mostly affects my hands and feet... I try not to let it affect me. I try to carry on and do everything that anyone else would, and probably more, just to prove a point that nothing’s going to stop me.”

Heather, DEBRA Member



# How to get involved?



## Donate

We couldn't do what we do without the generosity of our supporters. Help us continue our work by becoming a regular supporter, giving a one-off donation or donating in memory of a loved one.



## Leave a gift

Include a gift to DEBRA in your Will and help to build a pain-free future for people with EB. Your legacy will enable DEBRA to provide support and care to those living with EB, as well as funding EB research projects.



## Fundraise

Become a fundraising hero and take part in a DEBRA event - from golf to marathons, dining to cycling, we have an exciting calendar of events to suit everyone. Or, do something you love and turn it into a fundraiser for DEBRA!



## Corporate involvement

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.



## Shop

Help us keep our shops stocked and donate any items to your local DEBRA charity shop. Make your donation go further by signing up to Gift Aid and have the government give 25p for every £1 we receive. Or, if you have some spare time, why not volunteer?



## FightEB

Raise EB awareness through social media by helping to spread the stories of our Members with #FightEB. The more people who know about the condition, means the more people who want to do something about it.

Contact the Fundraising Team on **01344 771961** or  
**[fundraising@debra.org.uk](mailto:fundraising@debra.org.uk)** to get involved.  
Visit **[www.debra.org.uk/donate](http://www.debra.org.uk/donate)** to donate now!



“EB can be quite a difficult condition to cope with. Every day is different. There are some good days and there are some bad days. Then there are some days where you can cry your eyes out, as it can be difficult to see him in pain.”

Beata, DEBRA Member



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