



DEBRA UK



**Duke of Edinburgh (DofE)
Participants Pack**



*Thank you,
you are amazing!*

Thank you so much for volunteering in your local DEBRA UK charity shop. I hope that you enjoy the experience, make some friends, and learn some important new skills.

Giving your time like this makes a huge difference to people like me. I have epidermolysis bullosa (EB), also known as butterfly skin. EB makes my skin really fragile to the point that even the slightest knock or friction can cause it to blister and tear.

The worst thing about EB is the pain. The pain is incredible, everyday pain that does not go away. I take so many painkillers every day. Then there's the itch. Some days there is no itch and sometimes I have days where I just can't stop itching. The scarring of my skin, the fusion of my fingers, and the depletion of my skin tissue will only increase as I get older which will make life much more difficult for me.

There is hope though. There are drugs out there that could be life-changing for me and for thousands of other people like me living with EB. It just requires funding to be able to clinically test them.

DEBRA UK shops help generate the vital funding they need to be able to conduct the clinical trials that could lead to effective drug treatments for every type of EB. So, thank you for playing your part and for BEing the difference for EB.

I would be so grateful if you could stay with us on our journey to stopping the pain of EB. In this pack you'll find information on the different ways you can continue to support DEBRA UK, whether that's more volunteering, taking on a fundraising challenge, playing the DEBRA lottery, or just telling your family and friends about EB, as the more people who know about it and understand it, the better chance we have of beating it.

Please turn over to find out more about EB and the ways in which DEBRA supports the EB community.

Thank you again, you are amazing.

Fazeel

Fazeel Irfan
DEBRA UK member and ambassador

What is EB?

EB = Epidermolysis bullosa,

also commonly known as **butterfly skin**

EB is a group of rare and incredibly painful skin blistering conditions that cause the skin to blister and tear at the slightest touch leaving raw, open wounds.

There are four main types of EB which vary in severity but all cause life-long pain:

- EB Simplex (EBS)
- Junctional EB (JEB)
- Dystrophic EB (DEB)
- Kindler EB (KEB).

What causes EB?

People with EB have a faulty gene which is passed down through families, often unknowingly. The faulty or mutated gene means the skin cannot bind together, so any trauma or friction can cause painful blisters, open wounds, and scarring.

Which part(s) of the body can EB affect?

It can be feet only or any part of the body including blistering on the eyes and on internal organs including the throat.

How many people does EB affect?

The exact number is unknown as it often goes undiagnosed, but estimates suggest 5,000 people in the UK and 500,000 globally.

Are there any treatments or cure(s) for EB?

There are currently no cures for EB. Existing treatments are focused on easing and controlling the symptoms such as pain and itch, avoiding further skin damage and reducing the risk of developing complications such as infection, and malnutrition.



Genetic condition



Skin as fragile as a butterfly wing



Layers of skin tear and blister



Can affect internal organs



Affects an estimated 500,000 people worldwide



Not contagious



No cure



Fazeel lives with DEB

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Who are DEBRA UK?



Shybika lives with JEB

DEBRA UK is a national charity and patient support organisation for people living with EB.

What does DEBRA UK do?

DEBRA UK provides care and support for people living with EB, and funds pioneering research to find effective treatments and ultimately cures for all types of EB.

How does DEBRA UK raise money?

Through a network of UK wide charity shops, individual donations, corporate, trusts & foundations and an annual programme of fundraising activities.



Specialist healthcare

DEBRA UK works in partnership with the NHS to deliver an enhanced EB healthcare service through four EB centres of excellence located in the UK.



EB community care and support

The DEBRA EB Community Support Team works with the EB community, healthcare, and other professionals to improve quality of life for people living with EB. They offer support, advocacy, information, and practical help at every stage of life.

The **FREE** DEBRA UK membership scheme includes holiday home respite, grants, and bespoke events to support people living with EB of all ages.

[Click here to find out more.](#)



Pioneering research

DEBRA UK supports research programmes that aim to find treatments that will slow or stop the progression of EB. Repurposing drugs that are already available and successful in treating other inflammatory skin conditions is a key part of the research programme.

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Will your school help stop the pain of EB?



Duke of Edinburgh volunteers from your school are helping to change the lives of people living with the incredibly painful genetic skin blistering condition, epidermolysis bullosa (EB).

We would like to invite your school to be a part of this too.

There are many ways in which the students and teachers at your school can be the difference for thousands of children and adults living with the pain of EB. Every action takes us one step closer to a world where no one must suffer with EB. Please see below for some fundraising ideas:



dress down days



bake-offs



school fundraising challenge

ANYTHING YOU CAN DO WILL MAKE A HUGE DIFFERENCE.

For more information or to request a DEBRA UK fundraising pack please email Miranda.webber@debra.org.uk

If one of your students has EB, please contact communitysupport@debra.org.uk for information and resources to support them within school.

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Charity Shop

www.debra.org.uk • 01604 414372

Riley Newman

20, volunteers at the DEBRA
UK shop in Northampton

Hi. I'm Riley Newman and for the past 6 months I've been volunteering through the Duke of Edinburgh scheme at my local DEBRA UK charity shop in Northampton.

I typically spend 4-5 hours in the shop every month sorting through the items donated, fixing, or cleaning any items that need a bit of TLC, and researching them to ensure we get the best price. I take great satisfaction from knowing that I'm playing a small part in supporting the charity in its mission to ensure that no one must suffer with the pain of EB.

For me personally it's given me a different perspective, it's broadened my horizon and helped me in my day job with Balfour Beatty, where

I'm an apprentice training to be a construction manager. I've found it beneficial to meet and mix with different people, this has enabled me to learn new skills and has given me a good network of contacts.

Through volunteering with DEBRA UK, I've also learnt how to adapt my way of speaking depending on who I'm talking to, which has really helped me develop into my role at Balfour Beatty.

Days spent volunteering at the DEBRA UK shop are productive and fulfilling and I would highly recommend giving it a go, it doesn't matter how many hours you can spare, your contribution will make a real difference, and I can guarantee you'll get a lot out of it.

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Please continue to support people with EB

There are so many ways that you can continue to support the EB community.

The easiest is to make other people aware of it. Because EB is so rare, it's largely unknown, but it has a devastating impact on those directly impacted by it. By telling your friends and family about EB and what DEBRA UK does to support the EB community, you can help raise much needed awareness.

It only takes one person to take one action after hearing you talk about EB, and all these individual actions could add up to make a real difference to people like me living with this cruel disease.

Please turn over for some other ways that you can continue to support DEBRA UK and the EB community.

Thank you so much

Fazeel

Fazeel



Other ways that you, your friends, family, or work colleagues can help DEBRA UK support people living with EB:

- Give a presentation in your school, college, university, or where you work talking about volunteering with DEBRA UK and the difference people like you are making for the EB community.
- Raise awareness of EB by liking or sharing DEBRA UK social media posts with your network.
- Continue your volunteering journey at your local DEBRA UK store, it doesn't matter how many hours you can give, they all make a huge difference, and you'll get the opportunity to learn new skills, for example why not sign up to become an eBay lister!
- Share the enclosed information about EB and DEBRA UK with your parents and family as they or someone they know might be able to support us in the following ways.



[Click here](#) to find out about a corporate partnership with DEBRA UK



[Click here](#) to donate prizes for our fundraising auctions



Volunteer, donate, or shop in one of our stores.
[Click here](#) to find a DEBRA UK store



[Click here](#) to join one of our events



[Click here](#) to take part in one of our fundraising challenges



[Click here](#) to create your own fundraiser



[Click here](#) to leave a gift in your will



[Click here](#) to play our lottery where you could win £25,000 every week!



[Click here](#) to find more ways to get involved and help DEBRA UK stop the pain of EB.

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DEBRA Royal Patron - HRH The Duchess of Edinburgh, GCVO
DEBRA President - Simon Weston CBE

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