

2023 was a pivotal year for DEBRA UK and the epidermolysis bullosa (EB) community.

The 'A Life Free of Pain' appeal, which included an English Channel swimming challenge undertaken by DEBRA Vice President, Graeme Souness, member, Andy Grist, and a team of four, helped bring EB, an incredibly painful genetic skin blistering condition, to the public's attention. It also helped deliver new funding that enabled the first drug repurposing clinical trial to be commissioned.



The mission to stop the pain of EB must continue though.

Enhanced EB care and support for today

The EB community want effective drug treatments that will help reduce their blisters, reduce their pain, and itch, and improve their overall quality of life. This is their no.1 priority*, however the reality is effective drug treatments for EB could be at least 2-3 years away as this is the time it takes to complete a clinical trial. The EB community need more support today to improve their quality of life, whilst we work on securing effective drug treatments for all types of EB for tomorrow.

Effective drug treatments for tomorrow

We have commissioned our first drug repurposing clinical trial however this is only the start, there are many more drugs that we need to test.

Drug repurposing holds the key to unlocking treatments that could slow or stop the progression of EB.

We need funding to be able to clinically test existing licenced drugs used to treat other inflammatory skin conditions, such as psoriasis and severe eczema. We believe these drugs could significantly improve the symptoms of EB and be transformational in terms of quality of life, however we need clinical evidence to prove this, and a clinical trial can cost up to £500,000 per drug.

*Based on insights drawn from the DEBRA UK EB Insights study 2023

Our ambition for the 2024 appeal

The objective of the 'BE the difference for EB' appeal is to raise £5m by the end of 2024 to provide **enhanced EB care and support for today and effective drug treatments for all types of EB for tomorrow.**

With this funding we plan to:

- offer specialist mental health counselling and resources to the EB community.
- offer more financial grants to the EB community including funding for specialist products to alleviate EB symptoms, and grants and/or signposting to financial support available to ensure every member can attend their vital EB healthcare appointments.
- offer nationwide access to the DEBRA UK community support team including a programme of regional EB Connect events.
- continue to accelerate our drug repurposing programme as we seek to secure effective drug treatments for every type of EB.



You can BE the difference for EB in 2024

Together we can improve the care and support that the EB community receives today ensuring that EB families across the UK, like the Knight family, can access the specialist EB healthcare, products, and community support they desperately need, regardless of where they live.

Together we can ensure that in the future there are effective drug treatments for every type of EB, treatments that don't just manage the symptoms, but reduce blistering, pain, and itch, and improve overall quality of life for people like Fazeel who are living with the pain of EB every day.

Together we can BE the difference for EB.

Thank you

The Knight Family



Imagine having to choose between heating your house, putting food on your table, or getting the vital EB healthcare that your children need? That is our reality and that of many EB families across the UK.

There are only four EB healthcare centres of excellence in the UK, two in London, and two in the Midlands. We live in Newquay and both our children, Percy and Ayda, have severe EBS, which means we must make regular trips to Great Ormond Street Hospital in London.

The journeys involve 7-8 hours of excruciating pain spent in the back of our car for Percy and Ayda. It takes a toll on them physically and mentally and places a huge financial strain on our family as each journey costs up to £500 when you factor in accommodation, fuel, and parking.

DEBRA UK have helped us immensely with financial applications for disability living allowance, with the children's transition to school, and through financial support grants. There are thousands of EB families all over the UK who can't afford the crippling costs of attending essential hospital appointments. With your help DEBRA UK can ensure more families get the vital EB healthcare they so desperately need. ”



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Your support is vital
in our fight to stop
the pain of EB



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make a difference



Leave a legacy

Did you know, at
DEBRA UK we have
a FREE Will Service?



Making a difference to the EB community today and tomorrow



“

The worst thing about EB is the pain. The pain is incredible, it is everyday pain that does not go away. 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 more difficult for me. This is why I want effective drug treatments and ultimately a cure for EB. ”

Fazeel, 17 has recessive dystrophic epidermolysis bullosa (RDEB).

“

We achieved amazing things together in 2023; more people now know about EB, and we have started our first drug repurposing clinical trial, but this is just the start. With your continued support we can improve the lives of thousands of children and adults living with EB today, and we can ensure that in the future there is an approved drug treatment for every type of EB. Together we can do this, please BE the difference for people living with EB in 2024.

Thank you. ”

Simon Weston CBE
DEBRA UK President



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DEBRA UK's £5m appeal to provide enhanced EB care and support for **today** and effective drug treatments for all types of EB for **tomorrow**.