



Imagine your skin being in constant pain?
No one should have to live like this.



**DEBRA's £5m Appeal funding life-changing treatments
for people living with Epidermolysis Bullosa (EB)**

A life free of pain is what we all want. For people living with EB, excruciating pain is something they must live with, every day.

EB is an incredibly painful genetic skin blistering condition. It causes the skin to blister and tear at the slightest touch. With skin as fragile as a butterfly's wings, it's often referred to as 'butterfly skin'.

EB can affect the hands and feet only or in the most severe cases any part of the body, including blistering on the eyes and internal organs.

People living with EB live in constant debilitating pain and in severe cases it can be fatal.

There is hope though.

Drug repurposing

Drug repurposing holds the key to unlocking effective treatments which could slow, stop, or reverse the progression of EB.



There are drugs already available within the NHS to treat other inflammatory skin conditions such as Psoriasis and Atopic Dermatitis which could significantly improve blistering and overall quality of life for people living with EB. To prove the effectiveness of these drugs for the treatment of EB requires clinical testing.

Isla

Isla is 14 and has Recessive Dystrophic Epidermolysis Bullosa (RDEB).

EB affects every part of Isla's life - the continual blistering causes constant pain and itching as well as severe problems eating and drinking. She has lost a lot of weight and cannot run around like other children.

“ EB stops me from having a normal life, and that is what I want. ”



Our ambition for the appeal

The objective of the **A Life Free of Pain** appeal is to raise £5,000,000 by the end of 2023 to develop treatments that will enable people to live free from the pain of EB.

The cost per clinical trial for drug repurposing is estimated at between £250,000 and £500,000 per drug and there are up to 20 drugs already available within the NHS that we potentially want to test.

Our aim is to find 2-3 approved treatments that will radically improve quality of life for people living with EB.

We will prioritise testing drugs that have the greatest potential to enable people with EB to live a life free from pain.

How you can help

We need to fund:

- £3,000,000 to accelerate our drug repurposing programme
- £1,000,000 to fund life-changing treatments
- £1,000,000 to continue providing EB community support and healthcare

With your help we can help people living with EB live a life free of pain.

Thank you.

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From the time I have spent with Isla and her family, I have seen first-hand the extreme pain this devastating condition causes and the daily challenges it creates.

Please join me in supporting DEBRA's A Life Free of Pain Appeal so that we can find effective treatments to help stop the pain of EB for Isla and thousands of other people who currently have to live with this awful condition.

Thank you. ”

Graeme Souness
DEBRA Vice President



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THE BUTTERFLY SKIN CHARITY

Help stop the pain of EB