

DEBRA

Quarterly Update

Q4 2025

(October - December 2025)



DEBRA Quarterly Update

In the latest DEBRA UK Quarterly Update, our Board of Trustees provide an update on the key activities undertaken in the last quarter of the year and the progress we are making on our journey to a world where no one suffers with EB. Feedback on the Quarterly Update is very welcome, please email debra@debra.org.uk

Q4 2025 (Oct-Dec)

Research

During EB Awareness Week in late October, we were delighted to announce a new multi-million-pound, multi-stage drug repurposing clinical trial in EB.

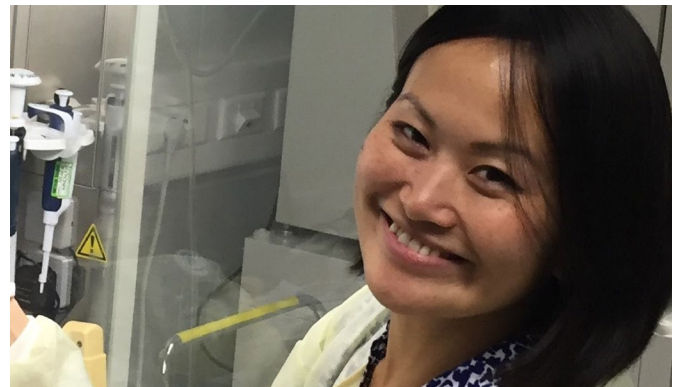
This new five-year project, known as the ART (Advancing Repurposed Therapeutics) EB trial, is the single largest investment to date, anywhere in the world, into EB research.

The ART-EB project, which will be led by Dr Su Lwin at Guy's and St Thomas' NHS Foundation Trust and King's College London, is made possible thanks to funding secured from LifeArc, and money raised by DEBRA supporters.

ART-EB will use an innovative approach to clinical trials that enables multiple drugs to be tested at the same time and two different phases of the trial to be completed within the same study. It will test whether drugs already used to treat related inflammatory skin conditions, including psoriasis and eczema, could also be used to treat EB. These drugs target the immune signals thought to be involved in the inflammation that plays a significant role in EB.

We hope that this project will lead to effective drug treatments for EB that significantly improve wound healing and overall quality of life for people living with EB.

For more information about this and the other EB research projects that DEBRA is funding, please [click here](#).



Dr Su Lwin

Member Services

Member services evaluation study

During the fourth quarter of the year the final stage of our member services study was completed.

This important study seeks to evaluate our complete member services offer. It aims to help us understand whether what we do really helps our members. With this insight we can plan to deliver the activities that have the most positive impact on them in the future.

Thank you to the circa 300 members who completed the study. We will be sharing the results in early 2026.

New EB Voices Ambassadors

To garner the support we need it is important that as many people as possible are aware of EB and the challenges it creates. We cannot do this on our own, we need as many voices as possible which is why we were delighted to be able to officially appoint two new EB Voices Ambassadors in November.

Grace Fincham and Lisa Irvine are both DEBRA members living with EB who have spoken in public at DEBRA events and in the media about their lived experiences of the condition.

We are very grateful that they have both agreed to continue spreading the word in an official capacity as DEBRA EB Voices Ambassadors.

To find out more about Grace, Lisa and our other DEBRA Ambassadors, please [click here](#).



Grace Fincham



Lisa Irvine

The last quarter of the year is traditionally a busy one for the DEBRA fundraising team and 2025 was no different.

20th Anniversary Fight Night

In November the 20th annual Fight Night, held at the Hilton Hotel in Park Lane, London, was attended by over 700 guests and raised an incredible £340,000 to support the EB community.

Before the evening's boxing commenced, guests enjoyed a three-course meal and listened to a moving speech from Grace Fincham who spoke about living with EB and the loss of her brother Freddie, who had EB and passed away five years ago.



Kilimanjaro Trek 2025

In October, a courageous team of DEBRA fundraisers completed an epic eight-day trek up Mount Kilimanjaro in Tanzania to raise funds for the EB community.

Several of the group had personal connections to EB, including DEBRA members, Anna Ritchie, whose daughter Jasmine has EB, Sarah Thomas, whose son Oliver sadly lost his battle with EB in 2021, and Mark Algar and Jennifer Naujeer who have family members with EB. Their presence brought even deeper meaning to the challenge, reminding everyone why DEBRA exists and why treatments and cures need to be found.

To date the challenge has raised over £140,000. It also generated much-needed awareness through interviews before and after the event on ITV's Good Morning Britain programme featuring Anna and Jasmine Ritchie and DEBRA Vice President, Graeme Souness CBE.



Haydn Hertz's 365-day cross trainer challenge

As the year ended so did long-time supporter Haydn Hertz's year-long cross trainer challenge for DEBRA.

This epic challenge involved Haydn taking to a cross trainer for an hour a day, every day for an entire year! If that was not enough, he decided to finish off with a 6-hour marathon session on New Year's Eve! Over the course of the year, Haydn cross trained for 370 hours (22,200 minutes) and travelled 2,755km - the equivalent of London to Moscow!

Haydn was inspired by his good friend Grace Fincham to take on this epic challenge.

Speaking in May, this is what Haydn had to say about the challenge:

"I have taken on a lot of physical challenges in my life, and it takes you two or three days to recover. This time around I have decided to do something physical every day. Those with EB must contend with its challenges every day. Taking on this challenge means the EB community are always in my thoughts. And the six-hour finale, it seemed like a good idea at the time!"

This amazing challenge has raised over £8.5k. Congratulations, Haydn.

If you would like to sponsor Haydn, there is still time, you can do so at [Haydn Hertz is fundraising for DEBRA](#)

A sincere thank you to everyone who supported us in 2025. Whether you took on a physical challenge like Haydn, attended one of our events, participated in a DEBRA golf day, ran a bake sale or sponsored the Graeme Souness English Channel Swim Challenge, every action makes a big difference and enables us to continue supporting the EB community whilst we strive to secure effective treatments for the future. Thank you.



Fundraising

Darts for DEBRA

Later in the quarter, the very first 'Darts for DEBRA' event took place in Glasgow.

The evening event brought together local businesses, fans, and legends of the game for a fun-filled night of top-class darts.

As well as being a fun evening, this event raised £13,000. Funding like this enables DEBRA to support the EB community and conduct vital research that could lead to effective treatments and cures for EB.

One of the speakers on the night was Professor Gareth Inman. Gareth is a DEBRA Ambassador and is leading a project at the CRUK Scotland Institute in Glasgow to identify potential drug treatments to target the processes that can lead to skin cancer in patients with EB.

Before the darts action started, Gareth spoke to guests about EB and the difference that research could make for people with EB. This is what he had to say:

"I would like to take this opportunity to say a few words about how critically important DEBRA UK funded research is to understand disease biology and enable us to reveal exciting opportunities for new potentially life-changing treatments for people with EB.



Imagine living in a world where the slightest touch - putting on a shirt, holding a loved one's hand - could tear your skin and leave painful wounds. For thousands of people in the UK, this is daily life with EB.

DEBRA UK is the national charity supporting individuals and families affected by EB. Founded in 1978 it has grown into a lifeline for patients, providing practical care, emotional support, and funding pioneering research. Our shared vision is simple but ambitious: a world where no one suffers from EB.

EB is a rare genetic condition that makes the skin as fragile as a butterfly's wing. Even minor friction can cause blisters, open wounds, and scarring. In severe cases, EB affects internal organs, making eating, walking, and even breathing painful. There is currently no cure for EB and managing the condition often means hours of wound care every day.

Beyond the daily pain, EB carries a devastating long-term risk. People with severe forms face a higher chance of developing aggressive skin cancers. These cancers often appear in early adulthood, recur frequently, and are the leading cause of death in severe EB patients. This is why early detection and better treatments are critical. This is where our Team

at the CRUK Scotland Institute here in Glasgow come in. I am extremely privileged and honoured to work with incredibly talented colleagues. With funding from DEBRA UK in partnership with CRUK we are tirelessly working to tackle this devastating condition on three fronts.

Firstly we are developing sector changing experimental models of EB and EB cancer, secondly we are employing the most advanced technologies available to define the biology of disease so we can reveal new ways to tackle it. Thirdly we have performed a screen of over 3000 drugs already in use in patients for other conditions and have identified many exciting hits that after rigorous and robust testing in our biologically informed models we believe will become effective new treatments in the near future.

Research is our greatest hope. Thanks to decades of work, we now have breakthroughs like gene therapy skin grafts and promising drug trials. But we need more - more funding, more collaboration, more innovation. Every pound raised accelerates progress toward treatments that relieve pain today and cures that save lives tomorrow.

To patients and families: you are the heart of everything we do. Your courage, and resilience is truly inspirational. To our supporters: your commitment drives change. And to everyone listening tonight: awareness is power. Please share the story of EB, support research, and help us create a future where no child grows up fearing a simple hug.

Together, we can turn pain into progress and hope into reality".

We could not have put it better ourselves. Thank you to Gareth, and to all our guests, sponsors, auction donors, hosts, speakers, and the teams behind the scenes who make events like these possible.



Fundraising

Winter appeal

The DEBRA Winter appeal 'The Longest Night' launched in November and featured a young family from Suffolk adapting to life with EB.

Ben and Alice's daughter Darcie was born in December 2024. It should have been a time of celebration. Instead, there was fear and anguish. Darcie was born with missing skin on her tiny wrists, her nails had not formed, and no one knew why, until after countless hospital visits, Darcie's condition was diagnosed as being EB.

It has been a tough first year for the family but alongside the team at Great Ormond Street Hospital, who have offered the family expert EB healthcare support, DEBRA's EB Community Support Team have been there to support the family with practical and emotional support. Some of the items provided by DEBRA, made possible by donations, include seam-free clothing, that has enabled Darcie to wear pretty outfits like other infants without experiencing the pain of rubbing, sheepskin liners, that help protect her delicate skin when in her cot, and a changing table that has helped ease the strain on Ben and Alice's back during dressing changes, which can take many hours, multiple times a week.

Commenting on the support received so far from DEBRA, Alice said:

"DEBRA have been amazing. They have managed to support us in many ways including with Darcie's clothing. We were having to put Darcie's clothes on inside out because the seams would rub her delicate skin. That wasn't pretty for her to go out in, and people would say 'do you know your child's clothes are inside out?' but now she can look like a normal baby. It has been invaluable to have DEBRA, and Amelia, our EB Community Support Manager, in our lives to support us on Darcie's journey through EB. When you are given a small timescale of how long she could live for I cannot put her into nursery, I can't expect other people to give her the care I do because I know her the best, she is my daughter. I do her dressings and I want to spend that time with her so I've been talking to Amelia about the options we have financially to ensure that I can be at home with her to give her the care she needs and not have to worry about being at work. Life without DEBRA would be very hard."

To date 'The longest Night' appeal has raised £34k excluding Gift Aid. We would like to thank everyone who has supported the appeal thus far. Donations like these enable DEBRA to continue to support Ben, Alice, and Darcie, and hundreds of other families throughout the UK on their journey through life with EB.



Retail

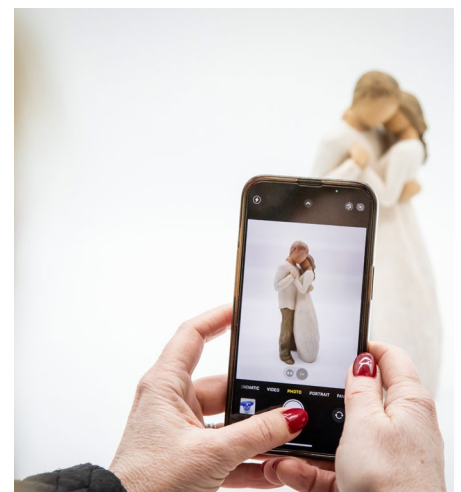
Volunteer for DEBRA

Online continues to be a key driver of growth for our retail division. To maximise its potential though does require a good understanding of what items are worth and whether a better price can be achieved online than in store. To support our retail teams with this we have been conducting training sessions. These have included one-to-one training on the eBay listing process, training on how to use our new AI tools to create better listings quickly and more easily and hosting drop-in sessions with additional training on key topics including jewellery listing, spotting counterfeit goods, and improving listing images. All the above helped deliver some good 'wins' in 2025. Our Northampton store sold a vintage guitar pedal for £864, Fleet sold a solid silver teapot for £900, and Milngavie sold an Oyster Rolex for an incredible £3,590! All these sales were made via our eBay store.

Gold sales also performed strongly in 2025 generating £13,000 from 136 pieces with the highest individual sale being a bangle which sold for £482.

To be able to capitalise on the opportunities that eBay presents though we do need support. Primarily we need volunteers willing give their time to list items on eBay for us.

If you are interested in volunteering for DEBRA, whether that's as an eBay lister or a more general store volunteering role, or volunteer roles that support our events and support functions, we would love to hear from you. For more information about volunteering at DEBRA, please [click here](#).



DEBRA Board update

New Trustees

Two new Trustees joined the DEBRA Board in the last quarter of 2025.

Zoe Bailey and Jas Jhaj bring with them a diverse set of skills and knowledge from their respective areas of specialism that will support our decision-making, policy setting and planning, and help ensure that our resources are used effectively to achieve our charitable goals.

For more information about Zoe, Jas, and the other DEBRA Trustees, please [click here](#).



Jas Jhaj



Zoe Bailey

DEBRA's former Chair awarded an MBE

In December, DEBRA's former Chair of Trustees, Jim Irvine, was recommended to His Majesty The King for the Honour of Member of the Order of the British Empire (MBE) in the New Year 2026 Honours List.

The award is in recognition of Jim's services to people living with EB over the past 25 years.

Commenting on the award, Jim said:

"I'm delighted to have been recognised for my work with DEBRA but want to dedicate this award to the EB community."

"I've been inspired by and have learned so much from the EB families that I've met over the years and have consistently been in awe of their stoicism. Those living with the daily challenges that come with having EB are the ones who deserve recognition and I thank them for everything they have taught me over the last 25 years."

"Whilst we have come a long way, there is still so much to be done. I look forward to help continuing the fight in whatever way that I can".

On the behalf of everyone at DEBRA and the EB community, we would like to extend our sincere thanks to Jim for everything that he has done to support DEBRA and the EB community and congratulate him on this richly deserved award.



Jim Irvine



DEBRA provides life-long care and support to the EB community and funds pioneering research with the objective of securing effective treatments for every type of EB. We make a difference today and strive to create a better tomorrow.

Together we can stop the pain of EB.

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DEBRA President - Simon Weston CBE

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