

IMPACT

January 2024

Linking supporters with
the impact of their donations





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Online volunteers needed!

Help us grow our online sales and develop your own digital skills.

We're looking for enthusiastic volunteers with a passion for fashion and collectables.



Ask the team in store or scan to find out more

www.debra.org.uk/e-commerce-shop-volunteer

Welcome

I have the pleasure of sharing our latest edition of Impact, following a truly incredible year of support for DEBRA UK and the EB community.

You may have seen the news that since we launched our A Life Free of Pain appeal back in October 2022, you have helped to raise over £5m to help stop the pain of EB. There is still much to do but it is hugely satisfying to have secured this funding which has enabled us to invest in our first drug repurposing clinical trial.

I'd like to extend a heartfelt thank you on behalf of everyone at DEBRA UK and the EB community.

Not forgetting those individuals who took on challenges and the people who sponsored them, our lottery players, regular givers, corporate partners, grants from Trusts and Foundations and those who left gifts in their Wills. Everyone has made a huge difference to thousands of children and adults living with EB.

Thanks to funding raised through this appeal, you have also helped families like the Knights (who feature on our front cover) access the specialist EB healthcare they desperately need.

As we look to this year, we are confident that more drug repurposing clinical trials will follow, as over £1.8 million of



research grants have been awarded in 2023 - you can read more about this on page 6.

Our mission to stop the pain of EB goes on though. Today, people living with EB need enhanced community support and better access to specialist EB healthcare. We need to raise awareness of this terrible condition with GPs so that more people are officially diagnosed and referred so they get the specialist treatment they need. There are also more drugs we need to clinically test as we strive to secure effective drug treatments for every type of EB.

Keep an eye on our news channels for the launch of our 2024 appeal and please do stay with us on this journey.

Together we can BE the difference for EB.

Tony Byrne

Tony Byrne
CEO, DEBRA UK

New DEBRA holiday home in Newquay!

We're excited to announce that in August we were pleased to open a new holiday home in Newquay, Cornwall.



Our holiday homes are available to members at discounted rates thanks to donations from supporters like you. They provide vital respite and help remove the stress associated with holiday planning for people living with EB and their families.

“

If we didn't have the support of DEBRA, we would not afford a holiday. We cannot thank you enough for helping us to make memories.

DEBRA Member

”

EB Awareness Week 2023



25th-31st October was EB Awareness Week (EBAW), a week dedicated to increasing awareness of EB.

Due to a lack of awareness, living with a rare condition, like EB, can mean you are more likely to face misdiagnosis, treatment inequality and isolation. This is why it is really important that more people know about EB.

To help raise awareness, DEBRA UK President Simon Weston CBE and Vice President Graeme Souness were busy throughout EBAW raising awareness through media including BBC local radio, TV stations and Talksport. Their combined efforts ensured we reached over 6.3m people during EBAW. Impressive hey!

Please continue to help by starting a conversation with friends or family members about EB, or by sharing our social media posts. If you or someone you know could benefit from DEBRA UK's free help and membership, please **email membership@debra.org.uk, or call the team on 01344 771961 (option 1).**

Find out more about DEBRA UK membership here

www.debra.org.uk/support-membership



A Life Free of Pain appeal reaches £5m!



£5m

£4m

£3m

£2m

You did it!

Since we launched DEBRA's A Life Free of Pain appeal back in October 22, you have helped to raise over £5m to help stop the pain of EB.

So many people played their part in making this appeal a success. From the swim team led by our Vice President, Graeme Souness, and member, Andy Grist, who swam the English Channel, and the many thousands of people who sponsored them. Our loyal customers who continued to shop and donate goods in our stores, and the guests who attended our events up and down the country.

Thanks to funding raised through this appeal, we have commissioned our first drug repurposing clinical trial. As we look to 2024, we are confident that more will follow. A huge thank you once again and please do stay with us on this journey. Together we can BE the difference for EB.

14 new EB research projects awarded funding in 2023



We're delighted to share that DEBRA UK received close to 30 applications for EB research funding in 2023 because of our first open call to researchers in the UK and around the world.

Thanks to your support, we have awarded funding to seven exciting new projects that will run for two-to-three years, five small grants to fund single-year projects, and our first two non-clinical PhD students. These four-year PhD studentships will bring vital new researchers into the field of EB.

This impressive addition to our research portfolio would not have been possible

without supporters like you. Thank you for enabling DEBRA UK to continue the essential research into drug repurposing and treatments that could help stop the pain for all types of EB.



Read more about the research projects funded here.

www.debra.org.uk/news/research-expansion-in-2023

Filsuvez® marks UK's first EB drug treatment for DEB and JEB

In September, Filsuvez® became the UK's first approved drug for the treatment of partial thickness wounds associated with dystrophic EB (DEB) and junctional EB (JEB).

Amryt Pharma, DEBRA UK, and crucially our members, contributed significantly to this decision. DEBRA UK members' firsthand accounts highlighted unmet needs and the impact of EB on daily life.

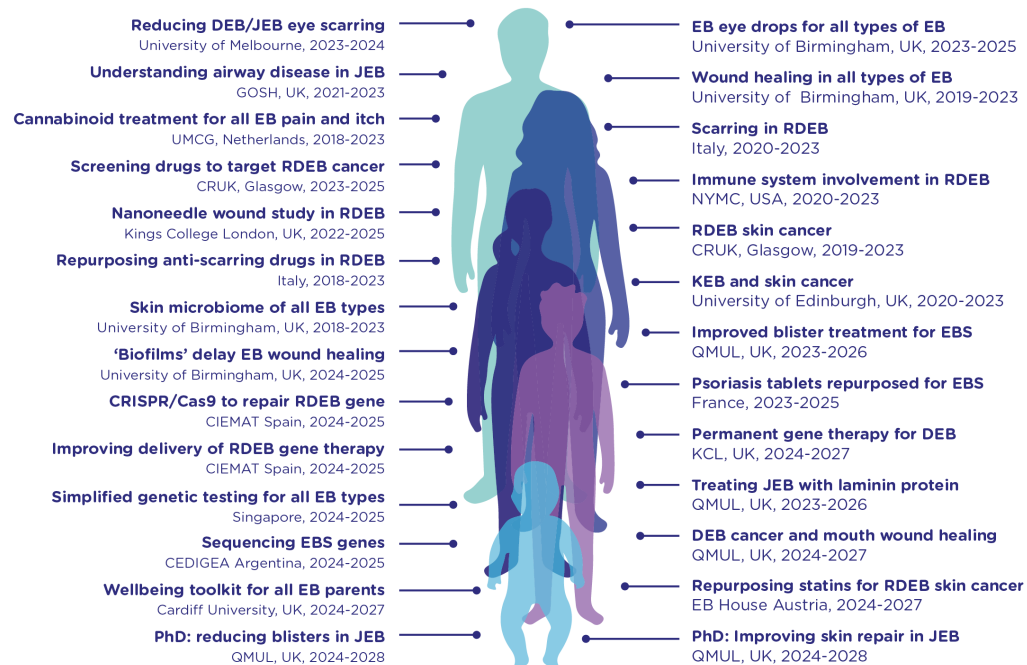
Their testimonies revealed the profound struggles of living

with EB, such as how the time spent on dressing changes was like a full-time job, and the severe pain. We would like to thank our members for their impactful testimonies.



Read more here
www.debra.org.uk/news

Our current research portfolio





Celebrating 25 years of supporting the EB community!

In August, we were delighted to celebrate volunteer Brian Stalley's 25th anniversary with DEBRA UK. Brian volunteers at the Send shop and was presented with an award and gifts for his long service by the team. There was even a special rosette for Brian's faithful guide dog Rosie.

Support from our amazing volunteers like Brian helps make a real difference

to people living with EB. Without them, we couldn't fund life-changing research and vital community support services.



Feeling inspired by Brian?

Find out more about volunteering with us
www.debra.org.uk/volunteer



Find your local store
www.debra.org.uk/find-a-debra-shop

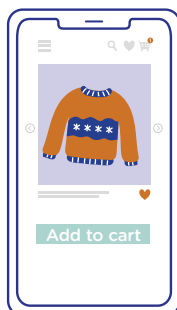
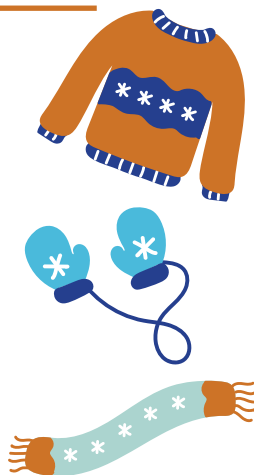


Visit our eBay store
www.ebay.co.uk/str/debracharity

Donate your unwanted Christmas gifts

Did you receive any unwanted Christmas presents? This is the perfect opportunity to support the EB community by donating these items to your local DEBRA store. Your unwanted gift could be someone else's treasure and could help generate much needed income for the charity.

We can also claim gift aid* on the sale of your items, generating additional income at no extra cost to you. It's a win-win!



Shop at our eBay store

Find your next wardrobe staple or favourite collectable on our eBay store. New stock is listed every week, so visit now and be quick to buy before you miss out!

*if you are a UK tax payer and register as a gift aid donor with DEBRA.

A reason to remember DEBRA



There is no obligation to leave a gift to DEBRA UK in your Will, but please do remember us. Every gift, no matter the size, will help us move closer to our vision of a world where no one suffers with EB.

If you wish to leave a gift in your Will to DEBRA UK, it is incredibly easy to do, whether you are writing a new Will, or updating an existing one.

We're pleased to offer you the opportunity to write your Will for FREE through one of our three Will writing services.

Simon Weston

Simon Weston CBE,
President, DEBRA UK



Scan here to find out more
www.debra.org.uk/leave-a-legacy

Great Ormond Street nurses complete skydive to help stop the pain of EB

The GOSH team finally completed their jump for DEBRA on 21st August at 11am. The team were inspired to take on this challenge by the determination and spirit of the patients they meet living with EB, and their families.

The team raised an incredible £6,215 to #StopThePain for people living with EB. Thank you again!



Golfers unite: £200k raised in 2023

In 2023, we hosted the incredible support and enthusiasm of 900 golfers across 14 remarkable golf days. Their collective efforts raised an astounding £200,000 towards our A Life Free of Pain appeal. We extend our thanks for everyone that 'tee'd' off in support of DEBRA and contributed to this significant milestone. We look forward to seeing you on the greens this year!



Your attendance at our major events helped to raise £400k!

The second half of 2023 saw major events raise an astounding £400,000 for those living with EB. This included the first DEBRA Food & Music Festival in Scotland, Great Chefs Dinner with Michel Roux and the annual Fight Night amongst others. A heartfelt thank you to all of those who attended our events, donated auction items, and donated to help stop the pain.

Planning is well underway for our 2024 events with some exciting new dates for your diary, including on 20th February, a Sports Dinner in London with rugby legend Jason Robinson, or if you're in Scotland, a Sports Dinner, celebrating Glasgow's football icons, on 21st March. **If you'd like to attend one of our events, please email: events@debra.org.uk.**



Find an event here
[www.debra.org.uk/
events](http://www.debra.org.uk/events)

What a difference a ball of yarn can make

Throughout November, we held our first virtual knitting challenge, and non-physical virtual challenge of its kind. There were some wonderful creations, from dog coats, to baubles, and a collection of 25 birds from a mini amigurumi bird book!

The support our participants received was incredible and we're pleased to share that the wonderful community of knitters raised almost £7,000.

Thank you to those that joined in and a huge welcome to the new supporters as you cast on together to support people with EB. Keep your eyes peeled for another crafty challenge later this year.



A Knights Tale Christmas appeal

You have raised almost £35,000 for EB families like the Knights!

The Knight family kindly shared their story for the 2023 Christmas appeal and hundreds of you responded. Because of your support, families like the Knights and people suffering with EB will receive the support they need, including through our grant scheme.

Thank you so much for helping EB families access the specialist healthcare they so desperately need.

#TeamDEBRA take on Santa in the City!



On 6th and 7th December, runners from our corporate partners Pantheon; Eleanor Healthcare Group; the Landmark Hotel; The Langham, London and Clifford Chance, alongside a group of DEBRA UK head office staff, took to the streets of London

for a 5km Santa in the City run! There were 50 runners over the two days, and our incredible Santas raised over £5,000 to help #StopThePain of EB. **If you'd like to sign up and join Santa's nice list for this year, please contact Sinead Simmons: sinead.simmons@debra.org.uk.**

New year, new challenge?

Now's the time to sign up to one of our runs and challenges in support of DEBRA UK. There are half marathons up and down the country, including the Reading Half, and the Hackney Half. Or what about Race to the Stones – join #TeamDEBRA to explore Britain's oldest path, the Ridgeway, on an epic ultramarathon with 50k or 100k routes available.

“

I've signed up to the Manchester Marathon in April in support of DEBRA UK. I feel blessed to be able to run with my type of EB, and want to raise vital funds for those living with the more severe types of EB.

David Poole,
DEBRA member

”



For runs & challenges
sign up here
[www.debra.org.uk/
challenge-events](http://www.debra.org.uk/challenge-events)



DEBRA
The Capitol Building
Oldbury
Bracknell
Berkshire
RG12 8FZ

☎ 01344 771961
✉ debra@debra.org.uk
🌐 www.debra.org.uk

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@CharityDEBRA
in /debra-uk
@CharityDEBRA

Thank you
for all your support.



We are conscious of our impact on the environment. If you would like to switch from postal to email for all fundraising communications, please scan the QR code and fill in the form online.

www.debra.org.uk/paperless



Please recycle

Ways to get involved



Sign up to be a regular giver

Regular gifts are vital to ensure we can continue to #StopThePain of EB.



[debra.org.uk/
regular-giving](http://debra.org.uk/regular-giving)

Join an event, run or challenge



www.debra.org.uk/events

Visit your local charity shop

Donate an item or shop instore



✓ Find your
local store



www.debra.org.uk/find-a-debra-shop

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