

DEBRA

Quarterly Update

Q1 2024

(January 2024 – March 2024)



DEBRA Quarterly Update

In the latest DEBRA Quarterly Update, our board of trustees provide an update on the key activities undertaken in the last quarter, and of the progress we are making in our mission to stop the pain of EB. Feedback on the Quarterly Update is very welcome, please email debra@debra.org.uk

Q1 2024 (January - March)

Member Services

New holiday home

In March, with the help of our President, Simon Weston CBE we officially opened our newest DEBRA holiday home in Newquay.

Thanks to Geoff and Fiona Squire, who generously funded it, we are now able to offer highly discounted holiday breaks to DEBRA members in six 5-star rated holiday parks across the UK.



Scan to find out more about
DEBRA holiday homes.



Involvement opportunities

In the first quarter of the year, we were able to offer 17 involvement opportunities to DEBRA members including the Helix project, which is focused on co-designing a product that will improve quality of life for people living with EB, and the James Lind Alliance study, focussed on identifying research and treatment priorities for all types of EB.

If you would like to get involved with either of these two projects, or the many other involvement opportunities that we have available to DEBRA members please scan the QR code below.



Get involved with DEBRA



Research

DEBRA's Royal Patron hosts meeting with NHS England

In March, our Royal Patron, HRH The Duchess of Edinburgh GCVO kindly hosted a meeting which brought together representatives from DEBRA UK and NHS England to discuss the needs of the EB community, and the need for further collaboration to support enhanced research and clinical services for the EB community, and to secure effective drug treatments for every type of EB.

The meeting was an opportunity to clarify with the NHS senior representatives the importance of effective drug treatments for every type of EB and to discuss the opportunities that exist through drug repurposing.



Feedback was shared from the EB insights study including some of the challenges that the EB community face due to the geographic imbalance of EB healthcare, insufficient mental healthcare and podiatry provision, and the need for beneficial drug treatments.

Commenting on this important meeting, DEBRA UK CEO, Tony Byrne said:

“ We are very grateful to have the support of our Royal Patron, The Duchess of Edinburgh, in championing the needs of the EB community, and we hope that the output of this important meeting will see a commitment from the NHS to support drug repurposing for all types of EB, increased research capacity, and continued development of EB clinical services across the UK.



Scan the QR code to read more
about DEBRA UK meeting our Royal Patron



Research (continued)

DEBRA UK meets with the Minister of State for Health and Secondary Care



Just before Christmas, representatives from DEBRA UK met with the new Minister of State for Health and Secondary care, Andrew Stephenson CBE.

The meeting was an opportunity to bring him up to speed on the developments we have made with our drug repurposing programme, to share with him some of the challenges we have faced in clarifying the clinical trial requirements for repurposing drugs for a rare condition such as EB, and to discuss how we can get the drugs approved in the NHS.

We are pleased to be able to count on the support of the Minister and look forward to continued dialogue with him.

New ambassadors appointed

In the first quarter of the year, we were delighted to announce the appointment of four new DEBRA ambassadors.

Emma Dobbs, a leading Scottish broadcaster, presenter, and public speaker, has committed to using her public profile and connections to help raise awareness of EB and our charitable activities.

We are also grateful to be able to count on the support of three leading health professionals - Dr Anna Martinez, Professor Gareth Inman, and Professor John McGrath. Each are experts

in their field and will use their extensive knowledge and experience of working with EB to help raise awareness of the condition and support for our key research initiatives.

We are delighted to welcome all four as part of Team DEBRA and look forward to working with them.



Emma Dobbs, DEBRA ambassador



Scan the code to find out more about our newest ambassadors.

Fundraising

New fundraising appeal for 2024

In January we launched our brand-new appeal for 2024 – ‘BE the difference for EB’.

The objective of the appeal is to build on the momentum started in 2023 through our A Life Free of Pain appeal and get as many people involved as possible to help raise another £5m to provide enhanced EB care and support for today, and effective drug treatments for all types of EB for tomorrow.



Find out more about
the appeal & how you
can get involved.

Major new corporate partnership with Peninsula Group

In March DEBRA UK entered its largest ever corporate partnership when global employment law and HR consultancy, Peninsula Group, chose us as one of three charity partners and committed to raising a minimum of £1m over the next 3 years to support the EB community.

We are hugely grateful to Peninsula Group CEO and Founder, Peter Done, and the entire team across the Peninsula Group of companies for this opportunity and we’re looking forward to working with them on some exciting fundraising initiatives.



Find out more about
this new partnership.

Events

In Q1 we successfully delivered two new fundraising events, ‘The Great Divide’ sports dinner in Glasgow, and an evening with rugby legend, Jason Robinson, combined these events raised over £120,000 towards the BE the difference for EB appeal.

If you would like to join a DEBRA event or participate in one of our runs and challenges, please scan below for more information.



Scan the QR code
to find out more



Retail

More re-furnished DEBRA stores

In March we re-opened two popular DEBRA UK shops (Ewell and Stockbridge) following extensive refurbishment which included an update to our new branding.

These stores, both in popular locations, are the latest to get a fresh, modern look, which creates a more inviting retail environment where consumers can browse quality pre-loved clothing and homewares and find out more about EB and our work.

DEBRA UK shops are an important means of generating vital revenue that enables us to provide vital EB community care and support and continue our journey to securing effective drug treatments for every type of EB.



Scan to find your
local DEBRA shop.

Strong on-line sales growth in Q1

During Q1 DEBRA stopped using the Shopiango listing platform for on-line shop listings and instead switched to shops listing directly on eBay and shipping using their own Click & Drop accounts. This change has given shops access to eBay's listing automation tools and empowered them to take control of their listing and despatch processes.

The move has been received very positively by our shop colleagues and drove a 57% increase in Q1 sales (Q1 24 £101,155 vs. Q1 23 £64,302) with 64 DEBRA shops selling on eBay in Feb 24, it has also helped reduce our costs by eliminating the cost of eBay hubs and the 5% Shopiango listing fee, and by using Click & Drop we have reduced shipping costs from an average of £4.46 per item to £2.89 per item. By moving to using Royal Mail's Tracked service we have also reduced the number of refunds that we are making due to items lost in transit, with our Feb 24 refund rate reduced to just 5.98%.

Health & Safety

In March we were delighted to have achieved a MERIT in the British Council Safety Awards. These awards go to organisations that can demonstrate to independent H&S professionals that health and safety is managed to a high standard within the organisation. Organisations are assessed and then graded, fail, pass, merit, or distinction. The award for DEBRA highlights that the processes and arrangements put in place over the last 2 years have been independently verified to be of a high standard.



DEBRA funds pioneering research, specialist healthcare, international best practice and life-long care and support to the EB community. We make a difference today with the aim of a better future for those suffering from the condition.

Together we will #StopThePain.

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DEBRA Royal Patron - HRH The Duchess of Edinburgh, GCVO

DEBRA President - Simon Weston CBE

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