

DEBRA

Quarterly Update

Q4 2023

(October 2023 – December 2023)

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 fight to beat EB. Feedback on the Quarterly Update is very welcome, please email debra@debra.org.uk



Fundraising

It was mission accomplished in December as DEBRA announced that it had successfully achieved it's A Life Free of Pain £5m fundraising target.



There are many DEBRA fundraising activities throughout 2023 that have contributed to this result including activities this quarter such as the Butterfly lunch, Dinner with Graeme Souness and Richard Corrigan, the Fingal Lunch and Fight Night, which raised a combined £260k and the DEBRA Christmas appeal featuring the Knight family from Newquay which raised over £28k.

There are so many people across the UK and beyond who played their part this year and the DEBRA Board of Trustees would like to pass on their sincere thanks to all who have contributed, whether that is supporters, members, staff, or volunteers, we couldn't have done it without you.

Not only has the appeal been successful in raising funds to help accelerate DEBRA's drug repurposing programme, but it has also raised much needed public awareness of EB and DEBRA, and crucially brought new members of the EB community to DEBRA, so that they can also benefit from the support and services that the charity offers.

There is still much to do but thanks to the support received this year we have started our drug repurposing journey. We must now continue this momentum into 2024 and beyond.



Member services



DEBRA member lunch with HRH The Duchess of Edinburgh

In November a small group of DEBRA members who have supported the charity this year, attended a lunchtime event with our Royal Patron, HRH The Duchess of Edinburgh GCVO.

The event, which took place at St. James's Palace, was an opportunity for members to connect with each other, to share experiences, and to meet with our Royal Patron and share with her some of the ways that they have been involved with DEBRA this year, and how DEBRA has supported them.

We are very grateful to our Royal Patron for her ongoing support of the charity and to all our members who have supported us in many ways this year.

To find out more about how you can get involved with DEBRA please visit <https://www.debra.org.uk/Pages/Category/get-involved-with-debra>

EB Connect

During EB Awareness Week (EBAW) which took place between 25th-31st October, DEBRA was pleased to be able to launch a new group for the UK EB community on EB Connect, a private online social collaboration platform for the global EB community.

EB Connect features many different groups for different types of EB, different age groups etc. that enable people with EB to connect with other members of the global EB community online.

We have previously received feedback from our members that they love being able to connect face to face at events such as the annual DEBRA Members Weekend but would like to be able to connect anytime on-line. We hope that with this new group on EB Connect, members of the UK EB community will be able to share experiences and ideas, make friends, or to just have a chat.



To access the DEBRA UK page on EB Connect, please visit <https://ebconnect.org/topics/2536/feed>



Awareness

Also, during EBAW, DEBRA President, Simon Weston CBE, Vice President, Graeme Souness, and DEBRA member, Andy Grist were back on the airwaves conducting a series of radio and TV interviews to help raise awareness of EB and DEBRA.

During the week interviews held on channels including TalkSport, BBC South and BBC local radio reached a combined audience of over 6.3m and not only raised much needed awareness but also generated more donations towards our A Life Free of Pain appeal.

To listen to the interviews please visit

<https://www.debra.org.uk/news/eb-awareness-week-2023-tv-and-radio-interviews>



Research

In December DEBRA was delighted to announce that it had extended its research programme to include a further 14 research projects.

In response to an open call to researchers in the UK and around the world, DEBRA received close to 30 applications and awarded funding to seven exciting new projects (worth up to £200,000 each) that will run for 2-3 years, five small grants (worth up to £15,000 each) to fund single-year projects, and our first two non-clinical PhD students (up to £140,000 each) which will bring new researchers into the field of EB.

To find out more about these exciting research projects and the impact they could have on the EB community please visit

<https://www.debra.org.uk/news/research-expansion-in-2023>



Campaigning

In the last quarter we have continued our government lobbying journey with productive meetings held with the health ministers in both England and Scotland - Minister of State for Health and Secondary Care in England, Andrew Stephenson CBE, and Minister for Public Health and Women's Health in Scotland, Jennie Minto MSP. The DEBRA team also met with Michael Gove, Secretary of State for Levelling Up, Housing and Communities, and Minister for Intergovernmental Relations.

In these meetings the team from DEBRA covered several topics including the need to establish an EB population register using the data held within NHS Scotland in a similar way to what we are doing with NHS England, so that eventually we have data that covers the entire UK EB population. The team also shared an update on the progress that we have made with our drug repurposing programme, including our first clinical trial with apremilast, and spoke about some of the challenges we are facing such as getting clarity over the clinical trial requirements for EB and how to get the drugs approved in the NHS.

Whilst we haven't got answers to all our questions yet, the dialogue we are having in these meetings is very positive and we look forward to continuing this dialogue and hopefully getting some firm actions agreed in the new year.



Governance

The trustees of DEBRA would be delighted to hear from anyone who has EB, or knows of anyone who has EB, or of someone who relates to our charitable objectives that would like to become involved with the charity either as a trustee or a non-trustee committee member. Please contact hr@debra.org.uk for expressions of interest.



For more information on our trustees please visit
www.debra.org.uk/our-trustee-board

We would like to pass on our congratulations to Dan Mundy, who has been appointed Chair of the Finance, Risk & Audit Committee, and welcome Debbie Install who was appointed as a DEBRA trustee in December 2023. To find out more about Debbie please visit
<https://www.debra.org.uk/our-trustee-board#debbie>.



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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