

DEBRA

Quarterly Update

Q1 2023

(January 2023 – March 2023)



DEBRA Quarterly Update

The DEBRA Quarterly Update is designed to improve how we keep our membership, and those interested in the work of DEBRA, up to date on the activities and progress we are making in our fight against EB. Therefore, in addition to our existing communications platform, we are producing a short update with some of the highlights from the previous quarter. Feedback on the Quarterly Update is welcome, please email debra@debra.org.uk

Q1 2023 (January - March)

Governance

New Trustees and Non-Trustee Committee members

DEBRA is delighted to appoint the following non-trustee committee members Gareth Jones and Paul Cotton. The work of our committees is vitally important in the governance of the charity, ensuring best practice from members from all backgrounds who contribute to the success of DEBRA.

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 either as a trustee or a non-trustee committee member. Please contact hr@debra.org.uk for expressions of interest.

We are actively seeking new trustees and would be interested in talking to candidates with a financial services background. Please contact hr@debra.org.uk

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

Research

In February 2023, the DEBRA Board approved the following research project:

DEBRA has collaborated with Action Medical Research for Children – a UK charity funding research to help sick and disabled babies, children and young people in a project concerning EBS. We have contributed 50% of the total amount of the project lasting three years.

Researchers: Main Applicant: Professor John Connelly
Co-Applicant: Professor David Kelsell
Co-Applicant: Professor Julien Gautrot

Title: “Improved blister repair for EBS using epigenetic inhibitors”

Grant amount: £100,000

This important new research study aims to build upon the progress made in recent laboratory studies undertaken by Action Medical Research for Children. These looked at the makeup of the skin’s DNA in children with EBS to understand if correcting mutations in the structure of the skin cells could lead to significant improvements in terms of wound healing and blister resolution.

The research will be conducted by teams based at the Faculty of Medicine and Dentistry and the School of Engineering and Materials Science at the Queen Mary University of London, and the Institute of Inflammation and Ageing at the University of Birmingham. Results of the research study are expected by January 2026.

Commenting on this important new research study, DEBRA CEO Tony Byrne said:

“We were delighted to be approached by such an esteemed organisation as Action Medical Research for Children, who have an enviable track record of funding vital research to help sick and disabled babies, children, and young people. We look forward to working with them and the research teams at the Queen Mary University of London and University of Birmingham over the next three years to get a step closer to having treatments to alleviate some of the symptoms for children living with EBS.”



Research (continued)

In early April members of DEBRA's senior management team visited the Blizzard Institute – Faculty of Medicine and Dentistry at the Queen Mary University of London. The Blizzard Institute is a world-class biomedical research institute that integrates all stages of research from basic science through to clinical studies across a diverse range of fields including cell biology.



The visit presented a great opportunity for the DEBRA team to have a tour of the impressive facilities and to get an update on the various research projects that the team there are currently working on related to EB. These include research studies focused on reducing scarring and promoting wound healing for patients living with EB. We very much look forward to strengthening our relationship with the EB research team at the Queen Mary University of London over the coming months and years as we work together to find more effective ways to alleviate the symptoms of EB.



For an update on the research projects that DEBRA is funding please visit www.debra.org.uk/current-projects



Marketing

DEBRA have been delighted to take part in various radio and television interviews linked to Rare Disease Day and intended to raise awareness of EB and the A Life Free of Pain appeal. The interviews went out on a number of regional radio stations including BBC local radio and also regional and national TV stations, reaching an audience in excess of 2m. As well raising awareness of EB and DEBRA, they have also created good media connections that can help us amplify the key asks of our appeal throughout the rest of the year. You can listen to the interviews through the following links:

www.debra.org.uk/news/a-life-free-of-pain-radio-interviews

GB News Interview: www.youtube.com/watch?v=WM56n-p7L8Q&t=2s

London Live Interview: www.youtube.com/watch?v=sz_QiKwan24&t=10s

We are very grateful to Lucy Beall, Myra Ali, and Simone Bunting, who contributed and explained about EB and what it meant to them living their lives, and to Claire Mather who spoke about the services that DEBRA offers and what we are trying to achieve through the appeal.

Member Services

In February 2023 the Trustees signed off as approved The Member Services Strategy 2023-2026. This has now been published. A copy can be found via this link [here](#).

Members Weekend

Preparations are well under way for this year's Members Weekend which takes place at **Drayton Manor - 13-14 May 2023**. If you have already booked to join us and you would like more information or if you would like to make a booking please click the link below:

www.debra.org.uk/event/members-weekend-2023

Holiday Homes

Our two new holiday homes in Weymouth were officially opened in March 2023. We look forward to you and your family visiting them in the years to come to get much needed respite and to make those special, magical memories.

For more information on DEBRA holiday homes please visit

www.debra.org.uk/community-support-respite-holidays

Patient Insight Study

The Insight study has commenced, and the draft qualitative (in depth interviews) element of the study has been completed – we are now in the process of the final stage of the study which will be an on-line 20 minute questionnaire. We would ask all members to complete this survey as patient insights give us as the patient support organisation for EB, healthcare providers, and life science companies the capacity to gain an accurate understanding of the experience of living with EB. By gaining an in-depth understanding of the patient experience – listening to patient needs and gathering evidence about what is influencing their healthcare journey – we can collectively improve outcomes for EB patients.

For more information on the Insight Study, please visit:

www.debra.org.uk/eb-insights-study

Fundraising

In March 2023 at The Landmark Hotel in London we were delighted that our Patron HRH Duchess of Edinburgh hosted a lunch to discuss drug repurposing and thank donors for their support.

Also in March 2023, DEBRA Vice President, Graeme Souness, hosted a Question of Sport Quiz Night in Glasgow. This event in front of 350 people promoted our 'A Life Free of Pain' appeal and raised £67,000 on the night. The event was also supported by Lenore England, fellow DEBRA Vice President.



For more information on the appeal please visit:

www.debra.org.uk/a-life-free-of-pain



Retail

DEBRA was delighted to be chosen to be part of the UK's latest multi charity shop, Charity Super.Mkt in Reading.

Charity Super.Mkt is a month-long pop-up shop based at The Oracle, Reading, featuring the nation's best charity retailers including DEBRA!



Running until Sunday 30 April, Charity Super.Mkt can be found on level 2 of The Oracle next to H&M.

Brand awareness

In the latest YouGov brand awareness tracker, brand awareness of DEBRA was up from 15% in 2022 to 17% in 2023. Awareness of the term epidermolysis bullosa remains low at 6%, with awareness slightly higher for butterfly skin at 10%.

We are confident of significantly improving brand awareness for both DEBRA and EB / butterfly skin through the retail re-brand roll out which is due to be completed by the end of June 2023.





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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