

# DEBRA

## Quarterly Update

**Q2 2023**

(April 2023 – June 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 against EB. Feedback on the Quarterly Update is welcome, please email [debra@debra.org.uk](mailto:debra@debra.org.uk)

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## 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](mailto:hr@debra.org.uk) for expressions of interest.



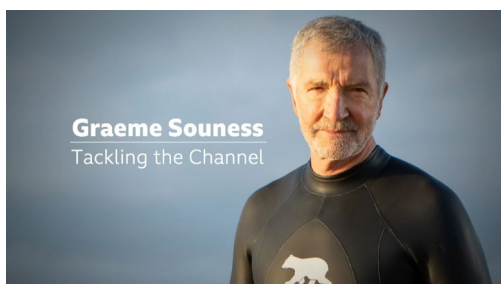
For more information on our trustees please visit  
[www.debra.org.uk/our-trustee-board](http://www.debra.org.uk/our-trustee-board)

## Fundraising

May and June were busy but extremely important months in the A Life Free of Pain fundraising appeal. Lots of planning and media engagements culminated in DEBRA Vice President, Graeme Souness, member and former trustee, Andy Grist, and a team of four taking to the water on the evening of Saturday June 17th to swim the 21 miles of the English Channel.



The team achieved this incredible feat in a speedy 12 hours 17 minutes and the media attention which the challenge attracted, including extensive coverage through the BBC and ITV's This Morning, has led to donations to date of over £1.3m (as of 19/7/23). These donations will go towards the A Life Free of pain appeal which by the end of 2023 aims to raise £3m to accelerate DEBRA's drug repurposing programme, £1m to fund life-changing treatments, and £1m to enable DEBRA to continue providing EB community support and healthcare. On the behalf of the EB community and everyone at DEBRA, we would like to say a huge thank you to everyone who has supported the channel swim challenge and the appeal so far.



To find out more about the channel swim, please watch the [BBC mini documentary - Graeme Souness - Tackling the channel.](#)



## Awareness

Not only has the English Channel swimming challenge made a significant financial contribution towards DEBRA's A Life Free of Pain appeal it has also delivered much needed awareness of EB, and of DEBRA, and what the charity does. This is evident from the latest YouGov awareness study which shows **awareness of EB amongst the public has increased from 6% in March-23 to 10% in July-23 and over the same period awareness of DEBRA has increased from 17% to 23%.** Overall awareness of EB and DEBRA is still low and so we need to continue to work on awareness initiatives, particularly amongst healthcare professionals, but it very encouraging to see this positive movement in such a short period of time.



## Isla Grist wins the Pride of Scotland Teenager of Courage award

Everyone at DEBRA would like to congratulate 14-year-old Isla Grist who recently won the Pride of Scotland's 'Teenager of Courage' award.



Isla is living with recessive dystrophic epidermolysis bullosa (RDEB) and was the inspiration for Graeme and the team's English Channel swim. In Graeme's words,

“this is a very special lady you're in the company of.”

Congratulations Isla!

## Public Affairs

### House of Commons Reception

The day after the English Channel swimming challenge was completed, DEBRA held a parliamentary reception in the House of Commons. This important event was an opportunity to raise awareness with MPs and to secure their support for DEBRA's drug repurposing programme.

The event, which was kindly sponsored by Bracknell MP, James Sunderland, included speeches from Shadow Health Secretary, Wes Streeting, who spoke about the need for cross-party support for the rare disease community, DEBRA President, Simon Weston CBE, who spoke passionately about the need to stop the pain of EB, DEBRA Vice President, Graeme Souness, who spoke about the Channel swimming challenge, Vice-Chair of the DEBRA Board, Carly Fields, who shared an insight into some of the challenges that her family faces due to EB, and Professor Chris Griffiths OBE, who spoke about the opportunity that exists through drug repurposing, to improve quality of life for people living with EB.

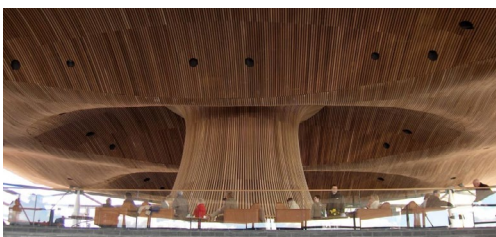


The event, which was attended by a number of MPs including Orpington MP, Gareth Bacon, who led the recent adjournment debate on EB in parliament, was closed by DEBRA Chairman, Jim Irvine who called upon everyone present to do whatever they can to help DEBRA secure effective treatments to help stop the pain of EB.

### Senedd Drug Repurposing Debate

DEBRA continued to make progress on its journey towards securing government funding for drug repurposing with a debate held on Wednesday 21st June in the Welsh Senedd.

The eight minute debate raised awareness of some of the challenges that people living with rare diseases such as EB face, including a lack of awareness and understanding of the condition amongst healthcare professionals, which can make getting a diagnosis and access to specialist healthcare difficult, and limited or as in the case of EB, no licenced drug treatments being available.



We are very grateful to Joel James MS for South Central Wales for his continued support and for speaking in this debate.





## Retail

### Play your part

DEBRA stores played their part during the month of June to support Graeme and the team's English Channel swimming challenge.

From a walking challenge at Castle Douglas in Scotland to tombola's in Worthing on the south coast and everywhere in between, in the run up to the big Channel swim, DEBRA stores across the country played their part to #StopThePain of EB.

Fundraising activities held in our stores including raffles, cake sales, colouring competitions, fashion shows and more, **helped contribute over £20,000 towards the A Life Free of Pain appeal**, another brilliant effort from our staff, volunteers, and their customers.



### New DEBRA stores

During the last quarter we also opened two brand new DEBRA charity shops, both boutique style stores in the new DEBRA branding, one in Bridge of Allan, Scotland, and in Sudbury in Suffolk.



## Members

### Member Services

We are very grateful to all our members who have helped raise awareness of EB and support for DEBRA throughout the A Life Free of Pain appeal, including during the recent English Channel swimming challenge.

Many members have shared with us how pleased they were to see EB featured so prominently in the media and how that awareness is making a difference, for example not having to explain what EB is to friends and colleagues. Healthcare colleagues and members have also welcomed the opportunity to get involved in raising awareness and we now have a range of interviews with EB healthcare professionals ready to share. This increased awareness of the charity and EB has also led to an increase in member numbers with an additional 112 members joining us in Q2. This is hugely encouraging as it means we are reaching more of the EB community who can now benefit from the services we offer.

### Members' Weekend

Another very successful members' weekend was held in May at Drayton Manor Park and attended by 329 people including 249 DEBRA members.

Thank you to everyone who came including the adults and children with all types of EB who travelled from across the UK to join us, and to the healthcare professionals, researchers, speakers, and workshop leaders, plus our generous sponsors, who were in attendance.



As always, it was wonderful to be able to connect as a community, meet old friends and new, share experiences, enjoy workshops and presentations, take part in activities, and have fun.

**Members' Weekend 2024 will be held at Drayton Manor on 17th to 19th May.**



Content from the day including the research and workshop presentations can be found at [www.debra.org.uk/pages/category/members-weekend-2023](http://www.debra.org.uk/pages/category/members-weekend-2023)

## EB insights study

DEBRA's largest ever EB insight study was completed in May and officially launched at the House of Commons parliamentary reception on Monday 19th June. The insights study was completed by 300+ members of the EB community and 150+ healthcare professionals.

The insight will help ensure that the services DEBRA offers are in-line with the needs of the EB community, and it highlights the important issues to address which will be built into DEBRA's strategic plan for 2024 and beyond.

You can read the insight study final report [here](#).





## Research

### British Association of Dermatologists Annual Meeting

To help create much needed awareness amongst dermatologists and to strengthen relationships with pharmaceutical companies who could support us in our mission to stop the pain of EB, DEBRA was present at the 103rd British Association of Dermatologists annual meeting in Liverpool, which took place from the 27th-29th June.

As well as making these crucial connections the event also presented an opportunity for DEBRA to share the different faces of EB through large photographs on display within the Galleria at the ACC conference centre of some of the members who have shared their stories through the A Life Free of Pain appeal. We are very grateful to the BAD for allowing us this opportunity to help increase awareness and understanding of EB with such an important group of healthcare professionals.



### Working with NICE

DEBRA members, James and Margaret Hinchliffe, have been supporting DEBRA by sharing their experiences of living with EB with NICE, the National Institute for Health and Care Excellence during their recent committee meeting to consider new drug treatments for EB.

Patient engagement in such committees is crucial to ensure that any future treatments are fully in line with the needs of EB patients and James and Margaret's testimony was powerful and visibly affected the other experts in the room, not least because James joined the call while finishing off having his bandages changed, a process which started at 6am that day.

NICE commented on the strength of DEBRA's patient testimony throughout the process and were impressed with our thorough member engagement with the patient experts to help them take part in a very complicated and time-intensive process, and with our engagement with pharmaceutical companies.

Thank you, James and Margaret, for your support with this important initiative.

**We hope our members agree that Q2 2023 was a landmark quarter for DEBRA and for the EB community. We look forward to providing more exciting updates following Q3.**





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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