

DEBRA

Quarterly Update

Q3 2023

(July 2023 – September 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



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

Member services

Filsuvez

In September we were delighted to hear that Filsuvez®, the gel developed by Amryt Pharma as a treatment to promote the healing of partial thickness wounds associated with dystrophic EB (DEB) and junctional EB (JEB), successfully passed the NICE appeal process and will now be available in the UK on prescription by the end of December 2023.

Filsuvez® will only be available for patients aged 6 months+ with DEB and JEB, but it is hugely satisfying to know that at the end of what has been a very significant year in terms of raising awareness and support for the EB community, we will have the first, of what we hope, will be many approved drug treatments for EB.

We are very grateful to the DEBRA members who played an integral part in the approval of Filsuvez® by providing patient testimonies. Their contribution was recognised by NICE with Helen Knight, Director of Health Technology Assessment commenting:

“We’re particularly grateful to the patient organisation, DEBRA, and the patient experts for their powerful testimonies giving a valuable insight into the experiences of people living with this debilitating and distressing condition.”

Apremilast

In another first, during September we announced that our first drug repurposing clinical trial was approved. This clinical trial will see an existing licensed drug treatment for psoriasis (apremilast) clinically tested on children and adults with severe EB simplex.

The clinical trial, which is due to begin before the end of 2023 and estimated to take up to 2 years to complete, is only possible due to the funding received through the A Life Free of Pain appeal, which we’re hugely grateful for.

This is the first of many clinical trials that we will approve as we seek approved drug treatments for all types of EB.



Scan [here](#) to find out more



Scan [here](#) to find out more



Member services (continued)

New holiday home

We are delighted to be able to extend our holiday home offer for DEBRA members with a new home at the Newquay Holiday Park in Cornwall.

DEBRA holiday homes give members the opportunity to get some much-needed respite and family time together in some of the UK's most beautiful spots, all at highly discounted prices.

The latest holiday home in Newquay sleeps up to six people and offers a spacious open-plan living room and dining/kitchen area, a large veranda with outdoor furniture, and beautiful views across the Cornish countryside and coastline.



DEBRA can now offer to members holiday homes in the following UK destinations - Lake District, Newquay, Norfolk, North Wales, Poole, and Weymouth (2x homes).



For more information, please visit
www.debra.org.uk/holiday-homes



Fundraising

2023 has already been a very successful year in terms of fundraising but we've kept the momentum going as we seek to achieve our A Life Free of Pain target of raising £5m by the end of 2023.

Amongst the many fundraising activities undertaken in the last quarter, for which we are hugely grateful, in August, the amazing EB nurses from Great Ormond Street Hospital did a skydive which raised over £6k. We cannot thank you all enough for literally jumping out of a plane for DEBRA(!) but also for everything you do to support the EB community, you really are heroes to everyone affected by EB. Thank you.



And in September we held our annual Great Chefs Dinner at The Langham, London. This year our host Michel Roux Jr was joined by famous TV chefs Simon Rimmer, Ravneet Gill, Bryn Williams and recent winner of Channel 4 and Netflix's 'Five Star Kitchen: Britain's Next Great Chef', Dom Taylor.

This year's event, which also included a Q&A with honorary swim team member, John Maguire from the BBC posing the questions to DEBRA Vice-President and Channel swim team member, Graeme Souness, raised over £100,000 towards a life free of pain.

A big thank you to Michel Roux Jr and all the chefs, to Graeme, and John, The Langham Hotel, and to all our sponsors, auction donors and to everyone who contributed to making this a great evening, and for all your invaluable support for DEBRA, we couldn't do it without you.



Find out more [here](#)

The fundraising team up in Scotland have had a busy few months too with August's inaugural DEBRA Montrose Music & Food Festival attracting over 2,000 visitors and raising £30,000. And more recently the team hosted a Ladies Butterfly Lunch at Cameron House on Loch Lomond. With over 200 guests on the day, the event raised a further £15,000 towards the A Life Free of Pain appeal.

Well done to the DEBRA team up in Scotland for putting on these new events and many thanks to everyone who attended and contributed to their success, we're excited about further expanding our Scotland events programme in 2024.



Retail

After an extensive refit our popular shop in Merrow near Guildford re-opened in August.

A crowd of eager locals gathered outside on re-opening day, keen to explore and grab a pre-loved bargain at the new look shop ahead of the official re-opening being announced by Guildford Town Crier, David Peters, with the ribbon being cut by Deputy Mayor of Guildford, Councillor Sallie Barker MBE.

Merrow now joins a growing number of newly renovated DEBRA stores up and down the country featuring our fresh new branding with more scheduled to be completed by the end of the year.



Please do pop into your local shop, your support makes a huge difference.

Campaigning

It has been a busy quarter in terms of government campaigning with DEBRA hosting events at both the Scottish Parliament in Holyrood, and the Welsh Senedd in Cardiff. Both events gave the opportunity for DEBRA members to directly engage with members of parliament, sharing with them some of the challenges they face day-to-day living with EB.

It was very encouraging that both Jennie Minto MSP and Minister for Public Health and Women's Health in Scotland, and Eluned Morgan MS and Minister for Health and Social Services in Wales, both took the time to join us and find out more about EB.



A big thank you to our event sponsors, Bob Dorris MSP, and Joel James MS and their teams, and to the DEBRA members, DEBRA President, Simon Weston CBE, Graeme Souness, and Professor Gareth Inman who attended and spoke at these events.



As a follow up to the Scottish reception, Bob Dorris posed a question to the Scottish government in Holyrood asking what work is being done to secure effective treatments.

Click [here](#) to find out more

We look forward to continuing our campaigning journey into 2024 as we seek support from Westminster and the devolved nations in our quest to improve access to EB specialist healthcare for all members of the EB community, whilst securing effective drug treatments for all types of EB.



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.

📍 DEBRA, The Capitol Building, Oldbury, Bracknell, Berkshire, RG12 8FZ

☎ 01344 771961

✉ debra@debra.org.uk

🌐 www.debra.org.uk

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DEBRA Royal Patron - HRH The Duchess of Edinburgh, GCVO

DEBRA President - Simon Weston CBE

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