

## Conference Report of the 3<sup>rd</sup> Conference of EB-CLINET

24-25 September 2015, London, UK

For the first time, both the EB-CLINET and DEBRA International conferences were held at the same venue. They have been run as two conferences with one shared day of the programme. DEBRA UK was proud to host two conferences for clinicians and professionals working with EB, the 2015 EB-CLINET and DEBRA International conferences, in London from 24 – 26 September 2015.

The conferences were opened by Anna Martinez (Dermatology Consultant, Great Ormond Street Hospital) and Jemima Mellerio (Dermatology Consultant, Guy's and St. Thomas' Hospital) for EB-CLINET and Ben Merrett (CEO, DEBRA UK), Rainer Riedl (President of DEBRA International) and David Spence (Chair of Trustees, DEBRA UK) for DEBRA International.

For the first time, the EB-CLINET and DEBRA International conferences were held at the same time and shared one day of the programme. With over 320 delegates (more than ever before) from over 35 countries attending one or more days of the conferences, this exceptional event exceeded expectations. The DEBRA International Conference was the largest ever held and over twice the number of delegates attended EB-CLINET than in previous years, providing an unparalleled opportunity to share expertise and make connections with leading clinicians and DEBRA organisations from around the world.

*'... everything was informative and well organised.  
It was lovely to network with clinicians and patients from all over the world.'*

The programme, covering a wide range of clinical and research projects and DEBRA supported initiatives, included first class presenters from around the world.

*'Therapy forum was extremely beneficial!'*

Multi-disciplinary care, the development of best practice guidelines, initiatives undertaken to develop professional community support for people living and working with EB, psychosocial support, developments in fundraising and the importance of increased information and knowledge sharing were common themes across both conferences. Delegates also had the opportunity to enjoy three evenings of social events, including wine tasting and a boat trip on the river Thames.

*'Patient panel session on Friday  
was uniquely informative, inspirational  
and insightful. Thank you!'*

A number of people living with EB shared their experiences in a moving and informative session. Each individual's experience of living with the condition was unique, but all emphasised the value of DEBRA groups in supporting individuals and families living with EB and providing vital opportunities for people living with this rare condition to connect with each other and share experiences. EB-CLINET and the specialist EB clinical teams were also widely praised for their valued contribution to promoting clinical and research expertise in EB.

The Royal Society of Medicine provided a wonderful venue with great catering and space for lectures and networking. Numerous positive comments were also received on the quality of the

presentations, the high level of participation and stimulating debate in discussion sessions and forums.

*'The content covered a broad spectrum so the presentations were complementary pieces of a jigsaw - my first conference and a valuable opportunity to get a deeper understanding of life with EB.'*

The enthusiasm, passion and commitment to working together locally and internationally across specialities to support people living with EB was evident across both conferences. On behalf of DEBRA International, EB-CLINET and DEBRA UK, I would like to thank everyone who attended and helped to make them such a success.

Warmest thanks go to our sponsors and supporters who made it possible to host these very valuable conferences, CliniMed, PolyMem, CliniSupplies, Mölnlycke Health Care, APA Parafriacta, Crawford Healthcare Ltd, H&R Healthcare, Bullen Healthcare, Keraplast Research, Dermatronics Ltd and Reed Medical Ltd, as well as our other exhibitors – the DEBRA Community Support and Membership teams, Solihull Hospital, Great Ormond Street Hospital, Guy's and St. Thomas' Hospital, Birmingham Children's Hospital, specialist EB dietitians and DEBRA UK Retail.

And finally, thank you to all the delegates, many of whom travelled many miles and gave their personal time to participate in the conferences. The continued commitment and passion from many professional disciplines from around the world to enhance the quality of life for people living with EB was truly inspirational and a great motivation to keep on fighting the challenges presented by EB. Thank you all!

*Claire Mather, Director of Healthcare, Membership and EB Community Support, DEBRA UK*