

The Brothers Trust made a wonderful donation totalling £80,000 to DEBRA earlier this year, with £55,000 being ring-fenced for our community support work, and £25,000 going to our research. Each of these gifts is making a real and demonstrable difference to the goal that people with EB should be able to live “a life free of pain”.



Our research work has seen some significant breakthroughs in just the past few weeks.

We are thrilled to report that, in mid-August, a gel called *Fisuvez* by Amryt Pharma was approved by the National Institute for Health and Clinical Excellence (NICE) as a wound healing treatment for people with dystrophic and junctional EB. DEBRA members were instrumental in working with Amryt Pharma to provide the evidence to support this application, the success of which makes the UK the first country in the world to be able to offer this treatment for two of the most severe forms of EB.

August also saw the approval and commencement of our first drug repurposing trial. Drug repurposing trials seek to clinically prove that treatments already approved for different conditions (usually other skin conditions) are beneficial to people with EB. Such trials are particularly efficient and cost-effective ways of establishing new treatments for rare conditions.

The trial involves a medicine called *Apremilast* which is currently used to treat psoriasis, and which it is hoped will substantially ease the blistering, pain, and itching that comes with EB. It will be tested on twenty people over the age of six who currently suffer from at least four new blisters each day as a result of their severe cases of epidermolysis bullosa simplex (EBS).



The vital work we do to support people with EB in their daily lives has also continued and is making a life-changing difference. The heat of the summer months, even though this year has been relatively cool, causes considerable difficulties for people with EB, and our teams have been busy trying to mitigate the impact: not least by providing support grants for suitable, high-quality fans and cooling equipment.

This comes on top of their ongoing work to support families in their interactions with health professionals and with the benefits system, sourcing specialist healthcare where standard provisions are not capable of serving people with what is a rare and little known condition, and supporting people in the particular challenges that their EB presents for their education and employment.

The publicity that came from football pundit Graeme Souness swimming the English Channel for us in June has – pleasingly – increased the number of people with EB getting in touch with us and seeking our support, and donations such as yours have ensured that we have been able to meet that increased demand.

On behalf of all of the people with EB with whom we work, we would like to say a heartfelt THANK YOU for your support!