

Patient Panel Newsletter

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Updates from CEBD

- There are some great things to celebrate for the [Rapid Eczema Trials](#) project. The 'Keep Control Study' has just opened to recruitment—this study will investigate if treating an eczema flare for two days longer than usual will help people get better control of their eczema. It's an online study and you don't have to see a healthcare professional to take part so please consider getting involved if you have eczema and please help spread the word if you are able. Results from the first Rapid Eczema Trials online study, the 'Eczema Bathing Study' were recently presented at the British Association of Dermatologists (BAD) annual meeting and were awarded 'Best Scientific Paper'. A huge thank you to all the CEBD Patient Panel members involved in helping to make this project a success.
- Please see [this video](#) from CEBD Patient Panel member Kate Heneghan-Sykes which was part of a [recent CEBD conference](#) on the skin condition hidradenitis suppurativa (HS).
- If you have eczema, please consider taking part in our summer art competition. Further details are available [here](#) and in the email accompanying this newsletter.
- Laura Howells and Paul Leighton have been successful in securing funding from the National Eczema Society to undertake a project looking at talking about Topical Steroid Withdrawal (TSW) in healthcare consultations. Well done to all involved!
- We have been out and about again doing a range of outreach activities over the past couple of months including stands at a City Farm in Nottingham, supporting a widening participation event at the University of Nottingham (pictured right), carers roadshows in North Notts and citizen scientists from Rapid Eczema Trials joining EczemaNet researchers from Imperial University at their Great Exhibition Road event. Over the past three years we've estimated we've reached over 1,500 people with our outreach activities which is an achievement to be proud of. Particular thanks to panel member Amanda Roberts for her support at these events, especially the [Carer Roadshows](#) which she attends on her own!



Interesting things that caught our eye

- Did you know about Patient Voices? This is a new initiative from the British College of Dermatology (BCD) to put patients at the centre of BCD educational content. Patient Voices is a [dedicated hub](#) where patients discuss their personal experience with skin disease, to inform and support compassionate patient care for all dermatology learners.
- Have you seen this [article on the effects of climate change on the skin](#). Although not everything is relevant to us here in the UK, it's an interesting and thought-provoking read.
- Did you realise that over 1 million people took part in clinical studies in the UK last year? And that for every £1 invested in research by the National Institute for Health Research (NIHR) society receives more than £13 of benefits? You'll find this information and lots more besides in the NIHR [2024-2025 annual report](#) which was published in July.
- There was an interesting [press release](#) from the British Association of Dermatologists (BAD) last month about the use of AI in dermatology which calls for stronger regulation and better training and data as AI gets closer to mainstream use.

The ongoing struggle for effective treatments for vitiligo in the UK – Emma Rush on behalf of Vitiligo Support UK

We are [Vitiligo Support UK](#), a charity that provides [vitiligo](#) patients, their families and friends, with medical advocacy and support and we were recently involved throughout the process where the National Institute of Health and Care Excellence (NICE) considered a new treatment for vitiligo.

It was great to see the article on *New Dermatology Treatments* in the last edition of the newsletter. The arrival of JAK inhibitors in oral and topical form is a major advance in the treatment of many inflammatory skin diseases. To date, if treated at all, vitiligo has mainly been managed in primary care with unlicensed treatments. These have limited efficacy for most patients, and clinically achieve just one step in the treatment pathway for this complex autoimmune disease.

The introduction of ruxolitinib, following research trials led by US vitiligo advocate [Dr John Harris](#) was an extraordinary step forward for vitiligo patients. Ruxolitinib is a topical treatment, which allows the patient convenience in following the treatment, and means that concerns that have arisen with oral JAK inhibitors are also allayed. It is the first treatment that specifically targets the cellular changes that occur allowing vitiligo patches to develop. Ruxolitinib was approved across Europe by the European Medicines Agency and had previously received approval in the United States by the Food and Drug Administration, without any prolonged battles to convince those bodies of the efficacy of the drug or of the significant impact that the drug would make on a long-overlooked group of patients.

Vitiligo is a disease whose impact is predominantly

psychological, something that should not be conflated with language such as ‘body-image’ which is so often used in the press (and so was copied over to the patient panel article). Our argument as a patient advocacy group is that this does not and should not diminish its overall effect on patients, an effect that is not trivial. A total of 65% of vitiligo patients are assessed as having either anxiety or depression. If a disease is predominantly psychological in impact, this does **not** render the disease distinct from biological processes and certainly should not be dismissed (as vitiligo unfortunately still frequently is by doctors).

It is long past time when a disease should be judged on physiological impact alone and we believe that a disease with a profound psychological impact, affecting physical, emotional and social integration, is as impactful as one that has physical symptoms. In addition, society has recently changed so dramatically. The influence of social media on people’s lives has inevitably increased their consciousness of their appearance, and this effect is here now and cannot be undone. This means that having a visible difference through any skin disease is not simply a question of “body image” but can create a profound disruption in the social contract, which in turn affects all the wellbeing of an affected individual.

Sadly, ruxolitinib was not approved by NICE, meaning that UK patients cannot access this as a licensed treatment in the UK. NICE felt that it was not cost-effective to provide vitiligo patients with the first specific treatment for our disease. They believed that a disease with a profound and disabling psychological impact did not rate as highly as treatments for other diseases. We are now waiting for further applications to be made and getting ready for the task of representing a group of patients who have, despite their visibility in real life, been invisible to NICE to date.

CEBD Patient Panel meetings

Many thanks to the eleven panel members who gave up part of their weekend to join us at the face to face panel meeting on Saturday 10th May at Jubilee Conference Centre. It was great to catch up with old friends and also meet some of our new panel members. Following an update on CEBD activities from [Kim Thomas](#), there was a session on Knowledge Mobilisation in research which was delivered by Emma Campbell, a senior research fellow at CEBD. The afternoon was spent contributing to CEBD research projects including a study looking at the use of AI in measuring eczema severity and a research programme looking at diagnosis of skin conditions in primary care.

All who attended have had feedback on how their input and comments have helped shape these projects. The day finished with providing feedback on an activity that will be used in community settings to encourage people to get involved in research. We had some great feedback about the day with many commenting on the warm and friendly atmosphere and how good it was to be able to meet with like-minded people and make a positive difference.

Our next panel event is taking place online via Teams on the morning of Saturday 1st November. This meeting will just be for a couple of hours and along with an update on CEBD activities will include a session on ‘research wastage’ from CEBD Co-director [Hywel Williams](#). If you’d like to attend and haven’t told us already, please do [get in touch](#) and we’ll add you to the list for this meeting (and ideas for sessions at future meetings are always warmly welcomed!).

