

Patient Panel Newsletter

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Updates from CEBD

- The [top 10 research priorities for the blistering skin diseases](#) bullous pemphigoid, pemphigus vulgaris and mucous membrane pemphigoid have now been published. CEBD Panel member Ingrid Thompson has been an active member of the Steering Committee for this project along with other patient representatives from the patient support group [PemFriends](#). Well done to everyone for getting this Priority Setting Partnership (PSP) over the finishing line. A total of [twelve PSPs](#) have now been conducted in skin disorders and are informing research funding applications and projects in a wide range of conditions.
- The [Rapid Eczema Trials](#) citizen science research programme is really moving forwards. We're hoping that the first online study (In people with mild to moderate eczema, is less frequent bathing better than more frequent bathing?) will be recruiting by the end of the year. The project has started the next round of prioritisation so if you have lived experience of eczema and would like to be involved in deciding what trials are done next then please get in touch. There are some [great blogs on the website](#) which are well worth a read!
- We are always looking for new panel members, so if you know anyone who is keen to get involved (and is affected by a skin condition—either as a patient or carer) please encourage them to take a look at the [CEBD website](#) and to [get in touch](#) to find out more.

Eczema sculpture visits QMC Nottingham

A sculpture highlighting the experiences of people living with eczema has been on display at Nottingham's Queen's Medical Centre (QMC) for the past month. ['Colouring Adult Eczema – getting under the skin'](#), was developed and produced by artists Julia Vogl and Peter Hudson (pictured right), after they held workshops across the UK with 30 adults living with eczema. The sculpture comprises coloured light boxes, each representing the different experiences of the 30 people consulted during the creation of the artwork. It was commissioned by Professor Sinead Langan from the London School of Hygiene and Tropical Medicine, supported by the Wellcome Trust.

The visit to QMC is part of a tour around five UK hospitals (also at Derby, Burton, Newcastle and Guys and St Thomas, London). The official unveiling at QMC was attended by a number of CEBD Patient Panel members including Amanda Roberts (pictured above, who was involved in the project and workshops to create the sculpture) other patients and members of staff from CEBD and Nottingham's hospitals.



Updates from the National Institute for Health and Social Care Research

- Have you seen the [Shape the Future](#) campaign to help celebrate the NHS 75th birthday?
- Almost [one million people took part in NIHR research studies 2022/23](#). This means that on average 100 people an hour were recruited as participants into studies, what an achievement!
- Think about sharing [this video](#) with your friends and family on how research helps transform lives.
- Read more about the [new NIHR £40 million investment in mental health research](#)—Mental Health Mission (MHM).



SAFA adult female acne study results published in BMJ

Results from the SAFA study (spironolactone for adult female acne) have just been [published in the BMJ](#), and there is also a [useful video explaining the study results](#). CEBD Patient Panel members Irene Soulsby and Sophie Dove and former panel member Karen Bright were all involved in the study team. This NIHR Health Technology Assessment (HTA) funded study shows that spironolactone is an effective treatment for adult female acne. The study recruited over 400 women, aged over 18, with acne that had persisted for more than 6 months and where oral antibiotics would have normally been the next treatment. Half were randomly allocated to take spironolactone, while the other half were given a placebo. The women were asked to complete questionnaires on their acne and quality of life relating to the condition at the start of the trial and then at 12 and 24 weeks into their treatment.

The results showed that the women taking spironolactone saw a significant improvement in their acne after 12 and 24 weeks compared to those on the placebo. A significantly higher proportion also reported that they felt satisfied that their skin had been helped compared with those receiving placebo, and any side effects were uncommon and very minor. These results show that spironolactone could offer an alternative to antibiotics for many women with persistent acne to use alongside topical acne treatments.



CEBD Patient Panel Event Saturday 7th October

We're holding this annual one day meeting at Jubilee Conference Centre in Nottingham and all patient panel members are welcome to attend. The day will be a mixture of learning and development activities along with the opportunity to contribute to a range of dermatology research projects. It's also an excellent way to meet up and network with your patient panel colleagues and meet members of the CEBD team. We're really pleased to be able to let you know that the meeting is being funded by the local [Nottingham centre](#) for the [National Institute for Health and Care Research School for Primary Care](#) (NIHR SPCR) which CEBD is a research partner with.

If you haven't been in touch already, [please let us know](#) if you'd like to attend this event so we can make sure you have a place. Travel expenses will of course be covered and we can book train travel, taxis etc in advance if that helps. We're still putting the programme for the event together so if there is anything you would be interested in hearing about on the day [get in touch with your suggestions](#).

Welcome to new CEBD member of staff Rheanne Leatherland

Rheanne joined CEBD as a research assistant in July 2023 to support Dr Rosalind Simpson with a research project ([SHELLS](#)) that will involve working together with professionals and patients to establish a diagnostic criteria that can be used by services and service users to diagnose lichen sclerosus. Currently, this condition is often misdiagnosed, or not diagnosed early enough, meaning that this is often under-recognised and undertreated. They look forward to sharing the project progress.

Rheanne is a BSc psychology graduate with a drive to help people and improve their health and wellbeing, which she

knows can be achieved through research. Before this role, Rheanne was a research coordinator in the [Children's Brain Tumour Research Centre](#), supporting research into childhood ependymomas. She also previously worked with the research governance team at Nottingham University Hospital Trust to set up various research projects across the NHS.

Outside of work, Rheanne loves painting, spending time with her whippet, Jasper, and all things fantasy!

