



Patient Panel Newsletter

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Updates from CEBD

- The first study from the [Rapid Eczema Trials](#) research programme looking at whether it's better to have a bath/shower just once or twice a week or every day has recruited to target! The '[Bathing Frequency](#)' study recruited 440 people (including 109 children) in just over 5 months which is a great achievement. One aim of this research programme is to get research results out more quickly so watch this space for the results coming soon!
- CEBD Patient Panel member Amanda Roberts was awarded the [UK Dermatology Clinical Trials Network](#) (UK DCTN) 'Honorary Lifetime Membership Award' earlier this month. This award is made in recognition of those who have made a sustained and significant contribution to the efforts of the UK DCTN and have championed dermatology research to improve patient care. Congratulations Amanda!
- The [PEARLS study](#) investigating reactive vs proactive therapy for the vulval skin condition lichen sclerosus has recently opened to recruitment with the first study patients being recruited from Nottingham University Hospitals Trust.
- CEBD Co-Director Prof Hywel Williams received a prestigious International Leadership Award from the [International League of Dermatological Societies](#) at the British Association of Dermatologists recent annual meeting in July (pictured below). Well done and well deserved Hywel!
- The CEBD [Annual Evidence Update Meeting](#) took place as an online meeting at the end of May with a focus on acne. Aimed at healthcare professionals, this meeting summarised recent developments in the field of acne clinical trials, reviews and treatment guidelines. CEBD Patient Panel members Grishma Ramesh and Sophie Dove joined the Q&A panel at the meeting to help ensure the patient voice was heard and a huge thanks to both for taking part. A number of presentations from this and previous meetings (covering topics including eczema, hair loss, psoriasis and urticaria) are available on the [conference website](#).
- We've had some staffing changes at CEBD over the past few months. We've said goodbye to Arabella Baker (research fellow on Rapid Eczema Trials) who has left to take up an academic post at Birmingham City University. We were also sad to say goodbye to Helen Scott who worked for us in the [Cochrane Skin](#) team and then as an administrator on a number of research projects. Good luck in your new role as a Trials Co-ordinator in the [Nottingham Clinical Trials Unit](#) Helen! Please see over the page to find out more about our new CEBD team member Lydia Tutt and new patient panel member Tracy Owen.



CEBD Patient Panel Meeting 22nd June

Many thanks to the nine CEBD Patient Panel members who gave up their Saturday morning on 22nd June to take part in this online meeting. After kicking off with introductions and an update on CEBD activities, the meeting focussed on giving feedback to study ideas at very early stages from [groups of trainee dermatologists](#). These dermatologists from across the UK are working with the UK Dermatology Clinical Trials Network (UK DCTN) to develop their skills in clinical research early in their careers and this was their first experience of working with patients and carers in this way.

The four study ideas considered were looking at spironolactone for acne in girls and young women, metformin for the treatment of hidradenitis suppurativa, using non-sterile gloves for dermatological surgery and spironolactone for the treatment of hidradenitis suppurativa. The teams got some great feedback to help with the development of their study ideas and we'll keep you updated about any involvement opportunities that might arise as these studies progress.

Our next online meeting will take place towards the end of year, [please do get in touch](#) with your suggestions for topics you'd like to see covered.

Meet a panel member—Tracy Owen

As someone born with eczema, over the years I had generally managed it OK (obviously spending a vast amount of money in the process).

But a couple of years ago, my wellbeing and health were at risk and there were times of feeling utter despair, affecting my relationship with my partner, and spending much time sleeping whilst trying to conserve energy, staying warm under a duvet, and limiting socialising. I had weeping eczema, infections, bacteria was attacking me. Fungal on my feet due to too much moisture, and scaly scalp with clusters of dried skin. I couldn't bathe as it was so painful, and then felt cold all the time as my skin was not effective as a thermostatic regulator.

I'd tried both pharmaceutical and complimentary methods, and also researched alternative and complimentary treatments all my life, and knew my skin wasn't easy to manage especially as I was ageing, with the skin being thinner and more prone to flare ups.

I noted via social media that Nottingham University ([Centre of Evidence Based Dermatology](#)) were looking for Public Patient Involvement (PPI) for the innovative online [RAPID Eczema Trials](#), so applied and the life changing

journey started here.

I'm now also with CEBD on the Patient Panel to hopefully help other people with eczema and other skin conditions find better management techniques and make a change to the future of others. A recent activity was with the UK DCTN Trainee Dermatologist

Groups, who are largely new to research projects and PPI involvement. The concept is to provide a broad PPI on four new dermatology research projects. An exciting opportunity to go forward with even more PPI at the very beginnings of our future Dermatologists.

I've learnt so much by being a PPI, and hands up, thought I had tried 'everything', and now know, there is so much more to learn and share via research, and others. It has enhanced my computer, and interpersonal skills via the use of 'TEAMS', shared documents, creating [blogs](#) and [vlogs](#). Plus, the bigger picture of being part of that Eczema and Dermatology Community, plus the wonderful innovative world of research where I now believe we can be the change.



Other things that caught our eye recently....

- Did you know that Monday 8th July was World Skin Health Day? Please see this [website](#) for further information.
- We all know the risks of seeking health information via social media. To try and help combat this, the [Patient Information Forum](#) have developed [tips and guidance](#) for finding trusted health information on social media.
- The Health Research Authority (HRA) are really keen to help 'de-mystify' the systems involved around clinical research. As part of this, they are opening up a number of online Research Ethics Committee (REC) meetings for members of the public to attend to see what the meetings involve and are hoping that this will encourage more people to get involved in such committees. If interested in this learning opportunity, [find out more here](#).
- Are you aware of the [Vulnerability Registration Service](#)? This is a not-for-profit organisation providing a central, independent register of vulnerable people helping companies to identify vulnerability and keep people safe. By giving vulnerable consumers a single place to register their status, the VRS helps them avoid having to repeat the same conversations every time they engage with different organisations.

Welcome to new member of CEBD staff Lydia Tutt



Hi, I'm Lydia.

I started off my career as a community pharmacist. After a few years, I decided it was time for a new challenge and I've been working in health research for almost 10 years now.

I joined CEBD in January but I'm not new to Nottingham as I did my PhD here, so it's nice to be back! My current research topics include topical corticosteroid withdrawal, autoimmune blistering diseases, and most recently, I've also joined the Rapid Eczema Trials team.

Outside work, my interests include travelling, anything history-related and getting out and about in nature.