



Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

CEBD related news and updates

- A [blog](#) about the CEBD Patient Panel and review of activities against the National Standards for Patient Involvement in research has now been published on the CEBD website— please do take 5 minutes to read it and many thanks indeed to all involved in putting this together.
- An outline application has been submitted to the [National Institute for Health Research](#) (NIHR) programme grant scheme for the RAPID eczema project. This programme grant on mild to moderate eczema has workstreams including efficient online trials in the NHS, an online platform to allow patient led trials and implementation and process evaluation including work with seldom heard groups . We are really grateful for all the support we've had from panel members in helping to develop this project and panel member Amanda Roberts is a co-applicant on the application.
- We also continue to be busy at the [UK DCTN](#) with another outline application submitted to the National Institute for Health Research (NIHR) for the SCC-AFTER study which is investigating the role of adjuvant radiotherapy in high-risk squamous cell carcinoma patients, with panel member Pat Fairbrother involved. Sadly, the outline application for the COUNT study investigating the use of nicotinamide to prevent skin cancer was unsuccessful.
- CEBD Co-director Hywel Williams has now completed his term of office as Director of the NIHR Health Technology Assessment programme. Please see his [final directors message](#) as he reflects back on his five years in this post.
- The application for the ATHENA shingles study (previously known as ZAP) led by CEBD collaborator [Matt Ridd](#) in Bristol has been successful. This study , which will investigate the use of pain relief to prevent neuralgia in shingles, is at very early set-up stages and should be recruiting it's first patients in about 18 months time. Many thanks to those panel members who contributed to the development of this project last June by responding to surveys and sharing their experiences .
- A [podcast](#) is now available for the blistering skin disease bullous pemphigoid project that was highlighted in the last newsletter.



Panel member Peter Smart appointed as Cochrane Skin's first patient editor

We are delighted to be able to let you know that CEBD Patient Panel member Peter Smart was appointed as Cochrane Skin's [first ever patient editor](#) in July. Peter has been involved in [Cochrane Skin](#) for a number of years now and has reviewed a number of protocols and papers in addition to speaking at their annual meetings. Many congratulations to Peter!!

SECURE-DERM

[SECURE-DERM](#) is an international collaboration to find out how patients with a range of dermatology conditions have been affected by COVID-19. This includes an anonymised patient survey , [SECURE-AD](#), for patients with eczema who have had (or suspect they've had) COVID-19. You can find out more by watching a video presented by CEBD Patient Panel member Tim Burton (please just scroll down the webpage to find it). If relevant, please do complete the [survey](#)—it should take no more than ten minutes.

APPGS report on skin and mental health published

The [All-Party Parliamentary Group on Skin](#) has now published the findings from its Inquiry on 'Mental Health and Skin Disease'. The 80 page report is available [here](#) and includes an executive summary at the beginning. Please do help to publicise this amongst your own groups and many thanks to those who shared their experiences to help with this really important piece of work.

CEBD Patient Panel Online Meeting Sat 10th Oct 10am-12noon

The programme for our meeting, taking place online using Microsoft Teams 10am-12noon on Saturday 10th October, has now been finalised and is outlined below. Many thanks to the panel members who have already expressed an interest, so far eleven of you will be taking part. If you'd like to join us there is still time [get in touch](#)—this will be an excellent opportunity to catch up with other patient panel members and CEBD colleagues including CEBD co-directors Kim Thomas and Hywel Williams. We're hoping that meetings such as this will enable the panel to meet up more frequently in addition to an annual face to face event.

Time	Session	Session Lead
9.45am (15mins)	Dial in Please be ready to join the meeting from 9.45am onwards to help a prompt 10am start	
10am (15 mins)	Introductions Give a very brief introduction of yourself to the rest of the group (1 min each)	Kim Thomas
10.15am (15 mins)	Update on CEBD activities A short update on what's been happening at CEBD over the past 12 months	Kim Thomas
10.30am (45 mins - to include a comfort break)	BEE study A group discussion to help look at how we can best communicate the results of this study which investigated the most acceptable and effective type of emollients to use for childhood eczema.	Matt Ridd
11.20am (20 mins)	Dr Google - how to find out more about your skin condition An interactive session looking at evidence based resources for your skin condition and how to find them. Please share how you've found information about your condition in the past during this session.	Amanda Roberts
11.40am (20 mins)	How has this worked? Online meetings are a new way of doing things for the patient panel so we need to discuss how it's worked, what we can do to improve things and how it could be a new way of working in the future	Paul Leighton
12noon (30 mins)	Networking An optional 30 mins session to stay on the meeting at the end and chat to other panel members and staff	Carron Layfield

I have a dragon who lives in my skin....

At the annual CEBD Patient Panel event last year, Stephanie Lax and [Fiona Cowdell](#) shared an idea for an educational outreach project with a potential collaboration between CEBD and local professional orchestra [Sinfonia Viva](#). Taking into account the views of the panel, and in subsequent creative discussions with Viva, the central focus has shifted to creatively sharing key points from Fiona's [NIHR Knowledge Mobilisation fellowship about eczema](#) with a Key Stage 1 audience (children age 5-7), and will be funded as part of that project.

We are excited to say that the development and delivery of this will now be digital; whilst this has become a necessity due to the COVID-19 pandemic, it will enable a

geographically much broader reach for the project activities.

At the present time, Hazel Gould (writer and theatre director) and Jay Nolan-Latchford (illustrator) are developing a storyline and visuals to use in a series of online workshops for children who have eczema. Hazel and a music workshop leader will work with young people and their families to record parts of the story and create musical material for a digital performance accompanied by an 8-piece ensemble from Sinfonia Viva. Outcomes will be a book and recording created for, and by, children with eczema, which can then be shared widely online and in educational settings. If you would like further information about this project please contact [Fiona Cowdell](#).

EFA allergy and respiratory patients digital conference 23rd October

The [European Federation of Allergy and Airways Diseases Patients' Associations \(EFA\)](#) is an independent non-profit organisation that connects 39 allergy, asthma and chronic obstructive pulmonary disease patients associations in 24 countries. They are holding a [digital conference 23-24th October](#) and have asked us to let you know that this will be **available for all to access free of charge for the first day, Friday 23rd October**. The theme of the meeting is patient-centred care through innovation and digitalisation so if you're interested please [register](#) now.