



Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

CEBD Patient Panel meeting Sat 24th Sept, Jubilee Conference Centre Nottingham

The annual CEBD Patient Panel meeting will be taking place on Saturday 24th September at the Jubilee [Conference Centre](#) in Nottingham. This one day meeting is an excellent opportunity to meet and network with your fellow panel members and CEBD staff, learn about research and contribute to studies. Sessions will include an update on recent CEBD activities, interactive training on the terminology used in clinical research and clinical trials, a ‘journal club’



type session to explore and discuss a research publication and a number of workshops where you will get the opportunity to feed into ongoing CEBD studies and contribute to studies in development.

Please do remember that travel costs are paid and we can book these for you in advance if preferred. If you would like to attend (and haven’t let us know already) then please contact [Carron Layfield](#) as soon as possible as places are limited.

Meet a panel member—Tressa Daly

Hello, I’m Tressa Davey and, as a recent addition to the panel, I would like to take this opportunity to introduce myself and to tell you a bit about why I am interested in dermatology research. I live on the beautiful Isle of Wight with my husband John. Around a year ago, I joined the Southampton Primary Care Research Centre where I am now a core public contributor. Since then, it has been fantastic to learn about a whole variety of health research projects and to discover the various ways to become involved at each stage of research projects.

Although I am interested in many areas of health research, I have a particular (and personal) interest in dermatology. This is partly because in my very large wider family we have a range of skin conditions including eczema, acne and psoriasis. I also find dermatology a fascinating and hugely important area in health research. My own academic background is in health psychology so I am particularly interested in the psychosocial aspects of skin conditions. Personally too, I have both witnessed and experienced the impact that skin conditions can have on quality of life and on mental health and wellbeing.

We all know that skin is our largest organ and the first line of defences against the outside world but, more than

that, it is the outer surface that we present to the world - and society makes judgements about us based on our skin. So skin is very much integral to our identity.

“Skin deep” is an expression that simultaneously suggests that something is superficial or shallow *and* that something more serious lurks beneath the surface. Skin conditions are often treated as not very important although it’s known that they can be indicative of more serious underlying conditions and can cause a great deal of suffering.

We all want to feel safe and comfortable in our own skin. Skin conditions often prevent that. They can influence how we face the world and even dictate what clothes we wear. At worst, they can force people into social isolation, loneliness and depression. For these reasons, I believe that people who work in or are involved in dermatology tend to have a special kind of social awareness so I am very proud to have been invited to join the panel. I’m keen to find out more, to contribute to progress in the area and to generally support the work of CEBD in any way I can.



Eczema Care Online website now live

We're really pleased to be able to let you know that the Eczema Care Online website is now live and available at EczemaCareOnline.org.uk. This is a free to access online toolkit to support people with eczema to self-care. The website provides top tips on how to live well with eczema and has been designed to be accessible, comprehensive, and suitable for both adults and children.

This toolkit has been developed as part of a National Institute for Health and Care Research (NIHR) funded programme grant led by Prof Kim Thomas (CEBD) and Dr Miriam Santer (University of Southampton). It has been developed with extensive input from people with eczema, clinical experts, health psychologists and the most up-to-date evidence. Many thanks to all the CEBD Patient Panel members who have contributed to the development of this resource over the past few years including Amanda Roberts, Kate Sykes, Amina Ahmed and Amina's children Taheeya and Tahmid who provided essential input from a younger persons perspective.

Please do feel free to share the link widely, and to encourage colleagues and people with eczema to signpost to and use the website.

If you would like further information about the Eczema Care Online research programme, please visit the [website](https://EczemaCareOnline.org.uk) or contact the team on ECO@soton.ac.uk.



Updates from CEBD

- The UK Dermatology Clinical Trials Network ([UK DCTN](https://www.ukdctn.org/)) is celebrating it's 20th birthday this year. To help celebrate we have launched a series of '[20 at 20 blogs](#)' sharing different perspectives of the network. There will be a new blog each week including from patient panel members so please do take a look.
- The second stage survey of the [Blistering Skin Diseases Priority Setting Partnership](#) is now live. If you know anyone affected by a condition such as bullous pemphigoid or pemphigus vulgaris please encourage them to take part to help define future research priorities in this area—you can access the survey [here](#).
- Results from the BEE (Best Emollient for Eczema) study have been [published](#) and have shown that while lotions, creams, gel and ointments were equally effective at treating the symptoms of eczema, no one type was suitable for everyone. A key message from the study is that patient choice is key for effective emollient use—please see the [study website](#) for further information including a video summary of the study results.
- We were sad to say goodbye last month to CEBD member of staff Elizabeth Doney who was the Information Specialist for Cochrane Skin and wish her well in her new post with Nottinghamshire Healthcare NHS Trust.

Updates from the NIHR

- The NIHR have just published [key statistics](#) from the Clinical Research Network for 2021-2022 including that 1,289,937 participants took part in over 4,600 portfolio studies in England during this 12 month period.
- Please see this [video](#) from the NIHR Blood and Transplant Research Unit in Organ Donation and Transplantation which has highlighted five key learnings crucial for effective collaboration when working with patient and public co-applicants for research studies.
- Take a look at this [blog and short video](#) from the East Midlands Research Design Service about capturing the impact of patient and public involvement on studies they're developing.