



Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

Welcome Back to the CEBD Patient Panel Newsletter!!

After being absent for a couple of years we have taken the decision to resurrect the CEBD Patient Panel Newsletter. We hope that this will help all panel members keep better updated about what's happening at CEBD and hopefully feel more involved in what we do. The format is the same as last time around but if you would prefer to see things done differently (eg newsletter content directly in an e-mail) please let me know. We hope to circulate the newsletter every 2-3 months—suggestions for articles and updates will be gratefully received and we will be looking for volunteers for the 'meet a member' section in the future!

Recent Funding Successes

We are pleased to announce the following new funding awards to CEBD. We'll find out at the end of March if we have been awarded the new NIHR Programme Grant (in collaboration with the University of Southampton) on eczema that was discussed at the last panel training day.

- £83,000 awarded to Prof Kim Thomas by the British Skin Foundation to fund a PhD student for 3 years to undertake validation of the [POEM](#) score for eczema.
- £10,000 awarded to Dr Sally Wilkes by the UK Dermatology Clinical Trials Network to run a [Priority Setting Partnership on cellulitis](#).

Follow CEBD and the UK DCTN on Twitter



You can now follow the UK Dermatology Clinical Trials Network (UK DCTN) and CEBD on Twitter. See [@UK_DCTN](#) on Twitter for up to date news about UK DCTN activities and [@CebdNottm](#) for more general Centre updates.

Meet a Panel Member—Amina Ahmed

Hi, I'm Amina, a mother of 3 children aged 4, 11 & 13. My eldest 2 children have suffered from severe eczema from the age of 3 months and it has been an absolute ordeal for our family as we have struggled to adapt to this condition and learn to manage it whilst trying to live "normal" lives. We have had the blessing of being surrounded by a strong dermatological team in the QMC who introduced me to the CEBD patient panel a number of years ago. In the first year or two of being part of this panel, I simply attended a couple of meetings a year which were very much a case of listening and learning from other more experienced patient members who were actively involved in research trials.



Over the past couple of years I have built up my confidence and understanding so that I could start to be actively involved (in varying degrees) in a number of trials. Some of this input has been as simple as reviewing literature for patients or families through to being part of formal review meetings to help set the priority list of what patients, carers and clinicians feel should be answered in relation to eczema. I was a co-applicant for the [CLOTHES](#) study (the use of silk clothing to treat childhood eczema) and have been involved in the management of the study. I will also be involved as a patient/carer representative for the upcoming TREAT study which is looking at different systemic treatments for more severe childhood eczema.

Meet a Member of CEBD Staff—Prof Kim Thomas

Kim was appointed as Professor of Applied Dermatology Research (non-clinical) at the University of Nottingham in August 2013, and is currently Co-Director of the Centre of Evidence Based Dermatology—a role she shares with Prof Hywel Williams.



She joined CEBD back in 1999 as a Research Associate, and was at first responsible for the design and conduct of a randomised controlled trial of topical corticosteroids for the treatment of eczema in children. Since then, Kim has worked in various roles within CEBD, and has conducted many independently-funded clinical trials to evaluate interventions for the treatment and prevention of skin disease (including eczema, cellulitis, vitiligo, verrucae, and rare skin diseases).

Kim's particular interests are in the design and conduct of dermatology clinical trials, and in clinical trial methodology. She is a founder member of the [UK Dermatology Clinical Trials Network](#), and is a member of the Executive Committee for the international Harmonizing Outcome Measures for Eczema ([HOME](#)) initiative. Kim is a panel member for the National Institute for Health Research Programme Grants for Applied Research programme (NIHR PGfAR), is an adviser to the National Institute for Clinical Excellence (NICE), and an affiliate member of the National Institute for Health Research Health Technology Assessment (NIHR HTA) Commissioning Board.

When not at work, Kim enjoys handicrafts—in particular making clothes and enjoys going to the theatre.

New NIHR Dissemination Centre

[The NIHR Dissemination Centre](#) is a new initiative from the [National Institute for Health Research](#) which aims to help healthcare professionals, commissioners and patients/carers make informed decisions about which treatments and practices are most effective. It does this by producing reports which set out the latest research evidence in a clear and accessible way and also offers blogs, podcasts and events where the latest research evidence is discussed and put into context.

Three types of report are available in different levels of depth—NIHR Signals, NIHR Highlights and Themed Reviews and you can sign up to receive relevant updates or even to become a 'rater' - reviewing research abstracts and helping to decide what you feel is important and should be disseminated more widely—see www.dc.nihr.ac.uk/get-involved/raters for information on how to do this. Feedback from CEBD has led to them including skin conditions as a search category so the site should now be easier for us all to use!



Focus on the Hi-Light Study

[Hi-Light](#) is a National Institute for Health Research Health Technology Assessment Programme (NIHR HTA) funded trial assessing hand-held narrowband UV devices, both alone and in combination with topical steroids for the treatment of early focal vitiligo. The £1.3 million trial, led by Dr Jonathan Batchelor a Consultant Dermatologist in Derby and Prof Kim Thomas at CEBD, is aiming to recruit 440 participants aged 5 years and above. Patients will be recruited over 18 months from 15 centres across the UK (Birmingham Children's Hospital, Sandwell in Birmingham, Bradford, Cannock, Cardiff, Derby, Glasgow, London, Norwich, Solihull, Kent, South Tees, North Durham, Nottingham and York) with the treatment period lasting for 9 months and follow up for 12 months.

Recruitment started in July and is going really well – the

target for the end of January was to have a total of 128 patients and by the middle of the month 151 patients had been recruited. This demonstrates the level of interest in this study from the patient community in what is considered by many as an undertreated condition.

This study really demonstrates the importance of involving patients throughout the research process. It was one of the areas illustrated as being an important research gap in the treatment of vitiligo in a [vitiligo Priority Setting Partnership](#) undertaken by CEBD in 2012. This was underlined by the results of a [Cochrane Systematic Review on treatments for vitiligo](#) (led by vitiligo patient Maxine Whitton) which emphasised the need for more high-quality trials in this condition. In addition, a huge amount of patient involvement work was done to help develop the patient reported outcome measure for the study (self-reported improvement in appearance of a target area) and we are working closely with the [Vitiligo Society](#) to promote the trial.