



Patient Panel Newsletter

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Funding Successes

We're really pleased to be able to let you know about a number of recent funding successes as outlined below. Many thanks to all those patient panel members who have helped with the development of these projects.

NIHR Fellowship Award— Dr Esther Burden-Teh has been successful in obtaining an NIHR Clinical Fellowship Award to undertake a project developing diagnostic criteria to help improve the early recognition of psoriasis in children. The work will also improve the quality of research studies in this area and will be undertaken over the next 3-4 years.

NIHR HTA Process Evaluation for Hi-Light Study — additional funding for the [Hi-Light vitiligo study](#) has been provided to allow a process evaluation of this clinical trial. This will include carrying out interviews with trial staff, healthcare professionals, commissioners and study participants and their family members. This will help the research team interpret the trial findings and help support the implementation of the study results into clinical practice.

University of Nottingham HERMES award for POEM App — funds have been obtained from this University of Nottingham grant stream to develop a phone app for [POEM](#). Developed at Nottingham, POEM is a tool used for monitoring the severity of atopic eczema. It focusses on the illness as experienced by the patient and has been recommended for use by a number of clinical guidelines including NICE. It is hoped that such an app will make POEM more accessible to patients and less of a burden than completing paper forms.

Meet a Panel Member—Fiona McOwan

My name is Fiona McOwan and I have had eczema since a baby, with one of my earliest 'skin' memories wearing a finger stall to keep an ichthymol paste bandage in place! I joined the Patient Panel in November 2009 after reading about the CEBD in the Christmas 2009 edition of Exchange, the magazine of the National Eczema Society. I kept in touch with the Panel through reading the regular newsletters and was keen to be involved.

However, due to work commitments I was unable to attend any Panel meetings until a training event held on Saturday 28th February 2015 at the University of Nottingham. I found the day truly inspirational and thoroughly enjoyed meeting the researchers and hearing about the planned projects and have been involved in commenting on a number of projects and grant applications relating to eczema since then. One of the projects that really caught my interest was 'Prioritising

Research for an entire clinical area (atopic eczema) using value of information methods' led by Prof Tracey Sach.

I became involved in this 5-year project in May 2015 as a patient representative at the first annual advisory group meeting. I found it really valuable to meet the other members of the group with their particular expertise, whether as researchers, clinicians or as statisticians, and of course other patient representatives. I was subsequently invited to be a member of the project's Expert Panel. Although extremely doubtful of my expertise I was delighted to be involved and attended the first meeting of this group in February of this year. The second advisory group meeting was a great opportunity to learn all that had been achieved and I am really looking forward to following their progress.



Update on Cellulitis Priority Setting Partnership

The first stage of the [cellulitis priority setting partnership](#) is now complete— over 600 uncertainties were submitted and many thanks to all of those who took part. About half the people who responded were patients, with the remainder being a variety of health care professionals.

The study team are now reviewing the uncertainties submitted and grouping them into categories for the next survey which will take place towards the end of the year. We will circulate this nearer the time—please do send this on to those you may know who have had cellulitis, it is a surprisingly common condition. For further information on priority setting partnerships please see the [James Lind Alliance website](#).

Help shape future research! Parents'/carers' opinions needed on food allergy testing in children

University of Bristol researchers working in collaboration with staff at CEBD are seeking parents'/carers' views on food allergy testing in children with eczema. Whether you are a parent/carer of a child with an established food allergy or with eczema or both, information from all kinds of parents/carers will be helpful for designing an upcoming research study into this area.

Please click on the survey link below to help shape this important future research! We would be grateful if you could also ask other parents/carers you know to fill out the survey, but we need everyone's responses by Wednesday, 26th October.

<https://primarycare.onlinesurveys.ac.uk/role-of-allergy-testing-in-eczema>

EUPATI resources for patients and carers involved in research

The European Patients' Academy ([EUPATI](#)) is a pan-European [Innovative Medicines Initiative](#) with partners from patient organizations, universities and not-for-profit organisations, along with a number of pharmaceutical companies.

The academy focus on education and training to increase the capacity and capability of patients to understand and contribute to medicines research and development and also improve the availability of objective, reliable, patient-friendly information for the public.

A number of resources are available free of charge including an easy to search tool box covering areas such as [evidence-based medicine](#) and different types of [clinical trial design](#) and an [on-line course](#) is also available.

Meet a Member of CEBD Staff—Jo Chalmers

Following a biochemistry PhD in cell signalling pathways from the University of Sheffield, Jo spent five years in pharmaceutical clinical research. She joined the Centre of Evidence Based Dermatology in 2003 and spent several years as the Trials Development Manager for the [UK Dermatology Clinical Trials Network \(UK DCTN\)](#), supporting the development and conduct of several large pragmatic trials in a variety of skin conditions.

Jo's research interests are mainly focused on the treatment and prevention of eczema, and on outcomes, particularly around core outcome set development. She is also actively involved in a number of CEBD projects on vitiligo and cellulitis. Jo coordinates the international Harmonising Outcome Measures for Eczema (HOME) initiative and is an active member of the symptoms, quality of life and long-term control research groups within HOME. She continues to work with the UK DCTN to support trial design and funding applications and outside of work Jo is a keen runner and musician.

