



# Patient Panel Newsletter

[www.nottingham.ac.uk/dermatology/3patientscarers.htm](http://www.nottingham.ac.uk/dermatology/3patientscarers.htm)

## CEBD Patient Panel Training Event

**Monday 14th June**

The next CEBD Patient Panel Training Event will take place at Attenborough Nature Reserve, Attenborough, Nottingham on Monday 14th June as this was by far the preferred date and venue for the majority of panel members. The programme for the day is shown below and if you would like to attend,

please let Carron know as soon as possible. We will of course pay all travel expenses and do let us know of any special dietary requirements. If you need train tickets booking in advance or are travelling a long way and need a hotel booking, tell us when reserving your place at the meeting and we'll get it done.

We've included a jargon busting session as part of the day as this has been requested by many of you. Additionally, we're delighted to have a guest speaker at the meeting, Derek Stewart, who has long standing experience of being involved in the development of cancer research as a patient representative. We're hoping that those panel members who have joined in CEBD research activities will be happy to share their experiences to start the day off and we will of course feedback to you how this involvement has helped our research. The final session of the day is a hands on workshop looking at prioritising research topics for eczema treatments .



<b>10.00-11.00 (with refreshments)</b>	<b>Introduction and Feedback</b> (To include feedback from panel members on activities to date and CEBD staff on the impact of activities on CEBD research)
<b>11.00-11.45</b>	<b>Guest Speaker: Agents for Change, a Personal Viewpoint of PPI</b> Derek Stewart, Associate Director for Patient and Public Involvement, National Institute for Health Research Clinical Research Network Co-ordinating Centre, Leeds
<b>11.45-12.00</b>	Coffee and Tea Break
<b>12.00-12.45</b>	<b>Jargon Busting for Clinical Research: What does it all mean?</b> Kim Thomas, CEBD, Nottingham (to include a presentation and activities)
<b>12.45-1.45</b>	Lunch Break
<b>1.45-2.30</b>	<b>How to Spot a Good (or Bad!) Clinical Trial</b> Hywel Williams, CEBD, University of Nottingham
<b>2.30-3.30 (with refreshments)</b>	<b>Prioritising Eczema Research</b> Helen Nankervis, CEBD, University of Nottingham

## Feedback on Acne Survey

Thank you to those panel members who helped us with the design of a survey for children and young people to help with a study we're developing looking into the prevention of acne in children aged 9-13. The survey has now been circulated through the Medicines for Children Research Network and over 40 children and teenagers responded. In general, they gave the idea the thumbs up so we're now working to develop the research idea further.

## Getting Involved in Cochrane Systematic Reviews

**CEBD Patient Panel member Carolyn Hughes writes about her experiences of getting involved in Cochrane Systematic Reviews.**



Inspired by Maxine Whitton's talk on Cochrane reviews at the last CEBD Patient Panel meeting, I travelled to Cardiff to take part in an informative afternoon workshop on 1st March aimed at consumers who are interested in becoming involved with the Cochrane Collaboration.

The workshop (Cochrane Needs Me – Why and How?) was informal and there were less than 10 participants, including three facilitators. It began with a question – we were given a brief description of two different emergency treatments and asked to choose which one we would prefer to receive in the event of a serious accident. Both options sounded good, we could see different potential advantages or disadvantages to each, but we had no information on which one worked best. We all wanted to be sure that we would choose the one that gave the better outcome.

Thus began an interesting discussion of how to conduct a trial to test whether a particular treatment works, using real examples of clinical trials. We covered the design and planning of the trial, how to conduct it and the interpretation of the results. We looked at collecting reliable evidence about the effectiveness of treatments and using the best up-to-date research evidence to inform health care decisions.

The aim of the Cochrane Collaboration in producing, regularly-updated, systematic reviews on a wide range of healthcare topics is to ensure that treatment decisions can be based on the most up-to-date and reliable evidence. We discussed ways to make the evidence obtained from Cochrane systematic reviews more widely available to the public, and learned about the Cochrane Consumer Network and the different ways that consumers can contribute. One workshop participant had written many "plain English" summaries of Cochrane reviews. Since attending the workshop I have now provided my first consumer comments to the Cochrane Skin Group for a proposed protocol of a review on the use of ustekinumab in the treatment of psoriasis. The protocol was interesting reading and it didn't take long to fill out the structured comment form provided.

The workshop in Cardiff was very small - only three of us consumers were "new" to Cochrane. I hope that more consumers will want to get involved.

## Feedback on Eczema Studies in Development

Thank you to those panel members who helped us with a survey on treating infected eczema in young children. The aim of the survey was to help with the design of a study investigating how to best treat infected eczema in young children. Unfortunately, the outline proposal we put forward to the organisation funding the research (part of the NHS) describing how we planned to do the work was not successful and so CEBD will not be involved in this research study.

In addition, the eczema clothing study (which was run as a workshop at the initial panel training event) will not be progressing any further due to problems with the design of the study which unfortunately cannot be addressed. We're sorry for all this disappointing news, and hope to have some new suggestions for eczema research over the next 6-12 months as part of a research prioritisation process project for eczema treatments (a workshop on this will be held at the next training event in June).

## Contact Details



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