



Patient Panel Newsletter

www.nottingham.ac.uk/dermatology/3patientscarers.htm

Welcome to the first edition of the CEBD Patient Panel Newsletter. This issue will focus on feedback from the first panel meeting and training event held recently at Attenborough Nature Reserve in Nottingham along with projects to get involved in.

Initial Patient Panel Training Event, Attenborough Nature Reserve, 9th November

We're really pleased to report that the first CEBD Patient Panel meeting was a great success! Eighteen panel members attended the event held at Attenborough Nature Reserve in Nottingham and over 90% of attendees reported that they found the day extremely useful.



The morning was spent giving an introduction to the Centre of Evidence Based Dermatology and clinical research. In the afternoon, three workshops were held giving a taster of the type of research activities panel members could get involved in. Again, most panel members found the presentations and workshops extremely useful. The feedback forms showed that the best aspect of the day were:

- Meeting others with similar conditions
- Enthusiasm of the group
- Being able to have a constructive input
- The open nature of the group and discussions
- The workshops



It was agreed that the panel should meet twice a year basis, with the next meeting to be held in June. Suggestions for sessions for the next panel meeting included:

- Specific examples of how to get involved
- A 'Jargon Busting' session
- Case studies of involvement and how this made a difference to the research
- 'What is' session on skin disorders to help understand other conditions
- Clinical trial design eg what makes a good study protocol

If you have any suggestions to make for topics and/or locations for the next meeting, please contact Carron.



Feedback from the Patient Panel Workshops

Panel members indicated that feedback on activities they'd taken part in was really important to them, so key points from the afternoon workshop sessions are given below. Full notes from the workshop sessions will be provided as a separate document to those who took part.

Workshop 1: The BEEP Study (Jo Chalmers)



The BEEP study (Barrier Enhancement for Eczema Prevention) is a pilot study looking at whether emollients used from birth can prevent or delay the onset of eczema in high risk babies. The workshop involved a group discussion about the study. Key feedback points were as follows:

- An advantage to being in the study could be that you are 'in the system' already and have a foot in the door for access to a dermatologist— a bit like first class rail travel. The study team agree that this will be really important to those taking part and we will promote this aspect where possible.
- The group felt that many people will say they have applied the emollient when they haven't. It needs to be made clear to the families that they aren't being tested and that it's really important to know what they've actually done than what they think we want to hear.
- Discussions revealed that it is difficult to understand why a control group is needed for the study. Scripted information will now be provided to the research nurses recruiting into this study to explain this concept properly.

Workshop 2: The Eczema Clothing Trial (Kim Thomas)



The research question being considered here is '*Does wearing specialist clothing reduce the severity of disease in children with atopic eczema?*' This project is at the very early stages of development and the study team are currently collecting evidence to help with the design of the study and subsequent funding applications. The workshop involved looking at the clothing to be used in the study. Key feedback points included:

- Make it clear on the Patient Information Sheets that there is no high quality information to support the use of specialist clothing to treat eczema. Patients will assume that these products have been proven to work and may be confused as to why the trial is needed.
- Refer to the products as clothing not bandages, as these have immediate associations with wet wrapping.
- Consider repackaging the items in trial specific packaging rather than the manufacturers own to remove potential bias.
- Relevant feedback from the discussions has been passed on to the product manufacturers.

Workshop 3: Research Prioritisation (Sally Crowe and Maxine Whitton)



A prioritisation exercise to establish the most important research gaps for the treatment of vitiligo is being carried out in the department. Hundreds of uncertainties about vitiligo treatments that have been collected from healthcare professionals and patients/carers now need to be filtered down into a top 20 list. This will be carried out using a ranking website and the workshop focussed on looking at the website and suggesting how it could be improved. All feedback will be incorporated (if technically possible) and key points included:

- An image of vitiligo should be included on the introductory page.
- The options should change position after the exercise is completed so they are in a different order for the next user and the same one isn't at the top every time.
- Use the term 'living with vitiligo' not coping with vitiligo on the website.

Don't forget to send in
your expenses claim
form !!!!!

Specific Examples of How to Get Involved in CEBD Research

Many of you have said you'd like some specific examples of projects to get involved in. Please refer to the delegates pack from the training day, as summaries of **ALL** the specific projects and the involvement needed are listed in there. Projects that will need involvement in the next 6 months are shown below, along with ways of getting involved in Cochrane Systematic Reviews and the UK Dermatology Clinical Trials Network. If any of them interest you, please get in touch with Carron for more information.

Cochrane Systematic Reviews

Input needed: We need 2-3 panel members to get involved as referees of reviews (on-going commitment).

UK Dermatology Clinical Trials Network (UK DCTN)

Input needed: We need 1-2 panel members to become consumer representatives on the UK DCTN Steering and Executive Committees to ensure that the needs of

patients and carers are addressed in this organisation (on-going commitment, 3 meetings per year).

SWET: Softened Water Eczema Trial

Input needed: We need 1-2 panel members to get involved in helping to write a lay summary of results for this study of childhood eczema (Spring 2010).

STOP GAP: Pyoderma Gangrenosum Trial

Input needed: We need 1-2 panel members to sit on the Trial Steering Committee for this study (on-going commitment, 1 meeting per year).

Acne Prevention Study

Input needed: We need 1-2 panel members to help review a survey for children and young people (now).

Vitiligo Prioritisation Project

Input needed: We need 4-5 panel members to get involved in continuing to help with the ranking website.

Eczema Treatment Prioritisation Project

Input needed: We need 2-3 panel members to help in identifying and prioritising unanswered questions about the treatment of eczema.

And finally....

A very big thank you to all CEBD patient panel members for getting involved in our research. This newsletter will be e-mailed out to you on a regular basis to keep you updated of CEBD research and panel related activities (most likely every other month). If you have any suggestions of anything you'd like to see in future editions, please don't hesitate to let us know.

Contact Details



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