



Patient Panel Newsletter

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

Have your say in eczema research

One of the activities at the last panel training event held in June was looking at research priorities for the treatment of eczema and we are now looking for panel members to get actively involved in this process. The work will take place between February 2011 and December 2011 and is funded by our NIHR Programme Grant.

Traditionally, research topics have been decided by researchers who are specialists in their field. They identify a treatment uncertainty, check that the answer is not known, and then apply to relevant government bodies or drug companies for research funding. Until recently there has been very little emphasis placed on the questions raised by patients, carers and clinicians in their everyday lives. Over the last few years, an organisation called the James Lind Alliance (www.lindalliance.org) has been working with groups of patients and clinicians in order to identify such questions and shared priorities for treatment uncertainties and some of you have been involved in such a research prioritisation process for vitiligo.

Over the coming months, we will be working with the James Lind Alliance again to establish a working partnership of patients, carers, clinicians, patient support groups and charitable bodies to establish what the most important treatment uncertainties are in the field of eczema. Once these have been identified, they will be uploaded onto the UK Database of Uncertainties about the Effects of Treatments (DUETs) (www.library.nhs.uk/DUETs), where they can be freely viewed by funding bodies.

In early 2011, we will be sending out a survey to vote on such uncertainties and for you to submit your own and we'd like as many panel members as possible to take part in this. It's only by making your questions known that we can establish what the most important future research questions should be.



All submitted questions will be processed so that similar questions are combined and checked to see if they are true uncertainties that require further research. We will then be asking patients, carers and clinicians to work with us to prioritise the questions, and to agree to a list of the top 10 most important treatment uncertainties in the field of eczema. This list will then be used to develop trials (and other research) that can start to answer these questions.

We are looking for 2-3 individuals (patients with eczema or carers of children with eczema) to get more heavily involved in this project. One of the ways we want you to help us is to ensure that the questions are written in a manner that are easy to understand before they are sent out for voting on. Also, we'd like you to join the Stakeholders Group for this project and be involved in meetings (3 over a 1 year period) where the decisions are made about how the project is managed and which questions are taken forward to potential research projects. Please let Carron know if you'd be interested in getting more involved in this way.

The SPaCE Project

We have been approached by an NHS funded research team based at the University of Southampton to find out if any CEBD Panel members would be interested in helping them. They are looking for carers of young children with eczema to help develop an interactive website. The aim of the website is to help families to manage eczema better through providing information, support and feedback.

They are looking for people who would be happy to participate in a focus group discussion which would last up to 2 hours. They would like to do this to get your opinions to help design website content and would also like you to test the website at home at a later date if possible. They will then carry out a small preliminary study of the website to help design a full-scale trial. The full scale trial will then test whether the website helps children and their families and if it is cost-effective.

Contact Carron if you are interested in taking part and if we have enough people on board, we can run this as part of the next Patient Panel Training Event which we hope to run in January/February.

Life in my houseful of boys—Kirsteens blog

CEBD Patient Panel member Kirsteen Murray has started writing a blog about her life in a houseful of boys. Unfortunately, Kirsteen hasn't been able to make it to any of the panel training events (living in Scotland with four young children being the major reason!) but is always happy and enthusiastic to help us out when she can. Three out of four of Kirsteen's sons (along with her husband) are affected by eczema and a variety of allergies.

Kirsteen's blog outlines some of the challenges they have faced and how they've got through them along with the comings and goings of everyday life in a busy family. The link below will take you through to a moving account of her youngest son Alasdair's battle with eczema, which included a stay in hospital when his eczema became infected.

<http://lifeinmyhousefulofboys.blogspot.com/2010/09/alsdairs-skin-story.html>

The blog also contains an ever growing number of dairy, wheat and gluten free recipes which some of you might find useful (I'll be testing out the Magic Chocolate Pudding one myself shortly!!).



Experiencing Dermatology Service Problems???

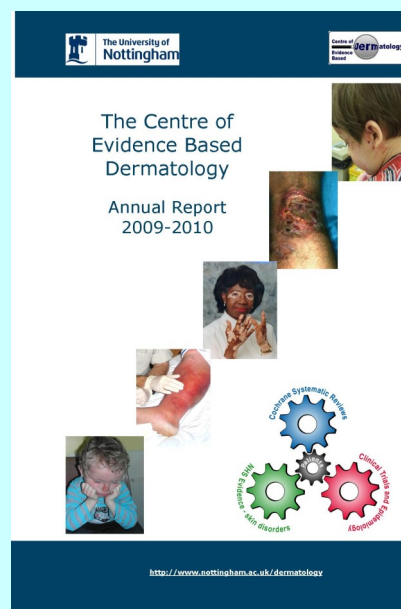
Please let us know if you are experiencing any problems with dermatology service provision in your area or if you are aware that changes in service provision are planned. We will then pass on these details to the Skin Care Campaign who are logging and investigating such issues across the UK. If you would prefer to contact them directly, please contact their Chief Executive Andrew Langford on alangford@skincarecampaign.org.

'Talk... ' Websites

Talk websites are a patient information service and forum dedicated to helping people living with, and trying to manage, the day to day difficulties of a variety of health conditions. Each site features:

- A care section & comprehensive directory providing information about products & treatments.
- A features section & latest news providing relevant articles & stories.
- A secure Members' Area where visitors can make friends, share experiences & talk via the forum.

Established by new CEBD Patient Panel member Deborah Mason, websites are available for a variety of skin conditions as follows: www.talkeczema.com, www.talkacne.com and www.talkpsoriasis.com.



The 2009-2010 CEBD Annual Report is now available. Please let Carron know if you'd like a copy and we'll send one out to you.



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