



Patient Panel Newsletter



Season's Greetings from all at CEBD

Panel Activities to Date

We're really pleased with the response we've had so far from panel members about getting involved in CEBD research activities.

Some examples are shown below:

- Becoming consumer referees for Cochrane Systematic Reviews
- Helping with the design of surveys to assist with clinical trial development
- Taking part in focus group discussions to help design patient decision aids for treatments for severe childhood eczema
- Joining various committees to help with clinical trial design and management
- Helping with the vitiligo research prioritisation process

If you haven't done so already, please do let us know what you'd like to get involved with.

Study on Infected Eczema

We are putting a grant application together to try to get funding for a study investigating the treatment of infected childhood eczema. The proposed study will look at the use of oral and/or topical antibiotics to treat this condition compared to using more potent topical steroids (without antibiotics).

If you have been affected by infected childhood eczema in any way (either as a patient or a carer) and would like to help by giving your perspective please do get in touch.

We are applying for funding from the Health Technology Assessment Programme (HTA), which is funded by the NHS. The HTA have recognised this area as being important and needing further research following on from the publication of a Cochrane Systematic Review on the topic in July 2008.

The Vitiligo Website needs your help!!!!

The number of research questions for the vitiligo research prioritisation project has now been reduced from 800 to just over 100. The website for the on-line ranking system which was previewed at the patient panel training day is due to go live early in the New Year. The pilot version is available now at <http://ctu.nottingham.ac.uk/ts0907/index.asp>. We'd really appreciate it if as many of you as possible (you don't need to have vitiligo to give it a try!) could take a look and give any feedback (especially regarding the structure of the website and the on-line voting procedure) to Carron as soon as possible.





Would you like to help record a podcast to promote CEBD?

We are looking for 2-3 panel members to help us record a podcast about the CEBD patient panel for our website. This is to let the public know what we're doing and to get more patients and carers like you involved in our work. To take part you'll need to be able to travel to CEBD, which is based at The Kings Meadow Campus of Nottingham University (old Central TV studio site). Please contact Carron if you'd like to take part.

Have You Heard of the Skin Care Campaign (SCC)?



The SCC is an umbrella organisation which campaigns for improved healthcare for people affected by skin conditions. You can find out

more on their website

www.skincarecampaign.org. One of their key aims is to educate and inform the public, healthcare staff and the government about skin conditions and their treatments.

Involve have just published a document summarising the impact of public involvement in NHS, public health and social care research. To download a copy please go to <http://www.invo.org.uk/pdfs/InvolveExploringImpactSummary3.11.09final.pdf> or contact Carron for a hard copy.

UK Dermatology Clinical Trials Network (UK DCTN) Committee Member Needed

We are still looking for a volunteer to join the UK DCTN Steering and Executive Committees as a patient/carers representative. Amanda Roberts (who is affected by eczema, both as a patient and carer) has very kindly put her name forward for the position, but we really would like someone else to join her so that you can give each other support. The role entails attending 2-3 meetings a year (all travel expenses are paid) and involves ensuring that the needs of patients and carers are considered throughout UK DCTN activities.

For information on the UK DCTN please see www.ukdctn.org and contact Carron, who is also the UK DCTN Network Manager.

Contact Details



Carron Layfield, CEBD Patient Panel Co-ordinator, Centre of Evidence Based Dermatology, University of Nottingham, Room A103, Kings Meadow Campus, Lenton Lane, Nottingham NG7 2NR
phone 0115 8468625 e-mail carron.layfield@nottingham.ac.uk

Hope you all have a lovely Christmas and best wishes for a happy and bright 2010.

