



Patient Panel Newsletter

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Eczema Project Updates: Some Good News to Report!!!

CLOTHES Study



We are delighted to announce that the full application by the UK Dermatology Clinical Trials Network (UK DCTN) to run a clinical trial funded by the National Institute for Health Research (NIHR) investigating the use of silk clothing to treat childhood eczema has been successful. CEBD Patient Panel member Amina Ahmed is part of the study team (led by Kim Thomas, CEBD) for this £1 million study which will start recruiting in five centres across England towards the end of 2013. Thank you to all panel members who have helped with the development of this study by taking part in workshops at training events and responding to surveys.

BEEP Study



This study is investigating the prevention of eczema in newborn babies with a high risk of developing eczema (family history of eczema/asthma). It will compare a skin barrier enhancement package (daily emollients and gentle wash products) to normal care. The study was shortlisted following on from a special funding call from the National Institute for Health Research (NIHR) for studies that had arisen from pilot work carried out as part of an NIHR Programme Grant which of course BEEP has. We will know the outcome of this £2million study application by December.

BATHE study

Many thanks to the CEBD Patient Panel members who helped with the design of this study at the last training event. The good news is that the study which aims to find out if bath emollients help children with eczema has now been shortlisted for full application by the National Institute for Health Research (NIHR) and the study team (including CEBD Patient Panel Member Amanda Roberts) are now working on the full application.

CEBD Patient Panel Activity at INVOLVE 2012 Meeting

CEBD Patient Panel activities are well represented at the forthcoming Involve meeting which is being held at East Midlands Conference Centre, Nottingham 13th-14th Nov. INVOLVE is a national advisory group that supports greater public involvement in NHS and other research www.invo.org.uk. Panel members Amanda Roberts and Maxine Whitton are attending the event along with panel co-ordinator Carron Layfield. They will be presenting the poster which was planned at the last training event 'CEBD Patient Panel: Wider Benefits for Patient Health.' In addition, Amanda will be taking part in a workshop session outlining the benefits of Priority Setting Partnerships for identifying research priorities. This is following on from her experiences with the eczema treatments priority setting partnership carried out by CEBD which identified the top 14 priorities for further research in this area. If you would like further details about this project, or would like to see a copy of the poster please contact Carron who will send them out to you. Thank you to all panel members who contributed to the poster either at the workshop or by responding to the survey.

Book Chapter

Carron Layfield and patient panel members Amanda Roberts, Jason Simons, Colette O'Sullivan and Anjna Rani have co-authored a book chapter entitled 'The role of patient and public involvement in evidence-based dermatology' for the dermatology textbook 'Evidence-Based Dermatology' (3rd edition). Hywel Williams (involved as one of the book editors) would like to thank all for their contribution, commenting that he feels the chapter was a 'superb collaborative effort'. If anyone would like a copy of the chapter which aims to give an overview on this topic please let Carron know and she'll send one out to you.

Vitiligo Study Update



Two of the prioritised topics for future research identified by the Vitiligo Priority Setting Partnership (carried out by CEBD a couple of years ago) have been the subject of a funding call from the National Institute for Health Research. The topics they have asked for a study to be carried out on are:

- Is NB-UVB better than topical corticosteroid for the treatment of non-segmental vitiligo?
- Is the combination of NB-UVB with potent topical corticosteroid better than either treatment when used alone.

CEBD Patient Panel member Maxine Whitton has been instrumental in driving this work forward and we have submitted an outline application for this project and will know if this has been successful by December so that we can go ahead and submit a full application. We hope that our experiences from the HI-Light pilot study investigating the use of hand held NB-UVB devices to treat vitiligo will help enormously with this application.

Dermatology Speciality Group Video

CEBD patient Panel members Jason Simons and Colette O'Sullivan represent the views of patients on the National Institute for Health (NIHR) Dermatology Specialty Group http://www.crnc.nihr.ac.uk/about_us/ccrn/specialty/dermatology/. As part of this they recently filmed a video outlining their roles and their past experiences as patients involved in a clinical trial. The video will be available on the website above shortly and we hope it will also be available for use in clinic waiting areas to encourage more dermatology patients to become involved in clinical trials and clinical research in general.

CEBD Annual Review 2011-2012

The CEBD Annual Review covering the period Sept 2011 –August 2012 will be available shortly. Please let Carron know if you'd like a copy of this document which aims to summarise CEBD research activity, the impact this has on dermatology and our collaborative links with others and we'll add you to the mailing list.



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