



Patient Panel Newsletter

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Feedback from SPRUSD day

Thank you to all those Patient Panel members who attended the SPRUSD (Setting Priorities and Reducing Uncertainties for People with Skin Disease) update meeting which was held earlier this month at the Post Graduate Medical Centre, QMC, Nottingham. The aim of the day was to provide an update on a number of the projects (including the CEBD Patient Panel) funded by the SPRUSD Programme Grant to a variety of stakeholders involved including researchers, clinicians, nurses and of course patient panel members. This is quite different to the meetings patient panel members have attended in the past which have been training events with only panel members in attendance.



We've had some great feedback from those who came to this meeting with a high percentage stating that they are pleased to see the projects involved (such as the BEEP eczema prevention pilot study and the squamous cell carcinoma project) making good progress. As with previous events, many of the patient panel members commented that a highlight of the day was catching up with other panel members and finding out what others have been getting involved in so it really is worthwhile coming to these events if you can. Some panel members have kindly let us know what they struggled to understand on the day or would like more information on and we will use this as a starting point for planning the next training event which we hope to hold next spring (see overleaf).

If you weren't able to attend on the day, but would like a delegate pack containing copies of the presentations from the day then please let Carron know and she'll send one out to you.

Vitiligo Pilot Study

Please read below for details of a pilot study on vitiligo which follows on from the vitiligo priority setting partnership which took place about 18 months ago.



This study will be the first pilot double blinded randomised controlled trial (RCT) on home light therapy for the treatment of vitiligo in the UK. The **HI-Light** (Home Intervention of **L**ight therapy) trial for vitiligo is a small pilot trial comparing hand-held light therapy (NB-UVB) devices with placebo devices. These devices will be used by the participants to treat their vitiligo at home for a period of four months. The main purpose of the trial is to test various logistics around a future multi-centre full scale RCT of these devices for example, if the participants will be happy to receive this treatment at home with limited medical supervision. An educational package for patients with early vitiligo i.e. a few symmetrical patches is also being trialled as part of this pilot study. During the educational session, participants will learn how to perform light therapy at home, deal with redness, increasing and decreasing the dose accordingly and ask for help when appropriate. Please note that the study has not started recruiting yet but will do so shortly.

This trial is conducted as part of Dr Viktoria Eleftheriadou's PhD on vitiligo. If you would like to find out more please contact Viktoria at Viktoria.eleftheriadou@nottingham.ac.uk.

Ideas for Next Patient Panel Training Event

We are planning a CEBD Patient Panel training event for Spring 2012 and would like to know what panel members want to see covered at this meeting. Suggestions so far include the lifecycle of a clinical trial and a jargon busting session on terminology related to systematic reviews.

Please let Carron Layfield have any ideas and suggestions as soon as possible to help us put an interesting and informative programme together. In addition, if you have any proposals for an alternative venue for the training day (it is usually held at Attenborough Nature Reserve, Nottingham) then again please let us know.

Eczema Prevention Overview– Can You Help???

We have recently published an overview of all the evidence around the different strategies for preventing eczema in infants and children. It covers most strategies that have been tried out including timing of weaning, hydrolysed formula, changes to the mothers diet and probiotics. We found that there is no clear evidence that any of the strategies that have been assessed can prevent eczema. If you would like a copy of the full report, you can view it online at <http://onlinelibrary.wiley.com/doi/10.1002/ebch.827/abstract> or we can send you a paper copy.

This overview has been published in a scientific journal called Evidence-based Child Health: A Cochrane Review Journal. It is currently published in a long and detailed scientific format, so we are keen to produce a patient friendly version which can be distributed to parents of young children who are interested to know what they can do to prevent their child(ren) developing eczema. We would appreciate input from any of the panel who are willing to read drafts of a patient friendly version and comment on anything that isn't clear or where they would like to see more detail. If you are willing to help, please get in touch with the project lead Joanne Chalmers at joanne.chalmers@nottingham.ac.uk or on 0115 8232435.

Opportunity to Join RCP Academic Medicine Committee

The Royal College of Physicians (RCP) are trying to find a lay member to join the RCP Academic Committee. The successful applicant must have a keen interest in academic clinical research and be willing to attend meetings in London 3 times a year.

For further information please contact their Patient Involvement Unit Administrator Nikki Coleman on Nikki.Coleman@rcplondon.ac.uk or 0203 075 1237.

Company Volunteering Schemes



We are aware that many of you are using annual leave in order to take part in CEBD Patient Panel activities. It is well worth checking with your employer (especially if you work for a larger company or organisation) to find out if they have a 'Volunteering Scheme' as the types of activity involved are highly likely to be covered by such schemes.

We will happily provide your employers with further information about the panel, the type of activities your taking part in and the importance of your involvement along with signed statements of support if this will help. Please contact Carron if you need any help at all with this matter.



Contact Details

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