



Patient Panel Newsletter

www.nottingham.ac.uk/dermatology



SPRUSD Annual Meeting, Tuesday 8th November

Setting **P**riorities &
Reducing **U**ncertainties for
people with **S**kin **D**isease

The programme for the SPRUSD annual meeting is now available and is shown below. Do remember that all CEBD panel members are invited to this meeting (which replaces the Winter 2011 training event) and it's an excellent opportunity to find out more about the Programme Grant which of course funds the panel. If you'd like to come and haven't already let Carron know, please do so by 30th September. Remember, we can provide help with booking train tickets, taxis etc. Don't hesitate to get in touch if you've got any queries about the day at all.

| Time | Topic | Presented by |
|---------------|--|------------------------------------|
| 12.30 – 13.20 | LUNCH and arrivals | |
| 13.20 – 13.30 | Welcome and introduction | Kim Thomas |
| 13.30 – 13.50 | Systematic review of treatments for eczema – key developments over the last 10 years | Helen Nankervis |
| 13.50 – 14.10 | Observation studies for squamous cell carcinoma – challenges and highlights from an area with no RCTs | Louise Lansbury |
| 14.10 – 14.50 | Results of the STOP GAP audit study | Tony Ormerod / Fiona Craig |
| 14.50 – 15.30 | Coffee break | |
| 15.30 – 15.50 | Preliminary results of the BEEP pilot trial | Joanne Chalmers |
| 15.50 – 16.10 | Feedback from members of the patient panel – reflections on how the CEBD patient panel is progressing. | Members of the patient panel (TBC) |
| 16.10 – 16.30 | Harmonizing Outcome Measures for Eczema – update on progress and plans for the future | Hywel Williams |
| 16.30 – 16.40 | Summary and close | Kim Thomas |

Panel Members Join Dermatology Specialty Group

CEBD Patient Panel members Jason Simons and Colette O' Sullivan have joined the Dermatology Specialty Group (DSG) to provide PPI input for this group. The DSG is chaired by Hywel Williams and the aim of the group is to help with the successful delivery of dermatology studies on the National Institute for Health Research portfolio, including CEBD studies such as STOP GAP. The group meets three times a year and is the first of its kind to have PPI representation. More information on the DSG can be found at www.crncc.nihr.ac.uk/about_us/ccrn/specialty/derm.

Helping Researchers Outside CEBD

We have been approached by a research team in London about CEBD Patient Panel members helping them with the development of research projects on eczema and psoriasis. We don't have any further details as yet, but would be interested in finding out how you feel about getting involved in projects not connected with CEBD. Please let Carron know any thoughts you might have about this.

Volunteers Needed to Speak at SPRUSD Annual Meeting

The eagle eyed amongst you will have noticed that the Programme for the SPRUSD meeting on 8th November includes a session on 'Feedback from members of the patient panel – reflections on how the CEBD patient panel is progressing'. This means we need 2-3 volunteers who have been actively involved in CEBD research over the past 2 years to step forward and volunteer to speak informally for 5 minutes at the meeting about their experiences. The meeting audience will include researchers, clinicians, nurses and members of the panel and we're expecting no more than 50 people on the day. If you'd be interested in sharing your experiences, please let Carron know as soon as possible so that we can give you further information and provide any support you might need.

Opportunity Within the NIHR Research for Patient Benefit Programme

The National Institute for Health Research Central Commissioning Facility (NIHR CCF) is looking for patient and public representatives (lay members) for the Research for Patient Benefit (RfPB) programme to take a part in the work of the ten regional advisory committees. The committees meet three times a year with individuals from clinical, academic and methodological backgrounds to discuss and decide which applications to the programme should be recommended for funding. Lay members take a full committee role and have the key task of providing the patient and public perspective in the research assessment processes. There are up to three lay members on each committee at present.

Committee experience and some healthcare background are useful. For example, you may be a service user or a carer, been a member of an ethics committee, or have worked with volunteer groups in a health related role. You must also reside in England. If you are interested and would like to know more please contact Liz Scott, Patient and Public Involvement (PPI) Assistant Programme Manager, using the contact details below.

Lay members of the Research for Patient Benefit programme are also invited to take part in an annual PPI workshop where they can update their knowledge of the programme and network with other members and the RfPB programme team from the NIHR CCF.

For further information on the NIHR Research for Patient Benefit programme, please go to the website www.ccf.nihr.ac.uk/rfpb/ppi. If you would like to be considered or would like more information, please contact Liz Scott by email to: liz.scott@nihr-ccf.org.uk, or tel: 020 8843 8041.

On-line Clinics for Skin Conditions

In collaboration with NHS Choices, Talk Health will be running a series of on-line clinics over the next 12 months, with a number being on skin conditions as outlined below. Clinicians and other experts will be on hand to answer queries you may have related to these conditions.

- **Eczema:** 23rd—29th September (in partnership with British Skin Foundation and Nottingham Support Group for Carers of Children with Eczema)
- **Psoriasis:** October (exact dates to be confirmed).

For further details please go to the talk health website www.talkhealthpartnership.com.

Eczema Research Update

We received over 1,000 questions related to uncertainties about research for eczema treatments and the research team are now categorising these to make them easier to manage. A ranking survey will follow in October and a top ten list will be produced at a workshop in January. Many thanks to all of you who contributed questions and to those panel members involved on the Steering Committee for this project.

The National Institute for Health Research (NIHR) are commissioning a research project on the use of silk clothing as a treatment for eczema. Those who attended the very first patient panel training event may remember that this is something CEBD have been interested in for a while and Kim Thomas is working on an outline grant application which will be submitted in September. If this is successful we'll then go ahead with a full application early next year.



Contact Details

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