



# Patient Panel Newsletter

[www.nottingham.ac.uk/dermatology/3patientscarers.htm](http://www.nottingham.ac.uk/dermatology/3patientscarers.htm)

## Jo Clayton and Amanda Roberts join UK DCTN Committees



### What is the UK DCTN?

CEBD is home to the co-ordinating centre of the UK Dermatology Clinical Trials Network (UK DCTN) which was established in 2002 to provide much needed evidence for dermatology clinical practice. The Network has grown to a collaborative group of over 560 dermatologists, nurses, health service researchers and patients/carers. The aims of the UK DCTN are simple—to conduct independent clinical trials for the prevention or treatment of skin disease that are important to health care professionals, patients and the NHS. On-going studies are investigating skin disorders including cellulitis, pyoderma gangrenosum and lentigo maligna while trials in development include studies of eczema, psoriasis, female pattern hair loss and epidermolysis bullosa. More details can be found on the website [www.ukdctn.org](http://www.ukdctn.org).

Membership of the UK DCTN is free and open to anyone with an interest in research into skin disorders. All UK DCTN members are eligible to submit trial ideas, and these are then developed with help from staff at the UK DCTN co-ordinating centre into fully funded studies. The Network has a rigorous trial development system for developing these ideas and central to this is the UK DCTN Steering Committee which decides which ideas should be developed further.

### Why involve patients and carers?

The Steering Committee is composed of approx 30 members and it is vital that patients and carers are involved so that their views are considered at all stages of the trial development process. In addition, the Network is managed by an Executive Committee of eight members, and again representation from the patient/carer community is vital to ensure that the organisation takes into account the needs of patients and carers and the public as a whole.

Maxine Whitton (who spoke at the CEBD Patient Panel Training Event last year) has been the patient representative on the UK DCTN Steering and Executive Committees for a number of years but unfortunately has

had to step down due to other commitments. Following a call to the CEBD Patient Panel for interested individuals to become involved, we're delighted to announce that Amanda Roberts and Jo Clayton are the new patient/carer representatives on the UK DCTN Steering and Executive Committees. Thank you to other members of the CEBD Patient Panel who expressed an interest in these roles and I'm sure all panel members will join us in wishing Jo and Amanda good luck in their new roles.



Jo Clayton (pictured left) and Amanda Roberts (pictured right) join the UK DCTN Steering and Executive Committees.



### What's it like being involved?

Amanda reports on their first Steering Committee meeting below.

'Last autumn members of the CEBD patient panel were asked if they might be interested in joining the Steering Panel of the UK DCTN since Maxine Whitton was standing down. My background is that of eczema, having been involved with the Nottingham Support Group for Carers of Children for many years. From this stepping stone I have been a patient representative on several committees and groups (the NICE Guideline for children with eczema, the East Midlands Research for Patient Benefit panel, HTA Clinical Evaluation and Trials Prioritisation Group and Asthma patient research panel), so it seemed appropriate to volunteer.

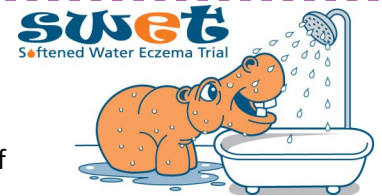
Jo Clayton (the other patient volunteer who has Hailey Hailey disease) and I were asked to attend the steering meeting on 23<sup>rd</sup> February so that we could see if it was what we had imagined. The meeting proved to be a relaxed and inclusive forum to debate proposed trials and provide a pool of knowledge to advise how a trial can be developed further. Jo and I are not experts in our own segment of skin disease, let alone in every skin disease, but we both felt that we could help provide an empathic general patient perspective and enjoyed being involved in some very interesting and lively discussions.

Luckily we must have passed muster and look forward to many more meetings.'

## Reminder about NHS Evidence-skin disorders

Another CEBD cog, NHS Evidence-skin disorders (formerly the NLH Skin Disorders Specialist Library) is an on-line resource which brings together all the latest evidence for the treatment and prevention of skin disorders in one place and can be accessed through its website [www.library.nhs.uk/skin](http://www.library.nhs.uk/skin). Each year, it hosts an Annual Evidence Update on eczema, psoriasis, skin cancer and acne and these include a commentary on what's new in the area and its significance for clinical practice. Although primarily intended for medical professionals, this site can be an excellent resource for patients and carers to keep up to date with new developments.

## Can you help us with the SWET study?



The SWET study, investigating whether the use of water softeners in hard water areas can help improve childhood eczema is now complete. We are in the process of writing up the results of the study and are looking for 1 or 2 individuals to help us write the summary of the results. This will involve commenting on the summary document, making sure that it's simple to read and giving us feedback on how we could improve the summary so that it is clear for the public to understand.

This work will need to be done mid-April with a quick turn around of a few days. Those taking part would need to sign a confidentiality agreement as it is really important that the results of the study are not revealed until it is officially published in May.

## Update on the Vitiligo Study

Despite a number of initial teething problems with the vitiligo study website ([www.vitiligostudy.org.uk](http://www.vitiligostudy.org.uk)), the on-line prioritisation exercise for research uncertainties for vitiligo finally went ahead and over 230 individuals (both patients/carers and health care professionals) have now voted for their TOP3 priorities. It must be remembered that this is the first time a research prioritisation exercise such as this has been conducted on-line and it has been a huge learning curve for all involved. We would like to thank those panel members who gave us feedback on the website and persisted with registering their priorities.

This on-line exercise has reduced the 100 uncertainties posed down to 20 and a final meeting will be held in London on 25th March to decide the TOP 10 priorities to be considered for potential clinical trials. CEBD panel member Lisa Sharples will be attending the meeting along with representatives from the Vitiligo Society to ensure that the views of patients and carers are taken on board during this meeting.



## CEBD Patient Panel Podcast

Apologies to those panel members who have volunteered to be interviewed for the CEBD Patient Panel Podcasts. This initiative is on hold for a while until we can decide the best way to promote the podcasts and make sure that people listen to them! Any ideas you may have for this would be gratefully received.



## Contact Details

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