Issue 7

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CENTRE OF EVIDENCE BASED DERMATOLOGY (CEBD)

Patient Panel Newsletter

Season's Greetings from all at CEBD

CEBD Patient Panel Training Event Monday 7th March

The next CEBD Patient Panel Training Event will take place at Attenborough Nature Reserve in Nottingham on Monday 7th March 2011. The programme for the day is shown below and if you would like to attend please let Carron know as soon as possible (see contact details later). We will of course pay all travel expenses and do let us know of any special dietary requirements that you have. If you need train tickets booking in advance or are travelling a long way and need a hotel booking for the Sunday evening tell us when reserving your place and we'll gladly get them booked for you.

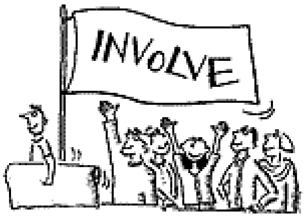
10am (with refreshments)	Introduction and feedback Carron Layfield, Kim Thomas
10.30am Presentation	The Importance of involving consumers in Cochrane Systematic Reviews Finola Delamere Managing Editor, Cochrane Skin Group
11.00am	Tea and Coffee
11.15am Presentation	Getting stuck in– what else can you do? Amanda Roberts, Panel Member
11.45am Presentation	The science of suncare and Skcin Guest Speaker Anthony Hubbard, Skcin
12.30pm	Lunch
1.30pm Presentation and Workshops/Small Group Work	Patient decision aids What are they? What is needed for decision aids for skin conditions? Kim Thomas, Hywel Williams
3.30pm (with refreshments)	Summary and close

Involve Conference 2010 – Public Involvement in Research: Innovation and Impact

CEBD Patient Panel Member Anjna Rani writes below about her experiences of visiting the recent Involve conference.

I decided to attend the above event as I wanted to see what opportunities were available for me (a person with no background in healthcare) to have further involvement in healthcare research. I have been affected by atopic eczema since birth and as such am a regular user of NHS services. I've previously peer-reviewed some protocols for the Cochrane Collaboration, become involved in the CEBD Patient Panel and "got a taste" for more involvement from these experiences! My fees for attending the 2 day meeting were kindly paid by funding from the Programme Grant which supports panel activities.

Arriving at the East Midlands Conference Centre, I was amazed by how many people were attending. At the opening session, it was announced that over 440 people were in attendance. That figure surprised me, but I soon understood why and it wasn't just for simple reasons, eg people like me wanting to get more involved in healthcare research (one third of the people there) or healthcare professionals presenting what public involvement they had in their research. The emphasis placed by the Government that patient and public involvement (PPI) is paramount to healthcare research had many healthcare professionals attending to find out more information on PPI.



Over the course of the two days, many talks were running simultaneously and I picked sessions that I thought were relevant to me. Many interesting discussions were had on whether PPI actually was an obstruction or not for obtaining funding for a particular piece of research. One presentation by Nanik Pursani, a stroke patient who led a research project on improving stroke services in South London, reported their funding bid was turned down because the panel that had reviewed it felt the main author did not have any experience in that area. How frustrating! A lot of encouragement was given to Nanik, particularly from professionals, to re-apply for funding and I hope this advice has been taken. On the other hand, many presenters stated that the paperwork required for applying for funding asked what PPI was being carried out, and examples were given of turning down applications for funding if this PPI work was not done.

The final afternoon of the conference started with a soapbox session. This was an opportunity for everyone to write down their thoughts about PPI and "lucky" individuals were picked out to have their say (a time limit of 3 minutes was in place!). This proved to be a chance to express frustrations on the limitations of PPI – why a person with mental health illness would not be considered to participate in healthcare research – to an individual asking for help to develop a product that would help with their illness. Finally, the conference ended with a session of talks titled "next steps" to improve PPI in healthcare research.

For me, the conference was useful and I found the information I was looking for to be involved in healthcare research and learnt more about the various stages of research that I could participate in.

Contact Details

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First Vitiligo World Congress, Milan, Italy September 2010

CEBD Patient Panel Member and experienced researcher Maxine Whitton writes below about her experiences of attending the first world congress on vitiligo.

I was honoured to be asked to speak at this prestigious event, the first ever Congress devoted exclusively to vitiligo. The sessions covered all aspects of the disease, its history, research, vitiligo through the eyes of patients, management of the disease and treatments, including complementary therapies. Not only was there a scientific programme with speakers who were experts in their field, but the final day was a Patient Day. This was free to patients, who had the opportunity to hear some of the speakers from the main scientific meeting covering the same topics in a way that was more understandable to them.

I spoke in two sessions – Vitiligo Through the Eyes of Patients, where I covered my experience of living with the disease and its influence on my interest and involvement in research, and also at the Patient Day, where I talked about the CEBD SPRUSD Programme Grant as a unique example of patient engagement in research. The Congress was very well attended, with delegates mainly from Italy and other European countries but with some from much further afield including the US, Japan, India, Saudi Arabia, Singapore, Australia, Africa, China and Japan.

Many sessions ran over time and involved an Italian to English translation and I noticed that there were few presentations covering the important psychological implications of vitiligo. Nevertheless it was a great opportunity to speak to people who were prominent in their field, as well as those whose studies I had assessed for the Cochrane systematic review of interventions for vitiligo. It was gratifying to realise that the review has had an impact, indeed it was referred to as “a milestone” by one of the speakers.

The opportunity to speak to people from all over the world who had the disease and to hear their experiences was a bonus. I remember the young girl from Africa who lost her job working in tourism because of her vitiligo. It started at the site of henna tattoos on her arms and then spread to her face and other areas. She saved for two years hoping to attend just such an event as the Congress. Lee Thomas, the Fox News presenter who “came out” to the public on American television and who has written a book about his experiences of living with vitiligo (“Turning white: a memoir of change”) was there. He has set up a support group and travels to speak about how he copes with his disease. He appeared on the platform and throughout the event without any cosmetic camouflage. An accomplished communicator, his talk was inspirational and received a standing ovation from the Congress delegates.

Around 300 patients attended the Patient Day, some of whom were keen to set up support groups in their own local areas. Jennifer Viles, the Manager of the Vitiligo Society in London, with the encouragement and support of one of the speakers, Professor Raymond Boissy, President of the National Vitiligo Foundation in America, held an impromptu meeting in the lunch break to explore the possibility of establishing an association of worldwide vitiligo support groups (WAVS). It is early days but it is envisaged that there will be a website, an expert panel of doctors and scientists, and that the site would provide a forum for information and support.

Hope you all have a lovely Christmas and best wishes for a happy 2011.