Issue 7
April 2017

CENTRE OF EVIDENCE BASED DERMATOLOGY (CEBD)

Patient Panel Newsletter

Vacancies on UK DCTN Steering and Executive Committees

CEBD is home to the co-ordinating centre of the UK Dermatology Clinical Trials Network (UK DCTN) which has grown to a collaborative group of over 1,000 dermatologists, nurses, heath 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.

The UK DCTN has a rigorous trial development system for developing these studies, and central to this is the Steering Committee which decides which ideas should be developed further. This group is composed of approximately 30 members, and it is vital that patients/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 important to ensure that the organisation takes into account the needs of patients and carers and the public as a whole.

We are looking for two volunteers to join the UK DCTN Steering and Executive Committees as patient/carer representatives. The role entails attending 2-3 meetings a year in London (all expenses are paid) and involves ensuring that the needs of patients and carers are considered throughout UK DCTN activities. To find out more, please contact Network Manager Carron Layfield.

Reviewing research proposals on skin health for older people—can you help?

Every year the UK DCTN have a themed research call in a particular area and for 2017 the theme is Skin Health for Older People. The aim of this £10,000 award is to help study teams overcome hurdles that may be impeding the development of clinical trials in an often neglected and under-researched area. The research conducted should be pilot/feasibility work or other work (such as a Priority Setting Partnership, outcome measures) that will eventually help with the development of a clinical trial. Previous calls have led to a number of projects, including the acne Priority Setting Partnership, the HEALS study on wound healing in the lower leg and outcome measures projects on alopecia and hidradentitis suppurativa.

We are looking for one or two patient panel members aged 65+ to help review short-listed applications for this award on a one-off basis. (We would also welcome interest from panel members younger than this who have experience of caring for elderly relatives.) This activity will involve attending a UK DCTN Steering Committee meeting, which is taking place on Tuesday 17th October 2017 at BAD House, London and reviewing the short-listed applications (maximum of three) in advance of the meeting. Travel expenses will of course be paid and we'd ask anyone interested to get in touch with Network Manager Carron Layfield for further information.

Healthtalk On-line SKINS resources launched

The SKINS resources on Healthtalk.org were officially launched earlier this month at an event chaired by Jon Snow of Channel 4 news in Oxford. The launch of the resources on young people's experiences of acne, alopecia, eczema and psoriasis marks the 100th health condition covered on Healthtalk.org. Many thanks to those patient panel members who helped review the test sites, and please do circulate these links to others who might find them useful. Additional areas that might be of interest on the site include a section on people's experiences of taking part in clinical trials and one on patient and public involvement in research (with a familiar face!!).

Meet a member of CEBD staff

Sue Davies-Jones

Sue qualified in North Wales as a nurse in 1995 and worked in a variety of adult nursing specialities in both Kent and the East Midlands, including Endoscopy, Theatre Recovery, Rheumatology and Dermatology. She joined CEBD in March 2007 as a research nurse, working initially on the Softened Water Eczema Trial (SWET), investigating whether water softeners help reduce the severity of eczema in children.

After SWET completed recruitment in September 2009, Sue worked as a Clinical Research Nurse on various trials within the Dermatology Department, including PATCH, STOP GAP, BLISTER, BADBIR, Hi-light Vitiligo, Genetics in Acne Vulgaris, and the BEEP feasibility study.

Sue is currently working as the research nurse in Nottingham on the main BEEP study (Barrier Enhancement for Eczema Prevention). She is thoroughly proud to be working on this NHS funded study and since starting the 24 month follow up phase for BEEP, Sue is also assisting the teams at Derby and Leicester with their follow up visits.

Outside of work Sue enjoys the outdoors, listening to an eclectic mix of music, spending time with friends and family, especially her two grandsons!

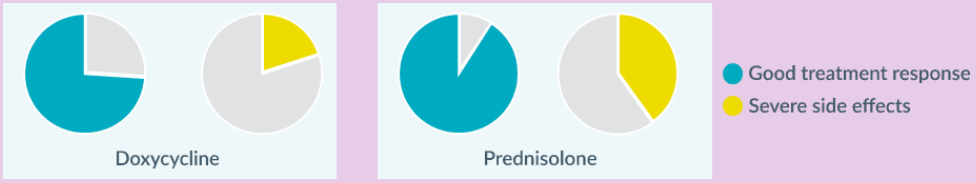
Blister study results published in The Lancet

The Blister study, recently published in the Lancet, compared two medications for the treatment of the rare, blistering skin condition bullous pemphigoid and is a really good example of how different aspects of CEBD work together to help provide better evidence for patient care. The need for more evidence on how to treat this condition was highlighted by a Cochrane systematic review and the study was developed by the UK Dermatology Clinical Trials Network. Over 250 patients were recruited into the study from 61 hospitals (54 in the UK and 7 in Germany), which shows how effective working collaboratively can be, when looking at rare diseases. The results of the study are summarised here and you will find a helpful video explaining the results on the study website. We are working actively to share the results of the study to help make sure they are taken up into clinical practice effectively and in a timely manner.

Oral steroids such as prednisolone are the standard treatment for bullous pemphigoid; they work well and there is good evidence for their use. However they can have serious long-term side effects and are not an ideal treatment, particularly as the illness is more common in the elderly. Antibiotics are also sometimes used, but there was very little evidence available for how effective they really are. The BLISTER study was carried out to see how safe and effective prednisolone (an oral steroid) was compared to doxycycline (an antibiotic) for the treatment of bullous pemphigoid. We suspected that doxycycline would not work as well as prednisolone, but thought that it would work reasonably well, and that the trade off would that doxycycline would be far safer in the long term.

As illustrated in the graphic below, after 6 weeks of treatment 74% of patients in the doxycycline treatment group had a good treatment response (3 or fewer blisters) compared with 91% in the prednisolone group. Over 12 months of treatment, 4 out of 10 patients taking prednisolone experienced serious side effects compared to 2 out of 10 patients taking the antibiotics. The results didn't really differ depending on the severity of the disease.

The results of this study therefore give doctors and patients another option for bullous pemphigoid as they show that starting treatment with antibiotics is reasonable effective and much safer than starting treatment with oral steroids long term.



A patient perspective of bullous pemphigoid and the BLISTER study– Ingrid Thompson

CEBD Patient Panel member Ingrid Thomson shares her experiences of living with bullous pemphigoid and attending the BLISTER study results investigator meeting as a patient.

In April 2015 I was diagnosed with bullous pemphigoid (BP) and hospitalised for 3 weeks. I had had a worsening rash for a few months but the development of the blisters happened extremely quickly. My body was covered in blisters (467 to be precise); some burst leaving raw skin and I was very ill. I was immediately put on a wheelbarrow full of drugs, including the dreaded steroids. By December 2015, I was still on lots of drugs but only 5mg of prednisolone and 100mg of azathioprine. A lot of the other drugs were to combat steroid side effects (lansoprazole, alendronic acid) which emphasises how important this study is. BP has completely changed my life.

I approached the investigator day with mixed emotions and not a little trepidation. It was the first time I'd been out for a whole day by myself since my diagnosis eight months before. I am normally an outgoing person but pemphigoid leaves more than just physical scars. It also is very tiring to the body, so fatigue sets in easily. Would I be welcome? Would they view me as a "lab rat"? Where had my confidence gone? On the plus side I really wanted to find out more about my horrible illness, how to treat it and how it is viewed in medical circles. I needn't have worried. From the moment I arrived I was made to feel very welcome and there was an obvious understanding, from those looking after us at the conference, of the difficulties I might face on the day. So many people think I suffer from a "bit of a skin condition" and that I don't look ill, so am not ill. I was very pleased to be very involved in the question session as, again, they were mindful of who the trial was done for. I found some of the clinicians were a little obsessed with the blisters. That is: how many blisters were acceptable, but I said that it's all relative to how many a patient had to start with. Three blisters is fine when you have been covered, and there are so many more things about the illness to cope with than a few blisters. The use of doxycycline over steroids would be most welcome. I have since had more reason to see what a double edged sword steroids are. Weight gain, moonface, aching joints, mood swings and extreme fatigue (especially when tapering) are some of the less serious ones. It has been a year since the conference, and I can add cataracts and being put on the diabetes register to the list. Whilst I still feel there are some cases where steroids are needed (my blisters needed treating quickly), doctors prescribe them fairly easily. Patients going on them may not realise the consequences and BP patients are often elderly so do not have the resources to check, or the confidence to ask the doctor about other treatments. I cannot emphasise too much how hard it is coming off steroids and how slowly it should be done. For these reasons there is a necessity to publish and spread the word about this trial so that GPs are aware and may start prescribing doxycycline early, before steroid action is needed.