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CENTRE OF EVIDENCE BASED DERMATOLOGY
(CEBD)

Patient Panel Newsletter

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CEBD Patient Panel Event Saturday 9th October

Many thanks to the ten CEBD patient Panel members who joined us for our first face to face meeting in two years, which was held at The Orchard Hotel in Nottingham, earlier this month. Thankfully, it was quite a mild and sunny day and so we weren't too chilly despite having all the windows open to ensure good ventilation!!

Once we'd all introduced ourselves, the day kicked off with an update on CEBD activities over the past 6 months from CEBD Co-director Kim Thomas and was followed by a very thought-provoking presentation from our guest speaker Alia Ahmed (a consultant dermatologist based in London) on the link between mental health and skin conditions. This presentation included a summary of the All Party Parliamentary Group report on skin disease and mental health and resources such as the BAD website Skin Support which aims to collate information to help the wellbeing of those affected by skin conditions. This session was voted the highlight of the day by most attendees.

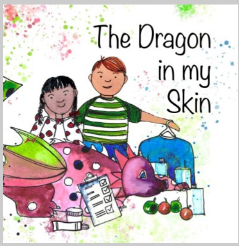
The morning was rounded off by a session on how to get more involved in Cochrane Skin reviews which was co-presented by patient panel member Peter Smart (the first patient editor at Cochrane Skin) and Cochrane Skin Managing Editor Laura Prescott and a further session from Kim Thomas on how the results of studies are communicated and publicised to different stakeholder groups. The afternoon focussed on getting panel members input into a number of ongoing projects at CEBD and studies currently in development. This included communicating the results of the skin tone survey that was conducted as part of International Clinical Trials Day (over 1,300 responses received which was fantastic!), an application for a National Institute for Health Research (NIHR) Commissioned Call for a study on acne and how to engage patients and carers in 'Citizen Science' approaches to dermatology research.

It really was great to meet up with our panel members again and one new member commented 'I love how friendly everyone was. This was my first event and I felt very welcomed and was able to express my views comfortably' which is heartening to hear as we do try to create a welcoming environment. We will continue to hold these one day meetings face to face on an annual basis, with shorter online meetings in between as these have also proved popular with panel members, especially those who live a long way from Nottingham. If you have any suggestions to make about the content of future meetings (such as guest speakers etc) please do get in touch and let us know.

New WhatsApp Group

Many thanks to CEBD Patient Panel Irene Soulsby who is co-ordinating the new WhatsApp group for panel members. This is an informal way for you to keep in touch with each other outside CEBD activities—if you'd like to be added to the group (and haven't let us know already) then please get in touch with your mobile number.

Dragon in My Skin Books Available



We have a limited number of Dragon in my Skin books available. These are an educational resource aimed at children in Key Stage 1 (age 4-7) and explain about living with eczema. If you have a child, grandchild or other younger relative or family friend affected by eczema that would benefit from the book please let us know and we will post one out for you.

Eczema Public Lecture Available Online

The public lecture 'Do You Know Someone With Eczema?' that CEBD Co-Director Prof Hywel Williams gave about eczema earlier this year as part of the University of Nottingham Medical School's 50th anniversary celebrations is now available to view online.

What's happening at Cochrane Skin???

- Cochrane Skin's Instagram is now live! Please follow them at www.instagram.com/cochraneskingroup. They already have 142 followers, and the team running the account post regularly.
- A new review 'Botulinum toxin type A for facial wrinkles' was published in July. In addition to the more traditional skin diseases seen by dermatologists, the scope of Cochrane Skin includes any skin problem that leads an individual to consult a healthcare professional and thus also includes areas that may be perceived as cosmetic, such as skin ageing.
- We're sad to announce the cancellation of Cochrane Colloquium Toronto, which had been rescheduled for 11-14th September, 2022. The Governing Board felt that the event was untenable due to continuing uncertainties and restrictions affecting international travel, delegates' willingness and ability to travel, and financial challenges in the coming years due to Cochrane's pledge to become fully Open Access by 2025. A Cochrane Skin annual meeting was scheduled to coincide with the colloquium, and we will confirm what's happening with this as soon as possible.

Patient panel member Kate Henaghan-Sykes co-authors a systematic review on Hidradenitis Suppurativa

Hidradenitis Suppurativa (HS) is a long-term condition that causes abscesses on the skin. These are usually in the groin, between buttocks, under breasts and in armpits. In the past, HS has been an under-researched condition, but there is a lot of ongoing research and promising developments in treatment options. At CEBD, we are really interested in HS research and are currently working on a study with colleagues at Cardiff University called the THESEUS study, that is looking at different treatments for HS. As a team of researchers wanting to understand more about the patient experience of HS, we also wanted to conduct a systematic literature search to pool together all the qualitative studies on HS to better understand people's experiences of living with HS, and their experiences of treatment for HS. Qualitative studies usually collect data through interviews or focus groups, and they focus on the meaning of what people say.

Patient involvement

Kate Henaghan-Sykes has been a long-standing member of the CEBD patient panel and is usually involved in studies from the point of view of a parent with a child with eczema. But, knowing from her own experience what a challenging condition HS can be, she was really excited to find out we were doing HS research too. We knew we needed a patient as part of the team to help us make sense of the findings, so we were really pleased to have Kate on board!

So, what did we do…?

Through a systematic process, we searched scientific databases for literature on HS. Sifting through 5500 publications resulted in us finding 14 qualitative studies from across the globe that covered this topic. We pulled all the findings together, summarised the themes that were covered in each, and came up with some main themes that we felt offered helpful insight into the experiences of people with HS.

What did we find…?

There are many physical, psychological and social challenges of living with HS and these challenges can profoundly impact people's lives. As a result of shame and embarrassment, people attempt to hide their HS, but this creates a fear of being exposed. They might hide the condition by covering up their HS or by not disclosing their HS to people in their life. People found social support and psychological acceptance helpful for coping. People with HS fall through the cracks of healthcare systems because of delayed diagnosis, lack of access to care, and patients not feeling supported in managing the condition. From these findings we were able to offer recommendations for clinical practice and ideas for future research.

How did Kate get involved…?

Kate read early versions of the analysis, shared her reflections, and engaged in discussions to help us better understand the data. This dialogue was key to finalising the analysis and writing up the final paper. For example, she really helped us to understand the different ideas of the notion of 'acceptability' within the data. Kate also helped to point out wording that had negative connotations (for example, sometimes we used the word 'odour', but by using 'smell' instead, the language felt less judgemental). She also helped to highlight aspects of the experience of living with HS that might be missing from the data, such as the impact of living with comorbidities (other conditions as well as HS).

On behalf of the THESUES study team and everyone at CEBD, I would like to say a huge thank you to Kate for being part of our team and improving HS research! You can read the full systematic review here.