

CENTRE OF EVIDENCE BASED DERMATOLOGY (CEBD)

April 2024

Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

Patient take over edition: Produced by Irene Soulsby, Anjna Rani and Amanda Roberts

Date for your diary: The next online CEBD patient Panel meeting - it's going to be Saturday 22nd June, morning only. Let us know if you'd like to come by emailing carron.layfield@nottingham.ac.uk

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Getting “the” message out – CEBD engages with the public

The Centre of Evidence Based Dermatology welcomes opportunities to engage with members of the public. Essentially, they have three drivers to do this: encouraging researchers of the future, helping to explain research concepts such as “randomisation” and to spread the word about their trials. Over the last year this has included: [Science in The Park](#), Talks to [U3A](#), children’s outpatients and a [Science Fun Day](#). We have given out leaflets at a local duck race and will be having a stand at a shopping centre in [Derby](#).

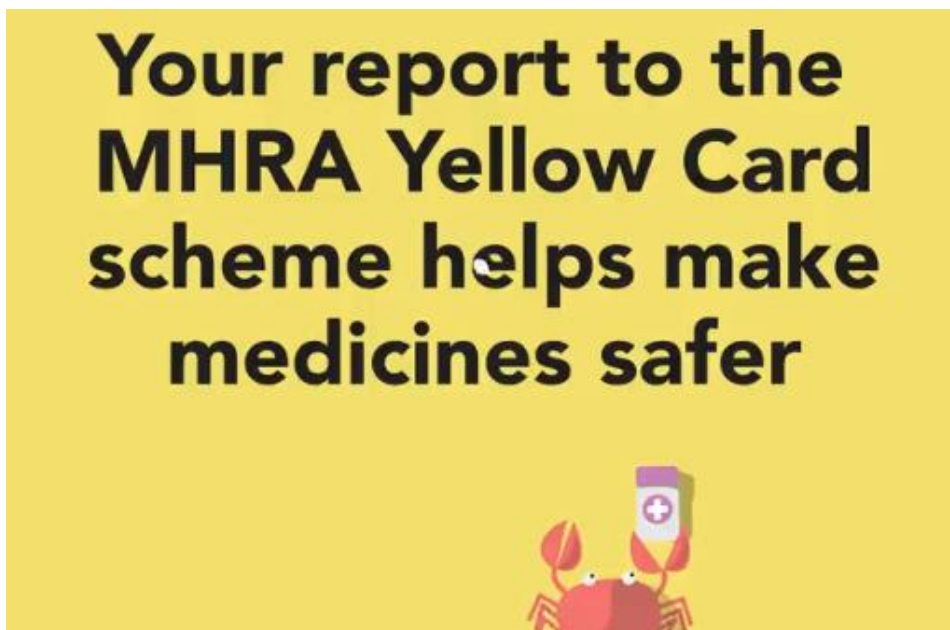


Each spring the Centre for Evidence Based Dermatology holds an **Annual Evidence Based Update Meeting** on a selected skin topic. These meetings are for healthcare professionals although patients may be on the Q&A panel. So just mentioning this, as it is indicative of all the great work CEBD doing on behalf of skin conditions.

The meeting summarises the most recent evidence in the form of systematic reviews, recently completed trials and guidelines for the treatment and management of the chosen skin disease. The topic area for the 2024 meeting on 23 May will be **acne**. More details can be found here:

<https://www.nottingham.ac.uk/conference/fac-mhs/medicine/evidence-based-update-meeting/>

Side effects? The role of the MHRA



Please will EVERYONE in the UK dermatology community report any side effects of their skin treatments to the Medicines and Healthcare products Regulatory Agency (MHRA) Medicines and Healthcare products Regulatory Agency (MHRA). Do this using the online 'Yellow Card' scheme. This is the way to have your voice heard about the safety of the medicines you are prescribed or purchase.

Report suspected side effects to medicines, vaccines, e-cigarettes, medical device incidents, defective or falsified (fake) products to the to ensure safe and effective use. <https://yellowcard.mhra.gov.uk/>

Here is a little animation about the scheme:

<https://x.com/MHRAgovuk/status/1722177209849229644>

Irene Soulsby on how acne affects mental health



I was quite young, about 11, when I started getting “spots”. Horrible, itchy, bumpy things. They were on my forehead, face, back and arms. I was so embarrassed. My mam would take me occasionally to the doctors, but nothing seemed to help. I really did not have a clue what was going on. However, I did have an awful time at school, feeling so unattractive, kids were horrible, if I am honest. At the time, people said that “spots were due to chips and

chocolate” or “part of growing up”.

I can’t remember what my diet was, but nothing seemed to control “them” and this continued until I was about 30 when they disappeared, literally overnight. We didn’t have the pharmacy products or support that we have these days. It was truly a miserable time for me. I don’t think that I had many photos taken, a lot were destroyed because of the spotty me. I hated looking at myself but well aware that people would look at me all of the time.

Decades later, I noticed a request for “someone with acne, has had acne” and I responded to this and found myself involved with a Southampton project, SAFA (Spironolactone for Adult Female Acne). I found it so interesting, and I learned so much about running a trial, and a lot about acne! The strange part was that I had not forgotten how much I had been affected by my experience of acne. Times move on and treatments move on (hopefully) but the experience of acne can affect us throughout our lives, losing confidence when we really need it.

I appreciate that my acne was many decades before social media, before people used mobile phones. I had a really hard time growing up and I appreciate how difficult it must be for people growing up in this digital world where we are on show constantly. The British Association of Dermatologists’ acne support website has really helpful stuff:

<https://www.acnesupport.org.uk/>

I am now involved with the project below (ACO), and younger me "would have greatly appreciated having ACO for guidance.

Jargon Buster

If you are unsure of any of the terms used in this newsletter, check this out

<https://www.nihr.ac.uk/about-us/glossary.htm>

An update on ACO - Acne Care Online trial



Acne Care Online is a 5 year research programme that aims to improve the health of people with acne by increasing use of effective treatments and reducing overuse of long-term oral antibiotics. The programme started in March 2022 and in the first two years we developed an intervention to support acne self-management. This involved seeking feedback from the intervention development group and a young person's advisory panel of 24 young people with experience of acne. We then refined the intervention through 53 think-aloud interviews with young people ranging from 13-25 years, also with acne or experience of acne. We are now in the final stages of set-up for the feasibility trial, to be followed by a full-scale trial, to evaluate the effect of the intervention. More information:

<https://www.southampton.ac.uk/primarycare/acnecareonline.page#home>

CEBD Patient Panel member update



Firoza Davies has lived experience of eczema both for herself and as a carer of a child. She is particularly concerned about mental health impacts for eczema. Over 30 other people with lived experience have helped the Rapid Eczema Trials citizen science programme prioritise, develop, monitor and spread generated knowledge. Firoza has helped to prioritise and then develop the first randomised control trial. She enjoyed the experience so much that she is now helping to develop the next trial. The first trial was exploring whether bathing (bath or shower) frequency has an impact on eczema skin. It has already recruited over half of the 400 people it needs to answer this question – so join up quickly if you want to take part. The link is <https://rapideczematrials.org/eczema-bathing-study/>

The second trial, which is still in development, will be about keeping control of eczema skin to minimise flares.

PEM Friends (Support for patients with Pemphigus and Pemphigoid and their carers)



It's official! On 15th February 2024, PEM Friends became a Charitable Incorporated Organisation (Foundation).

Being a charity was something we had resisted for a long time. We had anticipated

that, at some time, we would need to face the need to formalise our work, and the effort involved was daunting.

We have spent the last few years behaving as if we are a charity and creating the processes and policies that charities and small businesses adopt. We were told we had little re-organising and setting up systems in order to function as a charity because we were well organised and reasonably disciplined.

Once our income went above £5000 due to grants and some very generous donations last year, the need to register became inevitable.

The first thing we had to do was to decide what sort of charity we should be. There are several types. It was a dilemma and we are very grateful to the assistance given to us by Brian Seaton of Small Charity Support <https://www.smallcharitysupport.uk>. He gave us loads of reassurance and guided us through the options and implications. Thank you Brian.

Eventually, we decided to apply to be a Charitable Incorporated Organisation (Foundation). That meant all of PEM Council being Trustees and the main decision makers for our plans and operations. We are unusual in that the Trustees and the people doing the main work in keeping PEM Friends operating are the same. I can't emphasise enough how much commitment and effort this small team of volunteers provide to keep PEM Friends going. We all suffer with PEM too.

Completing the Charity Commission registration application with a deadline of the day before Christmas Eve was a daunting task, but we managed to get the form in with an hour to spare. The reward was a positive response and registration commencing on 15th February.

As I write, we have applied for HMRC registration too, which will enable us to claim Gift Aid on any donations we receive from UK tax payers.

We hope that, by becoming a charity, we will be able to access more support than before and that the increased workload isn't too challenging.

Ingrid Thompson

Telephone psychological support to reduce depression and loneliness



Depression and loneliness can be prevented with psychological care support delivered via telephone calls, according to a new research study. [How telephone psychological support can help reduce depression and loneliness](#)

Other Opportunities Be Part of Research



Get involved in “Be Part of Research” which is run by the National Institute for Health Research (NIHR). Every time someone receives treatment for a health condition, it’s because of the contributions from hundreds of thousands of people who take part in UK health and care research every year. Research is only possible if patients and healthy volunteers are willing to take part but some people may find the idea of taking part in research scary. Read the [NIHR blog](#) for further information.