



Patient Panel Newsletter

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CEBD News and Updates



It perhaps won't surprise you to hear that, in these very unusual times we all currently find ourselves in, the CEBD office is now closed with all staff working from home. You can still get hold of us all by e-mail and if you do need to speak to someone please e-mail them first to arrange a call, or even a video meeting!! We are all slowly getting more used to working and communicating remotely and look forward to our daily photographs from our keen wildlife enthusiast Natasha (see left for a beautiful photograph of a recent visitor to her garden). There are quite a few updates this time around as outlined below.

- We mentioned in the last newsletter that results from the BEEP eczema prevention study had been accepted for publication in the Lancet. The paper has now been published and links to the publication and a video from the study lead Prof Hywel Williams explaining the results can be found on the [study website](#).
- There has been a disappointing delay to the full application for the BEACON study which was discussed at the last patient panel event. The study is comparing a new biological treatment for eczema (dupilimab) with two other treatments—methotrexate and ciclosporin. Just as the study team were about to submit the application to the [National Institute for Health Research](#) (NIHR) the drug manufacturers withdrew their support to provide the treatment for the trial free of charge which meant that the study couldn't continue in the format originally planned. The NIHR have agreed to an extension to the deadline for the full application and the study team are now working on an alternative design to ensure that this important trial has the best chance possible of being funded.
- The new [CEBD blog](#) is now live! Please do take a look and if you would like to suggest any articles or perhaps even write one please get in touch with [Carron Layfield](#).
- Something to celebrate—the first participant has been recruited into the [THESEUS study](#) which aims to identify the best treatment options for Hidradenitis Suppurativa (HS) when first line treatment fails. The development of this study was supported by the [UK Dermatology Clinical Trials Network](#) and the qualitative work is being led by CEBD.
- The CEBD Patient Panel Action Plan team are planning to write a paper for publication in the journal [Research Involvement and Engagement](#) about the work that's being going on related to reviewing panel activities against the [national standards for public involvement in research](#). Do [let us have your suggestions](#) for things you'd like to see included.
- And finally....as most clinical trials go on hold (please see overleaf for further information) some CEBD clinical staff are being re-assigned to frontline clinical duties. One of our local research nurses (Jo Llewellyn) shared the photograph on the right of a recent lecture updating her critical care skills (social distancing and good hand hygiene of course being observed). We are really so proud of our colleagues in taking these roles on and are sure you will join us in thanking them for their fantastic efforts.



Update on CEBD Patient Panel event—Saturday 10th October 2020

As this event is quite a long way in the future we are still planning for it to go ahead. This one day meeting will be taking place at the [Orchards Hotel, Nottingham](#) and if you would like to attend (and haven't done so already) please contact [Carron Layfield](#) and she will reserve a place for you. We have taken feedback on board from attendees at the last meeting and also from those panel members involved in the action plan review of panel activities to help inform the programme for the day. In addition to an update on CEBD activities and study workshops, where you will be able to contribute to a range of studies in development, we are also hoping to include sessions on research around skin conditions and mental health, dissemination of research results and knowledge mobilisation and a workshop on the co-production of research. If you have any suggestions for things you'd like to see covered on the day please do [get in touch](#), we'd love to hear them!!

NIHR response to Covid-19

Many of you will be aware that the vast majority of CEBD and CEBD-related research is funded by the National Institute for Health Research (NIHR), which is in effect the research arm of the NHS. The NIHR have issued very clear guidance on their [response to Covid-19](#) which indicates that all NIHR funded research should be paused where possible to allow staff to either return to frontline clinical duties or focus on [research related to Covid-19](#). The set up of new studies and new sites for existing studies will be put on hold and studies that are recruiting will stop recruiting new participants temporarily. The NIHR have made it very clear that extensions will be made available for studies to continue when the time is right so they will not be adversely affected in the longer term —this [useful Q&A page](#) provides all the details.

CEBD response to Covid-19

We are really pleased to be able to let you know (thanks to some hard work from our Information Specialist Douglas Grindlay) that we have very quickly developed a [new resource](#) for the CEBD website which pulls together guidelines, web resources and journal articles relevant to coronavirus and skin conditions and dermatology. There is a [specific section for patients and the public](#) which includes a video from CEBD Co-director Prof Hywel Williams giving some really [helpful advice about hand washing](#) for those with eczema and other dry skin conditions.

Although recruitment into ongoing studies has paused we feel it's important to let you know that it is pretty much business as normal at CEBD. We are all still very busy indeed writing up various reports and publication and work of course also continues on a wide range of studies and projects in development. We will keep in touch with you as usual about opportunities to get involved in these on an on-going basis.

All Party Parliamentary Group on Skin (AGGPS)

Please take part in this important survey on mental health and skin disease

The [APPGS](#) was established in 1994 and aims to increase understanding about skin care issues in Parliament and to achieve improvements in the treatment and management of patients with skin disease. It also provides a means of responding to threats to dermatology services and acts as a forum for partners in skin care to engage with politicians with an interest in the issue. As with other such groups (600+ in total), the APPGS is an informal body with no parliamentary powers; it has a large and active membership that includes MPs from all political parties, members of the House of Lords, health professionals, patient groups and commercial interests.

The group are currently compiling a report around the theme of 'mental health and skin disease' which expects to make a number of recommendations, including on psychodermatology coverage, service design, healthcare professional training and research priorities. It will inform national policymakers as well as local commissioners.

To help inform this report, they need patients and carers affected by a skin condition to complete [this survey](#). It should take no more than 15-20 minutes and really will help to make a difference. If you would like to find out more about this report then please contact the [APPGS secretariat](#).