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CENTRE OF EVIDENCE BASED DERMATOLOGY (CEBD)

Patient Panel Newsletter

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Hi-light study results and patient involvement in this vitiligo study

We are delighted to be able to let you know the results of our Hi-Light trial on vitiligo now they have been published. Vitiligo causes loss of pigment in the skin and affects around 1% of the population worldwide. Hi-Light (which was funded by the National Institute for Health Research, NIHR) tested the effectiveness of home-based light therapy and topical steroid cream, used alone or in combination, for the treatment of vitiligo and involved 517 patients aged 5 years and over. This large, multi-centre trial has shown that combination treatment is likely to be superior to the individual treatments alone.

Using a patient reported outcome measure, those taking part judged how noticeable a 'target' vitiligo patch was after 9 months of treatment. Over a quarter of those (27%) who used both treatments together said that their vitiligo was either 'no longer noticeable' or 'a lot less noticeable' after this time period. This compared to 17% of those using steroid ointment on its own and 22% of those using the hand-held light therapy on its own. All treatments were able to stop the vitiligo from spreading, and were relatively safe, but light treatment required a considerable time commitment (approximately 20 minutes per session, 2-3 times per week). The trial also found that the vitiligo tended to return once any of the treatments were stopped. This video summarises the study results really well.

It has been wonderful to see that patients (including a number of members of the CEBD Patient Panel) have been involved across all areas of trial design and delivery of the Hi-light study. They were involved in prioritising the initial research question; completing surveys to inform trial design; the development of trial documentation including a video of how to use the devices); developing the primary outcome; assisting in trial conduct, recruitment and oversight; and contributing to the analysis and interpretation of trial results. This is an excellent example of how patients and carers can be involved throughout the lifecycle of a study and many thanks indeed to all those who were involved.

CEBD 2019-2020 Report

We are just putting the finishing touches to the 2019-2020 CEBD report and it will be ready for circulation in the New Year. If you would like to receive a copy please just let us know—unfortunately this time around printed copies will not be available and it will be circulated by e-mail.

CEBD Patient Panel meetings

Many thanks to the ten panel members who gave up their Saturday morning to take part in our first ever CEBD Patient Panel online event in October. Although it was no replacement for a face to face meeting, the feedback from those who took part was that it was really worthwhile. Those who live geographically distant from CEBD commented that they really appreciated being able to participate without having to travel and it enabled some to take part who haven't been involved for a long time. Bearing this in mind, we will have a mixed approach for these meetings in future with shorter, online meetings in addition to our full day, annual face to face meeting. We have two dates in the diary so far for 2021—please do get in touch and let us know if you would like to attend either (or both!) of these meetings. We will of course circulate further details nearer the time and fully welcome your suggestions for content for either of these meetings. Please do remember that travel expenses are paid for the face to face event (including accommodation if needed) and that travel can be pre-booked by CEBD if preferred.

- **Sat 6th March 10am-12noon** - online event via Microsoft Teams. Suggestions for sessions include reviewing websites linked to the Eczema Online project, how to improve the diversity of the panel and planning for a 'citizen science' initiative linked to International Clinical Trials day in 2021
- **Sat 9th October 10am-4.00pm**—face to face event at The Orchards Hotel, Nottingham. Suggestions for sessions include a workshop on co-creating research, an update on research in the field of skin disease and mental health and how the results of research can be more effectively shared.

HOME completes the first core outcome set for dermatology

(but what does that actually mean.....)

When we undertake clinical trials we need to measure how effective the treatments and interventions are that are being tested. It's really important that we have reliable ways of assessing these outcomes so that the results that come out of clinical trials are meaningful, high-quality and applicable to better patient care.

Bearing this in mind, it is fantastic news that the tools to measure the four agreed core domains of clinical signs, symptoms, quality of life and disease control in eczema clinical trials have been agreed and finalised by the Harmonising Outcome Measures for Eczema (HOME) initiative. This is the first complete core outcome set (COS) across dermatology, and one of only a handful across the whole of medicine and is a great achievement for this international project which is co-ordinated from CEBD. A number of the tools agreed for use have been developed at CEBD including POEM (used to measure patient reported symptoms and RECAP (for measuring disease control) and many thanks to all those panel members who have contributed to the success of these.

In addition to improving the quality of individual studies, one of the key advantages of using COS in clinical trials is that findings from all trials of a particular condition using these tools can be combined. This is known as a meta-analysis and the outputs from HOME should greatly improve the evidence base for eczema treatments as they will allow treatments to be more effectively compared across different studies. The challenge now for HOME is to ensure that the COS is implemented widely. This should be helped by the international scope of the project and the involvement of key stakeholders including patients, the pharmaceutical industry, representatives from the scientific publishing industry and a range of healthcare professionals and researchers. The HOME initiative has also expanded to look at clinical practice in addition to research—there will be a wider range of tools applicable here due to the differences in clinical practice across the world.

Similar projects are on-going to develop COS for a range of dermatology conditions including acne, skin cancer, vitiligo, vulval disorders and hidradenitis suppurativa . CEBD are involved in some of these and they are being promoted under the umbrella of the Cochrane Skin core outcome set initiative (CS-COUSIN).

Dermatology podcast on Spotify

Dermatology UK is a great new podcast on Spotify that has been set up by two dermatology nurses. The podcast involves interviews with experts in the field and will share tops tips and practical advice about a range of skin conditions with the aim of promoting self-care.

Pemfriends website revamped

The blistering skin disorders patient support group Pemfriends have recently revamped their website—please do take a look. This group have been instrumental in supporting the blistering skin disease research that we do at CEBD. Also see panel member and Pemfriends co-founder Ingrid Thomson in a recent BSF blog. If you have a group you'd like to highlight in this newsletter please just get in touch.

Impact of CEBD research—contributing to the 2021 Research Excellence Framework

The Research Excellence Framework (REF) is the UK's system for assessing the quality of research in higher education providers such as universities. The aims of REF are to: provide accountability for public investment in research, produce evidence of the benefits of this investment and inform the selective allocation of research funding. It is a complex process of expert review carried out by panels made up of senior academics, international experts and research users. Three distinct elements of research are assessed across 34 different research areas; quality of research outputs (e.g. publications and exhibitions), the impact of research beyond academic interest (eg benefits to the economy, change in public policy or health/social care, improving quality of life) and the environment that supports the research.

Last carried out in 2014, REF is underway for 2021 and CEBD are proud to be contributing one of the eleven research impact case studies that will be considered as part of the University of Nottingham's 'Clinical Medicine' REF submission. Our case study is centred around the wider impact of a number of clinical trials published over the past ten years including SINS (basal cell carcinoma), PATCH I and II (cellulitis), BLISTER (bullous pemphigoid), STOP-GAP (pyoderma gangrenosum) and CLOTHES (eczema). As part of this, we have recently published a paper showing the international impact of some of these studies which has helped to demonstrate their reach and influence. Pulling this impact case study together has been hard work and a real team effort, but it has also been a great opportunity to reflect on what CEBD has achieved. It is really important that as part of this we thank and recognise all the study participants, panel members and other patient and public contributors that have been involved in these studies over the years; we really would not have been able to put this case study together without them.