

Psoriasis Patient and Public Involvement meeting

31st October 2017

Guy's Hospital

Prof Catherine Smith welcomed everyone and introduced the event highlighting how psoriasis is a common disease (>1.8million people affected in the UK) which significantly affects all aspects of a patient's life. A lot of research is being carried out to better understand the disease and make improvements to care and treatment. The Psoriasis Association in the UK promotes "[Psoriasis Awareness Week](#)" alongside a global "[World Psoriasis Day](#)" with the aim of raising awareness of the support available for patients and the chance to be involved in psoriasis research.

Talks:

1) Dr Satveer Mahil – Genetics of psoriasis

Dr Mahil talked about the work that has been done at [St John's Institute of Dermatology](#), and around the world, in the identification of key genes that might be involved in psoriasis. Knowing about the potential causes of psoriasis helps us to develop specific and better treatments. Recent "biologic" treatments for plaque type psoriasis (eg Cosentyx) being prime examples. Work at Guy's in particular is currently looking at the causes of pustular forms of psoriasis, a form of the disease that is not as well understood but is just as important. Dr Mahil also discussed with the group how it is not just genes that influence psoriasis but also lots of environmental and lifestyle factors.

Discussion points:

The group asked lots of questions following Dr Mahil's talk particularly around the environmental and lifestyle causes of psoriasis, many drawing on their own experience, and also the best ways to access treatment and dermatologists.

The [NICE guidelines](#) were highlighted as a source of further information around the recommended NHS treatment pathways for psoriasis: <https://pathways.nice.org.uk/pathways/psoriasis>

It was agreed amongst the group that many aspects affect a person's psoriasis throughout life and that there is a need for further research into environmental factors to understand their influence better.

2) Lucy Moorhead – Psoriasis Priority Setting Partnership

Lucy Moorhead, Advanced Nurse Practitioner, talked about the Psoriasis Priority Setting Partnership (PSP) which has been driven by the [Psoriasis Association](#) and aims to identify the top 10 most important "uncertainties" around psoriasis. Opinions are being sought from everyone involved in psoriasis including patients, public, doctors, nurses, academics, industry. The results will genuinely influence the path of research and funding in the coming years so everyone is encouraged to participate.

If you would like to put your opinions forward they would be most welcome, see: <https://www.psoriasis-association.org.uk/research/psp>

3) Q&A

Following the talks the floor was open to questions. Panel included Prof Smith, Dr Mahil, Lucy Moorhead, Mark Turner (clinical psychologist), Louise Griffiths (research nurse), and Francesca Capon (senior lecturer and research lead).

Topical steroid withdrawal was raised by the audience as an area of unmet need and it was agreed to explore the possibility of producing guidance for local GPs to help in discussions with patients. Further information can be found in a recent review paper: [http://www.jaad.org/article/S0190-9622\(14\)02209-9/fulltext](http://www.jaad.org/article/S0190-9622(14)02209-9/fulltext) and opinion piece: [http://www.jaad.org/article/S0190-9622\(16\)30384-X/pdf](http://www.jaad.org/article/S0190-9622(16)30384-X/pdf)

We also asked the following questions regarding our future research projects. If you would like to add any additional input please don't hesitate to contact us; dermatologytrials@gstt.nhs.uk

- 1) Where do you find out about research and trials?
- 2) How acceptable is taking a small skin sample? If it would help us to discover how well you might respond to treatment would you be happy to have one or two taken during your normal clinic appointment?
- 3) How much is a reasonable sum for reimbursement of inconvenience? Should we separate out travel expenses?
- 4) What are your thoughts on whole body imaging (e.g. similar to airport security scanners) for skin assessments?

