

A patient perspective of bullous pemphigoid and the BLISTER study– Ingrid Thomson

CEBD Patient Panel member Ingrid Thomson shares her experiences of living with bullous pemphigoid and attending the BLISTER study results investigator meeting as a patient.

In April 2015 I was diagnosed with bullous pemphigoid (BP) and hospitalised for 3 weeks. I had had a worsening rash for a few months but the development of the blisters happened extremely quickly. My body was covered in blisters (467 to be precise); some burst leaving raw skin and I was very ill. I was immediately put on a wheelbarrow full of drugs, including the dreaded steroids. By December 2015, I was still on lots of drugs but only 5mg of prednisolone and 100mg of azathioprine. A lot of the other drugs were to combat steroid side effects (lansoprazole, alendronic acid) which emphasises how important this study is. BP has completely changed my life.

I approached the investigator day with mixed emotions and not a little trepidation. It was the first time I'd been out for a whole day by myself since my diagnosis eight months before. I am normally an outgoing person but pemphigoid leaves more than just physical scars. It also is very tiring to the body, so fatigue sets in easily. Would I be welcome? Would they view me as a "lab rat"? Where had my confidence gone? On the plus side I really wanted to find out more about my horrible illness, how to treat it and how it is viewed in medical circles. I needn't have worried. From the moment I arrived I was made to feel very welcome and there was an obvious understanding, from those looking after us at the conference,

of the difficulties I might face on the day. So many people think I suffer from a "bit of a skin condition" and that I don't look ill, so am not ill. I was very pleased to be very involved in the question session as, again, they were mindful of who the trial was done for. I found some

of the clinicians were a little obsessed with the blisters. That is: how many blisters were acceptable, but I said that it's all relative to how many a patient had to start with. Three blisters is fine when you have been covered, and there are so many more things about the illness to cope with than a few blisters. The use of doxycycline over steroids would be most welcome. I have since had more reason to see what a double edged sword steroids are. Weight gain, moonface, aching joints, mood swings and extreme fatigue (especially when tapering) are some of the less serious ones. It has been a year since the conference, and I can add cataracts and being put on the diabetes register to the list. Whilst I still feel there are some cases where steroids are needed (my blisters needed treating quickly), doctors prescribe them fairly easily. Patients going on them may not realise the consequences and BP patients are often elderly so do not have the resources to check, or the confidence to ask the doctor about other treatments. I cannot emphasise too much how hard it is coming off steroids and how slowly it should be done. For these reasons there is a necessity to publish and spread the word about this trial so that GPs are aware and may start prescribing doxycycline early, before steroid action is needed.

