

Suzanna's story

Sophie was born with one of her leg's completely black and covered in thick black hair, we got referred to Great Ormond Street who said it was a Pigmented Naevus. At the time Great Ormond Street said they didn't have the facilities to help Sophie as she required laser treatment to try and lighten the colour and to reduce the hair growth. We did discuss skin grafts but this wasn't an option as it covers her whole leg and they wouldn't be able to take the skin from anywhere else. Also they did discuss cutting layers of her skin off her leg and to then see how it grew back but this could cause more problems as she could end up with restricted leg movement.

We started going to Hertfordshire (Mount Vernon's) who started doing laser treatments - the treatments definitely were working and the skin is now a lot lighter and the hair is taking longer to grow back. More recently we got transferred to a hospital in Hampstead (London) as Hertfordshire closed down the unit. They have been very reluctant to do any further treatments as they feel they cannot help Sophie any further as they believe the treatment has stopped working.

We were advised that they would only be able to do a certain amount of treatments as it would never go entirely. In total Sophie has only had about 6 treatments in the last 7.5 years. Originally they did say they would do at least ten but now are not so keen!

I do have to say since she had her last treatment in Jan it hasn't made any difference so I can understand why they are stopping the treatment but I feel something must be able to be done with the technology these days.

Its very hard for Sophie as she cannot reveal it to the sun due to the risks of cancer.

I have been in touch with my local MP who contacted Hampstead and she managed to get me an appointment for Hampstead (which was the one in Jan) and I can keep in touch with her to ensure they continue her appointments but as the treatment has stopped working it is no longer for her involvement.

I'm at a point now where I don't know where to turn and don't just want to be pushed to one side as the doctors are not sure what to do next (or just don't want to!)

Thank you ☺