

Local families with bleeding disorders

Support for families, by families



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Family Stories Series

Penelope's Story

Affected carrier of Haemophilia A

Penelope was born on the 24 May 2016 at 2:11am weighing 7lb 4 Oz. Unfortunately Penelope was having difficulties feeding and would not take a bottle and initially she lost a lot of weight. We were later informed that Penelope had a tongue-tie. We were informed that in order for Penelope to have her tongue-tie cut she would require having her levels tested first and she was an obligate carrier of Haemophilia A (Penelope's dad has severe Haemophilia A).



On 11 July 2016 at 7 weeks old we went to Great Ormond Street to have her levels tested and I was later informed that her levels were 19.5% and that Penelope was an affected carrier of Haemophilia A. If I am completely honest I did not even think that this was a possibility. We had always been told that if we had a daughter that she would be a carrier but did not realise there may be a possibility that she may be symptomatic as well. It was a big shock and was very difficult to digest initially.

Even though my husband has Haemophilia and deals with his condition, well, he had no experience with a girl with the condition and did not know what to expect or when to seek medical attention so it was a learning curve for him as well, even though he had experienced the condition his whole life.

It has been a difficult journey as when you talk about Penelope's condition you receive blank looks or that "girls cannot have it" and you find yourself constantly having to explain the situation. It is also assumed that I passed the condition to Penelope when in fact it came from her father. It is very difficult to understand the diagnosis when the people around you do not understand it themselves and I hope with time and further education that people will become more knowledgeable and it will be more accepted that girls bleed too and in turn are treated the same as boys with the same condition/levels.

I hope that as Penelope grows up it will become more accepted and that literature is changed to include girls or explain to potential parents that there may be the chance that your daughter could have a bleeding disorder as this was never told to me before/after pregnancy.

We would like to extend a special thank you to all the families who have contributed to this important series of experience-sharing stories, in particular, the children with haemophilia who have allowed their photo to be shared.

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Local families with bleeding disorders is a registered charity in England and Wales (1186979).

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