

Local families with bleeding disorders

Support for families, by families



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Family Stories Series

Ollie's Story

Severe Haemophilia A

This is my son Ollie, Ollie is 9 years old, and has severe Haemophilia A.

Oliver is the second haemophiliac to be born in our family, prior to my nephews diagnosis we never even knew what Haemophilia was!

We have since found that that both my sisters, my mum and I are all symptomatic carriers of the haemophilia gene. And so my son's birth took place at the Haemophilia centre at The Royal London Hospital, not only to look after my son who had a 50% chance of inheriting the gene, but to look after me too as my factor levels are lower than normal.



Ollie was diagnosed with Haemophilia shortly after birth, bloods were taken from the cord to do this. A few days after Ollie was born the hospital decided to take another procedural blood test to make sure the first test was correct. Unfortunately the Paediatric doctor who took the bloods decided to use the heel prick method, and as a result Ollie had his first treatment later on that afternoon, as we could not get the bleeding to stop.

The next 12 months were quite scary, not really knowing how to identify bleeds, always watching him, always questioning if something was wrong that I couldn't see, it was a huge learning curve and I must have read every single Haemophilia book or article out there! Ollie started prophylaxis at 1-year old as he was a very active toddler, and had his port fitted at GOSH at around 15 months.

Having a port gave us a new lease of life, we were no longer tied to the hospital and we could manage our sons condition at home, or even abroad on holiday! Haemophilia was no longer in control of us, we were in control of Haemophilia. Ollie's port lasted 7½ years, and then one day just stopped working. We have since had the port removed and have moved onto vein access in the last 12 months, and hoping Ollie will start to self infuse this year.

I am happy to say that Ollie has developed into a very happy, balanced and active young boy. Infusions don't seem to bother him at all, and I'm proud to say that he seems to take it all in his stride.

As parents we try not to let his Haemophilia hold him back, always Ollie first, Haemophilia second and as such he gets on very well at school, he regularly plays football and tennis, and enjoys swimming too.

Ollie has created a video to share with members how he makes up his factor in the morning. To view the video and read other family stories, visit our website at the address below.

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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