

Local families with bleeding disorders

Support for families, by families



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Family Stories Series

Paul's Story

Severe Haemophilia A

I was born on the 4th February 2001. As a known carrier, my Mum knew there was a possibility of me having a bleeding condition. I was diagnosed with severe Haemophilia A at 2 hours old. My brother is also a haemophiliac and my sister a carrier.



Things were fine, until I was 5 months old. Mum tried to wake me but, I was floppy and unresponsive and she noticed my forehead appeared to swell. I had an intracranial bleed and was put into an induced coma for 5 days. A seizure caused left-side paralysis for 4 days but, thanks to quick treatment and a wonderful Haemophilia nurse, I can tell the story in good health.

Within a week, I had a port-a-cath fitted which I had until I was 3 when it became infected. When I was being examined for my port infection, the Doctor found a heart murmur which turned out to be Mixed Aortic Valve Disease, and is monitored every 6–12 months.

As I bruise more than my brother, I had a blood test and found that I had a platelet disorder – no name for it but treatable. When I was much younger, I used to watch my older brother play cricket and was very keen to play. I started playing as soon as I could and from then on, my life has revolved around cricket. When I was 7, I played for an older age group and almost lived at the local cricket club. That year, further to my mother's distress, I was hit by a car and had very bad bruising and a haematoma on my head. I spent 3 days in hospital. I also started self-treating which helped me become more independent.

As I was growing up, I struggled with my anger. I was assessed and diagnosed with ADHD. Cricket was instrumental in helping me control my anger as it gave me something different to focus on. When I was 14, I was selected for Berkshire U14s development team. I played 1 game for them against the county age group side and performed well enough to be asked to join the side. I then played for the county until I was 17. I played my first game for my club's 1st XI when I was 15 and I ended up playing every game that year. We won the league and got promoted. I attended cricket college at the Ageas Bowl and achieved a BTEC in Sport. I passed my Level 2 cricket coaching qualification – I love doing this and intend to make it my career.

I volunteered at the Cricket World Cup and was lucky enough to be a flag bearer for England. Living a positive life, active lifestyle is important for anyone's physical and mental health. I feel that being active and keeping myself physically fit has helped my muscles and joints become stronger which I believe has meant that I have had less bleeds. I hope this story encourages more people with Haemophilia to become more active and positive with their lives.

"I won't let Haemophilia define me" Will you?

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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<http://www.bleeding-disorders.co.uk>



info@bleeding-disorders.co.uk



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