

## Local families with bleeding disorders

### Support for families, by families



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#### Family Stories Series

# Theo's Story

Our second son Theo was born 1 day late after a very quick labour and waterbirth. We had no obvious problems with Theo until he started to walk. A few days after he walked for the 1st time he woke one morning very unsettled and wouldn't and couldn't put any weight on his right leg. I took him to A&E as it wasn't normal for him. He had a red rash up his leg and the hospital took a x-ray and said he had a slight fracture to his big toe and it will heal and to give him ibuprofen. Theo didn't begin to walk again for about 12 days.

A few months later the same thing happened and I was told it was 'soft tissue' damage and to give ibuprofen again – he didn't walk for 1 week. We had an issue with his arm and the Dr told me he had got into a habit of holding it bent and there was no problem. I believed them as they seemed to fix themselves.



Then at 22 months Theo fell down the stairs at home. Looking back and with hindsight, I would have taken him to hospital quicker but I didn't. There was no blood but a big bump came up. The following day we took him to hospital as the bruising had got so much worse and he couldn't now put weight on his right leg. As soon as we were taken in, it was obvious they didn't believe us that he had fallen down the stairs as the 'bruising wasn't that expected of a stair fall'.

He was admitted and I then went in and swapped with my husband as I wanted to stay the night with him. It was then I was asked if there was any history of bleeding disorders. Now this now sounds silly but I didn't know anything about Haemophilia and the genetics of it, so I said "oh I think my Grandad had Haemophilia but he had it with a question mark on his death certificate. He died in 1957 on the operating table". New bloods were done and lo and behold, it came back that he had severe Haemophilia A. It was a total shock. I was distraught and not knowing anything about the condition looking online made me even more upset. Knowing those times with him not walking were 'joint bleeds' and we should have never given him ibuprofen. I felt so very guilty.

Fast forward a month and we were under the care of St. George's and our favourite ever nurse took us under her wing and helped us through the next few tough months of Theo having a port fitted and being trained up to do Theo's treatment at home.

Theo turned 7 in April and he still has the same port working well after 5 years and is off to junior school. We've dealt with Theo's needle phobia which was very stressful and pushed my husband and I to the limit of refusing to give Theo his treatment unless he had a bleed. Luckily that is all sorted now and we have a happy, crazy boy who I wouldn't change for the world.

**Haemophilia does not and will not define Theo. Haemophilia lives with Theo and not the other way around. He is my little bleeder and a true superhero.**

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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