

# Local families with bleeding disorders

## Support for families, by families



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### Family Stories Series

# Lenny's Story

I knew I was a carrier of Haemophilia as my Granddad had it and my mum was a carrier. When me and my husband decided to start a family we weren't worried about the Haemophilia. As my mum is a carrier but both my brothers didn't have Haemophilia, I thought I'd be the same.

My first child was a girl, so we didn't have the worry. I was told by the hospital that we have to wait till she is at least 14 until they test her to see if she is also a carrier (she has to be able to sign a consent form!).

Then 18 months later we wanted to extend our family. At my 5 month scan they confirmed we were having a boy, we were asked if we wanted to have the test whilst I was pregnant to see if Lenny had haemophilia, but we decided that we did not want to know until he was in our arms.

The day come when Lenny arrived, they took bloods. Because the labour went smoothly, they let me go home the following day. To be honest, we didn't really think about it any more. 2 days later, the hospital called and told me that Lenny in fact had haemophilia. I can't really remember what was said as I think I was in shock. I just remember them telling me that they would be in contact for a clinic appointment.

During Lenny's first 18 months we had no problems with him until he was fully walking, or should I say running!! Lenny attended nursery and the support that I got from them was amazing. Never once did he have any accidents. I could not had asked for a better nursery. I knew he was in good hands, and he loved going and playing with his friends.

The scariest part of Lenny having having haemophilia was him starting school, as Lenny is a very out going crazy little boy and always wanting to make people laugh. I was fully aware of how big the school was and how many children attend as my daughter is a couple of years older and attends the same school.

Before Lenny started the school his nurse attended the school and gave a big presentation to all the members of staff so that they were fully aware of haemophilia and what do in case of a bleed. The school straight away asked that Lenny had a 'one-on-one' carer to supervise him. We explained that he didn't need this, just that he needed supervision to keep him safe from any bleeds.

This is when all our problems started, Lenny was having a lot of accident/bleeds during school time. So we were spending a lot of time at hospital receiving treatment and Lenny wasn't able to walk due to joint bleeds. There was one occasion when the school called to say that Lenny had hurt himself, so as my husband was nearer to the school, he went to check on him. He was not happy as Lenny had a lot injuries. When my husband took Lenny out of school, Lenny told him that he fell of the big climbing frame. My husband went straight back into the school to ask how high he fell off as we had in place that Lenny was allowed on the climbing frame but not with his whole class. Instead, he had a 'special time' when he picked 2 friends to play with under the supervision of the teacher but this day Lenny, had asked the teacher if he could go on and the teacher let him with 30 other children!

*(Continued overleaf)*



**Lenny has created a number of videos to share how he is living life to the full, including treatment and travel. To view these videos and read other family stories, visit the Family Stories page of our website: <http://www.bleeding-disorders.co.uk/lenny.html>**

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>



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

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# Lenny's Story (Contd)

When my husband asked the school no one was aware. Lenny was worried that he had done something wrong! When we were at hospital, I couldn't answer any of the questions as I was not present when he fell and no other adults saw him fall. The hospital had to treat him for a head injury and CT scan. After this incident, we called a meeting at the school. This meeting did not go as planned. They tried to blame Lenny saying that he was aware that he had his 'special time' (they ignored the fact that Lenny had actually asked a teacher and that the teacher had allowed him on). They then tried to blame my daughter as said she should have been looking after him! No apology just ignoring what had happened.

After this, we decided to safe guard Lenny from school until we had in writing who was responsible for him during play times, so we knew we could ask a member of staff and get an answer when Lenny had a bleed. But the school was unwilling to as I felt they didn't want the responsibility when a bleed occurred. I also wrote to the school Chairman but once again the school didn't help.

We e-mailed the school everyday, but had no response. I then received a phone call from social services about Lenny not attending school, I explained all that had happened and with the great support from our hospital social services were shocked. The following morning I received the email we had been waiting for - that a senior member of staff would supervise Lenny in the playground. Lenny returned back to school!!

Following our next hospital appointment, Lenny's doctor and nurse informed us that they wanted to start Lenny on prophylaxis, so he would need a port-a-cath. We were very shocked and upset that it had come to this, as before Lenny was being treated on demand. Within a few months the day had come for Lenny to get his port-a-cath. I was so scared upset and angry! So many questions I wanted answering - Why Lenny? Why us? Were we ready for this life change as a family? How will Lenny cope? How will we cope being a parent and injecting our own son? The questions were endless. I had so much guilt (and it did not help that I was also 6 months pregnant with another boy... would I be doing this all again in a few years?)

Lenny did amazingly well in hospital and took everything in his stride. He made us so proud!! During the stay in hospital, myself and my husband were both being trained to self-treat Lenny using his port-a-cath. I remember so clearly the first time I had to inject Lenny. I felt that the walls were closing in around me. The guilt I felt was awful but Lenny, being Lenny, still had a smile on his face. We decided to name his port-a-cath his "button"!

The months flew by and before we knew it we were pro's (don't get me wrong some days we missed his button and had to have a few attempts but we got there!). I just had to learn to change from being Lenny's mum to his nurse whilst I was treating him. Some days Lenny found it hard so we got him a reward chart and after a certain amount of stars he got a treat. We also got my daughter one as we didn't want her to feel left out, so she got stars for being helpful when we were treating Lenny.

Lenny has now had his "button" for just over 2 years. Looking back now, I can honestly say that it is the best thing we have ever done. We now only attend hospital for clinic check ups. Lenny is living a great life. Nothing gets in his way! On days where Lenny is doing something a bit risky, we give him factor and let him crack on!!!

### **Haemophilia definitely does not stop us!!**

This group is very close to me. I love the fact when we all get together the children are all the same (on our last event I sat and watched all the boys comparing their scars from their port-a-caths. The silly things that make them feel normal!) whilst the parents share their stories advice and support. All our stories are so different.

I decided to become a fundraiser for this group as it's just an amazing feeling to be able to give back, knowing that all my hard work has paid off when we meet at events. Knowing we can do this because of the fundraising!

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