

He's a little boy first ...

Dressing my five month old son, Ryley, I was surprised to see two bruises – one near his left armpit and the other on his right side. As I gently ran my finger over them I could feel lumps underneath.

"Maybe he rolled onto a toy," I said showing my husband Daniel and mum Diana.

"The one on his armpit looks like a thumb-mark from picking him up," Mum suggested.

No-one had ever been rough with Ryley but after that we took extra care picking him up.

A week later the bruising had faded but the lumps remained, so I took him to our GP.

"They're probably just bruises but to be safe I'd like him to see a paediatrician," she said.

We went to the Children's Hospital at Westmead, where they did some tests.

Daniel stayed by Ryley's side in the high-dependency ward while I slept in a room nearby. Then in the early hours of the morning Daniel came in. "Ryley's a haemophiliac," he said.

I stared at him in disbelief. I'd heard of haemophilia. It interfered with blood clotting and had badly affected the Russian royal family. But it had never been in my family.

"In 30% of cases it occurs as a genetic mutation in the mother, who passes it on to her son," a doctor explained.

"We'll have to do more tests to see if that's the case with you."

I was shocked that I could be the cause of Ryley's illness.

The tests showed I was the carrier. My genes had mutated when I was conceived. If we had another son he would have a 50/50 chance of also having haemophilia. I was devastated.

"I feel so guilty," I said.

"It's okay," Daniel soothed.

It made us rethink whether we would

have more children. But in the meantime we learnt all we could about Ryley's condition. His blood was deficient in a substance called factor VIII, which helps blood clot.

There are varying severities of haemophilia and Ryley was classified as being severe.

Although cuts cause problems for those with haemophilia, internal bleeding was more

of a concern because bleeding into joints could cause permanent damage. And the joint bleeds didn't just happen if they were injured. They could happen at any time.

"Does this mean Ryley can't play sport?"

Daniel, a former PE teacher asked the GP. We were thrilled to find that because of the advancement in treatment most haemophiliacs do play some sport – but not rough sports like rugby! "He's a little boy first and a haemophiliac second," the doctor said.

When Ryley started sitting up we propped him up with heaps of pillows, and when he started walking his knees and bum were permanently black so we put tennis wristbands on his knees and lined his pants with bubble-wrap.

Whenever he had a bleed we had to take him to hospital for an injection of synthetic factor VIII. By the time he was three we seemed to be at the hospital every week. His right ankle was very susceptible and so the doctors decided to give him prophylaxis of factor VIII.

"It means you can give him factor VIII every second day at home and the bleeds should be less frequent," the doctor said.

At first we injected it but then Ryley was fitted with a portable catheter, which changed our lives. By the time Ryley started school his bleeds were infrequent, generally occurring towards the end of the second day when his stores of factor VIII were depleting.

Meanwhile Daniel and I had decided to have another child. We coped with Ryley's disorder and we could handle another child with haemophilia.

But we were relieved when our second son, Callum, was cleared of the blood disorder.

As for Ryley, now eight, the prophylaxis has allowed him to lead a relatively normal life. He plays soccer, tennis and even skis – although Daniel follows tentatively behind him!



Of course there are some things that are risky for Ryley. He can't go barefoot in case he cuts himself, he has to go to the dentist at the hospital, in case of bleeds and although he needs his adenoids removed the surgery is just too risky.

Treatment for haemophilia really has come a long way and I hope it continues to improve so that my son and all other haemophiliacs grow up to be strong, healthy men.

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(From left): Ryley, Callum, Penny and Daniel



What is haemophilia?

Haemophilia is a rare blood clotting disorder in which one of the essential clotting factors is deficient or missing.

It is incurable and, without treatment with replacement clotting factor, it can be life threatening.

Haemophilia is hereditary, but in one third of cases it appears in families with no previous history of the disorder.

It affects males almost exclusively and is passed on through females who carry the defective gene. Some women are symptomatic carriers of the haemophilia gene and may also experience bleeding problems.

Currently in Australia there are approximately 2,000 people with varied degrees of severity.

von Willebrand disorder is a related bleeding disorder which affects both men and women. It is caused by insufficient von Willebrand factor which is a protein necessary to stop bleeding, or where the von Willebrand factor does not work properly.

How do your generous donations help?

Camps and adventure weekends ~ enable children, young people and families to attend family camps and adventure weekends. The camps provide a unique situation for families affected by bleeding disorders to meet and to share experiences of living with a bleeding disorder and for children and young people to be taken out of their comfort zone.

Men's and Women's Support Groups ~ the groups are opportunities to talk and support each other and to help cope with issues surrounding bleeding disorders.

Youth Mentoring and Leadership Program ~ nurturing and guiding our young people to becoming leaders in the community.

Hepatitis C Project ~ understanding the needs of our community infected with hepatitis C through contaminated blood products in the late 1980's.

Haemophilia Foundation Research Fund ~ the fund has provided for 21 research projects over its 13 year history, representing a total amount of \$467,592.

Resources and Publications ~ providing the community with up-to-date information on bleeding disorders and relevant topics.



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