

Helping Australians with bleeding disorders lead independent, fulfilling, active lives

Haemophilia

- A rare genetic bleeding disorder
- Caused by an alteration in the gene making factor VIII (8) or IX (9)
- Occurs when blood doesn't clot properly as there is not enough of a protein in the blood (called factor VIII or IX) that controls bleeding
- Usually inherited, but 1/3 of people have no previous family history
- Incurable and can be life-threatening without treatment
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems
- Most people diagnosed with haemophilia are male
- Women and men can have the genetic alteration causing haemophilia and pass it on to their children
- Most females with the gene carry it without symptoms; but some have haemophilia

Affected Australians

- In Australia there are more than 5,900 people diagnosed with haemophilia, von Willebrand disorder or other related inherited bleeding disorders.

***Haemophilia Foundation Australia** is committed to improving treatment and care for the bleeding disorders community through representation, advocacy, education and promotion of research.*

Looking forward to change

"And with that love and hope we allow our children to amaze us with what they can do, instead of what they may not be able to." Jacqui, mum to Mason

When Jacqui's baby boy was gingerly holding his leg at an odd angle she knew that something was wrong. With her husband, Todd, away for work she was left alone to take baby Mason to the doctor for what she thought would be a fairly routine appointment.

Jacqui & Mason

Inconclusive tests and bruising behind his knee sent them to the hospital where it was feared he had a spiral fracture in his leg – a condition that automatically flagged them with child protective services and led to a tense hospital experience.

Any parent's first visit to the emergency room can be traumatic, but not knowing what was going on with her baby left Jacqui feeling distraught. "I know that a lot of children do slip through the cracks, so I understood why they questioned me like they did, but it was still really daunting being kept in the dark."

When they were told that Mason was diagnosed with haemophilia, his bruising suddenly made sense. Flooded with information about what haemophilia was, they were sent on their way feeling lost and unsure about how their lives would change.

Within four weeks, Mason had back-to-back knee and ankle bleeds, and at just five months old he underwent surgery to have a port inserted so he could begin his prophylactic treatment to help prevent future bleeds.

"It was completely overwhelming. You think instantly about how the rest of your life is going to be affected, how your son's life is going to be affected and what limitations will be put on him…I was really scared about holding him back."

Getting through this time was helped by "some pretty amazing" specialist haemophilia nurses, and Jacqui also connected with their local haemophilia foundation and had great assistance from them.

I was lucky enough to find another mum at our hospital with a little boy only two or three months older than Mason, who was diagnosed around the same time. So I was really lucky that I had her there for support."

As Mason has grown in size and confidence, and connects with other children in the same situation through Haemophilia Foundation camps and events, he has been able to become an active boy with a love for BMX bikes.

Jacqui hopes that by raising awareness of haemophilia, there will be a better understanding of this rare condition among families, teachers and the general community so that Mason and other children with haemophilia can grow up with a healthy feeling of acceptance and support from their community.

Living with VWD ~ Susie's Story

I keep learning new things in my journey with a bleeding disorder and I've come to the opinion that this is actually OK. Up until the diagnosis of my second son with type 3 (severe) von Willebrand disorder (VWD), I had no idea I had a bleeding disorder. I was one of those statistics - a woman with symptoms but no diagnosis and so inadequate treatment. Fast forward to now: I have gained knowledge and perspective and I am being well treated by my Haemophilia Treatment Centre (HTC).

I have type 1 von Willebrand disorder, which is often explained as a mild condition which does not impact heavily on most people's lives. But everyone's experience is different. Growing up I was prone to bruising and bled freely. However, my mother maintained that our family were fast healers so it was OK. I remember hearing, "oh we just bruise, that's what we do".

However when my son was diagnosed with type 3 von Willebrand disorder, this led to the testing and diagnosis of both my partner and me. Initially I was shocked, but the more I read about the condition, the more the pieces of the puzzle fell into place. The massive swellings on my legs the size of my fist I got with mosquito bites. The flooding and the massive clots passed with my periods. The time I grazed the back of my foot going down stairs and it bleed for hours, prompting a hospital trip for care. The oozing bleeding after routine dental visits. The countless other times I noticed, "Oh, I'm still bleeding, like it's just oozing..."

So now, I engage with my health care professionals from a position of knowledge. My employer knows about my condition, I can manage my bleeding for dental work properly, manage my abnormal menstrual bleeding with good results and plan elective surgery with the involvement of the HTC to minimise issues. This has all been a direct result of my diagnosis.

So, whilst I don't have daughters, I can share my story and appeal to women to share theirs, talk to their daughters, keep the lines of communication open. And if you're working through a diagnosis, information is power. Sift through as much information as you can, attend the events held by your local Haemophilia Foundation for women and go to the conferences and camps for people with bleeding disorders, be a part of the community – it's diverse and supportive. Being a part of something bigger than yourself is a fabulous way to gain perspective and new strategies for treatment. Become informed so you can be an active participant in your care. And share your story. Listen to the stories of others. We can all learn so much.

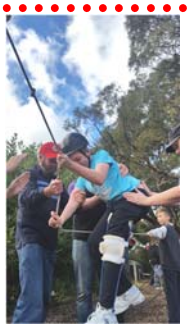
Von Willebrand disorder (VWD)

- An inherited bleeding disorder
- Occurs when people do not have enough of a protein called von Willebrand factor in their blood or it does not work properly
- Many people with VWD have mild symptoms but some people have a more severe form. With all forms of VWD there can be bleeding problems
- Many people are not aware they have the disorder and are currently undiagnosed
- Both men and women can have VWD and pass it on to their children.

Other Factor Deficiencies

- Other bleeding disorders include rare clotting factor deficiencies and inherited platelet disorders
- Factor XI deficiency is the most common of the rare bleeding disorders, estimated at one in 100,000 people, and is the second most common bleeding disorder to affect women after von Willebrand disorder

Programs and Services



The following programs greatly enhance the lives of people living with a bleeding disorder and their families. The programs are transformative and empowering - providing education, fellowship and support.

Family Camps Across Australia
Camps provide a fun, supportive atmosphere where children with a bleeding disorder can build friendships and learn to manage their condition independently and with confidence. They get vital opportunities to learn how others have dealt with similar experiences and to meet older role models. Camps also help parents overcome their worries about their children's safety and focus less on the dangers of raising a child with a bleeding disorder.

Peer Support Groups
Men's, Women's, Carer and Grandparent peer support groups are held across Australia. They bring people together and give them a safe and encouraging environment to talk about their issues, experiences and feelings.

Youth and Mentoring Program
HFA supports a youth program across Australia and provides information to young people through our youth website www.factoredin.org.au.

HFA also produces specialist **education materials** and **workshops** for adults, children and their carers.

How can you help?

Our aim is for every person with a bleeding disorder to lead an active, independent and fulfilling life.
This is a lifelong goal for people with bleeding disorders which can take perseverance, constant attention to their health, and courage. Your support and understanding of the issues they face every day can make a real difference

- Learn more about bleeding disorders by visiting **www.haemophilia.org.au**
- Share this information with friends and family
- Register for our email newsletter or like our Facebook page to stay in touch with the latest activities
- Support our programs and services including peer support, camps, workshops and education activities by making a donation.

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