



Connecting the Dots

Raising awareness about inherited bleeding disorders such as haemophilia and von Willebrand disorder

Haemophilia

- A rare genetic bleeding disorder
- 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
- Caused by an alteration in the gene making factor VIII (8) or IX (9)
- 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
- Some females who carry the gene can also have bleeding problems; some have haemophilia

Affected Australians



- In Australia there are more than 5,600 people diagnosed with haemophilia, von Willebrand disorder or other inherited bleeding disorders

Connecting the dots

For some families a diagnosis of haemophilia can come out of the blue.

Kasey and Gerrin knew something was wrong when they started noticing bruises on Archie's legs as a small baby. When he was six months old bruising on his spine took Archie to hospital. He had several tests, including one that involved a small puncture in his skin.

"When we took him home that night, he just bled everywhere. We took him back in the morning not thinking anything of it, saying he's bled through the bandage. They wrapped it and within 15 minutes that bandage was soaked, so they tested him that day, and by the afternoon we had a diagnosis."

"Archie was in hospital for six days while we were taught all about haemophilia and that he has the most severe type. We were young parents; our first baby, six months old and our world had been changed in an instant."

One in three children born with haemophilia has no family history of the condition, and this was the case for Archie.

Haemophilia is rare and Kasey and Gerrin had entered completely unknown territory.

"I didn't know anything about it," said Kasey. "It was really overwhelming, it was scary, our precious baby boy. We have really great family support, but we were determined to learn as much about haemophilia as we can, with the realisation that it is something he will have forever."

Archie, now five years old, has started school and Kasey made sure that the teachers and students were aware of his condition and what it means for him on a day-to-day basis.

"I had a few meetings with the teachers; they've been really great and taken everything on board. They call if they are worried about anything. We gave them as much information as we could."

The work that Kasey has done to educate others and advocate for Archie's health has paid off and he is loving school.

"He has met new friends and he loves it. He's very confident, he doesn't want to sit out and so he has a crack at everything. He's doing really well."

Story continued on next page

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



Kasey, Archie, Gerrin and Tilley

Connecting the dots (cont.)

Another important source of support was connecting with the only other family in their town of Echuca affected by haemophilia. Tara and Jamie have a son, Kelly, who is a year younger than Archie.

“Archie knows that Kelly has haemophilia and they do have that special bond. Archie knows they both have this same special condition and it makes it that little bit easier for him knowing that he’s not the only one going through it.”

With the constant advances in treatment and care, Tara has found HFA conferences and information resources to be extremely valuable. The family camp offered by their State Foundation is another special place to connect with others like themselves and see firsthand the older boys who are self-treating confidently and running around normally.

“It is making such a difference to our family - we are able to think that the future for us and for Kelly will be okay. If we were without those things we would find life really difficult and quite isolating.”

Together Kasey and Tara have worked hard to raise awareness of their sons’ haemophilia, using events like Red Cake Day to build support and share their stories.

“I just really wanted to get the word out there,” said Kasey. “We want the best for all the boys that have it, not just Archie but all people with haemophilia.”



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.

Red cakes can change lives!

It’s true. They can. That’s why HFA is calling on our supporters to participate in Red Cake Day during Haemophilia Awareness Week!

It’s easy...all you have to do is bake delicious red cakes or cupcakes, decorate them, and share them with your friends or work colleagues in exchange for a donation or a gold coin.

HFA has promotional items such as Red Cake Day napkins, balloons, pens, temporary tattoos, colour in sheets and stickers to assist your activity. Some are downloadable from the Red Cake Day web site.

To receive more information about Red Cake Day visit www.haemophilia.org.au/redcakeday email donate@haemophilia.org.au or phone **1800 807 173**

 Like RCD on Facebook www.facebook.com/RedCakeDay

 Follow HFA [@Haemophilia_Au](https://twitter.com/Haemophilia_Au) and join the conversation [#redcakedayhaemophilia](https://twitter.com/redcakedayhaemophilia)



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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