



Haemophilia Awareness Week
11-17 October 2015

P: 1800 807 173 W: www.haemophilia.org.au

HAEMOPHILIA AWARENESS WEEK 2015

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 with haemophilia are male
- Women and men can have the haemophilia gene and pass it on to their children
- Some women who carry the gene can also have bleeding problems; some have haemophilia

Affected Australians



- In Australia there are more than 5,300 people with haemophilia, von Willebrand disorder or other inherited bleeding disorders

Facing the future together

Haemophilia occurs in families – and overcoming its challenges can be a family affair as well.

Adam was diagnosed with severe haemophilia A when he was only one week old, after developing an intracranial bleed at birth. But the combination of his determination and the encouragement of his family have enabled him to deal with the many challenges he has faced.

His bleed left him with core balance problems and he has worked hard at overcoming these through a broad range of activities and sports. Adam is active on the family hobby farm as well as pursuing interests such as swimming, horse riding, fishing, motorbike riding, playing basketball with his local team and having fun on the trampoline at home.

'Adam is an inspiration to us all. He's always on the move proving that just because he has haemophilia doesn't mean he can't participate in activities just like all his friends,' says his mother, Donna. 'He has come ahead in leaps and bounds in recent years.'



Donna and Adam painting the town red

Adam's family have played a key role, making sure Adam has a positive, supportive environment. Donna has helped him to stay on track to meet the personal goals he has set himself – and, in fact, he often exceeds these goals.

For Adam, none of this is achieved without effort and Donna is committed to bolstering his strength and wellbeing:

'Adam tires easily so we make sure he gets enough rest, eats well and is involved in a number of sporting or physical activities to build up his muscle tone and stamina. Even though Adam's balance is very good, he actually has to work hard both mentally and physically to achieve that look.'

With severe haemophilia, Adam has to have clotting factor concentrate injected into a vein every second day (and extra if he is playing sport) to prevent bleeding. Learning to self-infuse your treatment is one of the challenges of growing up with haemophilia and Adam is well on the way to handling this. Adam assists with the preparation for his infusions, getting everything ready and putting on the tourniquet.

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.

Facing the future together (cont.)

'At this stage I insert the needle into his veins, as sometimes they can be a little hard to find,' says Donna. 'Adam is not ready to complete that step just yet but we are working towards it.'

Awareness and understanding in the community is also invaluable. Over the past 7 years, Donna has seen a small initiative she began in her community grow and grow. In 2009 she began contributing to Haemophilia Awareness Week by organising **'Paint the Town Red'** events locally in Neerim South. These events have been well-supported by the local community. Donna's workplace, the Neerim District Community Bank® branch of Bendigo Bank, has also been involved. Last year other Bendigo Bank branches in her regional area of Gippsland also took part. This year Bendigo Bank branches nationally will participate in the Week, with activities and information to raise awareness about haemophilia.

'It's important to get an awareness of haemophilia out there so that people understand what it's really about and can have a bit of empathy,' explains Donna.

'The community here in Neerim South knows a lot about haemophilia now. We are really hoping to see the same effect nationally!'

Adam recently won a kayak in the prize draw at a local fishing contest - the perfect opportunity for him to add another interest to his already extensive list.



'I want to take my kayak to the Blue Rock Dam so I can complete two laps of the dam,' says Adam. With the Dam's official length at 600 metres, that will be no mean feat!

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
- Symptoms are usually more mild than haemophilia but some people have a more severe form
- 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.

Order and register online 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.



HAEMOPHILIA FOUNDATION AUSTRALIA

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