



Haemophilia Awareness Week

12-18 October 2014

P: 1800 807 173 W: [www.haemophilia.org.au](http://www.haemophilia.org.au)

# HAEMOPHILIA AWARENESS WEEK

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

## Haemophilia

- Is 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
- Is caused by an alteration in the gene making factor VIII (8) or IX (9)
- Is usually inherited, but 1/3 of people have no previous family history
- Is incurable and can be life-threatening without treatment - which can help prevent repeated bleeding into muscles and joints that causes arthritis and joint problems
- Approximately 3,000 people in Australia have haemophilia and most are male
- Women and men can carry the haemophilia gene and pass it on to their children
- In the vast majority of cases the males with haemophilia in a family will have the same level of severity, but this is not always the case



## Haemophilia in women

- Some women who carry the genetic alteration for haemophilia can have bleeding symptoms
- Symptoms in women include bruising easily, heavy or long menstrual periods, bleeding for a long time after childbirth, surgery, dental extractions, accidents
- Many women who carry the genetic alteration do not have bleeding symptoms.

## Haemophilia - all in the family

**Meet two sisters, Julia and Rebecca. Their father Len has haemophilia. Between the sisters they have four sons, all toddlers - and three have haemophilia.**

*"Haemophilia has always been a part of my life, and my family's life – my dad Len has haemophilia and we grew up in an environment in which he chose not to let it dominate. Most of the time it didn't alter his or our lifestyle choices, but the times he had a bad bleed it involved some real challenges for him and the rest of the family in managing the bleed and the subsequent recovery,"* said Julia.

Julia's boys are 4 and 2½ years old, both with moderately severe haemophilia. Rebecca has one son who is 3½ years with severe haemophilia – but her youngest, who is not yet a year old, does not have haemophilia. Julia isn't a symptomatic carrier so never had bleeding issues, while Rebecca can remember she would always bruise easily, *"but it was never a huge*



Brothers Elliot and Zachary

*problem for me"*. She was given some recombinant factor VIII (8) coverage for a knee reconstruction as a precaution. *"A few days before my first day of Year 7, I had been jumping on my sister's bed and banged my eyebrow really hard and got a bad black eye. By the time my first day of school came around the bruising had spread to the other eye, so I had two eyes in various colour shades. That was quite a challenge when I just wanted to blend in with the other kids!"* recalls Rebecca.

Both girls were very open with their partners about haemophilia and their carrier status. And both partners responded in a very positive way. *"For us my carrier status was not really an issue,"* said Julia. They both had genetic counselling before starting a family and both had the view that the process was not too difficult. *"My Dad has always tried hard not to let haemophilia change his lifestyle and he has remained physically active. This was a great role model,"* said Rebecca.

*Picture left, Zachary, Alessandro and Emiliano*

*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.

## FAQs:

### Women with Bleeding Disorders

**Q1:** Don't bleeding disorders just affect males?

**A:** No. Bleeding disorders can affect females as well as males.

**Q2:** Which bleeding disorder most commonly affects women?

**A:** Von Willebrand disorder (VWD) is the most common bleeding disorder. It affects males and females equally, though women tend to have the added issue of menstruation.

**Q3:** Can females have haemophilia?

**A:** Many girls or women who carry the altered gene causing haemophilia do not have symptoms of a bleeding disorder. But some do have a bleeding tendency. They are often described as "symptomatic carriers". If their factor levels fall in the range for mild haemophilia (5-40% of normal clotting factor), they may also be referred to as having "mild haemophilia". In very rare cases, some girls or women have particularly low factor levels causing them to have moderate or severe haemophilia.

### Von Willebrand disorder (VWD)

- Is 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.

## Haemophilia - all in the family (cont.)

*"I do recall a sense of shock when we found out our first baby had haemophilia," said Julia. "But I think the real sense of shock came from finding out our baby's factor levels: less than 1%. We'd been told factor levels generally 'run true' in a family, and my dad's levels were 4-6%, but I knew that less than 1% was classified as 'severe' and was something altogether different to 'moderate' haemophilia. However, since birth their levels have varied and in fact, we've been very pleasantly surprised – both by our first boy and our second, who was also diagnosed as moderately severe – at the relative infrequency of their bleeds and their ability so far to live like normal toddlers."*



Rebecca, Julia and Len

Rebecca had a similar experience of shock when finding out her son's factor levels. *"Having our first newborn was such a new experience, that this was just another thing in the mix to work out how to deal with (along with nappy changes, feeding etc etc!). Our short time living in the US with a child with haemophilia gave us a small insight into some of the challenges associated with health insurance*

*coverage and the high cost of product. When our second son came back negative to haemophilia, it was a strange feeling. Of course we felt the relief that he wouldn't have to deal with hospitals and needles and all the challenges along the way. However, it also felt a bit strange, as his big brother, two cousins and grandfather all have haemophilia, so in a way he'll be the 'odd one out'," said Rebecca.*

## 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.

**Order and register online [www.haemophilia.org.au/redcakeday](http://www.haemophilia.org.au/redcakeday) email [donate@haemophilia.org.au](mailto:donate@haemophilia.org.au) or phone 1800 807 173**



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## 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](http://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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