



Haemophilia Awareness Week  
13-19 October 2013

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

## HAEMOPHILIA AWARENESS WEEK 2013

**Raising awareness about achieving the dreams  
of people with bleeding disorders**

### ABOUT BLEEDING DISORDERS >

#### 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 usually inherited, but 1/3 of people have no previous family history
- Is incurable and can be life-threatening without treatment
- More than 2,800 people in Australia have haemophilia and are nearly all male
- Women and men can carry the haemophilia gene and pass it on to their children
- Some of these women also have bleeding problems
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems.



*Growing up with haemophilia involves the whole family*

### Haemophilia - the missing ingredient

Nathan and his little brother Max both have severe haemophilia.

Haemophilia became a part of their family's life when Nathan was 3 months old. He suddenly developed a very painful swollen ankle. After a lot of blood tests, he was diagnosed with - not a broken ankle, as was first thought - but haemophilia.

Shocked, parents Michelle and Michael thought it was the end of the world. Their families had no known history of haemophilia and they had no idea what to expect. Michelle and her mother were stunned to find out they also carry the genetic alteration that causes haemophilia. But they soon learned that with today's medical advances, the boys can have a bright future.

Both boys are busy and active. They do Auskick - non-contact football - and Nathan wears a protective helmet, like

many children playing football. The boys also play basketball, cricket and have swimming lessons. And like all brothers, there are plenty of rough and tumble

games. Bike riding, scooters and skate boards are all part of their lives, even though they sometimes have a crash and may have a bleed.

To help prevent bleeding, the boys have their "prophylaxis" treatment injections three times a week, and more often if they have a bleed. Both Michelle and Michael take turns to treat the boys at home.

*"This has become part of our morning routine in our house,"* said Michelle.

#### *The story of two young brothers with haemophilia*



It isn't easy to manage the pain of injections and bleeds, but the comfort of a brother can make a big difference.

Older brother Nathan learned how to self-infuse his treatment into a vein at the Haemophilia Foundation Family Camp. Before long his younger brother wanted to have his treatment into his vein too.

His first treatment into a vein became a proud moment for Max, with Nathan reassuring him and taking photos.

*"They are little boys first, then a child with haemophilia."*

Red Cake Day has a special meaning for this family. When Nathan was small, he asked his mother why he had to have treatment.

Michelle explained that it was like making a cake - that if an ingredient was missing then the cake didn't work out as well. He was missing a factor or ingredient in his blood to make him stop bleeding, and the treatment replaced the missing ingredient. Baking red cakes is all about getting the right ingredients together!

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

## ACHIEVING INDEPENDENCE WITH VON WILLEBRAND DISORDER

Growing up with von Willebrand disorder (VWD) has its challenges - but as a parent Lyn's aim is to make sure her children can handle it and be in control of their lives.

She and her husband have encouraged their children to lead active lives, but to know their limits. They have all been taught how to deal with emergencies, and their friends know what to do and help out if anything happens.

*"It's always in the back of their mind, but we don't make it a big part so they live a reasonably normal life. They've had some long nights with blood noses where they lost two to three hours sleep, but still got up in the morning and went to school. Now the older kids are going to university."*

What does the future hold? Like most families, life for Lyn and her children is a "work in progress", just with more challenges. Her daughter is working with her medical team to get her severe menstrual bleeding under control with medication, while one of the boys has plans to work in a remote area, depending on the requirements. Whatever happens, Lyn is confident her children will handle their challenges with strength and resilience.

## BEING INSPIRED BY HAEMOPHILIA

**Haemophilia inspires people in many different ways.**

### BRYAN'S STORY

As a young boy, Bryan Sheehan was frustrated by not being allowed to play competitive sport because it was too dangerous for him to have impact injuries with his haemophilia. But he discovered football umpiring and eventually rose to become a leading AFL umpire. In 2013 he was honoured for his umpiring by being inducted into the AFL Hall of Fame.

What has he learned about life from having haemophilia?

*"Haemophilia has taught me that no matter what adversity you face, you can overcome anything if you put your mind to it. Whilst I had some restrictions in what I could and couldn't do, ultimately it didn't stop me from still being involved in the sport I loved."*

*"I know there are many other young boys with haemophilia (and girls for that matter) who have followed my career and are now aspiring to become AFL umpires, which makes me feel that my life with haemophilia has been a positive and fulfilling experience.."*

*"I wouldn't have wished it to be any different."*



*Bryan in action  
Photo: AFL*

### EMILY'S STORY

From the time she was a small child Emily has wanted to become a doctor.

Emily has mild haemophilia. Some of her family members have other medical problems as well. Because of this, Emily spent a lot of her time as a child and teenager in hospitals, learning about different types of medicine and developing a deep appreciation of what it means to be a doctor.

Emily recently started her medical training. She reflected that her experiences growing up have really shaped her approach to her life and career.

*"Seeing the way my family deals with health challenges has been a big influence in my life. The way they tackle the world regardless of what is thrown at them constantly amazes me."*

And when she has completed her medical degree? In the future Emily hopes to be able to use her medical training to be able to make a difference for the bleeding disorders community – helping with education programs and acting as an advocate for her community.

## MYTH BUSTING!

**Myth: People with haemophilia bleed to death if they get cut or scratched**

**Fact:** People with haemophilia have blood that doesn't clot properly so they will bleed for a longer time, but not faster than other people. With appropriate treatment, bleeding can be prevented and will stop. Minor cuts and scratches need only a band-aid® and some pressure at the wound. Bleeding is mostly internal, often into muscles, joints and sometimes organs.

**Myth: People with haemophilia cannot play sport**

**Fact:** Sport strengthens joints and muscles, which can prevent bleeds. Care is taken when choosing a sport, as high contact sports such as football and boxing could cause bleeds. People with haemophilia learn to manage their condition and play a wide range of sports.



### 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.

Need a recipe? We have a yummy Ruby Red Velvet Cake Recipe in the host kit!

Order and register online -

[www.haemophilia.org.au/redcakeday](http://www.haemophilia.org.au/redcakeday), email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au), or phone **1800 807 173**

*Thank you to our supporters*

- The Cupcake Bakery
- Neerim District Community Bank® and Bendigo Bank South Gippsland Region

## How can you help?

**Our aim is for every child with a bleeding disorder to grow up 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

**W:** [www.haemophilia.org.au](http://www.haemophilia.org.au)  
**E:** [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
**T:** **1800 807 173**