



Life Challenges the real issues

Haemophilia Awareness Week 10-16 October 2010



HAEMOPHILIA AWARENESS WEEK 2010

Raising awareness of the challenges faced by people living with haemophilia and other bleeding disorders.

About bleeding disorders >>>

Haemophilia

- Is a rare genetic bleeding disorder.
- Occurs when people don't have enough of an essential clotting factor in their blood to control bleeding or it doesn't work properly.
- Is usually inherited, but 1/3 of people have no previous family history.
- Is incurable and can be life-threatening without treatment.
- About 2,000 people in Australia have haemophilia.
- Almost all people with haemophilia are male.
- Women and men can carry the altered gene and pass it on to their children.
- Some of these women have bleeding problems.
- A small number of people develop antibodies ("inhibitors") after treatment, which make treatment less effective.



Von Willebrand disorder

- 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 have vWD and can pass it on to their children.

What is it like to live with haemophilia? *Another life challenge.*

Haemophilia Awareness Week is about sharing experiences of living with a bleeding disorder — the challenges faced every day, the reality of living with a lifelong health condition and celebrating the ways we overcome these challenges.

It's Bright Time!

Michael Lucken describes life with a toddler while living with severe haemophilia.

"Get up!! Dad, Dad, get up, it's bright time!" That's the way a typical day starts around here. Scarlet is my daughter who is 3. Scarlet knows that I have mobility issues first thing every morning, so she often wakes me up by jumping on my belly asking to play with my mobile phone. Then she can play her games and colouring while I get all my joints moving. With arthritis this can take up to 30 minutes some days but if I wake

up with a bleed it may take a lot longer to get moving, if I can at all. So after helping me with my crutches, Scarlet and I head out to the kitchen to get breakfast. Nutrigrain

is the favourite at the moment which she likes to help me get ready.

I am the proud owner of a bleeding disorder. I have severe haemophilia, with inhibitors. There are many things they teach you about haemophilia. However they don't give you any tips on training a toddler so they don't accidentally put you in hospital! It's taken some time but I must admit Scarlet is now a very helpful and caring daughter. If I'm trying to get my leg working and she sees I'm having trouble, she offers to get my crutches. One by one she will drag them to whatever room of the house I'm in, or

she will grab me by the hand and try and help me walk. Sometimes she is so impatient that she will stand in front of me and mimic how I walk, saying "like this Daddy", as she waddles off like a penguin. At other times she will get my shoes for me if they're out of reach and try and put them on my feet. The cheeky little monkey is very considerate for a 3 year old! She has also learnt how to charm tea ladies into giving her biscuits

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when I'm in hospital — very clever girl! I'm not like other Dads who can run around after their kids in the backyard, kick a ball, roll around wrestling on the floor and I can't just get up and

and be ready to go somewhere or do something on a moment's notice. Scarlet seems to understand my limitations but she does love it when she gets to ride on daddy's 'motorbike' (my mobility scooter) down to the supermarket, to day care, or to walk the dog. As I reach the end of my typing, this not so little voice starts asking me "Daddy, I have more nutrigrain please? It's ok, I get it" So I'm going to end this here because if I don't there is going to be half a box of nutrigrain on the kitchen floor in less time than it takes me to get out of this chair, so here goes.....

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

THERE'S NO STOPPING DARCY!

Beth Large gives some insight into life with a child who has haemophilia.

Darcy was just 10 months old when Beth noticed very bad bruising on her son's knees from crawling, and around his stomach from the imprint of a bath ring. At first Beth thought the bruising was caused by the normal rough and tumble of life with his older sister and brother. But the bruising seemed too severe, so Beth took Darcy to their doctor.

"The GP immediately ordered a blood test", says Beth. "It was thought it could be either leukaemia or haemophilia because of the bruising". At midnight, the doctor telephoned to tell Beth that Darcy had haemophilia. "Thank goodness for the HFA and other websites – I did all my reading that night", says Beth.

Darcy is the only one in his family with haemophilia. Later Beth was tested and found she carries the haemophilia gene.

Darcy is now 6 years old and does not let haemophilia stop him! He has three-times-a-week prophylaxis (preventative treatment) injected through a port in his chest. Darcy loves playing soccer and loves swimming which helps to keep his muscles strong.

"Darcy understands his condition; he knows how far he can go", says Beth. Darcy hasn't escaped periods in hospital; he has spent several five-day stints in hospital from port infections.

Meeting other families through Haemophilia Foundation social activities is vital. "It's important that Darcy sees other boys living full and active lives. The camps are great for the whole family; my other children are just as involved, and learn a lot too!"

Beth looks forward to the day when longer acting clotting factor treatments are available, so that Darcy may only need intravenous injections once a week.

Foundation health education also plays a big part. "As Darcy gets older, we want him to be independent and to be able to look after his health and well-being", says Beth.

Darcy and his older sister enjoying a camp activity!



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.

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
- Share this information with friends and family.
- Register for our email newsletter or become a fan on 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.

For more information:

Web: www.haemophilia.org.au

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Phone: 1800 807 173



The Challenges of von Willebrand disorder

Below are some quotes describing what it is like to live with von Willebrand disorder (vWD) – it can vary greatly from person to person, even in the same family.

"We all have vWD in my family – some have minimal symptoms, some mild, some severe. All have had issues with blood noses, but seem to have grown out of the nasty blood noses that used to go on for hours. All have bruising which varies and our youngest daughter has had problems with periods."

"My husband found out he had vWD in his thirties after a minor haemorrhage having a wisdom tooth out."



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