



Health and wellbeing into the future

– the decade ahead

Haemophilia Awareness Week • 9-15 October 2011



HAEMOPHILIA AWARENESS WEEK 2011

Raising awareness about improving health and wellbeing into the future for 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
- About 2,400 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 have bleeding problems
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems.



Jack at play

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 can have VWD and pass it on to their children.

Towards a better future

"When I was told Jack had haemophilia I was devastated for him. It brought up a lot of sadness in me and emotion about what had happened to my Dad," said Holly, mother to Jack.

Haemophilia is for life. It touches entire families, like Holly's, passing from one generation to the next. Holly had grown up watching her father's generation facing great challenges. For Holly and her husband Matt, coming to see that their small son Jack could have a different - and better - future than her father has been a journey.

"I remember Dad having haemophilia, having constant problems with his joints, always having needles for treatment and constant visits to the hospital. He limped around, living with chronic joint pain because of his bleeds."

In the 1980s, Holly's father contracted HIV and hepatitis C from his clotting factor treatment for haemophilia. By 1990 new testing and viral inactivation processes had made the

risk of infection from clotting factor products extremely low – protecting new generations with haemophilia, but too late for Holly's father, who died at 50 from hepatitis C.

Holly recalls the uncertainty and fears she felt when Jack was first diagnosed - *"When is he going to have his first bleed? How am I going to know?"*

At eighteen months Jack had his first bleed. One morning Jack woke up and was limping, and Holly discovered swelling around his ankle. She knew then something wasn't right. Jack was rushed

Holly tells the story of finding out her little boy Jack has severe haemophilia

to the Children's Hospital and given immediate treatment.

"A couple of months later, Jack banged his head and got a big haematoma. Two days later he banged it again - he had a bleed and his little forehead joined his nose. His face was so swollen."

Haemophilia treatment and care has changed greatly in the last 30 years. In Australia treatment now aims to prevent the bleeding, pain and joint damage experienced by Holly's father. Clotting factor products are injected up to three times weekly to prevent bleeds. But the reality that their child will need treatment for the rest of their life can be very confronting for new parents like Holly and Matt.

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"When is he going to have his first bleed? How am I going to know?"

For Holly, there is also the knowledge that she carries the haemophilia gene. Her baby daughter Lily may also carry the gene. How will things be for Lily as she grows up?

Haemophilia Foundation family camps and workshops have given Holly and Matt the opportunity to meet other parents and see other children with haemophilia and find out how they manage. As Jack grows up, the programs for young people will also be important.

"If he is connected with other kids with haemophilia, we think he will learn and understand more and feel like he is not the only one."

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

THE CHALLENGES OF VON WILLEBRAND DISORDER

What is it like to live with von Willebrand disorder (VWD)? People with VWD and their partners and parents give some comments:

"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."

"Sometimes the kids do have to stop and think about themselves. A sprained ankle from netball can take a little longer recover from due to severe bruising and that ankle has to carry them around for lots of years."

SPEAKING UP!

Paul Bonner talks about what motivates him to be involved

At 35, Paul has personally faced many challenges since he was diagnosed with haemophilia when he was 5 years old.

Growing up with haemophilia exposed Paul to some of the hurdles he would continue to deal with as an adult.

"I remember as a kid going into hospital, seeing the doctors and helping to mix up my own treatment. When I had bleeds it was quite painful. I missed so much school one year they held me back."

Like many men with haemophilia, Paul has had to deal with long term joint damage and arthritis as a result of bleeds into joints and muscles at a young age.

"I had to have a career change because of arthritis in my left ankle. I was a boat builder for 14 years, but due to the number of bleeds in my left ankle and the pain they caused, it was hard to keep working in that field."



Paul relaxes at the Youth Camp

"I've seen younger kids leading full and active lives, and other people who have limited mobility. It's good to be able to share my experiences so that other people might not have to go through the same things."

Paul began working as a health and safety officer, but was still experiencing a lot of severe pain. He had an operation to have his ankle fused to improve his pain and ability to get around.

"There were complications. They missed a blood vessel and it kept oozing causing swelling, so I went back to hospital. First, they thought it was infected but it wasn't. Then I was back 2 days later in extreme pain. I went back into surgery and they found the problem and fixed it."

Paul's experience highlighted for him how much he has learned over his life and why it is important to share this. He has become involved as a community leader, both locally and nationally. He has also been involved with the HFA Youth Committee since it formed and now acts as a mentor.

"I've seen the difference the Youth Committee makes to some people. They know themselves and their condition better and are more able to advocate for themselves. It's about empowering people to manage themselves – to be strong enough to speak up if they think something's not right and ask the health professionals to investigate further. Or if they don't understand a diagnosis, to give them the power to ask for an explanation."

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:

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