

Achieving your dream

Haemophilia Awareness Week
7-13 October 2012



HAEMOPHILIA AWARENESS WEEK 2012

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
- 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 also have bleeding problems
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems.



Chris umpiring at the 2011 AFL Grand Final
Photo: AFL

Achieving a dream

What if you are passionate about playing Australian Rules Football, but have severe haemophilia? How can you keep doing something you love and avoid the high impact injuries that young men often experience with football?

Chris Gordon is a remarkable young man who has been able to balance his dreams and the reality of having severe haemophilia. Now 23 years old, Chris is an Australian Football League (AFL) umpire and studying primary school teaching.

Chris watched his first AFL game with his mother at the Melbourne Cricket Ground on a Friday night.

"I was 6 years old. I knew then that I loved the game - the lights, the size of the stadium and all the people."

Chris played AFL Auskick with his mates all through primary school. He learned

general co-ordination and skills and played football games regularly. Auskick is an AFL program to introduce children to Australian Football.

But when Chris left primary school, he struck the same problem as many boys with haemophilia. In secondary school the size and weight of boys playing football increases dramatically and contact injuries can be much more serious. His doctor at the Haemophilia Centre advised Chris and his parents that he should stop playing AFL football because it would be too dangerous.

Chris tried very hard to prove to his doctor and parents that it would not be a problem for him, but they were not convinced.

"Haemophilia is not a barrier to most things in life. The main thing is to give most things a go."

Chris Gordon tells the inspiring story of following his passion



Photo: AFL

"Then a friend's father suggested I have a go at boundary umpiring. I still felt part of the game, even though I wasn't playing football, and I trained and was on the grounds and in the rooms afterwards with my mates."

Chris threw his energy into improving his skills and performance.

"Running, fitness and accuracy are crucial to umpiring - you can't make any errors."

Chris has had prophylaxis (preventive) treatment since he was two years old and infused his own treatment since he was 10 or 12.

He has regular contact with the Haemophilia Centre and his high level of fitness helps him to have greater resilience, strong muscles to support his joints and better health.

What's next for Chris?

"I'm currently training to be a primary school teacher - my aim is to become a Physical Education teacher and manage school sporting events."

It will be a great way for Chris to share his skills with the wider community.

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.

MAKING DREAMS COME TRUE

Watching the Olympics has inspired many of us and 8-year-old Adam is no exception. The difference is that Adam has haemophilia - so making his dreams come true means he has some unusual priorities.

"Adam was watching the water polo in the Olympics and said, 'I'd love to do that. What's that called?'" said his mother, Donna. *"He loves sports with balls, like soccer, but he's been swimming since he was a baby and especially loves anything to do with water."*

For Donna, encouraging Adam's ambitions involves talking to his swimming instructor about how he can learn water polo. But for Adam, other things are more important - he wants to have his port removed so that he can be the same as his friends.

Adam has severe haemophilia and has to have clotting factor concentrate injected into a vein every two days to prevent bleeding. To protect his veins while he was young, he had a device called a "port" inserted surgically into his chest. The clotting factor can be injected straight into the port rather than into his arm.

"We are working towards having Adam's port taken out," explained Donna. "I'm starting by injecting into his arms on the weekend when we have some time. He does the tourniquet and prepares his veins. It won't be long before he can do it himself."

Adam's determination to overcome his challenges has meant he has come ahead in leaps and bounds in the last few years.

Adam was diagnosed with haemophilia



Adam on his scooter

when he was a week old after developing an intracranial bleed at birth. The bleed left him with balance problems, which he is now overcoming by being active in a range of sports.

"Adam is such a little fighter. Learning to ride a scooter properly was a big achievement for him. Now he can ride his scooter equally well with his left and right legs - and his mates are trying to learn this from him as well."

Donna organises "Paint the Town Red" events locally in Neerim South during Haemophilia Awareness Week. In 2012 her employer, the **Neerim District Community Bank®**, is supporting awareness with a "casual clothes for a cause" day.

"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. The community here knows a lot about haemophilia now."

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.

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 help us celebrate Haemophilia Awareness Week by taking part in our inaugural Red Cake Day!

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.

Want your cakes to look extra special? Why not order some of our specially made H logo cupcake transfers? They're fully edible and will turn your red cupcakes into something truly fabulous!

Download an order form from our website www.haemophilia.org.au (click on the Awareness Week logo on our homepage to be directed or look under Events and Awards) or email hfaust@haemophilia.org.au.



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