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

Haemophilia

- A rare genetic bleeding disorder where the blood doesn't clot properly
- Caused by an alteration in the gene making clotting factor VIII (8) or IX (9)
- Usually inherited, but 1/3 of people have no previous family history
- Incurable and can be life-threatening without treatment
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems
- Most people diagnosed with haemophilia are male
- Women and men can have the genetic alteration causing haemophilia and pass it on to their children
- Some females who carry the gene can also have bleeding problems; some have haemophilia

How common?

- In Australia there are more than 6,000 people diagnosed with haemophilia, von Willebrand disease or other related inherited bleeding disorders.

Von Willebrand disease (VWD)

- 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
- Many people with VWD have mild symptoms but some people have a more severe form. With all forms of VWD there can be bleeding problems
- 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.

Other Factor Deficiencies

- Other bleeding disorders include rare clotting factor deficiencies and inherited platelet disorders
- Factor XI deficiency is the most common of the rare bleeding disorders, estimated at one in 100,000 people, and is the second most common bleeding disorder to affect women after von Willebrand disease.

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

Living life with VWD ~ Shauna's Story

The journey for women with bleeding disorders is not always straightforward. Shauna explains what has helped her along the way to get the most out of life.

Shauna was very young when she was diagnosed with von Willebrand disease (VWD). She was barely 12 months old when she was admitted to hospital for excessive bleeding. "*I was hospitalized after biting my lip. It bled all night, soaking my entire cot. We had a diagnosis before being discharged."*

Armed with the information they needed, Shauna's parents made a point of telling anyone involved in her care about her bleeding tendency. *"From a young age my teachers and friends' parents were often made aware of my VWD so they usually told their students or children. My peers always 'just knew' and it seemed normal. As I've gotten older I usually bring it up with new friends whenever I have a particularly visible bruise. I've always been quite open about my bleeding disorder with my friends. Often they are quite interested to learn about my bleeding escapades."*

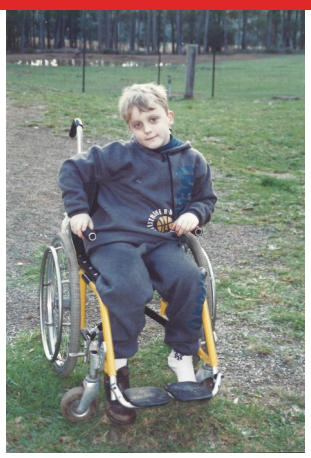
Shauna has been doing classical ballet since she was 13 years old and yoga a few times a week. *"I had a bad bleed in my knee last year, and I was able to keep doing yoga which is great for me mentally and for my fitness. We shouldn't limit ourselves, but we need to look after our bodies and stay strong".*

Shauna loves to travel and is heading to Canada this month. Like anyone else she needs to prepare for her travels, but with a few extra things to think about. *"Having a bleeding disorder shouldn't hinder travel plans. I need to ensure I have enough treatment, travelling documents and doctor's letters and have been in contact with the Haemophilia Treatment Centre in Canada just in case".*

Living life to the full with a bleeding disorder? It's not about stopping yourself, but understanding what you need, preparation and then following your dreams.

Making your own future ~ Andrew's Story

In the past 10 years 31-year-old Andrew Selvaggi has turned his life around so that it is almost unrecognisable from his childhood years.



GROWING UP WITH INHIBITORS

Andrew was diagnosed with severe haemophilia A at 15 months old when, on top of always bruising very easily, he cut his upper lip on a bottle and it wouldn't stop bleeding. There was no family history of bleeding disorders in Andrew's family. Like around 30 per cent of all people with haemophilia, his condition was the result of a new or 'spontaneous' occurrence of the haemophilia genetic mutation.

Andrew developed inhibitors, which are a complication where treatment with factor VIII is not effective. He says he spent "*around five years collectively*" as a hospital inpatient by the time he was 11 years old.

'From age 0-11 there was not a treatment for me that worked properly, so I'd get a bleed and I'd pretty much have to sit there and ride it out until it went away, which without treatment can pretty much be weeks or months.

'Most of my young childhood memories are of spending time in hospital with bleeds and being in a wheel chair constantly. I missed out on a lot of school and other things because of bleeds.

'Once treatment that worked with my inhibitors became available when I was 11, it opened up a few more doors for me. I could do things like go to school more often, go on camps, do things I hadn't really been able to do before.'

'I come from a very sport-orientated family. My father played football for 20 years and still plays, but I couldn't play any sports, especially contact sports. Growing up through school and seeing all the kids do Auskick, or even really basic things like playing four square, I couldn't do it. I would have given anything to be able to do all those things. I'd go and watch my father play football and think to myself I wish I could do that. It was very hard and it affected me a lot both physically and mentally.'

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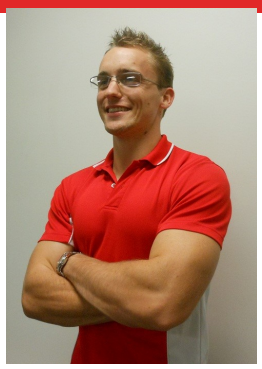

Because of the severity of damage to Andrew's joints, he was in a wheelchair '*nearly 100 per cent*' of the time, and needed a full knee reconstruction by the age of 19.

'Any time I got out of a wheelchair I'd bleed into my knee, if I went on crutches, I'd get an elbow bleed and I'd be back into the wheelchair. That was pretty much my life.'

Due to his immobility Andrew put on a lot of weight, becoming clinically obese. This in turn put tremendous stress on his body and joints and had a devastating effect on his self-esteem.

TURNING HIS LIFE AROUND

Bringing the clock forward to Andrew was 20, he was not in great shape. *"To be honest I was in a pretty bad place mentally. Physically I was in an even worse place*." Andrew made the decision to turn his life around with the support and guidance of his Haemophilia Treatment Centre.

He admits it wasn't easy, but Andrew kept going, bringing about tremendous health and fitness changes in almost every area of his life. He started exercising on an exercise bike, and put together an individualised program of resistance and cardio training with his Treatment Centre, along with a new treatment plan. He lost 30 kilograms in weight and went from having three bleeds a week to having one bleed a month. His bleed recovery times were almost halved. If he had setbacks, he worked around them. He became a qualified Personal Trainer.

LIVING LIFE TO THE FULL

Five years down the track, Andrew is on new treatments and has a new definition of living life to the full. *'I have a gorgeous wife and two dogs, a mortgage and full-time job in IT. Being on a new treatment that stops me having bleeds (via clinical trial) has enabled me to plan from week to week and turn my life around. I will always have haemophilia and still require treatment, but I know my limits.'*

Andrew decided to step back from full-time personal training four years ago due to the strain on his knee joint and needing a knee reconstruction. Instead he helps others with bleeding disorders with their sports and fitness programs. And he still maintains his health and fitness regime to prevent a return to the pain and complications he experienced as a boy.

'As I get older I appreciate limits – knowing what your body is capable of and not pushing it too far. You need to listen to your body and live your own life.'

Busting the Myths….

Can you 'catch' a bleeding disorder?

No. Bleeding disorders are nearly always caused by changes to the genes responsible for blood clotting. The altered genes can be passed down from parent to child. People with genetic or inherited bleeding disorders are born with them. They are lifelong conditions.

The exceptions are acquired haemophilia and acquired VWD, which are autoimmune disorders that can occur in adults. These conditions are very rare – but they are not contagious either.

Can people with haemophilia play sport?

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.

Will people with haemophilia bleed to death if they get cut or scratched?

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.

Red Cake Day & Bleeding Disorders Awareness Week 2019
13-19 October 2019

Bleeding Disorders Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia during the week of **13-19 October 2019.**

HFA is calling on our supporters to participate in Red Cake Day during the 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.

HFA has promotional items such as Red Cake Day napkins, balloons, pens, temporary tattoos, colour in sheets and stickers to assist your activity.

Email donate@haemophilia.org.au or phone 1800 807 173 for more information.

RED CAKE DAY

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**
- 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.

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