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COMMITTEE MEMBERS' INTRODUCTIONS...



An Introduction from Robert...

My name is Robert McCabe, and I am one of the Western Australian representatives for the Youth Committee. I am currently the secretary of the Youth Committee.

My involvement with the youth committee began early 2003, when I was invited to be a part of this exciting new initiative. Since then I have been involved in teleconferences and attended the 2nd Australasian Haemophilia Conference held in Queensland during October 2003.

To introduce myself, I am a 19-year old student from Perth, Western Australia. I am currently in my second year of study at Notre Dame University, Fremantle, and I am studying Law. Apart from my studies, I spend the majority of my time hanging out with my friends, going to the movies, the beach, and so on. I have a devoted interest in football and surfing amongst other things.

Haemophilia has often been a pivotal aspect in my life. Diagnosed with severe haemophilia at nine months I have grown and matured with the will to ensure that this disorder will not limit me. To this day, I have led my life by this philosophy and (within reason) my haemophilia has not limited me.

I have decided to join the committee for many reasons. One of those reasons is to give back what the Foundation has given my family and me. Because I received so much support, it is only fitting that I have offered support to the younger people with haemophilia, one of the main tasks of this committee.

I feel very privileged to have been offered a position on this committee, and I hope that I can make a substantial contribution to its efforts. I am confident that we will be a success because the people involved are very incredible people, and I feel privileged to be amongst such company.

I hope to meet many new faces in the coming years, and also learning and listening to other people's experiences.

An introduction from Paul...

My name is Paul Bonner and I would like to take a moment to introduce myself. I am 27 years of age and live in Eudunda, South Australia, which is about 120 kms out of Adelaide. I have severe haemophilia B which was diagnosed when I was five, and I have been administering my own clotting factor since I was 15.



I have been working as a Shipwright for the last nine years in Morgan for Transport SA. At work we are responsible for carrying out ferry installations, as well as doing the maintenance, repairs, and refits to the ferries on the Murray River in South Australia.

Out of work I enjoy spending time with family and friends, as well as camping, swimming, boating, fishing, mountain bike riding, motorcycle riding, kayaking, bush walking, and most things to do with the country and outdoors. I also help out some groups in the local community.

I personally believe that the best thing a person with a bleeding disorder can do is learn to administer their own treatment. This makes life less inhibited and enables you to take charge of your life, as you are not so worried where the nearest hospital is. I have found this especially true, as I have had to treat myself while away working in remote areas. The other thing that I believe is important is to develop a good relationship with your haemophilia treatment centre and all of the staff who are involved in them.¹

In October last year I was lucky enough to go to the 2nd Australasian Haemophilia Conference that was held on the Gold Coast in Queensland. There I met a number of people from the haemophilia community who had similar ideas to me. We spent many a free moment discussing problems and issues that affected us all, and ways that we could overcome them.

I was approached by Haemophilia Foundation Australia to be part of the Youth Committee, which I accepted. As a member of the Youth Committee I hope that we are able to address some of the issues and problems that were raised at the conference, as well as any other issues that people from within the haemophilia community may have. For the Youth Committee to be successful we need ideas and feedback from you in the haemophilia community.

COMMITTEE UPDATE...

We have a very exciting update about the Youth committee. We are currently organising a leadership training weekend to be held in July. All committee members will get together for a weekend to develop leadership, mentoring and communication skills. We are very excited and see this as a major step forward. We will update you in the next newsletter about the training weekend.

Please feel free to contact any of the committee members and HFA by emailing hfaust@haemophilia.org.au or telephone 1800 807 173, and contact us if you are interested in joining the committee.

ROLE MODEL ~ DR FIONA WOOD AM



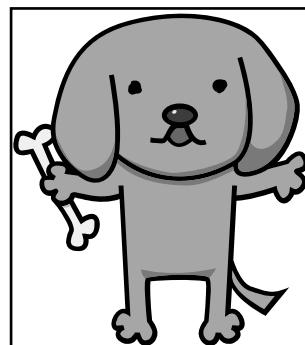
Australian of the Year for Western Australia –
Recipient 2004 Awards

In October 2002 Fiona Wood made headlines. She and her team treated badly burned Bali victims at the Royal Perth Hospital with spray on skin, her own medical breakthrough that is revolutionising burns treatment. This new treatment, which is continually developing, aims to improve the quality of life for those suffering from burns. Promoting motivational discussion groups and speaking to the youth of our nation, Fiona works around the clock, yet continues to remain modest and unassuming. Through her enthusiasm and positive attitude, Fiona has saved and improved countless people's lives, and has inspired a nation.

¹ See Matt and Robert's story in *National Haemophilia* about how they learnt to self treat.

DID YOU KNOW?...

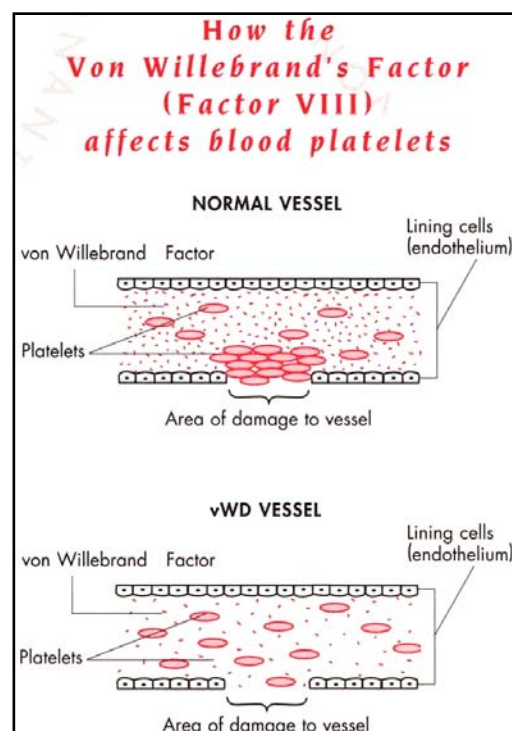
- ⌘ A dog was the first in space and a sheep, a duck and a rooster the first to fly in a hot air balloon.
- ⌘ Dinosaurs did not eat grass: there wasn't any at that time.
- ⌘ The earth is not round; it is slightly pear-shaped. The North Pole radius is 44mm longer than the South Pole radius.
- ⌘ Music was sent down a telephone line for the first time in 1876, the year the phone was invented.
- ⌘ Hot water freezes quicker than cold water.
- ⌘ Today there are almost a billion TV sets in the world.
- ⌘ Milk chocolate was invented by Daniel Peter, who sold the concept to his neighbour Henri Nestlé.
- ⌘ Coca-Cola was invented in Atlanta, Georgia by Dr John S Pemberton in 1886.
- ⌘ The first electronic mail, or "email", was sent in 1972 by Ray Tomlinson. It was also his idea to use the @ sign to separate the name of the user from the name of the computer.



WHAT IS VON WILLEBRAND DISORDER (vWD)?

A common question we are asked is what is von Willebrand disorder and we thought we would take the opportunity to explain this other bleeding disorder.

vWD (named after a Finnish doctor, Erik von Willebrand) is a bleeding disorder in which people do not have enough of a protein called von Willebrand factor in their blood or the von Willebrand factor does not work properly. Because of these problems, it takes longer for bleeding episodes to stop. vWD is not as well known as haemophilia yet it affects 1% of the population. Many people with vWD however, do not experience more than mild symptoms. Symptoms may include frequent nose and gum bleeds, bleeding after dental surgery, easy bruising, heavy menstrual periods or severe bleeding after trauma or surgery. In some cases, bleeding occurs into joints and muscles. It is mostly a genetic disorder in which males and females are affected equally. There is a 50% chance of a parent passing a von Willebrand disorder gene to each of his/her children. Most people will not require medication if they have a mild form except when they are having procedures such as surgery or dental extractions. Sometimes people may require treatment with synthetic hormones, or in the case of serious bleeding episodes infusions of clotting factor product made from human blood plasma and containing von Willebrand factor may be required.



What do you want to know? Do you have any specific questions that you want the answers to? Who is your role model???? Please let us know by emailing hfaust@haemophilia.org.au.

For more information on haemophilia, von Willebrand disorder and other bleeding disorders please visit our website on www.haemophilia.org.au – don't forget to visit the Youth Section.

SOMETHING FOR THE KIDS...

THE OLYMPIC GAMES – A BRIEF HISTORY. DID YOU KNOW?...



The first Olympic Games were held at Olympia in Greece in 776 BC. Olympia was famous for its temples that belonged to the gods Zeus and Hera. The Olympics started out as a religious event and gave competitors a chance to show off their creativity and excellence in sport.

In 393 AD an emperor by the name of Theodosius thought that the Olympic Games were very unreligious and therefore bad, so he banned the games.

In 1896 the Olympic Games began again in Greece as a way to promote friendship and understanding between different countries - the games have been running ever since.

The whole world became involved in the games and they were known as the biggest celebration on earth. Eventually the games were held in other countries around the world as well as Greece.

In 1896 there were nine different sports to compete in, these were: Track and Field, Swimming, Cycling, Fencing, Gymnastics, Shooting, Lawn Tennis, Wrestling and Weightlifting.

The games have become larger over the years and today there are more than 28 different sports to compete in including: Volleyball, Aquatics, Fencing, Judo and Softball. The aim of the Olympic Games in 2004 is to bring together history, culture, peace and sport. The Olympic Games will be held in Athens, Greece, in August 2004.

The Olympics will run this year from 13-29 August. For more information visit www.athens2004.com.

OLYMPIC WORD SEARCH

Can you find the hidden 20 words related to the Olympic Games?

A	T	H	E	N	S	D	F	M	J	K	M	F
R	R	D	A	R	S	D	H	E	H	S	B	E
E	H	C	D	F	U	V	N	D	R	P	N	N
L	F	K	H	F	H	N	G	A	U	E	M	C
A	S	D	G	E	T	V	N	L	B	C	F	I
Y	D	G	J	J	R	D	I	S	A	T	T	N
T	C	F	D	R	F	Y	M	I	S	A	D	G
F	T	L	D	D	I	N	M	Y	H	T	T	G
J	O	D	H	S	T	D	I	T	G	O	F	T
G	T	O	C	N	N	N	W	G	D	R	G	K
F	E	Q	R	V	E	O	S	E	P	S	H	B
D	Z	A	O	B	S	B	D	G	M	T	Y	R
G	N	Z	T	C	S	D	B	U	U	D	G	E
J	O	F	S	P	O	R	T	C	J	F	H	V
L	R	O	L	Y	M	P	I	C	S	G	P	L
D	B	W	R	E	S	T	L	I	N	G	M	I
B	A	S	K	E	T	B	A	L	L	H	J	S

Archery	Medals
Athens	Olympics
Athletes	Relay
Basketball	Run
Bronze	Silver
Fencing	Spectators
Fitness	Sport
Gold	Swimming
Judo	Torch
Jump	Wrestling



Why not try fencing? See the article in *National Haemophilia* on fencing.