

No.18 June 2008

you + H⁺ News

HAEMOPHILIA FOUNDATION AUSTRALIA

Contents:

MESSAGE FROM THE CO-CHAIR

WA CAMP

MOVING OUT OF HOME

LIVEWIRE

HIGHLIGHTED SPORT - AFL

WORD SEARCH

message from the co-chair - Robert McCabe

TALKIN' TURKEY

On 28 May 2008 I will be embarking on a great journey to Istanbul, Turkey. I will be attending two significant events – the World Federation of Hemophilia National Member Organisation (NMO) Training and the World Haemophilia Congress.

Attending these events will provide me with a full circle perspective on haemophilia, giving me the opportunity to see haemophilia from an international perspective.

The NMO Training, as I understand it, is about discussing the way haemophilia support organisations are run (that's HFA and all of the State/Territory Haemophilia Foundations). From this not only will I get the feeling of what level Australia is in terms of world standards, but I will also be able to take away knowledge which will be useful for Australia's State/Territory Haemophilia Foundations for the years to come.

Attending the World Congress I am hoping to learn a lot about Australia's position and what it is Australia can look up to in terms of moving forward. Some important questions that may be answered from an international perspective include, how do we continue to gain specialised treatment? What role does haemophilia play in developing economic, social and health policies in Australian Government? What roles can our support organisations expand into?

There are many more questions and I anticipate that perhaps more questions will be asked than answered. Nevertheless, it provides me with a great opportunity to learn from a different perspective and bring something back to the local community.

I am keen to see another city and tour through Istanbul. Having never been overseas it is an experience I am looking forward to. Hopefully I can bring back something more than just a Turkish rug.



WA CAMP - DALE SPENCER



I was very excited about attending the 2008 camp as it was a great way to catch up with old friends and make new ones.

The camp was planned by the Purple Soup Team which consisted of Tim, Mel and Sam. They were great, they pushed us carefully out of our comfort zone and beyond with such activities as flying fox, giant swing and spooky ghost stories.

On the more informative side the parents really benefited by having Rob, Gavin and myself to talk about issues affecting their child. Also, it was great for partners of people with haemophilia such as my girlfriend Ashlee, and Rob's girlfriend Helen, because Ashlee (and I'm sure Helen too with Rob) is a big part of my treatment and life.

Overall it was a brilliantly organised camp!



MOVING OUT OF HOME - ERIN JAMES

Hi all, I'll start by introducing myself - I'm Erin, a 17 year old guy with mild/moderate haemophilia A. Like a lot of people around my age, I finished school, started working, made a lot of new friends and really started thinking about moving out of home.

I worked out all the things I would need to move out - a lot of my clothes, furniture for my room, and as nobody else had really thought of it, a kettle and a big pot for pasta. Then I realised that I would need to organise how I would get my factor. When I moved out I didn't actually move very far, about 20 minutes away. So getting my factor didn't really change much, it was just a longer drive to the local hospital. The bigger challenge was telling the people I was staying with that while it might look a bit weird I was going to have to keep my factor in the fridge.



With something like haemophilia I have found that it's best to keep those surrounding you as well informed as possible, so I sat them all down and explained that there would be some times when I would sit at the kitchen table with a bunch of needles, and the little boxes in the fridge would diminish. They asked the usual questions, "Will you bleed to death?", and "Is there anything we can do to help?" The first question I laughed at and explained 'no, I'm just about as likely to bleed to death as you are', and the second I said that I really appreciated it, but all they would really need to help with would be to be a little patient if I needed to use the kitchen table for 20 minutes.

Other than explaining it to my mates, living out of home has been a lot of fun, and my treatment regime has changed only in that I now travel further for my factor but that's about it.

LIVEWIRE - WWW.LIVEWIRE.ORG.AU

Are you between 10 and 18 years old and interested in being part of an online community with other kids of your age? Livewire is a free online community only for teenagers living with serious illness or disability in Australia. It is run by Starlight Children's Foundation. Starlight is working with HFA to see whether teenagers with bleeding disorders would like to take part in Livewire. In the future, if there are enough young people with bleeding disorders involved, Livewire may include special chat forums and activities for teenagers with bleeding disorders.

How does it work?

Go to www.livewire.org.au and fill out the registration form.

Get a parent to complete the Parental Consent Form, which you download from the site. Livewire may also confirm your identity with another person, eg your Haemophilia Nurse, (this is to make sure the web site is secure), and then your membership will be activated.

What's on Livewire?

- Chat room with chat host and special guests
- Blogs and forums for discussions
- Entertainment – the latest music, movies, sport, TV news, interviews, competitions, quizzes and puzzles
- Each age group has its own set of rooms

Check it out and let us know what you think!

HIGHLIGHTED SPORT - AUSTRALIAN RULES FOOTBALL

~ Sourced by Matthew Blogg

The information below is an extract from "Boys will be Boys" (2005) by Brendan Egan, Senior Physiotherapist at the Henry Ekert Haemophilia Treatment Centre at the Royal Children's Hospital, Melbourne.

Participation:

Australian Rules football is a favourite pastime of many Australians, particularly those living in the southern states. It is a highly physical sport that involves a high level of contact, particularly as the players mature

and therefore is a sport not usually recommended for people with a blood disorder. Football is played on a large oval shaped field with goals at either end. There are usually 22 players to a team, 18 on field and 4 on interchange. The aim of the game is to kick goals and outscore the opposition. The match is made up of four quarters, each 20-35 minutes long. Players require a high level of strength, flexibility, agility, endurance and fitness, which some people with a bleeding disorder may find difficult to attain.

Auskick is a modified version of the game and is non-contact. It looks at developing the skills of the children in a safe and supervised environment. Some people with a bleeding disorder have participated in this type of football.

Common Injuries:

The types of injuries obtained in Australian Rules football are sprains and strains, bruises, fractures and dislocations, and concussion; they all range from mild to severe. The most common areas injured are the lower limbs, followed by head and fingers.

Injury Prevention:

Warm up:

Jogging side to side, backward running and run throughs are general warm up activities for football. Kicking, handballing, and agility/body contact skills are also important to practise before games. It is also important to warm down after a game or training, using the same stretches used when warming up.

Protective Equipment:

Mandatory:

Appropriate footwear - football boots that have spikes on the bottom of them designed to increase grip.

Strongly recommended:

Mouth guard type III and protective headgear.

Optional:

Chest/biceps guard and ankle taping.

Additional Protective Considerations:

Supervision is important to discourage risk-taking behaviours. Umpires should always control the game and penalise dangerous play. Goal posts should be padded to prevent unnecessary trauma if a player runs into it.

Please remember to speak to your Haemophilia Treatment Centre health professionals before participating in high contact sports, such as Australian Rules Football.



AFL WORD FIND ~ MICHAEL LUCKEN

BLUES	BOMBERS	BULLDOGS	CATS
CROWS	DEMONS	DOCKERS	EAGLES
FOOTBALL	HAWKS	KANGAROOS	LADDER
LIONS	MAGPIES	POWER	PREMIERSHIP
SAINTS	SEASON	SWANS	TIGERS

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

A special thanks to Molly for her article in the last "Youth News". If there are other members of the HFA community who have interesting articles or stories which are relevant to include in "Youth News", please send them into us via the website.

Haemophilia Foundation Australia

Registered No.: A0012245M ABN: 89 443 537 189
 1624 High Street, GLEN IRIS VIC 3146
 Freecall: 1800 807 173 F: 03 9885 1800
 E: hfaust@haemophilia.org.au
 W: www.haemophilia.org.au

Editor: Natasha Coco

Contributors: HFA Youth Council & Leaders

Youth Council

Co-Chairs ~ Paul Bonner (SA), Robert McCabe (WA),

Council Members ~ Anna Szynter (TAS),
 Scott Christie (SA), Simon McMenamin (ACT),
 Craig Bardsley (QLD), Sam Duffield (NSW)

Youth Leaders Members

Matthew Blogg (VIC), Chantel Roberts (VIC),
 Michael Lucken (VIC), Dale Spencer (WA),
 Erin James (NSW), Kat McGowan (QLD)

HFA Representative ~ Natasha Coco