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YOUth H⁺ News

HAEMOPHILIA FOUNDATION AUSTRALIA

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Twinning program between Thai Patients Club, National Haemophilia Foundation of Thailand and Haemophilia Foundation Australia.

Paul Bonner

— Paul is the Co-Chair of the HFA Youth Committee and represents HFSA.

I was lucky enough to be asked to participate in the Twinning Program between the Thai Patients Club, National Hemophilia Foundation of Thailand and Haemophilia Foundation Australia in April this year. This involved Gavin Finkelstein, Sharon Caris, Rob Christie, and myself visiting Bangkok, Thailand for the weekend of the 28th & 29th April to help with a workshop.

The weekend was very worthwhile and beneficial for all those who participated, with knowledge, personal experiences, and friendships being shared. Over the course of the weekend we were kept busy doing presentations, facilitating focus groups, answering questions, and learning about the Thai people and their culture, as well as learning more about haemophilia care in Thailand.



Workshop topics included how HFA represents the haemophilia community around Australia and how it works with local Foundations, policies and procedures, brainstorming ways to help strengthen the Thai Patients Club, developing education and support activities, strategic planning, goal setting, working together as a team, recruiting and retaining members, working with volunteers, coaching and training for leadership, and living with haemophilia.

An interesting thing that I noticed between the Thai and Australian Haemophilia Foundations, despite the many different cultural and other differences is the fact that as a haemophilia community we both share and face similar problems and issues, such as access to sufficient supplies of the best treatment available, a keenness to improve care and treatment and increase support, and assistance to people. Although each country has different access to treatment and care, many of the issues experienced by Australia over the years are also faced by the Thai haemophilia community. We are able to share our experiences, especially how we have met some of the challenges.

On the Saturday night we were all treated to a banquet meal which was followed by entertainment—a Thai Cabaret, traditional Thai dancing, and karaoke, which was great!

The hospitality and welcome extended by the Thai people was fantastic. It was great to meet so many young members as well, who are so keen to help develop and strengthen the Thai haemophilia community. We heard all about the great youth camp they had late last year, around the same time as the Tasmania youth camp in Australia.

I look forward to catching up with the new friends I made and the continued involvement between Thailand and Australia in the twinning program.

If given the opportunity I would highly recommend participating in twinning activities, as you can learn a lot about yourself, other people, their culture, and the haemophilia community as a whole. It's also a great opportunity to make new friendships and learn more.

WFH TWINNING PROGRAM

The World Federation of Hemophilia (WFH) Twinning Program has developed to improve haemophilia care and treatment around the world over many years and now supports 48 twins in 51 countries.

The Haemophilia Organisation Twinning (HOT) Program links haemophilia organisations in developed and developing countries to share knowledge in areas such as patient education, outreach, fundraising, and all aspects of operating a successful haemophilia organisation. Twinning is a positive two-way experience that motivates staff and volunteers, attracts youth involvement, and enables both sides to learn from each other.

In 2006, WFH announced that Australia will be twinning with Thailand and provided funding to support this relationship. This is a great opportunity for the Australian haemophilia community to work closely with our near neighbours in Thailand.



Red Run Classic

Sunday 27 May 2007, New Farm Park, Brisbane

Over 200 runners and walkers participated on Sunday 27 May 2007 for the inaugural Red Run Classic. The event was the first of its kind for Haemophilia Foundation Australia and Haemophilia Foundation Queensland.

Congratulations to the following winners in the Girls and Boys categories:



1st Girl **84 Emily Leydin** 25.21



1st Boy **44 Liam Fogarty** 25.28

OVERSEAS TRAVEL ~ Simon McMenamin's personal experience and tips!

— Simon is on the Youth Council and represents HFACT.

I've been many places in my time. After I finished school it was on and in the last 3 years I have been to 14 countries. It has been so much fun and I recommend it to anybody. The annoying thing (and unfortunately the most necessary) is I have had to take into account my haemophilia at every step. Being able to treat myself has made travelling so much better because I have been able to walk around Paris instead of sitting in a hotel room nursing a bleed. But no matter how great treatment is, it is still quite a lot of bulk in your luggage and a lot of time preparing back here so that way everything runs smoothly over there.

First things first, I always talk to Haemophilia Foundation Australia (HFA). HFA keeps up to date with customs and regulatory issues and the appropriate forms you need in order to be allowed to travel with the amounts of product you will need for your journey. It changes a lot. I've been 3 times and each time I have needed a different form and it was good to be prompted to check out issues I needed to take into account when visiting other countries. You need to check up on that because you don't want to be in a foreign country and run into problems there as you try to take your treatment product in and out of that country. They might have different rules and policies, so you need to find out about the countries you are going to as well as the requirements of the Australian end of it all. If you don't sort it out ahead of time these sorts of problems are going to make your trip 'not-so-tops'. So you need to sort out all the paper work before anything else because without it not a lot else can happen.

Now the thing to do is head on up to your local Haemophilia Treatment Centre and have a chat. If you are going overseas for an extended period of time you will need quite a lot of product. Large amounts can take time to get in so its best to give them a heads up on when you are going and organise this stuff about 2 months before you leave. While you are there it's also a good idea to get a letter of introduction from your doctor. These come in handy in case of any emergencies whilst overseas. If you happen to get a bleed and need to go to the hospital the letter will save you a lot of trouble. But you also need a letter about what treatment product you use, and any other medicines you might be carrying with you during your trip.

Now a handy thing to have is a list of all the Haemophilia Treatment Centres around the world. The first time I went overseas I went onto the World Federation of Hemophilia website (www.wfh.org) and they had a list of all the HTC's in every country with a member organisation. I printed them off and carried them around with me in a big folder. You can dispose of them as you go if you aren't going to use them again. Believe me when I say this thing will help you beyond reason. It's all good and well to be able to treat yourself but when things go down and you need a doctor, it is so much better going to a place where they understand haemophilia, instead of going into emergency and coming across some inexperienced doc telling you to ice your knee!

After you have taken care of all the formalities of travelling you finally get down to the fun part, packing. Ideally you want a product in packaging that doesn't take up too space. Early on, I always took a second suitcase with me for my product. Each time I went was for at least 2 months so I would have to take mass quantities with me. The killer wasn't the amount of product I would have to take, or even the supplies like butterflies and syringes, it was the padding. It is a really good idea to put a lot of padding around your product when you go. I would usually pad my product with towels. They will always come in handy when travelling for other things too. I would wrap my product in towels, with a few ice packs thrown in for good measure and then I was in business. You might get some good ideas on packing your product if you talk to your haemophilia nurse.

Remember you need to plan in advance to get travel insurance and think about how you would deal with different things going wrong. Remember our treatment product is special stuff and you need to take care of it when you are travelling. Once issued it cannot be easily replaced and remember there are many countries in the world where there are no products like ours. So you need to think about your trip carefully well in advance and plan – that way it will all be good!

After all that comes the practical side of travelling. Depending on where you are going it changes. If you have been treating yourself for a while you should be able to figure out where is a good place to treat yourself. Hotel rooms made the best places for me, although I did camp while I was overseas but there is normally a first aid centre or an administration building at any campsite you go to. I shall leave it up to you to figure out how that one works. Part of the fun is figuring stuff out. That is what makes travelling such a good thing because you will grow as a person when you realise you are stuck in Rome with only 6 Euro left for dinner!

For a more detailed article about travelling in Australia and overseas see the article by Megan Walsh in National Haemophilia, March 2007.

HIGHLIGHTED SPORT - GOLF

The information below is an extract from Boys will be Boys by Brendan Egan, Royal Children's Hospital, Melbourne (2005).

The publication helps people with haemophilia to be better informed about their sporting choices and understand the risks of different sports for people with bleeding disorders.

Participation

Golf is a fantastic leisure and competitive pastime that has many benefits for its participants. Golfers use their clubs to hit a small ball into the hole with the smallest amount of shots. It is a non contact sport that is very popular with all age groups and fitness levels. There are many development and coaching programs assisting newcomers to the game to learn the skills to play golf.

www.agu.org.au

Common Injuries

- Back injuries are the most common injury sustained in golf.
- Bones in the hand may also be injured when the club hits a hard, unyielding surface.
- Other injuries include impacts to the head, wrist, shoulder and "golfers" elbow (tendonitis).

Injury prevention

- Warm up
- Low force practice swings and putting should be incorporated into the warm up before full swings are made.
- Stretches.

Protective equipment

- No protective gear is required for participation in the sport of golf.

Additional protective considerations

- The biggest contributor to injury is over practice and incorrect technique so it is important to limit practice sessions and to get coaching to ensure your technique will not cause an injury.
- As there is often a lot of walking involved in golf, ensure you are wearing firm shoes that won't cause blisters.
- Ensure that the clubs used are an appropriate size.

14th Australian & New Zealand Haemophilia Conference Canberra 4-7 October 2007

bleeding disorders ~ achieving success to last a lifetime

www.haemophilia.org.au



For the past two conferences, on the Gold Coast and in Melbourne, the program has had a dedicated youth stream catering for ages 14 years and up. After feedback and comments from the last conference, this year's conference targeting youth will be in the mainstream conference with an adventure activity on Sunday afternoon.

Youth delegates must be aged 14 and over and will attend mainstream conference sessions on Friday and Saturday and any of the workshops on Sunday morning. On Sunday youth delegates will have an offsite activity at Pitch n' Putt golf. This is included in your conference registration costs.

Conferences are a great opportunity to meet other people, re-unite with old friends and learn more about bleeding disorders, treatment products and prophylaxis, and complications like inhibitors, and preventing problems such as joint problems.

Junior delegates (aged 14 and under) may play golf on Sunday with consent of parent/guardian. If you are under 14 and are interested in the activity please email your details to hfaust@haemophilia.org.au or call 1800 807 173.

For more information visit the conference website www.haemophilia.org.au/conferences

WORD FIND BY KRISTI JORGENSEN

— Kristi is on the Youth Council and represents HFV.

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A	S	I	V	D	W	K	A	J	F	R	B	V	S	J	R	S	Q	K	T

Find these words to make your next trip a breeze! Look backwards, forwards, up and down – check the diagonals too!

Passport
Letters
Treatment
Camera
Immigration
Swimmers
Crutches
Beach towel
Ice pack
Visa
Travel diary
Sling
Hat
Contact numbers
Book
Pressure bandage
Sunnies
Talisman
Sunblock
Money

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),
Anna Szynter (TAS), Kristi Jorgensen (VIC), Scott Christie (SA),
Simon McMenamin (ACT), Craig Bardsley (QLD), Sam Duffield (NSW)

Youth Leaders

Joe Chivers (TAS), Chantel Roberts (VIC), Dale Spencer (WA),
Michael Lucken (VIC), Matthew Blogg, (VIC) Erin James (NSW),
Lauren Albert (QLD)

HFA Representative ~ Natasha Coco