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Youth News

HAEMOPHILIA FOUNDATION AUSTRALIA

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MESSAGE FROM CO-CHAIR ROBERT MCCABE

What a busy year 2009 has been, especially with the successful conference. Conference is a great time to meet others, share experiences and find out up to date information on treatment and care. In this newsletter you will read some reflections of youth delegates at the conference.

International congress is also a great opportunity to experience. The congress will be held in Buenos Aires in July 2010. For more information visit **www.hemophilia2010.org**

I'd like to thank the Youth Committee for their work and dedication throughout the year. I am pleased to hand over the role of Co-Chairs to Dale Spencer from WA and Lauren Albert from QLD in 2010.

Have a safe and happy festive season!

15TH Australian & New Zealand HAEMOPHILIA CONFERENCE Life Challenges

Brisbane, 8-10 October 2009 www.haemophilia.org.au

CONFERENCE REPORTS

It was great that 15 youth delegates from all around Australia attended the conference. They had different experiences - some had bleeding disorders, and there were siblings, partners and women carrying the haemophilia gene.

All the presentations are available for download online at **www.haemophilia.org.au/conferences** and follow the links to Presentations or read *National Haemophilia* for some more conference reports.

Some of the youth in attendance have provided the following reports.

Andrew Selvaggi, VIC
"Treatment and management of Inhibitors" chaired by Dr Chris Barnes from the Royal Children's Hospital Melbourne and speakers Dr Simon Brown & Cody.

Having had inhibitors for as long as I can remember I was really interested to see the latest treatment protocols and new tolerisation methods that might be over the horizon. The talk started off with Cody, a young man from Melbourne giving his personal experience of growing up with inhibitors and how he and Dr Barnes are managing his condition. Cody talked about his past bleeds and the impact that inhibitors have had on his life so far, along with the current tolerisation treatment he is going through.

Max Janiszewski, VIC
I took part in abseiling with Purple Soup and abseiled in a total time of 1 min 10 sec – what a great time! There was a good amount of youth delegates there and a lot of catching up with some mates from Adelaide last year, and I met some new people too. The conference was a really positive experience and I got to meet a lot of guys with haemophilia and a few other familiar faces which is something I don't get to do a lot.

Zoe Larkin, VIC
The reason I went to the conference is because my partner has haemophilia. I was really interested in gaining a great variety of information and perspectives of this condition. My knowledge prior to this was limited and mostly informed by wikipedia.

My partner really enjoys sport but due to bad joints in his ankles he can no longer get too involved. A session that addressed this issue was conducted by Kathy Mulder, from the children hospital in Winnipeg Canada 'Good joints for a better life'. Kathy spoke about one of the best ways to reduce bleeds……RICE!!! (Rest, Ice, Compression and Elevation) - it is so simple yet forgotten in our household.

The speakers at this session also spoke about having regular physiotherapy. Also that your physiotherapist can suggest sports that will least affect the 'bad' joints in your body. The opinion that haemophilia prevents sport involvement is now outdated but the speakers were collectively saying it is best to seek advice from a physiotherapist and other health specialists before you begin a sport.

On the Saturday I attended the women's breakfast. This was one of my highlights of the conference. I sat with a group of women who have a family member with haemophilia. It was really good to hear the points of view of mothers and sisters. There were two women at our table from Thailand. One of them is a mother of a child with haemophilia. She told me her son is only entitled to 2 x 500 i.u of clotting factor per month! This seemed so unreal to me, and she went on to explain that it doesn't matter about the weight of the person, or the type of bleed that it is, that each month will be the same – 2 X 500 i.u. This resonated with me and I have done some research into haemophilia in the world and found some more alarming facts about how many people in the world have little or no access to clotting factor products.

Dale Spencer, WA
The session I enjoyed the most was the first plenary session with Dr Michael Carr-Gregg. I hadn't thought much about his topic much - how chronic disease has affected me as an adolescent, how it affects my siblings and how to deal with it. I found him very well spoken, informative and he really got the audience to interact and understand what his talk was about.

Overall I thoroughly enjoyed the conference, its programs, social events and catching up with everyone. I have gained some new knowledge through being older and wiser, and mostly more into my own treatment and care. Being able to discuss issues about haemophilia with people of my own age benefits me greatly!

Tom Davidson-Lim, TAS

A most interesting presentation was by Kathy Mulder, a physiotherapist from Canada who gave a talk about the benefits of physiotherapy for people with bleeding disorders. The biggest eye opener was that Kathy showed in her presentation what happens if bleeds are not treated. There were pictures of kids in communities where there was no adequate treatment so their knees were the size of footballs and damaged beyond repair. You then realised that we are so lucky to have the accessibility that we do for treatment. I also learned that treatment was not something that you deal with "later". If you need treatment then you use it, this was important for me to take on board because I am not one to want any medication and don't do myself any favours by making a bleed or injury worse. A significant factor is the 8-12 hour half-life of FVIII (FIX 18-24 hours) meaning that a 40% factor level can drop to 5% in 36 hours. Timing is everything. Kathy recommends morning prophylaxis infusions rather than bedtime treatments and participation in sports on prophylaxis days. Physiotherapy is something that if used properly for someone with a bleeding disorder can be very beneficial and let you get the best out of your joints.

Another session that was relevant for me was on von Willebrand Disorder. I am a vWD type1 so it is not as bad as many other people. I heard people's stories and most have more severe vWD than myself, and I then realised I didn't have it as bad as some other people. Hearing about kids that were limited in their physical activities because of their disorder made me feel lucky.

Lauren Albert, QLD

After sitting through only five minutes of the first plenary session, I realised just how many areas of the bleeding disorders community I was completely oblivious to. Dr Michael Carr-Gregg spoke in a way that allowed medical professionals and youth alike to not just understand, but to connect with what he was saying.

My favourite session by far, however, was the final plenary session, chaired by New Zealand Foundation President Deon York, as it discussed the most important questions of all in regards to treatment; where have we come from and where are we going? And of course, why haven't we found a cure yet? Prof John Rasko's talk on the delays in gene therapy really opened my eyes to a whole area I had never considered before. I found myself completely drawn into the world of gene therapy and the search for a cure.

The youth activity was abseiling, an idea which both excited and terrified me at the same time. I am morbidly afraid of heights and was sure I would die, even just from fear, but I was determined to do it none the less. It was an amazing, breathtaking view from the top of the Kangaroo Point cliffs, but the feeling I got walking back up the hill knowing I had gone abseiling despite my almost paralyzing fear, was the best feeling of all.

Ethan Edward, NSW

Abseiling

That is the rock that we all climbed down.

The View from the top

Climbing down was lots of fun. The whole group enjoyed abseiling. The rock was about 15 metre high. Some people had trouble getting started, (the straight drop to the ground was a little off-putting..)

Hamish Robinson and I before we went down the rock.

Little Bit More About Abseiling

Abseiling was great. Here are some more pictures I took: someone just about to go on the top left. The other 3 are some views you can see from the top of the cliff and when you get down from the cliff.

Good joints for a better life

Spoken by Kathy Mulder

She told us when we have a needle and put the factor in a person with Haemophilia VIII has 8-12 hours of protection. She also talked about the fact that it was the 1960's before factor VIII became available in some countries. She talked about how blood affects the joints in a short and long time of having blood there. For a bleed, just having factor alone is still not enough. You need to have Rest, Ice Compression and Elevation to stop a bleed.

There was a full room for the Good Joints program.

It was very interesting because I learnt lots of new things in that program.

I learnt to stop a bleed you have to have factor AND use the RICE method (Rest, Ice Compression and Elevation).

- I would like to tell others that going to this presentation you can learn something new that you didn't know before.

I would recommend it for others so they can learn more about haemophilia and effective treatment methods.

PLANNING TRAVEL AND HOLIDAYS

Sharon Caris

If you are going interstate or overseas during the holidays you should have made arrangements for supplies of treatment product by now. Don't forget to start your planning early with your haemophilia centre to ensure you have sufficient clotting factor and equipment, other medicines and medical letters etc to take with you. If you are going overseas you will need to ensure you have the necessary customs and quarantine documents for leaving Australia with treatment product, and for returning to Australia and for the countries you will be visiting. Even if you are in transit through a country, remember there may be documentation requirements to carry your clotting factor, needles and other medicines with you through security/quarantine/customs.

Make sure you select carefully where you will travel, especially if you might need medical assistance. Check whether there is expertise in the care and treatment of people with bleeding disorders in the places you are visiting, and how you would access these services. Be aware that treatment may be limited, unavailable or unaffordable in many countries. Make sure you have appropriate insurance and a plan in the event that you are unwell or have an accident.

If you have been issued with additional supplies of clotting factor for your trip, make sure you take care of it when you are travelling and that you bring any remaining product home with you – you will not be issued with more product on your return if you took larger quantities than your usual supply away with you for that period.

Make sure you contact your treatment centre staff well in advance so they can help you with your travel plans. HFA can also provide more information about your planning for overseas travel, including where to find haemophilia centres in different countries.

ARE YOU INTERESTED IN JOINING THE HFA YOUTH COMMITTEE?

If you are, contact Natashia at HFA on 1800 807 173 or email ncoco@haemophilia.org.au.

On behalf of the Youth Committee we wish you all a safe and happy festive season.

Please note the HFA office will on the afternoon of Wednesday 23 December and will reopen on Monday 4 January 2010. Please leave a message on the answering machine, however if the matter is urgent please call Sharon Caris on 0410419914

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