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YOUTH

News



HAEMOPHILIA FOUNDATION AUSTRALIA

Contents:

MESSAGE FROM THE CO-CHAIR

WORLD CONGRESS

ADVENTURES WITH CARPET

HAEMOPHILIA AWARENESS WEEK

WORD FIND

News from the World Congress



Hemophilia
World 2010
Congress

Buenos Aires • ARGENTINA
Saturday, July 10 - Wednesday, July 14

message from the Co-Chairs



Dale Spencer

Over the past month or so HFWA and other states have had their AGM (Annual General Meeting). The AGM is a wrap up of the financial year and where new members can join the committee. David Bell decided to step down as HFWA President after doing a great job for so long now and Gavin Finkelstein has taken over again, so welcome back Gavin.

There has been a lot of talk by the Youth Committee members about getting more youth involved in youth activities in states as there hasn't been enough interest with numbers and turnouts for the activities. I cannot stress enough how important it is to support your local foundation and activities. They are a lot of fun and you get to meet a lot of people with haemophilia around your age and everyone can benefit from sharing experiences.

HFA has won the privilege to hold the 2014 World Congress in beautiful Melbourne. For those of you who are not aware of the World Congress, it is a meeting of countries from all over the world coming together to share and learn about haemophilia, von Willebrand disorder and other bleeding disorders. Craig Bardsley was lucky enough to be chosen to attend the World Congress this year. He greatly benefitted from the experience and we will hear from him about it in a later issue.

Lauren Albert

We're currently looking at revamping our newsletter to make it more exciting for you guys, so feel free to send us any suggestions you may have for it. We are also looking for people to send anything they would like to see in the newsletter, whether it's a story or a picture, or anything at all!

We also have recently been told that we are going to be hosting the 2014 World Congress in Melbourne. This is a huge honour and very exciting news for everyone in the haemophilia community. On behalf of the Youth Committee we would also like to congratulate Natasha Coco on the birth of her baby girl recently. We're very excited about the adorable new addition to the Committee!

So let us know what you'd like to see in the newsletter, and keep those photos, stories and drawings coming in and you might get to feature in the newsletter!



Haemophilia 2010 – a report from the World Congress

By Robert McCabe, HFA Youth Committee Co-Chair 2007-9



I was privileged enough to attend the Haemophilia World Congress in Buenos Aires. This was also the Second World Congress I have attended and it was a great experience the second time round. I arrived in Buenos Aires a week earlier and got a feel for the city. The city is electric, and one that never sleeps! I recall walking past a restaurant at 8.00pm and it was empty, only to walk past it again at 11.30pm and there were no empty seats!

The Congress had an excellent program, with sessions on specific topics not only for medical professionals but many that were relevant to people with haemophilia and their families. I attended an excellent session on sports for people with bleeding disorders where

people from around the world gave their perspective in looking at sports deemed appropriate for people with bleeding disorders. Despite the differences in sport preferences around the globe, the message similar to ours in Australia. Sports has risks, but there are many sports where the benefits outweigh those risks.

Throughout the Congress I was able to renew friendships from people that I met at the last World Congress. It was a nice feeling to know that you have friends all over the world who have had similar experiences to yourself. The other benefit to attending the Congress in Buenos Aires was to experience Argentinean culture. We were fortunate enough to see a number of tango shows, eat enormous steaks and drink some of the world's best red wine.

The Argentinean hospitality was superb, and now that it confirmed that Australia is hosting the World Congress in 2014, hopefully we can repay some of that hospitality! I would recommend to anyone to attend a World Congress: it provides you with a new perspective on your bleeding disorder, gives you an understanding of how lucky we are in Australia and how important it is to continue to maintain the level of care we have - and finally you begin to realise how small the world is when the problems we have faced in Australia are very similar to those faced around the world. I can guarantee that if you attend at least one World Congress in your life you will not be disappointed.



Adventures with carpet

By Dale Spencer, HFA Youth Committee Co-Chair



Hospitals and haemophilia are very similar subjects in my opinion: they worry some people, and some people like me don't mind them, but I think we can all say we have had some interesting experiences in hospitals. This certainly happened for me recently - and with the accident/incident that led to the hospital visit.

While fixing up the unit I currently live in, my parents, my fiancé and I were painting the master bedroom walls with the old carpet still down, and I was making my way over to pour some more paint when I felt a sharp pain in the bottom of my foot. I immediately took a soccer dive and fell to the floor. It hurt so much that I thought it must be serious, but I couldn't see anything and we all put it down to me standing on something and just puncturing my foot.

I continued on with my daily activities, including more painting, two weeks of work and an awesome gig where I was jumping around having a great time. I still had the pain in the bottom of my foot but just kept having my factor and putting it down to the tiny black bruise on the bottom of my foot which had now surfaced. The pain became too unbearable after the two week mark to the point where I was on crutches, so I made my way to hospital.

After seeing the haemophilia nurse and the doctor, I was sent to X-Ray, where we discovered to everyone's horror (especially mine!) that there was a sewing needle lodged under my foot. All the walking and jumping I had done over the two weeks had pushed it further and further until the tip was into my foot bone. I was admitted into hospital that day unprepared - no phone charger, phone credit or any means of electrical entertainment! - and early the next day was operated on to remove the foreign object.

The valuable lesson from this is that you know your body better than everyone else, so listen to your body. I knew my pain threshold, because I put up with a lot of pain with my arthritis. I had a feeling it was more than bruising, and if I think back I should have gone in earlier, rather than waiting until the pain was unbearable to get it checked out. So if you're not convinced by what people are telling you, and your body's telling you something different, don't be afraid to go into the Haemophilia Centre and get it checked out.

And I have to say, I love the new carpet I have in my unit.



What is Haemophilia Awareness Week?

Working together to raise awareness in the wider community about inherited bleeding disorders.

Our theme for 2010 is "*Life Challenges – the real issues*" with the aim of telling people exactly what it is like to live with haemophilia and other bleeding disorders every day. It's also about celebrating the ways we overcome these challenges.

When is it?

In the week of 10-16th October local events will take place across Australia including school fetes, sausage sizzles and promotion across schools, hospitals, doctors' clinics and workplaces.

Can I help?

Absolutely! There are so many ways you can get involved and help raise awareness of bleeding disorders during Haemophilia Awareness Week. Here are some ideas:

- set up an information stand at work, school or your local community centre or library
- offer to help out your local Haemophilia Foundation during the week
- organise a casual clothes day at school or work
- organise a lunch, sausage sizzle or morning/afternoon tea.

Is there anything available to help me do this?

Lots of stuff! If you decide to organize a local event or want to promote Haemophilia Awareness Week at school, work or anywhere else, we can give you promotional items to help.

We have wrist bands, stickers, tattoos, posters, balloons, bookmarks, pens and many more. If you'd like to order any of these (free!):

- download an order form at www.haemophilia.org.au
- call Janine on 1800 807 173
- email jstaunton@haemophilia.org.au

Get in quick as stock is limited!

If you do get involved...

If you do anything for Haemophilia Awareness Week, we would love to hear about it! Please get in touch and let us know what you did and if you have any photos, please send them! Just email jstaunton@haemophilia.org.au

Would you share your personal story?

We are always keen to hear from people of all ages who are willing to share their personal stories of life with haemophilia. Personal stories are the best way to raise awareness of life with haemophilia – both during Haemophilia Awareness Week and throughout the rest of the year.

If you would be willing to discuss sharing your story, please call Janine on 1800 807 173 or email jstaunton@haemophilia.org.au. (If you are under 18, we will need your parents' or your guardian's permission as well).

Haemophilia Word Find

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Created By Michael Lucken



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