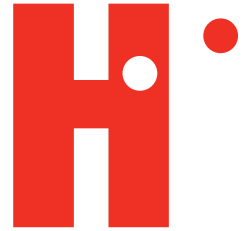


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Youth News



HAEMOPHILIA FOUNDATION AUSTRALIA

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message from the co-chairs

Hi Guys and welcome to the final issue of Youth News for 2011. Recently, both Dale and I were lucky enough to attend the 16th Australian & New Zealand Haemophilia Conference, which was held at the Novotel in Sydney. It was a wonderful weekend and we are both very grateful to HFA for the opportunity to attend. The conference allowed us to learn new things about bleeding disorders, catch up with old friends and make heaps of new ones.

The conference provided an opportunity for us to meet with the Youth Project Officer, Kate Walton, and at the youth 'Meet and Greet', meet other young people in our community. This allowed us to speak to one another and discuss ways we can better communicate and stay connected as a group. It was a great experience meeting so many different young people and to hear more about Kate's project.

An exciting development is the HFA Beyond Prophylaxis Project. Kate will be working with young people and others in the bleeding disorders community to develop a web based education and communication program for youth. We are looking forward to this and the Youth Working Group (YWG) Kate is currently putting together to work on the project. This is a great chance for us all to be part of the new development and we encourage everyone with an interest in participating making contact with Kate about joining the YWG. We are all very excited about the changes that are coming in the next year and would encourage all young people to get involved, as the more input we get, the more effective the project will be.

As things have evolved, members of the original Youth Committee are now invited to transition to the YWG and to be part of the new look for youth communication and connection at HFA.

Thanks to each and every member of the Youth Committee for their hard work and commitment over the years to discussions, camps and workshops and for all the contributions made to Youth News. We hope all of you have enjoyed reading Youth News and attending youth activities and we hope to see you all at World Congress in Melbourne in 2014 if not before! Please take advantage of every opportunity to be involved with the youth of our community, as the memories and friendships you make will last a lifetime.

Lauren & Dale
Co-chairs 2009-2011

**Ho Ho Ho! Merry Christmas!
Have a safe and happy festive
season from the Youth Committee!**



Lauren Albert Co-chair and Dale Spencer Co-chair

Impressions of the Conference

Three members of the Youth Committee share their thoughts and impressions of the 16th Australian & New Zealand Haemophilia Conference...

Inhibitor Workshop - Michael Lucken

This was the 1st Australian and New Zealand Inhibitors Workshop EVER so I was excited to be a part of it but at the same time a little hesitant as I was not sure what to expect, so I went in with an open mind.

The workshop started on Saturday evening (an hour after the conference finished) with a meet and greet, introductions, ice breaker games, group activities and team brain teasing/problem solving. If our brains hadn't already been full from the conference, they were now!

The next day started with a mix of personal journey stories and inhibitor life struggles and then we had two social workers speak about wellbeing and how it is more than just looking after your physical body but also your spiritual, emotional, mental, family and social wellbeing. We had a physiotherapist talk to us who made some very important points about joint bleeds and how you must rehabilitate joints properly after each bleed otherwise you could have more joint damage and muscle problems.

We then did some Tai Chi with John Gough, Tai Chi Master. John explained that Tai Chi can reduce stress, lower blood pressure, improve muscle strength and flexibility and can even relieve some arthritis pain. It wasn't totally my thing but it was fun to give something new a go.

Sunday morning we had a Haematologist come and talk to us about the different types of factor and tolerisation. Then we had a lovely lady from the Independent Living Centre come and show us lots of gadgets and gizmos for getting through the day. A lot of things got passed around the room and it was quite fun.

So... the workshop was very good, informative and well planned out, not to mention full on, nonstop and brain busting BUT... in saying that, this was the first workshop I have been to where I have gone away with motivation to improve myself, even if it's only a little bit. :)

Rarer Bleeding Disorders – Lauren Albert

I attended many interesting sessions during the 16th Australian & New Zealand Haemophilia Conference. However, the standout session for me was on the rarer bleeding disorders which had a personal story by a mother of a child with severe factor XI deficiency. Then 3 nurses presented their experiences of looking after people with rare bleeding disorders. Growing up with a brother with severe haemophilia A, and being so involved with the Haemophilia community, I thought I had a pretty good grasp on bleeding disorders. However, once again, the conference proved me wrong but in doing so, provided me with an environment to learn about these bleeding disorders. I learnt a lot during the course of the conference, but learning about the lesser known bleeding disorders was a real eye opener for me. It has made me realise how much I still have to learn about some of the disorders people in our community are living with and has ignited a desire to gain more knowledge about these conditions.

5 Questions with Dale Spencer

Youth News Editor, Kate Walton asked Dale Spencer 5 questions about his Conference experience...

1. What was it like being a speaker at the Conference?

It was scary at the start as I'm not a public speaker although it became a lot of fun when the nerves dropped and I could argue my point (in the Can of Squirms session).

2. How much preparation did you do?

Not much what so ever. Part of Can of Squirms session was that we didn't really know what questions we were going to be asked, so we just met up during morning tea for a quick run through.

3. How did you feel when you were presenting?

It was a great experience being a speaker. I was nervous at the beginning although it soon past and became easy as I was speaking from my heart about the issues presented.

4. Did you get good feedback?

I got mixed feedback. A couple of mothers asked about my severity and said their child wanted a tattoo and asked how to go about it, and the other half were people who don't see it my way. Everyone has their own opinion and I appreciate that but I won't change my personal opinion for the "taboo topics" that I'm often criticised for.

5. What advice would you give other young people who are asked to do public speaking about their bleeding disorder?

Go for it. It's an experience and it gets a lot of people talking. You may find some people in the crowd you've just helped.

Bonjour Richard!

Richard Davidson-Lim won the Vision and Leadership Award in 2010 which provided him with the opportunity to attend a school exchange program with the world-renowned Lycee Racine School of Performing Arts in Paris. Richard's life goal is to perform on the stage dancing or singing and by winning this award he is one step closer to realising that dream. Here, Richard recounts his experience...

Hi I'm Richard Davidson-Lim and I have von Willebrand disorder. This year I had the incredible fortune to win a Vision and Leadership Award as well as a grant from the Damon Courtney Memorial Endowment Fund to go on a school exchange trip to France for 5 weeks. The trip was a way for me to work on my French conversational skills as well as advance my passion for the theatre by attending a performing arts school.

So on the 25th of September 2011 I jumped on a plane to Melbourne (from Tassie) and took the longest and loneliest trip of my life all the way to France. When I got there I was greeted by my host family and was taken all the way to a suburb called Belleville translated to 'beautiful town' – which is near the centre of France.

As I arrived a week before the start of the school year I had the chance to do almost every well-known tourist attraction in Paris. This included going to the Louvre, the Champs-Elysees and of course the amazing Eiffel Tower and Arc de Triumph.



Richard in France

Once my vacation week was over it was time to get stuck into school. I attended all the same classes as my exchange student, the hardest of which was learning Spanish and their own French class however; I seemed to excel in English class! I made lots of new friends, learnt a lot about the French culture and also had a great time learning dance in a different language, especially ballet, as most ballet terms are French.

I am extremely grateful for winning the Vision and Leadership Award as it has changed my life by providing me with an opportunity I would otherwise have not had. Even better is that now my exchange student is in Australia attending all of my classes!

Shivam Skills Up

Shivam Agrawal won the Advance Your Passion Award in 2011 and has used the funds to further his drumming skills. Here is Shivam's story...

Prior to receiving the Advance Your Passion Award, I was a self-taught drummer, using books and online videos. I had been playing for about two years, and had been using a small electronic drum kit. I was fortunate enough to play with a group of fellow university students in university sketch comedy shows, as well as other performances. Our band decided to play at events outside university, and in 2010 we played at events such as the UTS Law Ball, UNSW Medical Faculty Staff Party as well as the Sydney Special Children's Christmas Party at Rosehill Racecourse. Playing at a variety of private functions and charity events has been rewarding and enjoyable.

I have been practising quite a lot since I started, however I never pursued lessons due to cost. I knew I had errors in my technique but tried to fix these myself. Once I received the award, I immediately began to search for drum teachers in my area. I decided to try two different tutors before making a solid decision. I have now had 6 lessons with my current tutor and feel much more confident and comfortable when playing. My teacher has been able to point out flaws in my technique, and I have been able to fix most of these. Our band has had two performances since I began having proper lessons and both my band and I have noted my improvement in timing and general skills. This has been very pleasing, especially when I receive compliments from audience members. I am aware there is still a lot to learn and practise is the key so I hope to continue with my current tutor.

I would like to thank HFA and the Advance Your Passion Sponsors, Baxter Healthcare, for providing me with this grant enabling me to advance my passion for drumming.

Youth Project Update

Since the last edition of Youth News I have been madly working on the youth project. I attended the National Conference in October where I got to meet a lot of you, listen to your speeches (which were awesome, by the way) and talk to you about the youth project.



I have been recruiting the Youth Working Group (YWG) which has some strong numbers, but we could still do with more people. The YWG will look at the information and resources you and other young people need about bleeding disorders to make positive and informed choices about your health and lifestyle. I am currently drafting some questions for the YWG to answer – so prepare yourself! Soon it'll be your turn to have your say and I'm looking for honest answers and ingenious ideas!

There is still time to join the Youth Working Group, so get on board!

Cheers
Kate

Conference Word Find

AIRPORT
FRIENDS
PACKING
TRAVEL
CONCURRENT
HOTEL

EXPERIENCE
LISTENING
CARERS
CHALLENGES
HEALTH
QUESTIONS

LEARNING
SYDNEY
GUESTS
HAEMOPHILIA
PROFESSIONALS
DISCUSSION

SPEAKERS
BREAKFAST
PARENTS
PLENARY
YOUTH
INHIBITOR

BLEEDS
FUN
TOLERISATION
TREATMENT
CONFERENCE
REPORTS

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W	E	F	B	R	E	A	K	F	A	S	T	T	A	S	T	S	E	U	G	X

By Michael Lucken

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: Kate Walton

Contributors: HFA Youth Council & Leaders

Co-chairs ~ Dale Spencer (WA) & Lauren Albert (QLD)

Youth Council ~ Paul Bonner (SA), Craig Bardsley (QLD),
Hamish Robinson (NSW)

Youth Leaders ~ Michael Lucken (VIC), Chris Poulton (VIC)
Belinda Broughton (WA)

HFA Representative ~ Paul Bonner