

No.28 Dec 2010

# Youth H<sup>+</sup> News

HAEMOPHILIA FOUNDATION AUSTRALIA

## Contents:

MESSAGE FROM THE CO-CHAIRS

WORLD CONGRESS REPORT

ANKLE FUSION

OVERSEAS TRAVEL

WORD FIND

## message from the co-chairs



### Dale Spencer

Over the past months each state and territory has been having their AGM (Annual General Meeting). A lot of planning and effort is put into keeping the State Foundations going and it's great to see more members joining and receiving our monthly newsletters. Lauren recently attended the HFA Council Meeting and she brought up a lot of important issues: funding towards another youth activity, reaching out to more people and other issues. I would like to thank Lauren for taking the time out of her busy schedule to attend. Youth activities in State Foundations are important for bringing young people together to get to know each other. Hopefully they will continue to stay involved and the Youth News magazine is part of this. I've been brainstorming ideas for a HFWA youth activity to be held sometime on the school holidays. I look forward to seeing everyone attending state activities and the Conference in 2011!



### Lauren Albert

I was lucky enough to represent the Youth Committee at the Haemophilia Foundation Australia Council meeting in Melbourne last month. I'd never been to Melbourne before, or a Council meeting, so I was excited but had no idea what to expect. I took part in some fantastic discussions about youth and have lots to talk about with the Youth Committee so we can look at lots of different ways to keep you guys interested and involved. If you have any ideas of ways we can make the newsletter, or youth activities, more exciting and interesting for you, make sure you let us know. We want to do everything we can to make it fun for you!

In Queensland we are also going to get a Youth section happening in our newsletter to keep all you guys in our area up to date on everything that's happening with the youth. This is our last newsletter for the year so I really hope you like it and we will back early next year. Can't wait to show you what we have in store for 2011. Be prepared for some pretty exciting stuff!

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

Please note the HFA office will be close on the afternoon of Thursday 23 December 2010 and will reopen on Monday 3 January 2011. If you have any queries or need to contact HFA, please leave a message on the answering machine. However, if the matter is urgent, please call Sharon Caris on 0410419914.





## Report from Buenos Aires - Youth Delegates on the world stage

By Craig Bardsley, Youth Committee member



Craig seeing the World Congress in 3D

Having the opportunity to go to the World Congress in Buenos Aires was fantastic for so many reasons, but I think for me the best part was because I got the chance to meet people with bleeding disorders from all over the world.

I spent a lot of time with the other Youth Delegates. There were more than 40 of us, all from different countries. We hung out and exchanged info, including our emails and Facebook pages and mobile numbers to keep in touch with each other – some of the people I'm now in contact with come from countries like the US, Sweden, Poland and Switzerland. The social activities were a great way to get to know each other. One night we all went out for dinner at a big restaurant, and another night we went to a pub and danced. We talked about what Youth Delegates could do in the future - we are even looking at the idea of a "World Youth Committee" where we would be able to have our voice heard on a global stage.

It was amazing to hear how other people deal with their issues and reinforced to me that we are at the top of treatment here in Australia.

It's fantastic that we will be holding a World Haemophilia Congress in Melbourne in a few years!! I encourage everyone to come along and enjoy and learn as I have had the chance to do!!!

## On the move again

By Paul Bonner, Youth Council member

Hi, for those of you who don't know me, my name is Paul Bonner, and I have severe haemophilia B.

A lot of the younger people with haemophilia who are on prophylaxis are lucky they don't have major joint problems.

I thought I would share my experience with my ankle so people can get a bit of an idea what joint problems can be like, and hopefully encourage people to stay on prophylaxis to prevent the same thing happening.

Ever since I can remember, my left ankle has always been my target joint. I had many trips to hospital to treat it because at that stage prophylactic treatment was not available. Growing up I wore ankle braces to try to protect it, which worked to varying degrees.

It wasn't until I left school and had been in the workforce for around 6 years that the accumulation of all the bleeds in my ankle started to take their toll on the joint itself. I was starting to experience pain from arthritis, as well as bleeds. Things were still manageable at this stage, but I would have a bad day here or there.

When I was about 27 my ankle was causing me quite a bit of pain and trouble, so I spoke with my haematologist about options. We talked about ankle fusion surgery, but the recommendation was not have the ankle fusion surgery until I couldn't bear or cope any more with my ankle, so nothing happened and for some reason my ankle settled down a bit and became reasonable to manage.

Fast forward several years and my ankle was now causing me constant pain. After 14 years as a boat builder I decided I needed to change jobs as I didn't feel I could continue to fulfil all of my job requirements. I was lucky enough to get a job with an earthmoving company as a Health and Safety Officer, so things weren't as strenuous on my ankle, but I was still experiencing severe pain and having problems. I was using stronger pain relief to start and finish the day more often than not.

I talked with my haematologist about ankle fusion surgery again. This time I was serious - I wanted it done as I was "over" everything. I saw an orthopaedic specialist, who also recommended the surgery. So I filled out the paper work for the operation and was put on the priority list for surgery.

I had my ankle fused in April 2010. The doctors said the surgery went well; I was in a resting cast so they could monitor the site of the operation. I needed very little pain relief post surgery; the doctors were going to release me after 5 days in hospital - I was happy. The day of my discharge I started to experience excruciating pain in my ankle so I ended up staying in hospital for another couple of days.



When things had settled down I was discharged from hospital. It was home to my wheelchair and crutches. I was managing quite well around the house taking things easy, having my daily dose of clotting factor.

After being home for 5 days my ankle again became excruciatingly painful so I was readmitted to hospital for another two days. They thought that I had developed an infection in my ankle, but tests showed this was not the case. The pain settled down again but things didn't feel quite right to me, so I raised it with the doctors who said, don't worry, it's just a different type of pain to what you are used to.

I was discharged again, and went back home, this time in a full cast. I had been home for 4 days when my ankle became unbearably painful. It was worse than the previous two occasions. I used the pain relief I had been given which did nothing for the pain. I could feel my leg and ankle swelling up in the cast. The pain was so bad I could not even concentrate long enough to have a dose of clotting factor.

Back to the hospital I went - it was right up there with the worst two hours of my life. While in the back of the car I managed to cut the cast off which relieved some of the pressure from my ankle. By the time I had got to see the doctors my leg and ankle were so swollen that the stitches from the operation had started to pull open. I was given a large dose of clotting factor and copious amounts of pain relief. Eventually the pain started to become more bearable (I was told "that might be as good as it gets for the night"). I was readmitted to hospital and the next morning I was back in surgery to find out what was going on.

As it turned out when they performed the first surgery they missed sealing off one of the blood vessels and it was just slowly oozing which was causing the swelling and pain. Once they fixed this my ankle and leg felt totally different. I stayed in hospital for 7 days this time just to make sure all was good. Since this surgery I have had no problems with pain in my ankle.

I had nearly two months off of work after the surgery with a my leg in a cast, using crutches or a wheelchair to get around as I was not allowed to weight bear and I needed to keep my leg elevated. After the cast I spent 3 months in a cam or moon boot, and I have just progressed to an ASO brace which I will probably need to wear for the next 6 months.

The recovery period is long which can be a bit frustrating. Sometimes you want to do things but are unable to, but then you stop and think about it and it's not too bad; the time has been going relatively quickly.

Each week I can feel my ankle getting stronger but the best thing is that I am now not living with chronic pain, or relying on pain relief to get through the day which is a definite good thing for one's all round health.

It was definitely worth having the surgery!

## What is an ankle fusion?

When a person has severe haemophilic arthritis in their ankles, there can be some or all of the following changes inside the joint:

- The cartilage lining the inside of the ankle joint will be damaged
- There will be reduced space between two bones in the joint
- There can be new bone spurs (outgrowths on a bone called "osteophytes") at the end of the bones.

These changes in the joint will lead to severe pain and reduced movement in the joint.

In ankle fusion surgery, the joint surfaces of the bones in the ankle are removed and screws are inserted to hold the ankle bones together until they have fused, or grown together. The aim of ankle fusion is to relieve pain and help a person to walk and do their usual activities again, pain free.

The person's ankle joint will be fused and there will be no movement, but most people in this situation would already have lost a lot of motion in their ankle. With any surgery, there can be complications, such as infections or the wound not healing well, as well as the bones not being fused properly, so it is important to understand the surgery and what might happen before deciding to go ahead. Another side effect of this surgery is that pain and arthritis can develop in neighbouring joints like the foot and knee as they have to work a bit harder to compensate for the loss of movement in the ankle.

Your haematologist, orthopaedic surgeon and you have to make the decision to have this kind of surgery collaboratively. Any type of surgery is a last resort and has to be avoided as long as you can with prophylaxis, strengthening or with other conservative methods.

*Thanks to Venkat Acholi, Physiotherapist, Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital, who reviewed and edited this article.*

## Overseas Travel



By Sharon Caris, Executive Director, Haemophilia Foundation Australia

Check with your Haemophilia Centre health professionals about the planning you might need to do if you are going overseas. Do not assume that it will be possible for you to access product wherever you want to go.

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 services. Treatment may be limited, unavailable or unaffordable in many countries. Make sure you have appropriate travel insurance and a plan in the event that you have a bleed or have an accident.

It can take a while to get approval for larger amounts than your usual supply of clotting factor. If you are going overseas you will also need medical, customs and quarantine documents for your treatment product and equipment, both for leaving and returning to Australia and for the countries you are visiting. Even if you will be in transit through a country, remember there may be documentation requirements to carry your clotting factor, needles and other medicines through security/quarantine/customs at airports or borders.

Make sure you get advice about how to care for your product when travelling. If you are supplied with spare product to take away with you "just in case", remember that is part of your usual supply so make sure you bring any remaining product back home with you as you may not be eligible for more!

Make sure you contact your treatment centre staff well in advance so they can help you with your travel plans – especially for ordering supplies of clotting factor and the necessary documentation required during your travel. HFA can also provide more information about your planning for overseas travel.

## Train Word Find

**ACCOMMODATION • EXPLORING  
PACKING • SHOPPING • TENT  
AEROPLANE • FAMILY • PARKING  
SIGHTSEEING • TOGETHER  
BAGS • FISHING • PHOTOS  
SLEEPING • TRAIN • BEACH  
FUN • RELAXING • SUN • TRAVEL  
BUS • HOLIDAY • ROAD  
SUNGLASSES • TRIP • CAR  
LAUGHTER • SAND • SUNSCREEN  
TRUCK • DESTINATION • LUGGAGE  
SCENERY • SWIMMING • VISIT  
WATER • ZOO**

By Michael Lucken



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

**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](mailto:hfaust@haemophilia.org.au)**

**W: [www.haemophilia.org.au](http://www.haemophilia.org.au)**

**Editor:** Suzanne O'Callaghan

**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