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MESSAGE FROM THE CHAIR...



On behalf of the Youth Committee I would like to say hello to you all in our first newsletter for 2006.

2005 was a successful year for the Youth Committee with the organisation and development of the Youth Stream at the 13th National Haemophilia Conference held in Melbourne from Friday 30th September to Sunday 2nd October last year.

Feedback from everyone who participated in the Youth Stream was very positive, with suggestions for improvements for the next Conference that will be held in Canberra in 2007.

At the Conference I was elected Chair of the Youth Committee. I would like to take this opportunity to thank Anna Sznyter for the work she has done during her term as Chair of the Youth Committee, as well as Robert McCabe for his efforts as Secretary. Sam Duffield and Simon McMenamin are now jointly carrying out this duty. I would also like to thank the rest of the Youth Committee for their work over the last twelve months, and welcome the new members to the Youth Committee.

This year I am lucky enough to be attending the Haemophilia World Congress in Vancouver, Canada. I have been invited to speak in the session titled "Recruiting Young People Into National Member Organisations". The title of my presentation is "Youth Leadership and Mentoring Program: The Australian Experience". I was also fortunate to be offered a Global Training Youth Fellowship Award by World Federation of Hemophilia and will attend the Global National Member Organisation training before the Congress. I look forward to reporting about our international friends after the Congress and feel sure this opportunity will encourage new relationships and joint initiatives.

Paul Bonner, HFA Youth Committee Chair

WELCOME TO OUR NEW COMMITTEE MEMBERS...



Scott Christie

Hello, my name is Scott and I am 21. I have lived the majority of my life in rural South Australia. I enjoy water skiing, working with livestock and catching up with mates all over the State! I also play Aussie rules, basketball & volleyball.

Michael Lucken

My name is Michael Lucken and I live in Victoria. I have severe haemophilia and love to get out and about, living life to the full and having fun. At the same time I love talking and listening to other people and helping out as much as I can with anything. Some of my interests are collecting key-rings, watching some sports, visiting friends and driving my car. I joined the Youth Committee because I wanted to be part of the team that has helped me, so that in turn I can help others to receive the support they need.



13th National Haemophilia Conference
“THE FIRST TIME” SESSION REPORT, FRIDAY 30 SEPTEMBER 2005
Chair: John Vernon

The Youth Committee worked with the Conference Program Committee which was chaired by Dr Chris Barnes, so that the youth stream was relevant and interesting for youth. “The First Time” presentations follows.



Leaving Home/Independence ~ Robert McCabe

In February 2003 I moved out of home in Beldon to South Perth. I moved for a variety of reasons, pre-dominantly to be closer to university.

I lived in South Perth with my friend from school and his family for 4 months, and then moved with him to Mount Pleasant.

- This truly put me in charge of my life for the first time. I was of mixed emotions, but mostly excited.
- I discovered the joys of paying bills, searching for different sources of income, while trying to include many hours of study at university.
- I also discovered how time consuming cooking, cleaning and food shopping is.
- I also found that I had to do all my self treating for bleeds (as my mum often did it for me), sought out specialist appointments, and generally looking after myself.
- I had to organise my supplies of treatment product.

Basically I had to manage certain things in my life that for 18 years I had taken for granted.

Shortly after I moved out of home, my mum moved interstate to South Australia. All my immediate and distant family was now in South Australia. This distance added a new challenge. I now couldn't move back home even if I wanted to!

It isn't all bad, I live with two really close mates, and have a good laugh most of the time. Support from my family, if and when I need it, is a three hour flight away, which is quite re-assuring.

- I had to “grow up” and take charge in a reasonably short space of time. All of a sudden I felt I almost didn't have time for anything!
- Making the transition from the Children's Hospital to Royal Perth was a bit like moving out of home as well.
- I had to organise my own treatment and appointments, instead of the hospital contacting me. I was in charge of my health, rather than being “advised” what to do.
- I was responsible for turning up to clinics and appointments. It was important to respect the staff and attend when they gave me appointments.
- I had to make choices about my treatment program and weigh up advice on my own, without my mum's counsel.
- I have also had to start thinking about hepatitis C treatment. This will be a decision I am ultimately responsible for.

Haemophilia is only one PART of my life, it ISN'T MY LIFE completely. While it is an influencing factor in many of the choices I make, it isn't the only one.



Choosing a Career Path ~ Paul Bonner

I am 29 years old and have severe haemophilia B which was diagnosed when I was five. I also have hepatitis C from contaminated clotting factor.

When I was 15 my family and I moved to the country, about 120 kms out of Adelaide where my parents bought a hotel. This is when I first started administering my own clotting factor.

In high school I decided I wanted to be a tradesperson, but I wasn't quite sure exactly what, as I enjoyed both wood and metal work in technical studies.

When I left school I applied for an apprenticeship as a Shipwright. While I was waiting to see if I was successful I worked in a roadhouse as a console operator. There I was responsible for opening and closing the Roadhouse, handling money and serving customers, cleaning, stocking shelves and fridges, fuel readings, and organising the storeroom.

One Sunday morning before my shift started I developed a bleed in my left ankle. I still went to work and did my shift, but by the end of it I could hardly walk. Consequently I did not do all of the things that I was meant to do. A day or so later the boss had words with me over it. I explained to him what had happened, and that I didn't want to put him out by having to find someone to work the Sunday shift at short notice. After this he understood and apologised to me. Because of this I think he gained a lot more respect for me.

After about three months working at the Roadhouse I was very lucky to get the apprenticeship as a Shipwright. My doctor was concerned because the job involved lifting and carrying heavy objects, but he supported me to make my own decision.

When I started the apprenticeship I was worried about informing my employer that I had haemophilia, but when I did he was really good about it. He asked for information on haemophilia and after he had read the material I gave him, we talked about it and I was able to answer his questions. He wanted to know if I needed any special items to manage my haemophilia, but the only thing I could think of was a small car fridge to take my factor with me when we went away on jobs. After this we then had a meeting with all of the staff and I briefly explained to them that I had haemophilia and what it was, and how it affected me. The first aid officers had some questions about what to do in different situations, and I answered those. It was best to talk about it - everyone understood.

I work with river ferries. When I started at the dockyard my duties included metal work and welding, machining and fitting timber planks to ferry hulls or decks, ferry fit outs, online maintenance, and breakdown maintenance. I am now the leading hand of the yard and occasionally act in the position of Yard Supervisor. This involves organising and coordinating different work groups, and the parts they require, and administrative duties, I also continue to do some of the hands on jobs. I also captain the tow vessel used to carry out ferry changeovers.

I keep clotting factor at work and can treat bleeds immediately which means I lose little time at work and have minimal recovery time to get over bleeds. I have treated myself in all sorts of odd places, such as the back seat of a ute, in the office, and at the table of the tow vessel while we were cruising along the river.

I am very lucky to have a good supervisor at work who understands my haemophilia and allows some flexibility in arranging my workload. I appreciate this a great deal as some days can be tough because I have arthritis in my left ankle from numerous bleeds. My workmates are understanding as well, which makes things easier. I think this is because I have been "up front" with them about my haemophilia.

The best way to deal with haemophilia in my workplace has been to be honest with my employer, and make sure he and other staff know what is happening, so they don't get upset with me if I am not capable of carrying out my normal duties. The best sort of work environment is one where all workers are cared about, not just me because I have haemophilia.

The best thing a person with a bleeding disorder can do is learn to administer their own treatment and understand and manage their condition. This makes life less restrictive and you can take charge of your life - not worrying about where the nearest hospital is. I have treated myself in some very remote areas.

I also have some hobbies that may not be recommended for people with haemophilia, but with caution I participate without any trouble. I always take clotting factor with me just in case I have a bleed, so I can treat it.

It is great to feel independent because I can treat myself. I only need to attend Royal Adelaide Hospital about three to five times each year, but the staff offer me great support and are only ever a phone call away if I need any help.

WHAT IS HAPPENING IN YOUR STATE/TERRITORY?

South Australia

In November a small, enthusiastic group enjoyed a challenging family camp at Woodhouse Scout Camp.

The main highlight of the camp was the “Challenge Hill” obstacle course where the group worked as a team to help each other under, over, through, along, and sometimes around obstacles.

A “mummy wrap” was enjoyed by the children, with the adults laughing as much as them.

With torches at the ready, intrepid explorers set off on a night walk, made more treacherous due to recent rains washing the path.

Parents got together to discuss, learn, support and share things that we all deal with in the haemophilia community, and the kids had a great time. Paul Bonner and Scott Christie, HFSA representatives on the Youth Committee, helped with the camp organisation and activities.



New South Wales

In the last weekend of November, the annual NSW camp at the Sydney Academy of Sport was held. 145 adults and children enjoyed the weekend of fun and networking. Everyone participated in activities such as swimming, surfing, canoeing, ropes course, archery, and self infusion and physiotherapy workshops.

The weekend gave parents an opportunity to network and share experiences with others and brought families together in a fun environment.

Santa made a surprise visit and gave all the children a very special Christmas gift.



WHAT IS HAPPENING IN 2006?

The Committee had its first meeting for the year in February and is planning an exciting 2006. Keep a look out in the next newsletter for an exciting activity planned for later in the year. Don't forget, the next National Conference will be in Canberra in 2007. But more importantly make contact with your youth representative from your local haemophilia foundation and see how you can be involved. Contact HFA for contact details.

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HFA Youth Committee

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Secretary ~ Simon McMenamin (ACT) and
Sam Duffield (NSW)

Members ~ Anna Szynter (TAS), Chantel Roberts (VIC),
Craig Bardsley (QLD), Jodie Stephenson (QLD), Robert
McCabe (WA), Scott Christie (SA)

Executive Board Representative ~ Gavin Finkelstein (WA)

HFA Representative ~ Natashia Coco (VIC)