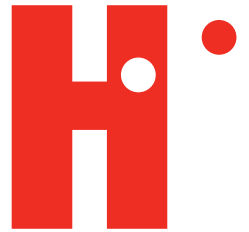


No.20 Dec 2008

YOUTH



HAEMOPHILIA FOUNDATION AUSTRALIA

Contents:

MESSAGE FROM THE CO-CHAIR

DUKE OF EDINBURGH AWARDS

HIGHLIGHTED SPORT -
STRENGTH TRAINING

YOUTH TRAINING WEEKEND

2009 YOUTH COMMITTEE

SEASONS GREETINGS WORD FIND

ERIN JAMES - 2009 ELECTED CO-CHAIR



Hello, I'm Erin, for those of you who do not know me; I'm an 18 year old guy, with haemophilia A. I come from the small town of Bowral, in New South Wales. This, as a point of reference is where Sir Donald Bradman came from as well. As I am so bad at cricket, we shall move on.

I have been involved with the Youth Committee for the last three and half years, and next year I will be very honoured to be one of the Co-Chairs. So I am taking this opportunity to introduce myself, and also try and get across that the Youth Committee is here to work with the youth of the bleeding disorders community. So if you have anything you want to voice, contact us at hfaust@haemophilia.org.au or 1800 807 173. We are doing some very interesting things next year so keep an eye out in this newsletter for updates.

Thank you to Paul Bonner who has been in the position of Co-Chair for the past 2 years for his hard work and dedication. Robert McCabe has continued his Co-Chair position for 2009.

YOUTH TRAINING WEEKEND



Back (l-r)

Craig Bardsley (QLD), Anna Szynter (TAS), Luke Peters (TAS), Erin James (NSW), Kyle Peters (TAS), Sam Black (TAS), Helen Singer (WA), Robert McCabe (WA), Matthew Blogg (VIC), Kim Round (VIC), Scott Coulter (SA), Dale Spencer (WA), Max Janiszewski (VIC)

Front (l-r)

Hamish Robinson (NSW), Paul Bonner (SA), Andrew Selvaggi (VIC), Lauren Albert (QLD), Ashlee Amos (WA), Chris Poulton (VIC)

19 youth from around Australia attended the Youth Training weekend in South Australia from 19-21 September. The weekend was a great success and gave the young men and women participants a chance to learn more about living positively with bleeding disorders as well as develop new relationships and benefit from the peer support. A summary of the reports from each of the participants follows:

Erin (NSW)

From a Youth Committee perspective, I thought the weekend was great. We got some new members, all with different backgrounds and perspectives, that really stimulated the conversation. I am very glad to have the opportunity to be a Co-Chair this year and am really looking forward to what we can all come up with. Overall I think that the camp exceeded expectations.

Hamish (NSW)

On the evening of Thursday 18th September 2008, I flew (for the first time unaccompanied) to Sydney then stayed the night at a family friend house and flew onto Adelaide on Friday morning. The bus trip to Sunset Cove was uneventful, with not much conversation, a stop for McDonalds. The very first session was a 'Get to know you' sorta thing, where a beach ball covered in questions and unfinished sentences was passed around the room and we all had to answer or finish the sentence, until it said someone had to 'Dance like a ballerina for 5 seconds'. That was Craig! We then went sea kayaking; I never saw any white pointers, pity. This was an awesome weekend.

Lauren (QLD)

The Youth Training Weekend in Adelaide was the first one I had attended, and I really had no idea what to expect, except maybe the cold weather. However, I left with an even wider understanding of the many different aspects of haemophilia, as well as many fantastic memories. During the weekend, we went sea-kayaking, dressed up as prison guards and even did a very entertaining air guitar performance! We took part in discussions about everything and anything. I listened in awe to the stories of guys only a few years older than my brother, who have been through more than any person should ever have to. It's made me realise just how lucky we are to have access to the treatments and hospital facilities that we do, because it wasn't always so. The weekend was a great format for the sharing of experiences, the building of skills, and the beginning of some fantastic friendships. I can't wait for the next one!

Craig (QLD)

I learnt heaps of stuff about the way other people with haemophilia manage their condition and it was interesting to note that so many people do it in many different ways. It was really good to meet so many new people. Sharing experiences and just generally getting to know these guys and girls was really good. I have made friendships that will continue on now that we have gone back to our states and territories. I think it was a great idea to combine it with the SA Family camp. It gave parents of kids with haemophilia an idea of what to look forward to as well as showing the kids "that it's all good".

Paul (SA)

I feel that the weekend was a success; there were lots of positive comments from everyone that attended. I found the weekend to be very enjoyable, it was great to catch up with old friends and make new ones. It is good to see that most people that attended the weekend have shown interest in continuing on the youth committee or becoming members on the youth committee.

The speakers that presented the sessions were very good, they knew what they were talking about and tailored their sessions to the group, and were able to adjust to suit peoples' needs on the run. One of the speakers felt like they learned more from the weekend than what they had passed on to others.

Scott (SA)

On this weekend we got to do a lot of different and fun activities like kayaking which I really enjoyed because we all got to be active and get to know each other better. Getting to know all the other people with haemophilia was really great and they knew so much more about it than I do and they seemed really interested in it, but I have never really cared about it. I sort of tried to pretend I didn't have anything and tried to avoid telling people I had it but thanks to the weekend and the people on it I'm not ashamed of it any more.

Anna (TAS)

The stand out sessions for me were the maze, sea kayaking and the warm fuzzy books. The information sessions were valuable as well. We listened to guest speakers talk on a number of issues, ranging from moving out of home, getting a job, through to keeping yourself fit. All aspects of life applicable to any youth - not exclusive to people living with a bleeding disorder! One of the best things about the weekend was watching some of young boys living with a bleeding disorder who were part of the SA Family Weekend, being run alongside the Youth Training Weekend. It was great to see them running around acting like 'normal' kids – well, they are normal aren't they!?!

Luke (TAS)

Arriving and not knowing absolutely anybody except for my brother but within an hour all of us were interacting with each other, meeting new people every different place we went to. The whole weekend experience for me was a great chance to actually understand what the disease haemophilia is, how severe it can be and what the treatments are for different factor levels.

Kyle (TAS)

Having only mild haemophilia made me wonder how much more severe others were and if this was going to make things awkward at all? After getting to know the youth throughout the activities and meal times, I knew that I was involved with happy, caring, funny, good spirited, sometimes wacky bunch of people who like to have a good time and who don't let many obstacles stop them in achieving this!

Sam (TAS)

The weekend away in Adelaide was brilliant, I couldn't fault it. When I was first asked if I'd like to go along I wasn't sure due to the fact that my haemophilia condition is something not many people know about.

The weekend was a long way from what I expected, the information I got out of it was great because before the weekend I didn't really have a good understanding of haemophilia.

Matthew (VIC)

On Friday night we took part in fun activities including "navigating the maze" which was very interesting and great fun, followed by an open discussion on a range of topics including: relationships, challenges, disclosure, and lots more. I personally found this session to be very moving and helpful.

We finished off the night with the "warm fuzzy story" activity where everyone at the camp gets a book and people write warm fuzzy things about them in their book and people take their book with them home which has lots of memories. This is a good activity for confidence and self-belief.

Kim (VIC)

I really enjoyed the weekend experience, and found it both fun and inspirational. I look forward to the next opportunity to catch up with the gang.

To help us get to know each other we participated in different activities, which we needed to work as a together team and trust each other, this was a good start to the weekend. Our next adventure was sea kayaking, one of the highlights of the weekend. Tackling the windy conditions was a challenge for all, gliding along the wavy water, playing games and racing each other while trying to avoid getting splashed by our kayaking partner.

Chris (VIC)

The weekend was a great getaway and a good time to get to know other people with all types of haemophilia and was good to see other family members were getting involved to learn more about haemophilia.

It was my first time away with the HFA and realised that there is more ways people (with haemophilia) look after themselves. It was interesting to see and hear other stories that others had.

Andrew (VIC)

Having being thrown into all of this and going through some of these intense and amazing experiences with all of the people who attended was truly one of the most enjoyable and enthralling times of my life. From learning from the others who were there, to passing on my own knowledge, it was 100% spot on. The weekend went seamlessly. I found talking to the children and the parents who also attended as a part of HFSA was a great time and felt like they also learnt a lot from the weekend even though they weren't there for as long a time.

The friendships that were formed over the weekend will last for a long time and those that were forged stronger will continue to grow. I feel coming away from the weekend I have a new group of friends that I can talk to about virtually anything and will definitely be talking to in time to come.

Dale (WA)

The bus ride to our accommodation was a quiet and awkward one as there were a lot of shy new faces but that would soon change. The first major activity for the youth was sea kayaking and I wasn't too keen on falling into the cold water so Erin and I became professionals pretty quick. This activity definitely broke the ice!

Overall the 2008 SA weekend was a great success as we set a great example for the kids, the parents could chat about issues with us and team building activities got everyone so much closer.

Ashlee (WA)

I also think the sessions were really good and helpful. I definitely took some valuable information away with me from every session. By the end of the weekend I remember saying that I didn't wanna go home and the bus trip to the airport was so different from the one to the resort. Everyone was talking and getting along like they'd know each other for years. Overall I had a great experience and it's something I'll remember for a long time!

Helen (WA)

I went with an open mind, not really knowing what to expect but hopeful to make an impact on the haemophilia community as a partner of someone with a bleeding disorder.

The camp provided plenty of opportunities to meet other young people that are involved in the haemophilia community. This was definitely a highlight of the camp as it gave me the ability to meet others, not just from my home state of Western Australia, but from all over Australia.

Robert (WA)

The impression that I got from the camp was that HFA and HFSA has a lot to get excited about. There was a fantastic turn out for the weekend, with a lot of enthusiasm.

What I found positive from the weekend was meeting some new faces. It was a breath of fresh air to find some new people interested in getting involved with the bleeding disorders community.

I have hopes following the weekend that the enthusiasm from the weekend can resonate and cast the net wider for young people to get involved.

It is hoped that in the years to come the training weekend can bring new people together whilst at the same time allowing an opportunity for others to meet and discuss issues affecting their local Foundation.



DUKE OF EDINBURGH AWARDS

Do you love a challenge?

Haemophilia Foundation Australia has been offered access to 10 scholarships for young people to complete a Duke of Edinburgh (DoE) Award. This opportunity is available to people with bleeding disorders and/or their siblings aged between 14-25.

The program will be facilitated by Purple Soup and is a great chance to learn new skills and complete a highly regarded personal development program which can be tailored to suit everyone.

The program involves community service, recreation and adventure and special projects. DoE encourages self esteem, positive self talk, personal development, and community participation.

For further information contact Sam Carroll on 0438 282 509 or Natasha Coco at HFA on 1800 807 173.

2009 YOUTH COMMITTEE

Thank you to 2008 committee members for their tireless work and efforts. We welcome our new members.

Co-Chairs ~ Robert McCabe (WA) & Erin James (NSW)

Youth Council ~ Paul Bonner (SA), Anna Sznyter (TAS), Craig Bardsley (QLD), Matthew Blogg (VIC)

Youth Leaders ~ Sam Duffield (NSW), Dale Spencer (WA), Michael Lucken (VIC), Lauren Albert (QLD), Chris Poulton (VIC), Hamish Robinson (NSW), Scott Coulter (SA)

ARE YOU GOING ON HOLIDAYS?

HAVE YOU ARRANGED A SUPPLY OF CLOTHING FACTOR TO TAKE WITH YOU?

Don't forget if you're flying interstate or overseas, you need to take documentation with you about your treatment needs and the product and equipment you are carrying. Talk to your Haemophilia Centre health professional or HFA on 1800 807 173 if you need any information about this.

HIGHLIGHTED SPORT - STRENGTH TRAINING

The information below is an extract from "Boys will be Boys" by Brendan Egan, Senior Physiotherapist at the Henry Ekert Haemophilia Treatment Centre at the Royal Children's Hospital, Melbourne (2005).

Participation

There are many benefits for all people participating in strength training, particularly those with bleeding disorders. These benefits include stronger muscles helping to decrease the stresses acting on joints, which may then decrease the number of bleeds. Other benefits include strength gains, injury protection, improved self-concept, improved motor performance, increased bone density and preparation for other sports.

In the past resistance training for this population has been controversial and thus discouraged. However recent literature has revealed that it can be safe and extremely beneficial if appropriate guidelines are followed.

Common Injuries

- Muscles strains due to excessive weights being used.
- Overuse injuries of muscle/ligament due to incorrect technique

Injury prevention

Warm Up

- A general warm-up program including stretches and aerobic exercise (bike, treadmill or rowing machine) should always be at the beginning of a strength training session because of the strenuous nature of the exercise
- The muscle groups targeted within each session will help to guide which stretches to emphasise.

Protective equipment

No protective equipment is needed for stretch training.

BELLS CANDLES CARDS CELEBRATE
FESTIVAL GREETINGS HOLIDAY MERRY
SEASON SPIRIT TOYS

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

*On behalf of the Youth Committee, we wish you
and your family a safe and happy new year.*



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