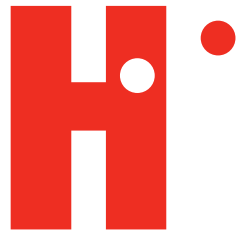


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Youth News



HAEMOPHILIA FOUNDATION AUSTRALIA

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message from the co-chairs
Dale Spencer



Hi my name is Dale Spencer from Western Australia and I am Co-Chair of the Youth Committee for 2010. I am 21 years old and have severe haemophilia A. I am interested in the music scene and being a provider for my beautiful fiancée Ashlee and my 1 year old daughter, Ebony-Rose. I think of myself as someone who can be a mentor for others, as I have a positive outlook towards my condition and have never let it hold me back from doing the things I wanted to try and do.

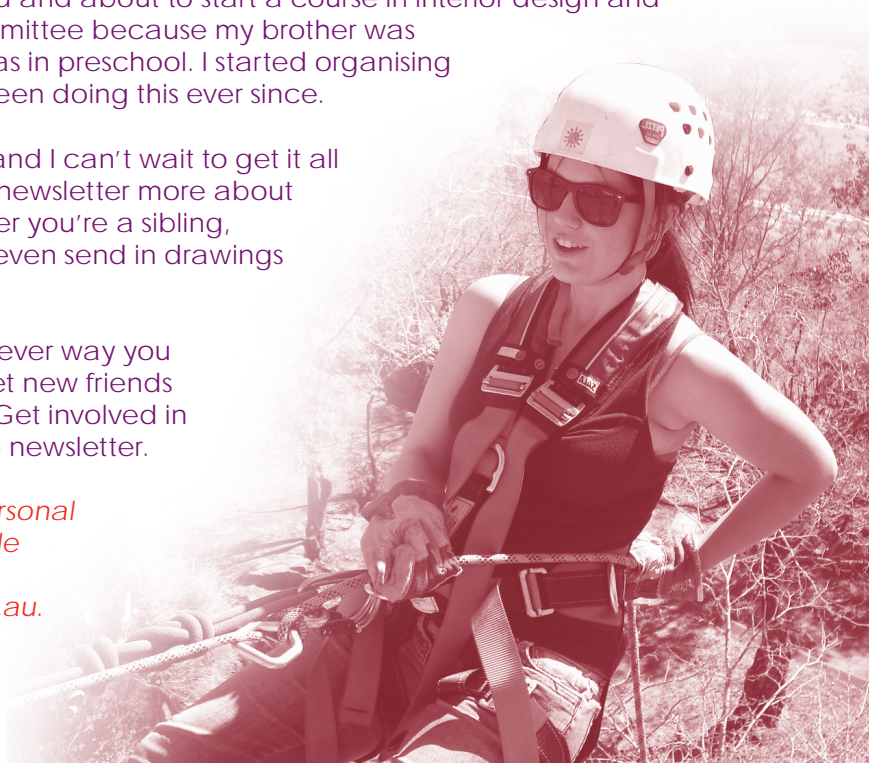
Lauren Albert

Hi everybody! My name is Lauren and, along with Dale, I am your Co-Chair for 2010. So I'll start by telling you a bit about myself. I am eighteen years old and about to start a course in interior design and decoration. I got involved with the Youth Committee because my brother was diagnosed with severe haemophilia when I was in preschool. I started organising fundraisers at my school in grade 3 and I've been doing this ever since.

We've got some really exciting plans for 2010 and I can't wait to get it all started. This year we've decided to make the newsletter more about you guys. We want to hear your stories, whether you're a sibling, friend or have haemophilia yourself. You can even send in drawings or anything you'd like to share.

I encourage everyone to get involved in whatever way you can. It's great fun and the perfect way to meet new friends who you can share experiences and advice. Get involved in your local youth activities. Hope you enjoy the newsletter.

We would like to hear from you about your personal experiences. If you would like to write an article for Youth News contact Natasha at HFA on 1800 807 173 or email ncoco@haemophilia.org.au.



Highlighted sport - Soccer

The information below is an extract from "Boys will be Boys" by Brendan Egan, Royal Children's Hospital, Melbourne (2005). The publication helps people with haemophilia to be better informed about their sporting choices and understand the risks of different sports for them.

As always, it is best to get information from your haemophilia centre staff about how to prepare for sports and what to do if you get an injury.

Participation:

Soccer is the most popular sport in the world, with estimates that there are over 120 million players. There has been a huge surge in the popularity of soccer in Australia over the last 20 years. It is a game that can be played by all ages and at all different skill levels. There is some contact in soccer, particularly in the lower legs during tackles. There are many clubs catering for soccer enthusiasts. Goal kick is a program run for five to ten year olds, offering a fun and safe environment to learn the skills of the game.

www.australiansoccer.com.au



Common Injuries:

- Most injuries are to the lower limbs, including muscle sprains, ligament strains and contusions (bruises).
- Lacerations and abrasions are also common.
- A small number of injuries are fractures.
- Lower back and pelvic pain are also seen.

Injury Prevention:

Warm up

- Jogging, side to side, backwards running and run throughs are appropriate general warm up activities. Shots at goal, passing and dribbling skills should also be included.
- Stretches.

Protective equipment

Mandatory

- Shin guards.

Strongly recommended

- Mouth guard Type III.
- Appropriate footwear.

Optional

- Thigh guards/padded shorts.
- Protective headgear.
- Chest and shoulder guard.
- Ankle/knee brace.

Additional protective considerations

- Goal posts securely anchored and padding around the goal post well maintained.
- Research has found that, during game situations forwards were the most frequently injured, followed by midfielders and then by defenders. Therefore, it would be worth considering the placement of a person with a bleeding disorder in the statistically safest position.
- Playing on soft grounds surfaced with a good coverage of grass may reduce the incidence of abrasions and lacerations.
- The action of heading the ball in soccer presents the possible event of head injuries. Repeated minor head trauma can lead to a cumulative chronic injury. This may, however, be less of a problem now as balls are lighter and less prone to getting waterlogged and heavy. The use of protective headgear in soccer would need to be given clearance by those in charge of the game. In general, the person with a bleeding disorder should show caution when heading the ball, as even minor head trauma must be taken seriously. Correct heading technique should be taught from a young age.



The 2010 FIFA World Cup will be the 19th FIFA World Cup, the premier international football tournament. It is scheduled to take place between 11 June and 11 July 2010 in South Africa.



The Socceroos have won a place in this year's world cup and will play their first game on 14 June against Germany. For more information and fixtures visit www.fifa.com/worldcup

Other related links

www.footballaustralia.com.au

www.australia2018-2022.com.au

Personal story ~ Lauren Albert

My name is Lauren and I don't have haemophilia, my younger brother does. There are so many people out there who forget about the brothers and sisters of people with haemophilia so I'd like to share my story with you.

My brother was diagnosed when I was in preschool. I'll never forget the day Sam was diagnosed, or the months and months he spent in hospital after it. The good thing about our family is that we never let Sam's diagnosis define him, or us. We spent a lot of time apart in those first years, but Mum and Dad made sure they never missed any important events in my life. They were there for my first day of school, my first boyfriend, my graduations from primary and high school.

Some people would think that I might grow up resenting my brother's illness and the times it took my parents attention from me. At times I did resent it. I'd be lying if I said I didn't, but as I grew up I realised that my parents were doing the best job they possibly could to include me in everything. They were always up front with me about what was happening with Sam, about changes to his treatment, when the hospital stays were longer than expected or when he had big scary bleeds. I didn't always understand why my baby brother had to be in hospital but I was glad my parents trusted me enough to keep me in the loop.

We've always taken the approach that you can't wrap someone in cotton wool. Watching Sam playing his many games of soccer, a sport he loves more than anything, I would flinch every time he ran into a tackle but now I'm on the sidelines encouraging him to get in there, and head the ball!

There's no way I could ever resent the time my parents spent with Sam instead of me, when I look at him and see, not the sick little boy he used to be, but the amazing person he is growing into. My brother's experience makes me realise every day is special because of what he has been through. He is so full of life and love, and I feel honoured to be related to such an incredible person.

My brother's haemophilia has never defined him or us, and although it took us apart from each other in the beginning, now it has brought us closer than ever. I love my baby brother and feel so lucky to get the chance to watch him grow up and do the things he loves, without his haemophilia overshadowing everything.

For more information and resources for siblings visit www.siblingsaustralia.org.au



WORLD HAEMOPHILIA DAY 2010

World Haemophilia Day is celebrated on 17 April, the birthday of World Federation of Hemophilia (WFH) founder, Frank Schnabel, who died of AIDS in 1987 as a result of contaminated blood products.

This year's theme is "The Many Faces of Bleeding Disorders: United through the WFH to achieve Treatment for All". An estimated 400,000 people worldwide are living with haemophilia. 75% of people with bleeding disorders throughout the world are undiagnosed and untreated

On April 17, the WFH will launch "The Many Faces of Bleeding Disorders" video podcast. For more information, resources and the podcast launch visit WFH website www.wfh.org



- Sunday 16 May 2010
- 5km & 10km Route
- Meet and Finish at New Farm Park, Brisbane
- Registrations from 6am (Pre-registration is encouraged as last year the event was sold out before the day and we had to turn people away)
- All entrants will receive a free commemorative RRC cap OR RRC drink bottle (while stocks last)
- Race Starts 7.30am

The Red Run Classic (RRC) will be staged again in May for the fourth consecutive year. This successful event has proven to be a must on the Brisbane Running Calendar.

RRC is a fundraising run/walk for Haemophilia Foundation Australia and Haemophilia Foundation Queensland. Funds raised will provide programs and services for the bleeding disorders community in Queensland and across the nation.

Register with a group of friends, your mum and dad, or get your school on board and register a school team. A first prize will be awarded to the first place getter of each school!! We have special school packs with lots of information. If your school is interested call Natasha for a school pack.

For more information or to register online visit www.haemophilia.org.au or call 1800 807 173.



LIVEWIRE (livewire.org.au)

You have probably heard about Livewire, but might not have had a chance to look at it. If you are going to a Haemophilia Foundation camp or picnic, Livewire will probably be there – check it out, register and see if you can win some of their prizes (lots available and a good chance of winning!).

The Livewire team have come to several events recently to show how Livewire works and how you can join:

- Haemophilia Conference
- HFNSW Family Camp at Narrabeen Sport & Recreation Centre
- HFWA Camp at Point Walter
- HFV Christmas picnic at Werribee Zoo
- HFV Camp at Portsea

What's Livewire about?

Livewire is an initiative of the Starlight Foundation and has joined in a partnership with HFA. It aims to give young people with chronic health conditions and their families a safe place to chat online, have some fun and feel supported. And because kids with chronic health conditions think it's uncool and not much fun to talk about their health, Livewire is all about fun and entertainment, games, music, computer games and people's interests generally.

There are three different communities:

- Members - available to young people with bleeding disorders, 10-21 years. There are separate rooms for kids of different ages
- Siblings - for brothers and sisters 10-21 years
- Parents.

What can you do on Livewire?

- Find someone who shares your interests – there are more than 4500 members, so there should be someone out there, and it's a very friendly group! Or touch base with other members of your age with bleeding disorders, or siblings – just make sure you select "bleeding disorders" when you are creating your profile to connect with the bleeding disorders group
- Enter competitions with prizes such as a mobile phone, iPod touch or Notebook, play games, have chat sessions with celebrities, read and talk about news on all sorts of things, including the latest computer games, football, bands and animals – what's on depends on what the group is interested in
- What else? Try it out and let us know.

How do you join?

- Collect a registration pack from the Livewire team, or
- Ask HFA or your Haemophilia Foundation for a registration pack, or
- Join online – check the Livewire page on the HFA web site www.haemophilia.org.au under Kids and Youth – Fun Stuff, or
- Contact the Livewire Support Team on (02) 8425 5971

Prize draws for new registrations

If you join before 30 May 2010, Livewire members have a chance to win a mobile phone, siblings a Nintendo Wii, and parents a \$250 Caltex gift voucher.

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