

No.29 March 2011

# Youth News



HAEMOPHILIA FOUNDATION AUSTRALIA

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## message from the co-chairs

Dale Spencer



Hello everyone, welcome back from your holidays as we begin our work, school or uni time of the year. I think I speak for most when I say 2010 was a hectic year full of ups and downs. Already 2011 has started really well for me. I have a new partner who is very keen to get involved in our state Foundation and to learn about haemophilia, I am in the process of buying my first home and am hopefully starting a new job with much better future prospects. I can feel it in my bones that 2011 is going to be a good year, with a lot of attention being put towards the 2011 Haemophilia Conference in Sydney. This is going to be the highlight of the year and I urge everyone to look into it either on the HFA web site or to contact your local Haemophilia Foundation. Some state or territory Haemophilia Foundations might also be offering grants to attend the conference, so check with them if you are interested in applying for funding. Have a great start to the year!

Lauren Albert



Hey everyone and welcome back to Youth News. We've all had a great break and are refreshed and ready to tackle the new year with a whole new approach. So get ready for some exciting changes! We got some great feedback from you guys from the recent survey sent out by HFA so we are now more aware of the issues that interest you, and what you want to read in this newsletter. We're going to have more of a focus on growing older, and how haemophilia plays a part in the whole growing up process. We've got some great articles this month with the focus on some really different areas we haven't talked about before. We on the Youth Committee are really excited to get into this new year with all of you, especially with a Conference coming up. We'd love to see all of you at the Conference so make sure you get in touch with your state foundations if you need some help getting there. I know I am really looking forward to 2011 and all the exciting things it holds for us at the Youth Committee. But I won't hold you up any longer – get in and have a look at all the exciting stuff we've got in this issue!

## HFA National Survey 2010

Thanks to everyone who completed the HFA National Survey. There were 228 people who sent HFA their answers and 13 of these were young people under 25 years of age. Important things that the under-25 group told us:

- They have found a lot of information about bleeding disorders in Youth News and thought it was useful
- They would like to see more stories about growing up, playing sports and music, exercise, travel, siblings
- They would prefer to get information about bleeding disorders on the HFA web site, in Youth News and in National Haemophilia

## Advance Your Passion!

The 2011 Advance Your Passion Awards are now open. Make your passion a reality with grants from \$2500 to \$5000! Visit [www.advanceyourpassion.com.au](http://www.advanceyourpassion.com.au) for more information and to apply.

Applications must be submitted by midnight 30 April 2011.

## Sam on Soccer

Sam Albert is interviewed by his sister Lauren

Sam Albert is a fifteen year old boy like any other who loves his sports, Xbox games and friends. He also has severe haemophilia A. But he's never let that stop him doing anything he's wanted to do. Sam has been playing soccer for nine years now and shows no signs of stopping any time soon. He's also tried cricket, volleyball, karate and basketball.

Sam is sometimes disappointed that he can't play sports such as rugby and boxing but he doesn't let it get him down because he still gets to play his favourite sport of soccer. He has made many great friends over the years through his sporting teams. Injuries are part and parcel of playing sports, especially contact sports like soccer but Sam commented, "I've had some problems with my ankles, but you should never let it stop you from doing what you love. It's important to keep your treatments up-to-date so that you can continue to stay active and avoid injuries as much as possible in the future."

So does Sam have any words of advice for other guys out there with haemophilia?

"Sometimes life will get you down when you can't play certain sports because of your haemophilia, but it's a lot better than not that long ago when kids weren't allowed to play a lot of the sports they are today. It is important to try and keep active and make sure that your joints get plenty of exercise because this will help as you get older."

Do you have a story to tell? Youth News would love to hear from you. Send your stories to Youth News at [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au).

### A reminder from your physio!

From Wendy Poulsen, Physiotherapist at the Queensland Haemophilia Centre, Royal Children's Hospital, Brisbane

Make sure you get a full musculo-skeletal assessment from your physiotherapist at the Haemophilia Centre before you start participating in sport at a competition level.

This involves looking at your muscles and joints, both what their range of movement is and their strength. If there are any particular problems, such as weakness in muscles or target joint problems, the physiotherapist can give you exercise programs and advice on how to improve any problem areas, eg orthotics, taping or bracing.

## Alex Dowsett champion cyclist

This article is a shorter version of the Alex Dowsett feature article, published on the Blood, Sweat and Tyres web site ([www.bloodsweatandtyres.com](http://www.bloodsweatandtyres.com)) and is reprinted with permission. Blood, Sweat and Tyres is an off-road mountain-biking group dedicated to raising money and awareness for the UK Haemophilia Society.

Alex Dowsett is a member of the Great Britain Olympic Academy Programme and has severe haemophilia A.

Competing on the Velodrome, but specialising in road-racing, his aim is to earn a full professional contract next year and compete at the 2012 Olympic Games in London!

*How do you remember haemophilia most affecting you as a child?*

Two things stuck out in my mind:

The first was often going into primary school with either a sling or on crutches whilst having a bleed and having to explain why I was in a situation where it looked like I had broken a bone, but with no plaster cast to show for it - I was always conscious that the others thought I was faking it.



The second thing I remember most was the injections!! I wasn't slim as a child and finding veins was always a bit of a mission, even for doctors! I used to not be on prophylaxis so I only had treatments when I had a bleed and would often try to pretend it was never there. Often when my parents suspected I had a bleed they would make me walk or try to bend the joint properly to see if I was in pain whilst I was trying to conceal it.

*What was it like at school when it came to sports?*

I've always been into the individual sports where I could prove to myself and others to be fitter, stronger or faster and this became more of an incentive and would help later on after my school days.

Fortunately these were all sports that everyone was happy I took part in (eg, swimming; running at school; then cycling later on).

*What was the reaction of your doctors to someone with severe haemophilia wanting to become a professional cyclist?*

Well the exact reaction was this:

'We would rather you played chess or a musical instrument, but there is nothing we can do to stop you.'

And I knew it too!



I'd found a sport at which I was very competitive and I'm determined to reach the top and not let my haemophilia stand in my way!

My doctors have been extremely supportive throughout my career so far, helping me with sports related injuries as well as fitting in check ups and the one operation I've had to have on a damaged joint into and around my racing and training schedule. Nurses have informed my coaches and managers about my condition and what to do in the event of an accident. Healthcare has also provided me with extra large lots of Factor VIII for my long stints abroad and extra plasters for wounds that I sustain in falls.

I really couldn't ask for more in terms of support from the National Health Service.

*Do you have a different training regime to your team-mates because of your haemophilia?*

No, I am treated like any other rider on the squad.

All my team mates know about my condition and know that things may be different if I take a nasty fall, but otherwise I am treated no differently. They often enquire about it especially after a fall and what would be different with me, which other than getting Factor VIII into me quick, isn't a lot.

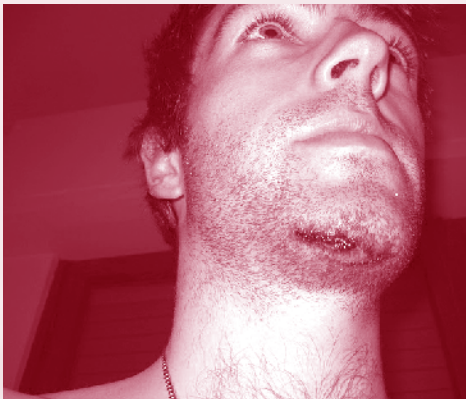
*How often do you have to inject Factor VIII?*

Usually every other day during training.

If I'm racing I will make sure I am topped up on the day.

If I'm on a rest day I won't bother with treatment as I usually spend a lot of my day sitting down and resting and I'm sure a lot of readers will sympathize with the fact that injections aren't exactly convenient or something you look forward to!

*What happens if you crash?!*



Usually in a crash I would just suffer from losing a fair amount of skin on hips, legs elbows and shoulders (or the chin as was the case recently), which isn't a problem for haemophiliacs.

Sometimes bruising can occur if I go down with more of a bang than a slide but in both cases I will have been topped up before the ride and will give myself an extra treatment when I get back home just in case.

*Do you wear any kind of special sports 'medic alert'?*

I have a medic alert necklace that is always on me.

This is so important as if I'm out on my own and take a fall I need to be recognised as having haemophilia by any doctors that treat me. If I'm unconscious they need to know somehow as there are many medications that would be detrimental to me as a haemophiliac.

*What would be your message to someone with a bleeding disorder?*

Stay as fit and healthy as you possibly can! I rarely get bleeds and I believe this is due to my fitness and active lifestyle. Most importantly never let it stop you or hold you back!

*Find Alex Dowsett on Facebook to follow his progress and see how he goes in the Olympics!*

## Featured sport: Cycling

The information below has been taken from *Boys will be boys* by Brendan Egan, Royal Children's Hospital, Melbourne, 2005. The publication helps people with bleeding disorders to be better informed about their sporting choices and understand the risks of different sports for them.

### Participation

Cycling is a highly recommended sport for people with bleeding disorders. Participants are able to increase lower limb muscle strength without putting weight-bearing stresses through their joints. However, injuries are common.

### Common injuries

- Most injuries from cycling are caused by a fall
- Fractures and abrasions/lacerations are common during a fall. It is also important to be aware of head injuries as these may lead to serious complications in the person with a bleeding disorder
- The remainder of the injuries are a result of overuse, including the neck, back and lower limb joints
- "Saddle sores" are also common in cyclists

### Injury prevention

Warm up: a good general warm up may be to ride at a low intensity on a flat course, or to jog on the spot; stretches

### Protective equipment

**Mandatory:** helmet

**Strongly recommended:** padded shorts with mountain biking

**Optional:** protective eyewear, padded bicycle shorts, cycling footwear

# Life choices - leaving school

Dale Spencer

I left school at the age of 16. I had nearly finished Year 11 but was finding the urge to make money with full-time work too hard to resist. I was an average student at school - I excelled at English and lagged in Math. I had begun Tertiary Entrance Examination (TEE) classes at the start of year 11 and wasn't doing too badly, although I was feeling the pressures of trying to keep my social life and school work separate. By the time I had completed half of Year 11, I was down to one TEE subject (English Literature). I thought it was a waste of time to stay at school, as I had no interest in university. By the end of Year 11 I had started my first labouring job.

I have had many jobs since then, mostly labouring. I'm currently a glazier, but am looking into a mature age apprenticeship, as the starting wage is higher than my wage now. I would like to work in the mines getting the big dollars, but I'm a bit concerned about my joints and if I would be able to manage the work, with the stress of 12 hour days and constant heat. Sometimes I wish I had tried a bit harder at school so that I could have a comfortable job with less stress on my body. But we make our own life choices and I am making a decent living for myself.

## Conference Word Find

By Michael Lucken

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

CHAIRPERSON	COMMITTEE
COMPUTERS	CONFERENCE
DISCUSSION	FOOD
HAEMOPHILIA	INFORMATION
LISTENING	MEETINGS
NOTES	PEOPLE
PROJECTOR	REPORT
SESSION	SEATING
TALKS	SPEAKER
TRAVEL	TOPICS

One word is not in the puzzle,  
Can you find which is missing?



Have you thought about going to the 2011 Haemophilia Conference? It will be held in Sydney on 20 -22 October 2011 and will have the latest information what's up in the decade ahead for people with bleeding disorders: new treatments, growing up with bleeding disorders, lifestyle issues, exercise, diet and taking care of your joints. You will be mixing with other people with bleeding disorders, and also with the people who work in the area, and there will be loads of opportunities for discussion. There will be special social activities for Youth Delegates.

Want to know more? Visit the HFA web site - [www.haemophilia.org.au](http://www.haemophilia.org.au) - or talk to your state or territory Foundation. Some of them may also have grants to cover the costs to attend that you can apply for.

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