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Youth News

HAEMOPHILIA FOUNDATION AUSTRALIA

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message from the co-chairs



Dale Spencer

Hi All! May has been a very busy month for me - a trip to country NSW, finance for my house being approved and work, work and more work. In this issue is an article with Dan Muszynski, who plays drums for the band *Glass Towers*. Dan has von Willebrand disorder and should be a great role model for anyone interested in music.

The Conference is coming up. If anyone is interested in attending, contact your state or territory Foundation and you might be able to apply for a grant to cover some of your costs.



Lauren Albert

Hi everyone and welcome to another issue of Youth News! In this issue we have some really interesting articles, one from a member of the Youth Committee, so make sure you check them out. We've got an interview I did with Chris Poulton who is involved in a wide variety of activities in his home state of Victoria, and spreads the message of how important it is for everyone to get involved in things that they are passionate about and really enjoy. Possibly most exciting in this issue is an interview Dan Muszynski did for Youth News about his band *Glass Towers*. Dan won an Advance Your Passion Award in 2009. I'm really looking forward to reading all about how the Award has helped Dan and his band and I'm sure you guys will all enjoy it too. Don't forget to apply for the Award if you have a passion you would like some help

with. You never know - you might just win it and make that dream a reality!

Hope you all enjoy this issue of Youth News and don't forget to email hfaust@haemophilia.org.au if you would like to submit anything at all. We would love to hear from you all.

Beyond Prophylaxis Project

Beyond Prophylaxis is a new HFA project. It's all about understanding what is happening now for young people with bleeding disorders and making a space on the internet for young people with bleeding disorders to talk, share stories and find out information on topics such as work, travel, sport, relationships and socialising. We're not sure yet how this space will work - that's up to you to decide!

HFA has received a government grant to employ a Youth Project Officer for a year to work specifically on this project and they will get together a group of young people affected by bleeding disorders to work on creating the internet space. If you think you or someone you know would be interested in joining the group, contact HFA on 1800 807 173 or hfaust@haemophilia.org.au or let your state or territory Foundation know - you don't need internet skills or a computer, just ideas! More information will be available soon!

Beating the Drum

Dan Muszynski talks to Youth News

Dan Muszynski is 19 years old, and is passionate about the drums and music. He plays in a band called Glass Towers and finished high school last year. He also has von Willebrand disorder.

Dan started learning the drums at the age of 10, which means he has been playing them for 9 years now. His band, Glass Towers, formed when four friends, who were in the same music class, started playing together - Ben, singer and guitar player, Sam, lead guitar, Cameron, bass guitar and Dan on drums. The band plays indie rock music drawing influences from other bands such as Sonic Youth, Pavement, Velvet Underground, as well as contemporary bands such as Foals, Bloc Party and Arctic Monkeys.

One of the band's biggest gigs so far was Splendour in The Grass in 2009. "It was amazing just walking around the VIP area and being in the same room as so many famous artists (Bloc Party, MGMT, Flaming Lips, etc) - just crazy!" said Dan, "then playing to an enormous crowd, our biggest ever."

Dan was diagnosed with von Willebrand disorder when he was about seven. "Well, I'm lucky I don't have to have treatment every day but just when I have bad bleeds, so at school and with sport I just have to be wary. It's kind of the same with my activities outside of school, I surf and wakeboard and just have to be careful."

In 2009 Dan won an Advance Your Passion Award for his passion for playing the drums. Youth News caught up with him in 2011 for an update.

Youth News: Congratulations on winning the Advance Your Passion Award. What did you do with the Award?

Dan: With the Award I bought a brand new Pearl Masters drum kit which sounds so amazing and so much more enjoyable to play compared to my old drum kit.

Youth News: Do you think the Award has made any difference for you and your music?

Dan: YES DEFINITELY! It has simply made it so much more fun for me to play the drums and increased my passion. The Award has also helped me with my music. I used my new drum kit in my HSC music exams giving the drums a clearer and more professional tone, and as a result they helped fill and excite my exam pieces. I am also a drummer who records a lot in studios either in my band Glass Towers or playing as a session musician on other people's tracks and the Award has allowed me to use my own drum kit to record at a professional standard.

Youth News: You've had some more successes with your music lately – what are they?

Dan: As of late my band, Glass Towers, won the nationwide band competition My School Act [www.myschoolact.com] which signed us to Sony Music and Sony ATV Publishing. Our EP (5 track album) is due for release early July 2011 and just this week we made the finishing touches on it.

Youth News: What are you hoping to do with your music in the future?

Dan: Simply to be able to continue playing and enjoying it. I would love to play the drums for the rest of my life, haha, but we will see.

Youth News: Has having von Willebrand disorder made any difference to your music?

Dan: Von Willebrand's hasn't really made a difference to my music. It's more the physical side of playing the drums where it can be tricky. For example, accidentally smashing my fingers on cymbals or the rims of the drums which my sticks should be doing.

Youth News: What do you do to manage your VWD in the rest of your life?

Dan: Just being aware of it and knowing my limits.

Youth News: What would be your advice to other young people with bleeding disorders?

Dan: Just be aware of what you're able to do and don't put yourself at risk.

Youth News: How can people find out more about what you or Glass Towers are up to at the moment?

Dan: The best place would be www.facebook.com/glasstowers



Glass Towers – Cameron, Ben, Dan and Sam

What is von Willebrand disorder?

Von Willebrand disorder (VWD) is an inherited bleeding disorder where people do not have enough of a protein called von Willebrand factor in their blood or the von Willebrand factor does not work properly. In some people with VWD, it takes longer for bleeding episodes to stop. VWD is more common than haemophilia but not as well known. Many people are not aware they have the disorder and are currently undiagnosed.

Most people with VWD only have mild symptoms. Others only realise they have a bleeding problem when they are diagnosed with VWD after an unexpected or prolonged bleeding episode with an injury or a dental or surgical procedure. Unlike haemophilia, von Willebrand disorder occurs in males and females equally. Symptoms may include frequent nose and gum bleeds, bleeding after dental procedures, easy bruising, heavy menstrual periods or prolonged bleeding after trauma or surgery. In rare cases, bleeding occurs into joints and muscles.

Taking on the world

Lauren Albert interviews Chris Poulton. Chris is a Youth Leader with the HFA Youth Committee.



Chris in his Army Cadet Instructor role

Chris Poulton is a 23 year old Instructor of Cadets for the Australian Army Cadets and volunteer fire fighter for the Victorian Country Fire Authority. He umpires and coaches local AFL matches and works full time as a builder. He also has severe haemophilia.

Being a person who thrives on being active, Chris has been playing sports such as baseball, softball, cricket and football umpiring for the local leagues since the age of 12. He is currently involved with the Australian Army Cadets and the Country Fire Authority (CFA), while also working full time as a builder. He has found that keeping active has helped him avoid many bleeds. "Growing up and before I started playing sports I always had a bleed in my knee, ankle or elbow, but since I was 12 I have been a pretty active person. The only bleeds I get now are only from mucking around with mates or not paying attention to what I am doing," he says.

Chris started umpiring at the age of 12 and recently started it up again when he moved back to Victoria and is now the Boundary Umpire's Assistant Coach and Senior Development Mentor for a local AFL club. Since beginning in the army cadets as a young boy, he has advanced through the ranks to his current role of Instructor of Cadets and Chris explained what this involves: "I now instruct to 130 girls and boys teaching such lessons as leadership, navigation, radio communications, first aid, weapon's handling, and live firing."

Chris' real passion is, and always has been, his work with the CFA, which involves state-wide fire and related emergency coordination, fire suppression, road and technical rescue, flood assistance as well as non-emergency assistance and activity. Chris had simple, yet very important advice for young people with haemophilia who might want to get involved in sports or finding other ways to keep active: "Start young, and don't let anyone tell you that you can't do it. Just give it a go"

World Haemophilia Day



On April 17 World Haemophilia Day is celebrated internationally to raise awareness about bleeding disorders. This year the theme was *Be inspired, get involved in Treatment for All!* and people with bleeding disorders around the world shared their stories, describing their struggles and successes. This was to show how having a bleeding disorder affects people and their families and get people around the world involved in making haemophilia treatment available in every country.

Nine-year-old Felix Fogarty from Brisbane and his family appeared on Channel 10 News to tell the story of growing up with haemophilia and learning to treat yourself. Felix and his younger brother Clancy have severe haemophilia. Felix talks about what it was like to share his story for World Haemophilia Day.

Q. Felix, why did you think it was important to share your story for World Haemophilia Day?

Felix: I think that I should let people know what it's like to have haemophilia and so people who don't have a condition like me can see that they are actually quite lucky that they don't have to have lots of needles and treatments.

Q. A few years ago you had some visitors from Thailand whose sons have haemophilia. Do you remember their visit? Did they tell you anything about life in Thailand for boys of your age with haemophilia? Is it different to your life?

Felix: I don't remember that much about them coming except that they were really nice and friendly. But when my dad went to Thailand he told me how the boys don't have treatments and have a lot of joint problems and can't play sport. I felt really sorry for them and lucky that I live in Australia.

Q. What was it like being filmed for the television news show?

Felix: I think it was a good experience for me because not everyone gets to go on TV and be in the newspaper.

Q. Did anyone from school or other people you know tell you that they saw it? What did they say?

Felix: A few kids did but they weren't so sure it was me and they asked me if it was me on TV.

You can watch the video of the Fogarty family story at http://www.youtube.com/watch?v=gBr_DkPlgqk
Thanks to Channel 10, Brisbane, for permission to provide access to this video.

Beating The Drum Word Find

By Michael Lucken

ALBUM

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BAND

PASSION

BEN

RECORD

CAMERON

ROCK

CYMBALS

SAM

DAN

SONY

DRUMMER

SPLENDOUR

DRUMS

STUDIO

GLASS

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VONWILLEBRAND

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The 2011 Haemophilia Conference is coming up soon. It will be held in Sydney on 20 – 22 October 2011 and there is an exciting program with the latest information on 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. There will be a special program for Youth Delegates. It's a great opportunity to attend the Conference with other people your age and meet and mix with other people who have bleeding disorders and the people who work in the area.

Want to know more? Visit the HFA web site – 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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