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Youth News

HAEMOPHILIA FOUNDATION AUSTRALIA

Contents:

Message from the Co-Chairs

Dale Spencer

I recently attended the 2010 HFWA camp which was situated in the beautiful Point Walter campsite. The camp was a great mix of new faces among young people with haemophilia and their families.

Our activities included lots of team games which really help everyone to get to know each other, daytime spotlight game and some of the younger (more game) campers took a dip in the (icy water) pool. The camp activities were divided up by very yummy camp food and some cheery camp fire songs. The highlight for me was the high ropes course. It involved a team climb which was a challenge for me but with the help of Aaron my climbing buddy we overcame that and reached the top, and last but certainly not least was the "leap of faith", it was really great seeing the adults give it a go and the younger campers on their own high ropes course, seeing their folks giving their best.

Overall it was another fantastic and successful camp, I urge anyone to attend local foundation camps, as it's a great way to meet new friends who have come across the same issues and dilemmas and it's also a fun weekend – I always look forward to it.

Lauren Albert

We've had some exciting stuff happening in QLD this month with the annual Red Run Classic in May. I painfully dragged myself out of bed at a ridiculous hour of the morning, and travelled to New Farm Park where the run was held. I was surprised, as always, to see so many people volunteer and participate to support such a worthy cause.

I encourage all families and youth to get involved in your local foundation's activities. It's a great opportunity to meet new people and catch up with old friends, and it also helps out the foundation. Contact your local foundation to find out what's happening in your area, it can be great fun, and a great learning experience. It was a real pleasure to be involved in RRC, and I can't wait for next year!

This is Hepatitis...

You might be wondering what hepatitis C has to do with you? Or why HFA writes so many articles and fact sheets about hepatitis C?

Did you know?

- Most people with haemophilia in Australia now use recombinant clotting factor treatment products. These are genetically engineered and have never been known to pass on blood borne viruses like hepatitis C

Why did this happen?

- Before 1990 most people with bleeding disorders in Australia used clotting factor treatment products made from human blood plasma. Some of the products carried hepatitis C virus and many Australian children and adults got hepatitis C from their clotting factor treatments
- In the early 1990s the blood banks began to test blood donations for hepatitis C. Manufacturers developed steps to inactivate or remove hepatitis C virus from clotting factor treatments when the products are made – clotting factor treatments made from human plasma are now considered very safe from blood borne viruses
- But this is why HFA works so hard with government and manufacturers to make sure treatment products are as safe as possible and that safer products like recombinant products can be available to everyone - to make sure this situation never happens again!

What happened to the people who got hepatitis C before 1990?

- Some have now cleared the hepatitis C virus from their blood naturally or through treatment, but others still live with hepatitis C. This is an ongoing challenge.

Some personal stories:

My son was actually very ill when he was first diagnosed with hepatitis C. He was off school for quite a long while and it was difficult to go back - how do you explain why you've taken this period of time off school? He had incidents where his hepatitis C was used against him at school with people he thought he could trust. They threw it back at him or let the whole world know about it, then no one wanted to be around him. So that made him withdraw even more into himself. That's when the depression started, in his late teenage years.

Looking back I would say I probably contracted hepatitis C when I was about 16. My first experiences with alcohol were disastrous - not so much drunk as ill. But apart from that, I had no obvious symptoms until 10, 15, 20 years later when I got increasing fatigue and that was the biggest thing - the fatigue and just feeling drained of energy and going to sleep.

World Hepatitis Day

World Hepatitis Day was celebrated globally on 19 May 2010. It was launched with a rock concert at Federation Square in Melbourne. This year the bleeding disorders community campaign message was:

This is hepatitis...
For people with a bleeding disorder and hepatitis C, it's another life challenge.

On World Hepatitis Day, HFA released two new resources on the HFA web site:

- **Hep C – what is it all about?** Web pages for young people about hepatitis C
- ***Hep C – my story*** – inspiring personal stories of people with bleeding disorders and hepatitis C

Thanks to Chris Poulton and Erin James from the HFA Youth Committee who joined the HFA Hepatitis Awareness Week Working Group to help put the campaign together.

Hep C – some facts!

- Hepatitis C is a virus carried in the blood that can affect the liver
- More than 210,000 people in Australia have hepatitis C
- New infections are highest in 20-29 year olds
- Symptoms can include tiredness, pain in the abdomen, nausea/feeling sick in the stomach, irritability, depression, forgetfulness
- Treatment can cure 50-80% of people, but side-effects can be hard to manage
- To be passed on, hep C-infected blood from one person needs to get into the bloodstream of another person. This is usually through piercing the skin, eg through sharing injecting drug equipment, unsterile tattooing, blood products before 1990.

Find out more about hep C!

Go to the new web pages on the HFA web site - **www.haemophilia.org.au** > Kids and Youth > About bleeding disorders > Hep C

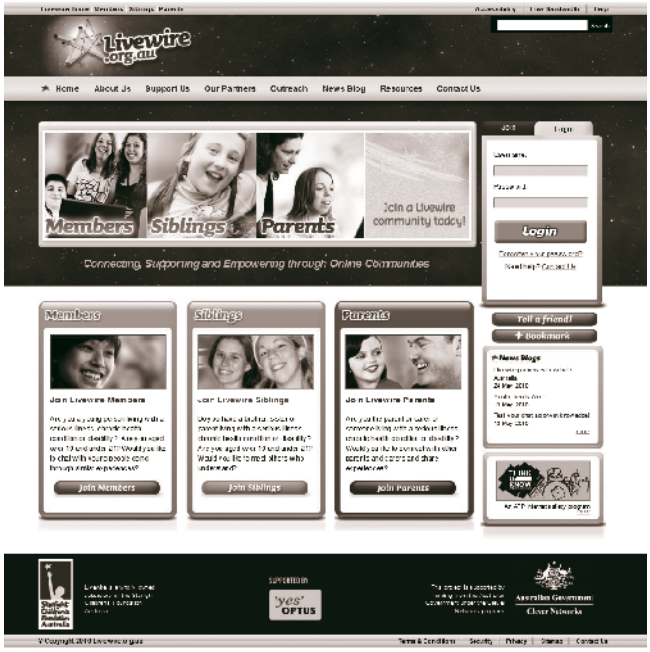
Sharon Caris, HFA Executive Director, with hepatitis organisation friends at the World Hepatitis Day launch. The band is Fasttrack

Livewire

By Hamish Robinson, NSW Youth Committee Member

Livewire is an online community for people aged over 10 and under 21 with a serious illness, chronic health condition or disability. There is also a siblings and parents/carers community. The features of the members site are community, chat, forums, blogs, find a friend, tips & skills, games, Livewire TV, Entertainment, life & style, science & tech, sport.

- Community takes you to the page that shows the latest articles and competitions.
- The tips & skills page has blogs and articles that have tips & skills.
- The games page has plenty of action, platform, puzzle & board games.
- Livewire TV has tons of videos which are linked to the Entertainment page.
- The entertainment, life & style, science & tech, sport pages have blogs, articles, videos and galleries related to their category.



The site is great for connecting and supporting others with the same or different condition.

To join visit **www.livewire.com.au**

What is an inhibitor?

Written by Janine Furmedge, Haemophilia Nurse Coordinator, Henry Ekert Haemophilia Treatment Centre, Royal Children's Hospital Melbourne

An inhibitor is a type of antibody. Our immune system produces antibodies in response to substances it thinks are foreign in order to fight off disease. When a person has an inhibitor to factor VIII or factor IX the body thinks the factor is foreign and inactivates it before it has a chance to stop the bleeding. The development of an inhibitor makes treating bleeds much more challenging.

Inhibitors develop in up to 30% of people with haemophilia A and up to 5% of people with haemophilia B. Inhibitors are more common in severe haemophilia. Most people develop inhibitors when they are very young, usually after having only a small number of treatments. Fortunately many inhibitors disappear on their own or with treatment. However inhibitors can persist and be a serious problem for some.

There are a number of options for treating bleeds in people who have inhibitors. The choice of treatment will depend on the type and level of the inhibitor. Sometimes large doses of factor VIII or IX are effective but for those with high level inhibitors, treatment with products that bypass the inhibitor are necessary. Commonly used 'bypassing agents' are FEIBA and NovoSeven.

Tolerisation treatment can be used to retrain the immune system so that it no longer rejects the factor. This involves giving high doses of factor usually every day and sometimes additional medication to suppress the immune system. Tolerisation treatment is not effective for everyone and there is much effort being directed by both researchers and physicians towards improving our understanding of why inhibitors occur and how to best treat them.

Each person with haemophilia and an inhibitor is unique and their treatment must be individualised. If you have any questions or concerns about inhibitors please contact your Haemophilia Treatment Centre.

"Its bright time! - Get up!! Dad, dad get up its bright time!!!!"

By Michael Lucken, VIC Youth Committee Member

That's the way a typical day starts around here, Scarlet knows that I have mobility issues first thing in the morning, every morning, so she quite often wakes me up by jumping on my belly asking to play with my mobile phone. The reason she wants my mobile is so she can play her games and colouring while I get all my joints moving. This can take up to 30 minutes some days but she is more than happy to sit and play till I get to my feet. So after helping me with my crutches, Scarlet and I head out to the kitchen to get breakfast, Nutrigrain is the favourite at the moment, which she likes to help me get ready.

It is quite difficult most mornings with the arthritis, but if I wake up with a bleed it may take a lot longer to get moving, if I can at all. You see, I am the proud owner of a bleeding disorder - I have severe haemophilia, with inhibitors (or inhibilas as Scarlet would say). Scarlet is my daughter who is 3. There are many things they teach you about haemophilia, eg treating bleeds, pain management, sports you can or can't participate in etc. However they don't give you any tips on training a toddler so as they don't (accidentally) put you in hospital! It's taken some time and effort but I must admit Scarlet is a very helpful and caring daughter because of it, if I'm trying to get my leg working and she see's I'm having trouble she offers to get my crutches, one by one she will drag them to whatever room of the house I'm in, or she will grab me by the hand and try and help me walk. Sometimes she is so impatient that she will stand in front of me and mimic how I walk saying "like this Daddy" as she waddles off like a penguin, and at other times she will get my shoes for me if they're out of reach and try and put them on my feet. The cheeky little monkey is very considerate for a 3 year old! She has also learnt how to charm tea ladies into giving her biscuits when she comes to visit me in hospital, very clever girl!!

With all pro's there are also some con's that go with it, I'm not like other Dad's who can run around after their kids in the backyard, kick a ball, roll around wrestling on the floor and I can't just get up and be ready to go somewhere or do something on a moment's notice, which requires a considerable amount of patience. I'd love nothing more than to ride a bike around the block or to dance around to "The Fairies" but Scarlet seems to understand my limitations. However, Scarlet does love it when she gets to ride on daddy's 'motorbike' (my mobility scooter) down to the supermarket, to day care, or to walk the dog... How many Dad's can do that?

On a more serious note, before having Scarlet there was a whole other range of things to consider. Would we use IVF to only have boys so as to stop haemophilia from me onwards or would we go the cheaper and natural option and just see what we get? Well you can guess the option we chose. Our thoughts behind this were, that by the time our daughter gets to childbearing age the technology will have (hopefully) improved greatly from where it is now and the options for her to have a non-affected child will be easier to access and obtain than they are now. As it stands right now Scarlet is a carrier, her boys have a 50% chance of having haemophilia or not. We're hoping that after watching me as she grows up that she really considers her options thoroughly so she knows what's possible for her children. Besides that she will have a wealth of knowledge.

As I reach the end of my typing, this not so little voice starts asking me "Daddy, I have more Nutrigrain please? It's ok, I get it" So I'm going to end this here because if I don't there is going to be half a box of nutrigrain on the kitchen floor in less time than it takes me to get out of this chair, so here goes.....

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