Haemophilia Foundation
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HFNZ

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Newsletter of the Haemophilia Foundation of New Zealand Inc

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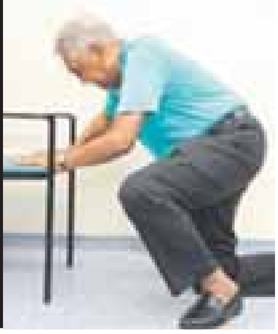

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The H Word

Welcome to the September issue of Bloodline. This edition contains an article on the much anticipated Women's Retreat and the latest Parents Empowering Parents (PEP) workshop – with our biggest ever attendance!

Also mentioned in the magazine is a reminder for you all to be thinking about next year's world congress of the World Federation of Hemophilia being held on our doorstep in Melbourne next May. Please look at the details on how to apply for sponsorship to attend. This is a fantastic opportunity too good to miss.

A special mention to KiwiFirst, who have just celebrated their 20th Anniversary of operation. HFNZ simply could not exist without the generosity of the New Zealand public – so thanks KiwiFirst, for all the hard work you do fundraising on behalf of us all!

Remember, if you wish to contact me please do so, my email address is on the inside cover.

Happy reading everyone.

Deon York
HFNZ President

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Cover photo:
Women's Retreat pamper session.

I Am Woman - Women's Retreat 2013

After four years of anticipation, 53 women attended the second Women's Retreat held at Copthorne HarbourCity Hotel in Auckland from 19-21 July. The women aged 16 plus came together for a weekend focused on all about them and their bleeding disorders such as von Willebrand disorder, factor VII deficiency, platelet function disorders and haemophilia gene carriers.

Day one started on Friday with the Mihi Whakatau opening by Patience Stirling, the Piri Toto delegate, who welcomed the manuhiri (visitors) and tangata whenua (women of Auckland) to the retreat. We were also delighted to have special guest Sharon Hawkins attend the weekend. She is a Haemophilia Counsellor from the Haemophilia Centre of Western Australia, who along with her colleague, Claire Bell, Haemophilia Nurse, is planning to run a similar Women's Weekend in Western Australia in December.

With the retreat rules and expectations setting the tone for weekend, the women were ready to commence a weekend filled with a sense of community where they could enjoy learning, experience love and laughter, and be treated with respect by their peers.

During the afternoon the women split into their daily discussion groups - Bleedy Bunch, Claret Chat, Plasma Yak, Clot Club and the Young Bloods. They later formed back into the main group to hear the stories of four very brave women - Patience Stirling, Catriona Gordon, Dee Kimble and Annatjie Pretorius, who shared their personal haemophilia journeys. This was an extremely powerful and emotional presentation that demonstrated the resilience, strength and courage of the amazing women within our bleeding disorder community geographically and through time.

A special pampering time was provided in the early evening courtesy of the Elite Beauty School Graduates who donated their time to come along and treat the attendees to their choice of a mini manicure, mini pedicure, eyelash tint or eyebrow shape and tint. The pampering, complete with a complimentary glass of wine, was much appreciated by the women who find it difficult to find time to spoil themselves while managing a busy family life.

This was followed by the Wahine Christmas Quiz Night that tested attendee's knowledge of all things Christmas and a Prize Steal-athon which was hilarious as favourite prizes were stolen numerous times until they found their final owner. The women next enjoyed the opportunity to sit and craft beautiful felt brooches to keep.

To finish the night off , the women learnt about 'Bleeding Disorders Around the World' from the United States, Australia and New Zealand to countries less fortunate than ourselves such as India, Zimbabwe and Cambodia. This was followed by a chance to spend up large at the 'Bring and Buy' Craft Market Table where the attendees donated a gift to sell to raise money for the Twinning Project. A silent auction was also held for a hand-crafted quilt donated by women with bleeding disorders in the United States. After realising how fortunate we are in New Zealand, the women spent up large at the market and raised $1026 which will be used to enable HFNZ to take a physiotherapist on the 2013 Twinning Visit to Cambodia.

After an early start to the day to catch flights for many women from regional New Zealand, and such a busy and fun first day, the attendees collapsed into bed for a well-earned sleep to recharge for Saturday – a full on day focused on information and education.

The next day started with a new tradition that originated at the Great Plains Women's Retreat in Texas that Sarah Preston, Northern Outreach Worker, attended. Each morning the woman energetically sang and danced to 'I am Woman'. The woman

belted out the powerful lyrics 'I am woman, I am strong, I am invincible'. Most people in the hotel lobby could hear the singing and it was even reported that the women working at the front desk joined in with the singing and dancing.

Once again three brave women shared their personal journey. This time Nicola Cuthbert, Jessica Hirst and Theresa Stevens shared their journey on 'von Willebrand Disorder – A Bloody Nuisance' in a session facilitated by Linda Dockrill. This was the perfect introduction to the next education session by Laura Young, Haematologist and Claire McLintock, Haematologist and Obstetric Physician which covered bleeding disorders in women, and all aspects of bleeding including menoraghia, reproductive choices, managing pregnancy and childbirth. The information was delivered in a way that was easy for everyone to understand.

On Saturday afternoon the women split into two groups. The women aged over 25 years attended a session on 'Unravelling the Adolescent Brain' by Kathryn Berkett from the Brainwave Trust. Her presentation deciphered why teenagers behave as they do as their brains go through the second biggest growth stage of their lives. The information was perfectly timed for many women as they cope with adolescent children and the women with pre-teen children gained an insight into the stage that they will soon encounter.

In a small group setting the younger women learned about the genetics of each bleeding disorder and had the opportunity to ask Mary Brasser, Haemophilia Nurse Specialist, questions before heading off for a game of ten-pin bowling at Auckland's newly opened 'Metrolanes'.

Saturday evening saw the women dress in their glad rags and catch the ferry across Auckland Harbour to Devonport for dinner at the Esplanade Hotel in Devonport for a special Mid-Winter Christmas meal created by award winning chef Peter Thornley. Much laughter filled the restaurant as the very saucy Mother Christmas (Sarah Preston) and a very able Christmas Fairy (aka Barb Hodges from Baxter) had fun delivering Christmas gifts for all.

After another rendition of 'I am Woman', Sunday morning commenced with HFNZ time lead by National Council members Catriona Gordon - Vice President, Patience Stirling – Piri Toto delegate, Deborah Weir-Honnor – Midland delegate and Stephanie Coulman – Central delegate. They explained the HFNZ structure and purpose, the governance role of the National Council, and the role of the Member Representative Group's (MRG's) and delegates.

The final session of the weekend was entitled 'Back off Creep - Self Defence for Everyday'. Rana Moir, the self-defence instructor, gave suggestions on tactics the women could use to best protect themselves from predators.

Following afternoon tea and final good byes the women departed for home, hoping the next Women's Retreat is repeated not too far down the track in a couple of years time.

Thanks to Baxter for sponsoring the weekend and helping to make it a success.

Combined with the wonderful women, the well-planned programme provided a perfect mix of education, time for discussion and support, pampering and socialising to create a the recipe of success for the Women's Retreat but most important of all was it was fun. Here's an insight into some of the participants comments about the weekend:

"Women's Weekend was so awesome. I loved hearing the speakers and other women's stories, as well as meeting new people and catching up with old friends. Women's Weekends definitely need to be more often! Thanks HFNZ!" Courtney, from Dunedin.

"Awesome Time! Loved it. Bring on the next one! Loved meeting people with the same sort of problems and know that people know what I am going through and understand." Erin, from Christchurch.

"Thoroughly enjoyed the whole weekend. It was absolutely fantastic – so good to meet other women with bleeding disorders and so good to meet some more von Willebrand Disorder people. All of us von Willies feel we have more support now than we had five years ago. So good to see the von Willebrand Disorder group growing. So well done!" Jessica, from Auckland.

"Overall, I found the weekend to be very worthwhile; it gave me a personal insight into the options that I will have to face when I have children later in life" Gabrielle – from Invercargill.

"Coming to Auckland for the Women's Weekend was awesome. I feel re-connected with the HFNZ and empowered for the future. Having other women to contact who have similar experiences is great. Definitely met and exceeded the mission statement / goals of HFNZ." Hannah – from Palmerston North.

"This has been a wonderful opportunity to learn from the team how to organise and replicate a Women's Weekend in Australia. Thanks so much for sharing the details of your preparation and implementation. Brilliant!!" Sharon Hawkins, Social Worker, Perth, Western Australia.

"Ka Maute wehi (awesome). Learning – caring and sharing." Patience, from Auckland.

"Had a wonderful time. Enjoyed the times of connecting with the other women, both new and others from a long time ago who live elsewhere in New Zealand. The sessions were presented by passionate people who were able to put across the message with fun and humour. Great Job. Fantastic organisation. Great mix of story and education." Robyn, from Christchurch.

"Attending the 2013 Women's Weekend was a unique and rare opportunity to meet with other women involved in caring for children with haemophilia and suffering from bleeding disorders to learn from experiences, to receive valuable education from excellent speakers, all of which left me able to go back to my family and continue my essential role of providing best care for my sons." Catriona, from Rotorua.

"I had a wonderful time spending the weekend with like-minded people with wonderful stories. Loved the education side as the speakers were engaging and learnt so much! The social side was perfect, enjoyed the laughing and crying! Thank you so much." Dee, from Napier.

"An amazing weekend with lots of information / wisdom sharing. I feel empowered and ready to 'pay it forward' supporting the Foundation for the future generations." Kellie, from Napier.

"Thank you HFNZ for such a fabulous opportunity. I especially enjoyed hearing other people's stories / journeys. We are all incredibly strong which was reinforced throughout the weekend." Sarah, from Gisborne.

"Fun, educational and supportive environment are the three things that I will think about when I look back on this experience. I encourage anyone that has not been to come to the next Women's Weekend, as you always get something out of it." Amy – from Palmerston North.

Parents Empowering Parents - Learning Together, Supporting Each Other

Over the weekend of the 17-19 May, 2013, 19 parents of children affected by a bleeding disorder attended the third Parents Empowering Parents (PEP) workshop run by HFNZ in Auckland. Parents came from all over New Zealand to attend the event including some from Christchurch, Napier, Wellington, Gisborne and Auckland. Most of the group hadn't met each other before but if they had, they had met at family camps in the past.

Linda Dockrill, Southern Outreach Worker from HFNZ, facilitated the event in conjunction with trained parent facilitators, Lynley and Richard Scott, parents of Andrew who has severe haemophilia A. Stace Hardley, a young man with haemophilia, came as a guest speaker to talk about his experience of growing up with severe haemophilia B, and Mary Brasser, Haemophilia Nurse, kindly filled in for Daryl Pollock at short notice due to illness.

Parenting is an incredibly important job and one that presents us with many challenges. If you add a bleeding disorder into the mix it adds even more challenges. The PEP course is designed to help parents learn skills around parenting a child with a bleeding disorder while helping them to adopt a "can do" approach to parenting.

During the weekend, parents learned about:

- The basics of bleeding disorders
- Child development and how to balance expectations within the age and stage of each child
- Behaviour management techniques such as positive reinforcement, time out , setting limits, and how to institute the three family golden rules
- Making a family plan that can be used as a blue print for success as a family as well as supporting a child with a bleeding disorder to become a responsible, reliable member of the community
- Communication skills and dealing with conflict in a positive way
- How to grow a child's self-esteem
- How thoughts and feelings affect parenting
- The impact an individual's "world view" has on their role as a parent

The weekend wasn't all about all work, work, work though as the group enjoyed a fun meal out at a Cambodian restaurant on the Saturday night, which was a great way to cement friendships and decompress after the day's events.

By the end of the weekend many of the parents reflected that they will now be able to see their child as a young boy first and his haemophilia as a secondary element. This is a very important step towards independence for these children. Along with the connections the parents had formed they will go on to keep in touch and provide support for each other with skills that will help their child grow into the independent, responsible and empathetic adults.

HFNZ and all the parents who participated in this PEP programme wish to extend their sincere gratitude to Bayer for making this opportunity to focus on parenting a child with a bleeding disorder possible.

Participants commented:

"It has given me a new insight into using good parenting skills and also made me feel better knowing I am not alone."

"I found the PEP programme very powerful and informative, not quite what I expected – it was so much more!! Thank you."

"I have gotten so much out of the weekend and will be using a lot of what I have learned in my life."

"Brilliant, brilliant, brilliant. Met amazing people and even surprised myself with my own participation. I don't think I will ever forget this weekend."

"Wow!!!!!

The wife suggested we attend this weekend and after a bit of coaxing I agreed.

As a typical bloke I went into the weekend with horror thoughts of role playing and team bonding sessions occurring all weekend. Yes they did happen, but were very relevant, practical and useful for the every-day situations we are all dealing with. It's the old saying "what you put in, you get out".

We arrived as strangers however left 3 days later with 20 sets of friends we did not know previously existed. Over the weekend we all shared some very deep and emotional stories, an experience that will stay with us for a very long time, but had some great laughs as well!

The tutors presented the information during the workshops in a professional manner and the literature we received is a useful tool to reflect back on now we are back in our home towns. I cannot speak more highly of the team from HFNZ who arranged and spoke over the weekend.

Without hesitation I would recommend this parenting workshop to anyone parenting a child with a bleeding disorder.

Rob and Bo Silva

p.s. take plenty of tissues (blokes too!)."

"I would like to thank the Haemophilia Foundation for organising such a productive and insightful parenting weekend recently in Auckland.

The experience is one that we as a family will never forget. Besides the amazing experience of sharing our feelings and thoughts with fellow parents going through the same "fears" as us, we were able to bring back some valuable practises in our day to day lives in bringing up our children.

The friendships we made on the weekend, still continue today and thanks to a page set up by one of the parents we have remained in contact and continue to receive and offer support from all involved. We would never have networked with these parents were it not for this weekend and this experience is and continues to be invaluable.

We still refer to our manual today during trying times with the kids and the lessons we learnt on parenting will always steer us in the right direction.

Besides the haemophilia bond we all have and the support we now glean from each other, the day to day parenting skills we learnt were amazing.

I would recommend this course to anybody and have not stopped telling our friends what an amazing and wonderful experience it was."

Scott and Dee Kimble

Unravelling the Adolescent Brain

During the Women's Retreat Kathryn Berkett from the Brainwave Trust presented to the participants aged over 25 about 'Unravelling the Adolescent Brain'. The Brainwave Trust is an organisation that aims to raise public awareness about new brain research and emphasises the importance of early experiences on infant brain development and the implications of the experiences later in life. Kathryn's discussion was on brain development of teenagers and how it can affect behaviour.

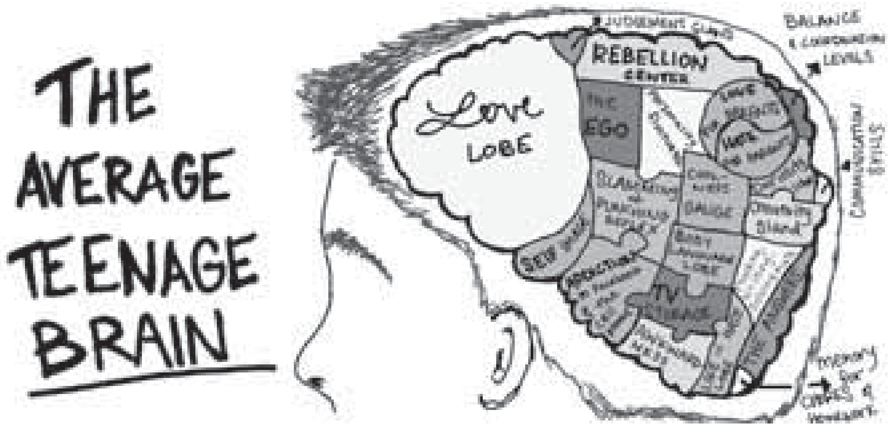
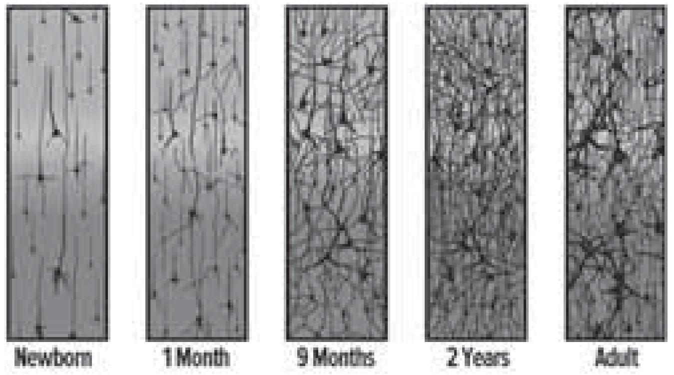


Illustration - Alexas Masters

To comprehend how a teenage brain works you first need to understand how a brain develops. Brain development starts in utero. A new born baby's brain weighs 350g, a one year olds 1kg, a three year olds 1.2kg and an adults 1.4kg (approximately). Babies are born with approximately 100 billion neurons in their brains of which 95% remain in an adult. Once a baby is born the neurons start to develop connections between them. The connections occur when the child interacts with the environment. These interactions can include the quality and quantity of the experiences they are exposed to. A person needs to be exposed to something to learn it. Repetition of experiences causes the brain to hardwire the learning. The experiences are important as they will influence how a person behaves and learns in different situations. Most of the learning up to age three involves the development of trust, sense of self, cause and effect, and sequencing.

A child brought up in a loving and caring environment will have a brain containing more dense connections and pathways than a child who does not receive enough care, attention and stimulation. Consequently a lack of neuron connections can affect a child's behaviour, ability to learn and ability to make friends. This is why it is considered important for children not to watch too much television as they cannot learn the same as they would from human to human interaction and behaviour. Severely neglected babies can have a brain 20% - 30% smaller than others their own age. Children brought up in violent and abusive environments who constantly live in fear will produce more stress hormones as they stay alert to real or imagined danger.



The development of neuron connections in a human brain.

The second most important growth period for the brain occurs during adolescence, around the time of puberty at about 12 years for girls and 14 years for boys. This is a stage when teenagers need to separate (or gain more independence) from their parents to become better equipped with skills. This is because instinctively, humans are driven into survival, procreation and protection modes. Babies are driven to interact with people and forge connections so they will be protected for survival. At puberty the procreation and protection modes kick-in. Adolescents can reproduce so the human instinct is to become better equipped to protect their off-spring. In other words to become better equipped to be a parent they need to take risks and to learn the consequences of their actions. Also at this time peer groups are more important than parents as friends validate who they are.

Another instinctive mode for humans is the fight / flight / freeze response to stress. During adolescence it is an important time to learn how to cope with it. The cortex of the brain is where humans learn to keep themselves calm, however the process needs to be learned. The more stressful situations an adolescent experiences, the better they will become at dealing with it. It is suggested that if an adolescent is misbehaving, instead of punishing them immediately let them subconsciously undertake an activity that calms them down. Once they are calm is the time to instigate a punishment. This process reduces the negative connotation around an activity you want them to succeed in.

During the growth period of the brain, adolescents are capable of making sound judgements because they can determine the level of risk involved, however their brains tend to opt for the more novel solution to issues due to increased dopamine levels. The logical, rational decision making part of the brain in the prefrontal cortex is normally over-ridden by 'I want, I take, I like, I do' rationale. Adolescents also struggle with recognising facial expressions and understanding another person's perspective as some parts of their brains become less accessible than when they were younger. The use of Facebook and texting enhances this issue due to the lack of face to face interaction. Drugs and alcohol taken during adolescence have also shown to have long term effects on the brain, which is suggested to reach solidification at around 18 years of age.

To learn more about adolescent behaviour, read the article 'Risk Taking in Adolescence' on page 7.

Risk Taking in Adolescence

By Sharon Hawkins, Haemophilia Counsellor, Haemophilia Centre of Western Australia.

Does the haemophilia gene come accompanied with a risky behaviour gene?

If I had a dollar for every time a parent has asked me this, while seemingly joking, but with a real sense of concern, I'd be very wealthy!

My response is usually to chuckle and tell them the above which really says it all, that there's been many before them that have thought the same thing and they're not alone with their concerns. I think maybe the only genetic link is their gender, with more boys participating in problematic risk taking behaviours.

Concerns about risk taking

In the Haemophilia Foundation Australia Beyond Prophylaxis Project Needs Assessment Report, haemophilia health care professionals and Haemophilia Foundations also expressed concern about risk taking behaviour among young people and the consequences on their health and "had particular concerns about young people discontinuing treatment, making uninformed decisions and taking risks related to career choice, sports and other physical activities because of the permanent musculo-skeletal damage or injury that could result." Also noted further in the report were their concerns around drugs and alcohol.[1]

These concerns aren't limited to Australia or to the current generation. Literature on the behaviour of boys with haemophilia dates back at least three decades and from different parts of the world. One study conducted in the USA examined the prevalence of hyperactivity-impulsivity in boys with haemophilia and noted an implication that "haemophilia is a risk factor for ADHD-related symptoms" - an indicator for risk taking behaviour. However, to balance this it was further noted that "follow-up studies conducted at multiple sites, perhaps with match of control group subjects on several demographic variables, are needed to confirm the findings of this study".[2]

Risk taking and growing up

Risk taking can be seen as an important and positive step in growing up. For example, one behavioural psychology theory decribes it as "when you experiment with a new behaviour. It can be healthy and a positive way to: test your limits; test other people's boundaries; learn new skills and experience new things (including in work, study, relationships); experiment with new identities; increase your self-esteem; or take on more independence and responsibility for your life."[3]

When you look at the main developmental tasks that occur in adolescence, risk taking and adolescence go hand in hand. For example, Headspace, a national Youth Mental Health Initiative Program which provides health advice, support and information to young people aged 12-25, identified these tasks as:

- Independence from parents and other adults
- Development of a realistic stable positive self-identity
- Formation of sexual identity
- Negotiation of peer and intimate relationships
- Development of realistic body image
- Formulation of their own moral/value system
- Acquisition of skills for future economic independence.[4]

Adolescence is therefore a particularly significant and challenging stage of development where there are psychological and physiological changes and where risk taking behaviours can increase.

I believe that most parents' fears about their child's bleeding disorder impacting on their ability to lead a "normal" life can be intensified by a very normal protective response.

What's "risky"?

What is deemed to be risky behaviour is subjective and will be different for all individuals. Most particularly what is seen as risky by parents is often not by teenagers. Parents note that teenagers do not acknowledge their fears or concerns around risks, and often they do not seem aware of them. This is demonstrated in the Haemophilia Foundation Australia Beyond Prophylaxis Project report, where the groups to identify risk taking as a significant issue for young people with bleeding disorders were adults from Foundations, parents and health professionals working with people with bleeding disorders – not the young people who participated in the project.[1]

It is a natural response for parents to be concerned by risk taking behaviour. Most parents see themselves as their child's protector and therefore want to avoid anything that has the possibility of causing their child harm. However, it's important to take the wider picture into account. The avoidance of activities might potentially cause more harm to a teenager's development towards independence and their own ability to set limitations than the actual participation in the activity. Responsible risk taking is a desirable aspect of adolescence. Independence and self-responsibility develop when parents give their adolescent the chance to make their own choices, decision and mistakes.

Problematic risk taking

Of course there is a difference between responsible risk taking when normal safety precautions are in place and problematic risk taking. There is a lot of literature on young adult risk taking which agrees that "risk-taking behaviour can be functional, necessary, and appropriate in some situations, but can also be dangerous and inappropriate".[5]

Types of risk that might be problematic for teenagers include unprotected sex, drink driving, train surfing, drug or alcohol abuse including binge drinking, deliberate self-harm, severe or excessive dieting, dropping out of school or getting suspended regularly, breaking the law, eg. shoplifting. There might be added risk when a challenge or dare is set by someone else or is out of the adolescent's control.

The reasons why adolescents might partake in problematic risk taking can be linked directly to developmental changes, for example:

- Immaturity but striving for maturity
- Seeking independence and sense of identity

>>>

- Trying to fit into peer group – peer pressure
- Feeling immune to danger – indestructible
- Reacting to perceived attempts to control
- Experimenting with alcohol and drugs which will affect judgement.

Problematic risks can be further complicated for people living with haemophilia or another bleeding disorder by the following:

- Decreased compliance to haemophilia treatment
- Unrealistic expectations of their ability to participate in physical activities
- Isolation from others with bleeding disorders who would be experiencing similar transitions
- Peer pressure and self-applied pressure to be like others without a bleeding disorder
- Ignoring bleeds
- A belief that prophylaxis cures all.

The parent's role

A parent's role changes with their child's transition to adolescence and this can be a challenging time. Parents generally spend a lot of energy raising their children to become independent, responsible and fulfilled adults. However, some parents will find it hard to let go when the time actually comes, particularly when the parenting role has also involved managing and treating their child's bleeding disorder. It can be a very anxious time for parents but also an important time to recognise that some of your adolescent's behaviour will be normal developmental changes. As noted by an Italian team of haemophilia specialists who investigated this issue: "studies have not confirmed early clinical impressions that haemophiliacs [sic] may be uncomfortably interested in physical activities at risk of bleeding: risk-taking attitudes by affected males increase with age, but they are similar to those in age-matched controls".[6]

What can parents do?

- Seek knowledge about the changes that occur in adolescence – this can help parents understand and cope with the transition.
- Objectively assess whether the risks your adolescent is taking are problematic as opposed to responsible risk taking.
- Offer suggestions of safety precautions.
- Stress the importance of looking after your body and not harming yourself in preference to risk taking behaviours being "wrong".
- Set a good example for your adolescent.
- Trust that your adolescent will have learned from you what your values and beliefs are but that they will challenge them while seeking their own sense of self.
- Gradually hand over responsibility.
- Offer support but don't feel rejected if your adolescent can cope without your support – they often rely on friends as much as family.
- Keep communicating, most particularly listening, and be open to negotiation. As a parent you have the right to set rules and the responsibility to provide limits. However an adolescent will respond with less conflict if the rules and limits are negotiated.
- Take opportunities as they arise to ask your adolescent about their knowledge of their bleeding disorder and continue to encourage them to update their information – without lecturing. A great resource for information is the Haemophilia Foundation Australia website for young people, Factored In (factoredin.org.au) [7]
- Understand that adolescents will resist parents trying to keep them dependent.
- Keep in mind that adolescence doesn't last forever. In a few years you will be surprised how much your young person will have matured.

The health care professionals at the Haemophilia Treatment Centre your adolescent attends can provide further information and support or refer to other appropriate services.

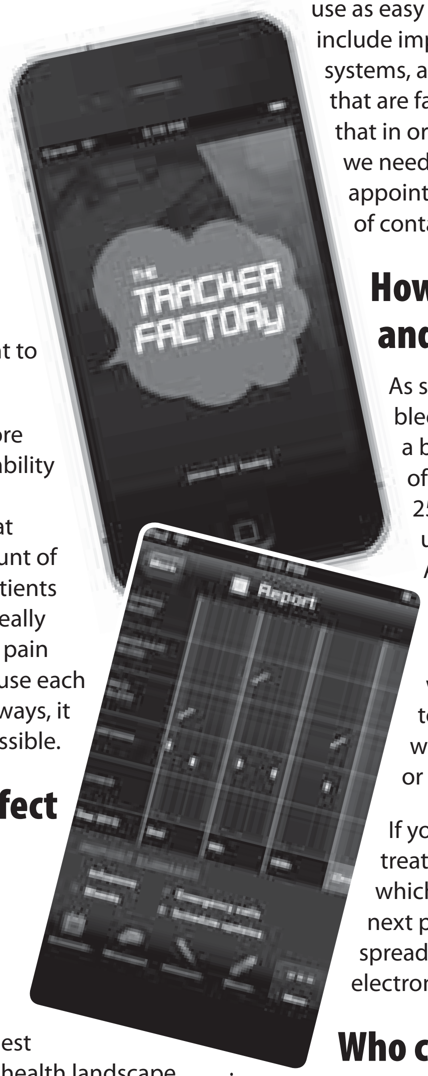
REFERENCES

1. *Haemophilia Foundation Australia. Beyond Prophylaxis Project: understanding and addressing the unmet needs of young people with bleeding disorders. Melbourne: HFA, 2012.*
2. *Spencer MLS et al. Inattention, hyperactivity-impulsivity, academic skills and psychopathology in boys with and without haemophilia. Haemophilia 2009:15: 701- 706*
3. *Hamilton J. Motivation and risk taking behaviour: a test of Atkinson's Theory. Journal of Personality and Social Psychology 1974:29(6): 856-864.*
4. *Headspace – Australia's National Youth Mental Health Foundation. Adolescent development.<http://www.headspace.org.au/parents-and-carers/find-information/adolescent-development>*
5. *De Haan L. The RT-18: a new screening tool to assess young adult risk-taking behaviour. Int J Gen Med 2011:4: 575-584*
6. *Coppola A et al. Confronting the psychological burden of haemophilia. Haemophilia 2011:17: 21-27*
7. *Haemophilia Foundation Australia. Factored In <http://www.factoredin.org.au >*

The Auckland Bleed Reporting Project

By Ian d'Young, Haemophilia Project Manager, National Clinical Lead, Haemophilia Physiotherapy

The Auckland DHB Haemophilia Treatment Centre (HTC) is currently running a project to improve the rate of timely bleed reporting for adults with moderate and severe haemophilia who live in the Auckland region. Having reviewed the data, we know that fewer than 50 percent of the bleeds our patients experience in a year are reported and of those that are, more than 70 percent are outside of a time frame where we can most effectively manage the bleeding episode.



Why is it important to report a bleed?

The sooner a bleed is reported, the sooner clinicians can start to work with patients to manage it. Delayed reporting increases the likelihood that a single bleed will result in further bleeds and joint damage. This is because the adaptive changes that occur in limb musculature and mechanics following a bleed happen quickly and predispose the joint to repeated bleeding episodes.

The longer it takes to manage a bleed, the more pain, time off work and risk of permanent disability there is for a patient. The longer it is before a bleed is assessed, the harder it is to ensure that patients are receiving the right type and amount of treatment. A good example of this is when patients have a lot of arthritic joint damage. It can be really difficult to tell the difference between what is pain related to bleeding and what is arthritis. Because each of these issues are managed in very different ways, it is important to assess joint pain as early as possible.

How does reporting a bleed effect the standard of haemophilia care in New Zealand?

Reporting bleeding episodes quickly is not just important to ensure the best clinical outcome for our patients. As clinicians, we are accountable to national funders who request data on the use of clotting factors. In a global health landscape where the cost of treatment is rising and budgets are under more pressure than ever, reporting bleeds in a timely manner and accounting for each vial of clotting factor is more important than ever to maintain the high standard of care we have access to in New Zealand.

How are we making it easier to report a bleed within 48 hours??

To determine what is reasonable in terms of timely bleed reporting, we have been meeting with patients and the Haemophilia Foundation through focus groups and one-to-one sessions to discuss this issue. By consulting with our patients we have agreed that it is reasonable to expect that all bleeding episodes are reported within 48 hours of onset. For those that take regular prophylaxis, the HTC would also like home therapy records returned to them before each new product order. This is in line with international best practice for Haemophilia Treatment Centres.

We have also been developing a number of new policies and strategies to make reporting bleeding episodes and product use as easy as it can be for our patients. Some of these include improving our own database and data collection systems, and working with local service providers in areas that are far away from our treatment centre. We also know that in order for our patients to see value in reporting, we need to respond to each episode quickly and offer appointments, where required, within one working day of contact.

How do I report a bleed in Auckland and Northland?

As soon as you feel that you need factor to treat a bleed, we would like you to tell us about it. To report a bleed (even on a weekend), you have a number of options. You can call us on (09) 307 4949 ext. 25285 to speak to us or leave a message, or text us on 021 244 7067. You can also email us at AKHaem@adhb.govt.nz.

Alternatively you may want to use our iPhone app or website www.trackerfactory.co.nz. We will aim to respond within 24 working hours to ensure that you are recovering and to see whether you need further help, either in Auckland or closer to where you live.

If you take regular prophylaxis, you can record treatments by using our excel spread sheet template, which you can email to us prior to picking up your next product order. If you would like a copy of this spread sheet, just email us and we can send this to you electronically.

Who can I contact for more information?

We have sent letters to our patients in the Auckland region explaining this project and would be happy to discuss it further with anyone who requires more information, so please call or email us if you have any queries.

• Phone: (09) 307 4949 ext. 25285 • Email: AKHaem@adhb.govt.nz

Reducing Harm From Falls

Falls can happen to anyone but as people age the likelihood of having a fall increases. A loss of independence caused by a serious fall is a concern for anyone over the age of 55, and even if a person doesn't suffer from a physical injury, a fall can increase anxiety and create a loss of confidence, which makes people restrict their activity and actually increases their risk of falling from decreased muscle strength and balance. Falls can be caused by your health, medication and your surroundings and can impact your personal independence and wellbeing as well as your family, whanau and significant others.

Older people, ranging from healthy and active to frail and debilitated, are more susceptible to injury because of age related physiological changes and clinical conditions such as slower reactions, less effective balance correcting skills and osteoporosis. Aged-related impairments like vision, hearing or memory increases the likelihood of tripping, slipping or stumbling.

People over the age of 65 years living in the community have a 30 percent chance of falling once a year, with about 5 percent of those people receiving a fracture or requiring hospitalisation. This figure doubles for people aged over 75 years. The rates of falling are even higher for people living in aged-related residential care with 10-25 percent of falls resulting in fracture or laceration. There is a higher risk of falls while people are in hospital as well, intensified by people being unwell, the side effects of treatment and being in an unfamiliar environment. The most severe injuries caused by falls include fractures (hip fractures are most common) and head injuries. Statistics show 50 percent of hip injuries require long term care and the other 50 percent require help with daily living or mobilisation.

Aged- related impairments can include muscle weakness, deficits in balance, gait and vision, limited mobility, impairments in cognition and functional status and postural hypotension. Other factors can include side-effects from medications (including their effect on mental activity) and use of multiple medications, depression, dizziness, activity or daily living limitations, as well as other medical conditions including cardiac issues, arthritis, diabetes, pain and urinary incontinence. Frequently a person's risk of falling is increased when they have several inter-related issues which compound the risk of falling. Inactivity and loss of condition can mean an older person takes longer to recover and has an increased risk of falling again.

There are many things people can do help prevent a fall and maintain independence and quality of life. These include:

- Manage any health issues or age-related impairments and conditions that may increase your risk of falling.
- Make your home safe by removing or minimising hazards in the physical environment.
- Recognise your limitations and don't be too proud to ask for help.
- Have a plan in case you do have a fall.

Manage your health

Things you can discuss with your doctor/health professional to help prevent falls include:

General health

- Have regular check-ups with your doctor to discuss concerns and changes in your health early before they become big problems.
- Ask your doctor, physiotherapist or practice nurse to give you a balance and muscle strength assessment.
- Ask if a Vitamin D supplement is right for you. Vitamin D supplements increase muscle strength and bone density.
- Review your medications frequently with your doctor or pharmacist and be sure to inform them of any side-effects you are experiencing as well as any non-prescription medicines and natural therapies you are taking.
- Always take medicines as directed by your doctor or pharmacist.
- Talk to your doctor about diet.
- Ask about a referral to a continence nurse as rushing to the toilet can increase your risk of falling.
- If you have fallen more than once in the past six months, talk to your doctor as falls can be a sign of a new medical problem.

Eyes

- Have your eyes checked by your doctor once a year and by an optometrist at least every two years.
- Visit your doctor or optometrist as soon as you notice a change in your eyesight.
- Keep your glasses clean and wear the correct glasses if you have different glasses for different purposes.
- Give yourself time to get used to new glasses.
- Wear sunglasses and a hat outside on bright days.
- If the light changes suddenly, stop and give your eyes time to adjust before moving on.
- Ensure steps, stairs and walkways inside and outdoors are well lit.

Feet

- Wear well fitting, flat shoes with non-slip soles for increased stability.
- Wear well fitting slippers with non-slip soles.
- Don't walk around the house in socks or stockings.
- See a podiatrist or doctor if your feet are painful or swollen or if you develop problems like bunions.

Other things you can do:

- Stand up slowly after lying down or sitting.
- Eat a balanced diet and drink plenty of water.
- Keep as active as you can. Regular exercise will increase the strength of your legs and flexibility, improve your balance, help keep your bones strong, give you more energy, help you sleep better and help control blood pressure, blood sugar levels and weight.

Make your home safe

You can make your home safer inside and out by reviewing the following conditions including:

- Keep walkways wide and clear by removing or rearranging furniture, tucking electrical cords under furniture or close to a wall and tape them down.
- Remove rugs and mats that slide about, curl or fold over easily. Repair or replace torn carpet.
- Have a phone next to your bed you can reach easily.
- Have a bedside light you can turn on and off easily without having to get out of bed.
- Keep a torch next to your bed in case of a power failure.
- If you often get up in the night to go to the toilet, consider installing nightlights.
- Install hand or grab rails in the bathroom and toilet.
- Have a bathmat or non-slip surface next to your shower or bath.
- Arrange your kitchen and bathroom so items you frequently use are in an easy to reach place.
- Ensure all stairs and steps inside and outside your home are well lit. Consider installing automatic security lighting on the driveway, in the garage and front and back door steps.
- Keep footpaths in good repair.
- Install handrails on both sides of steps and stairs.
- Paint the edge of a step so it is easy to see.
- Have a chair, bed and toilet at a height that is easy for you to get in and out of.

What to do if you have a fall

If you live alone or spend long periods of time on your own prepare a plan in case you fall and have trouble getting up. You can practice getting up off the floor while you have a friend or helper visiting at your home.

- Have a telephone you can reach from the floor. This could include keeping a mobile phone in your pocket.
- Leave a spare key for a trusted friend or relative who lives nearby or in a combination 'lock box' outside so it is easy for a person who helps you to get in your house.
- Have a personal medical alarm if you have a history of falls or fear of falling.

What to do if you do fall

- Remain calm and assess the situation.
- Make a decision on whether to try to get up.

If you can get up:

- Use sturdy furniture to support yourself getting up.
- Tell someone you fell and seek medical help if you need it.
- Tell your doctor about your fall on your next visit.

If you can't get up:

- Activate your personal alarm if you have one.
- Try sliding or crawling to get help and to reach the telephone.
- Make a loud noise if you can't reach the telephone.
- Try to make yourself comfortable and keep warm until help arrives.
- Gently move around to stop one part of your body from being put under too much pressure.

To receive a copy of a home safety check list to help prevent falls, please contact your outreach worker.

Source: www.hqsc.govt.nz, www.acc.co.nz.

Master's Group Update

The Master's Group Steering Committee is working on two upcoming events and we look forward to seeing you all there if you can make it. We will be holding meetings at the Adult's Weekend in Christchurch during September and also in Napier later in the month.

The committee has made some great progress with the list of issues that was created at the Master's Weekend and later in Wellington last year. We need to update you with the latest news and to also start the hard work.

The Master's Group identified a number of issues that they wanted to address. We now need to identify what the issues are in depth, and once we do that we will put together a detailed report on the issues and present it to the National Council. We estimate this will take most of the next year to form and even then we will only cover the top of the list. It's a big list to be honest and each item calls on us to look at it properly and in depth. The Master's Group Steering Committee looks forward to this challenge but we can only do this with the ongoing help of the overall members.

I am pleased to tell you that the national office has also looked at the list of important issues and taken on board the issues that they are responsible for or have responsibility over and are working hard to address our issues on the subject, we are working with the National Executive on this as well.

We have, as you may know, a Facebook page (HFNZ Masters) and we welcome any of the Master's Group to join in. You can ask to be added to the page on Facebook or email me paul.longz@me.com and I will add you.

Communication will play a big part of the Master's Group and the Steering Committee is working hard to improve this within the group. Remember you can let us know your thoughts at any time and we welcome your input.

Profile: John Tuck - Through the Lens of a Camera

John Tuck has always had a spirit of adventure and a love of the outdoors. He grew up on the family farm in the Waikato finishing bulls for the American burger market and purchased his own motorbike at 8 years old. Neither riding a motorbike or chasing 700kg bulls is recommended for anyone with severe haemophilia A and inhibitors, but he wasn't going to let it get the better of him. He felt privileged to let loose and enjoy activities whilst his best friend, who also had severe haemophilia A, was wrapped in cotton wool. John was diagnosed with a haemophilia bruise at 6 months old by the family GP after a bump on the head.

For John, farming and contracting was his life up until 1993 when his right knee was fused. He had refused to have the procedure done for years as he knew it would be the last day he would ever be able to ride a motorbike, drive a tractor or excavator again - in other words dramatically change his lifestyle and means of livelihood. These days John is self-employed and based in Mt Maunganui. He still enjoys watching motorsport of any kind, and whilst he would love to be out on a bike himself he still gets a buzz attending motocross events.

When John took up photography he originally didn't think he had an artistic bone in his body but he surprised himself hugely over time. John had used a film camera for years but with the cost of developing the numerous photos he took becoming expensive he invested in a digital SLR camera. Consequently he decided to make the most of the new camera and enrolled in a course at specialist photography school located in Tauranga. There aren't many photography schools nationwide, so to have one located close to home was fortunate. John attended classes where he learnt how to use the camera correctly, point the camera to capture the best angle of the subject matter, and manually set up the camera. These prerequisite classes enabled him to complete the advanced courses, where he found his passion for night photography.

Each year John's tutor organises an annual photography competition which is judged by an outside panel. Last year's competition was based on waterscape themes. John was a high achiever with two of his entries placed in the top 5, including his photo 'Mirrored Sunrise at Mt Maunganui' (shown below) which won 2nd place.

John is passionate about day and night photography (sunrise, sunset and night photos) incorporating landscapes and waterscapes. It wouldn't be uncommon to find him out between midnight to 5am to capture the perfect image in a photo like the dawn of a new day when radiant colours burst out filling the horizon. He also sets up his camera with a slow shutter speed to capture different intensities of light in his photos. The slow shutter speed also works like a time lapse so he can capture stars shooting across the night sky as the planet rotates.

Haemophilia has affected John's ability to do photography at times. When he has a bleed he can't get out and about. He also has a stiff knee, and limited elbow and ankle movement which can make it difficult to carry a heavy backpack and equipment when he is taking photos in difficult terrain and around cliffs. Some of the locations he takes photos in can be risky and challenging as he can be in remote areas and out of cellphone coverage as he found out on while on one night photography trip on Skippers Canyon Road - an isolated back road near Queenstown. John had finished his photography for the night at 1.15am and awoke at 5.00am from a nap in his car with an illopsosa muscle bleed. He had lost range of movement and his foot could not touch the ground so he had to act quickly before he became immobile and couldn't drive. The drive out took half an hour on a challenging dirt road in the pitch black of night. When he finally got back to civilisation he found a well-lit area where he could infuse factor. The incident however left him taking refuge at a friend's place in Invercargill for a week to recover.

The unpredictability of haemophilia has meant John would never commit to do wedding or event photography. He wouldn't want to let someone down on their special day because of a bleed as you can't ask the bride and groom to come back 3 weeks after their wedding to take the photos.

Seven years ago whilst in Australia John had a brain haemorrhage. What was intended to be a 3 week holiday ended up being a 7 week stay, including 13 days in hospital. He was extremely fortunate to have survived and be left with no brain damage. This gave John a very real experience that life can be short, you don't know what is around the corner and you should maximise every opportunity and enjoy what you do. Consequently on John's bucket list is to own a motorhome with a small 4WD and travel around New Zealand to indulge in his passion for photography.

He knows his arthritis will get worse so he is contemplating fulfilling this dream while his body allows him to.

The once hobby photographer is now keen to promote his photos to the public and turn his talent into a professional service with the goal to help promote niche businesses in the tourism and hospitality sector through carefully photographed images. His passion for motorsport is not forgotten though as he plans to take photos of the action at as many events as he can with the intention of selling the images.

Through the images he captures in his photos, John wants to emphasise how beautiful a country we live in and if we all slow down and take the time to focus on the beauty around us, we will see how lucky we are. John wants to inspire people to get out, stop, look and enjoy these beautiful places.

If you are interested to learn more about John and his photography, please contact him by email at jtt1nz@gmail.com or phone 07 5757 230.

In Memoriam

Rob McIntosh

Rob McIntosh, former Southern delegate, from Invercargill passed away in June after a sudden illness. Rob regularly attended HFNZ events and contributed a story to HFNZ's book 'Still Standing' about his journey for new knees and his double knee replacement surgery.

Rob met his wife Jocelyn while in hospital in 1967 and they recently celebrated 45 years together. Within the community Rob was a member of the Ayshire Association had a number of winning Ayshire's at A&P Shows. He was also a leader and treasurer for St Aidans and the local scout district over 20 years. He was also involved with Young Farmers Association; and an active member of his church.

He will be sadly missed by his many friends, his wife, two children Tania and Murray, and grandchildren and great grandchildren.

Ian Church

Teacher, author and historian, Ian Church passed away in June after a short illness. The Southern member from Port Chalmers was 71.

Ian was qualified with a MA in history and was a well-respected and popular teacher, careers advisor, debate leader and leader of the student council. He also worked as an archivist at the Wanganui Regional Museum and as a curator at the Port Chalmers Maritime Museum. He wrote a number of published books.

While Ian did not have any children of his own, he enjoyed spending time with this nieces and nephews and grandnieces and grandnephews. He was the eldest brother of Rolland and Russell and is survived by his sister Pat.

Lisa Boston

Much loved mother, wife, daughter, sister and friend, Lisa Boston from Midland region was tragically killed in a car accident in June in the Lower Kaimais. She will be remembered for her fun, selfless and carefree personality. Lisa aged 42, leaves behind her husband and two children.

Frank Hancock

HFNZ notes with sadness the passing of member and friend Frank Hancock from Palmerston North in August. Frank was 92. An article will follow in the next issue of Bloodline.

HFNZ Congress Funding Applications Close 14 October

Applications to attend the World Federation Haemophilia Congress, held in Melbourne in 2014, are now being accepted. Congress is a wonderful opportunity to learn about the advances in haemophilia care, and to meet international people with bleeding disorders and members from the comprehensive care teams.

To apply to attend Congress you must:

- Be available to travel to Melbourne from 11-14 May 2014
- Hold a valid passport – must be valid for at least six months from the time of travel (and a current visa if applicable)
- Not have any criminal convictions that would stop you from entering Australia
- Have a strong command of the English language and be able to write reports on the sessions you attend for Bloodline

Please note - child care is not available at Congress and children are not allowed to attend sessions.

The deadline for applications is set at Monday 14th October 2013. Recipients will be notified on or before Friday 1st November 2013.

Information and application forms are available at www.haemophilia.org.nz, from your MRG or Outreach Worker. Completed Forms must be received by email or POSTMARKED on or before 14 October 2013 to HFNZ, as stated on the application form.

6 REASONS TO ATTEND WFH 2014 WORLD CONGRESS IN MELBOURNE, AUSTRALIA

1 PARTICIPATE IN THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY
and network with thousands of members, from around the world, convening in Melbourne, Australia.

2 GAIN KNOWLEDGE
of cutting-edge scientific research and clinical trials, profiling future advances in treatment products and clinical care.

3 SHARE INSIGHTS
on holistic patient healthcare issues and multidisciplinary care.

4 EXCHANGE WITH HEALTHCARE PROFESSIONALS AND PATIENTS
on challenges and solutions to improve treatment and care throughout the world.

5 COLLABORATE WITH LEADERS
of various stakeholder groups to ensure ongoing innovation that advances the WFH's vision to achieve Treatment for All, laying the foundation for the next 50 years.

6 DISCOVER UNIQUE AUSTRALIA
with your family before or after the congress, as this might be a once in a lifetime opportunity to visit down under.

WFH World Congress 2014 Sessions

A great reason to go to the World Federation Hemophilia Congress in 2014 is the vast list of plenary, multidisciplinary and medical sessions available to attend. The sessions cover a broad spectrum of topics that will cater for everyone's special area of interest.

The plenary speakers are reputable members of the international bleeding disorder community and are guaranteed to provide informative sessions on the latest research and treatments. The multidisciplinary sessions include topics that are developed for people with bleeding disorders, caregivers and healthcare professionals. The medical sessions are still in development with ten sessions announced to date and 29 more to come.

A summary of the sessions and speakers is available at www.wfh.org/congress/en/speakers.

Plenary Sessions and Key Note Speakers

Treatment for all: Forging ahead
Mr Alain Weill, WFH President

Primary hemostasis - Newer insights
Professor Michael Berndt, BSc (Hons), PhD. Pro-Vice Chancellor, Health Science, Curtin University

Epidemiological aspects of inhibitor development
H. Marijke van den Berg, MD, PhD, BSc (Hons), PhD. Pediatric Hematologist, Department of Health Science and Epidemiology, University Hospital of Utrecht, the Netherlands

Inhibitors - Cellular aspects and novel approaches for tolerance
David W. Scott, PhD. Vice Chair for Research, Department of Medicine, University Uniformed Services School of Health Sciences (USUHS), Bethesda, MD, U.S.A.

With blood in the joint: What happens next?
Carl Blobel, MD, PhDSenior Scientist, Hospital for Special Surgery, New York, NY, USA

Defining care in hemophilia: Beyond the treatment guidelines
Alok Srivastava, Professor of Medicine, Head, Department of Haematology Christian Medical College Vellore, Tamil NaduIndia, India

New products for the treatment of clotting factor deficiencies: Current status
Prof. Johannes Oldenburg, MD, PhD. Director, Institute of Experimental Haematology and Transfusion Medicine and the Haemophilia Centre, University Clinic in Bonn, Germany

The future of hemophilia prophylaxis with novel therapies
Manuel D. Carcao, MD, MSc. Paediatric Haematologist/Oncologist, Haematology/Oncology, The Hospital for Sick Children, Toronto, Canada

Multidisciplinary Session Themes

Multidisciplinary management of chronic pain
Topic 1: What is pain?
Topic 2: The multidisciplinary chronic pain team approach
Topic 3: Top tips for PWH in managing chronic pain

Beyond registries: integrated information systems
Topics and speakers to be confirmed.

Management with no or limited CFCs: What is possible
Sessions currently in development.

Embracing women's sexuality
Topic 1: Gynecological issues for women with bleeding disorders
Topic 2: Women and their partner's perspectives
Topic 3: Intimacy and self-esteem
Topic 4: Questions and answers

Non-adherence strategies explanations and strategies to overcome it
Topic 1: Non-adherence and its impact on treatment efficacy
Topic 2: Tools to assess adherence
Topic 3: Tools & techniques to improve adherence
Topic 4: Demonstration of a motivational interview: Patient and nurse

Black and blue and still golden: Coping skills developed as you age
Topics and speakers to be confirmed.

Recipes for healthy living – Beyond the vegemite sandwich
Topic 1: How nutrition affects coagulation
Topic 2: The effect of obesity on joints & osteoporosis
Topic 3: A real concern in PWH

Disclosure: when, how, and who to tell about a bleeding disorder
Topic 1: Overview of social and cultural aspects of disclosing a bleeding disorder
Topic 2: Experiences of disclosure – stories from the field
Topic 3: Psychological aspects of disclosure

Leadership development strategies: Am I ready to "Carry the flag"?
Topic 1: The importance of leadership development and succession training
Topic 2: What exists within the BD community with respect to leadership development
Topic 3: Youth experiences – stories from the field

Differentiating arthropathic pain from pain related to acute bleeding
Topic 1: Signs, symptoms, and indicators: Is it really a bleed?
Topic 2: Patient-reported issues indicative of arthritic pain
Topic 3: Coping with the transition from 'pain is a bleed' in childhood to 'is this arthritis?' in adulthood.
Topic 4: "I managed my arthritis better and suddenly I seemed to stop bleeding so much"

Stronger together: Medical and lay collaboration
Topics and speakers to be confirmed.

The future of hemophilia care – understanding global demand for treatment
Topics and speakers to be confirmed.

We should talk: Sharing information with carriers and those who care for them
Topics and speakers to be confirmed.

Building a team and learning how to work together: multi-professionals and patients
Topic 1: Facilitating communication when working together: the different languages of different professionals
Topic 2: Effective multi-professional's teamwork stories
Topic 3: Occupational therapist, welcome on board!
Topic 4: Patient perspective on being a team member

Approaches to inhibitor management
Topics and speakers to be confirmed.

Education and employment issues for people living with a bleeding disorder
Topic 1: Data on Education and employment: Now and then
Topic 2: "What will I be when I grow up?"
Topic 3: Rights, duties, challenges and tips for entering the job market
Topic 4: United we can do it: How NMO's can work on solutions to provide opportunities

Medical Sessions

Genomics of bleeding disorders
Rare bleeding disorders
Gene therapy and other novel therapies
Enhancing hemophilia care through registries
Inhibitors
Prophylaxis: higher-dose model
Prophylaxis: lower-dose model
Vwd and platelet disorders
Co-morbidities
Clinical trial design

Plus 29 more sessions in development:

Eight free paper sessions
Two late-breaking sessions
Six professional development sessions
Six musculoskeletal sessions
Four laboratory science sessions
Three dental sessions

WFH 2014
WORLD CONGRESS
MELBOURNE, AUSTRALIA • MAY 11-15

Outreach Invited to the Great Plains Women's Retreat

Northern Outreach Worker Sarah Preston attended the Great Plains Women's Retreat in April, courtesy of the Texas haemophilia community, to share ideas about running events for women with bleeding disorders. The event was facilitated by Social Worker's Ed Kuebler and Sabrina Farina, both from Gulf States Hemophilia and Thrombophilia Center. Sarah describes her experience below.

The Great Plains Women's Retreat was held at Camp Allen located 45 minutes outside of Houston, Texas, for women with bleeding and clotting disorders from the wider Great Plains area, which covers many different treatment centres and chapters. During the weekend they were also concurrently running their first ever Great Plains regional girl's camp.

Camp Allen was a lovely location set on 950 acres with woods, a big lake and a range of recreational activities. The Women's Retreat had about sixty participants (and one therapeutic dog), with the women staying in 'cabins', which were actually really nice rooms. All of which made for a very peaceful get-away for the women.

The girl's camp was a new initiative and was for girls aged 13-17 years with bleeding disorders. There were seven girls altogether and they were staying on the other side of the camp, completely separate to their mums in real log cabin bunkrooms. They had the theme of the 'Hunger Games' throughout all of their activities and sessions.

The women started each morning with an optional walk for 45 minutes before breakfast which gave a chance for the women to bond and also to enjoy nature. This was followed by an after breakfast song and dance to get the energy up to start the day.

There was a range of educational sessions (two each morning) such as anaemia and vitamins, the structure of the organisation, medical education, self-defence and my New Zealand presentation. My presentation during a morning plenary session was about the experience of women with bleeding disorders in New Zealand. It included information about New Zealand and Maori culture, the structure of the HFNZ, the member representative groups, what we provide for our women, and the history of where we have come from in working with women and where we are today. I illustrated this with some stories of our members. Throughout the weekend we shared insights on the similarities and differences between our organisations, camps, and care models which enabled lots of information and ideas to be gathered to put into use for our HFNZ Women's Retreat.

The educational sessions were followed by break-out sessions, and the afternoon was left for therapeutic and fun activities such as massage, reiki, kayaking, horse riding, zumba, art and crafts, yoga, great outdoors walk and some optional sessions. Each evening had an activity such as the ice cream social, shoots and ladders quiz game, and a fiesta casino night.

The girls had sessions on sexual health, medical education and I spoke to them about the experience of New Zealand girls with bleeding disorders, Maori culture and empowerment. They had fun activities such as yoga, canoeing, nature survival, campfire making and hut making, arts and crafts, movies and board games.

The retreat was coordinated and facilitated by the social work and medical staff but run in most part by the women themselves. They have their own steering committee and come up with what they wanted sessions for, themes, things they want to incorporate, and they do a lot in the setting up and organising throughout.

A big hit was their Country Store. This is where each camper donated something from home that might be handmade or something special and other participants could purchase it from the store. It was a great way to get presents and gifts and all the money went back to the Foundation.

On the final night they had a Fiesta Casino night. Everyone dressed in theme and got into teams to play blackjack. It is all set up properly with dealers, gaming chips and tables and there is a lot of screaming, yelling and celebrations! The night finished with a White Elephant Steal-athon so everyone goes away with a gift.

The Great Plains Retreat was a wonderful experience to be a part of and a real privilege. I learned so much from the amazing women I spoke with or who shared their stories and it was really inspiring and refreshing to feel the love and comradery that built up over the four days.

Exotic Places for a Roadie to Factor-Up on Tour

By Joseph Veale

Joseph Veale describes how he manages life on the road as a sound engineer with severe haemophilia.

I'm privileged to have a job that takes me from my home in Christchurch to destinations all over the world – often exotic places filled with even more exotic people. Myslovitz, Wuhan, Seoul, Berlin, Tianan and more have all been host to this traveling bleeder.

As a sound engineer for touring bands, I'm lucky enough to traverse the globe under the guise of work, clocking up more than my fair share of air miles in the process. However, with a condition like haemophilia, these trips require a little more than the usual dose of travel logistics.

Most people don't long for long haul flights (except perhaps those in that elusive ottoman-rich world of first class), and especially not severe haemophiliacs. The incredible boon of the new Factor8 is the formula's ability to survive at room temperature, in turn increasing my ability to survive a hike halfway around the earth.

Thanks to these tours I've learnt the art of packing the bare minimum of injecting accessories. I've also developed a knack for squeezing maximum product into a 23kg case already overburdened with microphones and tour necessities. The newer Factor8 means formerly formidable 48-hour flights or 24-hour cross-Europe drives are now entirely manageable.

Though my carry on now includes an ergonomic pillow instead of an esky of coagulant, caution is still a close companion. Taking some Factor8 and spare kit on board with me, in case of lost luggage, is a must. Improvised injection spots are also essential. Between long drives, load ins, sound checks, dinners, support acts, shows and load outs, there is precious little time to be fussy about locations to draw up and dose.

Here are my top three strange locations to self-infuse to date, hopefully there's more to come...

①

Number one on the list has to be the first class 747 bathroom flying to Auckland direct from Las Vegas. Air New Zealand had booked a band I was working with to play a show in a ritzy casino. A week of Vegas antics and 43-degree days was rounded out with a rocking show replete with all the trimmings. Thanks to the friendly Air New Zealand staff, my lowly crew were upgraded to first class seats along with the band. After falling asleep to stars flying past the window, a painful elbow woke me up. With the rest of the plane sleeping off seven days of excess, I had the opulent first class cabin all to myself. After a successful injection, I helped myself to some midnight (Western Standard Time) snacks and slipped back into bed.

②

Between bands at a venue in Dublin, my left elbow began to blow up. The mezzanine bar was closed, so I asked one of the bar staff if they minded if I used the bar top upstairs. There was some good down lighting and the bar top and stools were an ideal height. I had a great view of the stage as the local crew changed the stage over to my band's setup and, freshly loaded with Factor8, I made it back downstairs in time to mix a killer set.

③

After sound-check for a 'steam punk' band at a festival in Brisbane, my crew's changing room was hijacked by burlesque dancers switching stockings between acts. Wanting to give them privacy but needing to dose for a swollen left ankle before show time, I locked myself into one of the VIP Portaloos backstage and made use of the Egyptian cotton towels as a pillow while the "Gypsy punk" support acts bellowed through the plastic walls at 110dB, ably assisted on stage by freshly costumed twirling dancers!

MRG Reports

HFNZ operates six groups that represent our members, four regional branches (Northern, Mildand, Central and Southern), the National Youth Committee (NYC) and the Piri Toto, which represents Māori members.

Northern Region

By Lynley Scott

May saw Northern MRG continue with what now seems to becoming a tradition – the Ladies High Tea. This year we held simultaneous events in Northland and Auckland on a Sunday afternoon. About 20 Auckland women gathered again at Cornwall Park Restaurant in the lovely Cornwall Park and in Northland about 7 women joined together at the Oceans Resort in Tutakaka. Both groups enjoyed a fantastic high tea and great company. There never is a shortage of conversation when women get together and there was a great sense of community knowing that we had two groups meeting together at the same time.

In the last weekend of the school holidays, a small group of Northerners braved the 2 hour drive to Waitomo Caves. We enjoyed a great 45 minute trip through the caves with our own guide and a short boat ride through the glow worms. We were all fascinated by the caves and the glow worms that we saw. Many of the group had never been through the caves so it was a great opportunity to see some of New Zealand's countryside and treasured spots. We then moved on to a park close by to enjoy light lunch and more conversation. While it was a small group, it provided ample opportunity to talk with everyone.

Over Labour weekend, Northern again have the opportunity to provide some 'man/woman power' and volunteer at the Armageddon Expo. The money raised will go towards sending participants to WFH Congress in Melbourne next May. We'd love to break the shifts into half day and have as many people help out as possible. So watch out for the email asking for volunteers and put your hand up to assist the Foundation.

The committee is busy planning events through to the end of the year including a Cambodian dinner, a Zoo Christmas Party and a few others. We'd love to see you there! Make sure you keep an eye in your inbox as we are sending our event invitations by email if you have one recorded with National Office.

Looking forward to the spring and all that it brings with it.

Central

By Stephanie Coulman

We farewelled our Treasurer, Blair Wightman, who has gone to the UK to live for a couple of years. "We are starting to settle in to our lives here and have found a nice flat to live in here," says Blair. We look forward to hearing how he manages his haemophilia while working in the UK.

A small group attended a café evening in Napier in July. It was held at the RSA which was absolutely packed when they arrived being a Saturday night. The queues were long at first but the place emptied out quite quickly. Thanks to Ricki Conwell for getting this event off the ground. He is determined this should not be a one off and is planning a day time family event in the summer.

Some Central region members attended the women's workshop in Auckland and came away having learnt a lot about their own condition. We learnt that for every man with haemophilia there are 5 women around him who are affected by it in some way. It was a weekend to remember in another way. Earthquakes in Wellington disrupted the return for several of us. Just as we were about to land in Wellington the flight had to return to Auckland as the runway needed to be inspected.

We are looking forward to our combined Midland/Central camp in September at Kennedy Park, Napier.

Southern Region

By James Poff

Welcome to this Southern Region MRG update.

It has been fairly quiet over the last couple of months in the region however some brave parents and children went to see the Crusaders vs Blues in May on a cold a rainy day. Great to see some new faces and the children all enjoyed a good game with free flags from the Rugby Union.

There has been plenty of activity in the planning for Southern's 30th Anniversary celebrations planned for Labour weekend 2013. The organising sub-committee has been very busy planning this event. A venue has been booked and guest speaker booked – Jim Hopkins – think of big red framed glasses. I have heard Jim speak before and he is very entertaining and always carries out plenty of research prior to any event. Planning is also underway for a family / picnic event on the Sunday for all members and their families. So please join us to celebrate this fantastic milestone for our branch and the wider HFNZ Family.

Upcoming Events.

A fundraiser has been planned for Saturday 17 August. The evening event will consist of a play by David Tristram about the trials and tribulations of a long-married couple who are bored with their marital state, and to alleviate the tedium they fantasise about other people and situations! Directed by Heather Giles. A great night to be had out! Licenced bar and fundraising raffles will be held on the night.

- Southern MRG 30th Anniversary Celebrations. Labour weekend 26 -27 October, 2013. Please get your registrations in as soon as possible.
  - Saturday 26th – Evening celebration and dinner from 6pm, Blossom Lady Lounge (note room change) in the Metropolitan Stand, Addington Raceway.
  - Sunday 27th – Family picnic at Cracroft Guiding Centre, 11am-2pm. Lunch is provided with activities for the children and a great chance to socialise.
- Christmas party - Sunday 8th December. The venue and activities to be advised!! Calendar now.

A Southern MRG meeting was held on Tuesday 6th August and the final one for the year will be on 12th November 2013.

I would like to conclude by giving a big thanks to those people who have given up their time to assist with organising the Southern MRG 30th Anniversary celebrations. As with any volunteer organisation these events would not happen without these people being prepared to give up their time to help. Please support this important gathering, acknowledging & remembering the past & looking forward to the future for our members, families and the Foundation.

Youth

By Lauren Nyhan

The National Youth Committee recently held a meeting via Skype to discuss our roles and obligations within the Foundation as well as our upcoming event.

At the moment we are in the planning stages of a 'spring break' event coupled with some R'n'R on the 11th-13th October for those aged between 18 and 30. We will be holding this event in one of the main centres (Auckland, Christchurch or Wellington). Invites will be out shortly so watch the Facebook page and your inbox for details. Places are very limited so please get in quick if you want to have say in the direction of the Youth Committee.

Courtney Stevens recently attended the Women's Retreat held in Auckland and provided the committee with come great feedback from the event. One of the key ideas that arose was the lack of awareness about the NYC, our accessibility and essentially what we do as Member Representative Group. Leading up to our next event we will be focussing on member engagement and in particular maintaining our Facebook page and updating contact details so that we are able to get the information about events out to everyone!

We have also recently set up a Google Drive to store all of our minutes, agendas, a working contact list and other important documents in one place for all committee members to access. We chose to do this as a means of backing up data as well as being able to easily share important information that is accessible from wherever we are.

If you want to get in contact with us about upcoming events or any ideas that you may have, email us on hfnzyouth@gmail.com, also we really encourage you to provide the HFNZ with your up-to-date contact details and to get onto the Facebook page (HFNZ Youth). As we are all spread out over the country we want to make this an online community for sharing HFNZ information as well as facilitating discussion.

Advance Your Passion

Thanks to the support of Baxter the Advance Your Passion 2012 winners have successfully achieved their goals.

Jack Finn
- Kayaking the Kangerlussauq Fiord

For many years I have had a passion for expedition sea kayaking and wanted to learn more about how the kayak evolved and where it all began in the remote and wild, yet beautiful country that is Greenland. With thanks to HFNZ and Baxter this passion became reality.

A lot of preparation and planning had to get underway before the journey could begin. I had a contact based in Greenland who I found out about through a friend. He would fit in perfectly to accompany me in making a sea kayak expedition with his local knowledge of the history, weather and hunting for food. With many an email exchanged across the globe, we secured the dates, location and gear needed for the trip.

Getting to Kangerlussauq in Greenland is not exactly easy, but after 40 plus hours flying I eventually landed on the biggest island in the world. The town is located roughly 50 kilometres north of the Arctic circle. Greenland is also the least populated country in the world with only 55,000 people living there. Kangerlussauq, where we departed from has a total population of 500.

Upon arrival I'm greeted by Jens-Pavia (Greenlandic/Danish) the local sea kayak guide and with him several hundred armies of the worst mosquitoes I have ever experienced – thank goodness for mozzy nets I say!

Our plan is to paddle out the Kangerlussauq Fiord retracing the original Inuit kayak route used for hunting and fishing. Finally with all the kayak gear, rifle, fishing line and blood products packed (shouldn't be a problem keeping these chilled!) we are set to go.

Several challenges I faced straight away was how cold the water was (about 3 degrees!) as the fiord water flows straight from the massive Greenland ice cap which is only about 5 kilometres away. So we were both kitted up with layers of merino under our drysuits to stay safe and warm whilst kayaking. The second issue I had to overcome was I had to use a traditional Greenlandic wooden paddle which was a bit like paddling with a thin plank of timber!

Progress over the first day or so was good and we covered 20-30kms each day - with 24 hours of daylight it is easy to maximize your time. The only food supplies we take with us are some powdered milk, muesli and hot chocolate – the rest we had to hunt for ourselves. We also have no gas cookers so relied on open fires for cooking each day. Arctic snow hare is on the menu for the first few days – cooked stir fry style on a flat rock, I also managed to catch a fiord cod fish which we also gulp down after big days paddling on the water. Streams flowing into the fiord provided us with the necessary drinking water and fortunately there are also large amounts of dry wood for cooking.

On day 3 and 4 we contended with 25 knot, icy cold head winds whistling down the fiord making progress very tiring and arduous. Jens-pavia managed to shoot a Musk Ox, so we had no shortage of meat now (luckily I'm not a vegetarian otherwise I would have starved!).

It is clear from being in this harsh environment how 'hardy' and tough the Inuits must have been, no such things as gore-tex then just heavy wool, seal skins and wooden kayaks. Jens-pavia explains how his people focus on the simple things in life – love, shelter, food, water and happiness. As we headed further out the fiord we see old Inuit graves alongside the water – made up of rocks just piled on top of the dead.

We are lucky enough to catch delicious and rare Arctic char (like trout fish) which we cook on top of the fire – perfect after a tough days paddling.

The surrounding landscape is far more remote than New Zealand, snow covers the surrounding mountains. Dropping down the glaciers are crystal clear streams into the fiord. Colourful purple and red flowers are appearing everywhere and wild berries will soon be ready to eat. When the wind calms in the evenings the silence is incredible –apart from the horrid drone of the monster mosquitoes on the outside of the tent!

Nearing the end of my journey we camped in a large bay. With some 150 kms covered, we both sleep well and rest as the body is tired, sore and well used! I don't really wish to return to reality and the hustle and bustle of the city life and could quite easily just continue out the fiord and never return!

Greenland is a truly magical country, isolated from the rest of the rat race of the world it has amazingly warm and friendly people, jaw dropping scenery and wildlife. I feel very privileged to have visited it and take home many great values, photos and learning's to share with others about sea kayaking and its roots.

Special thanks to all involved especially HFNZ and Baxter, my children, my mother, my wife Sian and grandfather Merv Hancock for being my inspiration in life.

Raukura Riwaka
- Equipped to Complete His Degree

With the Advance Your Passion grant Raukura purchased equipment to use for his Bachelor of Creative Technology. This included a laptop and hard drive, both of which were critical to his success during study.

The equipment also enabled him to help his brother, Neville James Reedy, to produce a film. In October 2012, he took part in a documentary about his cousins, Te Ahuriri Stirling, journey with haemophilia biking around the East Cape of the North Island, while dealing with haemophilia and its long-term effects.

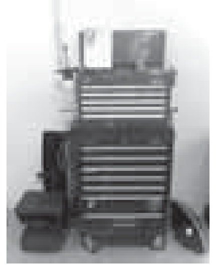
As an aspiring filmmaker, this was the journey of a lifetime for Raukura and provided him with the necessary experience and confidence he needed to continue through to his final year of study at Weltec.

Neville James Reedy
- Blood, Land and Journey

Neville James Reedy was in his final year of study towards a Bachelor of Digital Media when he produced a short film with his Advance Your Passion grant last year. The grant enabled the film crew to travel to the East Cape to capture the story of Te Ahuriri Stirling's journey with haemophilia where he grew up.

Neville was the producer/director of the film which was created to encourage other people with haemophilia to manage their wellbeing, not give up on their dream and to live their lives. The footage was used to develop a short film for his final assessment. He recently also completed a film trailer and intends to release a feature length edition of the film later this year.

Connor McQueen
- Grant Revs Up Skills and Confidence



Connor McQueen is a second year apprentice in the motor industry paint and panel sector. He utilised his Advance Your Passion grant to purchase a 16 draw toolbox and specialist tools for his trade. He also brought a work seat on wheels with a storage draw which means he does not have to get up and down constantly putting strain on his joints.

Previously Connor had to borrow tools from the other tradesmen at the workshop, but now he can focus on developing his skills. During his apprenticeship he has progressed from spending some of his time cleaning the workshop and customer vehicles to solely repairing cars. His skills have advanced from fixing dents to cut and welding new panels, which he loves as it tests his panel beating skills. The advance in his skills has built his confidence and trust in his own judgement.

Connor has one year left on his apprenticeship which is sponsored by State Insurance who pays for his fees and off-the-job training. He was one of three people in the country to receive this last year.

News in Brief

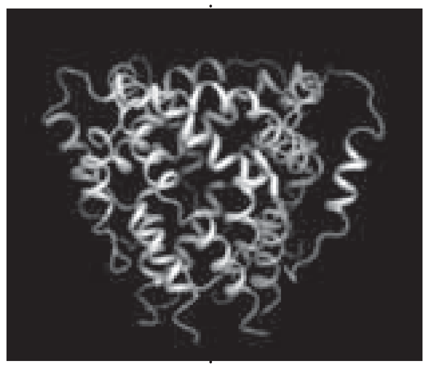
Christchurch Clinical Studies Phase 1 Trial

The Christchurch Clinical Studies Trust Limited (CCST) is commencing a recombinant factor VIIa phase one trial. The study aims to determine the best dosage level in humans of a single dose of this new clotting factor protein. Study participants must have haemophilia A or B, and do not have to have inhibitors. The participants have an initial 3 day inpatient stay followed by several short outpatients visits over 2 months.

The purpose of a phase one trial is to test a drug on humans for the first time. Animal testing has already been conducted. In humans the study measures how long the drug stays in the blood stream after dosage and how the body reacts to the drug which helps determine the best level of dosage.

Scientific research is important for the development of new and potentially lifesaving treatments. Trials in New Zealand are conducted under strict Medsafe regulations. If you are interested in further information about this trial please contact Dr Mark Smith, Haematologist, at Mark.Smith@cdhb.health.nz or 03 364 0387.

Hepatitis C Virus P7 Channel Could Help Researchers Find New Ways to Fight the Disease



Scientists have located a binding site that has the potential to block HCV. The p7 channel is a membrane protein that has a three dimensional structure and presents ion activity which is essential for virus infectivity. Discovery of this gives scientists a target for drugs to fight the disease and break the infectious cycle of HCV.

“We were absolutely surprised by the highly unusual architecture adopted by this viral channel, which doesn’t look anything like any of the known prokaryotic, eukaryotic or viral ion channels,” James Chou (HMS professor of biological chemistry and molecular pharmacology) said. “We also found information that will be useful for immediate pursuit of new anti-HCV compounds targeting this viral channel.”

With approximately 150 million people infected worldwide with hepatitis C and 350,000 people dying each year from the associated liver diseases such as liver cancer, new drugs are needed to help fight the infection.

Of the six genotypes of the HCV virus, some strains have developed varying degrees of drug resistance. HCV is an RNA virus so it is able make copies of itself quickly and therefore it has fast mutation and evolution capabilities that can develop drug resistance within 24 hours.

“To take out an RNA virus, whether it’s flu or HCV, you need to find multiple targets and hit them all at the same time, using a cocktail approach. HCV currently has effective drugs targeting only a single type of target,” Chou said.

From studies in 2008 James Chou’s lab identified the structure of the M2 channel of the influenza virus which enabled the molecules in the drug rimantadine to fit inside the channels and block the virus’s infectious cycle. Rimantadine has the potential to be effective against HCV, however it only blocks the channels of some strains and not others. The M2 and p7 channel sizes and chemical structure are different, which led Chou to believe the physical structure of the p7 channel would offer important clues.

Chou believes a greater understanding of the p7 channel will help provide clues to why this occurs. The p7 protein only has 63 amino acids in comparison to bacteria that which more than 200. To form a stable structure, the p7 protein forms multiple links with neighbouring molecules and with the neighbours; neighbours.

Chou’s team observed the dynamics of the p7 channel in solution using Nuclear Magnetic Resonance techniques. It showed a critical function of the channel was to change from open and closed states like “breathing”. When the channel “exhales” it allows ions to pass across the membranes in key organelles located in the host liver cells.

The lab identified the binding site in the p7 channel in comparison to the M2 channel in influenza. The M2 channel gets plugged up by the drug molecule whilst in p7 the drug sits in pockets in the folded outside edge of the funnel which inhibit the channels ability to “exhale” and therefore release ions.

“It’s important to look at the chemical, electrical and mechanical aspects of this structure as parts of a dynamic system,” Chou said. “Once we know the structure of the channel and can visualize how the system works together, we can begin to think about other ways to block its function, and perhaps use those insights to develop new drugs for HCV.”

Source: http://phys.org/news/2013-06-hepatitis-virus-ion-channels-drugs.html

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Boceprevir to be Funded in New Zealand

From 1 September 2013, boceprevir (Victrelis) will be funded, under Special Authority, for the treatment of people living with chronic hepatitis C, Pharmac have announced.

Boceprevir will be funded for triple therapy with pegylated interferon with ribavirin to people with chronic hepatitis C, genotype 1 with the IL-28 gene CT or TT allele who have never received treatment for hepatitis C and also for those who have previously been treated with pegylated interferon with/without ribavirin who were partial responders, responder/relapsers or were treated prior to 2004. Treatment with boceprevir will be funded for a maximum of 44 weeks.

Boceprevir will be the only funded protease inhibitor for the treatment of hepatitis C in the community until 30 June 2016.

Extracted Stem Cells Could Provide Personalised Treatment for Hemophilia

A study on people with von Willebrands has shown stem cells called endothelia progenitor cells could be a future source to test new drugs. Endothelia cells produce von Willebrand factor and form the lining of every blood vessel in the body. The cells have previously been difficult to study because biopsies have proved to be invasive.

Routine blood samples were taken from patients with vWD and the endothelia progenitor cells were extracted. The research lab then grew and analysed the cells. From the research defects in patient cells were identified which could help doctors prescribe more effective treatments in the future. Drugs could potentially be tested on the patient’s own cells, before the actual treatment is given to the patients. Further research will help determine the cause of some diseases in individual patients. It is hoped the research findings will reduce severe bleeding in patients.

In addition, there is the potential haemophilia could be treated by extracting cells from a patient, the gene then replaced and the cells re-inserted back into the patient.

Source: www.scienceworldreport.com

FDA Approves New Drug For Haemophilia B

The first new recombinant coagulation factor IX treatment in more than 15 years has been approved by the Food and Drug Administration for marketing in the U.S. The treatment, Rixubis, for people with haemophilia B aged 16 years of age or older is for the control and prevention of bleeding episodes, perioperative management and prophylaxis.

Rixubis is a purified recombinant protein produced by DNA technology. It does not contain human or animal products. The treatment is supplied in single-use vials of freeze dried powder to be injected intravenously after reconstitution with sterile water.

The phase I/III study achieved a median annual bleed rate of 2.0 with no bleeds reported in 43 percent of patients on twice weekly prophylactic treatment over six months. No patients developed inhibitor antibodies. The most common side effects that occurred in less than 1 precent of the participants were dysguesia (distorted taste), pain in extremity and positive test for furin antibody. Patients in the prophylaxis study had a 75 percent lower annual bleeding rate in comparison to patients who ordinarily receive on-demand treatment. Further study is being conducted in a paediatric population.

This treatment is not currently available in New Zealand.

Source: www.fda.gov

Work May Lead to Effective Gene Therapy for Adults with Severe Haemophilia B

Katherine High, MD, and Director of the Center for Cellular and Molecular Therapeutics at The Children’s Hopital of Philadelphia, along with a team of researchers have produced a bioengineered decoy that tricks the immune system. The decoy enables corrective genes to be delivered to target cells in the liver intravenously before pre-existing antibodies stop it. The tests have been effective in animal studies and it is considered to have the potential to help genetic diseases such as haemophilia if it succeeds in humans.

Capsids, a protein shell that enclose a virus, are used as a decoy and adeno-associated viruses (AAVs) are used to carry the genetic material that triggers the production of factor IX. Tests in rhesus macaque monkeys indicated an increase in levels of factor IX production, with no adverse side effects.

“This decoy strategy could be individualised to patients and could greatly expand the population of patients who may benefit from gene therapy,” said High. “Right now, 30 to 60 percent of adult patients develop antibodies that block the ability of an intravenously infused vector to reach the target cells in the liver. This approach holds the promise of overcoming this roadblock pre-existing antibodies and allowing successful intravenous gene therapy in virtually all adult patients.”

“Our results, which held up over a range of doses, suggest that in clinical studies, it will be feasible to adjust the ratio of empty capsids to gene vector doses, depending on an individual’s pre-existing level of neutralizing antibodies. That means we could personalize gene therapy to make it more efficient for each patient,” concluded High. “This work should make it possible to bring effective gene therapy to most adults with severe hemophilia B. Each patient would receive a personalised final formulation that contains just the right amount of empty capsid to neutralize any pre-existing antibody, and allow the gene-expressing vector to reach the liver.”

Source: www.chop.edu

Twinning Connection

An update on the Cambodian Hemophilia Association (CHA) and Haemophilia Foundation of New Zealand (HFNZ) Twinning Project.

The Cambodian Hemophilia Association has been busy in recent months as they continue to build the foundations of their organisation and undertake the tasks on the 2013 twinning action list.

The Association renewed their registration with the Ministry of Interior which is necessary to enable them to operate and identifies them and a non governmental organisation.

CHA have established permanent contact details to make them more assessable to new and existing members. They purchased a mobile phone that is dedicated solely as an office line and opened a post office box. In addition, CHA have developed a Facebook page which they regularly update, and a number of HFNZ members have already connected with and 'liked' it. CHA have also produced a brochure about their organisation. A website is also being developed.

CHA board members and trained volunteers have been doing home visits to families in Phnom Pen, and in the provinces of Kandal, Banteaymean Chey and Siem Reap. A business card has been created to use as identification for visits.

The 2013 Annual CHA – HFNZ Twinning Visit will take place in Phnom Penh between 29th August and 3rd September. Colleen McKay will be accompanied by Christchurch physiotherapist Lee Townsend. During the visit Colleen and Lee will both speak at the Educational Workshop for patients and their families. They will also accompany CHA Board Members to meet with the Director of the Blood Bank, Secretary to the Minister of Health, Cambodian Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY), and the Disability Action Council.

In New Zealand our support of the Twinning Project continued with participants at the Youth Camp in April and the Women's Retreat in August learning about 'Bleeding disorders around the world'. The presentation had a focus on living with haemophilia in Cambodia.

The Women's Retreat participants also had some fun with a fundraising 'market table' for Cambodia. Each person donated a craft item to sell on the night with the proceeds going towards HFNZ work in Cambodia, specifically to enable the physiotherapist to assist patients in Cambodia. The women raised an impressive $1026.

To support CHA you can make a donation towards HFNZ's twinning venture with Cambodia by contacting Colleen McKay on 03 3717479 and by liking their Facebook page. Search for the Cambodia Hemophilia Association.

Council Corner

The National Council meeting on 25 May took place in Wellington.

HFNZ President Deon York reported on the recent WFH Congress Organizing Committee meeting in Melbourne. He advised that the Melbourne Convention and Exhibition Centre was an excellent facility and encouraged all members to consider attending Congress in 2014.

Following on from the success of the Men's Weekend and the Men's Masters Weekend in 2012 a Master's group has been formed. Steering committee representative, Paul Long, presented to the National Council the list of priorities developed by the group in conjunction with men's health specialist Greg Millan. Two priorities for the group included having a voice on the National Council and increasing communication between the older members. To date, a private Facebook page has been developed for older members to join.

As a result of the presentation, the National Council approved a budget that would enable representatives from the Masters Steering Committee to meet with older members nationwide over the next 12 months to determine the needs of the group within the regions; and have seconded Paul onto the National Council as a representative for the Masters.

The Master's group will consist of men aged 25 plus. Where there is an overlap in age with the Youth MRG, members can choose to join the group that will best meet their needs.

Colleen McKay, Manger – Outreach Services discussed the success of the Youth Camp in April and Parents Empowering Parents in May, with an increase in attendance at both events. She also discussed gaps in the educational camps and workshops for males aged 18-25/30 and potentially females aged 10-16. She will discuss with the Youth committee the needs of its members to determine if they could be met through the existing workshops.

The congress committee has developed the criteria for members to apply for funding to attend the WFH Melbourne 2014 Congress. Application forms and details are available on the HFNZ website and through the Outreach Workers. Applications close 14 October 2013 with successful applicants notified by 1 November 2013. National Council has urged the MRG's to promote this among their groups.

The Roopu Member Representative Group has renamed their group "Piri Toto" which translates as *"the blood that binds us"*.

Stay Connected With HFNZ

Keep up-to-date with the latest news and events from HFNZ through a range of channels. Choose one option or choose them all but most of all HFNZ want to stay connected with you.

Update Your Contact Details

Have you moved house, changed your email address or phone /mobile number? Then please contact your outreach worker to have your details updated on the database.

Like Us on Facebook

Like us on Facebook to stay informed of HFNZ's happenings at www.facebook.com/haemophiliaNZ.

Subscribe to HFNZ on YouTube

Subscribe to watch videos of HFNZ events and our members on www.youtube.com/user/haemophiliaNZ.

HFNZ Panui E-Newsletter

Have the latest HFNZ news delivered directly to your inbox. Panui is a monthly e-newsletter that contains information on upcoming national and member representative group events, competitions and news. Email info@haemophilia.org.nz if you would like to be added to the mailing list.

Bloodline Mailing List

If you would like to receive Bloodline quarterly magazine contact your outreach worker to update your postal address. Bloodline contains stories of HFNZ events, the latest news on bleeding disorders, personal profiles and what's been happening in the regions.

HFNZ Website

The home of HFNZ online is www.haemophilia.org.nz. The website is where you can apply for membership, find information on bleeding disorders, download forms, events and news, and read about the HFNZ.

HFNZ News

HFNZ Membership Renewals

With the change to HFNZ's end of financial year to 1 July to 30 June it's now time to renew your membership. Existing members will have received an invoice in the post, so please return your form to enjoy a year of full membership benefits. New members are welcome to join.

By joining HFNZ you have the opportunity to connect with other people who understand how a rare medical disorder can make you feel isolated. Bleeding disorders are lifelong conditions, so our educational programmes have been developed to target each stage of life parents, families, children, youth, men and women will experience. HFNZ member benefits include:

- Outreach services for information, support advocacy and advice
- Educational camps and workshops
- Bloodline quarterly magazine, Panui monthly e-newsletter and Facebook groups
- Regional Member Representative Groups as well as Maori and Youth groups
- Education grants
- Swimming and exercise programme grants
- Supportive footwear programme grants

Our Member Representative Groups also organise local social events from café evenings, to group outings, camps and family friendly activities.

For further information about the benefits of an HFNZ membership please contact your Outreach Worker on 0508 322 687 or to pay your membership fees by internet banking please contact Leanne on 03 371 7477.

Individual Membership - $25
Any New Zealand citizens with haemophilia, or the child, parent or guardian, sibling, or spouse, of the person with haemophilia may apply as an Individual Member.
Family Membership - $35
Two or more people from a family affected with haemophilia may apply together as Family Members.
Associate Membership - $25
Any individual, society, association, or other body of persons, whether corporate or non-corporate which is a non-profitable, charitable or welfare organisation, whose objects are similar to the objects of HFNZ or who work in any way for the benefit of people with disabilities, may apply to be admitted as an Associate Member. Associate Members are not entitled to vote.
Corporate Membership - $50
Any society, association, or company or other body whether Corporate or Non-Corporate who is interested in the work and activities of HFNZ and desires to be associated with it, may apply to be admitted as a Corporate Member. Corporate Members are not entitled to vote.
Friend of HFNZ - $20
Any person, who is interested in the work and activities of HFNZ and desires to be associated with it, may apply to the HFNZ National Council to be admitted as a Friend. A Friend of HFNZ is not entitled to vote.

Farewell from Kate

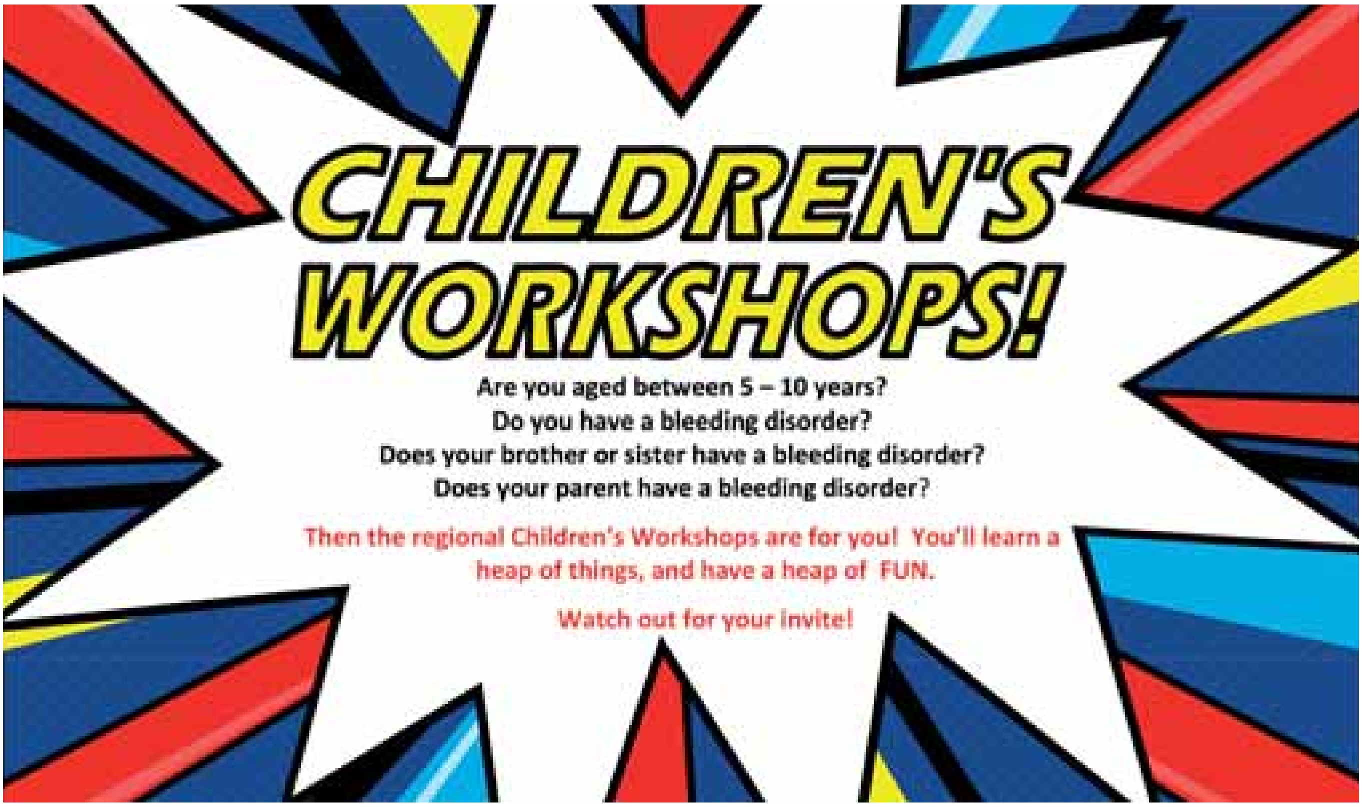
With Chantal returning from parental leave in late August it is time for me to say goodbye to the many wonderful people I have met during my time at HFNZ including the members, stakeholders, suppliers, HTC staff, pharmaceutical representatives and of course the HFNZ staff. The past 12 months as National Information Coordinator have been fantastic. It's been a great experience and a highlight of my career.

Thanks to everyone who contributed their time to write articles for Bloodline and to everyone I interviewed for stories.

I enjoyed listening and writing about your life and achievements as much as everyone would have enjoyed reading about them.

I am not one for good-byes, so I will say au revoir - until we met again.

Take care
Kate



CHILDREN'S WORKSHOPS!

Are you aged between 5 – 10 years?
Do you have a bleeding disorder?
Does your brother or sister have a bleeding disorder?
Does your parent have a bleeding disorder?

Then the regional Children's Workshops are for you! You'll learn a heap of things, and have a heap of FUN.

Watch out for your invite!

Dates to Note

More details on all events are available from your local Outreach Worker.

7 - 8 September
Central & Midland Camp
Kennedy Park
Napier

22 September
Northern WFH Closing the Gap Dinner
Sophera Cambodian Restaurant
Auckland

27 - 29 September
Adults Weekend - Come to Casablanca
Elms Hotel
Christchurch

26 - 28 October
Northern Armageddon Expo
Auckland

26 October
Southern 30th Anniversary Celebration Dinner
Addington Raceway
Christchurch

27 October
Southern 30th Anniversary Lunch
Cracroft
Christchurch

November
Midland Christmas Party
Date and venue TBC

1 December
Central Christmas Party
Zealandia Karori Sanctuary
Wellington

1 December
Northern Christmas Party
Auckland Zoo
Auckland

8 December
Southern Christmas Party
Venue TBC
Christchurch

Visit www.haemophilia.org.nz for more information on bleeding disorders, HFNZ news and past issues of Bloodline

Jeff Oliver Print - Whangarei