Haemophilia Foundation
of New Zealand Inc.
HFNZ

bloodline

Newsletter of the Haemophilia Foundation of New Zealand Inc

September 2014
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YOUTH LEADERSHIP WEEKEND - an HFNZ first

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For the first time, the HFNZ Annual General Meeting (AGM) will be held in September following the decision to move the Foundation's financial year from the calendar year to the more common 1 July – 30 June. Everyone is invited to the AGM at 2pm Saturday 13 September at the Holiday Inn Auckland Airport in Auckland. The HFNZ Annual Report, which covers the 18-month period from 1 January 2013 to 30 June 2014 will be available there or on the HFNZ website. One of the highlights of the Annual Report is always the President's Report, which you find reprinted in this issue.

It has been a busy time for HFNZ with both the Inhibitors Workshop and Youth Leadership Weekend taking place and the exciting appointment of the new Chief Executive, Richard Chambers. You can read more about him on page 3 and we are sure you will join us in welcoming him to the New Zealand bleeding disorders community.

Sincerely,

Chantal Lauzon
Editor and National Information Coordinator

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Masters Group (request to join)
www.facebook.com/groups/hfnzmasters

HFNZ Bank Details:

Account Name: Haemophilia Foundation of New Zealand
Number: 02 0828 0102656 000

President's Report 2013-2014

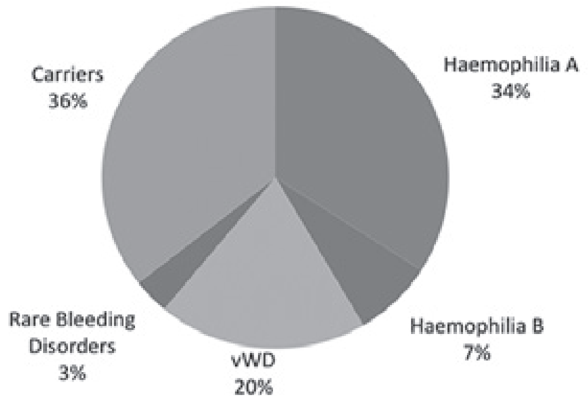
By Deon York, HFNZ President

This report covers the 18-month period from January 2013 to June 2014. With the Foundation's financial year no longer being the calendar year, we are reporting an extra six months this year. The previous year and these extra months have been a productive time for the Foundation, delivering even more programmes and activities. All our programmes and activities have one goal in mind – HFNZ's mission – to promote excellence in haemophilia care, education, advocacy and support.

Membership

As at 30 June 2014, HFNZ represents approximately 1030 individuals with a bleeding disorder. The membership comprises 428 (42%) people with haemophilia A or B, 366 (35%) carriers, 201 with von Willebrand's Disease (20%) and 35 (3%) with a rare bleeding disorder.

People with Bleeding Disorders known to HFNZ



Funding

The generosity of people throughout New Zealand is the fuel that helps HFNZ support families while a child is in hospital, deliver an amazing Youth Camp experience or provide supportive shoes to stabilise joints damaged from bleeds, just to name a few of our activities. We could not deliver many of our services without the donations fundraised with the help of KiwiFirst Limited.

HFNZ are fortunate to have a group of outstanding supporters who have committed to making an investment in our programmes and educational workshops. We gratefully acknowledge the support from Baxter Healthcare Ltd, Bayer Healthcare, CSL Behring Ltd, Novo Nordisk Pharmaceuticals Ltd and Pfizer Ltd.

We also acknowledge the funding received from the Ministry of Health that supports our members with Hepatitis C as well as from District Health Boards through the National Haemophilia Management Group which part-fund our Outreach service.

We appreciate the many charitable organisations and trusts that have provided funding towards a range of our programmes and services. All contributors to our mission are detailed in the financial report.

Representation

The National Council, the governing body of HFNZ, represents and is comprised of people whose families are affected by bleeding disorders. In addition to the officer holders, who are elected nationally, our six Member Representative Groups each elect a delegate to National Council to represent them.

In 2013/2014, the following people served on the National Council:

- Vice-President: Catriona Gordon (Midland)
- Vice-President: Richard Scott (Northern)
- Treasurer: Grant Hook (Central)
- Youth Delegate: Hemi Waretin (Northern)
- Māori Delegate: Patience Stirling (Northern)
- Masters Group Representative: Paul Long
- Northern Delegate: Greg Jamieson
- Midland Delegate: Deborah Weir-Honnor
- Central Delegate: Stephanie Coulman
- Southern Delegate: Rochelle Stott
- Belinda Burnett (former CEO, HFNZ), and Steve Waring (Managing Director, Kiwifirst) served as co-opted members.

Affiliated Organisations

HFNZ Catriona Gordon continued to represent the HFNZ on the National Haemophilia Management Group. This group is responsible for the management of haemophilia services and brings together clinicians, funders, key stakeholders and the HFNZ as the consumer organisation. We thank Catriona for her representation and the management group for its effective stewardship of services for people with bleeding disorders in New Zealand.

My role on the World Federation of Hemophilia's (WFH) Executive Committee concluded in May 2014. I have been re-appointed as a co-opted member of the newly-named Board of Directors of WFH, Chair of the WFH Fundraising and Resource Development Committee and Co-Chair of the National Member Organization Capacity Building Committee. I continue to remain involved with the research, youth, educational materials and public relations committees and working groups of the WFH.

National Programmes

In addition to our important Outreach service, the HFNZ provides a number of beneficial programmes to promote the health and wellbeing of our members. The Swimming and Exercise programme supports swimming lessons, therapeutic swimming and access to fitness equipment for people with moderate and severe bleeding disorders. HFNZ also provides vouchers for supportive footwear for those with severe bleeding disorders or joint damage as proper footwear is important in reducing the chance of ankle bleeds and long-term joint damage.

Highlights of 2013/2014

President's Report 2013-2014 continued

Every year, HFNZ runs a range of national educational workshops to target the needs of our members and deliver our core mission: to support people with bleeding disorders. Over the last 18 months, HFNZ have held several workshops, including:

- Youth Camp, April 2013
- Parents Empowering Parents (PEP) Programme, May 2013
- Women's Retreat, July 2013
- Adults Wellness Weekend, September 2013
- Regional Children's Education Workshops January and February 2014

You can read more about these activities in other sections of this report.

Other Activities

Across the globe, 75 per cent of people with bleeding disorders do not receive adequate care or any care at all. HFNZ take our global responsibilities seriously and in 2011 we entered into a 4-year WFH Twinning Organisation Project with Cambodian Hemophilia Association (CHA). One of the main goals of the HFNZ- CHA Twinning project was to help CHA operate effectively as an organisation and for CHA to be capable of running educational and social activities for people with haemophilia and their families. Three years later, we can report that CHA is succeeding with an increasingly strong patient organisation. HFNZ will continue to work with CHA for the remainder of 2014 and are confident that the bonds built will last after the formal end of the partnership. HFNZ has learnt and gained so much from this Twinning relationship.

One of the most anticipated events of the past year was the WFH World Congress which took place in Melbourne Australia in May 2014. Having the largest international meeting dedicated to haemophilia, von Willebrand disease and rare factor deficiencies so close by was a rare opportunity for the New Zealand bleeding disorders community. Never before have so many members of HFNZ, staff and healthcare workers been able to attend a World Congress. Their participation was largely thanks to the fundraising efforts undertaken throughout the community for the last 4 years. It was an amazing chance for learning and networking with other people with bleeding disorders, treaters, researchers and industry from all over the world.

All the people who spend their time supporting, sharing, connecting and inspiring at HFNZ are the heart of the organisation and why we are here.

One notable change in the people at HFNZ this year has been the departure of Belinda Burnett as Chief Executive Officer. HFNZ has faced many challenges and undergone many changes over the 10 years that Belinda had in the role. We thank Belinda for her contribution during her time as CEO.

Change brings opportunity and HFNZ are excited to welcome Richard Chambers to the position and look forward to the renewed direction and energy he will bring. I am confident that we are entering an exciting time in HFNZ's development and the capacity to work with our members to help them achieve the best possible wellbeing.

The full HFNZ Annual Report for 2013/2014 will be available on the HFNZ website by 13 September 2014.

Meet Richard Chambers

HFNZ's new Chief Executive

It is exciting to have joined the dedicated and capable HFNZ team. Not only is HFNZ growing in numbers, we are growing in diversity; this diversity presents us with new challenges now and into the future as we focus on meeting the needs of people with haemophilia (PWH). I am looking forward to working with our team; staff, council and each of you as we create the future of HFNZ.

So who am I?

I am an expat Southlander; I have taught in and lead schools in communities from the deep south to the mid-south of the South Island, attending both the University of Otago and the University of Canterbury. After an initial struggle I have adjusted to supporting Canterbury sports teams, having lived in Christchurch for 8 years, with my daughter Isabelle (10) representing Canterbury in Artistic Gymnastics and my son Christopher (7) born in Christchurch, my options are increasingly restricted. My wife, Noemi, works near the HFNZ office.

I have lead communities through the aftermath of fires, floods, earthquakes and the process of school mergers and closures and even been made redundant four times, while I wish many of these challenges had not occurred, every time I have learnt new skills and gained new understandings about myself and others; and every time there has 'eventually' been a positive consequence, one redundancy even put me in a position to meet Noemi.

I am excited to be working with the HFNZ community to add value to the work of the Foundation, to honour and build on the legacy of those who have passed away and those who are living who have worked with so much passion and success to support, care and advocate for people with bleeding disorders.

Youth Leadership Weekend

Over a chilly but sunny weekend in August, HFNZ held their very first targeted Youth Leadership Training Weekend in Spencer Park, north of Christchurch. Although there have always been chances for youth to step up at various events and camps, this is the first time HFNZ held a workshop focused specifically on leadership.

From 8th - 10th August 2014, 18 future leaders of our bleeding disorders community spent the weekend tapping into their leadership potential and thinking about how they can help shape the future of HFNZ. Participants went away energised and ready to pursue a specific personal goal related to the community.

To help set the scene, several participants from the North Island first took the opportunity to come to Christchurch to see the sights and the changes in the city. Sophie Rea, HFNZ's Social Work student, took them on a tour of the earthquakes sights in the central city to see the destruction, the empty sections, Cathedral Square, the CTV building site, the Cardboard Cathedral, memorial instalments, Gap Fillers and amazing street art. They also took a drive down some of the badly damaged 'Red Zone' streets of Avonside and New Brighton.

The workshop officially opened on Friday evening with Karakia, Mihi Whakatau and Waiata followed by introductions and dinner. Later National Youth Committee Chairperson Karl Archibald interviewed Youth Leaders Lauren Nyhan, Secretary of Youth Committee, Tuatahi Pene, Northern Youth Delegate on Piri toto, Hemi Waretini, Youth Delegate on National Council and Courtney Stevens, Southern Youth Delegate and Youth Fellow at World Federation of Hemophilia Global National Member Organisation Training. Together they discussed their involvement with HFNZ, the opportunities they have had and who they admire as leaders both within the HFNZ community and in the world at large.

The interviews were followed by Courtney Stevens leading a session defining leadership and brainstorming leadership attributes and qualities, these were posted around the walls as reminders over the course of the weekend.

The brisk Saturday kicked off with Karakia, Waiata and a hilarious Hat Game lead by Sophie. Then it was time to get down to business. Southern Outreach Worker Linda Dockrill first lead a session called Opportunity Knocks where they explored the different opportunities to get involved within HFNZ and associated responsibilities. Colleen McKay then looked at these responsibilities further discussing tricky situations surrounding working with children and young people at events, including issues such as safety, disclosure, the importance of personal boundaries, and reputation.

Inspiring young Christchurch local Coralie Winn joined the group to discuss stepping up after the Christchurch earthquakes and the Gap Filler projects. Gap Filler is a creative urban regeneration initiative that temporarily activates vacant sites within Christchurch with cool and creative projects, to make for a more interesting and vibrant city. Initially run by entirely by volunteers, the project now has several staff, including co-founder and creative director Coralie, to help manage the scale of work now involved.

The afternoon provided a chance to be challenged by choice and saw the participants get up in the trees of Adrenalin Forest. Then it was back to the Lodge where Hemi Waretini lead discussions around the MRGs and the role of youth in the MRGs. Plenty of ideas were generated that are sure to make their way back to MRG committees.

The National Youth Committee (NYC) held their Annual General Meeting on the Saturday night. Although taking part in the AGM was optional for participants, the NYC were very happy with the turnout. Youth delegates for the regional MRGs were nominated, and the NYC are really looking forward to making a difference in the coming year.

Led by Sophie Rea, Sunday's training was about bringing it all together. First participants spent time identifying their own leadership qualities, interests and values and then discussing how to turn their ideas into realistic goals.

The next step was to develop a plan for goal or activity to achieve within HFNZ. It was essential that the youth's plans were SMART – Specific, Measureable, Achievable, Relevant, and Timely. After working on their plans, participants had to present their ideas in the style of a 3-minutes 'elevator pitch' to the HFNZ CEO. The goals and ideas presented were varied and exciting. They ranged from workshops targeted at young women in the community, to extensions of current projects, to one-off fundraisers or events. As part of her role, Sophie will be following up on how the participants get on making their plans reality.

Overall everyone enjoyed the opportunity to learn and connect with each other. It is clear that bonds made between blood brothers and sisters are strong and last even without years of contact.

Colleen McKay, the workshop coordinator, commented, "I feel so privileged to have spent the weekend with these amazing young men and women as they plan for their future involvement in HFNZ. They demonstrate great leadership attributes, possess great values and have fantastic ideas. Awesome weekend. Thanks everyone."

In addition to thanking all the fantastic participants and speakers, HFNZ wish to say special thank you to Bayer Healthcare for their sponsorship of the event.

I had such an amazing time at the Youth Leadership Weekend! I loved the opportunity to catch up with old friends and make new ones. Learning skills to apply to everyday life was definitely a bonus. I'm so excited about the future of youth within HFNZ!- Courtney

Richard Chambers our new Chief Executive was able to be part of the Youth Leadership camp, he said "It was a privilege to be able to be part of the Youth Leadership weekend. The opportunity to meet such an incredible group of young people within my first few weeks at the foundation was reassuring and exciting. It is clear that the future of the Foundation is in good hands, the passion our young leaders exhibited for life and the foundation combined with the value they placed on the legacy of those before them was inspiring."

The Youth Leadership Training weekend was a fabulous opportunity for the youth of HFNZ to get together, meet new people among the group, share ideas and plan for the future. The schedule was pretty tightly packed with workshops so the opportunity on Saturday afternoon to get outside in the fresh air, high up in the pine trees of Adrenalin Forest was relished by many. – Laura

2014 Inhibitor Workshop

The red carpet was rolled out for the inaugural Inhibitor Workshop on Friday 11th July. Families with haemophilia and inhibitors had gathered in Auckland for a weekend of fun, education and support at the Hollywood-themed event.

This educational workshop aims to help people with haemophilia and inhibitors and their families to better understand and cope with the unique challenges they face. Approximately 15-20% of people with haemophilia will develop an antibody—called an inhibitor—to the product used to their treat bleeding episodes. Developing an inhibitor is one of the most serious complications of haemophilia. Both the person with inhibitors and the family face many challenges with inhibitors as the ongoing struggles associated with haemophilia are intensified. The 2014 HFNZ Inhibitor Workshop was an opportunity for individuals and families affected by this reality from across New Zealand to gather, learn and enjoy time together.

> *More than anything, I loved the chance to meet up and connect with the Inhibitor family. It can be such a lonely journey with inhibitors, so being together with others who know what it's like or who are on this journey is amazing. Thank you so much for this weekend.' – Anonymous*

The opening Karakia and Waiata was followed by lunch and introductions. A game of 'headbands' provided a novel and light-hearted way to kick off the afternoon. Everyone wore a mystery haemophilia or Hollywood picture stuck to a headband and they had to guess what the picture was - without looking. The pictures ranged from a bottle of Factor VIII, a pair of crutches to the character Shrek or Tinkerbell.

In the afternoon the kids were enrolled into the Hollywood Kids Club where the leaders Caroline, Courtney, Ashley and Amie kept them busy creating their own personalised 'Walk of Fame' Star, complete with handprints.

> *'Just a brilliant weekend. So good to learn. No price could be put on what I've learnt from others.' – Danny*

The adults went to a session with Colleen McKay. She introduced them to four speakers Danny Hancox, Richard Scott, Lynley Scott and John Tuck who discussed their haemophilia and inhibitor journey with the group. They described their experience with haemophilia, inhibitors and Immune Tolerance Therapy, as well as their biggest challenge, and what or who helped them along their journey.

> *'I'm so glad I got the opportunity to share in other's experiences, it was a great weekend that was fun, informative and interesting. Thank you HFNZ for having the McCarthy-Ferguson family along.' – Ross*

In the evening Barb Hodges from Baxter (Inhibitor Workshop sponsor) and Mary Brasser, Haemophilia Nurse Specialist (Auckland) joined everyone for dinner. This gave the participants an opportunity to acknowledge and thank Baxter for funding of programme.

> *The Inhibitors Workshop is great for people who spend a lot of time in hospital and have many bleeds to talk to others who understand this journey and can help make it easier.' – Richard*

After dinner, the evening's family entertainment was a Hollywood Quiz Night. It was a lot of fun with questions for all ages based on the latest blockbuster movies, Oscars and New Zealand stars. The group even got a sneak preview of the fun that was to follow over the course of the weekend with the HFNZ staff dressing up for the occasion.

Midland Outreach Worker Joy dressed as a Lego brick from The Lego Movie, Northern Outreach Worker Sarah dressed as Simba from The Lion King and Workshop Co-ordinator Colleen dressed as the Wicked Witch of the West from The Wizard of Oz.

> *Great weekend. So good to share our experiences with others and offer our knowledge I experience to new families. Thank you guys' – Victoria*

On Saturday morning the Hollywood Kids Club was 'chauffeur driven' to the Logan Campbell Centre to see the colourful and amusing pantomime 'Jack and the Beanstalk'.

The adults stayed for an interesting morning of presentations, starting with Mary Brasser, Haemophilia Nurse Specialist. She spoke about 'Haemophilia and Inhibitors 101'. The information was well received especially for families new to the world of inhibitors, but everyone gained new knowledge.

Next was a special guest speaker Andrew Selvaggi from Melbourne, Australia. Andrew has severe haemophilia and developed inhibitors as a child. At 18 years old, he was overweight and in a wheelchair; he had spent many days in hospital and only had a 30 per cent attendance rate at school. One day Andrew once decided to take better control of his life by eating healthy and exercising sensibly. Only a few years later he works fulltime and is a qualified personal instructor.

The adult's morning session concluded with HFNZ time. This was especially useful for those who were new to the Foundation. It gave information about the structure of the organisation and the programmes - in particular the camps and workshops that would benefit people with inhibitors.

> *'The Inhibitor Workshop was awesome in increasing knowledge about my son's condition, helping make better informed choices and meeting others in a similar situation – building a greater support network for us' – Iona*

In the afternoon everyone enjoy an outing together to Kelly Tarlton's Sealife Aquarium. It provided a great opportunity for fun times and was a real treat for the families.

Saturday evening began with a parade of Hollywood Stars walking down the red carpet. Everyone had dressed in costume and the paparazzi took pictures of Little Red Riding Hood, Tinkerbell, three Minnie Mouses, Spiderman and Batman to name a few, as well 'Nip and Tuck' Plastic Surgeon Dr Scott and Cosmetic Nurse Lynley who provided their services to the Stars on the night.

Following the parade, the adults attended a session on 'Coping with Stress'. It came complete with a mindfulness session as an example of a relaxation technique to help deal with stress. The Hollywood Kids Club was entertained by an in-house screening of the movie 'Frozen'.

> *I really am willing to take Nikau a really long way with the Haemophilia Foundation' – Rawiri*

On the last day of the workshop, Paul Ockelford, Haemotologist, presented 'Inhibitors: Now and in the Future' to the adults. He explained, in a way that we were able to understand, the very complex scientific components of the immune system when an antibody develops causing the neutralisation of the Factor VIII protein in the clotting cascade. Paul's talk demonstrated how the uniqueness of each person's immune system meant that treatment for inhibitor patients had to be personalised.

The final education session 'Building a Support Network' gave a visual example of the many tasks involved in everyday family life from the cooking, cleaning, school lunches, homework, sports with the added appointments, treatments and care that haemophilia and inhibitors bring. The experiment saw volunteer Vicky Harvey-Hancox overwhelmed trying to juggle many yellow 'task' balloons. After building a support network, Vicky was able to delegate her balloons and manage much better. The participants then split into groups to come up with tips and tricks to make life easier. A list of their ideas is included in this issue of Bloodline in the article 'Building a Support Network'.

> *Absolutely excellent' – Dee*
> *'Tumeke - awesome' – Willy*

2014 Inhibitor Workshop continued

During the morning the kids did craft activities and rehearsed a 'movie' skit written by Andrew Scott, "Factor Snatcher", coming soon to the HFNZ website.

As the weekend drew to a close, following more delicious food, everyone gathered together for the completion of Evaluation Forms, a Poroporoaki and the Academy Awards Ceremony participants headed home with heads full of knowledge and a newly found Inhibitor whanau refreshed to meet the challenges ahead.

> *HFNZ you ROCK!!! Thank you so much for all the hard work you do for us, we are EXTREMELY lucky to be able to do all the things we do and meet all the awesome people – without you it wouldn't happen. It is just so important.*
> *Thank you.' – Kelsey*

Thanks to:

- Baxter for sponsoring the workshop.
- Guest speakers:- Mary Brasser, Paul Ockelford, Andrew Selvaggi and Mira Riddiford for giving-up their weekend to share their experience and expertise with us. We are fortunate and grateful to have committed health professionals working with the haemophilia community in this way.
- Hollywood Kids Club caregivers:- Caroline, Courtney, Ashley and Amie for all their hard work, getting into the spirit of the weekend and giving the children a fabulous fun time.
- Outreach Workers:- Joy Barrett and Sarah Elliott for their leadership in the Adult Programme and in the Hollywood Kid's Club, for just doing whatever was necessary and for contributing to all the FUN.

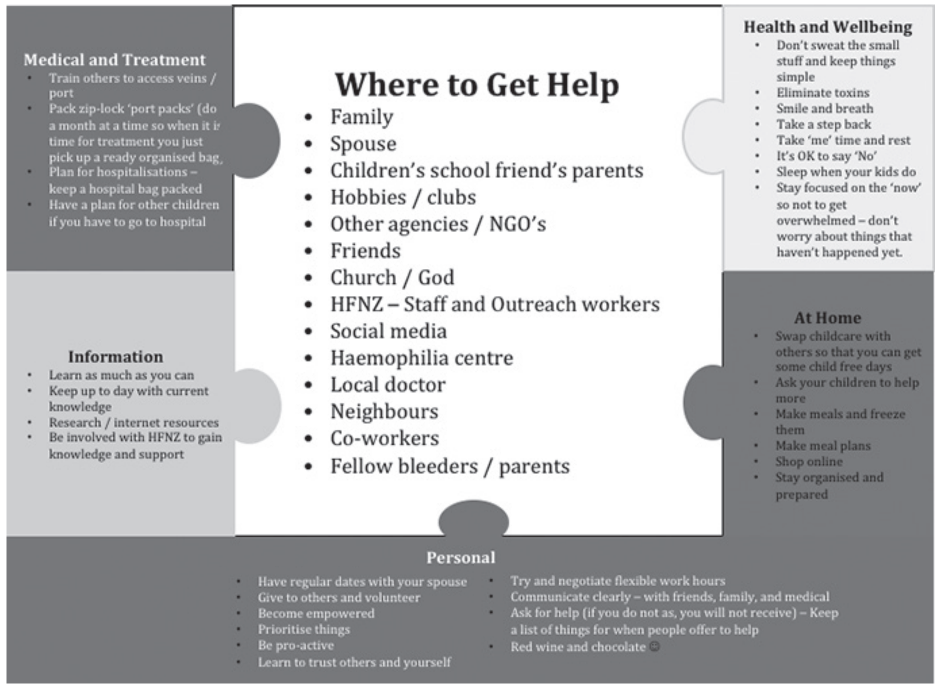
Building a Support Network

Everyone experiences stress whether or not they have haemophilia. But living with haemophilia, either yourself or as parent, partner or carer throws its own challenges that you might sometimes struggle to cope with. A strong support network can be critical to help you through trough.

Living well with a bleeding disorder will involve receiving support from a variety of sources. Take time to consider your current support system, and become aware of other support services available to you. Support is needed for both the individual with a bleeding disorder and family members. This support can come from a variety of sources.

The participants of the 2014 Inhibitor Workshop brainstormed various tips and ticks to help build up your network.

It's never too soon or too late to develop these important connections.



Where to Get Help

- Family
- Spouse
- Children's school friend's parents
- Hobbies / clubs
- Other agencies / NGO's
- Friends
- Church / God
- HFNZ – Staff and Outreach workers
- Social media
- Haemophilia centre
- Local doctor
- Neighbours
- Co-workers
- Fellow bleeders / parents

Medical and Treatment

- Train others to access veins / port
- Pack zip-lock 'port packs' (do a month at a time so when it is time for treatment you just pick up a ready organised bag,
- Plan for hospitalisations – keep a hospital bag packed
- Have a plan for other children if you have to go to hospital

Information

- Learn as much as you can
- Keep up to day with current knowledge
- Research / internet resources
- Be involved with HFNZ to gain knowledge and support

Health and Wellbeing

- Don't sweat the small stuff and keep things simple
- Eliminate toxins
- Smile and breath
- Take a step back
- Take 'me' time and rest
- It's OK to say 'No'
- Sleep when your kids do
- Stay focused on the 'now' so not to get overwhelmed – don't worry about things that haven't happened yet.

At Home

- Swap childcare with others so that you can get some child free days
- Ask your children to help more
- Make meals and freeze them
- Make meal plans
- Shop online
- Stay organised and prepared

Personal

- Have regular dates with your spouse
- Give to others and volunteer
- Become empowered
- Prioritise things
- Be pro-active
- Learn to trust others and yourself
- Try and negotiate flexible work hours
- Communicate clearly – with friends, family, and medical
- Ask for help (if you do not as, you will not receive) – Keep a list of things for when people offer to help
- Red wine and chocolate ☺

Infusing Love: On the Edge

By Sonji Wilkes, haemophilia mum from Colorado

Two boys who live on opposite sides of the International Date Line met this past May and it was magical.

The two boys, ages 10 and 14, both share a love of Legos, tormenting their siblings, and guzzling root beer. Both boys also have severe Hemophilia A, as well as a long history of high titer inhibitors. Each boy has had multiple ports, been on Immune Tolerance Therapy (ITT), tried immune suppression therapy, and developed target joints at a young age.

The boys, Thomas and Andrew, had never met before. They had only exchanged a few notes and small packages, after a mutual friend online introduced Andrew's mother, Lynley, and me a few years ago. Lynley and I had bonded instantly over our similar experiences as hemo moms and chatted online almost daily; the boys had connected, but those exchanges were most often tied to one or the other was experiencing a tough time with a bleed or hospitalization. It's interesting – as moms, we seemed to need that contact with one another more often while Thomas and Andrew were okay just connecting during the really rough stretches. Those short correspondences with Andrew another had certainly lifted Thomas during tough times and it touched me to see him bonding with another boy close to his age who had faced a similar path.

When the World Federation of Hemophilia (WFH) announced that their 2014 World Congress would be held in Melbourne, Australia, Lynley began nudging me to apply for a passport and plan to attend. She was going, since Melbourne is fairly close to her home in Auckland, New Zealand. This might finally be our chance to meet in person, she explained. My husband, Nathan, had always dreamed of going to Australia, so we made the decision to pack up the family and attend our very first WFH meeting. Attending WFH would take care of Lynley and I meeting, but I knew the trip wouldn't be complete if we didn't fly over to Auckland after the Congress so that Thomas and Andrew could meet one another too. What happened there was much more than two moms could have hoped for when the seed was first planted that their sons might find a kindred spirit on the other side of the world.

While Lynley and I had known each other for nearly six years, sometimes there is a bit of awkwardness when you meet someone for the first time, and in today's digital world, you never know if the person you met online will be the same in person. There was none of that when Lynley and I spotted one another in the opening session at WFH. We hugged and giggled (and maybe made a little bit of scene in a room full of people), but the deal was sealed – this was a friendship that was meant to be. Two hemo moms instantly connecting was one thing; how two pre-adolescent boys who had never met each other might react when suddenly face-to-face could play out quite differently.

A few days later, we hopped a plane to Auckland, arriving at Lynley's house even before she and her husband, Richard, had returned from the World Congress. Andrew was waiting for Thomas when we arrived at their home – and it took mere seconds before the boys had disappeared into Andrew's room to talk – no introductions, no hesitation, just instant friendship. And did they talk! We stayed with the Scott family over the next few days, and we'd hear the boys laughing and talking late into the night. They compared ITT doses, checked out each other's crutches and agreed that a certain make and model of tourniquet is the best. They made fun of each other's accents, but shared an appreciation for Dunkin Donuts.

One afternoon we headed into downtown Auckland. The boys were intent on experiencing the Auckland SkyTower's famous SkyWalk experience – where one wears a harness to walk around on a platform that's not quite four feet wide and 630 feet up in the air! To say it's a breathtaking view from below is one thing, but experiencing it high atop the city of Auckland along with Thomas and Andrew will be one of the highlights of my life.

As moms, Lynley and I agreed that far too often we have to say "no" to our boys with hemophilia and inhibitors. We constantly live on the edge of the next bleed. But on this day, we said, "Yes, you can." It was meant to be for Thomas and Andrew to share this experience together: to step out onto that pergola and then, literally, step out and over the edge. I was a nervous wreck standing behind them on that platform – when it was my turn to lean over the edge, I couldn't do it initially. But these boys who have faced so many challenges and trials, stepped out without hesitation. I'd like to think that they were able to face such height, such challenge, such risk because Thomas and Andrew are resilient, courageous boys because of all the adversity they have faced. I'm not sure if either could have handled it on their own, but they owned that experience and they did it together, because while they are strong, brave boys, they are even stronger together.

Thomas and Andrew will always have hemophilia. They will always have that experience high above Auckland. And they will always have each other as the Lego-loving, root beer guzzling, risk-taking blood brothers from the opposite side of the International Date Line that they are.

Sonji lives with her husband, Nathan, and three children Nora (12), Thomas, (10), & Natalie (8) in Colorado.

Haemophilia has given my son a blood brother in New Zealand

Infusing Love: On the Edge continued

The NZ side of the story….

Andrew:

Before I met Thomas I was nervous about what he might think of me and worried that we might not get along. After he arrived and we started talking, I realised no matter where we were from we shared something greater.

So many times I've felt that no one understands what I've gone through, especially with my inhibitors. That's what made us so close though; we knew what each other had experienced, we knew what it felt like to be us. I was very grateful to get to spend time with Thomas I've learnt that no matter how alone I can feel, I have a blood brother on the other side of the world and he is facing the same challenges as me every day.

Lynley:

How can you put into words the experience of meeting someone who you have only just known through cyberspace. It was so great to meet Sonji in person! We had talked so much and shared so many struggles that meeting her just reinforced our bond as friends.

The world of inhibitors can be very lonely and as a family at times we felt quite isolated, especially having 'failed' ITT and tried some other novel therapies, so having someone who 'got' our journey and had shared some of it was great.

Once I met Thomas, I knew that him and Andrew would be great mates. After only a few hours, it seems like they had known each other for years. I remember one night standing outside the bedroom they were sharing listening to them talk about pain, about how to respond to friends, about what to do when you have 'embarrassing' bleeds, and all sorts of things. The SkyWalk was definitely a highlight though. Two boys who were forever being 'cautious' about life, so often being told 'no' were told "yes, go for it". It was an awesome experience made even better that they shared it together - two blood brothers with similar hzaemophilia and Inhibitor journeys from different sides of the globe doing something that they never thought they would be allowed to do.

I am so grateful for the visit from Sonji, Nathan, Thomas, Natalie and Nora and for our relationship cemented by two boys with remarkable journeys; two boys who inspire us daily with their perseverance and courage.

**Note: This first part of this article originally appeared as a blog entry on "Infusing Love: A Mom's View," a blog collection of personal opinions and a representation of individuals experiences collected and published by the Hemophilia Federation of America. You can read Infusing Love stories from other mum's on the HFA website:*

http://www.hemophiliafed.org/

Dealing with Bullying

By Sarah Elliott, MANZASW. Haemophilia Outreach Worker – Northern, Haemophilia Foundation of New Zealand Inc.

Both children with and without haemophilia get bullied. Although children with special health needs such as a bleeding disorder can be at an increased risk of being bullied, haemophilia may not be the cause of bullying (in most instances it is NOT about haemophilia). Why a person is being bullied is hard to determine or change, but there are many things we can try to appropriately deal with the bullying.

Bullying is unacceptable and can really hurt people and have lasting effects. Violent behaviour by a bully can result in bleeds for children with bleeding disorders like haemophilia, so it can be more dangerous than for most kids.

Parents and other adults in a child's life should take bullying seriously. This means knowing and understanding what bullying is and strategies to help your child deal with bullies.

What is bullying?

Bullying is when someone, or a group of people, says or does something that hurts, embarrasses, frightens or upsets somebody else on purpose. It is aggressive and intentional behaviour that involves an imbalance of power. Being bullied can leave someone feeling sad, lonely, scared, and worried. Most often, bullying is repeated over time and sometimes has been around for many years.

In contrast, some behaviour such as light teasing or saying something mean in the heat of the moment is not bullying as it is not done over time or intentionally causing harm. Although they can still be hurtful, these types of behaviours take place for all children in testing friendship and social boundaries.

Many people do not realise that bullying comes in different forms that include:

- Physical - hurting a person's body or possessions;
- Verbal - saying or writing mean things, threatening;
- Social -hurting someone's reputation, embarrassing someone, not talking to them, leaving them out of joint activities or spreading rumours; and
- Cyber - using social media or texts to target and cause harm to others.

With teens, bullying can also have a sexual content to it and may involve sexual harassment.

Signs a child is being bullied

Bullying can make children and young people feel lonely, unhappy and frightened. It can make them feel unsafe and think that something must be wrong with themselves. They can lose confidence and may not want to go to school or other social activities.

It is hard to know if a child is being bullied, but there are some signs to look out for.

Has your child been:

- Coming home with cuts and bruises or torn clothes?
- Taking a different way to school or home?
- 'losing' possessions, money or food?
- Moody and easily upset, quiet and withdrawn?
- Aggressive with brothers and sisters?
- Having trouble with school work?

Strategies to deal with bullying or bullies

A workshop on bullying was held at a recent HFNZ regional camp. Together members of HFNZ's Northern branch discussed strategies to deal with bullying or bullies, both as recommended by professionals and from their own experience. The following is their list of approaches and strategies. Please note: Not all of the listed strategies will work for your child. All children are different so something might work for one and not another – it is about seeing what is the best fit for you and your family.

- Keep communication open – allow your child to express their feelings and emotions. They may like to write in a journal or express their feelings in other ways. As a parent just listening and understanding can help. If your child is telling you about their feelings it is a BIG first step.
- If you think your child is dealing with bullying but they do not talk about it then try and engage them gently – let them know that you see something is upsetting them and that when they are ready to talk about it you are ready to listen, you are there for them. Or let them know if they want to talk to someone else they could talk to another relative, teacher, and mentor or call a helpline (details below).

- If your child doesn't engage easily with you try having a chat at meal times or before bed and ask about specific things at school and in the class (not just 'how was your day') or just sit with your child and don't say anything and they may open up.
- A safety plan is great – 'who to tell if……' 'what to do if…… 'Go over this plan many times with your child so they feel confident of how to interact with a bully, or what to do when bullying arises.
- Build resilience, strength and self-esteem.
- Encourage them to say 'stop it' or 'leave me alone'. Encourage them to call out the behaviour 'don't hit me' or 'stop throwing things at me' – get them to practise what they might say to the bully.

Dealing with Bullying continued

- Encourage them to act: tall and strong, hold their head up, make eye contact, use calm and firm voice, and give a poker face to show confidence.
- Teach your child what to react/respond to and what to ignore. There are times when walking away or acting unimpressed are better than confronting the bully.
- As a parent learn to control your own emotions about the situation and try to look at it logically.
- Keep a bullying record – Who did what and when to your child. This can be helpful to keep perspective on the situation and to show teachers.
- Get to know your community and other parents at your school or in your child's class. By being connected or friends with other parents you could prevent bullying happening or quickly respond to it.
- It is hard for kids to know how to respond to bullies/bullying so do not make them feel bad about their initial response, even if you do not think it is the right course of action. Gently give them some other little ideas/tips for them to try next time
- Let your child know you are on their side and that you believe them.
- Validate and congratulate your child when they have dealt with the situation well, i.e. told you or a teacher.
- Do not encourage name calling or violence as a form of retaliation as it will just escalate the situation.
- Help nurture friendships with a non-bully, as having buddies can make dealing with bullying easier.
- Find places/hobbies that are away from the bully and in places where they will feel accepted.
- Encourage them to do things they enjoy like playing games, listening to music, reading books, playing sports, and hanging out with caring people. This might not stop the bullying, but it will help them manage their feelings, and help them to get through the tough times.
- Let them know bullying is never ok, it's not cool and that it is not their fault or something they 'deserve'. Let them know everyone has the right to feel safe and be treated with respect.
- Identify behaviour or actions which might aggravate the bully and try to curb them if appropriate and if there is a trigger.
- Educate your child about bullying and bullies.
- Encourage your child to come up with the solutions – What do they think might work? What do they think might make them feel better? Who would they like to talk to at school if it happens?
- As a parent talking to the school teacher or dean about bullying is a good idea– so they can keep an eye out for your child or address it with the bullies in an appropriate way.
- Ask the schools policy on bullying so you know what action they take.
- Even after the bullying has stopped the child might need to deal with the effects.

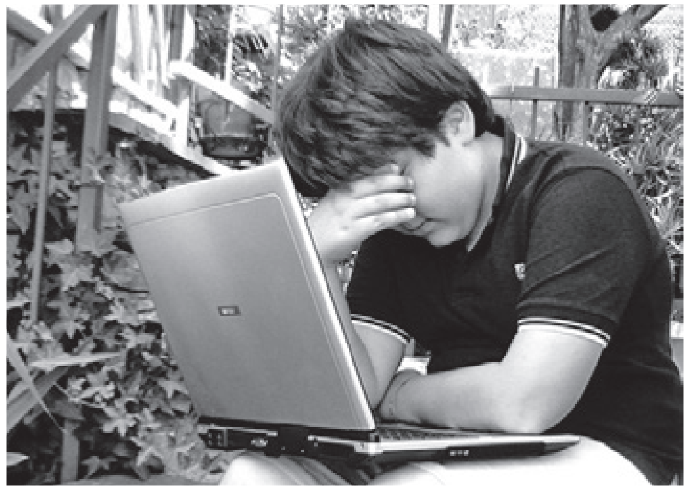
Violence is not a way to deal with bullying or any of life's problems. If we encourage a child to use violence whilst young, then they will often use it as a way to continue to deal with what life throws at them or as a coping mechanism and this is not good for anyone – especially someone with a bleeding disorder.

Further Resources

New Zealand

- *Kidsline - Kidsline is New Zealand's original telephone counselling service for all kids up to 14 years of age. Kidsline operates from 4pm to 6pm Monday through to Friday. When kids ring they will speak to a Kidsline buddy – a specially trained teenage telephone counsellor. Call 0800 54 37 54 (0800kidsline)*
- *0800What's Up – telephone counselling service for 5-18 year olds. Call 0800 942 8787 or visit www.whatsup.co.nz*
- *Youthline – offers telephone counselling for young people (aged 10-25), daily from 4-11 pm. Call 0800 37 66 33 or visit www.youthline.co.nz*
- *No Bully – call 0800 66 28 55 or visit www.nobully.org.nz*
- *Parent Help offer the only parenting helpline in New Zealand that is available 24 hours a day - Call 0800 568 856*
- *Cyberbulling – Resources for young people, parents and teachers. Visit: www.cyberbullying.org.nz/*

Focusing on Cyberbullying



These days, kids not only socialise in the physical world, but also in the virtual world. This has created what is now known as cyber-bullying. Cyberbullying is bullying that happens online. It can happen in an email, a text message, an online game or on a social networking site. It might involve rumours or images posted on someone's profile or passed around for other people to see.

Cyberbullying takes many forms and some of these may be harder to deal with than others. Depending on the situation, some young people are able to sort it out quickly, or simply shrug it off. Other situations may be more serious. About 1 in 5 New Zealand high school students say they have been cyberbullied and many say it makes them feel scared, depressed, angry or ashamed.

Receiving nasty messages outside of school can make it feel hard to escape the bullying. Some people say it's worse if you can't tell who the bullying messages are coming from.

Posting mean or nasty pictures or videos of people online can embarrass them in front of their school and spread quickly out of control. If you or your teen posts altered pictures of people online these can exist long after you delete them and can also be used as evidence by teachers and police.

What can you do to prevent cyberbullying?

- Be careful who you give your mobile number to and don't pass on friends' numbers without asking them first.
- Don't respond to texts from people you don't know. These can often be sent randomly to find people to bully.
- Don't post revealing pictures of yourself or others online - they may get sent on and used to bully you or other people.
- Keep your online identity safe - create strong passwords with a mix of lower and upper case letters and numbers. Pick difficult answers for your "secret question" on your accounts that people who know you wouldn't easily guess and don't share your password with anyone - even your friends.

What if you or your child is being cyberbullied?

- Tell people you trust - a good friend, a parent, or a teacher. They will want to help you stop the bullying quickly and safely. You can also report bullying to the police, even anonymously if this feels safer.
- Do not reply to the people bullying you, especially to text messages from numbers you don't know.
- Save evidence of all bullying messages and images. You can save messages on your phone and take screen shots of bullying on websites or IM chats. This may be used later if you report the bullying.

As a parent, educating your kids about cyberbullying is the first step to creating awareness around this important issue. Talk to your kids about the risk when being online. Start early and create an honest, open environment. Ask them to tell you if an online message makes them feel threatened or hurt. Keep an open channel of communication with your child, and hopefully he or she will come to you.

Defensive Driving Course

By Joy Barrett, Midland Haemophilia Outreach Worker

I attended one of the local Defensive Driving courses earlier this year with two aims: (1) to complete the course to highlight any personal skills that needed brushing up. (2) To be able to better promote this programme to members within our community of people living with a bleeding disorder and their whanau.

The Defensive Driving course comprised of three sections:

- 4 weeks of 2-hour class room type sessions. The material progressively builds on what was taught the previous week.
- An online "simulator" type series of tasks and skill responses, to be completed at your own pace over the first 3 weeks.
- A road drive with the Tutor, lasting between 30-45 minutes. If you were looking to use the course to shorten the Restricted License prior to sitting the Full Driver's License this is more of a test and would form the basis for that. If not, as in my case, it was valuable feedback about on road driving skills.

Some specific issues we looked at in depth were:

- Taking responsibility for our own driving. It is the only thing we can control. Most of the time all that separates us from others on the road is a bit of paint. That is not much when you are travelling at 100 km/hour.
- The faster you drive, the less you see of your total driving environment. At 50 km/hour, vision is reduced by 40 per cent. At 70 km/hour vision is further reduced by up to 60 per cent. At 100 km/hour you can only see 15 per cent of what you can see while stopped.
- Learning to use valuable scanning of our surroundings using 2, 4 and 12 second intervals so that you have time to predict what may happen and time and space to act and react.
- We have no control over the weather conditions, road conditions, and/or the other drivers on the road. That the nature of New Zealand roads and our rapid weather changes can create driving challenges each day.
- Our individual personalities will influence our driving.
- Distraction while driving, both in and outside the vehicle, raises the risk of danger.

Obviously passing a Defensive Driving course does not exempt me from having a vehicle accident in the future, but the experience has created some new awareness and given me some valuable skills.

But don't just take my word for it. **Stephen Snowdon** from Hamilton has still to complete the course but has found it valuable already. He comments, *"The group had a wide range of ages and driving experiences providing good discussions. I have become more aware of my over confidence when driving, and how who I am, influences my driving. I believe that I managed to avoid a serious accident a couple of weeks ago because I was much more aware of my driving and what the others on the road were doing."*

Speak to your Outreach Worker to find out details of what courses may be on offer in your geographic area and whether this is the right time to get onto a course.

HFNZ Defensive Driving Programme

Learning to drive defensively might help people with bleeding disorders, or their caregivers, avoid unnecessary road accidents.

The HFNZ Defensive Driving Programme provides financial assistance to take a Defensive Driving course either through your local AA Driving School, or a substitute school if no AA course is available.

The HFNZ Defensive Driving Programme is available to all HFNZ members with a bleeding disorder regardless of clinical severity, with are current financial member. Males aged 15-25 years are especially encouraged to undertake a Defensive Driving course. Primary caregivers who are normally responsible for the transport of children with a bleeding disorder of any clinical severity, are also encouraged to take part.

For further information please contact your Outreach Worker.

Masters Research Project

Research Opportunity: Explorations into the unique issues and challenges faced by older men with Haemophilia

Project Description

The research project will be investigating the impact of the unique issues and challenges facing men aged 45 years and over who are living with haemophilia, including their perceptions of supports and services available to them, in Aotearoa New Zealand.

The Researchers

Sarah Elliott is undertaking this research project as part of a Master of Social Work qualification from the University of Auckland under the supervision of Dr Kelsey Deane and Dr Barbara Staniforth. Sarah also works for HFNZ as the Northern Haemophilia Outreach Worker and although HFNZ is very supportive of the project the research is independent of her position with HFNZ.

The Study

The main part of the research project is a questionnaire that will be sent to all males 45 years and older with haemophilia in New Zealand. An initial focus group met recently in the Wellington area to review the questionnaire and the final survey is now being finalised.

Benefits to being involved?

This study is an opportunity to contribute to an important piece of research which could potentially help to raise awareness of the needs of older people with haemophilia in New Zealand. Therefore by being a part of this research you will be adding great value and depth to the findings. You could also be helping to provide older people with haemophilia, their support people, and individuals working with the bleeding disorder community an insight into what things this cohort may face as they continue to age. This will be useful in finding how best to support them, therefore offering opportunities for increasing awareness and preventative action.

Role of HFNZ

HFNZ have an interest in in the outcome/findings of this research and are therefore partial financial sponsors of the research project. HFNZ have provided their assurance that this will in no way compromise the integrity of the results and HFNZ will only have access to the final report, so it is hoped that participants will be open and honest in all their disclosures. HFNZ will also help with the identification of possible participants and some administration support.

Confidentiality, consent and safeguards

Only the research team will have access to individual information and no individual participants will be identified when the results are written up.

Participation is completely voluntary. The CEO of HFNZ has given his assurance that your participation or non-participation in this research will in no way impact upon your relationship with the organisation. Participants are free to withdraw from this study at any time without having to give reason and without penalty.

You should not feel obliged to answer any questions you feel uncomfortable about. If you would like to discuss any concerns arising from the questionnaire you are welcome to contact Sarah, her supervisors, or the Chair of the University of Auckland Ethics Committee at any time using the contact details supplied with the questionnaire. If the questionnaire brings up anything psychosocial for you that you would like to talk about, please contact your Outreach Worker

Dissemination

The findings will form part of Sarah's Master of Social Work thesis and may be published in academic journals or discussed in presentations or at conferences.

The final report and outcome of the research will be made available to you once it is completed in 2015. HFNZ will make you aware of this via an article in the Bloodline magazine and they will have a copy of the report which you could contact them to obtain.

How to participate

If you are a male with haemophilia, aged at least 45 years old and would like to participate in this research project look out for your invitation in the post.

Contact details for the researcher, supervisor and Head of Department

- Sarah Elliott 0275121114
  Email: spre607@aucklanduni.ac.nz
- Dr Kelsey Deane 09 623 8899 ext. 48685
  Email: k.deane@auckland.ac.nz
- Dr Barbara Staniforth 096238899 ext 48349
  Email: b.staniforth@auckland.ac.nz

Ovarian Cysts

By Sarah Aldridge, Reprinted with permission from HemAware, Spring 2014

Few medical conditions mirror the pain of a burst appendix. But women with a ruptured ovarian cyst say it comes close. "I couldn't walk or put pressure on my right leg because the pain was so excruciating," says Sarah Fey, 38, who has type 1 von Willebrand disease (VWD). "I thought maybe I was having appendicitis," says the project coordinator from Gilbert, Arizona.

Therein lies the problem—confusion about ovarian cysts and their complications. Women with bleeding disorders need to know if they're susceptible to ovarian cysts and how to manage them.

Ovulation obstacles

Every month, the body prepares for pregnancy by forming a follicle, a fluid-filled sac, around the egg. Normally, the follicle breaks open, releases the egg, then dissolves. However, if the follicle fails to open or dissolve, a cyst forms. As fluid builds up in it, this follicular, or functional, cyst grows. According to the US Centers for Disease Control and Prevention (CDC), ovarian cysts are common during the childbearing years. Most go away on their own without issue.

But the situation is different for women with bleeding disorders, says Andra H. James, MD, ob/gyn at the University of Virginia School of Medicine in Charlottesville. That's because these women can bleed even during normal ovulation, when the egg is released from the follicular sac. And the bleeding can be significant. "They're at risk for hemorrhagic ovarian cysts," James says. "They can bleed into the sac itself and into the abdomen."

An emergency room visit six years ago led to the discovery that Brooke Connell, 31, was prone to ovarian cysts. "I had a hemorrhagic ovarian cyst that ruptured," says the PR/marketing specialist from Kansas City, Missouri. "When they did the ultrasound, they could see the blood around it."

Connell, who has type III VWD, was then diagnosed with polycystic ovary syndrome, the inability to produce mature follicles. To get pregnant, she's undergone treatments for infertility. "During several cycles we've had to stop the medication that stimulates the ovaries to produce more eggs because I've had large cysts on one or both ovaries," says Connell.

Ovarian cysts also occur in women with other bleeding disorders, such as hemophilia, rare factor deficiencies and platelet defects.

Subtle and serious symptoms

Mild ovarian cyst symptoms can be easily dismissed. For instance, stomach pain, bloating and a dull ache in the back can be mistaken for premenstrual syndrome. Fey experienced a cluster of such symptoms in 2013. Pressure in her abdomen was one sign. "I felt full even at times when I was hungry," she says. Needing to urinate at night was chalked up to aging. But heavier menstrual bleeding sent her to her doctor. "An ultrasound last fall revealed cysts on both sides," she says.

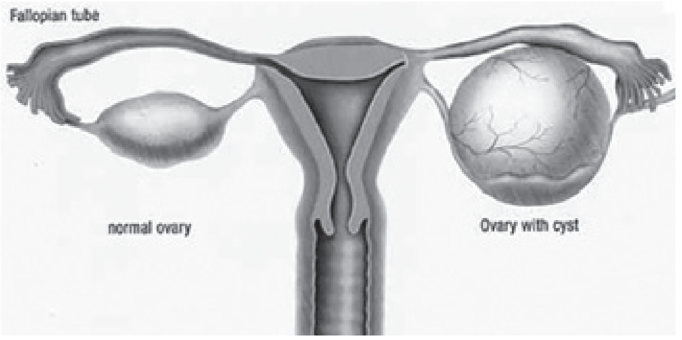
The larger the cyst, the more pain a woman will feel, says James. When they're about 5–10 cm (2–4 inches), they can begin to cause problems. Connell's was 6 cm (2 1/3 inches) when it ruptured. Ruptured cysts can cause internal bleeding, sometimes with severe pain. "Very large cysts can cause the ovary to twist on itself, but that's in extreme cases," James says. This torsion of the ovary can cut off blood supply, resulting in permanent infertility.

Treatment factors

Treatment for ovarian cysts depends on several factors. If they're small and asymptomatic, they may resolve on their own within three months or so. Although Fey currently has cysts on both ovaries, she's not anxious. "They're non-fluid-filled, so they are not a concern at this time," she says.

Sometimes conservative measures are called for when a woman has hemorrhagic ovarian cysts. "We'll try to correct the underlying bleeding problem and watch the woman very carefully in the hospital until the symptoms improve," says James. But other times surgery is needed to remove a cyst or damaged ovary, especially if there's acute pain and severe bleeding.

Preventive measures



Contraceptives can prevent ovarian cyst formation by inhibiting ovulation. The progesterone-estrogen combination pills that contain the same daily dose (monophasic), Depo-Provera injections and subdermal implants containing the hormone etonogestrel are all effective. "Only these methods are going to protect a woman from hemorrhagic ovarian cysts," says James. Progestin-only pills and the levonorgestrel-containing IUD, often prescribed for women with bleeding disorders who have menorrhagia (heavy menstrual bleeding), however, do not work, she adds.

Expanding education

Chances are, most women are not familiar with ovarian cysts. "My mom has mild VWD, but she never had cysts," Connell says. Much of her information and support have come from her hemophilia treatment center (HTC). "I am in contact with my nurse at the HTC a lot, so if I ever have trouble, I just call her," she says. "She's been a blessing when it comes to communicating with my other doctors about the plan for me or when I should dose."

Healthcare providers also need education about the risk of hemorrhagic ovarian cysts in women with bleeding disorders. "We've educated around this over the last decade, so more of them know about it," James says. Patients can take the lead, too. "Even as a teenager, women need to begin this discussion."

You can read this article and other great articles related to bleeding disorders in Hemaware magazine, produced by the US-based National Hemophilia Foundation at www.hemaware.org

Help us evaluate HFNZ's Outreach Service

Outreach is an integral part of HFNZ's mission. While traditional haemophilia outreach programme concentrate on identifying people with bleeding disorders (PWBD), the HFNZ Outreach Service aims to empower PWBD in New Zealand and their whanau / family with support, education and advocacy, appropriate to their age / stage / time of life. By providing individualised assistance and encouragement to access optimal care and treatment for their bleeding disorder, their health and wellbeing are enhanced.

New Evaluation Programme

HFNZ are launching a new evaluation programme to establish perceptions of people who use the Outreach Service and their satisfaction with the service. We aim to gather sufficient information to inform and improve the service. A secondary aim is to gather evidence about the effectiveness or impact of the Outreach Service in improving how PWBD manage their bleeding disorder in their lives.

The HFNZ Outreach Service Evaluation Programme consists of a short 10-question survey which can be done online or in print that will measure the satisfaction of recent users of the Outreach Service. The survey will sent by email or post (for those without email) to 15 service users per region per quarter (total 240 per year). The people who receive the questionnaire will be randomly chosen from among people who have had contact with an Outreach Worker in the previous 3 month period. The first surveys will be sent out in October 2015.

Why we need your help

The evaluation of Outreach needs to involve the community in assessing the service's processes and outcomes.

Evaluation is intended to be useful for stakeholders to make decisions. A useful evaluation is credible, timely, and of adequate scope. It is important to evaluate the HFNZ Outreach Service to demonstrate the results of the service and generate new knowledge so that the programme can be continually improved.

Good results are dependent on people participating in the evaluation process as there will be no information to review without your information and opinions.

Other outcomes

The evaluation programme may also identify whether there are disparities in satisfaction with Outreach Service according to region, ethnicity or the type of contact they had with an Outreach Worker.

Long term, when HFNZ Outreach Services are implemented well PWBD and their whanau / family will be well informed, actively involved in their treatment and care, able to self-manage their bleeding disorder, able to advocate for themselves, as well as able to participate in normal daily life.

Thank you in advance for your participation!

Travelling with HFNZ: Tips to Remember

We are a small community spread right across New Zealand. HFNZ never want the cost of travel to be a barrier to a person with a bleeding disorder or their family attending an educational event. Because of this travel to most national HFNZ events is free to members or included with the small workshop registration fee. However, this means that travel is one of HFNZ's most significant costs.

HFNZ are happy we are able to provide travel to events but we have to try to keep the costs as low as possible in order to make our 'H' dollars go as far as possible. The lower the costs the more people can travel to an event and/or the more events we can run.

As such, there are a few things we want you, as members and event participants, to keep in mind.

- If you live within a reasonable driving distance to a workshop or event, HFNZ ask that you/your family drive to that workshop.
- HFNZ will book all travel to and from events on your behalf. You are welcome to fund your own travel if you choose
- By booking travel with HFNZ you accept responsibility to undertake that travel as planned. You are ultimately responsible for your own travel – this means double-checking your flight details, arriving at the airport in plenty of time for check-in and having the right amount of luggage . If you miss your flights you are responsible for booking new tickets yourself. If you miss your flights and fail to travel to an event HFNZ will invoice you for costs from unused travel bookings if these cannot be refunded.
- If you know that you will be unable to travel due to illness or for another reason please contact the office as soon possible.
- Please ensure that you provide the full names of each person travelling as they appear on their identification on your travel booking forms. Please also include the birthdates of all children.
- Double check your travel documents/flight details as soon as you receive them. If any changes need to be made (date, time, incorrect name) please contact Leanne, the HFNZ Administrator, immediately.
- You are welcome to extend your travel to include a visit to the destination city before or after the Workshop, or to fly to other Centres, etc. While we will endeavour to meet your travel needs, please be aware that HFNZ will pay for the equivalent of Smart Saver Fares to and from the destination city, so if your travel is more expensive, in consultation with you, we will charge you the difference. Please also be aware that in order to get the cheapest fares, you may have an early start, an extra stopover or some waiting time.

If you have any questions regarding travelling with HFNZ please contact Leanne on 03 371 7477 or leanne@haemophilia.org.nz .

MRG Reports

Southern

By James Poff

Hi and welcome to the Southern MRG update. After a busy few months organising and running a successful fundraising event and then several of our members travelling to Melbourne for the WFH conference there has been a bit of change in pace. Although quieter, we have still managed to organise a successful outing – Take a Kid to Footy.

On Saturday 21 July several families went along to the CBS Arena to watch the mighty Crusaders take on the Highlanders. I am happy to report that the Crusaders were victorious (sorry Otago / Southland HFNZ Members) 34 to 8 over the Highlanders. It was a great night and fun had by all. On the 24th of August the Southern MRG AGM will be held at the International Antarctic Centre followed by entry into the Antarctic Centre. Although this event will have taken place before this issue goes to press please consider joining the Southern MRG Committee, or your regional MRG committee. Although it involves a little bit of work, overall it is extremely rewarding. You do not have to become an office bearer as we are always looking for committee members to assist with running the group.

Upcoming Southern Events

- Southern Family Camp, 3rd to 7th October 2014 - Tea Pot valley Christian Camp in Nelson. Planning is well underway for this event, always popular and loads of fun - even educational for all of us.
- Christmas Party. With only 142 shopping days left until Christmas Day 2014, the committee has started planning for the Southern MRG Christmas celebrations – more details to follow.

Auckland Ladies High Tea

Northern

By Lynley Scott

Northern has had a great few months with a couple of great events.

In May it was our annual Ladies High Tea, with simultaneous events both in Northland and Auckland. This time Auckland was at a new venue, the Wintergardens Cafe in the Auckland Domain. As always, this is a great chance for ladies to have a breather from the daily routine of life and gather with new and old friends to enjoy afternoon tea. We always seem to have a good mix of people.

May also saw a great contingent of Northern members head across the ditch to WFH Congress, so great to meet people from other regions and countries but also hear some amazing speakers.

June saw a large crowd in Auckland gather for some rock climbing and pizza. This was a hugely popular event with great numbers. It was awesome to do something active as a MRG and see a good mix of ages climbing. A gym event in July was cancelled due to low numbers but in hindsight we think this may have been too soon after the fantastic rock climbing event but keep an eye out for this at a future date.

Our AGM will be held at Butterfly Creek and by the time this goes to print we will have enjoyed this event. Keep an eye out for upcoming events – Men's Fishing Trip on November 8th and Northern Christmas Party on November 23rd. Look forward to seeing you at the upcoming events.

Midland

By Wendy Christensen

Midland members were recently taken on an unexpected journey to Middle Earth, climbing in hobbit holes, drinking Hobbiton beer and venturing into the world of hobbits. On June 29th Midland Branch got the chance to explore what it was like to live like a hobbit but first kicked things off with the all-important branch AGM.

Midland branch would like to thank returning members and welcome those who are new to the committee. Without a committee we wouldn't be able to achieve what we do so thank you. We were lucky to have Colleen and Carl McKay join us, with Colleen doing a presentation about the work she has done in Cambodia through the WFH Twinning Programme. The Twinning has helped to create more awareness about Haemophilia by helping the Cambodian Hemophilia Association (CHA) grow as a committee so they can get people together, support each other and most importantly have fun.

Well by the time we got through the important stuff and had lunch we were off to the buses to begin our journey through Hobbiton. We wandered the tracks looking through the little windows to see what we could find and guessing the occupation of the hobbits based on what you could see in front of the houses. When we finally reached the top of the hill we got the chance to go inside a real hobbit house. Towards the end of our journey some members gave stilt walking a go. Joy Barrett, Midland Outreach Worker, showed us she still has the knack. Then it was time to settle down to some hobbit beer at the Green Dragon Inn to relax and chat before boarding the bus back to the Hobbiton gift shop to buy some memorabilia to remember the great day had by all.

Central

By Stephanie Coulman

The Central Region has been all about boats, it seems! Members shook the winter blues at a successful mid-winter lunch at the Mana Boat Club in June. The Club overlooks the beautiful Mana Marina.

We held our annual 'Winter Escape' regional camp at Anndion Lodge in Whanganui in the first weekend of September. The camp actually heralded the first weekend of Spring (maybe we need to re-name our camp?) and it was also Father's Day so the fathers in the group had a special Whanganui experience. It's been a while since we visited that part of the country so thought it was time to return.

Making the most of being assembled in the one place, we held our AGM at the camp and welcomed a new Secretary, Kelsey Ferguson to the committee. After the formal bit was done, it was off the Bushy Park to visit the historic homestead and bird sanctuary. A ranger gave us a talk about the 100 hectare predator-free native bird sanctuary, set amongst one of the few patches of virgin lowland forest.

The following day we enjoyed a cruise on a steam boat on the Whanganui River.

Keeping with the boating theme, we are looking forward to our Christmas event, which is a dinner cruise on the Wellington Harbour on Saturday 29 November.

Twinning Connection

WFH 2014 World Congress

Mr Sem Sokpahna (Pahna), CHA Vice Chairperson and Mr Run Chearithy (Rithy), CHA Treasurer attended the Global National Member Organisation (NMO) Training & Youth Leadership Training Workshop, the World Federation of Hemophilia (WFH) World Congress and the WFH General Assembly held in Melbourne in May.

The Global NMO Training is a unique opportunity for national haemophilia organisations to come together to discuss the issues and challenges facing their organisations and bleeding disorder communities and to share knowledge and experiences.

HFNZ extends a big congratulation to CHA on becoming a full member of the WFH at the General Assembly.

Workshops & Public Awareness

Mr Pahna and Mr Rithy returned to Cambodia full of ideas and courage to face the challenges ahead, and inspired to make a difference in the lives of people with haemophilia in Cambodia. They first met with the CHA committee in order to plan how these two delegates should report back to others in Cambodia about the things that they had learned, while at the same time raising public awareness of haemophilia and bleeding disorders.

CHA decided the best way to do this was to run two workshops, one in Siem Reap and one in Phnom Penh. The Siem Reap workshop was held at the Angkor Hospital for Children (AHC). Presentations were presented to update patients and their families about CHA and the future plans of CHA. Dr Sing Heng gave a presentation to educate people with haemophilia about their condition

The Workshop was hosted by AHC Support Team who were able to announce that AHC approved that haemophilia patients up to the age of 16 years old are able to receive treatment at AHC. Congratulations.

After a delicious lunch more members from Siem Reap and the area registered with CHA.

The workshop in Phnom Penh on June 7th 2014 as held at Town View Hotel. Once again the purpose of the workshop was the dissemination of 2014 World Congress information and to give an update on CHA and their future plans. The workshop was very successful in raising public awareness as it was featured in a lengthy news item on national television. Although it is not in English it can be viewed through a link on the CHA Facebook page.

CHA members also continue to visit members at home and in hospital in order to provide valuable education and support.

2014 Twinning Visit

The final HFNZ – CHA Twinning Visit to Cambodia will take place from Thursday 9th October until Wednesday 15th October 2014. Colleen McKay and Grant Hook, current HFNZ Treasurer will conduct the final Twinning Visit, along with Robert Leung from the World Federation of Hemophilia.

Little boy at Workshop in Phnom Penh.
CHA was able to distribute supportive Tubigrip to families and instruct on its use., including 1. Ensure a firm fit, 2. Make sure no wrinkles, 3. Do not wear to bed.

Siem Reap

Card Design 1

Plans for the visit include a workshop for patients and their families, training sessions with CHA on various structures possible for Haemophilia Organisations, Strategic and Long Term planning, and other ideas for fundraising. Time will also be spent with the CHA Committee discussing the Annual Twinning Evaluation and Report that must be completed, as well as the End of Twinning Report.

The Annual Twinning Celebration Dinner will be an important event to celebrate the formal end of the CHA – HFNZ Twinning Partnership. Although the formal Twinning partnership will be ended the bonds that have been forged between the members of these two countries will go on far into future years.

Fundraising

In order to ensure that they are able to continue to operate successfully, CHA have undertaken a number of fundraising ventures. After a CHA Presentation to raise awareness about haemophilia and bleeding disorders a7th Grade Class undertook a month-long Fundraising Project – selling cupcakes and other activities. CHA representatives were delighted to receive a donation of $US 910.58; the results of their efforts.

During the CHA Workshop in Phnom Penh Mr. High Excellency Sem Sokha, the Secretary of State for Ministry of Social Affairs, Veteran and Youth Rehabilitation (MoSVY) was moved by the stories of the families and the work of CHA; he donated $US 500 for CHA's work.

CHA and patients would like to thank Angkor Hospital for Children, National Pediatric Hospital and Blood Bank, Haemophilia Foundation of New Zealand members and all donors who support CHA activities.

Here is another great way to support CHA - buy a pack of special greeting cards from Cambodia! CHA have organised this special fundraiser to help them continue to provide events for the members after our Twinning finishes this year. The cards were chosen by CHA and feature two Cambodian-inspired designs. All proceeds go directly to CHA. Contact Leanne at National Office for your packs.

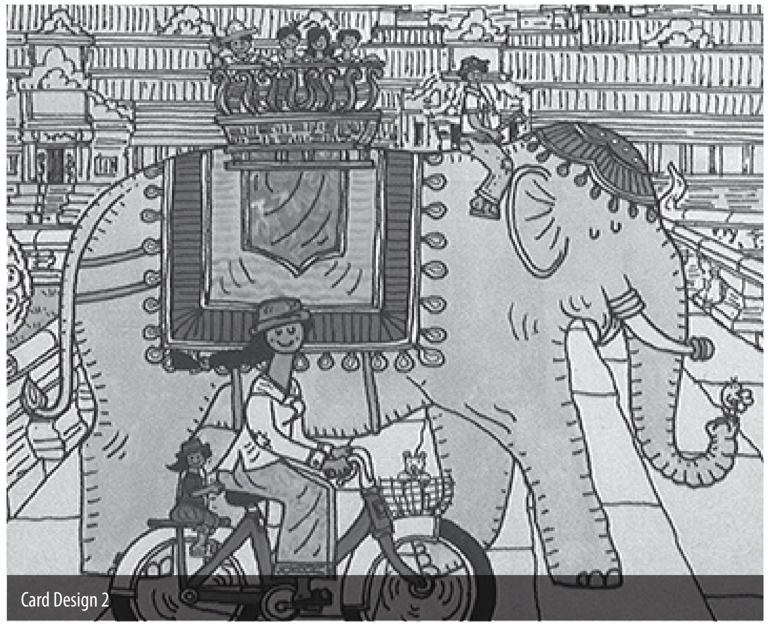
CHA Greetings Cards for sale

Available for sale at the AGM

or contact our Administrator
Leanne – Leanne@haemophilia.org.nz

8 Greeting Cards with envelopes,
4 of each design = $10.00.

All proceeds go directly to CHA for their work with the families with bleeding disorders on Cambodia.



Card Design 2

Phnom Penh

News in Brief

New Haemotology Ward in Auckland

There is a brand new ward for adults with bleeding disorders in Auckland. The new Northern Region Haematology and Bone Marrow Transplant unit (Ward 62) is now complete and ready for use as of the 12 August 2014. Ward 62 has been relocated to the new Motutapu Ward, Level 11, Building 1 – support building Auckland City Hospital.

Co-designed with patients and families in mind, Motutapu Ward is a purposely designed facility that will promote wellness and provide an outstanding environment for patients. It is a beautiful new ward with lots of colour, space, technology, and views. It also features a whānau room with kitchen facilities; a wellness room; and an area specially designed for adolescent patients.

"It was established with over $1 million from fund-raising and very generous contributors through the A+ Trust," says Mary Brasser, Haemophilia Nurse Specialist. "All the rooms have a view, are roomy and feel fresh, with phones and televisions in each."

HFNZ launch new website design

On World Haemophilia Day HFNZ launched our new website. More vibrant and easier to navigate we hope you will visit many times to check what is new with our community and with bleeding disorders worldwide. New pages and features such as Members Only area where you can update your contact details and get resources for your MRG committees is coming soon. Visit now **www.haemophilia.org.nz**

Our monthly e-newsletter Panui has also had a redesign. Subscribe today to get the latest news from HFNZ and the global bleeding disorders community in your inbox each month. Simply follow the link in the top right corner of **www.haemophilia.org.nz.**

A Negative proving to be a positive awareness raiser

In May 2014, the Canadian Hemophilia Society (CHS) launched A *Negative*, a first-of-its-kind awareness initiative targeted at young women ages 16-24. In an effort to educate a younger audience about the symptoms and risks of bleeding disorders this campaign leverages social media and the online story sharing platform Wattpad, to develop and launch an e-novella about a woman with an undiagnosed bleeding disorder and help spread the word in an engaging and memorable way.

Playing off the popular Harlequin romance genre, '*A Negative*' tells the story of a young woman unknowingly living with von Willebrand disease. *A Negative* has now been read by more than 100,000 people! The awareness efforts surrounding the e-novella continue to be developed and implemented. To read *A Negative* by author L.D. Crichton, please go to:

www.wattpad.com/story/16049004-a-negative

Inhibitor Study Stresses Screening Importance

Results from a six-year study of patients with haemophilia A and B in the United States produced interesting findings. The Hemophilia Inhibitor Research Study (HIRS) enrolled 1,163 patients from 17 federally funded haemophilia treatment centres (HTCs). One of the goals was to predict which patients were at highest risk for development of inhibitors.

A central laboratory performed periodic inhibitor tests using blood samples and genotyped the subjects. In all, 3048 inhibitor tests (some patients were screened more than once) were conducted. The main findings were:

- All people with haemophilia are at risk for developing inhibitors
- One-third of newly developed inhibitors were found in people with non-severe haemophilia
- One-half were older than 5 years old
- Six out of 10 people with haemophilia with an inhibitor had no symptoms
- 23 new FVIII inhibitors were identified
- 431 distinct mutations were genotyped, 151 of which had not previously been reported

HIRS investigators and CDC researchers determined that individuals with haemophilia of all ages were at risk for developing an inhibitor. Further, CDC now estimates that approximately 60 percent of people with an inhibitor have no symptoms. Without regular screening, a significant number of these patients may not be aware of the inhibitor until they experience severe bleeding.

The CDC concluded that patients with haemophilia receiving care in federally funded HTCs will be tested yearly for an inhibitor by the CDC Division of Blood Disorders laboratory as part of Community Counts, its new blood monitoring program.

Source: CDC or see Soucie JM et al. Hemophilia 2014; 20(2):230-7.

Biogen enter into haemophilia A and B markets

The June approval of Biogen Idec's second haemophilia drug by the US Food and Drug Administration (FDA) cements the biotech's entry into the haemophilia market.

Eloctate, Biogen's long-acting FVIII product, requires less frequent infusions than current treatments. Eloctate's approval comes 3 months after the approval of Biogen's first haemophilia product, Alprolix, a long-acting recombinant FIX product.

Both drugs mark the first significant improvements in the treatment of haemophilia in nearly two decades, according to Joe Ciaffoni, senior vice president of U.S. commercial efforts. "One thing that's different is what this community has gone through over the last several decades," he said. "The haemophilia community has had a long journey as products have advanced."

The big advantage of Biogen's newly approved drugs is that they reduce the frequency of transfusions from three or more times a week for current drugs to once every 3 to 5 days.

Eloctate is also pending approval in Canada, Australia and Japan, while Alprolix has gained approval in the US, Canada and Australia and is pending approval in Japan.

Alcohol consumption increased risk for liver fibrosis in patients with HIV, HCV

Consuming any amount of alcohol may negatively impact a person infected with HIV or hepatitis C virus by increasing their risk for liver fibrosis, according to data from a new study.

Researchers conducted a cross-sectional study of patients in the Veterans Aging Cohort Study who reported alcohol consumption upon enrolment. There were 3,565 patients who were current drinkers in the final study sample (701 were hepatitis C virus (HCV)/HIV co-infected; 1,410 were HIV infected; 296 were HCV infected; and 1,158 were HIV/HCV uninfected).

In the cohort, 41.5% of patients were considered non-hazardous drinkers; 34.6%, hazardous or binge drinkers; and 24% met an alcohol-related diagnosis, based on the Alcohol Use Disorders Identification Test-Consumption (AUDIT-C) questionnaire.

As alcohol use increased, advanced liver fibrosis increased among all HIV/HCV co-infected patients. Researchers observed associations between HIV/HCV-co-infected patients and advanced liver fibrosis among non-hazardous drinkers (OR=14.2; 95% CI, 5.91-34), compared with uninfected non-hazardous drinkers.

Advanced liver fibrosis also was more common among HIV-infected patients, compared with uninfected patients (6.7% vs. 1.4% among non-hazardous; 9.5% vs. 3% among hazardous or binge drinking; 19% vs. 8.6% in alcohol-related diagnosed patients). It also was more frequent among chronic HCV-infected patients compared with uninfected patients (13.6% vs. 2.5% in non-hazardous; 18.2% vs. 3.1%, hazardous/binge; 22.1% vs. 6.5%, alcohol-related diagnosis; P<.01 for all).

"We've shown a much greater risk for co-infected compared to uninfected persons at all levels of alcohol consumption — from non-hazardous drinking up to hazardous/binge drinking and abuse/dependence," said one of the researchers, Vincent Lo Re III, MD, MSCE, assistant professor of medicine and epidemiology, University of Pennsylvania. "This highlights how important it is for clinicians to be counselling co-infected patients on reducing alcohol consumption."

Source: Lim JK. Clin Infect Dis. 2014;doi:10.1093/cid/ciu097.

Alex Dowsett claims gold for England in men's time trial at Commonwealth Games

Fueled by disappointment following his controversial Tour de France snub, Alex Dowsett took a wonderfully gutsy victory in the men's time trial in Glasgow in July.

The Essex rider, 25, led early on the 38.4km course and although he fell behind at one stage Dowsett was not to be denied.

A single-minded individual who has managed to make it as a professional sportsman despite having from haemophilia, Dowsett dug deep and managed to turn around the deficit, crossing the line to win by 9.3sec from Dennis with Wales's Geraint Thomas.

"I fought like I've never fought before," said Dowsett, who took Commonwealth Games silver in Delhi four years ago. "I can't describe just how happy I am with that... It goes a lot deeper than simply winning the gold medal of the Commonwealth Games. It's a personal victory for me."

Alex Dowsett sprints for the line to win time trial. Photo: AFP

Welcome Sophie!

Sophie Rea, a 3rd year Social Work student at Christchurch Polytechnic Institute of Technology, is joining HFNZ to complete her final placement before she finishes her degree. Sophie has a passion for youth work and community development, and will be putting these passions to use in the Southern region working alongside outreach worker Linda Dockrill until mid-October.

When she finds time outside of study, Sophie is involved in the Christchurch amateur theatre scene, and enjoys crafts, reading, and playing the ukulele (probably rather badly!)

Sophie thanks HFNZ for the opportunity to spend time with the organization, learning new skills and developing as a social worker. She is looking forward to meeting with people, hearing stories, and supporting members.

Get Ready to Blast Off to...

NATIONAL FAMLIES CAMP

23-26 January 2015
Camp Keswick, Rotorua

Held every other year, HFNZ National Families Camps bring together young families with a child with a bleeding disorder under 10 years old from all over New Zealand. The whole family including siblings are welcome to join in the fun!

At Camp, parents gain strength through knowledge and understanding. Children enjoy having fun whilst being “just like everyone else”.

Mark your calendars now!!

Dates to Note

13 September 2014
HFNZ National Annual
General Meeting
Holiday Inn - Auckland Airport
Auckland

23-26 January 2015
National Families Camp
Camp Keswick, Rotorua

1-3 May 2015
Parents Empowering Parents
(PEP) Programme

June 2015
HFNZ Adult Wellness Weekend

8-11 October 2015
HFNZ Youth Camp

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

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

Jeff Oliver Print - Whangarei