



**Twinning  
with  
Cambodia**

**page 3**



**Christchurch  
Earthquake -  
3 Perspectives**

**page 4**



**Women and  
Haemophilia**

**page 18**





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# Contents

Wellness Weekend 2011.....1  
 HFNZ twins with CHA .....3  
 Christchurch Earthquake: Three perspectives .....4  
 Recovering from the earthquake.....7  
 Billy Crossen - AgriKid .....9  
 Open Letter - Wellington Haemophilia Memorial Trust .....10  
 Ankle bleeds and sprains in haemophilia .....11  
 Supportive Footwear Programme Update .....12  
 Becoming a Blackbelt: a personal victory .....13  
 New HCV Treatments Approved by FDA .....16  
 Women and Haemophilia: recognising their specific needs .....18  
 Research Update: ISTH2011 .....21  
 Council Corner .....23  
 MRG Reports .....23  
 News in Brief .....26  
 Farewell Aly! .....28  
 Useful Haemophilia Websites .....29  
 Dates to Note .....30

# Wellness Weekend 2011

*Following the success of last year's Wellness Weekend and the great feedback received, another workshop for adults with bleeding disorders was held over the weekend of 27-29 August, this time in our fair capital, Wellington.*

**'A great, well run, wonderful weekend. Always great to learn something new and meet up with other wonderful people with similar issues, concerns and funny stories'**

Over 50 people attended the Wellness Weekend, which was held at the Mercure Hotel, Willis Street. Partners were also welcomed to the workshop in recognition of the important role they play in the lives of adults with bleeding disorders. The workshop was superbly organised by HFNZ Manager –Outreach Services Colleen McKay, who, according to one participant, is the "last remaining Gestapo member" (we are sure he meant in the best possible way due to her dedication to time keeping).

**'Wellness Weekend was primo. We have informed our partners tenfold, and informed ourselves a lot'**

Saturday started with a Mihi Whakatau by John Wrathall, Karakia from Joe Wrathall and Waiata 'Tutira Mai Nga Iwi' sung by all. There were also some excellent presentations from Dr Julia Phillips, haematologist on the, **'Delivery of Haemophilia Care in New Zealand'**, who shed light on the unique healthcare model in place here, and by HFNZ CEO Belinda Burnett, who gave a **big picture view of HFNZ** as an organisation.

**'We both enjoyed our stay and meeting old friends and making new friends. Doctor Julia Phillips talk about von Willebrand Disorder was both informative and informal. We both appreciated that. Thank you to HFNZ for the opportunity'**

After a hearty dinner teams had lots of fun at the Quiz Night and 'Money or the

Bag'. Questions weren't all just trivial, but also had bleeding disorder questions and learning disguised inside. No-one could be persuaded to take the money (maybe the offerings were slim), with participants preferring instead to try their luck with the prizes within the bags.

**'Well organised - attention to detail - although I came alone, I felt very included - Thank You'**

After a full breakfast on Sunday morning, participants turned their attention to themselves, looking at the issues as they relate to living with a bleeding disorder. Sunday focused on speakers of a 'physical' nature.

- Ian D'Young's session on **'Physiotherapy & Arthropathy'** highlighted that treating a bleed involves more than factor and that physical rehabilitation is very important, especially the long term benefits.

- Te Whainoa Te Wiata & Steve Waring shared **inspiring personal stories** that demonstrated the benefits of their commitment to physio and exercise.

- **'The Importance of Supportive Footwear'** was covered by local podiatrist Johnathan Chapman. He spoke about gait analysis and foot function and the four main components of supportive footwear.

- BJ Ramsay then encouraged participants to **'Name That Pain!'** He shared useful tips to correctly identify and appropriately treat the pain caused by a bleed, synovitis or arthritis as they should not all be treated the same.

- Prof. Ed Gane gave an update on clinical Trials available with Protease Inhibitors, Polymerase Inhibitors and a treatment

which is not Interferon based for the treatment of **hepatitis C**. He also spoke about a new genetic test that can help indicate a person's likelihood to respond to treatment and promoted the new mobile Fibroscan machine.

- **The genetics of haemophilia and the reproductive options** that are available to women who carry the haemophilia gene were outlined by Alice Christian. She also gave a picture of the current reality for daughters and grand-daughters of men with haemophilia.

- Dr Julia Phillips gave interactive session on **vWD**, answering lots of questions from the participants.

- BJ Ramsay also gave a second talk on **Haemophilia Treatment Products**, where we've been and where we're at now. He spoke about how recombinant technology allows for much smaller volumes of factor, making life for those with bleeding disorders much more convenient. He also highlighted some innovations that might be available in the near future such as longer acting products, and gene therapy.

**'Really enjoyed this weekend, it was great to learn more about Genetics and such. Great Weekend.'**

That evening the group dined at Siem Reap, a local Cambodian restaurant with beautiful Cambodian food. The setting was perfect for Colleen McKay to speak about HFNZ embarking on the Twinning programme with the Cambodian Hemophilia Organisation. She painted a very compelling picture of her experience traveling to Cambodia to investigate the situation there and the harsh realities of living with a bleeding disorder in a developing country. All present felt very



## Wellness Weekend 2011

fortunate to be living in New Zealand and receiving comprehensive the medical care.

'Thank you for a lovely weekend. I enjoyed getting to know people and learning new information about haemophilia. The Twinning Project has really woken me up to what other people go through and how hard it must be for others.'

On Monday morning, speakers from Arthritis New Zealand came to deliver a session on **Working with Health Professionals**. They spoke about our responsibilities as patients when working with health professionals, making health decisions, being part of the team and effective communication. A lot of laughs were had practicing 'I' Statements in communication, as they proved more difficult than expected.

'We really enjoyed Wellness Weekend – good to catch up with old friends, enjoyed listening to all information. We need more weekends like this'

After lunch, Colleen wound up the workshop with an overview of the weekend, outlining the 'Take Home Messages' from each Session. Representatives from the group – T. A. Stirling, Stephen Snowdon and Grant Hook - all expressed their appreciation of the weekend. Joe Wrathall ended with a final karakia, and all joined for waiata. All participants eventually made a safe return to their homes in other cities and in regional New Zealand, vowing to return for another Wellness Weekend.

Thanks to:

- Joe Wrathall and Roopu for support with Māori Tikanga
- National Council for their vision in making adult educational weekend a priority
- Leanne, Chantal and Belinda for administrative support from the Office
- Regional Outreach Workers for attending, assisting and supporting
- All the Speakers for sharing their expertise and their weekend time
- Baxter for their support and Barbara Hodges for attending the first day and evening
- The participants for their FULL participation, for sharing and supporting others in the bleeding disorder whanau, and being an awesome group.



## HFNZ twins with CHA

*HFNZ are very pleased to announce that we will formally be embarking on a Haemophilia Organisation Twinning (HOT) programme with the Cambodian Hemophilia Association (CHA).*



Twinning is a formal, two-way collaboration or partnership between emerging and established patient associations. By linking the two, the Twinning Program has improved treatment and care for people with bleeding disorders around the world. Following the assessment visit last November, HFNZ and CHA completed, signed and lodged an Application for Twinning to World Federation of Haemophilia (WFH). On 19th March 2011 we heard that WFH had approved the Twinning Application. HFNZ soon received a formal letter of welcome to the WFH Haemophilia Organisations Twinning Programme, "Congratulations! You are now among the 33 Twins operating in 42 countries around the world".

Goals of the Twinning between HFNZ and CHA are:

- That the Cambodian Hemophilia Association (CHA) is able to operate effectively as an Association
- To build a stronger sense of community and fellowship within and between the haemophilia communities within the Haemophilia Foundation of New Zealand (HFNZ) and the Cambodian Hemophilia Association (CHA)
- That the Cambodian Hemophilia Association (CHA) is capable of running educational activities for patients and their families.

Planning is currently underway for one or two HFNZ representatives to visit Cambodia at the end of November 2011. Proposed plans include once again visiting Phnom Penh and another city further north in Cambodia called Siem Reap. In Phnom Penh, HFNZ reps will meet with the CHA Committee and assist them in working together as a group and discuss strategies for them to lobby and encourage their Ministry of Health and their Government to provide treatment products for haemophilia. At the moment people with haemophilia in Cambodia rely on donated factor products from the WFH, and in the past from SHARE.

Then HFNZ, along with Tiv Linat a volunteer Social Worker assisting with the group, and Dr Chean Sophal, haematologist, will conduct a workshop for bleeding disorder families in and around Phnom Penh.

HFNZ representatives along with Tiv Linat, and perhaps also CHA Chairperson, Kong Kimsua, will then travel

to Siem Reap and meet with families with haemophilia. These meetings in Siem Reap will be important as the Chair and the Social Worker have not previously had the opportunity to get together with these families. Siem Reap has a reasonably well-equipped hospital, Angkor Hospital for Children; a paediatric teaching hospital supported in part by an NGO where another haematologist, Dr Sing Heng, is based.

Although there are many challenges within any Twinning project, HFNZ is very excited about this opportunity. We recognise, however, that it is always necessary to be realistic about the challenges and set realistic goals. For example, due to the limited use of English, the language barrier is a challenge. There are also many differences in culture between Kiwis and Cambodians so it is important to always be open and communicate to ensure cultural appropriateness of all activities and discussions. One has to be very flexible when visiting, as plans often change and meetings happen at a moment's notice. Delivery of haemophilia care within Cambodia is limited, so the same level of care experienced by those in more developed countries is simply not possible yet. The key is to start small and build up gradually. It is important to be realistic in planning and realise that steps and progress may seem small – yet at the end of the day even small progress can improve the lives of people with haemophilia living there.

The development of an effective community from within is always more sustainable in the long term. CHA only formally began as an organisation in 2009 and although the Twinning may not make an immediate impact on haemophilia care in Cambodia, by helping strengthen CHA they can continue to develop for many years to come. After all it took HFNZ over 50 years to grow into the organisation we are today.

Further details on Twinning, haemophilia in Cambodia and the initial trip were featured in the December 2010 issue of Bloodline, available at [www.haemophilia.org.nz/bloodline](http://www.haemophilia.org.nz/bloodline)



Colleen McKay and Richard Scott visited Cambodia in 2010 to assess the possibility of Twinning with CHA

# Christchurch Earthquake: Three perspectives



*The effects of the earthquake have been felt across the country, but the experiences of those living and working in Christchurch continue to shock, amaze and fill us with a profound sense of sympathy and strength.*

*The events of September and February, and all the subsequent aftershocks have made residents of Christchurch and all over New Zealand think about how to cope with such disasters and maybe how they could better prepare.*

*Here we present three perspectives from members of the bleeding disorder community on their experience of the earthquake and the consequences; a mother of a child with haemophilia, a haemophilia nurse and an HFNZ Outreach Worker. Each presents some things to consider if you or family members have a bleeding disorder.*

## The Outreach Worker Perspective - Linda Dockrill

It seemed like any other day in Canterbury, one that was punctuated with the occasional aftershock, but with some sense of normalcy in a region that was trying to slowly piece itself together after the 7.1 magnitude earthquake on September 4th 2010.

It hit us at 12.51pm, a massive, violent, shake that saw 182 lives lost and many others changed forever. Tuesday, February 22nd will be etched in our memories permanently.

Out of the five staff based at the HFNZ National office only two were actually in the office when the quake struck. We are grateful that Belinda and Colleen were unhurt despite the damage done to the office contents. The day passed both quickly and at a snail's pace as the shock of the events unfolded. We continued to be rocked by aftershocks over the rest of the day, some nearly as big as the 6.3, while we all took stock, gathered water, dug toilets in our back yards and waited for the power to come back on. It took many hours for the enormity of what had happened to our beautiful city to become clear.

My first priority was to assess the safety of those I could contact and to ensure they were aware of how to get hold of factor from the hospital. I had rung the Treatment Centre and Pauline Connors, the Haemophilia Nurse, had told me how she needed people to pick up factor on the day they ordered as there was no storage facility due to the earthquake. Having little or no electricity highlighted the need for people to understand how to safely store factor products as well as assess what supports they needed. Many families had gathered a few belongings and left town, which further increased the need for them to order and pick up on time.

A week later we were able to gain access to the National office, do some cleaning up, and then sit down to make a plan about how to contact all the families in the area. We knew it was too many phone numbers for one person so we divided up all those I hadn't yet talked to and asked the other Outreach Workers to make those calls. I am grateful to my colleagues for their support at such a difficult time, as all of the Christchurch staff had our own families to worry about and look after.

As I write this we are 10 months on from September's earthquake and 6 months on from February 22nd. The aftershocks have continued, some have been extremely large, and in between life has returned to a familiar rhythm, but will never be the same as it was. We are learning about what the long term consequences of stress can be on the human spirit and mental health alongside discovering how resilient people can be in times of trouble.

Several of the families involved with the Foundation have been profoundly affected by the Earthquakes. Three families live in Red Zoned areas, those where the land cannot be fixed, and others live in areas where those details are yet to be decided. The grief and stress for these families is hard to describe. To deal with losing homes, communities and schools alongside the day to day management of a bleeding disorder is an incredible stress on a family's personal and financial resources.

One family has lost two homes. Another family has a new baby and three other young children all living in a red zone area in a house that has broken windows, broken drains and no doors that shut properly. Many families are dealing with school closures and site sharing which has seen their children bussing from one side of town to the other on a daily basis for an afternoon or morning session. Others are dealing with job losses, anxiety about leaving their properties for any length of time due to burglaries, and the general difficulties of living in a city with road works, flooding and containers lining the roads. It is very stressful.

As their Outreach Worker I have tried to maintain regular contact with these families, listening and trying to support them where I can. Children are most susceptible to trauma and many parents tell stories of bedwetting, nightmares and regressive behaviours. As some of these children have to deal with moving house and changing schools there will be ongoing resettlement issues for all members of the family, but particularly the children. It is normal to experience emotional distress, flashbacks, nightmares, problems with memory or concentration, anxiety or fearfulness following a natural disaster or trauma. However, it is important that you seek help if these issues are affecting you or your children in an ongoing way. Your Outreach Worker can help you access support from counsellors or other professionals as needed.

The people of Canterbury know it will take years for this event to loosen its hold on our day to day lives. We can be encouraged by the opportunity this has given us to support each other as communities, as families and friends. Kia kaha Christchurch.

## Family Perspective - Tania Kaa and whanau

**Tena Koutou I runga I te Rangimarie.**

How Ruaumoko (earthquakes) have changed our lives forever.

It all began early hours of September 4th – at 4.35am. Our home shook with such ferocity that Carlin woke everyone screaming 'Earthquake!!'. As we got our children up and positioned in the safety of a door frame, we heard glass breaking, furniture and frames falling and the loud deafening sound of the EQ. We were absolutely terrified.

With the power cut I recall making sure my children were all ok and checking as quickly as possible that no one was hurt. We then all moved to the car for comfort and warmth as no one knew if there was going to be a tsunami alert.

Once daylight came we were able to assess our situation and replenish supplies, i.e., water, food and medical needs.

My daughter Riana has haemophilia so it was terribly important that we had her medical needs covered. We packed an emergency kit and made sure we had enough needles and syringes as part of this pack.

Power was restored within 5 hours so we re-refrigerated the Kogenate 2000 immediately. Life restored to normal as much as it could, but always with the uncertainty if another 'BIG' one was going to hit.



February 22nd was like any other day in CHCH, kids off to school and both Carlin and I off to work. My day finished earlier than usual due to a cancellation – so I went home to complete some admin work.

I was at my table typing on my laptop when the 6.3 Magnitude earthquake hit – I sat thinking this is just another aftershock – only to realise it was HUGE, I went to stand and got thrown to the floor, I watched all my plates, glasses, bookshelves, fish-tank everything fall and smash, when I finally stood I went to try and exit and couldn't as doors were jammed. I started to panic as all I wanted to do was to get to my children who I knew would be terrified.

When outside I saw utter destruction – my driveway had lifted and I couldn't get my car out, I ran to check on neighbours everyone was as dazed and as shocked as I was.

I drove my car out of the driveway, which was munted, in order to get to my kids. Picking people up along the way it took me 45mins to get to my younger children's school - a trip which would normally be 2 minutes! I distinctively remember looking in my rear vision mirror and watching my street fill with water and liquefaction – it was surreal.

I was so pleased to see two of my children when I arrived at their school. They were cut off from us with liquefaction everywhere so I had to wade through it to get to them.

I remember assessing the road situation and deciding I would walk to my older daughter's school. I also realised at this point I had glass wedged into my foot and was in a lot of pain but I knew I had to get to my daughter. This would be about 2 hours after the quake had struck and I had had no contact from my husband Carlin,



The liquefaction blocked whole streets in some areas of the city.

Damage to interior of HFNZ National Office from February earthquake.

## Helpful contacts

**Skylight Foundation**  
[www.skylight.org.nz](http://www.skylight.org.nz)

Skylight are a NZ-based specialist loss, trauma and grief support agency. They have many resources and information available on line.

Free earthquake support counselling hotline: 0800 299 100

**Whanau Trauma Line**  
0800 222 042

**Free Counselling Helpline**  
0800 777 846 (8am- Midnight)

**Excerpts from Post-Quake Seminars**  
[www.heartfoundation.org.nz/blog-stories](http://www.heartfoundation.org.nz/blog-stories)

Search for "post-quake-seminars-in-Christchurch". The blog contains excerpts from seminars run by the Heart Foundation, in recognition of the acute emotional, health and social toll the earthquake had taken on many residents.

**Government Earthquake Helpline**  
0800 779 997

**Canterbury Health Info website**  
[www.healthinfo.org.nz](http://www.healthinfo.org.nz)

**Ministry of Social Development  
Emergency Information Page**  
[www.msd.govt.nz/emergency/](http://www.msd.govt.nz/emergency/)

Has a number of contact details and helpful factsheets on topics ranging from where to find help, financial assistance, counselling and emotional support.



The Catholic Cathedral and it's now missing dome can be seen from HFNZ's office.

## Christchurch Earthquake: Three perspectives

who works in the CBD, and I constantly choked back the tears thinking that he could either be hurt or dead.

After a long journey to get to my daughter, avoiding sink holes and huge cracks, I got to her only to find she had been injured (my worst nightmare). She had cut open her hand trying to take cover and was absolutely hysterical when I finally embraced her. I had no access to her medication and so I bandaged her till we could get first aid.

Four hours later my whanau were all reunited. We spent that night in our school hall due to our street being flooded and our home not being liveable. When we returned home the next day we realised that we had pretty much lost most of our valuables – including Riana's medication. Our fridge had been knocked to the ground and all its contents smashed all over the floor. Our roof had caved in on one side and an external and internal wall had to be removed. We were displaced for 6 weeks as we had no power or running water.

We returned home on the weekend of my birthday, 20th March, only to experience another significant aftershock. As a result we all slept in the lounge, marae style, for a further 6 weeks.

Emergency repairs have made our home liveable but we still struggle with blocked drains, no sewerage and power-cuts.

After the 13 June earthquake our drains were completely broken from the house to the street. Despite this I have been able to stop taking my family to the community showers and washing my clothes there as drainage guys now arrive to my home every 2 weeks to unblock the mess.

I don't know how long we will live like this or how much we will be able to take mentally and emotionally. We are in the 'green zone' but very much living like we are in 'red zone'. This is our new normal!

Thanks to Haemostasis and Haematology/Oncology at Christchurch hosp for replenishing Riana's factor. We now keep a separate kit in another part of the house, just in case...

### Nurse's Perspective - Pauline Connors

The savage force and noise of the 22 February earthquake immediately shocked us.

The Haemophilia Centre is part of the Haemostasis Service and is located within the Canterbury Health Laboratory building directly opposite Christchurch Hospital. Once we had evacuated our building it seemed to be only moments before we began to see injured people arriving at the hospital. Again within what seemed a very short time, army tanks arrived, and helicopters were landing in the cordoned off street by the Emergency Department. All of this signalled the likely severity of the earthquake.

The following day our clinic opened as 'normal'. We now entered the building on a sign in and out basis, and were working with ongoing issues around water supply, sewerage, and communications. Our building became the only functioning testing laboratory in Christchurch – the laboratories of the other providers had been destroyed. Scores of GP practices were out of action affecting thousands of patients. Across the hospital all outpatient clinics and elective surgery was postponed. A state of emergency was in place across the city.

Over the next few days those patients on home therapy began to phone in – some had already left the city, some were planning to leave and most were experiencing the same lack of essential services. The question from everyone was whether there was likely to be any problems with the availability of product and supplies. We had already checked with blood bank, pharmacy and the supplies department and were able to assure people that there would be no delays. The advice was to order as usual unless you were planning to go away. To relieve some of the demand on pharmacy, out of town orders were managed by the Dunedin and Auckland centres – thank you for your help and for offers of support. We knew it was difficult for all patients and families especially the negotiation of roads. The clinic had to ask for product and supplies to be collected on the day ordered as we were unable to store and there was always an uncertainty around communications.

The provision of a service involves many layers – in a time of disaster the things we take for granted are not necessarily there. Those individuals and families on home therapy seemed very well prepared at February 22. There are always reflections on what could have been done differently or better. The earthquake was a massive event and what shone through was the spirit of support and cooperation from every individual, family and provider – everyone did their best.



**People in the bleeding disorders community need to be prepared for any emergency, whether a small personal or family emergency or a community-wide emergency. Data from natural disasters such as earthquakes, flooding and hurricanes show that individuals with chronic conditions experienced the worst outcomes due to interruptions in their continuity of care.**

### Tips to remember...

Never leave it until the last second to replace supplies when running low on factor. You should always have sufficient factor on hand, not just when there is an emergency.

If electricity is off in your area, try and keep your factor in a cool place and store in a chilly bin with ice if possible. Most recombinant factor can be kept at room temperature for a long period of time. Consult with your haemophilia centre before disposing of unused factor and as early as possible so planning can commence to replace stock that has not been kept in the appropriate temperature range.

If you have to leave town for a length of time or move, your need to update your contact details with all the hospitals you attend, other health care providers and HFNZ, as these are not passed on automatically.

The Ministry of Civil Defence and Emergency Management website, [www.civildefence.govt.nz/](http://www.civildefence.govt.nz/), has a number of general resources on preparing for an emergency at home, at school and at work.



## Recovering from the earthquake



**As mentioned in the previous article, for those who live in and around Christchurch, the events of 4 September and 22 February have profoundly changed our lives.**

In the aftermath HFNZ received messages of support and concern from all around New Zealand and the world, from members, clinicians, Sustaining Patrons, other bleeding disorder organisations, and in particular the Haemophilia Foundation of Australia and the World Federation of Hemophilia. It was such a hectic time and it is possible that we did not get the chance to personally thank everyone. As such we would like to take this opportunity to thank you all for your calls, emails, texts, Facebook messages and hugs when next we met. It meant a lot to know you were thinking of us and wanted to help.

The HFNZ National Office is situated quite close to the Christchurch CBD, but luckily just far enough away that it was outside of the initial red zone cordon and accessible within a week or so of the disaster (after an engineer had cleared the building as

safe of course). When the staff arrived back we were confronted with quite a mess, but despite losing some equipment, materials and furniture, as we cleaned up we began to see just how lucky we were that there was no serious damage, no one was hurt and we had a place to work from. So many businesses and community organisations had lost much more. Even with frayed nerves, no water or toilet and ongoing aftershocks, it felt good to be back doing some work for the community.

Our first thoughts were with the members and families who live around Christchurch. Many had damaged homes, some can never to be lived in again, or had school or work displaced. Living here had become hard – stressful, tiring, and nothing felt solid anymore. As the city began its clean up, we wanted to find some way of helping those families worse affected by the earthquake to have a break from the city and from their worries. An opportunity for this came in the generous offer of a holiday flat in Mt Maunganui for the use of HFNZ members. With funds that had been donated to HFNZ specifically towards helping recover from the earthquake, we were able to offer five families the chance to travel to Mt Maunganui for a break from the shaking and the general chaos of their lives.

The generous offer of free accommodation came from Paul & Awhi Taft and was arranged by Sue McKay (sister-in-law of Colleen McKay); a huge thanks to these three for their generosity and

## Recovering from the earthquake

time. As you can see from the comments of some of the members who were able to take up the opportunity, the break was much appreciated.

*Nga Mihi to the wonderful whanau of HFNZ- we were gifted a holiday away, all flights and accomodation paid for to Mt Maunganui - my Whanau and I had a massive time absorbing the views of the mount and climbing it, the roar of the beach and the cafe' down Maunganui Rd..Our heartfelt thanks is extended to you all who made this happen as we try to rebuild a sense of normality here in CHCH. Kia pii te ora ki a koutou katoa. - Kaa-Goodwillie Whanau*

...The earthquake hasn't been much fun and to get away from Christchurch is something I've been wanting to do. Thanks so much for letting it happen!...Because of you I have also been able to walk into malls and not look at the ceiling or worry about how to get out. After I have been shopping in the malls in Christchurch with mum for a while I begin to get shaky and often get teary-eyed without knowing it...I have never felt so much peace and so relaxed since the September earthquake. I really appreciate all the help you have given me and from that, I know what it feels like to be myself. Thanks!! - Dominique Spence (age 13)

*When the earthquake happened I have been having a rough time. I'm not so keen on different places I have not been to before...I'm scared going into a building I'm not sure that are safe so it's great being somewhere the ground is stable. It was great getting away from here. I have had a great time at Mt Maunganui! - Chanelle Spence (age 12)*

The owner of the apartment visited us and we were able to thank him personally for the opportunity to stay in his apartment. It was a wonderful feeling staying in a house that was stable...Leanne and the children managed to catch up on good uninterrupted sleep while we away but received a few texts from Christchurch about aftershocks which brought us back to reality. Once again thank you for thinking of us and offering us a holiday we ordinarily couldn't take. The support the Foundation gives to its members still astounds us and is much appreciated. Thanks from all the Spencer family, especially from Leanne and I. - Paul Spencer

HFNZ also had grand plans for a way to get the community together and have a little fun, in the form of a Canterbury Seismic Activity Day out in Templeton. You know what they say about best laid plans though. Maybe it was too early for people to feel safe in large groups and the snow that fell during the week didn't help, but in the end the "quake escape" day had to be cancelled.

Although the aftershocks seem to have eased (cross fingers) living in Christchurch remains difficult for many. Essential services are still disrupted, for example some people still have to use outdoor port-a-loos, and schools, work, roads, etc remain disrupted and constantly changing it seems. There is also the unknown to deal with, such as the fate of land or jobs. As time ticks on, HFNZ will continue to look at ways of supporting families in Christchurch who've been affected by the earthquake, perhaps on a more individual scale.

Thank you to all that have contributed towards assisting HFNZ with the earthquake. Thank you to our close neighbours in the bleeding disorder world Haemophilia Foundation Australia for their generous donation and extending their support. We know it has been a difficult year in Australia with natural disasters of their own and appreciate you thinking of us. HFNZ has also received a generous donation from Paul Larkin, brother-in-law of HFNZ Vice-President Catriona Gordon, from the sale of an amazing bicycle. Paul, who is quite devoted to his nephews, is a very keen cyclist and after winning a particularly fabulous frame at a single-speed competition in Rotorua last year he auctioned it on Trade Me with the full sale price going to HFNZ to help with earthquake relief. HFNZ also received donations from individuals after seeing the state of the office. Thank you also to our Sustaining Patrons who donated prizes for the fun day in Canterbury; these will be put to good use at future events.

Thanks again to all for your support. If you live in or around Christchurch and are struggling with one thing or another, please do get in touch with the Southern Haemophilia Outreach Worker Linda Dockrill (Phone: 03 371 7485) and we will see how we can assist.



Spencers in Mt Maunganui - The Spencer family really appreciated their time away from the 'shaky city'



## Billy Crossen - AgriKid

*After his team from Springston Primary School placed first at the Tasman New Zealand Young Farmers AgriKids Challenge, Billy Crossen and his two teammates (all age 11 years) were on their way to test their farming skills against other schools in the national AgriKids Challenge final.*

In conjunction with New Zealand Young Farmers and the National Bank Young Farmer Contest, the AgriKidsNZ Grand Final Competition was held in Masterton from June 29 to July 2. The National Bank Young Farmer Contest is the flagship event for Young Farmers in New Zealand and is held in high esteem among the rural community. It's a multi-disciplined farming challenge which tests a range of practical skills, business management, problem solving and personal social skills.



AgriKids is a challenging junior competition that combines practical knowledge and physical skills in a 'top team' format. Competition consists of a series of activities related to the sort of afterschool/holiday hands-on rural bases tasks that all kids age 10-12 years can do. Teams of three Year 6-Year 8 students compete in tasks such as electric fencing, milking a cow, building a gate or assembling a horse's bridle. The competition has been growing in popularity over the last 6 years and in 2011 a total of 201 teams from the deep south to the far north competed in the seven regional finals. The top three teams from each region go on to Masterton to compete for one of the seven spots in the Grand Final.

Billy and his teammates, Hayden and Oliver, one of three teams from Springston Primary School took out first place at their regional event held during the South Island Agricultural Field Days at Lincoln, and earned a place in Masterton. Some of the activities they competed in for their win included pushing someone in a go-kart, using a slingshot, milking a fake cow, putting fake parts of a sheep together, building a gate, identifying machinery, putting a bridle together and putting it on a fake horse, identifying breeds of cow and whether they were for meat or

dairy and identifying safety checks and equipment for riding a motorbike.

So after a few weeks of practice at one of the boy's homes, Billy and his teammates, along with their fathers, travelled to Masterton. Billy has severe haemophilia, but that was never a problem with all the different actions they had to try. They competed in a number of activities such as a knowledge quiz, checking a lawn mower, making sausages, shooting an air rifle, separating sheep into pens and weighing them, helping a St John's Ambulance attendant choose equipment to help find and treat a person lost in the bush and saddling a horse. The competition was a big step up for Billy as in Lincoln they had used fake animals, but in Masterton they had to deal with the real thing.

"My favourite part was separating the sheep as it was not something I had done before but had an idea how it should work", says Billy, and it did!

Although Billy's team was not one of the seven to get into the Grand Final, he said the whole competition was a great experience and a lot of fun. When they weren't competing they got to watch parts of the National Bank Young Farmer Competition, which was really exciting and inspirational. The boys already have plans to enter the TeenAg competition once they are all together in high school in a few years.



Some of the cool activities Billy and his team competed in Masterton



In August 2011 an open letter was sent to all affected by haemophilia in the Wellington region with regard to the Wellington Haemophilia Memorial Trust.

### Wellington Haemophilia Memorial Trust.

In 1996 a successful partnership commenced between Kiwifirst and the Wellington haemophilia support group. The result has been a lot of money raised for haemophilia throughout NZ over the last 15 years. Our heartfelt thanks go to Steve Waring and his team for turning dreams into reality.

Early on, criteria were established for distributing the funds raised in the Wellington area. At the AGM in 1999, in response to the wise advice of Mike Carnahan from Nelson, it was agreed to form a charitable trust. The Trust was formally incorporated on 12 March 2001.

Over the years, the Trust has given grants for many different items to Wellington-based HFNZ members. These have included batteries for mobility scooters, fridges to store product, tuition, camp fees, and respite care. The Trust has also bought a television and videos for the children's hospital ward, paid for taxis and parking, as well as study books and computers.

However, over the last three years there has been little call on the funds of the Trust. This drop in applications is due to an increase in financial support being made available by HFNZ. At the time the changes in support were implemented by HFNZ it was clear that if they were successful the Trust would no longer be necessary. It is clear that these changes have been successful and are sustainable by the national organisation HFNZ. HFNZ members requiring financial assistance have a range of options available to them.

As Trustees our decision is to:

- a) close the Trust as at the 31 December 2011
- b) ask the central branch to advertise this fact to all members, giving Wellington-based people time to apply for funds
- c) ensure the remaining funds of the Trust will be distributed in accordance with the Trust Deed;
  - a. that is given to Haemophilia Foundation NZ to use for the purposes outlined below:
    - (a) To provide fun activities for people with haemophilia and their families in the Wellington area with the intention of facilitating support among families and a positive attitude to haemophilia among those affected.
    - (b) To provide special needs grants, especially for medical and educational needs, for people in the Wellington area.

We would welcome your applications (fitting the above criteria) before the Trust closes at the end of this calendar year (your Outreach Worker can put you in touch with a trustee to obtain a copy of the application form).

**Our closing date to receive applications will be November 30, 2011.**

Any money left in the Trust as at 31 December 2011 will be distributed as per the Trust agreement.

From the Trustees  
Rosalie Glynn

Lisa Habershon

John Carter

Stephanie Coulman

## Ankle bleeds and sprains in haemophilia

by Auburn McIntyre and Abi Polus



This article is adapted from the "Ankle sprains" brochure published in November 2009 by the Women's and Children's Hospital, North Adelaide, South Australia, and related article that appeared in the March issue of HFA's National Haemophilia magazine. It is reprinted with permission.

### What should I do if I have a bleed or sprain and how do I reduce the risk of reinjury?

Ankle pain is one of the most common presentations in haemophilia, particularly in the second decade of life. It is important to distinguish the reason for the pain in the ankle.

The ankle joint is made up of the tibia and fibula (shin bones) and the talus and calcaneus (foot bones). Muscles and ligaments attach the bones together provide structural stability. The ligaments on the outside of the ankle are most commonly injured (torn or sprained). These structures all have a blood supply, and injury to them may cause bleeding into the joint.

### Ankle bleeds

An ankle bleed is blood within the joint space of the ankle with any injury to the ankle, which may be very minor. You may even have trouble identifying how you did it. These are associated with the haemophilia population only.

### Ankle sprains

Ankle sprains are common in both the general and the haemophilia population. They can result in bruising, swelling and damage to the ligaments and joint surfaces. An ankle sprain may result in a joint bleed.

In most cases, a sudden loss of balance results in a roll outwards, known as a 'lateral inversion ankle sprain'.

There are three grades of ankle sprains:

- 1. Mild:** Minor tear and stretch of the ligaments. Mild swelling, locally tender and little loss of function.
- 2. Moderate:** Moderate, partial tear with swelling, bruising and tenderness over a wide area.
- 3. Severe:** Complete tear of the ligament. Substantial bruising and swelling up the leg and into the foot. There is marked loss of movement and function. Joint stability is compromised. A bony chip may become detached where the ligament attaches to the shin bone.

Physiotherapy is usually necessary with these injuries: examination, treatment and recovery are dependent on the type of injury, number of sprains and your bleeding history.

In people with haemophilia an ankle sprain must be treated very seriously. If it is not rehabilitated fully it may become more prone

to reinjury and become a target joint, where there are repeated bleeds into the ankle, with little provocation or injury.

### Initial treatment of a sprain

Immediate treatment ensures the ankle ligaments and soft tissues heal well and more quickly. It attempts to minimize swelling, reducing the time of exposure of the joint to blood and reduce joint damage.

Initial treatment: (even at scene of injury)

**F** actor  
**R** est  
**I** ce  
**C** ompression  
**E** levation

**FACTOR:** should be administered as soon as possible and injuries of this nature should be reported to the haemophilia treatment centre.

Seek additional medical advice if there is continued swelling OR your are unable to weight bear after 48 hours.

**REST:** Crutches and a splint are necessary for 48 hours for haemophilia patients. It would be usual to expect weight bearing through the leg after 48 hours within the limits of pain.



**ICE:** Cold in the form of crushed ice, frozen peas or cold packs should be applied to the ankle and lower calf immediately. To prevent ice burns the chosen product should be wrapped in a damp towel. Cold should be applied for between 10-20 minutes every two hours for 48 hours. Check the skin regularly for ice burns.



**COMPRESSION:** A supportive bandage should be applied from the toes up the leg to just below the knee in addition to using a splint. This should be worn continuously except when in bed at night.

The bandage and a 'U' shaped gutter foam under the ankle joint may be needed for up to two weeks when the leg has reduced bruising and swelling. It may be removed when swelling has disappeared.

Frequently a physiotherapist will make a splint to keep the ankle joint and calf in a good position.

## Ankle bleeds and sprains in haemophilia

**ELEVATION:** The leg should be elevated above the level of the hip when sitting, and above the heart when lying. The knee should be straight not bent when lying; a bent knee leads to a tight calf and longer rehabilitation.

[Editor's Note: In NZ, we also encourage **PROTECTION** as part of the P.R.I.C.E. regimen. This means reduce weight bearing or stress on the affected joint or muscle by using crutches or other supports. You may need to avoid putting weight on the affected side completely for the first 48 hours; and possibly longer if it is a severe bleed.]

### Further treatment

**PHYSIOTHERAPY:** Physiotherapy is likely to be prescribed depending on the severity of the injury. **It is essential that full range of motion, muscle length and strength and extremely good balance reactions are restored to prevent reinjury and reduce the risk of the ankle becoming a target joint, where there are repeated bleeds into the ankle, with little provocation or injury.**

**EXERCISES:** Exercises may be commenced safely when bleeding has stopped and the ankle is able to

move without pain. There should be no increased pain or swelling after exercise.

### REDUCING THE RISK OF RECURRENT ANKLE SPRAINS

There is a risk of repeated ankle sprains within the first 12 months of any ankle sprain. Muscles need to be rehabilitated to become strong, quick and efficient. It is essential to build up endurance to be pain free and protect from future sprains.

Semi rigid ankle supports, taping and bracing can be helpful for functional use but needs to be combined with specific functional exercises.

Prior to return to sport you/your child should have:

No pain or swelling.

- Should be able to walk normally (without a limp) and balance on either single leg with the same degree of balance and stability.
- Should be able to rise up and down on their toes on the sprained leg side whilst displaying the same balance skills as on their good leg, and also hop and stop-still on either leg with the same skill level.

- Have equal muscle size (calf and thigh) on the affected and unaffected side, or the same as pre-injury.

It is essential that you contact your physiotherapist at your local haemophilia treatment centre for assessment, advice and education after any ankle injury or bleed.

*Auburn McIntyre is Physiotherapist at the Women's and Children's Hospital, North Adelaide, South Australia*

*Abi Polus is Clinical Physiotherapist in Haemophilia at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne*

## Supportive Footwear Programme Update

**HFNZ is pleased to announce a new option for our Supportive Footwear Programme, Shoe Clinic.**

With 15 locations across New Zealand, Shoe Clinic is a specialised footwear company that feature over a 100 different models from the world's finest sport shoe brands. Each model has particular technical features designed for differing physiological needs. To help you find the pair that is just right for you and your walking style, Shoe Clinic offers a unique shoe fitting service.

By walking across the sensor pad of the Footscan Computer (an Adidas designed system), a digital print is produced of your foot as it lands. This indicates the anatomy of your foot, the pressure points and your

biomechanical walking style. Shoe Clinic specialists then give an expert assessment and prescribe the ideal shoe for your personal characteristics. This means your sports-type shoes work with your feet and walking style and not against them, and provide you with the correct type of support for your joints.

By going through their unique Shoe Fitting Process, you are guaranteed to have the best possible pair of shoes for your individual feet and requirements. Shoe Clinic Footwear Technicians undergo an ongoing technical training programme overseen by a podiatrist, with assessments/exams to ensure consistency throughout all Shoe Clinic stores. Shoe Clinic also offer a 30 day money back guarantee on any shoe purchased as

prescribed by one of their Shoe Clinic technician. If you are not convinced they are the right shoes for you bring them back (within 30 days) and Shoe Clinic will return your money or replace them. To find a location near you visit [www.shoeclinik.co.nz](http://www.shoeclinik.co.nz)

In future when requesting your Supportive Footwear vouchers, you will need to specify whether you would like them for Hannah's, Rebel Sport or Shoe Clinic. Please note that due to the specialised nature of the Shoe Clinic footwear the prices of their shoes may not be fully covered by the value of the HFNZ Supportive Footwear vouchers. Members will need to make up the difference in cost themselves.



## Becoming a Blackbelt: a personal victory

*By Paul Dagger, 1st Degree Blackbelt, International TaeKwon Do Federation*

**When I was six years old, my friend Andrew came to school with a gold medal he had won on the weekend at a Judo competition. At that moment, I decided I wanted to do martial arts as well, and announced as much to my Mum when she picked me up at 3pm. This was promptly met with "haemophiliacs don't do martial arts"; which in turn was promptly met with a power sulk like only a six year old boy can produce.**

I guess they expected that this sudden desire to dress up in white pyjamas and jump around was going to be the usual short lived idea, and within a week would be replaced with something more acceptable. Unfortunately for them I was hooked, and as the years went on I learnt that there were all sorts of martial arts out there, and you could use them to break boards – giving me a practical reason to explain to my parents why I should be allowed to do it (if a log blocked us on one of our regular bush walks, I could just chop it up with my hands). They didn't see the obvious benefits. Most importantly, I learnt that there were black-belts that could be earned – I WANTED one of those.

At about ten years old, I decided it was no longer a good idea to keep pushing the topic. All the literature and advice was very clear. Haemophiliacs don't do contact or high-impact activities, martial arts are generally both, and therefore they are not for Paul. Don't argue with the literature – just keep doing swimming, and walking in moist sand to improve ankle strength (yawn). So I shut-up, but I didn't forget.

Fast forward 16 years. I was legally in charge of myself, had built up strength around most of my target joints through activities such as archery and riding my mountain bike around Kapiti, and I thought I was reasonably fit. Talking with my cousin one night, he mentioned he was thinking about going back to the local TaeKwon Do club and picking up his training again. Aha – opportunity! Without a second thought, "I'll come to" sprung forth and the next Tuesday night off we went. I figured the worst that would happen is I'd see it was all punches to the

face and I'd run for the hills. Turned out there was almost no contact, and what there was was incredibly controlled. What people were doing, however, was the most intense cardio and body-weight workouts I'd ever seen, combined with some pretty spectacular kicks – and white pyjamas and coloured belts everywhere!

Joining in, by the end of the two hours I was absolutely exhausted, but on cloud nine. I had officially survived a martial arts class – and more importantly, hadn't had to sneak out the back for a spew like my cousin! I cornered the Head Instructor, and laid out my situation in detail. "No problem" was the response, "I know how haemophilia works and we can make this work." I signed up that night, but made a mental note not to tell anyone else I was training for a few months.

Over the next four months the number of bleeds I was having peaked initially (I learnt that I wasn't quite as flexible as I'd hoped, and from that was reminded that psoas bleeds really hurt), but then started dropping away until they were at half the number before I started, and those that I were still getting were nowhere near the severity levels they used to be. I could even smash my right elbow through a one-inch pine board and come off with no repercussions. It was at this point I fessed up to my Dad and the medical people what I was up to – along with the evidence I was safe and healthy.

For the next five years every Tuesday and Thursday involved me suiting up, and heading down to the training hall initially for two hours a night, and then with the Head Instructor's encouragement, adding an extra hour beforehand to help teach the kids class. Six hours a week. I was getting stronger and stronger, the number of push-ups I could do was increasing, I could out-sit-up most of the class (86 in two minutes), and an increasing number of pine boards were being smashed at the same time.

The technical sections of the classes were spent working out how the prescribed techniques and stances needed to be adapted for what my body could do, and every three months I religiously put myself forward for a grading examination along with a letter from my Instructor explaining

**Editor's Note:** According to Ian d'Young, Haemophilia Physiotherapy Practitioner, there is no one type of exercise or set of exercises that are 'best for haemophilia'. Each person is unique, and different exercises serve different purposes. You will need an assessment by your physiotherapist to determine what is the right type of exercise or sport for you, and this will be determined by your goals and level of ability. Remember, you will need to talk to your physiotherapist HTC before starting any new sport, and if a new sport is leading to regular bleeding episodes then it is not right for you.

any adjustments to the syllabus we had made. Not once did the official NZ governing body raise any complaints, and in-fact allowed me to fly to Christchurch to attend a make-up grading when I was too sick from treatment for my hepatitis C to attend the Wellington one. I was just another one of the few hundred people training in Wellington, and was delighted to be completely mainstream. After each grading, a new belt was issued and I hung my old one on my study wall along the



## Becoming a Blackbelt: a personal victory



associated certificate knowing my long desired blackbelt was getting closer every day. Within a couple of years the rest of my cousins that had been training with me had given up, and a few friends that had likewise been coming along and grading with me had also stopped. I was going all the way though, after 25 years I was so close.

Finally one Saturday in November 2010, I passed to red with black-stripes. That was it – no more colours, black was next. With my Instructor's assistance a submission was made to the NZ Technical Director and Head Examiner requesting dispensation to attempt my black-belt grading in April 2011. After a very nervous two week wait, the answer came back – not only was it a yes, but it was a yes with their complete willingness to accommodate whatever was needed. It turned out some of the senior examiners that had graded me through the colours (and although I thought they had no idea I existed), had spoken on my behalf! It was on.

Every spare minute of the next six months were filled with something to do with my grading: martial history, angles and weight distribution, and Korean on the days my body wouldn't co-operate; and stair climbing, 2.4k runs, and weekend trainings on those days it would. All this on top of the six hours a week of regular class training! Then before I knew it, the night before the weekend long grading was here.

The ITF TaeKwon Do Blackbelt grading in New Zealand is a two day affair, the first day is filled with 8 solid hours of intense training with only a couple of 10 minute drinks breaks, and an hour for lunch.

At the end of the 8 hours, a fitness test modelled off the NZ Police is given – at least 80 sit-ups in two minutes, 50 push-ups in about a minute, three two minute rounds of kicking and punching a pad, and then immediately you are sent off on a 2.4k run that should ideally be finished in ten minutes. The second day starts a bit more leisurely with a 2 hour written exam and a formal verbal interview, followed by more physical work in front of the public demonstrating patterns, sparring skills, and my personal favourite – board breaking. No half measures, I was either going to get my blackbelt or fail knowing I'd done my absolute best.

**"I was standing in a freshly ironed uniform in the back position of a class ... No backing out now. As soon as they arrived, the sweating started."**

8:30am on Saturday the 30th of April, I was standing in a freshly ironed uniform in the back position of a class of 19 other candidates waiting patiently for the two examiners (one of the four NZ Masters and another very senior blackbelt) to arrive. No backing out now. As soon as they arrived, the sweating started. For the next three hours, I kicked, punched, blocked, and ran. Sweat poured into my uniform, into my eyes, and down my arms and legs – yet I kept going full tilt. You are examined continuously over the weekend, and even little things like rotating a wrist the wrong way at the wrong time could cost you a point or two. All the time, the haemophiliac monitor that lives at the back of my brain kept an eye on the aches and pains that were developing, knowing that I still had a full day to go. I'd had a prophylactic of Factor VIII that morning, so was as well covered as I was going to be – the trick was going to be working through the arthritis.

After lunch (Drew had to peel my bananas and open my drink as I had the shakes!), it was back for another three hours – pad work, board breaking, and the first of the patterns I had to demonstrate. About an hour into it, as we were charging down the length of the 15m hall for what seemed like the millionth time smashing the snot out of a pad on the way, I felt the first pang of doubt – "Not sure how much more of this I can take," I mentioned to my sparring partner – "Keep going – come on, it can't last much longer" was

the response. It was right then I realised we were all in this together. While it was clear that I was different - from the fact my elbows don't straighten and that I can't jump like the others - this was accepted without any question. Two hours later though we were still at it with only a 5 minutes break, but the old determination was back.

By 4pm it was time to start of the fitness test. I absolutely nailed the sit-ups (84 from memory), smashed my way through the three rounds on the pad, didn't quite manage to pull off enough push-ups on my elbows with no bone, and then set off on the run. When your ankles don't flex any longer, even having expensive shoes isn't going to make finishing the run in less than 10 minutes possible, but I was determined to both finish and beat my best training time. It was a matter of pride. I had a team of friends both from the Taekwon Do community and outside it running with me, and they made sure I kept a steady pace and walked from time to time to let my ankles recover. With one block to go, and the stopwatch showing that I wasn't going to get any points towards the grading, but that my personal best was in reach I announced, "I'm off", and sprinted on my toes through the tape. I remember hearing my fellow gradees and their supporters cheering, and then Drew and Chris shouting "Stop, you're there!" My feet stopped moving and fortunately they grabbed me just before I went down to the ground. I'd done it – survived day one and I even beaten my previous best run time by 30 seconds (18 minutes).

The second day started with a joint and muscle status check at 5am, followed by another prophylactic dose of Factor VIII. Needless to say I was moving a little slower than the previous morning, but was pretty happy with the state of play. Putting on some dress clothes, I jumped in the truck and headed off back to Palmerston for the theory portion of the grading.

**"I told them how much it meant to me that I was here after all these years... people like myself were grown-ups and that all we wanted was for them to help us find a way to help us reach the goals we set for ourselves..."**

I'd been asked by the examiners if I would be willing to do a short verbal summation for the other candidates (some of them instructors going for their senior blackbelt grades) of my haemophilia, hepatitis, and training. Normally I don't like discussing such things, but after the camaraderie of the day before I decided why not.

Getting up, I proceeded to explain what severe haemophilia is, what it can mean, and what for those of my generation it does to your body over time. I explained why I can't jump, and why the run took so long. I explained how during the two years that I was on interferon (and 48 other tablets a day) for my failed hepatitis treatment, being able to go to training kept me from wallowing around the house in despair. I also described how this grading gave me a reason to get fit again afterwards. I explained in detail what I have to go through in order to keep training and to keep going over the weekend. But most importantly, I told them how much it meant to me that I was here after all these years, how much the inclusiveness of the federation was like a breath of fresh air, and how that over the last 5 years and during the grading weekend there were never any questions, comments, concerns, or cotton wool. I stressed to the candidates the importance of realising people like myself were grown-ups and that all we wanted was for them to help us find a way to help us reach the goals we set for ourselves – not to judge us for those goals. The message appeared to hit home as quite a few people afterwards made a point of coming up to pass on their appreciation of my sharing my view. During my formal interview later that morning, the examiners also expressed their appreciation.

Now feeling pretty fresh and pumped, it was into the home stretch – the public section. Three more hours and I was done. With my little gang of supporters in the wings, I went out and did my thing. Three more patterns were hammered out, and it was immensely satisfying when the lead examiner sat there with a smile as my final shout echoed around the hall for a few seconds. Then came free-sparring (essentially a fight). While contact is intentionally limited, there is always the chance for a misplaced blow to do some serious damage, so the federation had permitted me to pick my opponents. I had chosen my third degree blackbelt Head Instructor and the Senior Assistant Instructor, both 15 year or more veterans with excellent control and directions regarding "NOT THE FACE! NOT THE FACE!" After a round with each I was breathing reasonably hard, at which point the examiner suddenly decided two-on-one. So there I was, bit sore, bit puffed, with two blackbelt instructors ready to take me down. Staunch face on, I danced around – got a few good hits

in, then ran away as fast as I possibly could (in a superbly marshal artistic sort of way of course!).

Free sparring over, that just left my favourite part of the weekend – destruction. After being told for years that bumps and knocks were bad, there is something I always find incredibly satisfying about seeing two to three inches of pine board stacked in front of you one minute, and then your elbow or foot sailing through the next like wasn't even there. I have every single board I've ever broken dated, labelled, and stacked in my spare closet and when I'm having a particularly bad bleeder day I go stare at my pile and grin. The trick with having haemophilia and board breaking is that it only ever causes a bleed if you don't break it – and even then, if you have the technique down you can still often get away without injury even if it doesn't break. The key here though is technique, so definitely don't try this at home kids! However, if you want to learn how, come see me and I'll teach you the

same way I was taught – slowly and carefully with a massive amount of speed and strength training along the way.

But – back to the grading, Ian Reddie had driven all the way up from Wellington specifically to watch me "smash some wood!" and there was no way I was going to let him down. Two board back-kick first ... SMASH ... Next up, three board side kick (my personal favourite)... SMASH... and then only one more to go, the very first break I'd ever done in 2006, front elbow strike, however this time there were two solid wooden boards. Lined up, swung, and thump. I'd slipped forward on the ankle and hit it wrist first. The trick now was to hit it again fast before it all swells up, so adjusted a bit, pushed my foot hard into the floor so it wouldn't move again, swing. SMASH! followed by applause and cheering (there's always a lot of cheering during board breaking sessions). I then politely my way down to the back of the hall to raid my well stocked medical kit for an icepack and gauze for my wrist to be on the safe side.

Then it clicks – that's it, I've done it! Paul Dagger, severe haemophilia, chronic hepatitis C, busted ankles, busted elbows, surgically removed bits and pieces, has completed an entire black-belt grading and is still standing. Oh I was the man! Most importantly to me though, I was the man surrounded by and being congratulated by a bunch of other extremely fit sweaty people who saw me as nothing other than another martial artist that had done everything they had done in pretty much the same way. At that point, pass or fail I could honestly say the weekend with all its sweat, and all its pain, and all



From Top to Bottom  
Lined up to begin sparring  
Sparring – Paul in action  
Paul took on two instructors at once as part of his grading  
Breaking a final board with a side kick.

## Becoming a Blackbelt: a personal victory

its nerves, had been the absolute hardest, but most personally satisfying thing I had ever done in my life. School prize giving, drumming competitions, Masters thesis, cruising around in my Holden V8, nope – nothing was as cool as how I felt right then. Walking out of the grading venue, other blackbelts many of them instructors that had been watching the public display came up and started congratulating me, I'd never spoken to any of them before in my life – I didn't think any of them even knew who I was.

Two very nervous weeks later the results came out (during which time I had not a single bleed as a result of the weekend adventures, just alot of aching muscles). I'd passed! No special dispensation had been given, I was scored on my merits like everyone else (which did mean I got zero points for the run and zero points for my pushups!), but that was what I wanted – a level playing field not an easy one. At 33 years old, 27 years after the idea entered my head – I was officially a real internationally recognised blackbelt. To top it off, my Head Instructor also officially appointed me one of the two assistant instructors for our club of 77 members, something that was embroidered on my new belt for the world to see. Putting on my new uniform with its black edging, and the black-belt with gold lettering for the first time was everything I hoped for.

I received congratulatory emails from the other instructors in the Wellington region, from students I had graded with on the weekend, from the examiners, but the one that stands out and is sitting still in my kitchen is a handmade card from an eight year old from our kids class that she presented me along with a chocolate fish.

**"However, starting slowly, testing the waters along the way, and finding a way to say yes rather than no, I found something that not only dramatically improved my fitness and controls my body weight, but gave me a reason to stick with it ...[and] that dramatically improved my feeling of self worth."**

So, I've filled a few pages (unless Chantal uses a teeny tiny font or deletes the middle of this article!), and what did I want to say? As a haemophiliac we are often told can't or shouldn't, and often it's easy for us to start saying this to ourselves. But there is almost always a way, and giving up on a childhood dream without finding out if you can, or because its hard, or because you stumble, also potentially means giving up on an opportunity to discover something means more to you than you ever thought.

High impact martial arts and all that goes along with them have got to be at the top of the list of things that I always understood haemophiliacs don't do, try, or even think about. However, starting slowly, testing the waters along the way, and finding a way to say yes rather than no, I found something that not only dramatically improved my fitness and controls my body weight, but gave me a reason to stick with it even through interferon (one of the most terrible times in my life), and finally let me reach a very long term goal in a visible way that dramatically improved my feeling of self worth.

So what's next? December 2012 – 2nd Degree Blackbelt! (hey, I got another 8 ranks to go yet!)

## New HCV Treatments Approved by FDA

***In May, the U.S. Food and Drug Administration (FDA) approved boceprevir and telaprevir for hepatitis C treatment. These two new treatment options, both protease inhibitors, offer a greater chance at a cure for some patients. These new therapies are considered a major step forward in that they significantly increase treatment responses while potentially decreasing the overall duration of treatment compared to the current standard.***

While chronic hepatitis C can be 'cured', current treatment only works about half the time in genotype 1 patients. Standard treatment with pegylated interferon plus ribavirin (P/R) is less likely to be successfully in people with hepatitis C virus (HCV) genotype 1, requiring much longer treatment times (48 weeks). In general, people with genotypes 2 and 3 respond much better and usually only require half the treatment time (24 weeks). Treatment lengths are now often tailored to the patient's response to treatment (i.e., how quickly their viral loads drop), and can either be shortened or extended to 72 weeks in the hopes are achieving a sustained virologic response (SVR). Despite best efforts, in some people the

virus does not respond or relapses after treatment and people experience new rises in virus levels.

The side-effects of standard P/R treatment can be very difficult to deal with and it can be unpredictable how a person on treatment will feel from one day to the next. The most common side effects include flu-like symptoms, fatigue, nausea, diarrhoea, insomnia, irritability and hair loss. It can also suppress bone marrow function, which leads to anaemia. A more severe complication is decreased platelet counts, which can cause spontaneous bleeding.

Research is currently being done on new drugs that show promise in treating HCV

for shorter periods of time, with less side effects and with more success in achieving a sustained virologic response (SVR), indicating that the HCV infection has been cured.

The group that is furthest along and closest to being available are called protease inhibitors. This class of drugs works by binding to the virus and preventing it from multiplying. They inhibit enzymes that the hepatitis C virus needs to reproduce and release new virus particles from cells that have been infected.

Boceprevir, known by the trade name Victrelis™, is a protease inhibitor from Merck. It was approved by the FDA in May

2011 for the treatment of chronic hepatitis C genotype 1 infection, in combination with P/R, in adult patients (18 years of age and older) with compensated liver disease, including cirrhosis, who are previously untreated or who have failed previous P/R therapy. Boceprevir is a pill that needs to be taken three times a day with food along with the standard treatment.

In two Phase 3 clinical trials of boceprevir combined with P/R, two-thirds of the 1500 adults patients with HCV genotype 1 had undetectable levels of hepatitis C virus in their blood 24 weeks after treatment ended (achieved an SVR). Early responders were able to stop treatment after 28 or 36 weeks instead of the standard 48 weeks. According to further studies, people with hepatitis C genotype 1b respond better to boceprevir and are less likely to develop drug resistance than those with genotype 1a. The most common side effects were fatigue, low red blood cell count, nausea and headache. Boceprevir has also been approved in Europe and Canada.

Telaprevir, known by the trade name Incivek™, is another protease inhibitor that was approved by the FDA in May for people with genotype 1 chronic

hepatitis C, both for those who were not treated previously and those who were treated previously but not cured. Vertex is developing telaprevir in collaboration with Tibotec, who has the rights to commercialise the drug in New Zealand. Telaprevir is a pill taken three times a day with food. It should be taken for the first 12 weeks of treatment in combination with P/R. Most people with a good early response to the telaprevir combination regimen can be treated for 24 weeks instead of the recommended 48 weeks.

In Phase 3 studies, telaprevir was given for 12 weeks in combination with P/R followed by P/R alone for a total of 24 weeks or 48 weeks of treatment. Data from these studies demonstrated that people who received telaprevir-based combination therapy achieved significantly higher rates of SVR compared to treatment with 48 weeks of P/R alone, regardless of their experience with prior treatment. Among people who were not treated previously, 79 percent achieved a SVR with telaprevir-based combination therapy compared to 46 percent who achieved a SVR with P/R alone. Approximately two-thirds of people in Phase 3 studies who were not treated previously and who received telaprevir-based combination therapy were eligible to complete their treatment in 6 months – half the time needed with currently

available medicines. The most common side effects were rash, low red blood cell count, nausea, fatigue, headache, diarrhoea, itching (pruritus), and anal or rectal irritation and pain. Rash and anaemia occurred more frequently among those treated with telaprevir-based combination therapy compared with those who received P/R alone. Telaprevir has also been approved in Europe and by Health Canada

Due to the high costs, it may be a long time before the new treatments are available in New Zealand. Although it is likely that the price will come down as the drugs become available to more markets, treatment with telaprevir is currently approximately 22,000 Euros (\$38,500 NZD) per patient in France and around 30,000 Euros (\$52,600 NZD) with boceprevir. Nevertheless, even once they are available is likely that availability may be limited to seriously ill patients or those who have previously tried standard treatment without success. When the new medications reach the market, it is largely thought that these will be used as an addition to the current treatment instead of a replacement. Studies have shown there is a high rate of the development of drug resistance if these two newer medications are used alone.

Some researchers believe that the next generation of drugs to these protease inhibitors, with even higher cure rates and fewer side effects, is likely to reach the market within a few additional years. Nevertheless, depending on your health and genotype, people who have never tried P/R and are ready for treatment are still encouraged to do so instead of delaying as the current generation can lead to a cure, stop the progression of the disease and may be lifesaving in the long run.



**give  
a little**

### Give a little? Give a lot!

Charitable donations to HFNZ can now be made online at:  
[www.givealittle.co.nz/org/haemophilia](http://www.givealittle.co.nz/org/haemophilia)

# Women and Haemophilia: recognising their specific needs

Many women from haemophilia families lack enough information about their own risks of haemorrhage and transmitting their inherited genetic mutation to the next generation. Education allows woman to better identify their needs and areas where they need more information. It also allows them to improve their diagnosis, their treatments and care. This article will explore several areas all women from haemophilia families should consider.



## Carrier women bleed too

All women who carry the haemophilia gene do not experience increased bleeding, however, those with low Factor VIII or IX levels generally have a tendency to bleed more during their periods or after surgery, dental extractions or childbirth.

### What are the average FVIII or FIX levels in women who carry the haemophilia gene?

A large Dutch study examined the average factor levels in women who carry the haemophilia gene compared to non-carriers (1). The average was clearly lower in women who carried the haemophilia gene – 60 percent in carriers compared to 100 percent in non-carriers. In this cohort, 27 percent of carriers had factor levels lower or equal to 40 percent. On an individual level, however, the levels varied considerably, from 5 to 219 percent. This serves as a reminder that having normal factor levels does not eliminate the possibility of being a carrier of haemophilia.

### Bleeding severity is related to lack of factor

In the same Dutch study they found a great variability in bleeding tendency among carriers. Women with factor levels of less than 40 percent had 2.5 times higher a risk of bleeding after dental extraction and a 3.1 times higher risk after surgery compared to carriers with factor levels higher than 60 percent. The impact on menorrhagia\* was less pronounced, with a higher risk of just 1.3 times. Despite having close to “normal” factor levels, women with factor levels between 40 and 60 percent still experienced increased bleeding following trauma or surgery.

### Women carriers bleed more if the family mutation is for severe haemophilia

The same genetic mutation is present in all the males with haemophilia and females who carry the haemophilia gene within a family. As such, the mutation will be for the same type of haemophilia (A or B) and present as the same severity (mild, moderate or severe) in all the males with haemophilia in

the family. On the other hand, factor VIII or IX levels may vary between the carrier women in the family due to a process called lyonization\*\* of the gene. That is one woman who carries the gene for severe haemophilia might have mild haemophilia themselves due to having very low factor levels and yet her sister or cousin might have normal factor levels and very few bleeding problems. Nevertheless, a German study has recently suggested that generally bleeding episodes were more frequent among women who carry the gene for severe haemophilia.

## Prepared and cared for pregnancies

### Preimplantation genetic diagnosis (PGD) and Prenatal diagnosis

Thanks to amazing progress in genetic research huge steps have been taken towards identifying the genetic mutations responsible for haemophilia and the reliable diagnosis of carriers. For families with severe haemophilia, these advances offer couples who wish to take it up access to preimplantation genetic diagnosis (PGD) or prenatal diagnosis during pregnancy. It is essential for couples to have this information as soon as possible to give them time to make mature parental choices. Knowing your carrier status, being well informed about the quality of life of children with severe haemophilia today, and understanding the constraints of haemophilia and of current treatment are all important to know before choosing to embark on PGD or make a decision about your pregnancy.

The usual process for prenatal diagnosis involves the identifying the sex of the foetus by a blood test at around week 10 of the pregnancy. If the baby is a boy and if the couple wish to proceed, an amniocentesis around week 14 would be done to determine whether the foetus has the haemophilia gene. These complex choices are entirely up to the parents and may be affected by the medical history of their families and their own medical history. PGD has the advantage of avoiding having to make a choice about diagnosis, but can be a long and difficult process that does not always result in a pregnancy. All the risks, consequences and possible outcomes should be understood by couples thinking about this approach.

### Preparing for delivery and birth

Being well organised for birth limits the risk of haemorrhage for the mother and newborn, who does or might possibly have haemophilia. Factor VIII levels often rise progressively during pregnancy but drop soon after delivery. For those with haemophilia B in the family, it should be noted that pregnancy has little effect on FIX levels. It is recommended that factor levels be monitored during weeks 32 to 34 of the pregnancy to help better inform the choice of delivery method and options such as epidural anaesthesia. Factor infusion is sometimes needed. After delivery, FVIII levels slowly return to baseline levels, sometimes provoking haematomas on along stitching from an episiotomy or a

### Glossary:

\***Menorrhagia:** abnormally long (more than 7 days) or heavy (more than 80ml per cycle) menstrual periods.

\*\***Lyonization:** process that results in the inactivation of one of the two X chromosomes at an early stage of embryonic development in females.

\*\*\***Obligate carrier:** the daughter of a man with haemophilia, a mother of two boys with haemophilia, or the mother of a boy with haemophilia who also has a brother or maternal uncle with haemophilia.

caesarean section, or contributing to a post-partum haemorrhage and requiring specific treatment.

While the risk of haemorrhage to newborns with haemophilia at birth is relatively low, it is very real, especially with moderate or severe haemophilia. Thankfully severe bleeds, such as intracranial bleeds, are rare, but the risk justifies taking precautions such as avoiding the use of forceps or ventouse methods and discussing ahead of time when delivery would necessitate a caesarean. All newborn baby boys born to carrier mothers should be considered to have haemophilia until this is proven otherwise by laboratory testing. Activities that could cause bleeding in a newborn should be avoided and any bleeds treated promptly.

To best manage the risks to both mother and child, a multidisciplinary protocol should be established in consultations with health specialists such as an obstetrician, midwife, anaesthetist, paediatrician, pharmacist, haemostasis laboratory and haemophilia treatment centre. A large study in UK has clearly demonstrated the benefits of having such a protocol in place (3).

## Acknowledging unmet needs

### Bleeds, women and haemophilia: an impossible connection??

A point that is often raised is the lack of recognition of bleeding symptoms in female carriers of haemophilia. As haemophilia is usually associated with males, the risk of bleeding in a female relative is often overlooked, particularly female-specific symptoms such as menorrhagia. Women carriers with low factor levels are not often viewed as “patients” themselves with specific medical needs. More often than not they are simply viewed as parents of children with haemophilia. The woman themselves frequently put the priority on the more severely affected male members of their families and are not always encouraged by medical staff to seek treatment for their own needs. Consultations specifically dedicated to the woman carriers in the family can be rare in some places.

Many potential or obligate\*\*\* women carriers ignore their factor levels and so find themselves at risk of complications during surgery, trauma or giving birth. In the Dutch study already mentioned, 18 percent of women carriers had never had their factor levels measured, and only 7 percent of participants had had them measured following a bleeding incident.

Once factor levels are established, the management of women with low factor levels is still a long way from being as clearly established as for their male equivalents with mild haemophilia.

Medical jargon and definitions also play a part in the delay to recognise bleeding symptoms and risk in women carriers of haemophilia. Sentences such as “Only men get haemophilia, woman are unaffected” in outdated medical texts do not help. How many women with low factor levels are mislabelled due the lack of definition for their own condition despite experiencing bleeds? Expressions such as “symptomatic carriers” or “carriers with low factor levels” are sometimes used. While these terms might be technically correct they are insufficient to get a non-specialised doctor or GP to understand the real risk of bleeding that can occur. Management of these women should be the same as for males with mild haemophilia, with regular follow-up, a clear diagnosis and protocols established for any medical procedures, such as surgery, or any situation where there is a risk of bleeding, such as giving birth. On the other hand, women who carry the haemophilia gene but have normal factor levels should have access to education about their risk of transmitting haemophilia to their children.

### Barriers to diagnosis in women carriers

According to the various statistics reported in the literature, around 30-50 percent of women carriers are unaware of their genetic carrier status, even among some obligate carriers. The reasons for this are primarily a lack of information, a lack of dialogue amongst the family (especially where the subject of haemophilia can be considered taboo) and simply not knowing about the possibility of carrying the gene or that there are genetic tests available. Even among those who are well-informed about haemophilia, some women are reluctant to undergo testing. It is not always so simple to brave facing a positive diagnosis. It gives rise to a number of emotions and fears, and in some cases can bring back painful memories of the suffering of a loved one. Not getting tested is still hoping that you’re not a carrier!

Not knowing your carrier status hinders appropriate genetic counselling, especially when it comes to planning pregnancy and organising the delivery. The risk of post-partum and neonatal bleeding complications are significant. Not knowing your carrier status can delay diagnosis in your newborn, and consequently delay proper treatment in possibly serious situations. Waiting until you’re pregnant to undergo testing can also lead to worries that can be magnified by the pregnancy. Accepting the diagnosis of being a carrier of haemophilia is always difficult, and the feelings are compounded by having to consider complex choices about your pregnancy.

Sometimes a carrier diagnosis is made so late in the pregnancy that the only option is to make quick arrangements for a delivery assuming the baby might have haemophilia. Whether known early or late, the possibility can be very stressful for parents. Knowing earlier though gives time to consider the implications and perhaps reach a level of acceptance.



Having a plan for your pregnancy and delivery can reduce risks

Families and the healthcare team working closely together is vital for:

- Considering each woman carrier with low factor levels as a patient with mild haemophilia and seeing that they are, therefore, treated appropriately;
- Regularly updating family trees of patients with haemophilia;
- Having written confirmation of the genetic diagnosis and specific familial mutation;
- Understanding any legal obligations regarding disclosing genetic information about risks to relatives;
- Sharing information and resources that create a chain of information and discussions outside of the hospital;
- Increasing the knowledge of non-haematology specialist (gynaecologists, general practitioners, emergency doctors...);
- Helping fathers with haemophilia talk to their daughters about haemophilia and their genetic carrier status; and
- Not leaving women carriers to struggle alone with their diagnosis and the weight of transmission. After all, more times than not they inherited the genetic mutation from one of their parents.

HFNZ regional get-togethers and national education workshops such as the Women's Weekend are enriching and valued opportunities. These events and activities raise awareness, and allow women to share their experiences and knowledge with each other, benefitting all. They also often feature guest speakers with specific expertise in issues associated with carrying the gene for or having a bleeding disorder.

HFNZ plans to run another Women's Weekend in 2012 or 2013. Keep an eye out for details or contact your Outreach Worker to express your interest.



**Source:** The majority of this article was translated by C. Lauzon from "Femmes et hémophilie: des besoins spécifiques à chaque âge" in *Hémophilie et maladie de Willebrand*, N°194 – June 2011 published by the Association Française des Hémophiles (French Haemophilia Association).

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*The XXIII Congress of the International Society on Thrombosis and Haemostasis (ISTH) was held in Kyoto, Japan, on July 23-29, 2011. The Congress concentrates on science relating to thrombosis and abnormalities of haemostasis and vascular biology and aims to provide a forum for discussion of these problems and to encourage research. It is a place where important research in the area of new treatments for bleeding disorders is often showcased.*

*This year's Congress featured sessions on specifically on Factor VIII and IX, as well as related topics, on von Willebrand Factor, plasma coagulation inhibitors and much more. The following are some highlights of research presented at ISTH.*

### Cardiovascular Disease in Haemophilia

With increasing life expectancy, more haemophilia patients will be confronted with age-related problems like cardiovascular disease (CVD). CVD mortality is reported to be lower in haemophilia patients than the general population.

One study from the Netherlands reported that myocardial infarction (heart attacks) occurred significantly less often in patients with severe haemophilia than in the general population.



Although the study was based on retrospective data from a relatively small cohort of patients, the results support the protective effect of (very) low clotting factor levels against heart attack.

A joint Dutch-UK study reported increased prevalence of hypertension in haemophilia patients. High blood pressure has been reported in the past to be higher in haemophilia patients but this study measured the blood pressure of over 500 people with haemophilia from the Netherlands and UK over the age of 30 so the data could be analysed. The prevalence of hypertension was significantly higher in haemophilia patients (51%) than the general population (41%). The reasons for this remains unknown as there were no real differences in weight, age or other medical factors.

The same study group presented further findings that haemophilia patients showed an increased QRISK2 risk score compared with the general population. The QRISK2 cardiovascular disease (CVD) risk score assesses a 10-year cardiovascular risk based on age, gender, ethnicity, smoking, presence of diabetes, kidney disease, atrial fibrillation, rheumatoid arthritis, family history of heart disease, body mass index, blood pressure and cholesterol levels. A reduced occurrence of CVD in haemophilia patients would be present in spite of an increased CVD risk, further emphasising the protective effect of low clotting factor levels on CVD occurrence.

A German study also concluded that the prevalence of coronary artery disease will rise along with the increased expectancy of life in people with haemophilia. It is likely that coronary interventions and surgery will become more frequent, and so clear recommendations are needed for pre-, during- and post-surgery management. Finding antithrombotic regimens (anticoagulants and antiplatelets) for primary and secondary prophylaxis will remain a permanent challenge in people with haemophilia.

### BAX 499

BAX 499, a fully synthetic compound, is being developed by Baxter as a potential treatment for haemophilia A and B that could be administered via subcutaneous (under the skin) injection. The new drug blocks the activity of the tissue factor pathway inhibitor, helping patients with haemophilia achieve better clotting.

The studies presented on BAX 499 validate tissue factor pathway inhibitor as a viable target for subcutaneous haemophilia therapy and showed that BAX 499 also increased the rate and amount of thrombin, a key clotting protein, that was generated. BAX 499 is in phase I clinical trials, expected to be completed in the second half of 2011.

"We are encouraged by these data that help deepen our understanding of potential new approaches to address complex blood disorders," said Hartmut Ehrlich, MD, vice president, global research and development and medical affairs, Baxter's BioScience business.

### rVWF Therapy

Baxter also reported on a recombinant von Willebrand Factor (rVWF) therapy that, unlike current treatments made from plasma (pdVWF), contains no blood-based additives.

A Phase I clinical study was performed on 32 patients with different types of vWD, measuring the safety, tolerability and pharmacokinetics (processing and duration of a drug's effect in the body) of rVWF versus pdVWF. Four concentrations of rVWF were administered in a dose-escalating manner. Investigators reported no serious and 12 "nonserious" adverse reactions in patients with type 3 and severe type 1 vWD. The clinical data also showed that the pharmacokinetics of rVWF and pdVWF were comparable. Baxter announced that it will recruit patients for a larger study to evaluate safety and efficacy of rVWF, which will begin in the latter part of 2011.

### Longer lasting FVIII

Biogen Idec and Swedish Orphan Biovitrum announced the results of a Phase 1/2a clinical trial of the companies' long-lasting recombinant factor VIII Fc fusion protein (rFVIII-Fc). A-LONG, the global clinical trial launched in late 2010, is a multicenter study designed to evaluate the safety, efficacy and pharmacokinetics



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(processing and duration of drug's effect in the body) of rFVIIIc in previously treated patients with haemophilia A. rFVIIIc was well tolerated and demonstrated an approximately 1.7-fold increase in half-life when compared with an existing recombinant factor VIII product (rFVIII) in 16 previously treated patients with severe haemophilia A.

"This trial is a step toward addressing the significant unmet need for a long-lasting recombinant factor VIII product," said Neil Josephson, MD, Co-Principal Investigator of the Phase 3 rFVIIIc A-LONG trial "Results from the Phase 1/2a study show that rFVIIIc has an extended half-life, which may have the potential to provide extended protection from bleeding and reduce the number of infusions necessary for prophylactic treatment of severe haemophilia A."

The trial will eventually be expanded to 60 centres worldwide, with approximately 150 patients. The patients will be divided into high-dose, low-dose and on-demand groups.

### Recombinant Porcine FVIII

Inspiration Biopharmaceuticals, Inc. presented data from its clinical development program for OBI-1, an intravenous recombinant porcine (pig) factor VIII product (rpFVIII). rpFVIII is intended as an alternative for the treatment of bleeding in people with hemophilia A with inhibitors and in people with acquired hemophilia. Interim results from the first registration study in the OBI-1 clinical trial program, Accur8, were presented. Three patients with acquired haemophilia, who had experienced severe bleeds not controlled with bypassing agents, were treated with OBI-1. The drug successfully stopped their bleeds. Additional study data on haemostatic efficacy (the ability to stop bleeding) and safety are being collected as part of the Accur8 program.

A Phase 2 study of patients with hemophilia and inhibitors showed that the treatment controlled their bleeding, even in those with high titers. All 25 bleeds were controlled, 80% of which required two infusions.

### Collaboration between ISTH and WFH

Also at the Congress, ISTH and the World Federation of Hemophilia (WFH) signed a memorandum of understanding to formalise collaboration and coordination of activities between the two organisations. Both organisations have common interests and WFH President Mark Skinner said, "This partnership is an important step towards achieving our goal of improving and sustaining access to care for people with bleeding disorders



around the world through education and research." In the future the organisations plan to conduct joint educational and scientific sessions and produce joint educational materials, as well as collaborate in data sharing projects to improve treatment and advance scientific understanding of bleeding disorders.

### Other research highlights:

- A French study concluded that continuous infusion in children is effective and safe and could be a good alternative to bolus infusion for the management of severe post-traumatic bleeding events. Their regimen of 4.95 IU/KG/h seems to be effective and comparable to 50IU/KG given twice a day considering the cost/effectiveness ratio. Further studies are needed.
- Two-year results from the European Haemophilia Safety Surveillance (EUHASS) registry, which combines data from 50 European centres, showed that inhibitor formation is the main side effect of haemophilia treatment, occurring in 25 percent of previously untreated patients (PUPs) with severe haemophilia A and 4 percent with severe haemophilia B. The inhibitor rate for previously treated patients (PTPs) with severe haemophilia A and B was less than 0.1 to 0.6 per 100 patient years.
- A large UK study found that people with severe haemophilia remain at risk of new inhibitors throughout their life and this increases in older age. People with severe haemophilia should be tested for inhibitors through their life and especially before surgery.
- A UK study found that having multidisciplinary clinics for women with vWD provide a coordinated approach leading to prompt intervention and has led to improved clinical outcomes, such as improvement in bleeding symptoms, and increased Hb and ferritin. There is also a marked cost saving and substantial reduction in vWF concentrate usage.
- In the Danish haemophilia population death rates resulting from HIV and HCV related diseases are declining and life-expectancy is increasing. However, mortality amongst people with haemophilia remains higher than the general population despite modern standards of care.

All the abstracts from the Congress can be viewed at [www.isth2011.com](http://www.isth2011.com)

## Council Corner

### Updates from the HFNZ National Council

**In order to increase communication directly with the membership of HFNZ, Bloodline features Council Corner. Here, HFNZ National Council provide information and updates on their activities and decisions.**

HFNZ National Council held their latest meeting in August. They are happy to report that despite the tragic events of the past year, public donations to HFNZ have been steady and higher than anticipated in the first half of 2011. This, along with funding from various grants and support from our Sustaining Patrons, means HFNZ is currently in a solid financial position.

National Council continue to look to invest in a permanent property for the HFNZ National Office, however, given the current situation in Christchurch the decision has been to carry on saving and postpone the search for a couple years

until more options become available. The current office has remained structurally sound and accessible through the earthquakes and the staff feels safe working there.

Later in the year National Council will review a draft Governance Policy. The Governance Policy is an over-riding document that complements the HFNZ Constitution and outlines the Global Objectives and Governance Process of National Council, Executive Limitations of the CEO and Council-CEO Linkage. All HFNZ activities and programmes should be in alignment with the Global Objectives once confirmed. This will be a living document and will be amended as needed as time goes on. Further information on these Global Objectives will be published once the policy is adopted.

At the meeting CEO Belinda Burnett gave a presentation on how volunteer

organisations evolve and the different stages they go through. HFNZ has come a long way over the past 50+ years, and it is through the will of members and volunteers that we have grown into a professional organisation. HFNZ have reached a point where they are well resourced and well staffed, but while this is positive growth it also brings with it some disadvantages. A discussion was held on why this might be and how to better engage members who might feel they are no longer needed by the Foundation. While there have been some recent successes, for example the formation of the Roopu has involved some members in new ways, there are many places where we are not as successful. For instance, some regional committees find it difficult to recruit members. Further discussion is planned on outlining a shared vision to unite the membership and on activities that might reach new audiences.

## MRG Reports

**As HFNZ now operates six groups that represent different member groups, we thought it was time we change the format of our 'Regional Reports' to include them all: Northern Region, Midland Region, Central Region, Southern Region, Roopu (group that represents Māori members), and the National Youth Committee (NYC).**

**Collectively these six HFNZ groups are now known as the Member Representative Groups, or MRGs – a new acronym for all to learn!**

**Read below about what has been happening or is coming up for some of the committees and members represented by the MRGs.**

### Roopu

**For their first report, members of the Roopu committee take the opportunity to introduce themselves.**

**KO MAUI HE ATUA  
KO MAUI HE TANGATA  
KO MAUI HE MANU  
KO MAUI HE NGANGARA HOKI!**

Tihei Mauri Ora.

Mihi nui ki nga whanau whanui o te HFNZ.

Ko Neville-James Reedy taku ingoa. No te Tairawhiti ahau, mai te urunga tapu o Paikea, tae noa ki te papatipu o Uepohatu.

My name is Neville-James Reedy. I am from the most awesome place in the whole world, a huge city called Ruatoria, strategically situated two hours north of Gisborne. Just up the road from Ruatoria is another over-populated city called Reporua where the best boo-boo's in the world can be found.

Ko Hikurangi te Maunga,  
Ko Waiapu te Awa,  
Ko Ngati Porou te Iwi.

E noho ana ahau a tenei waa kei Waihopai(Invercargill). He tauira paetoru oTe Whare Wananga O Murihiku.

Kei te mahi whakaahua kiriata me nga paki waituhi me tuhi purakau hoki.

Ko Te Mangai ki te Tonga ahau. He takawaenga o te ropu Maori mo HFNZ.

I am currently living in Invercargill and in my 3rd year of a Bachelor in Digital Media studying Film and Animation at the Southern Institute of Technology.

I am the Southern representative for the HFNZ Maori group. (I wanted to be the chairperson but my aunty already got that job.)

MAURI ORA!  
Ph: 03)931-0430  
Mobile: 022)612-7264  
*P.S. Only call me, bcoz I can't afford to call you.*

Kia Ora Tatou Katoa.

Members of the Roopu at AGM – Members of Roopu (from left to right) at this year's AGM: Raukura Riwaka, Joe Wrathall, Carol Reddie, Kahurangi Carter, Hemi Thomas, Patience Stirling, Amaria Waretini-Thomas, and Tara Mounsey. (Insert) Neville-James Reedy



**Tena koutou katoa, Ko Hikurangi te maunga, Ko Waiapu te awa, Ko Horouta te waka, Ko Ngati-Porou te iwi, no Te Tairāwhiti ahau. E noho ana au ki Awakairangi . Ko Carol Reddie taku ingoa.**

Hi All! Hikurangi is my mountain, Waiapu is my river and Horouta is my canoe, Ngati-Porou is my tribe and I come from Gisborne and I live in Lower Hutt. My name is Carol Reddie. This is a bit of back ground about me for your information. I have three adult children, two boys and a girl. Both sons have severe Haemophilia. They have been managing their own Haemophilia since they left home. I am the current Maori representative for the Central Region. By taking on this role I thought I could be of value to assist with other families with Haemophilia and in particular whanau who identify as Maori.

Naku noa Carol

**Uia mai koia,whakahuatia ake Ask and you will be told  
Ko Poho- o- Rawiri te marae My marae is Poho-o-Rawiri  
Ko Titi Rangi te maung My mountain is Titi Rangi**

My name is Joseph Wrathall, I have severe haemophilia with an inhibitor, and I am from a family that has had a long history of Haemophilia. I am an 'older' member of the NZ Haemophilia Society/ Foundation as I have been a member since HFNZ first began in Wellington.

I have inherited British (both English and Scottish) ancestry from my father's family, and my mother's side of the whanau are the Rangi from the Ngati Porou, Te Aitanga-a-Hauti, and Ngati One One.

I have been the Maori National Representative since 2009, both at meetings and Hui, and also on the HFNZ National Council. I have largely been involved in establishing the Roopu, through providing planning and direction, the setting up of Māori representation, and the organising of Hui, AGM and Takawaenga meetings. The overall goal/aim being to increase Māori participation in HFNZ.

By living with haemophilia, I have been a participant and witness to the development and progression of haemophilia treatment and care, and also, the evolution and growth of HFNZ.

I look forward to continuing to work for and be involved with both the Roopu and HFNZ.

He honore	Honour
He kororia	Glory
Maungarongo ki te whenua	and peace to the land
Whakaaropai e ki nga tangata katoa	Goodwill to all mankind
Ake, ake, amine	Forever and ever, Amen

**Kia Ora!!**

My Name is Raukura Riwaka.

I am one of two HFNZ Wellington Youth Delegates.

At Weltec, our group of 7 have been presented a collaborative assignment which must benefit a charity. So it seemed like an awesome idea to support the Haemophilia Foundation of New Zealand!!!

Our project, "the H project" is to create a large scale collaborative mural on canvas to auction off. All proceeds will then go to HFNZ.

We are also currently filming our project to help raise awareness, also to encourage our younger members to get more involved - so keep an eye out for that!! We will be posting that up on Youtube!!!

I think the opportunity to be able to give back to the foundation is amazing and with the team knowing that i have Haemophilia, they all jumped at the opportunity to help out HFNZ.

Keep an eye out for how we went in the next HFNZ Issue!!

**Kia Ora Whanau in the Midland Region**

Ko Ngati Raukawa, Nga Puhi, Tainui toku Iwi. My name is Tara Mounsey and I live in Hamilton with my whanau. At the moment, I wear a few hats in my mahi, and I find each one stimulating and challenging for my development in the areas I have chosen to work in. I have been in the position of the Midland Takawenga (rep) for over a year now and have met new and re-aquainted myself with not just members from the Midland Region but also nationally.

I have endeavoured to encourage and support our Roopu and find that this is still a major work in progress, but all our Takawenga have made so much progress in connecting with our Haemophilia whanau that it is great to see them at Huis, camps and workshops. We live it, we breath it, we manage it everyday and I just want to say you're not alone. I look forward to the Hui in August which is a first for the Midland region to host at Kohinga Marama Marae. Hope to see you there.

No reira, tena koutou, tena koutou, tena koutou katoa

**Amaria Waretini-Thomas**

Roopu Secretary amaria.thomas@telproject.co.nz 021 239 4939

Currently, I live in Mt Maunganui working on the Tauranga Eastern Link Construction site as an Engineer. When I'm not working, I like music and going to the beach. I enjoy being a part of the Roopu as the members have a special bond and are very supportive of each other. Whenever I catch up with the Roopu members it's like a family reunion. We always have fun together and it's nice to have the support network available within the roopu. I always look forward to roopu events for the good fun, the great food and the awesome catch up with the other members. Come and join us! We want you!

**I am Kahurangi Carter** and I am a Haemophilia carrier. I am your Northern Roopu Representative on the Māori Roopu. This means I am always happy to help you in any way I can or guide you to someone who can. We are a new Roopu but have been working hard to pull all our Māori members together and give you a place where you feel happy to give us your ideas or suggestions on how to help improve how you and your whanau live with your blood disorders. The best way for me to contact you is by email because not only does the Northern Committee hold fun events but we will be holding a Māori event soon so watch this space! Please email me you contact details at kahurangicarter@gmail.com. Arohanui, Kahu x

**Kia Ora, Ko Hemi taku ingoa, Ko Waretini taku Whanau, Ko Taupiri te maunga**

**Ko Waikato te Awa, Ko Hotura te Tangata, Ko Maniapoto te Iwi Te Tookanganui a noho te Marae**

Hey guys. My name's Hemi. Along with Raukura I'm one of your youth delegates on the HFNZ Roopu. We represent the Māori youth in the Foundation. The Roopu is here to provide Education, Support and Advocacy for our members. We are a relatively new committee but we have high hopes for the future. We welcome any and all to get involved with what we do. If you have any questions, suggestions or comments, don't hesitate to contact me at hemi\_63@hotmail.com.

Mauri Ora,

Hemi Waretini

**Tena Koutou Katoa, No te iwi o Ngati Porou, Ko Patience Stirling toku ingoa.**

Greetings to you all, I come from Ngati Porou iwi and my name is Patience Stirling.

Our article has journeyed from Invercargill to Auckland giving you an update on our delegates throughout the motu (country). As the chairperson for the Maori roopu, I am delighted to be part of the vision which started as a conversation during the 1990s summer camp at Willow Park in Auckland. Even though

we are very new our delegates are full of enthusiasm and focused to enhance whanau Mauri Ora (wellbeing) by way of Hui (gatherings). I am a mother of two sons with severe hemophilia, both growing up in different eras of treatment. My younger brother passed away as a toddler with severe haemophilia and my sister has two sons with severe haemophilia therefore giving me vast knowledge and life experiences. As a Roopu we look forward to building new relationships and enhancing established relationships, so keep an eye on the updates and make enquiries with your local roopu delegates.

No reira e te whanau whanui

Tena Koutou, Tena Koutou, Tena Koutou Katoa

**Central Region Report**

**By Stephanie Coulman**

A variety of café evenings, lunches and events show that the central region has been busy mixing and mingling with as many members as possible.

**Palmerston North** - a small group enjoyed a luncheon and a good chat at a café lunch at the Rose & Crown Old English Pub on 24th July.

**Wellington** - Back in June a larger group, including some new members – enjoyed a Malaysian meal together. It was especially pleasing to meet some new members.

**New Plymouth** - Taranaki members have not missed out as Outreach Worker Lynne Campbell organised a Taranaki buffet evening in New Plymouth.

**Quad-biking** – A small group of men organised a mud-filled quad-biking event and meal in Paraparaumu on 3 September. The aim was to get a group of like-minded men (aged 20-45 years who like mud, petrol and fun) in the region together to go on the occasional outing. The cost of this event was funded by the Wellington Haemophilia Memorial Trust.

**'Winter Escape' camp** – Will be held 9-11 September at El Rancho, Waikanae. We've noticed low numbers responding and wonder if it is a conflict with World Cup Rugby or the type of accommodation. Please get in contact with your registrations or let us know why you cannot attend.



Central's Café Evening Wellington

## MRG Reports

However, it's not just central region members as there seems to be a trend across the country with generally slow responses from members to invitations for events via Head Office and from the local branch. It is so important for people to follow through and respond when they receive any invitation please.

### Midland Report

By Catriona Gordon

It has been a quiet time in Midland, but we thought this was a good opportunity to share some photos of our regional camp that was held at Totara Springs in March.



Everyone had a great time at the Midland Region camp

## News in Brief

### Cut-and-paste therapy fixes mouse haemophilia

Scientists have developed a gene-repair kit that treats the blood-clotting disorder haemophilia in mice. The technique, published online by the journal *Nature*, replaces genes in targeted organs without removing cells from the body, simultaneously correcting multiple mutations -broadening the range of diseases that can be treated with gene therapy.

The method uses enzymes called zinc-finger nucleases. These are molecular scissors that replace specific DNA sequences by cutting through the double helix, after which the cell's repair machinery fixes the break.

Until now, therapies using zinc fingers have required cells to be taken out of the body, genetically modified in a dish and returned. This works for some immune and blood disorders such as sickle-cell anaemia, and trials are underway for HIV and diabetic neuropathy, but not for diseases affecting tissues less suited to this type of manipulation.

To develop a way to correct mutations within the body, Katherine High, a haemophilia researcher at the Children's Hospital of Philadelphia in Pennsylvania, teamed up with



experts on zinc-finger nucleases at Sangamo BioSciences in Richmond, California. High and her team used mice engineered to carry a human haemophilia B gene and then designed zinc-finger nucleases to cut through the mouse DNA at the start of the factor IX (F9) sequence and insert the unmutated gene, fixing all the mutations at once.

The researchers injected the mice with the zinc-finger nucleases, along with a liver-targeting virus modified to carry the normal version of F9. After treatment, the animals' blood clotted in 44 seconds, compared with more than a minute for

mice with haemophilia, and contained 3–7% of the typical amount of the missing factor. In humans, such levels would result in only mild bleeding.

There are still some technical hurdles that have to be overcome before the process could become wide-scale medical therapy. Questions remain about how to get the right amount of DNA to the right cells, the risk that zinc-finger nucleases will cut the wrong bit of DNA and the availability of suitable viruses to carry the genetic payload.

"It's still early days," said Paula Cannon, who studies zinc-finger nucleases at the University of Southern California in Los Angeles. "I'm cautiously optimistic that this won't be at all hazardous, but it's appropriate to make sure that these treatments are indeed as safe as we hope they're going to be."

#### References:

Li, H., et al. *Nature* doi:10.1038/nature10177 (2011).

### Obesity and Joint Disease in Haemophilia

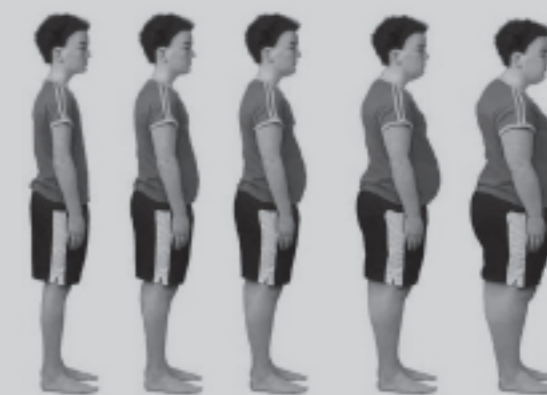
The U.S. Centres for Disease Control (CDC) is working with care providers to raise awareness in the haemophilia community about the importance of maintaining a healthy weight.

In a CDC study that examined the development of joint disease over time in more than 6,000 young boys and adolescents with haemophilia receiving care in federally supported haemophilia treatment centres throughout the U.S., children who were overweight or obese developed joint disease at a faster rate than those whose weight was normal for their age. As expected, the joints in the lower extremities including the knees and ankles were most adversely affected by the increased weight.

Among the children and adolescents with haemophilia, 32.5% were overweight or obese at the beginning of the study which is nearly identical to the 32.7% prevalence of overweight and obesity among all youth in the U.S. Although it is especially important that people with haemophilia maintain a healthy weight to protect their joints, losing weight may be particularly challenging because certain physical activities especially may be not be suitable for people who have a bleeding disorder.

To address these special challenges the CDC is working with care providers to raise awareness in the haemophilia community about the importance of maintaining a healthy weight and helping to develop safe and effective weight loss activities for people with haemophilia.

**Source:** <http://www.cdc.gov/Features/dsHemophilia/>



### Factor VIII Dose Should Consider Both Body Weight and Fat Mass

For patients with haemophilia A, an infusion dose of factor VIII should be modified according to the patient's body weight and fat mass index, and should be adapted for over or underweight patients, according to a study published online July 5 in the *Journal of Thrombosis and Haemostasis*.

Belgian researchers investigated the inter-individual variability of FVIII recovery and its dependence on variables dealing with size and shape, including body weight (BW), fat mass index (FMI), body mass index, and the difference between actual and ideal BW. FVIII was evaluated in 46 non-actively bleeding patients with haemophilia A who were already being treated with a recombinant FVIII concentrate.

The investigators found that the median recovery was 2.08, 2.63, and 1.87 for all patients, for those with a BW of 81 kg or more, and for others, respectively. A significantly higher recovery was seen in patients with an FMI of 20 percent or more, compared to those with an FMI of less than 15 percent (median recovery, 2.35 versus 1.74). Based on regression trees the median recovery for three groups was identified: BW and FMI of less than 80.5 kg and 22.3 percent, respectively, 1.80; a BW of less than 80.5 kg and FMI of 22.3 percent or more, 2.16; and a BW of 80.5 kg or more, 2.63.

"FVIII dosing should take into account patient BW and FMI, and it must be individually adapted to underweight or overweight patients. However, a FVIII recovery value of 2 can be used for normal BW patients with an FMI in the range of 15 to 20 percent," the authors write.

**Reference:** Henrard S, Speybroeck N, Hermans C. *J Thromb Haemost*. 2011 Jul 5. doi: 10.1111/j.1538-7836.2011.04431.x.



### Travel Tip

Going on holiday? Program the phone numbers and addresses of the local hospital and haemophilia treatment centre into your family's mobile phones. To find out the details of haemophilia treatment centres overseas contact your Outreach Worker or visit [www.wfh.org](http://www.wfh.org) to search their Global Treatment Centre Directory. Simply click on "Passport" in the links along the left side of the page.

# Farewell Aly!



*HFNZ are very sad to report that Aly Inder has moved on from her position in the Haematology Department at Christchurch Hospital.*

Aly has made a huge contribution over many years to the Haemostasis Service at the hospital and to HFNZ. Many of the boys with haemophilia were taught to access their veins by Aly either at the hospital or at camps, and she often offered up her own veins for their practise. Many older people with haemophilia often looked to Aly for guidance.

Over the years Aly has participated in many HFNZ camps and workshops, making the time to really get to know her patients and many have benefitted from her excellent teaching skills. She has been very generous with herself and her time, and always seemed willing to go the extra mile for her patients. Nothing ever seemed to shock her, and her non-judgemental attitude and great sense of humour have always been appreciated.

Rochelle Stott, mother of Harrison who has severe haemophilia, says, "As a family, we have found Aly to be a godsend; right from the start. Harrison adores her and when we were going through a very tough time with his port Aly went out of her way to support us, including visiting us at home. It will feel like a big loss for many families."

Aly has been a great friend and supporter to people with haemophilia throughout the South Island. She will be very much missed by patients, haemophilia families and colleagues alike.

On behalf of HFNZ and her many patients, we wish her well for her future.



# Useful Haemophilia Websites

*Although [www.haemophilia.org.nz](http://www.haemophilia.org.nz) has plenty of information on bleeding disorders and the happenings of HFNZ, there are lots of great websites dealing with bleeding disorders from around the world.*

## [www.haemophilia.org.au](http://www.haemophilia.org.au)

The website of the Australian Haemophilia Foundation is full of great info from our closest neighbours.

## [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

Featuring sections specifically for youth, women, people with inhibitors and those interested in the contaminated blood campaign, the website of the Hemophilia Society (UK) is another great resource.

## [www.haemophiliaandyou.com.au](http://www.haemophiliaandyou.com.au)

Haemophilia website with an Australia and New Zealand developed by Baxter with info geared towards parents of children with haemophilia and teenagers.

## [www.healthpoint.co.nz](http://www.healthpoint.co.nz)

### - Auckland DHB Haemophilia Centre

The listing gives a bit of background about the Centre and contact details/ referral processes. It also has a number of articles of interest such as how to recognise bleeds and steps to follow at home when a bleed occurs. It also has factor product information and what to expect from physiotherapy appointments.

## [www.hemaware.org](http://www.hemaware.org)

Website for Hemaware, the magazine of the National Hemophilia Foundation (US). It has a wealth of information including videos, blogs, community voices and research updates.

## [www.hemophilia.ca](http://www.hemophilia.ca)

The website of the Canadian Hemophilia Society has many great resources available for download.

## [www.inhibitorsupport.org](http://www.inhibitorsupport.org)

This international website provides an enhanced user experience with a chat forum, latest news, personal stories, research and information that is easily accessible.

## [www.stepsforliving.hemophilia.org](http://www.stepsforliving.hemophilia.org)

Steps for Living is U.S.'s National Hemophilia Foundation's new, life stages education resource with age-appropriate, tips and tools for everyone. Created by parents, patients, and healthcare professionals from the bleeding disorders community, the Steps for Living Web site provides information and resources to help you and your family adjust to life as your child with a bleeding disorder grows and matures. Although the content is American-focused, it does feature interesting info and tools to help you deal with the many facets of living with a bleeding disorder.

## [www.wfh.org.nz](http://www.wfh.org.nz)

The info-packed website of the World Federation of Hemophilia.

### Allan Coster Education Trust

The Trust aims to promote and encourage educational and vocational training for person with haemophilia and/or related bleeding disorders.

The Trustees will consider applications on the 31<sup>st</sup> March, 31<sup>st</sup> July and 30<sup>th</sup> November each year. In order to meet the deadline, the applications will need to be with your Outreach Worker by the 15<sup>th</sup> of the month in which they are to be considered.

Please contact your Outreach Worker if you have any questions

# Dates to Note

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## **4 September 2011**

Midland Family Winter Day  
Waitomo Caves

## **9-11 September 2011**

Central Winter Escape

## **22-23 September 2011**

World Federation of Hemophilia Seventh Global Forum  
Montreal, Canada

## **20-22 October 2011**

2011 Australia New Zealand Haemophilia Conference  
Sydney, Australia

## **23-24 October 2011**

Australia New Zealand Inhibitors Workshop  
Sydney, Australia

## **6-9 October 2012**

HFNZ New Families Camp  
Forest Lakes, Otaki

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

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**Visit [www.haemophilia.org.nz](http://www.haemophilia.org.nz) for more information on  
bleeding disorders, HFNZ news and past issues of Bloodline**