



2011
HFNZ AGM



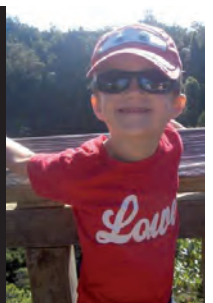
page 7

Obesity &
Haemophilia



page 14

World
Haemophilia
Day 2011



page 24



Haemophilia Foundation of New Zealand Inc.

CONTACT DETAILS
Website

www.haemophilia.org.nz

National Office

4 Washington Way,
Sydenham, Christchurch
PO Box 7647, Sydenham
Christchurch

Phone: (03) 371 7477
Fax: (03) 371 7479
info@haemophilia.org.nz

President

Deon York
deon@haemophilia.org.nz

Chief Executive Officer

Belinda Burnett
belinda@haemophilia.org.nz

Editor

Chantal Lauzon
chantal@haemophilia.org.nz

Manager Outreach Services

Colleen McKay
colleen@haemophilia.org.nz

Linda Dockrill

Southern Outreach Worker

PO Box 7647, Sydenham
Christchurch 8230
Ph: 03 371 7485
Fax: 03 371 7479
linda@haemophilia.org.nz

Lynne Campbell

Central Outreach Worker

PO Box 24014
Manners Street
Central Wellington 6142
Ph: 04 382 8442
lynne@haemophilia.org.nz

Joy Barrett

Midland Outreach Worker

PO Box 4357
Hamilton East
Hamilton 3247
Ph: 07 856 4442
joy@haemophilia.org.nz

Sarah Preston

Northern Outreach Worker

PO Box 41-062
St Lukes, Mt Albert
Auckland 1346
Ph: 09 845 4658
Fax: 09 846 8174
Mobile: 027 512 1114
sarah@haemophilia.org.nz



Have you thought about physiotherapy lately?

For some of us, as winter looms, the colder temperatures start to seep into those ailing joints. Often, it's difficult to distinguish whether the pain is from a bleed or because of previous joint damage. If it is the latter, then treating with factor replacement therapy more often for the pain will not be the answer. This is where physiotherapy can help.

Haemarthrosis (presence of blood within the joint) is more common in those of us who have not always been on prophylaxis, and even among some of us who have always had the prophylaxis option. Haemarthrosis alters the cartilage, among other things, causing pain and discomfort. Treatment will not necessarily resolve this pain – this is where physiotherapy may help.

For more information, please see page 14 where Ian D'Young and Kerry McLroy discuss the impact of obesity on the joints and how managing your weight and fitness can greatly improve the effects of haemarthrosis.

Deon York
HFNZ President

From HFNZ's Annual Report 2010



DEON YORK

President's Report

This report covers the period January to December 2010.

September 4th 2010 will be a date etched on the memory of Canterbury for many years to come. The magnitude 7.1 earthquake struck Canterbury in the early hours of the morning. Christchurch awoke to widespread damage but, fortunately, this quake did not result in loss of life.

Before the 2010 Annual Report went to press, another earthquake of lesser magnitude struck Christchurch on February 22nd 2011. While it did not measure as high on the Richter scale, this quake was located within only 10 km of the Christchurch CBD and was at a shallow depth of 5Km. It also occurred in the middle of the day.

The National Office of HFNZ is based in Christchurch and damage was sustained to property. We have been fortunate in that no staff or members have lost their lives to this quake. It is still an understandably difficult time for our staff and members in the Canterbury region. We are all thinking of you at this time. We have heard reports of a number of members losing their properties and being displaced.

The Haemophilia Foundation of New Zealand extends its deepest sympathies to the entire community of Canterbury.

Our membership

In 2010 our membership grew from 969 to 1001 members. Of these, 593 are affected by a bleeding disorder and 324 are carriers of a bleeding disorder.

Based on New Zealand's 2010 population, we can assume that approximately 440 people are affected by Haemophilia A, B or another rare factor deficiency. Our membership records, as at December 31 2010, show 426 people on our database in these categories. This is heartening as it demonstrates we are reaching the vast majority of people affected by haemophilia across the country.

Fig 1: Proportion of membership by bleeding disorder

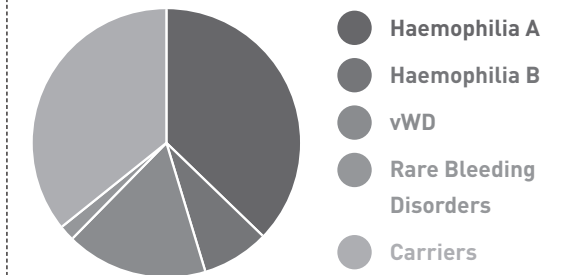
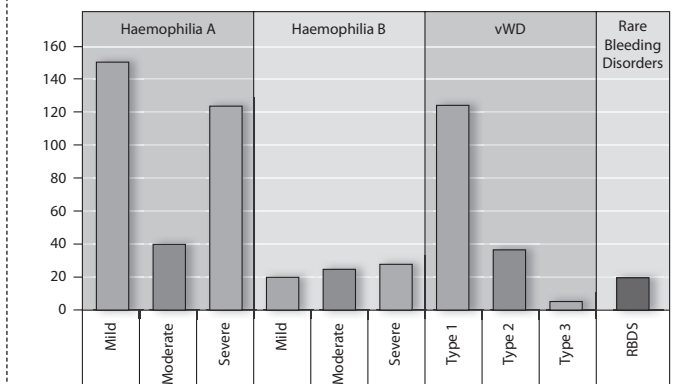


Fig 2: Representation of membership with a bleeding disorder by severity.



Contents

President's Report	1
2011 HFNZ Annual General Meeting	7
Letters to the Editor.....	8
Building Resilience in your Child	9
Profile: Te Whainoa Te Wiata.....	12
The impact of obesity for people with Haemophilia.....	14
Healthy eating for Hepatitis C	18
Advances in understanding vWD.....	20
Advance Your Passion 2011 Winners.....	22
World Haemophilia Day in NZ	24
People around the world Share their Story for World Haemophilia Day.....	25
New way to donate to HFNZ: Payroll Giving	27
Council Corner	28
News in Brief.....	28
Regional Branch Reports.....	30
PEP Talk: Train-the Trainers Seminar.....	31
Memoriam: Jeffery Oliver.....	32
Dates to Note	34

Cover photo:



Cousins Nicholas Coulman and Benedict Larkin, firm friends, applying firm pressure.



National Council

The membership is represented by the National Council of HFNZ. In 2010 the National Council comprised:

Catriona Gordon	Vice-President
Grant Hook	Vice-President
Phillip Cowley	Treasurer
Richard Scott	Northern Delegate
Lee Marjoribanks	Midland Delegate
Michael Ho	Central Delegate
Mark Uren	Southern Delegate
Joe Wrathall	Māori Delegate
Karl Archibald	Youth Delegate

Steve Waring, Director of KiwiFirst was co-opted to National Council and Belinda Burnett, CEO, attended in an advisory capacity.

The National Council composition well represents the full range of our community and includes people with haemophilia A and B, von Willebrand's, carriers, parents and partners of people with bleeding disorders as well as a range of ages and stages of life.

I wish to extend my thanks to the National Council for their work and commitment to improving the lives of people with bleeding disorders.

Fundraising

Our financial position for the year ending December 31 2010 is detailed on pages 18-20.

We remain mindful of the need to have a home for haemophilia and contingency in place for a lean year. Fortunately, we have continued to receive remarkable support from the public to enable us to continue to run our many programmes for New Zealand's bleeding disorders community.

HFNZ acknowledges the valuable contribution of KiwiFirst for their fundraising on our behalf and for effectively disseminating the work of the Foundation to the donating public. We also acknowledge the work of the national office in securing grants and donations for the work of the Foundation.

We acknowledge our Sustaining Patrons, Baxter, Bayer ScheringPharma, CSL Bioplasma, NovoNordisk and Pfizer. A small proportion of our funding comes from District Health Boards and the Ministry of Health and the remainder is obtained via membership fees.

National Services

The Exercise and Supportive Footwear programmes, special assistance grants, advocacy and support, regional activities and *Bloodline*, our national newsletter, were services that we continued to provide to members. Over 700 copies of *Bloodline* are distributed to members and supporters of HFNZ.

The National Office also embarked on disseminating a monthly electronic panui to members giving news and updates about the office and other important items. Feedback has been very positive around this initiative. You can also find HFNZ on Facebook™, so hit "Like" for further news and updates!

There were also a range of national educational events targeted to different sectors of our community in 2010. Thank you to our office-based staff for their role in delivering these services.

With Colleen McKay firmly in the position of Manager of Outreach Services, the team has really taken shape and outreach workers in all four regions are established:

Sarah Preston	Northern Region
Joy Barrett	Midland Region
Lynne Campbell	Central Region
Linda Dockrill	Southern Region

Outreach is frequently cited as one of the most important activities of the Foundation. Thank you to our dedicated outreach staff for their work and perseverance with our community. The bulk of our national events are run by our outreach staff.

National Activities

In addition to the many activities run by our Regional Committees, there are a number of national initiatives, presented here in order of event.



Hui

Hui continued to be held around the country in 2010. The first hui of 2010 took place on 13th March at Ako Pai Marae, Victoria University of Wellington. The objectives of this hui in particular were to discuss the adoption of the Terms of Reference for He Roopu Tautoko, and decide the Takawaenga (four Māori regional representatives) as well as the Māori Delegate to National Council. This resulted in Joe Wrathall serving as Māori Delegate to National Council and the following individuals representing their regions:

Kahurangi Carter & T.A. Stirling	Northern Region
Tara Mounsey	Midland Region
Raukura Riwaka	Central Region
Tania Kaa	Southern Region

Thank you to Joe and the Takawaenga for progressing the establishment of He Roopu Tautoko of HFNZ. With the group established and the inclusion of national representation of Māori enshrined in the Constitution, we look forward to seeing the development of this initiative.

National Young Families Education Camp

Between 9 - 12 April the National New Families Camp was held in Rotorua at Camp Keswick. Held every two years, the camp is open to all families with children with a bleeding disorder aged 10 years and younger, including siblings. These events are always a great chance to meet up with other parents facing the same issues and for both parents and children to learn more about bleeding disorders and share experiences.

World Haemophilia Day

Several events were held around New Zealand to celebrate World Haemophilia Day on 17 April, including a BBQ and children's entertainment in Christchurch, a youth event in Auckland and group meals in both Palmerston North and Wellington.

Adult Wellness Weekend

"I thoroughly enjoyed the chance to spend the weekend with a wide range of ages, yet many shared experiences"

Between 24 - 27 June the inaugural Adult Wellness Weekend was held in Auckland. There had been considerable discussion amongst the National Council and staff on the best way to provide education and social interaction for adults with bleeding disorders. Following on from the success of the Men's and Couple's Weekend, HFNZ produced a new format of educational workshop for adults with bleeding disorders and their partners. The end result was a weekend filled

with education around living healthier, dealing with hepatitis C and keeping active. Positive feedback from participants and staff support the continuation of this type of event.

Parents Empowering Parents (PEP) Programme

"I learnt a lot about myself and how to be a better parent"

This year, a Re-PEP programme was held between 6 - 8 August. PEP is an innovative, peer-to-peer skills programme that introduces parents to tools to better handle the realities of raising a child with a bleeding disorder. PEP programmes are led by an outreach worker, parents and a haemophilia nurse who use classroom discussions, role playing and hands-on experiences to educate parents about the types of skills needed for effective parenting. Re-PEP was a chance for previous PEP participants to come together and refresh the skills they had learned in the programme.

Children's Education Workshops

"It was a really fun day and I learned a lot!"

Four workshops were held around the country during the school holidays. These are great days for younger children with a bleeding disorder and their siblings, aged 6-10, to learn the basics and have a heap of fun meeting other kids in their region.

Grandparent's Day

A pilot of a new workshop, Grandparents' Day, was trialled in Christchurch on Saturday 6 November. This was a special day just for grandparents of younger children with bleeding disorders where the focus was on learning about bleeding disorders and how they can help support their families. They learned that the people that probably needed the most support from them were their children (the parents) and the siblings. The 14 participants shared their knowledge with each other, and overall had a fun and interesting day.

HFNZ investigates twinning with Cambodia

Since our humble beginnings in 1958, HFNZ has grown into a solid, well-organised, and prominent patient organisation. Over the last few years, HFNZ have been trying to be better global members of the bleeding disorders community. We have been raising funds for people with bleeding disorders in developing countries through activities such as Global Feast, art auctions and donations to the Global Alliance for Progress programme.

Earlier this year, The World Federation of Hemophilia (WFH) presented us with an opportunity to take this commitment a step further. We were asked if we would like to use our experience to help another country in the Asia-Pacific region, the Cambodian Haemophilia Association (CHA), on their journey to establishing a strong and effective haemophilia patient organisation by Twinning with them.

The Haemophilia Organisation Twinning (HOT) program links emerging and established haemophilia patient groups to share knowledge in areas such as patient education, outreach, fundraising, and all other aspects of operating a successful haemophilia patient society. The HOT program also benefits established societies by presenting them with new challenges.

Haemophilia organisation twinning can play a critical role in a country. Regular support and coaching through twinning helps a patient organisation become a driving force for change and progress. National haemophilia organisations promote access to haemophilia care. They work to maintain or improve the quality of care. They provide a support system for families who often feel isolated. They are a powerful voice representing the interests of people with haemophilia. However, the range and complexity of challenges facing haemophilia organisations are growing. Such challenges will continue to grow in the future.

The first step to Twinning is having an assessment visit with their potential twinning partner organisation in the emerging country. HFNZ representatives, Colleen McKay (Manager -Outreach Services) and Richard Scott (Northern Delegate to National Council), travelled to Cambodia for this visit in October. The WFH believes strongly in assessment visits as they allow potential twins to meet face-to-face and appreciate for themselves what questionnaires, emails and telephone calls cannot convey. Before the WFH officially recognises and funds a twinning partnership, an assessment visit must take place to allow both parties to decide if beginning this relationship is in their best interests. The Twinning programme is funded by the WFH through a grant from Pfizer and the WFH covered the costs associated with the assessment visit.

Due to the lack of awareness and research, the true number of Cambodians with haemophilia and other bleeding disorders is unknown. Cambodia has a population of nearly 15 million, yet there are currently only 66 registered haemophilia patients. Most are less than 13 years old, with a few teenagers and only two adults. Estimates are that there could be as many as 1,300 people with haemophilia in Cambodia; however, many of these people may have died due to



the absence of haemophilia services. These are starting to be established and some treatment is now available. Without adequate knowledge on how to live with haemophilia, patients are at greater risk of severe bleeds and permanent disability. They are more likely to have limited socio-economic participation (e.g., education, vocational training and income generation) due to their poorer health and physical disability. There may also be social stigma since haemophilia is hereditary, leading to discrimination in marriage for example.

In the meetings between representatives of HFNZ and CHA and families affected by haemophilia, the emphasis was on establishing a good family support system as the key to growing the organisation. Learning how to support each other is essential to providing long term benefits. Some families had travelled long distances on their 'motos' to be there and for some this was the first time they had met another mother who understood what they were going through or another boy with the same problems.

Following further discussion, a draft Twinning Application Form and draft Action Plan for the Twinning partnership was drawn up. These have been circulated to CHA and HFNZ councils for their approval and then sent to WFH. WFH will decide in 2011 whether the Twinning between HFNZ and CHA will formally go ahead.

Colleen McKay wrote the following shortly before returning home, "If it is accepted, the Twinning between HFNZ and CHA will be full of challenges along the way, but from the families that we have met, I know that it will be truly rewarding and that we can make a difference in developing their Association to be an effective patient group."

■ Conferences and Workshops

Tender Training

Brian O'Mahony, CEO of the Irish Haemophilia Society, delivered a 'Tender Training' course to the National Council in June. The workshop is aimed at helping members of haemophilia organisations play an informed and involved role in their countries' tendering process for haemophilia treatment products. This course ran at the same time as the Wellness Weekend at the same venue in Auckland. HFNZ want to make certain that those in the haemophilia community are able to access not only appropriate, timely treatment, but also the safest and best available. Participating in the training course is one way to ensure we have the necessary knowledge and skills to be part of the decision making process.

XXIX International Congress of the World Federation of Hemophilia

The XXIX International Congress of the World Federation of Hemophilia took place from July 10-14, in Buenos Aires, Argentina. Fourteen delegates from HFNZ were in attendance, including Mike Carnahan who spoke about ageing and haemophilia, Belinda Burnett who chaired a session featuring the expertise of people of different age groups, and I spoke about leadership in the bleeding disorders community and attracting the next generation of volunteers. Four of the delegates also had abstracts accepted for poster presentation. The information gained at congress was disseminated via the regional branches and through our national newsletter. Speakers were funded to attend by the World Federation of Hemophilia.

Affiliated programs

Step Up Reach Out (SURO)

Hemi Thomas is the tenth New Zealander to have been chosen to participate in SURO, an international youth leadership program, which draws together young men with haemophilia from around the world for leadership skills, personal growth, and collaboration. The first meeting was held in San Francisco. We are fortunate to have the second meeting being hosted in Auckland in 2011 and be able to welcome a group of future world leaders in the bleeding disorders community.

"I went to the SURO programme in San Francisco not really knowing what to expect. It turned out to be a great experience where I met a great bunch of guys from all over the world. Watching the presentations from other countries, I realised how lucky we are in New Zealand. During the course of the program we had some interesting discussions about haemophilia care and leadership...SURO has been a great experience."

HFNZ pledge to WFH

Continuing HFNZ's commitment to supporting the global haemophilia community, \$5,000 from membership fees and specific donations were donated to WFH's Global Alliance for Progress (GAP) programme again in 2010.

Other representation

National Haemophilia Management Group

HFNZ hold a permanent position on the National Haemophilia Management Group, the group responsible for the planning and funding of

haemophilia care across the country. This year the role rotated between Belinda Burnett, Catriona Gordon and myself.

World Federation of Hemophilia

In 2010, I successfully ran for a position on the Executive Committee of the WFH and will now serve a four year term with the Federation (commenced July 2010). I am looking forward to working a group of individuals that are committed to improving the lives of people with bleeding disorders globally. It is important to note that my position does not represent New Zealand, or people with haemophilia in New Zealand specifically, all Executive Committee members are there to serve the interests of the global haemophilia community. In addition to my role on the Executive Committee I was re-appointed to the Fund and Resource Development Committee and the National Member Organization Training Committee. In 2010 I also began serving on the Research Committee as well as the Educational Materials Committee.

Finally, I wish to reiterate my sincere appreciation to the Christchurch staff of HFNZ for their resilience through what has been a difficult year for all Christchurch residents. Thank you to our international community for their support during this difficult time. HFNZ entitled its 50 year history *Still Standing*; these words seem particularly relevant when reflecting on 2010.



Deon York
HFNZ President



2011 HFNZ Annual General Meeting

This year's Annual General Meeting (AGM) was held Saturday 26 March in Rotorua at the Kingsgate Hotel. Over 50 people attended including members, Life members, staff, supporters, one of our haemophilia nurses and HFNZ Patron, Dr Elizabeth Berry.

As President Deon York was away at the World Federation of Hemophilia executive meeting, the AGM was co-chaired by Vice-Presidents Catriona Gordon and Grant Hook. The AGM reviewed the business, programmes and achievements of 2010. On behalf of National Council, Catriona Gordon acknowledged the staff from Christchurch for their commitment to carrying on and getting back to work after the earthquake and also the staff in the North Island, who helped carry the workload while the office was out of service.

HFNZ CEO Belinda Burnett also acknowledged the impact of the earthquake, "every staff member based in the National office was affected by the earthquake. And every member turned up the following week to meet the engineers to check that the building was safe to re-enter. That is commitment, courage and fortitude in the face of adversity. These same people – with their shattered homes, frightened children and complete lack of services including power, water and sewage came to the office and helped clean up and make it safe to re-enter. All the while the North Island based staff offered emotional support to members in Canterbury who needed it. I have never felt more part of a team than during these last trying weeks. The staff has made me feel immensely proud and privileged to work with them."

Financially, after a large surplus in 2009 (\$40,684), HFNZ operated to a deficit of \$10,211 in 2010. Our net assets are still in a very healthy state (\$722,018). KiwiFirst again had a fantastic year of fundraising on behalf of HFNZ. In 2010, HFNZ also received generous support from our Sustaining Patrons (Baxter Healthcare, Bayer Schering Pharma, CSL Bioplasma, NovoNordisk and Pfizer), and grants from Canterbury Community Trust, COGS and Lotteries. The full financial reports can be found in the 2010 HFNZ Annual Report.

The HFNZ National Council for 2011:

- President: Deon York
- Vice-Presidents: Catriona Gordon, Grant Hook
- Treasurer: James Poff
- Youth Delegate: Karl Archibald
- Māori Delegate: Joe Wrathall
- Northern Delegate: Richard Scott
- Midland Delegate: Vicki Fitzgerald
- Central Delegate: Michael Ho
- Southern Delegate: Mark Uren

Those not standing for re-election to Council, Philip Cowley, former Treasurer, and Lee Marjoribanks, former Midland Regional Delegate, were acknowledged for their time and input.

No special resolution were made during the AGM, however, Youth Delegate Karl Archibald introduced the formation of the National Youth Committee.

Patron Dr Elizabeth Berry, a trustee of the Allan Coster Educational Endowment Trust, commented that six grants had been awarded by the Trust in 2010. The trustees were increasingly concerned by the number of



Vice-Presidents Catriona Gordon and Grant Hook



Guest speaker Ed Kuebler, with Madeline Cantini

grants to assist with learning difficulties school-age children and feel that only where the problem is significantly influenced by time away from school caused by a bleeding condition that they are able to support such grants. They encouraged applicants to follow the application guidelines carefully and to keep the feedback coming. They also thanked Outreach for their assistance.

After the conclusion of the AGM, the assembly was treated to an inspiring and entertaining talk from Texas-based haemophilia social worker Ed Kuebler. In addition to working with the University of Texas Gulf States Hemophilia and Thrombophilia Center, Ed co-directs their annual educational retreat for women with bleeding and clotting disorders and the Texas Summer Camp Leadership Program for males with bleeding disorders. Ed has also chaired the Parents Empowering Parents (PEP) programme and helped to develop and deliver the international Step Up Reach Out (SURO) leadership programme for youth with haemophilia. Ed and his colleague Madeline Cantini were in New Zealand delivering the latest round of the SURO, which took place in Auckland 18-21 March, and a PEP Train-the-Trainers programme 22-25 March.

Members of the Māori Roopu



Ed spoke about engaging, educating and empowering youth. Right from the start he engaged the youth in the audience and had them give feedback throughout the session. One of the most important things community groups need to do to 'engage' youth is simply ask them what they want or need and be prepared to listen. This will help to understand what they are interested in and what tools they need. Ed also suggested that every event or gathering or activity should be used as an opportunity to raise their level of education about bleeding disorders, other technical skills, leadership, awareness to community issues and awareness of themselves. Education equals empowerment and youth are our greatest asset for the future.

Full copies of the 2010 HFNZ Annual Report which include reports from the Patron, President, CEO, Youth and Māori Delegates, the Regional Delegates and Treasurer are available from National Office or as a PDF at www.haemophilia.org.nz

Many HFNZ Life Members were in attendance



Letters to the Editor

Importance of MedicAlert ID

The tragic events of the Christchurch earthquake in February reminded me of the value of wearing a medic alert bracelet if you have a medical condition and are not in a position to speak for yourself.

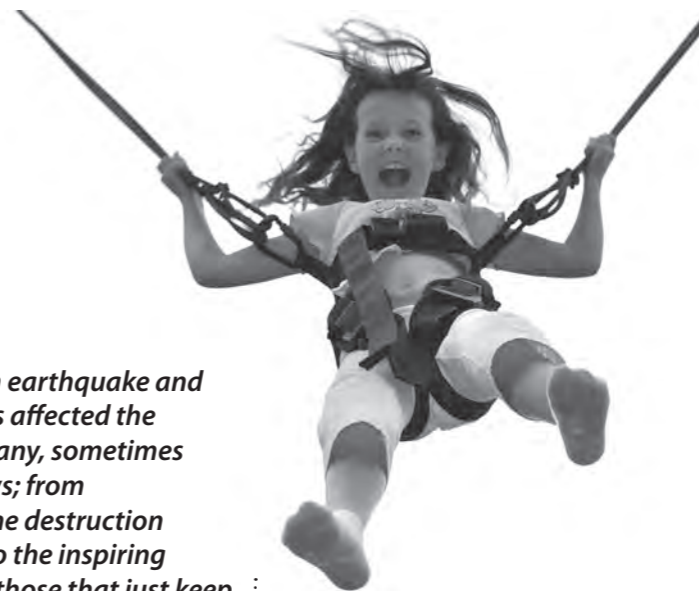
The medic alert bracelet is internationally recognised and identifies the fact you have a medical condition and may need certain medication. For those with haemophilia, Factor VIII will be more critical than ever in an emergency.

I will admit I have been complacent about replacing my son's bracelet when the latest one broke a year ago. It had been a hassle getting it resized and so I put it off.

But I have ordered a replacement and will take the time to find somewhere that will resize it for his tiny wrist.

Stephanie Coulman
Mother of Nicholas, aged 7 years

Building Resilience in your Child



The Christchurch earthquake and its aftermath has affected the community in many, sometimes unexpected, ways; from devastation at the destruction and loss of life, to the inspiring perseverance of those that just keep going despite their surroundings. It has been physically and emotionally draining.

Some people seem to be able to cope better than others when faced with a set-back or other adversity. We all know someone who amazes us with their ability to overcome a crisis, a family tragedy or a health condition, such as haemophilia, and come out of the situation a better, stronger person.

Some children are also more able to cope with problems and adversities than other. They handle the situation well, don't go to pieces or panic and bounce back afterwards. That special something is known as resilience – or the ability to bounce back, flexibility or toughness.

Temperament or personality is one factor, but not the only one. Parents can do a lot to help their children build resilience.

What is resilience?

Resilience refers to one's ability to successfully manage one's life and to successfully adapt to change and stressful events in healthy and constructive ways. More simply, it means our survivability and "bounce-back-ability" to life experiences – both advantageous ones and the really challenging ones. Young people have always needed effective

coping skills, however, the modern world is more challenging than ever before and it seems that many young people have fewer resources to deal with adversity than in previous generations.

Resilience should be understood as a vital ingredient in the process of parenting all children, a process that directs our interactions as we strengthen our children's ability to meet life's challenges and pressures with confidence and perseverance.

Developing resilience

Building resilience can help our children manage stress and feelings of anxiety and uncertainty. Being resilient does not mean that children won't experience difficulty or distress because emotional pain and sadness are parts of life. The ability to thrive despite these challenges arises from the skills of resilience. **The good news is that resilience skills can be learned.**

Children are not just born with resilience and it does not happen by magic either. International research has shown that it is a blend of three factors that occur in childhood.

First, there is the home environment the child grows up in. It needs to be one that provides unconditional love, is well-organised, provides a clear sense of right

and wrong, and is consistent.

Second, there are the inner strengths and qualities of the child's temperament. Given a secure, consistent, and loving home life, these will develop to the full extent of their individual personality.

Third, the resilient child has developed and well-trained interpersonal skills. They know how to get along with other people, find people they can trust and can communicate effectively.

There is no simple process that allows you to gain resilience all at once. All children are created uniquely and their development is determined by many factors – seen and unseen. Parents need to be constantly reviewing what is happening in each of their children's lives. Children need to experience disappointment, challenge, failure and boundaries to fully develop the interpersonal and personal skills that allow people to live in society. They also need to have a voice, and age dependent moments of autonomy where they get to have a sense of control over their life.

Providing the right framework

None of us have the same temperament. One person is outgoing, while the other is more detached. Some people are more confident and seem to be natural leaders. If the child is provided with the right environment for growing up then he has the best chance of developing the abilities with which he was born.

The resilient child grows up consistently supported by the parents and other adults. These supports need to be provided through the childhood. They include:

- **Trusting relationships**

All children need the unconditional love of their parents or caregivers. They also need to be confident of the loving support of other adults – other family members, friends and teachers.

• Structure and rules at home

The resilient child grows up in a well structured and orderly home life. Parents and caregivers therefore need to provide clear rules and routines, expect the child to follow them, and rely on the child to do so.

Rules need to be consistently applied. Consequences of breaking the rules need to be spelt out and consistently applied as well.

Show confidence that the child will play their part. Give praise and thanks when the child follows the rules and routines.

• Role models

Adults show how to do things, such as how to dress appropriately, or ask for information, and encourage the child to imitate them.

Make sure your behaviour models the behaviour that you expect from your child.

Other adults such as grandparents, older brothers and sisters, teachers and sports coaches are also important role models.

• Encourage independence

Encourage your child to try doing things on her own and to seek help when needed. Praise the child when he or she shows initiative. Help them, perhaps through practice or conversation, to do things independently. Even when she fails, make sure you praise trying.

Take into account the child's temperament and go at the child's speed.

• Access to public services

There are some things that the family can't provide – health care, education, emergency services. Help your child be aware that these services do exist in the community and that he has access to them.

Ideally the resilient child will have all this supports of certainly will have many of them. She will be aware of those she has access too.

This consistent and secure framework provides your children with the opportunity to develop a sense of self-worth and confidence in their ability to cope with future events.



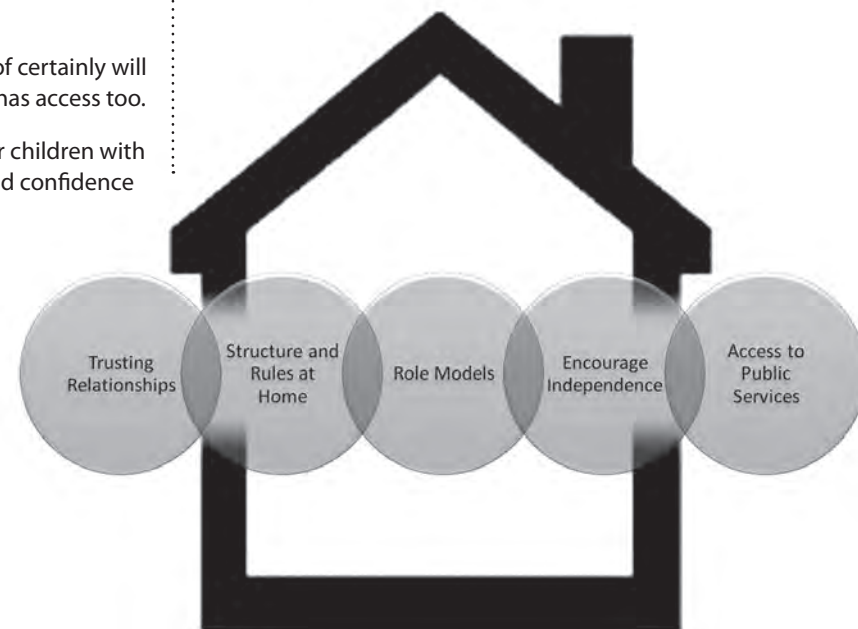
The journey of resilience

By building resilience in children, you give your children the opportunity to master the hard things in life for themselves. Don't do everything for them – it makes it hard work for you and cheats them of opportunities for building emotional and mental stamina.

Developing resilience is a personal journey and you should use your knowledge of your own children to guide them on their journey. An approach to building resilience that works for you or your child might not work for someone else. If your child seems stuck or overwhelmed and unable to use the tips listed here, you may want to consider talking to someone who can help, such as a psychologist or other mental health professional. Turning to someone for guidance may help your child strengthen resilience and persevere during times of stress or trauma.

The little things are often the big things later on in life. Memories from childhood build patterns of expectation in the brain for life. Children who experience repeated 'magic' moments like night time rituals of snuggling up with a book, singing songs in the car, family outings or trips to a special place tend to anticipate positive and optimistic

moments in life. Consciously create the magic moments that build delight and lightness – turn the screens off, play music, share meals and tell jokes - anything that builds the sense of belonging, being valued and noticed.



Framework to help build resilience

10 Tips for building resilience in children and teens

We all can develop resilience, and we can help our children develop it as well. It involves behaviours, thoughts and actions that can be learned over time. Following are tips to building resilience.

1. Make connections

Teach your child how to make friends, including the skill of empathy, or feeling another's pain. Encourage your child to be a friend in order to get friends. Build a strong family network to support your child through his or her inevitable disappointments and hurts.

2. Help your child by having him or her help others

Children who may feel helpless can be empowered by helping others. Engage your child in age-appropriate volunteer work, or ask for assistance yourself with some task that he or she can master.

3. Maintain a daily routine

Sticking to a routine can be comforting to children, especially younger children who crave structure in their lives. Encourage your child to develop his or her own routines.

4. Take a break

While it is important to stick to routines, endlessly worrying can be counter-productive. Teach your child how to focus on something besides what's worrying him. Be aware of what your child is exposed to that can be troubling, whether it be news, the Internet, or overheard conversations, and make sure your child takes a break from those things if they trouble her.

5. Teach your child self-care

Make yourself a good example, and teach your child the importance of making time to eat properly, exercise and rest. Make sure your child has time to have fun, and make sure that your child hasn't scheduled every moment of his or her life with no "down time" to relax. Caring for oneself and even having fun will help your child stay balanced and better deal with stressful times.

6. Move toward your goals

Teach your child to set reasonable goals and then to move toward them one step at a time. Moving toward that goal - even if it's a tiny step - and receiving praise for doing so will focus your child on what he or she has accomplished rather than on what hasn't been accomplished, and can help build the resilience to move forward in the face of challenges.

7. Nurture a positive self-view

Help your child remember ways that he or she has successfully handled hardships in the past and then help him understand that these past challenges help him build the strength to handle future challenges. Help your child learn to trust himself to solve problems and make appropriate decisions. Teach your child to see the humour in life, and the ability to laugh at one's self.

8. Keep things in perspective and maintain a hopeful outlook

Even when your child is facing very painful events, help him look at the situation in a broader context and keep a long-term perspective. Although your child may be too young to consider a long-term look on his own, help him or her see that there is a future beyond the current situation and that the future can be good. An optimistic and positive outlook enables your child to see the good things in life and keep going even in the hardest times.

9. Look for opportunities for self-discovery

Tough times are often the times when children learn the most about themselves. Help your child take a look at how whatever he is facing can teach him "what he is made of."

10. Accept that change is part of living

Change often can be scary for children and teens. Help your child see that change is part of life and new goals can replace goals that have become unattainable.

From: www.apa.org

References:

- American Psychological Association. Resilience Guide for Parents & Teacher. Available at: www.apa.org
- Barnados. Promoting resilience in your child. Barnados Information Sheet No. 71 (June 2009)
- Maggie Dent. The Little Things are the Big Things – Building Resilience in Children. Nov. 2007.

Profile: Te Whainoa Te Wiata

Twenty-seven year old Te Whainoa, 'Whai', feels very lucky for the life he is living and his work as a professional musician and guitarist touring around NZ and the world.



scene in Hamilton, watching a lot of bands and meeting other musicians. He began to play more acoustic and electric guitar and was soon on stage playing with friends in various bands most nights. At the time he was also involved in a local rugby league team as an assistant manager and masseur/strapper. His growing interest in music and becoming a first-time father led him to decide to concentrate on music as a career.

In the six years Whai has been working as a musician full-time he has met with increasing success. In addition to playing the guitar, he began singing after being left alone on stage one night. "The way I had been brought up I knew the 'show must go on'. That was pretty much the beginning of me being a covers musician," he says. Whai began fronting bands and also getting solo gigs as a cover musician.

Around this time Whai was accepted to the Step Up Reach Out (SURO) international leadership programme for youth with haemophilia. His travels to San Francisco and Montreal for the programme and the lessons learned really made him look at his life and consider which direction he wanted to be heading with his music. He had been overseas when he was younger with a kapa haka group but "SURO was an amazing experience and I really got the travel bug back," he says. He found renewed enthusiasm and travelled around NZ playing and visiting with his second child.

At the beginning of 2010, Whai found himself in a really positive place and agreed to try out as a guitarist for Cornerstone Roots. Although he admits he had doubts about playing with musicians he admired so much, he found himself onstage as part of the band only two days after their first practice together.

Within a month, Whai travelled with Cornerstone Roots to Samoa and then toured with them in New Zealand and Australia. His travel bug had well and truly been re-ignited and when asked at the last minute to join the band on a trip to Europe he jumped at the opportunity. Although his friends and partner were excited for him, Whai was anxious as he wanted to do his best for himself and

the band. In the end, the European tour turned into an incredible trip. He felt fortunate to be working with a group of older, experienced musicians and being able to learn a lot from them.

Touring involves long hours and lots of travel. This made Whai nervous about his health. Although he had kept fit with swimming and martial arts when he was younger he knew he had not looked after himself as well as he should have (for example by playing sports that he knew he shouldn't have), and this has resulted in severe arthritis in both knees. Twelve months year Whai had to constantly use crutches and sit on a stool onstage because of the swelling in his knees. To reduce the swelling he had begun to work with Ian d'Young, the adult Haemophilia Physiotherapy Practitioner in Auckland, travelling up from Hamilton for physiotherapy. Having physiotherapy with an expert in the effects of haemophilia on the body made a real difference and soon he no longer relied on the crutches all the time. Together they made a physiotherapy plan for Whai to continue while on tour.

"Our first gig was in Tabor, Czech Republic, at a huge music festival. I woke up in this amazing place and did something I never did, went for a walk. I saw all the history of the place and decided that I really needed to work on my physio to get through the tour," he says.

After that Whai got up each morning to go for increasing long walks in whichever of the 30 different cities he found himself in and continued with his physio exercises. It helped that some of the other band members were into their fitness and

On stage with Cornerstone Roots at the Uprising Festival in Bratislava, Slovakia.



would also be getting up for runs or other exercise. It was summertime in Europe while the band was there and the 40°C heat really helped with his knees. Doing the daily physio was essential to getting through the 3-month tour and meant he was able to stand and play on stage night after night.

The other factor that helped Whai get through the tour was literally that – factor replacement. Whai was on daily prophylaxis to keep a constant level of factor circulating. Because he is on recombinant factor VIII he was able to pack his whole supply, including the saline and syringes, into one backpack that he guarded carefully. He also packed a small pencil-case with around two treatments worth of factor and equipment that he kept on him at all times in case they had a

day where they were out playing or on the move and away from their gear.

Whai knows he is lucky. "I'm amazed that I could have travelled all that way with haemophilia. It was amazing to be there. There's no way I could have done it without being on recombinant," he says. A decade before or if he was still on plasma-derived product the trip would not have been possible for him. He would have needed to bring suitcases of factor if enough could have been found and to try to find a way to keep it constantly refrigerated. Having the pencil case of factor has become a habit and he always has one in case he gets a last minute gig out of town.

Whai is now living in Auckland and working on a few different musical projects, including playing with King Kapsi and continuing to play with Cornerstone Roots. He is concentrating on improving his skills on the electric guitar and his confidence as a songwriter in the hopes that one day he might perform his own music. He is also focusing on his health and has got into a regular routine of physio and working out at a gym. With the help of Ian d'Young, he has implemented a 3-year plan to get healthier and improve his joint function. He loves working with Ian and finds it lifts his spirits and makes him want to work harder.

"There are days when I wish I could go back in time and say no to things," he says. But growing up in a small town it was hard not to get in fights or play sports he knew

he shouldn't. He knows that life would be even better if he was healthier and fitter and he is working towards it.

Whai feels really lucky at the moment and has surrounded himself with motivated, positive people. "I want to be a singer and player that people will remember. I want to excel at something so that I can show my kids that I could do it, even with haemophilia and chronic joint damage, and to inspire them to strive for their goals, whatever they are." He seems to be on the right track.

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

The impact of obesity for people with Haemophilia

Ian d'Young, Haemophilia Physiotherapy Practitioner
with Kerry McIlroy, Charge Dietician



Obesity is a growing problem!

Obesity is a growing worldwide problem, particularly in developed countries. It is associated with increased morbidity from a range of conditions such as cardiovascular disease, high blood pressure, diabetes, respiratory diseases, stroke and osteoarthritis¹.

In developed countries such as the United States, the prevalence of obesity in the general population has doubled in adults since 1980, while the prevalence of being overweight has trebled in children and adolescents since 1990¹. Being overweight or obese is strongly associated with many serious health problems and greatly reduces quality of life².

New Zealand has had a very similar increase in both adult and childhood obesity compared to the United States, as have most developed countries over the last 30 years³. Between 1982 and 1994 the prevalence of overweight or obese men in New Zealand jumped from 52% to 64%, and in women from 36% to 45%³.

'Obesity' and 'Overweight' are calculated using the Body Mass Index (BMI). While not a perfect measure of obesity, it is considered to be a useful measure for the general population. The BMI is a simple calculation of height vs weight. For adults, a BMI of between 25-29.9 kg m⁻² (weight divided by height squared) is considered to be overweight, while a BMI over 30 kg m⁻² is considered obese¹.

Obesity and haemophilia

Since the introduction of effective factor replacement therapy, recombinant products and prophylaxis, the life expectancy of people with haemophilia

(PWH) has increased dramatically. In 1939, the life expectancy of PWH in industrialised countries was just 7.8 years, compared to over 70 years by 2001². Unfortunately, the down-side of this increased longevity is the increased incidence of obesity and associated conditions such as high blood pressure, high cholesterol, type II diabetes and osteoporosis, as well as the arthritic changes in joints that characterise a history of haemophilic bleeding.

Rates of obesity have therefore grown hugely over recent decades in PWH. In the Netherlands, in the ten years between 1991 and 2001 the prevalence of overweight PWH increased from 27% to 35%, while the prevalence of obesity in men with haemophilia doubled from 4% to 8%⁴.

By 2010 in the state of Mississippi in the United States alone, 51% of PWH were classed as being overweight or obese. In adults above the age of 20 years, 36% were obese, while a further 32% were classed as overweight. In adolescents between 5 and 19 years of age, these figures were 21% and 16% respectively¹.

Impact of obesity: the joints

As we all know, bleeding into joints causes arthritic damage, known as a 'haemophilic arthropathy'. Joints do not normally contain blood, and the exposure of the joint surfaces to blood and the iron it contains mediates a rapid destructive process, resulting in arthritis. Haemophilic arthropathy is therefore often referred to as '**blood-induced joint damage**'.

Joint damage in haemophilia is directly proportional to the number of bleeds that have affected the joint. Any issue that increases the risk of a joint bleed, or

aggravates joint damage present due to previous bleeding is therefore a major problem. The heavier a PWH is, the more load is placed on the joints, and the more the joints are subject to bleeding episodes^{5,6}. Arthritic joint damage related to previous bleeding episodes is also further aggravated by obesity⁴. The joints of overweight or obese PWH must cope with greater loads, muscles tend to be weaker, and balance and coordination are poorer relative to more active PWH, therefore leading to a higher risk of joint bleeds and accelerated arthritis^{5,6,7}.

The prevalence of arthritis or haemophilic arthropathy also appears to be greater in obese PWH. A recent Dutch study indicated that up to one third of obese PWH had significant arthritis, compared to just one fifth of PWH with a relatively normal weight⁶.

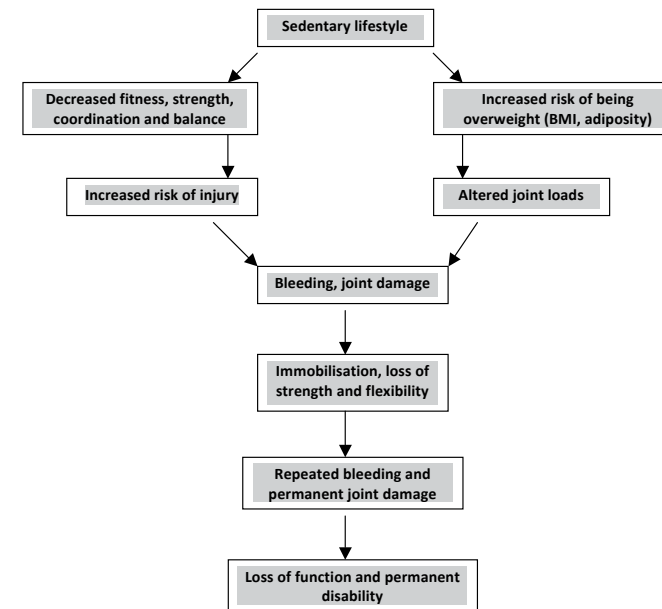
The amount of body fat (or 'adiposity') is also associated with decreased joint mobility. Excess body adiposity accelerates the loss of movement in the weight-bearing joints of the lower limbs such as the knees and ankles⁸. PWH with higher adiposity also tend to lose joint flexibility at a much faster rate than their healthy-weight peers. The authors concluded that this was due to greater mechanical stress being placed on the joints, resulting in both damage to the connective tissue surrounding the joint and structural damage to the joint itself⁸.

Consider this example: When you walk on level ground, you take up to 4x your body weight in loading through your knee joint in a normal situation. When you walk downhill, you take at least 8x your body weight through your knee joints normally. If you are 10kg overweight, that is an extra 80kg load through the knee joints with



every downhill step^{9,10}. That is a lot of extra load! Joints tend to wear out faster if they have to carry a lot of extra load.

A theoretical framework for the impact of an inactive, sedentary lifestyle and obesity has been proposed by two leading Canadian Haemophilia clinicians⁵:



Adapted from: Wittmeier K, Mulder K. Enhancing lifestyle for individuals with haemophilia through physical activity and exercise: the role of physiotherapy. *Haemophilia*. 2007; 13 (suppl. 2): 31-37



Inactivity and poor diet leads to obesity

Obesity is caused, in part, by a poor diet and an inactive lifestyle⁵. A sedentary, inactive lifestyle (i.e. people who sit around a lot) is linked to decreased strength, balance and coordination, and this increases the risk of injury and bleeding in PWH. 'Couch potatoes' are thought to be at a much greater risk of having a joint or muscle bleed than their healthy-weight peers⁵.

What is interesting from the recent Mississippi study is that no PWH under the age of 5 were obese, even though a significant proportion were by late adolescence. This suggests that an increasingly sedentary lifestyle during the adolescent period is associated with excess weight gain, and this weight gain tends to be independent of the severity of haemophilia¹. Coinciding with this excessive weight gain is the fact that a significant proportion of school-aged PWH spend most of their leisure time engaged in watching TV or playing video games¹¹, rather than engaging in physical activity.

Cost impact of obesity in PWH

Obesity is not just a problem that influences joint bleeding and arthritis. Because the dosage recommendation of factor VIII or IX for PWH is calculated by weight in kilograms, the greater the prevalence of overweight or obese PWH, the higher the costs involved with treatment¹².

In the United States, a recent study examined the projected yearly costs of prophylactic and on-demand factor replacement therapy based on a person's ideal body weight, and compared this to the costs involved with the patient's actual body weight. Not surprisingly, the greater the weight difference between 'ideal' and 'actual' body weights, the higher the cost difference¹².

For the 20 children and adolescents in the study, in one year only, if each overweight or obese subject was at their ideal body weight, their cost of treatment would be reduced by around US\$2 million. While the cost of treating obese children on average was more than US\$1.3 million, this fell to US\$325,000 for neither overweight nor obese children¹². That is a huge difference! Other studies have shown similar results. In the Netherlands, for the years 2008 and 2009, the mean FVIII usage for obese PWH was more than double that of their healthy weight peers⁶.



Physical activity is essential

Prior to the advent of effective prophylaxis and factor replacement therapy, most children were actively discouraged from physical activity due to the perceived risk of bleeding^{13,14}. What is now clear is that exercise and physical activity are very important for PWH. Physical activity is an essential element of weight control, alongside a sensible diet, and helps to improve muscle strength, coordination,

flexibility and balance, therefore minimising the risk of muscle and joint bleeding episodes^{15,16}.

Exercise and physical activity also improve fitness (or 'aerobic capacity'), increase circulating clotting factor and, especially when commenced before the onset of puberty, decreases fat mass⁵. Adults who are overweight who increase their level of physical activity have reduced rates of mortality and increased longevity relative to inactive adults⁵.

What is also important to note is that in order to get and then maintain the benefits of exercise, physical activity needs to be regular and consistent⁵. Young people should participate in at least 60 minutes of daily activity and adults for at least 30 minutes per day in order to accrue the health benefits of exercise. Activity can be accumulated in periods of 5-10 minutes or as continuous sessions⁵, and can comprise of a variety of activities – a brisk walk here, a swim there. Every little bit counts.

Maintaining fitness after a bleed

Maintaining appropriate levels of daily activity when there has been a bleed can be a big challenge for physiotherapists as well as PWH. During periods of inactivity, for example when recovering from a bleed, the physiotherapist must take into account the need to rest the affected joint or muscle, while maintaining fitness, strength and flexibility in other parts of the body.

If this does not happen, a vicious cycle of inactivity, loss of aerobic capacity (fitness), and muscle weakness occurs and this may lead to further injury and bleeding episodes⁵. So exercise is very important, even when you are recovering from a bleed, but it needs to be the right sort of exercise and appropriate to each person's specific needs.

If you have had a bleed or injury recently, it is important that you see your physiotherapist to make sure that you are ready to get started on a new exercise or activity. Remember your exercise program will be different when you are recovering from a bleed compared to when you are getting fit or playing sport. It is very important that you talk to your physiotherapist and rehabilitate the bleed properly before starting a new sport or exercise. Remember, doing too much too early can lead to another bleed.

You will need to start at a gentle level of exercise and gradually increase this as your body recovers after a bleeding episode. Forget the idea 'no pain no gain!' It's 'NO GAIN WITH PAIN'⁶, so remember to tell your physiotherapist if an exercise is painful or if you are becoming tired or sore.

If you have some pre-existing joint damage related to a prior history of bleeding, your exercise program will need to be gentle on the joints that are affected. Your exercise program will therefore ideally be 'low impact' and 'low resistance'. This means that while you will get fitter, strengthen the muscles and improve the balance around a joint, you will not be placing too much extra load on the arthritic joint surfaces themselves. For example, when you are looking to improve your general fitness, your physiotherapist might suggest swimming, the cross trainer and the bike as good ways to improve your stamina, rather than running on a treadmill or pounding the pavements.

Remember, every person is different and every person may react differently to a type of sport or exercise, so it is important that you listen to your body. If you notice a bleed every time you ride your bike or go for a run, your body is telling you that this is not the right type of exercise for you. Listen! Talk to your physiotherapist about alternative sports or activities.



Weight control

If you have a weight problem, it is best tackled by changing your eating patterns and choosing healthier foods that are life long choices, rather than seeing weight loss as a short term fix. To lose weight, the energy [as calories] consumed as food has to be lower than the energy expended as exercise – the concept is very much like a car and fuel usage. As with a car, the bigger the person, the more fuel [energy] they need to maintain their weight. They will also expend more energy when exercising.

Ideally it is advisable **to reduce both energy intake and increase energy output in the form of exercise to manage weight loss.**

Energy intake is determined by:

- Number of calories or kilojoules in our daily intake of food and fluids
- Portion or serve size of foods and fluids we consume
- How often these are eaten

When looking to lose weight

- Aim to lose 0.5-1.0kg per week. Weigh yourself once a week to view your progress
- Don't diet but make lifestyle choices about exercise and eating that are long lasting.
- Aim for at least 30 minutes of exercise a day

Type of Activity	*Calories used in 30 mins	Food equivalent
Brisk walking	120	1 banana
Cycling	140	4 pieces of sushi
Swimming	200	1 small slice pizza
Running	400	1 large cookie
*Approximate amount of calories used depends on body size.		
*One calorie =4.25kilojoules		

Top tips for sensible weight control

- Choose an exercise you enjoy, otherwise it will be a chore you will give up.
- Keep a food diary and write down all you eat and drink. This makes you very aware of what you are eating and the quantities consumed.
- Eating breakfast kick-starts your metabolism.
- Sit at a table to have your meals.
- Reduce your portion sizes, for example 2 small midloin chops rather than 3 or 4.
- Be careful with sweet drinks and alcohol. These add calories without filling you up.
- Water has no calories so foods with high water content have a lower calorie value.
- Fat has double the energy of protein or carbohydrate – foods with a high fat content have more calories.
- Keep your intake of fats/oils at a minimum and avoid fatty foods such as fish and chips



- Remove fat from meat and skin from chicken before cooking.
- Use lower fat varieties of dairy products such as trim milk, low fat yoghurt or cottage cheese.
- Eat slowly, have three meals a day and use fruit and vegetables as snacks. One apple is the equivalent of 60 calories but one chocolate caramel bar [70gms] equates to 410 calories, with a small packet of potato crisps [50gms] 260 calories
- Add vegetables and fruit to dishes to make filling, lower calorie meals. Add canned tomatoes, corn, beans or other vegetables to mince and casserole dishes.
- Try stir-fries and use 3-4 times more vegetables than meat or chicken and use different herbs and spices to add flavour.
- Keep a shopping list when you go to the supermarket so you are not tempted to buy 'non-healthy' foods.
- Remember treats are acceptable as long as they are not a regular part of the diet. Try including a dessert once a fortnight rather than daily.

Useful websites

Here are some useful websites where you can go to find out more about sensible weight loss:

www.nlm.nih.gov/medlineplus/ency/article/001943.htm
www.healthed.govt.nz/uploads/docs/HE1518.pdf
www.sparkpeople.com

Kerry McIlroy is a Charge Dietician at the Auckland District Health Board and is the president of the Australasian Society for Parenteral and Enteral Nutrition (AuSPEN)

Ian d'Young is the Haemophilia Physiotherapy Practitioner at the Auckland District Health Board and is the national clinical lead for haemophilia physiotherapy. He is co-chair of the Australia-New Zealand Haemophilia Physiotherapy Group (ANZHPG)

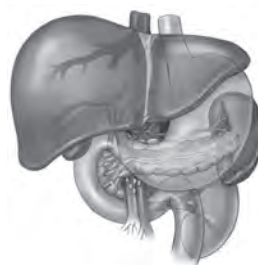
References and further reading

1. Majumdar S, Morris A, Gordon C, Kermod JC, Forsythe A, Herrington B, Megason GC, Iyer R. Alarming high prevalence of obesity in haemophilia in the state of Mississippi. *Haemophilia*. 2010; 16: 455-459
2. Mauser-Bunschoten EP, Franssen Van De Putte DE, Schutgens REG. Co-morbidity in the ageing haemophilia patient: the down side of increased life expectancy. *Haemophilia*. 2009; 853-863
3. Hofstede FG, Fijnvandraat K, Plug I, Kamphuisen PW, Rosendaal FR, Peters M. Obesity: a new disaster for haemophilic patients? A nationwide survey. *Haemophilia*. 2008; 14: 1035-1038
4. Simmons G, Jackson R, Swinburn B, Yee RL. The increasing prevalence of obesity in New Zealand: is it related to recent trends in smoking and physical activity? *New Zealand Medical Journal*. March 1996; 109 (1018): 90-92
5. Wittmeier K, Mulder K. Enhancing lifestyle for individuals with haemophilia through physical activity and exercise: the role of physiotherapy. *Haemophilia*. 2007; 13 (suppl. 2): 31-37
6. Biere-Rafi S, Haak BW, Peters M, Gerdes VEA, Buller HR, Kamphuisen PW. The impairment in daily life of obese haemophiliacs. *Haemophilia*. 2011; 17: 204-208
7. Majumdar S, Ahmad N, Karlson C, Morris A, Iyer R. Does weight reduction in haemophilia lead to a decrease in joint bleeds? *Haemophilia*. 2011; Online early edition: 1-2
8. Soucie JM, Wang A, Siddiqi A, Kulkarni R, Recht M, Konkle BA. The longitudinal effect of body adiposity on joint mobility in young males with haemophilia A. *Haemophilia*. 2011; 17: 196-203
9. Kuster MS, Wood GA, Stachowiak GW, Gachter A. Joint load considerations in total knee replacement. *British Journal of Bone and Joint Surgery*. Jan 1997; 79-B (1): 109-113
10. Kuster M, Wood GA, Sakurai S, Blatter G. Downhill walking: a stressful task for the anterior cruciate ligament? A biomechanical study with clinical implications. *Knee Surgery, Sports Traumatology, Arthroscopy*. 1994; 2 (1): 2-7
11. Gonzalez LM, Peiro-Velert C, Devis-Devis J, Valencia-Peris A, Perez-Gimeno E, Perez-Alenda S, Querol F. Comparison of physical activity and sedentary behaviours between young haemophilia A patients and healthy adolescents. *Haemophilia*. 2011; Online edition: 1-7
12. Majumdar s, Ostrenga A, Latzman RD, Payne C, Hunt Q, Morris A, Iyer R. Pharmoeconomic impact of obesity in severe haemophilia children on clotting factor prophylaxis in a single institution. *Haemophilia*. 2011; Online early edition: 1-2
13. Frome A, Dreeskamp K, Pollman H, Thorwesten L, Mooren FC, Volker K. Participation in sports and physical activity of haemophilia patients. *Haemophilia*. 2007; 13: 323-327
14. Broderick CR, Herbert RD, Latimer J, Curtin JA. Fitness and quality of life in children with haemophilia. *Haemophilia*. 2010; 16: 118-123
15. Schoenmakers MAGC, Gulmans VAM, Helder PJM, Van Den Berg HM. Motor performance and disability in Dutch children with haemophilia: a comparison with their healthy peers. *Haemophilia*. 2001; 7: 293-298
16. Mulder K, Cassis F, Seuser A, Narayan P, Dalzell R, Poulsen W. Risks and benefits of sports and fitness activities for people with haemophilia. *Haemophilia*. 2004; 10 (Suppl. 4): 161-163

Healthy eating for Hepatitis C

It is common for people with hepatitis C to worry about what they eat and whether their diet affects their liver.

The Role of the Liver and the effect of HCV



The liver is one of the most important organs of your body. It is the factory that converts raw materials from your digestive system into substances that your body needs. It detoxifies harmful substances, such as alcohol, and helps remove waste products. The liver also makes bile which helps in the digestion and absorption of fat.

Hepatitis C virus damages liver cells. This can result in mild damage at first, but that can become more serious the longer you have hepatitis C. Even if someone's liver is not significantly damaged they may still feel tired or ill. This may be due to the way the human body fights HCV.



What to eat

Eat a big variety of foods from all the food groups. This gives you a broader range of nutrients, vitamins and minerals than if you eat the same things all the time.

Organic food is higher in nutrients, and being spray-free means less detox work for the liver. Eat it if you can afford it.

Unless you have a special diet such as vegan, gluten-free or dairy-free, you should aim to eat something from the following good groups every day.

What to eat

Food Group	Examples	Comments
Whole grains	Millet, rice, wheat, brown bread, crackers	These assist movement of food through the intestines, as well as providing trace vitamins and minerals.
Vegetables	Beetroot, carrot, garlic, puha, cabbage, sprouts	Loaded with antioxidants and vitamins that help reduce inflammation and heal body tissues. Try to eat what is in season, but frozen or canned vegetables are good alternatives.
Fruit	Apples, kiwifruit, berries	Eat what you enjoy and what is in season. Peel or wash before eating.
Dairy	Yoghurt, cheese, milk	Yoghurt and goat's milk may be ok for lactose intolerant. Non-homogenised milk is better for the liver. Calcium enriched soy milks can be used as substitutes.
Meat	Fish, chicken, lamb, beef	Choose lean cuts or cut off excess fat. Avoid preserved meats containing nitrates like salami & bacon. Lean red meat is valuable source of iron, protein and B group vitamins.
Legumes	Peas, beans, chickpeas, lentils, mung beans, fermented soybean curd (tempeh)	Preparation of dried pulses takes time. Try lentils, beans, chickpeas ready-cooked in cans if you're in a rush or unfamiliar with cooking pulses.
Fruit	Almonds, sesame, pumpkin seeds	High in protein and quality oils. Eat raw or soaked in water for a couple of hours. Soak almonds overnight. Eat freshly roasted nuts.

What not to eat

Avoid over-processed foods. These can be loaded with:

- trans-fats (stress the liver);
- sugar (creates mood swings, wears out the pancreas, depletes the immune system); and
- artificial flavours and colours.

Choose biscuits, soft drinks, chips, crisps, sweets, savoury snacks and other treats only occasionally and in small amounts – just like everyone is encouraged to do.



Liquids

Ensure you get enough liquid daily. Drink approximately 2 litres a day, more in summer or if you exercise or perspire a lot. Water and herb teas are best, although there is no published scientific evidence

suggesting that tea or coffee, consumed in moderation, cause particular problems for people with HCV.

Alcohol and coffee are dehydrating. Your urine should be straw coloured. If it is dark with a strong odour you may be dehydrated.

Alcohol also creates additional stress for the liver and excessive alcohol intake can cause long term damage. The risk of developing cirrhosis is higher for people with HCV if they are also heavy drinkers. Reducing intake or avoiding drinking alcohol is recommended.



Dietary fats and oils

Many people with hepatitis C find fatty, oily food difficult to stomach. If eaten too much it can trigger mild to severe nausea. As a result, fats and oils are often restricted in the hepatitis C diet. However, the body needs good quality fats to make energy, hormones, cholesterol, and

healthy skin. Essential fatty acids are needed in every cell in the body to work properly.

A person with hepatitis C must focus on good quality, nutrient dense oils. Most supermarkets now have reasonable range of cold-pressed oils in glass bottles. Cold pressed oil hasn't been process with heat during manufacture. It contains more nutrients and the oil is not damaged or transformed into a trans-fatty acid.

It is also helpful consume to your fat in the middle of the day when you digestive fire is at its peak. If you eat too much in the evening you find nausea and discomfort disrupts your sleep.

Good quality oils

Olive oil	The best all rounder and most easily found is cold-pressed olive oil. It can withstand reasonable cooking temperatures and contains omega 9.
Flaxseed oil	Contains omega 3, which has anti-inflammatory effects. It reduces joint pain, is anti-depressant, and good for healthy skin. Use in salad dressings, mix with yoghurt, smoothies or cottage cheese. It is kept in black bottles and in the fridge after opening.
Fish oil	High in omega 3, and more potent anti-inflammatory than flaxseed oil. Look for high quality without mercury, PCBs or dioxins.

Evidence is mounting that excess body fat contributes to liver disease. People with HCV are advised to avoid becoming overweight.

Vitamin & Mineral Supplements

There is evidence that antioxidant nutrients (such as vitamin C and E) can play a role in limiting the damage that HCV causes to the liver. Most people get their vitamins and minerals from fruit and vegetables. Additional supplements may be useful for people who do not eat a variety of foods from each food group.

If you take supplements, be careful not to exceed the recommended doses as this may be harmful. Seek advice before starting any nutritional supplements to ensure that they are not damaging to the liver.

The above points cover what good nutrition is based on: variety, wholefoods, and the ability to relax.

For people with hepatitis C, the degree of severity and duration of infection will impact how food affects them too. However, even if you have few symptoms or have minimal liver damage, it is still beneficial to look after your liver now to prevent or delay progression. The can benefit many levels of your life.

CREDITS: The majority of this article was written by Mary Allan, Medical Herbalist MNZAMH and originally appeared in The Chronicle, Summer 2009/2010. Additional information was added based on Hepatitis C and Food, a pamphlet from The Hepatitis C Council of NSW.

PROUDLY DESIGNED AND PRINTED BY

Jeff Oliver Print Ltd
creative design • quality printing

24 Walton Street • Whangarei • Ph 09 438 8313 • Fax 09 430 8474
Website: www.jeffoliverprint.co.nz • Email: info@jeffoliverprint.co.nz

- DIGITAL PRINTING
- OFFSET PRINTING UP TO A2
- Also Business Cards & Business Stationery to Presentation Folder, Brochures and Full Colour Productions
- ALL WITH OUR FIVE STAR GUARANTEE



Advances in understanding vWD



von Willebrand disorder (vWD) was first described more than 80 years ago and is now recognized as the most common inherited bleeding disorder, with an estimated prevalence of 1.3% in the general population¹. Accumulating knowledge about the structure and function of von Willebrand factor (VWF), aided by the cloning of the VWF gene in 1985, has paved the way for advances in vWD treatment².

Diagnosis of vWD

VWF is one of the key uniting proteins in the clotting process and serves two basic functions. Firstly, it initiates the first steps in stopping the blood flow at the site of injury by promoting platelet adhesion. Secondly, it acts as a carrier of factor VIII (FVIII), protecting FVIII from becoming inactivated and increasing FVIII concentration around the plug that is being formed in the blood vessel.

The size and complexity of vWD had been difficult to characterise. These functions are explored by an array of laboratory assays, which have significantly improved in recent years, but no one reflects the whole spectrum of VWF activities³. An array of different tests is required for the full characterization of a patient with vWD. Over the last 15 years, significant progress has been made in defining the molecular genetic basis of this bleeding disorder. Over 250 mutations have been identified in association with the VWF gene. There are many types and degrees of vWD because molecular defects can occur in more than one of the functional areas of VWF.

Type 1 vWD accounts for up to 70% of all vWD cases¹. vWD type 1 is caused by a mild to moderate deficiency in the quantity of normal VWF. It is an autosomal dominant trait that is associated with variable bleeding severity (see Figure 1). It may also involve factors outside of the VWF gene⁴. Diagnosis of type 1 vWD can be challenging as the criteria for diagnosis are not always clear cut due to clinical and laboratory variability. The complexities of type 1 vWD diagnosis are related to the naturally broad distribution of VWF levels, the coincidental association of low VWF levels with non-specific, mild bleeding symptoms and variable genetic penetrance, meaning not all people who carry the gene show clinical symptoms⁵. A significant bleeding history is essential for diagnosis.

Type 2 vWD involves a defect in the VWF structure. The VWF does not work properly, causing lower than normal VWF activity, and symptoms are usually moderate. Genetically speaking, all variants appear to have higher penetrance than type 1, meaning that affected individuals are more likely to show symptoms.

Type 3 is the rarest vWD subtype, occurring in approximately 1 per million people in the United States and Europe¹. In type 3 there is a severe deficiency of normal VWF, less than 1%, and frequent bleeding episodes. In the classic description of type 3 vWD, both parents pass on their type 1 vWD mutation to the child, although it may not be symptomatic in the parents.

Clinical and surgical issues in vWD

The mainstay of vWD treatment is replacement of VWF at the time of bleeding or before invasive procedures are performed². Four strategies are used along or in combination: replacing VWF from internal stores (endogenous) or outside sources (allogeneic), support therapies (adjuvant) and additional (adjunctive) therapy.

Endogenous replacement therapy involves the intravenous, intranasal or subcutaneous administration of desmopressin (DDAVP), a synthetic hormone derivative, to stimulate the secretion of VWF stores within the cells that line blood vessels. DDAVP is useful in patients with mild-to-moderately severe vWD and FVIII levels exceeding 5% - specifically types 1 and 2A vWD. Although the adverse effects of DDAVP are usually mild, some serious complications can occur, therefore fluid restriction and monitoring are recommended during treatment².

External or allogeneic replacement therapy using plasma-derived VWF/FVIII concentrates is necessary to control or prevent bleeding in patients with severe vWD (e.g. types 2M, 2N and 3). Recombinant FVIII products are not used for this purpose because they lack VWF. The VWF component of replacement concentrate is considered more critical for mucosal bleeding, whereas the FVIII component is thought to be more important for surgical and soft tissue bleeding. Possible complications of replacement therapy in vWD include thrombosis, so again monitoring is important, especially with repeated dosing.

Adjuvant therapy with systemic and topical haemostatic agents is an essential component of vWD management. Many bleeding events associated with VWF deficiency, including nose bleeds, heavy menstrual bleeding and prolonged oral bleeding following dental extraction, continue in part because of the rich clot dissolving (fibrinolytic) activity in the mucosal tracts⁶. The antifibrinolytic agents, such as tranexamic acid, which are administered orally or intravenously, support treatment with DDAVP or VWF/FVIII concentrates. They may also be sufficient as therapy on their own for less severe forms of mucosal bleeding. Treaters now also have several choices of sealants (liquid adhesives) and solid matrix dressings.

Adjunctive therapies, such as platelet transfusions and oestrogens, are used to non-specifically influence the release of VWF into the circulation².

The incidence of inhibitors to VWF is thought to be similar to that reported for haemophilia B, around 1.5-3%⁷. In rare cases, people

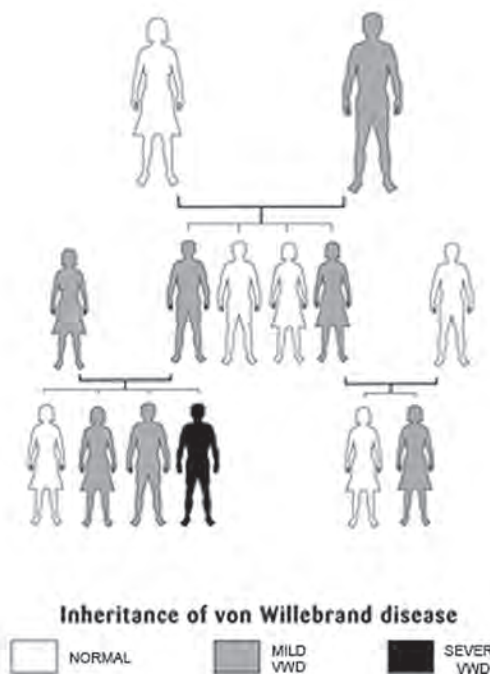


Figure 1. (Image courtesy of WFH)

with vWD with anti-VWF antibodies experience life-threatening anaphylactic reactions when treated with VWF/FVIII concentrates. Bleeding events in vWD inhibitor patients can be managed with continuous infusions of high-dose recombinant activated factor VII or with activated prothrombin complex concentrate².

Bleeding events in women with vWD

Because mucosal bleeding is a primary symptom of vWD, females with this disorder are frequently affected by reproductive tract bleeding and related complications⁸.

Menorrhagia, or heavy menstrual bleeding, is often the primary bleeding symptom in women with vWD, affecting an estimated 80-90%⁸. Oral contraceptives and other birth control methods that contain an oestrogen (e.g. transdermal patches or vaginal rings) reduce menstrual flow and likely increase VWF and FVIII levels⁹. Progestin-only contraceptives, including intrauterine devices, injections and subcutaneous implants, also decrease menstrual bleeding. When hormonal control is insufficient, or if a patient desires to become pregnant, antifibrinolytics, DDAVP and VWF/FVIII concentrates can be used to treat menorrhagia².

Both ovarian cysts and endometriosis occur significantly more frequently in women with vWD¹⁰. The majority of cysts are likely the result from bleeding into the follicle during ovulation. It is thought that endometriosis is caused by retrograde menstruation (blood exits via the fallopian tubes rather than the vagina). Because heavy menstrual bleeding increases the risk of endometriosis, women with vWD are especially vulnerable to this condition. Given the increased number of gynaecologic problems among women with vWD, it is not surprising that they are more likely to undergo hysterectomy - and at an earlier age - than females in the general population. Because of their bleeding disorders, women with vWD are also at higher risk for surgical

complications during uterus removal, including profuse bleeding and the needs for transfusions. As a consequence, alternatives to hysterectomy, such as endometrial ablation, may be more appropriate⁹.

Pregnancy brings with it different bleeding complications. The increase in VWF and FVIII levels vWD patients usually experience during pregnancy may help protect from the risk of bleeding following miscarriage or delivery, but their risk of bleeding complications still exceed those of women without vWD. A large study found that 59% of women with vWD experience postpartum bleeding compared with 21% of control women¹⁰. Women with vWD are significantly more likely to have delayed or secondary bleeding when VWF and FVIII levels decline, which usually occurs 7-21 days after delivery. Although 3-5 days of prophylaxis after a woman with vWD gives birth has been recommended, this duration probably provides insufficient protection from bleeding for women with VWF levels below 50%². Two to three weeks of prophylaxis may be a more realistic regimen in women with very low VWF levels⁹. Ensuring optimal outcomes for pregnant women with vWD requires a multidisciplinary approach. A recent article suggests that women with moderate or severe disease or complicated pregnancies are best served by delivering at a center with an obstetrician, haematologist, and anesthesiologist experienced in managing coagulation disorders¹¹.

vWD prophylaxis

Patients with severe forms of vWD may experience frequent episodes of mucosal bleeding, as well as joint and gastrointestinal bleeding. Studies in patients with haemophilia A have established that the routine, continued administration of FVIII can prevent bleeding episodes (primarily joint bleeding) and improve quality of life¹². There is, however, limited data regarding the efficacy of VWF/FVIII prophylaxis for vWD patients. Even so, VWF/FVIII infusions administered at least once weekly have been found to substantially reduce bleeding episodes and did not cause thrombosis¹³. In the PRO.WIL study, prophylaxis prevented bleeding completely in eight patients and largely reduced hospitalisation for blood transfusions in the remaining three¹⁴.

Major advances have recently broadened our understanding of the complexities and management of vWD. In the future, new products and new treatment approaches, such as recombinant VWF and routine prophylaxis for severe vWD, may further improve outcomes for patients with this common bleeding disorder. For example, investigational treatment for adult patients with severe vWD with recombinant VWF is currently being trialled. Research is also underway to better understand the variability in bleeding symptoms and predict which patients with vWD will bleed after surgery³. Neither the family history nor laboratory parameters seems to be able to anticipate surgical bleeding, and having access to better predictive markers will lead to better management and quality of life for people with vWD.

References

1. Pruthi, RK. A practical approach to genetic testing for von Willebrand disease. *Mayo Clin Proc.* 2006, Vol. 81, 679-691.
2. Mannucci, PM, et al. von Willebrand disease in the 21st century: current approaches and new challenges. *Haemophilia.* 2009, Vol. 15, 1154-1158.
3. Castaman, C, et al. von Willebrand's disease diagnosis and laboratory issues. *Haemophilia.* 2010, Vol. 16 (Suppl. 5), S67-73.
4. James, PD, et al. The mutational spectrum of type 1 von Willebrand disease: Results from a Canadian cohort study. *Blood.* 2007, Vol. 109, 145-54.
5. Dutt, T, et al. Application of UKHCDO 2004 guidelines in type 1 von Willebrand Disease - a single centre paediatric experience of the implications of altered or removed diagnosis. *Haemophilia.* Early View, 2011, 1-5.
6. Mannucci, PM. Treatment of von Willebrand's disease. *N Engl J Med.* 2004, Vol. 351, 683-694.
7. Warrier, I and Lusher, JM. Development of anaphylactic shock in haemophilia B patients with inhibitors. *Blood Coagul Fibrinolysis.* 1998, Vol. 9 (Suppl. 1), S125-128.
8. Greer, IA, et al. Haemorrhagic problems in obstetrics and gynaecology in patients with congenital coagulopathies. *Br J Obstet Gynaecol.* 1991, Vol. 98, 909-918.
9. Nichols, WL, et al. von Willebrand disease (VWD): evidence based diagnosis and management guidelines, the National Heart, Lung and Blood Institute (NHLBI) Expert Panel report (USA). *Haemophilia.* 2008, Vol. 14, 171-232.
10. Kirtava, A, et al. Medical, reproductive and psychosocial experiences of women diagnosed with von Willebrand's disease receiving care in haemophilia treatment centres: a case-control study. *Haemophilia.* 2003, Vol. 9, 292-297.
11. Lipe, BC, Dumas, MA and Ornstein, DL. Von Willebrand disease in pregnancy. *Hematol Oncol Clin North Am.* 2011, Vol. 25(2), 335-358.
12. Manco-Johnson, MJ, et al. Prophylaxis versus episodic treatment to prevent joint disease in boys with severe hemophilia. *N Engl J Med.* 2007, Vol. 357, 535-544.
13. Bernthorp, E and Petrini, P. Long-term prophylaxis in von Willebrand disease. *Blood Coagul Fibrinolysis.* 2005, Vol. 16 (Suppl. 1), S23-26.
14. Federici, AB. Highly purified VWF/FVIII concentrates in the treatment and prophylaxis of von Willebrand disease: the PRO. WILL Study. *Haemophilia.* 2007, Vol. 13 (Suppl. 5), S15-24.

Advance Your Passion 2011 Winners

Advance Your Passion is a grant competition sponsored by Baxter. This year the Advance Your Passion program offered the opportunity to be awarded up to \$5,000 as a development grant to individuals with bleeding disorders to use to help them develop their passion. The competition was divided into two age groups, those 14-21 and those aged over 21 years. In New Zealand, the judges selected three passionate winners this year with a wide range of passions.

Kimberley Drummond



Seventeen year-old Kimberley has mild haemophilia and a dream of becoming a professional hairdresser. After finishing high school at Linwood College in Christchurch last year, Kimberley enrolled in her first year of hairdressing college at CPIT.

"I have had a passion for hairdressing ever since I can remember and I was forever being asked why my dolls had their hair cut off", wrote Kimberley in her application. "I have chosen to do the hairdressing course because it is a great way to show my creativity and also because you get to meet a lot of different people and help to make them feel good about themselves, which is very rewarding."

Once she is fully qualified, Kimberley hopes to open her own salon with her sister, also a hairdresser. Kimberley plans to use her Advance Your Passion grant towards her course costs and student loan so that she get ahead on her dream of owning her own salon.

Curtis McQueen



After trying a few different professions, from butchery to retail, Hamilton native Curtis found his calling - design. From an artistic family, Curtis collected his ideas and in 2009 founded Bad Ass Clothing, specialising in street and skate wear. Apparently, the company's name is related to Curtis' mischievous streak.

Twenty-five year old Curtis has severe haemophilia B and has recently been dealing with some tricky health issues. With his Advance Your Passion grant, this young entrepreneur plans to further develop the BA Clothing and brand, especially their website, www.badassclothing.co.nz, so he can bring BA to a wider audience and make getting one of his designs even easier.



AYP 2011 Winners with Barb Hodges from sponsor Baxter Healthcare (far right) and one of the judges Sandy Kirby of Arthritis New Zealand (far left) and HFNZ CEO Belinda Burnett



Scott Nelson



Sailing is not only a passion of Scott's; it has played a huge part in his life. Scott, now 33, grew up listening to stories of his father's sailing trips with his uncles and helping his father build their very own boat in their back yard. His real love of sailing took hold after the boat was finally finished and launched on the water. Over the next few years Scott learned to sail and race on Auckland Harbour.

"I couldn't get enough, I was like a sponge. I learnt that going racing was a great way to spend time with friends and family... The sense of freedom and adventure showed me a side to life that I still love to this day", wrote Scott.

As he got older, Scott, who has severe haemophilia, planned to travel overseas and work on super yachts. Unfortunately his haemophilia and related health conditions held him back. The work was not only physically prohibitive, but logistically taking enough factor away with him posed a huge problem.

Scott career path's never ventured far from the sea though. He worked in the marine industry in sales and purchasing for some of NZ's leading marine distributors and manufacturers. All the while he continued to dream of actually being on the water. In 2006, Scott underwent a year-long course of interferon therapy to treat his HCV. The experience of treatment and the side-effects changed his life. He was eventually no longer able to work, especially in an office environment. Unfortunately, interferon treatment was unsuccessful and he has not been able to return to work.

Boating on the other hand has been very helpful, keeping Scott calm, centred and motivated. As such, being on the water is where Scott wants to be. Scott plans to use his Advance Your Passion grant to complete the Ocean Yacht Masters qualification. This will allow him to skipper a yacht up to 200 tonne anywhere in the world. It is something Scott has always wanted to do and now, thanks to the grant scheme, he began his first course towards his goal in April.



Sailing has long been a passion for Scott

World Haemophilia Day in NZ

April 17th is World Haemophilia Day (WHD). It is a day to acknowledge how bleeding disorders are part of our lives and raise a little awareness in the community. This WHD fell on a Sunday, and the day was marked with events across the country.

The Northern committee hosted a great trip to Rangitoto Island. The group enjoyed lunch on the ferry over to the island and the hike to the summit. With great forward planning, there was also a 4WD option to tackle the volcano for those with joint issues who might have trouble with the hike. Many wore red to mark the day and all had an enjoyable time.

In Midland, Haemophilia Nurse Maureen Hayes organised an event at Waikato Hospital.

In Central, a few members and Outreach Worker Lynne Campbell joined together at a local café, moving from their original outdoor location due to the weather. BJ Ramsay, haemophilia nurse at Wellington Hospital, also organised a celebration during a haemophilia clinic.

Unfortunately, the Southern WHD celebrations in Christchurch that had been planned for Hagley Park had to be cancelled due to the miserable weather over

the weekend. A real shame, but hopefully this will allow something even better to be planned for next year.

Members of the Youth Committee also came up with the great idea of a "Paint It Red" for World Haemophilia Day competition. Possibly due to the weather we only had a few entries, but special mention must go to Colleen and Carl McKay for their fantastic effort. The Christchurch festivities may have been rained out but their Captain Clot inspired costumes brightened the day. We will be holding the competition again in 2012 so start thinking of how you will Paint It Red next April.

Thanks to those who took the lead in organising WHD events, and to all the others who made an effort to attend or mark the occasion. Thank you also to Bayer Healthcare for their support of World Haemophilia Day and encouraging us all to - 'Live our best Life'



Northern celebrates WHD at Rangitoto Island



Tyler Anderson at Rangitoto



Carl and Colleen McKay "Paint It Red"

People around the world Share their Story for World Haemophilia Day

For World Haemophilia Day, the World Federation of Hemophilia (WFH) encouraged people with a bleeding disorder from all over the world to share their stories in their own words and inspire others. Here is a selection of a few of those moving stories. Although it is clear that having access to treatment makes a huge difference to physical health, the emotional impact of having a bleeding disorder expressed in these stories echoes feelings and ideas felt by many people in New Zealand. You can read many more stories at www.wfshareyourstory.org



My Story

by Betz (originally in Spanish and English)

When I speak with friends, and I tell them that my son have Hemophilia, many times I can see in their look and words the pity look, the pity words. Many times, they ask me if its hard, or if

I have regrets to have my son, or if I knew it before I take another decision, I smile, and said, no, I don't have regrets, and yes its hard, but what in life isn't?

Many people thinks, that hemophilia is a curse, or something really really bad, but I believed, that really really bad is ignorance.

Yes, definitely there are a bunch of things to learn and sometimes the speed to do it seems not to be enough faster to confront the new challenges, but is not how life works? With hemophilia or without it we have to learn to adapt ourselves (Darwin used to called "Evolution") and I believe that THIS life give us a great opportunity to do it.

When I spoke with other hemophilia moms, most of them speak of the fear, and I tell them that is normal, but, paralyze by the fear is the worst idea. Act! act is the solution!!

My grandfather born in 1921 (90 years ago!!), in his time, there was no treatments and nevertheless he lived 67 years!! My grandpa, teaches me, that the only thing that you can't do is give up. He used crutches, but never a handicap, cause he said, the handicap is in the mind.

My son's birthday is April 17th (World Hemophilia Day), and even when this looks like a weird destiny joke, I take this challenge with pride, because I know that with him and for him I will be a better person. My contribution in this day and every day is to share my experience and try to teach everyone around me.



My life story with HEMOPHILIA

By Amit Gulati (New Delhi, India)

"Some people are born to fight And I believe I am one of them"

My name is Amit Gulati and having Hemophilia B. I was six month old, when my parents discovered that I am suffering from this non-curable disease (HEMOPHILIA). They were shattered as I am the only child. To make situation worst some of my close relative blame my mother. She is carrier and hemophilia is in my family history, my maternal uncle was hemophiliac and he passed away in the absence of proper treatment (Factor IX) at that time in India. In his last days the disease turn worst, he had stomach bleed & HIV Positive (due to wrong blood transfusion).

One day my grandmother observed blue wound on my chest so my parents brought to the AIIMS hospital after blood testing I was diagnosed that I am having hemophilia B and Doctor referred me to Hemophilia Society Delhi because the treatment (F IX) was not available in the govt. hospitals and Doctors were not much familiar about the disease.

Hemophilia is not only a disease for us it is an "Expensive Disease" or I can say this is the only expensive thing I ever had in my life. I am not born with a silver spoon in my mouth; I belong to a middle class family. I saw my father struggled a lot to run his small General Store and my mother is housewife. After so many obstacles they learned survive with me.

I brought up in a very strange atmosphere, my parents are too protective for me and their behaviour also affects me. I was afraid to get mixed up with other children of my same age because the fear of getting hurt physically by chance is always kept in my mind, as I knew we don't have enough money to spend on my treatment.

I am the member of Delhi Chapter and they not only educate me and my parents about the disease, they give us a new courage to fight with this. To get along with the people who suffering from the same give me different way to see look at things. I still remember when suddenly I have suffered with "internal Bleeding in my brain", during that time when there was no option left for my parents as the treatment need high expense they (Delhi chapter) provided us Factor IX and other treatment at very subsidized rates and some time free of cost. Delhi chapter helped me a lot hence; I am emotionally attached with my Chapter. I considered myself lucky to being switched with The Delhi chapter.

I completed my Graduation in Commerce from Delhi University. Unfortunately I joined correspondence college because my elbow and ankle were not good and due to our economical problems.

One day I got news from my Society that Delhi Govt. would give us free F VIII and IX in emergency cases and I joined a regular course in Accountancy and I got the "Best Student" award for 100% attendance & good performance. After that I am enjoying my life as a normal person. The main problem in India is patients are not getting prophylaxis treatment, otherwise we can do everything. With the help of Govt. and Delhi Chapter I am able to do a job as well. I am Hemophiliac still I am strong I can face any kind of pain and having a "Royal Disease".

So I can say in the end of my story "I BELIEVE I CAN FLY WITH MY WINGS OF BELIEF".

Wishing for the best.



A baby with Hemophilia

By the Tanami family (Israel)

I had the most amazing and healthy pregnancy, with an easy birth (as easy as birth goes when it is natural without drugs) and then through some routine blood tests in the hospital we found out my son had Hemophilia. The tests were not genetic, but we discovered it because he continued to bleed throughout the day and night. Before we found out I didn't even know what Hemophilia was. Six months later we are still trying to figure it all out, but most importantly live normal lives. We are a very active family, so our son is already swimming (it's the cutest thing ever), he ran a half-marathon with us (he got the easy ride in the stroller) and we continue to stay healthy and strong, not for him but with him. With today's medical advances and the incredible socialist medical system that Israel provides us, we are extremely fortunate and blessed every day. I know we are just at the beginning of dealing with Hemophilia, but through a strong support network, amazing medical care and positive outlook, we will provide our son with everything he wants and needs. I believe Hemophilia is not a disease but a way of life, so until there is a cure, we are living life to the fullest, blood clots or not.



"Bleeding Out and yet, Still Living In"

By Jared Formalejo (The Philippines)

Stories of an adolescent with hemophilia in the Philippines.

I'm Jared Formalejo. I'm the youngest of three boys in my family and out of the three of us, I'm the only one who has hemophilia. I'm the first person in my whole family's line to have this disorder. Doctors traced my whole family and only came up with one conclusion: my hemophilia resulted from a mutation in my genes.

I was not diagnosed with this disorder until I was three years old. My parents always retell the story of how they were left puzzled with seeing me bruised up all the time even though I'm just stuck inside a crib or a play pen. They were left to the conclusion that something may be going on while they are away. Possibly my brothers getting too rowdy when they play with me back then, or even to the extremes of them or the house help hurting me. When my parents found the time to look after me, they knew something was wrong when I continued to bruise for no apparent reason. Even though it's been fifteen years now, I still remember how we jumped from hospital to hospital looking for someone who may be able to figure out what's wrong with me. Even my own doctor, my dad, was caught by surprise that it in fact was hemophilia; nor did he imagine that it would be hemophilia. Tests of all kinds were done ranging from CT-scans, x-rays to the blood tests which I distinctly remember running away from due to a fear of needles. Eventually, I was referred to a well-known hematologist, who is also my current hematologist, and she finally diagnosed me with severe hemophilia B.

Growing up, it was a pretty common thing for me to hear the words "What's hemophilia?" the day I was diagnosed. I was one

of the luckier ones, to be diagnosed at an early age and to be born in the time of fast-paced improvements in the field of medicine. My hematologist encouraged us to join a body of people with hemophilia in the Philippines known as HAPLOS or the Hemophilia Association of the Philippines for Love and Service. Knowing this organization was around really helped me overcome my feeling of being alienated from the rest of the crowd while I was growing up. It gave me the reassurance that I wasn't alone in this world and that I have my own family, a family of people with hemophilia.

It's very difficult to live a positive life knowing that something is off about you. I spent most of my early childhood like any other boy attending elementary school; only difference being that I was exempted of all physical activities. I looked at all the other boys with envy as they played and performed in their P.E. classes while I sat in the corner still in my school uniform. I had to admit though, all the special attention was nice and glossy but I didn't really want them. All I wanted was to live a normal life in a not-so-normal way. The bigger questions came along as I passed through the years. How can I live a normal life? How different am I really from all the other people around me? Do I have what it takes to actually live a full life? And the biggest of them all: is hemophilia really weighing me down?

At a young age I was in a small pit of depression because of all these unanswered questions, also because I wasn't able to gain what I really only dreamed of becoming, normal. I always found myself in deep introspection. I always try my best not to have to compare myself with the others around me but an inner force was telling me to continue to look. It may not have been the side of envy inside me after all that was talking, but my moral conscience trying to guide me to what I want. It didn't want me to just look at all the other kids playing; my conscience wanted me to observe them so I may be able to study myself a little bit more. My own family did a lot of this for me. My own mom and dad did encourage me to live life normally. My own brothers helped me get out of my rut in the house and start doing something for a change. Although these things would occasionally come with a price, a bleed somewhere in my body or maybe a small bruise. It didn't stop me from getting closer to one of my aspirations though. A bleed just isn't enough to break the human spirit.

Occasionally there comes a time in my life that I just wished I was born a happy, healthy baby so I didn't have to burden the people around me, myself and especially my family. But endless support would still come from them even though I see myself as this "mistake" They made me see, as well as my other family in HAPLOS made me see that life doesn't offer mistakes. Life only offers opportunities for us to see the true potential we have as living, breathing and active individuals. I learned that there's something behind my hemophilia that doesn't make it just an abnormality. I took the liberty of devising my own little definition of an abnormality. So I took the world abnormal and changed it into something more positive for the benefit of myself and for the uplifting of others like me, hemophilia makes me above normal.

As long as I know that I am living with a purpose and as long as you have the love for yourself and the love of people around you; you may not even think of hemophilia as a burden anymore but rather something that makes you unique. Not someone

who can't do something but rather, someone who can do something else. Enough of all the cant's because if we aspire to live a healthy, normal life, we can as long as we do something about it. All I know is hemophilia didn't stop me from doing the things I aspired, such as being a swimmer and being active in so many other sports, becoming an honor student, becoming a loyal and thoughtful son, a role-model in the community and

most importantly being an active member of society. There is no reason to be exempted in living your life the way you want it to be, and so I continue my own life, ready for whatever it throws back at me as I go ahead in the unexpectedness already of the life I've already been having.

PEP Talk: Train-the Trainers Seminar



Haemophilia Foundation of New Zealand (HFNZ), with the support of Bayer Healthcare New Zealand, held a PEP: Train-the-Trainers seminar in Auckland on 23-25 March 2011.

Parents Empowering Parents (PEP) is a programme designed to promote effective parenting skills to parents of children with haemophilia, and to educate and support parents through classroom discussions and exercises. The PEP programme is designed to enhance the therapeutic relationship between parent, child and treatment staff; increase the parents' understanding of the child's bleeding disorder; heighten the parents' ability to respond objectively and consistently to bleeding episodes; and provides the parent with the skills necessary to effectively parent the child at the earliest age possible. Initially developed in the United States, the programme has moved into the international bleeding community. Over a thousand parents have been through the programme, including 20 parents in New Zealand.

PEP: Train the Trainers was taught by programme developers Social Worker Ed Kuebler and Haemophilia Nurse Madeline Cantini from the University of Texas Gulf States Hemophilia and Thrombophilia Center, alongside Stephanie Coulman, a New Zealand parent from Wellington.

PEP programmes are co-delivered by an outreach worker, nurse and parent. Parents of children with haemophilia, HFNZ outreach workers and haemophilia nurses from throughout New Zealand completed the training course. The parent participants were chosen from among those who had previously taken part in the PEP course, such as Jo Turner of Nelson. "After completing both PEP and Re-PEP and being inspired by both, I feel privileged to have been asked on the PEP: Train-the-Trainer course so that I can take these experiences and help to empower other parents. With some incredible trainers from Texas and other national and international participants, this course helps to refine and refresh all of the lessons learnt and remind myself of how far we have come."

After reviewing the course contents, participants were assigned to teaching teams. As such each teaching team including all three and once becoming familiarised with the content, were charged with planning and implementing some of the ten

sessions that make up the course. Some extremely innovative and creative teaching methods were employed by participants in order to best convey the important parenting concepts / messages.

The benefits of the programme are multiple. One of the nurses, Sandra, felt that, "The knowledge and networking I have gained during the PEP: Train-the-Trainers programme has been invaluable. In my clinical setting, the parents and children I care for and even my own parenting will benefit from this course."

The feelings of many of the participants can be summarised by this one comment, "[It is] such a privilege to be part of PEP Train the Trainers. Can't wait to get out there and get this programme to more bleeding disorder parents. The strength of the haemophilia community will be enhanced by this Programme."

HFNZ is extremely grateful to Bayer Healthcare New Zealand for their commitment to the funding of PEP: Train-the-Trainers; this will ensure the continuation of this valuable parenting programme for parents of children with bleeding disorders here in New Zealand.

HFNZ will be running a PEP Programme 12-14 August in Christchurch. If you are interested in participating please contact your Outreach worker.



Council Corner

Updates from the HFNZ National Council

In order to increase communication directly with the membership of HFNZ, Bloodline will now feature Council Corner. Here, HFNZ National Council will provide information and updates on our activities and decisions.

During the weekend of the Annual General Meeting in March, National Council participated in Governance Training facilitated by Sandy Brindson from Board Clarity. And clarity was exactly what the training helped achieve.

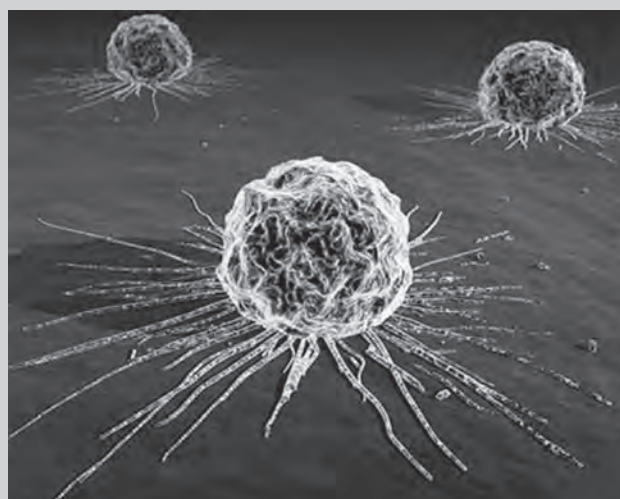
Council has made the decision to take steps to move away from working as a management committee to instead work at a higher level of accountability and concentrate on providing leadership and forward direction for the Foundation.

This move will require work for the Council as we better define our roles and set clear goals and limitations. Once these are in place, branch, Roopu and Youth Committee goals will be aligned with these. The whole process will help determine priorities for the branches and groups and making planning easier. It is our belief that having these clear goals and priorities in place will make volunteering for the branches more accessible and manageable, and will hopefully attract more people to actively take part in committees and activities.

Over the coming months will be working on the strategic aims and priorities for 2011/12. We will communicate with you further on these following our next meeting and look forward to your feedback.

If you have issues you would like to share or have considered please discuss these with your branch or Roopu chairperson, delegate, or youth delegate.

News in Brief



Cancer rates decreased in haemophilia?

In a study published in the January 2011 issue of *Haemophilia*, investigators reviewed epidemiological studies of haemophilia to survey the clinical data on cancer rates. Previous analysis in the literature proposed that having a factor deficiency might stop cancer from spreading because of the decreased activation of the thrombin – which also plays a part in coagulation. On the other hand, factor replacement might increase cancer rates.

The majority of the literature about haemophilia and cancer relates to virus-related malignancies caused by HIV or hepatitis C, so the investigators excluded cancers like non-Hodgkin-lymphomas and liver cancer from their analysis. They reviewed the causes of deaths for more than 8000 haemophilia patients, including more than 2700 HIV-negative patients. Results show virus independent cancer rates of 8-16% of deaths. The data analysis of corresponding standardized mortality rates supports the hypothesis that cancer rates, unaffected through HIV or liver cancer, are decreased in people with haemophilia when compared with the general population.

The authors conclude that planned research collecting data on factor consumption as well as severity of haemophilia in virus negative cancer patients is needed to further investigate the interaction between haemophilia and cancer.

High rate of ankle arthropathy in mild and moderate haemophilia

Arthropathy (joint disease) due to recurrent joint bleeding is well studied in patients with severe haemophilia, and generally affects the large joints (knees, ankles, hips, elbows and shoulders), but there is little data available on the prevalence and severity of chronic arthropathy in patients with mild or moderate haemophilia A. A study recently published in the journal *Thrombosis and Haemostasis* is the first study to document the level of chronic ankle

arthropathy in mild and moderate haemophilia A, using a database that is part of the Australian Bleeding Disorders Registry.

In contrast to severe haemophilia A, where arthropathy is common in multiple joints, the authors observed that in their patients with mild/moderate haemophilia A, mainly the ankle joints are affected. Of the 134 adult patients with inherited haemophilia A living in South Australia, 92 patients were contacted, 65 patients returned a completed survey, and 34 patients (6 moderate haemophilia, 28 mild haemophilia) had a clinical interview and assessment of ankle arthropathy. Evaluation of ankle arthropathy was by pain score, physical score and radiology score. Laboratory tests to determine their FVIII levels were also performed.

The results of this study confirmed the author's hypothesis that there is a high prevalence of ankle arthropathy in patients with mild and moderate haemophilia A. Of the 33 patients with ankle radiographs, 16 patients had ankle arthropathy (physical and radiological scoring), including 4 of the 6 patients with moderate haemophilia A, and 12 of the 27 patients with mild haemophilia A. Approximately two thirds of patients with ankle arthropathy were affected in both ankles. In many of these patients pain and disability were major problems. There was a significant relationship between FVIII level and radiology score, with ankle arthropathy being more common in patients with low FVIII levels. There was also a significant relationship between the presence of



ankle arthropathy and a history of ankle bleeding in childhood/adolescence, highlighting the importance of early and aggressive treatment of ankle bleeding in these patients.

The authors conclude that guidelines need to advocate prompt and adequate treatment of ankle joint trauma, often ankle joint sprains, with the infusion of FVIII concentrate and physiotherapy, with special attention given to patients with FVIII levels below 11 IU/dL.

WFH Launches Web-Based HemoAction Games



Children around the world can now learn about haemophilia in the language they know best: play! The HemoAction games were developed to help children learn about hemophilia in a fun, easy to understand, and interactive way. They can also be used by parents, nurses, and other healthcare providers to reinforce key concepts about the disease and its management. Children will also learn not to fear treatment by infusion and gain confidence and self-worth through educational play.

To play the games online, visit www.hemoaction.org

Dr Paul Ockelford named new chair of the NZMA

In May, Auckland Haematologist Dr Paul Ockelford was named the new Chair of the New Zealand Medical Association (NZMA).



Dr Ockelford says that he will continue to build on the unity and strength of the medical profession to make progress on core health sector issues. "The NZMA will continue its focus on advocating for a dramatic improvement in the recruitment and

retention of doctors so that our health system is able to deliver the treatments and health services our patients need."

The NZMA is also making health inequalities a priority issue, as New Zealand performs very poorly in this area. Dr Ockelford says that in this election year the NZMA will be urging the Government even more strongly to implement nationally driven, consistent, coordinated approaches to health issues. "This will ensure that health service delivery is more effective and equitable across the country. It requires greater Government leadership and less focus on individual DHB driven solutions."

Dr Ockelford, a graduate of the foundation class of the University of Auckland, is the Director of the Thrombosis Unit, Department of Haematology, Auckland Hospital heading a specialty team involved in the management of patients with clotting disorders and undertaking clinical research trials into new anticoagulant drugs. He is the Adult Director of the Haemophilia Centre at Auckland Hospital and a Clinical Associate Professor of Molecular Medicine and Pathology at the School of Health Sciences, at the University of Auckland. He is also Director of Clinical Services at Diagnostic Medlab Ltd.

HFNZ would like to extend their congratulations to Dr Ockelford on his successful nomination.

Regional Branch Reports

Northern

By Lynley Scott

Wow, is it really winter already?! Hard to believe really.

Once again, we have an awesome committee voted in at the Northern AGM – Mike Mapperson (Chair), Richard Scott (Delegate), Wayne Hunter (Treasurer), Lynley Scott (Secretary), Ritchyrd Hirst, Greg Jamieson, Hemi Thomas, Kahu Thomas and Patience Stirling.

Our year started off with our annual family camp at Waiwera, this was a smaller event than usual but a great time was had by all. As per other family camps, the Kayaks and Hot Pools were enjoyed, but this year the addition of a Bouncy Castle and Cupcake decorating added a new spin to the weekend while the adults enjoyed sessions by Sarah Preston on Schooling and a motivational speaker Cam Calkoen.

March saw Auckland host part of the SURO programme with Ed Kuebler and Madeline Cantini – Northern is grateful to Kahurangi Thomas for organising a great Māori cultural experience for the attendees. Following this, PEP Train-the-Trainers was held in Auckland with Richard and Lynley Scott attending. March also saw a number of Northern members making a trip to Rotorua for the AGM. A number flew down, however, didn't manage to land in Rotorua and ended up on a shuttle for a 4-hour journey.

This year we were determined to do something fun and memorable for World Haemophilia Day – a climb up Rangitoto Island. Members met at the Downtown Ferry building and enjoyed lunch on the ferry ride to Rangitoto. For those who were unable to walk/climb to the top a tour of the island and a trip almost to the top, while the rest clambered up the track to the summit. The clouds were kept at bay and once at the top we were treated with a great view over the city. Back down to meet the ferry home. It was great to see some new faces join us for this event. Everyone enjoyed their trip although I believe there were some very tired junior members that night (and one bleed the next day)

This month, for something different, the ladies of Northern branch are meeting for 'High Tea' at Cornwall Park. This will be a great opportunity for the mothers, daughters, sisters, partners, wives, etc to

get together and have a good time. (And men, don't worry you won't be forgotten – keep a watch out for later in the year!)

As we head into the cooler months, keep well and have fun!

Midland

By Catriona Gordon

Midland held a camp for its members at the beginning of March this year at Totara Springs in Matamata. Avid followers of Midland Branch reports may recall that it has been dogged by poor weather when running events, and that the camp in 2009 was run during an extreme weather event, including gale force winds, thunder and lightning, with the aforesaid lightning striking a transformer on the Saturday morning meaning that lunch that day had to be cooked on a BBQ.

This time at we were luckier, although it would be stretching it to say we were lucky. We still had rain, and quite a lot of it, but the wind, thunder and lightning stayed away. Our group of around 40 arrived on Friday night and caught up over dinner, followed by some games. On Saturday morning we all went down to the rock-climbing wall. There were some pretty confident climbers amongst our group, with a fair number of the children making it to the top.

We were able to have a swim in the lovely large thermal pool on Saturday afternoon. The pool was built after the camp owners, while putting a bore down for fresh water, found a hot spring instead, which keeps a constant temperature of 38 degrees. After the swim we had a very keen group ready to go down the incredible water slide. It would be hard to overstate the magic of this slide. You go down into the bush, where the slide is built on the side of a hill, with a wooden platform beside it, and after some careful instruction from our excellent guides, with quite a lot of stress on the need to be able to slow yourself down if necessary, we are allowed to start the sliding. Warm water is fed into the slide, which was a relief to us on that rather rainy afternoon. It takes a few corners to get going, but once you do, you really are rocketing! Midway down there is a cheer squad to encourage you if necessary, though more likely they are there to remind you how to use the brakes! At the very end you slide into a pool of lovely warm water, where, but for the fact that someone was likely to splash

into it and on top of you very shortly, it would have been nice to wallow a while. Instead it was a matter of dashing up to the top again for another go!

Our AGM was held on Sunday morning where we farewelled Lee Marjoribanks from our committee. Lee has been a very hard-working chairperson and regional delegate, and we will miss her input and enthusiasm. We are delighted that Vicki Fitzgerald has agreed to take on the regional delegate role this year. We are planning to go to Totara Springs in 2013 and hope lots more Midland members can join us.

This year it was Midland's turn to host the AGM, which was held in Rotorua. It was another great opportunity to get together with members from around the country, and for them to allow the sulphur to clear their nasal passages. Poor weather affected the AGM slightly, preventing some people from landing at the airport in time for the start of the meeting. This does seem to be a theme of our Midland events, so fingers crossed that our next family day out to be held this winter won't be affected!

Central

By Stephanie Coulman

Central region boasts two of its members are part of the new national youth committee; Raukura Riwaka is the Māori delegate and Lauren Nyhan is a committee member. Youth members can look forward to more activities planned with them in mind.

Wellington Hospital held a coffee morning to coincide with a paediatric clinic on World Haemophilia Day. They put up an information stand in the atrium of the hospital to raise awareness of haemophilia. The clinic was a comprehensive and busy one with haematologist, haemophilia nurse, paediatrician, physiotherapist all in attendance.

One young lad managed to answer all the questions put to him with a lollipop in his mouth (courtesy of Bayer) while simultaneously adjusting the height of the bed with the cool remote control. Central Outreach Worker Lynne Campbell also saw all patients afterwards in a separate consultation.

The Armageddon event in Wellington was

a roaring success with 23 HFNZ members and friends volunteering at the two-day event. Funds raised will go towards Central region members attending the World Congress in Melbourne in 2014. Thanks to all those who donated their time. You know who you are.

Southern

By Theresa Stevens

With winter around the corner it's time for an update from Southern. The National AGM was held at the end of March in Rotorua. It was a very straightforward event with every one evacuating rooms

at 0520hrs on the Sunday morning as rain had flowed into the hotel we were staying in! The dinner after the AGM saw three young members win awards with Advance Your Passion this was great to see three diverse areas win awards. I'm sure there will be an article within this issue outlining the winners and their passion. Sunday saw the office holders have some training and I was one of the lucky ones to be with Colleen McKay – this was most informative day.

We held our Southern AGM at the beginning of April which was very poorly attended. Our office bearers remain the same and we welcome Mathew Coleman to the role of Youth Delegate.

There will be a family fun day in Canterbury on 31 July. This will be a great hero-themed carnival day out for families as a little relief from the stress of the last few months. More details will be coming by post. On that note please also keep your eyes open for the invites National Adult Wellness Weekend in August and for the Men's Events that will be coming up in the region. The HFNZ have gone to great lengths to ensure these events happen, so please support them.

Until next time, stay safe and warm.

New way to donate to HFNZ: Payroll Giving

Payroll giving, where offered by your employer, gives you the opportunity to donate to approved donee organizations (such as HFNZ) direct from your pay and receive immediate tax credits that reduce your PAYE payable. You don't need to wait until the end of the year to claim your tax credit.

Only employers who electronically file their employer monthly schedule and deduction form can choose to offer payroll giving to their employees.

If your employer offers a payroll giving scheme and you want to join, you need to:

- check the donee organisation you wish to donate to is on IRD's approved donee list (HFNZ is listed as HAEMOPHILIA FOUNDATION OF NEW ZEALAND INCORPORATED)
- give your employer the:
 - name of the donee organisation
 - amount of the donation you want to make
 - pay period, or periods, you want the donation to be made
 - the donee organisation's bank account or postal address (contact National Office for HFNZ's bank account if needed).

If your employer's scheme allows, you can alter the frequency, amount and donee organisations you choose to donate to.

How tax credits for payroll donations work

Employers are responsible for calculating the correct tax credits for each payroll donation made by their employees.

The tax credit for payroll donations is 33.3333 cents for each dollar donated. Once the tax credit has been calculated, the employee's PAYE is reduced by the amount of the tax credit.

Individual employees will not be issued with receipts as the tax credits for donations made as part of payroll giving will be immediate in the form of reduced PAYE. They will not be eligible

to be claimed again through the end of year *Tax credit claim form (IR526)*. If you have made donations directly to an approved donee organisation and you have receipts you claim them on the *Tax credit claim form (IR526)*.

Example showing how the tax credit affects tax payable on salary or wages

Hannah makes a payroll giving donation of \$12 to HFNZ. She is paid \$2,140 every four weeks. This is her only job so her tax code is "M". Before the tax credit is applied her PAYE is \$435.48.

The tax credit for Hannah's payroll donation is \$3.99. Her employer applies the tax credit when working out Hannah's pay and Hannah's PAYE is reduced to \$431.49 for that pay period.

Hannah's new take-home pay is now:

Income		\$2,140.00
less	PAYE	\$435.48
less	Donation	\$12.00
plus	Tax credit for payroll donation	\$3.99
equals	Take home pay	\$1,696.51

Payroll Giving is an easy way to support HFNZ. It may especially suit individuals who support our work and prefer anonymity. It takes away the trouble of gathering receipts and claiming tax credits, and most of all it is a great way to support people with bleeding disorders and the community.

Donations via Payroll Giving will be most appreciated by HFNZ. For further information search for payroll giving on the IRD website (www.ird.govt.nz) or contact HFNZ National Office on 03 371 7477 or leanne@haemophilia.org.nz

Memoriam: Jeffrey Oliver

3 June, 1952 - 23 Jan, 2011



It seemed only fitting that the 33 Events Centre was filled to capacity as about 800 people came together to celebrate Jeff Oliver's life. Jeff's was a life well lived, despite the many hurdles he faced in his 58 years. His funeral was as much a farewell to his leaving us, as it was an opportunity to share in the celebration of his life.

For two hours, we were immersed in "Jeff's World", from the Bee Gees playing on the speaker system as we waited for him to make his entrance, to the PowerPoint images portraying the many joys and loves of his life – his wife Sandi, children Dean and Jennie, and their mother Judy, his grandchildren, brother Brian, sister Debbie, mother Iona, his dog Archie, and the many friends who had helped fill in his life's journey.

Somewhat, tapping our feet and swaying as we sang "I Can See Clearly Now" made it easier to accept. After all, no one can wish endless suffering and pain on someone just to keep them with us. As the words of Johnny Nash's song say, "I Can See Clearly Now The Pain Has Gone."

As Simon and Garfunkel's song "Bright Eyes" played, another memory was stirred of when Jeff and Sandi went to their concert in Auckland two years ago. Invited back to the Langham Hotel afterwards, Sandi was so overjoyed when Paul Simon casually walked in, jacket slung over his shoulder, that she ran over and hugged him, dragging him back for precious photos with Jeff. Just another amazing thread to Jeff Oliver's life, and one his mates still love to point out the obvious – there was actually someone shorter than Jeff!

And of course, there was the fishing. Everyone who knew Jeff knew how passionate he was about his boat and fishing. They also

knew of his immense dislike of cooking – unless of course, he was cooking fish – and then he was in his element.

Many stories were told of Jeff's colourful and rollercoaster life – an excellent synopsis of the value he placed on his friends and family.

Jeff never did anything by halves. From the moment he was born, he had a battle on his hands. Diagnosed with haemophilia as a baby, his start in life already came with a handicap. But it was a handicap he was determined would not stand in his way of a good time.

Jeff yearned to be "normal" and it's not hard to understand why. As a child he was paraded in front of his classes and the assembly at school so children, teachers and parents were aware of how fragile his life "could" be.

Despite not being able to play regular sport and unable to join in the rough and tumble games with his mates, Jeff still managed to cram as much fun and boyish mischief into his growing up years as he could. His mate Steve Carr recalled their many "hunting" adventures through the Ruahine ranges on the doorstep of their Dannevirke backyards, where possum and deer became easy targets for their homemade bullets, and their one foray into "poaching" resulted in Jeff laying claim to an Aberdeen Angus – that had obviously been well dead for a while!

Jeff's dad was an undertaker and it seemed only natural that his sons would learn the intricacies of the trade and follow in his footsteps. Jeff qualified as an embalmer, and his younger sister Debbie still remembers the day when she tried to find out what her brother was up to in the mortuary.

Sensing his sister was watching through the door, Jeff, as mischievous as ever, suddenly raised the cadaver's hand and waved to her, scaring the living daylight out of her and ensuring she never spied on her brother again.

When his parents moved to Whangarei to take over Newberrys Funeral Service, Jeff, Judy and the rest of the family followed suit.

He was always a bit of a tinkerer – in the early days it wasn't unusual to find car parts on the lounge floor. But it was when he started making printing plates for Newberrys, that the seeds were sown for Jeff Oliver Print, which opened its doors in 1986 and today holds a stake as one of Northland's top printing companies.

After 27 years of marriage, Jeff and Judy parted ways as a couple, though they remained in business together.

After the break-up of his marriage, Jeff moved on to his boat. His life changed in a second when he met Sandi, who was to be the love of his life for the next 12 years.

Life was full and happy for the couple, until the devastating news that rocked their lives. Just over three years ago, Jeff was told he had prostate cancer and was given 2 – 12 months. They were harsh words and a cruel blow – not just because the cancer was already in an advanced stage, but with the knowledge that he couldn't be operated on because he was a "bleeder".

To add insult to injury, while out on one of his fishing jaunts, a marlin leapt across the boat's duckboard, piercing his thigh. With his finger plugging the hole, Jeff was airlifted off his boat and flown to hospital, where he underwent emergency surgery to stem the bleeding. He diced death luckily, but it wasn't an easy road back for him. But it did make for a great story, with Jeff delighting in telling how the "hunter became the hunted!"

Determined not to let the cancer get the better of him – well not immediately anyway – Jeff and Sandi turned their home into a healing juice centre, their vegetable garden sprouting row after row of carrots and other veggies, which Sandi faithfully juiced for Jeff to drink twice a day.

He had a surprise in store as well. Proving his lack of finesse in the kitchen, all was forgiven when Jeff proposed to Sandi with an engagement ring served atop a tomato on a toasted muffin he had well and truly "cooked" for her breakfast. Apparently trying to get the ring inside an egg didn't work!

The couple married in a magical ceremony – a wonderful celebration of people and love – the reception in the primary school hall on the shores of Ngunguru where Jeff and Sandi lived.

Since their wedding, the couple have made the most of every opportunity to get out and about on their boat, and to travel around the country to be with friends and family.

Last year's work Christmas party was to be Jeff's last and he made it a good one, taking everyone on a magical mystery tour in a bus destined for ten pin bowls and a trip to Mangawhai and the local hotel. Back on the printing floor at work, the party continued, Jeff back in front of the Christmas tree, leaning on his now constant crutch and handing out gifts to his workers. But despite his obvious pain, Jeff wasn't going to give in and retire early. His glass of red stayed topped up throughout the night and he hung in – and out – with everyone just as he has always done.

It was after midnight when Jeff and Sandi retired to the gypsy campervan parked just outside the door. Despite having quite severe hematuria and crippling bladder spasms, the next day they were off on yet another adventure, a trip to National Park where Sandi took the wheel of a manual 6 berth campervan. The trip resulted in a tour of every hospital that started with a 'T' Tokeroa, Taupo, Taumararua and so on... These small rural hospitals were in

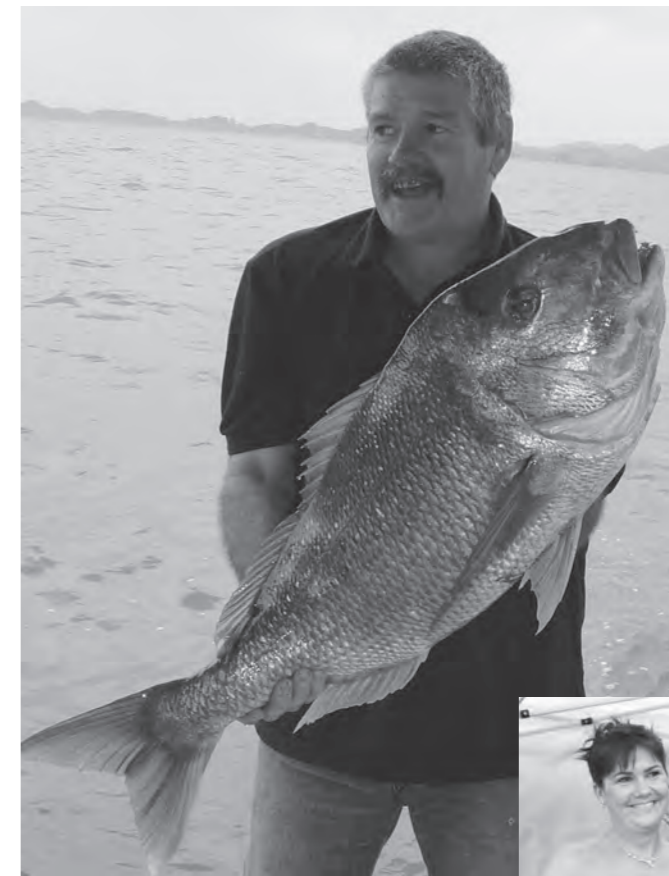
awe with the independence that this couple had and Sandi was frequently asked if she was a haematologist!

Jeff loved his launch 'Isobar' and in January just three weeks before he passed Sandi and Jeff took Isobar on what was to be their final voyage together. Jeff's hip had partially collapsed due to haemophilia problems and the cancer had taken toll on his liver and kidneys but in true Jeff style he displayed sheer guts and determination and propped up in a chair in the corner of the cockpit with Sandi close by his side ensuring he came to no harm, together they caught Jeff's last snapper.

On the morning of 23 January 2011 Jeff lost his battle with cancer and passed away peacefully surrounded by Sandi and his immediate family.

You can't put a value on friendship – and while we take all of our own memories with us when we go – it's good to know that everyone you have touched in your life is left with just that little part of a person in their heart.

Jeff Oliver - once a legend, always a legend.



Jeff & Sandi on their wedding day



Dates to Note

31 July

Canterbury Family Fun Day
Halswell Domain, Christchurch

27-29 August

Adult Wellness Weekend
Wellington

12-14 August

Parents Empowering Parents (PEP) Programme
Christchurch

9-11 September

Central Winter Escape

20-22 October

2011 Australia New Zealand Haemophilia Conference
Sydney, Australia

23-24 October

Australia and New Zealand Inhibitors Workshop
Sydney, Australia

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

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