

Newsletter of the Haemophilia Foundation of New Zealand Inc



Teen & Yoth  
Camp 2011



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of Good  
Footwear



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Staying  
Healthy with  
vWD



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When children receive care for haemophilia and other bleeding disorders, clinicians involve parents and caregivers with the decision making processes as much as possible.

In contrast, late adolescents/ young adults are encouraged to make independent decisions when managing their bleeding disorder. How can this transition from paediatric to adult care be made easier?

Where possible, try to set your life and career goals to maximize your potential – while many physically demanding career paths are difficult for anyone with joint issues, that doesn't mean exercise should be ruled out altogether!

Read and learn as much as possible about your bleeding disorder – your care is not just affected by how your clinician treats you, but how well you provide information about the bleeds you are having for example.

Discuss your activity timetable openly with your treaters – you may need to modify your treatment schedule in order to keep participating fully in your many life activities.

While you are not required to disclose your disability as such, in some cases, you may need to discuss your situation with your current or potential employer as well as a potential partner. Think ahead about strategies to do this. You can always consult with your outreach worker or treater to discuss.

Moving the responsibility from parents and taking personal responsibility when shifting from paediatric to adult care can be an uneasy time for both the individual and the parents. In the end, if you want the rights you need to take the responsibilities.

**Deon York**  
**HFNZ President**

Adapted from: [http://www.wfh.org/2/5/5\\_6\\_Youth\\_Issues\\_HWDec2010.htm](http://www.wfh.org/2/5/5_6_Youth_Issues_HWDec2010.htm) by Alison Street, Vice-President Medical, WFH.

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## Our Teen & Youth Have What It Takes

*HFNZ held our latest Teen & Youth Camp over the weekend of 14-17 January at YMCA Camp Adair in the Hunua. 12 Teens and 12 Youth took on the challenge of the 'boot camp' theme and proved they really have what it takes to meet the challenges of growing up with a bleeding disorder.*

Before even settling into their bunks, campers were put through their paces at the NZ Army Centre at Arch Hill and picked up some army-style leadership tips. This was after they were issued with their boot camp kit, including t-shirts and caps made by Hurell Apparel in Christchurch. Throughout the weekend campers enjoyed activities such as camouflaged laser paintball, rifle shooting, the amazingly high super fox, the strategic crate challenge, raft building and kayaking. The physical activities focused on team work and communication and allowed each camper to show their strengths.

Camp is also a chance to build on knowledge about bleeding disorders and how to successfully deal with some of the challenges they present. On the opening night inspirational speaker Cam Calkoen spoke about goal setting, overcoming setbacks/challenges, and how your attitude makes the difference. His main message was 'We are who we are, we have one life, so let's live it to the max!' On Saturday, Dr Laura Young from Auckland had a great session on compliance, the importance of prophylaxis and what to expect from your treatment centre as you transition to being an adult. That afternoon Sarah and Hemi Thomas hosted a quiz on being healthy and the teens had the chance to 'ask the experts' – the Youth - any questions they might have. On Sunday some of our haemophilia nurses took centre stage. BJ Ramsay from Wellington had a session with the campers with mild haemophilia and vWD

and Marry Brassler (Auckland) and Daryl Pollock (Palmerston North) helped those with severe haemophilia brush up on their self-infusion technique. On Monday morning the campers had a terrific interactive session with Ian D'Young, haemophilia physiotherapy practitioner, on physiotherapy, exercise and sport.

The Youth had time for themselves both on Saturday evening and most of Sunday when they were sent away on a Survivor Challenge. They had to complete a number of strategic challenges, including deciphering messages and swimming in the Hunua Falls. They were able to earn immunity idols which they used to save lives during a quiz. Getting everyone together to work as a team laid the groundwork for later discussions on setting up a national HFNZ Youth Committee. More on the Youth Committee is featured on page 3.

Despite a tummy bug unsettling some of the campers, everyone who attended had a really great time and made the most of getting together with their peers. Although the activities are always fun and the education side of things helpful, the real benefits and best remembered parts of Teen and Youth camp is spending time with others with bleeding disorders.

Thanks to all the helpers, supporters and to our main sponsors Bayer Healthcare.



*I found the activities very fun for my age-group, especially the crate-challenge and the raft building. The laser-strike [Pulse Ranger Combat Challenge] was good too. I enjoyed hearing from the speaker on the first night [Cam Calkoen] who spoke about his life and I also enjoyed having the physio come and talk to us.*

*Thanks Colleen and co for organising this camp.*

**Andrew Scott (Age 10)**



## Our Teen & Youth Have What It Takes...

I just wanted to say that I'm really glad that I went to the camp - it was a fantastic experience. I was happy to meet others in the same situation as myself! I enjoyed the army activity and the other activities and was thrilled as to win a medal in the corporate challenge - survivor! Looking forward to the next time. . .

Michael Stevens (Age 20)



...thoroughly enjoyed all the activities and challenges and meeting new people with von willebrands & Haemophillia.

Tom Watson (Age 16)



"As a Mum and Dad sending their wee lad away on a camp with no contact with us was big, he has come back with a new swagger. Liam really enjoyed the army activities and has a new obsession with models, he has completed the tank and moved on to an airplane and has more plans to get Dad back to the model shop. The information about haemophilia is definitely getting in, so I believe the mix of fun and education is fantastic".

Lisa Habershon, mother of Liam, aged 10 years.

# Introducing the HFNZ Youth Committee

By Karl Archibald, HFNZ National Youth Delegate

The attendees of The National Teen & Youth Camp had a great chance to discuss and create a structure for the NEW National Youth Committee (NYC).

**NOW The big Question....**

**ARE YOU AGED BETWEEN 18 & 30?!!!**

Because now is a great chance to stick your hand up prior to the National AGM on 26 March to be a part of the newly formed HFNZ Youth Committee!

If you are selected as a regional Youth Delegate you will have the chance to attend meetings in different parts of NZ in order to help decide on pressing youth issues. Some of your roll could involve:

- Potentially deciding how to benefit new parents, who may be unsure about challenges their children may face when growing up with a bleeding disorder.
- Deciding and arranging Youth specific activities.
- Creating an Awesome World Haemophilia Day experience on April the 17th
- Being a vital part of the future of HFNZ

Even if you do not become a regional youth delegate or if your region already has one (to find out all you need to do is ring the National Office and they will give you the details for your regional Committee)

we still want you to be part of the Youth Committee or you can become a secondary delegate and be the lifeline if your regional delegate cannot make national meetings. You are also more than welcome to attend any regional meetings that may be had.

Undoubtedly some of you may be thinking "I'm at uni... I have orientation to contend with... I have a social life... I don't have time, with work and every thing else!" Well the great thing is this role is not very time consuming. Once every 3 months you will need to attend 2 meetings, 1 for your region and 1 for the youth.

You will be giving a little, and yet helping so many, and it looks epic on your CV.

If you have any questions, please send me a Txt or Email, I will be more than happy to answer any of them.

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You can also find us on:  
[www.Facebook.com/hfnzyouth](http://www.Facebook.com/hfnzyouth)



give  
a little

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# Involve Your Child Early in their Healthcare

*Like learning to read or ride a bike, taking responsibility for your own healthcare is an important part of childhood development. By starting early, you can help your child with a bleeding disorder become more responsible for his or her treatment and begin building his/her involvement over the years.*



Traditionally, parents or guardians and doctors were the only two parties involved in making health decisions for children. There is now a shift to better involving children in decision making when it comes to their health. Involvement in health care may give the child a sense of control and ownership over a decision, positively impacting the medical experience.<sup>1</sup> Children should be encouraged to participate in decisions that affect their medical care as soon as they are able to communicate.<sup>2</sup> Of course involving children does not mean excluding parents, whose support children usually need, nor giving children the final say. Rather, it means involving children at a level that matches with their development, experience, and desire to participate, while affirming parents' responsibility.<sup>3</sup>

The first step is of course to teach your child about their bleeding disorder, including treatment and expectations. This should be age appropriate. As they grow and understand more about their condition, children should be given the opportunity to express their views and have these taken into account. Finally, young people can be respected as primary decision-makers, who still function in a partnership with parents or guardians and clinicians. The level of involvement will be determined by complexity and the significance of the decisions. For example, the child cannot decide not to have his prophylaxis, but may get to choose which arm to infuse.

Family members, friends and others your child interacts with daily can be important contributors to your child's educational development for living with haemophilia. Reassure your child that he's not solely responsible for his healthcare – that many people care and want him to be healthy.

Consider these tips for involving your child early<sup>4</sup>:

- Explain the condition in simple terms and use pictures (see right or ask your Outreach Worker).
- Provide a sense of control and involvement by giving realistic, age appropriate choices. For example:

- > Let your child decide to be infused on the left or right arm or hand
- > Let them choose whether they sit up or lie down if appropriate
- > Have them to hold the plaster or choose one vein over another
- > Ask them to help with record keeping
- Talk with your child about early signs of bleeding.
- Teach your child about activities that are safe and then allow him/her to participate in decisions about which to say yes to.
- Understand your child's individuality
  - > Is he an introvert or extrovert?
  - > How does he describe his haemophilia?
  - > Which of his friends know?
  - > How will he say "no" to danger?
  - > Rehearse saying no as what words will he use?
- Get involved! Resources can be found in many places, such as HFNZ, your treatment centre or the internet.

A new study found that boys ages 13-20 were misinformed about haemophilia.<sup>5</sup> Here are a number of resources to help educate your child or teen about their haemophilia so they can remain healthy throughout their lives.

- The World Federation of Hemophilia's Hemophilia in Pictures is an animated education program that provides an interactive way to learn about haemophilia ([www.wfh.org](http://www.wfh.org)).
- Your haemophilia treatment centre and the great staff there are valuable resources for families.
- HFNZ provides education, research, and advocacy on behalf of people with bleeding disorders. Visit the website [www.haemophilia.org.nz](http://www.haemophilia.org.nz) for information or see the activities in the Kids Corner.
- HFNZ has a number of programmes developed for youngsters, including the annual Children's Education Days, New Families Camp and Teen Camp.
- Parents Empowering Parents (PEP) is a programme designed to promote effective parenting skills to parents of children with haemophilia, and to provide education and support. The PEP programme is designed to enhance the 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 provide the parent with the skills necessary to effectively parent the child at the earliest age possible. HFNZ will be running a third PEP programme later in the year.



- There are several books and resources available to help parents teach their children about haemophilia, such as Raising a Child With Hemophilia: A Practical Guide for Parents by Laureen Kelley. Contact your Outreach Worker if you would like books or other resources.

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## New feature! PEP Talk

### Tips and reflections on raising children with a bleeding disorder from the NZ participants of Parents Empowering Parents (PEP) programme.

*PEP Talk is a new feature in Bloodline. Developed initially in the USA, Parents Empowering Parents (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. Two PEP programmes have been run in New Zealand, as well as a Re-PEP refresher workshop last year. Each PEP Talk will feature a guest writer from among the former participants or leaders of the NZ PEP programme who will offer a few words of wisdom from what they learned in the programme and how that is working in their home lives. Our first contribution comes from Jo Turner of Nelson.*

### Three Family Golden Rules

Recently I came to the realisation that the skills I'd learnt and adapted so well for my children after coming home from Re-PEP had started to slide and some of the old behaviours we'd worked so hard to change were sneaking back into our otherwise enjoyable time together.

Luckily, I knew I had three fail-proof skills that my youngest knew and understood, and indeed thrived on; the **three golden rules**. Fewer rules lead to fewer arguments. When there are too many rules, children tend to forget them. **The three golden rules** are simple and easy to adhere to once put in place.

- **Do not harm yourself,**
- **Do not harm others, and**
- **Do not damage your surroundings.**

Part of having kids with a bleeding disorder is obviously making sure they don't hurt themselves, but if they do - to feel safe and secure enough to tell you if they have hurt themselves and for you to stop and be able to help. This can also count at school (where we have action

plan in place now) or at other places. Also for the kids to know, "Okay, I've been running for too long (or other exercise) and my joints are feeling it - I need to rest and look after my body". This can be dependent on age and also personal responsibility.

Do not harm others is not just about physical harm, it's also words and actions. We have a rule of sorts which is 'if you don't have anything nice to say, don't say it' which is an extension on this rule.

Do not harm your property: this means taking care of your things and other peoples as well.

The great thing about the golden rules is they apply to every child, no matter how old they are, they just might need to be applied in different ways depending at which stage your kid is at. They also form the groundwork of any specific rules that may be needed later. The golden rules also help to develop responsibility because your children must think about whether they are following or breaking the rules.

This is really a basic overview of the rules and how they can be adapted to different

ages and needs. We have revised these rules and I'm happy to say that for my kids these work very well.

*Note: The next PEP programme is taking place Friday the 12th to Sunday the 14th August. Contact your Outreach Worker if you are interested in taking part.*



Logan, Joanne's son, working on the 3 Golden Rules

# The importance of good footwear for people with haemophilia

Ian d'Young  
Haemophilia Physiotherapy Practitioner

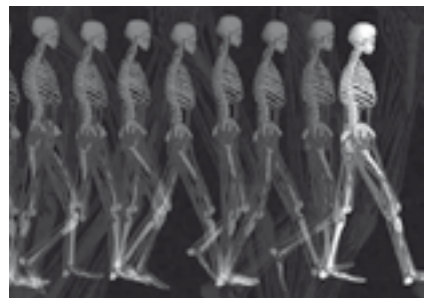


## Introduction

Good supportive footwear is hugely important for people with haemophilia and related bleeding disorders. It is an essential part of both minimising the risk of joint bleeds at the knees and ankles and managing any joint damage that may already exist because of a history of bleeding.

In order to understand why appropriate footwear is important, it is important to understand the nature of walking and the forces acting on the joints and muscles of the legs during this activity.

## Walking: a complex task



Normal walking (or 'gait') refers to the mechanical process by which the body achieves locomotion using the limbs in a series of joint movements and muscle forces that move the body in a desired direction while all the time maintaining a stable posture.

Most people achieve a 'normal' adult pattern of walking from around seven years of age, and this pattern is maintained (in the absence of lower limb joint damage) until around 60 years of age, where subtle age-related changes start to occur [Prince et al., 1997]. This 'normal' walking is referred to as a 'heel-toe' pattern: i.e. the heel hits the ground first and the toes push off to propel the body forwards.

During walking, the limb must absorb the shock arising from the transfer of weight on to the leg, while maintaining a stable position and allowing forward momentum. The leg must dissipate compressive, shear and twisting forces, adapt to changes in the ground surface and provide a rigid lever for propulsion in order to maintain this smooth, even pattern of movement [Whittle, 2002].

The symmetry and smooth reciprocal nature of walking, and the dissipation of the forces acting on the leg when it makes contact with the ground is dependent on coordinated joint movement, muscle activity, and joint position sense [Perry, 1992]. This means that each joint and muscle group in the leg is dependent on the next during walking, and this is termed 'coupling'. What is amazing is that all of this occurs without you having to think about it!

Consider then that normal walking is like a 'chain' of coordinated joint movements and muscle forces. We call this chain 'gait biomechanics', and where there is a disruption to one link in the chain, bleeds are more likely to occur and joints that are affected by arthritis are more likely to be painful.

This is because a deviation from the normal motion, alignment and strength at a joint or muscle during walking (the 'heel-toe pattern'), exposes the joint to greater stress and load. This leads to damage to the membrane that lines the joint (the 'synovium') and therefore bleeding and joint damage [Stephensen, 2000].

This leads us to the key concept of gait in people with joints affected by haemophilia: because muscle activity and joint movement is 'coupled' at the whole limb, changes in strength or movement at one link in 'the chain' affects the rest of the whole limb: i.e. something else has to compensate. This can often lead to a vicious cycle of bleeding related to these ineffective compensatory mechanisms.

For example, if the ankle is stiff, then there is, amongst other things, a decrease in the force generated by the calf required to propel the body forwards. This means that joints and muscles around the knee and hip, or joints on the other side of the body must work harder to compensate for the affected ankle joint. This places extra load on the knee joint in particular, and in turn makes it more likely to be the site of a joint bleed.

## Poor biomechanics and joint bleeding

The majority of all bleeding within the musculoskeletal system, up to 85% of all adverse haemostatic episodes, occur within the knee, ankle and elbow [Roosendaal et al., 2000].

These joints are termed 'synovial hinge joints', because they are lined with an important membrane called the 'synovium'. This membrane produces the nourishing, lubricating fluid inside the joints.

Joint bleeds occur as a result of damage to the synovium. This membrane has lots of tiny blood vessels and when they are

trapped and torn, blood fills the joint. This is what we call a haemarthrosis.

Blood contains iron, and the release of this into the joints damages the cartilage that protects the weight-bearing surfaces of joints, and makes the synovium more susceptible to further damage, and therefore further bleeding.

When there is a normal 'heel to toe' pattern of walking, the synovium is at a relatively low risk of damage and subsequent bleeding. When there is a disruption in the normal biomechanics of walking (for example where the heel is not well aligned or the knee remains bent when the foot makes contact with the ground), then the synovium is at a much greater risk of damage.

## The ankle: an at-risk joint

Damage to the synovium that lines the ankle joint is particularly common. This is because the ankle is actually two hinge joints, one on top of the other, that have to propel the entire weight of the body and absorb the forces of walking.

The ankle must also work in concert with a complex system of joints in the foot, as well as adapt to changes in the ground surface. This means that the ankle is a relatively unstable joint, and where ankle mechanics are poor, the synovium that lines the joint is more susceptible to damage, and subsequent bleeding into the joint cavity.

Let's look at one or two examples you may recognise. People who 'over pronate' the forefoot tend to be at a higher risk of ankle bleeding. Pronation is a normal movement at the foot during walking, however when this is excessive (often recognised in patients by the appearance of a flat foot or low 'medial' arch), it forces other structures at the ankle joint to compensate, making the synovium more susceptible to damage.



# The importance of good footwear for people with haemophilia...

People who have flat feet, wear jandals a lot, or alternatively women who wear high heels, tend to 'over pronate' the forefoot. It is important that if you recognise some of these issues in your own feet that you select a pair of footwear that helps to support and correct this 'over pronation', in conjunction with advice from your physiotherapist.

## The vicious cycle

Let's look at another example. When a bleed occurs at the ankle, the joint fills with blood and it is painful to walk on. Because of the extra fluid inside the joint, the body quickly adapts the pattern of movement at the whole leg to compensate for this painful joint: i.e. you limp or cannot put weight on the limb.

In response to this altered pattern of movement, muscle strength and joint movement change at the whole limb. If the bleed is not rehabilitated and the strength/ movement do not return to normal, then many of these subtle changes persist, even after the bleed appears to be settled. When these changes persist, the synovium is exposed to more stress and is damaged more easily, leading to further bleeding and accelerated joint damage.

## Footwear

*"Good shoes that fit well can be found in most shops and do not need to be manufactured individually"* [Heijnen et al. 2000].

So what is the best footwear for a person with haemophilia? This can be a very difficult question to answer as every person is different and will have their own unique set of requirements, however here are some 'top tips':

- A good shock-absorbing pad, especially under the heel, is important. Most types of sports shoes will have this built in.
- A support for the medial arch – many sports shoes will also have this built in, however you will need to check that this is at an appropriate height and you may need to consider putting an extra 'insole' into the shoe to support this part of your foot.

- A good, firm supportive upper around the heel that comes up to the bony points on either side of your ankle (the 'malleoli'). This needs to be firm and well fitting to keep the heel in the correct position when your foot makes contact with the ground.

- A firm sole that keeps the foot stable but has some spring in it – most modern sports shoes have this type of sole.

- The shoe needs to fit your foot correctly – not too tight, but also not too loose – if the shoe is too loose then it does not give support.

- Your shoes should have laces – Use them!. If your laces are not tied firmly then your shoe will not provide you with any protection.

- Many men with existing ankle joint damage find a 'sports walking boot' very comfortable: these tend to combine the arch support/ shock-absorbing heel pad of a sports shoe with an upper that comes over the ankle like a boot and provides good side-to-side support for the ankle.

- Many sports shoe retailers now offer an assessment of your walking pattern to help you find the right type of shoe. These assessments can often be useful.

- Remember, shoes wear out! A pair of shoes that is several years old and is looking a bit tatty is unlikely to be giving you any significant support.

- You may need an assessment by your physiotherapist to help you select the correct footwear. Your physiotherapist can also make a referral for orthotics to be made that suit the contours of your foot and can be inserted into your shoes if extra support is required.

- Remember, if you are used to walking in a certain way, it can often take a while to get used to new shoes or insoles. Be patient, but remember to report any problems you are having. Most people need to wear new footwear for at least two weeks to get used to them.

## And a few final points...

- People with a moderate or severe bleeding disorder in New Zealand who belong to the HFNZ are extremely fortunate to have access to financial support for footwear. Those with a mild

## The importance of good footwear for people with haemophilia...

bleeding disorder but who have a clinical need can also access the programme with the written support of their clinician. It is important to use this support wisely.

- If you have a history of bleeding into a knee or ankle joint, or joint damage because of previous bleeding, it is advisable to avoid wearing jandals (or high heels for that matter!).
- Remember to adapt your footwear to suit the terrain: if you are going for a walk in the bush on an uneven track do not wear thin canvas tennis shoes!
- There are many 'fads' in children's footwear (in particular). Avoid the current trend for 'heelies'. These are children's shoes that have a wheel inserted into the heel, and are very destabilising for the ankle.

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## HFNZ Beneficial Programmes Update

### Swimming & Exercise Programme

The criterion for access to the Swimming & Exercise Programme has been changed so that only people with clinical need (i.e., those with severe and moderate haemophilia and those with type 3 vWD) will have automatic access to the Programme. People with mild haemophilia, types 1 or 2a/2b vWD or other bleeding disorders can still access the Programme, but they must have a letter from their clinician, physiotherapist, or haemophilia nurse stating that there is a clinical need related to their bleeding disorder. The Swimming & Exercise Programme is now in line with the Supportive Footwear Programme.



### Supportive Footwear Programme

The criterion for access to the Supportive Footwear Programme remains the same. The programme is open to people with significant bleeding disorder (moderate or severe haemophilia or type 3 vWD) or with a clinical need. People with mild haemophilia, type 1 vWD, types 2a or 2b vWD or other bleeding disorders require a letter from their clinician, physiotherapist, or haemophilia nurse stating that there is a clinical need related to their bleeding disorder to be able to access the programme.



Supportive Footwear vouchers are available for either Hannah's or Rebel Sport. Please take note that vouchers can ONLY be used for the purchase of 1 pair of supportive footwear. Any other items purchased are your responsibility.



### Defensive Driving Programme

The Defensive Driving Programme remains open to all our members who have a bleeding disorder, regardless of severity, or are the primary caregivers responsible for driving a vehicle that a person with a bleeding disorder travels in.

Please note that you or your family must also be current financial members of HFNZ to access the above Beneficial Programmes. If have questions or would like to access any of the above programmes, please contact your local Outreach Worker.

## John Carter named in New Year's Honours List



HFNZ congratulates Dr John Carter for becoming a Member of the New Zealand Order of Merit (MNZM) for his services to medicine. As Clinical Leader for Wellington Hospital's Blood & Cancer Centre his long time dedication to patients and research was recognised as part of the New Year's Honours List.

Carter is a clinical haematologist who holds joint appointments in Wellington with the University of Otago and the Wellington Hospital Blood and Cancer Centre, where he is Clinical Leader. He was responsible for establishing the Wellington bone marrow transplant programme 20 years ago and more

recently led the reorganisation of the national Blood Transfusion service.

Carter has been treating patients with haemophilia since the early 1980s. In this era of 'the doctor always knew what was best', Carter was unique in trying to involve patients in clinical decision-making. In the mid-1980s, he was aware that the health and care of people with haemophilia in the Wellington region was not all it could be, and called a meeting with patients to try to identify priorities and issues that could be improved. Using the community in planning or service evaluation was a bit of novelty in the health service of the time, and led to a strengthening of the relationship between the hospital and the patients.

On behalf of his patients with bleeding disorders, we commend Dr Carter on the recognition for his services to medicine.



Dr John Carter with a few of the other members of the HFNZ Medical Advisory Committee, circa 1999 (Paul Harper, Mary Brassier and Elizabeth Berry)

## Staying healthy with vWD



It's another new year, and after a holiday season packed with the yummiest things in life, how many of you resolved to be healthier or lose weight. If you did, you're in good company...studies show that for most women, losing weight is their number one resolution, followed by exercising and improving relationships. For many women, the path to good health is not an easy one, with plenty of roadblocks along the way. Procrastination, family obligations, work demands, and lack of time and energy are only a few culprits that can stop the best of health resolutions in their tracks.

Being healthy is about more than what you eat and how much you weigh though, especially if you have von Willebrand Disorder (vWD). A few good habits can make a difference, both to the way you feel and how much your bleeding disorder

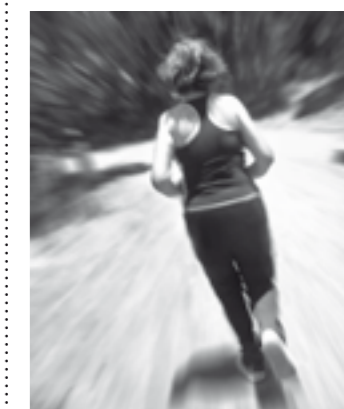
impacts on your life (and could possibly help with how your favourite jeans fit).

### Staying physically fit

Exercise is one of the few activities you can do that can improve every aspect of your life, body and mind. It is important that all people with vWD engage in regular exercise to keep healthy and keep their muscles and joints strong. Being in good physical condition can actually reduce the number of bleeding episodes a person has, especially in Type 3 vWD. Maintaining a healthy weight, and muscle training and fitness all act as a protection against bleeding.

People with mild forms of vWD can usually participate in most sports and activities. Some people with severe Type 3 vWD may need to avoid high-risk, contact sports like rugby, hockey, and skiing, which can lead to serious bleeds. Lifting heavy weights may also not be safe activities if you have bleeding problems. Some safe exercises and activities are swimming, biking, and walking. Many women who resolve to become more physically active think of going to the gym. They tend to hit the aerobic machines or join group exercise classes. They may get discouraged easily because they don't achieve desired

weight loss or muscle tone in a certain time frame. They may quit because of lack of time, energy, or money. Or, they may tire of the gym atmosphere. But exercise does not have to be done a certain way, at a certain place, at a certain time, and for a certain amount of time. There are plenty of ways to keep active – from walking the dog, to trying yoga or pilates, or playing with the kids. Try working in some type of resistance training. Most women do not get enough of this valuable type of exercise which can not only help better manage weight, it can also improve endurance, maintain the flexibility of joints, and reverse age-related declines in strength, bone density and muscle mass.



Regular exercise has many benefits

In the end, a person with vWD will have to find out for herself/himself what physical activities he/she can or cannot do. The specialists at a haemophilia/bleeding disorder treatment centre can assess each individual and make recommendations on which activities are appropriate based on his/her condition.



Remember to always stretch before and after

For people who have more severe types of vWD, prophylaxis might be necessary to achieve necessary factor levels prior to higher-impact or higher-exertion sports. Always use appropriate gear for the sporting activity; for example, helmet, knee and elbow pads, running shoes with good

ankle support and shock absorbent heels. What people with vWD want to avoid is bleeding into the joint. Not only is it painful, but it can also be problematic. The long-term consequence is that the blood in the joint is very destructive to the joint itself. You can end up with long-term and permanent joint damage. Although recurrent joint bleeding and development of chronic joint disease are predominantly seen in type 3 vWD patients, a small number of patients with type 2 vWD experience recurrent joint bleeds and develop chronic joint disease. This is extremely rare in type 1 vWD.

Prompt treatment of injuries is important. People with vWD who have sports injuries should use the P.R.I.C.E. protocol (protection, rest, ice, compression and elevation) and immediately contact their treatment centre to determine if medical treatment is necessary. Don't downplay injury. Playing through injuries so you don't miss practices or games can cause more problems and set you back further in your recovery. Rest after a joint or muscle bleed to help healing and prevent another bleeding incident and always stretch before exercising. Know your body and put it first.

Another benefit of regular exercise is the raising of the von Willebrand factor (vWF) levels. When you undergo periods of stress, like you do in moderate- to high-intensity exercise, your body actually has a reaction where it releases and increases the level of vWF in your blood. When you exercise, it causes that vWF factor to be released in the blood, raising the circulating factor level.

According to some research, some women who engage in sports frequently might gain an additional benefit from the exercise - a reduction in heavy bleeding during their menstrual cycles. If heavy menstrual flow is preventing you from participating in sports or fitness activities speak with your treatment provider about additional treatments and options.

Maintaining a healthy weight is important as being overweight increases the stress on knees and ankles and may augment the risk of a bleed in these joints. On top of all that, additional benefits of regular exercise include protection from heart disease and diabetes, lower high blood pressure, improved sex life and it can even make you smarter! Studies have shown that people who exercise during the day perform better, manage their time more efficiently, and are mentally sharper. So have a stretch and get out there!

### Avoid certain medications



To prevent bleeding and stay healthy avoid over-the-counter medicines that can affect blood clotting. Certain drugs affect the way platelets plug holes in blood vessels. A person with vWD should never take drugs containing:

- aspirin (ASA) and other drugs containing aspirin (Alka-Seltzer, Aspirin, Dristan, Midol, to name just a few). A single dose of aspirin will affect platelets for 5 to 7 days.
- non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Nurofen) and naproxen, unless prescribed by a physician knowledgeable about vWD.

Unfortunately, these drugs are often prescribed for dysmenorrhea (menstrual pain). They can make the bleeding, and thus the pain, worse. Drugs containing paracetamol can be used for fever, headaches and minor aches and pains. However, large doses beyond the levels prescribed on the label should be strictly avoided. They can cause damage to the liver, especially in people who are hepatitis C-positive.

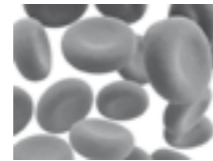
A new generation of anti-inflammatory drugs, called Cox-2 inhibitors, is now on the market. These drugs do not affect blood clotting, and seem to cause less irritation to the stomach.

Chinese herbs or supplements can also increase bleeding, so always check with your treatment centre first.

Blood thinners such as warfarin or heparin should be avoided.

Always check with your doctor before taking any medicines. Consider wearing a medical ID bracelet if you have a severe form of vWD.

### Replenish Iron after Anaemia



Blood loss, whether acute or chronic, can lead to anaemia. For people with bleeding disorders, anaemia is avoidable. There are ways to diagnose, treat and prevent it. Although there are several types of anaemia, iron-deficiency anaemia and haemolytic anaemia are the more common forms of anaemia in people with bleeding disorders.

Treatment for anaemia depends on the cause. Physicians need to assess whether the anaemia is due to a dietary deficiency, iron loss or inability to take iron. People with bleeding disorders are not immune to having dietary anaemia. It is recommended that people with bleeding disorders eat foods that are higher in iron, such as leafy green vegetables and meats.

After being diagnosed with anaemia, your doctor might recommend trying ferrous sulphate, an oral over-the-counter iron supplement. Since iron supplements can cause constipation or upset stomach, you should test brands to find one you can tolerate. How long a person takes iron is another matter. It can take up to a month or longer for iron stores to be rebuilt and to

prevent the return of anaemia. Some women can be chronically anaemic from heavy periods and may need to stay on long-term iron therapy until bleeding is managed or stops with menopause.

Iron injections are usually recommended for patients who have lost a large volume of blood or who cannot absorb iron taken orally. They are delivered to

### Do's and Don'ts of Iron Supplements

**Some foods, vitamins and medications can affect iron absorption. Consult your physician before you take iron supplements. These suggestions can help you get the most out of your supplement and avoid problems.**

#### DO

- Increase your intake of iron-laden foods, such as green leafy vegetables, dried beans and peas, lean meats, citrus fruits and iron-fortified cereals.
- Plan ahead. Taking your iron supplement one hour before meals increases the absorption rate.
- Take your supplement with a vitamin C supplement or orange juice, which increase absorption. Mega-doses, however, can cause excess absorption.
- Wait at least two hours after taking antacids or certain antibiotics, such as tetracycline or penicillin derivatives, before taking your supplement.
- Tell your physician that you are on an iron supplement. It can produce false positives in tests identifying blood in the stool.

#### DON'T

- Drink caffeinated beverages within an hour of taking your supplement. Coffee and tea can decrease absorption by 50% to 60%.
- Take your supplement with milk or calcium supplements, which decrease absorption.
- Leave your supplements within reach of children. Accidental overdose of iron-containing products is a leading cause of fatal poisoning in children younger than 6 years old.

the bloodstream, building red blood cells quickly.

Many women live for a long time with undiagnosed anaemia due to heavy menstrual bleeds. If you suffer from frequent fatigue, weakness, shortness of breath, lightheadness, palpitations, or looking pale, consult your doctor to be tested.

### Keep Hydrated



Buy a portable drinking vessel and keep it filled with water. Keeping yourself properly hydrated lessens the frequency of headaches and joint aches. As a bonus it can also keep your appetite at bay (to help with those New Year's resolutions). People with bleeding disorders who are properly hydrated are also more easily infused.

You may also want to avoid drinking alcohol. Alcohol affects platelet function, which can cause bleeding to occur more easily.

### Managing your condition

Lots of women live with a bleeding disorder and manage it well. They may bruise a bit easier and get heavier periods, but it is not the end of the world, and doesn't stop them from doing what they want. However, if menorrhagia is a problem for you it is important to seek help from your haemophilia treatment centre. Staying healthy and well with vWD also involves being prepared. Having your medication at hand, carrying bandages for cuts, scrapes, and accidents, and pads or tampons for your period are ways to help you manage and not let it slow you down.

Having a good relationship with the nurse at your treatment centre or your haemophilia Outreach Worker is a very useful source of support. Many women with vWD find that speaking to others with the same issues also helps.

Chances are you are related to someone else with vWD, but HFNZ events are another great way to meet others who share your symptoms and concerns.

So although it may be well and truly into 2011 by now and a little late for New Year's resolutions, it's never too late to develop a few good habits to live healthier with vWD.

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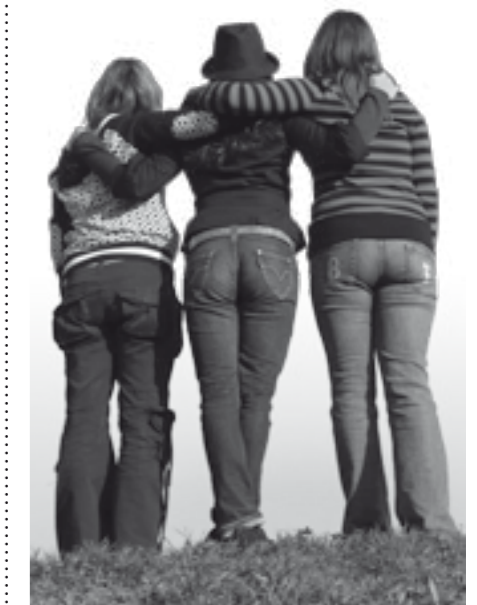
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World Federation of Hemophilia [www.wfh.org](http://www.wfh.org)



Sharing your concerns lightens the load

## Australian study shows significant fibrosis and cirrhosis in haemophilia patients infected with HCV

A letter featured in the early view online edition of Haemophilia, has reported that the majority (53%) of patients with haemophilia studied showed signs of at least significant fibrosis. The researchers assessed the prevalence of significant liver fibrosis and cirrhosis in patients with a bleeding disorders and HCV (with or without HIV infection) from a single haemophilia centre in Melbourne using transient elastography (FibroScan). Of the 61 patients, 59 (97%) had successful liver stiffness measurements (LSM). The mean age of patients was 45 years and bleeding disorders included haemophilia A (76%), haemophilia B (12%), von Willebrand's disorder (10%), and factor VII deficiency (2%). All patients were assumed to have acquired HCV from the mid 1970s to 1992. Over half (n=31, 53%) had LSM suggestive of at least significant liver fibrosis (more than F2 METAVIR stage) based on established cut-off criteria. Of these, 12 (20.3%) had LSM suggesting F2, seven (11.9%) F3 and 12 (20.3%) F4 or cirrhosis.

Until their Fibroscan, many of the patients had not been recognised as having significant or advanced state liver fibrosis and at risk of complications without treatment. The research highlights the utility of FibroScan in the management of patients with bleeding disorders and HCV.

The researchers go on to suggest a plan for investigating and managing patients with HCV, that routinely includes the performance of FibroScan. They recommend that all patients who are HCV RNA positive (or PCR positive, i.e., have an active viral infection) should have viral load plus genotype testing, full blood examination, liver function tests, international normalized ratio and liver ultrasound. If their FibroScan score is less than 7.5 kPa these patients should consider antiviral therapy and if over 7.5 kPa antiviral therapy is strongly recommended. Following antiviral therapy, all PCR negative patients should have repeat PCR testing and FibroScan performed, with ongoing liver ultrasound

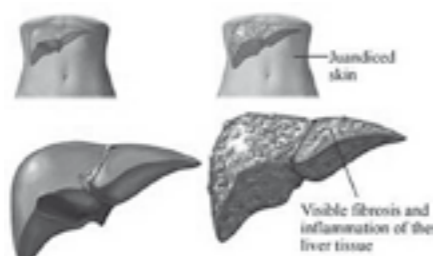
monitoring of those with high (10 kPa) liver stiffness measurement. For PCR negative patients with LSM less than 10 kPa they suggest discharging from the hepatitis clinic after 2-3 years. The patient's haemophilia treatment centre should be notified of changes.

## Understanding your fibrosis score

Sometimes it seems we're surrounded by all kinds of scores. For example, credit scores, sports scores, even joint function scores. If you have chronic hepatitis C, you may also have a fibrosis score, which assesses the health of your liver.

Liver fibrosis refers to the accumulation of tough, fibrous scar tissue in the liver. Formation of scar tissue is a normal bodily response to injury, but in fibrosis this healing process goes wrong. Light, moderate, or severe scarring of the liver (fibrosis) can eventually lead to even more severe scarring of the liver called cirrhosis. Early fibrosis can be difficult to diagnose because it often doesn't have any specific symptoms. But as inflammation and liver injury continue, scar tissue builds up and can disrupt the metabolic functions of the liver. If the disease progresses it can lead to cirrhosis, a condition in which the liver is severely scarred, its blood flow is restricted and its ability to function is impaired. In some people, cirrhosis can progress to end-stage liver disease or give rise to liver cancer.

The damage caused by hepatitis C is not linear – this means that once fibrosis and cirrhosis starts to develop, the progression of liver disease speeds up. In other words, it may take 10 years to progress from one degree or stage of liver damage to another, but the next increase in the amount of damage may take less time – say 7 years. Progression to the next



Healthy liver versus liver with fibrosis



FibroScan© machine

stage may only take 5 years and so forth. HCV treatment can help to reduce, slow down or stop or even reverse the disease progression especially if HCV treatment is successful. Lifestyle changes can also help the liver to stay healthy by maintaining a healthy weight, eating a healthy diet, avoiding alcohol and drugs, moderate exercise, stress reduction, etc.

It is very important to know the fibrosis state or health of your liver so that the appropriate decision can be made for managing hepatitis C.

## What Is a METAVIR Score?

The METAVIR score helps interpret a liver biopsy. When this biopsy is performed, doctors need a reliable way to quantify what is seen under the microscope. This scoring system assigns two standardized numbers: one to represent the degree of inflammation and the other the degree of fibrosis. The fibrosis is graded on a 5-point scale from 0 to 4.

Your METAVIR score is one of many "tools" doctors can use to help determine your treatment and monitor your progress. Sometimes a score of two or greater suggests that treatment should begin. This is not always the case, because individualised treatment can also be recommended for people with a lower score.

Like most things, the METAVIR system has its strengths and weaknesses. Other scoring systems are also available, such as the Knodell Histological Activity Index (HAI).

## What is a Fibroscan Score?

Although the METAVIR score is a popular way to express the degree of damage to your liver, most people with haemophilia do not undergo liver biopsies. Instead non-invasive tests, such as transient elastography (TE), can be used to find out how much liver fibrosis – or scarring – you have. For TE, a machine called a FibroScan is used. The procedure is painless and is similar to having an ultrasound scan. However, instead of using high-frequency sound waves to create a picture like an ultrasound, FibroScan uses a series of short, pulsed, low-frequency sound waves to measure your liver stiffness. The result is a number – a 'score' – rather than a picture, which tells us how much liver scarring you have. The score is in kPa (kilopascals) which is a unit of pressure and is the reference unit used for elastography.

The score indicates different levels of liver damage depending on the underlying cause. FibroScan cannot be used to find and monitor scarring in all liver conditions, but has been shown to very useful in assessing HCV-related liver damage.

## Putting it all together

So what does this mean for you? Well, some clever people have worked out how the FibroScan scores relate to METAVIR scores.<sup>1</sup> Your FibroScan result is not just a number, it is an indication of your level of fibrosis. You can see in the table below how the scores relate to each other in HCV infection.

Table 1. Relationship between liver stiffness (kPa) and fibrosis stage according to METAVIR score in HCV.

Degree of Fibrosis	METAVIR score	FibroScan score
No Fibrosis	F0	< 7.5 kPa
Mild Fibrosis	F1	
Moderate Fibrosis	F2	7.5 - 9.5 kPa
Severe Fibrosis	F3	9.5 - 12.5 kPa
Cirrhosis	F4	≥ 12.5 kPa

If you have chronic HCV or have cleared the virus through treatment and have not had a FibroScan yet, please contact your Outreach Worker or your Haemophilia Treatment Centre. FibroScan machines are currently available in Hamilton and Auckland and require a specialist referral to access (from your liver specialist or haematologist). Transport assistance is available through ACC if you have an accepted claim with them for your HCV infection.

## Reference:

1. de Lédinghen V, Vergniol J. Transient elastography (FibroScan). Gastroenterol Clin Bio. 2008; 32: 58-67.



By Colleen McKay,  
Manager - Outreach Services

*I was privileged once again to attend the 9th Annual North American Camping Conference for Haemophilia Organisations (NACCHO), held in Phoenix, Arizona, from 27th January until 30th January 2011.*

Although primarily a North American event, in recent years Pfizer have generously funded representatives from a range of international countries, and this year I met Camp Co-ordinators from Romania, Turkey, India, Canada, Mexico, the Czech Republic, the Netherlands and England. For four days it was just so amazing to look around the room full of people (around 180 people) and think that these people are all involved with, and have a passion for Haemophilia Camps, just like me! It gave me a real sense of being part of a bigger community, all with the same goal – creating wonderful, worthwhile and educative camp experiences for children with bleeding disorders and their families all over the world.

NACCHO is a great program that focuses on teaching practices and principles of camping for kids with haemophilia. This year the theme was 'thinking like a superhero', and 'what does it take to be a super hero'; many participants came in costume, enlivening the event.

The first Session of the NACCHO Conference encouraged Camp Co-ordinators and their teams to establish three core values for their Camp. Core Values are defined as a set of concepts and ideals that guide everything that happens at Camp. These values will assist to make decisions with regards to design of the camp programme and should be summarised into the mission statement of the Camp.

The 'Leadership Tools and Techniques' session explored the challenges and opportunities of being a leader; specifically a Camp Co-ordinator. A leader is a person who uses skills to help the group identify and achieve its goals. Being a leader takes integrity, intelligence and maturity and requires discipline, relentlessness, follow through and focus. The skills of successful



Colleen McKay with haemophilia author Laureen Kelley



leaders often fall into three categories: Technical Skills, Human Relation Skills and Conceptual Skills. The various styles of Leadership were explored. The style of Leadership employed in any situation is dependent mainly on three things: the Leader, the Group and the Situation.

**'A Leader - Knows the Way, Shows the Way and Goes the Way'**

(John Maxwell, internationally respected leadership expert)

The workshop on 'What Parents Want' explored the fact that even though the children and the camps are all very unique, the things that parents want for their child's camp experience are all very similar. According to research, the top five camper benefits that are most important to parents are ranked as follows:

- Safety
- High quality role models
- Skill development (physical skills, social skills and life skills)
- New and better friends
- Fun activities

This workshop provided useful tips for developing a camp programme which addresses these top five benefits that parents have identified for their children.

'Make it and Take It' was a favourite workshop lead by team building guru Jim Cain. Jim shared his favourite, newest and best team and community building activities from around the world using a variety of portable, ground-level team challenges that build valuable life skills. In true Kiwi DIY fashion I had the opportunity to make resources to bring back for games and activities at our upcoming camps and workshops.

Our friend Laurie Kelley gave an extremely moving presentation covering the realities of living life with a bleeding disorder in a developing country. Seventy-five percent of the world's haemophilia population does not have access to haemophilia treatment. Laurie outlined 'Project SHARE' (Supplying Hemophilia Aid and Relief) and 'Save one Life'; both of these projects attempt to address some of the needs in these developing countries. 'Save one Life' is a registered child sponsorship programme, where families in developed countries are able to sponsor a child or an adult from a developing country (such as Romania, India, the Philippines, Honduras, or Belize). Sponsorship of \$20 USD per month gives extremely poor families the money for transport to the hospital for treatment, money for schooling or food. Through the use of real examples, Laurie demonstrated how this small amount of money can make a very real difference in the lives of individuals with haemophilia in developing nations. NACCHO

participants took up a collection, and collected sufficient money to contribute to two 'Save one Life' people. It was decided to choose one child from Romania and one child from India, as representatives from both of these countries were present at the NACCHO conference. If as an individual, or as a family, you are interested in sponsorship, please check out and follow the links on Laurie's website [www.kelleycom.com](http://www.kelleycom.com) or [www.saveonelife.net](http://www.saveonelife.net).

**'For a community to be whole and healthy, it must be based on people's love and concern for each other.'**

(Millard Fuller, founder of 'Habitat for Humanity')

In the session entitled 'Thematic Programming: Unifying the experience' (read using themes at Camps) Pat Torrey (aka 'Big Dog') demonstrated how using a theme can bring unity to the entire Camp / Workshop experience. Recently, in New Zealand we have been Around the World at New Families Camp, and to Boot Camp at Teen / Youth Camp, where will we go from here? Why not come along and find out!!

Thanks must go to:

- Pfizer here in New Zealand who funded my attended at this Conference; thanks to Warwick Jeffery and Eliza Glanville for arranging the sponsorship.
- Lynn Barker, Roz Witte, and the others from Pfizer in the United States for their vision and continued commitment to support NACCHO; it is the only conference dedicated to camps that serve those within the bleeding disorders community.
- Cindy Komar and the staff of the Hemophilia Association of Arizona, hosts of the conference, thanks for their attention to every detail. Thanks to the fantastic, dedicated and enthusiastic 2011 NACCHO planning committee for the amazing programme that they put together.
- To all the NACCHO participants for sharing their planning, policy, procedure and programme ideas. It is the participation, input and collaboration of the attendees that adds to the information and education making this Conference so interesting, successful and fun!

I have come back to New Zealand with heaps of new ideas for implementation into the Haemophilia Foundation of New Zealand Camps and Workshop Programme; I left the Conference feeling inspired, motivated and more prepared for the co-ordination of Camps and Workshops.

**See you at the next Camp / Workshop!**

# HFNZ Events in 2011

*So far in 2011, HFNZ have already held the National Teen & Youth Camp and we have many other activities planned. Mark your calendars and keep an eye out for invites to the following plus all the great social activities planned by your local branch. If you have any questions on any of the events or want to express your interest in attending please contact your local Outreach Worker.*

## March

**5th HFNZ Hui**  
12 March, Wellington



The 5th HFNZ Hui will take place 12 March at Ako Pai Marae at the Karori campus of Victoria University in Wellington. Some of the objectives are the election of the Takawaenga (4 Māori Regional Representatives) and the election of the Māori Representative on HFNZ National Council for 2011.

All HFNZ members who identify as Maori are invited, however please RSVP to Leanne Pearce at HFNZ National Office, 03 371 7477.

**HFNZ National Annual General Meeting**  
26 March, Rotorua



This year's Annual General Meeting is taking place at 2.30pm at the Kingsgate Hotel in Rotorua. Everyone is welcome to attend, although voting is limited to individual, family and life members. This year we are lucky to have the excellent guest speaker, Ed Kuebler, a haemophilia social worker from Texas who has helped develop both the Parents Empowering Parents programme and Step Up Reach Out youth leadership programme. A copy of the agenda will be available online before the meeting. See the listing on the Events webpage.



**April**  
**World Haemophilia Day**  
17 April

On World Hemophilia Day 2011, inspire others with your story of living with or treating a bleeding disorder and show your commitment to achieving treatment for all. This year's theme celebrates supporting positive change for people with bleeding disorders and encouraging others to do the same. By working together and inspiring each other for a brighter future, we can contribute to achieving the WFH's mission of Treatment for All. Keep an eye out for local events to celebrate.

## June



**Adult Wellness Weekend**  
24-26 June, Christchurch

After the success of the first Wellness Weekend in 2011, HFNZ will be hosting another in 2011. This year the workshop for adults with bleeding disorders will be moving south to Christchurch. Partners are also welcome to attend. The idea is a weekend where there is plenty of information on keeping healthy and well and there is also time to relax and enjoy each others' company.

Registrations of interests and programme suggestions are welcome. Contact Colleen McKay at [colleen@haemophilia.org.nz](mailto:colleen@haemophilia.org.nz) or phone 03 371 7477.

## July

**Children's Education Workshops**  
Dates TBA, One in each region



The always popular regional Children's Education Workshops will be held again in 2011, this time during the winter school holidays. These are great days for younger children with a bleeding disorder, aged 6-10, to learn the basics and have a heap of fun meeting other kids in their region.



**August**

**Parents Empowering Parents (PEP) Programme**  
12-14 August, Location TBA



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. We have had rave reviews from parents who participated in the first two programmes in 2008 and 2009.

**October**

**2011 Australia New Zealand Haemophilia Conference**

20-22 October, Novotel Sydney Olympic Park, Sydney, NSW



Held every other year, the 2011 Haemophilia Conference in Sydney will be a chance for people with bleeding disorders, their treaters and others in the industry to get together and learn the latest about haemophilia care and support. The conference will feature a number of international guest speakers.

**Trans-Tasman Inhibitor Workshop**

23-24 October, Novotel Sydney Olympic Park, Sydney, NSW

This new educational workshop is being developed to help people with haemophilia and inhibitors and their families to better understand and cope with the unique challenges they face. The workshop will be an opportunity for individuals and families affected by this reality from Australia and

New Zealand to gather, learn and enjoy time together.

**Grandparents' Day**

Date and Location TBA



The pilot Grandparent's Day in Christchurch last year was a huge success. HFNZ will be holding another programme this year in the North Island to try to reach more grandparents of a child with a bleeding disorder. Come meet others in a similar situation and get some tips on ways to support your family.

# Sustaining Patrons

**Among our valued donors are those who have become partners with HFNZ in the Sustaining Patrons Programme to provide a generous amount of ongoing non-directed funding. This funding is goes to support all HFNZ programmes and is in place for three years at a time.**

**HFNZ is sincerely appreciative of the commitment of current Sustaining Patrons to improving the lives of people with haemophilia and other genetic bleeding disorders, and for the generous additional support they provide HFNZ to help us run educational workshops.**

**THANK YOU!**



# Regional Branch Reports

**Southern**

By Theresa Stevens

I hope you all had a fabulous holiday season spent doing what you wanted to do. Since our last report Southern have held their family camp this year with a new venue at Hanmer Springs Forest Camp. Held over 4 days near the end of January, it was a really successful camp with over 60 people in attendance from 16 families.

On top of many trips to the Hanmer Springs Thermal Pools, Southern campers visited a farm park where they came into close contact with a bull and deer and a whip expert. Some campers, like Paul Stott, were able to really take part in the action. Other activities included mini-golf and a maze. During camp Olympic Games were held, each family representing a country or imaginary

place of their choosing. After opening songs and dances, everyone had a ball competing in the various events. Thanks to the organisers from the Southern camp committee, Southern Outreach Worker Linda Dockrill and haemophilia nurse Aly Inder for all their help making the camp a winner.

In December, Otago and Southland folk enjoyed a gathering with Linda at Glenfalloch Gardens on the Otago Peninsula, a great meet and greet opportunity followed by afternoon tea. Also in December, Canterbury folk enjoyed their annual function at Orana Park. Families enjoyed a BBQ lunch and a chance to visit all the wild animals.

Congratulations to all of those individuals who were sitting external exams – I hope the results reflected the effort you put in. Best of luck if you are returning to school

or venturing onwards to university or the workforce.

Recently the Teen and Youth camp was held and from what I've heard it was fabulous with the three youth I spoke to all keen to return to future camps!

We have been invited to provide volunteers for a fundraiser in March. This involves putting posters up around Christchurch and surrounding areas advertising the local Armageddon Expo in April. So if you live in the Christchurch area and have a few spare hours, please contact me or the office.

Our regional Branch AGM is being held on March 5 at the office in Christchurch. We hope to have seen many of you there and will report on the outcome in the next issue.

Take care until next time.



Southern Branch Camp 2011  
Canterbury day out at Orana Park in Christchurch >



**Midland**

The committee is busy getting ready for Midland Camp, which is being held at Totara Springs in Matamata on the weekend of 4 – 6 March 2010. It is going to be a brilliant weekend and we will report on the activities (and hopefully better weather than last time) in the next issue.

Midland is also hosting the National Annual General Meeting in Rotorua on Saturday 26 March, from 2.30 to around 5 pm. The location of the AGM is moved each year to allow people living in the different regions a chance to attend. This year's AGM is featuring an excellent guest speaker, Ed Kuebler from the USA.

We highly recommend you come down to the AGM to participate and to hear Ed. A social worker at 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 leadership programme for youth with haemophilia. He has expertise in many areas and is always interesting to listen to, we are so lucky he is visiting New Zealand.



## Regional Branch Reports

### Central

By Stephanie Coulman

The Christmas picnic in December at Palmerston North's Esplanade Park was well attended with 32 people coming together. A coffee at the café started the morning, followed by a dip in the pool for some children, presents for the children, a ride on the train and picnic lunch.

Our AGM was held at Wellington's Museum of City and Sea on 13 February. After AGM formalities members had a simple lunch and visited the Museum which celebrates Wellington's social, cultural and maritime history. It is a really interesting interactive museum and there was something for everyone.

The local Armageddon event is taking place at the TSB Arena, Wellington, over the weekend of 9-10 April and we still need volunteers from HFNZ. Duties would entail checking wrist bands, minding celebrity guests, watching exit doors, giving directions from a map, etc. Jobs are matched to age/fitness so volunteers can be all ages (16-99 years). You can volunteer for half-day, full-day or multiple days. Funds Armageddon would have paid for these positions will instead be donated to HFNZ. We can raise around \$2,000 in Wellington if HFNZ can supply full numbers.

We also need a group of people to assemble boxes of materials to send out to local schools. This job would take a small group about four hours to assemble and needs to be done in early March.

Wellington needs you! Please contact Stephanie Coulman 04 383 5752 stephtony@clear.net.nz if you can give some time.



Central Christmas Function

# News in Brief

## Positive results from longer acting Factor IX study in haemophilic mice

In February Prolor Biotech Inc reported positive results from a comparative study of its longer-acting version of the haemophilia drug Factor IX (Factor IX-CTP) in Factor IX-depleted haemophilic mice. The study was designed to measure the potential increase in clotting activity and duration of therapeutic effect of the Factor IX-CTP when compared with commercially available recombinant Factor IX. Factor IX is indicated for the treatment of acute bleeding episodes and as therapy for prevention of bleeding in haemophilia B patients.

In the study, Factor IX-CTP demonstrated a significantly longer duration of clotting activity in the mice model when compared with commercially available Factor IX. Bleeding episodes were also significantly shorter and less intense for the group treated with Factor IX-CTP. In addition, none of the animals treated with Factor IX-CTP had any spontaneous re-bleeding events, compared with a 50% incidence of re-bleeding events for the group treated with commercial Factor IX and an 83% incidence of re-bleeding events for the untreated group.

The new study results support previous preclinical studies that demonstrated significant improvements in the half-life of Factor IX-CTP compared to commercially available Factor IX.

"We believe there is great need among haemophilia patients and their physicians for therapies that will provide prolonged protection from bleeding," said Dr. Abraham Havron, CEO of PROLOR. "The encouraging [results] show that Factor IX-CTP may be able to reduce the number of injections needed by haemophilia B patients to once-weekly or less."

Prolor plan to initiate their first clinical study of Factor IX-CTP in people with haemophilia in early 2012.

Source: The Medical News, www.news-medical.net, 3 February 2011



## US National Hemophilia Foundation Launches Victory for Women Initiative

The US National Hemophilia Foundation (NHF) launched its new initiative, Victory for Women, at their Annual Meeting last November. Since most women affected by the most common hereditary bleeding disorder, von Willebrand disease (VWD), don't even know they have it, the campaign is designed to generate awareness outside of the bleeding community and empower women to seek accurate diagnosis and healthcare.

At the center of the campaign is the music video, "Victory for Women," featuring emerging contemporary musical artist, Jessica Rae, who also composed the music. Tom Jordan, an award winning creative director at Hoffman York with a

portfolio of original music, wrote the upbeat and optimistic lyrics to unite and evoke emotion among women with blood disorders. The goal of the video is for people to "spread the word" about blood disorders through the various new communications and social media channels (Facebook, Twitter, etc.) and spark concern in women to protect their bodies and to form a community in which women with these blood disorders can turn to for support.

Also featured in the video is a maroon, silk scarf that was created for the Victory for Women initiative to serve as a symbol of unity and support for women with blood disorders. To be a part of Victory for Women follow the cause on Facebook and Twitter. For more information about the Victory for Women initiative or to make a donation, visit <http://www.victoryforwomen.org>

## New Film Documents Tragedy of HIV/AIDS and Hepatitis



Produced and directed by Emmy award-winning producer Marilyn Ness, *Bad Blood: A Cautionary Tale* movingly recounts the events in the U.S. as told by the people who were infected by contaminated treatment products and their families. Although the film is told from the perspective of the United States, the reach and implications for

the global community were no less significant.

"The lessons learned from this tragic time should not be forgotten," said Mark Skinner, President of the World Federation of Hemophilia. "Never again can we take for granted the safety of the medications and treatment products on which our lives depend. Blood safety is a shared responsibility of many organizations: government regulatory bodies, blood and plasma collection agencies, blood product manufacturers and – equally important – the patient's voice, heard through the organizations that represent them and their healthcare providers."

See the film's website: <http://badblooddocumentary.com> for further information. HFNZ have purchased a copy of the DVD. It is available on loan to members from National Office.

## Blood test for vCJD moves a step closer

British scientists believe they are a step nearer to developing a reliable blood test for variant Creutzfeldt-Jakob Disease (vCJD), and say their prototype is 100,000 times more sensitive than any previous attempt. Currently patients suspected of having vCJD have to undergo a series of tests, including a brain biopsy, to confirm a diagnosis. The new test, reported in *The Lancet*, offers the chance of earlier diagnosis and potentially the ability to screen donor blood.

Further studies are, however, needed before it can be widely used to screen healthy people who may be silent carriers. vCJD is the human form of BSE – "mad cow" disease. It affects the brain and is believed to have passed from cattle to humans through infected food. Most of the 170 who have died from the long-incubating disease in the UK since 1995 are thought to have contracted it from eating infected meat in the late 1980s. But three people are thought to have died because they were unwittingly given infected blood transfusions years before expensive restrictions on donated blood and blood products were introduced. Two other people who died

from other causes were found to have vCJD infection; one is thought to have had a transfusion of contaminated blood during an operation, and the other, a person with haemophilia, to have received contaminated blood products. A previous study has suggested one in 4,000 Britons could be incubating the incurable degenerative disorder without symptoms. Without a reliable test or filter for donations, there is no way of knowing how effective existing safety measures are. Trials of a filter are expected to be completed later this year.

A team from the government-funded Medical Research Council (MRC) based at University College London, found the infectious prion agents associated with the disease in the blood of 15 of 21 samples from people known to have had vCJD and says it has detected infection in blood spiked with vCJD to within one part per 10m.

The new test could provide more information on how many people have variant CJD in the UK and be used to screen for the disease. However, further large scale studies on populations where the disease is not present would be needed before it could be used as a screening test.

Although many have questioned the ethics of telling infected people they have a disease for which there is no proven treatment and no cure, Chris James, from the Haemophilia Society said they would push for the test to be used as soon as it is clinically available: "The Haemophilia Society has long called for tests to be offered, in combination with pre and post-test counselling, to people with bleeding disorders who have been told they are at risk for public health purposes in relation to vCJD."

### Sources:

Blood test for vCJD 'could identify carriers'; [www.waltainfo.com](http://www.waltainfo.com)

Melke J. Human BSE blood test moves a step closer. *The Guardian*. 3 February 2011; [www.guardian.co.uk](http://www.guardian.co.uk)

# Get Involved with HFNZ

**Giving back can be rewarding for both your spirit and your community.**

You may consider yourself an active member in the Foundation. You've attended your last regional camp. You've helped out at a family day out. You are in regular contact with your Outreach Worker. Maybe you used to be more involved but lately other things have seemed more important.

Even as a fairly active member it's easy to feel disconnected, as you juggle work or school, kids, and activity after activity. One great way to feel a part of the community and the organisation is to get more involved with your regional committee.

Charitable giving, though important and appreciated, isn't the only way to be involved in your community. Time is often much more precious than money. It is time that HFNZ needs most from its members.

Ever wondered how all the great activities you get invited to get organised? How things are run behind the scenes? Who those people smiling up from the pages of Bloodline are?

For the most part, many activities and initiatives are the result of the work of volunteers on your regional committee or the National Council. Aside from educational programmes, they organise all the social activities in the regions, including the regional camp.

Sitting on committees or the National Council may not always be fun, but it a great way to get involved and give back to the community. You might even enjoy it (but we aren't making any promises).

## Reasons to Get Involved

- **It feels good.** The satisfaction and pride that come from knowing you are helping others are important reasons to volunteer. When you commit your time and effort to an organisation or a cause you feel strongly about, the feeling of fulfilment can be endless.
- **Meet new people.** Our regions have committees made up from a great and varied group of people committed to ensuring the Foundation operates well for the members in their regions. Even if you've been introduced to others on the committee before, this is a great way to get to know others in your region or nationally that may face some of the issues you do or have been through them in the past.
- **Keep informed.** By being involved with the governance of the Foundation you will be up-to-date on developments within the Foundation, the healthcare system and any challenges facing HFNZ. You will also gain a better understanding of how the Foundation works with others services and the government.
- **It strengthens your community.** A committee with lots of energy and participants creates a dynamic for the region and the national organisation. When a community is doing well as a whole, its individuals are better off, too.
- **Attend committee meetings.** Ok, so maybe some people consider this a great reason not to get involved but it is certainly helpful to the Foundation. The number of meetings per year varies between the regions. And hot drinks are usually provided at the very least.
- **Ensure HFNZ will continue grow and provide for future generations.** As part of a regional committee or National Council you can help set the direction for the future. The Foundation has faced many disasters and hurdles in their past, and you can help ensure that HFNZ will be strong enough to face any battles that may arise.

# Dates to Note

## 4-6 March

Midland Region Camp  
Totara Springs

## 5 March

5th HFNZ Hui  
Wellington

## 26 March

HFNZ National Annual General Meeting  
Rotorua

## 17 April

World Haemophilia Day

## 24-26 June

Adult Wellness Weekend  
Christchurch

## 12-14 August

Parents Empowering Parents (PEP) Programme  
Location TBA

## 9-11 September

Central Winter Escape

## 20-22 October

2011 Australia New Zealand Haemophilia Conference  
Sydney, Australia

## 23-24 October

Trans-Tasman Inhibitors Workshop  
Sydney, Australia

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

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

**Be inspired, get involved in Treatment for All**

WORLD FEDERATION OF HEMOPHILIA  
FEDERATION MONDIALE DE L'HEMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA  
Treatment for All

**Engaging Individuals, Empowering Communities**

We all have a role in improving and protecting treatment for people with bleeding disorders. You can help by:

- Inspiring others by sharing your story
- Educating people about living with a bleeding disorder
- Getting involved with the bleeding disorders community at a local, national, or global level

WORLD HEMOPHILIA DAY | APRIL 17

To share your story visit [www.wfh.org/whd](http://www.wfh.org/whd)

Haemophilia Foundation of New Zealand Inc.  
cordially invites you to

# HFNZ 2011 Annual General Meeting

When: 2.30 pm, Saturday 26 March, 2011  
Where: Kingsgate Hotel Rotorua  
Fenton Street  
Rotorua

## AGM Business:

- Review performance for 2010
- Election of Officers to National Council
- Vote on proposed resolutions
- Guest Speaker: Ed Kuebler

Ed Kuebler is social worker at the University of Texas Gulf States Hemophilia and Thrombophilia Center. In addition to working with the 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 leadership programme for youth with haemophilia.

RSVP By Friday 18 March 2011 to  
[leanne@haemophilia.org.nz](mailto:leanne@haemophilia.org.nz) or 03 371 7477



The full Agenda will be available on  
[www.haemophilia.org.nz](http://www.haemophilia.org.nz) by 4 March 2011