



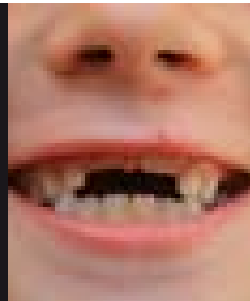
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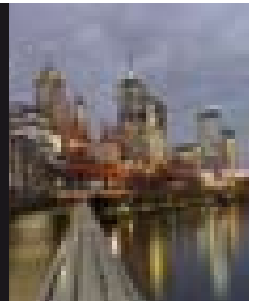
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As I write this, I am somewhere between Los Angeles and Montreal en route to my second executive meeting of the World Federation of Hemophilia. I have been travelling for a little over 20 hours now and am surviving on airline coffee. My brain has been jumping between the contents of the WFH meeting, the next HFNZ National Council meeting and other matters in my own employment along with various other musings. It has dawned on me that being captive on a plane for so many hours has provided one of the first opportunities in a number of months to collect my thoughts. So, having collected them, now what?

My vision for the Foundation in 2011 is that we build on being the outward looking organisation that we are. I am referring to outward looking in a very broad sense. To me, outward looking is more than reaching beyond our borders, it means looking out for each other, and sharing our knowledge and understanding locally. What has worked well overseas and how can it be implemented in NZ? What worked well in a region? How did Bob manage his treatment regimen and what could be learnt from it? Who is interested in becoming more involved and how can they be encouraged? What can be learnt from listening to our shared experiences of living with bleeding disorders? Being outward looking can make positive changes in subtle ways.

I believe that we have all been very good at sharing our ideas and opinions with each other (that is the understatement of the century). Sharing our knowledge can only be positive if it is improving the lives of people with bleeding disorders.

Through all your life responsibilities I do hope that you get the opportunity to spend some quality time with the people you care about over the summer period.

Seasons greetings,

**Deon York**  
HFNZ President

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Disclaimer:  
The information contained in this newsletter is not intended to take the place of medical advice from your GP, haematologist or specialists. Opinions expressed are not necessarily those of HFNZ. The purpose of this newsletter is to provide a wide range of accurate and timely information on all aspects of haemophilia and related disorders. Haemophilia is a dynamic specialty and therefore opinion may change or be varied from time to time.



# HFNZ investigate Twinning with Cambodia

*Earlier this year, The World Federation of Hemophilia (WFH) presented HFNZ with an opportunity to take our commitment to being better global members of the bleeding disorder community 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.*



Since our humble beginnings in 1958, HFNZ has grown into a solid, well-organised, and prominent patient organisation. 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. Twinning is a chance to really use the experience and knowledge we've gained and help the bleeding disorders community in a more hands-on way.

The first step to Twinning is having an assessment visit. HFNZ representatives, Colleen McKay (Manager -Outreach Services) and Richard Scott (Northern Delegate to National Council), travelled to Cambodia for this visit in October. An assessment visit is when a representative(s) from the established organisation visits with their potential twinning partner organisation in the emerging country. 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.

This article will explain a little more about the concept of Twinning, the situation for people in Cambodia with haemophilia and other bleeding disorders, how the trip to Cambodia went and the outcomes of the visit.

### What is Twinning?

Haemophilia affects about 400,000 people worldwide. Seventy-five percent receive little or no treatment. With treatment products and proper care people with haemophilia can live perfectly healthy lives. Without treatment haemophilia can cause crippling pain, severe joint damage, disability, and death.

As haemophilia organisations in developed countries learn more about the plight of people living with haemophilia in developing countries they often want to offer help. With time, they realise how much they can also benefit from this work.

Twinning is a formal, two-way collaboration or partnership between emerging and established patient associations. By linking emerging and established haemophilia organisations and/or treatment centres, the Twinning Program has improved treatment and care for people with bleeding disorders around the world.

Feedback from partners suggests that twinning is a positive two-way experience that motivates staff and volunteers, attracts youth involvement, and enables both sides to learn from each other.

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. A new challenge can invigorate an organisation.

Haemophilia organisation twinning can play a critical role in a country. Regular support and coaching through twinning helps a patient organisation become a

## HFNZ investigate Twinning with Cambodia....



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.

Twinning is a chance to increase experience and expertise. National haemophilia organisations must develop national policies and goals, understand the realities of their regions, and appreciate the global reality for people with haemophilia. The haemophilia community is worldwide and can work together to reach mutual goals.

As an active example of the WFH vision of Treatment for All, the Twinning Program has enjoyed much success and growth. Thirty-two twins in 41 countries now belong to the program.

### Haemophilia in Cambodia

Haemophilia and other bleeding disorders such as von Willebrand Disorder are rare diseases, and due to this rarity, awareness about them in Cambodia, both in the medical profession and in the wider society, is extremely low. Treatment

for bleeding disorders in Cambodia is almost non-existent. There are many obstacles surrounding to adequate care in Cambodia (training medical personnel, seeking affordable treatment, education and socio-economic support for patients and their families, etc) and because bleeding disorders are rare they are very low down the agenda of the Ministry of Health.

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 being treated at either the National Paediatric Hospital in Phnom Penh or Angkor Hospital for Children in Siem Reap. 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 complete absence of haemophilia services. Among those who have survived, anecdotal evidence indicates that families may spend large amounts of money seeking ineffective treatments. 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.

The first case of haemophilia in Cambodia was diagnosed in 2002. Doctors then had to be educated on how to treat it as haemophilia had never been recognised or treated there in the past. A small team of health professionals have been the driving force to get haemophilia testing and care established there, and have been instrumental in helping set up the CHA.

In Cambodia there is little to no treatment for bleeds. Factor replacement products are donated from abroad in limited amounts. Most people with haemophilia simply live with the consequences of bleeds, such as swollen limbs, pain and long stays in bed. It seems that even limited treatments can make a difference. One 12-year old has said that although his knee is twice the size of the other, following some treatment he can now ride his bike to school.

An event in 2009 was the first formal meeting organised by CHA. Their mission is for families to band together to convince the government and Ministry of Health to establish a national guideline for the treatment of haemophilia and provide the medicine patients require. CHA is now a recognised National Member Organisation of the WFH.



### Assessment Visit

After arriving in the capital, Phnom Penh, Richard and Colleen spent a little time learning about the Cambodian culture and history to gain a better understanding of the situation of the people living there. This included colourful visits to local markets, fascinating visits to local palaces, a boat trip along the river and an emotional visit to Choeung Ek (the Killing Fields). Their first impressions were of just how many people there seemed to be. Phnom Penh has a population of over 2 million but is growing by 3.2 percent each year. The streets are filled with a bustle of motorbikes (motos), cars, street vendors, and cyclists.

The next few days were a whirlwind of meetings, but the outcome has been uplifting and inspiring. They began with a day at the National Paediatric Hospital. CHA had organised a Bleeding Disorders Seminar there and around 120 people attended from around the country - doctors, paediatricians, nurses, and physiotherapists. Colleen and Richard had an eye-opening tour of the hospital. The children with bleeding disorders are treated in the same very basic ward as those with other haematological conditions such as thalassemia, as well as children with endocrinological, immunological, cardiological and other conditions. The treatment room is essential a bed in a hallway - much in the same way services began at Auckland Hospital all that time ago. There were also



very long queues at the cashier's desk as most treatment at the hospital must be paid for. Donated recombinant factor is, however, provided free to families with haemophilia.

The following day they headed back to the hospital, this time to meet with representatives of CHA and families affected by haemophilia. Establishing a good family support system is key to growing the organisation. While fundraising and giving are important aspects of a haemophilia organisation, learning how to support each other is essential to providing long term benefits. Some 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.

Richard said that main thing that impacted him were the things that the mothers and fathers said in Khmer that were translated during our meetings with the families.

*"Why should I go to school and study because I will die soon."* (Boy with Haemophilia)

*"I thought I was the only one with this problem and I was ashamed."* (Carrier Mother)

*"We want our sons to get together and share their experiences together."* (Mother)

In the past *"We have paid cyclos [bicycle taxi drivers] to give blood so we can treat our son but now we are afraid to do a blood test on our son to find out if he has been infected"* (Carrier Mother)

This meeting was the first time these families had talked openly with each other about their experiences. One of the mothers apologised because she felt *"I throw all my burdens on you."* This is because usually in their culture they would keep all these things to themselves. Richard felt that this is one of the values we can add to their Association, by encouraging them to meet and facilitating discussion of their feelings. Some of the issues have been temporarily resolved by having donated factor. The boys are now happy to go to school and the families at the moment are not using blood transfusions. The donated factor supplies are currently dependent on drug company donations, but there are plans for the Phnom Penh Blood Service to begin to produce their own cryoprecipitate soon.

Although language was a problem, it was clear that the Cambodian people really appreciated that HFNZ were there. With the help of Robert Leung from WFH,

## HFNZ investigate Twinning with Cambodia....



they talked about the Twinning Project, and Richard and Colleen each gave a presentation on HFNZ, its structure and services and also explained how they are both parents of boys with haemophilia (or men in Colleen's case). They stressed how slowly it took the Foundation to grow, especially in the beginning stages and how it was many years before we had our first camp and even longer before we had our first employee. They also explained how many people do the work, employees, Council and Branches, and how all members played a part.

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

The following day they had additional meetings with a social worker working in Cambodia and with Mr Noun Vearleck, the current CHA chairperson. One thing that Richard and Colleen learned from the experience so far was not to plan the days too tight - allow time for meetings that are sprung on you at a moment's notice and the need to be flexible as some meetings take much longer than expected. They also learned to never underestimate the complexity of working within another culture. It has been difficult for CHA to make the necessary steps to form an association and there is still a lot to learn from both sides.

The overall impression was that CHA is really in need of a great deal of direction, so HFNZ have a HUGE task ahead of us. But as a result of this visit, we now have a draft Twinning Application document and a draft Action Plan for 2011.

Colleen wrote the following shortly before returning home, "I have so loved it here, I could stay for another week. Even though Cambodia is hot, humid, developing in the true sense of the word, and people don't speak much English, it is such an adventure... I knew that I would love the challenge of the Haemophilia Twinning Project, but I didn't think that I would love the experience, the country and the people as much as I have.

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."

### How you can help now

While the paperwork is underway, we can still start helping the families with haemophilia in Cambodia. Most families really have very little and simple things like colouring books, felts, and small toys (like matchbox cars) are much appreciated. Colleen and Richard brought some of these things over for the Assessment Visit and they were treasured by the youth.

HFNZ National office have started a donation box in preparation for the next trip, so if you would like to donate new, small, light toys or writing materials please send these to us (HFNZ, PO Box 7647, Sydenham, Christchurch) and we will bring them on the next visit. Even the small things can make a big difference.

## Regional Children's Workshops 2010

**"It was a really fun day and I learnt a lot," Tama Halliwell**

Once again, HFNZ has been holding our annual regional Children's Workshops around New Zealand over the recent school holidays.

The workshops are a great chance for children aged 6-12 years with a bleeding disorder to learn a bit about their condition and get together with others in their region. This year siblings of a similar age were also invited to participate in all the fun.

The first workshop was held in Wellington on Saturday, 25 September, followed by Hamilton on 28 September, Auckland on 30 September and finally Christchurch on Saturday the 2nd of October.

The programme was roughly the same for all four locations, and allowed the kids to participate in variety of activities. Soon after arriving the children settled in to paint their wooden race cars, which they raced later in the day. This was followed by some fun learning on bleeding disorders and a game about the different components of blood. A talk with a physiotherapist was then followed by a healthy lunch. In the afternoon, the group had a workshop on thoughts, feelings and emotions which was very effective and then every headed off to try a local clip and climb venue.

This year the children also received a specially made workbook to help reinforce some of the information learned and work through some of the other themes such as feelings. They were able to bring this home and complete the rest of the activities or show their parents all the stuff they learned. Some of the activities are now featured on the Activities page of the Kids Corner part of the HFNZ website. Go to [www.haemophilia.org.nz](http://www.haemophilia.org.nz), and click on the Kids Corner logo on the front page to find your way there.

Thanks go to all those helped out on the day, organiser Colleen McKay, the regional Haemophilia Outreach Worker

## Regional Children's Workshops 2010....

Yael, Eli and myself enjoyed supporting and participating in the Children's Workshop. It was a nice way of encouraging the younger members to know more about their condition.

- Tara Mounicy



We drove to Hamilton early in the morning. We were making cars at the workshop. We had lunch and it was yummy burger, then went rock climbing. I was scared then I Did it. Joy helped me get on the rock wall. I felt remarkable that I did it. Then we went home. I had an outstanding day.

- Courtney Marjoribanks



Riana enjoyed painting her car as she got to choose her own unique colours. Tahu said awesome time at Clip and Climb and Amaia said, "Colleen was very nice to me and let me ask lots of questions and listened to my answers..."

All 3 had a wonderful time and I think it was an excellent idea inviting the siblings especially if we are promoting whanaungatanga (relationships).

- Tania Kaa



# Getting Ready for Back to School



*It won't be long before it's time to shake the beach sand off your jandals and think backpacks and homework. From buying supplies to soothing first-day jitters, parents have a lot to do to get their kids ready for the new school year. And if you have a child with a bleeding disorder, the start of school may feel especially stressful. Planning ahead - even with the summer sun still warm on your face - will help you and your family adjust to the back-to-school demands.*

Try thinking about the job in three distinct tasks... preparing your home, your children and the school(s).

## At home:

- Renew bed times and bedtime routines if these were relaxed over the summer. Start a week prior so children will have time to adjust. Kids between the ages of 6 and 9 generally need 10 hours of sleep, with older children needing about 9 hours.
- Review all of the school information you've received and mark your calendar with important dates & days off. Talk with each child about room and other assignments.
- Make extra copies of your children's health information to have on hand when they sign up for sports or extra-curricular activities.
- Designate and clear a space to "drop" backpacks at the end of the day. While you're at it, also establish quiet space for doing homework.
- Establish end of school day routines, i.e., empty lunchboxes, change out of uniforms, homework, etc.
- Consider assigning each child his or her own storage box to keep old assignments, notes, tests and artwork during the school year.
- Renew your focus on good nutrition. Stock up on healthy lunch and snack items to pack. Start their mornings off with nutritious but quick breakfasts that emphasise whole grains, protein, fruits, vegetables and low-fat dairy. Smoothies made from yoghurt and fruit are good for getting you out of the house quickly.



## Your child:

- Expect your child to show some anxiety at the start of a new school year. You can help by slipping encouraging notes into his or her school or lunch bag. Let him know you're confident he can manage what is expected of him and that it's natural to be nervous.
- Let him know you care but don't overreact. Children can absorb a parent's anxiety, so remain calm and confident. Chances are he/she will, too.
- Remind him of what to do if he has a bleed at school. While you're at it, also remind him about the kinds of activity that are safe for him to participate in.
- If there were difficulties last academic year, reassure him that you and he have worked on the problem. Let him know that this is a fresh start.
- Let him pack his own school bag, but check the final weight. Backpacks should never weigh more than 10 - 20 percent of a student's body weight.
- Review safety information with him for walking/cycling or taking a bus to school.

## At school:

- Schedule meetings with your child's new teacher and school nurse or office staff to explain about haemophilia and what to do. Your HFNZ Outreach Worker can help, either joining you at the school meeting or calling to follow up. Please call HFNZ should you require a haemophilia or vWD school pack.
  - If your child experiences frequent bleeds, your doctor or physical therapist may need to help the school develop a modified exercise program.
  - Use a handout to help you communicate with the school about haemophilia and what to do, who to call, in an emergency. Once again, please call HFNZ if you need handouts or other materials.
  - Make sure the school can reach you at all times. It's not enough for the school to have just one or two phone numbers; make sure the office staff has home, work, mobile and e-mail contact information for both parents and emergency backups.
- Encourage the school to treat your child like any other student. While safety always comes first, the goal should be to have active, independent and spirited children - sometimes that is difficult if they are stilling on the sidelines or receiving special treatment from teachers and staff.
- Ask for accommodations, but only when necessary. It's important to a thorough understanding of school policies and feel empowered to ask for an exception if it's necessary for your child's health. For example, if your child can't carry a heavy backpack, it may be easier for him to use a rolling suitcase, which some schools prohibit. Talk to school administrators if a situation like this arises.

Having your children start school can be an anxious time for parents as well. Worrying about your child when they are not surrounded by the safety your home provides is normal, but there are many ways to help alleviate some of this stress, especially if your child has a bleeding disorder. Communicating with those that spend the most time with your child when they are away from home is essential. Providing them with information about the condition will not only make them more comfortable around your child, but will help you ensure they have the best possible care.

Education about haemophilia isn't only for schools. Your child will be involved in lots of activities throughout the year. Everyone who interacts with your child regularly - from friends, to other parents, even a babysitter - needs to know the basics about haemophilia. Reassure them that you are just a phone call away and, in the event of injury, there is time to get help.

Here are some basic concepts to share with everyone spending time with your child:

- Describe haemophilia simply and accurately
- Explain basic signs and symptoms of bleeding
- Review basic first aid: **P**rotection, **R**est, **I**ce, **C**ompression and **E**levation (PRICE)
- Specify approved sports and play activities and provide protective gear when needed.
- Share your contact information and keep it up-to-date

Talk to your employer about your situation. Having a child with a bleeding disorder means you might occasionally have to leave work to administer a treatment or pick your child up. If your employer understands your child's condition, he or she may be more flexible if you need to leave work suddenly or adjust your regular hours once school begins.

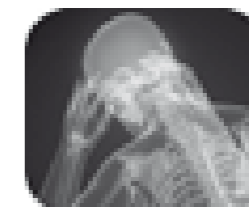
Educate and empower your child about his or her bleeding disorder. It's important for your child to know their body and condition so they can act responsibly in any situation. Attending HFNZ educational events such as New Families Camps, Teen Camps and regional Children's Education Workshops are great ways to help your child better understand their bleeding disorder. This knowledge will help keep him or her safe and confident during the school day. You may also want to provide your child's friends the same basic understanding about haemophilia that you've given to your other children.

Finally, it is important to recognise that every child is different. Even among children with the same condition, there are several variables - how the child feels about his condition, how frequent and severe his symptoms are and even whether he wants other kids to know about his illness. Make sure the school understands and respects your child's individual situation.

By practicing these tips, you can have peace of mind knowing your child (and you) will be ready for the school year ahead.

Sources: [www.livingwithhemophilia.com](http://www.livingwithhemophilia.com), the Northwest Herald (2010) and Colleen McKay

# Recognising Head Bleeds



*Intracranial haemorrhage (ICH), or bleeding within the skull, is a medical emergency. Without early recognition, ICH can cause severe neurologic impairment, paralysis or death. Aggressive and early management is crucial.*

ICH is the leading cause of death from bleeding in all age groups. In New Zealand, ICH resulting from a variety of circumstances has been the leading cause of death in adults with haemophilia in recent years.

Head bleeds can occur in children and adults with bleeding disorders. The obvious ones are a result of trauma, such as a fall or injury to the head, but some occur spontaneously from no apparent cause. Classified as one of the five major sites of life-, limb- or function-threatening bleeds, ICH needs to be recognised and treated promptly.

All injuries to the head need to be taken seriously because of the risk of bleeding into the brain. Early symptoms may not be evident due to the slow, oozing nature of haemophilia bleeding. Bleeding over or into the brain can continue and spread, then as the bleeding increases it compresses the brain.

Minor head bumps can be frustrating because it is difficult to know whether treatment is needed. Head bumps are especially common in young children at the toddler stage. Older age can also be a risk factor for spontaneous ICH, which is considered the most severe form of stroke. Bleeding in and around the brain/spinal cord can be life threatening and requires immediate medical attention. If in doubt, call your haemophilia treatment centre.

## Signs of a serious head injury may include:

- Drowsiness
- Headache (especially with increase severity)
- Blurred vision
- Nausea or vomiting
- Mood changes or personality changes
- Loss of balance or coordination
- Weakness or clumsiness
- Stiff neck
- Loss of consciousness/unresponsive
- Seizures
- Muscle weakness or paralysis
- Confusion, trouble paying attention, sluggishness
- Numbness, tingling or loss of feeling
- Dilated or unequal pupils, eyes not moving together →



## Recognising Head Bleeds....

In infants, look out for poor feeding, vomiting, unusual irritability or somnolence.

### These signs may be delayed. DO NOT IGNORE. Seek medical attention IMMEDIATELY!

If a person with a bleeding disorder suffers a severe blow to the head or exhibits any neurologic symptoms listed above they should be admitted to the hospital for observation. Ring an ambulance and explain that the person has a bleeding disorder and has had suffered head trauma or a suspected head bleed. Call your haemophilia centre or emergency department to inform them what is happening that you have called an ambulance.

According to WFH, all post-traumatic head injuries and significant headaches should be treated as a head bleed.

Raise factor level immediately. Do not wait for further symptoms to develop or for laboratory or radiologic evaluation. Immediately raise factor level to 80 to 100% when neurologic symptoms or significant trauma occur. If a haemorrhage has occurred, maintain at least a 50% factor level until the haemorrhage improves (usually two to three weeks) with an objective head imaging study performed. Consult the haemophilia treatment centre for further recommendations once the patient has been stabilized. These patients will often go on long-term prophylaxis.

Suspected head bleeds require immediate medical evaluation and hospitalisation for observation. A CT scan or magnetic resonance imaging (MRI) should be performed. Your haemophilia treatment centre should be contacted if you have not already done so.

### FIRST infuse major factor dose. THEN perform diagnostic studies, such as CT scan or neuro exam.

If discharged home, the family should monitor for signs and symptoms of neurologic deterioration and report any to the haematologist. Consult the haemophilia centre for follow-up factor replacement doses if the patient is discharged home from the emergency department.

After the acute period of an ICH, it is recommended that blood pressure be well controlled and that avoiding alcohol can be beneficial. Given the potentially serious nature and complex pattern of evolving disability, it is reasonable that all patients with ICH should have access to multidisciplinary rehabilitation. Where possible, it should be begun as early as possible and continued in the community to promote ongoing recovery.

## Step Up Reach Out 2010-2011 - The first leg

### By Hemi Thomas

#### Hemi Thomas is the tenth New Zealander to be chosen to participate in Step Up Reach Out (SURO).

*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. We each gave a brief introduction of ourselves, and haemophilia care in our country. 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. We also got to go on a tour of the Bayer Pharmaceuticals Factor VIII production plant in Berkeley followed by a question and answer session with a panel of experts. SURO has been a great experience and I'm looking forward to the second stage of the program next March in Auckland.*

SURO, an international youth leadership program, draws together young men from around the world for leadership skills, personal growth, and collaboration. This program consists of two conference sessions focused on leadership training, activities, and individual and group projects. Sponsored by Bayer HealthCare and directed by Ed Kuebler, LCSW with Gulf States Hemophilia & Thrombophilia Center in Texas, the program helps participants build self-esteem, develop concrete thinking abilities and make decisions that reflect true leadership qualities.

HFNZ are very proud to be able to help host the second leg of this cycle of SURO when it travels to Auckland in March 2011. This is only the second time that part of the programme will be held outside of North America and will be a chance for previous NZ participants to get together and play a part in the programme once again.

Hemi got to travel to San Francisco for the first half of the SURO programme



SURO participants 2011



## Ones to watch...

Here are a few people living with haemophilia from around the world that are achieving fantastic things...



### Alex Dowsett - Racing cyclist

Alex Dowsett is a 22-year old English racing cyclist who currently rides for the American Trek-LiveStrong team. He also has severe haemophilia A.

Competing on the Velodrome, but specialising in road-racing, his aim is to compete at the 2012 Olympic Games in London! He previously rode as a member of the British Olympic Academy development team. In 2008 and 2009 he won the under 23 British National Time Trial Championships. In 2010 he won the under 23 European Time Trial Championships and gained a silver medal at the Commonwealth Games, also in the Men's Road Time Trial.

With regards to his haemophilia, Alex says his doctors said they "would rather you played chess or a musical instrument, but there is nothing we can do to stop you. And I knew it too! I'd found a sport at which I was very competitive and I'm determined to reach the top and not let my Haemophilia stand in my way!... All my team mates know about my condition and know that things may be different if I take a nasty fall, but otherwise I am treated no differently. They often enquire about it especially after a fall and what would be different with me, which other than getting Factor VIII into me quick, isn't a lot."

A full interview with Alex about racing and having haemophilia is available at [www.bloodsweatandtyres.com/docs/AlexDowsett.doc](http://www.bloodsweatandtyres.com/docs/AlexDowsett.doc)



### Tony David - Dart Champion

Forty-three year-old Tony David reached the pinnacle of the world darts circuit back in 2002 and became the first Australian to lift the Embassy Professional Title in England and the World Trophy. In the years following his triumphs Tony underwent a severe decline in health due to the hepatitis C virus he contracted from treatments for his severe haemophilia. After being diagnosed with stage 4 liver disease and embarking on interferon therapy, it was decided that his liver was too damaged and he required a transplant. Early last year Tony underwent a successful liver transplant, and since then has been making the most of his second chance at life, including a return to competitive dart fixtures.

Tony says the transplant gave him a new zest for life that will prove wonders not just

for his sporting career, but all aspects of life. "Now that I've had the liver transplant and successfully got thought that, it now looks after my haemophilia, so I don't have any more blood disease technically as such. Genetically I'm still a haemophiliac, but the new liver now looks after all the clotting factors that my body wasn't making before."

"Straight after the operation I realised just how ill I'd been over the past 25 years, it was like I'd been living my life and looking at the world in technicolor, as soon as I'd had the operation I was now looking at the world in high definition," he said. "Everything was sharper, more clearer."

Tony is slowly getting back into darts competition, but his priorities are on his family and friends for the moment. To read more look for his interview on the Hepatitis Council of Queensland's website [www.hepqld.asn.au](http://www.hepqld.asn.au)

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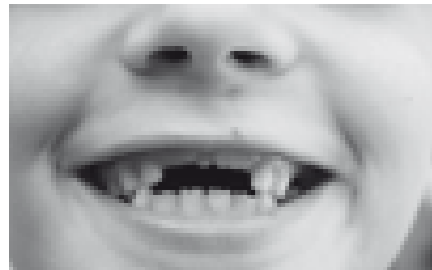
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# Taking your Dental Health Seriously

*It is important for people with bleeding disorders to take good care of their teeth and gums. Making regular visits to the dentist will reduce the chances of future problems such as needing extractions or mouth infections, which can lead to further complications.*



Your oral health also affects your overall health. Researchers are finding links between periodontal (gum) infections and other diseases throughout the body. The mouth is a warm, moist environment - a haven for sticky plaque-producing bacteria which forms hardened tartar on teeth over time. Plaque is an expert at turning sugars into acids which erode the tooth enamel. Gum disease can let bacteria enter your bloodstream and wreak havoc elsewhere in your body. Current studies suggest that there may be a link between gum disease, heart disease and other health conditions. In fact, research suggests that gum disease may be a more serious risk factor for heart disease than hypertension, smoking, cholesterol, gender and age. It is possible that inflammation in the mouth sparks inflammation throughout the body, including in the arteries, where it can lead to heart attack and stroke.

Oral health begins with clean teeth. Sometimes dental care falls to the bottom of a very busy list of things to do. However, when you have been diagnosed with a bleeding disorder, such as haemophilia or von Willebrand's Disorder (vWD), taking care of your teeth needs to be given high priority. Some research has shown that there are considerably more complications from dental disease in people with severe forms of vWD than what is seen in people with haemophilia, because of the mucosal bleeding common to vWD.

## Attending the Dentist

If you have mild haemophilia (more than 5% clotting factor) or type 1 or 2 vWD it is fine to attend your own dentist for routine care such as check-ups, fillings, scale and polish, root canal, crowns and

cosmetic work. You should inform your dentist about your bleeding disorder and advise him/her that further information is available from your haemophilia treatment centre.

The same applies if you have moderate or severe haemophilia, or type 3 vWD. You can attend your own dentist for routine care (check-ups, cleaning) and non-invasive procedures unless there is a specific concern. Your dentist should contact your haemophilia consultant or nurse for advice if you require any procedures as you may need a treatment protocol.

For all severities of bleeding disorder, your dentist should contact your haemophilia consultant or nurse if you need a tooth extraction, some deeper injections, gum surgery or a dental implant, as this type of treatment will usually need to be provided by a hospital or specialist dentist.

Your dentist will advise you about how often you need to attend for check-ups and give you information on how to prevent dental problems. Everyone with haemophilia should attend a dentist at least once a year. Children can see their school or community dental nurses, but be sure to inform them of the bleeding disorder and that the haemophilia nurse or consultant should be contacted if there is a need for any invasive procedures.

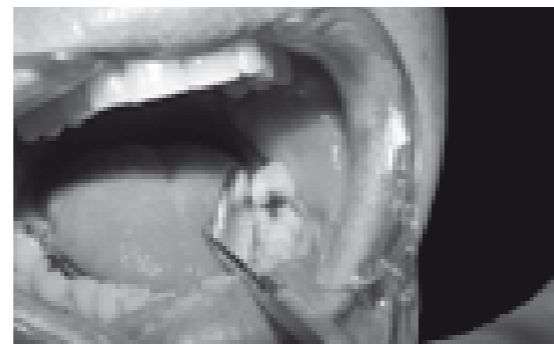
## FAQs

### Should I brush my teeth if it makes my gums bleed?

Gums that bleed after tooth brushing can be a sign of early gum disease, which is very common in all people. It is important that this does not progress to more severe gum problems. Mucosal or gum bleeding after tooth brushing is common in people with haemophilia, and even more so in



people with vWD (especially type 3). When gums bleed following brushing this results in negative reinforcement of brushing behaviour - you avoid brushing to avoid mucosal bleeding. Over time this leads to persistently poor oral hygiene that produces gingivitis that in turn increases the likelihood of further bleeding setting up a vicious feedback cycle.



However, it is important to continue tooth brushing with a soft brush to remove plaque and debris which causes the gum disease. The recognised treatment is to visit your dentist or hygienist for advice and to have your teeth professionally cleaned and monitored. Your dentist may advise you to use a medicated mouthwash and will recommend methods for brushing and cleaning your teeth more effectively. Your bleeding disorder may mean that gums bleed a little more easily and for a little longer, until the gums heal.

### What happens if I need a tooth extraction?

This should always be co-ordinated by your haemophilia treatment centre so that it can be carried out safely to prevent excessive bleeding. Depending on the severity of your bleeding disorder your haemophilia team may choose to give you factor replacement therapy and/or tablets before the tooth is extracted, and a special mouthwash afterwards. In addition, the dentist may stitch the wound and use a special surgical packing to stop any bleeding. This method has been used very successfully for many years to prevent problems after tooth extraction and has been recommended by the WFH.

## How do I keep my teeth and mouth healthy?

The key influence to retaining and enjoying one's natural teeth for life is being personally 'proactive' by regularly visiting a qualified dentist for oral screening and treatment advice.

Prevention is really the key to good oral health. As such, brushing twice a day or after eating is critical, as is regular flossing and thinking about the foods you are eating and drinking.

Fluoride contact with the teeth is very important as it helps to strengthen and protect the outer enamel of the tooth. Water and toothpaste are the main sources of this. Not all communities have a significant level of fluoride in its water, although many of the main cities in NZ do. Fluoride in toothpaste is also very beneficial. It is easy to mix fluoride tablets with water in non fluoridated regions (e.g., in the country and in Christchurch) to optimise the benefit of fluoride, especially for an individual with a decay problem.

Foods for healthy teeth include milk, cheese and yoghurt which provide calcium. Raw fruits and vegetables provide vitamin C to keep gums healthy.

Water washes away trapped food and acids from fruits as do fruit juices but they must be heavily diluted. Soft drinks and energy drinks should be avoided. Ian Esson, Special Needs Dentist at Christchurch Hospital says that fizzy drinks and juice cause concern for two reasons. The first is sugar, but the second is because the drinks also contain acid which will not only encourage the decay problem, but also erode and dissolve some of the tooth enamel of all surfaces it touches. This loss of enamel can become a major problem in the medium to long term.

When the enamel does erode, hot or cold foods such as coffee and ice cream, hard and soft foods or acidic foods and, of course sugar, can all heighten sensitivity or cause pain and means a visit to the dentist.

You should especially never drink juice or soft drinks before bed because you produce less saliva when you sleep. Stimulating saliva flow helps kill bacteria, neutralises acids and washes away food particles. Chewing sugar-free gum is one way to help produce saliva.

Everyone is responsible for their own oral health and following these simple steps will help you enjoy the benefits of healthy teeth and a healthy mouth.

## Main Strategies to Maintaining Good Oral Health

- Brush teeth twice a day with fluoride toothpaste
- Floss regularly
- Limit sweet food and drinks
- Be smokefree
- See a dentist regularly

## In Remembrance: Barry Keith Mabey

15.7.37 - 22.3.10

*On the 22nd March 2010, Barry passed away peacefully at home surrounded by his loving family, at the age of 72 after battling Hepatitis C. He was a gentle, kind man with a great sense of humour. Everyone that met him was very fond of him.*

Barry was born in Richmond in 1937 to Keith and Daisy Mabey and was one of six children. He grew up in Wakefield, Reefton, Motueka and his beloved Takaka. He worked on a dairy farm with his father as well as an apple orchard. The family then moved to Pahiatua where Barry and Keith both worked on Balfour Estate for 5 years. They then moved to Westella, where he met his wife Dorothy, and then started working for Snow Harvey Logging.

In 1976, Barry and Dorothy formed their own logging company, B.K. Mabey Ltd, with his first truck being a Ford D1000. This became the line of work he would do for the rest of his working years.

During the past few years Barry started showing an interest in classic cars (he purchased a few of them). Two of his favourite cars were Jaguars and he became a member of the local Jag club and enjoyed going on rallies and trips with them. He also loved going to his yard and cutting up firewood that his trucks carted in, or working on his vehicles. He restored a Mini 1000, which attracted a lot of attention when he drove it around (even from the boys in blue).

Barry was a brave man. When he knew he was really sick and didn't have long to live he started designing his own casket. He rung his bush mate and ordered the timber which had to be his favourite, NZ Honeysuckle and NZ Red Cedar, and an old two man crosscut saw which he had his trucks painted onto and which was fitted on the lid.

He loved his family and enjoyed spending time with his grandchildren and getting into a bit of trouble with them. Sadly Barry did not make it back to his beloved Takaka due to ill health.

Barry is survived by wife Dorothy, son Dean, daughters Paula, Melissa and Nicky, grandchildren Sarah, Nathan, Leighton, Bailey and Annalise.

### "Logger Base to 41 over and out"



The casket Barry designed for himself

# Regional Branch Reports

## Central

By Stephanie Coulman

The Central region **Children's Workshop** was held in Johnsonville in September. What wonderful workbooks Colleen provided for the children to work through and bring home. I especially loved the idea of thinking about our feelings of anger as an 'anger volcano'. What does it take to make yours erupt? It was a positive initiative to include siblings in the workshops as they live with haemophilia too.

Over 70 people attended the regional **Winter Escape** in Masterton in September and we received positive feedback about the informative education sessions (nutritionist, pain management, genetics).

It was a shame to see some people skip sessions that they would have benefited from. We target the programmes with the needs of those attending in mind. Some people missed sessions that related directly to them.

We had great support from Lauren Nyhan and her two swimming friends who did a marvelous job of the child-care, swimming instruction and a variety of other fun activities. Thank you!

Thank you to Judith Dudson and Tracy Nyhan and the rest of the committee for the huge amount of work they put in to make the weekend a success for our members.

The central region **Christmas Party** will be a family picnic held in Palmerston North on 5 December (10am-2pm) at The Esplanade. Families should bring a \$5 boy or girl gift if you want your child to receive a gift from Santa.

Some of the entertainment at Central's Winter Escape



## Northern

By Lynley Scott

Hard to believe that we are gearing up for Christmas - Northern Branch wishes you all a very Merry Christmas and a New Year full of wonderful memories and fun.

In August, we enjoyed a great night out at Genghis Khan for dinner to welcome our (new) Outreach Worker Sarah. The children loved choosing their own food to be cooked. As always, it was great to join together with old friends and enjoy each other's company.

September saw a family day out to Butterfly Creek. The crocodiles put on an awesome show, the petting zoo and butterfly house was a favourite with kids and adults alike, and a ride on the miniature train topped it off. September also saw the annual Roast and Movie Night at Ryder's Junction, Avondale. Northern Branch uses this as an opportunity to fundraise for Global Feast. As always the roast is a hit and then we moved into the 50-seat theatre to watch 'Charlie and Boots'. And while attendance was small, those who came had a great night.

Over Labour Weekend, a number of branch members volunteered their services at the Armageddon Expo. Huge thanks to those who helped out

Central Winter Escape 2010



and secured a donation towards the Foundation. This sort of event helps to raise the Foundation's public profile.

The Annual Christmas Party will be held on Sunday Dec 5th at the Auckland Regional Botanical Gardens. This is always a great event to catch up with old friends, meet new ones and enjoy the beautiful surroundings.

Be sure to mark out February 18th-20th on your calendar and join us at our Northern Camp at Waiwera.

Have a great Holiday Season and we look forward to seeing you all over the next few months at Northern Branch Events.

### Did you hear the one about Goldilocks in Island Bay Wellington?

A family in Island Bay were given a 1 litre sharps bucket which they found was **too small**. The asked for a bigger one and got a 22 litre one which was **way too big**. Then they got a middle sized bucket (5.1 litres with a swivel lid) which was **just right**.



Northern Movie Night



Northern family day to Butterfly Creek



Sara Preston at Armageddon

## Midland

By Catriona Gordon

The Children's Education Workshop on 28 September was a great day for our Midland children who were able to attend. An excellent book was produced by HFNZ and given to each child, full of information about bleeding disorders, which they could each take away with them for future reference. The rock-climbing was, naturally, the highlight for them, and the next Workshop Day in 2011 is eagerly awaited.

Midland held a café evening on 2 October 2010 in Hamilton as part of their fundraising for Global Feast. As always, these are excellent opportunities to get to know our members a little more, and the café provided a delicious meal for us. Lee Marjoribanks, with help from Renee Elliffe, Tara Mounsey and Outreach Worker Joy Barrett, put together a brilliant hamper raffle, and \$250 was raised that night.

We are looking forward to our Christmas Family Day on 7 November 2010, which will be held in Rotorua, starting with lunch at Pizza Hut and then a visit to Wingspan Birds of Prey, where we will get to see the falcons fly, and possibly sit on our shoulders! We are also starting to nail down the plans for our Midland Camp, which is to be held at Totara Springs in Matamata on the weekend of 4 - 6 March 2010. Mark your diaries now for what is going to be a brilliant weekend.

Midland wishes all our fellow Foundation members a happy and safe Christmas.

## Southern

By Theresa Stevens

Hello everyone and welcome to what has so far been a brilliant start to the warmer months ahead.

Since our last report Christchurch has been shaken by a rather large earthquake and approximately 2000 aftershocks. Our thoughts and prayers are with our Cantabrian counterparts as they face some big hurdles.

Southern Camp 2011 at Hamner Springs is well under way and by now most of us should have registered. Rochelle Stott and the team have a great programme organised along with great accommodation and meals, we just need you to attend. Sending your registration forms in to Lyn Steele is the first step in attending.

Congratulations to both Jayde and Nicky Peat for making the Metro Team for touch rugby - well done you two.

Thanks to everyone who contributed items for Cambodia - hopefully we can continue to collect and gather items that will be of use to our "twinning" counterparts.

Lastly I would like to wish all the senior high school students the very best of luck as they sit and await their external examination results - GOOD LUCK!

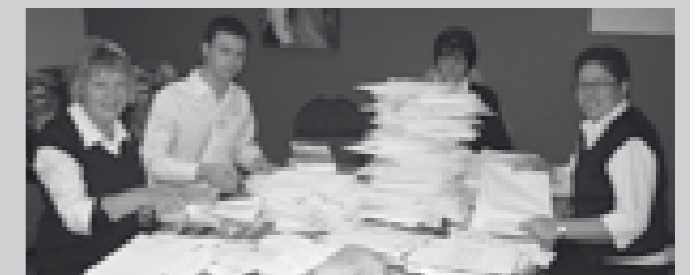
On behalf of the Southern regional committee I would like to wish you all a very happy and safe festive season. Drive carefully and respectfully and keep your family safe. Merry Christmas and a safe and prosperous New Year to all.

## Thanks PSIS Christchurch!

PSIS Staff hard at work mailing the September issue



HFNZ would like to acknowledge Sandra Bamford and the great team at PSIS on Armagh St, Christchurch, for all there help this year sending out Bloodline - even just days after the massive earthquake! The corporate volunteering scheme was set up through Volunteering Canterbury. Thanks so much!



# HFNZ funding in 2010

By Belinda Burnett, HFNZ CEO

I sometimes get asked how HFNZ manage to do so many activities - the many educational workshops, support to our members, training for our staff, face-to-face board meetings four times a year, a National Annual General Meeting in one of the four regions - to name but a few. The answer is always the same - we rely mainly on the generosity of the NZ public to fund our Foundation.

So far in 2010 the main source of HFNZ income has been through KiwiFirst, who fundraise with the general public on behalf of HFNZ. I have created a list of our main income sources below for your information. The final audited figures for the year will be published in our Annual Report next March.

## HFNZ Income Jan - Aug 2010

CEO	
Pharmaceutical Companies (Sustaining Patrons and programme sponsorship)	\$156,626.00
Grants	\$22,132.00
Lotteries	\$25,830.00
<b>CEO Sub Total</b>	<b>\$204,588.00</b>
KiwiFirst	
<b>KiwiFirst Sub Total</b>	<b>\$232,372.00</b>
Other Income	
MOH Contract (Hepatitis C)	\$60,000.00
DHB Contract	\$67,000.00
HFNZ Membership fees	\$4,715.00
General Donations	\$8,500.00
<b>Other Sub Total</b>	<b>\$140,215.00</b>
<b>Total</b>	<b>\$577,175.00</b>

Throughout 2009 and 2010 the recession has not affected our ability to deliver our programmes. Long may this continue to last. It is important to remember that through the generosity of the NZ public, HFNZ continues to deliver a world class service to our members. By the time you read this article the National Council will have met and decided the budget for 2011. This will be based on the funds we **think** we will raise in the coming year.

If you are contacted by KiwiFirst, or asked about them, I hope you will endorse them as an integral part of HFNZ and how we are funded.



# Australian & New Zealand Physiotherapy Haemophilia Group Meeting

By Lee Townsend

Senior Physiotherapist, Musculoskeletal / Orthopaedics, Christchurch Hospital

Thanks to HFNZ, I was one of two New Zealand-based physiotherapists who attended the Australian & New Zealand Physiotherapy Haemophilia Group (ANZPHG) Annual Meeting in Melbourne on 20 August 2010. The group consists of nine physiotherapists, some with extensive knowledge in this field and others like me new to our positions.

Some of the physiotherapists worked in dedicated positions while others held a shared position, mostly combining rheumatology and musculoskeletal fields. The set up of clinics were varied: most treat in and outpatients with some hospitals having a very well developed multidisciplinary team with regular clinics and easy access physiotherapy services; while others are still developing. My physiotherapy experience is in the musculoskeletal field, having worked at Christchurch Hospital for 23 years and only recently branching into this area.

Each physiotherapist presented a topic of interest. My presentation was on physiotherapy after elbow surgery, which generated plenty of discussion and sharing of knowledge. Of particular interest to me was the presentation on radioactive synovectomies that are being performed on selective patients in Queensland with good results so far. Several physiotherapists also discussed differential diagnosis and the importance of good history taking and thorough assessment to determine whether the patient's pain was due to a bleed or a routine musculoskeletal problem.

It was an excellent way of networking with other physiotherapists working with children and adults with haemophilia, and most reassuring to see our current practice is on par with international standards. That being said having a more dedicated physiotherapy service for both children and adults for ongoing review and acute episodes would be beneficial. Challenges to the current service include improved multidisciplinary involvement, with regular combined clinics with a physiotherapist and improving the knowledge base of physiotherapists working with these patients with ongoing training.

I think attendance at this meeting was essential to ensuring that we maintain and improve our standards of practice and continue to liaise with other physiotherapists practising in this field.

ANZPHG Meeting 2010, including New Zealand Physiotherapists Ian d'Young (far left) and Lee Townsend (second from right)



# Recent Events

## Roopu Hui

The latest Hui of the Roopu (Māori members of HFNZ) was held on 6th November, 2010 at the Kuratini Marae in Wellington. Twenty participants attended. The first speaker was from the NZ Society of Genealogists Inc and the Māori Interest Group. She provided a presentation from her book, WHAKAPAPA, and gave an introduction to researching Māori and Pakeha-Māori families, their history, heritage and culture. This was followed by questions and discussion. After kai there was a panel assembled of speakers fluent in Te Reo. They spoke and answered questions on their experiences in learning Te Reo, the best way to learn and what the benefits are for the individual - from the importance of identity and understanding Maoritanga and the career opportunities for those proficient in Māori.

Thanks go to Joe Wrathall, Māori Delegate to National Council, for his hard work planning the programme for the day.

HFNZ is committed to working in partnership with our Māori members. Helping with the formation and growth of the Roopu is one way we are honouring this commitment. Further information on the Roopu, including articles from members and a description of its goals and activities, will be featured in a future issue of Bloodline.



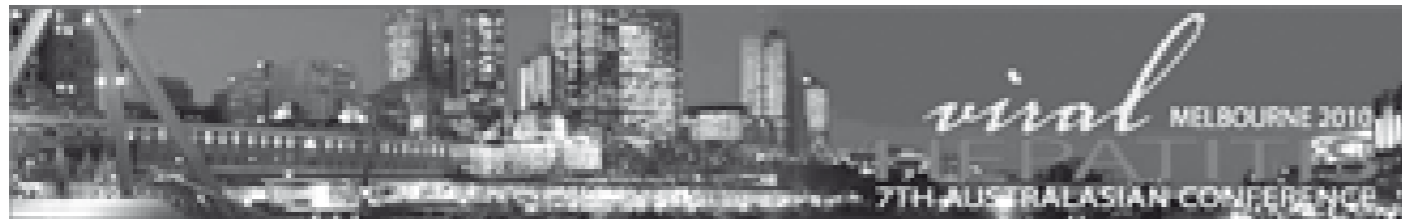
## Grandparents' Day

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.

All those that attended felt the programme was beneficial for them and would gladly come to another workshop. Due to the success, HFNZ will be looking to run further Grandparents' Days in the future in other regions. Keep an eye out for notices or let your Outreach Worker know if you or your family would be interested.

Thank you to Alison Inder, Haemophilia Nurse Specialist from Christchurch Hospital, Midland Outreach Worker Joy Barrett, and Outreach Manager Colleen McKay for their great work in delivering the programme.





# Notes from the 2010 Australasian Viral Hepatitis Conference

By Chantal Lauzon

The Australasian Viral Hepatitis Conference brings together people from all areas who work in viral hepatitis in Australia and New Zealand. Over 600 people attended the 7th Viral Hepatitis Conference in Melbourne in September, including many people from the Asia/Pacific region. This was my second time at this bi-annual conference, and found the tone of the conference much more optimistic than the previous as there seems to be so much research being done in so many areas related to hepatitis infection.

As the cohort of people with haemophilia and hepatitis (HCV) age, so does the increase in the health burden from HCV. We are now experiencing an epidemic of cirrhosis in those that had chronic HCV for 20-30 years. Not everyone will progress at the same rate and this report will hopefully give some information on the factors that contribute to liver disease progression. It should be noted that the following is my interpretation and summary of the many presentations, and that it is not intended as clinical recommendations. All treatment decisions should be made between you and your clinician.

## Treatment for Hepatitis C

The current gold-standard treatment for chronic HCV infection is pegylated interferon alpha plus ribavirin (PEG-IFN+RBV).

There are several HCV genotypes. Standard treatment for people with HCV genotypes 2 or 3 is 24 weeks, and 48 weeks for those with genotype 1. It is thought that genotype 1 is more difficult to treat because it evolved later.

Factors that influence treatment success/failure include:

- Fibrosis stage
- Virus genotype
- The outcomes of previous antiviral treatment
- Adherence to treatment
- Host factors
  - Genetics, Age, Obesity, Diabetes /insulin resistance, Hepatic steatoses (fatty liver), Immune status, Ethnicity, Gender

A rapid viral response (RVR) is a large drop in viral load by week 4, to almost undetectable levels. An early viral response (eVVR) is when the viral load drops to undetectable levels by week 12, and a partial early response (pEVR) is when the viral load drops more than 2 log at 12 weeks but is still detectable. A non-response (NR) is defined as less than a 2 log reduction in viral load by week 12 of treatment. A sustained viral response (SVR) is when a person stays virus free after treatment. If the virus

reappears after treatment is finished, the virus is considered to have relapsed.

For an individualised approach to treatment, treaters should:

- Assess non-modifiable predictors
- Modify (if possible) negative predictors (insulin resistance, BMI)
- Tailor treatment duration as required based on genotype
- Tailor treatment duration based on early response to treatment

Viral loads should be measured before treatment begins, at 4 weeks and at 12 weeks for all patients. For people with HCV genotype 1 patients who do not achieve an RVR the whole 48 weeks of treatment are necessary. In slow responders (partial early responders, pEVR), treating for 72 weeks has resulted in higher rates of SVR than treating for 48 weeks. However, not many patients can stand 72 weeks of treatment because of the side effects.

In people with genotypes 2/3, treatment can be shorted to 12 weeks if there is an RVR, but shortening treatment was not recommended as it increases the chance of relapse. Predictors of relapse in patients with shortened treatment include high BMI and low platelet counts. SVR rates are high in patients who relapsed after shortened treatment when a full course of treatment is later given. Treatment can also be extended to 48 weeks in genotype 2/3 in patients who only achieve an pEVR.

## Genetics Factors influencing treatment outcome



Host genetic factors can affect the outcome of treatment and the chances of spontaneous clearance. Lots of candidate genes have been studied. Most focus on the viral immune response.

A variant of the interleukin 28B (IL28B) gene has been associated with naturally clearance of HCV and treatment outcome. IL28B triggers our body to make more of a type of natural interferon called lambda ( $\lambda$ ) interferon. This natural interferon has also been found help to naturally suppress the hepatitis C virus. Having the C/C

genotype for IL28B is most favourable to successful treatment outcomes. In people who take INF+RBV therapy, the presence of the C/C variation of IL28B gives them a two-fold increased chance of achieving a SVR. People with the T/T genotype were less likely to respond to treatment, with those with C/T in between.

In the IDEAL study, when they looked at the SVR rates among different racial groups there was a definite correlation between the prevalence of the CC genotype and higher SVR rates. This finding may partly explain the well-known difference in treatment response rates different ethnic groups.

The C/C genotype is also associated with natural clearance of HCV. In one study, 73% of those with the C/C genotype were able to naturally clear the virus, compared to 46% of those who did not have the CC genotype (C/T or T/T).

Unfortunately, it is not as simple as if you have the C/C genotype you will have a response to treatment and if you don't you won't. There are a lot of factors at play. In the future, clinicians may do pre-treatment genetic screening for IL28B status, and add it to the pre-treatment predictors of treatment response that include HCV genotype, HCV RNA viral load, age less than 40 years, insulin resistance and race.

## Metabolic Factors influencing disease progression and treatment outcome

### Diabetes/insulin resistance

The link is now clearly established between HCV and diabetes. After adjusting for factors such as age, race, and socioeconomic status, researchers have found that people with chronic HCV were four times more likely to have Type 2 diabetes than those without an HCV infection.

Several hypothesis have been put forth to explain why Type 2 diabetes appears to be more common in people with HCV. One possibility is that HCV may infect and damage the insulin-producing cells of the pancreas. In addition, liver inflammation or damage due to HCV may affect the production of glucose or the metabolism of insulin by the liver, thus altering blood sugar levels. Studies have shown that cirrhosis of the liver, regardless of cause, increases the risk of insulin resistance.

Insulin resistance is known to improve if HCV infection is cleared.

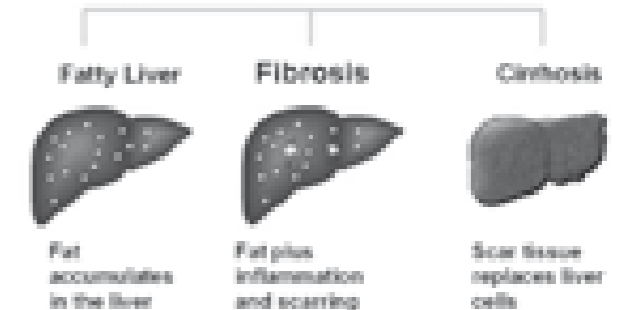


### Obesity/fat

Obesity has an effect on the inflammatory response in relation to liver injury and in response to antiviral therapy.

Fat is not benign in cells but secretes lots of inflammatory cytokines and hormones. Obesity and hepatic steatosis (fatty liver) is associated with liver damage and lower response to interferon treatment. Obesity and hepatic steatosis often occur in HCV.

## Liver Damage Spectrum



The underlying mechanisms for the association of insulin resistance and obesity to hepatic steatosis remain unclear. To explain these relationships, it has been suggested that excess 'portal' or intraperitoneal (abdominal) fat can increase the flux of free fatty acids via the portal vein directly to the liver and thus may induce hepatic insulin resistance and hepatic steatosis.

In people with HCV genotype 1, steatosis is linked to host-metabolic factors such as high BMI and insulin resistance. Having steatosis is also independently associated with fibrosis.

Fatty livers are more sensitive to injury such as HCV. When the liver undergoes an acute injury, the liver cells regenerate. In chronic HCV, hepatic regeneration is impaired. There seems to be an irreversible loss of regeneration capacity in cells, and so the cells senesce (get old and less functional). The percentage of senescent liver cells correlates directly with fibrosis scores. The senescence in chronic HCV is due to the increase turnover of the cells because of oxidative stress. Essentially, HCV wears out the liver cells and they become hard. Senescent cells are still active and still secrete proteins. They may even increase inflammatory signaling themselves, causing more cells around them to turnover.

There is more inflammation in obese people with HCV than lean people with HCV, and higher expression of inflammation molecules in the liver. A decrease in weight is associated with improved ALT scores and improved fibrosis.

In the presence of chronic HCV, the liver is already full of inflammatory messages. When there is also fat in the liver, the inflammation is compounded and more fibrosis occurs.

Obese people with HCV don't incite as big an immune response when treatment is started, most likely because there are already high levels of inflammatory signals present. Therefore they cannot mount an effective fight against the virus.

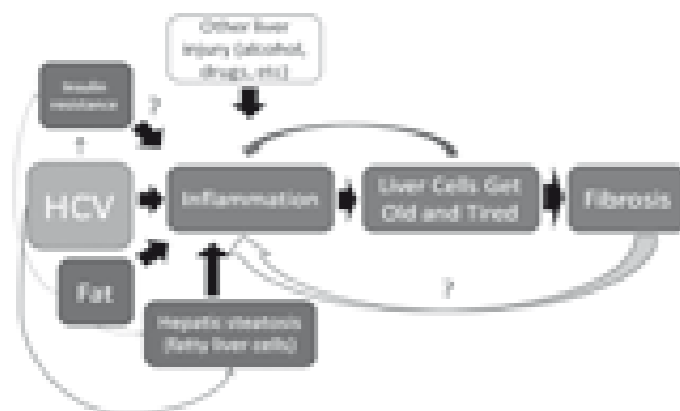
### Vitamin D

There is emerging data that HCV patients have lower vitamin D levels and a higher risk of vitamin D deficiency. Low vitamin D levels are associated with severe fibrosis/cirrhosis and a reduced SVR rate. Supplementation with vitamin may increase chance of SVR (cure).

**Diet**

A dietician should be included in the treatment plan, before and during treatment, and in both overweight and malnourished patients. Very obese patients should be encouraged to lose weight before starting treatment to raise chances of SVR.

Figure 1. Chantal's interpretation of how HCV and inflammation contributes to fibrosis



**Treatment complications**

**Cytopenia**

Different forms of cytopenia (reduction in the number of blood cells) can be a major problem during treatment, especially if the person has advanced fibrosis or cirrhosis. This can lead to reductions in treatment, and therefore undertreatment, and lower chances of achieving an SVR. Therefore cytopenia needs to be managed effectively so that dose reductions can be avoided if possible.

Neutropenia (a deficiency in white blood cells) should be tested for before the start of treatment and treated if found to be underlying.

Thrombocytopenia (reduced platelet count) is another common complication. Patients on treatment should be monitored for platelet counts, the incidence of gum/mouth bleeds, bruising, etc.

Anaemia (a deficiency in red blood cells) is big problem for patients and can severely affect their quality of life. Erythropoietin can be used to manage anaemia but it also has side-effects. Avoiding early dose reductions in ribavirin can help avoid severe drops in red blood cell counts. Iron levels should be in a normal range before starting treatment. If low, the clinician can try to slowly increase the ribavirin dose, but it important to maintain the ribavirin for the whole duration of interferon treatment. People with early onset of anaemia have lower SVR rates than late-onset anaemia.

**Irritability**

Irritability is defined as a negative affected state, a heightened or excessive sensitivity to external stimuli, or a state of physiological and psychological tension that may suddenly and rapidly escalate.

Irritability as a result of treatment for hepatitis C can have a big impact on relationships and employment. After all, a

person who is tired and itchy is likely to be a bit irritable. Both interferon and ribavirin can contribute to irritability. A common comment on interferon is that "it sends you a bit nutty". There is also a phenomenon known as riba-rage to term the extreme irritability that is attributed to treatment with ribavirin. It can hard to deal with and embarrassing, especially losing your temper with your children or at work.

Irritability is an under-appreciated but significant side-effect of treatment, and is thought to effect over 50% of people on IFN-RBV. Unfortunately, only one study has specifically investigated anger/irritability associated with INF+RIB treatment.

There is no clinical definition of irritability. Current assessment tools for other psychological conditions do not really pick up irritability and it is under-recognised. Irritability is distinct from depression. As such, treating with SSRIs may not help with irritability and may even increase it. It is important that all aspects of mood disorders are assessed not just depression.

**Future Treatment: Direct Acting Antivirals (DAAs)**

DAAs have been developed to address all five crucial steps in the HCV viral replication process. So far, the most promising of these have been those that block the protease complex and polymerase.

Telaprevir, a protease inhibitor, is likely to be the first DAA on the market. It is expected to be approved by the FDA mid next year, however, when it would be available in NZ is unknown or is the likely price. Telaprevir only works against HCV genotype 1.

The most likely and studied treatment protocols with DAAs will be what is known as triple therapy. This involves the use of a DAA plus PEG-IFN plus RBV for 12 weeks, followed by 12 weeks of standard PEG-IFN + RBV. It has been shown that ribavirin is an essential part of the treatment, helping to prevent the development of resistance and relapses. In treatment naïve patients, sustained viral response (SVR = cure) rates increase to 75% in genotype 1 and treatment duration is reduced to 24 weeks total. In previously treated patients, the SVR rate increased to 50%.

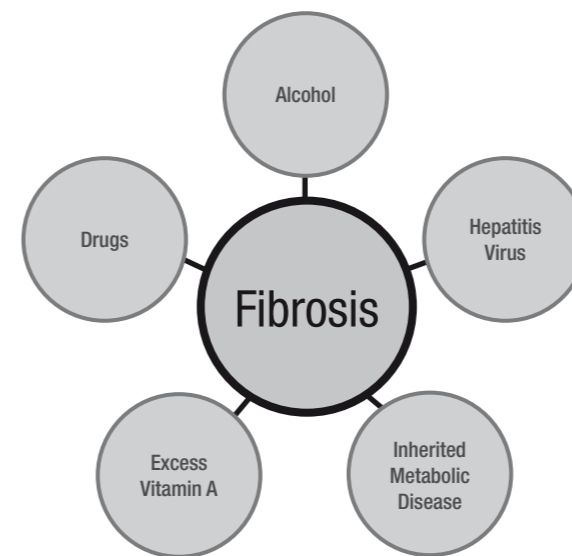
All that glitters is not gold though. Although DAAs can shorten therapy significantly for those with genotype 1, there are side effects (especially rash, itching and anemia) associated with DAAs and the development of viral resistance is a problem. All people with HCV will have some resistant HCV virus to begin with. After treatment with some DAAs, secondary mutations can emerge with high replicating fitness. There does not seem to be cross-resistance between DAAs and traditional PEG-IFN and RBV. This is one reason why triple therapy seems to be successful.

Trials are underway combining different DAAs together to try to cure HCV without having to also use interferon treatment as well.

**When Treatment for HCV doesn't work**

Most morbidity and mortality in HCV occurs in those with advanced fibrosis. So in people who don't or can't clear the virus, the management of fibrosis is important and the best management of chronic liver disease possible needs to be considered. It is important to remember that fibrosis can be reversible. Although many factors contribute to fibrosis, the liver has enormous regenerative capacity. This also means that people with HCV can be asymptomatic for years until liver disease becomes advanced. For most people with chronic HCV, fibrosis develops over 10-20 years which lead to cirrhosis and then can lead to either needing a liver transplant or the development of hepatocellular carcinoma (HCC). Some people are rapid progressors and some slower, it depends on a number of factors.

Figure 2. Factors that contribute to Fibrosis



Monitoring should include medical history (alcohol use, obesity, diabetes), a physical exam, blood tests, radiology, and fibroscans. This is important to monitor for complications, provide counselling on managing factors that contribution to liver disease (diet, etc) and deciding whether the person is a good target for re-treatment.

We need better markers of fibrosis stage and how progress can be predicted, preferably non-invasive biomarkers, not surrogates. Fibroscans are non-invasive but may be inaccurate in patients with lots of inflammatory disease. They are, however, good at making the distinctions between cirrhosis and non-cirrhosis.

What makes cirrhosis reversible? Not all cirrhosis is the same. The classification of cirrhosis was never sufficiently refined in the past because it was considered irreversible, but it is now known that this is not always the case. There is evidence of cirrhosis reversing in many diseases, including HBV and HCV. If the underlying disease that caused the fibrosis is treated, damage can be reversed, even if just partially. The less damage there is, the easier it is to reverse. Better functional and morphological discrimination is needed among cirrhotic patients to help determine who to refer to liver transplant and who to treat by other means.

If fibrosis decreases, this does not eliminate the risk of development of HCC in the future and patients should continue to be monitored for liver disease progression.

Antiviral therapy can have many benefits even when cirrhosis has developed, including:

- Reduced cirrhosis progress
- Reversal of fibrosis
- Reduced portal pressure
- Improved insulin resistance
- Improved survival
- Reduced incidence of HCC

Treatment to reverse fibrosis could take a long time, as it takes a long time to establish. Emerging anti-fibrotic therapies are taking different approaches. Some seek to reduce primary disease (anti-virals) and others to reduce injury to liver cells (reduce scarring signals). Others block growth factor with small molecules (i.e. sorafenib). These can be used at lower doses than when treating other conditions as aiming to just dampen down the effect. There are many other targets under investigation.

**Retreatment**

There are many factor to take into account when considering re-treatment:

- Host genetics and other health conditions
- Viral genetics
- Prior tolerability
- Prior adherence (especially to ribavirin treatment)
- Prior response to treatment (!)

People in whom the viral infection relapses after treatment have a better chance of achieving a SVR on re-treatment compared to non-responders. Only 6% of non-responders to PEG-IFN +RBV achieved an SVR on re-treatment in the EPIC study. Those with lower baseline viral loads and less advanced fibrosis also had an improved chance of SVR. EVR (at 12 weeks) was an important predictor of response. Giving people who relapse 72 weeks or treatment rather than 48 also seems to work well.

Long-term anti-viral maintenance therapy for HCV has been shown to not be effective and comes with significant side effects. It is not recommended.

Triple therapy with DAAs is an option once they become available. SVR rates were over 50% with telaprevir in patients who had previously failed standard therapy in the PROVE-3 trial. SVR was lower in non-responders than in relapsers.

**Recommendations:**

Consider what can be modified before stating treatment. A commitment to adherence is needed and underlying conditions (depression, alcohol use, diabetes/insulin resistance, weight, nutrition) should be treated. Also consider what cannot be modified (viral genotype, previous response to treatment, etc).

For those who relapsed after treatment could consider attempting 72 weeks of treatment. For previous non-responders experts at the conference would recommend waiting until DAAs became available in most cases.

## HCC: The problem is now

Hepatocellular carcinoma (HCC) is the 5th most common cancer worldwide. Once developed, it had a very high rate of mortality - the average survival from the time of diagnosis is around 1 year. The risk of HCC is 17 times higher in people with chronic HCC than those without. Other than HCV and HBV, other risk factors for HCC include: aflatoxin, heavy alcohol intake, obesity, and diabetes. People with type 2 diabetes as well as HCV have over 3 times the risk of developing HCC.

HCC is unique in solid organ tumours as it occurs almost exclusively in people with underlying disease and in an organ with a significant capacity for regeneration. This affects treatment options.

HCC requires a personalised approach to treatment as there are environmental and host factors that determine progression. Although there are no specific targeted therapies available yet, lots of compounds are being investigated.

If caught early enough, HCC can be curable. Treatment options for early disease include resection and radiofrequency ablation (where high-frequency electrical currents are passed through an electrode directly into the tumour, creating heat that destroys the abnormal cells.). The two procedures have similar survival profiles, but radioablation is associated with less morbidity and less recurrence of some lesions. With both procedures, there is the chance that secondary lesions will be missed. Liver transplants are also an option for those with early disease, especially for those with unresectable HCC. Five-year survival rates with liver transplants are excellent (over 80%). In Australia and New Zealand, HCC is the biggest indication for liver failure.

For intermediate stage disease (the majority of patients), transarterial chemoembolisation (TACE) is the main treatment option. As the HCC is too advanced to be operated on, TACE is given to reduce the size of the tumours. During TACE, chemotherapy is administered directly into the hepatitis artery via a catheter placed in the groin. As the chemotherapy goes directly to the tumour, the tumour receives a greater concentration of the drug/s and more cancer cells are destroyed.

Because the drugs remain mainly in the liver, there are fewer side effects than chemotherapy delivered via a vein. The techniques used are variable, but TACE does offer a survival advantage over no treatment. New technologies and forms of TACE are being developed that might lead to further survival advantage.

For advanced disease, there are really no treatment options. Chemotherapy with sorafenib is sometimes given, which does prolong life, but by weeks not years, and it has not been shown to improve quality of life.

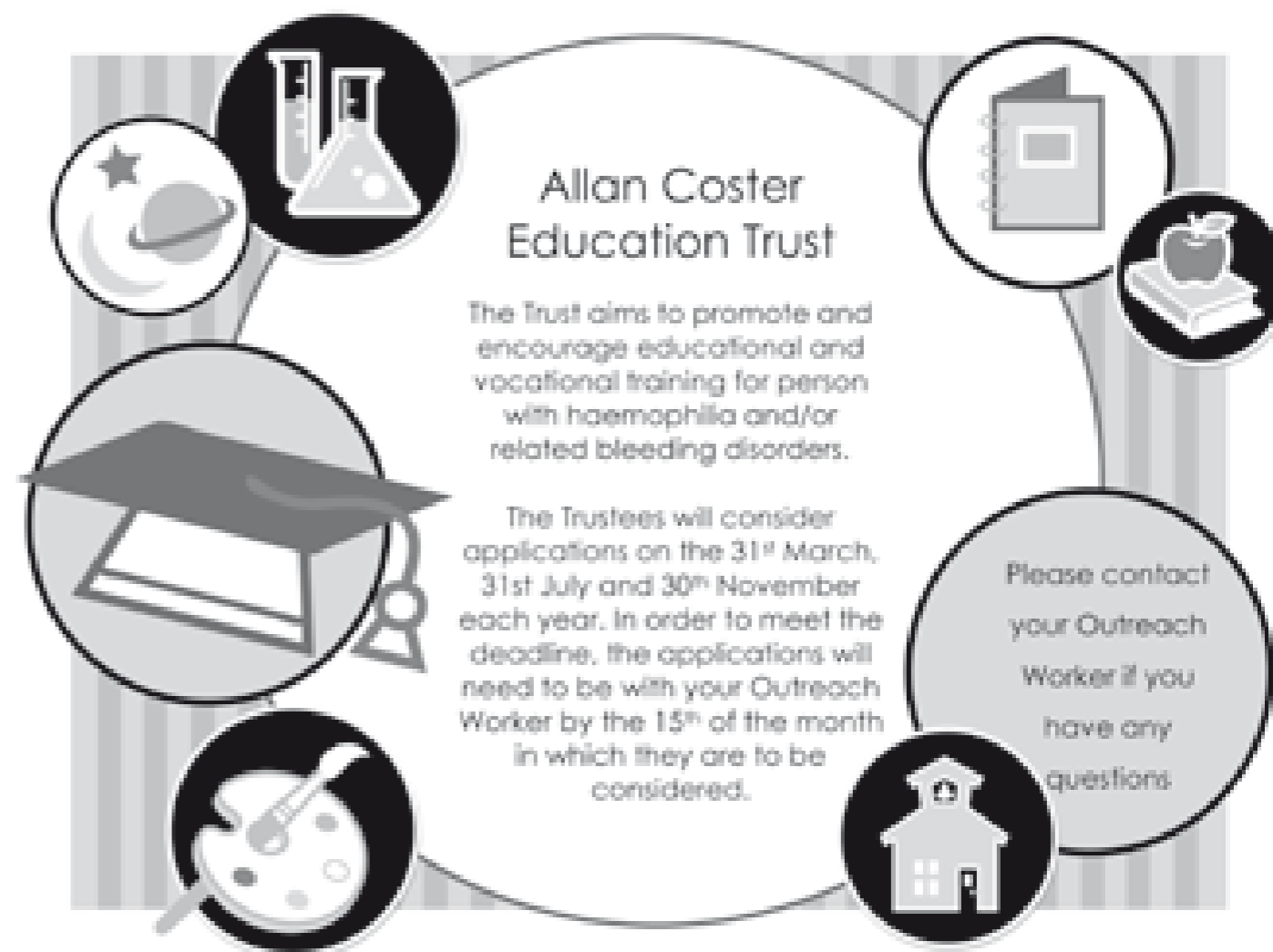
## Other messages:

Social exclusion can be a problem for those with HCV. The self-management model provides a good framework for hepatitis C, but requires the people with hepatitis C to be an active participant in the management of their condition. There are three tasks to self-management:

- Medical management
- Emotional management
- Life role management

All chronic illness is stigmatised and HCV additionally so because of the common association with illegal drug use. Fear of discrimination can be a barrier to a person accessing services. Self-management can be a turning point in adjusting to life with hepatitis C.

Firstly, in terms of medical management, a person needs to learn the facts about hepatitis C, treatment options and other things that can be done for their liver health or to manage the side-effects. For emotional management, it is important to find support. Coming to terms with the past is also a big task for many. Other elements of emotional management include disclosure, self-compassion, dealing with discrimination and managing emotions.



**Allan Coster Education Trust**

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

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

Please contact your Outreach Worker if you have any questions

## Melbourne



**Give a little? Give a lot!**

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



## Thanks Armageddon!

From October 23rd to 25th New Zealand and Australia's largest pulp culture event saw over 40,000 film, gaming and anime enthusiasts rush through the doors to meet their idols, take part in competitions, experience the latest in gaming technology and more.

For the second time, a Fantasy Ball was held on the Sunday night. Attendees had to come in either costume or mask with the \$5 entry fee and raffles going to HFNZ. After the evening's entertainment of bands and performers, the night culminated in a spectacular pyrotechnic event - the burning of a giant Wicker Man. Nearly \$3000 was raised for HFNZ on the night.

HFNZ would like to extend our thanks to Armageddon event organizer Bill Geradts for supporting HFNZ with the ball and providing us with the opportunity to raise even more through having volunteers work at the event. A special thanks also goes out to the 14 fantastic members who gave up time on their long weekend to work at Armageddon. All your efforts are much appreciated, and maybe next year we will be able to grow it even more.

## Dates to Note

### 5 December

Central Region Christmas Party  
The Esplanade, Palmerston North  
10am - 2 pm

### 5 December

Northern Region Christmas Party  
Auckland Regional Botanical Gardens

### 23 December to 9 January

National Office closed for holidays.  
Outreach will be available on call.

### 14-17 January

National Teen & Youth Camp  
YMCA Camp Adair  
Hunua, Auckland

### 21-24 January

Southern Region Camp  
Hanmer Springs Forest Camp

### 13 February

Central Region Annual General Meeting  
Location TBA

### 18-20 February

Northern Region Camp  
Waiwera YMCA

### 4-6 March

Midland Region Camp  
Totara Springs

### 23-25 March

PEP Programme: Train-the-trainers  
Auckland

### 26 March

HFNZ National Annual General Meeting  
Rotorua

### 3-4 September

Central Winter Escape

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