

# HAEMOPHILIA BLOODLINE

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NEWSLETTER OF THE HAEMOPHILIA FOUNDATION OF NEW ZEALAND INC

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## TREATMENT AND WELFARE PACKAGE FOR — PEOPLE INFECTED WITH HEPATITIS C —

**T**he Ministry of Health has announced the delivery of a treatment and welfare package for people infected with hepatitis C from blood and blood products. The Haemophilia Foundation of New Zealand (HFNZ) welcomes the package for their affected members and all New Zealanders who contracted hepatitis C from products containing infected blood.

The quest for recognition, treatment, apology and fair recompense began in 1992. Ninety percent of people with haemophilia regularly treated in the 1980's and early 1990's with human plasma based therapies contract hepatitis C from the blood products used to treat their bleeding condition. While the New Zealand blood supply was rigorously tested to screen out hepatitis C from 1992/93 people with haemophilia throughout the 1990's began to develop hepatitis C or learn of their earlier infection. When details of the catastrophe began to emerge in 1992, the campaign for full and fair recompense to the victims of bad blood was set in motion.

The present agreement was finalised between the Ministry of Health, Crown Law and HFNZ,



HFNZ representatives Steve Waring and Mike Carnahan

following comprehensive submissions and negotiations throughout 2005 and 2006. The package is based on improved access to treatment but also includes a formal statement of regret from the Prime Minister on behalf of the Government. The financial recompense is intended to address a

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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 speciality and therefore opinion may change or be varied from time to time.

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number of issues faced by people with haemophilia and hepatitis C including assistance to undertake treatment where financial constraints have been the barrier. In making this payment the emphasis is also on achieving equality of payment.

HFNZ President Dave McCone said, "It is a great result to finally have the package delivered. This has been a long and difficult road for the families affected and formal recognition from the government is an important step in the process. Our thoughts today are with those who lost someone as a result of hepatitis C without seeing this issue resolved."

The Treatment & Welfare package includes the following:

- A review of hepatitis C treatment services to allow improvement in the standard of that care. The review group will include a representative from HFNZ to ensure the specific needs of persons living with both haemophilia and HCV are met.
- A personal statement of regret and acknowledgement of suffering to individuals from the Prime Minister.
- Establishment of a one-stop shop at ACC for processing and managing ACC aspects of claims.
- An ex-gratia grant from the Crown based on ACC lump sum entitlements at the time this matter occurred in 1992.
- A provision is also provided for those receiving any earlier partial ACC settlement or ministerial settlement to receive a "top up" to ensure equity for all.
- A contribution to real and justifiable legal costs.
- A contribution to HFNZ costs of its service and representation role.
- Access to the package requires current legal claims to be brought to an end.

ACC have advised that affected people should contact their office on FREEPHONE 0800 689 001 to register for information regarding their claim or ex gratia payment and update their contact details.

HFNZ would like to acknowledge the following, without whom this treatment & welfare package may never have come to light and who impact the daily lives of those affected so profoundly:

- The support of our members who highlighted this issue from 1992 — notably Mike Mapperson, and Mary Hancock.
- The early investigative work carried out by Linda Kaye of Penney Patel Law and Roger Chapman of Johnson Lawrence Law to establish some facts.
- The visit of Brian O'Mahony World Federation of Hemophilia President, and Raymond Bradley legal council to Irish Haemophilia Society.
- The support of many members who completed questionnaires as part of the fact finding.
- Those involved with the HCV Working Party - Belinda Burnett, Mike Carnahan, Dave McCone and Steve Waring.
- Hon Annette King and Hon Pete Hodgson and the determined group of good people within the Ministry of Health who committed to seeing this package delivered.
- The nurses & clinicians who continue to provide excellent health care to people with haemophilia in a significantly under resourced environment.
- The ongoing support of Rt Hon Winston Peters, Hon Tariana Turia and Ms Jeanette Fitzsimons

McCone added, "No amount of compensation can fully make up for the personal injury many of our members have suffered, but we believe that the treatment and welfare package is broad enough to address at least the most urgent needs of people living each day with two chronic, life long, debilitating illnesses. Formal recognition from the government is an important step in the process and HFNZ now calls on the National Party to issue an apology for the part they played in the infection of innocent people with preventable hepatitis C."

HFNZ will continue to work on behalf of all our members to ensure fair treatment is accessible.



## CEO REPORT

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The front of this issue features an article on the announcement from the government of the treatment and welfare package for those who contacted Hepatitis C through tainted blood products. I can think of no better closure to the year than to finally see a resolution in place after more than 10 years of campaigning by HFNZ. On behalf of the Foundation, I would like to express our appreciation for all those involved over the years in keeping this issue alive and for the work involved in achieving this positive outcome.



*Belinda Burnett*

With this in mind, I would definitely consider 2006 a successful year for HFNZ. We now have approximately 600 members and are committed to continuing to provide quality programmes and developing new initiatives.

I think we can look toward the New Year with a positive outlook and renewed energy. For 2007, we are planning a Teen Camp, Young Women's Workshop Weekend and Couples Weekend. If any of you have, or are, teenagers who are learning to drive this coming year remember to ask your Outreach Worker about enrolling in a defensive driving course. We look forward to seeing you at the various events and reinforcing the community we have built over the years.

We wish you all a safe and happy holiday.

Belinda Burnett

## QUICK NOTE FROM THE EDITOR

As I am not usually terribly comfortable talking about myself, I just wanted to take this (very) brief opportunity to say hello and introduce myself as the new National Information Coordinator for the HFNZ and Editor of Bloodline.



*Chantal Lauzon*

Hailing from the (arguably) equally beautiful Canada, I am happy to embrace New Zealand as my new home.

Having lived here less than two years, I have always been impressed with the open-hearted welcome I have received from all I meet. Joining the team at HFNZ as been no exception.

I look forward to working with the team here in Christchurch and others across the country, and meeting as many members as I can as time goes on.

I see Bloodline as a newsletter for you the members, and should reflect information that interests you.

Please feel free to contact me at [chantal@haemophilia.org.nz](mailto:chantal@haemophilia.org.nz) with any comments or suggestions you may have.

All the best,

Chantal Lauzon

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## REMEMBERING THORA GRIFFITH

The Haemophilia Foundation would like to acknowledge the generous donation received in September 2006 of \$10,000 from Thora Griffith, Grandmother of John Tuck who is the Treasurer of the Midland Branch and Midland Delegate to the National Committee.

Thora was always very interested in the work of the Haemophilia Foundation and on learning of the Foundation's intention to purchase a property she chose to contribute towards this goal. HFNZ are most grateful for her thoughtfulness and generosity.



*John Tuck and Thora Griffith*

*By John Tuck*

This photo was taken of Gran and I in Auckland on 1<sup>st</sup> October 2006, just on one month short of her 94<sup>th</sup> Birthday. Corinna, Gran and I spent an enjoyable weekend visiting her old haunts in Auckland; she just loved the drive from Mt Maunganui via Kaiawha on the coastal road.

Thora was born in Cambridge, NZ on the 8<sup>th</sup> November 1912. She married Stuart Griffith in 1938, he was in the Police Force and they lived in Auckland. They had three children; Wendy, John and Pam. John was born in 1942 and was found to have Severe Haemophilia.

The only treatment available at the time was intravenous whole blood, bed rest and traction. John spent a lot of time during his early years in Auckland Hospital. When Stuart and Thora eventually purchased a farm in the Waikato in 1946, they then had to travel 50 Km in a Model T Ford to Waikato Hospital - at a time when tyres and petrol were in short supply. Gran spoke of the many months John spent in hospital. At the time, parents were not allowed to visit as it was believed to be too upsetting for the children when they left. She spoke of one occasion when John was hospitalised for 7 months. He wasn't well enough to

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attend the local school but was taught at the hospital school and also correspondence school. He was a brave little fighter with a happy disposition and had many friends. He had suffered major joint damage and sadly died at the age of eleven (we think from a possible brain haemorrhage).

I was born in 1965 before carrier status test were available. Gran was always very involved in my life

and Sue (my sister) and I spent many happy holidays with her and Da at Bucklands Beach. She was a regular visitor during my many stays at Auckland Hospital. I later boarded with Gran while attending Macleans College in Bucklands Beach and she was very involved with helping me in the new experience of home treatment and was very supportive. I had a great life — 5 days in Auckland then back

to the farm and my motorbike each weekend!!! Gran was very caring and tried hard not to bring her earlier experiences of haemophilia into my life. I am sure she held her breath many times!!

Gran spent the last 15 years at Mount Maunganui and sadly passed away on 27<sup>th</sup> October 2006, a wonderful mother, Grandmother, Great Grandmother and friend at rest.

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## YOUTH CAMP '06

This year's Youth Camp was held the 22-25<sup>th</sup> September, at the Palm Grove Christian Camp in Paraparaumu. Located in 10 acres of bush setting along the Kapiti Coast, the guys really had the chance to get away from everyday life, socialise and learn about their bleeding disorders.

The weekend was attended by 19 young men (aged 14-23) from across the country and was packed with opportunities to have fun, forge friendships and learn valuable life skills. Right from arrival on Friday evening the guys were engaged by a drumming workshop with Mabeth Ciurans, and the activities continued right through the weekend -despite the less than perfect weather.

As far as the participants were concerned the highlights seemed to favour the recreational activities, especially the field archery and Go-Karting at Indoor Raceway. On Saturday, the group visited the Southwards Vintage Car Museum, which houses the largest private collection of vintage cars in the Southern Hemisphere. Cars on display included Marlene Dietrich's Rolls Royce and a Chicago gangster's armour-plated limo.

One of the most popular activities by far was the

Junkyard War competition. Steve and Martyn Waring provided parts for two 3-wheeler vehicles, which teams competed to assemble and then race against each other.

The learning element of the weekend was also a success with the Q&A sessions and Quiz Show proving the most popular. Participants enjoyed daily hydrotherapy sessions at Raumati Pool with Carole Rodgers and sessions on CV/Job interviewing techniques.

Drew Mackenzie, who organised the camp, said the highlight for her was seeing the guys interact together in an environment where they all shared the weight of having a bleeding disorder. Youth Camp gives them a chance to catch up with guys they may have met at previous Family or Youth Camps and share how they are dealing with the challenges of growing into an adult.

Throughout the Camp the group was divided into two teams, Blue and Green, who competed for points during the various activities, especially during the Quiz Show and Junkyard War. Bloodline congratulates the Green Team on their overall victory and hopes many of the participants return in 2008.

Dear Drew,

Just letting you know how awesome this year's camp was! Hopefully if we ever get enough sponsors we can have one every year! It was awesome meeting all the fahas and making new friends. I definitely enjoyed the jam-packed weekend full of activities — most of all the Go-Karting. The car museum was OFF THE HOOK!! I got some pimpin' photos with me and Dylan (Big D) there. I also learnt heaps in our group talk with Doctor Carter and I'd like to say shame the Blue Team! It must be hard coming second place out of only two teams! Ha! Ha!

Thanks heaps to everyone who helped out with the camp — all the nurses, doctors, cooks and Drew, Colleen and Kate! I definitely have to thanks Vodaphone as well for even making this possible (can we have cell phones next time?). I'd like to shout out to Big D, Tama, Jordan, Stace, Blair x 2, Conner and all the rest of the boyz!

Raukura Riwaaka

# YOUTH CAMP AT A GLANCE



*Drumming workshop*



*Junkyard war*



*Showing off at the car museum*



*Green team*



*Chillin'*



*Blue team*

# SURVIVING THE HOLIDAYS

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By Mary Lou Cygan MSN, RN, CPNP for Parents Empowering Parents

The holidays are quickly approaching and all the hustle and bustle that goes along with them. Surviving the holidays can be more enjoyable if we employ some understanding of why we become stressed, situations where children may act-up and how planning ahead can help.



Holding a family meeting can be very effective with older children to outline family plans and expectations. Involve the children in the planning and assign them age-appropriate and specific responsibilities whenever possible. When children are involved in the planning process, they are more inclined to have ownership in the overall plan, which may eliminate conflicts when delegating tasks later on. If the child has accepted responsibility for a particular task, hold them responsible for their decisions unless there are uncontrollable circumstances that prevent them from following through, such as a bleed. Here are some helpful hints to help make the holidays more enjoyable for the entire family.

Our behaviours are influenced by internal as well as external factors such as what is going on in our immediate environment, our previous experiences

and our physical condition. If the child is experiencing recurrent bleeds, holiday plans may just fall apart. The key is to try to prevent bleeds whenever possible. This may be a time to consider prophylactic treatment before some family gatherings where young children may be exposed to unfamiliar environments. Check with your physician to see if this is appropriate for your child so you can try to avoid unplanned trips to the clinic or emergency department.

It is also very important to understand why children misbehave. Changes in routine can be confusing to children because they do not know what to expect. Try to maintain "normal" routines and structures as much as possible. Even as adults, we have a hard time adjusting to continually changing environments when we don't know what to expect next. Imagine the frustration of a child when his or her schedule is continually changed without notice without understanding why. Lack of sleep, missed naps, going to bed later than usual and getting up early can be confusing and exhausting to children. Compound that with overwhelmed parents who are trying to accomplish an unrealistic list of chores and chaos is sure to occur.

As we continue with our holiday preparations, various decorations that have been in storage emerge in our homes and are a natural curiosity to young children. The key is to keep the child's age in mind when deciding which items should be used. If children are old enough to understand that these items are to look at only, it is okay to have them out. If the child removes items from their display area, appropriate and consistent consequences should occur for this misbehaviour. Remember, children will test limits especially when they know that parents are distracted or tired. If the child is too young to understand "do not touch" it might be better to remove the temptation and disappointment of breakage by not using the items until the child is older.

As the final day approaches, try to remain calm while you complete the finishing touches to the holiday celebrations. Try to increase your child's desirable behaviour before having to tackle undesirable

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behaviour. Attention through praise and rewards can work wonders. As parents, we have a tendency to scold and punish when children misbehave and ignore their good behaviour. This holiday season compliment your child when they are quietly entertaining themselves or possibly offer an unexpected reward. A child's curiosity when you are making cookies or wrapping gifts can be a positive experience for you and your child if he or she is given a portion of the task to accomplish. So plan ahead and think what would be easy for them to do. When the child is engaged in his or her job it might actually be possible for you to accomplish more.

When the stress of it all finally comes and you are feeling overwhelmed with too much to do and not enough time, don't give up. It is time to identify the stressors and take action. Stop; write down what the issues are. If the culprit is too many tasks, decide which ones are essential and which ones are less important and can be forgotten. A wise aunt of mine told me you always pick up before company and clean after they leave. If you think about it, it makes sense. A houseful of people can mask almost anything.

Recognizing stress early gives you the opportunity to decrease it before it causes you physiological and emotional harm. Signals of stress can be physical, behavioural or emotional and are different for each person. Symptoms of stress can include frequent headaches, appetite changes, inability to concentrate, unexplained irritability, neck or shoulder soreness, upset stomach, depression, poor memory, insomnia or excessive sleeping, nightmares, feeling sad and feeling more tired than usual. Sources of stress can also be in our relationships. Family and friends may have unrealistic expectations over the holidays. It may be necessary to evaluate the situation, set priorities and place limits on what can be accomplished. Our children may be a source of stress if they misbehave or have a bleed. Remember the techniques previously discussed which might be helpful. Money may also be a source of stress at this time of year. Try to find economical shortcuts so that the holiday expenses will not follow you into the New Year. Remember that negative thoughts about yourself can result in feelings of stress and result in low self-esteem and depression.

Making an escape plan to decrease your stress is helpful. If you are going to be able to refocus your attention and deal with the causes of your stress, you must have temporary escapes from it. Good stress relief habits include learning to say NO, getting enough sleep, eating a well balanced diet, prioritising your chores, thinking positive thoughts, making time for yourself each day, and taking a fun break with you partner and/or child. Remember, the holidays are meant to be a special time.

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*Mary Lou Cygan is a Certified Paediatric Nurse Practitioner currently employed at Backus Children's Hospital Hematology/Oncology Clinic at Memorial Medical University Medical Center in Savannah, Georgia. She was previously employed for 28 years at Children's Hospital of Michigan, over 10 years of which were in the Hemostasis and Thrombosis Center of Michigan. Mary Lou has made numerous presentations both nationally and internationally on topics related to bleeding disorders, published several abstracts and articles and has served on national and international advisory boards. The National Hemophilia Foundation named Mary Lou Nurse of the Year in 2000. Mary Lou's special expertise and knowledge related to bleeding disorders comes from being the sister, cousin and mother of an individual with haemophilia.*

*Source: Reproduced with kind permission from the Chandler Chicco Agency. This original article appears on [www.pep-program.com](http://www.pep-program.com).*

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## ALLAN COSTER

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## EDUCATION TRUST

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

The three Trustees have recently met and reviewed the Trusts processes including financing applications. The guidelines and application forms will be updated and given to the Outreach Workers. The Trustees will consider applications on the 31st March, 31st July and the 30th November each year. In order to meet the deadline, the applications will need to be with your Outreach Worker by the 15th of the month in which they are to be considered.

It should be noted that the amount approved for each application would depend on the finance available in the Trust account.

**Please note that the Trustees have informed HFNZ that they will no longer be considering applications for computers at this time. Please contact HFNZ or your Outreach Worker if you have any questions regarding this.**

# THE AUSTRALIAN AND NEW ZEALAND PHYSIOTHERAPY HAEMOPHILIA GROUP MEETING — 18<sup>TH</sup> AUGUST 2006

In August, thirteen physiotherapists from all over Australia and two from New Zealand attended the 2006 physiotherapy meeting at HFA headquarters in Melbourne. The New Zealand representatives were Lynette Hing from Starship Hospital and myself from Christchurch Hospital.

The meeting was a great opportunity to network with colleagues, discuss treatments and research, update ourselves and make useful contacts. The program included feedback from the WFH Conference in Vancouver. One message from Vancouver was that prophylaxis doesn't equal treatment of bleeds on its own. Remember to use R.I.C.E. — Rest, Ice, Compression and Elevation to encourage evacuation of the blood from a bleed as soon as possible. Contact your physio for ongoing problems of pain, loss of movement and strength.

The group also discussed materials to use for compression. Some are using elastic self-adhesive bandage such as Coban. This can be adjusted to give a pressure you can tolerate. The alternative is Tubigrip. It can be good to have some available at home to use as needed. Children in particular have difficulty tolerating

By Kay Boone, Physiotherapist, Christchurch Hospital  
ice and an alternative suggestion was the use of "Cool Relief" patches that use menthol as a cooling agent.

One new initiative starting in Perth was a group for managing chronic pain especially for people with haemophilia. There are many chronic pain programs running in the bigger centres in New Zealand and attending one of these could be an option here. They give ideas on how to cope with pain, use of medication, improving fitness, and balancing work and rest. Talk to a health professional in your area if you would like more information.

The afternoon had round table discussions on treatment approaches including synovectomy, ultrasound with arnica for soft tissue bleeds, outcome measures and case presentations, some very complex. Rebecca Dalzell from Brisbane told of her use of laser on joints with synovitis to decrease inflammation.

Overall it was a very worthwhile day stimulating thoughts on ways to enhance our service.

I am very grateful to the Haemophilia Foundation of New Zealand for enabling me to attend this meeting.



*ANZ Physio Meeting - Australian and New Zealand Physiotherapy*

# PHYSICAL FITNESS PLAYS A PART IN SUCCESSFUL MENTAL AGING

As advances in treatment mean that the people with haemophilia are living longer than ever before, more attention and research is being focused on quality of life issues.

Although it has been clearly established that physical fitness can help strengthen muscles and reduce the likelihood of a bleed, recent research has shown that physical fitness may also contribute to successful mental aging.

The Scottish study, recently published in the journal *Neurology*, found that 79-year-old individuals who were more physically fit had greater mental acuity, even after accounting for childhood IQ (measured at age 11).<sup>1</sup>

The team sought to determine whether physical fitness contributes to successful mental aging over and



above their mental ability in youth, and so rule out the possibility that smarter people in youth get fitter in old age. The 460 participants took part in a variety of mental and physical tests to investigate this.

## A Sound Mind in a Sound Body

The research team found that physical fitness, determined as lung capacity, grip strength and ability to walk, contributed to later life cognition after adjusting for childhood IQ. Their findings imply that of 2 people starting with the same IQ at age 11 years, the fitter person at age 79 years will, on average, have better mental ability.

At a later interview the authors noted that, "At the level of the general population, being fit is not only good in itself, it is also associated with better cognitive functioning. Surely this just reinforces the message that is it a good thing to be as physically fit as one can be."

<sup>1</sup> Deary IJ, *et al.* Physical Fitness and Lifetime Cognitive Change. *Neurology* 2006; 67(7):1195-1200.

Source: Adapted from [www.medscape.com](http://www.medscape.com)

# WFH HOSTS THIRD REGULATORY WORKSHOP IN CAIRO

The World Federation of Haemophilia (WFH) hosted thirty-nine regulators and blood bankers from countries all over the Middle East and Africa in Cairo this September as part of an ongoing series of regulatory workshops. In collaboration with the World Health Organization (WHO) and the Egyptian government, the WFH hosted the Joint Workshop of the WFH and WHO on Regulatory Issues Relating to Plasma-Derived Products to educate national authorities about the evaluation and selection of haemophilia treatment products.

Workshop participants heard about plasma-derived treatment products, looking at the manufacturing process, safety factors, efficacy, and various licensing and regulatory systems. The workshop was chaired by WFH President Mark Skinner and Vice President Communications David Page. Australian regulator Albert Farrugia, WFH Blood Safety advisor and author of the WFH's popular publication *Guide to the Assessment of Clotting Factor Concentrates for the Treatment of Hemophilia*, also shared his vast knowledge of regulatory issues with the audience. Other speakers at the workshop included

international experts in the manufacturing, viral inactivation, and regulation of plasma-derived products.

The participating countries have very different economies and the state of haemophilia care varies greatly. The workshop was a chance for regulators from those countries to get specific information on how to make the difficult choices about safety and efficacy, and the regulators were eager to learn how to make these decisions rationally and responsibly in the context of their own healthcare systems.

The WFH plans to hold more regulatory workshops around the world in an effort to educate regulators about plasma-derived

haemophilia treatment products and to enable them to make the best choices, in terms of safety and efficacy, for their national healthcare systems to ensure appropriate treatment for people with haemophilia. Based on feedback from the participants, Prof. Farrugia is updating the clotting factor assessment guide for re-issue next year.

Source: World Federation of Haemophilia, *Safety & Supply News*, October 2006.



Cairo

# GETTING READY TO START SCHOOL

**A**s a parent of a young child with haemophilia or another bleeding disorder, you already understand many the medical and emotional challenges these conditions bring. When the school-age years approach, a new challenge awaits: your child is about to spend a great amount of his time with classmates and teachers in completely new surroundings. This is an important time in any child's social and mental development.

There is a lot you can do to help prepare for this important step. If your child enters school with confidence, a positive self-image, and a good understanding of their condition, the experience can be a positive and rewarding one. Similarly, if you educate the school staff about your child's needs they may be more likely to provide appropriate support.

Below are a few tips and suggestions to help both of you face this important next stage in life.

## Getting your Child Ready for School

Even if others have cared for your child, either at home or in preschool, the school-age years generally mark your child's first long-term experience in unfamiliar surroundings without your supervision. He will enter a classroom with children from diverse backgrounds and every day he will have make more independent decisions about his behaviour and take on more responsibility for his own care.

By the time they reach school age, children are generally capable of thinking logically and seeing cause and effect. A school-aged child will be able to report when he has a bleed. He will also start to understand that certain activities are more likely to cause bleeds than others and can be



encouraged to be cautious about those activities.

At this age, the child also starts to worry about adult feelings. If you react to his bleeds with anger, fear, and frustration, he may try to "protect" you by not telling you he is

**A** school-aged child will be able to report when he has a bleed.

bleeding until the pain becomes hard to bear. Respond to bleeds in a matter-of-fact, reassuring way.

For instance, you might say to the child, "I'm sorry you're hurt, and I'm glad you told me you had a bleed. Let's get your treatment started so you can feel better soon."

During this stage, it can be especially easy for parents to set too few or too many limits. "Permissive" parents may feel sorry for their child and try to "make it up to him" by not setting appropriate limits. "Protective" parents may set too many limits and monitor the child's every move in an effort to keep him safe. School-aged children need both clear and consistent rules and the freedom to develop their own interests and abilities. For instance, establish a rule that your child and his playmates may not hit each other. As long as no one is hitting, avoid jumping in to settle every argument that comes up. Let your child experiment with different ways to resolve conflict.

Help your child develop strong self-esteem by teaching him about haemophilia in an age-appropriate

way, by sharpening skills, and by finding activities in which he can excel.

School-aged children with haemophilia belong in regular classrooms, taking part in almost every activity with their peers. Your child may only realise how different he is as he interacts with peers. He may deal with feeling different by ignoring bleeds or crying wolf. This is a normal part of development.

One method that may ease your child's concerns about what school will be like is to play a "What To Do If..." game. You describe a situation, such as "you've just fallen off the climbing frame in the playground," or "another kid asks why you wear a bracelet," and ask your child what he would do. If he answers appropriately, go on to the next situation. If he cannot answer, discuss the situation and together determine what a good response might be. This game can help your child develop confidence that he will be able to handle these situations when they arise. You can play this game before school begins, and continue playing it through the school years to deal with new challenges as they crop up.

Your child's bleeding disorder is a very personal matter and the decision to let his classmates know should be discussed between the two of you if he doesn't wish to do so. This is a decision you should both make

**P**rotective parents may set too many limits and monitor the child's every move

together. If you do choose to share his condition with his classmates, they should learn the basics of haemophilia and understand that it is

normal for your child to miss school occasionally, have bruises, or wear protective clothing/equipment that they may not need themselves when playing. You can choose to make a simple presentation to the class, or just help you child prepare to talk about his condition simply and honestly. Keep in mind that if your child and his teachers appear calm

continued next page

and casual about the situation, his classmates may be more likely to understand his condition.

## Getting the School Ready for your Child

Ensuring your child is happy, confident and physically well in school is a team effort. Meet with school staff, including the teacher, principal, office secretary, physical education teacher/coach, and school nurse. If possible, include your haemophilia treatment centre nurse coordinator or outreach worker.

People with no experience of bleeding disorders know extremely little about them. Offer the staff children's books as an introduction. If you leave educational material with school officials, it's a good idea to attach your child's photo to it so they can make the association. Try not to overload them with information.

Work out a plan with teachers and the school nurse for how to identify a



problem, when to call you and what to do. Make sure they know how to reach you at all times by providing a mobile number or similar.

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**E**nsuring your child is happy, confident and physically well in school is a team effort.

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Explain to teachers that they should avoid overprotection, singling out your child, denial of haemophilia or bleeds, and overreaction. It is especially important to explain the

symptoms of a bleed and if there are specific activities you do not want your child to participate in.

Your child may miss school at times. When they have a bleed or have to go into hospital, you can keep them up in their schoolwork. Alert teachers that the child may miss some school. If necessary, ask a tutor to help out. Keep in touch with teachers throughout the school year to discuss your child progress, development, and any concerns he or she may have. If you develop a relationship based on open communication and trust with school officials it may help to improve your child's physical and emotional development.

Sources: Material adapted from information available in/on [www.haemophilia.org](http://www.haemophilia.org); [www.hemophiliagalaxy.com](http://www.hemophiliagalaxy.com); and Kelley, Lauren. *Raising a Child with Hemophilia — A Practical Guide for Parents*, Aventis Behring LLC, 2000.



## Checklist for Getting Ready for School

Preparing your child for school should begin early to allow enough time for you to help the school staff learn more about haemophilia and help your child adjust to a new school environment. Follow this basic timeline to stay on track while planning and preparing for the school year:

### Four Months Before School Starts

- Make a preliminary visit to your child's school before the end of the previous school year and introduce yourself to the principal and the school nurse (where available).

### Two Months Before School Starts

- Write to the school and schedule an informational conference during the next month with the principal, school nurse, and your child's teacher. Ask your haemophilia treatment center (HTC) nurse or outreach worker to accompany you and provide information about haemophilia and your child and answer questions from school staff.

- Develop an individualized health plan with your HTC, physician, and school.
- Supply the school with emergency phone numbers and educational materials about haemophilia.

### One Month Before School Starts

- Hold the informational conference at the school you scheduled with an HTC nurse or outreach worker and school personnel to provide information about haemophilia and your child and answer any questions that the school staff might have.

### First Day of School

- See your child off to the big adventure!

# CENTRAL'S FAMILY CAMP A BOUNCING SUCCESS!

Contributed by Joanne Kinnaird

**N**o fun event or nice cake was left untouched as the sunshine city of Napier was taken over from the Central Branch of the New Zealand Haemophilia Foundation's camp held over the weekend from the 1st September.

Families came from near and far to spend the weekend at the Kennedy Park Top 10 Resort holiday accommodation. Talking to the children, the park's facilities went down a treat with each youngster (both types the young and the not so young). For some of the families it was their first time in a motel and for others it was a well-earned break away from the usual humdrum of life. It was the first time some of the families had met others affected by haemophilia and other bleeding diseases.

High on the agenda for the mainly school-aged children, and one very special toddler called Connor, was the huge air pillow, which was in use from when it was inflated in the morning to around 9 pm at night when the air pump was turned off and the pillow slowly deflated. The enclosed circular trampolines also got a hammering as the children spent a carefree weekend just having fun - not worrying about the fact that they belong to an exclusive club!

It was inspiring to see that, despite living with different types of haemophilia, different degrees of the disease and other bleeding disorders like von Willebrand's, this did hold back any of the children as they spend hours on the air pillow, trampolines, and riding pedal driven cars around the complex. A couple of hardy souls even braved the complex's pool in search of a dead seahorse - which was recovered from the depths of the pool and buried in a nearby garden.

The parents got to eat copious amounts of food whilst chatting with other parents — sharing opinions, asking questions and looking for advice. The main

topic of discussion was the road they travelled themselves and with their children to get a diagnosis. This proved to be an interesting exercise as no two stories were the same and some of the stories were harrowing to say the least!

But the weekend was not all play and soon it was down to hearing about the important stuff — improvements and developments in the treatment of the various bleeding diseases.

David Habershon spoke about the safety and supply of blood products, the importance of the foundation's ongoing research and input into Government policy

on haemophilia treatment. Haemophilia Foundation CEO Belinda Burnett also spoke on the structure and history of HFNZ.

Central Chairman Grant Hook said it was interesting to see that a lot of the people involved with the foundation were unpaid volunteers who were drawn to the foundation

to improve life for this current generation by working very hard to provide education and support to people with haemophilia all around New Zealand.

"HFNZ has a good profile on the international scene due to being represented on world organisations and by attending conferences overseas to source the latest information and treatment protocols," Grant said.

Central outreach worker Drew McKenzie spoke of the importance of exercising and how, by increasing activity, it can strengthen a patient's pain thresholds.

Many thanks for the organisational skills and dedication of Grant and the rest of the Committee, as well as Belinda and Drew.

The biggest thanks must go to the fundraisers who tirelessly work on behalf of families — their work was really appreciated by all of those who attended the camp.

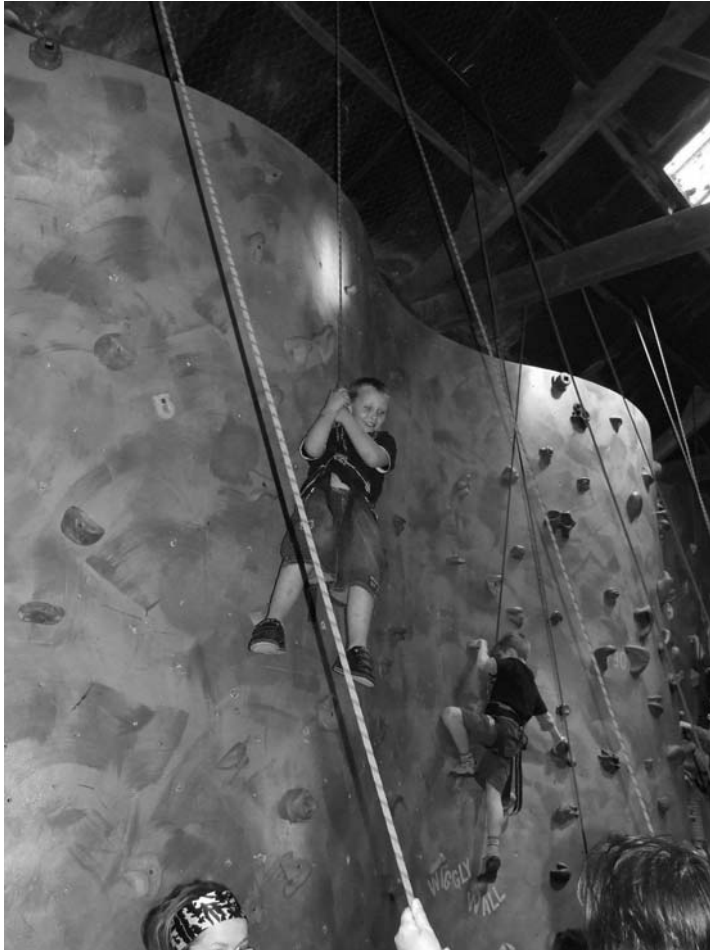


*The whole group*



# CENTRAL FAMILY CAMP AT A GLANCE

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*Just hanging out*



*Taking a moment*



*Bouncing the day away*



*Visiting the climbing wall*



*Making new feathered friends*



*Grant Hook and Belinda Burnet*

# SOUTHERN REGION CHILDREN'S EDUCATION DAY

On 2 October, HFNZ's Southern Regional Branch sponsored their first Children's Education Day. Educational sessions for this age group were a huge success at the last Family Camp in January. To build on the positive feedback from these sessions, sixteen children with bleeding disorders, aged 6-12 years, from Christchurch and Dunedin met up in Christchurch for a day of fun and learning.

Outreach Worker Colleen McKay organised a fantastic day for the kids which began with an educational session at the HFNZ head office. Together with eight helpers, the group discussed different types of bleeding disorders, different types of treatment, what happens during a joint bleed, etc. Key messages from what they learned were reinforced throughout the day.

The group then travelled to the Children's Haematology and Oncology Centre (CHOC) at Christchurch Hospital where Nicky Wollaston, a Children's Play Specialist at Christchurch Hospital, engaged them in a game about the pros and cons of having a bleeding disorder. After a healthy lunch by the river, the group crossed through the tunnel connecting Christchurch Hospital with the laboratory building to see first hand what happens to their blood samples. The kids got to see the machine where the assays for Factors VIII and IX, and vWD were done, as well as a television projection of a blood sample on a microscope so they could clearly see the different blood cell types.

The group then we all went by the Haemostasis Service to visit Ally Inder and Carolyn Lauren and to see where the adults with bleeding disorders go.

The tour was followed by a refreshing and fun session in the hydrotherapy pool led by Kay Boone, paediatric physiotherapist, and her assistants. The day wrapped up back at the HFNZ office with afternoon tea and more educational activities.

All in all, the day was a big success and kids went home full of new facts to help them as they grow and cope with their disorders, as well as a special bag of goodies.

*Colleen would like to extend a Special Thanks to the various people that helped out with the day — the youth that were Group Leaders, Parent Helpers, Leanne and Jayne in the Office, Nicky Wollaston, Kay Boone, Malcolm and Sarah at the Physiotherapy Department, and Carol in the Canterbury Health Laboratory.*



*The whole gang at CHOC*



*Hydrotherapy with Kay Boone*



*The tangled web of living with a bleeding disorder*

FIRST ANNOUNCEMENT



# Australian & New Zealand Haemophilia Conference

Canberra 4-7 October 2007

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

HAEMOPHILIA FOUNDATION AUSTRALIA

**The 14th Australian and New Zealand Haemophilia Conference is to be held at Hyatt Canberra from Thursday 4 October - Sunday 7 October 2007.**

This biennial national conference offers people with bleeding disorders and their families and health professionals an opportunity to come together to learn more about the treatment and care and future directions for the bleeding disorders community in Australia and around the world.

An exciting multidisciplinary programme will include presentations by Australian and overseas experts who will address current issues in treatment and care of children and adults with bleeding disorders, treatment product safety and supply, research and models for psychosocial support and wellness.

Who should come?

- People with haemophilia: von Willebrand disorder or other bleeding disorders and their parents and siblings
- Young people - a Youth Stream will be integrated into the programme with topics of interest to youth
- Health professionals - doctors, nurses, physiotherapists and social workers
- Treatment product producers
- Policy makers and government officials
- Haemophilia Foundation volunteers and staff

see further information next page

To register your interest and to receive regular updates email your contact details to [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or visit [www.haemophilia.org.au](http://www.haemophilia.org.au) and click on conferences.

Our website will be regularly updated. Registration forms will be available in early 2007 and programme details will be published in mid 2007.

**Haemophilia Foundation Australia**  
**1624 High Street, Glen Iris VIC 3146**  
**P: 03 9885 7800 F: 03 9885 1800**

**E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) W: [www.haemophilia.org.au](http://www.haemophilia.org.au)**



# 14th Australia & New Zealand Haemophilia Conference

from previous page

## FAMILIES

Our conference is family friendly and will be helpful for young families as well as people who have lived for many years with bleeding disorders

## YOUTH

Come along and enjoy friendship and fun, and the new opportunities for learning and peer support

## HEALTH PROFESSIONALS

Share information and knowledge and learn about new developments

## SPONSORSHIP

If your company wishes to participate in this exciting education event contact HFA to discuss an attractive sponsorship package

## EXHIBITION AREA

An excellent space will be available throughout the Conference for exhibitors to showcase new developments and ideas

## SUBMIT AN ABSTRACT

A call for Abstracts will be published on the HFA website soon. Register your interest so that we can send you details. The deadline for abstracts is March 2007

## GLOBAL FEAST 2006 REPORT

During September, HFNZ joined members of international Haemophilia Foundations including Australia, Ireland, United Kingdom, Portugal, Iran, Argentina and Netherlands for Global Feast 2006. Global Feast events were organised in an effort to raise money for haemophilia education and treatment in developing countries.

In New Zealand, Global Feast was an excellent opportunity to raise awareness regarding haemophilia and bleeding disorders, as well as funds for those who do not have access to the great level of care we enjoy here. Events were held across the country to celebrate and enjoy some tasty kai.

As a family, Lynley and Rob Scott from our Northern Region organised three separate events to celebrate Global Feast:

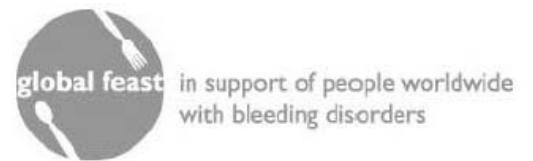
- Lynley organised a lunch for her work colleagues before their monthly meeting. She provided a light lunch and colleagues donated their lunch money to Global Feast. John Cook, HFNZ Northern Delegate also attended. It was a great way to open up opportunity for discussion on haemophilia. Around 15 people attended and about \$150 was raised.



ARTA staff helps to celebrate Global Feast

Colleagues commented on how fun it was and a great way to give to charities.

- Richard organised a typical Kiwi meal of fish and chips with L&P for his work mates at the Auckland Regional Transport Authority (ARTA). No dishes to wash! The staff donated their normal lunch money and had also held a raffle. Around 40 people attended and nearly \$700 was raised. The recent Bloodline and HFNZ newsletter were available to read and staff felt free to ask questions. It was a good way of involving his work mates in what haemophilia is like for them as a family and the dramatic contrast to what is available elsewhere. Everyone thoroughly enjoyed the event and suggested we do it regularly for other charities.
- Finally, as a family we opened our home one Sunday afternoon to celebrate one year without inhibitors to Factor VIII. It was a



great opportunity to join with family and friends to celebrate, and share in some afternoon tea. It was also an opportunity to thank those who have supported us through our journey through tolerisation and finally Rituximab to achieve no inhibitors. Having struggled so long with inhibitors, it has opened our eyes to how different life can be with prophylaxis. This also helped us see how important supporting such events as Global Feast is.

Global Feast provided us with an easy opportunity to spread the word about Haemophilia and provided us with a chance to make a difference for someone out there not as fortunate as our son.

Global Feast Events from the rest of world

- Melbourne: Sausage sizzle in the Melbourne City Square
- Montreal: Fiesta Salsera — a family event with South American dancing, food and performers

Perhaps some of the above will provide inspiration for Global Feast 2007! For more great ideas check out [www.globalfeast.org](http://www.globalfeast.org).

## MEET CARMEN TUPARA

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As many may remember from the HFNZ 2000 Fundraising Appeal brochure, Carmen Tupara is the mother of Jayden Tupara, who was born with severe haemophilia and suffered a near fatal internal bleeding episode during birth with left him with physical and mental disabilities. After intensive campaigning on his behalf, Carmen ensured Jayden received all the health care he deserved and has grown into an active 11-year old.



Carmen decided to use the strength and skills she had developed raising and caring for Jayden to try and make a difference for other people. For her this meant joining the New Zealand Police.

"My auntie originally suggested I join. I thought about — for over a year — before deciding. I was the first thing I have done for myself since Jayden was born and I thought it was time for me to get out there and make a difference", reflects Carmen.

After attending an information session and completing the enrolment exercises, Carmen embarked on her journey to becoming a policewoman, including 5 months away at the Royal New Zealand Police College in Porirua. Carmen and Jayden live in Kaiapoi, Canterbury and she had never spent more than 3 nights away from Jayden since he was born. While she was away training, Jayden stayed with his grandparents. Carmen was able to see him only about every 3 weeks, sometimes spending up to a month apart.

"Being away from him was the hardest part", says Carmen. During the training camp Jayden developed problems with his Porta-Cath requiring an operation. Carmen was able to return to Christchurch for the surgery, but had to return to training soon after. She says the physical side of the training was not as difficult as she expected and the written side required a commitment to study the whole way through, but it was the distance from her family that was the real test for her.

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"It's been hard, and I wouldn't have been able to do it without Mum and Dad"

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Carmen successfully graduated from training and will now spend the next two years as a Probationary Constable training with different police departments back in Christchurch. She has to constantly change from day to night shifts and work on weekends depending on her placement. She says her biggest challenge is time management, juggling shift work, spending time with Jayden and getting some sleep in somewhere. Jayden stays with her parents while Carmen is working, often staying overnight. She tries to spend as much time with Jayden as possible, and is committed to either bringing him to or picking him up from school.

"It's been hard, and I wouldn't have been able to do it without Mum and Dad", she says with thanks.

She has spoken with other mothers in the police who all expressed how difficult it is to juggle the responsibilities of being a mother and police work. During this first two-year training period, Carmen must also complete a paper through Victoria University in Criminal Law. Jayden, for his part, is becoming more involved in school than ever before, has joined the school choir and has regular swimming lessons. Carmen is under pressure to keep up with work, her studies and Jayden's busy schedule, but remains positive about the future when she can choose a department where she feels she can make a difference and develop a routine at home.

Carmen concludes, "There's so much to learn. If I hadn't had Jayden, I probably wouldn't have had the desire to join the police . . . ."

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Because of what I have learned being his mum, I look forward to really helping people".

# KEEPING YOUR BONES HEALTHY

Strong bones support a healthy body. Some children with haemophilia may have an increased risk for low bone mineral density. There are many risk factors associated with bone health, but there are also many actions we can take to promote bone health and prevent osteoporosis later in life.

A recent study published in the *American Journal of Clinical Nutrition* has reported that regular consumption of carbonated drinks might increase risk for low bone mineral density (BMD) in women.<sup>1</sup>

In a study of more than 2,500 adults, Dr. Katherine L. Tucker of Tufts University in Boston and colleagues found that women who consumed cola daily had lower BMD in their hips than those who drank less than one serving a month. The greater their intake, the thinner the bones,

"Because BMD is strongly linked with fracture risk, and because cola is a popular beverage, this is of considerable public health importance," the authors write.

Women who drank more cola did not drink less milk, but they did consume less calcium and had lower levels of phosphorus in relation to calcium. Both are important building blocks for bone health. Cola also contains phosphoric acid, the researchers note, which decreases absorption and increases processing of calcium.

Although the study reported that cola consumption did not appear to have an effect on BMD in men, previous research has demonstrated that increased cola intake is linked to reduced BMD in children. There may be a number of reasons for this. Caffeine is a defined risk factor for osteoporosis, and high fructose corn syrup may reduce bone density.



## BMD and Haemophilia

In 2004, a study published in the journal *Pediatrics* reported that children with severe haemophilia are at risk for reduced BMD.<sup>2</sup> The difference in bone density was independent of body size. Reduced bone density in childhood is a risk factor for osteoporosis in later life. As osteoporosis may complicate the future treatment of patients with haemophilia, people with haemophilia - especially children - should be encouraged to follow lifestyle and diet recommendations that promote good bone health.



*Physical fitness and aging*

## Prevention

Osteoporosis New Zealand advise that including plenty of calcium in the diet, getting adequate vitamin D and maintaining an active lifestyle are all key factors that can help lessen the effect of calcium loss from bones.

## Calcium

Calcium is a vital bone-building material — protecting against osteoporosis, however it cannot do its job without adequate vitamin D. Bone also provides the "calcium reservoir" for maintaining correct calcium levels.

Good sources of calcium include low-fat dairy products, such as milk, yoghurt, cheese and ice cream; dark green, leafy vegetables, such as broccoli, collard greens, bok choy and spinach; sardines and salmon with bones; tofu; almonds; and foods fortified with calcium, such as orange juice, cereals and breads. Depending upon how much calcium you get each day from food, you may need to take a calcium supplement.

continued next page

**Box 1: Recommended daily calcium intake\***

Children 1-7 years	700-800 mg
Children 8-11 years	800-900 mg
Boys 12-18 years	1000 mg
Girls 12-18 years	800-1000 mg
Men > 19 years	800 mg
Women 19-54 years	800 mg
Women pregnant	1100 mg
Women breastfeeding	1200 mg
Women after menopause	1000 mg

\* *Osteoporosis and Related Bone Disease National Resource Centre, Washington DC.*

**Box 2: How much sun exposure is needed?\***

Auckland	Christchurch
Dec-Jan, 11am or 3pm 6-8 min	Dec-Jan, 11 am or 3pm 6-9 min
Jul-Aug, 10am or 2pm 30-47 min	Jul-Aug, 10am or 2pm 49-97 min
Jul-Aug, 12 noon 24 min	Jul-Aug, 12 noon 40 min

\**Working Group of Australian and New Zealand Bone Mineral Society, estimates for people with moderately fair skin exposing their arms, hands, and face to the sun. In summer, deliberate sun exposure between 11am and 3pm is not advised.*

*Vitamin D*

Vitamin D occurs naturally in small amounts in some foods, such as fatty fish and liver, or some fortified foods such as margarines, milk, yoghurts, soy milk and cereals. Diet is, however, not the main source of vitamin D. It is mainly created through the action of sunlight on the skin and most diets (without supplements) are not thought to provide sufficient vitamin D.

- Normally, 90% of a person's requirement of vitamin D comes from the action of ultraviolet light in sunlight, which penetrates the skin and activates pre-vitamin D into vitamin D. How much vitamin D is obtained through this reaction depends on;
- skin pigmentation (darker skin needs more UV to produce vitamin D),
- season, time of day (the less intense the sun, the more is needed),
- coverage by clothing or sunscreen,
- whether sitting behind glass or plastic,
- and duration of exposure to sunlight.



***Keeping your bones healthy can start early***

*Exercise and Lifestyle*

Exercise is important during your whole life. Try and exercise for a total of 30 minutes at least three times a week. The exercise doesn't need to be strenuous.

Exercises such as walking or swimming create a pushing and pulling effect on the bones as they support your weight.

Your doctor is well aware of risk of osteoporosis and the promotion of bone health. They can help identify if you at risk of a deficiency, whether nutritional or otherwise, and can recommend supplementation of calcium or vitamin D if required.

<sup>1</sup> Tucker KL, et al. *Am J Clin Nutr* 2006; 84: 936-42

<sup>2</sup> Barnes C, et al. *Pediatrics* 2004;114: e177-e181

Additional Sources: Information gathered from Osteoporosis New Zealand Inc., [www.everybody.co.nz](http://www.everybody.co.nz), and [www.familydoctor.co.nz](http://www.familydoctor.co.nz)



Your Haemophilia Outreach Workers respond to your letters or questions.

## Emergency Room Treatment

**M**y husband Rob, my son Hugo and I all suffer from Type 1 von Willebrand's Disorder (vWD).

The consultant who diagnosed my vWD and my son's said to me that it was "extremely unlucky and unlikely for a child to have both parents with Von Willebrand's." We can't seem to win lotto but somehow we all hit the jackpot with vWD. All three of us suffer it in different strengths. I am worst and need an infusion of desmopressin (DDAVP) when having any kind of operation. My husband is two points behind me, and my son, luckily, does not have it as bad as us.

When we were diagnosed with vWD, my husband and I invested in Medic Alert bracelets, told our respective bosses and had our bleeding disorder put on our personal file at work.

This past June, Rob had an altercation with a cover on a forklift he was on and it cut the end of his finger badly. Rob rang me from the toilet where he was bleeding profusely into the wash basin. His colleague was in the medical room cutting 1-inch pieces of plaster. Rob went into the room and said, "You will need more than that!" as he started to buckle at the knees at the sight of his finger dangling.

I ensured that his work colleagues knew that he suffered from vWD and that he needed to call an ambulance if he didn't stop bleeding. Rob also faints at the sight of his own blood, which doesn't help matters much.



As a pre-emptive strike they took him to the nearest medical centre. I phoned the nurse before he arrived to tell him that he has Von Willebrand's.

"Can you spell that slowly for me? I haven't heard about that," was

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**S**ince the episode, we agreed that we should all carry a letter from our doctor outlining our bleeding disorder

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her response. She was the first of many medical professionals who were not familiar with vWD.

We arrived at the A & E department of the local hospital

where I told everyone, probably including the cleaner, that Rob had vWD - just to make sure everyone knew about it. The junior doctor at A & E didn't know what vWD was, and none of the nurses knew of it. The theatre staff took another look at Rob's notes and saw all the way through them I had made a point of making them aware that he was "A little bleeder."

Fast forward to the next day outside the operating theatre. The plastic surgeon came out and announced that he was ready for Rob. For the 100<sup>th</sup> time since the accident, I mentioned that he had vWD to which the anaesthetist said, "We can't do him, he may bleed." Finally someone knew what we were talking about and took us seriously! They called the closest Haematology centre and their advice was to infuse DDAVP and then operate. So back to the short stay unit we went to have the infusion set up.

The operation went smoothly. The finger was repaired and the cut nail was put into a specimen jar for our ten-year old to take to school on the Monday for show and tell. In summary, the average nurse at our local medical centre does not seem to have an idea what vWD is. The only person who knew what we were talking about was the anaesthetist. The nurses clearly underestimated the disorder as demonstrated by the

continued next page

way a tiny plaster was supposed to stem the blood from Rob's arm when the lure was taken out. It wasn't enough and Rob ended up bleeding everywhere again.

If there is some knowledge of the disorder the person automatically assumes that it requires Factor VIII like haemophilia treatment or, as a woman, how can I have haemophilia?

Since the episode, we agreed that we should all carry a letter from our doctor outlining our bleeding disorder so other doctors will take us seriously in the future.

From Joanne Kinnaird

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#### HOW say:

*Thanks, Joanne. We all know it can be a very frustrating experience visiting the hospital where no one appears to understand you, the treatment you require or your bleeding disorder, and your story raises a number of important issues.*

*Bleeding disorders are a relatively rare complication compared with the multitude of situations emergency room staff are trained to handle. There are a few things people with bleeding disorders can do to make visits to the A&E or similar less stressful and ensure they are receiving the care they need. The great thing you did were being sure to tell everyone about the fact that your husband has von Willibrand's Disorder (even the cleaner) and continued to repeat this message, especially as Rob faced surgery. Eventually, someone did understand.*

The following are a few suggestions we can all take on

board to make the most of receiving emergency care.

- Be as informed as possible with regard to your or your child's bleeding disorder, treatment and any medications/protocols that should be avoided. This will help to best prepare you to answer questions from hospital staff that may not be familiar

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**B**e as informed as possible with regard to your or your child's bleeding disorder . .

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with the bleeding disorder and advocate for yourself or your child about the care required.

- Learn which hospitals in your area have haematology units and, if possible, head to one of these in case of emergencies. The staff may be more familiar with bleeding disorders or be able to quickly access information or staff that does.
- Become familiar and enrol yourself with your local Haemophilia Treatment Centre (HTC). They treat a number of

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**I**t is important that you keep your Medic Alert information up to date

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bleeding disorders in addition to haemophilia and are best placed to give you the information and support you require.

- With the help of your consultant haematologist and haemophilia

nurse specialist, develop a treatment protocol that outlines your bleeding disorder, recommended treatment, who to contact for more information and your NHI number. You can keep this as a letter to show to hospital staff.

- Ask your Haemophilia Outreach Worker for a bleeding disorder identification card. You can fill out a summary of your treatment protocol on the card and keep it in your wallet for quick reference.
- In an emergency, Medic Alert bracelets are designed to alert ambulance and medical personnel to a condition that requires special treatment or attention; especially if you are unconscious and/or do not have someone around to remind everyone of your bleeding disorder. This does not necessarily mean they will completely understand your condition, but should have protocols in place to help treat you. For this reason it is important that you keep your Medic Alert information up to date. Should it change contact Medic Alert to update your details — visit [www.medicalert.co.nz](http://www.medicalert.co.nz) for contact details.

Few people have positive experiences when dealing with accidents and emergencies. These situations can be extremely emotional, and stressful, even when you don't have the additional worry of a bleeding disorder. By being as prepared as possible, you can ensure that the best possible care is delivered - even in unexpected or daunting situations.

# BRANCH REPORTS NOVEMBER/DECEMBER '06

## Northern Branch

The Northern Region held a dinner and film evening on the 14 October, which was well attended and featured a delicious homestyle meal that was thoroughly enjoyed by everyone. During the meal, Jack Finn gave us some background into his next adventure to the Auckland Islands. We then retired to a small movie theatre and viewed a delightful movie.



*Northern BBQ at Ngunguru*

Most members of the Northern Branch live in and around the greater Auckland area, so the Branch has traditionally socialized in Auckland. But over the past couple of years, the number of people scattered throughout the Far North has increased for various reasons, and it has become possible "to join the dots" a little more. During Helen's recent Outreach Trip to the north the first ever social gathering in the Far North was held at Ngunguru, northeast of Whangarei. Jeff Oliver and his partner Sandi hosted a great BBQ and evening. There was a great turnout from people living in Whangarei and north, with people traveling many kilometers to attend. And later in October, a wonderful afternoon was held in Kaeo, when the 3 northernmost families got together, and we now have a permanent record of our four most northern-living boys!

On Sunday evening, 12 November, approximately 200 people attended a piano recital given by Australian concerto soloist Jonathon Bradley at St Columba at Botany Downs. What a pleasure it was to hear such a talented pianist with such a list of performances to his name. Jonathan is the principal accompanist for a number of Melbourne's finest choral groups, including the Royal Melbourne Philharmonic Choir and the Australian Children's Choir. Also an organist, he has accompanied services on the organs of St. Paul's Cathedral London, Salzburg Cathedral, Manchester and Liverpool Cathedrals, Canongate Kirk in Edinburgh and Grace Cathedral, San



*Jeff and Northern's youngest member Corin*



*Far north family gathering at Kaeo - Brothers Connor and Ihimaera holding and baby Corin and young Austin*



*Jonathon Bradley in concert*

Francisco. Jonathon kindly agreed to come to New Zealand to perform at the invitation of his cousin, who lives locally, as a benefit for HFNZ.

Our December function will be the annual Christmas event to be held on the 3 December at the Auckland Botanic Gardens starting at 12:00. Lunch will be served at 1pm and we will be visited by the gentleman from the North Pole a little later depending on his schedule. Members will then have plenty of time to enjoy each other's company or explore the 64 hectares and over 10,000 plants of the Botanic Gardens.

## Midland Branch

We're having xmas a little early this year again, we figure that December usually is a busy period for families so, The Midland Branch of The Haemophilia Foundation of New Zealand is getting together with about 18 Midland families at The Rainbow Springs Nature Park in Rotorua on Sunday November 19<sup>th</sup>. After a look around the park, the Midland Branch will provide lunch and cold drinks in a large covered pavilion area. There also is The Kiwi Encounter at Rainbow Springs, a 45 min guided tour through a working Operation Nest Egg facility. It is unique, emotive and well worth a look. There is a lot happening there at the moment with over 25 eggs in incubation, several ready to hatch and approximately 10 chicks in the brooder room.

In March 2007, the Midland Branch will be hosting the National AGM in Rotorua. The venue is yet to be confirmed but you will be notified in plenty of time. We hope that we will get full support from our families, and attend this meeting, to experience first hand the important work our National

continued next page

Foundation does for each and every one of us. If there is anything you wish to contribute, you are welcome to voice your view. This is an excellent opportunity to attend this national meeting in our region. There will also be an evening dinner and an award ceremony for everyone who wishes to come along to — all members are more than welcome. There are some people within our foundation that deserve recognition to the selfless commitment to The Haemophilia Foundation and we would like to take this opportunity to honour this, so please come along and join us.

We wish everyone a Merry Christmas and a Happy Safe 2007.

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## Central Branch

What a fantastic time we all had at the Central Region Weekend Winter Escape in Napier. With attendance around 64 people and great weather, we had a weekend full of activities and education. (See the camp report on Page 13).

With the success of the weekend still fresh in our memories, we are already looking forward to our upcoming events in 2007. Planning is underway for a Men's Day Out with both a social and educational component. We are also organising the region for a strong turnout at the national AGM in Rotorua in March. Later in the year we are planning a von Willebrand's Education Day. And of course September would not be the same without the Weekend Winter Escape to look forward to!

All of this is not possible without the strong committee we have established in the area. Welcome to Maree Fraser who is our new regional treasurer. Welcome to Jo Kinnaird who is on board as our new publications officer. Stephanie Coulman has taken on the task of organising some social get-togethers in the Wellington area.

We are looking forward to a busy 2007 with an even bigger committee after our regional AGM on the 11th of February, place and activity to be advised.

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## NEWS IN BRIEF

### New Haemophilia Website for Kids Launched



HemophiliaKids.com was officially launched at the US National Hemophilia Foundation's Annual Meeting in October. The website highlights the importance of family communication, health education and fitness — all in language appropriate for children aged 6-12 years. The website hosts materials for children and their family and friends affected by haemophilia, including fun facts and activities about living well with a bleeding disorder.

The website also features an electronic version of the new children's book, Curtis and Jerry on Mount Omega. The story is about Curtis, a panda bear with haemophilia, and his best panda friend Jerry, who learn about fitness, communication and honesty while on a hiking trip with their fathers. You will soon be able to find a link to HemophiliaKids.com on the new

HFNZ website (to be launched very soon).

A companion website, HemophiliaParents.com, offers a Parents' Guide to the children's book as well as a message board for parents to share their stories with other families in the global bleeding disorder community. HemophiliaTeens.com is also currently under construction and will be aimed at providing a forum for the specifics issues of teens affected by blood disorders.

Source: PR Newswire, 11 October 2006 ([www.prnewswire.co.nz](http://www.prnewswire.co.nz))

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### Cash surplus should give medicine spending a boost, says ATM

The Access to Medicines Coalition (ATM) says it hopes a \$200 million cash injection by the Government into elective surgery waiting lists earlier this month will be followed up by similar efforts to help those on waiting lists for medicines.

A comprehensive healthcare system should be balanced in how it allocates its treatment resources,

says ATM spokesman John Forman. "While we welcome the decision to increase funding for elective surgery, it's important to remember that New Zealand is still falling behind other OECD countries with respect to funding new medications, many of which have already been approved by Medsafe as suitable for use in New Zealand."

The recent announcement of a substantial Government budget surplus provides an opportunity for greater spending on medicines. "There are thousands of New Zealanders waiting on medications which will greatly improve their quality of life," Forman says. "Pharmac itself has called for greater investment in medicines, and they must be given the financial support needed to improve access to new and currently restricted medicines."

A significant cash injection for Pharmac would be a suitable short-term alleviation for patients waiting on medicines, but in the long-term the whole drug funding system needs to be reviewed.

"It's clear that the current system is not working for many New

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## The all new [www.haemophilia.org.nz](http://www.haemophilia.org.nz)

### Features includes:

- Information on Bleeding Disorders
- Searchable News Archive
- Current and past issues of Bloodline
- Member Services

### And introducing:

### KIDS' CORNER

a special parent-free area for learning and activities



## Coming Soon!

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Zealanders," Forman says. "We would hope that the new long-term medicines strategy will put ethical principles first in the provision of healthcare, not financial ones."

ATM combines the voices of 25 non-

government organisations advocating for increased access to medicines in New Zealand. Members of the coalition are all disease-specific groups that provide support, information/education,

health promotion or clinical services to their constituent groups.

Source: Access to Medicines Coalition



## Dates to Note

### 3 December 2006

- Northern Branch Christmas Party

### 5 December 2006

- International Volunteer Day

### 22 December 2006 - 7 January 2007

- National Office Closed for the Holidays

### 19-23 January 2007

- Southern Family Camp  
Blue Skies, Kaiapoi

### 21 January 2007

- Southern Regional Committee AGM  
Blue Skies, Kaiapoi

### 11 February 2007

- Central Regional Committee AGM

### 23-25 February 2007

- Northern Family Camp  
Waiwera

### 25 February 2007

- Northern Regional Committee AGM  
Waiwera

### 24 March 2007

- HFNZ National Annual General Meeting  
Rotorua

### 13-16 April 2007

- Teen Camp  
Blue Skies, Kaiapoi

### 17 April 2007

- World Hemophilia Day

### 4-7 October 2007

- 14th Australian & New Zealand Haemophilia Conference  
Canberra, Australia

More Info:

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