

Newsletter of the Haemophilia Foundation of New Zealand Inc



**New
HFNZ
National
Office**

page 1



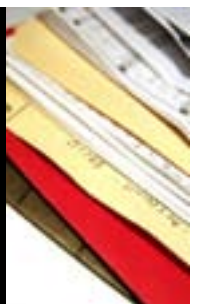
**Twins Make
History**

page 2



**Keeping
Medical
Records**

page 6



CONTACT DETAILS

Website

www.haemophilia.org.nz

President

Deon York

deon@haemophilia.org.nz

Chief Executive Officer

Belinda Burnett

Phone: (03) 371 7477

Fax: (03) 371 7479

belinda@haemophilia.org.nz

National Office

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

Phone: (03) 371 7477

Fax: (03) 371 7479

info@haemophilia.org.nz

**Northern/Midland
Outreach Worker**

Helen Spencer

0508 FACTOR

Phone (09) 845 4658

Fax (09) 846 8174

PO Box 41-062

St Lukes, Mt Albert

Auckland

Central Outreach Worker

Drew MacKenzie

0508 FACTOR

Phone (04) 905 2857

Fax (04) 905 2856

PO Box 2151

Raumati, Kapiti Coast 5255

Southern Outreach Worker

Colleen McKay

0508 FACTOR

Phone (03) 371 7485

Fax (03) 371 7479

PO Box 7647, Sydenham
Christchurch

Editor

Chantal Lauzon

Phone: (03) 371 7484

Fax: (03) 371 7479

chantal@haemophilia.org.nz

THE WORD



You will notice that this issue of Bloodline is much larger than normal! The extra volume is due to the inclusion of this year's Conference Supplement of the WFH's World Congress of Hemophilia which took place in Istanbul, Turkey from June 1 - 4th.

By far the biggest World Congress yet, HFNZ delegates have done a fantastic job of covering the many sessions available so that you might gain a better understanding of some the issues facing the global haemophilia community and developments that are expected to happen in the future.

This issue of Bloodline also includes two articles contributed by members on how they regard haemophilia and the role it plays in their life. HFNZ (and Bloodline) are always open to hearing your thoughts and stories, so if you have something to share please contact me or Chantal, our National Information Coordinator.

As you may know, HFNZ are preparing a book to tell the tale of our first fifty years. Another opportunity to commemorate our golden anniversary, the launch of the book is set for this coming November in Auckland. A title for the book is yet to be decided! If you have any suggestions for a title that captures our inspiring history please write to chantal@haemophilia.org.nz or at PO Box 16582, Christchurch.



Deon York
President, HFNZ

Contents

New HFNZ National Office.....	1
Dunedin Twins A First	2
WFH: Celebrating 45 Years of Achievements	3
Time for a Change	5
The Importance of Keeping a Personal Medical Record	6
New Pharmaceutical Schedule for Recombinant Factor VIII Products	8
The 'Gift' of Haemophilia.....	9
In Remembrance.....	10
Research Summary: You're Amongst Brothers	10
News in Brief.....	12-13
Regional Branch Reports	13-14
HFNZ Exercise Competition	15
Dates to Note.....	15

New HFNZ National Office

In August, HFNZ National Office shifted premises to 4 Washington Way, Sydenham, Christchurch.

We had outgrown our Hornby location and we had come to understand that the office was going to be demolished over the next year to make way for new developments. Being such a special year, it was felt it was a great time to make a move to a more central and professional location so that we could better serve the membership and the wider community.

On 15 August, HFNZ staff and Southern Branch hosted an "office warming" at the new National Office. National Council was in town for their meeting the following day and many local members and friends of the Foundation came to join in the celebration and admire the new space.

It was a pleasant evening with about 40 members in attendance, as well as Ali Inder and Carolyn Lauren from Christchurch Hospital. Thank you to Southern for their support.

We welcome all members to drop in for a visit whenever they are in town.



▲ HFNZ National Council during a break at their meeting

NEW HFNZ NATIONAL OFFICE CONTACT DETAILS:

Physical Address:

4 Washington Way, Sydenham, Christchurch
(just off Gasson St or Moorhouse Ave)

Postal Address: PO Box 7647, Sydenham, Christchurch

National Office Phone: 03 371 7477

Fax: 03 371 7479

Southern Outreach: 03 371 7485



▲ VP David Habershon and Southerners Rob MacIntosh and Mark Uren



▲ CEO Belinda Burnett welcomes all to the new office

Dunedin Twins a First

First children born in NZ following PGD specifically for haemophilia

In May, Dunedin twins Rania and Arian Najafi made New Zealand medical history.

The twins parents, Kelli and Parviz Najafi, opted to use pre-implantation genetic diagnosis (PGD) to start their family because Kelli knew she had inherited the haemophilia A gene from her father. Having watched her father and other relatives struggle with haemophilia, she decided that she wanted to avoid that for her children if possible.

Far from being “designer babies”, they are “just healthy children”, say their parents.

PGD is an alternative to prenatal diagnosis to avoid having a child with a serious genetic condition. Using IVF technology, an embryo is created and grown to the 3-5 day stage. At this point, 1 or 2 cells can be removed for genetic testing. The “unaffected” embryos are then implanted in mother’s uterus and the parents and clinicians hope that a viable pregnancy will then develop.

In New Zealand, PGD is available to both fertile and infertile couples to prevent the transmission of genetic conditions considered serious by the guidelines that result from a single gene mutation. Importantly the condition and gene mutation causing the condition must be known as a specific test must be developed for each couple to be able to check the embryos. For some X-linked conditions, only sex selection is available.

PGD is not new. The first baby born after PGD for cystic fibrosis entered the world in 1992. However, the clinical application to prevent transmission of human genetic diseases is still evolving.

A new technique developed by doctors in Christchurch enabled the couple to have twins free of haemophilia A. Previously, embryo selection to prevent haemophilia meant that all male embryos were discarded, whether or not they were affected, and there was no way of telling if female babies were carriers. But by the time of the Najafi’s successful pregnancy last year, the technology had developed to the stage where testing of cells taken when the embryos were at the eight-cell stage could establish specifically whether the embryos were affected by haemophilia A.

“PGD offers couples restored hope...Here in Christchurch we’ve taken the technology to an extra level of precision,” says Dr Mark Smith. “We can tell which embryos have the disease and which don’t, be they female or male.”

“We did not know their sex when they were implanted. We didn’t know their sex until they were born,” Kelli said.

The work was a collaboration between the Christchurch Fertility Centre, Canterbury District Health Board haematologist Dr Mark Smith and the board’s molecular technology laboratory. The Fertility Centre has commented that they are first babies born in New Zealand to a haemophilia carrier using the new technology, and only among a handful of babies throughout the world from embryos

subjected to such testing.

Fertility centres in New Zealand are eligible for government funding for up to 40 couples to undergo PGD for certain inherited conditions a year. For most conditions, the embryonic cells are sent to Australia for testing as the advanced technology to screen for specific conditions has only recently become available in Christchurch for haemophilia A genetic mutations. A specific test for haemophilia B is not yet available but is actively being developed.

The couple’s journey to parenthood over about five years has not been easy. The Najafis’ first underwent genetic counseling to understand all their options and the decisions they would have to face with each. There was always a risk they could have gone through all the IVF cycles and the testing without a healthy embryo being successfully implanted or resulting in a viable pregnancy.

To be eligible for PGD the couple first had to meet important criteria. For example, Kelli had to be suitable for IVF (age under 40 years, healthy weight, non-smoker, be able to respond to hormonal drugs). She also had to have an over 25% chance of passing on a serious condition. As the genetics of haemophilia are fairly well understood, this was able to be demonstrated. Genetic testing was then undertaken so that the lab could design a specific test for the genetic mutation for

haemophilia A she carries, as this can be different depending on the family.

Kelli, 36, had three rounds of IVF in Christchurch, using PGD to select embryos that did not carry the gene. The couple, who live in Dunedin, qualified for government funding for two rounds but spent thousands of dollars their own money on traveling back and forth to Christchurch and the first round of IVF as the approval for funding had not come through yet.

IVF was a stressful and lengthy process. Kelli became pregnant with the first cycle in 2006 but lost the baby. The second cycle, early last year, did not work. But the third cycle, last September, was successful. The twins were born naturally in early May at 34 weeks and three days, with first born-daughter Rania weighing 2.5 kg and son Arian 10 minutes later at 2.1 kg. To their parents, the twins are tiny miracles.

“I just wanted to have a healthy baby and I said let’s go for it, let’s just do it, and we did,” says Kelli.

The Najafi’s decision to have PGD means they can be confident that Arian does not have haemophilia and Rania will not pass it on. They say that peace of mind has been worth all the struggle. “When you see them looking at you and smile up at you, it’s worth it.”



The happy Najafi family. Photo courtesy of the Otago Daily Times

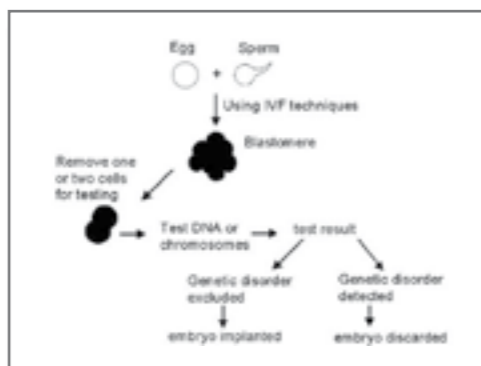


Figure 1. The PGD Process

Interested in PGD? Some things to consider...

- PGD is a useful and beneficial option, but it is not for everyone.
- Your willingness to put in the time and energy required – as the Najafis’ experience shows, PGD can be a long and often difficult process.
- Be realistic about the chance of success – depending on the situation, rates of a successful pregnancy can be 25% or lower.
- Data on long term affects of PGD are not yet available – It is however not expected to cause any problems, and the side effects of hormone therapy needed for IVF are often more of a concern to couples.
- Follow-up prenatal diagnosis (on foetus) recommended to confirm the presence or absence of the condition (97% accuracy).
- Can’t perform 2 tests at once – They can only test for one genetic condition per embryo, so there is a potential that another condition could be present.

If you would like to discuss PGD further, contact your HFNZ Outreach Worker (0508 FACTOR). Alternatively you can contact your regional genetic service for more information or a consultation.

- Northern Regional Genetic Services:
0800 476 123
- Central Regional Genetic Services:
0508 364 436
- Southern Regional Genetic Services:
0508 364 436

WFH: Celebrating 45 Years of Achievements

The Global Alliance for Progress - 5 Years of Success

Mark Skinner, WFH President

This year marks a number of important milestones for the WFH and our programs. Most notably, in 2008, we celebrate our 45th anniversary. In addition, the Global Alliance for Progress (GAP) project celebrates its fifth anniversary, and the WFH Data and Demographics program turns ten.

When the WFH started in 1963, founder Frank Schnabel had a dream to “alleviate the pain and plight of the world’s haemophiliacs.” Forty-five years later, while many things have changed, the basic purpose and goals of the organization have remained true to Frank’s dream. Today, our vision of Treatment for All has expanded upon his dream to include all patients with bleeding disorders.

Since we started collecting data in 1998, the number of identified people with haemophilia and other bleeding disorders has increased from 103,435 in 65 countries to 208,006 in 100 countries.

Over the last 45 years, our volunteers and staff have worked to make this dream a reality, especially through our programs in developing countries that have brought about long-term, sustainable care for people with bleeding disorders. The tremendous impact of our programs can be documented using data from our Global Survey. Since we

started collecting data in 1998, the number of identified people with haemophilia and other bleeding disorders has increased from 103,435 in 65 countries to 208,006 in 100 countries.

In 2003, the WFH launched the GAP project to improve treatment and build national haemophilia programs in up to 30 countries over 10 years. A primary goal of GAP is to increase the overall number of



patients diagnosed by 50,000 worldwide. Globally, since 2003, 41,395 new patients with bleeding disorders have been diagnosed including 31,189 with haemophilia.

Fourteen countries have been selected for GAP – Armenia, Azerbaijan, Ecuador, Egypt, Georgia, Jordan, Lebanon, Mexico, Philippines, Thailand, and Russia. In 2008, Belarus and Tunisia joined the list, along with China in preparatory phase.

Across the board, there is tremendous progress in each country. As we reach the halfway point in GAP, it is noteworthy to count the many accomplishments to date.

One of the keys to improving care for people with bleeding disorders is building a coalition including the medical community, patient organization, and Ministry of Health. Formal agreements have been signed with the governments of Armenia, Azerbaijan, Ecuador, Egypt, Georgia, Jordan, Lebanon, Thailand and Tunisia establishing a national haemophilia program.



We have achieved major breakthroughs in many GAP countries and substantially increased the level of government support for haemophilia care. For example, the governments of Azerbaijan, Jordan, Georgia, Thailand, and Russia officially launched full National Hemophilia Care Programs and more than doubled their budgets for haemophilia.

Outreach and diagnosis are the essential first steps in improving treatment. Over 8,500 newly identified patients with haemophilia, von Willebrand Disease and other bleeding disorders have been diagnosed and registered in the GAP countries alone.

One of the keys to improving care for people with bleeding disorders is building a coalition including the medical community, patient organization, and Ministry of Health.

In Mexico, for example, there was no national patient registry when GAP started.

The Hemophilia Federation of the Republic of Mexico developed a national registry and organized regional outreach projects to identify and register patients. The outreach projects in Mexico City and Mexico State were especially successful, identifying 406 new people with haemophilia in only one year. Now, the national patient registry includes 3,625 people with haemophilia and 67 with von Willebrand disease. Of these, 1,527 are newly identified patients.

Improving medical expertise through training of all members of the multidisciplinary health care team is another critical element of GAP. To date we have provided specialized training to 2,478 haemophilia care team members and more generalized education on bleeding disorders to another 4,438.

In Egypt, for example, treaters, the Egyptian Hemophilia Society, and the University of Cairo organized a training workshop for physical therapists in 2006. The next year, the WFH and the University of Cairo held a train-the-trainer workshop to teach physical therapists from around the country how to train other physical

therapists on exercises and proper techniques. Now, Egypt is poised to go one step further and organize train-the-trainer workshops for physical therapists in the whole Middle Eastern region.

Increasing the availability of treatment products is also a significant turning point to bringing about adequate treatment in a country and is a cornerstone of GAP. Since 2003, GAP countries have reported to

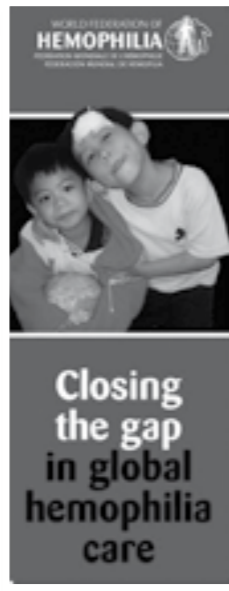
the WFH a total cumulative increase of 467 million units of clotting factor concentrates supplied in the GAP countries concentrates.

Russia joined the GAP program in 2004. At that time, treatment products were very limited and mainly available in St. Petersburg and Moscow. The central government purchased 1.4 million units of clotting factor concentrates in 2004. Over the years, the Russian Hemophilia Society successfully lobbied the government to purchase more factor concentrates for patients. Thanks to their efforts, now treatment is available in every region throughout Russia and a large number of children are on prophylaxis. In 2007, the government purchased more than 200 million IU of clotting factor concentrates.

The last key piece for GAP is the patient organization. Without a strong patient group to move the project forward, lobby for improved care, and educate patients and their families, success is unlikely. Through GAP, we have facilitated the education and training of 2,974 patients, family members, and patient organization board members. The increased resources and training focused on patient organizations have ensured the treatment gains will be sustainable long after the GAP project concludes.

We wish to thank all of our volunteers, national haemophilia organizations, government partners, and GAP sponsors for helping us achieve these goals. In particular, we are grateful for the support provided by our founding sponsor Baxter; sustaining sponsors the Andre de la Porte Family Foundation and CSL Behring; supporting sponsors Bayer and Wyeth; and Biotest, the Irish Haemophilia Society and the World Health Organization. We are also pleased to announce that Talecris is a new GAP sponsor.

Source: Hemophilia World, April 2008



Time for a Change

by Paul Dagger

Before beginning, and to put things in context, there's a few things about me that are probably worth sharing. I was born in 1977, for those of you that struggle with maths as much as me, that means I'm now 30 years old.

At 2 years old I was diagnosed with severe haemophilia A (less than 1% factor VIII), so I'm as severe as you get. From that point my life ran on the "inject when it hurts" approach, bags and bags of cryoprecipitate (essentially one step up from frozen blood). I think my dosage was somewhere around 100ml when I switched to concentrate.

I got and still have Hepatitis C from contaminated blood when I was about 12. Both my ankles do not flex up at all, have bone spurs growing off the ends of the tibias, and have limited cartilage. The radial head of both elbows grew wrong to the point that neither one straightens out anymore, and I've had the left one removed so the bone floats free in the tendons.

For at least the last ten or twelve years, I get up 30 minutes before I need to just so I can walk around for bit and get the joints moving. Every day starts with two Panadol and one Glucosamine tablet. I end the day with two more, and sometimes a codeine phosphate tablet.

I know there are others in a worse state, but hopefully you understand I'm broken enough to be able to have some understanding of what the majority face.

So now my point. Over the last 30 years, I've come to the conclusion that there are two ways people like you and I view the situation we find ourselves in; we are either SUFFERERS of the disease haemophilia, or we are PEOPLE who have a attribute called haemophilia. One runs their life around haemophilia, and the other runs their life, dealing with their attribute along the way.

Which are you? A simple test, when introducing yourself would you say, "Hi, I'm Paul and I'm a haemophiliac", or "Hi, I'm Paul and I have haemophilia"?

Its not just those of us with the attribute that view the world this way, the same views are evident in the literature, our caregivers, and the medical profession. As you may have guessed, I firmly believe the right view is that haemophilia is an attribute to be managed, and nothing more. For the last seven years or so, I've been seriously putting my crazy ideas into action (experimenting on myself?). The majority I've run into however, seem to see things the other way. Hence, I think its time for a change.

So what does it look like to be a person rather than a sufferer? Firstly, the only people that know I have haemophilia are the people who need to know. This tends not to include workmates, friends,

and fellow sports-club members. In fact, the circle is very very small indeed. Why? Because in the vast majority of cases, IT JUST DOESN'T MATTER! If you were asthmatic, would you scream that from the rooftops every chance you get? I'm not saying lie, just be realistic. Do you have any medical attribute that could affect your ability to do this job? Nope. I have had ten days sick leave due to haemophilia in the last 15 years of work (and 2 due to the flu).

Next, everyone agrees that exercise is good for people, especially those with haemophilia. I didn't really get this for a long time (perhaps because I found the exercises I was doing particularly boring), but now can't say enough good things about getting out there and getting a sweat on.

However, sufferers are great at making lists. Here are safe activities, here is the safe way to run your life, here are the dangerous things you mustn't do. People on the other hand go and try things, know



▲ Sometimes it's ok to explore your limits

what their limitations are, work around them, and then decide if they want to do it again. I describe it as dancing on the fence. One side is soft green grass and flowers, the other is hard, and rocky.

Boys are boys, and as such the most fun is normally held as close to the rocky side of the fence as possible. It is also OK TO WALK RIGHT ON THE EDGE as long as you do it consciously. The great thing is, that if you stick at it, the fence can be moved further and further into the rocks

safely. The human body is very clever at making itself stronger and stronger, the human body with haemophilia is no exception. You just need to make sure you start at a pace right for you, and build up into it.

I actively participate (and give the "norms" a run for their money) in various activities that are on the sufferer's no-go lists. Among the more interesting facts, I am a green-belt (with an "A" Pass) in ITF TaeKwon Do, a New Zealand certified archery instructor and shoot both target and field styles, kayaker (sea and surf), casual mountain biker, lift weights, and have just taken up surfing again. I take the stairs if there are less than eight floors, do 94 sit-ups in two minutes, and can break a half-inch thick pine board using my elbow with little to no repercussions. I also don't do this while wearing shin-pads, a crash helmet (except on my bike!), or padded suit. If you're interested, I also watch cartoons, play chess, draw, take photos, eat McDonalds, enjoy the movies and theater, and long walks on the beach at sunset after a fine dinner (preferably in the tropics)!

As a result of being physically active, I've gone from 110kg to 74.5kg (I just jumped on the scales), and reduced the number of bleeds I have that require an injection from 1-2 a week, to around 1 a fortnight. When I do have a bleed they are never as severe as they were, and have reduced my factor consumption from 2000 to 1000 units.

PROUDLY DESIGNED AND PRINTED BY

Jeff Oliver Print Ltd
creative design • quality printing

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

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



I'm stronger, faster, and healthier than I've ever been and I'm always looking for something else I can add to my portfolio.

I'm not suggesting that the lists should be thrown away, but USE THEM AS A GUIDE while you are LEARNING, not as the rule. After 30 years I know what I need to look out for, so I pick activities based on whether they look interesting, and then make an educated decision regarding whether to participate or not, and in what form. Before starting TKD (definitely on the no-no list), I went and watched a class, then sat down with my instructor and had a chat. He seemed to be open to my circumstances so we decided to give it a go. I don't do full contact sparring, so he always makes sure the class has a low/non-contact option, but other than that he has to do nothing special while running the class, and I keep up with everyone else for the four hours a week we train.



My body rebelled a little at the outset (I pushed too hard too fast, and busted my iliopsoas muscle). I persevered, learnt how far I could push the limits and how fast, and have had no problems for almost two years. So, go and find exercise that you find fun and works for you, then work into it.

Don't use the manifestations of your attribute as an excuse either. If your ankles don't work, archery, kayaking, etc don't use them. If your elbows are shot, walking, bike riding, hiking, and soccer aren't reliant on them. Also remember that generally limitations can be overcome, so just because you can't do something now doesn't mean you can't do it ever. I lift weights every day to build up the muscles around my elbows and chest so I can do pop-ups on a surfboard.

Finally, if you still have someone else in-charge of your life (cause you haven't been on the planet for enough years to know your limits), then their job shouldn't be to restrict what you do, but help you (and them) TO LEARN how to manage your attribute. Don't go and put yourself at risk, but realize its fine to explore those limits.

Please don't get me wrong, we've come along way from when the powers-that-be wanted to put me in a school for the disabled, I just think it is time for a real paradigm shift in the way people with haemophilia are viewed, and view themselves.

I want people to stop wincing when I tell them what I'm up to, or making comments that I'm sucking up the national supply of concentrate. My name is Paul, and it's my life. A fact that will surprise some is I'm not a sadist, and don't enjoy being awake all night in pain or zoned out on painkillers. As a result, I'm not going to do something that is causing me continuous injury. I AM RESPONSIBLE FOR, AND KNOW HOW TO MANAGE MY LIFE, ALBEIT WITH THE ADVICE OF OTHERS.

In summary;

- **Start viewing yourself as a person with an attribute**
- **Don't let others view you as anything else**
- **Take responsibility**
- **Take the opportunity to learn**
- **Realise that its ok to make mistakes along the way**
- **Push the limits**
- **Try new things**
- **LIVE YOUR LIFE**

If you live in the Wellington region and want to try any of the things mentioned in this article a go, feel free to get in touch with me through one of the outreach workers.

The Importance of Keeping a Personal Medical Record

The nature of haemophilia, and in fact all bleeding disorders, is the amazing variability in types, degrees and causes of bleeding. Comprehensive care aims to tailor therapy to each individual as much as possible so as to deliver the right amount at the right time. This will hopefully reduce long-term joint problems, decrease unnecessary factor use, improve personal control, and allow for changes due to changes in either activity (sports or travel) or body size.

Self-infusion programmes can benefit both health and social circumstances. However, with the change from hospital to home-based treatment, clinical staff now depend on patients or parents, for information on infusion practices, frequency of bleeds, outcomes and adverse events. In general, compliance with record keeping is notoriously poor. Absence of records compromises the potential for timely advice and education, hinders effective product recalls, and compromises the experience and education of haemophilia clinical staff.

Reason 1: Optimise your haemophilia treatment

Keeping track of your infusions and bleeds is an important part of making your treatment plan work. An accurate, detailed history and assessment of patients for bleeding episodes and trauma is essential for determining appropriate care. In planning how to best individualise treatment, the more information you have on timing and dosing, and the more accurate that information is, the better staff at the HTC are able to serve you. Patients or parents should

keep bleeding records that include date and site of bleeding, dosage and lot numbers of product used, as well as any adverse effects.

By keeping a record of your bleeds and infusions, you help your healthcare team track your response to certain treatments. This is essential in developing the right plan for you. Through your logs, the team might also identify a need to test for an inhibitor or if you have used a recalled lot number. Some also feel that in a publicly funded health care system there is a responsibility to ensure that extremely expensive medication is being used optimally.

Reason 2: Protect Yourself

Medical information is usually scattered in many different places. To receive the best possible health care, people are encouraged to gather information in one place and create a personal medical record – not just of infusions but with copies of test results, medical notes and diagnoses if possible.

Keeping detailed accurate records may be important for legal, ACC or insurance purposes. It's just not true that important medical information is likely to be complete and always readily available when you need it.

A doctor once commented, "It's interesting how many times people come to my office and I ask them a question about their past medical history or I ask them what medications they're taking, and they look at me sort of strangely and say, "Well, don't you know? Isn't it all right there in your record?" And the reality is that, frequently, we don't have all the information."

There are two reasons to keep good records about what's happened to you with your health care. One is that it could be that your information is the only source at a very, very important moment, and the second is that it actually gets people more engaged and sets them up to ask better questions. A lot of people believe that emergency rooms are able to look up your medical records in a crisis when they need to. And in fact, they can almost never do that. So if you don't have some emergency information about you in your pocket, or know how to reach it, they're not going to know much about you.

For example, access to the Hepatitis C Treatment and Welfare Package for many members was aided in large part by the copies of medical records they had kept safe at home. In a number of cases either ACC had lost them or they were no longer on record at the hospital or with the DHB as they were over 10 years old.

Most people receive care from many doctors in different places over time... another reason a personal medical record is a good idea. If you move and you want to share your previous information with a new doctor or a new provider, you pretty much have to bring

it with you or contact all of your previous doctors and have them individually send your information along.

The first step in compiling a complete personal medical record is knowing what kind of information to include. The basics are: lab results, the names and phone numbers of doctors, and details of injuries, illnesses, surgeries, allergies, and treatments.

Family history information is also important to have in a personal health history. There is a lot that can be known about the patient's risk for future medical problems and for discussions about prevention, by knowing a little bit about what the family history has been through – especially with a genetically inheritable condition such as haemophilia or von Willebrand disorder.

Find a System that Works for You

Information is the lifeblood of health care. Diaries are means of gathering data. The use of accurate data enables clinicians to deliver the best care possible. Accurate data is best done as it happens, not several days or weeks later. In short, when you infuse, that's when you fill in your diary.

Logs may be on paper or online. It's important to find a system that works for you to keep track of treatment information.

Most people have some personal health information at home, although many do not have an organized system for keeping track of it. It's important to have it in one place, and to have it where you know it's accessible, and potentially someone else who lives with you or is close to you would also know where to find it. It does not have to be fancy. A personal medical record can be as simple as a notebook or folder. Computer programs and Web sites are options, too. There is a growing array of programmes that you can buy or you can log into a password-protected website to protect your privacy. For people who are comfortable storing the information that way that can be a terrific way to do it – especially with programmes that allow you to make graphs or chart your infusions so you can visualise what it happening.

Some pharmaceutical companies now even offer systems to help track factor usage through handheld devices or websites, where the information is linked to a system your HTC can track. These can be a useful way of tracking changes in bleeding patterns or a need to provide supplies.

The future will likely bring better and more automatic systems for compiling individual medical information. But experts say even then patients will have to work hard to know and understand their personal medical records. The quality of their care depends on it.

SAMPLE Treatment Log – Version 1

Haemophilia Treatment Diary		Month: September			Name: Joe Bloggs	
Date	Time	Treatment Product	Prophylaxis	Bleed	Bleed Site	Comment/Other action taken
2nd	6pm	(stick label here)		✓	Right ankle	Sports day at school

SAMPLE Treatment Log – Version 2

Reason for infusion:
 Bleed Follow-up to a bleed Other: _____

Bleed Information
 Date: _____ Time: _____


Cause of bleed:
 Spontaneous Surgery/Dental Trauma/Activity

Severity of bleed:
 Minor (not so bad) Major (very bad) Life- or limb-threatening

Type of bleed:
 Joint Mouth Muscle/Soft tissue Other

Location: _____

Pain:
 Pain not specified or



Symptoms:
 Swelling Visible bleeding Limited range of motion/movement
 Bruising Warmth Numbness

Treatment Information
 Date: _____ Time: _____
 Product name: _____ Lot number: _____
 Number of vials: _____ Vial size: _____
 Total amount infused (number of vials x vial size): _____ (IU total units)

Treatment response:
 Excellent Good Fair
 Poor Don't wish to specify Can't tell at this time



Tips on record keeping:

- Tap into technology. For some people, keeping track of infusions and bleeds is easier with a computer or a personal digital assistant. Some companies offer a tool that allows you to track treatment information online, and then it transmits this important data to your healthcare professionals.
- Write it out. If you prefer keeping written records, you may want to use one of the sample Treatment Logs to track your infusions and bleeds.
- Be informed. If you know the “why” behind the treatment plan, you’re more likely to follow it. Your HTC team is a good source for answers to all your questions.
- The ultimate purpose of having a personal medical information is so that it’s available if needed, and so that you’re engaged with your health care. Even if the information systems of the future will solve the availability question, being engaged is something that you still have to do for yourself.

New Pharmaceutical Schedule for Recombinant Factor VIII Products

PHARMAC has announced a new pharmaceutical schedule for recombinant Factor VIII (rFVIII) products in New Zealand. This essentially means that they have agreed new supply contracts with rFVIII manufacturers Baxter Healthcare, Bayer Schering Pharma & Wyeth Ltd for the supply of Advate®, Kogenate FS® and Refacto®, respectively.

PHARMAC first contracted for the national supply of rFVIII in 2005 – prior to this DHBs arranged for their own purchases individually. The previous contract covered until June 2008. To

ensure those in the haemophilia community continued to be able to access appropriate and timely treatment, PHARMAC requested proposals to again secure the supply of rFVIII earlier in this year.

The Evaluation Committee, with included PHARMAC staff, clinicians and a representative of HFNZ, considered the various proposals submitted and reached agreements with the three suppliers. These agreements included price and supply terms for all three brands from 1 July 2008 until at least 30 June 2011. Under the agreement no brand has preferred supply status.

Your treatment will not be interrupted by these changes.

rFVIII products now available:	Vial Sizes:
Advate	250 IU, 500 IU, 1000 IU, 1500 IU
Kogenate	250 IU, 500 IU, 1000 IU, 2000 IU
Refacto	250 IU, 500 IU, 1000 IU, 2000 IU

The ‘Gift’ of Haemophilia

by John Rutten

It would have been easy for me to be a product of my social and medical conditioning, to have settled for compromise, to have yielded when I was given the last rites, to have listened when Doctors told the parents “he’ll be lucky to make 20” or to have adopted a “poor me” mindset.

Living with haemophilia in the 60’s and 70’s before the use of concentrated blood products became widespread, was not easy. A calf bleed that went horribly wrong as a young boy, ensured that haemophilia for this one, would always be visible in a culture so obsessed by physical appearance. Living with haemophilia as a teenager, when conforming and fitting-in becomes so vital for peers, was not easy either.

Haemophilia B is known as Christmas Disease because it was usually around Christmas time that it struck! The usual school routine disrupted, I would get into something physically different on the farm and often, start bleeding. The family twice holidayed while I was horizontal in hospital and plans to attend the Commonwealth Games in Christchurch in 1974 were similarly thwarted when I was again, sentenced to institutional bed-rest.

Haemophilia is a gift, although it felt like a burden during the teen years. Why when I’m lying down in the staff room at work, dealing with a nose bleed, do



my factor levels, but so that I was equally informed about how the penchant for bleeding was going to be managed and sustained post-surgery. The Orthopaedic Surgeon and I have agreed that we must convince the other that any joint surgery is necessary.

Living with a penchant for bleeding has provided me with some enthralling examples of human generosity, all positive and encouraging, some wonderfully inspiring. On one occasion a Ward Sister returned to work one evening, to ensure that the bandaging around my stitched thumb wasn’t too tight. On another occasion a Paediatrician who’d looked after me as a young boy, turned up out-of-the-blue at my bedside, when specialists were considering using a scalpel to find the source of internal bleeding. The Paediatrician told the specialists to continue replacing the blood I was losing, but to otherwise leave me alone; that I would pull through it (having himself seen me ‘pull through’ against other odds as a boy).

Living with a penchant for bleeding teaches you how to deal with adversity and it certainly provides lessons on tolerance (some argue the latter is still a work in progress, in my case!). It provides you with opportunities to show others how to overcome physical constraints, how to do, what some deem impossible. The experience of Haemophilia and the added-extras that sometimes accompany it, equips a person with robustness, a rigour, an unflappability, that makes people’s ordinary ailments sound like man-flu. The struggle (at times)

A penchant for bleeding is a wonderful privilege. It cuts you free from the ordinary, it gives you experiences and opportunities otherwise unobtainable, it challenges you, it changes you, it fosters a more considered approach to life

I get sent home because I could bleed to death? Why were others’ perceptions of haemophilia, so out-of-sync with my experience of it? Was there something someone wasn’t telling me? Or was their perception of a ‘bleeder’ simply fear-based? Having survived that tumultuous and emotionally formative period and then some, I began examining the lining of that cloud that others perceived haemophilia to be.

Living with haemophilia liberated me. Living with haemophilia helped me become a good listener, more of an observer than I might otherwise have been. It nurtured an interest in other people that saw me complete a BA in psychology and sociology. Living with haemophilia taught me empathy for others. It taught me that haemophilia was part of ‘who’ I am, but not ‘what’ I am. Sure people can call me ‘a patient’, ‘bleeder’, ‘haemophiliac’ or ‘cripple’. What’s important is NOT how people label me, but how I think of myself.

Living with a penchant for bleeding taught me about self responsibility (not always having been the most willing participant!). Prior to recent joint surgeries, I met with the Haematologist to discuss the treatment plan – so that not only were they demonstrably prepared to elevate

to live a full life produces, as the December 1981 NZ Haemophilia Society newsletter suggested, very special people.

Living with a penchant for bleeding is a wonderful privilege. It has cut me free from the ordinary, it gave me experiences and opportunities otherwise unobtainable, it challenges me, it changed (and continues to change) me, it fostered a more considered approach to life’s existential questions. As a teenager I looked at my parents in their forties and thought to myself ‘what a boring life they lead’. Preparing now for my fifties, I have to say that my forties have been the most exciting time of my life! But then ... my parents never had the ‘gift’ of haemophilia did they? They simply bestowed the ‘gift’ on me!

Inga Clendinnen’s words “the clear prospect of death only makes living more engaging” together with Harold Kushner’s “when you have learned to live, life itself is the reward” brings this article full-circle. How you look on living with Von Willebrand’s, Haemophilia or any medical attribute ... will always and forever be your decision. So ... here’s the fundamental and ultimately existential, question:

Will YOU make a ‘gift’ of it?

In Remembrance...

Earlier this year HFNZ lost two valued members of our community. Our thoughts remain with their families.

Chris White - 1.12.57 – 27.5.08

On the 27th May 2008, Chris died suddenly and very unexpectedly at the age of 50 as a result of physical health problems. He had a passion for life with a good sense of humour, and was one of those people who continually attracted others around him.

Following a building accident, Chris worked for the last 17 years on a farm as much as he was able. He really appreciated the outdoors, although joint pain and the effects of failing hepatitis C treatment slowed him down. A builder by trade, he took great pride in his house and garden, which was full of beautiful flowers, fish and aviaries (quite apart from the guinea pigs, the dog, the cats and the large indoor fish tanks). He bred birds and there would always be new and wonderfully coloured birds around.

Chris was born in Hamilton and lived there all his life. He had always wanted to go overseas (especially to the Australian Outback) and also go hot-air ballooning, but he never did either of them. Looking back, his wife Linda says: "If there is something you want to do, just go and do it before it's too late. Don't miss out."

His full life also had room for voluntary work, although he always put his family first and he loved children. Chris was on the original Midland Committee in the late 90s / early 2000s, and then after a gap he rejoined in the mid 2000s with his wife Linda. He was an active member at the time of his death. He also attended the first National Men's Weekend in 2006 and the first Couples Weekend with Linda earlier this year.



▲ Chris and Linda at the Couples Weekend early this year

Chris is survived by his wife of nearly 30 years, Linda, his son Jason and granddaughter Kaytie, and his daughter Melissa and her partner Dudley, who are expecting a baby in December.

Peter Hoskins - 17.04.1956 – 14.03.2008

Peter, a lovely gentle guy, first became a member of HFNZ in 2005. A hairdresser from Palmerston North, Peter is survived by his partner Maria. He was the much loved son of Faye and Peter Hoskins of Manaia, brother and brother in law of Claire and Gordon Lynch, and Vicky and Neil Gooding.

Research Summary: You're Amongst Brothers

by Drew MacKenzie



The first of the targeted camps/workshops began in 1993 to provide an opportunity to for youth to explore and share experiences with their peers. These camps have continued every second year however no long-term follow-up has occurred to assess the long-term impact, if any, they have had on attendees. Therefore what this report hopes to add is an overall understanding to formulate general themes of what the people attending the camps have gained from them.

A total of 11 participants from around New Zealand took part in the project. The age ranged from 20 - 26 years old. The participants were from a diverse range of backgrounds and the majority of participants had attended more than one camp. Seven participants had severe haemophilia, two had moderate and two had mild. Nine had contracted a viral infection as a result of contaminated blood products.

Findings

From the interviews three themes were identified: Feeling Real; Finding your Limits; Learning by Chatting Learning by Seeing.

Theme One: Feeling Real

The majority of the young men spoke of the camps being the place they realized they were not alone and that they could be themselves. Participant 9 said it's the place "... you can feel real...". Many of the men spoke of a lack of understanding and a need to explain their condition to others. This highlighted for them their difference. Attending camps allowed them to relax and as participant 5 explained others at a haemophilia camp "... treated me just as a person..." which he went on to say didn't always happen outside this environment as he was often treated with sympathy. >>>

For this group of young men this peer support enabled them to feel validated; gave them a sense of realness and a bond. For some getting together with those who have a similar life experience changed the way they viewed their haemophilia.

"...made you feel a little bit better about haemophilia, you know".
(Participant 6)

Theme Two: Finding your Limits

The majority spoke about having the opportunity during the camps to try something that they wouldn't normally have access to. For the majority of these young men the youth camps gave them a safe environment for pushing themselves and developing a sense of their own limits.

"It sort of makes you realise that you do have a choice. You don't have to do something if you don't feel you've got the ability to do so. Yeah, so in a way it did change my attitude."
(Participant 11)

The comparison between school camps and the haemophilia camps seemed marked in terms of how safe or overprotected participants felt. Attending the haemophilia camps gave ownership back to the attendees to be self-determining. This was also reflected for some in parent styles. Although none of the participants spoke negatively of their parents some felt overprotected. Being separate from their parents at the camps allowed the participants to experience life outside of the protectiveness

"[Mum] stayed at home and off I went. But it's good to get out of there and know that you can do things on your own"
(Participant 3)

The flow-on effect of being allowed to do activities they gauged for themselves they could manage, was to expand their ability and confidence in themselves to take on new things. With this growing sense of confidence some participants came to realize the importance of taking on more responsibility for their own haemophilia care.

Theme Three: Learning by Chatting, Learning by Seeing

Although an objective for the camps is education what was elucidated from the data was that the informal learning that happened outside of sessions carried greater importance for the attendees.

"... and then anything that was sort of interesting got talked about afterwards out with the frisbee ..."
(Participant 4)

Role modeling was also another important approach that these men learnt, not only about haemophilia but the possible consequences.

"But yeah, in terms of the haemophilia side of things, just looking up to them and seeing them treating themselves or doing okay, or not so okay, that's important."
(Participant 7)

The medical staff have traditionally attended camps both in a supportive role and to provide the education sessions. When the men talked of their relationships with the medical staff involved in their haemophilia care all spoke positively about their relationships however seeing them out of the hospital setting allowed a different level of relationship to form.

Although traditionally focused on education as a main objective of camps what has impacted on these men though to adulthood is the more informal, unstructured learning that occurs as a natural part of being together.

Discussion

The findings from this study show that attending the HFNZ camps has had an impact on their lives. What has been shown is that the greatest impact of attending a bleeding disorders camp is that it validated them as individuals. Attending the youth camps appears to have allowed them the space to feel real and have a sense of normality with their bleeding disorder. It allowed them to define themselves not as separate from their haemophilia but living with haemophilia.

When faced with haemophilia the task of becoming independent carries an added challenge. Attending the HFNZ camps provided an environment with enough safety nets in place, such as choosing to participate or not, medical staff on site and peer support, for the individual to decide on their own limits. This assisted them outside of the camp to define and assert themselves, leading to a more positive self-esteem.

Although education is part of the mission of HFNZ and certainly an objective of the camps, the informal education obtained through role modeling and 'chatting' has served as the greatest change agent. The role modeling provided by having older and more physically disabled men with haemophilia allowed them the opportunity to make a conscious choice about the options they would take with their life to maintain their well-being.

What has been made clear from the discussion with the participants is that the camps have had an impact on their lives. However this snapshot of attending camps between 1993 and 2002 is to be considered in the context of time. Therefore the question of the impact of camps on the youth, aged 15-25, will need to be re-evaluated periodically to ensure that resources are being utilized in the most cost-effective and efficacious way.

"...the most important part is just the kids get time to be with one another and get to know each other, and so long as there's provision for that probably the rest is a bit peripheral..."
(Participant 2)

Acknowledgements

Thank you to the Acorn Trust for providing a grant to undertake this research. I would also like to acknowledge and thank the young men who spoke so willingly to me about their experiences. Your generosity will allow the foundation to continue developing on the work it has embarked on to provide the best care and support for people with bleeding disorders.

The full version of Drew's research report is available from the HFNZ National Office; Email: info@haemophilia.org.nz

News in brief News in brief News in brief

200 patients groups unite for first ever World Hepatitis Day



On 18 May, six months after planning began, the day finally arrived when people living with hepatitis B & C could speak out.

The ultimate goal for all supporter sof the campaign was to raise awareness about the viruses – the fact that one in twelve people are living with hepatitis B or C and may of the world 500 million infected do not even know. World Hepatitis Day also proved the opportunity for patients to target governments, asking them to sign up to the “12 Asks” and finally put hepatitis onto their national health agenda.

Successful events were held around the world to commemorate the day. This is only the beginning and planning is already underway for 2009.

New liver scan eliminates need for biopsies

A new scan that tests for liver disease, could alleviate the need to undergo painful biopsies and identify potentially fatal disease in their early stages. The Fibroscan®, by Echosens, is a world first technology with a 95 per cent accuracy rate.

Up to now, biopsy has been the only option for some diagnoses. The new test can measure liver stiffness and scarring, accurately identifying the onset of disease without invasive action or anesthetic. A consultant holds a probe against the patient’s abdomen, on the right lobe of the liver. Vibrations from the probe create elastic waves through the liver and their spread is then tracked by ultrasound. The whole process can take less than fifteen minutes and can be repeated as often as necessary to monitor the progression of disease.

It has reported been able to also detect hepatitis, haemophilia, diabetes and diseases linked to obesity.

The sophisticated technology is not yet available in New Zealand. The closest known facility to receive the technology is the Alfred Hospital in Victoria.

US Senate passes Genetic Information Nondiscrimination Act

On 24 April 2008, the United States Senate Passed the Genetic Information Nondiscrimination Act (GINA, S.358) by a vote of 95-0. The passage of the historic legislation follows a 13-year effort by a broad coalition of grassroots organisation, including the National Hemophilia Foundation (NHF).

The bill prevents employers and insurance companies from requesting genetic testing or information and from discriminating

against someone because of his/her genetic status for the purposes of employment or insurance coverage. It only applies to people who have tested for specific genetic markers, not those who have been diagnosed with specific conditions. However, it helps individuals make proactive decisions about genetic testing and counseling without fear of certain negative consequences. In the bleeding disorders community, the law has particular significance for women who are considering genetic testing to determine whether they are carriers. In the past, some individuals have avoided such tests out of fear of possible discrimination.

The bill was passed into law when President Bush signed the legislation on 21 May.

Aerobic capacity lower in boys with haemophilia

According to a study published in the Journal of Pediatrics, boys with haemophilia have a lower aerobic capacity than their healthy peers, however, their overall muscle strength is comparable.



Aerobic capacity refers to the maximum amount of oxygen that the body can take in and use to generate energy – the more oxygen used, the greater the physical performance. This is also referred to as cardiovascular capacity. Good cardiovascular fitness is associated with lower risk of conditions such as high blood pressure and coronary heart disease.

Since clotting factors were introduced, haemophilia patients have fewer bleeding episodes and are no longer limited to sedentary lifestyles. In this study, researchers examined aerobic capacity in boys with haemophilia and if it correlated with aerobic capacity and muscle strength. A total of 47 boys from the Netherlands, average age 13 years old, were included in the study.

All participants were able to perform at maximal or near-maximal levels on exercise tests. None of the patients experience joint or muscle bleeds or other adverse events because of participation in the study. Total muscle strength was normal and almost no joint impairment or decrease in functional ability was found in patients with haemophilia compared to controls. However, compared with their health counterparts, the peak oxygen capacity, heart rate, and work capacity were significantly lower among the boys with haemophilia.

“The aerobic capacity of children with haemophilia is still lower than that of that of the normal population”, commented researchers from the University Medical Center Utrecht, the Netherlands. They also noted that many of the boys with haemophilia were overweight, although they reported participating in similar amounts of physical activity.

Source: *Journal of Pediatrics*. 152(6):833-838e1, June 2008.

▶▶▶

News in brief News in brief News in brief

Ban Repealed on Travel to U.S. for People with HIV/AIDS

On July 30, 2008, President Bush signed the H.R. 5501 bill which includes important language repealing the 20-year ban that prevented many HIV-positive people from visiting or seeking residency in the United States.

“This is an important step toward changing an odious and useless law that only served to discriminate against people living with a chronic condition,” said Val Bias, NHF Chief Executive Officer.

NHF and the World Federation of Hemophilia (WFH), along with other organizations and individuals in the community, urged members of the Senate to change the discriminatory policy. During the two

decades that the ban was in place, WFH could not hold meetings in the U.S. In addition, many members of the international community could not attend NHF Annual Meetings and other conferences.

“International visitors should never have been singled out in this way,” said Mark Skinner, WFH President. “Patients and healthcare providers in the United States and around the globe will now have equal opportunity to collaborate and share knowledge, enriching the lives of patients everywhere.”

The legislation also significantly expands funding for the international fight against HIV/AIDS and other infectious diseases, tripling the funding to up to \$48 million during the next five years. The program provides much-needed treatment for millions of people in Africa and around the world battling HIV/AIDS, malaria and tuberculosis.

Regional Branch Reports

Midland - by Catriona Gordon

Midland recently held a Cafe evening in Hamilton, on a cold wet and wintry night when the rest of the country were beside their television sets, fearful for the fate of the All Blacks.

The hardy and patriotic Midlanders, confident in Graham Henry’s mystical methods, opted instead for a very enjoyable evening at the Hydro Café beside the Waikato River, where new members were welcomed and old friends met up again. It was also an opportunity for us to meet Maureen Hayes, the newly appointed Haemophilia Nurse Specialist at Waikato Hospital who will be working with Julianne, our haematologist. While Maureen’s role working with adults and children with haemophilia is newly created, she has worked at Waikato Hospital for many years.

The Midland Committee has also been busy with preliminary plans for a Branch Camp, to be held at Totara Springs in Matamata from 31 January to 2 February 2009. The camp has wonderful facilities for our purposes, so we hope that a good contingent will join us. More details will be sent out in the next few months!

Central - by Judith Dudson

We had an adults’ luncheon on Sunday 27th August at the Loaded Hog, Levin which unfortunately, was not very well patronised. The eleven of us who arrived had a nice meal and good conversation.

Grant Hook and Michael Ho had lots to tell of their trip to the WFH Congress and lots more of their travel afterwards. They seem to be finding it hard to keep warm after having 30 + degrees and now being back to 5 degrees and that blessed “credit card”.

Our family camp is all go and buzzing along for September. This year we are returning to Kennedy Park in Napier. We found this was a great place for a camp when we were there two years ago and are eagerly looking forward to returning.



◀ Helen & Manasseh Karanga - Midland’s newest member



The Karanga family ▶ from Midland



▲ Midland Members enjoying good conversation

Regional Branch Reports

Southern - by Theresa Stevens

What a wintry blast has passed through the region lately, I hope you have all managed to stay warm and dry.

During May I attended the local HIV/AIDS memorial here in Dunedin – to say the least it was a very emotional service held in the cathedral. I tried to count the people around me and I think there were about 60 of us in the cathedral. Not many for a memorial service with such meaning I thought. However, candles were lit to commemorate the lives lost and as you can imagine this was hard for me, I silently recalled as many folk that I could, I felt quite honoured and privileged to be part of the service.

The first weekend of the July holidays saw a fantastic crowd gather for the Otago/Southland Outreach visit. Some folk travelled in miserable conditions to attend the festivities of the day. Despite a cold and wet day, we met in the Octagonal room at Dunedin Hospital for a pizza lunch and then on to a trip through Cadbury World. We had 35 people attend the lunch including our two youngest members Arian and Rania (You can read more about these babies in this issue of Bloodline). The trip through Cadbury World was awesome!! And the chocolate waterfall never ceases to amaze me, however; I do feel like many others the free chocolate on tour was a bit skimpy! Despite the weather the Southern families all had a wonderful Outreach trip and as usual it was great to catch up with some old families and to welcome the new ones to our fold. Thanks to the Southern Regional Branch for sponsoring this event.

In mid August I travelled to Christchurch to attend a branch meeting and the opening of the new HFNZ offices. The office looks grand and an informal gathering to officially open the premises was held with several local people attending the festivities. The Southern Regional Branch sponsored the supper for the opening and the staff very generously provided the drinks.

During the first weekend of November the Nelson region are having an Outreach visit, with an event being held at Sounders Park. A notice of this event is to follow.

By the time you are reading this Southerners should have received information about our regional camp. Please remember to book your space early as spaces are limited.

That's all for now, do take care and enjoy the spring weather!

Northern - by Frances Thomas

The idea for a Pamper Day came from one of our new committee members Caroline Davis, who is a beauty therapist.

We sent personal invitations to women, nominated by our Outreach Worker, in recognition of the care they have given to their family members with haemophilia over many long years. Two small groups of women traveled north to Reotahi on 7 June and 2 August for an afternoon of pampering – manicure, pedicure and massage. The women reported that they had a wonderful time. Thank you, Caroline.

Stace Hardley and T.A. organised a Hae.Von event for the youth of our region and a group of nine members went along to a Warriors v. Cowboys match at Mt Smart Stadium on 12 July. After the match they visited the Warriors gym to meet the players.

We look forward to a dinner and film evening on Sunday 14th September, now an annual event in our region. We hold it in conjunction with our Global Feast activity, inviting those who come along to make a donation towards improving the care of those with haemophilia in less developed countries.

Hae.Von Report - by Stace Hardley

After a long gap between events, Hae.Von, Northern's Youth group, finally made it out of the shadows and down to Mt Smart Stadium in Auckland for the Warriors v. Cowboys rugby league match on Saturday 12 July.

Clouds loomed overhead as our small group of nine ventured out prepared for the worst with umbrellas and raincoats. Rain started to fall as the players ran out onto the field but then cleared.

The Warriors put on a good show for us and even managed to pull out a good win. After the presentation to Ruben Wiki to celebrate his 300th game we were invited into the Warriors gym to meet the players, where we got to congratulate the team and mix with the likes of Steve Price, Sonny Fai, Michael Luck, Logan Swann, Brent Tate and Ruben Wiki.

If you are interested in being part of the next Hae.Von event or would like to know more about us, please don't hesitate to contact:

Stace Hardley 09 817 5750
or email stacehardley@hotmail.com

T.A Stirling 09 267-5836
or email eight.factor@hotmail.com

Helen Spencer 09 845-4658 / 0508 322-867
or email helen@haemophilia.org.nz

HFNZ Exercise Competition

Here are the results of the second round of the competition to date:

Region	Registered Participants	Points April-July	Total
Northern	6	4310	4310
Midland	3	2230	2230
Central	9	7633	7633
Southern	5	18074	18074

If you haven't registered yet now is the time! There are so many ways to be active and with the spring weather hopefully just around the corner you can start getting out and about in the fresh air.

Be well and contact your Outreach Worker for ideas and details on how to register.

Dates to Note

5-7 September
Central: Spring Fling
Napier

14 September
Northern: Global Feast Dinner & Film Evening
Avondale

3-6 October
HFNZ Youth Camp
Waiouru Army Base
Contact your Outreach Worker for details

10 October
National Children's Workshop
Christchurch
Contact your Outreach Worker for details

14-15 November
HFNZ Men's Weekend
Venue TBA
Contact your Outreach Worker for details

23 November
Midland: Christmas party
Venue TBA

5-7 December
Parents Empowering Parents programme
Wellington

7 December
Northern: Christmas party
Botanical Gardens, Manurewa

22 December – 4 January
National Office Closed for Holidays

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