

Dates to Note...

22-25 September 2007

HFNZ Young Women's Workshop Weekend
Waihonga Centre
Otaki Gorge, Kapiti

24-25 September 2007

**5th WFH Global Forum on the Safety and Supply of
Treatments for Bleeding Disorders**
Montreal, Canada

4-7 October 2007

14th Australian & New Zealand Haemophilia Conference
Canberra, Australia
More Info: www.haemophilia.org.au

23 November 2007

Global Feast – Fundraising Dinner and Silent Auction
Boaters Restaurant
Christchurch
More info: email info@haemophilia.org.nz

November 2007

HFNZ Couples Weekend
Details to be announced
Contact your Outreach Worker for info

25-28 January 2008

HFNZ Young Families Camp
Blue Skies
Kaiapoi, Canterbury
Contact your Outreach Worker for more information

1-5 June 2008

Hemophilia 2008
WFH Global Congress
Istanbul, Turkey

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bloodline

HFNZ

SEPTEMBER 2007
Volume 35 | Number 3

Newsletter of the Haemophilia Foundation of New Zealand Inc



CENTRAL ESCAPES
the winter blues

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

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Receives
Major
Haemophilia
Award

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THE WORD



Where does the time go? We are in September already and it's time for another Bloodline. As we move into Spring the weather is easing up, as are those arthritic joints.

HFNZ has had a busy and productive few months on many fronts, from the social to the political. The remainder of the year looks like it will be sprinkled with a range of challenges.

One challenge in many organizations that rely on volunteers is succession planning. Ensuring that a group has the knowledge and skills that it needs to move forward is not always an easy task. Many a branch committee and National Council have pondered this issue. With this in mind, this month I have some great news to report.

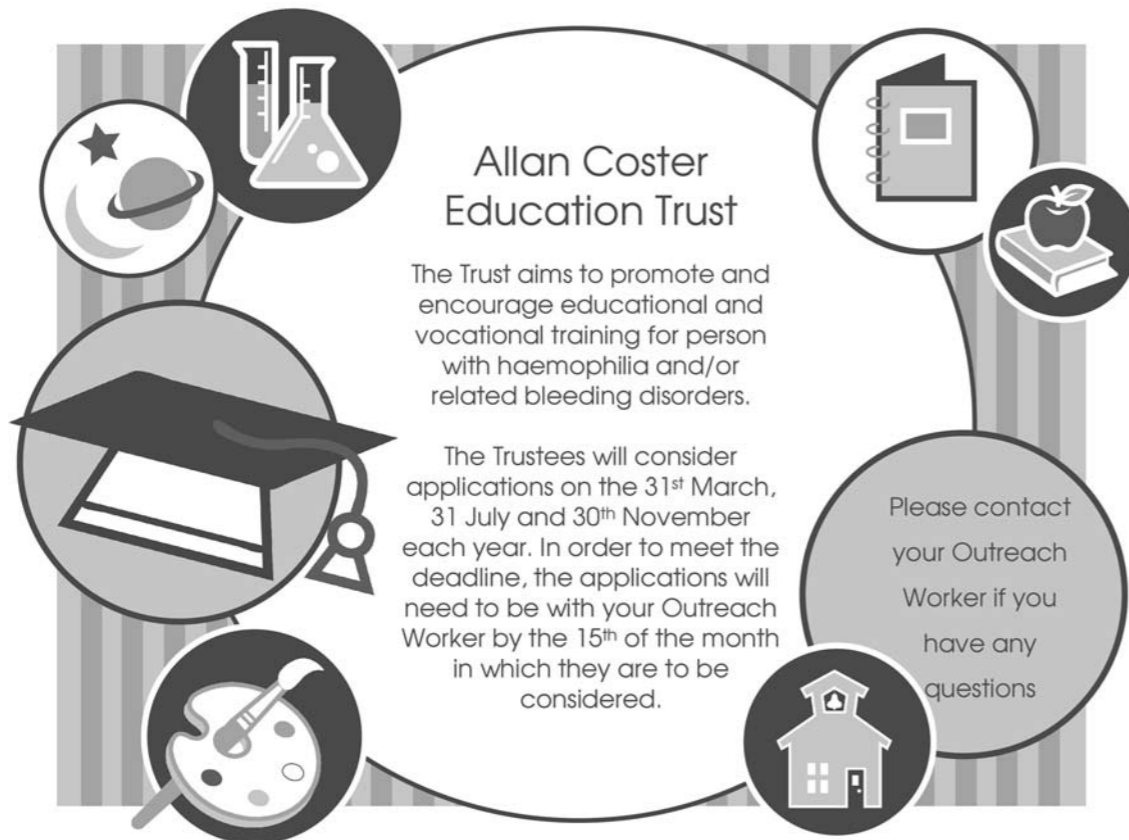
Four youth from New Zealand have been chosen to attend the first Global Youth Leadership

Forum with haemophilia organizations as the focus. HFNZ is pleased to congratulate Karl Archibald, Stace Hardley, Tama Pene and Blair Wightman who have all been chosen to represent NZ at this inaugural event.

This programme, Step Up Reach Out, will be run by the University of Texas. To be eligible, applicants needed to be between 18 and 24 years of age and have either haemophilia A or B. They needed to demonstrate their potential as future leaders in the haemophilia community. The participants will be attending two workshops, one in San Francisco this month and another in February 2008 in Houston, Texas.

Once again, I congratulate these four on being selected. There will certainly be a strong Kiwi contingent in attendance!

Deon York
President, HFNZ



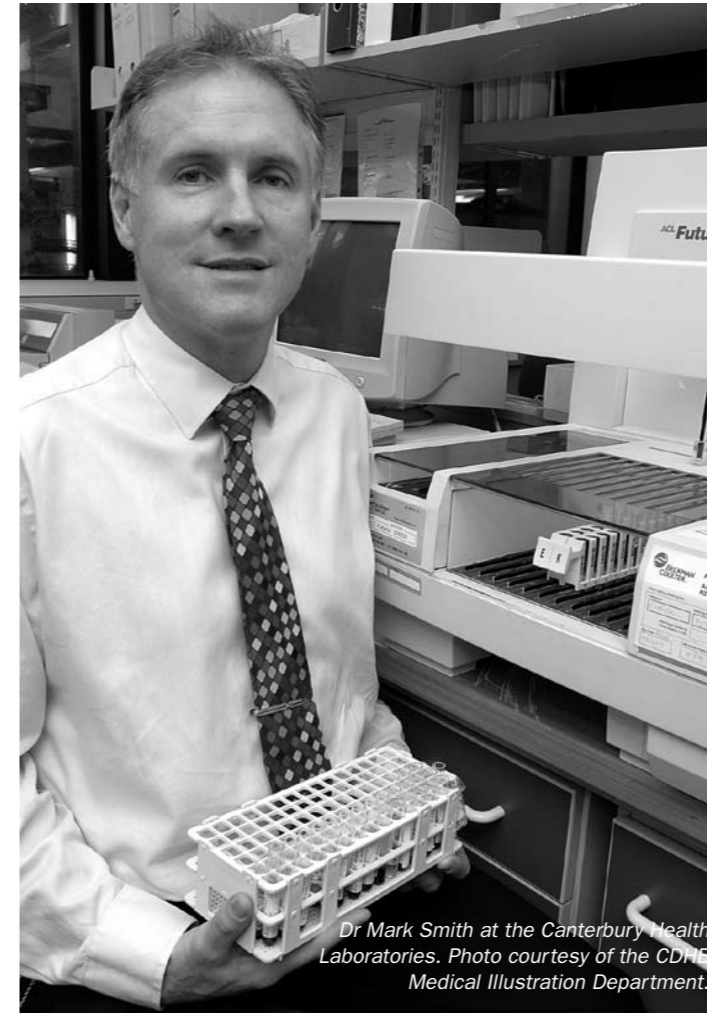
Allan Coster Education Trust

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

The Trustees will consider applications on the 31st March, 31 July and 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.

Please contact your Outreach Worker if you have any questions

NZ Doctor Receives Major Haemophilia Award



Dr Mark Smith at the Canterbury Health Laboratories. Photo courtesy of the CDHB Medical Illustration Department.

Christchurch Haematologist Dr Mark Smith has won an international research award for a project which may save millions of dollars in unnecessary and painful treatment trying to overcome inhibitors and their consequences.

Dr Mark Smith has been awarded a grant worth NZ\$205,000, one of six special projects awarded worldwide by the Bayer Haemophilia Awards Programme. Dr Smith flew to Geneva, Switzerland in July to formally accept the award at special dinner held during ISTH 2007, the XXIIth Congress of the International Society on Thrombosis and Haemostasis.

Launched in 2002, the Bayer Haemophilia Awards Program (BHAP) has awarded more than \$13 million in funding to 118 haemophilia researchers and caregivers over the last five years. The Special Projects award, which Dr Smith received, is designed to support a wide range of research projects in the field of haemophilia. The BHAP also awards research grants for Early Career Investigation, Clinical Training and Caregiver Education.

Dr Smith will embark on a two-year study of people with haemophilia who do not respond to Factor VIII treatment. "This is now the most significant complication facing people with haemophilia," he says. It "well and truly" surpassed the risk of infection from blood products which were now well-screened.

As discussed in the article by Dr Paul Giangrande later in this issue, the development of inhibitors means that Factor VII

treatment fails to work for about 15 per cent of people with haemophilia, often children. They then embark on costly and difficult year-long immune tolerance induction (ITI), aimed at training their body to respond to Factor VIII and overcome the inhibitors. It requires two injections a day, often through a plastic tube inserted in the chest. On average, one or two people in New Zealand undergo ITI each year.

"It's very difficult for the patient and their family," Dr Smith said. The treatment fails for about one in 10 patients. When ITI fails there is almost no way to control serious joint bleeds, which will lead to chronic joint damage.

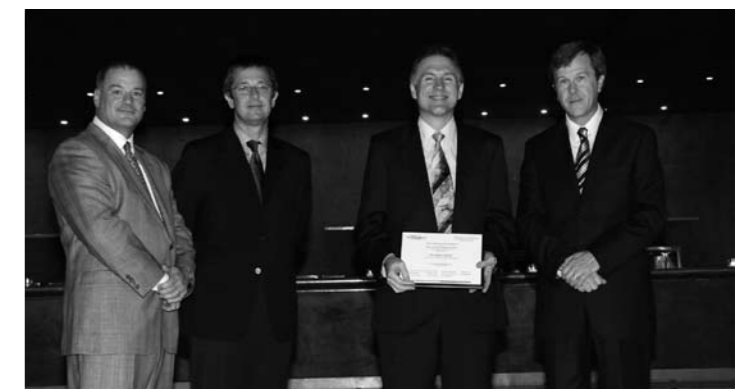
Dr Smith hopes his research into the immune system of people with haemophilia would help doctors predict which patients would not respond to Factor VIII and would not benefit from treatment to improve tolerance of it.

Based at the CDHB's Canterbury Health Laboratories, Dr Smith submitted his research proposal to the international Bayer Haemophilia Awards programme last year and was told in June that he has been selected from scientists worldwide for one of the Special Project Awards. In the next few weeks, a combined University of Otago, Christchurch and CDHB project team will be established to conduct the work.

"Through our research, I hope that clinicians will be able to better select people for ITI treatment, looking at other options for people that we know will be unsuitable and maybe offering it to some people who we would not currently select," he says.

In about 6 months time, after the project's scientific methods have been established, the team will be calling for people with haemophilia in New Zealand and Australia to take part in the research.

"I am really delighted that we have been given this opportunity to do some serious research into this area in Christchurch," he says.



Dr Mark Smith receiving his award in Geneva with fellow recipients.

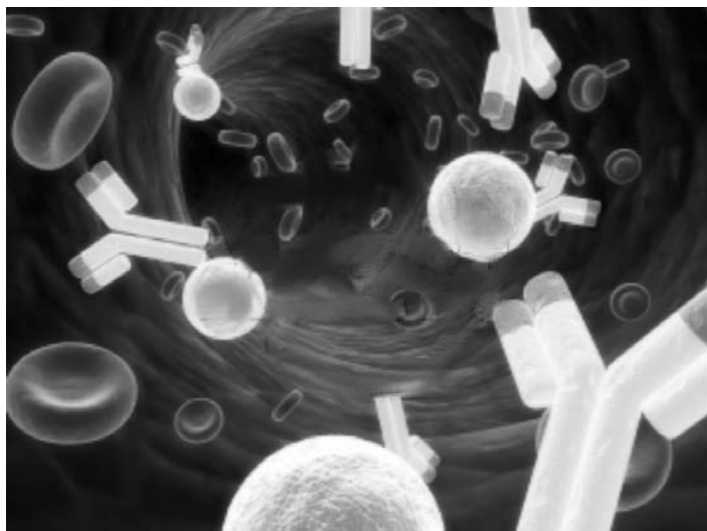
Disclaimer:
The information contained in this newsletter is not intended to take the place of medical advice from your GP, haematologist or specialists. Opinions expressed are not necessarily those of HFNZ. The purpose of this newsletter is to provide a wide range of accurate and timely information on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

In the last issue of *Bloodline* we featured an article on the basics of inhibitors. To further investigate this area of much concern, Dr Paul Giangrande explains...

Inhibitors still a major complication but new treatment products are on the horizon

Research on the molecular defects and genetic factors underlying inhibitor development is leading to new approaches.

Dr. Paul Giangrande
WFH Vice President Medical



Improved donor testing and screening, and the development of physical methods for viral inactivation have effectively eliminated the risk of transmission of pathogens, such as HIV and hepatitis C, by modern clotting factor concentrates. By contrast, the threat of the development of inhibitors (antibodies to infused coagulation factor) remains a potential and serious complication.

Genetic engineering and clinical trials of new products, however, suggest that better management is on the horizon.

The problem is significantly more common in haemophilia A than in haemophilia B. Data from the U.K. registry show that 16 per cent of all patients with haemophilia A and 6 per cent of those with haemophilia B had developed inhibitors by the age of five years. It is now clear that the major factor that determines the predisposition to inhibitor development is the underlying molecular defect.

Certain types of gene defects in haemophilia are definitively associated with a significantly increased risk of inhibitor development. However, there is also additional evidence from family and twin studies that other subtle genetic factors play a role. Race may also influence the risk of inhibitor development. Several studies have shown that people of Afro-Caribbean origin are more susceptible to inhibitor formation.

There is controversy as to whether the risk of inhibitor development in haemophilia A is higher in subjects who receive recombinant products than in those who receive conventional plasma-derived products. Although several studies seem to support this assertion, no prospective comparative study has

yet been undertaken. International initiatives to pool data, which could help to resolve this issue, have been proposed.

Although patients with inhibitors do not usually experience more bleeds than those without, the episodes can be much more difficult to control. The treatment strategy for patients with inhibitors has two distinct aims: to control individual bleeding episodes and to eradicate the underlying antibody through immune tolerance therapy. Infusions of conventional factor VIII concentrates are unlikely to be of any value in patients with a significant inhibitor titre.

The two therapeutic products used most widely to control bleeds in patients with inhibitors are activated prothrombin complex concentrates, such as FEIBA® (Baxter) and recombinant activated factor VII (NovoSeven® by Novo Nordisk). The recent FEIBA NovoSeven Comparative (FENOC) study found both products to be comparable in efficacy for treating joint bleeds, although a minority of patients appear to respond better to only one of these agents.

Immune tolerance therapy involves the regular administration of high doses of factor for up to two years. An international study is currently underway, which will assess whether the outcome can be influenced by the dose of concentrate given (www.itistudy.com). The immune tolerance regime can be very demanding for a child and family. In many cases it is also necessary to insert an in-dwelling central venous line, which carries with it risks of bacterial infection and/or thrombosis.

Patients with haemophilia B and inhibitory antibodies, though rarer, pose a particular challenge. Severe allergic reactions may develop after infusions of factor IX concentrate and the response to immune tolerance induction is also poor. The total cost of treatment for patients with inhibitors can be very high and stretch a hospital budget, even in affluent countries.

Looking to the future, it is likely that genetic engineering will help prevent inhibitors through the design of novel factor VIII molecules that are less likely to provoke an antibody response because of their modified structure. Clinical trials of a recombinant porcine factor VIII are expected to begin in the near future. The rationale for the use of this product is that the molecule is sufficiently similar to the human form to promote clotting while, at the same time, being sufficiently different enough to avoid inactivation by circulating antibodies.

Source:
Reprinted from *Hemophilia World* with permission of the WFH

The importance of your annual review

The concept of comprehensive care is to treat the whole person and the family, through continuous supervision of all the medical and psychosocial aspects of bleeding disorders. Comprehensive care is total care because every facet of the person is addressed, including their physical, emotional, psychological, and educational factors.

Studies have shown that the development and implementation of the comprehensive care model for patients with bleeding disorders have standardised treatment and provided these patients with the ability to lead close to normal lives and be productive members of society.

An important part of the comprehensive care model is the ability of patients to access a whole team to ensure they are receiving the best care possible. It is recommended that each person with haemophilia receive an annual check-up at their Haemophilia Treatment Centre, called an annual comprehensive evaluation or annual review.

At this visit, patients are seen by their haematologist, a physical therapist, a haemophilia nurse, and others who are integral to bleeding disorder care in a one-stop visit. By bringing together multiple disciplines in one visit, patients are evaluated on many levels. The medical staff then meet to make treatment recommendations in a coordinated effort to enhance the patient's treatment and quality of life.

In addition to the professionals, you are also an important member of the treatment team. The staff needs your input to develop a plan of care that will ensure you remain healthy, active, and able to live successfully with added challenge of haemophilia. It is up to you to ensure you are getting the right level of care for your needs and booking in for your annual review gives you the chance to voice your thoughts.

Even if you have been in and out of the hospital frequently over the year, it is still important to book in for your annual review to ensure all involved in your treatment understand what is currently happening and any changes to your body, treatment or care needs. Annual reviews provide a good opportunity to review your bleed history, and see if any changes in treatment regimen are necessary or if times of physical activity need to be modified. For children it is an especially good opportunity to review treatment dose, with regard to changes in weight and annual blood tests can be taken for monitoring purposes.

In general, patients with severe forms of haemophilia should be seen at least once per year no matter what age they are. People with moderate forms should be seen once per year or one time per two years depending on the decision of their haematologist, and mild cases might be seen every other year.

The National Hemophilia Foundation in the USA has long been using the "Do the 5!" message of the most important things you can do to take care of yourself. Number one is 'Get an annual comprehensive checkup at an Haemophilia Treatment Centre'. It's good advice even for us kiwis.



HFNZ's History Book Meeting

In 2008, HFNZ will celebrate its 50th birthday. Over the years the name has changed, but in 1958 an organisation was founded to try to improve the situation and care of people with haemophilia and create a supportive network of people who understood what it was like to live with a bleeding disorder. The spirit of that initial goal is still evident today, and while the issues have changed the aim of the organisation is still to work for people with bleeding disorders, keep them informed of the latest developments and try to ensure they have access to the best treatment available.

As part of the plans to commemorate how far we have come over the last half century HFNZ are writing a book on the history of the organisation and how it has evolved. The Foundation maintains an archive of Foundation newsletters and meeting minutes and letters that date back to the very early days of the then named New Zealand Haemophilia Society. Going through these archives there are some amazing stories and fantastic achievements that deserved recognition. As one of the oldest haemophilia societies in the world, we felt this anniversary is a great opportunity to capture the stories of our first 50 years.

There is a lot more to HFNZ than a room of files however. It is the dedication, spirit and true concern of the people involved that have made it the national and influential organisation it is today. To understand the personal side of events mentioned in the minutes and newsletters a meeting was arranged with a small group of people who have all played a significant part of the story.

Fifteen people, including longtime Secretary Tony Goodwin and a Committee member from the 1970's Elizabeth Wheeler, met together in Auckland this past July to talk about their experiences with haemophilia, how they became involved in the organisation and obstacles they faced, or continue to face. All agreed that having haemophilia or a child with haemophilia was maybe not a choice they would have made, and significant hardship, both



Familiar faces –
Tony Goodwin, Graham Waring,
Elizabeth Wheeler and Anne Waring

physical and emotional, was experienced by all. But the meeting was not all about the doom and gloom of haemophilia, there were stories shared that showed the strength and humour often needed to cope, of how families pulled together and simply got on with their lives, and how the relationships they made through the Foundation have truly been appreciated.

The story of HFNZ is a truly fascinating one. From its humble beginnings in Wellington, the involvement of clinicians, the resurrection of the Society in Auckland in the early 70s, dealing with big issues like HIV/Hepatitis C – there are so many stories to capture.

Special thanks to Mary Brassler, Mike Carnahan, Stephanie Forde, Tony Goodwin, Peta Hardley, Colleen McKay, Helen Spencer, Tony & Lyn Steele, Graham & Anne Waring, Steve Waring, Elizabeth Wheeler, Sarah Wheeler, and Deon York for sharing their stories.

If any members have memorabilia, pictures or stories they would like to share to help with the writing of the book, please contact Chantal at the National Office (email: chantal@haemophilia.org.nz, tel: 03 344 5201)



Further contributors –
Colleen McKay,
Mike Carnahan,
Peta Hardley,
Lyn Steele and
Tony Steele

Life insurance for PWH During the Q&A session at the Southern Family Camp the following question was raised.

“As my family is growing and we are getting older, I have been looking into obtaining life insurance to protect my family for the future. Do you have any information regarding life insurance for people with haemophilia?”

On first glance, life insurance can appear overwhelming and complicated.



Life insurance is a safer bet than the piggy bank

Life Insurance provides for a lump sum payout to a policy holder's heirs, estate or designated individual or charity when the policy holder dies. Most people will purchase life insurance as part of estate planning, to ensure their family is not left with a financial burden or to allow their family to survive financially with as little a disruption as possible.

There are many different life insurance products on the market, such as:

- **Term Life Insurance:** Offers life insurance coverage for a specific period, such as a 10 or 20 year term or coverage for up to age 65
- **Whole Life Insurance:** Offers a level premium over a designated period of time, building up savings through cash value on the policy and coverage for life based on the policy limit (example: \$250,000, \$500,000, or \$1,000,000). The cash value is the amount that you may exchange your policy for if you decide to cancel and take the savings.
- **Guaranteed Issue Life Insurance:** Offers life insurance without medical questions or with a few straightforward medical questions. Usually this type of insurance has a low benefit limit.



- **Universal Life Insurance:** Offers the flexibility of a tax advantage or an investment component.

As each person's family and financial situation and insurance needs are different, the discussion here will focus on what a person with a bleeding disorder - a pre-existing condition - could encounter while trying to get insurance, not the different types of insurance available.

In order to decide what insurance premium (the monthly or yearly payment) is appropriate, insurance companies rely on information that people give them about their individual circumstances (age, health, family history and so on). Then, using statistics based on world wide experience of insured people, the company makes an assessment of the overall level of risk.

While most insurance applications are accepted at standard rates, applicants with pre-existing conditions will be subject to terms and conditions designed to balance the additional risk. Each insurance company may weigh up the risks of pre-existing slightly differently, so it is important to shop around or use a broker with access to many products and insurers.

Pre-existing conditions such as haemophilia or von Willebrand's must be accurately declared at the time you apply for insurance, along with any other conditions such as hepatitis C. Having an insurance broker who understands your conditions, the severity and the treatment is very important and helpful in making sure the risks of insuring you are properly presented to possible insurers and that you obtain appropriate cover. A good broker will research your condition and give you realistic estimates of which companies and products will be most suitable.

Most insurers treat pre-existing conditions in one of following ways:

- by excluding your pre-existing condition from your insurance cover, or
- by charging a higher premium to cover your pre-existing condition (loading), or
- by covering your pre-existing condition only after your policy has been running for a set time, or
- by using a combination of the above.

Excluding Pre-existing conditions

Under the Human Rights Act 1993 people in New Zealand are protected from unlawful discrimination in a number of areas of public life, including the provision of all types of insurance. This means that, subject to some exceptions, insurers cannot refuse to provide a person with insurance on any of the grounds in the HRA. Prohibited grounds of discrimination include physical disability or illness, any abnormality of psychological, physiological or anatomical structure or function and the presence in the body of organisms capable of causing illness.

Although insurers cannot refuse to provide a person with insurance, insurers can include different terms and conditions in insurance policies on the grounds of sex, age or disability if the difference can be supported by statistical or actuarial data. Even if some conditions are excluded from cover, a person with a pre-existing condition would usually still get value from a life insurance contract because it provides cover for conditions other than those specifically excluded.

Loading

How much an insurer charges for your cover can depend a lot on how information about you is presented to them. There are lots of variables involved in determining the risk to the company for insuring you, and depending on your circumstances they may offer to insure you in exchange for loading an additional charge on top of the standard premium.

Generally speaking, the more severe your bleeding disorder, the younger you are (and so at higher risk of accidents) and the more health conditions you already have (hepatitis C, smoker) will result in higher loading. For example if you are under 40 years old, have both severe haemophilia and hepatitis C you would be considered a significantly higher risk to insure and so could expect an insurance premium with 250% loading – 3.5 times the standard premium.

For people with mild or moderate haemophilia who are 20-40 years old, loading could be from near standard to 100% (double the standard premium). Older people with similar clotting levels might be charged standard to 50% loading (1.5 times standard).

Moratorium Underwriting

A moratorium is a waiting period that must elapse before claims resulting from pre-existing conditions may become eligible. In some situations, insurers will agree to insure your pre-existing conditions only after a certain period of time, usually 2 to 3 years. There will be specific rules and conditions that must be met before pre-existing conditions would be considered by an insurance provider for cover.

Alternatives

Some insurers are now providing a life insurance product that may be that may be suitable to people considered to be high risk. It has a possibly lower total cover than some policies but has a set premium for life and there is no underwriting - so no

need to declare most pre-existing conditions. The only question that has to be answered is if you have been diagnosed with a condition that is likely to be fatal in the next year. The cover remains the same throughout life as well, unless you die within first 2 years in which case your estate would only get back the money you have paid into the policy.

This type of product might be a good option if to insure you regular products would be heavily loaded, and you do not need a lot of cover but want something in place to cover final expenses and the like (\$100,000 maximum cover). For example, someone who is 30 now and a non-smoker could expect to pay a \$50 premium a month – and receive \$67,000 worth of cover for rest of their life. Although this might appear to be a high premium now, as it will never increase it might seem a reasonable price to pay later in life.

Final thoughts

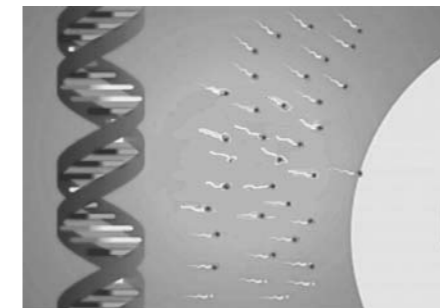
Life insurance is not impossible to get if you have haemophilia. Some companies are better than others to deal with and may be more or less understanding of the risks of having a bleeding disorder. The best bet is to shop around or engage a broker who can do the research for you and present you with the best options for your specific situations and needs.

Thanks to Brent Lewis, Insurance Broker at Lewis & Associates Financial Services, PO Box 27-171 Marion Square, Wellington (email: brent@blewis.co.nz; tel: 04 477-3018) for his help in preparing this article. Brent has clients with haemophilia for whom he has successfully obtained coverage and is happy to answer any queries from members.

PGD - an option for haemophilia carriers

Pre-implantation genetic diagnosis (PGD) is an alternative to prenatal diagnosis, and is distinguished from it by the stage at which decisions have to be made: at the embryonic rather than the foetal stage.

Until recently, the only testing option available to couples at risk of conceiving a child with a genetic disorder was prenatal diagnosis. This involves sampling of foetal cells through the



placenta (chorionic villus sampling) or the amniotic fluid (amniocentesis). If a foetus is found to be affected by a particular disorder, couples have to decide whether to proceed with the pregnancy or have an abortion.

PGD is a procedure used in conjunction with in vitro fertilisation (IVF) to test early human embryos for serious inherited genetic conditions and chromosomal abnormalities before they are transferred to a woman's uterus. The procedure is sought by both fertile and infertile couples at high risk of having children with a serious genetic condition.

PGD involves several steps:

- 1. The creation of an embryo via in vitro fertilisation (IVF)
2. Removal of one or two cells from the embryo
3. Genetic testing of these cells for specific genetic conditions or chromosomal abnormalities
4. The subsequent transfer of unaffected embryos to a woman's uterus.

PGD offers another choice to carriers of a serious genetic disorders, such as haemophilia, and involves making decisions about the future of an affected embryo, rather than an affected foetus.

Under current guidelines developed by the National Ethics Committee on Assisted Human Reproduction (NECAHR) registered fertility clinics in New Zealand will be able to test human embryos for serious inherited genetic disorder.

"For some couples the chance of serious genetic conditions has meant that becoming parents has been too risky," Minister of Health Pete Hodgson has commented. "Up until now, these couples have had to get pregnant first and test the developing foetus for disorders later. This causes significant stress. By testing first and ensuring that embryos with serious genetic disorders are not implanted, we can make it much easier for these couples to have healthy children."

Public funding for the full cost of up to two cycles of IVF/PGD is available to people who use PGD to test for serious inherited genetic disorders, such as haemophilia A. This funding includes the costs of the IVF treatment that must accompany PGD.

The Ministry of Health expects that of nearly 150 cycles of IVF/PGD to be carried out in New Zealand each year, 40 will be to detect serious inheritable genetic diseases. The funding will cover the approximately 40 procedures each year where there is a family history of sex-linked disorders passed on to babies by one parent's carrier status, or for a range of single gene disorders which may be inherited when both parents are carriers

of the same genetic disorder. Examples of such conditions include haemophilia A, Huntington's disease, leukodystrophies, lysosomal diseases, Muscular Dystrophy and Cystic Fibrosis. Unfortunately a test for haemophilia B is not yet available.

While not everyone agrees on the use of PGD or similar technologies, the New Zealand guidelines were developed after intensive consultation and are considered ethically acceptable. NECAHR Chair, Professor Sylvia Rumball says "The guidelines set clear criteria to ensure this technology is not misused. Use of PGD for non-medical reasons will be prohibited. It is not about 'designing babies', the aim is to help people with serious genetic disorders have children without the risk of passing on an inherited condition." Ultimately the decision to proceed with PGD lies with the parents.

The PGD process involves extensive counselling to help parents fully understand the decisions to be made. Providers must ensure that those seeking PGD are given all of the information relevant for informed decision-making, including the processes and procedures associated with IVF and PGD, the risks associated with the procedures, the background and experience of the clinic and clinicians, the success rate of the procedure, both in general, and at that particular clinic, and the alternatives to PGD.

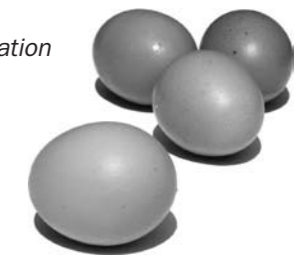
Providers must also ensure that those seeking PGD are given all of the following information prior to giving consent:

- Genetic and clinical information about the specific disorder/infertility
• The likely impact of the disorder/infertility on those affected and their families/whanau
• Information about treatment, counselling, and the extent of community and social support available
• The availability of prenatal testing following successful implantation

For people with familial disorders, providers must ensure that those seeking PGD receive genetic and psychosocial counselling from qualified counsellors who are trained in genetic counselling. That counselling must be culturally appropriate and take into consideration the nature of the disorder, its likely impact on the offspring and family/whanau and the availability of treatment, the family/whanau experience of the genetic disorder, the range of alternatives to PGD and subsequent decision-making processes, and the possible implications of undertaking PGD.

The first PGD procedure for haemophilia in New Zealand took place in 2006. Beyond the total annual number of funded cycles, there is no limit per genetic condition. The uptake of available funded cycles of PGD has been slow, and people who carry the gene for haemophilia A interested in the procedure are likely to be accepted in the programme. People who wish to use PGD should in the first instance see their general practitioner.

Sources: NEHCAR Guidelines on Pre-implantation Diagnosis, National Haemophilia Management Group



Working out the lingo...

Agent: An individual or firm authorized to act on behalf of another (called the principal), by executing a transaction or selling and servicing an insurance policy. The agent does not assume any financial risk in the transaction.

Broker: An independent agent who represents the buyer, rather than the insurance company, and tries to find the buyer the best policy by comparison shopping.

Loading: An amount an insurance company adds to the basic premium to cover the expense of securing and maintaining the business.

Policy: A contract of insurance, describing the term, coverage, premiums and deductibles.

Pre-existing conditions: Conditions that existed before a health insurance policy was issued. Not covered by some policies.

Premium: A regular periodic payment for an insurance policy, also called insurance premium.

Risk: Term used by insurers to describe the likelihood that the insured event will occur, thus resulting in a claim being paid.

Underwriting: The process by which an insurer decides whether a potential client is insurable and what the risk of insuring them is.

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HFNZ Exercise Competition Update

The HFNZ Exercise Competition is all about getting out there and getting moving. Since its launch in March over XX people have registered and are showing that having a bleeding disorder does not need to be a hurdle to being active.

Well done everyone!

As we are halfway through this year long competition we are pleased to announce the first prize winner. **“Congratulations to team Stirling Family of Manurewa for their commitment and hard work over the winter months.** Henry, Patience, T.A. and Holden kept each other motivated and active, each not wanting to let the team down. Each faced different hurdles - T.A. had ankle and knee surgery earlier in the year – but all did their best to stay active. Team Stirling have won a TEAC portable DVD player donated by Baxter Healthcare.”

By the end of the competition prizes will also be awarded for:

- The most improved individual
- The most improved individual with bleeding disorder
- The most consistent individual
- The most improved team

Remember everyone can participate - it's not too late to join. Registrations are for individual or teams of 4. Anyone can register as individuals. Teams must have at least one person with bleeding disorder. Contact your outreach work who will supply you with an exercise log and the details. For every 15 minutes of activity you gain 5 points.

Examples of activities various members have been trying include swimming, walking, non-contact Tae Kwon Do, dancing, canoe polo, cycling, archery, and specific exercises like knee exercises for a target joint.

Keep up the good work and remember to have fun.

Results as of End August 2007:

Here are the total results so far:

Region	People Registered	Total Points for Region
Northern	14	9311
Midland	13	5875
Central	19	15 973
Southern	11	2309*

*Unfortunately, points for 8 of Southern's participants were not available at the time of printing, so we should hopefully see some better progress next update

Making Children Safe and Choosing Activities



In keeping with our recent focus on physical activity and our Exercise Programme, the following is taken from “All About Haemophilia: A Guide for Families” and reprinted with the kind permission of the Canadian Haemophilia Society.

How Can You Create a Safe Environment and Prevent Injuries?

Safety precautions for your child with haemophilia are not much different from those for other children. By thinking ahead and providing safe surroundings for your child, you may be able to reduce the number of accidents your child will have. There are many good books available about keeping children safe from burns, accidental poisoning, drowning and choking. These safety tips apply to all children.

Many children fall, get cuts and scrapes and bump their heads. Most of these injuries are minor. For a child with haemophilia it is important to prevent the serious ones.

Here are some safety tips for infants:

- Always strap your baby in and stay with him when he is in his infant seat or high chair.
- Place baby carriers on the floor since they can fall or be knocked off high places.
- Stay close to your baby when he is on a changing table, bed or other high place.

As your infant begins to roll and crawl, you must make sure your house is as safe as it can be. A good way to do this is to get down on the floor and “see the world” from a child’s viewpoint. Try to think not only of what your child can do now, but also what he is likely to do next. He can surprise you by suddenly learning how to roll or stand up. Remember that children are curious and like to try new things.

To keep the mobile infant safe:

- Use child security gates at the top and bottom of stairs.
- Do not use a baby walker.
- Remove any furniture that tips easily.
- Remove loose rugs that can cause him to trip or slip.
- Remove or pad the corners of coffee tables, fireplaces and other furniture.
- Keep knives, scissors and other sharp tools out of reach.

With any toddler, learning to stand and walk involves some falls. For the child with haemophilia, this may cause bruises. Bruises on the skin are not a concern unless they are painful and cause the child to stop moving. Your Haemophilia Centre team will help you learn what types of bruises are causes for concern.

Your Haemophilia Centre team can also advise you about protective clothing for this period in your son’s life. Kneepads and high-top boots or shoes are sometimes recommended to protect knees and ankles. A soft helmet will provide some protection from minor bumps to the head.

In addition to your house, you will want to ensure that the play areas in your yard and local playground are safe too. Remove any sharp rocks or broken glass that could cause injuries. Make sure that swings and slides are smooth and won’t give splinters. When you go to the beach, protect your child’s feet with water, shoes or sandals. If your child goes to a baby-sitter or a playgroup, make sure the toys are in good repair. Ask the people in charge to remove toys with sharp corners or broken pieces.

As your child gets older, teach him safety precautions. Be sure to set a good example.

- Show him the safe way to carry sharp objects.
- Teach him the correct way to handle and store tools.
- Wear your own bicycle helmet and insist that your child use a helmet as soon as he starts to ride a tricycle.
- Wear your own seat belt and always insist that he buckle up too.

Why Are Exercise and Sports So Important?

Exercise and physical activity are important for all children. They are especially important for children with haemophilia. People involved in haemophilia care have learned that strong muscles protect and support the joints. This reduces the risk of bleeding.

Exercise develops strength, coordination and flexibility. These are all necessary to help prevent injury. Children who participate in sports also develop good concentration, have strong hearts and lungs, and feel a sense of accomplishment and achievement. Children who participate in team sports make friends and learn how to cooperate and work with others.

Studies over the years have shown that children with haemophilia are not as fit as other children of the same age. This may have been true in the past because children with haemophilia were not encouraged to participate in sports for fear of injury. However, today there are many activities a child with haemophilia can do safely.

What Activities are Safe for Children with Haemophilia?

Toddlers & Preschoolers

Toddlers and preschoolers love to move. They like to kick a ball, play catch and play running games. Some parents may try to stop their child with haemophilia from playing outside because they are afraid he will get hurt. However, outside play is needed for a child to develop strength, balance, coordination and judgement. With an adult nearby, outside play should be allowed and even encouraged.

The age for starting sports is different for each child. Swimming and water play can be started as infants. Some children begin T-ball or soccer at age four; others start when they are older. The age at which children are ready to ride a two-wheeled bike will also vary.

When starting any sport, it is important to have proper equipment that fits correctly. Some parents make the mistake of buying oversized equipment hoping that the child can use it as he grows. Equipment that does not fit properly can actually cause injuries rather than prevent them.

Sports for School Age and Older Children

It is important that a child with haemophilia take part in his school’s physical education programme. Changes to some activities may need to be made if they involve body contact. Parents, with help from the Haemophilia Centre team or Outreach Worker, can teach the school staff about haemophilia and what to do in case of a bleed.

School age children often begin to play organised sports outside of school, for example, at their local community club. This can be a difficult time – the child may choose a sport that is not ideal. Some parents tend to forbid the child to participate.

However, in many cases, the child will play the sport anyway and not tell his parents. Then he might be afraid to tell them if he gets hurt and delay treatment of a bleed.

It is important for parents to discuss the options openly with the child. The goal is to work together to find a solution. Some parents find it helpful to make a deal with the child in advance of starting a new sport. They all agree that if he experiences several muscle or joint bleeds because of the sport, he will find a different sport to play.

Selecting a Sport or Activity

When choosing a sport for any child, there are a number of questions to ask:

- What is your child interested in doing?
- What is your child able to do?
- What do his brothers, sisters and friends play?
- What programmes and facilities are available and popular in the community?
- Are the coaching and supervision adequate?
- Is special equipment required? Can you get equipment that will fit your child properly?
- Is it a year-round activity, or will you need to find other sports for the “off-season”?

For your child with haemophilia, you must also consider these questions:

- What is the severity of your child’s haemophilia? A child with mild haemophilia may be able to participate in some sports that would not be recommended for a child with severe haemophilia.
- Is he receiving prophylaxis therapy? Can the infusions be scheduled just prior to the riskiest activities?
- Does he have an inhibitor? The presence of an inhibitor may mean that he cannot be treated adequately if an injury occurs.
- Does he have a target joint? For example, soccer would not be recommended for a child with an ankle that has been bleeding often.
- Will he need factor therapy before he participates? Is this available?
- What will the coach do if any injury occurs?
- Are these sports that the whole family can do together? This way, you can be close by to supervise or manage injuries if they occur.

HFNZ Sustaining Patrons

Among the valued donors to the Haemophilia Foundation of New Zealand Inc., from individuals to trusts, to corporations and funding bodies, are those who have joined the HFNZ Sustaining Patrons Programme to provide a generous amount of ongoing non-directed funding. This funding is to support all HFNZ programmes and is in place for three years.

HFNZ is sincerely appreciative of the commitment of current Sustaining Patrons to improving the lives of people with haemophilia and other genetic bleeding disorders.



Your Haemophilia Centre team can help you find answers. The physiotherapist can discuss the advantages and disadvantages of specific sports and advise what preparation, such as protective equipment or conditioning exercises, might be necessary. Your nurse coordinator will help you arrange to have factor concentrates available to prevent and treat any bleeds. The Haemophilia Centre staff will also work with your child to teach him about bleeds and help him make sensible choices, so that he can participate safely.

Formalised Exercise Programme

Exercise programmes prescribed by a physiotherapist are often suggested for children with haemophilia. Exercises may be recommended:

- To build muscles and prevent bleeding.
- To assist with recovery after a bleed.
- To prepare for a specific sport or activity.
- To maintain good fitness.

Exercise can be designed to improve muscle strength, joint mobility, flexibility, balance, coordination and endurance. Strong muscles support and protect joints. They can actually prevent bleeds. Good balance and coordination mean few falls and accidents.

For a child with haemophilia, any new exercise programme should begin gradually, with small numbers of repetitions. Stretching exercises should be done slowly, without strain, so that muscles are not injured. Strengthening exercises may be done using some form of resistance, such as elastic tubing, exercise balls, weights or even water. A small amount of resistance should be chosen to start, and increased gradually as the muscles are able to tolerate it. Lifting very heavy weights for a few repetitions is not recommended for children due to the amount of strain this places on the growing joints and muscles. Smaller weights with larger numbers of repetitions can be used to build strength. The physiotherapist at your Haemophilia Centre is your best source of information about exercise programmes.

Investing Basics

Investment is a just a fancy word for what to do with your savings to make your money grow. Investing is not just for rich people or those saving for retirement.

Some of our members will have recently received the Government's ex-gratia payment as a result of the Hepatitis C Treatment and Welfare Package. For your interest and for that of readers in general here is a brief summary of investing basics to help you understand the basic terminology and concept of investing. This is not intended to be investment advice and is for informational purposes only. If you are interested in investing you should contact an accredited broker or financial adviser.

The basic idea behind investment is simple – use your money to make more money.

Your Investment Profile

There are four factors you should consider to help you work out the type of investment that might be right for you:

Duration - How long do you want to invest for?

Returns - Do you want income or growth?

Liquidity - Do you need to get to your money easily?

Risk - What is the chance that the returns on a particular investment may change?

You might have a couple of different investment goals. You might be saving for an overseas holiday, or a property and for your retirement at the same time. You will then have separate investment profiles to match each goal and the best investments for you will be different in each case.

Duration

The length of time you might want to invest for will change depending on your goals.

- Short term - 1 to 3 years
- Medium term - 3 to 7 years
- Long term - over 7 years

It's common to have different investments of different durations. Over longer periods of time you'll be interested in capital growth.

Returns

The question here is "Are you more interested in income or growth"? That is do you want to use the money your investment earns as income to live off during the duration of the investment or you want to reinvest it with the original lump sum to grow that sum as large as possible?

If you are looking at a short term income from your investment, it's probably best to put your money where you can guarantee how much money it will earn, such as a bank deposit paying a fixed amount of interest for a set period. On the other hand, if you would rather grow your lump sum as much as possible you could consider investments such as shares that don't guarantee a set return from year to year but have the possibility of higher returns.

Liquidity

Liquidity means the speed you can convert your investment into money before the end of your investment period without taking a loss. Investments with high liquidity mean you can get at your investment anytime, such as a bank savings account. A low liquidity investment means it may take time to get your invested money out or find a buyer at a price acceptable to you. Property is usually a low liquidity investment. Shares in public companies are generally in between these two examples, but may depend on the type of share. Some investments may be totally illiquid – you cannot get your money until a certain date or event (e.g. retirement). You will need to consider how important access to your invested money is depending on your goals or situation.

Risk

Risk and reward is the classic investor's balancing act. The higher the risk you take, the higher returns you could receive but the more chance you have of taking a loss.

With a low risk investment you generally know the return you will receive from the start. A bank saving account where there is a set interest rate is a low risk investment compared to shares, where the returns might be higher but so is the risk it will fail.

Higher returns are only available with higher risk. Risk comes in two types, volatility (the possibility that the value of your investment will go up and down) and performance (the possibility that the investment could fail and you would lose all or part of your money). If you are considering high risk investments, you can balance your risks with other investments in lower risk areas, like short term deposits or cash and bonds.

Risk vs. Return

It is impossible to get a return on an investment without facing a certain degree of risk. Investing in shares, debt securities or mutual funds all carry risk of different degrees.

No matter what you decide to do with your savings and investments, your money will always face some risk. If you stash your cash under your mattress or in a piggy bank then you face the risk of losing it all if your house burnt down or was robbed.

At the end of the day, what you need to do is make sure you'll make enough return on your investment, with an acceptable amount of risk for you. This acceptable amount of risk is different for each person, and if your investments are causing you anxiety you might want to consider lower risk options.

Types of Investments

Although there are many different types of investment, most fit into four asset categories: short term deposits, bonds, property and shares. Within each class there are investment to suit different kinds of risk, duration, returns and liquidity. There are also different ways of investing. You can invest directly by yourself in one or more of the asset categories or you can invest in a managed fund where fund managers make a wide range of investment decisions for you.

For most kiwis, their largest investment is their home. Depending on your needs and situation you may want to try to separate your emotional ties to your home from your investment objectives. For example, to achieve your long term goals is it wiser for you to buy a smaller house and spread your money across other investments? You may want to seek extra advice if you are considering investing in your first home.

People debate whether property is better investment than shares. Although they can both be good long-term investments, they are very different and need good management. You should be prepared to put some time into understanding the many aspects and issues of property investment or shares before rushing in. You can invest directly in term deposits, bonds, shares and property or you can place your money in superannuation scheme or managed fund and full specialists look after the decisions

for you. For some people making their investment decisions and taking a more hands on approach gives them personal satisfaction and possibly some tax advantages. You should seek advice from an accountant of financial adviser if you are interested in direct investment. However, unless you feel confident in your understanding and management skills, you might want to consider leaving the management to those qualified to do so. Managed funds do usually involve paying management and administration fees. As these can vary widely, you should shop around and check the competitions before making a decision.

The potential range of investment products you can choose from is huge. If you want to invest, work out your needs and ask advisers or providers to find you a few suitable products.

Tips for Success

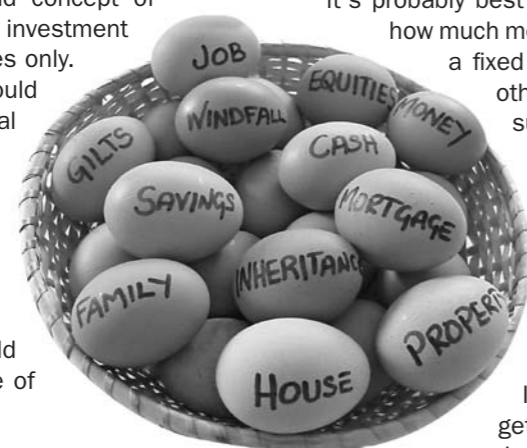
1. Plan: this includes working out your investment goals and what kind of investor you are. A plan based on your goals and circumstances will make decision making easier and help avoid many pitfalls. Financial advisers can help you with your plan.

2. Buy value: Success is more likely when you have your own well-informed views of the companies or assets you are investing in. Look for those that are sustainable and can reasonably expect to gain in profit or value.

3. Diversify: There is risk involved in any type of investment. The best way to manage those risks is to spread your money across a range of investments. Higher returns generally only come with higher risk. The extent to which you spread money across investments with depend on how much risk you are comfortable with.

4. Stay informed: Investments, especially long-term ones, are not meant to simply be forgotten once arranged. Success means that you will need to stay tuned to what is happening on the stock market/property market or with interest rates depending on your choices. By staying informed you will be able to better react to any changes on the horizon.

5. Live with risk: Patience is a virtue when it comes to long term investments. As some investments are bound to fluctuate is can be hard to maintain your cool while you wait for good returns over the longer term. The rule is usually to stick with the investments you have carefully chosen, until you see definite signals to move your money. The best returns are almost always over the long term and you will lose out if you respond too quickly to volatility.



Remember not to put all your eggs in one basket!

Types of Investments					
Description	Bank Savings Account	Fixed Term Deposit Lump sum	Bonds	Property	Shares
	Simplest kind of short term investment. Simply deposit your money in a bank account.	deposited for a set amount of time (3, 6, or 12 months). Receives higher interest rates than a regular savings account but there may be penalties if is money withdrawn early.	Bonds lock your money away with the government or a company for a set period, they then promise to pay it back with interest. Usually done through a managed fund not directly. Can sometimes be traded.	Typically safe and profitable investments, unless poorly managed.	Investing in shares in a public company listed on a stock exchange and so sharing in the future income and value of that company. Can be sold. Losses do happen.
Duration	Variable	Short or Medium	Medium or Long	Long	Short, medium or long
Risk	Low	Low	Medium	Medium	High
Returns	Low, but guaranteed	Low, but guaranteed	Medium	Medium to high	Can be high
Liquidity	High	Medium	Low to medium	Low	Medium to high
Best for	Short Term savings goals	Short or medium term goals	Medium or long term goals	Long term goals	Long term goals

Exercises for People with Bleeding Disorders

Continuing on from our publication of Exercises for the Knee in the June Issue of Bloodline, this issue we feature Exercises for the Ankle, another common target joint.

These exercises are featured in the WFH guide, Exercises for People with Haemophilia by Kate Mulder. Copies of the entire guide are available from chantal@haemophilia.org.nz, your Outreach Worker or online on the WFH website, www.wfh.org – simply follow the link at the bottom of the homepage under Recent Publications.

The exercises in this guide are not the only useful exercises for people with haemophilia. They have been chosen to meet specific goals, and because they are relatively safe to do with minimal equipment and supervision. Ideally, exercises should be prescribed for people with haemophilia by a skilled and patient physical therapist following a detailed assessment. If you have any questions about trying any of the following exercises contact the physiotherapist at your local haemophilia treatment centre.

Exercises for the Ankle

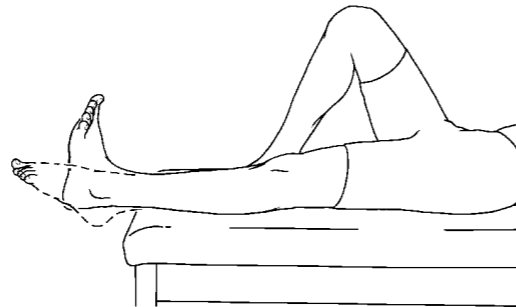
The ankle joint is also commonly affected by hemophilic bleeding. The **talocrural joint** is the usual site of bleeding, but bleeding can also occur into the **subtalar joint**. **Anterior** swelling interferes with ankle **dorsiflexion**. Repeated bleeding causes thickening of the synovium, which can further limit ankle dorsiflexion. Limited dorsiflexion causes the individual to walk on a plantarflexed ankle (on the toes), which is not a stable position, or to walk with the foot turned outward.

Range of Motion

LEVEL 1

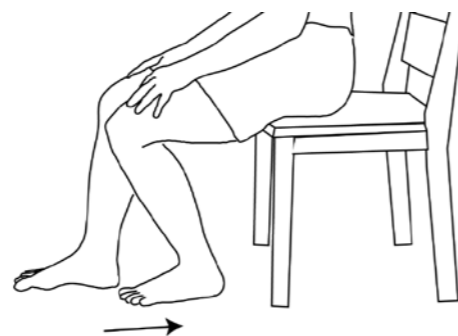
This exercise can be started as soon as bleeding has stopped.

Start: Lie in a comfortable position.
Exercise: Move foot up and down, in and out. Practice drawing shapes or letters of the alphabet with your foot, keeping the rest of the leg still.
Goal: Full ankle motion equal to the opposite ankle or baseline.



LEVEL 2

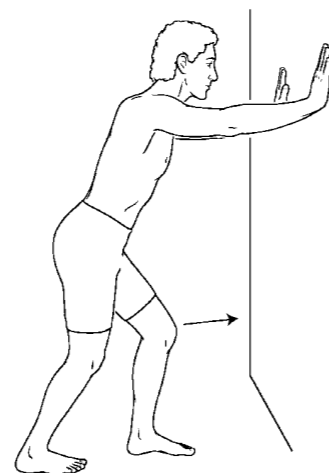
Start: Sit on a chair with knee bent and foot flat on floor.
Exercise: Slide heel back as far as possible, keeping heel down. It may feel as though there is pressure at the front of the ankle. Hold for several seconds, then relax. Repeat.
Goal: Try to slide the heel back a little bit further each time. Practice until full motion is restored. Compare to other ankle or baseline.



LEVEL 3

Note: Do not attempt this exercise if there is swelling or pain in the ankle.

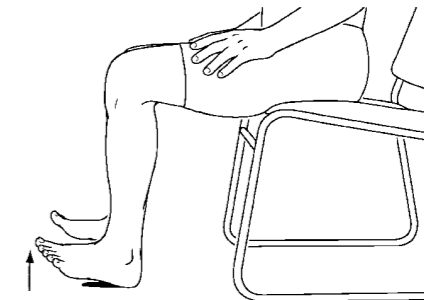
Start: Stand facing wall, with affected leg slightly ahead of the other. Place hands on wall, keeping both feet pointing toward wall.
Exercise: Gently move the knee toward the wall, while keeping the heel flat on the floor. Hold for a few seconds, then relax. Repeat.
Goal: Try to move knee closer to wall each time. Compare to other ankle or baseline.



Strength

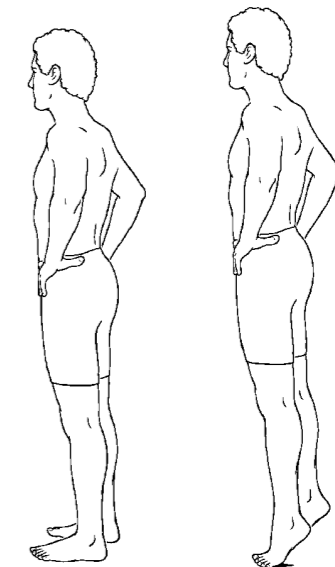
LEVEL 1

Start: Sit on a chair with knee bent and foot flat on floor.
Exercise: Lift front of foot off floor and hold for several seconds. Relax.
Goal: Repeat until leg muscle feels tired.



LEVEL 2

Start: Stand with weight on both feet.
Exercise: Lift both heels and stand on toes for several seconds. Relax.
Goal: Repeat several times, until calf muscle feels tired.

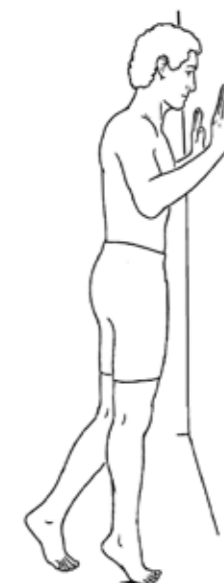


LEVEL 3

Start: Standing or walking.
Exercise: Walk several steps on tip toes. Then walk several steps on heels.
Goal: Repeat several times, until muscle feels tired. Increase by a few steps each day.

LEVEL 4

Start: Stand on affected leg. Hold onto something for balance.
Exercise: Raise heel off floor and hold. Relax. Repeat several times.
Goal: 25-30 repetitions. Do not continue if there is pain in the ankle during the exercise.



"Two of my patients have bad ankles. Because they each had both knees replaced in the last three years, they want to wait a little bit before thinking about ankle fusion. This can also be explained by the fact that their mobility and walking capacities improved a lot after the knee surgery. Nonetheless the pain is still severe in both ankles. So one part of the treatment was to teach them some exercises to mobilize the ankle combined by mobilization physiotherapy session each week. This treatment doesn't relieve the pain completely but the ankle surgery can be delayed."
 – Physiotherapist, Belgium

Regional Branch Reports

Proprioception

LEVEL 1

Start: Stand on affected leg.

Exercise: Maintain balance.

Goal: Practice until balance can be maintained for 30 seconds.

LEVEL 2

Start: Stand on affected leg with eyes closed.

Exercise: Maintain balance with eyes closed as long as possible.

Goal: Practice until balance can be maintained with eyes closed for 30 seconds.

LEVEL 3

Start: Stand on affected leg on an unstable surface (e.g., pillow, block of foam).

Exercise: Maintain balance.

Goal: Practice until balance can be maintained for 30 seconds.

LEVEL 4

Start: Stand on affected leg on an unstable surface and close eyes.

Exercise: Maintain balance with eyes closed as long as possible.

Goal: Practice until balance can be maintained with eyes closed for 30 seconds.

LEVEL 5

Note: Do not attempt this exercise if knee or ankle is swollen or painful.

Start: Stand on a stable surface at a small height (e.g., bottom step or low stool – 15-20 cm).

Exercise: Jump from the small height and keep balance on landing.

Goal: Practice until the landing feels secure. Increase height of jump only if required for function (e.g., dismounting from a bus or truck).



Other Ways You Can Help HFNZ

Making a bequest to the Haemophilia Foundation of New Zealand is another way of making a difference to the lives of those with bleeding disorders.

This can be directed to the work of a region, our National Office, or a particular area or project and we would be happy to help you decide where your bequest could best meet your wishes.

We recommend you get professional advice when drawing up your will and suggest the following wording:

I give to the Haemophilia Foundation of New Zealand Inc. for the general (or specific) purposes of the Haemophilia Foundation of New Zealand Inc. the residue of my estate (or the sum of \$.....) and I declare that the receipt of a proper officer of Haemophilia Foundation of New Zealand Inc. shall be a full and sufficient discharge to my trustees.

We ensure your money will be used as you have asked in benefitting people affected by bleeding disorders in New Zealand.

If you would like to talk to us about how you might help in this way, please contact us via our email: info@haemophilia.org.nz.

Thank you!

Midland Branch Report

By Wendy Livingstone-Scott

On May 27th, Northern Branch invited Midland Branch to join at the National Bank Cup Netball Match between Northern Force (Auckland) and Magic (Waikato), at the North Shore Event Centre in Auckland.

All watched the game with much cheering and anticipation. Midlanders were not disappointed when Magic finally took away the win.

After the netball both branches met for a cuppa and a bite to eat at a nearby café. All had an enjoyable afternoon with lots of hugs, chatter and laughter as people caught up with one another.

It was a fantastic day with a great turn out of families. Thanks very much Northern for inviting us.



Central Branch Report

By Joe Melser and Sally Coop

HFNZ Central Winter Escape, 31st August - 2nd September 2007

Central camp had 81 attendees this year, drawn from far and wide by the bright lights of Masterton. To set the scene, Solway Park has spa pools, heated swimming pool, trampoline, golf course, and plush dining and conference venues. It started on Friday night, as all campers were welcomed with a bag of treats (thanks Judith and Ron), a light dinner, and the sight of old and new friends.

Saturday morning came round with a beautiful Wairarapa day. A full cooked and continental breakfast was devoured, especially by those people who had taken advantage of a complementary bottle of champagne. Feeling full and content, we anticipated a sunny visit to Mt Bruce, a bird sanctuary including hyperactive Kiwi and cautious Takahe. By the time we got there, however, the weather flipped and there was suddenly cold wind and rain. Fortunately, the birds and native bush provided a great distraction, and an opportunity to catch up with fellow attendees. We had lunch at Mt Bruce, and despite a flurry on the sausage rolls, there was enough to go around.

Next, we travelled back to Masterton to visit the towns claim to fame – the shearing museum! Fortunately, it was much more interesting than it sounded; the buildings were relocated historic shearing sheds and we were given a demonstration by a golden shears winner. The kids got a chance to try their hand on manually driven shears, luckily without any bleeding (sheep or human).



A few weeks later on 23rd June, Midland Branch held an adults café at Indigo Café in Rotorua. Twenty-six people were expected, but due to bad weather and many getting the flu, we had a few last minute apologies, leaving us with about 20 members attending.

Loads of laughter and excitement filled the café in a fantastic warm friendly atmosphere as people either caught up with old acquaintances or made new ones. It was so nice to relax on big comfortable couches or chairs, around either the fireplace or heat pump (depending on which side of the café you chose to be).

Thanks very much to Indigo for catering to our needs and providing such a lovely meal in a comfortable and warm environment.

Thanks to Catriona Gordon for organising the adult café evening.



Then back to business at Solway Park, with Grant Hook leading a discussion about how the Haemophilia Foundation could further assist its members. Many ideas were generated, such as (a) developing an exchange programme

(e.g., giving city kids experience of the country and vice versa), which has the advantage of hosts knowing how to manage a bleeding disorder, and (b) supporting affected members to have an annual consultation with a pain management specialist. Meanwhile, the kids were watching Flipper!

Investment guru Lisa Dodson (also Ron and Judith's daughter) gave a talk on Kiwi Saver, which was very informative and interesting, provoking any questions. In summary, Kiwi Saver was recommended for most people, from children to those nearing retirement.

After a full and active day, the roast dinner and array of puddings were devoured. With most of the children off to bed, it was time to party!... Enter Ron with a box of hats... (Don't worry Grant, what happens in Masterton stays in Masterton).

Everybody was up to enjoy the breakfast on Sunday, with bacon, sausages, and hash browns. Tania Coombs, a nutritionist, gave a myth-busting talk on nutrition, turning most of our beliefs about on their heads (e.g., butter good, margarine bad).

After all, with a cup of tea, goodbyes were said. Anne and Graham Waring were awarded a gift for their past and continuing contribution to the Haemophilia Foundation. Special thanks are given to the camp organisers, without whom a great time would not have been had. Finally, many thanks to Grant and Michael for such a great camp. See you all again next year!



Bayer is sponsoring Step Up Reach Out

Kiwis get chance to Step Up Reach Out

Step Up Reach Out is an international youth leadership program designed to prepare young people with haemophilia to become advocates for their communities. Step Up Reach Out aims to draw together young people from around the world for learning, personal growth and collaboration.

This one-year pilot program consists of two conference sessions in the United States focused on leadership training, activities, and individual and group projects. It is hoped that participants will gain insight into the structure of the global haemophilia community and how they can emerge as future leaders.

Designed by experts at the University of Texas Health Science Center, Gulf States Hemophilia and Thrombophilia Center (UHSC), **Step Up Reach Out** is sponsored by Bayer HealthCare.

Congratulations to kiwis Karl Archibald, Stace Hardley, Tama Pene and Blair Wightman who have been chosen from applicants from around the globe to be part of the select group of 15 participating in the first program. We will feature more on the participants and this programme after they complete their first conference in San Francisco in September and their second conference in February 2008.

Landmark Study Shows Benefits of Early Prophylaxis

According to a new study published in the New England Journal of Medicine, prophylactic infusions of recombinant factor VIII significantly reduce the risk of developing joint damage associated with joint bleeding in young children with haemophilia. The findings, from the first and only randomised, prospective trial comparing prophylactic with on-demand treatment in 65 children with haemophilia A, showed that 93 percent of children who received prophylactic treatment with recombinant factor VIII had normal joints at the age of six years compared to only 55 percent in the on-demand group.

Participants in the 5-year clinical trial, known as the "Joint Outcome Study" were recruited from 15 haemophilia treatment centres in the United States and were randomised to use either recombinant factor VIII therapy daily or at least three doses at

the time of a joint bleed. The children were followed until the age of 6 years, when they were assessed for bone or cartilage damage using X-ray and MRI of damage-prone joints (elbows, knees, and ankles).

"Our results show for the first time that prophylaxis, initiated between 6 and 30 months of age, is effective at preventing joint bleeds and preserving joint function in young boys with haemophilia A", said Marilyn Manco-Johnson, MD, principal investigator.

Previous look back studies have suggested that regular, preventive infusions of factor VIII, given to young patients before they develop permanent joint damage, may reduce the risk of haemophilic arthropathy. This new clinical trial provides the strongest medical evidence to date comparing joint outcomes associated with prophylactic and on demand treatment approaches.

Some of the patients in the study had joint damage despite no or few obvious bleeds into these joints. The investigators suggest that subclinical bleeds – bleeds that do not show symptoms and often go unnoticed – play a role in the development of joint damage. They went on to say that subclinical bleeds may be prevented through prophylactic infusion.

"Results from the study indicate the importance of initiating prophylaxis before recurrent bleeding has occurred in individual joints in young boys with severe haemophilia", said Keith Hoots, MD, study investigator.

The article *Prophylaxis versus Episodic Treatment to Prevent Joint Disease in Boys with Severe Hemophilia* by Manco-Johnson MJ, Abshire TC, Shapiro AD, et al. can be found in the 9 August 2007 edition of the *New England Journal of Medicine*, Volume 357, pages 535-44.

A Year of Accomplishment

HFNZ is a national member organisation (NMO) of the World Federation of Hemophilia (WFH). 2006 marked the first year of their new strategic plan, and during the last year WFH achieved several important milestones worth noting:

- NMO skills training
 - One global, one regional and five country workshops
 - 17 specialised events providing advocacy, tender, registry coaching
- Organisation & center twinning
 - 32 HTC's & 18 NMO twins
- Humanitarian aid donations
 - 3.3 million IU in 2006 (over 125 million IU in past 10 years)
- Medical training fellowships
 - 29 fellowships (overall 95% retention in haemophilia care after 5 years)
- Multidisciplinary workshops
 - 14 laboratory, physiotherapy, nursing, dental and musculo-skeletal workshops
- Laboratory IEQAS (International External Quality Assessment Scheme)
 - 62 labs from 39 countries (including 12 new labs in developing countries in 2006)



Two UK public inquiries into HCV and HIV infection from blood products in the 70s and 80s

A privately funded independent inquiry into the UK's tainted blood scandal is currently being held in London. Lord Archer of Sandwell, a former solicitor general, is leading the independent inquiry, which is due to report in late summer. The Scottish Executive has announced a formal investigation into the same scandal. The full remit and timing of the Scottish inquiry will be finalized after the Archer inquiry reports. The WFH will report on the results of these inquiries when they become available. The UK Haemophilia Society is participating in the hearings.

More information is available on their website: www.haemophilia.org.uk

Treatment for All Wristbands

Going! Going! Gone! HFNZ have acquired limited quantities of WFH Treatment for All wristbands. Bright red and ever so trendy, by purchasing one (or two or three) you not only get a funky wristband but are contributing towards WFH Treatment for All initiative which aims to make treatment available to those in need in developing countries. Even though people with haemophilia in New Zealand are lucky enough to have their factor and other treatment products covered by the national healthcare system, many children and adults throughout the world are not able to even buy the treatment products needed.

Help us, help them. Wristbands are available for \$3 from the National Office (PO Box 16580, Hornby, Christchurch) or your Regional Chairperson.



Roald Dahl Day

Are you a fan of the books of Roald Dahl? Did you know that 13 September is Roald Dahl Day?

Whether your favourite is Matilda or the BFG, there is so many reasons to love his stories. But for kids with bleeding disorders there is another special one.

Roald Dahl was one of the most successful writers for children who ever lived. His life was almost as strange and exciting as some of the tales he told. It is clear from many of his books that he was always a bit of an outsider – someone who never quite behaved in the way people expected.

After Roald Dahl died, his wife set up the Roald Dahl Foundation. This charity helps children and adults who have serious illnesses and those who have problems with reading and writing in the UK. One of the main areas that the foundation help provide grants for is haematology. Haematology grants benefit children and young people with Haemophilia, Sickle Cell Disease, Thalassaemia and other rare blood disorders. Some of their largest haematology grants help to improve facilities for children and young people at haematology centres, and the small grants help individual sick children and their families with essential items such as household appliances and specialist equipment.

Roald Dahl would have loved this. Although the Roald Dahl Foundation is set up to help people in UK, there is no reason fans and kids with bleeding disorders down here in New Zealand can't get into the spirit of Roald Dahl Day. Check out our handy list on ways to honour the day or just sit back and enjoy your favourite of his stories along with a big slice of Bruce Bogtrotter's Cake or some Snozzcumbers?

More information and activity suggestions can be found at www.roalddahlday.info.



Celebrate by reading like Matilda



Get silly like the Twits

Take the Roald Dahl Day Challenge today, and see how many challenges you can complete

1. Wear something yellow - Roald's favourite colour!
2. Wear one or more items of clothing backwards
3. Drop "gobblefunk" convincingly into a conversation
4. Swap a Roald Dahl book with a friend
5. Talk backwards
6. Tell a silly joke – Roald Dahl loved swapping these with his kids
7. Play an "unexpected" prank
8. Give someone a treat – Roald was a great believer in treats, whether it was a bar of chocolate or a lovely surprise
9. Write your own revolting rhyme
10. Make up an Oompa Loompa dance and get all your friends to join in!