

HFNZ BLOODLINE

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NEWSLETTER OF THE HAEMOPHILIA FOUNDATION OF NEW ZEALAND INC

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PRESIDENT'S REPORT TO THE AGM

ISSUES TO PROMOTE EXCELLENCE IN HAEMOPHILIA CARE IN NZ

High Resolution Colour Version available!

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Disclaimer:

The information contained in this newsletter is not intended to take the place of medical advice from your GP, haematologist or specialist. 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.



Mike Carnahan and Belinda Burnett, Brisbane 2003

Haemophilia Working Party

In 2003 I indicated disappointment with the progress made by the Haemophilia Working Party in bringing about change. In 2004 the Group continued to operate and began to grapple with the organizational issues of the varying needs and priorities of participants for a national group to :-

- Plan and develop a national plan for development of a national approach to planning and provision of haemophilia services
- Provide a structure for governance
- Oversee haemophilia services
- Resolve how such a service might be funded
- Develop a national approach to the management of therapeutic products the projection of needs, procurement of ongoing supplies and day to day management and traceability of all products used. New Zealand has now moved from a policy of occasionally allowing the need for haemophilia therapeutic products to become the "blood collection driver", supplemented

by a controlled access policy to recombinant products, to a planned use of therapeutic products. This will be a major step forward. The main elements of the current and future approach are:

To limit blood collection in NZ to a level where all components of the blood or plasma donation are used.

- To introduce from July 2005, *BioState* [a CSL plasma derived monoclonal factor VIII product] to replace *AHF*. The introduction of a monoclonal factor VIII product for routine use is long overdue and HFNZ applauds the step. This product will also be used for treatment of vWD in some circumstances. The manufacture of *BioState* however, presents major implications to the volume of international units of product available.
- To supplement the requirements for product by expanding the use of recombinant products to circumstances such as surgery, and those over the age of 18 years.
- To maintain the use of *MonoFIX* [a CSL plasma derived monoclonal factor IX product] which has been in standard use for the past two years.
- To secure future supply by developing a national supply arrangement.

The table on page 4 compares product usage in 2003 with the estimated usage of product in 2006

continued on page 4

Dates to Note

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| Young Women's Workshop Weekend..... | 5th-7th August 2005 |
| 13th National Haemophilia Conference, Melbourne | 30th September-2nd October 2005 |
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April 2005

This issue of Bloodline brings with it some organisational changes which, I for one, am delighted with.

Nova Guern has been appointed as the National Information Co-ordinator for HFNZ and Nova is introduced in this issue.

The appointment of the N.I.C. means that some of my work as Editor is now safely in the hands of an HFNZ employee. "Music to the ears of any volunteer!"

I edited my 1st edition of Bloodline (although it wasn't called that then) in July 1997, when I took over from Peter Zind. As with any publication the HFNZ News letter has continued to grow and change over the past 8 years and it will continue to evolve over the next 8 I am sure.

We have been working towards having Bloodline available on our Web site and that looks likely to happen in the next few months. Bloodline will continue to be published though, as IT capabilities vary so much around the country, but it will mean that there will be choice for members as to how they would like to receive their Newsletter issues.

Nova will also be able to introduce a series of inserts on a range of best practice topics, which members will be able to save and call upon as needed.

Shelley O'Brien, the Haemophilia Outreach Worker for Central is also introduced in this issue, and hopefully many of you have taken the opportunity to meet with Shelley at the variety of functions that have already been held this year. We look forward to reporting on the Central Branch activities as they reap the benefits of having an Outreach Worker dedicated to their region again.

Following the National and Regional AGMs there have been a few changes as well, and we include in this issue the last President's report from Mike Carnahan as he steps down from the President's Role.

Dave McCone has taken over the reins from Mike and we all look forward to working with Dave over the coming months. If you are unsure who your regional committees and / or representative are, then please contact the national office and they can update you.

At the writing of this Editorial HFNZ is making the final

preparations for the visit of Brian O'Mahony and Raymond Bradley from Ireland, as part of the 1st HCV Workshop and also as part of yet another drive towards receiving adequate and timely treatment for our members as well as exploring recompense options. Those of you who had the opportunity to attend this Conference will hopefully have been educated and empowered, as you live with Hepatitis C.

There are 2 inserts with this Issue of Bloodline, so please take the time to read them. The first is a Dental survey which has been produced by 2 dentists at the Otago Dental School as they work towards putting together dental guidelines to be included in our Standards of Care document for people with Bleeding disorders.

We have included a prepaid addressed envelope for you to return the information to HFNZ and we really appreciate you taking the time to do this. We need as much feedback as possible in order to get an accurate picture as to the state and availability of Dental Care for members, in the past and in the present day.

The second is more information on the Australian Haemophilia Conference to be held in Melbourne later this year. I am sure that Regional branches are already working on fundraising plans to assist their members in attending this Conference, so please contact your Branch if you would like more information.

As we move into Autumn, the temptation to hibernate is strong, but at a national level I can assure you that Council will be busy, with workshop planning, PGD progression, implementing recommendations from the HCV Conference as well as attending the Women's Expos, preparing government submissions and keeping up to date with product safety and supply issues.

If there is anything that you feel National Council, should be doing, and apparently isn't, then please contact the National Office or the President, Dave McCone, so your issues can be put into the agenda.

As with most organisations, it is hard to fix what we don't know is broken. Unlike some politicians, the National Council does work for its constituents, and your input will make HFNZ a stronger Foundation.

Nikk Cunningham



ALAN COSTER EDUCATION TRUST

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

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

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

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



Belinda Burnett

Firstly, let me say a big thank you to all the members who responded to the Hepatitis C letters sent out prior to Christmas. As a result of our combined efforts, former WFH president Brian O'Mahoney and Lindsay Tribunal lawyer Raymond Bradley visited NZ in April. Brian and Raymond have each made a huge contribution to haemophilia care internationally, and I was thrilled to welcome them to New Zealand.

Brian and Raymond's visit coincided with Haemophilia Awareness Week, and they took part in many events and activities. Look out for a separate mailing telling you more about those events.

As you may know, the last few months have seen a few personnel changes. The staffing structure of HFNZ is now:

Chief Executive Officer Belinda Burnett (full time)

Northern/ Midland Haemophilia Outreach Helen Spencer (full time)

Central Haemophilia Outreach Shelley O'Brien (part time)

Southern Haemophilia Outreach Colleen McKay (part time)

Nova Guerin National Information Coordinator (full time)

Administrator Leanne Pearce (part time)

All contact details are on the front page of this edition, and your calls / enquiries are welcomed.

In 2005 HFNZ is attempting to get the subject of haemophilia into the media as much as possible, to create public awareness for our disorder. If you are aware of any event coming up in your area that concerns someone with a bleeding disorder, please let me or Nova know.

Finally, by now all the branches have had their AGMs and all the new committees for 2005 are established. Always remember

The consequence of not engaging is to live by the rules of those who did.

Join your local committee, get involved in branch activities and have a say in how YOUR foundation is run.

Belinda Burnett
CEO HFNZ

INTRODUCING NOVA GUERIN



Nova Guerin

Hello, my name's Nova Guerin and I'm the National Information Coordinator for HFNZ. I've been fortunate enough to meet or chat to a few of you, but for those of whose acquaintance I have yet to make, here's a little bit about me.

My professional background is primarily in marketing and communications, and I've managed to pick up some peripheral skills along the way (such as copywriting and strategic planning). I've come from a corporate environment where the most urgent issue is finding a decent cup of coffee each morning, and I find it incredibly refreshing to be working with people who are highly motivated and energized.

As the National Information Coordinator, I'm responsible for the HFNZ website, media liaison, development of the e-library, the production of Bloodline and various other information projects. Look out for upcoming developments, and if you have any suggestions and feedback please do drop me a line. Remember, I'm here to enhance the information services your Foundation provides for you so let me know what you need.

On a personal level, I've recently relocated from London, where I'm from, with my Kiwi husband, Sean. I

love New Zealand (what's not to love?) and am putting down roots thick and fast. I'm a keen reader and I also enjoy running and good food. I recently gained the distinction of being almost the last runner to complete a half marathon (probably ever).

I'm thrilled to be joining you at such an exciting time in the Foundation's development. In my first seven weeks I've been involved with preparations for the AGM, the Hepatitis C Conference, the Global Feast and, of course, Haemophilia Awareness Week. Now that my head's stopped spinning, I'm wondering what the next seven weeks will bring?!

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Alison Inder, Haemostasis Nurse, Christchurch Hospital

Our sincere apologies go to Alison Inder, who attended the World Haemophilia Federation conference in Bangkok last October. Although her name did not appear on the list published in the Conference supplement, Alison was a key member of the New Zealand delegation. We apologise to Alison for the oversight, and thank her for her ongoing commitment to the care of people with bleeding disorders.

From previous page

- Assured and reliable access to supplies necessary to maintain home therapy
- Monitoring and published comment on safety of therapeutic products
- Monitoring and published comment on availability and price of therapeutic products.
- A single national system of procurement is essential
- This must not imply a single supplier
- Our beliefs *if it involves haemophilia talk to haemophilia*
- Seek and expect continuation of a consultative approach

Options for Reproduction

HFNZ is preparing a policy entitled "Options for Reproduction" addressing the wide issues of identification of carrier women, education of men with haemophilia, and the developing field of assisted reproduction using pre-genetic diagnosis.

Medical Advisory Committee

HFNZ continued to support the Medical Advisory Committee which met twice in 2004.

Nurses Special Interest Group

HFNZ continued to support the Nurses Special Interest Group as required.

Australia and NZ Physiotherapists Special Interest Group

An *Australian NZ Physiotherapy Haemophilia Group* has been formed and we are pleased to see the intent to publish recommendations or guidelines for sport & recreation and to develop physiotherapy management guidelines and educational resources.

Resources to DHBs

HFNZ is pleased to see the seriously understaffed situation in the Waikato DHB area has been partially addressed with the appointment of Robyn Segedin, as Haemophilia Nurse and Dr Phillip Crispin as Haematologist.

In the Central area there is still no sign of a replacement for Natalie James, Nurse Specialist Haemophilia. HFNZ outreach workers have become inundated with Central issues, and people in the Nelson are continuing to visit both Wellington and Christchurch for review.

Actions for 2005

HFNZ will endeavour to:

- Participate in the Haemophilia Working Party to achieve our goals, especially the early resolution of the structure for haemophilia care and a national system of comprehensive care
- Complete the guideline on dental care
- Improve members' knowledge of Hepatitis C and ensure they seek treatment
- Lobby for the provision of care for all people with hepatitis C on the basis of best international practice
- Continue the watch on the evolution of vCJD and its implications for people with haemophilia
- Base our activities on the Decade Plan 2005-2015
- Publish a Paper "Options for Reproduction"
- Continue to support Medical Advisory Committee, Nurses Special Interest Group, and the Australia and NZ Physiotherapist Special Interest Group

ISSUES TO PROMOTE EXCELLENCE

IN HAEMOPHILIA EDUCATION IN NZ

Bloodline

Nikki Cunningham completed her seventh year as Editor, producing another 4 editions plus a supplement on the Bangkok conference. In 2005 we will seek to make Bloodline available on the internet and introduce a series of articles on "Best Practice".

Physiotherapy Booklet

Karli Roche, a physiotherapist at Waikato Hospital with a special interest in haemophilia and exercise, has almost completed a booklet on this topic for day-to-day use by people with bleeding disorders.

Website www.haemophilia.org.nz

At the November 2004 meeting Council agreed to dramatically change the nature of the website from a passive historical and static information source to a current and interactive information and educational resource for people with haemophilia, families, clinicians, funding bodies, and the wider community. With the appointment of Nova Guerin as National Information Officer, we are now able to start and achieve our goals.

Youth Camps

A Youth Camp was held in April 2004. This was set up as an educative experience and a chance for youth members to talk and interact with each other, and an opportunity to expose youth with haemophilia to successful men with haemophilia. Topics covered included understanding treatment, understanding therapeutic products, treatment and management, ideas for career and employment, disclosure, recreation and sport options, money and risk management, cars. Future Youth Camps will continue to have a haemophilia nurse and physiotherapist on site, involvement of older males with haemophilia, career discussions and probably a first aid course.

Educational Gatherings in 2005

Additional educational camps planned for 2005 include a pre-teens camp, a women's workshop and a workshop for older men. Family Camps have become a branch activity.

Sport & Recreation

National Council grappled with the issue of "should people with haemophilia participate in competitive or contact sports". We agreed participation in sport is beneficial to promote optimal health and well-being, subject to the following provisos: i) planning and discussion needs to precede participation; ii) all safety equipment should be used and; iii) people should develop into their activity. The outcome has become a categorization of sports and recreational pursuits from those activities not recommended through to those that are recommended.

Women with Bleeding Disorders

HFNZ is aware of a considerable group of people in NZ experiencing difficulties. Thus we have started to raise awareness by attending a range of Women's Expos in 2004 and 2005.

Actions for 2005

HFNZ will endeavour to

- Make *Bloodline* available electronically

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PRESIDENT'S REPORT TO THE AGM

| International Units of Factor Used in New Zealand -million | | |
|--|--------|----------------|
| | 2003 | 2006 estimated |
| Plasma derived f VIII | 8,900 | 4,300 |
| Recombinant f VIII | 7,900 | 12,400 |
| | | |
| Plasma derived f IX | 2,900 | 2,900 |
| Recombinant f IX | 0,650 | 0,650 |
| | 20,250 | 20,250 |

We are circumspect about PHARMAC's involvement in the procurement of haemophilia products because of their history and the way they appear to do business.

National Guidelines

We now have two important documents in place - *National Guidelines - Management of Haemophilia Service Specification and National Guidelines and Management of Haemophilia Treatment Protocols Compiled by the Medical Advisory Committee of Haemophilia Foundation of New Zealand (Inc) June 2004*

The production of these documents has been made possible by the persistent efforts of Dr Paul Harper, Chairperson of the Medical Advisory Committee.

vCJD

Cases of variant Creutzfeldt-Jakob disease (vCJD) have been confirmed in Japan (probably contracted during a month-long stay in Britain in 1989 and no record of blood product use or brain surgery) and in Saudi Arabia. France announced its ninth case of vCJD and that one person was a blood donor. A recall of in-date products made with the donor's plasma has taken place.

The number of countries reporting bovine spongiform encephalopathy (BSE) continues to increase, partially as a result of better testing.

In September 2004, health authorities in the United Kingdom (UK) informed many people with hemophilia and other congenital bleeding disorders that they are considered "at-risk" for vCJD. This risk comes from using clotting factor concentrates manufactured in the UK between 1980 and 1998 that were contaminated by plasma from donors who later died of vCJD, or which may possibly have been contaminated by donors who are still asymptomatic. More information is available at

<http://www.wfh.org/ShowDoc.asp?Rubrique=30&Document=37>

The risk of transmission of vCJD by plasma-derived products remains unconfirmed. There is no known case of transmission of vCJD via plasma products, and no person with hemophilia has been diagnosed with vCJD. We remain fortunate as NZ has not had a reported case of BSE.

Hepatitis C and Treatment

A survey of members in 2004 showed the primary issue with respect to hepatitis C was access to world's best-practice treatment. In March 2004 PHARMAC approved the introduction of pegylated Interferon. From membership surveys we learned there are 172 people in NZ with haemophilia (pwh) who have contracted hepatitis C (HCV). About nineteen have cleared the virus spontaneously or via chemical therapy. A number of respondents were not under regular review for their HCV, or were not aware of their current hepatitis C status. Few of the surveyed people were in active treatment.

HFNZ is aware of the need for individuals to become personally active and request a consultation with a

gastroenterology department to discuss and form a plan for their future monitoring and care. It is evident that NZ does not have a nationally consistent approach to care. Therefore HFNZ continues to advocate for the tracing and testing of every individual who has received clotting factor concentrates and to consider for active treatment, all people with HCV, irrespective of their HCV genotype. Members with haemophilia and HCV need to consider their individual needs for

- Testing being offered to all sexual partners
- Attendance at a gastro clinic for regular review at approximately 4-6 monthly intervals. Such review comprising clinical examination and laboratory determination
- Upper gastrointestinal endoscopy every 5 years for people over the age of 45 years or infected for 30 years

The continuing absence of a national strategy for coping with hepatitis C in NZ, and a national approach to standards of care has been taken up by HFNZ with the College of Gastroenterology.

Decade Plan 2005-2015

The Decade Plan, commenced in 2003 with a Workshop, has now been completed and published. We do not see a cure for haemophilia being accessible for the next twenty years. Haemophilia therefore requires management until a cure is developed. We wish to see the management and strategic planning undertaken in partnership with the stakeholders with a vital interest in haemophilia: Government as both funder and regulator, District Health Boards, HFNZ, and the pharmaceutical industry.

The Decade Plan is based on participants seeking to improve the care for people with haemophilia. In return for best international health care, people with haemophilia should be expected to also contribute to their care by:

- Accepting, at an early age, personal responsibility for their health
- Becoming informed about haemophilia and its lifetime implications
- Undertaking the cares in accordance with the Specification
- Completing home records of product usage when on home therapy
- Undertaking a lifestyle conducive to good health and economic usage of costly therapeutic products
- Managing life risks
- Conserving products and consequentially personal lifestyles in times of shortage of therapeutic products
- Agreeing to provide data to a database that is intended to enhance care.
- Becoming informed about reproductive choices
- Becoming informed about choices in sport & recreation and practice the management of risk

Access to therapeutic products should be based on best international choice of products for factor VIII, factor IX, von Willebrand Disease, and other genetic factor deficiencies, and manufactured from human plasma, recombinant technology, and transgenic sources. Of the presented options, HFNZ proposes that a mix of plasma derived and recombinant product is maintained. "Access" implies:

- An internationally benchmarked description of the standard of safety, efficacy, and availability expected in all products presented

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- Develop additional educational gatherings
- Develop awareness of women with bleeding disorders
- Continue to seek publication of a book for children using Capt Clot
- Redevelop www.haemophilia.org.nz to become an educational tool for HFNZ members

ISSUES TO PROMOTE EXCELLENCE IN HAEMOPHILIA ADVOCACY IN NZ

POLITICAL INTERACTIONS

Hepatitis C and Compensation

With respect to the issue of compensation, HFNZ has been vigorous in 2004. In August we finally established a dialogue with ACC and learned that of the 172 PWH and HCV, only 80 claims had been received by ACC. Of these, 20 had not been approved for various reasons.

HFNZ understands that no individual cases for compensation came before the High Court in 2004.

In May 2004 we learned via the media that blood was collected at some North Island prisons to form part of the plasma pool from which our therapeutic products were produced. This practice ceased about 1984. As this practice undoubtedly contributed to the reservoir of HCV in our starting plasma, and was information not made known to the 1992 Inquiry, HFNZ requested Ministers to immediately initiate a public inquiry. This request was declined. In the light of this information we also requested the Minister of Health remove all qualifying dates from the offer of settlement. The Ministers declined this request.

These issues generated considerable press coverage during which we learned that in 1986 some products used in NZ were being manufactured from "blended" plasmas sourced from NZ, Australia and possibly Asia, when clinicians and users were given to understand that the product was manufactured solely from NZ plasmas.

During the year HFNZ assisted some members to join a worldwide class action being conducted by Lief Cabraser, Lawyers San Francisco. This action is based on the plasma source being US prison blood for manufacture of Cutter's products of Koale and Konyne that were exported to a number of countries including Canada, Australia and NZ. This was an era when the FDA had banned the consumption in USA of "prison blood" from 1982 but allowed the products to be exported.

In 2004, Haemophilia Outreach Workers (HOW) focused on people with haemophilia and hepatitis C. Their first goal has been to improve the standard of care by ensuring all are under active care whether it be monitoring, preparing for active treatment, in treatment, or undertaking rehabilitation. HOW are also in contact with ACC about funding care. For some, these actions will mean making information available. The second stage of this project is to: i) ensure that all people with haemophilia and HCV have submitted a claim to ACC; ii) ensure that all claims are accepted, including those involving deceased estates and; iii) ensure equity among the 21 people who have received a lump sum settlement from ACC against a background where we have proven variability in the amount of

a lump sum payment.

The third stage of this project is to explore the possibility of multiple ACC claims and to file with ACC claims for those people exposed to CJD contaminated plasma products. During the year HFNZ produced the Paper *Sentenced Without Parole: Hepatitis C in New Zealand - An update on Issues*. The document concludes that:--

- In 1988 Government failed to introduce screening of donor blood and plasma supplies. It was 1993 before blood donations were routinely tested for HCV.
- In 1988 the Government failed to ensure timely ultra heat treatment of manufactured products used for treatment of haemophilia, it being 1993 before heat treatment of *Prothrombinex HT* became available.
- In 1990-1992 Government failed to withdraw from use *Prothrombinex HT*, used for treatment of haemophilia B, when the Ministry had been informed on three separate occasions of the unscreened nature of this product and that alternative products were internationally available.
- In 1990-1992 Government was driven by political and financial considerations for public health and not the adequacy, standard or safety of blood products.

During the preparation of this Paper we became aware of an anonymous document sent to HFNZ allegedly written by an employee of the Minister of Health in 1992 claiming that this issue has been the subject of a "political cover-up" that the truth is not known by the public.

I have also met with Hon Peter Dunne, Leader NZ Future and Judith Collins Opposition Spokesperson on Health to discuss the "bad blood" issue.

We also kept an eye on the Senate Inquiry carried out in Australia and note that the Australian Red Cross made a public apology to people who became infected from their products.

Submissions to Government

HFNZ made submissions to Government on

"The transfer of Human Genes to Other Organisms"
A review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights.

Bioethics Council on

Public consultation on Transgenics - the Insertion of Human Genes into Other Organisms

National Ethics Committee on Assisted Human Reproduction on

Pre-implantation Genetic Diagnosis in New Zealand

Charities Commission.

A submission was made on the proposed Charities Bill intended to be introduced to Parliament during 2005

Actions for 2005

HFNZ will endeavour to:

- Complete all three phases of the Haemophilia Outreach Workers programme for people with haemophilia and hepatitis C
- Publish *Sentenced With No Parole - Hepatitis C in New Zealand - An update on Issues*
- Continue the case for recompense for all people with

continued next page

haemophilia and hepatitis C irrespective of the era in which they might have become infected

ISSUES TO PROMOTE EXCELLENCE IN HAEMOPHILIA SUPPORT IN NZ

Personal Achievement

One of the outstanding personal achievements in 2004 was the ride of Jack Finn from North Cape to the Bluff. Such a ride is a significant challenge to any person, but to successfully complete the ride, do more than forty media interviews, deliver a letter about hepatitis C to the Prime Minister and donate \$3000 of the funds raised to the Allan Coster Fund is a noteworthy accomplishment.



Jack Finn delivers a letter about HCV to the Prime Minister, Helen Clarke

Outreach

The focus of our programme continues to be education, information and empowerment. Outreach is available to all people in NZ with a genetic bleeding disorder, including their family members. The report of the chief executive officers deals in detail with outreach services.

Database

The Database of People with Haemophilia and Other Genetic Bleeding Disorders comprises 239 entries. Thus we know that some members have not registered data but are now encouraged to do so. National Council has decided that this database and the membership database will never be sold or issued to any other organisation or company.

Financial Benefit Programmes

As occurs with many organisations, we found an open ended access policy providing financial subsidy on protective footwear and swimming for people with bleeding disorders had to become a targeted policy with emphasis on the need for protective footwear compared to mere footwear, and access to swimming also on a "needs" basis. We also wish to focus defensive driving at males aged 15-25 years and to expand the programme to include the Ford Car Control Course

Actions for 2005

HFNZ will endeavour to

- Achieve a longer term solution to the funding of Haemophilia Outreach Workers
- Continue with financial benefits

ADMINISTRATION OF HFNZ

The Past

During the year we began to assemble our archives minute and annual reports from 1958 and media cuttings from 1960. It appears the inaugural meeting of the NZ Haemophilia Society was held at Lower Hutt on the 13 May 1958. However we hold no records for the period September 1961 to June 1971. We would appreciate anyone with any old records

making material available to the office for copying.

The Future

During the year we examined HFNZ activity: what do we measurably achieve, where does the money come from, where does the money go, and what benefits do we get for that expenditure. The aim of this exercise was to develop a focus for future HFNZ activities and the services we need to provide in the future and to ensure efficiency and effectiveness in our expenditures. The direction is reflected in this report.

Operation Discovery

National Council identified the need to prepare and train people to assist haemophilia at branch and national level and even international level. Thus "Operation Discovery" was born to develop, empower and educate people to contribute to National Council by becoming informed about the role of a voluntary organisation. This programme will cover the legal and financial aspects of governance and accountability, the role of office bearers, and the major role of seeking grants, formulating grants and being accountable for grants. This programme will be taken up in 2005.

National Council

During the year Council met on 4 occasions.

New Initiatives

Last year I proposed a range of new issues for HFNZ to address:

- HFNZ is developing its position on genetic technology
- HFNZ looked at the cost of pharmaceuticals and found that while a number of people are paying \$100 per month or more for pharmaceuticals, virtually all are recovering their costs via the benefit system
- The Southern branch decided to purchase a mobility scooter for a member
- The remaining issues of assisting with employment were addressed by discussions about employment and careers at the youth camp. This issue will be developed in 2005
- The development of the internet to enhance our communications should take off in 2005

Actions for 2005

HFNZ will endeavour to

- Generate additional human resources by introducing Operation Discovery

APPRECIATIONS

Again we acknowledge that we cannot possibly get by without our friends and supporters, most notably:

- **KiwiFIRST** - without whom we would not require a report as extensive as this, because our activity would be minimal!
- **Temperton & Associates** - for professional accounting services over the last eight years
- **Paul England** for creating and maintaining our website
- **Lobank Farm Ltd** - for administrative services for the President, including time to do 3100 emails in 2004
- **Clutha Print** - who continue to provide their knowledge and expertise in publishing Bloodline and the supplements to such a high standard.
- **Audrey Blackwell** - who has provided a specialist Management Consultant service at no cost
- **Dave Blackler** -for building the access ramp at the national office
- **IRD** for the donation of two used computers.

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As members of HFNZ we rely on **four regional branches** to carry out the work at regional and district level. It is at this level that we all need to contribute the varied skills we all have. A vast amount of time and effort is given voluntarily each year by all these people, to undertake HFNZ activities.

We all say thanks guys to our 2004 staff, **Belinda Burnett** (Chief Executive Officer) **Claire O'Connor** (Central Outreach Worker) to February 2004, **Shelley O'Brien** (Central Outreach Worker) from December 2004, **Colleen McKay** (Southern Outreach Worker), **Helen Spencer** (Northern and Midland Outreach Worker), **Doreen Waugh** Administrator to May 2004 and **Leanne Pearce** as Administrator from November 2004.

Haemophilia care also relies on a network of clinicians, nurses, social workers, physiotherapists, and dentists, to make a difference in people's lives. Many willingly give of their free time to take a telephone call, to give advice, to provide a talk to a group of parents, to attend a camp, or to participate in advisory groups. They also have to keep up to date with the latest information in a rapidly developing specialty. We all say thanks indeed.

We are grateful to the efforts made by the pharmaceutical industry, **Baxter Healthcare Ltd**, **Bayer NZ Ltd**, **CSL Bioplasma** and **Wyeth Ltd**. We continue to value the personal interaction with the people working for the companies supplying therapeutic products in a very unique relationship.

Our appreciation also goes to

- **The Allan Coster Education Endowment Trust**, and Trustees Elizabeth Berry, Pela Hardley and Barbara Sutherland for their support via the Trust
- **The Wellington Haemophilia Memorial Trust** and Trustees Dr John Carter, Rosalie Glynn, and Margaret Temperton
- **New Zealand Post** and **Vodafone**, for their generous support of Jack Finn's journey
- **The thousands of Kiwis** that regularly donate via **KiwiFIRST**, and the donors who make significant contributions during the year. During 2004 donors of more than \$100 were:

| | |
|------------------|-------------|
| Allison Murray | \$500 (Feb) |
| B L O'Leary | \$500 (Feb) |
| Malcolm McKenzie | \$500 (Mar) |
| Alan Anderson | \$500 (Apr) |

| | | |
|-------------------------------------|-------------|---------------------|
| Jocelyn Evison - Piako-Waikato East | | |
| Rural Women | | \$1000 (Apr) |
| Ralph & Pat Wichers Hawkes Bay | | \$10,000 |
| Fred Forge of Ohope | | \$100 |
| Omakau Commercial | | \$250 |
| Bendigo Valley | | \$6,000 |
| Lotteries Grant | admin wages | \$8,437.50 incl gst |
| Lotteries Grant | youth camps | \$1,620.00 incl gst |

- **Baxter Healthcare** for providing funding for **Nikki Cunningham** to go to **London** for the **Women and Bleeding Disorder Conference** in November 2004.
- **The Misses Hallins**, for a donation of **jewellery** for resale.

And finally, I would like to express my personal appreciation to the members of **National Council** for their hundreds of hours of work for haemophilia in New Zealand. People who have served on **National Council** in 2004 have been: **Shirley Bongard**, **Nikki Cunningham**, **John Cook**, **Malcolm Hanson** and **John Tuck**, **David Habershon**, **Dave McCone**, and **Deon York**. Members need to realise that the work goes on amidst sometimes difficult family circumstances, such as sickness and hospitalization. During the year the **Scott/Cook** family the wonderful supporters of **Andrew Scott** featured in our 2004 national publicity and photographed in the 2003 report with **Dr Donna D Michelle** lost **Emma**, a very treasured sister to **Andrew**, daughter of **Richard** and **Lynley** and granddaughter of **John** and **Janice Cook** at the age of 11 weeks.

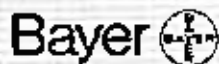
When I agreed in 2000 to be President of HFNZ I said I would do it for five years. That time is now up. I believe every organisation needs change to bring about different priorities and issues. Haemophilia has a number to choose from. For me to act as President it has also meant **Cheryl** has had to accompany me on trips meetings and visits. While I have been in the HFNZ office **Cheryl** has not gone shopping but spent hundreds of hours achieving a reasonably respectable filing system, attended to purchasing the office wants, cleaned, done dishes, cleaned computers, hung pictures, made shelving and supplied hundreds of coffees. Thank you **Cheryl**, from us all.

Mike Carnahan

Mike Carnahan
President

Sustaining Patrons

Among the valued donors to the Haemophilia Foundation of New Zealand, from individuals to Trusts, Corporations and Funding Bodies, are those who have joined a new specific programme to provide a generous amount of ongoing, non-directed funding. This funding is to support all HFNZ programmes and is for a period of three years. HFNZ would like to express its sincere appreciation to our current Sustaining Patrons:



- BAXTER HEALTHCARE LTD
- BAYER NEW ZEALAND LTD
- CSL BIOPLASMA LTD
- WYETH GENETICS INSTITUTE



NZBS BEGINS PRODUCTION OF BIOSTATE

In late 2004 the New Zealand Blood Service received permission from the Ministry of Health to begin production of Biostate. Manufacture of the new product commenced in January 2004. This will eventually replace AHF-HP in New Zealand. NZBS is building stocks of Biostate with the goal of it being clinically available around July this year.

Biostate is a high purity Factor VIII product manufactured by CSL Bioplasma. The product made for New Zealand is being made from plasma donated in New Zealand.


Biostate is suitable for treatment of both Haemophilia A and von Willebrand's disease. It is a proven product having been licensed and used in Australia for almost two years. The Biostate manufacturing process incorporates two specific viral inactivation steps (Solvent Detergent treatment and dry heat) as opposed to the single step used in manufacture of AHF-HP (dry heat). The safety record of AHF-HP

is excellent, the two inactivation steps used in the manufacture of Biostate will ensure that is an even safer product.

In common with other high purity Factor VIII products, the yield of Biostate is reduced when compared to other products including AHF-HP. This means that less Biostate is produced per litre of plasma than was the case with AHF-HP. In discussion with the Haemophilia Treater's and HFNZ a decision has been made to use this as an opportunity to increase the availability of recombinant Factor VIII in New Zealand. The total amount of Factor VIII available will remain the same, the proportion of recombinant will increase and that of the plasma derived product reduced. This means that some people who currently receive AHF-HP will in future receive Biostate whilst others will receive recombinant Factor VIII. People currently treated with recombinant product will continue on this.

The Haemophilia Treater's group will define which patients receive which product. The decision will be based on clinical grounds and the aim is that these will be applied consistently across the country. If you currently receive AHF-HP then your treater will discuss the implications of this with you over the next few months. Some people will be changed to the recombinant product in the near future to ensure that sufficient supplies of AHF-HP are maintained during the period of change.

NZBS is co-coordinating the transition from AHF-HP with CSL, the treaters and HFNZ. This is a positive step for the management of haemophilia in New Zealand. Overall supplies of Factor VIII will not be affected by the change. Information on the new product and the plans for its introduction will be made available in the near future.

Peter Flanagan
Medical Director NZBS. 

WORLD FEDERATION OF
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Hemophilia 2006

World Congress, Vancouver, Canada

May 21 to 25, 2006

Register for Hemophilia 2006 and discover Vancouver:

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- ✓ A spectacular setting — bordered by mountains, ocean, and parkland
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Dear Delegate,
The WFH World Congress continues to get bigger and better. Hemophilia 2006 will offer the most extensive and exciting program yet!

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- Researchers
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- Psychologists
- People with Hemophilia
- National Hemophilia Associations

**Hope to see you in
Vancouver.**
Visit www.wfh.org

NEW CENTRAL OUTREACH WORKER

Hello from Central Outreach. I cover the Central region which includes Wellington, Kapiti, Wairarapa, Hawkes Bay, Taranaki and Manawatu. Colleen McKay, who has been covering this area since Claire O'Connor left has now retreated back to her favourite island across Cook Strait. Colleen has been working with me through a handover period and it is great to know I can call upon her knowledge and experience as I grow into this work. I appreciated having the opportunity to meet some of you already at dinner and Tenpin bowling in late January.



The year looks to be full of efforts to continue the work of the Haemophilia Foundation for its members such as the Hepatitis C workshop and camps for pre-teens and women this year. In the central region I offer my services

as the outreach person for support, advocacy and education in your managing of haemophilia. A phone call, a chat, drop in and see me, a home visit, a social get together with other members are just some of the possibilities I can offer you.

I will be travelling to Manawatu, Hawkes Bay and Taranaki as three separate trips during the year. For those members in these areas I will send a letter a few weeks ahead to let you know when I am around and suggest a social get together for the Saturday at the end of my visit.

I'd also like to mention the programs available from the HFNZ for shoes, swimming and defensive driving, along with grants for education and items to support you in your managing haemophilia. You may like to call me about these.

I look forward to meeting and hearing from you.

Best wishes
Shelley O'Brien
Central Outreach

PGD GUIDELINES APPROVED BY THE GOVERNMENT

PGD guidelines developed by the National Ethics Committee on Assisted Human Reproduction (NECAHR) have now been approved by Health Minister Annette King. HFNZ was active in the submission process and, at this stage, we are happy with the guidelines.

PGD, a procedure used in vitro fertilization (IVF) to test for early embryos for serious inherited conditions and chromosomal abnormalities, such as haemophilia, before the embryos are transferred to the woman's uterus. Previously, the only test available in New Zealand was prenatal diagnosis. PGD allows couples to decide the future of an affected embryo rather than an affected fetus.

Fertility clinics now have to gain approval from NECAHR and the Government has yet to approve funding. It could cost around \$10,000 for the IVF-PGD treatment. NECAHR chairwoman Sylvia Rumball said the guidelines set clear criteria to ensure the technology was not misused. She said, "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."

PGD testing is likely to be available at centres in Christchurch and Auckland. If you would like to know more about the options for you please contact your Outreach Worker.



Parviz and Kelli Najafi (who is a carrier of haemophilia) celebrate the news that embryo testing for serious genetic conditions is one step closer to reality.
Photo: Otago Daily Times

HOLDEN STIRLING — Profile Of A Young Swimmer

by Helen Spencer

Holden Stirling is a young man of 13 with severe haemophilia A, who was successfully tolerised for inhibitors as a small child. He lives with his parents Henry & Patience, and his older sister Chevy. His older brother, T.A., has left home but lives nearby. Holden is in Year 9, and attends the Total Immersion Maori School within the Southern Cross Campus in Auckland.

Holden's inhibitors developed at birth and when he was 3, a serious headbleed prompted the decision to begin tolerisation. By this time the family had relocated to Auckland from Gisborne, which was many hours (or a flight) away from the nearest Haemophilia Centre. On his 5th birthday, his third infection resulted in his portacath being removed, and Holden went on home treatment. By the time Holden was 9 he was routinely doing his own infusions.



Holden at the Junior National Swimming Championships February 2005

In July 2002, when Holden was 10, Patience enrolled him in the swimming programme offered by HFNZ. Holden's aims were to learn to swim properly and to become confident in the water. Patience says that she has always known swimming to be the safest activity for her sons. When T.A. was 8 years old, he attended swimming classes in Gisborne, but with his many hospital admissions, it became an impossible task. She believes that HFNZ has given Holden a great start to life with the swimming programme.

Halfway through 2003 Holden was promoted to the training squad, and by the end of the 3rd term he started training for his first competitions. In July 2004 Holden competed at the Regional Club Championships. It was here that he took 6 seconds off his best time for freestyle, and it was realized that he was only 2 seconds away from qualifying for the New Zealand Junior Nationals, and almost there for the butterfly event. Serious training started in the 3rd term, and 5.30 am starts began in the 4th term on Monday and Friday mornings that's 5.30am in the water, not getting out of bed! There was also weekly afternoon training, and a weekly race night. During the first month Holden had difficulty keeping his eyes open at school, but he's used to it now.

Holden missed the Northern Regional Camp as he qualified just in time for the 50m butterfly Junior Nationals. It took determination and perseverance as he had been trying since July to crack the magic barrier and carve the remaining .2 of a second off. He was down to the last qualifying race

before the Juniors, when he finally did it, and then, he pulled everything out of the hat and carved almost 3 seconds off his race.

Patience believes swimming has made Holden much stronger and has noticed the drop in the number of bleeds since he took up swimming. He does need to be absolutely 100% sure that he warms up and stretches properly, and she thinks that the one time he didn't have time to do it could have been responsible for the

consequent knee bleed. Interestingly, Holden has had no shoulder problems from doing butterfly stroke, and his times rank better nationally than for freestyle.

Because the training regime is unrelenting, the family is working with the comprehensive team at the Haemophilia Centre. Lochie Teague, his paediatric haematologist has advised Holden to balance his activities and look after his body. (That's when Lochie and Holden aren't talking about EVO cars!) Swimming is the only sport Holden takes part in, as he doesn't actually have time for anything else! His haemophilia nurses Mary Brassler and Louise Moore are always there for him, and Haeley Mato his physiotherapist checks him out when necessary. His coach, Jane Logan has talked to lots of people and learnt a lot about haemophilia. She spaces out his races to make sure that he doesn't have too many clumped together.

Already this year Holden is the overall top swimmer for his school. Holden's aim is to keep going and "to become a faster swimmer" and qualify for the 13-16 year old Division, with the possibility of going to Australia at the end of the year.

Holden says the best things about swimming are his friends at training, the swim camps, and striving for his PBs (Personal Best times). What makes him go faster? When they blow the whistle to get on the starting blocks, Holden remembers his grandfather who passed away two years ago, and thinks of his brother T.A. And when he does well, he thinks to himself "I did that for me and T.A." 💧

CURRENT THINKING IN WOMEN'S BLEEDING DISORDERS

AND HAEMOSTASIS 25th November 2004

The Royal College of Obstetricians and Gynaecologists, Regent's Park, London

The following are reports on a cross section of the topics presented at the Conference. Some sessions ran concurrently, but information is available on any of the sessions not covered in this report. Please contact Nikki Cunningham if you would like more information on any of the topics.

This day Conference was organized by the U.K. Haemophilia Society as part of their larger Women's Project, which aims to educate and raise awareness of women's bleeding disorders amongst healthcare professionals and the general public. The Haemophilia Society also continues to provide support and information for those women who are affected by a bleeding disorder.

This particular Conference was aimed at assisting healthcare professionals with their management of Women with Bleeding Disorders.

According to recent research, 15,000 people in the U.K. have been diagnosed with a hereditary bleeding disorder, but estimates of the numbers who remain undiagnosed are as high as 600,000.

The misconception that women are not at risk from bleeding disorders only serves to fuel the problem of identifying potential cases.

Any healthcare professional could be faced with the challenges of a woman patient who suffers from a clotting complication, either knowingly or otherwise. Therefore the UK Haemophilia Society chose to hold the first ever educational Conference on this topic; Current thinking in women's bleeding disorders and haemostasis.

The all-day conference was aimed at the full range of healthcare professionals, in both primary and secondary care settings, providing a comprehensive clinical update from an esteemed panel of experts in the areas of haemostasis, obstetrics and gynaecology.

The Chair for the Conference was Christine Lee, and the opening address was by the Baroness Ruth Henig of Lancaster, Chair for the Association of Police Authorities.

She explained her association with Women and Bleeding Disorders or in particular with haemophilia, because of her work as an historian.

For her, haemophilia changed the face of the world, due to the fact that Prince Alexi of Russia had haemophilia and his parents had Rasputin to assist with his care. Rasputin was then trusted with the government of Russia while Nicholas was away at war, and the rest is History!!

Why Women's Bleeding Disorders are important: Rona Macdonald

Rona was diagnosed with von Willebrand's (type 1) in her early 20s, having spent years suffering from heavy periods and frequent nose bleeds. Rona has a brother with severe haemophilia and her diagnosis was made during tests to discover if she was a carrier of haemophilia A.

Rona is registered at the Royal Free Hospital. She receives DDAVP (Desmopressin) during knee surgery and uses desmopressin nasal spray on a monthly basis to control menstrual bleeding. She leads a normal active life including vice Chairmanship of the UK Haemophilia Society.

Rona spoke about the importance of recognizing women with bleeding disorders. 1 % of the UK population could be potentially affected by von Willebrand Disease.

She felt that a proper diagnosis provides relief and ensures the affected person receives the right treatment. It also provides knowledge on how to better manage the condition, such as avoiding drugs that contain aspirin.

A diagnosis also empowers the patient to educate themselves about their condition, seek out self-help or support groups and make informed choices when planning a family. It also ensures that an affected woman receives appropriate care during and after childbirth.

Rona explained that symptoms of a bleeding disorder are not all physical but also involve emotional and quality of life issues. There is often guilt at being a carrier as well as difficult reproductive choices to make that require proper information, support and counseling.

For women who are not diagnosed, quality of life can often be poor and there is a continuous sense that you are different especially during the teenage years and a feeling that the medical profession is not taking your problems seriously.

Undiagnosed women suffer huge emotional strain and in addition may receive inappropriate treatment and unnecessary gynaecological procedures such as hysterectomies. There may also be bleeding complications during surgical procedures that are not well managed. A joint Haemophilia and Gynaecological clinic is very reassuring that the "women's" problems are being taken seriously.

In 2004 you can talk about anything, but not periods. If only a programme such as Eastenders would cover the topic. Imagine how enlightening it could be.

THE AVERAGE TIME FOR A FEMALE TO OBTAIN A BLEEDING DISORDER DIAGNOSIS IS 16 YEARS.

continued next page

More than just heavy periods.....?;

Dr Paul Giangrande

Dr Giangrande has been a Consultant Haematologist at Oxford Radcliffe Hospitals since 1991 and currently works at the Oxford Haemophilia Centre and Thrombosis Unity, Churchill Hospital, Oxford.

Dr Giangrande is also Vice-president (Medical) of the World Federation of Haemophilia and Chairman of the WFH Medical Advisory Board.

Dr Giangrande has published widely in medical literature

Dr Giangrande emphasized the importance of taking a full medical history.

A Dr needs to know if there has been bruising, nose bleeds, bleeds after dental procedures, or around operations or the birth process.

This is to get a clear picture of a patient's haemostatic system.

They also need to know the possible family history and also any medications taken.

Objective criteria is needed as it is no use to just ask the question

"Do you bleed a lot??" as a yes or No answer cannot be objectively measured. The clinician needs to know if the patient required stitching or a blood transfusion after a medical procedure, or if the patient has persistent anaemia. Any of these are a more objective measure, when deciding if a bleeding disorder could be the reason.

Dr Giangrande discussed the well known coagulation cascade and how a variety of things can affect coagulation.

If a person has a platelet count below 80 then bleeding can occur. If the platelet count is below 20 then Thrombocytopenia (pinpoint haemorrhages in the skin) can occur. Low platelet production or destroyed platelets can also cause Nosebleeds, heavy periods and bruises.

This can be due to the platelet count or the platelet function.

Von Willebrand disorder is a bleeding tendency due to a deficiency of von Willebrand factor (either qualitative or quantitative), which is the "glue" for the platelets.

Von Willebrand's is the most common hereditary bleeding disorder, affecting 1/1000, but it can also be the most difficult to diagnose, as many things can affect the plasma level.

Type 1 = Quantitative deficiency which usually responds to DDAVP.

Type 2 = Qualitative deficiency

Type 3 = total Quantitative deficiency = No vWF produced

Apparently Factor XII is one factor that you can miss out having without any bleeding problems.

Expressed Carriers of haemophilia gene tend to have a level of about 50%. Some have a level of 20-50%. They should avoid aspirin and non steroidal anti inflammatories (NSAIDs).

DDAVP can boost the levels of Factor VIII. This can be delivered via IV, sub-cutaneous, or nasal spray and the peak effects occur after 1 hour.

Tranexamic acid is also used, but is contraindicated in cases of haematuria.

Diagnosing bleeding disorders:

Professor John Pasi

John Pasi is a Professor of Haemostasis and Thrombosis at Barts & The London Hospital. His main clinical and research interests are haemostasis, thrombosis and gene therapy.

Although in concept simple, defining a bleeding disorder in practice remains a major diagnostic challenge. Despite a huge variety of diagnostic tests that are available to clinicians, as well as all clinical consultations, taking a careful history is the first and probably the most important aspect. However in relation to bleeding disorders obtaining a meaningful history can be far more difficult than it sounds. Many individuals are convinced they are "bleeders" or have a bleeding tendency, although no definable disorder can be found. Some studies have shown that 50% or more of the population consider themselves to bleed excessively. Indeed concern about bleeding may even represent non-haematological disease. Conversely many people (also up to 50% in some studies) who belong to families with a clear bleeding disorder might consider significant bleeding as "normal", as compared to other members of the family. Ironically the least specific symptom of "bruising" appears to be the best indicator of a bleeding tendency. Sorting the "wheat from the chaff" is therefore quite hard on the basis of a history alone.

Professor Pasi discussed the need to elicit and interpret clinical data in relation to bleeding and identifying objective markers of bleeding to maximize the value of the consultation. These principles provide a guide to identifying appropriate individuals for subsequent referral and diagnostic tests.

Pre-conceptual Planning to delivery and Beyond A medical and emotional Journey : Dr Rezan A Kadir

Dr Kadir is a Consultant Obstetrician and Gynaecologist with a special interest in women with bleeding disorders as well as fetal medicine.

Dr Kadir runs a multi-disciplinary clinic in the

continued next page

Haemophilia Centre at the Royal Free Hospital, together with the Haemophilia specialist, Haemophilia nurse and family therapist. The clinic has been very useful for audit and research purposes and has helped to improve quality of care for families with bleeding disorders.

Prenatal diagnosis of Haemophilia has been available for 20 years and carrier testing for an even longer period. Preconception care is vital for timely carrier detection, counseling and planning for prenatal diagnosis and management of pregnancy.

There are several methods available for prenatal diagnosis including invasive (chorionic villus sampling [CVS] and amniocentesis) and non-invasive (fetal sex determination) techniques. The choice of method depends on how much information is available about the family and whether the causative mutation has been identified. The couple's plans for pregnancy and attitudes towards invasive prenatal testing and termination of an affected pregnancy are also important.

Dr Kadir told the Conference that quite often mothers change their mind about having an invasive procedure in association with reproduction

For example with Pre-implantation Genetic Diagnosis, collection of eggs can create haemorrhage in a low factor level mother, as can the placement of embryos. Bleeding can also interfere with the placement procedure.

There are always safety concerns, with some procedures possibly having an effect on viability and development as 12.5% of the genetic material is removed for the pre-implantation genetic diagnosis.

The pregnancy rate following this procedure is 20-25%, with 9% of mothers carrying twins and 7% carrying triplets. These multiple pregnancy rates can be higher, because the demographic group, using the procedure in regards to haemophilia tends to be young, healthy, fertile mums.

Because there is still the possibility of misdiagnosis, other prenatal diagnostic techniques are still used later in the pregnancy.

In the future, diagnosis could be made using maternal blood in the 1st trimester and sperm selection and insemination using a flow cytometer.

Some mothers have shown psychological distress up to a year after PGD which reiterates that the reproductive choices for carriers of bleeding disorders are part of an emotional journey.

Factor VIII levels have been shown to increase significantly in carriers of Haemophilia A during pregnancy, though a small proportion may still demonstrate low levels at term. In contrast factor IX levels do not rise in carriers of Haemophilia B. The risk of early-pregnancy bleeding and miscarriage in

haemophilia carriers is not known, but there is evidence that the risk of ante partum haemorrhage (>24 weeks' gestation) is not increased. However excessive bleeding can occur following spontaneous miscarriage, invasive prenatal techniques or termination of pregnancy. The mothers FVIII/ FIX levels should be monitored and recombinant FVIII or FIX used when administration of these factors is indicated.

Labour and delivery may also present haemostatic difficulties to both mother and fetus. Affected fetuses are at risk of developing serious head bleeds during birth. Therefore, delivery should be achieved by the least traumatic method and early recourse to Caesarean section should be considered.

Carriers of Haemophilia are at increased risk of post-partum haemorrhage. The risk is significantly greater when factor levels are below 50%: therefore it is vital that factor levels are checked and maintained above 50% for at least 3-4 days (4-5 days if caesarean section has been performed)

Cord blood should be collected from all male neonates born to carrier mothers to assess FVIII or FIX levels. Such babies are at risk of bleeding with any surgical intervention (usually circumcision) and opuncture sites. Special care should be taken to avoid Risk.

From Patient to Person Personal Perspectives from those affected : Eloise Collins and Ros Cooper

These two women shared with us their personal journeys from childhood to adulthood.

Eloise spoke as an obligate carrier of FIX, her father and 2 of his brothers all had FIX deficiency. Eloise is 28 years old, married to Andrew and planning to start a family in the next few years, however as an obligate carrier, this must be taken into consideration.

Her father, David Collins, had severe haemophilia B and caught Hepatitis from a blood transfusion from a blood transfusion when he was younger. In his mid 40's the disease affected his liver dramatically and he died suddenly and unexpectedly aged 48 in March 1997. David lived a full and active life, despite pain management and factor injections and was always keen that Eloise was aware of the hereditary condition of being a carrier, and to gain as much information on the implications of one day having a son with Haemophilia. He also felt it was important to track the medical advances in this field.

Eloise told us that living as a carrier of Haemophilia B gene in no way affects her daily living. However Andrew and Eloise's main concerns with starting a family are to ensure that they are well informed about the condition. They have been advised to seek further medical advice before coming pregnant and to review their choices available with regards to screening. Finally they felt they needed to be aware of the additional responsibilities any

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difficulties with having a son with haemophilia and how this may affect their lives.

Ros spoke as a woman with von Willebrand's Type 3. Ros was diagnosed at 7 months old when her GP followed up on abnormal bruising. During her childhood Ros was in and out of the Royal Manchester Children's Hospital and at the age of 14 she learnt to self infuse. At age 19 Ros was diagnosed with Hepatitis C and following two courses of treatment, cleared the virus at 29. Ros married in 2003 and currently lives in Worcestershire where she works as an IT consultant.

Throughout her adult life, Ros has been regularly attending the Queens Elizabeth Hospital in Birmingham.

Ros stated that her experience of von Willebrand's involved multiple bleeds per month, bleeding gums, nose and into joints as well as internally.

These bleeds could be spontaneous or triggered. Menstruation in the past had involved blood transfusions and hospital stays and is now controlled by high dose hormones (Noramine and Norafistronone) which are taken continuously. Her bleeds were initially treated with cryoprecipitate and then Haemate P Both DDAVP and tranexamic acid had been ineffective.

Ros has a positive approach to living with von Willebrand's but felt that there was still emotional impact on her, family and friends. Ros emphasized the importance of support, and the question as to whether normal life is possible and if there can be any quality of life.

She questioned how to plan for the future — physically, mentally and medically.

Editor's note: *Ros and her husband were traveling to New Zealand 3 weeks after I met them in London. Ros contacted me on her arrival and she spent some time at*

the National office in Christchurch and met with Hayleigh Burnett to share experiences of being a young woman with a bleeding disorder. Unfortunately the photographic evidence of Ros's visit with HFNZ was lost when the camera which took the photo was lost, so you will just have to take my word for it.

It was great to make contact with someone who could be a resource for some of our younger girls and the timing of her visit to New Zealand was perfect. Ros and I continue to keep in touch as I work towards implementing a full scale Women and Bleeding Disorder's project for New Zealand

I would like to take this opportunity to thank Tony Shelton and **BAXTER HEALTH CARE** for their support of my attendance at this Conference. It will provide the foundation for the development of a comprehensive Women and Bleeding Disorders project for HFNZ. 💧



The UK display at the Women and Bleeding Disorders Seminar, London



Typical London with the old and the new. This was outside Buckingham Palace



The view from the London Eye back towards Parliament and Big Ben

HAEMOPHILIA IN THE NEWS

Many of you will have noticed the increased coverage our community has received in the last month or so. Whilst HFNZ welcomes the opportunity to tell the wider public about the challenges faced by our members, we are disgusted that we have been pitted against another group of patients (people with arthritis). The following media release was issued in response to the article published in the Christchurch Press on 14th March.

Advocates call for more efficient haemophilia care

Haemophilia treatment is expensive, but could be managed more cost-effectively, according to the Haemophilia Foundation of New Zealand (HFNZ). Responding to suggestions that haemophilia is the most expensive lifelong condition to treat, HFNZ president Mike Carnahan said, "The patient referred to as "Canterbury's most expensive" has a condition which is complicated by the presence of inhibitors in the blood which suppress treatment. That is by no means typical of people with haemophilia. That said, we are aware that haemophilia care is complex and costly, but we also know that treatment could be delivered far more efficiently if a coordinated care scheme was in place at national level."

Dr Paul Harper, a haematologist at Auckland Hospital supports such a scheme. He said, "High quality care depends on cooperation between all care providers GPs, dentists, surgeons, anaesthetists. The clinicians who treat haemophilia are working with the Ministry of Health and DHBs to develop a national shared care approach to treatment. This will allow us to maximize resources as we are very aware of the need to keep cost manageable."


According to Mike Carnahan, people with haemophilia are also aware of the mounting costs of their care. He said, "People with haemophilia don't simply guzzle resources thinking, 'There's more where that came from.' Kids with

haemophilia quickly learn to be responsible for their own well-being, and are forced to value caution over fun from the minute they are able to make decisions for themselves. It's a way of life that they adopt permanently.

Although haemophilia cannot be cured at present, treatment is available to manage the effects of bleeding episodes. HFNZ member Mike Mapperson said, "There are measurable economic benefits in treating people with haemophilia with prophylaxis (preventative therapy) - there are savings of expensive treatment in later years and savings by keeping patients capable of gainful employment. Take me, for example! If I had not had access to Factor replacement concentrates, I would be sitting in a wheelchair and drinking through a straw, rather than running a business and paying taxes."

Health care funding decisions are always difficult, and have never been managed entirely successfully, says Mike Carnahan. "For a long time now, health funding has been allocated on a basis of need, and that only comes unstuck when the Government decides that health care should be rationed. Why should it be rationed? The haemophilia community has already borne the brunt of what happens when health decisions are made on a purely financial basis, and we simply can't allow history to repeat itself."

One positive outcome was that one of our members was profiled on Close Up on the 21st March. Trey told reporter John Sellwood about the things he can and can't do, and Grandmother Elaine spoke about the extra measures she takes to ensure Trey's ongoing health and wellbeing. Viewer response was largely supportive, and we thank Elaine and Trey for taking part in this programme, which offered viewers a compassionate look at the human side of the debate.

National Information Coordinator, Nova Guerin. 

WHY WOMEN ARE GOOD LEADERS

HFNZ CEO Belinda Burnelt was featured in December's Hemophilia Leader as part of a piece about "Why women are good leaders".

"Women are generally more passive, respectful and tolerant than men. I have learnt that assertion and being direct will win over aggression any day. Women have the natural instincts of protecting, teaching, nurturing and counseling. These great leadership qualities are brought out in bucketfuls when a child is threatened by hemophilia and a complicated healthcare system. Add empathy, listening skills and the ability to negotiate outcomes that benefit both parties. Many of these skills

just come naturally to women.

"Being the mother of a child with haemophilia inspires us. Every day, I see women doing things they never thought themselves capable of doing: public speaking, community organization and administering factor.

"As CEO, I am the person who liaises with the HFNZ council and employees. My biggest leadership lesson so far is that everyone's opinion must be respected and heard. If not, the organization will forever be divided in its efforts.

Reprinted with kind permission from Laurie Kelley, Hemophilia Leader

Survival Strategies for Marital Stress

HEMLOG ● Vol 14, number 3, Sept 2003

Having a child with a chronic medical disorder can be highly stressful for the parents' relationship or it can set the stage for greater closeness and understanding.

By: Shelagh Ryan Masline

Research is clear about this: when someone in the family has a chronic medical condition it affects all members of the household. It also has a strong impact on the dynamics in the relationships among family members, especially the primary one, the marriage. It's not uncommon for parents in their earnest desire to meet the needs of a beloved son or daughter, to begin to overlook the needs of their own relationship. Of course making a marriage work is a challenge for every couple and the issues couples face are as varied and complex as the individuals involved. Yet for couples raising a child with a chronic disease certain common patterns arise again and again.

A change in Priorities

Caring for a child with a chronic condition is enormously time consuming and demanding and becomes a way of life. For many families the concern about the child leads to an atmosphere of heightened anxiety in the home. Parents fear getting away on their own even for an evening in case the child needs emergency treatment. "The worry always on a parents mind is what if something goes wrong," says Goldie Mulak, a social worker at the Mount Sinai Haemophilia Treatment Centre in New York City.

Naturally there are issues among parents that are unique to

haemophilia. Which parent is going to be responsible for administering home infusion? How can factor costs and medical bills be handled in the face of insurance caps and other problems? Because haemophilia usually results from a defect in the mother's genetic make up mums frequently carry a great deal of guilt along with the affected gene. Consequently the mother often becomes over protective of the child and takes on much of the day-to-day responsibility for his care. While she may begin to resent her spouse for not assuming more responsibility in some cases the father starts to resent the mother for being 'responsible' for the child's condition, or for excluding him from the child's life.

"Initially it's very hard for parents to work their way through the diagnosis," observes Mulak, "and later on there are issues with day-to-day coping. But parents are resilient," she adds.

Although living with these issues can be an emotional roller coaster couples have found effective ways to meet these challenges and take control of their child's health and their overall family life.

Adjusting to the Diagnosis

It may seem contrary to reason, but when a child is born with haemophilia one of the first priorities for the mother and father should be to sort out their own attitudes and reactions to the diagnosis. Adjusting to the diagnosis-whether or not there has been haemophilia in the family-is an extremely difficult and demanding process for any couple.

"Parents need to grieve over the loss of the expectation of a healthy child," explains Danna Merritt, a social worker at the haemophilia program at The Children's Hospital of Michigan, and a creator of the PEP (Parents Empowering Parents) program. During this emotionally and physically

draining period, the couple must prepare themselves to deal with such feelings as anger, shock, anxiety and depression. "Grief like many other experiences is a process," emphasises Mulak. "You must take time to think about the other person despite your own concerns and anxiety about the future." Once parents have acknowledged and accepted the situation something that occurs over time, they can begin to take a more positive role in managing their child's illness.

Nimia and Rodrigo Pangilinan, originally from the Philippines and now resident of Ardsley, New York, had no family history of haemophilia when their newborn son Marc, began to bleed following his circumcision. "He only eight days old and it was devastating not knowing what was wrong," recalls Mrs Pangilinan. After experiencing the shock of their son's diagnosis she and her husband decided to come together as a team to learn as much as they could about bleeding disorders. The Pangilinan's consulted their treatment centre, pored over all the available research and were able to resolve their own differences in opinion as they absorbed information about their son's disorder. "Learn more acquire more knowledge," advises Mrs Pangilinan, who is a nurse. "Knowledge helps you to agree."

"Use every resource available and learn everything you can. The illness is not going to go away....."

According to Mulak, having a family history of meo may influence the parents' outlook in either a positive or a negative way. Some women find that old memories haunt them and heighten their anxiety "Even though today's treatment makes it possible to have much better outcomes if a mother had a severely disabled brother or father her personal experience can create a lot of fear in her for her son's well-

continued next page

being," says Mulak. On the other hand the family history can prepare couples for the challenges they may face in having children. Virginia Rivera, the mother of four boys (three of whom have haemophilia) feels that growing up with a brother who had haemophilia gave her a better sense of what to expect when she started her own family. "Before our oldest son was born, my husband, David, and I had genetic counselling, so he could learn more about the disease," says Mrs Rivera, who lives with her family in New York City. "That way we both knew what we were getting into and knowing what to expect really helped our marriage."

Taking Charge

Both the Pangilinan and Rivera families took the best possible first step: learning as much as they could about haemophilia. That knowledge is available in many different forms—from the Internet, to publications such as HEMALOG to the national and local haemophilia associations. Whatever information highway parents choose, Merritt urges you to, "Use every resource available and learn everything you can. The illness is not going to go away so your best bet is to get armed for the long haul. That way you will have more resources to cope with the challenges. There will be less strain on your marriage and you will both start to relax and enjoy your child a lot more. Knowledge gives you more peace and a greater sense of control."

Next Steps

In addition to acquiring as much knowledge as possible our experts recommend a number of other strategies. These will enable you to take charge of your child's needs but at the same time continue to strengthen your marriage.

Become a regular at your haemophilia treatment centre

If your child was diagnosed at the local hospital there's a good chance

that he was the only haemophilia patient the medical staff there had ever seen. Given that it's understandable that parents experience a nearly overwhelming sense of relief when they first visit a haemophilia treatment centre. The professionals they find there—doctors, nurses, physical therapists, social workers—know all about haemophilia and deal with it everyday. Mulak stresses, "Whatever you need to learn it's there at the treatment centre for you. As one of your first goals try to develop an open and trusting relationship with the people at your TC."

The treatment centre is also your gateway to a wide array of services. For example, TC professionals can refer you to support groups such as PEP (see box). Merritt points out, "it's extremely beneficial to talk with other husbands and wives who are confronting the same problems you are and to see how they handle them." This kind of communication helps couples realise that they are not alone and that it is normal for a child's chronic illness to put additional pressure on a marriage.

Learn home infusion

Staff at the TC will also teach parents the skill of home infusion. "We first started doing factor infusing at home eight years ago and I can't tell you how much that reduced the stress in our family life," reports Mrs Rivera. "Before that getting our son's treatment was really hard," she says. Now the family is able to avoid just about all late night trips to the hospital, the boys can protect themselves with infusions before they play sports and the couple feels safer going off for the occasional evening out.

Keep talking—keep listening

Spouses adjust to stressful situations in different ways and often at a different pace, notes Merritt. One may want to talk while the other withdraws and wants to be alone. In the early days following diagnosis, Merritt says

that it is common for parents to grieve individually. "Instead of talking about the situation they withdraw from each other," she reports. "At just the moment when they need to lean on one another they turn away." This kind of separation can lead to difficulties in their relationship as resentment builds over the lack of understanding of each other's fears and needs. Communicating with one another is the only way to prevent this from happening, although it may at first be difficult to achieve. "Some men say they are not talkers," acknowledges Mulak, "but even a little support goes a long way. The smallest sentences can be powerful. And of course, listening to what the other partner has to say is very important."

Being forthright in your communication also allows couples to work out practical plans and share responsibilities. For example, to prevent the burden from falling too heavily on one or the other spouses may elect to alternate responsibility for home infusions or trips to the hospital. Spouses must also talk through controversial and sometimes uncomfortable issues such as what constitutes the proper degree of protectiveness. "My husband and I had two different ways of dealing with Marc's illness," says Mrs Pangilinan. "He tended to be more protective, while I was less likely to restrict Marc's activity." Over time the more they learned from their own reading and from consultations with the doctor and physical therapist at the treatment centre the more comfortable they became with their son's activities, including his participation in sports.

Set up a support system

When the Pangilinan family learned that Marc had haemophilia Mrs Pangilinan's parents uprooted themselves from the Philippines to move to the United States so that they could help out. Her parents were willing to move because they understood what is so important to

continued next page

families in this situation: a strong support system. Family and friends provide essential coverage in both emergency situations (like those early morning trips to the ER) and day-to-day activities so that a couple can take an occasional breather. One of Mrs Rivera's hopes for the future is that the haemophilia community will more actively acknowledge and respond to the need for family support by making available services to such as more child care programs.

Reserve time for your relationship

Once you have your support system in place take advantage of it to spend time with each other. Even small activities such as an evening walk together are vital lifelines for your relationship. Also plan bigger occasions for going out, say to dinner

or to the movies, to enjoy shared experiences and to create a balance between caring for your child and nurturing your marriage. "You must find time for just the two of you to relax together," urges Mulak. Otherwise you're not doing your children any favours, she says, "Because when parents feel stress, children feel stress."

When necessary seek counselling

Parenting a child with a chronic illness brings its own challenges certainly but stress often magnifies pre-existing problems in the marriage as well. This creates a timely and important opportunity to sort through your relationship and the best way to do that is with a marriage counsellor. You may see results in a short period of time. "Many people think that counselling is something that lasts forever," says Merrill. "But often a

half dozen sessions are enough to help you work through your feelings." The social worker at your treatment centre can refer you to a counsellor.

Making it work

All marriages need lots of work and tender loving care to survive. Consequently when a couple encounters additional challenges-such as those involved in caring for a child with a chronic illness-it may seem at first like the odds are stacked against them. But with understanding, communication and support, spouses successfully meet these challenges everyday. In fact, couples like the Pangilins and the Riveras say that thanks to their children their marriages are stronger than ever.

Shelagh Ryan Masline lives in New York City and is the co-author of several books on medical advice.

SUCCESS AS A HEMOPHILIA LEADER:

How to create, grow and sustain a national hemophilia organization by Laureen A. Kelley

Produced and distributed by Bayer HealthCare LLC, 2004



LA Kelley

What could be more painful than watching your child suffer from untreated bleeds? What could be harder than trying to make your voice heard on behalf of a rare and expensive medical disorder? What can be more challenging than trying to change the healthcare system in countries preoccupied with epidemics, poor infrastructure or economic hardship? What can

overcome these roadblocks to improved hemophilia care?

Leadership. Without leadership, hemophilia patients and families have little hope for permanent change. Without leadership, no one hears the cries for help. Without leadership, every person acts alone and everyone loses eventually.

Effective leadership makes the difference between passively accepting an uncertain future and achieving reliable and safe hemophilia treatment. Leadership is an art that can be learned. Success as a Hemophilia Leader not only encourages people with hemophilia to become leaders, it also shows them how to do it. In this first book of its kind, you'll learn how to:

- Develop a vision for your people
- Form a Board of Directors
- Create a Medical Advisory Committee
- Publish a Newsletter
- Set goals and objectives
- Procure medicine
- Hold a children's camp
- Work with government

- Become an international player
- Develop a strategy

Laureen A. Kelley shows you that no matter who you are male or female, patient or physician, rich or poor you can become a Hemophilia leader and produce lasting change.

Laurie is Director of L.I.G.H.T., a program that identifies, trains and supports leaders in the hemophilia community in developing countries. She is also founder and chair of Save One Life, a nonprofit child sponsorship agency for children with bleeding disorders in developing countries. She lives in Georgetown, Massachusetts with her husband, Kevin, a process scientist for New England BioLabs, and their three children: 17-year-old Tommy, who has hemophilia A, 14-year-old Tara, and ten-year-old Mary. Laurie is a fitness enthusiast, and enjoys traveling, rock climbing, reading and playing classical piano.

For your copy of this book please contact Nova at HFNZ or write to info@kellycom.com.

NORTHERN BRANCH REPORT

On February 18-20 we started 2005 off with a family camp held at the YMCA facility on the banks of the Waiwera estuary and just down the road from Waiwera Hot pools. The camp was attended by 40 people with a number of families from the far north as well as those from Auckland. The camp started on Friday evening with a meal and although it was to have been a barbeque, the barbeque was not working and the team cooked all the sausages in fry pans. This was only seen as a minor problem. Following dinner a games evening was held.

Saturday dawned bright and clear and following a leisurely breakfast the morning was filled with a series of educational workshops. These included oral health care, and a session with a physiotherapist, who demonstrated a collection of supports available for supporting various joints. Helen Spencer addressed the group about her visit to the WHF Congress held in October 2004.

Following lunch we relocated to Wenderholm Regional Park five minutes up the road complete with seven kayaks and, under the guidance of YMCA staff, had the opportunity to try our hand at kayaking. We had a thoroughly entertaining time with a number of us overturning and having an enforced swim. A group paddled all the kayaks back to Waiwera at the end of the afternoon, a journey of approximately 30 minutes.

In the evening following dinner the group had a swim at

the Waiwera hot pools - a great way to finish the day.

Sunday saw a number of options available with a workshop followed by the choice of a second workshop or orienteering. The group who took the orienteering option were treated to a magnificent view of the Whangaparoa Peninsula and the Hauraki Gulf. Following lunch all were given the opportunity to attempt the climbing wall and all of those who attempted it succeeded in reaching the top.

Late in the afternoon, after a very enjoyable weekend where new friends were made and acquaintances renewed, regretfully we all went our separate ways.

A few weeks later, a group of members attended the Australia / New Zealand one day cricket match to support the Black Caps.

Our Annual meeting was held on March 6 and attended by 15 members and a similar number of apologies. Shirley Bongard was re-elected as President with John Cook re-elected as secretary and National Council Delegate. The majority of the previous committee has returned and we welcomed Henare Maihi to the committee. We look forward to another good year and, at the first committee meeting, look forward to planning the year ahead.

John Cook,

National Council Delegate ♣



MIDLAND BRANCH REPORT

Kia Ora

Midland Christmas Gathering

Late last November members of the Midland Branch attended a Christmas Gathering in Hamilton. We met up

at The Excite Science Gallery at the Waikato Museum and visited the exhibition 'Body Odyssey' before moving to The Rotunda by the river for a picnic lunch. It was a beautiful day with a lot of interest in the exhibition. Thank you to all who attended. It was a good close to the year, and we're looking forward to 2005.

Midland Branch activity dates:

The following dates were set for 2005 activities and meetings:

- **Dr Stephen May Farewell** February 27th 12-noon aboard MV Waipa Delta
- **Midland AGM** February 27th 3pm, after The Waipa Delta cruise to be held at nearby church
- **Midland Branch Committee Meeting** Thursday 21st April 7pm @ Lloyds Lane
- **Waikato Café Evening** Saturday 14th May Venue TBA
- **Midland Branch Committee Meeting:** August 18th 7pm @ Lloyds Lane
- **Tauranga Café evening:** September 17th @ 7pm Venue 'Le Deux Soeur' Devonport Rd
- **Midland Branch Committee Meeting:** October 13th 7pm @ Lloyds Lane
- **Midland Branch Xmas Party:** Yet to be decided.

The Midland Café Evenings

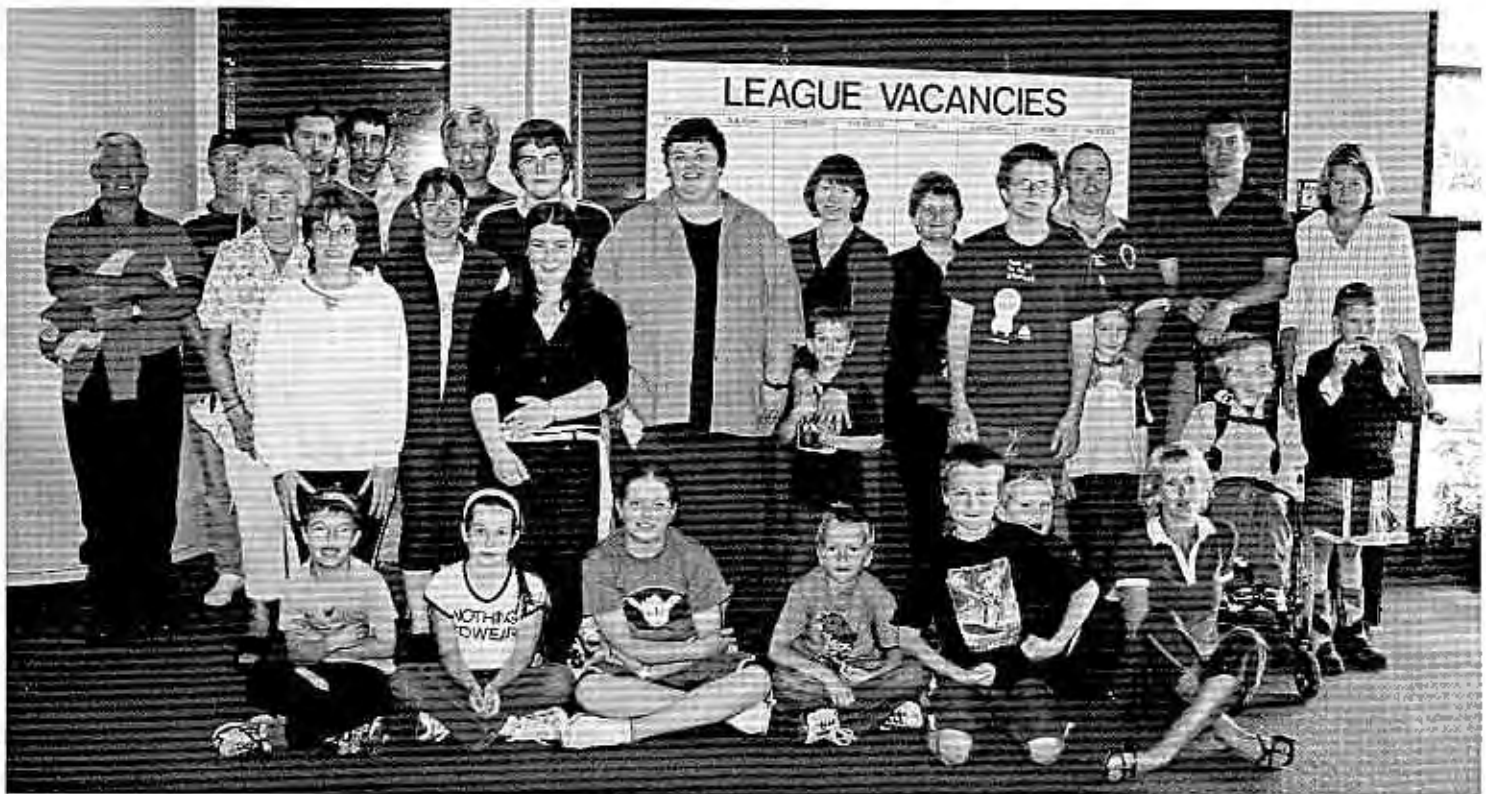
These events, held in Tauranga and Hamilton last year, worked wonderfully, and we are arranging the same again this year. The dates are likely to be Saturday 14th May (Hamilton) and Saturday 17th September (Tauranga). A regional newsletter will be sent out with more information regarding these events.

Camps

Camps are an important tool for HFNZ and we are always looking at ways of improving them. We are pleased that the next camp is for pre-teens, which we fully support. The Midland Camp has been postponed, as there are quite a lot of events within the Foundation over the next few months. We will be basing our decision on appropriate weather, and the date will be decided at our next meeting.

Malcolm Hanson
Midland Branch President

SOUTHERN BRANCH REPORT



Southern branch members enjoy a game of ten pin bowling with Outreach Worker Colleen McKay in Dunedin in November 2004.

Bleeding Nuisance: Update Study

We have recently received ethics approval and support from HFNZ to go ahead with another update on this 10-year-old study. This update is to be called 'New Technologies and Haemophilia: Individual and Social Implications'.

The main focuses will be:

- Gene Therapy
- Hepatitis C
- Carrier Diagnosis and Testing
- Pre-implantation Genetic Diagnosis (PGD) and pre-natal genetic diagnosis in general (CVS)

While there will be specific focus on these areas, ALL haemophilia-related experience is relevant.

Your haemophilia nurse/health provider or outreach worker may invite you to take part in this study. They will provide you with more detailed information.

Julie Park

Deon York

Anthropology Dept., University of Auckland

Haemophilia drug may aid stroke recovery

A single dose of a drug already used to treat haemophilia can help limit brain damage caused by the deadliest and most debilitating form of stroke, according to results of an international study.

Chief author Stephan Mayer says he is "stunned" by the finding involving the drug recombinant activated factor VII, which is sold for haemophilia treatment under the brand name NovoSeven.

The study, which pharmaceutical maker Novo Nordisk financed, also found the drug poses a "small" risk of causing a heart attack or another type of stroke.

Its use as a stroke treatment is still regarded as experimental.

"By preventing just five millilitres of additional blood - about one teaspoon - of bleeding in the brain, we were able to increase the chances of patient survival by nearly 40 per cent," Mr Mayer, of Columbia

University College of Physicians and Surgeons, said.

Strokes caused when a blood vessel breaks and releases blood into the brain, called acute intracerebral haemorrhage (ICH), are the deadliest.

As many as half of those stricken die within a month and only one in five become independent again.

ICH affects 15 per cent of all stroke victims in the United States, or some 70,000 cases a year.

In other parts of the world the incidence of bleeding stroke is even higher - in Asia, ICH affects 30 per cent of all stroke victims.

The finding "offers new hope for targeted therapy for this frequent cause of neurologic disability and death," Devin Brown and Lewis Morgenstern, in an editorial in this week's edition of *The New England Journal of Medicine*, said.

Both Dr Brown and Dr Morgenstern are at the University of Michigan Health System.

According to the results of the study, which involves 73 medical centres in 20 countries, more than two-thirds of the 96 patients who got a placebo died or ended up severely disabled.

Yet the rate ranged from 49 to 55 per cent among the 303 who got one of three varying doses of the drug.

The death rate after three months was 18 per cent for the stroke patients who were given the haemophilia drug, and 29 per cent among those who were not.

Unfortunately, a drug that encourages clotting also carries a risk of a heart attack or another type of stroke, where blood flowing through the brain is blocked.

The Mayer team found that while 2 per cent of the patients given a placebo developed a serious heart attack or blocked blood vessel in the brain, the rate was 7 per cent among those treated with the haemophilia drug.

However, the researchers characterise that risk as "small."

The Mayer team also found that the timing of the treatment seemed

important.

"The best results were seen when patients were treated within three hours after the onset of symptoms," the researchers said.

That suggests that once the damage is done, brain bleeding rapidly diminishes over time.

-Reuters

Australia, New Zealand announce start-up date for Joint Therapeutic Products Agency

The New Zealand and Australian Governments have announced a firm operational date for the new Trans Tasman Therapeutic Products Agency of no later than 1 July next year, though it could start earlier.

Health Minister Annette King and Australian Parliamentary Secretary for Health, Christopher Pyne say it is vital to ensure the new regulatory scheme is world class and to recognise the importance of consulting with industry, consumers and other interested parties. "This is a ground breaking move and that is why it is so important to get it right," says Ms King.

The joint regulatory agency will replace Australia's Therapeutic Goods Administration (TGA) and the New Zealand Medicines and Medical Devices Safety Authority (Medsafe).

The election cycle in both countries has made it difficult to adhere to the original timetable of establishing the agency in July of this year, Ms King says.

Both Ministers also recognised that industry "needs certainty around the introduction of the new scheme and needs time to review and comment on the rules of the regulatory agency, and to put in place transitional arrangements," she says.

The role of the new agency will be to safeguard public health through regulation of the quality, safety and efficacy or performance of therapeutic products in both Australia and New Zealand. This

continued next page

includes prescription and over the counter medicines, complementary medicines, medical devices and blood.

The new agency will be accountable to both the New Zealand and Australian Governments. It will be recognised in law in both countries and will assume responsibility for the regulatory functions undertaken by the TGA and Medsafe.

Ms King said the new agency offered a number of benefits for both countries by creating a single market for drugs and therapeutic products regulation which should

ensure that consumers have early access to new products entering the market, while maintaining confidence in public health and safety.

"Over the past three weeks, including today, I have had meetings with representatives of all sectors affected by the establishment of the new agency, starting with pharmaceutical, medical devices and over-the-counter medicines. My last meeting was this morning, with complementary health products representatives, who speak on behalf of more than 75 per cent of

the New Zealand market in dollar terms.

"I am very pleased at the commitment they have all given in principle to the establishment of a joint regulator. Between now and the start-up a joint working party of all sectors will work through the remaining details of how the scheme will operate."

More information about the proposed Trans Tasman regulatory agency can be found on www.jtaproject.com

MoH, Hon Annette King

10 February 2005

NZORD - the New Zealand Organisation for Rare Disorders

Snippet from the NZORD newsletter —

Lobby group on access to therapies

There are many NGOs working with communities that have difficulties accessing adequate and appropriate drugs. The New Zealand AIDS Foundation is co-ordinating a group of NGOs to advocate for a better system for accessing drug treatments in New Zealand. The first meeting was held on

Feb 17 2005 and the next one is scheduled for April 5 2005, in Wellington. The plan so far is to look at the whole drug funding system in NZ and identify exactly where the system is breaking down, and then to work as a group to plan and implement a strategy to bring about change. For more information contact Emily White Ph 09 300 6964 Email emily.white@nzaf.org.nz

BOUQUETS

Barb Sutherland: Barb Sutherland was awarded with Life-Membership of HFNZ at a Central Branch function in 2004. This was followed up with a second recognition (and more flowers) at the HFNZ National AGM, held in Wellington in March 2005.

When National Council was looking back through the meeting papers and archives of the 70's and 80's many of us were finding letters and newsletters penned by Barb

Sutherland.

Her commitment to the then Haemophilia Society of New Zealand was plain to see, and she was a most formidable force to be reckoned with as the mum of a young boy with severe Haemophilia. It was interesting to see that many of the Safety and Supply issues that Barb was lobbying for are still at the forefront of our lobbying in the 21st century.

May 1999 saw Barb reappearing on

the HFNZ scene as the Regional Delegate for Central, a position which she held until her resignation in March 2004. She continues as an active member on the Central Branch Committee and I am sure that her knowledge and dedication will continue to be appreciated by those members with whom she has contact

Thanks Barb for all those many years of untiring service and we look forward to achieving some of those Safety and Supply goals which you strived to achieve in the 70's and 80's.

We welcome you as the newest Life Member of the Haemophilia Foundation of New Zealand.

Vice President Shirley Bongard presents new Life Member, Barb Sutherland with a Bouquet. Barb Sutherland was thanked for her many years of service to people with haemophilia and is now a life member of HFNZ.



COUNCIL OFFICE BEARERS

At the HFNZ National AGM, held in Wellington on March 19th 2005, the following members were elected.

President : Dave McCone.

Vice Presidents: Nikki Cunningham. Shirley Bongard.

Treasurer : Mike Carnahan.

Southern Regional Delegate : Steve Peal.

Central Regional Delegate : David Habershon.

Midland Regional Delegate : John Tuck

Northern Regional Delegate : John Cook.

Youth Delegate : no nominations received. 📍



Nikki Cunningham addresses the meeting with the tribute for retiring President Mike Carnahan.



Newly elected President, Dave McCone addresses the meeting at the National AGM in Wellington.



The 2005 HFNZ AGM meeting attendees.

BOUQUETS

Mike Carnahan: HFNZ president Mike Carnahan did not stand for re-election at the 2005 HFNZ National AGM. Unfortunately Mike was unable to attend the AGM this year, but his commitment to, and in-depth knowledge of Haemophilia, were highlighted in his absence. Nikki Cunningham told the meeting of Mike's long association, with the Society and Foundation, when as a young boy his father was the first Secretary of the Society.

Mike's own involvement had been sporadic for many years, but the Foundation was delighted to get his "full time" input starting in June 1997. When Nikki had been researching Mike's history with the Foundation she noted that in June 1997 he attended a National Council meeting, not as an elected member but as a "nosey poke"! Meant in the nicest way of course.

His contribution at that time was of such great value that he bypassed the usual Regional Branch and National Council

succession planning and leapt straight into the President's role in March 1998. Mike said that he would give the Foundation five years and we are very grateful that he can't count, (even though his background is in Hospital finance) and Mike ended up leading the Foundation for seven years.

Mike will continue his involvement with HFNZ as Treasurer to the National Council and also as the Spokesperson for the HCV Campaign.

HFNZ "presented" Mike, via courier post, with a Crusader Rugby Jersey, even though it had been suggested that a jersey from another franchise such as the Highlanders might have been more appropriate if we wanted to give Mike a winners jersey!!

Thankyou Mike for continuing tireless campaigning on behalf of all people with Bleeding Disorders and lets hope that the HCV Spokesperson role, is a portfolio that you will only need to have for a few more months. 📍



"The Crusaders jersey is like the All Black jersey — it's not worn it's earned!" - Mike Carnahan.