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THE WORD



We find ourselves in 2009 already and two months have already flown by! I hope with two months having already passed that your new year's resolutions are still at the forefront of your mind. I have a number of resolutions for this year.

One that is more routine is keeping up a proper treatment record. It's easy to slip into old habits and leave a pile of treatment events scribbled on random pieces of paper that you then forget about (or misplace). Does this sound all too familiar? Maybe it's just me. Keeping a record is not just useful for your haemophilia treaters - it's also useful for you to know where you are having bleeds. It can be difficult to remember exactly how many left elbow or right ankle bleeds you have had. It's better to have this information at hand. You can keep tabs on your joint health and product usage at the same time and make life every-so-slightly easier for your treaters.

On another note I wanted to thank Sandra and James Poff for the great photo of their son Rorie who appears on the cover of this issue. Rorie's story will feature in this year's Supporter's Newsletter, which is distributed to all prospective donors by our fantastic fundraisers KiwiFirst.

I look forward to seeing you in Wellington at the Annual General Meeting on 21 March.



Deon York
HFNZ President

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Cover photo by T Edwards

Still Standing Book Launch

After many, many months the final event to celebration HFNZ's 50th birthday arrived – the launch of Still Standing: Haemophilia Foundation of New Zealand 1958-2008.

As the anniversary approached, many felt it was time to capture the Foundation's history in a concrete and accessible form to preserve the stories, the tragedies and triumphs for future generations. Work on the book officially began in 2007, but many of the records, files and oral histories that were consulted had been previously collected and organised by members with great forethought.

It cannot be said that the story of the past fifty years of the Haemophilia Foundation of New Zealand (formerly the New Zealand Haemophilia Society) is shared by a particularly large number of people, nor can it be said that the volume and importance of a story is dependent upon the number of people involved.

The story of this organisation and its people is an example of individuals coming together and turning what could be viewed as a tragedy, into a success. For some, *Still Standing* may be a first glimpse into the many facets of HFNZ's past. For others, this is a long-standing and well-worn relationship. Like any relationship, there will be aspects that you admire, aspects you are not so fond of, aspects that make you laugh, or cry; frown or smile. The book aims to portray all these.

It would have been impossible to depict the experiences of each member, and so really this is only one version of HFNZ's history, and each reader familiar with the Foundation will all have your own recollections. Every effort had been made to capture the many stories of HFNZ and we do apologise for any unintended omissions.

The book launch, held 28 November at the Ferndale House in Auckland, was a great opportunity for members, past and present, to gather and share memories of their experiences with the Foundation. A number of life members were present and we were treated to speeches from both HFNZ's Patron, Dr Elizabeth Berry, an integral part of much of the history, and President Deon York, whose words are reflected here.

HFNZ wishes to thank its members for their contributions to our history; in particular, but not restricted to, the many note takers, letter writers, document creators, and minute minders. These jobs are not always the most glamorous, but are certainly the most essential to preserve an organisation's history. In particular, thanks must be paid to Mike and Cheryl Carnahan and Jayne Sutherland for the comprehensive reorganisation of our archives. Mike also contributed a great many hours to reviewing the chapters and contributing his own experiences.

Of course, a history does not write itself. HFNZ wishes to thank Chantal Lauzon for her many months of research and writing that made this book possible. She has had the momentous task of taking the many voices of HFNZ and turning them into a cohesive whole. Honoured to have been a part of the process, her only hope is that she was able to do justice to the people and the incredible stories she encountered. Thanks must also be paid to the participants of the book meeting held in July 2007 who were instrumental in getting the themes and structure of this publication together.



1. HFNZ Patron Elizabeth Berry delivering her speech.



2. Stephanie Forde, author Chantal Lauzon and John Tuck.



3. Robyn Coleman and Helen Spencer.



4. Mike Mapperson, Tony Steele and Theresa Stevens.



5. Ian Hardley, Mary Brassler and Julie Park.

6. HFNZ Life Members we were pleased could attend the launch: Elizabeth Berry, Lyn Steele, Peta Hardley, Stephanie Forde, Mike Mapperson, Tony Goodwin, Tony Steele and Steve Waring.



Still Standing Book Launch

Deon York also acknowledged the members who have lost their life to a bleeding disorder and to the brave and blameless few who we lost to HIV and Hepatitis C. You live in our memories and you live within the pages of this history, unforgotten.

Deon concluded by summarising the spirit of HFNZ history in a single message: Here we are, still standing; with no chance of standing down.

Copies of *Still Standing* are available from the HFNZ National Office for \$10 (postage included). Contact Leanne on 03 371 7477 to order yours.

Preface from *Still Standing*

It is a pleasure and a privilege to be asked to write the preface to this 50 year history of the New Zealand Haemophilia Society (NZHS), now the Haemophilia Foundation of New Zealand (HFNZ).

The chronological format and use of personal histories paints a graphic picture of the 'bad old' days when pain, suffering and crippling were the lot of a person with haemophilia through to the '70s when small volume concentrates of the missing factor became available allowing the freedom and joy of self therapy. It then moves to the shock and devastation associated with viral contamination of the blood supply, particularly HIV, and more recently the cautious optimism of today when using products made by recombinant technology. It has been a roller coaster ride but courage, determination and enthusiasm shine through.

The objectives of HFNZ have changed over the years to meet the new challenges and a glance at the contents page indicates the immense amount of work which has been done by HFNZ to

provide support to families, most notably through family camps (first established in New Zealand), educational grants and funding of outreach workers. As well, there has been significant political lobbying to ensure that New Zealand has the best and safest factor concentrates possible and that adequate compensation has been given to those with transfusion related viral infections. Membership of the World Federation of Hemophilia (WFH) has been very important in realising many of these aims. HFNZ has a proud record of achievement for its members locally and on the international scene, where most recently our President Deon York has been appointed to both the WFH Fund and Resource Development Committee and the NMO Training Committee.

Many people have contributed to HFNZ but several – John Davy, Jan and Tony Goodwin, Mike Mapperson and Mike Carnahan – need special mention for their persistence, immense work and their willingness to be the public face of haemophilia.

Is HFNZ still required? The answer is resoundingly 'yes' and will be until such time as there is a cure for haemophilia – a goal which remains tantalisingly elusive despite advances in genetic technology.

I can heartily recommend this very readable account of haemophilia in New Zealand to anyone with an interest in this bleeding disorder and congratulate HFNZ on a fine and timely publication.

Elizabeth Berry, QSO
Patron HFNZ

NZHS Committee Member 1976-1988
Medical Advisor 1989 -2001

National Haemophilia Men's Weekend

The National Men's Weekend held last November for men aged 25 and over was the second residential weekend to be held in New Zealand. The first was held in June 2006, and was very possibly the first in the world of its type.

Since then a number of events have taken place. A National Couples Weekend (January 2008) was the direct outcome of a strong recommendation from the first Men's Weekend. The idea of regular Men's Dinner for the guys in the Central Region came from conversations at the airport while they were waiting for their flights home. It is interesting to see that nearly 50% of the registrations for the 2008 weekend were from the Central region - maybe as a direct result of these dinners. The experiences of the first weekend were preserved in poster form and presented at the World Haemophilia Congress in June 2008.

Always enjoy catching up with old friends and making new ones. Trading "war" stories and sharing experiences is most valuable!

So the programme for second Men's Weekend was based on the experience and recommendations from the first one, coupled with careful analysis of the evaluations. While some areas of interest were retained, such as hepatitis C, orthopaedics & physiotherapy, there were a number of new topics. These included

- Diet / Acupuncture
- Orthopaedics / Physio / Chronic Pain
- Comprehensive Care / National Haemophilia Management Group
- Group Facilitated Session
- A Question & Answer session with the President and CEO.

The group of 22 men reflected a very even age range: 6 in the 25-35 age group, 7 in the 40-50 group, and 8 aged 50 and over.

Assoc. Prof. Ed Gane began the weekend on a high note with his session on hepatitis C, detailing current and future treatments. He also explained the benefits of a fibroscan for people with haemophilia. A fibroscan is the equivalent of an accurate biopsy, and can diagnose fibrosis and cirrhosis with no pain, invasion or risk. At the time of the weekend there was no fibroscan in NZ, however one is now in operation at Waikato Hospital.

Professor Ed Gane, Hepatologist at Auckland Hospital provided useful insight.

The weekend was a great chance to discuss how haemophilia has affected their joints...



Or any other issues that came to mind.



Shane Steele and Ron Dudson catch some sun during a break.

The rest of Friday afternoon was taken up with an interactive session on diet by Kerry McIlroy, Clinical Director of Dietetics who works with Ed Gane - not just for those with hepatitis C - and Dawn Lucia from Auckland gave an overview of the benefits of acupuncture. Some really interesting discussions took place concerning the individual effects of some foods, compared with the impact on the body if they are mixed with other foods. The overview of acupuncture included a discussion on how it can help alleviate both pain and some of the side effects of hepatitis C, especially for those on treatment.

I thought the programme was superbly suited to my needs and I couldn't fault it. I was impressed! All the sessions were so relevant.

Mary Brasser from the Auckland Haemophilia Centre was our guest speaker on Friday night. She is a member of both the Haemophilia Management Group and the Haemophilia Treaters' Group. She explained how they both work, and how they dovetail together.

Saturday morning began with an orthopaedic session. Mr Stewart Walsh looked at issues in haemophilia such as joint health and specific surgical interventions, including joint replacements. This session had been so well received last time that it was repeated here for the benefit of those who did not attend the 2006 Weekend.

NZ still does not enjoy the services of the physiotherapist trained in working with adults with haemophilia - in fact at the last Men's Weekend, a haemophilia physiotherapist from Australia was 'imported'. This time, Lynette Hing who is the paediatric physiotherapist at Starship Hospital, explained the benefits of

physiotherapy and exercise and also discussed how she works with children, which would have been new information for many of those present. When they were growing up they would not have had the benefit of physio help during acute bleeds or rehabilitation.

The session on managing pain and arthritis by Dr Mike Butler, rheumatologist from the Auckland Regional Pain Centre, delivered detailed information coupled with fascinating side-trips down interesting paths concerning pain. He gave examples of chronic pain symptoms - symptoms which most people don't realize are connected with this condition - and his informal survey of the audience revealed just how much pain the group do suffer. Dr Butler's information on pain clinics was welcomed and he was thoughtful enough to produce handouts that have added materially add to our resource base.

Another new topic, again as a result of the discussions and evaluations from the first weekend, were two group facilitated sessions. These were organised because of the high number of requests in the 2006 evaluations for more time to address the spiritual, mental and emotional needs of the group at the next Men's Weekend. The first took place on Saturday afternoon, with the wrap up session on Sunday morning. The sessions - "Beneath the Surface" - were led by two group facilitators, Martin Hosking and Warren Yee and were exclusively for the men with bleeding disorders. It seems the participants either loved the sessions or rated them their least favourite of the weekend. Regardless, it is clear those sessions have continued to have a positive impact on some of the guys. People who would not normally keep in touch are doing so including some visits.

National Haemophilia Men's Weekend

Saturday night saw everyone pile into cars and make the trip across the city - not a trip for the fainthearted, but at least it wasn't rushhour traffic. We spent the evening at a private dining room in a restaurant on Mission Bay, a beach on the waterfront of the Waitemata Harbour. Wonderful food and great conversation - and these conversations were continued by many back at the hotel afterwards.

The next morning at the crack of dawn, the lounge / bar area was opened especially at 6am to enable the international rugby game to be watched. A stalwart 8-9 took up the offer and had their first breakfast at half-time (and their second at the end of the game), although it is strongly suspected that a few didn't have to set their alarm - they had never gone to bed.

Sunday morning saw another new topic and speaker: BJ Ramsay, our new haemophilia nurse at Wellington Hospital, has just emigrated from the British Isles with his family. We are very fortunate to have him on board, and his session on Comprehensive Care took a detailed look at "What you can expect from us and what we should be able to expect from you". The title really says it all - and maybe it should be compulsory reading for all!

After the wrap-up of "Beneath the Surface", our patron, Dr Elizabeth Berry, joined us for lunch before the last session of the day. The President, Deon York, and the CEO, Belinda Burnett, chaired a question and answer session from the participants with the view of hearing comments, concerns or recommendations.

The weekend was judged to very valuable by all the participants, with getting together, meeting old friends, making new ones and sharing experiences being noted as the real benefits.

A special thanks to CSL Bioplasma for their support of the event.



What did you like most about the weekend?

All of it, especially Martin Hosking and Warren Lee (Beneath the Surface).

The hepatitis C update.

Interaction with the group socially and in the group sessions (Beneath the Surface).

On reflection, "Beneath the Surface" was stimulating and interesting. It was challenging, but ultimately I found out a bit more about myself and a lot of the guys.

Togetherness. Talking about relevant issues with guys/ people who share common experiences, and receiving good supportive advice and information.

I really enjoyed Ed Gane talking about things to come with hep C and Mike Butler's very enthusiastic presentation on pain management. Also BJ's session on Sunday morning (Comprehensive Care) was very good.

Beneath the Surface. Very much self-driven or group driven.

Interacting with others. The diet segment on Friday and the Saturday morning sessions (orthopaedics, physio and chronic pain) were very informative with very good speakers.

Hamish Rollinson is on the Midland Committee, and was the youngest participant in the Men's Weekend. He writes here of his experience:

I was not sure what to expect from the 'Men's weekend', but knew it would be worthwhile... and I was not disappointed. There were numerous guest speakers including a joint replacement specialist, dietitian and acupuncturist just to name a few... Prof Ed. Gane's Hepatitis C presentation was particularly impressive, with cutting edge information on the success rate of current treatments, and the very promising news of new improved treatments in the next 5 years... He also informed us of a new liver scanner. There was a session on the programme called 'Beneath the Surface' which many of us were skeptical of initially, but it turned out by the second session that most found it very beneficial including myself. We were able to ask questions about different issues from people who had experienced them first hand, including issues that are not usually talked about. The facilities were more than adequate. I caught up with some old friends and made some great new ones. I now have places to stay all round the country! (thanks guys). I had a very enjoyable weekend, returning home feeling very positive and very informed. Thanks Helen for organising a great weekend...

Hamish Rollinson,
Midland committee member

In Remembrance...

Sadly, two longstanding members of HFNZ have recently passed away. HFNZ extend our sincerest condolences to their families, friends and loved ones.



Jack on his recent OE

Jack Donald Walmsley

Jack first became involved as a Midland Committee member in 2002, and helped on the last and biggest ever national HFNZ camp at Rotorua in 2003. Over the last couple of years he came up with some great ideas for events, and was very supportive of the Midland executive.

Jack had only just come home from an extended trip to Europe, which he thoroughly enjoyed and was already making plans to go back. His sudden death in December at the age of 43 has both shocked and saddened all those who knew him. Jack was very close to his family, and his loss is especially felt by his mother Inez, his partner Heather, and his brothers and sisters.

Ronald Sidney Dudson

Ron left us unexpectedly on 4 February 2009. He was a fun loving man with a wicked sense of humour. He had a passion for the outdoors, but above was a wonderful family man. Ron was an active member in the Central Branch for many years and his absence at HFNZ events will be felt by all who had the pleasure of knowing him.

He will be missed most by wife Judith, daughters Lisa and Treena, son-in-law Paul, and grandchildren Rico and Luca.

I quickly learnt that Ron wasn't a guy to sit around and complain about his ills. He would say to me with a laugh "no use complaining no bugger would listen anyway".

Laughing smiling and joke telling was in fact his trademark.

Ron was a guy with the biggest heart, who would do anything for anyone. A guy who was so proud of his family.

The only time I saw Ron riled was the lack of acknowledgement for those who had medically acquired Hep C. His outrage wasn't so much for himself but what he saw as a lack of fairness for others who were suffering.

But it was Ron's relaxed easy manner, his "you take whatever comes your way and make the best of it" attitude that will stay with me. He was an inspiration to me.

You're a great loss Ron - the haemophilia community will miss you, I will miss you.

Walk well on your next adventure - until we met again.

Drew Mackenzie



Ron at Central's Winter Escape in 2005

Good-bye Drew...

In December, Central members said good-bye to their Outreach Worker Drew Mackenzie at a gathering at Murryfields Clydesdales at Tokomaru.

Drew took over the position of Central Haemophilia Outreach Worker in 2005. Her background and calm understanding meant she was immediately felt to be a great asset to the region. She was integral to many of the programmes began or run by HFNZ over the last few years, especially the HFNZ Exercise Competition. Drew provided the inspiration and commitment to get the competition up and running, and get the membership moving. With her to provide motivation, it was no surprise when Central was named winning region in the first year of the competition.

Drew always provided a voice of reason and her opinion was much respected by her colleagues and members in region. There is much I could say about her, but I instead leave you with words that others have contributed.

We wish you well in your new adventures Drew and look forward to seeing you from time to time.

A breath of fresh air

A will of a wisp

A lamb

(This is only funny if you know The Sound of Music)

Drew brought a fresh perspective to the role and an energy that had been sadly lacking due to staffing issues and a stretched Outreach service. Drew's ability to encourage people to become involved with the foundation after they had lost contact over the years was a huge boost to the region. Drew's employment was a cause of enabling the Central region to become a well organised, energetic bunch of people responsible for some great family camps and innovative dinner meetings over the past few years.

- Belinda Burnett

Through, at times, sheer force of will, Drew has managed to both bring a number of central representatives back into the fold, and foster a greater acceptance within the region of a diverse range of activities. I never thought I'd see the day where 10 haemophiliac kids would be running around, participating in a mainstream martial arts class, and breaking boards with their elbows, all organised by the Foundation.

- Paul Dagger

Drew will be very much missed by the region, our events have seen great growth during her time with us and I am delighted to see many positive changes in our member's health and outlook due to Drew's ability to identify, motivate and provide appropriate support to make improvements in members lives.

Her work in bridging the gap between our doctors, Haemophilia nurses, healthcare workers and members has made a big difference in members lives - empowering them to help themselves.

- Grant Hook

CEO Belinda Burnett farewelling Drew in December



Snapshots of Drew's time with HFNZ



"Who's the parent?"

by Stephanie Coulman

Parents Empowering Parents course - a New Zealand first.



Parents and presenters of the first PEP programme to be run in New Zealand, 5 - 7 December 2008.

Last December the US-based Parents Empowering Parents (PEP) programme was held in New Zealand for the first time. Held at Kilbirnie's Brentwood Hotel, outgoing Outreach Worker Drew Mackenzie, Haemophilia Nurse Daryl Pollock and parents Stephanie Coulman and Di Bell presented the programme to twelve parents from around the country. Participation from the attendees was superb and programme evaluations indicated they rated the programme highly and took away new positive parenting techniques to use at home.

To help families successfully live with the challenges of a bleeding disorder, the PEP programme was designed to educate parents and improve confidence in parenting skills. The programme is presented to parents by parents of children with bleeding disorders, in tandem with a social worker and nurse. This team approach combines the strengths of peer support with professional expertise.

The PEP programme was co-authored by Children's Hospital of Michigan Social Worker Danna Merritt and the director of MapleTree Counselling Centres in Livonia, Michigan, Sandra Joseph, Ph.D.

The programme has been running in the USA since 1995. However, it only made it Downunder in 2007 when American trainers Danna Merritt, Madeline Cantini and Ed Kuebler brought the course to Canberra to coincide with the biennial Australian and New Zealand Haemophilia Conference. As many of Australia and New Zealand's haemophilia community attend the Conference this was an opportunity to train the trainers and introduce the programme to Australia and New Zealand.

Trained and equipped with the material and resources the novice Central region presenters spent a couple of weekends honing their material and waiting for parent numbers and an appropriate venue to be finalised. Thanks to Drew's efforts and funding by Bayer this came about in December 2008.

Lynley Scott from Auckland is the mother of 8-year old Andrew who has severe haemophilia. "Richard and I had the extreme privilege of attending the first NZ PEP programme," says Lynley.

"We went not quite knowing what it was all about and who we would meet on this course. While it was an incredibly full-on weekend, we left with some amazing, practical, and excellent tools to use, not only useful for raising a child with a bleeding disorder but in raising any child. We also left with a group of new friends who had shared parts of their lives and struggles with each other. My only hope is that every parent gets an opportunity to attend. Thanks so much to those who organised, funded and participated in the course!"

Some other comments from parents:

"Great ideas for shaping children's personality"

"I would recommend it to any parent looking for new tools to help them parent better"

"A fantastic starting point"

"Good to link parenting skills to specific issues that children with haemophilia have"

"I now have new ideas on developing our family together"

"The group together was really supportive and fun"

"The presenters were excellent"

"It gave me a great opportunity to re-evaluate myself and parenting"

Final evaluations indicated all parents would recommend the programme to others, all said they felt they had new insights to parenting and knew how to develop their parenting techniques at home. Eleven of the 12 participants rated the programme as "very valuable". Many said at the closing session they felt the group now had a special bond having shared so many personal experiences over the weekend and not least always having haemophilia in common.

While giving up an entire and (very sunny) December weekend to attend the programme was already proof of their commitment and dedication to their children, the parents went away determined to further develop their positive parenting techniques.

As we reminded ourselves over the weekend - "Who's the parent?" "WE'RE THE PARENTS!"

Editors Note: HFNZ is planning on running another PEP programme later in the year, so keep your eyes and ears open for registration details. For further information in the meantime visit www.pepprogram.org or speak to your Outreach Worker.

The teenage years

It's amazing really that most young people and their families survive adolescence. Being a teen is difficult enough without haemophilia – it is time characterised physical, psychological, and social changes that are all happening at once. At times, living with haemophilia can be a lonely journey, accompanied by feelings of isolation, anger, denial and frustration. It's a burden that affects not only the individual with the bleeding disorder but their whole family as well.

Adolescence is a challenging time for people with haemophilia, as well as their families and health care providers. While parents need patience, a sense of humour and seemingly bottomless bank account, teens need both the security of home and the space to grow into the independence of adult life. This article will look at some of the issues that face teens with haemophilia and their parents as they move towards that independent life.

Control: the key to maturity

During these years of change and growth, males and females tend to have polar self images. Boys tend to feel that they are too thin, short and that the onset of puberty arrives too late. Girls tend to feel that they are overweight, too tall, and that the onset of puberty happens too early. During these dramatic physical changes, at an age where all strive to blend in, many feel uncomfortable with their bodies.

Maturing in psychological terms includes the development of intellectual skills, independence and social networks with peers, however, at the same time adolescents also show signs of psychosocial regression – withdrawal and childlike behaviour. Academic performance at school can deteriorate and clashes with parents and other authority figures are not uncommon. Though processes during puberty may include denial of the bleeding disorder, while emotional reactions may include fear.

The key to navigating a way through this frequently troubled period is control. Control allows a person with haemophilia to take charge of their health, instead of allowing their disorder to govern their life and cloud their happiness. Learning to put life first and their bleeding disorder second is the single most important feature of growing up.

"To be in control requires discipline. It is useless to simply 'forget' haemophilia and not to, for instance, have a dose of factor VIII or IX before an event know to provoke a bleed. It is silly to imagine that a run of bleeds into a major joint will just 'go away' without therapy or subsequent damage. It is foolhardy to go off on holiday without packing the equipment needed to treat a bleed, or finding out the location of the nearest haemophilia centre. In all these cases common sense planning ensures that life can run smoothly without the disruption of untreated haemophilia." - Dr Peter Jones, 1994.



It's important to stick to your treatment protocol.

No one wants haemophilia, but it is there and cannot simply be ignored. Coming to terms with it and at the same time wanting to create some distance from parental influence can be frightening and hurtful. Most children will have learnt to control haemophilia before puberty. They are in command, knowing exactly when to ask for treatment, judging the dose, mixing their concentrate, increasingly doing their own infusions. By allowing young people to take responsibility for their haemophilia gradually as they grow up, it allows them to get on with the far more exciting events of life with their friends at home and school.

Prophylaxis and compliance

It is well known that teenagers with chronic disease have problems complying with their treatment and an association between regressive behaviour and non-compliance with prophylactic factor replacement therapy by adolescents has been documented. The majority of children and adolescents with severe bleeding disorders in New Zealand are on prophylactic treatment to prevent the majority of bleeding episodes and minimise the impact of haemophilia arthropathy. Reduced compliance (aka not sticking to their treatment protocol) may result in preventable bleeding episodes that could affect future joint mobility.

In a global survey of treatment strategies in haemophilia A involving 147 haemophilia treatment centres, compliance with all types of prophylactic treatment was highest in children up to 12 years of age, with 90% reported high or very high adherence. This number dropped to 54%, however, in adolescents aged 13-18 years.

Teenagers tend to focus on the present and may not perceive the prevention of potential future joint disease as a high priority. As short-term goals are more likely to seem relevant, adapting their treatment regimen to prevent bleeding episodes only in the immediate future may be more readily understood. For example, most patients in Sweden reduce their factor concentrate injection frequency during their late teens, but maintain a prophylactic treatment regimen consisting of factor infusion at least 1-2 times per week, prior to planned physical or social activities. One survey reported that 60% of adolescence patients who were on prophylactic treatment took additional treatment before physical activities, travelling, on vacations and going to parties.

Today, prophylactic treatment is often tailored to individual person's bleeding pattern and lifestyle, and an individualised approach when training adolescents to take responsibility

for their own treatment is recommended. Frequent visits to health care providers build familiarity and allow adjustment to accommodate the changes that accompany puberty. Participation in events hosted by the HFNZ, especially Teen and Youth camps, can provide education, encouragement, positive feedback and peer support that can help the teen with haemophilia to actively participate in his/her own care and can support the perception that treatment is a normal and necessary part of life.

Sports and Physical Activity

Most children with haemophilia in developed countries have fairly unlimited access to factor concentrates and prophylaxis enables a variety of physical activities and sports. Many of the activities young people with haemophilia today engage remain a shock and surprise to those of the previous generation where physical activity was usually discouraged if not outright banned.

Young haemophiliacs are good at keeping to certain exercises but despite this, some studies have shown that when physical intervention is not performed at early ages muscle strength, especially lower limb strength, is reduced in haemophilia patients compared with a matched population of boys from the general population. One study found that 160 of 195 children with haemophilia had subclinical or 'silent' orthopaedic symptoms, such as tender points in joint capsules and ligaments or shortening of muscles. These symptoms suggest disturbances in joint function that could lead to an increased risk of injury during sport activities.

Generally, sports encourage better coordination, endurance, flexibility and strength. The active child or teen has improved muscle-to-fat ratios, falls less frequently, has muscles that operate more efficiently and optimised joint loading. Participation in regular physical activity has been shown to reduce or prevent joint bleeds in people with haemophilia, and lead to healthier joints and a better quality of life.

Despite this knowledge, the dispute about which sport activities should be practiced by people with haemophilia continues. A large majority of authors whose works cover sport among people with haemophilia focus on which sport activities should be recommended and which should be ruled out, arguments which are probably fuelled by the fear of a risk of haemorrhaging.

Traditionally it is suggested that people with haemophilia do not practice any 'contact sport', and instead 'non-contact' sports, or at the most, those termed as 'restricted contact' sports are recommended. Other authors mention to always consider the severity of the disease as there are references about people with

haemophilia who practice contact sports for years, and even adventure sport, with no bleeding problems.

With an ever increasing list of sports and modifications to sports available to try, some people have suggested reviewing the 'recommended' sports classifications with a view to increasing categories and adopting new criteria. Many adolescents with haemophilia are highly attracted to the most popular sports regardless of their level of danger. There is every possibility that they take serious risk to feel part of socially relevant activities.

It is necessary to reach a decision among all the parties involved when it comes to recommending which sport to practice. The doctor will have to consider attractive alternatives which should, in turn, be considered carefully on the teens', parents' and trainers' parts. Having successfully considered the alternatives, less standard sports may even be an option (e.g. Tai-Chi), but which still provide the patient with many potential benefits.

One important point would be that the decision-making for each person becomes more individual in terms of their clinical status. Therefore, it is necessary to not only

Attending Youth Camp is a great way to meet others who are facing the same challenges.



It's all about taking control.

study the risk the sport involves but to establish a link between the person in question and their sporting activity in light of both the demands of that sport and the person's physical capacity.

This new approach to classifying sports is particularly important for children and adolescents as it is long-term prevention work which will allow strength and skills to build and will help to improve the young persons' self-image.

For this to come about however, it is important to minimise the risk of bleeds through education with both the individual and the community so that people with haemophilia may practice sport with optimum safety.

A patient who exercises regularly can improve their overall fitness. Preventative physiotherapy can be implemented to improve movement in troubled joints and physical training can increase muscle strength and performance, especially before starting a new sport. While the aim of haemophilia physiotherapy is to enable a 'normal' way of life, extreme competitive sports should not be considered 'normal' and do carry a risk of injury. In fact, any sport can be harmful if performed too intensively, so the key is to know one's current limits and slowly build towards increasing them. Prevention of injury can be achieved with regular training and the choice of the right sport at the right age.

The teenage years

Some people now believe that it is essential to teach young people the importance of physical exercise to prevent musculoskeletal problems. With this practice, it is possible for young people with haemophilia, with healthy joints and whose everyday activities are not restricted, to enjoy a similar physical condition and aerobic capacity, and lifestyles that are as active as those of their healthy counterparts.

Regular, enjoyable sport also results in feelings of well-being and fulfilment, which can help counterbalance any unease or loneliness that haemophilia can provoke. Being part of team is especially powerful in dispelling feelings of isolation. Overall, the benefits of physical activity outweigh the risks for persons with haemophilia, including increased self-esteem, social contacts and a normal way of life.

Careers

Choice of career is especially important these days. Heading into uncertain financial times, economists predict youth unemployment will rise at an even greater rate than for the rest of the population. Luckily today few jobs are closed to those with even severe haemophilia. The armed forces and emergency services are still largely off limits, as should be jobs that might put one at risk of being isolated from special medical help should an emergency arise. With these exceptions however, there are an ever growing number of possibilities, even manual positions.

There are obvious benefits in becoming as highly qualified as possible before leaving school or university; the choice becomes much wider. In the context of severe haemophilia, it is important that choices as to possible careers are explored sooner rather than later. Early planning helps ensure that any disruption caused by unexpected bleeding is catered for, and special help with difficult subjects provided.

Fading is the fledgling, romantic notion of what one's youth is for: meeting people, trying different jobs and travelling, all in an effort to find out what kind of adult you might want to be. More and more being in your twenties is seen as a time to put your head down and get ahead. No time to go on the road, or into the wild; there's work to be done and identities to be forged. While this new outlook doesn't apply to everyone, of course, it does seem as if there has been a cultural shift in this direction.

Most young people need time to develop their own ideas about what they want to do with their lives. While getting a head start is great, it is important to remember that early decisions can always be changed later in light of new interests and work experience.

Conclusion

Haemophilia is a problem to a teenager. It is possible to lead a relatively normal life with haemophilia, but there are a number of things that the teen with haemophilia has to consider, such as having infusions several times a week, treating bleeds promptly, knowing alcohol increases the risk of injuries, and performing sports without proper equipment or treatment increases the risk of joint bleeds.

A 2004 survey of Swedish adolescents with haemophilia reported that 86% of the participants felt they experienced the same possibilities as someone without haemophilia, with some exceptions when it came to performing some sports and martial arts. The participants considered the most difficult things about having haemophilia was to remember to take the concentrate, perform venepuncture, having some restrictions regarding physical activities and having to tell other about their condition.

None of the participants considered their health to be poor, and most considered it to be excellent/very good. It should be noted that Sweden is known for its very high concentrate usage and initiated prophylaxis much earlier than in other countries, and that patients with inhibitors were excluded from the survey. Despite the good health scores, many still thought longer acting concentrates would provide a better quality of life.

These results are very different to the answers of 13 to 21 year olds in a survey undertaken in the United States in 2001. On social issues, 42% of adolescents stated that haemophilia causes problems at school or work and 60% stated they manage haemophilia by avoiding physical activity. Only 30% stated that they treat a bleed within one hour of its occurrence in contrast to 52% of adults and 67% of parents of children with haemophilia. It would seem that the high levels of treatment promoted in Sweden do have a positive effect on teenagers' quality of life.

Having survived parents, brothers, sisters, teachers, doctors, nurses and adolescence, the average young person with haemophilia wants nothing more than to live life their way. Being active and having a high degree of knowledge of haemophilia and awareness of the benefits of regular treatment for future wellbeing is of great importance to ensuring young people keep up their treatment regimen, giving them the chance to experience that life to the fullest.

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Physical activity can be a real benefit, both to build strength and socially.

Conference Updates

NACCHO 2009: Making good camps great

Colleen McKay, HFNZ Outreach Manager recently attended the North American Camping Conference of Hemophilia Organizations (NACCHO) held at the Tempe Mission Palms Hotel in Tempe, Arizona, February 5-8.

The conference - the only one of its kind - serves as the source for education and information on camps for children with bleeding disorders. It is the place for chapter and haemophilia treatment center (HTC) staff, counselors, camp committee members and even fundraisers to congregate to share resources and ideas to help other programs improve the camping experience for all children. This year pre-conference sessions for camp directors were on best practices, training staff and managing a camp, with information on funding, administration and supervision.

NACCHO is organized by the Arizona Hemophilia Association in Phoenix and funded by a grant from Wyeth Pharmaceuticals.

"NACCHO has provided me with lots of good ideas and inspiration for the upcoming Youth and Teen Camps", reflected Colleen. "Many of the sessions centred on teaching leadership to teens and we will be able to incorporate the principles of goal-centred programmes learned at the conference in future HFNZ educational camps".

HFNZ represented on Hemophilia 2010 Planning Committee

The WFH 2010 Hemophilia World Congress is to be held in Buenos Aires, Argentina, July 10-14, 2010. New Zealand is already playing a part in Congress, as CEO Belinda Burnett has been invited to be a member of the planning committee, whose responsibilities are to finalise the Congress programme.

The members of the multidisciplinary programme committee are:

Co-chairs: Gordon Clarke (UK)
Carlos Safadi-Márquez (Argentina)

Members:
Belinda Burnett (New Zealand)
Martial de Haro (France)
Antonio Gómez Cavallini (Argentina)
Assad Haffar (WFH, Deputy Program Director)
Aris Hashim (Malaysia)
Elizabeth Paradis (Canada, Chair-Nurses Committee)
Sylvia Thomas (Brazil)
Sylvia von Mackensen (Germany, Chair-Psychosocial Committee)

Belinda recently travelled to the meeting for the Congress Program Committee in Atlanta, GA, U.S.A. from January 30-31, 2009. Although the final programme will not be available until the end of 2009, Belinda promises an exciting series of interactive and engrossing sessions.

HFNZ congratulates her on the honour of being invited to part of the Committee.



NACCHO 2009: Colleen with her "Babez and Stud" team from the team building exercise held at Phoenix Raceway Speedway where they got to race high speed go-karts. Other team members hailed from Portugal, Scotland, and the US.



Interested in attending the 15th Australian & New Zealand Haemophilia Conference in Brisbane this October?

Attendance at international meetings provides an excellent opportunity to increase the profile of HFNZ, making valuable contacts and keeping New Zealanders aware of the latest issues and advances regarding haemophilia and other bleeding disorders. Past attendees have always found participation a valuable and educational experience.

From 8-11 October 2009, hundreds of people with haemophilia and their family members, clinicians, nurses and supporters will meet at the The Sebel, King George Square, Brisbane for the 15th Australian & New Zealand Haemophilia Conference. HFNZ will be funding a limited number of delegates to attend the conference.

HFNZ is now accepting applications from members who would like to attend as representatives of HFNZ. The following process is only for those who wish HFNZ to fund their participation.

Criteria for funded conference delegates include:

- Applicants must be financial members of HFNZ for 2009.
- Applicants should have previously attended regional or national meetings, events or programmes.
- Completed application form returned to their Regional Branch by 20 March 2009.

Responsibilities:

- Acceptance of HFNZ funding to attend an international meeting shall be seen as a commitment from the member to work with HFNZ at a Regional and / or National level for at least 12 months following their return from the overseas event.
- Representatives will endeavour to attend all such sessions that are available, including those which may be discussing a topic they deem not necessarily relevant to their own personal situation if assigned.

Conference Updates

- Representatives agree to attend an HFNZ meeting with all the other NZ participants and the Bloodline Editor or other designated person, prior to the Conference (on site) to discuss Workshop/Symposium/Plenary allocation and the reporting framework and timeframe. They also agree to present such reports on sessions attended as requested by HFNZ.

Acceptance of HFNZ funding to travel to an international meeting also implies a commitment by the recipient to attend all sessions, liaise with members from other countries and generally act as a good ambassador for haemophilia in New Zealand. Failure to do so may result in HFNZ pursuing reimbursement from the member concerned.

Successful applicants will sign a volunteer contract agreeing to the above before travel arrangements are booked.

Please contact your Regional Branch for a copy of the application form or write to info@haemophilia.org.nz. Applications should be returned to your Regional Branch no later than **20 March 2009**.

Please note that all interested people are welcome to register and attend the conference.

Details are available at www.haemophilia.org.au

give
a little

Give a little? Give a lot!

Charitable donations to HFNZ can now be made online at:
www.givealittle.co.nz/org/haemophilia

National Office to Attempt Half Marathon

The staff at the HFNZ National Office have entered the SBS Marathon on 31 May 2009 to either run or walk the half marathon.

Since 1974, the fast, flat streets of Christchurch have been home to one of the world's fastest marathon courses. The SBS Marathon - Christchurch was inspired by the 1974 Christchurch Commonwealth Games marathon, and today runners and walkers from all over the world can experience that historic route.

This will be the first time for most of the staff to attempt such a physical feat, except for CEO Belinda Burnett who completed the half marathon walk in 2006. So they could really use your inspiration and sponsorship, and will be collecting donations for HFNZ for their efforts. For example, a pledge of a \$1 per kilometre will total \$21.10.

If you would like to sponsor a CEO Belinda, Outreach Manager Colleen, Administrator Leanne or National Information Coordinator Chantal contact National Office on **03 371 7477** to make your pledge.

All members in the Christchurch area are invited to join in for the race. The event caters for runners and walkers of all age, ability and aspirations with a full marathon, a half marathon for runners and walkers, a 10km fun run and a Kids Mara'fun. Contact National Office for more information.

Central Boys Day Out

by **Raukura Riwaka**

My name is Raukura Riwaka. I recently had a wicked day with some of the BOYS.

This was part of my interim project for the "Step Up, Reach Out" programme, a US-based programme sponsored by Bayer that aims to assist 18-24 year old people with haemophilia to develop their leadership skills and give back to the broader haemophilia community. As part of this I have chosen to try to encourage, support and mentor a younger generation of boys with haemophilia. To do this I helped organise a fun day for boys between 8 and 14 with severe haemophilia in my region. The idea was to help them have a positive experience with those who are a bit older with haemophilia and to allow them to try some fun activities that may be new to them, within a positive environment.

I organised this with the help of Drew Mackenzie, our Central region Outreach worker, Paul Dagger who is another young man with haemophilia and BJ Ramsay our local haemophilia nurse from Wellington Hospital.

So on 24 January we had a bit of an adventure. We met up bright and early at BJ's place and when we were all together, I did my prophylaxis (with an audience). Then we were off to the inlet for some kayaking. After crossing the Pauatahanui inlet we rafted up and had a few games seeing how many people we could get standing up at the same time. I showed the guys how not to try to get back on a kayak after falling in !!!!

Me, giving archery a try

After drying off we were back to the base for lunch, some chatting and basketball. Then it was on to archery. Paul, who is a trained archery instructor, took us through the basics and we were soon putting arrows in to the target. After a close competition with the losers having to do the lunch dishes we had a break and then, after being begged, more archery!!

We rounded the day off with a BBQ with parents and family of the boys coming to join us. All in all a great day which everyone seemed to really enjoy and which hopefully helped show these guys that we still have a lot of fun as we grow up and that with a bit of planning the haemophilia doesn't have to get in the way.

Thanks to all those who helped - Drew, BJ, Paul and those who came along and to HFNZ for sponsoring such a great day.



Paul helping one of the boys take aim



A much needed tea break



The Haemophilia Foundation of New Zealand Inc announces they will hold their 52nd Annual General Meeting

Brentwood Hotel,
16 Kemp St,
Kilbernie,
Wellington

2 pm
21 March 2009

All welcome

RSVP Tel: 03 371 7477



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Pain Management Services in NZ

More than 20% of New Zealanders suffer from chronic pain, which can affect the ability to work and cause much distress. People with bleeding disorders are no strangers to pain, both acute and chronic. Chronic pain, usually associated with arthropathy, can sometimes be very disabling and also difficult to control.

Persistent pain can often only be helped by small changes in many areas. Some of these may involve lifestyle changes. Aside from just prescribing pain medication, the health system does offer some more comprehensive choices to help people deal with chronic pain.

Pain management programmes are based on well established research and are used internationally to assist people with chronic pain. Pain management means assisting a patient gain a greater understanding of their ongoing pain, plus providing strategies and coping skills to enable them to manage their pain more effectively.

Difficult persisting pain problems need the skills of more than a single professional. Because chronic pain is a complex problem, you can meet a team of professionals with different backgrounds and who are used to dealing with persistent pain problems. Most Pain Management clinics use a multidisciplinary team approach. The core assessment team can include an anaesthetist, clinical psychologist, psychiatrist, nurse, occupational therapist and physiotherapist

Most services first provide an initial Comprehensive Pain Assessment. This usually is a lengthy process which can involve up to three different members of the clinic's team. The medical assessment will explore the medical aspects of your pain, review texts, x-rays, medication that you have had and discuss options for further treatment or other medications, if this is appropriate. This assessment provides the team with an understanding of your pain and how it affects you in everyday life. A functional assessment can

be performed by a Physiotherapist to identify your current abilities and any challenges regarding movement and daily activities and how pain has impacted on your ability to function physically. Finally, a psychological assessment may also be conducted to explore with you ways that your pain is impacting upon your life and how you are currently managing this. They will listen to what issues you feel are most challenging and important to you.

The aim of the assessment is to ensure that you have your pain addressed, and provide you with some options for the management of your pain. This may include an explanation for the pain, ways that you can help yourself, plus any other treatments that may be useful.

Finally an individual treatment plan will be developed with you and if it is felt that specialty pain management treatment would be beneficial, this may be provided by the clinic. Ultimately ongoing medical care would be provided by your GP or specialist but with advice from the Pain Management team.

Access to almost all the clinics and programmes in NZ are by referral from your GP or specialist. Referrals then usually go through a prioritisation/scoring phase ("triage") to determine their place on a waitlist. Cases with a known basis and usually problems for which help can be offered tend to get higher priority scores and the waiting times are not currently inordinate in most centres.

The following is a list of pain management services available in New Zealand. While efforts have been made to provide accurate information, there may be further services in areas where no information could currently be found. If you think you may benefit from this type of service the first step is to speak to your GP or specialist who may be able to refer you to the service in your area.



District	Location	Services	Details
Otago/Southland	Pain Clinic, Medical Outpatients, Dunedin Hospital (Invercargill and Central Otago patients also referred here)	<ul style="list-style-type: none"> • Pain Management Clinic • Comprehensive Pain Assessment (CPA) • Perioperative Pain Management • Follow-up visits 	<p>A team approach is used in Dunedin and they have had some experience with haemophilia patients in the past.</p> <p>Use of their referral form is preferred.</p> <p>There is also a limited private service in Central Otago.</p>
Canterbury	Burwood Hospital, Christchurch	<ul style="list-style-type: none"> • Pain Management Clinic • Comprehensive Pain Assessment (CPA) • Procedure Clinic • Multi-disciplinary Persistent Pain Management Programme (group) • Individual Pain Management Programmes 	<p>All patients undergo a CPA to fully assess all aspects of the individual's pain and discuss individual treatment options.</p> <p>Programmes are based on a cognitive behavioural approach and the focus is specifically on assisting patients to understand their pain, to enable them to use skills in their daily life to enjoy, rather than endure the activities they want to engage in.</p> <p>Programmes include some of the following: understanding pain, and the many factors that affect it, self-regulation, biofeedback, TENS trials, hydrotherapy, developing a Home Exercise Programme, couple counselling, managing pain at work, understanding and managing thoughts and emotions that occur with pain.</p>
Capital & Coast	Capital & Coast DHB Chronic Pain Service, Wellington Hospital Serves the lower half of the North Island and the upper half of the South Island.	<ul style="list-style-type: none"> • Comprehensive Pain Assessment (CPA) • Medication Management • Interventional Clinic • Outpatient physiotherapy • Outpatient psychology • Pain Management Programme 	<p>The service is a multidisciplinary service and is engaged in the various aspects of pain management, including multidisciplinary assessments and treatment, medication reviews, pain management programmes, functional assessments and interventional procedures.</p> <p>Access to this service is via a referral from a specialist, GP or health professional and through the acute pain team of the Hospital.</p>
Taranaki	Level 2, Taranaki Base Hospital Pain Specialist via Outpatients Dept Psychology and physiotherapy via Physiotherapy Dept Persistent Pain Educator via Physiotherapy	<ul style="list-style-type: none"> • Triple Assessment • PUEA Pain Management Programme • Follow-up visits 	<p>The multidisciplinary 'Triple Assessment' includes three separate appointments, each taking 45-90 minutes.</p> <p>The PUEA (Pain: Understand, Exercise and Adapt) 12-week programme runs over 16 days and is the first in New Zealand to be held in this format.</p> <p>Access to this service is via referral to the persistent pain service.</p>
Hawkes Bay	Hawkes Bay Hospital Soldier's Memorial	Specific details unavailable	

District	Location	Services	Details
Bay of Plenty	Tauranga Hospital	A Chronic Pain Clinic was in operation but unclear if the service still exists	
Lakes (Rotorua)	Rotorua Pain Specialists Ltd (The Public Pain Clinic at Rotorua Hospital was closed in 2007)	Private pain clinic	<p>Patients should obtain a referral from their GP or a Specialist.</p> <p>Patients who are able to finance their assessment themselves will be accepted without further requirements.</p> <p>They also accept ACC patients and those with private insurance.</p> <p>Costs are approx \$300/hour – about \$500 per appointment.</p>
Waikato	No information on services available		
Auckland	TARPS (Auckland Regional Pain Service), Greenlane Clinical Centre	<ul style="list-style-type: none"> • Comprehensive pain assessment • Medication management • Outpatient Interventional Clinic • Outpatient physiotherapy • Pain Management Programmes (Individual or Group) 	<p>Provide outpatient services including clinical assessment and management of acute and chronic pain utilising a multidisciplinary approach.</p> <p>The Pain Management Programme is a structured 3-week course (Monday to Friday - 8.15am to 3.00pm) for patients with chronic non-malignant pain. It has been designed to help when standard medical or surgical treatment may have provided little, or minimal relief from pain.</p> <p>Access is via referral from a GP, and the clinic expects that a primary care medical work-up and specialist consultation has occurred, where appropriate.</p>
Northland	Northland DHB Pain Management Service, Whangarei Hospital	<ul style="list-style-type: none"> • Inpatient Services • Outpatient Services • Multidisciplinary (MDT) Clinics • Doctor/Nurse Clinics • Procedural Pain Clinics • Procedural Pain Assessment Clinics 	<p>Demand is much greater than the available spaces and that is why waiting times can be up to a year.</p> <p>Referrals should be from your GP or specialist. Once a referral is received by the Service, it is graded (triaged) on a 1-5 scale. 1 = urgent, 5 = least urgent.</p> <p>On return of the questionnaire, your details will be processed and your name placed on the waiting list.</p>

Other sources of support are organisations such as PAINZ – a patient-powered support group. Since 1985 PAINZ has worked to improve the quality of life for pain sufferers in New Zealand. Membership is open to any person in chronic pain, and their partners, parents or guardians who meet the Aims and Objectives of the society. Based in Christchurch, PAINZ has members throughout New Zealand. They provide a drop-in Centre (Christchurch), information, newsletters, coffee groups, home and hospital visits, help with access to local hospital hydrotherapy pools, and more. Further information available from painz@snap.net.nz or 03 366 0716.

Regional Branch Reports

Southern Region photos - left to right
 • Rorie and Joseph prepare for the showdown
 • Colleen lead the root-scootin' boogie
 • Blue Skies was made to feel cosy.
 • Everyone had a go jet boating on the Waimakariri river



Southern Region - By Theresa Stevens

Hope you all had a wonderful and safe festive season with family and friends. The Southern branch families have recently enjoyed our biennial family camp in Kaiapoi. We had 60 individuals arrive at camp from Nelson, Blenheim, Christchurch, Dunedin, Central Otago and Invercargill. The weather was great every day of camp as we enjoyed various activities which included a visit to the Antarctic Centre. This was an exciting adventure as we got to see up close and personal a little blue penguin. It was priceless to watch the faces of the little children as the penguin flapped around in the education room. During this visit we also learned about "life on the ice" in Antarctica – this talk was most informative and especially informative for me as my brother was down on the ice at the time!

We also enjoyed picnic lunches, swimming and the hydro slide at QEII park, Clip 'n Climb, Western themed Disco, crafts, Woodford Glen speedway, Lollipops play land, jet boating and a DVD night. The youth had an evening of go carting organised by Karl Archibald – thank you Karl for your great attention to detail. We had a "Meet the Experts" panel which was great – lots of questions where asked of the panel and all participants answered honestly and informatively which was most beneficial especially for our new parents.

Our AGM was held at camp, and an invitation was extended to those who travelled out to camp to stay for a meal. Belinda Burnett the CEO of HFNZ, spoke of the change of direction for outreach work and it was at this time we learned that our own dedicated Outreach worker Colleen McKay, will be leaving her position as Outreach Worker to take up a new position of within the foundation. We will hold a farewell for Colleen at some stage during the next few months. The election of officers was extremely smooth with the re-election of Tony Steele as Treasurer, Robyn Coleman as Secretary, Mark Uren as Regional Delegate and Theresa Stevens as Chairperson. A huge thanks to those folk who have volunteered for the committee and include Lorraine Porter-Bishop, Sandra and James Poff, Lyn Steele, Anne Leslie, Carl McKay, Liz Grenfell, Rochelle Stott, Tania Kaa, Leeann Spencer, Karl Archibald, Tony, Robyn, Mark and Theresa. Well done and congratulations to all.

Once again camp was an awesome experience and a fabulous opportunity to meet up with old friends and to meet the new ones who will become our old friends, thanks to the committee for

organizing a wonderful venue, fantastic meals, awesome activities and whoever organised the great weather – THANKS!

Events to look forward to – National AGM in Wellington March 21, 2009.

So, until next time continue to enjoy the fantastic summer weather remembering to take care in the sun.

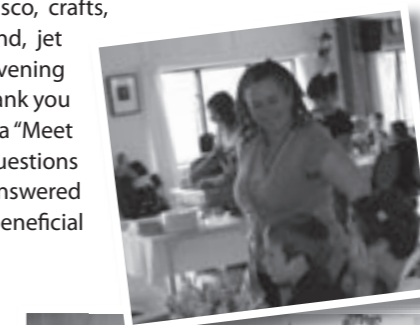
Central Region - By Stephanie Coulman

Central region can boast being the first to host the first Parents Empowering Parents (PEP) course in early December. Held at Kilbirnie's Brentwood Hotel, outgoing Outreach Worker Drew Mackenzie, Haemophilia Nurse Daryl Pollock and parents Stephanie Coulman and Di Bell presented the first PEP course to be run in New Zealand. Twelve parents from around the country gave up an entire and (very sunny) weekend to attend the parenting course aimed specifically at parents of children with a bleeding disorder. Participation from the attendees was superb and the course evaluations indicated they rated the course highly and took away new positive parenting techniques to use at home.

PEP was perhaps Drew's "swan song" as later in December Central region members fondly farewelled her at a luncheon at Levin's Murrayfield Clydesdale complex. Drew was presented with a glass waka, perhaps symbolising the HFNZ adventure she has just been on or the new one ahead? Certainly for us it was a gesture of thanks for her enthusiasm and intelligent compassion over the three years we have been lucky to know her. We wish Drew all the best for whatever 2009 may bring. We look forward to having a new Outreach Worker in due course.

Before the lunch at Murrayfield Clydesdales the children enjoyed the menagerie of farm animals. The adults enjoyed the rural setting beneath the Tararua Ranges and the sun on the deck

as well as the chance to meet new faces including Wellington Hospital's new haemophilia nurse Brian Ramsay. Better known as BJ, he is adding the personal touch to patient interaction. BJ has been known to make home visits bringing the hospital to you rather than you going to the hospital!



• Outgoing Outreach worker Drew Mackenzie at her farewell lunch at Murrayfield Clydesdales, Levin, with James and Lisa Habershon.
 • Grant Hook farewelling outgoing outreach worker Drew Mackenzie at Murrayfield Clydesdales, December 2008.



Central Region- left to right

- Liam Habershon, age 8, on the low flying fox at Akatarawa, 1 February 2009
- Nicholas Coulman, age 5, on the flying fox
- Isaac and Tracy Nyhan, Central Region Treasurer
- Ron Dudson was the first person to jump up to offer to do the lunch clean-up with his ever-present grin.

BJ and Raukura Riwaka ran a successful "boys day out" for 8-14 year old boys in January (see Raukura's article in this edition).

2009 has brought some changes to the Central region. We lost our President Di Bell to the Midland region last year and Judith Dudson was formally elected to take over this role at the region's AGM on 1 February. The new committee is Treasurer Tracy Nyhan, Secretary Stephanie Coulman and committee members Lisa and David Habershon, Ron Dudson, Grant Hook, Michael Ho. Joe Melser advised he was no longer available and Sharyn Herbison and Paul Long did not stand. About 24 members attended the family day/AGM at Wellesley Country Park, Akatarawa. Following the meeting and lunch, the younger ones spent the afternoon whizzing over a low flying fox and braved the outdoor swimming pool. It is disappointing that 10 people who RSVP'd did not attend. HFNZ still has to pay for their lunch and attendance at the venue.

Sadly, three days after this happy family day our dear friend Ron Dudson passed away unexpectedly. This is perhaps the last photo of him alive and captures his humorous and cheeky smile. He was the first person to jump up to offer to do the lunch clean-up with his ever-present grin. May he rest in peace.

Midland Region - By Catriona Gordon

It has been a few months since our last report was published – the one for the December 2008 is still floating in the ether – so here is a recap of what we have been doing in the last six months:

Midland held a Café Evening in Tauranga in October for our adult members which was well-attended. Lee Marjoribanks kindly organised some raffles to raise money for the Global Feast, and we were thrilled to be able to pass \$450 over to the National Office after this.

Our Christmas function was held at the Papamoia Blokarts, a rescheduling of the 2008 AGM when we had to cancel due to the bad weather. This time the weather was perfect and everyone had a marvellous time after some clear instruction about how to operate these speedy little vehicles. Only a few had their tip, due to excessive envelope pushing, and we all loved racing around the track powered by the wind.

We are holding our first camp in some years on the weekend of 27 February 2009, at Totara Springs Camp in Matamata. We are expecting 14 families and at the recent committee meeting finalised the details of the camp, which will be a very enjoyable weekend for all.

Northern Region - By Frances Thomas

Another well-attended Christmas party event was held at the Botanical Gardens in Manurewa on 7th December. The main event, of course, was the arrival of Santa bearing gifts for all the children. Afterwards many of us enjoyed a stroll in the beautiful gardens.

Then the summer recess. The northern part of the country has basked in record temperatures this year. Auckland, whose two nearby oceans usually moderate extreme highs and lows, topped a 137-year-old record with a high of 32.4 degrees in the second week of February.

So warm sunny weather was on order for our annual regional camp at Waiwera on 13-15 February, but it was not to be. On Saturday the rain fell all day – but it was no problem. Okay, there were no takers for the orienteering, but the kayakers were keen and 16 members, mainly father and sons, donned wetsuits and paddled over the lower reaches of the Waiwera River. After lunch everyone went across the road to the Hot Pools and relaxed in the warm waters, as the rain continued to fall. Perfect. Again this year, the facilities over flowed and members without young children slept offsite. But we are reluctant to move as the venue is ideal for young ones – and we had 11 members aged two years or younger attend this year!

The sun returned on Sunday. Other Northern members joined us at camp for our annual AGM held late morning. John Cook is standing down as Northern president this year, and we thanked him for his work over the years, for his generous spirit in dealings with people, and for staying on this past year even though work demands and health issues were an extra burden for him in 2008. A big thank you, John, from us all.

Another milestone for Northern is that Helen Spencer will this year mark ten years in her role as Outreach Worker. Dr Elizabeth Berry, HFNZ Patron, spoke about Helen's good work and genuine spirit of service, and we presented Helen with gifts in appreciation. Thanks for all your work, Helen.

The 2009 committee members, all elected unopposed, are: Richard Scott (chair), Frances Thomas (secretary and delegate), Caroline Davis (treasurer), Robin Thomas, Andrew Davis, Stace Hardley, T.A. Stirling, and newcomers Shannon Marino, Kahurangi Carter, Lorraine Leaf, Dominique Elisa, Richard Hirst and welcome back to Lynley Scott (after a six year break).

After lunch Chantal, who flew up from HFNZ head office in Christchurch to join us for the day, held a forum to discuss membership needs and ideas for future initiatives. Thank you to everyone who contributed their thoughts.

All the best for 2009 to members throughout the country from all of us at Northern.



Patron Dr Elizabeth Berry congratulates Helen Spencer on her 10 years of being Northern's Outreach Worker.

Frances Thomas present outgoing Northern chair John Cook with a token of appreciation from the region.

News in brief News in brief News in brief

Recombinant vWD Trial Announced

Baxter Healthcare Corporation announced the start of a Phase I, multicenter clinical trial for its investigational, recombinant von Willebrand factor (rvWF). The therapy is being initially tested among patients with type III von Willebrand disease (vWD). The controlled, randomized, single-blind prospective trial is underway in Europe and North America.

Type III vWD patients have only 5%-10% of the normal vWF levels in their blood, experiencing such symptoms as nosebleeds, and joint and muscle bleeds. Women can experience menorrhagia (heavy and prolonged menstrual bleeding) and postpartum bleeding.

"All current therapies for von Willebrand disease are derived from human plasma. A plasma- and albumin-free recombinant therapy would eliminate the potential risk of transmitting blood-borne pathogens since no blood components are added at any stage of manufacturing," said Hartmut Ehrlich, MD, vice president of global research and development for Baxter's BioScience business. "Achieving this milestone is significant in supporting our commitment to improve care for the bleeding disorder community."

Source: Baxter press release dated December 4, 2008

New Test Developed May Predict HCV Therapy Success

A team of researchers from Saint Louis University (SLU) in Missouri recently published a study advancing a new technique to predict if a patient infected with the hepatitis C virus (HCV) will respond to treatment. HCV can cause liver cancer, cirrhosis, end stage liver disease and ultimately liver failure. Such a test is needed because current therapies are costly, cause severe side effects and have a high failure rate.

Led by principal investigator Rajeev Aurora, PhD, professor in the molecular microbiology and immunology department, the team examined the genetic makeup of HCV to discern patterns that might reveal which patients would respond to therapy. Although a combination therapy of pegylated interferon and ribavirin is the standard treatment for patients with chronic HCV, nearly 50% do not respond.

However, even patients who do respond to treatment often suffer from debilitating side effects that can last the duration of the treatment – either 24 or 48 weeks. Interferon side effects include severe flu-like symptoms, irritability, depression, skin rash, fatigue and insomnia. Ribavirin can cause anemia, skin rash and itching, nasal congestion, fatigue and birth defects. Another disadvantage of this combination therapy is the prohibitive cost of both drugs.

These considerable drawbacks provide the impetus for the development of an accurate, preliminary therapy response predictor. "If you can identify those patients who aren't going to respond anyways because they've got a strain that is highly resistant to the drug, then you just don't treat those patients and you save them \$20,000 to \$30,000 in medical bills just from drugs alone—not to mention the side effects," said John E. Tavis, PhD, professor of molecular and microbiology at SLU, during a phone

interview. He is a member of the study team.

The SLU team analyzed the ribonucleic acid (RNA) chains of HCV from 94 patients in the Virahep C Study Group, looking for indicators of treatment success or failure. Employing a mathematical formula, they uncovered a pattern of changes called "covariance networks." The patterns, according to investigators, proved to be viable predictors. "What we found will allow a doctor to predict whether or not a medication will work in a patient," added Tavis in a statement.

The study, "Genome-wide hepatitis C virus amino acid covariance networks can predict response to antiviral therapy in humans," was published online on December 22, 2008 in *The Journal of Clinical Investigation*.

Source: Reuters, December 23, 2008

Drugs from genetically engineered animals to debut in U.S.

Medication from genetically engineered animals are set to appear in the U.S. after the Food and Drug Administration (FDA) approved Atryn, a blood thinner made from the milk of genetically engineered goats in February.

The drug will be used to help treat patients with a rare blood-clotting disorder called hereditary antithrombin deficiency. It is estimated that about 1 in 2,000 to 5,000 people in the U.S. have an inherited antithrombin deficiency. The drug could be also used by some pregnant women and patients undergoing surgery who cannot be given blood-thinners normally used to treat the condition.

An FDA committee gave a green light to the drug, manufactured by GTC Biotherapeutics in January. The European Commission already approved the drug in August 2006, and the FDA formally approved it for sale in the U.S. in February.

Although Atryn's use would be initially limited to about 100,000 patients, the approval marks the foundation for broader use of genetically engineered animals in medicine.

The recent FDA guidelines for such drugs outlined a much more stringent review process for genetically engineered animal products than cloned animal products. Unlike clones, which are supposed to be genetically identical to animals that already exist, genetically engineered animals have DNA from other organisms, often other species, inserted into their genome. Milk and meat from cloned cows, pigs and goats received a blanket approval from the FDA in January 2008.

The FDA evaluates every different "recombinant DNA construct" – foreign DNA inserted into an animal – on a case-by-case basis. Developers who want to market products from transgenic animals have to submit a new animal drug application to the FDA. Approval can take up to 10 months.

So far the only genetically engineered animals for sale in the U.S. are a glow-in-the-dark zebra fish sold in pet stores and laboratory animals like mice.

News in brief

Consumers remain wary of the new technology. Of the 28,000-plus comments the FDA received on the draft guidelines last fall, the overwhelming majority opposed genetic engineering. But that isn't stopping developers. One report showed genetically engineered animals are popping up in dozens of sectors, including:

New Medicines – Other transgenic animal-produced drugs are being developed. Researchers have created milk from genetically engineered sheep and pigs that can treat a type of haemophilia. Another strain of genetically altered pigs secretes milk with a hormone to help anaemia patients produce more red blood cells. Other animals are under development for use as sources of scarce cells, tissues and organs for transplantation into humans. Animals are also being developed to produce drug substances that can be used to combat salmonella and *E. coli* bacteria that can cause severe illness.

Eco-friendly Animals – Researchers created the Enviropig in 2001, a pig that can excrete 60 percent less phosphorus than normal pigs, reducing pollution. Scientists at the National University of Singapore engineered the GloFish, a fluorescent zebra fish now sold in the U.S., to detect water pollution.

Human-Animal Transplants – Some have greeted this as the solution to the organ shortage problem. Transgenic pig hearts have lasted in baboons for up to six months. Researchers also hope insulin-producing pig cells could help diabetes patients and transgenic pig livers could act as temporary transplants while patients wait for permanent replacements.

Animal Health – Genetically engineered dairy cows are already able to begin resisting mastitis, an infection that decreases milk production, by secreting the bacteria-killer lysostaphin into their milk. Other possibilities include creating cows resistant to mad cow disease and brucellosis, a bacterial disease that can be transferred to humans.

Source: *MediII Reports*, 22 Jan 2009; *The Wall Street Journal Online*, 6 February 2009.

Thank you Sustaining Patrons!

HFNZ is fortunate to have five partners in the Sustaining Patrons Programme who provide a generous amount of ongoing non-directed funding. The funding goes to support all HFNZ programmes.

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

Baxter product specialist Barbara Hodges with HFNZ CEO Belinda Burnett at the last WFH Congress

Bayer's Christie Murzello and Shelley Clark amongst others at last year's World Haemophilia Day event at the Sky Tower

CSL's Christopher Fry and Giulio Manzonetto with Belinda at the HFNZ book launch in December.

Glenda Dagger from Novo Nordisk

Sally Loffhagen and Warwick Jeffery at the HFNZ book launch.

Together, we care

Involving a specialized team in hemophilia care ensures:

- Accurate diagnosis
- Prompt and effective treatment
- Fewer hospitalizations
- Healthy joints and muscles
- Support for families

WORLD HEMOPHILIA DAY
Celebrating 20 years, April 17, 2009

Haemophilia Foundation of New Zealand Inc. **HFNZ**

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA
Treatment for All

Allan Coster Education Trust

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

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

Please contact your Outreach Worker if you have any questions

HFNZ's new book

Still Standing

Haemophilia Foundation of New Zealand: 1958-2008

Order yours now!

Only \$10
including postage

HFNZ's new book chronicling the incredible achievements of the organisation over the last fifty years is now available. It offers a glimpse into life with haemophilia over the years and how an amazing group of people have turned what could be viewed as a tragedy into a success story.

Complete the order form below and send with payment to:
HFNZ,
PO Box 7647,
Sydenham, Christchurch 8240

Yes! Please send me a copy of Still Standing

Name: _____

Address Line 1: _____

Address Line 2: _____

Address Line 3: _____

Phone: _____

Along with my \$10, I have enclosed _____ as a donation towards the production of the book.
Receipts will be provided.

Dates to Note

21 March

HFNZ National Annual General Meeting
Brentwood Hotel
16 Kemp Street
Kilbirnie, Wellington

17 April

World Haemophilia Day

17-20 April

HFNZ Teen & Youth Camp
Blue Skies, Kaiapoi

DATE TBA

Women's Workshop Weekend
Crawford House, Christchurch

8-10 October

15th Australian & New Zealand Haemophilia Conference
The Sebel, King George Square
Brisbane, Queensland
Australia

13-15 November

Couples Weekend
Location TBA

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