



ANNUAL REPORT

2009



Our Mission



To
Promote
Excellence
in Care
Education,
Advocacy
and
Support

HFNZ aims are:

- To provide support for people with haemophilia A and B, von Willebrand's disorder, other rare factor deficiencies or platelet function disorders, and their families/whanau.
- To educate families, health professionals and others on bleeding disorders.
- To secure a high standard of treatment for bleeding disorders throughout New Zealand.
- To represent the haemophilia population at a government level and to health services providers.

A bleeding disorder is a health problem that makes it hard for a person to stop bleeding. For blood to clot, the body needs a type of blood cell called platelets, and blood proteins called clotting factors. In people with bleeding disorders, the blood platelets or clotting factors do not work correctly or are in short supply. Severe bleeding disorders are usually diagnosed in infancy as they are caused by an inheritable genetic mutation.

Although medication can help control bleeding and research into better, longer-acting treatment is underway, a cure for haemophilia and other related bleeding disorders remains elusive. HFNZ strives to educate our members and provide support so they are able to live their lives to the fullest. We provide the tools to give our members a voice and try to ensure they receive the best care possible.

To continue to reach toward our goals HFNZ rely largely on public donation. HFNZ are grateful for the incredible generosity of the NZ public and the amazing support of our Sustaining Patrons and Corporate Donors for helping us continue to promote excellence in care, education, advocacy and support to all people with bleeding disorders in New Zealand.



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Care
Support
Education
Advocacy



President's Report

2009 will be characterised as a period of transformation for HFNZ. The Foundation has undergone staffing and structural changes and grappled with a year that could have resulted in program cuts with the widespread effects of the recession. Through this change and potential constraints, the Foundation has delivered a range of important programmes for its members and continued to remain a strong voice for people with bleeding disorders in New Zealand. This report covers the period January to December 2009.

Membership in 2009

By the end of 2009, HFNZ's membership had increased from 893 to 969 members, 736 of which have a bleeding disorder.

Fig 1: Proportion of membership by bleeding disorder.

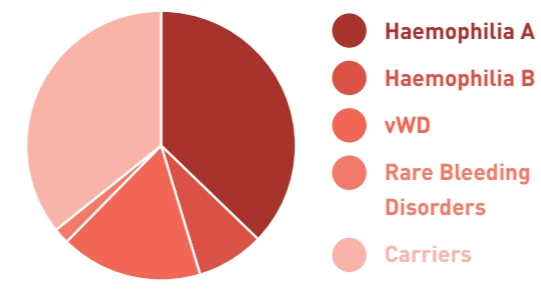
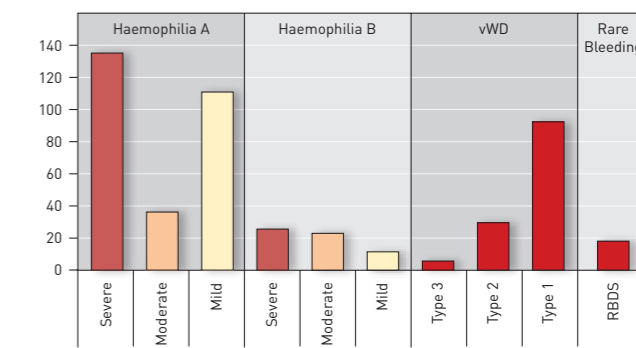


Fig 2: Representation by severity.





National Council

Representation to the National Council in 2009 was as follows:

- Vice-President – Grant Hook
- Vice-President – David Habershon
- Treasurer – Phil Cowley
- Northern Delegate – Frances Thomas
- Midland Delegate – Catriona Gordon
- Central Delegate – Michael Ho
- Southern Delegate – Mark Uren
- Māori Representative - Jo Wrathall
- Youth Delegate – Karl Archibald

Steve Waring, Director of KiwiFirst, was seconded to National Council and Belinda Burnett, CEO, attended as a non-voting member. Once again, I wish to extend my gratitude to the National Council for their dedication throughout 2009. Funding

The bulk of HFNZ funding came from our chief fundraiser, Kiwifirst (representing 69% total income). This year was their best fundraising year to date, a particularly noteworthy achievement considering the recessionary climate under which we all operated. HFNZ acknowledges the extremely valuable contribution of Kiwifirst. The next greatest proportion of our funding came from grants from the pharmaceutical industry, in particular our Sustaining Patrons, Baxter, BayerScheringPharma, CSL Bioplasma, NovoNordisk and Wyeth. The proportion of funding received by government slightly increased with the securing of a contract with the Ministry of Health. District Health Boards continued to fund 21% of Outreach Services. The remainder of funds were obtained via grants, other donations, bequests and membership fees.

National services to members

The swimming and footwear programmes, special assistance grants, advocacy and support, regional activities and Bloodline, our national newsletter, were services that we continue to provide to members. Bloodline is mailed to a total of 670 households comprising members and supporters of HFNZ.

There were also a range of national educational events targeted to different sectors of our community in 2009. Thank you to our office-based staff for their role in delivering these services.

• National Outreach Services

Colleen McKay was appointed as Manager of Outreach Services in 2009. The Northern region has welcomed two successive outreach workers, Hilary Funari-Roche and Dawn Howitt. The Northern Branch has been very accommodating to both of these staff members and I would like to thank the region for their understanding during this period. The Midland region welcomed a new outreach worker, Sarah Preston. 2009 was the first year in which the Foundation has been able to employ a dedicated outreach worker for the Midland region, one of the last outstanding goals of HFNZ's Decade Plan 2004-2014. Central welcomed Lynne Campbell to the role of Central Outreach Worker.

With Colleen being appointed to a new role, the Southern Branch welcomed a new Outreach Worker, Stu Morris. In addition to his role as Southern Outreach Worker, Stu also took on the role of hepatitis C liaison. We thank the outreach staff for their service to HFNZ in 2009.

• Monitoring of hepatitis C progression

As a result of a three-year contract secured with the Ministry of Health in the last quarter of 2008, work towards enhancing the support and services for people in our community affected by hepatitis C was able to occur in 2009. Stu Morris, Southern

Outreach Worker, also took on the role of Hepatitis C liaison with the Accident Compensation Corporation (ACC). In July, a survey was sent to members affected by hepatitis C in order to understand their current health status. Although the majority of respondents felt their health was in the good to fair range, most reported feeling worse than a year ago. Fatigue was reported to be negatively effecting physical activity, and participation in recreational or social activities. Knowledge of hepatitis C, transmission risks and the long term consequences of infection was high among respondents.

An important milestone for the monitoring of hepatitis C was gaining approval to access transient elastography (FibroScan®). This technology is a way of assessing progression of cirrhosis of the liver without the need for invasive liver biopsy (gastroscopy) that is problematic for people with bleeding disorders. This procedure is now available in Auckland and Hamilton. HFNZ wishes to thank Professor Ed Gane who has been instrumental in facilitating access to this technology, including access for those who live outside of the Auckland and Waikato regions. Liaison with ACC has also resulted in transport costs being covered to access this technology. Members were encouraged to contact their treatment centre to obtain a referral for transient elastography.

National events

• Teen & Youth camp

In April, a national Teen and Youth camp was held at Blue Skies, in Kaiapoi near Christchurch. The age range was from 10 to 24 years. The younger members were able to learn from each other: how to self infuse, tackle challenges and not be limited by the potential limitations of living with a bleeding disorder. Activities at camp were designed to build confidence, self-esteem, trust and courage in a safe, fun and supportive environment. This year's camp had the quirky theme



of 'breaking out', focusing on the idea of breaking out of prison! When each camper arrived they were "processed" and had mug shots taken. The theme centered on removing the shackles of living with a bleeding disorder.

Thank you for everything over this weekend. I really enjoyed it and I'm looking forward to the next camp. I was quite sad this morning when I woke up and realised I wasn't going to see Trey, Matt, Rex, Rau, Nev, Connor, Dylan, Hayden, Phil and all the others for awhile. Anyway, I must be off. Thank you again so much. I had the time of my life. (Jordan Young)

'I really enjoyed the camp, the abseiling was one of my favourite activities. I also enjoyed making new friends. I am looking forward to going on another camp' (Connor McCone)

• World Haemophilia Day, April 17th 2009

The camp coincided with World Haemophilia Day. Camp participants formed the HFNZ logo and an aerial shot was taken before the 100 red balloons were released to mark the occasion. The theme of this year's World Haemophilia Day was the importance of comprehensive care.

Around the world on April 17 this year, from Peru to New Zealand, national hemophilia organizations celebrated the 20th anniversary of World Hemophilia Day. While the events held were wide-ranging, all shared the same purpose - to raise awareness about inherited bleeding disorders and to advocate for improved treatment and care. For World Hemophilia Day this year, the World Federation of Hemophilia produced a video podcast that emphasized the importance and benefits of comprehensive care for people with bleeding disorders. Thousands of people from over 136 countries have viewed the video at www.wfh.org/whd. We have heard back from many of our national member organizations who incorporated this video into their World Hemophilia Day celebrations, as well as those who are now using it as part of their wider advocacy or educational activities. This World Hemophilia Day, a record number of countries organized activities. Over 35 countries have sent in their photos and stories.

(Source: http://www.wfh.org/2/6/6_4_World_Hemo_Day.htm)

April 17th also marked the day that Helen Spencer, a long-standing Outreach Worker of the Foundation, was

thanked for her dedication to the Foundation and the Northern and Midland branches in particular. Many members attended Helen's farewell and spoke of her dedication over many years to the cause of haemophilia. The Northern and Midland branches have welcomed subsequent outreach workers to their regions while still acknowledging the significance of Helen in the history of HFNZ. World Haemophilia Day was an opportune time to celebrate Helen's time with the Foundation.

• National Hui

Seventeen Māori members of the Foundation from across New Zealand attended the inaugural hui held at Manukanuka O Hoturoa Marae in Mangere, Auckland. The aims of the hui were to establish, for all members who identify as Māori:

- experiences of bleeding disorders and HFNZ
- expectations of HFNZ
- recommendations that build on these expectations
- further involvement with HFNZ

The second hui built on expectations established. The second hui had greater attendance (22 members). A key result of the second hui was the resolution to have Māori representation on National Council and for this to be enshrined in our Constitution. Jo Wrathall was appointed as the Māori representative to the HFNZ National Council. It is also planned that a Māori representative be appointed to each regional committee. The second hui also focused on discussing aspects of the Whānau ora model and how this could be applied across the Foundation.

I attended both hui and feel it was a privilege to be part of both of these meetings.

• National Women's Weekend

HFNZ have previously hosted a Young Women's Workshop Weekend (2005) and a Mothers' and Daughters' Weekend (2008). Over the weekend of 21-23 August 50 women between the ages of 16 to 77 years took part in a National Women's Weekend in Christchurch. The educational aspects of this weekend included von Willebrand disorder with Christchurch-based haemophilia nurse Alison Inder, issues for carriers of the haemophilia gene with haematologist Dr Mark Smith, prenatal genetic diagnosis with Jan Sullivan of Central and Southern Regional Genetic Services, as



well as personal stories of members. Amongst the educational focus, there was time for competitive ten pin bowling as well as plenty of opportunities to get to know one another.

• Parent's Empowering Parents (PEP)

Once again, HFNZ ran this successful programme in Wellington in November. This programme was designed to educate parents and improve parental confidence in raising a child with a bleeding disorder. The key to this programme is that it relies on parents presenting to other parents in tandem with a social worker and haemophilia nurse. Sponsored by Bayer Schering Pharma, PEP uses classroom discussions, role plays, and hands-on exercises. All the participants have gained immensely from the experience.

• Children's Education Days

For the first time, HFNZ held a local Children's Education Day in each region. Having regional workshops made it possible for more children to attend. These days were targeted at those aged between 5 to 12 years.

HFNZ needs assessment 2009

Following a strategic planning meeting in 2008, HFNZ began a process of assessing the needs of the membership. The focus was on ensuring that HFNZ delivers relevant, beneficial and cost-effective programs to members. A grant secured in the last quarter of 2008 from the Acorn Trust made this assessment possible.

The needs assessment was conducted by Chantal Lauzon, HFNZ's National Information Coordinator. It involved three stages: focus groups, a postal survey and local community reviews. Feedback obtained from this process produced HFNZ's first national needs assessment document.

Although the care of people with haemophilia and other inherited bleeding disorders has changed dramatically over the last few decades, the emotional and psychosocial support required has not changed.

The response rate to the survey was only 16%, which can make it difficult to draw definite conclusions. All sectors of the community were, however, represented by respondents, geographically and by type of member (person with a bleeding disorder, parents, etc).

Overall, members of the community were highly satisfied with the programmes and services accessed through HFNZ. The programmes that were most valued by respondents were: HFNZ's Outreach Service, both for their formal work and providing an open ear; Camps, both education and the social get-togethers organised by the regions; and education from all sources. Respondents also felt it was important that HFNZ maintain the relationships it has established with government and health care providers so that it can continue to advocate for people with bleeding disorders.

Several areas of focus were identified such as a need for improved one-on-one support from Outreach, improved communication, improving awareness among allied health care professionals, the needs of older males with haemophilia and empowering members to ensure that they have the knowledge and the skills to advocate for the best health care possible for themselves.

Haemophilia is a rare medical condition and the isolation this can create is still very real. Despite all the educational programmes and services, it is still the opportunity to meet, talk and learn from other people who understand the condition that mattered most to people with bleeding disorders and their families.

Conferences and workshops

• *Regional Advocacy Initiative for Established NMOs*

I presented on behalf of HFNZ at WFH's first regional advocacy training for established NMOs. This one day workshop was organised immediately prior to the WFH Global Forum in September. Attendees covered Australia, Canada, the United States and the European Haemophilia Consortium.

• *Sixth Global Forum*

The World Federation of Hemophilia's Sixth Global Forum on the Safety and Supply of Treatment Products was held in Montreal, Canada just prior to the Australia and New Zealand Haemophilia Conference. Belinda

Burnett, Catriona Gordon, Chantal Lauzon, and myself were among the 175 representatives of patient groups, regulators, commercial and not-for-profit fractionators, as well as doctors who treat people with bleeding disorders. Along with the usual issues of safety and supply, including inhibitors and variant Creutzfeldt-Jakob disease, use of factor around the world, and the prospects for future increases in supply, participants discussed several important new issues. Among these new topics was the concept of Health Technology Assessments (HTAs) and Comparative Effective Research (CER). These methods of evaluating current healthcare practices and treatment products are becoming more popular. Impending US legislation on "biosimilars", or "generic biologics", and their potential in the area of rare diseases were also introduced.

15th Australian & New Zealand Haemophilia Conference

This year's conference was held in Brisbane from October 8 – 10. The theme of the conference was Life Challenges to reflect the experiences of people in the bleeding disorders community in their lives and work. Every two years these conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry representatives. It provides an opportunity to learn more about the care and treatment in Australia and New Zealand and around the world, and what the future holds for the bleeding disorders community. This year 20 delegates were funded to attend from New Zealand. Belinda Burnett, Lorraine Porter-Bishop, Chantal Lauzon and myself presented at the conference.

Other representation

NHMG

The National Haemophilia Management Group maintains an important relationship with HFNZ. David Habershon attended most of the NHMG meetings in 2009 on behalf of HFNZ.

WFH

I served on the WFH Funding and Resource Development Committee, the National Member Organization Training Committee and the Youth Working Group of the WFH in 2009.

Affiliated programmes

Step up Reach Out

This year we were represented by two future leaders at the Step Up Reach Out programme, sponsored by Bayer Schering Pharma, Sam Glynn and Sam Hawkins. In total, X young New Zealanders with haemophilia have now participated in the international youth leadership development programme. This is fantastic achievement by our youth and casts a bright light on the future of the Foundation.

Pledge to GAP

Continuing HFNZ's commitment to supporting the global haemophilia community, \$5,000 from membership fees and specific donations were donated to WFH's Global Alliance for Progress (GAP) programme.

Advance your Passion

Sarah Morrison, a young woman with von Willebrand's disorder and a passion for Rhythmic Gymnastics, was the New Zealand recipient of the Advance your Passion award. This programme, sponsored by Baxter, provides grants to young people with bleeding disorders in Australia and New Zealand to pursue a vocation or recreation they are passionate about.

HFNZ's focus for 2009 has been on growing healthy families and preparing them for some of the challenges ahead. Some of the programmes listed above are well established and will of course continue to be offered to our members. While no less emphasis will be placed on such programmes, as we plan for 2010, emphasis must also be placed on our aging haemophilia population. Improved haemophilia care has resulted in life expectancy being virtually the same as the general population for a person with a bleeding disorder. While this is excellent news, it also means that for the first time we have a group of older people with haemophilia facing the morbidities associated with aging, which can often be complicated or exacerbated by having a bleeding disorder.

HFNZ continues to be outward looking and participate globally. 2009 has been no different in this regard. In addition, the Foundation has spent a lot of time focusing on its internal processes and asking some important questions about the way processes are structured and implemented. The National Council commissioned an independent review of the Foundation's processes following staff changes earlier this year. The review has resulted in a range of recommendations, most of which are not fundamental changes to structure of day-to-day processes, but focus on strengthening existing practices of the Foundation. As with any review, time must be allowed to implement these recommendations and reflect on their effectiveness. My hope for 2010 is that membership-driven decision making and participation can be built on and rejuvenated. We have a joint responsibility in making this happen.

Thank you to everyone for your support this year.



Deon York
HFNZ President

Patron's Message



I have been an enthusiastic member of the Haemophilia Foundation of New Zealand (HFNZ) for over forty years and am pleased and impressed with the way it has grown and evolved to meet the needs of people with bleeding disorders and their families.

Last year the HFNZ celebrated its fiftieth anniversary in style. What started as a small group of parents and medical professionals trying to put families in touch with one another and to help youngsters get a good education is now a national organisation with paid staff, many programs and an international profile.

This year it was the turn of the Allan Coster Educational Endowment Trust (ACEET) to celebrate a birthday. Thirty years ago this trust was established to help with coaching and tuition fees for boys who had missed school with bleeding problems; to assist young men with tuition fees which would lead to suitable employment and to adults who needed to retrain for a job with less physical demands. As a Trustee I have been delighted at the success of this program and the innovative ways these grants have been used. In addition to improved basic reading, mathematical and computer skills

for younger pupils, tertiary students have studied such diverse subjects as photography, architecture, leadership, welding, hospitality and oenology. Increasingly there is a need for financial support at the tertiary level.

This is one small but important area of HFNZ activities. The Foundation also funds outreach workers, workshops and camps for families, and smaller groups such as teenagers, new parents and Māori families. Swimming and footwear programmes are also funded. Such activities provide the education, practical help and support to families and individuals so that they are able to live life to the full and be productive citizens.

The Foundation has greatly improved the lives of people with bleeding disorders over the years and I look forward to the ongoing evolution of the organisation and to my involvement with it.

Elizabeth Berry

Dr Elizabeth Berry, QSO

CEO Report



2009 could have been potentially disastrous for HFNZ as we, along with the rest of the world, faced an economic recession. Despite this, we managed to set a new record for fund raising, and have ended the year with a profit of \$40,000.00. This increase in funds is due to the superb performance of KiwiFirst and a boost in the amount of grants and donations received.

In 2009 I represented HFNZ on the following committees:

- The Disability Sector Chief Executive Forum NZ (I am the current Chair).
- The National Haemophilia Management Group of NZ.
- The New Variant CJD NZ Ministry of Health Taskforce.
- The newly established National Community - Government Forum for Disabilities.
- Planning committee for the 15th Australia/ NZ Haemophilia Conference in Brisbane 2009.
- Multi - Disciplinary planning committee for World Federation of Haemophilia 2010 congress in Argentina.

In 2009 I spoke at the following meetings/ conferences;

- "Combined Haemophilia Support Group Meeting" in Sydney 2009.
- Presented and chaired the "Women's Issues" session at the 2009 Australia/ NZ Haemophilia Conference in Brisbane.
- The 3rd Asia Pacific Haemophilia Advisory Board meeting, Tokyo 2009.

When I began working for HFNZ in 2003 HFNZ was in a deficit of \$32,892 and had assets of \$594,509. The financial statement for 2009 reads a profit of \$40,684 and assets

of \$908,481; this equates to a conservative estimated growth of 2% p.a.

I am proud to report to members that under my stewardship the Foundation has:

- Introduced and increased the HFNZ targeted educational workshops;
- Incorporated all regions into a National body;
- Incorporated all finances and administration into the National office;
- Expanded the staff from 5 to 8;
- Increased the annual income substantially;
- Moved National Office to a more appropriate location;
- Moved Northern Office to a more appropriate location;
- Become registered with the Charities Commission; and
- Taken an increasingly professional approach to HFNZ governance and management roles that was required for employment regulations.

I will take this opportunity to say a huge thank you to the HFNZ staff who have worked with me in 2009. I am privileged to work with a group of people who are as dedicated and hard working as the employees of HFNZ.

I feel very fortunate to be working with such a committed team.

Belinda Burnett
CEO HFNZ

B. Burnett



Youth Report

This year has been a fun, challenging and rewarding one for youth within HFNZ.

There has been another group of men accepted onto the latest Step Up Reach Out Program, another fantastic success to carry on from previous years. Applications open each year for anyone with haemophilia A or B aged between 18 and 24. Visit www.stepupreachout.net for more information.

Many youth have been and still are actively involved in a lot of HFNZ's events over the past year, from helping with children's workshops and camps, through to running activities in various parts of the country.

Recent undertakings have involved the planning and hopefully soon the implementation of a Mentor Program. The goal of this programme will be to assist parents/ caregivers with children with a bleeding disorder who are moving into a new Primary/ Intermediate/ College or High school, to help with some questions of uncertainty that they may have. This is not limited to the parent/ caregiver as the person with the bleeding disorder will be able to discuss this with Youth Mentor as well.

In addition, we are looking into the set up of an anonymous 'Ask the Experts' email

address within the Foundation. Emails would be answered by someone with knowledge on the subject at hand – Outreach Worker, Haemophilia Nurse, etc. The goal of this is to promote understanding of various subjects if a person with a bleeding disorder does not feel comfortable asking someone they know.

Another goal that has been on the cards is to have a Youth Delegate representing each region throughout the Foundation. This would allow for youth representation on every level from local, regional and a national prospective.

I feel that my first year as National Youth Delegate has been a positive experience and rewarding for youth within the Foundation. I wish to express my gratitude to all the volunteers that have helped throughout 2009 and look forward to working with you in 2010.



Karl Archibald
HFNZ Youth Delegate

Regional Branch Reports

HFNZ has four regional branches, each with their own committee of volunteers who plan and run a number of social activities for members in their regions, including branch camps. Having a rare medical condition can feel very isolating. The regional branches represent the heart of the Foundation and continue the tradition of providing mutual support and connections with others in the local area.

Southern

2009 has been a year of continued change and excitement.



We enjoyed a Southern Camp early in 2009 at which time we held our AGM. The camp was a great success and it was very pleasing to hear parents of younger children comment on how the "older kids took over and looked after their younger counterparts". It was indeed a complete circle as some of those older kids were in fact my own who had once been the little kids looked after by the older ones. We had a wonderful western theme evening with members of a local line dancing group assisting with dance routines. Thanks to all who contributed in some way to making the camp a huge success.

At the National AGM Karl Archibald was elected Youth Delegate and Carl McKay was awarded both Life Membership and Volunteer of the Year award – well done once again to both of you.

World Haemophilia Day was celebrated around the country on April 17.

The exercise competition saw Southern take the trophy, the Elizabeth Berry Exercise Cup, home and whilst I believe Southern

needs a bit of a push for folk to remember to log their exercise with our outreach worker (including myself) I hope we may have had some late entries and retain the cup down in the South.

Meetings for our branch were once again adhered to as per our constitution; and again it was most pleasing to have well attended meetings despite the geography of our membership!

It was great to have Stu Morris as our outreach worker albeit it for a short while. Stu brought some great qualities to the position and we most certainly wish him well as he journeys forward following his passion. During his tenure the Otago/Southland folk enjoyed a trip on the Taieri Gorge Rail. Thanks to Southern Branch for funding this event. The Christchurch gatherings included a Christmas picnic.

We welcome our new Outreach Worker, Linda Dockrill, to the HFNZ family and I'm sure that in time we will all have the pleasure of meeting her face to face.

In October a large contingent on New Zealand members headed across to Brisbane for the Australia and New Zealand Haemophilia Conference. There was a lot of information shared and new concepts to learn about. As always, it was a privilege to attend the conference, meet new people and renew friendships with those met before.



In November, we had meetings regarding the consultation process and what members wanted or needed from the Foundation. These meetings were well attended and assisted in giving HFNZ an overview of needs of the members.

I would like to take this opportunity to thank the office staff who organised flights, venues and accommodation to enable those travelling to get to the destinations on time. National Council delegate Mark Uren ensured our ideas, needs and wants were voiced appropriately with council members. Thank you Mark for your dedication, commitment and time away from your family to ensure what needed to be said and done was carried to the council. Thanks to Robyn for her efficient documentation and completion of minutes. And lastly huge thanks to Tony for keeping our books and financial matters in pristine condition for more than 25 years, whoever takes on your role will have large shoes to fill. I would also like to thank my own family for their support for allowing me the time to participate in this role of Southern Regional Chairperson.

*By Theresa Stevens
Southern Region Chairperson*

Central

Another year has passed by. In late January we held our AGM at Wellesly Park in Upper Hutt. Whilst the attendance was low those who came along had a great day, especially the children on the flying fox and in the pool, no accidents so that was a bonus. After taking an hour to get there off the main highway, it was a good talking point with everyone vowing not to travel that road again - never - ever!!!!

During the year we have had café meetings and a men's dinner, which have been enjoyed by all that came.

In August we had our yearly camp at Kennedy Park. Again another very successful weekend was had by all. I don't know who got the most fun out of the kites, I think it was a competition between the adults and the children. On Saturday night we had a very informative presentation by Ian D'Young on pain management. Whilst I never heard the talk (doing a bit of babysitting) the opinions of all who attended, said it was most informative with question time taking it well over the time allocated.

In September 3 of us from the Central region attended the Brisbane Conference, very full-on, but we all learnt a lot that we are very keen to pass on.

In November we held our Central Region Assessment meeting. Even though there were only a few of us that attended, a lot of groundwork was covered to be put together for the final draft.

Whilst I feel that this year has been disappointing by low attendance at functions that we have arranged, the ones who came along have had great times and some neat friendships have developed. The Foundation has so much to give to its members

May 2010 be a year of new committee members who will bring fresh ideas and energy to the task!

Finally I would like to thank those committee members who have helped me so much over the past year, I really have appreciated your time and patience. May 2010 build on the successes of 2009.

*By Judith Dudson,
Central Region Chairperson*

Midland

Midland's year began with a blast – our first-ever regional camp which was held at beautiful Totara Springs near Matamata. At least when Lee and John Tuck checked the place out it was looking beautiful with so many activities available – we thought our members would be worn out by morning tea on Saturday morning! As it was, our members were lucky to survive till morning tea on Saturday, due to the arrival of Tropical Storm “Let's Wreck Midland Camp” on Friday night, which was followed by a fireball blowing out the electricity at the front gate and an enormous tree breaking the hydroslide in half.

But Midland people being plucky sorts, we hunkered down, played lots of indoor soccer, enjoyed our inside (but sufficiently well-ventilated) BBQ lunch and braved the wild outside to rock climb as the wind tried to rip the tarpaulins around us away. Little Taonga was like a crab scuttling up the wall. The girl has no fear! Every time we turned around Curtis Barnes had got to the top again. Ethan Charleston overcame his quiet sensible concerns about this activity and abseiled down the wall.

Everyone tried, most got to the top, and everyone gave it a good go. In the evening some of us decided to have a swim in the thermally heated pool even though it was full of oak leaves and various other storm debris, which in the dark felt like seaweed and really quite creepy. Children don't care about these things.

At our AGM we farewelled John Tuck as a Treasurer for Midland and thanked him for his many years of service and friendship. Di Bell was welcomed on as Treasurer as his replacement. It was agreed that we would hold another camp at Totara Springs in 2010, because surely we wouldn't get the same kind of weather! We shall let you all know next year.

In April we held lovely farewell afternoon tea at the Hamilton Gardens for Helen Spencer, who had been the Midland Outreach Worker for nearly 10 years. It was a sad day, but also a great opportunity to let Helen know how much the Midland people had appreciated her support and friendship.

In June we held a horse trekking day, which had to be held in a small barn, due to tumultuous and this time rather cold rain. We had another internal but well-ventilated BBQ, and then headed to Ten Pin Bowling where David Charleston got the top score and Curtis Barnes was the highest scoring child.

In August our Haematologist, Julie-Anne Bell took maternity leave and in early November had a baby boy.

At the end of September about 10 boys from our region had a fantastic day in Hamilton with our new Outreach Worker, Sarah Preston, who came to our region in June. This was the Children's Educational Workshop which is to be an annual event. There was some education about how the body works, the importance of physiotherapy in treating a bleed with Nikki Laker from Waikato Hospital, and a bag of goodies for each child, which was received with general delight.

In November we returned to the Hamilton Zoo for our Christmas Function. This time the weather was very kind, and a large contingent of members, new and old, were able to enjoy this very beautiful park before we had a delicious lunch by the playground. It turned out that all the children had been very good that year, enabling Santa to visit and hand out presents. We also ran some successful raffles to raise money for Global Feast which helps people with haemophilia in the developing world.

We are looking forward to 2010, with our Camp in March, and more events planned for Midland's members.

*By Lee Marjoribanks
Midland Region Chairperson and
and by Catriona Gordon
Midland Delegate to National Council*

Northern

The Year that was 2009. The year began as usual with the Waiwera camp at the YMCA. A great time was had by all.

The children playing and the parents talking, some later into the night than others. The camp is always a great way to catch up with old friends and make new ones. The Northern AGM was held on the Sunday of the camp including the election of the committee for the year. With John Cook standing down as Chair I took on the role.

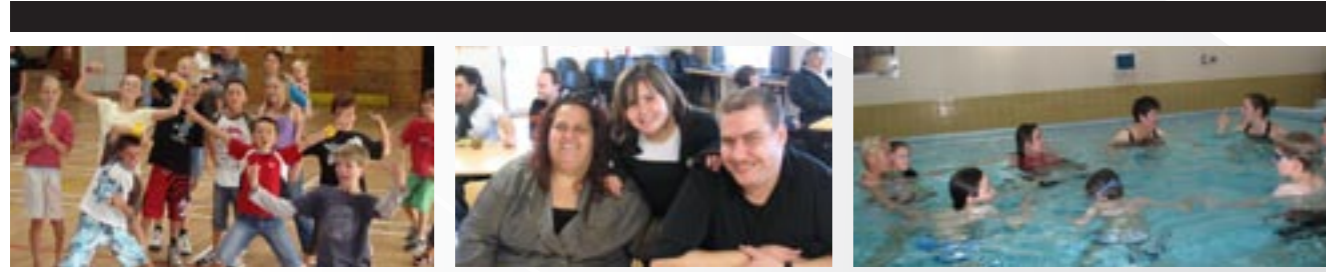
The committee for the 2009 year was:

Richard Scott (Chair)
Frances Thomas (Secretary and Delegate)
Caroline Davis (Treasurer)
Kahurangi Carter
Andrew Davis
Dominique Elisa
Stace Hardley
Richard Hirst
Lorraine Leefe
Shannon Marino
Lynley Scott
Robin Thomas

We started the year with a large committee of twelve (hooray!) and got on with the task of planning events for the year. As usual the committee did shrink over the year with most meetings having fewer than seven committee members present.

Northern and Midland Outreach Worker Helen Spencer resigned on the 17th of April, after 10 years of service. We held a farewell for Helen in the week of World Haemophilia Day, to celebrate her long service. Helen's knowledge of haemophilia and input into our families was well recognised and is dearly missed.

The loss of Helen has been the main issue for us as a region this year. We have had two replacements for the



role of Northern Outreach Worker in 2009, and are looking forward to the appointment of a permanent replacement in 2010.

Events held during the year included

- Mini golf- The indoor Jungle golf venue was handy as it rained heavily we had a great time playing mini golf and having a few snacks and ice cream afterwards.
- Trivia night – We met Hilli and her family and enjoyed trying to answer those pesky trivia questions
- Film evening – At the quaint private film studio in West Auckland always a favourite venue for our annual dinner and film night.
- Armageddon expo Ball – Hopefully this becomes an annual fundraiser. Dawn represented us well in full costume.

- Christmas Party at the Auckland Zoo - A nice change from the botanical gardens we learnt a few new things about animals and also that the Zoo doesn't like red balloons even to mark Haemophilia Christmas lunch picnic spots. Also we learned that balls are also not welcome at the zoo even if they are Christmas present for children.
- Waiwera camp and the year has come full circle.

The challenges for the year ahead include having a enough volunteers on the Northern committee hopefully enough people will put their hands up to help serve the rest of our members in the Northern region.

*By Richard Scott
Northern Region Chairperson*

In Memorium

HFNZ notes with sadness the passing of the following members and friends of the Foundation during 2009.



Ron Dudson



Dr David Heaton

HFNZ formally acknowledges their valuable contributions to the Foundation, as well as the cause of haemophilia and inherited bleeding disorders over the years.

Appreciations

HFNZ is indebted to its sponsors and donors, from individuals to trusts, to corporations and funding bodies, whose voluntary donations of time and money make it possible for us to deliver services to people with haemophilia and related bleeding disorders, and their families.

Sustaining Patrons

Among our valued donors are those who have become partners with HFNZ in the Sustaining Patrons Programme to provide a generous amount of ongoing non-directed funding. This funding is goes to support all HFNZ programmes and is in place for three years.

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

And a Very Special Thanks to



For their longstanding commitment to raising funds and awareness of bleeding disorders on behalf of HFNZ.

The HFNZ runs a financial year the same as the calendar year, the following report covers donations received from 1st January 2009 till 31st December 2009.



Donor:	Purpose:	Amount:
Sustaining Patrons		
Bayer Schering Pharma	Sustaining Patron Programme 2009	\$10,000.00
Baxter Healthcare Ltd	Sustaining Patron Programme 2009	\$10,000.00
CSL Bioplasma Ltd	Sustaining Patron Programme 2009	\$10,000.00
Novo Nordisk	Sustaining Patron Programme 2009	\$10,000.00
Wyeth Ltd	Sustaining Patron Programme 2009	\$10,000.00
Major Donors		
Acorn Charitable Trust	Needs Assessment Research	\$9,133.00
AXA Hearts in Action	National Children's Workshop	\$10,000.00
Baxter	2009 Women's Workshop	\$12,500.00
Baxter	2009 WFH Safety & Supply Global Forum	\$10,000.00
Baxter	Clinical Meeting	\$35,000.00

Donor:	Purpose:	Amount:
Major Donors		
Bayer	Youth/ Teen Camp	\$30,000.00
Bayer	Parents Empowering Parents (PEP)	\$10,000.00
Canterbury Community Trust	Southern Outreach Salary	\$20,000.00
COGS Wellington	Central Outreach Salary	\$1,125.00
COGS Banks Peninsula	Southern Outreach Salary	\$2,250.00
COGS Hamilton	Midland Outreach Salary	\$1,350.00
Community Post	Administration	In kind
Eureka Trust	Bloodline	\$500.00
Lotteries	Administration	\$25,000.00
Novo Nordisk	15th Australasia & NZ Haemophilia Conference	\$6,000.00
Novo Nordisk	Inhibitor Education Summit	\$3,500.00
Wyeth	15th Australasia & NZ Haemophilia Conference	\$6,000.00
Wyeth	NACCHO	In kind
Wyeth	HFNZ Staff Meeting	\$8,000.00
Individual Donations (over \$100)		
A Crew Yeo Tide		\$300.00
Alan Hook Estate		\$530.00
Allan Paulling Estate		\$135.00
Andy Byers Estate		\$10,000.00
Angus Macdonald		\$100.00
Anonymous		\$100.00
Armageddon Ball		\$682.00
Bayer Social Club		\$265.20
Desmond Mills		\$100.00
Frances Schuster-Keith		\$500.00
Inland Revenue Social Club		\$499.00
J Hammond		\$1,000.00
John Hunter		\$100.00
KJ O'Sullivan Charitable Trust		\$700.00
Nick Lingard Foundation		\$500.00
Reginald Fuller		\$100.00
Ross & Andrea Wightman-Mockford		\$100.00
SBS Marathon		\$1803.00
Shana Carlan-Riddell		\$1205.00
Sue McHardy		\$200.00
Tony & Lynn Steele		\$250.00
Wyeth Social Club		\$100.00
Total		\$291,127.20

HFNZ Financial Statements

Haemophilia Foundation of New Zealand Inc Consolidated Statement of Financial Performance For the Year ended 31st December 2009

	2009 \$	2008 \$
REVENUE		
KiwiFirst Revenue	1,003,814	811,586
Fundraising Support Programmes	420,913	456,706
Interest Received	34,836	46,049
TOTAL REVENUE	1,459,563	1,314,341
EXPENSES		
KiwiFirst - Campaign Costs	357,358	288,904
KiwiFirst - Printing Costs	311,852	252,154
Audit Fees	6,160	4,828
Bank Charges & Interest Paid	608	474
Rent and Office Costs	64,801	53,348
Other Expenses	671,628	705,044
TOTAL EXPENSES	1,412,407	1,304,752
NET SURPLUS/(DEFICIT) BEFORE DEPRECIATION	47,156	9,589
Less Depreciation		
Office Equipment - Depreciation	6,472	7,002
NET SURPLUS/(DEFICIT)	40,684	2,587

NOTE: This Statement is to be read in conjunction with the Notes to the Financial Statements.

Consolidated Statement of Movements in Accumulated Funds For the Year Ended 31 December 2009

	2009 \$	2008 \$
Balance at Beginning of Year	691,545	691,670
SURPLUS		
Net Surplus/(Deficit)	40,684	2,587
Total recognised revenues & expenses	40,684	2,587
Movement Regional Equity		(2,711)
BALANCE AT END OF YEAR	\$732,229	\$691,546

NOTE: This Statement is to be read in conjunction with the Notes to the Financial Statements.

Consolidated Statement of Financial Position
As at 31st December 2009

	2009 \$	2008 \$
CURRENT ASSETS		
Bank Balances	14,167	15,189
Short Term Deposits	15,000	15,000
Westpac – Property Investment Saver	49,061	47,906
Westpac Online Saver	106,570	14,674
Westpac Branch Online Saver	230,417	225,280
SBS Term Deposits	249,918	243,432
TSB Term Deposit	130,070	125,000
SBS Savings Account	1,000	1,000
GST Refund Due	20,269	15,043
Taxation	2,377	2,172
Accounts Receivable	57,803	146,595
Payments in Advance	16,462	2,491
Interest Receivable	3,460	12,645
Total Current Assets	896,574	866,427
NON-CURRENT ASSETS		
Fixed Assets	11,907	15,181
Total Assets	908,481	881,608
CURRENT LIABILITIES		
Accounts Payable	80,207	84,464
Income in Advance McGregor Bequest	55,000	55,000
Receipts in Advance	41,045	50,598
Total Current Liabilities	176,252	190,062
Total Liabilities	176,252	190,062
NET ASSETS	\$732,229	\$691,546
Represented by:		
ACCUMULATED FUNDS		
Accumulated Funds	732,229	691,546
TOTAL ACCUMULATED FUNDS	\$732,229	\$691,546

The accompanying notes form part of these Financial Statements and should be read in conjunction with the reports contained herein.

For and on behalf of the National Council;

 Deon York
HFNZ President

 Phillip Cowley
HFNZ Treasurer

Notes to the Financial Statements - For the Year ended 31st December 2009

1. STATEMENT OF ACCOUNTING POLICIES

The financial statements presented here are for the entity The Haemophilia Foundation of New Zealand Inc. The financial statements comprise the National Office, four regional branches and The Wellington Haemophilia Trust.

The accounting principles recognised as appropriate for the measurement and reporting of earnings and financial position on an historical cost basis have been used, with the exception of certain items for which specific accounting policies have been identified. The Foundation has elected to delay the mandatory adoption of New Zealand equivalents to International Financial Reporting Standards as allowed by the New Zealand Preface. The Foundation qualifies to make this election as it is not subject to the Financial Reporting Act 1993; and is not publicly accountable and not large as defined in the Framework for Differential Reporting.

(a) Changes in Accounting Policies

There have been no changes in accounting policies. All policies have been applied on bases consistent with those used in previous years.

(b) Differential Reporting

The Haemophilia Foundation of New Zealand Inc is a qualifying entity in that it qualifies for Differential Reporting as it is not publicly accountable and it is not large as defined under the Framework for differential reporting.

All differential reporting exemptions have been applied.

(c) Fixed Assets & Depreciation

The entity has the following classes of fixed assets; Office Equipment - 20% Straight Line
All fixed assets are recorded at cost less accumulated depreciation.

(d) Goods & Services Tax

These financial statements have been prepared on a GST exclusive basis.

(e) Receivables

Receivables are stated at their estimated realisable value. Bad debts are written off in the year in which they are identified.

(f) Consolidated Financial Statements

The consolidated financial statements include the National Council and regional branches along with the Wellington Memorial Haemophilia Trust and have been accounted for using the purchase method. All significant interbranch balances have been eliminated on consolidation. No parent entity (the National Council and regional branches) financial statements are prepared because they are not materially different to the consolidated financial statements. Accumulated funds of the in-substance

subsidiary (Wellington Memorial Haemophilia Trust) total \$24,011 at year end (2008:\$24,184), and a net surplus/(deficit) of \$(172) was recorded for the year end by the Trust (2008: \$1,080).

(g) Revenue from Grants

Grant revenue is recognised when the conditions associated with those grants are fulfilled.

2. KIWIFIRST INCOME & EXPENDITURE

The Haemophilia Foundation of New Zealand Inc discloses the following information relating to KiwiFirst income and expenditure.

(i) KiwiFirst Income & Expenses

KiwiFirst income records all monies collected from the public. KiwiFirst expenses record all direct marketing costs and the costs of preparation, publication, printing and distribution of a brochure about haemophilia.

(ii) Expenditure on KiwiFirst

The cost of \$311,851 relates to the assembling, publication, printing, and distribution of an information pamphlet on haemophilia produced to inform the public of the disease and to attract people with bleeding disorders in the wider community.

3. CONTINGENT LIABILITIES

At balance date there are no known contingent liabilities (2008:\$0). The Haemophilia Foundation of New Zealand Inc has not granted any securities in respect of liabilities payable by any other party whatsoever.

4. RELATED PARTIES

There were no related party transactions during the year under review.

5. SECURITIES AND GUARANTEES

There was no overdraft as at balance date nor was any facility arranged.

6. FIXED ASSETS

	2009 \$	2008 \$
Office Equipment		
At cost	64,517	61,319
Less Accumulated Depreciation	52,610	46,138
Total Fixed Assets	11,907	\$15,181

7. BAD DEBTS

Bad debts comprise - Debts that in the opinion of National Council are unlikely to be recovered.

8. BEQUESTS

A bequest was received from the Estate of Verona McGregor during 2004 for an amount of \$55,000. The amount has been invested until a suitable purpose that fits with the donor stipulation has been identified.

HFNZ Auditors Report



Audit report

To the members of the Haemophilia Foundation of New Zealand

We have audited the financial statements on pages 19 to 20. The financial statements provide information about the past financial performance of the Incorporated Society and its financial position as at 31 December 2009. This information is stated in accordance with the accounting policies set out on page 21.

National Council responsibilities

The National Council are responsible for the preparation of financial statements which give a true and fair view of the financial position of the Incorporated Society as at 31 December 2009 and the results of its operations for the year ended on that date.

Auditors' responsibilities

It is our responsibility to express an independent opinion on the financial statements presented by the National Council and report our opinion to you.

Basis of opinion

An audit includes examining, on a test basis, evidence relevant to the amounts and disclosures in the financial statements. It also includes assessing:

- the significant estimates and judgements made by the National Council in the preparation of the financial statements;
- whether the accounting policies are appropriate to the Incorporated Society's circumstances, consistently applied and adequately disclosed.

We conducted our audit in accordance with New Zealand Auditing Standards except that our work was limited as explained below. We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to obtain reasonable assurance that the financial statements are free from material misstatements, whether caused by fraud or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

Other than in our capacity as auditors we have no relationship with or interests in the Haemophilia Foundation of New Zealand.

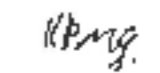
Qualified Opinion

The Haemophilia Foundation of New Zealand recorded revenue includes fundraising support programs revenue of \$420,913 (2008: \$456,706). Control over revenues from donations and grants prior to being recorded is limited, and there are no practical audit procedures to determine the effect of this limited control. In this respect alone, we have not obtained all the information and explanations that we have required.

In our opinion:

- Except for adjustments that might have been found to be necessary had we been able to obtain sufficient evidence concerning donations and grants, the financial statements on pages 19 to 20 give a true and fair view of the Haemophilia Foundation of New Zealand's operations for the year ended 31 December 2009;
- The financial statements on pages 19 to 20 - comply with New Zealand generally accepted accounting practice; give a true and fair view of the financial position of the Haemophilia Foundation of New Zealand as at 31 December 2009.

Our audit was completed on 3 March 2010 and our qualified opinion is expressed as at that date.


Christchurch

Treasurer's Report

HFNZ has a balance date for annual accounts of 31 December.
The following notes are included in the 2009 acknowledgements.

Income and Expenditure

There was an increase in income compared to previous years. This can be attributed to a very successful year of fundraising by Kiwifirst. The Kiwifirst revenue less campaign and printing costs is \$334,604 compared to \$270,528 last year so a 24% increase. This is a great result given the tough economic climate during the year, which also meant that we had 25% drop in investment income.

Expenditure is down on 2008 because that year included the 50th anniversary celebrations.

We have made a surplus of \$40,684 for the year ended 31 December 2009. The National Council is focused on building a sustainable future for the Foundation and running accounting surpluses helps to achieve this aim.

Special note

On 31/12/06 it was disclosed that HFNZ would adopt the International Financial Reporting Standards (IFRS). Since that time government legislation has changed for smaller entities and there is currently no requirement for HFNZ to comply with IFRS. HFNZ will continue to monitor this.

Summarised income & expenditure

The following outlines a detailed list of income and expense for 2009: →



TOTAL INCOME - \$1,459,563

Kiwifirst Revenue	\$1,003,814.00					
Funds Raised for Camps/Workshops	\$68,316.00					
District Health Boards	\$67,000.00					
Ministry of Health - support PWH & HCV	\$60,000.00					
Sustaining Patrons	\$49,975.00					
Funds Raised for Clinical Meeting	\$35,000.00					
Interest Received	\$34,836.00					
Funds Raised for World Interactions / Conferences	\$32,990.00					
Grants for Outreach	\$32,700.00					
Grants & Lotteries	\$25,000.00					
General Donations	\$20,582.00					
Funds Raised Research Programme	\$9,133.00					
Funds Raised Staff Training	\$8,000.00					
Other Income	\$4,451.00					
Subscriptions	\$4,369.00					
Southern Branch	\$1,240.00	\$200,000				
Central Branch	\$1,130.00		\$400,000			
Northern Branch	\$557.00			\$600,000		
Midland Branch	\$470.00				\$800,000	
						\$1,000,000
						\$1,200,000

TOTAL EXPENDITURE - \$1,412,407

Kiwifirst Fundraising Costs	\$357,358.00				
Kiwifirst Educational & Promotional Costs	\$311,852.00				
Wages	\$288,835.00				
Camp/Workshop Expenses	\$73,003.00				
Rent and Office Costs	\$64,801.00				
Conferences/World Interactions	\$57,558.00				
Meeting Expenses	\$42,004.00				
Clinical Meeting	\$34,810.00				
HR - Outreach	\$27,193.00				
Newsletter/Brochures	\$14,242.00				
Staff Training	\$13,880.00				
Haemophilia in Maori	\$13,756.00				
Swimming Programme	\$13,117.00				
Southern Expenses	\$12,906.00				
Outreach Regional Visits	\$12,239.00				
Outreach Support to Individuals	\$11,299.00				
Northern Expenses	\$10,848.00				
Central Expenses	\$9,921.00				
Midland Expenses	\$9,049.00				
Audit Fees	\$6,160.00				
Other National Council Costs	\$5,558.00				
Research Programme	\$5,011.00				
Other Information Costs	\$4,204.00				
Footwear	\$3,963.00				
ACC	\$3,474.00				
Other Administration Costs	\$2,993.00				
Kiwisaver	\$1,095.00				
Other Outreach Costs	\$670.00				
Bank Charges	\$608.00				
		\$100,000			
			\$200,000		
				\$300,000	
					\$400,000

The following breaks down the Income and Expenditure for 2009 as shown in the previous graphs in more detail.

Details of 2009 HFNZ Income

KiwFirst Income	Camps/ Workshops
Public donations	AXA Hearts in Action Bayer Baxter
District Health Boards	Ministry of Health
For Outreach	Support of Health for People with haemophilia & Hepatitis C
Sustaining Patrons	Clinical Meeting
Baxter Bayer CSL Novo Nordisk Wyeth	Baxter
Interest	World Interactions
Westpac Trust Taranki Savings Bank Southland Building Society	Baxter Bayer Global Feast Novo Nordisk Wyeth
Outreach	Lotteries & Grants Scheme
Canterbury Community Trust COGS Wellington COGS Banks Peninsula COGS Hamilton Novo Nordisk (Inhibitor Summit Attendance)	Lotteries Commission
General Donations	Research Programme
General Donations General Bequests KJ O'Sullivan Charitable Trust SBS Marathon	Acorn Charitable Trust
Staff Training	Other
Wyeth	Eureka Trust Book Sales (Still Standing) CEO Honorarium Eureka Trust (Bloodline)
Subscriptions	Southern Branch
HFNZ Members	Registration Fees for Southern Camp
Central Branch	Northern Branch
Registration Fees for Central Camp Bequest for benefit of Central	Registration Fees for Northern Camp
Midland Branch	
Registration Fees for Midland Camp	

Details of 2009 HFNZ Expenditure

KiwiFirst Fundraising costs	KiwiFirst Educational & Promotional costs
Wages Chief Executive Officer Manager Outreach Services National Information Coordinator Administrator Northern Outreach Midland Outreach Central Outreach Southern Outreach	Camps/ Workshops Youth/ Pre teen Camp Women's Weekend Parents Empowering Parents (PEP) National Children's Workshops
Rent & Office Costs National Office Outreach Offices Phones/Post/Stationary HFNZ Database Website Maintenance	World Interactions/Conferences WFH Safety & Supply Conference Global Alliance Programme Contribution Australia & NZ Haemophilia Conference Australian HCV Conference Volunteering NZ Conference World Haemophilia Day
Meeting Expenses Admin Staff meetings Annual General Meeting National Council Meetings National Haemophilia Management Group	Clinical Meeting Education day for clinicians and other haemophilia health care workers
Human Resources - Outreach Interviews Mediation Supervision Travel & Accommodation	Newsletters/ Brochures Bloodline magazines x 4 Information Posters Leaflets
Staff Training Outreach Administration staff	Haemophilia in Maori Hui x 2
Swimming Programme Swimming/ exercise programme	Southern Branch Expenses Education Family Camps Education Day Events Appreciations Newsletters/Stationary/Administration
Outreach Regional Visits Southern x 3 Central x 5 Midland x 4	Outreach Support to Individuals Financial assistance Needs Grants

Details of 2009 HFNZ Expenditure

Northern Branch Expenses Education Family Camps Education Day Events Appreciations Newsletters/Stationary/Administration	Midland Branch Expenses Education Family Camps Education Day Events Appreciations Newsletters/Stationary/Administration
Central Branch Expenses Education Family Camps Education Day Events Appreciations Newsletters/Stationary/Administration	Other National Council Professional Fee-Accounting Professional Fee -Legal Appreciations Seminars President Travel Volunteering Programme
Audit Audit costs (HFNZ & ACEET)	Other Information Hepatitis C Resources vCJD vWD & Women's issues Subscriptions
Research Needs Assessment Survey	ACC Levies for staff (8)
Footwear Programme Protective Footwear	Kiwi Saver Employer contribution
Administration Staff Amenities Professional Fees MYOB Advertising Training/Workshop's/Seminar/Human Staff Travel & Accommodation	Bank Charges
Other Outreach Costs Hepatitis C	

Full Financial Statements including the Auditor's Report can be found on pages 19 to 22.



Phillip Cowley
HFNZ Treasurer 2009

Allan Coster Education Endowment Trust (ACEET)

This has been a quiet but steady year with 5 new grants awarded. Finances are in a reasonable state.

Applicants 2009

There were 6 applicants 5 of whom were successful. All were male. Three were for tertiary studies (business studies (2), retraining in visual arts) and 2 were for primary pupils (tutoring). Candidates came from both town and country. The unsuccessful tertiary applicant did not provide the additional information requested.

Finances

The main source of income was from interest of \$7,288, the lower figure reflecting the fall in interest rates. No additional funds were received from HFNZ.

Fortunately, two former ACEET grant recipients made a very generous donations totalling \$3000 for which we are most grateful.

The Principal of \$155,000 continues to be on a revolving term deposit. The accumulated funds stand at \$167,146.

Funds available for distribution to candidates in 2010 are approximately \$8,500.

General

The trustees had one face to face meeting in June 2009 and have otherwise communicated by email and telephone. Discussion centred mainly around the importance of adequate documentation of the proposed course of study and expected qualification, whether any other avenues for funding have been explored, the necessity for applications to be on time, how payments are to be made and the need for 'cover' for Haemophilia Outreach Workers (HOW) who are away. HOW have always played an essential role in helping with application preparation and follow up of grant recipients and there have been some hiccups associated with the change in structure of the HOW group. A more formal manual about ACEET is in preparation and hopefully these problems will soon resolve.

Several feedback letters have been received and are much appreciated.

A major event this year was the resignation of Peta Hardley as Trustee. Peta has made a major contribution to the smooth running of ACEET with her prompt, pertinent, thoughtful and often proactive comments and suggestions. We are most grateful for her input. Thank you Peta. A new trustee has been appointed, Mike Mapperson, who, as a former President of HFNZ has a wealth of experience and knowledge. We are very pleased to welcome Mike.



ACEET Financial Statements

Statement of Financial Performance For the Year ended 31st December 2009

	2009 \$	2008 \$
REVENUE		
Interest	7,294	12,623
General Donations	3,000	1,000
TOTAL REVENUE	10,294	13,623
EXPENSES		
Bank Charges & Interest	35	15
Grants	5,175	7,680
General Expenses	458	28
TOTAL EXPENSES	5,668	7,723
NET SURPLUS/(DEFICIT)	\$4,626	\$5,900

NOTE: This Statement is to be read in conjunction with the Notes to the Financial Statements.

Statement of Movements in Accumulated Funds For the Year ended 31st December 2009

	2009 \$	2008 \$
Balance at Beginning of Year	162,520	156,620
SURPLUS		
Net Surplus/(Deficit)	4,626	5,900
Total recognised revenues & expenses	4,626	5,900
BALANCE AT END OF YEAR	\$167,146	\$162,520

NOTE: This Statement is to be read in conjunction with the Notes to the Financial Statements.

Statement of Financial Position
For the Year ended 31st December 2009

	\$ 2009	\$ 2008
CURRENT ASSETS		
ASB Cheque A/C	3,319	802
ASB Short Term Deposits	163,714	162,417
Interest Receivable	1,762	801
Total Current Assets	168,795	164,020
TOTAL ASSETS	168,795	164,020
CURRENT LIABILITIES		
Accounts Payable	1,649	1,500
Total Liabilities	1,649	1,500
NET ASSETS	\$167,146	\$162,520
Represented by:		
ACCUMULATED FUNDS		
Accumulated Funds	167,146	162,520
TOTAL ACCUMULATED FUNDS	\$167,146	\$162,520

NOTE: This Statement is to be read in conjunction with the Notes to the Financial Statements.

Notes to the Financial Statements - For the Year ended 31st December 2009

1. STATEMENT OF ACCOUNTING POLICIES

The Allan Coster Education Endowment Trust is a Trust. These Financial Statements are general purpose financial statements and have been prepared in accordance with New Zealand generally accepted accounting practices.

The accounting principles recognised as appropriate for the measurement and reporting of earnings and financial position on an historical cost basis have been used, with the exception of certain items for which specific accounting policies have been identified. The Trust has elected to delay the mandatory adoption of New Zealand equivalents to International Financial Reporting Standards as allowed by the New Zealand Preface. The Trust qualifies to make this election as it is not subject to the Financial Reporting Act 1993, and is not publicly accountable and not large as defined in the Framework for Differential Reporting.

(a) Changes in Accounting Policies

There have been no changes in accounting policies. All policies have been applied on bases consistent with those used in previous years.

(b) Differential Reporting

The Allan Coster Education Endowment Trust is a qualifying entity in that it qualifies for Differential

Reporting as it is not publicly accountable and it is not large as defined under the Framework for differential reporting.

All differential reporting exemptions have been applied.

(c) Goods & Services Tax

These financial statements have been prepared inclusive of GST as The Allan Coster Education Endowment Trust is not registered for GST.

2. AUDIT

There are no audit fees disclosed in the Statement of Financial Performance. The audit costs are invoiced to and paid for by The Haemophilia Foundation of New Zealand Inc.

3. CONTINGENT LIABILITIES

At balance date no conditional grants have been approved for payment by the Board of Trustees, for which the terms and conditions for payment had not been met. There are no other known contingent liabilities at balance date. (2008:\$Nil)

4. SECURITIES AND GUARANTEES

There was no overdraft as at balance date nor was any facility arranged.



ACEET Auditors Report

Audit report

To the readers of the financial statements of the Allan Coster Education Endowment Trust

We have audited the financial statements on pages 29 to 30. The financial statements provide information about the past financial performance of the Trust and its financial position as at 31 December 2009. This information is stated in accordance with the accounting policies set out on page 30.

Trustees Responsibilities

The Trustees are responsible for the preparation of financial statements which give a true and fair view of the financial position of the Trust as at 31 December 2009 and the results of its operations for the year ended on that date.

Auditors' responsibilities

It is our responsibility to express an independent opinion on the financial statements presented by the Trustees and report our opinion to you.

Basis of opinion

An audit includes examining, on a test basis, evidence relevant to the amounts and disclosures in the financial statements. It also includes assessing:

- The significant estimates and judgements made by the Trustees in the preparation of the financial statements;
- Whether the accounting policies are appropriate to the Trust's circumstances, consistently applied and adequately disclosed.

We conducted our audit in accordance with New Zealand Auditing Standards. We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to obtain reasonable assurance that the financial statements are free from material misstatements, whether caused by fraud or error. In forming our opinion, we also evaluated the overall adequacy of the presentation of information in the financial statements.

Other than in our capacity as auditors we have no relationship or interests in the Trust.

Unqualified Opinion

We have obtained all the information and explanations we have required.

In our opinion the financial statements on pages 29 to 30:

- comply with New Zealand generally accepted accounting practice;
- give a true and fair view of the financial position of the Trust as at 31 December 2009 and the results of its operations for the year ended on that date.

Our audit was completed on 3 March 2010 and our unqualified opinion is expressed as at that date.

Christchurch

Bleeding Disorders

As there is no cure, HFNZ is dedicated to improving the lives of people with haemophilia and related bleeding disorders. Here are descriptions of a few of the most common of these relatively rare disorders.

Haemophilia A

Caused by a deficiency of a protein known as factor VIII, which circulates in the body and helps the blood to form a clot. This is the most common form of haemophilia in the world, accounting for about 80 per cent of cases. Although it is hereditary, about a third of children born with haemophilia have no family history. As the gene responsible is on the X chromosome, mainly males have haemophilia A. Women with low levels of factor VIII do however often suffer many of the symptoms of haemophilia, which include frequent bruising and internal bleeding, especially into the joints. The long term affects of bleeding into joints are similar to arthritis and can cause disability. Severe bleeds, especially into vital organs or the brain, can be fatal. Bleeding in people with haemophilia A can be treated by infusing the missing factor VIII back into the blood.

Haemophilia B

Caused by a deficiency of a protein known as factor IX, which circulates in the body and helps the blood to form a clot. Also known as Christmas Disease, this is rarer type of haemophilia and accounts for only about 15 per cent of cases. It is hereditary, and as the gene responsible is on the X chromosome mainly males have haemophilia B. Women with low levels of factor VIII do however often suffer many of the symptoms, which are outwardly identical to those of haemophilia A. Bleeding in people with haemophilia B can be treated by infusing the missing factor IX back into the blood.

von Willebrand's Disorder (vWD)

Caused by a deficiency in another clotting protein, known as von Willebrand's factor, vWD is said to be the most common bleeding disorder in the world. In most people it is so mild they are not aware they have a bleeding disorder until they undergo surgery or suffer an accident. When the deficiency is severe, the symptoms can be similar to that of haemophilia but are characterized more by bleeding into muscles than joints. vWD is also hereditary but affects males and females equally. Bleeding in people with vWD can be treated with a few different medications to help their blood to clot normally depending on the type of vWD, however there is no cure.

Life Members

Life member	Region	Year of Award	Passed Away
Miss Gray	Wellington	1972	1977
Mr William [Billy] R Stolz	Wellington	1974	---
Margaret Roberts	Wellington	1976	1986
William [Bill] K Carnahan	Nelson	1983	1989
John Davy	Auckland	1988	2005
Tony Goodwin	Auckland	1988	
John Milne	Auckland	1988	2004
Dr Elizabeth Berry	Auckland	1993	
Sir John Staveley	Auckland	1993	2006
Alex Cain	Auckland	1994	1999
Graeme Kinred	Auckland	1994	1992
Pat Sheary	Auckland	1994	2005
Mike Mapperson	Auckland	1997	
Jock Church	Auckland	1997	1997
Stephanie Forde	Auckland	1998	
Lyn Steele	Christchurch	1999	
Tony Steele	Christchurch	1999	2010
Peta Hardley	Auckland	2000	
Barbara Sutherland	Wellington	2005	
Michael Carnahan	Nelson	2007	
Cheryl Carnahan	Nelson	2007	
Rex Temperton	Wellington	2007	
Steve Waring	Wellington	2007	
Anne Waring	Wellington	2008	
Graham Waring	Wellington	2008	
Mary Hancock	Auckland	2008	
Carl McKay	Christchurch	2009	

Jeff Oliver Photo - Whangarei 21218

HFNZ Directory

National Council 2009

President:	Deon York
Vice Presidents:	David Habershon Grant Hook Philip Cowley
Treasurer:	Frances Thomas
Northern Branch Delegate:	Catriona Gordon
Midland Branch Delegate:	Michael Ho
Central Branch Delegate:	Mark Uren
Southern Branch Delegate:	Karl Archibald
Youth Delegate:	

Branches 2009

Northern Branch Chair:	Richard Scott
Midland Branch Chair:	Lee Marjoribanks
Central Branch Chair:	Judith Dudson
Southern Branch Chair:	Theresa Stevens

Staff

National Office

Physical Address:
4 Washington Way, Sydenham, Christchurch

Mailing Address:
PO Box 7647, Sydenham, Christchurch 8240

Ph: (03) 377 7477
Fax: (03) 377 7479
Email: info@haemophilia.org.nz

Chief Executive Officer:

Belinda Burnett
Ph: (03) 377 7477
Fax: (03) 377 7479
Email: belinda@haemophilia.org.nz

Administrator:

Leanne Pearce
Ph: (03) 377 7477
Fax: (03) 377 7479
Email: leanne@haemophilia.org.nz

National Information Coordinator

Chantal Lauzon
Ph: (03) 377 7477
Fax: (03) 377 7479
Email: chantal@haemophilia.org.nz

Haemophilia Outreach Workers (HOW) Manager Outreach Services

Colleen McKay
PO Box 7647, Sydenham, Christchurch 8240
Ph: (03) 377 7477
Fax: (03) 377 7479
Email: colleen@haemophilia.org.nz

Regional Outreach Workers

Free Phone : 0508 FACTOR

Nominated Service Providers

Solicitor

Catriona Gordon
Olphert Sandford
Box 99, Rotorua
Admin@olphertsandford.co.nz

Auditor

KPMG
34-36 Cranmer Square
Christchurch
Ph: (03) 363 5764
Fax: (03) 363 3765

Banker

Westpac
Manukau City, Auckland

Accountant

Phillip Cowley
Anglican Aged Care Finance
PO Box 25315
Victoria Street
Christchurch

HFNZ Memberships

World Federation of Hemophilia
1425 René-Lévesque Blvd. West
Suite 1010
Montreal, Québec H3G 1T7
Canada
www.wfh.org



PO Box 7647, Sydenham
Christchurch
New Zealand

Phone: +64 (03) 371 7477
Fax: +64 (03) 371 7479

Email: info@haemophilia.org.nz
Web: www.haemophilia.org.nz