



ANNUAL  
REPORT  
**08**



**Our Mission:**  
To Promote Excellence in Care, Education, Advocacy, and Support.

2008 marked the 50th Anniversary of the Haemophilia Foundation of New Zealand (HFNZ). The occasion provided an excellent opportunity to look back on how far we've come and set some direction for the future.

**A**s might be expected, HFNZ's story begins with one family seeking further education and information about the unpredictable bleeding disorder that affected their two sons. Over the following years, a spirited, resolved and talented group of people came together as a haemophilia organisation to try to improve their lives, those of their families and the children with bleeding disorders yet to come.

Despite dramatic changes experienced over the last 50 years, the New Zealand haemophilia community is still standing due to the passion we have for our community and for life, because we all know first-hand that what can first appear as a tragedy can be a triumph. We have gained much of our strength from the challenges of the past and we are in a strong position to move forward. Underpinning the strength of the Foundation has always been the strength of the volunteers within our community. There is not a thank you too large to pay the figures of our past.

Haemophilia and other related bleeding disorders still provide many hurdles to daily life. 2008 was also a year where HFNZ set some clear goals for the immediate future for how we can better serve the needs of our community. 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 that medicine can offer.

We are proud to have achieved many successes on these fronts over the last half century. To continue to reach toward our goals we rely largely on public donation. Although, it is our ultimate wish that one day there will no longer be a need for the Foundation as a cure will have been found for haemophilia and related bleeding disorders, with the incredible generosity of the NZ public and the amazing support HFNZ receives from our Sustaining Patrons and Corporate Donors we look forward to many more success stories in our future.

*HFNZ has fought countless battles in its lengthy history and as the organisation celebrates its 50th birthday we are able to focus on education and empowerment of members. Everything that is done for people with haemophilia in New Zealand today is thanks to the people who came before, and the HFNZ is what it is today – an independent, self-sustaining organisation – because of the tireless work and dedication of the many, many volunteers and staff who preceded us.*

Belinda Burnett, HFNZ CEO



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# Highlights of 2008

2008 was a very special year for HFNZ as we celebrated our 50th anniversary.



**January**  
Newly Diagnosed Family Camp



**January**  
National Couples weekend



**April**  
World Haemophilia Day



**June**  
Attendance at the WFH Hemophilia World Congress



**October**  
Children's Education Days

I'd just like to express my thanks to the Haemophilia Foundation for giving us the opportunity to meet other families and share experiences with people who understand what we face day-to-day with our son. I think I learnt as much from talking to other Mums and Dads as I did from the medical experts, both of whom I consider invaluable fountains of knowledge.



**February**  
Mother and Daughter Weekend



**August**  
Relocation of HFNZ National Office in Christchurch



**December**  
National Men's Weekend



**March**  
Annual General Meeting



**March**  
50th Anniversary Celebration dinner



**November** - Book launch for *Still Standing: The Haemophilia Foundation of New Zealand 1958-2008*



**December**  
Parents Empowering Parents programme

# President's Report



2008 will be remembered as a year of both celebration and consolidation for HFNZ. This year marked the 50th celebrations of the Foundation. On both a national and a regional basis, our community explored the many pasts of this organisation and how they have shaped and consolidated where we now stand. Taking a moment to reflect on our history gives the Foundation a strong position moving forward.

Celebration was an important focus of this year; this was balanced with a range of programmes being offered to our community and a more outward looking organisation.

This report covers the period January – December 2008.

## > Membership in 2008

In 2008, HFNZ's membership increased by 200 to 893 members (individual, family, friend or corporate). While there has been a "boom" of bleeding disorder births in the past year, the particularly marked increase in membership can be attributed to the number that have now officially registered with the Foundation as members and improved record keeping.

Fig 1: Proportion of membership by bleeding disorder.

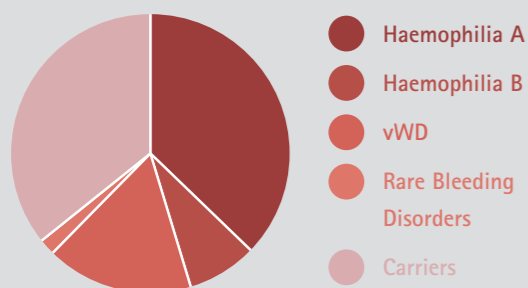
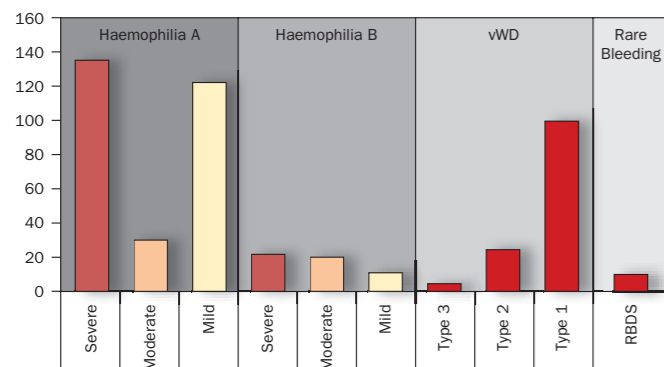


Fig 2: Representation by severity.



## > National Council

HFNZ's National Council met five times in 2008. Members serving the council were Catriona Gordon, David Habershon, Michael Ho, Grant Hook, Mark Uren, T.A. Stirling and Frances Thomas. Steve Waring of KiwiFirst was seconded to National Council and Belinda Burnett was invited to attend meetings as a staff representative and non-voting member.

The council continue to serve HFNZ as the governing body of this organisation. 2008 was the first complete year of the Foundation operating under a centralised finance system and re-visiting the Decade Plan to add other goals of long-term strategic importance. These include:

1. Continuing to build a committed volunteer base.
2. Continuing to work towards a sustainable long-term financial plan.
3. Constantly evaluating if and how services are meeting member's needs.
4. Establishing joint planning with NHMG, and
5. Increasing our commitment to the global haemophilia community.

I extend my gratitude to the National Council for their support in 2008.

## > Funding

Baxter, Bayer, CSL and Wyeth continued as our sustaining patrons. Novo Nordisk was also welcomed as a sustaining patron of HFNZ. KiwiFirst remains the chief fundraiser of HFNZ. HFNZ acknowledges the valuable contribution that these organisations make to the Foundation. Without this support, HFNZ would not be able to provide its many services and programmes to members.

Late in 2008, HFNZ progressed with the **treatment** aspect of the *HCV Treatment and Welfare Package*. An agreement has been signed with the Ministry of Health to increase outreach services and support. This is a great achievement for the Foundation. Mike Carnahan and Steve Waring have been instrumental in achieving this outcome.



HFNZ wishes to acknowledge the individual bequests and donations made by the community and the grants received from other charitable trusts. Details of these contributions can be found in the financial report.

## > 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.

A range of targeted educational events occurred in 2008. These events are wholly implemented by our dedicated team of outreach workers Colleen McKay, Drew McKenzie and Helen Spencer.

### • Newly Diagnosed Family Camp

In January, HFNZ held a newly diagnosed family camp at Blue Skies, Kaiapoi, near Christchurch. 32 families attended with a total of 39 children. The four day camp provided the opportunity to share experiences with other families and learn from each other about living with a bleeding disorder. The emphasis on these camps is always a balance of education and socialising.

*We did all really enjoy the camp. It was very well organised and everyone was very friendly, a good chance to mix and mingle. A great range of activities and topics to participate in. I think these camps are excellent and much needed. We really appreciate all the work that goes into organising such an event. Well Done - Karen McCone.*

*As a parent new to haemophilia the Blue Sky's camp offered an outstanding learning experience for both my wife and I. Not only did we learn a lot from the workshops but having the opportunity to network with other parents that have been through what we are about to go through and debate/share experiences around difficult decision areas such as ports, prophylaxis etc was invaluable. - Greg Jamieson*

### • National Couple's Weekend

For the first time, HFNZ produced a programme addressing the specific nature of a relationship with haemophilia. Also held in January, 14 couples attended aged 25 years and over.

It was decided that a weekend for couples needed to be implemented following recommendations from participants at the first Men's Weekend in 2006. Participants from that weekend felt that it would be a great opportunity to bring their partners to a forum where they could be included and become more informed. >>>



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*I won't go into detail about the various subjects, speakers, etc. but will say that most relevant subjects were discussed, some taboos were broken, and some really good information exchanged. For me the weekend was about being able to talk about our common problems freely and frankly with people willing to bare all in the groups and combined sessions. The new friendships, renewal of old ones, discussion with young men and women, old men and women, experts and experienced people all coming together made for a great weekend.*

- Russell Church

#### • Mother and Daughter's Weekend

In February, a group of 20 women affected by bleeding disorders travelled to the Waihonga Centre for this event to learn about bleeding disorders and reproductive options. Participants reported a memorable weekend once they found the venue.

The weekend was a follow-up to the very successful 2005 Young Women's Weekend. As bleeding disorders are hereditary and often affect generations in different ways, the weekend was opened up to young women who either affected by haemophilia or von Willebrand's disorder or carry the haemophilia gene and their mothers. It was a quiet weekend of learning, relaxing and sharing experiences in the picturesque setting of the Otaki Gorge. Some of the session dealt with some of the emotional and difficult issues of living with a bleeding disorder or raising a child with one. It was clear that real strength is gained from the experience.

*Thank you to all those that attended the weekend. I certainly learned a lot from you and appreciated your willingness to participate, share and lend a hand where needed.*

#### • Parents Empowering Parents (PEP) Programme

In December the US-based PEP programme was held in New Zealand for the first time. A team approach to teaching was taken with a haemophilia Outreach Worker, haemophilia nurse, and trained parents presenting 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.

*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!*

#### • National Men's Weekend

The National Men's Weekend held in 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. The first weekend generated a number of successful initiatives such as the National Couple's Weekend and regular Men's evening in the Central region. The programme for this 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, the 22 participants were also introduced to a new topics such as nutrition, chronic pain, and a facilitated group discussion session.

*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.*

#### > HFNZ celebrates 50 years

Undoubtedly, the emphasis of 2008 was celebration. HFNZ marked its 50 year throughout the year. In particular, the 2008 Annual General Meeting (AGM) was like no other. Held in Christchurch, the location of our national office, nearly 200 guests instrumental in helping the Foundation achieve this milestone attended an evening of celebration, nostalgia and community.

We were privileged to have in attendance representatives from WFH, HFA and government. We welcomed Dr Paul Giangrande, Consultant haematologist and Director of the Oxford Haemophilia Centre in the United Kingdom, honorary senior lecturer in haematology at the University of Oxford and Vice-President Medical of the World Federation of Haemophilia. We welcomed Brian O'Mahony Past President of the WFH, CEO of Irish Haemophilia Society, Rob Christie, Vice President Finance for WFH and Robert Leung, Regional Program Manager for Asia and the Western Pacific, WFH. My counterpart from Australia, Gavin Finkelstein, President of Haemophilia Foundation Australia was also in attendance. The honourable Ruth Dyson was another fitting guest for this event as she held the portfolio of Minister for Disability Issues and the Community and Voluntary sector.

More importantly, a sizeable number of HFNZ members were in attendance. This event marked a reunion of a nationwide community.



During the dinner awards were presented to our newest Life Members, and to the Goodwin Family **Volunteer of the Year**. Jack Finn, our young adventurer, was nominated for the Volunteer of the Year award in recognition of his amazing efforts to circumnavigate the Auckland Islands by kayak in 2007, all the while raising awareness of haemophilia and providing inspiration to the youth of New Zealand with bleeding disorders. Special recognition was also given to several key figures that played a significant part in helping HFNZ reach an agreement with the New Zealand Government regarding a Treatment & Welfare package for people infected with hepatitis C through tainted blood products after 14 years of campaigning.

#### • Documenting our history: *Still Standing: Haemophilia Foundation of New Zealand 1958-2008*

Chantal Lauzon, our National Information Coordinator, had the momentous task of documenting our history and producing a book. Our history is now documented and available to all members for a nominal cost of \$10.

*The struggle for survival brought on by the consequences of haemophilia pushed a group of people into action to try and improve the lives of children born with this rare bleeding disorder. The past fifty years have brought many tears but also opportunities for incredible achievements. The story of the Haemophilia Foundation of New Zealand and its people is an example of individuals coming together and turning what could be viewed as a tragedy into a success - back cover, Still Standing*

#### > HFNZ welcomes new Patron

In 2008 we welcomed Dr Elizabeth Berry as our new patron.

Dr Berry formerly held positions as a Pathologist at Auckland City Hospital and as a Haematologist at Auckland's Haemophilia Centre, which she established in 1974. From 1988 to 1992, Dr Berry chaired the Medical Advisory Board of the World Federation of Hemophilia and has been a member on the Editorial Boards of *Haemophilia* and *Haemophilia Forum*. She is a graduate of the University of Otago School of Medicine and a Fellow of the Royal College of Pathologists of Australasia and of the Royal Australasian College of Physicians. Dr Berry was one of only a few women studying medicine at that time at Otago. She was also awarded a Queen's Service Order for public service in 1988.

Now officially retired from Auckland Hospital, Dr Berry continues to serve as a Trustee of the Allan Coster Educational Endowment Trust. An avid trumper and art critic, she now has a rather international flavour to her life, often visiting her siblings overseas.

Dr Berry's many professional achievements and her in-depth knowledge of the world of haemophilia made her the obvious choice for patron. These attributes, in isolation, more than fulfilled the criteria. What is equally important is the esteem that Dr Berry is held in by the medical and haemophilia patient community alike. She is admired and respected by the whole haemophilia community. Dr Berry has always fought hard for the haemophilia cause and continues to care greatly for her former patients (whom she affectionately refers to as 'her boys') and all people with haemophilia. Dr Berry has a long association with



the Foundation. She played an active role on the Committee of the then New Zealand Haemophilia Society for 16 years. In 1989 she took on the new role of Medical Advisor when her international commitments made it difficult for her to attend the monthly Committee meetings. From 1976 until the early 2000s, Dr Berry attended nearly every single haemophilia camp the NZHS/HFNZ organised, often living in and helping out wherever she was needed. She even hosted meetings for mothers with young children with haemophilia in her home. This meant that haemophilia families had the unique opportunity for personal contact with their doctor outside a hospital setting and the chance to form a truly special relationship.

#### > Other representation

##### • NHMG

The National Haemophilia Management Group maintains an important relationship with HFNZ. David Habershon continued as HFNZ's representative on this group.

##### • WFH

Following congress attendance, I was invited on the WFH Fund and Resource Development Committee and the NMO Training Committee. The term is two years.

##### • NZBS donor deferral criteria

During the year the NZ Blood Service convened a working party which included HFNZ views, to examine current issues arising from the donor deferral criteria. The focus was on ensuring the safety of the NZ blood supply. The primary issues resulting in proposed policy changes were about men who have sex with men.

#### > Conference attendance

##### • World Congress

The XXVIII International Congress of the WFH was held in Istanbul from 1 – 5 June attracting 4200 participants from 115 countries. HFNZ had 10 representatives and had a modest but

effective display in the conference hall that generated lots of interest in the activities of the New Zealand bleeding disorders community. CEO Belinda Burnett was honoured to be asked to speak on women and bleeding disorders during the Congress.

##### • Global NMO training

The World Federation of Hemophilia (WFH) runs a three-day training for National Member Organisations (NMOs). HFNZ is an NMO of WFH. There were approximately 100 participants. Workshops and plenaries were divided according to "emerging" and "established" NMOS. HFNZ participated in the established streams.

These streams focused on recruiting and retaining volunteers, planning programmes, ensuring adequate funding and caring for an aging population. Plenary sessions included managing pharmaceutical relations, patient representation on government committees and involvement in the wider healthcare system.

I ran a three hour workshop on demystifying medical research for patient organisations. WFH fully funded flights and accommodation for my attendance at NMO training.

#### > Affiliated programmes

##### • World Hemophilia Day

Every April 17th marks World Hemophilia Day. In 2008 HFNZ celebrated for the entire week. On 11 April the Midland branch held a café evening in Rotorua with a very large turnout. There they had the chance to welcome their new haematologist at Waikato Hospital, Dr Julie-Anne Bell, and also speak with their haematology nurse Robyn Segedin in a social setting.

The most exciting event by far took place on 16 April when Stace Hardley, who has severe haemophilia B, took a SkyWalk around the Sky Tower in Auckland to raise awareness of haemophilia and the advantages of good treatment like we have in New Zealand. Representation from Auckland Hospital, National Council and Stace's family as well as representatives from Bayer were in attendance. Whether a coincidence or the result of a request we can never be sure, but the SkyTower was bright red for the whole week.

On Saturday 19th April, a children's party was held in Christchurch to celebrate both World Haemophilia Day and HFNZ 50th birthday. There was cake, clowns and plenty of fun for all 60 kids, parents and grandparents present.

Haematology nurses Alison

Inder and Carolyn Lauren from Christchurch Hospital also came for the party.

On Sunday 20th April, the Northern and Midland branches held a joint event at the Mt Gabriel Corn Maze.

##### • Global Feast

Each region organised their own Global Feast celebrations to raise awareness and funds for people with haemophilia in the developing world. Events included movie nights, café evenings and a dinner at the Christchurch Town Hall.

##### • Advance your Passion

This Baxter-sponsored programme was run across Australasia. Phillip Warmerdam and Holden Stirling were recipients of this award of \$5,000 each. This award is used to advance an individual passion. You can find out more about their passions at [www.advanceyourpassion.com](http://www.advanceyourpassion.com)

##### • Pledge to GAP

As part of HFNZ's commitment to supporting the global haemophilia community, \$5,000 was pledged to WFH's Global Alliance for Progress (GAP) programme. These funds were only sourced from membership fees.

*WFH believes in HFNZ's work to improve the health and quality of life for people with bleeding disorders in New Zealand. You have proudly served the hemophilia community for the past fifty years. Your vision is parallel to our own vision of Treatment for All. We are proud to celebrate your success with you and encourage you to keep expanding your commitment to helping people with hemophilia abroad...Because of you, many lives will be saved next year. Through HFNZ's humanitarianism, you are helping WFH in its goal of Treatment for All. We are grateful to have you as part of our global caring community. – Claudia Black, CEO, WFH.*

Thank you to HFNZ staff and volunteers across the country and to our many supporters.

Underpinning the strength of the Foundation has always been the strength of the community and the strength of the volunteers within that community. They are drawn in by a desire to help others, because of a passion for a particular cause, or an interest in learning more. For the many motivations to get involved, a constant source of inspiration is the community itself.

In keeping with a report that marks the year HFNZ turned 50, you should all feel a sense of pride in being affiliated to HFNZ. There is a not a thank you too large to pay to the figures of our past that have made all of this possible for you today. As the Foundation always has, our members will all continue to challenge the boundaries, inspire us all and be the momentum that makes HFNZ the organisation that it is.

Deon York  
HFNZ President



# Patron's Message



*It was with great pleasure that I accepted the invitation of the Haemophilia Foundation of New Zealand (HFNZ) to become the Patron in 2008, a special year celebrating 50 years of support, encouragement and advocacy for the haemophilia community.*

Bleeding disorders are relatively rare and in 1958 a small group of parents and medical professionals in Wellington formed the original New Zealand Haemophilia Society to try and connect families with each other, to help younger members with their education and provide information about the latest treatments. In the intervening 50 years the Society, now the HFNZ, has grown to become a professionally run national organisation with 4 branches, a youth group and international affiliation. The objectives today are much the same with a focus on family support and education.

Advances in medicine and comprehensive care have meant that most people with haemophilia and related bleeding disorders now live 'normal' lives free of the crippling and pain of earlier times. However, it is still very frightening and stressful to have a newborn baby or young child with haemophilia and there is much to learn. Family camps, started in 1976, have been particularly successful in reducing feelings of isolation, giving education and confidence to parents and children and teaching skills such as self injection. More recently a range of workshops and camps for smaller specific groups such as new parents, teenagers, and women with bleeding problems have been much appreciated.

In addition, the Foundation supports an education trust and funds outreach workers, special needs grants, swimming and footwear programmes, advocacy and a newsletter. It has also been very active in raising their political voice to ensure that New Zealand has the best and safest factor concentrates and that

adequate compensation has been given to those with transfusion related infection such as hepatitis C and HIV.

These important milestones have been recorded in the excellent publication *Still Standing: HFNZ 1958-2008* which through personal stories and records paints a graphic picture of life with haemophilia in NZ from early days of minimal treatment to the joy and freedom of self treatment, through the devastation of viral infection, to today using safe products made by recombinant technology. It has been a roller coaster ride but courage, determination and enthusiasm shine through. I heartily recommend this book to anyone with an interest in bleeding disorders.

The HFNZ has achieved many successes over the last half century and I am proud to have been part of such a dynamic and progressive organisation for almost forty of those years. I congratulate and thank all those who have given financial support and continue to give so generously of their time and energy. The Foundation is doing a wonderful job for its members and I look forward to my ongoing involvement with HFNZ.

Dr Elizabeth Berry, QSO

# CEO Report



*2008 was a year filled with so many highlights it is difficult to choose which to feature in this annual report. The 50th celebration started with the Annual General Meeting and formal dinner in March and ended in November with the launch of the HFNZ book *Still Standing*. Both events were an honour to be part of and I shall treasure the memory of meeting so many members and putting faces to so many names that played a part in HFNZ's history.*

The year started with a milestone by receiving our official Charity registration number from the Charities Commission. Sadly, the year ended with Drew MacKenzie leaving her role as Haemophilia Outreach Worker for the Central region. Drew had worked for HFNZ for around three years and in that time had become a part of the lives of members and their families' lives in coping with their haemophilia and related bleeding disorders. Drew will be thoroughly missed, and we wish her well for her future.

In May, HFNZ staff, council and some ten invited members participated in a strategic planning meeting in Wellington. This extremely useful two-day workshop helped focus the attention of the Foundation and plan how we are to develop and improve our services to members. The continuation of the planned strategy will be carried out over the next few years. 2009 should see many of the changes that have come about through the strategic planning put into practice.

June saw nine representatives from HFNZ, staff and members, attend the World Federation of Haemophilia (WFH) Congress in Istanbul, Turkey. This was an informative and thought provoking conference that provided an important opportunity for people from around the globe dedicated to improving the lives of people with bleeding disorders able to come together. Deon York and I were honoured by being invited to speak at the Congress. Helen Spencer (Northern Outreach) and Colleen McKay (Southern Outreach) also presented posters at this prestigious event. As a result of the NZ input into the Istanbul meeting, NZ is now represented on several WFH committees.

of funding from the MOH which will allow us to work on many of the unfinished aspects to hepatitis C care for our members throughout the country.

The National Haemophilia Management Group (NMHG) continues to work alongside HFNZ in providing the best practise and product selection for all our members. HFNZ are proud to be a vital part of their collective group. While David Habershon (Vice-President) remains as the lead Safety and Supply Officer, Deon York (President) and I have participated in NHMG meetings throughout the year when David was unavailable.

2008 saw an increase in HFNZ fundraising by 40%. This was largely due to the 50th celebrations, and the generosity of our sustaining patrons.

Another significant event of the year was the relocation of the HFNZ National Office to a more central location in Christchurch. The Foundation has outgrown their previous offices, and the move to more professional and accessible premises means the Foundation can now better serve the membership and wider community.

I will conclude my report with a quote from Elbert Hubbard -

*"One machine can do the work of fifty ordinary men. No machine can do the work of one extraordinary man"*

I continue to be surrounded by extraordinary people from the President, through the council, staff and members. This is what continues to make working for HFNZ such a pleasure.

Belinda Burnett  
HFNZ Chief Executive Officer

After several years of working collaboratively with the Ministry of Health (MOH) regarding the issue people with haemophilia infected with hepatitis C, HFNZ finally reached an agreement that was finalised in December 2008. HFNZ now look forward to putting into action the increase



# Regional Branch Reports

HFNZ has four regional branches that provide a support network and social events for members and families in their area. It is thanks to the many volunteer hours on the part of the regional committees that HFNZ is able to organise many of the activities that help create the important bonds felt by those living with rare bleeding disorders across the country.

## Northern Branch

Another summer is here and another year passes by, we are all making the most of the great weather to enjoy the beach and other pastimes while the schools are on Holiday. By the time we all read this we report summer may have faded into the memory bank and it will all be a distant memory.

This is what has happened to 2008 where we have had some great fun, some memorable times and also we no doubt have had some sad times. What a great organisation we are part of and needless to say those of us who have had the privilege to read the book "Still Standing" written by Chantal Lauzon with the assistance of numerous others has recorded the history and memories of the Haemophilia Foundation over the past 50 years.

I would recommend this book to you all as compulsory reading so as to gain an insight in to what has happened in the past 50 Year. Reading through all the phases the Foundation has progressed through should make us all proud of the organisation of which we are part. Having been involved in the Foundation for a relatively short time, only approx 9 years, it has grown over this time and when we look back the life of a person with Haemophilia is considerably better now than 50 years ago.

Northern Region have during the year held a number of functions which have been well attended starting with our regular family camp which has been held for a number of years at the Waiwera YMCA campsite, which provide access to water, orienteering, kayaking and also the Waiwera Hot Pools.

The Northern AGM was held on the Sunday and a great committee was elected for the year.

From the perspective of the Northern Branch in 2008 we tried to expand our committee to include members from the far north and while we succeeded there were some difficulties in meeting regularly with these committee members. It has been worthwhile and has added some great input from the new committee members. This included the Pamper Day which proved a great success and was great to see the Aucklanders move from the comfort of their surroundings to go North. Men, is it about time to get a group together and go fishing or something similar?

The current committee has served the Northern region well and I would encourage anyone who is willing to join the committee and you may be able to bring something

new to support the work of the Foundation. The role of the committee has changed over the last few years and in particular the centralising of the finances to the National Office has reduced the role of the treasurer considerably.

I would encourage you all to be part of this excellent organisation and help it reach out to those who are newly diagnosed with a bleeding disorder. I see all of us having a part to play in HFNZ as it moves forward in the years to come. We all have something to offer whether it is on the committee or just being a voice on the end of the phone offering some advice to those who have not experienced the ups and downs of Haemophilia. Remember we were all in that position of not knowing what to expect next and through sharing that we learn.

Finally I am standing down as Chairman for 2009 due to work commitments. I have enjoyed being a part of the Northern Region committee over the past years and have been a very worthwhile experience.

*John Cook*  
Chairperson Northern Branch 2008

## Midland Branch

Midland had a busy year, starting with our branch Annual General Meeting at Papamoa, which was a substitute venue due to bad weather.

We were going to head to the Blo-karts at Papamoa, but more on that later.

Following that we have had café evenings in Rotorua, Hamilton and Tauranga which have all been well attended. We greatly appreciated our members' willingness to travel so that we can all be together. We also had a family day in Hamilton at the Waikato Museum where we enjoyed the fantastic exhibition of Antarctica memorabilia and information about that amazing continent.

In November we had our Christmas party at the Papamoa Blo-Karts. This time the weather was fantastic and everybody enjoyed a go at racing around the rack on these amazing little machines. We will definitely be returning!

We've had two very sad losses this year from our Branch. Christ White passed away in May but we are grateful that his lovely wife Linda will continue on with the Midland Branch. In December Jack Walmsley died and we will very much miss his



quirkiness and his passion for good outcomes for people with haemophilia.

In 2009, the Midland Branch will be holding their first ever branch family camp. We are all really looking forward to getting together, supporting each other and enjoying a few days together.

Thank you to all the committee and especially Lee Majoribanks who has achieved a lot in her first year as Chairperson.

*Catriona Gordon*  
Midland Delegate to the National Council

## Central Branch

2008 was another successful year for the Central region. We held a number of events:

Two café evenings in Wellington; three men's dinners at Paekakariki; our annual Family camp at Kennedy Park, Napier; a regional lunch in Levin and a farewell luncheon for Drew at the Clydesdale Café near Levin.

As the years progress, we are finding that we have a "core" of families that attend most of our functions and they are really getting to know one another, especially at the family camp. It is great to see the children grow up. By the way they enjoy themselves you would never know they had Haemophilia.

Unfortunately our chairperson Di Bell shifted to another region after putting in a lot of work organising our family camp. We also had a change of treasurer. Both positions were filled on a temporary basis until being elected into the positions at our AGM.

In December, we had a farewell luncheon for Drew, Central's Haemophilia Outreach Worker (HOW). This was the first time I have ever seen Drew lost for words. She was genuinely sad that she was leaving her position as our HOW, although I am sure that many of us will still keep in contact with her. We were also delightfully surprised to have Belinda with us, thank you Belinda for making your time available.

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.

In the upcoming year we are hoping to attract more Central region members to our ever successful functions. It is not only about what you get from attending it is also about what you contribute and the support you give to others in our community by swapping stories and your experiences.

A big thank you to the committee members who have willingly given up their time to make our many activities possible.

*Judith Dudson*  
Chairperson Central Branch

## Southern Branch

This year has been a year of excitement and change, but also one that has continued with huge volunteer involvement. I would like to say a huge thanks you to our endless volunteers who have helped a the Family Camp in 2008, the Southern

and National AGM's both held in Christchurch – our branch involvement was extensive with members driving vans to organizing the social day on Sunday. It was (as always) a wonderful opportunity to catch up on those from our Haemophilia past and to meet those who will become part of the HFNZ future. Our local volunteers also assisted when the national office shifted premises, and of course with the 50th anniversary of HFNZ celebrations. If I have missed something or more importantly someone please accept my apologies.

The 50th anniversary of HFNZ was well received and it was a special moment in time for those involved, remembering the folk who worked so hard before us and are no longer involved in our community. The celebrations were held in Christchurch with a celebratory meal and wonderful speakers.

National Council activities that included our branch members included the strategic planning day in early May 2008, a special breakfast meeting for chairpersons and delegates at which we discussed the expectations of our involvement. The book launch in Auckland during November was a fantastic event which



**Regional Branch Reports**

included pharmaceutical company representatives enjoying the history of our foundation.

World Haemophilia Day was celebrated with a children's party which was attended by several families in the Christchurch region. Thank you to Bayer for their generous sponsorship.

Karl Archibald continued with his work from the Step Up Reach Out Programme, organizing the youth event and the question and answer workshop for our Southern Camp. Well done Karl, it is indeed a privilege to have you as part of our committee.

The exercise competition continues and Southern is holding its own so to speak, however, if we can all do just a little more the results will be fantastic and may even lead to Southern bringing the trophy home! To be inspired take a leaf from Colleen's book and register for a half marathon.

The new office opened in August and this was attended well. A huge thanks to our Southern branch for not only sponsoring the food for this event but, for also assisting with the moving.

Meetings this past year were adhered to as per the constitution; it was pleasing to see the meetings so well attended despite the geography that accompanies the Southern region. The meeting dates were also used wisely to have camp planning meetings – although I do believe that our camp committee is so experienced we could organise a camp with little trouble.

Outreach worker Colleen continued her job with great enthusiasm and zest for life. We have had some wonderful social events with Colleen that included a visit to Cadbury World in Dunedin followed by a pizza lunch. Not sure if Colleen or Cadburys was the draw card as we had 36 folk from Otago and Southland attend in absolutely shocking weather conditions. Christchurch folk enjoyed a swim day, playgroup and a Christmas function at Laser Strike followed by a picnic tea with a clown entertaining the crowd. Nelson area folk enjoyed a get together at Founders Heritage Park. The 10 – 14 year olds had a great "Boys Day Out" and as a direct result of this Connor McCone started home infusion. Well done Connor! Global Feast was again held in the region with approximately \$400 being raised.

Lastly, I would like to take this opportunity to thank the office staffs who have organized flights and accommodation to enable those people travelling to get to the destination on time. Colleen, our fantastic outreach worker who continually "no matter what" advocates for us and our families. It is at this time we need to acknowledge the years that Colleen has dedicated to the HFNZ as our Southern Outreach worker, as she moves up the ladder within the foundation. Colleen you will be sorely missed as our outreach worker. Mark Uren our regional delegate who has kept us well informed on National Council matters. Thanks to Robyn for her efficiency in completing minutes. Tony a huge thanks for keeping our books and financial matters and to all our volunteers who have assisted our branch in some way – thank you. I would also like to thank my own family for allowing me the time (which despite working full time has not always been easy!) to participate in this role as Chairperson of the Southern Regional Branch.

*Theresa Stevens  
Chairperson Southern Branch*

## In Memoriam

*HFNZ notes with sadness the passing of the following members and friends of the Foundation during 2008.*

**Peter Hoskins**



**Chris White**



**Jack Walmsley**

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.*



Donor:	Purpose:	Amount:
<b>Sustaining Patrons</b>		
Bayer Schering Pharma	Sustaining Patron Programme 2008	\$10,000.00
Baxter Healthcare Ltd	Sustaining Patron Programme 2008	\$10,000.00
CSL Bioplasma Ltd	Sustaining Patron Programme 2008	\$10,000.00
Novo Nordisk	Sustaining Patron Programme 2008	\$10,000.00
Wyeth Ltd	Sustaining Patron Programme 2008	\$10,000.00
<b>Major Donors</b>		
Acorn Charitable Trust	Community Needs Assessment	\$4,500.00
Argent Financial Services Ltd	Newly Diagnosed Families Camp	\$10,000.00
Baxter Healthcare Ltd	WFH Turkey	In Kind
Baxter Healthcare Ltd	YWWW	\$10,000.00
Baxter Healthcare Ltd	50th/AGM celebration/ Clinical Meeting	\$70,338.99
Bayer Schering Pharma	PEP Programme	\$9,000.00
Bayer Schering Pharma	National Council Meeting	\$5,000.00
Bayer Schering Pharma	World H Day 17th April	\$1,000.00
Bayer Schering Pharma	WFH Turkey	\$10,000.00
Bayer Schering Pharma	AGM March 2008	\$8,000.00
COGS CHCH/ Banks Peninsula	Southern Outreach Salary	\$3,375.00
COGS Auckland	Northern Outreach Salary	\$5,625.00
COGS Otago	Southern Family Camp	\$562.50
Community Post	Bloodline	In Kind
CSL Bioplasma Ltd	Couple's Workshop	\$20,000.00
CSL Bioplasma Ltd	Men's Weekend	\$20,000.00
Nick Lingard Foundation	Central Family Camp	\$500.00
Lotteries 2007	Administration	\$30,000.00
Lotteries 2008	Administration	\$5,000.00

# HFNZ Auditors Report

Donor:	Purpose:	Amount:
Maurice Paykel Charitable Trust	50th Anniversary Book	\$3,000.00
Ministry of Health	HCV	\$50,000.00
Novo Nordisk	WFH Turkey	\$3,000.00
Pharmac	ANZSWC Meeting Sep 2008	\$1,500.00
Roche Products (NZ) Ltd	Hep Conference Brisbane 2008	\$3,000.00
Roche Products (NZ) Ltd	WFH Turkey Jack Finn Travel	\$5,000.00
Wyeth Ltd	AGM March 2008	\$10,000.00
Wyeth Ltd	WFH Turkey	In Kind
<b>Individual Donations</b>		
Andrew Eastwood		\$1,550.00
Murray Read-Smith		\$200.00
Mike Carnahan		\$1,550.00
Des Mills		\$ 300.00
Mr A Galli		\$500.00
South Otago Trefoil Guild		\$350.00
Mike Mapperson		\$400.00
Carmen Tupara		\$1,144.00
Mike Carnahan		\$400.00
BDO Spicers		\$313.00
Chris White (Bequest)		\$341.70
Jack Walmsley (Bequest)		\$151.00
Peter Hoskins (Bequest)		\$525.00
Anonymous		\$1,000.00
<b>Total</b>		<b>\$347,126.19</b>

And a Very Special Thanks to



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



## Audit Report

### To the members of the Haemophilia Foundation of New Zealand Incorporated

We have audited the financial statements on pages 18 - 19. The financial statements provide information about the past financial performance of the Incorporated Society and its financial position as at 31 December 2008. This information is stated in accordance with the accounting policies set out on page 20.

### National Council's Responsibilities

The National Council is 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 2008 and the results of its operations for the year ended on that date.

### Auditor's responsibilities

It is our responsibility to express an independent opinion of 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. 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 Incorporated Society.

### Qualified opinion

The Incorporated Society's revenue includes fundraising support programmes revenue of \$456,706 (2007:\$283,848). Controls over these revenues prior to being recorded is limited, and there are no practical audit procedures to determine the effectiveness of these limited controls. In this respect alone, we have not obtained all the information and explanations that we require.

In our opinion:

- except for adjustments that might have been found to be necessary had we been able to obtain sufficient evidence concerning revenue from fundraising support programmes, the financial statements on pages 18 - 19 give a true and fair view of the Incorporated Society's operations for the year ended 31 December 2008;
- the financial statements on pages 18 - 19:

comply with New Zealand Generally Accepted Accounting Practice;

give a true and fair view of the financial position of the Incorporated Society as at 31 December 2008.

Our audit was completed on 4 March 2009 and our qualified opinion is expressed as at that date.

Christchurch

# HFNZ Financial Statements

## Consolidated Statement of Financial Performance

For the Year ended 31st December 2008

	2008 \$	2007 \$
<b>REVENUE</b>		
KiwiFirst Revenue	811,586	780,934
Fundraising Support Programmes	456,706	283,848
Interest Received	46,049	55,824
<b>TOTAL REVENUE</b>	<b>1,314,341</b>	<b>1,120,606</b>
<b>EXPENSES</b>		
KiwiFirst - Campaign Costs	288,904	277,996
KiwiFirst - Printing Costs	252,154	242,626
Audit Fees	4,828	5,416
Bad Debts	-	-
Bank Charges & Interest Paid	474	316
Rent and Office Costs	53,348	54,339
Other Expenses	705,044	567,230
<b>TOTAL EXPENSES</b>	<b>1,304,752</b>	<b>1,149,157</b>
<b>NET SURPLUS/(DEFICIT) BEFORE DEPRECIATION</b>	<b>9,589</b>	<b>(28,551)</b>
Less Depreciation		
Office Equipment - Depreciation	7,002	7,451
Loss on Sale	-	1,274
<b>Net Depreciation</b>	<b>7,002</b>	<b>8,725</b>
<b>NET SURPLUS/(DEFICIT)</b>	<b>2,587</b>	<b>(37,276)</b>

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 2008

	2008 \$	2007 \$
Balance at Beginning of Year	691,670	728,946
<b>SURPLUS</b>		
Net Surplus/(Deficit)	2,587	(37,376)
<b>Total recognised revenues &amp; expenses</b>	<b>2,587</b>	<b>(37,276)</b>
Movement Regional Equity	(2,711)	-
<b>BALANCE AT END OF YEAR</b>	<b>\$691,546</b>	<b>\$691,670</b>

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 2008

	2008 \$	2007 \$
<b>CURRENT ASSETS</b>		
Bank Balances	15,189	8,871
Short Term Deposits	15,000	15,000
Westpac - Property Investment Saver	47,906	44,666
Westpac Online Saver	14,674	94,576
Westpac Branch Online Saver	225,280	297,643
SBS Term Deposits	243,432	273,414
TSB Term Deposit	125,000	-
SBS Savings Account	1,000	-
GST Refund Due	15,043	10,391
Taxation	2,172	2,793
Accounts Receivable	146,595	92,840
Payments in Advance	12,645	43,362
Interest Receivable	2,491	4,766
<b>Total Current Assets</b>	<b>866,427</b>	<b>888,322</b>
<b>NON-CURRENT ASSETS</b>		
Fixed Assets	15,181	19,033
<b>Total Assets</b>	<b>881,608</b>	<b>907,355</b>
<b>CURRENT LIABILITIES</b>		
Accounts Payable	84,464	107,330
Income in Advance McGregor Bequest	55,000	55,000
Receipts in Advance	50,598	53,355
<b>Total Current Liabilities</b>	<b>190,062</b>	<b>215,685</b>
<b>Total Liabilities</b>	<b>190,062</b>	<b>215,685</b>
<b>NET ASSETS</b>	<b>\$691,546</b>	<b>\$691,670</b>
Represented by:		
<b>ACCUMULATED FUNDS</b>		
Accumulated Funds	691,546	691,670
<b>TOTAL ACCUMULATED FUNDS</b>	<b>\$691,546</b>	<b>\$691,670</b>

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



David Habershon  
HFNZ Treasurer



## 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 \$24,184 at year end (2007:\$23,103), and a net surplus/(deficit) of \$1,080 was recorded for the year end by the Trust (2007: \$(2,227)).

### (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 \$252,154, 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 (2007:\$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

	2008 \$	2007 \$
Office Equipment		
At cost	61,319	58,169
Less Accumulated Depreciation	46,138	39,136
Total Fixed Assets	\$15,181	\$19,033

## 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 has a balance date for annual accounts of 31 December. The following notes are included in the 2008 acknowledgements.

### > Lotteries

It should be noted that an oversight occurred in the publication of the 2007 annual report, in which the Lotteries grant made in December 2007 was included in the 2007 accounts but not acknowledged. The 2008 report therefore acknowledges two grants paid by lotteries in December 2007 and December 2008.

### > Argent Financial

It should be noted that an oversight has occurred in the publication of the 2007 annual report, in which the Argent Financial Services Ltd grant made in December 2007 was acknowledged, but not included in the accounts. This amount has now been included in 2008 earnings.

### > Income

There was an increase in income compared to previous years. This can be attributed largely to additional fundraising specifically to cover additional expenditure required for the 50th Birthday celebrations. In 2008 HFNZ gained another Sustaining Patron - Novo Nordisk, so this is an increase of \$10,000.00 to the Sustaining Patrons Programme.

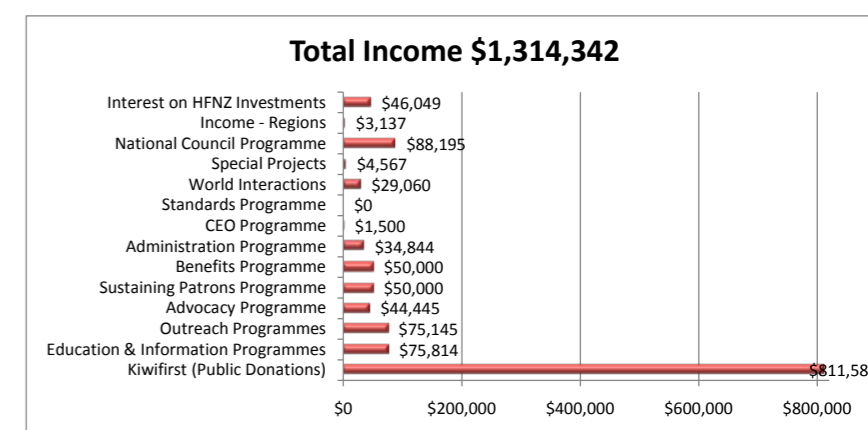
### > Special note

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.

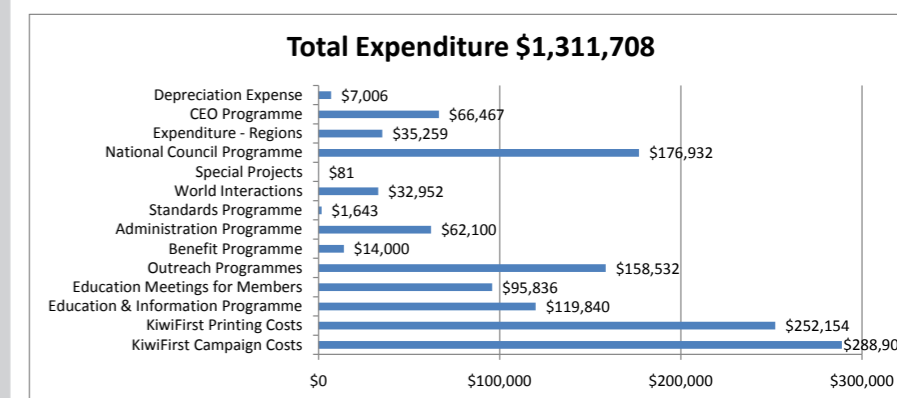
### > Summarised income & expenditure

The following outlines a detailed list of income and expense for 2008:

## 2008 Income



## 2008 Expenditure



Full Financial Statements including the Auditor's Report can be found on pages 17 to 20.

David Habershon  
HFNZ Treasurer 2008

# Allan Coster Education Endowment Trust (ACEET)

# ACEET Auditors Report

ACEET continues to function well and complements other resources available from HFNZ. All 5 applicants in 2008 were awarded grants. Four were for tertiary students doing such diverse studies as wine making, hospitality, engineering and automotive mechanics. One was for a lap top computer for a school boy with exceptional needs. A further tertiary grant for a leadership course which had been deferred pending other possible funding sources was also funded bringing the total distribution for the 6 grants to \$8,000. All applicants were male and again, there was a good geographical spread.

ACEET finances are in a reasonable state at present but the sharp fall in interest rates will significantly affect future income. The main source of income is from interest. Fortunately ACEET has continued to use bank term deposits rather than other financial vehicles so the capital remains intact. In the latter part of the year the trustees elected to add a further \$10,000 to the Principal Fund.

In contrast to previous years, no funds have been received from HFNZ this year.

An individual donor generously gave a donation of \$1000 which is gratefully acknowledged.

Funds available for distribution in 2009 are estimated to be about \$8,500.

ACEET – HFNZ was successful in its application to register with the Charities Commission as a separate entity to HFNZ. One outcome of this separate status is that ACEET has to stand alone in terms of expenses and HFNZ is unlikely to be in a position to apply to the corporate sector on behalf of ACEET. Thus, all donations/bequests will be most welcome!

The trustees took the opportunity to have a face to face meeting in March 2008 during the HFNZ 50th Anniversary Celebrations. The trustees also met with Outreach Workers and the HFNZ President. Otherwise business was conducted by email and telephone. These discussions affirmed that the three main funding streams are remedial/tuition including early input so children do not get too far behind, tertiary training and retraining. The trustees are happy to consider preliminary enquiries from Outreach Workers prior to formal application.

While computers in general are no longer available through the Trust, laptops in a special needs situation will be considered. Because of financial constraints, on the Trust, the total number of grants that can be awarded to one individual continues to be \$4,500 or 3 grants with a maximum of \$1,500 each. Families/individuals can decide at what stage funding will be most helpful to support their educational needs.

Feedback letters continue to be somewhat sporadic but are always welcomed and of great interest to us. In fact, a report on progress is one of the conditions of an ACEET grant.

Finally, the trustees again express their appreciation to the HFNZ Outreach Workers for the excellent job they do in helping to prepare applications and following up grant recipients.



## Audit Report

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

We have audited the financial statements on pages 24 - 25. The financial statements provide information about the past financial performance of the trust and its financial position as at 31 December 2008. This information is stated in accordance with the accounting policies set out on page 26.

### The Trustee's 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 2008 and the results of its operations for the year ended on that date.

### Auditor's 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 with 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 24 - 25:

- 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 2008 and the results of its operations for the ended on that date.

Our audit was completed on 4 March 2009 and our unqualified opinion is expressed as at that date.

Christchurch



# ACEET Financial Statements

## Statement of Financial Performance For the Year ended 31st December 2008

	2008 \$	2007 \$
<b>REVENUE</b>		
Interest	12,623	11,023
Grants from HFNZ	-	7,500
General Donations	1,000	1,000
<b>TOTAL REVENUE</b>	<b>13,623</b>	<b>19,523</b>
<b>EXPENSES</b>		
Bank Charges & Interest	15	25
Grants	7,680	13,627
General Expenses	28	70
<b>TOTAL EXPENSES</b>	<b>7,723</b>	<b>13,722</b>
<b>NET SURPLUS/(DEFICIT)</b>	<b>\$5,900</b>	<b>\$5,801</b>

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 31 December 2008

	2008 \$	2007 \$
Balance at Beginning of Year	156,620	150,819
<b>SURPLUS</b>		
Net Surplus/(Deficit)	5,900	5,801
Total recognised revenues & expenses	5,900	5,801
<b>BALANCE AT END OF YEAR</b>	<b>\$162,520</b>	<b>\$156,620</b>

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

## Statement of Financial Position As at 31st December 2008

	2008 \$	2007 \$
<b>CURRENT ASSETS</b>		
ASB Cheque A/C	802	1,647
ASB Short Term Deposits	162,417	152,289
Interest Receivable	801	3,004
Total Current Assets	164,020	156,940
<b>TOTAL ASSETS</b>	<b>164,020</b>	<b>156,940</b>
<b>CURRENT LIABILITIES</b>		
Accounts Payable	1,500	320
Total Liabilities	1,500	320
<b>NET ASSETS</b>	<b>\$162,520</b>	<b>\$156,620</b>
Represented by:		
<b>ACCUMULATED FUNDS</b>		
Accumulated Funds	162,520	156,620
<b>TOTAL ACCUMULATED FUNDS</b>	<b>\$162,520</b>	<b>\$156,620</b>

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 Trust;

*Elizabeth Berry*

Elizabeth Berry  
Trustee

*Peta Hardley*

Peta Hardley  
Trustee

**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. (2007:\$1500)

**4. SECURITIES AND GUARANTEES**

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

# 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 more 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	
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	

# 2008 HFNZ Directory

## National Council

President: Deon York  
 Vice Presidents: David Habershon  
 Grant Hook  
 Treasurer: David Habershon  
 Northern Branch Delegate: Frances Thomas  
 Midland Branch Delegate: Catriona Gordon  
 Central Branch Delegate: Michael Ho  
 Southern Branch Delegate: March Uren  
 Youth Delegate: T.A. Stirling

## Branches

Northern Branch Chair: John Cook  
 Midland Branch Chair: Lee Marjoribanks  
 Central Branch Chair: Diana Bell/Judith Dudson  
 Southern Branch Chair: Theresa Stevens

## Staff

### National Office

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 Email: belinda@haemophilia.org.nz

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### National Information Coordinator:

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## Haemophilia Outreach Workers (HOW)

### Northern / Midland Outreach Worker:

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 Fax: (09) 846 8174  
 Email: helen@haemophilia.org.nz

### Central Outreach Worker:

Drew MacKenzie

### Southern Outreach Worker:

Colleen McKay  
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 Ph: 0508 FACTOR or (03) 371 7485  
 Fax: (03) 371 7479  
 Email: colleen@haemophilia.org.nz

## 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

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