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# 2010

ANNUAL REPORT



## Our Mission

### To Promote Excellence in Care, Education, Advocacy, and Support.

The Haemophilia Foundation of New Zealand Inc. (HFNZ) is a national voluntary health charity (Charities Commission Registration CC22765). HFNZ was established in 1958 to serve the needs of people with haemophilia and other related bleeding disorders. It is a member of the World Federation of Hemophilia, which is officially recognised by the World Health Organisation.

#### 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 other key stakeholders on bleeding disorders.
- To maintain 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.
- To be a responsible member of the global haemophilia community.

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 haemophilia and related bleeding disorders in New Zealand.

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# Care, Education, Advocacy, Support

## Highlights of 2010



DEON YORK

## President's Report

This report covers the period January to December 2010.

**September 4th 2010 will be a date etched on the memory of Canterbury for many years to come. The magnitude 7.1 earthquake struck Canterbury in the early hours of the morning. Christchurch awoke to widespread damage but, fortunately, this quake did not result in loss of life.**

Before the 2010 Annual Report went to press, another earthquake of lesser magnitude struck Christchurch on February 22nd 2011. While it did not measure as high on the Richter scale, this quake was located within only 10 km of the Christchurch CBD and was at a shallow depth of 5Km. It also occurred in the middle of the day.

The National Office of HFNZ is based in Christchurch and damage was sustained to property. We have been fortunate in that no staff or members have lost their lives to this quake. It is still an understandably difficult time for our staff and members in the Canterbury region. We are all thinking of you at this time. We have heard reports of a number of members losing their properties and being displaced.

The Haemophilia Foundation of New Zealand extends its deepest sympathies to the entire community of Canterbury.

### Our membership

In 2010 our membership grew from 969 to 1001 members. Of these, 593 are affected by a bleeding disorder and 324 are carriers of a bleeding disorder.

Based on New Zealand's 2010 population, we can assume that approximately 440 people are affected by Haemophilia A, B or another rare factor deficiency. Our membership records, as at December 31 2010, show 426 people on our database in these categories. This is heartening as it demonstrates we are reaching the vast majority of people affected by haemophilia across the country.

Fig 1: Proportion of membership by bleeding disorder

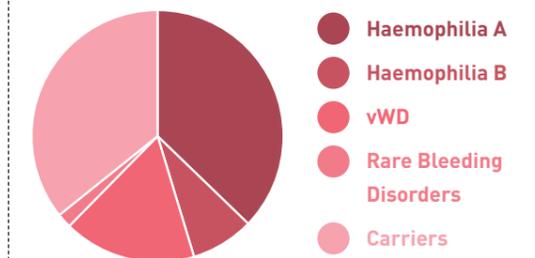
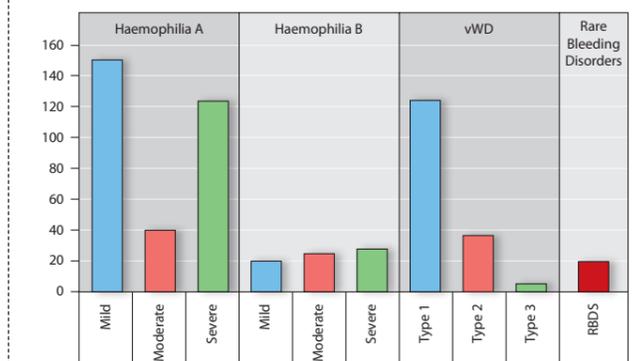


Fig 2: Representation of membership with a bleeding disorder by severity.





## National Council

The membership is represented by the National Council of HFNZ. In 2010 the National Council comprised:

Catriona Gordon	Vice-President
Grant Hook	Vice-President
Phillip Cowley	Treasurer
Richard Scott	Northern Delegate
Lee Marjoribanks	Midland Delegate
Michael Ho	Central Delegate
Mark Uren	Southern Delegate
Joe Wrathall	Māori Delegate
Karl Archibald	Youth Delegate

Steve Waring, Director of KiwiFirst was co-opted to National Council and Belinda Burnett, CEO, attended in an advisory capacity.

The National Council composition well represents the full range of our community and includes people with haemophilia A and B, von Willebrand's, carriers, parents and partners of people with bleeding disorders as well as a range of ages and stages of life.

I wish to extend my thanks to the National Council for their work and commitment to improving the lives of people with bleeding disorders.

## Fundraising

Our financial position for the year ending December 31 2010 is detailed on pages 18-20.

We remain mindful of the need to have a home for haemophilia and contingency in place for a lean year. Fortunately, we have continued to receive remarkable support from the public to enable us to continue to run our many programmes for New Zealand's bleeding disorders community.

HFNZ acknowledges the valuable contribution of KiwiFirst for their fundraising on our behalf and for effectively disseminating the work of the Foundation to the donating public. We also acknowledge the work of the national office in securing grants and donations for the work of the Foundation.

We acknowledge our Sustaining Patrons, Baxter, Bayer ScheringPharma, CSL Bioplasma, NovoNordisk and Pfizer. A small proportion of our funding comes from District Health Boards and the Ministry of Health and the remainder is obtained via membership fees.

## National Services

The Exercise and Supportive Footwear programmes, special assistance grants, advocacy and support, regional activities and *Bloodline*, our national newsletter, were services that we continued to provide to members. Over 700 copies of *Bloodline* are distributed to members and supporters of HFNZ.

The National Office also embarked on disseminating a monthly electronic panui to members giving news and updates about the office and other important items. Feedback has been very positive around this initiative. You can also find HFNZ on Facebook™, so hit "Like" for further news and updates!

There were also a range of national educational events targeted to different sectors of our community in 2010. Thank you to our office-based staff for their role in delivering these services.

With Colleen McKay firmly in the position of Manager of Outreach Services, the team has really taken shape and outreach workers in all four regions are established:

Sarah Preston	Northern Region
Joy Barrett	Midland Region
Lynne Campbell	Central Region
Linda Dockrill	Southern Region

Outreach is frequently cited as one of the most important activities of the Foundation. Thank you to our dedicated outreach staff for their work and perseverance with our community. The bulk of our national events are run by our outreach staff.

## National Activities

In addition to the many activities run by our Regional Committees, there are a number of national initiatives, presented here in order of event.



## Hui

Hui continued to be held around the country in 2010. The first hui of 2010 took place on 13th March at Ako Pai Marae, Victoria University of Wellington. The objectives of this hui in particular were to discuss the adoption of the Terms of Reference for He Roopu Tautoko, and decide the Takawaenga (four Māori regional representatives) as well as the Māori Delegate to National Council. This resulted in Joe Wrathall serving as Māori Delegate to National Council and the following individuals representing their regions:

Kahurangi Carter & T.A. Stirling	Northern Region
Tara Mounsey	Midland Region
Raukura Riwaka	Central Region
Tania Kaa	Southern Region

Thank you to Joe and the Takawaenga for progressing the establishment of He Roopu Tautoko of HFNZ. With the group established and the inclusion of national representation of Māori enshrined in the Constitution, we look forward to seeing the development of this initiative.

## National Young Families Education Camp

Between 9 - 12 April the National New Families Camp was held in Rotorua at Camp Keswick. Held every two years, the camp is open to all families with children with a bleeding disorder aged 10 years and younger, including siblings. These events are always a great chance to meet up with other parents facing the same issues and for both parents and children to learn more about bleeding disorders and share experiences.

## World Haemophilia Day

Several events were held around New Zealand to celebrate World Haemophilia Day on 17 April, including a BBQ and children's entertainment in Christchurch, a youth event in Auckland and group meals in both Palmerston North and Wellington.

## Adult Wellness Weekend

**"I thoroughly enjoyed the chance to spend the weekend with a wide range of ages, yet many shared experiences"**

Between 24 - 27 June the inaugural Adult Wellness Weekend was held in Auckland. There had been considerable discussion amongst the National Council and staff on the best way to provide education and social interaction for adults with bleeding disorders. Following on from the success of the Men's and Couple's Weekend, HFNZ produced a new format of educational workshop for adults with bleeding disorders and their partners. The end result was a weekend filled

## President's Report

with education around living healthier, dealing with hepatitis C and keeping active. Positive feedback from participants and staff support the continuation of this type of event.

### Parents Empowering Parents (PEP) Programme

**“I learnt a lot about myself and how to be a better parent”**

This year, a Re-PEP programme was held between 6 - 8 August. PEP is an innovative, peer-to-peer skills programme that introduces parents to tools to better handle the realities of raising a child with a bleeding disorder. PEP programmes are led by an outreach worker, parents and a haemophilia nurse who use classroom discussions, role playing and hands-on experiences to educate parents about the types of skills needed for effective parenting. Re-PEP was a chance for previous PEP participants to come together and refresh the skills they had learned in the programme.

### Children's Education Workshops

**“It was a really fun day and I learned a lot!”**

Four workshops were held around the country during the school holidays. These are great days for younger children with a bleeding disorder and their siblings, aged 6-10, to learn the basics and have a heap of fun meeting other kids in their region.

### Grandparent's Day

A pilot of a new workshop, Grandparents' Day, was trialled in Christchurch on Saturday 6 November. This was a special day just for grandparents of younger children with bleeding disorders where the focus was on learning about bleeding disorders and how they can help support their families. They learned that the people that probably needed the most support from them were their children (the parents) and the siblings. The 14 participants shared their knowledge with each other, and overall had a fun and interesting day.

### HFNZ investigates twinning with Cambodia

Since our humble beginnings in 1958, HFNZ has grown into a solid, well-organised, and prominent patient organisation. Over the last few years, HFNZ have been trying to be better global members of the bleeding disorders community. We have been raising funds for people with bleeding disorders in developing countries through activities such as Global Feast, art auctions and donations to the Global Alliance for Progress programme.

Earlier this year, The World Federation of Hemophilia (WFH) presented us with an opportunity to take this commitment a step further. We were asked if we would like to use our experience to help another country in the Asia-Pacific region, the Cambodian Haemophilia Association (CHA), on their journey to establishing a strong and effective haemophilia patient organisation by Twinning with them.

The Haemophilia Organisation Twinning (HOT) program links emerging and established haemophilia patient groups to share knowledge in areas such as patient education, outreach, fundraising, and all other aspects of operating a successful haemophilia patient society. The HOT program also benefits established societies by presenting them with new challenges.

Haemophilia organisation twinning can play a critical role in a country. Regular support and coaching through twinning helps a patient organisation become a driving force for change and progress. National haemophilia organisations promote access to haemophilia care. They work to maintain or improve the quality of care. They provide a support system for families who often feel isolated. They are a powerful voice representing the interests of people with haemophilia. However, the range and complexity of challenges facing haemophilia organisations are growing. Such challenges will continue to grow in the future.

The first step to Twinning is having an assessment visit with their potential twinning partner organisation in the emerging country. HFNZ representatives, Colleen McKay (Manager -Outreach Services) and Richard Scott (Northern Delegate to National Council), travelled to Cambodia for this visit in October. The WFH believes strongly in assessment visits as they allow potential twins to meet face-to-face and appreciate for themselves what questionnaires, emails and telephone calls cannot convey. Before the WFH officially recognises and funds a twinning partnership, an assessment visit must take place to allow both parties to decide if beginning this relationship is in their best interests. The Twinning programme is funded by the WFH through a grant from Pfizer and the WFH covered the costs associated with the assessment visit.

Due to the lack of awareness and research, the true number of Cambodians with haemophilia and other bleeding disorders is unknown. Cambodia has a population of nearly 15 million, yet there are currently only 66 registered haemophilia patients. Most are less than 13 years old, with a few teenagers and only two adults. Estimates are that there could be as many as 1,300 people with haemophilia in Cambodia; however, many of these people may have died due to



the absence of haemophilia services. These are starting to be established and some treatment is now available. Without adequate knowledge on how to live with haemophilia, patients are at greater risk of severe bleeds and permanent disability. They are more likely to have limited socio-economic participation (e.g., education, vocational training and income generation) due to their poorer health and physical disability. There may also be social stigma since haemophilia is hereditary, leading to discrimination in marriage for example.

In the meetings between representatives of HFNZ and CHA and families affected by haemophilia, the emphasis was on establishing a good family support system as the key to growing the organisation. Learning how to support each other is essential to providing long term benefits. Some families had travelled long distances on their 'motos' to be there and for some this was the first time they had met another mother who understood what they were going through or another boy with the same problems.

Following further discussion, a draft Twinning Application Form and draft Action Plan for the Twinning partnership was drawn up. These have been circulated to CHA and HFNZ councils for their approval and then sent to WFH. WFH will decide in 2011 whether the Twinning between HFNZ and CHA will formally go ahead.

Colleen McKay wrote the following shortly before returning home, “If it is accepted, the Twinning between HFNZ and CHA will be full of challenges along the way, but from the families that we have met, I know that it will be truly rewarding and that we can make a difference in developing their Association to be an effective patient group.”

## ■ Conferences and Workshops

### Tender Training

Brian O'Mahony, CEO of the Irish Haemophilia Society, delivered a 'Tender Training' course to the National Council in June. The workshop is aimed at helping members of haemophilia organisations play an informed and involved role in their countries' tendering process for haemophilia treatment products. This course ran at the same time as the Wellness Weekend at the same venue in Auckland. HFNZ want to make certain that those in the haemophilia community are able to access not only appropriate, timely treatment, but also the safest and best available. Participating in the training course is one way to ensure we have the necessary knowledge and skills to be part of the decision making process.

**XXIX International Congress of the World Federation of Hemophilia**

The XXIX International Congress of the World Federation of Hemophilia took place from July 10-14, in Buenos Aires, Argentina. Fourteen delegates from HFNZ were in attendance, including Mike Carnahan who spoke about ageing and haemophilia, Belinda Burnett who chaired a session featuring the expertise of people of different age groups, and I spoke about leadership in the bleeding disorders community and attracting the next generation of volunteers. Four of the delegates also had abstracts accepted for poster presentation. The information gained at congress was disseminated via the regional branches and through our national newsletter. Speakers were funded to attend by the World Federation of Hemophilia.

**Affiliated programs**

**Step Up Reach Out (SURO)**

Hemi Thomas is the tenth New Zealander to have been chosen to participate in SURO, an international youth leadership program, which draws together young men with haemophilia from around the world for leadership skills, personal growth, and collaboration. The first meeting was held in San Francisco. We are fortunate to have the second meeting being hosted in Auckland in 2011 and be able to welcome a group of future world leaders in the bleeding disorders community.

**“I went to the SURO programme in San Francisco not really knowing what to expect. It turned out to be a great experience where I met a great bunch of guys from all over the world. Watching the presentations from other countries, I realised how lucky we are in New Zealand. During the course of the program we had some interesting discussions about haemophilia care and leadership...SURO has been a great experience.”**

**HFNZ pledge to WFH**

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 again in 2010.

**Other representation**

**National Haemophilia Management Group**

HFNZ hold a permanent position on the National Haemophilia Management Group, the group responsible for the planning and funding of

haemophilia care across the country. This year the role rotated between Belinda Burnett, Catriona Gordon and myself.

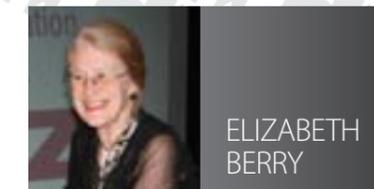
**World Federation of Hemophilia**

In 2010, I successfully ran for a position on the Executive Committee of the WFH and will now serve a four year term with the Federation (commenced July 2010). I am looking forward to working a group of individuals that are committed to improving the lives of people with bleeding disorders globally. It is important to note that my position does not represent New Zealand, or people with haemophilia in New Zealand specifically, all Executive Committee members are there to serve the interests of the global haemophilia community. In addition to my role on the Executive Committee I was re-appointed to the Fund and Resource Development Committee and the National Member Organization Training Committee. In 2010 I also began serving on the Research Committee as well as the Educational Materials Committee.

Finally, I wish to reiterate my sincere appreciation to the Christchurch staff of HFNZ for their resilience through what has been a difficult year for all Christchurch residents. Thank you to our international community for their support during this difficult time. HFNZ entitled its 50 year history *Still Standing*; these words seem particularly relevant when reflecting on 2010.



**Deon York**  
HFNZ President



**ELIZABETH BERRY**

**Patron's Report**

**HFNZ has a proud record. In over 50 years it has grown from strength to strength and is now a robust organisation able to inspire, assist and support its members to achieve their goals. These achievements are well recorded in this annual report.**

HFNZ also has an increasing profile on the international scene and a number of our programmes such as the family camp have been adopted with enthusiasm by other countries. At the most recent World Federation of Hemophilia (WFH) Congress several members were invited to speak on topics as diverse as women's workshops, fundraising and issues concerning the ageing population. Six of our young men have been chosen to participate in an international leadership programme and our current president, Deon York, is the first New Zealander to be elected to the WFH Executive. Congratulations Deon!

The WFH is an interesting organisation which has done much to improve haemophilia care worldwide. New Zealand joined shortly after its formation in 1963 and membership has been invaluable in gaining knowledge, getting to know people, learning about political lobbying, keeping up to date with product information, and best clinical practice. Their two yearly congresses are unique in that they are attended by people with bleeding disorders as well as doctors and others concerned with their care. As such, they present a wonderful opportunity to meet experts in all areas,

learn about all aspects of comprehensive care, and to exchange and bring back new ideas. I remember with pleasure attending my first WFH Congress in Kyoto in 1976 and meeting knowledgeable people and helpful physicians who were happy to answer my queries and who have become lifelong colleagues and friends.

Not everyone is as fortunate as people with haemophilia in New Zealand - in fact about 65% of the people with haemophilia in world have little or no treatment and in recent years the WFH has established a twinning program where a partnership is established between an emerging and an established association. The HFNZ has been asked if they would like to use their experience to help Cambodia to establish a strong and effective haemophilia patient organization by twinning with the Cambodian Haemophilia Association. This is an exciting development and a mark of the strength and maturity of HFNZ that it is in a position to enter this support role for a Pacific neighbour.

I look forward with pleasure to being part of the continuing activities of HFNZ both here and further afield.



**Dr Elizabeth Berry, QSO**



# CEO's Report



This report covers the period  
January to December 2010.

BELINDA  
BURNETT

**2010 was an extremely busy year for the HFNZ staff. We delivered a record number of educational workshops and activities. Having relatively new Outreach Staff added to the pressure that all HFNZ employees thrived under in 2010. HFNZ Outreach delivered 25 more hours of outreach service per week throughout the year than in 2009.**

## 2010 highlights for me were:

Assisting and speaking at the **New Family Camp** in April. It was a great experience to see all our newer members in one place, all with the same desire and passion- to assist their children in learning to cope with an inherited bleeding disorder.

*The important thing is not to stop questioning*  
- Albert Einstein

In July I facilitated a session at the **World Federation of Haemophilia Congress** in Argentina. This was for youth and men from developed and developing countries speaking of their personal experiences. This session was very well received by the attendees. The idea came from an educational camp HFNZ ran in 2008, so it was a real honour to be able to share this idea with a worldwide audience.

The **Tender Training** that HFNZ hosted in July for the National Council was exceptional training for staff and volunteers. The importance of safety and supply of our treatment products can never be overstated. All the education we receive as an organisation on this subject is invaluable to *all* our members.

Helping the **Roopu** establish itself in 2010 has been another highlight for me. I have learned a lot from our members who identify as Māori, and I am proud to report that some of the teachings from the Takawaenga have become an integral part of procedures at National office meetings.

## *Ma tini ma mano ka rap ate whai* Many hands make light work

Each year I report on what has been achieved and delivered in the previous 12 months. This year I decided a table would be a better way of illustrating the services delivered to members by the National office and Outreach staff.

### 2010 in Numbers

934	Outreach phone conversations with members
649	Outreach email/text contacts to members
573	Face to face Outreach visits
7020	Outreach hours
29.1%	The percentage by which Outreach contacts have increased since 2008
335	People attended a national education workshop
\$11,500.00	Dollars granted for the Swimming/Exercise Programme
65	Pairs of Supportive Footwear granted
2,700	Copies of Bloodline distributed
60,310	Visits to www.haemophilia.org.nz

On a personal note, 2010 was a difficult year for me. I want to take this opportunity to thank the staff and volunteers who gave me their good wishes, their blessings and their time for me to talk about my family and the sadness we suffered throughout the year.

Sincerely,  
Belinda Burnett

**Kei te waiata te Tui  
Karanga Te iwi  
E nga hau e wha  
Tenei te aroha nui e tu atu nei  
Anei te aranga o te ra**

**The Tui bird sings;  
Call to one and all,  
Extending to the four winds,  
This is an affirmation of our affection  
and appreciation;  
Behold! The sun rises.**

**He ika kai ake i raro**  
As a fish nibbles from below

**He rapaki ake i raro**  
So the ascent of a hill begins from below

*(Every journey starts with the first small step forward,  
Working together must start somewhere)*

## Kia ora katou katoa,

**The 2010 Whakatauaki (proverb) of the Haemophilia Foundation of New Zealand He Roopu Tautoko (Māori Support Group) was certainly appropriate, setting a vision and pathway for the Roopu year.**

Each individual and collective 'small step forward', proved to be a positive progression towards the Purpose, Goals, Values and Principles outlined in the Roopu's Terms of Reference. These Terms of Reference are:

### 1. Te Takoto o te Roopu (Purpose);

- to provide a medium for Māori membership of the foundation and their whanau to meet and discuss issues relevant to them and to be supported.
- to ensure active involvement and participation by Māori in the activities of the HFNZ.
- to provide Māori representation to the HFNZ National Council and the election of four regional representatives to meet regularly.
- to promote the inclusion and implementation of Whanau Ora (Family wellbeing/wellness) in Māori Health and across the Foundation.

### 2. Nga Whaingā o te Roopu (Goals);

- to provide support and to advocate for Māori health gains and participation within the foundation.
- to ensure and uphold Māori representation on the National Council and regional representation.
- to identify projects and activities that promotes Whanau Ora within the whanau and Foundation.

### 3. Te Kawa Whakaruruhau (Values and Principles);

- Haemophilia Foundations mission.
- Treaty of Waitangi.
- Whanau Ora.
- Te Reo Māori me nga tikanga.



JOSEPH  
WRATHALL

# Māori Delegate Report

Mason Durie's holistic Te Whare Tapa Wha (the four-sided house) was adopted as the Model of Health, and has become a constant feature at Roopu Hui and meetings. The Roopu has begun to implement the Whare Tapa Wha in both an educational and research capacity.

Some of the main highlights of the Roopu's 2010 year included: the Northern (Auckland) Roopu members organised the Powhiri at the June HFNZ Wellness Weekend; A Māori youth (Hemi Thomas) was chosen to attend Step up Reach Out; the Takawaenga (Māori regional representatives) meetings; Greater Māori coverage in the Panui and Bloodline, and the development of waiata.

Undoubtedly, a major event was our Educational Hui at Kuratini Marae, Wellington in November. Invited speakers included Brenda Joyce from the NZ Society of Genealogists Inc. and their Māori Interest Group, providing a presentation from her book, Whakapapa: An introduction to researching Māori and Pakeha-Māori families, their history, heritage and culture." Not only were we able to learn about our Māori ancestry, culture and genealogy, but also our haemophilia genealogy. The afternoon panel of Māori with haemophilia who are fluent Te Reo speakers was amazing and I believe the day took us all to a new level of awareness and understanding.

Looking forwards to 2011, the Roopu would like the Tonu te pito o te aroha (the full possession of affection) extended and present throughout HFNZ, and that the proposed regional Māori activities/events for all HFNZ members become a regular and popular feature of the HFNZ calendar.

Taikiha,  
Joseph Wrathall

*Aroha mai, aroha atu*  
Love towards us, love going out from us.



KARL ARCHIBALD

## Youth Report

### Year ending December 2011 has been an exciting and challenging one for youth!

We have had the ability to go from strength to strength and have learnt some valuable skills along the way.

In March 2010 two HFNZ youth, Sam Glynn and Sam Hawkins, attended the second part of Step Up Reach Out (SURO), an initiative developed by Ed Kuebler, and Madeline Cantini from the University of Texas Gulf States Hemophilia and Thrombophilia Center and funded by Bayer Health Care. This part of the leadership programme for youth with bleeding disorders saw Sam and Sam learn some valuable life skills and had another chance to interact with youth from all over the world who shared the same interests. Later in the year Hemi Thomas was chosen to participate in the 2010/2011 SURO programme and attend the first part in San Francisco.

April 17, World Hemophilia Day, was a great example of a learning and development opportunity. Unfortunately it didn't go as envisioned but an alternative came together with the help of some of the HFNZ staff in Christchurch. Youth in Auckland organised a go-karting day to celebrate.

In June, the past and present kiwi attendees of SURO had the opportunity to meet in Christchurch with for a meeting run by Ed Kuebler and Madeline Cantini who came over to arrange the second part of 2010/2011 to be held in Auckland in March 2011. This meeting was a chance to present our own individual experiences, and what we have done since attending SURO.

In July I had the opportunity to go the WFH Hemophilia World Congress in Buenos Aires, Argentina and participate in the member organisation training. There I met a lot of youth from all around the world, had the chance to see their perspective on haemophilia treatment, challenges and make some great mates.

One of the results of June meeting of previous SURO participants was renewed enthusiasm and backing of

youth to form a National Youth Committee (NYC). Although this has been discussed in the past, at the National council meeting in August, I moved for the official forming of HFNZ's first National Youth Committee. The role of this is to form a more formal voice for youth and to move us in line with Regional & Māori committees.

In preparation for the November Budget meeting, I applied for Youth Committee funding, this is to go towards associated meeting costs, youth events and development. This was met with positivity on a diverse and nationally represented basis, approved and past.

More recently, Sarah Preston and myself ran a youth meeting during the January 2011 Youth and Teen Camp in order to structure how this division of HFNZ would work, what focus we would have in regards to the direction we wished to presume in order to be the best we can be.

Our aim for 2011 is to have some new faces, a full youth committee, including representatives from each region who are involved in their local committee, a treasurer and Māori delegate. These roles are not limited to just one person per position and should allow for people with a variety of skill sets to work in more than one area. For example, the Midland region youth delegate could be the committee treasurer or Māori delegate.

Overall HFNZ Youth have had a productive and positive year, with a variety of opportunities and strategic direction changes. We are focused on improving youth engagement, involvement and providing a structured means to help others, the way our predecessors helped us.

Cheers,

**Karl Archibald**  
National 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

The South Island has been rocked with disaster over the past year with the Canterbury earthquakes and the Pike River Mining Disaster. 2010 has, however, been a year of continued change and excitement for the South Region and we continue to have a large volunteer contingency.

World Haemophilia Day was celebrated around the country on April 17. We aim to try for more impact next April as we join together for the better good of our loved ones affected by Haemophilia.

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!

During the past year Otago/Southland folk enjoyed a get together with our Outreach Worker Linda Dockrill at Glenfalloch Gardens on the Otago Peninsula. Thanks to Southern Branch for funding this event. The Christchurch gatherings included a family picnic at Orana Park and the World Haemophilia Day BBQ and entertainment.

We intended to have a global feast celebration dinner and art auction in November, but unfortunately due to constraints we were unable to pursue this venture at this time. Another date will be set for next year and we hope that it will be well supported by members and friends.

In January we learned of the passing of Tony Steele, a hugely valued member of our committee and Southern's treasurer for more than 25 years. A Life Member of HFNZ, Tony was diagnosed in 2009 with cancer and continued his role with us despite his illness. Tony was a man of integrity and passion (for his family, rugby - he was a one eyed Cantabrian! running and Ford Falcons - especially Black ones!). Tony you will be sorely missed by all of us and we wish to extend our sincere sympathies to all of Tony's family and many friends.

I would like to take this opportunity to thank the office staff who have organised flights, venues and accommodation to enable those travelling to get to the destinations on time. National Council delegate Mark Uren ensured our ideas including our 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 Coleman 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. James Poff, who has taken on your role well, has very 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.

**Theresa Stevens**  
Southern Region Chairperson



 **Central**  
Another year has passed and we are now into 2011 with a new committee and ideas for another year of events, get-togethers and an annual camp.

We started off 2010 with a café luncheon at Palmerston North for World Haemophilia Day and Wellington members held a café evening at a Chinese restaurant. A good time was had by all that attended.

In September, we held our annual family Winter Escape at Solway Park Hotel in Masterton with a very good attendance, including three new families. We had members from all over the Central region, including New Plymouth and Gisborne. The committee put a lot of thought and effort into the running of this camp, including three guest speakers; a pain management expert, a nutritionalist and a genetic counsellor. These speakers were very well received and I am sure that everyone learnt something that they could take away and put into practise.

In December we held our very first children's party at the Esplanade in Palmerston North. Whilst the weather was not that kind to us, we had four new families arrive for the picnic. This was so encouraging. After lunch we all piled onto the "little train" for a ride around the Esplanade.

This was a great way to end our year of events and to have five new families attend our events during the year has given encouragement to our small, dedicated committee.

I would like to thank those dedicated members of our Central Branch Committee that give up their precious time to be involved, and help organise events for all our members to learn and form friendships in the Foundation.

Also a big thank you to our Outreach Worker, Lynne, who is always only a phone call away for help and advice.

**Judith Dudson,**  
*Central Region Chairperson*

 **Midland**  
Midland were pleased to welcome new members our committee in 2010 to join those who have been working to promote events in the region. Committee members included Lee Marjoribanks, Catriona Gordon, Tara and Alan Mounsey, Vicki Fitzgerald, Renee Elliffe, Sharon Barnes, Diana Bell, David Charleston, Tony Cross and Marcia Morris. It was great to have new faces and a good coverage of the geographical area.

Midland members were delighted to participate and help organise the New Families Camp held in Rotorua in April. The Marjoribanks family in particular made a wonderful contribution by firstly, courtesy of Glenn, providing a traditional Māori welcome to our members and helping out in many other ways over the weekend. The weekend itself was a great opportunity for Midland members to get together, and also to reconnect with or meet for the first time other HFNZ members.

At a café evening in June, we farewelled Sarah Preston, our Outreach Worker, who moved to Northern, and welcomed Joy Barrett to the position.

At the end of July, Midland held a family day at Tauranga Baywave. Everyone had a great time in the pool and on the hydroslide.

Midland held another café evening in October, partly as a Global Feast fundraiser. As always it was an excellent opportunity to socialise with members and get to know

each other better, with the chance of winning one of the raffles put together from donations from members. In addition Vicki Fitzgerald and her family organised a fundraising afternoon tea for friends and raised over \$800, which we thought was an incredible effort.

As the year drew to a close, a Christmas Family Day was held in Rotorua which included a visit to Wingspan Birds of Prey. It was amazing to see the falcons fly and to get up close with the birds. It was another great day out and great chance to be with others facing the same challenges of living with a bleeding disorder in their family.

**Catriona Gordon**  
*Midland Region Committee & HFNZ Vice-President*

 **Northern**  
Northern Region's year starts and ends with a family camp at Waiwera which includes the AGM on the final day.

At the Northern AGM in February 2010, Frances and Robin Thomas stepped down from the committee, leaving the position of Northern Delegate to National Council vacant. Richard Scott was elected to replace Frances on National Council. Some new faces appeared on the Committee and Wayne Hunter returned as treasurer, although that role is largely symbolic in the current system of centralised funding.

For World Haemophilia Day a small group of Northern Region youth went go-karting.

In May, an afternoon of Mini Golf for all ages was held at the Jungle Golf venue in South Auckland and was well attended.

It was around this time that we heard the welcome news that Sarah Preston was to transfer from Midland Branch Outreach Worker to Northern. This was a great relief to all Northern members as we had had two new and inexperienced OWs in succession, after Helen Spencer resigned and some long gaps in between.

In June, many members attended the Adult Wellness Weekend held in downtown Auckland. Brian O'Mahony from WFH and the Irish Haemophilia Society arrived in Auckland to attend the weekend event, but after addressing a meeting for adult men on Thursday he was taken ill. Thankfully he recovered quickly and attended the last day of the weekend.

A welcome dinner was organised for Sarah in August after she returned from the World Congress and her holiday. We gathered at Ghengis Khan Mongolian Barbecue and those who had not been before enjoyed choosing their dinner ingredients, salads and sauces to be cooked as they watched. The dessert pancakes were a hit with the children.

In September another family day out was organised at Butterfly Creek, the somewhat misleading name for Auckland's crocodile zoo. Also in September, to mark the Global Feast, we returned to our traditional venue at Avondale for a home-style roast dinner and film evening.

Finally for 2010 our Christmas party was held on 5th December at the Auckland Botanic Gardens at Manurewa. Always a great get together with a visit from Santa and this year face-painting for the kids.

**Mike Mapperson**  
*Northern Region Chairperson*

# In Memorium

**HFNZ notes with sadness the passing of the following members and friends of the Foundation during 2010.**

- Louis James Comber
- Ian Hammington
- John Hanssens
- Barry Keith Mabey
- John Anthony (Tony) Steele

# 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 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.

HFNZ runs a financial year the same as the calendar year, the following report covers donations received from 1st January 2010 until 31st December 2010.



Donor:	Purpose:	Amount:
<b>Sustaining Patrons</b>		
Baxter Healthcare Ltd	Sustaining Patron Programme 2010	\$10,000.00
Bayer Schering Pharma	Sustaining Patron Programme 2010	\$10,000.00
CSL Bioplasma Ltd	Sustaining Patron Programme 2010	\$10,000.00
Novo Nordisk	Sustaining Patron Programme 2010	\$10,000.00
Pfizer Ltd	Sustaining Patron Programme 2010	\$10,000.00
<b>Major Donors</b>		
AXA Grants Programme	National Children's Workshops	\$5,500.00
AXA Grants Programme	National Children's Workshops	\$5,500.00
Armageddon Expo (Ball & Volunteers)	General	\$6,883.50
Baxter Healthcare Ltd	New Families Camp	\$25,000.00

## Appreciations

<b>Major Donors</b>		
Baxter Healthcare Ltd	2010 WFH Congress	\$5,000.00
Baxter Healthcare Ltd	Tender Training	\$25,739.00
Bayer Schering Pharma	Parents Empowering Parents (PEP)	\$10,000.00
Bayer Schering Pharma	2010 WFH Congress	\$5,000.00
Bayer Schering Pharma	Grandparents Day	\$5,000.00
Bayer Schering Pharma	World Haemophilia Day	\$1,000.00
Canterbury Community Trust	Southern Outreach Salary	\$15,000.00
COGS Christchurch Banks Peninsula	Southern Outreach Salary	\$2,875.00
COGS Central Otago	Southern Outreach Salary	\$1,150.00
COGS Waitakere City	Northern Outreach Salary	\$4,600.00
COGS Kirikiriroa / Hamilton City	Midland Outreach Salary	\$1,150.00
COGS Marlborough	Southern Outreach Salary	\$575.00
Community Post	Bloodline	In Kind
CSL Bioplasma Ltd	Sustaining Patron Programme	\$10,000.00
CSL Bioplasma Ltd	2010 WFH Congress	\$4,387.00
CSL Bioplasma Ltd	Von Willebrand	\$5,000.00
Hastings District Masonic Lodge	Youth Camp 2011	\$4,000.00
Lindisfarne College	Donation for speaking	\$832.00
Lotteries	Administration costs	\$25,830.00
Ministry of Health	HCV Advocacy	\$60,000.00
Novo Nordisk	Inhibitor Workshop	\$5,000.00
Novo Nordisk	2010 WFH Congress	\$5,000.00
Roche (New Zealand)	2010 WFH Congress	\$500.00
Sovereign Sunshine	2011 Youth Camp	\$800.00
Pfizer New Zealand Ltd	2010 WFH Congress (Mike Carnahan)	\$5,000.00
Pfizer New Zealand Ltd	NACCHO	\$5,000.00
Give- A- Little	General - Public donations made online	\$1,211.86
<b>Individual Donations (over \$100)</b>		
Andrew Eastwood - Rotorua Runs Red		\$2,180.66
Angus MacDonald		\$180.00
Diane & Maurice Wymer		\$100.00
Inner Wheel Club		\$150.00
John Hunter		\$100.00
Kaye Ward		\$100.00
Lindisfarne College		\$832.00
Madman Entertainment		\$1,259.19
Muriel Death (Funeral Donations)		\$180.00
Nick Lingard		\$500.00
Pride of Howick		\$300.00
Reginald Fuller		\$100.00
Sue McHardy		\$100.00
<b>Total</b>		<b>\$303,115.21</b>

# HFNZ Financial Statements

## Consolidated Statement of Financial Performance

For the Year ended 31st December 2010

REVENUE	Note	2010 \$	2009 \$
KiwiFirst Revenue	2	955,024	1,003,814
Fundraising Support Programmes		387,749	420,913
Interest Received		33,636	34,836
<b>TOTAL REVENUE</b>		<b>1,376,409</b>	<b>1,459,563</b>
<b>EXPENSES</b>			
KiwiFirst - Campaign Costs	2	339,992	357,358
KiwiFirst - Printing Costs	2	296,697	311,852
Audit Fees		6,254	6,160
Bank Charges & Interest Paid		513	608
Rent and Office Costs		60,599	64,801
Other Expenses		675,435	671,628
<b>TOTAL EXPENSES</b>		<b>1,379,490</b>	<b>1,412,407</b>
<b>NET SURPLUS/(DEFICIT) BEFORE DEPRECIATION</b>		<b>(3,081)</b>	<b>47,156</b>
<b>Less Depreciation</b>			
Office Equipment - Depreciation		7,130	6,472
<b>NET SURPLUS/(DEFICIT)</b>		<b>(10,211)</b>	<b>40,684</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 2010

	2010 \$	2009 \$
Balance at Beginning of Year	732,229	691,545
<b>SURPLUS</b>		
Net Surplus/(Deficit)	(10,211)	40,684
<b>Total recognised revenues &amp; expenses</b>	<b>(10,211)</b>	<b>40,684</b>
<b>BALANCE AT END OF YEAR</b>	<b>\$722,018</b>	<b>\$732,229</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 2010

	Note	2010 \$	2009 \$
<b>CURRENT ASSETS</b>			
		7,611	14,167
Short Term Deposits		15,000	15,000
Westpac - Property Investment Saver		50,402	49,061
Westpac Online Saver		121,305	106,570
Westpac Branch Online Saver		193,927	230,417
SBS Term Deposits		268,374	249,918
TSB Term Deposit		132,556	130,070
SBS Savings Account		1,000	1,000
GST Refund Due	1(d)	13,155	20,269
		2,593	2,377
Accounts Receivable		147,280	57,803
Payments in Advance		19,765	3,460
Interest Receivable		11,273	16,462
<b>Total Current Assets</b>		<b>984,241</b>	<b>896,574</b>
<b>NON-CURRENT ASSETS</b>			
Fixed Assets		10,715	11,907
<b>Total Assets</b>		<b>994,956</b>	<b>908,481</b>
<b>CURRENT LIABILITIES</b>			
Accounts Payable		80,762	59,470
Employee Entitlements	11	27,837	20,737
Income in Advance McGregor Bequest	9	55,000	55,000
Receipts in Advance		109,339	41,045
<b>Total Current Liabilities</b>		<b>272,938</b>	<b>176,252</b>
<b>Total Liabilities</b>		<b>272,938</b>	<b>176,252</b>
<b>NET ASSETS</b>		<b>\$722,018</b>	<b>\$732,229</b>
Represented by:			
<b>ACCUMULATED FUNDS</b>			
Accumulated Funds		722,018	732,229
<b>TOTAL ACCUMULATED FUNDS</b>		<b>\$722,018</b>	<b>\$732,229</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

10 March 2011



Phillip Cowley  
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 \$24,496 at year end (2009:\$24,011), and a net surplus/ (deficit) of \$484 was recorded for the year end by the Trust (2009: \$172).

**(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 \$296,697, 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 (2009:\$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**

	2010 \$	2009 \$
<b>Office Equipment</b>		
At cost	69,403	64,517
Less Accumulated Depreciation	58,688	52,610
<b>Total Fixed Assets</b>	<b>\$10,715</b>	<b>\$11,907</b>

**7. OPERATING LEASE COMMITMENTS**

Operating lease expenditure committed to but not recognised in the financial statements.

	2010 \$	2009 \$
Not later than one year	12,950	-
Later than one, not later than two	875	37,950
Later than two, not later than five	10,004	13,687
	<b>\$23,829</b>	<b>\$51,637</b>

**8. BAD DEBTS**

Bad debts comprise -

Debts that in the opinion of National Council are unlikely to be recovered.

**9. 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.

**10. DIRECTORS FEES**

An honoraria payment of \$2,100 was made to the President of the Haemophilia Foundation of NZ. The nature of this payment was to compensate the President for loss of earnings for time spent as an executive committee member of the World Federation of Haemophilia.

**11. EMPLOYEE ENTITLEMENTS**

Employee entitlements is a liability accruing to employees in respect of wages and salaries, annual leave, long service leave and sick leave.

	2010 \$	2009 \$
Holiday par accrual and other benefits	<b>\$27,837</b>	<b>\$20,737</b>

NOTE: These notes form part of and are to be read in conjunction with the accompanying Financial Statements.

# HFNZ Auditors Report



## Independent Auditors' Report

to the members of the Haemophilia Foundation of New Zealand Inc

### Report on the Financial Statements

We have audited the financial statements of the Haemophilia Foundation of New Zealand Inc on pages 18-20, which comprise the statement of financial position as at 31 December 2010, the statement of financial performance and statement of movement in accumulated funds for the year then ended, and a summary of significant accounting policies and other explanatory information.

### National Council Responsibility for the Financial Statements

The National Council is responsible for the preparation and fair presentation of these financial statements in accordance with generally accepted accounting practice in New Zealand and for such internal controls as the Foundation determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

### Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with International Standards on Auditing (New Zealand) and International Standards on Auditing. These standards require that we comply with relevant ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditors' judgement, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers the internal controls relevant to the entity's preparation of financial statements that give a fair view of the matters to which they relate, in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

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

PricewaterhouseCoopers, 5 Sir-Gil-Simpson Drive, Burnside, Christchurch 8053, New Zealand  
T: +64 (3) 374 3000, F: +64 (3) 374 3001, www.pwc.com/nz

# Treasurer's Report



## Independent Auditors' Report The Haemophilia Foundation of New Zealand Inc

**Basis for Qualified Opinion**  
In common with other organisations of a similar nature, control over the revenues from donations prior to being banked is limited. It was not practicable to extend our examination of donations beyond the accounting for amounts received as shown by the accounting records of the Foundation, or to determine the effect of the limited control.

In this respect alone we have not obtained all the information and explanations we have required.

**Qualified Opinion**  
In our opinion, except for the effects of the matter described in the Basis for Qualified Opinion paragraph, the financial statements on pages 18-20.

- (i) comply with generally accepted accounting practice in New Zealand; and
- (ii) present fairly, in all material respects, the financial position of the Association as at 31 December 2010 and its financial performance for the year ended on that date.

**Restriction on Distribution or Use**  
This report is made solely to the Foundation's members, as a body. Our audit work has been undertaken so that we might state to the Foundation's members those matters which we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Foundation and the Foundation's members, as a body, for our audit work, for this report or for the opinions we have formed.

Chartered Accountants  
10 March 2010

Christchurch

**HFNZ has a balance date for annual accounts of 31 December.**  
The following notes are included in the 2010 acknowledgements.

### Income and Expenditure

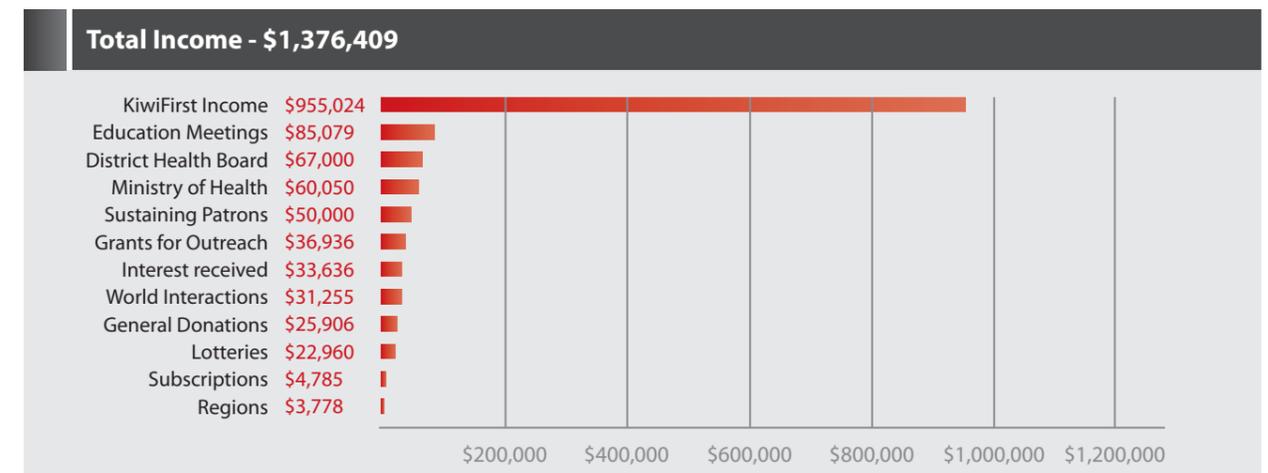
Income is down 6% on 2009. Kiwifirst income was down 5.1%. Disasters in the South Island have had impact on the charitable sector to some degree with the New Zealand public diverting their charitable giving towards Greymouth and Christchurch.

Expenditure is down 2.3% on 2009. Kiwifirst expenditure was down 4.9%. Other Expenses are \$675,435 and include the larger items of wages costs \$324,470 (2009 \$288,835), and education meetings for members, such as camps and workshops, expenses \$101,530 (2009 \$73,003). For further breakdown see graphs and tables below.

### Summarised income & expenditure

The following outlines a detailed list of income and expense for 2010:

#### 2010 Income

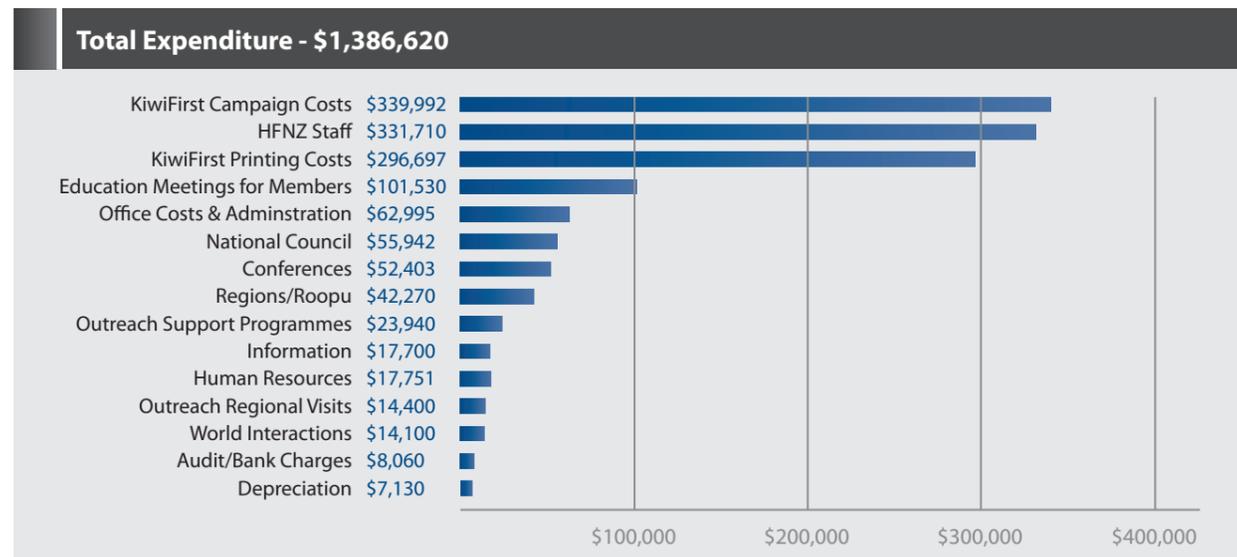


#### Details of 2010 HFNZ Income

<b>KiwiFirst Income</b> Public donations	<b>Education Meetings</b> AXA Hearts in Action Bayer Baxter Hastings District Masonic Lodge Novo Nordisk Sovereign Sunshine
<b>District Health Board</b> Outreach	<b>Ministry of Health</b> Support for PWH & Hepatitis C
<b>Sustaining Patrons</b> Baxter Bayer CSL Novo Nordisk Pfizer	<b>Grants for Outreach</b> Canterbury Community Trust COGS Christchurch Banks Peninsula COGS Central Otago COGS Waitakere City COGS Kirikiriroa Hamilton COGS Marlborough

<b>Interest received</b> Westpac Trust Taranaki Savings Bank Southland Building Society	<b>World Interactions</b> Baxter Bayer CSL Novo Nordisk Roche Pfizer
<b>General Donations</b> Community Post Armageddon Lindisfarne College Give a Little	<b>Lotteries</b> Administration support
<b>Subscriptions</b> HFNZ Members Subscriptions	<b>Regions</b> Regional Camp Fees Bequests

**2010 Expenditure**



**Details of 2010 HFNZ Expenditure**

<b>KiwiFirst Campaign costs</b>  <b>HFNZ Staff Wages</b> Chief Executive Officer Manager Outreach Services National Information Coordinator Administrator Northern Outreach Midland Outreach Central Outreach Southern outreach <b>Kiwi Saver</b> Employer contribution <b>ACC</b> Levies for staff (8)	<b>KiwiFirst printing costs</b>  <b>Education Meetings for Members</b> New Families Camp Wellness Weekend Parents Educating Parents National Children's Workshops Grandparents Day
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<b>Office Costs &amp; Administration</b> National Office Rent Outreach offices Phones/Post/Stationary Staff Amenities Professional Fees MYOB ACEET admin Staff Travel & Accommodation Insurance	<b>National Council</b> Council Meetings (x 4) Annual General Meeting Appreciations Assets Under \$500 Seminars President Travel Volunteering Programme National Haemophilia Management Group
<b>Conferences</b> WFH Congress Hepatitis C Conference Tender Training Volunteering Conference Physiotherapy Conference	<b>Regions /Roopu</b> Roopu (Māori) Northern Branch Expenses Midland Branch Expenses Central Branch Expenses Southern Branch Expenses
<b>Outreach Support Programmes</b> Support to Individuals Exercise programme Supportive Footwear Defensive Driving	<b>Information</b> Bloodline magazines Information Posters Leaflets Hepatitis C Info - Database Info - Website Maintenance Subscriptions
<b>Human Resources</b> Staff meetings (x 3) Interviews Supervision Travel & Accommodation Advertising Staff Training Outreach Administration staff ANZSWC Meeting Training/Workshop's/Seminar/ NACCHO	<b>Outreach Regional Visits</b> Southern Central Midland Northern
<b>World Interactions</b> World Haemophilia Day Global Feast Global Alliance Programme Contribution Twinning WFH Executive Committee	<b>Audit &amp; Bank Charges</b> Audit costs Suspense Account Professional Fee-Accounting Professional Fee -Legal Bank Fees
<b>Depreciation</b>	

Full Financial Statements including the Auditor's Report can be found on pages 18 to 22.

*Phillip Cowley*  
 Phillip Cowley  
 HFNZ Treasurer 2010



## Allan Coster Education Endowment Trust (ACEET)

**This has been a year of change and clarification for ACEET as there are two new trustees and new Outreach Workers.**

### Applicants 2010

Of the eight applicants, all of whom were male, six were successful. Four were for tertiary studies (civil engineering, BA/LLB, retraining as electrician, IT diploma) and two were for primary pupils (tutoring).

Candidates all live in North Island cities.

### Finances

Income available for distribution has been severely constrained by low interest rates and only one small donation giving a total income of \$7,424. With no funding from HFNZ, the need to protect the inflation adjusted capital value at the end of 2010 of \$160,000, as per the Trust Deed, and to pay, for the first time, accounting and audit fees of \$1,109, available funds were further reduced. This resulted in grants paid and owing of \$8,650 and a deficit for the year of \$2,335. The financial situation has been presented to HFNZ who have subsequently agreed to fund the cost of audit and trustee attendance to an annual face to face meeting.

### General

This year has seen the resignation of trustee Barbara Sutherland and we thank her for her many years of hard work and thoughtful decisions on behalf of ACEET. She has been replaced by Mike Carnahan, another former President of HFNZ with a wealth of knowledge and experience. Welcome Mike.

The trustees had their first face to face meeting in June 2010 and have otherwise communicated by telephone and email. The history of ACEET grants was reviewed - in all, 62 grants have been awarded to 47 recipients ranging in age from 4 to 42 years. There are two broad categories, early school age for remedial reading and maths and later for tertiary fees. Grants for computers other than for special needs ceased in 2004. The increasing numbers of requests for help with learning difficulties at 7 and 8 year old level is of concern and reflects in part decrease in available funds for special needs through the education system. Where the problem is significantly influenced by time away from school caused by a bleeding condition, the Trustees feel able to support a grant. However, where the learning difficulty is major and the bleeding defect is clinically minimal this is more difficult. Ongoing help is clearly needed for these children and other funding avenues as well as good information about long term effectiveness of tutoring is needed.

It is important that applicants follow guidelines in terms of application preparation, providing adequate information about the proposed course of study and ensuring that the application is filed in time. It should also be noted that funding is not provided retrospectively for completed studies.

Keep the feedback letters coming - they are an important condition of accepting a grant.

The trustees express their appreciation to the Outreach workers for their assistance in helping to prepare applications and following up grant recipients.

## ACEET Financial Statements

### Statement of Financial Performance

For the Year ended 31st December 2010

REVENUE	2010 \$	2009 \$
Interest	7,324	7,294
General Donations	100	3,000
<b>TOTAL REVENUE</b>	<b>7,424</b>	<b>10,294</b>
EXPENSES		
Accountancy Fees	253	-
Audit Fees	793	-
Bank Charges & Interest	13	35
Grants	8,650	5,175
General Expenses	50	458
<b>TOTAL EXPENSES</b>	<b>9,759</b>	<b>5,668</b>
<b>NET SURPLUS/(DEFICIT)</b>	<b>\$(2,335)</b>	<b>\$4,626</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 2010

	2010 \$	2009 \$
Balance at Beginning of Year	167,146	162,520
SURPLUS		
Net Surplus/(Deficit)	(2,335)	4,626
<b>Total recognised revenues &amp; expenses</b>	<b>(2,335)</b>	<b>4,626</b>
<b>BALANCE AT END OF YEAR</b>	<b>\$164,811</b>	<b>\$167,146</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 2010

	2010	2009 \$
<b>CURRENT ASSETS</b>		
ASB Cheque A/C	721	3,319
ASB Accelerator A/C	5,106	-
ASB Short Term Deposits	160,000	163,714
Interest Receivable	3,085	1,762
<b>Total Current Assets</b>	<b>168,912</b>	<b>168,795</b>
<b>TOTAL ASSETS</b>	<b>168,912</b>	<b>168,795</b>
<b>CURRENT LIABILITIES</b>		
Accounts Payable	4,101	1,649
<b>Total Liabilities</b>	<b>4,101</b>	<b>1,649</b>
<b>NET ASSETS</b>	<b>\$164,811</b>	<b>\$167,146</b>
Represented by:		
<b>ACCUMULATED FUNDS</b>		
Accumulated Funds	164,811	167,146
<b>TOTAL ACCUMULATED FUNDS</b>	<b>\$164,811</b>	<b>\$167,146</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;

Mike Mapperson  
Trustee



Mike Carnahan  
Trustee



10 March 2011

## Notes to the Financial Statements - For the Year ended 31st December 2010

## 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 &amp; 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 audit fees of \$793 disclosed in the Statement of Financial Performance.

## 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



## Independent Auditors' Report

to the trustees of the Allan Coster Education Endowment Trust

## Report on the Financial Statements

We have audited the financial statements of the Allan Coster Education Endowment Trust on pages 27-28, which comprise the statement of financial position as at 31<sup>st</sup> December 2010 and the statement of financial performance and statement of movements in accumulated funds for the year then ended, and the notes to the financial statements that include a summary of significant accounting policies and other explanatory information.

## Trustees' Responsibility for the Financial Statements

The Trustees are responsible for the preparation of financial statements in accordance with generally accepted accounting practice in New Zealand and that present fairly the matters to which they relate and for such internal controls as the Trustees determine are necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

## Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with International Standards on Auditing (New Zealand) and International Standards on Auditing. These standards require that we comply with relevant ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditors' judgement, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers the internal controls relevant to the Trust's preparation of financial statements that present fairly the matters to which they relate, in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Trustee's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Other than in our capacity as auditors we have no relationship with, or interests in, the Allan Coster Education Endowment Trust.

PricewaterhouseCoopers, 5 Sir Gil Simpson Drive, Burnside, Christchurch 8053, New Zealand  
T: +64 (3) 374 3000, F: +64 (3) 374 3001, www.pwc.com/nz



### Independent Auditors' Report

Allan Coster Education Endowment Trust

#### Opinion

In our opinion, the financial statements on pages 27-28

- (i) comply with generally accepted accounting practice in New Zealand; and
- (ii) present fairly, in all material effects, the financial position of the Trust as at 31<sup>st</sup> December 2010, and its financial performance for the year ended on that date.

#### Restriction of Distribution or Use

This report is made solely to the Trustees, as a body. Our audit work has been undertaken so that we might state to the trustees those matters which we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Trust and the Trustees, as a body, for our audit work, for this report or for the opinions we have formed.

Chartered Accountants  
10<sup>th</sup> March 2011

Christchurch

PricewaterhouseCoopers, 5 Sir-Gil-Simpson Drive, Burnside, Christchurch 8053, New Zealand  
T: +64 (3) 374 3000, F: +64 (3) 374 3001, www.pwc.com/nz

## 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 effects 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	

# HFNZ Directory

## National Council 2010

President:	Deon York
Vice Presidents:	Catriona Gordon Grant Hook
Treasurer:	Philip Cowley
Northern Branch Delegate:	Richard Scott
Midland Branch Delegate:	Lee Marjoribanks
Central Branch Delegate:	Michael Ho
Southern Branch Delegate:	Mark Uren
Youth Delegate:	Karl Archibald
Māori Delegate:	Joe Wrathall

## Branches 2010

Northern Branch Chair:	Michael Mapperson
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) 371 7477  
Fax: (03) 371 7479  
Email: info@haemophilia.org.nz

### Chief Executive Officer:

Belinda Burnett  
Ph: (03) 371 7477  
Fax: (03) 371 7479  
Email: belinda@haemophilia.org.nz

### Administrator:

Leanne Pearce  
Ph: (03) 371 7477  
Fax: (03) 371 7479  
Email: leanne@haemophilia.org.nz

### National Information Coordinator

Chantal Lauzon  
Ph: (03) 371 7477  
Fax: (03) 371 7479  
Email: chantal@haemophilia.org.nz

## Staff...

### Haemophilia Outreach Workers (HOW) Manager Outreach Services

Colleen McKay  
PO Box 7647, Sydenham, Christchurch 8240  
Ph: (03) 371 7477  
Fax: (03) 371 7479  
Email: colleen@haemophilia.org.nz

### Regional Outreach Workers

Free Phone : 0508 FACTOR

## Nominated Service Providers

### Solicitor

Sandford & Partners  
PO Box 99, Rotorua  
law@sandfordpartners.co.nz

### Auditor

Pricewaterhouse Coopers  
PO Box 13244  
Christchurch 8141

### Banker

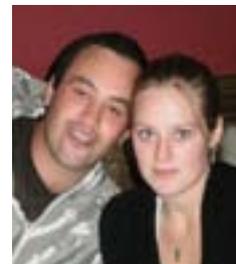
Westpac  
Manukau City, Auckland

### 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



Haemophilia Foundation of New Zealand Inc.

**HFNZ**

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Christchurch  
New Zealand

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Email: [info@haemophilia.org.nz](mailto:info@haemophilia.org.nz)  
Web: [www.haemophilia.org.nz](http://www.haemophilia.org.nz)

