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HFNZ ANNUAL REPORT COVERING JULY 1 2014 - JUNE 30 2015





The Haemophilia Foundation of New Zealand Inc. (HFNZ) was established in 1958 to connect and support people with Haemophilia and other rare bleeding disorders across New Zealand. HFNZ is a member of the World Federation of Hemophilia, which is officially recognised by the World Health Organisation. Today, thanks to the energy and drive of our members and supporters, HFNZ continues working for all those dealing with Haemophilia, von Willebrand's disorder, and a range of other inherited bleeding disorders.

This year's Annual Report highlights the power and importance of a connected network of members, supporters, and outside agencies. The participation and support of our members, supporters, and families, alongside government and business, helps make our workshops, regional events, and Outreach consultations happen. This connectivity is what makes it possible for HFNZ to continue to deliver on our mission:

To improve the lives and long-term outcomes for people with bleeding disorders (PWBD), enabling active, independent, and fulfilling lives.

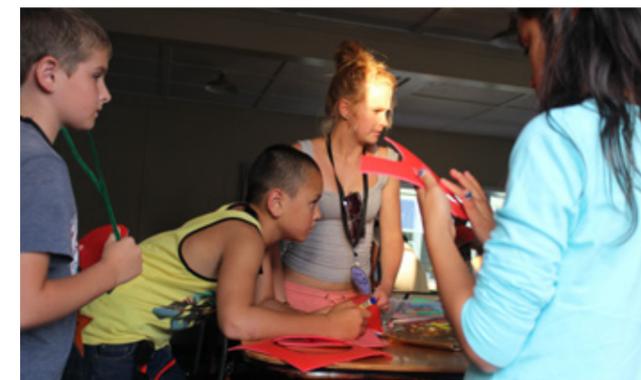
In this report you will see just how HFNZ's close connection to our members, to their families, and to the wider community keeps us all moving forward strongly. You will see smiling faces, determined eyes, and passionate hearts. You will see our people.

What you can't see in a report such as this, however, are all the generous New Zealanders who donate to HFNZ, all the grant-makers, government agencies, and pharmaceutical companies who provide support for HFNZ programmes and activities. Their support is the cornerstone to all the great work we are able to do.

Haemophilia and other inheritable bleeding disorders such as von Willebrand's Disorder are rare lifelong chronic conditions. In people with bleeding disorders the blood platelets, or proteins called clotting factors, do not work correctly or are in short supply. This means their blood cannot clot properly and they can suffer extended bleeding, especially after injury, surgery, or sometimes just doing daily tasks that most of us take for granted.

Each HFNZ member is a unique individual, yet they all have this one key thing in common – they are an integral part of the larger NZ bleeding disorder community. HFNZ creates ways to connect and unify this community, empowering those affected by haemophilia and related bleeding disorders.

Despite recent advances in genetic technology, a cure to these related bleeding disorders remains elusive. However, HFNZ's dedicated Outreach Workers, our innovative educational initiatives and camps, our physical activity and supportive footwear programmes, and our educational grants, continue to support people with these chronic disorders through all stages of their lives. We provide the tools to give people with bleeding disorders a voice and try to ensure they receive the best care that medicine can offer



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Patron's Message

By Dr. Elizabeth Berry



This is my 7th year as patron for the Haemophilia Foundation of New Zealand (HFNZ) and it is a pleasure to see the organisation continue to flourish and grow.

Support, encouragement, and advocacy have always been the main aims of the Foundation, and the enthusiastic and appreciative reports of educational and other activities, particularly camps and workshops, are a delight to read. They are a testament to how successful the HFNZ is in meeting the needs of members. Family camps have been in operation for 40 years but there are now a range of workshops and weekend camps for different age groups, partners, women with bleeding disorders, and couples. For the first time this year a Young Leadership Training Weekend was held. What a wonderful opportunity and source of inspiration for these young people.

Another very fitting and new innovation was the Buddy Award to recognise and celebrate the significant medical, emotional, and practical support provided by family friends, healthcare professionals, teachers, and others to people with bleeding disorders. The individual stories are inspirational.

The HFNZ also plays an important role in interacting with health services to ensure that the best possible replacement products, antiviral agents, and physical facilities are available for those with bleeding disorders. I am pleased to see that there is direct and ongoing consultation with Pharmac, the major funding agency, about these critical aspects of management. The importance of effective haemophilia treatment was very much in my thoughts recently when I visited Russia and traced the paths of the Romanovs and Rasputin. I pondered how different

European history might have been had Tsarevitch Alexsei not had the 'Royal' gene. Today, an infant born with haemophilia can expect to live a relatively normal life - what a long way we have come!

On the international scene the 4 year twinning programme with Cambodia is now completed, and a strong, independent, patient-led Cambodian organisation established, thanks largely to the support and knowledge of HFNZ.

Many other activities are mentioned in the annual report and as you will see 2015 has been another very busy and successful year for the HFNZ. I congratulate and thank all those who have given financial support and continue to give their time so generously. The Foundation is certainly doing a wonderful job for its members.





President's Report

By Deon York

I concluded my report last year by writing that change brings opportunity. Reflecting on the past year, change certainly has brought us opportunity but it has equally brought some uncertainty to our community.

As at June 2015 we were on the verge of announcements affecting the products available for use in New Zealand to treat bleeding disorders. While all proposed are safe and efficacious, the change is more than a new factor concentrate; it means adjustments to the routine, learning how to draw up a new product, and it can create anxieties. Exciting developments in hepatitis C treatment have heralded a new and highly effective treatment with a success rate of over 90%. Of the 186 members originally infected with hepatitis C through contaminated blood products, 39 remain affected. This reduction in members living with hepatitis C is bittersweet. For many this is a result of completing a successful course of treatment, but in some cases it has been a heart-breaking loss to a family and a community. This is why access to the most effective treatment for all 39 of these people remains a priority for us. The changes of 2014/15 have only emphasised the continuing importance of a strong national organisation dedicated to improving the lives of people with haemophilia and related bleeding disorders.

This past year has highlighted the remarkable commitment of our staff as they have supported our new CEO, as well as the dedication of our many volunteers as they support each other. A key challenge this year has

been to ensure that we support our community as a whole, so that we are not contributing to widening inequities. While our core work is for relatively rare bleeding disorders, the needs of our community are varied. This year I have seen a very positive and resilient community emerge, despite the challenges that we all face together.

Membership

As at 30 June 2015, HFNZ represents approximately 1074 individuals with a bleeding disorder. The membership comprises 437 (41%) people with haemophilia A or B, 383 (36%) carriers, 211 with von Willebrand's Disease (19%) and 43 (4%) with a rare bleeding disorder.

Funding

We could not deliver many of our services without the donations fundraised with the help of KiwiFirst Limited. It is through them that the New Zealand public can donate to our cause. We are truly grateful for the support given by such a wide range of people. Without this, we would not be able to deliver the support that our members need.

HFNZ remain fortunate to have a group of outstanding supporters who have committed to making an investment in our programmes and educational workshops. We gratefully acknowledge the support of Baxalta, Bayer Healthcare, Novo Nordisk Pharmaceuticals Ltd, and Pfizer Ltd.

We are also contracted by the Ministry of Health to support our members

with Hepatitis C, as well as by District Health Boards through the National Haemophilia Management Group which part-fund our Outreach services.

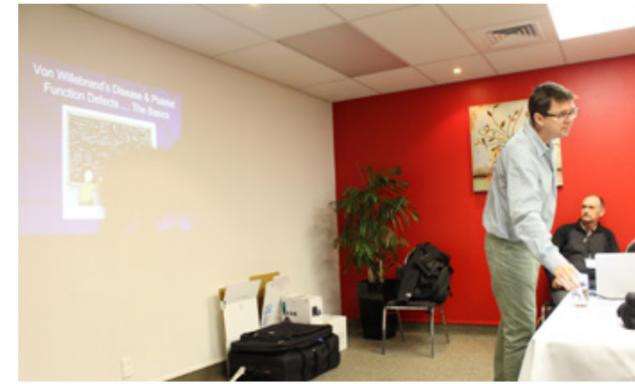
We appreciate the many charitable organisations and trusts that have contributed funding towards a range of our programmes and services. All contributors to our mission are detailed in the financial report.

Representation

The National Council, the governing body of HFNZ, represents and is comprised of people whose families are affected by bleeding disorders. In addition to the officer holders, who are elected nationally, our six Member Representative Groups each elect a delegate to National Council to represent them.

In 2014/2015, the following people served on the National Council:

- Vice-President: Catriona Gordon (Midland)
- Vice-President: Richard Scott (Northern)
- Treasurer: Grant Hook (Central)
- Youth Delegate: Hemi Waretini (Northern)
- Māori Delegate: Patience Stirling (Northern)
- Masters Group Representative: Willy Tekira
- Northern Delegate: Greg Jamieson
- Midland Delegate: Catriona Gordon



- Central Delegate: Stephanie Coulman
- Southern Delegate: James Poff

Richard Chambers (CEO, HFNZ) served as an *ex officio* member and Steve Waring (Managing Director, Kiwifirst) served as a co-opted member.

Affiliated Organisations

Catriona Gordon remained as the representative on the National Haemophilia Management Group. This group is responsible for the management of haemophilia services and brings together clinicians, funders, key stakeholders and the HFNZ as the consumer organisation. Once again, we thank Catriona for the time she has devoted on our behalf.

I continued on the World Federation of Hemophilia's (WFH) Board of Directors. I continue as Chair of the WFH Fundraising and Resource Development Committee and Co-Chair of the National Member Organization Capacity Building Committee and Youth Leadership Advisory Group. I also continue to remain involved in the areas of research and educational materials.

National Programmes

In addition to our important Outreach service, the HFNZ provides a number of beneficial programmes to promote the health and wellbeing of our members. The swimming and exercise programme supports swimming lessons, therapeutic swimming, and access to fitness equipment for people with moderate and severe bleeding disorders. HFNZ also provides vouchers for supportive footwear for those with severe bleeding disorders or joint damage as proper footwear is important in reducing the chance of ankle bleeds and long-term joint damage.

“We appreciate the many charitable organisations and trusts that have contributed funding towards a range of our programmes and services”

Every year, the HFNZ runs a range of national educational workshops to target the needs of our members and deliver our core mission: to support people with bleeding disorders. Over the last year, HFNZ have held several workshops, including:

- National Inhibitors Workshop, Auckland. July 2014
- Youth Leadership Weekend, Christchurch. August 2014
- National Family Camp, Rotorua.

January 2015

- Parents Empowering Parents Weekend. May 2015
- Adult Wellness Weekend, Wellington. June 2015

You can read more about these activities in other sections of this report.

Other Activities

HFNZ's formal twinning relationship with the Cambodian Hemophilia Association (CHA) came to an end this year. While this has concluded, the relationship has

only deepened and HFNZ will continue to work with the region as resources allow. We have learnt and gained so much from working alongside the

CHA.

I would like to take this opportunity to personally thank all the dedicated members, volunteers, and staff for their efforts in making this year a successful one. We are all working together to make lives better for those with bleeding disorders and their families. With such a great network of support I am confident that we will have another great year ahead.

Deon York. HFNZ President



CEO's Report

By Richard Chambers



The 2014-15 year has been an interesting time to be involved with HFNZ, we have run Inhibitor, Youth Leadership, National Family and Adult Wellness workshops. Our Outreach team has been very active in leading these workshops and providing regular support for people with bleeding disorders and their whanau. We have held our very first buddy awards (aligned with World Haemophilia Day), developed a new strategic plan, pushed the government (via ACC) to honour to it's obligations to provide the best treatments available for people with haemophilia who have the Hepatitis C virus as the result of infected blood products, and more recently worked with Pharmac to address HFNZ concerns about changes to the funding

of Haemophilia Treatment Products.

Your Member Representative Groups (MRG) have been active in providing local opportunities to develop supportive relationships. Everyone of you has much to give and to receive from being active within your region. Get involved, stay involved, this is your organisation.

As we adapt to the changing health and well-being environment we must continue to look for strength from each other, our past, and keep our purpose, our kaupapa in the front of our minds "to improve the lives and long-term outcomes for people with bleeding disorders..."

As a foundation it is important that we honour our purpose in everything we do and in doing so respect those that fund our work; our donors, our sponsors and other funders. HFNZ is part of a team with Haemophilia Treatment Centres, the National Haemophilia Management Group and Treeters group. Each part of the team brings vital skills and passion to "improving lives".

Piritoto (Tangata whenua MRG) recently held a Noho where a whakatauki was developed and is being proposed for the use of HFNZ. *He toto, he taimaha kia piri, tukua kia rere*, The blood, the burden that binds us, let it be free. The whakatauki reminds us that a bleeding disorder does not define the person, every person is their own creation.



Outreach Report

By Colleen McKay



For people with bleeding disorders and those who care for them.

HFNZ Outreach Workers offer support and services to people with bleeding disorders, and their whanau/family, across New Zealand. HFNZ has four region-based Outreach Workers, covering the Northern, Midland, Central, and Southern regions, whose role is to support and inform people affected by bleeding disorders and their whanau/family members.

HFNZ Outreach Workers provide education, support, and advocacy. They understand bleeding disorders and the New Zealand health and social services sector. HFNZ's Outreach Service is provided free of charge to all people affected by bleeding disorders. This service is funded through donations, grants, and government support.

Our Outreach Workers will help you to access the information you need about your, or your child's, bleeding disorder, from initial diagnosis and as you progress through the different life stages. Our Outreach Workers are committed to working in partnership with people affected by bleeding disorders, and their families/whanau, to help them to identify their own needs and to support them to achieve their potential. They help to explain often complex information and how it applies to your situation. They also help you to understand health and support systems and help you to access services where necessary, as well facilitating communications and co-operation between individuals and agencies.

Your Outreach Worker is available by phone, text, email, Facebook, and in person. Outreach Workers have many clients, so it is important that you contact them when you need them.

They are never too busy for you. They have flexibility to support individuals and families in different ways based on specific need.

Here's what one member had to say about their Outreach Worker:

"She is always helpful in every field. I always feel positive after meeting her and discussing things with her. She helps me to make decisions regarding my job, my health ... And I feel that there is someone who is always there to help me."

You're always welcome to contact your local Outreach Worker with any questions or regarding your, or your child's, bleeding disorder.

Just Call 0508FACTOR

All Outreach Workers work part-time and will respond to phone messages and emails as soon as they are available.



Member Representative Group Reports

HFNZ is all about the people, so we have seven Member Representative Groups that embody the different parts of our community. There are four Regional Branches; Northern, Midland, Central, and Southern; Piritoto representing our Maori members; the National Youth Committee; and the Masters Group. Each group has elected office-holders and a committed group of volunteers to keep it running smoothly. Our Member Representative Groups are the glue that keep HFNZ connected to its members across New Zealand.

Northern

The last year was a successful year for the Northern branch with some new members on the committee and many successful events.

With larger numbers turning up to events our costs have been higher and the year ahead may see slightly fewer events and some trimming of costs, but we have still got a great programme planned. The region is growing in diversity with many nationalities represented at events, which is great to see, and we hope that we can maintain this engagement across many cultures going forward.

The highlights of the year were the Christmas party at Rainbow's End, the Summer Camp (including the Karaoke competition), and the Buddy Awards and hike up Mt Rangitoto. We even got some press coverage in the NZ Herald.

Many people enjoyed the national events too and many northern members helped out at the New Families Camp and Teen and Youth camp. Thanks to everyone who turned up to events that were organised, it's great to see more people involved and meeting others.

It was good to finally get a new ADHB physio with specialist skills dealing with Adult Haemophilia patients. Those who

have had a break please get back into physio, as you will soon remember how much better you were health-wise.

Looking ahead, we have a new venue for summer camp. We have outgrown the Mangowhai heads camp and will be trying a larger venue. Upcoming events include our AGM, Genghis Khan dinner, Armageddon volunteering, Rock climbing, the men's fishing trip, and a Christmas party (venue yet to be determined). Challenges for the next year will be changes in product for many members as the Pharmac tender takes effect.

Also, we are always looking for new committee members and nominations will be needed two weeks before the AGM.

Richard Scott. Northern Chairperson



Central

Our region continued its tradition of an annual winter escape camp in September 2014 on the banks of the Whanganui River, attended by about 50 people. Although we are planning a camp in Taupo in 2015, the committee is considering changing our camp formula to every two years due to budget constraints.

To wrap up the year, members enjoyed a dinner cruise on the Wellington Harbour on 29 November 2014. It was a wonderful end to the year and great to see Wellington from a different perspective.

The Masters group has strengthened, literally and figuratively, with regular

hydrotherapy and physio gym sessions at Lower Hutt Hospital, in Wellington, which usually finish off with a coffee and a chat. The regular attendees find motivation and encouragement amongst their peers to pursue their physical health.

In April 2015 we celebrated our Buddy awards with a High Tea at the James Cook Hotel ceremony recognising four special people, all from Wellington.

Willy Tekira was nominated for an award by his nephew Ian Reddie for his positive attitude and dedication to his gym and physio sessions.

Dee Tekira was nominated by her husband Willy. For 42 years she has been by his side through good times and bad, and thoroughly deserved to be recognised.

BJ Ramsay was nominated by Marty Waring who said there was no comparison to the 'before BJ' level of haemophilia care and support.

Helen Dixon was nominated by Steve Waring for the difference her physio expertise has made to his health and fitness.

Stephanie Coulman. Central Chairperson



Midland

Midland held its AGM at Hobbiton, just out of Matamata in July 2014. It is a remarkable place to visit, and incredible to think that the set has been seen all round the world. Our members all enjoyed walking around and then finishing off with a beer at the Green Dragon Inn. As there was only one ring, we managed to get a committee elected without everyone disappearing on us. It was actually at the AGM that the new Adult Colouring-in craze started, with some committee members so engrossed in their drawings that they almost forgot to vote themselves on.

In December we organized a bus for an expedition to Rainbow's End. It was a huge amount of fun, with stomachs being left behind left right and centre.

In March we held a blow karting event at Papamoa which was attended by several families.

Joy did a great job rallying our teen

and youth following the National New Families Camp in January, resulting in Midland boys making up over half the attendees of the Teen and Youth Camp which was held in July.

We look forward to the coming year, meeting up with old friends and new families throughout our region.

A huge thanks to Joy, who does so much for our members.

Catriona Gordon. Midland Chairperson



Southern

The Southern MRG have had some fantastic events over the 2014/2015 period.

Take a Kid to Footy in the winter months is a good chance for the hardy to get out and support the Crusaders.

August was the Southern AGM which was held at the amazing Antarctic Centre. There was a fantastic turn out and the opportunity to look through this wonderful attraction after the AGM and afternoon tea.

Another amazing Southern MRG camp was held at Tea Pot Valley in Nelson. The snow through the pass made a long day for those who didn't have chains, and had to back track around the long way via Kaikoura. Some battled through the snow, oblivious to those that had been turned around.

All an adventure for the families who attended!! The children and adults enjoyed the full range of activities at the camp, a trip to an animal farm and a market morning for mums. Everyone had a memorable trip from Kaiteriteri to Bark Bay! It was great to see the children have such a good time and again, for

parents to meet, or to reconnect.

Also in October the Youth had a night out, to consolidate all their hard work, plans, and ideas on the back of the Leadership Weekend.

The Xmas event was again held at the Groynes with Santa in attendance.

A good representation from Southern went to the Families Camp in January 2015 in Rotorua, and fun was had by all that attended.

A Southern Men's dinner was held in February and more events for the wider group are planned.

Armageddon events were held in both Dunedin and Christchurch with HFNZ supporters using this as a great fundraising opportunity.

In April, to celebrate World Haemophilia Day, Buddy Awards were held at the Christchurch Gondola and some very special people were awarded certificates, nominated by people who they have helped on their journey. Big thanks to Robyn Coleman for the organisation.

In May another successful fundraising event was held. In conjunction with Heather Giles and Brick Road

Productions, tickets to the play Shirley Valentine were sold, and a fair portion of the sales went to the HFNZ. Supporters bought a plate and Lorraine again supported with wonderful raffle prizes, and Karl was our trusty barman!

Big thanks to the Outreach Coordinator Linda, and all of the formal and informal supporters of the Southern MRG. Lyn Steele continues to support unconditionally so special acknowledgement for her contribution.

Everyone has busy lives and I truly appreciate the support that you have given over the last year.

James Poff. Southern Chairperson



National Youth Committee

As always, it's been a busy year for all youth involved in the National Youth Committee. We are always looking for new members for our Youth Committee and any ideas/contributions for events are welcome from everyone!

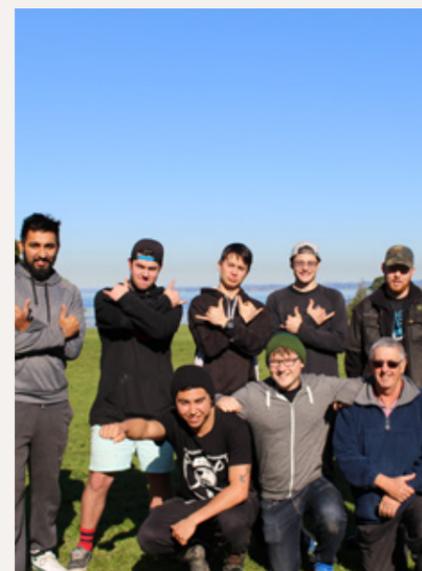
Whilst we haven't had any major events this year, we are constantly looking for ideas that push the boundaries of what people with bleeding disorders can do, but that also come within our budget. Our plan with future National Youth events is to keep the focus on activities that help us to keep active. The latest ideas involve the Queen Charlotte track in Nelson, Kayaking the Wanganui River and something in the Central Plateau – a region where there are plenty of things that would keep us busy! Our plan is to restrict National events to every two years due to budgeting but to fill in the gaps with some Regional events.

Our committee meeting in July was a chance for us to discuss the changes that are happening within the foundation, such as changes to our budget and the move to a 'preferred provider' system, as well as anything that is beneficial for youth with bleeding disorders in New Zealand. Each of the regional youth delegates provided a report about what has been happening in their regions, as well as discussing ideas for regionally focused youth events across all areas. We also worked on our 2-3 year plan and any regional and national events we can fit into this timeline in order to maximise and retain youth involvement. If anyone is keen to get involved and join our committee, make sure you let us know so we can get you on board!

Lastly, I would like to temporarily farewell Hemi on his adventure overseas and introduce myself as the Youth Delegate for National Council in his

absence. I would also like to thank the efforts of everyone involved with the National Youth Committee over the last year and extend an invitation for any youth who are keen to join us!

Courtney Stevens. Youth Committee Member



"He toto, he taimaha kia piri, tukua kia rere"

The blood, the burden that binds us, let it be free

Tena koutou katoa

Piritoto are continuing with one major event for the year. This year in June we gathered for a wonderful weekend Marae noho at Te Roro-o-Te Rangi Marae in Rotorua. Although quite makariri ki waho (cold outside) the Marae was heated by its natural thermal waters that kept everyone warm and happy. Another positive were the huge thermal baths at the Marae that were a great relief for those with joint pain and just a great time to chat with others while soaking away the day's events.

It was a pleasure to have our CEO Richard Chambers spend the weekend with us and involve himself really well with the Marae duties. Saturday morning was too wet to venture out, so when our manuhiri arrived for just the day's activities, we all participated in group discussions to chat over various topics with our CEO.

However the highlight of the weekend

was our afternoon spent at the tranquil Waikite Thermal pools, (yes I know, more chatting while relaxing in hot pools) and of course thoroughly appreciated by all those who attended.

A reminder to all HFNZ members that if we are participating in a Marae noho in your region, you are more than welcome to spend the weekend or even just a day with our Piritoto whanau, please don't hesitate to make enquiries with the outreach in your region.

I would like to acknowledge Tuatahi Pene for his commitment with the Hydrotherapy classes at Newmarket pools in Auckland. His kaupapa has been very timely while we have been without a Physiotherapist, his exercises combined with some Yoga sessions from Rosalie have been beneficial for all the attendees.

An acknowledgement also to Tama Pene for his stage performance at the 2015 Matatini with his roopu Te Iti Kahurangi from Hamilton, the hard work that's required for kapa haka at that level is so challenging, your commitment and wellness is impressive.

I would like to give a huge thanks to our roopu who continually volunteer their time to ensure our participation with HFNZ is a time for Whanaungatanga (connecting with each other) Awhi me te tautoko (embrace and support each other).

Therefore my gratitude firstly to our



Kaumatu/Kuia Pete Pene, Robyn Thomas and Helene Crown, who guide and maintain Tikanga and Kaupapa Maori for Piritoto.

And lastly to Piritoto Takawaenga - Te Whainoa Te Wiata, Rosalie Reiri, Hemirau Waretini, Tuatahi Pene, Tama Pene, Carol Reddy and Kahurangi Carter, your obligations to Piritoto is so commendable, nga mihi nui kia koutou.

He iti rā, he iti māpihi pounamu

Small things too, have their value

No reira e te whānau whānui

Tēna koutou Tēna koutou Tēna koutou Katoa

Patience Stirling. Piritoto National Council Delegate



Educational Events and Workshops

Every year HFNZ facilitate a range of events aimed at educating members and their families and whanau about different aspects of living with haemophilia and other rare blood disorders. Over the last year many people, from young children to adults, took part in one or more of our events. They had fun, met new people, and learned more about what it means to be a part of the HFNZ family.

2014 Inhibitor Workshop

The first Event of the HFNZ year was the inaugural Inhibitor Workshop on Friday 11th July. Families with haemophilia and inhibitors gathered in Auckland for a weekend of fun, education, and support at this Hollywood-themed event. The inhibitors workshop aims to help people with haemophilia and inhibitors and their families to better understand and cope with the unique challenges they face. 15-20% of people with haemophilia will develop an antibody, called an inhibitor, to the product used to treat their bleeding episodes. Developing an inhibitor is one of the most serious complications of haemophilia. Both the

person with inhibitors and the family face many challenges with inhibitors as the ongoing struggles associated with haemophilia are intensified. The 2014 HFNZ Inhibitor Workshop was a fantastic opportunity for individuals and families affected by this reality from across New Zealand to gather, learn and enjoy time together.

"The Inhibitors Workshop is great for people who spend a lot of time in hospital and have many bleeds to talk to others who understand this journey and can help make it easier."

Richard S.



2014 Youth Leadership Workshop

Future Leaders of HFNZ spent the weekend tapping into their leadership potential and thinking about ways that they could help shape the future of HFNZ. Discussions ranged around what it meant to be a leader, what opportunities existed within the HFNZ community, and who were their role models inside and outside the foundation.

There were educational sessions as well as chances to challenge themselves mentally and physically. A big favourite was high in the trees at Adrenaline Forest, where the young men and women had the chance to really test themselves and their leadership skills.

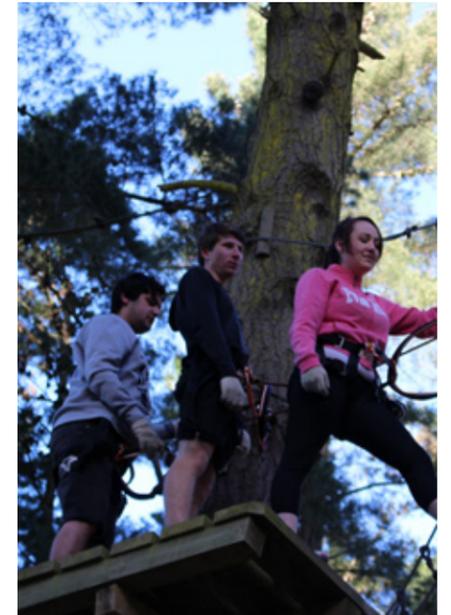
By the end of the weekend participants came away energised and ready to pursue a personal goal related to

community, and clearly a strong bond had developed between the Blood Brothers and Sisters.

These young men and women demonstrate great leadership attributes, possess great values, and have fantastic ideas to take into the future of HFNZ.

"The Youth Leadership Training weekend was a fabulous opportunity for the youth of HFNZ to get together, meet new people among the group, share ideas and plan for the future. The schedule was pretty tightly packed with workshops so the opportunity on Saturday afternoon to get outside in the fresh air, high up in the pine trees of Adrenaline Forest was relished by many."

Laura Rutten



2015 National Family Camp – Space Camp

It was Out of this World!!

HFNZ Space Camp, for families with a child aged 0 – 10 years who has a bleeding disorder, was great fun for young and old.

Every morning the Treatment Room was a hive of activity as parents and children learned self-infusion, or brushed up on their technique. This year we celebrated a record number of children learning to self-infuse for the first time.

The highlight for many parents is the 'Ask the Experts Panel Discussion' where they are able to ask youths with bleeding disorders what it's really like growing up with a bleeding disorder.

Adults also heard from HFNZ about how bleeding disorder care is delivered in New Zealand, and had an opportunity to contribute to HFNZ's strategic direction.

The family outing to Paradise Valley Wildlife Reserve was a chance for families to take some downtime, to see the lions being fed, and wander over the shady boardwalks visiting the other animals and sampling the waters of the spring. The Cosmic Disco, with so many great costumes from outer space and campers dancing the night away, was a highlight.

"Thanks for an amazing Camp. It was our first one. We were surprised (pleasantly) at how informative it was, and very well run with the kids being well looked after and occupied. We loved connecting with old and new friends, and particularly the connections our son Henry made with older boys whom he looks up to immensely. We WILL be back!!!"

Neil & Trinette Giborees-Smith



2015 Parents Empowering Parents Programme

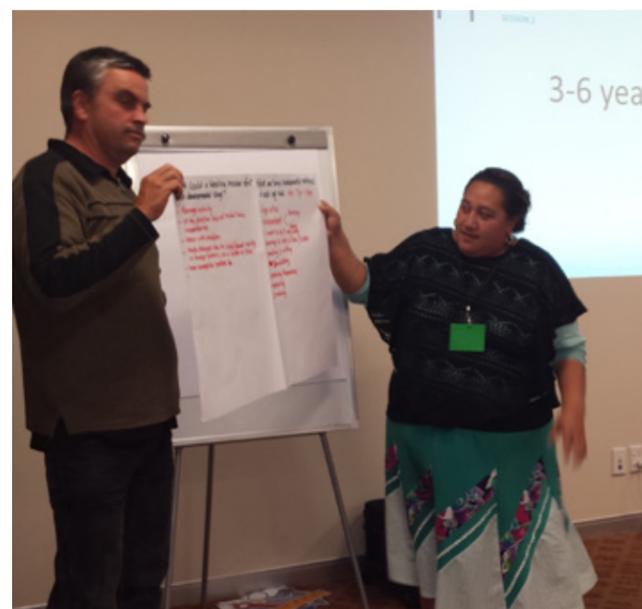
Raising a child with a genetic bleeding disorder is a challenge that impacts the entire family.

PEP – Parents Empowering Parents – is an international programme promoting positive parenting with a focus on the unique problems faced by parents of children with bleeding disorders. PEP aims to increase parent’s understanding of bleeding disorders, increase parenting skills, promote positive family functioning, and bring out a child’s potential. The programme is delivered by a trained team led by an Outreach Worker from HFNZ and including PEP-

trained parents of a child with a bleeding disorder and a Haemophilia nurse.

“Love the training material and life experiences of other parents and trainers...I appreciate the new methods empowering me to be a better parent. I will use the techniques learn with my wife to make our family closer and to have a better understanding of the conditions we have...”

“The most important message I will take away from the course is ... that I have achieved this goal to better myself as a mother and my children’s lives for a bigger and better opportunity”



2015 Adult Wellness Weekend

Adults with bleeding disorders and their partners from around the country flew into Wellington to share a weekend of learning, networking, and fun!

There were a range of educational sessions that catered to all participants, with bleeding disorders or without, from Haemophilia care to physiotherapy to platelet disorders. There were also interesting workshops where participants were able to share their experiences. Of particular interest was a session hosted by representatives of Pharmac, where there were some strong views expressed.

As well as the education there was time for some fun social activities too. We

got out and about to Te Papa and Weta Workshop, enjoyed a quiz night, and glammed it up at the Hollywood Glitz and Glamour dinner.

This was a great opportunity for adults with bleeding disorders, and their partners, to get away and focus on their own health and wellbeing.

“It was my first time to a weekend and we really enjoyed it. My partner found it most interesting and informative, he learnt more than I could teach him. Enjoyed listening to other people stories and meeting other women with the same problems as I had. So well organised, so much fun, would probably go again.”

Glenis Elliott

Financial Report

For the 12 Months Ended 30 June 2015

The Haemophilia Foundation of New Zealand recorded a small surplus for the year after several years of significant deficits. The surplus was the result of a combination of a significant one off bequest, the efforts of staff to manage costs, and the efforts of our fundraising team. The Foundation is well positioned going forward, retaining a capital base of \$420,650 for future property investment.

The recent updating of the foundation’s strategic plan has enabled us to closely align our budget with our core tasks and objectives. All of the foundation’s costs are aligned to our kaupapa, our purpose, which is to improve the lives and long-

term outcomes for people with bleeding disorders.

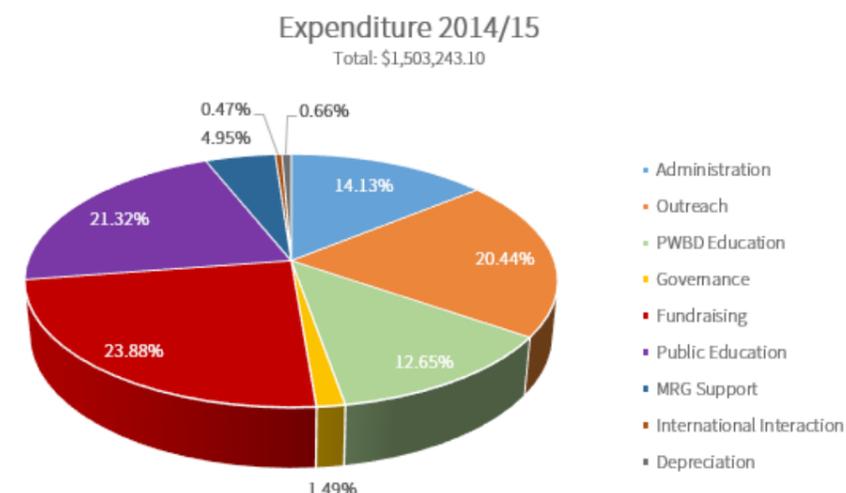
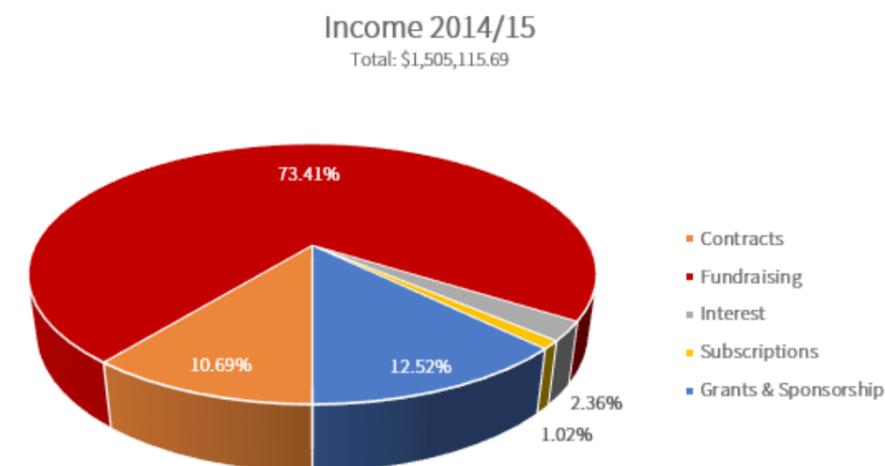
HFNZ is fortunate to have a very able public fundraising partner in KiwiFirst, they not only help us to raise funds, but also help to educate the wider community about how we can assist people with bleeding disorders.

The charity sector in New Zealand and HFNZ face interesting financial times; increased numbers of charities in New Zealand compete in a static funding pool. The Haemophilia Foundation must continue its focus on providing quality, cost effective educational and support

programmes for the bleeding disorder community. Having the right education and support in place (provided by HFNZ) and working with Haemophilia treatment Centres the costs for treating bleeding disorders and the consequences of bleeding disorders are significantly reduced for New Zealand.

Thank you to our donors, sponsors and partners; large and small for your contribution and support to improving lives of people with bleeding disorders and their families. Each of you make a positive difference.

Grant Hook, Treasurer



HFNZ Financial Statements

For the 12 Months Ended 30 June 2015

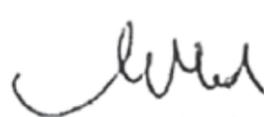
Statement of Financial Performance			
Haemophilia Foundation of NZ for the year ended 30 June 2015			
Account	Notes	12 Months Ended 30 June 2015	18 Months Ended 30 June 2014
Income			
Donations, Bequests & Grants		1,249,927	1,895,287
Other Revenue		219,737	296,051
Interest Income		35,452	41,446
Total Income		1,505,116	2,232,784
Expenses			
Depreciation		9,877	9,722
Audit Fees		475	11,047
Bank Fees & Interest Paid		278	2,500
Kiwifirst - Campaign & Printing Expense		679,570	1,012,604
Other Expenses		622,334	624,128
Rent & Office Expenses		190,709	617,684
Total Expenses		1,503,243	2,277,685
Net Profit (Loss)		1,873	(44,901)

Statement of Changes in Equity			
Haemophilia Foundation of NZ For the year ended 30 June 2015			
		12 Months Ended 30 June 2015	18 Months Ended 30 June 2014
Accumulated Funds			
Opening Balance		763,765	808,666
Current Year Earnings (Loss)		1,873	(44,901)
Balance at end of year		765,638	763,765

For and on behalf of the HFNZ National Council:



Deon York, HFNZ President
26 August 2015



Grant Hook, HFNZ Treasurer
26 August 2015

Statement of Financial Position				
Haemophilia Foundation of NZ as at 30 June 2015				
	Notes	12 Months Ended 30 June 2015	18 Months Ended 30 June 2014	
Assets				
Current Assets				
Accounts Receivable		108,513	120,476	
Bank Accounts and Investments		809,801	739,269	
Interest Receivable		3,172	23,646	
GST Receivable		20,733	12,600	
Prepayments		23,335	16,917	
Total Current Assets		965,554	912,908	
Non-Current Assets				
Property, Plant and Equipment	4	6,284	16,162	
Total Non-Current Assets		6,284	16,162	
Total Assets		971,838	929,070	
Liabilities				
Current Liabilities				
Accounts Payable		136,222	82,683	
Accruals		-	41,952	
Income Received in Advance		69,978	40,670	
Total Current Liabilities		206,200	165,305	
Total Liabilities		206,200	165,305	
Net Assets		765,638	763,765	
Equity				
Accumulated Funds		765,638	763,765	
Total Equity		765,638	763,765	

These financial statements should be read in conjunction with the accompanying notes and Independent Auditor's Report.

Notes to the Financial Statements

For the 12 Months Ended 30 June 2015

1. Statement of Accounting Policies

The financial statements presented here are for the entity Haemophilia Foundation of NZ. The financial statements comprise the National Office and four regional branches.

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.

2. Changes in Accounting Policies

There have been no changes in Accounting Policies during the year

covered by these financial statements. All policies have been applied on a consistent basis with those of the previous reporting period and in previous years.

The Minister of Commerce has approved a new Accounting Standards Framework developed by the External Reporting Board (XRB). Under this Accounting Standards Framework, The Haemophilia Foundation is classified as a public benefit entity and it is expected that it will be required to apply the new PBE Standards as applicable for private not-for-profit entities. These standards are being developed by the XRB based on current International Public Sector Accounting Standards (IPSAS). The

effective date for the new standards for private not-for-profit entities is expected to be for reporting periods on or after 1 April 2015. This means The Haemophilia Foundation expects to transition to the new standards in preparing its 30 June 2016 financial statements.

Due to the change in the Accounting Standards Framework for the public benefit entities, the XRB has effectively frozen the financial reporting requirements for the public entities up until the new Accounting Standard Framework is effective. Therefore all new NZ IFRS and amendments to existing NZ IFRS issued after 1 June 2012 will not be applicable to public benefit entities. Accordingly, no disclosure has

Depreciation Schedule

Haemophilia Foundation of NZ For the year ended 30 June 2015

Name	Cost	Opening Value	Purchases	Disposals	Depreciation	Accumulated Depreciation	Closing Value
Office Equipment at Cost							
Camera	1,010	559	-	-	375	826	185
Database	8,350	4,174	-	-	2,784	6,960	1,390
Epson Data Projector	1,114	315	-	-	223	1,022	92
Laptop - CL	1,995	1,309	-	-	655	1,340	655
Laptop - CM	1,995	1,309	-	-	655	1,340	655
Laptop - JB	1,995	1,309	-	-	655	1,340	655
Laptop - KR	1,045	522	-	-	348	871	174
Laptop - LC	1,995	1,309	-	-	655	1,340	655
Laptop - LD	1,995	1,309	-	-	655	1,340	655
Laptop - RC	1,758	645	-	-	586	1,699	59
Laptop - SP	1,758	645	-	-	586	1,699	59
Office 365	3,140	1,570	-	-	1,047	2,617	523
PA System & Speakers	577	415	-	-	166	328	249
Toshiba Copier/Printer	3,489	489	-	-	489	3,489	-
Workstation	923	280	-	-	-	643	280
Total Office Equipment at Cost	33,139	16,160	-	-	9,877	26,856	6,283
Total	33,139	16,160	-	-	9,877	26,856	6,283

These financial statements should be read in conjunction with the accompanying notes and Independent Auditor Report.

been made about new or amended NZ IFRS that exclude public benefit entities from their scope.

The Haemophilia Foundation of New Zealand changed their Balance Date from 31 December 2013 to 30 June 2014. Therefore the comparative figures in these accounts were for an 18-month period.

3. Differential Reporting

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 publicly accountable and not large as defined in the Framework of Differential Reporting.

4. Fixed Assets and Depreciation

All fixed assets are recorded at cost less accumulated depreciation.

	2015	2014
Office Equipment	33,140.49	33,140.49
Less Accumulated depreciation	(26,856.07)	(16,978.90)
Total Fixed Assets	6,284.42	16,161.59

Depreciation of the assets have been calculated at the maximum rates permitted by the Income Tax Act 2007, they were applied as follows:

Office Equipment:

40 - 67% Diminishing Value

Office Equipment:

0 - 33.34% Straight Line

5. Goods and Services Tax

These financial statements have been prepared on a GST-exclusive basis with the exception of Accounts Payable and Accounts Receivable which are stated inclusive of GST.

6. Revenue From Grants

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

7. KiwiFirst Income & Expenditure

The Haemophilia Foundation of New Zealand discloses the following information relating to KiwiFirst Income and Expenditure.

(i) KiwiFirst Income

KiwiFirst Income records all monies collected from the public.

(ii) KiwiFirst Expenditure

The cost of \$320,530 (2014: \$1,012,604) 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.

8. Capital Expenditure Commitments

There are no liabilities in respect of capital expenditure at balance date other than those provided for in the accounts (2014: \$0)

9. Contingent Liabilities

There are no contingent liabilities at balance date (2014: \$0). The Haemophilia Foundation of New Zealand has not granted any securities in respect of liabilities payable by any

other party whatsoever.

10. Related Parties

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

11. Securities and Guarantees

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

12. Bad Debts

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

13. Directors Fees

An honoraria payment of \$4,710 was made to the President of the Haemophilia Foundation of New Zealand (2014: \$5,300). The nature of this payment was to partially compensate the President for loss of earnings for the time spent as an executive committee member of the World Federation of Haemophilia.

14. Employee Entitlements

Employee entitlements are a liability accruing to employees in respect of wages and salaries, annual leave, long service and sick leave. The employee entitlements totalled \$37,545 (2014: \$34,918) for the period ended 30 June 2015.

15. Accounts Receivable

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

16. Audit

These financial statements have been subject to audit, please refer to Independent Auditors' Report.

INDEPENDENT AUDITOR'S REPORT

To the National Council of Haemophilia Foundation of New Zealand Incorporated

Report on the Financial Statements

We have audited the financial statements of Haemophilia Foundation of New Zealand Incorporated on pages 14 to 16, which comprise the statement of financial position as at 30 June 2015, the statement of financial performance and the statement of movements in equity for the year then ended, and a summary of significant accounting policies and other explanatory information.

Council's Responsibility for the Financial Statements

The 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 control as the Council determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's 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). Those standards require that we comply with 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 auditor's 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 internal control relevant to the entity's preparation and fair presentation of the financial statements 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 auditor, we have no relationship with, or interests in, National Council of Haemophilia Foundation of New Zealand Incorporated.

Opinion

In our opinion, the financial statements on pages 14 to 16:

- comply with generally accepted accounting practice in New Zealand;
- present fairly, in all material respects, the financial position of Haemophilia Foundation of New Zealand Incorporated as at 30 June 2015 and its financial performance for the year then ended.

Hilson Fagerlund Keyse

HILSON FAGERLUND KEYSE
26 August 2015
Christchurch

**HILSON
FAGERLUND
KEYSE**

CHARTERED
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Greg Cowles
B.Com, CA

Jane Jackman
B.Com, CA

Pamela Clarke
B.Com, CA

Craig Melhuish
BBS, CA, Grad Dip Bus,
Grad Cert Com (Hons)

Consultants:

Neville Fagerlund
M.Com (Hons), CA

Euan Hilson
B.Com

Kelran Horne
BOM, CA



HFNZ Statement of Service Performance

Description of Outcomes

To improve the lives and long-term outcomes for people with rare bleeding disorders providing quality comprehensive education for them and their whānau.

	Participants
Inhibitors Residential Workshop: July 2014	
Living with and managing life with a bleeding disorder and the complication of inhibitors	14
Youth Leadership Residential Workshop: August 2014	
Developing young people with bleeding disorders to be able to see opportunity for themselves and to support others	17
Young Family Residential Workshop: January 2015	
Information and support to families with young children with bleeding disorders in their early stage of understanding	100
Parents Empowering Parents: May 2015	
Empowering parents of young children with a bleeding disorder in their family life	12
Adult Wellness Residential Workshop: June 2015	
Support and education for adults and their partners in adulthood and as they age	55

Feedback

Inhibitors Workshop

The Inhibitors Workshop is great for people who spend a lot of time in hospital and have many bleeds to talk to others who understand this journey and can help make it easier

More than anything, I loved the chance to meet up and connect with the Inhibitor family. It can be such a lonely journey with inhibitors, so being together with others who know what it's like or who are on this journey is amazing.

The Inhibitor Workshop was awesome in increasing knowledge about y son's condition, helping make better informed choices and meeting others in a similar situation – building a greater support network for us

Young Families Workshop

Family camp for us has been firstly about learning, secondly about connecting with other families and reconnecting with those we have met along the way.

The education sessions are always so informative (and not always just about haemophilia). But the biggest benefit that we have found is mixing with people in the haemophilia community and sharing stories, ideas and tips – which no medical person or book can ever give you.

Adult Wellness Workshop

Attending the Adults Weekend was a humbling and at times an emotionally awakening experience!

My partner found it most interesting and informative, he learnt more than I could teach him.

We meet some amazing people and it was nice to be around people that could understand your situation.

In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 2014 and June 2015:

- John Ferguson
- Stephen Haggerty
- Liam Hales
- Mary Thomas
- Elizabeth Wheeler

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

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	

Appreciations

HFNZ gratefully acknowledges all the organisations and individuals whose generous financial contributions have made it possible for us to continue to deliver services and support to people with Haemophilia and other bleeding disorders, and their families/whanau. Without you there would be no us.

Sustaining Patrons and Corporate Affiliates

Among our valued donors are those who have made the commitment to partner with HFNZ and offer ongoing non-directed funding. It is our good fortune to be able to count on a group of exceptional donors who recognise the value in making an annual investment in HFNZ to support its core programmes.

HFNZ is indebted to our Sustaining Patrons and Corporate Donors. Your commitment improves the lives of people with Haemophilia and other genetic bleeding disorders.



Supporters

Throughout the year grants have been received from many trusts and foundations who continue to support our work in the community.



A Very Special Thank You Goes to Kiwifirst

Kiwifirst have made a longstanding and ongoing commitment to fundraising and to the promotion of the awareness of bleeding disorders on behalf of HFNZ. We appreciate it.



Major Donors and Grants	Purpose
Baxter Healthcare Ltd	Inhibitors Workshop
Canterbury CommunityTrust	Southern Outreach Services
COGS Rotorua	Midland Outreach Salaries
COGS Manukau	Northern Outreach Salaries
COGS Waitakere	Northern Outreach Salaries
COGS Wellington	Central Outreach Salaries
Pub Charity	Northern Outreach Salaries
Pub Charity	National Family Camp
Baxter Healthcare Ltd	Adult Weekend
Novo Nordisk Pharmaceuticals Pty Ltd	Buddy Awards
Eastern & Central Community Trust	General
Pharmac	Haemophilia Implementation Support Activities
Bay of Plenty Community Trust	Outreach Services
Pfizer New Zealand Pty Ltd	National Family Camp
Mainland Foundation	Southern Outreach
Mainland Foundation	Central Outreach
Waikato Community Trust	Midland Outreach
NZ Guardian Trust	Canterbury Swimming
Foundation North	Northern Outreach
Infinity Foundation	Outreach Manager Services
NZ Lotteries	Administration Salary & Costs
Bayer NZ Limited	Parents Empowering Parents
Pharmac	Adult Weekend
Bayer NZ Limited	Youth Mentoring & Education

Individual and general donations over \$100
Midland AGM
CM Whiting
Downer
Gay & Peter McDonnell-Nola
Reginald Fuller
Ho Seong Kim
Nick Lingard Foundation
John Hunter
Thomas Gascoyen Martin Miller Estate
Beyond Reality Media (Armageddon) - Auckland
Beyond Reality Media (Armageddon) - Central
Beyond Reality Media (Armageddon) Southern
Beyond Reality Media (Armageddon) - Midland
Sue McHardy
Izack Silva
L A McCool
Albert Roberts Estate
Lyn Steele
Michael Andrews
Quality Hotel Parnell - General Donation
BJ Phillips
Totara Trust - J Keesing
Eric Kemsley
Susan Inwood
In Memory of J Ferguson
Neville Findlay
Heather Giles - Brick Road Productions

Directory

National Council

President:	Deon York
Vice Presidents:	Catriona Gordon Richard Scott
Treasurer:	Grant Hook
Northern Branch Delegate:	Greg Jamieson
Midland Branch Delegate:	Catriona Gordon
Central Branch Delegate:	Stephanie Coulman
Southern Branch Delegate:	James Poff
Piritoto Delegate:	Patience Stirling
Youth Delegate:	Hemirau Waretini
Masters Representative:	Willy Tekira
Co-opted Member:	Steve Waring

Staff

National Office

Chief Executive:	Richard Chambers
Administrator:	Leanne Pearce
National Information Coordinator:	Chantal Lauzon/ Phil Constable

Haemophilia Outreach Workers

Manager Outreach Services:	Colleen McKay
Regional Outreach Workers	

Free Phone: 0508 FACTOR

Northern Outreach Worker:	Sarah Elliott
Midland Outreach Worker:	Joy Barrett
Central Outreach Worker:	Lynne Campbell
Southern Outreach Worker:	Linda Dockrill

HFNZ Affiliation

World Federation of Hemophilia
www.wfh.org

Member Representative Groups

Northern Branch Chair:	Richard Scott
Midland Branch Chair:	Catriona Gordon
Central Branch Chair:	Stephanie Coulman
Southern Branch Chair:	James Poff
Piritoto Branch Chair:	Te Whainoa Te Wiata
Youth Branch Chair:	Hemirau Waretini

Entity Information

The Haemophilia Foundation of New Zealand Incorporated, also known as HFNZ, is a Registered Charity (CC22765) and an Incorporated Society.

Our Mission is:

To improve the lives and long-term outcomes for people with bleeding disorders; enabling active, independent, and fulfilling lives.

The Foundation is governed by a council of twelve HFNZ members and whanau. The council comprises of the President, two Vice Presidents, a Treasurer, a representative for each of the four regional Member Representative Groups (Northern, Midlands, Central and Southern), a representative from each of the three National Member Representative Groups (Piritoto, Youth and Masters) and one co-opted member.

There are 6.75 Fulltime Equivalent Staff employed to provide support and education programmes. They are based in Auckland, Hamilton, Wellington, and at the Christchurch Head office.

HFNZ's Main Sources of Funding are Donations & Grants. Public donations are sourced via telemarketing, direct, and Givealittle.co.nz. There are also some Member Fundraising activities.

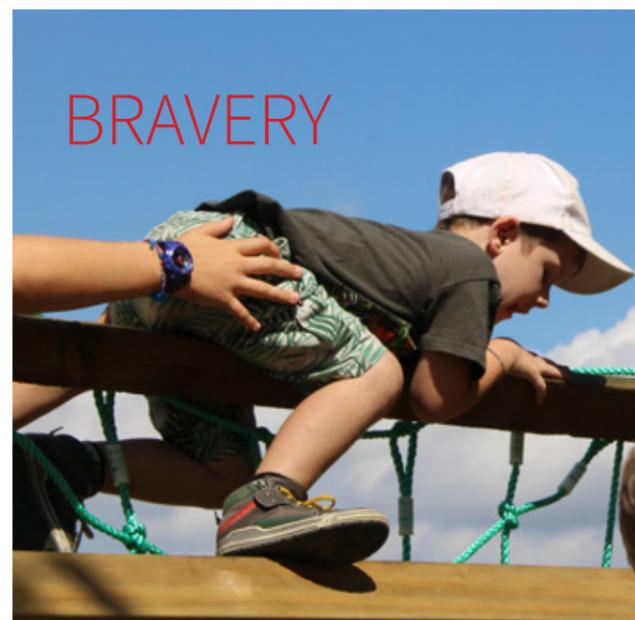
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