

HFNZ

Annual Report 2015/16

01 JULY 2015 TO 30 JUNE 2016





Your HFNZ

When it was established, in 1958, the core business of the Haemophilia Foundation of New Zealand Inc. (HFNZ) was to connect and support people with Haemophilia across New Zealand. Today, HFNZ continues working for all those dealing with Haemophilia A & B, and also represents people with von Willebrand's disorder, platelet disorders, and a range of other rare chronic bleeding conditions.

Being an inclusive organisation, that represents the needs of people with a variety of different rare and inherited bleeding disorders, enables us to work harder, and smarter, making a difference where it really counts. We understand that we're stronger together.

Our belief in the strength of the group is one of the reasons that HFNZ is a member of the World Federation of Hemophilia, which is officially recognised by the World Health Organisation. By joining other member organisations from around the world we can have a more powerful voice for our people internationally.

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 bleeding disorders across New Zealand.

This year's Annual Report highlights the strength of a connected network of members, supporters, and outside agencies working together. The participation and support of our people, 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:

Improving the lives and long-term outcomes of people impacted by bleeding disorders

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. 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 advocate for the best care that medicine can offer.



Elizabeth Berry: Patron's Message

It is with pleasure that I contribute this message for the 2015/16 Annual Report of the HFNZ

I have been reading Bloodline, the Journal of HFNZ, which is always a pleasure. The mix of local and world news, reports of conferences, workshops and camps, articles on life skills and personal profiles is full of interest and keeps me up to date with the many activities initiated and supported by HFNZ. The profiles, especially of our older members, tell of courage and determination and remind me of how far we have come.

When the first Newsletter was published back in 1972 the focus was on helping to support and provide information for families with haemophilia, many of whom had minimal treatment and were geographically isolated. Numbers were small, and the newsletter a single cyclostyled sheet. The broader aim, though, was to increase membership to include all people with bleeding disorders.

Nowadays not only has the treatment situation vastly improved, but the HFNZ has grown to well over 1000 members, embracing the many people with other bleeding disorders such as von Willebrand's Disease, rare blood factor deficiencies, and platelet defects, who together form part of the larger NZ bleeding disorder community. Here, males and females are equally affected and the women can have significant bleeding problems too.

In this context I was particularly pleased to read about the Young Women's Weekend – how reassuring and empowering for these young women to be able to learn and share their experiences. In another new and innovative workshop, children aged 6-10 were able to learn about bleeding disorders while having fun in the guise of pirates! A memorable way to start the lifelong learning process.

The most impressive account, though, was from teenager Andrew Scott, who has severe haemophilia complicated by antibodies to the missing factor. Andrew was in a bad way, but after a year with a personal trainer he is physically fit, with less pain, his bleed rate has reduced 10 fold, and he is missing far less school. What a wonderful example of true grit and perseverance as well as proving that strong muscles do protect joints!

The many enthusiastic and grateful comments from those who have attended workshops, camps and other events are testament to the effectiveness of HFNZ in supporting its members. However, the success of these many activities relies heavily on the contribution of many volunteers and the generosity of our donors. We owe our heartfelt thanks to both groups. With your help the Foundation can continue its excellent work and I look forward to my ongoing involvement with HFNZ.

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Deon York: President's Message

Another year rushes by and we reflect on another successful year for the Haemophilia Foundation of New Zealand (HFNZ).

As an organization representing approximately 1000 people with a bleeding disorder we are a relatively small and tight-knit community. I continue to be inspired by how a small group of people can make such an impact. Wherever you go, all over New Zealand, our members are living amazing lives while living with a bleeding disorder. HFNZ remains there to support and develop our community to live the best life possible.

In the 2015/16 period, nationally, HFNZ delivered a Youth Camp, Young Women's Weekend and Children's Workshop. Through the Foundation's special interest groups, and through the regions, other events were organised around the country to support people living with bleeding disorders and their families. I would like to acknowledge our many volunteers for being the backbone of our supportive network. Without the volunteer hours committed, regional events would not happen. Our Youth, Masters, and Piritoto groups also only remain as strong as the volunteer input.

HFNZ continues to provide outreach support services and specific support for those members living with hepatitis C acquired

through clotting factor concentrates. Outreach is rated by members as one of the most important services we provide, closely followed by our newsletter. Thank you to our staff for delivering these important services for our members.

We end this financial year with a modest surplus. While this is encouraging, it is important to remember that our main source of funding still comes from the generosity of people all over New Zealand. This generosity has become even more crucial in the current climate, where grants and trusts are stretched by the needs of many communities, and a number of our pharmaceutical partners are currently not in the New Zealand market. Of course, every contribution helps, and we remain extremely grateful to the grants, trusts, benefactors, and pharmaceutical partners that have made a contribution, enabling us to continue to support people with bleeding disorders.

I would like to personally thank all members of the National Council for their leadership in 2015/16, and, on behalf of the National Council, thank you to all of HFNZ's members for being such inspiring people that make working with this community so worthwhile.



Richard Chambers: CEO Report

The Haemophilia Foundation of New Zealand is a true grass roots organisation, grown from the desire of people to meet the specific needs of the bleeding disorder community. This same desire and focus continues nearly 60 years on.

In 1958, a small group of parents, people with haemophilia, and some doctors started this very special organisation then known as the New Zealand Haemophilia Society. Recently your council has revisited our strategic plan, with an initial focus on confirming that the purpose and role of the Foundation is as valid and as important as it ever was: improving the lives and long-term outcomes of people impacted by bleeding disorders.

Supported by funders, donors, and people who make gifts of time or money, HFNZ improves lives through a clear vision of excellence in care; advocacy, support, and education for all people with bleeding disorders and their whānau; and a schedule of work that reflects our five goals:

- 1. Care and treatment.** World-leading best practice bleeding disorder care throughout New Zealand that is safe, secure, and comprehensive.
- 2. Education and support.** Provide education, support and advocacy for people with bleeding disorders and their whānau.
- 3. Speaking up.** Effectively represent the needs and interests of the bleeding disorders community to government, non-governmental agencies and groups
- 4. Inclusive.** Efficient, sustainable, people first organisation, where the place of Māori as tangata whenua is valued
- 5. Global community.** Active in the world bleeding disorder community supporting care and treatment for all.

Through this report you will gain an understanding of how

effective HFNZ has been in working toward our vision. Working alongside the National Haemophilia Management Group, we are ensuring that New Zealand retains and improves its capacity to provide comprehensive bleeding disorder care that takes advantage of new developments. We have successfully negotiated with ACC to provide world best treatment of infusion acquired hepatitis C. Our educational camps and workshops are the envy of many countries in the world. The outreach team supports our members with education, support, and advocacy. We are working actively to plan the how New Zealand can achieve an even higher quality of bleeding disorder care. We provide mentoring for the Cambodian Haemophilia Association, seeing it build to become a much more effective and able group than it was at the start of our project seven years ago.

Our people are the biggest strength of our organisation. Our Council, our member representative group committees, and our staff, all provide the passion and commitment that is necessary to meet the next set of challenges for the New Zealand bleeding disorder community.

Special thanks to Grant Hook who is stepping down as HFNZ Treasurer and to Sarah Elliott (Northern Outreach Worker) and Chantal Lauzon (National Information Coordinator) who left us in 2015 for new roles.

To the current Council, Member Representative Group committees, and staff, thank you for your support of our community.

He toto, he taimaha kia piri, tukua kia rere

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



Colleen McKay: Outreach Report

Reaching out to people with bleeding disorders and those who care for them.

HFNZ has four Outreach Workers covering the Northern, Midland, Central, and Southern regions. Outreach Workers offer support and services to people with bleeding disorders, and their whānau/family, across New Zealand, they understand bleeding disorders and the New Zealand health and social services sector.

The Haemophilia Foundation's Outreach Team are one of our key assets. They are the face of the Foundation in the regions, and provide the core of staffing and expertise for our workshops and camps.

In the last year, outside of regular individual contacts, the Outreach Team have contributed education and support at a number of events, including:

- National Youth Camp
- Young Women's Weekend
- National Children's Workshop

Members of the Outreach Team have also been invited to present at international events such as the Australia and New Zealand Conference on Haemophilia and Related Bleeding Disorders, and WFH World Congress. They are well regarded, and leaders in their field.

We are committed to working in partnership with people impacted by bleeding disorders, helping them identify their own needs and supporting them to achieve their potential. Our Outreach Workers will help access the information you need about a bleeding disorder impacts on you, your children, or your partner from initial diagnosis through the different life stages.

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.

Outreach Workers are available by phone, text, email, Facebook, and in person. It is important that you contact them when you need them. If in doubt, contact your OR Worker. They have flexibility to support individuals and families in different ways based on specific needs.

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 has six Member Representative Groups that speak for the different parts of our community: Northern, Midland, Central, and Southern; Piritoto, representing our Māori members; and the National Youth Committee. Each group has elected office-holders, a delegate on National Council, and a committed group of volunteers to keep it running smoothly.

Northern

This year started with a Great Christmas party at Parakai hot springs, it was well attended and people sat around talking under the Marquee for hours afterwards. The summer camp was at a new venue at Marsden Bay. The highlight was the trip to the Waipu caves and many of us enjoyed seeing the glow worms and wading out of the cave in the river, others (the winner) may argue that the Karaoke was the highlight.

The movie night Finding Dory was a fun event and many families attended with their kids. The selection of Ashley Taylor-Fowlie to attend the World Federation of Haemophilia congress in Florida was great for us as region as Ashley has been a keen member on the Northern committee. The ladies afternoon tea at the Waipuna lodge was a success. The Buddy awards was a bit of a wet day but the few that attended were privileged to hear Jack Finns acknowledgement of his Grandfather as his buddy.

This year has been our first year with Nicky Hollings as our new Outreach Worker so it's been great to get to know her and it was a sad occasion saying goodbye to Sarah Elliott at the rock climbing event last year. It's been great to see the continuing progress made by those men attending regular physio and exercise programmes with Cat Pollard and for those that are not going, please make time to do so, as you are missing out on a fitter and better you.

This year has also been the year of new treatments on the horizon that look very promising in terms of ease of use and efficacy. Something many of us have been talking about. Many people have also switched treatment products this year.



Those that have done so, well done on what can be a difficult process emotionally. There will be children and parents that have begun self-infusion or begun infusing children for the first time in the last 12 months. This is a milestone worth remembering and well done to any who this applies to. The Northern committee has been a pleasure to work with in the last year and we would welcome anyone who is interested in joining to make contact and see how they can get involved.

Midland

Midland has had a year culminating in a selection of activities often determined by the weather and, of course, individual circumstances.

We have had opportunities to reacquaint with old friends and welcomed new families into the bleeding disorder community.

Activities as a group have ranged from great outdoor adventures testing agility of both, mind, body, and our ability to problem solve as a team; to a visit to the Hamilton Zoo to enjoy the facility and formally celebrate World Haemophilia Day and HFNZ's National Buddy Awards, where our members got to recognise a significant person that supported them – a great event that saw a huge turnout.

A dedicated group of members headed to Auckland to help fund-raise by volunteering at the Armageddon Expo. This is a great opportunity to raise some money, and also an entertaining spectacle to take part in.

It does get difficult for the group committee to sustain numbers and plan activities that cover a wide range of needs and desires, so this year's committee needs to hear from you!

Thanks must be given to our outgoing committee members for their commitment over more than one term, Catriona, Wendy, Dylan, and Cassandra we look forward to meeting you at coming events. Thank you for your tireless efforts.

To our Outreach Worker, Joy, thanks for your support, smiling face, and happy outlook.



Central

Our annual winter escape camp, attended by about 60 members, was held in Taupo at the end of August. We received good feedback from members, who enjoyed the accommodation on the lake-front, the food and the outings to Craters of the Moon thermal area and DeBretts hot-pools.

It was pleasing to see members mixing well and to meet some new families. As has become a trend, we hold our AGM at our camp and at this meeting we discussed the ideal frequency of our camp. An outcome of the camp was to survey members to see what they think. We had a very low response rate so the results were difficult to interpret. However, 55% who responded wanted a camp every two years and most people said they'd come even if the accommodation was more basic. That said, the committee decided to go ahead with planning an annual camp but at low cost accommodation venues.

Our Christmas event at Nga Manu Nature Reserve in Waikanae was blessed with stunning weather, fortuitously ideal for the

outdoor venue. We enjoyed a BBQ lunch, after an interactive educational presentation about the life cycle of the tuatara, with an actual tuatara in attendance.

At the end of February, Consultant Haematologist Julia Phillips left her role at Capital Coast Health. We farewelled her at a simple but intimate celebration at the James Cook Hotel in April. It was a lovely occasion to chat with her and say how much she will be missed.

Taranaki members attended a café evening at Marbles Buffet at the Devon Hotel in New Plymouth, arranged by Outreach Worker Lynne Campbell as part of her Taranaki outreach visit.

As we look towards our own 2016 AGM the central region committee would benefit from some new faces around the



meeting table. Currently the Chairperson doubles as National Delegate and our youth delegate position remains vacant. We would welcome anyone interested in joining the committee to help us organise fun events for members.

We remember Central region members who passed away; Merv Hancock and Josephine Sutton both passed away in May 2016.

Piritoto

“He toto, he taimaha kia piri, tukua kia rere”

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

Tēnā Koutou Whānau mā

This year has seen a great progression for the Piritoto whānau, having completed two major events for the year. Celebrating the Māori new year - Matariki, we hosted our first event located at the Auckland observatory where a show that inspired an informative outlook on the night sky was showcased. The second event for this year saw our yearly Marae Noho returning to Te Roro o te Rangi Marae in Rotorua in the first weekend of August. The theme of the noho was to promote whakawhanaungatanga or unity.

The first showing of the star constellation Pleiades, also known as Matariki, in the night sky before the rising of the sun, marks the start of the Māori New Year. Those present enjoyed a movie showcasing an informative look at Matariki, outlining the star constellation in relation to our perspective in New Zealand. The many Māori stories shown via animation gave an exciting and instructive outlook for all the family to enjoy. Lunch was provided with

a segment dedicated to people interaction with the aim of getting to know one another. Where fun and educational games were played resulting in children knowing more than their parents thought they would.

Returning to Te Roro o te Rangi Marae during the winter session was a pleasurable experience where the whānau took advantage of the natural thermal heaters and oversized baths located on site. The highlight of the weekend was the afternoon/evening we spent back at Waikite Thermal pools, enjoying the nice relaxing atmosphere with the whānau. To our wonderful surprise, falling snowflakes in the secluded valley made the whole experience magical.

On Saturday morning we had sat down and had discussions on how Piritoto was going so far, and what we could achieve in the near future.

In the spirit of, “Honour the past, celebrate the present, and embrace the future”, I would like to acknowledge Carol Reddie, who has stepped down from her position in Piritoto, and would also like to give thanks for her contribution to our whānau, the central region, and her involvement in the Armageddon Expo hosted in Wellington. Hemi Waretini

has also moved from being treasurer to becoming Youth delegate, replacing him as the Treasurer for Piritoto is Patience Stirling. We welcome back T.A. Stirling as Northern delegate, Kahu Carter who is now our Central delegate as well, as Mahia Pene representing the Midland region.

A huge thank you goes out to all who could attend the Marae Noho, the delegates, the committee members and the little rascals who spent most of their time running around. Without you all we would not be who we are as a rōpu and as a whānau and, to those who weren't there, I hope to see you all at our next get together.

Tēnā koutou, tēnā koutou, tēnā rā tātou kātōa.



Southern

The year to June 30th 2016 was another busy one for the Southern MRG.

We started, in September, with a farewell high-tea for Lyn Steele, who resigned after three decades of serving on our committee. Lyn, along with her husband Tony, were active committee members, and were made life members in 1999. The high-tea was well attended, and enjoyed by all. Lyn was presented with a beautiful handmade quilt as a token of thanks. We will miss you Lyn!

During November we held a get together/celebration at the home of the Waswo family. This too was greatly enjoyed by all who attended. Huge thanks to the Waswo family for their generosity in hosting this event.

Armageddon in Dunedin was held on March 19th and 20th. Once again the Southern MRG supplied volunteers as part of our fundraising efforts. As usual this was a busy weekend and the event was well supported by the community.

Youth

As always, it's been a busy year for the members of the National Youth Committee.

Firstly, I'd like to congratulate Courtney Stevens, Lauren Nyhan, Ashley Fowlie, Colleen McKay, and everyone else involved for their involvement in organizing the first HFNZ Young Women's Weekend at Hanmer Springs in February. This was the first time the Foundation has had an event focused solely on the young women in our community. Those who attended were able to have frank discussions about how their bleeding disorders affected them.

Haemophilia has in the past, seemed like a bit of a boys' club – I'm sure you've all heard that old chestnut “Only boys have haemophilia”. While this may have some truth to it, there is a growing realization that carriers can present symptoms of haemophilia, not to mention all the other bleeding disorders out there that are not gender biased. I think that it's

World Haemophilia Day was held on April 17th, and was a great day for families to spend time together and value the meaning of bleeding disorders. Buddy Awards were presented to Robyn Coleman, Lorraine Porter Bishop, Kathy Fawcett, and Lee Townsend. Well done to those fantastic women, you help make life easier for so many!

Again this year we ran our fundraising play-night in conjunction with Brick Road Productions. The play was held on 7th May, and was a great success. The Southern team are getting pretty good at running this annual event. Thanks to Sandra Poff for your guidance and support for this great fundraiser. We



collect 40% of the door, ran a raffle, and provided a bar. In all a grand total of \$1800 was raised.

On Wednesday 29th June Zac organised a youth dinner in Christchurch – it was well attended and everyone seemed to have a great time.

We were also very fortunate to win a \$250 donation from Gilmour Motors here in Dunedin. Thanks to Jacqui Woodford for the nomination and to Emma Gilmour and her team for the prize.

Finally, a big thank you to all our members, who continue to assist with all that is required to enable our Southern branch to run efficiently.

hugely important the we, as a Foundation, cater to all our members' needs, not just the majority. So again, a big congratulations to everyone who organized and attended the Young Women's Weekend, and made it such a success.



Secondly, Zac Porter organized a “Bleeders on Bikes” event, which was to be held over Waitangi weekend in Christchurch. Unfortunately, it didn't go ahead, but we are looking forward to it being held this coming year.

We had a meeting in Christchurch in July, to make some plans for the coming year. There were a few ideas floated, but the most popular was a winter getaway to Queenstown in

2017. Planning is currently underway, so watch this space, and make sure to keep an eye out for your invite!

I'm happy to announce that Zac Porter has joined the National Youth Committee as Treasurer. On a less happy note, Karl Archibald is leaving the National Youth Committee as he is no longer a “youth”. Karl has been a central part of the Youth Committee since it was started in 2011, and served on HFNZ's National Council for several years before that as Youth Delegate. Karl was pivotal in organizing our tramp through the Abel Tasman National Park in 2012, and ensuring that we had made sure that we had robust emergency procedures in place. On behalf of the National Youth Committee I'd like to thank Karl for all his hard work.

I'd like to let you know that I'm stepping down as Youth Delegate to National Council. I have greatly enjoyed my time on the Council, but it is time for another youth member to have the chance to see how the Foundation is governed. Courtney Stevens will be taking my place on the Council, and I will remain as a member of the Youth Committee.

Lastly, I want to thank all of the members of the National Youth Committee for all their hard work over the last year. I know that it's hard keeping in touch when we're spread out over the country, but when we meet we get a lot done.

Camps, Events, & Workshops

Each year HFNZ runs a variety of events aimed at educating different member groups about aspects of living with their bleeding disorders. Over the last year many people, from young children to adults, took part in our events. They had fun, they met new people, and they learned more about what it means to be a part of the HFNZ family.

Youth Camp

In July 2015 a fantastic group of young people, leaders, nurses, and staff gathered at Motu Moana Scout Camp in Auckland for Youth Camp.

All together 24 youth with bleeding disorders, 12 Youth Leaders, 3 Haemophilia Nurses, and 3 Outreach Workers joined together for a winter 'Search and Rescue' themed weekend escape. Even in balmy Auckland mid-winter actually means something, the days were sunny with blue skies, but the nights were very cold. We had to survive Auckland's coldest night in history in VERY basic scouting accommodation.

To begin the weekend, the youths were divided into four teams, the youth leaders taking their team through team building Games in order to get the groups to work well together and to have fun.



One of the first tasks was for each team to create a 'Haemo-man' mascot that had to safely undertake all activities in the programme, including rock climbing, the challenge valley obstacle course, and laser tag, alongside the group. Each team gave their mascot a name: X Man, Blue Barrymore, Viper, and Hugo. The twist was that each mascot had to have a raw egg securely packed inside his head. Much planning, strategy, and stuffing went into each mascot. On the last day of camp, the much awaited official autopsy revealed that all four mascots survived Youth Camp with raw eggs intact. No brain bleeds!

The education session 'Developing specific Bleeding Disorder knowledge' saw participants designing and filming three training videos to educate Search and Rescue medics about bleeding disorders, how blood clots, the signs and symptoms of a bleed, and all about joint bleeds. These are awesome, and can be viewed on the HFNZ YouTube channel. They are well worth watching, and are a testament to the knowledge of bleeding disorders that was developed, the teamwork generated by the Youth Leaders, and the creativity of all the participants.

Other educational activities included ones the Outreach Workers designed to increase general health knowledge and increase Life Skills – 'Let's get InQUIZative', 'Health Search and Rescue', and 'Where am I?' Haematologist, Nicola Eady came for a 'Question and Answer' session, Physiotherapist, Lisa Weaver talked about the benefits of physiotherapy, and Liam Brodie came and talked to the older youths about issues related to employment.

Alongside the education there were also some fun and social activities. We made the most of the Motu Moana Scout Camp facilities by having a go at the rock climbing wall and the Challenge Valley obstacle course. Team building initiatives included a very fun pioneering activity as well as Queen Scout Peter Leslie leading a bivouac building activity accompanied by campfire building and marshmallow toasting.

The Mystery Food Box MasterChef Challenge saw teams cooking their own dinner from a surprise collection of ingredients, and the three Haemophilia Nurses bravely judging each dinner for taste and presentation.

Youth Camp wouldn't be complete without the traditional Laser Tag. Sunday evening saw everyone, complete with team mascots (well maybe one poor Mascot was left behind and missed the fun...) board a bus and head off to Megazone Laser Tag in Manukau for a very competitive and lively game of Laser Tag. No injuries sustained, back to Camp with a bus full of exhausted Campers.

By Monday afternoon it was time for all the very tired but happy campers and leaders to wing their way home, having learned new things, made new friends, and had a fabulous and FUN time.

Young Women's Weekend

The idea of a weekend dedicated to education, support, and fun for young women with bleeding disorders came out of the 2014 Youth Leadership Training Weekend, where Lauren Nyhan and Courtney Stevens developed the concept and a plan for such an event.

Courtney, Lauren, and Ashley Taylor-Fowlie put the leaderships skills they'd learned at that weekend into practice, and joined Colleen on the planning team. They also took up the challenge to present and participate in a variety of sessions over the course of the weekend.

On February 26th 15 young women flew in from throughout New Zealand, to be met by Outreach Workers Nicky and Lynne. A couple of late flights caused a small delay, but eventually everyone was on the bus bound for Hanmer Springs, with a short stop at Waikuku Beach Park for lunch: Subway, Sushi, and fruit, delicious!

The weekend all happened at the Hanmer Springs Forest Camp, a former forestry camp surrounded by the beauty of the forest, just outside Hanmer Springs Village. We discovered on our arrival that the Camp was also home for what seemed like a million bees. While the bees generally kept to themselves, two of our young women got to experience bee stings first-hand.

The theme for the weekend was Reality TV, so every session was named after a reality television show. First up was 'The Amazing Race', where three teams competed for points in a range of challenges designed for teamwork and group thinking skills. Friday evening's activities began with getting to know each other a little better, and a panel discussion 'Meet the Experts' where Laura Rutten posed questions to Courtney Stevens, Lauren Nyhan, and Ashley Taylor-Fowlie. Then we enjoyed a 'Reality Television' Quiz Night, which gave us an opportunity for more teamwork, and some fun and friendly competition.

On Saturday morning the young women participated in educational activities presented by the haematologist, haemophilia nurse, outreach workers, and each other. The morning started with interactive games designed to teach about blood and haemostasis (how blood clots), which demonstrated the interaction between platelets, von Willebrand Factor, and Factor VIII and IX in the formation of a blood clot. This was followed by Outreach Worker Nicky's 'Fear Factor' Session where the young women learned some assertiveness skills, and practiced the valuable practice of making 'I' statements.

We were very lucky with our next educational activity. Haematologist Laura Young flew in from Auckland for a

comprehensive session entitled 'Women & Bleeding – everything you always wanted to know', then Kathy Fawcett and Laura Young answered all the questions that the young women had in the 'Question and Answer Workshop'.

After all that hard brain work, Saturday afternoon was dedicated to rest and relaxation at the Hanmer Springs Hot Pools. This provided a welcome opportunity for the young women to get off-site, to try out the Hot Pools, and to stroll through Hanmer Village.

Saturday evening was the big 'Master Chef Mystery Food Box Challenge'. Three Teams had 5 minutes for planning the challenge to produce a three plates of food for the judges – two main courses, one for vegetarians and one for carnivores, and a dessert. They then got just 60 minutes to cook a masterpiece for the judges, Kathy, Nicky, and Lynne. This was great fun, and the teamwork and creativity were superb.

After cooking up a storm, it was time for a relaxing evening of entertainment with 'Hanmer's Got Talent'. The evening started with Courtney, Lauren and Ashley demonstrating a range of activities that can be undertaken 'in your active wear', continued with two very brave solo performers, showcased the talents of the 'Pink Fairy' and the 'White Fairy', and concluded with 'chaos on the dance floor' as everyone got up to learn the line dance 'Mama Maria'. Let's just say that there were many interesting and creative moves!

Sunday was our last day, and the programme started with a quick look at 'What is health?', before settling in to take a closer look at Taha Wairua - Mental Health, and learning some tips and tricks for looking after yourself, based on the Mental Health Foundation's Five Ways to Wellbeing – Connect, Give, Take Notice, Keep Learning, and Be Active.

Following that, Courtney turned the meeting room into something that resembled a beauty clinic with face masks followed by cooling and soothing wheatie eye masks. Everyone had a chance to try mindfulness colouring, reflecting and taking notice while occupied with colouring in as a method of reducing stress. There was also a presentation about giving back to HFNZ, where a range of ideas and opportunities were discussed among the regional groups.

It was fantastic to see these young women supporting each other throughout the weekend - friendships were formed that will last a lifetime. As well as the valuable learning opportunities, we had fun, enjoyed some recreation time, and pampered ourselves. Perfect!



National Children's Workshop

21st April 2016 saw young pirates from around New Zealand gather in Auckland for the 2016 National Children's Workshop. The boys and girls were aged just 6 – 10 years, and have severe and moderate bleeding disorders including Haemophilia A & B, von Willebrand Disorder, and Platelet Function Disorders. The kids flew or drove in from all over the country and arrived bright and early at the Wiri Community Centre for a day of learning and laughter.

Upon arrival each pirate made themselves all of the essential gear necessary to be a successful HFNZ pirate; a specially named loot bag to hold all the goodies, a pirate hat, an eyepatch, and a sword.

Then they assisted in making a 'Bag of Blood' complete with:

- Red Blood Cells - for carrying oxygen around the body
- White Blood Cells - necessary to fight infection
- Platelets - sticky star shaped cells that clump together in order to make a Platelet Plug
- Plasma - containing Factor VIII, Factor IX, and von Willebrand Factors – all necessary to form a clot.

Once the pirates had completed their blood work, Haemophilia Nurse Specialist, Karen Slavin, turned up in all her pirate finery and set about increasing their knowledge of the various bleeding disorders, the signs and symptoms of a bleed, as well as many other tips for being a healthy pirate.

Next, Cat Pollard, a Haemophilia Physiotherapist reminded our little pirates of the importance of having strong and healthy joints and muscles. Treating bleeds with factor replacement and PRICE (Protect, Rest, Ice, Compression, Elevation) as well as

physiotherapy rehabilitation was the major message from Cat. She reminded us all that it takes more than just Factor to treat a bleed.

In order to keep the pirates switched on, the educational sessions were interspersed with fun 'Pirate Activities', like Swab the Decks, Walk the Plank, Captain Hook Toss, and the Cannonball Throw. Even though water was involved in the Cannonball Throw, our young Pirates did not get drenched, and many budding buccaneers commented that Walk the Plank was their favourite game of the day. Three teams competed in the games for points to allow first pick at the Pirate Prize Table.

After a hearty lunch of Subway, Sushi and Fruit, Pirates were able to explore the personal qualities necessary to be a successful pirate in control of his own Pirate Ship.

Southern Outreach Worker Linda Dockrill, helped the pirates to discover that it takes more than good luck to navigate the perilous waters of bleeding disorders. They found that they needed a compass, to help navigate life with a bleeding disorder; the correct equipment and tools, to look after themselves and do the things they want to do; and a good crew, support to help them when they need it. Our HFNZ pirates also learned that leadership on land and sea means having discipline, knowing when to ask for help, taking responsibility, showing courage and resilience and being a role model. An ancient treasure chest provided the group with valuable lessons.

A visit to 'Treasure Island' Mini Golf concluded the day, after which a shipload of very tired pirates headed home with a few extra pirate friends, heads full of knowledge, and wonderful, fun memories. Each pirate was sent home with a specially-designed Pirate Workbook in order to reinforce and continue the learning at home with their parents.



HFNZ Financial Report

For the 12 months ending June 30th 2016

This year we have recorded a second small surplus. This surplus enables us to move into the 2016-17 year with confidence, looking toward several of our more expensive, high-value workshops occurring during this period.

HFNZ remain well positioned moving into the future, retaining a capital fund of \$420 650 for future property investment.

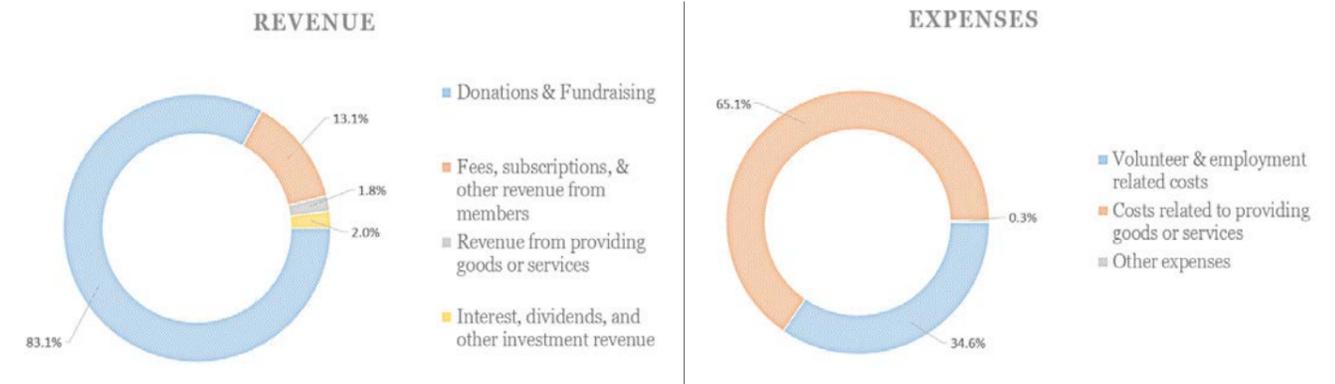
Funding of programmes and activities are strongly aligned to our purpose, improving the lives and long-term outcomes of people impacted by bleeding disorder; by providing high quality education, support and advocacy.

This year Pharmac introduced a preferred supplier for Factor VIII. This has resulted in an overall reduction of the level of financial

support pharmaceutical companies have been able to give to HFNZ educational and support programmes. This will be an on-going situation.

Our HFNZ office administrator, Leanne Pearce does a fantastic job managing our finances. Thank you.

A special thank you to our amazing fundraising team at Kiwi First, our incredible donors, sponsors and partners, large and small, it is only through your support that the Haemophilia Foundation is able to make a positive difference for the bleeding disorder community. Working together we are improving the well-being of individuals and families impacted by bleeding disorders, while contributing to reducing the cost of short and long-term patient publicly funded health care.



Statement of Financial Performance

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2016

	Notes	2016	2015
Revenue			
Donations, Fundraising, & other similar revenue	1	1,136,520	1,263,375
Fees, subscriptions, and other revenue from members	1	173,583	170,268
Revenue from providing goods or services	1	25,199	36,021
Interest, dividends, and other investment revenue	1	27,573	35,452
Total Revenue		1,362,876	1,505,116
Expenses			
Volunteer and employee related costs	2	432,425	439,662
Costs related to providing goods or service	2	909,074	1,053,704
Other Expenses	2	4,156	9,877
Total Expenses		1,345,655	1,503,243
Net Profit (Loss)		17,220	1,873

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

Statement of Financial Position

Haemophilia Foundation of New Zealand Incorporated as at 30 June 2016

	Notes	2016	2015
Assets			
Current Assets			
Bank accounts and cash	3	98,279	173,250
Debtors and prepayments	3	161,300	131,847
Other current assets		2,628	3,172
GST Receivable		23,818	20,733
Total Current Assets		286,024	329,002
Non-Current Assets			
Property, Plant and Equipment	5	2,128	6,284
Investments	3	640,457	631,835
Total Non-Current Assets		642,585	638,119
Total Assets		928,609	967,121
Liabilities			
Current Liabilities			
Creditors and accrued expenses	4	145,751	201,484
Total Current Liabilities		145,751	201,484
Total Liabilities		145,751	201,484
Total Assets less Total Liabilities (Net Assets)		782,858	765,637
Accumulated Funds		782,858	765,637
Total Accumulated Funds	6	782,858	765,637

Statement of Accounting Policies

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2016

Basis of Preparation

Haemophilia Foundation of New Zealand Incorporated (the "Society") has elected to apply PBE SFR-A (NFP) Public Benefit Entity Simple Format Reporting - Accrual (Not-For-Profit) on the basis that it does not have public accountability and has total annual expenses equal to or less than \$2,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. The Performance Report is prepared under the assumption that the entity will continue to operate in the foreseeable future.

Good and Services Tax (GST)

The entity is registered for GST. All amounts are stated exclusive of goods and services tax (GST) except for accounts payable and accounts receivable which are stated inclusive of GST.

Fixed Assets & Depreciation

The entity has the following classes of fixed assets:

Office Equipment 47%- 67% DV

Items of property, plant and equipment are measured at cost less accumulated depreciation and impairment losses. Cost includes expenditure that is directly attributable to the acquisition of the asset. Depreciation methods, useful lives and residual values are reviewed at each reporting date and are adjusted if there is a change in the expected pattern of consumption of the future economic benefits or service potential embodied in the asset.

Income Tax

The Society is registered as a charitable entity under the Charities Act 2005 and is exempt from income tax under the income tax legislation.

Bank Accounts and Cash

Bank accounts and cash are short term, highly liquid investments that are readily convertible to known amounts of cash and which are subject to an insignificant risk of changes in value.

Grants

Grants received are recognised as operating revenue, unless specific conditions attached to a grant require repayment if not met. In these cases, the grant is treated as a liability until conditions are satisfied. Non-cash grants are recognised as revenue at their fair value.

Investments

Investments are recorded at cost.

Accounts Receivable and Prepayments

Accounts Receivable and Prepayments are stated at their estimated realisable value. Bad debts are written off in the year in which they are identified.

Changes in Accounting Policies

There have been no changes in accounting policies during the financial year. However, it should be noted that the basis of preparation has changed from adopting NZ GAAP to Tier 3 Public Benefit Entity Simple Format Reporting - Accrual (Not-for-Profit) guidance issued by the External Reporting Board.

Statement of Cash Flows

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2016

	2016
Cash Flows from Operating Activities	
<i>Cash was provided from:</i>	
Donations, fundraising, and other similar receipts	1,108,999
Fees, subscriptions, and other receipts from members	173,583
Revenue from providing goods and services	25,199
Interest, dividends, and other investment receipts	28,117
Total	1,335,898
<i>Cash was disbursed to:</i>	
Volunteer and employee related costs	486,204
Costs related to providing goods and services	909,074
Net GST outflows (Trade only)	6,971
Total	1,402,249
Net Cash Flows from Operating Activities	(66,351)
Cash Flows from Investing and Financing Activities	
<i>Cash was disbursed to:</i>	
Investments (Term deposits)	8,622
Total	8,622
Net Cash Flows from Investing and Financing Activities	(8,622)
Net Increase/(Decrease) in Cash Held	(73,973)
Cash at beginning of period	173,250
Cash at end of period	98,277
This is represented by	
Cash and cash equivalents at the end of the period	98,277

Depreciation Schedule

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2016

Name	Rate	Method	Cost	Opening Value	Purchases	Disposals	Depreciation	Closing Accum Dep	Closing Value
Office Equipment at Cost									
Camera	67%	DV	1,010	185	-	-	124	950	61
Database	33%	SL	8,350	1,390	-	-	1,390	8,350	-
Epsom Data Projector	20%	SL	1,114	92	-	-	92	1,114	-
Laptop - CL	50%	DV	1,995	655	-	-	327	1,668	327
Laptop - CM	50%	DV	1,995	655	-	-	327	1,668	327
Laptop - JB	50%	DV	1,995	655	-	-	327	1,668	327
Laptop - KR	33%	SL	1,045	174	-	-	174	1,045	-
Laptop - LC	50%	DV	1,995	655	-	-	327	1,668	327
Laptop - LD	50%	DV	1,995	655	-	-	327	1,668	327
Laptop - RC	33%	SL	1,758	59	-	-	59	1,758	-
Laptop - SP	33%	SL	1,758	59	-	-	59	1,758	-
Office 365	33%	SL	3,140	523	-	-	523	3,140	-
PA System & Speakers	40%	DV	577	249	-	-	100	427	150
Toshiba Copier/Printer	18%	SL	3,489	-	-	-	-	3,489	-
Workstation		None	923	280	-	-	-	643	280
Total Office Equipment at Cost			33,139	6,283	-	-	4,156	31,012	2,127
Total			33,139	6,283	-	-	4,156	31,012	2,127

Notes to the Performance Report

Haemophilia Foundation of New Zealand Incorporated For the year ended 30 June 2016

		2016	2015
1. Analysis of Revenue	Donations, fundraising, and other similar revenue		
	Donations and Bequests	26,658	61,330
	Fundraising - External	964,992	1,025,224
	Fundraising - Internal	7,722	13,448
	Grants	132,240	158,451
	WFH Grants	4,908	4,921
	Total Donations, fundraising and similar revenue	1,136,520	1,263,375
	Fees, subscriptions, and other receipts from members		
	Contracts	168,135	160,936
	Registrations	5,448	9,331
	Total Fees, subscriptions, and other revenue from members	173,583	170,268
	Revenue from providing goods or services		
	Member Fees	5,199	6,021
	Sustaining Patrons	20,000	30,000
	Total Revenue from providing goods or services	25,199	36,021
	Interest, dividends, and other investment revenue		
	Interest Income	27,573	35,452
	Total Interest, dividends, and other investment revenue	27,573	35,452
2. Analysis of Expenses	Volunteer and employee related costs		
	Wages and Salaries	432,425	439,662
	Total Volunteer and employee related costs	432,425	439,662
	Costs related to providing goods or services		
	ACC Levies	1,425	1,368
	Accounting	2,569	3,487
	Administration	1,352	1,715
	Adult Programme	-	35,733
	Advertising	343	1,190
	Audit	5,820	475
	Bank Fees	348	278
	Children's Workshops	6,450	-
	Cleaning	1,500	1,320
	Consulting (including IT)	6,472	9,116
	Defensive Driving	726	612
	Family Camp	-	38,239
	Footwear Programme	6,775	7,839
	Fundraising - Advertising, Education	297,196	320,530
	Fundraising Costs	327,285	359,041
	General Expenses	1,791	579
	HCV Support	142	160
	HR - Appointments	746	-
	Inhibitors Workshop	-	16,253
	Insurance	5,768	5,288
	International Conferences, Workshops, Meetings	16,509	-
	International Programmes	4,879	7,089
	Light, Power, Heating	1,870	1,958
	Motor Vehicle Expenses	20,877	18,100
	MRG - Central	13,212	11,077
	MRG - Masters	504	345
	MRG - Midland	7,053	3,883

Notes to the Performance Report

	MRG - Northern	9,970	13,887
	MRG - Piritoto	463	3,369
	MRG - Southern	2,378	11,010
	MRG - Youth	595	1,233
	National Council	20,290	22,385
	Needs Grants	5,141	8,002
	Office Expenses	2,074	392
	Outreach	6,334	5,210
	PEP - Parents Empowering Parents	-	13,783
	Printing, Stationery, Postage	17,702	36,587
	Professional Development and Team Meetings	15,082	14,551
	Rent	39,463	42,893
	Repairs and Maintenance	752	611
	Resources	242	-
	Special Programmes	97	3,079
	Subscriptions/Memberships	2,541	2,120
	Swimming/Fitness	7,532	10,697
	Telephone & Internet	12,886	13,266
	Women's Programme	9,862	-
	Youth Camp	23,990	155
	Youth Leadership	68	4,805
	Total costs related to providing goods or services	909,074	1,053,704
	Other Expenses		
	Depreciation	4,156	9,877
	Total Other Expenses	4,156	9,877
3. Analysis of Assets	Bank accounts and cash		
	Westpac cheque Account - 00	-	155
	SBS Savings Account	1,000	1,000
	BNZ On Call Account	85,444	174,240
	Westpac Online Saver - 02	-	-
	BNZ Non Profit Cheque Account	15,476	2,572
	BNZ Visas	(3,641)	(4,717)
	Total Bank accounts and cash	98,279	173,250
	Debtors and prepayments		
	Prepayments	23,354	23,335
	Accrued Income	10,000	10,000
	Trade Debtors	127,946	98,513
	Total Debtors and prepayments	161,300	131,847
	Investments		
	BNZ Term Investment - 00003	53,823	51,740
	BNZ Term Investment - 00004	54,526	52,343
	BNZ Term Investment - Property	420,650	420,650
	BNZ Term Investment - 00002	33,097	31,844
	SBS Term Investment - No 10529944	78,361	75,258
	TSB Term Investment - No 08000071	-	-
	Total Investments	640,457	631,835
	<i>The BNZ Term Investment - Property, above, represents funds allocated for the purchase of property.</i>		
4. Analysis of Liabilities	Creditors and accrued expenses		
	Accounts Payable	115,049	131,505
	Money in Advance	30,702	69,978

Notes to the Performance Report

		Total Creditors and accrued expenses	145,751	201,484
5. Property, Plant, and Equipment	Office Equipment			
		Open Carring Amount	6,283	16,160
		Sales/Disposals	-	-
		Depreciation	4,156	9,877
		Closing Carring Amount	2,128	6,283
6. Accumulated Funds	Accumulated Funds			
		Opening Balance	765,638	763,765
		Accumulated surplus or (deficit)	24,887	1,873
		Closing Balance	782,858	765,638
		Total Accumulated Funds	782,858	765,638
7. Lease Commitments	The Haemophilia Foundation of New Zealand has the following lease commitments:			
	<ul style="list-style-type: none"> A premises leased from Craig Gordon Property Investments. The lease is for a term of two years commencing 1 April 2015 and will be reviewed two yearly. The rent is \$29,945.66 excluding GST per annum. An office leased from the Auckland City Council. The lease is for a term of one year commencing 1 October 2015 and is reviewed annually. The rent is \$500.00 excluding GST per annum. A photocopier leased from Ricoh. The lease term is for 58 months commencing 26 April 2015. The lease is \$270.17 excluding GST per month. 			
8. Related Party	Included within expenses are wages and honoraria paid to Richard Chambers (CEO) and Deon York (President). All transactions were carried out on normal commercial terms.			
9. Statement of Commitments	There are no commitments as at balance date. 30/06/2015 (Nil)			
10. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/2015 (Nil)			
11. Events After Balance Date	There were no events that have occurred after the balance date that would have material impact on the performance report.			

INDEPENDENT AUDITOR'S REPORT

To the National Council of Haemophilia Foundation of New Zealand Incorporated.

We have audited the Performance Report of Haemophilia Foundation of New Zealand Incorporated on pages 13 to 18, which comprise the Statement of Financial Position as at 30 June 2016, Statement of Financial Performance and Cash Flows for the year then ended, Statement of Accounting Policies and Notes to the Performance Report.

Council's Responsibility for the Performance Report

The Council are responsible for the preparation of a Performance Report that present fairly, in all material respects, the matters to which they relate, and for such internal control as the Council determines is necessary to enable the preparation of a Performance Report that is free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on the Performance Report 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 Performance Report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the Performance Report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation of the Performance Report that present fairly, in all material respects, 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 Performance Report.

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, or interests in, Haemophilia Foundation of New Zealand Incorporated.

Opinion

In our opinion, the Performance Report on pages 13 to 18 present fairly, in all material respects, the financial position of Haemophilia Foundation of New Zealand Incorporated as at 30 June 2016 and its financial performance and cash flows for the year ended on that date.

Nexia Christchurch Limited

Nexia Christchurch Limited
02 September 2016
Christchurch



Statement of Service Performance

Objective

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

Outcomes

National Youth Camp July 2015

The National Youth Camp, a Residential Workshop for 10-18year-olds, uses a combination of education, fun, and peer and mentor support, to help young people move to the next stage of managing their condition. The focus is on being well informed and better able to make decisions about treatment, lifestyle, education, work, and relationships.

- 24 Youth
- 12 Youth Mentors
- 5 Staff
- 4 Volunteers

"I hope that in the future I could come back as a leader? Thank you for your hard work making the camp so cool. My second camp which was this one, I liked it because I could meet up with some of my old friends and meet up with new people. I liked making the camp fire and roasting marshmallows. I hate doing my treatment 3 times a week but then I realized that some guys had to do it every day"

"It has been a fabulous way to meet amazing, strong women with bleeding disorders, and begin making my 'bleeding disorder' network"

Stacey Booth, Young Women's Weekend

Young Women's Weekend February 2016

Young women with a bleeding disorder (inc. carrier status) have a range of special concerns and needs that need to be considered and addressed, like understanding their bleeding disorder and its implications (genetic testing, menstruation, child birth, raising a child with a bleeding disorder, explaining to a partner)

- 17 Young Women
- 3 Staff

"An inspirational, educational and holistic weekend away with women facing similar challenges in life: something that shouldn't be missed"

"This weekend is so valuable to me, especially talking with other carriers which gives me an insight into the struggles I will experience when and if I decide to have children. Also how and when to talk to a partner about it."

"I found the weekend very useful. I met others like me that have been through the same challenges. I found a lot of support going through my current PGD challenge."

"What an excellent forum for young women with bleeding disorders to get to know each other, about each other and how they can support each other"

National Children's Workshop April 2016

Providing age appropriate education to children (6-10 years) with bleeding disorders, without their parents or siblings, developing the skills to identify, understand and minimise the impact of issues related to a bleeding disorder as part of other children with bleeding disorders.

- 14 Children
- 4 Youth Mentors
- 4 Staff

"I learnt a lot at the children's workshop. Something I learnt was that platelets stick together. We did lots of activities."

"Thank you for inviting me to the workshop in Auckland. I learnt that I have a common blood disorder, and that lots of children around the country have 'funny blood' like I do."

Other Significant Programmes

Hepatitis C support for people with bleeding disorders and infusion acquired Hepatitis C

38 people with bleeding disorders had infusion acquired hepatitis C as at June 2015. HFNZ negotiated a treatment package with ACC for all people with infusion acquired HCV to access new generation medications in October 2015. Six have since cleared, eight are waiting for clearance and another 8 are in treatment.

Outreach Support Services for people with bleeding disorders and their families

3500 contacts have been made by the outreach team with people with bleeding disorders with more than 50% of people with bleeding disorders have been actively supported by the outreach service; issues as diverse as working with schools, hospitals, social welfare, and housing.

World Haemophilia Day and Buddy Awards April 2016

Acknowledgement of people who make a positive difference in the lives of people with a bleeding disorder, making presentations at special events (held around World Haemophilia Day) 10 Awardees, in excess of 100 attendees at four regional activities

In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 1st 2015 and June 30th 2016:

- Maurice Wymer
- Mervyn Hancock
- Josephine Sutton
- Des Mills
- Hilda Gillan
- Hannah Strickett-Craze

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 impacted by bleeding disorders. Without you there would be no us.

Sustaining Patrons & Corporate Affiliates

HFNZ is indebted to our Sustaining Patrons and Corporate Donors. These donors are those who have made a commitment to partner with HFNZ and offer ongoing non-directed funding. It is our good fortune that these donors recognise the value in making an annual investment in HFNZ to support its core programmes.

Their ongoing commitment improves the lives of people impacted by bleeding disorders.



Supporters

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



Kiwifirst

A Very Special Thank You goes to Kiwifirst, for their long-standing and ongoing commitment to fundraising and to the promotion of the awareness of bleeding disorders on behalf of HFNZ.



Major Donors and Grants

Major Donors and Grants	Purpose
Canterbury Community Trust	Southern Outreach Services
Novo Nordisk Pharmaceuticals Pty Ltd	Youth Camp
CSL	Youth Camp
NZ Lotteries Grants Board	Admin Salary & Costs
Waikato Community Trust	Midland Outreach Services
COGS	Central Outreach Wages
COGS	Auckland Outreach Wages
COGS	Midland Outreach Wages
TG McCarthy Trust	Support and Education
Novo Nordisk Pharmaceuticals Pty Ltd	Buddy Awards
Novo Nordisk Pharmaceuticals Pty Ltd	Young Women's Weekend
Pfizer PFE NZ	NACCHO, National Children's Workshop, Sustaining Patron
Eastern & Central Community Trust	Central Outreach Wages
Pub Charity	Northern Outreach
Four Winds	Outreach
Waikato Community Trust	Midland Outreach

Individual and general donations over \$100

Reg Fuller
Lyn Steele
Carl McKay
Nick Lingard Foundation
John Hunter
Ho Seong Kim
L A McCool
Totara Trust
Quality Hotel Parnell
Albert Roberts Estate
Anglican Westshore Parish
Gilmour Suzuki
Canterbury East Women's Institute
Betty Johnsen
Oroua Downs School
Gwenn Rivoallan
Brick Road Productions - Heather Giles
Beyond Reality Media

Directory

National Council

President:	Deon York
Vice Presidents:	Catriona Gordon Richard Scott
Treasurer:	Grant Hook
Northern Branch Delegate:	Liam Brodie
Midland Branch Delegate:	Linda Mellsop-Anderson
Central Branch Delegate:	Stephanie Coulman
Southern Branch Delegate:	James Poff
Piritoto Delegate:	Te Whainoa Te Wiata
Youth Delegate:	Hemirau Waretini
Co-opted Member:	Steve Waring

Member Representative Groups

Northern Branch Chair:	Richard Scott
Midland Branch Chair:	Wendy Christenson
Central Branch Chair:	Stephanie Coulman

Southern Branch Chair:	Theresa Stevens
Piritoto Branch Chair:	Tuatahi Pene
Youth Branch Chair:	Hemirau Waretini

Staff

National Office

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

Haemophilia Outreach Workers

Manager Outreach Services:	Colleen McKay
Northern Outreach Worker:	Nicky Hollings
Midland Outreach Worker:	Joy Barrett
Central Outreach Worker:	Lynne Campbell
Southern Outreach Worker:	Linda Dockrill

HFNZ Affiliation

World Federation of Hemophilia www.wfh.org

Entity Information

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

Our Purpose is:

Improving the lives and long-term outcomes of people impacted by bleeding disorders.

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

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

HFNZ's Main Sources of Funding are Donations & Grants. Public donations are sourced via telemarketing, direct, and give-a-little. There are also some Member Fundraising activities.

PO Box 7647, Sydenham, Christchurch 8240

P: +64 3 371 7477

E: info@haemophilia.org.nz

www.haemophilia.org.nz



Our People



Our Support



Our Whānau





PO Box 7647

Sydenham

Christchurch 8240

P: +64 3 371 7477

E: info@haemophilia.org.nz

www.haemophilia.org.nz