

# HFNZ

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## Annual Report 2017/18

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01 JULY 2017 TO 30 JUNE 2018



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

# Your HFNZ

The Haemophilia Foundation of New Zealand Inc. (HFNZ) was established in 1958 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, inherited bleeding conditions.

At HFNZ, we understand that we're stronger together. That means being an inclusive organisation, which represents the needs of people with a variety of different rare and inherited bleeding disorders, enabling us to work harder and smarter, and make a difference where it really counts.

Our belief in the power of unity is one of the reasons that HFNZ is a part of the World Federation of Hemophilia (WFH). Joining other international member organisations gives us a more powerful voice for our people.

While each HFNZ member is a unique individual, all are an integral part of the larger NZ bleeding disorder community. HFNZ is committed to connecting and unifying our community, empowering those affected by bleeding disorders across New Zealand.

This year's Annual Report reflects on a time of transition. Times are changing at HFNZ as we look to secure our future, and ensure that we are effective for our members.

This year we ran two national events, and numerous regional ones, none of which would have been possible without

the cooperation of members, supporters, volunteers, and funders. These groups working together is what empowers HFNZ to continue to deliver on our mission:

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

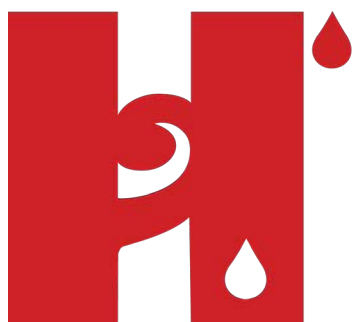
In the 2018 Annual Report it's clear how HFNZ's close connection to our members, to their families, and to the wider community makes us a more effective organisation. You will see fun, learning, and laughter. You will see our people.

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.

The bleeding disorders that affect HFNZ members are rare lifelong chronic conditions. This last year, more than ever before, promising advances in gene therapy, and the development of other novel treatments, have given hope of a better future for our members. With these advances in mind, HFNZ's dedicated staff, our innovative initiatives, and our willing volunteers continue to ensure that our people remain supported 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.

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Haemophilia Foundation  
of New Zealand Inc.

**HFNZ**

# Deon York: President's Message



The clear theme of 2017/18 has been transition. This year we continued the search for a Wellington-based 'home for haemophilia' and now operate a virtual office. We have had our share of staff farewells and changes to the organisation. Amongst all this we have continued to support people affected by inherited bleeding disorders all over New Zealand, showing the strength of our membership, network of volunteers, and dedicated staff.

A core role of HFNZ is advocacy: to ensure access to the best treatment and care for all people with bleeding disorders. We live in an exciting time. Longer-acting factor replacement therapies and novel therapies are set to revolutionise bleeding-disorder treatment. Gene therapy is increasingly looking less like that elusive ship on the horizon, and we are now hearing from people with haemophilia on gene therapy trials who have sustained levels of factor following the trials.

Longer-acting factor replacement therapies are licensed in Europe, the United States, and other parts of the world. They are also approved by Medsafe in New Zealand. This means that they are approved safe for use here. The next step is access to these medicines through the next tender round, which, at the time of this report, is still in process.

Equal funding prioritisation should be given to extended half-life recombinant FVIII and FIX. Any reduction in weekly infusions would have a positive impact on our community, particularly for those with difficult venous access, a large treatment burden associated with prophylaxis, and those who currently require Port-a-Cath insertion. Equally as exciting is the approval of emicizumab, commonly known as Hemlibra. The next step is to ensure access to all who need it, particularly those with inhibitors.

Another important role of HFNZ is support and education. This year's Adult Weekend was an opportunity for members aged 25+, and their partners, to get together and share experiences. It was also an opportunity to farewell Colleen McKay and Leanne Pearce for their collective contribution of more than 30 years, our longest-serving staff of the Foundation. A participant commented: "overall a very informative weekend with great speakers. The future is looking much better for the younger generation."

The Inhibitors weekend was held in August in Auckland. HFNZ member John Tuck shared how transformative emicizumab was for him while on trial. He has been able to go for walks without planning or forethought, plan for and go on a holiday, and he has not had a single bleed. A participant of this weekend commented: "another great HFNZ weekend in which I got to meet and reconnect with some awesome members of the community with which we share more commonalities than most."

A series of children's workshops were planned over this period, however, only the Midland one took place due to low numbers in the target demographic. This workshop went very well, with the children involved making comments like, "I enjoyed meeting other people with bleeding disorders" and "I learned that we all have white blood cells".

On behalf of the members, I would like to thank our sponsors and generous donations received from the New Zealand public. Without you, none of this would be possible.

This year, there have been many international opportunities to equip our staff and volunteers with skills and experiences to serve our community more effectively. In January, Courtney Stevens travelled to Phoenix Arizona to attend the North American Camping

Conference for Haemophilia Organizations (NACCHO). At this meeting people from around the world get together to share and learn about planning and running events for people with bleeding disorders.

Catriona Gordon attended the 10th WFH Global Forum on Research and Treatment Products for Bleeding Disorders just prior to this in Montreal. The WFH Global Forum addresses issues related to the safety and supply of treatment products for bleeding disorders, and brings together patient groups, regulators, representatives from industry, and not-for-profit practitioners, as well as doctors who treat people with bleeding disorders.

The WFH World Congress took place in Glasgow in May 2018. HFNZ was well represented by staff members Nicky Hollings and Lynne Campbell, and volunteers Te Whainoa Te Wiata, Karl

Archibald, Tuatahi Pene, and Mahia Nightingale-Pene. There were also several members who funded their attendance themselves.

I continue as a director of the board of directors of the World Federation of Hemophilia. Having these dual 'haemophilia' roles ensures there is no time to let the dust settle.

To the members, I hope that you have enjoyed being a part of the Foundation this year. The founders of HFNZ, in a dusty Lower Hutt town hall on 13 May 1958 founded this organisation on principles we still carry through to the present day, centring on care, education, advocacy and support for all people affected by inherited bleeding disorders.

I look forward to the year ahead as we formally mark 60 years of the Haemophilia Foundation later in 2019.



The team at the Midland Children's Workshop

# Richard Chambers: CEO Report



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

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

HFNZ has turned 60 this year and remains a vibrant, people-focussed, forward-thinking organisation. This is a real achievement and we can look forward to celebrating this milestone next year.

At the beginning of this financial year, the council made the decision to relocate HFNZ's head office from Christchurch to Wellington, and to purchase a building that will both house the office and generate income. This will make access to the Ministry of Health, the Minister, and PHARMAC easier, and will help to secure HFNZ's financial future. It will ensure that the needs of the bleeding disorder community can continue to be met.

It is a pivotal time for HFNZ to work closely with government, the Ministry and PHARMAC to ensure access in New Zealand to the new and effective treatments that are now becoming available internationally.

Toward the end of the financial year, the administration staff joined our outreach team in working from home. This decision was taken as part of the process of relocating to Wellington. We are continuing to improve our cloud-based systems to increase our ability to work with and for our community.

The staff, council, regions, Piritoto, and youth have been busy providing a wide range of opportunities for people to develop peer support relationships and education, as well as planning for the future. I encourage you to get involved; this is your organisation.

Thank you to Karen Melville (Administrator), Josiane McGregor and Ali Mitchell (Southern Outreach Workers), and Joy Barrett (Midland Outreach Worker), who all moved on to new roles during the year. These team members gave freely of their skill and spirit while with

us. Joy was the longest serving of this group, and I am sure people will always carry memories of her willingness to dress-up, have fun, and her commitment to doing her utmost for people in her region.

As this financial year ended, the process of appointing new outreach workers for Midland and Southern was underway. The appointment of a new administrator is on hold until the head office established in Wellington.

Thank you to our wonderful sponsors, funders, partners, and donors large and small.

Your generosity and support of the bleeding disorder community make our work possible.

Thank you to our clinical teams, who not only provide wonderful support to individuals but also freely give of their time to support the work of HFNZ at camps and workshops. Their involvement greatly enhances our ability to improve the lives and long-term outcomes of people impacted by bleeding disorders.

This is my fourth and last annual report as Chief Executive. Thank you for the opportunity to be part of this wonderful organisation. It has been an honour to contribute to bringing new generation treatment to members with infusion acquired HCV, and to see the changes it has made to our members' lives. It has also been an honour to be part of the team laying the groundwork for the introduction of new bleeding disorder treatments, meet members who take the risk to be part of clinical trials, and all the other members, funders, and partners I have had contact with.

All the best for the future. E hara taku toa i te toa takitahi, Engari he toa takitini. Success is not the work of one.



Fun at the Midland Children's Workshop

## Region & Group Reports

HFNZ has six Member Representative Groups that speak for the different parts of our community: the Northern, Midland, Central, and Southern regions; 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.



By Tuatahi Pene: Piritoto Chair.

He toto, he taimaha kia piri, tukua kia rere

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

Me mihi kia tika ki te Atua, nōna te timatanga me te whakamutunga.

Ki te Kingi Māori, te mangai mō ngai Māori katoa. Rire Rire Hau Paimarire.

Te hunga mate ki te hunga mate.

Ana, tēnā tātou katoa.

A lot has happened in this past year. Piritoto has always been a group that continues to deepen its relationships within the group, as well as with the wider HFNZ community. Knowing that our group is a national one, we always aspire to include members from the region our chosen activity takes place in, and in my mind we have far exceeded expectations. Keeping true to the proverb: Kotahi te kowhāo o te ngira e kuhuna ai te miro mā, te miro pangō, te miro wherō. Through the eye of the needle passes the white thread, the black thread, and the red thread, where each thread represents many people working as one for a single goal.

Before moving too far along I would like to take some time to mention those who have passed in the year. To all those who are in mourning over their loved ones, nei te mihi aroha ki a koutou.

Bringing the circle back, I would like to acknowledge all those who are here and those who couldn't be here; you are the hard working individuals who continue to make this whānau a whānau. Despite our busy lives I am in constant awe at everyone's passion and enthusiasm, fuelled by commitment to ensure that we as a committee function more as a family. Thank you.

There are lots of successes that I would like to highlight over the year. Our summer Noho in Raglan for one was a fantastic time. What made the event a success is the people who attended the Noho; it was a time to re-connect, a time to meet new people, and a time to have fun in the sun. A great appreciation to all those who made the weekend experience special. Nei rā te mihi ki a koutou katoa.

Another success was how we were fortunate enough to be able to send six members plus a teeny tot along to the World Haemophilia Congress in Glasgow.

A mihi goes out to two of our members, Te Whainoa Te Wiata and Māhia Nightingale-Pene, who presented abstracts on behalf of HFNZ to the congress members. The abstracts were submitted as an informative discussion to allow

members from all over the world to provide useful insights into what may be happening in their own countries.

Te Whainoa spoke about our own group, and how we are focused as a whānau to help those who identify themselves as Māori living with Haemophilia. His presentation showed the many activities the whānau are undertaking, from the Noho to Matariki celebrations and so on. His presentation was on how to engage with indigenous people of a land to best start a dialogue for cultural responsiveness.

Māhia presented on menstruation in carriers and women with bleeding disorders. The discussion focussed on how to change the attitudes about how heavy menstrual bleeding in women with bleeding disorders is treated, looking at what is necessary to first recognise the problem, and then provide the necessary steps to treat and support.



The last highlight I would like to mention goes to Te Tahawai Marae who again opened their doors to our people and gave us the opportunity to catch up with people we have not seen in a long time.

I would like to acknowledge two people specifically. Te Whainoa and Rose have been working tirelessly, helping those who are unsure about Māori tikanga and practices to be more open to how easy it can be to utilise Māori cultural practices.

In closing, it has been a great honour for me to continue serving as a Chairperson for Piritoto. A massive thank you goes out to all of you, the delegates, the committee members, and all the extended family members. Without you, we would not be who we are as a whānau. Finally, I hope to see you all at one or other of our get-togethers over the next year.

Tēnā koutou, tēnā koutou, tēnā rā tātou katoa.

By Blair Wightman: Central Chair

2017/18 was a very busy year in the Central region. We've held four successful events across the region and it has been great to meet so many of our members.

We started the year with our AGM, which was held at Owlcatraz in Shannon. The Central region covers a large geographical area, so we try to host our events in different parts of our region. It is always nice to connect with members from outside Wellington.

At our AGM, Stephanie Coulman stood down after seven years as Chairperson, and I have taken on the role. We were fortunate to have Stephanie remain on our committee and to represent our region on the National Council.

We saw out the end of 2017 with a Christmas cruise around the Wellington harbour. The weather couldn't have been better and once we had anchored in a sheltered spot we enjoyed a great BBQ dinner.

The weather hadn't played nicely earlier in 2017 so we had to postpone our inaugural fishing trip to January 2018. However, the January weather was great and around 15 members had a really enjoyable day fishing. Unfortunately, the fish were clearly also enjoying the weather and few could be enticed onto our hooks. We plan to hold another fishing charter in January/February 2019 – hope to see you there!

World Haemophilia Day fell on a Tuesday this year, and we celebrated with a Quiz night at the Khandallah Trading Co in Wellington. HFNZ entered four teams, each named with a witty Haemophilia Pun (hat tip to the Blood-knowses). Our wit wasn't enough to defeat the local quizzicians but it didn't dampen spirits!

Our committee met throughout the year in Levin, Wellington, and via teleconference. Thank you to everyone on the Central Committee for the time they all put into helping to organise events for members in the region. We are a friendly bunch and are always keen for new blood\*.

2018/19 has kicked off with our biennial Camp in Napier. We've got almost 30 members coming from Gisborne, Hawkes Bay, Manawatu, Taranaki and Wellington which covers the full breadth of the region.

*\*See what I did there*



Central Fishing trip

By Tineke Maoate: Midland Chair

Hi to all. I'm Tineke Maoate, and I took over from Linda Mellsop-Anderson as the Chairperson earlier this year. First, I would like to thank Linda for all the wonderful work she has done for HFNZ. Also, I would like to welcome all our new Midland members. I hope you will enjoy being part of this family and please attend as many events as you can.

This past year we have had a few events after a quiet first part of the year. We had a youth event in April, which was attended by our energetic youth. They had a competitive game of bowling, followed by a really nice lunch. It's great to see our future adults come together and supporting each other. Then there was the Midland Children's Workshop, which was enjoyed by many children. This was organised by Joy and Nicky. What a wonderful day they put together.

It was really nice to see R-leeo and Dylan helping out our younger ones. A lot of our children look up to the older boys and girls, right from family camp, and it's rewarding to see them give up their time, and to be such good role models.

Then we had the farewell of our beloved Midland Outreach Worker Joy. I'm sure everyone agrees that she has a special place in our hearts. Who else could pull off all those crazy outfits? I would like to thank her for all her support and the time she invested in us. We wish her all the best in her future.

Our family event, which included our AGM, was held at Rocktopia, and was another great event attended by many. We voted for our new committee members, and the roles they will hold. We are now looking toward to our end-of-year event, which is being held at Rainbow's End in Auckland in November. I look forward to catching up with everyone then.

It looks like there are going to be some changes in Midland in the next year. I would like to welcome our new Outreach Worker, Nicky. Nicky will be joining our team later on as she is going to cover Midland and Northern until Northern can find a suitable replacement. It is sad for Northern to lose such a great person/worker but a bonus for us in Midland. Lucky she is staying on with HFNZ, as she is a valuable team member and asset to this foundation.

Please feel free to contact me anytime. All the best to our members.



Joy's Farewell

By Karl Archibald. Southern Chair

A wee bit has been happening in Southern over the last few months.

Ali Mitchell, our Southern Outreach Worker has moved on early in the year. However, when one person departs a new opportunity arises. I am pleased to welcome Ross Paterson to the role of Southern Outreach Worker. Ross comes from a varied background of support and mentoring roles, and I am sure he will succeed in our region. Ross started on July 30. I am sure you will make him feel welcome as he begins to meet with our members and we thank Ali for her time.

Southern hosted its annual fundraising play in Christchurch on May 5. This was great, with just under 100 people attending, there were some amazing raffles, and the behind the scenes effort that made it happen was very impressive.

On Friday June 15, the Christchurch head-office officially closed in preparation for the move away from the mainland to Wellington. We had lovely farewell to the office at Winnie Bagoë's Christchurch on July 21, with a great turn out.

Saturday July 21 also the date of the Southern Region AGM, where new committee members have come on board to lead the Southern regional committee for the next year. I stepped down from the role of Chair, and Zac Porter has taken on the mantle. There are other new faces on the committee too, so things are looking good for the year ahead.

Thank you for your support over the last 12 months.



Youth Twinning in Nepal

## Northern

By Hemirau Waretini, Northern Treasurer

The committee for the past year has been: Neil Smith, Greg Jamieson, and Hemi Waretini.

I should make a start by thanking Neil Smith who is stepping down from the committee this year. Neil has been an integral part of the committee and taken the lead on many of our events.

The Northern Region ran some wonderful events this year and, as always it was great to catch up with everyone who came along.

We returned to Parakai Hot Springs for our Christmas Party. It was an absolute scorcher of a day so the pool and waterslides were perfect. This year we will be having our Christmas Party at Rainbow's End again, together with our friends from Midland. Our usual Summer Family Camp was

By Courtney Stevens. NYC Delegate

This year has been pretty exciting for the NYC! Our main focus has been our twinning with Nepal, as we centre our energies on trying to achieve and learn as much as we can from the twinning programme, not just for the Nepal Haemophilia Society's Youth Committee, but also for our own Youth Committee. We have also welcomed Outreach Worker Nicky as an "honorary youth committee member" to help us out and provide some guidance if needed.

Hemi Waretini and Courtney Stevens travelled to Nepal in October last year (2017), to complete the "assessment visit" part of the twinning programme, to ensure that HFNZ's youth had the right skills and experience to assist the NHS youth to get what wanted out of the twinning programme. One of the things we identified was a leadership weekend where they can learn about proposal writing, advocacy, and event planning. The final task of the weekend will include making a plan for the twinning going forward.

We have stepped up the frequency of our meetings in order to get our planning underway for the leadership weekend we are organising for the NHS youth committee to be held in Nepal in September. Having our own youth committee members co-facilitate this leadership weekend has been an amazing opportunity for us to put into practice all of the skills we have learned from attending HFNZ's leadership weekends over the years. Hemi Waretini and Lauren Nyhan will be co-facilitating the weekend with help from Deon York.

In addition, we have been working towards a national youth weekend where we can all get together, catch up, and make a plan for the coming year. We are hoping to have this early next year - watch this space for more information!

Finally, we would like to say thank you to everyone that has helped us out this year and provided assistance with our twinning programme. We look forward to giving you all an update on Nepal and sharing more about what we've been up to at home.

postponed this year but we hosted a meal at The Grounds Eatery in West Auckland where the adults spent the afternoon catching up and the kids had The Grounds' great playground to entertain them, after dinner some of the adults joined in on the playground too! We also held a dinner at Ghengis Khan Mongolian BBQ in July which was popular as always.

The committee for the next year is made up of Greg Jamieson and me. We are always looking for new ideas for events so if you have any suggestions or would like to join the committee please feel free to contact the National Office or email [northern@haemophilia.org.nz](mailto:northern@haemophilia.org.nz)

Lastly, a huge thank you to Nicky Hollings who has been the Northern Outreach Worker for the past three years. Nicky has been a great help to many of our members and she will be missed. Nicky will remain part of the HFNZ whānau as she takes up her new role as the Midlands Outreach Worker.



Tuatahi Pene and Laura Watson at Adult Weekend

## 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.

By the nature of the condition, inhibitor workshops are small in size, but big in value. In New Zealand there are about 16 people with inhibitors at any time, ranging in age from the very young to the not so young, they all have similar issues, concerns, and hopes. Twenty-two adults and children attended the 2017 Inhibitors Workshop, with four staff. That means 50% of our HFNZ members with inhibitors attended.

The August 2017 Inhibitor workshop for people with inhibitors, their partners or parents had an 'Escape' theme. Children had their own special programme, and the adults were able to learn useful information, to establish new relationships, or to renew old ones.

They spent time with Cat Pollard, the specialist haemophilia physiotherapist from Auckland, looking at and practising simple exercises to help strengthen their bodies without stress.

Paul Ockelford, a Haematologist from Auckland, reminded us about how inhibitors work, what it means

for the patient, and where we are, in New Zealand and internationally, with new treatment options.

HFNZ member, John Tuck, shared with us his dramatic story of being on the trial of the medication now known as Hemlibra. He spoke of going from frequent bleeds to no bleeds at all, and how wonderful it is that he can now enjoy a walk on the beach without worrying about doing himself damage.

Psychologist and Yoga teacher Sandra Palmer took us through some relaxation techniques that are gentle on the body. It was a very relaxing session, and may have sent a few of us to sleep.

To top it all off, everyone had the opportunity to 'escape' from an Auckland escape room. It was a great opportunity for people to build on their relationships and have a few laughs.

All in all this was a fantastic weekend with lots of openness, sharing of issues and ideas, and a wonderful sense of calm and support for each other.



Willy Tekira congratulates John Tuck at Inhibitor Workshop

On Friday September 29 2017, members and their partners from around New Zealand made their way to Auckland for the 2017 Adult Weekend. In a break from tradition, we also ran the 2017 AGM as an add-on to the weekend, on Sunday October 1.

A big part of this weekend was allowing the members the opportunity to connect with two of our long-serving staff members, who had moved on during the year. Colleen McKay and Leanne Pearce had, between them, over 32 years of experience working with our people, and this was a great chance to give them the send-off they deserved.

Attendees started drifting in to the Quality Hotel Parnell throughout the afternoon, so they could be present for the official welcome in the evening. Then, bright and early on Saturday morning, we gathered for the first proper session of the weekend. We heard about the personal bleeding disorder journeys of Eric Kemsley, Nicola Cuthbert, and Tineke & Jono Maoate. Their stories were touching and often hard to hear, and clearly resonated with everyone present.

Next, we heard from Dr. Karen Falloon, who spoke to us about the links between sleep and chronic pain. She had lots of very interesting information, and gave us plenty of tips about how to get the right amount of shut-eye each night. For the rest of the morning we split up into groups to talk about partner issues, men's issues, and women's issues.

Following a bite to eat and a cup of tea, we were treated to a clinical update from Maureen Campbell from the Waikato HTC. Maureen had plenty to say about new and upcoming treatments, particularly the rise of ACE910, now known as Hemlibra. It's very exciting to see all

the new treatments on the horizon.

The remainder of the afternoon was all fun and games, as we took our first chance to recognise Colleen and Leanne. We started in style with the skills of magician Thomas Hayman, who had some great tricks and a fine line in banter. Then, members had the chance to say a few words about how Colleen had influenced their lives. This was a very moving time, and several people shed a tear or two.

Next, we moved into the big HFNZ carnival. This was a great time, modelled on the vintage sideshows of old. There were some fantastic activities for people to get involved in, including Plucky Pearce's Precision Poultry Pitching and Camp Mother's Down-Home Antibody Shooting Party.

The Carnival merged into social time, before everyone gathered for the official dinner, and another opportunity to recognise Colleen and Leanne.

Dinner was followed by Quiz Time, where groups competed to prove just how smart they are when it comes to bleeding disorder facts, trivia, and general knowledge. There are some very clued-up people in our organisation, and the result was in the balance right up to the end of the night. Ultimately, Joy and Josiane's team snatched it at the end, to secure the coveted winners' medals.

Sunday morning saw the final sessions of Adult Weekend. To start the day we had four quick-fire sessions from Hemi, who spoke about youth issues, Josiane, who talked employment, John Tuck, who extolled the virtues of ACE910 (Hemlibra), and Te Whainoa and Tuatahi, who talked about their experiences as Māori with bleeding disorders.

The final session of the weekend was a talk by our special guest, Barry de Geest. Barry was born with the impacts of thalidomide, and he has very short, and minimally effective, arms and legs. While he was able to walk as a younger man, Barry is now mostly wheelchair-bound. However, he certainly hasn't let his disability get in the way of his life. The title of his presentation was 'No Cotton Wool for Me!', and he has very much lived up to that statement. The stories he told of his achievements and challenges were inspirational, and directly applicable to our people. It was a real treat to listen to him.

Overall, the whole weekend went very well. Everyone seemed to enjoy the educational and social activities at adult weekend, and the attendees left looking forward to the next one.



Colleen McKay & Patience Stirling at Adult Weekend

As part of our commitment to our youngest members, we try to run Regional Children's Workshops every two years. These workshops are for children aged 6 – 10 who have a bleeding disorder, or have a parent or sibling with a bleeding disorder. Unfortunately, this year three of the events were cancelled due to low numbers. This is a temporary issue related to birth demographics, which looks like changing in time for the next round of workshops.

We were, however, able to run the Midland workshop. Outreach Workers Joy and Nicky ran this daylong event with the help of five volunteers and the Haematology Nurse Maureen Campbell. The 14 children who attended had a fabulous time learning about bleeding disorders, and having fun.

The children fed back that the best things about the day were making new friends who also had bleeding disorders, or at least knew what having a bleeding disorder was like; learning about safety and how to look after themselves; that there are so many different bleeding disorders; and how clotting works.

The Outreach team ran a great programme, which enabled the children to learn in a variety of ways. They played a game that demonstrated how blood clots, using the children as the

component parts. They also made 'real' plasma and blood in a blender, using fruit and other ingredients to represent the different elements. They ended up with delicious, healthy smoothies to drink.

Part of the programme was offering the parents the chance to meet. After they had dropped off their children, Nicky took them out for a morning tea to a local café. This gave them a rare opportunity to make new friends, and share time with others who also have a child living with a bleeding disorder.

Because of this one-day workshop, the children and their parents discovered, or were reminded, that there is support for them within their community. They were also reminded of the benefits of coming to HFNZ events, including helping to develop relationships. It was really important that the children, who have other HFNZ events in their futures, know that they're not on their own and that they're not the only ones living with a bleeding disorder. For some, this was an impactful experience.

This workshop was Midland Outreach Worker Joy's last regional event. That it went off so well, and garnered such great feedback is a testament to her hard work, and the attention to detail she put in to organising it.



More fun at Midland Children's Workshop

# HFNZ Financial Report

For the 12 months ending 30 June 2018

I am happy to be in a position to report that the Foundation has recorded a surplus of \$293,483 for the year ended 30 June 2018.

However, this has been an anomalous year when the Foundation has been in a transitional period and several factors have led to this outcome.

The main influence has been that several substantial bequests were made in the Foundation's name this year, without which we would have recorded a small deficit.

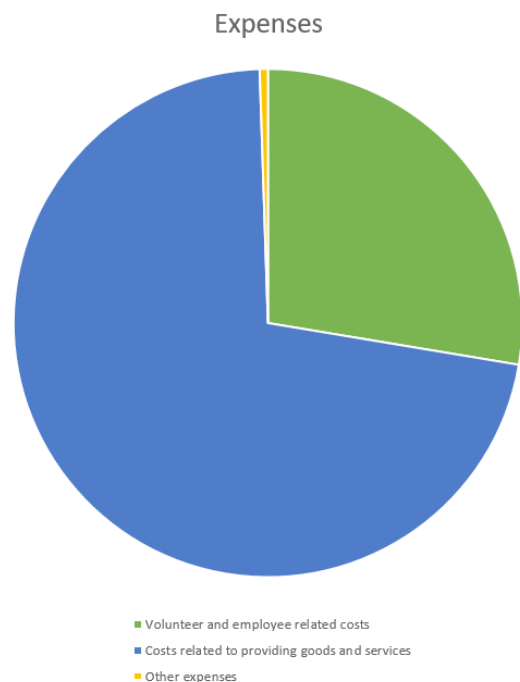
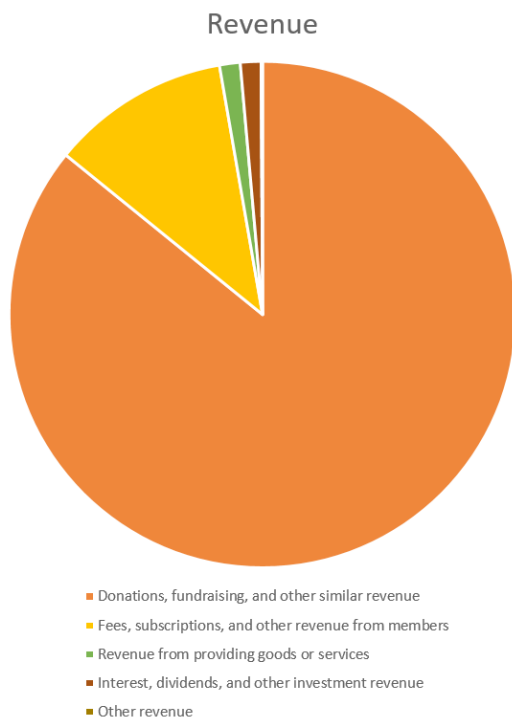
The National Office in Christchurch has closed after being based there for many years. We are currently looking to purchase a new office for the Foundation in Wellington. Some

of the bequests have been allocated to our property fund.

Lastly, the Foundation has been operating without an Outreach Manager or Administrator for some time now. While this has resulted in a reduction in salaries overall, the Foundation has needed to outsource some of the functions of these positions in the meantime which has decreased flexibility in some areas such as volunteer reimbursements which are currently done on a weekly basis.

My thanks to the staff for their continued efforts and for providing support to all of the Foundation's Members.

**Hemirau Waretini - HFNZ Treasurer**



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



## Statement of Financial Performance

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2018

	Notes	2018	2017
<b>Revenue</b>			
Donations, Fundraising, & other similar revenue	1	1,336,993	1,129,351
Fees, subscriptions, and other revenue from members	1	177,815	178,735
Revenue from providing goods or services	1	20,500	46,000
Interest, dividends, and other investment revenue	1	20,442	21,710
Other Revenue	1	1,516	5,065
<b>Total Revenue</b>		<b>1,557,266</b>	<b>1,380,861</b>
<b>Expenses</b>			
Volunteer and employee related costs	2	349,136	432,459
Costs related to providing goods or service	2	908,087	950,472
Other Expenses	2	6,560	6,653
<b>Total Expenses</b>		<b>1,263,783</b>	<b>1,389,584</b>
Net Surplus /(Deficit)		293,483	(8,723)

## Statement of Financial Position

Haemophilia Foundation of New Zealand Incorporated as at 30 June 2018

	Notes	2018	2017
<b>Assets</b>			
<b>Current Assets</b>			
Bank accounts and cash	3	372,310	114,956
Debtors and prepayments	3	110,780	121,808
Investments	3	655,929	648,041
Other current assets	3	29,130	29,037
<b>Total Current Assets</b>		<b>1,168,149</b>	<b>913,842</b>
<b>Non-Current Asset</b>			
Property, Plant and Equipment	6	3,208	2,032
<b>Total Non-Current Assets</b>		<b>3,208</b>	<b>2,302</b>
<b>Total Assets</b>		<b>1,171,357</b>	<b>915,873</b>
<b>Liabilities</b>			
<b>Current Liabilities</b>			
	4	103,739	141,739
<b>Total Liabilities</b>		<b>103,739</b>	<b>141,739</b>
Total Assets less Total Liabilities (Net Assets)		1,067,618	774,135
Accumulated Funds	5	1,067,618	774,135
<b>Total Accumulated Funds</b>		<b>1,067,618</b>	<b>774,135</b>

## Statement of Cash Flows

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2018

	2018	2017
Cash Flows from Operating Activities		
<i>Cash was received from:</i>		
Donations, fundraising, and other similar receipts	1,314,046	1,232,791
Fees, subscriptions, and other receipts from members	177,875	173,694
Receipts from providing goods and services	48,983	59,373
Interest, dividends, and other investment receipts	21,414	21,820
Net GST	-	-
Total	1,562,318	1,487,678
<i>Cash was applied to:</i>		
Payments to suppliers and employees	349,136	506,040
Costs related to providing goods and services	945,778	953,367
Net GST	1,065	2,701
Total	1,295,979	1,462,108
<b>Net Cash Flows from Operating Activities</b>	<b>266,339</b>	<b>25,570</b>
Cash Flows from Investing and Financing Activities		
<i>Cash was provided from:</i>		
Receipts from the sale of property, plant, or equipment	20	280
Total	20	280
<i>Cash was applied to:</i>		
Payments to acquire property, plant, and equipment	2,631	1,654
Payments to purchase investments	6,372	7,519
Total	9,004	9,173
<b>Net Cash Flows from Investing and Financing Activities</b>	<b>(8,984)</b>	<b>(8,893)</b>
Net Increase/(Decrease) in Cash	257,354	16,678
Opening cash	114,956	98,278
<b>Closing cash</b>	<b>372,310</b>	<b>114,956</b>
This is represented by		
Bank accounts and cash	372,310	114,956

## Notes to the Performance Report

Haemophilia Foundation of New Zealand Incorporated For the year ended 30 June 2018

	2018	2017
1. Analysis of Revenue		
Donations, fundraising, and other similar revenue		
Donations and Bequests	291,958	37,885
Fundraising - External (KF)	911,414	948,124
Fundraising - Internal	-	4,919
Grants	122,900	133,918
WFH Grants	10,722	4,506
<b>Total Donations, fundraising, and similar revenue</b>	<b>1,336,993</b>	<b>1,129,351</b>
Fees, subscriptions, and other revenue from members		
Contracts	169,534	167,759

## Notes to the Performance Report

	Registrations	3,465	5,933
	Member Fees	4,815	5,043
	<b>Total Fees, subscriptions, and other revenue from members</b>	<b>177,815</b>	<b>178,735</b>
	Revenue from providing goods or services		
	Sustaining Patrons	20,500	46,000
	<b>Total Revenue from providing goods or services</b>	<b>20,500</b>	<b>46,000</b>
	Interest, dividends, and other investment revenue		
	Interest Income	20,442	21,710
	<b>Total Interest, dividends, and other investment revenue</b>	<b>20,442</b>	<b>21,710</b>
	Other revenue		
	Gain on Sale of Asset	103	65
	Other Revenue	1,413	5,000
	<b>Total Other Revenue</b>	<b>1,516</b>	<b>5,065</b>
2. Analysis of Expenses	Volunteer and employee related costs		
	Wages and Salaries	349,136	432,459
	<b>Total Volunteer and employee related costs</b>	<b>349,136</b>	<b>432,459</b>
	Costs related to providing goods or services		
	ACC Levies	1,199	1,389
	Accounting	3,250	2,950
	Administration	266	1,522
	Adult Programme	32,201	4,545
	Advertising	761	371
	Bank Fees	238	222
	Children's Workshops	1,940	-
	Cleaning & Rubbish Removal	1,490	1,500
	Consulting (including IT)	31,076	4,507
	Defensive Driving	198	183
	National Family Camp	-	37,055
	Footwear Programme	7,197	8,210
	Freight & Courier	646	10
	Community Education (KF)	281,982	293,296
	Fundraising Costs (KF)	310,485	323,129
	General Expenses	2,085	2,996
	Physio Conference	-	1,828
	Loss on Sale of Asset	-	280
	Human Resources	-	405
	Inhibitors Workshop	14,306	-
	Insurance Assets/Liability	6,429	5,772
	International Conferences, Workshops, Meetings	-	19,563
	International Programmes (Twinning)	1,849	-
	Light, Power, Heating	1,671	1,905
	Motor Vehicle Expenses	12,537	15,473
	Region - Central	5,066	5,535
	Group - Masters	605	258
	Region - Midland	3,056	3,822

## Notes to the Performance Report

	Region - Northern	3,876	9,164
	Group - Piritoto	2,940	4,586
	Region - Southern	1,145	2,861
	Group - Youth	4,553	-
	National Council	16,627	21,869
	Needs Grants	1,955	4,536
	Office Expenses	712	446
	Outreach	5,905	6,713
	PEP - Parents Empowering Parents	81	9,052
	Printing, Stationery, Postage	20,902	20,287
	Professional Development and Team Meetings	29,480	24,021
	Rent	44,075	39,999
	Repairs and Maintenance	209	1,145
	Resources	-	269
	Special Programmes	32,722	710
	Subscriptions/Memberships	1,269	3,577
	Swimming/Fitness	6,976	9,563
	Tax Penalties	278	108
	Telephone & Internet	13,851	12,278
	Youth Camp	-	29,924
	Youth Leadership	-	12,641
	<b>Total costs related to providing goods or services</b>	<b>908,087</b>	<b>950,472</b>
	Other Expenses		
	Depreciation	1,435	1,470
	Interest Expense	-	73
	Audit	5,125	5,110
	<b>Total Other Expenses</b>	<b>6,560</b>	<b>6,653</b>
3. Analysis of Assets	Bank accounts and cash		
	SBS Savings Account	1,000	1,000
	BNZ On Call Account	311,367	81,745
	BNZ Non Profit Cheque Account	63,264	39,005
	BNZ Visas	(3,322)	(6,793)
	<b>Total Bank accounts and cash</b>	<b>372,310</b>	<b>114,956</b>
	Debtors and prepayments		
	Prepayments	3,258	15,410
	Trade Debtor - Accruals	-	67,280
	Trade Debtors	107,522	39,117
	<b>Total Debtors and prepayments</b>	<b>110,780</b>	<b>121,808</b>
	Other current assets		
	GST	27,584	26,519
	Interest Receivable	1,546	2,518
	<b>Total Other current assets</b>	<b>29,130</b>	<b>29,037</b>
	Investments		
	BNZ Term Investment - 00003	57,676	55,724

## Notes to the Performance Report

	BNZ Term Investment - 00004	58,165	56,359
	BNZ Term Investment - Property	420,650	420,650
	BNZ Term Investment - 00002	36,019	34,175
	SBS Term Investment - No 10529944	83,419	81,132
	<b>Total Investments</b>	<b>655,929</b>	<b>648,041</b>
	<b>Total Analysis of Assets</b>	<b>1,168,149</b>	<b>913,842</b>
	<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	102,705	117,027
	Money in Advance	1,035	712
	Grants in Advance	-	24,000
	<b>Total Creditors and accrued expenses</b>	<b>103,739</b>	<b>141,739</b>
	<b>Total Analysis of Liabilities</b>	<b>103,739</b>	<b>141,739</b>
5. Accumulated Funds	Accumulated Funds		
	Opening Balance	774,135	782,858
	Accumulated surplus or (deficit)	293,483	(8,723)
	Closing Balance	1,067,618	774,135
	<b>Total Accumulated Funds</b>	<b>1,067,618</b>	<b>774,135</b>
6. Property, Plant, and Equipment	Office Equipment		
	Open Carrying Amount	2,032	2,128
	Purchases	2,631	1,654
	Sales/Disposals	(20)	(280)
	Depreciation	1,435	1,470
	<b>Closing Carrying Amount</b>	<b>3,208</b>	<b>2,032</b>
7. Grants in Advance	Waikato Community Trust		
		-	12,000
	Pub Charity	-	12,000
	<b>Total Grants in Advance</b>	<b>-</b>	<b>24,000</b>
8. Lease Commitments	The Haemophilia Foundation of New Zealand has the following lease commitments:		
	<ul style="list-style-type: none"> <li>A photocopier leased from Ricoh. The lease term is for 58 months commencing 26 April 2015. The lease is \$322.35 excluding GST per month. This is currently being stored by Ricoh pending relocation to the Wellington office.</li> <li>A storage unit is being leased from Lock and Leave. The lease term is on a month to month basis as of June 5 2018. The lease is \$173.00 excluding GST per month.</li> </ul>		
9. Related Party	Included within expenses are honoraria paid to Deon York (President). All transactions were carried out on normal commercial terms.		
10. Statement of Commitments	There are no commitments as at balance date. 30/06/2017 (Nil)		
11. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/2017 (Nil)		
12. Events After Balance Date	There were no events that have occurred after the balance date that would have material impact on the performance report.		

## Statement of Accounting Policies

Haemophilia Foundation of New Zealand  
Incorporated for the year ended 30 June 2018.

### 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.

Measurement base: Unless otherwise specified the measurement base adopted is that of historical cost.

### Audit

These performance reports have been subject to audit, please refer to the Audit Report

### Good and Services Tax (GST)

The society 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 - Straight Line method 20% - 33.34% and Diminishing Value method 40% - 67%

All fixed assets are recorded at cost less accumulated depreciation. Depreciation of the

assets has been calculated at rates set by the Committee to allocate the cost of assets over their estimated useful lives.

### 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 in the Statement of Cash Flows comprise cash balances and bank balances (including short term deposits) with original maturities of 365 days or less.

### Grants Income and Grants in Advance

Grants are recognised as revenue at the date of receipt unless specific conditions are attached to a grant and repayment of the grant is required if these conditions are not met. In these cases, the grant is treated as a liability until the conditions are met, and are shown in the Statement of Financial Position as Grants in Advance.

### Changes in Accounting Policies

There have been no changes in accounting policies. Policies have been applied on a consistent basis with those of the previous reporting period.

### 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.



Brain food at Midland Children's Workshop

## INDEPENDENT AUDITOR'S REPORT

To the National Council of Haemophilia Foundation of New Zealand Incorporated

### Report on the Performance Report

#### Opinion

We have audited the performance report of Haemophilia Foundation of New Zealand Incorporated on pages 14 to 19, which comprises the entity information, the statement of service performance, the statement of financial performance and statement of cash flows for the year ended 30 June 2018, the statement of financial position as at 30 June 2018, and the statement of accounting policies and other explanatory information.

In our opinion:

- a) The reported outcomes and outputs, and quantification of the outputs to the extent practicable, in the statement of service performance are suitable;
- b) The accompanying performance report gives a true and fair view of the Society;
  - The entity information for the year then ended;
  - The service performance for the year then ended; and
  - The financial position of Haemophilia Foundation of New Zealand Incorporated as at 30 June 2018, and its financial performance, and cash flows for the year then ended

In accordance with Public Benefit Entity Simple Formatting Reporting – Accrual (Not-For-Profit) issued by the New Zealand Accounting Standards Board.

#### Basis for Opinion

We conducted our audit of the statement of financial performance, statement of financial position, statement of cash flows, statement of accounting policies and notes to the performance report in accordance with International Standards on Auditing (New Zealand) (ISAs (NZ)), and the audit of the entity information and statement of service performance in accordance with the International Standard on Assurance Engagements (New Zealand) ISAE (NZ) 3000 (Revised). Our responsibilities under those standards are further described in the *Auditor's Responsibilities for the Audit of the Performance Report* section of our report. We are independent of Haemophilia Foundation of New Zealand Incorporated in accordance with Professional and Ethical Standard 1 (Revised) *Code of Ethics for Assurance Practitioners* issued by the New Zealand Auditing and Assurance Standards Board, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Other than in our capacity as auditor we have no relationship with, or interests in, the Society.

## Responsibilities of the National Council for the Performance Report

The National Council are responsible for:

- (a) Identifying outcomes and outputs, and quantifying the outputs to the extent practicable, that are relevant, reliable, comparable and understandable, to report in the statement of service performance;
- (b) The preparation and fair presentation of the performance report on behalf of the entity which comprises:
  - The entity information
  - The statement of service performance; and
  - The statement of financial performance, statement of financial position, statement of cash flows, statement of accounting policies and notes to the performance reportIn accordance with Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit) issued by the New Zealand Accounting Standards Board, and
- (c) Such internal control as the National Council determine is necessary to enable the preparation of the performance report that is free from material misstatement, whether due to fraud or error.

In preparing the performance report, the National Council are responsible on behalf of Haemophilia Foundation of New Zealand Incorporated for assessing the Society's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate Haemophilia Foundation of New Zealand Incorporated or to cease operations, or have no realistic alternative but to do so.

## Auditor's Responsibilities for the Audit of the Performance Report

Our objectives are to obtain reasonable assurance about whether the performance report is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (NZ) and ISAE (NZ) 3000 (Revised) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this performance report.

As part of an audit in accordance with ISAs (NZ) and ISAE (NZ) 3000 (Revised), we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the performance report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit 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.



- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management.
- Conclude on the appropriateness of the use of the going concern basis of accounting by the National Council and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Society's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report. However, future events or conditions may cause the Society to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the performance report, including the disclosures, and whether the performance report represents the underlying transactions and events in a manner that achieves fair presentation.
- Perform procedures to obtain evidence about and evaluate whether the reported outcomes and outputs, and quantification of the outputs to the extent practicable, are relevant, reliable, comparable and understandable.

We communicate with the National Council regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

*Nexia Christchurch Limited*

**Nexia Christchurch Limited**  
**28 September 2018**  
**Christchurch**

# Statement of Service Performance

## Objective

Improving the lives and long-term outcomes of people impacted by bleeding disorders by providing quality, comprehensive, education and psychosocial support.

## Outcomes

National Inhibitors Workshop  
August 2017

The development of an inhibitor, an immune response to treatment with clotting factors, is a risk for people with haemophilia. If an inhibitor develops, it significantly changes the life of the individual, and their whānau. Inhibitor Workshops provide specific education for the whole family, and for all ages, on inhibitors and the management of their impact. The workshops help develop a supportive network for people with inhibitors and their whānau, reducing their sense of isolation.

- Adults - 15
- Children - 7
- Staff - 5

*"Another great HFNZ weekend in which I got to meet and reconnect with some awesome members of the community with which we share more commonalities than most. The hope of new treatments and the support with the current regimes and quality of the life discussions were great and I enjoyed it thoroughly."*

*"So glad we came. The experience has been invaluable. Have quite often been lost for words as people have been so open and genuinely care and want to hear your story. Very welcoming and relaxed weekend, Thank you so much."*

*"A must for all (people with) inhibitors and parents"*

Adult Education Weekend  
September 2017

Living with a bleeding disorder, or living with a person with a bleeding disorder, is challenging. The Adult Weekend is an opportunity for adults with bleeding disorders to openly discuss their

experiences, challenges, and concerns about living and aging with a bleeding disorder. The focus of the weekend is to increase knowledge about bleeding disorders, about upcoming trends and treatments, about aging with a bleeding disorder, and about the provision of health care in New Zealand, as well as learning about HFNZ and its activities. Some Adult Weekends also include partners.

- Adults – 39
- Staff – 6

*"Overall a very informative weekend with great speakers. The future is looking much better for the younger generation."*

*"More people especially women should start attending as this is a very interesting and informative weekend."*

*"Being with people who understand haemophilia and the respect shown to us by everyone involved"*

*"Overall a very informative weekend with great speakers. The future is looking much better for the younger generation."*

Adult Education Weekend

Regional Children's Workshop: Midland  
April 2018

One member having a bleeding disorder affects the entire family. The Regional Children's Workshops educate and support children with bleeding disorders of all severities, as well as their siblings, and the children of adults with bleeding disorders. In this environment, brothers and sisters can learn about bleeding disorders while having fun together, and with other children.

Four workshops were planned. Unfortunately, low numbers in the target age group and resultant registrations meant that we could only hold the Midland event this year. Children within Northern, Central, and Southern were

provided with individualised resources and programmes

- Children - 10
- Staff - 2
- Clinician - 1
- Volunteers - 5

Children were asked at the end of the day what one thing they learnt and what they enjoyed the most:

*Boy: That we have white blood cells*

*Playing the remote control game.*

*Girl: That some bugs have yellow blood*

*Coming to HFNZ event.*

*Boy: Playing.*

*Boy: That we have white blood cells.*

*Meeting people with bleeding disorders.*

*Girl: Learned about blood*

*Enjoyed whole day.*

*Boy: Learned about safety gear*

*Enjoyed making smoothies*

*Boy: Meeting a new friend Jack*

*Boy: Meeting new friends*

*Girl: Learned about von Willebrand*

*Playing the remote control game*

*Girl: Learned more about safety on trampolines*

*Enjoyed making smoothies*

## Other Significant Programmes

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

8 people with bleeding disorders had infusion-acquired active hepatitis C as at June 2018. HFNZ negotiated a treatment package with ACC for all people with infusion acquired HCV to access new generation medications in October 2015, this has had a positive impact and seen a steady reduction in people with HCV within the community. Several people have been unable to receive treatment due to other health issues or fear of treatment as a result of past treatment options. Outreach team continue to support and encourage those people to access treatment. There remain risks and concerns for the long-term health of people having been HCV positive for 20 -30 years. This will continue to be monitored for those who have had a sustained virological response to antiviral therapy.

Support Services for people with bleeding disorders and their families

2433 contacts were made with people with bleeding disorders by the Outreach team. Contact levels are slightly down on last year due to delays in the recruitment of a new member of the outreach team. More than 60% of people with bleeding disorders have been directly supported by the outreach service in the year July 1 2017 to June 30 2018; issues dealt with were as diverse as working with schools, hospitals, social welfare, and housing.

World Haemophilia Day and Buddy Awards  
April 2018

This year for World Haemophilia Day, there were some regional events, and we ran a campaign to have local NZ landmarks lit up red for the day, in line with an international, World Federation of Hemophilia initiative.



Carnival time at Adult Weekend

# 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	Purpose
Rata	Donation for Southern Outreach Services
Department of Internal Affairs	Grant for Auckland OR Wages/Programmes
Shire - Sponsorship	Inhibitors Workshop held in Auckland 18-20 August 2017
Foundation North	Programme Costs
Foundation North	Operating Costs
NZ Lotteries	Grant for Admin Rent, Phone & Administration
Pfizer PFE NZ	Sponsorship of Youth Camps
Pfizer PFE NZ	Sponsorship of NACCHO
Roche Products (NZ) Ltd	Parents Workshop Donation
Roche Products (NZ) Ltd	Workshops for children & women
Waikato Trust	
Public Donations via Givealittle	

## Bequests

Estate of Albert Roberts
Estate of Robert Frank Charles Pyle
Estate of LA McCool
Estate of Joan Alison Meyer

## Individual and general donations over \$100

John Hunter
Eric Kemsley
Tilsley
Lyn Steele
Nick Lingard Foundation
Godfreys Law
Chandler Moorie
Give A Little - Public donations
Give A Little - Spark Fund donations



# In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 1 2017 and June 30 2018:

- Daphne Walsh
- Graham Waring

HFNZ wishes to formally acknowledge their valuable contributions to the Foundation, as well as to 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	

# Directory

## National Council

President:	Deon York
Vice Presidents:	Catriona Gordon Karl Archibald
Treasurer:	Hemirau Waretini
Northern Branch Delegate:	Neil Smith
Midland Branch Delegate:	Linda Mellsop-Anderson
Central Branch Delegate:	Stephanie Coulman
Southern Branch Delegate:	Theresa Stevens
Piritoto Delegate:	Te Whainoa Te Wiata
Youth Delegate:	Courtney Stevens
Co-opted Member:	Steve Waring

## Member Representative Groups

Northern Branch Chair:	No Chair
Midland Branch Chair:	Linda Mellsop-Anderson
Central Branch Chair:	Blair Wightman

Southern Branch Chair:	Karl Archibald
Piritoto Branch Chair:	Tuatahi Pene
Youth Branch Chair:	Lauren Nyhan

## Staff

### National Office

Chief Executive:	Richard Chambers
Communications Manager:	Phil Constable
Administrator:	Karen Melville

### Haemophilia Outreach Workers

Northern Outreach Worker:	Nicky Hollings
Midland Outreach Worker:	Joy Barrett
Central Outreach Worker:	Lynne Campbell
Southern Outreach Worker:	Ali Mitchell

## HFNZ Affiliation

World Federation of Hemophilia [www.wfh.org](http://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 the President, two Vice Presidents, a Treasurer, a representative for each of the four regional Member Representative Groups (Northern, Midland, Central, and Southern), a representative from the Piritoto and Youth National Member Representative Groups, and one co-opted member.

There are 5.8 full-time equivalent staff employed to provide support and education programmes. They are based in Auckland, Hamilton, Levin, and Christchurch.

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.

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[www.haemophilia.org.nz](http://www.haemophilia.org.nz)

