# HFNZ

# Annual Report 2018/19

01 JULY 2018 TO 30 JUNE 2019

Haemophilia Foundation of New Zealand Inc.
HFNZ

*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 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.

# Contents

Haemophilia Foundation
of New Zealand Inc.
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# Deon York: President's Message

Last year I began by noting that the clear theme of the 2017-18 year had been ‘transition’. Looking back at the year to June 2019, I would characterise this year as heading towards transformation. Transformation does not mean complete reinvention. Care, education, advocacy, and support for all people with inherited bleeding disorders in New Zealand have always remained the core of HFNZ since 1958.

There has been a shift in access to therapy. This year, longer-acting recombinant FVIII and FIX became available for everyone, better for those with severe haemophilia A and arguably transformative for those with haemophilia B. For those with inhibitors, emicizumab (a novel bypassing agent) was made available. This is the first time in twenty years that there has been any substantive treatment change for people living with an inherited bleeding disorder in New Zealand.

Although HFNZ is not a member of the haematology subcommittee to the Pharmacology and Therapeutics Advisory Committee of PHARMAC, having been consulted on behalf of the membership, I believe that the funded therapies represent an equitable outcome for the majority of our members. The advice given to PHARMAC was that 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. The next step is for novel bypassing agents to be more widely available to our community – although it is heartening that one bypassing therapy is already available to several members with inhibitors.

We continued to run a virtual office in 2018-19. Our intent is still to purchase a small commercial property in Wellington. We are incredibly grateful to the bequest from an estate that makes this action possible. Once the matters of this estate have been settled, we will have a robust financial base for the property search. I would like to thank Catriona Gordon for all the time she has devoted to this as our lawyer, most of which has occurred on a voluntary basis.

The regions continue to be the life blood of HFNZ. You can always check in with one of our regional groups to know the health of the organisation. Some have been quite depleted in numbers this year, but not in spirit. My appreciation goes to all the dedicated volunteers who are involved in the regions and always come up with new ways to engage with members. For those who may sometimes feel disheartened by not getting the response they were seeking, remember that events are always meaningful for those who choose to attend. Thank you to our regional representatives Tineke Maoate, Hemi Waretini, Theresa Stevens, and Stephanie Coulman for bringing the views of the region to the national council every quarter.

It’s now hard to imagine that there has not always been a group specifically for people affected by bleeding disorders who identify as Māori. In 2009 the first meeting of what is now called Piritoto was held. The inaugural hui took place at Manukanuka o Hoturoa Marae in Auckland. The aims of the hui were to establish, for all members who identify as Māori, experiences of bleeding disorders, expectations of HFNZ, recommendations for HFNZ, and discussions about increasing involvement. I attended this first hui, and was delighted to attend another this year, marking the 10th anniversary of this group. I am grateful to Te Whainoa Te Wiata for being the voice for Piritoto at the national council table.

HFNZ’s national youth group is going from strength to strength, partly due to its role in the ‘youth twinning’ with Nepal. A couple of years ago HFNZ was selected as one of three ‘youth twins’ as part of the World Federation of Hemophilia’s twinning programme. The programme encourages the transfer of expertise and knowledge between established and emerging youth groups in the areas of leadership training, good governance of youth groups, fundraising, peer support groups, and patient education. A big thank you to the youth group, and particularly Lauren Phillips, Hemi Waretini, and Courtney Stevens for showing such initiative.

We have continued to offer our supportive footwear as well as exercise and swimming programmes to members and focused on delivering a family camp this year. I’m grateful to all the staff for all their hard work in delivering this national camp and continuing to connect members with our support programmes.

This year concluded our contract with the Ministry of Health for supporting people living with a bleeding disorder and hepatitis C. This is a double-edged sword. It is an encouraging story as virtually all members have been successfully treated for hepatitis C as at June 2019. However, the tragic side of the story remains. More specifically, the number of members HFNZ supports with hepatitis C has not just depleted due to successful treatment; we have also suffered loss. For those who have technically cleared the virus, there is still the residual impact on well-being. HFNZ will continue to support members impacted by hepatitis C and will be seeking new sources of funding.

The pharmaceutical industry, trusts, and benefactors, along with a small proportion of government funding, continue to keep us financially viable. Gratitude must be paid to the generosity of the many organisations and individuals who believe in our cause. Their further details are included in the financial report. Members of the public donate to HFNZ in order to improve the lives of people with bleeding disorders. I would like to personally thank every individual donor. Without you, much of what we do would be impossible. Thank you also to Kiwifirst for making it possible for the public to connect with our cause.

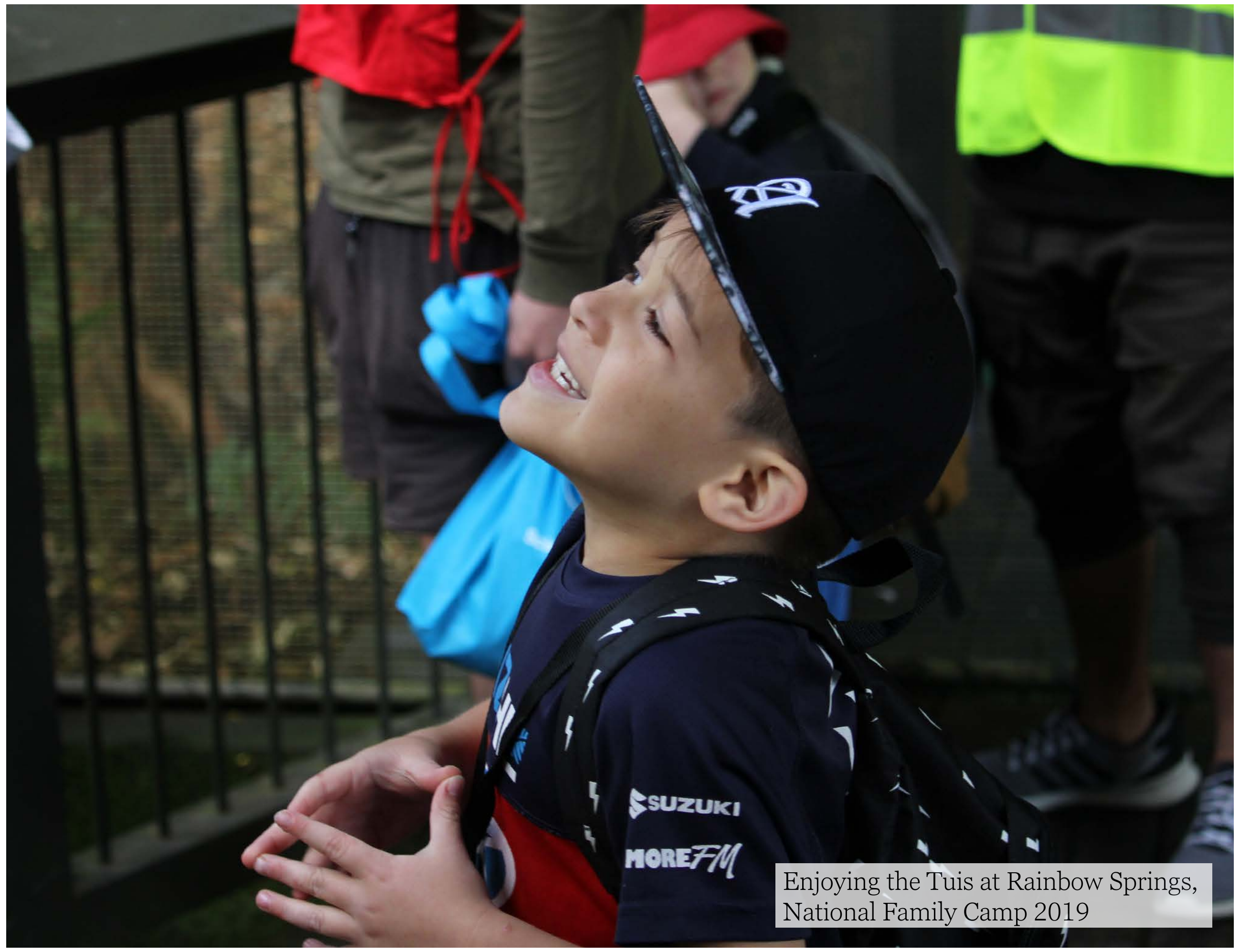
HFNZ typically runs a surplus budget one year, and a deficit the next. HFNZ's national council continues to adopt this principle as the steward of our financial resources. On that note, many thanks to our treasurer Hemi Waretini.

I would like to express my appreciation to all the staff of HFNZ for their contributions, and once again, thank as well as welcome our CEO Sue Ellis to the community. Like Sue, I am also particularly grateful for the return of Leanne Pearce to HFNZ. Thank you to the national executive of Karl Archibald, Catriona Gordon, and Hemi Waretini (who has worn several hats this year!) for supporting me in my role this year and for all the important skills, insights, and good humour you all bring to everything you do.

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

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

Finally, a special thank you goes to every member and volunteer of HFNZ. You remain the heart of this organisation. And you have collectively devoted many hours of your personal time to serve our community – imagine where we would be without all your knowledge and skills.


Enjoying the Tuis at Rainbow Springs, National Family Camp 2019

# Sue Ellis: CEO Report

I started in the role as Chief Executive for the HFNZ in November 2018. I am extremely grateful to all who I have encountered in my first year, for their patience and their willingness to guide and provide me with the necessary tools to ensure the organisation runs smoothly under new leadership.

I start my report with a number of thanks and acknowledgments:

I would like to express my appreciation to the President, the National Executive, Council members and especially to the staff for their ongoing support in helping the new CEO get into her role. I am particularly grateful for Leanne Pearce returning to the family of HFNZ to help make our administration run smoothly. A special thank you to Piritoto who have welcomed and embraced me in to their whānau

I would also like to acknowledge and thank the support from Steve Waring and the team at KiwiFirst who continue to provide great support and services for HFNZ. I enjoy the individual support and occasional banter with Steve, thank you.

I am appreciative of our friends in the pharmaceutical industry who have been so supportive and generous with grants and other funding to help us deliver our work programme. It is a unique and important relationship we have, and I value the personal interactions with them and will continue to build these relationships

This year saw changes to the Outreach Workers as Nicky Hollings moved from Auckland to Taupo as the Midland ORW and we welcomed Amber Maihi to the role of the Northern ORW. Amber brings a unique and important Maori lens to our work and has been embraced by Piritoto. We continue to all work from our home offices as we await bequests that will provide the opportunity to purchase a national office in Wellington.

In January, the President and I were invited to attend the Seventh Annual Global Haemophilia Advocacy Leadership Summit in Brussels, Belgium, sponsored by Bayer including support for travel and accommodation. The Summit brought together advocates from around the world who are committed to improving the lives of those living with haemophilia – to build on learnings from previous summits; to explore the important skills needed to be a leader in the haemophilia community; and to challenge the status quo and standard of access for reliable, evidence-based treatment for patients.

The two-day programme provided a mixture of workshops and interesting presentations from leading international advocates. What I took away from this summit was that no matter where in the world you may be, those who advocate for the haemophilia community are truly committed and passionate people.

Then, in February, we attended the Roche Emicizumab Advisory Board– Patient Support Programme for People with Haemophilia A in Wellington. Along with clinicians from the Haemophilia Treatment Centres, we listened to patients' journeys with haemophilia, their past ongoing issues with bleeding and joint damage over the years, and the psychological effects that this has had. A presentation was given by Dr Fiona Crichton, a Health Psychologist on the importance of taking into account the psychological aspects of treatment – or not - and the impact this can have on people's lives.

April saw the successful delivery of the National Family Camp, held at Camp Keswick in Rotorua. Congratulations to our Midland Outreach Worker, Nicky for her great leadership and organizational skills in pulling this together, with support from her colleagues (and the expert advice from Colleen McKay, thank you Colleen). A huge thank you to the clinicians, to the youth leaders and all the member volunteers who helped to make this another successful camp. The next National Family Camp is already being planned and organized for 2021.

As we celebrate the 60th anniversary of HFNZ in November, we can reflect on all who brought us to today's successful and vibrant organisation that continues to provide the care, education, advocacy and support for whānau and all those members with bleeding disorders.

Next year we will be building on our programme activities with an Inhibitors workshop 13th and 14th March and a Youth Camp (10 – 18 years old) 9th to 12th July – both to be held in Auckland.

I will conclude my report with a whakatauki (proverb) that underpins my belief in what I have learnt of the strength of the Haemophilia Foundation of New Zealand:

"He waka kōtuia kāhore e tukutukunha mimira

A canoe that is interlaced will not become separated at the bow. In unity there is strength".

Happy campers at Central Family Camp in Napier 2018

# 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.

## Piritoto

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 Kīngi Māori, te mangai mō ngai Māori katoa. Rire Rire Hau Paimarire.

Te hunga mate ki te hunga mate.

Ana, tēnā tātou katoa.

2019 is the year where Piritoto turns inwards and focus on some key questions such as 'what is important to us?' What can we hope to achieve being a MRG in the Foundation? Questions such as these will make us grow strong as a rōpū.

Living true to the proverb of Kiingi Tawhiao "Ki te kotahi te kakaho ka whati, Ki te kapuia e kore e whati." When reeds stand-alone they are vulnerable, but together they are unbreakable.

Before moving too far along I would like to take some time to mention those who have passed in the year. To Rosalie and her whanau and to all those who are in mourning over their loves 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 could not be here; you are the hard working individuals who continue to make this whānau a whānau. We all have our busy lives; I am humbled to be in the presence of people who are so passionate and fuelled by commitment to ensure that we as a committee function more as a family. Thank you.

Back to the key questions. Tikanga is what came out of our wānanga. Tikanga or rules that help guide cultural practices are going to be the focus of Piritoto in 2019. We are in discussions on what Tikanga looks like to us as a group. The outcomes will help solidify our autonomy of cultural practices not only within the group but as part of the HFNZ whānau.

Another outcome from our wānanga discussions is the Piritoto editorial piece that will be covered over the next few issues of Pānui. Piritoto will be writing segments about Pōwhiri – the formal welcome process. The segments will form a 'how to guide' to help whānau who might find themselves taking part in the Pōwhiri process.

Our wānanga base discussions were done and will continue to be held on Te Tahawai Marae. Again, the Marae has graciously opened their doors to our group of people and gave Piritoto the opportunity to once again catch-up with people who we have not seen in a long time.

There are two individuals I would like to acknowledge specifically. Te Whainoa and Rose who have been working tirelessly, helping those who are unsure about Māori tikanga and practises to be more open to how easy it can be to utilise Māori cultural practices. Tēnā kōrua, ngā mihi maioha.

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 all we would not be who we are as a whanau.

Tēnā koutou, tēnā koutou, tēnā rā tātou kātoa.

## Northern

By Greg Jamieson, Northern Committee

The Northern region has had a quieter year for events this year but the events we have done have been successful.

We have tried to provide a range of events, hoping you all find something that appeals to you. Getting together in a social setting promotes intergenerational interaction, the informal exchange of 'hot tips' for living well, friendship, and laughter.

We had a good turn out for dinner at the grounds in Henderson and we held a family event at the Tree Tops at Woodhill forest (pictured). We are currently planning a spring event, and were working on our annual Christmas catch up. We hope you can join us!

We have been very lucky to have Amber Maihi (Northern outreach worker) join our team this year. Amber has mixed in well with our community, goes over and above to help and is just a really nice person so if you haven't meet Amber yet please make an effort to get in touch and say hello.

Lastly we have had Rosalie Glynn join our committee so that makes us a team of 4 with Hemi, Rosalie, Amber and I. We always looking for new committee members so if your able to help in anyway please get in touch.

## Central

By Blair Wightman: Central Chair

2018/19 has been a busy year in the Central region with events held in most parts of our region. We started the year with our biennial camp. This was held in Napier at the Top 10 Kennedy Park where we have been on several occasions. We had 7 family groups and 25 people attending for the two days. Camp included a mixture of educational sessions, our AGM, excursions and plenty of free time to socialise with other families. The educational sessions were both very interesting with BJ Ramsay talking on new and future Haemophilia treatments and Helen Dixon on the new Ultrasound programme and Rheumatology access available in the region. We also had interesting excursions to the National Aquarium and the Hot Pools. Thanks to Stephanie Coulman for all of her work in organising Camp and BJ and Helen for travelling up to Napier to share their knowledge.

In November we had our Christmas celebrations with one of our best attended events in years at the Southwards Car Museum in Waikanae. We clearly have some closet petrol-heads in the region. It was also great to meet and welcome the Foundation's Chief Executive Sue Ellis.

We celebrated World Haemophilia Day in 2019 with a dinner in Wellington and Palmerston North (pictured). This was held at two Nepalese restaurants to link in with the Youth twinning programme with Nepal and we had reasonable attendance at both.

Throughout 2019 we've been trying to hold a Men's Fishing trip. This has been cancelled on us three times due to the Wellington weather but we intend to try again later in the year.

Looking forward to 2020, we'll be celebrating WHD again in April and holding another regional camp in August / September – likely in the greater Wellington region – watch this space.

## Midland

By Tineke Maoate: Midland Chair

This year has been a quite year for Midland. We had our amazing Christmas event at rainbows end with our northern members. This was attended and enjoyed by many. Deon and Sue were also able to join us.

We went into the new year with great enthusiasm but with busy lives and with issues with our email data base there was a few events that didn't get attended by many or by any at all.

The family camp was a great camp with some new families and some old faces. The camp went very well and was another opportunity for HFNZ members to get together.

We had bowling in Tauranga in September which was a lot of fun with a little bit of competition. Followed by pizza and fries for lunch.

I would also like to thank Nicky our energetic and enthusiastic out reach worker. I know that we have a big region and that you are still making your way around to meeting everyone. Also a thank you to Phil and Leanne for all their hard work.

Could everyone please take the time to update or check their details with Phil or their out reach worker, so that we can make sure that all our members are contactable and will never miss an event.

We are all now looking forward to our 60th celebrations in Wellington. We plan to have a summer event which we are now planning for. So any ideas or suggestions are greatly appreciated. Look after yourselves and each other.

The Maoate girls at Family Camp, 2019

## Southern

By Zac Porter. Southern Chair

The Southern HFNZ region has had a very successful past year.

We were lucky enough to have Ross Paterson join us as our Southern Outreach Worker at the end of July last year and Ross has proved himself as a extremely valuable member of the HFNZ team throughout his time with HFNZ.

On the 9th of December we held an excellent Southern Christmas event at Willowbank Wildlife Reserve in Christchurch (pictured), which saw a great turn out from members both young and old. We are currently planning our end of year event for 2019 and hope to have invites sent out in the near future.

Another highlight of the year was the annual Southern fundraising play night held on the 25th of May in partnership with Brick Road Productions. This was attended by approximately 90 people from the wider HFNZ community and the event raised just over $1800 which was donated to the HFNZ Youth committee to assist with running a youth leadership training programme with the Nepalese twinning partnership ahead of the 60th celebrations. We would like to thank all who attended or helped make this event happen as there was a lot of hard work which went into putting on a successful evening.

Southern Youth also attended Scared Scriptless at the Court theatre on the 1st of June. This was a great social event to bring some of the youth in the region together and share a laugh and some pizza.

Finally, Kyle & Ross have been organising monthly walks throughout the Port Hills as a great way to get some fresh air and keep active. These will continue to happen throughout the year so be sure to join in if this is of interest to you, all are welcome.

We still have a few events Southern coming up in the not too distant future so keep an eye out for an invite in your mailbox for these. We would like to thank you for all your support over the past year.

## Youth

By Courtney Stevens. NYC Delegate

Our focus this year has once again been our twinning partnership with Nepal. Since our last report, Hemi Waretini and Lauren Phillips (Nyhan) travelled to Nepal in late 2018 and co-facilitated a leadership programme for the Nepal Haemophilia Society's youth (pictured). Deon also attended the weekend to provide his assistance. This leadership programme covered topics including proposal writing, fundraising, advocacy, promoting awareness and the final step was to put forward our twining proposal to continue for another year.

This year we have been busy planning a Youth Development Workshop to be held in Wellington in November, in conjunction with the 60th Celebrations. This Youth Development Workshop (YDW) is a chance for some of our 'up and coming' youth members in New Zealand to come along, learn more about the Foundation, meet some new people and (hopefully!) get involved. We have also invited some of the members from the Nepal Haemophilia Society's Youth Committee to attend the weekend as part of our twining programme. We have invited a range of speakers to assist us with the facilitation of the YDW, where we intend to cover off sessions including: raising awareness, risk management and the practical aspects of living with a bleeding disorder such as workplace and educational rights & responsibilities and how to constructively raise these issues.

Finally, the National Youth Committee would like to give a shout out to Nicky for all her assistance over the year and willingness to help us out with whatever we need! As always, if you're keen to get involved with us, please get in touch or let your Outreach Worker know.

We are looking forward to hosting our Nepalese visitors at the Youth Development Workshop and catching up with you all at the 60th Celebrations in November!

Touching the pounamou at Rainbow Springs Rotorua, 2019

# 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.

In recent years, there has been increased recognition of the unique issues faced by women with inherited bleeding disorders.

We held this two-day event for Women with inherited bleeding disorders aged from 18 years and upwards at the Copthorne Oriental Bay in Wellington over October 15 and 16 2018. Although we held a Young Women's Weekend in 2016, it has been five years since women over 28 have had the opportunity to attend a Women's Workshop. In all there were 43 attendees aged approximately 18 – 80, and three Outreach Staff.

The aims of the weekend were to provide information and education, to empower participants to understand and work through the issues associated with their condition, and to develop a sense of community within the group.

This weekend was characterised by the way that a large group of women, who were diverse in so many ways, were able to come together and share their experiences with one another in a true bond of friendship. It was clear to a new person involved with the community that a proportion of the women new each other to some degree, and there was the rekindling of old friendships, but also evident was the blossoming of new relationships, which was wonderful to observe.

While education was the primary focus of the programme, recreational activities and time for bonding was included in the programme and appreciated.

A real factor in the bonding of the group was the presence of nine-month-old Hugo, who may have been a disruptive influence but was no trouble at all. While mum, Trinette, was engaged in activities over the weekend, this little boy was passed around the group. He was content to look at all the faces and activity, and to many he symbolised all that is good in the community. The group willingly and ably adopted him, and his presence did not hinder proceedings over the weekend at all, but rather enhanced them in a very special way.

Dr Claire McLintock's presentation "Women and Girls with Bleeding Disorders" was the outstanding favourite educational session. In their evaluation, several attendees commented that Claire's talk had changed their thinking and understanding around how haemophilia affects women. Claire proved to be the perfect choice for a women's weekend, not just because of her technical expertise, her knowledge, or even her qualities as an engaging speaker, but most importantly as a champion for women in the HFNZ community.

Theresa Stevens and her fundraising activities for the Nepalese community added a fun dimension to the weekend, and the group of women readily engaged in the activity of doll making. The dolls were impressive, and the laughter and discussion that went with it was infectious.

Fog at Hamilton airport unfortunately resulted in the Hamilton group missing all of day 1 and some other flights were to a lesser extent delayed. In their evaluations, many participants requested that in future, everyone arrive by the night before so that there were no delays in starting the main programme. In addition, some participants requested that an off site social activity be included for future Women's Workshops.

All participants enjoyed hearing the personal stories of others, catching up with old friends and meeting new Members. Participants left the event feeling more informed and empowered.

At Women's Weekend in Wellington, 2019

## National Family Camp

On April 16 2019, families from around New Zealand came together in Rotorua for the 2019 HFNZ National Families Camp.

This event is perhaps the most important in our calendar. At the National Family Camp parents get to connect with other parents in the same situation as them, new families get to see the levels of support available to them, children get to mix with other kids with bleeding disorders, while staff and clinicians are able to mix and mingle with members on a less formal level. It is an essential starting point for many conversations and a lifetime of belonging and acceptance.

This year's version was no different in many respects. The children were able to participate in a variety of new experiences, and the parents were able to make new contacts, reinforce old ones, and learn new things.

This was also the first Family Camp AC (after Colleen). Colleen McKay had run our camps for over 20 years. This time Nicky Hollings took the reins, and she did a fantastic job! We had plenty of really positive feedback, particularly around the relaxed atmosphere, and Nicky's ability to adjust the programme to suit the needs of the participants. Awesome work Nicky!

It was great to be able to get the children off-site to enjoy some activities. Operating in three groups, the crèche, 4-7 year-olds, and 8+, Outreach staff and our amazing youth leaders were able to take the children to visit Rainbow Springs, and the Redwoods Treewalk. Also, a small group went out at night to see the Rotorua town centre lit up red for World Haemophilia Day. These were all very successful outings, and a great opportunity for our children to try something new.

The children were also involved with on-site activities, including a movie night, newspaper fashion design, outdoor games, and arts and crafts.

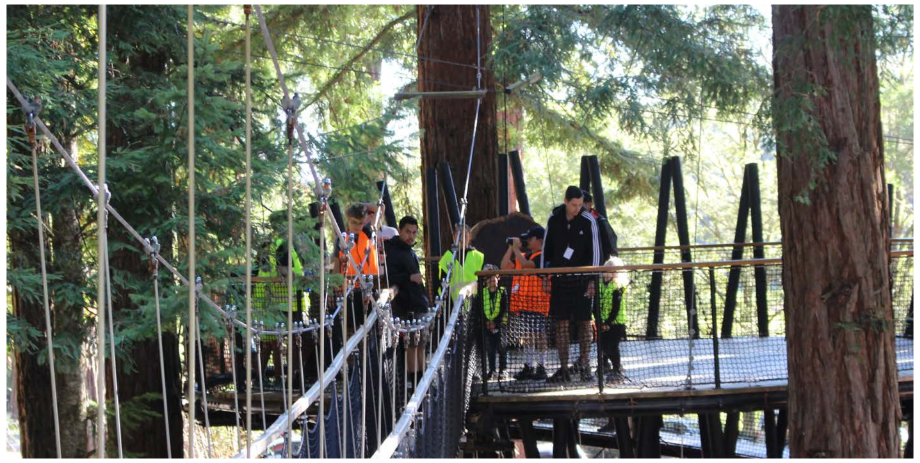
While the kids were otherwise engaged, the parents were able to forge new connections, support one another, and learn new things. Over the course of the weekend we had a number of sessions covering everything from managing life changes, to a Mum's afternoon tea. A big thank you goes out to the following for the sessions they presented, and the time they spent supporting our people:

- Lynne Campbell – Parent introductions
- Cat Pollard – Physiotherapy
- Julia Phillips – New treatments
- BJ Ramsay – Haemophilia
- Maureen Campbell – vWD and rare bleeding disorders
- Pharmac – The latest treatment-funding round
- Ross Paterson – Managing life changes
- Deon York, Catriona Gordon, and Karl Archibald – All about HFNZ
- Andrew Scott, Zac Porter, Karl Archibald, Catriona Gordon, and Benedict Larkin - Our Ask the Experts panel

Also to Amber, who wrangled the youth leaders, making sure they were in the right place at the right time, fed, and watered.

We can't put camps like this together without the support of the wider community. Special thanks this time are due to Roche, Shire, and Rangiora New World.


World Haemophilia Day at Family Camp 2019



Top to bottom:

*Relaxing at National Family Camp*

*Working hard at Women's Weekend*

*Adventures at Tree Tops Rotorua*

*Connecting at Women's Weeked*

# HFNZ Financial Report

## For the 12 months ending 30 June 2019

I'd like to start off by thanking the HFNZ staff for their assistance this past year. Sue and Leanne in particular have provided significant support and the three of us have worked closely to monitor the Foundation's finances to ensure that it is able to continue to provide support to members.

While HFNZ had a deficit for the FY 2018/2019, I would note the significant surplus in the previous year ($293,483) provides a safety net.

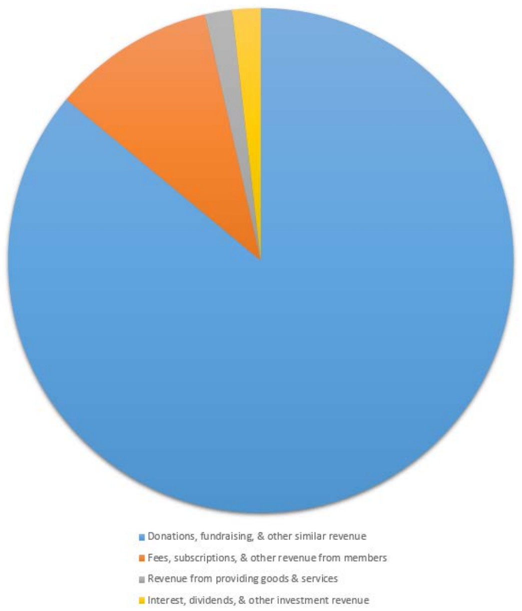
HFNZ has again been the recipient of a number of generous bequests. While we are unable to thank these donors directly, I would like to acknowledge the contribution that they have made which puts HFNZ in a stronger position to continue to provide services and support for our membership.

Kiwifirst continues to be our primary source of income, raising $959,110 in the FY 2018/2019. This year Kiwifirst has introduced an electronic donation system which will provide easier options for donations and reducing costs.

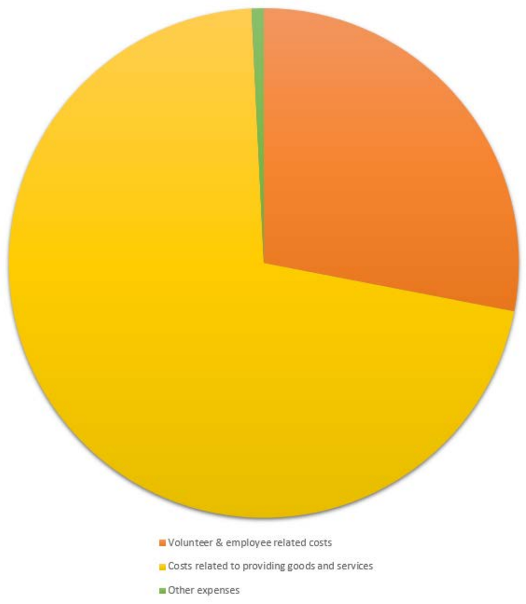
We have received a number of significant donations and grants this year. I would like to thank everyone who has donated to the foundation this year for their contributions.

**Hemirau Waretini - HFNZ Treasurer**

### Revenue



### Expenses



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 2019

| | | Notes | 2019 | 2018 |
|---|---|---|---|---|
| Revenue | | | | |
| | Donations, Fundraising, & other similar revenue | 1 | 1,052,998 | 1,336,993 |
| | Fees, subscriptions, and other revenue from members | 1 | 127,760 | 177,815 |
| | Revenue from providing goods or services | 1 | 21,200 | 20,500 |
| | Interest, dividends, and other investment revenue | 1 | 22,236 | 20,442 |
| | Other Revenue | 1 | - | 1,516 |
| | **Total Revenue** | | **1,224,194** | **1,557,266** |
| Expenses | | | | |
| | Volunteer and employee related costs | 2 | 358,040 | 349,136 |
| | Costs related to providing goods or service | 2 | 908,963 | 908,087 |
| | Other Expenses | 2 | 9,882 | 6,560 |
| | **Total Expenses** | | **1,276,884** | **1,263,783** |
| Net Surplus /(Deficit) | | | (52,690) | 293,483 |

## Statement of Financial Position

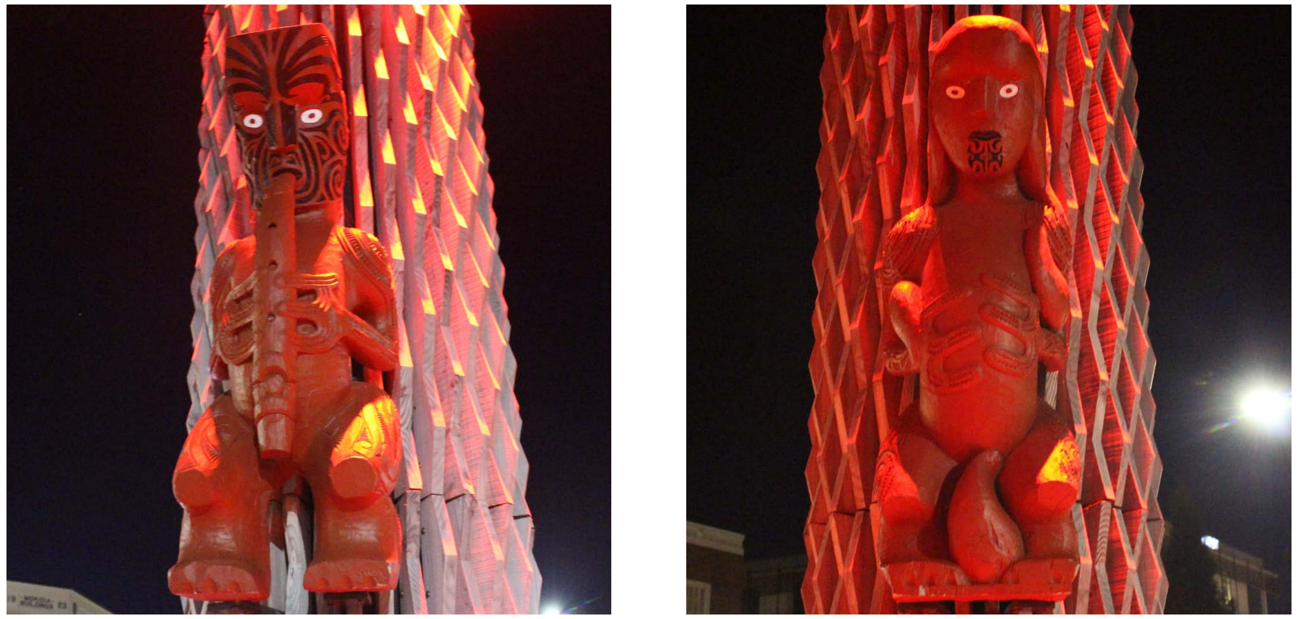
Haemophilia Foundation of New Zealand Incorporated as at 30 June 2019

| | | | Notes | 2019 | 2018 |
|---|---|---|---|---|---|
| Assets | | | | | |
| | Current Assets | | | | |
| | | Bank accounts and cash | 3 | 309,051 | 372,310 |
| | | Debtors and prepayments | 3 | 116,946 | 110,780 |
| | | Investments | 3 | 664,590 | 655,929 |
| | | Other current assets | 3 | 29,295 | 29,130 |
| | | **Total Current Assets** | | **1,119,882** | **1,168,149** |
| | Non-Current Assets | | | | |
| | | Property, Plant and Equipment | 6 | 5,048 | 3,208 |
| | | **Total Non-Current Assets** | | **5,048** | **3,208** |
| | | **Total Assets** | | **1,124,930** | **1,171,357** |
| Liabilities | | | | | |
| | | Current Liabilities | 4 | 110,002 | 103,739 |
| | | **Total Liabilities** | | **110,002** | **103,739** |
| Total Assets less Total Liabilities (Net Assets) | | | | 1,014,928 | 1,067,618 |
| Accumulated Funds | | Accumulated Surplus or (deficit) | 5 | 1,014,928 | 1,067,618 |
| | | **Total Accumulated Funds** | | **1,014,928** | **1,067,618** |

## Statement of Cash Flows

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2019

| | 2019 | 2018 |
|---|---|---|
| Cash Flows from Operating Activities | | |
| *Cash was received from:* | | |
| Donations, fundraising, and other similar receipts | 1,075,721 | 1,314,046 |
| Fees, subscriptions, and other receipts from members | 120,984 | 177,875 |
| Receipts from providing goods and services | 4,969 | 48,983 |
| Interest, dividends, and other investment receipts | 23,570 | 21,414 |
| Total | 1,225,243 | 1,562,318 |
| *Cash was applied to:* | | |
| Payments to suppliers and employees | 344,461 | 349,136 |
| Costs related to providing goods and services | 927,546 | 945,778 |
| Net GST | 2,652 | 1,065 |
| Total | 1,274,659 | 1,295,979 |
| **Net Cash Flows from Operating Activities** | **(49,416)** | **266,339** |
| Cash Flows from Investing and Financing Activities | | |
| *Cash was provided from:* | | |
| Receipts from the sale of property, plant, or equipment | - | 20 |
| Total | - | 20 |
| *Cash was applied to:* | | |
| Payments to acquire property, plant, and equipment | 5,182 | 2,631 |
| Payments to purchase investments | 8,661 | 6,372 |
| Total | 13,843 | 9,004 |
| **Net Cash Flows from Investing and Financing Activities** | **(13,843)** | **(8,984)** |
| | | |
| Net Increase/(Decrease) in Cash | (63,259) | 257,354 |
| Opening cash | 372,310 | 114,956 |
| **Closing cash** | **309,051** | **372,310** |
| This is represented by | | |
| Bank accounts and cash | 309,051 | 372,310 |



Rotorua lit up red for
World Haemophilia Day

## Notes to the Performance Report

Haemophilia Foundation of New Zealand Incorporated For the year ended 30 June 2019

| | | 2019 | 2018 |
|---|---|---|---|
| 1. Analysis of Revenue | Donations, fundraising, and other similar revenue | | |
| | Donations and Bequests | 48,888 | 291,958 |
| | Fundraising - External (KF) | 959,110 | 911,414 |
| | Grants | 45,000 | 122,900 |
| | WFH Grants | - | 10,722 |
| | **Total Donations, fundraising, and similar revenue** | **1,052,998** | **1,336,993** |
| | Fees, subscriptions, and other revenue from members | | |
| | Contracts | 119,734 | 169,534 |
| | Registrations | 4,834 | 3,465 |
| | Membership Fees | 3,191 | 4,815 |
| | **Total Fees, subscriptions, and other revenue from members** | **127,760** | **177,815** |
| | Revenue from providing goods or services | | |
| | Sustaining Patrons | 21,200 | 20,500 |
| | **Total Revenue from providing goods or services** | **21,200** | **20,500** |
| | Interest, dividends, and other investment revenue | | |
| | Interest Income | 22,236 | 20,442 |
| | **Total Interest, dividends, and other investment revenue** | **22,236** | **20,442** |
| | Other revenue | | |
| | Gain on Sale of Asset | - | 103 |
| | Other Revenue | - | 1,413 |
| | **Total Other Revenue** | **-** | **1,516** |
| 2. Analysis of Expenses | Volunteer and employee related costs | | |
| | WFH Honorarium | 13,893 | 6,700 |
| | Wages and Salaries | 344,147 | 342,436 |
| | **Total Volunteer and employee related costs** | **358,040** | **349,136** |
| | Costs related to providing goods or services | | |
| | ACC Levies | 1,005 | 1,199 |
| | Accounting | 6,360 | 3,250 |
| | Administration | 1,864 | 266 |
| | Adult Programme | - | 32,201 |
| | Advertising | 687 | 761 |
| | Bank Fees | 213 | 238 |
| | Children's Workshops | 48 | 1,940 |
| | Cleaning & Rubbish Removal | - | 1,490 |
| | Consulting (including IT) | 18,845 | 31,076 |
| | Defensive Driving | 364 | 198 |
| | National Family Camp | 36,610 | - |
| | Footwear Programme | 6,171 | 7,197 |
| | Freight & Courier | - | 646 |
| | Community Education (KF) | 292,906 | 281,982 |
| | Fundraising Costs (KF) | 322,758 | 310,485 |
| | General Expenses | 595 | 2,085 |
| | Human Resources | 15,847 | - |

| | | | |
|---|---|---|---|
| | Inhibitors Workshop | - | 14,306 |
| | Insurance Assets/Liability | 2,445 | 6,429 |
| | International Programmes (Twinning) | 5,436 | 1,849 |
| | Light, Power, Heating | - | 1,671 |
| | Motor Vehicle Expenses | 27,481 | 12,537 |
| | Region - Central | 5,823 | 5,066 |
| | Group - Masters | - | 605 |
| | Region - Midland | 2,961 | 3,056 |
| | Region - Northern | 4,801 | 3,876 |
| | Group - Piritoto | 1,411 | 2,940 |
| | Region - Southern | 2,300 | 1,145 |
| | Group - Youth | 1,492 | 4,553 |
| | National Council | 12,550 | 16,627 |
| | Needs Grants | 2,227 | 1,955 |
| | Office Expenses | 212 | 712 |
| | Outreach | 5,288 | 5,905 |
| | PEP - Parents Empowering Parents | - | 81 |
| | Printing, Stationery, Postage | 23,906 | 20,902 |
| | Professional Development and Team Meetings | 41,217 | 29,480 |
| | Rent | 10,353 | 44,075 |
| | Repairs and Maintenance | 60 | 209 |
| | Special Programmes | 289 | 32,722 |
| | Subscriptions/Memberships | 2,495 | 1,269 |
| | Swimming/Fitness | 9,668 | 6,976 |
| | Tax Penalties | - | 278 |
| | Telephone & Internet | 6,486 | 13,851 |
| | Women's Programme | 34,739 | - |
| | Youth Leadership | 1,047 | - |
| | **Total costs related to providing goods or services** | **908,963** | **908,087** |
| | Other Expenses | | |
| | Depreciation | 3,342 | 1,435 |
| | Interest Expense | 1,340 | - |
| | Audit | 5,200 | 5,125 |
| | **Total Other Expenses** | **9,882** | **6,560** |
| 3. Analysis of Assets | Bank accounts and cash | | |
| | SBS Savings Account | 1,000 | 1,000 |
| | BNZ On Call Account | 291,518 | 311,367 |
| | BNZ Non Profit Cheque Account | 22,035 | 63,264 |
| | BNZ Visas | (5,501) | (3,322) |
| | **Total Bank accounts and cash** | **309,051** | **372,310** |
| | Debtors and prepayments | | |
| | Prepayments | 19,489 | 3,258 |
| | Trade Debtors | 97,457 | 107,522 |
| | **Total Debtors and prepayments** | **116,946** | **110,780** |
| | Other current assets | | |
| | GST | 29,083 | 27,584 |

| | | | |
|---|---|---|---|
| | Interest Receivable | 212 | 1,546 |
| | **Total Other current assets** | **29,295** | **29,130** |
| | Investments | | |
| | BNZ Term Investment - 00003 | 60,035 | 57,676 |
| | BNZ Term Investment - 00004 | 60,217 | 58,165 |
| | BNZ Term Investment - Property | 420,650 | 420,650 |
| | BNZ Term Investment - 00002 | 37,183 | 36,019 |
| | SBS Term Investment - No 10529944 | 86,505 | 83,419 |
| | **Total Investments** | **664,590** | **655,929** |
| | **Total Analysis of Assets** | **1,119,882** | **1,168,149** |
| | *The BNZ Term Investment - Property, above, represents funds allocated for the purchase of property.* | | |
| 4. Analysis of Liabilities | Creditors and accrued expenses | | |
| | Accounts Payable | 95,872 | 102,705 |
| | Money in Advance | 14,130 | 1,035 |
| | **Total Creditors and accrued expenses** | **110,002** | **103,739** |
| | **Total Analysis of Liabilities** | **110,002** | **103,739** |
| 5. Accumulated Funds | Accumulated Funds | | |
| | Opening Balance | 1,067,618 | 774,135 |
| | Accumulated surplus or (deficit) | (52,690) | 293,483 |
| | Closing Balance | 1,014,928 | 1,067,618 |
| | **Total Accumulated Funds** | **1,014,928** | **1,067,618** |
| 6. Property, Plant, and Equipment | Office Equipment | | |
| | Open Carrying Amount | 3,208 | 2,032 |
| | Purchases | 5,181 | 2,631 |
| | Sales/Disposals | - | (20) |
| | Depreciation | 3,342 | 1,435 |
| | **Closing Carrying Amount** | **5,047** | **3,208** |
| 7. Grants in Advance | There were no grants that were received in advance as at balance date. 30/06/2018 (Nil) | | |
| 8. Lease Commitments | The Haemophilia Foundation of New Zealand has the following lease commitments:<br>• 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.<br>• 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. | | |
| 9. Related Party | Included within expenses are wages and 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. 30/06/2018 (Nil) | | |
| 11. Statement of Contingencies | There are no contingent liabilities as at balance date. 30/06/2018 (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 2019.

## 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% and Diminishing Value method 40% - 50%

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.

Leaders having fun at the National Family Camp dance

**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 statement of financial performance and statement of cash flows for the year ended 30 June 2019, the statement of financial position as at 30 June 2019, and the statement of accounting policies and other explanatory information.

In our opinion:

The accompanying performance report gives a true and fair view of the Society and the financial position of Haemophilia Foundation of New Zealand Incorporated as at 30 June 2019, 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)). Our responsibilities under this 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 the preparation and fair presentation of the performance report on behalf of the entity which comprises 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 Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit) issued by the New Zealand Accounting Standards Board, and 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 audit Christchurch.

**Nexia Audit Christchurch**
**27 September 2019**
**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

### Women's Wellness Weekend

September 15 - 16, 2018

Traditionally haemophilia and bleeding disorder education has been geared towards men. This residential workshop specifically targets women with bleeding disorders, and women who carry the haemophilia gene, of all ages. Women's Weekend offers a safe and supportive environment where women can increase their knowledge, and discuss issues that relate to their age, stage, or to being a carrier of the haemophilia gene.

- Adults - 43
- Staff - 4

*"Many thanks for an awesome getaway. Opportunities to share and learn within the HFNZ whānau are invaluable. I appreciate the support and education you impart, which allow us to make sense of our own experiences and challenges. Arohanui."*

*"I love coming to these weekends. It empowers me each and every time. Even though my children are now adults, it still helps me to be amongst women who understand the day to day struggles of being a mother who has passed on a genetic disorder."*

### National Family camp

April 16 - 19, 2019

Young families, where a child (0-10 years) is newly diagnosed with a bleeding disorder, often need support and information to manage the impact of the disorder on their family. The National Family Camp enables parents to access education in a supportive environment, while their children are enjoying their own recreational programmes. Opportunities are included for families to mix and mingle so that they can establish friendships and develop support networks with other families who understand and live with bleeding disorders.

- Adults - 31
- Children - 34
- Staff/Leaders/Clinicians - 28

*"The staff are always approachable and kind. Loved the food, my son ate heaps! Very relevant to the info I needed"*

*"Very informational. Camp was great, really good to connect with new families and build new relationships"*

## Other Significant Programmes

### Hepatitis C support for people with bleeding disorders and infusion-acquired hepatitis C

Our contract with the Ministry of Health to support HFNZ people with infusion acquired hepatitis C ended on December 31 2018.

As at that date, 22 people with bleeding disorders had infusion-acquired hepatitis C. HFNZ negotiated a treatment package with ACC for all people with infusion acquired HCV to access new generation medications in October 2015.

### Outreach Support Services for people with bleeding disorders and their families

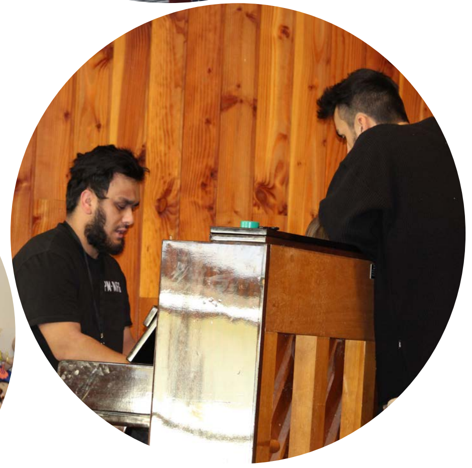
2281 contacts were made with people with bleeding disorders by the Outreach team. More than 50% of people with bleeding disorders have been directly supported by the outreach service in the year July 1 2018 to June 30 2019; issues dealt with were as diverse as working with schools, hospitals, social welfare, and housing.

### World Haemophilia Day

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.

*"I appreciate the support and education you impart, which allow us to make sense of our own experiences and challenges. Arohanui."*

Women's Weekend2018



# 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 Foundation | Outreach Services |
| Shire | Family Camp 2019 |
| NZ Lotteries | |
| Roche Products (NZ) Ltd | Sustaining Patrons |
| Roche Products (NZ) Ltd | Honorarium for those attending advisory board meeting |
| Quality Hotel Parnell | Sustaining Patrons |
| Novo Nordisk | Sustaining Patrons |
| Public Donations via Givealittle | |
| D.M. Taylor | |

| Bequests |
|---|
| Estate of Joan Alison Meyer |

| Individual and general donations over $100 |
|---|
| C Macdonald |
| John Hunter |
| JH Horne |
| RA Hook |
| Paul Williams |
| Milsons |
| Lyn Steele |
| Nick Lingard Foundation |
| Joplin |
| Give A Little - Spark Fund donation |

Waiata practice at the 2019 Piritoto marae noho

# In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 1 2018 and June 30 2019:

- Neville Findlay
- Leighton Mabey

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 | 2018 |
| 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: Hemirau Waretini
Midland Branch Delegate: Tineke Maoate
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: Tineke Maoate
Central Branch Chair: Blair Wightman
Southern Branch Chair: Zac Porter
Piritoto Branch Chair: Tuatahi Pene
Youth Branch Chair: Lauren Nyhan

## Staff

**National Office**

Chief Executive: Sue Ellis
Communications Manager: Phil Constable
Administrator: Leanne Pearce

**Haemophilia Outreach Workers**

Northern Outreach Worker: Amber Maihi
Midland Outreach Worker: Nicky Hollings
Central Outreach Worker: Lynne Campbell
Southern Outreach Worker: Ross Paterson

## 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 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, Taupo, 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

Haemophilia Foundation
of New Zealand Inc.
HFNZ