



# H F N Z A n n u a l R e p o r t : 2 0 1 9 / 2 0

01 JULY 2019 TO 30 JUNE 2020



A large, solid red teardrop-shaped graphic is centered on a white background. Inside the teardrop, the following text is written in a white, elegant, cursive font:

*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. More than 60 years later, HFNZ continues working for all those living with Haemophilia A & B, and also represents people with von Willebrand's disorder, platelet disorders, and many 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 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 2019/20 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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# Deon York: President's Message

Looking back on the year from July 2019 to June 2020, we have experienced everything from operating as usual, to rapidly adapting to new ways of working and connecting. I characterised last year as heading towards transformation. That now seems like an understatement. Our core purpose has not changed, but the way of connecting with our members has needed to adapt. Perhaps the theme of this year is 'gratitude'.

A special thank you to every member and volunteer of HFNZ. Thank you to our executive of Catriona Gordon, Karl Archibald and Hemi Waretini for your many volunteer hours and support. Thank you to Tineke Moate, Hemi Waretini, James Poff, and Stephanie Coulman for bringing the views of the region to the national council. Our central delegate decided to step down from the national council this year, so a special thanks must be paid to Stephanie for her many years of service to the national council.

Thank you also to Te Whainoa Te Wiata and Lauren Phillips for bringing the perspectives of Piritoto and youth to the national council table. Finally, many thanks to all regional chairs and groups for injecting some much-needed life into the regions.

I would like to express my appreciation to all the staff of HFNZ for their contributions. Thank you to the team of Sue, Phil, Leanne, Lynne, Ross and Amber and your willingness to adapt during uncertain times.

In terms of HFNZ activities, there were several events planned in 2019/20 which had to be delayed due to the Covid-19 pandemic. Our priority was to keep people safe and ensure that support networks were still in place for our members. Throughout the year the national council has continued to pay close attention to the financial health of the organisation, for now and the future.

We are so fortunate to have the continued support of the New Zealand public via Kiwifirst, generous benefactors, donors, companies, trusts and other organisations willing to support us financially. Times are tough out there for many, and I cannot emphasise enough our gratitude for this support. It really does make a difference to our community.

You will note in our annual financial statements that we ended the year with a surplus of \$194,082. This is incredibly encouraging and is largely due to a significant bequest received. We consider such bequests as enduring legacies for HFNZ and very

rarely are such donations an annual event. Like every donation we receive, such funds will be handled with care and consideration.

This year saw access to longer-acting factor replacement therapies. Overall, this has been a positive step forward for our members with haemophilia A or B, but as with all therapies, some experiences have been variable. We will continue to advocate for access to other novel therapies.

Although there were fewer face-to-face events around the regions, and around the world, there have still been opportunities to connect with many virtual events being offered. There have been opportunities to continue to connect with our global community despite the challenges of a global pandemic with the World Federation of Hemophilia (WFH) holding its first virtual summit this year and many other virtual events. My role on the board of directors of the WFH continued throughout 2019/20 with a slight extension into 2020/21 with the disruptive year that has been 2020.



A highlight of this year was our 60th celebrations held in November 2019. It is surreal to believe that more than 200 members and guests gathered at a function at Parliament, and a gala dinner the next evening to look back on the past 60 years of HFNZ. This event was certainly the focal point for this past year. This event offered a rare opportunity to recognise our achievements and milestones together, reminisce, connect, and reconnect. These celebrations now form another chapter in our history.

Our look back on 60 years delivered a number of firsts for us: the first time a sitting president of the World Federation of Hemophilia attended an HFNZ event in New Zealand; the first time a sitting member of cabinet welcomed us at Parliament, the first time we welcomed guests from Nepal (our youth 'twin'), and the first time Piritoto showcased to us all how they enrich our community to name but a few.

In reflecting on our past, we can only be inspired to look forward to a promising future together.

No doubt 2020/21 will bring new challenges and opportunities. We will be ready to take them on together.

*Noho tawhiti, tu kotahi*

Sit at a distance, stand as one

**Deon York**



# Sue Ellis: CEO Report

Tēna koutou, Tēna koutou, Tēna tatau katou.  
Greetings, greetings, greetings to you all.

This year marks the introduction of the pandemic, the Covid-19 virus. New Zealand, and indeed the rest of the world, continues to reel from the impact of this deadly virus. It's hard to keep calm and carry on when the world is no longer the one we all know. However, we have been blessed with the quick response by Government of "Go hard and go fast" to keep the restrictions tight and the numbers of people infected under control, despite sadly, people who have passed away from the virus.

New language, conversations and behaviour emerged from the pandemic including new meanings for bubble, meetings in zoom, alert levels, community transmission, isolation, border restrictions, clusters and lining up at supermarkets. Covid-19 has been a pivotal moment in our lives and has impacted on how we as an organisation manage and continue to support our members.

With the impact from Covid-19 including a potential drop in donations and funding, the Council made the decision to not replace the Midland Outreach Worker when Nicky Hollings left in April until we are on firmer footing financially. In the meantime Central and Northern Outreach Workers have been covering the Midland region between them. I want to thank them for coming forward and offering their time and support under very trying conditions. It is hopeful we can relook at recruitment of an Outreach Worker for Midland towards the end of 2020 or early 2021.

Covid-19 lockdown also removed the ability of Outreach Workers to travel and see people face-to-face for several weeks. However, they kept communicating with members via zoom, email and phone calls. It was a relief when the alert levels were reduced to allow travel once again.

Before Covid-19 hit the world, I attended my first WFH Global Forum in Montreal, Canada in November 2019. As snow fell outside I listened to presentations focused on safety, supply and access to treatments, emerging risks and treatment products, efforts to advance quality and availability of blood components, and the future of gene therapy. In January this year, the President and I were invited to attend the Eighth Annual Global Haemophilia Advocacy Leadership Summit in Lisbon,

Portugal, sponsored by Bayer and Biomarin including support for travel and accommodation. It was so good to meet up again with fellow advocates from the haemophilia community around the world. All of us were there to engage with leading advocates, key stakeholders and industry experts, working together to learn new ways of doing things, to cement those and previous learnings that will benefit our haemophilia community.

Despite Covid-19, we have been busy reviewing and developing policies, getting our long-standing database issues fixed with a kind offer from Salesforce through their pro bono programme. A user manual has also been developed. The Foundation website refresh and renewal, which is long overdue, is underway, and promises a smarter but also easier way to access relevant information. Ensuring up-to-date content will be a continual work-in-progress.



There was a great response from our annual member survey "How are we doing?"

Of the 537 surveys distributed to members by email and post, 182 responded, a response rate of 34%. The findings suggest members are interested in what the Foundation provides and relevance it has to their lives. Most people felt connected and supported. However, whilst largely positive, there is still work to do to improve the digital space, the need to engage younger members, and specific events for seniors. We also need to have a greater focus to support those with von Willebrand Disease and women with bleeding disorders. Check out the survey report on our website.

In March, just before lockdown, we held an Inhibitors Weekend workshop in Auckland, sponsored by Roche. It was a great weekend and people appeared to enjoy themselves. It was the first time for those whose family

member needed Hemlibra and those who were already receiving it were together. The outcome from this and the acknowledged need for ongoing support, a 'closed' Facebook page was set up for members with inhibitors. A

huge thank you to Christine Olsson from Roche who gave an interesting presentation and facilitated the sponsorship from Roche.

We were pleased to go ahead with the adult weekend workshop in Christchurch 6th – 8th November, "Life is a Highway, Route 66".

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

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

Although initially we had misgivings around safety, and holding an event in 'covidian' times may have been a challenge, we believed it was doable by following the safety measures we had all become familiar with. Members I spoke with were very keen to reconnect with each other. The movie premier of Bombardier Blood rounded off a successful weekend.

I want to thank the staff for their patience and ongoing support to members during very trying times. They have continued to ensure the support and care continues, despite the restrictions. A huge thank you too to the amazing people who have given generous donations and to the clinical teams for their support ensuring people got their treatment products throughout the lockdown.

Despite the looming economic crisis and the need to keep a watchful eye on our financial management, I believe we can emerge from Covid-19 stronger than before.

*Whāia te iti kahurangi ki te tūohu koe me he maunga teitei*

Seek the treasure you value most dearly: If you bow your head, let it be to a lofty mountain

This Whakataukī is about aiming high or for what is truly valuable, but the real meaning is to be persistent and don't let obstacles stop you from reaching your goal. Given the continued uncertainty, we need to ensure we keep striving for what matters: care, support, education and advocacy.

**Sue Ellis**



Sue and the Scotts at Parliament for the HFNZ 60th.





## 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 Te Whainoa Te Wiata

Piritoto, Piri tata, Piri tonu, Piri tonu ee..

Ko te mihi tuatahi ki te kaihanga o ngā mea katoa a ko Io tēnā,

Ko te mihi tuarua ki tō tātou kiingi a Tūheitia Pōtatau te Wherowhero te tuawhitu me te whare ariki, Paimaarire

Otirā, ki a rātou o te wā, o te tau kua huri atu ki tua o te ārai, haere, haere, haere atu rā.

Ko rātou ki a rātou, ko mātou ki a mātou, e te hunga tēnā tātou..

Kei ngōku rangatira o tēnei te whānau toto tepe kore,

Tēnā koutou katoa...

Well what can I say, this year, and Covid-19, has gone from one challenge to another and we are still here to tell the story which is always a good thing. However, due to these unfortunate circumstances we the whānau of Piritoto have been unable to properly touch base with each other. Generally for many of us, it is a juggle of work, whānau, iwi / hapū / marae obligations, and many other commitments and then Covid-19 hit us all and everything amplified. We took the approach of not touching base until quite late



into lockdown, because everyone was going online and emails were a little overwhelming, so a few texts here and there just to see if others were ok was how we did things. Lockdown #1 saw many positives and negatives and from my point of view, it brought about a whole new level of uncertainty, stress and an overall lack of wellbeing. So, I am grateful to say that thus far for those of us of the Piritoto whānau, everyone is ok.

Aside from planning a date to catch up online we have nothing on the horizon for the next few months, but once we have met together we will be sure to inform the wider HFNZ whānau of what we have coming up.

We want to give a quick mihi to HFNZ for the way we were kept informed about Covid-19, you are amazing, the brief messages were digestible, in other words, they were short and sharp which was hugely appreciated considering the amount of time many of us were spending online for work and non-work commitments. Also, to the wider HFNZ whānau as a whole, well done for seeing it through and although the challenges never stop we are a resilient whānau and always push through.

Kāti i konei...

Paimaarire ki a tātou katoa

## Youth

By Courtney Stevens

Our focus last year was the Youth Development Workshop we hosted in conjunction with the 60th Anniversary celebrations. The Youth Development Workshop, open to all youth members, ran several sessions, including risk management, leadership, and global opportunities.

As a committee, we decided our focus should be on hosting regional events and tasked each of the regional youth delegates to brainstorm some potential event ideas, even something as simple as a dinner out. Some fantastic ideas came out of this brainstorming so watch this space!

The Youth Development Workshop was notable because we had four young leaders from Nepal in attendance. This was part of the ongoing WFH twinning programme with which the NYC is involved. It was awesome to have the Nepalese attendees experience some Kiwi culture and our attendees enjoyed learning about living life in Nepal with a bleeding disorder.



We were pleased to hear that our twinning with the Nepalese Haemophilia Society's Youth Committee was extended for another year, albeit not a lot of our initial plans for the Twinning have eventuated given the Covid-19 situation but we are hopeful to pick this up again next year.

There isn't much to report for the remainder of the year, given the lack of events and ability to plan too far in advance with the ever-changing alert levels. We will aim to get some regional events on the calendar where possible in the coming months, so keep an eye out for events in your area!

As a result of the recent member survey, The Youth Committee has also asked HFNZ staff to consider how it can best meet the needs of teenagers and those in their early 20s. We are excited to hear their ideas.

Finally, the Youth Committee is contactable on Facebook or via phone if anyone needs some assistance. If you're keen to have a more active role in the committee, we're always keen for newbies so please get in touch!

## Central

By Stephanie Coulman

The central region has done its best to gather as a community despite the difficult times we are facing.

We held our 2019 AGM at the Carter Observatory in Wellington in August and members enjoyed a tour of the Observatory, a planetarium show and lunch at the Cable Top Eatery overlooking the expansive views of Wellington.

Many central members had less to travel than the rest of the membership on the occasion of the Foundation's 60th celebrations at Te Papa and Parliament. It was a pleasure for Wellington based members to be the host venue of this special event.

We had booked a small cinema, Time Cinema in Lyall Bay, Wellington in April and were set to screen Bombardier Blood, the inspiring documentary about haemophiliac Chris Bombardier who climbs Mt Everest. However, like many things that was not able to proceed due to Covid-19. We have a new date later in 2020.

We have also attempted on several occasions over the past 2 years to run a second men's fishing trip, following a successful one in 2017. Each time our plans have been hampered, mostly by the weather, and more recently Covid-19.

Just as life continually sets us challenges along the way, and those living with a bleeding disorder certainly experience this every day, we will persevere and meet these challenges head on!



Catriona & Stephanie at the 60th at Te Papa

## Midland

By Tineke Maoate

This is going to be a very brief annual report. Since June last year, unfortunately, Midland has had much interaction. We had the pleasure of seeing most of you at the 60th celebrations, which was a successful event and well organised. Covid-19 has swallowed up most of 2020 so it hasn't been possible for us to catch up. We had an amazing event planned for August but, unfortunately, Covid-19 hit us again.

We are organising our AGM and I hope that this will be able to go ahead face to face. I will be standing down from chairperson this AGM as I think it would be great to have some fresh people coming in to the committee and sharing their ideas. I hopefully will stay on in the committee as I really enjoy it and would love to continue to support whoever gets in to the committee and the Midland region.

Take care of each other and I look forward to when we can all meet again.



Tineke at Parliament for the 60th

## Southern

By Susan Inwood

It has been a very unusual year for all.

I was on my way to Canada again this year for four months work - and to see my youngest son Matthew and spend some overdue time with him - unfortunately that is postponed until 2021- or later.

Our fundraiser at the central Library had to be postponed due to the COVID outbreak and travel/lockdown restrictions.

However, we had a wonderful fishing trip in February to Moeraki. We had a great turnout and each member went home with a few good feeds of fish. The next fishing trip is to Nelson, at the top of the South Island, in November.

We are lucky to have the walking trips start again with Kyle Cunningham and Outreach Worker Ross Paterson taking charge. By the looks of things, they have a good turn out as well.

Our Christmas event in December was held at Abberley Park, St Albans. We had a wonderful time with rock painting, wooden cut outs to paint, bubble blowing, picnic fare, and a visit from good old Santa himself - it was such a lovely hot day the water guns were enjoyed by young and old alike - my grandchildren particularly liked wetting me !!

Thank you to all our committee who have helped me through this year as Chairperson-my first and last - and we shall just have to see how the next year unfolds.

I hope everyone is safe and happy and looking after themselves.



Hemi & Erica at Te Papa for the 60th



Ross & Kyle talk about the Southern walks at Te Papa for the 60th

## Northern

By Greg Jamieson

What a year...

We started strong with holding our Christmas catch up at the Grounds in Henderson. We had a solid turnout with close to 50 people. The kids got to enjoy the playground and the netted orb-shaped feature, while the adults were able to catch up over a meal.

Rosalie hosted a great day out at Parakai hot springs for our summer catch up. We had the wonderful Davis family join us for the day all the way from Whangarei, which was nice. Rosalie made sandwiches for lunch and the kids had a great time on the waterslides.

We then booked a movie theatre to host our region at the movies in April but this had to be cancelled due to Covid-19.

Due to the ongoing complexities with Covid-19 we have had to put events on hold. On behalf of the Northern Committee, I hope everyone is safe and healthy and we look forward to catching up once Covid-19 is behind us.





HFNZ President Deon York addresses the crowd at the formal opening of the 60th anniversary 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.

The biggest social occasion of the HFNZ year was our 60th anniversary celebration in Wellington. From November 8 – 10 HFNZ members from around the country, and special guests from around the world, gathered to acknowledge our Foundation's journey from the first meeting in a hall in Lower Hutt in 1958.

The weekend included two main events, and a number of other gatherings of representative groups from within HFNZ.

The first big event was the formal welcome, held in the Grand Hall at Parliament, and hosted by government minister, the Honourable Chris Hipkins. This was the formal part of the weekend, where nearly 200 members and guests had the opportunity to renew acquaintances, before being treated to a few words from some of our special people.

HFNZ president, Deon York, got things underway with a journey by the numbers through the history of HFNZ. He then introduced Chris Hipkins, who welcomed us to our Parliament, and outlined his own connection to the foundation. This was followed by a few words from HFNZ patron Elizabeth Berry, former president Mike Carnahan, and clinician Claire McLintock, before CEO Sue Ellis concluded the speeches with some appreciations and acknowledgements.

Following the formal part of the night, people continued to mix and mingle. They enjoyed the opportunity to reconnect and socialise in this wonderful setting.

The second big event was the gala dinner at Te Papa Tongarewa, the Museum of New Zealand. Again, we had close to 200 members and guests attend this fabulous event. The evening started with music and socialising in the lobby, where guests enjoyed a drink and hors d'oeuvres. We then moved up the stairs to the dining area, where Piritoto performed waiata from different regions of Aotearoa to welcome the guests.

Dinner service followed. The courses, washed down with two specially branded HFNZ wines, were punctuated by some speeches and presentations. Notably, Kyle Cunningham was awarded the Elizabeth Berry Exercise Cup by the patron herself, Piritoto were presented with a beautiful tokotoko to recognise their 10th anniversary, WFH president Alain Weill said a few words, and Lauren Phillips spoke about the activities of the National Youth Committee, and introduced us to the youth visitors from Nepal.

It was lovely to see members and guests enjoying themselves, and honouring all the work and commitment that has gone into the last 60 years. The gala dinner was a huge success.

In addition, other events occurred alongside the 60th celebrations.

The National Youth Committee held a three-day leadership-training workshop, where they continued the development of the next cohort of HFNZ leaders. This event was notable because they had four young leaders from Nepal in attendance. This was as part of the ongoing WFH twinning programme with which the NYC is involved. It was wonderful to see these young people experiencing a bit of Kiwi culture, and expanding their horizons.

There were also smaller gatherings. Members with von Willebrands and platelet disorders rode on the cable car and had morning tea at the top, a small group of Masters men enjoyed morning tea and a chat at the Bay Plaza, and current and former HFNZ staff got together for breakfast.

All in all this was a fantastic weekend, which appropriately celebrated the amazing milestone of 60 years of the Haemophilia Foundation of New Zealand. The Foundation acknowledges the support of our enduring partners Kiwifirst, and sponsors Takeda, Roche, and NZ Blood, as well as the work of the organising committee in making this celebration possible.



## Inhibitors Weekend

The Inhibitors Workshop is a space for love, support, connection, and education. At this year's workshop we had a great mix of our community; from people with haemophilia with inhibitors, to somebody who no longer has an inhibitor, the newly diagnosed, those taking Hemlibra, and those without.

The workshop offered a number of speakers and activities for adult attendees and for their children. While the adults were attending education sessions, the children were given fun things to do, or were taken out. There was also a crèche for the very young.

The power of people sharing their stories, the honesty and integrity of our members, led to a weekend of connection, empowerment, and growth. Lynley and Andrew Scott opened their hearts to the group, discussing their hardships living with inhibitors, and how living with no bleeds has changed the way that they live. This led to an open heartfelt discussion on people's journeys living with inhibitors, with many a tear and a laugh.

On the first morning of the Inhibitor's workshop, Zaheeda Patel and Ross Paterson took a group of eight children on an outing to the Auckland Zoo. A couple of the older children feigned boredom initially, because this was not a new experience for them. However, as time went on it was noticeable that everyone enjoyed the experience, in part due to them encountering new additions to the animal species housed at the zoo, as well as observing the funny antics of some of the animals.

The children particularly liked watching the otters being fed, and viewing red pandas, tamarins, baboons, and the aptly named pygmy marmosets. After two and a half hours at the zoo we walked next door to the Western Springs Lakeside Park and enjoyed a packed lunch and some time in the playground.

On Sunday morning, Lynne and Ross facilitated sessions for the adults. Ross ran a meditation session before morning tea, then Lynne's session looked at support mechanisms.

Ross's meditation session started with a brief outline of the benefits of meditation followed by listening to two recordings. The first of these described how meditation can reduce pain and increase one's pain tolerance. The second explained how to meditate. We were taken through a guided meditation where we transported ourselves to another place by either lying on the floor or simply leaning back in our chairs with eyes closed.

In Lynne's session, the couples were separated into two groups. The women (mothers of children with Inhibitors or partners of a member with Inhibitors) were in one group and the men (fathers of a child with Inhibitors or a man with Inhibitors) were in the other group.

The two groups worked through a structured series of questions, focussed on support needs. They recorded their responses then reported back to the full group for further discussion.

This discussion took most of the morning given the diversity of the circumstances experienced by individuals present; in terms of residential geographic location, relationship with HTC's, and the very real impositions caused by having an inhibitor.

Those with Inhibitors in the bleeding disorders community face significant extra challenges that not only affect the individual, but the whole family. Those with access to Hemlibra remain in need of Outreach support. It was impressed on Outreach that those with inhibitors appreciate a friendly call from their Outreach Worker regularly.

Christine Olsen from Roche, delivered the data and progress of Hemlibra. Christine's in-depth knowledge of what people need to go through to get Hemlibra allowed members to know what the process is to meet the criteria for treatment, gave them hope, and strengthened their knowledge on how to self-advocate.

Dr Louise Malone discussed the importance of developing a support network, and about educating them about what your needs are, so that they can be a voice for you.

Psychologist Gwendoline Smith discussed interrupting thought processes using cognitive behaviour therapy (CBT), recognising that your thoughts can determine how you feel, and can influence your physical health and how you behave. CBT can be used to interrupt thought processes when living in fear, ruminating, etc.

HFNZ would like to thank all participants in this workshop for sharing so generously and candidly aspects of their personal circumstances. Those new to the world of Inhibitors gained advice and learned a lot from discussing their concerns and drawing on the experience of others. Also, thank you to Zaheeda Patel and Ethan Mathews and Anna Ellis for giving of your time to help with members' children over the weekend, and to the Quality Hotel Parnell for all their support.





# Inhibitors Weekend 2020



# HFNZ Financial Report

For the 12 months ending 30 June 2020

Tēnā koutou e te whanau o HFNZ.

It has been a turbulent year, and Covid-19 has had the same impact on charities as on the rest of the New Zealand economy. While the full effect of Covid-19 is still to be realised, we are confident that the Foundation will be sustainable should we realise decreased donations in the coming year. I want to assure all people with bleeding disorders in Aotearoa that our core services and swimming, fitness, shoe voucher and defensive driving support programmes will continue to be delivered to meet the needs of our members.

Thus far, our funding commitments from Central Government remain unchanged, however approximately 77% of the Foundation's revenue in the past year was received through public donations (including those received via Kiwifirst), grants from funders, and bequests. I would like to express my

sincere appreciation and gratitude to the generous donors whose legacies and ongoing donations allow the Foundation to continue to provide services and support to our members. Your commitment and contributions are more important now than ever.

The Foundation ends the year with a surplus of \$194,082, due primarily to the receipt of some significant bequests.

We are keeping a close eye on our finances while keeping an open mindset and looking for ways to adapt to keep up with changes as they occur.

Thank you for your continued support,

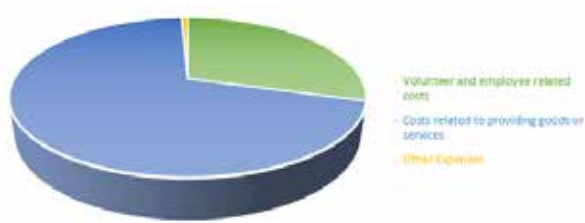
Nga manaakitanga,

**Hemi Waretini**

## Revenue



## Expenses



## Statement of Financial Performance

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2020

	Notes	2020	2019
<b>Revenue</b>			
Donations, Fundraising, & other similar revenue	1	1,367,606	1,052,998
Fees, subscriptions, and other revenue from members	1	13,578	8,026
Revenue from providing goods or services	1	79,934	140,934
Interest, dividends, and other investment revenue	1	21,231	22,236
Other Revenue	1	46,378	-
<b>Total Revenue</b>		<b>1,528,727</b>	<b>1,224,194</b>
<b>Expenses</b>			
Volunteer and employee related costs	2	392,305	358,040
Costs related to providing goods or service	2	933,027	908,962
Other Expenses	2	9,313	9,882
<b>Total Expenses</b>		<b>1,334,645</b>	<b>1,276,884</b>
<b>Surplus /(Deficit) for the year</b>		<b>194,082</b>	<b>(52,690)</b>

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

## Statement of Financial Position

Haemophilia Foundation of New Zealand Incorporated as at 30 June 2020

	Notes	2020	2019
<b>Assets</b>			
Current Assets			
Bank accounts and cash	3	525,395	314,553
Debtors and prepayments	3	44,177	116,946
Investments	3	672,202	664,590
Other current assets	3	19,982	29,295
<b>Total Current Assets</b>		<b>1,261,756</b>	<b>1,125,383</b>
Non-Current Assets			
Property, Plant and Equipment	6	2,466	5,048
<b>Total Non-Current Assets</b>		<b>2,466</b>	<b>5,048</b>
<b>Total Assets</b>		<b>1,264,222</b>	<b>1,130,431</b>
<b>Liabilities</b>			
Current Liabilities			
Creditors and accrued expenses	4	39,562	110,002
Unused donations and grants with conditions	4	14,975	-
Other current liabilities	4	676	5,501
<b>Total Current Liabilities</b>		<b>55,212</b>	<b>115,503</b>
<b>Total Liabilities</b>		<b>55,212</b>	<b>115,503</b>
Total Assets less Total Liabilities (Net Assets)		1,209,010	1,014,928
Accumulated Funds	5	1,209,010	1,014,928
<b>Total Accumulated Funds</b>		<b>1,209,010</b>	<b>1,014,928</b>

## Statement of Cash Flows

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2020

	2020	2019
<b>Cash Flows from Operating Activities</b>		
<i>Cash was received from:</i>		
Donations, fundraising, and other similar receipts	1,362,382	1,075,721
Fees, subscriptions, and other receipts from members	20,354	120,984
Receipts from providing goods and services	144,379	4,969
Interest, dividends, and other investment receipts	20,322	23,570
Net GST	10,221	-
<b>Total</b>	<b>1,557,658</b>	<b>1,225,244</b>
<i>Cash was applied to:</i>		
Payments to suppliers and employees	392,161	344,461
Costs related to providing goods and services	942,340	927,546
Net GST	-	2,652
<b>Total</b>	<b>1,334,501</b>	<b>1,274,659</b>
<b>Net Cash Flows from Operating Activities</b>	<b>223,157</b>	<b>(49,415)</b>



## Statement of Cash Flows

### Cash Flows from Investing and Financing Activities

<i>Cash was provided from:</i>		
Receipts from the sale of property, plant, or equipment	123	-
Total	123	-
<i>Cash was applied to:</i>		
Payments to acquire property, plant, and equipment	-	5,182
Payments to purchase investments	7,612	8,661
Total	7,612	13,843
<b>Net Cash Flows from Investing and Financing Activities</b>	<b>(7,489)</b>	<b>(13,843)</b>
Net Increase/(Decrease) in Cash	215,668	(63,258)
Opening cash	309,051	372,310
<b>Closing cash</b>	<b>524,719</b>	<b>309,052</b>
This is represented by		
Bank accounts and cash	524,719	309,052

## Notes to the Performance Report

Haemophilia Foundation of New Zealand Incorporated For the year ended 30 June 2020

		2020	2019
1. Analysis of Revenue	Donations, fundraising, and other similar revenue		
	Donations and Bequests	360,498	48,888
	Fundraising - External (KF)	946,111	959,110
	Grants	46,973	45,000
	WFH Grants	14,024	-
	<b>Total Donations, fundraising, and similar revenue</b>	<b>1,367,606</b>	<b>1,052,998</b>
	Fees, subscriptions, and other revenue from members		
	Registrations	10,169	4,834
	Membership Fees	3,409	3,191
	<b>Total Fees, subscriptions, and other revenue from members</b>	<b>13,578</b>	<b>8,026</b>
	Revenue from providing goods or services		
	Contracts	69,934	119,734
	Sustaining Patrons	10,000	21,200
	<b>Total Revenue from providing goods or services</b>	<b>79,934</b>	<b>140,934</b>
	Interest, dividends, and other investment revenue		
	Interest Income	21,231	22,236
	<b>Total Interest, dividends, and other investment revenue</b>	<b>21,231</b>	<b>22,236</b>
	Other revenue		
	Wage Subsidy	46,378	-
	<b>Total Other Revenue</b>	<b>46,378</b>	<b>-</b>
2. Analysis of Expenses	Volunteer and employee related costs		
	WFH Honorarium	10,105	13,893
	Wages and Salaries	382,200	344,147
	<b>Total Volunteer and employee related costs</b>	<b>392,305</b>	<b>358,040</b>

## Notes to the Performance Report

Costs related to providing goods or services		
60th Anniversary	102,140	-
ACC Levies	711	1,005
Accounting	3,344	6,360
Administration	4,179	1,864
Advertising	-	687
Bank Fees	1,866	213
Children's Workshops	-	48
Consulting (including IT)	5,710	18,845
Defensive Driving	261	364
National Family Camp	-	36,610
Footwear Programme	4,813	6,171
Community Education (KF)	289,854	292,906
Fundraising Costs (KF)	319,289	322,758
General Expenses	2,355	595
Human Resources	-	15,847
Inhibitors Workshop	19,973	-
Insurance Assets/Liability	8,402	2,445
International Programmes (Twinning)	13,901	5,436
International Meetings/Conferences	6,252	-
Motor Vehicle Expenses	-	27,481
Region - Central	1,566	5,823
Group - Masters	241	-
Region - Midland	4,663	2,961
Region - Northern	1,970	4,801
Group - Piritoto	3,891	1,411
Region - Southern	4,887	2,300
Group - Youth	1,334	1,492
National Council	14,232	12,550
Needs Grants	1,018	2,227
Office Expenses	10,540	212
Outreach	19,387	5,288
Printing, Stationery, Postage	12,890	23,906
Professional Development and Team Meetings	48,334	41,217
Rent	1,805	10,353
Repairs and Maintenance	49	60
Special Programmes	459	289
Subscriptions/Memberships	1,764	2,495
Swimming/Fitness	6,398	9,668
Telephone & Internet	8,426	6,486
Women's Programme	-	34,739
Youth Leadership	5,997	1,047
<b>Total costs related to providing goods or services</b>	<b>933,027</b>	<b>908,962</b>
Other Expenses		
Depreciation	2,459	3,342
Interest Expense	1,554	1,340
Audit	5,300	5,200

## Notes to the Performance Report

		<b>Total Other Expenses</b>	<b>9,313</b>	<b>9,882</b>
3. Analysis of Assets	Bank accounts and cash			
		Twinning	36	-
		SBS Savings Account	1,000	1,000
		BNZ On Call Account	475,087	291,518
		BNZ Non Profit Cheque Account	49,272	22,035
		<b>Total Bank accounts and cash</b>	<b>525,395</b>	<b>314,553</b>
	Debtors and prepayments			
		Prepayments	3,093	19,489
		Trade Debtors	41,084	97,457
		<b>Total Debtors and prepayments</b>	<b>44,177</b>	<b>116,946</b>
	Other current assets			
		GST	18,862	29,083
		Interest Receivable	1,121	212
		<b>Total Other current assets</b>	<b>19,982</b>	<b>29,295</b>
	Investments			
		BNZ Term Investment - 00003	61,744	60,035
		BNZ Term Investment - 00004	62,079	60,217
		BNZ Term Investment - Property	420,650	420,650
		BNZ Term Investment - 00002	38,282	37,183
		SBS Term Investment - No 10529944	89,446	86,505
		<b>Total Investments</b>	<b>672,202</b>	<b>664,590</b>
		<b>Total Analysis of Assets</b>	<b>1,261,756</b>	<b>1,125,383</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	31,275	95,871
		Money in Advance	8,287	14,130
		<b>Total Creditors and accrued expenses</b>	<b>39,562</b>	<b>110,002</b>
	Unused donations and grants with conditions			
		Grants in Advance	14,975	-
		<b>Total Unused donations and grants with conditions</b>	<b>14,975</b>	<b>-</b>
	Other current liabilities			
		BNZ Visas	676	5,501
		<b>Total Other current liabilities</b>	<b>676</b>	<b>5,501</b>
		<b>Total Analysis of Liabilities</b>	<b>55,212</b>	<b>115,503</b>
5. Accumulated Funds	Accumulated Funds			
		Opening Balance	1,014,928	1,067,618
		Accumulated surplus or (deficit)	194,082	(52,690)
		Closing Balance	1,209,010	1,014,928
		<b>Total Accumulated Funds</b>	<b>1,209,010</b>	<b>1,014,928</b>
6. Property, Plant, and Equipment	Office Equipment			
		Open Carrying Amount	5,047	3,208
		Purchases	-	5,181
		Sales/Disposals	(123)	-



## Notes to the Performance Report

	Depreciation	2,458	3,342
	<b>Closing Carrying Amount</b>	<b>2,466</b>	<b>5,047</b>
7. Grant Income	Grants Received in the Year		
	CSL Behring Australia	14,975	-
	NZ Lotteries	-	10,000
	Rata Foundation	-	20,000
	Roche Products	27,000	-
	Sanofi-Aventis Australia	9,973	-
	Shire New Zealand	10,000	-
	<b>Total Grants Received in the Year</b>	<b>61,948</b>	<b>45,000</b>
	Less: Unspent Grant Income	(14,975)	-
	<b>Total Grants Income</b>	<b>46,973</b>	<b>45,000</b>
8. Lease Commitments	The Haemophilia Foundation of New Zealand has the following lease commitments:		
	<ul style="list-style-type: none"> <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	<b>Description of related party relationship</b>	<b>Description of transaction</b>	
	Deon York - President	Honorarium and Wages	
	Catronia Gordon - Lava Law	Legal Services	
	Stephen Waring - Director of Kiwifirst	Major fundraiser of the Foundation	
10. Statement of Commitments	There are no commitments as at balance date. 30/06/2019 (Nil)		
11. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/2019 (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.		
13. Covid-19 Impact Statement	<p>The declaration from the WHO of a pandemic as a result of the outbreak of Covid-19 and the subsequent lockdown, has had the same impact on the Foundation as on the rest of NZ. This affected the Foundation's ability to meet with members face-to-face and to postpone planned events as well as any travel—nationally and internationally. However, these restrictions were mitigated with ongoing communication via our weekly website notices, phone calls, emails and through social media such as facebook.</p> <p>Although there was an expectation of a 30% drop in donations as many people were made redundant with an anticipated impact on the economy, the Foundation applied for and received the wage subsidy to ensure employees could continue to provide support and care. We also continued to receive donations, grants from funders and bequests, including our funding commitments from Central Government. These funds allowed the Foundation to continue to provide services and support to our members. In addition, the receipt of some significant bequests has placed the Foundation in a positive position. Nevertheless we will keep a close eye on our finances to ensure the Foundation remains viable.</p> <p>While New Zealand is now at alert level 1, and there remains uncertainty with the full impact of Covid-19 still to be realised, the Foundation remains confident it will continue to be sustainable if there is a decrease in donations in the coming year.</p> <p>There are no major impacts from additional developments of Covid-19 that should be documented as non-adjusting events.</p>		

## Statement of Accounting Policies

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2020.

### 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.



## INDEPENDENT AUDITOR'S REPORT

To the Members 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 (the "Society") on pages 7 to 19, which comprises the entity information, statement of service performance, statement of financial performance and statement of cash flows for the year ended 30 June 2020, the statement of financial position as at 30 June 2020, and notes to the performance report, including a summary of significant 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 presents fairly, in all material respects:
  - 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 2020 and its financial performance, and cash flows for the year then ended

in accordance with Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit) issued in New Zealand 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 the Society in accordance with Professional and Ethical Standard 1 International Code of Ethics for Assurance Practitioners (including International Independence Standards) (New Zealand) issued by the New Zealand Auditing and Assurance Standards Board and the International Ethics Standards Board for Accountants' International Code of Ethics for Professional Accountants (including International Independence Standards) (IESBA Code), and we have fulfilled our other ethical responsibilities in accordance with these requirements and the IESBA Code. 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.



### **Emphasis of Matter – COVID-19**

We draw attention to Note 13 to the performance report, which explains the impact of the Covid-19 pandemic on the Society. Our opinion is not modified in respect of this matter.

### **Responsibilities of the National Council for the Performance Report**

The National Council is 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 Society 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 report

in accordance with Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit) issued in New Zealand by the New Zealand Accounting Standards Board, and

- c for 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 is responsible on behalf of the Society 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 National Council either intend to liquidate the Society 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 Society'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 to the related disclosures in the performance report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of 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.

#### **Restriction on use of our report**

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

*Nexia Audit Christchurch.*

**Nexia Audit Christchurch**  
**15 October 2020**  
**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

HFNZ 60th anniversary

November 8 – 10, 2019

In November 2019 HFNZ held the official celebration of 60 years supporting and advocating for New Zealanders with bleeding disorders. There were two key parts of this weekend: a welcome ceremony held at Parliament, hosted by cabinet minister Chris Hipkins; and the gala dinner at Te Papa Tongawera. There were also other gatherings for special groups within the HFNZ whānau over the weekend.

- Adults - 193
- Staff – 7

*“a great weekend of re-meeting all the old faces. It was good to see HFNZ so well positioned – National Council with professional skills and people holding strategic positions; the number of younger people involved; the growth strength and mana of Piritoto; [and] a good flow of funds.”*

*“I wanted to pass on my congrats for the 60th celebrations. I enjoyed both nights and appreciated the different tone on the respective evenings. A lot of hard work for you all but everyone I spoke to were very positive about the night and seemed to have a great time.”*

National Inhibitors workshop

March 13 - 15, 2020

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 - 22
- Children - 7
- Staff - 14

*“I have really enjoyed my weekend with everyone, and have learnt so much about inhibitors and haemophilia in general. Looking forward to the next.”*

*“Truly fantastic to help and mentor the younger generation, passing on our journey and findings [about] what persons can access and the help they can get”*

## Other Significant Programmes

Outreach Support Services for people with bleeding disorders and their families

2122 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 2019 to June 30 2020; issues dealt with included working with schools, hospitals, social welfare, and housing. A large number of contacts later in the financial year were related to Covid-19. The Covid-19 lockdown and associated alert level changes meant that Outreach staff were unable to meet face to face with members during the latter part of the year. They maintained contact via telephone, email, social media, and live video.

World Haemophilia Day

The Covid-19 pandemic significantly affected World Haemophilia Day this year. While events were planned in each region, these had to be cancelled due to the restrictions accompanying the elevated alert levels.





## HFNZ 60th Anniversary

1958 - 2018



# 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
C & M Louisson	
Novo Nordisk	Sustaining Patrons
NZ Blood Service	HFNZ 60th
Roche Grant	Inhibitors Workshop
Quality Hotel Parnell	Sustaining Patrons
Roche Products (New Zealand) Ltd	HFNZ 60th
Sanofi-Aventis Australia Pty Ltd	HFNZ 60th
Shire New Zealand Limited	HFNZ 60th

## Bequests

Estate of Albert Roberts
Estate of F Davies
Estate of Verona McGregor
Estate of MA Knowles

## Individual and general donations over \$100

CREST
B I Wilson
B Smith
Betty Willis
Give A Little
Ho Seong Kim
J Phillips
Jeff Downs
John Hunter
Julie Park & Kathryn Scott
Kiwifirst
Lyn Steele
M & C Louisson
Memory of Reg Fuller
Michael & Cheryl Carnahan
Nick Lingard Foundation
Otonga Road Primary School
P Rackley
Pukekohe Lionesses
R Long
Reginald Fuller
Robert Field
S Pickles
Southern Branch High Tea



# In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 1 2019 and June 30 2020:

- Reg Fuller
- Enid Blacklaws
- Valerie Campbell
- Alan Bruce

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:	James Poff
Piritoto Delegate:	Te Whainoa Te Wiata
Youth Delegate:	Lauren Phillips
Co-opted Member:	Steve Waring

Southern Branch Chair:	Susan Inwood
Piritoto Branch Chair:	Tuatahi Pene
Youth Branch Chair:	Courtney Stevens

## Staff

### Administration

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

## Member Representative Groups

Northern Branch Chair:	No Chair
Midland Branch Chair:	Tineke Maoate
Central Branch Chair:	Blair Wightman

## 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 11 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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