# HFNZ Annual Report 2016/17 Of JULY 2016 TO 30 JUNE 2017





# Haemophilia Foundatio of New Zealand Inc.

# 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 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, making a difference where it really counts.

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

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 celebrates the effectiveness of members, supporters, and outside agencies working together. This year we ran four 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 this 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. Despite promising advances in gene therapy, and the development of other novel treatments, a cure to these disorders remains elusive. However, HFNZ's dedicated staff, and our innovative initiatives, 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

2018 will mark the diamond jubilee of the Haemophilia Foundation of New Zealand (HFNZ). As we enter our sixtieth year, it is timely to reflect on the previous decade and to look what we have all achieved, and where we need to go next. I do not claim to cover everything in this report, but I hope you get a flavour of the past decade, and how it has shaped HFNZ's current position.

Much like the formation of a diamond, as we continue our work for all people in New Zealand affected by bleeding disorders, there may be some pressure, it might get a little heated, and it will take time, but the end-result will be worth it.

### Many faces, one community

There has been a growth in membership over the past ten years and, with advances in treatment, the way HFNZ engages with the community has adapted. What it means to manage severe haemophilia, even in a decade, has changed considerably.

Treatment options for bleeding disorders are about to explode globally. If you live in the right place, there has never been a better time to have a bleeding disorder! We will continue to work with our clinicians to demonstrate the value of essential therapies to funders, and show the long term gains that can be realised by some smart short-term decisions to provide the best available therapies to our population.

As treatment has improved for people living with severe haemophilia, it has become possible to focus on other aspects, including other forms of haemophilia, symptomatic carriers, rare bleeding disorders, people living with inhibitors, and people with von Willebrand's, all as they relate to both men and women.

In past decades, there was no group specifically for people affected by bleeding disorders who identify as Māori. This changed in 2009 when the first meeting of what is now called Piritoto occurred. Seventeen Māori members of HFNZ across New Zealand attended the inaugural hui held 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 how to be more involved. The second hui had greater attendance (22 members). A key result of the second hui was the resolution to have Māori representation on National Council and for this to be enshrined in our Constitution.

The ability to focus on our broader community has resulted in the continuation of a Youth Committee and Piritoto, and more targeted programmes. I see a very connected community who now have many opportunities to get together. We should not forget those who remain isolated, however, and find ways to reach them. Now people with haemophilia are living longer than ever before, and experiencing the same aging process as the general population. It makes day-to-day life all the more exciting when balance is ailing, vision isn't what it was, and you are living with a condition that doesn't fit too well with falling, bumping, or scraping. While there is a position on the HFNZ national council for a Masters member, there have been a number of years where it has not been filled. This is an area where we can all do better. We need to reach everyone.

### Ten years of national programme delivery

There has been a concerted effort to run programmes targeted at all parts of our community. It is the delivery of these programmes that connects members from all parts of the country together to learn from one another, share experiences, and receive the latest information on living with a bleeding disorder. Nationally, approximately 30 events have been run over the past ten years in addition to those run by our regions and various groups. We have continued to offer our supportive footwear, exercise, and swimming programmes to members.

Looking at ten years of programme delivery, we have seen events targeted at newly diagnosed families, couples, mothers and daughters, men and women, children, teens and young people, grandparents, people with inhibitors, and all of the above.

The Parents Empowering Parents Programme has reached a milestone this year, celebrating its tenth birthday as a programme delivered by HFNZ. Its goal has always been to increase parents' understanding of their child's bleeding disorder, and to provide the necessary parenting skills. The HFNZ exercise programme also celebrates ten years of promoting the benefits of being active.

### Caring for people with bleeding disorders and hepatitis C

After a lot of hard work by HFNZ members, the treatment and welfare package was signed in 2006 to ensure that all people who contracted hepatitis C through contaminated blood products received the care they needed. This was turning point for the foundation in recen history. Looking after people affected by hepatitis C has not ended there, and there are still members who live with the aftermath every day. What we have seen since that time is a generation unaffected by blood-borne viruses, and families that, thankfully, have only ever known products free of viral contaminants. Ten years ago HFNZ were still resolving the final legal issues preventing access to payment for some members eligible for the treatment and welfare package. Today there are very few members living with

hepatitis C. This is both a success and a tragedy. Due to advances in treatment, many have been cured. However, some members were lost to us while waiting for an effective treatment. While the numbers of people still living with hepatitis C in our membership are few, the long-term impacts are significant and should never be underestimated or forgotten.

### Financial stewardship

Since 2007, HFNZ funds have been managed nationally with oversight from the national council. Overall, we have accumulated approximately \$8,000 year-on-year. This keeps pace with inflation. The inflation-adjusted increase to our surplus equates to just over \$30,000 over a ten-year period. KiwiFirst fundraising has been a major contributor to our financial health, and we are extremely grateful to them, and to the public who support us through them. We also acknowledge the contributions of industry, trusts, benefactors, and government. It

is important to stress that without the generous support of the public, and our funders, we would cease to operate. The effects on our community would be significant, as would the flow-oneffects to our health system.

Ensuring funding continues for the programmes that HFNZ provides, or will provide, is an ever-present challenge. We must always ensure that we continue to use our limited financial resources for those who most need support. Despite the challenges, we should not let financial constraints prevent us from striving to deliver excellent services, or from expanding our thinking. The key for us to continue to be

	Income and expense 2007 - 2017				
	Year	Income	Expenses	Surplus(deficit) after depreciation	Accumulated funds (excluding property fund)
	2007	1,120,606	1,150,431	-37,276	271,670
	2008	1,314,341	1,304,752	2,587	271,546
3	2009	1,459,563	1,412,407	40,684	312,229
a nt	2010	1,376,409	1,379,490	-10,211	302,018
	2011	1,647,458	1,533,702	107,402	409,420
e	2012	1,470,373	1,491,127	-20,754	388,666
n d	2013/14*	* 2,232,784	2,277,685	-44,901	343,765
	2014/15	1,505,116	1,503,243	1,873	345,638
1	2015/16	1,362,876	1,345,655	17,220	362,858
	2016/17	1,380,861	1,389,584	-8,723	354,135
av	*18 mont	hs			

able to fundraise is to demonstrate to our donors the value we place on every dollar, and the care we continue to take in using these greatly appreciated donations.

### Working with the National Haemophilia Management Group

The National Haemophilia Management Group (NHMG) has been running for more than 10 years, and HFNZ will continue to advocate for its existence. The NHMG has demonstrated benefits in terms of the creation of physiotherapy and nursing positions, management of costs, and made useful connections with key decision-makers. As a patient organisation, we can demonstrate the value this group has made to the lives of our community, and we tend to bring a longer-term view to any policy decisions. This year's NHMG has a new chair: Rosemary Clements is the Chief Executive Officer of the Taranaki DHB and brings a wealth of experience to the role.

### Acting globally

Since 2010, HFNZ has been particularly engaged with the global bleeding disorders community. I have been a director of the board of the World Federation of Hemophilia since 2010, and served on many of its committees and programmes. While the position is for all people affected by bleeding disorders globally, it has helped in connecting HFNZ with different parts of the world to share experiences and improve care for all, including here in New Zealand.

We decided to support twinning with Cambodia (a WFH programme), and for the volunteers who represented us, I know it was as enriching experience for them. In fact, both countries learnt just as much from each other. These relationships continue beyond the conclusion of this programme, and we will be now look at our responsibilities to the South Pacific.

This year HFNZ were selected as one of three 'youth twins' as part of the World Federation of Hemophilia's twinning programme. New Zealand will be conducting an assessment visit with Nepal. The objective of the WFH youth group twinning program is to help emerging youth groups strengthen their membership and empower the young members of each participating organisation. The program 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, patient education, among others. Hemi Waretini and Courtney Stevens



will be attending on behalf of HFNZ for the assessment visit.

### A foundation for haemophilia

To keep HFNZ strong, we cannot be idle. At a recent National Council meeting an important decision was reached to ensure this. A property search for the national office has been initiated to be relocated to Wellington and make use of the property fund formed by the four branches over ten years ago. There have been a number of discussions and some action taken from successive National Councils about using this fund according to the wishes of the membership. It has now been more than 10 years since the creation of the fund and a move is timely.

To provide some background to the fund; in 2007, the Foundation's four branches' bank accounts were amalgamated as a result of requirements of the Charities Act 2005. Without the amalgamation, we would have not been considered as one organisation. At an Annual General Meeting, the membership agreed that the funds were to be put aside for purchasing a property. This resolution was reached after a long discussion about how to fairly use funds raised in different regions for a national purpose. The fund has been left earmarked for property purchase ever since.

As your representatives, the National Council are unanimous in their commitment to this decision with the ultimate motivation of continuing to improve the lives of people with bleeding disorders and keeping us moving in the right direction.



Richard Chambers: CEO Report

One of the first haemophilia support and advocacy groups in the world; HFNZ continues to be relevant and true to its founding principles: working for and supporting people with bleeding disorders in New Zealand.

The HFNZ National Council, staff, and volunteers are committed to working closely to the strategic goals of the foundation:

### 1. Care and treatment:

World-leading best practice bleeding disorder care throughout New Zealand that is safe, secure, and comprehensive.

HFNZ works closely with the clinical teams at each of the New Zealand Haemophilia Treatment centres to support the bleeding disorder community. We are fortunate that we have such a passionate and skilful clinical team working with us.

The bleeding disorder • community is kept well informed of local and international treatment developments through our monthly Pānui e-newsletter, and Bloodline magazine, published three times a year

HFNZ is represented • at the World Federation of Haemophilia Global Forum on research and treatment products for bleeding disorders

### 2. Education and support:

*Provide education, support, and* advocacy for people with bleeding disorders and their whanau.

- An Outreach team consisting of four part-time staff based in Christchurch, Levin, Hamilton, and Auckland, supported by an administration, programme planning, and communications team based in Christchurch, provide oneon-one family and individual support to people with bleeding disorders throughout New Zealand.
- The staff team have coordinated and led four significant educational workshops in the past year:

Family Camp, Youth camp, an Advanced Youth Leadership Weekend, and a Parents Empowering Parents workshop, with the support of volunteers from within the bleeding disorder community and the Haemophilia Treatment Centre staff.

• Staff work to maintain contact with members of the bleeding disorder community on a regular basis, and encourage people to contact us if they have a support issue or just a question. Please email your local Outreach worker or phone us 0508Factor (0508 322867).

### 3. Speaking up:

Effectively represent the needs and interests of the bleeding disorder community to government, nongovernmental agencies, and groups.

- We have continued to work with ACC to provide 'best available' hepatitis C treatment to HFNZ members under the Treatment and Welfare Package.
- We continue to work with individuals who are not suitable for current HCV treatment, or where treatment is delayed for clinical or personal reasons.
- The Foundation is working to prepare the way for access to the new generation of haemophilia treatments as soon as possible after trials and regulatory issues are completed. These new treatments will significantly reduce the treatment burden and improve outcomes for people with bleeding disorders.
- HFNZ has begun work on exploring the additional burdens placed on women with bleeding disorders and the impact their bleeding disorder has on their lives: physically, financially and emotionally. This information will be used in discussions with Pharmac and the Ministry of Health.
- 4. Inclusive and Sustainable:

Sustainable, efficient, people-first organisation, where the place of Māori as tangata whenua is valued.

Staff are increasing their understanding of bleeding disorders within the context of Te Ao Māori. This work is supported by HFNZ's group, in particular Te Whainoa Te Wiata, a member of HFNZ council, who is developing a programme for the international bleeding disorder community about working with indigenous populations

The regional groups, Piritoto, and Youth continue their work to ensure that opportunities are available for people with bleeding disorders to meet one another and to develop peer support networks. This work is extremely

valuable, as the impact of a bleeding disorder on a family can be significant and lonely.

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

 Thank you to three very special staff members Colleen McKay, Leanne Pearce, and Linda Dockrill, who all moved on after nearly 40 years of combined service

• Following the retirement of Colleen McKay, it was decided not to replace the Education and Programme Manager position. While this decision was difficult, it reflects the challenging financial environment.

We welcomed two new staff members: • Administrator, Karen Melville; and Southern Outreach Worker, Josiane McGregor.

• HFNZ currently employs 5.8 fulltime equivalent staff.

### 5. Global community:

Active in the world bleeding disorder community supporting care and treatment for all.

HFNZ has been fortunate to be able to



continue its involvement in supporting the World Federation's goal of treatment for all. We have been able to fund this work largely through grants from outside of New Zealand.

• Cambodia – HFNZ invited a member of the Cambodian Haemophilia Association to participate in the Advanced Leadership Training workshop. Rithy's perspective added greatly to the development of the New Zealand participants

• Deon York is an elected member of the Board of the World Federation of Haemophilia (WFH)

He toto, he taimaha kia piri, tukua kia rere

Ashlev Taylor-Fowlie is a member of the Youth Committee of WFH. She attended the WFH youth leadership training facilitated by Deon York, and was

awarded the Susan Skinner Fellowship by WFH

• HFNZ representatives attended the North American Camping Conference of Haemophilia Organisations (NACCHO), the Global Haemophilia Advocacy Forum, and the World Congress, where there were five speakers from New Zealand.

Thank you to HFNZ council for their governance, to KiwiFirst for their commitment to fundraising for the bleeding disorder community, to our staff for their passion and professionalism and to the grass roots volunteers who have helped to staff workshops and run regional events.

A special thankyou to our wonderful sponsors, funders, partners, and donors large and small. Your generosity and support of the bleeding disorder community make our work possible.



# **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.

This has been another year where the focus of Piritoto has been to strengthen ties with everyone involved. Last year we had a great response to the Noho Marae and to the New Year celebration of Matariki. From that, we decided to continue these successful events into this New Year by combining them, and having the two events complement each other.

It has been a busy year. We all live our day-today lives with the coming and going, whether it's going to our jobs, keeping up with treatments or doctors' appointments etc., and it is hard



and find peace through it all. The weekend Noho has always been a social gathering centred on togetherness and the well-being of one another. This time around, it gave me a feeling of great relaxation; it gave me that moment of peace that I had long needed in my busy

Te Tahawai Marae opened their doors to our group of people and gave us a warm welcome to start our annual Noho Marae, which this year was held in Auckland. The focus of the weekend was on our whanau and the celebration of Matariki, the Maori New Year. It was great to see old and new faces attend the Noho.

The Friday evening saw people working hard towards providing a Hangi meal to those who were participating in the Matariki activity. Everyone had a role to play, from cleaning and cutting the vegetables, to preparing the stuffing & steam pudding, to the arranging of meats into dishes. This was a great team-building exercise that produced not only a good meal, but also a great way of getting to know one another.

A big mention must go out to the guest speakers Cat Pollard & Marlon Hepi, who spent Saturday morning sharing their expertise with the whānau. Cat spoke on how a bleed forms in a typical Haemophiliac, and well as the

to find the time to take a moment

importance of 'te whare tapawha', and how it can be used to treat patients in a more holistic way. Marlon spoke on the many avenues that are available to people who are in need of special services.

The Matariki event occurred in the Saturday afternoon and saw the whanau returning to Auckland's Stardome observatory to see a show that inspired an informative outlook on the night sky. The invitations went out to both the Piritoto and the Northern groups, in the spirit of better cementing our ideal of 'Kotahitanga', or unity.

The first appearance of the constellation Matariki in the night sky before the morning sun marks the start of the Māori New Year. The whānau saw an animated movie outlining the constellation in relation to our perspective in New Zealand; the many Māori stories presented gave an exciting and instructive outlook for all the families to enjoy.

Returning to the Marae gave the families who participated in the Matariki event a chance to taste the delicious Hangi meal that was prepared by the Piritoto whānau beforehand. A welcome followed by a hot Hangi put smiles to those who could attend the evening. People were enjoying themselves, songs were sung, and laughter was heard.

We held our AGM on the Sunday morning. The delegates and committee members all came together to discuss how Piritoto was going so far, and what we could achieve in the near future. The delegates all agreed to continue their positions in the New Year, but have concluded that there is a need for further training. There was a consensus that a job description with details outlining what is required of them would help aid the committee members in their positions.

Following on from this need for further education, we had held an all-day meeting to brainstorm ideas, charting our thoughts so we better-understand our roles. This is a first step of many that we are undertaking to better ourselves.

A massive thank you goes out to all those who could attend the Marae Noho, the delegates, the committee members, and all the extended family members. Without you we would not be who we are as a whanau, and, to those who weren't there, I hope to see you all at our next get together.

Tēnā koutou, tēnā koutou, tēnā rā tātou kātoa.

### Central

### By Stephanie Coulman: Central Chair

The opportunity to network with one's peers cannot be underestimated, and that is the strength of the regional committees; they provide the opportunity to mix and mingle and share our stories. We encourage members to accept these opportunities and make the most of what is offered.

Our region has held a range of smaller activities throughout the year. A café evening in July 2016 at the Petone Working Men's Club offered a very reasonably priced buffet meal.

Our biggest event of the year was our annual camp, held in August 2016 at El Rancho in Waikanae. Our winter escape was an enjoyable and active time for those who attended. The venue had been renovated since our last camp there and there was a great range of activities available; rifle shooting, archery, rock climbing, horse riding, and (best of all...) archery soft. Teams shot each other with soft arrows, bringing out the competitive streak in many of us!

Our Christmas event at the end of November was Ten Pin bowling, where having fun was more important than winning. I always enjoy the discussions I have with members at these events and appreciate them sharing their challenges and thoughts with me. Thanks to Lorraine Gordon for organising this event, as well as the cafe evening in Petone.

Judith Dudson, a long-time committee member organised her swan song event before she retires from the committee - a Buddy awards picnic at The Esplanade in Palmerston North in April 2017. Thank you Judith for all your efforts and dedication to the committee and for being a strong link in Palmerston North.

Ashley Taylor-Fowlie has been an asset to the region, I was very happy when I heard she was moving from northern to central! She is an up and coming leader and now an international speaker, having been invited to a youth haemophilia conference in Spain at the end of 2016. As well as serving as Secretary for the region, she organised a youth event bringing our young members together over pizza in Petone.

Another asset returned to us in the physical sense was Treasurer Blair Wightman. He has remained in the role as Treasurer while living and working overseas for nearly four years, in London and Sydney. He returned to New Zealand in mid-2017 with a slightly larger family than when he departed – welcome home

### Blair and Cherie.

Unfortunately, the men's fishing charter had to be postponed due to inclement weather. However, with a deposit already paid, the event is sure to proceed. The event will take place in January 2018.

It remains a challenge to organise events outside the wider Wellington region. To achieve that requires greater support from the members themselves, there is only so much local volunteers can organise and co-ordinate. That said, we shouldn't lose sight of the fact that our numbers are small, and in the smaller towns the number of members who would attend an event, let alone organise one, is even smaller.

As Chairperson since February 2012 (6 years) and committee member since February 2006 (11 years!) I have attended and organised many camps. These are the biggest events on our social calendar and perhaps the most important. My first regional camp was run by Grant Hook in Whanganui in 2005 and was a wonderful experience!

As I step away from the Chairperson role, I am proud of what I have achieved in bringing members together at regional camps to network with each other and

learn more about

their conditions, and, of course, to share fun activities together. However, it's time for me to move aside and allow a fresh face to lead the committee.

### Previous camps

- 2005 Whanganui
- 2006 Kennedy Park, Napier
- 2007 Solway Park, Masterton
- 2008 Kennedy Park, Napier
- 2009 Kennedy Park, Napier
- 2010 Solway Park, Masterton
- 2011 El Rancho, Waikanae
- 2012 no camp
- 2013 Kennedy Park, Napier
- 2014 Anndion Lodge, Whanganui
- 2015 Suncourt Motel, Taupo 2016 El Rancho, Waikanae

We remember Central region members who passed away: Peter Hook, Oct 1st 2016.

### Midland

### By Linda Mellsop-Anderson: Midland Chair

Midland has had a bit of a quiet year, with only a few events.

However, we did manage to get a group of Masters out on the beautiful Lake Taupo for a spot of fishing. The men enjoyed a shared lunch in a relaxing environment out on the lake, had the opportunity to share stories, meet each other, in some cases for the first time, and relax.

We also got out on the water at Raglan for a relaxed harbour cruise aboard the Wahine Moa. Our journey was not without excitement, however. We came across a boat that had engine failure, so, as a responsible craft, our captain took the boat under tow and we returned it to the wharf then set off again. Many of the children took the opportunity to steer the boat and to introduce themselves over the onboard P.A. system.

Despite some difficult circumstances for committee members through the year, which made it difficult to organise and implement activities, like the mighty phoenix we have risen from the ashes.

Our AGM, while not formally structured, was thoroughly enjoyed by all attending. We ran the AGM in conjunction with an outing to Steamfest. Starting in Otorohanga, aboard a

### Northern

### By Richard Scott: Northern Chair

The committee for the 2017 year was:

- Richard Scott (Chair)
- Neil Smith (Secretary)
- Liam Brodie (Delegate)
- Hemi Waretini (Treasurer)
- Greg Jamieson
- Jess Hirst
- Tim Lowe

Nicky Hollings Northern Outreach worker for HFNZ also attended meetings and took all the RSVP's for the events thanks Nicky!

### Events this year:

- Rainbows End
- Summer camp Mangawhai
- Buddy Awards
- Pizza at Okahu Bay with Rithy from Cambodia Haemophilia Association
- Dinner Genghis Khan
- Ladies afternoon tea
- Matariki (Combined with Piritoto)

This year we had slightly fewer events and numbers were down compared to previous years.

The challenges for the year ahead include having enough volunteers on the Northern committee. I hope that enough



mighty steam train, we raced to Te Kuiti,arriving just in time for the news of Sir Colin Meads' passing. On the way back we held our AGM and decided who was representing the region, and in which roles, for the next year.

Our committee remains the same, with Linda Mellsop-Anderson as Chair and Tineke Maoate as Secretary. It was great to see some interest being shown from some of our newer members, so we're hopeful we will soon be reporting their co-opting.

Last year's committee - thank you for efforts and onward and upward for 2017-18.

To our Outreach Worker - Joy Barrett, thank you for your efforts with our Midland Family and we look forward to fun

events over the coming year.

If you would like to be involved, please don't hesitate to contact Joy or myself.



people will put their hands up to help serve the

rest of our members in the Northern region.

This year has also been marked with excitement over new Haemophilia products that are under development and testing some by people in New Zealand. I look forward to seeing how long it takes for these products to become available on the market and eventually in widespread use. In the meantime it's great to see children making progress in their treatments and adults too.

The Foundation also said goodbye to Colleen and Leanne two

long serving staff at the National office we will miss them both and want to thank them for their dedication and service to all members of the Foundation and the Northern members in particular.



### Southern

### By Theresa Stevens. Southern Chair

Welcome to the Southern Regional Branch Report for 2016 - 2017. This year has continued to be one of constant change and excitement, which has been managed by a small and enthusiastic volunteer crew.

While we held meetings for our branch as per the constitution, it was sad to see that the meetings were not well attended these past twelve months. In some cases, we were not even able to reach quorum. restrictions and regulations the organisers placed on volunteers meant that we were unable to raise the members to assist.

Our Southern AGM 2016 was held at Silverback Café in Christchurch. Theresa Stevens was elected to be Chairperson and Southern delegate to National Council, Susan Inwood became Treasurer/Secretary, and Courtney Stevens is the youth delegate to National Council. Congratulations to the office bearers and the committee.



The Christchurch gatherings included a Christmas party at The Bower in New Brighton. This was a lovely evening where kids and adults alike were able to relax and enjoy the end of another HFNZ year.

In May we assisted Brick Road Productions with the annual play, which was a great success. This is a fantastic initiative, which proves popular every year. Big thanks must go to Heather Giles from Brick Road, Karen, who did a lot in the background, Bo Silva, who is a

Sadly, this year saw the resignation of our long standing Outreach Manager Colleen McKay. Colleen, we wish you all the very best for your future endeavours. You will be missed, not just by the Southern folk you provided such amazing and selfless care for, but also by the other HFNZ members throughout New Zealand.

We also said goodbye to Linda Dockrill who had served the Southern region for seven plus years. We welcome Josiane McGregor to the role of Southern Outreach – we look forward to meeting you as you journey through the region.

Sadly, Southern events have been rather nonexistent at the Southern end of the Southern Region. However, we did manage to get some events together in the Christchurch area during the year.

During March, we cancelled our participation at Armageddon simply because the new

ticket selling machine, and Karl Archibald who organised the bar! Southern were again able to raise a significant amount to contribute to HFNZ finances.

I would like to take this opportunity to thank the office staff who have organized flights, venues, and accommodation to enable those travelling to get to the destinations on time. Thanks to Susan for her efficient documentation and completion of minutes and keeping our financial matters in safe hands.

I would also like to thank my own family for their support for allowing me the time to participate in this role of Southern Regional Chairperson.

### Youth

### By Lauren Nyhan. NYC Chair

A roady, a trip to Barcelona, and a major announcement. It seems that the National Youth Committee always has a chaotic and exciting year to report on.

First though, I must make special note of the fairy god mother who made so much of this possible for us as a member group from the very start. It was with great sadness that we learned of Colleen McKay's resignation, and I can guarantee that we weren't the only one who shed a few tears at the thought of not having her around (as much). We have had Colleen's dedication and wisdom for so long as a Foundation, that it seemed unfathomable to have an HFNZ without her. However, we couldn't keep her to ourselves forever, we knew the secret of her greatness would leak eventually, and so we would like to say thank you. Thank you for the devotion, passion, and love that you have committed to the Foundation, and especially to the young people. We will miss you, but most importantly we'll make sure that we keep on building on the hard work that you and so many others have started.

This year has been a great year for the NYC, with our members continuing to assert their presence on the world stage, as well as making the most of opportunities at home and overseas.

We kicked the year off with a summer road trip around the beautiful Waikato for our first ever HFNZ Advanced Leadership Training Weekend over Waitangi weekend. Along with some of those who attended the inaugural Youth Leadership Training weekend in 2014, we were joined by Rithy from the Cambodian Hemophilia Association. All attendees found the weekend challenging on some level, and were stretched and encouraged to step outside of their comfort zone. Whether it was participating in a physical activity that they were afraid of, giving a presentation, or sharing a personal experience, we all walked away from the weekend enriched by the experience. As is always the case with the NYC, growing engagement and involvement in our member base, and ensuring the future of the Foundation was high on the list. Reflecting on this event, we can say with confidence that the Foundation will continue to head in the right direction.

Ashley Fowlie has continued her involvement on the world stage of haemophilia and bleeding disorders. In December 2016 she was invited by the World Federation of Haemophilia to attend the Youth Leadership Workshop held in Barcelona. Topics such as social media, youth engagement, challenges facing youth, and leadership and training opportunities were discussed. Ashley returned to the group with a wealth of knowledge, even higher levels of enthusiasm, and some great ideas.

And if the year couldn't get more exciting, in June of this year the World Federation accepted the NYC's application to partake in a pilot



youth group twinning project with the Nepal Haemophilia Society. NYC was selected as one of two youth NMO's to participate in the project. The depth of experience and knowledge that we have developed as a group since our inception, and the support that we receive, truly is the envy of many youth groups. We are extremely honoured to have been afforded this opportunity, and we look forward to sharing and learning with our friends in Nepal.

One of the key topics that have come out of discussions and events from the past 18 months has been the idea of succession and ensuring the future of the Foundation. Whilst we are more acutely aware as a group, particularly after meeting Rithy and engaging in the Nepal twinning project, of the challenges faced by developing countries, we have also become more aware of the need to protect our own interests as a charitable group. As times change, and funding to charities becomes less available, we are alert to the challenges on the horizon and the need to remain observant of the political and social landscape to ensure that our members medical and social needs continue to be met.

We would like to thank everyone who has made this year the success that it has been, and we look forward to reporting to you all next year on the work that we are doing at home and with Nepal.

# 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.

### National Family Camp

On September 30th 98 Campers assembled at Keswick Camp in Rotorua for the 2016 HFNZ National Family Camp. This was another fantastic weekend, even though the weather didn't quite play ball. The kids had a great time fishing, bike riding, and other fun stuff. Meanwhile, the adults learned heaps about bleeding disorders; including Haemophilia A & B, von Willebrand Disorder as well as those with Platelet Function Disorders; and the issues faced by people with bleeding disorders.



There were a number of really valuable workshops:

- BJ Ramsay, covered the basics of bleeding disorders.
- Outreach Worker Linda Dockrill taught parents about the building blocks to developing resilience in children, and ran a session on constructive communication
- Haemophilia Nurse Maureen Hayes ran a session for those with von Willebrand Disorder and other rare bleeding and platelet function disorders
- Dr Nyree Cole spoke on some of the complications of haemophilia, like venous access and inhibitors, and to promote a realistic view of the possibilities of future treatments.
- Haemophilia Physiotherapist Cat Pollard presented an session about Physiotherapy and took the time to offer individual consultations.

- Colleen McKay's presentation likened the process of building responsible children to building a house – it's important to start early and build a strong foundation
- The 'Ask the Experts' session, where parents were able to ask young adults about their experiences of growing up with a bleeding disorder, was again very popular

Big ups to Alex Rutherford and Izack Silva for doing their own treatment for the first time, with many other Campers making great strides in their self-management.

While the grown-ups were doing learning, the kids were divided into three age-based groups and were kept busy with interesting and fun activities.

A highlight for many of the kids was an afternoon out fishing. The day was organised voluntarily by Doug Stevens, an amazing man who has an absolute passion for fishing. There was much excitement along the lake-front when 10-year-old Joseph Esera landed the first trout, closely followed by Danny Guevara, Andrew Scott, Dylan Christiansen, and R-leeo Maoate. Back at Camp, Richard Scott carefully gutted and smoked the trout, and they were enjoyed by many.

Despite a lot of rain, the HFNZ Carnival Day went ahead as planned, with an array of activities for families to participate in and enjoy, including Archery, Mountain Biking, Kite Flying, Face Painting, and the novelty Motor Mower Challenge which generated much laughter. To top it all off, the generosity of Jan and Marcus Wilkins of the Rotoiti Explorer saw everyone off on a one-hour tour of the picturesque Lake Rotoiti.

At the Final Assembly eight children graduated from Family Camp. That means they're now ready to attend HFNZ Youth Camps. Well done Logan Turner, Alex Rutherford, Izack Silva, Danny Guevara, Lachlan Fergusson, Sinead Edwards, Joseph Esera, and Connor Daly-Wilson We also took the chance to farewell Southern Outreach Worker Linda Dockrill, as this was her last National Family Camp before taking up a new role.

So, HFNZ Family Camp was AWESOME! We loved it, and by all accounts our members loved it too. The countdown is on for next time...

### Advanced Leadership Training

Earlier this year a group of specially selected young people from around New Zealand were invited to participate in the first HFNZ Advanced Leadership Training weekend. Over Waitangi weekend, Rithy from the Cambodian Haemophilia Association (CHA) joined HFNZ Youth members for a weekend full of learning, challenges, and fun.

Other than Rithy, these young people had already been through the 2014 Youth Leadership Workshop in home. Christchurch, and had continued to demonstrate their leadership abilities in support of HFNZ. Many of these young One of the big challenges of the weekend was for the young leaders to set themselves goals to achieve within HFNZ. people have taken on committee roles at regional and national They are now looking forward to touching base in a couple level. This was an opportunity to really stretch these young people, to educate them in some of the history of HFNZ, and of months' time to assess their progress. This is a great to ensure that the future leadership of the Foundation is in opportunity to really see how good planning and followsafe hands. through can lead to positive results.

The weekend started out in Auckland, with the young participants having no idea what was in store for them. The first of many surprises was a road trip, leaving right now, to points unknown. The young leaders were divided into two teams and sent away in vans with a list of clues and tasks to complete. The Auckland traffic was a bit of a shock to some of our young leaders. As one of them said, "If this was Dunedin, we'd already be at Waitomo by now..." and one level-headed young future HFNZ Treasurer, with their eye on the bottom line, reminded their team: "If we get a speeding ticket just remember to ask for a GST receipt".

After visiting the Clotworthys, the ugliest town in NZ, and the kiwiana capital of the world, among other notable destinations, they all ended up at the home of arachnocampa luminosa (the glow worm) for their first bout of learning. That afternoon's sessions included sharing a bit about themselves, and finding out about the future of not-for-profit leadership from Karl Archibald. The day finished with a visit to the glow worm caves at Waitomo, and an early night. Because who knew what was on the programme for tomorrow...

The next day dawned with another secret road trip, which included dams, forests, and statues, before finding the next night's accommodation (a bit early for the cleaners...). The afternoon included some learning sessions with HFNZ Executive members Deon York & Catriona Gordon, and a chance for some 'Real-Time Risk

Management' (Mountain Biking...) before settling in to their new home in Rotorua for dinner, and some more learning about bleeding disorders.

Day three saw our young leaders heading into the treetops for a forest canopy tour and some zip-lining. The fun and games were again mixed with some great learning, including learning about higher-level advocacy with Deon & Catriona,



and some strategies to help manage group conflict with Lauren Nyhan.

The final day was the last chance for our young leaders to get some more learning under their belts, and plan for the future. Ashley Taylor-Fowlie shed some light on the world youth scene, before Karl Archibald led a session on SMART planning. Then it was off back to Auckland, and the plane ride home.

This was a fantastic weekend. The young people learned a whole lot, and really stretched themselves, and HFNZ will benefit from the skills these future leaders have developed. The Canopy Zipline Tour, the mountain biking, and the travel challenges were all very popular activities, and the educational presentations by other leaders went down very well too. Here's a just a couple of the comments the participants made in their evaluations:

"The ALT Weekend provided an amazing opportunity for experience, growth, and knowledge"

"The youth are the future! Thanks HFNZ for investing in us. With your help I feel more comfortable in my leadership skills to work towards a brighter future for those with bleeding disorders."

Special mention must go to Karl Archibald, who stepped up and assumed responsibility for running the show when Colleen and Ed became unavailable. He truly showed that we produce great leaders here at HFNZ.

### National Youth Camp

Over a chilly, but sunny weekend, HFNZ held another National Youth Camp – Hero Camp!

On Thursday April 20, 31 young HFNZ members, boys and girls with haemophilia, von Willebrands and Platelet Function Disorders, from as far afield as Hikurangi, flew in to Christchurch Airport. After arrival, everyone hopped on a bus and headed north to the Waipara Adventure Centre in North Canterbury.

The overall theme of the weekend was Heroes. With that in mind, Thursday's programme was devoted to discovering: What it Takes to be a Hero – the qualities, attributes, skills, and values that heroes possess.

After being put into teams, everyone introduced themselves, and the teams set about creating mascots from piles of junk. The mascots each had a raw egg in their chest cavity, in their heart, because heroes have big hearts! The teams were challenged to take care of their mascots while ensuring that the mascots were involved in all team activities within the programme. Biking and BMX, Rifle Shooting, Flying Fox, and Kayaking. The Waipara Adventure Centre staff ensured that these activities were undertaken safely and that they were heaps of fun.

On Friday evening – the youth leaders planned and implemented a surprise party for 'Camp Mother' Colleen McKay, complete with balloons, streamers, party poppers, and a huge cake, to honour her last ever HFNZ camp. As befits her status, this included a royal chair for Camp Mother complete with a special hat and crown. Various campers and youth leaders paid tribute to 'Camp Mother'- a very humbling experience.

It has been a tremendous privilege to be part of the lives of such inspirational youngsters. It has been wonderful to have seen many of them grow from newly diagnosed children attending Family Camp with their parents, to seeking their own independence by attending Youth Camp, then stepping up into leadership and assisting at camp as Youth Leaders, before going on to take part in Youth Leadership Programmes and stepping up within HFNZ. It has been an honour indeed.



In the evening, we were straight into bleeding disorder work. Six working groups were asked to learn about various aspects of bleeding disorders and devise a way to teach what they'd learned to the other groups later in the Camp. The topics included: What's in a blood drop? How does blood clot? Basics of haemophilia, Treating bleeds, Basics of Von Willebrands, Girls bleed too, and Genetics.

Friday morning was devoted to learning about: What do HFNZ Heroes (Heroes with Bleeding Disorders) Need? The sessions included a self-infusion workshop with Paediatric Haematologist Siobhan Cross; advice on staying fit, healthy, and strong from Physiotherapist Helen Dixon; as well as talk about managing risk to undertake a range of activities safely.

Friday and Saturday afternoons saw participants managing physical challenges without bleeds – Archery, Mountain

The theme for Saturday morning's programme was Skills for HFNZ Heroes. Throughout the morning, the campers enjoyed educational sessions on first aid with Ashley Taylor-Fowlie, employment with Josiane McGregor, and good nutrition with dietician Lea Stenning. After lunch, the groups were again involved in outdoor adventure activities under the supervision of the Waipara Adventure Centre team.

The first thing that happened on Sunday was a BIG Camp clean up, including bags packed, rooms cleaned etc. Then it was on to the final assembly. The first order of business was the Autopsy of the Mascots... well, what was left of them. They were a bit the worse for

wear from having taken part in all of the activities. Three of the four egg hearts survived the Camp Activities, much to the excitement of team members. The assembly also included the awarding of camp certificates to all the participants and of special Hero Awards to those who had earned them by selfinfusing for the first time, or something equally amazing.

After assembly, it was onto the bus and off to McLean's Island for a fantastic barbeque lunch and our traditional Youth Camp laser tag. This was a great way to finish off the weekend as a group, before heading to the airport and home for a welldeserved rest.

Over all this was an awesome camp, with the best-behaved group of campers ever.

### Parents Empowering Parents Workshop

On June 16th - 18th 2017 a group of 8 parents gathered at Aotea Lodge in Porirua for a weekend of full-immersion parenting skills development.

This was the fifth PEP weekend run in New Zealand, and was led by the PEP guru himself, Ed Kuebler. Ed is an International Coordinator and Facilitator for PEP and a long serving Social Worker in Haemophilia in the U.S. Of this

weekend, Ed said, "I am always so impressed how parents of children with a bleeding disorders, when given the opportunity to attend a PEP Program, find a renewed excitement in how they parent their children."

We were also lucky to have the PEP trained parent facilitators Richard and Lynley Scott, and the support of Outreach Workers Lynne Campbell (Central) and Josiane McGregor (Southern), and Haemophilia Nurse BJ Ramsey.

The PEP programme was first written in 1995, and has undergone a number of revisions as more information has become available, and advances in the care and treatment of bleeding disorders have occurred.



The PEP (Parents Empowering Parents) programme is designed to empower parents by teaching skills to improve quality of life when raising a child with a bleeding disorder. The topics covered over the course of the weekend include:

- Child Development
- Strengthening Skills for parenting
- Applying your Parenting Style
- You and Your World View
- How Thoughts and Feelings Affect Parenting
- The Role of Self-Esteem and Self-Confidence in Parenting
- Understanding the Process of Communication

There were also Getting Started and Moving Forward sessions at the beginning and end of the weekend.

The focus of the PEP programme is to develop a "can do" approach to parenting a child with a bleeding disorder. By working through the nine sessions over the course of the weekend, each parent learned and built on the skills and experiences they already had, while working towards completing a new plan, a blueprint, for their family life into the future. The goal was to use positive peer-to-peer education, grounded in evidence and strengths-based parenting strategies, to facilitate increased knowledge, nurture parents with similar struggles, and help them to become emotionally, behaviourally, and physically empowered to cope with parenting a child with a bleeding disorder. The PEP weekend certainly lived up to this, with parents, facilitators, and staff alike learning, sharing, and supporting each other.

Parent Iona Kahu shared her perspective on the weekend:

"As an initial sceptic of the PEP weekend I wasn't sure what to expect. What I experienced though I don't think I could have expected anyway. The small group of passionate parents that I met, who, like me, just want to be the best parents they can be for their kids whilst navigating their unique and ever changing journey with a bleeding disorder, is a group I will never forget. We shared, laughed, cried, ate lots, and had fun together whilst bettering ourselves for our children's' sake. I learnt lots thanks to the facilitators and host parents and have already started implementing things at home - as I most importantly learnt not to TRY but to DO. Thanks to HFNZ for providing this opportunity and thanks to those who attended for the life changing weekend."

Connection is a key aspect in our lives, and feeling connected to others in a similar situation helps us to have a sense of focus, hope, and confidence as parents as we confront and manage the difficulties of life parenting a child with bleeding disorder.

Well done to all involved.

# **HFNZ Financial Report**

### For the 12 months ending 30 June 2017

This year the Foundation operated a planned deficit to enable us to send a small group of representatives to the 2016 WFH World Congress. This deficit follows two years of small surpluses. The Foundation remains well positioned going forward, retaining a capital base for property investment in 2018, and an operational reserve.

The Foundation has been able to raise the funds necessary to deliver a quality education and support programme; involving workshops, outreach staff, and opportunities for people with bleeding disorders to talk about, share, and learn from each others experiences.

HFNZ is fortunate to have a very able fundraising partner in KiwiFirst.

HFNZ, and the charity sector in New Zealand, continues to face challenging financial times. The number of charities continues to increase, while overall funding remains static. Our staff and Council members continue to work hard to ensure that funders can see both the necessity and the quality of the work we do.

Thank you to Leanne and Karen who have both held the Administrator role this year. Thank you too to our donors, sponsors, and partners for your compassion, contribution, and support to improve the lives of people impacted by bleeding disorders.



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 2017				
	Notes	2017	2016	
Revenue				
Donations, Fundraising, & other similar revenue	1	1,129,351	1,136,520	
Fees, subscriptions, and other revenue from members	1	178,735	178,782	
Revenue from providing goods or services	1	46,000	20,000	
Interest, dividends, and other investment revenue	1	21,710	27,573	
Other Revenue	1	5,065	-	
Total Revenue		1,380,861	1,362,876	
Expenses				
Volunteer and employee related costs	2	432,459	432,425	
Costs related to providing goods or service	2	950,472	903,254	
Other Expenses	2	6,653	9,976	
Total Expenses		1,389,584	1,345,655	
Net Profit /(Loss)		(8,723)	17,220	

### Statement of Financial Position

Statement of Financial Posit	1011			
Haemophilia Foundation of New Zealar	nd Incorporated as at 30 June 20	)17		
		Notes	2017	2016
Assets				
Current Asse	ets			
	Bank accounts and cash	3	114,956	98,279
	Debtors and prepayments	3	121,808	161,300
	Investments	3	648,041	640,457
	Other current assets	3	29,037	26,446
	Total Current Asset	5	913,842	926,481
Non-Current Ass	set			
	Property, Plant and Equipment	6	2,032	2,128
	Total Non-Current Asset	5	2,032	2,128
	Total Asset	5	915,873	928,609
Liabilities				
	Current Liabilitie	s 4	141,739	145,751
	Total Liabilitie	S	141,739	145,751
Total Assets less Total Liabilities (Net Assets)			774,135	782,858
Accumulated Funds	Accumulated Surplus or (deficit)	5	774,135	782,858
	<b>Total Accumulated Fund</b>	S	774,135	782,858

### Statement of Cash Flows

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2017

	2017	2016
Cash Flows from Operating Activities		
Cash was received from:		
Donations, fundraising, and other similar receipts	1,232,791	1,108,999
Fees, subscriptions, and other receipts from members	173,694	173,583
Revenue from providing goods and services	59,373	25,199
Interest, dividends, and other investment receipts	21,820	28,117
Total	1,487,678	1,335,898
Cash was applied to:		
Payments to suppliers and employees	506,040	486,204
Costs related to providing goods and services	953,367	909,074
Net GST	2,701	6,969
Total	1,462,108	1,402,249
Net Cash Flows from Operating Activities	25,570	(66,351)
Cash Flows from Investing and Financing Activities		
Cash was provided from:		
Receipts from the sale of property, plant, or equipment	280	-
Total	280	-
Cash was applied to:		
Payments to acquire property, plant, and equipment	1,655	-
Payments to purchase investments	7,519	8,622
Total	9,173	8,622
Net Cash Flows from Investing and Financing Activities	(8,893)	(8,622)
Net Increase/(Decrease) in Cash	16,677	(73,971)
	98,279	173,250
Opening cash	,277	
Opening cash Closing cash	114,956	98,279
		98,279

Notes to the Performance Report						
Haemophilia Foundation of New Zealand Incorporated For the year ended 30 June 2017						
		2017	2016			
1. Analysis of Revenue	Donations, fundraising, and other similar revenue					
	Donations and Bequests	37,885	26,658			
	Fundraising - External (KF)	948,124	964,992			
	Fundraising - Internal	4,919	7,722			
	Grants	133,918	132,240			
	WFH Grants	4,506	4,908			
	Total Donations, fundraising, and similar revenue	1,129,351	1,136,520			
	Fees, subscriptions, and other revenue from members					
	Contracts	167,759	168,135			

### Notes to the Performance Report

	Total Fees, subscript
	Revenue from providing good
	Total Revenue from
	Interest, dividends, and other
	Total Interest, dividends, a
	Other revenue
2. Analysis of Expenses	Volunteer and employee relate
	Total Volunte
	Costs related to providing goo
	International Cor

Registrations	5,933	5,448
Member Fees	5,043	5,199
tions, and other revenue from members	178,735	178,782
ds or services		
Sustaining Patrons	46,000	20,000
m providing goods or services	46,000	20,000
r investment revenue		
Interest Income	21,710	27,573
and other investment revenue	21,710	27,573
Gain on Sale of Asset	65	-
Other Revenue	5,000	-
<b>Total Other Revenue</b>	5,065	-
ted costs		
Wages and Salaries	432,459	432,425
eer and employee related costs	432,459	432,425
ods or services		
ACC Levies	1,389	1,425
Accounting	2,950	2,569
Administration	1,522	1,352
Adult Programme	4,545	-
Advertising	371	343
Bank Fees	222	348
Children's Workshops	-	6,450
Cleaning	1,500	1,500
Consulting (including IT)	4,507	6,472
Defensive Driving	183	726
National Family Camp	37,055	-
Footwear Programme	8,210	6,775
Freight & Courier	10	-
Community Education (KF)	293,296	297,196
Fundraising Costs (KF)	323,129	327,285
General Expenses	2,996	1,791
HCV Support	-	142
Human Resources	405	746
Insurance Assets/Liability	5,772	5,768
onferences, Workshops, Meetings	19,563	16,509
International Programmes	-	4,879
Light, Power, Heating	1,905	1,870
Motor Vehicle Expenses	15,473	20,877
Region - Central	5,535	13,212
Group - Masters	258	504
Region - Midland	3,822	7,053
Region - Northern	9,164	9,970
Group - Piritoto	4,586	463

	BNZ Term Investment - Property	420,650	42
	BNZ Term Investment - 00002	34,175	(
	SBS Term Investment - No 10529944	81,132	
	Total Investments	648,041	64
	Total Analysis of Assets	913,842	92
	<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	117,027	1
	Money in Advance	712	
	Grants in Advance	24,000	
	Total Creditors and accrued expenses	141,739	14
	Total Analysis of Liabilities	141,739	14
5. Accumulated Funds	Accumulated Funds		
	Opening Balance	782,858	7
	Accumulated surplus or (deficit)	(8,723)	
	Closing Balance	774,135	78
	Total Accumulated Funds	774,135	78
6. Property, Plant, and Equipment	Office Equipment		
	Open Carrying Amount	2,128	
	Purchases	1,654	
	Sales/Disposals	(280)	
	Depreciation	1,470	
7. Grants in Advance	Closing Carrying Amount	2,032	
7. Grants III Auvance	Infinity Foundation		
	Waikato Community Trust	12,000	
	Four Winds		-
	Pub Charity	12,000	
	World Federation of Hemophilia	-	
	Total Grants in Advance	24,000	2
8. Lease Commitments	The Haemophilia Foundation of New Zealand has the following	lease commitr	ments
	• A premises leased from Craig Gordon Property Investments agreement expired in April 2017 and is now on a month to a 2017. The rent is \$29,945.66 excluding GST per annum.		
	• A photocopier leased from Ricoh. The lease term is for 58 m April 2015. The lease is \$322.35 excluding GST per month.		ncing
9. Related Party	Included within expenses are wages and honoraria paid to Richa Deon York (President). All transactions were carried out on norr		
10. Statement of Commitments	There are no commitments as at balance date. 30/06/2016 (Nil	)	
11. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/201		
12. Events After Balance Date	There were no events that have occurred after the balance date the impact on the performance report.	hat would have	e mat

Notes to the Performance Report	
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2,861 - 21,869 4,536 446	2,378 595 20,290
4,536	20,290
4,536	
	51/1
446	5,141
110	2,074
6,713	6,334
9,052	-
20,287	17,702
24,021	15,082
39,999	39,463
1,145	752
269	242
710	97
3,577	2,541
9,563	7,532
108	-
12,278	12,886
-	9,862
29,924	23,990
12,641	68
950,472	903,254
1,470	4,156
73	-
5,110	5,820
6,653	9,976
1,000	1,000
81,745	85,444
39,005	15,476
(6,793)	(3,641)
114,956	98,279
15,410	23,354
67,280	-
39,117	137,946
121,808	161,300
26,519	23,818
2,518	2,628
29,037	26,446
55,724	53,823
	20,287 24,021 39,999 1,145 269 710 3,577 9,563 108 12,278 29,924 12,641 950,472 73 5,110 6,653 5,110 6,653 5,110 6,653 114,956 (6,793) 114,956 15,410 67,280 39,117 121,808

3. Analysis of Assets

### Statement of Accounting Policies

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2017.

### **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

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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 with are stated inclusive of GST.

### Fixed Assets & Depreciation

The entity has the following classes of fixed assets:

Office Equipment - Straight Line method 18% -Diminishing Value method 40% 33.34% and - 67%

All fixed assets are recorded at cost less accumulated depreciation. Depreciation of the assets has been calculated at rates set by the Committee to allocate the cost of assets

over their estimated useful lives.

### Income Tax

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

### Bank Accounts and Cash

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

### Grants Income and Grants in Advance

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

### 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 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 7 to 19, which comprises the entity information, the statement of service performance, the statement of financial performance and statement of cash flows for the year ended 30 June 2017, the statement of financial position as at 30 June 2017, and the statement of accounting policies and other explanatory information.

### In our opinion:

a) The reported outcomes and outputs, and quantification of the outputs to the extent practicable, in the statement of service performance are suitable;

b) The accompanying performance report gives a true and fair view of the Society;

- The entity information for the year then ended;
- The service performance for the year then ended; and
- June 2017, and its financial performance, and cash flows for the year then ended

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

### **Basis for Opinion**

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

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

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The financial position of Haemophilia Foundation of New Zealand Incorporated as at 30





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

The National Council are responsible for:

- (a) Identifying outcomes and outputs, and quantifying the outputs to the extent practicable, that are relevant, reliable, comparable and understandable, to report in the statement of service performance;
- (b) The preparation and fair presentation of the performance report on behalf of the entity which comprises:
  - The entity information
  - The statement of service performance; and
  - The statement of financial performance, statement of financial position, statement of cash flows, statement of accounting policies and notes to the performance report

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

(c) Such internal control as the National Council determine is necessary to enable the preparation of the performance report that is free from material misstatement, whether due to fraud or error.

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

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

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

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

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

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- · Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management.
- may cause the Society to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the performance report, transactions and events in a manner that achieves fair presentation.
- 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.

xa Christchurch Limited

**Nexia Christchurch Limited** 29 August 2017 Christchurch

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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

including the disclosures, and whether the performance report represents the underlying

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,

# Statement of Service Performance

### Objective

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

### Outcomes

### National Family Camp

Sept/Oct 2016

"Investing in the future of HFNZ

demonstrates the forward thinking and

people-centred approach taken by our

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 40
- Staff 5
- Youth Mentors - 11
- Volunteers 5

"Such a wonderful Camp. Thank you so very much. I and my husband have learned

so much, but more importantly we have met and gotten to know people in the same boat. That has been most important and encouraging. The activities, warm welcome, gifts, friendly staff (especially the Youth Leaders) has been fantastic. Everyone has been so helpful and friendly. The staff have gone beyond the call of duty..."

directors"

"This Camp was again a very enjoyable time. It's always great to catch up with people who you've met in the past through Camps or PEP and re-connect and also to meet and help support new families. The educational sessions were all very informative. Fun and good mixture of activities for both children and adults. The Youth Leaders have done a fantastic job – Thank You. And thank you to all involved in making it all possible!!!"

### Advanced Leadership Training

February 2017

The HFNZ Advanced Leadership Training weekend is devoted to education and activities designed to develop the leadership skills and knowledge of HFNZ Youth members. This training follows on from the Youth Leadership Training. The participants are selected based on their attendance at the earlier event, and because they have continued to demonstrate their leadership abilities in support of HFNZ. Many of these young people have taken on committee roles at regional and national level, and have already participated in international events. This is an opportunity to really stretch these young people, to educate them in the history of HFNZ, and to ensure that the future leadership of the Foundation is in safe hands.

- Youth Attendees 13
- Staff 1
- Volunteers/Mentors 2

"The advanced leadership weekend was a unique and beneficial time. I developed conflict resolution skills, and a deeper understanding of how HFNZ interacts with local and overseas organisations. I would highly recommend to other youth, and would love to come again"

> "Invaluable opportunity, jam-packed with experiences/activities to develop the young people of HFNZ to step up and lead the foundation forward now and in the future.

### Laura Rutten, Advanced Leadership Training

Investing in the future of HFNZ demonstrates the forward thinking and

people-centred approach taken by our directors"

### National Youth Camp April 2017

Growing up is exciting, challenging, and often very confusing. When a bleeding disorder is added to the mix, the challenges of young-adulthood only increase. The Youth Camp, for 10-18 year-olds, uses a combination of education, fun, and peer and mentor support, to help young people move to the next stage of managing their condition. The focus is on being well-informed and better able to make decisions about their bleeding disorder treatment, education, work, life-style and relationships.

- Young people 31
- Staff 4
- Youth Mentors 16
- Volunteers 4

"The things I enjoyed doing at the camp were; kayaking where we all got wet and all got pushed in by the instructor. Another really cool thing we did was the building of our mascot 'the purple power ranger, and our egg didn't even break!!! Unlucky Green Team. I loved catching up with all of the other guys seeing how haemophilia, von Willebrands and Platelet Function Disorders affected them in a positive way and negative. It was interesting learning more about the disorders and how we can prevent injury and how we deal with it efficiently. It's a big reminder to all us young and older ones that are in their teens that these disorders won't ever go away and that we have to take it easy in some cases but these camps don't only teach us how to look after our body but that we can be independent young people"

"Tried to ask Rorie what he did at camp, he couldn't even talk on the way home in the car as he was so exhausted, so I gave up! Obviously a fantastic, busy, and fun camp! Thanks Colleen and all the team that works hard for these young people!"

### PEP

June 16 – 18, 2017

Raising a child or teenager with a genetic bleeding disorder brings challenges that impact on the entire family. The PEP programme promotes positive parenting with a focus on the unique problems faced by children with bleeding disorders. Parents are encouraged to consider, understand, and deal with the thoughts and feelings that come with having a child with a bleeding disorder, and how that impacts on their parenting. PEP is an opportunity to learn and to support each other through shared experiences.

- Attendees 8
- Staff 2
- Volunteers/facilitators 3

"The small group of passionate parents that I met who like me just want to be the best parents they can be for their kids whilst navigating their unique and ever changing journey with a bleeding disorder, is a group I will never forget. We shared, laughed, cried, ate lots and had fun together whilst bettering ourselves for our children's' sake. I learnt lots thanks to the facilitators and host parents and have already started implementing things at home - as I most importantly learnt not to TRY but to DO. Thanks to HFNZ for providing this opportunity and thanks to those who attended for the life changing weekend."

"I am always so impressed how parents of children with a bleeding disorders when given the opportunity to attend a PEP Program find a renewed excitement in how they parent their children. It was great meeting such amazing parents during the program. One of the quotes we talked about during PEP was "if you know better, do better" and that is what I saw happening. Thank you again I look forward to my next trip to NZ."

### Other Significant Programmes

Hepatitis C support for people with bleeding disorders

### and infusion acquired Hepatitis C

31 people with bleeding disorders had infusion-acquired hepatitis C as at June 2016. HFNZ negotiated a treatment package with ACC for all people with infusion acquired HCV to access new generation medications in October 2015. Ten have since cleared, eight are waiting for clearance, and another 15 are in treatment.

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

2857 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 2016 to June 30 2017; issues dealt with were as diverse as working with schools, hospitals, social welfare, and housing.

# World Haemophilia Day and Buddy Awards April 2017

Acknowledgement of people who make a positive difference in the lives of people with a bleeding disorder, making presentations at special events (held around World Haemophilia Day) four Awardees, in excess of 50 attendees at four regional activities



# **Appreciations**

HFNZ gratefully acknowledges all the organisations and individuals whose generous financial contributions have made it possible for us to continue to deliver services and support to people impacted by bleeding disorders. Without you there would be no us.

### Sustaining Patrons & Corporate Affiliates

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

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



### **Supporters**

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



### **Kiwifirst**

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



### Major Donors and Grants

Major Donoro and Granto	T di pose
Foundation North	Operating & Programme Costs
Eastern and Central Community Trust	Central Outreach Wages
Rata Foundation	Canterbury Outreach Services
COGS Waitakere	Auckland Outreach Wages
COGS Wellington	Central Outreach Wages
COGS Rotorua	Midland Outreach Wages
NZ Lotteries	Administration
John Ilot Trust	Parents Empowering Parents Workshop
Global Blood Disorder Foundation	Advanced Youth Leadership
The Southern Trust	Northern Outreach Wages
Youth Town Inc.	Youth Camp
Bay Trust	Outreach
Four Winds	Outreach
CSL Behring Pty Ltd.	Advanced Youth Leadership
Waikato Community Trust	Midland Outreach
Pub Charity	Northern Outreach
Pfizer PFE NZ	NACCHO
Pfizer PFE NZ	Youth Camp
Bayer NZ Ltd.	Resources
Quality Hotel Parnell	
Public Donations via Givealittle	

### Individual and general donations over \$100

Reginald Fuller
John Hunter
Ho Seong Kim
CM Whiting
Ross & Andrea Wightman-Mockford
In Memory of Hazel Miller
Sue McHardy
Freemason Wairau Lodge
Nick Lingard Foundation
In memory of P Hook
Donations from P Hook Funeral
Carl McKay
Lyn Steele
In Memory of Russell Thomas
R Merrifield
Violet McKelvie
Totara Trust
LA McCool
Myk & Marg Davis
Pam & John Lyons-Montgomery
IJ Wilson
Betty Johnsen
JH Horne
Beyond Reality Media
Barry Grant

### Purpose

# In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 1st 2016 and June 30<sup>th</sup> 2017:

- Peter Hook •
- Francis Marino ٠
- Glenis Elliott

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

# Life Members

Life member	Region	Year of Award	Passed Away
Miss Gray	Wellington	1972	1977
Mr William [Billy] R Stolz	Wellington	1974	
Margaret Roberts	Wellington	1976	1986
William [Bill] K Carnahan	Nelson	1983	1989
John Davy	Auckland	1988	2005
Tony Goodwin	Auckland	1988	
John Milne	Auckland	1988	2004
Dr Elizabeth Berry	Auckland	1993	
Sir John Staveley	Auckland	1993	2006
Alex Cain	Auckland	1994	1999
Graeme Kinred	Auckland	1994	1992
Pat Sheary	Auckland	1994	2005
Mike Mapperson	Auckland	1997	
Jock Church	Auckland	1997	1997
Stephanie Forde	Auckland	1998	
Lyn Steele	Christchurch	1999	
Tony Steele	Christchurch	1999	2010
Peta Hardley	Auckland	2000	
Barbara Sutherland	Wellington	2005	
Michael Carnahan	Nelson	2007	
Cheryl Carnahan	Nelson	2007	
Rex Temperton	Wellington	2007	
Steve Waring	Wellington	2007	
Anne Waring	Wellington	2008	
Graham Waring	Wellington	2008	
Mary Hancock	Auckland	2008	
Carl McKay	Christchurch	2009	

# Directory

### National Council

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

### Member Representative Groups

Northern Branch Chair:	Richard Scott
Midland Branch Chair:	Linda Mellsop-Anderson
Central Branch Chair:	Stephanie Coulman

# **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 whanau. The council comprises of the President, two Vice Presidents, a Treasurer, a representatives for each of the four regional Member Representative Groups (Northern, Midlands, Central and Southern), a representative from the Piritoto and Youth National Member Representative Groups, and one co-opted member.

There are 5.8 Full-time Equivalent Staff employed to provide support and education programmes. They are based in Auckland, Hamilton, Levin, and at the Christchurch Head office.

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

> PO Box 7647, Sydenham, Christchurch 8240 P: +64 3 371 7477 E: info@haemophilia.org.nz www.haemophilia.org.nz

Southern Branch Chair:	Theresa Stevens			
Piritoto Branch Chair:	Tuatahi Pene			
Youth Branch Chair:	Lauren Nyhan			
Staff				
National Office				
Chief Executive:	Richard Chambers			
Communications Manager:	Phil Constable			
Administrator:	Karen Melville			
Haemophilia Outreach Workers				
Northern Outreach Worker:	Nicky Hollings			
Midland Outreach Worker:	Joy Barrett			
Central Outreach Worker:	Lynne Campbell			
Southern Outreach Worker:	Josiane McGregor			

### **HFNZ** Affiliation

World Federation of Hemophiliawww.wfh.org



