


HFNZ Annual Report: 2020/21

01 JULY 2020 TO 30 JUNE 2021





*Improving
the lives of
people and whānau
affected by bleeding
disorders in Aotearoa New
Zealand by promoting
excellence in care,
advocacy, support,
and education.*

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, promoting connection, continuity, and growth, and making 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. Our vision is for a world without bleeding disorders.

This year, due to the ongoing impacts of Covid-19, we ran just one national event, the Adult Wellness Weekend, along with a small number of regional ones. None of these 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 of people and whānau affected by bleeding disorders in Aotearoa New Zealand by promoting excellence in care, advocacy, support, and education.

In the 2020/21 Annual Report it's clear that, despite outside events like the Covid-19 pandemic, HFNZ's close connection to our members, to their whānau, and to the wider community makes us a more effective organisation.

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 2020 to June 2021, I write with some certainty that virtually all annual reports across the country are not complete without a mention of COVID-19. As we continue to find ourselves amid a global pandemic, we have continued to adapt. The importance of connection and community have only become more important at this time. Physical distance cannot be replaced by meeting online and sustaining a sense of community has been a challenge for many organizations, no less the Haemophilia Foundation of New Zealand (HFNZ).

HFNZ was fortunate that one national event could take place in the past year, the national adult weekend held in Christchurch. Being in one room together and connecting was such a novelty that the volume in the room was ever-present, and the laughter was flowing. Some regional events were also held throughout the year, which was an amazing effort by local branches, particularly among pandemic uncertainty.

Two long-term trustees of the Alan Coster Educational Endowment Trust have now stepped down. Thank you to Mike Carnahan and once again to Mike Mapperson for your service to this trust, continuing to provide financial assistance for people with inherited bleeding disorders pursuing training and education.

With more time to be introspective, the HFNZ national council reviewed our mission, vision, and values and while a refresh was in order, the core of care, education, advocacy, and support are enduring activities of HFNZ. We have also refreshed our constitution to keep pace with current realities.

17 April was World Hemophilia Day. Across the globe our community took this day to share stories

of resilience during the COVID-19 pandemic. This year's theme was 'Adapting to change: sustaining care in a new world'. Many landmarks were lit up red to celebrate this. On a blustery but clear Wellington evening the Michael Fowler Centre lit up red for all locals to see. This was echoed around the country. While not the same as getting together face-to-face, a nod to our community, nonetheless.

I concluded my term as a board director of the World Federation of Hemophilia (WFH) in October 2020 after just over ten years working with this amazing board for a cause naturally linked to the mission of HFNZ. Our long association with the WFH will continue, and I will continue to support this organization as I can. In my time on the board, WFH achieved some notable results for people all over the world affected by inherited bleeding disorders and I have no doubt WFH will continue to strive for treatment for all.

As always, I would like to thank HFNZ staff for supporting our community, and thank all volunteers, including the national council, for remaining motivated during what were sometimes the most unmotivating of times. I would also like to thank Rosemary Clements for being such an engaged chair of the National Haemophilia Management group (NHMG). We appreciate your service on this group.

Appreciation must also be paid to all the donors, benefactors, and trusts who contributed to our mission with special mention of our enduring relationship with Kiwifirst, our key fundraiser. Thank you to everyone who contributed. Our mission is not possible without your support.



Sue Ellis: CEO Report

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

As I sit down to write this report, the country is again split into different alert levels as we continue to fight Covid-19 and now its delta variant. After a second year of this pandemic, more lockdowns, queuing for groceries and staying in our bubbles it all feels like déjà vu. However, we have continued to support our members throughout the changes and uncertainties, keeping in contact via phone calls, emails, Face Book and more recently zooms.

At the end of 2020 we sadly said goodbye to our Northern and Southern Outreach Workers. Successful recruitment in early 2021 to replace them and our Midland Outreach Worker meant we once again had a full contingence of staff to support members. A huge welcome to Rosie Maguire in Christchurch, Laura-Lee Perawiti in Hamilton and Darian Smith in Auckland. They have quickly got into their roles and understanding of all things bleeding disorders, thanks to support from Lynne Campbell and ongoing training from our Haemophilia Nurses.

Ehara taku toa, I te toa takitahi, engari,
he toa takitini – Success is not the work of one, but the work of many.

Webinars and zooms are the new normal for how we now work. The staff and I 'meet' each week or two weekly via zoom to keep connected and continue with our events planning. We have also begun webinars to provide educational and informational presentations to members. Our first presentation was provided by physiotherapist Abhi TikkiSETTY which was very well attended and enjoyed. We have more webinars planned throughout the year. I have also attended WFH webinars as well as the Global Haemophilia Advocacy Leadership group webinar.

A small group has been formed to develop an increased focus for people with von Willebrand Disorder and rare bleeding disorders. A survey undertaken in June asked are we meeting the needs for those with VWD/rare bleeding disorders and what else can we do? Whilst a

relatively low response rate, people noted HFNZ could do more, have events specific for those with VWD/ rare bleeding disorders, and VWD resources available to educate others. Further work will be undertaken to follow-up on these suggestions. It was pleasing to see WFH's published international VWD clinical guidelines out earlier this year.

Our Youth Camp, originally for April 2020 but put on hold due to Covid-19, was eventually held in July this year in Kaiapoi, North Canterbury. Despite lower number of registrations as expected, it was a great success with campers extending their skills and knowledge through leadership training, workshops and outside activities under the theme of Seven Summits from the movie Bombardier Blood.

This gave the youth opportunities to try rock climbing, and a visit the museum to see how mountaineers dress, climb and work.

Once again, we have received wonderful support from all those amazing people who have sent us generous donations. A huge thank you too to Kiwifirst whose teams have worked through the lockdowns to ensure our funding continues. I am also grateful to the pharmaceutical industry who have continued to support us with grants allowing us to provide the important events to members.

Despite our world of ongoing uncertainty and living and working in another way, we have adapted to this world to continue to provide the needed support for our members. On the horizon is a November weekend workshop in Dunedin for our women members. Registrations are showing huge support for this exciting event. We are also in the planning process to hold our national family camp in April next year, at the Ngaruawahia Christian Youth Camp. Another event in the pipeline is a youth 'get together' in early December 2021.

Kia Kaha, Kia Toa, Kia Manawanui Be Strong, Be Brave, Be Patient.

Sue Ellis
Chief Executive



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

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

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. The 2020/21 year was significantly impacted by Covid-19, which affected groups' ability to meet and to hold events.

Central

By Tracy Nyhan

The focus this year for World Haemophilia Day was adapting to change and the Central Region have certainly done that. Thanks go to the Central committee who despite the challenging times have managed to get our Region together on several occasions. Not sure if Camp would go ahead or not in Late August Camp was held at Level 2 at El Rancho in Waikanae. Being able to explore and experience the freedom of the outdoors was good for the spirits as we emerged from lockdowns. Lots of energy was expended in the indoor archery and 1 or 2 adults showed how age and experience can combat youth!! We were very privileged in November with the Bombardier Blood private screening then a great family get together in Palmerston North for xmas attended by over 40 members and families to share stories and provide the support to each other that is strong in the Central Region.

Blair finally managed to get the Men's Fishing trip underway which has been 2 years in the pipeline. Reports indicated that this was a great success where friendships and support networks were made and I am sure the tall stories will do the rounds over the years. We celebrated World Haemophilia Day at Murrayfields North of Levin with over 20 members joining for a lunch to continue to build the support networks and friendships that we call upon when times are tough and we need that shoulder to lean on.

The committee will be lighter this year as Ross and Lorraine Gordon who have supported the Committee for many years take a well deserved rest. We thank them for the years of service and support they have provided many families over the years. We see changing of the guard in the Regional Delegate role as Ana has stepped away and thank her for her service.

The next 12 months will be exciting as we start to plan how we will stay connected. Our AGM is to be held via Zoom for the first time as we adapt to Change.



Central fishing trip 2021

Northern

By Greg Jamieson

This is the second year in a row that it's been quiet for the Northern region.

In between lockdowns, we managed to host our Christmas party at the Auckland Zoo. It was a good turnout and nice to reconnect after a tough 2020. We had lunch together, the sun was shining and I'm sure the animals appreciated the company after a long period of lockdown.

We had organised a Rock climbing event for September but... as happened last year with our Movie event we went into lockdown so this has had to be postponed. All going well we will aim to host this late Oct/early Nov.

Planning is underway for a Christmas or Summer catch-up. Covid has had a huge impact on a number of businesses. We were in negotiations with Rainbows End over hosting our party there this year. Unfortunately due to the massive financial impact Covid has had they are unable to offer us the rates we have had in the past which makes this venue not viable so we are looking at other options to get our region together.

Northern has also had a change of Outreach worker. Amber has moved to take on a new challenge and Darian has joined us. Our next event will be a great way to meet Darian if you haven't already. Darian is keen to get involved and will be a great addition to our Northern team so please make him welcome.



Midland

By Tineke Maoate

Another brief Midland report for another year. Sadly, as Covid has decided to stick around, there hasn't been much happening in Midland.

We were able to fit a bowling night in, which was a lot of fun. Some of our Midland youth attended the youth camp in Christchurch. It was really great to see all the youth get back together and catch up with each other. Seeing some of them as leaders, after once being participants, was a highlight. Midland won't be holding a Christmas event this year with all the uncertainty, but are holding out hope for a summer event in the New Year.

We welcomed new Outreach Worker Laura-Lee Perawiti to the Midland region in 2021. She has fitted in perfectly and we have really enjoyed having her as part of our bleeding disorder family. It's always nice to hear from her and look forward to continuing working with her this coming year.

Everyone take care and stay safe for a Merry Xmas to everyone.



Midland bowling event 2021

Southern

By James Poff

I am pleased to advise that the Southern MRG has finally held the belated AGM.

We now have a full committee and as a result planning is underway for the coming year.

So far, we have planned a Christmas function, and there was a strong commitment to support the continuation of the popular monthly walks.

More to come as the re-invigorated Southern MRG puts their collective heads together!



Southern walking group 2021

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.

Adult Wellness Weekend

By Ross Paterson

The first national event on the calendar for HFNZ since March, was held in Christchurch over the weekend of 6 - 8 November. I think that for some of us, both staff and attendees, there was a degree of trepidation in the months leading up to the event about whether Covid 19 would intervene and force a postponement. Fortunately, this was not the case and we able to get together and enjoy one another's company.

On the Friday evening after a briefing and welcome, we headed out to a Vietnamese restaurant. We enjoyed a multi course meal but the restaurant had grossly underestimated the time it would take to serve a large group when the restaurant was already busy. This meant a rearrangement of the programme, but the meal itself was both delicious and substantial.

Saturday morning commenced with an hour-long session entitled Personal Journeys, in which Central Outreach Worker Lynne Campbell facilitated a five-member panel in responding to five pre-determined questions about their own personal journey with their particular Bleeding disorder.

Dr Sharon Green, Clinical Psychologist then spoke to the theme of "The impact of bleeding disorders over a lifetime". Sharon's presentation adopted a holistic view of these impacts and then viewed them through the lens of the various life stages of individuals. She was able to outline the psychosocial effects that can affect all of us, and ensured that we understood the differences between the normal emotional responses we can all experience, and clinical depression and other psychological problems. Dr Green encouraged all of us to express our emotions fully, offered strategies to cope with pressure, and suggested where to seek help if we need it.

The final morning session involved two workshops. Lynne Campbell facilitated a Self-Advocacy workshop for Men, while Amber Maihi ran a session entitled The HFNZ Café.

In her session, Lynne lead a conversation for men about how to advocate for themselves.

Participants were separated into groups of four or five. Most participants were men with a bleeding disorder, while others were the partner of a woman with a bleeding disorder.

Participants were encouraged to share their experiences and note their thoughts in relation to: What makes self-advocacy difficult?



Then, after thinking about when self-advocacy worked for them, they were asked to identify what skills they used to advocate for themselves, and how barriers or difficulties could be overcome.

Lynne would like to thank all participants in this workshop for so generously and candidly sharing aspects of their personal circumstances.

Amber's HFNZ Café session ran concurrently with Lynne's. In this session members were seated at one of four tables. They were given seven minutes at each table to answer and give feedback to a question relating to self-advocacy. At the end of each round they would each move to a new table indicated by a colour sticker in front of them. This way the groups were mixed up and new perspectives were heard.

The questions:

- Please describe a moment when self-advocacy worked well for you.
- What resources/ Skills do you use to advocate successfully for yourself?
- What has made self-advocacy difficult for you?
- How have you overcome difficulties with self-advocacy?

A recurring theme that came out of all four stations was the importance of education about bleeding disorders, rights to care and treatment, and what support is available to the person and their family. Overall the session worked well and all of the information gathered from participants will be used to help enhance self-advocacy.

The next educational session, an interactive one, was provided by Dr Julia Phillips. Dr Phillips stepped in at late notice after the sad passing of the late Dr Mark Smith, who was originally going to undertake this presentation. Dr Phillips provided us with an overview of how haemophilia works. She described the effects of long-acting treatments, and the efficacy of Hemlibra and its potential to impact on a wider population of our HFNZ community. Dr Christine Olsson from Roche was able to contribute to this conversation. Finally, Dr Phillips discussed the mechanics of gene therapy. Originally, the presentation had intended to include coverage of Von Willebrand's disease but a considerable number of questions curtailed the workshop before this could be done.

The afternoon session consisted of two outings one of which encompassed a tram ride through the CBD. We were taken around and through the Christchurch city centre, looking at what was new, and remembering what was no longer there after the Christchurch earthquakes. Following the tram ride, some people chose to have a short walk in the botanic gardens, while others had a look around town, and the remainder returned to the hotel for a rest.

The second outing was a trip on the gondola above the Heathcote valley in the Port Hills. This provided for a wee adrenalin rush on the ride and some stunning views, especially from the top where to the north we could look out over Christchurch and the estuary, as

well as over Lyttleton Harbour to the south. A café at the top provided sanctuary from the wind and refreshments while savouring the views. A time tunnel provided a three-dimensional experience, which sadly was culturally inappropriate in its depiction of the history of Banks Peninsula, and there were no staff to guide people on to the individual carriages. However, in the true HFNZ spirit we all got on and derived some fun from the experience.

A delicious buffet dinner was provided back at the Hotel during which a local singer, Mattie Smith provided background music. A quiz rounded the evening off with a tight finish seeing the winning team sneaking across the finish line by half a point. A few hardy types then watched a tense game of rugby in which the All Blacks on this occasion came second.

The next morning Karl Archibald introduced us to the Bombardier Blood documentary movie, in which Chris Bombardier, a U.S. citizen, demonstrated that with modern treatment and the correct preparation, it was possible to undertake some extreme physical challenges. The documentary revealed the impact that

severe haemophilia had on his life and the worry his sporting activities caused to his mother and partner. Chris explained his fight against acceptance of his bleeding condition in his childhood and youth. However, his gradual understanding of the need to look after himself and of the best options for exploring physical challenges led him ultimately to conquer the highest peaks on each of the seven continents of the world. Chris Bombardier also used his documentary to expose the plight of third world haemophiliacs, citing Nepal as an example, whose access to treatment is extremely limited.

The HFNZ Annual General Meeting concluded the weekend's activities. Notably the Elizabeth Berry Exercise Cup was presented to Rorie Poff. Rorie's dogged determination on the Port Hills walks impressed all in attendance and he was one of the more regular attendees. Rorie is now pursuing another sporting interest – the field events in athletics and we wish him every success. In addition, Torin Smith accepted the Sir John Staveley Health Professional Award, posthumously awarded to his late father, Dr Mark Smith, for his outstanding commitment to supporting and advocating for people with bleeding disorders.







Scenes from Adult Weekend 2020



HFNZ Financial Report

For the 12 months ending 30 June 2021

Tēnā koutou

The auditor's report of our financial accounts for the year ended 30 June 2021 confirms that the Financial report is in order and provides a true and fair view of the position of the Foundation.

I'm happy to report that the Foundation remains in a healthy financial position with an overall surplus for the year ended 30 June 2021 of \$273,157. This surplus is primarily due to another year of significant donations and bequests (just over \$222,000). We also adjusted our expectations of Kiwifirst's fundraising abilities as the COVID-19 restrictions played out, expecting a 30%

drop. Kiwifirst continued to work hard throughout the year and as such only realised a 12% drop in usual expected income.

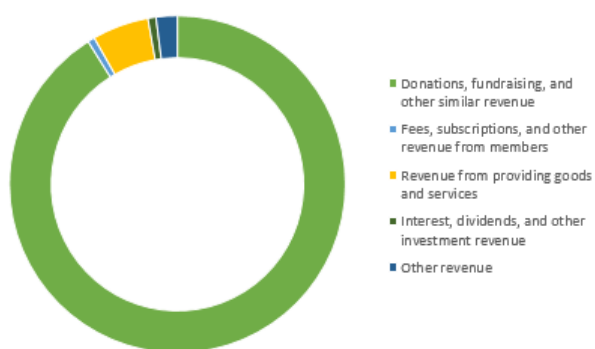
As a result of this strong performance, our total accumulated funds have increased to \$1,482,167.

As always, the Foundation is here to meet your needs. If there is anything you'd like included in our programme of work, or if you'd like to get involved, please feel free to contact me or the office.

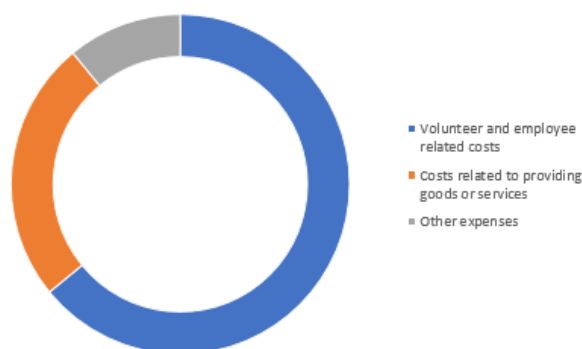
Nga manaakitanga,

Hemi Waretini

Revenue



Expenses



Statement of Financial Performance

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2021

	Notes	2021	2020
Revenue			
Donations, Fundraising, & other similar revenue	1	1,172,795	1,367,606
Fees, subscriptions, and other revenue from members	1	8,628	13,578
Revenue from providing goods or services	1	69,934	79,934
Interest, dividends, and other investment revenue	1	9,997	21,231
Other Revenue	1	26,232	46,378
Total Revenue		1,287,587	1,528,727
Expenses			
Volunteer and employee related costs	2	310,126	392,305
Costs related to providing goods or service	2	697,150	933,027
Other Expenses	2	7,153	9,313
Total Expenses		1,014,430	1,334,645
Surplus /(Deficit) for the year		273,157	194,082

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 2021

	Notes	2021	2020	
Assets				
Current Assets				
Bank accounts and cash	3	1,306,398	525,395	
Debtors and prepayments	3	44,413	44,177	
Investments	3	164,525	672,202	
Other current assets	3	26,867	19,982	
Total Current Assets		1,542,204	1,261,756	
Non-Current Assets				
Property, Plant and Equipment	6	12,278	2,466	
Total Non-Current Assets		12,278	2,466	
Total Assets		1,554,481	1,264,222	
Liabilities				
Current Liabilities				
Creditors and accrued expenses	4	54,501	39,562	
Unused donations and grants with conditions	4	14,340	14,975	
Other current liabilities	4	3,474	676	
Total Current Liabilities		72,315	55,212	
Total Liabilities		72,315	55,212	
Total Assets less Total Liabilities (Net Assets)		1,482,167	1,209,010	
Accumulated Funds	Accumulated Surplus or (deficit)	5	1,482,167	1,209,010
Total Accumulated Funds		1,482,167	1,209,010	

Statement of Cash Flows

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2021

	2021	2020
Cash Flows from Operating Activities		
<i>Cash was received from:</i>		
Donations, fundraising, and other similar receipts	1,166,740	1,362,382
Fees, subscriptions, and other receipts from members	23,619	20,354
Receipts from providing goods and services	86,464	144,379
Interest, dividends, and other investment receipts	11,050	20,322
Net GST	-	10,221
Total	1,287,873	1,557,658
<i>Cash was applied to:</i>		
Payments to suppliers and employees	308,588	392,161
Costs related to providing goods and services	698,020	942,340
Net GST	7,938	-
Total	1,014,546	1,334,501
Net Cash Flows from Operating Activities	273,326	223,157

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
Receipts from the sale of investments	507,677		-
Total	507,677		123
<i>Cash was applied to:</i>			
Payments to purchase investments	-		7,612
Total	-		7,612
Net Cash Flows from Investing and Financing Activities	507,677		(7,489)
Net Increase/(Decrease) in Cash	781,003		215,668
Opening cash	525,395		309,051
Closing cash	1,306,398		524,719
This is represented by			
Bank accounts and cash	1,306,398		524,719

Notes to the Performance Report

Haemophilia Foundation of New Zealand Incorporated For the year ended 30 June 2021

		2021	2020
1. Analysis of Revenue	Donations, fundraising, and other similar revenue		
	Donations and Bequests	222,055	360,498
	Fundraising - External (KF)	878,387	946,111
	Fundraising - Internal	415	-
	Grants	71,939	46,973
	WFH Grants	-	14,024
	Total Donations, fundraising, and similar revenue	1,172,795	1,367,606
	Fees, subscriptions, and other revenue from members		
	Registrations	4,129	10,169
	Membership Fees	4,499	3,409
	Total Fees, subscriptions, and other revenue from members	8,628	13,578
	Revenue from providing goods or services		
	Contracts	69,934	69,934
	Sustaining Patrons	-	10,000
	Total Revenue from providing goods or services	69,934	79,934
	Interest, dividends, and other investment revenue		
	Interest Income	9,997	21,231
	Total Interest, dividends, and other investment revenue	9,997	21,231
	Other revenue		
	Wage Subsidy	26,232	46,378
	Total Other Revenue	26,232	46,378
2. Analysis of Expenses	Volunteer and employee related costs		
	WFH Honorarium	-	10,105
	Wages and Salaries	310,126	382,200
	Total Volunteer and employee related costs	310,126	392,305

Notes to the Performance Report

Costs related to providing goods or services		
60th Anniversary	52	102,140
ACC Levies	1,178	711
Accounting	3,170	3,344
Administration	81	4,179
Adult Programme	44,066	-
Bank Fees	225	1,866
Central	7,427	1,566
Community Education (KF)	258,065	289,854
Consulting (including IT)	7,285	5,710
Defensive Driving	547	261
Footwear Programme	4,874	4,813
Fundraising Costs (KF)	284,165	319,289
General Expenses	1,157	2,355
Human Resources	5,434	-
Inhibitors Workshop	-	19,973
Insurance Assets/Liability	5,582	8,402
International Programmes (Twinning)	-	13,901
International Meetings/Conferences	-	6,252
Loss on Sale of Asset	-	123
Masters	282	241
Meetings	180	-
Midland	1,075	4,663
National Council	12,235	14,232
Needs Grants	570	1,018
Northern	909	1,970
Office Expenses	8,122	10,540
Outreach	10,248	19,387
Piritoto	350	3,891
Printing, Stationery, Postage	12,331	12,890
Professional Development and Team Meetings	10,366	48,334
Rent	1,805	1,805
Repairs and Maintenance	-	49
Resources	507	-
Southern	2,630	4,887
Special Programmes	52	459
Subscriptions/Memberships	876	1,764
Swimming/Fitness	5,773	6,398
Telephone & Internet	5,504	8,426
Youth	-	1,334
Youth Camp	27	-
Youth Leadership		5,997
Total costs related to providing goods or services	697,150	933,027
Other Expenses		
Depreciation	1,323	2,459
Interest Expense	530	1,554
Audit	5,300	5,300

Notes to the Performance Report

		Total Other Expenses	7,153	9,313
3. Analysis of Assets	Bank accounts and cash			
	BNZ Non Profit Cheque Account	465,664	49,272	
	Legacy Account	445,494	-	
	On Call Account	95,156	475,087	
	Reserve Account	300,048	-	
	SBS Savings Account	-	1,000	
	Twinning	36	36	
	Total Bank accounts and cash	1,306,398	525,395	
	Debtors and prepayments			
	Prepayments	12,795	3,093	
	Trade Debtors	31,619	41,084	
	Total Debtors and prepayments	44,413	44,177	
	Other current assets			
	GST	26,800	18,862	
	Interest Receivable	68	1,121	
	Total Other current assets	26,867	19,982	
	Investments			
	BNZ Term Investment - 00003	62,627	61,744	
	BNZ Term Investment - 00004	63,152	62,079	
	BNZ Term Investment - Property	-	420,650	
	BNZ Term Investment - 00002	38,745	38,282	
	SBS Term Investment - No 10529944	-	89,446	
	Total Investments	164,525	672,202	
	Total Analysis of Assets	1,542,204	1,261,756	
	<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	53,866	31,275	
	Money in Advance	635	8,287	
	Total Creditors and accrued expenses	54,501	39,562	
	Unused donations and grants with conditions			
	Grants in Advance	14,340	14,975	
	Total Unused donations and grants with conditions	14,340	14,975	
	Other current liabilities			
	BNZ Visas	3,474	676	
	Total Other current liabilities	3,474	676	
	Total Analysis of Liabilities	72,315	55,212	
5. Accumulated Funds	Accumulated Funds			
	Opening Balance	1,209,010	1,014,928	
	Accumulated surplus or (deficit)	273,157	194,082	
	Closing Balance	1,482,167	1,209,010	
	Total Accumulated Funds	1,482,167	1,209,010	
6. Property, Plant, and Equipment	Office Equipment			
	Open Carrying Amount	2,466	5,047	
	Purchases	11,134	-	

Notes to the Performance Report

	Sales/Disposals	-	(123)
	Depreciation	1,323	2,458
	Closing Carrying Amount	12,277	2,466
7. Grant Income	Grants Received in the Year		
	CSL Behring Australia	14,975	14,975
	NZ Lotteries	12,000	-
	Pub Charity	6,870	-
	Rata Foundation	21,800	-
	Roche Products	10,000	27,000
	Sanofi-Averntis Australia	-	9,973
	Shire New Zealand	-	10,000
	Takeda Pharmaceuticals Australia	500	-
	Total Grants Received in the Year	66,145	61,948
	Less: Unspent Grant Income	(14,340)	(14,975)
	Less: Refund of Grant Not Used	(2,841)	-
	Add: Previous Grant Accrual	22,975	-
	Total Grants Income	71,939	46,973
8. Lease Commitments	The Haemophilia Foundation of New Zealand has the following lease commitments:		
	<ul style="list-style-type: none"> A storage unit is being leased from Lock and Leave. The lease term is on a month to month basis as of June 5 2018. The lease is \$173.00 excluding GST per month. 		
9. Related Party	Description of related party relationship	Description of transaction	
	Catronia Gordon - Lava Law	Legal Services - \$530 expenditure	
	Stephen Waring - Director of Kiwifirst	Major fundraiser of the Foundation - \$518,023 expenditure to Kiwifirst, \$880,567 received from Kiwifirst and \$24,292 receivable due from Kiwifirst	
10. Statement of Commitments	There are no commitments as at balance date. 30/06/2020 (Nil)		
11. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/2020 (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.		
	In August 2021 the Government imposed a nation-wide lockdown at Covid Level 4. At the time of preparing this report the full impact of the lockdown is indeterminate, but it is not expected to have a material financial impact on the organisation.		
13. Ability to Continue Operating	The entity will continue to operate for the foreseeable future.		

Statement of Accounting Policies

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2021.

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

All fixed assets are recorded at cost less accumulated depreciation. Only assets costing \$1,000 or more are capitalised, those less than this are expensed. Depreciation of fixed assets prior to 1 July 2020 has been calculated at the maximum rates permitted by the Income Tax Act. Fixed assets purchased after this have been depreciated on a straight line basis as follows:

- Computer equipment - over 3 years
- All other assets - over 10 years

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.

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

Adult Wellness Weekend

November 06 - 08, 2020

The Adult Weekend is an opportunity for adults with bleeding disorders to openly discuss their experiences, challenges, and concerns about living and aging with a bleeding disorder. The focus of the weekend is to increase knowledge about bleeding disorders, about upcoming trends and treatments, about aging with a bleeding disorder, and about the provision of health care in New Zealand, as well as learning about HFNZ and its activities.

56 people attended this event.

“Another awesome HFNZ weekend; first and foremost seeing/socialising with my HFNZ whānau. The laughs, the korero. I don’t know how (thank you to the Foundation) but at every education session I learn more.

Final thank you to the Foundation for another great weekend, and for keeping us together.

Ka pai!”

“Being with other haemophiliac whānau means we can support each other, connect, and talk openly and

comfortably in a safe and loving environment. Our health is our wealth.

With the daily pressures of life, and dealing with health needs, it is hard to stay connected to HFNZ. The Adult Weekend means that we can re-connect and learn together.”

Other Significant Programmes

Outreach Support Services for people with bleeding disorders and their families

1174 contacts were made with people with bleeding disorders by the Outreach team. Due to reduced staffing levels, changed recording methods, and the impact of Covid-19, this is lower than previous years. More than 50% of people with bleeding disorders have been directly supported by the outreach service in the year July 1 2020 to June 30 2021; issues dealt with included working with schools, hospitals, social welfare, and housing. 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 again 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.

PRIVATE & CONFIDENTIAL

13 October 2021

The National Council
Haemophilia Foundation of New Zealand
PO Box 7467
Christchurch 8240**AUDIT OF THE FINANCIAL STATEMENT FOR THE YEAR ENDED 30 JUNE 2021**

We have completed the audit of the performance report of Haemophilia Foundation of New Zealand for the year ended 30 June 2021. We issued our Audit Report on 13 October 2020.

As required by the International Standards on Auditing (New Zealand), we report specific matters to you as presented below.

Audit Purpose

The primary aim of our audit is to form an opinion as to whether the financial statement fairly reflect, in all material respects, the results of your organisation's activities for the reporting period and its financial position at balance date. Our Audit Report expresses this opinion.

Our examination is carried out on a test basis and is designed primarily to enable us to form an opinion on the financial statement. Our audit procedures, therefore, cannot be relied upon to disclose errors or irregularities that are not material to the financial statement taken as a whole and may not include all possible comments and recommendations, which a more extensive internal controls review might identify.

In forming our audit opinion, we conduct detailed tests of selected transactions and review the key controls in place to ensure your accounting systems and internal controls are operating effectively. As a service to ensure you receive maximum benefit from our audit, we note our evaluation of your systems and highlight areas of possible weakness or where we believe improvements can be made. Our motive is to offer objective and constructive advice so that the accounting processes and related internal control issues can be improved in the future.

The organisation's accounting systems, internal controls and financial reporting process remain the responsibility of the Board. The audit of the financial statement does not relieve the Board of these responsibilities.

Dealings with the Management

We have had no disagreements, nor any difficulties, in dealing with Management during our audit.

Fraud Considerations

We have not identified any instances of fraud involving senior management, or any other frauds that caused a material misstatement of the financial statement.

Modifications to our Audit Report

There were no modifications to our standard Audit Report.

Audit Adjustments

There were Audit adjustments for the year under review. The material adjustments were passed by management and the remaining unadjusted journals were immaterial both individually and in aggregate.

Qualitative Aspects of Your Organisation's Financial Reporting

There had been no changes in the accounting policies during the year.

There had been no significant estimates made to the performance report.

We have not noted any significant risks or exposures that are required to be separately disclosed in the performance report.

Accounting Systems and Internal Controls**Credit Card Transactions – lack of authorisation**

From our review of a sample of credit card transactions, we noted that not all months were approved by Sue.

We remind you that it is a recommendation to apply a "one-up" principle of approving credit card expenditure for all months.

Credit Card Transactions – lack of supporting documentation

From our review of a sample of credit card transaction, invoices and supporting documents were not always attached to the credit card statements to support the payments.

Appropriate supporting documentation is important for tax reasons (including claiming GST) and to provide evidence that it was valid expenditure.

We suggest that all relevant supporting documents be attached to your credit card statements.

Journal Policy

We have noted that you do not have a formalised procedure for the process of journal entries. It is understood to be good practice to have a documented policy regarding the use, authorisation, documentation requirements and control over journal entries, even if it is the Service Provider that completes them.

Declaration of Interests

It is recommended that either an interests register for Board members to record any activities that might cause a conflict of interest or having a standing agenda item for declaration of conflicts of interest is good practice. We noted neither of these were in use by HFNZ and recommend that one of these be used.

Annual Leave Balance

It was noted that 2 employees leave balances are over 20 days. In order to keep the balance of payables down for HFNZ it is important that staff don't accrue more than 20 days leave. We recommend that the provision for holiday pay balance is monitored regularly throughout the year and staff are encouraged to take leave when it gets too high to allow them to take a break from all of their hard work.

These points arose during our audit which is designed primarily to enable us to form an opinion on the financial statements taken as a whole. Our report cannot, therefore, be expected to include all possible comments and recommendations which a more extensive special examination might indicate.

Yours sincerely

Nexia Audit Christchurch.

Nexia Audit Christchurch

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.

Supporters

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



Kiwifirst

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



Major Donors and Grants	Purpose
Rata Foundation	Adult Weekend
NZ Lotteries	
CSL Behring Pty Ltd	Womens Weekend
Roche Products	Adult Weekend
CSL Behring Educational Grant	Website
Takeda	Webinars
Pub Charity	Central Camp

Bequests

Verona McGregor Estate
Estate of F Davies
Trevor Newman Estate

Individual and general donations over \$100

Ho Seong Kim
John Hunter
Philip Salmon
P McNamara
Cara Stiven
Memorial Giving - Shella Lovell
St Georges
S Pickles
Nick Lingard Foundation
Claire Rutherford
P McAleer
B Hodgson
M & D Bassett
B Holmes
Freemasons Lodge - Manawatu Kilwinning
C & M Louisson
Buffalo Lodge
Dulcie Taylor
Dr Mark Smith Memorial
Angus MacDonald Memorial

In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 1 2020 and June 30 2021:

- Dr Mark Smith
- Dr John Carter
- Angus MacDonald

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

Member Representative Groups

Northern Branch Chair:	No Chair
Midland Branch Chair:	Tineke Maoate
Central Branch Chair:	Tracy Nyhan

Southern Branch Chair:	James Poff
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:	Darian Smith
Midland Outreach Worker:	Laura-Lee Perawiti
Central Outreach Worker:	Lynne Campbell
Southern Outreach Worker:	Rosie Maguire

HFNZ Affiliation

World Federation of Hemophilia	www.wfh.org
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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 affected by bleeding disorders.

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

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

HFNZ's main sources of funding are donations & grants. Public donations are sourced via telemarketing, direct, and give-a-little. There are also some member fundraising activities.

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