


HFNZ Annual Report: 2021/22

01 JULY 2021 TO 30 JUNE 2022





*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

Established in 1958 to connect and support people with Haemophilia across New Zealand, the Haemophilia Foundation of New Zealand Inc. (HFNZ) continues working for all those living with Haemophilia A & B, von Willebrand's disorder, platelet disorders, and many other rare, chronic, inherited bleeding conditions more than 60 years later.

At HFNZ, we understand that we are 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 was affected by the ongoing Covid-19 pandemic. However, we were still able to run two national events, the Teen and Youth Camp and the Women's Wellness Weekend, along with a small number of regional events. 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 2021/22 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.

Contents

02. President's Message	<i>Deon York looks at HFNZ's role in the larger bleeding disorder community.</i>
03. CEO's Report	<i>Sue Ellis reports on HFNZ's progress towards its strategic goals during the 2021/22 year.</i>
05. Region & Group Reports	<i>Find out what our regional and special-interest groups have been doing this year.</i>
07. Events & Workshops	<i>Learn about the educational events and workshops that took place in the 2021/22 year.</i>
09. Finance Report	<i>HFNZ's financial report and audited accounts for the 2021/22 year.</i>
16. Service Performance	<i>A breakdown of what HFNZ did through the year, and how that has helped our members.</i>
21. Appreciations	<i>Thanking those who have made significant financial contributions to HFNZ in the 2021/22 year.</i>
23. In Memoriam	<i>Remembering members who have passed.</i>
23. Life members	<i>Recognising those who have been awarded life-membership of HFNZ.</i>
24. Directory	<i>HFNZ office holders and staff members in 2021/22.</i>
24. Entity Information	<i>Information about HFNZ's operations, purpose, and charitable status.</i>



Deon York: President's Message

This report covers the period 1 July 2021 to 30 June 2022. This past year continued to be foreshadowed by uncertainty. It has continued to be a focus of the board that, despite the challenges, the Haemophilia Foundation of New Zealand (HFNZ) keep creating opportunities for people to connect. We were pleased to see two national events take place during this time.

The national teen and youth camp was held in Christchurch in July 2021. It was wonderful to gather young people together for this long overdue event. While the weather down south was chilly, it was lovely to hear about the fun and learning that occurred. I heard that the museum visit and the Galileo exhibition was a crowd favourite. It was also great to see the impetus getting together has given the National Youth Committee.

The women's weekend took place in Dunedin in June 2022. This important event was well attended and was a welcome opportunity to focus attention on the support needs of this group, which has often historically been overlooked around the world. Luckily the foundation was ahead of its time in ensuring such events went ahead. This event had been postponed several times, so it was fantastic to see it go ahead.

Events like these are important, because, not only do they provide an opportunity for education, they also foster the crucial connection between members that makes HFNZ such a close-knit organisation.

Seventeen April was World Haemophilia Day, and, while not many local events were able to go ahead, many parts of the country lit up red for World Haemophilia Day again this year. I am reminded at this time every year just how far we've come. As an organisation, and in terms of treatment and care. HFNZ members are now able to lead long and satisfying lives with their bleeding disorder, and the increased availability of novel therapies gives hope for the future.

Two long-term trustees of the Alan Coster Educational Endowment Trust stepped down through 2021. 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 board 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.

As always, I would like to thank HFNZ staff for supporting our community, and thank all volunteers, including the HFNZ board, for remaining motivated during what were sometimes the most demotivating of times.

I would particularly like to acknowledge CEO Sue Ellis, who has led the HFNZ staff team since 2018. Sue's time with HFNZ is now coming to an end, and it is appropriate to recognise the work that she has done to support HFNZ members. The board and I wish Sue all the best with her future endeavours.

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.

This year we had an interim 'twinning' arrangement with Fiji. While no travel took place, both New Zealand and Fiji connected, and Fiji hosted a workshop in one of the outer islands. I would like to acknowledge the funding received from the World Federation of Hemophilia to make this possible. The foundation will apply to continue this twinning relationship.

Looking to next year, I have always been committed to the member's resolution to look for a more permanent 'home' for the foundation when the regional funds were amalgamated more than fifteen years ago. I am therefore delighted that HFNZ will formally take possession of a commercial property on New Year's Eve 2022. More details on this significant step for HFNZ will be reflected in next year's annual report.



Sue Ellis: CEO Report

Sadly, this will be my last annual report as I am retiring at the end of November, my last working day attending the AGM on Sunday 27 November. After four years in the role of Chief Executive, I have learnt an enormous amount about bleeding disorders, the importance of being real and ensuring people are valued and listened to, about what the concept of family means and the ties that bind through the diagnosis of bleeding disorders.

I will always value my time with the Foundation, particularly the wonderful and supportive people I have met through attending events such as Family Camp, Youth Camp, Adult Weekend, Women's Weekend and regional events. It was also a great time to be here when we celebrated the 60th Anniversary of HFNZ.

Over the four years of my time, almost three of those years were taken up with the Covid-19 in our lives. This had a huge impact, with events either cancelled or postponed, and ensuring we stayed connected with each other, even if that wasn't face-to-face, was a challenge. It has been an interesting time, to say the least, and it was a relief to hear of the lifting of the government protections, which brings us almost back to normal.

I want to thank the staff who, despite the challenges, continued to work throughout the Covid 19 pandemic to ensure members are supported. They have taken the opportunity to come up with innovative ideas to reach out to members to keep the momentum going through different activities and offerings.

The beginning of the year was focused on getting Youth Camp underway. We were very pleased that, at long last, the camp was held from 17 to 20 July at Blue Skies in Kaiapoi, Canterbury. Although registrations were low, we still had 19 young members attending, along with 11 leaders including two in training,

and two very helpful partners. Everyone got into the activities with enthusiasm and were very happy to be reconnecting as well as making new friends. With the Seven Summits theme of the camp related to mountain climbing, the rock climbing activity was approached by all with serious focus and a joy of accomplishment, despite looking very scary. A visit to the museum to see the Antarctica exhibition also carried a lot of interest for everyone.

In June, after a postponement during lockdown, we eventually got together for a wonderful weekend in Dunedin for Women's Weekend. With 36 women in attendance, it was a clear sign how much the connections were important and needed. We enjoyed some entertaining and very informative presentations, particularly Dr Claire McLintock's keynote speech on Menstruation and Psychology, and Dr Richard Egan's workshop on Managing Life in Changing and Uncertain Times, as well as a great panel of clinicians led by Hematologist Catherine Neal who answered questions and clarified a number of concerns. Everyone enjoyed the outside visits around Dunedin, and the trip to Carey's Bay for dinner.

As the financial year ended, we published the results of our research looking at how well the Foundation is meeting the needs of our older members, Te Roopu Rangatira: Our holders of knowledge. Undertaken by Sarah Elliott as the lead researcher, the findings were mixed. A number of participants noted the support they receive from the Foundation, however there were concerns that we need to do more, especially helping our older members to navigate through the health system. The report on this research can be accessed on the Foundation's website.

As we look ahead, keep an eye out for Adult Wellness Weekend. This is being held from 25 to 27 November in Auckland. We already have a really interesting programme drawn



up, and I'm sure everyone will enjoy being back together again. The AGM and Board meeting is also linked to this weekend. Then, in April 2023, there's the National Family Camp at the Ngāruawāhia Christian Youth Camp. I will be sad to not be there to experience the great mahi that families will enjoy, but know they will be well looked after by the Outreach Workers and clinical team.

Also, a project is currently underway that looks at how girls, women and gender diverse people are affected by the symptoms of their bleeding disorders. The goal is to better inform and increase awareness of the signs and symptoms of bleeding disorders in primary health practices and in schools .

I am very pleased to note that, after years of waiting, the HFNZ now have a home to call our own, with the purchase of a national office. The new office is situated in Lower Hutt, Wellington. By the time you read this, the Foundation will be getting ready for the move into its home.

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

I want to take this opportunity as my last report to thank all the wonderful

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

people who have supported me during my time with the Foundation. In particular, the staff both past and current. I feel very confident the staff will continue to help support and care for members in their regions and across the country and members are in safe hands. I also want to thank the Executive and the Board for all their support, especially as we collectively navigated our way through the pandemic and lockdown.

In my report last year, I believed we would emerge from the financial impact stronger than before and this year has proved me right. Despite the initial concerns of a drop in donations, this has not been the case and we ended the financial year in a strong position with significant donations and bequests. This has been due to the hard working teams at Kiwifirst and the wonderful kindness of New Zealanders who have donated to the Foundation.

Saying 'thank you' will never be enough to all those wonderful people who continue to send us generous donations. Even during lockdown and pandemic restrictions, people are thinking about other's needs. It does give me hope. Again, the Kiwifirst teams just keeps on doing what they do best and constantly reaching above targets. Thank you to Marty and Steve for all your wonderful support for me, and your friendship. *Ehara take toa, he takitahi, he toa takitini:* My success should not be bestowed onto me alone, as it was not individual success but success as a collective.

I am also grateful to the Haemophilia Treatment Centre teams – you know who you are! Your fantastic support of the Foundation, and the training given to new Outreach Workers, have given them a greater understanding of all matters bleeding disorders and the confidence in their role to support and care for members.

Thank you also to the pharmaceutical industry who have continued to support us with grants allowing us to provide the important events to members. Our website has been refreshed

and redesigned, we had our first educational webinar offered to members in August 2021, and we are working to get a greater focus to support members with von Willebrands Disorder and other rare bleeding disorders.

As I sign off for the last time, I wish you all well and know the Foundation is in good hands and that there are exciting times ahead. I wish the new Chief Executive all the best and know they will enjoy their role as much as I have.

Ngaro atu he tetekura, whakaete mai he tetekura:
When one chief disappears, another is ready to appear
– No one is indispensable.

Branch Reports

HFNZ has six Branches that represent the different parts of our community: the Northern, Midland, Central, and Southern regions; Piritoto, representing our Māori members; and the National Youth Committee. The 2021/22 year was significantly impacted by Covid-19, which affected groups' ability to meet and to hold events.

The 2021/22 year has been a relatively quiet time for the HFNZ branches: Covid certainly has a lot to answer for. However, with the government protections easing, and people becoming more comfortable with the new normal, we are beginning to return to regular programming.

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

They had organised a rock-climbing event for September 2021 but, as happened in 2020 with their movie event, we went into lockdown so this had to be postponed. They were finally able to attend this long-planned event in April of 2022. While not too many members participated, those who did enjoyed the opportunity to reconnect with others.

Planning is underway for a Christmas or summer catch-up. Covid has had a huge impact on a number of businesses. The Northern crew were in negotiations with Rainbow's End over hosting a party there this year. Unfortunately, due to the massive financial impact Covid has had, they were unable to offer the rates they had in the past, which makes this venue not viable so Northern are looking at other options to get the region together.

Northern also had a change of outreach worker in May of 2021. Amber moved on to take up a new challenge, and Darian has joined us. He is now well established and has been a fantastic addition to the region during this past year

Things have remained very quiet in the **Midland** region. However, while there have not been any events, there has certainly been activity

in the region. Haematologist Julie-Anne Bell has moved away from her role in the Waikato Haemophilia Treatment Centre, after many years excellent service. HFNZ members appreciate the time Julie-Anne put into her role at the HTC, and thank her for all her hard work. Dr Gustavo Faulhaber has replaced Julie-Anne.

Also, while technically outside the report time-frame, the Midland region has welcomed a new outreach worker. Loren Silva joined the team in October, and is a welcome addition to the Midland whānau.

Central have come to realise over the last few months, more so even than last year, that it is face to face contact that they crave. The free flow of side conversations and anecdotes and stories shared amongst members that Zoom just doesn't provide. This was highlighted by the very low turnout for their AGM in September 2021, and reinforced by the participation in their Zoom-based Xmas event.

On the strength of their Zoom experiences, they worked hard to plan their bi-annual camp, which occurred in August 2022. This was a very positive event, which empowered them to focus on how they will provide the much needed contact local members have missed, as they work to strengthen the relationships they have made over the years, and hopefully forge some new ones.

The **Southern** crew also had a bit of a quiet year. The Southern walking group continued as well as it could until the New Year, when it ground to a halt. It was great to see the regular walkers improving as time went on. Maybe someone will step up to get this valuable group going again.



Northern rockclimbing



Southern dinner

Attempts were made to hold an AGM at the end of 2021. Like other branches, the Covid enforced need to do it remotely via Zoom meant that it couldn't go ahead. With that in mind, it was fantastic to get a good turnout to Halswell Quarry Park for the Xmas do. Members enjoyed a BBQ and the opportunity to reconnect in this lovely setting. Even better was the turnout for the WHD event at the International Antarctic Centre. It was great to see kids and adults having fun and learning new things.

The **National Youth Committee** have also had a quiet year. Due to Covid the youth twinning with Nepal did not finish as actively as it started. There are still plans afoot to round out the twinning in some way, so watch this space.

It was lovely to have a great bunch of young leaders along to help out at the 2021 Teen and Youth Camp. Just the act of getting a few of them getting together in one place sparked a renewed drive to make things happen. On the back of conversations started at the Camp, the NYC planned a national event, which took place in early September. It was awesome to see this group together again and full of ideas, and we look forward to what comes next.



Central camp

Piritoto has been very quiet this year. Covid and some leadership changes have meant that this group has had a difficult time meeting or planning events. With the New Year on the horizon the crew at Piritoto are looking forward to increased activity, and the opportunity to korero.

Each branch has plans to hold events over the coming year. Keep an eye on Bloodline and Pānui, as well as on your inbox.



NYC Youth Hui

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 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 whānau.

Women's Wellness Weekend

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

We held this two-day event for Women with inherited bleeding disorders aged 18 years and upwards in Dunedin from 10 to 12 June 2022. This event had been postponed from November 2021 because of Covid disruptions. It had been over three years since our last Women's Workshop.

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

Participants arrived late Friday afternoon and many enjoyed getting to know each other for the first time, while others enjoyed re-connecting. The programme went through to 1pm on Sunday.

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

After dinner on Friday night Kahurangi Carter delivered a thought provoking presentation on the importance of 'Giving back to HFNZ from a Maori Women's Perspective'.

Saturday's guest speakers were amazing, and focused their korero around Māori practice models and how they use these in their clinical settings of mahi. The workshops and presentations they did were engaging for us all, fun and educational.

Dr Claire McLintock was the keynote speaker and her presentation 'Menstruation and Psychology' was outstanding.

Dr Richard Egan's Workshop 'Managing life in uncertain and changing times' was also very well received and highly pertinent given we are all living with Covid and unpredictability in our daily lives.

This year we were extremely fortunate to have a medical panel of Haematologist Catherine Neal, Physiotherapist Lee Townsend, and Clinical Nurse Specialists Maureen Campbell and Kathy Fawcett to offer practical and immediate medical advice in response to participants' wide ranging medical questions.

The panel were able to offer support and answer most queries that the members had. This was invaluable to have over the weekend. It was good to have Southern and Midland panel members there, to talk about the way each region is practicing.



The sharing of members' lived experience was one of the highlights of the weekend. This sharing space encouraged members to resonate support for one another, and contribute to the kōrero. For members new to HFNZ, this weekend gave them a good knowledge-base and some understanding of what HFNZ is about. For the members that have been with HFNZ for some time, this was an opportunity to re-connect and offer support to the new members and others. Respectful relationships were established for the first time that will be maintained throughout life.

Teen and Youth Camp

HFNZ Youth Camp 2021 took place over the weekend of 17 – 20 July, but had been in planning for far longer than that. We first started signposting this event way back in October 2019. Our first date was July 2020, but Covid soon put paid to that. Then we looked at April 2021, but operational issues meant we had to push that back too. We finally settled on July 2021 in Christchurch, and were able to hold the event we'd been talking about for so long.

A winter camp in Christchurch! Sounds cold! However, the Blue Skies venue in Kaiapoi was lovely and toasty warm right through the weekend, and the odd spot of rain didn't get in the way of a great weekend.

We had the leaders come in for some education on the morning the camp started. It was great to have such a diverse group of young people keen to help support the attendees at the camp. The session was very useful, with some excellent contributions from Lauren Phillips and Laura-Lee Perawiti.

Then it was time for the campers to arrive...!

This Youth Camp had the Seven Summits as a theme. This relates to the feats of Chris Bombardier becoming the first person with haemophilia to scale the highest summit on each of the seven continents.

It focused on being prepared and resilient in the face of challenges.

For our campers that meant learning about some feats of resilience from the past, and practicing meeting challenges themselves.

We watched Chris Bombardier's movie about his exploits, *Bombardier Blood*, on the first night. That set the scene for our first off-site activity the following morning; rock-climbing at the YMCA Adventure Centre. It was wonderful seeing our young adventurers stepping up to meet this challenge. Not everyone was 100% confident at the start of this activity, but by the end they were all very pleased with themselves.

The outing the following day reinforced the learning

they'd already done. We visited the Canterbury Museum, where we were able to experience first-hand the different clothing Antarctica explorers used, explore Hillary's Hut in Antarctica via virtual reality, and tour the Antarctic exhibition. We were also lucky enough to be able to marvel at all the clever things Galileo came up with, in a fabulous interactive exhibition.

These outings were complemented by some excellent educational opportunities back at camp. BJ Ramsay hosted an excellent session on the ins and outs of bleeding disorders, which really got the campers thinking; Kathy Fawcett focused on the benefits of meditation and other relaxation techniques; and the quiz really got them thinking about bleeding disorders and the BD community. Throughout the weekend, campers were also able to learn first-hand about self-infusion and prophylaxis at the morning treatments. It was lovely to see experienced infusers sharing their knowledge with younger, less experienced campers.

The other key component of Youth Camp was physical activity. Central to this was 'Action Time with Rau'. On the first day, leader Raukura Riwaka got the campers out exploring their environment in an orienteering activity. Then, each morning Rau help the campers get their blood moving with a short burst of exercise.

He also instituted a points system, which continued through camp, rewarding good behaviour with team points. Congrats to the Blue team, which came out on top.

It was lovely to get some of our young people together, after over a year of disruption and delays. The campers all enjoyed themselves, and the leaders did a fabulous job with them.

A special thank you must go out to Tineke and John Maoate, camp Mum and Dad. Tineke really helped to keep things moving, making sure everyone was fed and watered, and that campers took responsibility for ensuring the campsite was in a decent state throughout.



HFNZ Financial Report

For the 12 months ending 30 June 2022

The audited financial statements for the Haemophilia Foundation of New Zealand can be found in this annual report. I am pleased to report a surplus of \$430,994 in the year to 30 June 2022. This represents another year characterised by strong financial performance by the Foundation.

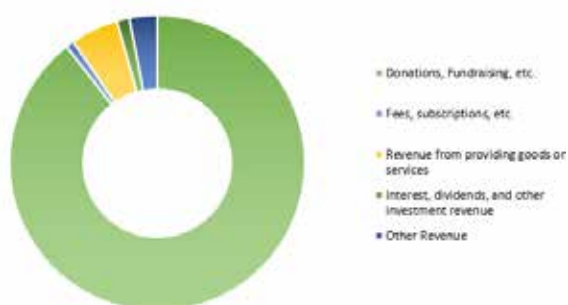
The majority of the financial surplus is due to the Foundation's receipt of several generous bequests and donations, as well as Kiwifirst having exceeded fundraising expectations by over 10%. Reductions in expenditure are also noted, due to the ongoing operational impacts of COVID-19 which reduced our capacity to deliver programmes. At 30 June

2022 the Foundation has total accumulated assets of \$1,913,161.

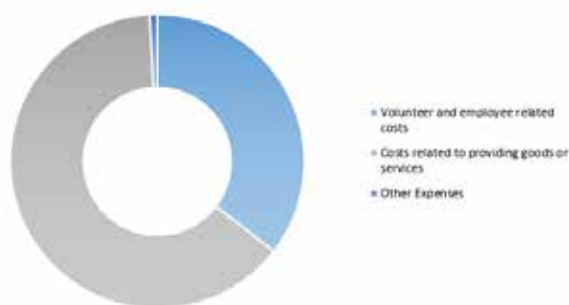
Although the Foundation has faced significant operational challenges over the last two years, predominantly attributable to COVID-19, we have maintained a sound financial position through effective financial management and the ongoing generosity of our donors.

I am therefore confident that the Foundation will continue to support members' individual needs, as well as bringing people with bleeding disorders and their families together as mandatory restrictions and general perspectives regarding group gatherings relax.

Revenue



Expenses



Statement of Financial Performance

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2022

	Notes	2022	2021
Revenue			
Donations, Fundraising, & other similar revenue	1	1,370,245	1,172,795
Fees, subscriptions, and other revenue from members	1	10,042	8,628
Revenue from providing goods or services	1	69,934	69,934
Interest, dividends, and other investment revenue	1	2,625	9,997
Other Revenue	1	600	26,232
Total Revenue		1,453,446	1,287,587
Expenses			
Volunteer and employee related costs	2	362,450	310,126
Costs related to providing goods or service	2	651,536	697,150
Other Expenses	2	8,466	7,153
Total Expenses		1,022,452	1,014,430
Surplus /(Deficit) for the year		430,994	273,157

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 2022

	Notes	2022	2021	
Assets				
Current Assets				
Bank accounts and cash	3	1,895,661	1,306,398	
Debtors and prepayments	3	92,896	44,413	
Investments	3	-	164,525	
Other current assets	3	27,483	26,867	
Total Current Assets		2,016,039	1,542,204	
Non-Current Assets				
Property, Plant and Equipment	6	13,529	12,278	
Total Non-Current Assets		13,529	12,278	
Total Assets		2,029,569	1,554,481	
Liabilities				
Current Liabilities				
Creditors and accrued expenses	4	106,588	54,501	
Unused donations and grants with conditions	4	7,805	14,340	
Other current liabilities	4	2,014	3,474	
Total Current Liabilities		116,408	72,315	
Total Liabilities		116,408	72,315	
Total Assets less Total Liabilities (Net Assets)		1,913,161	1,482,167	
Accumulated Funds	Accumulated Surplus or (deficit)	5	1,913,161	1,482,167
Total Accumulated Funds		1,913,161	1,482,167	

Statement of Cash Flows

Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2022

	2022	2021
Cash Flows from Operating Activities		
<i>Cash was received from:</i>		
Donations, fundraising, and other similar receipts	1,309,400	1,166,740
Fees, subscriptions, and other receipts from members	6,783	23,619
Receipts from providing goods and services	78,807	86,464
Interest, dividends, and other investment receipts	2,639	11,050
Net GST	-	-
Total	1,397,629	1,287,873
<i>Cash was applied to:</i>		
Payments to suppliers and employees	358,864	308,588
Costs related to providing goods and services	611,501	698,020
Net GST	552	7,938
Total	970,917	1,014,546
Net Cash Flows from Operating Activities	426,712	273,326

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	-	-	
Receipts from the sale of investments	160,537	507,677	
Total	160,537	507,677	
<i>Cash was applied to:</i>			
Payments to acquire property, plant, and equipment	-	-	
Payments to purchase investments	-	7,612	
Capital repaid to owners or members	-	-	
Total	-	7,612	
Net Cash Flows from Investing and Financing Activities	160,537	500,065	
Net Increase/(Decrease) in Cash	587,249	781,003	
Opening cash	1,306,398	525,396	
Closing cash	1,893,647	1,306,398	
This is represented by			
Bank accounts and cash	1,893,647	1,306,398	

Notes to the Performance Report

Haemophilia Foundation of New Zealand Incorporated For the year ended 30 June 2022

		2022	2021
1. Analysis of Revenue	Donations, fundraising, and other similar revenue		
	Donations	370,718	222,055
	Fundraising - External (KF)	892,578	878,387
	Fundraising - Internal	-	415
	Grants	60,231	71,939
	Legacies	46,718	-
	Total Donations, fundraising, and similar revenue	1,370,245	1,172,795
	Fees, subscriptions, and other revenue from members		
	Registrations	6,364	4,129
	Membership Fees	3,678	4,499
	Total Fees, subscriptions, and other revenue from members	10,042	8,628
	Revenue from providing goods or services		
	Contracts	69,934	69,934
	Total Revenue from providing goods or services	69,934	69,934
	Interest, dividends, and other investment revenue		
	Interest Income	2,625	9,997
	Total Interest, dividends, and other investment revenue	2,625	9,997
	Other revenue		
	Wage Subsidy	600	26,232
	Total Other Revenue	600	26,232
2. Analysis of Expenses	Volunteer and employee related costs		
	Wages and Salaries	362,450	310,126

Notes to the Performance Report

	Total Volunteer and employee related costs	362,450	310,126
Costs related to providing goods or services			
60th Anniversary	-		52
ACC Levies	723		1,178
Accounting	4,025		3,170
Administration	-		81
Adult Programme	-		44,066
Bank Fees	225		225
Central	-		7,427
Community Education (KF)	239,357		258,065
Consultancy (including IT)	9,303		7,285
Defensive Driving	-		547
Footwear Programme	3,905		4,874
Fundraising Costs (KF)	263,889		284,165
General Expenses	1,709		1,157
Human Resources	1,571		5,434
Insurance Assets/Liability	6,675		5,582
International Meetings/Conferences	1,741		-
Loss on Sale of Asset	20		-
Masters	140		282
Meetings	21		180
Midland	84		1,075
National Council	850		12,235
Needs Grants	512		570
Northern	1,078		909
Office Expenses	11,168		8,122
Outreach	5,513		10,248
Piritoto	-		350
Printing, Stationery, Postage	11,152		12,331
Professional Development and Team Meetings	4,748		10,366
Rent	1,863		1,805
Resources	-		507
Southern	1,968		2,630
Special Programmes	1,715		52
Subscriptions/Memberships	1,437		876
Swimming/Fitness	7,721		5,773
Telephone & Internet	5,492		5,504
Youth Camp	25,702		27
Total costs related to providing goods or services	651,536	697,150	
Other Expenses			
Depreciation	2,716		1,323
Legal Expenses	-		530
Audit	5,750		5,300
Total Other Expenses	8,466	7,153	
3. Analysis of Assets			
Bank accounts and cash			
BNZ Non Profit Cheque Account	75,845		465,664
Legacy Account	1,178,511		445,494

Notes to the Performance Report

	On Call Account	95,227	95,156
	Research Account	235,166	-
	Reserve Account	301,364	300,048
	Twinning	9,548	36
	Total Bank accounts and cash	1,895,661	1,306,398
	Debtors and prepayments		
	ACEET Funds Receivable	2,375	(77)
	Prepayments	4,522	12,795
	Trade Debtors	85,999	31,619
	Total Debtors and prepayments	92,896	44,413
	Other current assets		
	GST	27,429	26,800
	Interest Receivable	54	68
	Total Other current assets	27,483	26,867
	Investments		
	BNZ Term Investment - 00003	-	62,627
	BNZ Term Investment - 00004	-	63,152
	BNZ Term Investment - 00002	-	38,745
	Total Investments	-	164,525
	Total Analysis of Assets	2,016,039	1,542,204
	<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	96,939	53,866
	CG Twinning - Funds Held	9,419	-
	Money in Advance	230	635
	Total Creditors and accrued expenses	106,588	54,501
	Unused donations and grants with conditions		
	Grants in Advance	7,805	14,340
	Total Unused donations and grants with conditions	7,805	14,340
	Other current liabilities		
	BNZ Visas	2,014	3,474
	Total Other current liabilities	2,014	3,474
	Total Analysis of Liabilities	116,408	72,315
5. Accumulated Funds	Accumulated Funds		
	Opening Balance	1,482,167	1,209,010
	Accumulated surplus or (deficit)	430,994	273,157
	Closing Balance	1,913,161	1,482,167
	Total Accumulated Funds	1,913,161	1,482,167
6. Property, Plant, and Equipment	Office Equipment		
	Open Carrying Amount	12,277	2,466
	Purchases	3,988	11,134
	Sales/Disposals	(20)	-
	Depreciation	2,716	1,323
	Closing Carrying Amount	13,528	12,277

Notes to the Performance Report

7. 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 \$195.00 excluding GST per month. 		
8. Related Party	Description of related party relationship	Description of transaction	
	Stephen Waring - Director of Kiwifirst	Major fundraiser of the Foundation - \$502,339 expenditure to Kiwifirst, \$885,727 received from Kiwifirst and \$30,097 receivable due from Kiwifirst	
9. Grant Income	Grants Received in the Year	2022	2021
	CSL Behring Australia	-	14,975
	Novo Nordisk Pharmaceuticals Pty	8,696	-
	NZ Lotteries	-	12,000
	Pub Charity	-	6,870
	Rata Foundation	-	21,800
	Roche Products	-	10,000
	Sanofi-Averntis Australia	20,000	-
	Takeda Pharmaceuticals Australia	-	500
	The Trusts Community Foundation	20,000	
	Trust Waikato	5,000	
	Total Grants Received in the Year	53,696	66,145
	Less: Unspent Grant Income	(7,805)	(14,340)
	Less: Refund of Grant Not Used	-	(2,841)
	Add: Previous Grant Accrual	14,340	22,975
	Total Grants Income	60,231	71,939
10. Statement of Commitments	There are no commitments as at balance date. 30/06/2021 (Nil)		
11. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/2021 (Nil)		
12. Events After Balance Date	There were no events that have occurred after the balance date that would have material impact on the performance report.		
13. 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 2022.

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 affected by bleeding disorders by providing quality, comprehensive, education and psychosocial support.

Outcomes

Youth Camp

17 - 20 July, 2021

The HFNZ 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.

"I have really enjoyed my time at Camp. I have learned new things and experiences. I highly recommend this camp to my friends".

"I found camp very social and hands-on, which I loved. The staff are really friendly and will help you when they can. The food is great, in my opinion, and mascot making is particularly fun. I have made countless friends while here, so that is awesome."

38 people participated in this event.

Women's Weekend

10 - 12 June, 2022

Traditionally haemophilia and bleeding disorder education has focused on men. This residential workshop specifically targets women with bleeding disorders, and women who carry the haemophilia gene. Women's Weekend offers a safe and supportive environment where women can increase their knowledge; and discuss issues that relate to them, or

to being a carrier of the haemophilia gene.

"Thank you so much for this opportunity to engage with other women who are walking in my steps, or where I am about to embark. The empowerment I receive from these events is life-changing".

"It's the emotions and context of my experience that is invaluable. Hope for the future with hearing of new research and sharing of experiences. I am not alone. Support and reinforcement that I am part of a family with bleeding disorders. Confidence with understanding our bleeding disorder. Plus the tools to advocate for myself and my family."

46 People participated in this event.

Other Significant Programmes

Outreach Support Services for people with bleeding disorders and their families

During the 2021/22 financial year, the Outreach team made 3,332 contacts with people with bleeding disorders. This represents a 284% increase over the previous year. The Outreach service directly supported more than 50% of members with bleeding disorders in the year 1 July 2021 to 30 June 2022; issues dealt with included working with schools, hospitals, social welfare, and housing. Covid-19 meant that Outreach staff were sometimes unable to meet face to face with members during 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 many local landmarks lit up red in support this year, most regions did not plan events.

INDEPENDENT AUDITOR'S REPORT

To the Members of Haemophilia Foundation of New Zealand Incorporated

Report on the Performance Report**Opinion**

We have audited the performance report of Haemophilia Foundation of New Zealand Incorporated (the "Society") on pages 7 to 19, which comprises the entity information, the statement of service performance, the statement of financial performance and statement of cash flows for the period ended 30 June 2022 the statement of financial position as at 30 June 2022 and notes to the performance report, including summary of significant accounting policies and other explanatory information.

In our opinion:

- A. the reported outcomes and outputs, and quantification of the outputs to the extent practicable, in the statement of service performance are suitable;
- B. the accompanying performance report presents fairly, in all material respects,:
 - the entity information for the year then ended;
 - the service performance for the year then ended; and
 - the financial position of Haemophilia Foundation of New Zealand Incorporated as at 30 June 2022 and its financial performance, and cash flows for the year then ended

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

Basis for Opinion

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

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

Responsibilities of the National Council for the Performance Report

The National Council is responsible for:

- A. Identifying outcomes and outputs, and quantifying the outputs to the extent practicable, that are relevant, reliable, comparable and understandable, to report in the statement of service performance;

- B. the preparation and fair presentation of the performance report on behalf of the 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 on New Zealand by the New Zealand Accounting Standards Board, and
- C. for such internal control as the Members 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 the Society for assessing the Society's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the National Council either intend to liquidate Society or to cease operations, or have no realistic alternative but to do so.

Auditor's Responsibilities for the Audit of the Performance Report

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

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

- Identify and assess the risks of material misstatement of the performance report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management.
- Conclude on the appropriateness of the use of the going concern basis of accounting by the National Council and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the entity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the performance report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the entity to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the performance report, including the disclosures, and whether the performance report represents the underlying transactions and events in a manner that achieves fair presentation.

- Perform procedures to obtain evidence about and evaluate whether the reported outcomes and outputs, and quantification of the outputs to the extent practicable, are relevant, reliable, comparable and understandable.

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

Restriction on use of our report

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

Nexia Audit Christchurch.

Nexia Audit Christchurch

13 October 2022

Christchurch

Our People in 2021/22



Women's Weekend



Northern Rockclimbing



Youth Hui



Southern Xmas



Central Camp



Teen & Youth Camp

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

CSL Behring	Website upgrade and maintenance
Sanofi-Aventis	Youth Camp
Roche	Youth Camp and Women's Weekend
Takeda	Wellness Webinars
Novo Nordisk	Youth Camp
The Trusts Community Foundation	Outreach

Bequests

T E Dawson Estate
IC Ward

Individual and general donations over \$100

P Rackley
Give A Little
Louise Tupou on behalf on Angus Macdonald Family
Colleen McKay
Michael Andrews
Kathleen Thomas
Iona & Nathan Kahu
John Hunter
Give A Little - Donations
M & D Bassett
M & C Louisson
Brodie
C Mirams
Holwell
Ho Seong Kim
T McWhinnie
Donnithorne Directors
P Rackley
Lyons Directors
M & C Louisson
I E Jenkins
B & C Hodgson
IG Ireland
D Taylor
E Berry - ACEET
GKE Upritchard
Pickles Directors

In Memoriam

HFNZ notes with sadness the passing of the following members and friends of the Foundation between July 1 2021 and June 30 2022:

- Roland Pavarno
- Simon Holden

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:	Margaret Stewart
Southern Branch Delegate:	James Poff
Piritoto Delegate:	Tuatahi Pene
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:	Lauren Phillips

Staff

Administration

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

Haemophilia Outreach Workers

Northern Outreach Worker:	Darian Smith
Midland Outreach Worker:	Loren Silva
Central Outreach Worker:	Lynne Campbell
Southern Outreach Worker:	Tara Williams-Tuschling

HFNZ Affiliation

World Federation of Hemophilia www.wfh.org

Entity Information

The Haemophilia Foundation of New Zealand Incorporated, also known as HFNZ, is a Registered Charity (CC22765) and an Incorporated Society.

Our Purpose is:

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

The Foundation is governed by a council of eleven HFNZ members and whānau. The council comprises the President, two Vice Presidents, a Treasurer, a representative for each of the four regional branches (Northern, Midland, Central, and Southern), a representative from the Piritoto and Youth National branches, 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, Cambridge, 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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