

Haemophilia
New Zealand



Haemophilia New Zealand Annual Report: 2022/23

01 JULY 2022 TO 30 JUNE 2023

*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 HNZ Established in 1958, Haemophilia New Zealand (HNZ) connects and supports people across Aotearoa New Zealand who are affected by haemophilia, von Willebrand's disorder, platelet disorders, and many other rare, chronic, inherited bleeding conditions.

At HNZ, we understand that we're stronger together. That means being an inclusive organisation, which represents the needs of people of diverse needs and experiences, enabling us to make a difference where it really counts. Our belief in the power of connectedness is one of the reasons that HNZ 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 HNZ member is unique, we are all an integral part of the larger NZ bleeding disorder community. HNZ is committed to connecting and unifying our community, and empowering those affected by bleeding disorders across New Zealand.

HNZ comprises four regions throughout the country (Northern, Midland, Central, Southern), with an Outreach Worker assigned to each. There are also two national groups; Piritoto and the National Youth Committee. The HNZ Board is responsible for governance. All Board positions are voluntary and decided by election at the Annual General Meeting.

HNZ is very proud of the advances and successes we have achieved over the last 65 years. To continue reaching towards our goals, we rely largely on public donations. With the incredible generosity of the New Zealand public, and the amazing support received from corporate friends and grant applications, HNZ look forward to many more success stories in coming years.

The key roles of HNZ are:

- To promote the personal interest, treatment, rehabilitation, lifetime care, and advancement in life, of all people with haemophilia and related genetic bleeding diseases
- To offer information and guidance, which promotes effective measures of care
- To promote full participation and equal opportunity for all in community activities, education, recreation, and employment
- To provide or facilitate individual assistance welfare, participation, opportunity, and advocacy
- To provide representation, at a regional and national level, to ensure that adequate and safe supplies of treatment products, and other treatments or cares are available
- To advocate for adequate services to meet the needs of people with haemophilia
- To provide up-to-date information
- To act as a consultative body to Government
- To educate families, health professionals and other key stakeholders.

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Deon York: Board Chair & Acting CEO

Kia ora koutou,

Since December 2022 I have been the acting chief executive for Haemophilia New Zealand (HNZ), alongside my chair responsibilities. Despite many years of involvement with the board, this has offered a unique opportunity to strengthen the organisation.

We end this financial year with a strong and dedicated team, the re-emergence of national events for our members, a solid financial position, a home for our organisation, and the prospect of emicizumab (Hemlibra) becoming available for all people with severe and moderate haemophilia A.

With the appointment of Vic Turner to HNZ, we once again have a full outreach team. Vic works alongside Lynne, Darian, and Loren and builds connections both within respective regions and across the country. Phil and Leanne continue to keep the day-to-day running of the organisation on track, while our board of committed volunteers continue to devote time to advancing the organisation's mission. I would like to take the opportunity to thank the staff and volunteers alike for their dedication to HNZ. Thanks to Catriona and Karl (vice-chairs), Hemi (treasurer), Tineke (delegate), and Lauren (youth delegate) for your time on the board this past year. I would also like to acknowledge the crucial role Kiwifirst plays as our chief fundraiser. Thank you to all the staff at Kiwifirst who work tirelessly, and the public who loyally donate so it is possible for us to support our members.

Programme delivery has emerged from a challenging environment. Since early 2020, COVID-19 has significantly impacted our ability to connect members and run educational events for the community in the way we previously did. The organisation has gradually been increasing its support to pre-pandemic levels but still maintaining what we learnt when we connected more online.

We ran an adult wellness weekend in Auckland in November 2022. This event is an opportunity for adult members with bleeding disorders and their partners to openly discuss experiences, challenges, and concerns about living and aging with a bleeding disorder. The focus of the weekend was education about bleeding disorders, upcoming trends, and treatments, as well as socialising and reconnecting with peers. The members who attended gave glowing feedback, and we are all looking forward to the next one.

In April 2023 we were delighted to finally run our national family camp in Ngāruawāhia. Some participants had only recently received a diagnosis in the family, so learning about the fundamental

clinical aspects of bleeding disorders was particularly important at this event, alongside connecting with other families. Sessions for parents covered 'haemophilia 101', dental care, information about novel therapies, including Hemlibra, and progression towards gene therapy. A session on the importance of physiotherapy was also run, as well as a 'parents panel'. One of the participants self-infused his treatment for the first time, and parents learnt how to self-infuse on 'willing veins'.

Thank you to staff for pulling together and making this camp such a success. Many volunteers also made this possible, but I must single out someone who doesn't like a fuss: The camp could not have happened without Tineke (also a World Hemophilia Day star in the Women's Weekly!). Thank you, Tineke, on behalf of all of us! Another 'shout out' must go to Tuatahi and Te Whainoa who arranged an unexpected and uplifting visit to Tūrangawaewae marae. I would also like to thank our sponsors Roche, Rātā Foundation, Pub Charities, and Waikato Trust for supporting this event.

Members rated this event highly and HNZ received a favourable evaluation. Planning is now completed for a 'pipeline' of national events for members.

HNZ is affiliated with Rare Disorders New Zealand (RDNZ), and they have had an active year to date. On 28 February (Rare Disease Day), I attended the launch of 'Raising a child with a rare disorder: A guide for parents living in Aotearoa New Zealand' at Government House. The event was hosted by RDNZ's patron Her Excellency, the Right Honourable Dame Cindy Kiro and was attended by many people living with a rare disorder, proving the adage of RDNZ that



'rare is everywhere'. RDNZ wrote a submission in support of the funding of Hemlibra.

On May 10, I also attended the launch of RDNZ's BERL Rare Disorders Insights Report at Parliament. This report is based on publicly available data and a high-level literature scan of recent New Zealand and international studies that discuss the prevalence of rare disorders, as well as burden factors that need to be considered in the development of health policies. Both resources are available on RDNZ's website, raredisorders.org.nz.

As well as building and maintaining local connections, global connections have continued to feature. I would like to acknowledge Catriona's role on the bylaws committee for the World Federation of Hemophilia (WFH), Lauren's role on the Women and Bleeding Disorders Committee of the WFH, and our twinning partner, the Fiji Haemophilia Foundation (FHF). I also continue to serve as a mentor as part of WFH's PACT programme and on the awards committee. Building and maintaining our connections with the global community remains important and while many of these were undertaken remotely, I would equally acknowledge Hemi's involvement with the AFFIRM programme, which has taken him from Dublin to Dubai so far. The goal of this programme is to develop leadership in our community. Hemi also represented us at the last World Congress in Montreal in May 2022.

Property purchase has been a long-standing goal of HNZ and is now finally realised. When regional funds were amalgamated many years ago, a resolution was passed that these funds could only be used to find a permanent office space. The perfect opportunity arose alongside a bequest to bolster the property fund, and it is exciting to confirm that HNZ took possession of 44 Victoria Street, Alicetown on 31 December 2022. Our space is currently vacant and will be re-purposed for our needs, and the other space is currently tenanted.

I conclude my report with the most significant

He toto, he taimaha kia piri,
tukua kia rere

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

announcement for our members: As we conclude this year, Pharmac has announced its intention to extend the access criteria for Hemlibra to all with moderate and severe haemophilia A. Should this be funded, this will represent the most significant change and improvement to therapy for haemophilia in more than 25 years.

With this announcement in mind, I enter the new year thankful for the support of our staff, volunteers, and members, hopeful that the above therapy will be funded, and looking forward to the development of our new home for HNZ.

Ngā mihi nui,

Deon York

HNZ Chair & Acting CEO



Branch Reports

HNZ has six branches that represent different groups in our community.

The 2022/23 year was a quiet one for most of the branches. Many people are still understandably worried about Covid, which means that sometimes they were not keen to get out and about with others. That being said, there were still a number of excellent opportunities for HNZ members to get together.

In the **Northern** region members attended a community dinner on 16 October 2022. This was a great opportunity for members in the Northern region to reconnect, and start planning further ahead. The team had a super turnout for their combined Hobbiton event in conjunction with the Midland crew. It was great to see these two regions working together for the benefit of the members. Northern have planned ongoing coffee group meetings at Coffee Culture in Sylvia Park. The first of these was held on 25 May, then again on 25 June. Keep your eye out for future meetings. They also had a visit to Butterfly Creek on Sun 23 July, just outside the reporting period.

Things have remained very quiet in the **Midland** region as far as events go. However, the branch was very pleased to welcome their new Midland outreach worker Loren Silva, who started on 04 October 2022. As mentioned above, the branch enjoyed the opportunity to join the Northern group for an event at Hobbiton. At the end of the year the branch hosted an event at the Hamilton gardens, to farewell long-serving haemophilia nurse Maureen Campbell. It was good to be able to express our appreciation of all the time and effort Maureen had put into our people over the years.

Central Region had a camp at El Rancho in August 2022- thank you for Kiwifirst for sponsoring the kids packs for this. There was a talent show, quiz night, and kids cupcake decorating, while adults attended education sessions. There was also a trip to Nga Manu Reserve where they braved the rain to feed the eels. Christmas 2022 was at Te Manawa Museum, where they spent the morning decorating gingerbread houses, then visited the Christmas cave to see Santa before lunch. May 2023 saw a late celebration for world

haemophilia day, with a high tea and some games of bingo.

Since the last annual report, the **Southern** branch have welcomed two new outreach workers. Tara started in August 2022, and moved on in November. Her first order of business was to organise a community dinner. This was well attended and a great time was had by all. Then, in May this year Vic Turner was appointed to the vacant role. We held another welcome dinner for

Vic, before she commenced travelling the length and breadth of the South Island meeting members. Things are really looking up in this region, as new committee members come on board, and plans are made for future events.

In September 2022 the **National Youth Committee** held a youth hui in Wellington. This was an important first step in planning for what's coming up in the youth space. The focus of this event was reconnection. To that end, the group enjoyed the challenges of an escape room, and made sure to stand well back as they tried axe throwing! This event brought together a motivated group who have since planned and run further events. There is a bit happening in this space, so, if you're aged 18-30, keep your eye out for what's next!



Camps, Events, & Workshops

Each year HNZ runs events aimed at different member groups. 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 HNZ whānau.

Adult Wellness Weekend

Living with a bleeding disorder, or living with a person with a bleeding disorder, is challenging. The HNZ Adult Wellness Weekend is an opportunity for adult members with bleeding disorders and their partners to openly discuss experiences, challenges, and concerns about living and aging with a bleeding disorder. The focus of the weekend is twofold: education about bleeding disorders, upcoming trends, and treatments, as well as socialising and reconnecting with peers from across the motu.

At the end of 2022 members gathered in Auckland, at the Novotel Auckland Ellerslie, for a weekend of learning and laughing. The weekend ran from 25 - 27 November. It was lovely to see members enjoying seeing one another again as they arrived from around the motu for the initial meet and greet on Friday afternoon. This highlighted one of the most important aspects of these national events: connection.

After some socialising and a bit of dinner, people gathered for the formal welcome, some knot tying, and a few words from Board Chair Deon York. The theme for this Adult Wellness Weekend was 'The ties that bind us'. Deon spoke about how important it is that we carry our history with us, and that it informs our future decision-making.

The programme-proper commenced on Saturday morning, with the traditional members' panel. Deon joined members Hemi Waretini, Kathryn MacGregor, Leanne Spencer, and Patience Stirling to share their bleeding disorder journeys. This is always a very powerful session, with the members sharing very personal and sometimes painful experiences, as well as the joys that can come with adversity. The key point that came from this session was how important it is for patients to be a part of their own medical journey, and for clinicians to listen to their patients.

Appropriately, the members' panel was followed by a clinicians' panel. Nurse specialists BJ Ramsay, Maureen Campbell, and Vanessa Minor, Haematologist Nicky Eaddy, and physiotherapists Cat Pollard, and Abhi TikkiSETTY kindly gave us their time to introduce themselves to members and answer any questions from the floor. Coming right after the members' panel meant that the clinicians had an opportunity to respond to some of the historic issues raised, as well as answer some current questions. We

very much appreciated their time and expertise.

For the next session, we split into two groups. Outreach workers Darian and Loren took one session looking at 'Strengthening the Ties'. While CEO Sue and outreach worker Tara took the other, which focused on 'Ties from the Past to the Future'. Both sessions went very well. The first group talked about love languages, and how we support and empower one-another through our words and actions. The second group discussed how what HNZ have done in the past connects to what we do now, and how that might look in the future. It was fantastic to see members contributing and enjoying each other's company in a learning environment.

After a morning and early afternoon full of listening and learning, the rest of the day was given over to off-site activities. One group went to the Stardome Observatory, while the other headed out on

the water, catching the ferry across to Devonport. The observatory visit was spectacular, with awesome views of the cosmos, alongside some learning about what's what in NZ's night sky. The ferry trip also went very well. After a lovely calm ride across the harbour, members spent some time exploring Devonport village, before heading back on the ferry again. All had a wonderful time.

A long Saturday wound up with the, always contentious, quiz night. This edition was no exception. Teams battled it out over four rounds for the awesome solid plastic trophies, and the title of AWW quiz champs 2022. There was some intense competition, and laughter galore, before the winners were crowned, and everyone retired after a long day.

On the final day, members enjoyed HNZ president Deon York talking about how we can all strengthen our ties with HNZ. This included attending events, volunteering to support member activities, joining your local committee, and feeding back to the board and staff. This was a fabulous way to round out Adult Wellness Weekend, and allowed us all to reconsider the theme of the weekend: The ties that bind us.

This event was appreciated by all who attended. It wouldn't have been possible without the support of Kiwifirst, and the hard work of staff and volunteers. We're looking forward to the next one already.



National Family Camp

On 11 April nearly 90 people from around the motu gathered in Ngāruawāhia for the 2023 National Family Camp (NFC). This number included 17 whānau, along with leaders, staff, and clinicians. We were also pleased to welcome members of the HNZ board to this very special event in the HNZ calendar.

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

Usually, the age range for children with bleeding disorders at camp is 0-10. For this camp, the age limit for children was raised to 13 or under. This reflects the impact of Covid on our events and workshops, and that we've been unable to run a National Family Camp since 2019.

Members rolled in through the afternoon of Friday 11 April. It was lovely to see so many smiling faces after such a long wait for this event. Before the camp started, the weather forecast had been a concern. This was borne out on the first evening, when the heavens opened during our first activity: marshmallow toasting on the campfire. Luckily, there was some shelter for s'mores eating, and we headed back to the main hall for introductions and dryness.

Day 2 saw parents head off to the first of their education sessions, while our fabulous youth leaders entertained the children. Special mention must go to Louise Tupou, who ran our crèche. This was a tough job, which Louise and her team did very well.

The education sessions on day 2 started with the traditional parents' panel, where a group of parents was able to share their BD journeys, and respond to members' questions. This was followed by a presentation from the Waikato hospital dental team, before haemophilia nurse specialist BJ Ramsay talked about the basics of haemophilia and von Willebrands. In the afternoon, Julia Phillips talked about the latest advances in BD treatment.

While all this was happening, the older children built and sailed their own rafts before going kayaking, and the younger group spent time creating animal masks.

Later in the day, we were very privileged to be welcomed onto the Tūrangawaewae marae. This very important marae is the home of Tūheitia Paki, the Māori King. It was very moving to see the historic buildings and taonga, and hear some of the history associated with the marae and the Ngāruawāhia area. This visit really was a highlight.

The big HNZ disco rounded out the day. It was awesome to see kids and parents up dancing to the beats. I'm sure there were some tired bodies afterwards. The guest DJ did a great job, and the kids thoroughly enjoyed the games and fun.

Day 3 started with Deon talking to the parents about the history and future of HNZ, while the kids learned about the clotting cascade with BJ. Activities and education continued throughout the morning, before the whole group headed off to Hamilton Zoo for the afternoon. This was a fantastic trip, which was enjoyed by all.

After a couple of full days, the final night was movie night for the younger members, while their parents gathered to share and socialise. This was the perfect way to finish a very successful camp, with tired people all around enjoying the chance just to relax.

This event would not have been possible without the support of a wonderful group of leaders. A big thank you must go to Louise, Jessamyn, Evekanya, and Eshka for all their hard work in crèche, along with Benedict, Gabriel, Anna, Nicholas, Brendan, and Victoria for supporting the other children through a range of activities. The energy and enthusiasm this group added to the camp was priceless.

Finally, we'd like to thank Roche, Rātā Foundation, Pub Charities, and Waikato Trust for contributing funding towards this event. Without their support, we would not be able to offer such high quality events and activities to our members.



HNZ Financial Report

For the 12 months ending 30 June 2023

Tēnā koutou katoa,

The audited financial statements for Haemophilia New Zealand can be found in this annual report. After another exceptionally strong year, I am pleased to report a surplus of \$788,992 for the year to 30 June 2022. This represents another year characterised by strong financial performance by the Foundation, although accessing grants from charitable and industry funders remains a challenge. HFNZ continued to receive a contribution to outreach worker salaries from the Te Whatu Ora.

The majority of the financial surplus is again due to the Foundation's receipt of several generous bequests and donations, as well as Kiwifirst having exceeded fundraising expectations by over 12%. At 30 June

2023 the Foundation had total accumulated funds of \$2,702,153. The accumulated funds are made up of \$1,107,103 of net current assets and the Wellington property valued at \$1,595,050.

Given the strong financial position in which we finish the 2022/2023 financial year, I remain confident that Haemophilia New Zealand has the resources to advocate on behalf of people with bleeding disorders and their families; provide support to members individually; and continue to grow our educational and social events.

Hemirau Waretini

Treasurer

Statement of Financial Performance

Haemophilia New Zealand for the year ended 30 June 2023

	Notes	2023	2022
Revenue			
Donations, Fundraising, & other similar revenue	1	1,779,476	1,370,245
Fees, subscriptions, and other revenue from members	1	6,161	10,042
Revenue from providing goods or services	1	109,830	69,934
Interest, dividends, and other investment revenue	1	9,985	2,625
Other Revenue	1	336	600
Total Revenue		1,905,788	1,453,446
Expenses			
Volunteer and employee related costs	2	309,624	362,450
Costs related to providing goods or service	2	776,268	651,536
Other Expenses	2	30,903	8,466
Total Expenses		1,116,796	1,022,452
Surplus /(Deficit) for the year		788,992	430,994

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

Statement of Financial Position

Haemophilia New Zealand as at 30 June 2023

	Notes	2023	2022
Assets			
Current Assets			
Bank accounts and cash	3	1,188,180	1,895,661
Debtors and prepayments	3	84,124	92,896
Investments	3	-	-
Other current assets	3	30,110	27,483
Total Current Assets		1,302,414	2,016,039
Non-Current Assets			
Property, Plant and Equipment	6	1,595,050	13,529
Total Non-Current Assets		1,595,050	13,529
Total Assets		2,897,464	2,029,569
Liabilities			
Current Liabilities			
Creditors and accrued expenses	4	153,098	63,385
Employee costs payable		39,470	43,203
Unused donations and grants with conditions	4	1,770	7,805
Other current liabilities	4	973	2,014
Total Current Liabilities		195,311	116,408
Total Liabilities		195,311	116,408
Total Assets less Total Liabilities (Net Assets)		2,702,153	1,913,161
Accumulated Funds		2,702,153	1,913,161
	5	Accumulated Surplus or (deficit)	
Total Accumulated Funds		2,702,153	1,913,161

Statement of Cash Flows

Haemophilia New Zealand for the year ended 30 June 2023

	2023	2022
Cash Flows from Operating Activities		
<i>Cash was received from:</i>		
Donations, fundraising, and other similar receipts	1,779,303	1,309,400
Fees, subscriptions, and other receipts from members	6,161	6,783
Receipts from providing goods and services	181,719	78,807
Interest, dividends, and other investment receipts	8,358	2,639
Receipts from other revenue	336	-
Total	1,975,877	1,397,629
<i>Cash was applied to:</i>		
Payments to suppliers and employees	1,082,357	968,351
Net GST	1,000	552
Total	1,083,357	970,917
Total Cash Flows from Operating Activities	892,520	426,712

Statement of Cash Flows

Cash Flows from Investing and Financing Activities			
<i>Cash was provided from:</i>			
Receipts from the sale of investments	-	160,537	
Total	-	160,537	
<i>Cash was applied to:</i>			
Payments to acquire property, plant, and equipment	1,600,000	-	
Total		-	
Total Cash Flows from Investing and Financing Activities	(1,600,000)	160,537	
Net Increase/(Decrease) in Cash	(707,480)	587,249	
Opening cash	1,895,661	1,306,398	
Closing cash	1,188,181	1,893,647	
This is represented by			
Bank accounts and cash	1,188,181	1,893,647	

Notes to the Performance Report

Haemophilia New Zealand for the year ended 30 June 2023

	2023	2022
1. Analysis of Revenue		
Donations, fundraising, and other similar revenue		
Donations	15,651	370,718
Fundraising - External (KF)	972,633	892,578
Grants	34,035	60,231
Legacies	757,157	46,718
Total Donations, fundraising, and similar revenue	1,779,476	1,370,245
Fees, subscriptions, and other revenue from members		
Registrations	2,744	6,364
Membership Fees	3,417	3,678
Total Fees, subscriptions, and other revenue from members	6,161	10,042
Revenue from providing goods or services		
Contracts	72,032	69,934
Rental income	37,798	-
Total Revenue from providing goods or services	109,830	69,934
Interest, dividends, and other investment revenue		
Interest Income	9,985	2,625
Total Interest, dividends, and other investment revenue	9,985	2,625
Other revenue		
Wage Subsidy	-	600
Other revenue	336	-
Total Other Revenue	336	600

Notes to the Performance Report

2. Analysis of Expenses	Volunteer and employee related costs		
	Wages and Salaries	309,624	362,450
	Total Volunteer and employee related costs	309,624	362,450
	Costs related to providing goods or services		
	ACC Levies	1,009	723
	Accounting	6,945	4,025
	Adult Programme	37,128	-
	Bank Fees	3,777	225
	Central	8,887	-
	Community Education (KF)	245,272	239,357
	Consultancy (including IT)	7,753	9,303
	Defensive Driving	180	-
	Footwear Programme	3,815	3,905
	Fundraising Costs (KF)	270,362	263,889
	General Expenses	2,504	1,709
	Human Resources	4,917	1,571
	Insurance Assets/Liability	7,003	6,675
	International Meetings/Conferences	-	1,741
	Loss on Sale of Asset	-	20
	Masters	278	140
	Meetings	236	21
	Midland	831	84
	National Council	32,788	850
	Needs Grants	344	512
	Northern	3,545	1,078
	Office Expenses	8,557	11,168
	Outreach	7,285	5,513
	Piritoto	-	-
	Printing, Stationery, Postage	7,648	11,152
	Professional Development and Team Meetings	8,279	4,748
	Property expenses	31,270	-
	Rent	2,035	1,863
	Southern	1,302	1,968
	Special Programmes	1,925	1,715
	Subscriptions/Memberships	1,500	1,437
	Swimming/Fitness	3,899	7,721
	Telephone & Internet	5,812	5,492
	Women's programme	-	36,855
	Youth Camp	-	25,702
	Total costs related to providing goods or services	776,268	651,536
	Other Expenses		
	Depreciation	18,480	2,716
	Legal Expenses	674	-
	Audit	-	5,750
	Total Other Expenses	30,903	8,466

Notes to the Performance Report

3. Analysis of Assets	Bank accounts and cash			
	Cheque Account	178,725	75,845	
	Legacy Account	334,832	1,178,511	
	On Call Account	-	95,227	
	Property Account	45,865	-	
	Research Account	237,865	235,166	
	Reserve Account	377,169	301,364	
	Twinning	13,725	9,548	
	Total Bank accounts and cash	1,188,180	1,895,661	
	Debtors and prepayments			
	ACEET Funds Receivable	-	2,375	
	Prepayments	1,612	4,522	
	Accounts receivable	82,512	85,999	
	Total Debtors and prepayments	84,124	92,896	
	Other current assets			
	GST	28,429	27,429	
	Interest Receivable	1,681	54	
	Total Other current assets	30,110	27,483	
	Total Analysis of Assets	1,302,414	2,016,039	
4. Analysis of Liabilities	Creditors and accrued expenses			
	Accounts Payable	61,579	96,939	
	Accruals	8,500	-	
	CG Twinning - Funds Held	10,900	9,419	
	Contracts Invoiced in Advance	72,119	230	
	Total Creditors and accrued expenses	153,098	106,588	
	Unused donations and grants with conditions			
	Grants in Advance	1,770	7,805	
	Total Unused donations and grants with conditions	1,770	7,805	
	Other current liabilities			
	BNZ Visas	973	2,014	
	Total Other current liabilities	973	2,014	
	Total Analysis of Liabilities	195,311	116,408	
5. Accumulated Funds	Accumulated Funds			
	Opening Balance	1,913,161	1,482,167	
	Accumulated surplus or (deficit)	788,992	430,994	
	Closing Balance	2,702,153	1,913,161	
	Total Accumulated Funds	2,702,153	1,913,161	
6. Property, Plant, and Equipment	Office Equipment			
	Open Carrying Amount	13,529	12,277	
	Purchases	1,600,000	3,988	
	Sales/Disposals	-	(20)	
	Depreciation	18,479	2,716	
	Closing Carrying Amount	1,595,050	13,528	

Notes to the Performance Report

7. Related Party Transactions	Description of related party relationship	Description of the transaction	2023	2022
	Stephen Waring - Director of Kiwifirst and Co-opted Member of the Board of Haemophilia NZ	Kiwifirst Costs (Fundraising costs plus community education)	515,634	503,246
		Kiwifirst Fundraising	972,633	892,578
		Receivable from Kiwifirst (inc. GST)	35,240	30,097
8. Grant Income	Grants Received in the Year		2023	2022
		Novo Nordisk Pharmaceuticals Pty	-	8,696
		Pub Charity	8,000	-
		Rata Foundation	10,000	-
		Roche Products	10,000	-
		Sanofi-Averntis Australia	-	20,000
		The Trusts Community Foundation	-	20,000
		Trust Waikato	-	5,000
		Total Grants Received in the Year	28,000	53,696
		Less: 2023 Grants in Advance	(1,770)	(7,805)
		Add: 2022 Grants in Advance	7,805	14,340
		Total Grants Income	34,035	60,231
9. Statement of Commitments	There are no commitments as at balance date. 30/06/2022 (Nil)			
10. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/2022 (Nil)			
11. Events After Balance Date	There were no events that have occurred after the balance date that would have material impact on the performance report.			

Statement of Accounting Policies

Haemophilia New Zealand for the year ended 30 June 2023.

Basis of Preparation

Haemophilia New Zealand (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.

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.

Property, Plant, and Equipment

All Property, Plant and Equipment is recorded at cost less accumulated depreciation. Only assets costing \$1,000 or more are capitalised, those less than this are expensed. The Society has the following classes of assets, which are depreciated using the following rates:

- Land 0%
- Buildings - 2% SL
- Office equipment - 40-50% DV and 10-33% SL

Income Tax

The Society is wholly exempt from New Zealand income tax having fully complied with all statutory conditions for these exemptions.

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.

Changes in Accounting Policies

There have been no changes in accounting policies during the financial year (last year - nil).

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.

Revenue Recognition

Donations, Fundraising and Legacies

Donations, fundraising and legacies are recognised on receipt.

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 Unused donations and grants with conditions.

Contracts and Rental Income

Contracts and rental income are recognised when the goods/services are provided.

Registration and Membership Fees

Registration and membership fee income is recognised on receipt.

Other Income

All other income is recognised on receipt.

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

Adult Wellness Weekend

25 - 27 November 2022

Living with a bleeding disorder, or living with a person with a bleeding disorder, is challenging. The Adult Wellness Weekend is an opportunity for adults with bleeding disorders to 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 HNZ and its activities. Adult Weekends also include partners.

"I really enjoy HNZ gatherings, especially strengthening ties with others with similar stories, and friendships built through these workshops. I appreciate the support from HNZ clinicians and outreach workers, and learning to support others in our area".

"I find these events so rewarding. The fellowship and information that I receive when attending these functions is invaluable. Also, because of my location, there is nothing available within my area".

30 members and their partners, and 10 staff/leaders attended this event.

National Family Camp

11 - 14 April 2023

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

"Great experience with families in the same situation as us. Kids find a sense of belonging, with a huge amount of support from staff and other families alike".

"Had a fantastic time at the camp. The kids were all

well looked after, and will have fond memories of their time here for a long time. The information and relationships provided for the parents was so great. We are very grateful to have been welcomed and will look forward to attending future camps".

18 whānau, comprising 31 adults and 36 children, 7 staff and clinicians, and 7 youth leaders attended this event.

Other Significant Programmes

Outreach Support Services for people with bleeding disorders and their families

During the 2022/23 financial year, the Outreach team made 2367 contacts with people with bleeding disorders. This represents a 29% decrease over the previous year. This is largely due to several months with just two outreach staff available due to illness and delayed hiring. The Outreach service directly supported more than 634 individual members and whānau with bleeding disorders in the year July 1 2022 to June 30 2023. Issues dealt with included grants, physical activity, school support, and reproduction. Forty-seven percent of contacts were via email, 18% by phone, and 17% by text message. Other methods used included face-to-face, social media, and paper mail.

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 on pages 7 to 19, which comprises the entity information, the statement of service performance, the statement of financial performance and statement of cash flows for the year ended 30 June 2023, the statement of financial position as at 30 June 2023, and the statement of accounting policies and other explanatory information.

In our opinion:

- a) the reported outcomes and outputs, and quantification of the outputs to the extent practicable, in the statement of service performance are suitable;
- b) the accompanying performance report 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 2023, 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 by the New Zealand Accounting Standards Board.

Basis for Opinion

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

We are associated with Ainger Tomlin Limited who assisted with the compilation of the Performance Report. We have no other relationship with, or interests in, Haemophilia Foundation of New Zealand Incorporated.

Other Matter

The performance report of Haemophilia Foundation of New Zealand Incorporated for the year ended 30 June 2022 was audited by another auditor who expressed an unmodified opinion on the performance report on 13 October 2022.

Restriction on Responsibility

This report is made solely to the Members, as a body, in accordance with section 42F of the Charities Act 2005. Our audit work has been undertaken so that we might state to the Members those matters we are required to state to them in an auditor's 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 Members as a body, for our audit work, for this report, or for the opinions we have formed.

Responsibilities of the National Council for the Performance Report

The National Council are responsible for:

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

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

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

In preparing the performance report, the National Council are responsible on behalf of Haemophilia Foundation of New Zealand Incorporated for assessing Haemophilia Foundation of New Zealand Incorporated'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 Haemophilia Foundation of New Zealand Incorporated or to cease operations, or have no realistic alternative but to do so.

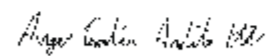
Auditor's Responsibilities for the Audit of the Performance Report

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

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

- Identify and assess the risks of material misstatement of the performance report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management.
- Conclude on the appropriateness of the use of the going concern basis of accounting by the National Council and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on Haemophilia Foundation of New Zealand Incorporated'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 Haemophilia Foundation of New Zealand Incorporated 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.



Ainger Tomlin Audit Limited
Christchurch
19 September 2023

Entity Information

The Haemophilia Foundation of New Zealand Incorporated, also known as Haemophilia NZ (HNZ), 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.

HNZ is governed by a board of eleven members and whānau. The council comprises the Chair, two Vice Chairs, 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 full-time equivalent staff employed to provide support and education programmes. They are based in Auckland, Cambridge, Levin, and Christchurch.

HNZ'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.

Directory

Board

Chair:	Deon York
Vice Chairs:	Catriona Gordon Karl Archibald
Treasurer:	Hemirau Waretini
Northern Branch Delegate:	Hemirau Waretini
Midland Branch Delegate:	Tineke Maoate
Central Branch Delegate:	Vacant
Southern Branch Delegate:	Lauren Phillips
Piritoto Delegate:	Vacant
Youth Delegate:	Connor McCone
Co-opted Member:	Marty Waring

Staff

Administration	
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:	Vic Turner

HNZ Affiliation

World Federation of Hemophilia www.wfh.org

Branches

Northern Branch Chair:	Vacant
Midland Branch Chair:	Tineke Maoate
Central Branch Chair:	Tracy Nyhan
Southern Branch Chair:	Vacant
Piritoto Branch Chair:	Tuatahi Pene
Youth Branch Chair:	Vacant

Appreciations

HNZ 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.

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 HNZ.



Supporters

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



Major Donors and Grants

Purpose

CSL Behring Educational Grant	Website
Roche Products (New Zealand) Ltd	Family Camp
Trust Waikato National	Family Camp
Pub Charity	Central Camp
Rata Foundation	Family Camp

Bequests

FrontinRolle Estate
H Bigger Estate
McClintock Estate

Individual and general donations over \$100

John Hunter
David & Alison Mountfort
Kiwifirst
R-Leeo Maoate
Givealittle
Jim Brambley
Toni McWhinnie
Sue Dench
Maude Ingham
J Holwell
B & C Hodgson Sub Trust
M & C Louisson

In Memoriam

HNZ 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
- Ray Ferguson

HNZ 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.

Haemophilia
New Zealand

