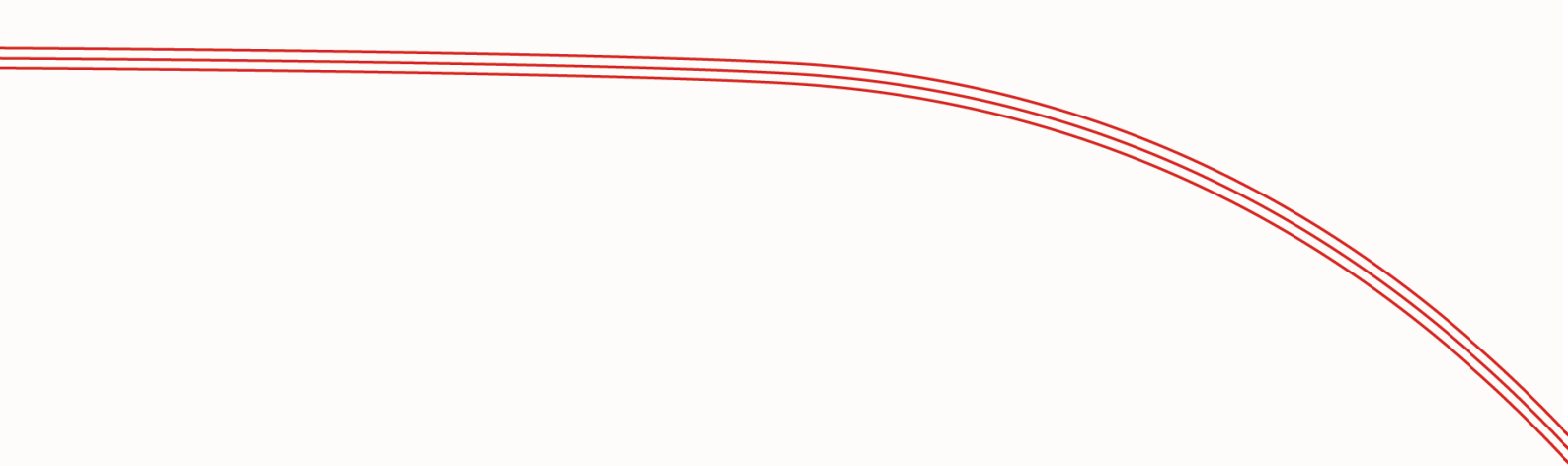


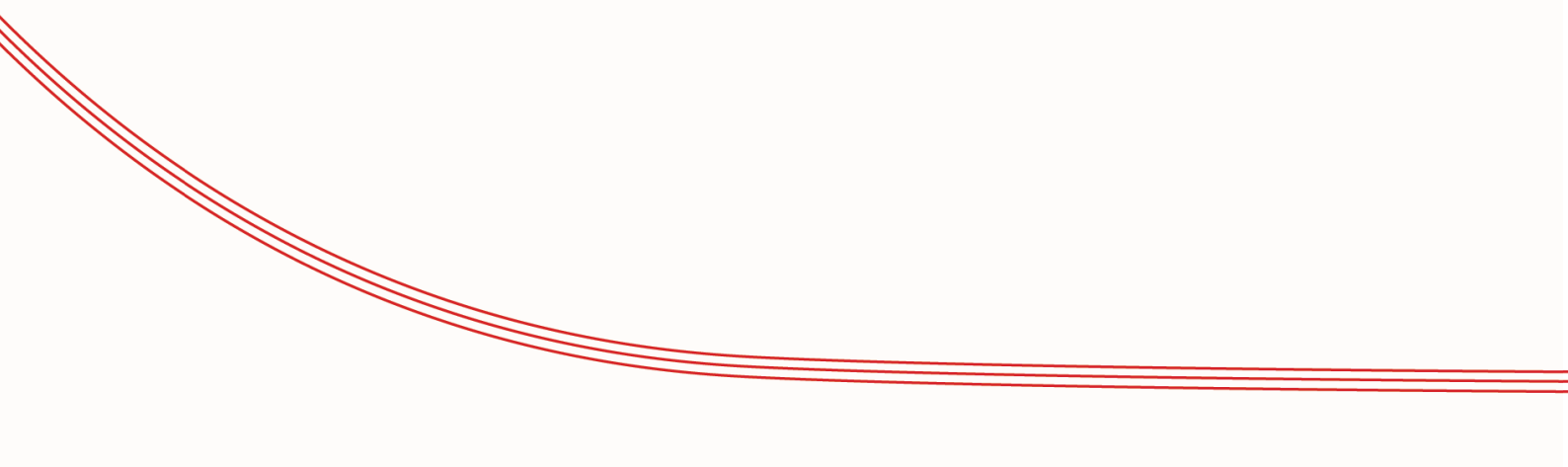


Haemophilia New Zealand Annual Report: 2023/24

1 JULY 2023 TO 30 JUNE 2024



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



About 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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02. Chair & CEO Message *Deon York looks at HNZ's role in the larger bleeding disorder community.*
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19. Appreciations *Thanking those who have made significant financial contributions to HNZ in the 2023/24 year.*
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Chair & Acting Chief Executive Report

Deon York

This report covers the period 1 July 2023 to 30 June 2024.

I concluded last year's report with hope that the funding of emicizumab (Hemlibra) would extend beyond people with haemophilia A and inhibitors to all people with moderate and severe haemophilia, stating that this would represent a significant improvement in treatment. As we reached the last quarter of 2023 this is exactly how the decision went. I was informed just hours before the announcement. This is the most significant achievement for our members in 2023/24. The advocacy in the background, the patience, and the perseverance all paid off. Of course, a therapy behaves differently from person to person, but this does not alter that this is the most significant step forward in therapy in more than 25 years, and that is something to celebrate. We will continue to follow the trends for the haemophilia B treatment pipeline, von Willebrand's and rare factor deficiencies.

We began this year with a full outreach team with Vic Turner joining us just prior to our new financial year alongside Lynne, Darian, and Loren, with Phil and Leanne continuing to keep the daily operation of the organisation on track. Thank you to the team for your commitment to improving the lives of our members. I would also like to take the opportunity to thank the volunteers alike for their dedication to HNZ. Thanks to Catriona and Karl (vice-chairs), Hemi (treasurer), Tineke (delegate), Lauren (delegate), and Connor (youth delegate) for your time on the board this past year. I equally acknowledge the crucial role Kiwifirst plays as our chief fundraiser. Thank you to all the staff at Kiwifirst who continue to work tirelessly, and the public who believe in our cause and loyally donate so it is possible for us to support our members.

I personally acknowledge the support of Roche, Sanofi, Novo Nordisk, CSL Behring Educational, Rātā Foundation, and Pub Charities. Your contributions made our events and education and training opportunities possible. World Federation of Hemophilia must also be acknowledged for its funding of the Fiji Haemophilia Foundation and HNZ twinning.

Activities for members included a webinar on Hemlibra, a youth sailing event (January 2024), and a successful teen and youth camp (March 2024). The camp, for 10- to 18-year-olds, used 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 was on being well informed and better able to make decisions about bleeding disorder treatment, education, work, lifestyle and relationships.

During this year, the outreach team made 2,489 contacts with people with bleeding disorders. This represents a 5% increase over the previous year. The outreach service directly supported more than 713 individual members and whānau with bleeding disorders in the year July 1 2023 to June 30 2024. Issues dealt with included grants, physical activity, school support, and reproduction. 16% of these were in person. The volume is one way to measure, but the quality is equally important with members reporting to us that the support has led to better outcomes in many cases. The demand for subsidised gym and swimming membership and supportive footwear continued for our members.

We took possession of 44 Victoria Street, Alicetown in the greater Wellington region in the last financial year, and since then, much work has been underway to obtain building consent, plan works and move items to the new office space. In 2024/25 the national office will be officially opened and be a space for all our members to come and visit reaching the aspiration long held by many of our members to have a permanent home for our organisation.

2023/24 also saw a range of educational opportunities for staff and volunteers alike. Darian and Loren attended Haemophilia Foundation Australia's conference in August 2023; Hemi continued with the (now retired) AFFIRM leadership programme; Lauren presented at the Global Summit on Women and Girls with Bleeding disorders in September 2023; Catriona, Hemi, and I attended the global forum in Montreal in November 2023, and a delegation of members along with nursing and physio staff attended the World Federation of Hemophilia's world congress in



Madrid in April 2024. The WFH twinning programme with the Fiji Haemophilia Foundation and HNZ continued. These opportunities combined offer years of presentation and written material to disseminate to our members.

The Madrid congress included a complete surprise and well concealed secret that saw me receiving the International Frank Schnabel Volunteer Award for 2024. As I stood on the stage to receive the award, completely speechless, every attendee witnessed a haka in the distance from Tineke, John, and Lauren. I was truly moved. Thank you.



As I conclude this year serving as the chair as well as the acting chief executive at unsociable hours with a focus on planning and fundraising, I can say with confidence that the organisation is in excellent shape and well set up for the future.

When I began as chair, HNZ was an organisation with accumulated assets of \$650,000. As we report this year, we are now the custodians of assets and accumulated funds of more than \$2.7 million. Every dollar is testament to stellar fundraising across the country, volunteer contribution, the grant support we have received over the years, the generosity of the public, and prudent investment.

Our role as a not-for-profit is to spend funds for our charitable purpose, although this must be tempered with sound financial management. It is also important to note that many funds have specific tagged purposes or are accumulated assets and therefore not 'liquid'. No one can predict future financial circumstances, but we can always plan for them. Diligent financial oversight will remain crucial in the years to come.

Over these many years, I have seen an increase in the breadth and depth of events, educational opportunities, and events for our members. I have noted the continuous improvement of care and treatment for people with haemophilia and related inherited bleeding disorders. The recognition of HNZ as a trusted advisor has improved year on year. We should all be proud of the steady growth of HNZ.

It is my intention to step down as chair in the next financial year. With Hemlibra now available, the property almost open, and the staff and board in good heart alongside many of our members, the time is right.

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

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

While I will likely be chair for part of 2024/25, my advice to any future board, staff, or volunteer is:

Stay true to our mission: Care, education, advocacy, and support for all people with haemophilia and related bleeding disorders. The emphasis is on all – in other words, no one should be left behind.

Constantly follow trends in the latest therapies and treatment: No one, not even the system itself, will take a greater interest in the potential new therapies on offer than you.

Continue to expand our horizons: Consider how to bring talent in from both our members and beyond. Remain committed to continuous improvement for both the organisation and our members.

Always remember our strength: Our people are our greatest asset and HNZ exists to serve our people. Our connections run deep, and our shared history binds us together. This is our strength.

I thank you all wholeheartedly for your support and sign off this year while looking to a busy coming year with regions all planning large events, a women's wellness weekend, family camp, and – finally – a home for HNZ to be officially opened in Wellington.

Deon York

Chair and Acting Chief Executive

Branch Reports

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

HNZ branches have been getting busier as the year has progressed. Early in the year, the **Northern** crew headed off to the Sweet Axe Throwing Co. for some sharp-projectile-based fun. While sharp axes and bleeding disorders may not seem like a great mix, the crew had a fantastic time, and we're pleased to report no injuries. Later in the year they enjoyed another active outing, this time the Game Over Auckland. There was fun for young and old with go karts, laser tag, and mini golf. Northern also enjoyed a couple of more relaxed outings to Goode Brothers New Lynn in November, then again in May. This was a great way for Northern members to connect over good food and conversation.



an Xmas event at the Staglands Wildlife Reserve in Upper Hutt. These were fantastic opportunities for Central members from different parts of the region to get together and reconnect. In April 2024 the Central branch were the only HNZ group to run an event to celebrate World Haemophilia Day. They enjoyed lunch at the Salt and Pepper Cafe in Levin.

The **Southern** branch year started with new outreach worker Vic Turner hitting the road to visit her patch in the lower South Island. She hit Oamaru, Cromwell, Winton, Invercargill, Balclutha, Dunedin, and Rolleston. While out and about she met and dined with a number of Southern members at a variety of small town locations. It was a real opportunity for members to get to know their new outreach worker, and to know that they're an important part of HNZ.

Meanwhile, the **Midland** crew enjoyed their own active event with a visit to Rocktopia for a rock-climbing adventure, followed by some lunch. This is a fantastic way to get members together and working to support one another. Later in the year the call went out for more people to join the Midland committee. In Midland, as in other regions, there are only a small handful of people working hard to plan and run opportunities for local members. Now they have a committee of five volunteers, which is much better than the one they had previously. To end the year the Midland crew headed for the Mighty River Domain for The Great Kiwi Summer Festival. This was a great way to end the year, with fun and games for all.



The Southern year ended with a Christmas pool party at Te Hāpua Halswell pool, which was enjoyed by all. The rest of the 2023/24 year was taken up with planning for the first Southern Camp in over 10 years. The first part of this was getting a committee together. In Southern's case there was no committee at all. Following Vic's efforts there is now an enthusiastic committee of 13 volunteers. The upshot was a fantastic family camp in Hanmer Springs late in 2024, but more of that next annual report.

Committee growth was also a focus for the **Central** group. They too put out the call, and were able to add three new committee members. This is an important role, and really helps HNZ to support and advocate for people with bleeding disorders. Please consider supporting your local committee if you are able.

Central held their AGM as part of a family event at the Herb Farm Gardens in Palmerston North in September 2023, then enjoyed



The **Youth** branch have become more active over the course of the year. This culminated in a youth sailing event on the beautiful Hauraki Gulf, aboard Whitbread Around the World yacht race winner Steinlager 2. This was an amazing experience that galvanised the Youth crew into planning more opportunities. As a result they are now meeting regularly and preparing for a youth twinning with Pakistan in 2025.

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.

Teen & youth camp

From 1 to 3 March 2024 young people aged 11 – 17 gathered in Auckland for the 2024 HNZ teen and youth camp (TYC). This event comes around every two years and is a key part of HNZ's psychosocial and educational pathway.

Growing up is exciting, challenging, and often very confusing. When a bleeding disorder is added to the mix the challenges of young adulthood only increase. TYC is an event aimed at for 11–17-year-olds, which 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, lifestyle, and relationships. Siblings of people with bleeding disorders are also invited to this camp because living in a household where a person has a bleeding disorder affects everyone.

The 2024 TYC was held at the Sir Peter Blake Marine Education and Recreation Centre (MERC) at Auckland's Long Bay. This is a fantastic venue, with good facilities, which offers a wide range of supported outdoor activities. For this event MERC offered our young people the chance to learn how to get out on the water safely, some tips for survival in the wilderness, and some fun with projectiles. The MERC staff were fun and skilled. They ensured that our young people had a great time and learned a lot.

This was a shorter camp than usual, just two nights, due to the availability of the venue. That meant a very full programme indeed.

On day one, everyone arrived at MERC via bus from the airport. We were not allowed on site until 5pm, so we took the opportunity for some getting-to-know-you activities on the beach. Once we were allowed in, we quickly allocated beds and got organised for dinner. The first big activity of the weekend was to get into our three teams and build our mascots. For this activity each group was given a raw egg and a bunch of junk. Their task was to make a mascot that could be a part of the group, attend all the activities, and keep the egg intact until the 'autopsy' at the end of camp. This is always a popular activity, and we ended up with some innovative creations.

With time up our sleeves, after making our mascots we headed across to the reserve for a game of spotlight in the dark. This was an excellent way to wind up the day and was enjoyed by all.

After not much sleep, and a whole lot of noise, day two dawned bright and clear. This was to be a very full day indeed, which kicked off after breakfast with Darian's big scavenger hunt. Each team was given a list of 15 things to find in the reserve/beach/camp area. This was a fantastic way for the campers to learn a bit about the area, and to bond as a team. It was great to see the mascots going along for the ride too.

Once everyone was all scavenged out, we took to the beach for a quick-fire sandcastle competition, before heading in for the first education session of the day.

HNZ treasurer Hemirau Waretini joined us after morning tea to talk about growing up in HNZ. He recounted his own journey through events like the national family camp and teen & youth camp, and he reflected on the strength of the life-long bonds of friendship he developed. It was valuable for the young attendees to see first-hand the direct pathway from this event to becoming a leader of an organisation like HNZ. Hemi followed up his talk by running a short workshop on events and activities that may be relevant to this age group in the future. This was a very successful session, and we are grateful to Hemi for offering us his time and insight.

After lunch it was time for the most anticipated activity of the weekend. One of the great things about MERC is the access to the beach and the sea. They also supply equipment and experienced instructors to allow campers to get out on the water. We were very pleased to be able to don life-jackets and wetsuits, and take to the water aboard kayaks, a giant paddle-board, and a trimaran canoe. This was a great time, which was enjoyed by all. Even better, those who were feeling brave were able to do a bit of snorkelling and admire the fish and kina. This was a long afternoon, but everyone returned to shore excited by the experience.

After some quiet time and some dinner, we were very lucky to have haemophilia nurse specialist Vanessa Minor from the Auckland HTC come in to talk to us about all things BD. Vanessa's talk was full of



interesting information, and a quick quiz afterwards showed that the young people had taken a lot on board. It was particularly pleasing to see the young men growing an understanding of the challenges facing young women with BDs. We really appreciate Vanessa making the time for us at this event.

As is traditional, the final night of camp is movie night. This year was no exception, and the crew enjoyed the chance to relax, eat popcorn, and wind down after a long day. It was telling that once we all hit bed it got quiet a lot quicker than the night before!

The final day of camp saw another MERC led activity. We were divided into two groups who swapped between a survival activity, and a projectiles activity. For the first, campers were taught to light a camp-fire using a flint and available natural materials. The payoff for this was marshmallows at the end. The projectiles activity involved contrasting a catapult and launching tennis balls, as well as learning to make and throw flax darts, known as teka. These were excellent activities that really got the kids thinking.

That was it for activities for the weekend, all there was left was to clean up, and reflect on another successful event. At the final assembly we took the opportunity to thank the fantastic leaders, who had volunteered their time and enthusiasm to support our young people. We also recognised the staff and board members who had contributed, especially Tineke and John Maoate who were our camp mum and dad once again.

The final act was to give out graduation certificates, and to award the winners of the top team. Throughout the camp we had been giving out points for good behaviour. When the points were tallied, we found that we had a tie! The only correct thing to do was to hold an elimination game of rock, paper, scissors. Congratulations to Cassie who secured the win for the mighty green team in the most exciting and tense game of rock, paper, scissors ever seen.

This camp would not have been possible without the support of Sanofi and Roche, who provided funding support. Without the participation of external funders like these we would struggle to offer the high-quality events we do. Thank you.



HNZ Financial Report

For the 12 months ending 30 June 2024

Tēnā koutou katoa,

The audited financial statements for Haemophilia New Zealand can be found in this annual report. Despite budgeting for a small deficit for the year to 30 June 2022, HNZ is reporting a modest surplus of \$83,248. This difference is due to higher income received and lower than expected spending. Income received through grants has rebounded significantly, following a marked increase in applications, HNZ also retains a steady income from the rented portion of the Wellington property. Interest income increased significantly following the receipt of a number of large bequests. HFNZ continued to receive a contribution to outreach worker salaries from Te Whatu Ora / Health NZ.

At 30 June 2024 the Foundation had total accumulated

funds of \$2,785, 401.

Given that we again end the year in a strong financial position, 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.

Now that the long-term goal of the HNZ membership of purchasing a ‘Home for Haemophilia’ has been attained, it is time to consider the best investment for our retained surplus funds.

Naku noa nā,

Hemirau Waretini

Treasurer. HNZ

Statement of Financial Performance

Haemophilia New Zealand for the year ended 30 June 2024

	Notes	2024	2023
Revenue			
Donations, Fundraising, & other similar revenue	1	1,083,644	1,779,476
Fees, subscriptions, and other revenue from members	1	3,800	6,161
Revenue from providing goods or services	1	99,154	109,830
Interest, dividends, and other investment revenue	1	44,765	9,985
Other Revenue	1	-	336
Total Revenue		1,231,363	1,905,788
Expenses			
Volunteer and employee related costs	2	354,538	309,624
Costs related to providing goods or service	2	765,019	776,268
Other Expenses	2	28,559	30,903
Total Expenses		1,148,115	1,116,796
Surplus /(Deficit) for the year		83,248	788,992

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 2024

	Notes	2024	2023
Assets			
Current Assets			
Bank accounts and cash	3	1,134,440	1,188,180
Debtors and prepayments	3	111,786	84,124
Other current assets	3	36,388	30,110
Total Current Assets		1,282,613	1,302,414
Non-Current Assets			
Property, plant and equipment	6	1,573,575	1,595,050
Other non-current assets	3	76,246	-
Total Non-Current Assets		1,649,820	1,595,050
Total Assets		2,932,433	2,897,464
Liabilities			
Current Liabilities			
Creditors and accrued expenses	4	99,508	153,098
Employee costs payable		47,524	39,470
Unused donations and grants with conditions	4	-	1,770
Total Current Liabilities		147,032	195,311
Total Liabilities		147,032	195,311
Total Assets less Total Liabilities (Net Assets)		2,785,401	2,702,153
Accumulated Funds			
Accumulated Surplus or (deficit)	5	2,785,401	2,702,153
Total Accumulated Funds		2,785,401	2,702,153

Statement of Cash Flows

Haemophilia New Zealand for the year ended 30 June 2024

	2024	2023
Cash Flows from Operating Activities		
<i>Cash was received from:</i>		
Donations, fundraising, and other similar receipts	1,086,964	1,779,303
Fees, subscriptions, and other receipts from members	3,800	6,161
Receipts from providing goods and services	27,318	181,719
Interest, dividends, and other investment receipts	44,612	8,358
Receipts from other revenue	-	336
Total	1,162,694	1,975,877
<i>Cash was applied to:</i>		
Payments to suppliers and employees	1,162,504	1,082,357
Net GST	6,124	1,000
Total	1,168,628	1,083,357
Total Cash Flows from Operating Activities	(5,934)	892,520

Statement of Cash Flows

Cash Flows from Investing and Financing Activities			
<i>Cash was provided from:</i>			
Receipts from the sale of investments	-	-	
Total	-	-	
<i>Cash was applied to:</i>			
Payments to acquire property, plant, and equipment	46,833	1,600,000	
Total	46,833	1,600,000	
Total Cash Flows from Investing and Financing Activities	(46,833)	(1,600,000)	
Cash balances			
Net Increase/(Decrease) in Cash	(52,767)	(707,480)	
Opening cash	1,187,207	1,895,661	
Closing cash	1,134,440	1,188,181	
This is represented by			
Bank accounts and cash	1,134,440	1,188,181	

Notes to the Performance Report

Haemophilia New Zealand for the year ended 30 June 2024

		2024	2023
1. Analysis of Revenue	Donations, fundraising, and other similar revenue		
	Donations	34,709	15,651
	Fundraising - External (KF)	959,724	972,633
	Grants	89,208	34,035
	Legacies	3	757,157
	Total Donations, fundraising, and similar revenue	1,083,644	1,779,476
	Fees, subscriptions, and other revenue from members		
	Registrations	-	2,744
	Membership Fees	3,800	3,417
	Total Fees, subscriptions, and other revenue from members	3,800	6,161
	Revenue from providing goods or services		
	Contracts	72,032	72,032
	Rental income	27,122	37,798
	Total Revenue from providing goods or services	99,154	109,830
	Interest, dividends, and other investment revenue		
	Interest Income	44,765	9,985
	Total Interest, dividends, and other investment revenue	44,765	9,985
	Other revenue		
	Other revenue	-	336
	Total Other Revenue	-	336
2. Analysis of Expenses	Volunteer and employee related costs		
	Wages and Salaries	354,538	309,624
	Total Volunteer and employee related costs	354,538	309,624

Notes to the Performance Report

Costs related to providing goods or services		
ACC levies	730	1,009
Accounting	2,195	6,945
Adult programme	-	37,128
Bad debts	30	-
Bank fees	172	3,777
Central	4,231	8,887
Community education (KF)	239,189	245,272
Consultancy (including IT)	11,874	7,753
Defensive driving	220	180
Footwear programme	4,361	3,815
Fundraising costs (KF)	263,845	270,362
General expenses	338	2,504
Human resources	-	4,917
Insurance assets/liability	7,675	7,003
International meetings/conferences	47,345	-
Masters	237	278
Meetings	-	236
Midland	887	831
National council	24,248	32,788
Needs grants	1,890	344
Northern	3,982	3,545
Office expenses	9,654	8,557
Outreach	24,327	7,285
Payroll costs	534	-
Period programme	89	-
Printing, stationery, postage	4,408	7,648
Professional development and team meetings	22,034	8,279
Property expenses	23,519	31,270
Rent	1,526	2,035
Southern	3,993	1,302
Special programmes	-	1,925
Subscriptions/memberships	1,089	1,500
Swimming/fitness	6,954	3,899
Telephone & internet	5,124	5,812
Youth camp	26,793	-
Youth leadership	21,526	-
Total costs related to providing goods or services	765,019	776,268
Other Expenses		
Depreciation	21,475	18,480
Legal Expenses	612	674
Audit	6,172	-
Total Other Expenses	28,559	30,903

Notes to the Performance Report

3. Analysis of Assets	Bank accounts and cash		
		BNZ Visas	(3,612) (973)
		Current Account	102,135 178,725
		Legacy account	346,000 334,832
		Property account	72,690 45,865
		Research account	209,431 237,865
		Reserve account	394,594 377,169
		Twinning Fiji	13,202 13,725
		Total bank accounts and cash	1,134,440 1,188,180
		Debtors and prepayments	
		Prepayments	34,364 1,612
		Accounts receivable	77,422 82,512
		Total debtors and prepayments	111,786 84,124
		Other current assets	
	GST	34,553 28,429	
	Interest receivable	1,835 1,681	
	Total other current assets	36,388 30,110	
4. Analysis of Liabilities	Creditors and accrued expenses		
		Accounts Payable	77,531 61,579
		Accruals	8,600 8,500
		Twinning funds held - Fiji	13,095 10,900
		Contracts invoiced in advance	283 72,119
		Total creditors and accrued expenses	99,508 153,098
		Employee costs payable	
		Gross wages payable	9,816 12,416
		PAYE payable	7,630 6,474
		Leave provision	30,078 20,580
		Total employee costs payable	47,524 39,470
		Unused donations and grants with conditions	
		Grants in Advance	- 1,770
		Total unused donations and grants with conditions	- 1,770
5. Accumulated Funds	Accumulated surplus or (deficit)		
		Opening Balance	2,702,153 1,913,161
		Net accumulated surplus or (deficit)	83,248 788,992
		Total accumulate surplus or (deficit)	2,785,401 2,702,153
		Total Accumulated Funds	2,785,401 2,702,153
6. Property, Plant, and Equipment	Office Equipment		
		Open Carrying Amount	1,595,050 13,529
		Purchases	- 1,600,000
		Sales/Disposals	- -
		Depreciation	21,475 18,479
		Closing Carrying Amount	1,573,575 1,595,050

Notes to the Performance Report

7. Related Party Transactions	Description of related party relationship	Description of the transaction	2023	
	Stephen Waring - Director of Kiwifirst and Co-opted Member of the Board of Haemophilia NZ. Ceased being member of National Council for the Haemophilia Foundation as at 30 June 2023.	Kiwifirst Costs (Fundraising costs plus community education)	Nil	515,634
		Kiwifirst Fundraising	Nil	972,633
		Receivable from Kiwifirst (inc. GST)	Nil	35,240
8. Grant Income	Grants Received in the Year			
		Novo Nordisk Pharmaceuticals Pty	20,000	-
		Pub Charity	-	8,000
		Rata Foundation	-	10,000
		Roche Products	25,000	10,000
		Sanofi-Averntis Australia	42,438	-
		Total Grants Received in the Year	89,208	28,000
		Less: 2024 Grants in Advance	-	(1,770)
		Add: 2023 Grants in Advance	1,770	7,805
		Total Grants Income	89,208	34,035
9. Statement of Commitments	The Board has approved upgrades to 44 Victoria Street. As at the year end, a building contract with Switched on Building Solutions has been agreed. The total contract is for \$101,128, \$55,349 has been completed and \$45,779 remains. Further work totalling \$20,897 has been completed, resulting in a total of \$76,246 in work in progress. (2023: Nil)			
10. Statement of Contingencies	There are no contingent liabilities as at balance date. 30/06/2023 (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 2024.

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 \$5,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. The Performance Report is prepared under the assumption that the society 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

Teen & youth camp

1 – 3 March 2024

The HNZ 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 had a great time at this year’s youth camp; the people were really nice and including and I learnt a lot. I really liked all the activities we did and I especially enjoyed the ones on the water. The food was great and I learnt a lot from Vanessa and Hemi. A huge thank you to MERC and HNZ, thanks for a great camp.”

“This camp has been really enjoyable because I’ve

met new people like me. We had lots of fun together. In the dorm rooms I met new people and we started talking a lot at night.”

27 children and 18 staff/leaders/clinicians attended this event.

Other Significant Programmes

Outreach Support Services for people with bleeding disorders and their families

During the 2023/24 financial year, the Outreach team made 2489 contacts with people with bleeding disorders. This represents a 5% increase over the previous year. The Outreach service directly supported more than 713 individual members and whānau with bleeding disorders in the year July 1 2023 to June 30 2024. Issues dealt with included grants, physical activity, school support, and reproduction. Thirty-three percent of contacts were via email, 29% by text message, and 16% face-to-face. Other methods used included phone, social media, and paper mail.

While there is only one national event recorded for this financial year, HNZ ran a national family camp in April 2023 and a women's wellness weekend in July 2024, just outside the notifiable time frame.

INDEPENDENT AUDITOR'S REPORT

To the Members of Haemophilia Foundation of New Zealand Incorporated

Opinion

We have audited the accompanying performance report of Haemophilia Foundation of New Zealand Incorporated on pages 7 to 18, 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 2024, the statement of financial position as at 30 June 2024, 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 performance report on pages 7 to 18 presents fairly, in all material respects:
 - the entity information for the year ended 30 June 2024;
 - the service performance for the year then ended; and
 - the financial position of Haemophilia Foundation of New Zealand Incorporated as at 30 June 2024, 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).

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 New Zealand Auditing Standard (NZ AS1) 'The Audit of Service Performance Information (NZ)'. 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.

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.

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.

Board's Responsibility for the Performance Report

The Board are responsible on behalf of the entity 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 which comprises:

- the entity information;

- the statement of service performance; and

- the statement of financial performance, statement of financial position, statement of cash flows, statement of accounting policies and notes to the performance report

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

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

In preparing the performance report, the Board are responsible on behalf of the entity for assessing the entity'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 Board either intend to liquidate the entity 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 ISAs and NZ AS1 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 decisions of users taken on the basis of this performance report.

As part of an audit in accordance with ISAs (NZ) and NZ AS1, 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 Board 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 Board 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 Utd.

Ainger Tomlin Audit Limited
Christchurch
29 October 2024



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

Acting CE:	Deon York
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:	Dylan Shadbolt
Piritoto Branch Chair:	Tuatahi Pene
Youth Branch Chair:	Connor McCone

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

Major Donors and Grants	Purpose
Roche Products NZ) Ltd	Youth Workshop
Roche Products NZ) Ltd	Teen & Youth Camp 2023
Roche Products NZ) Ltd	Support Nurses & Physios to attend WFH Congress 2024
Sanofi-Aventis Australia Pty Ltd	Educational Grant for Youth Camp
Sanofi-Aventis Australia Pty Ltd	Educational Grant for Youth Leadership
Novo Nordisk Pharmaceuticals Pty Ltd	Youth Camp
Novo Nordisk Pharmaceuticals Pty Ltd	Youth Leadership
CSL Behring Educational Grant	HNZ website

Bequests

Estate of L Shepherd

Individual and general donations over \$100

Bronwyn Dunn

C De Groot

David & Alison Mountfort

Donations in memory of Ron Fowler

Gay & Peter McDonnell-Nola

J Holwell

John Hunter

K Monk

M & C Louisson

M Nairn

Maude Ingham

P Lyons-Montgomery

Peter Anderson

Quality Hotel Parnell

S Pickles

Sheryl & Renier Venter

Shirley Bongard

SM Carr

Sue Dench

Toni McWhinnie

In Memoriam

HNZ notes with sadness the passing of the following members and friends of HNZ between July 1 2023 and June 30 2024:

- Joseph Nio
- Robyn Watson
- Bruce Marnoch

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

Haemophilia
New Zealand

