RARE DISORDERS NZ

IMPACT REPORT

2025 - 26

Amplifying the collective voice



raredisorders.org.nz

OUR MISSION

To enable and empower people with rare disorders to best benefit from services and therapies available in New Zealand, and to champion their collective voice, advocating for provision of world leading evidence based health, disability, education and other services.

OUR VISION

Best possible health and wellbeing for people and whānau living with rare disorders in New Zealand/Aotearoa.



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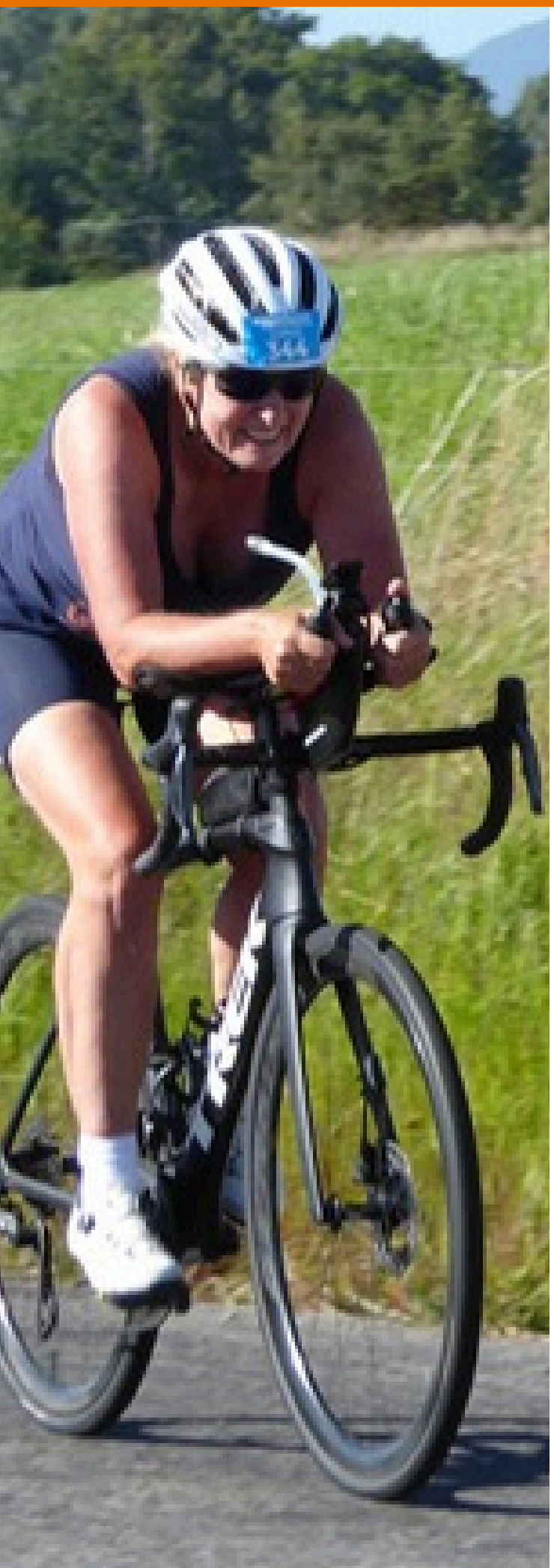
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Our Values

Aroha – we will demonstrate love, compassion, empathy and respect for people living with rare disorders and we will support and encourage our stakeholders to do likewise

Whakamana – we will advocate assertively and constructively with strength and resilience, supporting communities of people living with rare disorders to be similarly empowered

Manawa rahi – we will steadfastly and stout-heartedly maintain an unwavering evidence-based commitment to the RDNZ cause

Kotahitanga – we will exhibit unity, cohesion and collaboration both internally as a team of staff and volunteers, and externally in our relationships both with New Zealand's rare disorders community and supporters, and internationally.

Tiakitanga – we will do everything we can to sustain, protect and respect the viability and reputation of our organisation, our fellow team members, those living with rare disorders and the physical, cultural and spiritual environments which sustain us

CHAIR'S REPORT



E sui faiga, ae tumau fa'avae
Practices may change,
but foundations remain the same

This Sāmoan alagā'upu (proverb) resonated deeply with me as I've reflected on my first year as Chair. Despite RDNZ navigating some significant challenges, largely driven by an increasingly constrained funding landscape, it has been grounding to lead an organisation that remains firmly anchored in its purpose – to amplify the voices of people and whānau living with rare disorders.

RDNZ's persistent leadership and advocacy have been instrumental in achieving cross-agency commitment and collaboration, which has contributed to the publication of the Rare Disorders Strategy Implementation Plan 2026/27. This significant milestone is a testament to RDNZ's ability to bring diverse voices to the same table, to drive collective action and improve outcomes for the rare disorder community in Aotearoa.

It's this very community that lies at the heart of RDNZ's mission. I was privileged to attend the launch of the Impact of Living with a Rare Disorder in Aotearoa New Zealand in 2025 white paper. To the more than 1,000 New Zealanders who took the time to share their experiences of living with rare disorders – tēnā rawa atu koutou. It's difficult to read the statistics and stories and not feel a deep responsibility to do more and to act with greater urgency.

At the event, guest speaker Olivia Worthington spoke about the life-changing experience of receiving CRISPR-based gene therapy through a clinical trial for her rare disorder. Her story offers real hope, while reminding us that many barriers still need to be addressed before that hope becomes reality. Reducing the time to diagnosis, improving access to coordinated and expert care, and ensuring timely access to medicines and modern treatments are all areas where RDNZ continues to advocate relentlessly. The launch earlier this year of a two-year clinical pilot to deliver whole genome sequencing in New Zealand, rather than sending tests offshore, is a tangible example of the kind of system change that RDNZ and others have long been advocating for.

I have also been struck by the resilience of the support group leads I have met over the past year. Even while navigating particularly difficult day-to-day realities, many carry a generosity of perspective that is genuinely humbling. Their resilience should inspire us but never make us complacent in our pursuit of change.

It has also been exciting to see RDNZ's growing involvement in research, including the recognition of New Zealand as a host of a European Rare Diseases Research Alliance-affiliated National Mirror Group. These collaborations extend RDNZ's reach and open up opportunities for shared learning, stronger partnerships and greater international visibility.

It was incredibly disappointing and more than a little ironic that James McGoram had to step down as Chair to access life-saving treatment for his rare disorder in Australia. I know I have big shoes to fill, both literally (!) and figuratively, but I am grateful for the strong foundations he has left for RDNZ.

The transition has been made easier by the support of RDNZ's Chief Executive, Chris Higgins, and his small but mighty team. Chris has shown exceptional sector leadership, with his ability to connect and collaborate across agencies.

I feel very privileged to work alongside such a supportive, values-driven Board, who patiently share their collective wisdom. Special thanks to RDNZ's former and current Deputy Chair, Awhina Hollis and Sam La Hood, who have helped set RDNZ on a stronger path to honour Te Tiriti o Waitangi and give stronger voice to whānau Māori, through the establishment of RDNZ's first Māori Advisory Group. It has been a long time coming, with many hands involved to get us to this historic milestone.

The last few months have been hard for the organisation and I want to acknowledge the additional pressure it's placed on RDNZ staff. If you were to ask me what keeps me up at night, it would be ensuring RDNZ's financial sustainability, so that the team can continue to focus on the kaupapa and not worry about the bottom line. Raising RDNZ's profile and increasing awareness of rare disorders will be critical to ensuring the organisation has a strong and sustainable future. I hope to see more of you Glow Up and Show Up for the 300,000 New Zealanders living with a rare disorder in March.

Practices may change, but our foundation remains the same: standing with the rare disorders community until better outcomes are no longer the exception, but the norm.

Ariane Tuapola

CHIEF EXECUTIVE'S REPORT



Looking back on the 2025/26 year I'm reminded that even though we finished the year on a high, things did not start auspiciously, as we continued to see little interest from government health agencies in implementing the Rare Disorders Strategy (RDS).

Part of the strength of our advocacy approach however is that we do not accept indifference to our cause, and so we pushed ahead and initiated our own mahi on some of the actions outlined in the Strategy alongside continuing to call for an implementation meeting with the health agencies.

By November we had secured a meeting in the Minister of Health's office with senior representatives from Manatū Hauora | Ministry of Health, Te Whatu Ora, Pharmac and the Health Quality and Safety Commission. The Minister instructed the agency representatives to develop a twelve-month implementation action plan in consultation with RDNZ, and by May 2026 we had the agreed draft plan.

At a time when other long term health strategies were either gathering dust, not even getting Ministerial approval to be developed, or not getting sign off when they were developed, this was a hugely significant breakthrough. It will still take some time before people with rare disorders consistently experience improved outcomes through shorter or no diagnostic odysseys, evidence-based care and better coordinated services, but we've got off to an excellent start.

Improved access to rare disorder medicines is one of our strategic priorities, so it was significant that I was invited to be a member of Pharmac's Consumer and Patient Working Group for its twelve-month term, assisting with their reset programme. By the end of the term relationships between consumers and Pharmac had shifted from being hostile and adversarial, to valuing the lived experience and expertise of consumers, with improved processes to make sure this can be captured in Pharmac's decision making.

While this was a necessary first step it hasn't addressed the elephant in the room which is the number of medicines on Pharmac's waiting list, and the cost of funding them all.

Many rare disorder medicines languish indefinitely on this list, and we continue to advocate for a specific rare disorder medicines access pathway.

Other areas where we've made encouraging progress have been the development of the Rare Disorders Research Network and the formation of a Māori Advisory Group. Although these initiatives are expected to bear more fruit next year it is pleasing to note that New Zealand became the first southern hemisphere country to achieve affiliation as a National Mirror Group with the European Rare Diseases Research Alliance.

Internally we've benefited from advice from RDNZ's Clinical Advisory Panel led by Professor Stephen Robertson, and from the Rare Disorders Research Network Leadership Group. I would like to extend a special thank you to professors Phillip Wilcox and Louise Bicknell for their guidance and support.

We are also always appreciative of all the individual donors who have supported our work during the year, including through the One Percent Collective, as well as the many philanthropic grants organisations for their financial support. Our services contract with Te Whatu Ora has also been an important source of support.

But after all is said and done the hugest thanks go to our people. We couldn't be successful without the 160+ support groups represented by their support group leads. You are our "why" and a valued source of the knowledge, lived experience and expertise which we draw upon in everything we do. Thank you.

Thanks also to RDNZ Board trustees for your support, and particularly Ariane Tuapola as Chair.

Finally huge thanks to the small but mighty RDNZ team. Although there are seven of us, we comprise just over four full-time equivalents. We've said goodbyes to Laura and Susan during the year and welcomed Vicki as the year ended. In the meantime, Kim, Lewanna, Angela, Gemma and Alanna have continued to be committed to our mahi. Thanks for your support – you've been awesome.

Chris Higgins

Celebrating Achievements, **The year in numbers**

587
enquiries answered

7
new support groups joined

41
meetings with alliances, networks and advocacy groups

73
meetings with government officials and MPs

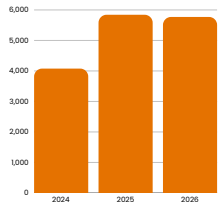
213
calls & meetings with support groups

15
submissions on policy proposals

1,000+
survey respondents

1,000+
new social media followers

Strategies & Impact Indicators

	We will fulfill our mission by	Impact/outcome indicators	Target	Result
1	Campaigning for full implementation of New Zealand's Rare Disorder Strategy (RDS)	No of health agencies engaging with implementation of the RDS No of RDS implementation agencies with RDS action plans	4 4	4 4
2	Raising awareness and understanding of rare disorders and strengthening RDNZ's presence as the collective voice for rare disorders in New Zealand	Number of recipients of RDNZ's monthly newsletter Number of usable "Voice of Rare Disorders" survey respondents	trending up min 1,000	 1,051
3	Making connections in the rare disorder community	Number of rare disorders support groups in the RDNZ collective	150	161
4	Becoming an effective and relevant Te Tiriti partner	% of Māori who respond to RDNZ's "Voice of Rare Disorders" survey	13%	10%
5	Ensuring RDNZ's long term financial and reputational viability and sustainability	Annual income from all sources Net assets	trending up reserves > contingency	 

Campaigning for full implementation of New Zealand's Rare Disorders Strategy

The central focus of our advocacy work for the year was campaigning for full implementation of New Zealand's Rare Disorder Strategy. After celebrating its long-awaited arrival in July 2024, we grew increasingly frustrated at the lack of government action to begin implementation.

Achieving the delivery of a Strategy is one thing, but if it is not used to deliver meaningful change, then is it worth the paper it's written on? We set about driving action on several fronts:

- We continued to keep our petition open to get our community engaged and adding to the call for implementation.
- We met with Health NZ to begin discussions on the establishment of a rare disorders clinical network.
- We sought advice from our Clinical Advisory Panel on the first action outlined in the Strategy; a Leadership and Coordination Mechanism in the health system for rare disorders.
- We surveyed the support group leads in our community on how they envision a Leadership and Coordination mechanism for rare disorders.
- With the support of our Cross-Party Parliamentary Group on Rare and Undiagnosed Disorders, we followed up with the Minister of Health on his commitment to arrange a meeting in his office with the four health agencies responsible for implementing the Strategy.
- On 11 November 2025 a roundtable meeting in the Minister of Health's office was held to begin discussions on an implementation plan for the Rare Disorders Strategy. Rare Disorders NZ attended along with the Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora, Pharmac | Te Pātaka Whaioranga and the Health Quality & Safety Commission | Te Tāhū Hauora. Prior to the meeting we made it clear in a letter to the Minister that there were four outcomes we wanted to achieve (see p. 9). He agreed these were reasonable and directed the officials present to confirm how they would meet these expectations.
- On 6 May 2026 Rare Disorders NZ sat down with Manatū Hauora | Ministry of Health, Te Whatu Ora | Health NZ, Pharmac and HQSC to develop an implementation plan for 2026/27, to be signed off and publicly released in July 2026.

Getting all four agencies around the table and committing to a plan was a significant milestone. It shows what persistence and strong advocacy can achieve. It has meant we can shift our focus to collaborating with government agencies to action changes that wil make a real difference for New Zealanders living with rare disorders.

OUTCOMES RDNZ SOUGHT TO ACHIEVE AS CONVEYED TO MINISTER

To support progress, RDNZ and the rare disorder community would like the meeting to achieve the following outcomes:

1. **Leadership and Oversight:** Agreement to a senior lead from both the Ministry of Health and Health New Zealand to oversee the implementation of the Strategy for their respective entity. We note Pharmac has already nominated [a senior lead].
2. **Implementation Planning:** Agreement that the Ministry of Health, Health New Zealand and Pharmac will each develop implementation plans for the Strategy, with support and coordination from the Ministry of Health (as per the Strategy) as appropriate.
3. **Ongoing Coordination:** Agreement to establish a six-monthly cross-agency forum involving RDNZ, the Ministry of Health, Health New Zealand, and Pharmac to share progress, address challenges, and coordinate implementation. We propose the first meeting occur in May 2026.
4. **Accountability and Reporting:** Agreement that Health New Zealand, the Ministry of Health, and Pharmac will report on progress in implementing the Rare Disorders Strategy through their existing performance and accountability reporting mechanisms.



OUTCOMES ACHIEVED AT ROUNDTABLE WITH MINISTER

1. **Leadership and Oversight** - Each agency appointed a senior lead to oversee the implementation of the Rare Disorders Strategy
2. I**mplementation Planning** - Agencies will develop an implementation plan to support the delivery of the Strategy, the Ministry of Health will both convene and coordinate the development. These plans will outline key actions, timelines, and responsibilities. A draft consolidated implementation plan will be provided to the Minister early 2026.
3. **Ongoing Coordination** - The Ministry of Health senior lead will chair a cross-agency forum to oversee delivery of the Rare Disorders Strategy. The group will include Rare Disorders NZ, Health New Zealand, Pharmac, and HQSC, and is intended to meet every six months. The first meeting will be scheduled for May 2026.
4. **Accountability and Reporting** - Health New Zealand, the Ministry of Health, and Pharmac will report on progress through their existing performance and accountability mechanisms.

RAISING AWARENESS AND UNDERSTANDING OF RARE DISORDERS & STRENGTHENING RDNZ'S PRESENCE AS THE COLLECTIVE VOICE FOR RARE DISORDERS

As the only umbrella organisation for all people living with rare disorders and their whānau in New Zealand we are in a valuable position to inform and educate about rare disorders, improve the visibility of rare, and bring stakeholders together.

Examples of the work we have carried out in this space over the past year include representing rare patients on Pharmac's Consumer and Patient Working Group, expanding the research network's reach beyond our borders, again utilising our annual Rare Disorders Month campaign to rally New Zealanders behind rare, and conducting our biennial survey of the rare disorder community to inform our advocacy work.

Representing the rare voice on Pharmac's working group

Rare Disorders NZ's Chief Executive was one of ten appointees representing the patient and consumer community on Pharmac's Consumer and Patient Working Group during the year. Pharmac established the group for a 12-month period to support their journey to improve transparency and their relationship with consumers.

"People living with rare disorders in need of a life-changing medicine face unique challenges to those with more common conditions. It was essential the rare voice was represented in this group and it provided a valuable opportunity to impact Pharmac's reset," - Chris Higgins.



Connecting rare disorders researchers with global networks



We continue to expand our research network and were thrilled to be recognised in December by the European Rare Diseases Research Alliance as a host of an affiliated National Mirror Group (NMG), making New Zealand the first Southern Hemisphere non-European country to host an NMG. This is a huge achievement for rare disorders research in New Zealand as it formally connects the research community here with rare disorders research networks in Europe and globally.

RARE DISORDERS MONTH

Rare Disorders Month is all about putting a spotlight on rare disorders and getting New Zealand talking about rare.

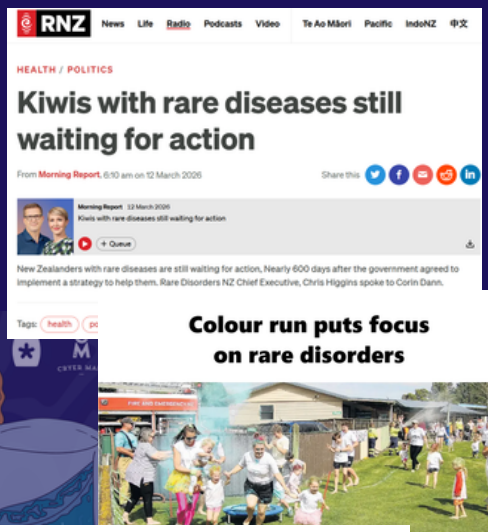
During March we secured over 20 pieces in the media on rare disorders, we had 51 landmarks around the motu light up, we brought support group leads together in Wellington, health professional students entered our essay writing competition, and the Rare Beer Challenge once again had brewers from around the country embracing rarity as they took on the challenge of creating Aotearoa's rarest beer.













We saw neat initiatives from Christchurch-based business *Neck's Best Thing* running a week-long fundraising campaign for RDNZ to the University of Auckland's COMPASS Research Centre holding a Community Session on Working together for Rare Disorders. Joanie Williams who lives with a rare and painful inoperable tumour inspired us all by competing in the Taupō Ironman and was one among many in the community graciously sharing her story during the month to help raise awareness

Spotlight

PARLIAMENT LAUNCH: WHITE PAPER 2026

The launch of the *Impact on Living with a Rare Disorder in Aotearoa New Zealand in 2025* white paper at parliament on 11 March was a highlight of Rare Disorders Month. With over 100 people in attendance, impassioned speeches and a wide range of stakeholders committed to improving the wellbeing of people with rare disorders, there was a general sense of optimism and energy that a brighter future for rare was within reach.



We were honoured to have both patient advocate Olivia Worthington and the Minister of Health Hon Simeon Brown guest speaking at the launch.

"People living with rare disorders should not have to fight the health system just to be seen, diagnosed and supported. This white paper paints a very clear picture of the challenges, and also the opportunites that we must continue to be focused on as a government," - Hon Simeon Brown, Minister of Health





Also in attendance at the launch were support group leads, senior health officials, researchers, academics, MPs, industry and patient organisations.

We are now routinely seeing strong representation from those at the highest levels of decision making at our events, which indicates that our advocacy is cutting through, the rare disorder community is valued and our organisation is highly regarded.

Voice of Rare Disorders Survey 2025

In the latter half of 2025 we conducted the Voice of Rare Disorders Survey. We achieved over 1,000 responses, 10% of responses were from whānau Māori, and over 460 diagnoses were captured.

The survey remains the largest reported survey of consumer reported outcomes for rare disorders in this country.



Over half of respondents waited more than a year for a diagnosis



Hospital admission rates are almost twice as high as the general population



66% experienced isolation from family/whānau and friends



53% felt the costs associated with the rare disorder were hard to manage

MAKING CONNECTIONS IN THE RARE DISORDER COMMUNITY

As an advocacy organisation representing New Zealanders who live with one or more of the over 7,000 known rare disorders, connection with our community is central to guiding our advocacy work.

We connect with our community in a number of different ways; through our enquiries line, through our support group collective and through social media.

Enquiries line

Our team can be contacted through our website, on email or by phone. We help people living with a rare disorder and their whānau navigate the health system and social and disability supports. We can also connect people with support groups or individuals with the same condition, help them find information and resources and offer advice on how to advocate for themselves.

587

enquiries answered

Thank you so so so much!!! .... I've been looking for someone else in New Zealand since this started but [this is] so far the only other person we've now found! – parent of a child with a rare disorder on being connected with someone else with the same disorder.

What a fabulous response to our request for help, with very useful information and links, – person supporting a friend with a child with a rare disorder.

Appreciate the kindness and time and energy that has gone into your response! – family member of a person with a rare disorder.

Thank you so much for your support, fantastic resources and guidance, – person supporting a whānau member living with a rare disorder.

SUPPORT GROUPS

The support groups in our collective are at the centre of everything we do. They convey to us the issues important to their respective groups, which we in turn convey to government agencies. As a collective voice we are much stronger.

7
new support groups joined

161
total support groups

213
calls & meetings with support groups

We arrange various opportunities throughout the year for support group leads to get together, to learn, and to provide feedback on relevant consultations.

- Webinar: Fast-tracking rare disease: from diagnosis to custom therapies
- Webinar: Feedback on the Draft Disability strategy
- Support group lead morning tea during Rare Disorders Month
- Support group leads attending Parliament event – White paper
- Feedback to RDNZ strategic plan
- Feedback on a leadership and coordination mechanism for rare disorders
- Online hui with Health NZ on establishing a clinical reference group for rare disorders

As we begin working more closely with government agencies on implementing the Rare Disorders Strategy, we will be including support group leads throughout the process to make the most of new opportunities to be heard and help shape implementation of the Strategy.

The lived experience and leadership within the community are vital to ensuring this work reflects the needs of those affected by rare disorders, and we look forward to enabling further opportunities as implementation progresses.



BECOMING AN EFFECTIVE AND RELEVANT TIRITI PARTNER

Rare Disorders NZ is on a journey to be a better Tiriti partner and we are committed to the implementation of the Rare Disorders Strategy being informed through a te ao Māori lens. In this way we will ensure Māori are not left behind and improvements in services and systems for people living with rare disorders will simultaneously benefit Māori and non-Māori alike.

Establishing a Māori Advisory Group

As part of this journey the Board of Trustees this year began recruiting for a Māori Advisory Group to ensure that our mahi is grounded in Te Tiriti o Waitangi and guided by kaupapa Māori values. The group will support Rare Disorders NZ's governance, advocacy, services, partnerships and strategic direction. The expressions of interest received represented considerable diversity of lived experience, professional expertise and community connections, and at the conclusion of the financial year six members were provisionally endorsed.

The next steps will be beginning a collective discussion about the group's purpose, mandate and ways of working, and formalising the Terms of Reference.

Analysing Māori vs non-Māori survey data

During the year the team at Costello Medical assisted us with analysing and presenting the Māori vs non-Māori results of RDNZ's 2023 Voice of rare Disorders survey. The analysis drew on the findings of Te Aka Whai Ora's *Whānau Voice 2023 Summary: Whānau Māori with a rare disorder and those who care for them*, and has culminated in a paper submitted for publication in the New Zealand Medical Journal titled "Disparities and Shared Burdens: A Comparative Analysis of Māori and Non-Māori with Rare Disorders in New Zealand – Aotearoa Through a Te Tiriti o Waitangi Lens".

Along with Costello Medical contributors its authors include tangata whenua RDNZ Board trustees Awhina Hollis (L) and Samantha LaHood (R).





ENSURING RDNZ'S LONG TERM FINANCIAL AND REPUTATIONAL VIABILITY AND SUSTAINABILITY

Since June 2023 RDNZ's operational expenses have increased and it was expected that these increased costs would have been covered by similar or better revenue increases.

However as at 30 June 2026 these increased revenue expectations were not fully realised, and RDNZ's reserves have been drawn upon to make up the difference between revenue and expenditure. In 2026/27 we'll be doubling down on our efforts to generate more revenue from more diverse revenue sources, while operating with an austerity expenditure budget to ensure that we live within our means.

ROUND TABLE OF COMPANIES

The Round Table of Companies continues to provide an important forum to foster transparent working relationships with industry and encourage open communication between industry and the rare disorder patient community. We were thrilled to welcome new members Canterbury Scientific Ltd, CSL Seqirus and Recordati this year. Vertex is no longer a member, and we thank them for their years of engagement.

Thank you also to the following members for your continued engagement - Alexion, Biogen, BioMarin, Canterbury Scientific Ltd, Chiesi, Illumina, CSL Seqirus, MSD, Novartis, Oxford Nanopore Technologies, Recordati and Takeda.

THANK YOU

We could not achieve as much as we do without the generous support and contributions of so many. Thank you to David Brabant for your pro bono IT support, to James McGoram of Digital Advisor for pro bono website support, to Māia for their discounted communications support during Rare Disorders Month, to 16 Tun and The Malthouse and all the craft breweries who got behind the Rare Beer Challenge, and to the many individual supporters who donated to us throughout the year.

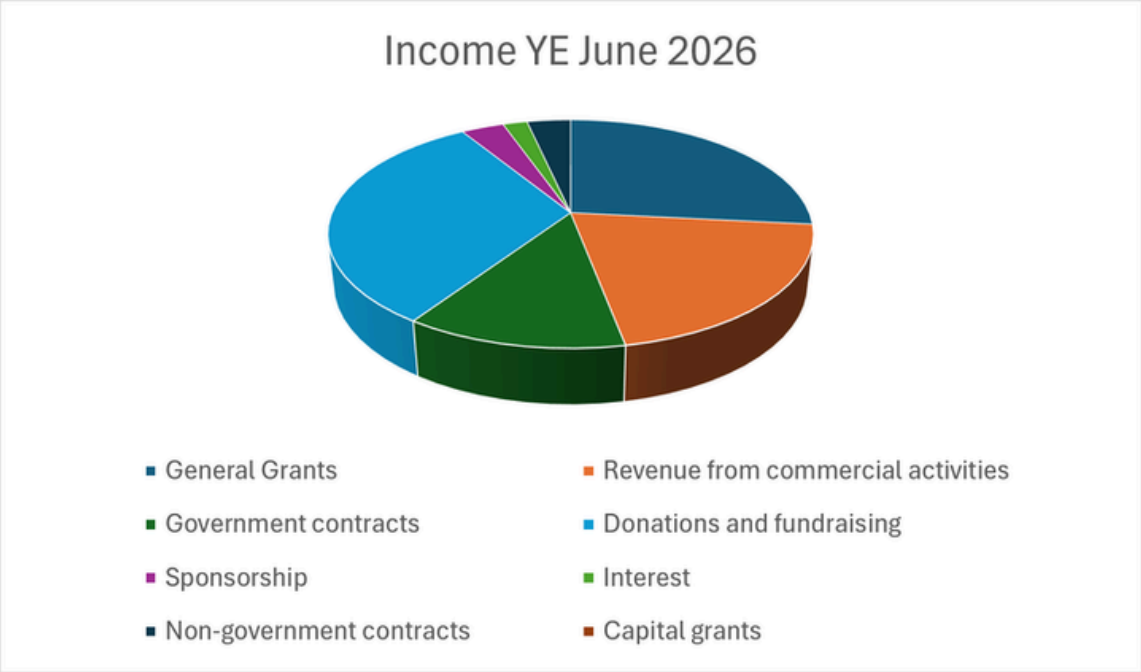
We are so grateful to the following foundations and organisations who continue to support our important work for the rare disorder community.

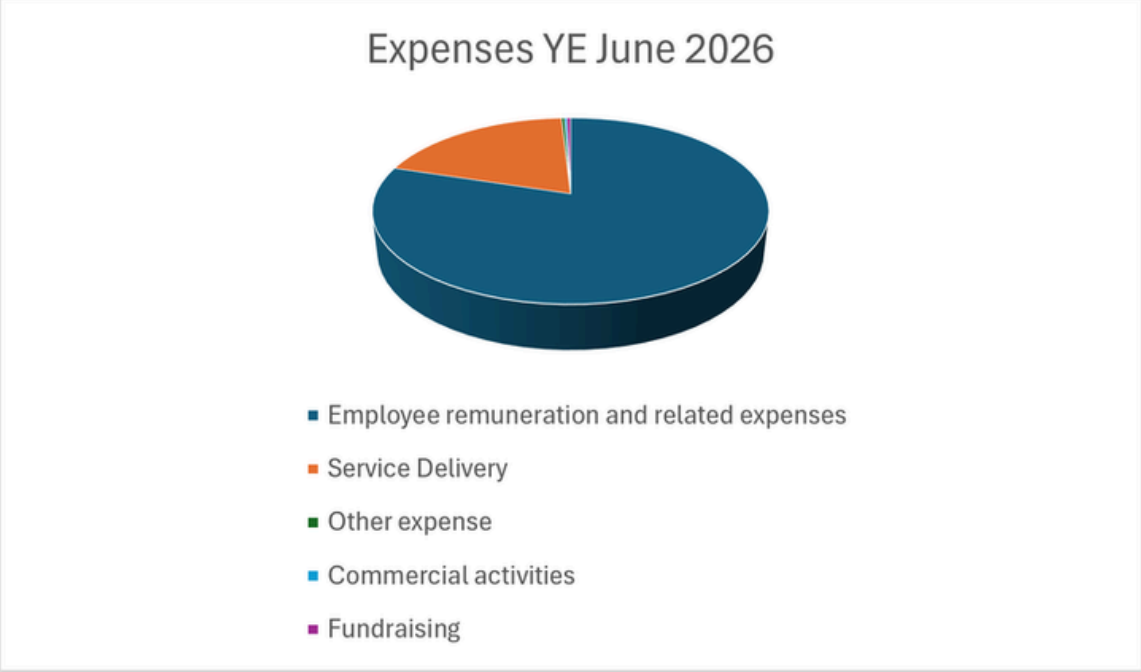
One Percent Collective
Rare Disease Month sponsorship: Alexion, Chiesi, Recordati, Takeda
Aotearoa Gaming Trust
COGS (Community Organisation Grants Scheme)
FH Muter & EM Pherazan Trusts
IHC Foundation
Jack Jeffs Charitable Trust
Kiwi Gaming Foundation
Lottery Community Fund
Pub Charity
Rata Foundation
Steadfast Foundation
TG Macarthy Trust
The Lion Foundation
Trust Waikato

FINANCIAL RESULTS

Summarised statements of financial performance for year ended 30 June 2026

Account	2026	2025
Trading Income		
General Grants	156,927	165,622
Revenue from commercial activities	120,000	74,500
Government contracts	73,230	71,098
Donations and fundraising	187,433	52,284
Sponsorship	20,000	38,500
Interest	11,365	21,251
Non-government contracts	20,430	8,260
Capital grants	0	1,716
Total Trading Income	**589,385**	**433,231**
Gross Profit	**589,385**	**433,231**
Operating Expenses		
Employee rem. & related expenses	473,291	432,455
Service Delivery	114,133	131,939
Other expense	1,795	6,459
Commercial activities	1,359	2,667
Fundraising	2,183	2,648
Total Operating Expenses	**592,762**	**576,167**
Net Profit	**(3,376)**	**(142,937)**


Income YE June 2026
General Grants
Revenue from commercial activities
Government contracts
Donations and fundraising
Sponsorship
Interest
Non-government contracts
Capital grants


Expenses YE June 2026
Employee remuneration and related expenses
Service Delivery
Other expense
Commercial activities
Fundraising

STAFF

Chris Higgins - Chief Executive
Kim McGuiness - Relationship Manager
Angela Nielsen - Communications Manager
Lewanna Pentecost - Navigator
Susan Langston / Vicki Unwin - Finance Manager
Gemma Jackson - Income & Partnerships Manager
Alexandra Nicholson / Laura Trobriani - Administration Officer
Alanna Peck - South Island Coordinator

BOARD MEMBERS

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Awhina Hollis - Deputy Chair
Rosemary Marks
Bice Awan
Martin Hanley
James McGoram
Samantha La-Hood
Nivedita Sharma Vij