IMPACT REPORT
2023 - 24

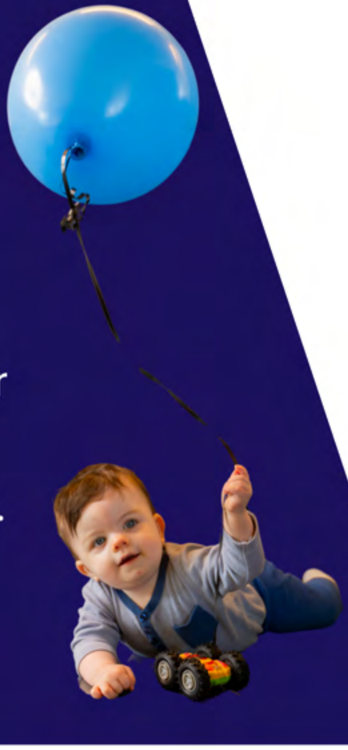
Amplifying the collective voice



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.

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

What an extraordinary 12 months it has been for the rare disorder community in Aotearoa.

In March our team built upon the success of the inaugural Rare Disorders Month to deliver multiple events around the motu - lighting up buildings, walking around mountains, drinking rare beer, and of course launching our white papers on the experience of living with a rare disorder to an audience of dignitaries and MPs at the parliament buildings in Wellington.

This last event was extremely successful, but was tinged with sadness as it took place on the very night that Te Aka Whai Ora was disestablished by parliament, with many staff from that organisation there to support us anyway. The genuine and heartfelt care we received from them - helping us to engage with and understand the Māori experience - was a big part of the story in 2023-2024.

Rare Disorders Month was a success in other ways too, raising the profile of our work through a highly successful media campaign.

Multiple volunteers made appearances and gave interviews in national media, a task which can be daunting and emotional. I feel indebted to their bravery, and I'm confident that their efforts have contributed to the excellent engagement we've subsequently enjoyed from policy makers, government agencies, and funding providers.

Each year, we build on the awareness achieved in the last. Our campaign of 'Glow up & Show up' is all about increasing our visibility and it has been fantastic to see this ambition become a reality, year on year.

On the political front the new government has presented both challenges and opportunities for our ongoing work.

We have welcomed increased funding for Pharmac and the prospect of reform, even as we are deeply concerned about the many difficulties our health system is facing.

Further pressure on disability supports and benefits, along with the restructuring of Whaikaha, are causing real distress among those living with rare conditions and disability.

But our role is to be ever pragmatic. We continue to work on building deeper connections with health agencies as well as with our allies and supporters, clinicians, researchers and our rare community. We also continue to have productive discussions with politicians from across the political spectrum.

One of RDNZ's values that I keep in mind in challenging times is Manawa rahi - our steadfast commitment to achieving the best possible health and wellbeing for people and whānau living with rare disorders, come what may. As always, this vision is not one we achieve alone, but together.

My thanks to our incredible staff, ably led by Chief Executive Chris Higgins, and my colleagues on the trust board. I would like to acknowledge two departing trustees specifically - Stephen Robertson & Carol Gernhoefer - both incredible, compassionate, and generous people who will be greatly missed by the entire team.

As we wrap the year that has been it is a good time to reflect on how far we've come, and to know that collectively we have the strength and the vision to achieve so much more.

Nga mihi nui,

James McGoram

CHIEF EXECUTIVE'S REPORT

As RDNZ's new CE at the start of this reporting year I'm beginning with thanks for the support that has been extended to me over the past year, from RDNZ Board Chair James McGoram, other Trustees and my colleagues on the staff team. Collectively we comprise less than four full time equivalent paid staff, and given what we've been able to achieve we clearly punch above our weight. This is a testament to every Board and staff member's passion for the RDNZ cause, and commitment to a fair go and improved well being for people living with rare disorders.

A main focus of the year was the Rare Disorders Strategy. For the first six months the emphasis was on creating, brokering and contributing to opportunities for consultation; and, reviewing successive drafts and advocating assertively for the Strategy's content to be sufficiently clear and specific to bring about real changes for people living with rare disorders.

The second six month period comprised a waiting game where we agitated for the Strategy to be signed off by the Minister of Health, and for there to be clarity about where the leadership would be for its implementation.

As the financial year came to an end for us, we were informed the Strategy would be released in July 2024, to be signed off by the Director General of Health (rather than the Minister). The fact that we will finally have a Rare Disorders Strategy at all is cause for celebration, and a testament to some two decades of persistent RDNZ advocacy.

During the year we took opportunities to affirm RDNZ's commitment to being a better Tiriti partner, including: affirming RDNZ's values in both te reo and English; bestowal of the name Te Toropaepae o te Kōtuku to mark the opening of our new offices; publication of the Voice of Rare Disorders White Paper "Impact for Whānau Māori of Living With a Rare Disorder in Aotearoa New Zealand"; collaboration with Te Aka Whai Ora, ensuring that whānau Māori voices were heard by Manatū Hauora | Ministry of Health in developing the Strategy; valuing mātauranga Māori as a key element in RDNZ's newly established clinical advisory panel and rare disorders research network leadership group; engaging a Kaitakawaenga Māori Advisor to recommend actions to the RDNZ Board for continuing on our Tiriti partner journey; and developing a position paper setting out how we intend to be a better Tiriti partner, including to advocate for implementation of the Strategy through a te ao Māori lens.

Impact comes in many forms, including the impact of the support we offer to individuals and their whānau living with a rare disorder, and our advocacy on specific issues including newborn screening, fair access to medicines, more responsive and accessible education and disability support systems to name but a few. Impact can also be measured by trends in key outcomes which we've identified in our strategic plan, and which are reported on in this report.

Impact is something often best achieved in collaboration with others. I'd like to acknowledge the role of those which have helped to amplify RDNZ's voice including Patient Voice Aotearoa, Carers' Alliance, the Neurological Alliance and our Round Table of Companies.

Finally to all our stakeholders and team, it's been a privilege to have shared in our kotahitanga and I look forward to further successes as we continue to work together.

Chris Higgins

Celebrating Achievements, **The year in numbers**

↑ **749**

enquiries responded to

↑ **12**

new support groups joined collective

↑ **3**

Health Ministers + the opposition health spokesperson at our white paper launch

↑ **1,076**

survey respondents (the largest-ever survey of people with rare disorders in New Zealand)

↑ **400%**

increase in survey participation from Māori

↑ **11**

submissions on policy proposals

↑ **80+**

news media pieces throughout the year

↑ **30%**

more followers on social media

Our Strategic Plan 2023-24

We evaluate our progress on the Strategic Plan and our impact through the following indicators:

RDNZ Strategic Plan 2023 - 24	**Impact/Outcome indicators**	**Target**
Campaigning for full implementation of New Zealand's Rare Disorder Strategy (RDS)	% of "Voice of Rare Disorders" survey respondents who say that: • It took less than six months to get an accurate diagnosis for the rare disorder • The rare disorder was misdiagnosed before getting the final diagnosis • They were provided with care coordination support which meets their needs	trending up trending down trending up
Raising awareness and understanding of rare disorders and strengthening RDNZ's presence as the collective voice for rare disorders in NZ	Number of recipients of RDNZ's monthly newsletter Number of "Voice of Rare Disorders" survey respondents	trending up trending up
Connecting all those in the rare disorder community to achieve improved health and wellbeing outcomes	% of *Voice of Rare Disorders* survey respondents who say that the person with the rare disorder and/or their whānau are fairly or very well connected with others with their condition	trending up
Becoming an effective and relevant Te Tiriti partner	Number of Māori who respond to RDNZ's "Voice of Rare Disorders" survey	trending up
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

Supporting the development of the Rare Disorders Strategy (commissioned by the Minister of Health in mid-2022) has been a central focus for Rare Disorders NZ. We regularly communicated with the Strategy development team at Manatū Hauora | Ministry of Health, providing input and feedback throughout the process.

We strongly advocated for both Manatū Hauora | Ministry of Health and Te Aka Whai Ora | Māori Health Authority to engage directly with the rare disorder community to ensure the Strategy would be informed by lived experience.

The engagement approach Te Aka Whai Ora | Māori Health Authority took was exemplary for the way in which whānau Māori were approached and able to provide their reflections and input.

While a similar process for the wider rare disorder community did not happen, Manatū Hauora | Ministry of Health, through our insistence and with our help, actuated webinars with the patient community, support group leads and experts as a way to collect their input to feed into the Strategy.

> ***“I just want to say that I'm really impressed with the MOH's engagement with the Rare Disease community on this strategy - that no doubt is due to the hard work from the Rare Disorders team. I was also involved in the Women's Health Strategy and there wasn't any opportunity to give feedback once the document was drafted which really was a shame - I think it would have been a lot stronger had they followed this process.“***
>
> *Webinar feedback from support group lead*

During the development of the Strategy we pushed in particular for the inclusion of the following four key implementable actions:

Action # 1

Establishment of a Rare and Undiagnosed Disorders Centre of Expertise

Action # 2

Recognition of RDNZ as a key enabler for the Strategy’s implementation

Action # 3

Incorporation of coding of rare disorders in the nationwide Electronic Medical Record and other data sets

Action # 4

Establishment of a single barrier-free pathway to rare disorder medicines

As we wait for the final Rare Disorders Strategy to be released in July 2024, we are preparing to shift our focus to ensuring the Strategy is implemented without delay.

RAISING AWARENESS AND UNDERSTANDING OF RARE DISORDERS

Through the news media, social media as well as our annual month-long awareness campaign during March, we continue to grow our reach and audience.

↑ **80+**

stories in the news media

↑ **30%**

more followers on social media

We have done important work this year to build awareness around rare disorders among agencies that can make a significant difference to people living with rare disorders:

Whānau Āwhina Plunket

We collaborated with Whānau Āwhina Plunket to improve early identification of rare disorders in children by designing an online course for Plunket nurses.. The course aims to upskill Whānau Āwhina staff in the early identification, referral and support of affected whānau with rare disorders.

Ministry of Social Development

We presented at a professional development session with the Ministry of Social Development's (MSD) Regional Health and Disability Advisors, to inform them about some of the challenges and barriers people living with rare disorders face when accessing support from Work and Income.

MSD webinars

We then built on this collaboration to develop a webinar series with MSD Health and Disability advisors outlining what's available from Work and Income for people living with rare disorders, and how to access it.

GLOW UP AND SHOW UP FOR RARE DISORDERS

Rare Disorders Month in 2024 was built on the successful inaugural awareness month held in 2023. It kicked off this year with 45 buildings and monuments lighting up for rare on Rare Disease Day, including Eden Park and Christchurch Airport.

The community got behind the campaign, with 22 schools, workplaces and community groups organising awareness events for rare disorders.

We hosted a researchers event, a morning tea for support group leads and had a stand at the Newtown Festival raising awareness.

The annual fundraising and awareness event, the Rare Beer Challenge, was once again hosted by Fortune Favours in Wellington and $10,000 was raised for Rare Disorders NZ.

STRENGTHENING RDNZ'S PRESENCE AS THE COLLECTIVE VOICE FOR RARE DISORDERS IN NZ

We currently have 164 rare disorder support groups under the rare disorder collective, representing over 1,600 different rare disorders.

We regularly host meetings with the groups to discuss advocacy priorities. We support the groups to make submissions on policy proposals, and we can help facilitate meetings for them with government agencies.

↑ **12**

new support groups joined collective

↑ **33,5k+**

support group reach

↑ **11**

submissions on policy proposals

Spotlight

2023 SURVEY

In late 2023 we conducted our biennial survey on living with a rare disorder in Aotearoa New Zealand.

We collected a total of 1,076 responses, making it the largest-ever survey of consumer-reported outcomes for people with rare disorders in New Zealand. We also achieved a 400% increased in participation from Māori.

The overall results painted a similar picture to previous survey results, indicating little improvement in public health and social service delivery for people living with a rare disorder.

61% of people with a rare disorder were misdiagnosed at least once before the final diagnosis was confirmed.

58% took longer than 1 year to get a diagnosis

Around half of respondents felt that organising care was difficult to manage.

Spotlight

WHITE PAPER LAUNCH AT PARLIAMENT

Rare Disorders NZ and Medicines NZ commissioned two white papers based on the survey results - one paper on the whole of population results, and for the first time a paper specifically on the results of those respondents who identified as Māori. We were able to do this having achieved the largest collective voice for Māori living with a rare disorder in Aotearoa.

On the eve of Rare Disease Day, a wide range of rare disorders stakeholders gathered together for the launch of the latest *Impact of Living with a Rare Disorder in Aotearoa New Zealand* and *Impact for Whānau Māori of Living with a Rare Disorder* white papers at parliament.

Over 130 people attended the event, including representatives from patient support groups, research institutions, government Ministries, pharmaceutical industry, advocacy organisations, as well as MPs from across the political spectrum.

It was encouraging to have the Minister of Health in attendance, as well as two Associate Ministers of Health and the opposition health spokesperson, demonstrating high-level recognition of rare disorders.

CONNECTING ALL THOSE IN THE RARE DISORDER COMMUNITY TO ACHIEVE IMPROVED HEALTH AND WELLBEING OUTCOMES

Enquiries line

Our enquiries line is open Monday to Thursday and offers a place people in the rare disorder community can turn to for information and support.

We can help people navigate the health system, provide advice on services and agencies that may be able to help. We also facilitate connections with support groups.

"Thank you so very much for the time you spent with me on the phone the other day, and this email full of helpful information."

Enquiries line feedback

Connecting the community

We keep the rare disorder community regularly informed and updated on news and developments within the sector through our social media platforms, our website and our bimonthly newsletters.

During the past year we have expanded information on our website about government supports and services available to make navigating these supports easier.

We also host a rare disorder community Facebook page for the community to connect with one another.

↑ **749**
enquiries responded to

↑ **11%**
increase in newsletter recipients

BECOMING AN EFFECTIVE AND RELEVANT TE TIRITI PARTNER

Rare Disorders New Zealand is on a journey to be a better Tiriti partner. During the past year, we have taken the following steps on this journey:

- The appointment of Awhina Hollis-English to the role of Deputy RDNZ Board Chairperson;
- RDNZ's values being conveyed in both te reo and English;
- Bestowal of the interim name Te Toropaepae o te Kōtuku to mark the opening of RDNZ's new premises in September 2023;
- Significant increase in participation from whānau Māori in our Voice of Rare Disorders survey in late 2023 as reported in the ensuing White Paper *2024 Impact for Whānau Māori of Living With a Rare Disorder in Aotearoa New Zealand;*
- Our collaboration with Te Aka Whai Ora, ensuring that whānau Māori voices were heard by Manatū Hauora | Ministry of Health in developing the Rare Disorders Strategy;
- Our steps to ensure that mātauranga Māori is well valued as we establish RDNZ's Clinical Advisory Panel and Rare Disorders Research Network
- The temporary appointment of a Kaitakawaenga Māori Advisor on the team.

↑ 400%

increase in survey participation from Māori.

↑ 21

whānau Māori living with or caring for someone with a rare disorder provided feedback to Rare Disorders Strategy

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

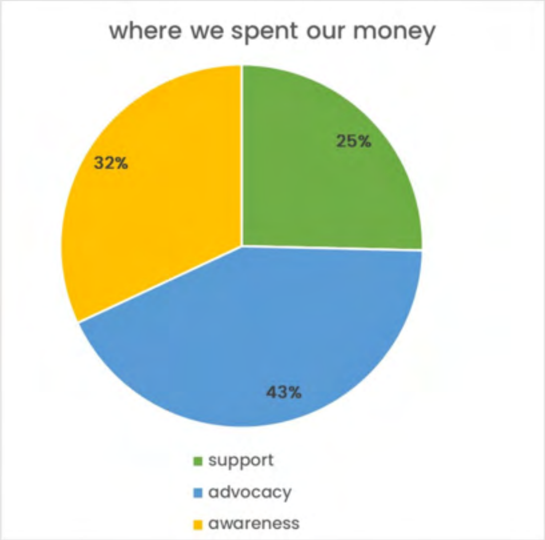
Thank you

We are extremely grateful to the following foundations and organisations who continue to support our important work for the rare disorder community, despite the financially challenging times that continue to be felt across the board.

One Percent Collective
Foundation North
COGS Committees: Waikato West, Hamilton City, Manukau, Rodney/North Shore, Wairarapa, Auckland City, Central Otago, Waitakere, Papakura/Franklin, Tauranga, Heretaunga
Lottery Community Fund
Trust House Foundation
Four Winds Foundation
Rata Foundation
Steadfast Foundation
Deane Endowment Fund
The Lion Foundation
Frimley Foundation
Grassroots Trust Central
JR McKenzie Trust
Kiwi Gaming Foundation
Aotearoa Gaming Trust
South Canterbury Trusts
TG Macarthy Trust
Foundation North
One Foundation
AbbVie Ltd
Pub Charity
Alexion
BioMarin
Biogen
Vertex
Takeda
Amicus Therapeutics
MSD
Fortune Favours
16Tun
GoCloud
Kilbirnie Pak'n'Save
Kilbirnie Countdown

Where we spent our money

Based on staff estimates of how much of their time was spent on different activities, together with proportional allocations of back office, fundraising and other support costs, we were able to estimate how RDNZ expenditure was allocated across our three major programmes of support, advocacy and awareness, as presented in the pie chart below.



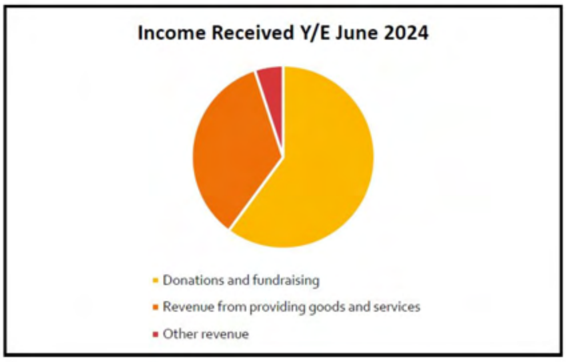
Support includes time and costs associated with responding to enquiries; educational activities; and supporting rare disorder support groups.

Advocacy includes time and costs associated with writing and presenting submissions; developing policy positions; writing letters and emails; meetings; and media releases and appearances.

FINANCIAL RESULTS

Summarised statements of financial performance for year ended 30 June 2024

	2024	2023
	$	$
Donations and fundraising	306,306	275,356
Revenue from providing goods and services	177,139	174,147
Other revenue	25,668	12,389
Total Revenue*	**509,113**	**461,892**
Operating Expense		
Volunteer and employee related costs	389,696	244,465
Costs related to providing goods or services	117,800	135,162
Public fundraising and other expenses	9,924	6,122
Total Expenses*	**517,420**	**385,749**
Surplus/(Deficit) for the Year*	**-8,308**	**76,142**



STAFF

Chris Higgins - Chief Executive
Kim McGuiness - Relationship Manager
Angela Nielsen - Communications Manager
Lewanna Pentecost - Navigator
Susan Langston - Finance Manager
Maurice Roberts - Business Development Manager
Julian Laking - Kaiāwhina Māori (Māori engagement officer)
Misty Kimura - Kaitakawaenga Māori Advisor
Lucy Bennett/Alexandra Nicholson - Administration Officer
Alanna Peck - South Island Coordinator

BOARD MEMBERS

James McGoram - Chair
Awhina Hollis-English - Deputy Chair
Rosemary Marks
Bice Awan
Stephen Robertson
Martin Hanley
Carol Gernhoefer