



IMPACT REPORT

2022/2023

Chair's Report



It is with great pride in our team and in our collective that I reflect on the work of Rare Disorders New Zealand over the past 12 months. It has been a year in which we've enjoyed significant wins; from increased visibility thanks to our inaugural Rare Disorders Month in March, through to the significant presence of rare voices in the development of the Pae Ora Health Strategies.

Most critically we're now working in earnest on the Rare Disorder Strategy itself. This work will shape our health system for generations to come and it has been foremost on our minds that we must seize this opportunity while we can. Like many of you, I've enjoyed participating in the Ministry of Health webinars - just one avenue through which we're gathering input into this essential work.

While I am thankful for these significant steps, I would also like to acknowledge the many unmet needs that remain a daily reality for our community. Our staff have done an amazing job this year of reminding the agencies we've been working with - whether it is on the development of the strategy, medicine access, carer support, or disability issues - that we will not stop pushing for faster action, more funding, and increased awareness. Indeed, that is our reason for existence.

As I made clear to the Minister of Health at our meeting earlier this year, each delay represents a tragedy for some family that may not receive a timely diagnosis, or the correct treatment, or essential support, or even just a connection with someone who understands what they're going through, a connection that can be a lifeline for someone isolated by their disorder.

The coming twelve months will be filled not only with the development of the rare disorder strategy, but with the ongoing growth – indeed the nurturing – of our network and our collective. The strength, resilience, and determination of our rare community, along with our compassion for each other, is what makes this work possible. We support each other, and we are formidable as a result.

Since last year we've also had a change of personnel at the helm, with Chief Executive Michelle Arrowsmith unfortunately leaving our shores (and Rare Disorders NZ) to head back to the UK. In her place we have been fortunate to appoint the talented and experienced Chris Higgins who has already taken significant strides in advancing our work, growing our team, and creating an ever stronger platform for change. I would like to thank Michelle for the unbounded energy, compassion, and spirit that she brought to our organisation in the short time she was here, and I welcome Chris in this new and challenging role.

It can be disruptive changing leaders in the middle of a busy year like this one has been – but our team has done an exceptional job across dozens of ongoing projects. My thanks to Kim McGuinness in particular for her leadership during this period, the staff for supporting her, and my board colleagues for supporting me!

Finally, I'd like to acknowledge my fellow trustee Awhina Hollis-English, who this year the board confirmed as Deputy Chair of Rare Disorders NZ. Awhina is a passionate and articulate advocate for rare disorders, and for Maori, and I'm thrilled to be working with her.

RDNZ has an exciting year ahead. While a General Election always holds some uncertainty, we've worked hard to build multi-party support for our work and we have good relationships with people across the political spectrum. We are also growing our relationships with Te Ao Maori, as we embark on our journey to become a genuine Te Tiriti organisation.

This report contains much for us to be proud of, but it is the many challenges and opportunities that lie ahead of us that fill our vision. I look forward to tackling them with you.

James McGoram
Chair, Rare Disorders NZ

Our Vision

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



Our Mission

To champion and amplify the collective voice of New Zealanders with rare disorders, advocating for access to world class and world leading health, disability, education and other services.

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.

We are the collective voice

After 20 years of strong collective advocacy, we are pleased to have reached an important new chapter for rare disorders in New Zealand. The Government's recognition, finally, that a Rare Disorders Strategy is needed and will be developed, puts us on an exciting new trajectory. No longer do we have to fight for recognition; we can now move towards ensuring the strategy is informed by lived experience so that meaningful, systemic changes are implemented.

We are honoured to be entrusted with the mandate of being the respected voice of rare disorders in New Zealand and our work this year has been focused on strengthening our collective voice and ensuring we are a co-designing partner for New Zealand's first Rare Disorders Strategy.

Our strategic priorities for 2022/2023:

- Connect all those in the rare disorder community to ensure improved outcomes for health and wellbeing.
- Raise awareness and understanding of rare disorders and strengthen our presence as the collective voice for rare disorders in New Zealand.
- Advocate for the establishment and implementation of a National Rare Disorder Strategy for New Zealand.
- Ensure Rare Disorders NZ is financially viable and sustainable long-term.
- Ensure Rare Disorders NZ has strong strategic governance leadership, that we are a good Te Tiriti o Waitangi partner and support human rights and we develop a collaborative culture.



**1 in 17 Kiwis
live with one
or more of
the over
7,000 known
rare
disorders.**



594

Total enquiries responded to over the past year - the highest number of enquiries we have responded to in one year.

14

New support groups joined our collective, bringing the total number of groups in our collective to 152.

17k

Raised at the Rare Beer Challenge - a new record!

47k+

Reached through Facebook - a 155% increase on the year before.

11

Submissions on proposals to policy changes.

50+

Pieces of media coverage achieved during our inaugural Rare Disorders Month campaign.

Connecting

Connecting people is a big part of what we do. In the field of rare disorders where information can be scarce, connecting with the right people can make a huge difference to individuals, families and professionals.

During this year, we have seen consistent growth in the engagement and reach of our primary tools for connecting with the rare disorder community - namely our enquiries line, website and social media platforms.

Enquiries have been consistently growing year on year as awareness of our organisation grows. Our enquiries line can be a lifeline for someone feeling isolated, invisible or misunderstood.

“ Thank you so much for taking the time to chat with me, it really helped to not feel isolated.

Enquiries line feedback

We also established a network for nurses working in the field of rare disorders to provide a space to support and share experiences and learnings.

A highlight of the year was enabling support group leads to reconnect following two years of Covid-19, with an in-person hui in Wellington.

594

enquiry
responses

155%

increase in
Facebook reach

14

new support
groups



Spotlight

Support group lead hui



On 11 November, Rare Disorders NZ hosted our first in-person support group lead hui in two years. It was a great day to come together, share learnings, hear about advocacy and rights and look ahead to how we can work together to achieve co-design of the National Strategy of Rare Disorders with the Ministry of Health and get rare disorders on the election agenda in the year ahead.

“ Thank you so much for organising! So much was packed in - lots to absorb on the day and thoughts to take away.

Prader-Willi Syndrome Association NZ

“ It was a wonderful day and good for us with our groups of varying size to feel the power of the collective voice.

Fabry Support Group New Zealand

“ I found it was run very well. Thank you. It was great to meet people and hear people's journeys to advocacy. Great opportunity for me to practice my awareness of my condition.

Anon feedback



Spotlight

Connecting nurses



On the 9th and 10th March 2023, Rare Disorders NZ sent New Zealand nurses, Sharron Meadows and Rebecca Nicol, to an international roundtable in Singapore, *Connecting Nurses Globally - A Roundtable in Rare and Undiagnosed Diseases*, to work with 33 nurses from 25 countries across the globe on the establishment of a global nursing network on rare diseases. The nursing network will inform and influence the development of nursing education resources to upskill and raise awareness of rare disorders across the workforce.

“ As one of only two nurse specialists in my field in the country, it is not only an incredibly demanding role, but can oftentimes feel like quite a lonely space to be in. I am really excited about the potential of the nursing network, to provide a space where I can receive and give support to others nurses in my position.

Rebecca Nicol, paediatric metabolic nurse specialist



Sharron and Rebecca shared their learnings in a webinar hosted by Rare Disorders NZ for New Zealand registered and trainee nurses interested in rare disorders. Following the webinar, we established a rare disorders nurse group to connect the rare disorder nursing community.

Raising Awareness

To improve public awareness and community support for people affected by rare disorders we initiated our first Rare Disorders Month campaign under the theme Glow Up and Show Up for Rare.

#GlowUpShowUp was chosen to demonstrate the need for rare disorders to be brought out of the darkness, and into the light.

The public was called on to *glow up* in bright colours and with temporary tattoos, and *show up* to events and on social media.



Aotearoa heard our call to #GlowUpShowUp during the month of March, and what a month it was! From Invercargill to Warkworth, events were held in local communities all around the country.

50+
pieces of media
coverage across major
broadcast, print, and
online news media

1.4M
total audience
impressions

It was heartening to see the wider community show their support for rare, with kindergartens, schools, workplaces and community groups all getting behind the cause.



“ Well done everyone!! So great to see and hear about rare everywhere!!!

Mum of a child with a rare disorder

Spotlight

Parent and Caregiver Guide

Our Rare Disorders Month campaign kicked off on Rare Disease Day at Government House with the launch of a parent and caregiver guide for the thousands of whānau of children diagnosed with a rare disorder.

We created the resource through the insights and advice from parents and caregivers who share this journey, as well as through other information and resources, to help parents and caregivers navigate the path in caring for a child with a rare disorder in New Zealand.

The guide was launched by our patron Her Excellency, The Right Honourable Dame Cindy Kiro, GNZM, QSO, Governor-General of New Zealand.



“ What a privilege to be able to speak at Govt House for Rare Disorders NZ and the Parent Caregiver Guide and be hosted by the beautiful Whaea Cindy Kiro - also to have my beautiful girl and whānau there too!! Ngā mihi aroha!

Misty Kimura, guest speaker and mum to a child with a rare disorder



Advocating

Rare Disorders Strategy

With the Minister of Health's announcement in June that Manatū Hauora - the Ministry of Health had been instructed to develop a Rare Disorders Strategy, the stage was set for our advocacy work for the year ahead to focus on ensuring the voice of those with lived experience would inform the strategy development.

Throughout the year, Rare Disorders NZ has had ongoing discussions with Manatū Hauora, on the development of the strategy and consistently emphasised the importance of stakeholder engagement throughout the process to ensure the strategy is fit for purpose.

As a result, a reference group was established that includes Rare Disorders NZ, support group leads, Manatū Hauora and rare disorder specialists to provide input and to review draft documents.

This relationship with the Manatū Hauora team helped us to ensure the rare community could feed into the development of the Pae Ora Strategies, which occurred through two webinars in March 2023 jointly hosted by Rare Disorders NZ and Manatū Hauora.

The information collected has helped with early work towards the Rare Disorders Strategy, and further webinars are planned for the rare disorder community to engage more specifically on the Rare Disorders Strategy.

We have been engaging with Te Aka Whai Ora to plan how to reach out to Māori and whānau to ensure Māori voices also feed in to the development of the Rare Disorders Strategy.



Spotlight

Berl Insights report

On 10th May, Rare Disorders NZ launched a new report, '*Rare Disorders Insights Report: Pathways towards better health outcomes*'. Rare Disorders NZ tasked Business and Economic Research Limited (BERL) to develop an insights report on rare disorders in New Zealand to help inform our advocacy work.



With the attendance of officials from the Ministry of Health, Ministry of Disabled People, Pharmac, and MPs from all major parties, as well as health professionals, pharmaceutical companies, academics, patients and patient advocates, we felt this reflected wide-reaching recognition that rare disorders can no longer be ignored.



The report found that it is not possible to accurately estimate the prevalence of rare disorders in New Zealand due to the classification system for diseases that New Zealand uses not including most rare disorders. This lack of data is not only a challenge to estimating prevalence, but also for improving diagnosis, treatment and research.



Acknowledgements

We would like to thank the following foundations for supporting our work through grants in the past year:

- Community Organisation Grants Scheme
- One Percent Collective
- Foundation North
- Rata Foundation
- IHC Foundation
- Kiwi Gaming Foundation
- Trust House Foundation
- Pub Charity
- Four Winds Foundation
- Lottery Community Fund
- Todd Foundation
- TG Macarthy Trust
- Lion Foundation
- JR Mckenzie Trust
- Ministry of Social Development
- Lottery Ministers Discretionary Fund
- Aotearoa Gaming Trust
- Grassroots Trust Central
- Deane Endowment Trust
- Frimley Foundation
- Nikau Foundation



It was great to see a couple of new funders this year, and this will be a real focus for us going forward as we try and grow our income. We were extremely grateful for the overall total received given the difficult grant landscape.



Thank you to Go Cloud Systems for generously providing website and email support pro bono.



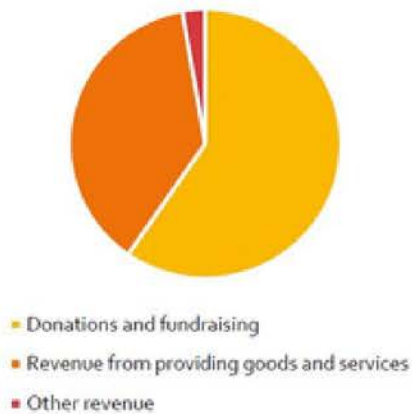
Thank you to phil&teds, the award-winning baby gear company for generously providing an office space and utilities free of charge since 2019.

FINANCIAL RESULTS

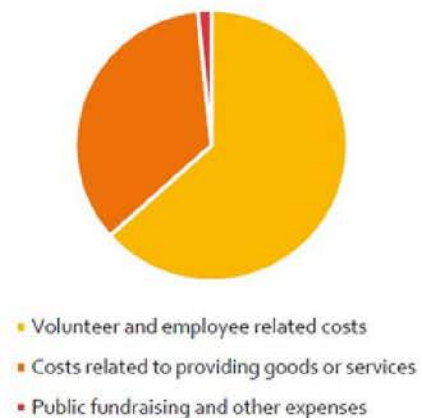
Summarised statements of financial performance for year ended 30 June 2023

	2023	2022
	\$	\$
Donations and fundraising	275,356	178,441
Revenue from providing goods and services	174,147	163,968
Other revenue	12,389	2,619
Total Revenue*	461,892	345,028
Operating Expense		
Volunteer and employee related costs	244,465	208,482
Costs related to providing goods or services	135,162	79,720
Public fundraising and other expenses	6,122	6,470
Total Expenses*	385,749	294,672
Surplus/(Deficit) for the Year*	76,142	50,357

Income Received Y/E June 2023



Operating Expenses Y/E June 2023



RDNZ Team

Staff

Michelle Arrowsmith - Chief Executive
Kim McGuinness - Relationship Manager
Angela Nielsen - Communications Manager
Susan Langston - Business Manager
Maurice Roberts - Grant Writer
Julian Laking - Kaiāwhina Māori
Lucy Bennett - Administration Officer

Board

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



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