



Annual Report 2020

July 2019–June 2020

Photos on cover:

Top left: Rare disorder support groups at the Fair for Rare NZ campaign launch at Parliament for Rare Disease Day

Top right: Graeme Swan and Lisa Foster creating the Rare Beer at Fortune Favours brewery

Bottom left: Amy Watson and Lisa Foster after meeting with Minister of Health David Clark

Bottom right: Five-year-old James, whose story was the focus of the Rare Disease Day fundraising and awareness campaign

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Highlights 2019/2020



Fair for Rare NZ campaign launch

Collective campaign launched at Parliament on Rare Disease Day to call for a National Rare Disorder Framework



Rare Disease researchers

Second special interest group meeting held in Wellington to allow researchers to collaborate



Enquiries

More than 200 families and health professionals assisted during the year



Rare Beer created

Collaboration with Fortune Favours craft brewery raised awareness and funds



NZ Voice of Rare Disorders survey

The largest survey of the rare disorder community ever in New Zealand, highlighting common issues and barriers



Awareness raising

Four major interviews on TV and radio for Rare Disease Day



MP Liaison programme

More than 20 people living with a rare disorder met with their local MP before the general election to share their experiences



International connections

Increased collaborations with partner organisations to benefit all people living with a rare disorder

Mission statement

Amplify the collective voice to improve healthcare and wellbeing for people and their whānau living with a rare disorder

Our organisation

The New Zealand Organisation for Rare Disorders (NZORD) was established in September 2000, and changed its name to Rare Disorders NZ (RDNZ) in 2019. RDNZ is the respected voice of rare disorders in New Zealand. We are the only national organisation specifically focused on supporting the 300,000 New Zealanders who live with a rare condition, the people who care for them and the professionals who help them.

RDNZ is the broad connector hub for families, health professionals, researchers and Government. We provide a strong common voice to advocate for health policy and a healthcare system that works for those with rare condition.

Chief Executive's report

During a time of unprecedented change and uncertainty, I am proud to present this report highlighting the broad scope of activities, achievements and strong connections we have formed to create increasing awareness of the challenges facing people living with rare disorders. Our vision of amplifying the collective voice has been at the core of everything we do and our value of Mahi Tahi remains our ongoing intention for collaboration, collective responsibility, accountability and commitment to support people with rare disorders in New Zealand.

The fact that even though disorders are rare, rare disorder patients are many and need to be acknowledged as a public health priority.

It is exciting there are opportunities ahead to 'build back better' and this must incorporate those who were already facing immense difficulties. Visionary leadership can guide us towards equity, acknowledgement, action and inclusion. Cohesive policies will enable alignment with our Asia Pacific neighbours and the rest of the developed world.

The Health and Disability review, whakamaua: Maori Health Action Plan and Ola Manuia: Pacific Health and Wellbeing Action Plan offer pathways and expectations for a fair system based on need not diagnosis with cohesion Care and equitable outcomes for all New Zealanders including Māori, Pacific and ethnic minorities. For this to be realised those with rare conditions must have current barriers addressed with improved systems established.

Our key achievements during the 2020 year include:

Māori engagement

- Connection with Māori Health and Pacific representatives through the Ministry of Health

COVID-19

- Reacted responsively to the increased need related to COVID-19 with 50% increase in supporting families via email, direct phone calls and through social media
- Connection with MOH COVID-19 crisis team to ensure issues were communicated and responded to
- Collaboration connection with affiliated partners to link up support for our collective
- Hosted webinars to share issues, anxieties and gain useful strategies of resilience

International

- Showcased the organisation at the international Asia Pacific Alliance of Rare Disease Organisations (APARDO) Conference in Taiwan in October
- Connection and engagement with APEC Life Sciences Innovation Forum Planning Group and the APEC Rare Disease Action Plan. Participation in international rare disease conferences and meetings: 15

- Appointed as Board Director and secretary for APARDO
- World Health Organisation and RDI initiative for Collaborative Global Network for Rare Diseases (CGN4RD) attendance from the perspective of the Western Pacific region

Fair for Rare NZ: Campaign and Petition

- Dr Liz Craig MP launched the Fair for Rare NZ campaign at Parliament. RDNZ calls for acknowledgement of the challenges faced by people living with a rare disorder, along with a commitment to develop a National Rare Disorder Framework
- Fair for Rare NZ campaign continued throughout 2020, with an MP liaison programme, Parliamentary Petition and Election Manifesto questions
- Our collective met with more than 20 MPs to share their stories and ask for Fair for Rare
- Strengthened the collective voice of people with rare disorders through increased engagement including monthly zoom meetings

Strengthening our presence and connection within health sector

- Membership with NZ Federation of Health & Disability Collectives and Disabled Persons Assembly
- Established relationship with Royal NZ College of GPs and gained endorsement from them
- Completed largest ever survey on rare disorders, Voice of Rare Disorders Survey
- White paper recommendations based on this survey shared with Ministry of Health

I wish to express huge appreciation to all organisations, partners and ministry officials for their willingness and commitment to support our work and acknowledge our community. However, without increased support from Government the sad reality is that RDNZ's sustainability is at risk as funding has now reduced by half to \$60,000 for the next financial year. Sadly, this will impact on RDNZ abilities to offer sustainable services, support and representation. We have requested that the Government review our funding status to ensure our continued viability.

COVID-19 highlighted the vital nature of our connection with one another and posed the possibility of creating an equitable system based on authentic solidarity and longer-term vision for true societal wellbeing; one that acknowledges all voices, including those with rare conditions often facing extraordinary isolation and challenge.

Lisa Foster Bsc (Hons)

Chief Executive

Chair's report

RDNZ was forced, like the rest of the country and the globe, to respond to the COVID-19 pandemic leading to our first lockdown in March. Inevitably the impacts are greatest for those who are already the most disadvantaged and this will continue well beyond the end of this financial year.

Challenges and disruption have confronted our small team as they worked from home, and cared for their own families, and adapted their processes and programme. In addition they managed the ongoing financial challenges and marginalisation of its stakeholders, which results from the ongoing failure of the Ministry of Health (MOH) and politicians across the House to understand the situation of those with rare disorders and their whānau, and what could be provided with a reinstated increase in funding.

This year of considerable achievements, and change has been largely resulted from the tireless leadership of our CE, and the ongoing hard work of our small RDNZ team (2.2FTEs).

Thanks are due too to my fellow Board members, including our Chair Jo Lusk, who stepped down temporarily from the role of Chair, to spend time with her new daughter. I was pleased to rejoin the Board, having been a member in 2012, and to take up the role of Acting Chair. Other new Board members during the year included James Mc Goram and Dr Rosie Marks. Thank you also to the generosity of Phil&Teds which has enabled us to continue at this level.

Mike Eccles stepped down from the Board along with Bronwyn Gray earlier this year, following 20 years of remarkable service.

Some Board members have generously taken up particular projects and roles in a volunteering capacity to support the team in finance, social media, brokering relationships, fundraising, meetings and supportive articles. Sincere thanks are due to all members of the Board whose commitments and activities demonstrate the importance of volunteering and the critical role of civil society in this country.

I completed my appointment as Acting CE in August 2019, with Lisa Foster appointed to the role. I am grateful to have had this opportunity and learning. Kim McGuinness was appointed as Relationships Manager in August and Amy Watson and Susan Langston continued to do invaluable work in their roles.

Major steps have been taken in this area this year as you will see from the reports. Strategies have involved meetings with DPA, the Carers Association and other NGOs as Lisa has outlined; inclusion of rare disorders in "the People's Report" on the SDGs; in discussions of violence against disabled people with the Joint Venture against Violence; meetings and correspondence with MPs, Ministries, funders, and the MOH. Generally any attempts to progress the rights and needs of those with rare disorders are forwarded to the Minister/MOH with little response. The development and Parliamentary launch of the petition and advocacy campaign, Fair for Rare, calling for a policy, strategy and register has been a major focus, in spite of challenges

related to the pandemic. Media and social media coverage have also progressed.

Internationally, Lisa has worked particularly hard to make New Zealand's situation better known internationally, resulting in support from influential international organisations. This is particularly valuable because New Zealand has been regarded as a champion of human rights, and more specifically, disabled people's rights for many years but appears to them, and to us, to be lagging behind.

Although there are clearly challenges, there is little doubt that New Zealanders champion human rights and there are a number of critical areas. There is no doubt that we are at a crucial point as a country and as an organisation. We have seen a glimpse of potential change by the call in the new Health and Disability Review for support to be provided on the basis of need not diagnosis. This must surely be a focus for RDNZ going forward as it seems the MOH and others fail to understand the social model of disability but prefer a more traditional medical model.

We are finishing the year with a firm belief that Fair for Rare can be achieved and I look forward to working with Board members, representatives of those with rare disorders and supporters as we strategise, prioritise and engage.

Thank you all for the privilege of working with you.

Gill Greer
Acting Chair

The RDNZ strategic plan

RDNZ's work plan for the 2019/2020 financial year is based on four strategic aims:

- 1) Connecting all those in the rare disorder community to ensure improved outcomes, including mental health and wellbeing
- 2) Campaigning for a New Zealand National Rare Disorder Framework
- 3) Raising awareness and understanding of rare disorders and strengthen our presence as the collective voice for rare disorders in NZ
- 4) Ensuring RDNZ is financially viable and sustainable long-term

These aims are underpinned by RDNZ's core value of Mahi Tahī (collaboration, cooperation, joint ventures).

Lisa Foster was appointed Chief Executive in August 2019.

1. Strategic priority: Connecting all those in the rare disorder community to ensure improved outcomes, including mental health and wellbeing

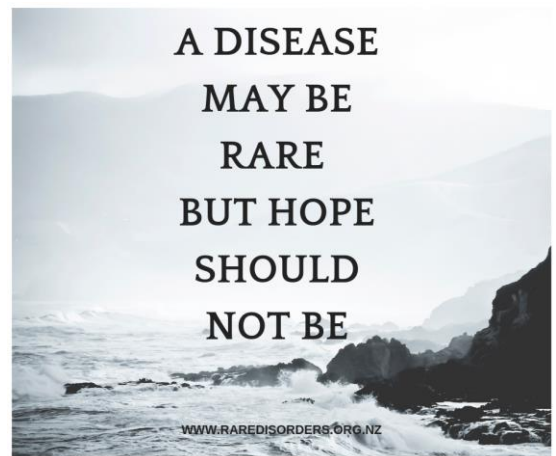
COVID-19

What this global pandemic has shown is that "the virus does not discriminate, but its impacts do"

Antonio Guterres, United Nations Secretary General

The COVID-19 pandemic has impacted the rare disorder community in 2020, and will continue to do so next year. RDNZ is the umbrella group for all rare disorders in NZ and we are connected to 140 rare disorder support groups. As the connector hub between these groups and our contacts at the Ministry of Health, our team worked hard to ensure that people living with a rare disorder and their families had the information and access to care they needed during lockdown.

RDNZ hosted a Resilience Webinar for this community alongside a Life Coach, had regular catch ups via video and phone calls to support group coordinators, connecting via email and through social media. We saw a 50% increase in connections with the rare disorder community during this time.



Our collective

Kim McGuinness was appointed Relationship Manager for RDNZ in September 2019, and has a strong background in the not-for-profit sector as well as a passion for helping people living with chronic conditions.

RDNZ's collective includes more than 140 rare disorder support groups. The size of these support groups ranges from a handful of people to thousands of members. Kim liaises with all groups to update them on issues and resources important to their members, as well as consulting the groups on RDNZ's work.

Responding to enquiries

Throughout this financial year RDNZ supported more than 200 families through our enquiries line and gave information to partner charities including Muscular Dystrophy NZ, Cystic Fibrosis and Fragile X. The way families connect with RDNZ has shifted, with more seeking our support through social media, especially Facebook. The focus of the enquiries has also changed, with a notable rise in queries about barriers of access to both medicines and services, access to specific diagnostic genetic testing and information requests from the media.

“Without RDNZ all people with rare disorders struggle to be heard. Not only that, we are ignored, because individually the rare disease groups are small. With an umbrella organisation like RDNZ, there are thousands of people who are represented and able to be heard. Together we are strong!” Allyson Lock, President, Pompe Network NZ

Website and social media

The organisation rebrand to Rare Disorders NZ and new website were launched in June 2019. This has continued to be a strong channel for connection and support, especially during the initial COVID-19 lockdown.

The most popular sections on our website were the Support Group Directory and the Rare Disorder Database pages. There has also been strong interest in the Fair for Rare NZ Parliamentary Petition and Rare is Everywhere personal stories.

Social media is becoming an increasingly important way to connect with the rare disorder community, especially young families. Support groups are managing their own Facebook pages, rather than establishing specific websites.

Lisa Foster's professional connections through LinkedIn are becoming increasingly important, especially within the international community.

2. Strategic priority: Campaigning for a New Zealand National Rare Disorder Framework

“No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases.”

Helen Clark, United Nations

A RARE DISORDER AFFECTS...



HEALTH



FAMILY



EDUCATION



WORK



ECONOMY

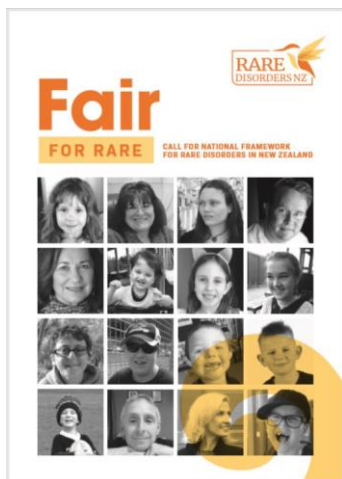


SOCIETY



RESEARCH

Fair for Rare NZ campaign



On Rare Disease Day (28 February) RDNZ and our collective of support groups launched the Fair for Rare NZ campaign, calling for the development of a National Rare Disorder Framework.

The launch took place at Parliament and was hosted by Dr Liz Craig MP. RDNZ and its 140 support groups are calling on New Zealanders to acknowledge the common challenges faced by people living with a rare disease.

More than 100 attendees attended the launch which was also an opportunity to celebrate Rare Disorders NZ's 20th birthday.

“A National Rare Disorder Framework would identify positive solutions to reduce the costs of chronic health conditions by addressing need earlier, enabling more people to participate in work and the community,” says Rare Disorders NZ chief executive Lisa Foster.

“Such measures would also lessen both the time required away from work and the mental stress for patient carers. All of which would directly benefit the New Zealand economy.”



Parliamentary Petition



Sue Haldane, a mother of a child with a rare disorder, has spent 17 years dealing with barriers within our health system to ensure her daughter Lizzie's needs are met. Now Sue is determined that the journey will be easier for future generations of New Zealanders living with a rare disorder.

Sue, on behalf of Rare Disorders NZ, launched a Parliamentary Petition in May seeking essential systemic changes that would benefit everyone within the rare disorder community, and wider society as well.

“My Petition urges the Government to acknowledge the universal challenges faced by people living with a rare disease, and the unfairness within the current system, by

committing to the long overdue development of a New Zealand National Rare Disorder Framework,” says Sue.

“I would make no changes to Lizzie's lovely self, but I crave many, many changes to the world she lives in.”

The Petition will close in March 2021 and will be delivered to Parliament by Sue, RDNZ and other members of our collective.

MP liaison programme

In the leadup to the general election, RDNZ created letter templates and key messages from the Fair for Rare NZ campaign. We supported our support groups to communicate with their local MP. More than 20 people living with a rare disorder met with their MP to share their experiences.



RDNZ Board member James McGoram with MP Deborah Russell

Election manifestos

RDNZ asked all the major political parties for their commitment to the strategic priorities within the National Rare Disorder Framework.

Only three parties - Greens, National and Labour - responded to our collective request for a stance on the issues important to the rare disorder community.

RDNZ contacted the Mana, NZ First, Act and Maori Parties and received no answer to these questions.

PHARMAC engagement

RDNZ has quarterly meetings with the Senior Leadership Team at PHARMAC to ensure that a continuing dialogue and timely communications with the sector can be maintained. We submit queries from our collective and other stakeholders and ensure information is reported back to our networks.

Briefing the Government

The Ministry of Health benefits from our close connections with the rare disorder community, and we are keen to share our expertise and knowledge to improve the health and wellbeing for people living with a rare disorder. Our partnership with Government as the only national organisation representing a vulnerable population is extremely important to our collective. The loss of this national collective voice and place of belonging for those who often have nowhere else to turn would be a human rights violation and not acceptable in New Zealand.

Chief Executive Lisa Foster met with a number of key government ministers to raise awareness of rare disorders at government level. These contacts included a meeting with then Minister of Health David Clark in August. The need for an integrated policy response to rare diseases to reduce the barriers, improve the outcomes and improve inter-generational wellbeing was discussed. Australia has completed its National Strategic Action Plan to reduce the uncertainty facing people with rare diseases and our hope is to encourage similar positive steps.

Alliances in New Zealand

RDNZ has built a strong relationship with the Royal NZ College of GPs, and received endorsement from the College for our work in June 2019.

“We recognise that a collective, intersectoral voice is necessary to strengthen advocacy and recognition for

people with rare disorders. As an organisation with members involved in caring for individuals with rare disorders,



**The Royal New Zealand
College of General Practitioners**

we are aware of the ongoing challenges of diagnosis and the variations in how these disorders present. In saying this, the College supports that more education, awareness, and policy for the rare disorder population is needed, and that this can only be sustainable through wider health system support.” Lynne Hayman, Chief Executive, RNZCGPs.

RDNZ collaborates and is part of several larger collectives such as Carers Alliance and Neurological Alliance and have close links with DPO Coalition hence we have been able to share updates, discussions and our own campaign launch with these alliance members.

International connections

In September the UN Member States adopted a political declaration on Universal Health Coverage that includes mention of rare diseases for the first time which is a fantastic achievement for global advocacy groups, which Rare Disorders NZ are part of. This is in alignment with the *2030 Agenda and the SDG’s Peoples Report* which offers summary findings and recommendations and now includes acknowledgement for inclusion for a more just and equal world with priority placed on those with most need: *Māori, Pacific, people living with disabilities and those living with rare disorders and other vulnerable groups.*

Lisa Foster is now a Director on Board of Trustees for Asia Pacific Association of Rare Disease Organisations (APARDO) and has strengthening connections across the Asia Pacific region for rare diseases. APARDO has links with Rare Disease International, Eurordis and WHO. The three-year action plan includes a commitment to increase and share collective knowledge, with comparisons of countries initiatives, projects and National Frameworks including the activities relating to the APEC Rare Disease Action Plan.



Lisa was invited to attend the Asia Pacific Alliance of Rare Disease Organisations Summit in Taiwan later this month in October to speak about the current lack of rare disease policy in New Zealand, despite being a leader on the UN Convention of the Rights of People with Disabilities.

Lisa received a scholarship to attend the Rare Diseases International 6th Annual Meeting and World Health Assembly (WHA) event in Geneva in May. This was a virtual meeting and the WHA event is deferred to 2021. Lisa also gained funding to attend the virtual meeting of EURORDIS Rare Diseases Europe group meeting in Sweden which was conducted over Skype.

Submissions

RDNZ actively engages with issues impacting the rare disorder community by responding to calls for submissions.

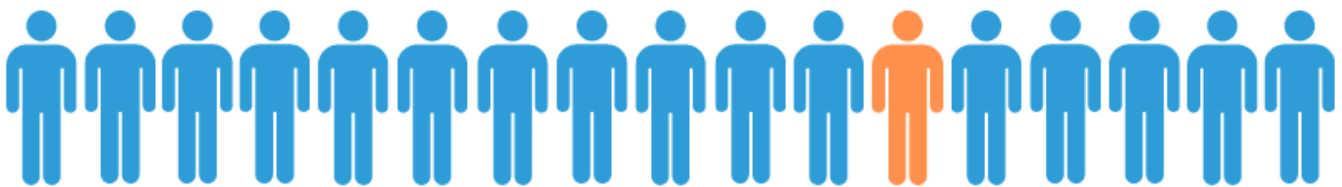
RDNZ wrote to Craig Hawke, the NZ Ambassador to the UN, to request for New Zealand to support a UN Political Declaration on Universal Health Coverage that addresses the needs of persons living with a rare disease.

A number of patient petitions for access to life-changing rare disease medicines have been presented to parliament this year. Petitions for funding for Spinraza for spinal muscular atrophy, and Myozyme for Pompe Disease were presented to the government in May. RDNZ attended the Health Select Committee meeting alongside these groups in August.

“Rare Disorders NZ helps our families with advocacy. It gives them a voice, an organisation to advocate and support them. There are only a few of us living with our condition in New Zealand but with Rare Disorders NZ we have an organisation which helps our needs be heard and seen.” 22q Foundation Australia and New Zealand

3. Strategic priority: Raising awareness and understanding of rare disorders and strengthen our presence as the collective voice for rare disorders in NZ

1 IN 17 NEW ZEALANDERS HAVE A RARE DISORDER



NZ Voice of Rare Disorders survey

In November 2019 RDNZ conducted a survey to highlight the barriers within the current health system for people living with rare disorders.

The NZ Voice of Rare Disorders survey had almost 300 respondents, making it the largest survey of the rare disorder community ever in New Zealand. Patients, whanau and carers shared stories of the challenges they face to access healthcare, as well as the impact of living with a rare disorder on education, employment and other areas of life.

The evidence from this survey led to the priorities in our Fair for Rare NZ campaign, which is calling for the development of a National Rare Disorders Framework.

Some of the clear barriers to access to vital services and supports are demonstrated below:

- Three quarters of all respondents have some or a lot of difficulty with seeing, hearing or moving;
- 80% have a decrease in income, and 30% are unemployed because of a rare disorder;
- 35% often felt unhappy and depressed (at the time of the survey);
- 31% felt they could not overcome their problems (this is concerning as current access to mental health support is very challenging as evidenced in the qualitative section);

- Over 60% felt communications and information exchanged between services was poor;
- 40% cannot afford the recommended treatment (rehabilitation equipment, home care);
- Almost half of carers and patients spend more than two hours a day on disease-related tasks (49% in NZ, compared to 42% in Europe);
- 81% of people had a specialist visit in the last six months.

The results provide a benchmark for future research as well as comparisons with the experience of people living with a rare disorder in other countries. Read the full white paper on the RDNZ website.

“I had to step down from a management position prior to diagnosis as I couldn’t cope with all the illnesses and hospitalisations. Once he started school and the learning and behaviour needs became apparent, I ended up stopping work altogether. We couldn’t really afford all the therapies we needed for him, but we needed to support him.”

Survey respondent

Rare Disease Day media

Rare Disease Day is a global day of recognition and is an important opportunity to raise awareness of rare diseases in our communities. Our CE, Lisa Foster, was interviewed four times for Rare Disease Day along with two mums of children living with a rare disease.

Lisa spoke about the need for a National Rare Disorder Framework, as well as the challenges facing people living with a rare disease and their families.

“This media attention means that policy makers and the general public will be talking about the 300,000 New Zealanders living with a rare disease,” says Lisa. “Rare is part of our communities and deserves a fair go.”

- TV3 Newshub 6pm News
- TV3 Newshub The AM Show
- Newstalk ZB The Mike Hosking Breakfast Show
- Radio New Zealand National Programme – Jesse Mulligan Show

Rare Beer

RDNZ and award-winning brewers Fortune Favours teamed up to create a unique beer to raise awareness of the 300,000 New Zealanders living with a rare health condition.

The beer was launched for Rare Disease Day in February. The brew day took place in mid-January, with members of the rare disorder community working alongside Dale and his team. Rare Disorders NZ Chief Executive Lisa Foster was involved in creating this beer, adding ingredients to the brew tanks and learning about the process.



“It’s awesome to have the support of Fortune Favours to create a beer that can bring people together, as travelling this journey of rare disorders is isolating, exhausting and frustrating,” says Graeme Swan, who took part in the brew

day with his wife Nicola. Graeme and Nicola's youngest son James died of an undiagnosed rare disorder at the age of five.

Rare disease researcher Special Interest Group

RDNZ established a Special Interest Group (SIG) last year for any researchers working on rare disorders in New Zealand. The group meet once a year to share research ideas, their results, collaborations, joint grant bids and expertise. RDNZ attend these SIG meetings and report back any relevant findings or invitations to participate in research, to our rare disease community.

The second meeting took place in August in Wellington. Feedback showed unanimous support for meetings of this type with the major advantage being the opportunity to bridge the gap between current and potential research, synergies between key research projects and improving government awareness. Having Dr George Slim as a speaker allowed the researchers to gain understanding of the role and the strategic vision of the Office of the Prime Minister's Chief Science Advisor. A request was to have more involvement of policy makers at future meetings to enable the researchers to showcase what they do and to improve collaborative connections.

4. Strategic priority: Ensuring RDNZ is financially viable and sustainable long-term

RDNZ has a renewed focus with a new Chief Executive and two new trustees joining the board this year.

RDNZ is now in a period of reduced funding from the Ministry of Health with \$60,000 a year until 30 June 2023.

We are actively seeking new sources of funding to ensure the long-term security of the organisation. Our organisation is also looking at ways to save money, including moving to a new office space in August 2019 which is kindly donated free of charge by Phil&Teds, the NZ baby buggy and car seat company based in Newtown.

RDNZ team

Staff

Lisa Foster – Chief Executive

Susan Langston – Administration Manager

Kim McGuinness – Relationship Manager

Amy Watson – Fundraising and Communications Manager

RDNZ board of trustees

Joanna Lusk (on maternity leave March 2019); Gill Greer – Chair

Bice Awan

Carol Gernhoefer

Martin Hanley

James McGoram

Rosemary Marks

Stephen Robertson

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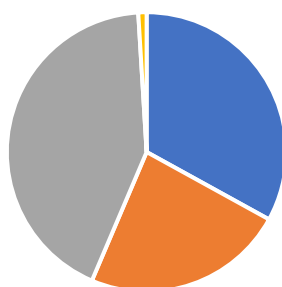
www.raredisorders.org.nz

FINANCIAL RESULTS

Summarised statements of financial performance for year ended 30 June 2019

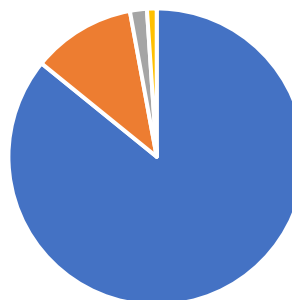
	2020	2019
Ministry of Health Contract	\$ 90,000	\$ 120,000
Other Goods and Services	\$ 63,775	\$ -
Donations and Fundraising	\$ 116,236	\$ 144,941
Other Revenue	\$ 2,617	\$ 5,044
Total Revenue*	\$ 272,628	\$ 269,985
Operating Expense		
Employee/Volunteer Expenses	\$ 186,685	\$ 213,745
Office and Administration	\$ 24,482	\$ 62,882
Fundraising Expenses	\$ 4,020	\$ 3,807
Other Expenses	\$ 2,296	\$ 2,295
Total Expenses*	\$ 217,483	\$ 282,729
Surplus/(Deficit) for the Year*	\$ 55,145	\$ (12,744)

Income Received Y/E June 2020



■ Ministry of Health Contract
 ■ Other Goods and Services
 ■ Donations and Fundraising
 ■ Other Revenue

Operating Expenses Y/E June 2020



■ Employee/Volunteer Expenses
 ■ Office and Administration
 ■ Fundraising Expenses
 ■ Other Expenses

Our supporters

