



# Annual Report 2019

July 2018–June 2019

Photos on cover:

Top left: Four-year-old Evie from Tauranga, who shared her story for Rare Disease Day

Top right: Rare Disease Day Award recipients at Government House

Bottom left: Lisa Foster with Prime Minister Jacinda Ardern

Bottom right: Seven-year-old Preston from the West Coast, South Island, who shared his story for Rare Disease Day

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## Highlights 2018/2019



### Rare Disease Day Education Session

This meeting in Wellington had two speakers and a workshop dedicated to addressing some of the challenges faced by those with rare disorders

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### Rare disease researchers

Annual special interest group established to allow researchers to collaborate

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### Enquiries

More than 120 families and health professionals assisted during the year

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### Rare Disease Day Awards

Five rare disease champions recognised with inaugural Awards

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### Rare Disorders NZ launched

The new logo features a kōtare, the New Zealand kingfisher

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### Awareness raising

New Zealand Herald double page feature for Rare Disease Day

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### Government briefings

Meetings with Finance Minister Grant Robertson; the Deputy Leader of the Opposition, Paula Bennett; and the Minister for Social Development and Disabilities, Carmel Sepuloni

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### National Framework and Action Plan

Rare Disorders NZ is developing strategic priorities to call for a National Framework and Action Plan for all people living with a rare disease

## Mission statement

To support, assist and promote better health care and wellbeing for patients and their families/whānau living with a rare disorder in New Zealand.

## Who we are

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 offers a central starting point for patients and families affected by rare disorders, and helps families, patients and healthcare providers find essential information and support groups.

RDNZ is the only umbrella group for rare disorders in New Zealand and provides a strong common voice to advocate for an equitable healthcare system that works for the 400,000 Kiwis with a rare condition.

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

Helen Clark, United Nations

# Chief Executive's report

It is my pleasure to present this report of RDNZ's activities and successes during the 2019 financial year, some of which was carried out under the leadership of my predecessor.

Our achievements during the 2019 year include:

- Recognising researchers through sponsoring two awards at the Queenstown Research Week Brain Diseases Meeting
- Rare disorder funding proposal submitted to Ministry of Health for consideration
- Special Interest Group of rare disease researchers established – first meeting held at Otago University; second meeting will take place in Wellington in August
- Ehlers-Danlos Syndrome clinical care pathway completed
- PHARMAC quarterly meetings and opportunity to discuss Rare Disorder Medicine funding
- Engagement with the APEC Rare Disease Network, Rare Voices Australia, and the UK Genetic Alliance to commence development of key strategic priorities and objectives. These strategic priorities will be presented at parliament on Rare Disease Day 2020 along with a call for a National Strategy and Framework for Rare Disorders in New Zealand
- Hosting a successful Education Session for patients and support groups, with talks from PHARMAC and the Carers Alliance, and a constructive meeting between patients and PHARMAC
- Established the inaugural Rare Disease Day Awards, hosted by our patron the Governor-General at Government House
- Rare Disease Day awareness raising, especially a double-page article in the NZ Herald featuring four people living with a rare disease
- 150% increase in visitors to the Rare Disease Day website in February compared to February 2018
- Organisation rebranded as Rare Disorders NZ, with new website and logo
- Showcased the organisation and raised awareness of rare disorders with GPs, specialists and other health professionals as the chosen nominated charity at the GPCME in Rotorua
- Raised awareness of rare disorders at governmental level through correspondence and key meetings including with Minister for Finance, Minister for Disabilities, opposition MPs and spokespeople, the Human Rights Commission, and Heather Simpson, Chair of the Health and Disability Review
- Transitioned hosted websites to independent web platforms

- Supported rare medicine petitions to parliament
- Draft discussion paper on 'Women's unpaid work: caring for those with Rare Disorders', for the Ministry for Women

During some of this time I was also co-writer of the People's Report on the Sustainable Development Goals, to which New Zealand committed, along with 191 other countries, in 2015. The SDGs call for a more just, equal and sustainable world where 'no-one is left behind.' The report included four recommendations to urgently address the challenges confronting people with rare disorders. This report was launched online in July, to coincide with the government's first report on progress across the SDGs to the UN, and a policy brief compiled for members of parliament.

Every year, New Zealand produces the New Zealand Handbook on International Human Rights. It is a signatory to the core legally binding Human Rights Instruments and led the development of the Convention on the Rights of Persons with Disabilities. It has won world attention for its new Wellbeing Budget and framework.

And so it remains incomprehensible to me, after six months in this role, why the Ministry of Health cannot decide clearly where some 400,000 New Zealanders with special disorders or diseases fit. Are the challenges that many of them, their many caregivers and whanau face to be defined as health issues or disability issues, or are they to be simply unseen and ignored?

RDNZ's funding has been reduced by \$30,000 for the new financial year and will be further reduced in a year's time. This will impact on individuals' need for information and representation, and the transaction costs of the 130 support groups that are supported by RDNZ. "Equity" and "wellbeing" are central to the vision our leaders hold, yet many of the most vulnerable in our society remain largely marginalised, and unheard. As a result, New Zealand has far to go before it can claim to deliver Universal Health Coverage, to be debated at the UN in September, or truly realise its human rights commitment to the highest attainable standard of health.

I'm delighted to announce that the RDNZ Board has appointed Lisa Foster to the role of Chief Executive. She has ideal experience in many ways for the role, as many of you know, and the "polite persistence" it requires.

Thank you all again - it has been a privilege to be part of your community. I have very much enjoyed being with you for this short time and will remain connected with RDNZ in any way that is useful.

Gill Greer  
Acting Chief Executive (March to August 2019)

# Chair's report

I'm pleased to provide a report on the year ended 30 June 2019.

Firstly, may I welcome you all to our 'New Look', as Rare Disorders New Zealand. After many years as the New Zealand Organisation for Rare Disorders, we felt it was time for a review – and to ensure that those we stand for come first. While our new trading name officially rolled out in June 2019, the work has been the result of enormous effort by the entire team in the year prior, and I congratulate them for their success.

The last year has been a time of change for our organisation. Our CE, Dr Collette Bromhead, made the difficult decision to step down early in 2019, and we were fortunate to secure the services of Gillian Greer as our acting CE while we reviewed the position and the organisation's needs. I am thrilled to confirm that our long-standing Relationship Manager, Lisa Foster, took up the CE role in August 2019. I must pass on my sincere thanks to both Collette for her leadership and guidance, and to Gill for not only picking up the baton and carrying it forward, but crossing many hurdles as she did so. Both have stood as true champions of our organisation, and of the wider rare disorder community.

I was particularly pleased to have the opportunity to attend the inaugural Rare Disease Day Awards in February, presented at Government House by our Patron, Governor-General Dame Patsy Reddy. While we may most often focus on the long road ahead, taking the time to take stock of how far we have come, and to celebrate those who have played such large roles in getting us to this point was an excellent way to celebrate Rare Disease Day 2019.

We do not, however, forget the work still to be done. This last year has seen a number of patient groups lobby for access to life-saving medications that are funded elsewhere in the world, but not New Zealand. Concurrently, much of the health system is faced with ongoing budgetary concerns, and aging infrastructure. In November 2018, New Zealand signed the APEC action plan on Rare Disorders, yet our Ministry of Health consider this a 'non-binding' endorsement, and no visible action has been taken to implement the plan into our health setting. We have a long way to go to achieve true equity in health outcomes.

Despite these challenges, our small but dedicated team continue to connect, educate, inform, assist and advocate for those impacted by rare conditions, and I thank them for their efforts. Some days your job may seem thankless, but your work is valued, and noticed. I also need to thank my fellow trustees, who freely give their time and expertise, and at some personal cost.

As I close my report, I feel positively towards the future. We have a strong and dedicated team in place and have been buoyed by recollections of past battles fought, and won.

Jo Lusk  
Chair

# The RDNZ strategic plan

RDNZ's work plan for the 2018/2019 financial year is based on four strategic aims:

## 1. Providing information and support

- Coordination and resources for rare disorder support groups, improving connection between people living with rare disorders and those who care for them
- Continue to improve information on navigating the health system

## 2. Advocacy at a national level

- Raise the profile of rare disorders and continue to drive the agenda with government around equitable access to rare disease medicines, a rare disease register and carer payments
- Work to ensure genetic and other specialist services are improved to deliver timely and accurate diagnosis
- Make submissions on relevant consultations and legislation, to represent rare disease interests

## 3. Facilitating research and clinical trials for rare disorders

- Promote research to improve the treatment and care of rare disorders, working towards cures

## 4. Building a sustainable organisation

- Build a sustainable organisation for the future both financially and through connection with our patients, their families/whānau and carers, ensuring we have their mandate for representation through a new partnership/alliance agreement

These priorities are underpinned by RDNZ's core values of human rights and universal health care; inclusiveness and respect for people; participation and cooperation; and a balanced philosophy that is representative of New Zealand's ethnic diversity and our commitment to the Treaty of Waitangi.

These goals and values are being revised by the RDNZ board and will be updated in 2020.

## 1. Strategic priority: Providing information and support

### Website statistics

The NZORD/RDNZ website was accessed by 22,127 unique visitors over 27,267 visits during this financial year. This is an increase of about 70% over the previous financial year.

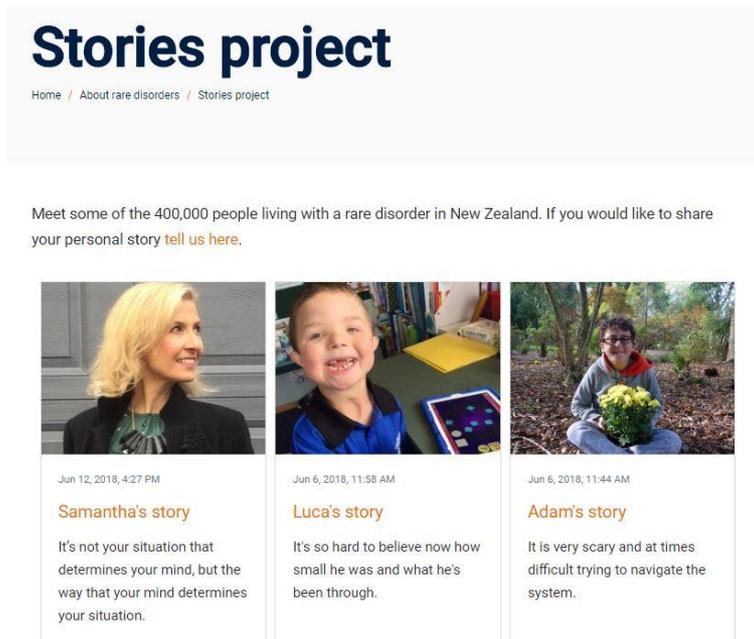
The most popular sections on our website were the Support Group Directory and the Rare Disease Database pages. There has also been strong interest in the Rare is Everywhere personal stories.

### Hosted websites

In 2018, it was decided that RDNZ's support group website hosting project would be wrapped up on 30 June 2019. It was apparent that the benefits of the scheme had greatly diminished in recent years as the barriers to creating websites are much lower and many groups are better served by social media for their online presence.

All the groups with a hosted website were informed of the closedown of the service in November 2018, well in advance of the 30 June 2019 close down date. The webmaster worked with the support groups to transition hosting for those groups who wished to continue with a website. In total, 12 groups have gone on to create new websites, some using the same format as their original sites and some with completely refreshed content.

## Rare is Everywhere: Stories Project



RDNZ launched the 'Rare is Everywhere: Stories Project' in April 2018 to gather stories from the rare disease community. We want to create a database of stories that cover the wide range of experiences, ages, ethnicities and conditions that exist in New Zealand. These stories will feature on the RDNZ website, in our newsletter and form the basis of future media releases. RDNZ wants to highlight the challenges faced by people with rare disorders and give patients and their carers a platform to share their personal journeys.

There are 20 stories on our website, with a number of stories in development.

## RDNZ social media

Social media is becoming an increasingly important way to connect with the rare disorder community, especially young families.

### Facebook

	2017/2018	2018/2019
Total page likes	1101	1380
Growth	12%	25%
Largest post reach	6200	18,600

The Facebook post with the largest reach was in May, a quote stating "Your illness does not define you. Your strength and courage does", reached 18,600 people, had 184 shares and eight comments. Twitter

RDNZ used our Twitter account to tweet 149 times over this period, averaging about 125 impressions per day.

The tweet with the highest engagement was about the establishment of the Ehlers-Danlos Society New Zealand.

## LinkedIn

RDNZ's organisation page on LinkedIn was set up in October 2017. The page has 67 followers and posted 80 updates.

## Responding to enquiries

Lisa Crawford was appointed Relationship Manager for RDNZ in June 2017 and has a background in bio-medical science with leadership in health support services. One of the responsibilities of this role is to manage any enquiries that are received in a responsive and effective way. RDNZ values the importance of gaining feedback in order to make quality improvements and identify any areas for development.

Throughout this financial year RDNZ supported 128 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.

## Rare disorder support groups survey

A survey was completed in June 2019 with the rare disorder support groups to gain evidence of assessing their ongoing service needs and their satisfaction of current performance of Rare Disorders NZ.

Overall analysis of the survey indicates that the rare disorder support groups value the current services provided by Rare Disorder NZ with some specific elements being felt to be of higher importance.

The question of what people with rare disorders about the priority focus areas for RDNZ was answered unanimously with 'all of the above' providing a clear message of the broad area of need within the rare disorder community and the appreciation of having a national organisation to offer recognition, acknowledgement and action to address their main concerns, challenges and needs.

A summary of other findings include:

- 'Rare disease awareness raising with GPs' was a top-ranking answer along with a desire for national advocacy by Rare Disorders NZ. This complements the desire expressed by clinicians and other health professionals during the GPCME for more support and understanding around rare conditions.
- A related question 'Do you feel it would be useful to have healthcare professionals trained in the mental health aspects of living with a rare disorder?' had a 94% positive reply.
- 'Information on navigating the NZ health and disability system' was a top-ranking answer followed closely by a request for 'regular national meetings to bring clinicians, researchers and patients together'. This highlights the feeling that is expressed regularly by many people with rare disorders that the current health system does not appreciate their needs and is structured around common diseases therefore can appear complex, difficult to access and dismissive and people expressed often feeling left behind feel left behind. The value of connection to each other and to health professionals is indicated by the second ranked answer of regular meetings to occur.
- A few questions on mental distress were added to this survey and the answers express extreme feelings of being at breaking point for at least 20% of the responders. This question elicited many direct comments detailing that most had felt at breaking point at some time. The need for further investigation in this area was clarified in our Ministry of Health report.

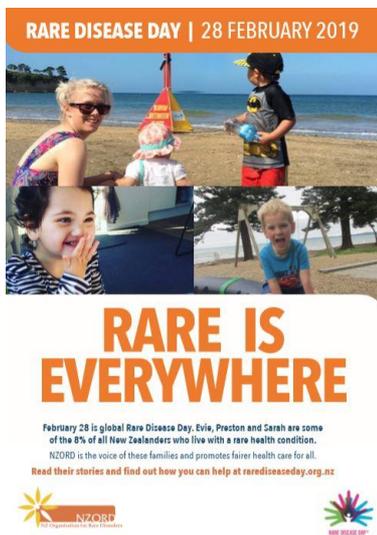
“The value of organisations such as RDNZ and their support in linking families and individuals with others living with the same condition can never be overvalued, as without the support and knowledge from others who had walked my path before me, I truly don’t know where I would be.” Sarah, Auckland

## Support group guidance information

In July RDNZ published guidance information to help patients and their carers establish a rare disease support group. The webpage describes what the role of a support group is, how to go about setting one up, and highlighting the benefits of peer support and connection. We can also offer advice on using online tools to enable connection between support group members where geographical distance is a barrier.

RDNZ offers newly established support groups advice and links to information that will assist their sustainability and effectiveness.

## Rare Disease Day



Rare Disease Day is a global day of recognition and is an important opportunity to raise awareness of rare diseases in our communities. The main message is Rare is Everywhere – 8% of the population live with a rare disorder and many more will be undiagnosed or ‘invisible’.

This diversity is reflected in our four Rare Disease Day families and their stories. We created a poster that was displayed in Auckland and Wellington, and in libraries, DHBs and community centres around the country. An exclusive, double-page article with the NZ Herald was published on 28 February.

## Rare Disease Day Education Session

RDNZ ran a free Education Session on Tuesday 26 February for the chance to meet, talk and share with others living with rare disorders. Following on from analysis of what the rare disorder community wanted we established this event to incorporate the main requests:

- Opportunities to connect with others in similar positions to share stories, gain advice on best practice and look for helpful strategies;



- Education on supportive lifestyle factors to improve daily challenges (mindful strategies);
- Mental health impact of rare disease was not recognised or appreciated by the sector (carer stress, ongoing continuous medical requirements, money issues due to inability to work).

A request was made for supportive information by RDNZ or links to associations who offer such support.

This was a morning meeting in Wellington with speakers from PHARMAC and the Carers NZ, as well as a workshop dedicated to addressing some of the challenges faced by those with rare disorders.

PHARMAC provided an overview of their processes and factors for consideration, highlighting the fact that a decline or deferral did not mean that the medicines needed to go back to the beginning of the process and that an open-door policy for new evidence or input was permitted to PHARMAC for consideration. PHARMAC advisors were present including the Deputy Medical Director Dr Peter Murray, Therapeutic Manager Sarita Von Afehlt and Alison Hill (Director of Engagement and Implementation).

Laurie Hilsgen presented on Carers NZ and Carers Alliance with updates on all the strategic documents, the new carers' strategy consultation process and key priorities.

Tracey Hancock formulated her session around what people felt was most important to them. Areas included financial constraints and impacts on employment; carers issues in relations to gaining support themselves; setting appropriate boundaries with other members of the same disease group; working with clinicians.

There were 38 attendees with many travelling from outside Wellington to take part in this event. Feedback from attendees was very positive with all participants valuing the opportunity to connect with others with similar experiences. RDNZ intends to host a similar event in Auckland or Christchurch next year.

## Rare Disease Day Awards

RDNZ hosted the inaugural New Zealand Rare Disease Day Awards to honour and recognise the rare disease champions in our community, some of whom have given their time for decades to improve the lives of people living with a rare health condition.



- Lifetime Advocacy Award – Lady Gillian Deane
- Patient Advocacy and Support Award – Allyson Lock
- Research Award – Associate Professor Mervyn Merrilees
- Health Professional Award – Dr Dianne Webster
- Future Champion Award – Brittany Vining

The winners celebrated at a high tea hosted by our patron the Governor-General and RDNZ at Government House on 28 February 2019.

## 2. Strategic priority: Advocacy at a national level

### Advocacy and networks

#### PHARMAC engagement

Dr Collette Bromhead arranged quarterly meetings with the Senior Leadership Team at PHARMAC to ensure that a continuing dialogue and timely communications with the sector can be maintained.

Issues discussed in these meetings included the following:

- Obtaining an infographic for RDNZ to share with patients that simplifies the processes for obtaining medicines for rare disorders
- Establishment of a rare disorder subcommittee of PTAC and its makeup and role
- Ongoing discussion of funding for rare disorder medicines

#### Briefing the government

Acting Chief Executive Gill Greer and Relationship Manager Lisa Foster met with a number of key government ministers to raise awareness of rare disorders at government level. These contacts included Finance Minister Grant Robertson; the Deputy Leader of the Opposition, Paula Bennett; and the Minister for Social Development and Disabilities, Carmel Sepuloni.

A meeting was secured with the Minister of Health Hon David Clark for 7 August 2019 to raise his awareness of the great complexity, barriers and unmet need facing people living with rare disorders in New Zealand. The need for an integrated policy response to rare diseases to reduce the barriers, improve the outcomes and improve inter-generational wellbeing will be 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.

#### Patient petitions

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 will attend the Health Select Committee meeting alongside these groups in August.

RDNZ supports Patient Voice Aotearoa and will continue to champion the stories of people with rare disorders who fall through the gaps in the system.

#### Rare medicines access proposal

PHARMAC assessment processes focus on gaining the best health outcomes that can be reasonably achieved within it. As stated by PHARMAC *'these medicines often do not compare favourably to other medicines that benefit larger populations and achieve greater overall health gains for less money.'*<sup>1</sup>

In consequence, medicine access for common disease can be accessed at reduced prices within the current PHARMAC model, however, access to often innovative and expensive medications is limited. RDNZ have been

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<sup>1</sup> <https://www.pharmac.govt.nz/assets/high-cost-medicines-discussion-document-2014-04.pdf>

discussing and advocating for an alternative pathway for medicines for rare and life-limiting diseases with different assessment criteria. Other OECD countries such as Australia and Scotland have implemented such pathways successfully and access to vital medicines has increased.

## Submissions

### RDNZ submission to PHARMAC Consumer Voice Consultation

The patient voice should be included from the start to ensure equity for all people requiring pharmaceutical treatment.

RDNZ believes that ensuring the patient voice is part of the process will make a difference to the health and wellbeing of patients with rare disorders, who are currently institutionally discriminated against through the purchasing process.

New Zealand lags far behind other countries in funding medicines for rare disorders.

Although patient factors such as health benefits and need appear to be part of the factors for consideration as part of the decision-making process, they don't seem to be given as much weighting as cost considerations.

These health benefits need to have an equitable weight along with input from health economists.

### RDNZ submission to Mental Health Inquiry

People with rare disorders are more likely to experience mental stress and depression. The stresses and mental hardships of living with a rare disorder were the focus of RDNZ's submission to the Government's Mental Health Inquiry.

Mental health is a major issue for people with rare disorders, and the people who care for them - 50% of patients with rare disorders are children, and 30% of those children will die before they are five years old. Many rare disorders are life-limiting and difficult to manage. This high level of uncertainty and challenge to access services designed for more common diseases create enduring and severe stress<sup>2</sup>. In a survey undertaken by EURORDIS- Rare Diseases Europe, it was found that patients and carers are three times more likely to suffer depression than the general population. NZORD believes the figures would be similar in New Zealand due to the current barriers in our health system for rare disorder patients.

## Conferences

RDNZ attended several conferences in order to connect with health professionals, researchers and other rare disorder stakeholders.

The conferences included:

- **Queenstown Research Week Satellite on Rare Brain Diseases, Queenstown, August**  
Dr Collette Bromhead was a key speaker at this event. Her talk highlighted the value of biomedical research to rare disease patients who may not currently have access to anything other than symptomatic

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<sup>2</sup> Mental health 2018 UK document

treatments. She also talked about the need for a national registry for all rare disorders, as well as RDNZ's upcoming initiatives to improve connections and collaborations between local researchers.

RDNZ also sponsored prizes for the best student presentations to recognise and encourage future rare disease researchers.

- **Tuberous Sclerosis Conference, Wellington, October**

Lisa Foster was a key speaker at this event and spoke about the advocacy work RDNZ does on behalf of all rare disease groups in New Zealand, as well as explained the services we offer to patients and health clinicians. A video of her presentation has been added to Youtube.

- **Australian Pompe Association, Noosa, October**

Collette was an invited speaker and gave an hour-long workshop for the 90 patients and caregivers on infectious diseases, infection control and vaccination for the immune-compromised. She represented both RDNZ and Massey University at this meeting.

- **Rare Voices Australia: 2018 Rare Disease Summit, Melbourne, November**

RDNZ received funding for Collette to attend this conference and learn more about the challenges and successes of our Australian counterparts.

- **General Practice Conference and Medical Exhibition, Rotorua, June**

This conference offered the opportunity to raise awareness of rare disorders with clinicians and specialists. Networking opportunities included discussion of the value that RDNZ can offer clinicians with the example of the clinical pathway for EDS and other potential projects of benefit related to raising awareness of rare disorders.

## Carers Alliance

RDNZ is part of the Carers Alliance, a group of 45 national not-for-profit organisations who are committed to creating a unified and clear voice to government for all carers' rights.

Four key priorities areas include:

1. Ministry of Health's Funded Family Care policy
2. Respite care policy
3. Continence issues (choice and dignity)
4. Improvement of current Flexible Funding mechanisms and processes (Carer Support and Individualised Funding and its variants)

“RDNZ gives me a lifeline to talk to fantastic people who are very supportive, understanding and empathetic. They are the only people who I've been in touch with that are a) interested in my condition and b) trying to find where I can get help.”

Patient

### 3. Strategic priority: Facilitating research and clinical trials for rare disorders

#### Rare disease researchers Special Interest Group established

NZORD has established a Special Interest Group (SIG) for any researchers working on rare disorders in New Zealand. Convened by Professor Mike Eccles of the University of Otago (and NZORD Board of Trustees member) the group will meet yearly to share research ideas, their results, collaborations, joint grant bids and expertise. NZORD will attend these SIG meetings and report back any relevant findings, or invitations to participate in research, to our rare disease community.

The first meeting took place at the University of Otago in Dunedin on 21 November 2018 and was very successful with 14 participants. The second meeting will take place in August 2019 in Wellington.



RDNZ Board member Professor Stephen Robertson is a world-renowned paediatric geneticist based at Otago University

### 4. Building a sustainable organisation

RDNZ has a renewed focus with a new chair and a new trustee joining the board this year.

RDNZ signed a new contract at the end of the financial year with the Ministry of Health. RDNZ will receive full funding of \$120,000 for 2018/2019, with reduced funding over the following two years: \$90,000 for 2019/2020; \$60,000 for 2020/2021.

We are looking at our strategic direction and 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 is working on a national rare disease framework and action plan, with input from our counterpart Rare Voices Australia.

## RDNZ team

### Staff

Dr Collette Bromhead (until March 2019); Gill Greer – **Chief Executive**

Susan Langston – **Administration Manager**

Lisa Foster (promoted to Chief Executive from August 2019); Kim McGuinness – **Relationship Manager**

Amy Watson – **Fundraising and Communications Manager**

### RDNZ board of trustees

Joanna Lusk – **Chair**

Bronwyn Gray QSM, JP

Mike Eccles

Martin Hanley

Stephen Robertson

Bice Awan

Carol Gernhoefer

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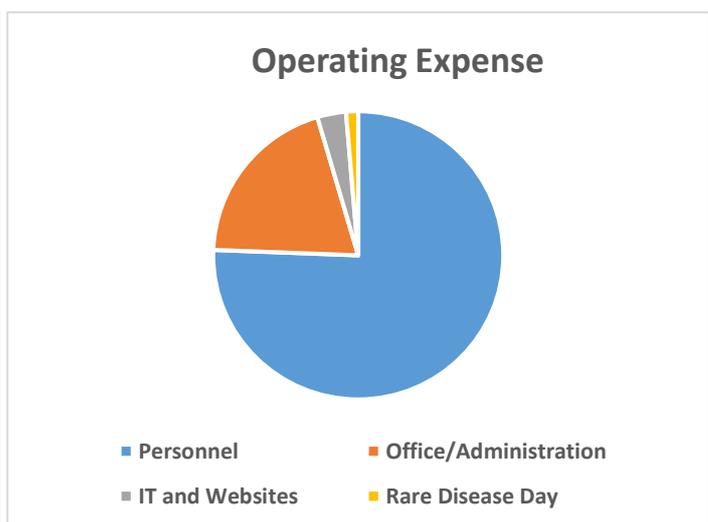
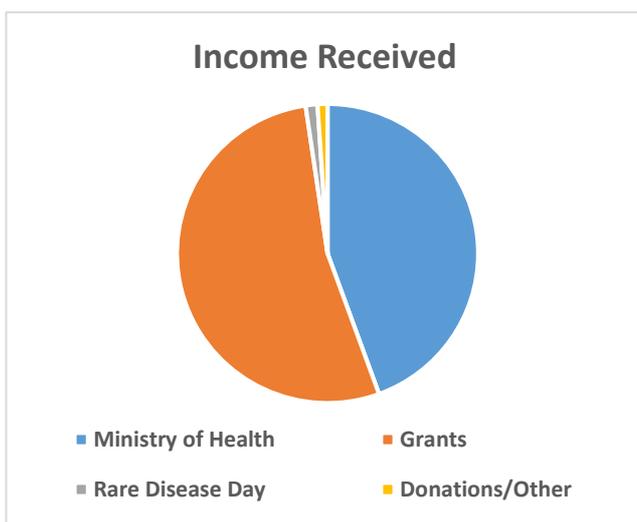
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# FINANCIAL RESULTS

## Summarised statements of financial performance for year ended 30 June 2019

	2019	2018
<b>Income Received</b>		
Ministry of Health	\$120,000	\$120,000
Grants	\$143,671	\$126,744
Rare Disease Day	\$3,432	\$4,098
Donations/Other	\$2,882	\$4,426
<b>Total Revenue</b>	<b>\$269,985</b>	<b>\$255,268</b>
<b>Operating Expense</b>		
Personnel	\$213,745	\$202,697
Office/Administration	\$56,127	\$65,903
IT and Websites	\$9,050	\$11,098
Rare Disease Day	\$3,807	\$23,322
<b>Total Expenses</b>	<b>\$282,729</b>	<b>\$303,020</b>
<b>Surplus/(Deficit) for the Year</b>	<b>\$(12,744)</b>	<b>\$(47,752)</b>



## Our supporters

