



# New Zealand Organisation for Rare Disorders Annual Report

# 2017

July 2016–June 2017



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## Mission Statement

To support, assist and promote better health care and well-being 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. NZORD 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.

Information is one of the best resources a newly diagnosed patient and their family can be given access to. Being diagnosed with a rare disease can be isolating and it can be hard to know where to turn after the initial diagnosis.

NZORD provide a large range of online resources to assist patients and their families, this includes the provision of a directory of support groups, free websites for small groups that otherwise couldn't afford one and regular bi-monthly newsletters.

# Chairperson's Report

On behalf of NZORD and all trustees, it is my pleasure to present this annual report for our 2017 financial year.

The year was a significant one for NZORD, punctuated by a number of personnel changes.

In December 2016 NZORD's former Chairperson, Lucy Elwood, made the decision to step away from her trustee role, and I was privileged to accept the Board's invitation to be her successor. Lucy has done a tremendous job of leading the organisation through a period of significant change and renewed direction during her term as Chair, including during the latter part of the financial year, and all of us at NZORD extend our thanks for her contribution.

We were subsequently very pleased to welcome Maria Berryman on to the Board to fill the vacancy created by Lucy's departure. Maria not only brings real heart to the role through supporting a child with a rare condition, but has also been making important contributions to Board decision making as a qualified and practising lawyer.

At the end of May 2017 our Chief Executive Letitia O'Dwyer resigned to take on a CEO role with the Asthma and Respiratory Foundation. During her time with NZORD Letitia raised our national awareness, professionalism and support group engagement. We're indebted to Leticia for her hard work and commitment, and wish her every success in her new role.

Following an interim period where I was NZORD's part-time Chief Executive, ably supported by Fundraising and Communications Manager Lyndal Bremer, who stepped into a day-to-day operational management role, we were delighted to announce the appointment of our new Chief Executive, Dr Collette Bromhead. She joined NZORD on 31 July 2017. Collette is a clinical scientist with 20 years' health sector leadership and academic experience. She comes to us from Massey University where her research has focused on improving the performance and accessibility of genomic tests. Collette has a strong background in health advocacy and has held multiple advisory roles for the Ministry of Health.

There were changes to the NZORD staff team where we farewelled our first ever Relationship Manager Vikki Ambrose and welcomed her replacement Lisa Crawford, and also farewelled Lyndal Bremer and recruited her replacement Amy Watson. Many thanks to both Vikki and Lyndal for their contributions.

Now we plan to consolidate our successes and use these as a springboard for growing NZORD in the future so that we can best serve and effectively advocate for New Zealand's rare disease community.

Our achievements during the 2017 year include: a review of NZORD's support for rare disease research; continued advocacy with PHARMAC for increased funding for rare disease medicines; lobbying for special recognition of rare diseases in the Government's Health Strategy; establishment of a new SWAN (Syndromes Without a Name) support group; strengthened relationships with the community of rare disease support groups; advocating for the introduction of folic acid in flour to reduce the incidence of spina bifida and other neural tube defects; research into understanding the impact of rare diseases on families and the health system; and a review of NZORD's website to ensure that we focus our support specifically on rare disease groups that would struggle to maintain traction by going solo.

We also continued to focus on ensuring that we remained in a strong financial position and it is pleasing to note that we have revenue streams and financial reserves which will enable us to continue and develop our current services. In particular, we were very pleased that we were able to renew our contract with the Ministry of Health, which has long been a financial mainstay for us. We are also very grateful for the financial support we have received from commercial companies which have a stakeholder interest in our work, including philanthropic community trusts and individuals.

The Board would also like to thank everyone who has supported our cause through discounted services and volunteer effort. Collectively, your support has allowed us to focus on our mission of supporting, assisting and promoting better health care and wellbeing for patients and their families/whānau living with a rare disorder in New Zealand.

I would particularly like to acknowledge the volunteer efforts of my fellow trustees Bice, Bronwyn, Maria, Joanna, Martin, Mike and Stephen. It is a pleasure working with such a passionate and dedicated team.

Thank you also to everyone living with or affected by a rare condition who shared their stories with NZORD during the year. We know that many of you have significant health and other stresses, and NZORD takes seriously the trust and confidence that you place in us. Our commitment is to continue to assist and serve you to the very best of our ability, striving to focus on what's possible and how we can make genuine differences for you, your families, and the health and other systems which have been established to support you.

Chris Higgins

Chair

New Zealand Organisation for Rare Disorders



## The NZORD strategic plan

No organisation can be run without a strong strategic plan that everyone is on board with and here at NZORD we continued to focus on the four key strategic priorities identified in 2016:

1. Providing information and support
2. Improving the health and disability journey
3. Promoting research
4. Building a sustainable future

These priorities are underpinned by NZORD’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.

## 1. Providing information and support

### NZORD social media

#### Facebook

	2015/2016	2016/2017
Total page likes	768	904
Growth	20%	18%
Organic average reach	336	366
Largest post reach	4082	2711

The Facebook post with the largest reach was in February and featured the Rare Disease Day billboard.

#### Twitter

NZORD renewed focus on Twitter in July 2016, with a tweet about our move to new offices on 27 July. We tweeted 58 times over this period, averaging about 200 impressions per tweet.

The tweet with the highest engagement was about our Rare Disease Day cocktail function.

### Website statistics

The NZORD website was accessed by 10,981 unique visitors over 14,821 visits during this financial year. While this is a decrease in overall visits from the same period for the previous year, engagement with

visitors was up significantly, with the number of pages visited and average visit duration both increasing by about 15% and 12%, respectively.

The most popular sections on the NZORD website were the Support Group Directory and the Rare Disease Database pages. The Helpful Information page also showed a significant increase in visitors.

## Health Professionals' Resources

In November 2016, NZORD launched a password-protected section for health professionals. This section provides:

1. A directory of specialists with expertise in treating rare disorders,
2. Access to Orphanet,
3. A facility for ordering NZORD support materials, including NZORD flyers and cards.

The Health Professionals' Resources section was visited 787 times in this financial year.

## Hosted websites

NZORD offers hosted websites and other web resources as a service to support groups, as well as assistance in managing these websites and resources.

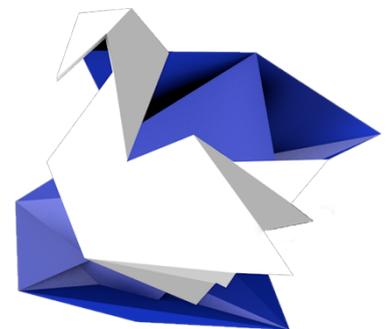
In early 2017, NZORD performed an audit of the websites we provide. After discussion with the support groups, a number of websites were retired and some groups took over responsibility for their own websites. NZORD currently hosts 40 websites for support groups.

The websites hosted by NZORD were accessed by 166,385 unique visitors over 221,294 visits, very similar figures to the previous financial year.

## SWAN NZ (Syndromes Without a Name)

SWAN New Zealand is a support group for patients and families affected by an undiagnosed genetic condition - a 'syndrome without a name'.

SWAN NZ was launched on 3 August 2016 with the SWAN NZ website going live that day. Information is currently being sourced to add to the website; patient stories and relevant articles and publications will add value to the site over time. NZORD also manages a SWAN NZ Facebook page and a closed Facebook group to allow members to ask questions and have discussions in private.



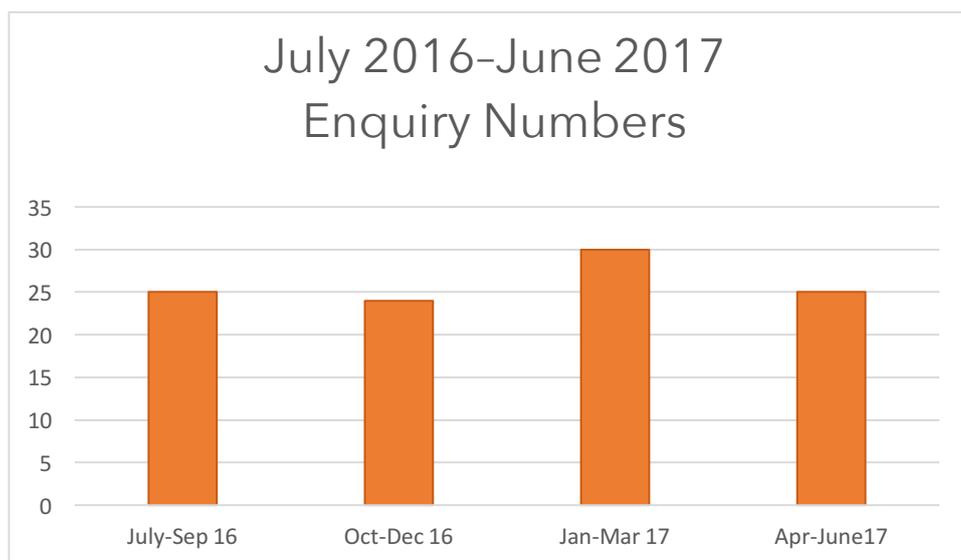
## Featured Rare Disorders

A section was added to the NZORD website to regularly highlight specific rare disorders, which is also displayed prominently on the home page. Rett syndrome, Castleman's disease and Pompe disease have featured so far.

## Responding to enquiries

Lisa Crawford was appointed Relationship Manager for NZORD 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. NZORD values the importance of gaining feedback in order to make quality improvements and identify any areas for development.

As the graph below indicates, there has been a steady number of enquiries over this financial year. NZORD expects increased usage of this service next year due to ongoing awareness campaigns targeting both the community and clinicians.



## Conference attendance

Lisa attended the Rotorua GP Conference and Medical Exhibition on 9 June 2017 which was held in conjunction with the NZMA in Rotorua. The NZORD stand was popular with around 200 visits by GPs, practice managers and nurses. Approximately 15-20 percent of visitors were already aware of NZORD, however this was a great opportunity to introduce NZORD to other healthcare providers. The Specialists Directory for GPs on the NZORD website was highlighted as well as the wider international databases. Stand visitors expressed genuine interest and gratitude about the resources provided by NZORD, and the fact that GPs could also refer their patients to gain specific support and information for themselves.

Some key clinical and health service provider relationships were established. The offer of adding information about NZORD in newsletters that cover many GP practices was made by Green Cross Health and can be replicated with other practice management providers.

New connections with other charity groups were initiated such as a breast cancer national educator, NZ Rural Health GP Network and health media service providers.

A wonderful benefit of NZORD's presence at this conference was meeting people who have a connection with rare disorders, either personally or through their family/whānau. The gratitude and appreciation in having an organisation that has support group information and specific guidance was clearly expressed.

## Rare Disease Day

Rare Disease Day takes place on the last day of February around the world and is an annual celebration and fundraiser. Rare Disease Day provides a wonderful opportunity to raise awareness of rare diseases and to highlight that, while these diseases are rare, together they equate to eight percent of the New Zealand population.

This special day provides rare disease support groups the ideal opportunity to plan their own fundraising event and to raise awareness for themselves. NZORD assists by providing posters for display and ribbons which can be purchased from NZORD and then sold to generate funds for the support groups.

This year's poster featured ten-year-old Adam Tiedemann who lives in Wellington and has rare chromosome disorder 1q44 deletion along with a 5q34q35 duplication. There was some media interest with a column in the Wainuiomata News about Rare Disease Day featuring Adam and his rare disorder. Adam also featured in a Rare Disease Day billboard displayed on the corner of Taranaki and Vivian Streets in Wellington during February.

NZORD hosts a Rare Disease Day website ([www.rarediseaseday.org.nz](http://www.rarediseaseday.org.nz)) where support groups can register their events for Rare Disease Day. NZORD promotes events via both the website and the Rare Disease Day Facebook page. The website provides useful information such as rare disease facts and figures, the history of rare disease day and ideas for running fundraising events.



**New Zealand  
Rare Disease Day**  
28 February 2017

www.rarediseaseday.org.nz  
New Zealand Rare Disease Day  
@NZORD

Rare Disease Day aims to raise awareness of all rare diseases in New Zealand. By working together we have a greater chance of improving the health and quality of life of those living with a rare disorder.

Meet Adam, who has recently turned 10 and has a rare chromosomal disorder - 1q44 deletion, along with a 5q34q35 duplication.

**rare gems**

givealittle visit [givealittle.co.nz/org/nzord](http://givealittle.co.nz/org/nzord) to donate to the NZ Organisation for Rare Disorders

## Rare Disease Day NZORD cocktail evening

This year NZORD hosted a cocktail evening at the Wellington Club in Wellington. Our 65 guests celebrated Rare Disease Day 2017 with cocktails and two live auctions.

We were also fortunate to have Tessa Prebble as the key speaker. Tessa is a journalism teacher from Wellington who lost her daughter, Eva, to complications of CHARGE Syndrome at 10 months old. She writes a blog, *The One in a Million Baby* ([www.theoneinamillionbaby.com/blog-2](http://www.theoneinamillionbaby.com/blog-2)), and produces a podcast of the same name. Through Tessa's blog she tells Eva's story, and the podcast focuses on families living with special and medically fragile kids.

Anecdotal feedback from those that came along was that the evening was thoroughly enjoyable, and some commented that they now had a better understanding of what NZORD does. Those from the rare disease community enjoyed the fact they could get together over a fun event and raise awareness.

## 2. Improving the health and disability journey

### Advocacy and networks

#### PHARMAC's rare disorders medicines pilot fund outcomes

In the period January 2016 to July 2017, seven of the ten medicines were in use through the Schedule listing or NPPA, with an eighth funded as part of in-hospital care.

RFP treatment funded	Indication	Schedule listing as at 1 October 2017
Bedaquiline*	Multi-drug-resistant tuberculosis	No
Icatibant	Hereditary angioedema	Yes
Siltuximab	Castleman's disease	Yes
Alglucosidase alfa	Infantile onset Pompe	Yes
Cholic acid	Errors in bile acid synthesis	No
Betaine	Homocystinuria	No
Sodium phenylbutyrate	Urea cycle disorders	Yes
Laronidase	Hurlers (bridge to transplant)	No
Idursulfase	Hunters (bridge to transplant)	Yes
Galsulfase	MPS VI	Yes

\* This drug treats tuberculosis, which is not a rare disorder.

Other medicines were provided through DHBs.

## Folic acid

Acting Chief Executive Chris Higgins attended a meeting of key stakeholders with an interest in the issue of fortification of bread/flour with folic acid in order to reduce the incidence of neural tube defects. He stated that NZORD's position is that there should be mandatory fortification of bread, and that in the meantime the Bakers' Association should consider reviewing its voluntary code of practice and revising its current 50% target upwards to 100%.

He was subsequently invited to participate in a meeting of the Bakers' Association Executive Committee, where he reiterated the same points. He also said that the science on the preventative effect of folic acid fortification was well established, that the matter should be responded to as a public health and human rights issue (e.g. the right to be born without a disability), and that NZORD would be communicating accordingly with the Minister of Health. He further noted that the NZ Spina Bifida Association had not been represented at either the MPI forum, or the Bakers' Association meeting and that he would attempt to contact them. Chris contacted the NZ Spina Bifida Association and they have confirmed that they are similarly in favour of mandatory fortification, and wish to be involved in future discussions.

## International conference attendance

Previous Chief Executive, Letitia O'Dwyer, attended the World Orphan Drug Congress in Washington, D.C. in April 2017. Letitia was invited to attend this event as a guest speaker and present on 'Changing the paradigm of access, recognition and collaboration of rare diseases in New Zealand'. The objective of this talk was to highlight some of the key initiatives NZORD has implemented, and to communicate what we are still hoping to achieve.

## 3. Promoting research

### Scripps collaboration

NZORD sought to broker a project between the Scripps Translational Science Institute in the US and the newly founded SWAN NZ support group, established by NZORD.

NZORD established contact with Scripps, obtained their protocol and convened discussions with all clinical geneticists from around New Zealand about the proposition of joining their research programme. It emerged that joining the programme would require ethical approval across all New Zealand clinical sites. It also emerged that in their programme there was little facility for iterative interaction with clinicians in NZ and the analysts in the USA, an ingredient that is considered to maximise the benefits of such diagnostic programmes. Consequently, progress on the Scripps initiative stalled due to the lack of substantial buy-in from local clinical geneticists. In its place an evolving ambition has

merged to establish this type of diagnostic pathway in New Zealand, coordinated through the Genomic Health Alliance of NZ (GHANZ).

To this end, NZORD's work in this sector has pivoted to supporting these local ambitions and our Chief Executive, Dr Collette Bromhead, as well as Board Member Professor Stephen Robertson are now part of the governance group of GHANZ. This group has the aim of coordinating activity in the diagnostic health sector and to lobby government and the Ministry of Health to establish a strategy to institute genomics into healthcare in New Zealand. The vision is for New Zealand to excel in the use of genomics in healthcare through a collaborative, coordinated, multidisciplinary and flexible approach so that gains can be efficiently and equitably realised.

## 4. Building a foundation for the future

NZORD continues to work on building a foundation for the future by improving the organisation's financial position and being mindful of operating expenses. Increasing NZORD's profile is another important task for the organisation moving forward.

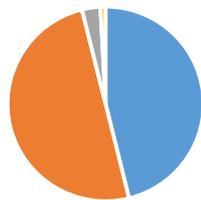
NZORD moved to a prominent position on the corner of Vivian and Taranaki Streets in central Wellington in July 2016.

# Financial Statement

## Financial Results Summarised Statement of Financial Performance For the Year Ended 30th June 2017

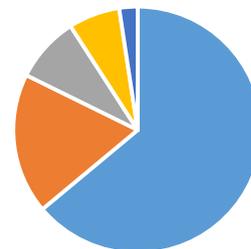
	2017	2016
<b>Income Received</b>		
Contract Income: Ministry of Health	\$ 120,000	\$ 120,000
Grants	\$ 129,886	\$ 156,194
Rare Disease Day Income	\$ 7,927	\$ 13,877
Other	\$ 2,170	\$ 12,306
<b>Total Revenue</b>	<b>\$ 259,983</b>	<b>\$ 302,377</b>
<b>Operating Expenses</b>		
Personnel Costs	\$ 165,394	\$ 141,063
Office and admin	\$ 47,720	\$ 50,181
IT and websites	\$ 22,243	\$ 19,309
General Expense	\$ 17,322	\$ 21,210
RDD Expense	\$ 6,173	\$ 6,982
<b>Total Expenses</b>	<b>\$ 258,852</b>	<b>\$ 238,745</b>
<b>Surplus/(Deficit) for the Year</b>	<b>\$ 1,131</b>	<b>\$ 63,632</b>

Income Received



- Contract Income: Ministry of Health
- Grants
- Rare Disease Day Income<sup>1</sup>
- Other

Operating Expenses



- Personnel Costs
- Office and admin
- IT and websites
- General Expense
- RDD Expense

## The New Zealand Organisation for Rare Disorders Team

### Staff

Dr Collette Bromhead - Chief Executive

Ben Chapman - Webmaster

Anne Merritt - Administration Manager

Lisa Crawford - Relationship Manager

Amy Watson - Fundraising and Communications Manager

### Board of Trustees

Chris Higgins, Chair

Bronwyn Gray QSM, JP

Mike Eccles

Martin Hanley

Stephen Robertson

Bice Awan

Joanna Lusk

Maria Berryman

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# Thank You to Our Supporters





[www.nzord.org.nz](http://www.nzord.org.nz)