



# Annual Report 2018

July 2017-June 2018

Photos on cover:

**Top left:** Anna and son Heath, who has spinal muscular atrophy (photo credit: Stephen Parker for the Rotorua Daily Post)

**Top right:** Allyson Lock, President of the NZ Pompe Network (photo credit: Wairarapa Times-Age)

**Bottom left:** Professor Stephen Robertson, Otago University and NZORD board member

**Bottom right:** Gabrielle, poster child for Rare Disease Day 2018

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## Highlights 2017/2018



### Rare Disease Day Symposium

94% rated the symposium Excellent/Very Good

97% rated the speakers Extremely Engaging/Very Engaging

94% Strongly Agreed/Agreed that their knowledge of rare disorders was improved

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### Survey

Results show patient groups value the services that NZORD provides

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### Enquiries

More than 200 families assisted during the year

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### Connections

Spoke at/attended seven conferences

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### NZORD website

40% more visitors compared to previous year

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### Awareness raising

Interview on Radio New Zealand's Nine to Noon programme alongside Minister of Health; TVNZ 1 News interview

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### Government briefing

To incoming Minister of Health (BIM)

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### Rare is Everywhere

Stories project launched to share the wide range of patient experiences



## 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. 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.

NZORD 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 more than 377,000 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

Tēnā koutou katoa.

It my pleasure to present this report of NZORD's activities and successes during the 2018 financial year. Following a number of staff and board of trustee changes, this was a year of consolidation and strategising for the future. Early on we were faced with significant political and funding challenges which we tackled head-on. With hard work, strategy and always keeping the needs of our rare disorder community at the centre of all we do, NZORD has ultimately emerged stronger and with a tighter focus on advocating for systemic change.

Our achievements during the 2018 year include:

- Radio New Zealand's Nine to Noon programme: In February I was interviewed by Kathryn Ryan (together with Minister of Health David Clark) about the "double blow" of NZORD losing our Ministry of Health funding as well as the Labour party promised \$20 million fund for rare disease medicines. Minister Clark stated "to find a way to support rare disorders is part of my personal agenda." Despite these conciliatory words, NZORD has not yet been able to meet with the Minister to discuss progress on a Rare Disease Medicine Fund. However, our Ministry of Health contract was renewed at the end of June for three years, on a reducing basis.
- Communications: professional update for our bi-monthly newsletter, regular posting on website and social media leading to significant upturn in hits for our websites.
- 'Rare is Everywhere' Stories Project: a webpage for rare disorder patients and caregivers to tell their unique stories to raise awareness and to reach out to others for support. These stories are beautiful, harrowing and inspiring and NZORD has been privileged to be a part of them.
- Continued advocacy with PHARMAC: for increased patient input into funding decision making as well as funding for rare disease medicines via newly established quarterly meetings with the Senior Leadership Team and Chief Executive.

- Poster child for Rare Disease Day: Gabrielle from Nelson shared her story of living with a rare progressive bone marrow disorder called dyskeratosis congenita.
- Rare Disease Day Symposium, Auckland: on 22 February we were very proud to host the first conference NZORD has held for five years. With a mixture of clinicians, researchers and personal stories of living with rare disorders, the day was an opportunity for people to connect. The event attracted 72 attendees and a post-event survey showed 100% of attendees found the event raised their awareness of rare disease; 95% found it valuable for networking to build support.
- Renewed contact's database information: a significant project to update the contact information for patients, clinicians, researchers, support groups and others. The aim of this was to improve targeting of communications and engagement with the rare disorder community.

As is the case for many patient support organisations, fundraising is an increasing challenge. With diminishing funding from our contract with the Ministry of Health, which has long been a financial mainstay for us, we are looking to alternatives. We continue to be 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.

I would like to thank my team, Lisa, Amy, Anne and Ben, for providing huge loyalty and support through my first year. Thank you also to everyone living with, or affected by, a rare condition who shared their stories. We know that many have significant health and other life stresses and want to assure you that the team takes seriously the trust and confidence that you place in us. Our commitment is to assist and serve you to the very best of our ability, focusing on what's possible and how we can make genuine differences for you, your families, and the systems which have been established to support you.



Dr Collette Bromhead  
Chief Executive

## Chair's report

On behalf of NZORD and all trustees, it is my pleasure to present this annual report for our 2018 financial year.

We were delighted to announce the appointment of our Chief Executive, Dr Collette Bromhead, who joined NZORD on 31 July 2017. Collette is a clinical scientist with 20 years' health sector leadership and academic experience. She comes to NZORD 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. She has been a tireless advocate both for the organisation, and for people in New Zealand living with rare disorders.

The election in September saw a change in government and an opportunity for NZORD to brief the incoming Health Minister, Hon Dr David Clark, advocating for the implementation of the following three key initiatives:

- Establishment of a national rare disorder database to drive improvements in treatment and support and to ensure resources are allocated to where they are needed.
- Establishment of an Orphan Drugs Fund which sits outside of PHARMAC, as we believe that treatment for specific rare disorders can be delivered cost effectively.
- Mandatory fortification of flour with folic acid to reduce the preventable incidence of neural tube defects to zero.

Any optimism that we had that the change of government might see rare disorders afforded greater priority by government policy makers has eroded over time.

This diminishing optimism was exacerbated by initial signals from the Ministry of Health that its contract with NZORD was to be discontinued in 2018. Following a multifaceted media and communications campaign NZORD was able to retain

its existing funding for the 2018/19 financial year, reducing over the next two years. At its June 2018 meeting the Board reluctantly decided in principle to accept this offer.

The organisational highlight for me was the Rare Disease Day Symposium held in Auckland to mark international Rare Disease Day on 28 February. It was an excellent opportunity to bring together clinicians, researchers, policy makers, NZORD staff and Board members, together with a significant number of people living with rare disorders. The feedback was universally positive and it was a great opportunity for all of us to learn something new from the perspective of others.

For most of the year the NZORD Board experienced a period of relative stability, and I wish to thank my fellow Board members for freely giving of their time, expertise and experience, for their commitment to the cause and for their support of me as Chair. As the year closed Maria Berryman made a decision to step down, and I also finished my tenure as both Chair and Board member at the Board's June 2018 meeting. At this meeting Joanna Lusk was unanimously selected to be NZORD's new Chair, and new prospective Board members were invited to join, as part of the process of filling the consequential vacancies.

It was also a stable year staffing-wise and thanks are extended to Collette and her team for their dedication and commitment throughout the year.

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 how we can make genuine differences for you, your families and to the health and other systems which have been established to support you.

Chris Higgins

Chair 2017-2018

# The NZORD strategic plan

NZORD's current work plan is based on four strategic aims:

## 1. Providing information and support

- Coordination and resources for NZORD 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 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. Strategic priority: providing information and support

### Website statistics

The NZORD website was accessed by 15,360 unique visitors over 21,348 visits during this financial year. This is an increase of about 40% over the previous financial year.

The most popular sections on the NZORD website were the Support Group Directory and the Rare Disease Database pages. There has also been strong interest in the featured rare disease pages on Rett syndrome and Ehlers-Danlos syndrome.

## Health professionals section

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

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

The Health Professionals Resources section was visited 723 times in this financial year.

## Hosted websites

NZORD offers hosted website 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 37 websites for support groups.

The websites hosted by NZORD were accessed by 146,643 unique visitors over 197,390 visits, very similar figures to the previous financial year.

“ It’s essential rare disorders have an umbrella organisation like NZORD to lobby for access to services, support, access to medication and good outcomes for rare disorders.”

Survey respondent

## SWAN NZ (Syndromes Without a Name)

The Syndromes Without A Name group was set up in 2017 to connect NZ patients and parents of children who have undiagnosed genetic conditions. The group of interested families has grown to more than 20 contacts. NZORD spoke to a number of people who had indicated they wanted to be involved in managing the group and one mother (Nicola) of a child with an undiagnosed condition agreed to run it. Nicola has set up a closed Facebook group to facilitate discussion and support amongst this isolated group. NZORD will continue to provide assistance to Nicola while she runs this new support group. The group currently has 40 members and the first coffee meeting in Wellington will take place at the end of October 2018.

## Featured rare disorders

A section was added to the NZORD website to highlight a featured rare disorder, which was also displayed prominently on the home page.

Articles on Ehlers-Danlos syndrome, dyskeratosis congenita and homocystinuria were featured this year.

## Rare is Everywhere: Stories Project

### Rare is Everywhere: Stories project

Meet some of the 377,000 people living with a rare disorder in New Zealand. If you would like to share your personal story [tell us here](#).

<p>Elizabeth's Story</p>  <p>Would it have made any difference all those years ago if I had known?</p>	<p>Olivia's Story</p>  <p>Not having a diagnosis means Olivia is not put in a box.</p>	<p>Samantha's Story</p>  <p>In a weird way it also opened my eyes to all the positives in my life.</p>
<p>Luca's Story</p>  <p>It's so hard to believe now how small he was and what he's been through.</p>	<p>Adam's Story</p>  <p>It is very scary and at times difficult trying to navigate the system.</p>	<p>Allyson's Story</p>  <p>I want things to be much better than they were when I was diagnosed.</p>

NZORD launched the 'Rare is Everywhere: Stories Project' in April 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 NZORD website, in our newsletter and form the basis of future media releases. NZORD 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 11 stories on our website, with a number of stories in development.

## NZORD social media

### Facebook

	2016/2017	2017/2018
Total page likes	904	1101
Growth	18%	12%
Organic average reach	366	524
Largest post reach	2711	6200

The Facebook post with the largest reach was in November and featured the rare disease databases on the NZORD website.

## Twitter

NZORD used our Twitter account to tweet 146 times over this period, averaging about 125 impressions per day.

The tweet with the highest engagement was about our Rare Disease Day poster child Gabrielle's story.

## LinkedIn

NZORD's organisation page on LinkedIn was set up in October 2017. The page has 40 followers and posted 80 updates.

## 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.

Throughout this financial year NZORD supported over 200 families through our enquiries line, and gave information to partner charities including Muscular Dystrophy NZ and Cystic Fibrosis.

## Rare disorder support groups survey

The updating of NZORD's contacts database included verifying and reviewing all rare disorder groups that had been listed with NZORD. This work identified 117 functional New Zealand support groups and our website has been updated to reflect that fact. This clean-up provided the perfect platform for a robust survey, which analysed the needs of the NZ rare disease support groups.

The survey focused on what NZORD already offers to support groups such as the enquiries line which provides relevant specific rare disorder links, technical support with website set-up and information, advocacy for rare disease issues, along with potential future projects. Therefore, survey questions were crafted around determining: (i) the perceived value of the services and sources of support NZORD currently offers and (ii) the future needs of the NZ rare disorder support groups to direct NZORD's strategic planning.

The results show that patient groups value the services that NZORD provides, particularly the provision of online information and support as well as national advocacy and support on issues such as equitable access to medicines.

In terms of new services NZORD could provide, advice for navigating the complex New Zealand health system was most popular, followed by tools that connect patients with clinicians, researchers and each other.

It was clear our support groups want more contact with NZORD and we are looking at the most effective ways of providing consistent regular communications with them through tools such as online videoconferencing.

## Support group guidance information available

NZORD has created a webpage featuring guidance on setting up a rare disorder support group. This page on our website hosts resources detailing advice and information for:

- Setting up a new support group
- The benefits and advantages of setting up a support group and what ongoing governance is needed
- Online tools for virtual meetings where distance is a barrier to members

NZORD will offer newly established support groups advice and links to information that will assist the sustainability of these groups.

“ I am still so taken back by all your effort. Having a child with such a condition is very isolating. I would have never imagined there truly are others out there trying to help our little man. I can't thank you enough.”

## Mother of child with spinal muscular atrophy

## Future support group coordination

NZORD conducted an audit of rare disorder support groups in NZ including those with websites we host, as well as the growing number that are found as only Facebook closed groups with no other web presence. It is notable the growth in social media support groups. We also occasionally find that support groups we do refer patients to are not responsive as the groups' administrators change frequently.

## Rare Disease Day

People with a rare condition are recognised and celebrated on a global scale each 28 or 29 February. NZORD created an awareness campaign centring around our “poster child” - Gabrielle from Nelson who is one in a million. She has an extremely rare progressive bone marrow disorder called dyskeratosis congenita.

Gabrielle's photo featured on posters distributed to community centres, libraries and other places around the country, as well as a

**Gabrielle is one in a million.  
But she's not alone.**

Seven-year-old Gabrielle has a rare progressive bone marrow disorder. There are over 7,000 known rare disorders, which affect around 8% of all New Zealanders. NZORD is the national voice for these rare individuals. By working together, our voices can be heard.

**Read Gabrielle's story and help us support Kiwis like her at [rarediseaseday.org.nz](http://rarediseaseday.org.nz)**



**Rare Disease Day  
28 February 2018**



giant billboard in central Wellington. Her story featured in social media posts, and articles in Parent2Parent Magazine, New Zealand Doctor and a spread in Woman's Day.

## Rare Disease Day Symposium

NZORD hosted an extremely successful one-day symposium for Rare Disease Day 2018. Entitled 'New Horizons: New Zealand Rare Disease Day Symposium', the aim was to bring together clinicians and people living with rare disorders to share information and experiences.

The symposium took place at the Marion Davis Event centre in Auckland on Thursday 22 February 2018. There were nine presentations, including a talk by Dr Fraser Burling who presented an Ehlers-Danlos Clinical Education Session as per our contractual requirement with the Ministry of Health. One attendee came from the United States to hear Dr Burling's presentation.



Dr Fraser Burling speaking at the Rare Disease Day symposium

NZORD secured sponsorship from three pharmaceutical companies, Biogen, BioMarin and Shire. Emerge Health sponsored one speaker, Tara Morrison, from Australia. Two of these pharmaceutical companies hosted trade stands at the event.

**“ Well done for putting together such a fantastic program in such a short time. It was well worth the trip.”**

**Symposium attendee**

Attendees were sent an evaluation survey the week after the event and almost 50% responded. The feedback was extremely positive:

- 94% rated the symposium Excellent/Very Good
- 97% rated the speakers Extremely Engaging/ Very Engaging
- 94% Strongly Agreed/Agreed that their knowledge of rare disorders was improved
- 74% rated the event as an Extremely Useful/Very Useful networking opportunity
- 87% stated they are Extremely Likely/Very Likely to attend another NZORD event

Ideas for other events/themes included: round table discussions; support group networking; session on funding process from PHARMAC/Ministry; overview of carers' support services; workshop focusing on specific issue; focus on generating greater awareness at the primary care level.

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

### Advocacy and networks

#### PHARMAC engagement

Dr Collette Bromhead has 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 include the following:

- Obtaining an infographic for NZORD 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 new government

In November NZORD sent a briefing to the incoming Minister of Health, Dr David Clark. This overview gave facts and figures for rare disorders in New Zealand, as well as highlighting three initiatives NZORD is recommending for these patients and their families.

The three recommendations are:

1. Establishment of a patient registry
2. Establishment of an orphan drugs fund
3. Mandatory fortification of flour to prevent neural tube defects

#### NZORD submission to 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. 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.

#### NZORD submission to Consumer Voice consultation

NZORD 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.

## Ehlers-Danlos (EDS) group update

The clinical care pathway for Ehlers-Danlos syndrome is in the final stage of review with the working group. It will be completed later in 2018.

“ NZORD is an essential organisation for all of us who have nowhere else to go after medical staff have put us in the ‘too hard basket’.”

Survey respondent

## Conferences

NZORD attended a number of conferences in order to connect with health professionals, researchers and other rare disorder stakeholders.

The conferences included:

- Conference for General Practice, 28-30 July 2017 in Dunedin. Held in conjunction with the New Zealand Medical Association with the theme of 'Whakamanawatia: working together we can do great things'.
- Conference for General Practice GPCME, 10-13 August 2017 in Christchurch
- Let's Talk: Our Communities, Our Health, 8-9 March 2018 in Wellington. Hosted by the Health Quality and Safety Commission.
- 2018 Health & Disability NGO Forum, 13 March 2018 in Wellington. Jointly hosted by the Health & Disability NGO Council and Ministry of Health.
- NZ Pompe Network Conference, 23-24 March 2018 in Auckland
- National Rural Health Conference, 6 April 2018 in Auckland
- General Practice Conference and Medical Exhibition, 7-8 June 2018 in Rotorua. This conference offered the opportunity to raise awareness of rare disorders with clinicians and specialists. Networking opportunities included discussion of the value that NZORD 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.



Lisa Crawford (NZORD) with the Hon David Clark at the National Rural Health Conference in April

## Carers Alliance

NZORD 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)



NZORD's Lisa Crawford (left) with the Carers Alliance at Parliament in April

## 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 twice 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 will take place at the University of Otago in Dunedin on 21 November 2018.

### AUT study

NZORD worked with researchers at Auckland University of Technology in June on a study focusing on people with rare conditions and their experiences of treatment with multiple specialists. We helped researchers recruit participants via our rare disease community networks.



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

## 4. Strategic priority: building a sustainable organisation

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

NZORD signed a new contract at the end of the financial year with the Ministry of Health. NZORD 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.

NZORD is working on a national rare disease framework and action plan, with input from our counterpart Rare Voices Australia.

“ NZORD 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

## NZORD team

### Staff

Dr Collette Bromhead - Chief Executive

Ben Chapman - Webmaster

Anne Merritt - Administration Manager

Lisa Foster - Relationship Manager

Amy Watson - Fundraising and Communications Manager

### NZORD board of trustees

Joanna Lusk - Chair

Bronwyn Gray QSM, JP

Mike Eccles

Martin Hanley

Stephen Robertson

Bice Awan

Carol Gernhoefer

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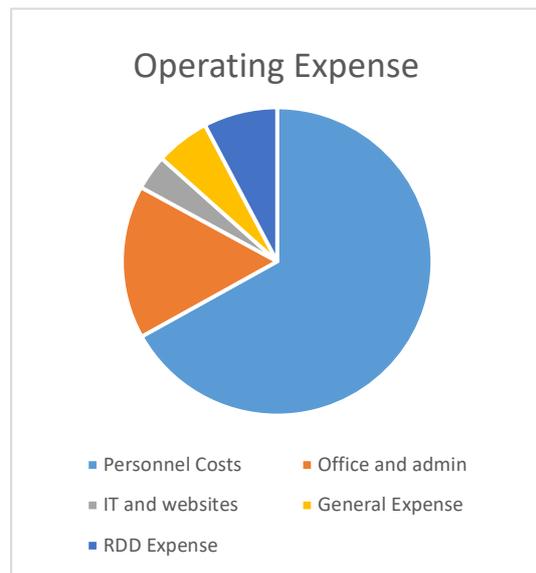
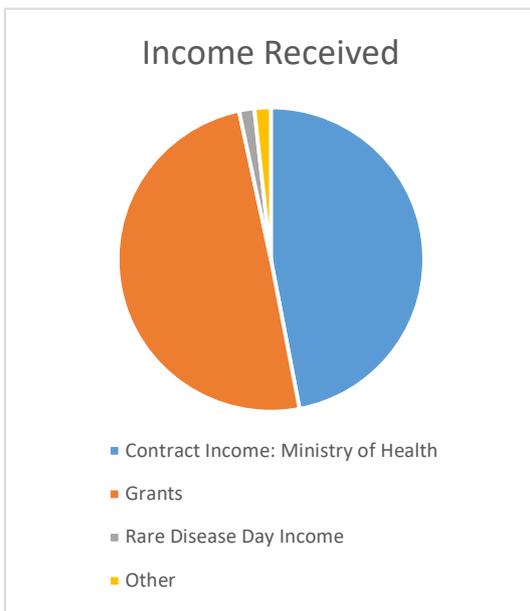


# Financial statement

Summarised statement of financial performance

For the year ended 30 June 2018

	2018	2017
<b>Income received</b>		
Contract income: Ministry of Health	\$120,000	\$120,000
Grants	\$126,744	\$129,886
Rare Disease Day income	\$4,098	\$7,927
Other	\$4,426	\$2,170
<b>Total revenue</b>	<b>\$255,268</b>	<b>\$259,983</b>
<b>Operating expense</b>		
Personnel costs	\$202,697	\$165,394
Office and admin	\$48,777	\$47,720
IT and websites	\$11,098	\$22,243
General expense	\$17,126	\$17,322
RDD expense	\$23,322	\$6,173
<b>Total expenses</b>	<b>\$303,020</b>	<b>\$258,852</b>
<b>Surplus/(deficit) for the year</b>	<b>\$(47,752)</b>	<b>\$1,131</b>



## Our supporters

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