



Annual Report 2021

July 2020–June 2021

Photos on cover:

Top left: Rare disorder support groups at the Fair for Rare NZ petition handover at Parliament

Top right: Paddy Gower and Lisa Foster celebrating the Rare Beer Challenge at Fortune Favours brewery

Bottom left: James McGoram, Lisa Foster and Sue Haldane after meeting with Minister of Health Andrew Little

Bottom right: Kim McGuinness at the New Zealand Respiratory Conference at Te Papa

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Highlights 2020/2021



Fair for Rare NZ petition handover

Rare disorder collective petition calling for a National Rare Disorder Framework delivered to Parliament with more than 8,200 signatures



Increased engagement with policy makers

Establishment of four meetings annually with Ministry of Health officials, focusing on data/digital and awareness raising within the sector



Enquiries

More than 300 families and health professionals assisted during the year – up 50% on the previous year



Rare Beer Challenge

Partnership with Fortune Favours craft brewery continues to grow, with 11 breweries now involved. A total of \$10,000 was raised



Formal endorsement

Royal NZ College of GPs, NZ Medical Association and PHARMAC formally endorsed Rare Disorders NZ's work



Awareness raising

Three major stories on Radio NZ, NZ Herald and The Listener for Rare Disease Day



Minister of Health meeting

Meeting with Minister Little to amplify the collective voice of rare disorders and call for recognition of this group as a health priority



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 conditions.

Chief Executive's report

Rebuilding, reviewing, and restructuring our health system have been key themes this year with a focus on equity to improve health and wellbeing for all New Zealanders. The upcoming 2022 year offers amazing possibility for transformational stewardship that can improve previous systems to ensure no one is left behind. This can only occur with consultation and engagement with the rare disorder community; to hear, understand and act from a place of awareness.

At this powerful time of potential, I am proud to present this report, which displays the high level of activity, collective engagement and reach that Rare Disorders NZ, with the support of key representatives from our collective, has made during this year.

The collective voice of our strengthening community was heard by the leaders and decision makers during this period and this momentum will continue and increase into the years ahead. Our Fair for Rare NZ petition led by Sue Haldane created a vital platform for Kotahitanga and solidarity, with the request for equity for the rare disorder community via establishment of a National Framework for Rare Disorders.

RDNZ met with Hon Andrew Little where Sue had the opportunity to explain her barriers personally, and the need for inclusion with positive hopes for change.

Other key achievements during the 2021 year include:

Fair for Rare NZ: Campaign and Petition

- Sue Haldane and RDNZ's petition calling for a National Rare Disorder Framework was handed over to Dr Liz Craig MP at Parliament on 24 March. People living with a rare disorder came from all over NZ to take part in this event. More than 8,200 signatures were gathered and the petition was announced in the House on the day
- Fair for Rare NZ campaign endorsement - 85 rare disorder support groups and partners, including the Royal NZ College of GPs, NZ Medical Association, and international rare advocacy groups

International

- Represented NZ rare disorder community in the World Health Organisation Collaborative Global Network for Rare Diseases; a five-year plan to establish global expert centres on rare disease
- Facilitated international conference as Board member of Asia Pacific Alliance of Rare Disease Organisations (APARDO)
- Attended international conference focused on the value of global rare disease patient organisations and alignment of improved access to treatment and medicine

- Developed and published an APARDO Newsletter on rare disease, including New Zealand overview of progress and challenges
- New Zealand's lack of rare disorder policy highlighted at UN meeting; RDNZ's CE Lisa Foster and Chair James McGoram contributed to a Rare Disease International Policy Event on a UN Resolution for Rare Diseases

Strengthening our presence and connection within health sector

- Organised quarterly meetings, which are hosted and facilitated by Ministry of Health New-born Screening Unit. One meeting had a focus on sharing personal journeys to improve understanding, and the other was on the importance of data on rare disorders and included the Data and Digital team
- PHARMAC formally endorsed the value of a peak body for rare disorders as a conduit between clinicians and people impacted by rare disorders in a letter dated 8 March
- Submission to PHARMAC Review Panel in June and facilitation of 14 support group submissions
- Submission on the Holidays (Increasing Sick Leave) Amendment Bill. CE Lisa Foster, alongside three support group leads, provided an oral submission on the positive impact of increasing sick leave for families living with a rare disorder. A total of 12 support groups/individuals made a submission

As is evident in this annual report, there have been intense and constructive activities with positive outcomes of increased engagement and awareness of rare disorders. This creates the perfect foundation for our new health system reform to provide a seat at the table and offer authentic inclusion for this sizable, connected, and strong community.

With hope for a future vision of an equitable New Zealand with clear prioritisation of those facing the challenges of rare disorders, I offer deep appreciation of all our champions, all our supporters and all those who follow our journey, both in New Zealand and around the globe.

Lisa Foster (Bsc Hons)
Chief Executive



Chair's report

Tēnā koutou katoa.

2021 has been a year to show our collective resolve for positive change in society in the face of some steep challenges. Ours is a community of supporters, volunteers, NGOs and advocates. It includes our wonderful staff and trustees, but most of all it is a community of those living with a rare disorder - and their carers. So many of us have personal stories of what rare means, and it has been a privilege to hear those stories told this year, clear and strong, in an effort to bring about the change we seek.

I'm proud of the work RDNZ has completed in the past 12 months, showing resilience and determination, and being a powerful advocate for the rare disorder community - something desperately needed in the face of reduced funding, a global pandemic and what can only be described as official indifference.

I had the privilege of stepping into the role of Chair in December last year thanks to the encouragement of the remarkable Gill Greer, whose mana and leadership has proven invaluable to RDNZ for many years. Gill is now stepping down from the board, and we thank her for her incredible service and wish her all the best for the future.

As 2021 began I found myself very much in the deep end as Rare Disease Day approached, working with the board to set new objectives, meeting with the Minister of Health, and even judging a beer competition - an upbeat event among the more serious work that did much to publicise our cause. The steady hand of our hard-working CE Lisa Foster, and the guidance and support of my fellow board members, has meant our profile as an organisation, and our reputation, has only grown this year. The publicity gained at the Rare Beer Challenge was a great example of this.

I'm also thankful to the practical stance adopted by the board, who are not afraid to roll up their sleeves to write articles, letters, attend events and fundraise - as well as providing their expertise and experience in the governance of our organisation.

As mentioned, we have been particularly active as advocates in the past 12 months - engaging with the Minister of Health, GPs, a great many MPs from across the political spectrum, the PHARMAC Review and even taking part in a submission to the UN. The highlight would

have to be the presentation of our petition proposing a National Rare Disorder Framework on the steps of parliament, and the great many supporters who joined us there. My thanks in particular to Sue Haldane for fronting this campaign so well, and with such poise and resolve.

Our advocacy is balanced with our strong working relationships with the Ministry of Health and PHARMAC, the last of which took the very rare step of endorsing us earlier this year. As such, RDNZ occupies a privileged place in the discourse on rare disorders - being able to strongly criticise policy while still productively working across multiple agencies to achieve practical results. Our staff - Susan, Kim, Amy and Lisa - have played a key role in this constructive approach. So it is with some sadness, and also a little pride, that we farewell Amy Watson as she moves on to the next challenge in her career.

It has been a goal of the board for RDNZ to be known as the 'go-to' experts on Rare Disorders for both the media and for health practitioners. The growing awareness of rare disorders and RDNZ - as demonstrated in numerous articles and media appearances, and in the endorsements we have received - is a testimony to these efforts.

Ultimately, the government has not yet adopted our proposal for a National Rare Disorder Framework, and many systemic obstacles continue to sit in the way of treatment and support for people living with a rare disorder. So over the next 12 months our Fair for Rare NZ campaign will continue, as will our efforts to raise the collective voice of our community, provide support, resources, and to connect people and research with each other. I remain hopeful for positive change and have great faith in our people to get us there.

He iti kahurangi. Small things can yet be precious.

Kia kaha e te whānau.

James McGoram
Chair



The RDNZ strategic plan

RDNZ's work plan for the 2020/2021 financial year was 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).

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 continues to impact the rare disorder community in 2021, and will continue to do so next year. RDNZ is the umbrella group for all rare disorders in NZ and we are connected to thousands of people through our rare disorder collective. As the connector hub between these groups and our contacts at the Ministry of Health, we continue to ensure that people living with a rare disorder and their families have the information and access to care they need as a result of this pandemic.

Our collective

RDNZ's collective includes 115 rare disorder support groups and the size of these support groups range from a handful of people to thousands of members. Our Relationship Manager, 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.

RDNZ supported the collective with building skills and capacity through the following webinars: pain management for rare disorders; media training for support group leads; support group advocacy training; and rare disorder research. These webinars were well attended and evaluated with one participant saying:

“Thank you so much for sending the link for the pain webinar through. I attended and thought it was brilliant. I really appreciate RDNZ organising this and allowing us to share the video with our members.”

Responding to enquiries

Throughout this financial year RDNZ supported more than 300 families and health professionals 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.

Website and social media

RDNZ's website is an important channel to increase our reach and raise awareness. Total visits to the website increased by almost a third compared to the previous financial year. The most popular sections on our website continue to be the Support Group Directory and the Rare Disorder Database pages. There has also been strong interest in the Fair for Rare NZ campaign and associated parliamentary petition.

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.

Chief Executive 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 2020 RDNZ's 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. It provided the opportunity for our rare disorder community to raise awareness and ask fellow New Zealanders to acknowledge the common challenges faced by people living with a rare disorder.

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. Sue, on behalf of Rare Disorders NZ, launched a Parliamentary Petition in May 2020 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 disorder, and the unfairness within the current system, by committing to the long overdue development of a New Zealand National Rare Disorder Framework,” says Sue.

The petition gathered more than 8,000 signatures and was delivered to Dr Liz Craig MP on 24 March by Sue, Lisa Foster, RDNZ Chair James McGoram and our collective of rare disorder support groups. The petition was presented to the Health Select Committee for consideration.

Campaign endorsement

The Fair for Rare NZ campaign has been formally endorsed by more than 85 organisations, including the Royal NZ College of GPs and international partners such as Asia Pacific Association of Rare Disease Organisations.

Meeting with Minister of Health



RDNZ CE Lisa Foster, Chair James McGoram and 22Q mum Sue Haldane met with the Health Minister Andrew Little in March on behalf of the 300,000 New Zealanders living with a rare disorder.

“Our meeting with Minister Little provided a fantastic opportunity to express the need for equity for people impacted by rare conditions,” says Lisa.

To explain the need for a National Rare Disorder Framework, RDNZ presented evidence of the barriers, and with support of Sue as a lived example, we covered all areas of diagnosis, education, health pathways, coordinated care, medicine access, data and registries, clinical trials and research.

The fact that New Zealand is falling behind internationally was discussed, along with the opportunity for solutions that other countries are already implementing – such as the Awareness and Education Pillar in Australia and the UK’s GP Education Programme.

Disappointingly, we have had no clear response from the Minister in relation to inclusion for people with rare disorders as a distinct marginalised community nor in relation to our reduced funding which terminates in 2023.

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.

In March RDNZ received formal endorsement of our work from PHARMAC:

“RDNZ provides a valuable conduit for communication and fostering understanding between people impacted by rare disorders, and the health system. PHARMAC is aware of the challenges faced by people with rare disorders in receiving a diagnosis and accessing effective treatment and is keen to remain connected to the rare disorders community Without RDNZ PHARMAC would find connection and communication with this community much more difficult.” Alison Hill, Director Engagement and Implementation, PHARMAC

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 a country known for its human rights commitments and values for equity.

In November, RDNZ sent a Briefing to new Minister of Health Andrew Little on behalf of the rare disorder community. The Briefing detailed the issues and opportunities to improve healthcare and wellbeing for the 300,000 New Zealanders living with a rare disorder and their whānau. It outlines the need, supported by our collective, for a National Rare Disorder Framework, in line with other OECD countries such as the UK, Australia and the US.

There has been no commitment from the Minister for people with rare disorders, despite ongoing clarity of their needs and increase in global expectations around human rights. We continue to pursue meetings, collaboration and advocacy across Government in hopes for formal recognition and commitment in our new health reformed system in 2022.

Alliances in New Zealand



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

RDNZ has built a strong relationship with the Royal NZ College of GPs and received endorsement from the College for our work in July 2020.

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

PVA protest at Parliament



Rare Disorders NZ and our rare disorder collective attended the Lie Down for Life at Parliament in May. This event was organised by Patient Voice Aotearoa to call for better access to modern medicines for genetic, undiagnosed and rare disorders.

Protesters lay down by the steps at Parliament for five minutes in the rain to show their determination for better access to medicines. Similar protests took place around the country in 11 cities including Auckland, Hamilton, Christchurch and Dunedin.

It was a very moving event, with politicians from every political party present to hear the call for improved access to life-changing medicines. Health Minister

Andrew Little acknowledged the dedication of the people campaigning for change but made no commitment to improving medicines access.

Examples of medicines for rare illnesses include a treatment for Pompe Disease, Myozome, which is funded in 76 other countries; a life-changing drug for Cystic Fibrosis named Trikafta; and Spinraza for Spinal Muscular Atrophy.

International connections

RDNZ's CE Lisa Foster and Chair James McGoram had a fantastic opportunity to contribute to a Rare Disease International Policy Event on a UN Resolution for Rare Diseases in March. They were inspired by the solidarity and support from standing with our global rare disease community as well as UN Permanent Missions for France, Spain, Qatar, Thailand and Brazil.

RDNZ continues to be an important part of the Asia Pacific conversations via APARDO and this provides fabulous opportunity for shared learnings, advocacy and support across both the Asia Pacific region and the world.

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 campaign coordinated by Rare Diseases International.

Submissions

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

In January RDNZ's CE Lisa Foster, alongside three support group leads, gave an oral submission to the Education and Workforce Committee on the impact of increasing sick leave for families living with a rare disorder.

RDNZ supported our collective to make a submission on the Holidays (Increasing Sick Leave) Amendment Bill through the creation of a template and explanation about the process. A total of 12 support groups/individuals made a submission to extend the annual entitlement of sick leave from 5 to 10 days' paid sick leave, and shared the impact this increase in leave would have on them.

Every submission also highlighted the fact that increasing sick leave entitlements is just one small step that the Government can take to support people living with a rare disorder, but there is so much more to be done to support the 1 in 17 New Zealanders living with a rare disorder and their carers.

RDNZ asked the collective through social media “What does more sick leave mean for you and your family?”

Here is some of the feedback shared through RDNZ’s oral submission:

“Both my partner and I being able to be at the hospital with my girl without worrying about not being paid.”

“I could finally take on a career and still be able to be home for my daughter during a flare.”

“Being able to take sick leave for myself and not get even more sick would be amazing!”

Sick leave entitlement will increase from July 2021.

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



Conferences

New Zealand Respiratory Conference



Rare Disorders NZ hosted a stand at the New Zealand Respiratory Conference at Te Papa in November. Chief Executive Lisa Foster and Relationship Manager Kim MCGuinness attended the conference on behalf of the 34 rare conditions in our collective with respiratory issues, as well as promoting our Parliamentary Petition for a National Rare Disorder Framework. Examples of rare disorders that have respiratory issues include Ehlers-Danlos Syndromes, Cystic Fibrosis and some chromosome disorders.

Lisa and Kim spoke to a wide range of healthcare professionals, including specialists, nurses and physiotherapists who were keen to learn more about rare health conditions and the resources available to help their patients.

Our support groups were grateful for the opportunity to be

represented, with one member of our collective commenting:

“Thank you so much! This makes my heart sing to see you educating our medical community. The more aware they are of underlying causes, the sooner we may get diagnosed and save a lot of heartache and searching for answers.” Support group leader

General Practice Conference & Medical Exhibition

Lisa attended the annual Rotorua GPCME in June to represent the rare disorder community:

“This conference was extra-special due to the fact last year’s event was cancelled. I was privileged to be an attendee and hear about current research, system reform impacts and expectations, as well as many other amazing topics. The chance to meet, network and find aligned areas is such an important aspect, especially for rare disorders, which are often an area of less awareness or understanding. Discussions about actions to improve awareness of rare disorders occurred and I will put forward a request to run a workshop next year focusing on education for clinicians. From this comes understanding and a shift in mindset to hopefully filter to all the people who will need that care and compassion when they are looking for a diagnosis and care from their clinician.”

Health Minister Andrew Little spoke about the shift from DHBs to Health NZ, as well as the challenges facing New Zealand due to COVID-19.

Rare Disorders NZ provided a flyer in all delegate’s bags to raise awareness of our organisation and the support available to patients.

GP awareness

An article entitled ‘Individually rare, collectively common’ was published on the Royal NZ College of GPs website and sent to their network of 5,500 GPs.

Rare Disease Day media

Rare Disease Day is a global day of recognition and an important opportunity to raise awareness of rare disorders in our communities. Media highlights this year included:

- Double-page article in The Listener ‘Seeking action’
- Radio NZ’s The Detail programme ‘Urgent call for framework to treat Kiwis with rare disorders’
- NZ Herald double-page article ‘Sliding around in the dark’: What it's like to have a rare disorder in New Zealand’

Rare Beer Challenge

The Pāua Man Porter won the first ever Rare Beer Challenge. Created by Fortune Favours brewers who took inspiration from the unusual ingredient, this beer beat ten other competitors to take first prize.

The inaugural Rare Beer Challenge took place on Friday 26 February to raise awareness of the 300,000 New Zealanders living with a rare disorder for Rare Disease Day 2021.

“We are chuffed to have won the inaugural Rare Beer Challenge! It was a great opportunity for our team to get creative and have some fun whilst also raising money



and awareness for Rare Disorders NZ,” says Shannon Thorpe, founder of Fortune Favours brewery.

These eleven rare brews were judged by a prestigious judging panel with Head Judge Stephanie Coutts of Craft Beer College, Hannah White from 8 Wired, journalist Patrick Gower and Chair of RDNZ James McGoram.

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

RDNZ has a renewed focus with an experienced Chief Executive and a group of dedicated trustees.

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

James McGoram (Chair)

Bice Awan

Carol Gernhoefer

Gill Greer

Martin Hanley

Joanna Lusk

Rosemary Marks

Stephen Robertson

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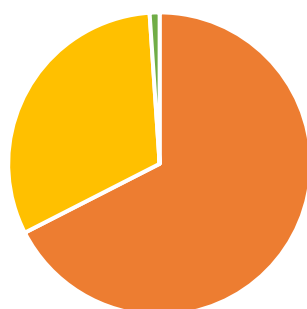
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FINANCIAL RESULTS

Summarised statements of financial performance for year ended 30 June 2021

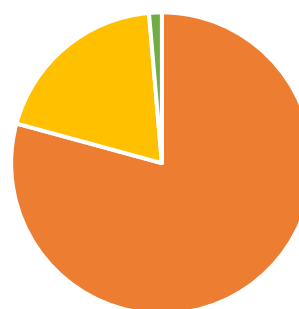
	2021	2020
	\$	\$
Donations and fundraising	217,224	116,236
Revenue from providing goods and services	101,250	153,775
Other revenue	3,410	2,617
Total Revenue*	321,884	272,628
Operating Expense		
Volunteer and employee related costs	188,153	186,685
Costs related to providing goods or services	46,058	24,482
Public fundraising and other expenses	3,249	6,316
Total Expenses*	237,460	217,483
Surplus/(Deficit) for the Year*	84,424	55,145

Income Received Y/E June 2021



- Donations and fundraising
- Revenue from providing goods and services
- Other revenue

Operating Expenses Y/E June 2021



- Volunteer and employee related costs
- Costs related to providing goods or services
- Public fundraising and other expenses

Our supporters

