



Annual Review  
**2021**

We're stronger **together**

## Acknowledgement of Country

Muscular Dystrophy Queensland acknowledges Traditional Owners of Country throughout Australia and recognises their continuing connection to lands, waters and communities. We pay our respect to Elders past and present.



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## Vision

Our vision is for life without limits for people with muscular dystrophy and similar conditions.

## Purpose

We empower people living with muscular dystrophy and similar conditions to make the most of opportunities and live the lives they choose.

## What we do

*"Every person has a right to be an active member of their community and to have a say in the decisions that affect their lives."*

Australian Human Rights Commission.

People who live with muscular dystrophy and similar conditions continue to experience barriers which limit their opportunities to socialise, find work, study and be included in community life.

Muscular Dystrophy Queensland's work focuses upon understanding the barriers our community faces, working directly with our community members to help them overcome those barriers and advocating to create positive, systemic change.

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# Values

Knowledge, service and community. Much more than something to strive towards, these values sit at the centre of Muscular Dystrophy Queensland's culture, uncompromisingly guiding our actions. By upholding these values we are better able to achieve the organisation's purpose and work towards its vision.



We grow our knowledge: **listening and adapting** to meet the changing needs of our neuromuscular community.  
We **amplify the voice** of the neuromuscular community for their benefit and wellbeing.



We work with **care, dedication and excellence** to serve our neuromuscular community.



We are a **diverse** group: people living with neuromuscular conditions and those who support them. We value inclusion, connection, respect and shared experience.  
**We are stronger together.**



## From the Chairperson

### Victor Attwood

The last two years have been consistently challenging, yet again proving Muscular Dystrophy Queensland's resilience through 43 years of service to the neuromuscular community. Everyone was confident COVID would be under control in 2020, and 2021 would be the new normal but we are still trying to provide services with major disruptions and we will be for some time. Most challenging thus far in early 2022 has been managing the surges of the Omicron variants.

In 2021, following extensive consultations with community members and other stakeholders, the Directors formed a new Strategic Plan 2022 – 2025. We were asked to further develop our community services and, thanks to our donors and supporters, we can do this work.

Since I have been Chair, I have observed some of our life changing services – over 250 hi-lo beds loaned before the NDIS existed; power chairs for boys with Duchenne muscular dystrophy who can move independently during an extended wait for NDIS funded chairs; knowledgeable and empathic support from our Infoline staff helping with a newly diagnosed child, or longstanding clients who know they can call us anytime; NDIS access support, giving just the right advice to get community members their first NDIS Plan. And we continue to be the advocacy voice of our community.

Our reputation as a quality service provider continues to build as we grow our professional services – allied health, support coordination and plan management. Most of our allied health and some of our support coordination services are provided in clients' homes because we understand the needs of people with complex conditions.

And that brings me to Muscular Dystrophy Queensland's most valued resource – our staff. Go to our new, wonderful website and you will see them:  
[www.mdqld.org.au/who-we-are/leadership-staff](http://www.mdqld.org.au/who-we-are/leadership-staff)

Under the leadership of our CEO, Helene Frayne and her right-hand person, Penny Deavin, our staff put our community members first. Without exception these people are extraordinary and deserve sincerest thanks from my fellow Directors and me. My thanks also go to my team of honorary Directors who have guided Muscular Dystrophy Queensland through 2021.

Our donors and supporters ensure the continuity of our organisation and fund our charitable work - from the glitz and glamour of the Ray White ball, bravely hosted during a COVID pandemic by Andrew and Greg Bell, to the dogged commitment of Chris Wiles who rides his bike an equivalent distance from Cairns to Brisbane each year and encourages us to undertake physical challenges with associated fundraising.

Most important, our gratitude extends to our loyal and constant community members who have trusted us to provide their services. With the NDIS, we have transformed our organisation but will not rest because our long-term goal is to ensure that Muscular Dystrophy Queensland thrives until treatments and cures render us redundant.

We continue to face immense operational and financial challenges in a highly competitive market, complicated by COVID and the complexity of the NDIS. However, our intent is to preserve and develop an already established culture of helping people, being kind and celebrating our influence in creating positive change for members of our community.

As always, our firm focus will be on empowering people living with muscular dystrophy and similar conditions to make the most of opportunities and live the lives they choose.

**Victor Attwood**  
Chairman



## From the CEO

### Helene Frayne

Because we are solely dedicated to people who live with neuromuscular conditions, Muscular Dystrophy Queensland has always been a 'go-to' place for our community members over their lifetimes spent dealing with progressions, personal challenges, and navigation of services, and that's how we want it to be. We hope our support enables people to be more independent and happier throughout their whole lives. I do not want this report to be about COVID, even though the pandemic has reduced our capacity to serve and increased our organisational risk and staff stress levels.

I do not want to unduly criticise the NDIS – its complexities and rhetoric around cost cutting – because I know that it has been transformative for members of our community. I do have to acknowledge though, that COVID and the NDIA have been the main barriers affecting growth and development of our services.

Reflecting upon 2021, I realise how lucky we are to have person-centred and dedicated staff who have been so positive and adaptable. I miss our office camaraderie as they continue to work from home, even continuing into early 2022. Given the circumstances, they have achieved extraordinary outcomes for our community.

For Muscular Dystrophy Queensland, the past two years have been about consolidation, achieving stability, and future planning. We are grateful to community members who have continued to value and use our professional services, and services have experienced modest growth.

Our allied health team extended its geographic reach, with regular visits to Gympie, Sunshine Coast, Gold Coast, Ipswich, Cairns and Toowoomba. In Brisbane, we expanded our popular hydrotherapy services, even though they had to be suspended during COVID lockdowns. We grew our service provision to children and were thrilled when the Specialist Disability Services in Schools program (SDSS)

awarded Muscular Dystrophy Queensland a grant to support students' educational outcomes.

I also acknowledge the hard work of the support coordination and plan management teams and all the staff who support our service provision. Our General Manager, Penny Deavin, is a constant support for me as are the Directors. Thanks to all for your commitment during 2022.

Unfunded needs are still extensive and in 2021, our charitable services received a steady flow of requests, especially the Infoline which takes several calls each day. Our extended care program which provides support during difficult times, NDIS Access and Assistance program, and various equipment loan programs were valued by community members.

There are so many issues which need advocacy. People who acquire a disability when they are over 65 years are inadequately funded and Muscular Dystrophy Queensland has joined other industry leaders in an advocacy campaign. We are concerned about our NDIS Participants who are not funded to take their trained disability support worker team to care for them when they are hospitalised and we have met with the NDIA several times to highlight their needs. While these issues – as well as others – may not be resolvable, we will continue to advocate for and influence positive change in systems.

None of our work could be done without our donors and supporters who fund many of our programs. Muscular Dystrophy Queensland operates a multi-pronged fundraising program and uses the proceeds for charitable services. We have appeals and a lottery, and receive huge support from our third-party fundraisers. Thank you all!

Several bequests were realised in 2021. I wish I had the means to thank people who make these special gifts. I particularly remember the generosity of one elderly Toowoomba gentleman. Periodically, I would visit him and we spoke of mutual friends in the small town in which he lived. I will not forget his generosity.

Muscular Dystrophy Queensland ended another difficult year with only a small deficit which is hugely positive given the challenges. The leaders of Muscular Dystrophy Queensland would feel an affinity with Martin Luther King who said:

*"We must accept finite disappointment but we must never lose infinite hope."*

A handwritten signature in blue ink that reads "Helene Frayne". The signature is fluid and cursive, with a long horizontal flourish extending to the right.

**Helene Frayne**  
Chief Executive Officer

# Financial Performance

We entered 2021 with a plan to slow the pace of growth and change Muscular Dystrophy Queensland had experienced in recent years and to invest in systems necessary to strengthen the organisation for its future. Our strategic direction would be updated using feedback gained through community consultation. We'd welcome new clients into our services and programs and maintain services for those already engaged. We would grow our fundraising activities and strengthen our ability to capture and share the outcomes we achieve by introducing a dedicated marketing and communications function for the first time in Muscular Dystrophy Queensland's history. With that investment, the 2021 budget predicted a significant deficit.

As the year progressed, further resources were needed to address the continued impact of COVID, as our teams redirected their efforts to respond to the many COVID related changes and restrictions placed on businesses.

In fundraising, implementing the tactics needed to grow revenue took longer than planned due to turnover of key staff. With adjustments made to improve profitability in the program, expenditure on appeals and lotteries, which included staffing and program development costs, reduced by 31 per cent compared to prior year. Conversely, revenue through these tactics fell by only 7 per cent. Gifts received through our major donor program, which was greatly impacted by the volatility of investment markets in 2020, increased significantly compared to the prior year up 48.5 per cent. We also benefitted from several generous bequests, as executors wisely waited for the value of estate portfolios to improve during 2020 before making distributions to beneficiaries at the start of 2021.

The Ray White Surfers Paradise Muscular Dystrophy Ball was generously supported both by event sponsors, who gifted items for the event and charity auction, and by guests who also supported the event on the night. The event's income was a record \$300,000.

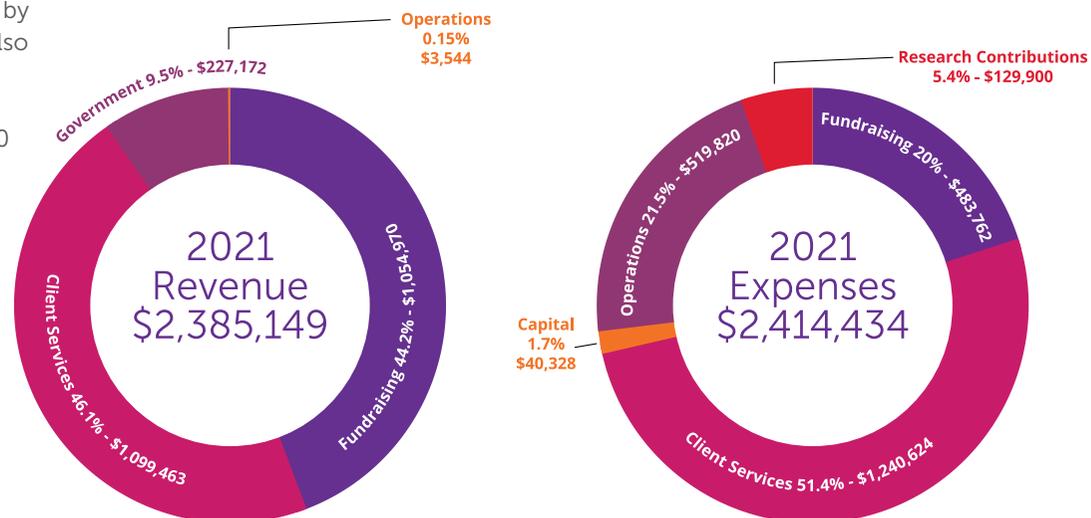
Our signature events also went ahead: the Red Bow Appeal in March raised \$19,330 (slightly above the prior year), the virtualised Ride Walk Roll almost doubled its income at \$11,000 and although the Brisbane Harley Owners Group Muscular Dystrophy Charity Ride could not proceed amid the uncertainty of lockdowns and close contact restrictions, generous club members fundraised to ensure their contribution to our community was made.

All this leads to the most important aspect of our work – delivering services which benefit our community members. The statistics show we assisted more people and provided more service hours than we did in the prior year. For example, the number of people accessing Physiotherapy grew by 10 per cent and those accessing charitable programs grew by 32 per cent.

Despite evidence of increased demand for our services, revenue generated from client services declined and despite rising costs, the rates we were able to charge for our NDIS services fell, as temporary levies that increased capped rates in 2020 to enable NDIS providers to recoup costs of addressing COVID, were removed in 2021. Unusually for a government funded system, rates did not increase in line with CPI or to reflect employment cost increases experienced across the sector.

Employment costs which have increased sharply across the sector for the past ten years due mostly to the compounding effect of an equal remuneration order (ERO) applied to the community sector award, which aimed to create parity for community services workers' wages compared to similarly qualified workers in other sectors, increased further in 2021. It was also necessary to increase salaries to compete in an increasingly narrow employment market and to retain, attract and recognise the experience of the professionals we employ. Like all employers in the sector, we also absorbed both a 0.5 per cent increase in the superannuation guarantee and a levy on ordinary wages of 1.35 per cent due to the introduction of the community sector portable long service leave scheme.

Despite the challenges of the year and thanks largely to the generous support of our donors and the success of our fundraising events, the year end results were more positive than budgeted. We closed the year with a deficit of \$29,285 and member's equity reduced to \$913,925. In 2022 and beyond, our team is tasked with reviewing and reducing costs where possible. We must evaluate the services we provide, particularly where high compliance costs, increasing staffing costs and a "worker shortage crisis" (ABC News, April 2022) make generating a surplus while providing a quality service increasingly difficult. We must ensure we are investing Muscular Dystrophy Queensland's resources well, not only for the benefit of the current generation living with muscular dystrophy and similar conditions but also to ensure its viability so that future generations can also benefit from its presence.





## Living with COVID in 2021

Throughout 2021, Muscular Dystrophy Queensland has put the safety and wellbeing of our community and staff above all else. We have been guided by our directors and leaders, our values and our Infection Control Committee. We continued our proactive response to COVID risk with our COVID Safe Plan and related procedures constantly revised and updated to respond as the situation evolved.

Our leaders have joined with others in Queensland's disability sector to understand the risks, keep up-to-date with rules and guidelines, and respond with care and diligence for our all of our stakeholders. It has been uplifting to see sector leaders working together and sharing resources.

### Our community

In this second COVID year, we continued to be aware of social isolation and mental health issues confronting our community members and for the first half of the year, were able to maintain our important, Queensland Health funded phone support and counselling program: Get Connected. Our community members valued this program and at the end of the funding were supported in a similar way through our Infoline and Extended Care programs, albeit on a smaller scale.

Within strict COVID Safe guidelines, our allied health team continued face-to-face services, supplemented by online services. Our Support Coordination services were provided through this mix as well, and readily adapted during high risk periods and lockdowns.

We were also concerned for the physical health of our community members and provided information and encouragement to get their vaccinations.

### Our staff

Team leaders monitored the mental health of each staff member, remained connected via the implementation of online team communications systems and staff adjusted to working mostly from home, and continued to offer our EAP program. Flexible work conditions reduced staff concerns and mitigated the risk of the virus being passed between staff and our community members.

By maintaining services, we were able to increase our staff cohort, expanding the allied health team and employing a marketing and communications team.

### Our business

Because our clients were rightly cautious about exposure to the virus, demand for services decreased overall, and particularly for NDIS services. Clients delayed appointments until they felt safer and at times, allied health staff were only able to provide consultancy face-to-face services, thus reducing income.

Unlike 2020, there were limited opportunities to access grants to offset the reduction in income and increased expense of addressing COVID.

Thank fully, our staff were fully vaccinated when the Queensland border opened on 17 December. We faced 2022 with increased COVID positive cases, both in both community members and staff. Preparations were made in late 2021 for new challenges on the horizon of 2022.

Thank you to our community members and staff for their trust in our ability to manage this unprecedented challenge to their health and safety.

# Our Community

75+

neuromuscular conditions  
that we support



621

clients we supported throughout  
Queensland in 2021

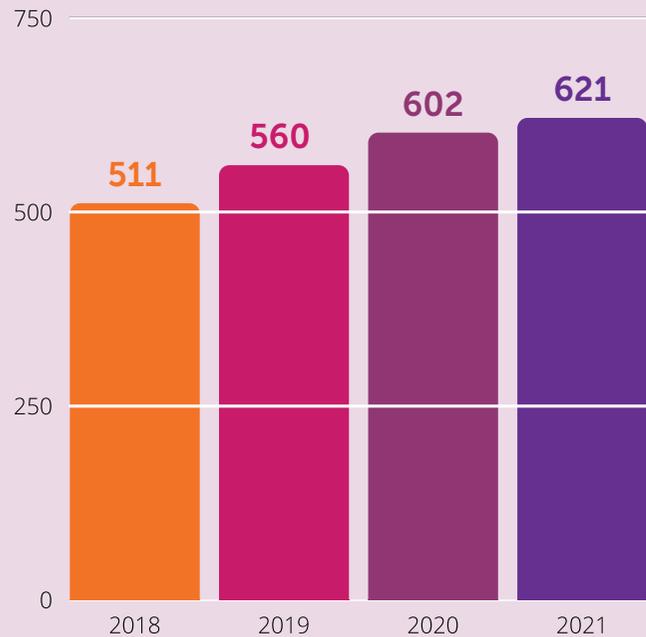


43yrs

Muscular Dystrophy Queensland  
has been providing whole of life  
support since 1978



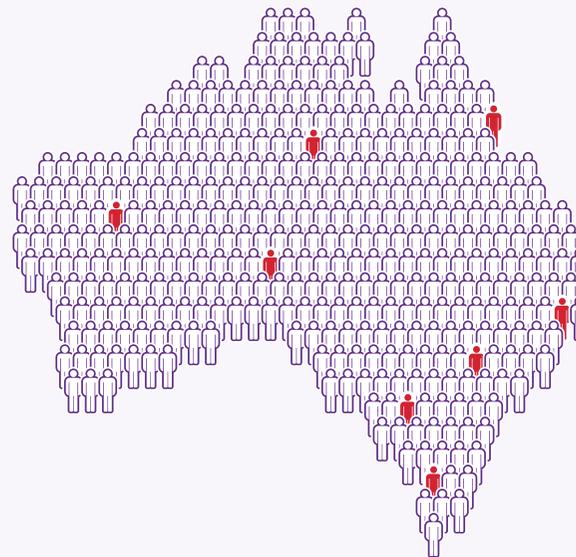
## Growth in Community Members



## Estimated Prevalence

41,200 in Australia

8,384 in Queensland



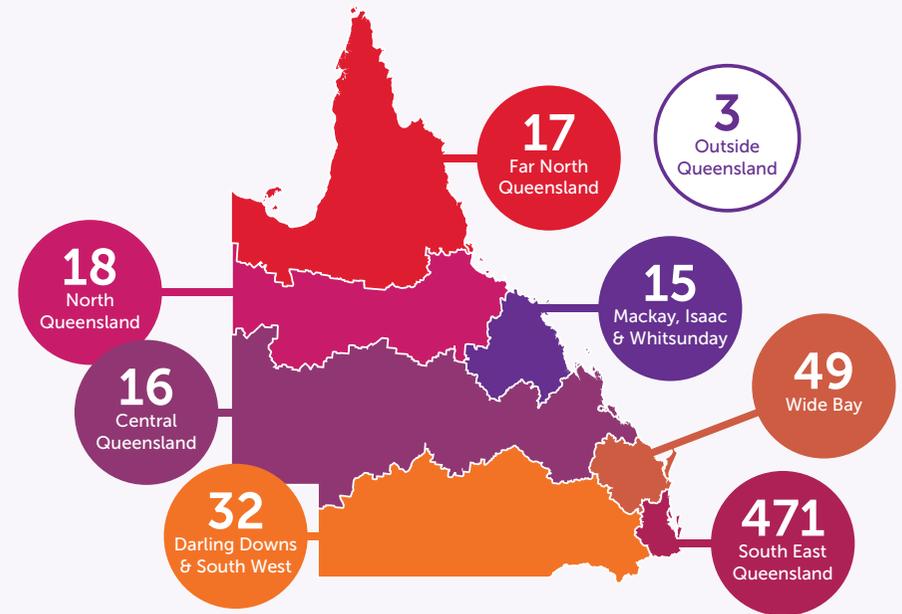
We estimate approximately 1 in 625 Australians  
live with a neuromuscular condition

## The conditions our community live with

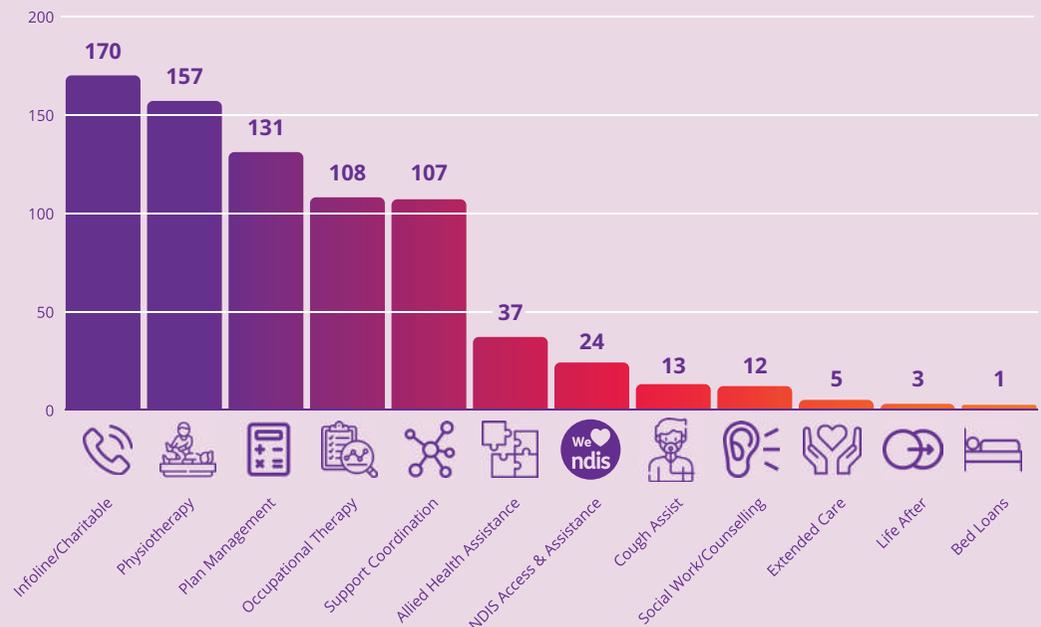
COMMON CONDITIONS	Total	Male	Female
Duchenne muscular dystrophy	129	124	5
Myotonic dystrophy	113	54	59
Facioscapulohumeral muscular dystrophy	72	47	25
Limb-girdle muscular dystrophy	41	22	19
Charcot-Marie-Tooth disease	41	16	25
Becker muscular dystrophy	37	34	3
Spinal muscular atrophy	33	16	17
Congenital muscular dystrophy	21	12	9
Inclusion body myositis	14	10	4
Congenital myopathy	12	3	9
Friedreich's ataxia	8	2	6
Mitochondrial disease	6	3	3

OTHER CONDITIONS	Total	Male	Female
Other neuromuscular conditions	60	24	36
Undefined neuromuscular condition	23	12	11
Non-neuromuscular conditions	11	3	8

## Where our community resides



## Services accessed by community members



# Our Services

## Infoline & Information Resources

Our community members benefit from information and emotional support, especially at crucial times in their lives; diagnosis; during a progression in their condition; during transitions in lives, such as starting school. There is also interest in research advancements, opportunities to join clinical trials, the availability of treatments and the pathways to access disability related supports, such as the NDIS. Our website and social media presence are often the first point of contact before people call our Infoline, where they receive individualised support and assistance. We also circulate our very popular Community Update eNewsletter.



**478**

Instances of individualised support via the Infoline

## Physiotherapy, Hydrotherapy and Allied Health Assistance

Throughout 2021, we continued face-to-face services where possible to maintain independence and functional ability for our clients through:

- Functional assessments and equipment prescriptions e.g. wheelchairs
- Community based respiratory care
- Hydrotherapy – both individual and group programs
- Stretch and balance programs.

Despite the challenges of COVID and NDIS price freezes, we maintained services in Brisbane and Ipswich, Toowoomba, Gold Coast, Sunshine Coast, Gympie, and Cairns. We were unable to extend services to more regional areas; however, we extended and increased services to children as planned.



**1,939**  
Hours



**1,397**  
Home Visits



**829**  
Travel Hours

When your baby boy has just been diagnosed with Duchenne muscular dystrophy, it takes courage to make a cold call to an Infoline. You hope that the person who answers the phone is knowledgeable and understanding. Late on a Friday afternoon, a grandmother made such a call to our Infoline.

Her baby grandson had been diagnosed with Duchenne, a condition she'd never heard of before. "What did this condition mean for him? And what did it mean for the whole family?" Over the next few weeks, our social worker spoke confidentially with several members of the baby's extended family.

She answered their many questions and provided support through their grief and fear. We advised on practical concerns. We counselled. Then the calls stopped. For now, the family members had received the information they needed. They know we will be there throughout the child's lifetime and they will call when they again have a need for information and support.



## Occupational Therapy

Our occupational therapist continued to assist members of our community to build their independence and actively participate in their daily lives, by:

- Assessing and mitigating safety risk in home and community settings
- Equipment prescription, for example hoists and hi-lo beds
- Prescribing minor home modifications
- Increasing access with smart technology
- Providing programs which support members of our community through progressions and changes in their life roles
- Assessing and supporting cognitive function

During 2021, we continually sought to grow this relevant and high-quality service, however were unable to secure staffing in what is increasingly becoming a sector facing worker shortages, especially in occupational therapy.



**550**  
Hours



**172**  
Home Visits



**134**  
Travel Hours

## Equipment Loan Services

Equipment is essential for people with disability, so it is not surprising that our equipment loan services grew to meet demand in 2021. Most commonly equipment is funded by the NDIS but to address the long wait times (typically 9 to 12 months), our allied health and fundraising teams used their networks to implement a free, short term loan program, where community members can access the equipment they need until their own, new equipment is ready.

### 'Breathe Well' Cough Assist Loan Program

Thanks to a recurrent Queensland Health grant and the support of our generous donors, we continue this valuable program which provides the Cough Assist device to support people to overcome acute respiratory infections. In 2021, we expanded to also provide respiratory assessments and inductions to use of the machines, throughout Queensland.

### 'Rest Well' Hi-Lo Bed Loan Program

We continue to provide free, long term loans of adjustable, electric beds for clients who cannot access funding elsewhere for this vital equipment. We also continue to fund the maintenance of beds placed on loan. Fortunately only one member of the community required a new bed through this program in 2021.



**13**  
Cough Assist Machine



**1**  
Bed Loans

A critical moment



Late on a Wednesday afternoon a 20-year-old with Duchenne muscular dystrophy, called his physiotherapist at Muscular Dystrophy Queensland to report that he had a respiratory infection and was finding it difficult to cough and breathe. It was getting worse. On Thursday, morning, the physiotherapist visited him at home to provide a respiratory assessment and to introduce him to a cough assist machine and by that afternoon, a new cough assist machine arrived at his home via our 'Breathe Well' Cough Assist loan program.

He regularly used the machine and in a few weeks, he began to recover. His physio continued to work with him, to discuss the need for a machine to be available in the longer-term - perhaps funded by his NDIS plan. While he waited for the funding approval, he was able to continue to access the loan program. Because this program is funded by our wonderful supporters, including Queensland Health, we were able to immediately respond to his needs. The cough assist machine cleared infected mucous from his lungs where his weak respiratory muscles could not. Immediate access to the cough assist machine may have prevented more serious diseases such as bronchitis or pneumonia. And, he could use the machine at home and was not admitted to hospital where he'd risk exposure to further viruses.

## NDIS Intermediary Services

Under the NDIS, Muscular Dystrophy Queensland provides Intermediary services – Support Coordination and Plan Management; which were relatively uninterrupted by COVID disruptions as the team members were able to transfer their service provision online.

### Plan Management

Much like a bookkeeper, the Plan Manager assists NDIS participants to manage the funding in their plan. This includes managing a plan budget, forecasting expenditure to manage over or under spending, claiming and paying supplier invoices and managing supplier accounts and related inquiries.

The NDIS anticipated this program would also include upskilling participants, to enable them to independently manage their own plans. In our experience, our clients value the plan management service and do not wish to take on such a significant responsibility, which given the average size of an NDIS plan, can be equivalent to running a small business. We advocated to peak bodies in the disability sector and to the NDIS directly, that this service is underfunded and worthy of review.

The capped fee of only \$100.14 per client per month does not recognise the financial risk plan managers face in taking on high value plans - where spending not aligned to the plan can be recouped directly from the plan manager rather than the supplier or participant.

The program relies on efficient systems and staff and in 2021, we have worked to create balance between efficiency, risk mitigation and providing a quality service that values both the participants, and their relationship with their suppliers. We were pleased to achieve

growth of 8 per cent in the program, with 131 clients at year end.



### Support Coordination

It is the Support Coordinator's job to assist Participants to implement their NDIS plan, connecting them with formal and informal supports and liaising with the Agency to facilitate this implementation. The Support Coordination team continued to receive many accolades for its commitment and dedication in 2021 through times of great stress and disruption for community members, as they cope with changes in their lives and to NDIS guidelines.

Because of the complex nature of their work, Muscular Dystrophy Queensland's support coordinators are more qualified than required by the NDIS and clients can expect a truly professional service from them. The team's stability and skills ensure a consistent service for its clients.



Bringing it all together



Early in 2021, one of our Support Coordinators assisted the parents of a boy with Duchenne muscular dystrophy to obtain a fair and reasonable allocation of funds in his NDIS Plan.

Afterwards, his mother commented to a colleague that the additional NDIS funding had made a very positive impact upon the child and also his family and that she felt forever indebted to our Support Coordination service.

*"Tien's talents as a support coordinator have been exceptional and provided benefits such as maximising my child's plan, assisting with sourcing suitable providers, putting together strong and thorough plan reviews and ultimately allowing us more time to be just a family."*

Linda, Harrison's mother

## Extended Care

This program exists for people who have an urgent need which must be addressed or who have no other recourse for assistance. Muscular Dystrophy Queensland uses its knowledge and contacts to solve the problem. Issues which arise in the extended care program inform future service development, e.g. the introduction of free, equipment loans that addresses extended wait time people experience between when equipment is requested via the NDIS, and when it can be funded, built and delivered.

Fortunately, since the inception of the NDIS, this program supports a smaller number of community members, however it is time intensive as the issues are often complex.



## Outreach

Our goal is to provide information, services and support to more regional areas in Queensland every year with the outreach program funding travel and accommodation costs, to bring our consultancy physiotherapy and occupational therapy services to the region.

In 2021, COVID affected our ability to provide more than an annual visit to Cairns or to expand our regional services, however we were able to provide quarterly physiotherapy trips to Toowoomba and maintain frequent visits outside greater Brisbane and to Gympie. With the opening of the Queensland

borders, 2022 is also looking more hopeful. In 2021, we placed more reliance on phone and online services and expansion of telehealth allied health online services.

## NDIS Access & Assistance

Even though the NDIS started in Queensland in January 2016, there are still people who are seeking eligibility for an NDIS plan and Muscular Dystrophy Queensland is there to help, providing information, assisting with completion of applications, and advocating for those members of our community whose applications are initially unsuccessful.

Once their application is approved, we can help prepare people for their first planning meeting. Because these meetings can be so daunting, we can also attend with our client and the NDIS Planner to ensure needs are not overlooked and to help setting goals - the first step in accessing an NDIS plan.

Once established, we are also supportive if there are subsequent issues in later plans, e.g. an unreasonable decrease in funding or removal of services on which our people rely.



## Advocacy and Awareness

Muscular Dystrophy Queensland's advocacy priorities remained the same in 2020 and 2021 because the matters are entrenched and issues take time to be resolved, however we continue to be the voice for Queenslanders and indeed Australians with

neuromuscular conditions. Increasingly, Muscular Dystrophy Queensland is using its membership of national organisations to strengthen our advocacy voice.

In 2021, we advocated both under our state banner and that of our national organisation, Muscular Dystrophy Foundation Australia (MDFA).

We represented MDFA in several partnerships, notably with Neurological Alliance Australia (NAA), FSHD Global, Rare Voices Australia (RVA), Post Polio Victoria, and Spinal Life Australia.



We advocated for:

- An end to age discrimination that exists in funding for people who are over 65 years with a disability
- Preserving the NDIS and advocating against cost cutting evident in NDIS plan allocations
- Greater understanding from the Agency regarding NDIS principles related to capacity building and parental responsibility and how they negatively affect our community
- Funding for a person's trained support workers to continue service provision in a hospital setting, currently not addressed by the NDIS or Queensland Health
- Operational issues affecting our clients including decisions made by the Agency

Every staff member also provides a voice for their clients, raising the level of understanding of the challenges of living with a neuromuscular condition in NDIS planning meetings, schools, in families and with generalist service providers.

## Filling the gaps



Boys with Duchenne muscular dystrophy go 'off their feet' as their condition progresses and need a power chair. This is an emotional time and cannot be prepared for in advance but it takes up to 12 months for the progress from NDIS assessment to delivery.

Our boys cannot wait that long so we have a team of people who help us adjust donated power chairs so our boys can mobilise independently while they wait for their very own power chair. We also stock other mobility aids and hoists for trial and loan.

## Get Connected

This popular, twelve month project was funded by Queensland Health's COVID response grants. Recognising the risk of social isolation and compromised mental health, we employed a project officer who attempted to call every member of our community across the state, to offer emotional support and informal case management.

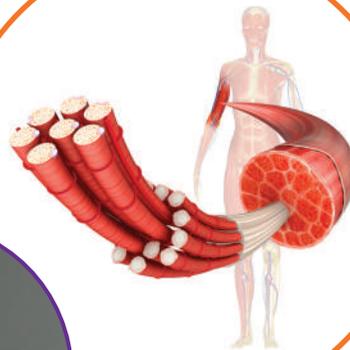
Funding for this project ceased at 30 June 2021 and recognising its value, we extended the program temporarily with the support of our donors and fundraisers.



## Supporting Research

Principally Muscular Dystrophy Queensland is a service organisation. We are not involved with raising funds for research, other than our involvement with the Greg and Andrew Bell Muscular Dystrophy Research Fund through the Ray White Surfers Paradise Ball. We support research activities that benefit our community by:

- Providing support to and joint advocacy with organisations whose mission is research oriented.
- Linking researchers with those community members who wish to be research subjects, for example in 2021, we supported Karen O'Maley in sourcing participants for her research study titled: Exploring the health care experiences of people living with Myotonic dystrophy type 1 (DM1).
- Communicating with our community about available Australian clinical trials and the Australian Neuromuscular Disease Registry and its importance.



## Checking in with Rian

### North Queensland Visit

In 2020 Rian, who lives in Far North Queensland, received a new powerchair through the NDIS. Like all teenagers, Rian has grown quickly and his new wheelchair needed adjustment.

In September 2021, during an outreach trip to Cairns, Lynne our Lead Physio was able to meet with the family to discuss and prescribe the changes needed to "grow his chair". Families in regional towns have expressed their relief in having an experienced team visit them to understand their needs and continue support via telehealth and subsequent visits through the year.

# Sectors in which we Operate

Muscular Dystrophy Queensland operates within state and national systems which support Australians living with neuromuscular conditions and more broadly, with a disability.

## National Disability Insurance Scheme (NDIS)

The NDIS provides all Australians with a permanent and significant disability, aged under 65, with the reasonable and necessary supports they need to live an ordinary life. As discussed throughout this document, the NDIS has become the major support system upon which the majority of our clients rely. Our work therefore involves understanding its systems, ensuring compliance with its requirements and of course aligning our services with the solutions it offers for our community.

## Queensland Health

Our aim is to strengthen the continuity of care for people with neuromuscular conditions, from acute hospital care to community support and also to improve integrated medical care for adults through specialised Queensland Health clinics which provide surveillance and treatment for our community members. In 2021, our allied health team has invested in strengthening the continuum of care from acute medical to community services, with positive outcomes.

## My Aged Care

The Australian Government offers My Aged Care for all Australians as they become older and their abilities decline. It is not designed to meet the high needs a person with muscular dystrophy usually experiences but often it is the only funding support available for those who are diagnosed after they are 65 or experience progressions in their conditions over 65.

Muscular Dystrophy Queensland offers allied health services funded via a My Aged Care plan. As funding plans are not usually sufficient to meet the complex needs people experience, we also provide some professional allied health services and a range of supports through our charitable programs.

## Education Queensland SDSS Program

Muscular Dystrophy Queensland's whole of life service model means that we are capable of supporting children to achieve improved educational outcomes, specifically through our newly attained funding through Specialist Disability Support in Schools (SDSS) program.

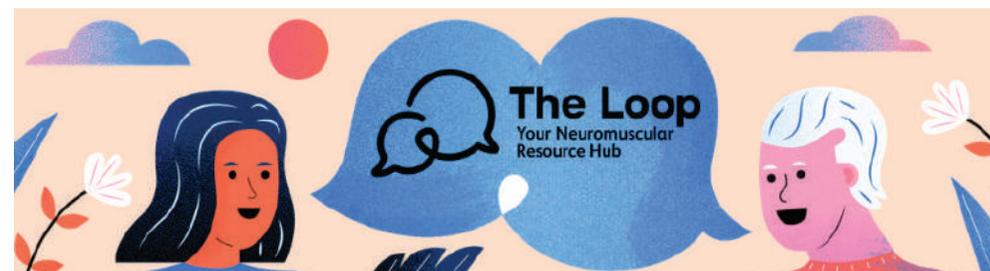
## Collaborations

We recognise that we can achieve more for our community by collaborating with like-minded organisations. Muscular Dystrophy Queensland is a member of a number of peak body organisations that serve the disability sector and community members.

Most notably, this includes our collaboration with Muscular Dystrophy Foundation Australia (MDFA), of which Muscular Dystrophy Queensland is a founding member. Its role is to advocate as a national voice, explore national initiatives and influence a national research agenda for the benefit of the neuromuscular community.

In 2021, we made significant contributions to advocacy campaigns and continued to support the development of MDFA's national information resource, The Loop Neuromuscular Resource Hub.

[www.theloopcommunity.org](http://www.theloopcommunity.org)



# Thanks to our Donors and Supporters

We could not have achieved all that has been outlined so far in this report without the generosity of our donors and supporters. Muscular Dystrophy Queensland manages a diverse portfolio of fundraising activities to enable businesses and individuals to support our work in a way that aligns with their interests. Our fundraising team works to understand the impact our donors wish to make through their philanthropy, to illustrate how that impact has been achieved and how their continued support can make a difference for the community in the future.

## Gifts in Wills

Many supporters choose to make their most profound and enduring contribution through a gift left to Muscular Dystrophy Queensland in their will. We acknowledge the contributions of the following individuals who made such a contribution this year:

- Lyndall Board
- Cecilia Brazil
- Janelle French
- Frank Goudge
- Patricia Hunt
- Joan Neumann
- Vincent Pengilly
- Richard Stuart

## Charitable Trusts and Foundations

We were grateful to the following charitable trusts and foundations and for their support in our projects during 2021:

- Community Benefit Fund – Website redevelopment
- Reuben Pellerman Foundation – Outreach Program

- YoungCare – Various grants directly assisting our clients through the At Home Care Grant.
- Cory Foundation – A vehicle for our allied health team to deliver services in client’s homes.

## Appeals

In 2021 the community responded generously to our appeals, donating almost \$375,000 in total throughout the year. Our donors showed interest in supporting our efforts to raise awareness of muscular dystrophy and similar conditions, support our advocacy work and provide information for our community members. They funded the free equipment and case management we provide through our extended care program for the most vulnerable members of our community who cannot access support from other sources. They helped re-establish our social connection program that assists families to get to know one another and build enduring friendships.

We also asked for help – and our donors responded generously – to continue our equipment loan programs, including the provision of Cough Assist machines for those experiencing respiratory infections, hi-lo adjustable electric beds which improve comfort and safety for our clients and their carers, and short-term loans of mobility equipment while they wait for their own equipment to be funded, built and delivered.

## Lotteries

In 2021 we refreshed our lottery program as the Lucky 13 Lottery, offering four draws through the year and the chance to win the major prize of \$13,000. Winners were delighted to get the call from our fundraising officers, letting them know their lucky ticket was drawn and the luck spread across the state, with winners living in Greater Brisbane, Dalby, Rockhampton and Bundaberg!

## Vale Dr Kate Sinclair



Kate, is remembered as a, “brilliant mind, cheerful soul and an empathic, kind and genuine heart” who had the courage to speak out when she recognised problems in the systems her patients relied on and the talent to overcome any backlash that resulted from being so outspoken.

A Brisbane-based Paediatric Neurologist, Kate founded the Ataxia Telangiectasia clinic and shared her family’s farm to give children with disabilities and other conditions the opportunity to mix with animals and to relax and unwind.

The impact of her sudden and tragic passing will be felt far beyond Queensland, by all those whose lives were made richer having known her and for others who may never know her but will benefit from her tireless advocacy and work to improve patient care.

Vale Kate Sinclair.

# Fundraising Events

## Red Bow Appeal

Every first Friday of March since the 1990s, the All Hallows' students have descended on city workers on their way to their offices, collecting for Muscular Dystrophy Queensland.

The Red Bow Appeal went ahead with great success with the use of a smartphone app to safely and securely process donations and product sales, raising \$19,328.

Even in a COVID environment we are so grateful to organisations which support our Red Bow Appeal, including Nexia's Brisbane offices (pictured here), who hosted a Red Bow Morning Tea for Muscular Dystrophy Queensland in March.



## Ray White Surfers Paradise Muscular Dystrophy Charity Ball

After cancelling the 2020 event and facing further uncertainty through 2021 due to COVID-19, it was an absolute relief and joy to get the Gold Coast community together, while raising crucial funds for Muscular Dystrophy Queensland.

Proudly hosted by brothers Greg and Andrew Bell, this black-tie event is regarded as one of the premier events on the Gold Coast social calendar. Featuring a 3-course a-la-carte meal and entertainment by Sneaky Sound System, attendees enjoyed a wonderful night out. Guests were extremely generous, raising over \$300,000 in a single night! A staggering \$3 million dollars has been raised since 1993, with these funds used in part to fund Muscular Dystrophy Queensland's client services and to support vital research.

We would like to thank Andrew and Greg Bell, Selena Carson and the team of Ray White Surfers Paradise, their major sponsors Bensons Property Group and Levantine Hill, and other generous sponsors who donated auction items. Also, a very big thank you to the people who came along and got involved, making this the most successful Ray White Ball ever!



## Ride Walk Roll

Ride Walk Roll morphed into a virtual, 100% accessible community fitness fundraiser in 2021 and many of us walked and rolled our way through September.

37 participants from as far north as Cairns and all the way down to Brisbane travelled a combined 8,839kms and raised \$11,249 for people living with muscular dystrophy and similar muscle wasting conditions in Queensland! As always our fearless leader Chris Wiles from Cairns led the charge, travelled 1,492kms and raised an incredible \$2,725! Thank you Chris.



People told us they loved getting involved and having the freedom to take part in their own neighbourhoods and in their own time. We are already looking forward to our 2022 event and we'd love to have you and your friends and family join us.

[ridewalkroll.org.au](http://ridewalkroll.org.au)

## Bridge to Brisbane

A change of date didn't stop Bridge to Brisbane from making a successful return to the Brisbane events calendar after a break in 2020. The event raised almost 1.2 million dollars for charities around the country.

Featuring a new course back over the Gateway Bridge and finishing at the Brisbane Showgrounds, our enthusiastic participants enjoyed a great morning taking in the sights of beautiful Brisbane together.

Over \$1,700 was raised for Muscular Dystrophy Queensland, thanks to our team of runners and rollers and their generous supporters.



# Our People and Culture

During 2021, we were focussed on supporting our staff through another difficult year of the COVID-19 pandemic and the stress of providing high quality services under the NDIS framework, we also aimed to establish a marketing team and a leadership team.

To reduce COVID transmission, most of the staff worked from their home offices during high-risk periods such as lockdowns. The leadership team ensured that their team members had ongoing contact with colleagues for communication and support. The allied health team was office based because of their frontline role.

Existing staff maintained their positions however thin markets affected growth in allied health, especially in occupational therapy. Because of COVID, volunteering was suspended. We were successful in recruiting a marketing team.

Staff were surveyed at end 2021 and almost all reported overall satisfaction with Muscular Dystrophy Queensland as their employer as well as feelings of being supported by the organisation.

Muscular Dystrophy Queensland's staff are our most valuable asset and the organisation is grateful for their dedication and commitment to our community.

19

Client facing staff



25

Staff members



7

Board members

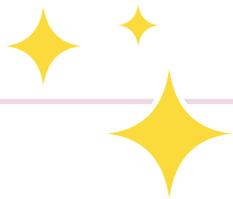


6

Fundraising & finance staff



# Our History



**1978**

A group of families whose children had muscular dystrophy joined forces to raise awareness and funds. The first executive board members of "The Muscular Dystrophy Family Support Association of Queensland" were appointed on 25 June 1978.

Without clinical or public recognition of the disorders, the group began the challenging process of raising awareness, fundraising for equipment and services, and supporting research that might one day find a cure.

**1991**



Muscular Dystrophy Queensland appoints Peter Denham as Executive Director, tasked to grow the organisation towards meeting its mission. He leads the organisation until 2007.

**1992**



The organisation becomes incorporated. The 'South East Queensland Muscular Dystrophy Assoc. Inc.' is listed as a recognised charity under the Collections Act.

Counselling and support services are funded. Equipment loans begin for items including electric beds, ventilators and wheelchairs.

**1994**



All Hallows' School Year 11 students collect donations for Muscular Dystrophy Queensland on the streets of Brisbane for Red Bow Day. This annual tradition continues more than 25 years on.

Andrew and Greg Bell from Ray White Surfers Paradise host an inaugural ball raising funds for muscular dystrophy. The annual events would raise millions of dollars for research and services. Events continue today.



**1995**

BrisbaneHOG host their first charity ride. More than 20 years later, this annual ride remains a highlight on our calendar.

**1999**

The organisation moves from premises at Rocklea Markets to inner city Wharf Street. Recurrent funding is in place from Queensland Government departments - Disability Services and Queensland Health. Case management style services and brokered in-home respite are offered to families.

**2013**



Fundraising and client services teams grow in new Hendra premises. In 2013, Muscular Dystrophy Queensland settles into its current Nundah premises. CEO, Helene Frayne is appointed in 2014.

**2017**

Muscular Dystrophy Queensland becomes an Australian Public Company limited by guarantee in preparation for the introduction of the NDIS which will allow the organisation to provide chargeable services to clients whose supports will be funded through the new scheme. Charitable services continue for people and families in need of support.

**2019**



NDIS rolls out across Queensland. Muscular Dystrophy Queensland employs Allied Health professionals and Support Coordinators to provide services to clients. Plan Management services are also provided.

**Today**

As needs and the sector have changed, Muscular Dystrophy Queensland has adapted and grown. Today, with a growing reputation as a knowledgeable service provider under the NDIS framework. It is our goal to continue providing high quality services to better meet the needs of members of our neuromuscular community.

# Our Future

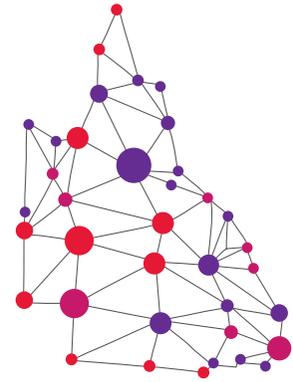
Our 2018 – 2022 Strategic Plan was focused upon the organisation’s transition to service provision under the National Disability Insurance Scheme (NDIS). During that time, state-based government funding was discontinued and we made the successful transition to a profit-for-purpose business, whilst maintaining many of our charitable services.

The organisation achieved the establishment of a new allied health service and built our NDIS support coordination and plan management services, instituting the business systems required to be efficient and effective.

In fundraising, we maintained excellent relationships with our donors and supporters and implemented fundraising tactics which were constantly updated. In 2021, as per the strategic goals, we introduced a new fundraising database and created a marketing team which delivered our new website.

## Strategic Plan 2022-2025

Late in 2021, the Muscular Dystrophy Queensland Strategic Plan 2022 – 2025 was launched. It focusses on the organisation we need to be in the future and tells the story about how we are going to strive to achieve our strategic goals.



### Our Strategic Goals

#### 1 Build our community

Muscular Dystrophy Queensland will grow and develop our community services according to the wishes and needs described by its members.

#### 2 Deliver services of superior quality and value for our clients

We will provide continually improving, dedicated, charitable and user pays services which best meet the unique and complex needs of our clients and contribute to Muscular Dystrophy Queensland being considered a provider of choice by our community members.

#### 3 Our community benefits from the philanthropy of others

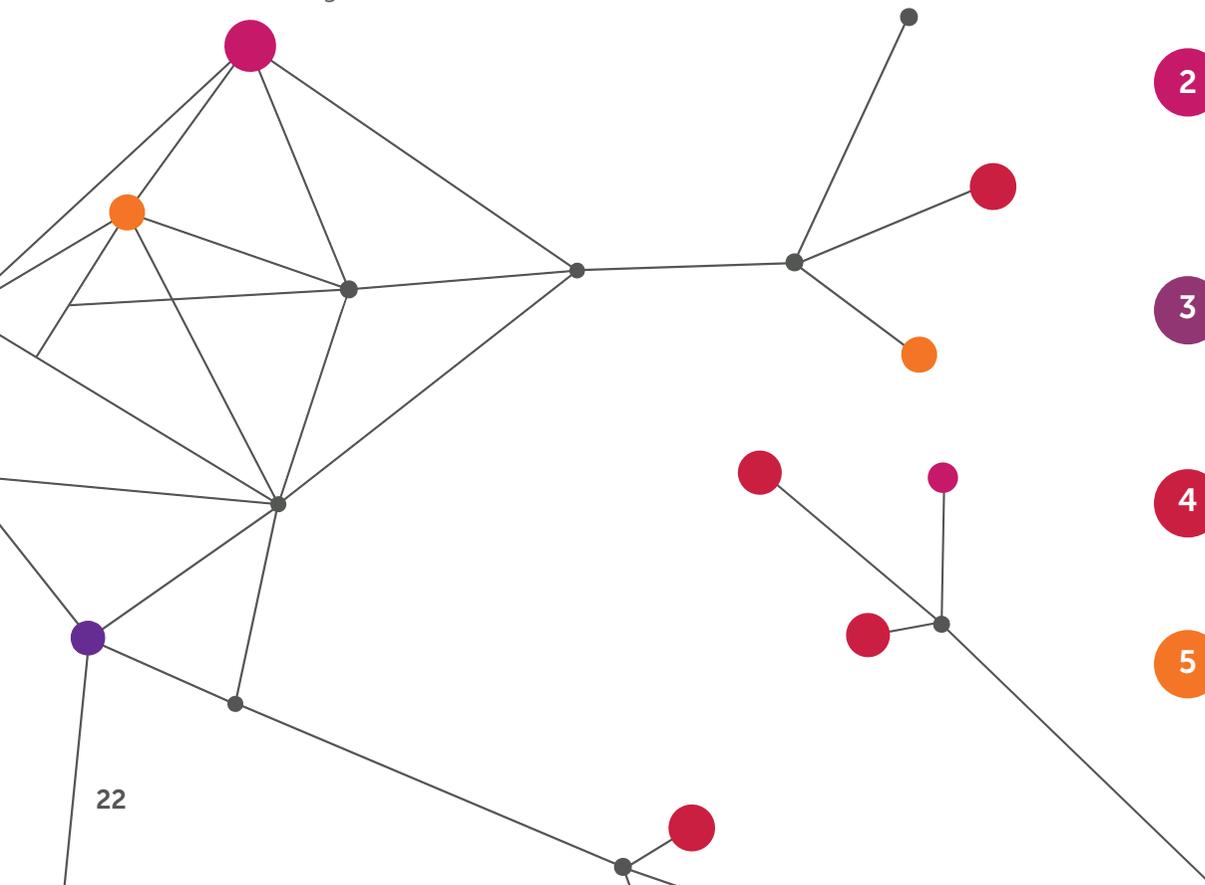
The philanthropic goals of our donors and supporters are met as they understand the benefit of their investment to our community of people and families living with muscular dystrophy and similar conditions.

#### 4 Grow, develop and empower our workforce

Our staff and volunteers are supported, resourced and empowered to have a balanced work and home life and develop their skills and knowledge.

#### 5 Strive for excellent organisational performance

Our business practices, innovation and accountability enhance financial sustainability, positive reputation, and ultimately, organisational excellence.



# Governance & Leadership

## Our Executive Team



**Ms. Helene Frayne**

B SpPath MBA

### Chief Executive Director

Helene is both an experienced leader and qualified allied health professional and has dedicated her career to helping people experiencing disability to improve their health and wellbeing.

For the past two decades she has held senior leadership and executive roles with some of Queensland's leading health and disability charities.

She feels that her first day with Muscular Dystrophy Queensland in 2014 was like coming home and is delighted to often have the opportunity to re-connect with our adult clients, who she had treated as children.



**Ms. Penny Deavin**

GCert Bus Adm

### General Manager

A familiar face to many, Penny worked across finance and fundraising roles with Muscular Dystrophy Queensland, before her promotion to GM.

Before joining Muscular Dystrophy Queensland Penny ran a successful business services consultancy, working in small businesses in various sectors.

She has drawn upon that background to improve business systems and oversee Muscular Dystrophy Queensland's business, finance, fundraising and marketing functions.

In 2021, Penny celebrated her 16th year working with us.

## Our Leadership Team

In response to the business oriented National Disability Insurance Scheme (NDIS), our growth in services, and our commitment to best practice and to our people, Muscular Dystrophy Queensland has developed a leadership team.

Our leadership team has driven improvements in both client services and fundraising, with oversight of compliance, service quality, awareness, culture and most importantly, support of our community and staff during a time of unprecedented challenges.

This stable, skilled and professional group of people embodies the spirit and values of Muscular Dystrophy Queensland – service and dedication, commitment to our community, and professionalism and knowledge.

The leadership team reports to the CEO and General Manager.



**Becky Mackenzie**  
**Client Services Team Leader**



**Lynne Borgert**  
**Lead Physiotherapist**



**Lindsay Paulin**  
**Finance Team Leader**



**Kathryn Chopping**  
**Community Engagement Team Leader**



**Bruce Nean**  
**Marketing Manager**

## Our Directors



Mr. Victor Attwood

### Chairperson

Victor brings extensive management, leadership and governance experience. Victor had a long career in local government, serving as Deputy Mayor of Ipswich City Council and as a senior member of several not-for-profit boards. Victor and his son live with Charcot Marie Tooth, a neuromuscular condition.



Mr. Gavin Ruddell

B.Com CA RCA

### Director

Gavin is a Chartered Accountant, Registered Company Auditor and a Director of Nexia Brisbane Audit with almost two decades of experience in public practice and commercial finance roles. As well as his financial skills set, he brings to the board considerable expertise in corporate governance and risk management.



Mr. Anthony Biggar

LL.B

### Director

Tony has practiced as a lawyer and has been a business owner for many years, including being the founding legal practitioner of Big Law Pty Ltd and other practices in rural Queensland. He is a member of the Property Law and Practice Committee of the Queensland Society and the Honorary Solicitor for several community organisations in Monto, Queensland.



Dr. Cullen O'Gorman

BSc(Hons) MBBS PhD FRACP AFRACMA

### Director

Cullen is a specialist Neurologist, Clinical Neurophysiologist and is the Head of Neurology at Brisbane's Mater hospital. He also consults at the Princess Alexandra hospital and is in private practice. Cullen completed his undergraduate studies in the UK and Australia and postgraduate fellowships at the Mayo Clinic, Rochester, USA.



Mr. Robert McDowell

B.Pharm

### Director

Bob is a retired pharmacist and was a pharmacy owner for over 30 years. He is a member of the Pharmacy Guild of Australia and has served on the Qld branch committee for 12 years, including holding the positions of Vice President Finance and member of the Local Advisory Committee of Pharmaceutical Defence Ltd (PLD). Bob lives with FSH muscular dystrophy.



Dr. Natasha Taylor

BVetSc (Hons) BVetBiol (Hons)

### Director

Natasha is a veterinary surgeon, business owner and runs two successful veterinary practices in Brisbane. Natasha has lived experience of a neuromuscular condition, with an adult son who has Duchenne muscular dystrophy.



Mr. Tristram Peters

BA/BJ MWEF

### Director

Tristram is a passionate sportsman, serving on the boards of several organisations promoting powerchair football, and is increasingly recognised as an advocate for people living with disability, including as co-host of Grow Bold with Disability podcast and facilitator with UnOther, offering immersion programs which build pathways to inclusion and understanding.



Muscular  
Dystrophy  
Queensland

Muscular Dystrophy Queensland Ltd

Locked Bag 3000, Eagle Farm BC, Qld 4009  
1149 Sandgate Rd, Nundah Qld, 4012  
ABN 14 908 553 738  
ACN 621 816 975

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