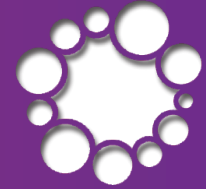




Muscular Dystrophy  
Queensland  
*We're stronger together*



# 2020 Annual Review



# Vision

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

# Mission

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

## Acknowledgement of country

Muscular Dystrophy Queensland acknowledges and pays respect to the past, present and future traditional custodians and elders of this nation and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

## Specialist focus

Muscular dystrophy (MD) refers to a group of complex, genetically inherited conditions which cause progressive deterioration of muscle strength and function. Muscular Dystrophy Queensland also supports people living with other similar, rare conditions. In total, these more than 75 conditions are collectively referred to as neuromuscular conditions (NMCs).

With rapidly evolving diagnostic techniques and the unravelling of the human genome, science is yet to uncover the actual incidence rates of these conditions. The prevalence of neuromuscular diseases is understood to be at least as high as Parkinson's disease worldwide and twice that of Multiple Sclerosis. We estimate approximately 8,000 Queenslanders live with a neuromuscular disease. During 2020 we were actively engaged in providing services for 594 people and their families.

## What we do

With more than 42 years' experience of providing whole of life specialised support and services, dedicated to Queensland's neuromuscular community, we supply disability related services – allied health, support coordination and plan management, as well as a range of charitable services, funded by our loyal donors and other supporters.

As Queensland's peak body for people with muscular dystrophy and similar conditions, we are the advocacy voice for our community. We also provide support for research.



### *Sarah's reflection on living with muscular dystrophy*

*“Being diagnosed with muscular dystrophy is like being told you have to go to a foreign country you don't want to go to. It's got language you don't understand, the food's terrible and you have no idea about the cultural conditions. So when you land, you're terrified. You have no idea what to do!*

*But eventually you learn the language, you get to like the food and the traditions become yours and you love them just as much as the traditions that you used to have. But it takes time. And it takes effort.”*



## A Message from the Chairman

**Victor Attwood**

Since the NDIS, Muscular Dystrophy Queensland (MDQ) has been building new programs to meet client needs and to ensure the company's resilience through difficult times. Australia could not have planned for more difficult times than the unprecedented events of 2020 however, we look back on that year as a survivor, healthier and stronger as an organisation, proud that we have been able to support our clients, and grateful to our supporters for their loyalty during the pandemic.

With the support of JobKeeper, we retained all of our staff without any reduction in hours. Most other allied health providers in Brisbane closed however we are pleased and proud to report that we continued to provide face-to-face services under strict infection control procedures throughout all of 2020. Lynne Borgert, our Lead Physiotherapist, calmly assured our community that safe allied health services could continue – and she was right!

We were concerned about the COVID related isolation and mental health challenges for our clients and their families and thanks to project funding from Queensland Health, we launched our Get Connected program. Through this program, people have been grateful to talk with our team members, who can empathise with people's fears and the challenges of living their life.

Despite COVID, we continued to grow, taking an opportunity to employ an experienced, local physiotherapist on the Sunshine Coast and to continue our outreach visits to Cairns, Gympie and Toowoomba. The Gold Coast was well supported

too, with almost weekly visits from our Support Coordinators and allied health team members.

Our donors and Art Union supporters remained loyal to our cause, however understandably, some were not able to maintain their usual level of support. Events were cancelled but several of our community fundraisers held alternate and very successful fundraising activities. We are grateful to them and to all of our supporters.

I cannot thank the staff enough for their commitment and adaptability during such a difficult year. Our senior staff are commended for their dogged determination to bring Muscular Dystrophy Queensland through 2020. My special thanks go to our CEO, Helene Frayne, and our General Manager, Penny Deavin.

Being an honorary director of a not-for-profit board is a responsibility and a commitment in a sector where there are no easy years. My fellow Directors have used their skills and experience and dedicated time to support the company and our community and to ensure that we are sustainable for

decades to come. Thanks to the wonderful team at Muscular Dystrophy Queensland and most importantly, thanks to our clients and their families for continuing to engage our services.

Frankly, we are relieved that 2020 is in the past as we look forward to a 2021 where vaccines are a reality and where we will continue to grow our support for our community.

**Victor Attwood**  
Chairman



## A Message from the CEO Helene Frayne

It was a daunting prospect to lead Muscular Dystrophy Queensland through this unique time, to maintain focus on our community which is so vulnerable to COVID, and to retain our wonderfully dedicated staff. We had prepared for 2020 to be a year of growth, had just opened our new MDQ Client Centre and introduced a range of new clinical services. The year we had planned was not to be.

To maintain the safety of our clients, we closed the Client Centre for a period but all services continued through lockdowns (and I'm pleased to report, are back to normal now). We are agile and experienced in adjusting to changing conditions. Our staff were exceptional in their support of our community and the organisation and I am deeply grateful for their loyalty and commitment during the difficult initial months of the pandemic.

During 2020, our voice in support of our neuromuscular community grew stronger. Our organisation represents upwards of 75 poorly understood, rare conditions, so education and advocacy are integral to our work, especially when communicating with the National Disability Insurance Agency (NDIA), where, perhaps understandably decisions are made with large, homogenous cohorts in mind and without in depth knowledge of, or focus upon, rare conditions.

Our services, particularly our charitable services, would not exist without our valued donors and supporters. All Hallows School was able to complete their city collection in early

March 2020 and then all fundraising events were cancelled. For the first time in my years as CEO, we reached out to our supporters with an urgent appeal for support. And they gave generously, providing an additional \$36,450 to support our work in a time of uncertainty for us all. It enabled us meet the higher demand for our charitable services. Our donors and supporters truly are the backbone of Muscular Dystrophy Queensland.

As always, the Directors and staff remain focused on clients and families and we are grateful to our community members for choosing Muscular Dystrophy Queensland as their service provider. I am particularly grateful to Muscular Dystrophy Queensland's Directors and superb leadership staff – Penny Deavin, Lynne Borgert, Kim McNab, Kathryn Chopping, and Lindsay Paulin – and to the committed and determined people who have chosen Muscular Dystrophy Queensland as their workplace.

At the beginning of the pandemic, Jacinda Ardern's mantra was:

*"Be strong but be kind. We will be OK"*

During 2020, we focused on being strong and also kind to our staff and members of our community and we have emerged from this difficult year, more than OK.

**Helene Frayne**  
Chief Executive Officer

# Summary Financials

2020 presented some of the toughest financial challenges Muscular Dystrophy Queensland had faced in its history. In order to meet demand generated by the NDIS roll out, there was great pressure to grow the organisation, increase already established services and to broaden our service offering. We also anticipated an increased demand for our charitable programs and to meet that demand, we had budgeted to revitalise fundraising programs and, in late 2019, had increased our fixed costs substantially with higher staffing, new IT and business systems and a new, leased client centre next door to our Brisbane office.

Compared to the prior year, the 2020 Financial Budget which was approved by the Directors in November 2019, anticipated increases in client services related revenue and expenditure of approximately 85%, maintained fundraising revenue against slightly reduced costs and increased operational expenses of approx. 8%.

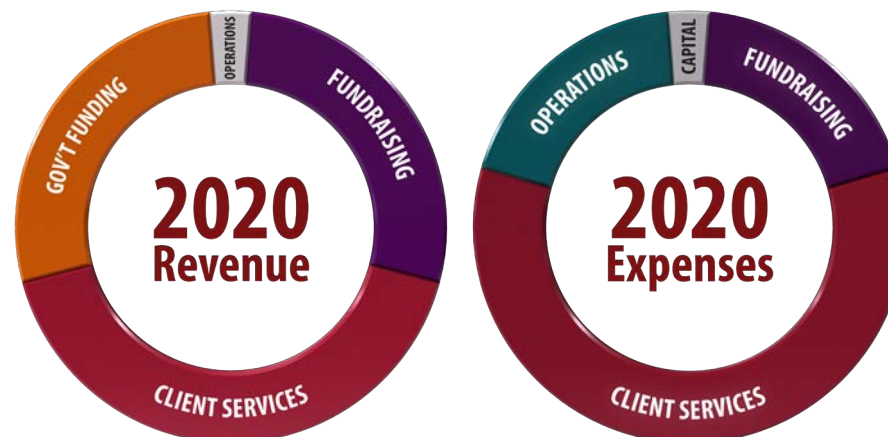
By the end of February we were exceeding those expectations, services revenue was three times that of the previous year and fundraising revenue was on par. The following month everything changed and, like so many organisations across the globe responding to the coronavirus pandemic, we re-thought that earlier planning. In the changing and difficult to predict operating environment, we anticipated the financial impact of the pandemic would have an immediate negative impact and be long-lasting. Our response to quickly adjust the way services were delivered and to communicate our community's changing needs with our supporters, alleviated some of the pandemic's impact on financial performance, providing the opportunity to maintain revenue albeit at a reduced rate, and to reduce expenditure.

The loss of fundraising event income was significant. Cancelling the Ray White Gala Ball which typically raises more than \$250,000 every September, impacted our funding to charitable programs and also meant that for the first time since it was established, we were unable to contribute to the Andrew & Greg Bell Muscular Dystrophy Research Fund, which, in the future, will fund Queensland based research towards curing muscular dystrophy. The reduction of income largely contributed to MDQ's eligibility for the Government's economic response packages including both the PAYG Cashflow Boost and JobKeeper, which we received between March and December.

The annual financial budget was redrafted. Between April and September 2020, the Risk and Finance Committee increased their schedule of meetings from quarterly to monthly,

closely monitoring financial performance and ensuring risk mitigation practices were sufficiently robust. MDQ fared well over the course of the year. With support of trusts and foundations, we could continue to invest in building an allied health equipment library.

Compared to prior year, client services revenue increased by 50% and related expenses increased by 26%, fundraising revenue reduced by 41%, related expenses reduced by 22% and operational expenses increased by 26% to provide a surplus at year end of \$256,080. We ended the year in a stronger financial position with member funds increasing to \$943,210.



	2020	2019
<b>Income</b>		
Fundraising	724,104	1,233,299
Client Services	1,081,944	722,429
Gov't Funding	688,982	116,681
Operations	12,266	11,415
<b>Total Income</b>	<b>2,507,296</b>	<b>2,083,824</b>
<b>Expenses</b>		
Fundraising	564,594	734,832
Client Services	1,266,205	888,330
Operations	403,451	407,777
Capital	16,966	35,697
Research Contributions	-	109,948
<b>Total Expenditure</b>	<b>2,251,216</b>	<b>2,176,584</b>
<b>Surplus/(Deficit)</b>	<b>256,080</b>	<b>(\$92,760)</b>



## *The most important steps*

*Don lives with a neuromuscular condition and usually relies on a walker for mobility but that was not going to stop him from standing tall and walking his daughter down the aisle unaided. Don and his physio partnered to achieve his goal, the physio providing expert guidance and Don determinedly practicing. On the auspicious day, not only did Don walk his daughter down the aisle but he was also her dancing partner.*



## Social Distances

*After disruptions early in the year, we were able to bring back our Outreach Programs. We also hosted 'meet and greet' sessions so clients could come and get to know some of the newer MDQ team faces, talk about our range of services and those available in the local community. Gold Coast locals pictured (above) enjoyed catching up with one another as well.*

## Living with COVID in 2020

In March 2020, Penny Deavin, General Manager, was acting as CEO. Whilst our CEO negotiated flight disruptions and two weeks of quarantine on her arrival home from overseas, Penny did a sterling job of managing alone, MDQ's initial responses to the first lockdown, including quickly and successfully transitioning staff to a work from home environment and developing an information hub on our website as a quick reference point to keep our community informed in the rapidly changing environment.

A COVID Safe committee was appointed and their first project was to develop a COVID safe plan which introduced strict infection control procedures and prepared for future re-opening of the office and resumption of client services. Support Coordination and Plan Management transferred to online/telephone-based service provision with little disruption. MDQ joined other organisations in offering online allied health services but the uptake was not high and as an essential service, we were soon able to resume some face-to-face allied health appointments under strict conditions.

MDQ obtained Queensland Health funding to establish our Get Connected program, a Queensland wide program focusing on client mental health. Services continued to grow, albeit at a slower rate. Our fundraising programs were significantly affected and although our supporters responded to our call for help via a Crisis Fundraising Appeal early in the year, generally our average donation income dipped sharply compared to performance in prior years.

Demand increased across all charitable programs, particularly our helpline and NDIS readiness services as people, staying home longer hours than ever before, found time to address

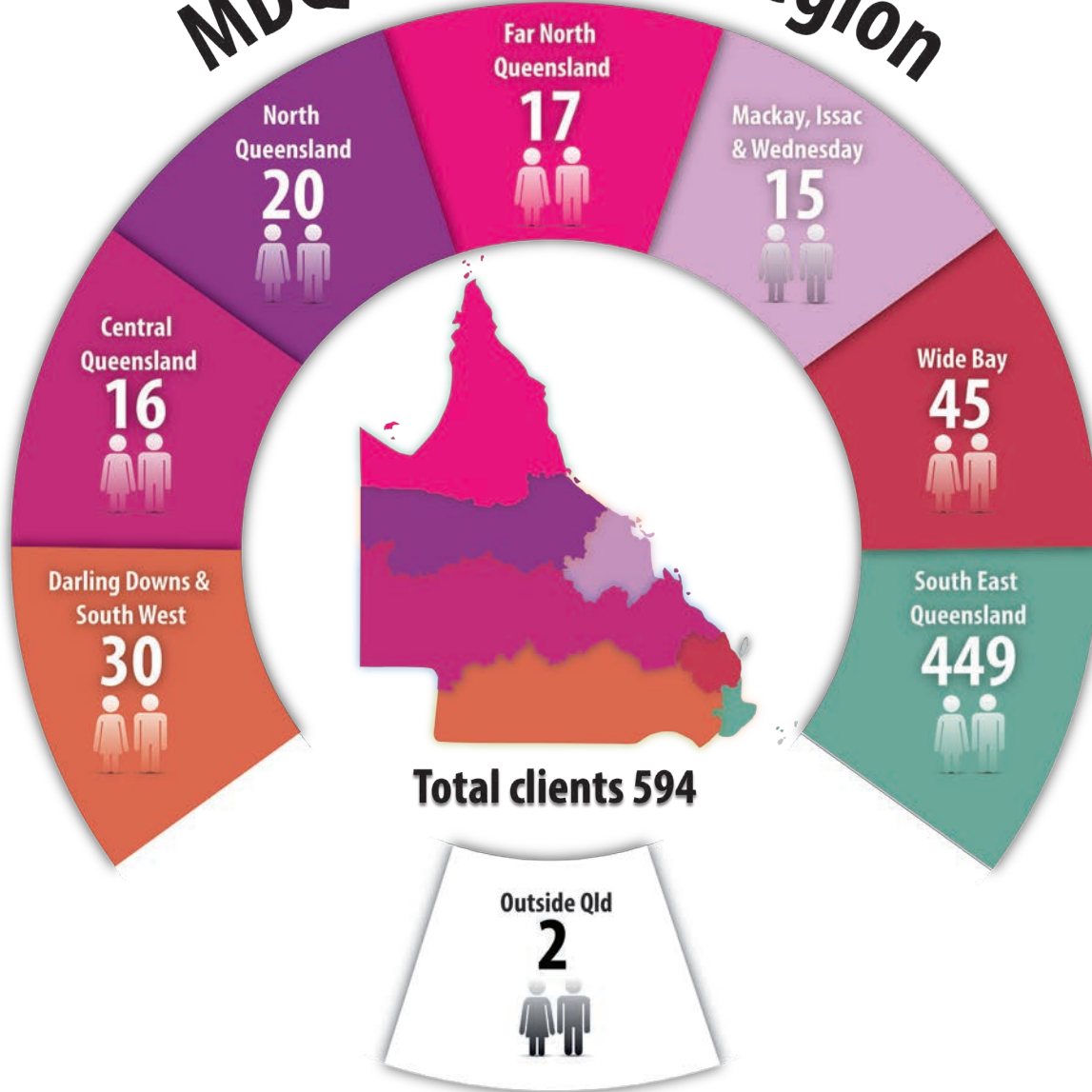
tasks they had put on hold, and needed information and guidance to get things moving.

From a Governance standpoint, Directors oversaw changes to budgets, workplaces, staff, and services. Leaders within the organisation stepped up – Helene Frayne (CEO), Penny Deavin, Lynne Borgert (Lead Physiotherapist), Kim McNab (Team Leader – Client Services), Kathryn Chopping (Call Centre Team Leader) and Lindsay Paulin (Finance Officer). MDQ was a grateful recipient of JobKeeper until end of 2020. Our staff are our most important asset and we were able to retain full complement without reduction in allocated hours. Staff remained positive and determined to support our clients and the organisation during this difficult time. We, in turn supported our staff with targeted professional development programs.

The new year, 2021, will be just as challenging with stalled vaccine roll out, programs re introduced and without the shot in the arm that was JobKeeper, however we continue to operate successful programs for our community and we have learned valuable, long term COVID lessons, knowing that our world is forever changed.



# MDQ Clients by Region



## Estimated Australian Incidence Rates

Australia

41,408



Qld

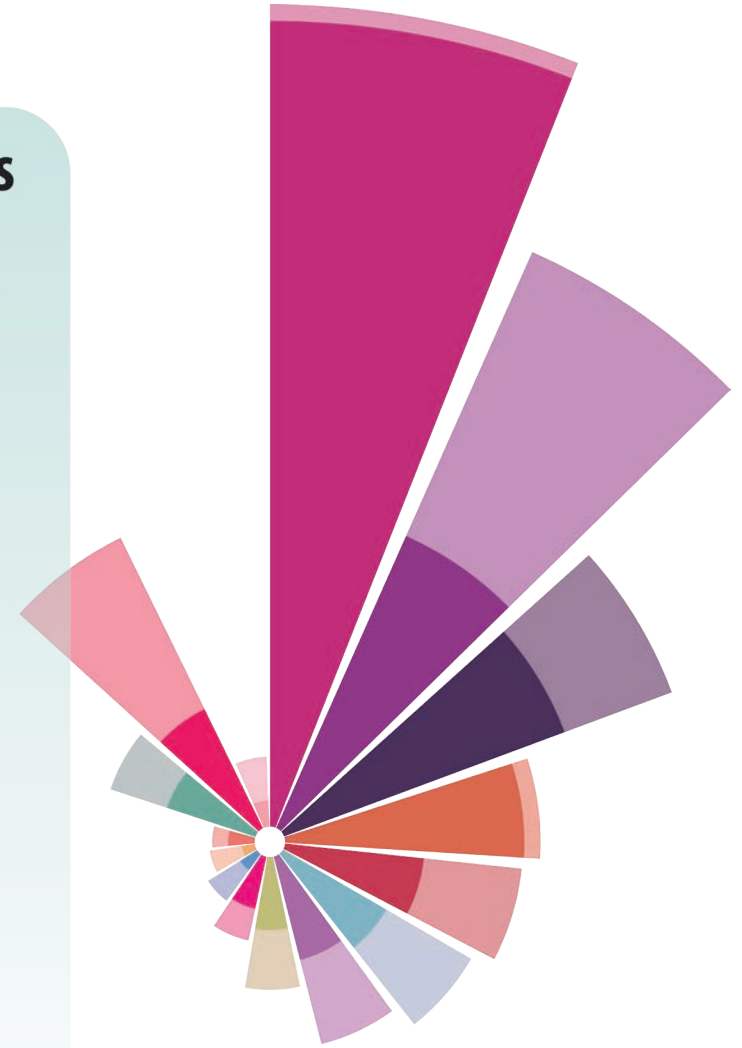
8,278



# Our Impact

## Common Conditions - MDQ Clients

Type	Total	Male	Female
Duchenne (DMD)	124	121	3
Myotonic MD	105	48	57
Fascio Scapulo Humeral MD	66	45	21
Becker MD	39	36	3
Limb Girdle MD	39	21	18
Charcot Marie Tooth	36	18	18
Spinal Muscular Atrophy (SMA)	32	16	16
Congenital MD	22	11	11
Inclusion body myositis	14	8	6
Congenital myopathies	10	3	7
Friedrich's Ataxia	8	2	6
Mitochondrial disease	7	4	3
Undefined neuromuscular condition	25	14	11
Other neuromuscular conditions	55	20	35
Non-neuromuscular conditions	12	4	8
<b>TOTALS</b>	<b>594</b>	<b>371</b>	<b>223</b>



# Meeting the needs of our Community



# Meeting the Needs of our Community

## Chargeable Services

### Allied Health Services

Muscular Dystrophy and similar conditions are rare, complex, progressive, and affect all of the body's muscles and systems. Because of all of these complexities, there must be a specialist provider dedicated to growing the evidence base needed to make a positive difference. Allied health services are central to supporting weakening muscles, slowing the progress of the condition, increasing the resilience and positive attitudes of the person living with the condition and overall, enabling them to live the lives they choose. At Muscular Dystrophy Queensland, the allied health team contribute their different skills sets to provide an integrated, holistic and client centred service.

### Physiotherapists

People with neuromuscular conditions engage physiotherapists to maintain or improve their independence, health, and quality of life. Tasks for the child or adult include:

- Assessment for and prescription of mobility aids, for example, a bespoke power wheelchair
- Hydrotherapy and muscle stretching programs
- Blocks of treatment as well as review and surveillance
- Respiratory care

Physiotherapy and (AHA) (allied health assistance) go hand in hand to provide a holistic, specialist service. In 2020, our services grew in these professions. We now have a local

physiotherapy service on the Sunshine coast, weekly services to the Gold Coast, physiotherapy in Toowoomba, Gympie and Cairns, and growing hydrotherapy services.

### Occupational Therapists (OT)

Occupational therapists assist members of our community to participate in activities of everyday life and build their independence. Tasks for the child or adult include:

- Safety, especially during progressions affecting muscle strength and independence
- Equipment prescription, for example hi-lo beds and shower chairs
- Transitions and management during changing in life roles
- Home modifications and access, including smart technology and environmental controls
- Community access and participation
- Assistance with thinking (cognition) and remembering

During 2020, our support coordinators and occupational therapist worked together to assist several clients to achieve their dream of living independently, and there were some very excited people moving into their new accommodation!

### Social Work

Social work is concerned with developing the potential of individuals, families and communities and works with people to understand, and overcome barriers they experience achieving their desired quality of life. We understand that having muscular dystrophy or a similar condition is tough and it can be helpful to talk to someone who understands

disability and has the training to help explore options and find a resolution for concerns. Members of our community are also more vulnerable to crises and may need support to ride the crisis wave. In 2020, our social worker also led the Get Connected program, generously funded by Queensland Health, in response to the social isolation and stress caused by the pandemic.

### NDIS Intermediary Services

Our clients tell us that they would prefer to work with people who understand their needs and who don't expect them to tell their story over and over again. The teams at MDQ provide what the NDIA describes as intermediary services – support coordination and plan management – efficiently and collaboratively, leveraging outcomes for members of our community.



## Support Coordination

The Support Coordinator assists the participant to implement their NDIS Plan and connects them with informal, community and funded supports. The support coordinator encourages the participant to achieve the most from their NDIS plan and achieve their goals. In 2020, MDQ also commenced offering Specialist Support Coordination.

This is what one of our clients, Tristram Peters wrote about his MDQ support coordinator

*“My Support Coordinator works for an NDIS-registered provider that specialises in my condition (the wonderfully titled Spinal Muscular Atrophy Type II). This means they have knowledge around the type of care I need and can help implement my plan around this. I’m not funded for specialist support coordination, but I still want my Support Coordinator to have specialist knowledge.”*

The NDIA expects high quality outcomes from support coordinators with no requirement for a relevant qualification. In mid-2020, we decided this was not working for our clients, so upgraded the necessary qualifications of our team, with almost immediate positive effect.

## Plan Management

Rather like a bookkeeping service, Plan Management assists NDIS participants to manage the funding in their NDIS Plan, align the supports they need to the NDIS price guide, pay their suppliers and maintain accurate records and supporting documents. The average NDIS plan for an MDQ client is twice the general Australian average, so our Plan Management team is twice as busy, processing twice the number of invoices per client for a minimal set monthly fee. A restructure and investment in a new business system early in the year made a real difference to efficient processes and client satisfaction and the service grew by 16% in 2020.



## An independent life

***“About a year ago, I was given a conditional offer for a unit. I needed to submit a housing application to prove my Specialist Disability Accommodation (SDA) eligibility. With the evolving nature of SDA, I needed someone who was across it. This was a gap in my knowledge of the system, but not for my Support Coordinator. They worked with my Occupational Therapist to complete this submission – and get me my own place!”***

***We take it for granted that we will be able to choose where and with whom we live. In 2020, because of the NDIS and a little help from our team, people like Tristram were able to live independently for the first time.***

## Charitable programs

In 2020, thanks to our donors and supporters we were able to meet increased demand for our extensive range of charitable programs which address needs not supported by government and other non-government services.

### Helpline

Our social worker is there for people newly diagnosed and other members of our community and their families, to provide emotional and practical support. We provided each caller with up to 2 hours of our time, and worked to address their immediate concern and then referred them into the programs or supports they required into the future.

On average during 2020, we managed 6 new enquiries per week, addressing varied concerns such as; a new diagnosis, supporting family members, providing advice about progression in their condition and how to go about ordering new equipment. This program is partly funded by Qld Health.

### NDIS access program

This new program responds to an emerging need expressed by many in our community, either to enter the NDIS or to receive funding that would adequately meet their disability related needs. On average we worked with 2 clients each month, to help them prepare for their application and to attend their first NDIS meeting which would address their needs and goals to inform the development of their first NDIS funding plan.

There were other people too, who had had their application rejected due to lack of supporting documentation or who had successfully entered the scheme but had received manifestly inadequate funding. We worked more intensively with these

people, supporting them to progress through the various levels of the National Disability Insurance Agency (NDIA) staff in order to have their application reassessed, or have their funding plan reviewed.

Commonly in 2020, we saw that people with impaired cognitive function, with difficult to observe disabilities or, those who relied heavily on informal supports (care provided by family members) would receive substantially less funding than a confident, outgoing person, even though their disability related needs might be quite similar. And so, our work attempted to equalise this imbalance.

### Life after

Each year, several members of our community sadly pass away. During these times, we support close family members. We stay in touch and, at an appropriate time, our social worker offers to assist them with counselling, including planning for their future. The Life After program is also available for close family members who experience grief and loss during other major transitions in life, for example when their loved one leaves the family home to live independently.

### Extended care

The extended care program works to resolve issues for people who have reached a roadblock and cannot access funded supports to help solve it – it is truly a last resort. We often work with the whole family, their community and within our professional networks to understand the problem, what is needed to bring about a resolution and solve the problem. It can be quite intensive work for our social worker who also manages this program. Fortunately during 2020, it wasn't necessary to refer families into this program more than 5 times.

### Breathe well cough assist program

A cough assist machine can provide an important contribution to promote the health and well-being of members of our community, as it simulates a natural cough and assists people to clear secretions that, for a person living with compromised breathing-related muscles, would be difficult or impossible to clear. The program focuses on meeting immediate needs when people are suffering from an acute respiratory infection by providing this life-saving equipment quickly, on a short-term loan for a few weeks or months. This quick turnaround is particularly useful as, although the equipment can be funded through an NDIS plan, it can often take weeks or months for the approval process which is time the person cannot afford. During 2020, we supported people to be able to access this equipment through their NDIS plan and directly funded 36 weekly loans for individuals. This program was partially funded by Queensland Health.

### Rest well bed loans

This service began more than twenty years ago after MDQ recognised that adjustable beds with “hi-lo” function would markedly increase a person's independence as their ability to transfer in and out of bed declined, and would offer a safer environment for carers needing to regularly lift and turn their loved ones. At the height of the program, MDQ maintained over 200 beds on long-term loan with families; and at a purchase price of over \$5,000 each, it was a significant investment funded entirely by our generous donors, charitable trusts and foundations.

We had also advocated for the beds to be recognised as disability related equipment that could be funded through

a person's disability support package. We were delighted for our community when, with the rollout of the NDIS, these beds and any necessary maintenance could finally be funded through a government package. Today we still offer this program for people ineligible for an NDIS plan and when necessary, we assist others to access this important equipment through their existing NDIS plan.

### Outreach

Often a face-to-face setting is the best method of delivering disability and health related services. Yet, more than 25% of our registered clients live outside Queensland's south-east corner. The outreach program funds travel and accommodation costs, to bring our specialist services to regions more than two hours away from our Brisbane office. During these visits our specialist staff also mentor local allied health professionals. After each visit we continue our support via a tele-health model. In 2020, with so many travel restrictions in place, it was necessary to reduce our planned outreach schedule but we could still offer weekly trips to the Gold Coast, regular services to the Darling Downs and South East, a visit to Cairns as well as establishing a local physiotherapy service on the Sunshine Coast.

### Get connected

Early in 2020, at the height of the first COVID responses, we anticipated our clients would need additional support and would appreciate a friendly check-in call, to discuss their mental health and resilience as they navigated COVID. Queensland Health also recognised this need and funded this short-term project which enabled our team to call every person on our client register. Mostly people were happy



## What to do when your chair is too small

*All round “great kid” Jesse, arrived in Australia in 2017 from New Zealand with his Australian-born mum, Steph. Since then, they’ve called the MDQ Helpline off and on for help and guidance. Unfortunately, Jesse doesn’t yet qualify for the NDIS and after beginning a teenage growth spurt, he was seriously outgrowing his rickety old wheelchair.*

*It was time for MDQ’s Extended Care Program to pull out all the stops and ensure Jesse got the chair he needed along with any necessary additions to support weak muscles. Jessie (above) was “all thumbs up” when donated funds enabled us to deliver his new chair, valued at over \$40,000.*



***Twelve year old, Rian who lives in Cairns, benefitted from an Outreach visit to this year. Our arrival in town coincided with the delivery of his new standing wheelchair, funded by his NDIS plan. Lead Physio, Lynne Borgert, spent three hours tweaking the chair to ensure he had the perfect fit to be safe and secure. She was also able to meet and talk with Rian's teachers about how best to support him.***

to receive a call and reported that they were doing well, and in fact had had more time to consider their health and wellbeing although their isolation had increased due to COVID related restrictions. Others did report they could do with some additional support, in these cases we were able to refer people into our charitable services, especially social work and counselling or to other providers who were better suited to address their needs.

### **Advocacy**

Muscular Dystrophy Queensland uses its influence as a peak body to advocate for the needs of our neuromuscular community, working towards creating equal access to social, economic and civil participation. National advocacy is also achieved through our Australian body, Muscular Dystrophy Foundation Australia (MDFA).

In 2020, MDQ advocated about the following:

- Proposed changes to NDIS support coordination which threatened to reduce the support our community relied upon
- For changes in NDIS rules which do not fund the participant's specialist support workers when they are hospitalised, leaving family members with the added responsibility of providing necessary additional care
- NDIS interpretation of parental responsibility asking for more funding for external support workers in the participant's NDIS plan rather than the child needing to rely on sleep deprived parents rising several times per night to meet disability related needs.
- For people reliant on the aged care funding system, whose disability related needs are inadequately funded

and managed through their aged care package.

Each staff member also provides a voice for their individual clients. They are focused on raising the understanding of the challenges of living with a neuromuscular condition in all settings.

### **Information**

MDQ is committed to providing relevant information for people living with muscle wasting conditions, helping professionals working within our community to improve their knowledge and understanding of the conditions and more generally, to raise awareness about muscular dystrophy and similar rare conditions in our community. Increasingly people are looking to MDQ as the peak body for people living with muscle wasting conditions and in 2020;

- through our connection with MDF, we made a significant contribution to the development of the Loop Community: neuromuscular digital resource,
- we shared our specialist knowledge with other professionals, presenting at the Respiratory Physio Conference in Brisbane and Cairns we provided free consolation time with educational professionals in schools attended by our young clients,
- we published regular "client update" newsletters addressing topics such as neuromuscular registers, trials, clinical guidelines, proposed changes to the NDIS, COVID updates and stories from clients sharing their experiences.



## Our Membership of the Muscular Dystrophy Foundation Australia

Muscular Dystrophy Foundation Australia (MDFA) is the national representative body for Australians living with neuromuscular conditions. Members are state and territory-based organisations providing specialised support and services for their neuromuscular communities. We are committed to advocating on behalf of our community to influence improved health, social and economic outcomes for all Australians living with neuromuscular conditions.

### Royal Commission Committee

MDFA has formed a national committee to monitor the issues being addressed in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and to provide a relevant and appropriate response should issues arise.

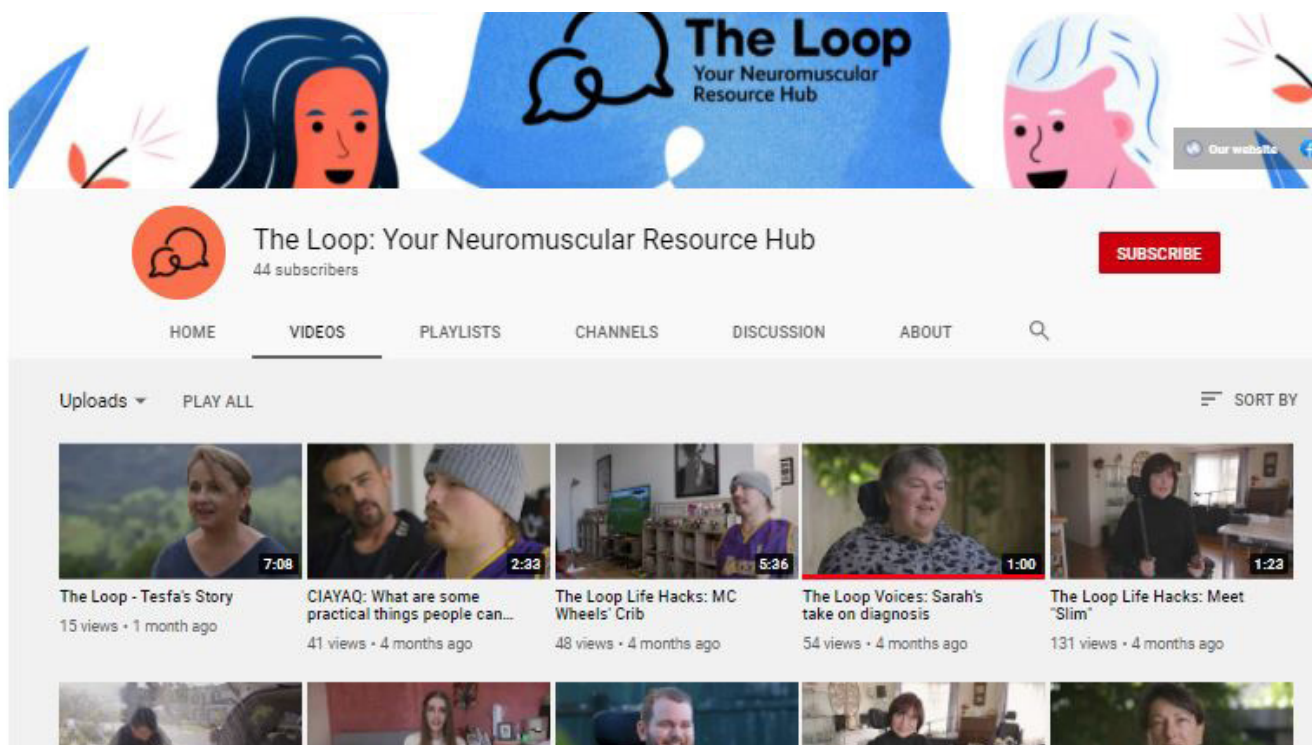
### COVID Survey

MDFA members collaborated on a national survey of Australians with Neuromuscular Conditions of our community with the aim of understanding their experience of COVID – 19. The results have been used for advocacy and to provide us with data and information to respond to federal, state and local government agencies about COVID – 19 related issues.

### The Loop Neuromuscular Resource

As well as advocacy, MDFA is committed to providing trustworthy, evidence-based information to our community. Funded through an NDIA Information Linkages and Capacity Building grant, an accessible website and forum were launched in 2020, solely focused on Australians with muscular dystrophy and similar conditions. The Loop connects people with information related to their health and wellbeing and provides practical peer advice about all aspects of life. (Go to [theloopcommunity.org](http://theloopcommunity.org))

Muscular Dystrophy Queensland was particularly proud to lead the development of a video series published on the Loop, based on the popular ABC television program “You Can’t Ask That”, with the aim of answering difficult to ask questions. Eight generous Queenslanders – including our Chair, Victor Attwood and MDQ clients; Tracey, Tristram, Nathan, Sarah, India, Harrison, Tesfa and their families – generously shared their time, their homes and stories about their experiences and skills (otherwise known as “life hacks”) with us. The result is content that is honest, entertaining, raw, informative, heartfelt and at times, too much! But, in every way definitely worth watching.



# Fundraising

Fundraising income is crucial to Muscular Dystrophy Queensland, financing all of our charitable programs and establishment of new client services. The impact of the pandemic made fundraising very challenging in 2020. We are grateful to our supporters for their commitment, supporting our fundraising appeals, art union and, when they could go ahead, our events.

## Red Bow Appeal

Every first Friday of March since the 1990s, the All Hallows students have descended on unsuspecting city workers on route to their offices, collecting for MDQ. The Red Bow Appeal went ahead with great success. For the first time this year, we trialled the use of a smartphone app, which the girls could use to safely and securely process donations and product sales. It was a success! Donations and proceeds from the merchandise sales increased by 30% on the past year. Sadly, in the following weeks COVID came to town and most other events planned to coincide with the Red Bow Appeal were cancelled. We are so grateful to organisations, including Nexia's Brisbane offices (pictured here), who in early March hosted a Red Bow Morning Tea for Muscular Dystrophy.

## Cancelled and re-imagined events

We took a cautious approach to event planning during the year and were guided by our event partners. Understandably, the Ray White Surfers Paradise Muscular Dystrophy Ball which usually hosts 500 people, could not proceed. Where we could work with our event partners, to re-imagine a way for their usual event to proceed, we did. The following events continued albeit somewhat differently:



## Brisbane HOG (Harley Owners Group) Ride

Quite simply, social distancing is impossible when you're riding pillion on the back of a Harley! The generous guys and gals of the club recognised that the annual Muscular Dystrophy Charity Ride, which usually runs in May, just couldn't go ahead so they came up with an alternative plan.

They raised funds throughout the year, mainly through raffles and on the spot fines (for silly things like forgetting paperwork, being a little late to a meeting or just being funnier than the person doling out fines). While strangers couldn't easily socially distance, there were no restrictions on members of the same household riding together and so the club dedicated the December club ride to MDQ and members invited their



family to pay for a place on the back of the bike. At their Christmas meeting, Brisbane HOG presented MDQ with a cheque for \$7,325. We are so grateful for their unwavering support and generosity.

## Ride, Walk, Roll for Muscular Dystrophy

For the past 7 years, at the end of August, Cairns has been the home of the Ride Walk Roll. With a hint of trepidation but a bucket load of determination, Chris Wiles redesigned the ride. His idea was to cycle circuit routes near his home but cover an equivalent distance to that between the MDQ Head Office in Brisbane, to the usual start of the ride on The Esplanade in Cairns – a whopping 56kms every day for 30 days to reach a total of 1680kms.

“There was no way I was going to let this pandemic completely stop the event, so I took matters into my own hands. I’m riding for my son and for every other family in Queensland who lives with this brutal disease”, he said. Chris knew his legs would be spent at the end of each day but felt grateful for his strength and good health, very aware of the debilitating impact muscular dystrophy has on a person’s muscles every day. Being a virtual challenge, anyone in the community could join Chris and accept to ride some of his kilometres. A few, hardy helpers took on the challenge and together they raised a little over \$5,800 for MDQ.

### Marathons for MDQ?

It was disappointing when both the Bridge to Brisbane fun run and Gold Coast Marathon were cancelled. For the past few years MDQ had entered a team in the B2B, where our staff, clients, their families and friends walked together and were supported by the Brisbane medical community, led by Dr Leanne Gauld. We had also planned to be involved with the Gold Coast Marathon for the first time and had been keeping in touch with two devoted supporters Cassie and Dan (pictured below left), who had planned to travel from their home in Townsville to compete in honour of Cassie’s brother Luke (pictured centre below with Cassie as children) who had

lived with Duchenne MD. It would be 10 years since he had died. Cassie was determined to complete the event despite facing a number of challenges in the lead up and even after Dan was unable to run with her, Cassie decided to run anyway and completed the 42.2km half-marathon in 7 hours and 9 minutes, smashing her personal best time and raising over \$5,000 along the way.



# Our Staff

Our Team	
Board Members	6
Staff Members	25
Client facing staff	18
Fundraising and finance staff	7

Muscular Dystrophy Queensland is focused on ensuring we have the right people with the skills to provide high quality and efficient services to our neuromuscular community, now and into the future. The resilience and commitment of all of our staff was evident in this difficult year with everyone

focused on the health, well-being and positive outcomes for our clients and their families.

Muscular Dystrophy Queensland offered more flexibility during COVID and reminded staff of our Employee Assistance Program as support, which offers staff free sessions with an external counselling service and additional paid leave. All staff were also offered professional development in coping with change and managing difficult conversations and situations.

We continued to invest in our staff by providing skill development and training relevant to their position. A staff survey conducted at the end of 2020 showed a high level of staff satisfaction.



# Management team



Ms. Helene Frayne  
B SpPath MBA GCert SustEnt  
**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 MDQ 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:  
Business & Development**

A familiar face to many, Penny worked across finance and fundraising roles with MDQ, before her promotion to GM. For several years, Penny ran a successful business services consultancy servicing small businesses in various sectors prior to her start with MDQ. She has drawn on her background in business administration, for the development of MDQ's new services and designing efficient business systems to support them. This year, Penny celebrated her 15th anniversary working with MDQ.

# Directors



Mr. Victor Attwood  
**Chairperson**

**Special Responsibilities:**  
Finance & Risk Committee  
Nominated MDF Australia  
Director

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  
BCom CA RCA  
**Director**

**Special Responsibilities:**  
Finance & Risk Committee

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  
LLB  
**Director**

**Special Responsibilities:**  
Nil

Tony is the founding Legal Practitioner of Big Law Pty Ltd Solicitors and has also practiced in rural locations in 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**

**Special Responsibilities:**  
Nil

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  
BPharm  
**Director**

**Special Responsibilities:**  
Nil

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**

**Special Responsibilities:**  
Nil

Dr Natasha Taylor 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.

# Thanks to donars and supporters



While this past year has been a difficult one, Muscular Dystrophy Queensland was able to draw on the contributions of past and present donors to ensure people living with muscular dystrophy and similar conditions receive the support they needed through our range of charitable programs. We appreciate the generosity of every donor who was able to make a contribution, no matter how big or small. We would like to acknowledge the following support.

## Gifts in wills

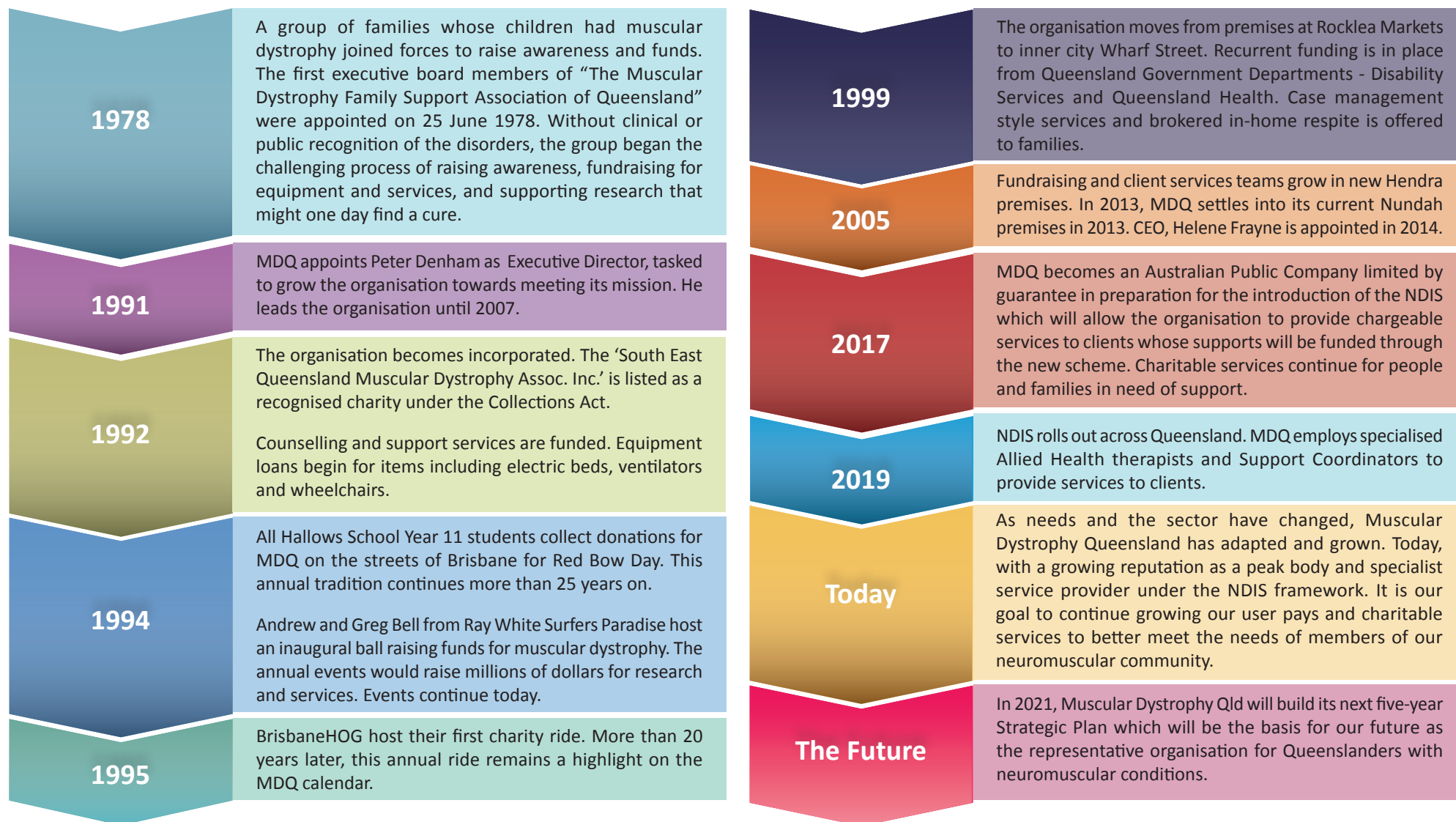
It is a such an honour to be nominated as a beneficiary in a supporter's will. The following individuals made such a gift the organisation in 2020:

- Frank Goudge
- Stella Denner
- Catherine O'Loan
- Gladys Kopp
- Emily Reinhardt
- Joan Neumann

## Charitable foundations and funders

- Cory Foundation
- Whitehouse Foundation
- Honda Foundation
- Reuben Pellerman Foundation
- RACQ Foundation
- Brisbane City Lord Mayors Charitable Trust
- Ford Burnett Foundation
- The Honourable Ms. Annastacia Palaszczuk MP, Premier of Queensland
- Queensland Health

# Our history and the future



Muscular Dystrophy  
Queensland  
*We're stronger together*



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Published April 2021