2024
Annual Review

We're stronger **together**

Muscular Dystrophy Queensland

Acknowledgment of Country

Muscular Dystrophy Queensland acknowledges the Traditional Owners and Custodians of the lands on which we operate throughout Queensland. We recognise their deep and enduring connection to Country, encompassing land, waters, skies, and communities, and we honour Aboriginal and Torres Strait Islander peoples' cultural heritage and ongoing contributions. We pay our respects to Elders past and present, and extend that respect to all First Nations peoples.

We respectfully advise Aboriginal and Torres Strait Islander peoples that this document may contain images or names of people who have passed away.

Commitment to Diversity and Inclusion

At Muscular Dystrophy Queensland, we are committed to fostering a culture of inclusion, equality, and accessibility. These values are embedded in every aspect of our work and reflect our belief that diversity strengthens our organisation and our community.

We recognise that the unique perspectives and experiences of individuals from all backgrounds and walks of life enhance our capacity to deliver meaningful, person-centred support. We proudly welcome and encourage participation and inclusion across race, culture, ethnicity, gender, sexuality, religion and ability.

We're stronger **together**

The conditions

Muscular dystrophies, and neuromuscular conditions more generally, are a group of 100+ rare, genetically acquired muscle diseases, that gradually reduce muscle strength and function over a lifetime.

We estimate that at least 8,000 people in Queensland live with these conditions. Research suggests prevalence is likely to be twice that of multiple sclerosis and at least as high as Parkinson's disease. However, the true incidence and prevalence rates of these conditions is unknown.

Although present at birth, symptoms don't always appear in childhood. These rare conditions emerge across all genders and cultural backgrounds in the world. Consequently, any family, at any stage of life may be coming to terms with a new diagnosis and navigating the challenges a rare, progressive muscle condition can bring.

As science unravels the role each genetic variation plays, clinical trials emerge and treatments improve, families with these conditions go on living, adpating and pushing forward to live their lives well.

Muscular Dystrophy Queensland's role

Our work centers on working alongside our community members; individuals living with muscular dystrophy and similar neuromuscular conditions, and their family members and caregivers, to understand the challenges they face and to deliver support and services, focused on empowering people to overcome these challenges.

We strive to raise awareness of these rare conditions, and of our services, so that no one living with a neuromuscular condition feels they're alone.

Contents

Impact snapshot (inc summary financials)	6
Welcoming our patron	7
A word for our Board Chair	9
CEO's review of 2024	10
Sector collaboration	11
Meeting the needs of our community	12
Giving highlights	16
Our people	18

2024 snapshot

Muscular Dystrophy Queensland continued to deliver life-changing support and advocacy for Queenslanders living with neuromuscular conditions throughout the year.

Our work remains centred on empowering individuals and families, expanding access to services, and driving systemic change through strong community engagement. All made possible by the generosity of philanthropic individuals and partners.

This snapshot highlights the tangible outcomes we've achieved together, demonstrating the real and lasting impact of your support across Queensland.

Everything we do is guided by our mission, shaped by our values, and driven by our vision for a better future.

Our vision

We strive for "lives without limits" for people with neuromuscular conditions

Our mission

Each day we work to empower people living with muscular dystrophy and similar neuromuscular conditions to make the most of opportunities and live the lives they choose.

Our values

More than aspirations, our values are the foundation of Muscular Dystrophy Queensland's culture, guiding our decisions, shaping our behaviours, and underpinning everything we do.

They empower us to deliver meaningful support, foster genuine connections, and continuously grow as a trusted voice and partner within the neuromuscular community.

Service : Community : Knowledge

Financials

This summary provides a high level review our financial performance in 2024.
Figures are based on the 2024 audited financial statements report, for detailed financial statements and notes please refer to the full report.

All values reported as ($'000)

Income vs Expenditure

	2024		2023	
Income				
Fundraising Revenue				
Lotteries	87	3%	83	3%
Bequests	790	26%	77	3%
Charitable Grants	34	1%	104	4%
Donations	341	11%	355	14%
Events	257	8%	368	14%
	1,509		**987**	
Services Revenue				
NDIS Fees	1,251	41%	1,416	55%
Government Grants	282	9%	141	5%
	1,533		**1,557**	
Other Revenue				
Investment Earnings	27	1%	24	1%
Membership	1	>1%	1	>1%
Other	4	>1%	0	>1%
	32		**25**	
Total Income	**3,074**		**2,569**	
Expenses				
Fundraising	478	18%	300	11%
Client Services	1,088	41%	1,124	43%
Capital	104	4%	71	3%
Operating	993	37%	1,116	43%
Total Expenses	**2,663**		**2,611**	
Surplus/(Deficit)	**411**		**(42)**	

Assets vs Liabilities

	2024	2023
Assets		
Current Assets	1,579	1,214
Non-current Assets	249	245
	1,827	**1,459**
Liabilities		
Current Assets	470	473
Non-current Assets	6	45
	476	**518**
Equity @ 31 Dec	**1,353**	**941**

100+
rare neuromuscular **conditions** we support

45,000+
Australians living with rare NMCs

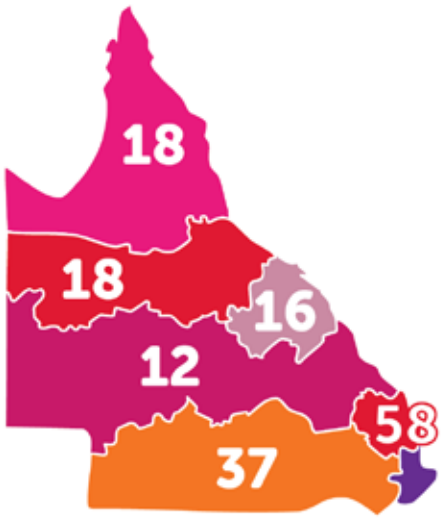
8,000+
Queenslanders living with rare NMCs

46yrs
of service since founding **in 1978**

730+
people connected with us **@31 Dec 24**

7 people
access charitable supports **every week**

4 people
connected for the first time **each month**



of the 731 people connected with MDQ 23% live outside South East Queensland, **18% live more than 2hrs away from our head** office and 10 people live interstate

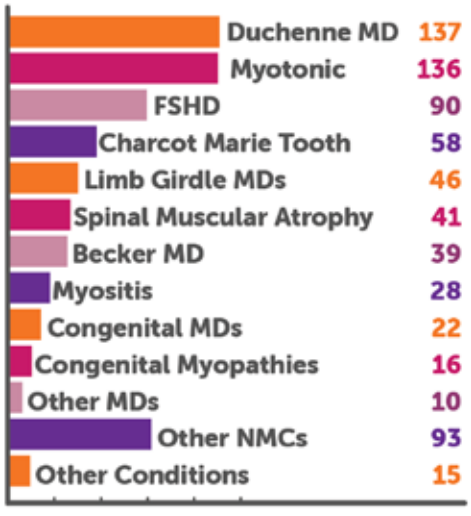
$33,945
funds invested via **charitable grants**

"I know you probably don't think you did much for me yesterday but you did. And you have given us hope."
~ Infoline caller

$282,323
funds invested via **government grants**

3,710
donors giving to progress our mission

Top 10 neuromuscular conditions (NMCs) experienced by MDQ community members



"These type of gatherings make a difference and for some are life-altering. I can't thank you enough."
~ Info Session Attendee

$790,227
bequests gifted to progress our vision

4,805
interactions via **support coordination**

4,714 hrs
delivered via **allied health** professionals

$58,600
won via Lucky13 **lottery winners**

$685,214
raised via **appeals, lotteries & events**

$1,250K
billed for services funded in **NDIS plans**

6,906 hrs
support delivered via **NDIS plans**

25,700+
invoices claimed via **plan managers**

Welcoming our new Patron

We were honoured when in September 2024, Her Excellency the Honourable Dr Jeannette Young AC PSM, Governor of Queensland, accepted our invitation to become our Patron.

Her Excellency is the 27th Governor of Queensland and representative of His Majesty King Charles III, Queensland's Head of State. The Governor's role representing the Monarch as our constitutional Head of State is to unify, uplift, support and authentically engage with Queenslanders, celebrating their achievements while championing progress and inclusivity to strengthen our state's future and global reputation.

Having graduated from Medicine at Sydney University in 1986, the Governor has dedicated her career to improving health outcomes for Australians. In August 2005, the Governor was appointed to the role of Chief Health Officer for Queensland, with responsibility for leading the State's preventative health and public health agendas, including response to public health emergencies.

In January 2020, when the COVID-19 virus outbreak was declared a pandemic, the Governor became the State Health Incident Controller. Her determination to keep the most vulnerable members of our community safe directly benefited us all, but particularly the members of our neuromuscular community who live with compromised respiratory function.

The Governor's patronage aims to unify and promote Queensland and Queensland organisations by undertaking activities that assist, promote, encourage and recognise Queenslanders across a wide range of community interests.

In accepting patronage, the Governor acknowledged outgoing Patron, Emeritus Professor John Pearn AO AM, and his enduring contribution to those living with neuromuscular conditions, both as a senior paediatrician who had diagnosed and treated so many young children throughout his career and through his efforts as Patron of Muscular Dystrophy Queensland.

A word from our Board Chair

It's a pleasure to present Muscular Dystrophy Queensland's Annual Report for 2024 and to reflect on a year that brought both continued challenges and, importantly, renewed optimism for the future. As this will be my final report as Chairman, it is also a moment of personal reflection—on the progress we've made together over the past seven years and on the strong foundations now in place for the road ahead.

Like many in our sector, we began 2024 navigating familiar difficulties; static NDIS pricing across services, rising operational costs, and the ongoing ripple effects of broader economic pressures. Our management team and staff continued to do an outstanding job of delivering valued, quality services in an environment where resources were stretched.

By November, the concerning outlook changed significantly. We were humbled to receive a substantial bequest from a donor who wished to remain anonymous. This unexpected gift was both a financial and emotional boost, reinforcing just how deeply the work of MDQ is valued by others.

We also received confirmation that our application for the NDIA Peer Support & Capacity Building grant was successful. This opens new doors for us to deepen our community work for those living with neuromuscular conditions, especially in areas that foster connection and crucially, funds services for family members and those ineligible for individualised NDIS funding - where there is such great need.

These developments mark a turning point. While we still face real challenges, the organisation closes 2024 in a much stronger position, with a renewed sense of momentum.

This year marked the first full year with Penny Deavin as CEO. Penny has brought calm and compassion to the role. Her longstanding commitment to MDQ, paired with her practical leadership style, has helped steady the ship and set a course for the future. I thank her - and every member of the team - for their contributions this year.

To the Directors, past and present, who I've served beside during my time on the board, I offer my sincere thanks for your governance and guidance.

My thanks go to Ken Robertson and Tony Biggar, for your outstanding work laying the groundwork for the organisation's evolution towards the NDIS, and to Gavin Ruddell, whose insight and care in his capacity as Finance & Risk Committee Chair have been critical in helping the organisation navigate difficult financial terrain. To our current Directors, thank you for your generosity in sharing your knowledge and your time for the benefit of our community. It has been my great honour to work alongside each of you.

In 2024, we supported over 730 individuals - nearly half without NDIS support -underscoring the importance of our charitable programs. The Community Liaison Group, ably chaired by Sarah Shaw, continued to shape the way we listen, learn, and act alongside our community. It was especially rewarding to see social connection events return and thrive; offering space for friendship, shared experience, and belonging.

As I step down from the Board after seven years, I do so with a full heart. MDQ has been an important part of my life, and although my formal role ends here, my involvement won't. I remain committed to this community and look forward to continuing my support in new ways.

To all our members, donors, staff and supporters—thank you. Your passion and generosity keep this organisation going. You've inspired me every day I've had the privilege to serve.

Warm regards,

VICTOR ATTWOOD
Board Chair

Photo previous page:
Her Excellency the Honourable Dr Jeannette Young AC PSM, Governor of Queensland and Patron of Muscular Dystrophy Queensland, photographed with Chairperson, Victor Attwood and CEO, Penny Deavin, during a morning tea hosted at Government House in March 2025.

CEO's review of 2024

In my first full year as CEO, I've had the privilege of working alongside a passionate team, guided by the organisations values and united by our mission, to empower Queenslanders with neuromuscular conditions to live the lives they choose. Together, we've continued to strengthen the organisation striving to respond to community need, even as we navigated persistent financial and systemic challenges. 2024 was a year marked by resilience, generosity and renewed hope for the future.

MDQ remains a specialist provider in a broad disability landscape—an organisation that exists because our community needs support that is highly focused, knowledgeable about rare, and even ultra rare conditions, and responsive to the complexities of life with a neuromuscular condition. In 2024, we continued to hear the same message we've heard for years: please retain your specialist focus. We're committed to doing so.

We've refined our operations to deliver services that are efficient but person centred. We've listened to feedback, introduced new connection opportunities, expanded our outreach, and delivered practical, hands-on support to hundreds of Queenslanders; those with NDIS funding - and many without.

This year marked the fourth consecutive year of financial pressure, and our management team worked tirelessly to balance the books while maintaining frontline services. The funding model of the NDIS does not reflect the true cost of delivering services to our cohort as well as meeting our quality standards and compliance obligations, so necessary in our sector, but only applicable to registered NDIS providers.

We continued our advocacy, participating in government consultations and working closely with sector allies, to raise the voice of small specialist organisations and to ensure the voices of our community members are heard.

In November, we were pleased to be one of just 69 successful applicants to be awarded a NDIA Peer Support & Capacity Building grant. This two year grant will encompasses our existing information, referral and community connection programs, and will allow for some expansion - for those navigating life with neuromuscular conditions, including family members and those not eligible for individualised NDIS plans.

Then, at the close of the year, we received two extraordinary gifts, a $500,000 bequest from a donor who wished to remain anonymous; and another significant bequest from the Estate of Kenny Broad, a well known member who along with his family, contributed to building MDQ since its earliest days. Bequests, large or small, provide stability and allow us to plan ahead with greater confidence and purpose. We honour the memory of all donors who left a gift beyond their life, and are deeply grateful for their belief in our mission.

Our small but determined fundraising team achieved budget across nearly all income pillars, despite significant staff turnover. Special thanks go to our event partners; All Hallows, Brisbane Harley Owners Group, Incito Business Solutions, Macquarie Bank, and to Andrew Bell, Greg Bell and Selena Carson, of Ray White Surfers Paradise, and to all the wonderful supporters who joined in and made a contribution.

Our short-term sustainability concerns were allayed by the end of 2024. However, our broader mission remains unchanged—and the structural challenges we face in the disability sector are far from resolved. We will continue advocating for pricing that reflects the real cost of quality services, and for reliable, ongoing support for those who fall outside the NDIS.

I want to thank every member of our team, from the frontline to behind the scenes, for your dedication and drive. I particularity want to thank our board for giving their time and expertise so freely, in pursuit of our mission. It is a privilege to work with you all. And to our community—our members, donors, volunteers and friends—thank you for your trust and your generosity. You make our work possible, and we carry your hopes forward into everything we do.

Warm regards,

PENNY DEAVIN
Chief Executive Officer

Sector collaboration

Muscular Dystrophy Queensland works within both state and national systems that support all Australians living with neuromuscular conditions and, more broadly, with disability. In 2024, we continued to navigate and contribute to these systems - raising the voice of our community, to advocate for improvements where gaps remain, and delivering responsive, person-centred support across all stages of life.

NDIS

The NDIS remains the primary source of support for most people in our neuromuscular community. In 2024, we continued our work extending beyond service delivery to help individuals and families understand the scheme, navigate its complexities, and successfully access the supports they need.

The NDIS is a powerful system; ife-changing when reasonable and necessary supports are adequately funded, but often difficult and distressing to engage with when things go wrong. This year brought significant change, responding to the *NDIS Review* and the Federal Government's *Getting the NDIS Back on Track* initiative reshaping the landscape.

We actively participated in consultations and advocacy efforts, calling for the role of small, specialist providers—like ours—to be recognised and protected. We continue to advocate for the unique needs of people impacted by progressive neuromuscular conditions to be met, including those living with the conditions and their family members.

Queensland Health

We remain grateful recipients of a small grant via the Community Self Care Funding Program, which contributes to our information and referral service. Our funding contract was set to expire by 30 June 2024. We advocated for increased funding citing unmet need in our community, seeking to increase the capacity of our charitably funded programs. We were only successful in renewing funding at the same level for a further five years.

Peak Bodies

We remain actively involved in work that influences systemic change and represents the neuromuscular community at a national level. Our long-standing membership with Muscular Dystrophy Foundation Australia (MDF Australia) continues to be central to our advocacy and research efforts. In 2024, we contributed to the collective voice as members of Rare Voices Australia, the Australian Neurological Network, and Amplify Alliance Australia, and our work with other patient advocacy groups and peak bodies.

Meeting the needs of our community

We continued to see growth in the number of clients and their families accessing our services and community activities during 2024. We welcomed another 40 new members into the community during 2024, with 731 people with muscular dystrophy or a similar condition, connected by year end.

Our clients continue to access our services and activities from throughout Queensland. The largest group of 562 living in the South East Corner, with 169 clients (23%) based regionally. The addition of 'Virtual Coffee and Chats' and regional social get togethers have meant that clients, families and carers from around the state have been able to meet regularly and form friendships. An increased number of regional events throughout the state are planned for 2025.

Outreach visits have continued with our Allied Health Team visiting Cairns, Hervey Bay, Sunshine Coast regions, and the Toowoomba district, providing a consultative service and focused interventions. The team conducted assessments and reviews, facilitated equipment trials, provided prescriptions, and completed NDIS applications. They also trained support workers and coordinated with local therapists and service providers. Telehealth services were available upon request for all Queensland clients.

Principally our community accessed services via their NDIS plan or relied on our free charitable programs, with some accessing subsidised supports via an aged care package or private funding. It was wonderful in November, to know we'd secured a substantial grant under the NDIS Peer Support and Capacity Building Grant, to expand services over the coming two years (possibly three). This vital injection also ensures family members and those ineligible for individualised funding under the NDIS will have their needs addressed.

PENELOPE HODGE
General Manager
Community Services

Allied Health Services

Throughout the year, 185 people living with a neuromuscular condition accessed our Allied Health Service which included Physiotherapy, Occupational Therapy or Allied Health Assistance. Our team of eight therapists provided 4,714 hours of face-to-face services from our Underwood treatment room, clients homes, schools, swimming pools or online through telehealth. The team is ably lead by our Allied Health Clinical Lead, Lynne Borgert who provides supervision and regular professional development.

Physiotherapy

With the aim of maintaining functional ability and independence our physiotherapists worked for our clients providing:

- Functional Capacity Assessments and equipment prescriptions a requirement for the NDIS
- Hydrotherapy – both individual and group programs
- Respiratory care
- Stretch and balance programs.

In past years, MDQ also employed Allied Health Assistants, who provided prescribed stretching and maintenance programs. Frozen NDIS pricing for a fifth consecutive year forced our decision to close this valued service.

Occupational Therapy

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

- Equipment prescription, e.g. hoists and hi-lo beds
- Assessing and mitigating safety risk in home and community settings
- Prescribing minor home modifications and referral for major home modifications
- Increasing access with assistive and smart tech
- Providing programs which support people through progressions and changes in their life roles
- Assessing and supporting cognitive function

Specialist Disability Support in Schools

Our team of therapists continued to provide Specialist Disability Support in Schools. Funding, provided by Education Queensland, exists to improve access to and participation in curriculum and educational outcomes for eligible school-aged students with disability.

NDIS Intermediary Services

NDIS intermediary services help participants manage and implement their plans, empowering them to make informed choices, stay in control of their funding, and connect with the supports they need. Despite uncertainty rising from the NDIA's plans to merge these roles into a single 'navigator' model within five years and frozen NDIS prices affecting the ability to cover direct costs, we remain committed to delivering these supports and the positive outcomes they create.

Support Coordination

Support Coordinators help participants put their NDIS plan into action, enhance their capacity by connecting them with both formal and informal supports, and work with the Agency to ensure smooth implementation. During 2024 the Support Coordination team of three assisted 112 clients, totaling 2259 hours of support through times of stress and uncertainty, as they cope with changes in their lives and NDIS guidelines. Given the complexity of their work, Muscular Dystrophy Queensland's Support Coordinators hold qualifications beyond those required by the NDIA, ensuring they consistently deliver specialised, high-quality services to our clients.

Plan Management

MDQ's Plan Managers help participants to manage the financial aspects of their NDIS plan, offering choice and control while reducing the administrative burden. Our Plan Managers process invoices, monitor budgets, and support participants to understand their funding without needing to navigate complex systems alone. In 2024, Muscular Dystrophy Queensland's Plan Management service supported 174 clients, processing over 25,700 claims. With a strong focus on personalised service, our experienced team ensures clients feel confident and informed about their NDIS spending.

Charitable Programs

Muscular Dystrophy Queensland's charitable programs provide essential support where government funding falls short, helping people navigate diagnosis and get on with living happy, engaged lives. We work alongside our community to understand the challenges they face and to deliver services that bridge the gaps they experience, so they are empowered to live the lives they choose. We are deeply grateful to our philanthropic supporters, whose generosity makes these programs possible.

Infoline (Information and Referral)

During 2024, 166 people contacted our Infoline, which is staffed during business hours, providing community members with vital information and emotional support, especially during critical moments in their lives.

Whether it's following a diagnosis, during a progression of their condition, navigating transitions, or accessing the NDIS for the first time, we are here to help. We also receive calls about research advancements, clinical trial opportunities, treatment availability, and ways to access disability-related supports outside of the NDIS. Our website and social media platforms often serve as the first point of contact, directing individuals to our Infoline where they receive personalised support and assistance.

NDIS Access Program

Accessing the NDIS can be overwhelming, and many people are unsure where to begin. During 2024 Muscular Dystrophy Queensland provided support to 25 people totaling 83 hours of direct support; offering information, helping with application completion, and advocating for community members whose initial applications were unsuccessful.

Once an application is approved, we guide individuals through the process and assist in preparing for their first planning meeting. We also provide ongoing support if issues arise in future plans, such as unreasonable funding reductions or the removal of essential supports and services.

Extended Care (Case Management+)

This program is designed to assist individuals facing unexpected and urgent needs where no other support options are available. Common services provided include help with delays in NDIS funding, housing support, Centrelink issues, equipment loans, and the taxi subsidy scheme. In 2024, Muscular Dystrophy Queensland utilised its charitable funds, expertise, and community networks to find solutions for 17 clients and their families, providing a total of 90 hours of urgent support. Challenges encountered through the extended care program have driven the development of new services, advocacy efforts, and submissions to government departments addressing the issues faced by people with muscular dystrophy.

Equipment Loans

Our equipment loan scheme provided 38 pieces of vital equipment to clients during 2024. While equipment is usually funded by the NDIS, long wait times can be a barrier and some people aren't eligible to receive NDIS assistance. We are thankful to donors who provide funds to purchase equipment and their maintenance and our community who donate good quality items including preloved wheelchairs, hoists and shower chairs.

Thanks to a recurrent Queensland Health grant, the support of our generous donors and the Community Benefit Fun who provided $99,035 of funding for us to purchase eight new machines we were not only able to continue, but grow our cough assist loan program which provides a Cough Assist device to support people to overcome acute respiratory infections.

Individual Advocacy

In response to a sudden surge in NDIS delays, leaving people waiting months for decisions and going without essential equipment, support workers, and other vital services—we leveraged our networks to advocate for urgent reviews. Many individuals told us they had lost the resilience to keep fighting for the supports they were entitled to, until we stood beside them and advocated on their behalf. Our intervention led to outcomes in days, where previously people had been left waiting for months.

Community Connection Events

The start of 2024 saw us developing our first annual MDQ Community Events Calendar so that all our clients and their families could save the dates for the

year and know what opportunities were available to meet and socialise with others in the MDQ community. A few highlights during the year were the

FSHD Medical Seminar

In partnership with FSHD Global Research Foundation, we hosted an informative community gathering sharing information and conversation about living with FSHD. Dr. Cullen O'Gorman's presentation on the latest research and considerations for getting involved in clinical trials was a highlight. With over 30 people in attendance, it is clear there is demand for further sessions moving forward.

Kid's School Holiday Fun Days

Our School Holiday Kid's Fun Days continue to be popular with families. Held in each of the school holidays, the kid's programs are led by our Physios and OTs with fun, theme-based activities catered specifically to school-aged kids with neuromuscular conditions. This year's themes were Pets, Music and Survivor. Mentors from our MDQ Community also participated in the days and are an invaluable source of information and inspiration for our younger clients. While the kids are having fun, parents also benefit from connecting with each other and also from the services of Social Worker, Geraldine Burgess, who facilitates sessions for the parents.

Regional Events

In 2024, MDQ expanded its Community Connection events into regions where many of our community members reside, aiming to broaden our connection with them, but also to provide an opportunity that might not otherwise be available, for people living similar lives to meet, establish friendships and benefit from shared experience.

A Gold Coast Social dinner saw around 45 people enjoying great food, drink, and socialising. Thanks go to the James Frizelle Charitable Foundation, for sponsoring this wonderful event. On the Sunshine Coast 25 lunched, over good conversation at the colourful Banana Bender Pub. We also took advantage of the Allied Health team's trip to Cairns to organise a social dinner for our Far North Queensland clients. Local community members met up with our physiotherapists Lynne and Lisa for a meal at the Cairns RSL Club

Family Christmas Party

Thanks to all our wonderful community members who came along to our MDQ Christmas Party. We had a wonderful night and hope that you did too! The gingerbread decorating station was heaps of fun - thanks to the ladies from the Community Liaison Group for making so many tasty treats for everyone to decorate. We are so grateful for the generous support of the Brisbane Lord Mayor's Charitable Trust and also the Brisbane Harley Owner's Group, for letting Santa know we'd be there! We have already started to plan for next year's Christmas party.

Giving highlights from 2024

In 2024, our community came together with extraordinary heart, purpose, and creativity to raise funds that support Queenslanders living with muscular dystrophy and similar neuromuscular conditions. From school students in red tutus to Harley riders with huge hearts, each event and act of kindness helped bridge the gap between diagnosis and living the life they choose..

30 Years of Red Bow Spirit

This year marked an incredible milestone — 30 years of Red Bow Day at All Hallows' School. The Grade 11 students showed up in style, dressed in red tutus and oversized bows, lighting up every corner of Brisbane City. Their spirited campaign raised a remarkable $18,693, all in support of children and families affected by neuromuscular conditions.

We're deeply grateful to the Kiwanis Club of Brisbane, who prepared 140 packs of Red Bow merchandise for the students and returned post-event to help repack everything with the same level of care and commitment. The Kiwanis team also generously served breakfast at the Muscular Dystrophy Charity HOG Ride — a true example of community in action.

Brisbane HOG Ride

The Brisbane Harley Owners Group (HOG) once again brought the thrill and joy of the open road to life with their annual Muscular Dystrophy Charity Ride. With the roar of engines and hearts full of purpose, experienced riders ensured their pillion passengers had an unforgettable day. From a delicious breakfast to a lively auction and raffle, the ride was about more than just the journey — it was about care, connection, and commitment.

Ride, Walk, Roll

With the enthusiastic backing of Incito Business Solutions as major event sponsor, and the support of Bowy Cycling Apparel, KND, and Active Truth, our annual Ride, Walk, Roll event raised over $23,000. Community teams like Hugo's Heroes, The Walkie Talkies, and Lindsay's Loafers led the charge with creative fundraising efforts that inspired everyone around them.

Personal Journeys, Powerful Impact

Stories of personal dedication touched all of us this year.

Ryan Besso

Ryan embarked on a 100-kilometre trek to the top of Mt Kosciuszko, raising almost $2,500 in honour of his friend Dan, who lives with Myotonic Dystrophy.

Jared Carney

Jared ran the fisiocrem GC50 Run Festival alongside his friends, Corey and Ethan, to honour his two cousins lost to Muscular Dystrophy — a powerful tribute of love and endurance.

Chris Wiles

On national TV, Chris Wiles joined Mark Beretta on Sunrise to highlight the importance of Myotonic Dystrophy Awareness Day, after raising funds through Ride, Walk, Roll. His determination to make a difference and voice helped raise national awareness for our cause.

Celebrating with Style and Purpose

The Annual Ray White Surfers Paradise Muscular Dystrophy Ball, hosted by Ray White Surfers Paradise brothers Andrew and Greg Bell, raised more than $150,000 this year. This incredible legacy continues to provide critical support to our programs and has delivered the opportunity to invest $1million into a perpetual fund dedicated to providing research in future years.

A special thank you to the members of the Indooroopilly Golf Club for choosing us to be one of three beneficiaries for their Charity Golf Day. It was a fantastic day on the green, raising over $25,000 for the three charities.

Heartfelt fundraising by the College St, North Lakes Goodstart Early Learning Centre — raising over $5,000 in honour of little Presley living with Ullrich Congenital Muscular Dystrophy — reminded us that even the youngest community members can inspire powerful change.

A Community That Keeps Giving

Our heartfelt thanks to the countless individuals who donated to our lotteries and appeals, spoke with Carol from our fundraising team, or made lasting commitments through gifts in wills and charitable foundations. Your trust in us fuels our mission — and genuinely changes lives.

Our people

Our Staff

Our dedicated staff bring a unique blend of professional expertise and deep compassion to their work, united by a shared commitment to improving the lives of people with neuromuscular conditions. Our team includes allied health professionals, community service specialists, and support staff who work collaboratively to deliver person-centred, responsive services. Their knowledge, empathy, and adaptability are key to meeting the complex and changing needs of our community.

Volunteers

Generously contributing their time and energy to support our mission. From the All Hallows' School students giving a few hours of their time to make Red Bow Day a success, the Kiwanis Club of Brisbane who regularly lend their hands to help our fundraising events run smoothly, to those who assist more regularly serving on our board and committees, we truly value the meaningful ways you to contribute.

Community Liaison Group

Our Community Liaison Group (CLG) is a committee of volunteer members with lived experience of a progressive neuromuscular conditions. The CLG exists to be the voice of Queensland's neuromuscular community and to provide strategic and operational advice to the CEO and Board on matters relating to our neuromuscular community. The CLG meet quarterly in during the year, chaired by Sarah Shaw. In 2024, the group focused on advocacy, social engagement opportunities and expanding membership. Members also coordinated a Peer Support Facebook group.

Board & Committees

Muscular Dystrophy Queensland is governed by a skilled and committed Board of Directors, operating under a constitution that ensures representation of people with lived experience of disability. As a skills-based board, it brings diverse expertise to guide strategic direction and oversight. Committees, including Finance & Risk and Fundraising & Marketing, support the board's work and help ensure strong governance, financial sustainability, and mission alignment.

Directors

Our Directors generously share their time, networks and expertise to progress the organisation's goals and to ensure support is available today and for future generations whose lives are impacted by neuromuscular conditions.

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.

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.

Bob 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.

Kim McNab
BAppSc(EnvHealth)
Director

Kim has experience in environmental health, health promotion and disability, working in government and the not-for-profit sector. For seven years until 2019, Kim was employed as MDQ's program coordinator and was influential in developing NDIS aligned services. Kim also led the development of the national online resource, TheLoopCommunity.

Tristram Peters
BA/BJ MWEP
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, building pathways to inclusion and understanding. Tristram resigned as a Director in October 2024 but remains engaged as a mentor for our kids school holiday events.

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. Gavin vacated his position as a Director at the 2024 AGM, but remains engaged through pro bono consulting and fundraising activities.

Management

Penny Deavin
GradCertBu, MICDA
CEO & Company Secretary

Penny became CEO and Company Secretary in 2023, after previously leading its finance, operations, fundraising and communications programs, having first stepped into a Bookkeeping role with MDQ in 2006. Penny also serves on Risk & Finance and Marketing & Fundraising committees.

Penelope Hodge
BA(BusPsych) CertClinSup CertSCWP
General Manager - Community Services

Penelope has over twenty-five years in senior leadership, program management, board director and social work practitioner experience in the community, government, disability and not for profit sectors.

Muscular Dystrophy Queensland

We're stronger **together**

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