MUSCULAR DYSTROPHY NSW
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

Impact Report

2024 – 2025

At Muscular Dystrophy NSW, our mission is to empower, connect and support the neuromuscular community, and be an effective advocate.

We offer services at every life stage. These include peer connection, camps and retreats, support at diagnosis, NDIS support coordination, access to the latest information, and advocacy.

Our target is a thriving neuromuscular community, spanning every region of NSW and led by lived experience.

Our vision

Every person with a neuromuscular condition is able to live the life they choose.

Our mission

To empower, connect and support the neuromuscular community, and be an effective advocate for the neuromuscular community.

Our values

- Empowerment
- Responsiveness
- Integrity and respect
- Partnerships and teamwork

Acknowledgement of Country

Muscular Dystrophy NSW acknowledges the Traditional Custodians of the land on which we live and work. We pay our respects to Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

We seek to build respectful relationships with Aboriginal and Torres Strait Islander communities, to ensure that people living with neuromuscular conditions can live the life they choose.

Contents

Message from the CEO & President

In 1957, Muscular Dystrophy NSW was founded to support people living with muscular dystrophy – a group of rare, complex genetic neuromuscular conditions (NMCs). Today, around 13,000 people in NSW live with an NMC.

Each person's journey is different – their goals, dreams and purpose are unique. Our role is to provide specialised, individual support so they can live the life they choose.

As we reflect on the 2025 financial year, we're proud to have continued to push this vision forward. We're also reminded of the people who make our work possible: our small but mighty team, our generous supporters, and the community who share their time, stories and experiences with us. It is our privilege to witness their dedication and strength.

This year, our commitment to the neuromuscular community remained steadfast. Camps and Retreats once again created memories and friendships, taking participants to Sydney, Canberra, the Blue Mountains and Lake Macquarie.

Peer Connect grew stronger, with two new groups being piloted to meet emerging needs.

Our NDIS Support Coordinators continued to deliver tailored, personalised services. And our advocacy work reached new heights – amplifying the voices of people with NMCs across the state.

We also strengthened our organisation behind the scenes. Updated systems and the launch of our new website have made it easier for people to connect with us. Moving into our new office in Concord has brought our team together in new ways. Plus, through our first Sunday Soirée and a record-breaking Big Red Roll & Stroll, we saw incredible generosity from our community of supporters.

This report shares highlights and stories from each program area.

In these pages, you'll read about Young Adults' Retreat exploring new locations, to the growth of peer networks and key advocacy wins.

As you read each story, we hope you see the thread of partnership running through our work – with community, supporters and our team.

Thank you for your generosity and for accompanying us on this journey.

With gratitude,

Jessica Henry

CEO, MDNSW

Robert Fraser

President, MDNSW

Message Her Excellency the Honourable Margaret Beazley AC KC Governor of New South Wales

As Patron of Muscular Dystrophy NSW, it is a great pleasure to provide this welcome message for the 2024-25 Impact Report which highlights the stories of the Muscular Dystrophy NSW community and this year's achievements.

Since its foundation in 1957, MDNSW has been an empowering advocate and ally supporting people living with neuromuscular conditions and their families. Over seven decades, it has been at the forefront of delivering specialised, practical support and connection while championing inclusion and dignity.

The heart of MDNSW's impact lies in its community; in its staff, volunteers and supporters who provide unwavering dedication and innovation in the provision of information, events, activities, and programs that support individuals and families at every life stage.

During my time as Patron, I have had the privilege to witness how MDNSW continues to evolve while staying true to its mission.

In March this year, I joined the MDNSW team and supporters at their Sunday Soirée in Glebe.

It was a pleasure to hear about the friendships formed through Camps and Retreats and how important Peer Connect was to members. The annual Big Red Roll & Stroll is another highlight in MDNSW community activities.

Whether coordinating essential support services, supporting research projects or providing important community connection, the team's expertise, their strong connections with the NSW community, and the generosity of volunteers and supporters forms the foundation of this success.

You can be proud of the hope and opportunity that you continue to create, in working towards your vision that “every person with a neuromuscular condition is able to live a life they choose.”

Her Excellency the Honourable Margaret Beazley AC KC, Governor of New South Wales

Our Approach

At Muscular Dystrophy NSW, we understand everyone's journey is different.

But some things are important to us all: learning, belonging and growing. Our programs and services are designed around these interconnected focus areas, ensuring support at every stage of the journey.

LEARN

So people understand their condition, make informed choices and navigate life with confidence.

BELONG

So people find their community and don't face their journey alone.

GROW

So people reach their goals, build independence, and advocate for themselves and their community.

Belong
Peer Connect

Learn
Information & Referral
NDIS Support Coordination
New Diagnosis Companion

Grow
Advocacy
Camps & Retreats

Our Year of Impact

Your Community

86

Camp & Retreat Participants

196

Peer Connect Participants

56

NDIS Support Coordination Clients

Our Programs

59

Peer Connect events

8

Camps & Retreats

601

program attendances

Your Impact

$1.3M

raised

975

donors

146

fundraisers

1 Learn


MUSCULAR DYSTROPHY NSW
July Camp 2022
MUSCULAR DYSTROPHY NSW

> *Without your Support Coordination, we would still be struggling with [our family member's] care… And no matter when or where you are, you always return my phone calls and emails and go searching for information to help us. So you have had a huge impact on our lives.*

NDIS Support Coordination

As a registered NDIS provider, we provide tailored NDIS support coordination to people living with neuromuscular conditions (NMCs).

Our team have a unique understanding of the often-complex needs that come with living with an NMC. And we understand that people have varying support requirements.

There is no one size fits all approach. Our dedicated team of support coordinators are here to provide the best care and services to suit our community's needs.

56

Support Coordination Clients

More than

1,000

hours of support provided to participants

Meeting Client Needs Amidst NDIS Changes

Our team has navigated a shifting NDIS landscape while staying focused on client needs. They provided guidance, helped participants understand changes and access supports. In this landscape, our team led some significant breakthroughs. They advocated for NDIS funding and ensured timely access to services. They helped clients navigate challenges with reassurance and peace of mind.

Information & Referral

As a neuromuscular support community, our role is to connect people with the right information, resources and services to help them feel informed, supported and in control.

Whether they're looking for specialised clinics, want to understand different conditions, or are curious about the latest research, we'll guide them through it.

More than

100

enquiries handled by our team

Listening to our Community

With significant changes to the NDIS, we received many enquiries about accessing and navigating the scheme. Some people reached out for support connecting them to specialist providers for services like psychology and genetic testing. Others enquired about assistance and tips managing changes in their condition.

For each enquiry, we provided tailored information and connected individuals with appropriate services.

This included referrals to neuromuscular clinics, organisations like Carer's Gateway, individual advocacy providers and peers who have navigated similar challenges.

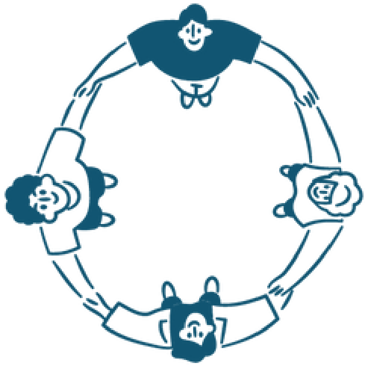
> “*I really appreciate the support I have received from MDNSW. You have always listened to my concerns, provided support and good advice.*”

New Diagnosis Companion

This year, we received a NSW Department of Communities & Justice Disability Advocacy Futures Program Special Projects Grant. It is to support the development of a program called the New Diagnosis Companion.

Receiving a neuromuscular diagnosis can be overwhelming. This new program will better support children and families across NSW during this challenging time.

The New Diagnosis Companion will provide early, personalised support, helping families feel informed and supported. By connecting early, we aim to reduce isolation and make sure families access the right support, at the right time.



Co-Creating Solutions with Families

Throughout the year, we undertook extensive consultation with community members and stakeholders.

Our goal was to shape the program's design. We met with neuromuscular clinics to strengthen collaboration. We also surveyed and interviewed parents who have navigated this journey.

These conversations helped us understand what families need and how to support them.

By mapping client journeys, we identified key pain points and developed solutions to address them. We then refined the program's design based on the valuable community consultation.

What will it involve?

Personal check-in calls

Regular, compassionate check-in calls from a trained staff member.

Tailored information and resources

Easy-to-understand resources tailored to each stage in the journey.

Peer support and mentorship

A support group facilitated by MDNSW staff and informal mentorship from experienced parents who've taken a similar path.

Research

We're committed to supporting research that investigates treatments and therapies, as well as other studies of neuromuscular conditions.

Across Australia, Muscular Dystrophy associations are supporting research projects that can lead to progress and breakthroughs in treatment and care. These advancements encourage the pursuit of new solutions for people living with neuromuscular conditions.

PhD Scholarship Program

One of the most direct ways we contribute to scientific progress is through our PhD Scholarship Program.

This year, in partnership with Hearts & Minds Investments Limited, we reinstated the program and awarded two full scholarships and one part-scholarship.

The goal: to develop new treatments and improve the lives of people living with neuromuscular conditions.

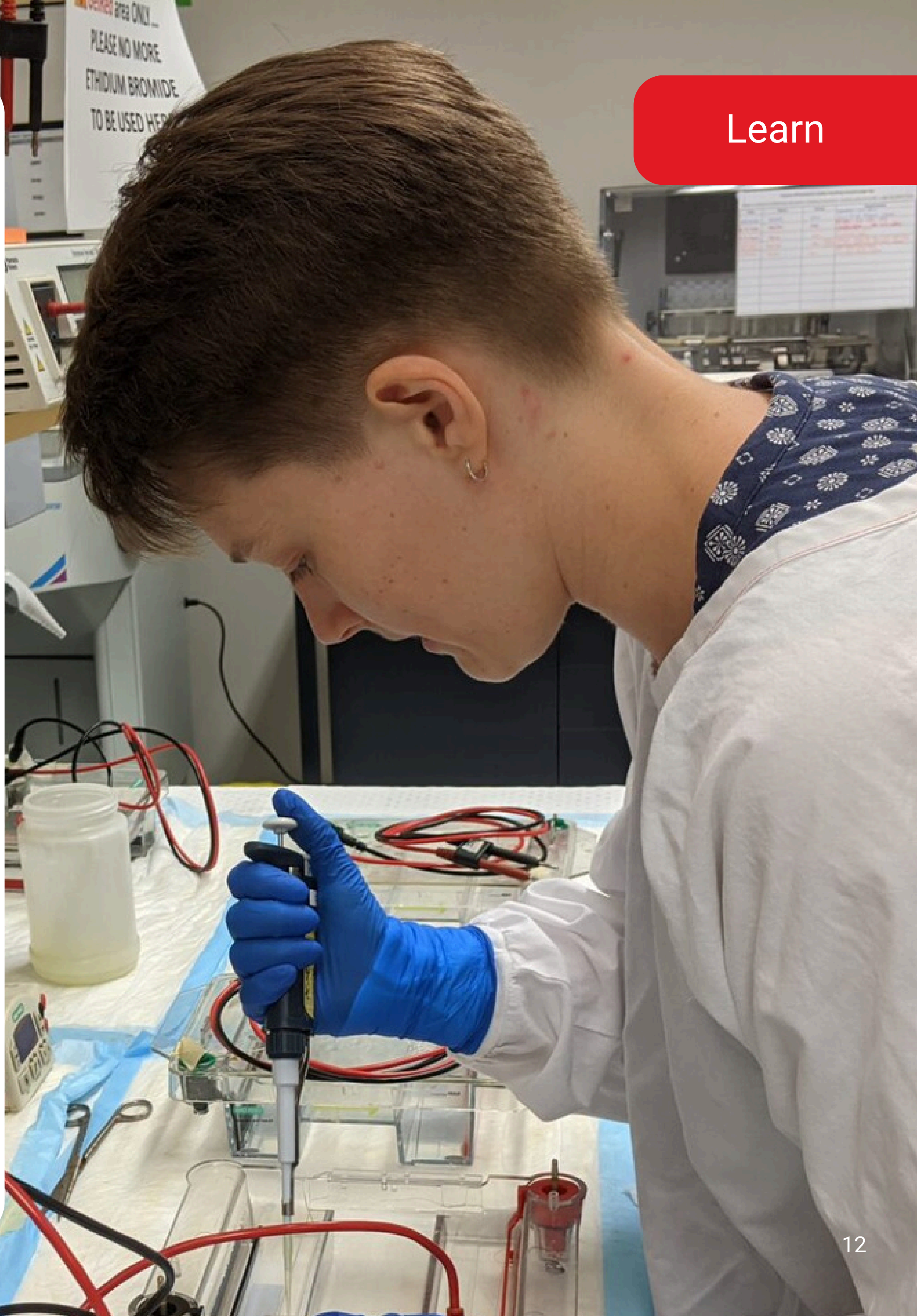
> “ *I wouldn't be [where I am today] if it weren't for the MDNSW scholarship. It was a leap of faith and I'm hugely grateful for the vision of the Board and teams. The MDNSW community has become a huge part of my life for so many years.*

TWO

full research scholarships awarded

ONE

partial research scholarship awarded



Research Projects

Improving Diagnosis of Muscle Disorders Using Advanced Genetic Testing

Dr Dennis Yeow

Diagnosing muscle disorders can be a lengthy and complex process involving multiple tests over several years. Dr Yeow is developing a new genetic test using Oxford nanopore sequencing, an advanced technology capable of identifying all genetic changes related to these disorders in a single step.

This approach aims to:

- Provide faster, more accurate diagnoses, reducing stress and costs for patients.
- Enable earlier access to appropriate treatments.
- Resolve diagnostic uncertainty for previously unsolved cases, offering patients condition-specific prognostic information, genetic counselling, reproductive risk insights, and management options.

Studying Fatigue in Children with Charcot-Marie-Tooth Disease

Miss Monica Marzouk

Fatigue is a major challenge for children and teenagers living with Charcot-Marie-Tooth disease (CMT). Miss Marzouk is taking preliminary steps to develop the CMT Fatigue Scale (CMT-FaS), a tool to measure fatigue in paediatric CMT patients.

Her work includes:

- Systematic review – examining how fatigue is measured across all paediatric neuromuscular diseases.
- Cross-sectional study – determining the prevalence and impact of fatigue in children with CMT.
- Longitudinal study – tracking how fatigue prevalence and impact change throughout childhood.
- Interview study – capturing the lived experiences of children with CMT.

Improving Care for Adults with Motor Neuron Diseases

Dr Aicee Calma

Adults with neurodegenerative conditions such as spinal muscular atrophy (SMA) and motor neuron disease (MND) need better ways to monitor disease progression and treatment response. Dr Calma's study follows patients over 18 months, using clinical and electrical tests to track changes in their condition.

The research aims to:

- Identify clinical and electrical markers that predict disease progression.
- Improve understanding of disease trajectories, severity and complications.
- Guide patient care and optimise treatment strategies for adults living with SMA and MND.

2 Belong

Peer Connect

Peer Connect is a vibrant community for people living with neuromuscular conditions and their families – offering support, connection and community. Because we know that talking to people with similar experiences is powerful.

Whether it's navigating the NDIS or exploring the latest medical research, we're here to help our community build a strong support system.

59
events

196
participants

> *For me, Peer Connect is a family… this is my family, and I enjoyed every minute of it. I enjoy talking to people and seeing we're not alone in our struggles and everything is doable, you just need to be resilient.*

> *Normally when I'm with a group of people, I'm always trying to hide my problems – my difficulties. I don't have to here because we've all got them and we all share them. It's what makes us who we are.*

> *Normally when I'm with a group of people, I'm always trying to hide my problems, my difficulties. I don't have to here because we've all got them and we all share them. It's what makes us who we are.*

Peer Connect

Building Connection and Belonging

Community and belonging are what Peer Connect is all about. Throughout the year, we offered 14 social events, including Community Day, Easter Lunch, Maker's Day, International Women's Day and more. They provided in-person opportunities to build friendships, share experiences and exchange advice. These events were complemented by virtual sessions such as Mums' Chat and Power Hour. They ensured a sense of connection reached participants across NSW.

Growing Knowledge and Skills

Through InfoShare sessions, our community deepened their understanding of a range of topics. These included accessible travel, accessible sport, NDIS updates and emergency planning. Social get-togethers like MD Dads gave fathers an environment to learn from their peers about everything from the NDIS to accessible school tips. We also collaborated with other organisations, including Biogen, to provide our community with the opportunity to understand niche topics. For example, the journey of a medicine from development to delivery. Plus, Neuromuscular Information and Research Day returned in 2024 – read more about it on page 19.

Increasing Confidence

Our programs help participants feel confident navigating life with a neuromuscular condition. They offer a space to ask questions, share experiences and learn from others who understand. Sessions often include time to discuss practical strategies for advocacy. This helps participants speak up for themselves, their families and communities. Condition-specific meetups are especially valuable, creating a supportive environment for problem-solving and self-advocacy.

Neuromuscular Information and Research Day

Seventy-four community members came together for our annual Neuromuscular Information & Research Day in August 2024.

It featured expert talks on treatments, sleep and education – as well as an NDIS panel. One of our favourite moments of the day came from a young community member sharing their journey to independent living at university. His compelling story grounded the day's discussions in lived experience. Attendees asked question, exchanged insights and offered support.

Every year, more people with neuromuscular conditions contribute to the event, strengthening its relevance and impact.

Recordings from each session are available here:

NIRD YouTube Playlist

Piloting Two New Peer Groups

This year we strengthened opportunities for connection by piloting two new peer groups.

MD Dads brings fathers in our community together for social evenings. Led by dad Chris Carrero and in collaboration with Duchenne Australia, we hosted two events during the period. Feedback has been positive, highlighting the value of shared experiences and peer support.

Student Life supports young people living with neuromuscular conditions at university. The group provides a space to meet others who understand and build supportive connections.

STRONGER TOGETHER: Joanne's Journey with Peer Connect

When Joanne joined her first Peer Connect retreat in Melbourne back in 2012, she didn't expect to find a circle of friends who would shape her life for years to come.

"It opened up a whole new world that I didn't know was there or didn't know was for us," Joanne says. "I just felt so much part of it. It was really fantastic."

Joanne's neuromuscular journey hadn't been straightforward. Though she knew from birth that she lived with disability, she wasn't formally diagnosed with central core disease until she was in her 40s. By then, she'd already married, travelled, worked and had a child – all without having a name for her condition.

In 2005, her husband Ian introduced her to Muscular Dystrophy NSW. He later joined the board for 12 years.

Meanwhile, Joanne became a familiar face at Info Share sessions, retreats and Community Days – watching the organisation grow and evolve.

For Joanne, the heart of MDNSW has always been the people:

> *"You've got something really important in common [with these people]. And that's what Peer Connect is about.*

Whether it's asking a peer about equipment, navigating challenges at work or planning accessible travel, nothing compares to being with people who just get it.

"It's those shared experiences that are really great and really helpful. It's being able to talk and hear other people's experiences... We're all stronger together."

The friendships formed through Peer Connect have long outlasted the events themselves. Joanne and her peers message often and catch up on their own.

Even Ian has found his place in the community, learning from others' coping strategies and realising he's not alone.

And that's what Peer Connect is truly about: connection, solidarity and hope.

3 Grow

Camps & Retreats

Our camps and retreats are designed to help kids, adults and families connect, build independence and have fun.

8
Camps & Retreats

86
participants

> *Retreat for me is somewhere I can let go and be myself. People understand me and I don't have to pretend. It's great to meet everyone in the same boat. We're all different but the same and we understand. It's nice to be spontaneous and do activities together.*

> *The camp has had a really positive impact. It provided a supportive environment for growth, learning and connection. Whether it was building confidence, making new friends, learning new skills, or simply having fun, the experience helped create lasting memories and personal development that will continue to make a difference.*

Summer Camp: Rolling into a Week of Fun

Who it's for: Kids and teens aged 6-18 who use a powerchair.

Summer Camp returned in January 2025 at Narrabeen Sports and Recreation Centre. We welcomed 20 campers for five action-packed days. Highlights included powerchair football, a reptile show, laser tag and swimming. A new 'open day' offered families a glimpse into camp life. Plus, two young adults joined older teens to share advice about moving into adulthood. Thanks to our volunteers, nurses, Jason from Powerchair Football NSW and DJ Joep. They make the fun possible!

Adventure Camp: Thrills and Skills

Who it's for: Kids and teens aged 6-18 who are independently mobile.

We help two Adventure Camps in the period – in July 2024 and April 2025. Twenty-seven campers joined, including a few new faces. Across five days each, campers got a taste for adventure at Stanwell Tops. They tried giant swings, drift cars, high ropes and archery. Some even directed and filmed their very own movie production. Along the way, they built friendships, confidence and made countless memories.

Young Adults' Retreat: New Horizons

Who it's for: Adults aged 18-30.

This year, our Young Adults' Retreats headed to new places. In October 2024, 13 young adults came together at The Lodge, Blacktown. They explored Sydney Zoo, swam in the hydrotherapy pool and shared laughs over meals. Then in March 2025, 15 headed to Point Wolstoncroft Sports and Recreation Centre. Here they enjoyed markets, fishing and a legendary karaoke night. The highlight of both weekends? Making new friends and strengthening bonds with old ones.

Women’s Retreat: Time to Reconnect and Recharge

Who it’s for: A weekend retreat for women.

In November 2024, we hosted Women’s Retreat in Canberra. It brought women together for a weekend of connection, relaxation and fun. They enjoyed meals, rolls and strolls around Lake Burley-Griffin, and trips to local markets. With crafts, birthday celebrations and games nights, the activities offered something for everyone. The retreat was such a hit that many asked to stay longer next time.

Peer Connect Retreat: Sharing Stories, Building Bonds

Who it’s for: A weekend retreat for adults.

Nineteen participants joined Peer Connect Retreat in Canberra in April. The weather was perfect and the company even better. Plus, a lively welcome dinner set the tone for a weekend of conversations and creativity. The group enjoyed exploring the National Gallery and a scenic explore. But the best part? The sense of connection among the group.

Mums’ Retreat: Connection and Care

Who it’s for: A weekend retreat for mothers of children living with a neuromuscular condition.

Over a lovely weekend in June, eight mums joined us in the Blue Mountains. The weather was warm and sunny during the day and chilly at night. The group held a ‘girls night in’, went on bushwalks, had time to themselves to read and relax, and enjoyed a high tea. The retreat buzzed with laughter, tears, discussions of families and support for each other.

CAMP MAGIC:
Unlocking Potential, Building Confidence, Making Memories

For Vanessa, there's nothing quite like seeing her boys just get to be kids. But for her sons Tarek (nine) and Riley (13), moments of carefree, mischievous childhood play can be few and far between. Both boys live with Duchenne muscular dystrophy.

Finding MDNSW gave Vanessa a community of "people who just get it." Through MDNSW camps, Tarek and Riley discovered a world of adventure and belonging. "Camp is an exciting adventure for them," she reflects. "It's an opportunity to do activities they don't generally get to do when they're at home or school."

Vanessa has seen her boys grow in confidence and independence, especially Tarek: "Before his first camp, he was really dependent on us. He wasn't confident to go out of that secure family environment… Spending time away from the family was a really different experience for him. It's given him the confidence to now go and be part of a different group and have support from different people as well."

Like most siblings, Riley and Tarek don't always agree. But there's one thing they're both sure of: camp is awesome.

When asked what he loves most, Tarek says, "The activities and how much fun I'm going to have with my friends." For Riley, it's "getting to meet my friends and hang out with them for a week – and it's pretty fun doing pranks on everyone else."

The boys light up when they talk about camp – recalling favourite activities, close friends and top-tier pranks. It's clear they've made memories that will stay with them for life.

And that's all any parent wants for their children. It's something Vanessa holds close.

> *"My hope for my boys is that they find positivity and enjoyment in any of the activities that they can do. They often miss out on a lot of the fun experiences that other kids get to do. So I just really hope that they continue to still have those positive experiences, regardless of all the hard times and to keep building those memories.*

MDNSW's camps have turned Vanessa's hopes into something real: two boys coming home full of stories, confidence and joy.

Advocacy in Action

Being an effective advocate for the neuromuscular community is part of our mission.

It ensures people have their voices heard and their rights upheld. We do this by engaging with policymakers and systemic advocacy organisations. We also develop resources to address the needs and concerns of our community.

85%*

agree we understand the issues facing the neuromuscular community

78%

believe we are actively advocating on their behalf

* Results from 2025 Community Survey

Amplifying Community Voices

Our representative advocacy is funded under the NSW Department of Communities & Justice Disability Advocacy Futures Program (DAFP). Under this grant, we leverage our programs to understand community needs and challenges. These then underpin our advocacy priorities. We regularly join NSW Disability Advocacy Network and Disability Interagency Policy meetings. These forums bring together DAFP-funded organisations. By being part of these discussions, we make sure the voices of our community are heard and prioritised.

Deepening Engagement with Decision-Makers

We strengthened relationships with MPs at state and federal levels. In February, we met with Sally Sitou MP (Member for Reid) to discuss our community's challenges in accessing supports. In June, we met with Stephanie Di Pasqua MP (State Liberal Member for Drummoyne, pictured above). Following our meeting, Stephanie made a formal acknowledgment of MDNSW in the NSW Parliament Legislative Assembly Hansard. Her statement recognised our work and the commitment of our team.

Championing School Inclusion for Children

We continued to advocate for children living with neuromuscular conditions to take part in school life, including social, recreational and sporting activities. We raised the issue with NSW Disability Inclusion Minister Kate Washington MP. She committed to supporting our efforts to reduce venue costs for our annual Summer Camp. Our former CEO, Charlotte Sangster, also joined a Missing School panel to shine a light on the challenges children living with neuromuscular conditions face at school.

Fundraising

We couldn't do what we do without the generosity of our partners, donors and fundraisers.

Whether you've made a donation, hosted a community fundraiser, joined the Big Red Roll & Stroll or partnered with us, your contribution is creating lasting impact across our community.

Thank you for making a difference!

975

donors

146

fundraisers

$1,251,925

raised from fundraising activities

SUNDAY SOIRÉE: Inaugural Event Raises $78,224

On Sunday, March 23, we were honoured to welcome partners, donors and friends – both longstanding and new – to our inaugural Sunday Soirée.

Graciously hosted by the Montrone family, the afternoon buzzed with warmth, connection and a shared purpose: supporting young people living with neuromuscular conditions. The event raised an incredible $78,224, reflecting the kindness and commitment of our supporters.

Guests were invited to hear firsthand about our programs such as Young Adults Retreats, NDIS Support Coordination, the Duke of Edinburgh Award and accessible social activities. Robert Fraser, Michelle Ball and Tait Jenkins shared powerful stories about their experiences with MDNSW.

Our Senior Community Support Specialist, Carolyn Campbell-McLean, was MC, guiding the afternoon with humour, warmth and grace.

A highlight of the event was an address from Her Excellency the Honourable Margaret Beazley AC KC, Governor of New South Wales and Patron of MDNSW, who spoke of our lasting impact and the bright future ahead.

With a silent auction, raffle and very popular ‘wine wall’ there was plenty of laughter and connection.

To everyone who attended, donated or lent a hand, thank you. Your support helps young people living with neuromuscular conditions truly thrive.

We can’t wait to see you again in 2026.

Special thanks to:
- Felice and Miranda Montrone
- Machiavelli’s Italian Restaurant
- Verve Photography
- Sydney Princess Cruises
- Pearson’s School of Floristry
- Huntington Estate
- Mudgee Wines
- Eling Forest Winery
- Australian Vintage Wines
- Freeman Vineyards
- Dawning Day Farms
- Hollydene Estate
- Mudgee Wine Association

> *It's a way for the community to come together. It's one place where we're all going 'Yeah this is a part of our lives.' Let's recognise it. Let's have a bit of fun and let's raise some money.*

Big Red Roll & Stroll

The Big Red Roll & Stroll is our annual community fundraising event, raising funds and awareness for people living with neuromuscular conditions.

On 10 May 2025, the event took over Sydney Zoo for the first time, attracting record-breaking numbers in both registrations and funds raised. Participants rolled, strolled and raced the 3km loop through the zoo, spotting animals along the way.

This year's event supported our Young Adults Retreat program, helping more young people experience freedom, flexibility and connection through a supportive weekend away.

Now in its fifth year, Big Red Roll & Stroll has raised over $317,600 and brought together hundreds of participants from across the community.

Thank you to everyone who took part, donated or cheered us on. You're helping create a world where people living with neuromuscular conditions can live the life they choose. And a special thanks to Sydney Zoo for generously hosting us.

We can't wait to make Big Red Roll and Stroll 2026 even bigger and better!

$92,600

raised

180+

participants

Donors and Fundraisers

Awards Night Raises $51,000 for Summer Camp

In October 2024, the Australian Fund Managers Awards Night brought together leaders from across the finance industry. MDNSW was honoured to be chosen as the Pledge Charity of Choice, with all donations on the night going towards our Summer Camp program. An incredible $51,000 was raised to help kids living with neuromuscular conditions enjoy a week of independence, adventure and connection at camp. Our gratitude to by everyone who donated.

The Dick and Pip Foundation: Backing Camps That Change Lives

Thanks to the generous support of the Dick and Pip Foundation, MDNSW is delivering safe, inclusive and empowering camps for young people with neuromuscular conditions. Their contribution is helping us train volunteer carers, replace essential equipment and provide the individual support each camper needs to thrive.
We're deeply grateful for their ongoing partnership and belief in our work.

Premer Pub Annual Fundraiser Raises $30,000

In the small town of Premer, big things happen for a great cause. Locals Darky and Jo once again hosted their annual Sheep Shear Fundraiser at the Premer Pub. It was complete with a shearing contest and auction featuring unique memorabilia.

Their efforts – supported by a generous and spirited community – raised $30,000 for our work. A huge thank you to Darky, Jo and the Premer Pub community for their ongoing dedication and generosity.

Owen Takes on the Nepean Half Marathon for His Son

At age 72, Owen ran the Nepean Half Marathon in a show of love for his son, who lives with myotonic muscular dystrophy. Training with purpose and grit, Owen completed the 21.1km course in just over two hours. He raised more than $6,000 for MDNSW. His determination and compassion remind us that together, we can support families living with neuromuscular conditions and bring them closer to the care and resources they need.

> ***“ It was one of the hardest things I've ever done. But I didn't stop. I knew if I did, I might not get going again…Hopefully I can make a difference. My hope is that one of the dollars I raise moves the research closer to a cure.***

Camp Carers Make Waves for MDNSW

Our community is filled with extraordinary people – like our Camp Carers. These volunteers give their time to create unforgettable camp experiences for kids – and then roll up their sleeves to fundraise too. This year, three of our return carers – Paityn, Oscar and Blake – formed the Pink Caps and Swimming Laps team and dived into the Cole Classic. They swam 2km from Shelly Beach to Manly Beach, raising over $1,100.

> ***“ There's something so rewarding about seeing campers grow in confidence and independence, participate in activities they may not otherwise experience, make lasting friendships and just enjoy being kids and having fun. To know you've played even a small part in the memories they make is a privilege.***

Corporate and Philanthropic Partners

We're deeply grateful for the supporters who make our work possible. In particular, we acknowledge the generosity of our major donors.

- CommBank Staff Foundation
- Dick & Pip Smith Foundation
- Felice & Miranda Montrone
- Hearts and Minds Investments Limited
- Heather Johnston
- Ian Williams
- Premer Hotel
- Robert Fraser
- Save Our Sons
- The Marian & E.H. Flack Trust
- The Tradewind Foundation
- Vinva Foundation
- Wales Family Foundation

Government Funding

National Disability Insurance Agency

- Peer Support and Capacity Building

Department of Health, Disability and Ageing

- Information Linkages and Capacity Building

Department of Communities and Justice

- Disability Advocacy Futures Program – Representative
- Disability Advocacy Futures Program – Special Projects

Volunteers

Volunteers are essential to all we do at Muscular Dystrophy NSW. This year, their generosity of time, care and spirit continue to make a difference for people living with neuromuscular conditions.

From lending a hand at community events to providing support as camp carers, volunteers helped create spaces of belonging, confidence and joy. Their contribution continues to strengthen our neuromuscular community.

73

volunteer camp carers

24

return volunteer camp carers

> ***I always look forward to coming back to camp. I've had a lot of memories, new friends. I think it's just such a rewarding place to be. You get a really good insight into what life looks like for these kids, as opposed to a clinical setting or a hospital setting.***

> ***The work I do... is really important to me because the kids get to be as independent as possible with our support.***

Thank You

Life Members

Keith Allen
Rhonda & Robert Murray
Carolyn Campbell-McLean
Martin Dalrymple
Ian Williams
Kristi Jones
Heather Johnston
Peter Debnam
Shannon Finch
Alastair Corbett
Jacqueline Morgan
The late Graeme Morgan
The late Percival Baptiste
The late Bruce Ellison
The late William Harding AM
The late Rick Arnheim

Community Partners

Australian Powerchair Hockey Association
Boccia NSW
Health Consumers NSW
NSW Powerchair Football Association
Physical Disability Council of NSW
Rare Voices Australia

Volunteers

Alicia Allan
Alisha Illarramendi
Allyssa Hansen
Alyson Parker
Alyssa Di Guglielmo
Amelia Martens
Amy Wood
Amy Moss
Ananya Nand
Angela Short
Blake Greuter
Chelsea Wood
Chelsea Hall
Chloe Jones
Christine Henderson RN
Daniel Mora
Danielle Lore
Divaanshi Chand
Eliza Gothard
Ella Frost
Ella Crossley
Ella Scerri
Eloise Stone
Emily Ralph
Emily Pascoe
Emma Sole
Emma Duncan
Felicity Chard
Georgia Stamatopoulos
Hannah Thorpe
Indra Ventura
Isabelle Maxwell
Izzi Harman
Jasmine Lindley
Justine Clout RN
Kadyn Judd
Kaitlyn Eyre
Kate Creighton RN
Kirrilly Moore
Kirthana Parbhoo
Kristie Gibbons
Kyle Souvleris
Kyleisha Ferguson
Lachlan Schneider
Lachlan Scales
Lilly Martin
Lori Webb
Lucy Corke
Maddison Healey
Maddison Harvey
Madeline Watson
Madison Ring
Massara Al-Mafrachi
May Panlee
Mikayla Patterson
Nicholas Gayed
Nina Flowerday
Olivia Papadopoulos
Olivia Heanly
Olivia Tommerup
Oscar Cavalletto
Paityn Garner
Rachel Torres
Rebecca Ayton
Renee Bugeja
Revathy Sawalha
Rhiannon Nosworthy
Samuel Larter
Sidney Mahinya
Sophie Zacher
Sophie Cole
Stephanie Triantis
Stephanie Charalambou
Tej Kehal
Victor Ho
Zara Christensen

Our Team

Behind every service, event and program at Muscular Dystrophy NSW is a team of passionate professionals. They're committed to empowering, connecting and supporting people living with neuromuscular conditions.

Jessica Henry
Chief Executive Officer

Angelito Escalada
Finance and IT Manager

Gracia Selina
Shared Services Coordinator

Milvia Harder
Quality and Operations Manager

Prue Steel
Fundraising Manager

Mimi Kilbey
Community Fundraising Specialist

Patrick Roberts
Relationships Manager – Strategic Philanthropy

Allyce Rui
Service Delivery Manager (Parental Leave)

Andrew Grant
Service Delivery Manager

Jenny Smith
Outreach Coordinator

Carolyn Campbell-McLean
Senior Community Support Specialist

Laura Howard
Senior Community Support Specialist

Ganesh Kakani
Senior NDIS Support Coordinator

Stephanie Caldwell
NDIS Support Coordinator

Madalyn Busby
Marketing and Engagement Team Lead

Katherine Wakeling
Marketing and Engagement Coordinator

Our Board

We extend our gratitude to the Board of Muscular Dystrophy NSW for their dedicated leadership, guidance and governance. Their oversight ensures that everything we do remains aligned with strategic goals while upholding all legal, financial and audit obligations.

Robert Fraser
President

Michelle Ball
Vice President

Tait Jenkins
Director

Prof. Michelle Farrar
Director

Prof. Alastair Corbett
Director

Nathan Teong
Director

Mark McCoy
Director

Susanna Montrone
Director

Harvey Blackney
Director

Financials

Muscular Dystrophy NSW continued to invest in our programs, fundraising and systems. These strategic decisions resulted in a loss of $609K for the year.

The loss reflects a combination of factors. Cost-of-living pressures affected the size of some donations. Our new fundraising strategy was in its first year of a five-year plan and needs more time to deliver full results. We also opened a new office in Concord to improve team collaboration and upgraded our customer relationship management system. As a result, expenditure for the year was $2.3m, up 14% from 2024.

Income for the year was $1.74m, up 14% from 2024. The second half of the year showed early signs of success for our fundraising strategy. We secured several significant grants, held our first Sunday Soirée fundraising event, and ran our largest Big Red Roll & Stroll to date. These activities, alongside our ongoing service delivery, will continue to support the sustainability of our organisation.

We hold reserves of $1.75m, providing a foundation to respond to future challenges.

The 2025 financial statements have been audited by McCarthy Salkeld Audit. An unqualified audit opinion was issued. Copies of the audited statements are available on our website:

Financial Statements

	2025 ($)	2024 ($)
REVENUE		
Revenue from fundraising activities	1,251,925	1,112,941
Financial and other income	485,812	411,306
Total income	**1,737,737**	**1,524,247**
EXPENSES		
Fundraising direct expenses	383,280	401,627
Fundraising indirect expenses	193,197	143,785
Client service provision expenses	1,352,208	1,190,757
Administration expenses	363,234	311,661
Depreciation and amortisation expenses	55,052	17,310
Total expenses	**2,346,970**	**2,065,140**
NET PROFIT/(LOSS)	**(609,234)**	**(540,893)**
Other comprehensive income	103,087	56,480
TOTAL COMPREHENSIVE INCOME/(LOSS) FOR THE YEAR	**(506,147)**	**(484,413)**

	2025 ($)	2024 ($)
ASSETS		
Current assets		
Cash and cash equivalents	1,572,174	1,889,979
Trade and other receivables	29,742	72,126
Other assets	100,908	73,889
Total current assets	**1,702,825**	**2,035,993**
NON-CURRENT ASSETS		
Financial assets	733,091	612,644
Property, plant and equipment	50,610	19,336
Right of use assets	79,124	17,733
Intangible assets	116,459	123,661
Total non-current assets	**979,283**	**773,374**
Total assets	**2,682,108**	**2,809,367**

	2025 ($)	2024 ($)
LIABILITIES		
Current liabilities		
Trade and other payables	73,307	69,127
Employee entitlements	184,693	172,802
Lease liabilities	26,021	6,864
Other liabilities	556,582	245,020
Total current liabilities	**840,604**	**493,813**
Non-current liabilities		
Employee entitlements	36,878	48,839
Lease liabilities	57,743	13,684
Total non-current liabilities	**94,621**	**62,523**
Total Liabilities	**935,224**	**556,336**
NET ASSETS	**1,746,884**	**2,253,031**
Retained earnings	1,746,884	2,253,031
TOTAL EQUITY	**1,746,884**	**2,253,031**

> “
>
> *The best part of camp was having fun with friends and all the fun activities. I enjoyed the independence being away from family and making new friends.*

How you CAN HELP

You can support people living with neuromuscular conditions and their families build strength and reach potential. Whatever you can do – big or small, once or regularly – will be truly valued and appreciated.

Donate
Your gift helps people with neuromuscular conditions access programs, care and connection to thrive.

Fundraise
Rally your community through a bake sale, challenge, event or your own idea to help strengthen services.

Partner with Us
Join us to expand opportunities that transform lives across our community.

Volunteer
Share your time and skills to connect, support and make a lasting difference.

MUSCULAR DYSTROPHY NSW

YOUR NEUROMUSCULAR SUPPORT COMMUNITY

www.mdnsw.org.au

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