

**MUSCULAR
DYSTROPHY** **NSW**

2021-22

Impact Report



Your
NEUROMUSCULAR
Support
COMMUNITY
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At Muscular Dystrophy NSW, we know you want to live the life you choose.

To do that, you need information on your neuromuscular condition, support programs, NDIS services, and a community that gets you.

It can be hard to find other people who have your condition, and service providers who understand your specific needs. Which can leave you feeling even more alone and unsupported.

We believe people with neuromuscular conditions deserve specialised support, and a community that understands them.

That's why for over 60 years, we've connected people across NSW living with neuromuscular conditions to the support programs they want, and the community they need.



We acknowledge Aboriginal and Torres Strait Islander peoples and communities as the Traditional Custodians of the land. We recognise the strength and resilience of Aboriginal people, and we pay our respects to Elders past, present and future.

Muscular Dystrophy NSW is committed to cultivating inclusive environments for all. We celebrate, value and include people of all backgrounds, genders, sexualities, cultures, bodies and abilities.



Contents

Welcome from the President & CEO	6
A Message from our Patron	8
Who We Are	10
Our Services	11
Our Community	12
Our History	13
Kobe's Story	14
Our Impact	15
FY2021-22 Highlights	16
Big Red Roll + Stroll	17
Adventure Camp	18
Young Adults Weekend	19
Peer Connect Program	20
Peer Connect Retreat	22
Sugar Free September	24
Neuromuscular Information & Research Day	25
Mums' Retreat	26
The Covid Collective	27
The Coogee Surf Life Saving Program	28

MDNSW PhD Scholarship 2018-2021	30
Our Partners	32
Hireup	32
Australian Neuromuscular Disease Registry	33
Tribute to Robert Lamb	34
Celebrating Our Team	36
Our Staff	36
Our Board	37
Our Patron	37
Our Life Members	38
Our Volunteers	38
Financials & Audit Report	39

Welcome

from the President & CEO

What an honour it has been to continue to serve the neuromuscular community this year.

As you know, there have been many challenges over the last 12 months as we've continued to navigate the Covid-19 pandemic, as well as multiple flooding disasters, which have resulted in the cancellation or rescheduling of some face to face programs.

Whilst these decisions are difficult and have been disappointing for everyone, the safety of our community remains our number one priority.

When faced with challenges, it is important to reflect on what you have been able to achieve. Our team recently took time to reflect on the values of the organisation: Empowerment, Responsiveness, Integrity, Collaboration, Respect and the many wins we've had over the past year, a few of which we would like to share with you below.

Empowerment:

This year we have continued to boost our engagement with members in regional NSW through our online Peer Connect groups. By continuing to utilise technology, Peer Connect has provided opportunities for connection across our community both online and in person. We are working to secure ongoing funding for Peer Connect, so that we can continue to deliver this popular program. Peer Connect has made such a big impact for so many in our community, by supporting them to empower each other, share their lived experience and providing connection to others who just get it.

Peer Connect via Zoom



Responsiveness:

The team have been working diligently over the last 12 months to develop our internal capacity by upgrading our contact database, a project which is ongoing and due for completion in early 2023. Alongside this, we've transitioned to cloud-based systems which allow for more flexible work in a hybrid environment and support the delivery of online training modules for our student volunteers. These important updates allow us to remain responsive to changes in the sector and NDIS. It ensures that our systems are contemporary, support excellence in service delivery and aim to improve the experience of our members!

Integrity:

We've been working to increase engagement with members across NSW through our online communications, including our monthly Talking Point e-newsletter and sharing updates via our multiple social media channels. We are committed to keeping our community up to date on disability sector news, research updates and sharing stories of the achievements of people in our community.

Collaboration:

We saw the successful roll out of the Coogee Surf Life Saving program, where three young MDNSW members gained qualifications in radio operations. This initiative saw the three lads become the first patrolling club members who use power wheelchairs for mobility. This is a huge step forward for accessibility and inclusion in Australian beach culture and a partnership that we are very proud of!

Respect:

We consulted with our team, Board and members of our community to refresh our brand and update our tagline to "Your Neuromuscular Support Community" - an important update which more accurately reflects who we are and what we do! We are grateful to all involved, who have helped ensure that our brand is a true reflection of your neuromuscular community.

We would also like to acknowledge our donors and funders who have contributed so much over the last year, we can't thank you enough for your support and endorsement of our work. To the late William Harding for the generous bequest which has made an incredible contribution to the financial sustainability of the organisation. It has further enabled our ability to innovate and continue to improve so that we can be an effective advocate and deliver on our mission to empower, connect and support people with neuromuscular conditions.

Looking forward, we'll continue to look at ways we can best deliver safe and impactful services to our community, while managing the ongoing safety, workforce and economic challenges in the wake of the pandemic.

Thank you to the MDNSW Board of Directors for your leadership, to our staff and team of volunteers who have remained flexible and committed during this period of intense change and challenges. We cannot do this without you, and we thank you for everything you do.

We hope you enjoy reading this report and seeing the impact of your contribution over the last 12 months.



Anthony Ball
President



Charlotte Sangster
CEO

A Message from Our Patron

This time last year, we were beginning the slow process of emerging from months of lockdowns, restrictions, and disruption brought about by COVID. Although cause for celebration, this transition to 'living with COVID' brought with it new challenges and anxieties, particularly for those, like many in the neuromuscular community, at increased risk of severe COVID symptoms. Added to this mix have been the devastating impacts of the floods and their aftermath, which continue to this day.

Through all these challenges, Muscular Dystrophy NSW has continued to do what it has done so well for more than 60 years, providing vital information, support, and community for people living with neuromuscular conditions throughout NSW. I congratulate the team for their efforts, their proactive flexibility, and their hard work. I also offer the deepest of thanks to our extraordinary neuromuscular community. Your resilience and support for one another remains, despite all the recent challenges, is nothing short of awe-inspiring.

An enormous 'well done' to everyone for the success of this year's Big Red Roll Stroll – the second ever. It was encouraging to see so many people registering and getting out to raise awareness and funds. Hopefully, next year will be even bigger, and the Muscular Dystrophy NSW family can finally get together at Parramatta Park to celebrate.

This year's annual Sugar Free September challenge was also a triumph – over \$200,000 raised – not only promoting healthy food and lifestyle options (the wonderful sugar-free recipes were particularly appreciated), but also raising critical funds for the many services and programs Muscular Dystrophy NSW provide. Congratulations to the team and thanks to the many participants, donors, partners, community ambassadors, and staff involved.



**Her Excellency the Honourable
Margaret Beazley AC KC**

In other good news, Muscular Dystrophy NSW's face-to-face Peer Connect retreats have recommenced, and community members are again able to catch up with old friends, make new ones, relax, and rejuvenate together. I know there are some particularly excited young people looking forward to December's Summer Camp!

In the virtual space, Peer Connect's online events and groups continue to facilitate peer-to-peer support and the sharing of wisdom, laughter, and knowledge. In the Peer Collective, members continue to contribute personal journeys and stories – everything from the frustrations of carer and support worker shortages and accessing PPE and RATs, to the latest tips, recipes, and jokes.

As proud Patron, I thank Muscular Dystrophy NSW, for all you have achieved this year in helping people 'live the life they choose' and wish you, and everyone in the wonderful community you support, the very best for the upcoming festive season and the year beyond.

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

Campers hanging out at Adventure Camp, Collaroy Beach



Who We Are

Our Services

At Muscular Dystrophy NSW, we know that a diagnosis or a change in your condition can make you feel anxious and alone.

That's why we're here with information, support programs and a community that's tailored to your needs at every step of your journey.

We've been part of the NSW neuromuscular community for over 60 years. For you, this means:

- Specialised support and services
- Respect for your specific needs
- Planning for your future as your condition changes

Which means you can feel less alone and anxious for the future, knowing we'll be here with the support and community you deserve, at every stage of your life.

You can download our Organisation Overview from our website for further information about who we are and what we do.

Everything we do comes back to our Vision, Mission and Values.

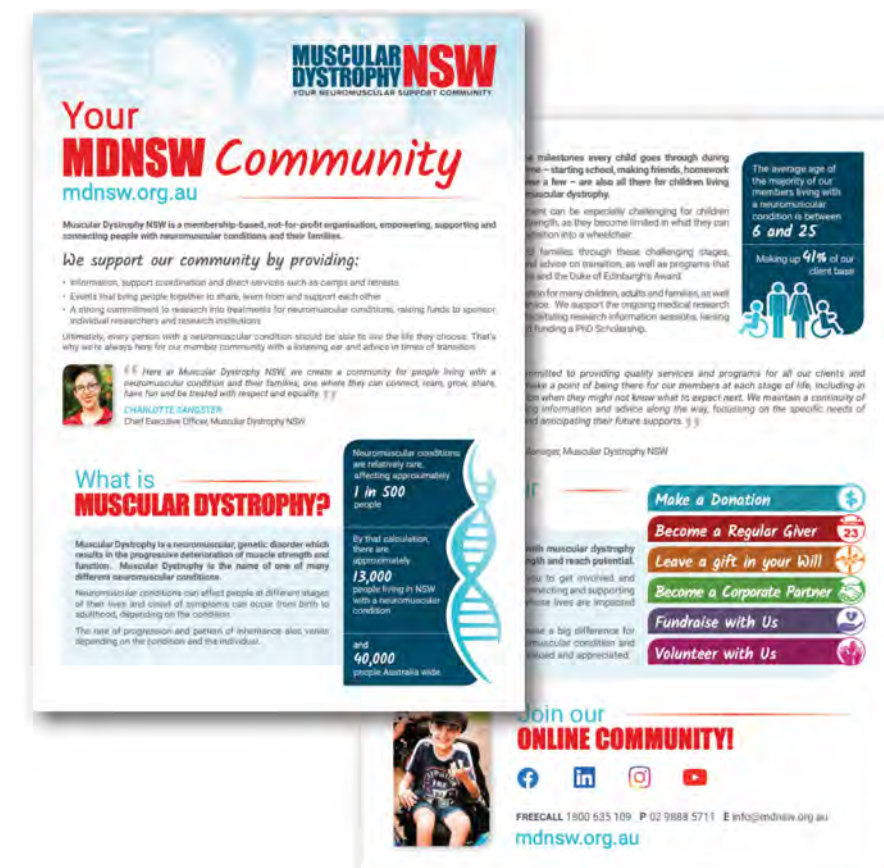
Our Mission is to empower, connect and support people with neuromuscular conditions, and be an effective advocate for the neuromuscular community.

Our Vision is for every person with a neuromuscular condition is able to live the life they choose.

We believe that people living with neuromuscular conditions have the same rights as others to live the life they choose; have relationships, work, enjoy hobbies and interests and live a life free from abuse or exploitation.

Our Values:

- Empowerment and Responsiveness
- Integrity and Respect
- Partnerships and Teamwork



“Here at Muscular Dystrophy NSW, we create a community for people living with a neuromuscular condition and their families; one where they can connect, learn, grow, share, have fun and be treated with respect and equality.”

Charlotte Sangster
CEO



MDNSW has over 2,000 members that make up a community of people living with a neuromuscular condition, their carers, family members, health professionals, and board directors. Across Australia, there are an estimated 40,000 people living with a neuromuscular condition, 13,000 live in New South Wales.

Ultimately, every person with a neuromuscular condition should be able to live the life they choose.

That's why we're always here for our member community with a listening ear and advice in times of transition.

Our Community

Neuromuscular conditions are relatively rare, affecting approximately
1 in 500
people

By that calculation, there are approximately
13,000
people living in NSW with a neuromuscular condition

and
40,000
people Australia wide

The average age of the majority of our members living with a neuromuscular condition is between
6 and 25

Making up **41%** of our client base



Did You Know?

For more than 65 years Muscular Dystrophy Association of NSW (MDNSW) has been serving the neuromuscular community of NSW.

Back in 1957, we commenced operation as a specialist support group within the Society for Crippled Children, now known as Northcott Disability Services. There was a need for a separate entity to be established to better focus on the specific and high support needs of those living with neuromuscular conditions (NMC). The community of members living with NMCs, and their families, were instrumental in seeing this change come to fruition.

On 1 July, 2000 MDNSW was endorsed as a Charitable Institution with DGR status.

In 2009, MDNSW transitioned to a not-for-profit company limited by guarantee.

In the early days, all of MDNSW's work was voluntary and completed by committed family members. The Association operated from offices in varying locations across Sydney for many years, before moving to the Multiple Sclerosis building in Lidcombe, Sydney in 2017.

During the pandemic, we transitioned to a hybrid workplace with a "home base" office for staff located within a co-working space in Parramatta.



Kobe's Story

“ I think we can all agree that 2021 wasn't a great year. Covid 19 really limited our movements, brought periods of isolation, and fears for the future.

But that's a lot like every other year for someone like me with muscular dystrophy. Still, I have a lot to be grateful for.

My name is Kobe, I'm 20 years old and live in a small rural area called Jaspers Brush, 2 hours south of Sydney. I don't know anyone who lives close by with muscular dystrophy, so when I joined Muscular Dystrophy NSW's (MDNSW) Summer Camp in 2013 it opened up my world.

Initially, it was daunting to leave my family, but camp quickly became one of the only places where everything felt normal.

At camp I noticed most kids didn't even talk about living with MD because it was something we all shared, so we didn't need to explain ourselves. This was a time I could just have fun, and the incredible memories and best friends kept me going back every year.

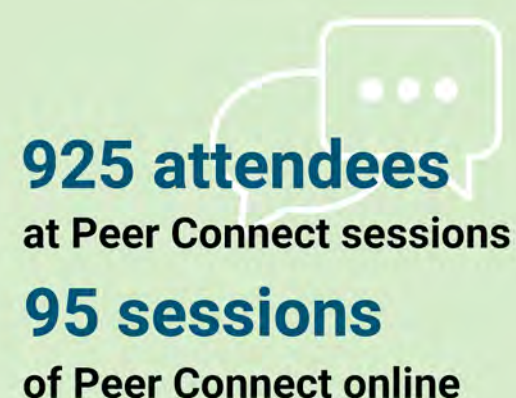
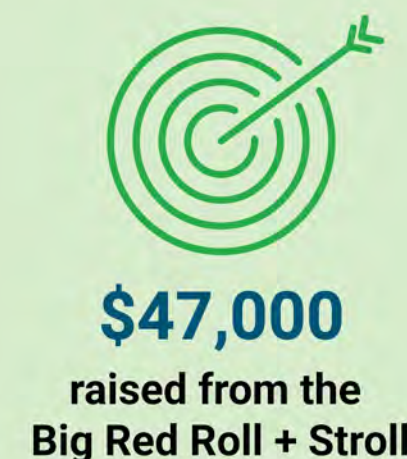
Since aging out of Summer Camp I've looked forward to seeing my mates at the annual MDNSW Young Adults Weekend. We didn't get to meet up in 2020, so I was grateful to catch up in the Hunter Valley in March. It felt great to travel, learn some independent living skills and eat some cheese from the Smelly Cheese Shop, which wasn't even that smelly! The best part was being surrounded by my friends, mates who just get each other. When we're together it's like our situation doesn't matter; we play games and just be ourselves.

Throughout the pandemic it's been difficult to stay connected. Which made me grateful that MDNSW created an online group called the Power Hour for all of us guys in power wheel-chairs to catch up virtually every fortnight. It's a chance for people in the same boat to hang out, just the guys, and have some light-hearted fun... including a few bad jokes! It's also a place where we feel safe to share our feelings.

Having MDNSW adapt their programs online was especially important to me as I live in a rural area and worry about missing out. Power Hour also motivated my mates to show up, and we even had a friend living in Europe dial in! During the toughest lockdowns we asked to increase our fortnightly sessions to weekly, and it became the time I look forward to the most.

Next year will hopefully be better for many of us as the restrictions lift, but one thing I know for certain will stay the same is the strong community and support from MDNSW.”

Our Impact





Bridget, Carsten and their son James Larsen participated in Canberra

FY 2021-22 Highlights

Despite once again having to change the Big Red Roll + Stroll to a virtual event, this time due to the Covid-19 pandemic, our MD community once again rose to the challenge and impressed us (as always) with your creativity and spirit.

Individuals and teams all got out and about in their red, white and blue and celebrated our neuromuscular community – raising more than \$47,000 to support MDNSW's services and programs.

A BIG THANK YOU to everyone who supported the event and made it possible, including:

Top Individual and Team Fundraisers

- Natalie Macaulay - raising \$3,731
- SMArties & Friends Team - raising \$18,986

Community Ambassadors

- Roisin O' Hagan & her son Patrick
- Carolyn Campbell-McLean
- James Dunstan
- Scott Green

Partners

- Hireup
- Kids Neuroscience Centre
- Housing Hub
- Physical Disability Council of NSW
- Winston Hills Lions Club

Big Red Roll + Stroll



SMArties Team



Team Mike's Muscles

Adventure Camp



John at his first Adventure Camp

Adventure Camp was the one and only Camp program we were able to hold in 2021-22 financial year, so everyone was so excited! In April, 15 kids living with muscular dystrophy aged between 7 and 16 headed to Collaroy for five fun filled days full of activities.

Campers challenged themselves by taking on a range of new activities on offer, including:

- High ropes
- Laser tag
- Raft building
- Boccia
- Kite making
- Paper plane throwing
- Card games and trivia
- Painting and Lego

For our youngest camper, and first timer, John (who is 7 years old and lives with Duchenne MD), Camp was a great experience! We asked him and his mum, Bryony, a few questions about it.

Q Was it scary going to your first camp?

John: No, it was exciting. I was a little bit nervous about meeting new people.

Bryony: I was a bit nervous as he'd not been away overnight without us before, but I knew he was in good hands.

Q What did you like most about camp?

John: Having special breakfasts and going to the beach.

Bryony: I liked that he would be with other kids with similar abilities and be given opportunities to do fun things he might not normally do. I saw it as an opportunity for growth and independence for John.

Q What was your favourite activity?

John: I liked building the raft because I liked helping and being part of a team.

Q Did you like the carers?

John: Yes because they were fun and looked after me and sat with me.

Q Do you think you will come back to camp?

John: Yes!



Lads out for a roll around Swansea

In May, six of our young male members living with MD set off up the coast for a weekend of catching up with each other, increasing their independence and sharing a laugh and a good time.

Collectively they planned their menu and tried their hand at cooking with their favourite recipes.

Opting for a more contained trip, they spent the time playing board games, watching some critical sporting matches and going for strolls along the waterfront.

After much deliberation we have finally landed on a new name for this inaugural trip: 'Lads by the Lake.'

Young Adults Weekend

Peer Connect Program

As we continued to navigate our program offering through the high risk environment of the Covid-19 pandemic, our online Peer Connect program remained a constant source of connection and support for our neuromuscular community.

We were lucky enough to hold some programs face-to-face, like our Taronga Zoo Family Day Out and our International Women's Day Picnic, which was so lovely.

All in all, we held 95 Peer Connect sessions throughout the year, which had 925 attendees in total!

International Women's Day Picnic



Taronga Zoo Family Day Out



The Peer Connect program is all about ensuring our members are empowered throughout life stage changes, through connecting with others with similar lived experience. Hearing about other people's journey and their experiences can make people feel like they are not alone. If others have had success, they feel more confident and motivated to try new things. Peer connection is powerful!

Topics our online sessions covered throughout the year have included:

- Getting Started with Support Workers
- Looking for Love
- Understanding your rights and making complaints
- Holiday in Your Backyard
- Make the Most of Your NDIS Plan
- Health and Wellbeing
- Independent Living and Support
- Spooky Trivia
- Springo Bingo
- Family Fun Night
- Adult Games Night
- Christmas Party

When surveyed, participants rated the program an overall 4.6 out of 5 stars!

And they told us that they experienced a variety of benefits, including:

- Information
- Learning from experience of peers, sharing ideas and problem solving
- Feeling connected and less alone
- Social contact / fun especially during the pandemic
- Skills building, leadership development and opportunity to be influential in the community

"The meeting was enlightening, informative and inspiring. It was so great for my son to be able to meet others with the same disability and I was so proud of him participating and sharing his issues."

"I am very physically isolated living where I do, especially from other people with FSHD. I don't get much support close to home, but I get good support in this group! Everyone has similar issues and we are learning all the time from each other."

"Enjoyed the meeting, good to connect with other people who are grappling with similar issues, to talk with others who just get you!"

Quotes from Peer Connect Participants

YOUR SAY ON PEER CONNECT



80%

HAVE INCREASED THEIR KNOWLEDGE AND SKILLS

86%

FEEL MORE CONFIDENT AND MOTIVATED



91%

FELT THEIR CONTRIBUTION WAS VALUED



100%

WOULD RECOMMEND PEER CONNECT TO OTHERS



93%

MADE USEFUL CONNECTIONS

"I like being able to talk about our experiences with others who share a lived experience"

Peer Connect Retreat

This year's Peer Connect Retreat was held at the Rydges Hotel on the Newcastle Waterfront from May 20–22. The weekend kicked off with meet and greet drinks in the hotel bar 'Wharf 350'. In addition to the six couples who stayed the weekend, our Welcome Dinner was also attended by eight Hunter locals. This was a wonderful opportunity to reconnect with old friends and meet some new folks. One couple came on their first MDNSW event all the way from Dubbo and took the opportunity to leave their teenage kids at home!

The three-course meal was divine, and the conversation and wine flowed freely. During the evening we played a game of 'Find Someone Who...' which was a nice way to get to know each other and tell a few stories. At the end of the evening, we formed a sharing circle where each person shared their gratitude and their plans for the weekend. There was an overwhelming sense of appreciation of being together again.

After a delicious Saturday big breakfast and lots of chatting, the group visited the Newcastle Museum and had some whimsical fun at the 'Alice in Wonderland' interactive exhibit, the BHP show and photography exhibitions. As soon as we left the museum, a parade of Variety Club Big Bash cars beeped and honked their way past. A few of the group took their chances with a break in the weather to roll on down along the waterfront, but it wasn't long before the rain was falling again, and we were ducking under cover and donning our ponchos.

A lunch stop at Harrys Café de Wheels and a drink at the Queens Wharf Hotel was a great adventure. A few couples explored further afield, and some took the chance for a relaxing afternoon nap, before the group reconvened for a fun games and 'craft'ernoon activities.

Saturday evening was an informal group dinner at 'The Landing Bar and Restaurant'. After an in-depth discussion about the functionality and availability of straws these days, the group retired to the lounge to enjoy solo guitarist entertainer Andy, who had an excellent repertoire of pop rock hits.

It wasn't long before Lisa, Leah and Carolyn were tearing up the dancefloor! We had all forgotten there was an election result in the balance. On the way back to the hotel a small group rendezvoused on the waterfront for an NDIS debrief, sharing their challenges, frustrations and successes. As it happened two of the participants work for the NDIS!

After another chatty brekkie and delicious corn and zucchini fritters, yoghurt and fresh fruit, the group played trivia over coffee and gave feedback on the weekend Retreat. One couple kindly shared their Persian sweets and the first comment was "When's the next one?!"

Written by Carolyn Campbell-McLean
Peer Connect Program Coordinator



The group at the Welcome Dinner



A lovely roll in the rain along the Newcastle waterfront

"Thank you to MDNSW for hosting the Peer Connect Retreat. Brendon and I always look forward to this event to meet up with other 'mature aged' fellow MD warriors. I only wish there were more events like this over the year. I would put my hand up for more for sure. Thank you again. Great networking, great venue and gracious hosts. Perfecto!"

Margaret Young
Peer Connect Retreat Attendee

Sugar Free September



Despite it being an especially tough year with lockdowns across the country, **1,400 amazing challengers** raised \$215,000 to support the MD community - absolutely incredible!

Some of the highlights included stories shared by our Community Ambassadors, Nathan and George, the Jones Family, and the Smith family, as well as the great awareness raised by our Ambassadors Shannan Ponton, Botille Vette Welsh and Ali Cavill.

Nutrition Australia NSW lead interactive Q+A sessions each week, shared helpful advice and even put on a few nutrition webinars. And everyone loved our very first Sugar Free September cookbook, made exclusively from challenger recipes!

A BIG congratulations and thanks to our top fundraisers for the 2021 Challenge Fara Touilii, raising \$11,781 and Team Sweet Nothings raising \$8,746.

The money raised will go such a long way; helping kids access our camps, mums connect through our retreats and online groups and helping both kids and adults build resilience through our 36 online Peer Connect Groups. Thank you for helping us create so many important opportunities for the neuromuscular community.

In October 2021, we held the MDNSW annual Neuromuscular Information and Research Day (NIRD), once again going virtual and getting a great turnout with people from all over the country attending.

The day kicked off with a keynote presentation from Prof. Monique Ryan and Robin Forbes on the updates in the world of clinical trials. They also provided information on the Australian Neuromuscular Disease Registry and the importance of getting involved.

The Plenary presentations to follow covered the important topics of Heart & Lungs from Cardiologist, Dr David Tanous, as well as Respiratory Care with Dr Amanda Piper.

Attendees then went into their selected breakout sessions, which focussed on SMA treatment (Assoc. Prof. Michelle Farrar, Paediatric Neurologist & Dr Christina Liang, Neurologist), Duchenne Update (Clinical Assoc Prof Kristi Jones & Dr Michelle Lorentzos, Sydney Children's Hospitals Network), and What can your neurologist do for you? (Assoc. Prof Lauren Sanders, Clinical Neurologist). It was great to have such informative speakers, experts in the field providing the medical answers to our questions.

One of the highlights of the day was the Lived Experience panel, with Jack, Lisa, Abraham and James, which led to some thoughtful conversations about empowerment and independence for people with neuromuscular conditions.

Huge thanks to everyone involved in making this event so successful!

Watch the recordings here!



SUGAR FREE SEPTEMBER

Go Sugar Free For MD!



Neuromuscular Information & Research Day

Mums' Retreat

A BIG thank you goes to the wonderful group of mums from our neuromuscular community who attended our Mums' Retreat in June 2022. We hope you all enjoyed your chance to get away, relax and connect with other mums who truly understand and can offer that important peer support.

After having to postpone this program multiple times throughout the year due to the Covid-19 pandemic and flooding, we were finally able to hold it at the picturesque Crowne Plaza Hawkesbury Valley – the perfect setting that our Mums needed with tranquillity and stunning scenery.

Our amazing group of Mums enjoying the retreat!



Ellie, member of The Covid Collective

The Covid Collective

Our story sharing platform, The Peer Collective, has grown over this past year with hundreds of stories from our neuromuscular community shared. Considering the times, we added a new section to the platform called, The Covid Collective, which is home to several articles from our community members and the media on the impact Covid-19 is having on their lives.

Here are some excerpts:

"I rang around all these government sites and my question was 'what do I do if I get COVID? Who is going to look after me? Do I need to go hospital? Will anyone care for me? I couldn't get any answers and it made me feel like shit, like a second-class citizen."

Ellie
'Omicron wreaks havoc on NSW's vulnerable'

"Living with a rare neuromuscular disorder that has slowly progressed over time, I know the need for planning ahead and adapting to make the most of a situation. Each time a symptom changes, I must recalibrate my 'normal'. This builds a level of resilience. However, no one could have foreseen or planned for the way this pandemic has affected our world."

Tayla
'In the midst of a pandemic, time is precious for those with a progressive condition'

"Day 5 – Feeling better. The hardest part has been coughing and stuffy nose while on BiPAP at night. (minimal but challenging). Sore throat lasting. Starting to scrapbook and journal so definitely on the mend. What a strange experience! So hard physical distancing from my darling Steve."

Carolyn
'Surviving Covid when you live with SMA'

Read these insightful stories and more at The Peer Collective on our website.



"Training to be a surf lifesaver was fun. I would love to go there again and be a part of the patrol."

-Jai

The Coogee Surf Life Saving Program

Last Summer, we partnered with Coogee Surf Life Saving Club (Coogee SLSC) for a NSW first, online training program, offering young people living with a neuromuscular condition the opportunity to become official volunteer Coogee SLSC Patrolling members, and hold a Surf Life Saving Award.

Patrick, Scott and Jai all joined the free program and completed three training sessions where they learned about radio operations (two online and one in person). The third and final session was held earlier this month where all three were assessed and successfully completed the course. They are now official members of Coogee SLSC!

It is hoped in the future they will be part of regular patrols, where they will be situated in the Surf Life Saving Club which looks over the whole beach and report via the radio on any issues they see like swimmers caught in rips or drowning.

"I would just like to say that I'm very proud to represent the community as a surf lifesaver as well as someone who has a disability and I think it is important for people to know that and how having a disability doesn't stop us from doing such things."

-Patrick

"Being part of the Coogee Surf Lifesaving Club has given me the chance to be part of the community. It's great to have an organisation so inclusive to people with physical disabilities such as muscular dystrophy. I would like to thank Muscular Dystrophy NSW and Coogee Surf lifesaving club for this opportunity."

-Scott



Patrick, Scott and Jai with the CSLSC Trainers and Mitch from MDNSW

MDNSW PhD Scholarship 2018-2021

Written by Sam Bryen
PhD Student



I work at the Kids Neuroscience Centre, part of Kids Research at the Children's Hospital at Westmead, in a team with many years of experience genetically diagnosing families with neuromuscular disorders. For the past 3 years MDNSW have supported me financially to complete my PhD degree, by providing me with the Sue Connor scholarship. I'm excited to announce that I have finally submitted my thesis in September 2021!

Our team has a cohort of 227 families with neuromuscular disorders, which were referred to us from clinicians in Australia and New Zealand. The families that are referred to us typically have already undergone many genetic tests that haven't revealed any answers. My PhD project focused on finding the genetic diagnosis for these undiagnosed families.

Specifically, I studied genetic variants that disrupt the cellular process of pre-mRNA splicing or "splicing variants" for short. Splicing variants are often missed by the standard genetic tests available for undiagnosed individuals with neuromuscular conditions. Therefore, by understanding how to better detect and interpret this type of genetic variant, we aimed to increase the diagnostic rates of neuromuscular disorders.

The work I did during my PhD helped to provide genetic answers for 51 affected individuals from 37 families, who presented with a range of neuromuscular conditions.

To find a genetic diagnosis for these families, our team collaborated with the Broad Institute of Massachusetts Institute of Technology (MIT) and Harvard in Boston. We sent DNA from our families to the Broad Institute, where they performed extensive genetic sequencing and provided us with large amounts of data to analysis. I spent many hours trawling through this data looking through the large numbers of genetic variants that each person has, searching for just the 1 or 2 variants that could be the cause of a neuromuscular condition.

Once we found a plausible candidate we would then aim to provide functional evidence to show that this was (or was not) the cause of a neuromuscular condition. By performing experiments in our lab that look at DNA, RNA and/or protein extracted from blood, muscle, and/or skin fibroblasts, we were able to show how these genetic variants could lead to a muscle or nerve defect, enabling a diagnosis to be established for these 37 families.

The genetic diagnoses provided had far reaching benefits for affected individuals and their families, often ending long diagnostic odysseys of 10+ years. Clinical management for affected individuals were often guided by genetic findings. For example, two affected siblings with congenital myasthenic syndrome were prescribed salbutamol, a treatment known to be effective for the gene we identified as causal, which significantly improved their mobility and quality of life. Family planning options also became available for some families. I found it incredibly rewarding to be able to help these families find genetic answers.

To date, we have diagnosed 56% of families in our cohort and finding the genetic diagnosis for the remaining families continues to be a major focus of our research (where funding allows). In time, the diagnostic approaches we have taken will become increasingly accessible to affected individuals with suspected inherited neuromuscular diseases as the cost-effectiveness and clinical utility are realised.

Already we are seeing increased availability of some of these sequencing technologies being used in standard diagnostic pipelines compared to when I first started my PhD.

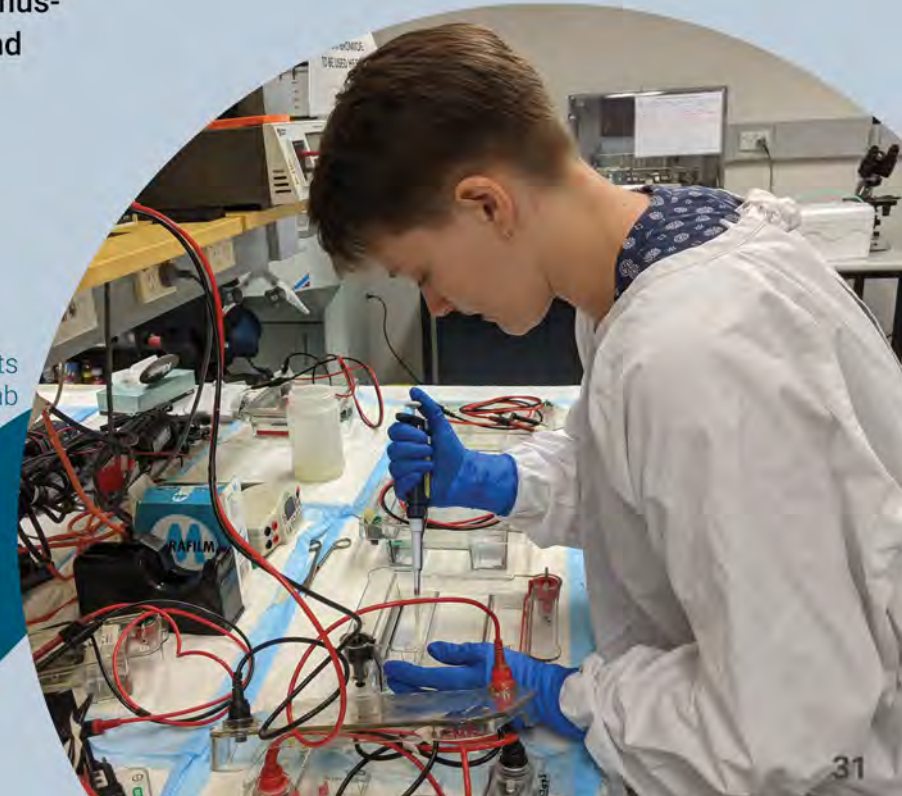
It is my hope that the work presented with my thesis will help pave the way for better detection and classification of splicing variants in the future.

Accurately identifying and classifying splicing variants will take us one step closer to providing a genetic diagnosis for every family with a suspected genetic disorder.

I am incredibly grateful for all the financial support provided by MDNSW that enabled me to complete this body of work. I would also like to thank MDNSW for inviting me to the Neuromuscular Information and Research Days which enriched my understanding and appreciation of the challenges faced by those living with neuromuscular disorders. I am honoured to have been given the opportunity to help this inspirational community with my research.

Thank you to the individuals and families in Australia and around the world who agreed to participate in this project.

Sam running tests
in the KNC lab



Our Partners

We officially announced our partnership with Hireup back in October 2020 and we were delighted to have them support us for another year in 2021.

Hireup is an organisation that shares similar values to MDNSW's of working to connect and support our communities, whilst improving outcomes for people with living with a disability.

Hireup is an NDIS registered online platform for people to find, hire and manage support workers who fit their needs and share their interests.

Members of MDNSW can sign-up to Hireup and receive their first 2 hours of support FREE!

You can learn more about the partnership and join Hireup by visiting hireup.com.au/partnership-mdnsw



Australian Neuromuscular Disease Registry

Starting in 2021 and continuing for three years, MDNSW and the Australian Neuromuscular Disease Registry (ANMDR) will partner to further the growth of the Registry and encourage our community to sign up.

The ANMDR is an Australia-wide registry of people diagnosed with a neuromuscular disease. It collects important medical information from adult and child patients across the country to improve the understanding of neuromuscular disease and accelerate the development of new therapies.

By having a database of patients with neuromuscular diseases, clinicians and researchers are better able to understand the underlying history of these conditions and how best to monitor and treat them. More immediately, recruitment into clinical trials, and finding clinics and services, will become more easily accessible through the registry hub.

Learn more about the ANMDR at www.australiannmdregistry.org.au

A Tribute to Robert Lamb

Written by Sharon Lamb

“ Bob and I met on 3 December 1966 at a Friday night dance for teenagers, I was only sixteen and had commenced a cadetship in Survey Drafting. Bob aged eighteen was also a Draftsman, so immediately I realised that we had similar interests. We also shared a love for social dances and competition tennis, and metal detecting and fossicking, which we pursued over the years. Sparks began to fly, so on 9 January 1970, we married.

Before we were married, I cannot remember missing a weekend together. We played competition tennis on the Saturday, and on the Sunday we would meet up with friends at the beach. During this time, we were both studying, at night, so our little secret rendezvous in the morning was so special.

In 1971 we moved into a new home at Seven Hills in Sydney. In 1973 our son, Craig was born and in 1975 our daughter Michelle arrived. During that time, our life was just so busy, meeting the demands of two growing children. I was a stay-at-home mother until 1981, when we decided to set up our own contracting business, with Bob as the Managing Director.

Things were going great until February 1985, when our lives would change for ever.

Bob had returned to work, after feeling quite relaxed after our annual camping holiday away. This was going to be the start of our life-changing event. Bob lost his memory at work, forgetting who he was, where he lived, and who he lived with. His colleague drove him to our local Doctor, who told Bob he was just stressed, however as Bob's faculties had returned to normal. He insisted that this could not be the case, so Bob had a brain CT the same afternoon.



Within a few hours, we received a call from a Neurologist who asked us to go to Westmead Public Hospital immediately. I drove Bob to Westmead and on arrival at the admissions area, Bob collapsed, and I thought that I was losing him then. Luckily, the Neurosurgeon was ready for him in theatre and after an exceptionally long operation on his brain he was sent to the Neuro Ward. Bob had suffered a most severe case of Hydrocephalus and required a shunt and valves to drain the fluid in his brain.

The ventricles in Bob's brain were the same size as duck eggs when they should have been the size of peas. His brain was about to implode, which would have killed him. Bob spent quite a bit of time in hospital because this condition had caused slight brain damage, mood changes, depression, and anxiety. He was now a changed personality, and it took a long time for all of us to cope.

We did survive this ordeal; however, it was our children, Craig (12) and Michelle (10), who found it difficult to accept that their fun-loving Dad had changed, and they had to be careful and not make too much noise around the house.

We were coping quite well until 1997, when Bob developed swallowing problems and eye lid drooping. He had been assessed during the next ten years for every muscular disease that was common in Australia and was told by a leading Sydney neurologist that he was a hypochondriac. After that comment Bob suffered a severe attack of depression which caused him to be admitted to a rehabilitation facility. There he learnt a few strategies to help him cope with his illnesses.

We had nearly given up seeking a diagnosis when we received a phone call from Bob's gastroenterologist, Professor Cook. He asked us to bring photos of Bob's parent's wedding photos. This seemed so strange. Professor Cook had travelled to Quebec Canada to a conference where there was a seminar on Ocular Pharyngeal Muscular Dystrophy (OPMD). He realized that Bob had all the symptoms of OPMD, so he referred him to the Genetics Clinic at Randwick Hospital, for a DNA test. Professor Cook suspected OPMD after looking at the eyes of Bob's mother, maternal grandmother, uncle and three aunts. They all had dropped eyelids, and a few had swallowing problems, which in 1944 were diagnosed as the aging process.

After an exceptionally fast 2 weeks, the results confirmed OPMD, an exceedingly rare muscular dystrophy disease. Bob was crying with happiness because the medical fraternity had eventually found a name for the symptoms that he had endured for ten years, and he now could prove that he was no longer a hypochondriac. Bob was the first person diagnosed with OPMD in Australia so doctors were practically queueing up to talk to him.

Bob's OPMD became active quickly, firstly his eyelids had to be anchored to his brow in about six operations, because they kept dropping over his eyes, causing him to trip, going up stairs. His muscles in the shoulders and legs were becoming weak and his throat was closing as the muscles were becoming affected. Soon Bob needed a PEG to be inserted in his stomach. He was now completely nil by mouth, using a bolus process. He progressed to a pump and bolus later.

We both had to learn to adjust to this change in our life. We had always had dinner parties, however because Bob could no longer put anything in his mouth, we all felt guilty eating in front of him. Although Bob had sudden mood swings, he was the life of the party, and a teller of funny jokes. He was fun and helpful at home. Bob and I would go everywhere together, even on a cruise circumnavigating Australia.

We moved to an RSL Independent Retirement Village in July 2014. We had a three-bedroom, two-bathroom, free standing house. It was designed for wheelchairs which we thought Bob may need in the future. We were the first ones to move into this amazing new village in the middle of cow paddocks, facing the magnificent Kurrajong Hills. Bob and I were so happy there.

On September 2018, Bob and I had a normal evening and went to bed about 10.30pm. At about 2am I woke up because Bob was choking. I got out of bed as quick as I could while calling his name. I could not wake him, and he was still choking. I rang Triple O and immediately the paramedic could hear him choking. I was trying to put the bed down so I could administer CPR to him, when Bob stopped choking and was breathing again. The Ambulance arrived and took him to Hawkesbury Hospital, where the nightmare started.

The staff at Hawkesbury Hospital were not familiar with Bob's medical complications, so he was transferred to Macquarie University Hospital. I visited Bob every day. Bob was once the life of the party and now he was like a broken man deprived of his retirement years. At first, he slowly faded away and then had a horrific death, choking. Craig, Michelle and I were by his side when he passed away on Saturday morning, 21 December 2018, at 12.30am. I had now lost the love of my life after 49 years of marriage.

We arranged Bob's funeral on Christmas Eve, and a church service on New Year's Eve. I expected that there would be about 50 people attending because of the busy time of the year. 150 people turned up on a very hot 40+ degree day. This showed how well he was liked and respected.

One regret that I have is that Bob and I never discussed where our ashes would end up. Bob loved history, so I arranged for his ashes to be interred in the collegium wall at the old historic church at Ebenezer, overlooking the fabulous Hawkesbury River. He loved it there.

Rest in Peace Bob. ”

Our Staff

2021-2022



Charlotte Sangster
Chief Executive Officer



Joan Martin
Client Services Manager



Alicia Ballesty
Communications & Engagement Manager



Angelito Escalada
Finance Manager



Zan Schmidt
Fundraising Manager



Milvia Harder
Operations & Quality Manager



Alex Marshall
NDIS Service Development Manager



Mitch Taylor
Client Programs Coordinator



Ganesh Kakani
Senior NDIS Support Coordinator



Carolyn Campbell-McLean
Peer Connect Program Coordinator



Jenny Smith
Client Services Administration Support



Chris Hastas
Administration Assistant



Gracia Selina
Finance Officer



Joyce Moretti
Community Fundraising Coordinator



Nuzaira Khaled
Donor Programs Coordinator



Henry Oboe
Support Coordinator



Roisin O'Hagan
Support Coordinator



Laura Howard
Client Services Coordinator



Anthony Ball
President



Richard Arnheim
Treasurer



Clinical A/Professor Kristi Jones
Medical Director



Kim Brislane
Director



David Kay
Director



Nathan Teong
Director



Stuart Uhlhorn
Director



Michelle Ball
Director



Christina Liang
Director



Laura Sheridan Mouton
Director



Shannon Finch
Director



A/Professor Michelle Farrar
Director



Tait Jenkins
Director

To read the biographies of our Board members, go to mdnsw.org.au/our-board

Celebrating Our Team

This year our staff had to deal with a lot of change. But they didn't let any of it get in the way of continuing to provide amazing programs and services for our community.

A BIG thank you also to our knowledgeable Board of Directors, our invaluable volunteers, our Life Members and Patron, Her Excellency the Honourable Margaret Beazley AC KC Governor of New South Wales. We would not be here without you all and are so grateful for your hard work, dedication and passion for helping people living with neuromuscular conditions live the life they choose.

Our Patron

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



Our Life Members

Dr. Jacqueline Morgan
Prof. Graeme Morgan
Dr. Heather Johnston
Keith Allen
Peter Debnam
Martin Dalrymple
Clinical A/Prof. Kristi Jones
Carolyn Campbell-McLean
Rhonda Murray
Robert Murray
A/Prof. Professor Alistair Corbett
Ian Williams
Shannon Finch

Vale Life Members

Helen Campbell-McLean
Dick Allen
William Harding
Percy Baptiste
Bruce Ellison

Financials & Audit Report

Our Volunteers

Donation Box Volunteers

William (Bill) McLean
Bryoni Macri
Robert Murray
Scott Green
Sandra Allen
Ewan Gemmell

Sugar Free September 2021 Volunteers

Abbey Schott - Designer
Zohal Arbabzada - Call Centre
Robert Gad - Call Centre
Emily Lee - Call Centre

Adventure Camp and Young Adults Weekend Volunteers

Alexandra Chrystie
Alexandra Robertson
Amy Benson
Blake Greuter
Caitlin Von Behr
Jasmine Gallardo-Bron
Jasmine Lindley
Lauren Graves-Burnnand
Josh Dransfield

Penelope Wren
Skye Brownlow
Alicia Allan
Georgia Price
Samantha Roots
Tayla Campedelli
Oscar Cavalletto
Kate Creighton

**Muscular Dystrophy Association of
New South Wales**

ABN 11 774 587 436

**Financial Report
For the Year Ended 30 June 2022**

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

INDEX

Directors' Report	1-4
Auditor's Independence Declaration	5
Statement of Profit or Loss and Other Comprehensive Income	6
Statement of Financial Position	7
Statement of Changes in Equity	8
Statement of Cash Flows	9
Notes to the Financial Statements	10-27
Declaration by General Manager in respect of the Fundraising Appeals	28
Directors' Declaration	29
Independent Auditor's Report	30-33

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

DIRECTORS' REPORT FOR THE YEAR ENDED 30 JUNE 2022

Your directors present their report on the entity for the financial year ended 30 June 2022. In order to comply with the provisions of the *Australian Charities and Not-for-profits Commission Act 2012* (ACNC Act), the directors report as follows:

Directors

The names of the directors in office at any time during or since the end of the financial year are:

Mr Anthony Ball	
Dr. Alastair Corbett	Appointed 26 th April 2022
Mr. Tait Royce Jenkins	
Mr. Richard Arnheim	
Ms. Kim Brislane	Resigned 30 th June 2022
Dr. Christina Liang	Resigned 26 th April 2022
Mr. David Kay	Resigned 28 th June 2022
Ms. Michelle Ball	
Mr. Nathan Teong	
Mr. Stuart Uhlhorn	Resigned 21st December 2021
Ms. Laura Sheridan Mouton	
Dr. Michelle Anne Er	
Mr. Mark McCoy	Appointed 26 th April 2022

Directors have been in office since the start of the financial year to the date of this report unless otherwise stated.

Principal Activities

The principal activity of the entity during the financial year was the provision of care and assistance to people with muscular dystrophy.

Review of Operations

During the year, the entity continued to engage in its principal activity, the results of which are disclosed in the attached financial statements.

The net current year surplus of the entity for the financial year ended 30 June 2022 amounted to \$875,277 (2021: \$400,244).

Short-term and Long-term Objectives

The entity's short-term objectives are to:

- Work towards a national collaboration with other State based Muscular Dystrophy Associations around Australia
- Continue to evolve MDNSW's client services and programs for the National Disability Insurance Scheme
- Provide high quality services and programs that MDNSW clients select as part of their NDIS packages
- Continue to provide the Duke of Edinburgh's Award for young people with a neuromuscular condition in NSW

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

DIRECTORS' REPORT FOR THE YEAR ENDED 30 JUNE 2022

- Ensure MDNSW's website and communication continues to and places increased emphasis on providing specialist information and connection to the lived experience and stories of people living with a neuromuscular condition
- Implement the annual Sugar Free September campaigns to increase regular income and raise awareness.

The entity's long-term objectives are to:

- Position MDNSW as the leading whole of life provider of choice of specialised services and expert information for people affected by neuromuscular conditions
- Raise MDNSW profile across NSW, as the provider of choice
- Ensure a strong governance and continuous improvement culture
- Attract and retain employees of high calibre in a safe and productive work environment
- Fund a substantial increase in information, services, training and events
- Fund research towards improving well-being, treatment and a cure
- Ensure MDNSW remains focused on the National Disability Insurance Scheme and stays current and up to date with all information that is available
- Ensure we build continuous improvements within our internal processes to remain compliant with the National Disability Insurance Scheme Practice Standards.

Strategies

To achieve these objectives, the entity will be considering the following strategies:

- Implementation of the 3-year Strategic Plan and annual Business Plan
- Increased profile through technology, social media and digital mediums
- Focus on the major fundraising strategies per annum
- Continual review of all services to ensure they fit within the changing requirements of the National Disability Insurance Scheme
- Production of all rebranded marketing materials and business collateral, updating of website and social media platforms to ensure a consistent and recognisable look.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

DIRECTORS' REPORT FOR THE YEAR ENDED 30 JUNE 2022

Information on Directors

<i>Name, qualifications and independence status</i>	<i>Experience, special responsibilities and other directorships</i>
Mr Anthony Ball <i>President</i>	President, Muscular Dystrophy Association of NSW General Manager, Government and Industry Relations ANZ/APAC, Aristocrat Leisure. Director, Gaming Technologies Association Director since August 2017
Dr. Alistair Corbett MBChB, MD, FRACP, FAAN	Neurologist, Consultant Emeritus and Honorary Visiting Medical Officer, RGH Concord Clinical Associate Professor, University of Sydney Director since April 2022
Mr. Tait Royce Jenkins BCom (ProfAccg)	Treasurer, Boccia Australia since June 2017 Senior Analyst, KPMG-Audit Assurance & Risk Consulting Director since June 2021
Mr. Richard Arnheim CFP, FFPA, CA ANZ, BCom <i>Treasurer</i>	Member of Institute of Chartered Accountants in Aus & NZ Authorised Representative and Principal of Shadforth Financial Group Director since April 2012
Ms. Kim Brislane	Chief Executive Officer, Asbestos Diseases Research Institute (World Health Organization Centre) 2022 Director, Forward Ability Support and Bright Sky 2022 Founder, Readhead.com.au Director 2014 – June 2022
Dr. Christina Liang MBBS, BSc (Med), FRACP, PhD	2010 Fellow of the Royal Australasian College of Physicians Director 2014 – April 2022
Mr David Kay	Director- Health, Ageing and Human Services at KPMG Non-Executive Director of Muscular Dystrophy Foundation Australia Non-Executive Director of Accessible Arts Director July 2017-June 2022
Ms Michelle Ball	Regional HR Executive APAC Talent and Learning Bank of America Board member, NSW Power Football Director since December 2018
Mr. Nathan Teong BCom, GradDipAppFin	Parent of George who lives with a neuromuscular condition. Director since February 2018
Mr. Stuart Uhlhorn	Fellow CPA Australia, Fellow AICD, retired company executive Director Owl Solutions (business consultants), Director May 2018 – December 2021
Ms. Laura Sheridan Mouton BA (Hons) JD GAICD FGIA	Executive General Manager - Legal and Governance at Anglican Community Services Director since July 2020
Dr. Michelle Anne Er	Associate Professor in Pediatric Neurology, UNSW Specialist Child Neurologist, Sydney Children's Hospital Director since June 2021
Mr. Mark McCoy BCom, MBA, FCA, FFin FGIA, FCG, FAICD	Director, Nucleus Software Australia Pty Limited Director since April 2022

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

DIRECTORS' REPORT FOR THE YEAR ENDED 30 JUNE 2022

Meetings of Directors

During the financial year, 6 meetings of directors were held. Attendances by each director during the year were as follows:

	<i>Number eligible to attend</i>	<i>Number attended</i>
Mr. Anthony Ball	6	6
Dr. Alastair Corbett	2	2
Mr. Tait Royce Jenkins	6	6
Mr. Richard Arnheim	6	6
Ms. Kim Brislane	6	4
Dr. Christina Liang	5	5
Mr David Kay	6	5
Ms. Michelle Ball	6	3
Mr Nathan Teong	6	4
Mr Stuart Uhlhorn	3	3
Ms. Laura Sheridan Mouton	6	3
Dr. Michelle Anne Er	6	6
Mr. Mark McCoy	2	2

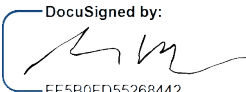
Member's Guarantee

The entity is incorporated under the *Corporations Act 2001* and is a company limited by guarantee. If the entity is wound up, the Constitution states that each member is required to contribute a maximum of \$20 towards meeting any outstanding obligations of the company. At 30 June 2022, the total amount the members of the entity are liable to contribute if the entity wound up is \$42,660.

Auditor's Independence Declaration

As required under section 307C of the Corporations Act 2001, a copy of the auditor's independence declaration for the year ended 30 June 2022 has been received and can be found attached to this report.

Signed in accordance with a resolution of the Board of Directors:

DocuSigned by:

 FF5B0FD55268442...

Anthony Ball
 President

DocuSigned by:

 2397DE2AE3084A1...

Richard Arnheim
 Treasurer

Dated this: 25 October 2022



**AUDITOR'S INDEPENDENCE DECLARATION
UNDER S 307C OF THE CORPORATIONS ACT 2001
TO THE DIRECTORS OF
MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES**


In accordance with section 307C of the Corporations Act 2001, we are pleased to provide the following declaration of independence to the directors of Muscular Dystrophy Association of New South Wales.

As the lead audit partner for the audit of the financial report of Muscular Dystrophy Association of New South Wales for the year ended 30 June 2022, I declare that, to the best of my knowledge and belief, there have been no contraventions of:

- (i) the auditor independence requirements of the Corporations Act 2001 in relation to the audit; and
- (ii) any applicable code of professional conduct in relation to the audit.

Name of Firm: MCCARTHY SALKELD
AUDIT PTY LTD

Name of Partner:


Jane Perry FCA

Address: Ground Floor, Suite 3
410 Church Street
North Parramatta NSW 2151

Dated this 2nd day of November 2022

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME
FOR THE YEAR ENDED 30 JUNE 2022

	Notes	2022 \$	2021 \$
REVENUE			
Revenue from fundraising activities	2	1,534,796	639,586
Financial and other income	2	941,022	1,007,652
Total income		2,475,818	1,647,238
EXPENSES			
Fundraising expenses		49,252	38,302
Client service provision expenses		1,169,043	892,471
Change in fair value – exchange traded funds		49,111	-
Administration expenses		308,417	248,685
Depreciation and amortisation expenses	3	24,718	24,541
Other expenses	3	-	42,995
Total expenses		1,600,541	1,246,994
Profit for the year	16	875,277	400,244
Total comprehensive income for the year		875,277	400,244

The accompanying notes form part of these financial statements

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

STATEMENT OF FINANCIAL POSITION
AS AT 30 JUNE 2022

	Note	2022 \$	2021 \$
ASSETS			
CURRENT ASSETS			
Cash and cash equivalents	5	2,362,134	1,524,918
Trade and other receivables	6	53,536	45,896
Financial assets	7	387,174	415,289
Other assets	8	67,102	35,206
TOTAL CURRENT ASSETS		2,869,946	2,021,309
NON-CURRENT ASSETS			
Plant and equipment	9	13,480	25,926
Right of use assets	11	29,555	24,574
Intangible Assets	10	58,739	8,903
TOTAL NON-CURRENT ASSETS		101,774	59,403
TOTAL ASSETS		2,971,720	2,080,713
LIABILITIES			
CURRENT LIABILITIES			
Trade and other payables	12	55,766	70,051
Provisions for employee entitlements	13	127,779	96,573
Lease liabilities	15	5,297	6,867
Other liabilities	14	273,562	302,680
TOTAL CURRENT LIABILITIES		462,404	476,171
NON-CURRENT LIABILITIES			
Provision for employee entitlements	13	37,421	13,730
Lease liabilities	15	24,258	18,450
TOTAL NON-CURRENT LIABILITIES		61,679	32,180
TOTAL LIABILITIES		524,083	508,352
NET ASSETS		2,447,637	1,572,360
EQUITY			
Retained earnings		2,447,637	1,572,360
TOTAL EQUITY		2,447,637	1,572,360

The accompanying notes form part of these financial statements

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

STATEMENT OF CHANGES OF EQUITY
FOR THE YEAR 30 JUNE 2022

	Business Development Reserve	Retained Earnings	Total
Balance at 30 June 2020	-	1,172,116	1,172,116
Profit (Loss) attributable to members of the entity	-	400,244	400,244
Balance at 30 June 2021	-	1,572,360	1,572,360
Transfers	300,000	(300,000)	-
Profit (Loss) attributable to members of the entity	(67,351)	942,628	875,277
Balance at 30 June 2022	232,649	2,214,988	2,447,637

The accompanying notes form part of these financial statements

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 30 JUNE 2022

	Note	2022 \$	2021 \$
Cash flows from operating activities			
Receipt of grants		597,567	639,138
Receipts from bequests donations and clients		1,851,534	914,135
Payments to suppliers and employees		(1,543,410)	(1,174,496)
Interest received		3,373	3,636
Net cash flow from operating activities	16	909,064	382,414
Cash flows from investing activities			
Net purchases of plant and equipment		(14,588)	(10,793)
Purchase of intangibles		(52,500)	-
Proceeds from sale of plant and equipment		11,998	-
Purchase of investments		(20,996)	-
Net cash flow from investing activities		(76,086)	(10,793)
Cash flows from financing activities			
(Repayment)/ proceeds of lease liability		4,238	(6,592)
Net cash flow from financing activities		4,238	(6,592)
Net increase in cash and cash equivalents		837,216	365,028
Cash and cash equivalents at the beginning of financial year		1,524,918	1,159,890
Cash and cash equivalents at the end of financial year	5	2,362,134	1,524,918

The accompanying notes form part of these financial statements

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Summary of Significant Accounting Policies

Basis of Preparation

The financial statements are general purpose financial statements that have been prepared in accordance with the Australian Accounting Standards – Simplified Disclosures of the Australian Accounting Standards Board (AASB) and the *Australian Charities and Not-for-profits Commission Act (2012)* and its regulations. The entity is a not-for-profit entity for financial reporting purposes under Australian Accounting Standards.

Australian Accounting Standards set out accounting policies that the AASB has concluded would result in financial statements containing relevant and reliable information about transactions, events and conditions. Material accounting policies adopted in the preparation of these financial statements are presented below and have been consistently applied unless stated otherwise.

These financial statements, except for the cash flow information, have been prepared on an accrual basis and are based on historical costs, modified, where applicable, by the measurement at fair value of selected non-current assets, financial assets and financial liabilities. The amounts presented in the financial statements have been rounded to the nearest dollar.

The financial statements were authorised for issue on 25 October 2022 by the directors of the entity.

Accounting Policies

a) Income Tax

No provision for income tax has been raised as the entity is exempt from income tax under Division 50-5 of the *Income Tax Assessment Act 1997*.

b) Plant and Equipment

Each class of property, plant and equipment is carried at cost as indicated, less where applicable, any accumulated depreciation and impairment losses.

Plant and equipment are measured on the cost basis and are therefore carried at cost less accumulated depreciation and any accumulated impairment losses. In the event the carrying amount of plant and equipment is greater than the estimated recoverable amount, the carrying amount is written down immediately to the estimated recoverable amount and impairment losses are recognised either in the profit or loss or as a revaluation decrease if the impairment losses relate to a revalued asset. A formal assessment of recoverable amount is made when impairment indicators are present (refer to Note 1f) for details of impairment).

Depreciation

The depreciable amount of all fixed assets, including plant and equipment, is depreciated on a straight-line basis over the asset's useful life to the entity commencing from the time the asset is held ready for use. Leasehold improvements are depreciated over the shorter of either the unexpired period of lease or the estimated useful lives of the improvements.

The depreciation rates used for each class of depreciable assets are:

Class of fixed Asset	Depreciation Rate
Plant and Equipment	10.00 – 50.00%
Motor Vehicles	8.33 – 12.50%
Leasehold Improvements	33.33%
Right of Use Asset	20.00%

The assets' residual values and useful lives are reviewed and adjusted, if appropriate, at the end of each reporting period.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Statement of Significant Accounting Policies (continued)

b) Property, Plant and Equipment (continued)

Gains and losses on disposals are determined by comparing proceeds with the carrying amount. These gains or losses are included in the statement of profit and loss and other comprehensive income. When revalued assets are sold, amounts included in the revaluation surplus relating to that asset are transferred to retained earnings.

c) Intangible Assets

Software

The organisation has developed two online portals to generate donations. The portals are initially recognised at cost. These portals will be amortised for five years and are carried at cost less any accumulated amortisation and impairment losses.

The directors will assess impairment for software on annual basis and make the required adjustments based on reliable evidence. Where software is acquired at no cost, or for a nominal cost, the cost is its fair value, as at the date of acquisition.

d) Leases

The Entity as lessee

At inception of a contract, the entity assesses if the contract contains or is a lease. If there is a lease present, a right-of-use asset and a corresponding lease liability is recognised by the entity where the entity is a lessee. However, all contracts that are classified as short-term leases (lease with remaining lease term of 12 months or less) and leases of low value assets are recognised as an operating expense on a straight-line basis over the term of the lease.

Initially the lease liability is measured at the present value of the lease payments still to be paid at commencement date. The lease payments are discounted at the interest rate implicit in the lease. If this rate cannot be readily determined, the entity uses the incremental borrowing rate.

Lease payments included in the measurement of the lease liability are as follows:

- fixed lease payments less any lease incentives;
- variable lease payments that depend on an index or rate, initially measured using the index or rate at the commencement date;
- the amount expected to be payable by the lessee under residual value guarantees;
- the exercise price of purchase options, if the lessee is reasonably certain to exercise the options;
- lease payments under extension options if lessee is reasonably certain to exercise the options; and
- payments of penalties for terminating the lease, if the lease term reflects the exercise of an option to terminate the lease.

The right-of-use assets comprise the initial measurement of the corresponding lease liability as mentioned above, any lease payments made at or before the commencement date as well as any initial direct costs. The subsequent measurement of the right-of-use assets is at cost less accumulated depreciation and impairment losses.

Right-of-use assets are depreciated over the lease term or useful life of the underlying asset whichever is the shortest. Where a lease transfers ownership of the underlying asset or the cost of the right-of-use asset reflects that the entity anticipates to exercise a purchase option, the specific asset is depreciated over the useful life of the underlying asset.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Statement of Significant Accounting Policies (continued)

e) Financial Instruments

Initial recognition and measurement

Financial assets and financial liabilities are recognised when the entity becomes a party to the contractual provisions of the financial instrument. For financial assets, this is equivalent to the date that the entity commits itself to either purchase or sell the asset (i.e. trade date accounting is adopted).

Financial instruments are initially measured at fair value plus transactions costs, except where the instrument is classified 'at fair value through profit or loss', in which case transaction costs are expensed to profit and loss immediately.

Classification and subsequent measurement

Financial instruments are subsequently measured at either fair value, amortised cost using the effective interest rate method or cost. Where available, quoted prices in an active market are used to determine fair value. In other circumstances, valuation techniques are adopted.

Amortised cost is calculated as: (i) the amount at which the financial asset or financial liability is measured at initial recognition; (ii) less principal repayments; (iii) plus or minus the cumulative amortisation of the difference, if any, between the amount initially recognised and the maturity amount calculated using the effective interest rate method; and (iv) less any reduction for impairment.

The effective interest rate method is used to allocate interest income or interest expense over the relevant period and is equivalent to the rate that exactly discounts estimated future cash payments or receipts (including fees, transaction costs and other premiums or discounts) through the expected life (or when this cannot be reliably predicted, the contractual term) of the financial instrument to the net carrying amount of the financial asset or financial liability. Revisions to expected future net cash flows will necessitate an adjustment to the carrying value with a consequential recognition of an income or expense in profit or loss.

(i) Financial assets at fair value through profit and loss

Financial assets are classified at 'fair value through profit or loss' when they are either held for trading for the purpose of short term profit taking, derivatives not held for hedging purposes, or when they are designated as such to avoid an accounting mismatch or enable performance evaluation where a group of financial assets is managed by key management personnel on a fair value basis in accordance with a documented risk management or investment strategy. Such assets are subsequently measured at fair value with changes in carrying value being included in profit or loss.

(ii) Loans and receivables

Loans and receivables are non-derivative financial assets with fixed or determinable payments that are not quoted in an active market and are subsequently measured at amortised cost

(iii) Financial liabilities

Non derivative financial liabilities (excluding financial guarantees) are subsequently measured at amortised cost.

Fair Value

Fair value is determined based on current bid prices for all quoted investments. Valuation techniques are applied to determine the fair value for all unlisted securities, including recent arm's length transactions, reference to similar instruments and option pricing models.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Statement of Significant Accounting Policies (continued)

e) Financial Instruments (continued)

Impairment

At the end of each reporting period, the entity assesses whether there is objective evidence that a financial instrument has been impaired. Impairment losses are recognised in the profit and loss.

Derecognition

Financial assets are derecognised where the contractual rights to receipt of cash flows expire or the asset is transferred to another party whereby the entity no longer has any significant continuing involvement in the risks and benefits associated with the asset. Financial liabilities are derecognised where the related obligations are either discharged, cancelled or expire. The difference between the carrying value of the financial liability extinguished or transferred to another party and the fair value of consideration paid, including the transfer of non-cash assets or liabilities assumed, is recognised in profit or loss.

f) Impairment of Assets

At the end of each reporting period, the entity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, the recoverable amount of the asset, being the higher of the asset's fair value less costs of disposal and value in use, is compared to the asset's carrying amount. Any excess of the asset's carrying amount over its recoverable amount is recognised immediately in profit or loss.

Where the future economic benefits of the asset are not primarily dependent upon the asset's ability to generate net cash inflows and when the entity would, if deprived of the asset, replace its remaining future economic benefits, value in use is determined as the depreciated replacement cost of an asset.

Where it is not possible to estimate the recoverable amount of a class of asset, the entity estimates the recoverable amount of the cash-generating unit to which the asset belongs.

Where an impairment loss on a revalued asset is identified, this is debited against the revaluation surplus in respect of the same class of asset to the extent that the impairment loss does not exceed the amount in the revaluation surplus for that same class of asset.

g) Employee Benefits

Short-term employee benefits

Provision is made for the entity's obligation for short-term employee benefits. Short-term employee benefits are benefits (other than termination benefits) that are expected to be settled wholly within 12 months after the end of the annual reporting period in which the employees render the related service, including wages, salaries, annual leave and sick leave. Short-term employee benefits are measured at the (undiscounted) amounts expected to be paid when the obligation is settled, plus related on-costs.

The entity's obligations for short-term employee benefits such as wages, salaries, time-off-in-lieu and sick leave are recognised as part of short-term provisions in the statement of financial position.

Other long-term employee benefits

The entity classifies employees' long service leave and annual leave entitlements as other long-term employee benefits as they are not expected to be settled wholly within 12 months after the end of the annual reporting period in which the employees render the related service. Provision is made for the entity's obligation for other long-term employee benefits, which are measured at the present value of the expected future payments to be made to employees. Expected future payments incorporate anticipated future wage and salary levels, durations of service and employee departures, and are

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Statement of Significant Accounting Policies (continued)

g) Employee Benefits (continued)

discounted at rates determined by reference to market yields at the end of the reporting period on 10-year Australian government bonds that have maturity dates that approximate the terms of the obligations. Any re-measurements for changes in assumptions of obligations for other long-term employee benefits are recognised in profit or loss in the periods in which the changes occur.

The entity's obligations for long-term employee benefits are presented as non-current liabilities in its statement of financial position, except where the entity does not have an unconditional right to defer settlement for at least 12 months after the end of the reporting period, in which case the obligations are presented as current liabilities.

h) Provisions

Provisions are recognised when the entity has a legal or constructive obligation, as a result of past events, for which it is probable that an outflow of economic benefits will result and that outflow can be reliably measured. Provisions recognised represent the best estimate of the amounts required to settle the obligation at reporting date.

i) Cash and Cash Equivalents

Cash and cash equivalents include cash on hand and deposits held at-call with banks, other short-term highly liquid investments with original maturities of three months or less, and bank overdrafts.

j) Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Taxation Office (ATO).

Receivables and payables are stated inclusive of the amount of GST receivable or payable. The net amount of GST recoverable from, or payable to, the ATO is included with other receivables or payables in the statement of financial position.

Cash flows are presented on a gross basis. The GST components of cash flows arising from investing or financing activities, which are recoverable from, or payable to, the ATO are presented as operating cash flows included in receipts from customers or payments to suppliers.

k) Revenue

Revenue recognition

Operating Grants, Donations and Bequests

When the entity earns or receives revenue, it assesses whether the contract is enforceable and has sufficiently specific performance obligations in accordance with AASB 15 *Revenue from Contracts with Customers*.

When both these conditions are satisfied, the entity:

- identifies each performance obligation relating to the grant
- recognises a contract liability for its obligations under the agreement
- recognises revenue as it satisfies its performance obligations.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Statement of Significant Accounting Policies (continued)

k) Revenue (continued)

Where the contract is not enforceable or does not have sufficiently specific performance obligations, the entity:

- recognises the asset received in accordance with the recognition requirements of other applicable accounting standards (for example AASB 9, AASB 16, AASB 116 and AASB 138);
- recognises related amounts (being contributions by owners, lease liability, financial instruments, provisions, revenue or contract liability); and
- recognises income immediately in profit or loss as the difference between the initial carrying amount of the asset and the related amount.

If a contract liability is recognised as a related amount above, the entity recognises income in profit or loss when or as it satisfies its obligations under the contract.

Membership subscriptions revenue comprises revenue from membership fees derived and relating to the financial year.

Donations are recognised as revenue when received.

Bequest amounts are recognised as revenue when received, unless there are unsatisfied conditions attaching to the bequest, in which case it is recognised as income as or when the respective condition(s) are satisfied.

Specific or tagged bequests are recognised as income when the appropriate program or research expenses as approved by the board are incurred.

Revenue for fundraising events is recognised in the year in which the event is held.

Interest income is recognised using the effective interest rate method.

Revenue from the rendering of a service is recognised upon the delivery of the service to customers.

Other revenue is recognised when the right to receive the revenue has been established.

All revenue is stated net of the amount of goods and services tax (GST), if any.

l) Finance Costs

Finance costs are recognised as an expense in the period in which they are incurred.

m) Training and Development

Training and development costs are expensed as they are incurred.

n) Prepaid Membership Subscriptions

Membership subscriptions received during the year but relating to the following financial year are included in unearned income.

o) Comparative Figures

When required by Accounting Standards, comparative figures have been adjusted to conform to changes in presentation for the current financial year. Liability amounts previously shown as 'bequest income in advance' at 30 June 2021 totalling \$49,069 (comprising current \$43,576 and non-current \$5,474 amounts) has been included in income for the year ended 30 June 2021 in these financial statements.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Statement of Significant Accounting Policies (continued)

p) Critical Accounting Estimates and Judgments

The directors evaluate estimates and judgments incorporated into the financial statements based on historical knowledge and best available current information. Estimates assume a reasonable expectation of future events and are based on current trends and economic data, obtained both externally and within the entity.

Key estimates

- i) *Useful lives of plant & equipment*
As indicated in note 1(b), the entity reviews the estimated useful lives of plant and equipment at the end of each annual reporting period.
- ii) *Useful lives of intangible assets*
As indicated in note 1(c), the entity reviews the estimated useful lives of intangible assets on at the end of each annual reporting period.

Key judgements

- i) *Performance obligations under AASB 15*
To identify a performance obligation under AASB 15, the promise must be sufficiently specific to be able to determine when the obligation is satisfied. Management exercises judgement to determine whether the promise is sufficiently specific by taking into account any conditions specified in the arrangement, explicit or implicit, regarding the promised goods or services. In making this assessment, management includes the nature/ type, cost/ value, quantity and the period of transfer related to the goods or services promised.
- ii) *Lease term and Option to Extend Under AASB 16*
The lease term is defined as the non-cancellable period of a lease together with both periods covered by an option to extend the lease if the lessee is reasonably certain to exercise that option; and also periods covered by an option to terminate the lease if the lessee is reasonably certain not to exercise that option. The options that are reasonably going to be exercised is a key management judgement that the entity will make. The entity determines the likeliness to exercise the options on a lease-by-lease basis looking at various factors such as which assets are strategic and which are key to future strategy of the entity.
- iii) *Provision for employee benefits*
For the purpose of measurement, AASB 119: Employee Benefits defines obligations for short-term employee benefits as obligations expected to be settled wholly before 12 months after the end of the annual reporting period in which the employees render the related service. As the entity expects that most employees will not use all of their annual leave entitlements in the same year in which they are earned or during the 12-month period that follows, the directors believe that obligations for annual leave entitlements satisfy the definition of other long-term employee benefits and, therefore, are required to be measured at the present value.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 1: Statement of Significant Accounting Policies (continued)

q) Economic Dependence

The entity is dependent on donations, bequests and special events for the majority of its revenue used to operate the business. At the date of this report the Board of Directors has no reason to believe these revenue sources will not continue to support the entity.

r) Fair Value of Assets

The entity measures some of its assets at fair value on either a recurring or non-recurring basis, depending on the requirements of the applicable Accounting Standard.

"Fair value" is the price the entity would receive to sell an asset or would have to pay to transfer a liability in an orderly (i.e. unforced) transaction between independent, knowledgeable and willing market participants at the measurement date.

As fair value is a market-based measure, the closest equivalent observable market pricing information is used to determine fair value. Adjustments to market values may be made having regard to the characteristics of the specific asset. The fair values of assets that are not traded in an active market are determined using one or more valuation techniques. These valuation techniques maximise, to the extent possible, the use of observable market data.

To the extent possible, market information is extracted from the principal market for the asset (ie the market with the greatest volume and level of activity for the asset or liability). In the absence of such a market, market information is extracted from the most advantageous market available to the entity at the end of the reporting period (i.e. the market that maximises the receipts from the sale of the asset or minimises the payments made to transfer the liability, after taking into account transaction costs and transport costs).

For non-financial assets, the fair value measurement also takes into account a market participant's ability to use the asset in its highest and best use or to sell it to another market participant that would use the asset in its highest and best use.

s) New Accounting Standards Adopted by the Entity

Initial adoption of AASB 1060: General Purpose Financial Statements – Simplified Disclosures for For-Profit and Not-for-Profit Tier 2 Entities

The entity has adopted AASB 1060: General Purpose Financial Statements – Simplified Disclosures for For-Profit and Not-for-Profit Tier 2 Entities for the first time this reporting period. The Standard, which sets out a new separate disclosure Standard to be applied by all entities that are reporting under Tier 2 of the Differential Reporting Framework in AASB 1053: Application of Tiers of Australian Accounting, replaces the previous Reduced Disclosure Requirements (RDR) framework. The application of this standard has resulted in reductions in disclosures compared to RDR in Revenue, Leases and Financial Instruments; however has resulted in new and/or increased disclosures in areas such as Audit Fees and Related Parties.

t) Amended Accounting Policies Adopted by the Entity

In the 2022 financial year, the entity changed the accounting policy to immediately recognise untied bequests to income in the profit and loss statement from the previous treatment of amortising the bequests over a three-year period. Comparative figures have been re-stated as a result of this change.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 2: Income	Note	2022 \$	2021 \$
Revenue from fundraising activities			
Revenue from events		246,808	260,486
Donations		342,548	193,438
Non-government grants		31,137	39,609
Bequests		914,303	146,053
Total revenue		<u>1,534,796</u>	<u>639,586</u>
Financial income	4	44,594	99,004
Other Income			
Membership fees		3,373	2,201
Grants received			
JobSaver and JobKeeper		76,972	230,250
COVID-19 business support		16,109	51,728
Other government grants		473,349	317,551
Other Income		326,625	306,918
Total financial and other income		<u>941,022</u>	<u>1,007,652</u>
Total income		<u>2,475,818</u>	<u>1,647,238</u>

Note 3: Profit for the year

The profit for the year includes the following expenses:

Depreciation and Amortisation

Plant & Equipment	9,846	7,195
Motor Vehicles	6,357	6,860
Leasehold Amortisation	-	2,664
Intangibles Amortisation Expense	2,664	800
Right of Use Assets	5,851	7,021
	<u>24,718</u>	<u>24,541</u>

Other expenses

Scholarship Grants	-	42,995
	<u>-</u>	<u>42,995</u>

Note 4: Financial Income

Financial income		
Interest income	3,373	3,636
Distributions – exchange traded funds	33,321	12,892
Imputation credits – exchange traded funds	7,900	3,373
Changes in fair value – exchange traded funds	-	79,102
	<u>44,594</u>	<u>99,004</u>

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

		2022	2021
	Note	\$	\$
Note 5: Cash and cash equivalents			
Current			
Cash on hand		-	551
Cash at bank		258,381	322,873
Cash on deposit		2,103,753	1,201,494
		<u>2,362,134</u>	<u>1,524,918</u>
Note 6: Trade and other receivables			
Current			
Trade receivables		18,750	22,150
Accrued Income		29,455	23,677
Net GST receivable		5,331	-
Other receivables		-	69
		<u>53,536</u>	<u>45,896</u>
Note 7: Financial assets			
Current			
Financial assets at fair value through profit or loss	7(a)	387,174	415,289
		<u>387,174</u>	<u>415,289</u>
(a) Financial assets at fair value through profit or loss			
Held for trading - Australian managed fund units		387,174	415,289
Securities in managed funds are held for trading purposes to generate income through the receipt of distributions and capital gains.			
Note 8: Other Assets			
Current			
Franking credits from receipt of dividends		7,900	3,374
Prepayments		57,358	28,616
Other current assets		1,844	3,216
		<u>67,102</u>	<u>35,206</u>

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

	Note	2022 \$	2021 \$
Note 9: Plant and equipment			
Plant and equipment			
At cost		27,009	67,593
Less: Accumulated depreciation		(14,337)	(49,168)
Total plant and equipment		12,672	18,425
Motor vehicles			
At cost		58,180	89,784
Less: Accumulated depreciation		(57,372)	(82,283)
Total motor vehicles		808	7,501
Leasehold Improvement			
At cost		-	8,175
Less: Accumulated amortisation		-	(8,175)
Total leasehold improvements		-	-
Total plant and equipment		13,480	25,926

Movements in carrying amounts

Movement in the carrying amounts for each class of property, plant and equipment between the beginning and the end of the current financial year.

	Plant and Equipment \$	Motor Vehicles \$	Leasehold Improvement \$	Equipment Leased \$	Total \$
2022					
Balance at the beginning of the year	18,425	7,501	-	24,574	50,500
Additions at cost	4,267	-	-	29,555	33,822
Disposals	(175)	(336)		(18,723)	(19,234)
Depreciation expense	(9,845)	(6,357)	-	(5,851)	(22,053)
Carrying amount at the end of year	12,672	808	-	29,555	43,035
2021					
Balance at the beginning of the year	15,627	14,361	-	31,595	61,583
Depreciation/amortisation expense	(7,996)	(6,860)	-	(7,021)	(21,877)
Purchase of Asset	10,794	-	-	-	10,794
Carrying amount at the end of year	18,425	7,501	-	24,574	50,500

Gains from the disposal of two motor vehicles and write off unused plant and equipment resulted in net result of \$11,998 (2020 - \$nil).

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

	Note	2022 \$	2021 \$
Note 10: Intangibles			
Software – at cost		65,820	13,320
Accumulated amortisation		(7,081)	(4,417)
Net carrying amount		58,739	8,903
Software			
\$			
Movements in Carrying Amount			
Balance at the beginning of the year		8,903	13,320
Additions		52,500	-
Disposals		-	-
Amortisation expense		(2,664)	(4,417)
		58,739	8,903

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 11: Right of Use Assets

Right of use assets

The entity's lease portfolio includes printer equipment. The existing lease with the larger printer was terminated in March 2022 and replaced by three new leases with smaller printers. The new 5 year leases were entered into by the company in May 2022, with the first payments due and payable in July 2022. Depreciation on the new printers will start in the 2023 financial year, in line with the first repayment of the leases.

The option to extend or terminate are contained in the equipment lease agreement. These clauses provide the entity opportunities to manage leases in order to align with its strategies. All of the extension or termination options are only exercisable by the entity. The extension options or termination options which were probable to be exercised have been included in the calculation of the Right of use asset.

i) AASB 16 related amounts recognised in the balance sheet

	2022	2021
	\$	\$
Right of use assets		
Leased Equipment	29,555	35,106
Accumulated Depreciation	-	(10,532)
Total Right of use asset	<u>29,555</u>	<u>24,574</u>
 Movement in carrying amounts:		
Leased equipment:		
Opening balance	24,574	35,106
Additions	29,555	-
Lease Termination	(24,574)	-
Depreciation expense	-	(10,532)
Net Carrying Amount	<u>29,555</u>	<u>24,574</u>

ii) AASB 16 related amounts recognised in the statement of profit or loss

	2022	2021
	\$	\$
Depreciation Charge related to right-of-use assets	5,851	7,021
Interest expense on lease liabilities	-	-

iii) Total future lease payments at the end of the reporting period

No later than 1 year	6,720	7,751
Between 1 to 5 years	26,880	19,377
Total future lease payments	<u>33,600</u>	<u>27,128</u>

	Note	2022	2021
		\$	\$
Note 12: Trade and Other Payables			
Current			
Trade payables		9,724	11,524
Accrued expenses		15,113	10,000
Credit Cards		3,894	2,947
Net GST payable		-	758
PAYG Withholding		22,904	13,004
Superannuation contributions liability		4,131	4,116
Other Payables		-	27,703
		<u>55,766</u>	<u>70,051</u>

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

	Note	2022 \$	2021 \$
Note 13: Provisions for employee entitlements			
Current:			
- Annual leave entitlements		96,838	72,449
- Time off in lieu entitlements		13,932	11,787
- Long service leave entitlements		17,009	12,336
Total current provisions for employee entitlements		127,779	96,573
Non-current:			
- Long service leave entitlements		37,421	13,730
Total non-current provision for employee entitlements		37,421	13,730
Movements in provisions (in aggregate)			
Aggregate balance at 1 July		110,303	89,676
Additional provisions raised during the year		143,720	87,157
Amounts used during the year		(88,823)	(66,530)
Aggregate balance at 30 June		165,200	110,303

Employee Entitlements

Employee entitlements represent amounts accrued for annual leave, time-off in lieu and long service leave.

The current portion for this provision includes the total amount accrued for annual leave entitlements and the amounts accrued for long service leave entitlements that have vested due to employees having completed the required period of service. Based on past experience, the entity does not expect the full amount of annual leave or long service leave balances classified as current liabilities to be settled within the next 12 months. However, these amounts must be classified as current liabilities since the entity does not have an unconditional right to defer the settlement of these amounts in the event employees wish to use their leave entitlement.

The non-current portion for this provision includes the amounts accrued for long service leave entitlements that have not yet vested in relation to those employees who have not yet completed the required period of service.

Note 14: Other Liabilities	2022	2021
	\$	\$
Current		
Contract liabilities	231,939	261,057
NEWS fund held	41,623	41,623
	273,562	302,680

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 15: Lease liabilities

Amounts due within one year	5,297	6,867
Amounts due between one and five years	24,258	18,450
Minimum lease payments	29,555	25,317

The entity entered into a new lease agreement during June 2022 for 3 Fuji Xerox Printers over a period of 60 months. The lease term will expire on 30 June 2027.

Note 16: Profit and cash flow reconciliation

	2022	2021
	\$	\$
Profit for the year	875,277	400,244
Non-cash flows in profit		
Net disposal of plant and equipment	(11,998)	-
Depreciation and amortisation expense	24,717	24,541
Unrealised (gain)/loss from investments	49,111	(91,994)
Changes in assets and liabilities		
(Increase)/decrease in prepayments	(28,741)	(5,983)
(Increase)/decrease in trade and other receivables	(11,171)	1,665
Increase/(decrease) in trade and other payables	(43,027)	33,313
Increase/(decrease) in provisions	54,896	20,628
Net cash flow from operating activities	909,064	382,414

Note 17: Events occurring after balance date

Other than the following, the directors are not aware of any significant events since the end of the reporting period.

The entity has considered the impact of COVID-19 and have determined that there are no adjustments required to the 2022 financial statements. Given the uncertainty surrounding COVID-19 a reliable estimate of its financial effect cannot be made.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 18: Key management personnel compensation

Key Management Personnel (KMP) are person(s) having authority and responsibility for planning, directing and controlling the activities of the entity, directly or indirectly.

The entity's KMP comprise its directors, who receive no remuneration, and chief executive officer.

	2022	2021
	\$	\$
KMP compensation	157,000	158,607

Note 19: Other related party transactions

Other related parties include close family members of key management personnel and entities that are controlled or jointly controlled by those key management personnel, individually or collectively with their close family members.

Transactions with related parties are on normal commercial terms and conditions no more favourable than those available to other persons.

Note 20: Financial risk management

The entity's financial instruments consists mainly of cash and cash equivalents, short-term investments, trade and other receivables, trade and other payables and lease liabilities.

The carrying amounts for each category of financial instruments, measured in accordance with AASB 9: *Financial Instruments* as detailed in the accounting policies to these financial statements, are as follows:

	Note	2022	2021
		\$	\$
Financial Assets			
Financial assets at fair value through profit or loss:			
Held-for-trading exchange traded fund units	7(a)	387,174	415,289
Financial assets at amortised cost:			
Cash and cash equivalents	5	2,362,134	1,524,918
Trade and other receivables	6	24,081	22,288
		<u>2,768,058</u>	<u>1,962,496</u>
Financial Liabilities			
Financial liabilities at amortised cost:			
Trade and other payables	12	50,436	70,051
Lease liabilities	15	29,555	25,317
		<u>79,991</u>	<u>95,368</u>

Refer to Note 21 for detailed disclosures regarding the fair value measurement of the entity's financial assets.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 21: Fair Value Measurements

The entity measures and recognises the following assets at fair value on a recurring basis after initial recognition:

- financial assets at fair value through profit or loss;

The entity does not subsequently measure any assets at fair value on a non-recurring basis.

Valuation techniques

The entity selects a valuation technique that is appropriate in the circumstances and for which sufficient data is available to measure fair value. The availability of sufficient and relevant data primarily depends on the specific characteristics of the asset being measured. The valuation techniques selected by the entity are consistent with one or more of the following valuation approaches:

- the market approach, which uses prices and other relevant information generated by market transactions for identical or similar assets or liabilities;
- the income approach, which converts estimated future cash flows or income and expenses into a single discounted present value; and
- the cost approach, which reflects the current replacement cost of an asset at its current service capacity.

Each valuation technique requires inputs that reflect the assumptions that buyers and sellers would use when pricing the asset, including assumptions about risks. When selecting a valuation technique, the entity gives priority to those techniques that maximise the use of observable inputs and minimise the use of unobservable inputs. Inputs that are developed using market data (such as publicly available information on actual transactions) and reflect the assumptions that buyers and sellers would generally use when pricing the asset are considered observable, whereas inputs for which market data is not available and therefore are developed using the best information available about such assumptions are considered unobservable.

Note 22: Fundraising activities

Fundraising activities conducted during the year included mail appeals, raffles and various other fundraising projects and receipt of indirectly solicited donations and bequests.

	2022	2021
	\$	\$
i) Results of fundraising appeals		
Gross proceeds from fundraising activities	1,534,796	590,517
Less: Direct costs of fundraising activities	(49,252)	(38,302)
Profit derived from fundraising activities	1,485,544	552,215
ii) Application of profit derived from fundraising activities		
Client service provision costs	1,169,043	892,471
Administration expenses	308,418	248,685
	1,477,461	1,141,156
Net fundraising profit/(loss) after application of funds	8,083	(588,941)

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

Note 22: Fundraising activities (continued)	2022	2022	2021	2021
	\$	%	\$	%
iii) Comparisons of certain monetary amounts and				
Total cost of fundraising	49,252	3.21	38,302	6.48
Gross proceeds from fundraising	1,534,796		590,517	
Net surplus from fundraising	1,485,544	96.79	552,215	93.51
Gross proceeds from fundraising	1,534,796		590,517	
Total costs of client services	1,169,043	72.59	892,471	71.56
Total expenditure	1,610,435		1,246,994	
Total costs of services	1,169,043	47.26	892,471	59.53
Total income received	2,473,386		1,499,165	

Note 23: Contingent Assets or Liabilities

The directors have determined that there are no contingent assets or liabilities except for the following:

Bequest from the Estate of William Leslie Harding

During the year, the entity was notified that it was a beneficiary of the Estate of William Leslie Harding (the Estate). During the financial year, the entity received \$900,000 in bequeathed funds from the Estate. As at the signing of this report, the Estate is still in administration and a final distribution is expected to be received during the 2023 financial year. The directors are not aware of the final distribution amount to be received, if any.

Note 24: Entity Details

The registered office of the Entity is:

Muscular Dystrophy Association of New South Wales
Level 1, 93 George Street
PARRAMATTA NSW 2124

The principal place of business of the entity is:

Muscular Dystrophy Association of New South Wales
Level 1, 93 George Street
PARRAMATTA NSW 2124

Note 25: Auditor's Remuneration

	2022	2021
	\$	\$
Remuneration of the auditor		
- audit of the financial statements	10,000	7,800

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

DECLARATION BY CEO IN RESPECT OF FUNDRAISING APPEALS

I, Charlotte Sangster, CEO of Muscular Dystrophy Association of New South Wales, declare that in my opinion:

- (a) the financial report gives a true and fair view of all income and expenditure of the entity with respect to fundraising appeal activities for the financial year ended 30 June 2022;
- (b) the statement of financial position gives a true and fair view of the state of affairs with respect to fundraising appeal activities as at 30 June 2022;
- (c) the provisions of the Charitable Fundraising (NSW) Act 1991 and Regulations under the Act and the conditions attached to the authority have been complied with during the year ended 30 June 2022;
- (d) the internal controls exercised by the entity are appropriate and effective in accounting for all income received and applied by the entity from any of its fundraising appeals.

DocuSigned by:

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CHARLOTTE SANGSTER
CEO

Dated this 25th day of October 2022

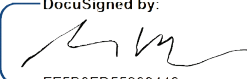
MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
ABN 11 774 587 436

DIRECTORS' DECLARATION

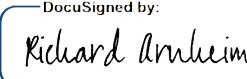
In accordance with a resolution of the Directors of Muscular Dystrophy Association of New South Wales, the directors of the registered entity declare that, in the directors' opinion:

- 1) The financial statements and notes, as set out on pages 6 to 27, satisfy the requirements of the *Australian Charities and Not-for-profits Commission Act 2012* and:
 - a) comply with Australian Accounting Standards – Simplified Disclosures applicable to the entity; and
 - b) give a true and fair view of the financial position of the registered entity as at 30 June 2022 and of its performance for the year ended on that date.
- 2) There are reasonable grounds to believe that the registered entity will be able to pay its debts as and when they become due and payable.

This declaration is signed in accordance with subsection 60.15(2) of the *Australian Charities and Not-for-profits Commission Regulation 2013*.

DocuSigned by:

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Anthony Ball
DIRECTOR

DocuSigned by:

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Richard Arnheim
TREASURER

Dated this 25th day of October 2022

**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES**

Report on the Audit of the Financial Report

Opinion

We have audited the financial report of Muscular Dystrophy Association of New South Wales (the Company), which comprises the statement of financial position as at 30 June 2022, the statement of profit or loss and other comprehensive income, statement of changes in equity and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies, and the Directors' Declaration.

In our opinion, the accompanying financial report of Muscular Dystrophy Association of New South Wales has been prepared in accordance with Division 60 of the *Australian Charities and Not-for-profits Commission Act 2012* (the ACNC Act), including:

- (i) giving a true and fair view of the Company's financial position as at 30 June 2021 and of its financial performance for the year then ended; and
- (ii) complying with Australian Accounting Standards – Simplified Disclosures and Division 60 of the *Australian Charities and Not-for-profits Commission Regulation 2013*.

Basis for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor's Responsibilities for the Audit of the Financial Report* section of our report. We are independent of the Company in accordance with the ACNC Act, the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110: *Code of Ethics for Professional Accountants* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Emphasis of Matter

We draw attention to the following:

1. Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared in accordance with Australian Accounting Standards – Simplified Disclosures of the Australian Accounting Standards Board and the *Australian Charities and Not-for-profits Commission Act 2012*. As a result, the financial report may not be suitable for another purpose;
2. The impact of COVID-19 pandemic on economic activity globally, combined with the uncertainties it has generated in Australia, has created operational challenges for the Company. At the date of signing this financial report, the directors have considered the potential impact of the COVID-19 pandemic on the Company's financial position and have determined that no material adjustments are required to be disclosed in the financial report for the year ended 30th June 2022; and

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES

3. Collections and fundraising income amounting to \$10,936 for the Company for the 2022 financial year. It is not always possible for the Company to establish controls over the collection of all sources of fundraising income prior to entry into its financial records. Accordingly, as the evidence available to us regarding revenue from this source was limited, our audit procedures with respect to fundraising and donation income had to be restricted to amounts recorded in the financial records. We therefore are unable to express an opinion whether the collections and fundraising income of the Company is complete.

Our opinion is not modified in respect of the above matters.

Information Other than the Financial Report and Auditor's Report Thereon

The directors are responsible for the other information. The other information comprises the information included in the Company's annual report for the year ended 30 June 2022, but does not include the financial report and our auditor's report thereon. Our opinion on the financial report does not cover the other information and accordingly we do not express any form of assurance conclusion thereon. In connection with our audit of the financial report, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial report or our knowledge obtained in the audit or otherwise appears to be materially misstated. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Responsibilities of the Directors for the Financial Report

The directors of the Company are responsible for the preparation of the financial report that gives a true and fair view in accordance with Australian Accounting Standards – Reduced Disclosure Requirements and the ACNC Act and for such internal control as the directors determine is necessary to enable the preparation of the financial report that gives a true and fair view and is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the directors are responsible for assessing the Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the directors either intend to liquidate the Company or to cease operations, or have no realistic alternative but to do so.

Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES

As part of an audit in accordance with the Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the Company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the directors regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES**

Report on Other Legal and Regulatory Requirements

In addition, our audit report has also been prepared for the members of the Company in accordance with Section 24(2) of *Charitable Fundraising (NSW) Act 1991*. Accordingly, we have performed additional work beyond that which is performed in our capacity as auditors pursuant to the *Australian Charities and Not-for-profits Commission Act 2012*. These additional procedures included obtaining an understanding of the internal control structure for the fundraising appeal activities and examination, on a test basis, of evidence supporting compliance with the accounting and associated record keeping requirements for fundraising appeal activities pursuant to the *Charitable Fundraising (NSW) Act 1991* and Regulations.

It should be noted that the accounting records and data relied upon for reporting on fundraising appeal activities are not continuously audited and do not necessarily reflect after the event accounting adjustments and the normal year-end financial adjustments for such matters as accruals, provisioning and valuations necessary for year-end financial report preparation.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Dated this 2nd day of November 2022 at North Parramatta

**McCARTHY SALKELD
AUDIT PTY LTD**





Jane Perry FCA

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