

Talking Point

MUSCULAR DYSTROPHY NSW NEWSLETTER AUGUST 2021



Peers Connect at Newcastle Retreat

On Friday 21 May, a group of 22 adults living with MD and their partners and carers arrived at a very wet Newcastle Rydges Hotel for the Peer Connect Retreat. After checking into to our lovely rooms with a view of the harbour, we shared a delicious three course dinner watching the ships and tug boats pass by. We got to know each other playing a fun facts guessing game, a lot of catching up was done, and some new friendships were made. As we gathered for our 'family photo' two people's mobility scooters got hilariously 'hooked up'- a real comedy sketch moment.

Over breakfast, people talked about all sorts of things such as wanting to go to theatre shows and talked about the challenges of booking accessible tickets; safely using accessible buses and trams and planes; and their experiences in hospital and how when they don't fit the box, sadly they don't get good treatment or care! There was so much people had in common, and so much to learn from each other.

On Saturday, the sun came out and a group of us set out for a long flat drive along the waterfront, stopping and chatting to people and puppies galore! Once we found the 'How's the Serenity?' mural we knew we had to pose for a pic, and somehow roped a couple of guys in muscle

Above: Marie, Carolyn, Michelle, Lisa and Christie out and about in Newcastle

tees into our shot. Ah the irony of people without muscle power 'muscling' the body builders into our photoshoot!



Comparing muscles with some locals

One participant tried out his new smart drive for the first time with coaching from two regular users - true peer support in action! For one participant this was her first night away from her Mum in 25 years, and she also hired an electric wheelchair and experienced the independence and freedom it offered - we were all so proud of her getting out of her comfort zone and trying new things!



WELCOME FROM THE CEO

Welcome to your quarterly edition of Talking Point, where you get a comprehensive summary of what's been happening in our community and a look at what's planned across our programs and events.

As most of you would be aware, we sadly had to cease all face to face programs and meetings due to the resurgence in Covid-19 cases across Sydney and the subsequent lockdown restrictions.

This has meant the cancellation of Siblings Day Out and our much-anticipated Snow Camp, for the second time in a row. We have also postponed any face-to-face Peer Connect meet ups, limiting them all to online for now.

We are so appreciative of your patience and understanding during this drawn out and very challenging time and we take assurance in your support in prioritising everyone's health and safety.

I encourage you to read this edition to find out about all the great virtual meet-ups we have coming up through Peer Connect, and also hear about our last face-to-face meet-ups prior to lockdown - the Myotonic MD Meet-up, Peers in Action Dooley's lunch and the Peer Connect Retreat!

I'd also like you to join me in farewelling long-serving Board Director Assoc. Prof. Kristi Jones as we welcome two new Directors to our Board, Tait Jenkins and Assoc. Prof. Michelle Farrar. We also have a new member of staff, Henry, joining the team.

Lastly, it's not too late to renew your membership for 2021/22 financial year. Just go to our website and you can renew online or give us a call and a member of the team will happily help you out.

I hope you enjoy the read!

Stay safe, yours sincerely,

CHARLOTTE SANGSTER CEO, MDNSW

cont. Peers Connect at Newcastle Retreat

The Peer Connect Retreat gang



A group had a lovely time visiting the markets, checking out the sustainable straw stall and everyone bought handcrafted gifts for themselves or others. And then there was all this honking and cheering and what do you know...the Variety Club car rally was in town beeping and waving at us as they streamed by!

On Saturday night, the group decided they wanted to eat together and although it was tricky to find a booking, a lovely dinner was had by all at The Landing bar, with some people utilising their chairs power elevation function to reach the bar tables. More hilarity was had at the games night, before Sunday morning trivia and everyone sharing their review of the retreat.

Although there were some challenges with ensuring everyone had the exact access features they required, the hotel were very accommodating and have even purchased some bed raisers to use when needing to raise guest's beds if required! It was a great location to have the Retreat as people got to explore museums, the local scenery and do as much or as little as they liked, and loved the opportunity

to deeply connect with others and experience timeout from home and the regular routine.

“ Thanks all for a fantastic weekend. It was great getting to meet so many people and be able to chat about all manner of things not only to do with our problems of managing day to day life...it has been too long since I have been in a group of people - last time would have been March last year. It also felt like we had a weekend away from COVID - it was very much in the background with check in scanning and sanitiser everywhere, but being able to mix as a group without fear and venture out amongst people was like a breath of fresh air.

I don't think I could suggest anything better than what we had for the weekend - that blend of organised and free time. The hotel was great, the room was perfect for us and the location sublime. Being able to just roll out the door and explore so far on the flat was brilliant - and so much to see.”

Joanne, Peer Connect Retreat participant

Article by Carolyn Campbell-McLean

Peer Connect

CALENDAR July - September

	MON	TUES	WED	THURS	FRI	SAT	SUN
JUN			30 JUN Siblings Day Out Go Karts & Virtual Reality	1 JULY		3 JULY 11am-3pm Peers in Action Boccia Social Day @ Dooleys Waterview Silverwater - Lunch provided	
JULY		6 JULY 5-6pm Power Hour Online - an online group for young men who are powerchair users	7 JULY 5-6pm Girl Power - an online group for girls living with MD aged 10-16 yrs			9-12 JULY Snow Camp @ Jindabyne	
	Snow Camp @ Jindabyne	13 JULY 7.30-9pm LGMD Online					
		20 JULY 5-6pm Power Hour Online	21 JULY 5-6pm Girl Power	22 JULY 7.30-9pm Mums Wine & Chat			
				29 JULY 11am-1pm Info Share Online Getting started with Support Workers			
AUGUST		3 AUG 5-6pm Power Hour Online 7.30-9pm SMARTies - via Zoom	4 AUG 5-6pm Girl Power				
						13 AUG 6-9pm Peers in Action Black Friday Tech Talk & Game Night @ Lidcombe & streamed - Free Pizza	
		17 AUG 5-6pm Power Hour Online	18 AUG 5-6pm Girl Power	19 AUG 7.30-9pm Mums Wine & Chat			
				26 AUG 11am-1pm Info Share Online Looking for Love Guest speaker - Liz Dore			
SEPTEMBER		31 AUG 5-6pm Power Hour Online	1 SEPT 5-6pm Girl Power				
					10 SEPT	11 SEPT 12-3pm Peers in Action Social Lunch @ Dooleys Lidcombe - Lunch provided	12 SEPT
					Mums Retreat for Northern NSW Mums @ Yamba		
		14 SEPT 5-6pm Power Hour Online 7.30-9pm FSHD Friends Online	15 SEPT 5-6pm Girl Power	16 SEPT 7.30-9pm Mums Wine & Chat			
			29 SEPT 5-6pm Girl Power	30 SEPT 11am-1pm Info Share Online NDIS Tips & Tricks		1 OCT	
		Siblings Camp @ Collaroy					

For more info or to register contact:

- Jenny on 0431 690 629 or jenny.smith@mdnsw.org.au for Mums & Siblings events
- Mitch on 0417 062 212 or mitch.taylor@mdnsw.org.au for Power Hour
- Carolyn on 0408 472 510 or carolyn.cm@mdnsw.org.au for all other events

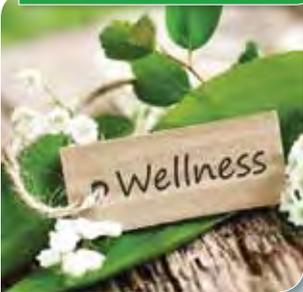
Peer Connect 2021

MUSCULAR DYSTROPHY NSW BUILDING STRENGTH REACHING POTENTIAL

Northern NSW Mums' Retreat

A Retreat exclusively for mums with a child with a neuromuscular condition

Fri 10 - Sun 12 Sept 2021



This weekend retreat is a chance to get away, to share stories and connect with other mums who have a child with a neuromuscular condition, staying at Angourie Resort & Spa, Yamba.

Angourie Resort is surrounded by a lush subtropical rainforest and unique natural wonders. Yamba, is the hidden jewel of the North Coast with spectacular beaches, and picturesque lookouts.

Accommodation will be in a number of 2-bedroom cabins with a variety of activities on site, such as a pool, tennis courts, bike hire and a gym.

Enjoy a brief time-out in the peace and tranquillity this beautiful resort has to offer.

\$100pp *Places are strictly limited!*

Price includes 2 nights shared accommodation and some meals.

RSVP Register your interest by emailing Jenny at jenny.smith@mdnsw.org.au or call on 9888 5711 ext. 3 or 0431 690 629 by Thurs 12 August 2021

mdnsw.org.au

Bring your Chair and let the good times roll!

MUSCULAR DYSTROPHY NSW BUILDING STRENGTH REACHING POTENTIAL

SUMMER CAMP 2021

Sat 18 - Wed 22 Dec | Sydney Academy of Sport Narrabeen

TRY SOMETHING NEW

Our Summer Camp gives kids aged 6-18 living with a neuromuscular condition who use a power chair for mobility the chance to experience teamwork and the thrill of a challenge, bonding with their peers, and reaching a huge sense of empowerment, achievement and inclusion.



REACH YOUR POTENTIAL

Camp is about kids stepping outside their comfort zone and learning to believe that they are strong individuals, capable of achieving remarkable things! Our activities provide something for everyone and are carefully designed so that everyone can take part.

"I had such a fun time at Camp this year! I especially liked my carer, Millie, who was super funny and cool. She took me swimming in the pool, we played laser tag and plotted multiple pranks on the other campers. She was my arms and legs the whole time I was there."
- Kamal (2019 Summer Camper)

MAKE LIFELONG FRIENDS

Are you ready for the most fun you can possibly have in five days? Build lifelong friendships, resilience and confidence in a safe, inclusive and fun environment.

"Daniel had a fantastic time, caught up with old friends, made new ones, was completely silly and even managed to miss his family, just a little. When he returns from camp each year we see a massive growth in self-esteem and confidence. Words cannot describe what this week away means to him."
- Joanne (parent)

To register or find out more information, please contact Mitch at mitch.taylor@mdnsw.org.au or on 0458 026 532, or Jenny at jenny.smith@mdnsw.org.au or on 9888 5711 ext 3

YOUR COST?
\$120 (this is a non refundable administration fee paid by you and is not covered in your NDIS package)

NDIS FUNDS COVER

All meals, accommodation and equipment hire. There will be at least one carer to each camper and a nurse on site.

MDNSW reserves the right to charge a cancellation fee due to the complex planning and preparation needed for these events.
Cancellation within 1 month of the event may incur a cancellation fee of up to 50% of the scheduled costs, and cancellation within 2 weeks of the event may incur a cancellation fee of up to 100% of the scheduled cost.



mdnsw.org.au

Peer Connect

MUSCULAR DYSTROPHY NSW BUILDING STRENGTH REACHING POTENTIAL

Siblings Camp

Wed 29 Sept - Fri 1 Oct 2021

Meet new friends and connect with others who also have a brother or sister with Muscular Dystrophy

For ages 6 - 16



Explore the bush setting. Spend some time at the beach. Hang out and play some games.

- Beach games • Flying fox
- Laser tag • High ropes
- Orienteering • and much more!

COST?
\$30 per child or **\$50** for two or more

WHERE?
Collaroy Centre
22 Homestead Ave, Collaroy Beach

RSVP Register your interest by emailing Mitch at mitch.taylor@mdnsw.org.au or call 0458 026 532 by Wed 30 July 2021



Spots are limited!

mdnsw.org.au | 80 Betty Cuthbert Drive, Lidcombe NSW 2141

Peer Connect 2021

MUSCULAR DYSTROPHY NSW BUILDING STRENGTH REACHING POTENTIAL

Sydney Mums' Retreat

Places are strictly limited!

A Retreat exclusively for mums with a child with a neuromuscular condition

Fri 22 - Sun 24 Oct 2021



This retreat is a chance to get away and connect with other mums who have a child with a neuromuscular condition, staying at Del Rio Riverside Resort, Wisemans Ferry.

Del Rio is set on 3kms of beautiful Hawkesbury River frontage at Wisemans Ferry surrounded by a majestic mountainous backdrop. Accommodation will be in a number of small cabins overlooking the river, with a variety of activities on site. The resort also has a small licensed sports club on site.

Enjoy a brief time-out in the peace and tranquillity this beautiful resort has to offer.

\$100pp

Price includes 2 nights shared accommodation and some meals.

RSVP Register your interest by emailing Jenny at jenny.smith@mdnsw.org.au or call on 9888 5711 ext. 3 or 0431 690 629 by Thurs 23 Sept 2021

mdnsw.org.au

Say "Hi" to Henry our new NDIS Support Coordinator

“ I am a Nigerian immigrant and have resided in Australia for 11 years now. I am married with 3 amazing daughters. I have mainly worked in the community services sector all through my migration journey. I have worked across disability, Out of Home Care residential settings and the corrective services sector.

My new role as a NDIS Support Coordinator at MDNSW has been an interesting one. I have enjoyed my time so far. I work with a supportive team and a positive work environment with staff members who are friendly and helpful. My main challenge has been the Covid-19 pandemic, which has restricted my visits to my clients, but I hope that soon this will be a thing of the past.

In my new role, I will be supporting NDIS participants through the life of their plans, to support them in achieving their goals and reaching new ones. I intend to work with proven and high standard service providers to ensure client focus services are delivered.”



Henry looks forward to meeting you!

PEERS IN ACTION PEERS & FAMILIES SOCIAL LUNCH

Our first face-to-face Peer Connect event in 18 months was held on Saturday 1 May over lunch at Dooleys Club in Lidcombe.

We had a great turn out with 18 adults with MD and their families and carers joining together to reconnect, meet others and chat about life.

The group enjoyed sharing their stories and exchanging handy information over a delicious lunch at Lloyds Bistro. Despite the value of online meet-ups, it is obvious that people really do value meeting up in person.

One participant said they liked:

“ seeing the community face-to-face and talking to people.”

Another commented that they:

“ always enjoy the interaction when meeting new folk and to hear how we are all handling MD.”

Everyone said that attending the day helped improve their motivation and confidence. Thanks to those participants who were interviewed about the return to face-to-face programs on the day.

We're hoping to hold another lunch before the end of the year, depending on Covid-19 lockdown restrictions.



Great chats with great food and people

Myotonic Meet-up Wrap up

On 15th June, we held our first specific peer group for people with Myotonic MD and their families. Twelve people came together to share coffee, cake and conversation. They asked each other questions, shared their experiences and offered advice and support.

The topics discussed included accessible and safe housing, health, end of life planning, NDIS,

choosing therapies, clothing and starting work. The conversations continued over lunch, and people shared contact details to stay in touch. Two families came all the way from the Central Coast to discover they live in the same neighbourhood! The next Myotonic Meet-up will be held in November.

“ Good to meet other people and hear other people's stories.”



Our first Myotonic Meet-up was a success!

said one participant.

“ You are not alone. There are people in same boat, who are going through same problems and share how they are getting through.”

said another participant.

My mates been diagnosed with an NMC

CONDITION: **HELP!!!**

Article from The Loop | Your Neuromuscular Resource Hub



The Loop

Your Neuromuscular
Resource Hub

It can often be difficult (and at times awkward) for the friends and family of someone recently diagnosed with a disability to know what to say and how to best support them.

The Loop - Your Neuromuscular Resource Hub has a great article from one of its community members, Sarah Shaw, to help you through it all.

“ Firstly, congratulations for seeking out information, being open to actually learning about the conditions and what you need to know to support your mate is a fantastic first step. Secondly, let’s start the journey by acknowledging that you’re probably going to realise at some point that you’ve done something that was hurtful, said something hurtful to your mate. That’s okay the reality is that sometimes it is very hard not to. There are some things you can do to be a better friend to them though.

Here are 10 things I wish all my friends knew when I was diagnosed till now:

1. Throw out all the clichés about chronic illness and disability that are typically used to discuss it. Don’t talk about karma or God only giving you what you are strong enough to bear. Just acknowledge that it is what is and what it is, is not great.
2. If you need to talk to someone about what my future might look like, I’m not your go to girl. When I’m ready I’ll do all of those responsible things like planning for the future. Let me do the hard stuff in my own time.
3. I’m still me, everything I enjoyed doing pre-diagnosis I still love. Every dream I had is still there. So, include me in everything if at all possible, especially all of your important life moments.
4. I still need to feel needed. One of my greatest joys pre-diagnosis was being able to do things for others, give to others. That doesn’t stop just because I now have a condition. Let me do that.

5. I still need to know all about you and your life including medical stuff. This is not a competition and I am not winning. Tell me about how awful the flu made you feel, and how your morning sickness is driving you insane. This friendship thing goes both ways.
6. One of the negatives of living with a disability is the planning. Having to ring restaurants and make sure they can accommodate the chair. If we are going out don’t delegate that to me all the time to organise, you can have those conversations just as well as I can.
7. Don’t make sweeping statements about doing anything I need. Tell me what you are actually comfortable doing and if you offer and I accept, follow through.
8. I may have periods where I don’t want to talk about it at all, I may have periods where I need to discuss it loads. Be willing to be there for all of it. Keep checking in.
9. Friendships evolve and grow over time. Keep evolving with me. Being diagnosed with an NMC is like being taken to a foreign country where you don’t know the language or the customs. Be interested enough to at least learn enough of the language and the customs so that we can still connect with each other.
10. Having a visible disability attracts paternalism and a loss of agency in this community. I may therefore sometimes be more sensitive than I was previously in some instances. Educate yourself on what ableist language is so that you know why I’m reacting the way I am.”

Read more stories from The Loop at
www.theloopcommunity.org

Inviting all members to join us for

SUGAR FREE SEPTEMBER

Have you ever thought about giving up sugary food like cakes and lollies but never had the motivation?

Why not go #SugarFreeForMD?

You’ll be helping your health and empowering the muscular dystrophy community. It’s a win-win!



MUSCULAR DYSTROPHY NSW
BUILDING STRENGTH
REACHING POTENTIAL



WHEN 1-30 September 2021

HOW Give up refined sugar - don’t worry you’ll have full support from our team!

WHY Empower our MD community to live the life they choose, by raising awareness & funds for vital programs like Camps, Retreats, Independent Living Skills Programs, Peer Connect & Advocacy



www.sugarfreeseptember.org.au



Changes to the MDNSW BOARD

Farewell to Associate Professor Kristi Jones who joined the MDNSW Board in 2006 and for the past 15 years has played an integral role in the success of many of our programs and activities.

She threw her support behind the PhD Scholarship program offered by MDNSW and has been a strong advocate for our commitment to research into NMCs. She has also been an active MDNSW fundraiser over the years.

Kristi brought her scientific knowledge, expertise and passion to support the neuromuscular community and she will be greatly missed.

Welcome to new Board Director Tait Jenkins, who is an Analyst within KPMG's Audit, Assurance & Risk Consulting division and a



former Australian boccia player! He has held several other governance positions most notably within Boccia NSW and Boccia Australia.

At 18 months of age Tait was diagnosed with Spinal Muscular Atrophy Type 2 and is driven to ensure others with neuromuscular conditions are also able to achieve their life goals.

Welcome also to Associate Professor Michelle Farrar, who works in Paediatric Neurology at UNSW Sydney and is a specialist child neurologist at Sydney Children's Hospital, leading the Neuromuscular clinical and research programs. Michelle and her team are doing game changing work in gene therapy for the treatment of children with Spinal Muscular Atrophy.

Pictured Top-Bottom: Associate Professor Kristi Jones, Tait Jenkins and Associate Professor Michelle Farrar

AUSTRALIAN BOCCIA PLAYERS READY TO 'SHAKE THINGS UP' AT TOKYO 2020

Daniel Michel competing for Australia



Australia will field its largest boccia team in more than two decades at the Tokyo Paralympic Games with Daniel Michel, Spencer Cotie and Jamieson Leeson confirmed as members of the Australian Paralympic Team. (Note: Daniel and Jamieson are both members of the MDNSW community!).

"We don't have much in the way of rich boccia history in Australia - we won a medal in Atlanta in '96," said Daniel, who competed in Rio in 2016 and is ranked No.4 in the world in the Individual BC3 classification.

"This is the first time in a long time that we're going to have a team at a really competitive level.

It's exciting to be part of that. It's a great opportunity to bring boccia to the forefront in Australia and get more talking about it, more people involved and to grow the sport."

Join AUS Squad and stay up-to-date with the latest news from the Australian Paralympic Team as they get set for Tokyo.

Boccia is played exclusively by athletes with high levels of impairment. Competing in wheelchairs, athletes

throw, kick or use a ramp device to propel leather balls as close as possible to the 'jack'.

Daniel won his first pool match at the Rio Games but lost his second and did not advance. He won the bronze medal in the Individual BC3 at the 2018 World Championships in England and teamed with Cotie to claim silver in the Mixed Pairs BC3.

"Spencer's come along in leaps and bounds," Daniel said. "He started competing internationally back in 2016, 2017, and has really applied himself since then. All the momentum that's come his way he really deserves. He's put the hard yards in and I'm excited for him that he gets to compete in Tokyo."

Of Jamieson, who is in Year 12 at Dunedoo Central School in the NSW Central West, Daniel said: "Jam's

come along very quickly. She came into the sport maybe about 18 months ago and is now a vital member of the team.

"I've really enjoyed being a part of her development and seeing her move forward."

Paralympics Australia Chief Executive Lynne Anderson said: "Only 15 boccia players have competed for Australia at the Paralympics since the sport was introduced in 1984 and I'm so proud of Spencer and Jamieson for the hard work they've put in to join that list."

"With Dan leading the way, this is a Team of fine ambassadors for our country and for the sport. I hope all three will feel boosted by the strong support they'll have back home when they compete at the Ariake Gymnastics Centre in Tokyo."

A TRIBUTE TO Michael Reid

29/08/1991 - 15/10/2012



When Michael suddenly passed away he was happy and in a pretty good place. He had a great 21st birthday; a couple of parties, and a holiday cruise with family and friends....At his passing, he seemed to be more at ease with all the things a young man needed to do and was realising his capabilities to deal with life.

Read more of this beautiful tribute from Michael Reid's father, Dave on our *In Memoriam* page, visit www.mdnsw.org.au/in-memoriam. You can also contribute your own tribute to a lost loved one.

WE'RE SUPPORTING THE AUSTRALIAN NEUROMUSCULAR DISEASE REGISTRY

The Australian Neuromuscular Disease Registry (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.

MDNSW has partnered with the ANMDR because we believe in their work and the benefits it can bring to our community.



To learn more, or to register, please visit www.australianmdregistry.org.au



Ask a SCIENTIST

Question from MD community member, Joanne

“ Just wondering if you could shine some light on any research that is going on around the world about LMNA CMD. I had heard over the parents grape vine that there may be a link with a second gene mutation causing muscle regeneration in some patients. Another area of interesting research has been on the progression of heart involvement. My son is now 12 and I am wondering what signs we should be monitoring for that may lead to discovering heart involvement we had not been looking for. ” - Joanne

Answer from Dr Manoj Menezes, Paediatric Neurologist & Head of Neuropathy at the Kids Neuroscience Centre

“ There is a significant amount of research going on worldwide into improving the muscle and cardiac abnormalities in LMNA-CMD. The Cure CMD website is an excellent place to start. Our protocol at The Children's Hospital at Westmead is for all children with LMNA-CMD to be referred to a cardiologist with expertise in neuromuscular disorders, and for them to have an annual holter monitor, echocardiogram and cardiology review. Signs of heart involvement can be varied and should be discussed with your cardiologist. ”

Contact and Feedback

We value your feedback!

If you have any feedback on what we are doing well or how we can do things better, please contact us.

Feedback, including complaints is an essential part of our improvement process.

You can provide your feedback through the following channels:

by post Muscular Dystrophy Association of NSW;
80 Betty Cuthbert Drive, Lidcombe
NSW 2141

email info@mdnsw.org.au

phone 02 9888 5711 or

free call 1800 635 109

website mdnsw.org.au/contact-feedback

follow us...

