

TALKING POINT

**MUSCULAR
DYSTROPHY NSW**
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

MUSCULAR DYSTROPHY NSW NEWSLETTER AUGUST 2022

SUGAR FREE SEPTEMBER

REGISTRATION IS NOW OPEN!



**We are happy to announce that
MDNSW's Sugar Free September is back for 2022!**

And we're inviting you to support your neuromuscular community by joining us to go sugar free for kids and adults with MD this September.

Together we will take on the one month challenge and at the same time raise vital funds and awareness to help empower, connect and support people living with a neuromuscular condition.

SIGN UP NOW!

www.sugarfreeseptember.org.au

WELCOME FROM THE CEO



Welcome to your quarterly edition of Talking Point. I want to share with you the difficult decision we had to make last month, which was to cancel our Summer in Winter Camp scheduled for the 7-11th July. This was primarily due to the hazardous weather and flooding across Greater Sydney leading up to the week Camp was due to start.

After an assessment of the increased risk and consultation with the camp venue, we made this decision with the safety and wellbeing of our community and camp participants as our top priority. Whilst it pained us to have to do so, we know that this is the best decision given the dangerous and unpredictable conditions in the area.

Thank you so much to the parents, children and camp carers for your patience and understanding during this uncertain and very challenging time. We appreciate your support and trust, and we hope to reschedule Summer Camp back to December this year when it is usually held.

In good news, we've had a lot of activity and participation through our online Peer Connect program, with a few recaps for you to read. There's a lot scheduled in this space over the next couple of months too, so be sure to check out our calendar on page 3 to see what's scheduled.

I'm also excited to announce the confirmed date for our annual Neuromuscular Information & Research Day as Saturday, 22 October 2022. Keep an eye out for program announcements soon on our website!

Lastly, next month brings our annual fundraiser, Sugar Free September. We're excited for another exciting campaign, with lots of prize incentives and helpful nutrition resources available. Your support by joining the challenge would be greatly appreciated, you could even join our MDNSW team – eMpowered! See our cover page article for all the details.

I hope that you are all safe and well, especially those in flood affected areas. Our thoughts are with you all!

Yours sincerely,

CHARLOTTE SANGSTER (she/her), CEO, MDNSW

IF YOU'RE WONDERING WHY YOU SHOULD TAKE ON THE CHALLENGE...



📣 2 in 1 - great opportunity to improve your own health as well as support people living with neuromuscular conditions.

😊 Health benefits - more energy, better sleep and life-long healthy habits plus nutrition guidance and resources from our education and nutrition partners.

🎁 Sweet rewards - exclusive free e-cookbook with delicious sugar free recipes, access to awesome fundraising prizes including a Hurom cold press juicer (worth \$649!), a month of free meals from Able Foods, access to a month of free online yoga classes, gift vouchers and more!

❤️ Amazing cause - your support will help kids, adults and their families impacted by MD to access camps, retreats and independence living skills program, peer connection, support coordination and advocacy.

“ My name is Fletcher and I'll be cheering you along on your Sugar Free journey for the entire month! Your support helps kids like me, living with Muscular Dystrophy, do the things we love, like going to Camp and playing sports. ”



As always, we'll be here to support you every step of the way with recipes, fundraising tips and sugar free inspiration to make your challenge extra sweet!

Create a Team or just register yourself. You'll be making a meaningful difference for others and improving your health at the same time, it's a win-win!

www.sugarfreeseptember.org.au

PEER CONNECT CALENDAR

July - September 2022

	MON	TUES	WED	THURS	FRI	SAT	SUN
JULY				7-10 JUL CANCELLED	🔥 Summer Camp in Winter @ Narrabeen		
		12 JUL 🚶 5-6pm Power Hour online 7.30-9pm FSHD Friends online					
		19 JUL 🚶 5-6pm Power Hour online			22 JUL 🎄 12-2pm Christmas in July Presents, lunch, vouchers & games via Zoom		
		26 JUL 🚶 5-6pm Power Hour online	27 JUL 👧 5-6pm Kids Club online	28 JUL 🍷 7.30-9pm Mums Wine n Chat online			
AUGUST	1 AUG SMA Awareness Month	2 AUG 🚶 5-6pm Power Hour online					
		9 AUG 🚶 5-6pm Power Hour online 7.30-9pm SMARtles online					
		16 AUG 🚶 5-6pm Power Hour online		18 AUG 🍷 7.30-9pm Mums Wine n Chat online	19 AUG 🔪 11am-3pm MD Makers: Creative Workshop & Showcase @ Silverwater		
		23 AUG 🚶 5-6pm Power Hour online	24 AUG 👧 5-6pm Kids Club online	25 AUG 💻 11am-1pm Info Share online Advocacy in Action: The issues that matter to you			
		30 AUG 🚶 5-6pm Power Hour online					
SEPTEMBER		6 SEPT 🚶 5-6pm Power Hour online	7 SEPT World Duchenne Day				
		13 SEPT 🚶 5-6pm Power Hour online 7.30-9pm LGMD Connect online					
		20 SEPT 🚶 5-6pm Power Hour online		22 SEPT 🍷 7.30-9pm Mums Wine n Chat online		24 SEPT 🌳 12-3pm Spring Roll & Picnic @ Bicentennial Park	
		27 SEPT 🚶 5-6pm Power Hour online	28 SEPT 👧 5-6pm Kids Club online	29 SEPT 💻 7.30-9.30pm Info Share online Accessible Transport & Travel	30 SEPT LGMD Awareness Day		

For more info or to register contact:

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

mdnsw.org.au Please note that event dates may change - visit MDNSW website or contact Carolyn for the latest updates

Peer Connect 2022

MUSCULAR DYSTROPHY NSW
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

SpringRoll

Get together with our MD community to celebrate the arrival of Spring!

Saturday 24 September | 11am - 3pm



JOIN US FOR A FUN DAY OUT!

- Accessible roll around the scenic parklands
- Treasure hunt
- Kite making & flying
- Bubble machine & games
- Fun food & delicious drinks provided
- BYO picnic chairs/rug
- Great prizes for best dressed in Spring Colour!

This is a **COVID safe** event so up-to-date vaccination status, social distancing, & check-in is required. RAT testing prior to arrival & masking while not eating & drinking is encouraged.

COST?
This is a **FREE** event for people with NMCs, their families & friends

WHERE?
Bicentennial Park | Egret Pavilion
Sydney Olympic Park

DRESS?
Spring Colour!

RSVP
Carolyn at carolyn.cm@mdnsw.org.au or on 0408 472 510 by Thurs 15 Sept with dietary requirements & numbers attending

mdnsw.org.au

MUSCULAR DYSTROPHY NSW
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

SUMMER CAMP 2022

SYDNEY ACADEMY OF SPORT, NARRABEEN

Wed 14 - Sun 18 December 2022

TRY SOMETHING NEW

Summer Camp is for kids aged 6-18 living with a neuromuscular condition who use a power wheelchair for mobility. Summer Camp will be 5 fun-filled days of connecting with peers, that offers a chance to experience teamwork and the thrill of a challenge, where campers can build on their independence and decision making skills.



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 all campers can participate.

"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 four 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 8986 9004, or Jenny at jenny.smith@mdnsw.org.au or on 0431 690 629

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.

MDSNW 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 cost, and cancellation within 2 weeks of the event may incur a cancellation fee of up to 100% of the scheduled cost.



mdnsw.org.au

BECOME A TEAM MD LEGEND,

Like Scot & Katie

A big THANK YOU to our community fundraisers – Scot and Katie, who challenged themselves in support of their loved ones with MD.

Scot shaved his head on Saturday, 14 May in support of people living with a neuromuscular condition, including his nephew Hugh Shipman who turned 18 on the day.

Katie ran in the Sydney Half Marathon on Sunday, 15 May in honour of her friend, Sarah Jenkins, who lives with a neuromuscular condition.



“ Despite Sarah's disability she gets up everyday with a can do attitude and continues to live life to the fullest. Having been part of her life for the last 4 years it has motivated me to get moving everyday and be so grateful for my ability to move. I am running for those who can't. ”

If Scot and Katie's stories have inspired you, why not create your own challenge today? Every dollar raised goes straight towards supporting our amazing neuromuscular community!

Join Team MD today!

www.team-md.org.au

SAVE THE DATE! Saturday 22 October 2022 | 1pm - 4.30pm

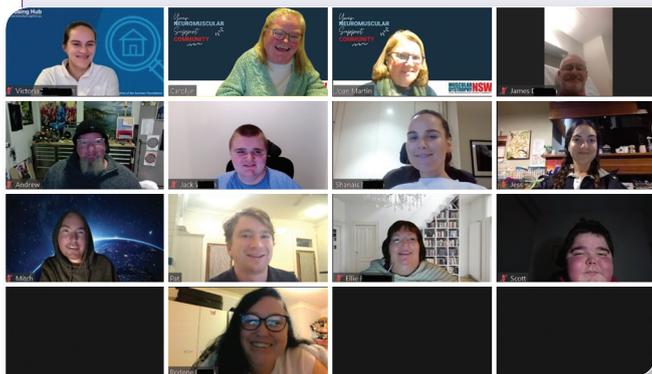
NEUROMUSCULAR Information & Research Day

The 2022 Neuromuscular Information & Research Day is on its way! Save Saturday, 22nd October in your calendar, so you don't miss out on this popular, free, online event for our neuromuscular community.

Program details and registration to be announced soon!

CLIENT SERVICES

PEER CONNECT WRAP UPS



Peers talk Independent Living & Support

Our June Info Share session was all about independent living and support. Ten peers joined knowledgeable guest speakers from Housing Hub and Hireup to hear all about different ways to achieve this dream goal. We heard from members in our community about how they have gone about moving out of home, securing accessible housing, and finding supports that suit them. Thanks to Andrew, Jack and Scott who shared their successes and challenges with the group – how powerful is peer to peer sharing?!

Topics covered included supported disability accommodation (SDA), Independent Living Options (ILO), priority housing and university campus accommodation. Some of the key messages to come from this discussion is that there are different options depending on your stage in life, and preferences; that you can have a pet in an apartment; and there are others to talk with and support available to help you explore the options that might suit you.

Adults with Limb Girdle MD meet up

MDNSW members with Limb-Girdle MD got together online to meet and connect. It was wonderful to welcome some new people to the group, including participants from the Illawarra, Hunter and Riverina. It was a really lovely evening of support, sharing of story and learning from each other. Topics included developments in treatments, genetic counselling, managing personal care and toileting, accessible pools and advocacy issues.

One participant shared raw feelings about his decision to take the step of coming along to the group:

“ Tonight is my first time coming in contact with others with MD. Hearing about the experiences of Ray and Fran, that they are still getting about gives me a lot of courage. I'm feeling a bit emotional!! I am so glad Carolyn called me to invite me along and I just said yes! Carolyn replied with 'It takes bravery to front up to your first Zoom meeting, and everyone was so pleased to meet you!' ”

If you would like to join a Peer Connect session, please contact Carolyn on carolyn.cm@mdnsw.org.au or 0408472510. Also be sure to check out our Calendar on page 3 for what's coming up.

Mums Relax & Revive at the Sydney Mums' Retreat

A BIG thank you goes to the wonderful group of mums from our neuromuscular community who attended our Mums' Retreat earlier this month.

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.

Thank you also to the picturesque Crowne Plaza Hawkesbury Valley for providing us with the tranquillity and stunning scenery our Mums needed.

The Mums!



A recap of our newly named 'Lads by the Lake' weekend



Earlier this month, 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.'

Patrick, Scott and Brandon prepping their food

JOHN'S FIRST TIME AT ADVENTURE CAMP



Our Adventure Camp was held in April, and for 7 year old John who lives with Duchenne MD, it was his first time attending. We thought we'd ask him about his experience!

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 (Mum): "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!"

Left: John having fun in a puddle and with friends in the games room

CONNECTION, COMMUNITY & CELEBRATION at the Peer Connect Retreat

written by Carolyn Campbell-McLean

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 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 gratitude's 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.

Lisa, Jenny, Leah and Carolyn enjoying the waterfront despite the weather



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?!"

Here's what Margaret had to say, who attended the retreat with her husband, Brendan...

“ 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. Thanking you again. Great networking, great venue and gracious hosts. Perfecto! - Margaret Young ”

It was a great turnout for our return to Newcastle!



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 a NDIS debrief, sharing their challenges, frustrations and successes. As it happened two of the participants work for the NDIS!

Graham, Assad and Farah in Wonderland





Join the new FSHD PORTAL

The FSHD Global Research Foundation focuses on finding treatments and a cure for FSHD. In doing so, they fund world-class medical research, awareness, and education. In 2020, they brought research, awareness, and education together through the creation of the "FSHD Medical Education Portal".

The Portal is a 'one-stop shop' for people living with FSHD. It provides education on advancements in the disease as well as a platform to connect people to professional health services that work with and understand FSHD.

Find out more and register at www.fshdmedicalportal.org

Updated eligibility for oral COVID-19 Treatments

From 10 July 2022, more people with disability may be eligible to gain access to COVID-19 treatments, including:

- ● immunocompromised people over the age of 18
- ● people with a broader range of chronic respiratory issues
- ● adults living with disability who have multiple medical conditions

Talk to your doctor about your COVID-19 treatment options. They can help determine your exact eligibility.

Our Tax Appeal raised more than \$50,000 - Thank you!

Please accept our heartfelt thanks to those of you who chose to donate to Muscular Dystrophy NSW this tax time. I am happy to report back to you that we were able to raise more than \$50,000, thanks to generous supporters like you.

Children like Ryan, who are diagnosed with a neuromuscular condition, need early intervention to ensure they get a prolonged life that they choose. Ryan's involvement in MDNSW's camps helped him discover his true passion for Powerchair sports, form new friendships and ultimately reach his potential. In a few weeks' time, Ryan will be travelling to Switzerland along with his dad to represent Australia in an international hockey tournament.

We will make sure to report back to you on how Ryan goes in Switzerland :)

Donations made at this tax time means more children like Ryan will get the opportunity to attend camps, stay connected to their peers and find a community where they belong.

“ Thank you to all the generous people who donated to MDNSW. Your contribution helps other people like me, achieve new things, and live our best lives. You're all legends! Thank you. ” - Ryan



Our appeals income is unrestricted funding for our organisation, meaning it will be used across a range of our programs, in the areas where it is needed the most. Unrestricted funds are vital to keep our programs running sustainably and helps us to plan in advance, especially now that we are moving back to a face-to-face world again.

Thank you again for your generosity and support!

Watch Ryan's thank you video on our Muscular Dystrophy NSW YouTube channel YouTube

Contact & 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:

post Muscular Dystrophy Association of NSW; PO Box 1450, Parramatta NSW 2124

email info@mdnsw.org.au

phone 02 9888 5711 or

free call 1800 635 109

website mdnsw.org.au/contact-feedback



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BUILDING STRENGTH REACHING POTENTIAL