

Talking Point

MUSCULAR DYSTROPHY NSW NEWSLETTER FEBRUARY 2021



CARS trial a huge success!

L to R: Scott & Patrick having lunch in Manly, Monique, Carolyn & Julie catching up in the Blue Mountains, Andrew & Jasna at Bungoona Lookout

Throughout December, we ran our **Community Access and Recreation Service (CARS) trial** with members who expressed interest in participating. The trial saw three separate groups 'choose their own adventures', heading to fun and exciting places across Greater Sydney.

Good mates Scott and Patrick, who live on opposite sides of Sydney and rarely get to catch up in person, went for a pub feed in Manly and rolls along the beach parade.



Self-proclaimed foodies and good friends Carolyn, Julie and Monique went to Glenbrook in the lower Blue Mountains to check out a recommended café and soak in the fresh air, sunshine and amazing views.



because it is so difficult to get to, but when I learned of the CARS program I saw it as a unique chance to see somewhere new and different. ” Monique said.

Andrew and Jasna enjoyed all nature had to offer, taking a roll through the beautiful bush tracks of the Royal National Park. Andrew says,

“ I haven't been able to get out of Sydney for a number of years and I feel in a way like I've lost my connection with the natural environment. So, when the opportunity came to get out into the bush, the whole idea really resonated with me.

I felt on the day like I was having a holiday from disability. I was able to do things so far out of my day to day capabilities that I'd forgotten that things like this were even possible! ”



Submit your application for CARS today!

If you would like to participate in the CARS program, you can complete the paperwork now and go straight on our waiting list for the program.

Due to COVID-19, we've had to postpone the CARS program for now, but as soon as we are safe and secure in doing so, it will be back up and running and ready to take you on your next adventure!

Submit the application form and any enquiries to our Client Programs Coordinator Mitch Taylor at mitch.taylor@mdnsw.org.au or on **02 9888 5711 ext 2**.



Our President Anthony Ball and
CEO Charlotte Sangster

WELCOME FROM OUR PRESIDENT AND CEO

To record and celebrate the achievements of our community, during what was a particularly challenging year for everyone, we've developed a new Yearbook!

The Yearbook features highlighted events and activities from throughout the year and stories from our member community. It also acknowledges our hardworking staff, Board and volunteers, without whom we wouldn't be here.

Here's an excerpt from the President and CEO's message summarising the impact 2020 had on our MDNSW community:

“It is difficult to know where to start this last message for the year, as we both reflect on all of the things that have impacted the neuromuscular community and the broader Australian community over the last 12 months. From bushfires to floods and now the COVID-19 pandemic, all of which have devastated so many lives.

One thing we can be proud of is the incredible resilience that the neuromuscular community has shown during this period. We have witnessed a community of people pull together to support one another and connect like never before.

At MDNSW, we have seen this firsthand through the delivery of our Peer Connect groups, which have been moved to a virtual format and enabled people all over NSW to connect, support each other and share information.

We have also seen this through the incredible fundraising efforts of individuals and teams for Sugar Free September, with many families and individuals sharing their stories and raising awareness of Muscular Dystrophy. Thank you for your continuous support through these extraordinary times.”

You can download your own copy of the 2019-20 Yearbook from our website or contact our office and we'll email you a copy.

Thank you,

ANTHONY AND CHARLOTTE

CLIENT SERVICES

MD Life, Love & Loss Group

Recently MDNSW started a new peer connect group for people who have lost someone with MD so they can share their story, support each other and advise MDNSW's work in this space. We recognise that we have lost so many members over the years and grief is a life-long process. These families and carers have a great deal of experience and information to offer others.



In our first meeting, participants shared stories and memories of the person that they had lost, and about how they and their families were coping living with this loss. Participants found this a positive and supportive experience.

Some of the ideas the group discussed included:

- **Creating a Tribute or In Memoriam webpage for people we have lost to MD**
- **Walk 'In Memory' of a family member or friend lost to MD at the annual Big Red Roll and Stroll**
- **Mentoring of young men with Duchenne MD**
- **Writing stories that include tips and resources for The Peer Collective**

This group will meet 3-4 times each year via Zoom, and potentially face to face in the future. If you would like to join, please contact Carolyn on carolyn.cm@mdnsw.org.au or **0408 472 510**.

Peer Connect

CALENDAR January - March

	TUES	WED	THURS	FRI	SAT	SUN
JANUARY			7.30-9pm Mums Wine & Chat - an online group for Mums & carers of children & young people with MD/a NMC			
	Australia Day	6-7pm Power Hour - an online group for young men who are powerchair users	11am-1pm Info Share Online <i>Let's Talk about Sex & Relationships</i> Sexpert - Liz Dore	11am-1pm MD Life, Love & Loss - for people who have lost a loved one with MD		
FEBRUARY		5-6pm Girl Power - an online group for girls aged 10-16				
	7-9pm Limb-Girdle MD Peer Connect - via Zoom	6-7pm Power Hour		Chinese New Year	Valentine's Day	
		5-6pm Girl Power	7.30-9pm Mums Wine & Chat			
		6-7pm Power Hour	11am-1pm Info Share Online <i>Parenting with MD</i>			
MARCH		5-6pm Girl Power	Young Adults Weekend			
	7-9pm SMARTies Peer Connect - via Zoom	6-7pm Power Hour				10am Big Red Roll n Stroll @ Parramatta Park
		5-6pm Girl Power	7.30-9pm Mums Wine & Chat			
		6-7pm Power Hour	11am-1pm Info Share Online <i>Writers Workshop</i> Guest Speaker - Nick Gleeson OAM	Mums Retreat		
		5-6pm Girl Power		Easter		

For more info or to register contact:

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

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

THURS
25 MAR
11am-1pm

Info Share

via Zoom

This group is for adults with MD, their carer's, family and friends.

Topic: *Writers Workshop with guest speaker Nick Gleeson OAM - Nick is an athlete, accessibility advocate and global adventurer who has published a book about his life, The Many Ways of Seeing. Nick will share a bit about his adventures, some tips for sharing your life story and encourage participants to follow their dreams.*

To join, contact Carolyn on **0408 472 510** or email carolyn.cm@mdnsw.org.au

Peer Connect 2021



Sydney Mums' Retreat

Places are strictly limited!

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

Fri 26 - Sun 28 March 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 24 February 2021

mdnsw.org.au

Peer Connect 2021



YOUNG ADULTS WEEKEND 2021

Belmont & Swansea

Join other young people aged 18-30 living with a neuromuscular condition



Fri 4-Sun 7 March 2021

Contact Mitch for more info: mitch.taylor@mdnsw.org.au or call 02 9888 5711 ext. 2

mdnsw.org.au

Bring your chair and let the good times roll!



ADVENTURE CAMP 2021

Wed 14 - Sun 18 April | Collaroy Centre

TRY SOMETHING NEW

Our Adventure Camp gives kids aged 6-18 living with a neuromuscular condition the chance to experience teamwork and the thrill of a challenge over five fun-filled days bonding with their peers, and reaching a huge sense of empowerment, achievement and inclusion.

"Only 1 full day left? I don't want to go home! Can't wait to come back to camp!"
- Finn, first time Adventure Camper



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.

"That was so scary, but I'm really happy I did it. I've never done high ropes before"
- Lachlan

"The abseiling was scary, but we did it!"
- Olivia

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)



mdnsw.org.au

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.

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.

HAPPY 1st BIRTHDAY

to the peer collective on IDPWD!

On December 3, for International Day of People with Disability (IDPWD), we celebrated the one year anniversary of our online story sharing platform The Peer Collective!

Over the past year, we've had more than 100 written and recorded stories submitted from members of our MD community on a diverse range of topics related to living with neuromuscular conditions.

Thank you to everyone who has contributed to growing our story library and for sharing your lived experience. As they say, life is a challenge made easier when shared.

A Story From the peer collective 'Escape from the Country'

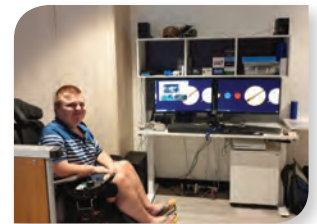
Meet 19 year-old Jack, from central NSW. Jack lives with Duchenne Muscular Dystrophy and has recently left his family farm to attend university in Wollongong.

He has written about his 'Escape from the Country' in our online story sharing forum The Peer Collective and talks about achieving his goals for study, independence and living the life he chooses.

because it is out there, and you should be taking every chance to make things easier for you to complete. ”

What great advice Jack!

Visit The Peer Collective to read Jack's full story and many more from others in the MD community
www.mdnsw.org.au/the-peer-collective



Perfect setup for study



Jack at campus accommodation

“If I only had one thing that I could say to other young people with neuromuscular conditions it would be, focus on what you can do, not what you can't do, then you don't get bogged down with feeling like you're missing out on life. Look to the now and the future, try not to worry about what you were once able to do in the past.

Work hard towards your life goals and dreams and take advice from others in your position, although everybody's experiences are different. Ensure that you get all the support you need,

The Peer Collective features stories from people like you. Stories and info about the things that help you in your daily life. Do you have an empowering and interesting story about your journey you'd like to share with our community? We'd love to hear from you! Please email our Peer Connect Program Coordinator, Carolyn at carolyncm@mdnsw.org.au or contact our office on **02 9888 5711**.



#GivingTuesday - A DAY OF GENEROSITY

A big THANK YOU to everyone who donated, spread the word and volunteered their time for the muscular dystrophy community as part of our celebration of world-wide generosity with #GivingTuesday.

Your generosity has achieved incredible things...you've raised over \$20,400 to get people with MD back into the community via our new Community Access and Recreation Service (CARS). These funds will help make CARS accessible to everyone!

Thank you also to our generous volunteers who made 215 phone calls to our donors and members to express our appreciation for their support through a tough year.

Your support makes a real impact, thank you for being so generous on #GivingTuesday.



**Big Red
Roll + Stroll**
for muscular dystrophy

**MUSCULAR
DYSTROPHY
NSW** BUILDING STRENGTH
REACHING POTENTIAL



Join us at the Big Red Roll + Stroll

for a great day out and chance to
connect with our community!

Together we'll be raising vital funds and awareness to empower every person with muscular dystrophy to live the life they choose.

- When** Sunday 21 March @9:45am
- Where** Parramatta Park, Sydney / Virtual
- What** 3km run, roll or stroll followed by a BBQ celebration and activities in our Event Village
- Who** Make a team of family, friends, workmates or school friends, or come along solo

[Register Here](#)

www.team-md.org.au/event/big-red-roll-stroll

TONY'S '60 before 60' CHALLENGE WIN

We first heard about Tony's challenge in November last year, as we were approaching #GivingTuesday and searching for stories to share from the MD community about generosity.

Twenty months ago, Tony, who lives with muscular dystrophy, hit rock bottom after having a severe fall that left him hospitalised. While lying flat on his back in the hospital, Tony made the decision to turn his life around and face his condition head-on.

Generosity had to start with himself...

Tony began regular physiotherapy and exercise physiology sessions and took back control of his life. Tony has worked incredibly hard to rehabilitate himself and is now reclaiming his mobility and zest for life... although zest comes naturally for Tony who is a vibrant, talkative and talented singing star!

Tony decided that before his 60th birthday on the 29th December, he

would walk 60km - hence the name '60 before 60'. For a man who, up until 12 months ago, couldn't walk unassisted, this would be a massive achievement. Well, we're so proud to let you know that Tony not only reached his 60km goal - he smashed it, walking 110km in 14 weeks!

With generous fundraising from Tony's physiotherapy clinic, Hastings Physio and Health, Tony raised **\$2,180** for the MDNSW community.

“ This dedication and hard work has proven that with the disease, even at 60, just moving brings improvement. I am happy I could help our cause, while creating a new awareness of the benefits of gentle movement. ” Tony said.



Tony (left) with his physio

Thank you to Tony and the team at Hastings Physio and Health for your great story and generous contribution to the MD community. If you would like to start your own fundraiser, check out our Team MD website and all the helpful fundraising tips available to get you on your way.

Join Team MD at
www.team-md.org.au

hireup

Muscular Dystrophy NSW is excited to announce our newest sponsor: Hireup!

Hireup is the NDIS registered online platform for people with disability to find, hire and manage support workers. You can use Hireup to find a range of support, from in-home care to out and about in the community.

“

Before Hireup, I was in the back seat of the car, watching someone else drive me in a direction, even if I knew that direction wouldn't work for me. **Now, I feel I'm in the driver's seat.**

- Mel, Hireup user

”

To learn more and register go to
www.hireup.com.au or call (02) 9113 5933



NEW SERVICES DIRECTORY ON THE LOOP NOW LIVE

Muscular Dystrophy Foundation Australia and The Loop are excited to announce the launch of The Loop's new Services Directory feature.

The Services Directory allows you to search for service providers in your area - whether that's a physio, occupational therapist, equipment provider or sports body.

The aim is for the directory to be built by the neuromuscular community, for the neuromuscular community, so we encourage you to jump on in and add some service providers that you recommend to get the ball rolling.

As a Loop user, you can submit your recommendations using the form at the bottom of the web page and show your support for a provider by 'clapping'.

This is your opportunity to share your recommendations and discover great service providers in your area.

Check out the Services Director in the 'Get Support' section of The Loop - www.theloopcommunity.org



In November, we proudly supported and celebrated National NAIDOC Week and its theme 'Always Was, Always Will Be'.

We'd like to acknowledge the traditional custodians of the land our Lidcombe office is located, the Darug people, and pay respects to their elders both past, present and future. We are mindful to do this in every staff, board and committee meeting we hold and last week got creative

NAIDOC WEEK: ALWAYS WAS, ALWAYS WILL BE

with our virtual backgrounds which were NAIDOC inspired.

We'd also like to take the opportunity to acknowledge our indigenous members. Know that we respect and support who you are and where you come from and the valuable contribution you make to our MD community!

Meet Olivia Eggleton. Olivia is a fifteen year old high school student at Pendle Hill High in Sydney. She lives with Congenital Muscular Dystrophy and has participated in

our programs for a number of years, including Summer Camp and our online Girl Power catch ups.

Recently, Olivia gave a Welcome to Country at our annual Neuromuscular Information & Research Day. She is a proud indigenous young leader in her community and a valuable contributor to MDNSW.

*Above left: MDNSW staff during NAIDOC Week
Right: Olivia Eggleton*



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...

