

Talking Point

**MUSCULAR
DYSTROPHY
NSW** BUILDING STRENGTH
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER NOVEMBER 2020



TOGETHER WE RAISED OVER \$207,000!

The **BIGGEST** thank you goes out to our amazing MD community for your incredible strength and support in going #SugarFreeforMD.

Thanks to you, and over 2,200 others like you, we were able to raise over a whopping \$207,000 for MDNSW - more than double from last year!

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 MD community.

Visit the SFS website www.sugarfreeseptember.org.au to see who our top fundraisers were, also keep an eye out for the SFS e-Cookbook coming soon!

We're incredibly proud of everything we've achieved together, thank you again for your support for the MD community.

THANK YOU!!!

Pictured: Some of the faces of our #SugarFree ambassadors, community ambassadors, top school team, fundraisers and impact families!



A MESSAGE FROM OUR CEO

WELCOME TO YOUR MDNSW COMMUNITY NEWSLETTER - TALKING POINT.

I'd like to take this opportunity to invite you to join us in celebrating our 60th Annual General Meeting (AGM), where we would like to thank you for your ongoing support as a member of the association.

We'll be using this opportunity to reflect on the year that was; both our achievements and challenges.

We'll be there to listen, engage and learn with you, so that together we can make our next year even better.

We'll hear from members of the MDNSW board, staff and membership to get their perspectives on how we have performed and represented our community throughout the 2019-20 financial year.

And, most importantly, we'll be thanking you and everyone in our MD community for your strength and support as we move forward together.

To RSVP, you can email me directly at charlotte.sangster@mdnsw.org.au or call Milvia at our office on **02 9888 5711**.

The program details are below, I hope to see you there!

AGM Details & Highlights

- **When:** Tuesday, 24th November, 2020 commencing at 6.00pm
- **Where:** Online Zoom Meeting Room (details emailed to registered participants)
- You'll receive a copy of our new 2019-20 Yearbook - a real celebration of the year that was! We'll take you through the key features
- Carolyn Campbell-McLean will be speaking about her experience as a life member of MDNSW, our work and the value of being a part of our association
- Join us in honouring our new Life Members

Kind regards,

CHARLOTTE SANGSTER

Chief Executive Officer, Muscular Dystrophy NSW

CLIENT SERVICES

CARS: IS ON ITS WAY

and you can be the first to experience it!

Are you ready for your next adventure?

We can take you there!

After receiving important feedback in our community consultations sessions earlier this year, we listened and developed a new and exciting program that enables our members to access the community in a Covid-Safe and fully supported way.

The Community Access and Recreation Service (aka CARS) provides you with the required accessible transport and support staff, so that you and your friends can get out in to the community and do whatever you want to do!

We're currently developing three different elements of the program, each with a unique experience and focus, and we're ready to trial one of them with you! The 'Choose Your Own Adventure' experience provides you and up to two other friends with your own accessible van and support staff to take you wherever you want to go (within metro Sydney and surrounds) for an entire day.



- Keen to spot Home & Away celebs at Palm Beach? **No worries!**
- Fancy taking in the awe-inspiring views of the Blue Mountains? **You got it!**
- Want to meet a cheetah at Taronga Zoo? **Why not!**

If you are an adult with a neuromuscular condition and a sense of adventure, and would like to participate in the CARS trial, we would love to hear from you!

The trial will take place during the November/December period. Please send your expression of interest or any questions to Mitch Taylor at mitch.taylor@mdnsw.org.au or call Mitch on **02 9888 5711**.

Peer Connect

For a list of all upcoming events please visit www.mdnsw.org.au/our-services/events-programs

Mums Wine & Chat

via Zoom

THURS
19 NOV
7.30-9pm

This group is a chance for Mums to come together to share stories & experiences with each other.

To join, contact Jenny on 0431 690 629 or email jenny.smith@mdnsw.org.au

SMARTies

via Zoom

SAT
21 NOV
2-4pm

MDNSW is hosting a peer group for adults with Spinal Muscular Atrophy.

Join us to meet new people, connect with peers and share information.

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

Girl Power

via Zoom

WED
25 NOV
5-6pm

Girl Power is an online catchup for girls aged 10-16 years old who attend our camps. We will be talking about many fun topics and things that matter to you.

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

Permission must be supplied by a parent or guardian

The Power Hour

via Zoom

WED
25 NOV
6-7.30pm

If you are aged 18-30 and are a power chair user, we would love for you to join us!

To join, contact Mitch on 0417 062 212 or email mitch.taylor@mdnsw.org.au

Info Share

via Zoom

FRI
27 NOV
11am-1pm

This group is for adults with MD & their carers.

Topic: Accessible Travel - *Sharing our travel tales & tips on equipment, transport & accessible accommodation*

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

Zoom Boyz

via Zoom

FRI
27 NOV
5-6pm

A group for boys aged 8-15 years old who attend our camps. We will be talking about many fun topics so be sure to come along and chat with your friends!

To join, contact Mitch on 0417 062 212 or email mitch.taylor@mdnsw.org.au

Permission must be supplied by a parent or guardian

A VIRTUAL SUCCESS AT THE Neuromuscular Information & Research Day



On Saturday 17 October, we held our annual Neuromuscular Information and Research Day (NIRD). Due to Covid-19, we decided to go virtual and hosted the event on Zoom, which enabled us to open the event up to almost 70 people from far and wide, some even from interstate!

Associate Prof Michelle Farrar kicked off the day with her down to earth approach to gene therapy, followed by our MDNSW PhD scholar Sam Bryden with an insight into her laboratory's work in diagnosing rare conditions.

The breakout sessions covered FSHD, SMA and Duchenne, as well as transition to Adult Healthcare and

Parenting with MD. It was great to have such informative speakers, both medical professionals and people with valuable lived experience had much to share.

One of the highlights of the day was the Lived Experience panel which led to some thoughtful conversations about empowerment and independence for people with neuromuscular conditions. **A huge thanks goes to everyone involved in making this event so successful!**

Recordings of each session are available to watch on our Muscular Dystrophy NSW YouTube account.

GIRL POWER PEER CONNECT Q&A

Jamieson (front row, far left) with her friends at Summer Camp



Being part of the MDNSW community allows you to have access to a wide range of fun, informative and educational activities throughout the year. Connections are so important, now more than ever during these difficult times of isolation.

To address this issue, we've been running a peer connect online group for young girls aged between 10-17 years. 'Girl Power' is held every second Wednesday from 5-6pm, for girls across all of NSW, who want to catch up and stay connected. The group provides an opportunity for girls to talk about many fun topics, share experiences, ask questions, and support each other.

We spoke to 17-year old Jamieson about her experience attending Girl Power:

Q: What contact have you had with MDNSW in the past?

A: "MDNSW has been helping me since I was very young. Every year I go to the MDNSW camp and that's where I met some of my current friends, who I now I get to see regularly at Girl Power."

Q: Why do you go to the Girl Power group?

A: "I go to Girl Power because it's a good way for me to catch up with my friends who are similar to me and share the same struggles. I normally only get to see them once a year at camp, so when I got the email telling me about the group, I was really excited to connect. We get to talk about a lot of different things and different issues we face such as how we pass our time during Covid isolation or the difficulty of finding wheelchair accessible cafés to hang out at with friends. We get to share stories about having a disability whilst going to school. We also just chat about anything we've been doing recently or got coming up."

Q: What are the benefits of connecting online? What is the best thing about the group?

A: "I think the best thing is being able catch up with my friends more often than ever before. The benefits would be that it's really easy to attend because it's all online and I don't have to travel anywhere to get to it. It's also great that it's open to people all over NSW so we can connect with people who live far away."

To join Girl Power, contact Chris on **0451 104 129** or at **chris.magdas@mdnsw.org.au**

WE'RE HERE TO HELP YOU NAVIGATE THE NDIS AND SUPPORT YOUR NEEDS



Meet MDNSW member Samson. Samson has Spinal Muscular Atrophy (SMA) and has been working with our Client Services Coordinator, Ganesh, for almost three years.

We have assisted Samson in navigating the NDIS and have also helped connect him to a range of therapists, as well as set him up for in-home/community support.

When we asked Samson about Ganesh and the support he provided, his response couldn't have been better.

“The support with Ganesh has been god sent. Without him it would be extremely hard to work with the NDIS.

Whenever there are any problems whether it be with the NDIS, my therapy, or repairs, Ganesh is always there to sort it

out. He explains things so well and makes it so easy for me to understand; he gives me courage going forward.

Work is very important to me as it gets me out of bed in the morning, and with SMA you need to always keep moving those tired muscles! My SMA can make daily tasks sometimes very hard. Weakness and tiredness is the main issue.

I work as a Medical Receptionist and I get support on a daily basis from the NDIS with work. The job keeps me going and it makes me feel that I am contributing to life. I get to be with people and help them, which makes me forget my SMA.

Muscular Dystrophy NSW puts the client first. They have always been there for me throughout all the years. Without them I would be lost.”

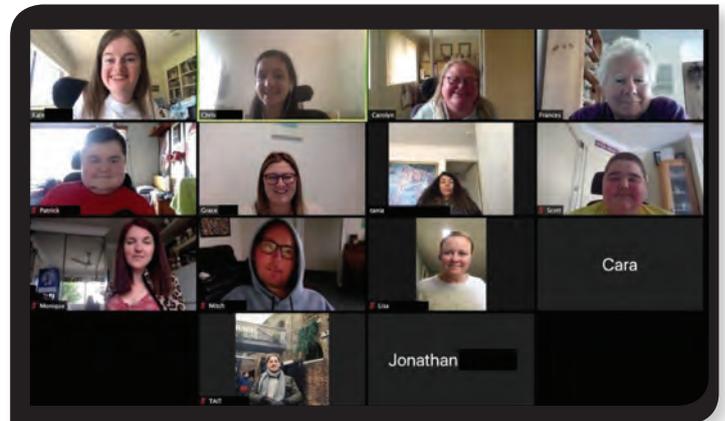
If you or a family member are having difficulty navigating the NDIS or need extra support with your Plan, contact our Client Services team. We also have handy free resources available for download, including an NDIS Toolkit on our website.

Peers Connect to Build their *Dream Team*

In September, our online Peer Connect - Info Share session discussed 'Building Your Dream Team'. Kate and Grace from Hireup presented to 12 MDNSW members about how Hireup can play a role in building a team of great support workers.

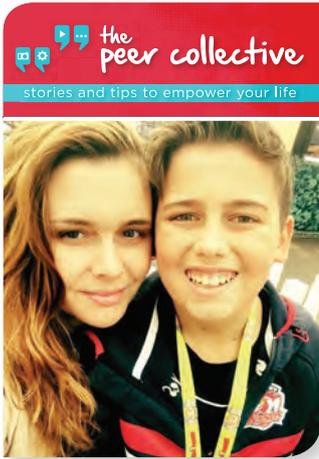
It was a packed session full of good info and answered a lot questions. We also heard loads of tips and strategies from participants for finding, managing and keeping support workers - the power of peer support was in action! It can be confronting, and certainly not easy thing to do, but team-building is an essential tool for independence and in achieving our goals.

The November Peer Connect - Info Share session will be about Accessible Travel (dreaming!) so pop 27 November in your diary!



Top 5 Tips for Building Your Dream Team

- **USE VARIOUS METHODS** - Use Hireup job board to advertise your job; Hire someone you know and get them to join Hireup; Use the search function for who you are after
- **USE PEER SUPPORT** - Network and refer good workers to your peers, for example connect via Facebook, Messenger
- **BE FAIR BUT FIRM** - Set expectations, know what you want and be assertive in communicating your needs
- **BE CREATIVE** - Learn to juggle a roster, use one service as a main service and one as a supplementary service, for example when travelling
- **BUILD COMMUNITY** - Build a tribe of workers (4+) and use WhatsApp or Messenger to keep your team informed and engaged (and cover shifts!)



Frances (left) with son, Jake

A Story From **the peer collective** *Why I Don't Want You To Feel Sorry For My Child*

Living in Sydney, Frances Vidakovic has two children, Savannah 15 and her son Jake 13. Jake has a neuromuscular condition called Charcot-Marie-Tooth disease.

With a degree in psychology and diploma in journalism, Frances is an author of 21 books, certified life coach and course creator. She now

creates parenting and self-development content, designed to help mums live their best life possible.

When you have a child with a disability, you learn to develop thick skin over time.

Life constantly throws you challenges that you somehow - as if possessing crazy superpowers - manage to surmount, even though if it often feels as if you are swimming against the tide.

It's pretty impressive the amount of stuff we mums manage to do on any given day. Most people would crumble under the pressure.

And then one day you find that the littlest thing knocks the wind right out of you and take your superpowers away.

For me that thing is always the same. It's when I hear the words: *"I feel so sorry for your child."*

Read Frances and Jake's story on The Peer Collective in the 'Parenting' section www.mdnsw.org.au/the-peer-collective

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 Project Officer, Carolyn at carolyncm@mdnsw.org.au or contact our office on **02 9888 5711**.



National Carers Week: October 11 - 17

We couldn't be more thankful to our carer community - parents, family members and camp carers. THANK YOU for the invaluable support you provide to people living with a neuromuscular condition and for the enormous amount you contribute to our organisation.

To coincide with National Carers Week, the NSW Government released its 10 year Strategy to help carers receive better support and recognition. Minister for Families, Communities and Disability Services Gareth Ward, said the Strategy aims to help carers overcome the challenges involved with caring for loved ones.

"Under the strategy, the NSW Government will make it easier for carers to access information and services, reduce financial stress and look after their own health and wellbeing."

The 2020 National Carer Survey Summary was also released by Carers Australia. In June we encouraged members to participate in the national survey, so if you did, the results are now in and you can hear the report summary in the National Carers Week launch video or download a full copy at the Carers NSW website - www.carersnsw.org.au

The typical respondent was a female primary carer of working age with a high school education, not participating in paid employment.

2020 National Carer Survey: Key findings

- The typical person being cared for was an adult son with physical disability who is not able to be left alone for more than a few hours
- Most respondents provided 40 or more hours of care per week, and more than half had been caring for 20 years or more
- Nearly half of the carers who responded were experiencing high or very high psychological distress, and one in three felt highly socially isolated
- One in three respondents said they never get time out from their caring responsibilities, with only around half having enough time to keep on top of other responsibilities

- It was relatively uncommon for carers to be asked about their own needs when accessing services or on behalf of the person they care for, and services were much less likely to meet carers' needs than the needs of the people being cared for
- The most common challenges carers experienced when accessing services were getting information about what services are available, and the time and energy it took to organise services. Waiting periods to access services were also a common challenge
- One in four carers reported spending more money than they made in the past 12 months
- Exiting employment and reducing working hours were common impacts of caring on carers' career trajectories.

Living in Strange Times - The COVID-19 World

MDNSW Project Officer and life member, Carolyn Campbell-McLean, shares her story about living through COVID-19, including how she's managed her supports and is keeping safe.

“ Hello, my name is Carolyn Campbell-McLean. Before COVID I worked two days out of home and two days from my home office near Parramatta in Sydney. This is my story.

I self-manage my NDIS package and a team of support workers who provide me with care four times a day. I live with SMA (Spinal Muscular Atrophy) which affects my muscles and breathing, and use assistive technology and a powerchair to buzz around.

When COVID-19 hit Australia in March I decided fairly quickly to stay home. My hubby and I did 44 days straight at home, and I've been out only five times since. I have actually surprised myself at how well I have adjusted to home life, and now I kind of enjoy it most of the time. Although there are many things I miss - hugs and concerts the most!

Those first few weeks were horrible. We were super anxious about how to keep safe while relying on support workers. I stopped eating and sleeping from worry, and the relentless news was feeding that anxiety. However, we wanted to stay up to date. Things were moving quickly. Each day I took in the advice from all my online sources and we worked out our plan to stay safe. ”



Carolyn (centred) with her COVID safe supports

What strategies have you used to keep well?

- "Reduced our team from eight to five and asked a support worker who was a part-time hairdresser to choose us or the salon; we paid each support worker to complete infection control training and paid sick leave; purchased masks, gloves, handwash, paper towel and hand sanitiser using my consumables funding."
- "Daily disinfecting of high touch areas and all products coming in such as packages and groceries."
- "Shopping is mostly online; support workers pick up items or run errands such as items from the Post Office or Pharmacy."
- "Telehealth appointments with GP, Respiratory clinic, Neurologist but need to get to Skin Check!"
- "Our regular taxi driver sanitises his accessible cab on a Friday afternoon so each month we booked him on a Saturday to take us out on a day trip drive somewhere - he invoices with his ABN and I use my social and community access NDIS funding - this has kept us sane!!"
- "Keep socially connected via Zoom, phone calls, messages online and texts."
- "Find things to keep us busy and happy - scrapbooking and making cards, watching Netflix and music, catching up on tidying, sorting, filling and new projects like joining Audible."
- "Supporting others - I made a box of groceries we didn't want and found a friend who met an older man who was in need."
- "Find hope and humour - I spend time watching Some Good News and following The Kindness Pandemic Facebook page."

Have any positives come of the past 6 months?

"There were lots of silver linings shining through during the darkest days. I have connected with my 10-year-old niece online for the first-time doing games, activities, treasure hunts and trivia. I have realised who my really supportive friends were and appreciated the kindness of strangers.

Working remotely from home and connection with networks was a lifesaver. It's awesome to see society embracing flexible ways of working and connecting, hopefully, this continues in the future.

You take stock of what is important, I mean really important - health, home, relationships."

How are you moving forward with life?

"The balancing act is between getting on with life and at the same time feeling and staying safe. Staff are still wearing masks, but we are having some socially distanced visits and making plans to see friends in outdoor locations. We don't go to shops or anywhere if we don't have to, however, we have started wheeling about our community as the weather warms up.

Overall, I am incredibly lucky to be okay financially (thanks JobKeeper) and have plenty to do at home. Each day I wake up hoping the numbers will drop and for a vaccine. I yearn for the day we can go to a concert again, train a room full of people and even go for a meal at a restaurant. Until then, we adapt, and we find new ways to enjoy life.

Every day is a gift."

Stay safe my friends.

CIAYAQ: CAN I ASK YOU A QUESTION?

How do you feel
about other people
doing your personal care?

The Loop has launched a new series called "Can I Ask You A Question?", where people respond to some of the awkward personal questions they're often asked as a person living with a neuromuscular condition.

If you haven't checked out The Loop yet, give it a try. It is your neuromuscular resource hub - full of helpful resources, stories from the MD community and information to help you get the support you need.

Go to www.theloopcommunity.org to watch more videos like this!



The Loop

Your Neuromuscular
Resource Hub

WE'RE EXCITED TO ANNOUNCE
OUR PARTNERSHIP WITH

hireup

We've been talking to the team at Hireup for months and we're excited to partner with an organisation that shares similar values of working to connect and support our communities, whilst improving outcomes for people with living with a disability.

Hear from MDNSW member Mel!



“ I have a team of ten support workers... I want to create an atmosphere for my whole team to come together and work as friends. That's only been made possible thanks to Hireup. ”

About Hireup - Hireup is an NDIS registered online platform for people to find, hire and manage support workers who fit their needs and share their interests. Thousands of people - including many people within the Muscular Dystrophy NSW

community - use Hireup every day to manage their own support workers.

MDNSW Member Offer!

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

Just visit www.hireup.com.au/partnership-mdnsw

Through the support received from Hireup, we'll be able to not only enhance our online Peer Connect program, but also introduce new and exciting client service programs to benefit our member community.

If you'd like to discuss your situation with someone at Hireup you can contact the team at hello@hireup.com.au or call on **02 9113 5933**.

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

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