

Talking Point

MUSCULAR DYSTROPHY NSW NEWSLETTER MAY 2021



Team Doing it for Mickey didn't let the rain stop them!

Big Red Roll + Stroll

A Virtual Success!



Team Noah celebrated cozy at home with both sets of grandparents
CONGRATS ON BEING OUR #1 FUNDRAISERS!

Despite having to change the Big Red Roll + Stroll to a virtual event due to bad weather and the true disappointment of not being able to connect in person, our MD community once again rose to the challenge and you impressed us (as always) with your creativity and spirit.

We didn't let torrential rain and flooding dampen our community spirit as we each celebrated the MD community together on Sunday, 21 March, for our first virtual Big Red Roll + Stroll.

A huge **THANK YOU** to those involved for your tremendous efforts to support kids, adults + families impacted by MD.

Together we raised over **\$76,000** to support face-to-face programs like Adventure Camp, Mum's Retreat and our weekly Peer Connect sessions.

Keep reading to be truly inspired by the many ways we each celebrated the MD community together for our first virtual Big Red Roll + Stroll. — **cont. page 3**



Mike's Muscle braved the elements & connected the team virtually to get in their 3kms - way to go!



A MESSAGE FROM THE CEO

Welcome to your quarterly edition of Talking Point, where you get the latest MD program and event information and community news!

I'd like to firstly thank the hundreds of people who registered for our inaugural Big Red Roll + Stroll. Through the efforts of our amazing fundraisers and generosity of donors, we have raised over \$76,000!

Sadly, due to the heavy rain and flooding that battered NSW that weekend, we had to cancel the physical event, but we still encouraged people to participate in the virtual component. We were blown away by the support and creativeness of people who still wore red and virtually participated on the day - we can't thank you enough.

I sincerely hope you all managed to stay safe and weren't badly impacted by the flooding, which impacted so many parts of the state.

This edition also covers off the latest in Client Services, including what's coming up in the online and face to face Peer Connect program, our 2021 Client & Family Survey results, and a recap of our Young Adults Weekend.

Also, keep on top of what's happening in the community and the many ways you can get involved in some of our latest initiatives, like 'Ask A Scientist' - a fun new partnership with the Kids Neuroscience Centre of the Sydney Children's Hospital Network .

I hope you enjoy the read!

Yours sincerely,

CHARLOTTE SANGSTER

CLIENT SERVICES

CLIENT & FAMILY SURVEY

RESULTS ARE IN

Earlier this year, we sent out our 2021 Client & Family Survey to the membership, seeking your thoughts and feedback on how we're performing and ways in which we can improve.

A big thank you to the almost 100 of you who took the time to complete the survey and provide us with your unique insights and valuable opinions on our programs, services and communications activities.

Overall, you ranked our communications, support and the quality our services 'good' to 'very good', but you let us know that you would like to see more programs offered in regional parts of NSW with too many programs focussed in metro Sydney.

We have taken this feedback on board and can let you know that we are currently planning to run a number of programs in the Hunter and Hawkesbury regions later in the year. We also have our online Peer Connect sessions running regularly, which are a great way for our members in regional and more remote areas to stay connected to our community and resources.

“ We enjoy the online peer group meetings. ”

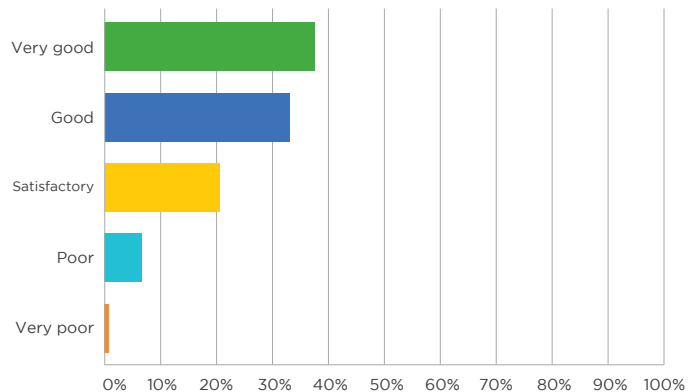
We will be working on addressing the survey results and incorporating them in to the way we work for the remainder of the year. Thank you once again for your support in helping us to continuously improve!

Congratulations to Anne-Maree who won our \$100 gift voucher for completing the survey!



How would you rate the overall support and quality of service provided by Muscular Dystrophy NSW?

Answered: 87 Skipped: 7



Survey snapshot

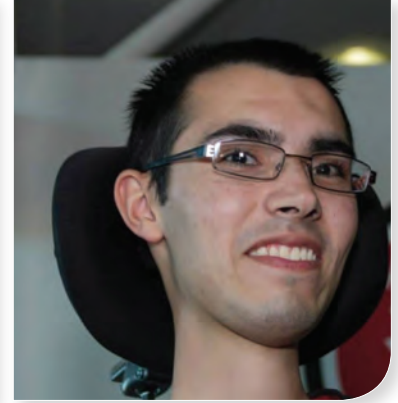
Big Red Roll + Stroll



The **BMD Bandits** wore red with pride while doing laps of the hallway - great soundtrack & celebratory spirit!



Our partner **Team Housing Hub** got creative on Zoom with a red background, accessories & fun props!



Team Pig's 25 members have organised their own mini roll + stroll for a sunnier day - we hope it's a great one!



Dr Lauren Saunders raised her voice from rainy Melbourne in solidarity!



Lachlan Ninham + his family hit the treadmill at home! Great effort!



The **Sydney City Rollers** led by Captain Caz got crafty! Great collage & efforts in remembrance of Tigerman Dan & loved ones we've lost to MD



Jack & his team completed 3kms around Bunnings! They tested display accessibility, discovered exciting items, received donations & had a sausage sizzle lunch! Great idea!



Chris Suffield shared words of thanks & encouragement for the **Powerchair Football Team** CONGRATS ON BEING OUR #1 TEAM FUNDRAISERS!



Team Rolley Moley got their adorable mascot Milo to help them raise awareness - too cute!



Ambassador Shannan Ponton kicked off the day with words of encouragement & celebration



The **Duchenne Wombats** didn't let the rain stop their loop of the local neighbourhood - great job!



Team Ready to Rock 'n' Rollers caught up on their 3kms and celebrated with a picnic on a cool but clear & sunny day

WE TALKED ABOUT SEX & RELATIONSHIPS

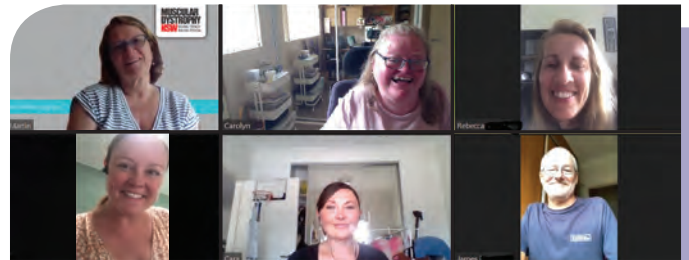
Of course, people with disability have sexual desires, feelings and want love and intimacy just like people without disability. This topic is rarely spoken about, but is an intrinsic part of life.



Last month, eight people attended our Peer Connect Info Share online session with guest speaker and 'sexpert', Liz Dore, from Relationships and Private Stuff. This was a terrific opportunity to share conversations in relation to the impact that MD has on this aspect of life.

Despite the sensitivity of such frank conversations, people had an opportunity to ask the questions that matter to them and brought a broad range of issues and suggestions to the table. Participants also received useful information on everything from how to meet people, being confident and creative, to options such as trained sex workers, alternatives to traditional intimacy and counselling.

Feedback has called for more sessions like this to be planned, so we are looking at holding one for singles and another for couples later in the year. We are always open to your ideas for topics so if you have some, please contact our Peer Connect Program Coordinator Carolyn at carolyn.cm@mdnsw.org.au or on 0408 472 510.



Recap of the Parenting with MD Session

Last month, a group of five parents with Muscular Dystrophy (MD) joined in for a fantastic 2-hour conversation about parenting when you have MD. Participants got to talk about very specific experiences of life as a parent with disability.

Topics included...

- Positive impact on children
- Transition to paid care & support
- Getting back to being a parent to my children
- Transition to using mobility equipment

“ Getting paid supports has enabled my children to become my children again. They had become more like carers for some time. Once I got over my concerns about using carers for personal care support, I can now be parent of my children and stop asking them to be my carer. ”

This group will meet every 3-4 months, hoping to continue online to include people from regional areas, as well as more face to face Peer Connect activities this year. If you are a parent with MD and would like to connect please contact Carolyn on carolyn.cm@mdnsw.org.au or 0408 472 510.

COVID-19 VACCINE ROLLOUT



The Therapeutic Goods Administration (TGA) has provisionally approved the Pfizer/BioNTech and AstraZeneca COVID-19 vaccines for use in Australia. What does this mean for people with a disability and when will they be able to access the vaccine?

People who most need protection will be vaccinated from February 2021. Vaccination will then be made available for the broader community later in the year. In the first round, Vaccination teams will go out to residential aged care and disability support settings. These in-reach services will be managed by the Australian Government.

COVID-19 vaccines are free for everyone in Australia. Vaccination in Australia is voluntary, and you can choose if you want to get vaccinated against COVID-19.

Visit the 'News' section of www.ideas.org.au for links to further details.

Learning Independent Living Skills

at the Young Adults Weekend

Taking the big step of moving out of home and into independent living is huge for any young person, but for a young man with Duchenne Muscular Dystrophy, there is so much more to consider and plan for.

Great mates Scott and Patrick have talked about moving out of home for quite a few years now, ever since they met at our Summer Camp when they were young teenagers. Now, in their early twenties, they were able to catch up again, along with a small group of other young men who use powerchairs, to test out their independent living skills (and have lots of fun!) at our Young Adults Weekend held in Lake Macquarie earlier this month.

The accessible accommodation venue was one of the best we've ever stayed at, with unique gadgets and gizmos, like automatic cupboards and sinks that moved to suit a person at wheelchair height.

Fun was had reuniting at the pub for a delicious dinner, followed the next day with a road trip to the Hunter Valley for cheese tasting, shopping and sight seeing. Back at HQ, the gang took time to learn important independent living skills, like doing your own laundry, how to work a washing machine, cooking skills and more!

Thank you to everyone who attended the weekend to participate and help out - a brilliant time was had by all.



Top - Three friends off to the Young Adults Weekend
Bottom - Delicious dinner at the pub

Peer Connect

Siblings

Wed 29 Sept - Fri 1 Oct 2021

Camp

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

Bring your chair and let the good times roll!




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)

Expressions of interest by 30 July 2021.

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 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

A TRIBUTE TO Michael Neary 22/11/1962 - 02/11/2019



Michael Patrick Neary was born 22 November in 1962 and was a happy, adventurous, sporty child who grew into a happy, adventurous adult with a passion for skiing, music, sport and his family.

Michael was a loving son, brother, husband and Dad and had some great mates who still got him out to see the Waratahs and Wallabies.

He loved to dance and had a cheeky and sly wit. Michael was diagnosed with Myotonic Dystrophy type 1 in 2008.

If you would like to read Michael's full tribute or publish your own tribute to our *In Memoriam* page, visit www.mdnsw.org.au/in-memoriam.



Say G'day to the team at the KIDS NEUROSCIENCE CENTRE

We've formed a partnership with the Kids Neuroscience Centre (part of the Sydney Children's Hospitals Network), to directly connect our MD community with the team of clinician-researchers and scientists who study and treat neuromuscular conditions that affect children and their families.

Through this exciting new partnership, you will have the opportunity to ask questions about Muscular Dystrophy research directly from the experts!

This will be through the new 'Ask A Scientist' segment which will be featured in our newsletter, Talking Point, and also our website and social media channels. So, what kind of question can you ask?

Here are some suggestions to get you thinking...

- Why don't I have a genetic diagnosis yet?
- How can genetic testing help me understand the cause of my MD?
- How does the gene therapy being used to treat SMA work?

Meet Prof Sandra Cooper and Clinical A/Prof Kristi Jones!



Sandra is a neuroscientist and is the Scientific Director of the Kids Neuroscience Centre where she leads a team of researchers who focus on gene discovery and genomics and a view to developing evidence-based therapies.

Kristi leads the Kids Neuroscience Centre Clinical Trials Unit and co-leads the clinical arm of the Genomic Medicine group alongside Prof Cooper. Her current research interests stem from her PhD and focus on genetic diagnosis and therapeutic trials for genetic muscle disease.



There's no such thing as a silly question! Sandra, Kristi and their team are eager to hear from you. So, if you have a research or science-based question, submit it today by emailing info@mdnsw.org.au. Answers will be posted in Talking Point.

Entries now open for the FOCUS ON ABILITY SHORT FILM FESTIVAL

The Focus on Ability Short Film Festival is back for its 13th consecutive year promoting ability. Entries close July 30, 2021. With over \$100,000 in prizes up for grabs and unparalleled International exposure, this is a festival you want to be part of.

Prizes range from a brand new car to money can't buy industry experiences.

The best part about this festival is that anyone can enter and each year many of the winners are first time film makers. It is all about how you tell the story. So get creative and explore the focus of the ability theme.

Go to www.focusonability.com.au to find out more!



NSW POWERCHAIR FOOTBALL Q&A

with player Jaxon Taylor



Jaxon excited to start the game!

With the 2021 Sydney powerchair football season kicking off on Saturday 20th February, Western Sydney Wanderers squad member Jaxon Taylor gave us his thoughts about the sport he loves.

Q: How long have you been playing powerchair football for?

A: "I have been playing powerchair football for 7 years now."

Q: What is your favourite position to play?

A: "My favourite position to play is on the wing."

Q: How do you feel when you're on the court?

A: "When I'm on the court, I have this adrenaline that pumps through me that doesn't pump through my blood when I do anything else. The feeling that matches can be decided in one move gives me such a great feeling."

Q: Favourite powerchair football experience?

A: "My favourite powerchair football experience would be achieving third place in the Club Championships in 2020. This experience gave me a sense of professionalism, as well as the privilege to play for a week straight, which was another great factor."

Q: What are your powerchair football goals in the next year or two?

A: "My powerchair football goal over the next two years is to play for the Western Sydney Wanderers first team. Currently, I am playing for their reserve league team, and I would really love the opportunity to perform and grow in a more intense environment, similar to the club championships last year. Being asked to play for the Wanderers second team is so exciting, let alone being a part of their squad. I can't wait to get the season started!"

Q: What would you say to someone who is considering giving powerchair football a try?

A: "To those who are considering powerchair football as their sport of choice, I say give it a good crack. Life is full of surprises. Even if you don't think you'll like it, you never know what may happen until you're playing a game and you have the adrenaline pumping. So, give it a good go. If you like it, then that's great, and if you don't, then there are always other opportunities for you in the future."

If you want to give powerchair football a try, get in touch with Chris Suffield at christopher.suffield@hotmail.com

Development sessions are a great chance for new players to get involved and run from 10am to 12pm at Valentine Sports Park on Saturday 1 May and 5 June. **Registration is free for new players!**

Join **Team MD** to make a difference!

Check out all the ways you can **fun-draise** to support the MD community.



Fitness events - collect donations to motivate you towards the finish line



Celebrations - donate on your birthday or wedding by asking for donations instead of gifts



At work or at school - get the whole crew involved in a fun activity or challenge



In Memoriam - honour your loved one by asking for donations in their name in lieu of flowers



Host an Event - organise a trivia night, a morning tea, a garage sale or hold a raffle

We'll support you every step of the way with an online donation page, fundraising guru and tshirt!
Visit www.team-md.org.au

NEW SERVICES DIRECTORY FEATURE NOW LIVE ON **THE LOOP**

Your Neuromuscular Resource Hub, **The Loop**, has launched a 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 this 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 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.

Visit www.theloopcommunity.org to access the Services Director and plenty more useful resources.



Have you accessed **the Housing Hub** yet?

Housing Hub is a national website that advertises properties for people with disability. It is free to use for people with disability searching for housing.

It has a lot of resources and events that support people with disability to learn more about their choices. Their national team includes people with expertise about their own housing journey.

Thinking about moving? Jump on the Housing Hub and create a Housing Hub profile. Just answer a few simple questions about where you want to live, and what you want and need in a place to live. The website then starts doing the work for you.

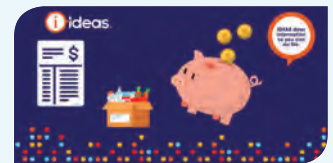
Visit www.housinghub.org.au to create your profile or call the Housing Hub team on **1300 61 64 63** or send an email with any housing questions to housingoptions@housinghub.org.au.

Housing Hub
Find the home that's right for you

FREE resource to help you **Manage Your Money**

IDEAS has released a free 60 page booklet to help people with a disability manage their money and offer real, practical advice.

If you're in trouble with money, if the bills are piling up or you can't afford to buy the basics, then this resource can help.



Get advice on...

- Paying Bills and Buying Things
- Income Support Payments
- Meal Planning and Budget-friendly Recipes
- And more!

To access this great resource, visit the 'Books' section of the www.ideas.org.au website

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...

