Talking Point



MUSCULAR DYSTROPHY NSW NEWSLETTER WINTER 2019



Chris & Ann-Maree Dogao hosted a trivia night on the 30 March 2019, inspired by their son Noah who is living with Myotonic Dystrophy. Their aim was to raise funds and awareness for MD and to directly support MDNSW Adventure Camp.

Meet Noah

Noah has just turned three and loves books and buses. We asked Chris & Ann-Maree to tell us a bit more about their little man with a big heart!

Strong - "After everything Noah has been through (medically) in his short life he is taking it in his stride"

Hero - "This word is one I would use to describe Noah.

There is only 2 people in my life I would call a hero, my soon to be 100 year old grandfather & my 3 year old boy Noah" Chris says

Funny - "'Aka Hilarious' - sometimes he is in stitches (resulting in the hiccups) over the smallest thing"

Very loving - "Always wanting to give daddy & mummy a big hug and kiss. He is just a beautiful and loving boy"

Very Handsome - "Must have got that from his dad lol"

Chilled - "Always sitting in his special chair with his hands behind his head like he doesn't have a care in the world. He also sleeps this way in his bed (like sun baking on a tropical island)"

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BUILDING STRENGTH REACHING POTENTIAL



EDITORIAL

HI EVERYONE, AND WELCOME TO THE LATEST EDITION OF TALKING POINT. THE YEAR IS FLYING BY, AND I HOPE IT HAS BEEN A PRODUCTIVE ONE FOR YOU SO FAR.

It certainly has been for us here at MDNSW, most recently helping with the staging of National Wheelchair Sports Electric (NEWS) at Narrabeen in Sydney.

I was privileged to be a part of this, and witnessed the opening by the Governor of NSW, His Excellency General The Honourable David John Hurley, and Mrs Hurley. This was one of Governor Hurley's final duties before he assumes the position of Governor-General in June, and we are fortunate to have his solid support. On behalf of our MDNSW family. I wish Governor and Mrs Hurley all the very best in their move to Government House in Canberra. I know that His Excellency is passionate about NEWS and a fierce supporter of the mighty Blues, and his support for our lads in the opening Powerchair footy game was strong! It obviously gave our team the boost they needed, and NSW went on to win the Powerchair Football and Rugby League championships. Congratulations to the players, coaches and support staff!

Of course, it's not just about sport, and NEWS gives players and supporters the opportunity to connect with

peers and make long-lasting friendships. It is also a fantastic opportunity to take a break from everyday For routines. narents and carers. knowing there are others around who understand the needs of their



With NSW Governor David Hurley and his wife Linda

loved ones and are willing to jump in and offer assistance when needed, provides a rare opportunity to relax.

ANTHONY BALL

President, Muscular Dystrophy NSW



cont. Noah's Trivia Night Raises \$9054





A fantastic night was had by all the North Rocks Community Church! Chris told us that they had been overwhelmed with the generosity of local businesses through donations of prizes and support.

We'd like to give a big shout out and thank Chris, Ann-Maree, Noah and their wonderful family and friends for co-ordinating the night and creating such a wonderful event in honour of Noah and for their support of Adventure camp!

If you'd like to host your own Trivia night please contact Louise on **02 8986 9006**, we'd love to hear from you!



Pictured L-R: Noah - The star of the show, Let the trivia begin!, Debbie Dogao & Michael Meredith



Bring your Chair and lef the good times roll!

SUMMER CAMP 2019

WHEN & WHERE?

Wed 18 - Sun 22 Dec

Sydney Academy of Sport and Recreation, Narrabeen

STAHW

Participation in a huge variety of unique activities. All meals, accommodation and equipment hire. There will be at least one carer to each camper and a nurse on site.

WHO CAN COME?

This camp is open to people aged 6-18 with a neuromuscular condition. Activities are age appropriate and cater for all levels of skill and ability.

MHX3

Because it's the most fun you can have in five days. Make new friends or catch up with old ones. Have a break from Mum and Dad!





mdnsw.org.au



Important Information NDIS Funding for Camp

NDIS prices change from year to year. We can provide you with an updated quote for current camp costs. It is very important that that there is sufficient time to get funding in your NDIS plan if you don't already have the necessary funding.

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)

Remember, this is a popular camp and takes a lot of organisation so please register ASAP!

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 he event may incur a cancellation fee of up to 100% of the scheduled cost.



Friendships formed over the weekend!

2019 MUMS' RETREAT

This year's weekend Mums' Retreat was held from 8 to 10 March at Collaroy, within walking distance to the beach.

Saturday morning saw some awesome challenges on Narrabeen Lake with kayaking and paddle-boarding - all those who participated managed to stay afloat and dry.

Others took on the 9 kilometre walk-around-the-lake challenge, while a few mums participated in the slightly less gruelling coffee-and-chat challenge, generously offering themselves as the encouragement and support team.

If you've never taken a break at a Mums' Retreat before, think about adding it to your to-do list for next year. It is a place for tears, laughter and fun, all with much-needed support for those who come along.

MD RETR

The weather put on a fabulous autumn weekend for the recent MD Retreat held in Parramatta and the staff at the Parkroyal were wonderful in ensuring everyone was well looked after.

The weekend was a great opportunity for people with a neuromuscular condition and their partners or family members to share and support each other, starting with a group dinner on Friday night. It was lovely to see the connections being made which continued over the whole weekend.



Exploring Parramatta



Friday night group dinner at Table 30

"I feel more connected - was able to network with new people and discuss things" - Carolyn

"It has provided time to connect with the MD community and take some time-out for myself" - Christie

"It's great enjoying a weekend away in a different place, sharing time with my husband and other couples.

It's fun and relaxing!" - Leah

"Gives me motivation to keep going and to know I am not alone" - name withheld

"It's good to talk to others with similar issues to myself and as always, realise there are others that understand what it's like to have MD" - Peter

Peer Connect

Friday 28 June, 2019 | 11am - 2pm



MDNSW Peer Connect Community Gathering is held once every month at Lidcombe Catholic Club. Come and join us for our next gathering on 28 June.

MDNSW welcomes adults with MD - and their partners, supporters and carers - for a great chance to meet new people, catch up with old friends, and build peer networks with other members of MDNSW community. It's a great opportunity to share information and offer each other support. Better yet, you can expand your own circle of support! Talk about what you want from your life and how you want to participate in a meaningful way - and much much more!!!

Please contact Ganesh to RSVP ganesh.kakani@mdnsw.org.au or call 0429 014 722

We look forward to seeing you on 28 June!

Future Dates... 26 July | 30 Aug | 28 Sept (Sat) | 19 Oct | 29 Nov | 14 Dec

Dooleys Catholic Club 17 Church St, LIDCOMBE



Expressions of Interest

SNOW CAMP 2020

Expressions of interest are invited from thrill seekers aged six to eighteen interested in trying sit skiing or supported stand skiing



Disabled Winterport Australia will provide experienced guides who will safely navigate you around the slopes. The trip will be held during the 2020 July school holidays and is for kids living with a neuromuscular condition. Those who use a power drive chair are welcome to attend. Please note we will need 6 participants to make the trip viable before confirming it will go ahead.

APPROXIMATE COSTS

Disabled Wintersport Membership..... \$149 plus a joining fee of \$49 Confirmation Fee...... \$130

Purchase or hire of Ski clothes...... \$50 approx.

INCLUSIONS

- 3 day lift passSki/board rental and adaptive equipment
- Adaptive snow sport guide support and lessons
- Adaptive show sport gaide support and lessons
- Program coordination and support from Disabled Wintersport Australia
- National Parks entry
- 4 nights/5 days accommodation and meals
- Transport
- · Support staff to help you throughout the trip

Be quick!
Places are limited

To register your interest or discuss the opportunities please contact Mitch on mitch. taylor@mdnsw.org.au or call 0458 026 532

mdnsw.org.au



Sugar Free September Challenge

When?

1-30 September

How?

Cut refined and added sugars for 30 days this September

Why?

To give SWEET opportunities to kids living with Muscular Dystrophy



#SugarFreeForMD

Going Sugar Free for 30 days is a challenge. Living with Muscular Dystrophy is much harder!

Sugar Free September is MDNSW's biggest fundraising event for the year and soon enough September will be around before we know it! Funds raised during Sugar Free September support MDNSW programs and services that wouldn't otherwise by covered by other funding sources. Last year our 300 participants raised a whopping \$65,000 which is a great achievement for our small organisation!

This year we aim to smash \$100,000 but to do so we need your help to spread the word.

Do you work for an organisation that participates in fundraising and/or health and well being programs? Or do you know of any businesses that would be interested in participating in the Sugar Free September challenge? If so we need you to reach out to your friends, family and networks and spread the word so we can get as many teams on board as possible! Not only does Sugar Free September raise money to support Muscular Dystrophy NSW's services, programs

and awareness, but it also is a great chance to improve the health and wellbeing of you and your team mates.

If you or someone you know is interested in participating please drop Louise a line at fundraising@ mdnsw.org.au, call 02 8986 9006 or you can pre-register your interest via http://comms.mdnsw.org.au/ SugarFreeSeptember2019 and stay tuned for updates!



This April we mixed things up and shifted the location for this year's five-day adventure camp to The Collaroy Centre. Choosing this great facility meant that the group could try out a ton of challenging activities right there on site. And you sure can't beat the views!









Cool 3D glasses Finn & Ned!

Kara flying down the giant Slip n Slide

Our first activity on Monday was the obligatory Easter egg hunt, and in the evening we got our hearts pounding with a stealthy game of spotlight. The next morning we were straight into one of the old favourites - team laser tag before everyone put their fear of heights aside for the high ropes course. This was an amazing spectacle, and it was fantastic to see how everyone challenged themselves. After lunch we enjoyed the giant slip and slide with a shaving





Some of the girls busting a move



The next day we started with a choice of abseiling for the more daring or archery for the eagle-eyed, followed by the 60-metre double flying fox (it was fast - very fast!). In the afternoon we put on our togs and went down to glorious Collaroy Beach for a swim and a muck around.

Thursday was a big day with an excursion to Taronga Zoo, which is always a hit. Then on the last evening we threw a farewell party with our amazing DJ Izzy. And then we slept...ahhhhh. As you can well imagine, there were some pretty tired bodies after such an exhilarating week.





Celebrating the end of a successful camp



Daniela giving archery her best



Thomas & Daniel abseiling

Lochie taking aim The feedback has been really positive, and the change of venue was a great success.

We have a secure Facebook account especially for family and adventure campers to reminisce and post your own pics. If you haven't received your invitation from Jenny yet, please email her at jenny.smith@mdnsw.org.au

Thank you so much to our amazing volunteers! Mitch Taylor Camp Manager

Here we are keeping our strength up

On 16 April 2018 MDNSW took on the challenge with an action-packed day for siblings organised at TreeTops Adventure Park in Pennant Hills. This was the perfect opportunity for the brothers and sisters of those living with neuromuscular conditions to come together and connect with others in a similar situation in a really fun environment.

The park is split into two sections with a number of courses catering for ages 3-9 and 10-15. Client services coordinatior Ganesh recalls feeling very challenged by the whole experience but even he came out empowered!

"I haven't done anything like that before and I am not a fan of heights but if the kids were going to do it, so was I...and I am glad I did!"

CELLENT DAY OF lventure FOR KIDS!

All 9 kids aged 6-16 in attendance had a great time once they overcame any fear of heights they may have had (although I think it was just me who was freaking out when compared to the little champs who were awesome and able to complete the course with ease). The younger kids thoroughly enjoyed their course, which was followed by 10-pin bowling, football and frisbee.

So what was the unanimous verdict? "We want more of these outings!"

See below for our next two dates!



Thumbs up and smiles for the camera!



Heading for the heights









You must be at least 6 years of age and no older than 16 years of age.





Let's talk about_ **WERCHAIR SOCCER**

Hi, I'm Jaxon and I'm 13 years old.

My mum and I had the idea years ago of starting a junior side for powerchair soccer to try and get me to join a team sport. We approached NSW Powerchair Football Association, and thankfully they were keen to get a junior soccer side started

I still remember my first time trying out the sport in 2015. We had only just started, and the turnout was quite underwhelming. Only three others showed up, who were all friends of mine from school. We felt a bit overwhelmed by watching the older players play and could tell that we had a long way to grow in the sport.

The older players had proper sports wheelchairs, with metal soccer guards that are used in competitive matches. Because we were all new, we didn't have that privilege yet. We used our everyday wheelchairs, but were lucky enough that a parent had made fibreglass guards that could be easily strapped onto our wheelchairs.

Once I was able to hit the large soccer ball with the guard attached by controlling my electric wheelchair myself, the intimidating feeling diminished and the excitement of the sport set in. In no time I was buzzing around, whacking the ball in all directions, and I knew I definitely was going to love this sport.

Over the next year, we started to promote powerchair soccer through many outlets. Posters were given to Northcott, Muscular Dystrophy NSW, Westmead Children's Hospital, schools and many more places. The sport was growing slowly, and we finally had enough people to play two teams against each other.

A few more seasons went by, and that was when the sport finally started to grow into something special that the disabled community could participate in. A wonderful mum of one of my fellow teammates approached Holden, who were kind enough to

grant the Holden Home Ground Advantage Sports Grant to the NSW Powerchair Football Association. It supplied us with eight sports wheelchairs for the juniors.

Finally the younger players could play in the professional sport wheelchairs too! Suddenly, more kids slowly started showing up, and the sport was become something much more exciting.

Around that time, an older player and his brother volunteered to take the junior development squad under their wing and devote some time to helping us further develop our skills. We started the 2018 season with over 20 players, some playing weekly and some playing monthly.

For Jaxon's full article go to

http://mdnsw.org.au/wp-content/uploads/sites/2/2019/06/ Lets-talk-aboutPowerchair-Soccer.pdf

Don't forget - you may be eligible for a \$100 Active Kids voucher, which can be obtained through your MyServiceNSW account.









imagine

assisting people with disability to explore their imagination with creative photography

E suemurrayphotographer@gmail.com | www.imagineme.com.au | M 0412 810 745

IMAGINE ME CREATIVE PHOTOGRAPHY WORKSHOPS

Explore the world around you as you use your camera to take inspirational photographs. Discover new ways of seeing and learn how to transform the ordinary into the extraordinary. Using accessible equipment, you can capture creative images that will amaze your family and friends.

No matter how far you want to take your photography - whether as an enthusiastic hobbyist or a passionate professional - these workshops can help you take better photographs.

Sue Murray teaches the art of photography with adaptive equipment, such as tripods that fit to a wheelchair, touchscreen cameras, and cameras controlled from mobile devices. And - she is an NDIS-registered provider in the category of Innovative Community Participation.

Ready to explore? Email Sue to discuss further at suemurrayphotographer@gmail.com, or visit her websites for more information: www.suemurray.com and www.imagineme.com.au

Save the Date!



NEUROMUSCULAR

Information & Research Day

Figtree Conference Centre, Sydney Olympic Park



Saturday 31 August 2019

Peer Connect



Sydney Adults with MD **Community Gathering**

Get together for adults with MD, their partners, carers and friends

Save the Dates!



Dooleys Catholic Club

17 Church St LIDCOMBE

or call **0429 014 722**

11am - 2pm

• 28 June

• 26 July

• 30 Aug

• 19 Oct

• 29 Nov

• 14 Dec

28 Sept (Sat)

Contact Ganesh for more info: ganesh.kakani@mdnsw.org.au





Expressions of Interest



YOUNG ADULTS

Fi 7 - Mon 10 Feb 2020 Retreat

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

Meet new people, enjoy some amazing experiences and take a well-earned break!



- Day trips on Northern Beaches
- · Live music, dinner and drinks at the Newport Arms
- Bonfire with guest acoustic musician
- Swim at Collaroy Rock Pool
- Much much more!

HOW MUCH?

WHAT YOU NEED TO DO

WHERE?

REGISTER YOUR INTEREST





UPDATE Online Community

Peer Info Hub

We will have some wonderful stories featured on the new website, written by members of the MDNSW community. This fabulous collection will grow over time. Let us know if you have an idea or would like to see a story on a particular topic.

Some of the stories written by people with their own direct experience will include:

- Some tips on starting high school with MD
- How to be your own boss when dealing with support workers
- How Myotonic Dystrophy can run through families and not be known until grandchildren are diagnosed
- Using the NDIS to get back into art and swimming
- Accessible travel tips for all sorts of destinations

A big thanks to the Peer Advisory Group who have been very helpful with feedback on the new website to date. We are sending a link so they can have a look and take it for a test drive. We might need to make some changes after they get back to us with feedback, and then we will launch to the wider MDNSW community.

National Resource

Dr Scott Hollier has been working on developing a website for the Muscular Dystrophy Foundation that will be a national resource for the MD community. Scott has completed a preliminary round of community consultations across Australia, including in NSW. While he was in Sydney we saw there were some real possibilities for collaboration between our projects. Stay tuned for updates on what that will look like!

SPORT

NATIONAL ELECTRIC NEWSUPDATE WHEELCHAIR SPORTS







Josh Rycken (VIC), Dylan Needham (WA), Shaun Mott (VIC) Dimitri Liolio-Davis (NSW), Jules North-Coombes (VIC)

Jack O'Keefe (WA), Shaun Mott (VIC)

In April, the 34th annual National Electric Wheelchair Sports {NEWS} competition was held in Narrabeen, Sydney, at Sydney Academy of Sport and Recreation. {NEWS} boasts a rich history of hosting athletes with neuromuscular conditions, and state teams came from all over the country to participate in three different sports over the course of a week: Powerchair Football, Powerchair Hockey and Rugby League.

This year, the competition was tightly contested, with many final scores hard fought, succeeding with narrow margins. We were delighted when New South Wales came out on top as the winners of the coveted Roger Melnyk Trophy, an award named after NEWS' founder. This Trophy is awarded yearly to the team with the highest winning percentage from the round robin phase of the competition.

Here are the final results of {NEWS} 2019...

- New South Wales came first in Powerchair Football, defeating South Australia 1-0
- Victoria defeated Western Australia 1-0 to win the Powerchair Hockey grand final
- New South Wales defeated South Australia in Rugby League, securing themselves first place with a final score of 12-4

National Electric Wheelchair Sports has concluded for another year, we can't wait for next year!

To find out more about National Electric Wheelchair Sports and how you can get involved, please contact the National Director, Luke David at director@newsports.org.au



Call 02 9888 5711, email info@mdnsw.org.au or by post at:
MUSCULAR DYSTROPHY NSW 80 Betty Cuthbert Drive, Lidcombe NSW 2141



NEUROMUSCULAR CLINICS

PAEDIATRIC

Sydney Children's Hospital Randwick

Neuromuscular Clinic Call SCH for Outreach Clinic at: Canberra Hospital, Canberra

9382 1845

Children's Hospital Westmead

Neuromuscular Clinic

Peripheral Neuropathy Management Clinic

Duchenne Monitoring Clinic

9845 1325

John Hunter Children's Hospital

Neuromuscular Clinic, Newcastle

4921 3932

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Nerve & Muscle Clinic

Chris Cormack - c.cormack@unsw.edu.au

0417 259 871

Westmead Hospital

Adult Genetics Clinic

8890 9780

Royal North Shore Hospital

Neuromuscular Clinic,

St Leonards

9463 1833 or 9463 1866

Concord Hospital

Neuromuscular Clinic

9767 6864 or 9767 6129

Feedback and Complaints

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 feedback@mdnsw.org.au

phone 02 9888 5711 or

free call 1800 635 109

website mdnsw.org.au/contact-us

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