

# Talking Point

**MUSCULAR  
DYSTROPHY**  
**NSW** BUILDING STRENGTH  
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER AUTUMN 2019



## JUST CHILLIN' ON THE NORTHERN BEACHES

*Keve, Mathew, Fletcher, Scott and Hayden heading out*

I'm sure I speak for everyone who came to the Young Adults' Retreat from 1 to 4 February that it was an amazing weekend away! The feedback has been really positive, and it was so successful we're certain it will be an annual event. This time fourteen young adults made the trip, with some travelling from as far as Canberra, Wagga and the Hunter region.

We planned the Retreat to provide a similar atmosphere to our December camp for kids - but with age-appropriate entertainment. I think we achieved that! Besides all the planned activities, the weekend gave everyone a great chance to spend time with old friends. It was also an opportunity to get out amongst it and experience some of the colour and action the Northern Beaches has to offer. We had dinner and drinks at the legendary Newport Arms, swam in the famous Collaroy

Rockpool, and went for a wander around the Manly Markets for a bit of retail therapy and lunch plus more. On the last night we all chilled by a fire, reminiscing about the great time we'd had, while DJ Wheels played some awesome tunes.

If you're aged 18-30 and you're living with a neuromuscular condition, we encourage you to start thinking about the 2020 retreat right now - especially as it could be covered by the NDIS. Just remember, if you don't already have funds available under your NDIS plan, it might take some time to get them organised.

To find out more, please contact Mitch or Jenny by calling **02 9888 5711**, or emailing [mitch.taylor@mdnsw.org.au](mailto:mitch.taylor@mdnsw.org.au) or [jenny.smith@mdnsw.org.au](mailto:jenny.smith@mdnsw.org.au)



## EDITORIAL

HAPPY NEW YEAR AND WELCOME TO 2019 FROM THE WHOLE TEAM HERE AT MUSCULAR DYSTROPHY NSW!

This year we look forward to holding some new events and continuing the work we have been doing on exciting projects like the development of our online community and information website which will be launching towards the end of the year! These projects are only possible thanks to the hard work of the team here and the much valued input of our peer advisory group and members. We will continue to consult through the year with members to ensure that everything we deliver is in true alignment with the needs of the neuromuscular community. We invite your feedback at any time as we are constantly trying to keep up to date and improve our services.

In February this year we held our first ever camp for Young Adults. Check out our front page for an update on how it went. We are also expanding our peer support groups in

2019 in hopes that more members of our community can link up in a variety of ways, share valuable information and learn from each other.

Fundraising, of course remains a vital component of what we do in 2019 and we are so grateful to the support that we receive from our member and donors which ensures our programs remain sustainable. We hope this year to double the amount we raise though Sugar Free September to an ambitious \$100K and hope that you will join us in these efforts by going Sugar Free for MD later in the year.

We hope you all have a fantastic year and thank you for your ongoing support in 2019.

*CHARLOTTE SANGSTER*

General Manager, Muscular Dystrophy NSW

## FAREWELL MARTIN DARYMPLE

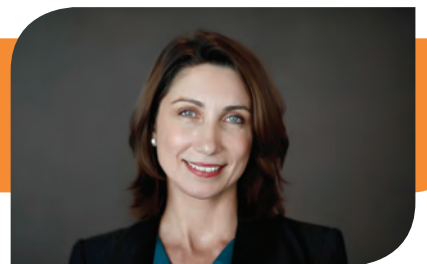


**Thank you, Martin, for all you have done.**

It is with sadness that we farewell Muscular Dystrophy NSW Board Director Martin Dalrymple after eight years of valued service.

Martin, along with his family, has made a significant contribution not only to MDNSW, but to the neuromuscular community as a whole. The Dalrymples have participated in many meaningful projects over the years, and their leadership of the National Electric Wheelchair Sports (NEWS) is valued by the whole community. NEWS will continue into the future with the wholehearted support of MDNSW. Thank you for your service, Martin. You will be missed, but we look forward to seeing you around often!

## WELCOME NEW BOARD MEMBER MICHELLE BALL



**Michelle is Senior Vice President and Head of Human Resources for Bank of America Merrill Lynch and a member of the Executive Committee for Australia. In addition, Michelle is the Regional Learning, Leadership Development and Diversity & Inclusion Executive covering 12 countries across Asia Pacific.**

Previously, Michelle held several senior regional European and Emerging Market HR roles in both the Banking and Pharmaceutical industries. Before moving into

HR, Michelle held a variety of roles within sales and marketing for Johnson and Johnson in the United Kingdom and Australia. Michelle is also a member of the Australia Institute of Company Directors. Michelle qualified as a Dietitian with the University of Newcastle and gained experience as a clinical and community Dietitian. Michelle is also an AOEC accredited Executive Coach.

Michelle is a mother of little boy with a rare form of Congenital Muscular Dystrophy and was one

of the leaders of a crowd fund campaign called Beat4life which connected people globally to fund critical research in the US. Michelle has attended several international conferences to help advocate for the required research pathways and remains very connected to key scientists, clinicians and patient groups globally, all with a united vision to make strides forward in research for suitable treatments and a cure.



# THE 2018 MDNSW ANNUAL NEUROMUSCULAR & RESEARCH SEMINAR

This inspiring seminar was held at the Figtree Convention Centre on Saturday, 10 November 2018. If you couldn't be there or want to review the discussions, you can view all the presentations on the MDNSW website at [mdnsw.org.au/neuromuscular-and-research-seminar-2018](http://mdnsw.org.au/neuromuscular-and-research-seminar-2018)



Here are the presenters and the topics covered...

**Sam Bryen - BSc, current MDNSW PhD Scholar**  
Making sense of splice variants in neuromuscular disorders

**Rachel Lindeback - Senior Paediatric Dietitian, Sydney Children's Hospital** Food, Fabulous Food!

**Fabienne Edema-Hildebrand - Clinical Nurse Specialist Neurology, Royal North Shore Hospital** Transition Care, let's make the transition to adult health care as smooth as possible.

**Dr Michelle Farrar - MBBS FRACP PhD, Paediatric Neurologist and Director of Neuromuscular Services, Sydney Children's Hospital** Lessons learned from SMA – what happens when a clinical trial works!

**Helena Young - Occupational Therapist – Neuromuscular team, Children's Hospital Westmead** NDIS – Challenges & opportunities for people with muscle diseases.

**Julie Duong & Kristie McCarthy - (panel discussion)** How to get the best from your NDIS funding, and your chance to share your experiences of the NDIS.

## CAMP KNG FUN!

### CHANGE OF DATE & VENUE

Join us for a unique adventure of a lifetime!

# Adventure Camp 2019

## Collaroy Centre — Mon 22 - Fri 26 April, 2019

To find out more about the Collaroy Centre and the activities offered please visit:  
<https://www.collaroycentre.org.au/>  
 Take a virtual tour at:  
<https://www.collaroycentre.org.au/virtualtour/>

**WHAT?**  
 Campers will be grouped according to their age and gender and will be looked after by experienced carers who have attended our camps before. There are a variety of activities to choose from that suit all ages, personalities and abilities.

**Team Laser Tag • Swim at Collaroy Beach • Taronga Zoo • and much much more!**

**WHO CAN COME?**  
 Our Adventure Camp caters for those with a neuromuscular condition who would benefit from trying new things and meeting new people. It is open to young people **6-18 years** who have some level of independent mobility.

**How MUCH WILL YOU PAY**  
**\$120** this is an administration fee paid by you and is not covered in your NDIS package.

**NDIS FUNDING**  
 MDNSW no longer receives government funding to run our camp program and now relies solely on funding through each camper's NDIS plan. Please review your plan now to ensure there is sufficient funding allocated in the CORE supports area of your plan to pay for camp.  
 If you are in the process of getting ready for your plan review, we can provide you with a quote for camp so you can request the funding needed.  
 The cost of the camp will come from your NDIS plan in the CORE supports area.  
 Please contact us if you're unsure if you have funding for camp in your plan.

**WANT TO REGISTER FOR CAMP OR FIND OUT MORE INFORMATION?**  
 Contact Jenny or Mitch *urgently* to book your place by ringing **9888 5711** or by emailing [jenny.smith@mdnsw.org.au](mailto:jenny.smith@mdnsw.org.au) or [mitch.taylor@mdnsw.org.au](mailto:mitch.taylor@mdnsw.org.au)  
 The camp is very popular and places are strictly limited, so **RSVP early to better your chances of going!**

[mdnsw.org.au](http://mdnsw.org.au)

## Peer Connect

# Siblings Day Out

**Tues 16 April 2019**

For kids who have a brother or sister with a neuromuscular condition.  
 You must be at least 6 years of age and no older than 16 years of age.

**WHAT? 2 hours of fun at TREETOPS ADVENTURE PARK!**

Climb, weave and fly through the tree tops on self-guided rope courses.  
 Flex your adventurous spirit and test yourself mentally and physically with over 100 elevated obstacles with rope ladders, wobbly bridges, tunnels, cargo-nets and zip lines.  
 Enjoy a bush walk, play some sports and meet new friends who also have a sibling with muscular dystrophy in their family.

**WHERE?**  
**TreeTops Adventure Park**  
 Cumberland State Forest,  
 95 Castle Hill Rd, West Pennant Hills

**COST?**  
**\$20**  
 BBQ lunch included

**TIME**  
**DROP OFF** | 9am at our Lidcombe office or meet at 10am at TreeTops  
**PICK UP** | 3pm from TreeTops or 4pm at our Lidcombe office

**Spots are limited!**

**RSVP** Please RSVP Mitch by **Friday 12 April on 9888 5711** or [mitch.taylor@mdnsw.org.au](mailto:mitch.taylor@mdnsw.org.au)

[mdnsw.org.au](http://mdnsw.org.au) | 80 Betty Cuthbert Drive, Lidcombe NSW 2141

# NATIONAL ELECTRIC WHEELCHAIR SPORTS } NEWS

National Electric Wheelchair Sports (more commonly known as NEWS) is a national sporting competition for people who use powered wheelchairs. The competition itself has enjoyed a 33 year history, created in 1986 by Roger Melnyk who had a dream to create a sports competition for people with a neuromuscular condition. Over the years, the sports played in the competition have adapted as the variety of powerchair sports played on the world stage have risen. Today, NEWS hosts 3 sports; Powerchair Hockey, Powerchair Football and Rugby League. NEWS gives athletes opportunities in sport. Not only opportunities in developing leadership and confidence, growing friendships in their teams and the wider NEWS community, but also in the development of skills that could take athletes to the world stage!

Athletes from New South Wales, South Australia, Western Australia and Victoria will travel to Narrabeen to compete in the three sports. New South Wales will be aiming for their 11th consecutive Rugby League championship, while Victoria has won the past three Hockey championships. This year will be the first time Powerchair Football will be played and every state will be wanting to get their hands on the first championship! NEWS has always been a competition that showcases highly skilled powerchair sport from around the country, and NEWS 2019 promises to be no different. **NEWS 2019 will take place at the Sydney Academy of Sport between April 15 - 19.** You can catch all of the action on the National Electric Wheelchair Sports Facebook Page!



NSW and VIC players playing hockey

Let me know if you would like more information and please feel free to change anything you'd like.

To find out more on how to get involved, please contact the *National Director of National Electric Wheelchair Sports*, Luke David on **0424 160 174** or [luke.david@vewsa.org.au](mailto:luke.david@vewsa.org.au)

## REPRESENTING AUSTRALIA



Kieran's jersey

Italy 2018 team photo

**In September 2018, I had the privilege of representing Australia on the world stage in the game of Powerchair Hockey.**

My journey to representing Australia began in February 2018, when I was selected to represent NSW at the Australian Powerchair Hockey Association's first-ever National Championships. After I was selected, I was made aware of the upcoming World Championships that were to be held in Italy. After the National Championships, I was named in the Australian Sliders squad. I felt honoured and humbled, but at the same time it didn't really sink in for a few months.

I had never flown longer than two hours, so naturally I was a little worried about flying over 20 hours. Because of my inability to support myself in a regular airplane seat, I made the very expensive decision to fly in business class with Emirates. I was able to lie flat most of the flight and even got a few hours' sleep.

I made the decision to stay in Dubai for four nights after one 14-hour flight, just because I wasn't sure how I would feel, but thankfully everything went off without a hitch! Accessibility-wise, Dubai is absolutely fantastic. In some aspects, it's better than Sydney - specifically the train system.

Once we arrived in Italy, we discovered that it wasn't quite the same as Australia. The buses in Venice are fully wheelchair accessible. However, there can only be one

wheelchair on board at a time - so keep that in mind if travelling in groups. The ferry system is also fully accessible, and is a great way to get around!

A few days later, the team gathered at the tournament and it was great to finally be in camp. Our first practice match was against Denmark. It was definitely a learning experience, but we did better than we expected.

Afterwards, they taught us a few tricks of the trade which we were able to practice and try to implement into a game.

Whilst we weren't able to manage a victory in the entire tournament, we played exceptionally well considering our team was substantially weaker physically.

At the conclusion of the tournament, I was voted 'MVP - Most Valuable Player' out of 78 players. This was definitely not something I was expecting, and was a huge honour.

**Kieran Watts**

## Club Championships FINAL STANDINGS

**Congratulations to the Sydney FC Powerchair Team, the champions of the 2019 APFA Club Championships! After a hard-fought week, a tough grand final was the only appropriate finale.** The Central Coast Mariners Powerchair Football Team put up a strong fight, but the Sky Blues took home the title with a narrow victory. Congratulations to all teams who competed with such good spirit in a fantastic week of competition!

For more information on the club championships results and everything Power wheelchair football go to <https://www.facebook.com/APFA/>



## SHAPING OUR Online Community

Our online community planning process kicked off with the first meeting of our Peer Advisory Group in October 2018. Twelve people with lived experience of MD came and shared their thoughts, providing valuable input for the planning process.

**Thank you to our PAG members!**

*Christie Peolwane, Julie Duong, Karen Peacock, Scott Green, Michael Perrin, Glenn Hourigan, Belinda Ryan, Lija Taylor, Lisa Brown, Kate Andrew, David Kay, Margaret Hourigan*

The next meeting will be held online, when we will be excited to check out Stage 1 of the new website build.

## Seeking Our Stories

The new website will feature a blog that we are seeking people to write for us. We are calling the blog **'Our Stories'**, because we want it to be the voice of our wonderful, knowledgeable and diverse MDNSW community. We are looking for stories reflecting all kinds of lived experience, from people with different types of MD, carers and family members, and those with the parenting perspective. From people with English as a second language, and people in regional NSW. And the topics will range from accessibility, to travel, to sport and employment, and everything in between. Share your life hacks, the ups and downs, and your tips and advice for others. We're basically going to solve each other's problems!

**So please email your story to us - something you think others might benefit from hearing. The more voices we have, the more interesting it will be for everyone!**

## Successful Story

We were thrilled to receive 86 responses to the survey we sent out about the online community. We'll use this info to help build a better website. Here's a snapshot of the responses...

- 45 people with a neuromuscular condition responded
- 35% only used the website around twice a year
- 56% could find the info they needed 'sometimes'

**People were particularly interested in seeing stories on...**

- Assistive technology - 80%
- Therapy - 64%
- NDIS - 63%
- Health & Wellbeing - 62%
- Travel 58%
- Just under 50% of the respondents said they felt 'somewhat connected' to the MDNSW community - our aim is for 100%!
- The majority of people said they would join an NMC discussion forum to get info and advice from others
- 83% said they would like to see condition-specific discussions - e.g. Myotonic, SMA, Duchenne, FSHD, etc
- 27 people offered to contribute a story to the blog, and were automatically in the running for a \$100 voucher

**And the winner was...** Nikki from Kingswood! Nikki met up with Carolyn at the Medical Seminar in November where she was thrilled to receive her prize. We can't wait to read Nikki's story about her son who lives with Myotonic Muscular Dystrophy.

For more info about this project and to contribute your story, please contact us by emailing [info@mdnsw.org.au](mailto:info@mdnsw.org.au) or call us on **1800 635 109**. We can't wait to share the many voices, stories, photos and videos of our MD community. **What have YOU got to say?**

**Carolyn Campbell-McLean & Milvia Harder** *Project Officers*

## SMArties MEET UP

On Saturday 24 November, MDNSW hosted the third annual SMARTies group Meet Up as part of its new Peer Connect program funded by the NDIA's Information, Linkages and Capacity Building (ILC) funding. Twenty-five adults and six kids came along to Hornsby RSL for a delicious deli-style lunch and to catch up with new and old friends. It was a great day for older and younger SMARTies and their families to get to know each other and chat about common issues. The topic of the day was definitely the new SMA treatment, Spinraza, that three of the children are on. It's great to hear about the difference this is making. And Theo and Matilda definitely stole the show! Thanks to everyone who attended, we will hold another event in mid-2019 and will stay connected via the SMARTies Facebook group.



*SMARTies of all ages*

If you are interested in joining the SMARTies group, please contact Carolyn at [carolyn.cm@mdnsw.org.au](mailto:carolyn.cm@mdnsw.org.au) or on **0408 472 510**



We love to see people challenging themselves. Whether it's stepping outside of your comfort zone, trying something new or achieving something you have always wanted to achieve, you can now set yourself a personal challenge and support **Muscular Dystrophy NSW** by raising funds and awareness at the same time!

## HOW YOU CAN GET INVOLVED TODAY!

Go to <https://www.gofundraise.com.au/> and create your individual page or team page and choose Muscular Dystrophy NSW as the cause. You can then select "Personal Challenge" to get started.

Set your own challenge and let everyone know **"MD made me DO IT!"**

Maybe it's to go without coffee for a month? Or not eating cake for a year? Or maybe you want to take on a gigantic challenge and cycle from Queensland to Newcastle to visit your long lost friend who is living with MD like Matt, or by participating in the City to Surf just like Lij!



MD made Mitch DO IT!

Make sure to document your achievement by making your own selfie video footage (doesn't

have to be fancy - you can do this on your phone) and answer the following questions...

- Why are you fundraising for Muscular Dystrophy NSW today?
- What activity are you are doing to raise funds and awareness?
- What does Muscular Dystrophy NSW mean to you?
- What would you'd like to say to all of the people who are following you and your challenge and supporting you through a kind donation?

Send us your footage and we will edit into a video for you and add titles and music!

Call Louise on **02 8986 9006** anytime to discuss your challenge ideas and remember, when they ask you why you're doing it, simply say **"MD made me DO IT, of course!"**

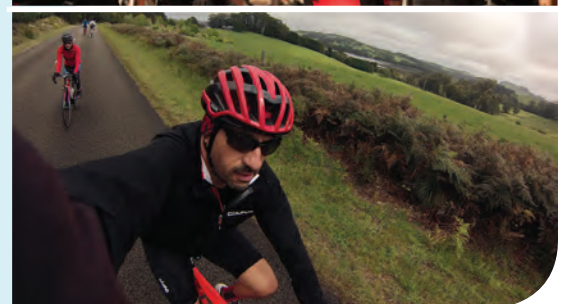
## PATRICH'S STORY

Patrich Ilufi previously participated in The Big Red Ride and decided last year to take on his own personal challenge by participating in the 2018 Bowral Classic to raise funds and awareness for MDNSW. Patrich had this to say about his experience!

*"I rode under grey skies but there was only a touch of rain during the day. The weather stayed cool and made it for comfortable riding over the 120k journey. Hills were challenging surprisingly, as I didn't know that Bowral had such inclines! There were two in particular that really tested me, but I was able to slowly get over them. To this date, I have been able to raise **\$611.00** for Muscular Dystrophy NSW, supported by family and friends"*

Thanks so much Patrich! You are a legend and we all thank you for taking on your own personal challenge!

#MDmademeDOIT



Top: Patrich at the start of the Big Red Ride 2017  
Bottom: Riding in The 2018 Bowral Classic



# MICHAEL'S JAPAN TRAVEL GUIDE

This is a shortened version of what Michael has written about his trip to Japan. You can find his complete guide, with lots more handy tips, on our website [mdnsw.org.au/wp-content/uploads/sites/2/2019/03/Michael-Perrin.pdf](http://mdnsw.org.au/wp-content/uploads/sites/2/2019/03/Michael-Perrin.pdf)



At the subway

## JUST A QUICK BIO

I'm 43, I have Duchenne Muscular Dystrophy, and I use NIV 24 hours a day. I travel with my partner, Alison, and on our last trip we took a carer along, who helped us with our luggage mostly, but was on standby for anything else. You'll definitely need a carer who can keep a level head, because the culture difference, if you're not expecting it, can be overwhelming.

## WHY TOKYO?

We had travelled to Europe twice before and, for me, the thought of another 24-hour flight was a bit much. I guess also, now that I'm in my 40s, I don't have as much energy as I used to. So I started researching closer destinations with shorter flight times. Tokyo was at the top of my list. I've been an anime fan from as far back as the '80s, so I wanted to experience the culture first hand. We also like cities rather than beaches. No jetlag, and the fact that it's warm there when it's cold here. Perfect! If you have an issue with humidity, maybe avoid the hotter months...it's extreme!

## DO YOU TRAVEL WITH A PARTICULAR AIRLINE? HOW DO YOU FIND THE AIRLINE/AIRLINES CATER FOR SPECIFIC NEEDS?

Qantas. They're ok with specific needs up to a point. Yes, they are supportive if, for example, you need a bi-pap machine for the flight, if you've submitted all of the required medical forms and you have the dangerous goods approval letter. They will also insist that you and your ventilator be near a power outlet in case the battery fails. I've only ever flown economy so I don't know what goes on up the front, but every power outlet seems to be at the back of the plane, right near the inaccessible toilets.

## WHAT'S JAPAN'S ACCESSIBILITY LIKE? HOW DO YOU GET AROUND WHEN YOU'RE THERE? PUBLIC TRANSPORT?

The streets are really accessible, and because Tokyo is a bike-friendly city you'll always find a way. Malls, parks, tourist sights and temples (for the most part) are all accessible. Some temples have specific access points for wheelchairs. Not every temple or castle is 100% accessible, but you can get pretty close, or at least close enough for a photo. You obviously can't get into the temples, but the access is limited for able-bodied people as well.

Restaurants can be tricky – a lot of them are quite tight and built for efficiency. Nearly every mall has a food court somewhere, usually the basement, so if you can't find an accessible restaurant on the street, you won't starve. Also, most of the larger hotels will have western style restaurants with fairly good access. Some of the alley restaurants will flat out refuse to serve you...! Most public restrooms are large, clean and accessible.

The Tokyo Metro is by far one of the most accessible ways to get around. Here's what I know...

You'll need a train pass – go to [www.pasmo.co.jp/en/](http://www.pasmo.co.jp/en/). You should also familiarise yourself with the Tokyo Metro subway map at [www.tokymetro.jp/en/subwaymap/](http://www.tokymetro.jp/en/subwaymap/). It looks really scary, but it will make sense in no time.

Everything is colour coded, numbered and labelled on the platform, along the route in the tunnels and inside the train. There's a scrolling LED with next stop info and an overhead announcement in English on most trains.

## WHERE DID YOU STAY?

We stayed in Ginza, for three nights at the Millennium Mitsui Garden Hotel first. The bathroom was perfect – it was basically a wet room. The room was a little tight but manageable. This shows you how a bit of research and cross referencing pays off. The next hotel was in Shinjuku, Hotel Sunroute Higashi Shinjuku. The room was large, but the bathroom was super tight.



Choose a hotel close to the subway

When you're booking a hotel, you want to look at **barrier-free** or a **universal** rooms. I say this because instinctively you find yourself clicking on access or accessibility – this will only show you how to get there.

The differences between each hotel and their universal/barrier-free rooms and bathrooms are substantial – while the bathroom might be perfect, the room might not be, and vice versa – and in my experience this is sometimes dependent on budget, but also on the level of your care needs and on being adaptable in some instances.

## HIGHLIGHTS? TOURIST DESTINATIONS?

Here's a summarised list of places we visited in Tokyo. We also had a day trip to Kyoto on the Shinkansen, and we were lucky enough to see Mt. Fuji from the train...

Koishikawa Kōrakuen Garden ★ • Shinjuku Gyoen National Garden ★ • Tokyo Metropolitan Government Building ★ • Tokyo Tower • Asakusa Sensō-ji Temple and Hōzōmon Gate • Edo-Tokyo Museum • Ueno Park • The Imperial Palace • Marunouchi Building • Nippon Budokan • Meiji Jingu • Ultraman World M78 • Tsukiji Fish Market • Godzilla Statue ★



Shibuya, Tokyo



Time with the locals

# contact us...

Call 02 9888 5711, email [info@mdnsw.org.au](mailto: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

ADULT

### Prince of Wales Hospital Randwick

Nerve & Muscle Clinic  
Chris Cormack - [c.cormack@unsw.edu.au](mailto: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

## MDNSW Staff and Board

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Joan Martin

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Louise Walpole

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Maralyn McCann

### Finance Manager

Angelito Escalada

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Stuart Uhlhorn

Michelle Ball

## 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](mailto:feedback@mdnsw.org.au)

**phone** 02 9888 5711 or

**free call** 1800 635 109

**website** [mdnsw.org.au/contact-us](http://mdnsw.org.au/contact-us)