

Talking Point

MUSCULAR DYSTROPHY NSW E-NEWSLETTER SPRING 2017

Muscular

Dystrophy NSW

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Hello Client

Welcome to the Spring 2017 edition of Talking Point

In this issue we take a look at our recent MDNSW Open Day and Members'
Consultation, Richard Ly tells us a little bit about his experience with the Duke of Edinburgh Award program and we have some exciting stories from across the globe that celebrate our world travel and sporting achievements!

If you have any stories that you think would be of interest in future issues of Talking Point, please contact me on <u>mitch.taylor@mdnsw.org.au</u> or by phone, 0458 026 532.

Mitch Taylor Client Programs Coordinator

This Issue:

- Members Open Up
- Reviewing your NDIS Plan
- Remembering Peter
 Dalrymple by Christopher
 Suffield
- APFA National Titles
- Medical & Research Seminar
- Boccia Bash 2017
- Welcome Lou
- The Little Red Ride
- In the Spotlight!
 Fundraising Update
- Help us give the gift of strength this Christmas
- Jacks European Trip
- 2017 FIPFA World Cup review
- Richard's going for GOLD!



Members Open Up

On 20 September MDNSW held a Members' Open House and Consultation Day. It was a great way to engage with a diverse range of people and hear directly from our community as to what they want from our organisation.

Old friends caught up and new connections were built as we chatted, lunched and took a tour of our new permanent premises at Lidcombe.

We discussed a range of topics such as Information, Peer Support, what MDNSW does well and what else you would like to see from MDNSW in the future.

Members expressed a desire for access to reliable online information that is simple to read and understand and to also have the choice about receiving Talking Point in print. Members also wanted one comprehensive source of information to access their community and information on how they live their lives, a source of information that can be reviewed by and added to by peers.

We are so thankful to those of you who took the time to share your super ideas, feedback and suggestions about our work with the neuromuscular community.

I have included feedback quoted on the day below and stay tuned for more details on some exciting new projects!

Carolyn Campbell-McLean Project Officer

Information

"All I've done all my life is stumble upon information"

"When my son was diagnosed I wanted to find out as much as I could, we were told there's very little info and finding it was so hard"

"We wanted to do some travel but we don't even know where to start"

"we just need some kind of portal with everything there...like trip adviser for NMC's"

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"we just need some kind of portal with everything there....like trip adviser for NMC's"

Peer support

"It's really important that you know people that you can talk about your life with"
"I was so empowered from meeting this woman face to face and using the information that she shared with me about what to do if someone passes away at home. That never would have happened if I didn't have the chance to meet her"
"When I was younger I felt like everyone was off racing and I was just stuck at the starting line, it was really tough"

"If I hear someone I trust's experience, I'm way more likely to give it a try"

"To have the friendship of other people is so important - you feel less isolated"

"You feel like you aren't alone anymore"

"it gives the older person a feeling that they are making a contribution"

What MDNSW does well

"You bring people together".

"This is the only place I ever met anyone else with Muscular Dystrophy"

"They say send a referral and we'll get in touch. The clinics hard to get into, MDNSW has helped us to get follow up appointments. I couldn't get in otherwise"

"those children at camp were given the opportunity to do things that other kids get to

do every day...the looks on their faces...so happy and the carers are amazing"

What else would you like to see from MDNSW

- More peer support and support opportunities
- Better office signage at the entry
- · A map in Talking Point for people who haven't been here before
- Communicating more about what we are doing!
- Working wheels
- Practical, daily life, self-advocacy and let clients tell their story
- · Share more info on what conditions there are
- Always be aware of the language and the voices that we use and the images that we use to portray our clients
- · Stories of successful adults and stories of things that they are doing
- Honest and transparent communications
- Support for families during drug trials or new treatments to share experiences with each other
- Access to portable equipment.

Reviewing your NDIS Plan

MDNSW has carefully developed an NDIS Planning Toolkit. If you or anyone you know could utilise the toolkit we urge you to please pass it on today. The toolkit is designed to be a guide to assist people with neuromuscular conditions prepare for their NDIS



planning and assist in their 12 month review meetings.

It's really important to put time and thought into preparing for an NDIS planning meeting. Being well prepared for the planning and review meetings will increase the chance of securing a plan you are happy with, being well supported and reduce the need to appeal decisions in the future.

Within the Toolkit there are a series of **fact sheets**, **editable forms**, **checklists** and **templates** that create a collection of handy planning resources designed specifically for people with physical, progressive disability.

It is best to read and use the resources in order, as planning is a process, however they can be used as stand-alone tools if required.

<u>Download your free copy of My NDIS Toolkit here today.</u>

If you'd prefer to have a printed version sent to you, please contact us.



APFA National Titles

The Australian Powerchair Football National Championships were held at Kevin Betts Stadium on Monday 16 through to Saturday 21 October!

Teams from Western Australia.

Queensland. South Australia.Victoria
and New South Wales competed. Two
sides from New Zealand were
represented by Northland and North Auckland



Northland claimed fifth place in an entertaining scrap with Western Australia before South Australia scored a narrow win over Victoria to earn third place. Queensland and NSW were to play for the championship.

In a hard fought championship game, Queensland found themselves down 3-1 with less than 10 minutes remaining in the final. Queensland then scored two quick goals to level the score which sent the game into extra time. Queensland dominated in extra time to become back to back champions of Australia!

Finals results

- Semi Final 1 New South Wales 6-0 Victoria
- Semi Final 2 Queensland 6-1 South Australia
- 5th place play-off Northland 4-2 Western Australia
- · 3rd place play-off South Australia 1-0 Victoria
- Final Queensland 5-3 NSW (after extra time)



Welcome Lou

My name is Louise Walpole but you can call me Lou!

I recently started at MDNSW as the Development Coordinator and I am excited about working to raise funds and also developing opportunities for better communication with you all.

I love pickling seasonal vegies, making jam and I'm a bit of a folk music tragic.

These are things that I thought were quite unfashionable when I was a teenager but are apparently is now my 'thing'!

I also really enjoy photography and I am passionate about people so would love to hear your story. I can be contacted on louise.walpole@mdnsw.org.au or 02 8986 9006. Please drop me a line, I'd love to talk to you.

Lou

Boccia Bash 2017

The 5th annual Boccia Bash was held on the 15th of October at the Sydney Academy of Sport and Recreation. The event saw the best of the Cerebral Palsy Alliance take on the might of Muscular Dystrophy NSW and what a competition it was!



The atmosphere was tense from the beginning...

The MDNSW team were up for a challenge from the start as many of their team mates were representing Australia at the Asia Pacific games and the team represented by Blake, Emma, Adam, Mathew, Daniel and Megan had their game faces on.

With each side having won two of the last four events there was more than a trophy on the line. The winner of today would be in the lead and this was huge.

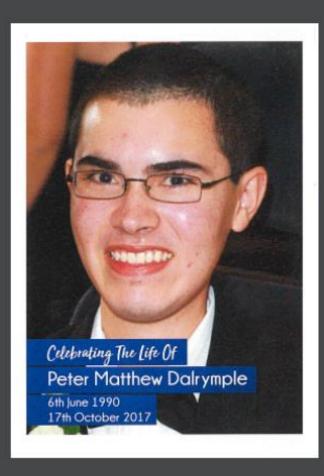
Team Muscular Dystrophy got off to a fantastic start. The Cerebral Palsy Alliance had brought a twelve strong team to our 6 and it seemed that some of the side were looking worried. The alliance were able to rotate their twelve players throughout the day while Team MDNSW played throughout with just a short break for lunch. What an awesome effort!

Team MDNSW gave it 110% but in the end the day went to the the Cerebral Palsy Alliance.

Everyone we spoke to enjoyed their time at Boccia Bash immensely. The atmosphere was electric amongst the players and spectators alike. The day was much bigger than the sport of Boccia itself however as we talked, played, socialised and competed.

This is really one event to put into your social calendar even if you have never played the game. We plan to hold the 2018 event in Western Sydney with the venue to be decided, so start dusting off your Boccia balls because we will need you on board to even up the score!





Remembering Peter Dalrymple by Christopher Suffield

My first memories of Pete involved wheelchair sports.

When I was first introduced to wheelchair sports, I was 9 years old and began playing Push and Power Rugby League.

Pete also played Push and Power from a young age with many of his school friends. I began playing NEWS or National Electric Wheelchair Sports a short time after, and that was when I really developed a close friendship with Pete. At NEWS, we played Rugby League, Balloon Soccer and Hockey.

Pete played 182 games at NEWS for NSW over 10 years, before coaching the NSW team for 72 matches in the following 5 years. I was lucky enough to play alongside Pete throughout those 10 years, and then on the team when he moved into coaching. Sport was a massive part of Pete's life, and he gave others the chance to gain the same joy from sport that he had. After the passing of his cousin Michael, Pete took on the role of National Director for NEWS.

I know Pete would agree with me when I say that on the court, he was an annoying little Sh%t. Pete was one of those players that would do anything the team needed. I remember in Melbourne in 2003, we were playing Rugby League against Victoria. Pete was out on the wing, matched up against Sam Morgan, a player 15 years his senior. Pete gave him hell all game, even scoring a try on him. Pete was one of those guys who would do any job the coach asked of him, always being sent to stronger players and pressuring them out of the game. In Balloon Soccer, Pete would harass the other team's best player all game. In hockey, he'd run blocks all day or keep all manner of shots out of his goal. But where he really excelled was in Rugby League.I couldn't even begin to count how many tries he set up throughout his NEWS career. Pete was an essential part of a very successful NSW team.

Pete played for several teams at Push and Power, most notably the Newcastle team, but also the Sharks, Roosters and Blue Wheelers. Pete also played power hockey (a different version to the NEWS one) and even went to Italy to play for Australia in 2010.

When powerchair football came to Australia, Pete dove in head first and was part of the Australian Poweroos team who went to Paris for the FIPFA World Cup in 2011. Having barely learned the rules, Pete and the boys came 7th in the world. I then had the privilege of playing alongside Pete for the Poweroos at the 2013 APO Cup. When the Western Sydney Wanderers were established, Pete became a massive fan and it wasn't long before the Wanderers were part of our powerchair football competition in Sydney. Pete went on to play for the Wanderers, Sydney FC and finally the Mariners who I play for. While it was only for one tough season, I'm really glad I got to play alongside Pete again. It reminded me once again what a team player Pete was, one of the most unselfish athletes you could come across, always making sacrifices for the team. He was both an excellent goal keeper and always a threat in front of goal.

Pete was always ready to put his hand up when another team was in need, playing for both Victoria and Canterbury at nationals once his NSW career came to a close. Without even knowing any of his Kiwi teammates beforehand, Pete gave everything he could to their cause, and really helped in giving powerchair football in New Zealand a kick in the right direction with the sheer knowledge of the game he was able to impart. I know a lot of you saw the tribute Pete was given at the Sydney Derby over the weekend, and this really shows just the impact Pete had on people's lives.

I don't think of Pete as just a sportsman, or a team mate, or a coach. He was far more than that to everyone he played with or everyone he coached. Pete was a leader in my eyes, willing to make sacrifices for his team or for sport in general. This was shown just last week at the powerchair football national championships. The emotion Pete's passing brought about was testament to just how much he meant to so many people. He was there with us all in spirit throughout the week and I know I played with him in my thoughts.

Pete was a fighter through to the end. The same attributes he displayed on the court, he also displayed through his life, never giving up until the final whistle. We are all better people for having known Pete and there's never going to be someone else like him. You're going to be sorely missed Pete.

Keep kicking goals up there, mate.

The Little Red Ride



Richmond Park Sunday November 26, 10am

This year the Little Red Ride will be at Richmond Park from 10am and will involve an obstacle/slalom course for the Little Red Riders to complete, with sponsorship from family and friends!

The Little Red Riders will challenge themselves and each other in a series of fun wheelchair races, and then we will cheer in all the Big Red Ride cyclists who have cycled from Bondi! We hope to give the riders some motivation to climb the big hill to Katoomba. It is going to be a fun family day with a BBQ lunch. kid's activities and a presentation ceremony for all the Little and Big Red Riders! Please let me know if you would like to join the Little Red Ride team and we will register you for free, so you will receive your own T-shirt, hat and fundraising page! All welcome to cheer on your Little Red Riders on the day!

For further details or to join the group, please contact Carolyn on 0408 472 510 or email cazza74@iinet.net.au or Mitch on 0458 026 532 or email mitch.taylor@mdnsw.org.au







In the Spotlight! Fundraising Update

Thank you to everyone who has supported MDNSW over the past year with donations, raising funds, gifts in kind and of course providing your precious time!

Please read on to hear about what we've been up to over the past few months

Sugar Free September

As most of you may already know, we all went **Sugar Free** this **September**. It's wasn't easy giving up the white stuff and we raised over **\$18,800** to support MDNSW programs and services in the process. It was a mammoth effort and we would like to say a massive **THANK YOU** to everyone who participated or supported with a donation!

Also as part of Sugar Free September, we had a 48 hour fit bit challenge and would like to take this opportunity to announce that the winner is drum roll... Sarah Dally-Watkins. Congratulations Sarah!

As we move into summer, we are getting the wheels in motion for this year's Big Red Ride on the 26th November. If you have any cyclist friends out there who would like to participate in the ride from Bondi to Richmond - or take on the mountain up to Katoomba - and raise funds for MDNSW, then please let them know about the event so they can join here!

Little Red Ride

Also, if you or your family would like to be a part of the Little Red Ride, this year there will be a wheelchair slalom course, family entertainment and we will be cheering in all the riders as they come into Richmond on the day! Carolyn has been working tirelessly to get the excitement happening so to register your interest, please email by clicking here or call Carolyn on 0408 472 510.

I have been hearing whispers from our riders that they are planning on hosting exclusive events to raise money for the ride. I think there are a few trivia nights and maybe a bake sale or two. We are excited about the innovative ideas people have come up and would love to see some photos and hear your stories about your fundraising events, so please send through!

NSW Kids In Need

The NSW Kids In Need annual fundraising event was held on the 21st of October at Kirribilli House. Guests and sponsors included NSW Kids in Need Patron, Dame Marie Bashir AD, CVO, former Prime Minister John Howard OM, AC and his wife Janette, while 2GB broadcaster Alan Jones was MC for the evening. We would like to thank **NSW Kid's In Need** for their continued support and congratulate them on such a successful event. They raised over \$60,000 and Muscular Dystrophy NSW is one of 6 small NSW charities who share in the proceeds raised at the event and we are very grateful for the support.

This is just a snapshot of what we have been doing to raise funds to support MDNSW programs and again, we would like to offer our big thanks to everyone who helps us to do that!

If you or someone you know would like to fundraise for Muscular Dystrophy NSW, please tell them to drop me a line and we can have a chat about your plans. I can be contacted on 02 8986 9006 or fundraising@mdnsw.org.au

I hope you all have a safe and happy Christmas!

Lou Walpole Development Coordinator





Join us for a unique adventure of a lifetime!





Adventure Camp 2018

One Mile Beach Holiday Park Port Stephens

Sat 14 - Wed 18 April, 2018 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.





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.

NDIS FUNDING

MDNSW will no longer receive government funding to run our camp program and will now rely 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 you plan to pay for camp. If you are in the process of getting ready for your first planning meeting or preparing for your plan review, we can provide you with a quote for camp so you can request the funding needed. If you are unsure about any part of the process please contact us

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.

mdnsw.org.au

HOW MUCH WILL YOU PAY?

\$120 (this is an administration fee paid by you and is not covered in your NDIS package)

WANT TO REGISTER FOR CAMP OR FIND OUT MORE INFORMATION?

Contact Jenny at Muscular Dystrophy NSW on 9888 5711 (option 3) or jenny.smith@mdnsw.org.au

The camp is very popular and places are strictly limited, so RSVP early to better your chances of going!

Jacks European Trip

In May this year my Dad, Mum, brother Harry and I travelled to Italy! It was a very big decision to make as we didn't speak any Italian and had never travelled further away from home than New Zealand.

I use my electric wheelchair full time and can't walk anymore so we had to make sure that everywhere we went had good accessibility. We decided to use a travel agent (Margie at Duck Creek Mountain Travel) who accessed specialist disability travel company called CIT Travel to book all our accommodation, transfers and activities. It was the best thing we could have done!



I was worried that the flight (22 hours!) was going to be really hard - I was really worried about having to go the toilet on the plane but everything went very smoothly. The flight attendants brought me an aisle chair whenever I had to move and were really helpful. The dividing wall between the 2 toilets on the plane got removed so we had a bigger space to get in to and move around in. It was definitely a long flight but not as bad as I thought it would be.

We arrived in Venice and were met by a wheelchair accessible van which took us to our accommodation. It was a long way from Venice Island but we quickly found out that the buses in Italy are really wheelchair friendly and the drivers and other passengers were great about making room and helping us on. In Venice I even got to ride in an accessible gondola with a company called Gondolas For All. We travelled all over Italy in 3 weeks by car, bus, vaparetto (water bus) and train. We went to Bologna to see the Leaning Tower of Pisa, Maranello to check out the Ferrari Dino car (that was pretty special as Dino had Duchenne, just like me) and Florence for the food. We spent a day in Pompeii which was amazing. Pompeii is definitely NOT accessible so we hired a wheel trekker (a one wheeled sleigh type contraption) that allowed 2 hard working guys to carry me around the ruins like a Roman Emperor! We visited Rome and and attended the Papal General Audience where the Pope comes out and gives a talk that is repeated in about 6 different languages by different people. At the end of the Audience, Mum and I were really lucky and got to meet Pope Francis. He blessed us and shook our hands. He was really lovely and asked us to pray for him.

While we were travelling there were some places I couldn't get to because they had steps or were narrow, like the tombs under the Basilica in Florence, but we got to skip a lot of lines and go places other people weren't allowed to behind the scenes so it all worked out in the end! I was really nervous about travelling so far from home, to an old country that isn't well known for being wheelchair friendly but I am so happy we went. We found out that we can make anything work and travelling with a disability just makes us expert problem solvers! I can't wait to travel overseas again - I've got my eye on a road trip through the USA!

Jack Bailey







2017 FIPFA World Cup review

I was fortunate to be part of the Australian Poweroos team who travelled to Kissimmee, Florida for the 2017 Powerchair Football World Cup in June.

Powerchair football is a version of soccer designed specifically for powerchair users. Metal guards are mounted onto the wheelchairs and these are used to hit an oversized soccer ball.

The Australian Poweroos team included 3 athletes from Queensland and another 5 from New South Wales. The two

contingents flew out from Australia at almost the same time, before we all met up at Los Angeles Airport, LAX. We all then took the same flight from LA to Orlando. In total, we travelled with 18 wheelchairs, which adds up to around 2 tonnes in weight. In fact, the weight was so much that some freight had to be unloaded from the LA-Orlando flight to keep it underweight. Despite some delays loading and unloading the wheelchairs, everything went smoothly and we all reached our destination in one piece.

We arrived close to a week before the start of the tournament, giving us ample time to recover from the lengthy travel. With several athletes with Muscular Dystrophy on the team, this extra time was invaluable. This also allowed us to do some training before the event began. After a few days of fine tuning, all the teams were given access to the official competition venue for practice matches and to finally see the competition courts. We had mixed results in our practice matches, including a 5-2 loss to the world champions, the USA, a 4-0 win over Canada and a 2-1 victory against Japan. We were in good touch before the games.

We also had to complete classification before the tournament. In powerchair football, there are two classes, PF1 and PF2. Each team must have a minimum of two PF1 classified players on the court at all times. PF1 athletes are weaker in terms of strength. The classification looks at vision, grip strength, body control and a number of other things. Each team was then presented to the crowd at the opening ceremony before the games began.

Our opening match took place against England. We were overwhelmed and came away with a 5-0 loss. We had a chance to make up for that bad start against Canada and won the match 4-2. With two matches left, we needed another win to ensure we made it out of the group stage, and in our first match the next day we scored an important 2-0 win against Ireland in a very tense encounter. Our last group match was against the eventual world champions France, and despite holding them out for most of the first half, we took a 4-0 loss.

Our results meant we would face Japan in the quarter finals, which we knew would be a tough match. It took some real strength of character to fight through a very difficult match. Going down 1-0 early, it took a lot of patience to get back into the game. We levelled the scores with 10 minutes to go, before finally scoring the winner and holding out for the last few minutes. Reaching the semi-finals was our goal for the tournament, and with our next match against France again, we knew we would have an extremely tough match ahead. Unfortunately, the French dominated and won 7-0. We then lost to England in the third-place play-off 3-0. Although it was a disappointing end to the tournament, we were incredibly proud to finish 4th. It's hard to explain just what an honour it was to wear the green and gold of Australia.

As a spectator, the championship game between the USA and France was one of the most exciting games I have ever seen. France won the match 4-2 after going in to half time at 2-2. After watching these two incredible teams, we now know what we have to strive towards for the next world cup in 4 years' time. It was an incredible event to be a part of. Bring on 2021!



Richard's going for GOLD!

My name is Richard Ly and I am 23 years old living with Muscular Dystrophy. I am currently on my Gold level with the Duke of Edinburgh Award and I will be going to the Royal National Park in December for my Adventurous Journey and Residential Project, which spans 9 days.



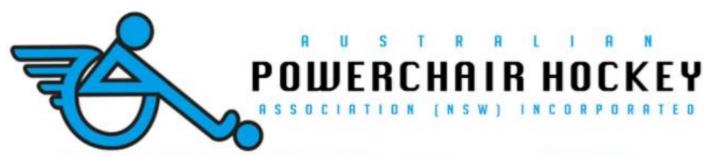
For my Adventurous Journey I will be going with a team, for 4 of these days. We will be going on hikes that are wheelchair friendly for easy accessibility. My Residential Project goes for 5 days. I will be doing different activities each day and I am excited to meet new people! I will be bird watching, view aboriginal gravings and participate in volunteer work.

I am very anxious for my journey but since I am always looking forward to a challenge - and as this is a new experience - I believe it will be exciting.

At first, I thought that there would be limitations for places to go and activities to do since I am in a wheelchair, but upon doing research I saw that there are many possibilities that are easily accessible and hence this encouraged me to give it a go.

My goal is to inspire others to believe in themselves and their abilities, to challenge themselves and reach their goals too!

Richard Ly





ARE YOU INTERESTED IN PLAYING HOCKEY?

WHO: OPEN TO ALL AGES

WHEN: SATURDAYS

TIME: JUNIORS 10am - 12pm

SENIORS 11am - 1pm

WHERE: KEVIN BETTS STADIUM

MOUNT DRUITT RALPH PLACE

Up Coming Events

NATIONALS - APRIL 2018 WORLD CHAMPIONSHIP - SEPT / OCT 2018

Events 2017



NEUROMUSCULAR Seminar & Research JPDATF

Figtree Convention Centre 5 Figtree Drive, Sydney Olympic Park

Plenty of free parking available

Saturday 11 November 2017

11am - 3pm REGISTRATION FROM 10:45am

Speakers

11am Rob Oakley

Everyday life with Muscular Dystrophy

Capital MD

11.30am Heather Best

Identifying a new genetic mechanism of muscle disease

Current MDNSW Phd Scholar

12 noon Associate Prof Amanda J Piper - BAppSc MEd PhD

Breathing problems in neuromuscular disorders -Let's take a deep breath and think about this

Senior Physiotherapist and Manager, Home Ventilation Service, Royal Prince Alfred Hospital

\$10 per member OR \$20 per family \$15 per non-member

includes lunch











12.30 - 1.30pm Catered Lunch

1.30pm Dr Michelle Farrar -MBBS, FRACP, PhD

Evolution of Standard Care in Spinal Muscular Atrophy



Paediatric Neurologist and Director of Neuromuscular Services, Sydney Children's Hospital

2pm Representative from the NDIS **Consumer Engagement**

Update on the NDIS

2.30pm NDIS Q&A Panel and Fact Sheets Launch

My experience of transitioning to the NDIS

The MDNSW 57th ANNUAL GENERAL **MEETING** follows at **3pm** for those who would like to stay



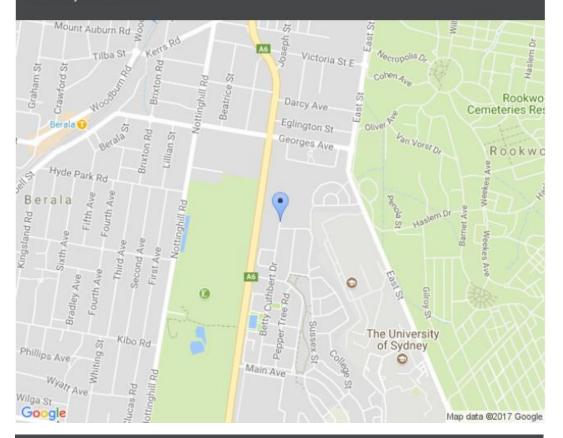
by Wednesday 25 October to: maralyn.mccann@mdnsw.org.au or call Maralyn on 9888 5711 ext.5

mdnsw.org.au

Where to find us:

MDNSW is located in the MS Studdy Centre, Lidcombe. We are open, 9-4pm Mon-Friday.

80 Betty Cuthbert Drive



MS Centre 80 Betty Cuthbert Drive, Lidcombe, NSW 2141 Ph: 98885711 or Freecall 1800 635 109 info@mdnsw.org.au Please click here to unsubscribe from our mail list.