

Talking Point

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER WINTER 2016

Couples Connect in Sydney



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EDITORIAL

IT HAS BEEN A BUSY YEAR FOR MDNSW SO FAR, WITH MANY EXCITING EVENTS TAKING PLACE INCLUDING OUR OFFICE RELOCATING TO MACQUARIE PARK, A SUCCESSFUL PORT STEPHENS ADVENTURE CAMP AND A FABULOUS MD COUPLES RETREAT!



I would like to take this opportunity to thank Pene for her strong leadership during her time here. We are sad to see her go and wish her success in the future. I plan to continue working with the same determination and drive to lead MDNSW into this exciting NDIS journey.

MDNSW proudly hosted the 'Building for the Future' Neuromuscular Conference at Sydney Olympic Park in June. It was a great opportunity for families and supporters to connect, establish new relationships and strengthen existing ones.

I would like to acknowledge all our families and supporters who so generously volunteered at the Kids in Need event. Thanks to your support, we were able to make this event a great success again!

CHAITALI DESAI

State Manager, Muscular Dystrophy NSW

A NOTE FROM THE PRESIDENT



WHILE 2016 IS SHAPING UP AS OUR MOST CHALLENGING FOR SOME TIME, IT SHOULD ALSO BE AN EXCITING YEAR AS WE TAKE STEPS TO BECOME AN EFFECTIVE NATIONAL ORGANISATION.

For years, your Board has pursued collaboration with Muscular Dystrophy Associations in other states and MDNSW is now on the verge of merging with MD South Australia, Northern Territory, Tasmania and ACT in the next few months and hopefully with other states in the near future. The merger will finally deliver a national voice for people with Muscular Dystrophy and also ensure our organisation has a critical mass to better innovate, fundraise and deliver the best state based services. While we're proud of MDNSW's history and services, we know we have an opportunity to grow and help more people. In the next month, we'll contact you with more details of this exciting development.

PETER DEBNAM

President, Muscular Dystrophy NSW

A FEW CHANGES TO THE MDNSW TEAM

Over the past few months we here at MDNSW have had a few changes to the team of staff. Chaitali Desai has taken over as MDNSW State Manager, we have two new members to the team, Natalie Kelly (Client Services Coordinator) and Emma King (Finance Manager), and we are looking forward to another familiar face joining soon! Carolyn Campbell-McLean will be coming on board to assist in the coordination of the upcoming Camp Kula N' Gadu in December.

Check out the profiles below to learn a bit more about Natalie & Emma!

NATALIE KELLY

What is your role at Muscular Dystrophy NSW?

I work as a Client Services Coordinator, providing; coordination of supports, case management, information and referrals, counselling and advocacy. I work across the Metro Sydney and Illawarra regions.



Tell us a bit about yourself

I am originally from South Yorkshire in England, and only moved to Australia in 2013. I am qualified as a Social Worker and have experience working in Child Protection, Mental Health, Youth Justice, Education, Disability and with Asylum Seekers and refugees.

What three traits define you?

Humour, resilience and kindness

What is the one thing you cannot resist?

Chocolate!

What is your greatest fear?

Spiders!

Where is your favourite place to be?

Relaxing in the sunshine, at a nice park or by the water

What is your favourite thing to do?

Read a good book

What book are you currently reading?

When Breath Becomes Air

What is the weirdest job you've ever had?

Assistant at the local bingo hall!

What would you do (for a career) if you weren't doing this?

Fiction editor at a good publishing house

EMMA KING

What is your role at Muscular Dystrophy NSW?

Part-time Finance Manager

A bit about me

Apart from working as an accountant, I am also a mum to a 3 and a half year old little boy. Working at MDNSW allows me a great life/work balance so I am able to spend time with my boy during these early years, which I am very grateful for. In my spare time, I enjoy going to the gym, catching up with friends and I may also have a small addiction to Netflix and coffee.



What three traits define you?

Independent, dedicated, happy

What is the one thing you cannot resist?

Anything sweet

What is your greatest fear?

Heights

Where is your favourite place to be?

The beach

What is your favourite thing to do?

Running around the park after my son on a warm and sunny day

What book are you currently reading?

The Love Affairs of Nathaniel P., by Adelle Waldman

What is the weirdest job you have ever had?

Assistant butcher

What would you do (for a career) if you weren't doing this?

Would love to be a midwife helping deliver babies

MDNSW IS ON THE MOVE AGAIN

As you know our current home is only a transitional move and we will be moving once again to other premises in Macquarie Park in mid-November. Whilst it is not ideal to move twice in one year, it was totally out of our control. Our current base is at a very good financial arrangement and this has allowed us to free up more funds for member services.

Our new office will be on the same road about a 15 minute walk away, our telephone and fax numbers will remain the same, and our new address will be:

Suite 2.04, Building 3
35 Waterloo Road, Macquarie Park NSW 2113

Phone (02) 9888 5711

Fax (02) 9887 4423

If anyone has an hour or two to spare and has a gift for packing boxes we would really appreciate your help with the move.

Please email maralyn.mccann@mdnsw.org.au

EVENT CALENDAR 2016 / 2017

Regional NDIS Information Sessions

14/10/16 | New England/Armidale
 29/10/16 | Upper Hunter
 3/11/16 | Far South Coast

Contact Kejanna 0429 565 222 or email kejanna@mdnsw.org.au

Sun 16 Oct, 2016

Come and represent MDNSW in our fun annual grudge match against the mighty CPA!



The Great Boccia Bash

Narrabeen

Sun 6 Nov, 2016



Are you up for the toughest one day ride in NSW from Bondi to Katoomba? Spend the day cycling in support for those living with a neuromuscular condition.

Regional Christmas Parties

20/11/16
Far & Mid North Coast

3/12/16
Central West/Orange

11/12/16
Wagga Wagga

Contact Kejanna 0429 565 222 or email kejanna@mdnsw.org.au

Sat 3 Dec, 2016

Sydney Metro Christmas Party

A day designed for the whole family including a free bbq lunch, lots of fun activities and a visit from Santa who always brings lots of pressies!

Parramatta

Sat 17 - Wed 21 Dec, 2016

Camp Kula N' Gadu

Booked out!



Sydney Academy of Sport

Regional Connections

Feb, 2017
A night at the Theatre, Dubbo

March, 2017
Sabor in the Hunter

April, 2017
Dine at Duncan's, Bathurst

Contact Kejanna 0429 565 222 or email kejanna@mdnsw.org.au

March, 2017

Mums' City Highlights Retreat



Sun 9 - Thu 13 Apr, 2017

Adventure Camp



Taking Applications Now!

COUPLES RETREAT AT THE QT IN SYDNEY



A beautiful dinner with everyone

Well some would say, it started off as a “FUR coat” type of weekend, even having some Jon Snow’s turning up, but an amazing one at that.

Arrived at the QT Sydney with service that only you would expect someone fit to be a queen would receive. We all met for dinner in the special function room at the QT with some different but surprisingly delicious food especially the dessert. We laughed and we cried but this all happened as new friendships were made and old friendships rekindled.

The next morning we met for breakfast at the QT which was delicious and then we all headed for our day adventures, some went to the Rocks, Opera House and some just went for a leisurely walk to Hyde Park and some even got in a bit of shopping. The night arrived when some of the oldies had some nibbles and then headed off to the State Theatre right

next door to see Georgy Girl, the younger couples headed out to dinner at “ZEST” which was a treat especially the size of the Lamb Shoulder for 2 and the amazing Banoffee Tart with Salted Caramel Ice Cream and Candied Popcorn.

We all met again for breakfast which would be the last gathering for the retreat. We all said our goodbyes for now but catching up again would definitely be on the cards.

We would like to thank Jenny and Joan for all the hard work they put into organising such a fabulous weekend away for everyone to get away from their normal everyday life to a spectacular weekend that won’t be forgotten anytime soon. Thanks so much MDNSW and all involved in the preparation, we all do really appreciate it.

Joanne Edgar MDNSW Member



A beautiful day in Sydney for the couples



Friendships continued to blossom!



A lovely bunch of people!

ADVENTURE CAMP DELIVERS ONCE AGAIN!



Ready!.....



A huge thumbs up from Brooke and Jordan

What a great bunch of people! Thank you so much for giving our daughter one of the best weeks of her life - she didn't stop talking about it all the way home! You really don't know how much you mean to these kids, and you are great role models for them all.

Cath



Boating with Joss and Megan



Perfect weather for a Dolphin Cruise



This Quad biking is tough work



Azalia braved the slide

Laser tag was the best! I love playing competitive sports and being part of a team.

Cowen



Don't mess with these guys!



MDNSW staff hard at work!





*I just love camp!
I wish that we stayed
at camp for a whole
year and that our
parents just came
and visited for one
week!*

Daniel

And they are off!

When the rain came, bowling was the activity of choice



Everyone jumped in and had a go at Boomnetting!

The girls loving Party Night

*Sandboarding
was a little scary
to start, but when
I did it I loved it!
It was the best!*

Aldo



Kieran was the king of the dunes!

Just some of the awesome Carers!

Ready to go Sandboarding!



The team was pumped and ready for laser tag

Ready to hit the sand with the Governor!

Nothing beats fish and chips after a boat cruise

WHAT'S HAPPENING IN THE WORLD OF BOCCIA?



Daniel Michel Makes Boccia Dream Reality



Australian Boccia returns to the Paralympic games with the confirmation of BC3 Athlete, Daniel Michel qualifying for this year's Paralympics in Rio.

Daniel, born with Spinal Muscular Atrophy type two and becomes the first Australian athlete since 1996 to qualify for the Paralympics. He is the first athlete to compete in boccia for Australia since Sydney 2000. His meticulous work ethic saw Dan finish 5th overall at this year's World Championships in Beijing and qualify for the 2016 Rio Paralympics.

Dan says, "It means everything to me. Representing Australia at the pinnacle of sport has been my life long ambition and to have achieved it by qualifying for Rio means I have achieved a monumental goal."

The Rio Paralympics will be held from 7 to 18 September

Boccia Junior National Titles

4 - 6 November, 2016



The 2016 Junior National Boccia Titles will be held at the Sydney Academy of Sport, Narrabeen.

This 3 day event is open for anyone to attend! It's a great way to meet new friends, learn new skills and participate in a great weekend of boccia and sport. Focused on developing the skills of Junior athletes, this is a great event to be part of.

For more details on this and all things Boccia contact admin@boccia.com.au

boccia.com.au or 0403306792 or go www.boccia.com.au

Want to Play Boccia?

There are a number of local clubs running throughout NSW that you can join now!

Contact the following people to find out more information including venues and meeting times.

Central Coast - hkhkozak@hotmail.com
Central West (Orange) - alandtrin@gmail.com
Hunter - hunterboccia@bigpond.com
Illawarra - pthoward@bigpond.com
Northern Beaches - selsworth@gmail.com
Penrith - michelle.hamlin@hotmail.com
South West Sydney - pat.vaz16@gmail.com
Tamworth - j.essex@sunnyfield.org.au

Are you interested in learning the Sport of Boccia at school? MDNSW may be able to help!
Give Joan from our Client Services Team a call on 9888 5711 to find out more!

Live the Dream

VALE BRUCE ELLISON

10 October 1953 – 29 May 2016

Sadly we have lost another of our MD legends. Bruce Ellison passed away aged 62 in May this year, survived by his darling partner Ursula, beloved Kermit the poodle and Yuki the Japanese Spitz and large family of 10 siblings. Bruce Ellison was an outstanding, active, positive man, compassionate friend and all round true gentleman.

Bruce was one of the strongest contributors to our Association in its history, serving 15 years as a Board Director and 3 years as President stepping down in 2007. His great contribution was not only in a professional capacity leading board meetings, fundraising campaigns, meeting with government, media and celebrities, but in his genuine understanding of the needs of people living with NMCs over different life stages. He developed Talking Point into a useful and member focused publication and was a fierce advocate for change for people with disability. Bruce was involved in access campaigns, the launch of Lime Taxis, and also served Push and Power Wheelchair Sports, National Electric Wheelchair Sports and a range of other community groups. All this community work and he worked full time in Accounts at Lifesavers Confectionery since 1974.

A proud "sportsnut" Bruce adapted his dreams to bat for Australia and play fullback for the Kangaroos into his skill on the wheelchair footy court. I fondly recall sitting up the back of the bus with Bruce laughing at all his jokes and he told me it was so good to have more girls play sports!

Bruce was well known for being the most knowledgeable and passionate sports fan in Northern Sydney. He spent much of his time at the SCG, following the North Sydney Bears and watching his beloved motor racing. In 1983 Bruce took an incredible opportunity to travel to Europe with a friend who set up an accessible van for them to live and travel in. They went to the San Marino GP, Monaco GP, Belgian GP and British GP and the 24 Hour race at Le Mans, visited as many of the normal tourist destinations as possible. Bruce recounted this trip in a great article in Talking Point in 2007 - clearly it was one the highlights of his full and active life.

We will treasure our time with you Bruce and always be grateful for the contribution you made to our Association, people with disability and the legacy you have left for our community. You have inspired me and may others to accept our disability, get on with life and 'Live the Dream'. We will miss you Wombat! In Bruce's own words...

**“ We must never despair;
life is too short to miss any of it.
Keep smiling. ”**

Carolyn Campbell-Mclean



Bruce and his partner Ursula



Bruce was acknowledged for his work by the Governor, Marie Bashir



Karen Peacock, Carolyn Campbell-Mclean & Rob Ferguson joined Bruce at Government House in 2007

OUR ADVENTUROUS DUKIES



Can't come to Sydney without stopping off at this iconic landmark

Our Dukies have been very busy in the past few months, planning, organising and going on their Adventurous Journeys. These journeys are an opportunity for The Dukies to push themselves out of their comfort zones, to set big goals, to go somewhere they have never been before and to do it independent of their families! The planning involved in each of these journey's is comprehensive, Dukies need to put in many hours looking at all aspects of their trip to ensure that everything runs smoothly and with minimal risk of incident. Well done guys on planning and executing some fabulous Adventurous Journeys!

JYE'S JOURNEY TOWARD INDEPENDENCE

I live in Maryland, up in the Hunter region. I chose to do my Adventurous Journey (Practice Journey) trip to Sydney to experience being independent and being away from family.

Whilst I was there I also tried to navigate public transport independently and met up with friends who live in Sydney. I felt that I achieved every goal from my journey as I used public transport, met up with friends and experienced

living independently without family. The weather played a big part in my trip, I needed to make changes to my original plans of visiting Taronga Zoo as it was pouring with rain on the first day. Instead I met up with a friend, caught the ferry and visited Wildlife Zoo and Darling Harbour. I explored quite a bit of Sydney whilst I was there and learnt further how to adjust to unplanned changes.

Experiencing living without family even for just one night can be really hard but is worth it as you realise I can live independently. I am now planning my



Making the most of sunny Sydney!

Qualifying Journey back to Sydney, where I will be pushing my limits even more!

Jye Donkin 20yrs, DMD

JACK'S EPIC SYDNEY ADVENTURES

Earlier this year I was nominated by my school, Ungarie Central School, in central NSW to participate in an Information Technology week (15th-20th May) in Sydney organised by the Rotary Clubs of West Wyalong and North Ryde. Five students from across NSW attended this trip. I was the only one in a wheelchair.



On the bus, ready to go!

I decided that this was the perfect chance to combine a great opportunity with my Adventurous Journey for my Bronze Duke of Edinburgh's Award. Some

of the things I organised to be able to undertake this trip were: booking my train ticket, hiring a shower chair, booking and organising the timetable for a carer, discussing my needs with my host family, booking the accessible taxi to fit in with the organised business visits, presenting to the Rotary Clubs at the end of the week and lots more.

I left Ungarie on Sunday on the Trainlink bus. At Cootamundra I boarded the train for Central Station in Sydney with Jason

(my support for the week). We were hosted by a Rotary family and a carer from 'Just Better Care' helped morning and night with my personal care.

For the rest of the week we used accessible taxis and trains to visit many businesses and places that focus on IT. This was the first time I had caught a city train in my power wheelchair. It worked really easily and it gave me the confidence to do it again. The places we visited included Optus, Oracle, Coles Distribution Centre, University of Technology, Cisco, Google, Macquarie University, Konica Minolta, Microsoft, IBM and the Powerhouse Museum.

My favourite activities were the visit to Macquarie Uni ICT centre where we each got to build a small robot using Lego Mindstorm EV3 kits and program it to follow a path on the floor and our time at the Powerhouse Museum where we had a go at controlling a replica of the Mars rover. We could then walk on the model of Mars and see where we had driven the rover. At all the businesses employees spoke to us about their training and qualifications, what their company did and what their exact job was.

The week also included some social activities. We went Tenpin Bowling, played Foosball, went out to dinner and

spoke at a Rotary meeting about our experience. The other boys went to Laser Tag but this was the only organised activity I couldn't participate in for the whole week as it had stairs at the entrance!



The hands on part was the best!

This week was a great trip away and I would like to thank all the members of both the Rotary Clubs of West Wyalong and North Ryde for helping me to organise this trip and ensuring they worked with me to make sure I could participate in my wheelchair and have a great experience I could never normally see by myself. I'd also like to thank Ungarie Central for nominating me to go and Jason for coming as my support person for the week. Finally thank you to MDNSW for supporting me and helping this to be a part of my Duke of Ed Award. I really enjoyed it and got a huge amount out of it. It will have an influence on my future when I leave school.

Jack Wason 15yrs, DMD

SCOTT TAKES ON NEW ZEALAND

On the 18th of April this year I had the great opportunity of going to Auckland in New Zealand for my Duke of Edinburgh's Award, Silver Adventurous Journey.

Blake Willis, who is one of our amazing camp carers, came to my house to stay the night before so we could leave straight away in the morning for our Virgin Australia flight (code shared with Air New Zealand) leaving at 10:50am. We got up, got ready and headed to the airport.

At the airport we checked in, said goodbye to my family and boarded the plane ready for the 3-hour trip to the Land of the Long White Cloud. On the plane we watched movies, ate lunch and talked about what we thought we would do whilst in New Zealand all the while being looked after like royalty by our Air New Zealand crew. The flight landed at about 3pm New Zealand time (2 hours ahead of Sydney). When we got off the flight we collected our bags, went through customs and found the Sky Bus terminal where we caught a bus to Auckland CBD, 15 minutes away from the airport. For the rest of the day we did some grocery shopping, cooked dinner (chops, chips and vegetables), then relaxed in order to get ready for a very hectic 6 days ahead.

We stayed at the Citylife Auckland which is part of the Heritage Hotels chain. The next day we visited the Domain where we saw many exotic plants in greenhouses and spent time looking at the nice view from up the top of the hill. For dinner, we cooked tacos.

On the third day we visited Kelly Tarlton's Sea Life Aquarium and went on a cruise across the harbour to Devonport. This is a beautiful and exclusive harbour-side suburb of Auckland with an old historic



Lovely to meet everyone at MDA NZ

military site used during WWII which had amazing views of the city. We visited Sky Tower that night where you could see all the lights of Auckland. Later, we made spaghetti bolognese.

The fourth day was a very exciting day. We woke up early, got ready and ate breakfast. Then we met Melissa Wentworth-Perry to discuss the day ahead; spending it with the Muscular Dystrophy Association of New Zealand. Melissa told us we were having an official Maori welcome. After our talk, and a long



What a view of NZ!

wait for our taxi, we made it to MDA NZ. We waited for them to set up and we met their CEO Ronelle, who has MD herself (which was pretty cool and inspiring). We headed inside and the ceremony started; the CEO and another

member of staff sang to us, a song which translated to being accepted peacefully into their tribe (in this case, to MDANZ). Then they sang a song of choice to us, which brought tears to our eyes it was so moving and then Blake, Mel and I sang Waltzing Matilda (which brought them to tears for all the wrong reasons; it was so tragic!!!). I was then presented with a greenstone necklace from the Chief, who officially welcomed us and we ate lunch (rolls, salads and lots of different cakes) after the chief had blessed it. After lunch we had a meeting with the staff to discuss activities we do at MDNSW such as the camps and the Duke of Edinburgh Award, which they sounded very interested in starting themselves. The meeting went for a couple of hours. That afternoon, as Ambassador for MDNSW, I had to make a speech about the Duke of Ed where I talked about my experiences and achievements whilst completing the Award. It was interesting to chat to people from another country, share experiences and hopefully bring our two organisations together. That night Melissa, Blake and I celebrated by going out to dinner at a fabulous steak restaurant where the steaks were half the size of the entire bull!

Day 5 we got up and headed out early to catch the bus to Auckland Zoo. At the zoo we saw many animals and the best part was seeing the cheetahs walked around the zoo by their keepers. Included



Scott & Blake brave the Sky Tower

in the admission price, we almost saw a young child eaten by them because the parents weren't watching the child run directly into the cheetah's path. For dinner that night we cooked chicken schnitzel which was blackened but tasty.

Our last full day we spent at the Auckland Museum, Tamaki Paenga Hira. We saw many Maori artefacts including the traditional houses and watched Maori dancing. It also doubled as the War Memorial where we saw planes, the Hall of Remembrance and saw a model of a trench. For dinner that night we went to a restaurant to celebrate our trip and to thank Blake for all his assistance, care and friendship.

The next day we got up early, cleaned out the mini bar and waited for the medical equipment to be collected. Then we checked out, headed to the airport and got ready to board our Air New Zealand flight home. We arrived back on Australian soil at 7pm Sydney time. I had a great time and can't wait to return, hopefully in the near future, to renew all my new-found friendships.

I will never forget the New Zealand hospitality, all that I have learnt about Maori culture and my incredible (and humbling) Maori welcome. Thanks to Blake, Mel, Duke of Edinburgh Australia, MDNSW and MDANZ for making this happen.

Now, it's onto my Gold Journey. Where to next? Stayed tuned.

Kia Ora,

Scott Green 16yrs, DMD

BUILDING FOR THE FUTURE NEUROMUSCULAR CONFERENCE

JUNE 2016
SYDNEY OLYMPIC PARK



From Thursday the 17th to Saturday the 19th of June, people from all over Australia gathered together for the annual neuromuscular conference, which this year was held at Sydney Olympic Park.

Jointly organised by; Muscular Dystrophy Foundation, Duchenne Foundation, Australasian Neuromuscular Network and Muscular Dystrophy NSW, the conference brought together people living with a neuromuscular condition, world leading researchers, clinicians, allied health professionals, service providers, representatives of the NDIS and industry providers.

During the conference there were over 25 different talks and sessions, covering a range of topics; Research and clinical trials, NDIS principles and practical planning, medication and the development and regulatory process, neuromuscular research updates,

Australian Care Guidelines and best practice, transforming disability into opportunity and success, The International Duke of Edinburgh Award, maintaining respiratory function in younger and older patients, supporting siblings of people with a disability, independent living and working, supporting transition into adulthood, physiotherapy, exercise and living well with neuromuscular conditions.

One of the most inspiring talks came from Karni Liddell. Karni has a neuromuscular disability and is one of Australia's most successful Paralympians, breaking her first World Record at the age of 14 and going on to win Paralympic medals at every Paralympics she competed at. Karni spoke about 'Transforming Disability into opportunity' and how she has not let her neuromuscular condition hold her back from achieving all she has wanted to in life; subsequently becoming an accomplished



Just some of the fabulous speakers to present

Paralympian, Motivational Speaker, Radio Presenter, Trainer, Social Worker and Ambassador for the NDIS.

It was an honour to have the opportunity to listen, learn from and be inspired by such an accomplished and talented woman and I highly recommend you check out the video of her talk, its well worth a watch!



A very impressive panel to discuss the latest clinical trials



A great insight from Kate, Siblings Australia



A huge thank you to our sponsors!



New friendships



Great to have information available from Clickability and Relationships & Private Stuff



Assistance Dogs were a big hit with everyone!

The conference was well attended and it was absolutely fantastic to see so many people come together to support each other and get the most up to date information and research.

Overall the feedback from the conference has been very positive, with people commenting that they really enjoyed having the chance to meet others, network, learn more about the NDIS, hear from the engaging speakers and check out the stalls and demonstrations:

“ Having been part of many conferences, I have to say that this has been my favourite by far. It was not only the great content and theme of the conference, but the true focus it had on the entire neuromuscular community. ”

“What a great weekend at the Neuromuscular Conference in Sydney albeit emotionally draining we are

taking home some very valuable information! Thank you to all the amazing organisers the speakers and health professionals what you all do to help all of us is just beyond amazing and we feel very grateful to have you all working so tirelessly to help our children!! Along with all of the learning we got to meet and connect with some very amazing Duchenne families!”

“I’m so glad we made the decision to attend the conference it has definitely changed our outlook on a lot of things for us! We are so thankful that we can go on this journey with so many other wonderful families!”

We want to thank all those involved in the conference, as well as those who attended!

For those who were not able to attend the conference in person, you can watch footage of all the talks at <http://nmconference.org.au>



People travelled from far and wide to attend



Just some of the attendees from Building for the Future 2016



MY NDIS STORY SO FAR...

The NDIS has been the talk of the town for months and if not, years. While the NDIS is an amazing system designed to give people with a disability the flexibility, choice and control of their lives, there has been many grey areas and unanswered questions. How does it work? How does it affect you and the people around you? What needs to be done to prepare for the rollout? What changes when an NDIS plan is put in place for you? These were the exact questions running through my head in the months leading up to the NDIS rollout on July 1 2016.

I receive services from multiple providers including Just Better Care, Northcott and MDNSW – my biggest question was when the NDIS comes along am I going to still have these services? I think of my support network as the engine in my car – they are the ones who keep me powering through my daily life and do what I love; so I knew that I had to make this absolutely clear when I meet with my NDIA planner to ensure that I don't lose anything I currently have.

In the months leading up to the rollout of the NDIS, I had several meetings with my case manager Joan (from MDNSW), to work out all the support I currently have, how it enables me to access and participate in the community and what I do everyday. It's almost like mapping out my whole life and putting it on paper, going into as detailed as what my schedule is like on a daily and weekly basis. This is the one thing I struggle with the most, because I don't have a set schedule or routine – between Uni and work I am constantly running between places. There are days when I work from home and other days I come home just in time for bed and head off again as soon as the sun makes its appearance. So I found it hard to pin point what my day/week looks like – we ended up doing a rough estimate, which would be enough to help the NDIA planner get an idea of what I do. Furthermore, it would help the NDIA planner understand that I wouldn't be able to do any of this if I don't have a strong support network in place.

The NDIS planning meeting came around sooner than I expected. Before I knew it, I was sitting in the room with my Case Managers, Occupational Therapist, NDIA planner and her manager. It was essentially up to me to decide who would attend the meeting with me – I specifically asked my Case Managers and Occupational Therapist to attend the meeting because they know me best. Apart from my family, my Case Managers and Occupational Therapist know my life story so well that they can probably say it out loud off by heart. Most of all, they know exactly what support I need and how much it means to me.

We went through a three hour meeting developing 'My First Plan'. I didn't quite understand what 'My First Plan' meant until then – it is essentially a plan that puts together all the services and support that you currently have and for

it to continue over the next 12 months. The aim of this is to ensure that every person with a disability can maintain and continue with the services they currently have so they can have a seamless transition over to the NDIS. In the meeting we covered areas including what support I currently have at home and in the community, as well as all my therapy hours with allied health professionals. It was an odd feeling mapping out my life and planning for the next 12 months with my NDIA planner as I literally only met her 5 minutes before the meeting – luckily all planners are well trained and prepared for this and come into the meeting with a client-centred approach. At this stage I am waiting to receive 'My First Plan', I am really looking forward to seeing it all come together!

Melanie Tran 20yrs, MDNSW Member

MY NDIS TIPS

My tips on preparing for the planning meeting

1. Know what you need

Nobody knows you better than you – make sure you articulate exactly what support you need and how it will affect you. Remember that not everyone is familiar with your conditions and support needs so go into as much details as you can. Write down every little thing.

2. Be organized

Spend some time with the key people in your support network and map out everything you currently have and do with as much details as possible.

3. Plan ahead

Try to map out your near future. Where do you see yourself in 12 months? What goals do you want to achieve and what do you need to make that happen?

4. Strong communication

Go into the meeting well prepared – know exactly what you need and make sure you get your ideas across.

5. Post meeting follow up

Expect to do follow ups after the meeting – your planner may contact you to clarify things or you may need to get some letters to support you

There is definitely a lot to take in, but it's worth it. Just remember to keep calm and power on!

PLANNING FOR MY SON

National
disabilityinsurance
Scheme

“ Your NDIS planning meeting is coming up ”

Just the thought of those words sent me into a tail spin. I was terrified of getting this first plan wrong.

Daniel's health has been very stable over the last few years, in spite of CMD we have actually seen many improvements, but that is not to say his life is without its challenges. His power wheelchair is now 5 years old and beginning to malfunction on a semi regular basis. Ok ... so I know I need that in my plan. He uses a positive pressure lung exercise machine every day plus a regime of physio stretches totalling around 90 minutes a day. Could I get someone to help with this in the morning so he has some time in the afternoon to play? The bathroom is not equipped for easy access and he has had a fall off the toilet. Need an OT assessment of the house and possible modifications. How many hours will I need? MD camp...Daniel loves going. I need to make sure I had money in the right spot so if he was lucky enough to get a position at camp he can attend. How many hours of Physio and OT do I need to cover a year? The list felt overwhelming.

I went to every community meeting I could, asked friends who had been through the process what I should do and I read thousands of articles on what to expect, I was still terrified and had no idea what I was going to write for his goals.

I went to my planning meeting with a disability agency worker as backup support and I laid out everything Daniel needed. I used very broad-based goals such as improving personal growth and independence. This covers nearly everything a 7-year-old does. Yes, I forgot stuff and yes, I got stuff wrong. I forgot to include OT travel time and report writing time. But basically I feel like that initial meeting went well.

Since starting this process we have had to find a new OT and physio who I can't rave about enough (this was because I didn't include OT and Physio travel time). The homecare team have made a huge difference to Daniel's life. He is more confident to ask others for help and capable of explaining his difficulties. He now gets time to play before dinner which means everything to a seven-year-old.

I have complaints. It has not been all plain-sailing. Daniel's NDIS planner has changed numerous times since February. Despite many attempts I am having great difficulty getting questions answered. Therefore I would say the big criticism I have encountered (despite many positives) is communication within the NDIS.

Jo O'Brien MDNSW Member



MDNSW CAN HELP YOU WITH THE NDIS!

Here at MDNSW we are committed to supporting you through the process of planning for your NDIS meeting and even attending the meeting with you if you like. We encourage everyone to attend an NDIS information session in your local area, details can be found at www.ndis.gov.au

Be sure to check out our website for lots more information about the NDIS and services that we can offer in your plan; www.mdnsw.org.au or call our Client Services Team at any time on 9888 5711.

Regional Information Sessions

MDNSW is holding a number of information sessions throughout regional NSW for our members including:

New England /Armidale on 14th October
Upper Hunter on 29th October
Far South Coast on 3rd November

For more information or to attend one of these sessions please contact Kejanna Taylor-King on 0429 565 222.

IMPORTANT CHANGES TO THE FlexEquip PROGRAM



There are changes to the FlexEquip program from 1 July 2016 which will affect members of Muscular Dystrophy NSW.

FlexEquip is an equipment service of the Motor Neurone Disease Association that was specifically developed to meet the short-term equipment needs of adults living with rapidly progressive neurological conditions. Since August 2013, FlexEquip had extended its service to include members of Multiple Sclerosis and Muscular Dystrophy NSW.

FlexEquip provided items of equipment for short term loan to clients for a period of 12 weeks or, if an Enable NSW application was approved for the item, the loan could be extended to 26 weeks.

Unfortunately, due to changes in funding, this service will no longer be provided to MS and MDNSW members. No new applications will be processed from 1 July 2016.

If you still have FlexEquip equipment on loan at this time, you will be able to continue to use that item of equipment until the agreed upon expiry date when FlexEquip staff will be in contact with you to arrange for the return of the equipment.

FlexEquip has announced that people diagnosed with Muscular Dystrophy, Multiple Sclerosis and other rapidly progressive neurological disease who live in NSW or ACT and are under 65 years and are NDIS participants will be able to access the full FlexEquip range of equipment from 1 July 2016 so long as FlexEquip is nominated and approved in their NDIS plan.

For more information about how these changes may affect you, contact FlexEquip on **02 8877 0999** or at www.flexequip.com.au or contact the MDNSW Client Services team.

goget NOW OFFERS A WHEELCHAIR ACCESSIBLE CAR-SHARE VEHICLE!

The car-sharing service GoGet now has an exciting addition to its fleet—a wheelchair accessible vehicle. This first GoGet accessible vehicle is an eight-seater Kia Carnival with a hydraulic wheelchair rear entry, and is located in a dedicated parking spot at Royal North Shore hospital at St Leonards.

GoGet is a car share service that allows registered users to book and pick up share cars from varying locations across Sydney. This pilot program was launched in April this year and makes GoGet the first mainstream car share provider to offer a wheelchair accessible vehicle for their members. If the trial is successful, there are plans to roll out more accessible vehicles in other areas.

To book the accessible vehicle, you must first become a member of GoGet and get your GoGet smart card and then apply for a GoAccessible Plan. The member must either have a disability or be the primary carer of a person with a disability. There are no joining fees for the GoAccessible Plan but the costs of a booking for the accessible vehicle is \$8.35/hr + 0.40cents/km, or \$88 per day.

For more information, call GoGet on **1300 769 389** or www.goget.com.au/accessible-plan



Philip & Peter demonstrate the new accessible GoGet vehicle!

AT LAST...AN INCREASE IN THE TAXI SUBSIDY!

From 1 July 2016, the Taxi Transport Subsidy Scheme (TTSS) maximum subsidy has been increased. This is great news for taxi customers with disability as the subsidy has remained unchanged since 1999 while the cost of travelling by cab has risen significantly over this time.

The maximum subsidy will now be increased from \$30 to \$60 per trip. When you use the new TTSS \$60 docket, you will continue to pay only half of the full taxi fare but now it will be up to a maximum of \$60 per trip.

If you are a current TTSS customer, you should have received a new book of the \$60 dockets in the mail. If you need to re-order a new book of \$60 dockets, it is the same process as before. You can use the green re-order form at the centre of your book of travel dockets or you can download the Reorder TTSS Travel Dockets form and send the completed form to the address provided.

There has also been an increase from 1 July in the Wheelchair Accessible Taxi driver incentive payment. This payment has been increased from \$7.70 to \$15 (ex GST) per ride and should help to improve taxi services for wheelchair users.

If you need further information on how the new TTSS \$60 maximum subsidy works, please call the TTSS information helpline: **1800 200 592** or email tss@transport.nsw.gov.au or go to www.transport.nsw.gov.au

WE LISTENED TO YOUR FEEDBACK

Every year, we ask you to participate in the MDNSW Client and family survey to get feedback about your experience of our services and your comments and suggestions about any improvements that we could make to MDNSW services. We listened to your feedback which was important part of our evaluation of current services and our planning for future directions.

We have responded to many of your suggestions which have been included in our service plans over the past year.

Help to prepare for the NDIS

- We have included articles in Talking Point about the NDIS and about the NDIS experiences of clients and their families
- We now have detailed NDIS information on the website, and are providing information on the website and our Facebook page about NDIS information sessions in your local area, and we have run a number of information sessions for clients and their families in metropolitan and regional areas
- We have met individually with clients and their families to provide information and support with preparation for the NDIS, and have attended NDIS Planning meetings as requested Improvements to services, programs and events

Improvements to services, programs and events

- We have extended the Connections program to offer more opportunities to meet with other clients and families with new groups meeting in metropolitan and regional areas including Blacktown, Central Coast, Armidale and Dubbo
- We held the Building for the Future Neuromuscular Conference which provided information of the latest medical research, condition specific sessions, sessions with a focus on concerns of adults, and NDIS information sessions
- We have extended our counselling service to include both telephone counselling and some face to face counselling

Participation in sports for people with a physical disability

- We have supported increased participation by providing loan sports equipment to clients wanting to try out new sports
- We are starting a new loan program of boccia equipment for schools to encourage increased opportunities for inclusion and participation in school sports programs

The 2016 MDNSW Client and Family Survey will be available soon and we encourage all clients and families to take the opportunity to give us your feedback on our services. We value your comments and suggestions and your feedback does make a difference!

TRIBUTE TO

RODNEY MUSCAT 1966 - 2016

Sadly on 27th February this year, we lost another valued member of our MD community.

Rodney Muscat was 49 years old and had lived with Beckers Muscular Dystrophy.

He was an amazingly talented jeweller and kept up with this profession throughout his life.

He was a very determined person who never gave up trying despite his physical limitations.

He loved music and was quite a good singer himself. He was also a mad Parramatta Eels supporter.

Rodney was part of a very supportive family-the proud father of Lindsay, aged 24 years, the second son of Rosalie and Jim Muscat, brother to James and Linda, and uncle to four nieces and nephews. Rodney will be very sadly missed by his family and friends.



FSHD 101: AN UPDATE ON CAUSES & TREATMENTS

Facioscapulohumeral dystrophy (FSHD) is the most common form of muscular dystrophy that effects both adults and children and there is a good chance you haven't heard of it. It is our mission at the FSHD Global Research Foundation to put FSHD on the map, to fund medical research and work towards a time when FSHD is treatable, curable and even preventable.

MDNSW have about 70 people with FSHD who they support. However, the hundreds of contacts in the Foundation database suggests that the numbers in NSW are much more than this. The estimated prevalence of FSHD is about one in 7500, or about 3000 people in Australia. This is probably lower than the real estimate. FSHD, like many muscular dystrophies, often goes undiagnosed or misdiagnosed.

FSHD is commonly associated with progressive weakening of facial, shoulder and upper arm muscles. However, this explanation does little justice to a disease that can rob people of their ability to walk, talk, smile or even eat. The progression often comes in bursts with sudden deterioration followed by periods of no change.

Genetic mechanism of FSHD

FSHD is one of the most complex genetic conditions currently known. FSHD involves a complicated interplay between genes and proteins in the muscle cell. FSHD is caused by mutations that actually increase the expression of a toxic protein that destroys muscle cells in the body. Currently there are two types of FSHD, type 1 and type 2 although the number of subtypes is likely to increase as more becomes known about this condition.

FSHD type 1

About 95% of FSHD cases are type 1 (FSHD1) and are associated with a mutation on chromosome 4. Chromosome 4 contains a series of repeated pieces of DNA, so called D4Z4 units. People without FSHD1 have 11 - 100 D4Z4 units. In people with FSHD 1 the D4Z4 array is shortened to 1 - 10 units.

The D4Z4 units act like a lock for this region of the genome. With fewer repeats a gene embedded in this region called DUX4 is expressed. DUX4 is a toxic protein that kills muscle cells.

FSHD type 2

The defect in FSHD2 was found to be in a gene called Structural Maintenance of Chromosomes Hinge Domain

Containing 1 (SMCHD1). This gene acts as a lock for regions on the genome, in people without FSHD this protein is keeping regions like the one that contains the DUX4 protein, closed. Mutations in SMCHD1 lead to a smaller amount of this protein being produced. Less protein means less repression on the D4Z4 region causing DUX4 expression.

Management

Like most of the other neuromuscular conditions there is currently no treatment and no cure for FSHD. However, this does not mean that there aren't options for management.

Exercise

The old thinking that exercise should be avoided has been replaced by a cautious optimism that exercise may help people with FSHD maintain muscle function, prevent falls and delay the use of mobility aids. Experts in this field suggest that moderate aerobic exercise (eg. 15 - 30 minutes on a stationary bike 3 times a week) is not harmful and may be beneficial.

It's important to consult a health professional before engaging in exercise. It may be most helpful to find a physiotherapist or exercise physiologist who has experience in neuromuscular conditions who you can work with to develop an exercise program that suits your unique needs and goals.

Surgery, massage and other management techniques

There are a number of options for surgical management of FSHD. The main one is scapula (shoulder blade) fixation to help with shoulder function. Surgery doesn't work for everyone, but it can be very helpful for people with poor shoulder function.

Respiratory support is usually not recommended for people with FSHD because they do not experience the same reductions in lung function that the other dystrophies do. However, the Foundation has reports that people with FSHD do have issues with breathing, particularly at night time and we will be exploring mechanical support as a potential clinical intervention.

Other strategies such as hydrotherapy and massage may help managing pain and function. Orthotics and mobility aids can also help you get around and prevent injury.

On the horizon: progress on treatments and a cure

It is an exciting time for FSHD research. Our most recent funding round received 22 high quality applications on diagnostics, therapeutics and infantile FSHD (a severe form of FSHD that manifests in childhood). The amount of research that is starting to bridge the gap from bench to bedside is impressive.

There are three main areas where efforts are focussing at the moment; gene therapy, small molecules and biologicals.

FSHD Global is currently funding projects in all three of these areas. Some are focussing on gene silencing technology to try and switch off DUX4, others are screening vast libraries of small molecules to find ones that prevent the expression of DUX4.

One area that is receiving a great deal of attention at the moment is myostatin inhibitors. Myostatin is a protein that inhibits muscle growth. Interrupting its activity increases muscle size and strength. The Foundation is exploring variations on myostatin inhibitors to promote muscle growth for people with FSHD. It is likely that there will be a clinical trial in Australia in the very near future.

For more information on causes and treatments for FSHD see our recent clinical consensus statement published in a leading neuromuscular journal [http://www.nmd-journal.com/article/S0960-8966\(16\)30096-7/abstract](http://www.nmd-journal.com/article/S0960-8966(16)30096-7/abstract)



Fast facts about FSHD and the Foundation

- FSHD is the most common form of Muscular Dystrophy affecting both adults and children
- FSHD affects men and women equally and can manifest at any point in your life from infancy to late adulthood. Infantile FSHD is particularly severe
- FSHD can affect all the skeletal muscles in the body
- At the moment there are no treatments and no cure for FSHD
- FSHD Global is the largest funder of medical research into FSHD outside the USA government
- In eight years FSHD Global has raised over \$7.5 million for research
- The Foundation has funded 34 medical research grants in 9 countries and supports 59 scientists including 18 Australians
- FSHD Global receives no government funding

FSHD Global Research Foundation: working hard to find a cure

The Foundation was formed in 2008 by Bill Moss AO. Bill has FSHD and has made it a life goal to find treatments and a cure for this condition. In just 8 years the Foundation has grown exponentially and is the largest funder worldwide of medical research into FSHD outside the US government. From creating the first FSHD stem cells to planning some of the first clinical trials into FSHD the Foundation has made, and will continue to make, a significant and lasting contribution to FSHD research.

Do you want to know more?

This year three of the world's leading scientists and clinicians will be joining us in Australia for a country wide tour. Our NSW event will be held on the evening of Monday 5th September. Join us at the Garvan Institute of Medical Research in Darlinghurst for an evening of science and debate. We would love to see you there. We will also be in Melbourne on the 6th of September, Brisbane on the 7th of September and Perth on the 8th of September.

For more information on this event see <https://fshdglobal.org/news-events/> or email admin@fshdglobal.org

A HUGE THANKYOU TO ALL OUR COMMUNITY FUNDRAISERS FOR THEIR ONGOING SUPPORT!

JOSH RYAN \$5000 raised!

It was lovely to see Josh and the Ryan family at our old office, who came in to drop us off a cheque for \$5000 from fundraising! Thank you so much for all your support!

Josh & the Ryan Family bringing us a cheque



GRAFTON ANNUAL GOLF DAYS \$3089 raised!

Another two great days of golf were held at the Grafton District Golf Club on the 13th and 17th of April when myself and my wife Kay held our annual charity golf day for Muscular Dystrophy NSW. The weather was beautiful as is normal most days in Grafton. Although it was close to Anzac Day weekend with lots of other things going on the attendance for both days was very pleasing. Wednesday 13th was ladies day with about 60 ladies turned up and to play. After the presentations were done (with the winner being Renae Amos), we did a 'pick-of-the-table' fundraising game, which was great fun and raised some money at the same time.

Sunday 17th was another successful day with 70 players turning up with the winners being a very happy husband and wife team of Warren and Marylan Powell.

With our major raffle and a few smaller ones, a sausage sizzle (can't do it without the sausage sizzle!) and an auction (myself being the auctioneer) we managed to raise a great amount for Muscular Dystrophy NSW.

This is our 4th year doing the MD golf day, which we enjoy so much and are happy it is for such a worthy cause, and we hope to continue for a few more years yet.

Reg McLennan

SINGING FOR A CAUSE \$189 raised!

On March 30 participants of The Mai Wel Group's Lifestyle and Leisure program put their dancing shoes on and let their singing voices roar with a Karaoke party fundraiser for the Muscular Dystrophy Association of NSW.

The key organisers were part of a learning and skills development program called "Giving Back", during which they practiced and developed their computer skills, money handling and budgeting skills and even event management, all under the general theme of contributing to the community.

Passionate and outgoing, Codie DeHaart took on a lead role in organising this event. She says that it is important to her to fundraise for an organisation that helps other people like her. Taking pride in the end result, she said "it was a really good day, a lot of the guys wanted to sing songs and we all had fun".

Codie, who has Myotonic Muscular Dystrophy, chose to fundraise so that more young people with the same condition could go to the holiday camps that she also loves to be a part of.

"The one that I enjoy is at Narrabeen Academy of Sports in Sydney," she said. "My favourite night is the last night when they have a big party."

The Karaoke party raised \$189, donated specifically to the camps run by MD NSW. From Barnsey to Beiber, everyone had a go, put on some fancy dress and had lots of laughs.

Codie De Haart



Codie dressed up for her fundraiser

WE WOULD ALSO LIKE TO THANK

The James N. Kirby foundation for \$15,000 towards our Duke of Edinburgh's Award program and their ongoing support

The Bennelong Foundation for \$15,000 towards our Duke of Edinburgh's Award program

The RSL Club of Dubbo for \$2000 towards our Kids and Young People for Life program

Magpies Waitara for \$1000 towards our Kids and Young People for Life program

City of Wagga Wagga for \$9000 towards our Kids and Young People for Life program

Bathurst RSL for \$6000 towards our Kids and Young People for Life program

Dick And Pip Smith and The Wales Family Foundation each for generously donating \$20,000 to our 2016 Tax Appeal.

KIDS IN NEED

\$20,000 raised!

On 21 May, Muscular Dystrophy NSW and five other children's charities came together to hold the 'World's Biggest Open House'. The five other children's charities are - the Burns Unit at the Children's Hospital Westmead, Bear Cottage Children's Hospice & Respite Centre, Central Coast Kids in Need, The Duke of Edinburgh's Award and SHINE for Kids.



One of the main attractions!



Official presentation of the funds raised

Events took place all over Sydney including at many different Fire and Rescue Stations, the RAAF Base in Richmond, the HMAS Canberra and included a Pop Up Kids Concert in the CBD featuring performances by Justine Clark and Nay Nay from the ABC Network and a dance routine by The Bubblegum Chicks.

We want to thank our amazing families, volunteers and staff who went to different venues across Sydney collecting donations and raising awareness for us and the other five charities. The day was a huge success that everyone enjoyed and overall raised \$120,000. We hope to see you there next year!



Daniel making his media debut



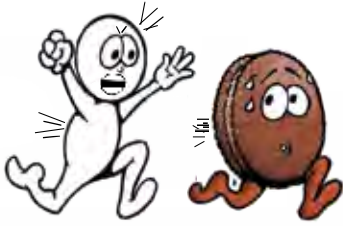
Just some of the fabulous volunteers at Richmond!



GWS Game Day!

PROUDLY
SUPPORTING





SUGAR FREE SEPTEMBER

1-30 September 2016



TAKE ON THE SUGAR FREE CHALLENGE THIS SEPTEMBER AND HELP SUPPORT PEOPLE LIVING WITH MD

SIGN UP NOW AT <http://sugarfreeseptember.gofundraise.com.au>
#SugarFreeForMD



/SugarFreeSeptember



@MD_NSW



SugarFreeForMD



BIG RED RIDE 2016 SYDNEY



6 November 2016

SEA TO SUMMIT

The toughest one day ride around

REGISTER NOW AT

<http://bigredridesydney.gofundraise.com.au>



Bondi Beach to Richmond - 85 km
Bondi Beach to Katoomba - 150 km

Join us for our
Little
BIG RED RIDE 2016

Parramatta - Richmond

We would love you to join us on **Sunday 6th November** for a lap of **Parramatta Park**, and then head on the train to **Richmond** to meet up with the Big Red Riders for lunch!

For further details or to join the group, please contact our Head of Fundraising and Partnerships Kags Garrard on **02 9888 5711** or email kags.garrard@mdnsw.org.au



Myositis Association Australia

Keeping in touch

Invites you to our

Second National Conference

Novotel Northbeach, Wollongong

Commencing **Monday 10th October 2016**

Registrations open at **2pm**

Concluding **Wednesday 12th October 2016**

9pm with Farewell Dinner

Full details are on our website www.myositis.org.au
or phone the secretary on **0421 314 138**

contact us...

Call 02 9888 5711, email info@mdnsw.org.au or by post at:
MUSCULAR DYSTROPHY NSW Suite 1.04, 82 Waterloo Road, Macquarie Park NSW 2113

Sun 9 - Thu 13 April, 2017

Adventure Camp

*Taking Applications
Now!*



NEUROMUSCULAR CLINICS

PAEDIATRIC

Sydney Children's Hospital Randwick

Neuromuscular Clinic

Call SCH for Outreach Clinics at:
Canberra Hospital, Canberra
Goonellabah Clinic, Lismore &
John Hunter Hospital, Newcastle

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

Royal North Shore Hospital

Neuromuscular Clinic, St Leonards

9463 1866

Prince of Wales Hospital Randwick

Nerve & Muscle Clinic

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

0417 259 871

Concord Hospital Neuromuscular Clinic

9767 6864 or 9767 6129

Westmead Hospital

Adult Genetics Clinic

9845 3273