

Talking Point

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER AUTUMN 2016

Dukies take on Denmark



in this issue...

EDITORIAL

I HOPE THAT YOUR 2016 IS OFF TO A GOOD START AND THAT YOU ENJOYED SOME REST AND RELAXATION WITH FAMILY AND FRIENDS OVER THE HOLIDAY PERIOD.



You may be surprised to read that I am still working at MDNSW. With the recent resignation of Loretta Downie and the imminent rollout of the NDIS in NSW, it was agreed that I should stay on and support the organisation through these changes.

I would like to take this opportunity to thank Loretta Downie for her five and a half years of dedicated service to MDNSW and its families and to acknowledge her innovation, passion and hard work. During this time Loretta created both our Duke of Ed and Working Wheels programs and developed camps, retreats and events to the high standard they are now at. We wish her all the very best for the future.

A busy calendar full of client events and fundraising activities has been organised for this year and has been included in this edition of Talking Point. Can I encourage you to take a look at these and see which client events may interest you or fundraising activities where you may be able to lend a hand. Please remember that we are here to provide support and services to you and your family.

PENE HODGE

CEO, Muscular Dystrophy NSW

A NOTE FROM THE PRESIDENT



AS I MENTIONED IN THE LAST EDITION, INNOVATION AND FUNDRAISING ARE CRITICAL TO OUR SUCCESS AND FUTURE.

Those two themes allow us to provide leading edge information to our clients and families and to develop world class programs such Working Wheels, our participation in the Duke of Edinburgh's Award and our extremely popular Camps and Retreats. We're rightly proud of our programs and the talented team working with our CEO Pene Hodge who created and continues these great services. In 2016, we will again innovate, fundraise and deliver the best services for you and we'll also more closely collaborate with our MD colleagues in other states to ensure your services in NSW are simply the best.

PETER DEBNAM

President, Muscular Dystrophy NSW

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EVENT CALENDAR 2016

Mon 11 - Fri 15 April, 2016



Adventure Camp
Port Stephens

Booked Out!

Fri 13 - Sun 15 May, 2016

Sydney MD Retreat

A Weekend Getaway specifically for adults with a neuromuscular condition and their partners/carers.



Fri 17 - Sat 18 June, 2016

International Neuromuscular Conference Sydney



Sun 26 June, 2016

Ladies Luncheon

A new event for ladies to come together and enjoy catching up over a lovely lunch

Canada Bay



Sat 24 - Wed 28 Sept, 2016



Camp Kula N' Gadu
Sydney Academy of Sport

Places filling up quickly already!

Sun 16 Oct, 2016

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



The Great Boccia Bash
Narrabeen

Nov, 2016



Young Adults MD Retreat

A new exciting retreat especially for those in their late 20's and 30's with a neuromuscular condition!

Sun 6 Nov, 2016



Are you up for the toughest one day ride in NSW from Bondi to Katoomba? Spend a day with Australian cycling legend Brad McGee!!

Sat 3 Dec, 2016

Sydney Metro Christmas Party

A day designed for the whole family including a heap of activities such as slot car racing, a free BBQ lunch and a visit from Santa who always brings lots of pressies!

Parramatta

THE BEST CAMP KULA N' GADU YET!



Girls at the beach



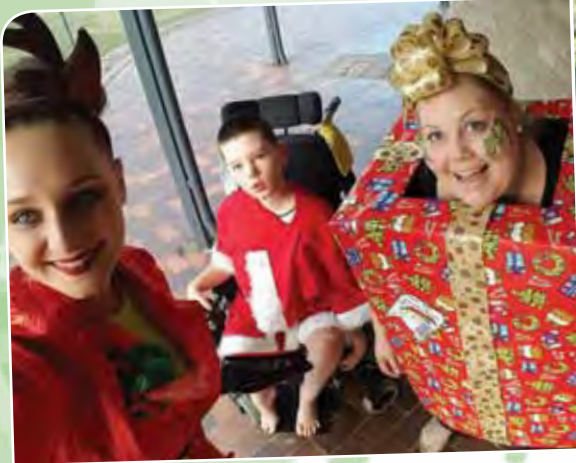
Lauren & Eliza enjoyed craft

Wow what can I say....
You truly made my daughters week at camp. She looked like she had the best time ever. This smile on her face all the time shows you did an amazing job with making her happy and caring for her, I can't thank you enough!

Natalie



Tiannah singing at party night



Christmas party dress up fun



New friendships were formed



Jess &



The Governor of NSW enjoyed playing lasertag with everyone

A huge thank you to Loretta for everything she has done for not only this camp, but for every camp and event she has been a part of! She poured her time, energy and heart into everything she did for MDNSW and for that we are all eternally grateful! We are all going to miss you!

Everyone



Jenny & Loretta ready for the party!



Dean loved his time at camp and wished it would last until he turns 10 lol. Thanks to each and every one of you for your hard work and positivity at camp. We've noticed Dean is more eager to be involved/participate, more confident and enthusiastic somehow. Thanks for the time out for us to recharge too!

Cindy

Dean bravely held a snake!

Joss & Shelly show us their muscles



Pamper time for the girls

A massive thank you to everyone involved in this year's Camp. Loretta, Jenny, Jay and Jim - you guys went above and beyond to make sure Jacko had an amazing time. Leaving a kid with additional needs with other people to care for them is tricky, but I never worry when he is at camp because I know he is in the best possible hands to help him be all he can. Thank you for being so generous with your time and talents.

Deb



Ella at lasertag

Crazy Creations with the Fragomeli's

The Governor & Sophie talk strategy



Slime time for Dom & Sam

Santa & the Gingerbreadman come to the party!

Boys adventure time

Thomas and Ryan Seck



CELEBRATIONS AT THE SYDNEY METRO CHRISTMAS PARTY

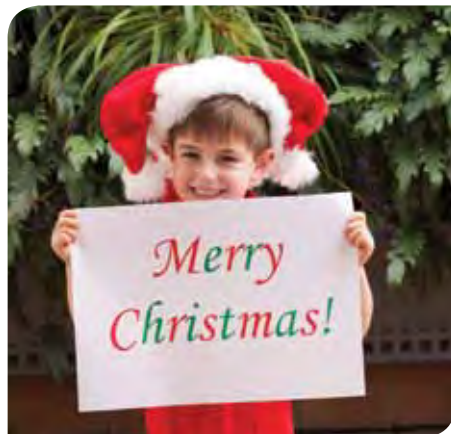
We hope everyone had a very Merry Christmas and happy new year with family and friends. We were very grateful to have so many of you join us again this year for the Sydney Metro Christmas Party. It was a wonderful celebration with a magician, face painting, electric cars, games and Santa! A huge thank you to the staff of CBA Direct Banking Sydney who generously supported our Christmas Party again this year. This year we have some great events happening where we look forward to seeing you all! See the MDNSW website for more details.



Josh getting his present



O'Brien Family



Merry Christmas from Lachlan

“ A huge big CONGRATULATIONS to you all for creating a magical family Christmas party on Sunday! You have this event down to a fine art now Loretta and co!!

The little and big kids alike had a ball and it was a positive friendly vibe with plenty of yummy food, fun games and generous presents! Thank you to all of you and the wonderful team at Commonwealth Bank for all your efforts, energy and precious weekend time in making this so special for our families. It really is what it's all about and the joy in the eyes of our kids is priceless.

The photo shoot was so lovely for the families to have a pic taken on such a happy occasion. Jimmy the magician was fab as was the slot car set up. Santa was a hoot like always, I think it's his 12th appearance so a big HO HO HO shout out to say thank you Santa from all the MD kids and families. ”

Email from one of our lovely members



Savage Family



Steve, Von and Luke



Everyone waiting patiently for Santa's arrival



Santa and Jett



Lunch was yummy! Thanks to CBA!



Another great effort by the team at CBA!

REGIONAL REPORT

OUT WEST

It was Christmas Time in the West and Wow what a party.... No-one wanted it to end! Trish and her lovely daughters provided hours of entertainment for the young and the not so young. While Millie was busy painting the smiling faces of the younger ones, Georgia had the older ones up on the dance floor rocking to the beat and taking song requests. Trish and Charlotte had their hands full at the craft table making Christmas crafts, space rockets and Christmas critters. No one will ever forget Kieran's famous Xmas Slug which delighted everyone as it made it's way around everyone's table. There was so much fun even the Dads and



Millie and Finn looking great with the face painting

Mums found themselves entranced in the day's activities. This was Maureen and Don's first MDNSW event and they said they enjoyed the day so much they will definitely be at the next event.



Adam loved his present



Samuel getting into the spirit



Tennis was a big hit at the Christmas Party!

UP NORTH

Christmas on the North Coast is always a special time and what a wonderful way to spent it with friends at the gorgeous Angourie Rainforest.

We had a number of new families join us for the first time and they felt so welcomed by the group. The children loved being entertained by "Poly-Ester" as she painted their faces with butterflies and super hero, tattoos on their arms with tribal designs and symbols of strength. There were indoor and outdoor games as well as magic tricks. "This was one cool party... I have loved every moment - I don't want to go home"

LITTLE WINGS



FREE AIR TRANSPORT FROM REGIONAL NSW TO JOHN HUNTER, WESTMEAD AND SYDNEY CHILDREN'S HOSPITALS

Little Wings is a not-for-profit organisation whose mission is to provide a professional, safe and free flight and hospital transfer service for children from rural and regional NSW to access specialised medical services. They support families to reduce the financial burden, emotional strain and travel fatigue experienced during this time.

They transport families with regular and ongoing medical appointments and bring children home for short breaks during their treatment to be with family and friends. They help keep families together during one of the toughest times of their lives.

Since establishment in 2012 Little Wings have travelled 240,000 kms in the air and 23,000 kms on the ground, helping almost 1,500 passengers with their vital transport needs.

This Free flight service covers the following regional areas;

Armidale | Bathurst | Bourke | Brisbane | Canberra | Cobar | Coffs Harbour | Condobolin | Coonabarabran | Cowra | Darwin
Dubbo | Forbes | Goulburn | Grafton | Griffith | Inverell | Kempsey | Lismore | Merimbula | Moree | Moruya | Narrabri
Narromine | Nyngan | Orange | Parkes | Port Macquarie | Scone | Tamworth | Temora | Wagga | Walgett | Wellington

For more information contact | Phone: 02 8860 9588 | Email: info@littlewings.org.au | www.littlewings.org.au

UNDERSTANDING ANXIETY

Is it ok, normal, a natural part of everyday life and stress?

Whether you feel depressed or anxious because of bad news, a new diagnosis, deterioration of your/a loved ones condition or if you live with those feelings every day—there are people who can help you through it.

At MDNSW we understand that a diagnosis and living with a neuromuscular condition can trigger anxiety or depression. Many people experience difficulties dealing with their emotion and anxiety from the impact of living with MD. Often these feelings are not physiological symptoms of MD, they are a by product of living with the condition and any associated physical disability. The repercussions of losing muscle tissue and muscle weakness can include feelings of loneliness brought on by social isolation, fear of the future and mourning the loss of what you pictured the future might look like. In addition, some people are predisposed to mood disorders regardless of physical health.

As MD progresses, our members often tell us that they strive to know their own limitations and this uncertainty can lead to fear and anxiety. “Muscular dystrophy chips away at our physical abilities sometimes so slowly that we don’t even know what we were physically capable of until it’s gone. This can be a challenge to both our mental and emotional stability. I find myself anxious, despondent and dependent on any available helping hand.”

The experience of anxiety will vary from person to person, common symptoms include; difficulty concentrating, restlessness, avoidance behaviour, rapid heartbeat, trembling or shaking, feeling lightheaded or faint, numbness or tingling sensations, upset stomach or nausea & sweating.

Anxiety can become a problem when it is very intense, happens a lot of the time, feels overwhelming or it interferes with your daily living and your ability to cope. For many diagnosed with a neuromuscular condition, an essential phase in corralling any stressful thoughts and mental gremlins in one’s head is finding a realistic and positive perception of reality. That means accepting ones limitations, acknowledging the stresses that come with muscular dystrophy, working through the difficult times and then finding a perception of reality that fits.

“When I lost my ability to walk and moved to a wheelchair, I was pretty depressed. In time though I learned that my wheelchair opened a world of opportunities. Now, as long as there’s a ramp, I go wherever I want. It took me a while to see it, but my wheelchair gave me freedom”.



Where symptoms of anxiety occur frequently, occur over a period of time, and interfere with daily life, it is typically considered an anxiety disorder. Anxiety disorders are the most common type of mental health disorders diagnosed in Australia.

There are a number of different types of anxiety disorders, including:

Generalised anxiety disorder - Spending most of your time worrying about a variety of everyday things that wouldn’t usually bother others. Worries seem out of control and you feel tense and nervous most of the time.

Social anxiety disorder - Experiencing intense anxiety in social situations because you’re terrified you’ll embarrass yourself or others will judge you. This often leads you to avoid social situations, such as talking in class, going to parties, being the centre of attention, meeting new people.

Specific phobias - Intense fear of a particular situation or object (like small spaces or spiders) that leads you to avoid the situation or object.

Panic Attacks - Can occur as part of any anxiety disorder, but not everyone with anxiety problems will experience them. Panic attacks are when you are suddenly overcome by strong fear and experience physical symptoms of anxiety, like a pounding heart, difficulty breathing, shaking, and feeling dizzy or feeling sick. Panic attacks are short (about 10 minutes) and usually feel frightening.

There is no cure for anxiety disorders but very effective treatment are available with a good evidence base. The treatments for anxiety disorders include medication like benzodiazepines or other general anti-depressants, atypical antipsychotics, as well as augmentative therapies. Several proven therapies can be effective like cognitive behaviour therapy, relaxation training, and prolonged exposure therapy. Yoga and meditation have also demonstrated benefits.

Tips to Manage Anxiety and Stress

When you're feeling anxious or stressed, these strategies will help you cope:

- **Take a time-out.** Practice yoga, listen to music, meditate, get a massage, or learn relaxation techniques. Stepping back from the problem helps clear your head.
- **Eat well-balanced meals.** Do not skip any meals. Do keep healthful, energy-boosting snacks on hand.
- **Limit alcohol and caffeine** which can aggravate anxiety and trigger panic attacks.
- **Get enough sleep.** When stressed, your body needs additional sleep and rest.
- **If possible exercise daily** to help you feel good and maintain your health.
- **Practice relaxation,** take deep breaths.
- **Count to 10 slowly.** Repeat, and count to 20 if necessary.
- **Accept that you cannot control everything.**
- **Welcome humour.** A good laugh goes a long way.
- **Maintain a positive attitude.** Make an effort to replace negative thoughts with positive ones.
- **Get involved.** Volunteer or find another way to be active in your community, which creates a support network and gives you a break from everyday stress.
- **Learn what triggers your anxiety.** Is it work, family, school, or something else you can identify?
- **Talk to someone.** Tell friends and family you're feeling overwhelmed, and let them know how they can help you.
- **Talk to your GP** who can provide an assessment of your psychological and physical symptoms. Your GP can provide you with treatment, referral to other specialist and allied health professionals. A treatment plan can be developed to assist you with your condition and a referral to a local counsellor can be arranged.
- **Contact MDNSW for support.** At MDNSW we can arrange a time to meet with you to talk and assist you. We can link you up to community support options and our telephone counselling service. A referral to MDNSW can be made with a simple call from Mon - Friday between 9am - 5pm on 9809 2111.

The most important thing to remember is that you are not alone. Anxiety and depression are not inevitable or insurmountable – at MDNSW we have counsellors who can help you!



WHAT'S HAPPENING WITH THE NDIS

As you are probably aware, The National Disability Insurance Scheme (NDIS) is the new way of providing support to people with a disability, it gives them more choice and control over their support.

The NDIS supports people who are under 65 and have a permanent disability that impacts on their day to day life. If you meet this criteria and currently receive support, the NDIS will arrange a planning meeting with you to discuss your goals and support needs moving forward. If you do not receive any support services at the moment, you will need to contact them to arrange a meeting. MDNSW are here to help you through this process. We can talk to you about it in more detail and even attend your planning meeting with you if you like.

Your planning meeting gives you the opportunity to get the right supports put in place to help you achieve your goals, therefore it is very important to prepare for the meeting and have some ideas of the types of things you would like to achieve over the next year or so and what kind of supports you have/need on a daily basis.

The NDIS is progressively being rolled out across NSW over the next 2 years and will be operating state wide by July 2018!

We understand that the NDIS process can be very overwhelming and confusing. We are already providing supports for people under the NDIS and we are here to help and support you through your NDIS journey every step of the way. If you would like to know how MDNSW can help you through this transition and assist you with which services we can provide, please do not hesitate to contact one of our experienced staff members on **9809 2111** or email us at **myndisplan@mdnsw.org.au**. We are happy to have a confidential chat so feel free to contact us for further information.

Keep an eye out on our website for more information on the NDIS:

www.mdnsw.org.au



WHEN IS THE NDIS COMING TO YOU?

1 July 2016 - 30 June 2017

- Central Coast
- Hunter New England
- Nepean Blue Mountains
- Northern Sydney
- South Western Sydney
- Southern NSW
- Western Sydney

1 July 2017 - 30 June 2018

- Illawarra Shoalhaven
- Mid North Coast
- Murrumbidgee
- Northern NSW
- South Eastern Sydney
- Sydney
- Western NSW
- Far West

1 July 2018 - 30 June 2019

- The NDIS is operating state-wide



MY NDIS STORY

My name is Ocia and I am 16 years old. I live in Cranebrook which is the current roll out area for the NDIS in the Nepean/Blue Mountains region. I have been on my first NDIS plan since September last year.

How did you feel getting ready for your NDIS planning meeting?

In the beginning, I was just trying to figure out what is was and what you can get from the NDIS, and how it was going to be different from the way things were.

How was your planning meeting?

The planner was really friendly and easy to talk to but I still found some things quite hard like having to think about my goals. I knew what I wanted but it was hard to find the words to make it into a goal.

Does your plan have all the supports you hoped for?

When they first wrote up the plan, there were some things that were not in the plan but we talked to the planner and worked it through. Some things that I needed were then added to my plan. There still are some things that I need to find more information about, like modification of our home, so that they can be put in my next plan.

So what has been the biggest change for you?

Before my NDIS plan, I only had help with personal care a few afternoons each week. I wanted more help than that but I could only get what was available. In my NDIS plan, I now get what I need which is 2 services a day, 7 days a week. That has made a very big difference for me, and for my family.

What do you like about having an NDIS plan?

I really like that I have control over my services. I can make decisions about my services, about the workers that I want and when I need them. I have more choice about what I do. I have 3 hours a week for going out in the community. I can decide what I am going to do each week, or I can decide to save my hours and go out for a longer time each fortnight. It's up to me!

CONNECTIONS

As the New Year begins, as do our Connections groups throughout NSW. MDNSW is busily planning and setting up new Connections groups in a number of areas to help promote support for people living with a NMC and their families. Below are some of the existing Connections groups, if you would like to be involved in setting up a new support group in your area, please contact our Client Services Team who will be able to help you get started!

Taree A new group that has formed for carer and families in the Taree region. At this stage the group is planning to meet every two months.

Armidale The Armidale group is a new group that have already had their first catch up. They enjoyed dinner and a show together and are keen for more people to come along to the next catch up. This group is planning to meet twice a year.

Dubbo We held our very 1st - Connections Group in Dubbo and wow what a great occasion. It was a rainy Saturday however this didn't dampen our day. We met for a scrumptious High Tea on the banks of the Lake Savannah in the Taronga Western Plains Zoo. The food and the company were divine. There was lots of laughter and chatting as we got to know each other and many of us were excited to know there will be some new members joining our next group meeting.

Illawarra The Illawarra support group meets on a monthly basis at various locations in the Illawarra and surrounding areas. Everyone is invited to attend, including people with a nmc, their families and carers.

Northern Rivers

This group meet regularly at a variety of venues for morning tea, lunches and dinner on weekends. It is a fun group that thoroughly enjoy each other's company and support. Everyone is welcome!



Central Coast

A new parent group that will continue to meet at Wallarah Bay Recreation Club every second month.

Liverpool

This is a Parent Group who meet in the Coffee Club at Mounties in Mount Pritchard on a Tuesday morning every six weeks for a coffee and a chat. We would love to expand this group and invite other parents in the area along.



Blacktown

This group meets at Blacktown Workers Club every second month. People with a nmc and their families are invited.

Hunter

The Hunter Social group meets every second month in various locations around the Hunter area. This group has a beautiful High Tea planned in Port Stephens, please contact Kejanna on kejanna.taylor-king@mdnsw.org.au for further details.

For further information about the Connections support groups, please call the **Client Services Team** on **9809 2111 ext.1**

TRIBUTE TO RICKY CAMILLERI 1967-2016

Sadly on the 12th January we lost another DMD warrior Ricky Camilleri. Ricky was an incredible 47 years old, perhaps one of the oldest people with Duchenne Muscular Dystrophy in NSW, if not Australia! As you can imagine Ricky was resilient beyond belief, remarkably strong in mind and spirit.

Ricky led a full and interesting life despite his physical limitations. He had played Push and Power wheelchair sports for many years, and was a proud member of the Northcott Eagles back in the day. He had studied history at Macquarie University and was a mad soccer and St George Dragons fan, attending the Sydney Olympics soccer final with his mate Danny



Campbell-McLean in 2000. One of Rick's most passionate interests was his fascination for medieval stories such as Lord of the Rings and he had an awesome collection of swords, castles and fantasy memorabilia. Rick was interested in the world and was a true and humble gentleman,

always asking about how others were going.

On 22nd January Ricky was surrounded by his loving family and friends as we bid him a final farewell. We can only imagine the reunion that is happening with his brother Danny Camilleri and all of the boys together again, I am sure the wheelchair footy and hockey matches are fierce!

Sending our love and condolences to Ricky's incredibly strong and loving family.

"Do not cry for me because I am gone, Smile for me because I have lived".

Carolyn Campbell-McLean

WORKING TOWARDS AN INDEPENDENT LIFE WORKING WHEELS SUCCESS

The last weekend in January saw participants from both phases of the Working Wheels program reunite in Sydney, together with family, MDNSW staff and Board as well as representatives from ADHC and funding bodies My Choice Matters and Duke of Edinburgh International. The occasion was an official graduation from the Working Wheels program, where participants shared their experiences and celebrated their achievements. There was also a bit of social time at The Brewery!



The Gang

During the past 2 years we did lots of work on self-reflection and awareness, knowing our needs and becoming confident in communicating them; holding a can-do attitude and great expectations for ourselves was key. The focus became much more than getting job-ready and practicing interview skills; our work was about gaining the tools for independence and becoming CEO of your own life! And I am so proud to report that this is exactly what has happened!

So what were some of the outcomes for participants? One participant is now working as a Lifeline Counsellor and studying counselling after years locked in his bedroom gaming; another is working as an Ability Linker supporting people with disability to connect with their community; another is a Project Officer for a Design project – their chosen career!; four are now in paid employment; one now has his own community radio program; at least three participants have secured their own care funding and one now has an accessible vehicle; four participants are doing voluntary work in their local communities and there is a really lovely little network of ongoing support, friendship and camaraderie between participants that can't be replicated in generic employment readiness programs.

At the graduation event each participant was asked to share their journey – their words were honest, insightful powerful and reflected the enormous difference the program has made to their lives. Each and every participant was so well prepared for their speeches and really spoke from the heart! It was obvious the participants matured and developed so much confidence over the past two years. The audience responded with tears, there were offers of further speaking engagements and the funding bodies were clearly impressed!

Kate Thomas presented a fabulous presentation about her adventurous journey to Denmark, with fellow Dukie Philip Hojgaard-Olsen. This was an excellent collaboration between MDNSW, Duke of Edinburgh Award International and My Choice Matters, and the entire idea stemmed from our very first Working Wheels weekend! WOWSER despite the freezing conditions – Denmark looks incredibly accessible!! (see Denmark article)

A huge thank you to ADHC for funding this important work. They trusted us to do something innovative for

young people with neuromuscular conditions – and their investment was definitely worthwhile. MDNSW genuinely cares about achieving better lives for people with NMCs, and I believe this pilot program has done just that!

Finally, a huge thank you to the young people who participated in the WW program. Thank you for your trust, your willingness to listen and try new things. I was truly touched to receive letters of appreciation and stories of what this has meant them. As I said in my article last edition I feel so honoured to have shared your incredible growth and development in our very special WW program, I will never forget our time together. Working with others to live a better more empowered life – how wonderful is it that our Association can work with such outstanding young people! The next generation of leaders is coming!

Carolyn Campbell-McLean Training Facilitator

WW had a focus on practical information and skills and finding opportunities to put them into practice in real life. Some of the areas covered included:

- goal setting, planning and thinking about the future
- understanding Neuromuscular Conditions
- understanding yourself – strengths and areas to develop - and presenting yourself to others
- identifying and communicating support needs in relation to employment
- care support packages, recruiting staff and planning for NDIS
- health care planning
- discrimination law, rights and resources
- consultancy / being a contractor / sole trader
- family dynamics and informal supports
- networking and forming community connections
- acceptance, loss and grief
- dealing with change

THE DUKE OF ED SHINES IN 2015

We had big plans for The Duke of Ed Award in 2015 and our Dukie's did not disappointed!



Our proud Dukies with The Governor

A total of 21 young people took part in the Award through MDNSW, with 14 working towards achieving their Bronze, 4 working towards their Silver and 3 towards their Gold. Kate, Codie and Scott completed their Bronze Award, while Tyran, Luke, Philip and Richard all worked hard for their Silver Award. A fabulous effort by everyone involved! We have seen our Dukies go on some remarkable Adventurous Journey's in 2015, including the snow, Melbourne, Canberra and even

Denmark! Many of our Dukies have already booked in Adventures for 2016, so stay tuned to see the next big things happening!

We have continued the roll out of the Award to MD South Australia, MD Tasmania and MD Queensland and have already seen some very enthusiastic young people begin their Duke of Ed Journey.

We were delighted to have the Governor of NSW, The Honourable

David Hurley and his wife, Mrs Hurley present 7 of our Dukies with their Awards and Pins at the 2015 Kula N Gadu Camp.

A huge thank you must go out to all of the volunteer Assessors that continue to make The Duke of Ed Award what it is today, without the support of these volunteers our Dukies would not be achieving the extraordinary things they are!



Luke Ventured to Melbourne for his Silver AJ



Tyran tried his hand at sewing for his Silver Skill, producing a blanket that got him through winter!



Richard braved the cold in Melbourne for his Silver AJ

If you are aged between 14 and 24 and interested in taking part in the challenge of a lifetime, The Duke of Ed Award is for you! **Please contact Melissa at Melissa.wentworth-perry@mdnsw.org.au to find out more!**

THE TRIP OF A LIFETIME DUKIES GO TO DENMARK!

“You should go to Denmark, they are innovative when it comes to independent living.”

So went the conversation with Peter, a mentor at Muscular Dystrophy NSW (MDNSW). He suggested that I should see how the Danes handle disability, after he heard how I was living at university. I have Spinal Muscular Atrophy type II. My Mum and I were driving the three-hour trip to Bathurst each week, so I could attend classes and experience university life. Mum became very learned on the life of an average university student, as she lived amongst six others while caring for me. However grateful I was, this was not an ideal situation for either Mum or my party life.



Ready to Go!

Fortunately, we were given the heads up on the government run organisation, My Choice Matters' application to complete a project that increases your "choice, voice and control". An application was submitted and the waiting game began.

Each of us signed up for our Gold Duke of Edinburgh Awards and completed the trip as the Adventurous Journey. Travelling with two wheelchairs made it extra adventurous. The forms required for the Muscular Dystrophy NSW Duke of Edinburgh program, allowed us to cover all necessities for travelling overseas.

Finding carers was next on the list. Luckily, Karen, a family friend of Philip's and Demi, a carer from MDNSW camps volunteered their time to put up with us and help us on this adventure. And so, Team Denmark was founded.

After all the paperwork and Skype meetings every Wednesday night, we learnt that our My Choice Matters application was successful.

We got in touch with Muskelvinfonden, the Danish version of Muscular Dystrophy NSW. Jens, our main contact, organised our accommodation, meetings with people and organisations.

Reality and excitement set in, we were on our way.

Katie Thomas



Braving the freezing cold at the beach

To be honest, I thought Peter was joking. I thought he was suggesting Denmark due to his heritage and that I would get a kick out of the idea of travelling to Scandinavia without my parents. He was serious.

Soon the Muscular Dystrophy NSW team was on board. Then, Philip, Peter's son who has Duchenne Muscular Dystrophy and Calum, a participant in the Working Wheels program, joined the team and gave momentum to the Denmark Project.

Even though Philip, Calum and I are at different stages in our lives (i.e. students at school and university) each of us have a neuromuscular condition and the want to be independent in the future. Thus, a project initiative was founded: research what is possible in independent living for people with a disability, in Denmark.

We planned to talk to people with a disability, establishments and behold the new modifications Denmark is using, to understand the social impact of independent living and what equipment can make life easier to live and easier to enjoy.

Next, came the strategizing, but how could we make this idea materialise?



The fabulous slide was fully accessible!

It was a very exciting trip and we learnt a whole heap about the living system for people living with a neuromuscular condition over in Denmark. The first place we stayed at was Musholm Bugt Feriecenter which is an absolutely amazing holiday centre completely disability friendly. The only thing that compares slightly to this awesome place would be Bear Cottage down in Manly. One of the activities I participated in and thoroughly enjoyed was El Hockey which is Electric wheelchair hockey which uses specialised hockey chairs. El hockey is very similar to wheelchair hockey in Australia but uses their own type of wheelchair with a hockey T attached to the front and they go a speedy 14km/h.

However, despite its brilliance and the seemingly difficult standard to top, we were blown away when we arrived at a folk high school known as Egmont Hojskole. Folk high schools are very unique and are not like normal high schools we know in Australia. In order to be able to apply to attend a folk school you must be 18 years of age. It is a school where you can go and study for a minimum of 4 months up to whole year and longer. However unlike schools where you must study in order to pass a test, these schools have no academic requirements for admittance and don't have



Enjoying the night life in Denmark

the pressure of exams, marks or grades. At these schools you can challenge yourself and choose any subject that interests you or that you excel in, for example mathematics, social studies, sports, woodwork, cooking, etc. During your studies at a folk high school you get to sleep, eat, and spend your spare time at the school and you receive a diploma as a proof of your attendance.

The folk high school we attended was specially designed to be fully equipped for disabled students and included an indoor heated swimming pool with waterslide, a gym, giant sports hall and fully equipped student dorms. We had a lot of fun at the folk high school making a lot of new friends and participating in a lot of different activities. Some of these included going down a giant water slide (using a hoist to get in and out) and swimming in 7 degree Celsius water in a dry-suit and the outside temperature being 5 degrees Celsius.

Denmark has a fantastic system of care put in place for people with disabilities. People living with a disability can apply for 24 hours of care 7 days a week if this is required. This is due to the fact that there is a 40% tax in place. As a result, the different communities are able to pay for



Experiencing School life in Denmark

the services the person with a disability may require for example assistive technology, house modifications, a carer, etc. At the folk high school, anyone is allowed to apply including people with disabilities, people who may have been involved in a car accident and people without any form of disability. There is a system in place so they can apply for a carer and the other students can apply for a carer position.

Once they have applied, they must then go through a selection process where the students submit a resume with all their interests, details and qualifications. The person who requires the support then reads through all the resumes and then selects a few people they would like to interview further. After interviewing them, their options are then narrowed down further and then interviewed again before making a decision. The carer then takes care of them during the breaks before dispersing to their allocated classes where the students in that class help each other out. There is also a rule that the carer may not take care of them on school nights as they must both be well rested for another day of learning and instead there is a night shift that helps anyone who may need it. However, on Fridays and the weekend the carers are then allowed to help.

Overall, this trip has been a huge success and we have collected a lot of useful information. Our next step is to create some articles and 2 documentaries which we will then present to both non-government and government organisations. We already have an idea of a housing design which we plan to incorporate some of the Danish social ideas into. With this idea, we will then demonstrate the effectiveness by building the first one and living in it.

Philip Hojgaard-Olsen



Even the Gym was fully accessible!

MEETING PRINCE CHARLES

I was intrigued! The phone call from MDNSW asked if I was free to come to Sydney on the afternoon of 12th November. I checked my diary (I'm retired, so I'm busier than I've ever been in my life!) and I said "Yes, I could." "Wonderful!" was the reply, "but I can't tell you any more about it at the moment."

Of course, things become more mysterious a few days later when another phone call said that "it was definitely happening, and you'll be really excited! "More details would be revealed in a week or so." Hmmmmmm!

Well, all was made clear when, a week or so later, a mysteriously official envelope arrived in the mail. Inside was an invitation; "His Excellency General the Honourable David Hurley, Governor of New South Wales and Mrs Linda Hurley request the company of Mr and Mrs P Bates at a garden reception in the presence of their Royal Highnesses The Prince of Wales and The Duchess of Cornwall on Thursday 12th November 2015 at Government House, Sydney."

Wow! So Lucy and I had been nominated by MDNSW to meet Prince Charles and Lady Camilla!

Now, normally we are shorts-and-t-shirt people but I recalled that I had a suit somewhere in the back of the wardrobe. I went in search of it, found it, and sent it off to the dry-cleaners. Being aware that thongs, no matter how new, wouldn't cut it, I polished up my best shoes. The information that came with the invitation suggested that a hat to protect one from the sun would be a good idea so, fondly laying aside

my old gardening hat, I went out and bought something more suitable.

On the day in question we got up early, put on our good clothes and drove the 160 kilometres from Newcastle to Sydney in a state of excitement. We arrived at the gates of Government House in time to chat with Philip Hojgaard-Olsen from MDNSW and a few of the other guests, but before long we noticed that there were a lot of helicopters hovering overhead. Then the official motorcade whisked down the drive and in through the gates.

Those of us in wheelchairs and the other guests followed, and we found our allocated tables in the beautiful gardens of Government House. It was a sparkling Sydney spring day, and the view over the harbour was delightful. Each table was allocated a host to help with the issues of security and protocol and to put us at our ease.

After a local Elder gave the Welcome to Country, the Governor made a short speech of welcome to the royal couple and we all returned to our tables where drinks and nibbles were served, and waited to see what would happen next. Our host, Daisy, had warned us that Their Highnesses would only have to time to visit every second table, and then only for less than a minute.

I was surprised and excited, then, when one of the attendants asked me if I would like to "come this way to meet the Prince." You know that feeling that you get when someone you've seen on TV or in the papers is suddenly they're in front of you? That's how I felt. We only chatted for a minute or so, but my impression of the Prince is that he is a person who is genuinely interested in the world around him, and in the people he meets.

It was one of those days that stay with you forever, and Lucy and I would like to thank the wonderful people at Muscular Dystrophy NSW for making it possible.

Philip Bates MDNSW Member



The Gardens of Government House



Phil & Lucy meet Prince Charles

31ST NATIONAL ELECTRIC WHEELCHAIR SPORTS 2016 } NEWS



Jordan Crane showing how it's done

NEWS is taking place from Monday 18th April to the Sunday 24th April at Sydney Academy of Sports and Recreation, Narrabeen. We are thrilled to announce His Excellency General The Honourable David Hurley AC DSC (Ret'd) opening the competition and staying on to cheer on NSW!

The teams competing this year are New South Wales Strikers, Victorian Pride Warriors, Queensland Gladiators, South Australian Scorpions and Western Australian Wasps. All of which will be out for revenge this year after New South Wales Strikers achieved the honour last

year. The three sports played are Rugby League, Balloon Soccer and Hockey.

NSW's team this year consists of Captain James Kim, Chris Suffield, Jordan Crane, Alex Scollard, Andrew Kim & Jye Mokluk. The team is coached by Peter Dalrymple & assisted by Ben Keyte.

We would love to see as many people as possible out at the competition supporting the athletes. So come along and cheer on your team!

Peter Dalrymple *National Director
National Electric Wheelchair Sports*

In the January holidays Philip, Chris, Scott and I went to watch a special wheelchair soccer competition where players came all over Australia to play in. Chris and I went in the MD bus early in the morning with carers Jim, Demi, Joey and Joey's brother who is a die-hard Western Sydney Wanderers fan. While in the car we all sang to the latest tunes and danced.

When we got there we met Jay and Paris and Jay was looking all classy in his nice black coat. We then went inside and found Scott and Philip chatting away. Chris kept screaming Go Sydney FC and singing all the chants and he was the only person there going for Sydney FC. We watched three games and the players were very skilful with passing, defending and shooting, the games were so interesting. While at the tournament Scott, Philip and I kept showing off our standing wheelchairs and everyone was impressed and wanted photos. The carers were all together in the stands away from us, so us guys could talk about guy stuff because that's what guys do. We then all went for lunch at the Kebab shop and I got the spicy kebab and was almost in tears and I had sweat all over.

Sadly the day ended and we all had to say our goodbyes again after camp and we had some sad carers again. It was a really fun day and it was a really great idea and fun way to spend a day with your friends. **Patrick Nolan** *14yrs, MDNSW Member*

WHEELCHAIR SOCCER A-LEAGUE SPECIAL



Ready to cheer the boys!

WHAT'S HAPPENING IN THE WORLD OF BOCCIA?

The Boccia season is in full swing with the Hunter Cup run and won and our very own Boccia Bash Champion Phil Bates winning his classification. Next up on the Boccia Calendar is the very popular NSW State Titles to be held on the 4-6 March at the Sydney Academy of Sport Narrabeen. This is one of the major competitions and lead in's for our NSW athletes to the Boccia Australia Nationals where last year over 60 athletes competed. The Boccia Australia Nationals will be held on 29 April to the 5 May, also at Sydney Academy of Sport.

Other boccia events across NSW in this calendar year will be the Boccia School Knockout Competition, Boccia Junior Nationals in November and of course the very competitive Boccia Bash where Muscular Dystrophy NSW go up against Cerebral Palsy Alliance (16 October).

Can MDNSW do a three peat!!

If you want to know more about Boccia, how to get involved, even join a club, go to Boccia.com.au or email at admin@boccia.com.au or **0403 306 792**



The Great Boccia Bash!

3RD ANNUAL BIG RED RIDE RAISES \$100,000!



Emma and Jim representing our Camp Carers!

On Sunday 8th November 2015 we had 92 amazing riders participate in our annual Big Red Ride cycling event. The Big Red Ride has two options where the riders tackle either Bondi to Richmond (85km) or Bondi to Katoomba (150km). This was the first year we introduced the 85km ride and it was a big success with many riders happy they could be involved even if they were not keen for the full 150km. The ride began at Bondi with everyone waving off the riders on their epic journey. We then had

a lunchtime stop held at Richmond where we had children, young people and families who will be supported through the *Kids for Life* program that the Big Red Ride raises money for. This section of the ride is always such a wonderful and inspirational part of the event for all the riders as they truly see that their fundraising is making a big difference to so many lives! Some of our riders finished here and some continued their huge uphill climb making their way to Katoomba to celebrate completing this incredible

challenge! It was an amazing day for all the riders and everyone who was involved. Definitely the best one we have had so far and we can't wait to make 2016 even bigger and better!

“ Thank you so much for a wonderful event. A classic ride, well organised, and in support of a genuinely good cause. It really was a pleasure to be able to take part in it. Tobias Wright ”

BIG RED RIDE SYDNEY 2016

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6 November 2016
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Bondi Beach to Richmond - 85 km
Bondi Beach to Katoomba - 150 km

Congratulations to our amazing 2015 Riders!

- Adrian O'Hagan
- Jim Anthopoulos
- Julie Barlin
- Jen Barling
- Steven Black
- Tony Bonaccorso
- Stephen Borg
- Lisa Bowman
- Louise Brierty
- Paula Brock
- Michael Browne
- Carly Bull
- Mark Bullock
- Julian Burgess
- Renee Calphy
- Mark Calphy
- Stewart Cameron
- Sean Castleman
- Stephen Choi
- Maria Clarkin
- Nick Collins
- Eden Connell
- Henry Cornwell
- Emma Cowley
- Peter Day
- Gerald de Haan
- Ben Di Qual
- Laurie Fairweather
- Daniel Forsythe
- Ewan Gemmill
- Gary Gillot
- Wayne Grech
- Alex Green
- Phillip Green
- Anne Grunseit
- Matt Haran
- Ralph Heredia
- Monique Hitter
- Michael Humphries
- Patrich Ilufi
- Kim Jenkins
- George Kambourglou
- Vincent Keir
- Mark Kelly
- John Kofiotis
- Robert Kolimackovski
- Michael Laoudis
- Carsten Larsen
- Gary Leong
- Jacqueline Liddicoat
- David Lipson
- Jenny Mahon
- Susie McBurney
- Brad McGee
- Samantha McGee
- Charlotte McLelland
- Colin McLelland
- Marie Mercer
- Andy Nixey
- Joanne O'Brien
- Darragh O'Hagan
- Roisin O'Hagan
- Anthony Papadopoulos
- Nick Polin
- Tania Polin
- Oliver Poss
- Jeff Rahme
- David Robb
- James Robson
- Jonas Schofer
- David Semaan
- Emma Smith
- Jason Smith
- David Speers
- George Stavliotis
- James Sullivan
- Alessio Tacca
- David Taylor
- Darrin Tucker
- Tania Tuckerman
- Joseph Vallis
- Tobias van den Broek
- Merrick van Wyk
- Michael Vogt
- David Waddell
- David Ward
- Alex Watt-Smith
- David Webster
- Tom Wilson
- Richard Wong
- Tobias Wright
- Con Zygouras



GACT Team getting ready to take on the Big Red Ride!

“ It is an incredibly well organised event for a great cause. Kylie and Ben were fantastic. So knowledgeable and generous. I felt like I was in great hands. The ride leaders (and followers) were fantastic and very supportive. Everyone I encountered on the ride was extremely friendly and welcoming. There was a great sense of camaraderie and I met some really lovely people I hope I will cross paths with again. One of the best things I have ever done. **Monique Hitter** ”



David Speers



Brad & Mel with our riders in Richmond

What our riders had to say...

“ It was an awesome event that was amazingly well organised with a great vibe. All the riders were encouraging each other along the entire way. It was an honour to help some of the people we were meeting when we came into Richmond. I was blown away by the positivity they showed and wish I had a bit of their fortitude as I was trying to pull myself up the hill. **Ben Di Qual** ”



Scott giving riders some motivation at the Richmond lunchstop

“ From when I first registered I was impressed by how well things were organised. From fundraising page setup, to training rides and responses to questions. I have done numerous similar walking/running events to this in the past and this was the most informed and engaged I've felt. Due to the limited numbers, it really did really feel like a 'family'. Inclusive, where everyone spoke and encouraged each other with the goal to get to the end. **Kim Jenkins** ”

Caz and Josh's Little Big Red Ride – over \$4000 raised!



Josh, Caitlin, Carolyn and Steve doing their Little Big Red Ride!

This year we wanted to have our own challenge to support MDNSW and be a part of the Big Red Ride so we organised – **The Little Big Red Ride!** I did this by rolling in my new powerchair from

my place in Rydalmere to Richmond and I was joined by 3 year old Josh Ryan and his sister Caitlyn. Josh, like me, has SMA and his own set of wheels, so the challenge was the young and the old, the little and the big members of MDNSW, wheeling together to Richmond. Taking off along the beautiful riverside bikeway, we met plenty of cyclists along the way and picked up some lovely donations. In Parramatta we boarded a train to Richmond and entered Richmond Park with a fantastic welcoming committee as we crossed the finish line!

Together we managed to raise over \$4000 for the Kids for Life program. This year we are planning a wheelchair convoy from Parramatta Park and would love you to join us!

Carolyn Campbell-McLean

Please contact Kags, Fundraising Manager on 9809 2111 ext. 2 or email kags.garrard@mdnsw.org.au

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

SINGING SANTAS \$1345.85 Raised!

This was our sixth year running the Singing Santas fundraiser for Muscular Dystrophy NSW. It usually involves a group of people getting together to sing carols at Martin Place for a few hours. Last year, we weren't sure it would go ahead, out of respect for the Lindt Café event. This year, we almost cancelled the event a few hours before it was to take place because of the terrible weather and the threat of a cyclone. At the 11th hour, Westfield Pitt Street Mall saved the day and allowed us to sing in the shopping centre and the food court. There were certainly less people around and a lot of the volunteers weren't able to travel in, but we did it! We still managed to raise funds and have the satisfaction of knowing we didn't give up. Every little bit helps. Thank you to Kags and the team at MDNSW and to the volunteers who could make it. Never give up!



Melissa with her Singing Santas at Westfield

Melissa Stewart Singing Santa's Coordinator



Gilgandra Craft Market

GILGANDRA CRAFT MARKET \$4238 raised!



On Saturday 14th November, twenty stallholders eagerly awaited their prospective customers. Four years ago, three community-minded women started an Annual Craft Market held at the Gilgandra Shire Hall. This year Muscular Dystrophy NSW was chosen as the benefitting charity, as my daughter Kate has a neuromuscular condition and she has participated in many of their programs and attended camps. On the day, there were stallholders selling many items including plants, cakes, candles, jewellery, patchwork items, craft items, books, antiques, pottery and soap. Raffle tickets were also sold prior to and on the day, for great prizes donated by the community including a patchwork quilt and an abundant hamper. The day was supported by many friends including local group, Wednesday Patchworkers and Quilters, who provided morning and afternoon tea and lunch. A great community day was had by all who attended.

Alison Thomas

CANADA BAY CLUB \$2900.92 raised!

Thank you to Canada Bay Club for donating \$2900.92 from their October Director's raffle. We really appreciate their generosity and ongoing support they continuous provide us.

and have a lovely ladies lunch together. This will be a subsidized event for clients with Muscular Dystrophy. For more information please contact Kags Garrard, Head of Fundraising and Partnerships on **02 9809 2111 (ext 2)** or email kags.garrard@mdnsw.org.au

Muscular Dystrophy NSW will also be hosting a Ladies Lunch on 26th June which will be sponsored and held at the Canada Bay Club. Come along with friends and family



TURRAMURRA HIGH SCHOOL \$2364.65 raised!

Thank you to Turrumurra High School for their annual donation of \$2364.65. We really appreciate their generosity and ongoing support every year.

DONATION IN MEMORY & BEQUESTS

We wanted to sincerely thank everyone who made a donation in memory of someone with Muscular Dystrophy and also those who chose to make a bequest to Muscular Dystrophy NSW in 2015. We truly appreciate all of the donations as they allow us to continue improving people's quality of life.

Donation in Memory 2015

Alicia Cannon, Barry Warren, Gareth Busch, Gwyneth Braun, Harry Anderson, Kenneth Noel Welsh, Marion Dallow, Mark Isaac Roberts, Sue Fitzgerald, Shaun Matthew Knight and Trevor Harrison

Bequests 2015

Carole Anne Kumar, Patricia O'Callaghan, James Samuel and Amy Doreen Bennett

EVERY LITTLE BIT HELPS : BE A VOLUNTEER COLLECTOR FROM OUR FOOD OUTLET DONATION BOXES



My name is Rob Murray and I do collections from our donation boxes located at Red Rooster and other food outlets in the Sydney Metropolitan Area.

About every Three months I do the collections and have been doing this for the past six or so years. The

collection process including banking is relatively easy to do. I love doing this work as it is a REAL way of gathering funds from the community at large who wish to support the Muscular Dystrophy NSW cause through their generous cash donations.

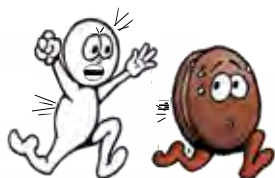
The donation boxes raise around \$40,000 a year for MDNSW so it is a huge amount and very helpful to the cause.

Why don't you come on board and be a Volunteer Collector? Red Rooster food outlets are generally located at easily accessible sites in the metro area.

Rob Murray

.....
Please contact Kags Garrard on **02 9809 2111 (ext 2)** or email kags.garrard@mdnsw.org.au for more details. We would be only too grateful to have you in the team.

Right now we are urgently seeking someone in the Coffs Harbour local area to collect and bank donations from the 3 local stores.



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ASSOCIATE PROFESSOR NIGEL CLARKE

PhD, MBChB, FRACP 1966 - 2015



"It is always doubly sad and tragic when a friend and colleague dies at the peak of their career. We have lost a dedicated friend and fellow traveller in myology." Victor Dubowitz 15.10.15

Nigel Clarke hailed from New Zealand

and completed his medical training (MBChB) in 1991 at Otago University in Dunedin, before moving to Australia to train as a Clinical Geneticist. In 2001 Nigel joined the Institute for Neuroscience and Muscle Research at the Children's Hospital at Westmead in Sydney, found his passion and never looked back. In 2006, he completed his PhD under the supervision of Professor Kathryn North and that year was awarded the Prize for Best Oral Presentation at the World Muscle Society for his definitive work on congenital fibre type disproportion and its genetic basis. In 2007 he was awarded a prestigious Australian National Health and Medical Research Council (NHMRC)/INSERM Post-doctoral Fellowship to work in Paris at the Institute de Myologie with Dr Pascale Guicheney. In that two years in Paris he developed a lifelong passion for cheese, and established the foundations of his many very productive international collaborations with a vast range of colleagues in Europe, UK, Japan and North and South America. In 2009 he returned to Sydney to complete his postdoctoral training and was appointed as a clinical academic at the University of Sydney, initially as a Senior Lecturer, with a promotion to Associate Professor in 2013. In 2013, he succeeded Kathryn North as Head of the Institute for Neuroscience and Muscle Research.

"Nigel was outstanding both as a clinician and a scientist - a rare combination of skills. He was driven by his deep-rooted caring for his patients and their families, and his desire to find answers where previously there were none."

Nigel's major research interest was defining the genetic basis and pathogenesis of weakness in inherited muscle disease. His PhD studies focused on defining the genetic basis of congenital fibre type disproportion (CFTD), which was first proposed as a disease entity in 1973. It was debated

whether this was a useful clinical entity until Nigel's research defined the first four (TPM3, RYR1, ACTA1 and SEPNI) of the six genetic causes currently known, and established CFTD as a diagnosis that gives doctors and families information about prognosis, inheritance pattern and aetiology. In recent years, his laboratory identified new genetic causes of nemaline myopathy (LMOD3), dominant spinal muscular atrophy (BICD2) and a peroxisomal-like disorder (PIGY) and has contributed to studies identifying further disease genes (GMPPB, KLHL40, KLHL41). He also had a passion for the tropomyosin family of proteins and made several major contributions to our understanding of their contribution to muscle function. In addition to his long-standing research partnership with Kathryn North and Nigel Laing in Australia, he had strong collaborative projects with Daniel MacArthur (Broad Institute, Boston, USA) and worked with the leading international centres involved in clinical myopathy research including London (Francesco Muntoni), Paris (Norma Romero), Washington DC (Eric Hoffman, Carsten Bonnemann), Boston (Alan Beggs), Toronto (Jim Dowling) and Japan (Ichizo Nishino) to advance diagnosis in neuromuscular disorders.

We in Australia will miss him especially. Nigel was one of the founders and pillars of strength of the Australasian Neuromuscular Network, which comprises over 300 clinicians and researchers around the country. His friendly and unassuming manner brought people together. Nigel had an amazing skill set, including an uncanny ability to "pick the gene" from his precise analysis and understanding of the clinical phenotype of a patient. His deep insight and thinking kept us all on our toes and brought out the best in all of us. Nigel was also an outstanding mentor both of his own students, and in his role as mentor to Early Career Researchers more broadly in the Sydney Medical School. He was honest, caring and patient and treated everyone as an equal, fostering their ability to contribute and to grow towards independence.

Nigel died on October 14 2015, 16 months after being diagnosed with an aggressive glioblastoma. He suffered a severe stroke during the initial surgery to remove the tumour and was never able to return to the work that he loved after his diagnosis. His sister Bridget provided the most amazing care to allow him to spend most of his last year at home, where he was surrounded by his many friends and family. He was honoured at a beautiful memorial service in Sydney on October 24th, attended by so many people that held him dear. He celebrated his many achievements, his talents as a musician and a singer and heard personal tributes from those whose lives he had touched, including many of his international friends and colleagues.

"We believe Nigel's legacy to the medical and research community will be long-lasting. Through the children whose lives he made better, and the families for whom his research provided answers. Through the scientists and clinicians he mentored through their PhDs - who will ensure the future of neuromuscular research in Australia and New Zealand. And through his substantial body of work which will continue to influence and underpin our future discoveries. Nigel's research team continues to be incredibly productive with 30 publications in the last three years, 11 of which have been published this year following his diagnosis with a brain tumour."

On a personal note, in Australia, it was a continuous source of joy to us to have the "two Nigels" flying the flag of neuromuscular research at opposite ends of the country, and making such a big contribution to the international neuromuscular community. Nigel's sense of humour, ability and humility will remain with us.

Nigel Laing Perth, Australia

Kathryn North Melbourne, Australia

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Neuromuscular Clinic

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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

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