

Talking Point

**MUSCULAR
DYSTROPHY
NSW** BUILDING STRENGTH
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER AUTUMN 2015



The Big Red Ride Sydney

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BUILDING STRENGTH, REACHING POTENTIAL

EDITORIAL

WELCOME TO OUR FIRST EDITION OF TALKING POINT FOR 2015. I HOPE YOU HAVE ALL HAD AN ENJOYABLE CHRISTMAS AND NEW YEAR CELEBRATING THE FESTIVE SEASON WITH FAMILY AND FRIENDS.



A highlight of the season for me was our Sydney Metro Christmas Party. With over 200 attending it was a wonderful opportunity to meet with many of you. Our latest Event Program for 2015 is now in full swing, as are our new Connection Groups throughout NSW, which are a great way of meeting others and giving and getting support from those who have had similar experiences. We have also developed our Counselling Service further this year, with the focus being on providing telephone counselling, making it readily accessible to more people throughout NSW. A major focus of my year will be to help prepare MDNSW and people with a neuromuscular condition to transition to the NDIS. If you have any questions, insights or concerns please do contact me as this is a journey we will all take together.

PENE HODGE

CEO, Muscular Dystrophy NSW

A NOTE FROM THE PRESIDENT



AT MDNSW, WE INTERACT WITH THOUSANDS OF PEOPLE EVERY YEAR - CLIENTS, FAMILIES, STAKEHOLDERS AND VARIOUS ORGANISATIONS - AND OUR YEAR IS OFF TO A FLYING START!

I suspect the changing and more competitive environment for charities, companies and Governments means people are focused on change, innovation and communication - just as we have been for some time. Pene Hodge, her team and our members have continued to entrench innovation as a key strategy for MDNSW, as we strive to be the leading whole of life provider of choice of specialised services and expert information for people affected by neuromuscular conditions. To keep our edge, we must continue to evolve and innovate as we seek to deliver the best possible services for you. Thank you to one and all in our MDNSW family for all your efforts.

PETER DEBNAM

President, Muscular Dystrophy NSW

EVENT CALENDAR 2015

Sat 21 February, 2015



Northern Rivers Ladies Spa

A pampering event for ladies in the Northern Rivers region of NSW within the breathtaking surrounds of Angourie Rainforest Resort.

Fri 13 – Sun 15 March, 2015

Ngundabaa Mums' Retreat

Enjoy this special weekend getaway on the banks of the beautiful Shoalhaven River, just for mums of children with a neuromuscular condition.



Mon 13 – Fri 17 April, 2015

Adventure Camp

*Booked
Out!*

Port Stephens

Fri 1 – Sun 3 May, 2015

Sydney Star Retreat

A Weekend Getaway specifically for adults with a neuromuscular condition and their partners/ carers. See Les Miserables as an added bonus!



Fri 11 – Sun 13
September, 2015



Broken Bay

Blokes in a Boat Weekend

A unique opportunity for Dads living with someone with a neuromuscular condition to spend a weekend away together and perhaps even enjoy some fishing in the process.

Sun 18 October, 2015

The Great Boccia Bash

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

Narrabeen



Sun 8 Nov, 2015



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

Date to be confirmed

Parramatta 2015 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!



Wed 16 – Sun 20 Dec 2015

Camp Kula 'N' Gadu Sydney Academy of Sport

Places filling up quickly already!

Taking RSVP's now - see website for details



CHRISTMAS CELEBRATIONS ACROSS NSW

Hoping you were able to pop along and join in the fun at one of our many Christmas Parties we held throughout NSW for parents, children and families who are living with a neuromuscular condition. A big thanks to the staff of CBA Direct Banking Sydney who do so much for our families with their support of our Metro Christmas party. Looking forward to seeing you all once again at some of our other events we will be holding throughout 2015! See our website for further details.



Geoff Huegill and our Dukies



Chris and Jo Ann enjoying themselves up at the Orange event



The Ambarber family come to our party every year and we love it!

"We had a wonderful day at the Metro Christmas Party with MDNSW. I watched as kids as young as two, zoomed around on power-chairs, kids of different age and size. A room full of complete strangers to us, yet we shared their same pain. I silently wept inside not showing my weakness to these amazing children who had nothing but the biggest smiles. Such a big thank you to MDNSW for bringing joy to our families; thank you for the amazing efforts you and your volunteers put into our children."

Social media post from a mother of a child with a neuromuscular condition whose family attended their first MDNSW Christmas Party



Christmas Craft was a huge hit across NSW!



Jacy and Vanessa loved their first MDNSW regional event



Table tennis fun



Even Batman made an appearance!



What a race track - and boy was it popular!



Amelia, Hayley and Jacinta are growing up way too fast in the North Coast!

MDNSW MEDICAL SEMINAR THE VALUE OF SIT TO STAND WHEELCHAIRS

Helena Young, OT from the Neuromuscular team at CHW, presented at MDNSW's Medical and Research Seminar in October 2014 on a new and innovative pilot study research project to assess the value of the powered wheelchair standing device for improving health and movement outcomes for boys with Duchenne (DMD).

With the progression of DMD and inevitable loss of ambulation, power wheelchairs are provided to boys with DMD to maintain independent safe mobility and participation in the community. An alternative device is the powered wheelchair standing device (PWSD). The Levo C3 power wheelchair standing device (supplied by MiTech) is a sit-to-stand wheelchair that provides the

user with the facility to drive and perform tasks in sitting or standing positions. In the pilot study, boys with DMD aged 7-18 years who are assessed as eligible for supply of the Levo C3, will be evaluated over a two year period. The study is not funded, but is an extension on the usual clinical process of power wheelchair prescription, with ENABLE funding, the generous support of Variety and MiTech



who have generously offered support for the study participants' equipment supply and maintenance. Ten children from various areas across NSW will be the focus of the study. This pilot study will provide preliminary data on the effect of PWSD on everyday life for boys with DMD. The study will determine the ongoing value of the PWSD for the client, carers and community, and whether prescription and supply of these types of power wheelchairs is best practice. Outcome measures will be taken before and after supply of the PWSD, to assess quality of life, psychosocial impact, participation, performance and satisfaction. The impact of the PWSD on the physical care and clinical course of DMD will also be monitored. This monitoring will provide rich information on the impact of the PWSD, which will be disseminated to the scientific and wider community.



KIDS SINGING UP A STORM

Tiannah preparing for the concert with Phoebe

Thanks to a grant from MDNSW through their Little Heroes programs, Sing for Fun sessions were held monthly from July to December 2014 in the OT Department at Children's Hospital Westmead.

Phoebe Cormack, our wonderful music therapist from Bear Cottage, facilitated the group for primary school-aged children with a neuromuscular condition and always brought a fabulous selection of instruments, craft and music-related activities to every session, so there was always something new happening to keep interest high! Our favourite camp carer, Emma Cowley, and Helena Young, OT from CHW, also volunteered at every session to help out. Activities were chosen specifically

to encourage participation, exploration, self regulation, socialisation and empowerment in the children. It was hoped that this would transfer to other activities that the children participate in at school in particular. The Sing for Fun choir made a CD at the end of it all, finishing with a great Christmas party on our last day, where we decorated wheelchairs for the festive season, before preparing for the final concert. New skills, confidence, friendships and joy were shared every session and the mums and dads had a chance for respite time for a few hours on each of the Saturdays.

A huge thanks to Phoebe, Helena and Emma for their efforts in facilitating this innovative program!



Shannon and Kaitlyn all dressed up ready for the concert with Emma



Abilgail and Helena in the festive spirit

LIFE AFTER AN ADULT DIAGNOSIS

Life is full of challenges, yet most of the time they flower into more strength, insight and wisdom...

It felt quite strange when I was diagnosed with a very rare degenerative muscular disease about four years ago. It was having an effect on me with weakening my limbs and breathing. I couldn't help but wonder how can such a tiny invisible missing enzyme disable such a complicated vehicle, "my body"? A lot of memories started to come back about the very early symptoms that were misinterpreted as signs of "stress" due to the ongoing difficulties I was having in my life. However, that did not change anything. All of a sudden I began to acknowledge the reality of my situation and understood the daunting truth that I needed to learn to live and cope with. I went from shock to anxiety, panic attacks, and depression. I'm a single parent with no family in Australia and the government will not subsidise my very expensive monthly treatment because they don't believe it will "prolong" my life, but for me, who will look after my son when I go away?

After few months of suffering, a light bulb went on in my mind and heart I said to myself,

"I have few years to live with my son. I can either spend them feeling depressed and sad, or live them to the full and leave my son with beautiful memories and a living example on strength."

I chose the positive option and decided to live each day as it comes. I made a conscious effort to stop worrying about the future or remembering the past, which has changed my life tremendously. I opened up about my disease and did not feel embarrassed to talk about it to friends and a few strangers when they asked.

I stopped feeling embarrassed about using a walking stick to avoid falls. In



fact, I've had lots of laughs with elderly people who use the stick and it always guarantees me a seat in the train when I go to work, even in peak hours! Instead of stressing about how many times I will have to wake up at night to adjust the C-Pap machine mask, I made jokes about it as it looks like an elephant trunk, and sent a photo to my friends to share the laugh. I am learning that being open and having some humour about adversity makes a big difference. As my body weakens more and more, I learn about the importance of accepting help from friends and loved ones. Doing so can be a challenge for me at times, as I have always been so independent in all areas of my life. It is a lesson in humility at its best, unlike what I originally thought.

Sometimes through adversity, life shows us how many beautiful people are out there. How cooperative and caring our community is. A bright example is all the help and support that I have been receiving from

Muscular Dystrophy NSW. Marie, one of the social workers there, is not just doing her job professionally; she is genuinely interested in providing all the help possible. She connected me with other services where I met very loving and kind people who helped me and my son. She also helped me to go on two days' respite, which was of extreme importance at the time. I relaxed in bed not having to worry about a thing in the world, just looking outside the big window at the beautiful trees and flowers reflecting on life and having very nice meals. I came back home feeling very light and refreshed.

We really don't need to be and cannot be super humans but we can discover the incredible strength within ourselves through our journey, if we pay enough attention, open up, and smile.

Lama Al-Akhras, 47yrs

Lama is a member of MDNSW and has an extremely rare neuromuscular condition called Pompe Disease



LET'S GET CONNECTED....

MDNSW is currently expanding our social support groups under the banner of *Connections*. As well as the current carer support groups around regional NSW, we have started up new social support groups in areas including Liverpool and the Central Coast region.

Attending a social support group can be a great way of connecting with others who understand you and share similar concerns and experiences. Your time with the group can be helpful in allowing you to talk with others about stressful times, whether you've had a bad day at work or a year filled with

loss or chronic illness. It can also be an opportunity to celebrate achievements and support each other in an environment that is friendly and safe. The social support groups will allow you to access information, advice, guidance and other types of assistance should you need them. They are a great way to learn more about resources, to exchange information and support each other with new strategies for managing life's challenges.

Coming along to a social support group offers a chance to meet others and to develop new friendships. Often people in groups say it makes them feel like

they're not on their own, and that the other members are a great support.

"In a support group, you can talk to somebody about your concerns and feel supported. I felt better and the isolation for me is now gone."

Social support groups provide a safe place for people to relax and be at ease with others who understand what they are going through. They can also allow an environment where people can feel comfortable to share their experiences, laugh and joke – and just be themselves!

CURRENT SOCIAL SUPPORT GROUPS IN THE SYDNEY METRO AND REGIONAL AREAS OF NSW

Liverpool Parent Group meets in the Coffee Club at Mounties in Mount Pritchard on a Tuesday morning every six weeks for a coffee and chat

Northern Rivers Social Group meets every second month at various locations on the Far North Coast

Hunter Social Group meets every second month in the Hunter area

Illawarra Carer Support Group meets 1st Tuesday of each month various locations in the Illawarra

BOB Blokes out Bush meets every second month in Narrandera

Wicked Rollers Central West Group meets every second month in Orange

There are a number of new *Connections* social support groups starting up in many areas and we are keen to hear from you if you would like to attend or find out more about these new groups.

The new Central Coast Social Group will meet every second month at Wallarah Bay Recreation Club

The new Armidale Social Group will meet every second month at the Armidale RSL Club

The new Orana Social Group will meet every third month in Dubbo

The new Central West Social Group will meet every third month in Bathurst

*For further information about MDNSW's *Connections* social support groups, please call the Client Services team on 9809 2111 ext. 1.*

TRANSITIONING FROM SCHOOL INTO UNI

I am an 18 year old woman who has Spinal Muscular Atrophy. I successfully completed my HSC in 2014 and received an ATAR of 85.5. I will be starting university this year. During my final year at school, I suffered great disadvantages due to my health but despite such barriers I was still able to accomplish my goals. I plan on pursuing a science degree, as it is my passion and will lead to the accomplishment of my aspiration to be a researcher.

I was confronted with many challenges as I transitioned from high school into the wider world:

- Travelling to and from university is a challenge, as I no longer have the convenience of being picked up and dropped off through transport previously provided by the department of education. I must now embark on an independent journey on public transport in order to reach my destination. This involves having to cautiously plan my voyage as I attempt to avoid any further obstacles such as dealing with broken elevators and

ensuring wheelchair accessibility at the train stations

- Other difficulties I faced were moving from children's care into adult care. Unlike children's care that I received at Westmead hospital, that provided all the facilities I needed in one place, adult care is a branched system and all the requirements I need are not situated under one roof. This meant I had to adapt to this new system, which can often feel confusing
- Moving from a school atmosphere into a university environment can be very stressful. University life is completely independent and provides no personal care facilities or other care needs which means, unlike school, I do not have anyone to assist me. Fortunately community participation funding and scholarships that I have received will greatly assist me during my university life as they can provide vast support that I may require during my tertiary education



As a person with a neuromuscular condition, the full time HSC year was exceptionally difficult, but the hard work was definitely worth it in the end. It may have seemed impossible at first but studying consistently and being resilient during the tough times aided the journey. The support of my family and friends provided the encouragement to continue on.

Eeman Shahzad, member MDNSW
Eeman is 18yrs old and has SMAIII

Next Generation Sequencing for people with CMD



I have recently completed my specialist training in Paediatric Neurology at The Children's Hospital at Westmead. I am interested in paediatric muscle disease, and in particular, in the genetic causes of disease. This has led me to pursue a PhD through the Institute for Neuroscience and Muscle Research and the University of Sydney entitled *Improving Diagnosis of Congenital Muscular Dystrophy by Next Generation Sequencing Techniques*. The last 5 years have seen a rapid expansion in our understanding of the genetic basis of muscle disease. An important contributor to this has been the development of a technology called Next Generation Sequencing. Instead of testing on a gene-by-gene basis, this technology provides an efficient way of concurrently screening the entire coding sequence of DNA. My research project has been applying this technology

to find a genetic diagnosis for a group of children and young people with Congenital Muscular Dystrophy.

Our preliminary data shows that Next Generation Sequencing is a valuable tool for diagnosing our previously undiagnosed patients. It is effective at identifying mutations in known neuromuscular disease genes and has also allowed us to identify new disease-causing genes. This helps us to provide better information to families about prognosis and recurrence risk. It also allows us to ensure appropriate surveillance for medical complications.

As this new technology moves rapidly from a research tool into clinical practice, my research will provide valuable insight into the challenges, limitations and benefits. It aims to inform safe, ethical and effective integration of this technology into our clinical practice.

Dr Gina O'Grady, winner of MDNSW's 2015 'Sue Connor PhD Scholarship'



WAGGA WAGGA DUCHENNE FAMILY DINNER

Last year, MDNSW and Northcott hosted the third annual Pre-Clinic Duchenne Family Dinner for families in the local region attending the Sydney Children's Hospital Neuromuscular Outreach Clinic in Wagga Wagga. We all had a wonderful evening of chatting, laughter, exchanging information and building new friendships. The dinner was a huge success and everyone there said how much they really enjoyed the night and meeting new families. It was great to see the siblings connect with each other too, as they are all going through a very similar journey together. A wonderful night with beautiful people!

Marie Adamou,
Client Services Coordinator

OUR NEXT DUCHENNE FAMILY DINNER WILL BE ON THE THURSDAY
PRIOR TO THE OUTREACH CLINIC. HOPE TO SEE YOU THERE!

MDNSW's Illawarra Carer Support meeting in October 2014 was really informative. Representatives from Ability Links explained that they have a very informal, flexible and proactive role to help people with disabilities link to community activities. Anyone with a disability can contact them directly to talk about what they are interested in and they will take it from there. The local workers are Sam Lucas salucas@unitingcarenswwact.org.au and Kem Agdiran kagdiran@unitingcarenswwact.org.au.

WE ARE SO LUCKY TO LIVE IN
THIS PICTURESQUE PART OF
NSW, SO LET'S GET OUT AND
ABOUT AND ENJOY IT!

For more information about the Illawarra Carer Support group, contact Marie Adamou at MDNSW on 9809 2111 ext.1.

WHAT'S HAPPENING IN THE ILLAWARRA REGION?

Boccia Several members continue to participate in the Boccia games held at Port Kembla Surf Club most Fridays from 4.30-6.30pm

Sailability is on fortnightly in 2015, on both Thursdays and Saturdays. This is a great activity for all age groups and abilities. There is a hoist, and life jackets are provided. Meet at the Illawarra Yacht Club from 10-2.30. For more information contact Len on 0438 873 447

Wollongong Council provides **Beach Wheelchairs** at several beaches. The chair at North Wollongong is located under the steps in front of the Pavilion. Ask the Life Guard on duty, or book it through the Council website.

The Illawarra- Shoalhaven MD Support group will meet at 11am on the following dates: Everyone is welcome!

- Tues 24 March, Wollongong Golf Club, Corrimal St Wollongong
- Tues 26 May, Bomaderry Bowling Club, Meroo Rd Bomaderry
- Tues 28 July, Wollongong Golf Club
- Tues 22nd Sept, Bomaderry Bowling Club
- Tues 24th Nov, Wollongong Golf Club
(may be changed for a Saturday end of year lunch)

HOW TO ACCESS MDNSW SUPPORT SERVICES THROUGH THE NDIS

MDNSW is registered to provide numerous supports under the NDIS. It can be tricky to know how to fit our support services into your NDIS plan, but talking to one of our Client Services Coordinators before your Planning Meeting can be really helpful, as we've been informed by many of our members who have gone through the process so far. Below is a table which shows what supports MDNSW can provide and how they fit into the NDIS terminology.

MDNSW SERVICES & PROGRAMS	Supports that MDNSW is registered to provide [NDIS Cluster Group]
<ul style="list-style-type: none"> > MDNSW Camps > Retreats for people with a neuromuscular condition 	Assistance with daily life tasks in a group or shared living arrangement
<ul style="list-style-type: none"> > The Duke of Edinburgh's Award > Wheelchair Sports > Boccia 	Participation in community, social and civic activities
<ul style="list-style-type: none"> > Working Wheels 	Assistance to access and maintain employment
<ul style="list-style-type: none"> > Case Co-ordination & Client support 	Assistance in coordinating or managing life stages, transitions and supports
<ul style="list-style-type: none"> > Accommodation assistance 	Accommodation/Tenancy assistance
<ul style="list-style-type: none"> > Counselling (Telephone only) 	Therapeutic Supports

IS FLEXIREST SUPPORT COVERED BY THE NDIS?

The NDIA has advised that respite for families/carers is currently not available under the NDIS; the scheme only funds the person with a disability. This issue is currently being reviewed by the government, however under the present system, the FlexiRest program is unfortunately not available for those who have an NDIS plan. Members who do not currently have an NDIS plan will be given priority for FlexiRest applications. However, those families who are on an NDIS plan and still wish to receive respite can do so by including personal care for the person with disability on their NDIS plan. Here, respite funds will be provided by the NDIS to pay for qualified staff from an external care facility/ personal homecare service to provide care to the person with disability, so respite can be taken by the family at their own expense.

WHO IS ELIGIBLE FOR THE NDIS?

To be eligible to become a participant in the NDIS you must live in one of the NDIS trial sites. Check out 'My Access checker' on myaccesschecker.ndis.gov.au to see if you are eligible.

The National Disability Insurance Scheme [NDIS] is a radical new way of providing support to people with a disability, their families and carers. It focuses on supporting individuals with disability to become more independent and achieve their goals including developing skills for day-to-day living.

How can I prepare for my NDIS planning meeting?

- Participants and their families/carers are encouraged to be prepared and informed for their NDIS planning meeting. The NDIS has published a Planning Workbook which is available on www.ndis.gov.au/document/820 to assist with assessing the current support needs and ensure no support is missed
- Participants are encouraged to take their carer/family member/health professional to the planning meeting
- Request an additional amount on the NDIS Budget for training personal care staff on neuromuscular conditions. We encourage you to take the Muscular Dystrophy Fact Sheets available from our website to your planning meeting
- Participants are encouraged to ask questions at every step of the NDIS process, not just during the planning meeting
- Participants can select service providers that are not registered with the NDIA. Participants have to pay out of their pocket for the expenses first and then claim it back from the NDIA
- Participants can still access the NSW Health System [Medicare] for children under the age of 16 years
- NDIS processes are becoming more flexible in their planning meetings and introducing more flexible plans with the bundling of supports options

Muscular Dystrophy NSW now offers a new Specialist Telephone Counselling Service

MDNSW understands that having a neuromuscular condition, or living with someone who does, can be tough at times. Having someone to talk to who understands the condition, who will listen in a confidential and non-judgemental way and can assist you to explore your options could be helpful.

Our members have told us it's not always possible to get to see a counsellor because of where you live, accessibility issues and the demands of family life. Our telephone counselling service means that wherever you live in NSW and whatever your level of disability, a counsellor is only a phone call away.

Our qualified counsellors can help with:

- **adjustment to living with a disability**
- **depression and anxiety**
- **grief, loss and anger**
- **intimacy and sexuality concerns**
- **self esteem and bullying**
- **family and relationship conflict**
- **social isolation**
- **pain and fatigue**
- **or any other area of concern to you**

Our telephone counselling service is available to all people who are affected by any kind of neuromuscular condition including carers, family members and friends. It is currently a free service, but for those with an NDIS Plan, it will be incorporated into your plan and a fee will apply.

To talk through whether counselling may be right for you or to make an appointment, please contact MDNSW on 1800 635 109 or email counselling@mdnsw.org.au.





Mitch Oates got a job with Ability Links

WE GOT THE JOB!!

WORKING WHEELS SUCCESS

In December, following support from MDNSW with job applications, mock interviews and instigating my very own carer support team, plus lots of my own hard work and determination, I was offered my first job! I was over the moon!

I started my job in January and am working on a new program to help promote social inclusion and community involvement of people with disabilities. I feel that this is very relevant to what I learned in the Working Wheels program ie helping people to reach their potential. Throughout the Working Wheels [WW] program we discussed many different things about searching for employment and being successful in the workforce, which allowed us to work together to overcome various obstacles that may occur. The fast-tracked course also taught us about job interview tips, to how best to catch public transport, funding/care packages and even handy wheelchair modifications. Having regular meetings with the WW team allowed for us to share stories and work with each other to extinguish any issues that may have popped up. I'm looking forward to the rest of this year and seeing where my job takes me and also look forward to hearing about the other participants' successes. I would like to thank all the people who contributed to the WW program from ADHC, the facilitators, the participants and guest speakers who made for a fantastic experience. Talking to one another and sharing ideas and experiences has really helped to open the door to a wide range of possibilities.

Mitch Oates, Albury
Mitch has SMAII and is 24yrs old

My Working Wheels internship with MDNSW and employment prospects have substantially expanded since the last update I gave you in Talking Point a few months ago. In order to gain some real experience in the online world and to put the skills I learnt studying Web Design at TAFE into practice, I have been given the opportunity to work on revamping the website of Right Price Conversions, a Sydney based company who modify vehicles to accommodate wheelchair users. This is no doubt pushing me outside my comfort zone as web design is still an area I am very new to. I am finding it super challenging, but once complete, the outcome will be of great benefit for both myself and Right Price Conversions. Looking back, I guess my initial expectations of the Working Wheels program was that it would mainly be about becoming job ready and simply finding employment. While it is employment focused, it has been much broader than that, with information and support in relation to managing aspects of life my life around work including transport and personal care amongst other things. Our discussions on these topics within the group were informative and encouraging, especially for those of us who have not yet ventured into looking at personal care outside the family for example. Beginning to organise this however is daunting but it's something which has got to be looked at sooner rather than later.

Monique Witsen, Sydney
Monique has SMAII and is 34 years old



Monique secured web design work as a contractor

DO YOU WANT TO WORK?

We are currently finalising the last positions in Working Wheels for phase 2 of this exciting pilot program. If you have a neuromuscular condition and are interested in moving into the workforce or changing careers and need some extra support to make it happen, email me your interest at melissa.wentworth-perry@mdnsw.org.au. Mature aged candidates are always encouraged to apply!

Working Wheels and Right Price Conversions team up

The primary aim of Working Wheels [WW] is to increase employment opportunities for people with a neuromuscular condition, support them in transitioning into work, increase awareness amongst employers, as well as support businesses to employ someone with a NMC. We are very excited to share a new connection we have made with a small business that is proving to have huge benefits for both the WW participants and for the program development.

Right Price Conversions [RPC] is a small business located in Wollie Creek who manufacture and install wheelchair conversions in cars. They offer a reliable and innovative design that involves the floor being lowered rather than a big ramp being installed. This design is unique and is patented worldwide. Up until recently, RPC has

mainly catered for taxis and a minimal number of personal vehicles. The owner, George Zisti, is now expanding the business in the hope that people all throughout Australia can benefit from this cost effective design. In order for this expansion to take place, obviously the business is going to need assistance in a few different areas! This is where the skills of our Working Wheels participants come in to play!

Monique Witsen [see previous page] has been employed by RPC to assist in the initial phase of the expansion process. At this stage she has been contracted to design a new website interface and an advertisement for the business that ensures potential customers are drawn in to the business. Monique has been able to put into practice many of the skills she has learnt through the WW program in addition to the training she completed

at TAFE. The advertisement below was designed by Monique as part of her role at RPC.

We are very excited with the possibilities that have arisen from this new relationship we have with Right Price Conversions. Discussions have already taken place with RPC about other possible roles that will be required through this expansion process and on an ongoing basis. Positions in areas such as accounts, administration, marketing and customer relations are all possibilities we will be looking at with RPC for our future WW participants.

Are you qualified or experienced in any of these areas? Why not enquire about our Working Wheels program?



www.rightpriceconversions.com.au

At Right Price Conversions we strive to offer the most cost effective wheelchair accessible vehicle conversions in Australia.

With our vehicles requiring minimal clearance to get in and out of, we are not only the *right price* but also the *right choice*.



Phone **02 9597 4068** for demonstrations of our conversions in your area

This ad was designed by Working Wheels participant, Monique Witsen

IT'S ALL HAPPENING IN THE HUNTER WITH THE DUKE OF ED

...thanks to the Commonwealth Bank Australia



MDNSW would like to extend a big thank you to the Commonwealth Bank for supporting MDNSW's Duke of Ed program in the Hunter region! We are very proud to announce that because of the Commonwealth Bank's support in 2014, four people completed their Duke of Ed Award in the Hunter, with others well on their way in 2015! Congratulations to Joe Sciuilli, Kate deHaart and Codie deHaart for completing their Bronze Award and to Cassie Robson who completed her Silver Award! We also wish Jye Donkin and Bodene Davies all the best with finishing their Bronze Awards in 2015.

Check out some of the interesting activities the Hunter Dukies have been doing for their different sections!

Skill

- Cooking
- Photography
- Fishing
- Tie Dying

Service

- Online Mentoring
- Soccer Coaching
- Childcare Centre
- School in-class support
- Collecting statistics for a football team

Physical Recreation

- Soccer
- Swimming
- Boccia
- Bowling

Adventurous Journey

- Fishing Trip on the Hawkesbury
- Port Macquarie Adventure
- South Pacific Cruise
- Train trip to Melbourne



Bodene snapping away for her Skill



Cass at the top of the Sky Deck on her AJ



Jye practicing Boccia for his Physical Recreation



Joe with the catch of the day



Congrats to Kate & Codie for completing their Bronze Award



MDNSW'S DUKE OF ED GOES NATIONAL

As the New Year begins, so does the National Rollout of The Duke of Ed Award. Thanks to funding received from the *Press Gallery* in Canberra, we have started working closely with MDQLD, MDSA and MDTAS to set up The Award in each organisation in preparation

for their first Dukies to start. It is very exciting to see the Award expanding to the other states and for other young people to have the opportunity to achieve great things like we have seen here at MDNSW!

The Duke of Ed throughout Australia has always sought to encourage young Australians living with a disability to do The Award. Up to when MDNSW embraced The Award, this challenge was taken up fairly haphazardly. The success of MDNSW embracing The Award has not only extended to other State and Territory MD support organisations but also to other specific disability support peak bodies. The Duke of Ed nationally is preparing its 2015-2020 Strategic Plan and is setting priority goals to substantially grow the number of young people living with a disability to take on The Dukies challenge. Organisations supporting disability groups such as cerebral palsy and down syndrome are being encouraged to follow the pioneering work of MDNSW.

Peter Kaye

CEO, The Duke of Edinburgh's International Award - Australia



Jono and Travis take on the Duke Challenge in SA!

Muscular Dystrophy **South Australia** is excited to be working with MDNSW to get The Duke of Edinburgh's Award up and running in South Australia. We currently have six clients who are either registered and beginning their Awards or are soon to get started. They are an energetic group of males who cannot wait to experience new things and broaden their horizons. Pictured is Jono who is completing his Silver Award and Travis who is completing his Gold Award. They are both doing their Service section through Muscular Dystrophy SA, helping out the Client Services Team on a weekly basis. We cannot wait to see what this year will have in store for our Dukies and we wish the NSW Dukies the best of luck.

Aisling O'Toole

Client Services Coordinator, MDSA

Muscular Dystrophy **Queensland** is delighted to collaborate with MDNSW offering The Duke of Edinburgh's Award to our clients. Thanks MDNSW for offering this opportunity to change and enhance the lives of young people living with neuromuscular conditions.

Susan Ball

Client Services Manager, MDQLD

MD **Tasmania** is delighted to have the opportunity to participate in the roll out of The Duke of Edinburgh's Award. We have two young people who have accepted the challenge and are developing their program ready to head off in directions which will be new to them.

Anne Ashford

MD Tasmania

Wheelchair Rugby League

35
YEAR
HISTORY



NSW Push and Power Rugby League Inc.

FUN FACTS:

- Played on an Indoor Basketball Court
- Both Electric and Manual wheelchairs can play
- Passing and catching by Voice Command
- Closely based on NRL rules
- For ages 8 and above

WHERE:

All games played at Kevin Betts Stadium,
Ralph Place in Mount Drutt NSW

CONTACT:

Phone: 0414 337 155

Web: www.pushandpower.org.au Email: pushandpowersports@gmail.com



NSW BOCCIA CLUBS

CLUB	CONTACT	NUMBER	EMAIL
Northern Beaches	Scott Elsworth	0414 771 033	selsworth@gmail.com
Penrith	Michelle Hamlin	0427 166 969	Michelle.hamlin@hotmail.com
South West	Patricia Vaz		pat.vaz16@gmail.com
Illawarra	Toni Howard	0438 627 585	pthoward@bigpond.com
Hunter	Lucy Bates	0411 961 250	hunterboccia@bigpond.com
Orange	Katrina McDonald	0428 658 733	alandtrin@gmail.com
Central Coast	Heather Kozak	0458 587 300	hkhkozak@hotmail.com
Tamworth	Jeff Essex		j.essex@sunnyfield.org.au



Want to play wheelchair sports?

If you have a neuromuscular condition and have an interest in sport and use an electric wheelchair for mobility, then I would like to encourage you to come to one or all of our training sessions. We play Rugby League, Hockey and Soccer and we warmly welcome beginners to come along and give it a go! Just bring yourself and your chair and get ready to have a heap of fun with some great people.

Coaching Days for March, 2015

Sunday 1st, 15th, 22nd, 29th March

10.00am to 12.00pm

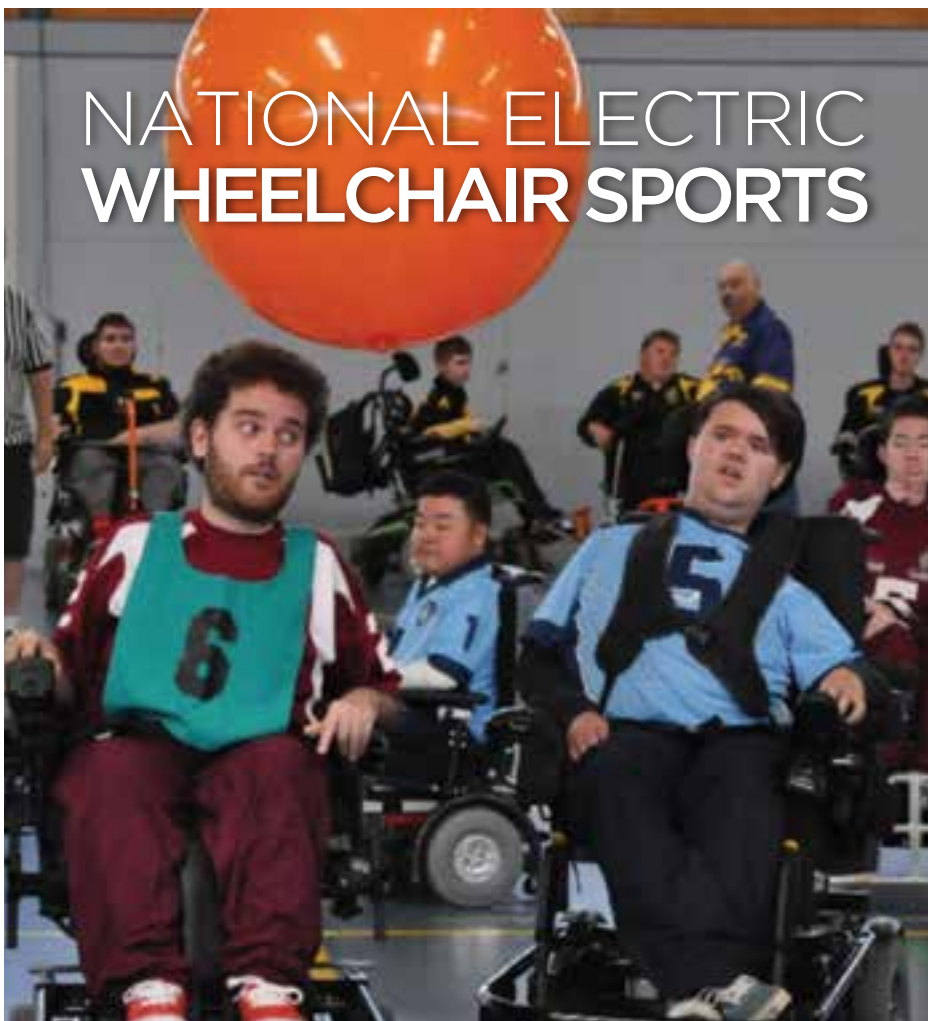
Kevin Betts Stadium

Ralph Place, Mount Druitt

Contact: Peter Dalrymple

Coach NSW Strikers & National Director of National Electric Wheelchair Chair Sports

Ph: [02] 8883 4485 Email: peter_dalrymple@hotmail.com



NATIONAL ELECTRIC WHEELCHAIR SPORTS

The 30th **Annual National Electric Wheelchair Sports** tournament is being held at the Sydney Academy of Sport and Recreation, Narrabeen from Mon 13 - Sun 19 April, 2015. The competing teams are the NSW Strikers, Queensland Gladiators, South Australia Scorpions, Victoria Pride Warriors and Western Wasps. The Competition starts with round robins for each Sport of Rugby League, Balloon Soccer & Hockey with a Finals Day on Saturday, 18th April 2015.



The NSW Strikers are looking for their 7th consecutive Rugby League Championships

THINKING OF SENDING YOUR CHILD TO CAMP?

One of our best and most experienced Camp Carers shares her thoughts on MDNSW Camps

When asked to reflect on my experiences with MDNSW camps, I felt this overwhelming gratitude to the children and their families for allowing me into their world and for teaching me more about myself and the different challenges of life than I thought possible! I had absolutely no idea what I was in for on my first camp. I remember walking into the training day with little knowledge about muscular dystrophy and walking out overwhelmed with the facts and a preparation kit on how to survive camp as a carer. I was nervous, excited, scared.... actually I could list a page of emotions that I'm sure I shared with all the children and parents on the first morning of camp!



After my first camp I was hooked; what an amazing week! Watching the delight on the children's faces as they developed friendships with other campers is priceless. Seeing the campers and carers work together in group activities makes you take a step back and just appreciate these moments in life. Camp becomes a little family! Like everything in life, camp can have its emotional and physical ups and downs but that's where the friendships developed between the carers and campers really helps. Often you see the unity of the carers stepping in to help out other carers but it's the behind the scenes moments when you see or hear the campers having discussions with the other campers about their muscular dystrophy journeys that

make you realise the importance and joy of these friendships for the children; they can see they are not alone and that there are other children just like them. At the conclusion of my university studies and six MDNSW camps later, I am truly humbled to have been given the opportunity to continue coming along to camps and enjoying the journey with many of the campers. I have taken so much away from all the camps including such achievements as the Campers' Carer Award, Camp Team Leader and, as a result of my camp experiences, the opportunity to complete my fourth year eight week placement with the extraordinary Occupational Therapist, Helena Young, at the Children's Hospital Westmead, where I was once again able to work with many of my

camp children. I also was a walking talking advertisement for camp, recommending its benefits to anyone who would listen.

Although my camp journey has been halted by the reality of having to get a job, this is not goodbye MDNSW! I will continue to volunteer where I can, including the continuation of the Sing for Fun program in 2015. I cannot say thank you enough to the camp team - especially Loretta - and to the families who entrust their children in our care! Watch this space; I will be around, and who knows a future job in paediatric occupational therapy could be calling!! Lots of love,

Emma Cowley

Emma is now a qualified OT and was one of our most beautiful and talented Camp Carers, attending six camps in total. We will miss her this year and wish her well in her career - hopefully in the neuromuscular field - where she has amazing potential. Thanks Em for all your hard work and dedication - it was very much appreciated by about 250 families and campers and of course all of us at MDNSW!



Emma's OT skills were amazing during parasailing



Emma was particularly great with the younger kids

Did you know?



REUSABILITY

Reusability is a classifieds website designed to help you sell equipment such as your electric scooter, toilet frame, or even your commode chair. It only lists private sales. It is free to list your equipment, or purchase a range of 'add ons' for a small fee to increase your chances of selling. www.reusability.com.au

STAYING SAFE IN YOUR OWN HOME

Personal Alarm systems

Are you worried about yourself, a parent or a relative who lives alone, or spends periods of time alone during the day or night? Is there a concern about the risk of a fall, or the need to contact help in case of an emergency? A personal alarm system allows a person call for help, at the push of a panic button, should they fall or become unwell. For more information about a wide range of personal safety products, contact the Independent Living Centre:

www.ilcnsw.asn.au
[02] 9912 5800 help@ilcnsw.asn.au

VOCAL SMOKE DETECTOR

People can become confused and upset in the event of a fire emergency. With a Vocal Smoke Detector you can leave a short message reminding them of what to do. To make this even more effective, have a fire drill in place and the message becomes a calming reminder of what to do. For people living on their own, this can be paired with an emergency call phone. The smoke detector alarm will trigger and send an alarm call through to let you know that it has been activated.

www.safelife.com.au
[03] 9588 0833 sales@safelife.com.au

COMPREHENSIVE INSURANCE FOR SCOOTERS OR ELECTRIC WHEELCHAIRS

Blue Badge Insurance Australia are specialists in mobility equipment insurance, with policies underwritten by Underwriters at Lloyd's. This includes repair or replacement of damage, loss or damage, Third Party Injury and Property Cover, new for old replacement for total loss (up to 2 years old), and covers any legal user you authorise, costs incurred to get you and mobility device home after an accident, overseas cover etc.

Annual fee for membership and insurance:
mobility scooter \$185 electric wheelchair \$235

www.bluebadgeinsurance.com.au
1300 304 802 info@bluebadge.com.au

FREE SMOKE ALARM AND BATTERY REPLACEMENT

Fire & Rescue NSW (FRNSW) is providing a free Smoke Alarm and Battery Replacement (SABRE) program to seniors or people with a disability now in NSW. If you are eligible for this program, a firefighter can visit your home to install a battery-operated smoke alarm or even change your existing smoke alarm batteries if you are unable to do so yourself. The service is free, but you must supply the battery operated smoke alarms and batteries. Eligibility is only if you are frail or aged over 65, or have a disability, do not have any access to family, friends or neighbours who can assist you and you must be living in your own or privately rented home in a FRNSW fire district.

For more information, visit www.fire.nsw.gov.au/page.php?id=306

ROTARY AND QANTAS SOAR WITH GENEROSITY

A huge thank you to Turramurra Rotary, Qantas Pathfinders and MDNSW for sponsoring Kieran on today's Jumbo mystery flight.

Kieran and Graham were treated as VIP's in business class while they enjoyed a free flight from beautiful Sydney to Wollongong, then north to Newcastle and back again. The weather was perfect and the care of the kids was just superb. Kieran says it was a really exciting day. I mean, how often do kids get to sit in the cockpit of a 747? These are the days when memories are made!



Keiran taking control of the plane!



Mitch in the cockpit

PEOPLE FOR AN AUSTRALIAN MUSCULAR DYSTROPHY DAY

The 3rd People for an Australian Muscular Dystrophy Day was held on Sunday, 30th November 2014 at Kevin Betts Stadium, Mount Druitt. This day is about celebrating the dreams, achievements and successes of people living with a neuromuscular condition and also aims to raise awareness of the 40+ different types of known conditions. Everyone wore their red ribbons on the day and the morning tea was scrumptious thanks to the generous contributions of those in attendance.

Eileen Baptiste,
Coordinator of P4AMDD

FOR SALE

Kia Carnival 2005

\$16,500

- Black with grey interior
- 5 Seats plus Wheelchair
- Modified with ramp at rear
- One Owner, serviced regularly and complete Log Book
- 114769 kms
- Air Con
- CD Player

Please contact Rita on 0424 474 922



Right Price Conversions - Modified Cars For Sale

Chery J11 2011 \$25,000



- Fully converted in RPC latest design
- Silver
- 36,892km
- Automatic
- 2 years warranty on the conversion

Kia Carnival EX 2005 \$25,000



- Silver
- 196,000Km
- Aluminium Rims
- Automatic
- Fully Converted
- 2 years warranty on the conversion

PHONE 02 9597 4068 www.rightpriceconversions.com.au

HARLEYS 4 MD Over \$10,000 raised

The HOG NSW Australia Chapters' annual Harley Ride for MD was held in September last year, supporting MDNSW by selling the seat on the back of a Harley for a scenic ride south to Austinmer Beach. The ride left from Frasers Motorcycles and made its way to Austinmer Beach taking in the beautiful scenery through Stanwell Tops then with beautiful coastal views to Austinmer Beach. Upon arrival, the Ladies of Harley had prepared a great morning tea for the weary travellers. This year was bigger and better, with 64 bikes with 31 paying passengers, raising over \$10,000 for MDNSW. It was a great day enjoyed by all.



HOGS in action for MDNSW

In Memory of Kris "Groovy" Grove

We would like to recognise all the amazing work and support that Kris "Groovy" Grove gave to MDNSW through our partnership with the HOG's. He always made the effort to attend our events, our Camps, meet with our clients and work on the Harleys 4 MD fundraiser, which this year made a record \$10,000. He was a wonderful and generous man and will be sadly missed by everyone at MDNSW.

SINGING SANTAS - \$2638 Raised!



On Thursday 18th December, 15 singers and volunteers dressed in festive outfits took to the streets of Sydney CBD to perform carols and Christmas songs to raise money for MDNSW. We had concerns about continuing with the events in Martin Place in December but knowing that we were doing this to help people, we decided as long as we were respectful then it would be fine to go ahead. First we headed to Martin Place to sing carols under the Christmas Tree where we seemed to brighten the mood somewhat. Then the carollers moved to Pitt Street Mall, where we managed to raise more than we ever have in the 5 years of running the event! Thank you to the volunteers and for your generous donations. We're hoping even more people can join us this year on 17 December from 6pm. Contact Kags Garrard on 9809 2111 ext.2 or email kags.garrard@mdnsw.org.au for more details.

Melissa Stewart,
Singing Santa's Coordinator

PUB 2 PUB - \$700 RAISED!

I decided that I would like to walk in the Pub2Pub so a few friends and I signed up to raise funds for MDNSW. My niece in New Zealand has the condition so I knew what a worthy cause it was. When I arrived for the event, there were people supporting all sorts of charities, people in silly outfits, and there was a great community vibe. We

had sunshine the whole way and made it to the finish line in two and a half hours. It was definitely worth getting to the end to enjoy a nice cold glass of champagne, as well as knowing that I had raised \$700 for a great cause!

Catherine Michaels,
Community fundraiser



Thanks to all our supporters for the \$63,518
you raised for MDNSW in 2014!

THE BIG RED RIDE RAISES \$100,000!



Brad McGee and some MDNSW supporters celebrate the finish with the other riders at Katoomba

On Sun 16 November, 70 amazing cyclists rode 150km uphill from Bondi to Katoomba for our biggest fundraiser of the year! This wonderful group of riders raised over \$100,000 for our Kids for Life program, with Matt and Tom raising more than \$4000 each and our largest team raising over \$18,000! The day was a huge success and despite the weather conditions everyone had a brilliant day.

The Big Red Ride is a unique, challenging, but above all, thoroughly enjoyable event in support of a very worthy cause! The route from Bondi to Katoomba provides an array of beautiful scenery, from crossing the Sydney Harbour Bridge and navigating Winmalee's serene countryside, before climbing seemingly into the clouds to reach the picturesque finish at the Three Sisters. The event is exceptionally well organised

and everyone involved, including organisers, volunteers, support crew and riders were extremely friendly and supportive throughout the day. It was also truly motivating and inspiring to have so many kids from MDNSW with their families there to cheer us on along the way, and remind us all of the reason why we were there. All-in-all, it was a fantastic experience and I can't wait to tackle the Big Red Ride in 2015!

A Big Red Rider, 2014



Sunday 8 Nov, 2015

We have now opened registrations for our Big Red Ride 2015, to be held on Sun 8 November. Riding alongside cycling legend Brad McGee, 150 participants will enjoy a celebration of Sydney icons in a ride of endurance they will never forget. This year we also have a BRAND NEW OPTION to finish the ride at Richmond for those people who want to participate in a shorter form of the event.

What better way to raise funds for such a worthy cause, being out in the sunshine & challenging yourself to achieve more than you thought capable. Whether you're participating because of being affected in some way by MD or simply because you want to personally challenge yourself this is an event that will tick all the boxes and more.

To register go to

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

This event will sell out so make sure you register to avoid missing out!



Our amazing riders celebrating after completing 150km uphill!

What our riders had to say

“ The whole event was so well organised, the best one I have ever been involved in. The level of detail was outstanding, the signs, the support, the cheering, the amount of support staff on hand to help, the massage at the end. It really was quite humbling that all these people had given up their time to support us getting up that bloody hill! ”

“ Sand to the Sisters, all it takes is 27107 revolutions of the legs to complete this fantastically run event for such a great cause. Thanks to all the support staff that helped make this the best event I have ever participated in. The whole energy around this event is so motivating, giving up was never an option. ”



Tom Wilson makes it to the top of the hill!



High Street Flyers Team

“ What a day.... I really enjoyed the whole event, even the pain and hurt. A great feeling of achievement. ”



Riders at the Richmond lunchstop with our Dukies

Congratulations to our amazing 2014 Riders!

Brad McGee
Adrian O'Hagan
Andrew Chitty
Andrew Lind
Ben Streckeisen
Carsten Larsen
Charlie Leggett
Charlotte McLelland
Colin McLelland
Damian Goodman
Darragh O'Hagan
David Clark
David Fernandez
David Gramosli
David Robb
Dougal Guild
Emma Smith
Frances Edwards
Geoff Ferris
Greg Stoneham
James Carroll
Jason Smith
Jen Barling
Jenny Mahon
Jeremy Swift
John Cadwallader
John Denyer
Julie- Anne Hazlett
Justin Daly
Kathy Truong
Keith Yu
Kelly Thompson
Leanne Taylor
Marc Tan
Marcello Ponze
Marie Mercer
Matt Farmer
Matt Haran
Matt Hutton
Michael Vogt
Mira Nikolic
Murray Sinclair
Nick Collins
Nick Polin
Nicolette Glazewski
Paula Brock
Peter Sklavos
Phillip Cornwell
Pino Giusti
Richard Carter
Rob Woodley
Robyn Walker
Roisin O'Hagan
Sam Rathanaatae
Sean Castleman
Shane Taivairanga
Sharon Watson
Silvo Severi
Steve Black
Stewart Cameron
Sunny Lee
Tania Polin
Tom Wilson
Tony Bonaccorso
Tony Small
Victoria Garamy
Vincent Keir

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

contact us...

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

Call 02 9809 2111, email info@mdnsw.org.au or by post at:
MUSCULAR DYSTROPHY NSW 5 Bay Drive, PO Box 1365, Meadowbank NSW 2114



Sunday 8 November 2015

BONDI TO KATOOMBA

BRAND NEW OPTION – This year the riders have the option of starting at Bondi and finishing the ride at Richmond

150 kms with Australian cycling legend
BRAD McGEE

REGISTER NOW
Strictly limited to 150

Cost \$165
Minimum fundraising per rider \$500

SEA TO SUMMIT

The toughest one day ride around

Register online at:

<http://bigredridesydney.gofundraise.com.au>
or email kags.garrard@mdnsw.org.au for more information

**MUSCULAR
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NSW BUILDING STRENGTH
REACHING POTENTIAL

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

mdnsw.org.au

BUILDING STRENGTH REACHING POTENTIAL

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