

Talking Point

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER WINTER 2018

Adventure Camp 2018





EDITORIAL

AT THE OUTSET I WOULD LIKE TO SAY WHAT AN HONOUR IT IS TO SERVE AS PRESIDENT OF MUSCULAR DYSTROPHY NSW, AN ORGANISATION THAT DOES ITS VERY BEST TO IMPROVE LIFE FOR THOSE WITH NEUROMUSCULAR CONDITIONS, AND THEIR FAMILIES.

I appreciate the support and confidence of my fellow Directors who elected me to follow Peter Debnam, who resigned from his position after 7 years of service in April of this year. Peter's legacy is strong, leaving our organisation focused and in a position to successfully manage the ongoing transition to the National Disability Insurance Scheme (NDIS). I would like to thank Peter on behalf of the Board and all in our broad family, and wish him well in the future.

In my role as CEO of ClubsNSW, the organisation that looks after registered and licensed clubs in NSW, I encounter many charities and organisations doing great work, often without much in the way of government or corporate support. I understand the fundraising challenge facing not-for-profits, and hope to be able to help MDNSW to continue to build a sound organisational footing. This will help us deliver on our strategic themes by: empowering

people affected by neuromuscular conditions to build capacity and independence; facilitate better connections; build knowledge and awareness of neuromuscular conditions; and be a strong and effective representative voice for our community.

Led by our General Manager Charlotte Sangster, our team is charging ahead working on exciting new projects such as the development of a network of Peer Support Groups and a new online information hub which we will build with the support of the NDIA; Information, Linkages and Capacity Building grants.

Thank you for your warm welcome and I look forward to seeing you at one of our events soon!

ANTHONY BALL

President, Muscular Dystrophy NSW



FAREWELL PETER DEBNAM

It is with a mixture of sadness and extreme gratitude that the Board of Directors announces the departure of MDNSW President, Peter Debnam, after more than 7 years of service.

Peter has greatly enjoyed his time serving MDNSW and feels that it is time to pass the baton to a new President.

Peter has played a critical role in the success of MDNSW over the years and has made an enormous contribution to the Association, for which we are so grateful.

Peter will continue to pop in from time to time, so you will have an opportunity to see him and give him your best wishes!

STATE COLLABORATION ILC GRANT AWARDED

The development of an online integrated, technology system to build the capacity and skills of all people living with Muscular Dystrophy and neuromuscular conditions, their families and carers is now possible thanks to a commitment of funding through the Information, Linkages and Capacity Building (ILC) Readiness Grants through the National Disability Insurance Agency (NDIA).

Announced on Monday 1 May 2018, this ground-breaking project will see our community more connected and informed to make decisions about their own personal needs and more integrated with specialist and mainstream service provision and

support networks in their local area.

Through Australian surveys, it is evident the neuromuscular community is overwhelmed by the lack of clear, consistent information that is specific to age, diagnostic stage, culture and condition.

Karen, a community member living with a neuromuscular condition, says she is excited to see something "targeted towards people's life stage and a place that we can get all information when, where and how we want it".

The project will be overseen by Muscular Dystrophy Foundation Australia (MDF), governed by an independent National Board

of Directors. The consortium of CEOs and Community Services Managers of seven state and territory neuromuscular associations will be directly involved in the operational management and delivery of the project. Content will be developed in consultation with neuromuscular specialists in primary and allied health sectors, and directly with the neuromuscular community through Community Consultation Groups.

Muscular Dystrophy Foundation Grant Awarded



2018 ADVENTURE CAMP

We had 26 keen attendees at Adventure Camp this year, a few new faces, many return campers and just as many amazing volunteers! We arrived to beautiful weather at our beachside cabins in Nelson Bay. After learning about the camp store (where we could choose our ingredients for meals that we would cook ourselves) we excitedly awaited the next day's activities..

We spent our first morning in a high-octane game of Laser Tag and then made our way to eat a lunch of fish and chips on Dutchies Beach.



Laser Tag

Rhys taking aim

Fletch with his game face on

The ladies striking a Laser Tag pose

We were greeted by crazy winds on arrival and thought that it

would put a stop to the planned beach based activities but we were wrong as the kids thought otherwise. We not only made it onto the beach but most of us didn't want to leave! Some awesome sand creations were made (in the middle of a sandstorm) and there were lots of laughs.



Fish and chips for lunch at the beach

Taya and Alex all smiles

Sophie and Rachel getting creative on the beach

The next day we all had "the need for speed" and jumped on a bus for a day of Go Karting and Tobogganing. Both activities were a huge hit and the GO Kart lap times were startling! Mexican night came upon us so we all made our way down to the store and picked out all our favourite ingredients for a Mexican themed feast. Tacos were definitely a camp staple. I'm not sure if it was the Mexican food or the lollies but that night everyone started

to cut a bit loose.

And then the make-up came out! Some of the boys gave it a go while most locked themselves in the cupboard, fearing the worst! We laughed until it hurt and had so much fun.



Go Karting

Strolling back for dinner after a swim

Pierce ready to take off on the Toboggan track

Day three saw us 4 -wheel driving and sandboarding – both old camp favourites. Lots of thrills and spills between friends, new and old.

On our last night it was party time and later in the evening the water and shaving cream came out!

In between all the fantastic planned activities, we got to make new friends and catch up with old ones, swim, play games, craft, watch movies, cook and of course, laugh. What a way to spend part of the April school holidays? Unfortunately, all good things must come to an end and after a fabulous BBQ breakfast we began the journey home with everyone thinking about how much fun they had during their time at Adventure Camp 2018.



Party Time!

If anyone is interested in joining the Facebook page Adventure Camp April 18 to see all the photos and posts from the please email Jenny Smith at jenny.smith@mdnsw.org.au. It's a private group page and you will need to gain permission to access. Again, special mention to all of our volunteers! Thank you thank you **THANK YOU** once again, we couldn't do it without you.

Mitch Taylor

Find out why kids
keep coming back
year after year!

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

Camp Kula N' Gadu 2018

WHEN & WHERE?

Sat 15 - Wed 19 Dec

**Sydney Academy of Sport
and Recreation, Narrabeen**

WHAT?

Participation in a huge variety of unique activities. All meals, accommodation and equipment hire. There will be at least one carer to each camper and a nurse on site.



WHO CAN COME?

This camp is open to people aged 6-18 with a neuromuscular condition. Activities are age appropriate and cater for all levels of skill and ability.

WHY?

Because it's the most fun you can have in five days. Make new friends or catch up with old ones. Have a break from Mum and Dad!



mdnsw.org.au

EXTREMELY IMPORTANT INFORMATION

To book your place at camp you will need to ensure that you have the necessary funds in the CORE supports area of your NDIS plan before we can confirm your place.

We can talk to you about how much funding you need in your plan; or we can guide you on how to get the correct funding in your plan.

It is very important that you book your place now to ensure that there is sufficient time to get funding in your NDIS plan if you don't already have the necessary funding.

To register or find out more information, please contact Mitch at mitch.taylor@mdnsw.org.au or on **0458 026 532**, or Jenny at jenny.smith@mdnsw.org.au or on **9888 5711 ext 3**

YOUR COST?

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

*Remember, this is a popular camp
and takes a lot of organisation so
please register ASAP!*

Sometimes there may be a waiting list for camp. To ensure the system is fair, we will assess applications based on priority. A full list of Priority Access Criteria is on our website <http://mdnsw.org.au/priority>

2018 MUM'S RETREAT

In March, 13 mums and 2 staff headed up the mountains to a beautiful bushland retreat at Blackheath for a weekend together. It was a time to enjoy some respite from the normal routine of caring for a child with a neuromuscular condition. There were times of laughter as well as tears; time to talk and listen and connect with others; a time to relax and enjoy the beauty of nature; a time to share ideas and feel valued. **Jenny Smith**



What did they most like about the Retreat?

- "Being away in a peaceful place with women similar to me. Sharing ideas and stories makes you feel connected where this doesn't happen anywhere else"
- "Being amongst nature with amazing mums that don't take the break for granted"
- "Networking, meeting other mums and talking with women who get it"
- "The friendships, the sense of belonging, the atmosphere"
- "Having time out and being able to just be me"
- "The opportunity to reconnect with other mums and take time for myself away from home and family"
- "Empowered by other strong and amazing mums"

COUPLES' RETREAT

What a fabulous weekend this was! The couples' retreat was attended by 22 people plus Joan and Jenny, at Parramatta Parkroyal - a great venue with wonderful, friendly staff!

Friday night dinner at Table:30 was excellent, with great food and wine, and gave everyone a chance to meet. Breakfast on Saturday and Sunday went until quite late each morning as people lingered to chat and connect. It was a welcome change in routine for some, and the weather proved to be just lovely during the day, encouraging time outdoors, sightseeing and relaxation.

It was terrific to watch the enjoyment of our members catching up with old friends and making new ones, swapping stories and sharing problems, providing a great opportunity to make some very valuable connections and friendship supports. **Jenny Smith**



CLIENT SERVICES



MEET Ganesh!

Ganesh Kakani has joined us as our new Client Services Coordinator!

Ganesh has worked in community services sector for over 15 years, and in the disability sector both in Australia and New Zealand where he was responsible for overseeing Accommodation Services and Community Participation Programs. He is passionate about providing a nurturing and positive customer service experience and enjoys working with clients, their families and staff.

Ganesh enjoys Thai food (not too spicy!) likes fixing things around his home and also loves to spend time with his family at the park on weekends.

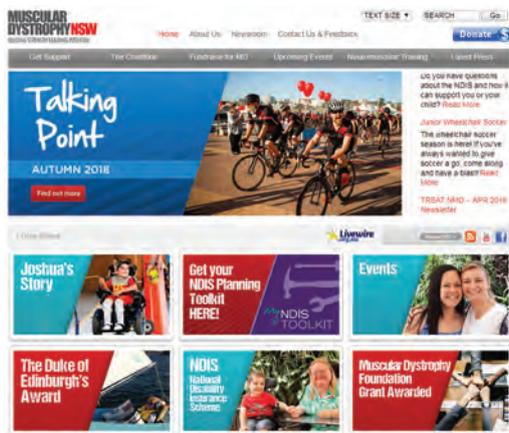
SURVEY RESULTS AND WEBSITE FUNDING

The recent client survey highlighted the need for us to update our website.

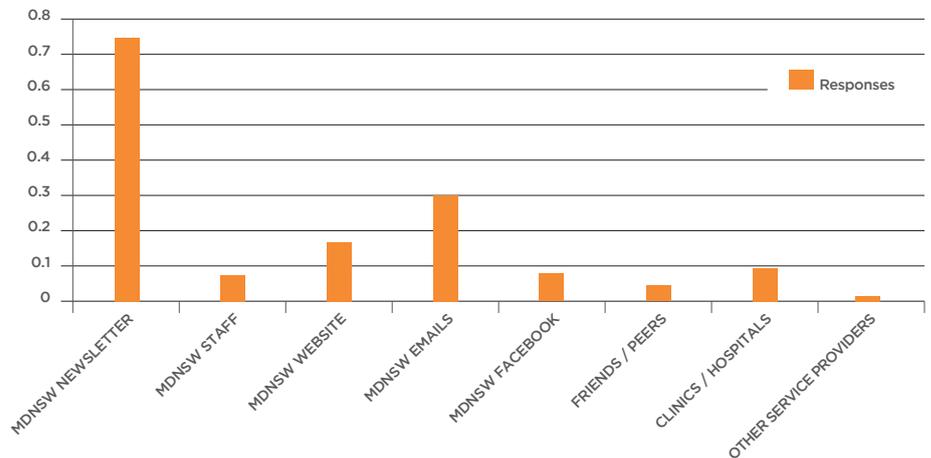
Two of the questions we asked were “Where do you mostly find out about what’s happening at MDNSW?” and “What suggestions can you make to improve the website?” Please see the graph and feedback received.

Your feedback helped us to achieve a government grant to develop the better website experience! Work will soon begin on making the website more user friendly and up to date with the latest information. Thank you to all those people that completed our survey, your feedback is making this happen!

What suggestions can you make to improve the website?



Where do you mostly find out about what’s happening at MDNSW?



- “More info on the latest trends and research (and clinical trials) from the USA and Europe.”
- “Needs redo, better navigation, more up to date”
- “None, I find it easy to use”
- “None, I think it is great.”
- “None, I think it is okay as it is”
- “Get Hospital website to link to MDNSW”
- “More info on research progress and interventions”
- “It is too cluttered - not a complaint - just too hard find things”
- “At this stage, our son is looking for are appropriate information on condition, promising trials, inspirational stories and health and lifestyle tips.”
- “Myotonic Dystrophy is under represented. Very little information on this condition”
- “It is a great website. I refer people to it all the time, especially staff to the training section-wonderful resource.”



SPINAL MUSCULAR ATROPHY DRUG SPINRAZA TO BE ADDED TO PHARMACEUTICAL BENEFITS SCHEME

The recent Pharmaceutical Benefits Advisory Committee (PBAC) made the decision to list SPINRAZA on the Pharmaceutical Benefits Scheme (PBS) for the treatment of paediatric patients (18 years and younger) with infantile onset or childhood onset of Spinal Muscular Atrophy (SMA). This will mean that from the listing date, eligible patients will only need to pay the standard PBS co payments for each injection. Patients would otherwise pay \$367,850 a year for this medicine. The PBS listing

will reduce the cost for patients to a maximum of \$39.50 per script for general patient, and \$6.40 for concessional patients. For all children with SMA type 1, type 2 and type 3a under the age of 18.

For more information please see the fact sheet included in this envelope and contact your doctor or **BIOGEN's Medical Information Department** on **1800 852 289**.



My Health Record

This year all Australians will have a My Health Record created for them, unless they choose not to. My Health Record is an individual's online summary of key health information and can be viewed safely and securely anywhere at any time.

Using My Health Record, individuals and their medical practitioners have access to information including shared health summaries, prescribed and dispensed medicines and hospital discharge summaries. My Health Record is particularly useful when travelling interstate, in an emergency or managing chronic conditions with multiple doctors.

Personally controlled settings allow the user to decide who has access to the information and what they see. My Health Record protects individual data using multi-layered safeguards

including encryption, firewalls and secure logins.

Individuals who choose to opt out can do so from 16 July to 15 October 2018. For more information, visit www.myhealthrecord.gov.au or call the helpline on 1800 723 471.

LINKS

www.myhealthrecord.gov.au/
www.myhealthrecord.gov.au/news/media-release-my-health-record-opt-out-date-announced

MY TRAVEL

HAWAII TRIP REVIEW

I went to Hawaii (Oahu) a few weeks ago and stayed at the Hilton Hawaiian village Waikiki.

The access around Hawaii itself was great with cut outs in all curbs and ramps into shops that had stairs. Medical equipment such as electric beds, hoists and shower commodes has to be hired from a medical equipment company. If an alternating air mattress is required a mattress an over lay is the only thing that can be provided in Hawaii for a reasonable price. The only full alternating air mattress was \$575 USD for the week as they would only hire it out for a minimum of one month.

The hotel had hoists around the pool but if non ambulant you have to be manually lifted onto the seat of the hoist or take the hotel room hoist you have hired to hoist onto pool hoist. Our room was in Tapa tower on the 3rd floor. The room we stayed in was a very large room that can cater for 6 people as it had 2 double beds and a double sofa bed. With enough room to add a single electric bed with those



other beds. The room had an accessible balcony with lots of room for a wheelchair. The bathroom was accessible under the sink and could get the commode in the shower and over the toilet. There was a bath in the room but this is not accessible.

To get to and from the airport we used Roberts Hawaii who said on their website the total weight of the wheelchair and user cannot exceed 226kg (500lbs) when it actually cannot exceed 362kg (800lbs). This is written on the lift of the coach.

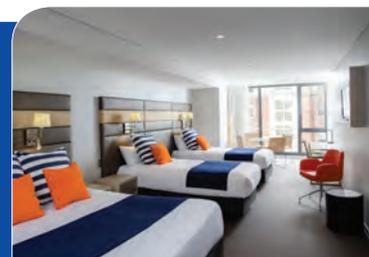
Scott Green



WHEELCHAIR ACCESSIBLE HOTEL *Novotel Newcastle*

Novotel Newcastle has 4 wheelchair accessible family rooms catering for up to 5 adults with the option of paying extra for an interconnecting room next door catering for 2 more adults. Dining table, sink and desk can fit wheelchair underneath, wide doors, power boards supplied if needed, low light switches, large bathroom and space under beds for hoists.

Scott Green 18yrs, MDNSW Member



Expressions of Interest

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YOUNG ADULTS Retreat

Fri 1 – Mon 4 Feb 2019

Join other young people aged 18-30 living with a neuromuscular condition

WHAT? We're organising a retreat that has a schedule of activities aimed at young adults, including...



- Day trip to Manly
- Live music, dinner and drinks at the Newport Arms
- Formal dinner party and DJ
- Bonfire with guest acoustic musician
- Swimming
- Much much more!

HOW MUCH?

Your NDIS funding will cover your accommodation, activities and equipment. We will provide trained carers and a nurse will be on camp. There will be a \$120 booking fee payable up front to hold your spot.

WHERE?

The Sydney Academy of Sport and Recreation, Narrabeen

WHAT YOU NEED TO DO

Ensure you have adequate funding in your NDIS plan. If you need advice or a quote, please don't hesitate to ask Jenny on **9888 5711** or at jenny.smith@mdnsw.org.au

We also want your input to make it an amazing experience for everyone who attends!

REGISTER YOUR INTEREST

Expressions of Interest strictly by 31st of August. If there are insufficient numbers the Young Adults Retreat will not be able to go ahead.

To register your interest or discuss the opportunities please contact Mitch on mitch.taylor@mdnsw.org.au or call **0458 026 532**

mdnsw.org.au



JAXON'S BALI... A WHEELCHAIR ACCESSIBLE HOLIDAY

When Jaxon Taylor went on holiday to Bali with his family he made a blog about the great time he had.

Jaxon especially highlights wheelchair accessibility while he was there. This is a great example of an accessible holiday a bit out of the ordinary for someone who uses a power drive chair. You can read Jaxon's full blog on the Have Wheelchair Will Travel website.

Hi, my name is Jaxon and I'm 11 years old and have Muscular Dystrophy. We flew with Garuda Airlines, it's around a 6 hour flight to Bali from Sydney. I transfer into a manual wheelchair provided by the airport and my electric wheelchair goes into Baggage along with our luggage. We arrived in Bali, and to my shock the Transport Guy my Mum had been given by a friend, didn't have a wheelchair van after all, and wanted to put my 180kg Wheelchair on his van roof with an Ocky strap. Needless to say thankfully this didn't happen and 5 Balinese men lifted my chair into a Milk Truck, and we knew from this moment "let's use Bali Access Travel again", that have a converted wheelchair van for the rest of the trip. We arrived at our resort "Legian Beach Resort", I had been here 4 years ago for my Cousins Wedding, but I forgot how beautiful it was. The whole resort has ramps and I loved buzzing about and checking it all out. We had a disabled room for the whole family, it wasn't huge but enough for me to get around and the bathroom was perfect. We could get a shower/toilet commode from Bali Access Travel too, which helps.



Our week was a whirlwind of great times, from swimming in the resort pool, to hanging at the Beach Bar, to listening to people sing at Restaurants, to experiencing a Balinese Traditional night of Food, fire and dancing, to shopping, and best of all having Breakfast with the Orangutan's, it was

truly one of the best holidays I've had. We even went to meet the people we were dropping the Beach wheelchair off too at Sanur and they had the best Disabled only Resort (Villa G at Ellora), that I hope we stay at next time now we know where it is.

They have a pool hoist, hoists, commodes and you can even get a carer if Mum and Dad want to go out. It would be our very own private place if we hired all three rooms. The owners were so lovely and helpful, I hope we go back there again, Sanur was beautiful. The water was very blue, and from what I saw it looked a little easier to get around the streets with my wheelchair too.



People are having photos with the orangutans one by one, when our number gets called up for the photographs. The photographer set us up in certain positions and got the Orangutan on my wheelchair! May I say that he loved my chair. Climbing all around my chair made the star of the show. Firstly, the orangutan started kissing the headrest of my wheelchair. Then, it started to PEE on my wheelchair. You heard that right, PEE. And that's why I now call orangutans "urinatatans".



Hope you enjoyed my little story, if you are like me and want to know if you can travel to places only in your Electric Chair, and not a manual chair it is doable. I struggle being in a manual chair cause I like having control of where I go, and I like just buzzing about in general. The streets of Legian where we were at, wasn't always perfectly accessible but the motorists and shop keepers on the road are always helpful to help you get to your destination, and we always worked it out in the end, with no drama.

Jaxon Taylor 11yrs, MDNSW Member



DUKE OF EDINBURGH AWARD NEWS SCOTT GREEN ACHIEVES SILVER!

As you may be aware the Duke of Edinburgh Award for young people with Muscular Dystrophy has three levels, Bronze, Silver, and

Gold. Within those levels it has four different sections to complete including Service, Physical Recreation, Skill and the Adventurous Journey.

We were thrilled to host Scott Green and his family at Lidcombe HQ to celebrate him achieving his Silver award!

Scott created a video raising awareness about bullying for his service section. He said "Victims of Bullying rarely speak about their experiences" and he hopes to encourage open discussion about bullying, so we can move towards more

support, understanding and inclusion.

Scotty wanted to supply fresh fruit and vegetables for his family so he sourced raised garden beds, set up and maintained a garden for the Physical recreation section of his Award.

Scotty also learned how to make online scrapbooks for the skills section and focused on documenting family holidays and his previous Duke of Ed Adventurous Journeys.

Finally, for his Silver Award Adventurous Journey Scott explored Auckland where he met the team at Muscular Dystrophy New Zealand. **Well done and congratulations Scott!**

30 SECONDS with Mitch Albert and his Mum Rachael

How did Mitch get involved with power wheelchair football?

Rachael: "I met Jo O'Brien at the MDNSW parents' retreat. They began talking, and Jo mentioned that Daniel was playing football. Mitch had a go in Daniel's chair for a game and he was hooked. He's played since that day. He loves it."

What team does Mitch play for?

Rachael: "Mitch participates in the monthly junior day to hone his skills. He also plays in division 2, and last season was asked to play for division 1 club Sydney FC - which Mitch was very excited about!"

When and where do you play Mitch?

"Every Saturday during the season at Kevin Betts stadium, Mt Druitt."

What's the best part of playing Power Wheelchair soccer?

Mitch: "Everything!"

Rachael: "Mitch is a competitive person by nature and football is a really good outlet for him. He loves being able to participate and not sit on the sidelines."

Has Mitch made any new friends playing sport?

Rachael: "He has made some great friends. A lot of

his friends that he plays football with also come to MDNSW's camps."

Have you got any aims to play at a higher level, such as for NSW or Australia?

Mitch: "I would love to one day play at a higher level. Maybe for NSW."

What would you say to someone who is thinking about playing football?

Mitch: "The competitiveness."

Rachael: "Go for it. Give it a go. You have nothing to lose. You can borrow chairs. It's so much fun. Anyone can play, girls and boys, of any age. The more people who get involved the better the competition will become."

From your point of view as a parent Rachael, what do you see as the benefits of Mitch playing sport?

"It gives Mitch a sense of being part of a team. Gives him something to look forward to on the weekend. He loves playing. He hates being a reserve or missing out playing because we have something on the weekend."



NATIONAL ELECTRIC WHEELCHAIR SPORTS } NEWS

The 33rd annual National Electric Wheelchair Sports (NEWS) competition was held in Narrabeen, Sydney from the 23rd-28th April. This unique event sees teams from around Australia, comprising solely of neuromuscular athletes who use a power wheelchair, competing in a round robin competition. This year saw four teams compete - the NSW Strikers, SA Scorpions, VIC Pride Warriors, and WA Western Wasps.

It was a ground breaking year for NEWS, with the introduction of a new sport known as Powerchair Hockey in addition to Balloon Soccer and Rugby League!

Balloon Soccer is a sport played with a large balloon on an indoor basketball court where players attempt to score goals with their head or wheelchair. This year was the final year of Balloon Soccer at NEWS, with the WA Western Wasps

securing the final championship trophy after an exciting grand final against the VIC Pride Warriors which saw the game go to extra time and a penalty shootout!

Rugby League is a modified version of touch rugby in which players pass the ball around by calling out the number of their team mates, subject to tackles by the opposing team. This year the NSW Strikers, for the 10th year in a row, took out the Rugby League championship after defeating Victoria!

The final sport, Powerchair Hockey, is a modified version of ice hockey. Players either use a stick or a t-stick attached to their wheelchair, to hit a plastic ball and score goals. Congratulations to the VIC Pride Warriors who defeated the NSW Strikers to take home the first ever Powerchair Hockey championship!



If you think this is something that you or your child may be interested in participating in, get in contact with your state electric wheelchair sport organisation listed below. It is a great opportunity to show your competitive spirit, work as a team, meet new friends and have fun! **Luke David**

New South Wales Organisation
ben.keyte@northcott.com.au

South Australian Organisation
admin@drssa.org.au

Victorian Electric Wheelchair Sports Association - info@vews.org.au

Western Electric Sporting Association
admin@wesawa.org

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

LIJ TAKES ON the City2Surf!

Elijah will be taking on this year's City2Surf in his manual wheelchair, powered by the strength of dad and his sister, he is raising funds for MDNSW!

You can support him by visiting his fundraising page via the link below!

We will be following his progress on Facebook so please share his story so others have the chance to support him as well. Yay, goooo LIJ!!

<https://city2surf2018.everydayhero.com/au/lij-takes-on-city2surf-for-muscular-dystrophy-nsw>



KAY'S DAY, Golf Day over \$1,400 raised!



Kay's daughter Vicki would like to share a few words from the day:

"In memory of our beautiful mum Kay, my Dad Reg and the golf ladies of Grafton Golf Club held their annual fund raiser "Kay's Day" for Muscular Dystrophy.

It was a perfect day, full of sunshine, love, champagne and lots of laughter.

We raised over \$1400 and the ladies all wore red and white. Mum was definitely with us on the day and would have been so proud of our Dad, just as our Family are"

Thank you to Reg and Vicki for organising such a wonderful event in memory of Kay and thank you to everyone who donated money, their time and goods to make this day once again, a beautiful success!

RYDE AUSSI MASTERS SWIM-A-THON JOINT FUNDRAISER over \$5,200 raised!

On Wednesday 16 May 2018 at Ryde Aquatic and Leisure Centre was all a buzz as Ryde Aussi Master Swim team swam 50m laps continuously in a relay format to raise money for MDNSW and to support the club.

Collectively, the members decide on a worthy cause to support each year that is close to their hearts. As some of their members family are affected or living with a neuromuscular condition, they chose MDNSW and we are so grateful for their support!

Muscular Dystrophy NSW was able to represent on the night with Louise calling out the laps as the swimmers came in and she also spoke on behalf of MDNSW on the night. Thank you once more to a great bunch of people who used their own strengths to help us to empower, connect and support those affected by a neuromuscular condition! **#LEGENDS**



contact us...

Call 02 9888 5711, email info@mdnsw.org.au or by post at:
MUSCULAR DYSTROPHY NSW 80 Betty Cuthbert Drive, Lidcombe NSW 2141

VERIFICATION AUDIT AGAINST THE NSW DISABILITY STANDARDS

We did it!

We passed our verification audit, which is a big deal. MDNSW is audited every few years to prove to our funders – in this case Ageing, Disability and Home Care (ADHC) – that we are providing quality programs and supports to our clients. Getting this tick of approval is a big relief. Hooray!

If you would like more information, please contact **Milvia Harder** at milvia.harder@mdnsw.org.au

Feedback and Complaints

We value your feedback!

If you have any feedback on what we are doing well or how we can do things better, please contact us.

Feedback, including complaints is an essential part of our improvement process.

You can provide your feedback through the following channels:

by post Muscular Dystrophy Association of NSW; 80 Betty Cuthbert Drive, Lidcombe NSW 2141

email feedback@mdnsw.org.au

phone 02 9888 5711 or **free call** 1800 635 109

website mdnsw.org.au/contact-us

NEUROMUSCULAR CLINICS

PAEDIATRIC

Sydney Children's Hospital Randwick
Neuromuscular Clinic

Call SCH for Outreach Clinic at:
Canberra Hospital, Canberra

9382 1845

Children's Hospital Westmead
Neuromuscular Clinic
Peripheral Neuropathy Management Clinic
Duchenne Monitoring Clinic

9845 1325

John Hunter Children's Hospital
Neuromuscular Clinic, Newcastle

4921 3932

ADULT

Prince of Wales Hospital Randwick
Nerve & Muscle Clinic
Chris Cormack - c.cormack@unsw.edu.au

0417 259 871

Westmead Hospital
Adult Genetics Clinic

8890 9780

Royal North Shore Hospital
Neuromuscular Clinic, St Leonards

9463 1833 or
9463 1866

Concord Hospital
Neuromuscular Clinic

9767 6864 or
9767 6129