

Talking Point

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER AUTUMN 2018



ANNUAL BIG RED RIDE RAISES \$57,000!

We were greeted with a spectacular morning at Bondi Beach for the start of the fifth annual Big Red Ride on 26 November 2017. The ride had been previously known for its “four seasons in one day” so, with no rain forecast, we were quietly hopeful that there wouldn’t be any particularly challenging weather conditions this year!

There was a collective cheer as the starter horn was blown by Deputy Mayor of Waverley, Councillor Dominic Wy Kanak. Morning joggers and dog walkers stopped to gawk at the 67-strong wave of red and black jerseys as they cycled out of Bondi.

Heading into late morning, the heat started to climb, but you could see it in the faces of our riders that it was all worth it when they were greeted with a rousing reception on approach to Richmond Park. A sea of Little Red Riders, friends and families celebrated the completion of the 85-kilometre leg, with fantastic catering from Rotary and food being donated by Aldi Richmond, Pace Farms and Riverview Produce – Fruit and Veg.

Those who chose to go on to Katoomba and complete the 150 kilometres jumped on their bikes and prepared for an even bigger challenge. As the Big Red Ride is a charity ride rather than a race, we celebrated its five-year anniversary by introducing the “Hawkesbury Heights King of the Mountain Challenge”, which resulted in Oliver Graham taking out the King of the Mountain and Michelle Williams being crowned Queen!

The day was a great success, and a total of **\$56,598.88** was raised!

Muscular Dystrophy NSW also had compelling media coverage with the Channel 9 News weather showcasing Big Red Ride footage and the Manly Daily printing a story on the FBETS team and their involvement in the Big Red Ride. We’d like to send a massive thank you out to all the riders and make special mention to the ongoing support of the FBETS and GACT teams as well as the Little Red Ride Team who raised \$7980 this year.

Thank you to our dignitaries, Councillor Dominic Wy Kanak – Deputy Mayor and Councillor Sally Betts from Waverley Council, Councillor Peter Reynolds from Hawkesbury City Council, and Councillor Mark Green Hill – Mayor of Blue Mountains City Council, for attending and participating in such a wonderful occasion for such a valuable cause, and thank you to Peter Debnam – Muscular Dystrophy NSW’s Chairman!

THANK YOU!

- Rotary, for once again providing catering at both Richmond and Katoomba
- Ben and Kylie Mildren from Mildren Events
- Alison Maher, event organiser extraordinaire!
- Lush catering for a wonderful breakfast
- Little Red Ride organiser Carolyn, Siobhan Reader, Imojean Best and Carl Neil
- Giles & Annouchka and the use of their beautiful house in Katoomba
- And everyone who donated their valuable time and funds – we just couldn’t do it without you!



EDITORIAL

HELLO EVERYONE, AND WELCOME TO THE FIRST OF THREE EDITIONS OF TALKING POINT FOR 2018! I HOPE TO COVER THE IMPORTANT CHANGES WE ARE FACING IN 2018 AND ONWARDS.

2018 is set to be a very exciting yet challenging year for Muscular Dystrophy NSW (MDNSW). As the end of this financial year approaches,

MDNSW is preparing for big changes in the way we are funded to provide services to those in NSW affected by neuromuscular conditions.

As you may be aware, from July 2018 we will no longer receive any block funding from the Department of Family and Community Services – Ageing, Disability and Home Care. We may no longer have access to the government funding that currently supports our information, advocacy and referral service, as well as funding for our much loved and extremely popular camps and retreats. From July 2018, we will rely on income from the individual National Disability Insurance Scheme (NDIS) plans to provide access to these programs and supports.

We are continuing to look at new ways to continue to provide all of our services, but it is important for you to note that from July 2018 funding for our camps will need to come from your child's NDIS plan. This means that you need to ensure that their plan includes the funding for this cost. If you need support to ensure that your child can attend future MDNSW camps via their NDIS plan, please get in touch with our Client Services team! Email info@mdnsw.org.au or call 9888 5711.

Please also remember that MDNSW is a specialist provider of Support Coordination via the NDIS, so please let our Client Services team know if you would like us to provide this support for you or the person you care for. It is in all our interests that MDNSW provides support coordination for as many of our members as possible.

So, as you can see, changes are coming in 2018 and we promise to keep you informed along the way as we continue to evolve our services under the NDIS.

Towards the end of 2017, we ran a member consultation session here at our Lidcombe office and we've listened to your feedback. This year we are working to improve the way we communicate with you via Talking Point, social media and making improvements to our website so that finding information about our services will be much easier.

We have developed some helpful FREE resources, such as our NDIS Planning Toolkit, which can be used to prepare for NDIS planning sessions and plan reviews.

We have also developed a NEW set of fact sheets that you can access online. These fact sheets will help educate your Local Area Coordinators on your condition and provide information on the kind of supports you may require in your NDIS plan. We hope these resources will assist you to get more of the supports you need.

We can't wait to see what else 2018 brings as we continue to make our way through the NDIS transition and we look forward to keeping you informed along the way. Whilst the NDIS will be the main source of funding, we are looking for help to promote fundraising and to stimulate support through donations. If you can help in these areas, please let us know by emailing fundraising@mdnsw.org.au

Thank you to everyone who has helped support our work by attending our community events and by fundraising.

I hope you enjoy this issue of Talking Point!

CHARLOTTE SANGSTER

General Manager, Muscular Dystrophy NSW



New!

Visit our website to view your brand new, downloadable fact sheets that have been specifically developed to help educate the NDIS on your condition and support needs during your planning.

www.mdnsw.org.au/NDIS

2017 Camp Kula N' Gadu

"I don't want to go home. I am so sad we have to leave camp."

Jamieson



This year, 43 kids came to Camp Kula N Gadu held at the Sydney Academy of Sport and Recreation, Narrabeen. We enjoyed some wonderful activities such as laser tag, swimming, orienteering, NERF wars and much, much more. But I think the most fun was just hanging out with the kids laughing and enjoying each other's company.

The atmosphere of the camp is really special. I think it's best described as a party-festival vibe. It's like nothing else I've experienced.

The commitment and effort put in by the return carers is truly amazing. For those volunteers who return year after year, simply saying "thanks" just does not suffice. Words cannot convey my heartfelt admiration and appreciation to them all. Their joy and passion for camp is something money just can't buy.

If you would like to get involved, please get in touch as soon as possible. You can email Jenny at jenny.smith@mdnsw.org.au or myself, Mitch at mitch.taylor@mdnsw.org.au, or call **9888 5711** or **1800 635 109**.

"I loved the NERF games - it was the best day ever."

Joshua

"Camp has gone so fast, I wish we could stay longer."

Kieran

"Is this on every year? I'm going to come back!"

Fletcher

"This is awesome, I am awesome, you are awesome and we are awesome!"

Anwen

"Great, great, great and great!"

Lauren

"Make it longer."

Ryan
(talking about camp)

"Look at me. I haven't done this in 6 years!"

Abigail
(swimming)



RICHARD'S DUKE OF EDINBURGH ADVENTUROUS JOURNEY

In December 2017 Richard Ly embarked on his Gold Award adventurous journey as part of his participation in the Duke of Edinburgh Award for young people with Muscular Dystrophy.

Richard's main aims were to volunteer in environmental clean-ups, study Aboriginal engravings, learn about Aboriginal culture and study birds in their habitat.



"This trip was a great experience for me to have with my team, and we formed a great bond together which I am grateful for. I was anxious before this trip, everything was planned out well and was worried if our plan had to be changed; we however were able to adapt to the change and the rest of our schedule was well played out. I was happy overall to learn about new and different things in the Royal National Park such as the plants, birds and Aboriginal art. We should never be afraid to push ourselves, because we would never know how far we can go if we never tried; that is why I encourage more people to do a journey like this. It is a worthwhile experience that I will definitely remember for a long time and sharing this experience with a team forms that strong bond."

Congratulations, Richard, on completing your adventurous journey – from all the team here at MDNSW!

For a full transcript of Richard's adventurous journey and to find out about signing up, please visit the Duke of Edinburgh's Award page on our website, www.mdnsw.org.au

MEL TRAN'S LAUREATE GLOBAL FELLOWSHIP PARTICIPATION IN SPAIN



Melanie Tran is a recipient of the Young Achiever Award and the Duke of Edinburgh's International Bronze, Silver and Gold Award which she completed through the program offered

by Muscular dystrophy NSW. She is currently studying a Bachelor of Digital Media with a Major in Interactive design at Billy Blue College of Design, and also works at Ability Mate and Hire Up as a user Experience (UX) designer. For someone so young she sure has a stack of wonderful achievements under her belt!

In 2017 she was selected as a Laureate Global Fellow. This fellowship supports young leaders who are working with social ventures that are transforming how age-old challenges are addressed in their own communities and countries. Each year, 20 young people are brought together from around the world. They are not only given the opportunity to join the global network of social entrepreneurs, but also learn the qualities of being

extraordinary young leaders and how to continue making positive change with social ventures through a week-long intensive leadership training program in Spain.

On talking about her experience at the fellowship Mel said...

"It's an absolute honor to be selected as one of the 2017 fellows and to be representing Australia in youth leadership and social entrepreneurship. The fellowship kicked off with an eight-day in-person retreat in Madrid, followed by a year of support from mentors to help the continual growth and development of our social venture and leadership skills."

You can find out much more by reading Mel's full blogs...

Part 1. The Laureate Global Fellowship

www.abilitymate.com/trueblog/2017/11/2/blog-series-part-i-laureate-global-fellowship-2017

Part 2. Accessibility in Dubai and Spain

www.abilitymate.com/trueblog/2017/11/6/blog-series-part-ii-accessibility-in-spain-dubai-1

THE 2017 MDNSW ANNUAL NEUROMUSCULAR AND RESEARCH SEMINAR

Held at the Figtree Convention centre on Saturday 11th November 2017, the seminar was attended by a large audience and was enjoyed by all.

You can watch three of the talks below by visiting our website, www.mdnsw.org.au

Rob Oakley - *Living Life with Muscular Dystrophy* Rob represented Australia in equestrian at the 2012 Summer Paralympics.

<http://mdnsw.org.au/rob-oakley-everyday-life-with-muscular-dystrophy>

Heather Best - *MDNSW PhD Scholar* Presented on 'Identification of new genetic mechanism of muscle disease'. Heather is the current MDNSW PhD Scholar.

<http://mdnsw.org.au/heather-best-identifying-a-new-genetic-mechanism-of-muscle-disease>



Amanda J Piper - *BAppSc MEd PhD* Presented on breathing problems in neuromuscular disorders. Amanda is a senior physiotherapist and Manager. She works at the Home Ventilation Service and Royal Prince Alfred Hospital. She has been involved in the care of people with respiratory muscle weakness for more than 26 years, and is recognised nationally and internationally for her expertise in assisted breathing techniques.

<http://mdnsw.org.au/associate-prof-amanda-piper-breathing-problems-in-neuromuscular-disorders>

SPORTS UPDATE

2018 APFA CLUB Championships



The 2018 Australian Power chair Football Club Championships were played at Kevin Betts Stadium, Mt Druitt, over six days in mid-January. Power chair football (or soccer) is exploding in popularity across the country, and the Club Championship had two new clubs participating from Adelaide and Perth – testament to the boom the sport is going through.

Eight teams participated, including Western Sydney Wanderers, Perth Glory, Brisbane Roar, Melbourne City, Newcastle Jets, Central Coast Mariners, Sydney FC and Adelaide United.

Congratulations to Brisbane Roar, who were crowned the 2018 APFA Club Champions after defeating the Western Sydney Wanderers team 2-1 in the final. It was a game worthy of a decider, with both teams fighting tooth and nail in an exciting display of power chair football. The 2017 reigning premiers, the Newcastle Jets, claimed third place after beating Sydney FC in another free-flowing match.

MDNSW members were represented in the following teams...

Newcastle Jets: Nick Nguyen, James Kim and Chris Hastas

Sydney FC: Jye Mokluk, James Kim and Jordan Crane

Central Coast Mariners: Kristie McCarthy, Chris Holmes, Chris Suffield and Jake Vidovic

Western Sydney Wanderers: Alex Schollard

Congratulations to all the players, volunteers and families for being part of these Championships.

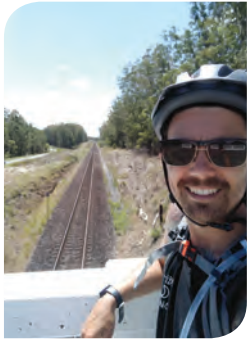
For more information and photos go to...

www.facebook.com/NSWPFA/

www.pbase.com/wrs864/powerchair_football_teams_nationals_2018

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

PEDALLING FOR MD, Matt's Story \$8,000 raised!



"Harley and I promised that we would always be in riding distance of each other's house. At age 12 Harley was diagnosed with Muscular Dystrophy and unfortunately I'd lost contact with Harley and believed in my mid 20's that I would not get to see him again ... but this was not the case! After a fortunate chain of events, I located Harley. Based on the promise that we had made all those years ago, I plan to ride

my bike from my home on the Gold Coast to his home in Newcastle and re-unite with him, this November. I am no "cyclist" but I am training hard to meet the challenge. Please support my journey by hitting the donate button and please share my story with as many people as you can and together let's help Muscular Dystrophy NSW continue to support people living with a neuromuscular condition and provide an improved quality of life, through their amazing programs." Matthew Rogers

Here at Muscular Dystrophy NSW, we work hard every day to see people **"build strength and reach their potential"**, and one of our supporters Matt Rodgers lives these values too. In November he proved that, by pushing himself way outside of his comfort zone when he hit the road for an epic bike ride from the Gold Coast to Newcastle to raise much needed funds to help improve the quality of life for people living with Muscular Dystrophy. Supported by many of his generous friends and admirers he managed to raise over **\$8,000**, and we think that's pretty impressive. Thanks Matt!

You can read up on Matt's ride and personally thank him on his campaign Facebook page...

<https://www.facebook.com/PeddlingforMD/>



PEEL HIGH SCHOOL, Coffs Harbour \$3,500 raised!



Every year, Year 12 at Peel High School collectively decide on a charity to fundraise for, and last year the class of 2017 chose Muscular Dystrophy NSW. The students worked tirelessly to raise funds through various activities including Bunnings bake sales, a Bunnings BBQ, a Bunnings car wash, sports carnival barbecues and selling chocolates in support of Muscular Dystrophy NSW. In total they raised **\$3,500** to help support Muscular Dystrophy NSW's programs and services. This is an awesome effort and we are so grateful for the support. From the pictures it looks like a lot of fun was had. Thanks guys!

ELDERTON HOMES \$4,300 raised!

Elderton Homes raised **\$4,300** at its annual contractors' party, held at Rosehill Gardens Racecourse on 2 December 2017, and was attended by over 170 people! This was the second year that they have provided monetary support to Muscular Dystrophy NSW. Word on the street is that they are super keen to get a team together for this year's Big Red Ride... so watch this space! Thanks again Elderton Homes! You ROCK.



We love to see people challenging themselves, be it physically, mentally or facing their fears! So if there's something you've been waiting for an excuse to do, then why not do it for MD! It's easy to create a fundraising page, and we'd love to hear about how you would like to build strength and reach potential too.

Please email fundraising@mdnsw.org.au **Go on! We dare you!** Just tell your mates that MD made you do it ;)

TO OUR VOLUNTEERS...

We'd also love to acknowledge all the wonderful volunteers who have helped us - in the office, at our camps, and supporting our events like the Big Red Ride. A big thanks to Rotary for their ongoing support of the Big Red Ride.

We really couldn't do it without you!



CAZ'S LITTLE RED RIDE

The Little Red Ride was held at Richmond Park for its fourth year, thanks mostly to Carolyn Campbell-McLean. Carolyn volunteers her time and has been the driving force behind the Little Red Ride. During the speeches Peter Debnam, Chairman of MDNSW aptly described Carolyn as "a force of nature". Her efforts have raised thousands of dollars over the years the event has run and contributed enormously to the atmosphere of the day.

In the beginning, Carolyn wanted to support MDNSW and be a part of the Big Red Ride, so she organised...the Little Big Red Ride! The event's aim was to get as many MDNSW members and their families as possible to get involved and fundraise. Carolyn said:

'It's really important that the riders meet with the kids, adults and families, as it reminds them of just why they are supporting us. It's a great opportunity to put on a fun event with our families who get so much from connecting with each other.'

This year there was an obstacle and slalom course for the Little Red Riders to complete. There was stiff competition from the youngsters with new wheelchairs and some of their brothers and sisters on scooters and bikes. The Little Red Riders then cheered in all the Big Red Ride cyclists who had ridden their bikes from Bondi.

This year's Little Red Ride raised **\$7,980**. Special mention goes to Jaxon Taylor, who raised **\$1,654.10**. Well done Carolyn and everyone involved!



Sat 14 - Wed 18 Apr, 2018

Adventure Camp



Join us for
 a unique
 adventure of
 a lifetime!

Contact Jenny on
 9888 5711 or jenny.smith@mdnsw.org.au

PLACES ARE STRICTLY LIMITED

Sat 16 - Wed 20 Dec, 2018

Camp Kula N' Gadu



Find out why kids keep coming
 back year after year!

Sydney Academy of Sport

Contact Mitch on 0458 026 532
 or mitch.taylor@mdnsw.org.au

Camp Funding and the NDIS

If you are in the process of getting ready for your first planning meeting or preparing for your plan review, we can provide you with a quote for camp so you can request the funding needed.

There have been some recent rate changes to camp funding initiated by the NDIS. Please contact us for a quote for this year's camp so we can ensure you have the right funding in your NDIS plan.

If you are unsure about any part of the process please contact us at any time.

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

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



STARTING 22ND APRIL, 2018

JUNIOR WHEELCHAIR SOCCER

**AT VALENTINE SPORTS PARK
235-257 Meurants Lane,
GLENWOOD NSW**

Registration cost for Season: \$10

2018 Season Dates

**Starting Sunday 22ND April
at 1:30pm**

**Saturday 5TH May
11:00am to 12:30pm**

**Sunday 3RD June
11:00am to 12:30pm**

**Sunday 1ST July
10:30am to 11:30pm**

**Saturday 14TH July
11:00am to 12:30pm**

**Sunday 5TH August
11:00am to 12:30pm**

AND MORE...

Contact: Lija Taylor

Email: Lta89302@bigpond.net.au

Phone: 0425 310 600

*Please note:
Division 2 games are weekly*

2017 Memberships Renewal Reminder

Just a reminder to those who have yet to renew membership for 2017. Currently we have 100 or so people who renewed with us in 2016 but have yet to do so in 2017 and with another year just around the corner we'd love for you to update your details with us!

Payment of membership fees is not a requirement to access our programs and services however we greatly appreciate your financial support.

You can renew your membership in moments online by visiting www.mdnsw.org.au and clicking the blue "Donate" button in right hand corner. In the 'What would you like to donate' field, please use the drop down and select one of the 'Membership' options to make your renewal payment of \$22.

If you would like to learn more about other ways to renew or to discuss membership, please contact us on **02 9888 5711**.

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

Prince of Wales Hospital Randwick

Nerve & Muscle Clinic

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

0417 259 871

Westmead Hospital

Adult Genetics Clinic

9845 3273

Royal North Shore Hospital

Neuromuscular Clinic, St Leonards

9463 1866

Concord Hospital

Neuromuscular Clinic

9767 6864 or
9767 6129