

# Talking Point

**MUSCULAR  
DYSTROPHY**  
**NSW** BUILDING STRENGTH  
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER SUMMER 2018



## SUGAR FREE SEPTEMBER RAISES \$52,000!

*Tony Real with Rebecca Martin & Ashleigh Shell from the Real Warriors*

Congratulations to everyone who **cut out sugar** and participated in Sugar Free September for 2018!

The goal was set high at **\$50,000** and this year as a team we **SMASHED IT**, collectively raising **\$52,317.91**

Muscular Dystrophy NSW is overwhelmed with the positive response to Sugar Free September and your support this year. The money raised will help MDNSW to continue to provide programs and services that empower, support and connect people within the neuromuscular community.

Topping the leader board are teams **Sugar Free For Connor, Sweet Enough Without Sugar and Sugar Free For Jamieson** and our top individuals were **Nathan Teong, Kristi Jones and Vanessa Huron!!**

During the challenge Ripples Leisure & Hydrotherapy

Centre participated in support of their client and friend Tony Real who is living with FSHD. They raised **\$1499** during the challenge and also hosted a BBQ fundraiser on the 13th October. They then raised a further **\$900** in support of Muscular Dystrophy NSW!

We'd like to thank everyone for your enthusiastic participation in Sugar Free September and if you'd like to register your interest for the 2019 challenge please go to <https://bit.ly/2pRnDht>

Please contact us if you'd like to host a fundraising event as well on 02 8986 9006, we'd love to hear all about your plans.

**Thanks again to everyone who participated and we hope to see you again next year!**



## EDITORIAL

WELCOME TO THE LATEST EDITION OF TALKING POINT.

### CAN YOU BELIEVE IT'S ALMOST THE END OF THE YEAR? AND WHAT AN INCREDIBLE YEAR IT HAS BEEN!

As you may know, July 2018 saw the completion of the roll out of the NDIS in NSW. To ensure that MDNSW stays current with the changes and challenges in the sector we have updated our organisational vision, mission and values which speak to the new world we operate in and communicate even more clearly the vision we have for the future.

**Vision.** "Every person with a neuromuscular condition is able to live the life they choose"

**Mission.** "To empower, connect and support people with neuromuscular conditions, and be an effective advocate for the neuromuscular community"

**Values.** Empowerment, Responsiveness, Integrity, Respect, Partnerships, Teamwork

We have also introduced our 2018 – 2020 Strategic Plan which comprises of 5 key areas of focus moving forward:

#### Goal 1. Independence and Capacity Building

Empower and support people affected by neuromuscular conditions to build their capacity and independence.

#### Goal 2. Connection

Facilitate better connections for people with neuromuscular conditions, their families and carers – with each other, to their communities and to the services and supports they choose.

#### Goal 3. Knowledge and Awareness

Build knowledge and awareness of neuromuscular conditions, and become a leading neuromuscular

knowledge hub.

#### Goal 4. Advocacy

Be a strong and effective advocate for people with neuromuscular conditions.

#### Goal 5. Organisational Sustainability

Place MDNSW on a sustainable footing.

**These 5 overarching goals will guide all that we do over the next three years ensuring that Muscular Dystrophy NSW can continue to serve the community for many years to come. We hope that you will continue on this journey with us.**

Thank you so much for your support and please enjoy this edition of Talking Point!

*\*If you have any feedback or suggestions on ways that we can improve Talking Point for future editions please let us know by calling 02 9888 5711 or emailing info@mdnsw.org.au*

CHARLOTTE SANGSTER

General Manager, Muscular Dystrophy NSW

## FOCUS ON ABILITY FILM FESTIVAL

The late Peter Dalrymple has left a beautiful legacy in the form of his short film "Mind over Muscle". In the film Pete explores the importance of focusing on the one thing he could control – his mind.

"Although physically his body was deteriorating, Pete was still very mentally strong and he was all about trying to portray a positive attitude for himself, as well as his family and the people who supported him." Pete's friend Ben Keyte said.

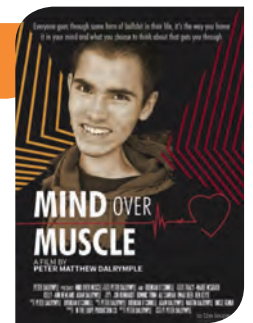
"This was so inspiring not just because he was my son but the vision he had to leave his legacy to help others was of great comfort." Peter's mum Margaret said.

The film premiered at the Riverside Theatre in

Parramatta and also opened the Focus on Ability Short Film Festival and is an emotional and touching tribute to Peter's contribution to the community. 297 films were entered in the short film festival with "Mind over Muscle" making it to the top 4 open entrants for most online votes. An incredible achievement!

We encourage you to watch and share this wonderful film to continue to raise awareness for Muscular Dystrophy to those within our community and abroad.

<https://www.focusonability.com.au/FOA/films/1539.html>



## IN MEMORY OF PERCIVAL ALWYN BAPTISTE



Percy was involved with MDNSW for many years before he came onto the board and served 12 years as a Director. His passion and support for National Electric Wheelchair Sport (N.E.W.S) was unwavering. Percy was instrumental in fundraising for the annual National Games and was highly active in the day-to-day running of N.E.W.S. Our condolences go out to the Baptiste family, Percy will always be remembered in our hearts.



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!



**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](mailto:mitch.taylor@mdnsw.org.au) or on **0458 026 532**, or Jenny at [jenny.smith@mdnsw.org.au](mailto: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>



[mdnsw.org.au](http://mdnsw.org.au)



**MUSCULAR DYSTROPHY NSW** BUILDING STRENGTH REACHING POTENTIAL

# Events 2018

## Sydney Christmas Party

**A FREE event for the whole family!**  
 Santa | Balloon Twister | Art & Craft  
 Face Painting | BBQ Lunch | Table Tennis

**Sat 1 Dec**  
**11.30am - 3.30pm**



Hosted by the team at CBA Direct Banking Sydney

**Function Room & Gardens Commonwealth Bank Australia**  
 Level 6, 150 George St, Parramatta  
 Enter building via Charles Street.

✓ Free parking  
 ✓ Fully accessible

All children under 12yrs who RSVP before the due date will receive a present from Santa.

Proudly supported by the **Commonwealth Bank**

**RSVP** by 5 November to: [maralyn.mccann@mdnsw.org.au](mailto:maralyn.mccann@mdnsw.org.au) or call Maralyn on 9888 5711 ext.5

[mdnsw.org.au](http://mdnsw.org.au)



**MUSCULAR DYSTROPHY NSW** BUILDING STRENGTH REACHING POTENTIAL

# Expressions of Interest

## 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

**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](mailto:mitch.taylor@mdnsw.org.au) or call **0458 026 532**

**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](mailto:jenny.smith@mdnsw.org.au)  
 We also want your input to make it an amazing experience for everyone who attends!

[mdnsw.org.au](http://mdnsw.org.au)



Join us for a unique adventure of a lifetime!

**MUSCULAR DYSTROPHY NSW** BUILDING STRENGTH REACHING POTENTIAL

# Adventure Camp 2019

**Sydney Academy of Sport & Recreation Narrabeen** **Wed 24 - Sun 28 April, 2019**

**WHAT?**  
 Campers will be grouped according to their age and gender and will be looked after by experienced carers who have attended our camps before. There are a variety of activities to choose from that suit all ages, personalities and abilities.




**Laser Tag • Beach Day • Taronga Zoo • Manly • Swimming and MUCH MUCH more!**

**WHO CAN COME?**  
 Our Adventure Camp caters for those with a neuromuscular condition who would benefit from trying new things and meeting new people. It is open to young people **6-18 years** who have some level of independent mobility.

**HOW MUCH WILL YOU PAY**  
**\$120** this is an administration fee paid by you and is not covered in your NDIS package.

**NDIS FUNDING**  
 MDNSW will no longer receive government funding to run our camp program and will now rely solely on funding through each camper's NDIS plan. Please review your plan now to ensure there is sufficient funding allocated in the CORE supports area of your plan to pay for camp. 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.  
 The cost of the camp will come from your NDIS plan in the CORE supports area.  
 Please contact us if you're unsure if you have funding for camp in your plan.

**WANT TO REGISTER FOR CAMP OR FIND OUT MORE INFORMATION?**  
 Contact Jenny at Muscular Dystrophy NSW on **9888 5711 (option 3)** or [jenny.smith@mdnsw.org.au](mailto:jenny.smith@mdnsw.org.au)  
*The camp is very popular and places are strictly limited, so RSVP early to better your chances of going!*

[mdnsw.org.au](http://mdnsw.org.au)

# JYE DONKIN IS AWARDED BRONZE DUKE OF EDINBURGH AWARD

Congratulations to MDNSW member Jye Donkin who was awarded his Bronze Duke of Edinburgh Award recently. Mitch caught up with Jye and asked him about his experience.



**How long did it take you to complete the bronze award?**

*"I took about 4-5 years from 2012-2017 to complete my Bronze award. It took this long as I also wanted to focus on my year 11 and 12 education as well as my university studies during that time"*

**What did you get gain from the experience?**

*"I enjoyed it! I developed and learnt new skills and was able to express myself in different ways. I made new friends too and developed more social skills. I also gained more confidence in myself."*

**What would you say to someone interested in doing the award?**

*"Do it! You can learn new or further develop life skills, social skills and skills in your areas of interest. You will also create new relationships with different people."*



## TODAY SHOW MEETS GEORGE AND HIS ADAPTED RIDE-ON CAR FUNDED BY MDNSW

It is well known that power mobility use can be beneficial in children as young as 18 to 20 months old but current options (such as power wheelchairs) are very expensive, heavy and bulky in child-sized environments. They also limit eye-to-eye interaction with children their own age.



George and his new car!



Over the past year MDNSW has sponsored the purchase of five ride on cars for children that were modified by Technical Aid to the Disabled (TAD) to allow the children to control the car

using a joystick, like those used in a power drive wheelchair.

contacted TAD, who came to our home to conduct an assessment. They then sourced and adapted a car that was appropriate for George's needs. George currently mobilises using a walking frame, but he is not able to use it on the grass. The biggest impact the car has had for George is that it allows him to independently play on the grass for the first time. The car has speakers that play his favourite music while he's driving, which makes it extra fun. He enjoys sharing the car with his cousins and friends. It's also a fantastic training tool, such that when he finally does get a power wheelchair, he will be familiar with using a joystick to move. Many thanks to MDNSW for funding the car for George!"

Our clients George and Noah were recently stars of the TODAY show! Check out the story at <https://bit.ly/2Nie2K4>

We spoke to George's dad about how this came about and the impact of the car on George's life...

*"We were referred to TAD (who adapt the cars) by Helena Young, who is the Occupational Therapy at the neuromuscular clinic at Westmead Children's Hospital. Following Helena's recommendation our key worker*

This was only possible through the generous support of our donors, in particular please join us in thanking Vladimir, Irina, Marival and Alex D'jamirze who helped make this happen!



## ONLINE COMMUNITIES

# Your Community

For years there has been a lack of a place to find quality, comprehensive and relevant online information about health, lifestyle, community and well-being for people with neuromuscular conditions.

Not anymore! The wonderful news is that we were successful in securing an NDIA Information, Linkages and Capacity Building grant and we plan to refresh your website and create a one stop shop of easy to find information as well as build online peer communities for people with NMCs.

Clients and members love MDNSW's camps and retreats, and want to find other ways to connect between events. We think the online community will help keep people connecting and supporting

each other. It's also a great way for people in regional parts of NSW to come together remotely.

### How can you get involved?

Many of you will have received an online survey in the past month with questions about how you feel about the website and online communities. We would love to hear your ideas. We want this to be YOUR community.

The more people who participate in your community, the better it will be. So to start with, we need you to share stories with us, write to us, make a video or simply tell your friends about it.

Our lived experience is so powerful, and we know that people with NMCs have so much to share with

each other. Our goal is to create an online space for our community to come together, meet, chat, share stories and advice from others who share the NMC journey.

Please help us to build your community and get in touch today by emailing [info@mdnsw.org.au](mailto:info@mdnsw.org.au) or call us on **1800 635 109**

**Carolyn Campbell-McLean and Milvia Harder**

*Project Officers*



## SCHOLARSHIP OPPORTUNITIES FOR

# STUDENTS WITH A DISABILITY

**Wendy Hall Scholarship** - Two Wendy Hall Scholarships are offered annually to support NSW students with disability access accredited further education such as TAFE and university. The scholarships can be used to pay for expenses like text books, library and internet charges, on campus accommodation, transport, stationery, computer equipment, personal care and other related expenses.

**Thomas Hepburn Lennox Scholarship** - The Thomas Hepburn Lennox Scholarship is open to TAFE or university students who have a physical disability and are present or past Northcott customers. The scholarship assists with expenses such as textbooks, accommodation, field trips, stationery and university travel.

**Gregory and Dolores Farrell Scholarship** - The Gregory and Dolores Farrell Scholarships are administered by the SpineCare Foundation and are open to students who use a wheelchair for mobility.

For more information on these three scholarships, go to <https://northcott.com.au/service/scholarship-opportunities/>

**The good universities guide** - This site is great for comparing courses offered at different Educational institutions. It also allows you to do a scholarship search based on your area of study.

<https://www.gooduniversitiesguide.com.au/>

**Young Carer Bursary Program** - The Department of Social Services (DSS) offers a Young Carers Bursary Program, which is an annual initiative to support young carers aged 12-25 to engage in education by awarding \$3,000 in scholarships. This past year, the initiative awarded over 340 young carers with a bursary.

For more information about this program, visit the website at <http://youngcarers.net.au/young-carer-bursary-program>

**Youngcare's At Home Care Grants** - Youngcare's At Home Care Grants program is critical in keeping young people at home with their families, and preventing new admissions to inappropriate housing. Youngcare's At Home Care Grants (AHCG) provide funding for equipment, home modifications and essential support/respite to enhance the quality of life for young people with high care needs and their carers. The grants provide one-off funding between \$2,000 and \$10,000 to help those aged 18-65 with high care needs who are living at home, and are at risk of entering inappropriate housing.

**Top tip...** individuals with or without NDIS funding CAN apply! <https://www.youngcare.com.au/>

# AUSTRALIAN FIRST: FSHD INFANTILE GRANT RECRUITS FOR STUDY

Researchers at The Royal Children's Hospital in Melbourne, Australia are looking for children aged 5-18 years who have been diagnosed with FSHD, to participate in one or both of these two studies. The Royal Children's Hospital and researchers would be really interested in hearing from anyone in the Australian FSHD community who meets the criteria.

**WHO?** Researchers at The Royal Children's Hospital are looking for children aged 5-18 years who have been diagnosed with FSHD, to participate in one or both of the studies...

1. The effect of the nutritional supplement (creatine monohydrate) on strength and muscle mass in children and young adults with FSHD

2. Investigating the use of FSHD specific patient reported and physical performance assessments to measure strength and function in children with FSHD.



**WHAT?** The creatine study involves 5 visits over an 8 month period and requires your child to drink a supplement in a glass of milk each day. We will assess strength and function to see if taking the supplement has any effect.

The assessment arm of the study requires two visits 2-4 weeks apart. These will be done in conjunction with the creatine study and will not require any extra time if you choose to participate in both research studies.

Recruitment of participants has begun at The Royal Children's Hospital and researchers would be really interested in hearing from anyone in the Australian FSHD community who meets the criteria.

**WHO TO CONTACT?**

If you would like more details about the research, please contact...

**Katy de Valle**  
Neuromuscular Research  
Physiotherapist and FSHD Study Coordinator

The Royal Children's Hospital, 50 Flemington Rd, Parkville, Victoria, 3052

**P** 03 9345 4287

**E** [katy.devalle@rch.org.au](mailto:katy.devalle@rch.org.au)



## PhD SCHOLARSHIP AWARDED



MDNSW offers a full-time postgraduate scholarship to a suitably qualified candidate in a relevant discipline to undertake research studies leading to a PhD. The Sue Connor Scholarship is currently available to a scholar who wishes to undertake a PhD degree in the field of research into neuromuscular conditions. This year the scholarship has been awarded to **Samantha Bryen** for her research project: **"Translating splicing variants into clinical genomics for patients with rare neuromuscular disorders."** Samantha commenced her scholarship in July 2018 and will conclude in 2020. Samantha will be speaking at the Medical Seminar in November so you will have an opportunity to find out exactly what her research is about!

You can read an interview with Sam by going to <http://mdnsw.org.au/sam-bryen>

### Events 2019



## Sydney Mums' Retreat

A Retreat exclusively for mums with a child with a neuromuscular condition

**Fri 8 - Sun 10 March 2019**



This retreat is a chance to get away and connect with other mums who have a child with a neuromuscular condition, staying at The Collaroy Centre at Collaroy.

This venue is situated in a bushland setting with beautiful views of the ocean. There will be opportunities to go for a hike or walk along the beach or simply to just sit, take in the views and chat with other mums. Enjoy dinner on Friday night at the beach as the sun sets.

**\$100pp**

Price includes 2 nights shared accommodation and all meals, including Sunday lunch.

**RSVP**

Register your interest by emailing Jenny at [jenny.smith@mdnsw.org.au](mailto:jenny.smith@mdnsw.org.au) or call Jenny on 9888 5711 ext. 3 by **Thursday 7 February 2019**. Places are strictly limited so RSVP ASAP.

[mdnsw.org.au](http://mdnsw.org.au)

*Tips  
&  
Tales*

## FROM CAZ'S DREAM TRIP!

Carolyn Campbell-Mclean recently embarked on an epic 6 week trip to the USA!

Here is Carolyn's top 10 tips to travelling to the United States! You can read more by visiting <https://bit.ly/2yjmwsw>



*The Chameleon portable shower chair*

### TIP 10 GET EQUIPPED

Service equipment before you travel. Do you need new tyres or batteries? Carry spare tubes and repair kit. Check chargers voltage and plugs. Take power board!

### TIP 9 MAKE THE MOST OF YOUR NDIS PACKAGE

Add goal of trip/travel into your plan. Self-managed = greatest flexibility. Additional disability costs can be claimed if they are reasonable and necessary - do checklist eg. accessible car rental minus the cost of standard car hire. Consider other funding sources Job access, tax deductions etc

### TIP 8 GET SUPPORT TO PLAN

Go through your travel plans with others along the way eg support coordinator, OT, family, friend, support worker, peer support, Facebook's Accessible Travel Club!

### TIP 7 GET ON THE ROAD

Hire accessible cars. We found we needed to book via phone to ensure they fully understood our needs. Remove front seat so you can be up the front! Take belt and pillow for comfort. GPS on phone kills battery so take portable charger or have back up plan.



*Front seat navigator!*

### TIP 6 GET UP IN THE AIR

Ask about the Eagle lifter. Get clearance approval certificates for batteries from airline before you go. Use high vis tape, bubble wrap, signs to help baggage handlers know how to manage and protect your equipment. Know your types of batteries and weight of equipment. Arrive 3 hrs before flights. Consider toileting options and health issues (I used bedpan when the lights were out and hostess held up blanket for privacy!). Consider business class.

### TIP 5 DO YOUR HOMEWORK

Booking accommodation and vehicles online can be helpful but often emails and phone calls are needed. Ask the hotel to send photos of the actual room you are booking. Look out for beds attached to the floor (if you need a hoist) and ask what the mattress height is. Research and more research. Ask others who have travelled to your destination.

Book early to get the best access. Can usually cancel without penalty if more than 3 days before booking. Keep all bookings electronic in multiple places to reduce paper weight and ink waste. Email feedback



*Caz at the White House*

if access or service is particularly good or poor. Get personal email contact with managers if possible.

### TIP 4 TRAVEL DAYS ARE LONG

Always leave extra time. Ask for/book accessible shuttle in advance. Save phone numbers of accessible cabs and shuttles in advance. Ask and ask again as often information is incorrect. Ask for help. People are so kind and really like to help!



*Eating \$1 pizza!*

### TIP 3 PICK THE RIGHT PEOPLE

Carefully choose support workers. Think outside the box about who can provide support/care. We used 2 people who live in Canada/US and took others from Australia. Break up the trip into legs. Break up days into shifts. Negotiate the arrangements. Be clear on who pays for what and what is expected. Get agreements done with 3rd party oversight. Get any financial contribution before the trip. Advertise the position or approach someone.

### TIP 2 MONEY CHANGES EVERYTHING

Do a budget a year out. Keep all receipts and put them in a plastic sleeve - sort out at home. Make the most of tipping - get help when you need it - the US are great at customer service. We got waiters to cut up food, get things in and out of our bags etc. Get a travel card with your name on it as some places don't accept general travel cards and you might cop fees. Always have a backup credit card. Find a wallet or purse that's easy to handle and safe for travel.

### TIP 1 STRESS LESS AND ENJOY THE JOURNEY (NOT JUST THE DESTINATION)

Some things won't go to plan along the way. Use your problem-solving skills. You can only control what you can and there's no problem that can't be solved. It will make for good stories. In the end everything will be ok! Travel is worth it. Travel is possible! Travel is life!

For even more information and details of hotels, transport and equipment please visit...

<https://carolyncampbellmclean.com/>



*Accessible ride at Disneyland!*



*Enjoying the Grand Canyon*



# MDNSW CHRISTMAS GIFTS

Each year Muscular Dystrophy NSW empowers, connects and supports people with neuromuscular conditions and works to be an effective advocate for the neuromuscular community.

This Christmas, we ask you to think about giving your friends and loved ones a Muscular Dystrophy NSW tax deductible donation gift card so that we can continue towards our vision that every person with a neuromuscular condition is able to live the life they choose!

## CHOOSE TO GIVE...

### \$25 - Gift of Independence

Your gift supports a young person with Muscular Dystrophy to become more independent and develop lifelong friendships by attending our new short-stay program for Young Adults aged 18-30.

### \$50 - Gift of Connection

Your gift can connect mothers of children with Muscular Dystrophy from across NSW; allowing them to take a much needed break while sharing and learning from each other.

### \$100 - Gift of Empowerment

Your gift can help build a child's emotional wellbeing and capacity by supporting them to attend our highly specialised camp for children who use a wheelchair for mobility.

\$25



\$50



\$100



**YES!** I would like to purchase a Gift Card and/or make a donation to Muscular Dystrophy NSW this Christmas!

Please go online or call us to order: **p** 02 9888 5711 **w** [www.mdnsw.org.au/christmasgifts](http://www.mdnsw.org.au/christmasgifts)  
Or mail this form to: Muscular Dystrophy NSW, Studdy MS Centre, 80 Betty Cuthbert Drive, Lidcombe NSW 2141

YOUR GIFT...	QUANTITY	PRICE	TOTAL
\$25 - Gift of Independence		\$25	
\$50 - Gift of Connection		\$50	
\$100 - Gift of Empowerment		\$100	
I would prefer to include a donation		DONATION AMOUNT	
			<b>TOTAL</b>

## PAYMENT DETAILS...

### Method of payment:

Cash  Cheque / Money Order  Credit Card  
(payable to Muscular Dystrophy Association of NSW)

Name: \_\_\_\_\_

Email: \_\_\_\_\_

Telephone: \_\_\_\_\_

Address: \_\_\_\_\_

State: \_\_\_\_\_ Postcode: \_\_\_\_\_

Credit card details:  Mastercard  Visa  AMEX

Card number:

□□□□ □□□□ □□□□ □□□□

Expiry Date: □□/□□

Cardholder Name: \_\_\_\_\_

Signature: \_\_\_\_\_

**PLEASE NOTE** that to ensure that all additional Gift Cards reach you prior to Christmas, orders must be received by Muscular Dystrophy NSW no later than Friday 8 December 2018.

*Any additional gift cards ordered will be sent to you to personalise before sending to your family & friends*





# contact us...

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

## NEUROMUSCULAR CLINICS

PAEDIATRIC

**Sydney Children's Hospital Randwick**  
Neuromuscular Clinic  
Call SCH for Outreach Clinics 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](mailto: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

# PHILIPS

**Philips Sleepeasy are offering a trade-in promotion for 2018**

*Discounted purchase of a Cough Assist E70 when trading in a Cough Assist 3200*



The **Cough Assist 3200** was discontinued in 2013 and can no longer be serviced. Philips Sleepeasy remains dedicated to supporting all patients using Cough Assist devices. For more information on this promotion, please contact Maroubra Sleepeasy on 1800 701 822.

**PHILIPS**

Sleepeasy

## 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](mailto:feedback@mdnsw.org.au)

**phone** 02 9888 5711 or

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