

## Kobe Makes A Wish with Roothy

Beau Ryan from the Cronulla Sharks came to our house to present Kobe his wish and to also give him a signed jersey. Kobe had no idea any of this was happening as we wanted to keep it a surprise. Kobe's wish was to meet his 4WD hero, John Rooth (Roothy). Kobe always buys his magazines and videos but never ever did he think he would be able to meet him, let alone go off-roading with him. Roothy and his mate Jamie picked Andrew and Kobe up from our hotel and went off-roading to the Glass House Mountains for the next two hours. Kobe had the best day ever and it is something he will never forget. We even made it on the local news that night! The accommodation was fantastic and we

were also given family passes to Australia zoo, Outback Australia and Sea world. It had been such a long time since we had been on a holiday together as a family, especially in the last two and half years since Kobe has been in his chair. It was wonderful for someone else to book the flights and accommodation as this normally takes a lot of time and research to do so. Thank you so much to Pam and Kevin the *Make A Wish* volunteers who organised Beau to present the wish. Also thank you to Sarah Mooney from *Make a Wish* who spent so much time getting our trip organised. We really appreciate everything that was done for us.

**Ione Andrew and Kobe Stower**  
MDNSW members



*Kobe's wish came true when he met Roothy*



*Kobe chats to the dolphins at Seaworld*



## Richard captures the Duke of Ed spirit

I chose to participate in the Duke of Ed Award because I wanted to challenge myself to try my best to improve my communication and relationships with others, build up confidence, and to start being responsible and independent. I am very happy that I chose to participate because it has helped me to achieve this. For my section of Skill I have chosen the TAFE course of information and technology to gain more knowledge in IT. For my other section of Physical Recreation I have chosen hydrotherapy and for the section of Volunteer I am hoping to do IT work.

For my Adventurous Journey I chose to go to Camp for the first time and take photos. At first I had a big digital camera from high school but my family thought it was too heavy for me so we used the funding from the Duke of Ed to buy a smaller black camera but it was still too heavy so my mother's friend who sold me the camera told her about the bracket that she can buy and can be attached to my wheel chair and hold the camera for me. I couldn't press the button to take pictures so he told me about an app called Play Memories that connects to my camera by Wi-Fi so it can take pictures or make movies and zoom in and out just



*Richard took photos at camp as part of his Adventurous Journey*

by a tap on the phone. And he gave me a few lessons on how to use Play Memories. I had fun learning how to do this and now enjoy taking lots of photos.

At first I was nervous about going to Camp because I was going to be taken care of by a complete stranger I never met before and I was worried because I thought that no one would be able to understand me and my problems. My mother was worried sick that she texted me all the time to see if I was alright but she soon stopped which was good because after taking care of me and my sisters she can relax. I see Camp as my Adventurous Journey because it was a chance to learn new experiences, meet new people, grow confident and feel comfortable when talking to strangers. What

I got from going to Camp is confidence and new experiences from the carers, staff and other campers and memories I will never forget. My mother got a break from taking care of me, even though she said she got worried some nights, and time to spend with her daughters and a long rest.

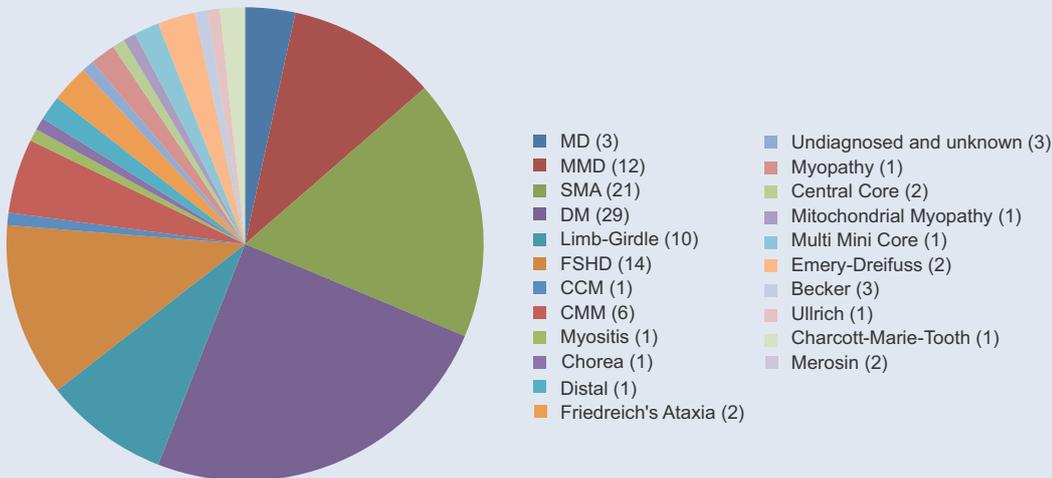
**Richard Ly**  
MDNSW's newest Duke of Ed participant



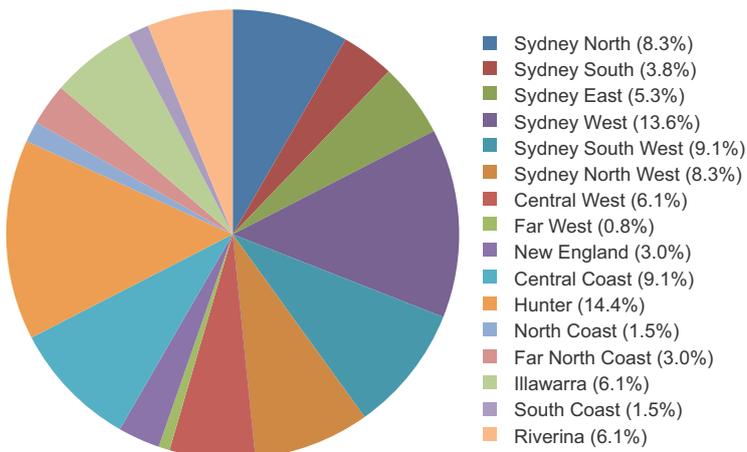
# Results of 2013 MDNSW Client and Family Survey

TOTAL NUMBER OF RESPONSES - 144

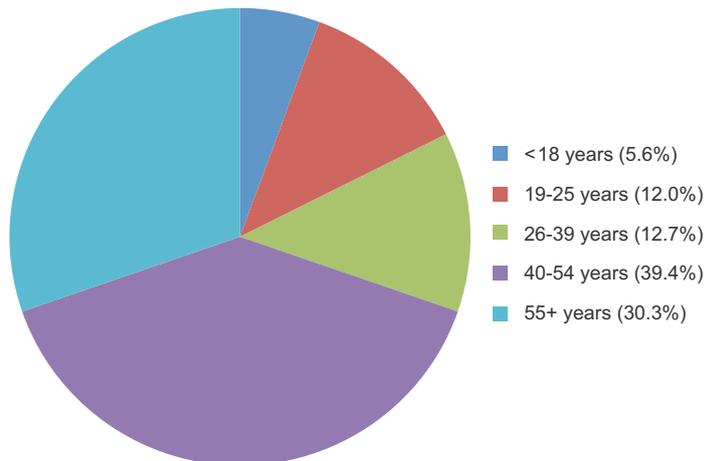
## Q1 What is the diagnosis of yourself or your family member?



## Q2 What is the location of where you live?



## Q3 What is your age?



## Q4A Which services provided by Muscular Dystrophy NSW have you used?

FlexiRest	36.8%
Social Events	34.6%
Equipment Funding	25.6%
Medical and Information Services	24.8%
Weekend Retreats	24.8%
Camps	24.1%
None of the above	21.8%
Home Visitation	21.1%
Carer Support Network Events	15.0%
Duke of Edinburgh's Award	12.0%
Information, Referral and Advocacy Services	10.5%
Counselling	6.0%

## Q5A Do you receive Talking Point?

YES - 90%  
NO - 10%

## Q5C Do you think we should continue printing Talking Point?

YES - 95%  
NO - 5%

## Q6 How often do you look at our website?

WEEKLY - 6%  
MONTHLY - 22%  
A FEW TIMES A YEAR - 56%  
NEVER - 16%



# Results of 2013 MDNSW Client and Family Survey

## Q9 In what ways have our services or events positively impacted your life?

- Reduced stress and anxiety
- Provided respite and someone to discuss issues as they arise
- The camps have been just fantastic both for our son but also for the rest of the family enjoying that bit of respite
- Given them opportunities in sport
- We've enjoyed retreats - its great doing something enjoyable without the stress of worrying about access
- By encouraging me to push my boundaries much further than I otherwise would have
- MDNSW has been very helpful with the cost of products that I wouldn't be able to afford on my pension
- Dads' retreat was a great opportunity to meet and talk with other dads who are in the same boat as myself
- Knowing my son is supported should anything happen to me
- Provided me with a manual chair at a critical point in my life
- Gave me more understanding of the disability
- The Mums' retreat positively impacted my life meeting other mums on the journey that I was beginning
- Attending the camp and being involved in DOE has given our son more confidence
- Providing friendly support and information. Knowledge that when needed in the future your support network is there
- FlexiRest has provided us with the opportunity to get away on holidays and short breaks
- MDNSW introduced me to the great sport of boccea
- Enabled me to go on holidays and provided me with wheelchairs
- Meeting others in similar situations, experiencing things you may not ordinarily get to including camp and weekend retreats
- Camp has provided me with a positive social experience and greater confidence to just be me and not worry about what other people think
- Allowed my daughter to meet others that are living the same life as her
- Adventure camp has radically changed my life. I am doing things I never thought possible. Even went kyaking last weekend
- Made me more aware that other people are in a more needing position instead of being single minded about my condition
- The Duke of Ed program has allowed me to grow as a person, try new things, help out in a community that has helped me so much and showed me that I can do what everyone else is doing in a slightly modified way
- Good to know the right people are there when or if you need advice or simply chat time
- Great for kids to be able to get together so they know they are not alone & can talk to others with similar issues

## Q10 In what ways could we improve our services or events?

- Providing more current information on Myotonic Dystrophy and a Myotonic Dystrophy support group would be ideal.
- Help members with self directed supports
- Some evening carers things for those of us who work fulltime
- More regional support
- Outreach to ACT. We do not have an effective local provider of these services
- Higher visibility
- More retreats so that more carers and adult clients can get away
- Cost of transport in wheelchair taxis precludes me from attending events

## Q11 What other services would you like to see Muscular Dystrophy NSW providing?

- Liaising with the Dept of Education directly and outlining the level of support that children with neuromuscular conditions require
- Transport assistance - cabcharge or van
- School visits to raise awareness about neuromuscular disorders
- Counselling for people whose condition is worsening slowly
- More post school services, helping people into employment
- Trade/Swap/Lend offers for equipment
- A support group for people with FSHD specifically
- Networking of similar families with same condition
- More local events for older people would be good
- Sibling events
- Providing carers for outings
- Physio and OT services
- Lobbying government on disability funding of equipment like car lifts and conversions



thank you to all our amazing fundraisers

## A Tough Challenge

In 2014 I will be taking on a fundraising challenge which will see me raising awareness and much needed funds for MDNSW. This cause is very near and dear to my heart as my youngest son has this condition. The challenge I have set for myself is to travel around Australia during 2014 and enter all Tough Mudder events (6 events and 12 races in total). I recently completed the Sydney Spring 2013 Tough Mudder event which signified the official start of my challenge.



For those that aren't familiar with Tough Mudder, they are extreme obstacle courses that are 18-20km long and made up of obstacles that were originally designed by the British SAS regiments to test their troops. They consist of everything from mud crawls under barbed wire to jumping off 5m platforms into water!

To help me in raising awareness for my challenge and my fundraising I have created a Facebook Page and Twitter account that are linked to my website [www.mudupformd.com](http://www.mudupformd.com).

**Nathan Brammer**

## Harley Ride 4 MD



On Sunday 29th September the New South Wales HOG chapter organised a charity ride from Concord down to Austinmer Beach for morning tea. We were really lucky as it was such a beautiful sunny day and the sight of 56 bikes heading down the freeway is not something you see every day! The ride included breathtaking sights of the ocean and a range of stunning landscapes from the National Park to the mountains. Arriving at the beach the ladies from the HOG chapter had prepared a wonderful morning tea for us all. After some amazing photographs with everyone and the ocean in the background we headed back to Fraser's for lunch. We raised an amazing \$5,000 for Muscular Dystrophy NSW and it was a spectacular day for all involved.

**George Cozis, HOGS**

*We would like to thank George, Groovy (Kris) Hutch, the ladies for their morning tea and everyone involved with HOGS and the day for their ongoing generous support.*

## Melbourne Marathon \$3550 Raised!

After breaking my finger, I decided that rather than sitting on the bench at basketball I would run the Melbourne Half Marathon. When I went on the website I realised I could donate to a charity and this made me think of my Uncle Bill, a lively chap with a high level of intelligence and a ridiculously positive outlook on life. Bill was well respected by all with a kind nature, a great sense of humour and a sparkle in his eye. Bill passed away last year after a lifetime of living with Muscular Dystrophy. So I set a target of \$700 and pressed submit with my subconscious reminding me 'Cam, you'd better train!'

The race was a mix of emotions - gruelling, fun, intense, enjoyable, character building and arduous. It was a great feeling running with all these other people on the same path with similar goals. Billy would have loved the outcome, as we raised funds to support the condition that inhibited his body but not his sharp mind and positive spirit.

With the help of my amazing and enterprising sister Briony and some very overwhelming donations we were very proud and happy to raise \$3550!

**Campbell Barclay**



## Deutsche Bank Staff Help Out

On Tuesday 24th September four Deutsche Bank Staff, Aaron Nguyen, Phillip Kaufman, Michael Chanpowsee and Steven Flood, came to volunteer at our Kula N' Gadu Camp at Narrabeen. They helped the children learn to play golf, participated in a water-balloon fight for the Great Race event and had the children entertain them at the Camp X Factor competition. It was a brilliant day and having them there really added to the enjoyment and fun the children experienced.



# how can you get involved?

## Blackmores Sydney Running Festival \$10,000 in Total Raised

Entering the Blackmore's Sydney Running Festival actually started off as a dare for Andrew De Jong! He then asked me join him. I have a physical disability called Arthrogryposis, a disability that prevents my muscles and joints fully developing from birth. I am able to walk short distances but often I use a wheelchair to get around. Andrew decided he would compete in the 42km marathon pushing me in my wheelchair! We decided to raise money for Muscular Dystrophy NSW as my friend Brendon Buecher passed away from the condition over 4 years ago and it is a cause very close to my heart.

On the 22nd of September on a clear sunny day in Sydney we managed to complete the 42km journey! The thoughts of the supporters both on the day and the monetary contributions spurred us on until the end. Through the support of friends, family and work colleagues we were thrilled to be able to raise an amazing \$3400!

**Daniel Mowbray**



Dan and Andrew after the race

**Muscular Dystrophy NSW would like to thank all of our amazing runners and all the volunteers who helped on the day! We are thrilled to have raised \$10,000 in total!**

If you are interested in volunteering or participating in a challenge event please contact Kags Garrard, Fundraising Manager, on 02 9809 2111 or email [kags.garrard@mdnsw.org.au](mailto:kags.garrard@mdnsw.org.au)



Maralyn and Joab

## Even on a Sunday, MDNSW Staff Work Hard for the Cause!

Although there is nearly 40 years between them in age, Joab and Maralyn did not seem to notice as they participated in the 9km Bridge Run in the Blackmores Sydney Running Festival. Joab insists that the Bridge Run was not about him but about supporting a friend and raising money for MDNSW. "We both realise how incredibly fortunate we truly are and what we've been given in life, hence we try to make the most of it," Joab said before the race. "Maralyn did the running and I wheeled right beside her, cheering her on all the way!" Maralyn and Joab's team was called 'We Ride We Run' and together they raised an incredible \$4000 for Muscular Dystrophy NSW!

**Maralyn McCann**

We want to say well done to our amazing MDNSW staff who completed the 9km Bridge Run – **Chaitali Desai** and our 'We Ride, We Run' team members - **Maralyn McCann** and **Joab Olding!** We are so proud of all three of you for all your hard work and dedication. Go Team MDNSW!

## Successful Grants 2013

**Lord Mayor's Charitable Foundation** for \$25,000 for The Duke of Edinburgh's Award program.

**The Wales Family Foundation** for their kind donation of \$15,000 for ongoing services.

**The Marian & E.H. Flack Trust** for \$10,500 for The Duke of Edinburgh's Award program.

**Commonwealth Bank** for \$10,000 for The Duke of Edinburgh's Award program

*We would like to say a huge thank you to:*

**Western Suburbs (Newcastle) Leagues Club Ltd** for \$5,000 for our Client Services program.

**Ingleburn RSL Club** for \$3,000 for our Ngundabaa Connect program

**Griffith Ex-Servicemen's Club** for \$500 for our Ngundabaa Connect program and Support Group.

**James N. Kirby Foundation** for \$10,000 for The Duke of Edinburgh's Award program.





## Need access to Equipment?

**FlexEquip is a service that assists adults with rapidly progressive neurological /neuromuscular conditions to access equipment to meet short term needs.**

You may be eligible for FlexEquip equipment if you have a relapse or accelerated crisis and equipment is required for short to medium term use OR if you have applied for equipment through the NSW government equipment service, Enable NSW, and FlexEquip equipment is required for short-term use whilst the application is in process.

You can find out about how to apply and eligibility for equipment at [www.flexequip.com.au](http://www.flexequip.com.au) or by contacting your local health professional.

*An application by a health professional is needed to access all FlexEquip equipment.*



- person-centered care specialists
- facilitating social care sector partnerships
- budget holder for packaged care solutions
- training and practice development
- organisational and sector development
- research and innovation



**resourcing and supporting the community care sector in these changing times**

**f /resourcingcommunitycare (02) 8002 4787**  
**@CareOptionsNSW communityoptions.net.au**

## Rapid Response Packs

case management plus up to \$1,500 for people experiencing rapid degeneration, helping them stay independent for as long as possible.

## High Needs Program

pilot program offering a one-off funds release to assist with the purchase of items or services and support the achievement of independent living.

## ComPacks

short-term and non-clinical case managed community care providing crucial support to people who are transferring from hospital to home.

# thank you to our sponsors

## Thank you to our very generous supporters who have so kindly given to us in 2013 the following donations:

### Donations over \$5000

AN & G Wales  
Denis & Fay Russell  
Denis & Fay Russell  
Shirley Williams  
Ian Williams

### Donations over \$1000

David Reid	Irene Caldwell - Ash	Bruce & Jill Vaughan	Kristopher Grove
Kristopher Grove	Shannon Finch	Colin Gunn	Bruce Duck
Ross Simpson	Anonymous	Douglas Kirkham	Rick Arnheim
Vicki Sciulli	Rick Arnheim	Mark Kelly	Ross Parker
John Freedman	Peter Debnam	Pene Hodge	Stuart Garton

### Donations over \$500

Aaron Conn	Ian Devlin	Alan Giumelli
Melanie Rankine	Olive Walker	Margaret Williams
Paul O'Sullivan	James Sullivan	June Holdsworth OAM
Donald Sanders	Nick Polin	Andrew Noble
Kristi Jones	Nick Polin	Angelina Ierardo
Anonymous	Karen Mcleod	
Geoff Peetz	David Torrance	
John Brindley	Peter Donkin	

### Donations over \$250

David BarclayC	William Harding AM	North Public School	Michael Binet	Ashley Hostnik
Marissa Brammer	William Harding AM	Valma Pfitzner	Filtton	Carole Cullen
Pino Giusti	Karl Priestly	Anonymous	Kasper Leschly	Keith & Moyra Heness
Farmer Robyn	Lorna Higgs	Charmaine Yu	Barbara Perry	Lionel Robberds
Peter Donkin	Greg Hickey	Kathryn Farmer	David Speers	
Joanna Fleming	Michael Binet	Taylor Dugmore	Beth Durran	
James Potter	Ian Williams	Todd Lyons	David Reid	
Brett Hillier	Baulkham Hills	Marcus Patrick Cullen	Gregory Burton, SC	

### Donations over \$100

Peter White	Lynn Joffe	Jenny Farrell	Christine Andrews - Windmill	Mitchell Futcher	Maralyn McCann	Aaron Flagg
Nathan Betteridge	Barbara Allan	James A Hislop	Barbara O'Connor	Stephen Atkinson	Y F Roden	Lorraine Symes
Edward Lord	Lewis Rangott	Angus Dorney	Harold Hunt	Glen Foster	Valma Pfitzner	John Samuel
Debra Cox	Stewart Gamble	Anthony Mansour	Noela Bell	Robert Kropman	Doug Crabbe	Scrogings
Rob & Kyrenia Thomas	Joycelyn Morton	William Bennett	Ione Stower	Robert Kropman	Craig Boettcher	Lorna Higgs
Lewis Rangott	Adam Linforth	Amanda Piper	Trish MacAlpine	Shearing Contractors SCAA	Jason O'Connor	Kristina Jaworski
Lynn Joffe	Anthony Dessel	George Georges	Harold Hourigan	Igor Stychinsky	Dorothy Chasing	Sharon Weir
Adam Friederich	Carolyn Watkins	Alison Perosin	Julie-Anne Lancaster	Tim Von Behr	Anne Burton	Margaret Williams
Michael Fordham	Alex Newman	Rick Arnheim	Frances Kaye Braybon	Paul Bigsby-Chemberlin	Rosemary Anderson	Janette Lundman
Margaret Polin	Annette Stage	Michael Powell	Trevor Wolfe	Kristopher Graydon	Ian Hunt	Jennifer Parker
John Kropman	Willyama High School	Reynaldo Bambo	David Butlin	Kate Colgan	Edward Lord	Alan Slade
David Sprouster	Rick Arnheim	Tim Powell	Peter Howes	Nives Clausen	Rob Erhardt	Graham Read
Ian Wilson	Terry Gordon	Roxanne Young	Julio Fuentes	Ross Brown	Beryl Benbow	Jenny Roddy
Catherine Murphy	Don Couch	Stella Heley	Tracey and Troy Wood	Alexander Rincon	Ian Coutts	Roy Wells
Tom Todd	James A Hislop	M Smith	Brendan Sullivan	Will Lavender	Lynette Walker	Alison Wason
David Forest	Anne Burton	G.A. Deudekom	David Fotheringham	Louisa Kolega	Pamela Heikkinen	Alys Anne Powell
Wayern Heartly	Leisa Bishop	Chaitali Desai	Ange Lloyd	John Hugo	Daphne Spurway	Andrea Watts
Kerry Spurrett	John Donnelly	Edmund Gralton	Greg Jones	Robyan Thompson	Doreen Best	Geraldine Hannah
Caesar Cirillo	Peter Duncan	Claire Gralton	Nicole Norton	Terry Lee	Eric and Shirley Griffiths	Janice Powell
Heather Johnston	Sophia Stollmann	Gordon & Colleen Cox	Norris Robertson	Matt Swan	Keith Houghton	Linda Favalaro
Manuela Crank	Patricia McPhail	David and Judith Kirby	Andrew Cox	Thomas Flannery	Andrew Aiton	Melanie Rankine
Bruce & Jill Vaughan	David Willis	Graeme Morgan	Glen Murphy	Grafton Travel Agency	Patricia Irving	Pamela Powell
Charles P Curran AC	Jen Barling	Michelle Harrison - Provenzano	Sarah-Jane Wilson		John Whitehurst	Wendy Clayton
MD Cullen	Lorna Higgs					

And to the very many supporters who gave donations under \$100!

Donations were also made in the memory of Michael James Reid, Anthony Russell, Douglas Harding, Graeme Pfitzner and Wesley Christopher Grivas

## Leave a Lasting Legacy

Consideration of Muscular Dystrophy NSW in your will or estate will greatly enhance the services we are able to provide for people in the future that really need us.

### Benefits

The benefits of giving to Muscular Dystrophy NSW are many and varied. For private donors and corporate sponsors there are tangible and intangible benefits to be enjoyed. We also give all our supporters feedback and reports to ensure they can remain closely involved.

For individual donors the benefits are often personal – the feeling of having done something significant and valued:

- Remembering a loved one through a permanent association with a special area of interest.
- Helping to build a caring and supportive society.
- Invitation to openings and events that Muscular Dystrophy NSW is hosting.

We welcome the opportunity to discuss bequest or estate matters with our members and supporters, or their advisors. Please contact our Fundraising Manager, Kags Garrard, on 02 9809 2111 or email [kags.garrard@mdnsw.org.au](mailto:kags.garrard@mdnsw.org.au) for more information.



If your life is affected by a  
**neuromuscular condition...**

*We're here to help*



#### **MUSCULAR DYSTROPHY NSW STAFF**

Chief Executive Officer  
Pene Hodge

Manager, Events and Client Programs  
Loretta Downie

Fundraising Manager  
Kags (Katharyn) Garrard

Marketing Communications Manager  
Allison Maher

Office Manager  
Maralyn McCann

Finance Manager  
Chaitali Desai

Finance Officer  
Gracia Selina

Client Programs Coordinator  
Melissa Wentworth-Perry

Client Services – Regional NSW  
Kejanna Taylor-King

Project Assistant  
Jenny Smith

Website Administrator  
Melanie Tran

IT Assistant  
Joab Olding

#### **PATRON**

Her Excellency Professor Marie Bashir  
AC CVO

#### **DIRECTORS**

Peter Debnam (President)

Ian Williams (Vice President)

Rick Arnheim (Treasurer)

Dr Kristi Jones (Medical Director)

Robert Ferguson

Martin Dalrymple

Shannon Finch

Fiona Slmson

Graeme Troy

Tracey Brown

Carolyn Campbell-McLean

#### **MUSCULAR DYSTROPHY NSW INFORMATION**

OFFICE 5 Bay Drive,  
Meadowbank  
NSW 2114

POST PO Box 1365  
Meadowbank  
NSW 2114

PHONE 02 9809 2111

FAX 02 9809 4177

EMAIL [info@mdnsw.org.au](mailto:info@mdnsw.org.au)

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



**MUSCULAR DYSTROPHY  
NEW SOUTH WALES**

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

#### **TALKING POINT DISCLAIMER:**

*The views expressed in these pages may not be the views of Muscular Dystrophy NSW. Care has been taken in the preparation of content, but Muscular Dystrophy NSW accepts no responsibility for detriment whatsoever arising from the reliance of content contained herein.*

### **NEUROMUSCULAR CLINICS**

#### **CHILDREN'S CLINICS**

Sydney Children's Hospital, Randwick

- Neuromuscular Clinic 9382 1845
- Outreach Clinics are held at Lismore-Goonellabah and Wagga Wagga
- Other services include home, school and rural visits

The Children's Hospital at Westmead 9845 1904

John Hunter Children's Hospital, Newcastle 4921 3932

#### **ADULT CLINICS**

Concord Hospital 9767 6864

Prince of Wales Hospital, Randwick  
• Nerve and Muscle Clinic 9382 0722

Westmead Hospital  
• Adult Genetics Clinic 9845 3273

