

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

ISSUE 86 WINTER 2013

PRINT POST APPROVED PP 255003/01200



Sailor of the Year!



MUSCULAR DYSTROPHY
NEW SOUTH WALES

A Word from the President

Our Annual Gala Dinner and our Golf Day were held in the last few months and both were a great success with congratulations due to all involved - attendees, supporters and organisers. Both events were also memorable for the contribution of one young man who held both audiences in the palm of his hand while he talked with them for a few minutes.

Joab Olding's quiet and confident manner quickly captured the attention of everyone in the room. In a brief speech, he discussed the nature of Muscular Dystrophy, the impact MD has on his body, the effect of his treatment, the problems he has suffered and how he deals with it all. With good humour and extraordinary grace, Joab delivered a great deal of information about the impact of Muscular Dystrophy and his attitude to dealing with it.

While Joab brought a few tears to the eyes and lumps to the throats of many in the room, everyone knew after a few minutes they had a much better understanding of Muscular Dystrophy, its effects and the courage of those people affected. Joab inspired us all. He is one impressive young man! For me, Joab was the latest person to inspire me and confirm again that MDNSW's work with all these young people provides tremendous support in their lives. Over the last two years of my involvement with MDNSW, I've been constantly inspired by the people I meet, whether they be those affected by MD or their family and friends or whether it be our staff and supporters. Everyone is making a very real difference to the quality of life of our clients.

In our last Talking Point, I noted 2013 was going to be a challenging year for all Australians with uncertain economic times and the usual political turmoil in the run up to this year's Federal Election. However, as we all know, it's also an exciting time as this year the community overwhelmingly supported dramatic improvements in the way Australia funds disability services. And more importantly, we now stand on the threshold of a new era designed to really empower Australians affected by disabilities. At MDNSW, we are proud to be playing our part in supporting the introduction of these changes.

Our Association's role remains clear - MDNSW is the leading whole of life provider of choice of specialised services and expert information for people affected by neuromuscular conditions. Our Association will also continue to evolve as we seek to deliver the best possible services for



you. But we do need your help. Regular advice and feedback are essential if we are to remain a Centre of Excellence for Muscular Dystrophy Services. Please take every opportunity to give us feedback - good or bad - whenever it crosses your mind. Brief emails to our CEO Pene Hodge pene.hodge@mdnsw.org.au are the best way for us to get feedback.

Also don't forget there are many people in NSW with neuromuscular conditions we are yet to reach. If you are aware of someone with a neuromuscular condition and you know they have not been in contact with MDNSW as yet, please give them a copy of Talking Point and suggest they give us a call. Tell them that MDNSW and our supporters are ready to help and we want to reach out to them.

As I've mentioned previously, our work has been greatly assisted by some visionary people who made our Association a beneficiary in their Will. Their vision and generosity allowed us to reach out to more and more families across the state with better services. If you are about to update your Will, please consider making The Muscular Dystrophy Association of NSW a beneficiary so one of your legacies will be underwriting our work into future years.

And finally, thank you to one and all in our Muscular Dystrophy NSW family for all your efforts.

Peter Debnam

President, Muscular Dystrophy New South Wales

SEA TO SUMMIT

The toughest one day ride around

BONDI to KATOOMBA
145km

With Australian
cycling legend
BRAD McGEE

Strictly limited to 120 riders

Cost: \$135

Minimum fundraising per rider: \$500
Register your interest now to reserve
your place.

EMAIL: kags.garrard@mdnsw.org.au
Registrations officially open



Sunday December 1



MUSCULAR DYSTROPHY
NEW SOUTH WALES

A Word from the CEO

I have been giving a great deal of thought in the past few months to our organisation's mission statement which is:

“ To improve the quality of life of all people living with a neuromuscular condition ”

Our mission statement speaks to me a lot about who we are as an organisation and what is important to us. It shows me the value we place on increasing the quality of life of all people regardless of their type of neuromuscular condition and that this support extends to the whole family. Our Board and staff have been asking ourselves how well we are doing in achieving our mission and how we could do better.

A significant part of this evaluation process was to gain your opinion and in response we recently sent out a Client and Family Survey. Thank you to everyone who completed the survey. We had an excellent response and will be publishing the results in the next edition of Talking Point. We valued your comments and suggestions and will be using them to evaluate our current services and for future planning. If you didn't have the opportunity to complete the survey please do email me with any feedback. I would appreciate receiving it.

By the time this edition goes to print, DisabilityCare Australia (NDIS) will have been launched in the Hunter region. It is an exciting and groundbreaking time for people with a disability living in Australia but we do acknowledge that for many there is some uncertainty and a lot of unanswered questions. Please call our office if

we can assist you with these questions in any way. We have asked our previous editor and Living Life My Way Champion Carolyn Campbell-McLean to keep us up to date on how things are progressing. She has written an article on her experiences with Self Managed Funding as a start to her regular column.

Whether you live in regional NSW and are visiting Sydney or live closer to our office, we would love for you to visit us. Remember we are here to help so please let us know if we can.

Pene Hodge
CEO, Muscular Dystrophy NSW.



Welcome to our New Team Member

Hi, my name is Allison Maher and I have recently joined the Muscular Dystrophy NSW team as their Marketing Communications Manager. I am responsible for creating and implementing a communications and marketing strategy aimed at building the profile of Muscular Dystrophy NSW, raising awareness of the condition and supporting Kags in her fundraising efforts.

The team at MDNSW have been incredibly welcoming and I was instantly impressed by their professionalism, dedication and enthusiasm for what they are striving to achieve. The passion rubbed off immediately and I am very keen to fulfil the objectives of my role over the coming months.

I have enjoyed working in the field of marketing for 20 years, initially in product and brand management roles across high end entertainment brands such as Columbia TriStar, Warner Music and Disney. The majority of my experience since that time, and where my passion

really lies, has been in the not-for-profit sector. I ran the Sydney Royal Easter Show Marketing Department for the Royal Agricultural Society of NSW, managed the Marketing & Events team at Macquarie University Student Union and worked as a marketing consultant for a number of not-for-profits when my family was young, including AustCycle and the Red Cross Blood Service.

I look forward to meeting many of you at our upcoming events and hearing your individual stories.

Allison Maher
Marketing Communications Manager





Muscular Dystrophy NSW was an exhibitor at the 2013 PossABLE IDEAS EXPO on May 3 & 4 at the Newcastle Entertainment Centre. The exhibition ran in alliance with the rollout of DisabilityCare Australia in the Hunter region and was a huge success with over 4500 people attending. There were more than 120 local service providers on display, as well as demonstrations of wheelchair and disability sports including basketball, rugby league, cycling, bowls and Sailability. Check out the workshops on their website www.2013possibleideasexpo.com.au/workshop-presentations. **Kejanna Taylor-King**, Client Services – Regional NSW

I had the pleasure of joining Kejanna at the 2013 Disability Expo held at the Newcastle Entertainment Centre recently. We spent



Lisa Burns helping out the Expo

the day chatting to lots of friendly people and met a few new and old faces from the Hunter who were interested in receiving more information about MDNSW. A great time was had by all and with no doubt our stand stood out as the most colourful. I thoroughly enjoyed the day and obtained a lot of handy information from the expo.

Lisa Burns Hunter Region

Training Program

After the successful launch of our e-learning tool, Understanding Neuromuscular Conditions we have now commenced our face-to-face training sessions for health and community professionals. We have had 5 successful sessions at the time of writing, with another 25 planned all over NSW. Maryanne Murray, Melissa Wentworth-Perry (formerly Steck) and Matthew Figgins have been in charge of the "Roadshow". It has been fantastic to meet many of the people whom our members work with on a day to day basis: Home Care workers, Social workers, Case Managers, Intake Officers, Physiotherapists etc. We are glad to be able to increase the knowledge about muscular dystrophy and other neuromuscular conditions in the community. Our overall aim is to improve the care which each of our members receive. This training has been funded by ADHC and therefore is free to all participants, so if you think any of the people who care for you would benefit, please get them to look at our website or contact Melissa on 9809 2111 or melissa.steck@mdnsw.org.au.



A Big Thanks to Little Heroes Care!

Little Heroes Care is a fantastic new project generously funded by *Little Heroes Foundation* offering diverse and flexible support to help meet the needs of children and young adults under the age of 25 years and their families. The aim of their project with Muscular Dystrophy NSW is to improve the quality of life for people with a neuromuscular condition by giving them access to the very best care regardless of their financial

circumstances or where they live. *Little Heroes Care* facilitates a wide range of supports and services including treatments and therapies, equipment, respite, information, advocacy and referral, transport assistance, practical supports and sibling supports. MDNSW has received lots of letters of thanks from recipients of this funding, so we thought we'd share a few of them with you below!



Powerchair Football equipment for Cassie

I recently found out about a sport called Powerchair soccer/football at the 2012 MDNSW Camp and was immediately in love with the sport. I had not played any real sport since being confined to my chair and by finding powerchair soccer my previously very active self was unleashed. Upon looking at purchasing equipment of my own I found it to be rather expensive, having to also get special brackets made for the guard to fit to my chair. This funding has allowed me to participate in sport and in a way be more like my old self who

used to always be out on my bike or bouncing or kicking a ball around. It has given me something to enjoy and allowed me to regain my old self. Thanks Little Heroes! **Cassie Robson**, Hunter Region

Tom loves fast cars and all things to do with Motorsport, so to be able to drive his own racing car gives him a thrill. He loves that he can compete as equally as the other Racing Club members despite his severe physical limitations, and this was assisted by the fact that the Club got together and built him a ramp to access the driving stand! Tom has off-road radio controlled cars that he races with the local Club, Radio Controlled Car Club of Orange (RCCCO), every 6 weeks and he looks forward to every race day. With the funding given to Tom from Little Heroes, he has purchased an on-road car. This means he can race every 3 weeks by also racing at the on-road race meetings. Tom enjoys mixing with the Radio Controlled Car Club members and it is great that he will now be able to do it a lot more often. Thank you to Little Heroes for providing the funding that enabled Tom to purchase his racing car. **Katrina McDonald**, Central West NSW



Tom Car Racing



Tilly the Therapy Dog for Daniel

We were looking at getting a new dog for our family but we wanted a dog that was 'Daniel friendly', one that was not going to knock him down as Daniel can be rather unsteady on his feet. Through Little Heroes we bought Tilly, our Pets as Therapy dog. She instinctively knows that Daniel is not able to tolerate her jumping and rarely jumps on him. I am looking forward to teaching Daniel how to walk Tilly on the lead while he is in his chair and while he is not. I think he will feel very proud of himself being able to walk a dog like all his peers do. We hope to be able to teach Tilly to pick things up for Daniel and have already looked into the training schools we need to use to make this happen. Tilly is first and foremost a family pet, but we hope she will always have a special place in her heart for Daniel.

Jo O'Brien, Blue Mountains

DisabilityCare Australia

From Mon 1 July, 2013 DisabilityCare Australia will roll out in the Hunter region. To be eligible you must be aged less than 65 years when applying and live in the LGA's of Newcastle, Maitland or Lake Macquarie. You can use the My Access Checker tool on the website to see if you are eligible for assistance from DisabilityCare Australia.

Are you...	When DisabilityCare Australia will contact you to discuss your plan:
A person who lives in Newcastle City and receives Australian Government disability services, NSW disability services	From 1 July, 2013
A person who resides in Lake Macquarie City and receives Australian Government disability services, NSW disability services	No later than 30 June, 2015
A person who lives in Maitland City and receives Australian Government disability services, NSW disability services	On or after 1 July, 2015

People living with a disability who are receiving assistance through the Australian Government carers programs or their carers will be able to discuss support needs as part of the planning discussion with DisabilityCare Australia when they meet. If you do not meet the requirements for eligibility to DisabilityCare Australia, you are still able to receive the same level of support you are already accessing through your disability programs. For more information visit www.disabilitycareaustralia.gov.au or call 1800 800 110.

Kejanna Taylor-King, Client Services – Regional NSW

28th Annual National Electric Wheelchair Sports

From the 8th – 14th April the 28th Annual National Electric Wheelchair Sports was held at Narrabeen, Sydney Academy of Sport. Each sports competition of Soccer, Hockey & Rugby League was friendly, competitive & passionate as every NEWS event has been in the past.

Queensland Gladiators dominated Soccer, winning the final in style without losing an entire game in the round robin. Victoria Warriors won the hockey competition going into a penalty shoot-out against the NSW Colts in a very exciting close encounter to be remembered. In Rugby League the NSW Colts once again won the title for a fifth consecutive time - what a great achievement!

It was a very enjoyable week and it was a great to see old & new faces, to watch competitive sport & to see the athletes represent their respective states with honour. I can't wait for the 29th NEWS event!

If anyone is interested in trying out for the 2014 NSW team, please contact the Head Coach Peter Dalrymple on 8883 4485 or at peter_dalrymple@hotmail.com.



Peter and Chris NEWS 2013

John Hunter Children's Hospital Neuromuscular Management Clinic

The Neuromuscular Management Clinic at the John Hunter Children's Hospital has been up and running for approximately 18 months now. Previously our clients had to travel to Sydney to attend a multi-disciplinary clinic, so we are very happy to be able to offer a more local service for our families. The majority of our families reside within the Hunter Region with several families travelling from more rural locations.

The clinic is staffed by a multidisciplinary team including Doctors, Physiotherapist, Occupational Therapist, and Clinical Nurse Specialist in Neurology. Other medical and allied health staff such as a Social Worker, Speech Pathologist or Dietician, may be able to consult with the clinic if needed. The clinic is also lucky to have access to a transition co-ordinator who will attend the clinics on request for specific clients.

The team has been delighted to be able to meet Kejanna Taylor-King, the regional caseworker from MDNSW. Kejanna attends each clinic and as a result has met most of our families and been able to provide them with invaluable information and support.

Like all new services there has been a 'teething' period as to how the clinic runs on a practical basis; however



with feedback from families, the team has developed a winning formula with clinics now running as smoothly as possible from our newly refurbished Paediatric Outpatients Department!

The Neuromuscular Management Clinic is held six times a year, with two of these clinics being dedicated specifically to clients with a peripheral neuropathy.

For new referrals please ask your GP to send a written referral to the John Hunter Children's Hospital.

Rachael Fallon

Neuromuscular Seminar and Research Update

Save
the Date!

Sat 2nd November 2013

Shepherd's Bay Community Centre,
Meadowbank

DETAILS COMING SOON TO OUR WEBSITE

PhD Scholarship

Last year we received a wonderful bequest in memory of Sue Connor with the condition that the money be used for research which will improve the lives of those living with a neuromuscular condition.

The MDNSW Research Committee decided to fund one or two PhD scholarships with the bequest in the area of muscular dystrophy. Applicants were invited to apply for the Scholarship on 1 May 2013 with their research proposal.

A Scientific Advisory Committee will assess the applications and will advise on the best candidate, based on merit and ability. The scholarship will be awarded to the candidate/s who can demonstrate a benefit to the MDNSW community, either in the short, medium, or long term.

We are all eager and hopeful for some significant advancements in finding treatments for neuromuscular conditions and there some exciting projects currently underway. It is hoped that the awarding of this PhD Scholarship will help in achieving this.





Thanks to everyone who attended our Gala Ball again this year for what turned out to be a truly wonderful evening for every person who came. As anyone there would confirm, the highlight of the Ball this year was definitely Joab Olding's speech. Joab is one of our most recent Duke of Ed recruits, who was also the winner of MDNSW's Young Achiever Award for his work and aspirations in the field of Information Technology. Joab totally captivated the entire audience with his speech and an excerpt from it is written below.

Loretta Downie - Manager, Events and Client Programs

A Remarkable Young Man

“ I would start by saying there is nothing special about me at all, except for the fact that I was born with Muscular Dystrophy. When I turned 13 I went through a growth spurt and my spine suddenly curved to 45 degrees in only a few months, resulting in agonising pain. I then had Harrington Rods Spinal Surgery which really helped my breathing & walking but did not alleviate my pain, so the Palliative Pain Team prescribed me opioid analgesics. These helped in the short term, but were disastrous in the long term as my body built up a natural tolerance with each increased dosage. Many hospital admissions resulted in me not being able to complete my HSC due to prolonged absences from school. My life seemed bleak and without purpose at that time and I sunk into a deep depression.

Last year, I went to sleep oblivious of the copious amounts of opioids in my body. I vomited in my sleep, and aspirated into my lungs and this resulted in cardiac arrest. My mum and sister performed CPR for some time until the ambulances arrived. My life hung in the balance



Joab receives his Duke jacket from The Hon. Barbara Perry, Shadow Minister for Disability Services and Peter Kaye, National Director of The Duke of Ed Award in Australia



Joab about to receive his Young Achiever Award from Pene Hodge, CEO of MDNSW

as I was on life support in Intensive Care over Christmas and New Year. I have now been weaned off the opioid medications.

This experience has brought home what really matters in life. It made me realise what's important and made me question if I was really getting the most out of life. Most people don't get a second chance at life, however I've been incredibly fortunate to have been given the chance to re-evaluate my priorities. Life has to have purpose and this necessitates pushing yourself out of your comfort zone.

I am intent on making the most out of my life and I am very excited about participating in The Duke Of Ed Award. Although I am predominately doing it for the challenge, I think it will also be beneficial for my employment later down the track. I believe most things are possible if you have a good attitude and put your mind to them. I don't let pain dominate my life and control what I do. Life isn't tied with a bow... it is a gift and I am certainly embracing my new chance in life! Thank you for helping me and many others achieve their dreams...

Joab Olding, 23yrs





MUSCULAR DYSTROPHY
NEW SOUTH WALES

Gala 2013 Ball

Friday 3 May, 2013



Some mums from our Ngundabaa Retreat decided to hook up again



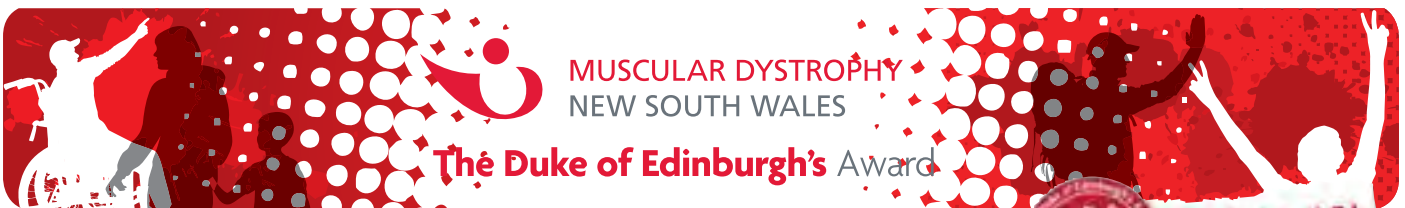
It was great to have Sandra and Margot from SCH attend again this year!



Yep they're a crazy bunch of camp carers Philip!



Mel and her lovely family after she received her Silver Award



Philip wins Sailor of the Year!



Philip Hojgaard-Olsen started his Duke of Ed Award this year and has attacked it with all guns blazing! For his Physical Recreation section he wanted to learn how to sail solo, so Manly Sailability took him on board to help him to do just that! The first couple of sessions involved measuring Philip up and modifying the boat so that it was a comfortable fit. Then for his first go on the water, Philip was tethered the whole time as the Sailability volunteers continued to modify the boat and teach him the finer skills of using it. Not long after that, they managed to let go of the tether, give him some basic instruction, and Philip was sailing on his own! The Club recently presented Philip with an Award for Sailor of the Year, and needless to say, we are all so extremely proud of him!!



Philip can now sail solo!



Philip receives his Award for Sailor of the Year

Loretta Downie - Manager, Events and Client Programs

www.manlysailability.com.au



A big thanks to the team at Manly Sailability above, with Philip second from the right.





MUSCULAR DYSTROPHY
NEW SOUTH WALES

Adventure Camp 2013 Port Stephens

Thanks to **ADHC** for your Continued Support of our Camp Program

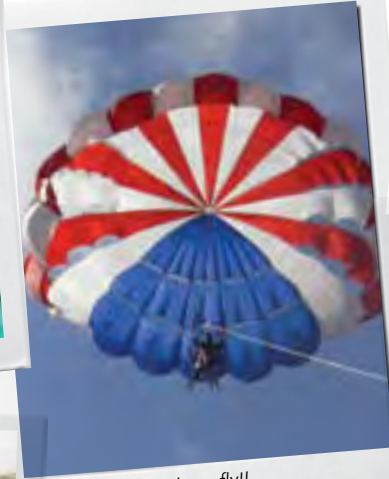
The beautiful weather set the scene for what was going to be yet another inspiring camp! We kicked it off with surfing lessons, where I've never seen a bunch of more determined people try to do their best and conquer the waves. Campers' other favourite activities were sandboarding, quadbiking, parasailing and simply hanging around with their new mates at the Holiday Park. I can't thank the carers enough for their commitment to ensuring that the campers had the time of their lives! This camp has become really popular and will now continue in 2014 thanks to the great support of ADHC.



Mariam, our special carer of the camp



A rowdy mob on the boat



I can fly!!



Patrick and Scott became great mates



Crazy quadbikers



Boomnetting Brothers



Von and KT couldn't stop smiling

“

My family as a whole cannot thank you enough. We have all had one amazing start to this year. The girls have now returned from what I suspect is another life changing event. Thank you again for all your wonderful hard work, time and dedication, these camps really are a credit to you and all the other staff at MD! Jo, mum

”



Sam grabs a piggyback from Erica





MUSCULAR DYSTROPHY
NEW SOUTH WALES

Adventure Camp 2013 Port Stephens

“

Thank you to you and your team for the past 5 days; Scott has had the time of his life and has talked non-stop about all the things he did and the wonderful people he met. Scott felt included like he had never been before and to exchange similar stories with the other boys was very comforting and therapeutic for him. He has made some great friends and can't wait to meet up with them again. *Suzee, mum*



Sophie loved her cuddles with Bec



Jenna impressed us all with her courage



Rowdy roommates



Jess the surfing girl!



Charlie gave great koala cuddles



The Mob!

Thank you for being so amazing at what you do and giving the kids an opportunity to step outside their boundaries and have an amazing time. It takes a lot of behind the scenes work to get these kinds of things up and running and it truly would not have been possible without you as the backbone! It was one of the most amazing things I have ever experienced, and truly reiterated that paediatric OT is what I want to do. So all credit goes to you for inspiring us all to do our best and create such an amazing event. *Mariam, camp carer*



Scott flew across the sand!



Karate Chop with Bec



What a day!



Patrick prepares to lift off



Blokes in a Boat *Port Stephens*

Luke O'Brien and Dwayne Hayes approached MDNSW and asked for us to run a weekend away just for the Dads. So we sent them away to Port Stephens for a fishing weekend together and the results were nothing short of amazing! **Loretta Downie**, Manager, Events and Client Programs

“ What a weekend. It was fantastic! Loved meeting the dads from other regions and catching up with dads I already knew. It has been a long time since I have been around people where I do not put my guard up or feel apprehensive talking about my family and sharing my experiences. This will be a time and a group of dads forever etched into my memory. I look forward to the time when our paths cross again. **Anthony** ”



Fish fingers anyone!

“ I have just returned from the boys' fishing weekend and all I can say it was a life changing experience for me. The guys were amazing and have given me psychological strength for the journey ahead. I was able to ask questions in a non-confronting environment, therefore I gained a lot of information for future consideration. I have met people I will keep in contact with, and with whom I feel comfortable to discuss anything relating to MD. **Marc** ”



Simon shows how it's done

“ The weekend was great and I enjoyed it! They were great blokes to put together and I thank you for making this possible for me. I met some incredibly great men who have great personality and were great to talk to about anything and they would listen and understand where you were coming from. **Dwayne** ”

“ The benefits of this time to get away with other Dads on the same path with their kids will be felt well into the future. The opportunity to share our stories with other human beings on the same path as us cannot be given a value! **Luke** ”



Blokes off the boat!

“ It was a wonderful weekend for me to have a chance to relax, do some fishing and have a bit of a sleep in. The most value I got out of the weekend was talking to the other dads, finding out information I didn't know, and knowing someone is going through the same stuff as me. There were dads at different stages of their journey so we all had stories and information to share. I think everyone who was there is looking forward to when we can next go again. **Kris** ”

“ Thanks to everybody making this fishing trip wonderful. MDNSW is a dynamic organisation that looks after its members! **Shahzad** ”



Nice flatty Peter!

Melbourne Hits the Mark...again!

A big thanks to ADHC for once again supporting our Retreat Program which aims to give carers a chance to connect with others in similar situations to themselves, strengthen their personal relationships, and give themselves some time out from home so they can continue in their caring role.

Loretta Downie, Manager, Events and Client Programs

Thank you so much for giving us a chance to go on this retreat. It was a very unforgettable time. We had an opportunity to meet other families and share our stories and now I really think that I am not alone any more! There are times when I feel very stressed and depressed and just don't know what to do. There are times I feel so helpless and would always ask, who can help? I have always felt that I am in the middle of nowhere until one day we met you, Loretta and your team. You guys give Mel and our family the opportunity to discover this world; to show us that there is love around us and there are hands always ready to help. You are the angels sent by God! During this retreat, the thing I preferred the most was the night we were in the restaurant and we all sat around the table and introduced ourselves and told our stories. I was so impressed and was very touched. THANK YOU! THANK YOU! **Monica**

This was my first retreat and it has given me the confidence to attend more outings and meet new carers. It was great to spend time with my daughter Jordan; we have never been away on our own before and we both enjoyed the time out. I would definitely recommend this retreat to carers as it creates a great opportunity to liaise with carers/parents. **Donna**



Andrew sampling the cuisine

We feel refreshed by our weekend and everything went fine with the kids while we were away! We enjoyed it and appreciate being included. It was also great to meet all those special people, make contacts and new friends. Great time! **Tara**



Donna on the Yarra

Andrew and I would like to thank you both so much for a wonderful weekend retreat away in Melbourne. It was just what we both needed. We met some fabulous people. You both are so dedicated to your jobs and we appreciate your amazing efforts as always. **Ione and Andrew**



Ione loved the shopping



Lisa and Marcus celebrated their engagement!

It was great wandering the streets and shopping til' I dropped with my beautiful mother. I have never been on a retreat before, it was a real eye opener realising there are other families in a similar situation to us. Everyone was lovely, down to earth and it was very easy to spark up a conversation. Dad and Jye had a great boys' weekend; they played Xbox until early hours of the morning! **Jordan**

Narrabeen Camp
Kula N'Gadu 2013
Mon 23 - Fri 27 Sept



The Great Boccia Bash
CPA, Allambie Heights
Sun 24 Nov



Sydney Metro Christmas Party
CBA Function Centre, Parramatta
Sun 8 Dec



Details on our website!



Transition to Adult Health Services

Is your child approaching Transition to Adult Health Services?

INTRODUCING TRAPEZE - A SUPPORTED LEAP INTO ADULT HEALTH

Trapeze is a Sydney Children's Hospital Network (SCHN) service that provides support for young people with chronic conditions as they transition from paediatric to adult health care. Young people must be 16-25 years old with a chronic health condition such as a neuromuscular condition. Trapeze will assist young people in developing stronger links with a GP and their medical specialist if required. The friendly Trapeze staff can provide telephone support, case management, health coaching and

general assistance in navigating the health services. Practical issues such as ensuring the young person is accessing appropriate entitlements and has obtained their own Medicare card can also be discussed.

If you are interested in gaining further information about this service, please phone Trapeze on 8303 3600 or email your enquiry to trapeze.schn@health.nsw.gov.au. Alternatively contact Melissa Wentworth-Perry at MDNSW on 9809 2111.



The NSW Agency for Clinical Innovation Transition Care Network

The NSW Agency for Clinical Innovation (ACI) formally known as the Greater Metropolitan Clinical Taskforce (GMCT) Transition Care Network commenced in 2004. The Network aims to improve the continuity of care for young people with chronic health problems as they move from paediatric to adult health services. Network Manager, Lynne Brodie, leads a team of three Transition Care Coordinators based at Westmead Hospital, Royal Prince Alfred Hospital and the Kaleidoscope Youth Health Team in Newcastle. The Coordinators are affiliated with the NSW tertiary children's hospitals in Sydney and Newcastle. The network extends across all local health districts in NSW.



How can we help

The Transition Care Coordinators work together to provide support to clinicians, young people and their families across NSW.

They help young people to prepare for the move, find appropriate adult health services, provide information and support when they transfer from children's services and follow up to help make sure they stay engaged in adult services.

Coordinators' Contact Details

The Western Area: Patricia Kasengele. Phone 9845 7787
Email: Patricia.Kasengele@swahs.health.nsw.gov.au

South Eastern Area: Katya Issa. Phone 9515 6382
Email: Katya.Issa@swahs.nsw.gov.au

Northern Area: Angie Myles. Phone 4925 7866
Email: Angela.Myles@hnehealth.nsw.gov.au

Visit our Website: www.aci.health.nsw.gov.au/transition

Upcoming Regional Events

Northern Rivers Social & Support Group	
Sun 1 Aug	Alstonville Dinner at 7pm
Sat 26 Oct	Come Spa with Me
Hunter	
Fri 12 Jul	Hunter Teams Cup, Boccia
Hunter Social Support & Events Group	
Sun 28 July	Heritage Cafe
Tue 5 Nov	Fashions on the Field
Illawarra/Shoalhaven	
Tues 23 Jul	Illawarra Shoalhaven Social Support Network
Tues 27 Aug	Illawarra Shoalhaven Social Support Network
Tues 24 Sep	Illawarra Shoalhaven Social Support Network

Riverina	
Thu 29 Aug	BOB (Blokes out Bush) Riverina Mens' Group, Narrandera
Thu 29 Aug	Duchenne Carers Dinner, Wagga Wagga
Central West	
Sun 1 Sept	Wicked Rollers, Boccia
Sun 3 Nov	Wicked Rollers, Boccia
2013 Regional Christmas Parties	
Sat 9 Nov	Illawarra Christmas Party
Sun 10 Nov	Far North Coast Christmas Party
Sun 17 Nov	Central West Christmas Party
Sun 1 Dec	Hunter Christmas Party

Tips 'n' Tricks

from the Client Services Team

Tips
& Tricks
for Living

Licence To Cook!

Do you have difficulty with swallowing, dysphagia or would like information on nutrition?

Disability SA's *Licence to Cook* kit provides useful information on nutrition, swallowing, dysphagia, meal time management, nutritious eating and how to reduce the risk of choking in people with disabilities. *Licence to Cook* costs \$95 and is available at www.shop.service.sa.gov.au.

Bear Cottage

Did you know that you can self refer to Bear Cottage?

Need to find services in your local area?

Check out IDEAS (Information on Disability & Education Awareness Services) at www.ideas.org.au/ and click on Directories, then Community Services to explore their in-depth database on services, equipment and accommodation!

Need Home Care Services?

Some people don't realise that they can refer themselves or people they know for Home Care by calling the numbers below.

Sydney Metropolitan Area: 1800 350 792
Hunter: 1300 731 556 Other regions: 1300 881 144
Aboriginal Access and Assessment Team: 1300 797 606

For more information visit www.adhc.nsw.gov.au and click on Individuals, then Help At Home & Homecare Services.

Need a higher level of Home Care?

The High Need Pool is for people that may need additional hours of support and may be available for people with a disability who need more than 15 hours per week of help from Home Care Service to continue living at home. This service is called 'High Need Pool'.

See more at: www.adhc.nsw.gov.au/individuals/help_at_home/home_care_service/services_for_people_with_high_support_needs

The Attendant Care Program (ACP) provides portable, flexible and individualised support for people with a physical disability and/or who need personal help to complete activities of daily living, and can provide more hours than the High Need Pool - See more at: www.adhc.nsw.gov.au/individuals/support/everyday_living_support/attendant_care_program

Mindspot

The MindSpot Clinic is a free telephone and online service for anyone to access who has stress, anxiety, low mood or depression. They provide mental health screening assessments, therapist-guided treatment courses and referrals to help people recover and stay well. The Mindspot Clinic team include psychologists, psychiatrists, social workers, and indigenous mental health workers. It is fully funded by the Australian Government Department of Health and Ageing www.mindspot.org.au

The NSW Home Modifications Information Clearinghouse Project

A website which provides useful resources to support frail aged people and people with a disability and their carers so they may live more independently. The website includes a Service Directory with quick links to Home Modifications Service Providers, OTs, tradespeople and suppliers as well as fact sheets and answers to FAQ's.

Visit: www.homemods.info

A special access key for people living with a disability

The Master Locksmith Access Key (MLAK) allows 24 hour a day access to public facilities e.g. disabled toilets or facilities that are normally locked afterhours. You need written authority from your GP. The Key can be purchased from the Master Locksmiths Association of Australasia. Call 1800 810 698 or www.masterlocksmiths.com.au.

CHILDREN'S CLINICS

Sydney Children's Hospital, Randwick
Neuromuscular Clinic

Outreach Clinics - Canberra Hospital,
Canberra, John Hunter Hospital,
Newcastle, Goonellabah Clinic, Lismore
Appointment & enquiries 9382 1845

THE NEUROMUSCULAR CLINICS

The Children's Hospital at Westmead
Neuromuscular Clinic

Appointment & enquiries 9845 1904
The Neuromuscular Management Clinic

John Hunter Children's Hospital
Newcastle 4921 3932

ADULT CLINICS

Concord Hospital Neuromuscular Clinic
9767 6864

Prince of Wales Hospital, Randwick
Nerve and Muscle Clinic 9382 0722
Adult Genetics Clinic, Westmead
9845 3273



meet our members

We thought you would like to be introduced to Carole Cullen and her husband, Tom. They have just celebrated their 50th Wedding Anniversary on board a ship crossing the Equator, where they reaffirmed their vows. Carole was diagnosed with FSHD at 18 years of age.



Where did you go on your first date?

Jiving (dancing) at the Church Youth Club

What about your partner made you want to go on another date?

Carole: He seemed very mature

Tom: She was a nice girl

What was Carole/Tom wearing?

Carole: A red shirt (the only decent one he had!)

Tom: No idea – it was dark!

If you found \$100, and could only spend it on your partner, what would you buy for him/her?

Carole: A meal at a restaurant and a taxi there and back so he doesn't have to drive

Tom: A ticket to see a Musical

Where in the world would you like to send your partner for a week by themselves?

Carole: He's not going anywhere I can't go too!!

Tom: Florida

.... and why?

Carole: What would he do for a week alone?!

Tom: It's got everything

What was the first present you bought your partner?

Carole: An Acrist watch from my Grandma's catalogue

Tom: A record – Jim Dale singing 'Crazy Dream'

If a movie was made about you both who would be most suited to play your partner's part?

Carole: Hugh Jackman

Tom: Judith Durham (The Seekers)

What do you think your partner would be talented at (something they haven't tried yet)?

Carole: Surfing

Tom: Mastering how to use our camera – then she can teach me

Who has control of the remote control?

Carole: I do. I send Tom in the bedroom if he wants to watch another channel!

Tom: I do. I can put it out of reach!

What was the most memorable day you spent with just your partner?

Carole: At a very romantic restaurant in Wigan England, looking through the window watching the snow falling – it was perfect

Tom: Our visit to the Grand Canyon at dusk

What's your partner's worst habit?

Carole: There's not enough room to list them!

Tom: Fiddling with her ear

What word best describes your partner?

Carole: Mr Wonderful

Tom: Brilliant

What is your partner really really not very good at?

Carole: Being told he's wrong

Tom: Playing darts!

What made you come to Australia?

Carole: Our only daughter and family emigrated – we followed. We love this country

Tom: Our precious family emigrated

Who does your partner sing like?

Carole: Bart Simpson!

Tom: Himself

Name one thing not many people know about you:

Carole: I was invited to a Garden Party at Buckingham Palace (the Queen was there)

Tom: I was a good soccer player

If you HAD to change your partner's name, what would you change it to?

Carole: Bruce

Tom: Sheila

If you could have dinner with anyone in the world who would you choose?

Carole: Sir Cliff Richard

Tom: Sir Alex Ferguson

Who is the chef and who is the bottle washer?

Carole: Tom does everything (I supervise)

Tom: Me

Is there anyone in particular who has inspired you along the way?

Carole: My dad

Tom: A priest in England– Neville Bateman

What is your secret to a long and successful marriage?

Carole: Still in love, still caring and sharing

Tom: Give and take and patience

What type of MD do you have?

FSH

Have you met anyone else with your type of MD?

Only at MDNSW events

What's been the hardest part about having MD?

Carole: Not being able to pick up our granddaughters as babies - and now our great grandson for cuddles

Tom: Frustration for Carole being dependent on others

What do you most admire about Tom/Carole?

Carole: Everything

Tom: Her intelligence and confidence

At what age were you diagnosed?

Aged 18 but the type wasn't identified then, just I had MD

*Happy 50th
Wedding Anniversary
Tom & Carole!*



MD Ireland and our Home from Home

Straws. A packet of drinking straws in the kitchen. That was one of the first things we noticed when we walked in to the apartment. For those who have been on an outing without drinking straws, you will know how thoughtful this small gesture is. This was an indication that we would feel right at home here at "Home from Home", and we did – what an amazing place!

"Home from Home" is an apartment in Dublin, set up and run by Muscular Dystrophy Ireland (MDI), and is available for stays as short as one night. MDI promotes independent living for people with Muscular Dystrophy and allied neuromuscular conditions, advocating for services to enable people with neuromuscular conditions to fully participate in society and to live a life of their own choosing.

We spent three nights in the apartment during May as part of our family holiday in Ireland. The apartment is modern, self-contained, and fully accessible. It has four large bedrooms – two with enormous shower rooms – along with a separate shower room, a living area, kitchen and laundry. Three bedrooms and all shower rooms have ceiling track hoists. The beds are height-adjustable and all bedrooms have a TV and a DVD player. The facilities were better than anything we could have imagined and during our three days and nights at Home from Home we got some great ideas for how we could modify our own home in Sydney as our daughter gets older.

The friendly atmosphere at Home from Home is helped by interaction with other guests in the common rooms, and with the wonderful staff from MDI who work in the offices downstairs during business hours. In particular, Sinéad from MDI made us feel very welcome throughout our stay.

The location of Home from Home is ideal, being only a short drive from both Dublin city centre and the orbital motorway that curves around the city. Wheelchair accessible buses to the city stop outside the apartment, and a taxi to the city costs around €20. We hired a wheelchair accessible van from



the Lucan Disability Action Group, who have a range of vans to suit most needs and are located about 15 minutes drive from the apartment.

In the apartment we found a helpful guide of things to do in Dublin for wheelchair users. We chose to visit the Dublin Wax Museum (accessible on all floors except the basement), and the Leprechaun Museum (fully accessible) for a bit of craic and Irish story telling. As for shops, pubs and restaurants, not all are fully accessible but there are more than enough in Dublin city to keep you fed, watered and clothed. And a relaxing stroll through St. Stephens Green (or the quieter Merrion Square) in the spring sunshine is highly recommended as a relaxing get-away from the bustling streets.



Thanks to MDI, we thoroughly enjoyed our stay in Dublin, and our only regret is not spending more of our holiday time there! The Home from Home apartment itself is a testament to the people who

work at MDI – their generosity and passion for improving the quality of life for families like ours is incredibly humbling. I can highly recommend Home from Home for anyone considering a trip to Dublin.

Martin Boers



My Surgical Boots are Made for Walking

With CMT my feet have never worked very well. I could never play sports and if I was made to do cross country running at school I was always last back, sometimes by hours, and sometimes I would often miss the rest of the school day. This was in the late 1950's and at the age of 14 I spent almost six months in hospital having feet operations/reconstruction [Pes Cavis] so that I could walk better. On leaving hospital I was given ordinary shoes to wear. These were an improvement and I could do most things until my muscles began to slowly deteriorate.

I have been having surgical boots made with a Klenzig below the knee with steel spring loaded callipers for both feet for 35 years. Although these boots helped me to walk they were very uncomfortable and weighed over 2 kgs each and often twisted out of shape requiring constant repairs.

On a visit to Professor Corbet two years ago at Concord Hospital, he suggested I get rid of the steel callipers as the weight was making me tired. I was told about a specialist boot maker Foot Power, so I called and made an appointment for that afternoon. On arrival I was made to feel very welcome and important. After a discussion they inspected my boots, feet, ankles and legs. I began a 3 step consultation program:

Step 1: I was asked to walk on a Gait Analysis treadmill. This is important as it assesses where your feet may need support. At the Foot Power clinic, a sophisticated computerised plantar pressure measurement system is employed to analyse your gait and help develop the optimum treatment plan.

Step 2: Empiric gait analysis which involves the Foot Power practitioner assessing your walking or running style. This is included in the basic consultation fee.

Step 3: Computerised gait analysis which utilizes two cameras and a sophisticated software program to analyse your personal running/walking style, ultimately generating a detailed report.

My new boots were then made. The steel Callipers are gone and with carbon fibre built in to the boots, half



David Jones from the Riverina Region

David's new surgical boots

of the weight is gone. I now have a pair of fashionable boots that are so comfortable they are like slippers; I don't even like taking them off at night. I can walk further and can now even stand in a queue which is something I have never been able to do without wobbling around. I also had trouble with one knee being thrown out of alignment and being very painful, however since having the boots this has righted itself, which is wonderful.

After 12 months of wearing my new boots 14 hours a day every day, they have not twisted out of shape and have hardly worn down on the heels. So if you are having surgical footwear made I would suggest that you go and see the team at Foot Power at Dee Why, 9972-4488 or email reception@shoetech.com.au. I do not work for the company, I'm just a satisfied customer! Enable also cover the costs of the footwear.

For other information:

<http://footpower.de/Footpower-Partner/footpower-Sydney/Gait-laboratory/412511/>

http://shoetech.com.au/about_us.html

David Jones, Riverina

Cory Tierney's story

Hi, my name is Cory Tierney and I have just turned 10 years old. I have been diagnosed with Duchenne Muscular Dystrophy (DMD) and I live in Armidale. I would like for you to read my story as it may help you or someone that you know.

It took some time for me to get used to being in my wheelchair full time as I used to be able to walk around the house holding on to grab rails. As time went by, things got harder and harder for me to the point that I could not bear any weight on my legs at all. My mum never gave up hope and she took me to the physio and hydrotherapy each week. Every night she would also make me do my stretches even though some nights I would fight with her over this.

The last 18 months of my life have been the hardest for me. My lungs are not working as well as they could be; my legs are locking at the knee joint in a 50 degree position and I was so sick in January that I spent a lot of time in hospital. When I came out of hospital my mum took me to see Lisa Rowe who is a massage therapist in Armidale. I see Lisa once a week. One day I asked Lisa if she could do anything to help my legs as I have asked many people and doctors about it and they said there was nothing they could do. Lisa

referred me to Michael Griffith, a chiropractor and I began to see Michael 3 x times per week and Lisa once a week.

As the weeks went by, I began getting movement back in my legs and they were getting stronger. I was able to kick my soccer ball although it didn't go very far. I love having movement back in my legs as I can now sit on the lounge and roll the soccer ball around with my feet. It was my 10th birthday in March and I was able to kick my soccer ball really well. My lungs are much better and I no longer need my puffer. I look much healthier and have a lot more energy. I am so happy with the wonderful work Michael has done on me. Just after my birthday I had to go to Newcastle to see the specialist and he was amazed with me he said "that he had never seen anything like this before". My legs are now that strong that I do not need my splints, which is a good thing as I don't like them. My lungs are still going strong which means I don't need to see Lisa as much. I will miss not seeing her each week.

When we got back from Newcastle, Mum told Michael what the specialist had said and now they have decided to try and get me back on my feet. I will give it all I have and we will see what happens. At this stage in my life I could not be happier. The changes Michael has made in my life has also changed my Mum's life as she is much happier and not so stressed anymore. I need to say a very big thank you to 3 x special people in my life that have supported me and have given me so much hope and they are my Mum, Lisa and Michael.

I will not be stopping here as things can only get better. I am living proof that the doctors do not always know everything. So give everything a go. You have nothing to lose and a lot to gain. My Mum has said "the only regret she has, is that she didn't find Michael sooner". The End

Cory Tierney, Armidale



Ella, Cory and Michael

Living Life Her Way Ambassadors and Champions Program

Congratulations to our member Carolyn Campbell-McLean for her successful application to become a *Living Life My Way Champion* in March, 2013. Nineteen Ambassadors and Champions were selected by the Minister for Disability Services, The Hon. Andrew Constance to raise community awareness about disability reform in NSW. Carolyn is using this opportunity to share her story of self directed support and, at this pivotal point of change, ask others how they might like to have more choice and control in their care and support services.

Attending the Person Centred Summit in 2010 Carolyn says she was truly excited that the NSW Government was embracing this policy move towards person centred and individualised models of care and support.



"Since then I have been talking to many people about the ways that services can be provided in more consumer-led or self-directed ways. I do this in my work at the Lifetime Care and Support Authority, through my private training workshops and presentations and through my networks with the In Control organisation, MDNSW and via social media".

"I want to use my role as Living Life My Way Champion to share information, encourage and support other

people with disability. I also want to network with all different people from peers to the media to academics and service providers about the 'new ways' of supporting people with disability. My goal is to challenge traditional ways of thinking, skill up and empower people with disabilities and their families so that they can take control of their support services - and get out there and live an awesome life!"



So far in her Champion role Carolyn has:

- Facilitated a workshop called *Choosing the Best Who for You*
- Presented as a guest speaker at the *My Choice Matters* Hornsby workshop
- Attended a leadership workshop about how the NSW Consumer Development Fund will work
- Spoken to family members of people with disability living in rural and remote NSW via a Google Plus "Hangout" – online from her lounge room!
- Spoken to the MDNSW Board members about DisabilityCare Australia and changes to disability services

Vision for a Person Centred Disability Support System

The NSW Government's vision for a person centred disability support system is one in which:

- People with disability, families and carers are empowered to choose and direct the supports they require to live a good life
- Families and carers can sustain positive and healthy relationships and pursue their own goals
- A diverse and sustainable disability sector offers quality, person centred and cost effective supports

About the Living Life My Way Ambassadors and Champions Program

The purpose of this two-year initiative is to raise community awareness and understanding of person centred supports and the Government's policy directions for self directed support and individualised budgets. The Government is looking for enthusiastic people who are passionate about person centred approaches, have experience in self-managing their supports and are willing to share their experiences and inspire others. Up to 50 community representatives from a range of backgrounds will each be appointed for 12 months as Ambassadors and Champions. Round 2 for this program closed in May and there will be a third round in 2014.

- For more information on the Living Life My Way Ambassadors & Champions program visit http://www.adhc.nsw.gov.au/about_us/strategies/life_my_way and click on Ambassadors and Champions program.
- My Choice Matters - NSW Consumer Development Fund
email info@mychoicematters.org.au phone 1800 144 653 or (02) 9211 2605 mobile: 0428 407 000
- Carolyn can be contacted by email at carolyncampbellmclean@gmail.com and she would be happy to help answer your questions



Scott does his part in Fundraising for MDNSW

Muscular Dystrophy NSW would like to say a HUGE thank you to Scott Green and his family for helping with our collection boxes in the Baulkham Hills Mall. Following his first camp with MDNSW in April this year, Scott wanted to give something back to MDNSW and so he put his hand up to help fundraise for us in his local area. Our collection boxes can bring in a lot of vitally needed funds and we would love to expand the areas we have them in but we don't have the resources to collect more ourselves. They can be placed in any shops from a local pharmacy to a café or bookshop. If you would like to help us with our collection boxes in your area please contact Kags Garrard, Fundraising Manager, on 9809 2111 or email kags.garrard@mdnsw.org.au



Participate in a Challenge Event!

We have some teams entering this year's **City to Surf** on Sunday 11 August and I've even decided to give it a go myself this time around! I'd really love to have as many people as possible join me in this iconic Sydney event as I'm sure I'm going to appreciate all the support I can get to help me get through those 14 kilometres!

We have also been chosen as an official supporter charity for this year's **Blackmores Sydney Running Festival** on Sunday 22 September. We would love people to run in this event and fundraise for us. We also really need volunteers to help out on the day so if you are not keen to participate, then you can always come and support us at one of the drink stations!

If you are more of a cyclist than a runner we have our **Big Red Ride** on Sunday 1 December. This unique ride covers a 145 km route from sea to summit. Participants will start in Bondi and climb to be king of the mountain at the finish line in Katoomba. To help keep you motivated, you will be riding alongside Australian cycling legend Brad McGee and under the watchful eyes of Ben and Kylie Mildren. If you are a keen cyclist, then this event is not to be missed!

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

A Cappella Choirs

On Saturday, 13th April, we had a thoroughly enjoyable evening, being inspired by the harmony and joy of the community a cappella choirs Timbre Flaws and Urban Voices. We had been invited by one of our members, Melanie Rankine, who had organised that the proceeds from the evening would be donated to Muscular Dystrophy NSW. We entered amongst a bustling throng to a full hall at Epping. Once proceedings got underway we were captivated by the melodies and harmonies given forth by both choirs. Truly this was a living example of how much greater the whole is when all the parts work together. A truly enjoyable night which raised an incredible \$770 for our organisation – thanks so much!

Maralyn McCann Office Manager



Timbre Flaws

Successful Grants 2013

We would like to say a huge thank you to:

The St George Foundation for their amazing grant of \$18,000 for our Counselling program

ANZ Staff Foundation for \$10,000 for The Duke of Edinburgh's Award program and for supporting and expanding our Boccia program

ING Foundation for \$25,000 for The Duke of Edinburgh's Award program

Canada Bay Club for \$1000 towards ongoing support for families

Annual Golf Day 2013

My playing companion and I arrived early on Thursday morning at Concord Golf Club and had the opportunity to wander through the amazing clubhouse. For a couple of golfing tragics, it was interesting looking at the various shields and honour boards that adorned the walls of the club and was of great interest to learn some of the greats had played and won at Concord such as Greg Norman. It had all the hallmarks of a great day, and the weather was being kind; a beautiful autumn morning.

Breakfast was served and then we moved to a coaching session with pro Ken Trimble, Director of Golf at Concord. He clearly demonstrated the need of correct body position, timing and weight transfer. It was a very impressive coaching session which benefited all.

A shotgun start set the day's Ambrose competition into progress, having moved to our various starting locations. The course was in delightful condition and a joy to play on. Regrettably even my playing partner (who is a member at Concord) was challenged with some of our positions, and I'm sure Mr Trimble would have politely suggested another sport! Never the less a great day and a wonderful opportunity to play on a great course with so much golf history.

Lunch, then a successful auction finished a delightful day's play as \$19,000 was raised from the event. It was interesting to hear David Speers and General Jeffery speak and one could not help being affected by Joab's story. To hear these inspirational people speak, who have overcome enormous difficulties in their lives as if it was an everyday occurrence, was truly inspiring.

Great day, and thanks for inviting us to play. Fantastic!

Rob Dawson MDNSW supporter

Muscular Dystrophy NSW would like to thank everyone who supported our Golf Day 2013 and say a huge thank you to our main sponsor D.J. Batchen Pty. Ltd.



The McLennan's Make a Motza for MD

Kay and Reg McLennan's 14-year old grandson Joe has MD and he has been heavily involved with MDNSW's Duke of Ed and Camp programs over the years. In April, Kay and Reg held not 1 but 2 Golf Days in Grafton to raise money for MDNSW and they said they'd been "absolutely blown away" by the response to both events.

A mixed round was played first, with over 60 locals lining up to participate in the day and the weather certainly turned it on. As the golfing drew to a close that day Kay, Reg and the family put on a BBQ, raffles and an auction to raise money. Even the grandkids got involved and held a jellybean guessing competition which Bernie, the bar maid, was more than happy to win. No-one was more deserving as she managed that bar single handed on the day and probably needed a sugar hit at the end of it!!

The following week, a Ladies' Golf Day was held where more raffles and prizes were in abundance and no one went home empty handed. Over \$4000 was raised over the 2 days! Kay and Reg are hoping to do some even bigger events next year! It just keeps getting better!

I love this quote from mum (Kay) when I commented on how exhausted she looked the next day.

"Don't be silly. Looking after a child or children with muscular dystrophy is exhausting. I can rest now and catch my breath but for a lot of families, that isn't always possible."

Thanks so much to my Mum and Dad, my family and the Grafton community who are always a loving support and great fun to be with.

Vicki Sciulli

If you would like to organise a golf day or any other fundraising event for Muscular Dystrophy NSW please contact Kags Garrard, Fundraising Manager, on 9809 2111 or email kags.garrard@mdnsw.org.au

Congratulations Tom

We would like to say congratulations to Tom Wilson for receiving a Community Service Award from Mike Baird, Treasurer of New South Wales, for his amazing fundraising for Muscular Dystrophy. He raised over \$30,000 during his ride Tour Duchenne and he will be joining us again for our Big Red Ride on 1st December!

Sarah Wilson (Tom's wife), Pene Hodge (CEO of MDNSW), Mike Baird (Treasurer of New South Wales) and Tom Wilson



Thank you to our very generous supporters who have so kindly given to us this financial year the following donations:

Donations over \$5000

Denis & Fay Russell, Peter Connor, Ian Williams, The Wales Family Foundation, Shirley Williams, Turramurra High School

Donations over \$1000

Ross Simpson (Concord Golf Club), Rick Arnheim, Peter and Deborah Debnam, Kay and Reg McLennan, John Freedman (The Artarmon Masonic Hall), Douglas Kirkham (Canada Bay Club), Katherine Holihan, Irene Caldwell-Ash, Stuart Garton, Shannon Finch, Ross Parker, Sally Egan, Bruce & Jill

Vaughan, Colin Gunn, Margaret Callister, Bruce Duck, HOGs, Graeme Troy, Team Budy Smugglers, John and Stanley Roth, Melissa Stewart (Singing Santas), Annabel Arnheim, N.E.W.S (NSW)

Donations over \$500

Joanna Fleming, Peter Donkin, Dr. Kristi Jones, Urban Voice (Melanie Rankine), Lorna Higgs, Angelina Ierardo, Donald Sanders, Valma Pfitzner, Lionel Robberds, Philip Bates, Andrew Noble, Beth Durran, Geoff Peetz,

John Brindley, Lewis Rangott, St Johns Bowling Club, June Holdsworth OAM Lioness Club of Camden, Alan Giumelli, Olive Walker, Greg and Pene Hodge, Denise Irvin, Belinda Randall

Donations over \$250

John Bridge, Gordon Love, Marissa Brammer, Rob Ferguson, William Harding AM, Wendy Buckley, Jeff Simmonds, Gregory Burton SC, Dan Williams, Carole Cullen, Keith & Moira Heness, Anthony Mansour, Barbara Allan, Baulkham Hills North Public School, Ivy Kanawati, Suzanne O' Connor, Alys Anne Powell, Chika Sakane, Cam May Chung-Wright, Ashley Hostnik, Marcus Patrick Cullen, Julie Tate, Lynette Walker, Sally Moon, Todd Lyons, William

Bennett, Koorinal Hotel, Anytime Fitness, Castle Outdoor Creations, Des Mullins Electrical, DS Taber Electrical, Fitzpatricks Real Estate, Ian Hurst Carriers, Inspirations Paint & Colour, JRM Accounting, PAH Innovative Construction, Richard Skellern, Riverina Australian Football Club Ltd, Riverina Gate and Fencing Warehouse, Riverina Pool Supplies, Steel Supplies, James A Hislop, Noela Bell, Barbara Perry

Donations over \$100

Alison Wason, Janice Powell, Melanie Rankine, Wendy Clayton, Robert Glynn, Debra Cox, Prof. Alastair Corbett, Barbel Stuhr, Charles P Curran AC, Doreen Best, Jason O'Connor, John Samuel Scrogings, Lynn Joffe, Manuela Crank, Mark Wilson, MD Cullen, Rob & Kyrenia Thomas, Patricia Irving, Rob Erhardt, Stewart Gamble, Anthony Dessel, Charmaine Yu, Margaret Williams, Beryl Benbow, Angie Devine, Kim Foster, Sharon Robson, Raymond S Chui, Nicole Murray, Annette Stace, Andrea Watts, Wilyama High School, Maria Salazar, Angus Dorney, Cosimo Martinis, G.A. Deudekom, Ian Coutts, Jenny Farrell, Lauren Harvey, Sharon Weir, Terry Gordon, Cameron Provost, Daphne Spurway, Graeme Green, Clara Loughland, Monica Lim, Stitching Group Gordon Uniting Church, Pamela Powell, Geraldine Hannah, Reynaldo Bambo, Lynne Nickols, Adrian Sobol, Kevin Yeung, Roxanne Young, Prof.

Graeme Morgan, Andrew Aiton, Anne Burton, Belinda Randall, Christine Andrews – Windmill, Claire Gralton, Craig Boettcher, David and Judith Kirby, Don Couch, Dorothy Chaseling, Doug Crabbe, Edmund Gralton, Eric and Shirley Griffiths, Geoffrey Graham, Gordon & Colleen Cox, Ian Hunt, John Whitehurst, Judith Ireland, Keith Houghton, Kristina Jaworski, Lorraine Symes, Lynne Bastock, M Smith, Michael High, Michelle Harrison – Provenzano, Pamela Heikkinen, Paolo and Antonella Petrone, R & S Jaques, R A & A D Gaff, Robert and Elaine Anstey, Robert Menadue, Rosemary Anderson, Solange Merdith, Tim McCabe, Tony Ryan, Vikki Bezina, Y F Roden, Antoinette Baron, Grafton Travel Agency, Lisa Kee, Megan Stewart, Aaron Flagg, Edward Lord, Janette Lundman, Janice Davis, Judy Herbert, Pauline Roberts, Peter Howes, Trish MacAlpine, Linda Favalaro

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

Donations were also made in memory of:

Anthony Russell, Graeme Pfitzner, Douglas Harding, Tom Bryne, Wesley Christopher, Phillip Stace, David Eric Nickols, Wesley Grivas, Sue Connor

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 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

Office Manager
Maralyn McCann

Finance Manager
Chaitali Desai

Finance Assistant
Gracia Selina

Manager, Events and Client Programs
Loretta Downie

Project Assistant
Jenny Smith

Fundraising Manager
Kags (Katharyn) Garrard

Client Services Coordinator
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