

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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Time to take a break



MUSCULAR DYSTROPHY
NEW SOUTH WALES

editorial

Spending time with family and friends over Christmas reminded me again of the importance of taking a regular break. In this issue of Talking Point our Education Coordinator, Liz Bailey writes on the benefits to well being when taking a break.

Illustrating the value of time out some of our members report on their special family break, and our FlexiRest program is again profiled offering financial assistance to make your getaway possible.

Our 2011 MDNSW Events Calendar has been recently published with something for everyone. Our 2010 year ended with Christmas Parties in Sydney and some regional areas and 2011 commences with the very popular Adult Retreat in March. Following the huge interest in our

Retreat we are looking at ways to add further weekends to the Retreat calendar.

NEWS (National Electric Wheelchair Sports) is very active, providing opportunities for the sports minded member to participate and develop their skills. We have many dedicated and successful athletes in NSW who represent the State at the annual NEWS Championship planned for April in 2011.

This issue of Talking Point also features an article on clinical trials by our new Medical Director, Professor Alastair Corbett, and introduces a member family in our new column, "Meet a Member."

MDNSW is very fortunate to have many amazing people volunteer their time in numerous ways. At the end of last year we acknowledged Dr Heather Johnston for the valuable role she has played as Medical Director over the past 10

years. She remains a Board member and continues to contribute. I would also like to acknowledge Carolyn Campbell-McLean, our Talking Point Editor for the past 5 years. She has been instrumental in overseeing numerous positive changes to Talking Point and supported the development of MDNSW.

Carolyn continues to be an advisor to MDNSW and involved in many activities as a member.

Each year Muscular Dystrophy NSW seems to get little busier with new ideas and services. If you have an idea for something which could benefit members, please let us know.

David Jack
CEO

All contributions can be sent to The Editor, PO Box 1365 Meadowbank NSW 2114 info@mdnsw.org.au Tel: 9809 2111

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A Word from the President

Hi there, and best wishes for 2011!

The Queensland floods, like the Victorian bushfires, as harsh and debilitating as they are bring out the best in the Australian character:- determination, tenacity and resilience.

But no one is immortal or impervious to adversity, and it takes a toll, both physical and emotional.

Similarly, those with a neuromuscular disorder, their loved ones and carers, fight an ongoing battle, which takes a considerable toll on them.

At times we all need to restore our physical and mental well being, with a break, rest, holiday, or respite.

Possibly the greatest need is an emotional rest and sustenance, and while we assist members through our FlexiRest program with funding for members' choice of respite, I'm sure there is more that we can do to assist with emotional needs.

For our members, the course of life is strewn with difficult decisions, the need to adapt, difficulty in coping with guilt, conflict, and grief, and the emotional strain of daily life.

Our Home Visit program allows us to get closer to our members and assist them with advice, tapping into resources or just making difficult decisions.



Perhaps the next step is to provide the emotional support our members need through specialised counselling, and professional therapy, to help overcome their greatest challenge of all: coping with the strain and stress of living with a neuromuscular disorder.

Rob Ferguson

President, Muscular Dystrophy New South Wales

A family's Getaway

The Hannah family is a very close, happy family. Children Kenneth 18 (who has Duchenne MD) , Kalen 14 , and Breeze 10, live with their Grandparents Gerry and Noel and their Dad, Ken.

We asked the Hannah family how they planned and organised their holiday and its importance to them.

How do you plan your holidays?

We plan our holidays around work. We ring 12 months ahead to book at the holiday cabins. We coordinate with Ken's family and brother as to when they will be staying at the Currarong camping grounds nearby.

How important are your holidays?

Our holidays are extremely important to us. We prefer to be together. It is a respite break. It is not too far to go from home, only one hour 20 minutes. We like Currarong, it is a getaway, different. Five to six families get together every year. It has been a family tradition.

Do you know about FlexiRest?

No, we did not know about it, but will in future.

What do you do on your holidays?

We relax, swim, meet up with family, play board games, check out the native animals i.e. the kangaroos, enjoy the different birds and go for walks.

What is most important for you to do?

Getting together with the Family, and relaxing and free time without ties.

What are the benefits of your holiday during the year?

Looking forward to it every year. It is very important to all of us.

COVER PHOTO:

Outside one of the Currarong cabins the Hannah family stay in during their week's holiday.



Why Taking A Break is Good For You!

For so many of us, it's easy to get caught up in the chaos and routine of life that we often forget to take time out from it. We can get so caught up in worrying about all the things we need to do to get through each day that the idea of a holiday just stays there in the back of our minds. However, with the right planning and preparing, taking a holiday really is achievable. Most importantly, there are great physical and emotional benefits of taking time out and relaxing that put us in a good position to then return to our normal routines feeling a little more refreshed. It's like recharging the batteries!

THE BENEFITS OF TAKING A BREAK

It doesn't matter where you choose to go for a holiday. Spending time with the special people in your life in a different place allows you to bond with each other. It might be a new and unfamiliar place, or favourite destination that you already have good memories of. Whether you're relaxing on a deck somewhere, or building a campfire and pitching a tent, it's time spent together outside the normal routine back home.

While on holidays, you can take a breather which allows time to focus on each other and for everyone to have some time out for themselves. Having this time away can free up some space to relax and enjoy time out. It can also be a good opportunity to take some new or different perspective on the bigger decisions and important things in life with a clearer mind.

RELAX!

There is more opportunity to spend time relaxing when on a holiday, and to feel the positive effects of quality relaxation. Sometimes we may not even realise that we need some time out to relax until we get out and breathe in the fresh air! Relaxation helps with stress reduction, which has a positive effect on our body and mind. Stress is hard to avoid when we have busy lives managing competing demands, but taking a few days out of our schedule and having a change of scenery can have lasting effects. By bringing the body and mind back into balance, we feel calmer, have an increase in energy, and can think clearer. It gives us time to laugh with those closest to us and enjoy quality time spent together.



HAVE AN EXPERIENCE - MAKE NEW MEMORIES!

Going away on a holiday where you have a few days to settle into a new environment allows time to do new things, learn new skills or build on the ones you have, teach each other and laugh with each other. These times spent together can create memories that we carry with us and remember years down the track.

Creating an experience means seeing new things, doing things differently, spending time with those close to us, and making memories. The most important thing is to enjoy!

Where are you going for your next holiday?

Liz Bailey

Education Coordinator

MUSCULAR DYSTROPHY NEW SOUTH WALES camp 2011

WHERE

Sydney Academy of Sport and Recreation, Narrabeen

WHEN

Monday 26 September
– Friday 30 September 2011

AGE

The camp is open to anyone with a neuromuscular disorder, ranging from young children through to young adults. Activities are age appropriate and many sessions will be grouped according to the age of participants.

COST

\$120 per person

Full cost of the camp, including transport there and back, can be covered under our Flexi-Rest program - just ask Loretta how we can organise it for you.

INCLUSIONS

Cost includes all food, accommodation, equipment hire, one on one care as required (carer provided or you can bring your own), and participation in a HUGE variety of unique activities and experiences.

WANT TO REGISTER FOR CAMP OR FIND OUT MORE INFORMATION?

Please contact Loretta at Muscular Dystrophy NSW on 9809 2111 or loretta.downie@mdnsw.org.au

The camp is very popular and places are strictly limited, so get your Application Form in early to avoid disappointment!

Meet A Member

Maralyn meets Rowena Newton, mother of two, from Umina Beach, NSW.

Rowena works in Marketing and PR and also does the publicity for Ettalong Public School

Can you name one goal you have?

To get books published, one on life lessons and children's books

What do you really like doing?

Writing and Photography

If you were to win \$10 million, what would you do with all that money?

Publish my books, travel, donate to charity and purchase a pink Combi

If you were to get an opportunity to live anywhere in the world, which part of the world would you choose?

Byron Bay, NSW, Australia

Why Byron Bay? **The scenic beauty, beaches and green hills, and its healing qualities**

If you had to evacuate your house immediately what two things would you grab (cannot be people or pets)?

Photographs and my writing

If a movie was made about you, who would play your part? **Toni Collette**

What would you like to be talented at? **Kicking a ball**

What was your best subject in school? **History**

If someone was to give you a gift, and money was no object, what would you want it to be? **World trip for family with Mary Poppins**

If you were visiting the zoo and could go into any cage with an animal, which animal would you choose to spend 20 minutes with? **An Orangutan**

What is the bravest thing you have ever done? **Drove to Queensland as a solo drive**

If the whole world were listening, what would you say? **The golden rule - 'treat other people as you would like to be treated'**

Are you a collector of anything? **Yes. Old books, photographs and family keepsakes, kid's artwork**

Is there anything you would like to collect? **Gold Bars**



Have any bad habits? **Buying too many books, taking too many photographs**

Who would you most like to sing like? **A modern day, female Louis Armstrong**

What would you like to learn more about? **How to keep going through all the tough times**

What family tradition/routine do you love most? **Going to the beach**

Name one thing not many people know about you? **Writing songs (but not a musician)**

Why did you become a member of Muscular Dystrophy NSW? **I joined in Dec 2010 wanting to know what supports were available to me.**

Inspiring Members

Lucy and Phil Bates and their beautiful native garden recently featured on Gardening Australia. Despite Phil having Muscular Dystrophy and a decreased freedom of movement, with the assistance of Lucy they have transformed their small suburban block in Newcastle into a wonderful garden oasis. For further details and to view the full story go to <http://www.abc.net.au/gardening/stories/s3056243.htm>



Case Management Update

I started with Muscular Dystrophy NSW in December and as I reflect upon my time here so far the first thing that comes to mind is the truly amazing welcome I have received from members and colleagues. Despite putting up with me learning the ropes and trying to remember names everyone has been very patient with me, and I would like to say thank you for this. I am very excited to be part of the Case Management service and I hope it will be a useful service to members. It is also exciting to be part of an organisation that is enthusiastic about the development of its services. For those I have already met, thank you for your patience and for making the time to meet with me over what is always a very busy time of the year. For those who have not taken advantage of the service please do not hesitate to contact the office to discuss what the service can provide and what it may be able to assist you with.

As the Case Management Service is new I have received several telephone calls querying what a Case Management assessment involves and what the

service can offer. The answer is an assessment involves meeting at a mutually agreed time and place to discuss your needs, and to develop an action plan together. The time an assessment takes depends on an individual basis. Some examples of reasons why Case Management assessments have been undertaken are; meeting new MDNSW members to discuss what Muscular Dystrophy NSW can assist with and help people find out about services in local areas, assisting members to plan holidays, look into accessible activities and transport, as well as to apply for funding assistance to obtain equipment. The action plan can be as big or small as you want as this is planning how to achieve your goals and meet your needs. The plan is reviewed to ensure it is flexible and responsive to change. I hope this has helped answer some questions but again if you have any questions please give me a ring!

A large amount of Case Management is researching and supporting individuals to access available services I am



building up my knowledge of Sydney Metro services and resource and would like to share a few I have found useful with you. If you have any experiences with services or resources that you would like to share, please either give me a call or send me an email at victoria.berg@mdnsw.org.au. The sharing of this information will help other members as well as help us keep our Service Directory up to date.

Victoria Berg
Case Manager

The second phase of Stronger together funding announced

The NSW Government has committed a record \$2 billion in new growth funding for disability services to the second five year phase of Stronger Together, taking the total extra funding over the 10 years to more than \$5 billion. This is the largest increase in funding for disability services in the State's history and the most significant investment made by a State Government in Australia.

The additional funding will increase disability services capacity by an estimated 47,000 places over the next five years and enable the disability services sector to better meet the individual needs of people with a disability, their families and carers. Key features of the second phase of Stronger Together will be the focus on families as key determiners of how resources are used, increased availability of individualised and portable funding arrangements, and a lifespan approach to meeting people's needs.

Download a copy of the policy from the ADHC website: Stronger Together: A new direction in disability services in NSW 2006-2016.

The next phase 2011-2016 http://www.dadhc.nsw.gov.au/dadhc/Publications+and+policies/stronger_together.htm

FlexiRest Review *By the Lancasters*

Venue Name	Quest Apartments Cronulla
Venue Address	1 Kingsway, Cronulla
Accessible facilities on site <i>Eg ramps, hoist access to beds, bathroom description, grab rails, shower seat, flooring, equipment on site, beds, doors, access around the venue, toilet facilities, freewheeler, accessible pool/hoist.</i>	The unit block has two apartments with facilities for disabled. This review is of Apartment 11. Apartment 11, is the disabled apartment with water view. Apartment 11 is on ground level. Has grab rails in bathroom and easy access shower ie no step. Fold down shower seat.
Venue facilities <i>Eg dishwasher, washing machines, pool, spa, BBQs, verandahs etc.</i>	Dishwasher, washing machine, hair dryer, swimming pool, fully equipped gym, fully equipped kitchenette. Could not access small balcony in electric wheelchair, possibly could in manual. Also balcony was noisy, however with door shut the noise closed out.
Room configuration <i>Describe type of rooms. How many rooms, number and type of beds, linen supplied, facilities in the rooms eg TVs, ensuite etc.</i>	Both apartments are studio apartments with one king size bed that can be split into two king singles. TV and DVD. All linen supplied and plentiful. Serviced daily. The Lancasters hired electric bed, which fitted in beautifully. The Lancasters took hoist and commode chair. Apartment was compact, more due to equipment but still adequate.
Activities available on site <i>Eg swimming, putt putt golf, recreational facilities, basketball courts, sporting equipment available, access to beach, fishing opportunities, birdwatching, boat hire, bikes etc. Basically anything on site that can be utilised by guests.</i>	Swimming, fully equipped gym. Beach easily accessed. Board walk that went for ever.
Activities available off site <i>Eg movies, sailing, tours, indoor sports centres, swimming pools, beaches, clubs, bushwalking etc.</i>	Cinema, beach, board walk, clubs, café, restaurants etc, picnic area.
Recommended food spots <i>List names, accessibility, quality of food/service etc</i>	Only tried one Hog Breath Café – accessible. Teenager thought the food was excellent.

Our holiday experience

Best Experience

Being away as a family for three days, first time in six years. Lancaster's were away over the New Year and really enjoyed the hype of the festive season.
Being able to take to time to go for walks, feel the fresh salt air.

Worst Experience

That the Best Experience did not last long enough!!

Would you recommend this venue to our members? Why/Why not?

Definitely, it worked well physically, which is so important for family with a member with Muscular Dystrophy. Staff were excellent – helpful and friendly.

Other-

Julie-anne hired the electric bed from Hospital at Home, dealt with Maureen who made the whole process very easy. The cost of the bed was \$40 per week, delivery and pickup \$60, a total of \$100.

Your overall rating out of 10 – 8.5



The Lancasters: L to R: Julie-anne, Chris and their son Jacob

Sydney Christmas Party

This year the Sydney Metro members were fortunate to have their Christmas Party sponsored by the Commonwealth Bank of Australia (CBA). The weather was looking dicey up until the day before the event, but then we were blessed with gorgeous sunshine which lasted the entire day at Bicentennial Park, Homebush Bay.



Approximately 25 CBA volunteers arrived early to help set up and prepare for the party, which made it so much easier for us! Members and friends started arriving around 11am and it wasn't long before the kids started getting into a traditional game of cricket, and a quick round of Boccia. Almost all tried their hand

at canvas painting, ably led by the CBA staff, and we were lucky enough to be given one of the brilliant artworks, which was quickly placed in the MDNSW Gallery!

It wasn't long before Matt from Walkabout Reptiles arrived and put on a great show for the kids and adults alike. Kevin got wrapped up like a present with a python, and Noah and Elijah were over the moon when a snake slid in their direction as they sat patiently on the floor. Holly loved touching the Blue-Tongue Lizard, but Lucy wasn't too sure about the crocodile coming too close to her nose! Cody simply couldn't stop laughing, and I'm pretty sure we also saw someone grow a turtle on their head! We all learned lots about the adaptations of reptiles and amphibians to their environment, and even got to participate in a sing-along with Matt. Then someone yelled "Lunch" and a stampede followed!

CBA had put on a magnificent BBQ for us all, including steaks, snags, a multitude of salads and some scrummy desserts that I've chosen to believe were entirely calorie-free. Our wonderful CEO David Jack thanked CBA staff for their amazing effort, before presenting Carolyn Campbell-Maclean with a gift of thanks for her tireless work as Editor for our Talking Point magazine. One of the highlights of the day was celebrating "Nan's" 85th birthday. It was such an honour to have Lillie there with us all on the day, and we wish her continued good health and happiness in the year to come.

Just as we were finishing up the last crumbs of our feast, we saw Santa heading our way in the distance. There were roars of excitement as he pulled up in the Ranger's Buggy and, with the assistance of the CBA elves, handed out lots of pressies to all the beaming children. You



can never get enough of that in your lifetime! No time to rest though as Konrad from THRILL began a series of water games for the kids, although there were many adults who couldn't resist this too!! As if we weren't all wet enough after that, the water pistols and buckets appeared. Maralyn from the office led the charge and powered after Greg from CBA, but Bethany was the one who eventually caught and drenched him!

As we all dried off really quickly in the hot conditions, it was time to go. What a great day we all had! We would really like to extend our deepest gratitude to the Commonwealth Bank of Australia for their presence on the day. Not only were their volunteers enthusiastic and extremely helpful, but as soon as they arrived they became part of the team, and by all accounts were very much appreciated by all of our members. They even provided each family with a delicious Christmas Hamper to take home and enjoy - what an extraordinary gesture! Staff from Muscular Dystrophy NSW were particularly thankful for the involvement of CBA this year, as it meant that we didn't

have to worry about food service and preparation in any way, and could actually mingle with our members and their families. Some had only just joined up with us so it was a great opportunity for us to welcome them into the family.

We'd also like to express our gratitude to NEWS who sponsored all of the wonderful activities for the Christmas Party. Their generous donation made a huge difference to the type of activities we could provide for the kids, and ensured maximum participation and enjoyment on the day.

So for the 130 or so people who made it to the celebration, we hope you had a wonderful time. For those unable to make it this year, look out for an even bigger and better event next year!

I hope you all had a great Christmas with your families and friends, and I'm so very excited about all the upcoming events and programs I hope to implement in the New Year for our members. Apparently I just need to have a quick chat with some bloke called David...

Cheers

Loretta
Events Corodinator

A Queensland holiday! (With a little help from FlexiRest)

Okay, I'm not the best at remembering details about dates, but I'll give you the best information I can! Sometime during January 2011, my family and I prepared for what was to be the drive of a, well, it wasn't exactly a lifetime but it was a day at least and the worst thing about it was that we had to wake up at 6 a.m.! Well, that's what my mum would tell you, but in actual fact I quite enjoyed the early rise and beating all the traffic!



Daniel inside Knotsofar Cottage

Our first stop was near Hexham, which was where we tried our best to plan the rest of the drive. However by the time we reached our target, it was only 4 p.m. and mum decided to keep driving.

At 6 p.m. we decided to stop and look for accommodation for the night. We were at Brunswick Heads and there was not much around at the last minute. The Caravan Parks all had accessible cabins, but they were taken, so we finally ended up at a motel with an accessible room, right near the Highway, but we were happy to put our heads down after a long day of driving. We find that, with our ramp, most places suffice for wheelchair access, if you are happy to just have a sponge down at night for once, then it doesn't matter if the bathroom is not any bigger (because that's all accessible tends to mean to me!).

Before I go off on a tangent, let me explain Queensland. We stayed with our friends firstly in the so-called "flood ravaged" southeast Queensland district. In reality, besides the areas that were badly affected, the majority of the area was looking in shipshape. We had family members ring us up thinking that virtually the whole of Queensland was like a giant mill pond. Most of the weather while we were there was complementing what their numberplates say; "the Sunshine State".



Knotsofar Cottage



Daniel and friends



Pool area of Knotsofar Cottage

Now, about the FlexiRest funding, this \$1000 bonus really made our holiday something special. It firstly gave us enough money to afford such amazing accommodation in both Byron Bay and the Gold Coast, and, even better still, it is available to most people with disabilities! MDNSW are the people to talk to if you have any questions.



Daniel with brothers Ben (left), Jesse (right), Susan (Mother middle)

Our house in the Gold Coast had three bedrooms and a pool and was completely accessible if you have a portable ramp, and even then it is only a very small step at the front door and then you're right! The people who own it are also the most lovely people you'll ever meet and they happily look after your dog/s while you're out and about!

The Byron Bay accommodation was something a little different however. Being a studio apartment with not much room was not the best thing to move on to with our memories still filled with our three-bedroom house in amongst the wildlife, though, in hindsight it wasn't actually that bad compared to some other places we've stayed in. It was again another very accessible place to stay, in fact, we didn't even need a ramp! As probably a lot of you already know, Byron Bay is famous for its lighthouse and picturesque beaches. The lighthouse is a little confusing to get to but it is worth the trouble. It is also the most easterly point on the Australian mainland!

I hope I have been of some assistance to you if you are booking a holiday. And I also hope that I have encouraged some people to take advantage of the FlexiRest funding.

Until my next adventure beckons!

Daniel Michel





Events and Programs for 2011

We have certainly worked extremely hard this year to put together a diverse program of events that we hope you'll absolutely LOVE!

We will still be running our exciting annual events such as camp, weekend retreats, regional and metro Christmas parties, medical seminars, and group outings to events such as the Easter Show and theatre matinees. Our HOGS Day will be even bigger next year, with a proposed change in location to Eastern Creek. This change gives us the opportunity to provide lots more family activities and entertainment for all, whilst enhancing its fundraising potential at the same time.

This year we are also offering new and innovative events/programs such as our Siblings Adventure Trip, Dads' Sporting Trifecta group, extending our Retreat program interstate, courses for parents, Boccia Day Camps, and

our first Muscular Dystrophy NSW Ball! For the benefit of all new members, we have implemented New Member Information sessions to give Muscular Dystrophy NSW staff the opportunity to introduce themselves and explain all the services and support available to you as a member.

Perhaps one of our most exciting initiatives to commence this year is the Duke of Edinburgh program, where a small group of 16-24 year old members will be offered the opportunity to participate in an unprecedented pilot project which could not only set the benchmark for people with disabilities throughout NSW and Australia, but globally as well! Watch this space!!

Our Carer Programs Coordinator makes many visits out to the Regional areas of NSW, as we are always looking at how we can improve our services to those in the remote areas as well.

Our website is in the process of being updated with all of these events and programs, so you'll be able to get more information about each event by clicking on the link provided. You will have also noticed our new look for all Events run by the Client Services team, and we thank all of you who have kindly given us some excellent positive feedback on our flyers already! We like it too!

Lastly, don't forget to RSVP! It not only makes our job so much easier, but it also gives you a better chance of securing a place on some of our more popular events!

It's all happening and it's all good - can't wait to see you there!!

Loretta
Event Coordinator

FEBRUARY

Tuesday 15th	Members' Advisory Committee Meeting
Thursday 17th	Equipment Committee Meeting
Thursday 24th	Carers' Information Day and Luncheon (Ballina)
Saturday 26th	Boccia Day Camp (Sydney)

MARCH

Tuesday 1st	New Members' Information Evening
Wednesday 2nd	Carers' Morning Tea (Kiama)
Wednesday 9th	Hunter Network Meeting (Newcastle)
Friday 11th – Sunday 13th	Weekend Retreat (Sydney)
Saturday 19th	Boccia Day Camp (Gosford)
Monday 28th – Wednesday 30th	New England Carers Visit (Tamworth)

APRIL

Thursday 7th – Friday 8th	Far South Coast Regional Visit (Bega, Moruya, Bateman's Bay)
Monday 11th – Monday 18th	National Electric Wheelchair Sports 2011
Wednesday 20th	Sydney Royal Easter Show
Thursday 28th – Saturday 30th	Central West Carers Visit (Dubbo)
Saturday 30th	Family Fun Day (Dubbo Zoo)

MAY

Monday 2nd – Tuesday 3rd	Far Central West Carers Visit (Broken Hill)
Tuesday 17th	Members' Advisory Committee Meeting
Saturday 21st	Muscular Dystrophy NSW Ball Waterview Convention Centre
Wednesday 25th	Carers' Advisory Committee Meeting
Thursday 26th	Equipment Committee Meeting





JUNE

Wednesday 8th – Thursday 9th	Hunter Network Meeting (Newcastle)
Wednesday 15th	Dads' Sporting Trifecta Trip #1 (State of Origin)
Wednesday 29th – Thursday 30th	South Coast Carers' Meeting (Bomaderry)

JULY

Monday 4th – Friday 8th	Riverina Network Meeting (Wagga Wagga and Griffith)
Monday 18th – Friday 22nd	Mid North Coast Carers' Network Meeting (Coffs Harbour and Armidale)
Wednesday 29th – Thursday 30th	Hunter Network Meeting (Newcastle)

AUGUST

Saturday 13th	Parenting Seminar
Thursday 18th	Equipment Committee Meeting
Tuesday 23rd	Members' Advisory Committee Meeting
Friday 26th – Sunday 28th	Central West Regional Visit (Orange and Bathurst)
Wednesday 31st	Carers' Advisory Committee Meeting
Saturday 27th	Dads' Sporting Trifecta Trip #2 (Bledisloe Cup)

SEPTEMBER

Monday 5th	New Members' Information Evening
Wednesday 14th – Thursday 15th	Hunter Network Meeting (Newcastle and Maitland)
Monday 26th – Friday 30th	Muscular Dystrophy NSW Camp 2011

OCTOBER

Tuesday 11th – Wednesday 12th	South Coast Carers Visit
Saturday 22nd	Medical Seminar
Saturday 29th	Dads' Sporting Trifecta Trip #3 (Hawkesbury River Fishing)

NOVEMBER

Monday 7th	Muscular Dystrophy NSW Annual General Meeting
Saturday 12th	Siblings Adventure Trip (Vision Valley)
Tuesday 15th	Members' Advisory Committee Meeting
Friday 25th – Sunday 27th	Weekend Retreat (Melbourne)
Thursday 24th	Equipment Committee Meeting
Friday 25th	Ladies' Matinee Christmas Event
Saturday 26th – Sunday 27th	Riverina Family Fun Weekend (Wagga Wagga)
Wednesday 30th	Carers' Advisory Committee Meeting

DECEMBER

Thursday 1st	International Day of People with a Disability
Saturday 3rd	Hunter Region Christmas Party (Carols by Candlelight)
Thursday 8th	South Coast Regional Visit
Friday 9th	South Coast Region Christmas Party
Sunday 11th	Sydney Metro Christmas Party
Thursday 14th – Friday 15th	Far North Coast Regional Visit (Coffs Harbour and Grafton)
Friday 16th	Far North Coast Region Christmas Party (Ballina)

Dates to put in your diary ...



Regional Update

Dear Members,

Welcome to a New Year and another edition of Talking Point magazine. It's an exciting time for the team at Muscular Dystrophy. There is such a buzz in the office, with two new staff members in Client services, a flourishing Case Coordination program and talk about weekend retreats. I hope you have all had an opportunity to glance through the Events calendar for 2011. The Client services team had a great time last year discussing plans, new ideas and activities for regional and metro programs. You may notice some events have changed from last year's events; we hope the new events like NEW Boccia Day Camps, Mens' Trifecta Outings, Sydney's Royal Easter Show family day and an interstate weekend retreat provide both interest and the opportunity to take some time out of your busy day to day routine.

Speaking of breaks and taking time out, it's been great to see many more members applying for respite funds

through The ADHC funded FlexiRest Program. I would like to encourage new members, members who have not applied in over 6 months, and carers just looking at having a short break away to call me or email your ideas for discussion. The wonderful aspect of FlexiRest funding is its flexibility. I have families quite surprised by some of the respite options available with the program. Not to mention FlexiRest also funds transportation expenses, an option not available through generic respite packages. For more details please refer to the eligibility criteria in the article So tell me more about FlexiRest Funding!

I have included for our regional carers some exciting new events on the Muscular Dystrophy NSW 2011 events calendar. I will shortly be sending official flyers and letters to all 2011 events. Please review up and coming regional events to stay up to date with events in your region. We have been fortunate to obtain a small amount of additional funds to expand on some regional services. You may have noticed that Muscular Dystrophy NSW will be both

in the Hunter and South Coast regions more often this year.

For those interested in more personalised support, Muscular Dystrophy NSW has been fortunate to have received recurrent funding, a three year contract to continue running Care for Carers.

Care for Carers is a support program funded by NSW Health which specifically supports the needs of carers living in Rural and Regional NSW. The program continues to be a well needed service and is in its seventh year of programming. Muscular Dystrophy NSW hopes to continue similar services to the regions. I would like to encourage regional clients to make contact with me with ideas or thoughts about the programs. Could you email me your thoughts to carers@mdnsw.org.au

I really hope you enjoy reading this edition of the Talking Point. I look forward to hearing from you soon.

Kind regards,
Georgina Christofis

Muscular Dystrophy NSW celebrates Christmas at the Hunter Valley Gardens

The weather was simply fine and the setting was beautiful. The Christmas event at the gardens was spectacular commencing with an afternoon of carolling, a two course dinner then a walk through the magically lit gardens. The garden which spans 8 kilometres was an amazing visual show of colour, sensational sights and fragrances. This event is one of six events Muscular Dystrophy NSW runs in the Newcastle (Hunter region) for members. If you are interested in finding out more about this event or about the Hunter network group please contact Georgina Christofis at the Muscular Dystrophy NSW office on 9809 2111.



So tell me more about FlexiRest!

For some of you this maybe the first time you are reading about the Muscular Dystrophy FlexiRest Program. For others you may have applied one year ago and not sure if your eligible to apply again. In this article, I would like to clarify some common misconceptions about the funding and also provide you with choice about the type of respite available to you as the primary carer/s.

Who funds the FlexiRest Program?

FlexiRest operates with funding from Ageing, Disability and Home Care, Department of Human Services NSW (ADHC) formally known as DADHC.

The program is run by a Consortium consisting of Muscular Dystrophy NSW (MD NSW), the Motor Neurone Disease Association of NSW (MND NSW) and MS Australia ACT/NSW/VIC to provide funding for flexible respite.

What are the aims of the Program and how frequently can I apply for respite?

FlexiRest aims to reduce the potential for premature admission into residential care facilities for people with a neurological disorder.

Wherever possible, respite is planned and allocated as equitably as possible based on client and carer need. Funding will be allocated according to the client/carer's workload, their needs and priority of needs. Weighting of funds may vary due to differing costs involved according to the individual needs of each client.

FlexiRest is not an on-going service but can be accessed at planned intervals throughout the year to help support the primary care-giving relationship between client and carer

Applications for respite must be submitted at least one month in advance of planned respite dates. In some circumstances, more urgent requests will be considered.

Retrospective applications will not be accepted.

Who is Eligible to apply for funds?

To be eligible for FlexiRest clients must:

- live in NSW and have an unpaid carer
- be registered with MD NSW, MND NSW or MS Australia ACT/NSW/VIC
- have a demonstrated respite need that cannot be met by on-going community services

What type of respite is funded under the program?

Examples of flexible respite include but are not limited to:

- respite funding for families to access annually, either constituted in terms of cost or hours of service
- host family
- support for a holiday
- in-home respite
- peer support
- individual support
- vacation care
- centre-based
- before and after school care
- family day care integration
- transport support
- skills programs
- age- appropriate respite programs, concentrating on people aged between 20 and 40 years old
- respite where the primary carer is in paid employment
- services that cover regional and remote areas of NSW
- other options as suggested by client/families/relevant services to be considered

Who reviews my application and how do I find out my respite application been approved?

Applications are completed by a staff member at Muscular Dystrophy NSW and forwarded to the FlexiRest Coordinator for consideration.

Approval will be given according to the client's respite needs and FlexiRest funds available at time of application. On approval the FlexiRest Coordinator will notify the client and applying staff member in writing.

Who do I contact if I am interested in applying or have enquiries about the program?

Georgina Christofis, Carers Programs Coordinator manages enquires and the initial application process. Please ask for Georgina on 9809 2111 or email your enquiries to carers@mdnsw.org.au



The O'Briens Go Camping

How do you go camping with a child in a wheelchair? To be specific, how do you go bush camping with a child in an electric wheelchair in a place with no electricity, pit toilets and a couple of cold water showers near a beach with only dirt track access? These were a few of the first questions that popped into our heads as we began the journey of learning about our third child's muscular condition. Bush camping has been our family's favourite holiday style and we can truly say we revel in camping rough after 7 years living in the Northern Territory. Living back in Sydney and having our youngest, Daniel, diagnosed with LMNA Congenital Muscular Dystrophy (LCMD) made us wonder if we had to change our holiday habits drastically. This summer gave us our first real go at bush camping with a child with CMD, at least 6 months before he gets his first motorised wheelchair.



My name is Joanne, and my husband (Luke) and I have three children: Erica, (8) Samantha (6) and my son Daniel (2) who has LCMD. He was diagnosed May 2010 at 16 months old, a day when we thought everything in our lives would change for ever. Our lives have changed but we have been blessed with a little boy who livens up our house with hilarious comments, antics and he has given us a different view on life. He is truly the most resilient and capable little boy who constantly pushes

his physical boundaries. He learnt to scoot on his bottom at around 14 months of age and this is still his only mode of transport. As yet he is still not standing unaided and is not expected to walk. Daniel had his second trial of a motorised wheelchair just before Christmas and had an amazing time. We can't wait until he actually gets his chair. It was amazing to see this not quite 2 year old getting to go where he wanted too; just as satisfying as watching our two older daughters take their first steps. He was unstoppable and extremely capable. But for the moment we just need to be patient. While we wait we are also looking at house modifications and a new car... all expensive items but essential. These big decisions are being made with one thing in mind. We need to still be able to go camping.

This year was a test. We usually spend a week or two camping at Mystery Bay, with Luke's family. With Daniel scooting around



and rain predicted for the entire week I was not looking forward to going. I could not imagine how I was going to keep Daniel clean and dry and if he was wet constantly was he going to end up sick, what would we do then?

Thankfully the weather was glorious up until the last day. The other kids all played well with Daniel and he even managed a couple of swims at the beach (away from the waves of course). He was thoroughly exhausted and slept more than his usual 15 hours a day. Dinners were not all that interesting for him. Daniel has difficulty chewing and at home I take the family meal and pulverise it until it is like baby mush. So I decided to take tins of baby food which worked quite well but were a bit monotonous every day and by the end he was fed up of eating them. Baths were in a big blue tub (which Erica still just fits into) and he has just started to use a potty so that came with us also.



We spent a lot of time looking at the surrounding area for access problems and we think we have these under control. The other five children spent a large portion of the day riding around the camping grounds on their bikes and we are hopeful that next year Daniel will be able to follow them everywhere they went in his chair. We have

settled on a front wheel drive wheelchair as they seem better over rough terrain so this will help. We have also decided on a rear lift for the van so we can get a tow ball mounted for our trailer. A major issue we had to consider was charging Daniel's chair as there is no electricity at the camping grounds. The local gas and ice man has agreed to let us drop off Daniel's chair each night and retrieve it each morning.

Daniel celebrated his 2nd birthday with cake around the campfire and we hope we will be able to celebrate his 3rd birthday in a similar way. We have no idea what will happen next year, what if we get rain for the whole time we are away? We still have a lot to learn but we drove home heartened by the idea that we may just be able to rough it with Daniel, at least for the next few years. If anything we are more determined to make camping an option for our family for as long as we can. So here's to hoping that next years camping experience will be just as amazing and full of fun.



26th Annual National Electric Wheelchair Sports

To be held in April 2011

The New South Wales team is gearing up for another successful National Electric Wheelchair Sports (NEWS) campaign in April this year. The tournament itself runs from the 11th to 17th April with matches to be played on the 12th, 13th, 14th and 16th April in the sports of Soccer, Hockey and Rugby League. The most successful team from the combined results of the Round Robin competitions in all sports will be awarded the Roger Melnyk Trophy. The teams that finish first and second in each sport will qualify for the Grand Final, with the next two teams qualifying for the third place play-off.

This year NEWS is now under the auspices of Muscular Dystrophy Foundation (MDF) as it is a national event for people with neuromuscular disorders and it is an opportunity to raise awareness of neuromuscular disorders and highlight one of the positive ways in which people with neuromuscular disorders can have a high quality of life. The event is hosted by MDNSW and will once again be an exciting week for all involved.



This year the NSW Colts will be competing against Queensland Gladiators, Western Wasps, South Australia Scorpions, Victoria Warriors and the ACT Wheelers. The ACT team is a composite team of players from all states.



The NSW team for NEWS 2011 is Peter Dalrymple, (Vice Captain), Steve Webb (Captain), James Kim, Chris Suffield, John Shepherd and Alex Scollard. James and Alex will be making their debuts for NSW. It is the first NEWS for James, while Alex has previously played for ACT.

Hamish Armitage and Jordan Crane from NSW will be playing for ACT.

This year is extra special as it will be my 20th year at NEWS. Over that period I played for NSW for 14 years and this will be my 7th year as Coach, including one year as player/coach. I currently hold the record for most games for

NSW of 259, but I am sure that a couple of the guys in the side this year will eventually surpass that. This period also includes 16 years as National Director. It's been a wonderful experience. I also share the 20 Year milestone with Adam Hart who has played for South Australia and Western Australia during his career and has now returned to South Australia for this

year's tournament. Adam is one of the greatest players to have ever played at NEWS, has been a multiple Overall Best and Fairest winner, All Australian player and has the record for most games played at NEWS. I am honoured to share this milestone with him.

Also this year our Captain, Steve Webb, and our Vice-Captain, Peter Dalrymple, will be receiving 10 Year Service Awards and they join me and Chris Suffield who are also on this Honours List. Our current National Umpires' Co-ordinator, Martin Dalrymple, will also receive a 10 year Service Award as a result of his contribution as an official at NEWS.

The team is training very well at the moment. These players are very dedicated to their sport. They play their local competition games on Saturdays and train for NEWS on Sundays.

NEWS 2011 will once again be held at the Sydney Academy of Sport and Recreation, Wakehurst Parkway, Narrabeen. I encourage members to come out and watch the tournament. The finals day on the 16th April, is a great day as you will see all the three sports on the one day, but the round robin days are very exciting as well.

For more information about the tournament or if you are interested in getting involved in electric wheelchair sports, feel free to contact me on (02) 9643 1429 or email MBaptiste@bigpond.com

Michael Baptiste

National Director NEWS & NSW Coach

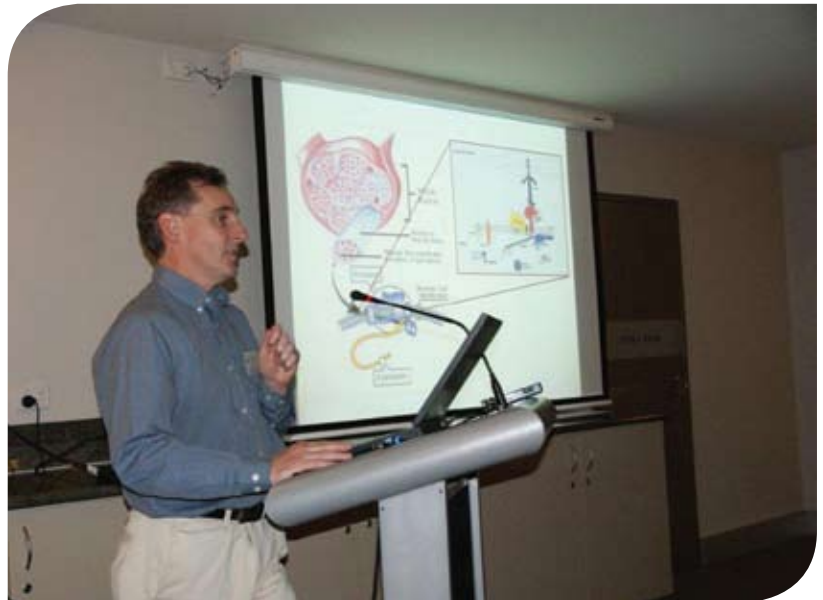


Medical Matters

We are entering an exciting time for people with Neuromuscular disorders. Over the last 15 years the genetic basis for most disorders has been discovered. Most people can now be given a definite genetic diagnosis. We are learning more about how the genetic defects result in muscle weakness and cause disability. Knowing the genetic defect causing an inherited muscle disorder enables us to establish how the muscle is damaged. This in turn has resulted in the development of new specific treatments for muscle disorders. When a genetic defect is known and understood then animal models of disease can be produced often by introducing the abnormal human gene into tissue culture cells or animals such as the rapidly breeding zebra fish. If these disease models can be developed to produce a measurable disease state (phenotype) then they can be used for developing treatments for the human diseases that they represent by determining the effects of treatments on the disease phenotypes and outcomes. Treatments can be developed based on knowledge of the way that the genetic defect causes muscle damage and this has led to the recent trials for patients with Duchenne dystrophy using the agent Ataluren that causes skipping of premature stop codons that shorten the dystrophin molecule or prevent its production and to trials of exon skipping to produce better functioning dystrophin. There is another way of developing potential treatments for inherited muscle disorders. Large libraries of potential therapeutic substances are available that are known to be safe for use in human subjects. These can then be screened using the animal or tissue culture model system to see if they reverse or improve the disease phenotype. This is a process called high throughput screening and is capable of finding potential treatments that can then be trialled in humans. It is reasonable to expect new treatments for many inherited muscle disorders to become available over the next 10 years. These will require human trials to ensure that they are effective and that they are safe.

It is important that we in Australia are involved in developing these new treatments. If we participate in the development and clinic trial stage of introducing a new treatment we are more likely to gain rapid access to it for our patients. Australian patients have participated in recent international trials of Ataluren and now exon skipping for Duchenne dystrophy.

We in Australia can contribute to the global research effort and a number of Australian researchers are making major contributions by finding new genes, developing new tests and assays and new treatments. Our researchers require



financial support through fund raising. National funding bodies have priorities and it is important for disorders like Neuromuscular disorders to have a high profile and seen to be able to generate public support and funding for themselves. This is an important role for MDNSW and the MDF to raise funds, advocate for people with Neuromuscular disorders and develop a strong, positive and highly visible profile. This improves our standing with national health providers and with funding agencies both within Australia and overseas and makes Neuromuscular disorders an attractive target for research funding. We believe that MDNSW and the MDF have made considerable progress in improving the public profile for Neuromuscular disorders in recent years and will continue to do so. To achieve this your support is essential.

It is very important that we are well organised and ready to participate in clinical trials when they become available. We have strong competition from our European and United States colleagues. We were able to participate in the recent Duchenne trials because we were well organised and because the gene testing procedures developed in Sydney for Duchenne muscular dystrophy were world class. Not all Duchenne patients are appropriate for all forms of treatment and knowing the exact genetic defect for each patient was crucial in being ready to participate in these internationally run and sponsored trials.

What more can we do to be ready to make the most of trials and treatments as they become available? It is important that we know who among our patients are likely to derive benefit and who are likely to be able to contribute. It is important that we become organised on a national basis and are then able to talk with our international partners on an equal basis.

The Australian Neuromuscular Network has recently been formed as a group of researchers and clinicians in Australia and New Zealand with a commitment to the treatment of Neuromuscular disorders. Our aim is to coordinate a national collaborative diagnostic service and research network for neuromuscular disorders that is cost-effective, maximises availability and minimises duplication of services. This will include introduction of new diagnostic methods into Australia and New Zealand, as well as introduction of screening for newly identified genetic disorders.

We plan to develop nationwide disease registers, based on accurate molecular diagnosis for patients with neuromuscular disorders, aligned with international registries such as the TREAT-NMD registries used in Europe. These will form the basis of a clinical trials framework for neuromuscular disorders accessible to patients throughout Australia and New Zealand.

The ANN has the goal of ensuring excellence in diagnostic methods and clinical management, and equal access to clinical trials and new therapies, for all individuals in Australia and New Zealand affected by neuromuscular disorders

What can people with neuromuscular disorders do? As disease specific registries are developed I strongly encourage you to become involved. These registries will collect information about people including their diagnosis, demographic information, clinical state, disabilities, employment etc. They will enable clinicians and their patients to be ready for trials and new treatments but also give much better information about the impact of neuromuscular disease on people's lives. This in turn will help us to determine what people require and also allow us to advocate to Health networks and government.

To date the registries for Duchenne muscular dystrophy, Becker muscular dystrophy and Spinal muscular atrophy are complete and beginning to enrol people. Registries for Myotonic dystrophy and Facioscapulohumeral are currently

being constructed. Each will be compatible with European (TREAT-NMD) and US registries and further registries are likely to follow. Each registry will be subject to ethical approval and supervision and stored patient data will be de-identified and secure. Data in part will be entered by patient's or their surrogates and in part by their clinicians and will be curated by the patients treating clinicians.

It will be an increasing challenge to Health Providers and governments to determine how to fund some new and potentially expensive treatments as they become available. There are already treatments available for rare muscle diseases



that are effective but have not been funded by the Australian Pharmaceutical Benefits Scheme. In Australia treatment for acid maltase deficiency, a rare inherited metabolic muscle disorder, is funded for children who gain the greatest benefit but not for adults. In Europe and the US treatment is also funded for adult patients who when treated have slowing of their progressive muscle weakness and difficulty breathing. Treatments like this are very expensive to develop and can cost several hundred thousand dollars a year to treat one patient.

In April the Australian Neuromuscular Network will be launched as part of a national conference on Awakening Australia to Rare diseases. This will enable us to discuss how we should make treatment decisions for our patients with rare disorders and how best to influence our health providers and state and federal governments to get the best outcomes for our patients.

Dr Alastair Corbett is the Medical Director of Muscular Dystrophy NSW and a Clinical Neurologist based at Concord Hospital specialising in Neuromuscular Disorders



Fundraising Matters

How was last year's Fundraising?

We were fortunate in 2010 to have an increase in our Fundraising and Government income. This is partly because of a bequest being recognised and partly due to receiving new Government grants. This increase correlated with a huge increase in our service provision, with an expansion of our existing services and the creating of new services, such as the Case Management Program.

In 12 months, we have gone from employing two Client Services staff to employing five staff. This is a huge leap and the challenge now is to continue this momentum. Not only do we need to deliver our current services to a high standard, but we need to further expand our support to all of regional and rural NSW, ensuring that no matter where you live, if you have a neuromuscular condition we are there to support you and your family.

Tour Duchenne 2010

Tour Duchenne 2010 was an amazing group effort with each of the Muscular Dystrophy Foundation member States playing a part, along with the Founder Julian Thompson, and other external volunteers.

The ride was a huge success with all 23 riders crossing the finish line on Sunday 19th September at Darling Harbour, having ridden over 1,000 kms from Brisbane. Over \$400,000 was raised by the individual riders seeking donations and sponsorship. In response to a recommendation from the Australasian Neuromuscular Network (ANN) \$280,000 has been awarded to the two leading neuromuscular clinical research sites in Australia, the Institute of Neuroscience and Muscle Research (INMR) in Sydney and the neuromuscular clinic at Royal Children's Hospital in Melbourne. These grants will support their clinical trials, including the upcoming Exon 51 trial and their important mentoring role to other Australian neuromuscular clinics.

The remaining funds were distributed to the participating States and to Muscular Dystrophy Foundation. This funding will go towards extending existing services and programs to ensure more individuals and families are supported and that awareness, education and advocacy work continues to be done.

Watch out for Tour Duchenne 2012! Planning is underway for this event and it will likely happen over 7 days in April 2012. If you would like to be added to the Tour Duchenne 2012 mailing list of interested people, please send an email to: GiveSupport@mdnsw.org.au.

Other fundraising activities conducted in 2010 included:

- **Golf Day**
- **Mail Appeals**
- **Applying for grants**
- **Third party events, including City2Surf, Singing Santa's and Jazz at the Dam**



We would like to extend a huge thank you to our 2010 sponsors



What's Happening in Fundraising

How you, or people you know can support us

Why do we need Fundraising Dollars?

Muscular Dystrophy NSW is a charitable organisation that does not ask for fee for most services. Many of our events have a low cost to them to help cover the costs of the event, but our essential services are offered for free to our members.

This means that we need to cover the costs of our services through other channels. Currently, our income is generated through:

- 4% Interest on Investments
- 19% State Government Grants (for pilot programs from Ageing, Disability & Home Care and NSW Health)
- **77% Fundraising**

Fundraising income is generated through bequests, donations, philanthropic grants, events, sponsorship and collection boxes. A significant 35% of our fundraising income is generated through bequests which highlights the importance and gratitude we feel to be remembered in someone's Will. If you would like more information about leaving a bequest to Muscular Dystrophy NSW, please contact our Fundraising Manager on 9809 2111 or: GiveSupport@mdnsw.org.au.

Please read below for information about our upcoming events and campaigns. If you, or someone you know would like to become involved in one of these activities, please contact our Fundraising Manager on: 9809 2111 or: GiveSupport@mdnsw.org.au.

Ride4MD

On August 9th 2011 Muscular Dystrophy NSW will be running a one-day bike ride for the fit, the moderately fit, and those who would like to be fitter! The ride will be 50 kms long with a shorter option of 50 kms available.

The \$50 entry fee will cover your costs on the day including a t-shirt, riding number and lunch at the end of the ride. Each rider will be encouraged to raise funds for Muscular Dystrophy NSW through Everyday Hero and there will be prizes for the top three fundraisers.

In the park, at the end of the ride there will be lots of fun, fully accessible activities for adults and children. If you are interested in joining us on this fun cycle ride, and would like to find out more, or join our mailing list, please email our Fundraising Manager on: GiveSupport@mdnsw.org.au. or call 9809 2111



Your Change Will Make a Change

Loose Change Month

It is always surprising how much your loose change adds up to in a month, and just for that one month, your change can go towards supporting people with a neuromuscular condition.

The month of April 2011 will be the Muscular Dystrophy NSW Loose Change Month. Temporary collection containers will be distributed to individuals and workplaces to collect your loose change throughout April.

Join us today on Loose Change Month by contacting our Fundraising Manager on: 9809 2111 or: GiveSupport@mdnsw.org.au and we will send you and/or your workplace collection containers.

Muscular Dystrophy NSW Charity Golf Day

Muscular Dystrophy NSW welcomes you to a very special day of golf at Concord Golf Club, one of the oldest and finest championship golf courses in Australia. We promise you a great day of golf, with great company, great food, great wine, great prizes and the opportunity to support an important charity.

Join us as a sponsor, a team or an individual player and you'll be helping us to provide much needed support and services to people whose lives are impacted by neuromuscular disorders.

Entry is \$180 per person or \$720 per team of four. Sponsorships start at \$3,000 which includes a team entry and many promotional opportunities. Contact our Fundraising Manager today on 9809 2111 or: GiveSupport@mdnsw.org.au for details, or go to: www.mdnsw.org.au to download a brochure.





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Sydney Children's Hospital
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We could not do all we do for our members without the generous support of individuals, community organisations and companies. If you would like to make a tax-deductible donation as a once-off, or on a monthly basis, simply complete this form and return to: Muscular Dystrophy of NSW, PO Box 1365, Meadowbank NSW 2114.

Yes, I would like to make a tax-deductible donation to help those with muscular dystrophy

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I enclose my Cheque/Money Order made payable to Muscular Dystrophy Association of NSW for \$ _____, or

Please debit my card: once only every month **amount \$** _____ card type: Visa Mastercard

cardholder's name _____ card No _____

cardholder's signature _____ expiry date _____

Thank you. All gifts of \$2 or above are tax-deductible.

