

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

ISSUE 80 SPRING 2011

PRINT POST APPROVED PP 255003/01200

Family Ride 4 MD



MUSCULAR DYSTROPHY
NEW SOUTH WALES



I would like to begin by saying thank you to all who have sent me congratulations and best wishes for my new role. I thoroughly enjoyed my time as Manager of Client Services and Operations and am excited about the opportunities and challenges of the new position. I count it a privilege to have been appointed as your CEO and will endeavour, as our vision says, to *Improve the Quality of Life for all People with a Neuromuscular Condition*.

To me the heart of Muscular Dystrophy NSW is the people, whether they are those with a neuromuscular condition,

their family or carers. The focus of this issue of Talking Point is to emphasise that this is your organisation, that we are keen for you to be involved and value your ideas and feedback. One way of doing this is through our Member Advisory Committee which has recently gone online so that it is accessible to more people. (See page 5 for more details)

As a response to your feedback we have been focusing on increasing ways of providing both practical and emotional support. We are now offering Case Coordination, Home Visits, Counselling and Support Groups. Our Counsellor, Liz Bailey, has written an article titled *Anxiety, Fear and Coping*. (See page 13)

I find in my travels that because our name is Muscular Dystrophy NSW people don't realise that we provide services to all people with a Neuromuscular Condition. Dr Kristi Jones has written an article explaining what a Neuromuscular Condition is and who is eligible to receive our services. (See page 16-17)

There has been a great deal of talk in the media about the National Disability

Insurance Scheme and the NSW Government's move to make Disability funding client focused and driven. We see this as a very positive move but realise that at the same time it may be daunting. Victoria Berg our acting Client Services Manager has written about the *Person Centred Approach – Living Life My Way Summit*. (See page 5)

I recently had the privilege, while on holiday with my family in London, to attend an evening at Windsor Castle for the Duke of Edinburgh's Award. Prince Edward hosted the dinner and was very interested in our Duke of Ed pilot program. He has asked to receive regular updates on how our team of young people are doing. Events Manager, Loretta Downie introduces the team to us on page 6.

I hope you enjoy this edition of *Talking Point* and remember that we would love to receive your contributions for our next edition.

Pene Hodge
CEO, Muscular Dystrophy NSW.

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

contents

EDITORIAL	2	TRIFECTA TIME FOR DADS	11
MESSAGE FROM THE PRESIDENT	3	OUR SPECIALIST COUNSELLING SERVICE	12
NEW CEO – A FAMILIAR FACE!	3	COUNSELLOR'S CORNER	13
MEET TOM OLIVER	4	MUSICUS MEDICUS	14
CHANGE IS IN THE AIR..., PERSON CENTRED APPROACH	5	HAS BOCCIA GOTCHA YET?	14
MEMBERS' ADVISORY COMMITTEE TO GO ONLINE	5	NEWS PREPARATION FOR 2012	15
INTRODUCING OUR DUKE OF ED TEAM	6	BUT I DON'T HAVE MUSCULAR DYSTROPHY...	16
AGEING , DISABILITY & HOME CARE OUTCOME REPORT	8	THE O'BRIEN'S GO FUNDRAISING	18
DATES FOR YOUR DIARY	10	ST PATRICK'S PRIMARY SCHOOL FUNDRAISE	18
		HARLEYS 4 MD	19



A Word from the President

WHAT THE BOARD IS DOING TO MAKE MUSCULAR DYSTROPHY NSW A BETTER PLACE FOR YOU!

This year marks the end of the last three year Strategic Plan which the Board developed in early 2008, and refined with the appointment of David Jack as CEO later that year. This followed a survey from which we sought out your needs and priorities. This plan has taken our membership and services a long way in just over three years.

But now recognising the need for our next phase of development, and new people to take us forward, the Board is currently developing a new path for our organisation.

The first step has been for David Jack to move to full time CEO of Muscular Dystrophy Foundation, so that the full potential of this national organisation can be realised. Muscular Dystrophy Foundation now resides in a separate city based office with four staff, including David.

We were fortunate to be able to provide a seamless transition in leadership between David and Pene Hodge, our highly respected and well liked Client Services Manager.

Having recently secured two grants from ADHC for a second camp, and a mentor, education and training program, an ADHC

grant for the new Duke of Edinburgh's Award program, and a grant from Muscular Dystrophy Foundation for a Little Heroes program, it was important to consolidate our growth, and maintain staff continuity.

The next key step was to provide new skills and experience at Board level. We are excited to have attracted two outstanding additions to the Board, with very different skills and backgrounds. They are:-

- Peter Debnam, former naval officer, businessman, leader of the NSW state and Parliamentary Liberal Party, and recently retired MP for the state seat of Vaucluse. Peter's business and political background, and connections, and his organisational skills, will be invaluable to us.
- Annette (Nettie) Burke, currently Director, Marketing and Communications, National Breast Cancer Foundation, well known for its highly successful "pink" campaign. Nettie has a background spanning fundraising, advertising and marketing, with a particular interest in the disability and not for profit sectors. These skills will be most important in developing our profile and maintaining funding levels.

The key step in the process of change is finalising the planning process. This has been in progress during several Board and Planning meetings, highlighted by a facilitated planning day at the Marriot



Courtyard Hotel North Ryde on July 28th where directors and staff took a day out for Muscular Dystrophy NSW. It was particularly significant that directors and staff are working hand in hand to provide better outcomes.

A key part of the process will require feedback from members, and the outcome will be a plan for sustainable growth over a five year period.

The results of this planning process will materialise over the next few weeks, and I look forward to sharing them with you all.

I'm sure you will agree the Board is beavering away to the best of its ability to make Muscular Dystrophy NSW a better place for you!

Best wishes,

Rob Ferguson

President, Muscular Dystrophy New South Wales

New CEO - a familiar face!



The Board of Muscular Dystrophy NSW is delighted to advise that the newly appointed CEO is already well known to most members and clients. Pene Hodge who joined us as Client Services Manager about

15 months ago was appointed by the Board recently to replace outgoing CEO David Jack, who has been appointed as full time CEO of Muscular Dystrophy Foundation.

Close to 50 applications were received, many a very high standard, however Pene was a clear choice.

Pene not only has a thorough understanding of our operation, and an excellent relationship with clients and staff, but has a very good grasp of our NSW Government and other grants and conditions applying to them. She is a compassionate, altruistic person, who endears herself to those that get to know her. So the transition to a new

CEO should be as "seamless" as possible.

Pene has an impressive record with the not for profit sector in New Zealand where her last role was Director of the Care Waitakere Trust in Auckland, which provided community services including counselling and therapy to people in need. Before that Pene had a variety of community support and social work roles caring for children and families in need.

Pene has a Bachelor of Arts majoring in Business Psychology from Massey University in Auckland (2007), and earlier training in clinical supervision and social and community work.

Pene lives at Castle Hill with husband Greg, and has a busy family life with two teenagers Olivia (16yrs), Ashton (14yrs) and their dog Ralph. When she is not at work she is often the family taxi driver delivering her children to social, school and sporting activities. In her spare time Pene likes experimenting in the kitchen, travelling, listening to music and going to the movies.

Supporting people with disabilities is something very close to Pene's heart. Her nephew has and her late niece had significant intellectual and physical disabilities. For a number of years Pene and Greg provided respite care for Michael a young boy with a disability.

Pene feels that our society sometimes gets it wrong when resources are spent on elaborate community events and an accumulation of luxury items when people are not receiving essential medical equipment, education, personal care and accessible housing. She has a great desire to make Muscular Dystrophy NSW the provider of choice for people with neuromuscular disorders. She intends to stabilize the recent growth while maintaining the momentum that we have as an organisation.

If you haven't yet met Pene, please make a point of introducing yourself, whenever you get the chance.



Meet A Member

Maralyn talks to Tom Oliver from the Northern Beaches.

Tom is 12 years old and his interests are wheelchair rugby, fishing, playing with his friends, his X-Box and eating steak!



Can you name one goal you have?
Would like to be able to get out of the wheelchair and walk again one day

What do you really like doing?
Playing wheelchair rugby

If you were to win \$10 million, what would you do with all that money?
Give half to Muscular Dystrophy NSW and use the other half to have a big holiday

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

Why America?
Like the idea of Disneyland, I went there once when I was a kid and it was really fun!

If you had to evacuate your house immediately what two things would you grab (not people or pets)?
My wheelchair

If a movie was made about you who would play your part?
Jimmy – one of my friends at school

What would you like to be talented at?
Rugby

What is your best subject in school?
Maths

If someone was to give you a gift, and money was no object, what would you want it to be?
A cure

If you were visiting the zoo and could go into any cage, which animal would you choose to spend 20minutes with?
The Meerkats

What is the bravest thing you have ever done?
Once I spoke in front of one thousand kids at school and talked about Muscular Dystrophy

If the whole world were listening, what would you say?
"How ya goin', peace out!"

Are you a collector of anything?
Different currencies

Is there anything you would like to collect?
Always wondered about stamps – might be fun!

Have any bad habits?
Playing too much computer, chewing my nails

Who would you most like to sing like?
Michael Jackson or Eminem

What would you like to learn more about?
More about fishing, I really like fishing

What family tradition/routine do you love most?
I used to like cycling with all my family

Name one thing not many people know about you?
I like dancing

If you HAD to change your name, what would you change it to?
Axel

If you could have dinner with anyone in the world who would you choose?
Cadel Evans (cyclist, Tour de France winner) and Jamal Idris (NRL player, Bulldogs)

Save the Date!

ANNUAL GENERAL MEETING

You are invited to attend the Annual General Meeting of the Muscular Dystrophy Association of NSW.

5.00pm Monday 7th November 2011

at Shepherds Bay Community Centre

3a Bay Drive, Meadowbank 2114

RSVP to Maralyn.McCann @mdnsw.org.au or on 02 98092111

Change is in the air....

Georgina, Liz and I recently attended the 'Person Centred Approach – Living Life My Way 2 Day Summit'. This summit was held by the NSW Government, Family and Community Services, Ageing Disability and Home Care at ACER Arena. We were also very happy to see some members of Muscular Dystrophy NSW at the summit and we valued the opportunity to hear your thoughts about the proposed future direction of services in NSW. For those of you who were not able to attend I would like to provide you with a summary of the summit, and to those members who attended, I hope you felt the summit was worthwhile.

The summit was the start of a yearlong state wide consultation process for people who have a disability, their family, carers and service providers, to feedback their views, hopes, and concerns about the proposed shift in Disability Services. This shift will hopefully see a change from a one service fits all approach, to recognising everyone is an individual with individual needs, wants, and aspirations. This will see the person who has a disability and their families and carers at the centre of decision making instead of on the outside looking in.

Person Centred Approach and Individualised Budgets are not new ideas; they have been in around in various ways in other states as well as in other

countries. The shift in the NSW system has come about through 'Stronger Together: A New Direction for Disability Services in NSW 2006 – 2016' and 'Stronger Together: The Second Phase 2011 – 2016'.

Some of the key aims of **Stronger Together** are:

- The commitment to more flexible and innovative support arrangements
- Care and support are to be provided in accordance to an individual's needs
- Embedding Person Centred and Family Centred Approaches into everyday practice
- Make structural changes to the disability services system
- To provide support and services to strengthen family and carer relationships whilst maximising the independence and skills of the individual who has a disability

These aims are a result of previous reports and investigations into disability services and another key aim is to reduce experiences of isolation and to enhance and increase social presence and inclusion.

At present it is hard to predict what the final result of the consultation period will



be, but after speaking to some members I have become aware that some are concerned and even anxious about these changes. Change is a difficult process and we will all take time to adjust to whatever the new system looks like, but please remember if you are uncertain or would like to talk to someone about the changes and what it might mean for you and your family please do not hesitate to contact one of the Client Services Team.

Carolyn Campbell-McLean is currently managing her own services through the Attendant Care Program and has very kindly agreed to share her experiences with you in the next edition of Talking Point. In the meantime if this article has raised any questions for you, please do not hesitate to contact the Client Services Team.

Victoria Berg

Acting Client Services Manager / Case Manager

Members' Advisory Committee To Go Online

Dear Members,

As you may be aware Muscular Dystrophy NSW has a Members' Advisory Committee (MAC) which is a vehicle for members to share ideas and feedback regarding the services and support offered by Muscular Dystrophy NSW. It gives members an opportunity to discuss a range of issues with other members and staff of Muscular Dystrophy NSW. MAC also provides feedback to the Board which can help to formulate programs to meet members' needs.

For a number of years MAC has operated by way of regular meetings, however, it has been decided that there should be an online format for MAC. It is sometimes difficult for members with neuromuscular disorders to attend meetings and generally members of the committee were only from the Sydney Metropolitan area. Muscular Dystrophy NSW provides support throughout the state and the views and input of members in regional areas is very important and this online forum will provide that opportunity.

The other advantage is that members can be involved in online discussions at their convenience and in the comfort of their own homes.

Through Google+ Muscular Dystrophy NSW is organizing a Members' Advisory Committee "Circle" which is essentially an online group. In the next few weeks, you will receive an email with instructions on how to set up a Google+ account and be part of the online group.

I encourage members to get involved as this will assist Muscular Dystrophy NSW to provide the services you need.

Michael Baptiste

Chairperson
Members' Advisory Committee





Introducing our Duke of Ed Team



We are so excited to announce that Muscular Dystrophy NSW has officially started our very own Duke of Edinburgh's Award (Duke of Ed) for young people with a neuromuscular condition. Ten very keen participants across NSW have joined the Pilot program, thanks to the generosity and vision of Ageing, Disability and Homecare and The Duke of Edinburgh's Award Australia.

The Duke of Ed is a self development program for young people aged between 14-25 years which encourages them to set and achieve goals at a level appropriate to their needs and abilities. There are 4 sections that our Dukies have to complete in order to qualify for their Bronze Award as part of this Pilot: Volunteering, Skills, Fitness/Sport, and an Adventurous Journey. They must participate in their chosen activities for each section on a regular basis over a specified period of time, and should take ownership of as much of the planning, decision making

and record keeping as possible. The idea behind the Duke of Ed program is for young people to challenge themselves; to develop new skills and to enhance confidence and self esteem. Unfortunately however, people with neuromuscular conditions do not often get the opportunity to participate in this Award due to a great number of reasons. Conducting a Pilot such as this one allows our Dukies to participate in the Award whilst being supported by people who understand their needs.

We are therefore working very closely with both the National and State offices of the Duke of Edinburgh's Award to implement this Pilot, which obviously will require an enormous amount of communication between many keen people to help it succeed. The Duke of Ed staff have already shown an undeniable willingness to adapt certain aspects of the program to accommodate the varying abilities of our Dukies, whilst still maintaining the

integrity of the Award. It is a learning curve for all of us, but already our short journey has proven to be an extremely positive one.

Participating in the Duke of Ed will greatly assist in improving the quality of life of young adults with a neuromuscular condition by reducing social isolation, enhancing motivation and self esteem, and promoting increased community engagement and participation.

We at Muscular Dystrophy NSW are extremely appreciative of the faith shown in us by the State Government and the National office of the Duke of Edinburgh's Award, and we hope that you all get as much out of sharing the experiences of our Dukies on this wonderful journey as we no doubt will! I am so very proud of each and every person participating in this Pilot, and their willingness to give it a red hot go! Watch this space!

Loretta Downie
Event Manager

Far North Coast Region

Kate Hepton, 15

Skill: Short story and poetry writing

Fitness: Tenpin Bowling

Volunteering: After school care

I think it's a fantastic idea. It's a good chance to prove that even though I'm in a wheelchair, I can still get involved and participate in the local community. I'm very privileged to be included in this pilot program.



Nathan O'Connell, 22

Skill: Family Tree

Fitness: Wheelchair Hockey

Volunteering: Converting VHS to DVD for Aspect (Autism Organisation)

I want to challenge myself and to encourage younger people with Muscular Dystrophy by showing that you can do anything you put your mind to. It will allow people with Muscular Dystrophy to achieve their dreams by allowing them to follow their passion.



Hunter Region

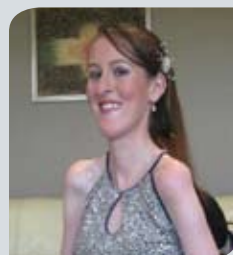
Cassie Robson, 19

Skill: Web Design

Fitness: TenPin Bowling

Volunteering: Working for Livewire

It allows people with disabilities to look outside the square and participate in something that other people do. It gives us something to look forward to and achieve, when most of the time our physical achievements cannot be met.



Bodene Davies, 18

Skill: Driver's Licence

Fitness: TenPin Bowling

Volunteering: Helping in special needs classes

The reason I wanted to be involved in the Duke pilot program was that it would give me more motivation and independence to do things myself. I'm looking forward to doing my community service, because I love helping other people.



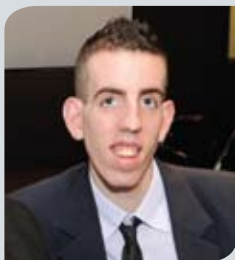
Nepean Region

Sean Disbray, 22

Skill: Drumming and
Puppy Training

Fitness: Grid Iron

Volunteering: RSPCA



Hayley Bellamy, 22

Skill: Toastmasters

Fitness: Alternative Therapeutic Exercises

Volunteering: Muscular
Dystrophy Schools
Ambassador



Luke Berkery, 17

Details TBA

While this is an individual program, part of it offers the chance to work in a group, allowing us to make new friends and to experience new things. We build our own journey and lay down our own path; we are only pushed by ourselves and what we wish to achieve. I thought this was a great opportunity. I had ideas and goals I wished to accomplish, and thought this would be a great way I could achieve them.

“ This program is a great idea; it lets individuals explore new skills in the confinements of their own abilities. It's not often that we get these types of opportunities granted to us. *Hayley Bellamy* ”

Sydney Metro

Melanie Tran, 15

Skill: Online training for product
designing in PTC University

Fitness: TenPin Bowling

Volunteering: Web Design for
Muscular Dystrophy NSW

I think the program is a good idea because it pushes people's limits further; they can gain experiences that last a lifetime; they get opportunities that may help them in their future career; they get to see a larger part of the world meeting new people and even make their dreams come true. The other good thing about the program is that it is non competitive; people can set goals and work their way through it step by step at their own pace. Although I'm a little nervous about spending time away from home and family for the first time, I'd like to use that great opportunity to gain confidence and independence. I also get the amazing opportunity to gain experience working in an office environment...



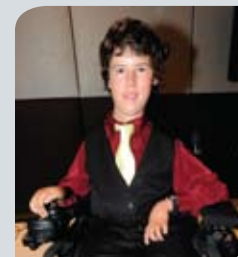
Daniel Michel, 16

Skill: Singing

Fitness: Swimming/hydrotherapy

Volunteering: Soccer team
manager

My brother does the DoE at High school and I have seen how much fun and great experience he has had. I also support this implementation of a pilot programme for students with disabilities and hope to encourage others after us. It's a great idea as we live in a world today where access is a priority for PWD, so why not the DoE programme too!



Julie Duong, 19

Skill: Learning Chinese

Fitness: Swimming

Volunteering: Homework Program
with Refugee Kids

I have always heard during high school of everyone doing this amazing Award and never thought I would have a chance, so when Loretta called me up and asked if I wanted to be involved, I just had to snatch this one in a life time experience. I also wanted to experience new things but also challenge myself while doing the things I love and meet new people.



Please note that Adventurous Journeys will not be finalised until later in the year.

**A big thank you to our
Volunteer Coordinators!**
Jill King, Vicki Sciuilli and Jo Brown

“ It really allows people to go beyond their limits by challenging themselves to go one step further yet allows you to do things you love most. It also teaches you lifelong skills that are so important for the future such as planning, commitment and communication skills. I also love it because I have met such wonderful and strong people on the way and it inspires me to keep going. *Julie Duong* ”



Findings from The Case Management and Sector Development Project

In June last year we launched the Case Management program. The program was funded by Ageing, Disability and Home Care (ADHC). The program had several objectives. ADHC were interested in finding out what the specific needs for people with a neuromuscular disease are and what is required to remain living independently in the community. The program also functioned to step in where mainstream services could not, and to identify the gaps in generic or government funded services.

The project was completed at the end of June this year. One hundred and twenty families were involved over a 12 month period, and a number of patterns emerged. These patterns have been compiled in a report and sent back to ADHC. These patterns include:

1) Issue: The need for service provider awareness

People in receipt of government funded services, including in-home personal care and domestic assistance, reported that staff providing assistance are often unaware of the specific needs of caring for a person with a neuromuscular disease.

Outcome: Within the next 12 months, Muscular Dystrophy NSW will be developing a training program and employ a mentor who will be able to implement the program, providing training and education to community service providers about the best way to implement a care plan for someone with a neuromuscular disease.

2) Issue: The need for representation

Frequent requests for representation across a variety of settings were made. This involved having a Muscular Dystrophy NSW case worker attend appointments with families to explain to various audiences what it means to have a neuromuscular disease.

Outcome: In the next 12 months, Muscular Dystrophy NSW will employ additional case workers to be able to provide representation, advocacy and support within a flexible program.

3) Issue: The need for emotional and psychological support

A large number of people reported that they would appreciate counselling and emotional support. Many



people said that they had accessed counselling previously through generic services, however were frustrated as the counsellors did not have an understanding of what it's like to have, or care for someone, with a neuromuscular disease.

Outcome: Muscular Dystrophy NSW now offers a counselling program that is flexible. Our counsellor is available from our office in Meadowbank, and is available to attend in-home and telephone appointments. The service is free of charge and proudly supported by the Shane Warne Foundation.

4) Issue: The need for a whole-family support model of case management

We found that support programs need to consider all family members, friends, carers and anyone who is involved with a person with a neuromuscular condition.

Outcome: Muscular Dystrophy NSW will continue to consider the whole family when developing programs and services.

5) Issue: The need for episodic case management within a continuative care model

We found that the best model of case management for individuals and families affected by a neuromuscular condition is one that can respond episodically to changed needs as they occur, and avoid lengthy waiting periods like some generic services. Best case management practice for people with a neuromuscular condition is one that continues throughout the lifespan.

Outcome: In the next 12 months, Muscular Dystrophy NSW will employ additional case managers who will have specialist knowledge so that changing needs can be responded to in a timely manner.

6) Issue: The provision of information, referral, support and training

We found that there is a need to provide specialist information to a range of audiences within the community through training and mentoring initiatives.

Outcome: In the next 12 months, Muscular Dystrophy NSW will implement the new training program and offer mentoring sessions to community participants.

Other key findings

- The sensitive issues associated with the diagnosis of an Neuromuscular Dystrophy Disorder (NMD) means individuals and families seek expertise in an organisation they can trust to be able to appropriately respond to crisis and provide psychological and emotional support through challenging times, particularly around areas of grief and loss.
- Neuromuscular conditions can differ vastly in age of onset, speed of deterioration, expression of restricted mobility, and age and cause of death. Sound understanding of these sensitivities is critical to providing best case management practices for this group.
- Individuals and families require varied levels of case management across the lifespan. The model needs to allow for an immediate response to increased/changed needs episodically or at any point as needed and responded to in a timely and appropriate manner.
- The project has revealed that there is a strong need for more focus and support of emotional health and wellbeing.

Future Directions

- Muscular Dystrophy NSW will continue to be the primary source of resources, information and referral in NSW.
- Muscular Dystrophy NSW will continue to provide support that is equitable across NSW, regardless of location.
- The current project has identified the need to provide ongoing training, mentoring and support to the sector and ADHC has commissioned Muscular Dystrophy NSW to develop a web-based training and mentoring program.
- ADHC will also fund additional case worker positions to provide ongoing support that functions to:
 - 1) Step in where generic or mainstream programs are unable to; and
 - 2) Refer to generic or mainstream programs where appropriate and possible.
- Muscular Dystrophy NSW will continue to foster key relationship and influence sector change.
- Muscular Dystrophy NSW will continue to provide representation and advocacy at both individual and systemic levels.





Our events program is in your hands

I have tried out some new event ideas this past year, based on conversations I've had with many of you, as well as feedback I've received from our wonderfully dedicated team of staff here at Muscular Dystrophy NSW. Event funding is extremely limited, so I need to be very careful with which events are chosen to go ahead. My aim is to run events that serve a specific purpose based on demand and need, and their success is often judged by the response we receive from you – normally indicated by your RSVPs. I really want to stress that I am here to run events for YOU; events YOU want to be a part of; events YOU'LL really get something out of. I am guided by you – by comments you make; by your interest; by your attendance. If we get a low interest or low RSVP to any new events, I won't include them in the calendar year ahead and will try something different next time. Alternatively, events that get a great response will continue for as long as the demand and funding are there!

Dates to put in your diary ...

Sat 22 Oct	Parents' Seminar
Sat 12 Nov	Siblings' Adventure Trip at Vision Valley
25 - 27 Nov	Melbourne Weekend Retreat
Fri 25 Nov	Ladies' Matinee Theatre Event
Sat 3 Dec	Hunter Region Christmas Party
Fri 9 Dec	South Coast Region Christmas Party
Sun 11 Dec	Sydney Metro Christmas Party
Fri 16 Dec	Far North Coast Region Christmas Party

I really encourage you to email or call me with your suggestions as to what type of events YOU'D like to see happen at Muscular Dystrophy NSW. The events program is completely and entirely here for YOU!!

DON'T MISS OUT ON EVENT INFORMATION. HAVE WE GOT YOUR UPDATED EMAIL ADDRESS?

Please note that most event flyers and all confirmation letters outlining important details are now sent via email. Don't miss out on the exciting events that are now happening at Muscular Dystrophy NSW! Email: maralyn.mccann@mdnsw.org.au and put "updated email address" in the subject column. It's that easy!!



Boccia

As you may know by now, Muscular Dystrophy NSW is working closely with Boccia NSW to develop the paralympic sport of Boccia throughout NSW for all people with a neuromuscular condition. It is a strategic sport which is perfectly suited to people of all abilities, as a ramp and a carer are used when mobility is limited.

Based on previous interest shown, I am currently trying to set up Boccia Clubs in:

- **The Central Coast region**
(currently running every Thursday)
- **The Illawarra**
- **Sydney Metro**
- **The Sutherland Shire**

If any other regions show a good interest, I'm happy to run a Day Camp there too. Please email or call me to get on the Boccia E-Distribution list so as you can receive information as soon as it comes to hand. Contacting me will also help me realise where the interest lies.

Here's an exciting opportunity to get into a sport which not only involves strategy and skill but also gives you a chance to meet other people and have a great time together. It needs YOU to make it work though, so register your interest by contacting me today!



Trifecta Time for Dads

Not many events were scheduled during the winter months, but our Dads' Trifecta Group braved the torrential weather conditions and became part of the Great Blue Cloud at ANZ Stadium to watch NSW finally beat the Maroons! Adorned in blue wigs and blue t-shirts provided by the Blaxy's Blues consortium, the boys apparently had a ripper of an evening regardless of the driving wind and rain. A big thanks to Anthony for facilitating the evening and to all the keen Dads who attended. The second event of the Trifecta saw the boys head to Oneworld Sports Bar to watch the Wallabies wallop the All Blacks and win the Tri-Nations Cup for the first time in 10 years. It seems our Dads are on a winning streak!!



Muscular Dystrophy NSW offers Specialist Counselling Services

We offer face-to-face appointments at our office in Meadowbank, and in some circumstances our counsellor can come to your home. We also offer telephone counselling for people who live in remote areas or who are unable to attend in-person appointments.

Counselling is confidential and non-judgemental. It is available to all people who are affected by any kind of neuromuscular condition and to all people who need support, including carers, family members and friends.

Our Counsellor, Liz Bailey, understands many of the specific issues associated with having a neuromuscular condition in the family. These include:

- Emotional support in coming to terms with initial diagnosis
- That everyone deals with stressful situations differently
- How additional stress places significant pressure on relationships
- Possible feelings of guilt that parents or carers may feel
- What it means to be a young carrier planning a family
- Anger and resentment issues regarding diagnosis and the reality of the disability
- That grief and loss issues are ongoing
- Feeling alone, disconnection from friends and family who don't, and may never fully understand everything that you're going through
- Fear and anxiety about the future
- The journey to acceptance, and the barriers and hurdles along the way.

Counselling sessions are free of charge, as the cost is covered by the generous people at the Shane Warne Foundation.

We encourage you to book an appointment if you've ever thought that you might benefit from talking things through with someone who understands.

To book an appointment, please contact Liz on 9809 2111 or liz.bailey@mdnsw.org.au



MUSCULAR DYSTROPHY
NEW SOUTH WALES



Anxiety, fear and coping

We all experience worry and anxiety throughout life. We experience anxiety at all ages, in childhood, adolescence and adulthood. Anxiety is a normal reaction when we are in a situation that elicits feelings of fear. Sometimes feelings of anxiety are short lived, like when we are about to make a speech to a group of people, and other times it can be ongoing, like when worries about the unknown future overwhelm us.

Anxiety can be experienced in a number of ways. Physical symptoms of anxiety include increased heart and breathing rates. Our minds might then tick over and we could say things to ourselves like "something bad is about to happen". Our behaviour might change, with an urge to "get out of there" or avoid situations that increase the anxiety, and sometimes we might lash out. This can affect our emotions and we can feel fearful and worried. It is important to recognise these aspects of the cycle of anxiety, both within ourselves and in the people close to us.

Anxiety: A useful messenger

I often tell people that feelings of anxiety, and depression, are sometimes little messengers that can steer us into a new direction. These feelings come up at times when we feel that something isn't right. It is therefore important to go within and listen to what these sensations are trying to tell us. We need to be our own personal investigators. We need to ask ourselves questions about what we can do and what we can't do in particular situations that cause us anxiety. This process is often called "reality testing".

The thinking-feeling connection

The way we think affects the way we feel. At the heart of anxiety are thoughts about all the bad things that might happen, either in the immediate moment or in the future. When anxiety spirals out of control, it is because our thought processes become fixated about the worst possible scenario. Being our own personal investigators involves recognising thoughts that lead to excessive worry, identifying practical solutions to solve problems, and searching out what is fact and what is fear. This is a difficult process and can take time to develop, but like anything, practice make perfect.

Validating feelings

Through the process of managing anxiety, it is important to validate all the feelings that come up. When we are confronted with uncertainties of the future, when our healthcare is placed in the hands of others, when we are forced into situations that we didn't expect or plan for, we all have unique ways of responding and dealing with that. It is ok to be angry, anxious, sad, frustrated. It's also expected that the people around us will have their own unique way of dealing with the same situation. Allowing ourselves to feel the things we do is essential in dealing with the situation. Being our own personal investigator means recognising our feelings, allowing them to come up, and working through them in a practical way.

Tolerating uncertainty

Not knowing what the future holds can be scary. We are all uncertain about what will happen to us in the immediate and distant future, and it's especially scary when questions about our health and all the associated aspects are considered. One of the most common causes of anxiety is an inability to tolerate uncertainty. Accepting that uncertainty is a part of life is key to managing the fear, anxiety, and worry that it brings up.

Acceptance

There are some things that we just can't change, regardless of how much we would like them to. Feelings of anxiety are often associated with a resistance to accept things that we wish were different. It is through acceptance and knowing that other people are going through similar things is where true healing can occur. Acceptance means being realistic about our capacity as well as our limitations, and working with those in a way that provides us with a quality of life. Acceptance also means validating our feelings, and those of the people around us. *It means not comparing our lives to those of others, but accepting everyone in their own journey and accepting our own.*

Liz Bailey
Counsellor



Save the Date!

The Muscular Dystrophy NSW Parents' Seminar will be held on **Saturday 22nd October 2011.**

The day will consist of a presentation from Occupational Therapist and Researcher Paula Bray, as well as a "Triple P" Positive Parenting Program workshop.

More information to come soon!

Musicus Medicus - a thank you note

Have you ever heard of musicus medicus? No? Well I hadn't either until a few Sundays ago when I attended a concert in the Sydney Conservatorium of Music, presented by the NSW Doctors' Orchestra with all proceeds going to the Sydney Eisteddfod and Muscular Dystrophy NSW.

The programme was titled "From Paris to Moscow" and featured guest artist Sandy Sin on the Marimba. What an amazing performer she was, full of verve and dash and truly mesmerising to watch as she played an arrangement of some Hungarian folk songs by the Spanish composer Sarasate, and the Rondo Capriccioso by Saint-Saens.

After the interval, the orchestra returned to play the beautiful 6th Symphony of Tchaikovsky, the "symphony pathétique", lyrical and melancholy and very moving.

The NSW Doctors' Orchestra, conducted by Dr David Banney, was formed 7 years ago and plays at least annually for charity

as well as supporting an Instrumental Scholarship for students aged 16-25 years who compete in the Sydney Eisteddfod each year. The players, who come from all areas of medicine, wish to combine their work in medicine with their passion for music. Ah!! Musicus Medicus!!

This year Muscular Dystrophy NSW benefited from their generosity and David Jack publicly expressed the Association's gratitude at the beginning of the concert, explaining how his team worked to support those living with a neurological condition and their families and carers.

I would like to add my thanks to the orchestra and to hope that we can continue to work toward raising the profile of Muscular Dystrophy NSW and the role it plays in its members' lives.

Krythia Reid
Member

Has Boccia Gotcha Yet?

Recently Talking Point readers were invited to attend introduction days to the sport of boccia. There was an event organised on the Central Coast, which is where I live, so I thought I'd go along and have a look.

Boccia (rhymes with 'gotcha') is a bit like lawn bowls and similar to bocce, which Italians play, and boule, which the French play. Bocce and boule tend to be played by older men standing around in parks smoking cigarettes. Lawn bowls is played on a large green lawn with men and women all dressed in white. Boccia however is played indoors. Oh, and one other thing, it's played from a wheelchair.

I was a middle-aged wheelie who wanted to be able to take up a sport. Was boccia going to be the game for me? I love watching sport but was I up to the challenge of actually playing? After all, those guys in National Electric Wheelchair Sports (NEWS) squad look much younger and fitter than me!

Well, I tried it and guess what? It was lots of fun. Shortly afterwards, Boccia NSW, the state body, established a weekly training group at Woy Woy. I went along on the first day and haven't missed a single session since. I love it. What a great game!

The rules and classification of players mean that any wheelie can play, regardless of your physical attributes. Like most sports, it can be played purely for fun as a social outing, or competitively to championship level. It's open to wheelies of every persuasion. There are no age limits and all competition is mixed. It's great to have a sport in which you can compete together across genders as well as across age groups. There are junior groups for those who don't particularly want to mix it with us oldies.



Why not contact your local group, have a look, and maybe even give it a go? The Boccia NSW website (www.bocciansw.org.au) will give you an idea of where some clubs are located. There are others and one may well be in your area. Telephone Peter King on 0418 467 702 for details.

Should you find yourself totally hooked (and believe me, that's not difficult) you may want to go into competition. There are regular tournaments as well as state and national titles. And it doesn't end

there. Boccia is a fully fledged Paralympic sport.

If you want to see some top players in action, you can find some clips on YouTube. But nothing compares with going along and watching the game played live.

Boccia NSW originally formed to provide opportunities for cerebral palsy (CP) participants. Muscular Dystrophy NSW would love to see its members participating as well. Funding is available through the FlexiRest Respite Program to help cover the costs of tuition and transport to and from venues. Contact Georgina for further information.

So come on, you MD wheelies. Let's show those CP's a thing or two. Hope to see you on a court someday soon.

Dean Nottle



The NSW Colts Prepare for News 2012

After an historic 2011 tournament, the all conquering NSW Colts prepare for another successful campaign at NEWS 2012, which will be held once again in Sydney from 16th to 22nd April 2012.

Our NEWS squad includes players who did not represent NSW this year however some of them represented ACT, while others are players who are coming up through the ranks.

I encourage anyone interested in playing electric wheelchair sports to attend the training sessions. It is a chance to come and try the sports. There are also opportunities to play in some of our local competitions which are run by other organizations. All the players in the NEWS squad participate in local competitions which are run by Push and Power, Australian Electric Wheelchair Hockey Association and Australian Powerchair Football.

There are growing opportunities for people to participate in electric wheelchair sports and it is a fun leisure activity, a great way to make many friends and to aspire to compete at an elite level.

The NSW NEWS training sessions will commence in October 2011 and will be held on Sundays from 10.45am to 12.45pm at Kevin Betts Stadium, Ralph Place, Mt Druitt.

Here are the training dates for 2011/2012:

16th, 23rd & 30th October, 2011

6th, 13th, 20th & 27th November, 2011

4th & 11th December, 2011

5th, 12th, 19th & 26th February, 2012

4th, 11th, 18th & 25th March, 2012

1st April, 2012

Muscular Dystrophy NSW greatly supports our NSW NEWS squad and on behalf of all the players and their families, I take this opportunity to thank the Association for all its assistance, support and encouragement.

For any more information about the training sessions or the sports in general please feel free to contact me any time on (02) 9643 1429 or email MBaptiste@bigpond.com

Michael Baptiste

National Director NEWS
NSW Coach



FREE to a Good Home!!

Actron Air has very generously donated three Split Ducted Air Conditioners to Muscular Dystrophy NSW. These units have just either been bench tested or inspected by our laboratory technicians, when tested these units would have only been ran for a couple of days, all systems are nominal capacity. Installation costs would be at the member's expense.

System 1) Accent Air model No AEC22 22KW

System 2) Temperzone model No ISD160K/OSA160TD 16.6KW

System 3) Temperzone model No ISD210KG-DN/
OSA210RKTGV 21.8 KW

If you would like to contact the office for the specifications please contact Maralyn McCann. You would need to pick up from our office in Meadowbank.

But I don't have a muscular dystrophy.

Is Muscular Dystrophy NSW still the organisation for me?

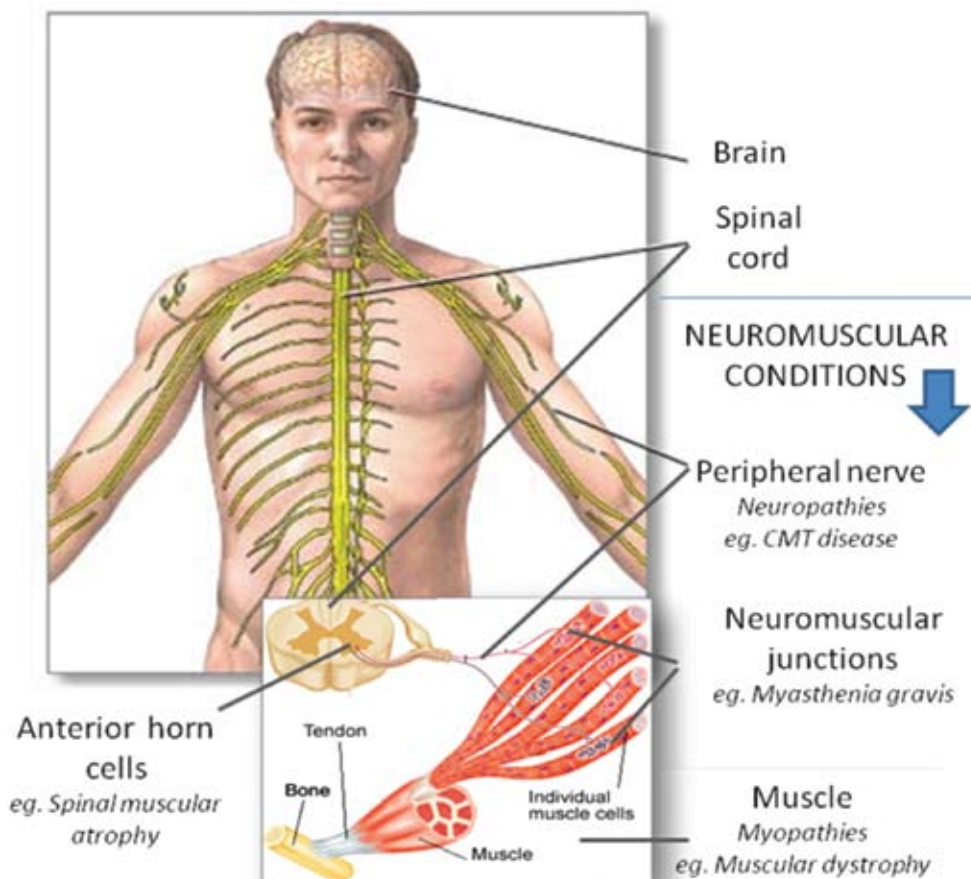
Kristi Jones, Muscular Dystrophy NSW Board member
Neuromuscular Clinic, CHW

Muscular dystrophy is just one of many neuromuscular conditions now covered by the Muscular Dystrophy NSW program. The name 'Muscular Dystrophy Association' is historical, reflecting the origins of the organisation.

What is a neuromuscular condition?

When we want to move an arm, or a leg, messages originate in the brain, travel down the spinal cord, where the anterior horn cells give rise to the peripheral nerves. The message is then transmitted across the neuromuscular junction, finally reaching the muscle. Problems affecting any part of this system – from the anterior horn cell to the muscle result in the so called '**neuromuscular**' conditions (see diagram below).

- For example, primary disorders of the nerve are called 'neuropathies', and Charcot Marie Tooth disease is the most common of these.
- Spinal muscular atrophy results from deterioration of the anterior horn cell (the cells in the spinal cord that give rise to the peripheral motor nerves),
- And primary problems in the muscle are called 'myopathies'. The **muscular dystrophies** are a sub-group of the myopathies – with characteristic clinical findings and changes seen on muscle biopsy.



Here is a list of many of the conditions covered by the Muscular Dystrophy NSW programme – but if your condition is not listed here – please email or give us a call, and we will help you find the right organisation for you.

MUSCULAR DYSTROPHIES:

- Duchenne Muscular Dystrophy (**DMD**)
(Also known as **Pseudohypertrophic**)
- Becker Muscular Dystrophy (**BMD**)
- Emery-Dreifuss Muscular Dystrophy (**EDMD**)
- Limb-Girdle Muscular Dystrophy (**LGMD**)
- Facioscapulohumeral Muscular Dystrophy (**FSH or FSHD**)
- Myotonic Dystrophy (**MMD**)
(Also known as **DM or Steinert Disease**)
- Oculopharyngeal Muscular Dystrophy (**OPMD**)
- Distal Muscular Dystrophy (**DD**) (**Miyoshi**)
- Congenital Muscular Dystrophy (**CMD**)

MOTOR NEURON DISEASES:

- Amyotrophic Lateral Sclerosis (**ALS**)
(Also known as **Lou Gehrig's Disease**)
- Spinal Muscular Atrophy Type 1 (**SMA1, Werdnig-Hoffmann Disease**)
- Spinal Muscular Atrophy Type 2 (**SMA2**)
- Spinal Muscular Atrophy Type 3 (**SMA3, Kugelberg-Welander Disease**)
- Spinal Bulbar Muscular Atrophy (**SBMA**)
(Also known as **Kennedy Disease and X-Linked SBMA**)

METABOLIC DISEASES OF MUSCLE:

- Phosphorylase Deficiency (**MPD or PYGM**)
(Also known as **McArdle Disease**)
- Acid Maltase Deficiency (**AMD**)
(Also known as **Pompe Disease**)
- Phosphofructokinase Deficiency
(Also known as **Tarui Disease**)
- Debrancher Enzyme Deficiency (**DBD**)
(Also known as **Cori or Forbes Disease**)
- Mitochondrial Myopathy (**MITO**)
- Carnitine Deficiency (**CD**)
- Carnitine Palmityl Transferase Deficiency (**CPT**)
- Phosphoglycerate Kinase Deficiency
- Phosphoglycerate Mutase Deficiency
- Lactate Dehydrogenase Deficiency
- Myoadenylate Deaminase Deficiency

DISEASES OF PERIPHERAL NERVE:

- Charcot-Marie-Tooth Disease (**CMT**)
(Also known as **Hereditary Motor and Sensory Neuropathy (HMSN) or Peroneal Muscular Atrophy (PMA)**)
- Friedreich's Ataxia (**FA**)
- Dejerine-Sottas Disease (**DS**)

DISEASES OF THE NEUROMUSCULAR JUNCTION:

- Myasthenia Gravis (**MG**)
- Lambert-Eaton Syndrome (**LES**)
- Congenital Myasthenic Syndrome (**CMS**)

INFLAMMATORY MYOPATHIES:

- Dermatomyositis (**DM**)
- Polymyositis (**PM**)
- Inclusion Body Myositis (**IBM**)

MYOPATHIES DUE TO ENDOCRINE ABNORMALITIES:

- Hyperthyroid Myopathy (**HYPTM**)
- Hypothyroid Myopathy (**HYPOTM**)

OTHER MYOPATHIES:

- Myotonia Congenita (**MC**)
(Two forms: **Thomsen and Becker Disease**)
- Paramyotonia Congenita (**PC**)
- Central Core Disease (**CCD**)

- Nemaline Myopathy (**NM**)
- Myotubular Myopathy/Centronuclear Myopathy (**MTM or CNM**)
- Periodic Paralysis (**PP**)
(Two forms: **Hypokalemic and Hyperkalemic**)



Ride 4MD

I set myself a goal of being able to ride the 50km 'Ride 4MD' as soon as I heard it was going to be on. As most mothers are aware finding time to do things for yourself can be difficult. I thought the ride would be a good way of increasing my fitness as well as doing something for Muscular Dystrophy NSW and consequently of course for my son, Daniel, who has LCMD.

I set about on a fairly ambitious training regime, a bit of yoga twice a week, running a few mornings a week and then a hefty ride once a week.

(Sounds like a lot, but to be honest only the first week consisted of all of these grand deeds). I enlisted the help of my father and mother for the big ride on Fridays. I would borrow a bike and Dad and I would ride off along the numerous bike paths between Greystanes and Fairfield. Mum would look after Daniel.



We got the news a couple of months ago that the official ride had to be postponed for logistical reasons. My first thought was 'Yay, I can stop the training' (I actually hate running) and I could return to a sane wake-up time. My second thought was that I wanted to fulfil the promise I had made to all my supporters. You see by this point we had managed to raise over \$3000... an extraordinary amount. So we made the decision to run the event on our own with the support of a few family members. On Saturday 20th August we rode the 50km from Pemulwuy to Homebush and back. The weather was beautiful (the previous day had been cold and wet). We paced the ride well and in the end had a great time and completed the distance with

energy to spare! Daniel joined us in his wheelchair for the last 2 kilometres.

I would like to personally thank each and every person who contributed money and support for this event. There are a few people I would like to acknowledge for their help and contributions. First and foremost my father for training with me, providing me with a bike and ultimately designing the course and riding with me on the day. Many thanks also go to Rob and Vicki for riding with me and coping with the resulting bottom pain. Thankyou Mum for providing the much needed food to restock our fuel tanks on our return. My support crew Luke, Erica, Samantha, Justine and Thomas. Muscular Dystrophy NSW for contributing t-shirts and other advertising material as well as encouragement and overall support. And of course my beautiful little boy Daniel for completing the last stage of the ride with us on his new wheels and being our inspiration.

A very special thankyou also needs to go to all my sponsors who have helped make my Ride4MD such a success. Everyone has given so generously, and thankyou is not enough. Together we have raised a total of \$4225.00! This is an amazing amount, both humbling and heart-warming. Now my legs have recovered I can't wait to get into another fundraising effort for Muscular Dystrophy NSW!

Joanne O'Brien
Member

St Patrick's Primary School raise money



The SRC at St Patrick's Primary School had a meeting and decided to hold a casual day to raise money for the Muscular Dystrophy Association NSW as we have a child at St Patrick's who has Muscular Dystrophy.

All the St Patrick's children dressed up in pyjamas and brought a gold coin donation. We decided to hold this day on the last day of Term 1.

The children all had a lot of fun wearing their favourite pyjamas to school. We raised a total of \$521.05.

SRC members on behalf of the children of St Patrick's Griffith

HARLEYS 4 MD

SUNDAY 16TH, OCTOBER 2011

DEPARTS FROM HOGS BREATH NORTH PARRAMATTA @ 10.00AM

**\$150 WILL GET YOU LUNCH & 2 HOURS OF
HARLEY DAVIDSON
EXCITEMENT**



LUNCH PROUDLY SUPPLIED BY
HOGS BREATH CAFÉ

Go to www.mdnsw.org.au and click on the "Donate Now" button - select HARLEYS 4 MD to purchase your tickets.

For more information please call the Fundraising Manager on 9809 2111.

All proceeds from the ride go to



MUSCULAR DYSTROPHY
NEW SOUTH WALES





MUSCULAR DYSTROPHY NSW INFORMATION

OFFICE Suite 101, 7 Bay Drive,
Meadowbank NSW 2114

POST PO Box 1365
Meadowbank NSW 2114

PHONE 02 9809 2111

FAX 02 9809 4177

EMAIL info@mdnsw.org.au

WEB www.mdnsw.org.au

MUSCULAR DYSTROPHY NSW STAFF

Chief Executive Officer
Pene Hodge

Acting Client Services Manager/Metro
Case Manager
Victoria Berg

Office Manager
Maralyn McCann

Finance Manager
Chaitali Desai

Data Entry and Admin. Assistant
Gracia Selina

Fundraising Manager
TBA

Events Manager
Loretta Downie

Carers Program Coordinator
Georgina Christofis

Counsellor and Educator
Liz Bailey

PATRON

Her Excellency Professor Marie Bashir
AC CVO

HONORARY DIRECTORS

Robert Ferguson (President and
Chairperson of the Board)

Colin Gunn (Vice President)

Graeme Troy (Honorary Treasurer)

Prof. Alastair Corbett (Medical Director)

Percival Alwyn Baptiste

Ross Parker

Dr Heather Johnston

Ian Williams

Dr Kristi Jones

Martin Dalrymple

Peter Debnam

Annette Burke

HONORARY SOLICITOR

Simon Gates

HONORARY AUDITOR

Domenic Cutrupi
CBC Partners

Letters to the Editor
can be addressed to:
The Editor, Talking Point
PO Box 1365,
Meadowbank NSW 2114.

THE NEUROMUSCULAR CLINICS

CHILDREN'S CLINICS

Sydney Children's Hospital, Randwick
Neuromuscular Clinic
Appointments & Enquiries 9382 1845

Sydney Children's Hospital
Outreach Clinics are held at
Canberra Hospital, Canberra
John Hunter Hospital, Newcastle
Goonellabah Clinic, Lismore
Enquiries through Sydney on 9382 1845

The Children's Hospital at Westmead
Neuromuscular Management Clinic
9845 1904

ADULT CLINICS

Concord Hospital Neuromuscular Clinic
9767 6864

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

Adult Genetics Clinic, Westmead Hospital
9845 3273

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

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

name _____

address _____

phone _____ email _____

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.

