

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

ISSUE 79 WINTER 2011

PRINT POST APPROVED PP 255003/01200



Inaugural Gala Ball



MUSCULAR DYSTROPHY
NEW SOUTH WALES

A Word from the President

Hi there, and I hope 2011 is going well for you?

Sigmund Freud, the first great philosopher to focus on the complexities of the human mind placed great store on the correlation between achievement and wellbeing.

Most of us gain a lot of pleasure from achievement of any sort, and the most rewarding is where we stretch ourselves further than we expect possible.

Whether the achievement is physically or mentally orientated doesn't matter, but I'm sure the more balance we have in our achievements the happier we are. We tend to focus on the things that we are best at, and to try to improve things we don't do so well. In setting goals we should always be mindful that they need to be realistic; to set goals which we are unlikely to achieve is to set ourselves up for disappointment. Ideally if we can set a series of long term

goals that we can adjust and reprioritise as we go, we gain the greatest fulfilment.

The Board operates on long term strategic plans and takes pleasure in achieving the goals it sets to achieve these plans.

The next significant phase of the Board's strategic plan, it refer to as a "For Life" program, which focuses on life for people with neuromuscular disorders after leaving school. In essence it is about looking at what we can realistically achieve, to more fulfil ourselves.

The Young Achiever Award and the Duke of Edinburgh program which have now been introduced, are the beginnings of the For Life program. They are programs which encourage setting goals towards realistic achievement, taking into account our own particular abilities, and circumstances.

I am always impressed that many members achieve so much in their circumstances.



Their example inspires us to follow in their footsteps.

Rob Ferguson

President, Muscular Dystrophy New South Wales

A Farewell from the CEO

During the past 3 years I have been privileged to meet many of our members and enjoy the challenge of developing new programs supporting children, families and adults. This has been a period of significant change for Muscular Dystrophy NSW and I have appreciated feedback from members which has both guided our growth and ensured the development of new initiatives in response to members' needs.

It has been exciting to be involved in initiating our camp and retreat program, the home support and case coordination program, funded counselling, Duke of Edinburgh for young people with disabilities and other important services. These have been delivered by our excellent team here at Muscular Dystrophy NSW. This growth enabled by the substantial and generous support of Ageing, Disability and Home Care (ADHC), NSW Health, Muscular Dystrophy Foundation and other foundations, trusts and individual donors.

In May 2008 I joined Muscular Dystrophy NSW and also took up the position of CEO, Muscular Dystrophy Foundation and was invited to set up this new national body. This has been an enormous challenge that began

with engaging State Muscular Dystrophy Associations and encouraging them to begin to work together. We now have a national logo and Muscular Dystrophy Associations in NSW, Queensland, Tasmania, South Australia and Western Australia work collaboratively together.

With the Muscular Dystrophy Foundation requiring increasing time to ensure it is sustainable and able to achieve its objectives, I have been invited by the Foundation to take up a full time role, with the blessing of the Muscular Dystrophy NSW Board. While this is an exciting challenge, I will miss the day to day contact with members and regular participation in members' events.

Attending camps, medical seminars, Christmas parties and numerous other member events and occasions has been a wonderful experience. I have enjoyed the friendships and been inspired by the many people I have met who have taught me lessons in persistence, patience and achievement.

Importantly this decision enables the appointment of a full time CEO for Muscular Dystrophy NSW. This is a significant step and will enable Muscular Dystrophy NSW to continue to grow and provide increasing support to members.

I have been privileged to lead a professional, competent and compassionate

team. Their ideas, passion and initiative have ensured the successful implementation of the Muscular Dystrophy NSW vision. With new funding and opportunities Muscular Dystrophy NSW will employ an additional five staff during the next few months providing increased support to members.

I have also appreciated working with the Muscular Dystrophy NSW Board. Each Director has played an important role in shaping our vision and supporting its implementation. I am grateful to the Board for their confidence and willingness to step outside the square and invest in new ideas. Our President, Rob Ferguson has been encouraging and a helpful sounding board, providing wise counsel and invaluable support.

I now look forward to being able to support Muscular Dystrophy NSW (in a consulting role as requested by the Muscular Dystrophy NSW Board) during the transition period to a new CEO, and all member States through building a strong national body.

David Jack
CEO

David Jack moving to Muscular Dystrophy Foundation



After leading just over 3 years of transformational change and growth at Muscular Dystrophy NSW David Jack will move to Muscular Dystrophy Foundation as full time CEO from July 1.

This transfer was envisaged to occur within 5 years of David's commencement with Muscular Dystrophy NSW in April 2008, and as

testimony to David's skill and application, this milestone has been achieved after 3 very successful years.

The store of knowledge and David's contacts will not be lost, with an agreement between Muscular Dystrophy NSW and Muscular Dystrophy Foundation ensuring that David will be available on request as a consultant to Muscular Dystrophy NSW for up to 20% of his time for up to 12 months.

We are now advertising for a new CEO, and David will remain CEO until that appointment is made. This new CEO will provide different skills and background that the board feels is appropriate for our next phase of development.

Some of the more notable achievements that David has driven in the last 3 years include:-

- Increasing membership from about 488 to 821 active members
- Moving to centrally located suitable office premises, with excellent transport access, parking, shops and nearby community centre which has been ideal for a number of functions, seminars and meetings
- Adopting a new easily recognisable logo and graphics
- The development of a well maintained, informative and popular web site, and a new look Talking Point
- Launching and developing a highly successful annual camp program, which we hope will become a recurrent biannual program
- Developing increasingly successful home visit and subsequent case management programs
- Developing a very popular weekend retreat program
- Launching the first Duke of Edinburgh program for young people with disabilities
- Initiating Government funding from Ageing, Disability and Home Care (ADHC) now totalling over \$500,000 pa for annual camp funding, case coordination and home support program and training programs for disability workers, in addition to the highly successful FlexiRest funded by ADHC, and Carer's programs funded by the Department of Health.

- The development of online communication access for younger members using Live Wire
- Vastly improved accounting procedures using MYOB
- Successful implementation of a state of the art (CRM) data base, for all membership and fundraising purposes
- Gathering a group of very capable people to implement new services, and provide excellent back up
- In 3 years our staff numbers will have grown from two to fifteen following the recent receipt of 2 more State Government grants and negotiating a \$100,000 annual (ongoing) grant from a Foundation for a new program
- Development of Muscular Dystrophy Foundation (as a part time CEO) to a point where it has a solid base, and should provide substantial benefits to Muscular Dystrophy NSW and other states in coming years

While David will be missed at Muscular Dystrophy NSW, he leaves a very healthy legacy, and will be available where needed; an ideal transition situation.

David's next step is an even bigger challenge, but one that I'm sure he will take in his stride. Already Muscular Dystrophy Foundation has made huge leaps and bounds, and will continue to do so. Western Australia has joined NSW, Queensland, South Australia and Tasmania, and David has been instrumental in bringing these states together in a focussed, collaborative effort.

Jerry Lewis will be making his third visit to Australia later this month, a contact that was initiated and forged by David and Muscular Dystrophy Foundation has raised substantial funds in the last two years. Muscular Dystrophy Foundation now has its own city offices and will have 4 highly qualified staff.

On behalf of the board, I wish David every success in his new challenge, one that will serve those with neuromuscular disorders well, both in NSW and most other states of Australia.

Rob Ferguson

President, Muscular Dystrophy New South Wales



Meet A Member

Maralyn meets Robert Bruce, father of six, from Nowra NSW.

Robert is a stay at home Dad and an emerging artist in the field of photography.

Can you name one goal you have?
To learn how to do Tai Chi

What do you really like doing?
Photography, hanging with my children

If you were to win \$10 million, what would you do with all that money?
Set my family up so that they are financially stable and need never worry about money again

If you were to get an opportunity to live anywhere in the world, which part of the world would you choose? **Right where I am**

Why is that? **Family! Where a person lives means little without family to share my experiences, hopes and dreams. Anywhere can be a paradise; it is what we make of where we are.**

If you had to evacuate your house immediately what two things would you grab (not people or pets)?
Photos and my guitar

If a movie was made about you who would play your part? **Gerard Butler (Born in Paisley, Scotland**

who was a trained lawyer but turned to acting in the mid 1990's)

What would you like to be talented at? **Music**

What was your best subject in school? **Visual Art**

If someone was to give you a gift, and money was no object, what would you want it to be? **Honda Shadow (Motorcycle)**

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

What is the bravest thing you have ever done? **Hitchhiked from QLD to NSW**

If the whole world were listening, what would you say? **We don't have to like each other, but let's not hate**

Are you a collector of anything?
Yes, I collect dragons, painted miniatures and clowns



Or is there anything you would like to collect? **Motorbikes!!!!**

Have any bad habits? **Lots, but to remain unrevealed**

Who would you most like to sing like? **Tom Waits - (born December 7, 1949) is an American singer-songwriter, composer and actor**

What would you like to learn more about? **Everything**

What family tradition/routine do you love most? **Shopping days rock!!**

Name one thing not many people know about you? **That I am always afraid**

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

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

Don't miss our next New Members' Evening - Monday 5th September!

New Members' Evening

My name is Inbal and I recently attended the *New members' evening* with my father Eddy Osmo who is a new member to Muscular Dystrophy NSW. Dad and I had discussed him becoming a member as a way of understanding more about what services and assistance exists for sufferers of Muscular Dystrophy in NSW.

The *New members' evening* was fantastic! It enabled me to see with my own eyes the faces behind this great organisation. There is nothing like putting faces to names and chatting with people whose voices you have heard over the phone. Each of the staff that I met and spoke with were so kind and motivated about this cause and that resonated extremely well with me. I also learned

about the contribution that each member of staff makes. For new members and carers, what is great about this is that you know who to direct your enquiry too.

I was so inspired by the evening that Muscular Dystrophy NSW became my preferred charity for the marathon that I ran in Canberra on April 10th.

You guys rock!!! Looking forward to seeing and interacting with you a lot more.

Inbal Osmo (New member)

Sarah Inspires us with her Speech

My name's Sarah, I'm in a wheelchair, I'm 13 and I'm a catholic. But that's only the outside stuff, the obvious things. I have Irish heritage on my dad's side, and Scottish on my mum's side. I have a thing called Ullrich Congenital Muscular Dystrophy which basically means: weird skin, weak muscles, thin bones and this is all caused by a lack of collagen 6. But the weird thing is, I didn't have that diagnoses until I was 7, so for 7 years of my life, I was basically living a lie.

Over the years, I've had many significant moments, all worthy of being in this speech. But there's only one moment that really deserves to be said aloud. That moment, is my first MD camp.

You see, in 2007, I had an operation to try and help me walk, but it had the opposite effect. It stopped me walking all together. So, I kind of wasn't myself for 2 years, saying things like 'I hate myself' and apologising when anything happened that involved my wheelchair, as I felt it was my fault I was like this. Really, when I think about it, the only thing that ended up taking me out of that phase was this camp.

I can remember that I wasn't too thrilled to be going – I don't like being put out of my comfort zone, and the idea of making new friends really scares me. Of course, seeing as nothing ever happens in Canberra, we had to go to Sydney for this camp – Narrabeen Sports and Rec camp to be precise. The drive took at least 4 hours; so naturally, I was bored out of my mind. When we arrived, you can imagine I was nervous as. I just couldn't imagine 30 kids in wheelchairs being in one spot all week. It would just be hectic and there wouldn't be enough space. Or so I thought. So, we went to meet my carer who would help me with everything throughout the week, Kelly. We went to our room and a few minutes later, my roommate arrived. Her name was Bodene and her carer was Elise. Bodene was 4 years older than me, but that didn't stop

us from clicking straight away. After we got settled in and had the first awkward conversation and figured out that Bodene and I were completely obsessed with Twilight, we were told we had to go out and do the first activity. We were put into groups and, because this camp was near Halloween, we made banners for our groups with Halloween kind of names. My group was called the 'Bloodsucking Campers'. Unfortunately, Bodene and I weren't in the same group but it was also a good thing. A little friendly competition never hurt anyone.

The rest of the week went by in the same way; spending time in our room getting to know each other, an activity, and back to the room partying and getting to know each other more. The more I got to know Bodene, the closer we got, and I found myself somehow forgiving myself for what happened in '07. Forgiving the surgeon and realising that I can be who I was, I just needed to understand that I won't be the exact same, that things have changed. When I realised that, I was able to have more fun, throw more of me into the activities and not be so reserved.

My favourite thing on this camp had to be the party – Halloween party! It was awesome!! It was on Wednesday night, so I had basically fully become a child and was doing everything I wanted and doing it with a smile on my face, a smile that almost never left my face, which hadn't happened since the operation. We all had face paint on – and it wasn't the face paint you get at fete's... this was movie worthy face paint! Warts, blood and all! The hall was filled with all sorts of things: streamers, Halloween decorations and Halloween food. All of which, Bodene and I helped set up. They also had karaoke! I was so happy there was karaoke because



I've always wanted to do it and I said to Bodene 'Dude, we have to do that!' but, of course, she said no, because she was too chicken! So, I went with Elise because I didn't want to go up alone. Then the next few times I did it, Bodene did it with me!

I remember saying goodbye on Friday was really hard. There were quite a few tears, but I knew I was coming back next year as I just had so much fun and for the first time in ages, I was fully myself, and I felt as though I belonged somewhere.

This camp had helped shape my identity by making me realise that I'm not alone in what I'm going through. If I'm having a rough time, all I have to do is call my best friend up and ask her for help seeing as she's already been through most of it. This camp also shaped my identity by making me who I was when I was 10: a person who always smiles and makes pathetic jokes but still laughs like crazy at them. Without this camp, I would still hate myself, wishing I was normal. I'm perfect just as I am. And that's the most important thing this camp had taught me.

MUSCULAR DYSTROPHY
NEW SOUTH WALES **camp 2011**

As a result of the flyer we placed in our last edition of Talking Point, and following on from the success of the last two camps, this year's camp in September is now already fully booked! I realise that many of you will be very disappointed that you will miss out this year, but I urge you to email me ASAP to put your name on a waiting list in the event that we are successful in our application to run a second camp early next year. As with all our events now, it's so important to register early!



First Gala Ball

What a wonderful evening we all had at Doltone House for our first Gala Ball! We were blessed with a beautiful evening, a full house, and a night to remember for a very long time for a great number of reasons.

Everyone took the opportunity to get dressed up and feel really glamorous for one night, so it was no wonder that the smiles seemed to last until the very end. It was great to see so many people from the regional areas of NSW use FlexiRest to attend the Ball and stay in the city for the entire weekend.



Our Duke of Edinburgh Team

made it into the Junior NSW Squad after only a few games, and presented Daniel with his NSW tracksuit on the night. A huge thank you to Sydney IVF and Rob Ferguson for their continued generous support of the Young Achiever Award which inspires our youth to chase their dreams by giving them the means to be able to do so with the \$2000 prize money on offer.

One of the many highlights had to be the launch of the Duke of Edinburgh's Award pilot program. Ten of our young members have decided to complete the Award and learn a new skill, participate in a sport, volunteer in the community and go on an adventurous journey over the next 12 months. The Hon. Sandra Nori gave a warm speech outlining all of the Award specifics and welcomed the excited group into their Duke family. Hayley Bellamy touched everyone in the room when she spoke on behalf of all 10 Pilot participants on what it means to be a Dukie and why it's important that they embark on this challenging journey. It was a remarkable speech and totally inspirational! Well done Hayley – you truly made us all very proud! All participants were presented with a commemorative pin from the Governor of NSW - Her Excellency Marie Bashir, who then told us about how much she fully supported this exciting new concept. We were extremely honoured to have the Governor involved with some of the official



Melanie Tran with the Aide de Camp

A big congrats to Melanie Tran and Daniel Michel for winning the prestigious Young Achiever Award to develop their skills in literacy and Boccia respectively. Thanks also to Ken Halliday, the Elite Ramping Coach for Boccia NSW, who announced that Daniel had



Daniel Michel and Ken Halliday from Boccia NSW

Gala Ball

saturday 21 may 2011



MUSCULAR DYSTROPHY
NEW SOUTH WALES

generously sponsored by **Doltone House** and **Sydney IVF**

proceedings on the night, and it was an absolute pleasure simply having her there amongst us chatting with as many people as was physically possible.

Thanks to the staff and Board of the Duke of Edinburgh's Award of Australia, particularly Kim Brislane for your passionate support of the Duke Pilot so far. Your belief in what we are trying to do is so very much appreciated! Thanks also to Sydney IVF and Doltone House whose sponsorship enabled us to keep the cost of the tickets to an absolute minimum.



The team from Genzyme Australasia

A special mention of thanks to Genzyme Australasia for once again supporting Muscular Dystrophy NSW with your presence on the night. Finally a huge pat on the back to a remarkable team of staff here who assisted greatly throughout the evening, especially to Pene Hodge for her outstanding leadership of the team - and for coming up with the idea in the first place!

The venue was magnificent, the food was unbelievable and the company was second to none! What a ripper of a night!

Loretta Downie
Events Coordinator



Her Excellency Marie Bashir and David Jack



The Lancaster family



Welcome to our new Finance Manager Chaitali Desai

I started working at Muscular Dystrophy NSW in April and it has been an amazing journey so far. I am currently working part time as I have 2 young children. This has provided me with the opportunity not only to focus on my professional capabilities but also lead a balanced life and spend more time with my family. I can honestly say that I love coming to work every day and interacting with such a dedicated, talented and fun group of people.

I attended my very first Muscular Dystrophy NSW function recently at the Gala Ball and it was such a memorable evening for me as I met many of the members for the first time. As I was driving home that evening, I felt so proud of working here at Muscular Dystrophy NSW and listening to the very inspirational stories from the young members and their families.

I look forward to many more events such as these and thank you for the opportunity to be part of your team!



Benefits of Goal Setting

Small goals can be set to lead to a larger goal to make the outcome seem more achievable

Aids Personal Growth and Development

Improves Self – Image, Self – Esteem and Confidence

Defines real life actions by separating them from wishful thinking

Benefits of Goal Setting

Helps to set priorities and reduces time spent on distractions

Makes you responsible for your own success

Helps to develop skills such as planning skills, problem solving skills, organisational skills

Provides a structured path to follow

SMART Goals

S = Specific
M = Measurable
A = Achievable
R = Relevant
T = Time Bound

TIPS TO SUCCESSFULLY PLAN GOALS

All Goals should be **SMART** Goals, as without specific goals it is impossible to have any clarity on what you want to achieve. If you cannot measure your Goals you will never know when you have achieved them.

Care for Carers Corner

Hello Readers!

I'm sure you're all feeling the cold now that it's winter. I've certainly added my scarf, beanie, and warm jacket to my dress routine each morning. It's been an interesting but busy couple months for me. I've travelled to many parts of regional New South Wales including Bega (Far South Coast), Dubbo and to the Far West (Broken Hill).

During one of these visits, I met with families from the Central West region of NSW at the Western Plains Zoo on Saturday 30th April. Here I had the privilege of walking through the zoo with three very adorable yet talkative 4 year olds! I don't know about you all, but my favourite part was the Asian elephant exhibit. I was fascinated by the female elephant's ability to consume an entire log of wood using its trunk and teeth. Thank you once again to all the families who joined me from the regions and I hope you are all thinking about what we can do next when I visit Orange in late August!

Apart from organising regional events and providing individual case coordination to many families living in the more remote areas of NSW, I've also had the awesome opportunity to educate service providers about muscular dystrophy itself. Members tell us that it's a common misconception amongst health professionals that muscular dystrophy is a disorder that only affects young males. As many of you know, this is simply not the case. Fortunately the Care for Carers program gives us the opportunity to disperse some of these misunderstandings. This wonderful program is now under the auspice of Ageing, Disability and Home Care, enabling Muscular Dystrophy NSW to support regional carers through support groups, education, and social events. I'm so pleased to announce that it is now guaranteed to be funded until mid June 2013!

Finally, when thinking about this year's achievements, I was pleasantly surprised by the response I received to the one page article about FlexiRest in the last edition of our Talking Point magazine. I've received over 60 applications during the past three months - the highest in FlexiRest history! I would



like to encourage many of you who haven't applied yet, to contact me with your respite requests and for those who have accessed the funds already, I hope you enjoyed your break. I would love to hear from you all so please don't be shy - email your comments to carers@mdnsw.org.au.

It's been great to connect with you all again, until next time...

Georgina Christofis

Carer Program Coordinator

Dear Ladies

We're organising a support group for women and would love you to be involved.

It's an opportunity to talk freely about issues with like minded ladies over a light afternoon tea.

We're keeping it informal and flexible. Transport options to and from Meadowbank within the Sydney Metropolitan area may be available.

Are you interested? Please register your interest by emailing me at liz.bailey@mdnsw.org.au

Kind regards,

Liz Bailey
Counsellor

Do you need someone to talk to?

Muscular Dystrophy NSW Counselling Services are now available.

Members can receive up to six face-to-face or telephone sessions with our counsellor who understands the emotional and psychological impact families experience when affected by a neuromuscular disorder. For more information or to book an appointment, please see the Muscular Dystrophy NSW website or contact Liz Bailey on 9809 2111.





Two Very Different Types of Trips!!!

Two Adults, One Bag and One Respite Weekend

Two parents, one 8 year old child with a neuromuscular disease and one 7 year old sibling.

An enjoyable 4 hour car trip to Sydney, uninterrupted conversation, a quick stop for lunch and the freedom to listen to our choice of radio station. Very much looking forward to a two night getaway.

Consult the packaging list again to make sure all essentials are in the bags; bipap, wheelchair charger, feeding pump, feeding equipment, formula, medication, cough assist, pads and overnight pants, splints, pram, power board, toilet insert seat, extension cord and additional pillows. Can't fit in shower chair, will creatively improvise with outdoor chair. Van loaded, DVD players in position, all contingencies plan for carsickness, extreme hunger or thirst.

A rest and short walk around Darling Harbour before dinner. A Chinese banquet with plates of yummy food that kept coming and coming. An opportunity to meet others from across NSW. It doesn't take long for the conversation to flow, though we have just met we all share a common experience that is understood by all.

Rearrange hotel room to accommodate equipment. Father/logistics manager has set up the feeding system by hanging a modified wire coat hanger from curtain rail to hold feed bag. Extension cord and power board has wheelchair charger, feeding pump, bipap and cough assist connected. Child in bed with all necessary cushions behind back and between knees that will be repositioned several times throughout the night. Sibling excited to sleep with big brother.

A whole night's sleep in a king size bed. An early morning walk/run together – admiring what a beautiful place Sydney can be away from the congested roads. The digestion system was still processing from the night before however we managed to enjoy the extensive breakfast buffet. Walked around the city and appreciate the freedom of being able to wander in and out of shops and not just look through the windows – though my husband may not agree on this statement. Saw a bus with "Bondi Beach" on it and decided to make a quick run to catch it. Enjoyed the trip watching the action along Oxford Street. The beach was full of activity with a surf carnival and the weekend crowds.

Going to the beach is a well executed military operation. The beach plan; hope to find a park close enough to carry child, ocean pool in case surf too rough, get floppy child in wetsuit as can only swim in water above 28°C, identify a safe place to park wheelchair, dig a big hole in sand to support child, bring umbrella for shade protection and work out where to shower child as he will have sand everywhere. Negotiate which parent swims with sibling. It is never a spontaneous decision.

The afternoon was spent enjoying the fantastic swimming complex at Star City. Lazing around the pool and getting to read more than just column 8 in the SMH – bliss. Our only deadline was dinner at 5.30pm. More eating, more talking and then on to enjoy the spectacle of live theatre.

Going out in public with a child whizzing around in an electric wheelchair generates looks and comments – sometimes you feel like public property. The conversation usually centres on his competent driving ability, questions about how long he has been in the chair and if he ever will be able to walk. I'm always hoping my child

is not in hearing range. Then perhaps you might get to hear about a distant family member that had some form of disability just to let you know that your not the only ones facing this challenge. Or the comment about how medical technology will come up with a cure, you know that in China they are using stem cells to get paralysed people walking again. You then politely make some cliché comment about staying positive and optimistic and remind yourself that people are being kind. However, there are times you just want to sit and anonymously enjoy your coffee and blend in with the crowd.

Another full night's sleep and feeling great, no groaning and ignoring the alarm. One more opportunity to tackle the Breakfast buffet that has everything you could imagine to eat for breakfast though can't reconcile that salami is a breakfast food. Another chance to talk to our fellow retreatees. To an outsider the discussion may seem strange but when you're a member of the club everyone has something to say and learn. We discuss modified vans, how the upcoming NSW elections will affect disability/health care, respite services, frustrations dealing with government agencies, the stress of hospitalisation and making care decisions. The list is extensive and way more interesting than discussing the weather.

Sadly, the time had come to an end and we all travel back to our respective parts of NSW and lives. I think everyone agreed what a great weekend it was and recognised the fantastic effort the NSW MDA team did in organising this experience. THANK YOU.

Katrina

Muscular Dystrophy NSW goes to the Show!

The Sydney Royal Easter Show event was held on Wednesday 20th April at Sydney Showground Homebush. It was certainly a popular choice for parents looking for something to do during the school holidays and for members who simply needed to enjoy the heart stopping rides the show is so famously known for!

Coordinated by the events team here at Muscular Dystrophy NSW, the Show was a screaming success with 80+ members registering to attend with family and friends.

Some positive feedback received by the Harper family from Wagga NSW is expressed below:

Dianne and I would like to thank you and the team for the wonderful work you all did organising our day at the Easter Show. We had a great day, not having visited the show for at

least ten years. It was a great excuse to get in the car and go somewhere, made all the more enjoyable because we were able to afford the amazing convenience of staying at the Novotel, just 100m from the gate! We walked the whole place and visited almost every pavilion, including some empty ones! It will be the highlight of the year!





Wow - our events have really taken off these past few months! Don't forget to RSVP early to better your chances of securing a spot, especially when the event only has limited places available. Hope to see you at an event soon! Loretta

Dads' Trifecta

For Dads of Kids with MD

- Wed 15 June** State of Origin match & Harley ride*
- Sat 27 August** Bledisloe Cup at the pub
- Sat 29 October** Hawkesbury River Fishing Charter*

Meet other Dads who have a child with muscular dystrophy and join the Trifecta Group where you'll attend, watch and participate in 3 different sporting events throughout the course of the year. Attend all 3 events and get to know a great bunch of blokes with whom you'll all have at least a few things in common! Places are filling fast!

OTHER EVENTS COMING UP IN 2011

- Sat 3rd Sept** Medical Seminar
- Mon 5 Sept** New Members' Information Evening
- Sat 12 Nov** Siblings Adventure Trip at Vision Valley*
- 25th - 27th Nov** Melbourne Weekend Retreat*
- Fri 25 Nov** Ladies' Matinee Theatre Event*
- December** Christmas parties galore!!

**limited places available*

Remember that anyone can use FlexiRest to attend any of these events. It's particularly useful for those in regional areas. Stay a night or two with your partner or family or even by yourself, and have FlexiRest cover such expenses as accommodation, transport and meals.

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 important details. Email: maralyn.mccann@mdnsw.org.au and put "updated email address" in the subject column. It's that easy!!

Hayley speaks about the Duke program

Her Excellency, and all guests of the Muscular Dystrophy Association here tonight.

Tonight; on behalf of all the participants, I would like to tell you a little about what it means for us to be involved in the Muscular Dystrophy NSW, Duke of Edinburgh pilot programme.

We chose to participate for a variety of reasons. To meet new and interesting friends, to push ourselves just that little bit further to achieve that goal we always thought was beyond our reach.

It is my intention to complete the Award by attending toast masters, to develop essential skills and to build confidence. Learning an electric wheelchair sport; and going on outings where I leave my nana home.

For those who don't know my Nana is very special to me, someone who I look up to and depend on for the simplest of things, my companion and my carer. To go out without her by my side on the shortest of outings is challenging for me but a skill I wish to develop.

These challenges I have set will hope to teach me perseverance, as it is my goal to live independently. Something that Muscular Dystrophy and Duke of Edinburgh award can set me on my path to achieve, an adventure that I can experience for rest of my life.

For me, representing the muscular dystrophy association of NSW is an honour. We wish to provide each other some support and encouragement for each of the Duke of Edinburgh participants and have the chance to talk about our progress or challenges we are facing. But most of all it is to develop new friends and long-lasting relationships.

Muscular Dystrophy NSW and The Duke of Edinburgh's Award gives us the opportunity to achieve within our limitations, in hope of one day pushing pass our restraints so we can proudly say; there is nothing we can't achieve.



Hayley Bellamy speaks at the Gala Ball



Blue Mountains Getaway

The Problematic Pre-Trip Planning

As a surprise birthday present for my fiancé Steve, I planned a short getaway to the Blue Mountains in January. As many of you would have experienced yourselves, organising to getaway when you have a disability can be tricky, what with equipment, transport and care needs to arrange. Finding suitable wheelchair-friendly holiday accommodation can be equally challenging. I spent many hours trawling the internet for accessible options within cooee of Katoomba. My original plan was to get a train to Katoomba and stay locally so we could just wheel around in our chairs. I had negotiated special arrangements with our terrific band of carers. Just 2 nights away only a short distance from Sydney. Simple plan. Not so simple implementation.

First issue was the lack of accessible accommodation in Katoomba, in fact in the Blue Mountains entirely. I thought I had found the perfect spot but on enquiry I found that their brand new accessible apartment has a built in bed with no gap underneath to roll a hoist under. Not very accessible! Sitting in my chair for 3 days was not an option so it was back to the search. I found an abundance of heritage hotels, backpackers, camping sites and B and B's, none of which had accessible bathrooms and circulation space for my chair and Steve's scooter. After a good bit of research I found the Fairmont Resort at Leura ticked all the boxes, except that it was at Leura, and Leura train station is not accessible!

Another question was how was I to transport my hoist to the hotel? It doesn't fold up into the carers car and we can't take it by train. Options were becoming scarce. The plan was on hold until I could find a way for a wheelchair, a scooter and a hoist to get to Leura. I approached Muscular Dystrophy NSW to see if they could help solve my problem. As it turned out they were able to offer the use of their new accessible van so that we could get us and all our equipment to the resort, safe and sound - thanks Muscular Dystrophy NSW. The 'birthday surprise getaway' was back on track.

Day 1 Freedom and Food

To have a van parked in our driveway was a real novelty. It was also a dead giveaway to Steve that I had been up to something! It felt awesome to load the van at our own pace and even better to set off without the 'taxi meter' ticking, and make our own decisions about when and where



to stop along the way. I think this is something that only people without their own transport may relate to. The taste of freedom is so liberating!

As luck had it we arrived in Leura in the middle of their 'Food for Floods' village fundraiser, and the level of community spirit was soaring. We bought handmade jewellery from youngsters, tasted wine, pastries and smoothies, checked out the quaint shops, all whilst listening to live jazz and bagpipes. How handy that much of the fare was out on the streets and footpaths as most of the shops have steps into them. Nevertheless, it is a charming little town, our Leura.

That afternoon we took the opportunity of having 'wheels' to visit friends who had recently bought a holiday cottage in Leura. A gorgeous sloping block with huge pines, home to an array of native birds including Black and White Cockatoos,





Galahs and Rosellas (Steve the birdwatcher was in his element). For me, it was all about the scones with jam and cream and spending time at friends' place – something us wheelchair users aren't able to do very often.

By 6pm we reached our final destination and home for the next few days, Fairmont Resort at Leura www.fairmont.com.au A spectacular entrance and comfortable accessible room (apart from the mini fridge at floor height) with garden views. Another plus was the temperate climate and fresh air, much cooler than the hot Sydney days we had been having. We had a delicious dinner at the resort restaurant, certainly a Room with a View. Huge cathedral ceiling and fireplace with bar overlooking the escarpment, this was the classiest fish and chips I'd ever eaten!

Day 2 Scenic Sights

The whole trip had been planned around the fact that Steve had not been to the beautiful Blue Mountains (having left Sydney by age 7) so we were hoping for a clear, dry day so we could fully explore. And yes it was clear and dry but woow was it windy! We were impressed by the renovated Echo Point scenic lookout and the Three Sisters are still majestic as they have always been. Steve the intrepid "bushwheeler" took me down the track to see another amazing view and some gorgeous wildflowers and butterflies.

Next it was on to Scenicworld www.scenicworld.com.au, via a wrong turn and subsequent cliff top road with incredible views. Scenicworld offers a variety of options to get amongst the wilderness; scenic railway, Skyway and we chose the Scenicender cablecar ride to the bottom of the valley – fully accessible! The cablecar lowers you deep into the cool valley where you can explore the accessible boardwalks on the forest floor, natural wonders and historic sites. The only drawback is the large groups of tourists that do tend to spoil the serenity a little.

The afternoon was topped off by a romantic stroll around the grounds of the Fairmont, tennis courts, gardens and duck pond – and that view! Room service and a cosy relax in front of the Australian Open tennis was on the menu that night evoked utter relaxation!

Day 3 Homeward Bound

After a scrumptious hotel brekkie, we set out on a relaxed journey home. Packing up always makes me super paranoid as I've left important pillows behind before, and its pot luck as to whether you get them back! We meandered down the mountains at our own pace, veering off at Wentworth Falls to see the Wentworth Falls – spectacular! (and good accessible track).

This day was also the 6th anniversary of the loss of my beloved late husband Danny, "Danny Day" as we affectionately call it. It was evident his love was all around with the amount of butterflies about.

The Post-Trip Philosophy

The old adage of its nice to go away but its nice to come home is so true. The excitement of going away of a change of scenery or fresh air and new experiences is an essential life experience for everyone – no matter what your particular 'special needs' may be. But for me getting away is also about that feeling you get when you return to the comfort and safety of Home Sweet Home. It's amazing that only a few short days away can feel really refreshing, and certainly get you thinking about that next break you can plan. So go on, plan a getaway – you know you want to!

Carolyn Campbell-McLean



New South Wales Colts Clean Sweep at National Electric Wheelchair Sports 2011

The 26th Annual National Electric Wheelchair Sports was held at the Sydney Academy of Sport and Recreation, Narrabeen, from the 11th to 17th April 2011. This year NEWS was held under the auspices of Muscular Dystrophy Foundation.

The NSW Colts team for 2011 was Steve Webb (Captain), Peter Dalrymple (Vice-Captain), Chris Suffield, John Shepherd, Alex Scollard, James Kim and coached by Michael Baptiste. This year was a debut in NSW colours for Alex Scollard, who had previously played for ACT, while it was a debut at NEWS for James Kim.

NSW squad members, Hamish Armitage and Jordan Crane represented ACT, which is a composite team made up of players from other states as, sadly, ACT currently do not have enough eligible players to form a full team.

The competing teams at NEWS this year were ACT Wheelers, NSW Colts, QLD Gladiators, VIC Pride Warriors, SA Scorpions and Western Wasps (WA).

The Opening Ceremony was held on Tuesday, 12th April and the games were officially opened by Mr Rob Ferguson, President, Muscular Dystrophy New South Wales.

There were a number of special presentations made at the Opening Ceremony. The first awards were for 20 years service to NEWS. I was fortunate to be one of these recipients and it included my 14 years as a player and 6 years as a Coach and during



Can you see the Coach under all that Silverware?

that period my 17 years as National Director. I also played 258 games for NSW and coached 123 matches. The other recipient was Adam Hart from SA. Adam and I first attended NEWS in 1992. Adam played for SA before moving to WA in 1995 and continued to represent WA until 2010, when he moved back to South Australia. Adam has the record for most games which now stands at 368; 6 times Overall Best and Fairest and 15 times All Australian player.

Steve Webb and Peter Dalrymple received their 10 year Service Awards, as players, while Martin Dalrymple, Margaret Dalrymple and Louise Suffield received 10 year awards for their roles as officials. There were a number of players and officials from interstate who also received 10 year awards.

After the official proceedings concluded, Pene Hodge, Operations Manager, MDNSW performed the ceremonial coin toss and then the serious competition began.

Tuesday, 18th April, was the Soccer Round Robin competition. NSW went through the day undefeated, scoring 33 goals and only conceding 1. NSW would face Victoria in the final.

Wednesday, 19th April, was Hockey. It was a tough day but NSW were able to qualify for the final against Victoria who were undefeated on the day but had a draw with Queensland who had a very new team this year, but performed extremely well. NSW scored 33 goals and only conceded 3. Our only loss on the day was 2-1 defeat to Victoria.

Thursday, 20th April, was Rugby League. The day started off amazingly with South Australia upsetting Victoria, 22-18. NSW of course started like a house on fire and dominated the day and were undefeated. Our toughest game was against Victoria, who we beat 14-12 which promoted South Australia into the Rugby League Grand Final. NSW scored 184 points and conceded 38, which was the best attack and defence.

Our performances in the Round Robin competition won NSW the coveted Roger Melnyk Trophy as overall best team.

Friday, 21st April, was the free day, which was an opportunity for people to rest and go sight seeing. In the evening however there was the traditional All Australia Team vs The All Stars matches. The All Australian Team was Andrew Brandreth (Captain) (VIC); Chris Suffield (Vice Captain) (NSW), Steve Webb (NSW), Luke David (VIC), Santo Bongiovanni (SA), Tristram Peters (QLD) and coached by Michael Baptiste (NSW).



NSW Colts 2011; (left to right) Chris Suffield, Alex Scollard, James Kim, Peter Dalrymple (Vice Captain), John Shepherd, Steve Webb (Captain), Michael Baptiste (Coach)

It was a fun night with The All Australian Team winning the matches for each sport. After the matches, we turned back the clock and had a Slalom competition. When NEWS was first started in 1986, it included Slalom. In 1990 when Rugby League was introduced, Slalom was no longer part of the program.

Saturday, 22nd April, was D-Day, otherwise known as the Finals Day. The day began with the Participation Awards for all players and coaches. After this, was the 3rd Place Play-off in Soccer. QLD were too strong for SA, winning 7-0. The Grand Final followed and it was a very tough match but defending champions NSW were always in control and ran out winners 2-0 against VIC to go back to back in Soccer for the first time for NSW.

Then it was time for the Hockey. QLD defeated SA, 6-2 in the 3rd Place Play-off. After lunch, was the Hockey Grand Final and featured arch-rivals VIC and NSW. VIC was defending champions and had played in 25 of the 26 Hockey Grand Finals. It was an epic encounter, where NSW were in front but faced a late rallying from VIC. There was late drama when Peter Dalrymple, as Goal Keeper, had his T-stick broken and James Kim was thrown in as Goal Keeper and had not trained much in that position.



Chris Suffield attacking the SA goal; NSW defeats SA 11-0

The Rugby League 3rd place play-off was between VIC and QLD. In a highly entertaining and competitive match, VIC won 34-20. Now it was time for the Grand Final. Could NSW make history of their own, or did SA have other plans? It was SA's first Grand Final in any sport since the 1994 Soccer Grand Final, which featured Adam Hart and now that he was back in SA, he had master-minded their qualification to the rugby league grand final. SA got off to a brilliant start, scoring the first try and shocked the crowd by leading 4-0. Then it was the time for the Colts to break their shackles. In a great performance NSW dominated SA to win 32-4 and then make history by clean sweeping NEWS 2011.

Steve Webb was by far the best player on Finals Day, which backed up his great performance during the week. After the traditional lap of honour and

The Players' Player award was won by Tristram Peters (QLD). The Rookie of the Year Award was won by James Kim (NSW). There were also Umpires' Awards for each sport. The Umpires' Awards for Hockey and Soccer went to Jeff Toon (WA), while Rugby League was won by Dale Holman (SA).

At the end of the presentation, Peter Dalrymple called a team meeting with the NSW players, including those playing for ACT, to announce his retirement as a player at NEWS. Peter has played for 10 years, including 182 games. Peter will join the Colts coaching staff next year and will continue as NSW Delegate on the NEWS Sports Committee. Congratulations to Peter on a great career at NEWS, but Peter will continue to play sports at a local level.

All in all, it was a great week and of course the games were played in an atmosphere of tough competition and great sportsmanship. It is a wonderful event for people with neuromuscular disorders.

For the NSW Colts, it was a true team effort. All players contributed to our success and the six months of hard training paid off.

I take this opportunity to acknowledge and thank the NSW Organising Committee, which consisted of myself, Percy and Eileen Baptiste and Martin and Margaret Dalrymple; the Sydney Academy of Sport and Recreation; Muscular Dystrophy New South Wales and Muscular Dystrophy Foundation.

The NSW squad will begin training and selection trials in October 2011 and NEWS 2012 will be held again in Sydney from 16th to 22nd April.

Michael Baptiste

National Director NEWS
NSW Coach



The Players Assemble at the Opening Ceremony

Ultimately NSW came out on top in this classic match to win 5-4. This result meant true tears of joy from James Kim, which really highlighted how much this tournament means to the players. NSW now had a chance to clean sweep all major trophies, which had only been done once before in NEWS history in 2003 by Western Australia. Standing in the way was South Australia.

celebrations, it was time for everyone to get ready for the Presentation Night. The first awards were the Best and Fairest for each state. The winners were Andrew Brandreth (VIC), Jordan Crane (ACT), Dylan Needham (WA), Josh Merkas (QLD), Santo Bongiovanni (SA) and Steve Webb (NSW). The Overall Best and Fairest went to Andrew Brandreth.

Congenital Muscular Dystrophy **Standards of Care**

Two years ago, Cure CMD, an organization dedicated to finding treatments for children with congenital muscular dystrophy, launched the first and only international registry (CMDIR) to identify people with this disease, improve standards of care and, most importantly, prepare for clinical trials to find potential drug treatments.

To reach even more people with similar conditions, the international registry has expanded to collect key information from people affected by congenital myopathies, thanks to the successful partnership of several congenital muscle disease advocacy groups.

"We're very excited about this expansion," explained Anne Rutkowski, chair and co-founder of Cure CMD. "Finding more people with these diseases will enable us to create a critical mass to participate in clinical trials. Simply put, we will not be successful in finding a treatment or cure for these diseases unless we know who the affected individuals are, what the diagnosis is and how the disease is affecting the individual."

Patient registries provide an essential and important interface between patients, clinicians and researchers, added Dr. Kathryn North, professor at the University of Sydney in Australia. "Expansion of the registry for congenital muscle disorders is essential in raising standards of care for this rare group of conditions and ensure equity of access to clinical trials for all patients."

The registry includes demographic, health and diagnostic questions. Its mission is to act as a central hub for up to date clinical study and trial information, collect data on baseline medical information and treatment interventions and support genetic confirmation through referral to national centres of diagnostic excellence. The registry is available in English, Spanish, French, Portuguese and German.

There is significant work to be done to locate people affected by both the congenital muscular dystrophies and congenital myopathies, explained Dr. Susana Quijano-Roy, MD, PhD at the Neuromuscular Centre, Raymond Poincaré University Hospital in Garches, France. "Congenital muscular dystrophies and congenital myopathies have made extraordinary advances in the last decade on diagnosis and identification of their genetic origin but this knowledge is still far from accessible for many patients and families, due to the rarity of the diseases and the difficulties to get expert advice, even in developed countries," she said "That the registry is now reaching out to more people with congenital muscle conditions is very good news."

For more information, go to www.cmdir.org

Australasian Neuromuscular Network (ANN) is officially launched during the Australian Rare Disease Symposium

The Rare Disease Symposium held recently in Fremantle, Western Australia, was the ideal setting to officially launch the Australasian Neuromuscular Network (ANN). The ANN is committed to achieving health equity for the more than 20,000 individuals living in Australia and New Zealand who are affected by neuromuscular disorders. The network was officially launched in front of an audience of patients, parents, advocacy groups, government and industry representatives, researchers and health professionals.

The ANN has also joined with the European neuromuscular initiative TREAT-NMD, allowing Australia and New Zealand to gain from and contribute to global efforts in this area. The recently established Australian Duchenne muscular dystrophy (DMD) registry connects Australian and New Zealand DMD patients with more than 10,000 patients worldwide across more than 30 countries. The ANN will promote integrated training programs for clinicians and researchers, and will also provide a single voice to advocate for patients and their families. The diagnosis, prevention and treatment of neuromuscular disorders will benefit greatly from this integrated and united national approach.

The sports fact sheet was prepared by Anna Everett (nee Phillips) who is an Occupational Therapist in the Neuromuscular Clinic at Sydney Children's Hospital, a position she has held since 2006. She has eight years experience working as an Occupational Therapist with people Neuromuscular Conditions. Her passion for working in this area began in 2000 with her university clinical placement as a camp worker with Northcott Disability Services and continued with her employment as a respite worker at Northcott. She is interested in working with people with neuromuscular disorder to assist them to identify and achieve their personal goals.

Muscular Dystrophy NSW is fortunate to have three doctors as directors on our board, Professor Alastair Corbett, Dr Heather Johnston and Dr Kristi Jones who provide for us a medical article in each issue of Talking Point. They would like to hear from members what topics you would like information on and find beneficial so they can tailor their articles to best meet the need. Please contact our Office Manager - Maralyn on 02 9809 2111 or email her at Maralyn.McCann@mdnsw.org.au with any suggestions.



Exercise and Sport for Students with **Neuromuscular Conditions**

Students with neuromuscular conditions will all have weakness, some more than others. They need to remain as active as they can within their limits, but will not get stronger with more exercise. Overexercising can be harmful in some cases. They need to conserve their energy to get the most out of school and there needs to be a balance of activity and support.

What to remember about exercise and the neuromuscular student

- They will not get stronger with more exercise.
- Improvement in motor skills is not always achievable.
- More support is needed to enable the student to participate in sport.
- Being asked to perform a skill which is too strenuous may result in the student being exhausted for the rest of the day.
- **Sport is still an important part of schooling and can be fun!**

Levels of inclusion

Use the level of inclusion that best suits the student. They are listed below, from least restrictive to most restrictive.

1. Regular physical activity
2. Regular activity with adjustments (eg all team members must touch ball before goal is scored)
3. Parallel activity (eg. student with disability is allowed two bounces instead of one)
4. Adapted activity - included (eg. sitting volleyball using a balloon)
5. Adapted activity - segregated (eg. smaller version/tabletop version of game played with a small group while the rest of the class play cricket)

Who can help?

Contact the child's occupational therapist or physiotherapist or:

The **Australian Sports Commission** has several relevant resources:

1. Disability Education Program (DEP) which includes face to face or online courses under the **Sports Connect program** which assists teachers/coaches to include people with disabilities in sports activities. For more information Ph: (02) 6214 1792
2. Sports Ability Kit: Includes information and equipment for a range of adapted sporting activities- available through Modern Teaching Aids
3. Written resources: available from www.ausport.gov.au/participating/disability/resources
 - a. What is Disability Sport CD Rom
 - b. Give it a Go and Opening Doors books: Step by step guide for inclusion of people with disabilities
 - c. Activity cards with step by step instructions on how to play modified sports such as Wall Tennis and No- Go
 - d. Information sheets on topics such as Adapting and Modifying sport for people with disabilities

Physical as Anything: Collaborative support for students with physical disabilities and medical conditions - by: New South Wales Department of School Education, Australia, 1996. A copy of this has been provided to each Department of Education School.

Inclusive Games: Movement Fun for Everyone: By Susan L Kasser (1995)

Information adapted by Sydney Children's Hospital from the resources listed in this handout www.sch.edu.au, Occupational Therapy Department Ph: 9382 1073

The TREE principles

Sport is one of the hardest parts of the curriculum for a child with a physical disability to access. The TREE principal, developed by The Australian Sports Commission, is great when modifying the sport program. It ensures that you maintain the integrity of the game and don't take away the challenge for the other children while enabling the child with a disability to participate to their level of ability.

The TREE Principle	Helpful hints
Teaching styles - how instructions are given.	<ul style="list-style-type: none"> • Make sure every child understands, explain the rules one step at a time, use pictures and visual cues, demonstrate. • Deal with competitiveness: the aim is not to win or lose it's to keep getting better and have fun!!
Rules	<ul style="list-style-type: none"> • Everybody bowls underarm • Everyone else hops from one base to another. • Substitute walking for running or allow runners • Hit off a tee rather than being bowled to. • Sit to bat rather than stand (French Cricket with a 180 degree bowling semicircle) • Allow the ball to bounce twice • Allow the ball to be hit a number of times e.g. in volleyball. • Everyone play with similar limitations e.g. sit to play volleyball or shoot hoops • Prepare the other kids, encourage them to come up with new rules • Incorporate rest and stretch times • Substitute players often
Equipment	<ul style="list-style-type: none"> • adapted or alternative • Change the weight, size, shape of objects and target size • Bigger, lighter, softer balls (balloons, beach balls, Gertie Ball (from Modern Teaching Aids) "whiffle" balls with holes in them. • Lighter bats with shorter handles (cardboard tube filled with newspaper and taped together) • Deflating a ball slows it down • Tether ball (ball in a stocking or on a string) hung off a tree branch or beam to play tether tennis • Use a garbage bin instead of a basketball hoop
Environment	<ul style="list-style-type: none"> • Change the space involved eg: distance, height • Reduce the size of the playing field • Lower the height of nets, targets and hoops

The sports fact sheet was prepared by Anna Everett (nee Phillips) who is an Occupational Therapist in the Neuromuscular Clinic at Sydney Children's Hospital, a position she has held since 2006. She has eight years experience working as an Occupational Therapist with people Neuromuscular Conditions. Her passion for working in this area began in 2000 with her university clinical placement as a camp worker with Northcott Disability Services and continued with her employment as a respite worker at Northcott. She is interested in working with people with neuromuscular disorders to assist them to identify and achieve their personal goals.



Inaugural Junior Boccia Titles contested in Avalon

The inaugural Boccia NSW Junior Titles were recently held at the Avalon Recreation Centre. Sixteen athletes ranging from 12 to 18 years old from Sydney, regional areas of NSW, and even New Zealand, attended the event.

These athletes represent the best of the young talent coming through. The level of play they demonstrated and the confidence they displayed in front of a large crowd was proof that the Boccia NSW Coaching team has been selecting the right young athletes over the last few years.

A special mention must also be made of two athletes from the Muscular Dystrophy Association who were playing in their first event. Daniel Michel and Kevin Cheung displayed a lot of confidence, and Daniel even took home the bronze medal in the hotly contested BC3 division.

Over June and July, Boccia Australia will be promoting the sport of Boccia in the Newcastle area and looking to start up a weekly clinic. Newcastle already has a Boccia club that operates several times a week, with both an adult and a junior training squad.

For further information about the event, and the sport of Boccia, call Peter King on 0418 467702, or go to www.bocciansw.com.au



Two wheelchairs For Sale

\$8,000 or near offer.

- A. ELECTRIC CHAIR
CAN TILT AND IN GOOD CONDITION.
- B. MANUAL CHAIR
IS MADE FROM QUICKIE & IN
GOOD CONDITION
CAN FOLD & BE DISASSEMBLED.

For further information contact:
Andy on 0408476875



Disability Vehicle Available

Toyota Hi-Ace 1998

- 11 months rego
- Odometer reading 240,000km
- Mechanically sound
- Rear hydraulic wheelchair lift, which has only been used approx 6 times
- Seats 7 (3 in front, 4 in rear) + wheelchair

\$7,000 NO OFFERS

Contact: Cheyenne Maston on 0423 527 530



The following items are available "FREE" for anyone who will find use for them.

1. **PLV-100 Ventilator** –
useful as a second back up ventilator.
2. **Electric bed** -

Recently custom made to fit through normal sized doorways. Back rest and height adjustment.

Please contact:

Ph: 94282916 Mobile: 0417696554

Regards DR R Thangavelu

Fundraising Matters

City2Surf

The City2Surf is coming up again on Sunday August 14 2011. Muscular Dystrophy NSW will again be encouraging all our supporters to enter and choose Muscular Dystrophy NSW as your charity of choice for the event.

Last year \$3,829 was raised just from City2Surf fundraisers! This year we are hoping to reach \$5,000, and with your help we can! If you are a keen runner, then we encourage you to enter City2Surf. If you are not so keen on running, we encourage you to support one of the runners. Please go to: www.city2surf.com.au for further information.

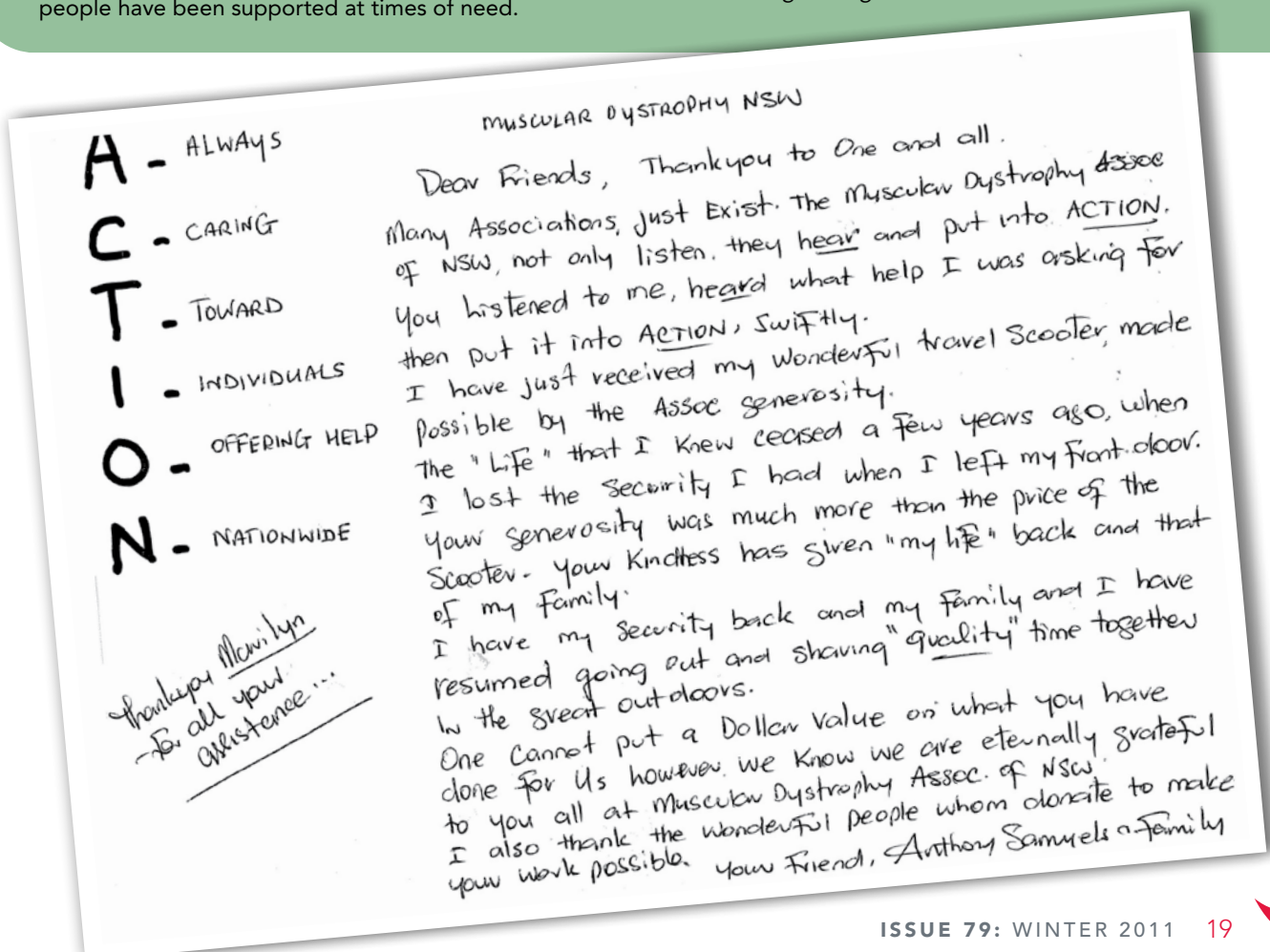


Thank you to our supporters

In the last financial year we have raised enough money to continue our existing projects and offer a new Case Management program to support people with a neuromuscular condition. On behalf of the staff and members of Muscular Dystrophy NSW I would like to thank you very, very much for helping to make this happen. Through your generous donations we have helped many people purchase essential items of equipment, attend respite, attend camp, and many people have been supported at times of need.

Unfortunately I will be leaving Muscular Dystrophy NSW at the beginning of June. I have really enjoyed meeting our wonderful members and working at Muscular Dystrophy NSW. I am moving back to New Zealand to be closer to my family and my new baby niece. Thank you again to all the wonderful people who have responded to our calls for support.

Rebecca Scelly
Fundraising Manager





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
David Jack

Operations Manager/Client Services
Pene Hodge

Office Manager
Maralyn McCann

Finance Manager
Chaitali Desai

Data Entry and Admin. Assistant
Gracia Selina

Fundraising Manager
Rebecca Scelly

Carers Program Coordinator
Georgina Christofis

Events Coordinator
Loretta Downie

Case Worker
Victoria Berg

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

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.

