

# *talking point*

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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Jaxon Taylor  
surfs with the  
help of his  
dad, Leon.

story on pg 14

in this issue: **sport, leisure & recreation**



muscular dystrophy  
new south wales



Carolyn and partner Steve cruising the Brisbane River onboard the accessible CityCat.

### Hello friends

Welcome to the winter edition of *Talking Point*. I hope it finds you well and avoiding those nasty colds and flus that are so prevalent this time of year. To escape the winter blues I recently spent a lovely long weekend north of the border in Brisbane, with the assistance of the MD Flexi-rest program. It was a final blast of warmth with balmy June temperatures of 23 and 24 degrees each day. Virgin Blue gave excellent customer service, and were very flexible in their approach to my special needs, I even had the pilot assist with my transfer from the plane! The accessible accommodation was fairly good, although the bathroom was on the small side. I recommend the service of the Oaks on Felix, and the views from our apartment on the 28th floor were fabulous! I found Brisbane to be a young, vibrant and accessible city, with much progress and development taking place. My weekend was filled to the brim with eating out, wheeling along the river, exploring the Botanic Gardens, Queen St Mall, Treasury Casino and a trip up river to Portside on the fully accessible City Cats. The party spirit was in full swing with many in town for the Green Fest and Horse Races. At times I felt it was busier than Sydney! Thanks to the Flexi-rest program coordinators for their funding assistance for this truly special spot of R and R. I strongly recommend this program to other MD members and families.

This edition we focus on Sport, Leisure and Recreation pursuits.

Recreation, simply termed as "fun," is the expenditure of

time in a manner designed for therapeutic refreshment of one's body or mind. Recreation can be seen as diversion, as in an activity that diverts or amuses or stimulates. It also serves as a form of refreshment and may be in the form of activities that refresh, recreate and renew your health and spirits by enjoyment and relaxation. So next time you feel like you don't have time to rest, go out to lunch or watch a movie, think of the health benefits!

Inside these pages you will find info on heaps of recreation activities you can get involved with. From craft to camping, footy to footspas, there's something that should spark your motivation to remain active and in touch with others during the cooler months. We have a touching story from mum Lija Taylor, research on leisure pursuits for people with neuro-muscular conditions and continue with Chris Suffield's adventures. You will find info on activities for kids, sporting options for people with disability and social events for carers. We report on all the goings on from fundraising events to client services. The Association is working hard to provide you with a range of groups, events and opportunities for members and their families, carers and friends. There is a lot happening in the second half of 2009, and I hope you enjoy some fun and beneficial activities, and reap the rewards of being active and involved in the MD and broader community.

take care and stay strong

**Carolyn Campbell-McLean**

All contributions can be sent to The Editor, PO Box 1365 Meadowbank NSW 2144 email: [cazza74@bigpond.net.au](mailto:cazza74@bigpond.net.au) tel: 9684 6443

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### We certainly have an active group of members!

During April I was amazed and impressed at the skill, competitiveness and achievement of those who participated in the Annual NEWS Tournament. Congratulations to the NSW team for taking out the top award and to Michael and Percy Baptiste and your supporters on running such a successful event.

We can choose to be active in so many different ways. Just last month Anne Patterson, a member of MDNSW, organised a research team from the University of Sydney to come and present their findings to a small group of MDNSW members. I thoroughly enjoyed the presentations and of course the social interaction was great.

Our MDNSW team are committed to planning opportunities for our members to be active. Whether by participating in an event, attending the MDNSW Camp in October or by joining the MD group on Livewire, I encourage you to be active and get involved.

To ensure MDNSW is able to continue providing these services to our members, DADHC (Department of Ageing, Disability and Home Care) has responded positively to our application for funding assistance. A grant has been approved to support our MDNSW Camp and Weekend Retreat program for 3 years with the funds to be available this year. This is the first time DADHC has provided funding to MDNSW and it provides a platform for a future partnership with the department.

Some members have been active in communicating with me on a number of issues, including the proposed National Disability Insurance Scheme. This proposal is being discussed widely and MDNSW has added its voice to the large group of supporters for this scheme. See [www.natdis.com.au](http://www.natdis.com.au)



NSW Colts dominate the Western Wasps in a 2009 NEWS soccer match.

Other members have expressed appreciation to me for our new Home Support program. We believe it is important to spend quality time with our members in their home discussing needs and ways in which we can assist. If you would like to be a part of this program, please call Renee on 9809 2111.

Finally, I welcome your feedback and comments. This will guide our efforts and ensure that our activity is purposeful and makes a positive difference in the lives of our members.

David Jack



14/4/09

Hi Carolyn,

Talking Point looks wonderful in colour. Well done.

Cheers,

Ursula H.

29/4/09

Hey Carolyn,

I just read the current MD mag, and enjoyed it as always, and I read your note about wanting feedback for what we would like to see, and I thought, well why not! ha :)

I would love there to be sections on:

**Different types of Muscular Dystrophy and what they entail** (to gain a better understanding of all types of MD).

**Individuals or carers stories about their experiences with MD** (highs and lows).

I love reading personal stories about people in similar situations as ours, as it makes you feel not alone, if that makes sense, and you can gain knowledge from them.

**Any ideas about different ways of physio, and different equipment on the market etc** (would always be a bonus).

**Where clinical trials are at currently**

**and general MD research whether it be overseas or in Australia.**

We have virtually stumbled across most things we have got for Jaxon on our own, and I think there would be a lot of families that don't have the correct guidance or don't know that they can contact TAD for example and get a special bike made to suit their child etc. Thank you so much for adding that detail in Jaxon's story, he got so excited to see himself in the mag, it was great!

It brought a tear to my eye with the Roe family's little note, it's so nice to hear about those stories, and of course Mia's, as she had the same condition as Jaxon, and just to generally know what other families are experiencing is wonderful.

Thank you for a wonderful Mag.

Hope you are well...

Lija Taylor

15/4/09

Carolyn,

This current TP was sensational!

Feedback from staff, Board and members has been very positive.

Thank you for all of your hard work.

David Jack



## HELLO FROM THE PRESIDENT



### Don't miss our first camp for anything!

I strongly encourage members take the opportunity of going to our first camp in October at Sydney Academy of Sport at Narrabeen!

Having supported Camp Quality for many years before joining the MDNSW board, I know what a wonderful opportunity camps present to change our lives, or add so much fulfillment to them! I also know that Victoria and South Australia have been running successful camps for years, and this success speaks for itself.

Whether you are 7, 17 or 27, it is all about sharing a wonderful few days with people who may become your friends for life, and make your life so much more fulfilling.

Adolescence is a particularly difficult time for all of us, and much more so if you live with a disability. A camp presents an opportunity to meet people with similar difficulties, and share the fears, issues, dreams and joys, that you face, and make new friends. Just one such friend may make become a friend for life, and change a life forever. And, after all, it is a great opportunity to just have fun!

The venue – the Narabeen Academy of Sport, is ideal for a camp. I recently had a look through the centre which has been used for the Annual National Electric Wheelchair Sport most successfully for some years now. It is very accessible, with excellent accommodation, leisure rooms,

indoor sport/activity rooms, and open park areas.

There are so many interesting activities planned, including:

- Mad Science Fire and Ice show
- The Halloween themed party with DJ and Karaoke
- Wheelchair sports
- Reptile show
- Team games, improvised sports,
- Craft and lots, lots more

The carers are all carefully screened volunteers, mostly university students studying in an appropriate field such as OT or nursing. If mum and or dad want to act as a carer this is fine also.

And most of all because most costs are paid for by grants we have organised, the most you will pay is \$120!

I know just how hard Renee, David, and others have worked to make this first camp a success, and I do ask you to ring Renee, and ask some questions about it. You may feel some threat or intrepidation – that's only natural, but these experiences can be so much fun if nothing else, and may even be life transforming – so please pick up the phone, and give it a go!

Best wishes,  
**Rob Ferguson**

## FOR YOUR INFORMATION

For more information, call our office on 9809 2111



### Nutrition seminar

A Medical Seminar on Nutritional Care for people with Neuromuscular Disorders

**program** Saturday August 29, 2009

1.30pm	Registration
1.45pm	Welcome and announcements
<b>FIRST SESSION – CHAIR KRISTI JONES</b>	
2.00pm	<b>'Food: what we need and what we don't need'</b> Speaker Hannan Saleh, dietician, 'The Food Doctor'
2.30pm	<b>'Eating and Beyond – My Story'</b> Speaker Michael Baptiste, MDNSW member
3.00pm	Refreshments
<b>SECOND SESSION – CHAIR ALASTAIR CORBETT</b>	
3.30pm	<b>'What is a surgeon doing here?'</b> Speaker Susan Adams, paediatric surgeon
4.00pm	Question and Answer session – Chair Heather Johnston



### coming events

<i>SEPTEMBER</i>	
Sunday 13th	HOGS Day 10am at Fraser's and 11:30am at the Dam
Tuesday 29th – Wednesday 30th	South Coast Carer Workshop (KIAMA)
<i>OCTOBER</i>	
Monday 5th – Friday 9th	MDNSW CAMP (Sydney Academy of Sport and Recreation, Narrabeen)
Monday 26th	MDNSW AGM Meeting (Sheppard's Bay Community Centre)
Tuesday 27th – Thursday 29th	Riverina Carers Visit (Wagga Wagga, Narrandera and Griffith)
<i>NOVEMBER</i>	
Tuesday 3rd	MDNSW Melbourne Cup Function 1:00–4:30pm
Friday 13th	Women's Group Meeting 12–4pm
Saturday 28th	Family Day out 11am–3:00pm Featherdale Wildlife Park
<i>DECEMBER</i>	
Sunday 13th	MDNSW Christmas Party – Sydney 11:00am–3:30pm



# MDNSW camp 2009

Join us for  
the very first  
MDNSW Camp!

## WHERE

Sydney Academy of Sport and Recreation,  
Narrabeen

## WHEN

Monday 5th October – Friday 9th October

## COST AND INCLUSIONS

\$120 per person

*(Please talk to Renee about claiming the camp fee and travel to and from the camp through our Flexible Respite Program)*

INCLUDES All food, accommodation, one to one care (carer provided or you may bring your own) and a HUGE variety of age appropriate activities and experiences.

## AGE

The camp is aimed at children, young people and the young at heart!

## WANT AN APPLICATION OR TO KNOW MORE?

Contact Renee McBryde at MDNSW on  
9809 2111 or [renee.mcbryde@mdnsw.org.au](mailto:renee.mcbryde@mdnsw.org.au)



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



## introducing Maralyn



Hello, I am Maralyn McCann, recently appointed as Executive Assistant to the CEO and Office Manager. I am happily married, have two lovely grandchildren and a golden retriever named Bella.

I have long experience as an Executive Assistant and Office Manager, mainly working in organisations which

have a significant community purpose. In recent years these cover roles at the Australian Dental Association, Scouts Australia and an Aged Care provider.

I have been President of the local Netball Association, the P&C and have in recent times had the wonderful experience of being a volunteer at Westmead Children's Hospital where I got to nurture little babies whilst giving their parents a break.

I am really delighted to be joining the wonderful team here at the Muscular Dystrophy Association of NSW.



Dear Members,

As the current Chairperson of the **Members' Advisory Committee (MAC)**, I would like to take this opportunity to call for members to join the Committee. We generally meet on the third Thursday afternoon of every second month, at the Association Office.

The purpose of MAC is for members to get involved and help the Association to better serve its members. Members of MAC are encouraged to offer suggestions and feedback regarding fundraising and social events and other ideas to benefit the members of our Association. It is also a more formal link between the members and the Board.

Any member of the Association is eligible to join. If you are interested, please feel free to contact Renee McBryde or David Jack.

Kind regards,

**Michael Baptiste**

## RED ROOSTER COLLECTION COORDINATOR



Muscular Dystrophy NSW need a well organised, reliable volunteer, to assist for 2 - 3 hours a week, accounting for collections from Red Rooster stores around the state, and liaising with designated collectors and Red Rooster.

Please call Maralyn McCann on 9809 2111 or email

[maralyn.mccann@mdnsw.org.au](mailto:maralyn.mccann@mdnsw.org.au)

## arts grants up for grabs

(these articles brought to you by [www.redbubble.com/people/monica](http://www.redbubble.com/people/monica))

Call for Papers:

### SECOND ARTS-ACTIVATED CONFERENCE IN 2010

**WHAT** Accessible Arts invites submissions from presenters at the conference "Arts - Access - Excellence", which will explore the process, practice and innovation relating to inclusion of people with disability in the arts. Creative and interactive presentations that incorporate participatory elements are welcome - see [www.aarts.net.au/arts-activated-conference-2010](http://www.aarts.net.au/arts-activated-conference-2010) for information and the application form. People with a disability are encouraged to apply.

**WHERE** Powerhouse Museum in Sydney

**WHEN** 25-26 March 2010

*Closing date for submissions is 30 August 2009.*

**INFO** Phone Jane Pollard on 9251 6499 or email [jpollard@aarts.net.au](mailto:jpollard@aarts.net.au)

### Don't DIS my ABILITY Accessible Arts Small Grants Open

Applications are open for Accessible Arts Small Grants of up to \$1000 for organisations and arts workers to create high quality arts events as part of the 2009 Don't DIS my ABILITY campaign of events that run throughout November in the lead up to International Day for People with a Disability (IDPWD) on December 3. Accessible Arts will offer grants to a small number of high quality, sustainable projects that involve partnerships between the professional arts and disability sectors, plus advice to any organisers of arts events who need guidance and support. The deadline for funding applications is August 17. Application forms and detailed guidelines on planning your event are at [www.aarts.net.au/projects/idpwd](http://www.aarts.net.au/projects/idpwd)

Phone Becky Chapman,  
Arts Development Officer, on 9251 6499  
or email [bchapman@aarts.net.au](mailto:bchapman@aarts.net.au).  
See the Don't DIS my ABILITY website at [www.internationaldayofpeoplewithadisability.com.au](http://www.internationaldayofpeoplewithadisability.com.au)





# a sporting life

**At the end of a hard week, it is important to give yourself a break. A long week of classes or working can tire you out, both physically and mentally, and at the end of it everyone wants a chance to unwind.**

Usually Australians like to undertake some form of sport or recreation on the weekend. Particularly in Australia, families and individuals like to watch a game of their preferred code of football in front of the TV, or head out to the game and watch their team play. Whatever happens to be the case, it is often an enjoyable end to the week, before doing it all again. When I've had classes all week, I always look forward to my weekend. For a long time now, part of my weekend has involved wheelchair sports. Just this weekend I was out at Kevin Betts Stadium in Mount Druitt for one of the numerous times already this year. I was playing Rugby League again, approaching the end of the season at this time of year. By the time I reach Thursday each week, I'm itching to get out onto the court and have a game. It's also a good time to catch up with my friends from sport, with Saturday's being one of the few times that we actually get to see each other. It may be a contradiction when I say that I play sport to relax, particularly after a tiring struggle against another good team. Even if you may not win, you are able to set goals as a team and individually. Many times I've been involved in a game against a stronger opponent, but setting goals such as scoring a try or conceding less than a certain amount of points allows the team to gain some satisfaction from the result if the goals are met. Sport improves your team work and creates a bond with friends. I've gained many close friends through my sports, and it's great to see those people on the weekends and play alongside or against them. Another important thing to mention is the satisfaction you get when you teach a team mate something and it helps them out. If you tell someone something and then they use it to improve their game or help the team, it's amazing how happy you feel about it. Leadership is an important life skill, and playing sports helps to develop this useful skill. I think anyone would agree with me that playing footy is much more enjoyable than burying your head in a text book. Especially around exam time, I find that my sport becomes even more important to my weekend. There is only so long that you can study for, before you become bored and irritable. Just ask my parents or my brothers! Sometimes I'm not the best person to be around when I have exams approaching. At other times when I have nothing much to do, particularly during holidays, sport is one thing I really look forward to. Just recently I was competing at the National Electric Wheelchair Sports Tournament at the Sydney Academy of



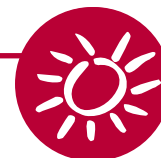
Sport and Recreation in Narrabeen. I'll admit right now that it was a tiring week, but we did have a successful games and I was proud to represent my state. It really is a long week, but an enjoyable one at the same time. I had 2 weeks off from University, and one whole week was taken up by this tournament. Once again though, it gave me something to do instead of sleeping in until midday everyday!

Whether you watch sport or play sport, for Australians, sport is a vital part of the weekend. Everyone needs to escape from the stresses of a busy week. However you choose to do this, as long as you're with your mates it's a fun and enjoyable pastime. I have a feeling that sport will me part of my weekends far into the future.

**Chris Suffield**

**"If bread is the first necessity of life,  
recreation is a close second."**

*Edward Bellamy*



# leisure and neuromuscular



In 2000 I graduated with a Bachelor of Health Science (Rehabilitation Counselling) from the University of Sydney. In 2004, I converted this degree into a First Class Honours Degree. As part of the Honours program I completed a Thesis titled **"Life Choices for People with Neuromuscular Disorders."**

I sent out surveys to members of our Association at the time, who were aged 17 or over (to avoid difficulties with consent) and there were a total of 184 individuals. In the end I received 102 completed surveys. There was a cross-section of people with different types of Neuromuscular Disorders (NMDs) and 67% were from the Sydney Metropolitan Area. Overall the age range was 17 to 81.

In the full thesis, I focused on multiple issues in relation to the lives of people with NMDs, including health, equipment, services used, vocational outcomes, which included education and employment, psychosocial issues, particularly coping with a Neuromuscular Disorder, as well as leisure. Unfortunately, due to ill health, I have not been able to publish the thesis as yet, but I hope to do so in the near future.

**Given the theme of this edition of *Talking Point*, I wish to share with the members the results of the leisure outcomes section of my thesis.** I wanted to find out what sort of activities people with NMDs pursued and what factors influenced those decisions. An obvious expectation would be that the level of disability would influence what choices people made about the activities they chose. I also wanted to see if there were any other factors, such as age, type of disability, geographical location, as well as any other barriers, such as lack of transport and wheelchair access.

In my thesis, the raw data was converted into an overall Leisure Outcome Score, which had a value out of seventy two (72). This score was made up of two sub-categories. The first category was the Passive Leisure Score, which is a score out of thirty six (36) and included activities that were home based and less physical, such as, watching television, listening to music or reading. The second category was the Active Leisure Score, which was also scored out of thirty six (36) but included activities which occurred outside of the home or more physically oriented, such as, playing sport, going out to dinner or doing arts and crafts. The reason for two sub-categories was to highlight the difference in functional limitations among subjects with varying levels of physical disability. An initial hypothesis was that a high proportion of subjects in this study, particularly those more severely affected with their NMD would be more likely to choose to participate in less physically oriented activities. Higher scores were deemed to indicate greater levels of leisure participation and, therefore, better leisure outcomes. Conversely, lower scores indicated poor leisure outcomes.

The results of the study were quite interesting. I will spare you all the boring statistics, but will give you a snap shot of the findings. When comparing the passive leisure score with the active leisure score, I found that the mean (or average) for passive leisure score was almost double that of the active

leisure score. This clearly proved the hypothesis that **people with NMDs are more likely to undertake passive leisure activities.** These results reflected the progressive and severe nature of NMDs.

Most subjects in this study participated in passive or sedentary activities like reading, listening to music or watching television, but not so many people using the internet or playing computer or video games overall, which was more popular with younger people. Subjects were less likely to undertake more strenuous activities like playing sport, or musical instruments, sailing or art or craft activities. It is worth noting here that electric wheelchair sports, while having some physical components, are not as strenuous as other sports, such as a game of backyard cricket.

Outings like shopping, going to the movies and attending sporting events were quite popular but the restrictions of wheelchair access and transport, especially in rural areas, may have been an issue in the choice of these activities.

When asked to list what other leisure activities subjects participated in, on a regular basis, the most common activity put forward was swimming. However, in many cases swimming was combined with a hydrotherapy program. Other activities listed included going to concerts, going to the theatre, going fishing and gardening.

Not surprisingly when I analysed the statistics by type of NMD, I found that the type of NMD respondents had did influence the choices they made, whereby **people with more severe levels of disability tend to do things that were less physically oriented.** For example, one person with Becker Muscular Dystrophy undertook pistol shooting at an elite level while nobody with Duchenne Muscular Dystrophy even attempted to do this type of activity because they simply do not have the physical strength or dexterity. Some people may have also chosen not to participate in or even attempt activities that they either know are, or perceive them to be, too difficult.

**It seems that age is a major factor in the choices people with NMDs make regarding their leisure choices.** There was a significant difference found for both active and passive leisure activities as well as the overall leisure outcome. People with NMDs, as with people without NMDs, either make their choices or their choices are determined by their physical difficulties, which, with the passing of time, become more limiting.

**One of the surprising things was that there was no statistically significant difference between the scores of those living in rural areas compared to those in urban areas.** It was expected, given that rural areas tend to be more isolated, that this would affect the choices. However, one of the factors was that out of necessity, people in rural areas would have their own vehicles which would eliminate transport issues. Lack of access seemed to be the same for those living in rural and urban areas. There may be more choices for people in the metropolitan area but the results of the survey did not support that idea. There was also no significant difference by gender in regards to leisure choices.

The major barriers to the participation in leisure activities were proven to be lack of access, transport restrictions, lack of information on appropriate leisure options and the severity of disability which determines the variety of quality leisure choices available.



# disorders

Overall, the major determination in leisure choices was the age of the person with a NMD. However, the quality of options available to people with NMDs may be enhanced by the appropriate support of a Leisure Consultant, especially as only 4% of subjects in the entire study had any involvement with a Leisure Consultant.

In the whole thesis there were other scores that I used to determine severity of disability as well as access to other health and community resources. In the section on employment, I explored the situation where, because of the progressive nature of NMD, some people are unable to continue pursuing employment (paid or voluntary) or are no longer able to participate in the workforce are often left in the situation of trying to find something to fill the void. Sometimes leisure is a great way of dealing with that. It does not matter what one chooses to do but rather that they have something to keep them interested. In another section of my thesis, I found that **those people who were not very active in work or leisure also indicated that they were at high risk of suffering depression.**

Being able to cope with a disability is also very important. If one fully accepts and comes to terms with their situation of living with a NMD, they are better able to have a fulfilling life.

**Sport and Recreation has played a major part in my life.** As you probably know, from my other articles that I have been involved in electric wheelchair sports. I started playing



*NSW Colts' Steve Webb scores in the 2009 NEWS tournament hockey final against Victoria (see story on page 12).*

when I was 12 years old and first went to the National Electric Wheelchair Sports in 1992. I was a player from 92 to 2005 and coached since 2005. I have also been involved as the National Director since 1995. I have also been quite active in terms of going to sporting events, concerts, movies, etc, as well as going to sport and recreation camps. In 1991, the Association sent a group of young members to the MD Camp in Victoria. That particular year, we went to Puckapunyal Army Base. I am excited to know that the Association is organizing a camp of their own later this year. **Pursuing leisure is a valuable way of providing quality of life for people with Neuromuscular Disorders.**

**Michael Baptiste**

## Cricket Day for People of All-Abilities

### WHAT

Cricket NSW is conducting a skills development and games day for people with a disability. There are no prerequisites and people of all ages and abilities are welcome to join in the fun!

### WHEN

Saturday 15 August:  
Skill development 10.30am-12noon,  
Lunch 12-1pm, Game 1-3.30pm.  
Register and pay by 31 July.

### WHERE

SCG Indoor Centre, Driver Ave, Moore Park  
(Parking - MP1 on Driver Ave and entry to Indoor Centre via Venue Services at the main gate of the Sydney Football Stadium).

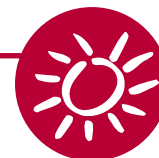
### COST

\$30 per person and all equipment supplied (bring your own if you wish!).

### INFO

For registration form,  
email Donna Little at Cricket NSW on:  
donna.little@cricketnsw.com.au  
or mail to:  
Donna Little, Cricket NSW, PO Box 333,  
Paddington NSW 2021.  
Credit card payments/forms can be marked attention to  
Donna Little and faxed on 8302 6080, or emailed.





## EFFECT OF EXERCISE ON DIFFERENT MUSCLE DISEASES

disease category	nerve or muscle problem
<p><b>Muscular Dystrophies</b> Duchenne, Becker, congenital, distal, Emery-Dreifuss, facioscapulohumeral, limb-girdle, myotonic, oculopharyngeal</p>	<p>These are degenerative muscle diseases, meaning the normal ability of muscle to regenerate and repair damage is limited, resulting in a net loss of muscle tissue over time.</p> <p>Some (BMD, DMD and some LGMD forms) involve fragile membranes around skeletal and/or cardiac muscle fibers.</p> <p>Many muscular dystrophies (DMD, BMD, some LGMD, EDMD, myotonic MD) involve cardiac muscle deterioration or abnormal heart rhythms.</p>
<p><b>Motor Neuron Diseases</b> amyotrophic lateral sclerosis, spinal muscular atrophy (all types),</p>	<p>Nerve cells in the central nervous system (spinal cord and brain) that control muscle movement are lost, leaving muscles "orphaned" and undernourished.</p>
<p><b>Inflammatory Myopathies</b> dermatomyositis, polymyositis</p>	<p>Muscle fibers are attacked by the immune system, causing inflammation and tissue destruction.</p>
<p><b>Diseases of the Neuromuscular Junction</b> myasthenia gravis</p>	<p>Communication between nerve fibers and muscle fibers is compromised, in most cases by a mistaken attack on the neuromuscular junction by the immune system.</p>
<p><b>Peripheral Nerve Diseases</b> Charcot-Marie-Tooth disease, Dejerine-Sottas disease</p>	<p>In CMT, and DSS, nerve fibers and/or the insulation around them are abnormal, compromising communication to muscle fibers.</p>
<p><b>Friedreich's ataxia</b></p>	<p>In FA, an abnormal cellular distribution of iron leads to diminished cellular energy production, with damage to the heart and nerves</p>
<p><b>Metabolic Muscle Diseases</b> acid maltase deficiency, carnitine deficiency, carnitine palmityl transferase deficiency, debrancher enzyme deficiency, lactate dehydrogenase deficiency, mitochondrial myopathy, myoadenylate deaminase deficiency, phosphofructo kinase deficiency, phosphoglycerate kinase deficiency, phosphoglycerate mutase deficiency, phosphorylase deficiency</p>	<p>Processing of fuel (carbohydrates or fats) in muscle fibers is inadequate, leading to subnormal energy production and/or a toxic buildup of fuel.</p>
<p><b>Ion Channel Diseases</b> paramyotonia congenita, periodic paralysis (hypokalemic &amp; hyperkalemic)</p>	<p>Channels in muscle fibers that allow the passage of sodium or calcium are abnormal.</p>
<p><b>Centronuclear Myopathies</b> myotubular myopathy, autosomal centronuclear myopathies</p>	<p>Muscle fibers show centrally placed nuclei, in contrast to their normal position, which is around the periphery (edge) of each fiber. Mutations in genes for the muscle proteins myotubularin, dynamin 2, MYF6, amphiphysin 2, and probably others result in weakness, the precise cause of which remains uncertain. Outcomes range from severe weakness affecting all muscles, including those involved in breathing, to weakness so mild it leads only to poor athletic performance.</p>

implications	
	<ul style="list-style-type: none"> <li>• Muscle fibers can be damaged by strenuous exercise, and the damaged sustained may be permanent.</li> <li>• In DMD, BMD and the sarcoglycan-deficient LGMDs, exercise involving eccentric (lengthening) contractions is particularly damaging.</li> <li>• If the heart's pumping ability or rhythm is affected by the disease, sudden, strenuous exercise could trigger an acute heart problem, respiratory problem or even death. A cardiologist should be consulted before undertaking an exercise program.</li> </ul> <p>Warning signs of an acute cardiac problem are chest pain, shortness of breath, nausea, sweating without strenuous exercise, a feeling of fullness or pressure in the chest, or a gurgling sound during breathing (a sign that fluid may be backing up into the lungs).</p>
	Theoretically, remaining nerve cells can become overburdened if too much is required of them with exercise.
	Exercise should vary with disease activity. During severe disease activity, when strength is very poor, assisted or passive range-of-motion exercise can be undertaken. During periods of mild to moderate disease activity, when muscles can work against gravity, light aerobic exercise, isometric strengthening, and active range-of-motion exercise are recommended. When the disease is inactive (in remission), recreational aerobic and progressive resistance exercise are OK.
	<ul style="list-style-type: none"> <li>• Exercise can be undertaken when the disease is under good control. In periods of acute disease exacerbation, or when the disease is not well controlled, exercise may increase weakness.</li> <li>• Exhaustion, lasting joint or muscle pain, or shortness of breath means the exercise is too strenuous.</li> </ul>
	<ul style="list-style-type: none"> <li>• Exercise is good for the heart and lungs but will not overcome muscle wasting, which is the result of damage to nerve fibers and loss of input from the nervous system.</li> <li>• Low-impact exercise, such as swimming or biking, or yoga, is better than high-impact exercise.</li> </ul>
	Moderate exercise may help slow the loss of motor skills in FA and help offset weight gain.
	<ul style="list-style-type: none"> <li>• Muscle fibers may break down in an attempt to meet the energy requirements of exercise.</li> <li>• Do not engage in aerobic exercise that causes the heart rate to exceed 65 percent of maximum (220 minus age, multiplied by 0.65).</li> <li>• Light resistance exercise, such as lifting no more than 5 to 10 pounds, can help build muscle mass.</li> <li>• Warning signs to stop are pain, muscle tightness or cramps, exhaustion or cola-colored urine. Seek medical help if urine turns dark.</li> <li>• If the heart is involved, cardiac precautions apply.</li> </ul>
	<ul style="list-style-type: none"> <li>• People with periodic paralysis benefit from good fitness. However, vigorous exercise followed by rest can precipitate a bout of weakness or paralysis. (In hyperkalemic PP, attacks generally occur within an hour of exercising. In hypokalemic PP, they're more likely to occur the morning after exercise.)</li> <li>• Low-intensity exercise is best. Some people find they can ward off weakness by cooling down slowly.</li> <li>• In paramyotonia congenita, muscle cooling can increase myotonia (inability to relax muscles) and transition into weakness and paralysis.</li> </ul>
	<p>Because these conditions are not progressive and don't have specific defects in the muscle fiber membrane that lead to its fragility, exercise is likely safe if the myopathy is not too severe. Check with your doctor before beginning an exercise regimen. There are no data on exercise for children with severe centronuclear myopathies, such as the X-linked, myotubularin-related type.</p> <p><i>Used with permission of the Muscular Dystrophy Association of the United States.</i></p>

## Children and teenagers have a great desire to move.

When they have a disability, they often cannot satisfy this need for activity and movement. In many cases, spasm cramps cause malpositions with shortened ligaments and tendons which consequently restrict their mobility even more. This happens frequently with conditions such as cerebral palsy, spina bifida, muscular diseases, traumatic brain injury, multiple disabilities and children with heavy spasticity.

In this situation a daily movement therapy is vital to keep or improve the flexibility. It should be made possible for children to carry out the activities of daily life independently or with assistance.

Therefore, flexible joints and mobility are essential. RECK **MOTomed gracile12** offers therapy opportunities for little children. Thanks to the small distance of 12 cm/5 inches between the inner rims of the foot shells, the children can use the therapy machine optimally, even with narrow hip and leg positions. Over-straddling of the legs can be avoided. Moreover, with the **MOTomed gracile12** it is possible for the first time to adjust a Movement Therapy System to different wheelchairs and seating heights. The **MOTomed gracile12** serially provides height adjustability of the pedal axle with foot shells. Heights can be adjusted in a range between 26 and 46cm/10 and 18 inches, measured from the ground to axle/foot shell level. For the new **MOTomed gracile12**, RECK uses software recognised around the world including features such as Spasm Control with change of direction, Smooth Drive System, Movement Protector and ServoCycling (for active training with minimal residual muscle strength).

**Walk on Wheels Comfort and Mobility Centres** has stores throughout Australia you can call on their National telephone number **1300 766 266**.

Source: IDEAS Newsletter May/June 2009





# NSW Colts dominate NEWS 2009

The NSW Colts had an amazing tournament, winning the Roger Melnyk Trophy, the Hockey Championship and Rugby League Championship.



NSW are Rugby League Champions again (left to right: Peter Dalrymple, John Shepherd, Michael Baptiste, Stephen Webb, Jordan Crane, Dean Crane, Chris Suffield).

The 2009 National Electric Wheelchair Sports was held from the 20th to 26th April, at the Sydney Academy of Sport at Narrabeen. I had the pleasure of coaching the Colts again and the team was Stephen Webb (Captain), Chris Suffield (Vice Captain), Peter Dalrymple, John Shepherd and Dean and Jordan Crane. It was only the 2nd time in Colts history that brothers had played in the same team. Representing ACT, were Hamish Armitage, who was the Captain, and Alex Scollard who was making his debut at NEWS.

**The tournament began** with the games being officially opened by Mr Alan Overton, OAM, AM, who is probably best known as a long serving Board Member and President of the Parramatta Leagues Club. The first match was the Colts against SA Scorpions and things got off to a great start, with a dominant 6-0 victory. Following this were the Western Wasps, who the Colts had been arch-rivals with, and once again NSW was on fire, with a 6-1 victory. Then it was crunch time, NSW had to face their toughest test against the Victorian Vipers. In what was a very tough match, NSW prevailed 2-0. It was then time to play the Queensland Gladiators. The Colts put on a soccer clinic to win 5-1. In their last game of the day the Colts faced the ACT Wheelers. NSW won 11-1 and would then face the Vipers in the final.

**The Hockey was going to plan** as NSW defeated the Wasps 9-2. All of the results were as expected, until an amazing thing happened. Unfortunately, NSW were on the receiving end of one of the biggest upsets in NEWS history. NSW were defeated 3-2 by SA Scorpions. This stunning performance by SA meant that NSW not only were at risk of missing the Hockey final, as they were yet to play the two strongest teams in VIC and QLD, our quest to win the Roger Melnyk Trophy also was shaky. VIC had comfortably beaten SA 8-3, so the pressure was on. But in true NSW spirit and after inspirational speeches by Coach and Captain, NSW lifted and scored a dramatic 7 all draw, after Stephen Webb scored with 10 seconds remaining on the clock. NSW then went on to defeat QLD 6-3 and ACT 15-0 to qualify for the final against VIC.

**The next day was Rugby League.** During the year there was a major rule change whereby tackles had to be effected by wheelchair contact only. In the past those who were able to use their hands or feet to make contact with an opponent could do so. We had the biggest adjustment to make of all the teams, but we trained very hard and it seemed that we were rewarded. We thrashed SA 28 – 0 and then played VIC. We had to win this match if we wanted to have a chance at

winning the Roger Melnyk Trophy. We trailed 12-6 at half time, but in a second half white-wash we ran out winners 22-12. We then beat QLD 38-0, then WA 34-0 and the ACT 32-0, to secure the Roger Melnyk Trophy. NSW has now won the most Roger Melnyk Trophies in NEWS history, with 8 in total.

**Significantly the finals were held on ANZAC Day** and proceedings began with a moving commemorative service. The third place in Soccer was won by the Western Wasps, with a 2-1 win over the Gladiators. We faced VIC in the Soccer and led 1-0 early in the second half. With 2 minutes remaining in the match, VIC made a break and scored to take the game to extra time. Unfortunately, for the second time in three years, we lost the Soccer final in a penalty shoot-out.

**Hockey was next** and QLD defeated SA 3-2, to secure third place. NSW dominated VIC in the Hockey final. At one time NSW led 7-4. VIC got a couple of late consolation goals but the Colts held on to win 7-6. This was the second Hockey title for the Colts in NEWS history.

**The Rugby League final** did not start too well for NSW, as WA Captain, Adam Hart, scored the first try. The Colts re-grouped quickly and normal service resumed as we tied up the game. Once on top, NSW ran away with the game 28-6. This was only our fifth Rugby Title.

**Chris Suffield and Stephen Webb were both selected in the All Australian Team for 2009.** Stephen also received the Best and Fairest for NSW and was second in the overall voting. Hamish Armitage, from NSW, won Best and Fairest for ACT.

Apart from coaching, I also have the dual role of National Director for NEWS, which involves the overall responsibility of running the tournament, while Martin Dalrymple is our National Umpires' Co-ordinator and deals with the on-field aspects of the games. The Association always supports NEWS. David Jack and Colin Gunn were responsible for putting together a NEWS section on the website and kindly put up all the scores throughout the week.

**The games will be in Sydney again next year**, when we will also be celebrating the 25th Anniversary of NEWS. NSW NEWS training sessions will start in September this year, so if you are interested in getting involved, please feel free to contact me on (02) 9643 1429 or email MBaptiste@bigpond.com or call the MDNSW office.

**Michael Baptiste**

National Director, National Electric Wheelchair Sports  
NSW Coach

# Winter crafts with Crafty Caz

I am an official Stampin' Up! Demonstrator.

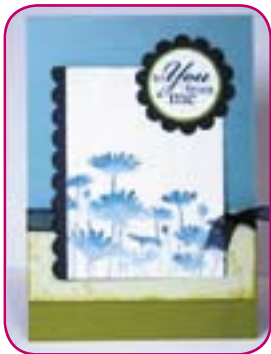


Yes that's right I have taken my stamping and scrapbooking hobby to the next level where I can help you discover the fun of making your own cards, gifts and memory albums.

If you haven't heard of Stampin' Up! you can take a look at the Stampin' Up website [www.stampinup.com.au](http://www.stampinup.com.au) Later this year I will have my own website where you will find lots of crafty ideas, tips and inspiration to create.

I like the Stampin' Up! range because they are quality products, reasonable price with good value, and everything is coordinated to make sure your crafty creations look very professional. Stamps come in coordinating sets and in handy storage boxes, and the inks and cardstock also match so you can't go wrong. I also like their philosophy which is based on expanding your circle of friends through craft and sharing the joy of creating something yourself. A nice sentiment in this commercial world.

Home-made cards are easy to make and much less expensive than one from the newsagency! For example this card uses the Upsy Daisy stamp together with the Circle, Circle Scallop and Scallop Edge punches and a touch of ribbon. Stampin' Up! also has a great range of papers, cardstock, scrapbooking products and other crafty items.



## Caz's Crafty Mementos services include:

- **Stampin' Up! Products** from the great Stampin' Up! online catalogue – 10% discount for MD members and families
- **Personal lessons and instruction** – I have 9 years experience in papercraft and a strong desire to share what I love

- **Weekend workshops** at my home near Parramatta, Sydney - probably 4 times a year, dates to come
- **Crafty activities** for groups such as Mothers Group, Seniors, groups of friends etc
- **School holiday kids classes** – everything is provided, they are having fun and learning new skills, plus out of your hair for a few hours!
- **Homemade card orders** - just let me know who you need a card for and let me create - most cards \$5 (why pay Hallmark when a handmade one is so much nicer)
- **Regular newsletter** full of tips, ideas and samples plus prizes and freebies

If you'd like any further info on anything papercrafty just drop me a line or give me a buzz. I hope I can help you discover the joy of making things. The first person to order something will receive their very own glossy 2009 Stampin' Up! Idea Book and Catalogue worth \$12.95.



Keep caring and creating,  
**Crafty Caz**  
**Caz's Crafty Mementos (CCM)**  
**Stampin' Up!**  
**Independent Demonstrator**  
 4/27 Myrtle St ,  
 Rydalmere NSW 2116  
**H** 9684 6443  
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[www.stampinup.com.au](http://www.stampinup.com.au)  
 Carolyn Campbell-McLean

## travel to Tassie

**More than anywhere else in Australia, Tasmania enjoys four distinctly different seasons, each with its own special pleasures.**

**SUMMER** is the season of fun and festivities at the Launceston Festive, the Hobart Summer Festival, where the Taste of Tasmania is a must, and the North-West's athletic carnivals.

**AUTUMN** is a mellow season with calm, sunny days. It's the time when the native deciduous beech blazes with colour.

**WINTER** is a dusting of snow on highland peaks and toasting your toes by an open fire. Winter days are often crisp, clear and bracing.

**SPRING** is cool and fresh. Gardens around the State come to life and Tasmania celebrates with the Blooming Tasmania festival.

Paraquad Tasmania have produced the **Wheelie Good Guide of Tasmania**.

The guide lists accessible accommodation, attractions, restaurants & services across all regions of Tasmania, as well as the accessible toilets available. Car, bus & taxi services are also included.

**If you would like a copy of the Wheelie Good Guide, please contact Paraquad TAS on 03 6272 8816 or email: [info@paraquadtas.org.au](mailto:info@paraquadtas.org.au)**

ACCESS  
ALL AREAS

## IDEAS online Travel Directory

This disability information service has an online travel directory [www.ideas.org.au/travel](http://www.ideas.org.au/travel) allowing users to search for information on accessible accommodation, travel services and other travel resources. The directory is easy to use and includes information on, for example, camps for people with disabilities, accommodation and specialist travel operators. Each entry includes some details and forward links to the service or facility described.



## Jaxon's story



Jaxon Taylor playing Wii in his Bambach chair.



Leon and Jaxon on the Wiggles slide.

Jaxon is 3 and half years old and was born with Merosin Deficiency Muscular Dystrophy. Our story began on the 13th November, 2005, when our little man was brought into the world, he was born as the doctors described as "floppy" and we were told by pretty much by day three, after poor feeding, and an extremely high CK reading, that he most likely had Muscular Dystrophy and would never be able to sit, roll, walk or stand due to his severe weakness. At 6 months old Jaxon went in for a muscle biopsy, and after this and an MRI, our fears obviously were confirmed, and were told he was going to require ongoing physiotherapy, aggressive treatment for chest infections and a lot of specialist equipment for the rest of his life.

This first year of Jaxon's life was intense; it seemed as if all we were doing was constant physio, and constant crying, and feeling very isolated from other kids and people around us. Around Jaxon's 1st birthday we noticed changes in him, and he was able to grasp more objects with his hands and even managed throwing light balls, and attempting to feed himself. We started to appreciate the little things; there were more tears of joy than anything with every little new thing he did! He started to sit for a little while with pillows behind him, and he would think it was hilarious when he fell over.

We started doing a lot more hydro therapy, and adopted more therapy through play, and we seemed to all enjoy it more. Jaxon currently does his stand frame daily, and we change daily depending on the weather, with water therapy, walker, chaley cart, ball therapy etc, but the therapy he adores most is the special bike we got made for him through TAD. We have recently come across a seat called the "Bambach" chair too, and it is sensational, he is like a new little boy. He can sit up at the dinner table with us, and most importantly for him, play Wii (computer game) in it. He manages to spin around on it, and can turn around now when someone's talking to him. We are currently getting his manual wheelchair made and are anticipating its arrival, so I'm sure he's going to feel even more independent.

Jaxon's only started to ask questions recently about his condition, which is heartbreaking, but we try and involve him in everything if it's physically possible. If we have kids over playing soccer, we will pick him up and he'll play along too. If we are dancing, he is dancing away too.

Jaxon is like any average 3½ year old, he loves the footy, golf and cricket; he loves his cars, books, music and computer games. He is such an extremely bright little boy who has a real zest for life; he blows me away with his little made up stories, his singing, and even now starting to read a few words and counting backward from 100. But most of all his kisses and "I love you"s! He has taught me patience and an appreciation of life, and he brightens me up each and every day... I now try and concentrate more on the positives, and am so amazingly blessed to have him as my little boy...

Lija Taylor

### CONTACTS:

#### The Bambach Saddle Seat Pty Ltd

4b 3-9 Kenneth Rd, Manly Vale NSW 2093

phone: (02) 8966 4800

fax: (02) 9948 9834

email: Sue Johnston  
SJohnston@Bambach.com.au

direct line: (02) 8966 4803

#### Technical Aid to the Disabled NSW

Locked Bag 2008, Wentworthville NSW 2145

phone: 1300 663 243 Ext 3433

fax: (02) 9890 1912

email: mthornton@tadnsw.org.au

direct line: (02) 9912 3433

web site: www.tadnsw.org.au

"If you watch a game,  
it's fun. If you play it,  
it's recreation. If you  
work at it, it's golf."

Bob Hope





### Hello members!

Well it is that time again to update you on all the happenings in the Client Services Program since the last edition.

The program has been busy as usual with the main focus being on the **Home Support Program** and of course preparing all of our up and coming events. The **camp** continues to occupy much of my time with lots of interest from both campers and carers alike! I have planned lots of fun and fabulous activities for the week which is destined to be an exciting week for all!

Aside from organising camp; preparations are well underway for the up and coming **medical conference** - to be held at our community centre in Meadowbank on Saturday the 29th August. This year the theme will be Nutrition - as suggested by our members, so be sure to put the date aside in your diaries.

In May Georgina and I were very lucky to be able to attend the **Window on Tomorrow Neuromuscular Conference** in Auckland which was an invaluable learning opportunity for both of us. The conference covered a range of material including nutrition, cough assist machines, orthopaedics, bone health, exercise, end of life issues, and individualised support for varying conditions and of course much, much more.

There are a number of dates for members to remember with lots of exciting events coming up in the next few months – a few to keep in mind are:

- 14th August • **Women's Pamper Day** 12.30 – 4pm
- 29th August • **Medical Conference: Nutrition**
- 13th September • **HOGS Day**
- 5th-9th October • **Camp** (Applications closing soon)
- 3rd November • **Melbourne Cup Function** (MDNSW Office)

Well that is it from me for another issue. If you have any needs, assistance, information requirement or you would like to register for an event or book in your home visit please email me [renee.mcbryde@mdnsw.org.au](mailto:renee.mcbryde@mdnsw.org.au) or call me on (02) 9809 2111.

**Renee McBryde**  
*Client Services Manager*

# Camp Q & A for worried parents!

**Please contact Renee McBryde if you have any more questions about Camp on 9809 2111.**

### What is the value of the MDNSW Camp?

**For young people:** Camp offers a fun and safe experience and the opportunity to develop important life skills such as confidence, independence and social ability. The camp experience also promotes a great sense of self-esteem and achievement. Campers will leave with a more positive outlook on life and take with them lasting friendships and memories.

**For parents/guardians:** Camp is a brief respite for caregivers. MDNSW staff and trained volunteers assume all camper care, including physical and emotional support, allowing caregivers a little time to attend to their own needs.

### What kind of medical care is provided at camp?

MDNSW camps will be staffed by medical professionals from Westmead and Sydney Children's hospital (Medical team composition depends on camp size, campers' needs and medical volunteers.) The medical professionals will dispense medications, take care of injured or ill campers, and provide general first aid.

### What kinds of activities will be on at camp?

Although each camp is unique, some common activities include: music, cooking, arts and crafts, movies, dancing, talent shows, themed parties, archery, wheelchair sports, lots of team games, trivia night, cookout etc

These activities happen in an environment that promotes:

- Exploration of self and nature;
- Informal interaction with peers;
- Interesting, exciting and safe experiences with limits and supervision;
- Structured reflection on camp experiences.

Safety is the number-one priority of camp staff and volunteers, who all receive training in the special needs of children with neuromuscular diseases. All activities are strictly monitored, overseen by qualified personnel, and designed to accommodate campers' unique needs and abilities.

### What is the Camper-to-Carer ratio?

Most sessions offer a one-to-one ratio between campers and Volunteer Camp Carers. The camp carers goal is to provide campers with a safe and fun experience while helping them develop the skills necessary to become caring, self-confident and successful people.

**Volunteer Camp Carers duties include:** attending to physical needs (dressing, bathing, feeding, transferring, toileting, turning, etc.); reporting health problems to the medical staff; promoting cooperation and respect; encouraging participation; ensuring safe practices; participating in activities; and sharing an upbeat attitude.

**Applications for camp will close on the 31st August 2009, subject to spaces being available – lodge your application soon to avoid disappointment!**



# "we don't care what the weatherman says!"

## MUSCULAR DYSTROPHY ANNUAL GOLF DAY 2009

As the record field of 115 golfers bedded down the night before MDNSW Annual Golf Day, I doubt that many were expecting to play the next day due to the unusual low pressure system which caused so much Queensland flooding during the week. But as it happened we were "shone upon", with only 10 minutes or so of squalls, if plenty of almost gale force winds. Nothing to a keen golfer making the best of 18 holes on one of Australia's finest championship courses, Concord.

Dedicated players, obviously mindful of previous successful MDNSW golf days, loyally registered, this year receiving an MDNSW cap, and golf towel, as well as somewhat redundant sunscreen, in their bag of goodies. After a heartwarming breakfast, players were treated to a masterful 30 minute teaching clinic from Ken Trimble, Concord's long serving professional, who showed us a lot about chipping. Once a year golfers were pitching beautifully after three minutes, which I hope at least lasted the full round.

The players headed off in the lap of the weather gods to their starting holes for an 8.40am shotgun start, this year without golf carts, which were abandoned due to the still damp course. The 29 teams of players did very well to be back in the club house by around 1.30pm, where they were treated to an open bar before an ample BBQ buffet lunch and a glass or two of Bundurrah Cabernet Merlot, which had them feeling their old self again in no time!

This gave MDNSW's new CEO David Jack a golden opportunity to thank players and sponsors, and say some nice things about the good work MDNSW does, and encourage players to buy raffle tickets and bid for some great auction items.

### Winners of the golf prizes were:

<b>Winning Team</b>	M&E Equipment Traders (George, Phil, Robert, Steven)
<b>Runners Up</b>	M&E Equipment Traders (John, Michael, Richard, Terry) [tied with Ord Minnett, decided on count back of last 9 holes]
<b>Longest Drive (male)</b>	Brad Martin (David Mowat team)
<b>Longest Drive (female)</b>	Sally Armati (Mayo Healthcare team)
<b>NTP (4th)</b>	Brad Martin (David Mowat team)
<b>NTP (14th)</b>	George Gaitanos (M & E Equipment)
<b>Fastest Drive (male)</b>	Tim Hood - 267 km/h (Ord Minnett team)
<b>Fastest Drive (female)</b>	Sally Armati - 160 km/h (Mayo Healthcare team)

I must thank our erstwhile sponsors for their loyal support. These were:

- Advanced Planning Services(AMP) – Vaughan Woods
- Crane Group
- Iplex
- Tradelink
- Ord Minnett – Peter Dick
- Canterbury Leagues Club – John Ballesty
- J D Batchen – James Batchen
- M & E Equipment Traders – Seven Baldini

I think it fair to say that when players left for home around 3 pm, they felt they had had enough pleasure in one day to hardly notice themselves being tactfully "pick pocketed", to the point where most were saying they would love to do it again next year on May 20, again at beautiful Concord.

**Rob Ferguson**



Colin Gunn and David Jack at the registration desk.



Ken Trimble, Concord professional giving a chipping clinic.



Colin Gunn, one of the organising team with Louise the policewoman who booked players for "driving" too fast.



# Muscular Dystrophy Association Charity Golf Day



Join in the fun of our golf day and help us help people living with Muscular Dystrophy



**When:**

Friday, 25th September 2009

**What Time:**

Registration at 11:30am. Start at 12.30 pm

**Where:**

Carnarvon Golf Course, Nottinghill Road, Lidcombe 2141

**The Event:**

➤ **4 Person Ambrose**

\$550 for sponsorship of hole with a team of 4

\$300 for a team of 4 persons

\$80 per individual player

➤ **Team & Individuals Prizes to be Won**

➤ **BBQ Lunch Provided**  
as well as beer, soft drinks and fruit.



**Contacts:**

Rob Murray:

Phone:

9872 2481

Mobile:

0419 629 686

Martin Dalrymple:

9680 1700

0419 294 705

Percy Baptiste:

9643 1429

0407 065 774

Association's Office:

9809 2111

## Entry Form

	Name	Handicap (if no handicap then 18)
1.		
2.		
3.		
4.		

**Cheques Payable to:**

Muscular Dystrophy New South Wales  
PO Box 1365 Meadowbank NSW 2114

**Credit card payments can be made by calling the Association's office on 9809 2111**

ABN: 11 774 587 436      CFN: 12219







The Riverina carers meeting was held at the Wagga Wagga RSL Club.



Attendees of the Hunter/Newcastle carers meeting.



Georgina Christofis in charge of the MDNSW stall at the Greek Festival of Sydney.

**Hello Carers,**

Welcome to another Carers' Corner. It's been a very busy few months and I would like to share news with you about events past and new carer activities planned for this new season.

So let's backtrack to February that seems so long ago now - the event: the Ladies Pamper Day. This event was all about indulgence; our metro carers were pampered from neck to foot. For those of you how missed out on this event, don't worry MDNSW will be running another Ladies Pamper Day on the 14th of August, 2009. Please call MD office if you are interested in attending this event.

The month of March was also busy on the regional side of things. A scheduled dinner at the Wagga Wagga RSL was a hit. Carers and members enjoyed a buffet style dinner with the added company of staff from the Wagga Wagga Regional Office. Thank you to all who attended this event, I look forward to seeing you at one of MDNSW carer information days later on in the year. Feel free to contact me on suggestions on topic areas you would like to see covered in the November workshop.

On CALD Carers activity, MDNSW held two specific cultural events: The Multicultural Luncheon and also attended the Greek Festival of Sydney as a Stall holder. This was a great opportunity to increase awareness of the condition to the general public, of all the visitors to the stall; a total of 20 persons had some connection with MD. I would like to thank MDNSW Greek Carers for coming to this event. I would greatly appreciate your feedback on future ideas to continue the contact that has already been made.

Our Metro events are also well underway with a group of carers attending our social event at the Sydney Aquarium in Darling Harbour on the 16th of May. Carers not only enjoyed the sights but enjoyed a wonderful social luncheon afterwards. For up to date information on upcoming metro events like the day trip to Bowral on the 31st of July contact Georgina on 9809 2111 or email [carers@mdnsw.org.au](mailto:carers@mdnsw.org.au)

**Georgina Christofis**  
Manager, Carer Services

## YOUNG CARERS PROGRAM

**Are you under the age of 25 years and provide substantial care and support for a parent, sibling, partner, child, relative or friend with a disability?**

Then take a minute to ask yourself the following questions:

- Do you frequently miss school because of your caring responsibilities?
- Do you have little or no time to do your Homework?
- Do you find it hard to communicate at school or hang out with school friends?
- Are you thinking about leaving high school before the end of year 12?

**The Young Carers Program may be of interest to you!**

Did you know...?

There are around 347,700 Australians, under the age of 25, providing care to family member who has a long term illness or disability?

The young Carer program at Carers NSW was developed to make a positive difference to the lives of young carers (25yrs and under) and their families.

Young carers are children and young people who care for and support a family member who has a long-term illness or disability.

# INTERRELATE FAMILY CENTRES - strengthening family relationships since 1926

Interrelate Family Centres is a community based, not for profit organisation that has been a leading provider of quality services in NSW for over 80 years. It has a network of centres across metropolitan, regional and rural NSW. Interrelate is committed to providing easily accessible, high quality relationship services enabling individuals, couples, families and children to work through life's challenges and improve their relationships.

## Services provided through Interrelate include:

### Personal Counselling

During life's hard times, friends and family are able to support for only so long; Interrelate is there with counsellors whose only job is to listen and to help.

### Family Counselling

Helps couples, or any two or more family members or friends.

### Relationship Support programs

Developed for the specific family or Individual needs.

## A note for carers: counselling is FREE!

To call your nearest  
Interrelate Family Centre  
call head office on:

**1300 736 966**

### Regional Service Centres:

Dubbo	(02) 6882 4699
Coffs Harbour	(02) 6651 1010
Gosford	(02) 4363 8050
Newcastle	(02) 4957 8888
Lismore	(02) 6621 4970
Port Macquarie	(02) 6584 9293
Orange	(02) 6360 0895

## How does the program support young carers?

- Camps (8-12yrs, 13-17yrs, 18-25yrs)
- Quarterly newsletter
- Talk line (Telephone group counselling)
- Face to Face Counselling
- Telephone support/information/ referrals
- Interactive young carer website
- Development of regional networks

Source: [www.youngcarersnsw.asn.au](http://www.youngcarersnsw.asn.au)

## MDNSW invites Carers to enjoy a day out in Bowral



**On Friday 31st of July, 2009**

Meeting place: MDNSW Office

**9am departure** - 4pm return

Lunch has been arranged at Wolfgang's Restaurant Shop 4/279-287 Bong Bong Street, Bowral at 12 midday.

**Places are limited so reserve early!**

To RSVP for this event contact  
Georgina Christofis on 9809 2111  
or e-mail: [carers@mdnsw.org.au](mailto:carers@mdnsw.org.au)



## COMPANION CARD NSW

The Companion Card has now been launched in NSW. It is for people with a significant and permanent disability who always require an attendant carer to support their participation in community activities and venues. The card holder is entitled to a second ticket for their companion at no charge when presented at affiliate organisations.

The Companion Card boasts a rigorous application and audit process which ensures that the card reaches its intended audience. To be eligible for the Companion Card, the applicant must meet all of the following eligibility criteria:

- a resident of NSW
- have a significant and permanent disability
- are unable to participate in most community-based activities without significant assistance with mobility, communication, self care, planning and the use of aids and other technologies does not meet those needs
- their level of support is life-long

A recent survey in Victoria showed that since having a Companion Card, cardholders had more than doubled the number of times they go out from an average of 16 outings per year to 37 outings per year.\*

For more information on the NSW program please visit [www.nds.org.au/nsw/companioncard.htm](http://www.nds.org.au/nsw/companioncard.htm) or the National website [www.companioncard.org.au](http://www.companioncard.org.au) or Free Call 1800 893 044.

\*Source: [www.vic.companioncard.org.au](http://www.vic.companioncard.org.au) (May 2008)

## Accessing the Future: Assistive Technology in Education & Employment

### WHAT

Hands on sessions to use and learn assistive technology programs, information on the issues relating to the use of technology, assessment strategies, a range of technology options covering a variety of support needs and costs (including freeware). For individuals with a disability, their families, friends and carers; teaching staff, educational and disability support staff (Years K-12 and tertiary sectors); DADHC 'Transition to Work' and 'Community Participation' Program staff, as well as clients and their families; employers; disability employment network staff; Job Network staff; disability support agencies; related government agencies. Supplier expo.

### WHERE

Auditorium, Bankstown Sports Events Centre, 8 Greenfield Parade, Bankstown.  
Access the Club from the carpark via the lift or stairs.

### WHEN COST

Wednesday 19 August. (Newcastle Friday 21 August).

\$70 includes GST, full program (including the hands-on training strand), 4 GB flash drive pre-loaded with AccessApps and Forum resources Forum bag, morning tea, lunch, and afternoon tea. Secure online registration with automatic confirmation.

### INFO

Phone 9709 3899. Registration closes 29 July.

Convened by National Disability Co-ordination Officers (NDCOs)

Kay Dean - [kay.dean@newcastle.edu.au](mailto:kay.dean@newcastle.edu.au), Timothy Hart - [thart@med.usyd.edu.au](mailto:thart@med.usyd.edu.au), and Debi Toman - [d.toman@uws.edu.au](mailto:d.toman@uws.edu.au).

Source: Warringah Disability Newsletter



# Shorten is a true ally for people with disability

If you missed Bill Shorten's speech at the National Press Club recently, here is the link to his speech.

It's long but well worth a read.

[http://www.fahcsia.gov.au/Internet/billshorten.nsf/content/right\\_to\\_ordinary\\_life\\_01apr09.htm](http://www.fahcsia.gov.au/Internet/billshorten.nsf/content/right_to_ordinary_life_01apr09.htm)

Here are a couple of snippets from the speech:

*'If someone was told they could not get on a bus, train or taxi because of their sex, or their old age, or the colour of their skin, there would be an outcry.*

*If someone is unable to get on a bus because their wheelchair won't fit - we make no comment, we turn a blind eye. The range of accessible public buses is around 25% to 70% - depending on where you live. Again the availability of timetable and surrounding infrastructure also varies greatly. NSW has around 700 accessible buses out of nearly 1800.*

*It's easy enough to rationalise in those circumstances, to find reasons why it's too hard, or too expensive for that person to be allowed on the bus.*

*And it's somehow also too hard to ask the question: How would I feel if that was me? If that was my mother or father or my child?*

*Some of you may think the person in the wheelchair should demand their rights, that it's up to them. They've got it, they own it, they should deal with it, I'm busy.*

*I think it's up to us, to all of us, to say: "This bus isn't moving until we're all on board."*

*Take this example of four people looking for work: One, let's call him Leo, is deaf, the second Frank is in a wheelchair and the third Helen, is blind and the fourth, Steve, can not make himself understood.*

*It is likely that all four resumes would be put on the bottom of the pile by a boss or a job agency too concerned about the problems that these unhappy unfortunates might cause.*

*That boss would have turned down Ludwig van Beethoven, Franklin D. Roosevelt, Helen Keller and Stephen Hawking.*

*How many Beethovens, Roosevelts, Kellers and Hawkings are we missing out on in our nation because of this willed blindness, this inability to move beyond looking at someone's impairment to the whole person?'*

## New Disability Parking Permit Scheme in Australia

The Australian Government seeks feedback on the proposed Australian Disability Parking Scheme that harmonises present permits, so a new permit will be recognised across Australia with one set of rules for its use. The 2009/10 Federal Budget has \$3 million to develop the scheme across Australia.

See [www.fahcsia.gov.au/sa/disability/progserv/people/disability\\_parking\\_scheme/parking\\_scheme\\_discussion\\_paper/Pages/default.aspx](http://www.fahcsia.gov.au/sa/disability/progserv/people/disability_parking_scheme/parking_scheme_discussion_paper/Pages/default.aspx) which also includes a submission form. If you wish to attend a public information session in June, phone 1800 630 740, 1800 555 677 (TTY) – from which you can also get a copy of the discussion paper in Easy English, on CD, in Braille or in another language.

Email your completed submission to [accessparking@fahcsia.gov.au](mailto:accessparking@fahcsia.gov.au) or post it to Australian Disability Parking Scheme submissions (East Wing), FaHCSIA, PO Box 7576, Canberra Business Centre ACT 2610 by 5pm Friday 31 July.

See [www.rta.nsw.gov.au/rulesregulations/mobilityparking/mobility\\_concessions.html](http://www.rta.nsw.gov.au/rulesregulations/mobilityparking/mobility_concessions.html) for the current NSW parking concessions. Some people feel that the proposed scheme places more stringent limitations on parking, especially for people restricted to wheelchairs and their carers.

Source: Warringah Disability Newsletter



muscular dystrophy  
new south wales

MDNSW INFORMATION

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TALKING POINT DISCLAIMER

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Letters to the Editor  
(Carolyn Campbell-McLean),  
can be addressed to:

The Editor, *Talking Point*  
PO Box 1365,  
Meadowbank NSW 2114

FOR YOUR  
INFORMATION



One of our members Nadine Roe has set up a website about her experience with clinical diagnosis.

[www.clinicaldiagnosis.net](http://www.clinicaldiagnosis.net)

CLASSIFIEDS



FOR SALE

Mercedes VITO XLWB van, 2004 model.

Body: Short wheelbase. Engine: 2.0 litre petrol. Transmission: 4 speed automatic. Odometer: 184,000km. Rego: 6 months. Seats: 4 plus wheelchair.

Layout: driver + passenger in front, 2 x single seats on right hand side one behind the other, wheelchair in the middle just behind the 2 front seats.

Ramp: Wheelchair access via rear with manual aluminium folding ramps. Fitted with air conditioning, tinted windows and power steering.

Price: **\$15,000** ONO

Contact: David Reid (MDNSW member in Nowra)  
on **4423 4070** or **0419 201 435**

email: [dreid@fastrac.net.au](mailto:dreid@fastrac.net.au)

FOR SALE

Kia Carnival, 2003 model - Silver - Automatic

Modified by Freedom Motors to occupy one wheelchair passenger. Ramp access at rear of vehicle.

Cost: **\$44 000**

Low Kms - Odometer: 23,000km. Rego: March 2010

Can seat 6 people plus wheelchair passenger

Many extras including reverse sensor, 16 inch alloys, tinted windows, front and back chrome nudge bars, side step, new tyres, new battery and much more.

Contact: Helen Hinds on **4960 0557** anytime for further information.

THE NEUROMUSCULAR CLINICS

CHILDREN'S CLINICS

Sydney Children's Hospital, Randwick  
Neuromuscular Clinic 9382 1700

Sydney Children's Hospital  
Outreach clinics at Canberra Hospital, Canberra  
and John Hunter Hospital, Newcastle  
contact through Sydney on 9382 1700

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



Muscular Dystrophy NSW for  
National Electric Wheelchair Sports,  
Proudly invites you to their annual charity ball...



"A Night at the Races..."



'Cocktail Dresscode'

Saturday 19th September, 2009 at 7.00pm

The Wentworth Room - Parramatta Leagues Club  
13-15 O'Connell St, Parramatta NSW

\$70 per head (includes 3 course meal)

\*All proceeds go to National Electric Wheelchair Sports (N.E.W.S)

Auctions  
and  
Raffles

Tickets On Sale Now

For tickets and details please contact Margaret Dalrymple on 0439 766 075

Lucky  
Door  
Prizes

All Cheques to be made payable to: Muscular Dystrophy NSW,  
PO Box 1365 Meadowbank 2114

Credit Card Payments can be made to the MD NSW Office on 02 9809 2111



MDNSW PRESENTS...

# Ladies Pamper Day

**WHEN** Friday 14th August 2009  
**WHERE** Shepherds Bay Community Centre  
3a Bay Drive  
Meadowbank  
(two minutes walk  
from the MDNSW office)

**TIME** 1pm - 4pm

**COST** FREE

**DETAILS** Come along to MDNSW's  
Ladies Pamper Day and indulge!

Let us spoil and relax you with an  
afternoon that begins with a champagne  
lunch and your choice of  
manicures/pedicures/massage  
and of course the chance to socialise!

**RSVP** You must RSVP to Renee or  
Georgina by Friday the 7th August  
on 9809 2111 or  
renee.mcbryde@mdnsw.org.au or  
georgina.christofis@mdnsw.org.au



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 Association 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.

Office use only: TP71/11220

