



Ngundabaa Mums' Retreat

We mothers came to this picturesque, tranquil location on the Shoalhaven River as the foundations of a structure screaming silently to be built so as to harness the beauty and strength that already existed. Sadly, the foundations were a little cracked, and on their own unsupported. Simply, we needed help to find a way to bind and repair each other. The answer came in the form of these amazing, warm, crazy, compassionate, clever and strong engineers, who knew that to connect our foundations could help build a formidable structure. To make it endure they had to provide more than just a plan and a lick of paint, they had to be there for the long term construction, they too had to become part of the structure and in so doing share a part of themselves.

The result?? An unyielding connection that will ignore physical boundaries, with each of us taking a little of everybody away.

Roisin O'Hagan, Retreat mum



Connection through artwork



Many mums can sometimes feel very isolated and lost at various times throughout their MD journey for a variety of reasons. This Retreat aimed to highlight that they are not alone, that they have each other to lean on, that there are people out there who have been through exactly what they have and they can be there for each other. It was also a rare chance to rest, rediscover and recharge - to have some time out just for themselves...

Loretta Downie, Event Manager

We are together We are Connected We protect each other

I greatly appreciate the wonderful opportunity to attend such an amazing Retreat full of meaning and special memories. I will hold everybody I met close to my heart and I will carry them and the things I have learned with me on my journey with my precious boys.

I have been able to relax and still my mind for the first time in a very long time.

We now have an amazing new family connection with truly beautiful people.

Wow what a Retreat. It was like a great feel-good movie where you laugh & cry and go through every emotion in between, then walk away feeling ahhhhh...

I don't feel alone in my circumstances now. I've found other mothers, who are now friends, who understand the journey that my entire family is on.

Before the retreat I felt alone. I hoped to find another SMA mum, but soon realised that regardless of the neuromuscular condition that all mums share such a similar journey as do their sons. I now feel like I've learnt so much and this guidance has boosted my morale. It's a relief to see forward through the eyes of others who have been there and done it too. I truly feel connected to all these amazing strong women, a family that really understand.



Roisin & Jo in our Talking Circle



Teresa, Rena, Wendy & Jo, our beautiful facilitators





Welcome to our new Dukies!



Sarah Walsh
15yrs

I wanted to do the Duke of Ed because I wanted to go beyond what I thought my limits were. I wanted to get the chance to do the kinds of things that all my able bodied friends could do, and I wanted to stretch my abilities and try new things. I wanted to prove, not only to others but to myself as well, that I really can do anything I set my mind to, and that my wheelchair does not and never will control me from living out my life the way I want to.

I was most apprehensive about the sport aspect of the Award. I've never enjoyed any kind of

sport in my life, and was concerned about how I could find a sport I'd enjoy doing since I cringe at the words 'physical activity'. However, once we discovered horse riding and once I got used to riding and being out of my chair, I've found that I love it!

I was most looking forward to my Skill, which was acting. I've always been told I was a drama queen and enjoy being overly dramatic. I also get shy around people often, so by doing this I had a feeling I'd be able to gain more confidence around the people who I'm not closest to.



Glenn Harris
18yrs

I am not apprehensive about any part of the Award and plan diving right into it with the aim to challenge myself. Completing the Duke of Ed also looks good on a resume.

All the sections are rewarding in their own way but I am most looking forward to do my Video Game programming course through the Academy of Interactive Entertainment. My goal is to get a job in the video game industry and this Award is a major stepping stone to achieving that goal.



Joe Sciulli
14yrs

I am most looking forward to doing a Fishing Trip for my Adventurous Journey because I am passionate about fishing and want to learn new skills in the sport.



Jye Donkin
16yrs

I want to do the Duke of Ed as I think it will boost my confidence and I will be able to do things that I haven't done before. I am most looking forward to doing the Adventurous Journey as I will be able to go where I have never gone before.

I wanted to do the Duke of Ed because it sounds interesting, and my father told me it's a special chance for me to practice myself. I am most looking forward to the Volunteering section because I think everyone should feel happy when they are helping others.



Joab Olding
23yrs

I wanted to do the Duke of Ed as I thought it would be an ambitious goal for me to stick to for 6 months and I knew I would thoroughly enjoy it! It will also expand my horizons, keep me busy, and minimise my back pain as a result. For future job prospects, I see it as a wonderful advantage too. I can't wait to do the Adventurous Journey as I

believe it will do my confidence a lot of good after completing the trip on my own.



Lena Zhu
14yrs

I love kids and can't wait to volunteer in a Child Care Centre. I want to get some qualifications in Child Care and try to get a job in the field.

I am most looking forward to the Volunteering section because I love being around people and want to gain some retail experience.

Philip Hoigaard-Olsen
14yrs



I thought The Duke of Ed would be fun committing to a Skill, Sport, Volunteering and an Adventurous Journey. I am mostly looking forward to doing the Skill Section as it's an opportunity to learn new techniques when painting a lot of models I have for my hobby called Warhammer 40,000.



Codie de Haart
19yrs

The Boccia Brag



The Great Boccia Bash

On Sunday the 25th of November, 2012 my mum and dad took me to the Sydney Academy of Sport for the Boccia Bash organised by MDNSW. I sort of had an idea how to play and what it was about as I had played it before at Camp Kula 'n Gadu. However I learned a lot more

about Boccia from the Paralympians and Professionals there, especially Dean. He gave me tips on what tactics to use and taught me some skills of Boccia. In the competition everyone played in, I came equal second with Dean. Daniel came first and he was awesome at Boccia; no wonder

he is a junior state representative! I had a great time and got to catch up with some friends I made at Camp as well. Can't wait to play again but hopefully next time it will be in Newcastle!

Jye Donkin, Our latest Boccia Whizz from the Hunter region

Western NSW Boccia Introduction Course

On 25 January, 2013 I headed to Orange with my parents to attend an Introduction to Boccia Course that was being held at the Orange Ex-services Club. Peter King & Sue Olsen from Sport Development Cerebral Palsy Alliance attended to run the course. It was a great evening with 15 people attending. We were shown skills and techniques to be able to play Boccia for fun and competitively. Peter even demonstrated how to play if someone was unable to communicate verbally by showing us eye movements and nods of his head just to name a few of the techniques. It was very informative and it was also good to



The Wicked Rollers Central West Boccia Team

catch up with some of the other people who are interested in playing Boccia in our area. We are going to organise regular get togethers as well as attending a Club Day in Sydney in April. We are looking forward

to this as we are all learning the skills and techniques to enjoy the game of Boccia. Some of us are also looking forward to hopefully getting involved in the competitive side of the game by attending these Club Day events and eventually holding our own Club Day competition. Thank you to Peter & Sue for driving to Orange for the evening and then heading back to Sydney the same evening, this is dedication! Also a big thank you to Kejanna for organising and attending as well.

It is great to have people come to our area to help us out.

Michael Melhuish, member of the new Wicked Rollers team in Orange

Save this date!
Sun 24 Nov

~ The Great Boccia Bash ~

Don't miss what we've all been waiting for... a Botch-off between CPA and MDNSW. We need all the experienced and novice players we can get as CPA reckon they have it in the bag!!!

Where can I play Boccia?

Greater Western Sydney

Penrith
Anthony Bucco
thebuccos@tpg.com.au

Prairiewood

Patricia Vaz
p_vaz@hotmail.com

Parramatta

Keira Aikenhead
keira.aikenhead@northcott.com.au

North Sydney

Scott Elsworth 9975 8456
selsworth@cerebralpalsy.org.au

Central Coast

Dean Nottle
playitloud21@gmail.com

Hunter Region

Phil Bates
philip.bates6@bigpond.com

Far North Coast

Loretta Downie
loretta.downie@mdnsw.org.au

Central West

Katrina McDonald (Orange)
alandtrin@gmail.com

Tamworth

Jeff Essex
j.essex@sunnyfield.org.au

Riverina

Loretta Downie
loretta.downie@mdnsw.org.au

Illawarra Region

Nick Rousch
nick.rousch@ahm.com.au



Life after diagnosis

Since Jassy's diagnosis last year we have done a lot of work around our home throughout 2012. Marc has worked hard on the outside areas and made a wheelchair ramp in the backyard. Throughout February he created an inclusive play environment for Paige, Jassy and our youngest baby, Hugh born in August last year. The area will include a swing with lumbar support for Jassy and sandpit for sensory play plus a craft table letting us wheel Jassy right up to the table, so she can draw and paint. Marc has also built Jassy a special portable table that supports her to sit up and be included in what is happening around her. Every day she is doing more and more with her tiny hands - she is now able to reach and grasp things. Jassy is full of wonder with the world around her but unlike other children of her age at 18 months she cannot physically explore on her own as she is unable to crawl or pull herself up. However, we are all able to share in her experiences outside the home and it is a real pleasure for all of us.

“ We have come a long way since meeting *Kejanna* and joining *MDNSW*. We are now more positive about our future than we were a year ago when we were faced with trying “to find our way” with *Jasmine’s* condition, *Merosin-deficiency Congenital Muscular Dystrophy*. The diagnosis placed our family on a different path and our priorities changed immensely especially for me with working outside the home to becoming a full time carer, everything that we knew and had plans for changed. ”



Jassy swimming with Daddy on their FlexiRest holiday.

We are approaching a different stage with her and feel ready to take on new adventures this year.

Last November we were lucky enough to receive support from FlexiRest and took a couple of days at “Mantra Sun City” on the Gold Coast. Jassy loved spending most of her time in the pool and the rides really caught her attention. It was so wonderful to be able to take a break from our everyday routine and just spend quality time with our young family and to watch and admire Jassy's delight as she engaged with her new surroundings. We are now planning to take Jassy on another holiday next August.

Tara and Marc Oliver, Hunter region

Upcoming Regional Events

Tue 26 March	Shoalhaven/ Illawarra Social Support Network
Tue 23 April	Shoalhaven/ Illawarra Social Support Network
3rd – 4th May	Possible Ideas Expo 2013
Thu 9 May	Blokes out Bush - Riverina Men's Group
2013 Regional Christmas Parties	
Sat 9 Nov	Illawarra Christmas Party
Sun 17 Nov	Central West Christmas Party
Sun 24 Nov	Far North Coast Christmas Party
Sun 8 Dec	Hunter Christmas Party

Illawarra/Shoalhaven Social Network

Following on from our "Brunch by the Beach" Christmas party that was such a success we have decided to meet on a regular basis for coffee, cake and a chat each month. Our meetings will be on the 4th Tuesday each month at 11am and we will vary the venue to make it easier for people coming from different areas within the region. So if you live in the Illawarra or Shoalhaven areas and would like to catch up with other MDNSW members and their families, email Jill on jill@notjustsheep.com or call Kejanna on 0448 018 377.

Jill Coleman, member of the new Illawarra/Shoalhaven Social Network

Blokes out Bush (BOB) Riverina Men's Group

Muscular Dystrophy NSW and Northcott are working together to support a local Men's Group in the Riverina catering for men aged 40+yrs living with a neuromuscular condition. The group meets every two months from 11:30am to 1:00pm at the Narrandera Ex-Servicemen's Club. Lunch is provided free of charge and there will be the occasional guest speaker too.

For more information contact Kejanna on 0448 018 377 or email kejanna.taylor-king@mdnsw.org.au

Funding available

Interested in starting your own social network or group in your region? Funding is available from MDNSW for you to host groups or run social activities within your region with other carers or people living with a neuromuscular condition. Contact Kejanna for details!

Working Carers

Working carers are people who are in paid employment and care for a relative or friend who is ill, frail, has a disability or is ageing. They can work full time, part time, casually or manage their own business. Caring responsibilities can impact on your ability to manage your work, and work responsibilities can impact on the care you provide.

One of the objectives of the Workplace Relations Act 1996 is to assist employees to balance their work and family responsibilities. It also prohibits unfair dismissal on the grounds of family responsibilities. Most Awards have family-friendly provisions such as Carers Leave and Make Up Time. Carers Leave is now combined with Sick Leave and Personal Leave. You should have at least five days a year paid leave that you can take either when you are sick, or to care for dependents or take them to medical appointments. Make Up Time allows you to request time off from work to attend to the needs of the person you are caring for and make it up later.

Points to consider

It is advisable to inform your manager of your role as a carer as you may be able to negotiate more flexible working arrangements. Some of the working conditions that employers can set up to support working carers may include:

- Allowing staff to leave work on time
- Allowing staff to use a telephone to check on the person they support, make appointments, etc.
- Setting up flexible work arrangements such as flexitime, part-time work, job sharing, flexible rostering and making time up later
- Being flexible with the amount of paid or unpaid leave staff can take and when they can take it
- Allowing working from home on a temporary or long-term basis

Despite being in paid employment you may be still entitled to the Carers allowance from Centrelink. *The Working Carers support Gateway is a website that offers a variety of resources and information to support your role as a working carer. Also sign up for their free newsletter "Work n Care" www.workingcarers.org.au*

Breathing under pressure – non-invasive ventilation for respiratory muscle weakness

People with neuromuscular disorders often require breathing assistance at some stage in their lives. For some, breathing problems develop slowly over months or years. For others, respiratory complications may occur suddenly following an apparently minor event such as a cold or chest infection. In both situations, the role weak respiratory muscles are playing in these problems needs to be recognised and appropriate care put into place in a timely fashion.

Inspiratory muscle weakness makes breathing in fully difficult. Over time this promotes underbreathing or *hypoventilation*. If this is severe enough or occurs over a long period of time it will affect the level of oxygen and carbon dioxide in the blood, causing *respiratory failure*. In addition, shallow breathing limits expansion of the chest wall creating stiffness of the rib cage which then makes taking a normal sized breath more difficult, promoting further underbreathing. The expiratory muscles also play a key role in maintaining lung health. Weakness of the abdominal muscles reduces the ability to build up pressure to create an effective cough. This can severely affect clearing secretions from the lungs leading to respiratory failure during a chest infection.

Abnormalities in breathing first appear during sleep. It is normal to reduce the depth of breathing slightly during sleep. For people with respiratory muscle weakness however, these normal changes in breathing and oxygen levels can become exaggerated, and significant underbreathing can occur. This is referred to as *nocturnal hypoventilation*. Initially people will wake up briefly to limit how much their oxygen and carbon dioxide levels change. However, over time the brain gradually adapts to more abnormal breathing to the point where shallow breathing occurs even when awake. The lack of chest wall expansion further stiffens the rib cage so that more effort has to be put into taking a normal sized breath or the breaths will be smaller, further worsening oxygen and carbon levels. Since these changes in breathing usually occur over months or years, people are often unaware of the problem. Even if symptoms are reported, these may be mistaken as just the natural changes in the neuromuscular disorder rather than a sleep disorder and not investigated further.

Once problems related to either inspiratory or expiratory

muscle weakness are recognised, appropriate respiratory therapy can be offered.

There are a range of devices to assist “breathing in”. Generally, we use a technique known as *non-invasive ventilation* which allows assistance of someone’s breathing without the need for an invasive breathing tube. Basically, a mask fits over the nose (or nose and mouth) and is attached to a small portable device that is able to pump air into the lungs to expand them. Most commonly (and ideally) this is started when someone is otherwise well but shows signs of sleep disordered breathing. However, it can also be started when a person is unwell in hospital and having breathing difficulties, for example during a severe chest infection or pneumonia. A *bilevel* ventilator is the most common device currently used. It provides two levels of pressure: a higher pressure in to inflate the lungs and increase the depth of breathing with a much lower pressure on breathing out to allow carbon dioxide to be cleared from

the system. Additional breaths are usually added to maintain a regular and normal breathing rate. Non-invasive ventilation during sleep is now seen as a standard part of care for people with respiratory muscle weakness.

It is important to identify the appropriate window of time to start night time ventilation. Evidence suggests that starting treatment before respiratory problems are present may actually be harmful. On the other hand, delaying therapy for

too long could lead to people presenting in a crisis situation, limiting treatment options. There are three opportunities for commencing night time ventilation: when awake carbon dioxide levels are found to be above normal (which is why blood gases are taken); when symptoms of underbreathing are reported (which is why a sleep history is taken) or if underbreathing during sleep is detected (which is why a sleep study or other night time monitoring is performed).

Initially, therapy is used at only night, which effectively reverses daytime respiratory failure and symptoms. However, if the underlying muscle disorder is progressive, daytime breathlessness or fatigue can appear months or years after commencing treatment as weakness increases. If this occurs, additional daytime ventilation will be needed. However, bilevel ventilators are not suitable for continuous use and the nose is



Dr Amanda Piper

not meant to have pressure on it constantly. Once ventilation is required more than 16 hours a day, alternative masks and methods of breathing support need to be considered. Most commonly a mouthpiece is used combined with a different type of ventilator that has an internal battery which can operate for 4-6 hours without being connected to the mains power. By using a combination of mask ventilation at night and mouthpiece or nasal plugs during the day, a substantial number of people with little or no spontaneous breathing capacity can have their breathing supported 24 hours a day.

While ventilators deal with the problems of weak inspiratory muscles, it is also important to develop skills in managing chest infections and to maintain good chest wall expansion. This is done by undertaking a program of regular lung inflation using a technique known as "lung volume recruitment" or "breath stacking". With this technique, a series of breaths are "stacked" together to maximum capacity before exhalation. Not only does this help maintain chest wall flexibility, it is also used to

improve the effectiveness of cough by increasing expiratory flow rates. The simplest and most accessible way to achieve this is to use a self-inflating bag to squeeze breaths in via a mouthpiece or mask, filling the lungs with air (see photo).

If secretions in the chest are present and cough remains ineffective despite using breath stacking, a mechanical cough assist device can be used. Both breath stacking and mechanical cough assist are techniques which require training and practice to perform correctly, but are important and valuable additions to the respiratory management of people with respiratory muscle weakness. Being aware of the options for managing the complications arising from respiratory muscle weakness is important so people have the opportunity to discuss and trial different treatment techniques.

Amanda Piper PhD, Physiotherapist,
Dept of Respiratory and Sleep Medicine
Royal Prince Alfred Hospital, Camperdown

Medical Seminar

On Saturday 17 November 2012, MDNSW hosted a Medical Seminar at Shepherd's Bay Community Centre, which was attended by about 60 members and their families.

Dr Amanda Piper, from the Department of Respiratory and Sleep Medicine at Royal Prince Alfred Hospital at Camperdown and Dr Nigel Clarke, Clinical Geneticist and Senior Lecturer from the University of Sydney Institute for Neuroscience and Muscle Research, were the guest speakers.

Dr Piper spoke on muscle weakness of the chest wall and the use of non-invasive ventilation and the equipment available.

Dr Clarke informed the group about the major advances in DNA testing and how these advances are now being adopted by diagnostic laboratories.



Victoria Berg and Maryanne Murray



Prof Corbett and Dr Nigel Clarke

After a delicious afternoon tea, our very own Maryanne Murray and Victoria Berg introduced the new online Training Program developed by MDNSW and funded by ADHC. This program is easily accessible on our website and will provide a basic understanding of neuromuscular disorders for people living with a neuromuscular condition as well as health and community professionals.

The afternoon concluded with the opportunity to ask questions of the guest speakers. People were reluctant to leave at the end, wanting to stay around and chat.

Our new offices were officially opened at the conclusion of the Medical Seminar, where members and their families enjoyed inspecting our new larger office!

Jenny Smith, Project Assistant

A brief glimpse into purchasing a wheelchair accessible vehicle

In the world of disability, often the hardest part is to find your way 'through the maze' of suppliers, funders, medical professionals and well meaning people with a variety of opinions. In the process of applying for an updated and larger version of a powered wheelchair for my son Daniel, we stumbled upon the fact that all powered wheelchair bases are now delivered to us from a minimum floor to seat height of 44.5 cm, around 5-10cm taller than any current version. Daniel's head was already almost scraping the entry to our current vehicle, so entry in a new wheelchair was going to be impossible! The hunt for a new vehicle was on and ploughing through the maze, the resulting information may be of value to others in a similar situation.

Types of vehicles that suit modification

There is a big difference in width and height between a manual wheelchair and a powered wheelchair. Manual wheelchairs sit much lower to the ground, so entry height is not as much an issue as it is for powered wheelchairs that are higher due to the battery being under the seat. The lowest floor to seat height powered wheelchair is the Permobil range of M300's.

What do I need to consider?



- The wheelchair itself
- Size of vehicle
- Holiday equipment needs
- Floor space
- Headroom
- Door openings
- Windows
- Ride, comfort & communication
- Vehicle drivability
- Impact of modifications on vehicle
- Parking
- Wheelchair loading/unloading

Larger vans, suitable for powered/manual wheelchairs:

- Volkswagen Transporter
- Mercedes Vito/Sprinter
- Kia Carnival
- Toyota Hiace



Pro	Con
Up to 5 passengers	Higher fuel consumption
Extra room for additional equipment	High roof, not good in garages
Can carry >1 wheelchair	More expensive than smaller car

Smaller vans, suitable for powered/manual wheelchairs:

- Volkswagen Caddy
- Renault Kangoo
- Peugeot Partner
- Holden Combi
- Citroen Berlingo



Pro	Con
Up to 5 passengers	Not as much extra room for additional equipment
Great fuel consumption	Can only fit one wheelchair
Less expensive than larger van	
Full access to most undercover garages	

Cars, suitable only for manual wheelchairs:

- Toyota Rukus
- Kia Soul
- Holden Zafira



Pro	Con
Small car, smaller footprint	Only room for max 3 incl. wheelchair
Better petrol consumption	No room for extra equipment
Aesthetically appealing to some	Restricted headspace for taller users, restricted to manual wheelchairs

Types of modifications/ conversions

Different approaches to providing wheelchair access into a vehicle are:

1. Lowering the vehicle floor
2. And /or raising the roof line
3. Raising the door entry height
4. Power lifter (under floor, rear internal, rear external)
5. Extending the vehicle overhang

Once you have gathered this information, consideration needs to be given to available internal car designs. The most popular ones for rear entry cars are:

When considering what type of modification you want to your vehicle, take in account the following:

- Do you want rear entry or side entry?
- How much are you willing to spend?
- Consider the weight added to your vehicle, if you are using the vehicle for personal use without the wheelchair, it may be worth just carrying a manual ramp to keep the constant weight down and this in turn will curb your fuel cost!
- What is the minimum access entry height-measured from floor to top of head and add 3 cms
- What size is the wheelchair and will it fit a specified design?
- How many extra seats are needed in the vehicle for other family members/ friends?
- What position would the wheelchair like to be in-next to the driver, first row or behind the first row?
- What care needs to be provided while travelling - consider positioning of wheelchair
- How comfortable will the ride be - again related to positioning
- What is the visibility from the wheelchair position? A lot of vehicles that do not have a lowered floor can push the wheelchair occupant's head up higher and restrict their vision through the front and side windows
- Can the vehicle still fit into my garage?!
- How will the wheelchair be restrained? There are so many types of restraints available, from a Freedom lock or Permalock for Permobil chairs that just click into place once wheelchair locks in, to a ratchet system (old!), to an electric system with retractable restraints (Flashcab) to the Q-strait

Family Member Design

This design is ideal for people who do not need to travel with a family. The wheelchair can roll up to the back of the driver / passenger seats.



Seating

- 2 passengers + 1 wheelchair access
- 4 passengers (with optional double fold down seat)

Front Row Design

This design places the wheelchair occupant all the way to the front of the vehicle next to the driver without having to move from the wheelchair. This design gives you the freedom to virtually position the wheelchair and yourself anywhere in the vehicle.



Seating

- 2 passengers + 1 wheelchair access
- 4 passengers (with optional double fold down seat)

Family Design

This design is ideal for situations where the wheelchair occupant wants or must be close to the driver or passenger's position. The wheelchair can roll through the middle of the vehicle and fits in between the two single modified bucket seats.



Seating

- 4 passengers + 1 wheelchair access
- 6 passengers (with optional double fold down seat)

Self Drive Design

This design is ideal for a situation where both the wheelchair occupant and other persons will be driving the wheelchair accessible vehicle.



Wheelchair Drive Design

This design is ideal for wheelchair occupants who have trouble transferring to a driver seat but still want the freedom to drive a vehicle. This design allows the wheelchair occupant to ride the wheelchair to the driver's position.



Passenger Design

This design places the wheelchair occupant behind the second row seats.



Seating

- 4 passengers + 1 wheelchair access
- 6 passengers (with optional double fold down seat)
- 5 passengers + 1 wheelchair access
- 7 passengers (with optional double fold down seat)

Two Wheelchair Access Design

This design is ideal for smaller organisations where the transportation of a second wheelchair occupant may occur on a regular basis. This design is only possible with the larger van type vehicles. Also seating arrangements for other passengers are very flexible.



Susan Heetveld Exercise Therapist - Sylvanvale Foundation
Mother of Daniel, Ben and Jesse

For Susan's complete article, including information on the international market, funding possibilities, vehicle suppliers, and whether to buy a new or second hand vehicle, please see our website under Get Support/Information and Referral.



Connor's Trip to Glen Innes

During the December school holidays Connor accompanied his grandparents, Terry and Gay Milham, and his Auntie Donna to Glen Innes to visit relatives, some of whom he had not met before. On the way we visited places of interest and increased the profits of many of the McDonald's and KFC restaurants in the towns we passed through!

Connor was particularly interested in the life and times of bushranger Captain Thunderbolt and we visited his gravesite at Uralla and Thunderbolts Rock on the outskirts of the town where he carried out many of his bushranger activities. We would have liked to have visited Thunderbolt's Cave but it was not accessible by wheelchair.

At Glen Innes we visited the Australian (Celtic) Standing Stones, looked at Sapphire fossicking areas and other local historical sites. Connor was able to participate in many interesting activities some of which were:

- catching yabbies in the local creek
- playing darts in the shed
- performing karaoke

Connor also had the opportunity to sample the delights of The Super Strawberry Farm on the outskirts of Glen Innes and by his look in the photo attached it was one of his favourites. On the way home we stopped at Tamworth to see the Big Golden Guitar which he had heard about but had not seen. We stayed with his Auntie Donna in Newcastle for several days over the New Year period and welcomed 2013 on the Newcastle Foreshores watching the fireworks display.



Connor with a yabby

It was a great time for all of us. It provided Connor's parents with some respite where they were able to enjoy the New Year festivities knowing Connor was having a great time with other family members and friends. This was Connor's first excursion in the wheelchair accessible vehicle recently purchased and modified with the help of funds supplied by the Variety Club of Australia. Cost for the trip was assisted under the generous provisions of the FlexiRest Program. Our sincere thanks to Muscular Dystrophy NSW for helping to make it all happen.

Terry Milham, Connor's Grandfather



Connor at the Super Strawberry Glen Innes



At Captain Thunderbolt's grave site



At the Standing Stones Glen Innes

Let's Go Camping O'Brien Style

Christmas holidays would not be Christmas holidays for our children if we did not manage to go camping. This year we spent a week with my family camping in a caravan park near Nowra. The caravan park was great, facilities awesome and the weather, although a little hot on some days, quite favourable for being outdoors. Pitching a tent on a powered site at a caravan park means we have everything we need close at hand - powerpoint to charge Daniel's chair and a bar fridge to keep his predmix cold. At our max we had 16 people camping on four sites this year, a mix of accommodation options from tents (us) to camper trailers and of course the grandparents who have now graduated to a flash new caravan. The caravan was awesome. Daniel, who has LCMD, is only four and is in desperate need of day sleeps while camping (which in a tent in the middle of all the action he finds quite difficult). The caravan was parked a little further away and had air conditioning. This allowed him to get his much needed rest and keep everybody sane.

From Nowra we drove three more hours south just past Narooma to a place called Mystery Bay for camping with Luke's family. This is a primitive camp ground. The only facilities supplied are pit toilets and cold showers. Now this does not mean we live it rough. With a camp, that at its maximum caters for 20 people, we have the works. Water boiling in big billies all day except fire ban days, means we have hot showers at the ready. Food is usually collected every other day; milk this year came direct from the cows at a nearby farm. There the kids all got a turn on the tractor. But bush camping does provide its own unique set of problems. We need to charge Daniel's chair at least every other day. Luckily for us the local gas and ice man is happy to accommodate for the small fee of



Jo and Daniel O'Brien

a nice bottle of red. The walk to the beach takes you through some quite uneven ground so at the moment Daniel is carried in a baby backpack to the beach every day. Not sure how we will get him there when he gets too big, keeping weight on him at the moment is not all that easy so we probably won't have to worry about this for a while. Since starting steroids Daniel has learnt to walk and amazed even himself when he managed to walk the length of the beach unaided and back. Something we could only have dreamed of last year. This trip was another wonderful time outdoors with our family and an opportunity to reset and recharge before another year of preschool, school and work.

Joanne O'Brien

John Farnham at The Star

It was so easy to apply for FlexiRest. Matthew did all the work then it was approved and money was quickly deposited in my bank. I had the most memorable night of my life staying at The Star in Darling Harbour. The ambience is beautiful and the entertainment venue is huge, holding 4200 people. The new Event Centre was opened on the night and John Farnham was on stage for 90 minutes!

The outdoor setting of the new Event Centre is such a nice place to spend a night having a good harbour view and a full moon - it was awesome! In the outdoor area there was drink and noodle bar, barbeque and ice cream carts. It's a great place to go.

I needed to clear my head and I am now feeling fresh and relaxed after my stay. Thanks heaps FlexiRest!

Kathleen Deane



Kathleen Deane

Doing something new

Everyone's journey is unique and yet they all have something in common: a past, a present and a future. Our past experiences and lessons often affect our present experience, and what we expect to happen in the future. Sometimes this is really good and at other times this is unhelpful. We often get stuck in a comfort zone, thinking that things can only happen in the future the way they always have. This is often an unconscious process that we're not even aware of. But if we bring this to our attention, we can make changes in life that can create a whole new future that we didn't realize we could have. Even some small changes can make huge differences.

Whether we spend most of our time at home, at school, at work or at a day program, there will always be opportunities to think outside the square and try something new. You just have to be open to it and look out for it!

"Why should we be on the lookout for new activities?" You might be asking. Well, there's a lot that can open up for us when we try new things, which can have bigger effects. For instance, doing new things can lead to newfound interests that can create more opportunities for meeting other like-minded people, and even opportunities for study or work. It's just a matter of being creative. It's also really important so that we don't get bogged down with the same routine and get bored. Did you know that boredom can often lead to all kinds of bigger problems with concentration, mood and low feelings about the future? By simply finding new activities in places that you hadn't thought of, you can keep your mind active and have positive feelings about what you're doing each day. In effect, we can bring these new experiences into making a positive future for ourselves.

So if you find that you have spare time and are a bit bored of the same thing, try something new! You may awaken a part of yourself that you never knew existed and that was just waiting to be discovered! Perhaps there's an artist in you, or a poet. Or perhaps you have a knack for jewellery making or growing herbs. Maybe you're a good listener and if given the chance, people would seek out your listening ear and wisdom! Maybe you've had unique experiences that other people would like to hear about through a mentoring program. What about that second language you speak – perhaps you could help someone who is studying to converse in your language!



Sometimes the hardest part is finding something new to try. It's not always right there in front of us waving around to get our attention. That's okay. If you start by being open to trying something new, something is sure to come up. You just need to be a little flexible and think outside the square.

Until next time!

Liz Neal.

Liz is a Registered Psychologist. Appointments are bulk billed through Medicare and can be accessed by all friends and family members associated with Muscular Dystrophy NSW. More information about Liz can be found at www.elizabethneal.com.au.

Tips 'n' Tricks Maralyn McCann

Tips
& Tricks
for Living

A comprehensive Mental Health Resource, useful for accessing a range of relevant services throughout NSW.

Website: <http://www.wayahead.org.au>

The Recreation, Sports and Aquatics Club (RSAC), is an unfunded community organisation based in Bankstown, which provides sport, recreation, social activities and opportunities for people with a disability.

Website: <http://www.disabledsportsac.org.au/index.html>

The Commonwealth Respite and Carelink Centre (CRCC) is a free and confidential service, providing information to the community about aged, disability and mental health support services. Enquiries can come from any member of the public. They will talk you through which services may be most suitable, service costs, eligibility and how to register and what services are available in your area.

Telephone: 1800 052 222

Website: http://www.wesleymission.org.au/centres/retirementliving/community_support/CRCC.asp

If you have any **Tips & Tricks** please share with our readers. Send your T&T's to :

maralyn.mccann@mdnsw.org.au

Sydney MD Women's Group



The group is a small supportive network of women who are either living with a neuromuscular condition (NMC) or are a family member of someone with a NMC. The group meets 4 times a year for lunch and a few hours of supportive chatting. Sometimes we will organise a topic, guest speaker or outing, but primarily we focus on sharing and learning from each other.

In 2013 we will meet at the MD office in Meadowbank from 11.30 – 2pm on:

- **Thurs 30 May**
- **Thurs 29 August**
- **Thurs 28 November**

We are also looking to have a few Friday nights this year to cater for those working during the week - perhaps at a café or pot luck style dinner at each other's homes. If you would be interested in coming along to a women's group event, please contact Carolyn on 0408 472 510 or email cazza74@iinet.net.au



Sydney MD Women's Group Christmas lunch

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 Clinic
Neuromuscular Management Clinic
Peripheral Neuropathy Management
Clinic
Duchenne Monitoring Clinic
Appointment and enquiries
9845 1904

The Neuromuscular Management Clinic
John Hunter Children's Hospital
Newcastle, NSW
4921 3932

ADULT CLINICS

Concord Hospital Neuromuscular Clinic
9767 6864

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



Powerchair Football

The first ever APO Cup (Asia Pacific Oceania Zone) in Powerchair Football was held at the Sydney Olympic Park Sports Centre between the 23rd and 26th January. The Australian Poweroos Green and Gold sides took on Team Japan and Team Nippon over the 4 days, with Team Japan becoming the inaugural winners, defeating the Australian Green side 2-1 after extra time in the final.

Powerchair football is a 4-a-side sport for users of motorised wheelchairs. Athletes have plastic, rubber or metal guards attached to their wheelchairs which are used to knock about an oversized soccer ball. Chairs are speed limited to 10 km/h and are speed tested prior to each game to ensure that no chairs are going too quickly.

For many of the Poweroos, this was their first taste of international competition. However, with 8 Poweroos having competed in the November 2011 World Cup in Paris, there was a mix of youth and experience.

Green won their opening match 1-0 against Team Nippon, earned a respectable 2-1 loss against Team Japan and won 1-0 against Gold. Gold were less lucky, being defeated 3-0 by Team

Japan and drawing 0-0 against Team Nippon before losing to their counterparts. Gold found their form the next day with a 2-1 win against Green and a 2-0 win against Team Nippon. After losing to Gold, Green had a fantastic 1-1 draw against Team Japan. With both Australian teams on 7 competition points after 5 matches, each side had one more match to gain their place in the final. Green side found themselves 2-0 down against Team Nippon before roaring back to earn a 2-2 draw, while Gold found themselves up 1-0 to Team Japan but had to settle for a 1-1 draw against the undefeated Japanese. Green side would sneak into the final against Team Japan on goal difference. In what was an epic match, the Japanese and Australian Green sides fought to a 1-1 draw at the end of regulation time. Team Japan found their winning goal at the end of the first half of extra time, breaking the Australians' hearts. Overall it was a fantastic tournament. The next APO Cup will be in Japan in 2014.

The Western Sydney Powerchair Football competition begins again in April. For more details, please contact Matt Cross on 0409 839 788 or mcross6@bigpond.com.



The two Australian Teams at the recent Asia Pacifica Oceania Cup. Kyle Scolari, Andy Waite, James Kim, Alex Scollard, Andrew Kim, Luke David, Kristie McCarthy, Dimitri Liolio - Davis, Josh Merkas, Jacob Cross, Tristram Peters, Peter Dalrymple, Ben Keyte and Chris Suffield. At the rear, Coaches Rob Newland and Luke Robinson with games Ambassador Rale Rasic.

National Electric Wheelchair Sports Tues 9th – Sat 13th April, 2013

The National Electric Wheelchair Sports for 2013 will be held from the 9th to 13th April at the Sydney Academy of Sport and Recreation, Narrabeen. The New South Wales Colts take on the rest of Australia in the three sports of Soccer (played with a Balloon), Rugby League and Hockey. The Colts are looking to win their 5th straight Rugby League crown and would greatly appreciate any support.

The Opening Ceremony will be held at 10.00am on Tuesday 9th, followed by the Round Robin games of Soccer. Wednesday is Hockey, Thursday is Rugby League,

Friday is a rest day and Saturday 13th April is Finals Day.

This year's team includes James Kim, Andrew Kim, Chris Suffield (Captain), Alex Scollard, Dean Crane and Jordan Crane. The team is coached by Peter Dalrymple.

For anyone looking to try-out for the 2014 side, please contact Peter Dalrymple on 0438 224 644 or email peter_dalrymple@hotmail.com

Peter Dalrymple
National Electric Wheelchair Sports

For Sale

2005 Kia Carnival

- Freedom Vehicle Conversion
- Colour - Black, Grey Interior
- Automatic
- 5 Seater Plus Wheelchair
- Travelled - 94000 km
- Registration - May 2013 with logbook

Asking price: \$31,000 O.N.O

Location: Bonnyrigg NSW

Contact: Rita 0424 474 922



2008 Kia Grand Carnival Sports EX (Wheelchair converted)

- 12/2008 Sports model
- Freedom vehicle conversion
- 3.8 ltr V6 automatic
- 60,000 kms serviced regularly
- Seats 4 + wheelchair passenger
- 6 months rego
- Pull down ramp
- Side doors
- Power steering
- Wheelchair tie downs included
- Air conditioned front & rear
- CD player
- Excellent condition

Asking price: \$50,000 price negotiable

Location: Bomaderry, NSW

Contact: Dave 0419 201 435



FREE

Donated Electric Wheelchair



C650PW folding power wheelchair Max.weight 100kgs

SPECIFICATION

1 Seat Width 406mm (16 in) / 457mm (18 in)

2 Seat Depth 406mm (16 in) / 457mm (18 in)

3 Seat Height front 513mm (20 in) / rear 490mm (19 in)

Overall Width 570mm (16 in) seat width 620mm (18 in) seat width

Overall Height Height adjustable from 911mm (36 in) ~ 986mm (39 in)
(from underground to push handle)

Weight 33kg (72.6 lbs)

Base incl. controller, motors, leg rests w/o anti-tipper, seat cushion, batteries

Please register your interest for this wheelchair by contacting Maralyn at MDNSW on 9809 2111 or maralyn.mccann@mdnsw.org.au.



How you can help MDNSW

As it is a new year we are hoping to get more and more people involved in our fundraising. There are so many fun ways to get involved and you know how important the money raised is to us! Please have a read and see if you would like to be involved in any of these ways to help.

Donation Boxes

We can give you a Perspex donation box to put in your local café, shop, food outlet to collect people's change. We have started to do this all over NSW and it is going brilliantly. We would love to expand this opportunity so please contact us if you would be able to take a box or more!

Volunteer for us

We always need people to help out at events and help us with fundraising. If you would like to be a part of this and can spare us some time that would be hugely appreciated.

Have a Sausage Sizzle at Bunnings

Every Bunnings will let you hold a Sausage Sizzle for charity at their store. We can give you a Guide outlining all the details and advice you will need for this but it is a really fun way to help us raise some vital funds.

Hold a Fundraiser

We can offer you lots of great ideas and advice on how to hold your very own fundraiser. It can be anything from a Ball to selling cakes in your office on a Friday afternoon. This can be a fun and rewarding activity to get involved with and we are so grateful for all donations that come in!

For more information on any of these please contact **Kags Garrard**, Fundraising Manager, on **9809 2111** or email kags.garrard@mdnsw.org.au

Vince Sorrenti shines at our Cocktail Party Fundraiser!

On Sunday 31 October we held our first Muscular Dystrophy NSW Cocktail Party hosted by our President Peter Debnam and his wife Deborah. We were thrilled to have our Celebrity Ambassador, Vince Sorrenti, fly in to host the evening for us. Vince not only gave a very humorous and insightful speech, but he also participated in a lively question and answer session with our Young Ambassador, Hayley Bellamy. Listening to Hayley and Vince interact with each other was hilarious and was most definitely the highlight of the evening for everyone there. It was a really successful event for MDNSW and we were delighted to make over \$11,500!

I extend a warm invitation to you all to attend our next Cocktail Party in Sydney on Thu 11 April, hosted by MDNSW Director Shannon Finch, where we look forward to hearing from NSW Treasurer, The Hon. Mike Baird MP. For more information on this event please contact Kags Garrard, Fundraising Manager, on 9809 2111 or email kags.garrard@mdnsw.org.au.



Singing Santas

In 2010, my beautiful niece, Holly, was diagnosed with muscular dystrophy. I felt helpless living so far away from her, so I decided to run a fundraising gig to support a charity that supports so many people with muscular dystrophy and their families.



If you were anywhere near Martin Place on Thursday 20th December, wandering the City for a spot of late

night shopping, you may have heard the angelic voices of the 'Singing Santas' singing carols and raising money for Muscular Dystrophy NSW! Santa and his elves (along with a few mini angels this year) under the guidance of our musical director, Jessica, managed to raise \$2119.25!!! A significant increase on last year's total of \$1500. The total amount also included online donations from generous people who couldn't attend on the night or who were too shy to sing.

I would like to thank everyone who was involved, everyone who made a donation and a special thanks to Kags Garrard, Muscular Dystrophy



NSW's Fundraising Manager, who supported us and joined us on the night with a bucket in hand! This was the third year running for the Singing Santas, and so far it has been bigger and better each year. Join us this year on Thursday 19 December and keep an eye out on the MDNSW website for details.

Melissa Stewart, Singing Santas founder and proud Aunty

Swim in honour of Danny



I wanted to fundraise for Muscular Dystrophy NSW in honour of Danny Campbell-Mclean - an amazing bloke who lived life to the fullest in spite of the challenges he faced with muscular dystrophy. Danny sadly passed away seven years ago, and knowing how involved his wife Carolyn is with Muscular Dystrophy NSW I was thrilled to have the opportunity to fundraise for them.

I have been swimming for years, but the 1km Cole Classic was only my second ever ocean swim! I was more than a little nervous, especially when the organisers had to cancel the 9km portion of the swim due to rough waters. However, with the overwhelmingly positive response to my fundraising efforts there was no way I was going to back out! People had been incredibly generous and my fundraising had got to just under \$1000!

Thankfully that weather came good - the water was calm at Shelly Beach and I could have easily kept on swimming! I want to thank everyone who sponsored me and encouraged me for the day. This one was for you Danny!

Denise Irvin, keen fundraiser





MUSCULAR DYSTROPHY
NEW SOUTH WALES
INFORMATION

**MUSCULAR DYSTROPHY NSW
INFORMATION**

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Meadowbank NSW 2114

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Meadowbank NSW 2114

PHONE 02 9809 2111

FAX 02 9809 4177

EMAIL info@mdnsw.org.au

WEB www.mdnsw.org.au

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If your life is affected by a
neuromuscular condition...

We're here to help

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

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

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.

