

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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Community Strength



MUSCULAR DYSTROPHY
NEW SOUTH WALES

A Word from the President

I'm often asked by people about my involvement with Muscular Dystrophy NSW and I find myself summing up my experience as – *simply being inspired ... day after day after day.*

I'm lucky to work with a crowd of inspirational people and I usually mention a few of the many.

Whether it's Michael Baptiste whose endless determination and grace will inspire me all my days and whose life constantly reminds me of the last verse of Rudyard Kipling's poem If.

*If you can fill the unforgiving minute,
With sixty seconds' worth of distance run,
Yours is the Earth and everything that's in it.*

Or I tell them about the excitement of visiting NEWS at Narrabeen where Michael had inspired team after team of champions to delight the watching crowd of family and supporters. And while at NEWS, watching Keiran Watts compete - he's just plain gutsy.

Often I mention meeting Melanie Tran and her parents and being inspired by Melanie's speeches at recent functions – speeches which reinforce my commitment every time I hear her speak.

And I have to tell them about the countless parents, brothers, sisters, spouses and friends whose love and care is on display every day.

I tell people about our Office Manager, Maralyn McCann, whose efficiency, helpfulness and relentless good humour are legendary.

And I mention the people who choose to volunteer their time to be Directors on our Board and who make a real difference by guiding Muscular Dystrophy NSW in an increasingly challenging environment. People like two former directors - Colin Gunn and Ross Parker who left our Board earlier this year after many years of service and whose expertise and dedication had encouraged our Association to grow, evolve and strive to deliver more and more support to greater numbers of people across the state. And I mention very successful business people like Rick Arnheim and Shannon Finch who have agreed to join our Board this year.

It's certainly one of the highlights of my life to be involved with such an inspirational bunch of people.

Thank you to one and all in our Muscular Dystrophy NSW family.

Peter Debnam

President, Muscular Dystrophy New South Wales



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

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“ Save this date
Saturday 17th November,
the Muscular Dystrophy
NSW Medical Seminar
and the opening of our
new office, details to
be advised ”



Welcome to our winter edition of Talking Point

This time of year makes me want to curl up at home with a

mug of soup, a piece of toast and a good magazine to read.

I hope you enjoy this edition of our magazine Talking Point as much as I have reading the many articles that have come across my desk in its preparation. What I particularly enjoy reading are those articles written by you and this edition is full of them. Whether it's about attending a Muscular Dystrophy NSW activity or sporting event, your own family holiday or information you think would be useful for others, we love to hear about it and to include it.

In this edition Sharon Lamb shares Bob and her wonderful evening out at the 2012 Muscular Dystrophy NSW Gala Ball and also how we congratulated Melanie Tran, Cassie Robson and Hayley Bellamy for being the first people in the world to receive a Bronze award in The Duke of Edinburgh's Award pilot program.

Vicki Sciulli and Lisa Burns organised a fantastic Sunday Hunter Roast for over 70 family and friends living in the area and Sally and Simon Longmore tell of their fabulous time at the Muscular Dystrophy NSW Retreat in Melbourne.

Our new Bocchia Champions Dean Nottle and Daniel Michel wrote articles to motivate us to join in the exciting sport of Bocchia. Peter Dalrymple writes an informative and inspiring account of the 2012 NEWS Tournament and Percy and Eileen Baptiste give tribute to their wonderful son and National Director of NEWS, Michael, who sadly passed away in April of this year.

Megan Jackson tells us of the Mothers' group that meets regularly in the Lismore area and Ian and Anne Payne write about the Hunter Valley Carers' and Support Group. If you attend a small group, would like to, or are keen in getting one going in your area please contact our office and we would be happy to promote it and keen to assist you in any way we can.

Muscular Dystrophy NSW is all about people with a neuromuscular condition, their family, carers and friends. If you know someone with a neuromuscular condition who doesn't know about us please give them our details or contact our office and we can send them a copy of Talking Point or information about our services.

Pene Hodge

CEO, Muscular Dystrophy NSW.

Meeting You Meeting Me

Hello I am Kejanna better known as Katie. Last month I joined the great team at Muscular Dystrophy NSW as your new Care for Carers' Coordinator. It has been my pleasure to catch up with many of our families during their medical appointments at John Hunter Hospital and Children's Hospital Westmead. I also enjoyed meeting some of you at the Hunter Roast, Melbourne Retreat and our first "Carers' Connect" meeting in Kiama as well as a number of home visits in the Central West and Illawarra regions. I would like to thank everyone for the warm and friendly welcome I received and I look forward to personally meeting you and your family on my next visit to your region.

I am very passionate about my work and have many years of experience and dedication in supporting people living with a disability. During the coming year I will plan 3 specific events in your region including:

Carers Connect – A great opportunity where carers can meet up with old friends and make new ones over a friendly and relaxing lunch, while catching up on the latest information on available services and coming events in your region.

A special family event – This is a local event where you and your family can enjoy a great time out together. Families have attended musical shows, family picnics at the local zoo, outdoor spit roast and much more, so please email your suggestions to Kejanna.taylor-king@mdnsw.org.au.

A family Christmas Party – Get your 'thinking hats on' and let me know a great local venue to host this merry event.

Remember, I am only a phone call away on 9809-2111 or 0448 018 337, I am so looking forward to chatting to you soon... Katie



Katie lives with her daughter on a rural property in the Hawkesbury about 2 hours from Sydney where they have a performance horse stud and breed Kalahari Red Goats and Alpacas. In her spare time Katie is an active rural and village fire fighter, and enjoys photography and organic gardening.



Nice to Barcelona

Hi everyone! My name is Annabel Arnheim and I am a 23 year old exercise physiology student. On the 18th June, I will be setting off on the first stage of 'La Grande Boucle des Pyrénées' - a cycling trip through the French and Spanish Pyrenees in order to raise funds for Muscular Dystrophy NSW.

My trip begins in Nice at the Côte d'Azur with the finish lying 20 days and 2000 kilometres later in Barcelona. From Nice, we turn inland to the quiet mountains of Haute Provence and cycle along the northern rim of the Grand Canyon du Verdon. We then approach the beautiful lavender fields before tackling Mont Ventoux (1912m). A very important rest-day is scheduled soon after giving us time to relax before we are faced with the Gorges de l'Ardeche, the Cévennes National Park and Gorges du Tarn. The best however is yet to come with the Pyrenees looming dangerously close - we have six climbs on the French side and four climbs on the Spanish side reaching altitudes greater than 2000m (the highest being the Col du Tourmalet at 2115m, one of the most famous climbs on the Tour de France).

On average I will be cycling 115km per day with the longest stage being 155km (...I think I'm quite safe to assume that I'll be sleeping like a baby every night)! Many of my friends have asked why on earth I would voluntarily put myself through "2000km's of torture" but the answer is very simple to me - it allows me to combine my love of sport (and my perverse enjoyment of challenges!) with my strong desire to find a cure for Muscular Dystrophy. I've no doubt it will be both physically and mentally exhausting but my challenge will only last 20 days, the challenge for those living with Muscular Dystrophy lasts a lifetime.



“ ... my challenge will only last for 20 days, the challenge for those living with Muscular Dystrophy lasts a life time. *Annabel Arnheim* ”

“If you would like to donate or keep track of my progress, I will continue to update my blog at www.everydayhero.com/annabelarnheim”



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NEW SOUTH WALES
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"ZOOFARI" at Western Plains Zoo

Towards the end of March, Lucy and I took a trip from our home in Newcastle to the Western Plains Zoo in Dubbo. The zoo has a program called "Zoofari" that allows visitors to get a "behind-the-scenes" look at the way the zoo works and get up close to some of the animals.

After a leisurely five hour drive through the bush and rolling green farmlands of the Hunter Valley, we arrived at the zoo where we checked into our Zoofari tent. Generally speaking, I prefer not to have anything to do with tents, but these were very different from the pup tents of my youth, being about the same size as a motel room, with wooden floors, electricity, a screen door and a fully tiled ensuite bathroom.

We'd asked for wheelchair accessible accommodation, and our tent was easy to get into, with three single beds and a double, and plenty of circulation space. The bathroom was well set up for my needs with plenty of space for my wheelchair and a good shower.

No sooner had we settled in than it was time for our afternoon tour. There were eight of us in our group and six of them jumped into the zoo's bus driven by one of the keepers, while Lucy and I were provided with a wheelchair accessible taxi, arranged by the zoo as part of our package. We set off around the zoo, arriving at the African wild dogs enclosure in time to watch them being fed. We visited the meerkats, who had two very cute babies, and many other animals that the keeper introduced us to.

Then it was back to the tents for a quick cup of tea and a shower before heading up to the Main House for a delicious three-course meal. Then we were whisked off again for our night-time tour. By this time the nocturnal animals such as the echidnas and hippopotamus were more active. As the zoo was now closed to the public, most of the animals were in their night



enclosures which allowed us to get very close while remaining safely behind fences. This was reassuring when we visited the tigers, who looked particularly huge when they stretched up on their back legs to reach the treats that the keeper was feeding them.



After visiting many other animals, we arrived back at the tent village and fell into an exhausted sleep, knowing that we had to be up and ready for our morning tour at seven o'clock.

We woke just before dawn, and Lucy went for a short walk to watch the zebras move out across their huge paddock while I, not being a morning person, woke myself up with a cup of coffee on the veranda. Back in the bus, with me in my "pope-mobile", we were off to hand-feed giraffes, visit the elephants as they were being fed and washed for the day, and meet the cheetahs. When we arrived at the lion's quarters my cab driver, Col, pushed me right up to the fence where a large male lion took quite an interest in me. The keeper explained that the lion had identified me as its potential breakfast – quite a disconcerting feeling!

After visiting many other animals, we were returned to the Main House for a very welcome, and scrumptious, breakfast. We checked out of our accommodation, then we were free to spend the rest of the day travelling around the zoo at our leisure.

Getting away from home for a few days, seeing new things and meeting new people, opens up all sorts of new horizons, and I would recommend a visit to Western Plains Zoo as a refreshing short break. A big "thank you" to FlexiRest for their help.

Phil Bates

VALE

MICHAEL ALISTAIR BAPTISTE

Our beloved son, Michael, passed away on Tuesday, 10th April 2012, at Westmead Hospital. He was 33 years old.

Michael was born in Calcutta, India, on 21st August 1978 and came to Australia in 1981.

Despite his disability and physical restrictions, Michael led a full and active life. His latest achievement was to start a Facebook page called, "People for an Australian Muscular Dystrophy Day" and within 3 days over 600 people had signed up to the group. The day will be 30th November each year.

From 1984 to 1990, Michael attended Auburn Central Public School. In 1986 Michael was diagnosed with Duchenne Muscular Dystrophy. Michael attended the Granville Little Athletics Club and the St John's Under 8s Soccer team. It was because of this participation in sport which highlighted that Michael had some sort of mobility difficulty. Ultimately, medical tests eventually led to the diagnosis. In September 1990, at the age of 12, Michael stopped walking.

In 1991 Michael started high school at Macquarie Boys' Technology High School in North Parramatta and was the first student with a disability to attend. Michael completed his HSC in 1996 and was Vice Captain of Macquarie Boys'. Michael attended fully main stream classes and had assistance from a Teachers' Aid who would help with note taking, etc.

In 1997 Michael began his Bachelor's Degree in Health Science, majoring in Rehabilitation Counselling at the Faculty of Health Sciences at the University of Sydney. Michael graduated in 1999 and was then invited to convert the degree to an Honours Degree which he completed in 2004. Michael had to defer his studies after serious illness in 2001. Michael recommenced his studies in late 2002. His Thesis was titled "Life Choices for People with Neuromuscular Disorders" and he received Honours Class I.

Since 1991, Michael had been involved with wheelchair sports in one capacity or another. In 1991, Michael joined the Push and Power Sports Association and began wheelchair rugby league.



Michael was involved with Push and Power from 1991 to 1999 full time, which involved rugby league, soccer and hockey and played in the Soccer competition in 2004 and 2005. During that period Michael was always involved with the Push and Power Sports Committee and was once Vice-President of the Association.

In 1992, Michael was selected for the New South Wales team to compete in the National Electric Wheelchair Sports in Adelaide. He was part of a very young and inexperienced New South Wales team that won just 2 games in the tournament, but the highlight of his first year was scoring a long range try in Rugby League against Victoria and winning NSW Best and Fairest as a 13 year old Captain.

The following year NSW had a stronger team but it was in 1994, in Canberra, that Michael really made his mark as a player when he stunned Queensland by scoring a hat trick in the Rugby League Grand Final. That year NSW went

through the tournament undefeated in Rugby League. This experience changed Michael's direction in life.

While Michael only won Best and Fairest for NSW in 1992, he won many finals as a player and coach and was part of the only team both as a player and coach to have won 4 consecutive Roger Melnyk Trophies.

The National Electric Wheelchair Sports (NEWS) was Michael's greatest passion. His playing career spanned from 1992 to 2005, where he played a NSW record 258 matches and is ranked 7th all time. From 2005 to 2012, Michael coached the NSW Colts, leading them to 21 grand finals; Michael coached a total of 123 matches and was selected as All Australian Coach on 3 occasions. Although he coached for just 7 years, he was ranked 5th all time.

In 1995, at the age of 16, Michael was elected National Co-ordinator of NEWS. This title was changed in 2001 when Michael became the National Director of NEWS and remained in this position until his passing in 2012. This position involved all the administrative tasks and policy and procedures related to running the tournament each year, with the support of Delegates from each competing team and host state organisers. Some of his achievements included writing the Handbook for NEWS, the establishment of a Judiciary system, introduction of a Code of Conduct, as well as contributing to the introduction of many rule changes to improve the sports.

In 2001, Michael managed the Australian Team as they participated in the Power Hockey World Cup in Minneapolis, Minnesota, USA. Michael also participated in the team and was considered the best goal keeper in the tournament.

Michael's service to Electric Wheelchair Sports in Australia was recognised by an Australian Government Sport Achievement Award in 2004, which was presented by Hon Mr Laurie Ferguson, Member for Reid and signed by Hon Mr Rod Kemp, who was the Federal Minister for the Arts and Sport.

Prior to the 2000 Olympics, Michael was invited to be a member of the Advisory Committee in the Volunteers Program for SOCOG.

In 1997 Michael received the Rotary "Shine On" Award which is given to young people with disabilities for outstanding community service.

In 1999 he was chosen to attend the Rotary Youth Leadership Awards. Michael later was involved with Rotaract and was

a member of Padstow and Holroyd Rotaract Clubs over a period of six years.

In 2003 Michael was presented with the Senior Sports Person Award by Auburn Council in recognition of his service to sport for people with disabilities.

Since 1986, Michael had been a client of Northcott Disability Services and over the years had assisted them by speaking at some of their fundraising events. Michael saw this as a means of thanking Northcott for the assistance they had given him with equipment and support over many years, which helped him to accept his disability.

Michael was also a member of the Auburn Council Access Committee.

Besides sport, Michael had a great interest in politics and keenly followed international politics.

Michael had a great interest in supporting and promoting the lives of people with Neuromuscular Disorders and encouraged them to live a full and active life. He was a member of the Muscular Dystrophy Association of NSW since 1986 and assisted the Association in many ways, particularly speaking at functions, writing articles and assisting the Association when and where he was able to. He was also the Chairperson of the Members Advisory Committee of the Muscular Dystrophy Association of NSW. In 2006, Michael was admitted as an Honorary Life Member of the Muscular Dystrophy Association of NSW, in recognition of his contribution to the Association and to wheelchair sport over many years.

From a very young age, Michael had a unique ability to retain information. He also had an amazingly analytical mind. He was a researcher by nature and the internet was a wonderful tool for him. He was always studying something via the internet.

Michael loved people and found it so easy to make friends and make people comfortable to speak to him. He was a simple and gentle person.

Although our beloved Michael's passing leaves a huge void in our lives he will be forever loved and remembered.

Percy and Eileen



National Electric Wheelchair Sports

April 2012



Peter Dalrymple – National Director 2013

For those who don't know me I am 22 years old and I have been playing Electric Wheelchair Sports since I was 9. I have Represented New South Wales for 10 years. I am very passionate about wheelchair sport and I can't wait for National Electric Wheelchair Sports 2013.

THE THRILL OF SPORT

On the 16th to 22nd April 2012 at the Sydney Academy of Sport and Recreation, Narrabeen NSW the annual National Electric Wheelchair Sports (N.E.W.S) was held. The competing states of New South Wales, Victoria, Queensland, South Australia, Western Australia and Australian Capital Territory participated in three different sports Hockey, Balloon Soccer and Rugby League in a round robin style competition.

This year there were three different champions for each sport, Victoria won the hockey Championship, Queensland won the Balloon Soccer Championship and the mighty New South Wales won their fourth consecutive Rugby League Championship. The prestigious Roger Melnyk trophy of the overall round robin points went to Victoria.

From a New South Wales point of view was a very emotional and proud moment to lift the rugby league trophy and dedicate the victory to our Coach Michael Baptiste who sadly passed. It was a moment that Captain Chris Suffield, Vice-Captain James Kim, Andrew Kim, Alex Scollard, Jordan Crane, Dean Crane and Assistant Coach Peter Dalrymple will never forget.

Now New South Wales is looking to the future N.E.W.S



Competition which will be held from the 8th to 14th April 2013. Preparation for training is under way with a new training schedule and drills being prepared. We will start training around September 2012, the coaching group are happy for any newcomers to come and join training to try out for National, our team, or even just to have look if you are interested to participate in some sport activities.

If you are keen to join Contact Peter Dalrymple at:
Phone: Home – 888 34 485 Mobile – 0438 224 644 Email – peterdalrymple@bigpond.com

The Boccia Brag



Boccia is opening up doors

MDNSW now has a National Boccia Champion!

Less than 12 months ago I knew nothing about the sport of boccia. But there was a flyer in Talking Point that announced a boccia 'Come & Try Day' in my local area. I didn't have much else on that day so I thought I'd go and have a look. That little trip changed my life.



Dean Nottle, National Champion

This game of boccia intrigued me. Sure, it's a sport, but it's so much more than that. For a start, it can be played by both those in a wheelchair and those who aren't, and the classification process matches people with similar physical abilities. Boccia is not just a game of skill, it's a game of strategy. It's no accident that some of the best players have a background in games such as chess.

You make a lot of friends playing boccia. And it's hard to explain why, but they are as great a bunch of people as you're ever likely to come across – players, officials, families, carers, volunteers.

"It must be something to do with the sport opening up doors for people who've had so many closed in their faces."

When I'm on the boccia court, I'm on my own. I don't have to work around anyone else's schedule, I can make my own choices, I control my own destiny. And from that little beginning less than a year ago, big things have grown for me. The friends I've played with range in age from 10 to over 60, male and female, from all over Australia.

More and more juniors are taking up the sport and junior clubs are sprouting up all over. Australia missed out on qualifying for the London Paralympics by just one spot, so the Australian Paralympic Committee and Boccia Australia, along with muscular dystrophy organisations throughout Australia, are aiming to increase participation rates nationwide. MDNSW in particular, is behind a drive to expand the sport for those of us in NSW with neuromuscular conditions.

Personally speaking, my journey is far from complete. Although I've only been playing about nine months, I became NSW State Open Champion in January and now, four months later, National Champion in both events in which I am eligible to participate. I was fortunate enough to receive the thrill of a lifetime by being awarded the Sportsmanship Award at the recent National Titles. I now have my sights set on a number of international competitions leading to the 2016 Paralympic Games in Rio de Janeiro.

"Who would have believed it? I've never been much good at sport – my body just wasn't right for it. But now I've found something I can do where I can challenge myself to the greatest of heights while doing something I truly love."

I can't recommend the game of boccia highly enough. Why don't you give it a go? It may or may not change your life, but I guarantee you'll have a fantastic time whenever you wheel out onto a court at your local club. I hope to meet you there some time.

Dean Nottle, National Champion (BC4 Division), 60yrs old

Daniel aims for the 2016 Rio Paralympics!

I was introduced to Boccia at the first MDNSW camp at Narrabeen. After giving it a go I realised it was something I could actually do myself. It dawned on me that I had finally found my sport. The idea of playing a sport at the elite level was so foreign to me that I at first rejected the idea. However, I was encouraged by both my family and by the people at Boccia NSW and I decided to take it on. In my very first competition, the junior titles of early 2011, I finished third. I was very pleased with my effort, however I made a promise to myself that the next time I would finish better than third. November of that year, the junior titles came around and I managed to finish first! The biggest test of my Boccia career was the 2012 NSW State Titles where I finished fourth overall, only just losing to Terry Cooper, Australia's number 1 player. Recently, at the Australian National titles, my two teammates Tait (from Ballina/Lismore), Siobhan and I took out the pairs title. In the singles I again managed to finish fourth.

"Boccia has given me something to aim for in life."

My future goals in Boccia include being selected to represent Australia in overseas tournaments and competing at the Rio 2016 Paralympics. If you have not given Boccia a go, I strongly urge you to. It provides you with a strong feeling of satisfaction and really boosts your self confidence.

Daniel Michel, 16yrs old



Paralympian Terry Cooper just got up by 1 against our Daniel (left)

Regional Boccia Camps

ILLAWARRA	Fridays	4.30pm-6.30pm	Port Kembla Surf Club
FAR NORTH COAST	Wed 20 June	4pm - 7pm	Lennox Head Cultural and Community Centre
RIVERINA	Thu 26 July	2pm - 6pm	Glenfield Community Centre
HUNTER	Mon 6 Aug	3.30pm - 5.30pm	HOWZAT Newcastle
CENTRAL COAST	Thu 9 Aug	4pm - 7pm	Peninsula Community Centre
NEPEAN	Wed 15 Aug	5pm - 7pm	Penrith PCYC

Don't forget **The Great Boccia Bash Sun 25 Nov** Academy of Sport Narrabeen



A self directed model changed my life!!

by Carolyn Campbell-McLean

In recent times I have been asked a lot about how I manage my care support at home, and this together with thinking about the NDIS (National Disability Insurance Scheme) and how support can be much more individualised, I decided to write this article. I hope it will explain some of what I do and share what I have learnt along the way with those of you who might be looking at self directed supports at home.

Back in 2007 I worked as a research associate on an evaluation of the pilot of the self management of Attendant Care that is, a group of people using Attendant Care elected to receive the funding directly and organise their care themselves rather than have their funding go through a service provider. During this process I spoke with lots of people similar to myself with high level physical disability using their 35 hours per week for care and support at home. I figured out there are 3 types of ways to manage your Attendant Care package:

- Traditional service provider administers your package
- Direct funding or self management
- Brokerage agency supports you to employ your own staff

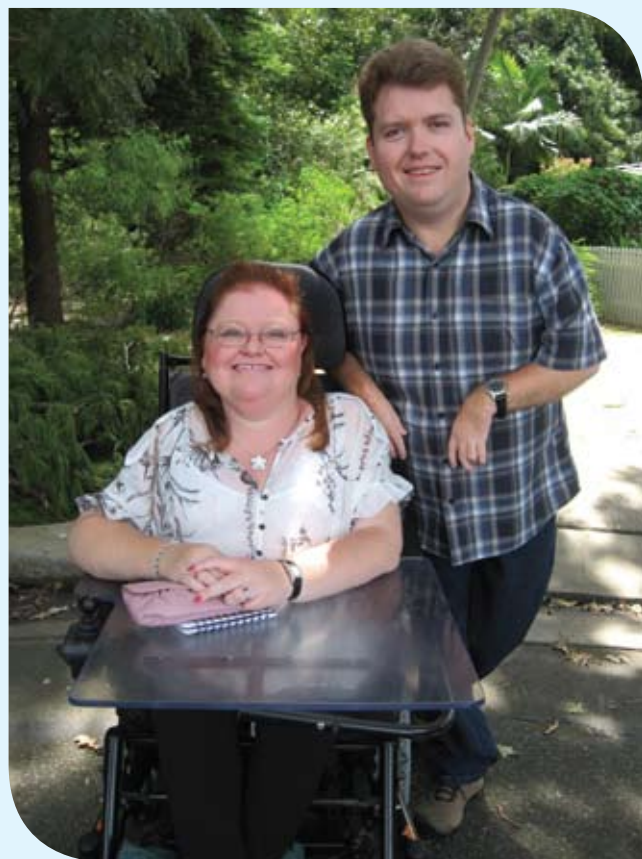
This got me thinking that it would be great if I could have more choice, flexibility and control over my own care and make it work better for me. But I definitely didn't want to be concerned about tax, insurance, running a payroll and those type of financial/administrative issues. I wanted the best of both models, I had been doing a lot of the work myself anyway but the providers were taking a large cut from my funding, with little support to me or the care staff.

So it wasn't long before I switched from a traditional type of service provider to what's known as a brokerage style arrangement. At the time it was a huge decision but honestly I haven't looked back! I use a financial intermediary or broker to deal with the administration of my Attendant Care package, but I am in the driver's seat – responsible for my own care arrangements. Yes I do the work, but I am in control of my life! I moved from being a client (burdened and powerless) to being an employer (empowered and in control).

Having my own self directed supports has had many many benefits for me. My brokerage agency is THE BEST service I have ever had. They are friendly, understanding, helpful and let you manage the service so it suits you. The Board of the community organisation are all people who use Attendant Care so they implement policies that foster good arrangements and ensure participants (rather than clients) are supported with their care, for example, my expenses in organising care (phone, internet and advertising) are covered with a regular allowance.

This has resulted in happy carers who are paid well and not given lots of paperwork or headaches by any type of "middle-

men". I have gained excellent skills in the process of managing my services, people skills, management, rostering, negotiation and so on. These can all be applied at work and in life. The other great thing about my broker is that they only do Attendant Care so they are experts in the management of the funding and can share how others get the most out of their Attendant Care.



Carolyn and Steve

Recruitment

One of the things I value most in self directed support is that I can recruit and choose my own staff (and fire them if necessary!). I can employ someone of the right gender, age, someone who shares my interests. This in my opinion is one important aspect of why I have secured a successful team of care staff. I can honestly say after almost 20 years of independent living that I believe the success of my care is based on the quality of the relationships I have with the staff – I have to like the person – and they have to like me. They see me at my best and my worst – so I firmly believe that any prohibition on 'being friends' is inappropriate and patronising. Many work colleagues socialise together at times.

I advertise through local paper, university career boards/web pages, word of mouth and sometimes I circulate an email

through my wide networks. Facebook and Gumtree are options I have not explored yet but if I was recruiting tomorrow I might try them!

I only accept applications via email as this proves they are able to communicate via email (important as the roster is sent out this way) and allows me to cull out people who are not suitable. I then contact people who look suitable by phone or email and arrange interviews. I always interview with a current carer or family member.

Planning and day to day management

I do the rostering, recruitment and manage the carers on a daily basis. My broker takes care of all the boring stuff like insurance, payroll and OHS. They are also very supportive of me in my role. They assist when needed but don't interfere.

I do the day to day management of my team of 7 carers. What this means in practice is that I do a roster (just a table in a Word document – I'm sure there are other ways) every 6-8 weeks. This is based on each carers' availability and preference to work mornings, dinner times and bedtimes, weekdays and weekends.

It is very empowering to be in control of who is doing what and when – but this does take my time and energy. Coordinators get paid \$60,000+ to do this type of role. There should be recognition that I am managing a team of 6-7 staff.

It takes skills in negotiation and sometimes creative thinking if shifts need to be swapped or changed in emergencies. Carers contact me directly if they are sick or have another problem getting to their shift. I can then assess the situation, and because I generally know the commitments and schedules of each carer it is usually possible to find someone to pick up the shift. Sometimes I swap a shift, sometimes I offer a bonus if it is very late notice. If I get stuck I have the numbers of a few agencies that are 24 hour contactable who could find staff. I rarely rely on family to fill in, unlike the bad old days when I was constantly getting stuck without support, busting for the toilet or missing out on meals.

Before a carer leaves each shift they fill in the hours book and at the end of the fortnight they fill in a timesheet that is checked and signed by me. I then fax these to my broker who arranges the payroll.

Training

I provide on the job training to my care staff. I choose what is important to tell them, and I always train them with one of my experienced carers. I am given 5 hours of training for each new worker, and this does not come out of my hour's allocation.

They also have to undertake a one day training course in quality personal care, and hopefully soon this can have a neuromuscular focus with Muscular Dystrophy NSW developing training for care staff. There has been a real gap in training for care staff who work with people with NMD. Often my staff would come

back after being trained by Spinal Injury focussed training with concerns about me developing autonomic dysreflexia (a condition common for people with spinal injury not SMA).

Self directed model compared to traditional service model

I found that traditional service providers' focus was always on carer issues and OHS, often resulting in them sprouting reasons why they couldn't do something. On the other hand I have found that with self directed care the focus is on how I can make the system work for me, and I have a vested interest in making it work for the carers – a real teamwork approach.

With self directed care – I am in the driver's seat – responsible for my own care – yes I do the work, but I am in control. I can value my attendants in the way I want and I think they will most appreciate – carers have a greater identity – and we have a Christmas party. Previously I was not invited to my carers' Christmas party. The power dynamic has changed in the relationships, my staff are now actively positive and trying to please their employer, in order to gain more Sunday shifts!

So as you can see, changing to a self directed model using a brokerage agency has certainly changed my life!!

What do you need to get started on self directed support?

The system needs to provide support for people to get the information and develop skills to manage their own services, for example:

- someone able to stand beside and assist at the outset – help you build your skills to be able to direct their own support (services often have a different idea about what I need compared to what I believe I need)
- negotiation/ communication skills – could come from generic courses
- system for advertising / training
- role models
- information – choices
- access to training
- scope for backup from agency for emergencies

I have found great information from an organisation called In Control

<http://www.in-control.org.au/>

If you'd like to ask me any questions or get further information on how you can self direct your supports at home feel free to email me at cazza74@iinet.net.au

Carolyn Campbell McLean



Living Independently

I guess the whole story began about two years ago. My parents and I had just received yet another letter from the Disability Services Commission (DSC the government agency in WA responsible for allocating care funding) informing us that we had been unsuccessful in our application for funding once again. All we wanted was a little bit of extra help so that I could be more independent and my parents less relied upon to look after me. This had been the 6th time that we had been knocked back and was the final straw. We decided then to take a new approach.

It was clear that no matter how bad our situation might become it wasn't going to matter to the DSC and we would still be unlikely to receive any funding. My mother decided we needed to confront the problem head on and she proceeded to write a 6 page letter outlining the care that she was being expected to provide to me on behalf of the state government and the strain this was placing on our family. She sent this letter to every politician in the state of Western Australia both at a state level and federal level asking for their help in getting our situation addressed and shedding light on issues that disabled people in WA and around the country were having to face.

This letter made waves and was picked up and carried by a handful of politicians many of whom have become friends of ours due to the



I was inspired by Conor Murphy when I met him at the NEWS Tournament in April. I asked him to share his story with you. He shows what determination can achieve. Conor is 23 years old and was diagnosed with Duchene when he was 3½ years old.

Maralyn McCann, Office Manager



help they provided. The disability minister at the time now had a big problem to deal with. He had an angry mother on the war path and with that in mind concessions were made. Only a couple of months later we received word that we would be given access to some emergency relief funding of about \$16,000 which would help us for about 4 months leading up to the next funding round. We used this funding for the weekends and so when a Friday would come around Mum and Dad would go and stay with my brother and I would be left at home with support workers to look after the house and do my own thing till the Sunday.

After about three months of this the application process started up again and this time we had someone come and assess our needs and this was when we came up with a great idea. My parents offered to move out of their own house and we would get my friend Kyle who also had DMD and was ready to be independent to move in and combine funding to be able to live totally independently with support workers 24/7. The people at DSC thought this was a great idea and so a couple of months later we received word that both Kyle and I were getting enough funding to be able to implement this idea. Once this happened we hit the ground running deciding to share manage the funding with an agency which meant we had to find the workers, set the pay rates and manage everything. By May of 2011 everything was set and Kyle and I began living independently on the 23rd of that month while my



Conor & his Dad

parents moved in with my brother. It has now been just over a year since we started and things are going great.

Living independently has been a massive change for both Kyle and me. We have had to mature a lot in a pretty short time and master the things everyone does normally like make sure we have enough food, make sure the washing is done, clean the house all those mundane things. Independence has also made a lot of things possible for me that I thought would never be. Independence has allowed me to find employment, to forge relationships and most importantly to live a meaningful life just the same as anyone else. Independence has not only benefitted Kyle and me but it's also benefitted our parents. I now have a much more normal relationship with my mother and father one that is the same as any 23 year old. I don't live out of my mother's pocket anymore, she doesn't know everything I get up to which is a good thing and I don't have to rely on my parents for everything reducing their stress and strain as well as mine. All this has also enabled my dad to take on a fly in fly out job and got my mother back into the workforce working for MD WA.

My story is an example of why now more than ever the country is crying out for initiatives like the NDIS so that every disabled person not just those with MD can have a chance to live as normal a life as possible, to experience the same things everyone does and as I said before live a life of meaning.

Conor Murphy



Conor and his friend Matthew Goddard Jones

Let's talk about ANXIETY



It makes sense that we would experience anxiety about the things that will happen to others and us in the future. It is therefore very important to know techniques that we can use to manage our anxiety, so that we can keep it at bay.



Everyone experiences anxiety at different points of life. You may not realize this, but symptoms of anxiety are actually normal reactions to situations that we perceive to be threatening. We are conditioned to respond in situations that threaten our livelihood in ways to keep us safe. However, we also experience anxiety when we process situations that we fear we cannot control, or make predictions about how we will cope based on past experience. Anxiety is felt in a few ways:

Physical: Our heartbeat increases, we get sweaty palms and we can get shortness of breath.

Thinking: We say things to ourselves like "I am really worried about this", "I can't cope", and "what if something bad happens".

Actions: We tend to avoid places or situations that we will feel anxious in. If we can't avoid them, we may have difficulty talking with others. We may feel as though our words don't come out right.

A lot of people experience these symptoms just before and during giving an important speech, or going on a first date, or going to a job interview, or when there's pressure to perform. This makes sense, because in all of these situations, we can't predict how things will go.

It also makes a lot of sense to experience anxiety when we, or someone we care for, is affected by a neuromuscular condition.

Our doctors do an excellent job at helping us make decisions about treatment, and it's really important to get as much information about treatment and care as we can, so that we can feel as best in control as possible.

It makes sense that we would experience anxiety about the things that will happen to others and us in the future. It is therefore very important to know techniques that we can use to manage our anxiety, so that we can keep it at bay.

It's not about "getting rid of it". It's actually about "riding the wave" through and re-programming our thoughts. When we have done this, the strength and frequency of symptoms of anxiety will decrease.

Psychologists use a Cognitive Behaviour Therapy model to treat anxiety. The course of treatment usually consists of 10 one-on-one appointments.

If you would like to find out more about this, or make an appointment, you can contact me on 0416 561 769 (leave a message and I will return your call), or email me confidentially at liz.neal@mdnsw.org.au.



Congratulations to the radiant Bride and Groom
"I recently got married so my surname has changed from Bailey to Neal" Liz.

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





Generously funded by **Ageing, Disability and Homecare**

Boy were we treated to a wonderful week of absolute madness and mayhem at our first ever Adventure Camp at Port Stephens during the April School Holidays! Using One Mile Beach Holiday Park as our base, 37 of us put on our thrill-seeking hats and challenged ourselves to go beyond what we ever thought was possible to learn that we are all capable of extending ourselves in so many different ways. A variety of life skills were learned, lifetime friendships were formed, and personal achievement was reflected on every single face at camp's end. This Adventure Camp was such a huge success for such a wide variety of reasons, and we can only hope that we are able to do it all again sometime in the near future.



Ro and Steve cooking a BBQ

Independent Living Skills

With an average age of 18 years, this was a camp which encouraged the development of independent living skills. Campers were all responsible for preparing shopping lists, cooking dinner, planning activities with others, making their own packed lunches, organising themselves for the day ahead, and learning how to function within small group situations. This was all great preparation for when they start thinking about the possibility of living more independently in the future. There were some ripper Apricot Chicken dishes, BBQs, and home-made pizzas cooked – and the best part was that the staff didn't have to lift a finger to get a scrummy meal!



Campers cooked a huge feast for lunch



A great bunch of kids

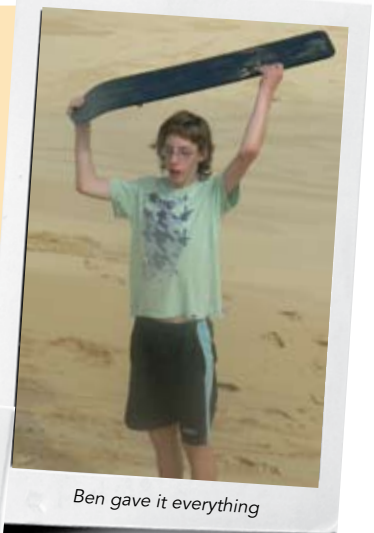
“I felt so loved. It was quite incredible. I felt like I was in a love bubble by the time I came back. *Rowena, adult camper*”



MUSCULAR DYSTROPHY
NEW SOUTH WALES

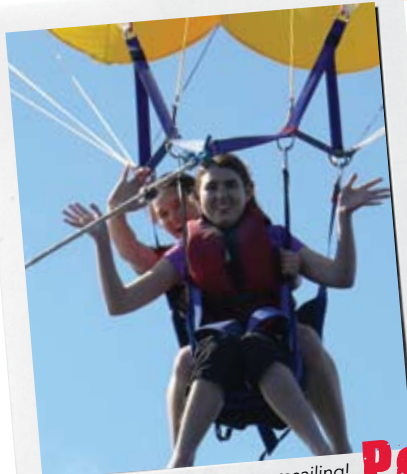
Adventure Camp 2012

One of the best things about this camp was that we were able to completely challenge campers to go well outside their comfort zone and try the riskier activities of parasailing, camel rides, skateboarding, boomnetting, a giant ocean slide, feeding sharks and rays, sandboarding, and quadbiking. Participating in activities such as these requires a total change in thought processes, from realising that it's ok to struggle up a sand dune – because then you get to go down again; to trusting that someone will be there to keep you safe as you walk over a gap onto a boat; to climbing onto a spitting camel; to overcoming a fear of heights and all things deemed safe to sail through the sky. Small steps lead to believing you can overcome even bigger challenges and each challenge instils a greater sense of self-belief and confidence. One thing became very apparent by the end of camp - the words *I can't* had totally disappeared!



Ben gave it everything

Taking Risks



Bianca opened her eyes parasailing!

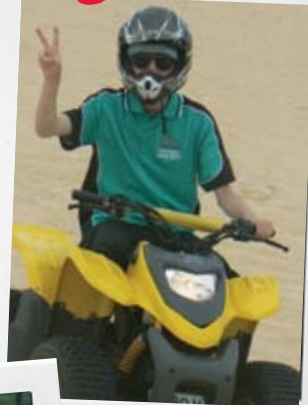


A camel ride on the beach

Personal Challenges



Boomnetting with dolphins in the rain!



Hold on Luke!!



Up up and away!



Liam and Joe conquered sandboarding



Liam and Sam feed the roo

Sense of Achievement



Dudes on the Dunes





Free time

MDNSW boasts some talented staff in Kags and Jenny who ran tennis lessons, aquarobic classes, and craft sessions, all of which were thoroughly enjoyed by those who chose to do them. Having great staff on board certainly makes life easier for Ms Camp Coordinator... and far more fab for the campers! Thanks heaps girls!



Von at the early morning Tennis Clinic



Aquarobics - note instructor Kags is dry!!

Sport

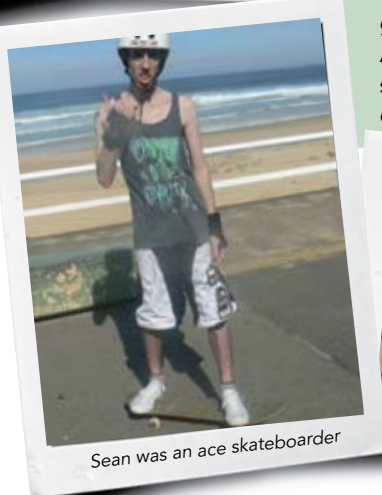
Port Stephens provided a wonderful opportunity for campers to participate in some great sports. Tenpin Bowling was a huge success, not only because of the remarkable scores and personal achievements we saw, but also because of the mateship that formed as a result. The joint was pumping after they all got back to camp! Some campers also made the most of the putt putt golf course nearby, and many chose to have an exhilarating swim at the beach which was only metres away from our cabins. A few were even fortunate to get a private skateboard lesson from current Australian Champion Jamie Goodwin, who somehow managed to jump over them and onto the footpath below!!



Erica at Putt Putt Golf



Jamie jumps over us!



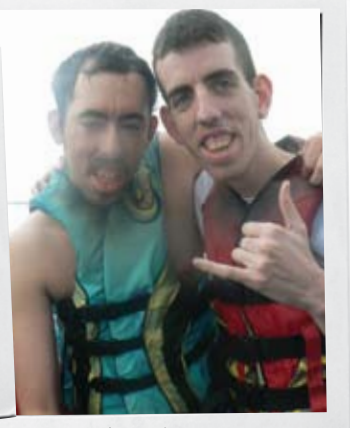
Sean was an ace skateboarder



Hugs for Codie, Kags and Kate



Jenna and Grace



Chris and Sean became mates

Party night!!!

Oh my..... can these campers party or what?!!!! Air guitars, crazy dancing, ACDC, and absolute mayhem hit the BBQ Arena that night. It was a huge night where even the other Park tenants joined in all the fun with us. Campers helped prepare and serve the dinner, and some even cooked their first-ever BBQ! The Awards presentation was quite teary in parts where campers' individual achievements were publicly acknowledged by each of their carers. Then the party continued into the night courtesy of Stingray and his crew from within their jumpin' and jammin' party pad!



Onya Grace!



Siblings and Mums



Club night Erica Sam Jacinta

This camp allowed us to pilot the inclusion of 3 beautiful siblings of children with MD on our camp. A big thank you to Erica, Samantha and Jack for all that you brought to this camp. It would have been quite daunting for you to join us, and you each had your own personal challenges to overcome, but it was an absolute pleasure to have you there and watch you embark on this incredible journey of growth.



Ro and Lisa on a dolphin cruise

We also welcomed a couple of mums to camp who had MD and wanted to challenge themselves in an entirely new way. Lisa and Ro certainly did that.... but they also brought a wonderful warmth to camp and added an entirely new perspective to their own lives and to the lives of all the campers and staff there.



Jack & Liam

The Perfect Team of Volunteers



The Carers take a dip



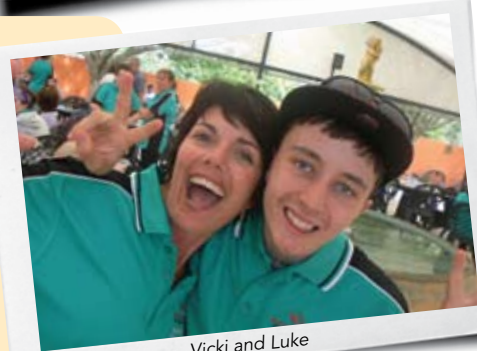
Bianca, Emma, Bec and Bek



Chris shows Dylan and Ross how to do it in style

A big thank you to the return OT volunteers from UWS, Brookvale TAFE, Michelle, and Jilly our Camp Nurse who all did a remarkable job. Special mention to Dylan and Emma who both received Carer Awards for their personal efforts at camp, and to Michele, Vicki and Sally who contribute enormously to the success of these camps each year they attend. Finally to Ross Benitez, our veteran volunteer, who gets voted by the campers and staff every year as being the best dude ever, congratulations on your promotion to the position of Camp Team Leader. You are a true gem Ross, and Pene and all the team at MDNSW would like to formally acknowledge how valuable you have become to us as an organisation and wish to thank you sincerely for enhancing the spirit of the camp environment.

What a ripper of a camp! Loretta Downie, Event Manager



Vicki and Luke

A big thanks to ADHC, Pene and the Board of MDNSW who encourage staff from within MDNSW to think outside the square, which allows us to provide such wonderful programs as these to those with a neuromuscular condition and their families.





regional events 2012

The Hunter Reunites with a Roast

What a wonderful Sunday we had under the Rotunda at Speers Point Park on Sunday 27 May. The sun eventually pushed the wind aside and gave us a lovely afternoon, complemented by local singer 14yr old Abby Butler, a delicious Spit Roast, and the wonderful buzz of endless conversation.

We welcomed Loretta and Jenny from MDNSW for the day and they were also joined by Kejanna (Katie), our newly appointed Regional Case Manager, who didn't waste any time on the job, going home with plenty of follow-up work to do! Katie is a breath of fresh air and very much needed in the regional areas.

Phil Bates facilitated the popular sport of Boccia and it was amazing to watch the adults' confidence grow as they felt a sense of achievement realising they could now be part of a sport, having never played a sport before. Even the kids loved

it as it can be played by those of all ages and all abilities. I also saw a mum introduce her 9 year old boy to another boy about the same age who had the very same rare muscular condition as he did. The look of joy on this little boy's face was one I'll not forget, as it somehow helped him feel less alone. He now wants to go to the next camp and bunk in with his new mate!!

As I talked to different people on the day the most obvious feeling was that we don't have to do this by ourselves!! We have support from people who are going through a similar thing and it's great to get together and talk about our experiences, both the good and the bad, and the different ideas people have about doing things. It really made me realize how important these gatherings are. We have everything to gain and nothing to lose.

It also made me realize what an important role MDNSW plays in our lives. I have never

met a more dedicated, selfless team of people as the ones that are there in the office now. So if there is one bit of advice I have for other regions who are thinking about doing something to bring you all together is why not make a phone call to either MDNSW or a few other people you know in your area and get the ball rolling as soon as you can! Thanks to all 70 of you who made the Hunter Roast a success simply by attending and sharing your story with others, and I look forward to many more events in the Hunter from here on in.

Vicki Sculli, Hunter Roastee



Amazing talent!



Adult catch up



Souths fans Megan & Alan



Gorgeous location



Beautiful!



Ann gives us a wave!



The kids loved bocce!



Mr Bocce, Phil Bates



Roast Organisers Lisa and Vicki