

# talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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

*We're here to help*



MUSCULAR DYSTROPHY  
NEW SOUTH WALES

## A Word from the President

Our MDNSW support family has grown with our Ambassadors' Program which harnesses the goodwill of some very successful and high profile people who want to help. In later pages you'll read we've been joined by Luke Jacobz, Dr Joanna McMillan, Vince Sorrenti, Major General Michael Jeffery, Fiona Simson and David Speers.

These high profile Australians joined us to make the point that people and families coping with neuromuscular conditions are not alone. MDNSW, our friends and supporters are here to help wherever and whenever we can. Our Ambassadors will help get that message out to more and more families across the state as well as help us with the ongoing need to fundraise to extend the reach of our services.

In fact, there are many people in NSW with neuromuscular conditions we are yet to reach. If you're aware of someone with a neuromuscular condition and you know they haven't been in contact with MDNSW, please give them a copy of Talking Point and suggest they give us a call. Tell them that MDNSW and our supporters are ready to help. We want to reach out to them.

I must also mention that last month, I had the pleasure of again visiting our Camp at Narrabeen. With other Board Directors, Ambassadors, MDNSW staff, supporters, parents and carers

we watched the laughter and relentless energy of teams taking on challenge after challenge. The young people attending the Camp were just amazing. Once more, I was inspired by the Camp's Awards Ceremony at the end of the week as person after person proudly accepted their award surrounded by friendship and care and under the ever watchful eye of Loretta - the Boss. Congratulations to Loretta and her team for making this Camp another resounding success.

As I said in the last edition, it's an honour 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](mailto:info@mdnsw.org.au) Tel: 9809 2111

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I'm very pleased to introduce to you our new Client Services promotional material featured on the cover of this edition of Talking Point.

Whether you are new to our organisation, have been a member for a long time, or you have previously had a loved one pass away, the message we want you to know is *If your life is*

*affected by a neuromuscular condition ... we're here to help.*

We chose the theme of the umbrella because we wanted to acknowledge that at times the journey can be tough, dark and raining and our aim is to provide some relief, protection and shelter during these times. Our umbrella is bright to show energy, fun and creativity, which is how we want our services, events and programs to be.

We included both an adult and child in the picture as neuromuscular conditions affect people of all ages and their whole family. You will notice the two people are holding hands symbolising the

support people with a neuromuscular condition give to each other and the significance we place on these relationships.

Finally the rainbow because it is the international symbol for diversity and inclusiveness; of hope and of yearning, and it is the beautiful aura that arises following a period of rain.

Thanks once again to all of you who have provided wonderful stories, practical information and interesting articles for Talking Point. We love receiving them and know from constant feedback that everyone appreciates reading them. Please continue to send through to us anything that you think maybe of interest to others.

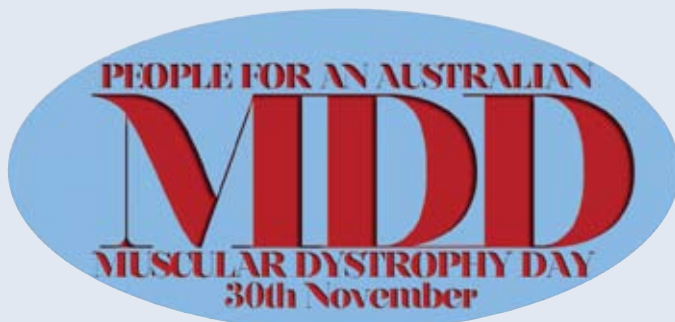
The office is very busy at present preparing for several medical conferences, our annual Christmas parties and end of the year events. It is hard to believe the festive season is fast approaching. I hope I have the opportunity to meet with many of you during this time. I wish you all a happy Christmas and a time of relaxation with family and friends.

**Pene Hodge**  
CEO, Muscular Dystrophy NSW.

## People for an **Australian Muscular Dystrophy Day** **Friday 30th November, 2012**

In November 2011, Michael Baptiste started a Facebook page called, *People for an Australian Muscular Dystrophy Day*.

Michael's vision was to have one day a year set aside dedicated to people with a neuromuscular condition. It will be known nationally that this is *People for an Australian Muscular Dystrophy Day*, and then each state would decide how they wished to be involved. To celebrate this day in NSW, everyone is invited to attend a morning tea at **10.30am on Friday 30th November** at the Muscular Dystrophy NSW office located at Meadowbank. Please RSVP by ringing Maralyn on 9809 2111 before Monday 26th November or emailing Eileen Baptiste at MBaptiste@bigpond.com.



# Meet our Members

Last month Pene, Victoria and Maralyn went to the *Riding the Wave Conference*. The Conference was presented by Muscular Dystrophy Queensland and the Duchenne Foundation and was held at Bond University in Queensland. It was a very worthwhile weekend and we all learnt a lot at the Conference. Below are comments from one of the families who attended, Philip, his mother Lilian and his father Peter.

## What were you looking to get out of attending the Conference?

**Philip:** To make a holiday out of the trip as I wasn't actually planning on going to the conference.

**Lilian:** I am always desperately hoping to find out about a new potential cure for Duchenne, but apart from that, merely finding out what is new.

**Peter:** Finding out from the experts where the research is at and what works as the best care for boys with DMD.

## What aspects most reached your expectations?

**Philip:** I didn't really have any expectations as I wasn't expecting to attend the conference.

**Lilian:** The quality and variety of speakers exceeded my expectations.

**Peter:** The deep insights into adulthood living with Duchenne Muscular Dystrophy (DMD) and Becker Muscular Dystrophy (BMD) and the way this was explained and shown. The insights from across the globe USA/Canada/Holland/Denmark were great. The speakers were of the highest quality from all over the world.

## What were the highlights for you?

**Philip:** The highlight for me was watching the short video on the lifestyles of other Duchenne boys.

**Lilian:** Meeting some of the older boys and hearing their stories, as well as watching Jos Hendriksen's film.

**Peter:** The taboo subject of addressing sexual needs for people with a disability. This was very professionally handled and extremely informative and I think a great help to anyone with a disability. I can highly recommend offering MDNSW adult members access to the sources provided.

## What was more important for you, to listen to the speakers or to meet with other members?

**Philip:** It was more important to meet with other members.

**Lilian:** A bit of both, it is always nice to meet other parents in the same situation and share stories but also very important to listen to the speakers.

**Peter:** I really enjoyed listening to the speakers and gaining the latest insights. Also the conference provided me with opportunities to talk one on one about care and treatments. Meeting young parents on the 'discovery' is heartfelt and the opportunity to connect is great.



## What did you find inspiring from the conference?

**Philip:** I was very inspired by the video.

**Lilian:** Pat Furlong she is truly inspirational! I have heard her before but her story never ceases to amaze me!

**Peter:** That there is real hope and that breakthroughs are happening right now. Listening to the DMD/BMD boys' personal experiences as they become adults was very inspiring and a positive session.

## How will you use what you learnt from the conference?

**Philip:** I will use what I learnt to live a good, fun life.

**Lilian:** An important lesson I learnt was that the boys need their independence so I shall strive to be a less dotting mother. I am in the process of organising a carer for Philip to come and spend some time with him on a weekly basis.

**Peter:** To me it reconfirmed the need to get every expert together and share the information available. It is by far the best place for parents who may recently have discovered that their child has MD and wants to find out what to do – this is a great place for comfort and sharing.

## What were the topics that most interested you and why?

**Philip:** I was interested in the video as I was inspired that I should take every opportunity that comes in life. The lifestyle was also great and I liked the idea of living with other boys with similar disabilities.

**Lilian:** The Deflazacort research, the Ace Inhibiter, the endocrine aspects of growth and maturation, and to some extent the scoliosis information.

**Peter:** Our son Philip is 14 and we are thinking about young adulthood and independent living. I can highly recommend the Jos Hendriksen video that was shown on the topic: Duchenne With A Future: The Power To Live

Contact Jos Hendriksen for a free copy: [hendriksenj@kempenhaeghe.nl](mailto:hendriksenj@kempenhaeghe.nl)

## Is there anything that you learnt from the conference that you will use immediately in your life?

**Philip:** After the conference we have decided that I should get a carer like the other boys there. You only live once so take every offer and don't reject an opportunity you might regret.

**Lilian:** We might be looking into getting Philip started on a Beta Blocker and also getting a carer for Philip on a weekly basis.

**Peter:** News on equipment and drugs was important and we will investigate putting our son on Beta Blockers as he is already on Ace Inhibitors. It seems that there is strong evidence that starting early with drug treatment before any symptoms to protect the heart is very important for boys with DMD.



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# FlexiRest

## Flexible Respite Program

**Supporting people in NSW with progressive neurological disorders, their families and carers**

FlexiRest funds a range of services that can offer respite either in-home or out-of-home that cannot be met by existing community and respite services.

Respite, is the provision of planned, short-term and time-limited breaks for families and other unpaid carers of people with muscular dystrophy, motor neurone disease and multiple sclerosis and to provide a positive experience for the person with the neurological condition.

FlexiRest aims to be flexible and responsive to individual needs.

### Examples include but are not limited to:

- Respite provided in home for a limited period
- Short breaks that support family members to spend time together
- Peer support/age appropriate respite involving leisure and recreation activities with people of similar age with like interests
- Transport support to access respite services
- Vacation care and before and after school care where schools provide integrated services that employ support staff to help children with disabilities

### Eligibility:

- You must live in NSW and have an unpaid carer
- Be registered with Muscular Dystrophy New South Wales, MND NSW or MS Australia ACT/NSW/VIC
- Have a demonstrated need that cannot be met by existing community and respite services

Applications are assessed and completed by a staff member of your organisation and must be submitted at least 6 weeks in advance of planned respite dates for consideration and approval.

This initiative operates with funding from the Ageing, Disability and Home Care, Department of Human Services NSW (ADHC), and is run by a Consortium consisting of Muscular Dystrophy New South Wales, Motor Neurone Disease Association of NSW and MS Australia ACT/NSW/VIC.

### For more information

Please contact your organisation on the following telephone numbers for available respite options:

Muscular Dystrophy  
New South Wales  
**1800 635 109**

Motor Neurone  
Disease Association  
of NSW  
**1800 777 175**

Multiple Sclerosis  
Australia  
**1800 042 138**

Updated  
Jul 12

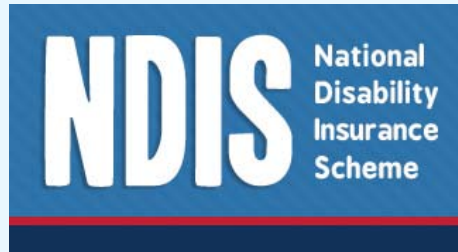
# What is the National Disability Insurance Scheme [NDIS]?

This question is being asked time and time again, sometimes with excitement, sometimes with some anxiety and sometimes with trepidation. I would like to try and answer the question, help reduce any anxiety and to break down what NDIS may mean for you. NDIS means a lot of exciting things and will result in people being seen as individuals, with individual needs, wants, hopes and dreams. As you may know several sites over Australia have been chosen to be pilot sites and that includes the Hunter Area in NSW, but what does the NDIS aim to achieve?

Despite the fact that every 30 minutes someone in Australia is diagnosed with a disability, services and support can sometimes be described as a lottery depending upon where you live, what disability you have and how you attained that disability. The Productivity Commission found, while there are pockets of success in some states, no disability support arrangements in any state or territory are working well in all areas. This is despite the enormous effort of disability workers on the ground helping to provide support and services to people with disability, their families and carers, and with funding from all levels of government.

The Prime Minister released the Productivity Commission's report on 10 August 2011 and all governments agreed with the recommendation to establish a National Disability Insurance Scheme (NDIS). An NDIS will turn the way disability services are currently provided on its head. This means that funding will no longer be based on budget allocations, but that a funding pool will be based on individual assessment of need.

The scheme recognises that a disability is for a lifetime and so it will take a lifelong approach to providing care and support. This means that assessment will look beyond the immediate need and across the course of a person's life. For example, home modifications might be expensive



up front, but if they afford a person with the opportunity of greater independence, or if they mean that a parent carer can continue to care for their loved one, it's a good investment.

NDIS will support choice for people with a disability, their families and carers and will put people in control of the care and support they receive, based on needs. There will also be safeguards in place to support people in exercising this choice and control, and to help make informed choices.

An NDIS will ensure people are no longer "shut out" from opportunities and from independence by providing the appropriate and necessary supports that allow people with a disability to reach their full potential. It will aim to nurture and sustain the support of families, carers and friendship groups — the very communities of support that are critical to improving the lives of people with a disability. It will also include a comprehensive information and referral service, to help people with a disability who need access to mainstream, disability, and community supports.

A National Disability Insurance Scheme will give all Australians the peace of mind to know that if they have or acquire a disability that leaves them needing daily assistance with everyday life, or if they care for someone who has a disability, that they will be supported.

If you would like any more information please log on to the NDIS website at [www.ndis.gov.au](http://www.ndis.gov.au). This is the government website explaining NDIS which also keeps you up to date with what is happening. Alternatively, you can visit the Every Australian Counts website at [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au) which is the National Advocacy Website to make NDIS real.

**Victoria Berg**  
Client Services Manager

**MAKE IT REAL**

**NDIS  
2012**

## Our very own Drummer Boy

Liam has Congenital Fibre Type Disproportion, (CFTD), a condition where he is born with smaller than average muscle fibres and low muscle tone. This affects a lot of his body movements. In Liam's particular case his speech, upper limbs, breathing, and eyes are affected. He has had speech therapy since he was a gorgeous 3 year old. He worked hard on his speech; a real trouper. His mouth wouldn't make the sounds he wanted it to but he made it. He practiced and practiced. He had a lot to say and wanted me to understand it. He still corrects himself. I'm so proud of him and I know he is going to have a wonderful successful life with an attitude like that.

He wasn't trying to get out of cleaning his teeth or having a shower. He was in pain. To save his embarrassment I piggybacked him. All the other children understood. I was exhausted by the end of the day and think a wheelchair will be best in the future.

Liam first became interested in drumming last year. In our yard we can hear our 17 year old neighbour, Phillip, playing the drums. Liam loves to ride his scooter headbopping to Phillip's drum beat so we approached him about some lessons and he agreed. It's a nice neighbourly arrangement. Phillip and his family were also kind enough to let Liam have Phillip's old Drum set and Liam loves to bash out a beat with it.



*Liam was handpicked to perform at the end of term concert*

At 3, Liam also had physio and occupational therapy organised through the 'Cerebral Palsy Alliance' here in Valentine/Newcastle and they are currently looking at getting a wheelchair for Liam as he can now only walk short distances. I remember one excursion when he was in year 2 and we were walking about 100m up a very slight slope and he looked at me and said "this is killing me". I knew he meant it.

A few of Liam's fellow classmate's attend "Rosie's School of Rock". Liam has always enjoyed listening to rock music and likes to wear skull necklaces and rock T-Shirts like "ACDC". He also likes long hair, to his parents' horror. Luckily his parents are rock music lovers and were keen for him to have a go, so we enrolled Liam in "Rosie's School of Rock" and he loved it with a vengeance. The atmosphere is fabulous. The foyer of the studio is decorated with rock star red carpet and a massive rock star chandelier.

The drum kit looks like it's made out of beautiful pearl. Travis his drum teacher is really enthusiastic and understanding of Liam's CFTD and he organised lessons according to what time of day suited Liam best. Drumming is an exhausting musical instrument, but Liam loves it and that's all we need. Travis and Philip let him have lots of rests and talk with him about the instrument and the methods of playing it.

The first song he was taught at Rosie's was "Rolling in the Deep" by Adele. I love that song. Liam had a half hour lesson at Rosie's and then a half hour lesson with Phillip next door. Phillip would go over everything Travis had taught him and help Liam get his beat. Towards the end of term Travis asked Liam to have a jam with some student guitarists, keyboard players and vocalists. Liam loved it. He thought it was so much fun. Then he was "handpicked" to perform at the end of term concert. He was so excited, and we were so excited for him. He performed so well in the concert. His parents, grandparents, Phillip and Vicki Sciulli from MD came to watch. Travis was on stage helping him keep his beat. He looked so small up there behind that big drum kit on the stage. When he played it was awesome, and we all shed a tear. He's a boy with a muscle problem getting on with his life and loving it. Just so inspiring!

**Michelle D'Amico**, mother of Liam





# MDNSW's New Ambassadors

## Luke Jacobz

Luke Jacobz was best known to viewers as Angelo in Seven's Home and Away – a role he received a Most Popular Actor Logie nomination for.

In 2008, he and dance partner Luda Kroitor took home the winner's trophy on Dancing With The Stars.

Giving up a plumbing apprenticeship at 17 years old paid off for Jacobz, after appearing in several commercials and guest roles he landed his first full time acting gig as Zac Croft in Heartbreak High.

Having the gift of the gab scored him a job as a promotional representative for the Pepsi Taste Challenge campaign in the summer of 1999-2000, which led to a hosting role on Channels Seven's children show The Big Arvo.

In 2004 Luke hosted the popular Popstars program and co-hosted Iron Man. In 2005 he returned to acting, joining the cast of McLeod's Daughters, before taking up his role on Home and Away.

He is now known for presenting the hugely popular show the X Factor, joining judges Mel B, Natalie



Bassingthwaighe, Guy Sebastian and Ronan Keating, on the search to find Australia's next big singing sensation.

## Fiona Simpson

Fiona Simson was elected President of NSW Farmers in 2011 on a platform of renewal, excellence and inclusiveness and is the first woman to fill this role.

Fiona holds a Bachelor Degree in Arts/Business, and has tertiary qualifications in workplace training and adult education.

She is a Director of Plantation Trading Pty Ltd, a 5500ha mixed family farming enterprise near Premer on

the Liverpool Plains. With broadacre farming and commercial and stud poll hereford cattle operations, Fiona is responsible for the administration, marketing and risk management of the business.

With husband Ed, and children Jemima and Tom, Fiona is passionate about ensuring a strong future for agriculture, and maintaining a strong and united voice to ensure that farmers' voices are heard and taken into account at all levels of Government.



## Dr Joanna McMillan

Joanna is one of Australia's best-known nutrition and healthy lifestyle experts. She is a regular on the Nine Network and the official nutritionist for TODAY. Joanna is an author of several books including the award winning Inner Health Outer Beauty and the internationally published The Low GI Diet, has a weekly column in Sunday Life and blogs for Essential Kids.

Her accent gives her away as a Scot, but she made Australia her home in 1999 where she subsequently

gained her PhD in nutritional science from the University of Sydney. Her university studies started with psychology, followed by a Bachelor of Science, all the while working as a fitness instructor, which she did for over 15 years. Together this gives her a holistic approach to health and wellbeing, and the best thing is she never sits on the health high horse! As a down-to-earth Scot, all her advice is tempered by what is practical, doable and fun whilst still giving the desired result.

Joanna is vice-president of the Australian Lifestyle Medicine



Association (ALMA) and a member of Dietitians Association of Australia and The Nutrition Society.



## Major General Michael Jeffery, AC, AO(Mil), CVO, MC (Retd)

Major General Michael Jeffery, AC, AO(Mil), CVO, MC was born in Wiluna, WA in 1937.

He graduated from the Royal Military College, Duntroon into Infantry serving operationally in Malaya, Borneo, Papua New Guinea and Vietnam, where he was awarded the Military Cross and the South Vietnamese Cross of Gallantry.

After command of all combat elements of the Army he headed both the logistics policy and equipment procurement branch of his Service

before retiring in 1993 to assume the appointment of Governor of Western Australia.

For services to the State he was appointed a Companion in the Order of Australia, a Commander of the Royal Victorian Order and a Citizen of Western Australia.

Post retirement as Governor he established in Perth, a not for profit strategic research institute – Future Directions International (FDI).

From 2003 to 2008 he served as Governor-General of the Commonwealth of Australia where his key interests were in youth, education and landscape regeneration matters.



Currently he is Chairman of the Royal Flying Doctor Service, FDI and Outcomes Australia and an active patron of some other 16 charitable organisations.

## Vince Sorrenti

Vince Sorrenti is one of Australia's most loved and leading comic entertainers.

In 2012 Vince Sorrenti won the coveted Mo Award for Australia's Best Stand-Up Comic for the fifth time!

Vince Sorrenti has a long performance history, cutting his teeth in Architecture Revues in the early 1980s and in the burgeoning stand up comedy scene that he helped create. Graduating as an Architect in 1985 he threw full weight behind his real talent and has performed to ecstatic crowds on thousands of stages all over the world.

Over the past 25 years he has hosted TV programs in Australia and the United States, appeared in movies, released comedy albums, performed in festivals, and been a guest on countless talk and variety programs. His most recent TV programs include The Great Aussie Cook Off (Channel 9), Sunrise (Channel 7), Wide Open Road (ABC), and Celebrity Apprentice (Channel 9).

Vince Sorrenti is a writer. He has won a Gold medal at the New York Film Festival for his documentary No Laughing Matter in which he also starred (playing all 7 characters!). His feature film script Gino won full FFC funding in 1990 (\$2.5 million). Vince



has also written hundreds of feature articles for publications including The Bulletin, Sydney Morning Herald, The Weekend Australian, Vacation, The Daily Telegraph and many others.

## David Speers

Sky News Political Editor David Speers is one of the nation's most respected and connected political journalists. He lives and breathes politics, working from the corridors of Parliament House.

David hosts "PM Agenda" each day on Sky News and "The Nation" each week, where he regularly interviews political and business leaders.

So highly respected is David by both sides of politics, he was chosen to moderate the Leaders' Debates at the last two elections. He stood between John Howard and Kevin Rudd in the 2007 debate and then Julia Gillard and Tony Abbott in 2010.

David has interviewed many world leaders including US President George W. Bush at the White House.



MDNSW's New Ambassadors

# Transition to Adulthood for Young Men with Duchenne Muscular Dystrophy

## Research Summary

**David Abbott and John Carpenter at the School for Policy Studies (University of Bristol) in partnership with the International Centre for Life (University of Newcastle), the Duchenne Family Support Group, the Muscular Dystrophy Campaign, and with support from Action Duchenne.**

Duchenne Muscular Dystrophy (DMD) is an inherited neuromuscular disease which affects boys. During the last few years there have been significant improvements in the ways DMD is managed. As a result, those who are the focus of this study, have reached, or are reaching stages of adulthood that were, at the time of their childhood, largely unexpected. Given increases in life expectancy, young people with DMD should be looking forward to living independently, with appropriate support, as adults. The key objectives of this study was to investigate, from their own perspectives, how the health and well-being of young men living with DMD, and that of their parents, can be maximised, particularly at the transition to adulthood.

## Key Findings

- Although around half the families recalled having been involved in some planning for transition for school and from children's to adult services, there was an alarming absence of examples of formal transition planning as required by relevant statutory instruments and policy guidelines. Two thirds of parents had insufficient information about options for what their son did next in his life.
- While many young men had good things to say about their time at school, college and university, there were many examples of systemic failures to meet their needs in relation to physical access, access to a full curriculum and, most commonly, to participation in activities outside of school.
- Families and young people felt that they did not have enough specific information about choices post-school and post-college. Only one young man had had experience of paid work. Others who had looked for work had faced insurmountable obstacles.
- About one third of young men were at home during the day and not doing any kind of education, training or work. Most of them felt that being at home was not stimulating enough and their parents agreed. These young men had very limited social opportunities or friends beyond their immediate family.
- All but three of the forty families interviewed characterised their overall experience of service provision as problematic. Families described having to constantly prove their needs and getting them met was often a protracted and acrimonious process. In a postal survey completed by parents, over 80% reported clinical levels of anxiety and depression. Most had been woken by their son every night of the previous week (average 4.6 nights a week).
- There were very wide variations within and between regions in the nature and level of support available to families in terms of care packages provided. Most parents were still doing a lot of physical care and support.
- The ways in which families talked about living with and being affected by DMD was highly individual. The main theme was that young men said that they preferred not to think about it very much. Parents were not always sure what their sons did, or did not know, about having DMD.
- Both young men and their parents said that they tended to 'live for the day', in large part because the future was so uncertain. There was a strong desire to 'get on' with the ordinary business of family life. The young men with DMD their siblings and parents demonstrated huge resilience in the face of some extraordinary challenges. Relationships within families were often extremely close, mutually supportive and characterised by warmth, humour, and an overwhelming desire to 'lead a good life' despite the obstacles that they faced.

## How we did the research

The research comprised:

- A postal survey of parents with a son with DMD aged 15+ living in the South West, the West Midlands and the North East of England.
- Face to face interviews with 40 young men, their parents and siblings (total n=102) about growing older with DMD and the issues they faced at transition.

The data was collected between October 2007 and November 2008.

## Additional Information

- A full, 167 page report about the research is available to download here:

[http://www.ltn.org.uk/download\\_files/final%20reports/PRP\\_Revised\\_Final\\_Report\\_053009.pdf](http://www.ltn.org.uk/download_files/final%20reports/PRP_Revised_Final_Report_053009.pdf)

- An abridged, 49 page version of the research is available to download here:

<http://www.bristol.ac.uk/norahfry/research/completed-projects/becominganadult.pdf>

- A summary of the research written by young men with DMD for other young men is available to download here:

<http://www.bristol.ac.uk/norahfry/research/completed-projects/becomingaman.pdf>

For further information contact David Abbott: [d.abbott@bristol.ac.uk](mailto:d.abbott@bristol.ac.uk)

The research was funded by the Department of Health's Research Initiative for Long Term Neurological Conditions.

# Going to dark places to see the light

Elizabeth Neal



*Doing therapy doesn't mean there's something wrong with you, in fact, it's the opposite. It means you're brave enough to unleash your imagination, find out who you are and go on to succeed*



Whenever I see someone for counselling for the first time, I usually hear one of two things. Either they've had lots of counselling before, are familiar with the process and are ready to do some more therapy or they've never really seen a psychologist before, and are not quite sure that they really "need to see a psychologist" and it's taken a few months of changing their mind back and forth as to whether or not to go. It's really unfortunate that society has created a stigma around this stuff and that doing something positive, like looking after your mental health, can be perceived as though there's something "wrong". Yet it's actually the opposite and taking that leap of faith to work through the "hard stuff" is actually a sign of a well rounded, grounded and insightful individual.

I have recently been working with some successful creative professionals in private practice. You might think, "Why would someone so successful need to see a psychologist?" You'd be surprised! In fact, it's often the "STUFF", the dark corners of the mind, the inner turmoil, deep fears and obstructing insecurities that successful artists use to build and form their work. Counselling can hold the artistic hand in winding through the maze of the mind in order to get to the heart of creativity. So it's not about being afraid, embarrassed or ashamed of your STUFF. The goal of counselling is not about "GETTING RID of it". It's about getting to know it and USING it. Doing therapy doesn't mean there's something wrong

with you, in fact, it's the opposite. It means you're brave enough to unleash your imagination, find out who you are and go on to succeed.

You are on your own unique journey and if you're reading this, then you're probably on a journey that's been very different to the journeys of many other people you know. There are always hurdles along the way, there are always injustices, struggles, sadness and fear and that comes with managing life. However, you CAN take control of how you deal with these things, find strength in adversity in the strangest of ways, and surprise yourself about how resilient and amazing you actually are.

Counselling is available to members and friends of Muscular Dystrophy NSW at the Meadowbank office. Liz is a registered Psychologist and counselling is confidential and non-judgemental. For more information or to book an appointment, email Liz at [liz.neal@mdnsw.org.au](mailto:neal@mdnsw.org.au).

Connect with your creative self and unleash your imagination!

**Liz**



**P.S. There's some more information about me on my website at [www.elizabethneal.com.au](http://www.elizabethneal.com.au)**

## The Training Program IS FINISHED!!!

The web-based training program for those who care for people living with neuromuscular conditions is complete and will be launched at NSW Parliament House on 14th November, 2012.

A big thanks to everyone for all your help with the program, providing invaluable advice based on your experiences. A special thanks to those who welcomed

me into their homes to talk about these experiences, some of whom were brave enough to speak on video for the program!! I'm glad I was only on the other side of the camera for that!

The program will be accessible from the MNDNSW website ([www.mdnsw.org.au](http://www.mdnsw.org.au)) after the launch. As always, your feedback would be welcome.

It is sometimes difficult for those who provide care and support to understand what exactly is required for each person's care. We hope that this training will help in that understanding so that the care that you and your family members receive is improved.

**Maryanne Murray,**  
Training Project Officer







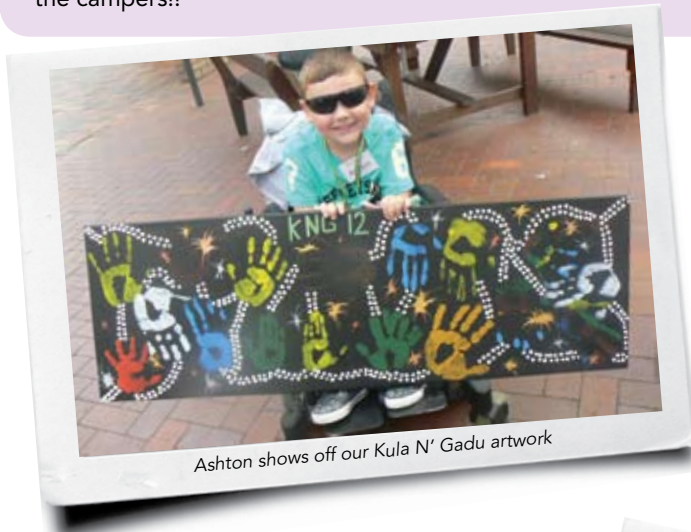
## Generously funded by **Ageing, Disability and Homecare**

Just when we thought that Camp couldn't possibly get any better, along comes another bunch of courageous campers, committed carers and keen activity facilitators!!

The scene was set with a symbolic smoking ceremony to celebrate our new Camp name – Kula N' Gadu – which basically means being proud of who you are and where you have come from. We all walked through the smoke and felt an immediate sense of peace. It was a sign of wonderful things to come! Wendy, Jo & Jordana headed an excellent Indigenous Art & Craft session which included stories of the Dreamtime. Then we headed off to Eggstreme Adventure which saw crazy team building activities ending with a ceremonious throwing of the eggs at Brett from Great Race – a huge highlight for the campers!!



Sophie shows Wendy her Indigenous Art



Ashton shows off our Kula N' Gadu artwork



Eggstreme Team

## Sense of Achievement



Working together



Ross and Luke



Brett the Eggterminator





A big thanks to staff from Deutsche Bank who joined us on the Tuesday and helped to create an amazing atmosphere throughout the Tennis Clinic and Survivor Olympics. Our mini campers were lucky enough to have a few activities designed just for them throughout Camp and these included Maralyn's Scavenger Hunt, Jenny's Cooking Class and Ross' Balloon Volleyball, all of which were a huge hit! The oldies teamed up for an hilarious Drama Class with The Great Race and also participated in the Shane Warne Workshops conducted by Justin Reid.

Late afternoon sessions gave campers an option of participating in unique craft sessions or Singational classes. The latter highlighted the talented singers we have within MDNSW especially Sarah and Daniel, with Michael and Bodene improving every year; such a wonderful activity for campers' self esteem and confidence.



Tom did well at tennis

## Radio Car Racing



Radio Controlled Cars



The wonderful volunteers from Deutsche Bank



Clare, Phil, Dan & Bek line it up

As expected, the Radio Controlled Car Racing sessions ranked highly amongst the campers, with the younger campers surprising us all and showing an enormous amount of skill and patience. Congrats to Jye and Joe who took out the coveted Racing Car trophies but a special mention must also be made to Kamal and Ashton who showed us great skill and that it's not all about being the fastest!

According to the Camp Evaluations, the highlight of Camp was the Laser Tag activity facilitated by Rob from Aim 4 Fun. Conducted on the Oval and including large inflatable bunkers, Tom and Michael earned the title of Laser Tag Champions of 2012 with their amazing agility and ability to line up their opponents. The carers all deserved a medal in this activity with some having to push campers in manual chairs on grass, and others having to run alongside those in electric chairs as the guns became a little heavy. Check out pics on their facebook link found at [www.aim4fun.com.au](http://www.aim4fun.com.au)



Bo & Joss Racing Cars

## Laser Tag



Matt's Laser Team of carers



Commando Kags



Anwen and Emma Lasering it







## Sports Day



Mummy Tom!

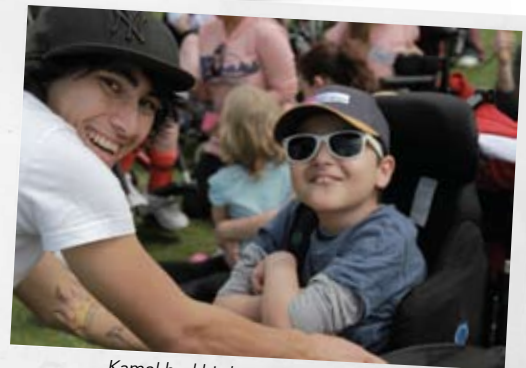
Sports Day was a huge success once again with Peter King from Boccia NSW leaving very excited about the potential Boccia Champions he identified within. Max and Rex were stand outs... and who could forget the last ball our Paralympic hopeful, Daniel, threw to beat about 6 other players by millimetres. It was the Ball of a champion! Northcott also provided us with a couple of talented Powerchair Football players to show us this relatively new paralympic sport which saw Chris and Cassie excel after they were fitted with the specially designed football guards.



Cassie loved the Power Soccer

MDNSW staff Katie, Chaitali and Gracia conducted a Karma Workshop for the girls which was a huge success, and Young Guns Fishing ran another successful casting session for the campers which included some live yabby fishing – a hit with everyone!

As usual, some of the more mobile campers went fishing on the Brisbane Waters where Steve took out the Biggest Fish Award, and the rest went on a tour of Manly, stopping off at North Head for lunch.



Kamal had his best camp yet!



Bec & Fanny



Michael and the Vege!



Max & Tyran

## Party night!!

By far, the most highly ranked activity on Camp this year was the Party Night which saw Chris take on ACDC, Lena move us with Somewhere Over the Rainbow, Fanny and Dan give an emotional duet, Michael singing Superman, and many other group and individual performances. The Australiana theme saw the Irwins, Vegemite, Dame Edna, Sporting Heroes, indigenous animals and many patriotic fans turn up for the celebrations. What a night it was!! Camp ended with a bout of Laughter Yoga; a fitting end to a most enjoyable Camp.



Samson the convict



Steve and Loretta double the Dames







## Leadership Skills

Special mention to Patrick Nolan who showed superb sportsmanship throughout the Camp, and to Cassie Robson who led by example and inspired others with her participation and leadership skills. Our annual Carers' Awards went to Demi and John, and a big thanks to Ross for his role as Camp Team Leader. Lisa Burns from the Hunter was our wonderful Camp Mum and Jenny (now nicknamed Madge) was a huge support to me personally and ensured all was organised and ran smoothly. Jilly once again supported all campers and administered meds flawlessly and a big thank you to Sarah, Nigel and Helena from the Neuromuscular Clinic for the valuable hands-on roles you played throughout Camp as our Camp Doctors and OT. Finally to the Camp Carers from UWS and Brookvale TAFE... what an amazing team you were and what a brilliant job you did to bring everyone together and create such a warm and vibrant atmosphere. Thanks a heap!!

*We were proud, we were strong,  
we discovered alot about ourselves  
and we shone! Well done team!!*



Blaise receives his Baseball trophy from Peter Debnam



Patrick, Samson and Joe take off!



Leon and Lena



Camp Mama Lisa & Arjuna



Ross and Sally receive an Award for attending all 4 camps so far



The young ones loved their tea party

## The Perfect Team of Volunteers

Check out all your radio control car needs at [www.venom-group.com.au](http://www.venom-group.com.au)  
Major supporters of Muscular Dystrophy NSW.

