

# talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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**Growing Strong**



**MUSCULAR DYSTROPHY**  
NEW SOUTH WALES

Spring has sprung and we are all loving the lighter look and feel to the day, minus the heavy jumpers and freezing cold crawls out of bed. Well it sounds so cliché but I have just realised that the way to know how time flies is to see how quickly children **grow**. My adorable niece Sophie has gone from a roley polley newborn to a young lady with strong personality (where on earth did she get that from?) in the space of just 6 months! Not long now til she will be giving cheek and outsmarting her Aunty at all things Dora, Wiggle and Barbie!



Muscular Dystrophy NSW too is growing. **Growing** in number of staff, programs and members; growing stronger in its capacity to provide services for its

members and developing new and expanded areas of work. Awareness and much needed financial support is also mounting to help with the massive cost of equipment, services and research to assist people with neuro-muscular conditions. What is also growing in strength is in the spirit and tenacity of individuals and families affected by MD.

Throughout this time of growth I hope you can reach out and form strong relationships, learn new things and take up opportunities which will enrich your life. I think Muscular Dystrophy NSW is better equipped than ever to offer these things to its members. What do you think?

In this Spring edition of Talking Point you will find loads of news about the ever **growing** Muscular Dystrophy NSW. There are exciting developments in client services and the fundraising / PR team have been on fire! We showcase a pictorial story on the remarkable Tour Duchenne campaign, and put the spotlight on our friends at Spotless Services.



Member events have been increasing in popularity and we have reports on the 'wheelie fun' HOGs day and activities for carers in country areas. Continuing our series of Access All Areas articles, we have an excellent travel story from our outback explorer Daniel Michel. There is also a medical article on dystrophin research and an invitation to the Muscular Dystrophy NSW medical seminar in October.

Sit back in a sunny spot and enjoy the Spring edition of Talking Point.

Take care

**Carolyn Campbell-McLean**

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## Hello from the President

Dear members

In July I listed many of the achievements that I felt the Association had made in the last 2 years, and I felt we had reached a level which could be a good base for future growth.

Already we are growing from that base once again!

Growth can be good, if its for the right reasons, and when it is at the right time. In our case, we have so much more we can provide for our members, and the level of our service provision is mainly a function of the funds that will enable us to do that, and the direction we chose to go.

We are fortunate that we have people with a clear vision of our members needs driving Muscular Dystrophy NSW, at a board, and executive level, and the results are speaking for themselves.

The important thing about our growth is that it is not for growth sake but it is to increase the benefits we provide for our members. The area with most focus is, as it should be: Client Services.

We now have a dedicated Case Manager; Camp & Event Coordinator, Loretta Downie; and Educator, Liz Bailey, to assist Pene Hodge, Client Services Manager. Georgina is continuing and improving our regional and CALD carers. A new mobility van, to carry several members at once was recently bought as a result of grants from the Shane Warne Foundation and the NSW Government.



On the national front we are hopeful that Muscular Dystrophy Association of Western Australia which recently participated in Muscular Dystrophy Foundation of Australia's successful strategic planning workshop will agree to join Muscular Dystrophy Foundation. Muscular Dystrophy Foundation is forming a critical mass and providing a significant increase in national profile and funds for Muscular Dystrophy in Australia, as it was planned to by the wise individuals at Muscular Dystrophy NSW who were responsible for establishing it in 2005.

Best wishes,

**Rob Ferguson**

President, Muscular Dystrophy New South Wales

## around the office

### Maralyn's Musings

As we come into spring, the growing cycle, new blooms and new shoots are coming up everywhere and so it is with Muscular Dystrophy NSW. A great burst of new energy is brought by the addition of all the new team members. Each brings something different but all have the same desire to



improve the services to our Muscular Dystrophy members and to increase the knowledge which will make a difference to the future of many members.

It is inspiring to see the breadth of knowledge and experience that each of these people bring to Muscular Dystrophy NSW. Each have specialised experience but are blending together like the colours in the rainbow to produce a vibrant team.

It is an exciting time and we all look forward to both our own growth and to enjoying the beauty that nature provides us in this spring season.

**Maralyn McCann**

Office Manager



## Growing Up

As I write this piece I am immersed in the bright lights and energy of Las Vegas. It's no holiday! Following Jerry Lewis around for the week leading up to his Telethon is a blur of interviews, celebrities, production meetings and encouragement to a crew of over 200. Not to mention the numerous conversations about "Jerry's Kids" – the essence and heart of this whole extravaganza.

This iconic event has raised over \$2.5 billion and this year's Telethon is expected to raise another \$60+ million to support people who live with a neuromuscular condition. A crew of over 200 prepare for months leading up to the Telethon, held on Labour Day Weekend every year and running for 21 hours. I think of it as the 'Telethon Juggernaut', such is its complexity, influence and inspiration.

Jerry Lewis and Dean Martin commenced the Telethon in 1955 in New York. It was a modest event with a nominal income for "Jerry's Kids". During 1959 to 1965 there was no Telethon as Jerry Lewis built his movie career. In 1966 Jerry Lewis recommenced the Telethon which has run annually ever since. Over the years the Telethon has GROWN to become a national icon and with it, Muscular Dystrophy one of the best known charities.

In Australia Muscular Dystrophy is one of the least known charities, support for those who live with a neuromuscular condition is inadequate and with Jerry Lewis we are taking our first few steps towards increased support and research for people in Australia who live with a neuromuscular condition. All of this being facilitated under the national body, Muscular Dystrophy Foundation.

When I return to Australia in just a few days I will join the Tour Duchenne bike ride in Brisbane. We will cycle down the coast to Sydney over 10 days, raising much needed funds and awareness for Muscular Dystrophy. To date nearly \$500,000 raised by the 23 cyclists participating this year. This will GROW the profile of Muscular Dystrophy in Australia and importantly invest significant funds in research.

Closer to home here in NSW, new programs are enabling our support to people living with neuromuscular disorders to GROW. Our new Home Support Program and Education Program funded by ADHC (Ageing, Disability and Home Care) have now commenced.

During the short few weeks the Home Support Program has been operating, our new Case Worker has made over 25 home visits and followed up on many issues on behalf of families. In just a couple of weeks our new Education Officer, Liz will join the team. Her role will be to develop materials which can be shared with families and used to train workers in other disability organisations to better understand the needs of people with neuromuscular conditions.

Our Muscular Dystrophy NSW team is GROWING, and now includes Loretta, our new dedicated Event Coordinator. Loretta has prepared a fabulous program of activities and fun for our Camp. Also joining the team is Gracia, our new Finance Assistant who is already lightening the load for Sandra.



With GROWTH come GROWING PAINS! Perhaps you have experienced those. Whilst we aim for excellence, there are times when we don't achieve our own expectations or those of our members. Feedback will help us to better understand your needs and how we may best be responsive and helpful. Drop me a note, let me know what works and what doesn't and I will respond.

This year our Camp theme is "Heroes". We all have our heroes and Jerry Lewis is one of mine. Not so much for his celebrity status, nor his acclaimed film career, but for his compassion and for his generosity. He genuinely loves and cares for people, especially those who live with neuromuscular conditions. This support has enabled many to GROW in confidence, capacity and achievement.

I will be on the plane home tomorrow evening following 21 hours of live national television with Jerry Lewis, telling the story of people who live with neuromuscular conditions. Muscular Dystrophy will again be centre stage here in the USA, millions of ordinary people in this country will GROW as they GIVE, and the many thousands who will benefit from this generosity will also GROW as they RECEIVE. That is true community!

**David Jack**  
CEO

# Wild HOGS 2010

The beautiful roar of 200 Harley Davidson engines was heard well before any of the bikes were seen by the Muscular Dystrophy NSW members waiting at Warragamba Dam last Sunday. 12th September marked the 19th Annual HOGs Day where HOG Chapters from all over NSW come together to put on a wonderful day for Muscular Dystrophy NSW members and their families.

The sun shone brightly and Dangerous Dave wowed the crowd with his incredible feats of daring. Several of our members had an electric wheelchair race, both forwards and backwards! Electric wheelchair wheelies are even better than motorbike wheelies!

The NSW HOGs Chapters put on a lovely BBQ lunch and cake for everyone and it was a treat to sit in the sun and enjoy a BBQ. The day ended with Harley rides for all members, their families and staff. Most of the kids had at least 3 rides and always returned with huge smiles on their faces!

Thank you very much to NSW HOG Chapters, for putting on such a fun day each year, and for your generous donations to enable Muscular Dystrophy NSW to support people with neuromuscular conditions. Your kindness is greatly appreciated and we can't wait to see what happens next year!



## Client Services are **Growing**

I have been giving some thought to the theme of this spring issue of Talking Point 'Growth'. It reminds me of a saying I have often used which is 'Good things take time and even better things take longer'. There has been an incredible amount of growth in the Client Services team in the past three months with the appointment of a Case Worker, Loretta our Event Coordinator and Liz our Educator. Our aim as a team has been to significantly grow the support we can offer to our members with a neuromuscular condition and their families and carers. Good things have happened, great things are starting to happen and with time these will be even better. If, in any way, we can provide assistance to you or your family, please contact Georgina or myself on 02 9809 2111.

September is always the busiest month for our team. While writing this we are organising another fantastic Camp and Adult Weekend Retreat, H.O.G.S day, Neuromuscular Medical Seminar, Melbourne Cup Day and the many regional family events and seminars Georgina so ably organises. Please make the most of attending some or as many of these activities as possible. They are always loads of fun, a time to meet staff, other members and an opportunity to gain further information. If there is an activity or event you would like to see happen please let us know and if possible we will try to include it in our annual calendar of events. We value your ideas, input and feedback.

I have been encouraged recently when looking at correspondence that has come across my desk to see that the voice of our members' is being heard. We often ask for feedback, for a questionnaire to be completed and your thoughts when completing a government submission. Regularly David Jack our CEO meets with government ministers, state officials and heads of government departments and uses members' feedback and experiences to advocate on our behalf.

Two such documents I have recently received where we asked for member comments and participation in were:

### **Inquiry into provision of education to students with a disability or special needs.**

400 of our members were surveyed and 73 responded in writing. The survey results identified a consistent theme that the provision of education to persons with a disability is inequitable; sporadically available; inadequately funded, and difficult to obtain and negotiate. I am pleased to advise that as a result of ours and other disability organisations submissions, 31 recommendations are now with the Government for their consideration. For those interested a summary copy of the recommendations is available through the website [www.parliament.nsw.gov.au/gpsc2](http://www.parliament.nsw.gov.au/gpsc2).

### **NSW Health NGO (Non-Governmental Organisation) Review.**

In December 2008 NSW Health, who fund our carer and regional program, along with a number of NGO representatives agreed to undertake a review of the NSW Health NGO program. In July of this year a recommendations report was completed and the outcomes sought from this review were:

- Where possible, reduce red tape and improve governance, transparency, efficiency and effectiveness of the NSW Health NGO Program.
- NSW Health and the NGO Sector work together to ensure that the health funded NGO services provide value for money services and are broadly complementary with NSW Health priorities.
- NSW Health and the NGO Sector to strengthen partnerships to improve the health and planning and health service delivery across all NSW health services

If you are ever in the Meadowbank area of Sydney we would love you to drop in and visit our office and meet the team. With some notice we can even organise coffee and cake!

**Pene Hodge**  
Client Service Manager



*Just like a good old country song... I've been On the Road Again... I've been everywhere man! Broken Hill – Kiama – Orange – Newcastle – Bathurst – Parkes and Figtree... It's been an incredibly busy time for me over the past 3 months. I have travelled to the farthest parts of our beautiful state and covered over 2500 km by car. Here is what I've been up to...*

My regional trip to the Far West was my first. I arrived in Broken Hill on June 24 after a long 5 hour flight with a stopover in Dubbo. During my visit to Broken Hill I had the opportunity to meet with the Carers NSW team, Home and Community services staff and the Physiotherapist at the Broken Hill Hospital to discuss Muscular Dystrophy NSW services and raise awareness of neuromuscular disorders. I had the opportunity to also meet one of our Muscular Dystrophy NSW members living in the surrounding regions. Overall, I felt it was a very productive trip, though the flight at times seemed never-ending.

On my next regional visit I found myself in the South Coast of NSW. A family night out at the Hog's Breath Cafe followed by a night



Patricia Kasengele and Georgina Christofis (Transition Care Program Coordinator) was a guest speaker on the Carers Day in Orange

out at the movies to see Step up 3 was popular with members, with over 25 clients and carers attending this social event. During this visit I had an opportunity to meet with 5 families individually through the Home Support Program. We have had a very positive response to our home support program. If you are interested in meeting with me please call me in the Muscular Dystrophy NSW office on 9809 2111.

My regional journey in late August to Bathurst, Parkes and Orange clocked over 1000km on my odometer. It was wonderful to meet families in some really rural and remote parts of the Central West. It was great to

work with the Greater West Area Health Service, Australasian Genetic Support Association and the Spastic Centre in running our second annual Carers day at the Orange Ex-Services Club on Saturday 28th August which was a great success.

My final regional trip this quarter was to Newcastle. We had the pleasure of having guest speakers from Samaritans and Nortcott Disability Services talk about their family support programs - I know many of you benefited greatly from the information that was shared. If you could not attend this meeting and are interested in finding out what services are available for you, contact me in the office. I have a pile of information to send out to you.

We have some amazing events planned for you over the next few months. I hope you can attend our Melbourne Cup event in Sydney on Tuesday 2nd November and the fabulous Christmas events scheduled in the South Coast on November 30th or Hunter Valley Christmas Party on Saturday 4th December, 2010.

Kind Regards,

**Georgina Christofis**  
Carers Program Coordinator



Carer Rhonda Murray shows off her manicure to MD member Anne Patterson at the Ladies Pamper Day in August.





# Tour Duchenne

On Father's Day 2006, Julian and Sharyn Thompson heard the words that hundreds of other families have heard and cried over all across Australia, 'your son has Duchenne Muscular Dystrophy'.

When Duchenne chose the Thompsons, it chose poorly because they are devoting their lives to finding a cure for their son. This year Muscular Dystrophy Foundation teamed up with the Thompsons and ran the Tour Duchenne.

23 riders cycled from Brisbane to Sydney gaining extensive media coverage of the cause wherever they went. Each rider pledged to raise at least \$25,000 and by the time the last of the money is counted, close to \$500,000 will have been raised.

It was an incredible effort for each of the riders to reach their target. Some were fortunate to gain corporate sponsorships for a portion



Julian Thompson and Patrick Thompson.



Newcastle welcome for the riders.



David Jack and Cassie Robson.



Scott Fotheringham and Tom Williams.



# Cycles to Victory

of the total and some riders held large and small events to gain the amount they needed. All riders shared one thing in common, very supportive friends and family who personally donated to their total.

Throughout the ride, local radio stations, newspapers and TV stations covered the ride, giving a public voice to the Tour. The Tour was supported by well known figures like Mike Goldman, Tom Williams and Tony Abbott. This support increased the level of media attention, especially at the end of the ride when Tony Abbott crossed the line in front of four TV cameras.

There has been a lot of support from members of the muscular dystrophy community and our many supporters and we would like to say a very big thank you!



Glen Condie.



The riders at Greenmount Beach.



Steve Mater, Nathan O'Connell and David Jack.



Julian Thompson, David Jack and Tony Abbott.



The riders crossing the finish line at Darling Harbour.



# Spotless - A Friend Indeed

In early 2008, with the then CEO of Muscular Dystrophy NSW, I asked an assistant in a café at Sydney Domestic Airport whether it may be possible to place a collection box for Muscular Dystrophy NSW.

The response was – I'll pass this on to my manager and he will be in touch.

As luck would have it, the café was operated by Spotless Services Australia Limited.



Minakshi Santoshi and Elizabeth Zdravkovska, welcome customers to Velluto.

Even more fortunately, the manager, Duane Houston, was (and still is) one of the nicest, thoughtful and empathetic people I have met. He cared - and said yes! Better still, he told us "we have 6 outlets at the T1 International airport

and several at the T2 Domestic Airport".

Now some 2 ½ years later we have a very special relationship with the managerial and café staff at both terminals after making around 500 box collections from around 70 visits.

Bronagh Schulties and Caterina O'Reilly at the International Terminal (T1) have taken us under their wing as have their staff, who make sure our collection boxes are in front of the till, and take pride in the donations which they encourage from patrons.

Caterina explains that "the staff have responded very warmly to the Muscular Dystrophy Association as they learnt to understand the work the charity does for those it cares for." Particularly "when they realise the importance of a wheelchair and a hoist to a child who can no longer support themselves." (The funds raised from the Spotless Retail Outlets at Sydney Airport annually would fund 3 of these highly specified electric wheelchairs.)

Andre Slootweg at the Domestic Terminal (T2) took over from Duane Houston at T1, and encouraged staff support for MD. When he moved



Andre Slootweg, Operations Manager at Sydney Domestic Airport, has plenty to smile about with Rosie Loprot and Uttam Sitaula, at Sumo Salad.

to manage T2, he invited Muscular Dystrophy NSW to collect at Spotless' 6 outlets at that terminal. Andre has been a wonderful supporter and Mick Watkins from Muscular Dystrophy NSW developed a special relationship with Andre and his staff over a year or so, retiring from this role recently due to ill health.

Laura Pisanau at MisterBianco at T2 smiles broadly as she explains:-



Laura Pisanau – keeps the toast hot at Misterbianco

"When customers ask: can I leave a tip? I always tell them to support our charity, Muscular Dystrophy Association, instead.

Altogether we have 14 collection boxes at the 2 terminals which raise \$40,000 - \$50,000 each year. This has been a wonderfully reliable source of income, and to us a very pleasing and rewarding relationship.

## Rob Ferguson

President, Muscular Dystrophy New South Wales



Caterina O'Reilly and Bronagh Schulties Operations Manager at Sydney International Airport enjoying a well earned break at Brumby's

## Bequests are Invaluable

Because Muscular Dystrophy NSW has never had the resources to run a proper bequest program, it has instead relied on the generosity of members, and associated families to assist us with bequests, which have occurred sporadically over the years.

In the last year we have been most fortunate to receive two major bequests which we have invested to provide a financial income stream and medium-term security.

For us it would be a perfect world if we could concentrate all our resources on the considerable support our members need from us, and leave the fundraising to someone else. But it isn't a perfect world and despite the wonderful individual, corporate and NSW Government support we receive, it is very difficult to provide regular predictable income.

If we can continue to receive these important bequests we can invest for the future and our service provision becomes a whole lot better and more sustainable. We can progress with confidence.

Consideration of Muscular Dystrophy NSW in wills or estates will greatly enhance the services we are able to provide.

From a financial perspective we account for bequest receipts over a five year period. Effectively the two bequests recently received will contribute 30 per cent of our budget for each of the next five years – a great base to provide services and launch new programs.

We welcome the opportunity to discuss bequest or estate matters with our members, and supporters, or their advisers.

In the first instance please contact David Jack, CEO via our Meadowbank office on 9809 2111.

Please consider providing a lasting gift and brighter future.

**Graeme Troy**  
Treasurer

## around the office

### Accounting Update

Spring is just around the corner, and I am starting to notice the change in season...along the same lines there has been changes in the accounting team at Muscular Dystrophy NSW. We have had a move, a new member has started and a main project is on the way.

Firstly, on behalf of Muscular Dystrophy NSW I would like to welcome the newest member to the team, Gracia Selina. Gracia will be working in the accounts department as a data entry and administration assistant. She will be processing memberships, renewals, donations and performing other administrative and accounting related tasks. Gracia has recently completed a Masters of Accounting at Curtin University.

Muscular Dystrophy NSW continues to grow significantly in size over the last six months and as a result there have been extra demands and responsibilities placed on the accounting department.

Recently we have moved rooms within the office in Meadowbank to a larger space. I believe this space will ensure the accounting function has room to grow and best manage the increase in activity that is occurring at Muscular Dystrophy NSW.

Over the next month the main focus for the accounting department at Muscular Dystrophy Association of NSW will be the 2009–10 audit, ensuring all is ready from a financial perspective for the Muscular Dystrophy Association of NSW Annual General Meeting.

**Sandra Stavrou**  
Finance Manager



## A Trip to the Sunburnt Centre

During the April school holidays, my family and I decided to take a trip to Central Australia primarily to see the Olga's and Uluru but also Alice Springs and the many attractions in and around the area. We decided to fly due to that we only had a week and it would almost take a week to drive there! We flew with Qantas as they were the cheapest at the time and are known to be a generally good airline. Beverages and snacks were served on board and the crew were very kind and happy to help in any way they could.

The accessibility to the plane at Sydney airport was obviously very good as it is one of the largest airports in the country, however, on the other hand, Uluru local airport was kind of awkward in the sense that they did not have a tunnel to the plane, instead, they had a set of stairs to get off. Now common sense obviously tells you a wheelchair can't get down a flight of stairs. Luckily they had an odd looking contraption which acted as a lift that you would simply have your aisle chair rolled onto and you, accompanied by an airport staff member, would be lowered by a forklift.

Now another twist arises, how to get to your accommodation. Because there is only one place to stay at Uluru, the site sends out someone to pick you up from the airport. They will most often bring an 8 seater Toyota Tarago. This would be okay if you only have a manual

wheelchair and can walk enough to be able to climb into a seat with assistance available, but, I, and many others, would use an electric wheelchair and would not be able to walk enough to climb into a seat. So what happened in our case was that the man they sent out had to go back to the site and send out another man who took a minibus which could take an electric wheelchair.

Yulara, which is the name of the site, is a large place which contains apartments, cabins, a large sort of community square nearby which has an IGA, some touristy sort gift shops and a few coffee places, and a deluxe area which contains VERY expensive cabins and sort of the same as the other place, just more expensive! Oh! Did I forget the

pool. Nothing too special really, just an ordinary pool with some beach chairs around it, however, the odd mud wasp occasionally freaked me out even though I was assured they were not interested in me!

The cabins we stayed in were nice and were very easy to access. The pool however is not. Although you can get down to the waterside, you cannot go much further than that unless you are able to shift yourself out of your chair and into the water unassisted.

On our first day we decided to take the walk around Uluru. Now, being quite frank, I honestly don't see how you would be able to get to Uluru if you can't drive a car, Unless you can possibly catch a taxi or maybe a bus. When you are there you may be able to get around the rock with

your wheelchair, however, I believe it is best to do it in an off-road wheelchair. The track around Uluru is 10 km in circumference and takes around three hours to walk if you are just cruising along. You can probably cut the time in half if you were really motoring.

The Trail is generally quite kind in the sense that it is not nearly as rocky as many of the other trails we did. I used a



Uluru.

Hippocampe off-road wheelchair which needs to be pushed by a companion as it is not electric. It is very lightweight compared to other wheelchairs and handles rough surfaces with ease. I would recommend it very highly for this trip even though the best of the Olga's and the majority of Standley Chasm was too much for it.

The Mala Trail, which is the name of the track around Uluru, is quite tedious and although Uluru is spectacular from whatever angle you look at it, looking at it for three hours can become quite boring, so just consider whether looking at a rock for three hours is worth it or not.

On our second day we decided to go to the Olga's, or Kata-Tjuta as the local aboriginals call it. The spectacular Valley of the Winds walk is sadly very inaccessible as you must climb over rocks to even get to the first lookout. However, my very determined mum, her not so determined partner, my



Kata Tjuta, Valley of the Winds lookout.

two brothers who couldn't really care less and I, made it to the first lookout through not much blood, a lot of sweat and nearly a few tears. Although the view was amazing, it was definitely not worth the struggle of getting to it.

Our days at Yulara had come to an end. It was time to take the long and occasionally treacherous route to Alice Springs. We decided to drop in on Kings Canyon which is a large and very beautiful....umm...Canyon (obviously). Again, the Trail into Kings Canyon was not particularly wheelchair friendly and we could only get part the way in. My Mum and brother Ben went the rest of the way in and took a few photos to show the rest of us.

The next part of the journey was probably the worst, no, second worst part of the holiday. The 200km long off-road loop which acted as a connection between Kings Canyon and the final straight through to Alice Springs. It was horribly rough in some places and by the end of it I could barely move my neck because all the muscles in it had been loosened so much that they were hardly working any more, I even had trouble eating for the next few days, so, a tip from me, it is definitely a no-go.



Alice Spring, where Alice Springs was named after.

Alice Springs is a rather small town which has a CBD (ha-ha, it's more like the main strip of a suburb), a few apartments and hotels, and many

historical attractions. We stayed in the Crowne Plaza hotel which was very good accommodation that didn't cost you the earth. It had a main foyer which contained a reception and a couple of restaurants, which, might I say, did cost more than they were worth. It also had nice rooms which had Foxtel for free and comfortable beds.

While we were at Alice Springs, we visited the telegraph station which was meant to be the birthplace of Alice Springs. It was pretty boring and we found the spring in the river behind it named Alice (which is where the name Alice Springs comes from) much more exciting. We also visited the Royal flying Doctor service main base and had a guided tour through the building.

Then, we finally decided to visit some more of the spectacular natural wonders around the area. After some torrential rain, the Todd River began to flow. The locals said it only happens four times in a lifetime, so I think we were pretty privileged to witness that. Simpsons Gap, which was my favourite attraction, was awesome. It looked like someone had taken a big cut out of the mountain range and filled it with water. The gap in the mountains was spectacular on its own but the waterhole in it put it in a whole different league. The accessibility to this one was probably the best overall, aside from Uluru,

and you could witness almost the full wonder of it.

On the other hand Standley Chasm was completely inaccessible and Brett



Simpsons Gap.

(who is my mum's partner) and I had to stay at the little coffee shop and wait for the rest of the troops to return. It is probably better just to look at some pictures of it rather than go there yourself. This rounded off our stay at Alice Springs which means we had to return home. It was a time of mixed emotions as we sort of didn't want to leave, but we also wanted to be back home.

Alice Springs airport did have a tunnel and as we mounted the plane, in pouring rain, we were really hoping it wasn't going to be weather like that back in Sydney. The Qantas flight back home was as good as the one going to Ayer's Rock local airport, and we were pleased to see the weather had cleared back home. As we settled in back home we thought of what a great time we had, and what an interesting time we had. Let's just say there was never a dull moment during our stay. I highly recommend the trip if you're looking for a thrill, or, if you are a daredevil (especially in a wheelchair). It is definitely not cut out for the more fragile personalities out there. I give it an 8/10.

**Daniel Michel**



## Connect with others who understand Livewire.org.au

Livewire.org.au, an initiative of the Starlight Children's Foundation, provides safe and supportive online communities for families affected by serious illness, chronic health condition or disability.

Join a Livewire community today to connect, share experiences and gain peer support from others who understand you, in a safe and accepting environment.

Each Livewire community features social networking tools including chat rooms, blogs, forums and private messages. Users have their own profile and can make friends.

There are also entertaining and helpful articles, music, online games, videos and competitions which run every week.



*Brent, he is one of the Livewire members who has muscular dystrophy.*



- Livewire Members is for young people aged over 10 and under 21 living with a serious illness, chronic health condition or disability. Join Livewire Members today!

<http://members.livewire.org.au>

- Livewire Siblings is for young people aged over 10 and under 21 who have a sibling or parent living with a serious illness, chronic health condition or disability. Join Livewire Siblings today!

<http://siblings.livewire.org.au>

- Livewire Parents is for parents & carers of someone living with a serious illness, chronic health condition or disability. Join Livewire Parents today!

<http://parents.livewire.org.au>

To join a Livewire community or for more information please visit [www.livewire.org.au](http://www.livewire.org.au) or contact the Livewire Support Team on (02) 8425 5971

## letters

### Do you have Limb-Girdle MD?

Hi my name is Jim Loughland,

I live on my own, with great support from my family and friends, but I suffer from Muscular Dystrophy, I have Limb Girdle Type 2a. Just wanting to know if there is any males or females living in the Sydney Metro area, so we could catch up for a chat, to talk about general being and how you go about your daily lives.

I am 44yrs old and not in a wheelchair, but there seems to be no information from doctors to tell me how it will be in the future, as it seems that if you are not in a wheelchair that you are OK.

Looking forward to catching up with anyone with Limb Girdle Type 2a.

All the best,

**Jim Loughland.**

*For Jims' contact details please telephone Maralyn at the Muscular Dystrophy NSW office on 9809 2111*

Dear Carolyn

Congratulations on the 75th Ed.

Full of everything for everyone. We always enjoy TP but this issue was really something.

Give our best wishes to Mum and Dad.

Love

**Jacqueline and Graeme**

## Introducing...Larrikin Loretta

Hi everyone!

I couldn't believe it when I found out that Muscular Dystrophy NSW was looking for an Events Coordinator in their Client Services department! It was a job of a lifetime for me, having a great love of both the events industry and for providing unique opportunities for people with disabilities.

After meeting all the staff here though, I knew the working conditions would be tough...could I retrain myself to be a little quieter; could I hide my "Tidy-Challenged" disorder until after the probation period; would I have time to study "Kiwi" after work hours to enable me to one day decipher what Pene and Rebecca were saying to me, and more importantly, could I work with these Kiwis at all considering the current Bledisloe situation? I needn't have worried – I learned very quickly that everyone at Muscular Dystrophy NSW was so adaptable, that they simply came up with ways of coping with me!

On a serious note though, one thing is very apparent here at Muscular Dystrophy NSW. There is a spirit here unlike any other I've ever seen in any workplace before.

Each staff member drops everything to support the other as needed; everyone has such a positive attitude towards their role in making Muscular Dystrophy NSW the best it can be, and any new ideas are embraced with a "let's-work-out-ways-of-making-this-happen" approach, instead of putting it all too quickly in the "too hard" basket. It is a working environment very few get to experience, and I'm so very grateful to be a part of it.

I truly look forward to meeting and chatting to as many members as I can in my first year at Muscular Dystrophy NSW, to discover your unique spirit which I hope will help me create some fantastic opportunities for you – some of which we may never have even thought possible. Now that's the job for me!!

**Loretta "Ernie" Downie**



## poem

### Nicole Giles 10-3-87 to 10-10-07

This touching poem was written by one of our dear members Nicole Giles who is sadly no longer with us. Nicole's mother Sharon reflects on her special girl:

Nicole came to us in a whirl wind and in a hurry and even then she had a lot to say. As we hoped and dreamed of what she would become, this precious little girl so perfect, so cute. Little did we know what was about to unfold. Her body would grow weak and her mind would grow strong, her artistic abilities would live on.

Her strength and her character would stand above all the rest and she would adjust her goals to meet the challenges ahead. Right to the end she would insist on being heard.

Through her poetry she expressed her joys and her hurt, her frustrations and her loss with all her honesty, with all she could muster she left us a legacy to embrace. To comfort, to teach, to allow all to know all that you feel, but are afraid to be told.

*By Sharon Robson, Nicole's Mother*



# What is exon skipping and how does it work?

In order to explain the concept of exon skipping, it is first necessary to explain how genes work and how mutations in the dystrophin gene can cause both Duchenne and Becker muscular dystrophy.

## What are genes?

DNA is an extremely long molecule which contains the instructions to create and maintain our bodies. A gene is a section of DNA that contains the instructions for the production of one specific protein. Proteins are essential parts of cells and play a role in every process occurring within the cell, as well as having structural or mechanical functions which help maintain the cells' shape. It is estimated that we have about 30,000 different genes.

## What are exons?

Genes are divided into sections called exons and introns. Exons are the sections of DNA that code for the protein and they are interspersed with introns which are also sometimes called 'junk DNA'. The introns are cut out and discarded in the process of protein production, to leave just the exons. The dystrophin gene is our largest gene- it has 79 exons which are joined together like the pieces of a puzzle.

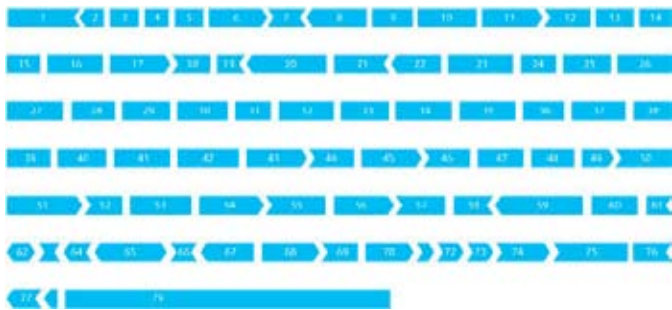


Diagram of the 79 exons of the dystrophin gene which fit together like the pieces of a jigsaw puzzle.

## What happens in Becker muscular dystrophy?

Let's zoom in on exons 48 to 54 to look at this a bit more closely:



In Becker muscular dystrophy an exon is deleted, for example exon number 53 in the diagram:



Although a part of the gene is missing, exon 52 can join up with exon 54, and the puzzle can be completed to the end of the gene:



## What impact does a Becker mutation have on the dystrophin protein?

The dystrophin protein normally sits in the membrane that surrounds muscle fibres like a skin, and protects the membrane from damage during muscle contraction. Without dystrophin the muscle fibre membranes become damaged and eventually the muscle fibres die.

Dystrophin is a very large protein with a section in the middle consisting of lots of repeated segments (in green below) and it is known that the protein can still work to some extent if some of these repeated segments are missing. Individuals with Becker muscular dystrophy have some of these repeated segments missing and have relatively mild symptoms- often being able to still walk into their 40s and 50s.



Diagram of the dystrophin protein

A man has even been known to be still walking at 61 years of age, despite having a deletion of 46% of the dystrophin gene!



Illustration of the dystrophin protein in Becker muscular dystrophy

## What happens in Duchenne muscular dystrophy?

In Duchenne muscular dystrophy an exon, or exons are deleted which interfere with the rest of the gene being pieced together. In our example, exon 50 illustrates



this:



Exon 49 can not join up with exon 51, which prevents the rest of the exons being assembled. For the dystrophin protein to work it must have both ends of the protein. Therefore, this mutation results in a completely non-functional dystrophin protein and the severe symptoms of Duchenne muscular dystrophy.

## How can exon skipping help?

As the name suggests, the principle of exon skipping is to encourage the cellular machinery to 'skip over' an exon. Small pieces of DNA called antisense oligonucleotides (AOs) or 'molecular patches' are used to mask the exon that you want to skip, so that it is ignored during protein production. In our example, if we use a 'molecular patch' designed to mask exon 51:





Exon 49 can now join up to exon 52 and continue to make the rest of the protein, with exons 50 and 51 missing in the middle:



Therefore, exon skipping may be able to reduce the symptoms of Duchenne muscular dystrophy, to those more like Becker muscular dystrophy.

### Does this really work?

So far scientists have shown this technique to be effective in a mouse model of Duchenne muscular dystrophy (the mdx mouse) and in human Duchenne muscular dystrophy muscle cells grown in the laboratory.

A phase 1 clinical trial involving nine boys with Duchenne muscular dystrophy was completed in December 2008. In this trial a 'molecular patch' (called AVI-4658) was injected into a muscle in the foot. This resulted in dystrophin production in this muscle and no serious side-effects were observed. This trial was intended to prove the principle of the technique and wasn't expected to show any improvement in symptoms since only one small muscle was injected.

Preliminary results from the next phase of the trial were released in June 2010. In this trial the molecular patch was injected into the blood stream of boys with Duchenne. At the higher doses dystrophin production was seen in muscle biopsies taken at the end of the trial. Read more about these preliminary results.

### Is there a clinical trial?

Preliminary results from the UK exon skipping trial which delivered the molecular patch to the whole body via the bloodstream were encouraging but we are still waiting for news of the full results. Indications are that although dystrophin production was seen in the muscles of the boys receiving the higher doses, the response was highly variable from boy to boy, with some only producing very small amounts of dystrophin.

AVI Biopharma now plans to test higher doses to try to gain a consistently strong response to the molecular patch. They are planning to conduct this trial in the US.

The Dutch pharmaceutical company Prosensa is testing a slightly different chemical formulation of molecular patch in Europe and in partnership with GSK in the US.

The challenge with all of these trials is to produce enough dystrophin in as many muscles as possible (including the heart) to prolong and improve the quality of life for boys with Duchenne muscular dystrophy.

### Will it work for everyone with Duchenne muscular dystrophy?

It is thought that skipping one or two exons would be able to treat around 83% of the genetic errors causing Duchenne muscular dystrophy.

### Will the same 'molecular patch' work for everyone?

No, the dystrophin gene is very large and the genetic errors associated with Duchenne muscular dystrophy occur in different places along this gene. There are however some common areas for mutations and initially 'molecular patches' will be made for these. The clinical trials are starting with exon 51 which would be applicable for around 13% of boys. Once the technology has been shown to be effective for a particular error it will be possible to design other 'patches'.

### Are 'molecular patches' a cure?

Scientists hope that this type of therapy will halt or even reverse the symptoms of Duchenne muscular dystrophy so that the symptoms are more like those of boys with Becker muscular dystrophy. It will not be a cure because if proven to be effective, this treatment would need to be repeated regularly- how often will become apparent during clinical trials.

*Printed with acknowledgement to Muscular Dystrophy Campaign, UK*

## NATIONAL DISABILITY INSURANCE SCHEME

A national case is being developed to make significant improvements in the way people with a disability living in Australia receive an appropriate level of care and support. Called the **National Disability Insurance Scheme (NDIS)**, this scheme is being promoted by National Disability Services as the model that will transform the disability sector.

If you would like to know more and would like to have your say in how this may work, the Productivity Commission is calling for feedback - Productivity Commission. [www.pc.gov.au/projects/inquiry/disability-support/make-submission](http://www.pc.gov.au/projects/inquiry/disability-support/make-submission)

Please visit the links below to find out more about the **NDIS** or visit the **NDIS website**. [www.ndis.org.au](http://www.ndis.org.au)

### NDIS - Summary.

[www.sunnyfield.org.au/attachments/db/su2/266.pdf](http://www.sunnyfield.org.au/attachments/db/su2/266.pdf)

### NDIS - Ten Things You Need to Know.

[www.sunnyfield.org.au/attachments/db/su2/269.pdf](http://www.sunnyfield.org.au/attachments/db/su2/269.pdf)

### Productivity Commission - Key Questions.

[www.sunnyfield.org.au/attachments/db/su2/267.pdf](http://www.sunnyfield.org.au/attachments/db/su2/267.pdf)

### Productivity Commission - Issues Paper.

[www.sunnyfield.org.au/attachments/db/su2/268.pdf](http://www.sunnyfield.org.au/attachments/db/su2/268.pdf)



# Muscular Dystrophy NSW Seminar

## *Research Update*

1-4pm

Shepherds Bay Community Centre, 3a Bay Drive, Meadowbank

Cost free

**23 October 2010**

### **Program**

- 1.00 - 1.30pm** Registration
- 1.30 - 1.40pm** Welcome
- 1.40 - 1.50pm** Brief overview of the XII International Congress on Neuromuscular Diseases, Naples, Italy 17-22/7/10  
*Dr Heather Johnston*
- 1.50 - 2.30pm** More precise diagnosis in the Neuromuscular disorders: some new and some 'old' investigations  
*Dr David Mowat and Susan Brammah*
- 2.30 - 3.00pm** Refreshments
- 3.00 - 3.20pm** Genetic approaches to treatment for Duchenne & Becker muscular dystrophy  
*Prof. Kathryn North*
- 3.20 - 3.40pm** Better understanding spinal muscular atrophy and potential treatments  
*Dr Heather Johnston*
- 3.40 - 4.00pm** What's new in fascioscapulohumeral and myotonic muscular dystrophy  
*A/Prof. Alastair Corbett*

**RSVP to [info@mdnsw.org.au](mailto:info@mdnsw.org.au) or by calling 02 9809 2111  
by Monday the 18th of October**

## Sailing on the **young endeavour**

On the 24th September 2010, some of Muscular Dystrophy NSW members had the unique opportunity to go on a half day sail on the Young Endeavour.

Our members, most of them carers and parents enjoyed the sun, lots of yummy food and drink while taking in some of Sydney's most gorgeous views. Don't fret if you missed out on this opportunity for this year. Muscular Dystrophy NSW will have another opportunity next year to go sailing again.



## Quality of life and sexuality **Research**

Research is being undertaken by a member of the Muscular Dystrophy Association of South Australia, Shane O'Dea, in association with the University of Sydney. If you are over 18 years and have a neuromuscular disorder you can participate.

The research is seeking to identify **quality of life** issues affecting people with muscular dystrophy and other neuromuscular disorders, especially (a) the impact of contact with medical personnel, (b) if muscular dystrophy affects a person's sense of well-being, or (c) if muscular dystrophy influences a person's intimate relationships and sexuality.

Muscular Dystrophy NSW is aware that there is very little research around the world concerning people with a neuromuscular disorder and their day to day lives. However, this research will help to alter that to some degree.

The research is anonymous and has been fully approved by the Human Research Ethics Committee of the University of Sydney.

We encourage you to support this research by completing the online survey at:

[www.nmdsurvey.com](http://www.nmdsurvey.com)

## **Muscular Dystrophy NSW** – Specialised Case Management

Muscular Dystrophy NSW is thrilled to announce our new Case Management Service is now up and running. Generously funded through Ageing Disability & Home Care and available throughout the Sydney metro area and regional and rural NSW, our case worker is able to provide you with specialised short term case management that is based on your individual, goal based outcomes.

We understand that many of our members are not certain about where to go to for more information or what they should do if they have a concern about their own, or their child's needs. Similarly, we appreciate that many of our members can often find the process of finding a service that best meets their needs extremely overwhelming.

Our Case Management service enables our members to access services that they need to improve their quality of life. We focus on practical assistance, emotional support, and providing opportunities to participate in the wider muscular dystrophy community, by offering a brokerage and referral service at no cost to our members.

If this is a service that you think would be beneficial to you or anyone in your family please call our Case Worker on 98092111 to arrange a home visit at time most convenient to you.



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**THE NEUROMUSCULAR CLINICS**

**CHILDREN'S CLINICS**

Sydney Children's Hospital, Randwick  
Neuromuscular Clinic  
Appointments & Enquiries 9382 1845

Sydney Children's Hospital  
Outreach Clinics are held at  
Canberra Hospital, Canberra  
John Hunter Hospital, Newcastle  
Goonellabah Clinic, Lismore  
Enquiries through Sydney on 9382 1845

The Children's Hospital at Westmead  
Neuromuscular Management Clinic  
9845 1904

**ADULT CLINICS**

Concord Hospital Neuromuscular Clinic  
9767 6864

Prince of Wales Hospital, Randwick  
Nerve and Muscle Clinic  
9382 0722

Adult Genetics Clinic, Westmead Hospital  
9845 3273

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

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

name \_\_\_\_\_

address \_\_\_\_\_

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I enclose my Cheque/Money Order made payable to Muscular Dystrophy Association of NSW for \$ \_\_\_\_\_, or

Please debit my card:  once only  every month **amount \$** \_\_\_\_\_ card type:  Visa  Mastercard

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**Thank you.** All gifts of \$2 or above are tax-deductible.

