

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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in this issue: **First Ever Camp**



md

muscular dystrophy
new south wales

Festive Greetings to all our Readers

Our CEO David's sentiments this issue are so true and have touched a raw nerve in me - its definitely about the **quality of your life** and not necessarily about the quantity of the time we are given. In this edition we focus on what everyone should be planning this time of year – **TIMEOUT!** After googling this word, I found that timeout is a "form of respite, a break from doing something such as work" not only one of my favourite chocolate treats!

In November I took a wonderful two weeks off work to spend precious time with my sister who was here from London – with an engagement party, a baby shower and family wedding it was family time, special time - time out! Since then I have been reflecting on how lucky I am to have so much to **celebrate** in my life, and despite the busyness and overwhelming amount of activities at this time of year, it is so important to put energy into those special relationships.

Another set of **relationships** I am thankful for are my MD family. It is so reassuring to know there are other people that experience similar things during this journey, the highs and the lows; the frustration of battling bureaucracy, the TLC of a giving support worker; the satisfaction of overcoming obstacles and the sadness in losing friends. Remember that we are not alone, we have each other, we have the **support** of our MD friends, the Association, our caring professionals and we have that resilience, that inner strength that builds inside us, in living with neuro-muscular disability.

As we say farewell to 2009 this issue of Talking Point we feature one of the highlights of the Association's achievements this year, the first MDNSW camp at Narrabeen. We hear stories from campers and carers about their adventures and there are lots of gorgeous photos of our youngsters.

Member Joanne Hutchins shares her travels in the Winter Olympic country of Canada, and Justin Reid talks about his pathway to his counselling practice. There is lots of information on upcoming MD activities and we thank Professor Kathryn North for her article on the Institute from Neuromuscular Research. We are seeking contributions for Talking Point in 2010 from members, families and professionals – I hope to hear from you soon.

Wishing you all a safe and enjoyable festive season and lots of fabulous timeout! All the best for a healthy and happy 2010!

Kind wishes

Carolyn Campbell-McLean

All contributions can be sent to The Editor, PO Box 1365 Meadowbank NSW 2144 email: cazza74@iinet.net.au tel: 9684 6443

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Front Cover: MD members Michael Reid and Scott Fotheringham with Camp Carers Samuel and "the two ravis"; ravi haaken and ravi tiwari.



Hello from the President

First, I would like to wish all members, donors, and supporters a very happy festive season. I thank you for your participation in the important work we are doing, and look forward to doing it better again next year.

The October camp was a huge milestone in the evolution of our service provision, and gathering from anecdotes, and chats with members, carers and family, I am sure it was most successful – and particularly so for our first. I believe it was an experience of a lifetime for most of our members who came along. They had fun, made friends, and developed some relationships that I'm sure will be of significant support to them in years to come.

The carers that I met, were enthusiastic, loving it, and the best test of all - keen to do it again next year! Thirty nine attendees was an extremely good response, and I'm sure that next year we will have so many more applicants. Renee, with the full support of the whole team in the office, obviously did an outstanding organisational job. Congratulations!

The success of the services we provide can be best judged from their popularity to members. It is very heartening to see a very marked increase in new memberships of MDNSW, and an even greater participation rate in a variety of our services and activities.



I look forward to 2010 with the confidence that we are heading in the right direction, with the right people, and with an improving financial position.

Best wishes to you all.

Rob Ferguson

President, Muscular Dystrophy New South Wales

The NSW Government will commence a \$130 Medical energy rebate in January 2010 that you may be eligible for.....MDNSW members and carers should check out the following website to see if you are eligible:



<http://www.industry.nsw.gov.au/energy/customers/rebates/medical-energy-rebate-questions>

What is the Medical Energy Rebate?

The Medical Energy Rebate is for eligible customers who have an inability to self-regulate body temperature when exposed to extremes (hot or cold) of environmental temperatures.

It is associated with certain medical conditions such as Parkinson's disease and multiple sclerosis.

How much is the Medical Energy Rebate?

A flat rebate amount of \$130 per year will be paid to all eligible customers from 1 January 2010.

The Rebate is indexed to inflation (CPI) and will increase annually starting on 1 July 2010.





Time to take a Break!

"We got a finite amount of time on this earth. Better use it wisely Einstein!" (Quote from the movie, "A Perfect Day")

So how does our group of MD Einstein's use their time? Where do you live most of your life? How do you spend most of your time? Striving to be a great student at school? A successful employee or employer at work? A supermum or dad at home? Perhaps the best internet surfer of all time!

So think about the square in which you live most of your life. What is in that square?

Probably much of that square is consumed by sleep, work, school or home duties, recreation, shopping, eating, email and internet.

In the movie "A Perfect Day" Rob Lowe is a wildly successful author who gave everything to have the perfect career in order to achieve the perfect life – he had it all. Only to lose all that really matters, his family and relationships. So he changes course in pursuit of the Perfect Day. One that would include all that really matters.

Did you have the perfect day this week? What does that perfect day look like for you?

How often do you live them? Most days? Weekdays or weekends? Special days?

We need to spend time living outside the square!

By 'living outside the square' I'm not talking about cramming your life with more good stuff. I'm not talking about being more involved at work or school, or spending more time in the community, or taking up a new hobby, or whatever?

It's easy, yet frustrating to run around with a long "To Do List"! These lists can drive achievement, but often leave us feeling like under-achievers as we focus on what is not completed rather than what has been achieved.

Nothing wrong with To Do lists, but if you are struggling to find the perfect day filled with things that really matter and

you are tied to things in the square of life which prevent this perfect day, then time to make some changes.

Time to take a break!

Taking a Break doesn't mean being alone. It is sometimes about sharing experiences with a group of friends. Eating together. Seeing a movie.

Taking a Break doesn't mean taking on an overly positive, optimistic stance all the time. At times it means shaking your fist and asking the difficult questions. In the rat race of life there isn't always time to have these conversations with friends or family. Too often it's easier to put on a façade than to be real and say "I'm struggling or disappointed or angry!"

Taking a Break can also be about sifting through the past day or so and exploring the unanswered questions and the seemingly impossible

challenges! A time to both debrief the past and prepare for the future. It can be about taking stock and finding a new direction or a better way to do things.

Taking a Break can be a time when relationships or experiences we enjoy can be relived, rediscovered and celebrated! Right now I enjoy nothing more than going to the park with my family and our two dogs (one is the cutest little 8 week old puppy). Simple, yet it rejuvenates me. It is a time when I can recalibrate after a busy day or week and regain my focus on what is important in my life!

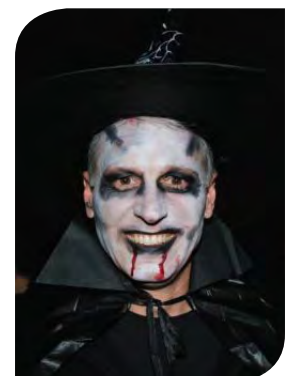
If you are wornout, burntout, tired out, had it! Take timeout! It will refresh you, energise you, enthuse you!

And when you do return to the everyday of life you discover that the Perfect Day is not about the fading dreams we chase every day, but is all about family, friends and relationships and experiences.

During one of those walks in the park I have had time recently to reflect on the past year with MDNSW. Most of the vivid and meaningful memories are of people. Children enjoying their first MD Camp; members thrilled to meet Jerry Lewis and hear of his passion for people and commitment to MD here in Australia; appreciation expressed by a member following a home visit or a Carer meeting; stories of families who have done something special funded by our Flexirest Program; our younger members riding a Harley at HOGS Picnic Day. And more!

Take a Break this Christmas and I pray that you will find peace and joy and rest.

David Jack
CEO



Celebrate the New Year

Welcome to the last Carers Corner Page for 2009! What an amazing year it has been at the Muscular Dystrophy Office this year. The Christmas season has given us yet a wonderful excuse to celebrate right into the New Year.

It has been a lovely couple months with our end of year socials and family events being major highlights during November and December.

Renee and I were very happy to host our first ever end of year party for the Ladies of MDNSW on Friday 13th of November. This event was held at the Olivetti Italian restaurant in Rhodes. The wonderful water views were the perfect setting for stimulus conversation and guilt free eating.

I would like to thank our wonderful Chief Editor Carolyn for coordinating the art of scrapbooking in the making of our Christmas cards. I hope many of you will send your creations to family or friends this festive season.

Also in this month, MDNSW members also had the opportunity to attend

our family day event at the wonderful Featherdale Wildlife Park. Some had the rare opportunity to hand feed kangaroos, while many of us enjoyed a face to face encounter with the friendly Koalas. The park boasts the largest private collection of Australian native animals and bird life; it definitely kept to its reputation. I would like to thank MD families for attending this family event; I hope our choice of families' events scheduled into next year's calendar meet your expectations! Please refer to the 2010 events calendar on the back page of this magazine.

In the month of December, we also had the opportunity to connect with members living in both the Hunter and South Coast regions of NSW.

The Hunter Christmas event was a blast, this family event was held at the Blackbutt reserve. The reserve provided wonderful nature trails and wildlife exhibits for members to enjoy. A wonderful barbeque lunch was prepared with a surprise visit from Santa



topping off the day's excitement. To those of you who attended thank you for your wonderful company, I look forward to connecting with many of you in the New Year.

Members of MDNSW living in the South Coast equally enjoyed a two course lunch at the wonderful Beach Seafood Restaurant in Wollongong.

Thankyou to all for coming along to MDNSW events in 2009, we hope to see you at some of our scheduled events in 2010!

Best Wishes,

Georgina Christofis
Carers Program

Sometimes change is as good as a holiday.

FlexiRest provides respite, or a short break, for family and unpaid carers of people with muscular dystrophy, motor neurone disease and multiple sclerosis. Through funding, we provide a range of services that offer either in or out of home care that other community and respite services cannot provide. Making time for you.

FlexiRest provides support for families and carers of people in NSW who are registered with:

- Muscular Dystrophy NSW
- Motor Neurone Disease Association of NSW
- MS Australia – ACT/NSW/VIC

To learn how you can take "time out", please contact your organisation on the following telephone numbers:

Muscular Dystrophy NSW

1800 635 109
www.mdnsw.org.au

Motor Neurone Disease Association of NSW

1800 777 175
www.mndnsw.asn.au

MS Australia – ACT/NSW/VIC

1800 042 138
www.msociety.org.au



This initiative operates with funding from the NSW Department of Ageing, Disability and Home Care (DADHC).



Wonderful year for MDNSW

Well we are officially in the silly season – my favourite time of year! And what a pleasure it is finish off the year by regaling the excitement, fun and success of MDNSW's first ever camp!!

First and foremost I must admit that the week of camp was unequivocally the most fun, challenging and rewarding responsibility I have ever had in my working life! 82 Campers, Carers and MDNSW staff embarked on the Sydney Academy of Sport for our week of fun and adventure on the 5th October. We left one week later with countless great memories, probably a lot of paint still on our faces but most importantly friendships that will last a lifetime!

Throughout the week we conquered fears of snakes and crocodiles and other various reptiles; tried out our artistic abilities with ceramics, painting and various other arts and crafts; tested our minds with trivia and interpreting kite making instructions (sorry guys! haha); trialled our scientific and drama abilities with Improv Sports and the Mad Science show; got physical with wheelchair sports and yoga and scared the living day lights out of each other with our wicked Halloween transformations.....and varying karaoke skills! (See all staff profile pics for proof of Halloween transformations!) It is safe to say we had a wonderful week, with a wonderful group of campers and carers alike!

As much as I would love to recount all of the funny stories and adventures we had at camp in detail, I must also report on LAC (life after camp) in the world of Client Services! Following Camp we held the inaugural MDNSW Melbourne Cup Day – strictly for those members who could keep up with the party atmosphere here in the MDNSW office! It was a great day of celebrations with yummy food, champagne and of course fancy headwear and of course the big race on the big screen!

We also held the final Ladies day of the year at Oliveto on Friday the 13th – a wonderful afternoon with great conversation, great company and you guessed it..... great food!

Finally as I mentioned earlier it is the silly season.....and the MDNSW metro Christmas party was held in true silly season style on the 13th December complete with Santa, Snow, presents and most importantly lots of fun and Christmas cheer – a wonderful way to finish off a truly wonderful year at MDNSW!

Aside from all the social activities, it is also important to remember all the other ways MDNSW can support you: our members. Some of you may not be aware or may have forgotten about all the other core services we offer to members that could make a difference in your life. Such services include: advocacy for members in any area you need assistance or advice in, funding assistance with essential equipment, home support program and in line with this months theme assistance with respite needs both in the way of our cabins at Currarong and also through our Flexirest program – which is detailed elsewhere in this edition and is a huge benefit to members and one that every family should be taking advantage of.

Of course the support groups and events that we run are of utmost importance to members and carers because they are focussed on fun and opportunity to get out and do things that you may not otherwise get to do – it is up to you how much you get out of your membership! Next year there are a whole lot more opportunities and programs that have been added to our ever expanding calendar such as a Natural Therapies workshop, a weekend retreat, a males only night on the town and an excursion to the Easter show plus lots, lots more!

I hope you all have a happy and healthy Christmas and I look forward to seeing you for an even bigger and better year in 2010!

Wishing you lots of Christmas cheer,

Renee McBryde
Manager Client Services





Camp MD Narrabeen

A Fathers Perspective

Hi every one, just thought I would drop you a note, to say thanks for putting on Camp MD 2009. Kerrie and I spoke to Scott about going when the Camp was first announced. [Scott is 17 and has Duchenne] At first, he wasn't too keen, saying he would rather just stay at home over the school holidays, and simply do the usual stuff that he's interested in – computer, play station, guitar hero, the usual hi tech communication with his mates etc. We really did try to convince him, but the more we tried, the more he went against the idea. Scott said that he doesn't know any one else who would be going, and that was that.

Not ready to give up that easily, I asked Renee to send me more information about the Camp, including the range of activities. Once we received the info pack, I was surprised to see how much effort and organisation had gone into the planning of the event. The range of activities were brilliant, to suit all kids no matter how their disability affected them. I said to Scott, 'just have a look, and then at least you'll know what's on offer before we agree that you don't have to go' I left it at that, and kept quiet for a while, so as not to pressure him. Well, it didn't take long, and he was asking questions about particular activities, and said that he liked the idea of every child going having their own carer, and even the option of bringing your own. Then he started saying it would be nice for a change to spend some time away, to give the rest of the family a break. Not long after, and Scott decided that he wanted to go, and wouldn't stop asking questions about the Camp. He was very excited, and that was all he talked about for days!

Camp time came, we met Michael, who Scott was sharing his room with [all rooms were wheelchair and disability friendly] Michael is 18, and also has Duchenne MD. The 2 carers for Scott and Michael were very funny, and before we left, they were getting on as though they had all known each other for years! Personally, we thought the venue at the Sydney Academy of Sport was excellent and it really suited what the Camp was all about, and what MD was trying to achieve. We left Scott, feeling confident that the right choice had been made.

5 days later, we returned to collect Scott, and arrived half way through a presentation ceremony with all of the kids, the staff and Renee and David. It was very moving to see the enthusiasm and genuine interest that all the kids were expressing, especially Scott. His face was beaming! We heard lots of funny stories, and we can tell you that Scott never shut up about it for days after! He's hooked, and can't wait for next year. We can't thank David Jack, Renee McBryde and Georgina Christofis enough, for the hard work that was put into the planning and running of the event., and for turning a blind eye to some mischievous events that were revealed. It was nice to see that they were all really genuinely getting to know each and every one of the kids there personally.

So, for those of you, that were thinking of going, but didn't because you may have been a little nervous or apprehensive about not knowing any one, you can put your mind at rest. We felt like that at first, but it's really great to feel that our family is a link in the MD chain, and Kerrie and I both know that Dave and Renee gave 100% to give the MD kids five days of fun and laughter. Oh; and the week's solace that we experienced at home was a welcome relief.

Dave Fotheringham

Hi fellow members.

My name is Scott Fotheringham, and I have Duchenne MD. I recently went to the first camp that MD NSW has ever had. It was held at the Sydney Academy of Sport at Narrabeen from Monday 5th September till Friday 9th, during the first week of the school holidays. I had a great time, and can't wait to go again next year. Not only that, but it was good to have a break away from home.

There were plenty of activities to keep every one entertained, with lots of time to relax, and socialise with the others there, including the carers. Some of the highlights were a fun fancy dress Halloween night, science show and a reptile show.

I suggest that if you are interested in this great camp, you should put your name down for next year's camp. I can assure you that you'll have an excellent time! So just let Renee and the MD staff know that you're interested, and they can give all the info that you need to know. I would really like to thank Renee, David and Georgina for a great week.

Thanks,

Scott Fotheringham



2009 MUSCULAR DYSTROPHY CAMP

At the Halloween party by Carer Kate

I walked around the hall, munching contentedly on a chocolate crackle that had been made that morning by our own campers. I said hi to Darth Vader, had a quick fight to the death with a devil (apparently, in a devil versus pirate battle, the devil will always win) and a dance with a skeleton. You know, the usual Wednesday night.

Suddenly, I was being attacked by a flock of birds! Flashes of colour whizzed past me, almost too quick to see! As I made a move to shelter under the fairy-bread table, I realised that the flashes were actually amazingly decorated wheelchairs being driven demonically fast around the dance floor. At first, I was going to recommend that the camp cut down on the party snacks and cordial, but then I thought back to my first day at camp:

I was so nervous I thought I was going to be sick. I didn't have much training – what if I said the wrong thing? What if I broke the hoist? Most importantly – what if my camper didn't like me? I would be crushed, I would leave in tears! As the campers started to arrive, I felt so clumsy, walking around tripping over my own feet. In contrast, the campers just looked so excited; whizzing about the place at break-neck speed, trying to out-do each other with wheelchair models, and coolly ignoring their parents (personally, I had said a tearful goodbye to my mum that morning – shhhh).

No, I decided, it wasn't sugary goodness fuelling these kids – they were just naturally full of energy and happiness. Myself, I had to go and grab another chocolate crackle. Not everyone can be so energetic at that time of night without a little help!

Soon the Karaoke started up. I didn't know how successful it would be, because most of the campers had only just met one another. I needn't have worried though – the microphone



Daniel with his carer at Camp MD Narrabeen

wasn't put down all night. In fact, the DJ had to shut it down for a while because he was getting jealous that no-one wanted to listen to his music!

I know what you're thinking: "Karaoke? Ugh, a bunch of people standing up and whining into the microphone about their broken hearts..." well - you couldn't be more wrong! The closest thing we had to that scenario was some rocking renditions of "My achy breaky heart", which became somewhat of a crowd favourite during the night. We had all kinds of hits: from Eric Clapton, to Britney Spears, to Lady Gaga. Let me tell you something – you haven't lived until you've seen 3-4 guys who look like they've been in horrific car accidents (thanks to the professional make-up artists, not due to the dodgy road that led to the camp) belting out "Poker Face".

As I looked around the hall at all the campers and carers in their costumes, I could see little memories everywhere. Some people had chocolate around their mouths, some had fingers still glued together from kite-making, and others had sore tummies from laughing at our theatre-sports comedians. It had been such a fun-packed few days; I think I had a right to be ready for bed by 10pm.

The campers, on the other hand, had other ideas, and the singing continued until the early hours.

Halloween Party





2009 MUSCULAR DYSTROPHY CAMP



Institute for Neuroscience and Muscle Research, Sydney

The Institute for Neuroscience and Muscle Research (INMR) is based at the Children's Hospital of Westmead and affiliated with the University of Sydney. The INMR was established in 2000 under the leadership of Professor Robert Ouvrier and Professor Kathryn North with the goal of improving the lives of those affected by muscle and nerve diseases through cutting edge laboratory and clinical research.

Our neuromuscular research is focussed on the following areas:

- **Identification of the CAUSE**
The identification of the genes that result in many muscle and nerve disorders is essential to enable accurate diagnosis.
- **Understanding the MECHANISM**
Developing an understanding of WHY dysfunction of the particular gene or protein results in weakness is critical for the development of specific therapy.
- **Development of THERAPY**
The ultimate goal of our research is the development of specific therapies and interventions that will overcome or alleviate physical disabilities.

In 2010 the INMR commemorates its 10th anniversary. Over that time we have grown from a small group of 8 to a multi-disciplinary team of over 40 clinicians and scientists. The questions we seek to answer are directly relevant to our patients - the INMR is a research and treatment centre all under one roof within a Hospital setting and this ensures our research is promptly translated into improved health care. The INMR is closely integrated with the Neurogenetics Clinical Service that cares for more than 1800 children and adults.

We have a weekly muscle clinic attended by neurologists, geneticists, genetics counsellors, an orthopaedic surgeon, a physiotherapist, occupational therapist, psychologist and social worker. In addition, with the Rehabilitation team, we run a monthly Muscle Management Clinic and a Peripheral Neuropathy Management Clinic in which the prime focus is on day to day functioning and preparation for major changes such as starting high school.

We also run a monthly steroid clinic to frequently monitor response to steroids in boys with Duchenne Muscular Dystrophy and a monthly clinic with the Orthopaedics team to prepare patients for surgery and to monitor them postoperatively. The laboratory and clinical team also meet every 3 weeks to review patients with undiagnosed muscular dystrophies and myopathies to plan their laboratory based diagnostic workup.

Our Neuromuscular Research Program

Our research program includes a broad spectrum of neuromuscular disorders. Our goal is to enhance the translation of our basic research (gene discovery, study of the disease pathogenesis and development of novel therapeutic approaches) into improved patient care and quality health outcomes in the clinical setting.

Our research teams include:

Gene discovery in inherited myopathies and dystrophies

Accurate genetic diagnosis is essential in guiding management, for the prediction of prognosis and recurrence risk, for prevention through prenatal diagnosis and, increasingly, for guiding appropriate therapy and eligibility for clinical trials of new therapeutic agents. In addition we are studying the the most important elements that contribute to muscle weakness to identify the best targets for therapy.

Disease mechanism in muscular dystrophies and membrane repair for therapy

Many forms of muscular dystrophy including Duchenne muscular dystrophy (DMD) are associated with a structural fragility of the muscle membrane, whereby membrane damage exceeds the ability of muscle to repair itself, resulting in the progressive degeneration of muscle fibres. We are studying muscle membrane repair pathways in normal skeletal muscle and in disease. Modulation of skeletal muscle repair pathway(s) holds enormous potential for treatment of many forms of muscular dystrophy, cardiovascular insult, as well as for recovery from injury or surgery.





Skeletal muscle and athletic performance

INMR researchers discovered a variant in the ACTN3 gene that is associated with muscle performance in elite athletes. This has led to studies of how normal genetic variations can impact on the severity and onset of muscle weakness in patients with muscular dystrophy.

Clinical Research : Clinical trials and quality of life

The INMR has developed a comprehensive clinical trials program with a number of clinical trials underway or in preparation for therapeutics options for neuromuscular disorders. Clinical trials include:

- Ascorbic acid for Charcot-Marie-Tooth disease,
- Deflazacort and PTC-124 in DMD,
- L-Tyrosine in nemaline myopathy.
- Preclinical trials of antisense oligonucleotides in patients with DMD.

Our clinical trials initiatives are conducted in collaboration with international consortia (Cooperative International Neuromuscular Research Group (CINRG), PTC Therapeutics and TREAT-NMD). We are also studying how to improve outcome measures for clinical trials so that can be conducted reliably in very young children – as future therapies are likely to have the best effect if they are started early. It is also essential to study the impact of medical interventions and new therapies on the day to day life of the patient and their families and we have a research focus on how to best assess quality of life in both children and adults.

Some of our achievements over the last 10 years

- Discovery of several new genes responsible for inherited muscle diseases. This provides immediate benefits to families in terms of the availability of genetic and risk counselling and prenatal diagnosis.
- Development of novel diagnostic techniques aimed at improving diagnostic accuracy and reducing the amount of tissue required to make a specific genetic diagnosis. These techniques have been adapted by laboratories internationally.
- Establishment of a diagnostic service for inherited myopathies and congenital and limb girdle muscular dystrophies (screening for >30 different disorders). This service is available free of charge to clinicians throughout Australia and South- East Asia. Ten years ago our diagnostic success rate for muscular dystrophies apart from DMD was 10%, now it is approaching 50%, and our rate of discovery of novel diagnostic markers is accelerating.
- Access to improved therapies through our clinical trials program - no longer do patients and their families need to seek better treatments overseas. As soon as new treatments are proven to be safe and effective and are made available through clinical trials the INMR will deliver these to patients.

Over the past 10 years, our researchers have been awarded over \$9 million in peer reviewed research funding, predominantly for our laboratory based research, and we have published over 200 research manuscripts in peer-reviewed medical and scientific journals. We have trained 35 research students – including 25 PhD students – and our students have been awarded prizes for the best research presentations at international conferences on 15 occasions. Partnerships with the community are an essential part of our research and clinical care, and we actively fundraise to support our translational research and to underpin our ongoing clinical trials initiatives.

We have many more questions that we are challenged by and our research teams are dedicated to unravelling the answers for tomorrow and into the future. Over the next 10 years we are adapting novel technologies to increase our rate of discovery of new genes and to further unlock the mechanism of disease to identify potentially reversible causes of muscle weakness. Most importantly, we will expand and accelerate our Clinical Trials Program in collaboration with our colleagues nationally and internationally.

Professor Kathryn North

Head, Institute for Neuroscience and Muscle Research





"When our precious little boy Noah was diagnosed with Duchenne, earlier this year it was the worst news of our life, we felt so alone. Since joining MDNSW we feel like we have been welcomed into your Muscular Dystrophy family. We truly appreciate all of your care and support – it makes a huge difference knowing you are there! Thank you."

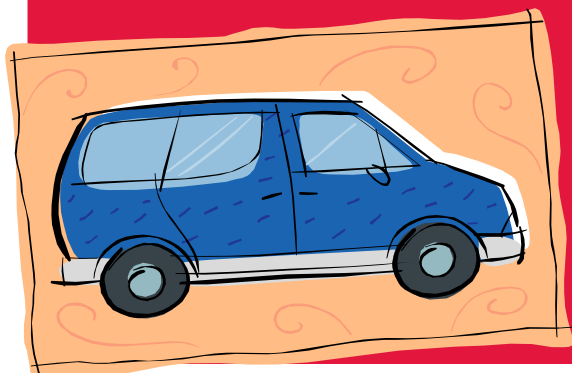
Diane Rewa with son Noah

"My sincere thanks to the MDNSW team for all the kindness you have extended to our family over the years and particularly during this last chapter of our journey– the support has been unwavering; Your team even though all new has treated me like you have been here all along."

Leonie Toohey

Leonie recently lost her beautiful grandson Angus – who just missed out on attending the camp with his dad Michael and Leonie. The camp was something Angus was very excited about and it was also going to be an opportunity for Angus and Leonie to spend some precious time together. Leonie sent this not long after Angus' passing along with a very generous donation which was specifically tagged for another child's costume for the camp Halloween party. All our love and support goes out to Leonie and family at this very difficult time.

Van is required urgently – will pay cash!



Thomas Barrett urgently requires a van for his son Dion who has Becker MD. He is looking for an air-conditioned van in good condition; preferably a 2005 + model.

Please call Thomas on 02 6882 9782

Thank You!

A big thanks to Team P.I.G (aka the Dalrymple family and co) who recently competed in the Rebel Sport Run4fun on Sunday the 8th November, nominating MDNSW as the recipient charity of their wonderful efforts.

Team P.I.G, aptly named after an inside family joke referencing Peter's nickname had 27 team members in total with hopes for an even bigger turn out next year!

Thanks for the wonderful support!!



Photos by Sandy Smith, Mudgee.

Morrison goes Motown for MD

On the 7th November 09 Mudgee came alive in support of the Muscular Dystrophy Foundation. Esteemed jazz entertainer James Morrison led the Motown themed night in a truly magical fundraising performance, resulting in \$25,000 being raised for the Foundation.



Rock'in Rob'in

MDNSW member Rob Matthews recently rocked out with fellow band members from the acclaimed Melbournian band KUSH after reforming after 35 years! Rob, who has FSH, was delighted to have played to a sold out crowd of nearly 800 people at the Melbourne Casino in October this year. Rob plays the bass and is pictured in the red beret. After seeking out some reviews on Rob's band I found the following: "Kush are a genuinely enjoyable experience and, although defunct (for 35 years), remain one of Melbourne's greatest rock children" – Rock on Rob!!!



North America

With the Winter Olympics in Canada quickly approaching I asked intrepid traveller Joanne Hutchins to recount her journey to North America.

This time last year my mum and I took a 12 day 'Maritimes Adventure' tour of Nova Scotia. We then spent a week visiting my friend in Nevada. What a contrast: from greenery & 20 degrees to desert and 40 degree days, but both have their own natural beauty.

Our tour started in Boston, which I immediately fell in love with. It is a pretty harbour city without the chaos that I imagine a city like New York to have. It is relaxed with gorgeous parks, a historic university and plenty of cafes & tree lined streets. And the history, oh the history. This is after all where the American Revolution started.

From there the tour headed north along Maine's coast; lots of lighthouses and rugged, coastline. There is so much natural beauty in this area of the world – water, water everywhere and trees turning in fiery colours of red, amber and yellow. We visited several national parks, the first being Acadia National Park. Here Cadillac Mountain is the first place in continental US to see the sunrise. It is so pristine it feels like no one has touched it bar the sun.

From Bar Harbour we left the US via ferry, entering Canada. Our stop for the next 2 nights was Halifax. What can I say about Halifax to fully express my feelings? I could write a whole newsletter on it. Remembering my time there, 12 months on, makes my breathing slow, my mind swoon and makes me ache to go back. To me it was breath taking and I can totally imagine myself living there. It has become a dream to spend 12 months there one day.

Halifax has the second largest harbour in the world; Sydney being the largest. We visited the citadel, where this photo was taken with 2 of the guards (god I love men in uniform hehe); Peggy's Cove, where there is a lighthouse and other attractions; and Lunenburg. Lunenburg is like out of a fairy tale; a quaint little seaside village with beautiful coloured houses.

For a history buff like me Halifax is a dream. There is way too much for me to go into here, but the most touching for me was Fairview cemetery. It is somewhere I have wanted to visit all my life and a large reason I wanted to do this tour. This is where 121 of the over 2000 victims of the Titanic now rest. It is a sobering place to visit; grave after grave with the stark inscription of 'Died April 15, 1912'. There was 1 Australian on the Titanic who is buried here; a 32 year old man from Sydney, University of NSW.

Five years after, Halifax had its own disaster to rival Titanic. In December, 1917 the SS Mont-Blanc, a French cargo ship, fully loaded with wartime explosives, accidentally collided with Norwegian SS Imo in "The Narrows" section of Halifax Harbour. Mont-Blanc caught fire 10 minutes after, causing 100's of people to rush to the waterfront to see what had happened. Fifteen minutes after that it exploded, killing 2,000 people and injuring a further 9,000. The most common injury was from shards of wood piercing the watching public's eyes and bodies.

All buildings and structures covering nearly 2 sq kms along the adjacent



shore were obliterated. The explosion caused a tsunami in the harbour and a pressure wave of air that snapped trees, bent iron rails, demolished buildings, grounded vessels, and carried fragments of the Mont-Blanc for kms. This is still the world's largest man-made accidental explosion.

After a few nights on Cape Breton Island, where we visited the Alexander Graham Bell Museum and drove the Cabot Trail through Cape Breton Highlands National Park, we took another ferry to Prince Edward Island (PEI), home to Anne of Green Gables. PEI is a quaint, picturesque place, with pastel coloured weather board houses and a slow paced lifestyle. There is a meandering boardwalk around the harbour and a crisp Atlantic chill in the air. PEI was another highlight on the tour.

We left PEI across the 8 mile Confederation Bridge to New Brunswick. For someone with a fear of bridges this took some deep breathing; especially under the circumstances. The night before our driver was unsure if we'd be allowed to cross the bridge due to high winds (it is closed if winds exceed certain strength), meaning we would need to back track for hours in order to leave the island via ferry. Nova Scotia was experiencing Hurricane Kyle

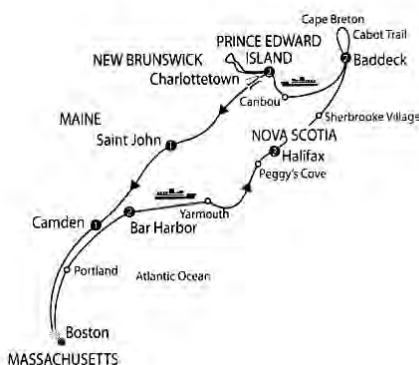
(what an apt name for a hurricane). We went to bed that night not knowing what to expect. We were only affected by a storm, the Hurricane hitting where we had previously been in Halifax and Yarmouth.

We drove on to Saint John, visiting the Summer House of Franklin D. Roosevelt, which sits on the coast in a 3,000-acre memorial park. From here we re-entered the USA, visiting Camden; a pretty town in Maine on the Penobscot Bay. There are many islands in the bay, known as 'summer colonies'. Many celebrities and wealthy people have homes on these isolated islands, including John Travolta & Kirstie Alley. I can see why; it's a stunning area.

Our tour ended in Boston. From here we flew to Las Vegas and stayed with my friend, exploring Las Vegas' many casinos, shows and attractions.

What I loved about Canada was the wheelchair access wherever you went; every toilet block, every café, ever rest stop no matter how little, if it had toilets, it had accessible toilets. As the tour went on it was so lovely to know that as soon as you needed to go you could just go and didn't have to search, hold on, search some more. It's something I could get used to. Buildings and houses were also extremely accessible. As we drove along a predominance of houses had ramps into them.

Joanne Hutchins



Accessible accommodation

NSW

Uki Guesthouse

www.ukiguesthouse.com.au

Address: 1453 Kyogle Rd, Uki NSW 2484

45 minutes from Byron Bay, Bungalow and Currumbin

Phone: (02) 6679-5777

Rates: Private bathroom per night = \$135 for 2, \$60 per extra person

Features:

- Free breakfast, in-house movies, broadband
- Trained assistant animals welcome
- Pool (complete with motorised hoist)
- Premium quality latex mattresses, hypoallergenic, queen sized
- Wall-mounted pull-down slotted shower seats
- Delicious home cooked meals and special diets by arrangement
- Escorted outings (e.g. Riding for the Disabled) and day trips

These guys seem to have planned everything! And if they don't have it, you can request it! One of the owners is disabled herself, so you can be sure everything is well thought out.

O'Carrollyns

http://www.ocarrollyns.com.au/accessibility/ocarrollyns_grounds.php

Address: 5 Koala Place, One Mile Beach, NSW 2316

Phone: (02) 4982 2801

Rates: \$180 p/night for a family bungalow

Features:

- Open-plan bungalow accommodation
- Pool with hoist
- Hoists, commodes, shower chairs all available with notice
- Accessible tours can be arranged for fishing, dolphin watching, etc.
- Access underneath beds for hoists
- Free-wheeler beach chair is available (free) for use on any of Port Stephens beaches

Port Stephens is only 2 hours from Sydney, and the O'carrollyns website provides information for accessible activities around, such as sand-dune 4-wheel driving and boat trips. They also offer a diesel powered six-wheeler 'all terrain' buggy for transport to and from O'Carrollyns to One Mile Beach.

QLD

Tropicana Lodge Motel

<http://www.tropicalalodgemotel.com.au/index.html>

Address: 158C Martyn Street Parramatta Park, Cairns, Queensland.

3 minutes from Cairns CBD and 5.7km from Cairns airport.

Phone: (07) 40511729

Rates: \$60 for two people, but rooms can hold 3

Features:

- The lodge is ground floor with 7 Disability friendly wheelchair access units.
- All Units have Queen size beds and 1 single bed.
- Room for hoists behind/beside beds
- Separate wheelchair height shower nozzle also fitted with knob controls
- Wi-Fi
- Door in bathroom opens sideways providing more space for manoeuvring
- Pets allowed
- Sheltered swimming pool

Seems like a bit of a bargain! A good place to stay if you want to check out the barrier reef – SunLover cruises also do accessible tours of the reef, including accessible snorkelling, a semi-submersible platform, and divers fully trained to assist with wheelchair user scuba diving: www.sunlover.com.au



What's happening at MDNSW in 2010?



Dates to put in your diary ...

JANUARY

Thursday 21st	MAC Meeting (Meadowbank office) 2-4pm
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FEBRUARY

Tuesday 9th – Friday 12th	Mid/Far North Coast Regional Visit (Grafton, Coffs Harbour and Ballina)
Thursday 15th	MDNSW Board Meeting (Meadowbank Office) 5.30pm
Friday 19th	Ladies Members Meeting
Saturday 20th	Chinese Members Event – Chinese Friendship Garden (Darling Harbour) 10.30am – 12.30pm
Tuesday 23rd	South Coast Regional Visit 10.30am – 1.00pm
Friday 26th and Saturday 27th	Towards a Brighter Future Conference

MARCH

Wednesday 10th and Thursday 11th	Hunter Regional Visit (Newcastle)
Thursday 18th	Carers Advisory Committee (Meadowbank) 10.00am – 12 Noon
Thursday 18th	MDNSW Board Meeting (Meadowbank) 5.30pm
Saturday 20th and Sunday 21st	Greek Festival of Sydney (Darling Harbour)
Thursday 25th	MAC Meeting (Meadowbank Office) 2-4pm
Saturday 27th	Men's Social Event – HSBC Waratahs v Blues (Sydney Football Stadium) 6-10pm



APRIL

Wednesday 7th	Family Day Out – Royal Easter Show (Homebush Bay) 10.00am- 4.00pm
Tuesday 13th – Saturday 17th	News Tournament (Narrabeen)
Friday 16th	Multicultural Luncheon (Meadowbank) 12 Noon – 3.00pm
Thursday 22nd	MDNSW Board Meeting (Meadowbank) 5.30pm
Wednesday 28th – Friday 30th	New England Regional Visit

MAY

Friday 7th	Ladies Members Meeting 11.00am – 1.30pm
Tuesday 11th – Wednesday 12th	South Coast Regional Visit
Thursday 20th	Annual Golf Day (Concord Golf Club)
Thursday 20th	MDNSW Board Meeting (Meadowbank Office) 5.30pm
Saturday 22nd and Sunday 23rd	Members Retreat
Thursday 27th	MAC Meeting (Meadowbank Office) 2-4pm
Friday 28th	Natural Therapies Workshop (Venue to be confirmed)

JUNE

Wednesday 9th and Thursday 10th	Hunter Regional Visit (Newcastle)
Thursday 17th	Carers Advisory Committee (Meadowbank Office) 10.00am – 12 Noon
Tuesday 15th, 22nd and 29th	Arabic Members Parenting Course (Bankstown) 10.00am – 12 Noon
Thursday 17th	MDNSW Board Meeting (Meadowbank Office) 5.30pm
Wednesday 23rd – Friday 25th	Far West Regional Visit (Broken Hill)



An Article Without a Writer?

I have to confess that this is my second attempt at writing an article about setting up my counselling practice, Human Being Counselling. My first attempt was just a story of the things I did in setting up, and honestly about half way through writing it I was boring myself! So I decided to write about why I set up my counselling practice and how it exemplifies my philosophy of living beyond Muscular Dystrophy.

My name is Justin Reid, I'm 46 years old and I have FSH Muscular Dystrophy. My first love is music and I played and wrote music for many years until the MD affected my hands. I then spent a number of years wondering what I could do to give meaning to my life. I guess that was my time in the wilderness.

It was when I was at my lowest that my sister suggested I talk to a counsellor. During the counselling sessions I was able to identify, challenge and eventually disempower the angry, negative and critical inner voices that had shut me down. It was quite a revelation to realise that the thing that really stopped me was not my physical limitation but the destructive thoughts and feelings I had about it.

A few months later it occurred to me that counselling was something I could do from a wheelchair. It was both challenging and rewarding, and was a brilliant way of turning the difficult experiences of my life into a resource for helping myself and others. I found a course offered by the Institute of Counselling at the Catholic University (Strathfield Campus) where I could study part-time. To cut a long story short I graduated last year with a Graduate Diploma of Counselling which qualifies me to practice as a counsellor.

I mentioned earlier my philosophy of living beyond Muscular Dystrophy. After fighting a fierce personal war against FSH MD for 25 years I had experienced how the condition could cause feelings of isolation, depression, anger and hopelessness. As I worked with my counsellor I began to see how I had made MD the centre of my life. Everything I did was an aggressive/defensive reaction to the undeniable progress of my MD. Even the heartfelt support of family and friends moved my focus back onto my condition. I needed a new way to relate to my MD, a way of accepting it as part of my life that then left me free to open up my horizons.

I started by asking myself a new question,

“Given that I have MD, what kind of life can I have and what sort of person do I want to be?”

That question bubbled around in my brain for quite a while. I asked my heart as well as my head and listened to my gut feelings. Slowly the answer coalesced within me. I wanted to have a life that inspired other people and motivated them to rise above adversity, to live with wide open horizons. I wanted to be a person who loves being alive, a person who shares that *joie d' vivre* with everyone he meets. I realised that the way for me to live beyond MD was to focus on other people and the positive impact I could have on them.

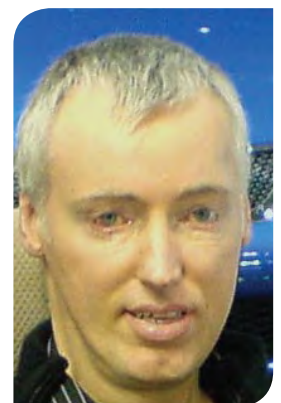
I've almost finished reading a brilliant book called "Thoughts Without a Thinker". It looks at how Buddhist philosophy and meditation can complement modern psychotherapy. One of the basic tenets of Buddhism

is that the cause of suffering also contains the means of release from that suffering. In other words rather than denying, avoiding or fighting a problem, it is by connecting and opening up to the problem that things begin to move. It means going into places where you feel fear and discomfort because that's where you'll heal and grow. So for me the challenge is to "be there" for others by being a counsellor, to go into the world of emotions (which for me can be scary) and create a place that is safe and available to everyone.

On Wednesdays and Fridays I run my practice in the E.J. Ward Community Centre, 189 Underwood St, Paddington. I can be contacted on 0437 124 212 or at humanbeing@sirroden.org.au. I am offering the first 1 hour session free to MDNSW members and their families. I am also hoping to be available as a support worker at the Prince of Wales Hospital Neuromuscular Clinic in the New Year. I hope to meet some, or even all of you in the near future.

Cheers,

Justin Reid.



THE MUSCULAR DYSTROPHY ASSOCIATION OF NSW

Invites you to a

Trivia Night

VENUE

Parramatta Leagues ClubWentworth
Room13-15 O'Connell Street,
Parramatta

DATE

Saturday 27th
February 2010

TIME

7:00pm for 7:30pm Start

COST

\$15.00 per person

 20 Tables of up to 10 people are available

 Bar available

 No food to be brought to the venue

Proceeds will be used to send our team of wheelchair athletes and carers
to the **National Electric Wheelchair Sports**
in Sydney from 12th – 18th April 2010

FOR BOOKINGS PLEASE CONTACT:

Percy Baptiste
on 9643 1429

Stuart Brown
on 0418 861 610



muscular dystrophy
new south wales

Dennis Everard
on 0409 317 117

Association's Office
on 9809 2111



muscular dystrophy
new south wales

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Neuromuscular Clinic 9382 1700

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

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

ADULT CLINICS

Concord Hospital Neuromuscular Clinic
9767 6864

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

Adult Genetics Clinic, Westmead Hospital
9845 3273

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

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

name _____

address _____

phone _____ email _____

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

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

cardholder's name _____ card No _____

cardholder's signature _____ expiry date _____

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

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