

What a Weekend!

We had an absolutely fabulous time at the MDNSW Retreat in Melbourne. From the moment we left home we felt relaxed and excited about the 'foodie' treats ahead. The drinks on Friday night were a lovely way to meet our fellow 'Retreaters' and the group dynamics were fantastic. Loretta and Katie were wonderful hosts and made us all feel welcome and instantly comfortable. It was lovely to sleep in and enjoy an enormous breakfast before having the day to ourselves to shop and eat (we still found room for a lunch



Tom and Carole from the Far North Coast celebrated their wedding anniversary!



Joanne and Ian



A rowdy group at Guy Grossi's Merchant restaurant!

at the Richmond Hill Café and Larder-yum!) before heading back to prepare for our evening at Guy Grossi's Merchant Restaurant. The night was filled with laughter, good food, wine and friendship. We soon found ourselves back at the Crown Promenade for nightcaps before a second peaceful night's sleep.

Sunday saw us enjoying another enormous breakfast - more food, fun and laughter before exchanging numbers and saying our goodbyes. We enjoyed another fantastic day in Melbourne before flying home to see our beautiful children. Thanks again to MDNSW for a fantastic weekend that will keep us inspired and motivated for weeks to come.

Sally and Simon Longmore
Wagga Wagga

Our Retreat program is generously supported by Ageing Disability and Homecare

Off-road Radio Controlled Car Racing program

Sat 4 August 2012
10.00am - 1.00pm

Harold Gregson Reserve, Maitland
Accessible Driving Stand

Limited equipment available - so RSVP early!

See MDNSW Events website for further details



Photo courtesy of Dan Power

Come along to the first of our radio controlled car racing workshops and learn how to race cars on the spectacular off-road track. Cars are provided but please BYO if you have your own and learn how to maximise its performance. This is your chance to get behind a great Club who are prepared to get behind you and start up a regular program!



Oh What a Ball!!

Bob and I are now in our 60's and apart from attending the Muscular Dystrophy NSW Gala Ball for the last two years we rarely venture out in the evening. Wheeling the rubbish bins out on a Thursday night is our weekly night excursion. This might sound strange or boring to most people, but for people with some form of disability it may be familiar.



The Hunter table

to take this challenge. This year's event highlighted the journey that those participants had since taken, and I am certain that there was not a dry eye in the room during Melanie Tran's speech!

In addition to hearing from the young achievers, the Ball is a wonderful event to meet other people who have been affected in some way by some form of muscular dystrophy. Bob and I would like to thank everyone that played a part in planning and organising the 2012 Muscular Dystrophy NSW Gala Ball and we certainly look forward to the 2013 event. Thank you also for providing a function where we can dress up and enjoy ourselves, amongst very understanding people.

Sharon Lamb



Petrone family and friends

The Muscular Dystrophy NSW staff ensure that the venue selected for the Ball each year fully supports the needs for people with every type of mobility problem and they provide an atmosphere of elegance. The Lake Room at the Waterview Convention Centre at Bicentennial Park had plenty of room for people to move around. The jazz quartet complemented the ambience perfectly, and the 3 course menu selected was superb! I really enjoyed the complimentary red wine too, so I am thankful Bob could still drive me home! I hope I have whet the appetite of people who have previously not attended the annual Ball, but the best is yet to come.

At last year's Gala Ball, The MDNSW Duke of Edinburgh's Award was launched by the Governor, Her Excellency Marie Bashir, and we were introduced to the group of 10 young participants who had decided



Margot and Sandra from SCH joined Maryanne from MDNSW



Justin Reid and Jo Santos



The Hon. Sandra Norie and MP Mr Ray Williams (centre) presented the Awards



Steve and Vicki McCormack



MUSCULAR DYSTROPHY
NEW SOUTH WALES

Gala Ball 2012

Saturday 24 March, 2012



The Duke of Ed
Experiences that last a lifetime

A World First



Winner of the Young Achiever Award and
The Duke of Ed Bronze, Cassie Robson

A big congratulations goes to Melanie Tran, Cassie Robson and Hayley Bellamy for being the first people in the world to receive a Bronze Award in this pilot program of The Duke of Edinburgh's Award! These remarkable women challenged themselves to learn amazing new skills such as Product Design, Toastmasters and Web Design. They participated in a variety of sports, and also volunteered in the community by updating charity websites, writing articles for Livewire and being ambassadors for MDNSW.

trips lasting 5 days – 2 weeks, travelling without their parents. Mel went on her first independent living experience to Port Stephens, Cassie embarked on a 2 week Roadtrip to Melbourne and Hayley decided to go on a South Pacific Cruise! The girls were all presented with their Bronze Awards at the Ball by the Hon. Sandra Norie and MP Mr Ray Williams. They have since started their Silver or Gold Awards, and all are wonderful role models not only for the 15 participants now registered in the Pilot, but for people both with or without a disability throughout the world. How proud are we of all of you?!!

Perhaps the most challenging part of the Award for all of them was their Adventurous Journey where they planned individualised

Loretta Downie, Event Manager



Nathan's family came down from Ballina to see him receive a Regional Award



MDNSW & MDF staff



The Duke of Ed Assessors Gracia, Sherrin and Abbey



Hayley, Bronze Awardee, with Marjorie



The Duke of Ed volunteers Vicki & Jill receive their Award



Our first Bronze Awardee, Mel Tran with
Kim Brislane – National CEO
The Duke of Edinburgh's Award in Australia

“ This Award made me believe that I have the one thing everyone else has, and that is the power to fight for my own dreams. It is like a force pulling me into the circle of life instead of watching from the outside. I am now a step closer to reaching out for something I've always seen at a great distance but never been able to hold in my hands... My future. My dreams.

An excerpt from Melanie Tran's inspirational speech at the Gala Ball



Royal Easter Show

On Wednesday, 11th April, 55 Members met Victoria Berg, Client Services Manager and Maralyn McCann, Office Manager at the pylons with red and white balloons attached to them. The weather was at least dry, but the day had, as Bob Lamb said a *cold and lazy wind*, meaning the wind went straight through you, not around you. Everyone went off with eager looks of expectation. Victoria and Maralyn had a wander around the Food Hall and couldn't resist their passion for cooking and each purchased a range of oils and vinegars.

We met back up with some members for lunch and a much needed refuelling, and Pene Hodge (CEO) joined the party. It was brilliant to hear the members' excited discussions as they caught up and exchanged experiences of the previous year.



Sharon and Robert Lamb



Elijah and Noah Rewa

The children quickly ate their lunch and then were keen to get going to have more adventures. The adults had to rearrange their purchases so they could go off to see what other Easter Show goodies they could take home.

We waved everyone goodbye as they went off for more excitement. It was wonderful the animated calls of "we are off to the dodgems", "we're going to the Haunted House", "we're going to find the Food Hall", "see you next year".

Maralyn McCann

Fundraising on April Fools' Day

On Sunday 1st April, the Cheltenham Recreation Club hosted an April Fools' Fundraising Day to raise funds for Muscular Dystrophy NSW. A number of stalls such as cakes, jewellery, barbecue and sweets were available while the Club bar was open for parents and soft drinks. In addition the Club had manufactured a special wheel chair ramp to enable our members to watch bowls. The tennis courts and croquet greens were also in use during the afternoon for everyone to learn and witness these sports.

The sun was shining, it was a fun day for everyone involved and it raised over \$1000 for Muscular Dystrophy NSW.

Muscular Dystrophy NSW would like to sincerely thank Bill Harding for all his hard work and support. Thanks to everyone who donated their time and prizes to the day.

We would also like to thank the Board and Management of the Club for thinking of us and giving us the opportunity to fundraise and to spread the word about what we can do to help people with muscular dystrophy.

If you would like to organise a similar event, please contact our Fundraising Manager Kags Garrard on 9809 2111 or email kags.garrard@mdnsw.org.au

The Lismore Group

The Lismore area Mothers' Group for Muscular Dystrophy is a great group of ladies who meet regularly for lunch and a chat. We do this monthly and go to a different restaurant each time.

Andrea Watts, mother of Samuel, says "I really enjoy getting together with the group. We sample the local restaurants, swap happy and sometimes sad stories but mainly cheer each other up and try to have a fun time whilst we are together".

This group of ladies has been getting together for about one year now. It was started by Vivienne Cox and Kerrie Rogers who were looking for other Mums in similar circumstances so that they could share and receive support amongst each other. Over the last few months the group has grown to approximately nine friends and we would love to add a few more people to our group. So if you live in the Lismore area and would like to join us for lunch one day please contact Kerrie through the Muscular Dystrophy office in Sydney.



front l to r: Megan Jackson then Kerrie Rogers
Back l to r: Vivienne Cox, Andrea Watts, Julie Pederson and Keron Auckram.

This group is not restricted to Mums of children with MD as we also have adults with MD we welcome as well.

Megan Jackson (Evans Head)

Golf at Grafton – a successful Ladies' Day

On 16th May 2012, we organised a Ladies Golf Day at the Grafton golf club in aid of Muscular Dystrophy NSW. We had 60 local women attending and a lot of fantastic support for the event. The club looked lovely decorated in the Muscular Dystrophy NSW's colours and many players were dressed the same which added to the fun of the day! We decided to show a DVD on muscular dystrophy to make everyone aware of the condition and it was very well received.



We had a wonderful prize giving for the winners. Very kindly, the winner actually donated the major prize back (a weekend at Yamba Health Retreat for two people). So I had the opportunity to present the prize to a family that had recently

lost their son to muscular dystrophy, which was a really special moment. It felt like it was meant to be.

Throughout the event, everyone commented on what a great day it was and said they were really looking forward to a bigger one next year. I would like to say a huge thank you to Reg, my husband, for all his support.

The day was a great success raising \$1100. This enables Muscular Dystrophy

NSW to help people who really need their support and provide life changing experiences for them. We are just so happy we could help.

Kay McLennan, supporter

If you would like to organise a similar event then please contact our Fundraising Manager Kags Garrard on 9809 2111 or email kags.garrard@mdnsw.org.au

Hunter Valley Carers' & Support Group Supported by Muscular Dystrophy NSW

Are you interested in expanding your local circle of friendship in the **HUNTER** and **SURROUNDING AREAS** who are facing similar challenges posed by neuromuscular diseases? Contact Ian and Anne to receive local leisure alerts, chat, and join the friendliest network of people.

"We are looking for interested members to assist in the establishment of leisure activities, who have vision to share friendship and good times in a caring, positive environment.

"We look forward to your response and ideas..."

Ian & Anne mail to: ipayne@westnet.com.au (Supported by Muscular Dystrophy NSW)

MEETING THE CHALLENGES OF CARING FOR CHILDREN AND ADULTS AFFECTED BY NEUROMUSCULAR DISORDERS IN AUSTRALIA AND NEW ZEALAND



The Australasian Neuromuscular Network (ANN) is a coordinated and collaborative network that enables health professionals to work together across Australia and New Zealand, for the well-being of people affected by neuromuscular disease.

Nationally, the ANN is partnered with patient support groups including the Muscular Dystrophy Foundation. Internationally, the ANN is part of the European neuromuscular network as a partner of TREAT-NMD, and is closely affiliated with US consortia - allowing us to gain from and contribute to a global effort. For example, the recently established Australian Duchenne muscular dystrophy (DMD) registry connects Australian and New Zealand DMD patients with more than 10,000 patients worldwide across more than 30 countries.

The aims of the ANN include working towards equitable access to clinical trials (via TREAT-NMD), new gene discoveries, improved diagnosis and new therapies to name a few. The overarching goal is to achieve coordinated excellence of care for people with neuromuscular conditions throughout Australia and New Zealand.

In Australia and New Zealand an imbalance exists in the care and treatment provided to individuals affected by neuromuscular disorders. Currently, doctors and medical professionals have no centralised framework to draw on when treating these disorders, nor is there an established pathway for new laboratory discoveries to find their way into clinical practice. This means that for many patients, their diagnosis remains unknown and their treatment may not be optimally tailored for their disorder.

Given the rare nature of the disorders, and the geographical spread throughout Australia and New Zealand, a collaborative network to address diagnosis, prevention and treatment is extremely important. The ANN involves over 280 doctors, medical professionals, scientists and representatives from advocacy groups. This network aims to facilitate the translation of evidence from our clinical and laboratory based research into best clinical practice.

Research into neuromuscular disorders has entered a new era. Advances in sequencing technologies are accelerating gene discovery and therefore our ability to provide an accurate genetic diagnosis is improving. Clinical trials for novel drugs and gene-based therapies are currently underway and hold great promise. The ANN will provide a forum to advance and disseminate information and guide best practice in diagnosis, care and treatment. This includes promoting integrated training programs for clinicians and researchers.

Importantly, the ANN will also provide a single voice to advocate for persons with a neuromuscular disorder and their families. The diagnosis, prevention and treatment of neuromuscular disorders will benefit greatly from a more integrated and united national approach.

The ANN is structured into various areas including clinical care, diagnosis, clinical trials and research. Each area has a steering committee comprising individuals with expertise in each area. These different areas have short (1 year) and long term (5 year) goals. These goals and progress reports are all available on the ANN website (www.ann.org.au), with newsletters available to provide regular updates on progress.

Within the next five (5) years, the ANN has committed to:

- o Increasing access for patients to new therapies by expanding clinical trial centres in Australia
- o Expanding registries so that patients can access trials undertaken anywhere in the world
- o Promoting the expansion of multi-disciplinary clinics
- o Ensuring that 90% of patients will receive an accurate diagnosis
- o Promptly translating research advances into improved health outcomes
- o Making best practice guidelines widely available to clinicians
- o Training clinicians of the future.

“
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ONE VOICE

OVER **280 MEMBERS**
 CLINICIANS PATHOLOGISTS ALLIED HEALTH RESEARCHERS
 ADVOCACY GROUPS

FOR **EVERY** INDIVIDUAL AFFECTED BY A
 NEUROMUSCULAR DISORDER TO HAVE EQUAL ACCESS TO
 CARE & TREATMENT

FREE to a good home

HOIST: used and well cared for.

We have been asked to find a home for this battery operated hoist, it is in good working order, has lost some paint along the way and is not state of the art but it will give the lift you are looking for! 8 years old, excellent condition. Maximum weight 127kg. Complete with battery charger.



TRIKES x 2: made by Tempo Tricycles.

Suitable for ages 3-9yrs old. Our sons both have Duchenne and were able to ride these up to age of 9. Both come with a bar to attach to the back of the bike to enable an adult to assist a child to be able to ride up hills etc. Fantastic bikes. 6 years old, 'cosmetic wear and tear' but are still fantastic bikes. Located in Jindabyne NSW.

If you are interested in either of these items above please send an email to Maralyn (maralyn.mccann@mdnsw.org.au) by 14th July. The hoist must be collected from The Muscular Dystrophy NSW office. The Trikes could be collect from Jindabyne, or we could try to them get to Meadowbank at some stage before the end of the year.

FOR SALE

1994 Volkswagen transporter van

With under-carriage hoist and carries 5 persons including a person in a wheelchair. 128661 kms. **\$7,500.00.**

No offers. Contact Eileen Baptiste on 02 96431429 or 0418 497 110



JAMES N. KIRBY
FOUNDATION

LORD
MAYOR'S
CHARITABLE
FOUNDATION



Aussie
Farmers
Foundation

A BIG thank you!

We would like to say a big thank you to the James N. Kirby Foundation, ANZ Staff Foundation, Aussie Farmers Foundation and the Lord Mayor's Charitable Foundation for their amazing generosity.

Recent successful Grants –

James N. Kirby Foundation - \$9,000 to help fund our Duke of Edinburgh's Award program for young people with muscular dystrophy.

ANZ Staff Foundation - \$5,000 to help fund our Duke of Edinburgh's Award program for young people with muscular dystrophy.

ANZ Staff Foundation - \$5,000 to help us support and expand the game of Boccia for people with muscular dystrophy.

Aussie Farmers Foundation - \$25,000 to help us develop both a supplement to the Duke of Edinburgh's Award Handbook as well as a best practice model to enable more individuals with a disability to participate in The Duke of Edinburgh's Award program.

Lord Mayor's Charitable Foundation - \$10,000 to help fund our Duke of Edinburgh's Award program for young people with muscular dystrophy.

We are extremely grateful for this support from the **James N. Kirby Foundation, ANZ Staff Foundation, Aussie Farmers Foundation and the Lord Mayor's Charitable Foundation** and could not continue to support our clients and provide life- changing experiences without such amazing generosity.



Annual Golf Day 2012



On Thursday 24th May, over 20 teams of keen golfers gathered to enjoy the annual Muscular Dystrophy NSW Golf Day, hosted at the stunning Concord Golf Club. The day started early with breakfast followed by a very informative golf clinic provided by local pro, Ken Trimble. By the look on many faces, it was the last minute tips from Ken that was going to improve the golfing outcome of the day!

The weather started in reasonably fine and cool conditions then turned against us, not to the discouragement of the golfers and the Muscular Dystrophy NSW staff (ladies, if you give out umbrellas you are asking for it to rain!!). The ladies then collected plenty of willing entry fees for the long drive and nearest to the pin competition (congratulations to

Mario Cuena for a sensational hole in one). The course was in great shape and I am sure the whole field enjoyed the ambrose format, giving everyone a chance to contribute to the result. After the game, a hearty lunch was enjoyed in the clubhouse, along with the usual golf stories.

The highlight of the day was listening to Melanie Tran speak about The Duke of Edinburgh's Award program and the support of Muscular Dystrophy NSW. It has really given her the opportunity to shine and do things she had never contemplated. I believe that everyone in that room could see what Muscular Dystrophy NSW is all about and dug deeper into their pockets for the main auction and silent auction. Too often fundraising is separate to the real beneficiaries, so

well done Muscular Dystrophy NSW for having Mel come along. It was also very pleasing to see some of the Duke Ambassadors come along to show their support for the world first Duke of Ed program involving young people with Muscular Dystrophy.

Well done to the Muscular Dystrophy NSW team, led by Kags. Whatever your success this year, I am sure you will set your goals even higher next year. All the golfers will be back next year and will bring with them a few more mates and some more sponsors. This year I was the only Muscular Dystrophy dad in the field; next year we need a few more dads to come and share the experience.

See you next year!!!

Darren Robson

Muscular Dystrophy NSW would like to thank our wonderful sponsors on the day DJ Batchen, Sucrogen and Genea for making the whole event possible. We would also like to thank Melanie Tran and her family for coming to the day and giving an amazingly inspiring speech, Dean Woodham from Concord Golf Club for all his help along the way (and getting up at 4am to help us set up!), Vaughan Woods for all his help on the day and being wonderful at sorting out the winners and

losers – (who were his own team!), Mark Robertson for all his amazing prizes, Ken Trimble for doing a wonderful Clinic and donating two lessons for the auction and our brilliant auctioneer Eddy Piddington.

If you are interested in playing or sponsoring next year's even then please contact Kags Garrard on 9890 2111 or email kags.garrard@mdnsw.org.au as we will be doing an 'Early Bird' discount for teams who sign up for next year in advance!

Your ideas are needed!!

In this edition we announce the start of a new section to be in each edition of Talking Point. This column will include contributions from members giving Tips & Tricks which they have learnt through experience which allows them to deal with the tricky little situations in their lives. This idea is the brainchild of our Ladies' Group which feels that there is much to be gained from the collective experience of all members to make life just that little bit easier.

Tips
& Tricks
for Living

- For instance did you know that NRMA can be called out to mend your wheelchair AND you do not need to be an NRMA member?
- Have you heard of the Companion Card? If you have a significant, lifelong condition and require attendant care for the rest of your life, a Companion Card will allow you to participate in community activities and events without discrimination.
- This means you will no longer be required to pay two admissions or booking fees in order to take your attendant carer with you to participating venues and events.
- And a website regarding Continence Aids Payment Scheme: <http://www.bladderbowel.gov.au/caps/>
- Public Toilet Map, to help you plan your trip and find convenient toilet stops on the way! <http://www.toiletmap.gov.au/default.aspx>
- <http://www.health.nsw.gov.au/living/transport/iptaas.html> Isolated Patients Travel and Accommodation Assistance Scheme [IPTAAS] – Did you know that you might be able to apply with assistance towards the cost of travelling to medical appointments? For more information please check this website out.

So DO YOU have any Tips & Tricks to pass on to other members?
Please forward to maralyn.mccann@mdnsw.org.au



Join us on Australia's Gold Coast this Spring for Riding the Wave 2012
– advances in the treatment and research of inherited neuromuscular conditions.

This conference will present early intervention approaches to treatment and care, showcasing the latest life enhancing techniques, with a focus on both quantity and quality of life for those who are now living longer with neuromuscular conditions.

Conference dates
Bond University Gold Coast
5 - 6 October 2012

Pre-conference workshops
MontroseAccess Corinda
4 October 2012

Find out more

Proudly presented by



MUSCULAR DYSTROPHY
QUEENSLAND

- Scan profiles of over a dozen international speakers.
- Submit a poster to present your research or practice.

www.ridingthewave.org.au





Jazz in the Vines **Retreat**

**Fri 26 - Sun 28
October, 2012**
**CYPRESS
LAKES RESORT,
HUNTER VALLEY**

*It's the 20th Anniversary of the
largest Jazz festival in Australia*

So you've always wanted to go but never had the opportunity?? This is your chance to get away for the weekend with someone special and experience all that is Jazz in the Vines! Not only will you be staying two nights at the prestigious Cypress Lakes Resort, complete with a championship golf course and award-winning Day Spa, but you'll also enjoy all the sights, sounds and tastes that the Festival has to offer within the comfortable setting of the Alfresco Jazz Club within Tyrell's Vineyard. So why not kick back and relax just for one weekend and treat yourself to some remarkable music with some amazing people? You deserve it!



**\$90.00
per person**
Includes
accommodation,
all breakfasts,
Fri dinner, entry
into the Festival
and Jazz Club

RSVP Phone Maralyn on 9809 2111 or email Loretta on loretta.downie@mdnsw.org.au before **Fri 3 August, 2012**. This is one of our most popular events and there are strictly limited places available.

TALKING POINT DISCLAIMER:
The views expressed in these pages may not be the views of Muscular Dystrophy NSW. Care has been taken in the preparation of content, but Muscular Dystrophy NSW accepts no responsibility for detriment whatsoever arising from the reliance of content contained herein.

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

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

name _____

address _____

phone _____ email _____

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

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

cardholder's name _____ card No _____

cardholder's signature _____ expiry date _____

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

