



EVENTS FOR JUNE

Melbourne Weekend Retreat

*Experience the
culinary culture
of Melbourne!*



Guy Grossi, Celebrity Chef, great supporter of Muscular Dystrophy NSW

Due to popular demand, we are running another Retreat in Melbourne this year! This is a unique chance for adults to get away for the weekend with someone special to enjoy some quality time together in the heart of Melbourne. Staying two nights at Melbourne's classy Crown complex, you'll experience a big taste of Italy at Guy Grossi's infamous Merchant restaurant and also have plenty of you time to enjoy the sights of the city. It's a great opportunity to recharge, relax, and run away from the routines of home, whilst meeting other wonderful people at the same time. No wonder our Retreats have quickly become one of our most popular programs!

*Fri 1 - Sun 3 June 2012
Crown Promenade,
Melbourne*

Only \$90.00pp

Includes flights, accommodation,
breakfasts, and Sat dinner. Excludes
transfers, lunches, free time
activities and Fri dinner.

Generously sponsored by Ageing Disability and Home Care

RSVP

Phone Maralyn on 9809 2111 or email Loretta at loretta.downie@mdnsw.org.au before **Friday 30 March, 2012**. Places are strictly limited, so register your interest quickly!!



regional events 2011



The Hunter Region's Christmas in the Gardens

On this lovely evening in December, fifty members attended a very special Christmas Party for the Hunter Group. The initial venue was Oscar's Café and Restaurant in the centre of the Hunter Valley Gardens, Pokolbin, where members enjoyed a delightful two course meal. There was a very festive air about the occasion due to not only the presence of children and the proximity of Christmas but the anticipation of seeing the Christmas Lights Spectacular. This is the Christmas Lights Spectacular's fifth year and it has won the prestigious Hunter Region Tourism Award for 'Best Festival or Event' three years running. This year's Christmas Lights Spectacular had over a million Christmas lights on show throughout designated areas of Hunter Valley Gardens, the display covering 20 acres.

It was terrific to be part of such a fun filled event where members reconnect and enjoy the proceedings with a great deal of laughter and friendship. Attending the function from the Muscular Dystrophy NSW office was Loretta Downie, Event Manager and Maralyn, Office Manager. This event also saw two newly appointed members of staff Matthew Figgins, Client Service Coordinator and Jenny Smith, Project Assistant attend their first Muscular Dystrophy NSW function where they were warmly welcomed by all members.



Following our very pleasant meal we all entered the Gardens and were entranced by the spectacular variety and display of lights in a beautiful garden setting. They ranged from Cinderella's coach complete with horses, a walled garden where the Twelve Days of Christmas was playing with an illuminated portrayal on the four walls of all the gifts, three huge Christmas trees whose lights were synchronised to music, a lake with the Sydney Opera House, and literally hundreds more. Amazing!!



After two hours of 'oohing' and 'aahing' at the lights we all made our weary but happy way home!

Maralyn McCann
Office Manager



Vicki and Ava

South Coast Christmas Luncheon Friday 9th December at the Crooked River Winery.

On a wonderful sunny day, ten members took advantage of this great opportunity to meet and mix socially in the lovely environment provided by Crooked River winery and restaurant overlooking the mountain ranges and spectacular vineyards. Following a wine tasting for those who wished, a lovely luncheon was enjoyed by all.

It was a great opportunity for me to meet members whom I have spoken to many times. For Victoria Berg, Client Service Manager, it was good to meet and get to know, on a more personal level, members whom she supports and helps throughout the year.

The very fine food served by Crooked River restaurant was accompanied by a mixture of conversations covering plans for the festive season through to the sharing of personal anecdotes and experiences. We left the Crooked River Winery feeling satisfyingly weighed down by good food but lightened by the spirit of goodwill that characterised the luncheon in general.

Maralyn McCann
Office Manager



Jill Coleman and Arthur Kirby



Anita and Geoff Chalmers



regional events 2011

Ballina Christmas Party

On a sunny Friday in December last year, Pene Hodge and I took off our city-life shoes and put on our coastal-life sandals for the northern region Christmas lunch in sunny beachside Ballina.

Our group was first entertained by local comedian and writer Mandy Nolan who was certainly not shy with her fabulously colourful descriptions of the ins and outs of marriage, family life, bikini waxing, and medical checkups.

The Ballina RSL provided us with a tasty three course lunch which we all enjoyed very much.

The most enjoyable part for me, however, was putting faces to names, chatting with people whom we have known for a while, and meeting new people. It was a great opportunity to hear stories about the year passed and to celebrate with each other.

There were lots of laughs and Pene and I were reluctant to return to Sydney!

Liz Bailey
Counsellor



Kelly & Gordon at the Christmas lunch



Sydney Metro Christmas Party

Hosted by the team at CBA Direct Banking Sydney

This year we tried something new for the Sydney Metro Christmas party and it went off with a bang! The staff from CBA Direct Banking Sydney put on a wonderful BBQ lunch for us at their function room in Parramatta and made us all feel extremely welcome.

Many members successfully tried their hand at Boccia for the first time, and all the kids loved the Craft Corner we'd set up outside which involved canvas painting and making Christmas decorations from wool, balloons and glue. Santa also couldn't resist popping in to give out remarkable presents to all the kids – in fact I'm not sure how the parents were able to fit them all in their car! Each family also received a beautiful Christmas hamper from all the Commonwealth Bank staff which was greatly appreciated by all.



Jaxon and Santa

As the huge storm came over, we all retreated indoors to partake in an hilarious session conducted by the boys at The Great Race. Tim Tams were smeared with vegemite and slammed down with speed, grown men were shaking their bootie to release the ping pong balls (had to be there!!), Oreos were crawling down peoples' faces trying to find their way into



The tissue challenge

a mouth without hands, and people were wrapped in toilet paper like mummies! I'm sure one of the teams won something great in the end but I think everyone was having too much fun to notice!!

A big thank you once again to the team at CBA Direct Banking Sydney for their amazing generosity with the venue, the presents, the hampers and perhaps most importantly their personal time and effort! Thanks also to The Great Race and the NEWS group for their donations towards the event. It was a blast and by all accounts the best Metro Christmas Party yet!!

Loretta Downie
Event Manager



Attribution Biases and LOCUS OF CONTROL



Throughout the day, every day, we make sense of the things that are going on in our lives. When things occur, big or small, we make a judgement about whom or what was responsible for its outcome. Thus we attribute the outcome of actions and events to either internal or

external factors. We can have positive and negative attribution biases that can affect our outlook on the same situation. It's important to recognise our patterns of thinking and the frames that we view subjective experiences through. People attribute outcomes to one of four cases:

- Internal stable attribution: *E.g. I attribute my performance on a test based on my **ability** to complete it*
- External stable attribution: *E.g. I attribute my performance on a test based on how difficult or easy the test has been set*
- Internal unstable attribution: *E.g. I attribute my performance on a test based on how much **effort** I have put into studying for it*
- External unstable attribution: *E.g. I attribute my performance on a test based on **luck***

Our attribution biases influence our sense of how much control we have over situations, and therefore our experiences of things. I guess the "glass is half-full or half-empty" saying is a simplified example of attribution bias.

It's important for us to think about the way we view events, and therefore how much we feel we have control over them or not. The way we interpret current outcomes influences how we will perceive similar experiences and opportunities in the future. This is particularly important when we are dealing with medical issues, treatments and therapies, services and support.

There are some great questionnaires that can help you to identify your attribution biases and tools to get the balance right.

If you'd like to explore this more, contact our Counsellor Liz Bailey for a confidential discussion at liz.bailey@mdnsw.org.au or 9809 2111.



“ Our attribution biases influence our sense of how much control we have over situations, and therefore our experiences of things” Liz Bailey.



MUSCULAR DYSTROPHY NEW SOUTH WALES INFORMATION

MUSCULAR DYSTROPHY NSW INFORMATION

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CBC Partners

27th Annual National Electric Wheelchair Sports

16th to 22nd April 2012

The New South Wales Colts are in training for the upcoming National Electric Wheelchair Sports (NEWS) in April 2012. Last year the Colts won all major trophies. This year we have a new look team, after the retirement of some players. The team is excited about the challenge in front of them and cannot wait for the tournament.

The tournament is held over four match days, including the Round Robin Competitions for Hockey on the 17th, Soccer on the 18th and Rugby League on the 19th, with the Finals on the 21st. The most successful team from the combined results of the Round Robin competitions in all sports will be awarded the Roger Melnyk Trophy. The teams that finish first and second in each sport will qualify for the Grand Final, with the next two teams qualifying for the third place play-off.

NEWS is under the auspices of Muscular Dystrophy Foundation (MDF) and the event is proudly hosted by MDNSW .

The NSW Colts will compete against Queensland Gladiators, Western Wasps, South Australia Scorpions, Victoria Pride Warriors and the ACT Wheelers. The ACT team is a composite team of players from all states.

The NSW team for NEWS 2012 is Chris Suffield (Captain), James Kim (Vice Captain), Alex Scollard, Jordan Crane,

Hamish Armitage and Kieran Watts from NSW will be playing for ACT.

NEWS 2012 will again be held at the Sydney Academy of Sport and Recreation, Wakehurst Parkway, Narrabeen. This is a terrific venue for NEWS and the staff of the Academy is very supportive of our tournament. I encourage members to come out and watch the tournament. The finals day on the 21st April, is a great day as you will see all the three sports on the one day, but the round robin days are very exciting as well.

The NSW squad trains every Sunday at Kevin Betts Stadium, Ralph Place, Mt Druitt. The remaining training dates are: 26th February, 4th, 11th, 18th and 25th March and 1st April. All sessions are held from 10.45am to 1.45pm.

For more information about the tournament or if you are interested in getting involved

in electric wheelchair sports, feel free to contact me on (02) 9643 1429 or email MBaptiste@bigpond.com

Michael Baptiste

National Director NEWS & NSW Coach



NSW Colts on the attack against SA Scorpions in soccer

Dean Crane and Andrew Kim. Andrew is making his debut at NEWS and for NSW. The team is coached by Michael Baptiste, with Peter Dalrymple as Assistant Coach.

THE NEUROMUSCULAR CLINICS

CHILDREN'S CLINICS

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

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

The Children's Hospital at Westmead
Neuromuscular Clinic
Neuromuscular Management Clinic
Peripheral Neuropathy Management
Clinic
Duchenne Monitoring Clinic
Appointment and enquiries
9845 1904

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

Remembering Angus

Angus was born on the 21st December 1989 and passed away on the 20th August 2009

Angus came to teach us what the ancient Greek playwright Aeschylus taught in 525 B.C. "He who learns must suffer. Even in our sleep, pain that cannot forget, falls drop by drop upon the heart and on our despair, against our will comes wisdom to us by the awesome grace of God".

Such was the pain that our family endured when we had to say goodbye to the dreams that we all had for Angus, and his brother Clem. We expected both their lives to play out to fullness in the circle of life. Instead the family had to muster the courage to rise above the pain of the diagnosis of Duchenne Muscular Dystrophy and live each day knowing that this day would come, at a young age, for them both. Somehow,



when a challenge such as this presents itself, the value of each day becomes paramount.

Angus shared many dreams with us! His dream of one day driving his own car was his greatest passion. His friends and family helped him with the car he purchased. With me, his grandmother, he shared his dream of winning lotto so he could donate the proceeds to science so they could find a cure for Muscular Dystrophy.

We were excited about sharing the first Muscular Dystrophy NSW camp at Narrabeen Sports Centre but sadly he did not manage to attend. My only consolation about him not making it to camp is that we

were enjoying the planning of it. Angus is now in "The next Place" and I believe experiencing the best that the next place offers, that of fulfilment of a soul freed from the limitations of his body and a place where all his dreams can come true and be shared with his brother Clem.

This is the eulogy I read at the funeral;

"It is a profound tragedy to lose one's life at 19 years of age.

For Angus' parents, siblings, friends and extended family, care workers and the McLean Community in general he will be greatly missed and forever remembered in all our hearts.

Angus' mission on earth, I believe, was to be a teacher. His mission is complete. We have learned much from him".

Leonie Toohey, Proud and Loving Grandmother



Angus and his brother Clem



On the 2nd December 2011, Pene Hodge, CEO, Victoria Berg, Client Services Manager, Justin Reid, Member of MDNSW and their partners attended a Cocktail Event to celebrate the Don't DIS my ABILITY campaign, along with over 200 other guests, the Minister for Disability Services Andrew Constance and campaign ambassadors. The evening was held at the Australian Museum and hosted by John Foreman, from Good Morning Australia.

The campaign celebrates the diversity and ability of people with a disability. It is about promoting positive perceptions and building an environment that encourages active participation in careers, leisure pursuits and social activities.

Don't DIS my ABILITY continues to support the aims of Stronger Together funding by raising community awareness of the needs of people with a disability and their ability to make life choices relating not only to their care, but their career aspirations, relationships and social activities.

This event provided us with the opportunity to learn, meet new people and start to develop relationships with other organisations and make people aware of the work of Muscular Dystrophy NSW. This is a high priority on Pene and Victoria's agenda. We were treated to some fantastic performances and we even managed to find time to sample a few canapés and a glass of champagne!



Justin Reid and Joana Santos

New Members' Information Session - 21st May, 6.30pm

Muscular Dystrophy NSW is excited to invite you to an Information Evening for the benefit of all new members of Muscular Dystrophy NSW. We hope that by attending this evening, new members will:

- Gain an understanding about what services are available to you as a member of Muscular Dystrophy NSW and how to access those services eg equipment funds, FlexiRest, camps, case coordination, counselling, community events etc
- Meet all staff at Muscular Dystrophy NSW and chat to those specific staff who may be able to help you most and get things started as soon as possible
- Meet other new members of Muscular Dystrophy NSW, build networks and hopefully not feel so alone
- Feel a greater sense of belonging and support
- Have the opportunity to ask any questions about anything you're unsure about
- Have a chat to people who care about how you are

This informal evening will be held on Monday 21st May 2012 at 6.30pm at the offices of Muscular Dystrophy NSW - **101/5 Bay Drive, Meadowbank, NSW, 2114**. Parking is available on the street immediately outside the building or in the Shepherd's Bay Shopping Centre car park underneath (free of charge). Light refreshments will be provided.

We really encourage you to come along to this evening and realise just how important you are to Muscular Dystrophy NSW and that we aim to do everything we can to get the appropriate services and support that you need.

If you have any questions about the evening, please feel free to call Maralyn on 9809 2111. You can also email me if you'd prefer at victoria.berg@mdnsw.org.au. If you would like to join us on this evening please **RSVP by Friday 11th May 2012** so we can organise catering and room logistics.

Hope to see you there!



Secret Santas

If you happened to be in Sydney city centre on Thursday 22nd December 2011 you might have seen a very special sight. There were 15 *Singing Santas* (well a mixture of elves, Miss Santas and even Santa Claus himself!) going around the city singing Christmas carols and well known songs for donations to the charity. With online donations around the event and the money we made on the night the grand total was a fantastic \$1500!



We just wanted to say a HUGE thank you to Melissa Stewart and all her friends for their hard work and support on this event. Melissa organised this event as her gorgeous niece has muscular dystrophy and she wanted to do something to support the charity and help others. We will be doing this again next year so please make sure you come and find us and have a sing-a-long!

Be a part of making a difference...

Would you be keen to organise a charity event or know somebody who would? We are currently looking at getting more people involved in our fundraising and so are keen to recruit volunteers as *Community Fundraisers*. As you can see from the articles about our amazing *Singing Santas* and the girls from Warwick House, Meriden School everyone can really make a difference! We would love for more people to organise events or speak with their local schools to get them involved.

We can provide balloons, posters, a fundraising guide and all the support you need to organise your fundraising event – all you have to do is give us a call or drop us an email to get started today!

Please contact the Fundraising Manager, Kags Garrard, on 0298092111 or email kags.garrard@mdnsw.org.au for more information or to sign up as a Community Fundraiser.

X Factor fundraising

On the 24th February 2012, two past X Factor contestants, Lazy J and Big Guy, came to Meriden School to help fundraise for the Muscular Dystrophy NSW. This week was our 'Service Week' for each House Group. Our House is called Warwick. We had lots of different activities from cakes sales to a 'Meriden's Got Talent' show to fundraise and create awareness of muscular dystrophy.

Lazy J and Big Guy kindly came to perform for the school and showcase their new Album, "The Lazy Fridays" which is available now! Their R'n'B performance caught the attention of the girls the second they started the show.

The funds raised that day exceeded the expectations of the Captains of the House Group Warwick and raised over \$1100 - selling autographs, photos and the chance to meet these two talented singers.

Throughout the week, the total reached up to \$2776 and 100% of the money raised was given to support Muscular Dystrophy NSW.

We would like to thank Lazy J and Big Guy for coming to support such a good cause.

Written by Serena Tran, March 2012



Girls from Warwick House (Meriden School) with Lazy J and Big Guy from X Factor



Enjoy a special day of golf at one of Sydney's most prestigious clubs.

For registration or more information, email: kags.garrard@mdnsw.org.au

For all you keen Golfers!

On Thursday 24th May we will have our annual charity Golf Day at Concord Golf Club. Grab your friends and get a team together for this awesome day out.

It can be a fun thing to do or a great opportunity to treat those corporate customers you are working with!

We are also looking for a few more sponsors so please contact us if you are interested in this unique opportunity! For more information please contact Kags Garrard on 9809 2111 or email kags.garrard@mdnsw.org.au



MUSCULAR DYSTROPHY
NEW SOUTH WALES

April Fools' Family Fun Day!

What

A family fun day out.
Everyone is Welcome!



Tennis Croquet
Lawn Bowls
Sausage Sizzle
Lots of Fun Stalls
Face Painting
Amazing Prizes
cakes and coffee
A Mystery Guest

Where

Cheltenham Recreation Club



When

Sunday 1st April 2012

What Time

Registration is at 10am and the activities run until around 3pm

Dress in something **RED** to show your support to the charity and you will receive a **Free Gift** at the door!

Tickets are \$10 for adults, \$5 for kids and \$20 for a family. This will include gaining instruction and an opportunity to play Tennis, Lawn Bowls and Croquet.

For more information please contact the Fundraising Team at Muscular Dystrophy NSW on 0298092111 or email kags.garrard@mdnsw.org.au



Perhaps one of our most exciting initiatives to commence last year was the Duke of Edinburgh's Award for young people with a neuromuscular condition. Here, a group of inspiring 14-25 year old members have been given the opportunity to participate in an unprecedented pilot project which could set the benchmark for people with disabilities throughout not only NSW and Australia, but globally as well! Participants need to complete a minimum amount of time in the sections of Physical Activity, Community Volunteering, and Skill, as well as embark on an exciting Adventurous Journey (AJ) for at least 4 days. Participants have all

made all their own choices as to what their Journey will entail and have decided how their individual funding will be spent. Some have even organised their own fundraisers for any shortfalls! They must travel without their parents as part of the challenge, and set their own goals for the Journey. Some of the AJs registered so far include a South Pacific Cruise, a whale-watching trip up near Ballina, an independent living experience at Port Stephens, and a ski trip down at Perisher! Cassie Robson writes about her exciting 3 week AJ below which took an enormous amount of work to pull together. Well done Cass – it was certainly a huge project!!

Cassie's Adventurous Journey

My adventurous journey was a Roadtrip to Melbourne and covered a 3 week, 10 stops pack and unpack mission. We encountered nearly every weather possible except snow and some rather interesting versions of disabled accommodation. All in all it was a great success with a couple of hiccups, but nothing we couldn't manage.

I met some amazing people along the way from Livewire, Jess (Ballarat), Grant aka Monkey (Melbourne), Nicola (Canberra), my cousin Duncan (Canberra) and of course my dear friend Abbey (Wagga) who came with me on my AJ.

Although she did get sick and hospitalised, it would not have been the same without her. Yes, she even got me in a puffy girly dress! It was great to meet these people in person they are truly inspirational and just as nice in person as they are online.



Sherrin, a volunteer came with us as my Carer and now a friend. She was great value with a nursing



background and had a fun, energetic personality; she helped make the journey fun, independent and safe. Can't ask for more than that.

The journey was exhausting but well worth the effort and so much fun. I am so glad I had the experience. This is one of those lifetime memories and I really appreciate all the support, either by encouragement or financial support, that people gave me to make this dream a reality.

Cassie Robson

Duke of Edinburgh's Award participant

Freewheeler Balloon Tyre Wheelchair

This Freewheeler Balloon Tyre Wheelchair is six years old, stainless steel, does fold down and is made by Northcott. These wheelchairs are often used by surf clubs who provide them to people with disabilities to get into the surf, or it can be used in a pool. Applications from MDNSW members with muscular dystrophy will be considered. Applications must be in writing and sent to Maralyn (maralyn.mccann@mdnsw.org.au) by 31st March. Please note the successful member must collect the wheelchair from the Muscular Dystrophy NSW office at Meadowbank.



Electric Scooter Available

Celebrity X 4-wheel: SC4401AUS. This scooter has been described as the **Ultimate in Style & Performance.**

We have been asked to find a good home for this scooter, which is in very good condition. It has only been used twice. Applications from Muscular Dystrophy NSW members with muscular dystrophy will be considered. Applications must be in writing sent to Maralyn (maralyn.mccann@mdnsw.org.au) by 31st March. Please note the successful member must collect the Scooter from the Muscular Dystrophy NSW office.

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.

