

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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Connecting



MUSCULAR DYSTROPHY
NEW SOUTH WALES

A Word from the President

2013 is going to be a challenging year for all Australians with uncertain economic times and the usual political turmoil in the run up to this year's Federal Election. That uncertainty will coincide with increased regulation, changes in taxpayer funding and strong competitive pressure over the next year.

Despite that uncertainty, our Association's role is clear - MDNSW is and will remain the leading whole of life provider for choice of specialised services and expert information for people affected by neuromuscular conditions. And very importantly we will have our clients very much in the forefront of our mind as we strive to improve our services and be cost-effective. Our Association has successfully evolved into being a Centre of Excellence in Muscular Dystrophy services and we will continue to maintain that very high standard.

But we must acknowledge there are many people in New South Wales with neuromuscular conditions we are yet to reach. If you are aware of someone with a neuromuscular condition and you know they have not been in contact with MDNSW as yet, please give them a copy of Talking Point and suggest they give us a call. Tell them that MDNSW and our supporters are ready to help.

We want to reach out to them.

We have some very loyal financial supporters who have been strong donors for many years and we are extremely grateful for the growing number of new donors as well. It is only with their financial support that we can keep reaching out to more and more families across New South Wales.

I must say that our day to day work has been greatly assisted by some visionary people who made our Association a beneficiary in their will in recent years. We will be forever indebted to people like the late Mary Tilden and Edith Laube whose vision and generosity have allowed us to reach out to more and more families across the state with better services. If you are about to update your will, please consider making

The Muscular Dystrophy Association of NSW a beneficiary so one of your legacies will be that you are underwriting our work into future years.

On behalf of your Board, I also wish to very warmly acknowledge Professor Alastair Corbett who has stepped down from our Board after eleven years outstanding service including recent years as Medical Director. Alastair has been an invaluable contributor to our Association and our Board and a much valued adviser to me as President. I am delighted to let you know that Alastair has agreed to continue supporting us month to month in an advisory role and we're extremely grateful to him for that continued commitment of service.

To fill the vacancy on our Board, we have appointed Fiona Simson as our new Director. Fiona and her family live in on a mixed family farming enterprise near Premer on the Liverpool Plains. She has a Degree in Arts/Business and has tertiary qualifications in workplace training and adult education. Fiona is the current (and first woman) President of the NSW Farmers Federation.

Her expertise will be invaluable as we extend our services across regional New South Wales. Fiona, welcome to our team.

Thank you to one and all in our Muscular Dystrophy NSW family for all your efforts.

Peter Debnam

President, Muscular Dystrophy New South Wales



Christmas Appeal 2012 – Thanks to our Supporters

To the very many supporters who kindly gave us a donation under \$100

To those who gave donations over \$100

Sally Egan, Moon Plumbing, Marbel Medical Pty Ltd, Lauren Harvey, Anthony Mansour, Lorna Higgs, Stitching Group Gordon Uniting Church, Ross Steele, Lynne Bastock, Janice Davis, Lynette Walker, G C McCabe & Co (Parkes) Pty Ltd, Paolo and Antonella Petrone, Tony Ryan, Judith Ireland, Geoffrey Graham, Snap Eastwood, Gundagai Pharmacy, R & S Jaques, Patricia Irving, Robert and Elaine Anstey, Michael High, Alys Anne

Powell, Anthony Dessel, Doreen Best, Barbara Allan, Judy Herbert, Beryl Benbow, Margaret Williams, Menadue Floor Covering Pty Ltd, Lionel Robberds, Solange, International Conveyor Products Pty Ltd, R A & A D Gaff, Mark Wilson, Rob Erhardt, William Bennett, M Smith, Regent Street Physiotherapy, Vikki Bezina, Dorothy Chaseling, Visage (Australasia) Pty Ltd, Anne Burton, Noela Bell, Belinda Randall

And to those who generously gave donations over \$500

Margaret Callister, Commercial Club Albury, Charity Greeting Card Co., Joanna Fleming

All contributions can be sent to The Editor, PO Box 1365 Meadowbank NSW 2114 info@mdnsw.org.au Tel: 9809 2111





I was sitting at my desk about to write my editorial for this edition of Talking Point and one of our team sent me this quote...

“ The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen. ”

Elisabeth Kübler-Ross.

I have now been working at Muscular Dystrophy NSW for three years and have had the privilege of meeting so many beautiful people. As the quote says, people who have felt pain, faced hardship, experienced loss and despite their daily struggle continue to give and care for others. One such group I would like to honour is those who volunteer for Muscular Dystrophy NSW, many of whom have a neuromuscular condition themselves. Whether it is helping at the office or with our facebook and website pages, running or participating in a fundraising event, helping young people achieve an award with The Duke of Ed program or volunteering at one of our camps. I would particularly like to thank Rob and Fran Ferguson for the many years they have been volunteers. Rob, known mostly for his work on the

Board has travelled every month to the International Airport to empty our collection boxes. Fran has been instrumental in the development and production of Talking Point including two stints as editor in 2005/6 and again in 2011/12. Thank you to Fran, Rob and all our volunteers we simply couldn't do what we do without your help.

I had the privilege last Saturday of driving down to the Shoalhaven and spending the morning with a group of mums on our first Mums' Weekend Retreat. What a beautiful setting with truly amazing women! They had the opportunity to laugh, eat great food, relax, share their stories and support one another. I love the

photo on the front cover of this edition of Talking Point taken at this Retreat. The red and yellow string shown around their wrists formed part of a symbolic ceremony highlighting the very strong connection the group formed with each other. Each person there knew they were now part of a new and very special family, and to me, the photo is a perfect visual of the opening words mentioned above by Elisabeth Kubler-Ross...

Pene Hodge
CEO, Muscular Dystrophy NSW.

A big thank you to our 2012 Volunteers

- Sandra Allen
- Ann Arciuli
- Percy Baptiste
- Eileen Baptiste
- Janice Bartlett
- Sonia Baxter
- Hayley Bellamy
- Ross Benitez
- Lisa Burns
- Carolyn Campbell-McLean
- Heather Carney
- Emma Cowley
- Martin Dalrymple
- Keval Desai
- Louise Dickson
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- Fran Ferguson
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- Rebekka Myles
- Michele Omundson
- Stefan Petrich
- Eddy Piddington
- Melanie Rankine
- Sebastian Rebeiro
- Donna Riley
- Vicki Sciulli
- Leanne Smith
- Claire Strohfeldt
- Julia Su
- Melanie Tran
- Ralph Wakewood
- Nathaniel White
- Tegan Williams
- Vaughan Woods
- The Team at CBA Direct Banking Sydney
- The Students at Brookvale Tafe and UWS
- The Team at Red Roster
- The Harley Davidson Owners Group

Annual Golf and Spa Day



THURSDAY 16TH MAY 2013 - CONCORD GOLF CLUB



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



Meet our Members

Maralyn introduces James Kim who is 23 years old and has a twin brother Andrew. James plays Electric Wheelchair Sports and is studying at university.



Can you name one goal you have?

I would like to complete my university degree I am currently studying

What do you really like doing?

I really like playing my sports, which include hockey, rugby league or soccer, and I like spending time with my mates

If you were to win \$10 million, what would you do with all that money?

Buy a brand new mansion

If you were to get an opportunity to live anywhere in the world, which part of the world would you choose?

I would like to live in Japan

Why Japan?

Because Japan has nice food, good technology and video games are made there

What would you like to be talented at?

Playing the piano

If you had to evacuate your house immediately what one thing would you grab (cannot be people or pets)?

The computer and my brother

What is the bravest thing you have ever done?

I went on the giant swing at the Year 6 Camp

If the whole world were listening, what would you say?

Be happy with what you have!

Are you a collector of anything?

No

Or is there anything you would like to collect?

Comic Books

If you HAD to change your name, what would you change it to?

James, I like my name

What was your best subject in school?

Didn't really have a best subject, I was pretty well rounded in all subjects. I did enjoy doing Visual Arts in Year 12

If someone was to give you a gift, and money was no object, what would you want it to be?

A new computer

If you were visiting the zoo and could go into any cage with an animal, which animal would you choose to spend 20minutes with?

A monkey

Have any bad habits?

I sometimes leave things to the last minute, I can be very disorganised!

What family tradition/routine do you love most?

I love my family tradition of gathering together at Christmas and having a feast

Name one thing not many people know about you?

I am left handed

Name one goal you have?

I would like to complete my university degree I am currently studying

The Training Website has been **LAUNCHED!**

The launch was held at NSW Parliament House on 14 November 2012, attended by the Minister for Disability and Ageing, Andrew Constance. The aim of the website is to increase the knowledge of health and community care workers in all aspects of neuromuscular conditions. We also demonstrated the website at the Medical Seminar in November, 2012 where it was well received.

You can have a look at the training at: www.mdnswtraining.org.au. You may find some useful information there for yourself. If you are working with case managers, carers or anyone else to assist you with living with a neuromuscular condition, it would be great if you could mention the training website to them so we can increase information and knowledge. MDNSW hopes that this will improve the care you receive over time.

This year, with the support of ADHC, we are also starting some face-to-face training sessions on neuromuscular conditions. These will be held in different areas of NSW commencing in March 2013. There will be details about when and where these will be held on our website (www.mdnsw.org.au). These are for health and community care professionals so you are welcome to mention this to those working with you if you think they may be beneficial.

Maryanne Murray, Project Officer



Pene Hodge at the launch of the MDNSW Training Program website, 14 November 2012



Minister Andrew Constance at the launch of the MDNSW Training Program website, 14 November 2012

When will we see the launch of the National Disability Insurance Scheme [NDIS]?

This is a question that is being asked all around Australia and the answer is almost like the controversial bestselling novel '50 Shades of Grey', as in, it's exciting, a little outside of comfort zones, and an unknown to begin with. But, for people living in the local government areas of Newcastle, Lake Macquarie and Maitland, otherwise known as the Hunter Region the answer could be as close as July 2013. The Hunter Region was selected in 2012 as a launch / trial site for the scheme which means it will be available for eligible residents living in this area.

Over the coming months, government departments will work together to ensure that everybody is ready for when the scheme starts. Information will be rolled out to people living with a disability, their families and carers as

well as to local service providers and their workforces to prepare everyone for the transition to the NDIS. At the moment we cannot be certain what this information will look like or include, which will mean the next few months will be mixed with feelings of trepidation and excitement. The NDIS Launch Transition Agency has also been set up by the Australian Government to implement the first stage of a National Disability Insurance Scheme (NDIS). The Agency will be working with all involved parties to ensure improved support for people with a disability, their family and carers, and to deliver the first stage of an NDIS.

However I can say with confidence that if you or someone you care for is currently receiving care and support in the Hunter Region, this will continue.

Service Providers will work with you and the NDIS Launch Transition Agency to discuss and plan how best to support you to transition your support into the new scheme. This transition will also mean you will have the option to discuss your aspirations and goals, what you want from your support and how you can continue to have certainty that your support needs will be met.

We hope you will use MDNSW as your safe place, and ask us questions or talk through your excitement or worries. We as an organisation are dedicated to staying up to date with the NDIS and aim to be able to offer you support through a process which will see you having control over your care and support.

Victoria Berg, Client Services Manager



MUSCULAR DYSTROPHY
NEW SOUTH WALES

Gala 2013
Ball

SAVE THIS DATE

Fri 3 May, 2013

Tickets from \$45

*includes 3 course dinner, beverages
and entertainment*

*Enquiries or RSVP to
Maralyn 9809 2111 or*

loretta.downie@mdnsw.org.au



The Hon. Sandra Nori (front left), Melanie Tran (front right), Sharon Tran and staff of MDNSW at the Awards night

Muscular Dystrophy NSW wins Business Chamber Award for innovation

I always see the big formal events and elegant evening dresses...on TV. I've always wondered what the atmosphere would be like and how it feels to be around so many successful businessmen and amazing people. Recently, I finally got a chance to experience it myself.

It was such a privilege to be there with Muscular Dystrophy NSW on the NSW Regional Business Chamber Awards at Manly Novotel. I will always remember that exciting and joyful moment when MDNSW was announced as the winner of the Roger Pysden Excellence in Innovation Award. It was a truly heart warming moment to see the smile spread widely on everyone's face when the CEO of MDNSW, Pene went on stage to accept the Award they deserve after all the hard work they did to make The Duke of Edinburgh's Award possible for us.

It was another unforgettable night at the NSW State Business Chamber Awards. It was held at the Hordern

Pavilion and it was very glamorous!! When I went in the venue there was one short second when I actually thought I was at the Oscar Awards... especially after seeing all the cameramen and photographers flashing their camera lights everywhere! I was lucky enough to spend that amazing night with my sister and the staff at MDNSW. The host for the night, Australian comedian Julia Morris kept everyone in the massive ballroom entertained along with an outstanding performance by Darren Percival from The Voice.

I had the opportunity to meet so many amazing people and see many successful businesses accept the Award with pride and joy. It was an absolutely wonderful and unforgettable journey with MDNSW through both the Regional and State NSW Business Chamber Awards.

Melanie Tran, Duke of Ed Gold participant



Dates to put in your diary ...

Mums' Getaway Retreat

Shoalhaven Lodge, Longreach

A unique opportunity for Mums of children with MD to take time out for themselves for a relaxing weekend away in the beautiful Shoalhaven.

Booked out!

Fri 22 Feb - Sun 24 Feb



Blokes in a Boat

Port Stephens

An event we've organised just for the Dads where they can spend the weekend fishing and relaxing in the beautiful surrounds of Port Stephens.

Booked out!

Fri 8 Mar - Sun 10 Mar



Sat 13 Apr - Wed 17 Apr

Adventure Camp 2013

Port Stephens

Booked out!



Gala Ball 2013

**The Waterview
in Bicentennial Park**

Our popular annual event held within a beautiful modern venue, with tranquil views overlooking the Lake.

Fri 3 May





Dates to put in your diary ...

Melbourne Retreat

Get away for the weekend with someone special and experience the retail and culinary delights of Melbourne.

Fri 31 May - Sun 2 Jun



Mon 23 Sept - Fri 27 Sept

Camp Kula N'Gadu 2013

Narrabeen

Places filling up very quickly!!



The Great Boccia Bash

CPA, Allambie Heights

The time has come for MDNSW players to take on the might of the players of CPA for our first ever Botchoff!! MD v CP - it should be a cracker of a tournament!!

Sun 24 Nov



Sydney Metro Christmas Party

CBA Function Centre, Parramatta

This event has been a huge hit in previous years as guests played hilarious games conducted by The Great Race, enjoyed a BBQ lunch and a visit from Santa, participated in Boccia and art & craft, and chatted to a heap of people in similar circumstances to them. It really does keep getting better every year!

Sun 1 Dec





MUSCULAR DYSTROPHY
NEW SOUTH WALES

events 2013



Christmas with friends of MDNSW

CBA shines in Sydney

The Christmas Party was the first MDNSW event that my family and I attended. We were apprehensive initially as we didn't know what to expect but the warmth from each and every person involved made us feel so welcome. It was lovely to meet your team and mingle with other families. My son, Dean, has SMA III and will receive his manual chair in February. This was the first experience for Dean (and family) to be surrounded by other children happily rolling around. I'm sure that this will have a positive impact for Dean in accepting/bonding with his chair. It was a cherished moment for all and we are so grateful – thank you. Please pass on our thanks to the CBA team for their generosity. The venue was great! The gifts given to my sons by Santa were awesome. They loved the arts and crafts immensely and the activities run by The Great Race were nothing short of amazing!

Cindy Tangimetua



Chris thanks Santa in Sydney



The Far North Coast spends Christmas at Summerland Farm

Not even cyclone weather could stop us from enjoying our Christmas Party at Summerland Farm. It was great to connect with other families who live in the area and are also affected by neuromuscular illnesses. While we relaxed over a lovely meal we chatted, laughed and shared wonderful stories. A fantastic activity table kept the kids happy, helping each other with craft and art, while the adults swapped stories and helpful information. A lovely time was had by all and new friendships were started on that day.

Katie Kranicz



Emma and Clarie Howes loved Summerland Farm

Hunter's Roast by the Coast

This year's Christmas party was on the foreshore of Murrays Beach overlooking beautiful Macquarie Lakes. Around 70 people attended our Roast on the Coast which consisted of a delicious two course buffet kindly donated by Hudson Catering. Santa brought joy to all as he listened to their wish lists and delivered bags of candy. Jenny's craft table was a smash hit with the girls, while Phil Bates led the rest in a game of Boccia. A big thanks to Marcus Brown, Lisa Burns and their wonderful family for their huge effort on the day!!

Kejanna Taylor-King, Client Services - Regional NSW

Lexie and Phil



Breakfast by the Beach in the Illawarra

The Illawarra Christmas Party saw us having "Breakfast by the Beach" at Kiama's Harbourside Brighton and it was a fabulous opportunity for everyone to catch up and enjoy the amazing food, fantastic scenery and seaside fresh air that only the coast can provide. The young ones were so excited about the Christmas holidays, while us older ones chatted about the past year, our plans for 2013 and swapped ideas on great holiday venues.

Jill Coleman, member of the new Illawarra/Shoalhaven Social Network

