

# Twilight Walk



Making sure everything is under control: Chris Mikalanis



Michelle Pomeroy, Hilary Rowe and Lee Grigg



Phill Kiosses and MDSA volunteers enjoy the food and wine



Attendees line up for Mediterranean cuisine



Jamie Riggs, Phil Martin, Jennifer Mooney, Scott Grandfield, & Heather Martin



Phill Kiosses with partner PJ and friend enjoying Twilight Walk

MDSA would also like to say a big thank you to the following sponsors who generously donated goods and services to our event:



Lastly, we would like to thank all of you who attended the event and for making it a day to remember. We look forward to seeing you next year and many more to follow.



# Camp Capacity 2011 "Sun, Surf and Magical Moments"

This year's camp was one of sun, surf and magical moments. With many of the camper's ticking off Christmas Day as just another day before Camp began, the organisers were under the pump to make this the most fun and exciting camp to date. This year's magical group was made up of 46 campers, 32 volunteer carers and 4 MDSA staff. Camp is a fun and exciting week where a great group of people spend 5 days and 4 nights at the Mylor Baptist Campsite in the Adelaide Hills.

Throughout the week a competition between 7 teams raged as everyone competed in a variety of games and challenges in between enjoying a range of fun activities.

Some repeat activities were planned again with Laser Skirmish and The Harley Owner's Group with their meticulous machines with rides for all having everybody out on the oval shooting and racing. Action on the court with electric wheelchair sports and competitions was also a favourite again this year and for the second year running Mylor offered its high ropes and giant swing with only the brave attempting either. The flying fox was fun with some people even trying adventurous new moves never before seen on a flying fox.

To fit with the sun and surf part of the theme for this year, surfing lessons and an afternoon at the Beach House at Glenelg were also available. With the smallest waves ever seen at Glenelg and non stop rain, not a lot of big waves were conquered but the smallest people certainly showed the bigger ones how to stand on that board. The same rain stopped "Sailability" but did present the opportunity for some people to visit the maritime museum or have a sheltered walk down Jetty Road consuming that old beach essential, some hot chips. Magic hit the camp when George the magician arrived. He had everybody befuddled and bemused. The sudden appearance of sand, palm trees and the odd seahorse in the dining room at camp had the same affect but contributed to the magical beach quiz night where teams yelled and laughed their way through the evening. The next day saw the completion of the surf board decorating competition where the Bananas in Pyjamas team took a well deserved first place.

Camp fun finished on Thursday evening with dinner out for the older campers and a movie night with popcorn for the younger ones and all that was left was to pack up and head home. A Friday morning last swim was the motivation needed to get all the packing up done though where all the mess comes from is a mystery to all. The play station final was also held on Friday bringing the teams competition to an end and with prizes for the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> teams, magic wands for the last team and certificates to all presented the trek back to MDSA was all that was left.

Months and months of planning goes into Camp Capacity every year and it would not be possible without the dedication of MDSA's fundraising team to come up with the \$21,300.00 of additional funds needed to run the camp. MDSA would specially like to thank the Crows Foundation who contributed an amazing \$3,000.00 to the activities portion of Camp Capacity and to Community Benefit SA who contributed \$11,700.00. MDSA can not run Camp Capacity without the generous support of its volunteer carers who so kindly give up a working week to participate in the great adventure. MDSA would also like to thank the following people for generously donating their time or services to Camp Capacity in 2011:

*Crows Foundation*



*Brighton Surfing Club*



*SA Taxi Trucks*



*Harley Owners Group*



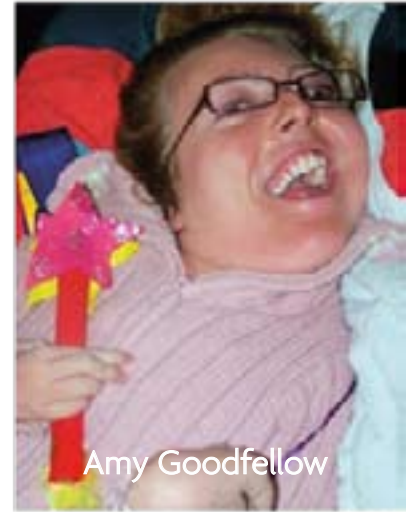
MDSA would like to thank the following people for selflessly donating their time to Camp Capacity in 2011:

Bow Tie Bears

John Clements

Janice Phillips

Darryl McLean



Amy Goodfellow



# Camp Capacity 2011 "Sun, Surf and Magical Moments"



Shelley Edwards, Nathan Sahazaar, Michael Cursaro



Cooling Down, Alessa Dumbrell and Shane Healy



Hope Wrist Bands



Abracadabra: Matthew McKuen-Taylor



Magic: Emma Harwood with George the Magician



Amiee Harwood and Courtney Healy



Girls just wanna have fun: Sasha van Leuren, Laura Wallis & Emily Cullin



Charlie Rowland



Mexican style: Megan Holman and Ruby van Leuren



Wheelchair Sports at ETSA Park



Helping hand, Julian Tantzaris and Brayden Francesca

## MOTS

Hello to all MOTS fans, and welcome to 2011 and once again I intend to enlighten, and entertain you with my usual flair. Last year just seemed to fly by so fast, but I have been informed, when age is creeping up on a person, our lives go that much faster, in that case I am going to start fibbing about my age

John and I once again spent our Christmas holidays in our favourite river town of Mannum at the very accessible cabin in the caravan park, now boasting an electric bed; it is our home away from home. Our stay this time around was a little more interesting than in past years as we had little creatures visiting us in our cabin. We had locusts, a mouse and a small lizard.

The very day we arrived at the park, there was water coming into the park resulting in some sandbagging and the boat ramp having to be completely blocked off with a levee. It was the first time we had a river view from the porch as the cabin faces away from the river, but the very best part of our time spent in Mannum, my very first ride in a speed boat. Couldn't do the skiing bit though, not a pretty picture me in a wet suit.

A 'cute' semi resident of the park named John has this very neat looking boat and he asked what would be involved in getting me into the boat, he was not deterred when I replied, he just went ahead and planned a day and arranged some able bodied men from the park to get me in and out. What a rush, fantastic, I have to admit being lifted up on the back of the boat with John cradling me in his chest was the icing on the cake (or should I say boat ride).

Jenny



# Muscular Dystrophy South Australia Response to Disability Sector Reform

As a result of ongoing dysfunction in the disability system many reviews and changes are currently being undertaken in the disability sector.

- Within South Australia the management and provision of services for people with a disability and older people are being combined and called the Aging and Disability Service Improvement Project.
- The Social Inclusion Board is developing a blueprint for long-term reform of the way people with a disability are supported in South Australia.
- The National Disability Agreement replaced the Commonwealth State Disability Agreement.
- The Productivity Commission is conducting an enquiry to look at the feasibility, costs and benefits of replacing the current system of funding disability services with a new approach. The approach being suggested is a National Disability Insurance Scheme.

Muscular Dystrophy South Australia is considering its future direction as outlined in the 2009 – 2012 Strategic Plan in conjunction with the sector changes as outlined above.

To do this effectively we would like to have as much information in regard to what people with neuromuscular disorders and their families and carers think about the issues.

This year we plan to provide clients and families with information about current topics and issues affecting people with disabilities about which it would be useful for MDSA to have thoughts and feedback.

Responses can be provided in whatever way most suits the individual. This could be by phone to Amber, Richelle or Nicola, through a letter or an email, by visiting Client Services at the office or by any other method people can think of. We would just like to hear what people have to say.

For significant topics we are looking at having focus groups where we will be seeking clients, family and carers who are particularly interested in the specific topic to meet and discuss the issues. We hope that this will make it easier for clients to have input into the provision of effective services by MDSA.

The February issue of the Client Services newsletter has a range of issues about which MDSA is seeking opinions and thoughts. If you do not receive the newsletter and would like to provide input to MDSA please contact us for a copy of the newsletter.

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## Australian National Duchenne Muscular Dystrophy Registry Launch

The Australian National DMD Registry was launched in South Australia on the 19<sup>th</sup> November 2010 at the MDSA Information Seminar held at the Parks Community Centre. Guest speakers included Dr Sui Yu- Head of the Department of Genetic Medicine, Dr Andrew Tidemann- Senior Staff Specialist, Linda Burrows- Medical Scientist and Duncan McFetridge- Shadow Minister for Health. Information covered at the seminar included Duchenne genetic testing- what happens in the laboratory, potential treatments for DMD, new treatment guidelines for DMD and information on how to register with the Australian National DMD Registry.

The formation of the Australian National DMD Registry has been in part as a result of considerable lobbying and advocacy by parents in particular, and is a significant development for everybody affected by this condition.

The registry has been developed to collect and collate the gene sequence and clinical information for everybody who has Duchenne muscular dystrophy, Becker muscular dystrophy or is a carrier with symptoms. The registry enables clinicians, researchers and clinical trial sponsors to quickly identify people suitable for studies and trials. People who are potentially eligible will be informed about new studies and trials through the Registries' clinical network. The Australian National DMD Registry is a member of the TREAT-NMD global network of national patient registries for Duchenne MD. In South Australia MDSA will be working with the Women's and Children's Hospital to collect all information and enter it in the data base, for more information about registering on the Australian National DMD Registry please contact Client Services.



# Introducing New Staff



**Kate Mclean** is our new part time Finance Administrator. Kate has completed a Bachelor of Accounting and Marketing Degree. She is a qualified Certified Practising Accountant. Kate's passion to work for MDSA was an opportunity to work for an association that supports people with disabilities and MDSA is especially close to her heart as her sister-in-law Kelly lives with Muscular Dystrophy and it's great knowing that she is working for an organisation that is helping her and others like her.

**Gemma Butterworth** is our new full time receptionist Five years ago she commenced her Traineeship in Administration at a Law Firm, Perry Lawyers. After three years at the Law Firm she moved on to working at a Financial Planners, Australian Financial Services. Gemma is looking forward to meeting everyone as she is the face of Muscular Dystrophy South Australia.



**Vanessa Lionello** has joined MDSA as our full time Marketing and Fundraising Coordinator and has come from a strong background of marketing and events with not for profit organisations. She has completed a Bachelor of Applied Science in Recreation Planning and Management at University SA. Her main tasks will be managing MDSA fundraising events and activities. Vanessa is looking forward to the year ahead and says she already feels right at home at MDSA.

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## Volunteers Wanted



Have you got some free time and energy? Got an urge to volunteer? We love volunteers at Muscular Dystrophy South Australia – they are the backbone of the association– we'd be lost without them! If you want to get involved we need volunteers form special events, administration duties, mailouts and future projects. Register your interest as a 2011 volunteer.

Please contact Richelle Clements on 8234 5266 or email [richellevol@mdasa.org.au](mailto:richellevol@mdasa.org.au) for more information.



# Corporate Partners



TERRY HOWE  
PRINTING  
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# Bow Tie Bears

DO YOU HAVE ANY UNWANTED DICE ?

The Bow Tie Bears are looking for dice for an upcoming fundraising event to raise funds for MDSA.

Do you have any dice that you can donate for this fun event? Or can you ask at your local op shop?

Please post or drop off to MDSA office. or call Janice on 82345266

**\*\*nota bene**

dice cannot be returned so please do not donate your children's board game dice !



## WANTED BOW TIE BEARS

Have you been thinking about joining an exciting fundraising committee to give back to your community?

Then look no further..... Bow Tie Bears is right for you! Bow Tie Bears Volunteer Events Committee is an auxiliary of Muscular Dystrophy South Australia who raise much needed funds to support children and adults living with a neuromuscular disorder in South Australia and Northern Territory.

Bow Tie Bears hold fantastic fun events such as Music Quiz Nights, Craft Stalls, Karaoke Nights and Bingo. They need your help to continue to make a positive difference in people lives. If you are interested in becoming a Bow Tie Bear, or helping them with an event please contact Janice on (08) 8234 5266 or [jphillips@mdasa.org.au](mailto:jphillips@mdasa.org.au)

## Lotteries



Our Multi Choice Lottery is now open and you could be our next lucky winner!

Your first prize is a choice of either a Mercedes Benz B 180 Sports Tourer plus \$10,000 cash or a Harley Davidson Fat Boy Low plus \$20,000 cash or you may choose to take \$50,000 CASH!!

Tickets are on sale now and there are only 10,000 tickets in the draw with 100 prizes in total to be won.

The lottery is drawn on the 24<sup>th</sup> June 2011

So you don't miss out on this fantastic offer, purchase your \$35 ticket today!



# Appeal Letter

Ordinary day in the life of .....

## TOM



**7.00am:** Alarm goes off and Tom jumps out of bed, showers, gets dressed in his school uniform. He grabs something for breakfast, packs his lunch in his bag and walks to school.

**10.20am:** Tom plays soccer with his mates during recess. He likes to play goalie, because he's fast and agile.

**12.50pm:** Tom attends band practice during his lunch break. He plays the drums. He and a couple of friends are thinking of starting their own band.

**3.40pm:** Tom meets his big sister after school and they catch the bus into town to go and buy their Dad a birthday present.

**7.00pm:** It's dinner time and Tom and his family discuss the day's events and plan what they are going to do on the weekend. Tom helps with the dishes and his mum reminds him that he has to do his homework before he can watch television.

**9.30pm:** It's time for bed. Tom gets his gear ready for tomorrow, puts on pyjamas and hops into bed. He reads for a while and then leans over and turns off the light.

## JONO



**5.00am:** Jono calls out for someone to turn him and he may ask for a drink or to go to the toilet. Dad often assists him at this time as mum has already responded to his call out at 11.00pm and 2.00am.

**7.00am:** Jono lies in bed waiting for his mum to come in and help him sit up. Mum has been up since 6.00am getting things ready. Mum only has a short amount of time to have a shower and get ready for work as she doesn't want to leave Jono waiting. His mum brings in his breakfast as he can't take all his medication on an empty stomach.

**7:15am:** Mum dresses him. His clothes need to fit just right without any wrinkles or it has the potential to become irritating to Jono during the day.

**7.30am:** Mum manoeuvres Jono to sit over the edge of the bed, putting his sling under him, she then uses the hoist to lift him into his powered wheelchair. Positioning is critical, too far one way or the other means that Jono could spend the day in discomfort.

**7:45 am:** Mum assists Jono to clean his teeth, wash his face and brushes his hair for him. She then gets his lunch ready, and packs everything he needs for the day in his school bag and hangs it on the back of his wheelchair.

**8.00am:** It is now time for Jono to leave for school and for mum and dad to head to work.

Mum doesn't have time to do the dishes, housework or preparation for dinner as they have now run out of time.... And it is only 8am..

So often we take our good health for granted. We sometimes forget that there are many people in our community who cannot do the things that we take for granted.

Kind regards

Stephanie Columbus

Fundraising & Marketing Manager

I want to support Muscular Dystrophy South Australia!

Please accept my donation of:

\$50     \$30     \$20     Other \$



Mr/Mrs/Miss/Ms:      Name :

Address: \_\_\_\_\_ Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_ Fax: \_\_\_\_\_

Enclosed is my cheque/money order **OR** please debit my:  Visa  Mastercard  Other

Credit Card No: □□□□ □□□□ □□□□ □□□□

Name on Card: \_\_\_\_\_ Signature: \_\_\_\_\_ Expiry Date: \_\_\_\_\_

I would like some information on giving a bequest

**Muscular Dystrophy South Australia is a tax deductible gift recipient. Thank you, your donation no matter how large or small will help make a difference.** Cheques should be made payable to **Muscular Dystrophy South Australia**—a receipt will be sent to you.

Please return to: **Muscular Dystrophy South Australia**

**Reply Paid 414, Adelaide SA 5001** Phone: 08 8234 5266 Fax: 08 8234 5866