

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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True Heroes



**MUSCULAR DYSTROPHY
NEW SOUTH WALES**

Changing of the Guard

Here we are at the end of another busy year! This bumper edition of Talking Point celebrates our **True Heroes**, with a special feature on all the action from the MDNSW Camp. My heroes are many, both famous and everyday people. One Hero that stands out for me is my late husband Danny. Living a full and interesting life until age 40 (yes he had Duchenne MD) Danny inspired others to LIVE well with MD. He taught me how to love, many how to laugh and lots of kids how to kick it at wheelchair sports. His "Tigerman Dan" legacy of his passion and enthusiasm for life is inspiration for us all.



Dan at Tiger Island

It is with mixed feelings that I report that after 5 years at the helm of Talking Point I have made the decision to resign as Editor of our client magazine. This will free up more time for me to work

on my disability training consultancy and *Stampin' Up!* papercraft hobby and business. Those activities, together with work, family & friends and managing my health and carers, mean my plate is full! I feel confident that the Association now has the staffing and resources to handle the job of coordinating TP, and continuing to create a quality, client-centred read. Of course, as an active member of MDNSW, I will be keeping a close eye on TP and sending in feedback and the occasional article.....and I encourage you to have a go at penning a story - it can be a very worthwhile experience!

My time as Editor of TP has been so rewarding for a number of reasons. I have really enjoyed developing my technical and writing skills, as well as being able to share the stories of our MD family and provide handy and interesting information. I have always advocated for the voices of people with neuro-muscular conditions and their families to be at the forefront of the Association, and indeed this publication. Its production is an important outreach strategy for keeping in touch with members and encourages you to seek support and assistance from the MDNSW. I hope you would say we have achieved this goal.



Carolyn and Danny married in 1996

A big thank you to everyone I have worked closely with over the time including past and present staff, board members, members, service providers and design gurus Louise, Mardi and Rick. I'd also like to acknowledge my predecessor Bruce Ellison for inspiring me to take on the role. We all play our part in this MD story, and in this time of growth and change lets continue to support each other to achieve great things for the MD community.

So all my best wishes to everyone for a super, safe Chrissy and wonderful 2011. No doubt we will stay in touch and catch up at MDNSW events. May your plate be full - but not too full!!

Take care and keep well

Carolyn xx

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

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Festive wishes from the President

I would like to send my best wishes to all my heroes for a very happy festive season.

My heroes include:-

- Each and every one of our members with a neuromuscular disorder, who are so determined and courageous
- Each and every carer – so often parents of someone with a neuromuscular disorder, who dedicate their lives to someone they love unconditionally
- The volunteers who give so unselfishly to others who need a leg up, but never ask for anything in return – and especially Carolyn, Pene and Mardi for their production of Talking Point.



And last but not least:-

- The staff at Muscular Dystrophy NSW who work so hard to help make life a better place for the Muscular Dystrophy “family”
- The Board, who are also volunteers, and give their time and wisdom selflessly towards guiding the Muscular Dystrophy “ship” along its course.

Best wishes,

Rob Ferguson
President,
Muscular Dystrophy New South Wales



around the office

The heart of Christmas is family

We are entering that very special time of year when we celebrate the values of family, community, love and peace. Here at Muscular Dystrophy NSW we are motivated by the growth in the resources we are able to bring to support our members. We hope that Christmas in 2010 is the best one yet for all our members, and are striving to ensure that 2011 is better again.



The heart of Christmas is family. We believe we are all part of one big family, enjoying the good times together and pulling together when times are tough.

We have enjoyed HOGS Day, the camp and look forward to the Metro Christmas Party whirl, sponsored this year by the Commonwealth Bank of Australia and NSW N.E.W.S Group. It looks certain to be wonderful.

We have also this year joined with other members of our community as one big family taking part in the Show Your Strength Rally on the steps of the Opera House. We asked our political leaders to realise that we are all part of the family that they lead, and to treat our members as they would their own family. We ask then that this Christmas they are comfortable knowing that all their family are loved and looked after.

Maralyn McCann
Office Coordinator

Heroes

So, who is your hero? Is it a fictitious character that slew the dragon and rescued the maiden? Perhaps a superhero, or a sports hero! Maybe it is a successful entrepreneur or someone with a great intellect. Or it could be your mum or dad, or that favourite uncle or aunt. Heroes come in all shapes and sizes, but too often we stereotype what a hero looks like and what they must achieve to take on the mantle of HERO!

During our week at Camp I met a whole bunch of heroes. Young people who blew me away with their creativity, sense of humour, talent (there were one or two amazing singers who entertained us at the Heroes Party) and wonderful attitude. Heroes in every sense of the word!

But what was unique and encouraging was the lack of "Hey check me out, I'm pretty good!" No-one acted the hero! But all deserved the hero badge.

Camp this year was great! It was great because 39 young people got to hang out together. Make some new friends. Do some new things. And be challenged to pursue life in a different way.

Camp 2011 is already being planned and I would love every young person who came along this year to turn up next year. No-one should miss out. Everyone who came was appreciated and valued, even the scallywag teenagers. So pencil 26-30 September in your 2011 diary and plan to come to Camp.

And if you missed out this year, we have a room with your name on it for next year.

Note to mums, dads and carers: Our Muscular Dystrophy NSW team ran a great Camp – they are also on my Hero List (along with the 30 wonderful Sydney IVF staff who helped us out at Camp and the medical professionals from Sydney Children's Hospital and The Children's Hospital, Westmead who came



From Left to Right: Gracia Selina, Maralyn McCann, Georgina Christofis, David Jack, Pene Hodge, Liz Bailey, Natasha Sanyasi, Rebecca Scelly, Sandra Stavrou, (Loretta Downie absent)

and helped out at Camp.) So, go and do other stuff for five days, your kids will be in good hands.

This year has rushed by and Christmas is almost here. Whether your Christmas focus is baby Jesus, down time with family and friends or just a chance to catch up on some gardening, I trust that you will enjoy some time to relax and reflect.

On behalf of our team I would like to wish you a wonderful Christmas break and a happy new year. I look forward to catching up at one of our events in 2011. In the meantime if there is anything we can do to give you a hand, please drop me a note at David.Jack@mdnsw.org.au, or give me a call on 9809 2111.

David Jack
CEO

A special thank you to Carolyn

Carolyn has been the Editor of "Talking Point" for the past five years, during a period of significant change in Muscular Dystrophy NSW. She has overseen the development of its member publication ensuring that it not only kept pace with the change, but in many respects led the way. During the five years, Carolyn has guided the production of 20 issues and given wonderful leadership and support to our members through her editorials and support of numerous events. Carolyn is an engaging personality, has a can do attitude and always on for a chat and a laugh. She is also very insightful and has inspired many with her stories of achievement and success in life despite the challenge of living with a disability.

Carolyn, thank you for your vision, tenacity, incredibly positive outlook on life, hard work and determination, friendliness and the skill and creativity you have brought to your role as Editor of "Talking Point."

David Jack and Pene Hodge



Welcome **Liz Bailey**

I came onboard in September and it's already been quite the journey! I've been truly amazed at the things I've already seen during events like HOGS day and Camp. I've had tours of Neuromuscular clinics and seen some of the fascinating things going on in the labs. I have also been touched by the strength and humility of our members who I have spoken with and met through our new case management service. I have been truly amazed by the passion and commitment of all the people involved, particularly my new marvellous colleagues, and all those who make MDNSW such a wonderful community.

I have come into the Client Services Team to be involved in the new case management service. In addition to providing case coordination, I will also be working behind the scenes to gather information for Ageing, Disability and Home Care about gaps in current mainstream services. This is an exciting opportunity to voice our needs to government funding bodies and speak up about what is needed specifically to support families and individuals whose lives are affected by a neuromuscular disorder. In order to better educate government bodies, schools, community organisations and support services, we need educational resources and materials to generate awareness and make information seen, heard, and understood. My role also incorporates compiling these resources.



I will be working in a part time role with MDNSW as I also work as a provisional psychologist three days each week.

I look forward to the journey ahead with MDNSW, thanks for having me onboard!

Liz Bailey
Case worker

FOR SALE

Volkswagen Transporter T4, 1997. Automatic, fully lined, side entry ricon wheel chair hoist, tie downs, 4 doors, air conditioning (needs regassing), engineering certificate, seats 6 plus wheelchair, non smoking owners, always parked under cover, good condition, 147,000km, rego till 26/5/2011, XDM880. Owner upgrading to another VW transporter.

Located in Orange NSW. \$19,500 ono.
Ph 0428 250 724 or 02 63 658733.



R is for Rest, Relaxation and Retreat!

On the 12 – 14 November, Muscular Dystrophy members, both carers and clients enjoyed a fabulous weekend away at Sydney's Star City Hotel. The time away from home enabled retreaters an opportunity away from normal daily routine to relax, indulge a little, create fond memories, and make new friendships.

The three day retreat which commenced on the Friday night was a good ice breaker to the weekend. Dinner at the Lotus Chinese restaurant was great, there was much laughter and the food was of fine quality. Our Saturday morning was a little more leisurely with a stroll to the Powerhouse Museum to see the 80's and AC/DC exhibitions.



Karen, Georgina, Leah, Peter

A definite highlight of the weekend was seeing FAME the Musical. The energetic performance by some of our country's best dancers was a perfect end to a Saturday evening. It got that little bit more exciting for member Luke Berkery as we were fortunate to meet the performers backstage. So what did our members have to say about the weekend away?

Retreater's Comments;

"We have met such lovely people. It was nice to talk to people that understand what I am going through, as it is hard to explain (my condition) to others."

"It is a huge benefit for us to have quality time to refresh and share our experiences. Breaks like these give us hope and helps us continue our family life. It's so important to have such a good organisation to help us as carers to build up our strength and confidence. Thank you very much."

"The Retreat provided a refreshing change of routine and environment, helping to recharge the batteries! It provided a special family time in a relaxed environment, and it was so good to have the program planned for us, without me having to check accessibility first."

"We got to relax and spend time together. We really enjoyed meeting other members, and getting to know the MDNSW staff. Thanks very much. It was a lovely experience and we appreciate the effort and preparation, as well as the great atmosphere."

"It has been nice to meet other families with similar situations to us. We also enjoyed the planned activities without any worries of organising it yourself! We both had a really great time. Thank you!!"

Muscular Dystrophy will run two retreats next year. Please keep an eye out for the new Client Services events calendar in 2011.

Georgina Christofis



Some of the group outside the Capitol Theatre



Luke and Charlie from So You Think You Can Dance and FAME



Bruce, Diane, Margaret, Brendon

TRUE HEROES

The theme of **Heroes** at this year's camp and of this Talking Point starting me thinking about what do I think a hero is? My thoughts lead me to the dictionary, which states that a Hero is a person who is admired for doing something very brave or great. In our culture we often make celebrities and the rich and famous our heroes but I can think of many everyday people that more accurately fit the above definition. I think of our members who despite difficulties with mobility, accessibility, financial constraint and illness strive to better educate themselves, participate in sport, the arts and in the workplace. Those members facing unrelenting pain, those carers providing ongoing daily care and those who live with the knowledge of an unknown life expectancy, to me, they should be called **Heroes** and honoured as they are the **brave**. I think of the medical staff in the hospitals, clinics and the community who work long hours, study and research, they should be called **Heroes** and honoured as they are doing something **great**.

We honoured two young heroes at the Muscular Dystrophy NSW camp, Julie Duong and Hayley Bellamy as our first ever MDNSW Young Achievers. Both received a trophy, \$1000 and a letter of congratulations for their academic attainment, community involvement and leadership ability. If you have Muscular Dystrophy, a career, sporting, business or creative ambitions don't forget to apply in 2011.

I am writing this article following the Client Services Team Planning Day for 2011. What a great team we have and what a wonderful year planned for next year. We began by recalling and evaluating all of our Client and Carer events in 2010. There have been so many highlights but several that have stood out in my mind, they were the weekend retreats, the recent Medical Seminar, HOGS Day, Christmas parties and of course the unforgettable camp. We will continue with all of these wonderful events but are pleased to let you know we have many new and exciting events planned. We are in the process of completing the 2011 events calendar and will forward a copy to all members as soon as completed.

It was with sadness we farewelled our Case Manager Mandy Newton but with pleasure I announce that her replacement Victoria Berg will commence at Muscular Dystrophy NSW on 6th December. Victoria comes with considerable experience in Case Management and particularly in the Disability sector. If you would like to know more about our Case Management Program and how to receive it please contact one of the Client Services Team.



Victoria Berg

We really appreciate all those members who volunteer and so generously give of their time to assist us in the office, with fundraising and through the Members and Carers Advisory Committees. We would love more volunteers to assist at camp, the new members evenings, drive our accessible vehicle and help with mailouts. We particularly would appreciate any nominations from people who would like to be part of our quarterly Members Advisory Committee.

As this year draws to a close I would like to wish you all a wonderful Christmas and a well-deserved holiday break with those you love and the heroes in your life.



Merry Christmas

Pene Hodge
Client Services Manager

Carers Corner

I can't believe how fast and furiously 2010 has surpassed us. It's been an amazing year, one filled with spectacular moments like seeing Mr Jerry Lewis at his very best during his trip to Australia, the Muscular Dystrophy camp, and visiting clients in the farthest region of the state in outback Broken Hill.

I've been working at Muscular Dystrophy NSW for almost three years now, and it's exciting to see how many positive transformations and changes the organisation has made in the short period I've been with the association. It's been a positive year with an increase in staff numbers from four at the start of 2010 to a total of 11 staff within an eight month period. I know 2011 will bring with it some amazing opportunities for the organisation as a whole. I really look forward to seeing what's installed for us in the New Year.

I encourage many of you to use this festive season particularly parents and carers, as an opportunity to focus your energies to

bonding more closely with your loved ones. I encourage many of you feeling tired and exhausted from the demands of caring to nurture your wellbeing by taking a short holiday, having a massage or simply spending an hour or two focusing on what your goals and aspirations for 2011 will be .

I encourage you all to call Muscular Dystrophy if you wish to talk through any of the ideas above – please call us on 9809 2111.

I wish you all a wonderful Christmas, and a very happy New Year in 2011. May you be filled with the joy and laughter that comes from this very special season!

Kind Regards,

Georgina Christofis
Carers Coordinator

letters

Hi Georgina, Loretta and Pene

I just wanted to thank you all for such a great Carer's retreat. I know my husband, Brendon had a really great time, as did I.

Your event management and planning was very thorough. I know events never run to plan, but if there were any problems, it certainly wasn't evident from our perspective...and that's the sign of a good event manager!

I know my LGMD is very mild compared to others, and I can only admire the stamina of other families...that's where the carer's weekends are just the ticket!

Both of us are feeling quite relaxed and I was so pleased to meet all of you as well as others affected by MD or associated disorders.

WELL DONE to all involved. Good to know that Georgina has a fall-back job as a flight attendant, should she ever need it..not that I ever think she will.

Cheers

Margaret Young

Dear David and staff,

Thank you for having chosen me for the Young Achievers Award. I am amazed and touched by the generosity and encouragement shown to me throughout my life and especially during my studies. It is an honour to be one of the first to receive the Award from the Muscular Dystrophy Association and I will always try to be a good example to others who want to follow their dreams in some special way. I proudly banked my \$1,000 cheque and my first trophy takes pride of place in the lounge room. Thank you once again for your encouragement and confidence in me.

Yours faithfully,

Hayley



Muscular Dystrophy NSW Young Achievers 2010



Camp 2010

Generously funded by Ageing, Disability and Home Care

The weather forecast was looking good; the carers were trained and rearing to go; staff from the Neuromuscular Clinics were ever so eager to be involved; and campers couldn't wait to catch up with old friends. The stage seemed set for yet another great camp in 2010!

Jo and Loretta arrived at Narrabeen on the Sunday evening to equip the rooms with all the gear that the campers and carers would need for their stay. It was a long night, but they got there in the end. The carers arrived first thing Monday morning for a final briefing and then we all waited in anticipation for the arrival of the campers, who quickly tucked into a scrumptious BBQ after settling in. Any nerves seemed to disappear quickly as our great bunch of carers made everyone feel comfortable almost instantaneously. Des in particular had created some excellent signs outside his room for his campers, much to the delight of all who saw them. They seemed to multiply as the camp went on too!

There was barely time for Loretta to mess up her room, before the first activity was underway. The Gymnasium shook to the sound of about 50 drums and other percussion instruments as InRhythm Drumming tried to get us all in tune with each other. We had to search for objects according to the noise level created, and played lots of other rhythmic and fun games. This was a great first ice-breaking activity and it certainly served its purpose to help blend the group together in readiness for the rest of the camp. Arjuna and Brittany in particular seemed to thrive in this session. The first of our TAFE Challenges then began, as the campers attempted to make their own volcanoes, some of which even erupted!



Matthew Artrageous



Wheelchair painting

Day 2 Discovery Day

Today was sponsored by Sydney IVF, and 30 volunteers from their organisation came along to provide assistance on the day. It all kicked off with Artrageous, where THRILL conducted some crazy Pro Hart-like painting activities. Kamal was extremely proud of how he squirted Loretta with a syringe filled with paint; Tom created a 3-dimensional masterpiece; sponges were thrown, bodies were painted, straws were blown, and some are still wiping the paint off the wheels of their chairs due to the unique rolling techniques they used on canvas. To cap it all off - it was all done to music! The final results (apart from pure mayhem) were 7 brilliant works of art that we will use to raise funds for muscular dystrophy, although it will be hard to part with them they are currently displayed in our office and look absolutely spectacular! Can anyone remember what colour shirts the Sydney IVF staff wore that morning? I do recall that they looked quite different on the way home!!



Brittany drumming



Kamal

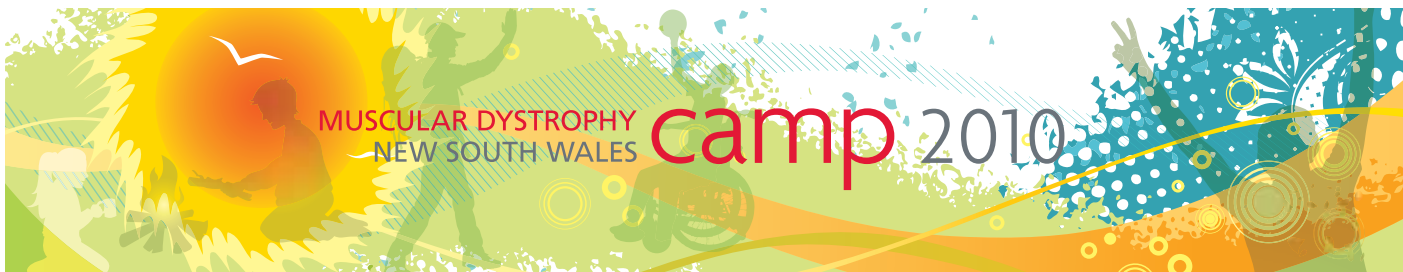


Artrageous Work of Art



Team Sydney IVF





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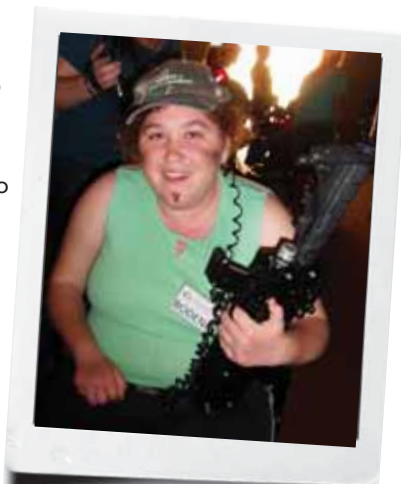
The scene was set for combat. The now colourful Sydney IVF Team were going up against the MDNSW teenagers in a Mobile Laser Skirmish battle of the brave! It was dark; it was tough; it was downright nasty – but Team MDNSW showed no mercy in fighting for their State! One by one we cornered the opposition, applying strategies never quite seen before on the battleground. Kevin, Joe, Lucy and Sarah showed their true grit and fought to the end - we literally had to drag them away! Sally was totally exhausted, but hung in there for the sake of the campers – a true gutsy effort from one of our toughest carers. Everyone else then took turns to cream whoever stood in their way. To the credit of Sydney IVF, a few courageous team members kept coming back to shoot whoever they could find standing as the battle drew to a close. A reporter from the Manly Daily couldn't resist this story and came down to see the combatants for themselves, which resulted in a great write-up in the paper the next day. Thanks to Juan from Mobile Laser Skirmish for his efforts in ensuring the kids had a great time today.

Day 3 Adventure Day

Everyone got to bed at a reasonable hour last night to make certain all would be well rested for the big day ahead. Survivor had come to town! Run once again by Thrill, Konrad organised the group into teams of 4 to tough it out in a bid to find the ultimate survivor. Teams were put through a variety of challenges including races, puzzle solving, walking the plank, and navigation skills. The best activity was left til last, and involved firing wet balls at a target via a huge slingshot! It was a finale to behold as campers sought their revenge, choosing to ignore the designated target and fire instead at Jo and Loretta! Alex took great pride in hitting them the most, although to their credit, they did catch quite a few. Philip was the only shooter who managed to land one in the bucket, and Daniel only missed by a whisker, but shot an absolute screamer - the biggest one by far! The game eventually boiled down to 6 finalists – Philip, Alex, Lucy, Bodene, Mustafa, Von and Joe, with Mustafa winning the overall title. In a tight race for Best 'Slave' Ross beat Tony and Jess at the line to claim the title. Survivor was a fantastic game for our campers and carers to work together with different people to overcome challenges in a team environment. It was voted one of the most popular activities on camp. Bodene's sportsmanship and team encouragement was one of the highlights of the day, and depicted exactly what we aspire to achieve on camp.

Thanks so much to Konrad and his team at Thrill for accommodating our campers and staff so magnificently throughout the camp. Talks have already begun with Konrad for him to look at running The Amazing Race next year, thanks to the suggestion of enthusiastic camper Jordan!

Unfortunately fishing in the Lake had to be cancelled due to the biting wind that surfaced that morning. A contingency plan had been put in place well in advance, so the fun was able to continue without too much disappointment. Mel and Todd from Young Guns Fishing Adventures captured



Bodene Laser Skirmish



Tom giving it all for Survivor



Morgan & Lorraine fishing



Jo & Von

everyone's attention with 3 rotational stations set up around the subject of fishing. Fish Bingo was a huge hit amongst the campers, especially with Morgan, as was the slimy, grimy bait workshop. The area that impressed most though was the 10 Steps to Casting program. It was unbelievable how quickly and accurately the campers learned to cast, and some even hit the small targets! Jenna was determined to learn how to cast entirely without assistance, and her perseverance paid off! Jordan was our star fisherman though, showing great technique, enthusiasm and accuracy. Mum and dad - I think he's hooked!!

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It didn't seem to worry anyone that some rubber lures ended up in the basketball hoop or wrapped up in the soccer nets. It was all just a heap of outright fun, although it was also great to see everyone concentrating really hard to achieve the skills required to learn the proper technique. Having an achievable goal always brings out the best in people.

We were also really fortunate today to have Des Hasler (Manly Sea Eagles Coach) pop in for a quick chat to our young fisherpeoples. He was asked quite a few tough questions by the excited gallery, then further gave up his time to have his photo taken with quite a few camper fans. Des is a true gentleman, and if you weren't a Manly fan before, I think you would have edged that little bit closer to becoming one today.



Boccia Paralympian Terry Cooper & Tash (MDNSW).



Matthew, Tom & Philip fencing under the guidance of Rebecca (MDNSW)

Boccia is a sport that MDNSW would really encourage our members to give a go, and you will find further information about it in this edition of Talking Point. Already some of our campers have taken it up as a regular sport, and we're so excited that the camp was able to help facilitate that important step. Thanks to Tash for her effort in helping to organise Boccia for the campers.

We were also fortunate to have the support of Peter and Leslie from Fencing NSW on this camp, to help MDNSW's very own former National champion, Rebecca, in showing the campers how to play the paralympic sport of fencing. Equipped with real metal swords, complete with masks and protective gear, the campers bravely took to the art of fencing. Those unable to hold the heavier metal swords still enjoyed participating in the sport by using the foam versions provided. Philip, Joe and Matthew all had a semi-professional fencing bout, playing strictly to the rules and learning the correct terminology in the process. Jossy and Lucy were our female stars of this sport, although from what I saw, Cassie wouldn't have been too far behind – she seemed to be having way too much fun though!!

Carers Anita and Mary energetically facilitated the Paralympic sport of Sitting Volleyball during the rotation. Although the rules were adapted slightly to suit the varying abilities of campers, this sport proved to be a real hit, and we may even include it in the camp program next year, but using a soccer balloon ball instead.



Kieran with Des Hasler



Bodene & Jossy



Mustafa & Kevin

Day 4 Paralympic Sports Day

There was a real buzz in the air today, as campers were looking forward to all the sporting activities that were in store for them. The day began with a Paralympic Sports Rotation, where each of the 4 groups got to participate in 4 different Paralympic Sports for people with disabilities.

Peter from Boccia NSW brought out his Team to coach the campers in the sport of Boccia. This was by far the most popular sport played on the day, and everyone picked it up really quickly. Peter was impressed with many of our campers, indicating that some would already be capable of playing at a representative level. We were also extremely privileged to have Terry Cooper come along to participate in the day, who is Australia's current Paralympic Boccia champion.



Arjuna eating





Ross chose Track events as his Paralympic Sport to conduct for the group rotation, and there certainly was a lot of laughter coming from that part of the venue during the course of that program.

It was a bit of a wait, but a wait well worth it, when Wheelchair Sports came to town! Kieran, Daniel, the Crane brothers, Alex, Adam, James and Scott got into the thick of it and demonstrated how to play soccer and hockey. Sam was by far our keenest female player and showed great skill throughout, taking on the boys with no hesitation whatsoever. A big thank you to Michael, Martin, and the boys from N.E.W.S for their involvement on the day, and for once again providing the opportunity for the campers to give Wheelchair Sports a go.

With the theme being Heroes and Legends, the party on the last night of camp had a lot to live up to! No-one was disappointed as they all walked the red carpet into the hall, with faces all made up by our wonderful make-up team from Reel FX. Cassie was dressed as her doctor, which shows how important the medical teams are to people with muscular dystrophy, and how much they mean to them. Some dressed up as superheroes, and some were famous singers, actors or sports people, whilst others preferred to simply just dress up! Of course Party Night wouldn't be the same without Karaoke, and the evening kicked off with the MDNSW staff band, Muddy, doing an interesting interpretation of "We are Family". With that performance out of the way, many campers, carers and visitors took to the mic and sang songs well into the evening. Notable performers were the Northern Beaches carers contingent, with memorable renditions from Trixi, Barbie, Tegan and Des. Joss and Lucy wowed us all with

Old McDonald Had a Farm, Shane enjoyed his time in the limelight, and Shirl couldn't resist singing P!nk for the final song of the night with Tegan and Steve Irwin (aka Loretta). One of the highlights of the evening though was when our newly discovered talent, Jacob, sang some Green Day hits, much to the delight of the loud crowd and the proud mum! Camp tends to consistently produce great moments such as these, and they're moments you wish you could relive over and over again.

Daily activities

Composeability

Each afternoon, Mark Shepherd from Compose-Ability worked tirelessly with each of the 4 groups to help them write a song that they could call their own. Each member of the group was encouraged to contribute to the lyrics of the song in some way, then choose the type of rhythm/style of song that inspired them. Somehow after a couple of hours of work and laughter, a song miraculously came out of nowhere, and Mark used his equipment to record all the groups' voices, before mixing it all together onto a CD. Chris showed his talent on keyboard, whilst Von and Shirl showed us their diversity on vocals. All four songs produced were totally different, with the younger kids singing about icecream and coke; the teenage boys coming up with a great footy song; the all-girls band sang of their experiences on camp, and the adults put together a love song! All four songs were compiled onto the one CD and will now be a lasting memory of a unique experience. Mark will certainly be back next year!

Aqua Physiotics

Each evening we were fortunate enough to have a qualified physiotherapist in Suzie Hayden volunteer to run pool sessions for the campers. Those who participated in these sessions rated it very highly, especially the water games she conducted. Luke was our star swimmer, and Joss and Lucy made us all proud of their personal underwater achievements. Unfortunately the hoist in the pool wasn't adequate to allow all campers to access the pool, but rest assured that this feedback has been passed onto the Academy management in the hope that it may be rectified before our next camp. Thanks so much to Suzie for volunteering her time out of her busy schedule to provide this great opportunity to our campers!

Neuromuscular Clinics

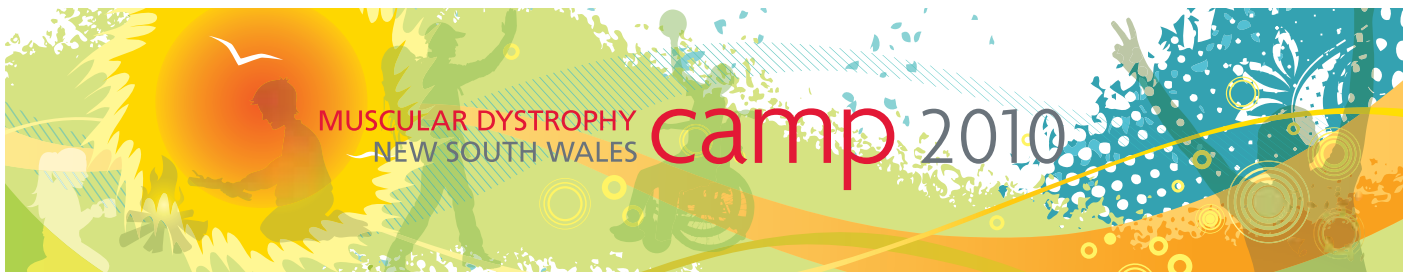
This year we had an even greater involvement from staff at the Neuromuscular Clinics at the Children's Hospitals at Westmead and Sydney. Not only did the campers and carers



Michael, Chris, Jo & Valeria at Party night!



Party night!



Daniel with his Survivor team, including carers & staff from CHW



Shirl & Jess



Shane & Ross

Day 5 Tears, Hugs and Farewells

It's the final day and the mood has changed. Tears of joy were replaced by tears of sadness as the realisation hit that another camp was over for another year. Livewire gave us another visit this year to help campers stay in touch with each other online after camp. Mary, Anita and Ross had organised for all campers to plant a tree at the rear of the Hotel, in the hope that each year we will be able to add to it, and eventually turn the area into an accessible maze for all to enjoy. The parents arrived to join us for the final BBQ, before moving into the Common Room for the Awards presentation, where many received their first trophy ever. It should be noted that both Scott and Bodene were recognized for their inspiring camp spirit and sportsmanship, and both have been asked to come on board next year in the newly created role of Mentors for our campers.

It was also important for MDNSW to acknowledge the outstanding work of the carers this year, who not only worked magnificently as individuals, but were also unbelievable as a team unit. Des and Trixi received acknowledgement awards for their committed contribution to the camp, whilst Sally was awarded the Best Performance of a Carer, and Ross received the coveted Campers' Choice Award. There were so many other awards we could have given out to carers, and it was extremely difficult to narrow it down to just a few - which is indicative of the high standard of care that was offered at camp this year.

We should also thank the services of Jill King, our Camp Staff Supervisor, who put in a tireless effort catering to the needs of all the carers and campers. Jill administered medication, went on evening rounds to monitor all carers and campers and assist them with any issues they were having, was our First Aid officer, and was awoken every night for one reason or another! Feedback from the carers was extremely positive about the way they felt supported by Jill, and the team from MDNSW certainly appreciated having someone so experienced there to help out when required.

It's also important to acknowledge those carers who returned from last year – Jo, Jess and Rebecca. Their commitment to take one week off work to attend the camp must be commended, and we can only hope they are able to come back again in future camps.

It was a great camp, shared with inspirational people, and we can't wait to do it all again next year!

benefit immensely from their presence at camp, but the Clinic staff themselves genuinely loved seeing the kids simply being kids, and having fun outside the clinical setting they would normally meet within. The OTs were particularly helpful, assisting with the carers' training sessions before camp, and running refresher courses on the first day of camp. They also were invaluable to have around when campers' equipment broke down or stopped working properly. A twist with a tool here, and a push of a knob there, and wheelchairs began to work efficiently once again. The OTs mentioned that it was also important for them to see how the kids' equipment was working for them in an active setting, as they could then evaluate the situation better, and pass on their observations and/or recommendations to the parents when they got back to the office. A big thank you goes out to Kristi, Sandra, and their teams of Fellows, OTs and Social workers for their dedicated involvement in Camp 2010. We would sincerely love to have you all back again next year!

Note

Quite a few adult campers came on board this year, and Scott, Steve, Von, Michael, Chris, Blaise, Shirl and Rex all enjoyed getting together of an evening simply just to chat as a group. Next year we'd like to cater more for this specific group and foster some of the friendships formed by considering the option to participate in some structured adult time in the evenings, such as therapeutic group sessions, or possibly even going off site occasionally to enjoy a cup of coffee or a movie together.





MUSCULAR DYSTROPHY NEW SOUTH WALES camp 2010

Thank you's

A huge thank you to the Academy Staff especially Wendie, Brendan, Pip and Abe for being so remarkably accommodating and generous with their time and resources! We also need to thank Bunnings, Garo from Stop, Shoes Plus, Anything Themeing, Wholesale Trophies, and Merrienne and Julie from the Northern Beaches and Meadowbank TAFEs. However, the camp would not be able to go ahead without the extremely generous funding from Ageing, Disability and Home Care (ADHC). Their support of the camp program so far is certainly very much appreciated by MDNSW, campers, student carers, and all families of children with muscular dystrophy throughout NSW.

Benefits of camp

The Camp Program has many benefits to participants. Campers realise the importance of inclusion. They mix with different people at various stages throughout the camp program, and learn to respect others' differences. Activities increase skills and enhance self-confidence and allow participants to discover and explore their interests, values and talents. As camp traditions are created over time, campers begin to feel as though they belong to their own unique community and become comfortable listening, talking, relaxing and reflecting with others. The camp environment therefore acts as the building blocks of self-esteem, and these traits are commonly transferred back into campers' daily lives upon their return home.

For those of you who have yet to give it a go, we would really encourage you to go on this amazing journey of self discovery, and emerge feeling part of this unique and special team. Camps also give families much needed respite from the hard work and responsibility that they face every day. There may only be one camp to go, pending funding, so now could be your last chance to experience something truly remarkable!!

Note

Both of our camps so far have been run at capacity, and next year we anticipate even more people wanting to go on camp. Therefore unfortunately some people wanting to go on camp will inevitably miss out. So please ensure you apply before the closing date to better your chances of securing a place for this unique experience!

Dear Loretta,

I am writing to express my appreciation of all the work that you and your team at MD NSW put into the recent MD Camp. I had the pleasure of attending on the afternoon of the first day to help with last minute questions regarding equipment and a refresher in manual handling training for the camp's volunteer carers.

I saw a lot of kids at the camp who are patients of the Neuromuscular Clinic at Sydney Children's Hospital, and also many who are not. Some were a little shy at first, as is to be expected on a first day, but you could even see the changes in their confidence by the end of the first day. It is such an important skill for our patients to learn to be comfortable having other people care for them, and to be able to describe their needs to their carers. The campers were certainly getting that opportunity, and having fun doing it too- it really seemed to make them feel like the experts they are in knowing their care needs and teaching their carers.

Some of these children had not been away from their parents before, so it was a big and scary step for them to take to come out on their own, but they were helped along by the great camp leaders and other campers who had been in that situation the year before.

I look forward to working with you to make next year's camp even better!

Regards,

Anna

(OT) Sydney Children's Hospital

Dear Loretta,

Having just returned from your camp at Narrabeen I thought I would write this brief letter. Not only was the event run in a most professional manner but it had a profound effect on me personally.

The reason I chose to volunteer for Muscular Dystrophy NSW was to see if I was suited to work in disability services. At first I was daunted by the idea of looking after two young guys with disabilities, but the training your team gave helped me to prepare.

My camper information said that they just wanted to have fun with their carer, and so I was determined to try my best.

I quickly came to admire the spirit and determination of all the campers, my guys in particular and found them to display the very best traits of humanity. They touched me deeply with their honesty, kindness, and generosity. I left feeling that I would never be the same.

I have already applied for positions working in the industry, and have also offered to do some more volunteering next weekend.

If I should end up within an organization as professional and dedicated as yours I would consider myself fortunate indeed.

Yours sincerely. 4/10/2010.





MUSCULAR DYSTROPHY
NEW SOUTH WALES **camp** 2010

Comments from Clinic staff

Hi Loretta

I am writing to commend you and your colleagues at MDNSW for the excellent organisation of the most recent MDNSW camp. It was the first one I have attended and it was great seeing all the kids having such a wonderful time. Each activity was designed so that every child could participate, irrespective of their functional ability.

It was great to see the kids among their peers and appreciate that they have a great quality of life, something not immediately apparent when they are seen in a brief clinic appointment. It was also good for the allied health therapists to attend as many OT issues were identified and sorted during the camp. It was also a good for us clinicians to see how their functional limitations affect their daily activities, and more importantly, how they tackled them. All of us from the CHW Neuromuscular clinic also enjoyed attending the camp. It also served as a meeting place to exchange ideas with allied health staff from other NSW muscle clinics.

Many of the kids who attend our muscle clinic tell us how much they look forward to the camp and now I know why! Looking forward to another successful and enjoyable camp next year.

Regards,
Manoj

Thoughts of a camper

It was my first time at camp with Muscular Dystrophy. I was excited and a little nervous but it didn't take me too long to settle in. There were great activities like artrageous, compose-ability, fishing, laser skirmish, party night, sports, survivors etc. The activities I enjoyed doing which was survivors, compose-ability, playing sports and party night. The staff and carers were lovely, helpful and were easy to talk to even though I have communication problems and also I made some nice friends. I was glad to be there.

Many for the first time, campers begin to trust their own instincts and gain a sense of independence and also making new friends! Camp is their chance to see themselves in a different light; to focus on the amazing things they can do, rather than the things they can't.

Campers have a chance to try new things like artrageous, canoeing, fishing, e.g. it's also an opportunity to learn a little more about being independent.

You might find that you feel a little homesick. Homesickness is the feeling of missing your family and everyday things that's normal for everyone. Just going away to camp is a huge step in building self-confidence. For the first time away from home, the child has positive experiences and makes friends. Many parents are worry when before their daughters and sons go on camp. Usually, the camp mails out information to your parents and a camper before a camper goes e.g. medications and what to bring. The camp counselor can be sure campers are up to date with their medications and know about any health problems that the campers have.

Parents should let their daughters and sons go on camp so they can have a break from them and do other things.

Children and adults with disabilities do not often have the opportunity to test their abilities in the context of everyday life.

I think camps are great activity to have because it separates parents and daughters/sons so they can meet new people and do awesome activities and also have fun!!

Shirl

A mother's perspective

My comments will be from a Carer's perspective. What does camp offer me?.

The Muscular Dystrophy camp is a quality experience for both my child and myself. Along my journey with Muscular Dystrophy I have supported and provided many opportunities and experiences but I can never fill that social independence that all young adults desire and enjoy. The MD camp gives my child acceptance for who they are as a person. This acceptance provides them with the confidence and value in themselves. Much of their life is a struggle physically to keep up with their peers and as they progress into early adulthood for many reasons, sometimes access, sometimes social acceptance, sometimes progression of the dystrophy itself but isolation becomes a very real problem. No matter how smart they are, how hard they try and how much we as a family try to compensate we cannot fill that void, This camp gives her all of this in one hit. Fun filled independence designed to fit her ability and even broaden her possibilities. All of the above is hugely important to her as a person and her personal growth and me as her mum.

This camp provides a two fold effect. For me it is the one time I can have a truly guilt free, decent break. If I take in home respite you are limited to very short periods of time and are very aware that your child is at home not necessarily having a great time. If you choose respite accommodation those houses generally either don't deal with the physical demands and the majority of residence have intellectual disabilities. This does not provide my child with any social stimulation at all. The consequence of this is that although we are told repeatedly to take time, to look after ourselves so that we can continue to provide quality care ourselves we hesitate and do not take those breaks, The MD camp is the one place where people are at her level and quality care is proved. For me to relax, rejuvenate and take a quality break myself it is imperative to me that my child is happy and receiving excellent care that I can trust.

We have participated in the MD camp for two years now with positive outcomes for both of us. I feel that I can take that time guilt free and am better able to manage the continued demands. For my daughter I see renewed confidence. She comes home tired but full of joy and stories to tell of her experiences. I feel she is more confident and outgoing on her return and more prepared to seek opportunity as opposed to withdrawing from life and its social experience. She comes home with a belief in herself and her abilities.

Regards
Sharon Robson

Our wonderful camp carers

Dear Loretta

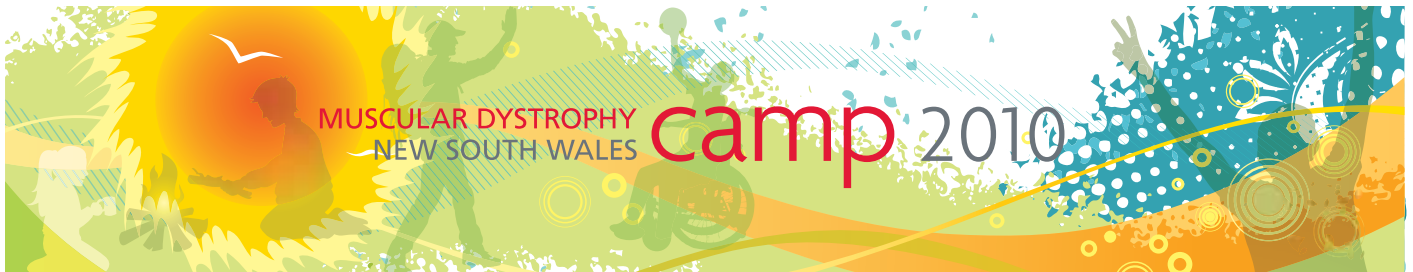
I would like to take this opportunity to thank you once again for allowing me to be a team member in the Muscular Dystrophy NSW camp, September/October 2010. This was a wonderful experience for me on both a personal and educational level. The skills and practical experience I gained will stay with me forever and be a real asset in my future career.

Prior to the camp I had only a little knowledge of Muscular Dystrophy or Epilepsy, but through research leading up to the event and experience gained during it I now feel that I have a much broader understanding of these conditions and the difficulties faced by those who deal with them on a daily basis.

As a result of all the hard work done by all involved in the Muscular Dystrophy organisation I saw the campers have the opportunity to shine in a caring environment which allowed them to socialise with others facing challenges similar to their own. I feel proud to have played some small part in this.

Lorraine





MUSCULAR DYSTROPHY
NEW SOUTH WALES **camp 2010**



Camp comments

Parents of campers

"We struggle with (our son's) long term sickness... To us it is like the end of the world. However since we have joined the organisation and (participated) in their camp we have found it to be very helpful, giving us our own time to release the tension".

"We hope this camp continues to be funded, so we can keep smiles on the faces of the kids that suffer this dreadful disease."

"My 3 children all have muscular dystrophy, and attended the camp. It is the only respite we receive all year."

"While (my children) are at camp we know there's no need to worry, because the carers/workers do their very best for the kids, to ensure they have the best time possible."

"This camp gives (my daughter) the unique opportunity to meet people and do lots of different activities. It gets her out socialising and is like a holiday for her."

Benefits to the campers

"(Our son) enjoyed the activities very much and became more positive in mind and vision, which he can't get from being around other people."

"(Our son) seems calmer, and finds it easier to control his anger and deal with the emotions (relating to his condition)."

"This camp provides the opportunity for (our son) to interact with other children who also have his form of Muscular Dystrophy. This is the only time he has been able to meet others with the same MD form. This experience is invaluable in a life where he normally doesn't have anyone else to talk to about what it is like for him."

"My children love camp and don't stop talking about the things they did, and the friends they made."

Family benefits

"My husband and I had great quality time together for the first time in 10 years; refreshing our relationship, and learnt to re-love each other. Thanks for the camp that gave our family new hope and happiness."

"The caring, positive atmosphere at the camp, the carers and wonderful organisation, allows me as a parent to have some time alone, and to spend quality time with my (daughter)...without a worry in the world about his care and happiness."

"This camp gave my son and I some 1 on 1 time together and our family at home a bit of a break."

"The camp has given the rest of our family...the opportunity to plan holidays that do not involve wheelchair accessibility issues."

"It gave me a chance to rest, and see people I don't get to see very often. I felt so much more refreshed to enjoy the rest of the school holidays with (my daughter) after she came back from camp."

"The organiser and carers have done a wonderful job with the clients... sharing their love, care, kindness and patience with the sick children. They are our angels."

Campers' comments

"The 2010 camp was one that appealed greatly to me because of the unique friendships already made at the previous camp."

These friendships are ones that I don't get to experience very often, as I don't regularly see other people with disabilities. The camp creates the right environment to make these bonds."

"My brother came out of his shell and engaged in all activities, which he doesn't do at home."

"The camp experience gives us a great break from everyday living."

Carers comments

"The comradery between the campers was beautiful to watch as it grew very strong over the week."

"As a result of all the hard work done by all involved in the Muscular Dystrophy organisation, I saw the campers have the opportunity to shine in a caring environment which allowed them to socialise with others facing challenges similar to their own. I feel proud to have played some small part in this."

"This was not just a Placement, this was a very personal journey for me. I learnt some key things about myself. Camp changed my life."

"This was a wonderful experience for me on both a personal and educational level. The skills and practical experience I gained will stay with me forever and be a real asset in my future career."

"I was aware that being the parent of a child with a disability would be incredibly challenging and demanding, but I did not comprehend the magnitude of how hard it really is (until camp)."

"Not only was the camp run in a most professional manner, but it had a profound effect on me personally."

"Prior to the camp I had little knowledge of muscular dystrophy, but through research leading up to the event, and experience gained during it, I now feel that I have a much broader understanding of these conditions and the difficulties faced by those who deal with them on a daily basis."

Transformation

"The transformation of two particular campers is very prominent in my mind. Both were very withdrawn and quite depressed at the beginning of camp. With the gentle encouragement of carers and camp coordinators, by the end of the week, the smiles on those boys' faces were something I'll never forget."



Muscular Dystrophy NSW new set of wheels!

With great thanks to the Shane Warne Foundation and ADHC, Muscular Dystrophy NSW has recently been able to purchase a mobility van.

The van has room for three wheelchairs and has six fixed seats, including the driver. The van has already come in handy for Camp and the recent Medical Seminar. In the future, the van will be used for all client events and to assist in supporting our clients.

If you have some free time on your hands, experienced in driving a mobility van or willing to learn, please contact the office, as we would love to have one or two volunteers to help us with transportation. You only need a standard licence, and the van is fully automatic.

We are extremely grateful to the Shane Warne Foundation and ADHC for greatly assisting in the purchase of this van. Look out for its distinctive sign writing in a suburb near you!



Duchenne Registry Initiative

A major new initiative for children and young people with Duchenne muscular dystrophy was announced on 15th November and launched at Parliament House and Muscular Dystrophy NSW, Meadowbank. This initiative represents a significant step forward in the fight to find treatments for the disease, setting up a registry and linking into the TREAT-NMD global network of registries. The following media release explained the project in more detail:

Children and young people with Duchenne Muscular Dystrophy (DMD) have increased access to lifesaving treatments through clinical trials as a result of the newly established National Duchenne muscular dystrophy Registry to be launched on Monday 15 November between 1.30 and 2.30pm at Shepherds Bay Community Centre, 3AW Bay Drive, Meadowbank, Sydney.

The DMD registry initiative was driven by patient support and advocacy groups in response to recent developments in genetic technology, and in particular clinical trials currently being planned, that offer the hope of treatments for this devastating disease.

Today's launch represents the culmination of a unique collaboration between patients (and those with affected family members), clinicians and clinical trial sponsors to step up the global fight to find a treatment for this devastating disease. This collaboration does not end with the establishment of the Registry – it will continue on through the long term commitment of **patient support groups** to continue to promote the opportunity for patients wanting to participate in trials, of **clinicians** who keep their clinical information current and provide information to their patients about the existence of new trials or treatment options, and finally, of **clinical trials sponsors** to make feasibility enquiries of the Registry and to notify clinicians, through the Registry, of new studies.

The Registry, collates the patient's clinical and genetic mutation data to improve the care of DMD patients, and to accelerate the recruitment process for Australian DMD patients into international multicentre clinical trials. The Registry links into the TREAT-NMD global network of registries, opening up opportunities for Australian DMD patients to participate in clinical trials being undertaken anywhere in the world. www.nmdregistry.com.au/dmd

The TREAT-NMD global network of national registries has proven effective in improving the health and management of boys with DMD. The next step is to launch registries that will enable rapid access for trials of other neuromuscular and rare diseases such as spinal muscular atrophy (SMA)



Peter Hojgaard-Olsen President of the Duchenne Muscular Dystrophy Foundation which has been significant to the instigation, development and launch of the registry.



Fiona and Adam Cook. One of many Australian families who will benefit from the Duchenne Registry.

Siblings Australia

This national organisation, headed by Kate Strohm, aims to meet the needs of siblings of children and adults with disability and chronic illness.

1. SibworkS peer support program for siblings aged 8-12 years 2nd edition - now released. Facilitator manual, pack of 10 workbooks Order online at www.siblingsaustralia.org.au.

2. Facebook – connect to their page at www.facebook.com/pages/Siblings-Australia/178545022595?ref=ts.
3. Website - regular updates on the News page.
4. Other projects – soon to complete a DVD for parents (funded by Woodend Foundation) and a parent booklet (funded by the NSW government); workshops for providers and parents.
5. Funding - lobbying for siblings to be included in policy and government funding. You can become a member online.

Medical Director Baton passes from Dr Heather Johnston to Dr Alastair Corbett

The role of Medical Director at Muscular Dystrophy NSW is a very important and responsible one, and it was pleasing that at the AGM on November 15th, it passed smoothly from Dr Heather Johnston, Director of the Neuromuscular Clinic at Sydney Children's Hospital, to Dr Alastair Corbett, Clinical Professor of Neurology and Director of the adult clinic of Neurology at Concord Hospital.

Dr Heather Johnston

Heather approached the role in a very conscientious and thorough way during her 10 year incumbency. She has only missed board meetings where they have unavoidably clashed with important conferences, and has presided over (or organised):-

- Hundreds of (often complex) equipment applications
- Numerous research funding allocations
- Numerous Medical Seminars, for which she compiled the content and arranged the participants
- Very comprehensive information material provided for members

Often Heather drew from her experience to provide wise advice of a general nature to Muscular Dystrophy NSW staff in regard to different aspects of their service provision.

Heather's understanding of the medical issues which face so many of our members, has been called upon on many occasions over the last 10 years. She has been very generous with her

time and made herself available to answer questions and to assist staff and members where required. She will remain a valued member of the board of Muscular Dystrophy NSW.

It was very appropriate that the last Medical Seminar which Heather organised on current research into neuromuscular disorders on October 23 had the highest attendance, and was one of the most interesting for years. Heather gave an interesting summary of some of the important work being done around the world, as well as introduced the interesting list of speakers from the leading clinics in Sydney, including Dr Alastair Corbett.

Dr Alastair Corbett

We are most fortunate to have someone of the calibre of Dr Corbett to take over the Medical Director role. He has contributed to numerous neuromuscular studies and papers over many years, and is a clinical professor with Sydney University, and a clinical neurologist specialising in neuromuscular disorders and stroke at Concord Hospital.

Alastair is already well known to many of our members, and has been a director of Muscular Dystrophy NSW for some years.

We look forward to his approach to the role and his significant experience of consultation on neuromuscular disorders which will in different ways be of great benefit to our members.

Rob Ferguson

President

Members' Advisory Committee

The Members' Advisory Committee (MAC) is an important part of the Association. If you have any issues or suggestions of how the Association can be of service to you, then feel free to let us know.

The committee is made up of members from diverse backgrounds. MAC also puts forward suggestions for events and seminar topics, as well as reviewing events held by the Association, so that we can make recommendations to the Board. This process helps the Association to continually provide dynamic services to members.

MAC meets approximately four times a year on a Thursday afternoon and it involves the MAC members as well as the Association staff including David Jack, Pene Hodge and Georgina Christofis. It is a great opportunity for Members

to have face to face interaction with the staff and have a positive impact on the way the Association provides its services to members.

The next MAC Meeting is scheduled for February 2011.

If you are interested in joining MAC, or putting forward any ideas, suggestions or comments, please feel free to contact Pene Hodge, Client Services Manager, at the Muscular Dystrophy NSW office or myself on 9643 1429, or email me at MBaptiste@bigpond.com

Michael Baptiste

Chairperson, Members Advisory Committee



Boccia Anybody?

The Game of Boccia

Boccia is often described as a game played in ancient Greece that is related to other types of bowling games around the world. The most common association is with the game of bocce which originates from Italy. However, boccia is an adapted sport for people with disabilities, but can be enjoyed by anybody who wants to test their hand eye coordination. The intensity of competition can vary considerably. Boccia can be a fun game of brightly coloured plastic balls played by the family on the beach. It can be a more structured recreational game, played on an agreed court area. While at the highest level, it can be played formally under the full weight of the 52 page international 10th Edition rule book. Like any sport played by kids or adults around Australia every day of the week, it's about fun, friendships, being part of the community, setting personal goals and to some extent competing. For a very few it's about high level competition, long-term commitment to training, representing the State or country, and international travel leading to the Paralympics games. But none of that happens without giving it a go at some level. More of that later.

How to play Boccia

Essentially, the game is based on a contest between 12 coloured balls being thrown or launched towards a jack ball. The person, or team, who gets closest to the jack after all balls have been thrown, is awarded points towards winning the game. All competitive games are played indoors on a badminton sized court. Games are played over four ends, which means the full set of balls is thrown four times. The four agreed scores at the completion of each end are accumulated to form the final score. Levels of complication can then be added on. More complication requires more structure, and that is when the participants need to identify what they want to get out of it. It is always important to enjoy sport, and more structure does not necessarily deliver more fun. Most people start with fun and progress into more structure.

The critical skills are easy to define. It is deciding what shot to play, executing that shot and then evaluating the game situation. That simple sequence of events equally applies to two people competing with 12 oranges across the living room floor. The simple advice to new starters is to look around the house, and see how you can replicate the game with what's at hand.

How to get started

Having beaten all your family or housemates with the oranges, it may now be time to think outside the home arena. A number of opportunities will present themselves with minimal research;

- Schools are designed to deliver sport to all its pupils. A few schools deliver boccia, and you just need to ask the Principal to consider it.



- Local sports programs for all people with disabilities are run across the state under the NSW Department of Sport and Recreation. A trained recreation officer may get it started, but they are typically run by a group of volunteers that emerge from the community. These local groups are given a "Sports Ability" package free of charge by the Australian Sports Commission (another legacy of the 2000 Sydney Olympics and Paralympics). This package includes a brand new set of international standard boccia balls worth about \$400. Find your local club, have a go and make some friends.
- Disability sports "come and try" days occur all year round. These can be run by disability organisations, NSW Sport & Rec, or can be talent search days run by the Australian Paralympics Committee.
- Established boccia competitions happen in NSW and anybody can join them. There is the NSW State League, and NSW State Titles, both of which lead up to the National Championships. The leap from beginner to national competition is more achievable than you may think. Registration is easy and cheap, and assistance with equipment is usually possible. (See info box)

Basically, boccia is happening around you at some level, and you have no excuse to keep it in the too hard basket. Get out there and get involved!

Boccia Anybody?

What equipment will you need to get started

Since all equipment is provided at "Come and Try" days and at Clubs, no initial investment is required. After that, the options to consider would be these; whether to buy your own set of balls, whether to get your own ramp (if you are a classified BC3 athlete), and whether to adapt your wheelchair to maximise performance. Second hand equipment is usually available, and costs and quality vary. You could pick up a decent set of balls, or ramp, from about \$100. The upper limit of top class equipment would be a new set of imported Portuguese balls at \$750, to a hand made marine ply ramp at just under \$1,000. Mid range options would include a new set of balls at \$550, or a standard wooden ramp at \$500.

Boccia NSW can advise you, and provide the contacts. Probably the more challenging costs are those involved in getting transported to training, and getting the personal support needed. These are probably costs that affect every boccia player whatever they choose to do with their recreational time.

The key thing is to carefully invest time and money in proportion to your own goals and aspirations. Grants and sponsorship are available at all levels. Indeed, an athlete can learn a lot from this process, which will benefit them in all other areas of their lives.

How Boccia NSW can help you

Boccia NSW (BNSW) is an Incorporated Association run by a volunteer committee. It is affiliated to Boccia Australia, and is recognised by NSW Sport & Rec as the peak representative body for the sport across the state. A quick browse of its website will give you the whole story. Also, by getting yourself on the distribution list for the bi-monthly newsletter will be kept up to date with all you need to know (See info box). BNSW supports boccia at all levels. The appropriate level of advice and training is available for newcomers to elite athletes. It may assist a new athlete to visit a training session of the NSW High Performance Training Squad which is run by the Spastic Centre of NSW at Avalon (See info box)

Boccia at the International Level

Boccia is an adapted Paralympics sport which is regulated by the international body called CP-ISRA. At this level it is reserved for people with high levels of cerebral palsy or related physical disabilities. However, below that it is a game that any person with, or without a disability can play. As with all Paralympics sports, athletes are classified according to their level of disability, and only compete against comparable athletes. The key principle is to create the level playing field. While this targeted group of athletes is small, and the level of physical disability is high, they are typically very intelligent people who are very committed to achieving goals. In terms of drive and commitment they are comparable to any other sportsman.

The commitment of a sporting icon such as Ricky Ponting is easily matched by an international standard BC3 boccia athlete, who in relative terms, probably devotes more of their available time to training and playing.

An Opportunity to Play Sport

My own sport over the years has delivered great health benefits, friendships, positive learning experiences and the occasional moment of glory. My whole weekend is spent transporting my kids around various sporting venues, cheering them on at the sidelines, and seeing them getting the same benefits. On this personal basis, and aside from all the research that is available, I am convinced that boccia is able to provide the very same benefits to any person with a physical disability. Typically this group of people don't think they have the same sport opportunities, but they do. I have seen the face of joy of a beginner, and have taken athletes to international tournaments. Physical ability is not the key requisite, it's having the desire to give it a go. For people with physical disabilities this is your sport. What have you got to lose?

About the author

Peter King - whose current involvement in boccia includes;

- Manager of the Spastic Centre's pilot project called "Boccia Community Access Service"
- President of Boccia New South Wales
- Vice President of Boccia Australia
- Member of the APC's Sports Advisory Panel for the Paralympics Preparation Program for boccia

Key Contacts

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APC - Anna Muldoon; anna.muldoon@paralympic.org.au

Key websites

Boccia NSW – <http://sites.google.com/site/bocciansw//home>

Boccia Australia – <http://www.boccia.com.au>

NSW Sport & Rec – <http://www.dsr.nsw.gov.au>

CP-ISRA – <http://www.cpisra.org>

Australian Paralympics Committee - <http://www.paralympic.org.au/>



The NSW Colts Prepare For Another News Campaign

In December the NSW NEWS (National Electric Wheelchair Sport) squad will begin trials to select the team for NEWS 2011. From the hopefuls, the team of six players is selected to play the sports of Hockey, Soccer and Rugby League at the Annual NEWS Tournament which is specifically for people with Neuromuscular Disorders who use an electric wheelchair for mobility.

In April 2010, NEWS celebrated its 25th Annual Tournament and NEWS 2011 should be another big year for competitors from NSW, VIC, QLD, WA, SA and ACT. Last year NSW provided players for ACT and QLD, who unfortunately were unable to field a full complement of their own players, which provided some young NSW players an opportunity to compete at NEWS. Hopefully there will be another opportunity for players who miss out on selection in the NSW team to still compete at NEWS 2011.

Nonetheless, there is great competition among players striving to be selected in the NSW team, so the upcoming trials will be quite intense. The players in the squad have been playing sport for many years and this means that NSW will have a very strong squad to choose from as the Colts aim to reclaim the Roger Melnyk Trophy from Victoria, who are the current holders, as well as defend their Soccer and Rugby League titles. NSW also want to avenge their Hockey Grand Final defeat. It will be a tough ask as Victoria are very strong and WA and SA have some emerging talent, so the tournament will be a hard fought competition.

The NSW squad training begins in December but anyone who wants to come and try the sports or just watch is always welcome. The training dates are as follows:

December: (Saturdays) 4, 11, 18 from 1pm to 3pm.

January 2011: Saturday 8, (1 – 3pm),
Sunday 23 (11am – 1pm),
Saturday 29, (1 – 3pm).

February 2011: Sundays 6, 13, 20, 27 from 11am – 1pm.

March 2011: Sundays 6, 13, 20, 27 from 11am – 1pm

April 2011: Sunday 3 from 11am – 1pm.

All training sessions will be held at Kevin Betts Stadium, Ralph Place, Mt Druitt.

Muscular Dystrophy NSW greatly supports our NSW NEWS squad and on behalf of all the players and their families, I take this opportunity to thank the Association for all its assistance, support and encouragement.

For any more information about the training sessions or the sports in general please feel free to contact me any time on 9643 1429 or email MBaptiste@bigpond.com

Michael Baptiste
National Director NEWS
NSW Coach

Muscular Dystrophy NSW Director – Role Description

Muscular Dystrophy Association – New South Wales

MDNSW is a major and successful not-for-profit organisation providing a wide range of advocacy, care and support services for people with Muscular Dystrophy & other related chronic neuromuscular conditions. It operates under the direction of the board of directors.

Skill:

MDNSW is seeking two non-executive directors committed to the vision of the organisation, with clarity in debate, integrity & courage and able to work alongside others. Future directors should be prepared to contribute at both Board and Board Committee levels.

Attributes that would be valued are past board experience in guiding the strategic vision of a complex not for profit enterprise and experience in gathering government, business and donor support for the activities of the Association.

Experience and knowledge in healthcare and social services, and in marketing, fundraising, and advocacy would all be valued, but of more importance are the personal attributes of the candidate, and your ability to make a valued contribution to the success of the Board and the Association.

Organisation type:

Not-for-Profit (Charity)

Industry:

Health Care and Social Assistance

Remuneration:

Volunteer

About the Organisation:

Muscular Dystrophy Association of NSW commenced operation in 1957. The Association operated out of its own offices at South Sydney for many years, before moving to the current location of Meadowbank (Ryde) in 2008. In 2008 the name and logo was changed to Muscular Dystrophy NSW, reflecting its modern role being one of several states and territories providing services to its members. Further information on Muscular Dystrophy and the activities of MDNSW can be obtained from our website www.mdnsw.org.au

N.E.W.S. Trivia Night

Join in the fun of our Trivia Night and help us to support people living with Muscular Dystrophy

Proceeds will be used to send our team of wheelchair athletes and carers to the National Electric Wheelchair Sports in Sydney from 11th – 17th April 2011



When: Saturday 26th February 2011

Where: Parramatta Leagues Club, Wentworth Room, 13-15 O'Connell Street, Parramatta

Time: 7:00pm for 7:30pm Start

Cost: \$15 per person



The Event:

20 Tables of up to 10 people are available

Bar available

No food to be brought to the venue

For Bookings, please contact:

	Phone
Stuart Brown	0418 861 610
Dennis Everard	0409 317 117
Percy Baptiste	9643 1429
Muscular Dystrophy NSW	9809 2111

Cheques payable to:

Muscular Dystrophy NSW

PO Box 1365, Meadowbank, NSW, 2114

Credit card payments and invoices for sponsorship can be made by calling the office on: 9809 2111



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Letters to the Editor
can be addressed to:
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PO Box 1365,
Meadowbank NSW 2114.

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 Management Clinic
9845 1904

ADULT CLINICS

Concord Hospital Neuromuscular Clinic
9767 6864

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

Adult Genetics Clinic, Westmead Hospital
9845 3273

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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.

