

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

ISSUE 75 WINTER 2010

PRINT POST APPROVED PP 255003/01200

Time After Time

Celebrating

75TH

**Special
Issue**



md

muscular dystrophy
new south wales

Well its time for the Winter edition of Talking Point and I am excited to be bringing you our bumper **75th issue!** As you will see by the centre spread, TP has evolved over the years, however continues as an informative magazine for people with neuromuscular disabilities, their families, carers and supporters. I hope that today Talking Point can also be seen as an effective education and marketing tool, as we highlight the work of MDNSW, developments in research and services and the many achievements of our members.

It is timely in our 75th issue that we pay tribute to the father of Talking Point **Mr Bruce Ellison**, who has retired after 18 years service to MDNSW. Before my time as editor, Bruce led the way putting together 60 informative issues of TP. A role model to me since I first joined the association in 1991, I have fond memories of the early days sitting up the back of the Northcott bus with Bruce chatting away (really?) on our way to Mt Druitt to compete for the North Sydney Bears in the Push and Power wheelchair sports competitions. It was in a large part due to Bruce's encouragement that my close association with MDNSW began. Over the time he

has contributed, Bruce has been a friend, role model and mentor to many in our MD community; he has advocated for the rights of people with disability and he has led our Association into a bright future. Bruce truly is a living treasure!

Last month I was honoured to be asked to be a **spokesperson for the Muscular Dystrophy Foundation** and appear in a DVD created to promote awareness, and be used for the Jerry Lewis corporate events. It was such fun to be treated as a star for the day and join some of our younger starlets in a production studio in Surry Hills (not at all like me to love the spotlight?). I believe the TV ad and 4 minute DVD are available on YouTube – contact Rebecca Scelly to find out more. An added bonus from the day was having professional hair and makeup glam me up the very same day I joined MDNSW members at the CATS musical matinee! Thanks MDNSW - I wish every Wednesday was that exciting!

In this edition you will discover many **exciting opportunities** you can get involved with. There is news from Client Services (near and far), fundraising events and the sporting arena. Sandra Holland from the Sydney Children's Hospital has



prepared a terrific article on the clinic services for our kids.

Our upcoming **Spring** edition of Talking Point will feature a range of stories from members and their families sharing their ups and downs in life. Would you like to share your experiences and insights with others? Would you like to be published? Do you have useful tips for our members? Like to share your photos, poems, art, hobby or event? If you answered yes to any of these questions please contact me or Pene at MDNSW.

Looking forward to seeing you again when spring is in the air!

Stay warm and well.

Carolyn Campbell-McLean

All contributions can be sent to The Editor, PO Box 1365 Meadowbank NSW 2144 email: cazza74@inet.net.au tel: 9684 6443

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Hello from the President

I am delighted to be able to say that at the start of David Jack's 3rd year as Chief Executive Officer, the MDNSW board can look back at the 3 year strategic plan which emerged from the board's Building Strength program, satisfied that the majority of its major goals have been achieved.

These include:-

- Moving to centrally located suitable office premises, with excellent transport access, parking, shops and nearby community centre
- Adopting a new logo and graphics
- The development of a well maintained, informative and popular web site
- Developing a successful camp program
- Developing a weekend retreat program
- Developing a home visit program
- Receiving increasing amounts of Government funding (\$300,000 over 3 years for annual camp funding from ADHC, in addition to the highly successful existing Flexi- Rest, and Carer's programs)
- Assisting with the development of Muscular Dystrophy Foundation to a point where it should provide substantial benefits to MDNSW in coming years
- The development of online communication access for younger members using Live Wire
- Vastly improved accounting procedures using MYOB
- Successful implementation of a state of the art data base, for all membership and fundraising purposes

I believe the appointment of Pene Hodge as our new Client Services Manager and Rebecca Scelly as Fundraising Manager will herald the future achievement of a new level of fundraising and service provision for MDNSW over the next 3 years. Two recently successful grant applications for a total of \$40,000, with continuing applications for specific project funding, and plans underway for a "For Life" program to assist school leavers and others achieve their life goals, augur well for our members.

During April Bruce Ellison retired from the board. Bruce made an outstanding contribution to the development of MDNSW, serving for 15 years as a director and 3 years as President, stepping down in 2007.



Bruce's greatest contribution in my view was his understanding of the needs of those living with MD over the different stages of their life.

His successful development of Talking Point over many years, particularly the inclusion of content that mattered to members, was probably the best way Bruce could express this understanding, and assist his fellow man. It is fitting that we are now celebrating the production of our 75th Talking Point, built on the original foundation which Bruce established.

His sharp wit and sense of humour will be greatly missed by the board.

We wish Bruce and Ursula well with their new life at West Chatswood.

And I wish you all well in the celebration of our 75th Talking Point, and with your own personal achievements.

Best wishes,

Rob Ferguson

President, Muscular Dystrophy New South Wales

Time After Time

In her song Time After Time, Cyndi Lauper acknowledges the importance of our friends and family,

*if you're lost you can
look--and you will find me
time after time
if you fall I will catch
you--I'll be waiting
time after time*

In this 75th Edition of Talking Point we reflect on the many amazing stories told of how, time after time, carers and parents love and support their children and young people. There have also been many stories of young people mentoring children, whether on the court at a NEWS tournament or at the MDNSW camp.

These heart warming recollections reflect the very best in people and remind us all that we can both give and receive.

During these past 75 issues of Talking Point MDNSW has also increased its support to members. Camps, retreats

and home support just some of the new opportunities available.

I am also very pleased to announce that the Department of Ageing, Disability and Home Care (ADHC) has approved a new grant of \$135,000 to fund a full time home support worker and a part time education officer. It is our aim that over 200 families will receive a home support visit during the next 12 months and provide some follow up support. This will enable a stronger connection to all families including those living in regional areas.

To ensure that our members receive the very best care from all their service providers, ADHC is also funding a part time education officer position. A resource and training package will be developed and able to be delivered to other disability services which have clients with neuromuscular disorders. This will enable the knowledge and experience of MDNSW to be shared ensuring that care to members is of a high standard.

Talking Point is important to our members and 75 issues of Talking Point would not be possible without the amazing contribution of people such as Bruce Ellison. As a Director, former President and inaugural editor of Talking Point, Bruce is appreciated for his vision in establishing Talking Point. Current editor, Carolyn Campbell-McLean has done outstanding work in overseeing the recent development of the magazine to full colour and has set a very high standard. I would like to also acknowledge Louise West who did the graphic design work for twenty issues and enabled Carolyn and Bruce's vision for a valuable client focussed magazine to be fulfilled.

Time after time we meet wonderful people in our MDNSW network who inspire our team. It is our very special privilege to serve the needs of our client and carer members and we do appreciate your friendship.

David Jack
CEO

letters

Dear Carolyn

I really enjoyed your article on your holiday - great to see you and Steve having such a good time.

Your article was timely as we are planning a holiday in Melbourne with Hamish and having problems with accommodation - we thought we had the ideal place but the 'lift' next to the two steps at the front will not take the weight of a person in a powered chair and the only level access is via the back lane - a bit scary at night!

So I have now emailed off to Mantra on Little Bourke to see if they have vacancies at that time. I am going to save the websites mentioned in your article for future reference.

I wonder if there is any value in having a section of the MDA website with lists of accessible

accommodation and transport which members could add to. It would make holidays much easier if we could use others' experience as general websites on accommodation don't tend to focus on disabled access for people in powered chairs. We found a house at Shoal Bay a couple of years ago which had level access, a large accessible bathroom and an adjustable bed (such luxury) which suited us well and it would be good to share information.

Anyway thanks for your article, and all the best to you and Steve. And 'go the Tigers' and the Swans!

Kind regards

Heather Gordon

Note from Editor:

"Great idea Heather, I'd also like to encourage other members to share their accessible travel information and experiences for more Access All Areas articles in Talking Point." Carolyn

Farewell to MD NSW

Dear fellow members, after 18 years of service to MD NSW I have decided to retire. Over this time I have made many friends, too many to name. But I must mention two people that have been of great encouragement to me and fine examples of commitment and camaraderie, Keith Allen & Jacqueline Morgan. I have also been privileged to have worked with such a fine group of like minded people dedicated to helping others.

Over the years our society has at times been very slow in understanding the needs and desires of people with neuromuscular disorders. We are just one segment of a many varied physical disability community, all trying to be heard. We must continue to strive as people with neuromuscular disorders, families, carers and supporters to do our bit.



One of the things that irks me is the person who pities me, this demeans me and makes me angry. Pity is not what I am looking for when I meet someone, I would prefer that they would treat me as equal, and ignore my physical disability.

To many people a disability seems to mean that you are living a life of less quality and that you cannot contribute much to the society you live in. I believe this is not true, in fact it is quite the opposite. Sure people with a disability

require assistance in daily living to live, work and play but they contribute to the best of their ability and can increase the general well being of our society. Before I became involved with the MD community I was working for Life Savers Confectionery (before they were gobbled up by Rowntree & then Nestle). When applying for the job as Credit Officer I convinced the personnel office that my disability would enhance the company and provide stability within the department as they were having a high turnover of staff, which it did.

I was diagnosed with probably Becker muscular dystrophy at age 10. I was told at that stage that I would be confined to a wheelchair by age 15 and most probably die in my early twenties, such was the knowledge at the time. Obviously I am still here, aged 56, confined to wheelchair since age 23.

Through my life I have spent many hours following sport. Like many young boys I once dreamed of playing either football or cricket for Australia. But having been diagnosed with MD I had to change my dreams. I realised

that playing sport would be very difficult but by watching sport I could still be involved.

In 1977 I went to watch my brother Robert, play cricket for St Andrews, Lane Cove, the local church team. The cricket was becoming very boring so I said to one of the team players if I could do the scoring. He showed me how to do it and I started scoring the match. This involvement made the game more interesting. I went on to score for the team until 1992, by this time I was an



integral part of the team. I have been the scorer, the coach, the selector, the mentor, the treasurer and drink boy. I have also umpired from square leg and on one occasion from behind the stumps. My pride and joy are my premier caps for winning B grade and C grade.

During the late 70s and early 80s I also assisted my mate, Chris during his cycle racing career. This involved many hours following and feeding him throughout country NSW. One race in particular holds fond memories, namely, the Grafton to Inverell Classic, which is held in September each year. The race goes from the flat land of Grafton up over the Great Dividing Range mountains to Glen Innes and then on to Inverell a distance of 226kms. I had three riders to look after, Richard came first in B grade, Mike who retired and Chris who came last. Richard won 169cm TV and trophy, Chris won an electric knife (maybe to slash his tyres!).

I have been a fan of motor racing since my early teens and have been to many race tracks over the years, namely Amaroo Park, Oran Park, Warwick Farm, Bathurst, Winton and Surfers Paradise. Overseas I have been to Monaco, Silverstone, Spa, Imola for Grand Prix and Le Mans for the 24hours race.

As you can see my disability has not stopped me enjoying sport and living a full life.

Bruce Ellison



Inspiring Times

Since starting at MDNSW in April of this year one word has gone through my mind on numerous occasions and that is the word 'inspirational'. I was inspired when I met families at the Easter Show, when meeting clients and their carers at the weekend retreat, during a home visit and meeting the Members Advisory Committee. What inspired me was our members attitudes, their warmth and openness, their passion and the way, despite some significant challenges, they live their life to the fullest.

This 75th edition of Talking Point pays special tribute to a member of MDNSW – Bruce Ellison whose many years of dedication to our organisation, its Board, the families and to this magazine is truly inspirational. One of my first introductions to MDNSW was viewing Talking Point from the website in my office in New Zealand not realising at the time I would get to be a part of this wonderful magazine and the people and organisation it represents.

The word inspirational has also formed the theme for this year's children's camp, which is Heroes, and Superstars. Whether they are sporting, television or someone who has achieved something great against all odds, we all have them. Preparation for camp is well underway

with registrations starting to come in, activities and entertainment booked. I have heard from many that last year's camp was fantastic and everyone really enjoyed themselves. Can I encourage you to get your or your children's registration in early so you don't miss out. Please ring me if you have any questions or concerns.

So much has been happening in Client Services since the last Talking Point. Events have included the Easter show, natural therapies workshop, the multicultural lunch, scrapbooking class, the CATS weekend retreat and matinee with brunch. We have been fortunate enough to employ a part time events coordinator to help organise the many events on our annual calendar. This will be particularly helpful for the up and coming HOGs day planned for Sunday the 12th of September and the camp later that month.

Last month we launched the Muscular Dystrophy NSW Young Achievers Award which is an opportunity for our younger members to receive financial assistance to realise an academic, business, creative or sporting dream. For more details see the advertisement in this issue of Talking Point or phone me for further details.



I was fortunate enough to spend some time with Renee prior to her leaving and noticed that in her last article in Talking Point she promised to provide us with an update of her exciting travels. She sent one through to me last week, which is included on the next page. It was great to hear she has having such a wonderful time.

Thank you all for such a warm welcome it really did make a difference. I look forward to meeting you all over the next few months. Please do contact me by phone or email if there is anyway the Client Services team can help.

Pene Hodge
Manager Client Services

It's only Natural

The MD Natural Therapies Workshop was an afternoon not to have missed. We started with sharing a light lunch which was an opportunity to meet with other MDNSW members.

Our first speaker was Marian Walker, who has over 23 years experience in adult education and is an instructor in Qigong an ancient Chinese practice of simple exercise, breathing and meditation. Marian spoke to us specifically about Qigong Therapy and provided both a theoretical and practical workshop.

Our second speaker was Dr Russell a Consultant at the Paediatric Haematologist and Oncologist Centre



for Children's Cancer & Blood Disorders at Sydney Children's Hospital. Dr Russell provided us with an overview of natural therapies, what to consider when looking

at complementary and alternative medicines and the possible dangers. Her message was to always consult with your General Practitioner or Specialist prior to undergoing any complimentary or alternative therapy.

The final speaker was Dr Xiaoshu Zhu who is Head of the Chinese Medicine Program at the School of Biomedical and Health Sciences at the Centre for complementary Medicine Research at the University of Western Sydney. She is a qualified Chinese herbalist and acupuncturist. She spoke with us about traditional Chinese medicine and in particular acupuncture.

Hello from Renee

Dear MDNSW,

Jambo from Africa!! Well it has been almost 2 months now since we left Australia and we have been having an amazing adventure traveling around the place until we start work in Kenya in June. Aside from visiting our expat friends we have been lucky enough to go to the Pyramids in Egypt - a wonderful experience and a definite highlight.

As I write this we have just got back from a safari in the Serengeti in Tanzania. We had an incredibly lucky trip full of cheetah, leopard, elephant, zebra and giraffe sightings BUT the highlight was seeing a female lion

hunt, kill and devour a wildebeest. It was like being in an animal planet dvd!!

I have enjoyed keeping up to date on all the MDNSW news including the weekend retreat - which sounded



great! I hope you are all doing well and keeping out of the NSW rain and cold - I hear the weather is awful.

Will send another update from Kenya - thinking of you all.

Renee

WELCOME to Winter!

Welcome to another page of Carers News for 2010 - Winter Edition. It feels as though it has been only a couple weeks since we communicated last. How time flies!

I imagine that many of you are feeling the cold; winter is definitely in the air! I hope you are rugging up and keeping

yourselves warm from the winter chills. I suppose this provides you the perfect opportunity to read through fabulous articles MDNSW has sourced for your reading enjoyment.

What an amazing couple months it has been attending events and activities in Client Services.



It has been wonderful to see so many new faces and a surge of new applicants seeking respite funding for a range of different respite needs.

For those not aware of this funding, FlexiRest provides respite, or a short break, for family and unpaid carers of people with muscular dystrophy. Through funding we offer either in or out of home care that other community and respite services cannot provide. To learn how you can take "time out"

please contact me on the following number: 1800 635 109.

As I mentioned earlier, it's been great to see some new faces at recent metro and regional events. Some of the highlights for me have definitely been the Multicultural event, the family day out at the Royal Easter Show and The Natural therapies workshop. For those who attended the workshop, I hope you reaped the physical rewards of participating in the Practical Qigong workshop with therapist Marion Walker.

For those of you who couldn't attend these events, I have posted some great pictures for you to look through! Hopefully the pictures will entice you to attend the many more exciting events MDNSW has planned for 2010.

Georgina Christofis
Carers Program Coordinator



Neuromuscular Clinic at Sydney Children's Hospital Randwick, NSW.



Established in 1963, the clinic cares for the complex needs of children and their families whose lives are affected by a neuromuscular disorder. These include: **muscular dystrophies, spinal muscular atrophies, peripheral neuropathies, congenital myopathies, dermatomyositis and others.**

The **multidisciplinary** model of care used at the clinic helps to:

- ensure our patients have the best medical care and psychological support so that they can achieve their full potential both physically and educationally
- keep families informed of the latest advances in neuromuscular treatment and research.
- provide a full range of services during a 1-2 day visit, so family routines are disrupted as little as possible.

We are keen to have feedback as to how to continually improve our service and have recently established a **Family Advisory Council**. This has become an extremely important communication tool which encourages interaction and ideas from families about what's important for them. We encourage children and families to join external groups and meet with like-minded people as a form of support away from the clinic setting.

Once a child and family have been referred to the Neuromuscular Clinic, by either a General Practitioner or specialist, a typical visit to clinic would include seeing a variety of health professionals who look after complex neuromuscular problems. Their roles are complex and are interdependent of one another.

The different members of the team and their roles are therefore described.

Clinical Nurse Consultants (CNC) liaise and coordinate the Neuromuscular

Clinic. The CNCs are the contacts for inpatients and outpatients and external providers. They provide support for families face to face and on the telephone. CNCs extend their role beyond the clinic to the home, school and community by providing expertise, resources and education. CNCs liaise with and assist acute care hospital admissions.



Medical specialists

Paediatric Neurologists provide specialist medical care for their neuromuscular patients. They take a history, perform an examination and work towards establishing a diagnosis. An individual management plan is then set in place.

Clinical geneticists help with diagnoses and guide the patients and families through the complexities related to genetic information and implications. Research in the areas of neuromuscular disorders is always moving forward and some patient groups who were previously without a diagnosis have now been able to be tested. The implications of this are enormous and encouraging for families.

Respiratory physicians help to provide the best possible respiratory management. Respiratory function testing is routine for most patient groups. "Fitness to fly" tests are available for patients wishing to use air travel.

Sleep Medicine physicians are involved in performing and interpreting overnight sleep studies and recommend nocturnal respiratory support for patients with significant respiratory problems.

Cardiologists are responsible for heart health. Electrocardiograms (ECGs) and cardiac ultrasounds are performed on children with neuromuscular disorders who are at risk of heart trouble.

Orthopaedic surgeons help us in the management of scoliosis. Children's backs are assessed at regular intervals for evidence of scoliosis otherwise known as curvature of the spine. Foot posture is monitored and in some cases corrective surgery may be required.

Endocrinologists have established bone health protocols and oversee management. As per protocol certain groups are screened annually. Endocrinologists are called upon to evaluate pubertal issues and provide management strategies.

Palliative Care physicians help children with symptom management. Access to pain services and respite care is available.



Allied health specialists

Physiotherapists play an integral role in the care of neuromuscular patients. The physical assessment they conduct of the children gathers data about development and strength and goes towards formulating a management plan.

The optimal outcome is to maintain physical functioning and flexibility. The family takes an active role in continuing with the plan in the home. The physiotherapists liaise with local services to ensure a continuum between clinic and home.

Occupational therapists work with families to find solutions for the difficulties they face in everyday activities related to age, interest, ability and future goals. As needs change local OTs become engaged to ensure we are keeping up to the challenge of providing and modifying care accordingly.



Social workers provide assessment of family needs and support at the time of diagnosis. Follow up for the child's and family's needs is ongoing.

Clinical Psychologists assess the emotional, behavioural, social, academic and cognitive functioning of children and adolescents across the ages. In line with this, the giving of information about their disorder at an age and stage appropriate time is encouraged. Gradual communication about the child's disorder often is a concept that families find difficult, however with encouragement and support it has proven to lead to better psychological adjustment.

Genetic Counsellors provide counselling regarding the genetic implications of a diagnosis for individuals and the wider family.

Dieticians are consulted regularly to develop healthy eating plans to ensure optimal nutrition for children, especially those on corticosteroids. We are aware that bone health is essential in this group

of children and we strive to ensure their diet is adequate or supplemented accordingly.

Palliative Care team help us to manage patients in their homes. A respite care break is encouraged for families to relieve the stress that can be associated when a family member has high dependency needs.

Outreach clinics, school and home visits

Liaising with general practitioners and specialists is an essential component of the service. The team is committed to developing and maintaining the link between community and hospital. Sydney Children's Hospital Neuromuscular Service extends across NSW and the ACT. Outreach clinics are provided in Canberra twice a year, Newcastle three times a year and Lismore once a year. Various rural areas are also visited by members of the team annually.

Transition

Transition is a staged process to help the young person plan for their future needs. Links with adult Neuromuscular Services are promoted to ensure smooth transition from our Neuromuscular Clinic. Patients will remain under the care of the clinic until they leave school and then will be transitioned to adult services



Research

The team members are actively involved in research with the following areas of current interest:

- rapid sequencing of the dystrophin gene (relevant to Duchenne and Becker muscular dystrophies and carriers of same)
- longitudinal assessment of learning in Duchenne muscular dystrophy
- development of DNA testing for congenital muscular dystrophies including Laminopathies and Collagen 6 myopathy/dystrophy
- developing bio-markers in Spinal Muscular Atrophy and Motor Neuropathies to help evaluate treatment interventions
- development of respiratory testing for very young or uncoordinated patients



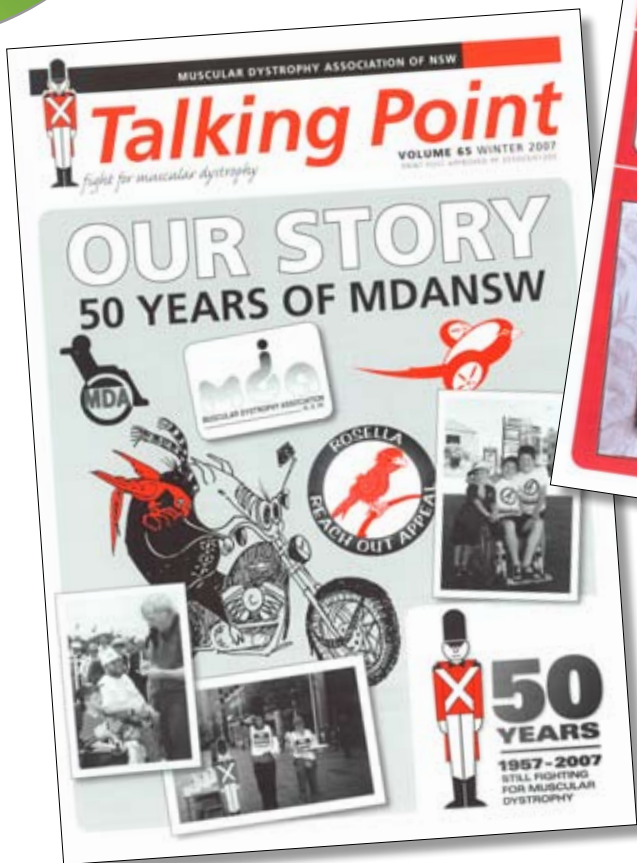
As you can appreciate caring for children and families who have a neuromuscular disorder is extremely complex. We hope we have managed to demystify the roles and services the Sydney Children's Hospital Neuromuscular Clinic provides. Our team is highly motivated and gains great satisfaction when dealing with these complex issues. The team ensures the Clinic provides an understanding environment and a safe haven for children and their families in an otherwise complex world.

Thank you to our families for your continued support.

Compiled by:
Sandra F Holland, Neuromuscular CNC
Sydney Children's Hospital.



75TH
Special
Issue



TALKING POINT CELEBRATING OUR 75TH ISSUE

“ I have written before about how the members and staff of the Association continually inspire me with their dedication, determination, persistence and joy of life and caring for others. To realise that this is the 75th edition of Talking Point makes me realise the way that the services have grown and inspires me again.

Talking Point brings together for me a tangible collection of all our stories in a way which brings our work and our connections to life. It is like our own Message Stick travelling between us all and comforting and reinforcing us. Seventy-five editions of good and still counting!! A continual connection and a continual inspiration.

Maralyn McCann
Office Manager



The 25th Anniversary of The National Electric Wheelchair Sports

The 25th Annual National Electric Wheelchair Sports tournament was held in Sydney from the 12th to 18th April 2010. Once again, the tournament was held at the Sydney Academy of Sport and Recreation, at Narrabeen.

This year the teams, along with the NSW Colts, are ACT Wheelers, Victoria Pride Warriors, South Australia Scorpions, Queensland Gladiators and Western Wasps. NSW loaned players to ACT and Queensland, so our entire squad were able to compete at the games.

The NSW team included Peter Dalrymple (Co-Captain), Chris Suffield (Co-Captain) Steve Webb, Dean Crane, John Shepherd and Jordan Crane. I was once again Coach of NSW.

NSW squad members, Hamish Armitage and Alex Scollard represented ACT, and Kieran Watts, was part of the Queensland team.

Teams arrived on the 12th April and began the process of speed checking the wheelchairs, which is quite a time

consuming process. Some teams and their players found time for practice before the opening day.

Tuesday, 13th April, was the Opening Ceremony and the Hockey Round Robin competition. The games were officially opened by Mr David Jack, CEO of MDNSW and MDF. David spoke about some of the activities of MDNSW and MDF, as well as the importance of participating in events such as NEWS. He paid tribute to the dedication of the athletes who were selected to represent their states.

NSW performed very well in the Hockey Round Robin competition. The Colts only lost 1 game, which was a close match against Victoria who won 5-3 and were undefeated on the day. NSW and VIC qualified for the final, while SA and



Coach watches on as NSW take on SA.

WA qualified for the 3rd place play off.

Wednesday, 14th April, was the Rugby League Round Robin competition. NSW dominated early, but the pivotal game was against VIC in terms of the Roger Melnyk Trophy, which goes to the team with the most aggregate points from the 3 Round Robin competitions. NSW led 22-10 at half time, but unfortunately, were beaten 28-32, in the last minute of the game. NSW and VIC qualified for the final, while SA and WA qualified for the 3rd place play off.

Thursday, 15th April, was the Soccer Round Robin competition and unless something unusual happened, VIC had virtually secured the Roger Melnyk Trophy. They eventually wrapped it up by beating WA. NSW, in Soccer, were supreme and went through the day undefeated, with comfortable victories over all teams, including a 4-0 thrashing of VIC, to qualify for the final. VIC joined NSW in the final, with WA and SA qualifying for the 3rd place play off.

The Annual Delegates Meeting was held in the evening of the 14th and I was re-elected as National Director. Following this meeting was the selection of the All Australian Team.



Pictured is Michael Baptiste and Hans Boers from Victoria.

Stephen Webb from NSW was one of the 6 players selected in the All Australian Team, along with Andrew Brandreth (VIC), who was the Captain, Jack O'Keeffe (WA), Luke David (VIC), Tristram Peters (QLD) and Santo Bongiovanni (SA). The Coach was Hans Boers (VIC).

The Free Day was held on Friday, 16th April. During the day people had an opportunity to do some sight seeing, or just relax. In the evening, the All Australian Team took on the All Stars Team in each sport, which consisted of the next best 6 players in each sport. Chris Suffield, Peter Dalrymple and Jordan Crane from NSW were involved in the All Stars matches, while I was the Coach of the All Stars Rugby League team. Australia won all 3 matches.

So, it was time for the finals, on Saturday, 17th April. The day began with the presentation of the Participation Awards to each player and Coach, by MDNSW Vice-President, Mr Colin Gunn.

It was then time for the Hockey Third Place Play-off match between SA and WA. It was a very close game, with SA leading at half time. WA then got ahead in the second half, before a late SA goal levelled the scores at 2-2. The game then went into extra time. Finally, SA scored and hung on for a memorable 3-2 upset victory.

The Hockey Grand Final was not quite as close on the score board but was a skilful game. Unfortunately for the NSW Colts, Victoria edged out NSW 4-2 to win the Hockey Championship.

Rugby League was the next sport on Finals Day and while NSW was plotting revenge on Victoria for the Hockey Grand Final and the Rugby League Round Robin match, WA took on SA and ran away with the match 34-16 to win Third Place.

NSW completely dominated the Rugby League Grand Final, to win 28-12 over Victoria and defended their Rugby



NSW Colts 2010 is our team, after winning the rugby league final. Pictured from left to right is John Shepherd, Michael Baptiste (Coach), Stephen Webb, Peter Dalrymple (Co-captain), Jordan Crane, Dean Crane and Chris Suffield (co-captain).

League title. It was a complete team effort for NSW and a sense of relief for the Coach!

Soccer was next and once again WA and SA battled it out for Third Place and WA was the eventual winner 4-0. In the Final, the first half was very tough and quite an even battle between NSW and Victoria with teams going to the break at nil all. In the second half NSW came out firing and scored early in the second half. Victoria then levelled the scores with an own goal. This spurred the NSW Colts into action who then dominated the remainder of the game to take out the Championship 3-1.

So, the sports were finished and it was now time for the Presentation Dinner. The Best and Fairest Awards for each team were announced. NSW Best and Fairest was Stephen Webb, while for ACT, the Best and Fairest was Hamish Armitage, who was on loan from NSW. The Players' Player Award was won by Tristram Peters from Queensland. The major award was the Overall Best and Fairest, which was won by Stephen Webb from NSW. Finally, to conclude the night and celebrate the 25th Anniversary, myself as National Director and Hans Boers, Coach of Victoria, and the only person to attend 25 NEWS

tournaments, cut our 25th Anniversary cake. All that was left was for people to party on into the night!

The NEWS tournament would not be possible without the hard work of many people. Firstly I would like to thank my parents, Percy and Eileen, who helped me with all the organising of the games, along with the assistance of Martin and Margaret Dalrymple. Martin had the added job of being the National Umpires' Co-ordinator during the tournament. I wish to thank all the staff at MDNSW for their support as well as the staff from the Sydney Academy of Sport. The games will be on again in April 2011, with the NSW team trials starting in September 2010.

Michael Baptiste
National Director NEWS
and NSW Coach



CATS Retreaters Weekend Away

On May 21st- 23rd Muscular Dystrophy of NSW ran its first ever weekend retreat away.

The Weekend Retreat was held at the fabulous Star City Hotel in Darling Harbour.

During the couple days away, retreaters enjoyed two wonderful dinners out at the best restaurants Star City had to offer.

Friday night's dinner at Sean's Kitchen Restaurant and bar preceded seeing the CATS Show at the Lyric Theatre, Star City.

The next morning also involved a full day of activity for the 20 retreaters who discovered the excitement of the Sydney's Powerhouse Museum.

Saturday's dinner at the Lotus Pond Chinese Restaurant did not disappoint, with the eight courses served fitting for a king and queen.

MDNSW was pleased to receive such wonderful feedback from its members, I have included some of the Feedback below;

MDNSW hopes to run another weekend retreat for members in the not too distant future.

Georgina Christofis



"The retreat was relaxing and enjoyable weekend. I enjoyed the Cats show and meeting new people. I never enjoy going home after such a great weekend"

"Very Good, very enjoyable and a really special treat. Thank you I had a lovely time"

"We thoroughly enjoyed our weekend couldn't ask for any better or more excellent experience"

"Unbelievable! We had an excellent Weekend"



Changes to CAAS

A brochure came across my desk from **BrightSky Australia**, (a supplier on the IDEAS database) on the changes happening from the **Contenance Aids Assistance Scheme (CAAS)** to the new scheme **Contenance Aids Payment Scheme (CAPS)** this July.

I went on the BrightSky website for further information as follows:

The Contenance Aids Payment Scheme (CAPS) is an Australian Government payment that will assist eligible people who have permanent and severe incontinence to meet some of the costs of their continence products.

The Contenance Aids Payment Scheme commences from July 2010

and replaces the Contenance Aids Assistance Scheme (CAAS).

The Contenance Aids Payment Scheme will consist of a direct payment to clients. It will be delivered by Medicare Australia and will be paid directly into a client's nominated bank account.

Eligible clients can purchase their products from their preferred supplier, including BrightSky Australia.

The Contenance Aids Payment Scheme will be in line with the current value available under the CAAS. It will continue to be indexed annually.

Eligibility for the Contenance Aids Payment Scheme will remain the same as it is for CAAS.

People who are five years of age or older and have permanent and severe incontinence due to an eligible neurological condition or have permanent and severe incontinence caused by another eligible condition, (provided they have a Centrelink Pensioner Concession Card) will continue to be eligible.

For a full list of eligible conditions and further information on the CAPS Scheme please visit www.bladderbowel.gov.au

Source IDEAS Newsletter May 2010

We would love to know what you think

The Australian Government are carrying out an inquiry into a long-term care and support scheme for people with disabilities.

They are currently asking for submissions and we would like to make one on behalf of the Muscular Dystrophy Foundation.

Some of the questions they would like answered are and we would value your comment on are:

- 1) Which groups are most in need of additional support and help?
- 2) How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?
- 3) What kinds of services particularly need to be increased or created?
- 4) How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?
- 5) How could a new scheme encourage the full participation by people with disability and their carers in the community and work?
- 6) What should be done in rural and remote areas where it is harder to get services?

Could you please forward your responses to Pene Hodge on Pene.Hodge@mdnsw.org.au by Friday 30th July.

At www.pc.gov.au/projects/inquiry/disability-support/issues, you can find (in PDF, RTF and Daisy text):

- A full issues paper that covers the issues in great detail
- A short set of questions that address the main issues for people wanting to send a personal response
- A short Auslan presentation of the key questions and a text version of the Auslan presentation
- An Easy English version of the key issues.

If you want to be kept informed by email or post, or to make a submission on the issue, you can register on www.pc.gov.au/projects/inquiry/disability-support. Or you can also download a registration form, to be sent to Disability Care and Support inquiry Productivity Commission, GPO Box 1428, Canberra City ACT 2601.



Hope in Our Hearts

An amazing fundraising event took place in Newcastle yet again, last year in October. Here it is mid 2010 and I'm finally getting around to letting you know the outcome.

Before I do that I would like to tell you how it all came about, this 'little' idea of having a black tie dinner to raise money for Muscular Dystrophy NSW.

A dear friend of ours Robert Moretti came on holidays with our family in March 2008. Around the dinner table one night, Rob mentioned he wanted to organize a fundraiser for MDNSW. My husband Frank and Rob discussed it a bit more and I have to admit, I was a bit apprehensive as I have been involved with organizing fundraising luncheons that seated 100-120 people and that was big enough for us (3 MDNSW members Janene Oborn, Lisa Bramble and myself)



In no time at all, a committee was formed and the organising was under way. Rob, Frank & Peter Fallon (another close friend), had a date, venue & fantastic contacts. Also the committee grew to about 25 members, with Newcastle Harbour Rotary coming on board. I was getting nervous as this was growing bigger by the minute. I needn't have worried as these guys did an amazing job!

Not only did they organize a black tie dinner but also a rugby day to be held on the same day! "WHAT THE!! ARE YOU ALL MAD!!!" were my initial thoughts. Mauling for Muscles was born.

It was a fantastic day despite the weather and the injuries incurred by the "old boys". Ex-wallaby players & local players all mauled together & a total of \$12,000 was raised from that event alone. It was full of family fun, face painting trampolining, BBQ's, wine, beers, coffee etc, etc. As the boys watched the rugby all afternoon, many of the ladies were off to set up for the evening dinner. This was going to seat 416 guests!!!

We had some very experienced volunteers who delegated with ease all the jobs needed to make this night not only run smoothly but also be one that our guests would go away thinking "WOW". Of course there were a few hiccups but everyone's cool was kept under wraps, thanks to Marg and Liz. With our room looking and tables looking gorg, the prizes sorted, wrapped and positioned, all that was left was to wack on a suit and frock up.

We had the pleasure of Professor Kathryn North, from The Westmead Children's Hospital, grace us with her presence as our guest speaker. She spoke of the progress being made in her research department and the huge amount of pleasure she gets out of her clinics which she runs at WCH. She was an absolute delight. David Jack also joined us for the night and gave a very heartfelt speech about MDNSW. We are very lucky to have him at the front of MDNSW.



The auction prizes were amazing (one being a trip for 2 to Mauritius including airfare & accommodation). The generosity was very overwhelming to say the least. A HUGE \$81,000 was raised on that night. We finished off the night with some shoe shuffling on the dance floor. It was truly one of those special events.

We cannot thank our friends Rob & Alison Moretti enough for planting that seed and Rob's unrelenting energy. Also the committee members and Rotary for all their help, suggestions and cash counting. It is just incredible what can be done. We are truly blessed with so much support and love around us.

In late February this year we presented MDNSW with a cheque of \$20,000, which David Jack gladly accepted. Kathryn North was also presented with a cheque for a whopping \$72,000, which was going to help fund one of her up and coming researchers.

We will have the Rugby Day annually and the ball bi-annually as I'm sure it will take that long to recover.

With Hope In Our Hearts

Vicki Sculli

Do you have a child with a disability living at home?

We want to hear from you

Do services work together to help you?

Are you getting help to support your child to live at home?

We are very interested to hear from families about:

Specialist disability services including:

- information about disability services and being taken on to receive services
- intensive family support and other family support
- respite
- early intervention
- therapy
- case management
- transition support services (transition to school, from school to work, and when leaving care to adult disability services.)
- support for carers
- physical aids and equipment
- the way specialist services work together and link to mainstream services for families and children.

Services for families in the community such as:

- child care, out-of-school hours care and vacation care
- pre-school and primary and secondary school
- health services
- public transport
- sport and recreation.

It is important that children with a disability and their families get the help they need. We will let government know what families say about the support and services they need.

Share Your Views

You can share your views in person, by telephone or by email. To participate please contact:

Christine Flynn, Project Manager

Telephone: (02) 9265 0410

email: cflynn@ombo.nsw.gov.au

Linda Blue, Project Officer

Telephone: (02) 9286 0950

email: lblue@ombo.nsw.gov.au

Or phone toll free: 1800 45 1524

We will be talking to families between May & August 2010

Privacy and confidentiality

What you tell us will be kept confidential by our office. Your personal information, for example, your name, will not be used in the report. Individual services will not be named – we are looking at the overall system.

Independence

The NSW Ombudsman is independent of government and community and disability services.



HOGS UNITE SUNDAY SEPT 12th 2010!!



NSW Hog chapter is proudly continuing our 19 year association with Muscular Dystrophy NSW.



We will be holding the day at Warragamba Dam Picnic Area with the convoy leaving Frasers Motorcycles at 10am.



Come along and be part of this special day.



Help raise funds, join in the raffles, enjoy some great food and get ready to be amazed by Dangerous Dave & his ServinItUp Team!



The Twisted Art Factory will be doing their infamous Airbrush Tattoos.



MDNSW Young Achievers Award

The Muscular Dystrophy NSW *Young Achievers Award* is intended to assist a young person with a neuromuscular condition to achieve his or her career aspirations. This award is designed to be flexible so funds may be used for a variety of purposes including: course fees, publishing a book, holding an exhibition, achieving a business plan or sporting endeavours.

Whatever it is, this Award could help you get there!

Eligible applicants will meet the following criteria:

- Have a Neuromuscular Disease
- Be under 25 years at the time of application
- Be able to demonstrate a strong commitment to an area of study/business/interest that may lead to a career path
- Provide evidence of current commitment to area of interest i.e. current enrolment in study, draft business plan, formatted idea (draft manuscript, poems, book, artwork etc)
- Have demonstrated leadership qualities and community involvement
- Be an Australian Citizen and reside in NSW and be a member of MDNSW

There are two *Young Achievers Awards* available each year to the value of AUD\$1000 per Award.

This award is kindly sponsored by Sydney IVF and Mr Rob Ferguson.

Enquiries and requests for application form to:

Pene Hodge

Client Services Manager

Telephone: (02) 9809 2111

Email: Pene.Hodge@mdnsw.org.au

Applications must be received by close of business, 30 August 2010

02 9809 2111 www.mdnsw.org.au



Generosity wins at Golf Day 2010

True to its fine tradition, MDNSW Annual Golf Day 2010 at Concord Golf Club was once again a great success.

Thanks to the goodwill and generosity of sponsors and players, Golf Day 2010 raised nearly \$40,000 which will go to making this year's Annual Camp at Narrabeen even better than 2009.

Around eighty players arrived at Concord as the early morning autumn sun did its best to warm the day and burn off the overnight dew on one of Sydney most beautiful and challenging championship golf courses.

While waiting for the ground staff to give the OK, players enjoyed breakfast, practised on the putting green and then gathered around Concord golf pro Ken Trimble to get some great tips on driving.

By 9 o'clock play was underway, each of twenty teams going to their assigned starting tee for a magic morning of golf. As an Ambrose competition, players work very much together with the



Ken Trimble, Concord Golf Pro, demonstrating how and how not to drive.

team's best shot selected as the start of the next shot until the ball is in the hole, with one score being recorded by the team.

Even though the standard of golf varied enormously (even within teams!) the

level of enjoyment and enthusiasm was universally high. The great feature of Ambrose golf is that it lets players of all standards compete without anyone feeling intimidated by better players yet competition between teams remains high.



Teeing off at the 10th by the clubhouse.



Taking the next shot on one of Concord's magnificent fairways.

At the end of the day's play, first timers Dr Michael Oei and his team were thrilled to take out the Winner's Trophy just ahead of last years' two top teams both representing M&E Equipment Traders led by Steven and Robert Baldini.

Returning for lunch in the elegant dining room of the clubhouse players enjoyed a

hearty buffet meal, quenching ales, fine wine and player prize presentations.

And there were more wins for all concerned as players further extended their generosity - and got some great bargains - by keenly bidding for the silent and not-so-silent auction prizes.

David Jack, CEO of MDNSW, spoke

to the room and acknowledged the significant contribution funds raised by Golf Day would make to the running of the Annual Camp at Narrabeen, an event which had proved itself to be not only a lot of fun but also deeply rewarding and fulfilling for the kids and young adults attending.

Thanks to everyone involved in making MDNSW Annual Golf Day 2010 an outstanding sporting and fundraising success.

In particular our appreciation goes to staff and members of Concord Golf Club and our sponsors and supporters – Advanced Planning Services, Crane Group, Ord Minnett, D J Batchen, Tradelink, Canterbury League Club, Jerry Lewis, Alan Jones & 2GB, Ken Trimble, Travelex, Brosnan Golf, Ensemble Theatre, Belvoir Street Theatre, Prestige Brands, Taylor Made, Bel Paese Restaurant, Sydney Observatory, Australian Maritime Museum, Great White Shark Enterprises and Australian Broadcasting Corporation.

For photos of the day visit the MDNSW Photo Gallery at:

<http://picasaweb.google.com.au/mdnsw.org.au/2010GolfDay#>.



The eventual winning team (with photographer's shadow) before heading off to play.



Much is happening in the world of MDNSW fundraising!

Another three months has zoomed by at MDNSW and there are many fundraising projects on the boil. This year, the staff, members and supporters of MDNSW are entering a City2Surf team. Some people are going to run the distance from Sydney City to Bondi Beach, some are going to walk and some are going to wheel the distance (chairs not bikes!). So far we have a team of 20 and we would love to double our numbers so we have a strong presence on the day. Every team member who raises over \$100 will receive a t-shirt to wear during the event. If you would like to join our team, please go to:

www.everydayhero.com.au/event/City2SurfMDF

By now you would have received your membership renewal pack in the post. Renewing your membership with MDNSW gives you the opportunity to access our many services including Home Support, Flexirest, Camp and retreats. If your renewal pack hasn't arrived, please call the office on 02 9809 2111 and we will send one out to you.

On a final note I hope you have all been watching the World Cup and seen what a wonderful performance the New Zealand All Whites have been putting on – Go the All Whites!

Rebecca Scelly
Fundraising Manager

Transition Time

Although written by the Spastic Centre for teens with cerebral palsy, the Transition Toolkit for Teenagers is relevant for teens with different disabilities as well. The transition after leaving school open opportunities and challenges, as services change and teens take more responsibility for their health, wellbeing and lifestyle. Planning can start from about Year 9 of high school.

The 21 factsheets cover many major areas: Introduction - Transition to Adult Life, Education and Learning (Post School Planning (DET, Catholic and Independent Schools), Post School Programs - Community Participation, Transition to Work (TTW), Post School Study, Accessing Apprenticeships) Managing Money - Money Matters, Technology (Technology, Equipment and Technology Funding), Transport (Getting Out and About on Public Transport, Learning to drive, Travel - additional assistance), Social & Leisure (Friends, Leisure and Recreation, Respite), Health - Healthy Body, Healthy Mind, Independence (Moving Out, Home Help, Disability Advocacy Services), Feelings and Emotions (Feeling OK About Yourself, Stress).

Source: www.thespasticcentre.org.au/about_cp/transition_youth.htm

Important Volunteer Role

ASSISTING MDNSW WITH COLLECTION OF CASH FROM SYDNEY AIRPORT

The Spotless Group have provided MDNSW with the opportunity to raise \$40-50,000 each year from collection boxes placed on counters at its 14 Sydney International and Domestic Airport food outlets.

One, or possibly two people are needed to collect and bank cash from Sydney Domestic Terminal (T2), and to relieve with collections at Sydney International Airport (T1).

Reliability and dependability will be essential characteristics of the volunteers we need.

Please call Rob Ferguson on 0412 221 250, or email Rob.Ferguson@mdnsw.org.au to discuss the role

The quote on my calendar today said:

"Look at everything as though you were seeing it either for the first or last time."

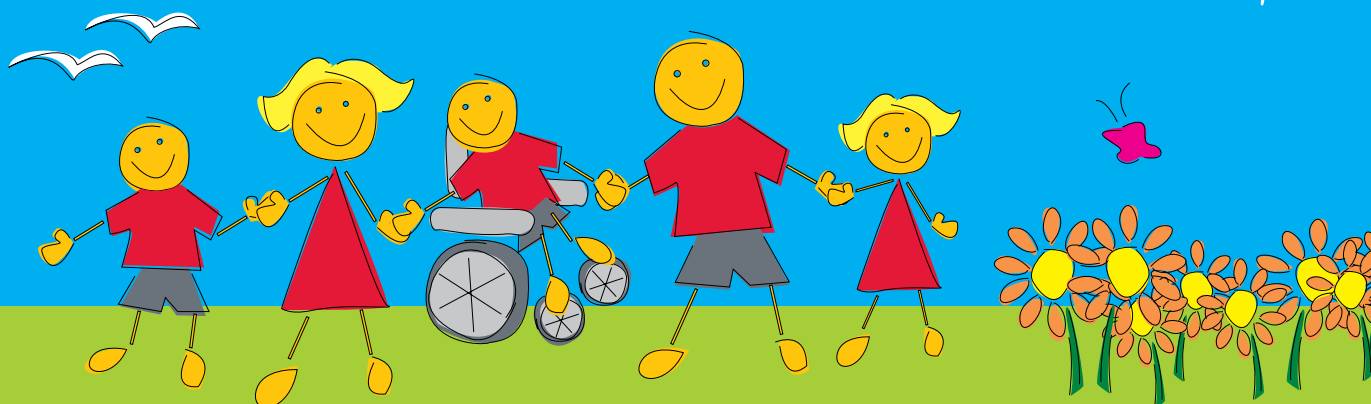
Betty Smith

"Be the change you want to see in the world"

Gandhi

MDNSW camp 2010

Join us for
another fantastic
MDNSW Camp!



WHERE

Sydney Academy of Sport and
Recreation, Narrabeen

WHEN

Monday 27th September
– Friday 1st October

AGE

The camp is aimed at children,
teenagers and young adults with
a neuromuscular disorder.

COST AND INCLUSIONS

\$120 per person

*(Please talk to Pene or Georgina about claiming
the camp fee and travel to and from the camp
through our Flexible Respite Program)*

INCLUDES All food, accommodation,
one to one care (carer provided
or you may bring your own) and a
HUGE variety of age appropriate
activities and experiences.

WANT AN APPLICATION OR TO KNOW MORE?

Contact Pene Hodge at MDNSW on 9809 2111 or Pene.Hodge@mdnsw.org.au



www.mdnsw.org.au

Muscular Dystrophy NSW: Suite 101 - 7 Bay Drive, PO Box 1365, Meadowbank NSW 2114 t: 02 9809 2111





muscular dystrophy
new south wales

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Sandra Stavrou
Fundraising Manager
Rebecca Scelly

HONORARY SOLICITOR

Simon Gates

TALKING POINT DISCLAIMER

The views expressed in these pages may not be the views of MDNSW. Care has been taken in the preparation of content, but MDNSW accepts no responsibility for detriment whatsoever arising from the reliance of content contained herein.

Letters to the Editor (Carolyn Campbell-McLean), can be addressed to:

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PO Box 1365,
Meadowbank NSW 2114

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THE NEUROMUSCULAR CLINICS

CHILDREN'S CLINICS

Sydney Children's Hospital, Randwick
Neuromuscular Clinic
Appointments & Enquirie 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

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.

