



MUSCULAR DYSTROPHY ASSOCIATION OF NSW

# Talking Point

*fight for muscular dystrophy*

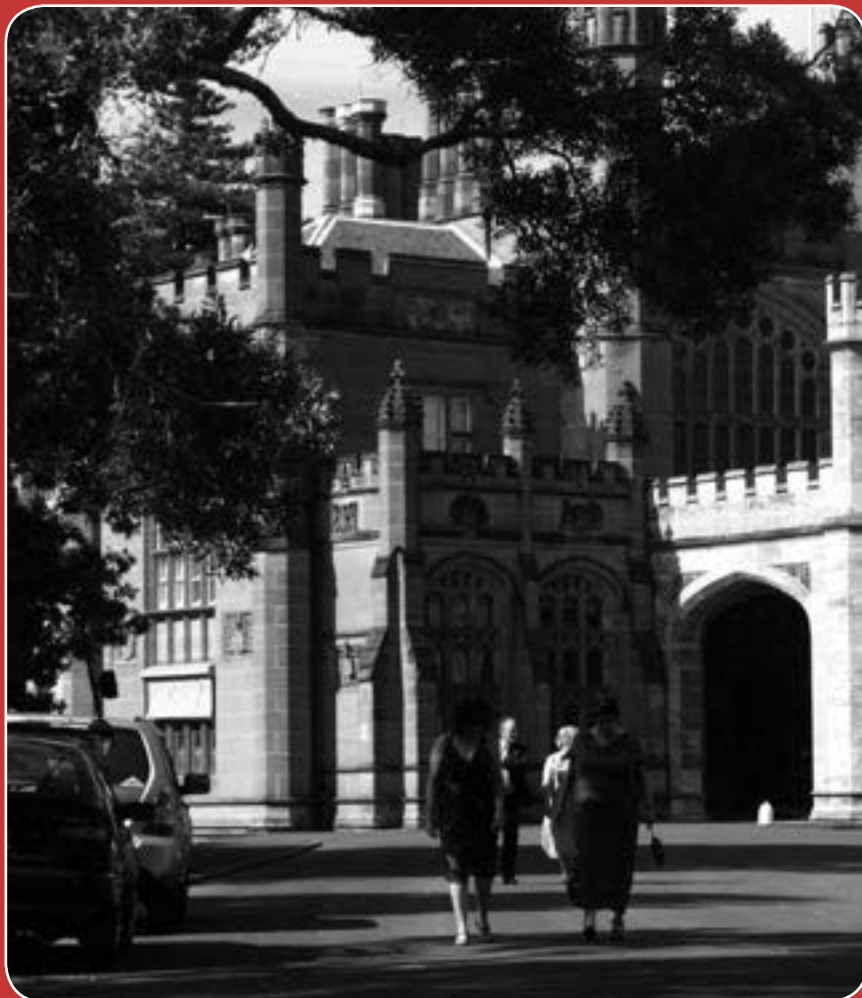
VOLUME 66 SUMMER 2008

PRINT POST APPROVED PP 255003/01200

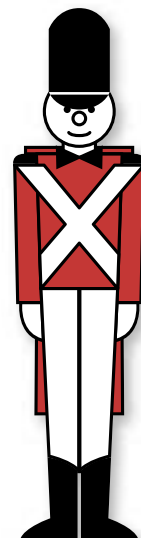
## 50TH ANNIVERSARY



# celebration



*See the back cover for more photos of our 50th anniversary event at Government House.*



# 50 YEARS

**1957 to 2007**  
STILL FIGHTING  
FOR MUSCULAR  
DYSTROPHY



Well, the end of 2007 has definitely come quickly (isn't everyone is saying that). But I still haven't worked out why it seems to get quicker each year; oh dear, I am sounding old! I hope that 2007 has brought many good things, nice memories and special people to you. If you have been faced with challenges or struggles may you find the silver lining and a glimmer of hope for a brighter new year?

This year has been a year of change and with that new beginnings emerge. Change on many levels, personal, political, social; wanted or not; positive and negative. One thing is for sure – change will happen. I was recently in Canberra, an exciting time to visit our national capital, with the new Labor Government sworn in. I met two new Federal Ministers, Hon. Jenny Macklin (Family and Community Services) and Bill Shorten (Parliamentary Secretary for Disability and Children). They were enthusiastic and keen to listen, and learn about what needs to change for people with disability. Let's hope that this national change produces good results and positive change for our community.

This edition of *Talking Point* again celebrates the 50th birthday of our association, and the wonderful people

*The Editor, Locked Bag 1005, Rosebery NSW 1445 email: cazza74@bigpond.net.au tel: 9684 6443*

that have been part of the journey. There is a special feature on the reception held at Government House by Her Excellency, Marie Bashir, a truly special day (see back cover). We report on changes to the Board after Bruce stepped down last month, and we welcome our new President Rob Ferguson; changes in staff at MDANSW; and the very hardest of all change, the very sad loss of two young members Lachlan Riley and Nicole Giles. My sincere condolences and best wishes to everyone who has lost someone they love. Always remember the words of Helen Keller: 'All that we love deeply, becomes a part of us'.

There is a fabulous travel piece by our intrepid AAA reporter John Little, and a postcard from a peaceful place closer to home by Sandi Simmonds. Chris Suffield completes his series on surviving the HSC, and we hear what Monica Ellis is up to. Regular updates about NEWS, fundraising and as well as a range of information about services, events and classifieds, round out a very full Summer edition of *Talking Point*.

Hope Santa brings just what you wish for, and health and happiness to you all in 2008.

Take care,

**Carolyn Campbell-McLean**

**Just because everything is different doesn't mean anything has changed.**  
— Irene Peter

**CONTENTS**

Editorial	2	Access All Areas goes international	12 - 13
CEO report and thank you, Mr President	3	Access All Areas – Currarong and Lennox Head	14
Welcome to MDANSW, Bob!	3	<b>Fundraising Roundup</b>	15 - 18
Get to know the new Client Services Coordinator	4 - 7	Drought-breaking Golf Day	15
Let's Go Surfing Day	4	Successful soccer day	16
Client Services Update	5	Elvis is in the building	17
Breaking news on PADP	6	Kokoda Track trekker	18
Home modifications help	7	Chris Suffield completes his school diary	19
Carers Corner	8	Research News – the hope & the hype	20
M.A.C. Chat	8	<b>Christmas celebrations</b>	21
Fallen Soldiers	9	Clinics & Contacts	22
Letters to the Editor	10	N.E.W.S Update	23
<b>Silly adventures</b>	11	<b>Tea with the Governor</b>	24

**Entertaining books**

Joanne Murray has raised \$700 for MDANSW simply by selling Entertainment™ Books to family and friends. Look out for 2008-2009 books in April next year – they are such great value and help support MDANSW. Many thanks, Joanne!



## FROM WHERE I SIT



Hello friends.

We are fast approaching the end of another busy year, made even more so by a number of special events celebrating our 50th year.

In the first five months of this financial year we will have run our inaugural golf day at Concord Golf Club, held a medical conference and hypothetical, held our annual general meeting, celebrated our 50th anniversary with our patron, run an Elvis fundraiser at HMAS Penguin and held two Christmas parties.

Time and tide, however, wait for no man and we are already planning further events into 2008. We are also, with the help of our new Client Services Coordinator, Viktoria Butler, reviewing the services we provide to our members and hoping to receive confirmation from the Department of Health of the renewal of our Carers program grant. This would allow us to extend the program into two other regional NSW areas as well as expand the groups of carers we are targeting.

This October we also said farewell to two of our directors, Ellie Carew and Vaughan Woods, our Treasurer. In addition our President for the last three years, Bruce Ellison, handed over the reins to Rob Ferguson who has been a Board member for five years and Colin Gunn as Vice President. I thank Ellie and Vaughan for their dedication and help they have given the Association. I am delighted also that Bruce has agreed to remain a member of the Board and I thank him very sincerely for his work as President. He has been an invaluable source of information and advice, particularly regarding the history of the Association.

So, we finish the year with lots of plans in the pipeline and an encouraging year ahead of us. I wish all our members a very happy and healthy Christmas and New Year. I look forward to helping wherever we are able and to catching up at the various events in 2008.

Bye for now.

**Ian Dear, CEO**

## Annual General Meeting

### 27 October 2007

At the annual general meeting of the Association held on Saturday 27 October 2007, Bruce Ellison stood down as President after three years and will remain a Board member. Bruce provided a report on the activities of the Association over the preceding year and expressed his thanks to the outgoing directors Ellie Carew and Vaughan Woods Treasurer for their work on behalf of the Association.

Rob Ferguson was appointed President and paid tribute to Bruce's considerable efforts as President. Bruce's presidency had been a stable and productive period for the Association and Bruce had made a major contribution to the recent medical conference and hypothetical. Rob complimented Bruce and the CEO on the excellent organization of the 50th anniversary events this year.

Colin Gunn was appointed Vice President and Dr Heather Johnston Medical Director of the Association.

The position of Treasurer was left vacant pending an imminent appointment. The CEO presented the highlights of the year and joined in paying tribute to Bruce and expressing his thanks to Ellie Carew and Vaughan Woods.



*Bruce Ellison, pictured with his partner, Ursula, proudly accepted a certificate of appreciation for his time as President of MDANSW, presented at our 50th anniversary celebrations at Government House by our Patron, Her Excellency, The Governor of NSW, Professor Marie Bashir AC CVO.*

## Welcome to MDANSW, Bob!!



We are delighted to introduce our new Office Manager, Bob Horan. You might meet him over the phone next time you call the MDANSW office.

With accounting and company secretarial qualifications, Bob has worked in a number of accounting and management roles and is looking forward to making a contribution to the advancement of the association.

Bob has two adult children, the eldest a daughter, Jacqueline, who has cerebral palsy and a son, Matthew.



## Get to know Viktoria – our new Client Services Coordinator



Hello to the Muscular Dystrophy Association! I am the new Client Services Coordinator and I am about to tell you a little about myself. I have had a some what chequered career but have thoroughly enjoyed my career path!

On leaving school I studied at a Design School for two years and left to become a Display Artist for the following two years. I then became a Textile Designer which eventually led me into painting. This then led me to go back to study and gain a Diploma in Art at Alexander Mackie College of Advanced Education, marriage and an instant family of three children and eventually an additional two children.

During this time I had solo and group exhibitions with Gallery A, Paddington and by now had decided to go back to study for my Post-Grad in Art at NSW University's College of Fine Arts. Upon finishing these studies I was able to work part-time and sell the occasional works, in the printmaking and painting mediums, to various Corporations.

Over the next few years, working in various art fields, I again got the urge to go back to study and ended up doing my Bachelor of Social Work at the University of Sydney. It was the closest to our home. In my final year

I was asked to work with The Benevolent Society where I became the Social Worker for the Centre on Ageing, specialising in dementia over four years, working at five separate sites throughout the Sydney region.

Realising how quickly 'time flies', I decided I needed another challenge and decided to take on a new role with MDANSW. I am still discovering my new role, and hope to successfully work with the MDANSW team, Ian Dear (CEO), the Carers' Program Coordinator, Bob Horan (Office Manager) and our wonderful volunteers to expand our services.

*With Christmas at our door, through my researching for existing venues for accommodation, I have become aware of a delightful and extremely accessible 'respite' venue at Port Stephens! This thoroughly caters for disabled people, with wonderful access to the beach on a Free-wheeler beach chair, a Diesel powered six-wheeler 'all terrain' buggy, great facilities, grounds and amenities. Some of you might already know of this venue known as 'O'Carrollyns at One Mile Beach' – looks a fabulous place for a break.*

*If anyone is planning to go further a field for a holiday, I was excited at discovering Hamilton Island in Queensland has just purchased a Wheelchair Accessible Public Bus! The bus covers the organs route and circles the island daily every 40 mins between 7am and 11pm – so start saving!!*

Enough dreaming for now. I am looking forward to meeting more members at our coming events.

Regards,

**Viktoria Butler**



## LET'S GO SURFING DAY



**DATE:** Saturday  
February 23, 2008

**SITE:** Collaroy Beach

**COST:** \$20.00  
for non-members  
of group

Members  
Volunteers  
Carers – FREE

**TIME:** 9.30am  
for 10.00am start.

**GO TO:** [www.surfers helpingsurfers .com/calendar](http://www surfers helpingsurfers .com/calendar)  
and book in  
and enjoy the day!

## FUN FOR EVERYONE

**Jindabyne Central School** is looking at ways of making school life a little more accessible and dare we say 'fun' for boys with Duchenne muscular dystrophy and kids with other disabilities. The general access of the school is sorted, now they are thinking outside the square (and the classroom). If you have used, seen or heard of any equipment or activities that may make the classroom, playground and school life more user friendly please let Viktoria at MDANSW know so she can pass it on to the school. Tel: 9697 9111, or toll free 1800 635 109, or email [services@mdansw.org](mailto:services@mdansw.org).

## Client Services update

Within my first month with the Association, apart from gathering information about MDANSW, working through the computer maze and patiently awaiting approval to visit and introduce myself to the Neuromuscular Clinics, I have managed to participate in some MDANSW events!

My first enjoyable event was a luncheon with the **Women's Group**. This was held at Sandy Simmonds' newly renovated house on the North Shore. Besides the wonderful food provided, it was an opportunity to meet various MDANSW members and enjoy the uplifting conversations, gain knowledge of holistic therapies and revel in such good company.

The following week I was involved in a **Multi-cultural Luncheon** organised at Hansard Street by Rachel, the Carer's Program Development Coordinator. This gave me another informal opportunity to meet and speak with more members, meet some staff from MS, visitors from Canberra and MDANSW volunteers. An extra plus was to meet a former CEO of MDANSW, Eugene Pamerter, who was able to expand my knowledge of the history and contribution of the founding members of the Association. The dissemination of knowledge of MD and educating the community about the various muscular dystrophies is still quite a challenge!

The following weekend brought two more events, the **"Pathways to a Cure" Medical Conference and Hypothetical** on the Saturday and the annual **HOGS Day** outing on the Sunday. Although I was unable to attend, I heard from our CEO, Ian Dear, it was once again a good way to spend a Sunday!

"Pathways to a Cure" had the phones running hot within my first few weeks, as we had 150 acceptances. This proved again a great opportunity to meet and speak with some members of MDANSW. Many had travelled from afar (Dubbo) and spent hours travelling in quite a heat! The only hiccup was the unforeseen need for 'coins', necessary for the use of the outside car park, something to keep in mind for other events we might have at the Novotel Sydney Olympic Park.

The conference opened with a retrospective on Muscular Dystrophy over the past 40 years followed with the outcomes of the recent research over only the past decade. Topics discussed by the speakers focussed on trials and therapies for MD, studies of stem cell transplantation with possible restoration/cell growth and the ethics involved in such research. The focus was on the 'lack of the protein Dystrophin' in DMD, with great detailed diagrams (most informative) and discussion on the various therapies that will hopefully enhance the muscle regrowth for future clinical application. Stem cell research with therapeutic cloning was explained with the hope of future application resulting in cell regrowth.

Speaking with some members and visitors during the breaks, the majority agreed "the conference was a unique opportunity to gain knowledge and more insight of the research into MD over the past decade".

I would like to thank Professor Graeme Morgan for his introduction, and Professor Kathryn North, Professor Anne Cunningham and Dr Bernadette Tobin for their expert knowledge on research in MD and ethical issues. My further thanks to Ms Louise Suffield (MDANSW member), Ms Sophie Scott (ABC medical reporter) and the exceptional moderator Robyn Williams (ABC Science presenter) who joined our experts to form the creative, Hypothetical Panel! They addressed a fascinating scenario of a wealthy philanthropist whose five year old son is diagnosed with Duchenne muscular dystrophy. The philanthropist wishes to donate a large sum of money to a researcher who is claiming success in the treatment of muscular dystrophy in mice.

The following week I was able to join Dr Heather Johnson (our Medical Director) for the day, at the Neuromuscular Clinic at Sydney Children's Hospital, Randwick for a most enlightening workshop. Various people from the team spoke about their knowledge and experiences of working with people with muscular dystrophy. In one of the workshops, I was able to inspect two of the 'coughing machines' from the clinic - the latest was most impressive! (Please see the article on this page about Medibank Private and funding available for this type of equipment).

The good news is, I have been given clearance to visit the clinics and am looking forward to meeting the various Teams and families at each hospital in the coming weeks. I will also be accompanying Rachel Spencer to events in the Hunter and Illawarra Regions to meet MDANSW members.

Looking at the calendar many more events are approaching leading up to Christmas and I hope to continue to meet many more members before 2008 is upon us!

Wishing you all a Very Merry Christmas and Great New Year!

**Viktoria Butler**

Client Services Coordinator.

### **Medibank Private Special Purpose Fund**

I would like MDANSW members to be made aware of the Medibank Private Special Purpose Fund that has granted a person funding for a 'Cough' machine.

The purchase of \$9,950 was approved for the Cough assistance device in July, 2007.

For more information, call Viktoria at the MDANSW office on 9697 9111.

## SHIPS AHOY!!



Sailors with DisAbilities have provided opportunities for three family members to experience an exciting day's outing on our superb Sydney Harbour.

This is a wonderful experience everyone should enjoy at least once.

There are no more places left this year but the programme continues from January, 2008!

If anyone is interested please contact me at MDANSW so we can form another group booking of members and their families/carers.

Call Viktoria Butler 9697 9111 or email [services@mdansw.org](mailto:services@mdansw.org).

## FLEXIREST PROGRAMME

I would like to let you know of some funding from a new programme known as **FlexiRest**, that has become available through the collaboration of three associations funded by DADHC.

This is a new programme that will offer financial support to members for respite- related services, either in-the-home or out-of-home.

This new initiative is run by a consortium consisting of Motor Neurone Disease Association, MS Society of NSW/VIC. and MDANSW.

Some examples where the funding would apply are:

- In-home respite where the respite is provided in your home for a nominated period of time;
- short breaks that you may use your funding to purchase support for the whole family to go on a short holiday together;
- peer support/age appropriate respite involving leisure and recreation activities with people of similar age like interests etc...

This is a programme available to our members and I would be only too pleased to speak with any member who would like to apply. Feel free to phone me (Viktoria) at MDANSW on 9697 9111.

## Breaking news on PADP

PADP is a health funded program that supplies aids and equipment to people with disabilities living in the community. PADP is currently administered at a local level and attached to Area Health Services.

A review was undertaken by PWC a couple of years ago and NSW Health last week released the final report and recommendations as well as the government's response to it. Advocates in the disability sector have been calling for the release of this paper for some time.

The review made 30 recommendations relating to three key issues of PADP: management and administration, target population and demand, and budgetary requirements and financial management.

The key changes to be adopted are mostly administrative and include:

- Management of PADP was transferred on 6 August to a statewide administrative service called HealthSupport - over the next 18 months HealthSupport will work with AHSs to centralise administration of the PADP.
- EnableNSW will be the new name of the program encompassing PADP and other similar programs (see media release at above link).
- AHSs currently operate Equipment Loan Pools and are working to develop minimum standards for the short term loan of equipment to help people being discharged from hospital.
- Standards and performance indicators to be developed in relation to the application process including processing and waiting times.
- A statewide advisory committee will be established (the recommendation to establish a steering committee was not supported by the Government).
- HealthSupport will produce an annual report including budget, expenditure and performance of PADP.
- There is a 1800 statewide information line enabling consumers to seek general advice from a PADP officer.
- A new information system will enable clinicians to electronically submit referrals and managers to produce reports on waiting lists etc.

Further work is to be done by NSW Health on co-payments and eligibility criteria and further consideration will be given to departmental responsibilities especially the future role of DADHC in policy development / program delivery.





## MDA CAMPS

One of the enjoyable tasks so far has been to gather research into the future possibility of running 'Camps' for MDANSW Members.

MDA Victoria has been running successful camps for many years for MDA members. I have been lucky enough to encounter a person who has participated when he was a university student as a carer, at two different camps in Victoria. Both he and Stella, from MDA Victoria, were able to impart some information to me on what this entails.

Here is a little information on the camps:

- They use various camp sites (mostly YMCA) and are mainly school sites;
- beds are mostly bunk beds but come apart to accommodate a hoist;

- each camper has their own carer who are mostly volunteers (some campers bring their own carer or family member);
- the majority would have their parents/carers drop them off or catch a train;
- the cost depends on the campsite – approx. \$220-250 for a 5-6 night camp; and
- 80% of the boys are affected by DMD, some have SMA and Myotonic. The camps are open to anyone with a neuromuscular disorder.

If any one is interested in participating in a **future MDANSW camp**, has any suggestions or information on venues and the type of activities you would like to be involved with at a camp, please don't hesitate to contact Viktoria at MDANSW and have a talk!

Tel: 9697 9111, or toll free 1800 635 109, or email [services@mdansw.org](mailto:services@mdansw.org).

## Home Mods Help

NSW HMMS State Council has appointed a Specialist Occupational Therapist, Margaret Neuss.

Margaret has come to us with extensive experience of environmental modifications and, as you may already be aware, co-authored and presented a training program for OT Australia NSW. All of Margaret's work with State Council will be a collaborative and consultative process with Occupational Therapists, Builders and Managers/ Coordinators of Home Modification and Maintenance Services across NSW.

Margaret's role includes:

- The development of resources for the sector such as standardised pro-forma, information fact sheets

and resource manuals designed to promote leading practice and minimum requirements within the Home Modification and Maintenance Services industry;

- capacity building initiatives via industry-specific training to increase the skill and knowledge of Occupational Therapists working in partnership with Home Modification and Maintenance Services in NSW;
- facilitation and enhancement of collaborative working partnerships with Occupational Therapists, Builders and Home Modification and Maintenance Services in NSW.

As Margaret has extensive experience and practical application knowledge of environmental modifications, you may wish to contact her if you require advice regarding recommendations. To contact Margaret, please email her at [ot@nswhmms.org](mailto:ot@nswhmms.org).

## MDANSW for National Electric Wheelchair Sports



# Charity Ball



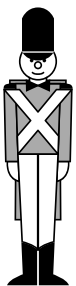
Raising money for  
NSW National Electric

Wheelchair Sports Team to pay  
for accommodation and expenses  
to play in Sydney, April 2008.

**Tickets \$70.** Includes 3 course meal  
and gift. Prizes to be won.

- Date:** Saturday 16th February 2008  
**Time:** 7:30pm  
**Venue:** The Wentworth Room, Parramatta Leagues Club  
**Dress:** Formal  
**Address:** 13-15 O'Connell Street, Parramatta  
 Silent Auction will be held on the night.  
**Contact:** Margaret Dalrymple – 0439 766 075  
 Tracy-Maree Dalrymple – 0410 64 00 81

All cheques payable to MDANSW,  
 Locked Bag 1005, Rosebery NSW 1445,  
 or credit card payments to MDANSW office, tel: 9697 9111.



*fight for muscular dystrophy*



**Thanks, not goodbye.**

Goodbyes have never been one of my strengths, so as I prepare to leave my role as Carers Coordinator at MDANSW

I choose not to say goodbye but thank you. Thank you to:

- MDANSW for giving me the opportunity to develop and coordinate such an exciting and worthwhile project;
- NSW Health for funding the project for an initial three years and hopefully for another three;
- colleagues at MDANSW and other organisations for support, sharing of ideas, resources, laughs and challenges;
- Members Advisory Committee (MAC) and Care for Carers Project Committee (in particular Robyn Pedersen) for direction, support and encouragement;
- members, carers and families of MDANSW; for welcoming me into your lives (and occasionally your homes), sharing highs and lows, ideas and information, cups of tea and long lunches. I believe the success of the Carers program is in a small way due to my contribution but mostly due to yours – we made a good team!

I have so many memories and highlights from my time here at MDANSW. I will be staying on as a member of the Association and look forward to regular updates of members in Sydney and of course in the regional areas of NSW.

I wish you all safe and enjoyable end of year celebrations.

Best wishes, bye for now.

**Rachel Spencer**

Carers' Program Development Coordinator



One of the highlights for Rachel was the Carers Seminar held at Orange in 2006.

**GET THE FACTS**

Earlier this year MDANSW updated the following fact sheets:

- Genetics and Neuromuscular Disorders
- Duchene and Becker MD
- Spinal Muscular Atrophy
- FSH
- Friedreich's Ataxia
- Limb Girdle
- Myotonic Dystrophy
- Myasthenia Gravis
- Inflammatory Myopathies; DM, PM & IBM
- Later Onset MD
- Metabolic Diseases of Muscle

- Motor Neurone Disease
- Charcot-Marie-Tooth Disease
- Myopathies (Inherited Myopathies)
- Rare MDs

These fact sheets are available on our website [www.mdansw.org](http://www.mdansw.org) or by contacting Viktoria at the office on (02) 9697 9111. You can receive them via email or in hard copy.

Duchene and Becker MD and Spinal Muscular Atrophy fact sheets have recently been translated into Arabic, Chinese and Vietnamese and are also available on the website or from office.

Translation of this material was made possible through the Care for Carers program funded by NSW Health.

**M.A.C. CHAT**

The Members Advisory Committee (MAC) continues to serve the members of MDANSW and aims to represent the needs of our members.

MAC meets every two months, usually on a Thursday, from 2 – 4 pm, at the Association office.

The current members of MAC are:

**Member Representatives**

- Michael Baptiste
- Sandie Simmons
- Anne Patterson
- Eileen Baptiste

Martin Dalrymple  
Janene Oborn

**Executive Representatives**

- Rob Ferguson (President)
- Ian Dear (C.E.O)
- Viktoria Butler (Client Services Coordinator)

MAC is here for all members and if there are any issues you wish to raise, or would like MAC to take up with the Association, or if you would like to join MAC, feel free to contact myself or any member of MAC.

**Michael Baptiste**  
Chairperson, MAC.





**Clem Scott Ballard**

19/10/1988 – 17/7/2007

***He will live in our hearts forever.***

Our grandson Clem has influenced us all to draw on our inner strengths. He also shone a light on our human weaknesses. He taught us humility!

Clem’s determination to reach his personal goals was rewarded; he passed his Higher School Certificate with excellent results in maths and science. He attended his Year 12 formal dressed in a lovely plum silk shirt, black trousers and patent leather black shoes. His class mates surrounded him on the dance floor as they had included him in all facets of school life. Clem went on to study accountancy at TAFE and completed his first term with once again good marks.

Clem had “a beautiful mind” that was matched only by his beautiful smile. Clem’s courage and intelligence empowered him to achieve spiritual victory over the ravages of Duchenne muscular dystrophy.

Our hearts are as one with Clem’s parents, Kerry and Michael along with Clem’s brother Angus and sister Georgia. Their personal journeys with Clem have been profound in their endurance and individual commitment to meeting the daily challenges that were presented to them along the road. He will live in our hearts forever.

**Leonie and William Toohey**

*The race is not to the swift;  
or the battle to the strong  
nor does food come to the wise,  
wealth to the brilliant or  
favour to the learned;  
but time and chance happen to them all.*  
ECCLESIASTES Chapter 9 – V.11

**Lachlan Matthew Riley**

One of our younger members, Lachlan Riley, passed away on September 11, 2007, aged 11.

A service was held at Rookwood South Chapel on 17 September to celebrate his all-too-short life. The chapel overflowed with family and friends who came to share the memories of this cheeky Rabbitohs/ Ford “nut” with his parents Rob and Donna, and sister Emma. Eulogies by Rob, Lachlan’s uncle Craig and his teacher Kris all paid tribute to a young boy who was so often the life of the party, very caring about others, and also very forthright in his views. There were also readings by Lachlan’s aunts Kelly and Nicole.

Our deepest sympathy and thoughts are with Rob, Donna, Emma and Lachlan’s family and friends.



***We need your help!***



**The University of Sydney**

It is often a difficult thing to know what and when and how much to tell your son, family and friends about Duchenne muscular dystrophy. It is a hard conversation to have and many parents do not feel confident in deciding what they should tell their child.

This is an invitation to participate in a research study being conducted by Ms Judi Single and Dr Chris Lennings from the University of Sydney. The study is seeking to find out how parents talk to their sons and family about DMD and what they tell them and when. We would like to know what

parents think is the best way to talk to children about their condition and how they manage it.

You will be asked to take part in an informal interview that we expect to last for about one hour. If you decide to participate, one of the investigators will visit you at your home or meet with you in another location where you feel comfortable.

*If you are interested in participating in this important research study or would like more information, please call Judi on 9351 0352 or 0416 190 755.*

# Letters



Send your letters to The Editor, MDANSW,  
Locked Bag 1005, Rosebery NSW 1445  
or email [cazza74@bigpond.net.au](mailto:cazza74@bigpond.net.au)

Dear Ian,

I would like to offer the Association my feedback on the recent medical seminar and "hypothetical".

I would like to sincerely congratulate the Association for the efforts in organising the day. It certainly was an impressive line up of speakers, who gave valuable information to members on the progress of research into NMD and potential treatments for people affected. I think the program was highly appreciated by the audience, as seen by the good turn out on the day. The information, although much of it was highly technical and admittedly not my 'special subject', was useful in presenting the message that much work is being done in the area and there is hope for the future, albeit not immediate future.

I was particularly impressed with Louise Suffield's statement that it is also important to focus on the here and now (please note the spontaneous applause from the audience), and one of the medicos' reflections of how critical social and emotional well-being is in quality life outcomes for people with NMD. I whole-heartedly agree. However, I thought it was quite peculiar that Robin Williams found it ironic that the venue for the seminar was held at Olympic Park - had he not heard of the Paralympics?!

My constructive feedback would be that a person with a NMD should be a central figure on such a "panel". I would of also liked there to be time for questions or comments from the audience. The views of those personally experiencing living with NMD must never be underestimated, and are central to the debate and such ethical and practical dilemmas.

The venue was central, accessible and you provided excellent catering. It was a great chance for members and others involved to network and socialise together. I met two young girls with similar conditions as myself and also managed to catch up with some old friends and acquaintances.

The Association should be proud to have hosted such a successful and rewarding event. Thank you to those involved in the development and organisation of the day. I hope that another such event can be held in the future.

Kind regards,

Carolyn Campbell-McLean.

Hi Carolyn & Ian,

Attached photo of me with the new car which has just arrived! It's great. I would like to take this opportunity to thank both Rotary and MDANSW very much for this fabulous prize!

Kind regards,  
Janene Oborn.

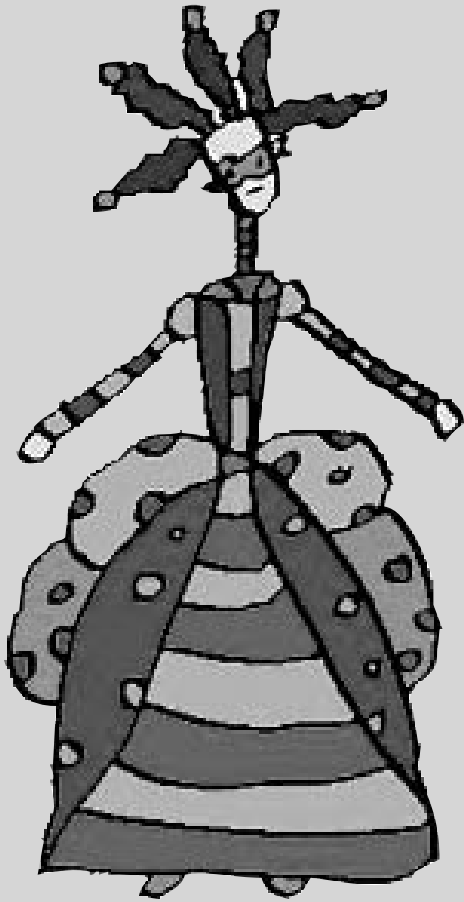


REPLY from Ian Dear, CEO  
Carolyn,

Thanks very much for your feedback. I do appreciate you taking the time and offering constructive suggestions for the future.

You mentioned Robyn Williams' ironic comment re the venue. I agree absolutely with you. In fact because I had been involved with both the Sydney Olympics and Paralympics I did point out to Robyn beforehand the fact of the Paralympics being such a success and the venue therefore being entirely appropriate. The point obviously did not register with him!

# This is really Silly!



You may remember hearing from one of our members, Monica Ellis, a few issues ago. She talked about her life living with muscular dystrophy and lots of other things including her dog Molly.

I was lucky enough to catch up with Monica and Molly recently to see how they were both travelling.

Molly is a cross-Poodle Maltese Terrier; I suppose a Moodle. She was interested in most of what Monica and I were discussing although she did seem to spend a lot of time with her eyes closed!

Monica now has her own website [www.itssilly.com](http://www.itssilly.com) which features the character Silly and her various adventures. Silly is a product of Monica's wonderful imagination and sums up her never-say-die spirit. Molly tags along with her just for fun. You can read about Silly's adventures on the website and also order Silly merchandise such as T shirts and cards. The website is well worth a look.

Monica is, in typical fashion, preparing for a solo exhibition of her work next year at a converted studio in Balmain. More on that later.

Monica and Molly have a lovely relationship which at times is tested by Monica's carers who are besotted with Molly. Mon and Moll go out each day and are well known in the neighbourhood. Monica's spirit and sense of humour are inspirational.

**Ian Dear**



## Now and then

There are many a weeks where MD hardly causes a ripple in our lives let alone even rates a mention. Then there are weeks like this one. In the doctors waiting room, where I am sure that we have all been. The conversation began simply enough. "Beautiful day, isn't it, love?" asked the 70-something lady across the room. During the ensuing chit chat I happened to mention that my husband has MD. "Oh" she said, "my three brothers had MD as well! One of them has gone now, one is in a nursing home and the other is in a wheelchair". I was surprised to say the least and asked her what type of MD they had. She gave me a confused look and simply said, "you know, the one where the muscles waste away. When it came on my youngest brother he went away and hid. Lived alone and kept to himself he did."

I left the doctors that day thinking back on the conversation. I felt sad for the lady and her family and their lack of information. Even to the point of not realising that there were different types of MD. It was fairly typical of those times though, when sometimes there was not even a diagnosis, just a 'take him home and keep him happy'. It made me wonder how the brothers fared throughout their lives in general, and what about herself, perhaps she was a

carrier and may never have known it.

The very next day a friend of mine collected a teenage boy who has Duchene MD to take him to out. During the travel to and from the event, there was plenty of chatting and the topics ranged from schoolwork, post school options, "gee, I hope I can get a girlfriend", "I wish I had a car to drive" and even "Do you think that I'll be a dad one day?" Think of the possibilities.

**Today** while driving an hour each way to my destination, I couldn't help contemplating the two very different lifestyles I had come across indirectly this week. In this the 50th year that MDANSW has been around it certainly shows to me personally just how far we have come as a society in general. Not only by being more informed about the conditions that affect us through MDANSW, we have more equipment at our disposal, and also have many, many more life choices available to those who have a neuromuscular disorder than the lady's three brothers could ever imagine. At least here in 2007, there is no need to hide away and live alone simply because we are different.

Remember there are only two times in life, now and too late.

Stay well,

**TY** (pen name).

**If you don't like something change it; if you can't change it, change the way you think about it.**

— Mary Engelbreit



# ACCESS ALL AREAS

goes international

## *It's a cruising life with a new wheelchair for our intrepid correspondent and MDANSW member, John Little.*

So here we are nearing the end of week 16 of a 30-week overseas travel adventure. I am sitting by a large picture window onboard the Norwegian Dream, a 60,000 tonne cruise ship docked in a very wet, windy and bleak Helsinki in Finland. Which is why I am on board and not out and about seeing the sights with Suzanne. I tried to go ashore but I was drenched by driving within 50 metres, so I declared defeat and returned to spend the day on board and write this story.

This ship is very accessible; we even have a cabin with wide doors and a roll-in shower. There is not a part of the ship I cannot access, well if there is I haven't found it yet. However I do need to explain that I have a new wheelchair because my Glide 6, that I brought with me, rattled itself to death on the cobbled streets and poor footpaths of south east London, well all of London really. Our Aussie chairs aren't built to withstand such challenges. So I tracked down a wheelchair service guy in Surrey who also happened to be a sales agent for a brand of chair made by a Dutch company called Moving People and he was able to help me purchase a demo model with everything on it that I could imagine.

It has electronically controlled tilt in space, seat raiser, back recline and leg rests, with large front wheel drivers which allows for a step climb three times that of the Glide. It also has 73ah batteries that have only ever dropped one light, and that was after a 15km shopping and walking trip through central London. Finally it has solid tyres so no more punctures Yey! Don't let anybody tell you solid tyres make for a hard ride (it would probably just be an excuse to cover the fact they don't sell them), solids have the same softness as well inflated normal tyres and with a good suspension system they not only provide a comfortable ride, but I am told they last three times as long. All this in a fully adjustable chair for approximately half the price of anything remotely similar in Australia.

The underlying secret to my new chair is that it is designed by an engineer who is also a wheelchair user. Not like most of the Aussie chairs that are designed by business people purely to make unreasonably huge profits out of vulnerable people with a disability. Sorry if that sounds bitter, but it is my one big gripe, and as I often say at home, D doesn't only stand for disability, it also stands for dollars. We are taken advantage of over and over again by greedy uncaring people.

One of the most important aspects I found about power wheelchairs is that in the UK the technicians and sales people have so much knowledge about their products. For instance I didn't know that my Glide was basically an indoor chair, because nobody ever told me! I thought a chair was a chair. Yet in buying my new one I was asked about my daily use and where and what it was likely to be asked to do, before I was advised on the grade, style and model of chair I would need.

Anyway in my new 'freedom machine' I am able to go to many places and do many things that I have not been able to before. For instance in Tallin in Estonia the most perfectly preserved medieval city in Europe I managed the incredibly cobbled streets, like some older areas of London, in my new chair. It was a great experience because it was a chair designed to cope with outdoor use as well as indoors.

Cruising is an OK thing to do in a wheelchair if you do your research on the ship and port facilities first. There are probably ten other wheelies on board with me, many of them in the autumn of their years who seem to be enjoying the experience. But what is most likely to put a cloud over cruising is actually the places visited by the ship. On board is great, but for instance, in Warnemunde, the nearest port to Berlin there were no accessible tours. What they call accessible in shore excursion language on this trip means you have to have a folding chair and be able to do a standing transfer to a van or bus. That would not suit most of the people I know with MD. Although I am told some shuttle buses have ramp access. I believe there is one in Helsinki but I didn't book on it because I wanted to go wandering with Suzanne. As it is I got neither because of lousy weather. However it is autumn, and this is the Baltic!

Later: I discovered that Stockholm is a truly wonderful city where I would love to spend more time. Lots of cobbles in the old city but the new modern areas are billiard table smooth. Copenhagen is also a lovely accessible city with a fantastically "disability aware" population. I saw accessible buses in both cities.

But Oslo in Norway, although it is supposed to have the highest standard of living in the western world, it certainly has the highest prices – try \$40 for three coffees! It has the most homeless people begging on the streets and the poorest infrastructure. Its crappy footpaths offer few useable kerb cuts. The pitted and potholed road surfaces would probably be no better than you would expect in rural Bangladesh. We had to queue at the railway station for 30 minutes to find out where the nearest accessible toilet was – even Tallin was blessed with an easy to find accessible toilet. The seemingly only one in Oslo was in a very hard to find place on a remote part of the station. The good old standby department stores don't have toilets at all let alone accessible. There seems to be no awareness of physical disability at all in Norway. So my advice is give it the widest berth possible and stick with Sweden and Denmark there you won't be disappointed and you will be treated with dignity and the greatest respect.

Back on board, our cabin has wider doors, more turning space and a great bathroom. The bed was too low for me so we asked our stateroom stewards to rustle up an extra

mattress which they did very quickly, and that solved the height issue for us. We experienced a little rough weather but it wasn't a problem being beautifully overcome by the ship's stabilizer system. So sea sickness has not been an issue. Over-eating is much more likely to cause problems. Food and entertainment on board, and there is lots of both, are included in the price of the cruise ticket, but everything else is at cost, and a pretty high one at that. Norwegian Dream, strangely, is an American ship and its standards are set by the very demanding American cruise passenger market.

Would I do it again? Maybe, but probably closer to home, though from what I have heard I would stay a long way from a P&O boozeliner. Besides as far as I have been able to discover P&O is not keen on wheelchair passengers because they make no effort to build access into their ships.

### **London so far and a trip to France**

After an uneventful trip with Qantas and no damage to my electric wheelchair, we spent our first nine days at the London Bridge hotel which was enough, if a little cramped and the bathroom was a compromise, with plenty of space but no roll-in shower. We had finalised our flat lease before arriving but could not move in for a couple of weeks. Anyway we had an appointment for dinner with old friends up in Suffolk before moving in, so we just used the time to get used to the London Bridge area that was to be our home base for the next six months.

I was delighted to discover that every bus in London is fully accessible, with an automatic extension ramp and a great parking bay inside which is prioritised for wheelchair users. Buses are a great way to see London and as a wheelie a cheap way too because we travel FREE. I have become quite an expert on London buses and can even get around without referring to the route planner.

Taxis are also accessible but in my electric chair brought from Australia I had problems because it is a high chair because of a poorly designed seat raiser and I am 6 foot, so head room became an issue. In a manual chair I had no problems, but London taxis are expensive, even more so if you are travelling on Aussie dollars (the Pacific Peso!)

We hired a wheelchair accessible van (Fiat Doblo) to drive up to Suffolk, from Wheelchair-Travel in Surrey Tel 01483 237 668 or email [trevor@wheelchairtravel.co.uk](mailto:trevor@wheelchairtravel.co.uk) Trevor delivered (at a cost mind you, £60 which is \$150) to our hotel. The rental rate is £65 a day or £340 per week. It worked well for us, and the company is the only one in Britain that I could find offering this service and Trevor is a very friendly soul.



*Every day has been an adventure for John.*

We have really settled in to living in London. We have our favourite, accessible, pubs where we have become locals. We know our way around the city, though it is constantly being dug up to replace the 19th century water pipes. We shop at the amazing Tesco's in Old Kent Road (a Monopoly address!!) with wide aisles and lower shelves as well as wheelchair accessible trolleys that clip on to the front of your chair so you can push the trolley and drive the chair. We have been many times to the West End. We have seen Shakespeare at the Globe Theatre, a 15 minute walk away for us and like all state run arts venues fully accessible. We are planning to go the Opera and Ballet at Covent Garden in the November and December.

Next week we are driving all the way to Rome for a few days followed by some time in Tuscany with a side trip to Switzerland. We have already had a five day trip to Paris and eight days in the South of France and it was wonderful. Of course not always hugely accessible but we managed and loved it. Being unsure I went in a manual chair, but could have easily taken my electric. I must say, Paris is really getting much better. Since our trip in 2001 the footpaths and kerb cuts are much improved, though small portable ramps would always be advisable and you can even get an accessible taxi now.

G7 Taxis in Paris can be booked by phoning 01 47 39 00 91. But be warned the meter starts when they take the job not when they arrive. Our two experiences, going not very far, cost about \$80 each time. But it beats the stress of missing a train or plane or being stuck at a cold railway station. And they provide a very good service with English speaking operators. When we got back to Paris from the south, we were met actually on the platform by the driver. He was standing right where our carriage stopped and he escorted all the way to his taxi. He even carried a bag!

Hotels are still a problem with very few roll-in showers. We stayed at Novotel Les Halles, very central and the best of a not very good selection if you can manage without a roll-in shower. On the road we have found that Mercure Hotels are both reliable and economical. We have even struck a couple with roll-in showers, one in Clermont Ferrand in the Auvergne region of Central France and one in Montpellier in the south.

All in all we have had a very good trip so far but with much to still see and do. But we are very happy that we undertook this crazy adventure while we are still able to enjoy it and we hope that this report helps in some way if you are planning a trip. You can always write to me via *Talking Point* with any questions. If I can help, I will.

Bon voyage!

**John Little**



# ACCESS ALL AREAS

"After having spent a lovely week at the cabins, I encourage other MDANSW families to spend some time out in Currarong."

– Rob and Rhonda Murray

**Cabins 1 and 2** have been joined together. Entry is by newly constructed ramp which leads into the kitchen (with fridge, stove, microwave, china/cutlery), dining and lounge area. The separate two-bedroom sleeping accommodation consists of one bedroom containing two sets of two bunks, and the other containing a double bed, storage area and washbasin. It has its own outside toilet and shower.

**Cost: accommodation \$20 per day + cleaning \$50.**

**Cabin 3** has just been painted in a "beachy" theme. It contains its own outside toilet and shower. The barbeque area, for use by both cabins, has been concreted and relocated beside Cabin 3. There is also plenty of room for children to play. A new washing machine has been installed.

**Cost: accommodation only \$10 per day + cleaning \$40.**

## CURRARONG CABINS – a fun experience and relaxing respite for MDANSW members.



Vacancies exist in the new year!

View of Currarong Creek inlet – flowing to Crookhaven Bight and the open sea just north of Jervis Bay and Point Perpendicular.

Currarong is a unique, small fishing village on the ocean 2½ - 3 hours from Sydney and ½ hour from Nowra. Pelicans soar over the pristine beaches and the village is quite level, wheelchair accessible and safe for children of all ages. We now have an amphibious wheelchair to enable beach and water access and full immersion in still water! Accommodation, cleaning and travel costs are currently refundable, along with travel expenses, up to \$750.

To enjoy the changes at Currarong Cabins, and discuss the current respite and travel grants, call Viktoria Butler on 9697 9111.

**Rob & Fran Ferguson**

## GREETINGS FROM LENNOX HEAD

It is so lovely to hear the surf rolling as we go to sleep. It's strange isn't it how as adults we rediscover the power of the lullabies that the natural world provides. Lennox Head suits us very well as everything is flat and within walking distance, so I am walking much more than I do at home which is good for me. Our apartment has a huge balcony where we have our breakfast and watch the early morning surfers and swimmers. We couldn't have asked for a better location!

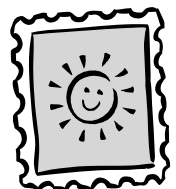
The national kite surfing championships were held here over the weekend so we were entertained by loads of colourful kite sails zooming across the water. I also sighted my first whale in the wild having a lovely time flapping his enormous white tail. On the Saturday a helicopter was hovering over the beach. Later we heard that three eight-foot white pointers were circling in the water and that everyone was ordered out but nobody paid any attention. So then the police were called to force people out. They are pretty laid back up here; I wouldn't have needed any encouragement! We are next door to the pub which has a great

restaurant upstairs (not wheelchair accessible) and thankfully a downstairs bistro with excellent food that we enjoy alfresco on the street-front verandah.

The pub is to be demolished in February, and rebuilt and modernised (and I would assume wheelchair friendly) at a cost of about 7 million dollars, in readiness for Christmas 2008. So we think we will holiday there in 2009 when the building work is over and the hotel is over any teething problems.

My 50th birthday dinner was celebrated at the Seven Mile Cafe; a gorgeous restaurant run by two flamboyant guys who really helped to make the night special. The next night we ate outdoors at a fabulous Thai restaurant and a big, bright moon added to the ambience. We feasted on local prawns another night in the apartment, accompanied with some lovely white wine and a couple of DVDs. On our last night we bought some homemade Lebanese and ate in the apartment as a very loud tropical storm raged outside.

x Sandi Simmonds



[www.lennoxholidayapartments.com](http://www.lennoxholidayapartments.com)



## Rain, rain, go away!

Over the month of June 2007, Concord Golf Club recorded nearly 530mm of rain (or close to two feet in language many of us understand). "So what?" you may ask. The answer is very simple. The golf day in support of the Association had been scheduled since November 2006 in the middle of a crippling drought across NSW and one of the most prolonged on record! The sun broke out on June 21 almost mockingly on a course that was flooded and had been closed for ten days. The result? No golf and back to the drawing boards to reschedule.

Happily for all concerned, the weather on the rescheduled day of July 19 was picture-perfect and 92 keen golfers descended on Concord for a day wielding golf clubs in a team Ambrose event, preceded by a golf clinic with Concord's professional, Ken Trimble, and followed by lunch, a raffle and auction. Along the way, the players had been challenged to be nearest the pin on three holes, to hit the longest or fastest or slowest drives, and generally to have a lot of fun. The winning team was one of the Macquarie Real Estate teams and the runner up the team from M & E Equipment Traders. Ian Hood and Kate Sauer won the longest drives for male and female respectively and Craig Holland won two nearest the pins. Craig was also a member of the winning team. Michael Edgetton won the fastest drive and Justin Stark the slowest drive. Ten other people took away raffle or novelty prizes. We will however not embarrass a certain member of the Board of the Association by naming him as the winner of the nearest the tee competition!

The day was extremely successful from a fundraising as well as a general enjoyment for all concerned point of view. Our sincere thanks to Stephen Turner, General Manager of Concord Golf Club, for his help and support for the day, to Ken Trimble and his pro shop staff, to our volunteer Board members Rob Ferguson, Colin Gunn and Vaughan Woods, Ged and Sally Dear, Anthony Herden, the Golf Events team, all our sponsors and donors and everyone else who participated. Let's do it all again next year!



## Christmas in July RANDWICK LABOR CLUB

Randwick Labor Club held their annual children's party this year a little later than usual on July 28. Our members and their families were treated to lunch, terrific entertainment by Marty and Emu and they even managed to say hello (sort of) to Santa himself as the accompanying photos show. The Club President, Ken Murray, also presented our CEO, Ian Dear, with a cheque for \$10,000. Ian thanked the Club for their long term ongoing support spanning many years of the Association's 50 year history.



Award winning staff from Best & Less Wetherill Park (L to R): Caden, Crystal-Leigh, Kristy, Rikki, Liana.

## The very best

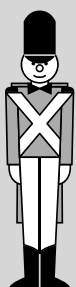
Once again this year, our good friends Best & Less ran a campaign in May throughout their stores in NSW and the ACT selling our soldier pens and badges. In the process they collected almost \$16,000. This was down on last year due to late delivery of stock but still a very pleasing result.

The top three stores were Wetherill Park, followed by Penrith Plaza, followed by Castle Hill. Certificates of appreciation and chocolates were awarded to these stores for their efforts on our behalf.

A huge thank you to the customers and staff of all the Best & Less stores. We are extremely grateful for your very generous support.

**If nothing ever changed, there'd be no butterflies.**

— Author Unknown



*fight for muscular dystrophy*



## Myer goodness

We were very fortunate again this year to have been supported by the staff at Myer Macquarie Centre and the Myer Community Fund. The funds raised by the staff were matched by the Fund with a total donation of \$4528.62.

The funds donated are to be applied towards our equipment funding program.



Our CEO, Ian Dear, was presented with the cheque and in turn presented a certificate of appreciation to the Operations Manager, Mr Femi Oni, as shown in the accompanying photo.

Sincere thanks to the Myer Macquarie staff and the Myer Community Fund.

## Those "foxy" ladies do it again

We have been extremely fortunate in recent years to have had the very generous support of the Associates of Fox Hills Golf Club.

This year the Associates raised \$2150 at their charity day on our behalf.

Our CEO, Ian Dear, presented a certificate of appreciation to the President, Mrs Maureen Reed, after a brief talk on our services and our 50th year celebrations. He thanked the committee and associates on behalf of the Association.



*Maureen Reed (with certificate) and other members of the committee with Ian Dear at the presentation.*

**Change always comes bearing gifts.**

— Price Pritchett

## BOSSLEY PARK GALA SOCCER DAY

You'd have to say that the weather did not exactly smile on the organisers of this day in support of the Association! It was cold and wet when we arrived for the day, and cold and wet when we left!

The day, however, was a wonderful success, with almost \$5200 being raised on our behalf by Bossley Sports Club. Its focus was a round-robin soccer tournament, with lots of other entertainment such as a magic show, car display and raffles.

Following the day, our CEO Ian Dear received a cheque at a special presentation and in turn presented a certificate of appreciation (see photo top right).

Sincere thanks to Bossley Sports Club, Horsley Park Soccer Club, the organizers (Alan Schembri, Rick Mattiuzzo, John Currao, Sergio Garcia, Sam Di Gracia, Phil Cook and Peter Kirby) and everyone else who contributed to making the day the success it was.



*The Kirby family at the gala soccer day.*

## GTK City to Surf Team

We were delighted that the GTK Rehab team participate in the City to Surf in August this year. Kitted out in their 50th anniversary T-shirts and caps, the team cut a swathe through all opposition (or at least looked absolutely wonderful!). Not only did they enjoy a very healthy 14 kilometres but they also managed to raise \$2000 in sponsorships and donations on our behalf.

Our congratulations and sincere thanks to all the GTK Rehab staff who participated as well as the donors and sponsors.



## HOGS DAY

It was a picture-perfect day for our annual HOGS day at Warragamba Dam on Sunday October 7.

The competition amongst the "wheelies", as the HOG people call our wheelchair experts, was very keen as the slalom, barrel-rolling and sausage-munching challenges got under way. Our wheelies performed extraordinarily well and were rewarded with a beautiful lunch, stickers, and a "hot lap" around the grounds on the back of the magnificent Harley bikes. Parents, other family members and friends of the wheelies received similar rewards and all had a wonderful time, as will be seen from the accompanying photographs.

Dave Charteris, the NSW HOG Chapter Director, presented our CEO, Ian Dear, with donations totalling \$1144 from the NSW and Blacktown Chapters. Our sincere thanks to our HOG friends for putting on another terrific day and all the hard work with the planning and preparation, cooking, catering, competitions and so on. You are all champions and we greatly appreciate your long and continued support for the Association.



## THE 'KING' AND US – A BEAUTIFUL PARTNERSHIP!

In planning our final 50th anniversary fund-raising event for 2007, we came across a coincidence that we thought was worth promoting. We shared our "birth" with the launch of the original hip-swiveller himself, Elvis Presley! Did we need any other excuse to put together a fun night for all concerned? No way!

We called the event "The King and Us" (with no offence intended to Yul Brynner or the English language!) and we held it at HMAS Penguin, Mosman, courtesy of the Senior Sailors' Mess Committee headed by its President Warrant Officer Ken McPherson on Saturday 1 December 2007.

Over 160 fun-seekers joined us, many of whom would have made Elvis proud of their attempts to fashion themselves in his likeness. There were big wigs, jump suits, hair dye, gold sunglasses, chains, bangles, glitter, etc. There was even a cigar! Go figure! And the guys were even more spectacular!

We raised over \$55,000 net on the night and are very grateful to HMAS Penguin, chef WO Colin McKenzie, the Mess Manager Jane Sliker and her staff and John Kinsella of Bilbergia for having underwritten our costs. We also received magnificent support from over 50 very generous donors. Our sincere thanks to everyone who helped and those who attended, as well as our new President Rob Ferguson for all his hard work.

The accompanying photos will confirm that part of the excellent meal for the night was not the only "ham" present!



## OUR FAVOURITE TREKKER

Readers may recall that last year one of our wonderful supporters, Mandy Smith, raised over \$5000 in sponsorships competing in the Sydney Marathon. Mandy has a very good friend whose eight year old son has been recently diagnosed with muscular dystrophy. I spoke to Mandy earlier this year and told her of the fantastic experience I had had walking the Kokoda Track with two of my daughters in 2005. I also showed her my photos of the eight days we spent in New Guinea.

To put it mildly, Mandy's interest was aroused. Great! Another challenge and an opportunity to raise some more money!

So, armed with the tips and information she had gathered and with a lot of kilometres of training behind her, Mandy set off for the Kokoda Track in July. Being the super athlete that she is, she took the whole 96 kilometres of it in her stride(s). In fact when we were comparing notes after she returned I was sort of hoping that she would declare it the toughest

and most gruelling physical experience of her life. This would make me at least feel that my experience had been nothing exceptional. I was not therefore quite prepared for her answer when I asked her what the toughest part of the trek was for her.

Her reply?

Her tent, followed by the awful food! Enough said, so we moved on to check out her photos!

Mandy managed to raise nearly \$10,900 on our behalf from her Kokoda efforts and hopes to repeat the experience in a few years time with her husband. Maybe I should show her some photos of Mt Everest to see if there is any spark of interest there!

I was delighted to present Mandy with a framed certificate of appreciation for her outstanding efforts on our behalf. A fantastic supporter and a real champion.

Well done, Mandy.

Ian Dear

### NEWS

## Mandy's on track for daunting fundraiser

MARATHON runner Mandy Smith is donning a pair of sturdy boots for a gruelling 110km challenge.

Next month, the Dee Why mother of three will walk the Kokoda Track to raise money for muscular dystrophy.

"It's a little bit of self-satisfaction as well as helping the fight against muscular dystrophy," Mrs Smith said.

Her 10-day jungle ordeal is personal.

A year ago her good friend Nikki Carlyle's son Tom, now 8, was diagnosed with a rare form of muscular dystrophy.

"I'm a mum with three healthy children. It's a fatal, long drawn-out disease with no cure. Stem cell research could be a real breakthrough for this disease."

Super fit - Mrs Smith has a strict early morning cycling and running program to prepare her for the rigors of the infamous Track. She will undertake her daily 7-12km assault on the track carrying a 7kg backpack and water; a porter will nimbly carry the bulk of her tent, equipment and food rations.

Her major concern - apart from her boots, the



Runner Mandy Smith with Tom Oliver, son of her good friend Niki Carlyle.

Picture: ROS CANNON JNP199163

leeches and mosquitoes - is the humidity.

"Being British, I don't cope well in the heat," she said. "It's going to be hot during the day and cold at night."

Humidity aside; she has had needles galore - tetanus, cholera and hepatitis B as well as vitamin B to discourage the mosquitoes in the equatorial heat. Then there are the malaria tablets to

take before, during and after the 10-day trip.

Last year Mrs Smith raised \$5500 for muscular dystrophy research in the comparative ease of a 40km marathon run - this year she hopes to better that figure. "It's not hard to raise money - it's hard to ask. But it's for a good cause and one lady has already donated \$5000."

If you would like to make a donation call Mandy Smith on 0412 776 449.

# A school DAY IN THE LIFE of Chris Suffield

**Chris Suffield completes his HSC 2007 diary:**

Approaching the end of year 12, and the end of school life, are some difficult times for HSC students to maintain their focus. From the end of the Trial HSC exams, I found it difficult to stay completely focused. By this time of the year, practically all of the course content for the year is completed. The tedious process of revision can be a little mind-numbing at times, but you can see the light at the end of the tunnel.

The process of revision is one that can really be boring, but I found that it was essential in helping everyone get through the HSC exams. During the last few weeks of term, I was writing essays in class, doing maths revision and going over parts of the syllabus that we weren't too clear on. Everyone is out on their own once formal classes are over. This is the most difficult time that many students will have trying to stay motivated. Honestly, I struggled to stay focused for long periods, but this couple of weeks is very important. This is not the time where you can slack off, but it is the time where you should go over everything you know and fill in the gaps. The last thing that any student wants to be doing a week out from the HSC is panicking. During the last few weeks of school, it is important to actually talk to your teachers if you are worried about anything. They will be more than willing to help if you can ask, I know because I asked. The HSC Advice Line is also good for this. Just make sure you have your question, and then someone will help you out.

The best way to go into an exam is confident. Not so confident that you think the exam will be easy, but rather, confident that you know everything you need to. Then it is a matter of putting it down on paper, nothing more.

During the HSC examination period, I was able to maintain my normal routine. I have to say, it is integral that you have the support of your family during this time. Without mum and dad



being there, I may have struggled. The night before the exam, I just went over things I was not as confident on. Also, getting a good night's sleep is so important to your exams. Staying up until midnight and getting 6 hours of sleep is not helpful to anyone. On the day of the exams, what I was doing was just reading over some little notes before the exam. If you are doing a subject like maths or science, go over

your formulae. If you are doing history, know your events and dates. In English, go over some potential essay structures you could use. But importantly, be ready to adapt to whatever the examination throws at you. The examiner does not want to know everything you know, but rather they want to see you answer the question.

If you have Special Examination Provisions, make the best use of these as you can. I was using a computer, rest breaks and extra time during my exams. If I was getting a little tired, I took a break and then got back into it. Breaks are also useful to maintain your focus. If you happen to be panicking, then taking a break is the best thing you can do. But after all this, the HSC exams are not the end of the world. Of course they deserve some focus and work, but they are just like any other exam. Apart from your best, there is nothing you can do. And once you finish each exam, you can tick it off your list. It's a really good feeling when you finally finish that last exam.

My HSC exams finished on the 7th of November, but the exams continued for a few days after this. Now the only thing to do is to wait for exam results. Hopefully everyone across the state does as well as they can.

**Chris Suffield**

**Note from Editor:** Congratulations Chris (and everyone else who has sat these dreaded exams). Hopefully now you have enough energy to party!!! Thank you so much for such a great series of articles about your senior school experience. We shall update MDANSW readers with Chris's plans post HSC.

## Neuromuscular disorders in the 21st century – the hope & the hype

**Here is a brief summary of Professor Kathryn North's talk at the recent medical conference and hypothetical, which covered three broad topics:**

1. Gene discovery and genetic diagnosis
2. Understanding disease mechanism
3. Better symptomatic and specific therapies

### **Gene discovery and genetic diagnosis**

The identification of the underlying genetic cause of a particular neuromuscular disorder allows researchers to begin to understand the mechanism of disease, ie how a mistake in a particular gene causes the disease. This then enables us to develop therapies that target the specific disease process, and therapies that aim to replace the faulty gene or correct the mistake. Knowing the specific genetic change in a particular individual allows us to provide that person and their family members with accurate counseling about genetic risk, and the option of prevention or prenatal diagnosis.

The genetic basis of an enormous number of neuromuscular disorders has been identified in the last ten years. For example, in 1996 there were four known genes for limb-girdle muscular dystrophy (LGMD) – alpha-, beta- and gamma-sarcoglycan in addition to dystrophin (for Duchenne and Becker MD). Now, ten years later, there are at least 23! Despite this there are still a significant number of LGMD in which the genetic basis remains a mystery.

### **Understanding disease mechanism**

Researchers are now studying all the genes known to be associated with muscle disorders to understand the complex process involved in the disease and the factors that lead to muscle wasting and muscle weakness. For example, dystrophin is known to be an important structural protein involved in protecting the muscle membrane from the forces generated when muscle cells contract. However, it is becoming clear that dystrophin's role is much more than just structural, and it is involved in the complex signaling pathways in the muscle cell itself.

### **Management of muscular dystrophy: better symptomatic and specific therapies**

**Medical therapies:** Although the focus in most people's minds at the moment is very much on the possibility of future curative therapies, it is important not to forget that excellent medical care continues to make a major impact on the quality of life and survival of children and adults with neuromuscular conditions. For example, the introduction of spinal surgery for scoliosis and respiratory support has significantly improved survival of boys with Duchenne MD (DMD).

**Drug therapy:** Corticosteroids have been used for some years now in DMD and in some boys result in rapidly improved strength. This is usually measurable in 10 days, and the maximum benefit is reached by about three months. Steroids slow the loss of function for up to three years, and can prolong the ability to walk for a number of years. The exact mechanism of action of steroids is not well understood, and

we know that they have an effect on many different processes within the muscle eg. they promote muscle regeneration, stabilize the muscle fibre membrane, have an anti-inflammatory effect and decrease muscle degeneration.

**Gene therapy:** Most of these therapies aim to convert the disease to a milder form eg. from Duchenne MD to a milder disease like Becker MD by producing at least some dystrophin that is partially functional. The biggest challenge for these therapies is to deliver enough of the therapy to the muscle cells themselves. Many of these therapies are successful in mice – but a whole mouse only weighs 25g and a single mouse muscle weights a lot less than 1g!

- o **Cell replacement:** myoblast transfer therapy aims to introduce immature muscle cells with a normal or functioning gene into a patient's muscle – these normal cells can then differentiate into normal muscle tissue.
- o **Gene replacement:** directly replacing the faulty gene using a carrier called a 'vector' – e.g. the aim is that the new gene can be put into an altered virus and given to the patient where it will multiply and spread into the muscle.
- o **Gene repair:** aims to fix the patient's own faulty gene
  - Drugs that cause 'read through' of early stop signals (called 'nonsense mutations'): In some patients, the fault in the gene results in an early stop signal, so that the gene is not read all the way to the end, and the protein is not formed normally. PTC124 is an example of one of these drugs, and is in an early trial currently starting in the UK.
  - Compounds that provide a 'gene band-aid' – and allow the muscle cell to 'skip' over the part of the gene where the mistake is (called 'exon skipping'). At least some functional protein will be formed.
- o **Gene up-regulation or inhibition:** we know that although there is degeneration of muscle cells in muscular dystrophy, there is also a lot of regeneration. This regeneration is not enough to keep up with the muscle damage. Therefore, rather than just trying to replace the missing or faulty protein, we can try to boost other pathways of muscle regeneration or dampen the degenerative pathways. For example blockade of the protein myostatin results in loss of the normal inhibition of muscle growth in mature muscle and results in muscle hypertrophy. Also there are other proteins that may be capable of taking over at least some of the function of the missing protein and we may be able to increase the production or activity (up-regulate) of these eg. Utrophin is an immature version of dystrophin that can replace some of its functions in skeletal muscle.

There is a huge amount of exciting research happening, and although progress seems slow, it is important that above all we do no harm. Side effects of experimental therapies can be severe, and therefore they need to be tested thoroughly before they become widely available. A catastrophic side effect will be a dramatic set back to the process, a set back that we cannot afford.

**Professor Kathryn North**

# It's Christmas!

## Aussie Christmas

### **SPEERS POINT PARK, LAKE MACQUARIE**

Not only did we enjoy full sunshine and blue skies, but the venue for the Christmas Party with the Hunter and Central Coast members was superb!

The 'Aussie Christmas' arranged by Rachel, our Carers' Coordinator, was held at Speers Point Park, on Sunday November 25, 2007 with a BBQ lunch, expertly cooked by Janine, Phil and our CEO, Ian!

The park was packed with many Christmas revellers of all ages and the MDANSW members were able to 'eat, drink and be merry' with the stunning views from the open shelter smack bang in the midst of the park festivities.

Santa found time to join our group in his usual jovial spirits (he was constantly being seen during the day throughout the park!) and indeed being in such demand, he had forgotten to change out of his trainers!!

The time flew by and some of us had a fair journey home so Santa, Rachel, Ian, Ged and Viktoria said their farewells leaving members to party on!



## Sydney Christmas

### **RHODES PARK, CONCORD WEST**

Great weather arrived just in time for the MDANSW festivities on Sunday, December 2, 2007. Entertainment appeared in the form of a 'Clumsy Clown' named Yuri – he was great! He arrived with his suitcase and fold-up table and was surrounded by eager young onlookers within minutes.

Yuri began with his magic tricks, aweing his wide-eyed audience. From 'magic tricks' we culminated into a 'congo line' dancing to the music of the bag-pipes played by the talented Yuri. When we finished our dance around the shelter we were entertained with Yuri's intriguing balloon art! Not to stop there, this talented clown proceeded to bring out his box of paints and decorated all the children's cheeks.

All too soon Yuri had to leave as lunch was ready to serve. Wonderful salads, sausages and hamburgers, chicken and platters of fruit were devoured. After this it seemed a 'siesta' would have been appropriate but who should put in an appearance but Santa! He was surprised to see so many

people but luckily had brought enough presents for all the kids.

It was a most enjoyable day and great to have so many celebrating Christmas 2007 together!

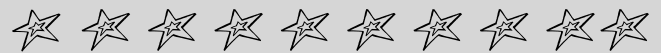


## Christmas Luncheon

### **ILLAWARRA/CENTRAL COAST**

The Christmas luncheon for MDANSW members and carers in the Illawara/Central Coast region was held on Friday December 7, 2007 at the Gerroa Boat Fishermen's Club.

What a spectacular view this club encompasses looking out along the South coastline! We filled two long tables and celebrated in the Christmas spirit in wonderful company with great food.



## Women's Group Xmas

The Women's Group had a great lunch to celebrate Christmas at the Drummoyne Rowers' Club near Birkenhead.

Rachel Spencer was able to join us to say farewell as she moves to part-time work to enable her to complete her studies.

Great company as usual and a wonderful venue!

**Change is inevitable – except from a vending machine.**

— Robert C. Gallagher





B.E.E. Printmail is proud to support  
MDANSW

# B.E.E. Printmail

**SPECIALISING IN THE PRINTING AND MAILING  
OF NEWSLETTERS AND PUBLICATIONS**

**We can provide for all  
your production needs**

- Artwork • Printing • Finishing
- Mailing • Database Management

B.E.E. can offer every type of printing – from the humble 4 page black and white digital newsletter to the finest quality full colour offset production – at very competitive prices.

1/5 Waltham Street ARTARMON NSW 2064

**Ph:** 9437 6917 **Fax:** 9906 4911 **Email:** beeprint@tpg.com.au

## MDANSW INFO

**OFFICE** 49 Hansard Street,  
Waterloo NSW 2017

**POST** Locked Bag 1005  
ROSEBERY NSW 1445

**PHONE** 02 9697 9111

**FAX** 02 9697 9092

**TOLL FREE** 1800 635 109

**EMAIL** info@mdansw.org

**WEB** www.mdansw.org

### OFFICE BEARERS AND STAFF

**President and Chairperson of the Board**

Mr Robert Ferguson BA

**Vice President**

Mr Colin Gunn BA (Hons)

**Honorary Treasurer**

Mr Graeme Troy BComm CPA

**Medical Director**

Dr Heather Johnston BSc MB ChB Dobst  
RCOG DCH FRACP

**Honorary Directors**

Mr Percival Alwyn Baptiste JP

Mr Ross Parker BA

Prof. Alastair Corbett MB ChB MD FRACP

Mr Ian Williams BEc, MBA

Dr Kristi Jones MB BS PhD FRACP

Mr Bruce Ellison

**Honorary Solicitor**

Mr Simon Gates

**Chief Executive Officer**

Mr Ian Dear BA LLB AFAIM FAMI CPM

**Office Manager**

Mr Bob Horan

**Client Services Coordinator**

Ms Viktoria Butler BSW

**Carers' Program Development Coordinator**

vacant

### DISCLAIMER

The views expressed in these pages may not be the views of MDANSW. Care has been taken in the preparation of content, but MDANSW 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:

The Editor, *Talking Point*  
Locked Bag 1005,  
Rosebery, NSW, 1445

## TALKING POINT

### THE NEUROMUSCULAR CLINICS

#### Children's clinics

Sydney Children's Hospital, Randwick  
Neuromuscular Clinic ..... 9382 1700

Sydney Children's Hospital  
Outreach clinics at Canberra Hospital, Canberra  
and John Hunter Hospital, Newcastle  
Contact through Sydney on ..... 9382 1700

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



**N.E.W.S.  
UPDATE**



**WANTED: new talent for N.E.W.S.**

In April this year the NSW Colts had another successful N.E.W.S. tournament. It is now the off-season and focus shifts to next year. The next National Electric Wheelchair Sports tournament will be hosted by our Association and held in Sydney from 14-20 April 2008, at the Sydney Academy of Sport, Narrabeen.

Once again, our squad is looking for some new talent and we are interested in promoting sport to those with any type of neuromuscular disorder. Over the last couple of years we have successfully brought through some young players who have gone on to represent NSW or filled in for ACT.

Even if you are interested to come and try and not necessarily want to try out for the squad you are also welcome. If you are just starting to use an electric wheelchair and are still walking, you are also welcome to participate. There are stricter rules in the national competition but our Sunday training sessions are about encouraging people to have a go.

All sessions will be held at Kevin Betts Stadium, Ralph Place, Mount Druitt, from 12 – 3pm.

**2008**

- February** Sunday 3rd, 10th, 17th, 24th
- March** Sunday 2nd, 9th, 16th, 23rd, 30th
- April** Sunday 6th

If you are interested in getting involved in electric wheelchair sports and would like more information, feel free to contact me.

phone: 9643 1429  
email: MBaptiste@bigpond.com

**Michael Baptiste**

National Director, N.E.W.S. & NSW Coach

**Want to buy, sell or donate equipment, products or vehicles that other members may be interested in?**

Contact **Viktor** on **9697 9111** or [services@mdansw.org](mailto:services@mdansw.org)

**CLASSIFIEDS**

**FOR SALE Luxury Pride Power Wheelchair**

As new, electric seat elevator (allowing driving whilst elevated), high max speed capabilities for indoor/outdoor use, luxury seating, full suspension with 'Active-trac' and an all over ultra sleek sporty design in stunning Onyx Black! Original cost approx \$12,000 but sell for **\$4,990 – ONO**.

AND

**NEW height adjustable chair**

with high back-rest. It has leather-look upholstery in pastel Guava colour, with upholstered armrests and steel legs in pale vanilla colour. Never used. Sell for **\$99** which will be donated to MDANSW.

If interested in either item, contact **Carlos** by email on [cteixero@au1.ibm.com](mailto:cteixero@au1.ibm.com) or by phone on 02 9899 9611.

**FOR SALE Toyota Tarago**

2003 model with rear floor modification to accommodate manual or powerchair. Would prefer to sell vehicle with fully adjustable 12-month-old **Roller M1 Powerchair** (chair can be fully adjusted to suit persons size), as the vehicle has docking system which is compatible with this powerchair.

Also available: 1 **Lifting Hoist** & 1 **Shower/Commode chair** which were both brand new in January 2007. 1 fully adjustable bed & wave mattress.

Items required/costs can be negotiated as per purchaser's requirements.

If you are interested in any or all of the above items please do not hesitate to phone: **Rob** or **Donna Riley** on 02 9774 3870 (home) or 0417 249 025 (mobile).

**FOR SALE Toyota Hiace**

**Year:** 1992  
**Body:** Short wheelbase  
**Engine:** 2.4-litre petrol  
**Transmission:** 5-speed manual  
**km:** 300 000  
**Seats:** 5 plus Wheelchair  
Redbook value is between \$3500 and \$5900 for the Van on its own without modifications – we would be happy to sell for **\$5900 ONO** – with all equipment.  
**Layout:** Driver + 2 seater in front, 2 x single seats on right side rear (one behind the other), wheel chair on left side, beside single seats Wheel chair restraints: 4 x Q-Straint retractable restraints + Q-Straint Inertia reel lap / sash seat belt  
**Ramp:** 2-Meter Decpac  
**Mechanical:** good order  
**Interior:** average for age  
**Body:** average for age  
**Tyres:** 80%  
Call **Viktor** at the MDANSW office on 02 9697 9111.

**FOR SALE Manual Wheelchair**

Quickie 2 Kids padded armrests, folding frame, swingaway footplates, 17" seat width, 15" seat depth, 24" quick release mag rear wheels, relatively good condition **\$800**  
Contact **David Reid** (MDANSW member in Nowra) by email on [dreid@fastrac.net.au](mailto:dreid@fastrac.net.au) or by phone on 02 4423 4070.

**FREE Manually operated adjustable bed**

Very good condition. Fully adjustable.  
Contact **Dave Fotheringham** by email on [gt1500@idl.net.au](mailto:gt1500@idl.net.au)

# Tea with the Governor



In cricketing terms, 50 is the start of a pretty good innings and on Saturday November 17, 2007, we celebrated our 50th anniversary with our Patron, Her Excellency, The Governor of NSW, Professor Marie Bashir AC CVO at Government House.

Over 140 members attended the function which began with speeches by the Governor and the recently elected President of the Association, Mr Rob Ferguson. The Governor also presented a certificate of appreciation to Mr Bruce Ellison, our outgoing President, in recognition of his many years of work on behalf of the Association and his last three years as its President.

The day was picture postcard perfect and we were treated to excellent catering as well as the music of the eighteen-piece Turrumurra High School Stage Band who performed brilliantly and received many extremely positive comments.

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 simply complete this form and return to Muscular Dystrophy Association of NSW, Reply Paid 78684, Rosebery NSW 1445.

**Yes, I would like to make a gift for muscular dystrophy of \$** \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

I enclose my: Cheque/Money Order made payable to Muscular Dystrophy Association of NSW, or

Please debit my:  Visa  Mastercard

Cardholder's Name \_\_\_\_\_ Card No \_\_\_\_\_

Cardholder's signature \_\_\_\_\_ Expiry Date \_\_\_\_\_

**Thank you.** All gifts of \$2 or above are tax-deductible.

