

June 2007

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Greetings from Ulladulla

"Two belles! Two belles!", cried the lookout.

"Where away?", asked the Skipper.

"Two points off the port bow."

Two points? How wrong he was; everyone was pointing.

"Hand me those binoculars."

Those on one side looked this way; those on the other side twisted their necks, wondering what it was that so held the attention of the crew.

So the beauties of Sydney Harbour were enjoyed by all on board. Or nearly all on board. One lovely passenger was meditating on the Scripture passage, "Watch and pray that you do not fail the test. The spirit is willing but the flesh is weak."

That's the trouble with MND. The spirit wills, but the flesh fails.

The crew, ever alert, enjoyed the sights but were not distracted from their prime purpose of sailing with people with disabilities. Even as her feet dipped into the harbour waters, strong hands clamped onto her shoulders and she was hauled back on board; deck-hauled, not keel-hauled.

"Thanks. Thank you. I was on the high side until we tacked. Then I was on the low side. My leg just wouldn't come with me. Boy! Am I having a good time!"

And so she was. Sailing on Sydney Harbour; the best harbour; the best yacht; the best crew. How could she not be happy? What chance has a broken windscreen, a flat tyre and two falls have against a narrow blue band inscribed with 'Never give up'? What chance against a group of strong, compassionate women and men dedicated to their task, sailing with the less able?

Blue sky, gentle breeze; gliding out of Rushcutters Bay; Clarke Island; Garden Island; looking at the Navy ships where the 'QE 2' had been; Woolloomooloo Bay; Fort Denison; under the Bridge; Berrys Bay; 'Goliath' Devonport, its bulbous bow pushing aside the water under the Bridge; Comedy Crew on 'Rhythm Boat'; Shark Island; Sow and Pigs; huge spinnakers on maxi yachts; tiny sailboats literally flying across the harbour, hulls right out the water; seaplanes out of Rose Bay; cruise boats

with decks lined with sightseers; ferries avoiding collisions; water taxis; big ships, little ships, motor yachts, sailing yachts, racing, cruising, all the wonderful sights and sounds of Sydney Harbour on a beautiful Saturday afternoon in April.

April 14, in fact. That

was the day **Sailors with Disabilities** hosted the MND Association. What a wonderful atmosphere.

The best of the day was the opportunity to share, with each other and the crew; to share smiles and worries, problems, worries, heartaches; hopes. To laugh together; to weep together, silently, knowing without being told; sufferers and carers; thankful for the opportunity to grasp at least one wonderful time together. A day to remember.

All this thanks to Sailors with Disabilities, and the crew of the lovely yacht 'Kayle', Matt, Jason, Bob, Carly, Tony, and Allan; and especially Jo Fowler, of the MND Association, organiser. We who sailed on this cruise offer our sincere thanks to those who made the day possible. Thank you, all of you.

*Bruce Nicholls
Ulladulla*



(l-r) Hanna Nostler, Bruce and Diane Nichols, and Peter Ellwood on the 'Kayle'

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries. The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.

A Message from the CEO

As part of MND Week 2007, MND Australia asked each State Association to undertake a 'Call to Action' to address a national issue facing all people living with MND. This year's issue is the Commonwealth State Territory Disability Agreement (CSTDA) and the continuing inability of federal, state and territory governments to reach an agreement to fund unmet needs to support people living with MND and their carer and any provision for future growth of this agreement.

MND NSW and MND Australia have been arguing that funding under the Commonwealth State Territory Disability Agreement (CSTDA) should be:

- Appropriately indexed so that investment in services maintains its value, and
- Increased to address the unmet need for disability services that exists within the community, and particularly for people living with MND.

I would like to thank everyone who participated in our 'Call to Action' during MND Week in May. I received many requests from members for further information and the electronic versions of the letter. For those still intending to write to their local member about the CSTDA it is not too late and more information is available on the MND NSW website at www.mndnsw.asn.au or ph. 8877 0999.

In New South Wales MND Week was kicked off with our launch at the Waterview Convention Centre, Homebush Bay. Our guest speaker was Associate Professor Roger Pamphlett of the University of Sydney. Attendees included the Minister for Disability Services the Hon Kristina Keneally, our Vice Patron Melinda Gainsford Taylor and many members and supporters from across the State. Dr Paul Brock AM, a tireless advocate for people with MND and until recently an MND NSW Board member, was conferred as a Vice Patron. His speech can be read on page 4 of this edition of *Forum*.

Congratulations and thank you to the recipients of the MND NSW Volunteer Medallions announced at the launch - Libby Gole, Pamela Hennessy, Debra Larizza, Gregory Morrison, Margaret Orr, Joy Pogson, Judith Saladine and Christine Williams.

MND NSW has formed a consortium with Multiple Sclerosis NSW/Vic and Muscular Dystrophy NSW to advocate for people with progressive neurological diseases. Our initial focus has been on flexible respite care and we have met with the Director General of Ageing Disability and Home Care who has shown a great deal of interest in our proposed model. It is through partnerships such as these that MND NSW is seeing incremental system-wide improvements in the care of people living with MND. Our Regional Advisors will be able to keep you up to date with the progress of our discussions.

MND NSW, as a member of the New South Wales Motor Neurone Disease Advisory Group, a group formed to report directly to the Minister for Disability Services, have helped draft a report that will be used to address the complex systemic needs of people with MND by liaising with the Director Generals of both Health and Disability Services.

I would like to welcome two new family support staff to MND NSW. Noelle Smith, who is based in our Newcastle office, and Jane Barrett who works out of the MND Centre at Gladesville, introduce themselves below. Christina Jason, Regional Advisor, has resigned from her position and we wish her well in her new position.

To all those who have lost loved ones and friends to MND I extend, on behalf of the Board and Staff, our deepest sympathy.

Graham Opie
Chief Executive Officer

MND in the media during MND Week



Introducing...

Noelle Smith

Regional Advisor, Newcastle

I'm a Sydney girl who has been seduced by the beauty and pace of Newcastle and the Hunter for the last eleven years. I am a social worker with some recent training in mediation and my work background in Newcastle includes stints with NSW Health, a special school and the Spastic Centre of New South Wales.

I have three young sons and I enjoy reading, cycling, movies and the beach. I have received such a warm welcome at MND NSW that I can tell I am in for an adventurous and inspirational ride. I am looking forward to meeting some of you in my travels.



Noelle Smith and Jane Barrett

Jane Barrett

Family Services Coordinator

I began my career as a nurse and in the years following have studied social anthropology, religious studies, adult and health education. My work background includes HIV/AIDS, sexuality and body image in people with cancer, and the compilation of a manual on drug overdose for heroin and other drug users. I have also

been involved in educational and workforce development for non-government services.

I am enjoying the varied work my position offers and getting to know and working with our members, their families and carers.



MND Week 2007

MND Week Launch

Lots of volunteers, beautiful weather, new merchandise and determination were the ingredients of this year's MND Week and Cornflower Blue Day.

The week started with the annual launch of MND Week on Thursday 3 May, again at our new venue, the Waterview Convention Centre in the grounds of Bicentennial Park at Homebush Bay. The March of Faces banners provided an inspiring display along one wall of the venue – a tangible reminder of the need for events such as MND Week and Cornflower Blue Day to raise community awareness about motor neurone disease.

Associate Professor Roger Pamphlett of the Stacey MND Laboratory at the University of Sydney was our guest speaker. He provided a comprehensive overview of current research into motor neurone disease across the world, including the exciting work being undertaken by our own scientists in Australia. The scientific research at the Stacey MND Laboratory and at other Australian and international locations is progressing in small steps towards de-mystifying the many unknowns of motor neurone disease.

It was wonderful to see so many of our country members and friends attend the launch and their efforts to join us were acknowledged by Graham Opie, CEO MND NSW during his welcome speech. Board member and Secretary of the Association, Bob Howe, congratulated Graham on his leadership and thanked the staff of MND NSW for their commitment and efforts towards meeting the needs of people living with MND.

MND Week Events

Throughout MND Week we had an army of volunteers out on the streets, at stations and in shopping centres selling merchandise and spreading the word about motor neurone disease and the Association. Sitting or standing for hours trying to catch the eye of people passing by is not the most exciting thing to do so we really do value the Association supporters who participated in this way.

Thank you to the people who held events during or around the time of MND Week. In particular, Lorraine Walker at Binalong for her 'Out of the Blue' dinner auction, Gemma Cooney at Penrith for her Irish Night and Amanda Mowbray for her 'Stars behind the Bars' at the Roxy Theatre.

MND NSW Volunteer Medallions

MND NSW was able to thank its volunteers on two occasions in May. At the launch of MND Week special medallions were awarded to eight volunteers, who have volunteered over a number of years to assist the Association in a variety of ways. Thank you Libby Gole, Pamela Hennessy, Debra Larizza, Gregory Morrison, Margaret Orr, Joy Pogson, Judith Saladine and Christine Williams.

When extra help has been needed these wonderful people were only too happy to help with some of the, sometimes, tedious and monotonous tasks of stuffing envelopes, packing merchandise, counting cornflowers and photocopying family support publications. They have been our receptionists, entered masses of data and turned a chaotic merchandise storeroom into a sparkling showroom. Some have utilised special talents and skills and helped acquire gifts for auctions and prizes, organised large events and held special massage clinics for our members.

The next day the Fundraising Institute of Australia held a special presentation and luncheon for volunteers during Charity Awareness Week at Parliament House. Debra Larizza received the certificate from Michael Foggo, Commissioner, Department of Gaming and Racing, on behalf of all our volunteers.

This was followed by lunch in the Strangers' Dining Room where Debra was joined by Fundraising Manager Judy Ford and two other long serving volunteers, Bob and Suzanne Ballinger.



Jo Fowler, MND NSW Regional Advisor with members Trish and Phil Brady at the Launch



Melinda Gainsford Taylor, Vice Patron MND NSW, with Jim Simpson, whose wife Leone (Flippy) is remembered on the seventh MND NSW March of Faces banner



Debra Larizza receiving the certificate on behalf of all volunteers



At the MND Week launch, Volunteer Medallions were presented to (l-r) Joy Pogson, Margaret Orr, Debra Larizza and Judith Saladine, who were able to be present on the day

MND in the media during MND Week



MND Week 2007 (cont'd)

Dr Paul Brock AM - Vice Patron MND NSW

Dr Paul Brock AM, a tireless advocate for people with motor neurone disease and until recently a MND NSW Board member, was conferred as a Vice Patron of the Association at the launch of MND Week 2007. Paul's speech at the launch was inspirational and is reproduced below.

"I would like to thank the Board for inviting me to become Vice Patron of the Association. You can be assured of my loyalty to the Association and its goals - which I like to summarise as awareness, advocacy, care, fundraising, and support for research. When I was diagnosed in 1996 I was told I had only 3 to 5 years to live; that there was no cure; and that a drug called Riluzol or Rilutek, not then on the PBS and costing about \$600 a month, could extend the end of life by a few months. I found out that there were about 1400 people then living with MND in Australia.

Eleven years later, thanks to the Association and its State and National counterparts, Riluzol is now on the PBS. The Australian Institute of Health and Welfare statistics show that in 2002, 508 people died from MND - over four and a half times more than the 111 deaths that were attributed to HIV/AIDS in that year; while the Institute reported 530 deaths from MND in 2003. Approximately 5,000 Australians will have died with MND since my diagnosis. There is still no cure.

For a disease first identified in the scientific literature by the great French neurologist Jean Charcot in 1869, it is a scientific / medical research disgrace that in 2007 nobody still fully understands the cause and nobody has yet discovered a cure for MND. To what extent this sorry state of affairs can be attributed to indolence, apathy, ignorance, lack of funding, failure to adequately support our researchers, or whatever - these have not been the characteristic features of the more successful research and therapeutic strategies applied to other diseases such as AIDS, leukemia, heart disease, diabetes and prostate cancer - for example - over the last two decades or so.

One of my former neurologists warned me in 1996 not to join MND NSW because, in his view, the Association was focused too much on dealing with the inevitable grief associated with MND and too little committed to finding a cure by advocacy for research. He said something like "it is too bleak an organisation for somebody like you". Two years later when I decided to join the Association I was to learn that his assessment was quite an unfair

exaggeration. Certainly today in 2007 no one could validly make such an assertion. Supported actively by my colleagues on the Board and on our research sub-committee, and the Association's CEO and staff, I strove hard to raise the profile of and advocacy for research in as many contexts as I could.

As Vice Patron I hope to be able to continue my advocacy for the MND research bar of expectations to be raised significantly higher: in order to better understand the causes, to help extend the quality and expectancy of life, and - above all - to find a cure or cures for MND. To urge those in positions of policy and research who have the power to make a difference, but who may need some prodding and support, to

make such a difference. And, taking my cue from the remarkable Christopher Reeve, to constantly remind not only the research community, but the Australian community as a whole, that for those of us with MND, our families, and our loved ones, "our houses are already on fire and we need you to put them out now". "

Paul Brock AM
Vice Patron MND NSW



Dr Paul Brock AM Vice Patron MND NSW (centre), with (l-r) Carol Birks, National Executive Director MND Australia, Associate Professor Roger Pamphlett, Stacey MND Laboratory, and Janet Nash, Executive Officer MND Research Institute of Australia.

Congratulations to MNDRIA funded researcher **Steve Vucic** who was awarded the 'James Lance Young Investigator' Award at the 2007 Australian Neurologists Meeting

'Ask the Experts' and DNA Donor Drive - ask questions and give blood!

Do you have questions about MND - current therapies, research, what palliative care can offer people living with MND, what a multidisciplinary MND clinic is? Bring your questions to the 'Ask the Expert's' forum.

Speakers include

Dr Helen Herz
Dr Mathew Kiernan
A/Prof Roger Pamphlett
Dr Dominic Rowe

Monday 23 July

10.30am-3pm
Royal Rehabilitation Centre
Ryde

For further information about this event contact Jane Barrett, Family Support Coordinator ph. 8877 0999.

You will need to **book** early for the forum as places are limited.

Family Support

Recently it has seemed that each time there is a new edition of *Forum* we also have a farewell to acknowledge. Several of the recent family support staff changes have occurred because staff are choosing to continue their involvement with the MND Association in a different capacity. Valued staff members such as Anita Richter, who worked for MND NSW for more than ten years in Carers Services and Special Projects, continues her involvement on a project basis, while Carol Birks, who provided eight years service to the Association as Family Support Manager, left us to accept a position with MND Australia as National Executive Director.

On this occasion we say goodbye to Christina Jason from our Newcastle office. Christina has worked with MND NSW as Regional Advisor for over five years. During this time Christina has contributed to the Association in many ways, including her key involvement in the development and implementation of the MND NSW Volunteer Visitors Program and, in 2006, setting up the Newcastle office. Christina leaves us to take up full-time employment and we wish her all the best in her new role.

Times of change provide new opportunities and over the past few months we are fortunate to have some great staff join us, including Jane Barrett, Family Services Coordinator and Noelle Smith, Regional Advisor Newcastle office. Jane and Noelle introduce themselves on page 2.

Our newest recruit is Karen Kemp who started in early June, based in the Newcastle office. Karen has a nursing background and has worked in disability, nursing and foster care. She has a wealth of experience in both the government and non-government sector and also has experience in presenting education programs which will be of great assistance in continuing to educate professionals involved in caring for people with MND.

On 24 May I attended the launch of National Palliative Care Week with our CEO, Graham Opie. The theme this year is 'Making a difference – to someone living with a terminal illness'. This is also the name given to the National Community Education Initiative. The aim of the initiative is to increase awareness of palliative care for people at different stages of the relationship with someone living with terminal illness. This includes friends, family, caregivers, work colleagues and health professionals as well as the general public.

As part of the initiative, a package of information has been developed, including a great booklet called '*What can I say, what can I do?*'. It has practical suggestions for people who know someone who is living with terminal illness. There is also a brochure about palliative care and a booklet called '*Asking questions can help*'. This booklet is designed to help people to know what questions to

ask when living with a terminal illness. To find out more about how to get this information go to www.pallcare.org.au or contact 1800 660 055. As one of the invited speakers, Kari Baynes, a past carer, said at the launch, palliative care team members were like little angels helping her and her husband when they needed it the most. Kari also said that she wished she had been referred to palliative care much earlier in her husband's illness as it would have made things a little easier.

During May, the family support staff had the privilege of visiting the MND DNA Bank at the Stacey MND Research Laboratory at the University of Sydney, which is managed by Associate Professor Roger Pamphlett. The DNA Bank provides researchers with information about DNA that can really assist them in their research. This information is used not only in Australia but also in other parts of the world. If you are interested in finding out more about the MND DNA Bank you can contact Lorel Adams at the DNA Bank directly on ph. 9036 5456.

We will also be conducting a DNA Donor Drive at our 'Ask the Experts' Forum to be held on Monday 23 July (see page 4). This is a great opportunity for you to fire away with your questions about MND. I am looking forward to catching up face-to-face with members and their families on the day.

Gina Svolos
Manager Family Support

Family Support Calendar

- 29 June** **Past Carers Meeting**
MND NSW Centre, Gladesville
- 23 July** **Ask the Experts**
Ryde (see notice previous page)
- 6 Aug** **MND DNA Bank Newcastle Visit**
10am-1pm, 44 Dudley Road, Charlestown.
Take the opportunity to meet the two new MND Regional Advisors based in Newcastle and hear about the latest research on MND. There will be plenty of time to enjoy some good company and a scrumptious morning tea as well. Contact Noelle Smith, Regional Advisor MND NSW for more information ph. 4921 4157.
If you are planning to donate a small blood sample contact Lorel Adams, MND DNA Bank ph. 9036 5456, so a timeslot on the day can be allocated to you.
- 3, 10, 17 and 24 Sept** **Care for Carers Workshop**
MND NSW Centre Gladesville

If you would like assistance with travel to attend any of the family support sessions or would like us to organise an MND information session in your region, please speak to your Regional Advisor.

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Special Projects and Carers

My first three months at MND NSW have been challenging and very interesting. I have been out with Regional Advisors to meet members, attended two multidisciplinary MND clinics to talk to staff and patients and attended my first Past Carers Group. In my first week, as part of my orientation, I went to the 'Partnerships for Better Health Outcomes: Carers and Professionals Working Together' conference organised by Carers NSW.

The impression I gained was of the uniqueness of each caring situation combined with the shared complexity of getting access to care, treatments and services. In addition, the costs of caring were discussed, not just costs related to loss of employment and reduction of work but the many hidden costs to the carer - physically, psychologically, socially, emotionally. While caring is an integral part of human relationships which brings its own rewards, carers need to be supported and recognised at all levels of society.

As Family Support Coordinator at the MND Association with responsibility for carer programs I am finding out just how much of what was discussed is relevant to all carers and what issues are different because of the nature of MND itself.

The NSW Carer Action Plan 2007-2012 was launched at the conference, putting carer issues clearly on the political agenda. It has five priority action areas: Carers are recognised, respected and valued; hidden carers are identified and supported; services for carers and the people they care for are improved; carers are partners in care; carers are supported to combine caring and work. The implementation of these action areas will be a challenge over the next five years

Past Carers Group

I enjoyed meeting members of the Past Carers Group which was held at the end of March. This 3-monthly event is open to all past carers including people who live outside of Sydney who may want to call in when they are in the city. The next meeting of the **Past Carers Group** is on Friday, **29 June** from 12-2pm at the MND NSW Centre at Gladesville. It was agreed at the last meeting that members will continue to bring a small contribution towards lunch.

Care for Carers Program

The next **Care for Carers** Program will begin on **3 September**. It will be run on a Monday for four weeks and will be held at the MND NSW Centre at Gladesville. It is open to carers new to the role and also those who have been caring for longer periods. Topics include physical management of a person with MND, available services, managing swallowing difficulties, emotional issues and self care.

For further information about these contact Jane Barrett, Family Support Coordinator on 8877 0902.

Jane Barrett

Family Services Coordinator

Equipment

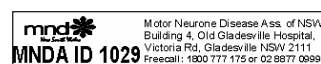
Due to the differing rates of individual progression of MND, member need for certain types of equipment fluctuates during the year. Since the beginning of 2007 demand has been high on the larger 'stay at home' items. During this period \$44,400 has been spent on new equipment to better meet the need for equipment loan to MND NSW members.

New equipment items purchased include an electric hospital bed, five raiser recliner armchairs, five manual wheelchairs, five electric hoists and slings, two alternating air mattresses, two environmental control units and a powered tilt in space wheelchair. All of this equipment is currently out on loan.

Over the past year 1,013 equipment loans have been made through the Equipment Loan Service.

Identification of MND Equipment

Members can access equipment from a variety of services as well as from MND NSW. This can make it confusing when it comes to the return of equipment to the correct service. To help with the identification of equipment loaned by the



Association, a white sticker with MND NSW address details

and a unique identification number is placed on a main part of the item. This unique identification number enables equipment staff to track and record the loan and service history of each individual item.

Support Group Talks

It is not often I get the chance to put faces to names when dealing with members and health professionals regarding equipment. Most of my contact involves phone or email conversations so it has been a great experience meeting members and some health professionals during my recent talks with some of the MND NSW support groups. These groups include Northern Beaches, Western Sydney, Northern Sydney, Gladesville and Central Coast. I would like to thank everyone for being so friendly and welcoming.

Maree Hibbert

Equipment Services Coordinator

...Farewell from Christina Jason

I am sad to announce that as of 11 May I will no longer be a Regional Advisor for MND NSW. It has been my privilege to provide support to people living with MND and their carers in the Hunter and surrounding regions for the past five years. I have been uplifted by people's spirit and determination to overcome adversity and make the most out of what they have.

Noelle Smith and new MND NSW Regional Advisor, Karen Kemp, will soon be working at full strength out of the Newcastle office. They can be contacted on ph. 4921 4157.

Warmest regards,
Christina

Care for
Carers
Workshop

MND NSW
Centre
Gladesville
3, 10,
17 and 24
September

Support Group News

Southern Highlands/Monaro

This group is for people who live anywhere from the Southern Highlands through to the Snowy Mountains including those in the ACT. Our numbers have shrunk in the last 18 months so please come along and join us to ensure the continuity of our meetings. We welcome those with MND, their families and carers and new members always enjoy a warm welcome. We also welcome any ideas on how to make the group more relevant and enjoyable for those who attend.

Sharing your experiences can build your knowledge of how to deal with MND on a daily basis and we always have time for some social chat as well. Meetings are usually held on the first Saturday of every second month at Clare Holland House, Menindee Way, Barton, ACT. For further information contact Allison Pearson ph. 6238 3769.

Allison Pearson
Regional Advisor

Central Coast

Central Coast Support Group meets bi-monthly at 2pm Saturday at the Gosford Senior Citizens Centre, as we have been doing since September 1994. The group was set-up by Lloyd and Naomi Affleck and in May 2007 we met at our 73rd meeting. Five of the early members who are now past carers are still very active members. Throughout the years many others have also stayed on with us. We are a very caring group and welcome new people to our meetings.

In May, Maree Hibbert, MND NSW Equipment Service Coordinator, and Gina Svolos, MND NSW Family Support Manager, attended the group. Maree gave a very informative talk about the equipment pool and showed us many useful items which are readily available to make life a little easier. Gina said she is still on the 'learning curve' - we are sure she is a good learner and will be a great asset to the Association. All of us are learning and this builds confidence and character. Both Maree and Gina were accomplished speakers and did extremely well against the competition from the square dancing meeting in the auditorium next door.

During MND Awareness Week our local media coverage was good and many more in the community will now be aware of MND and no doubt supporting us in our endeavours. We were happy to donate the proceeds of our involvement in the Rotary Raffle again this year to the Equipment Loan Service and know Maree will make good use of the \$1200 to purchase necessary equipment.

We are sorry to have lost some of our dear friends this year. We are still in support of their beautiful families.

Audree Dash
Central Coast Support Group Coordinator

Support Group Contacts

Central Coast

Audree Dash
Ph: 02 4384 2907
Sheila Holmes
Ph: 02 4392 5513

Central West

Jenny Judd
Ph: 02 8877 0999
jennyj@mndnsw.asn.au

Coffs Harbour

Lily Jenkins
Ph: 02 6652 2571

Illawarra

Julie Hutchings
Ph: 02 4223 8000

New England

MND NSW
Ph: 1800 777 175

Newcastle & Hunter

MND NSW
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Northern Rivers

Helen Gates
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Riverina & SW Slopes

Susan Chambers
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Southern Highlands/Monaro

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Caroline Gleig
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Northern Beaches (Mona Vale) and Northern Sydney (Hornsby)

Jo Fowler
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and

Western Sydney

Jenny Judd
jennyj@mndnsw.asn.au

All Sydney metropolitan groups are coordinated through the MND Gladesville Centre.
Ph. 02 8877 0999 or Freecall 1800 777 175

Central West

We had a good turn-out at the Orange Ex-Servicemen's Club on 17 April to meet the new Orange Community Options team who are settling into their new roles. We look forward to a positive relationship with them.

Graham Opie, CEO MND NSW also attended the meeting and spoke to the group about MND Week and the 'Call to Action'. Additionally, Graham spoke about the Association's strategic plan (despite his hard copies having been left at the airport) and advised us of the links that are being developed by MND NSW with other organisations.

At the meeting, Graham was presented with a generous donation for MND NSW from Lee Bradbury who undertook a long distance bike ride in support of the activities of the Association.

Meetings are held bi-monthly at a venue in either Orange and Dubbo. All are welcome.

Jenny Judd
Regional Advisor

Do you have a question about MND?

Ask the Experts

Ryde
23 July

Connecting for Sound



Janet
Monaghan

In the eleven years I have been affected by a rare form of MND I have taken an interest in how I can use technology to remain independent and enjoy life. I use a LightWriter to speak for me and the internet to take care of everyday business. I use email, instead of the telephone, to stay in touch with friends, family and health

professionals. I listen to audio books from the Vision Australia Library because I have difficulty holding books and turning pages.

I love music, but found physically handling my compact disks difficult. This led me to get an iPod which is very small and easy to operate portable music player. The iPod holds my entire music collection and it comes with earphones, so I can listen anywhere, anytime, without disturbing anyone around me.

One thing has seemed to lead to another in my journey in technology - my latest interest is in podcasting. Using the internet and podcast receiving software, my favourite radio programs

are automatically downloaded to my computer. I then plug my iPod into my computer and my radio programs are transferred to my iPod so I can listen to them anytime.

I listen to podcasts in bed at night before going to sleep and sometimes if I wake during the night. Also when resting during the day I can close my eyes, recline, and listen to a program. There are many programs to choose from – my personal favourites are from my favourite radio station ABC Radio National (576 am): 'Late Night Live' – interviews with eminent people from all over the world. 'All in the Mind' – about the mind and the brain, 'Big Ideas', 'The Philosophers' Zone', 'The Science Show', 'The Book Show', 'In Conversation', 'Encounter' and 'The Spirit of Things'.

In my journey with MND, I have sometimes felt very alone – even though I have family and friends - but podcasting my radio programs is like having an old friend with me at anytime. I enjoy it immensely.

Janet Monaghan
Gladesville

What is a portable music player?

A portable music player stores audio files (voice and/or music) in an electronic format called MP3. There are many portable music players available in addition to the iPod, which is manufactured by Apple Computer Inc. Other brands to look out for include Benq, Creative, Samsung, Sandisk, Sony and Toshiba. Some players have greater ease of use than others so you might need to try several out to find the right one for you. Prices start from around \$70.



How do I get audio files onto my computer?

Music files can be 'ripped' (copied) from a CD to your computer using a program such as Windows Media Player. Be aware of copyright issues. You can also download music files from the internet onto your computer by locating the site with the file and saving the file to your computer.

Many service providers now produce voice files in MP3 format for people to download. These may be regular programs (podcasts) or just one-off audio files. You can download these manually by locating the site with the files (such as the ABC at www.abc.net.au) and saving them onto your computer.

However, if the program is a podcast, you can also use software that enables you to subscribe to a particular program and have newer editions of the program automatically downloaded to your computer as they are released. This type of software is called a podcast receiver.

How do I get a podcast receiver?

The Apple iTunes software (that comes with an iPod) has a built-in podcast receiver. You can use that to subscribe to your favourite programs. Even if you don't have an iPod you can download it for free (see <http://www.apple.com/itunes/download/>). There are other free podcast receiving programs available such as Juice Receiver (see <http://juicereceiver.sourceforge.net>).

Do I need a MP3 player to listen to podcasts?

No. Once you have downloaded the audio files onto a computer that has speakers or headphones you can listen to any audio files without transferring the files to the MP3 player.

How do I get audio files onto the MP3 player?

How the files are transferred from your computer to the MP3 player depends on the type of MP3 player and software you use. Some MP3 players will allow you to transfer the MP3 audio files from your computer using a 'copy and paste' in Windows Explorer. Some come with software that is designed for that particular MP3 player. Others have a very automated process in which you just connect the MP3 player to your computer and it updates itself with any new audio files.

More information about podcasting

Choice Magazine: www.choice.com.au

Wikipedia: <http://en.wikipedia.org/wiki/Podcast>

ABC Radio: <http://www.abc.net.au/rn/podcast>

Lists of free audio content on the internet

www.freedigitalcontent.com

<http://podcastempire.com>

Tell other's living with MND about your tips and tricks.

Email or write to The Editor (see back page for contact details)

Out and About

Thought about visiting Norfolk Island?

MND NSW member Paul Douglass and his wife Chris did. They found several disabled friendly accommodation facilities and shower/ commode chairs available for hire from the Red Cross on the Island. There is no public transport, so if you are still able to transfer into and out of a car or coach, and travel with someone who can drive/assist, then this is a pleasant travel destination with enough to see and do for a week.

To get around Paul and Chris hired a car - and joined into organised activities by using the car instead of getting on the coach. These included the Mutiny on the Bounty Show and the Sunset Cliff Top Tahitian Culture show. South Pacific Resort offered accessible night time shows but you need to book. Even though only a few historic sites were accessible, Paul and Chris enjoyed their stay on this island which is only a short plane trip off the coast of New South Wales.

Contact Norfolk Tourism for more detailed information ph. 0011 6723 22147
info@norfolkisland.com.au or see
www.norfolkisland.com.au

Other ideas

Have you thought about a trip to the Southern Highlands of New South Wales? The region enjoys four distinct seasons and stunning scenery ranging from native wilderness to cool misty pastures reminiscent of England, to hidden valleys with remarkable waterfalls. All this and only two hours away from Sydney!

Bruce Mumford has written a great article highlighting accessible accommodation, parks and picnic areas, toilet facilities, waterfalls, wineries, clubs, museums, bookshops, cinemas and transport. See www.holidayinspirations.com.au/Articles/The-Southern-Highlands---acces.htm for more information.

Bruce, who has multiple sclerosis, has also penned two terrific articles filled with sage advice and lots of extremely useful travel tips covering his extensive travels in Europe and a recent journey to New Zealand. You can access these at www.e-bility.com.



Paul Douglass at the Convict Dinner on Norfolk Island (above) and (below) enjoying the view



Accessible self-guided walking tour

www.SelfGuidedWalkingTours.com have just released a new wheelchair accessible tour around the Rocks district in Sydney. The tour consists of a 21 track audio (MP3), map and information about how to get there. For more information see www.selfguidedwalkingtours.com

Travel tips

- Plan ahead.
- Make reservations for transport, accommodation, tours and hire equipment well in advance, and confirm all bookings and arrangements 48 hours beforehand.
- Notify others about your needs. Inform your travel agency or companies you are using, including airlines, that you will be travelling with a person with MND.
- If flying, book direct flights where possible and when making bookings allow plenty of time for any necessary transfers between planes or other forms of transport.
- Call airports and airlines well ahead of time to find out about services, including seating arrangements, special meals and shuttle services.
- If you are using public transport, contact the local tourist authority to find out if the public transport system accommodates your disability.
- Access can mean different things to different people. If you have checked that the bathroom is wheelchair accessible, also ask about the front steps. Try to speak to somebody who has actually seen the facility.

The Internet can be a great source of holiday information. In general, searching online for the location you want with '+ disabled' as your other search term will be a good start.

Accommodation needs survey

A survey of tourism accommodation and information needs of people with mobility disabilities is being undertaken by Simon Darcy of the University of Technology Sydney. To access the survey see www.surveymonkey.com/s.asp?u=63033650891 or contact Simon Darcy, ph. 9514 5100 or email simon.darcy@uts.edu.au

Your experiences of air travel

Is air travel difficult or just not possible? Or was it so bad you don't want to do it again? Maybe you had a great experience with the airlines in the past few years? The Disability Standards for Accessible Public Transport will be reviewed shortly and the Accessible Airlines Project will be making a submission. To aid this project the Public Interest Advocacy Centre (PIAC) is seeking your story in a couple of paragraphs or dot points. You can post your story to Brenda Bailey, PIAC, Level 9, 299 Elizabeth St Sydney 2000 ph. 8898 6522 or email brenda@piac.asn.au

The MND Carers Kit 2nd edition has an updated travel section full of tips, ideas and resource lists. For more information contact your Regional Advisor

MND FORUM

Boys Help Raise Funds for MND

Seeing the affects first hand of motor neurone disease has led to Wests Tigers half-back John Morris and prop Bryce Gibbs doing their bit to help raise funds into research for a cure.

Morris lost his father to the disease in 2002 with Gibbs losing his uncle last year. The boys decided to help raise awareness during this week's Motor Neurone Disease Week by donating signed jerseys for auction.



The West Tigers boys with one of the signed jerseys

At the Wests Tigers players sponsor dinner on Tuesday night, a City jersey signed and framed by Gibbs sold for \$3000. Morris also put up for auction a fully signed and framed Wests Tigers jersey which sold for \$5500. The \$8500 will be donated to MND NSW.

Furthermore, a signed Gibbs jersey and a Wests Tigers jersey signed by the 17 players that beat the Melbourne Storm in round eight are currently being auctioned through the Wests Tigers website in support of MND NSW.

"I just wanted to do something good to help raise awareness and this is a great cause," Gibbs said.

Morris said he wasn't even aware of motor neurone disease until his father was diagnosed with it. "By raising awareness, we can raise some funds that can go a long way to helping with the research in finding a cure for the disease.

Irish Craic

A great evening was had by all at the Penrith Gaels Club in May to raise funds for the MND association. There was fantastic music from George and the Unicorns who kept young and old dancing for hours. A total of \$4000 was raised by a very hard working team led by Gemma Cooney, whose sister is living with the disease in the United States. A big thank you to all concerned.

Binalong - 'Out of the Blue'

The Dulux dog formed part of the most successful auction item at the Binalong 'Out of the Blue' dinner on Cornflower Blue Day for MND NSW at the Motel Royal Tara in Binalong. What a great night!



(l-r) Belinda Pigram, Tom Duffy, Maree Ings, Lorraine Walker and Libby Elliot at the Binalong dinner and auction with the Dulux dog

Good Guys are Good Guys

The Good Guys at Warrawong, and in particular, store manager Robert Barnhill, continue to support the MND NSW through donations and selling merchandise during MND Week. It is the partnerships we have with retail outlets and other commercial businesses that not only provide valuable financial assistance but also vital public awareness. Thank you Good Guys!



MonStar Cup is a Monster Effort

On Tuesday 20 March a most successful golf day was held at the Pennant Hills Golf Club. Organisers Hamish Pearce and Mark Golding planned this wonderful day to help two charities - StaR Association and MND NSW.

Starting at 11am the golfers registered and set out for a hot and sunny day of golf. Thunder storms in the late afternoon did not deter them from having a fantastic day. In the evening they were wine and dined, danced to the Jelly Bean Jam and had the opportunity to bid on fabulous auction items like a Deluxe Blue Haven Spa, a box for six at Telstra Stadium to watch Wests Tigers, a Sony audio visual packet and much, much more. Prizes for the raffles were equally outstanding in quality and value and many happy party goers left clutching their new possessions.

Many thanks to Joy Pogson and Liz Sandwith who helped sell merchandise during the day and Bob and Suzanne Ballinger who took over for the evening shift. Once again our volunteers were there when we needed them.



Liz Sandwith, Joy Pogson and Judy Ford at the MonStar Cup

The financial outcome of the day was dazzling and divided equally between the two charities. The cheque presentation took place at Goldram Financial Service office where both Mark and Hamish work. We are most grateful to Hamish for making all this possible and contributing so much to MND NSW. We look forward to next year's MonStar Cup.



MND NSW CEO Graham Opie, Fundraising Manager Judy Ford with Hamish Pearce and Mark Golding, organisers of the MonStar Cup

**MND
Global Day
raffle
tickets...**
don't forget to
return them by
20 June for
the draw on
MND Global
Day
21 June

Fashionable and Fun Fundraiser

On Tuesday 20 March Armidale came out in force to support a Benefit Night for MND in conjunction with The Australian Wool Fashion Awards (TAWFA) held at the New England Girls' School (NEGS) Equestrian Centre.

The event was organised by a committee of Armidale families whose lives have been touched by MND including Dianne and Bruce Sewell, Steve Sewell, Sally and Chris O'Shea and Kerrie Pearson. Liz Foster, Managing



Steve Sewell, Dianne Sewell, Sally O'Shea, Kerrie Pearson and Roslyn Adams

Director TAWFA was instrumental in providing the inspiration for the event as the fundraiser followed on from the gala TAWFA parade held the previous Saturday. Our sincere thanks go to the models and backstage attendants who gave their time, to all the sponsors, those who loaned their services and equipment for the event, and to other volunteers.

Invest Blue Armidale through the AMP Foundation's Community Fundraising Program which supports the community work of Financial Planners matched donations up to \$10,000 dollar for dollar. It was a wonderful evening and we were thrilled to be invited to be part of such a prestigious event. Fundraising exceeded expectations and we are most grateful to the committee for their enthusiasm and contributions to MND NSW.

Fun and Dance Evenings

The Swing into a Night of Fun and Dance at Coffs Harbour in March was organised by Sharon and Steve Buckley whose lives have also been touched by MND and attended by CEO Graham Opie. Money raised for MND research went to the Australian Rotary Health Research Fund where every dollar is matched with another dollar. Thank you for a successful evening arranged by wonderful volunteers and supported by the local community.

Graham also attended the Good Fun Dancers annual supper dance in Griffith during May. Money raised throughout the year was donated to MND NSW and a local Griffith charity. Thank you!

Are you planning to run in the City to Surf?

Do you want to get people to sponsor you in an event?

Here are two ways to ensure your sponsors are able to support you easily.

Everyday Hero

This organisation has been appointed the official sponsorship site for people entering the City to Surf event this year. If you would like people to sponsor your effort in the City to Surf just go to www.everydayhero.com.au for more information.

Sponsor Me

www.SponsorMe.com.au is a great new way to raise funds for MND NSW. We are a nominated charity with Sponsor Me so all you have to do is choose an existing event and away you go. Sponsor Me can send a single email to your friends instead of you asking them or knocking on their door! You don't handle any money either as it all comes directly to us. If your chosen event is not yet registered with Sponsor Me just tell them to go to the site to register, or do it yourself! Sponsor Me is simply the easiest way to raise money online.

Dates for the Diary

23 June	MND Global Day Dinner Dance <i>Roseville Memorial Club</i> <i>Ph. 9419 6849</i>
24 June	Nicholas Merry trekking up Kilimanjaro in Africa
12 August	City to Surf <i>Register with the official site</i> <i>www.everydayhero.com.au to sponsor our runners</i>
25 August	Fancy Dress Dinner Dance <i>Rotoract Club of Lismore</i> <i>Lismore Workers Club</i> <i>Contact Robyn Gillies ph. 0400 475 660 or alstony1@hotmail.com</i>
15 Sept	'Spring into Action' Fundraiser <i>Organised by Meg Tudehope, Sydney</i>

New booklet just released

The Motor Neurone Disease Association of NSW has just published a small booklet "Preparing for the Future". It is free to members and discusses such issues as keeping your Will up to date, information on choosing executors, solicitors and trustee companies. It also gives guidance in valuing assets and the difference between the six types of bequests.

It also gives details about joining the *Blue Cornflower Society*. If you would like a free copy posted to you please phone Anne on 8877 0999 or 1800 777 175.



The beautiful photographs of cornflowers used by MND NSW for illustrations have been taken by Paula Trigg

Noticeboard

Carer Bonus in Federal Budget

The Government announced that the 2007 Federal Budget provides a one-off lump sum payment to eligible carers as follows:



- A payment of \$1,000 will be made to carers who receive Carer Payment.
- Recipients of Carer Allowance will receive a payment of \$600 for each eligible care receiver.
- Recipients of Carer Allowance who also receive Wife Pension or the Department of Veteran's Affairs (DVA) Partner Service Pension will also receive a payment of \$1,000 in addition to the \$600 Carer Allowance bonus,

The payment will be automatically made to the majority of eligible carers by 30 June 2007.

Economic Impact of MND on Well-Being

Last year, members of MND NSW were asked to participate in a research project looking at the Economic Impact of MND on Well-Being. This is a collaborative research project between Deakin University and MND NSW. Professor Marita McCabe and Dr. Lucy Firth of Deakin University and are researching the financial impact of MND on the quality of life of people with MND and their families.

The researchers are now starting to compile the results. If you have not returned your questionnaire please do so as soon as you can. If you have any questions or comments regarding this project, Elodie O'Connor of Deakin University can be contacted by phone on 03 9251 7258 or via email at elodie.oconnor@deakin.edu.au.

Angel Flight Reaches Out to Help People Living with MND

Angel Flight Australia is a charity that co-ordinates non-emergency flights for financially and medically needy people. All flights are free and may involve patients and/or carers travelling to or from medical facilities anywhere in Australia.

Angel Flight works to particularly assist those in isolated areas. In the past, members of MND NSW have benefited from the care and generosity of Angel Flight.

For more information contact Angel Flight on 1300 726 567 or see www.angelflight.org.au



Speaking from Experience

Information about people's experiences with MND is now available in video format on the web.

Developed from the video 'Speaking from Experience', individuals with MND talk about diagnosis, reaction, concerns, physical symptoms, coping, relationships, lifestyle issues and closing thoughts. See www.realtimehealth.com/conditions/motorneuronedisease.



New South Wales Ombudsman and You



The New South Wales Ombudsman is an independent watchdog that oversees government departments and their employees.

In New South Wales any community service that is run by a government department (such as the Department of Community Services and the Department of Aging, Disability and Home Care), or is funded by the government, must abide by certain standards. To make sure this happens the Community Services Division of the New South Wales Ombudsman can take complaints from members of the public and then decide to independently investigate.

As a consumer of community services, you may have wanted to make a complaint about a service occasionally. Generally the first thing to do is to discuss your concerns directly with the service. Sometimes, though, this isn't appropriate, or doesn't solve the problem. If this is the case and you need further help, you can contact the Office of the New South Wales Ombudsman on ph. 9286 1000 or toll free from outside Sydney on 1800 451 524.

You can ask someone else, like a friend or relative, welfare worker or advocate, even your local Member of Parliament, to contact the Ombudsman on your behalf. If for any reason the Ombudsman's complaints staff can't help, they will try to refer you to someone who can.

The Office of the New South Wales Ombudsman can consult closely, investigate widely and make recommendations that are generally taken on board by agencies and government departments and acted on.

For more information about the NSW Ombudsman go to: www.ombo.nsw.gov.au

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Do you have a letter or ideas for Forum? Contact The Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675

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DISCLAIMER All care has been taken in the preparation of this newsletter. The MND Association of New South Wales disclaims any liability for its content. The information contained within is of a general nature. For medical advice, consult your doctor.

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