



FORUM

June 2008

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Governor of New South Wales*

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MND Week 4 to 10 May 2008

MND Week 2008 started with the 'Let's Launch MND Week together' event at the Waterview Convention Centre in the grounds of Bicentennial Park. We were very fortunate to have Her Excellency, Professor Marie Bashir AC CVO, Governor of NSW officially launch MND Week.

Professor Bashir spoke with warmth and wisdom about motor neurone disease. Our guest speaker, Professor Garth Nicholson of the University of Sydney and ANZAC Research Institute at Concord Hospital, spoke about the latest research into MND, focusing particularly on the background to the TDP-43 study. Carol Birks, National Executive Director of MND Australia, provided an overview of MND Associations around Australia and explained about some of the work being done internationally through the International Alliance of ALS/MND Associations. Through this global camaraderie, initiatives such as the Professor Stephen Hawking promotional message about MND are developed and, as demonstrated through the distribution of this promotional message Australia-wide during MND Week, benefit MND State Associations enormously.

Channel Nine presenter, Ben Fordham, was a wonderful master of ceremonies and brought us all together for a time of reflection when Professor Bashir lit the candle of hope and remembrance. Following Her Excellency's words of acknowledgement of people whose lives have been touched by motor neurone disease, there was one minutes silence.

In the days following the launch, our merchandise again proved to be in high demand. Thank you to the volunteers who came into the MND NSW Centre at Gladesville to pack the merchandise orders to be sent far and wide; to those who volunteered at railway stations or set up stalls in shopping centres; to others who sold merchandise at workplaces, the Sydney Qantas terminal and at hospitals; and also to the supporters who organised special MND Week events.

MND Week is an important awareness raising time in the MND calendar and it is only through your support that an MND presence is possible in communities throughout New South Wales. Thank you for your efforts.

Roslyn Adams
Fundraising Coordinator



The NSW March of MND Faces banners were a poignant reminder of the effects of MND.



Her Excellency, Professor Marie Bashir (centre) with Paula Trigg (left) and Gina Svolos.



(Left) Carol Birks with Paul Brock AM, MND NSW Vice Patron (centre) and Ralph Warren, President MND Australia. (Right) Carol with Phil and Trish Brady.



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

During MND Week 2008 our national theme '**Living Better for Longer**' resonated with a large audience. A 40 second awareness-raising message, delivered by Professor Stephen Hawking, was broadcast on commercial and community television throughout Australia. We anticipate that the broadcasting will continue throughout the year. If you haven't seen the message yet, you can view it on the MND Australia website at www.mndaustralia.asn.au.

The New South Wales launch of MND Week, held on Thursday 1 May, was attended by more than 140 people. A special thank you must go to the speakers including Her Excellency the Governor of New South Wales, Professor Marie Bashir AC CVO; Professor Garth Nicholson, The ANZAC Research Institute, Concord Repatriation General Hospital; and Carol Birks, National Executive Director, MND Australia. Our appreciation also goes to master of ceremonies, Ben Fordham, from Channel Nine. Ben coordinated the formalities of the event with great competence and his personal memories of Sarah Turk, who recently died from a familial form of MND, struck chords with all of those present.

The New South Wales Department of Ageing, Disability and Home Care has asked that MND NSW provide expertise in identifying gaps in the

continuum of care for people with MND. This would entail the identification and implementation of pilot programs throughout 2008-2009. We'll keep you informed of progress.

The 2008 National MND Conference, titled 'Living Better for Longer, Pathways for the Future', will take place in Melbourne on 24 June and is hosted by MND Victoria. The conference themes include:

- integrated services, partnerships and pathways
- client focused services
- challenges and dilemmas
- innovation and opportunity.

Full details and a link may be found on the MND NSW website.

Our new staff members - Kym Nielsen, Iva Plessnitzer and Michael Walker have commenced in their roles. They bring great experience to MND NSW and introduce themselves below.

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

**17 June
Information
Evening**
*For people
recently
diagnosed with
MND and their
families and
friends*
MND NSW
Centre
Gladesville

Introducing...



Kym Nielsen
Fundraising Manager

I'm a country girl living in the beautiful Southern Highlands. I have been working in fundraising for over 15 years with groups such as CareFlight, Westpac LifeSaver helicopter and, most recently, with Australian Foundation for

Disabled. I enjoy the variety in my work and the opportunity to work with so many inspirational people. I have a 16 year old daughter, one husband, three horses, three dogs and two cats, so it's quite a menagerie at home. I look forward to working with our members, their families and all of the wonderful individuals and support groups working for MND.



Michael Walker
Equipment Assistant

I am a recent migrant to this great country and hopefully will be able to use some of my previous experience and engineering background to the advantage of the Association and its members. I have two married children and three

grandchildren for whom we are truly blessed. My hobbies are home improvement and a life-long interest in motoring vehicles. I'm looking forward to meeting, by phone, the members and their families and carers; and hopefully over time, introducing myself to you in person.



Iva Plessnitzer
**Regional Advisor for the Australian Capital Territory
and Southern New South Wales**

I am very excited to be working for MND NSW and the team have made me feel very welcome. I will be located in Canberra but expect to be doing lots of travel to meet with members, as well as regular visits to the MND NSW Centre at Gladesville. My background includes work as an occupational therapist in Maitland and then in Canberra. More recently I was an Inclusion Support Facilitator, supporting child care services to include children with high support needs, in south-eastern NSW.

At home in Canberra I have a great husband and four lovely girls, who all keep me very busy. In any spare time that I do get, I enjoy reading, cooking, art and visiting friends. I hope to catch up with members and their families in my area before too long, so you can all expect a letter or phone call from me in the near future.

Family Support

New Family Support Staff

It has taken a little bit of time but we have finally employed a new regional advisor for the Australian Capital Territory and southern New South Wales. Iva Plessnitzer commenced in this role on 12 May. Iva will be based at the Shout office in Pearce, where MND ACT was previously located; the MND association in the ACT no longer being incorporated. MND NSW will continue, as it has for many years, providing family support services to people in the ACT and southern NSW. Once Iva has completed her orientation she will be in contact with members. She also hopes to recommence the support group later this year.

In April we welcomed Michael Walker as our new equipment assistant, and both he and Iva introduce themselves on page 2 of this edition of *Forum*.

National MND Conference, Melbourne

The Family Support Service staff will be attending this conference during the week of 23 June and will be unavailable for a few days. This is a great opportunity for staff to find out the latest information on the care of people with MND and we will provide a report in the next edition of *Forum*.

Information Evening for People Recently Diagnosed, Their Family and Friends

The next evening will be held on Tuesday 17 June at 6.30pm at the MND NSW Centre at Gladesville. This evening provides people with information about MND and is an opportunity to meet staff based at Gladesville and other people whose lives are affected by MND. Please contact MND NSW for further information and bookings.

Services – Who and When

MND NSW has for many years worked with government departments to look at ways to improve community support services for people with motor neurone disease. Over the last few years we have been working very closely with the New South Wales Department of Aging, Disability and Home Care (DADHC) to improve response times for service delivery for home care. Many of you will be aware of the Home and Community Care services (HACC) that are provided through this department. These include services such as Home Care, Community Options Programs (COPS), the High Needs Pool and many more. At times it can be very difficult to understand how all these services work and one of the roles of the MND NSW regional advisor is to assist you to link in with these services.

...and farewell from Trevor Rakuraku

For the last four years I have been assisting Maree Hibbert in the MND NSW Equipment Loan Service and the biggest change I have seen would have to be the move from Concord to the new MND Centre at Gladesville.

So what are some of these services? One that your regional advisor will probably talk to you about is having a case manager through the community options program. The role of the case manager is to work with you to determine what mix of services is best going to meet your needs. They undertake a comprehensive assessment and assist you to access appropriate services. This can take some planning. Sometimes, your regional advisor may suggest a referral before you think you need one. This allows time for planning the best services for you, rather than you waiting until the last minute and hoping you get what you need.

Home care services provide domestic assistance, personal care and respite care to help people live independently in their own homes. It may be suggested that you be referred to the High Needs Pool or Attendant Care Program. These programs are designed to give you up to 35 hours a week care at home. You can be referred to these programs before you need them so that when you do need them it is much easier for services to start, as your paperwork and assessments will have been done.

So when is the right time to be referred to services? This is a really difficult question as sometimes a person's situation can change quickly and if referrals are left until the service is needed it may take time for them to be organised. No one likes to think about losing their independence and needing help but one of the things that people often say is that by accepting services they actually gained more quality time with their family and friends because they don't have to spend so much time and energy trying to get their daily living tasks done. Some of the work MND NSW has done with departments such as DADHC is to have their services recognise that circumstances can change quickly and unpredictably for people with MND and as a result of this, DADHC are more willing to accept early referrals for people with MND. Unfortunately there is a lot of demand for these services and there are never enough to go around, but with advanced planning you are more likely to get the support you need.

If you want further information on services available talk to your regional advisor and remember, if they are encouraging you to accept early referral to services, it is because they want to ensure you get the services you need when you need them.

Gina Svolos
Manager, Family Support

It is with some sadness that I leave MND NSW, as I have really enjoyed working with all the staff and members here. However, we must all move on and I feel my time to do so has come. My best wishes to you all. Trevor

The MND NSW Info Line is attended by a Family Support Team member five days a week, 9am-4.30pm, phone freecall 1800 777 175

Special Projects and Carers News

FlexiRest

No doubt many of you have seen references to FlexiRest. Since the start of the program in October 2007, 28 members and/or their carers from MND NSW have applied. Over 50 people altogether, including members in our consortium organisations, the Multiple Sclerosis Society and the Muscular Dystrophy Association, have taken advantage of the program.

The program is about choice and flexibility. It gives people time out from caring, and from their usual routine. It is a chance to re-charge the batteries, to reconnect with friends, family, to spend quality time with one another, to get right away.

People's choices have been varied. Two sisters, one with MND, visited their mother in Melbourne. Another carer had a pampering day including a facial and massage. Two others went to see *Billy Elliott*. A member and his wife wanted to be together and travel to Tasmania. In another household a mother and her daughter decided to get their 'rest and recreation' in Sydney on a package with accommodation, a show and food as part of the deal. As you can see, there are many ways to take a break!

Julie Becke, FlexiRest Coordinator, contacts people after they have taken a break to check out how things have gone as part of the evaluation process agreed with the funding body, the New South Wales Department of Ageing, Disability and Home Care.

If you and/or your carer need a break and cannot get the type of respite you need from existing services, ask your regional advisor about FlexiRest.

Ask the Experts

This annual event will take place on Monday, 4 August at the Ryde-Eastwood Leagues Club. We have excellent speakers including Professor Dominic Rowe, MND Specialist; Professor Garth Nicholson from the ANZAC Research Institute; Trish Reynolds, Clinical Nurse Consultant who will talk about respiratory matters; and Lorel Adams from the MND DNA Bank. Bring your questions along. If you don't want to ask a particular question, feel shy or are unable to ask, please pass it on to MND NSW staff who will ask on your behalf. You must book for Ask the Experts. Phone 8877 0999 to reserve a place. Lunch is provided.

Sailors with disABILITIES

Our planned Sailors with disABILITIES event was cancelled due to a late change of date to a week day which most people could not make. Hopefully we will get a space in September. Apologies to those of you who were looking forward to the trip.

New Group for Bereaved Carers

Carers who are bereaved often feel at odds with the world as they try to make sense of their lives without the person they have been caring for. It can be helpful during this time to talk with others who have experienced a similar loss. Our new group for bereaved carers will be a casual get-together, with those present deciding what they want from the meeting. The first meeting will be on Thursday 3 July from 12-2pm at the MND NSW Centre at Gladesville. Lunch will be provided. If you are interested in coming along, contact Jane Barrett ph. 8877 0902 for more information.

NSW Strategic Carer Action Network

Working in a consortium with the Muscular Dystrophy Association and the Multiple Sclerosis Society, as in the FlexiRest program or joining with other organisations to establish a collective voice, is an integral part of the work of MND NSW.

For several years MND NSW has been a part of a Carers Coalition now re-born as the NSW Strategic Carer Action Network. We are part of a bigger picture as a member of an interagency group which will address carer issues across NSW. It will foster a partnership approach, assist with the sharing of knowledge between organisations, allow us to have a collective voice to government and to work collaboratively to address carer needs. Members are peak bodies, non-government organisations who support carers across community, health and residential sectors and other services providers. Twenty two organisations were represented at the first meeting.

Care for Carers Program

At the time of writing in May there are eleven people enrolled for Care for Carers. The program covers not only the practical aspects of care but also explores the emotional impact of caring and ways people can look after themselves.

Jane Barrett

Family Services Coordinator

*Ask the
Experts and
DNA Donor
Drive*

*Monday
4 August*

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

Do you have questions about MND – current therapies or research? What palliative care can offer people living with MND? Are more people being diagnosed with MND? Bring your questions to the 'Ask the Experts' forum.

Speakers include
Ms Lorel Adams
Professor Garth Nicholson
Ms Trish Reynolds
Professor Dominic Rowe
Monday 4 August
10.30am-3pm
Ryde-Eastwood Leagues Club

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.

Equipment

Many of our members have had contact over the last four years with Trevor Rakuraku, Equipment Assistant at MND NSW. Trevor recently left the Association to pursue other adventures and we wish him all the best. In April, we welcomed Michael Walker as our new Equipment Assistant. Michael works Tuesday to Friday and arranges couriers and repairs for the equipment loan pool. On Fridays, Michael works in this role with Matthew Fowler, our other Equipment Assistant. Michael will be valuable member of our Equipment Service Team.

Members of MND NSW, with a confirmed diagnosis of MND, can access the equipment pool free of charge after their need for equipment is assessed by a health professional. An MND NSW equipment loan form needs to be completed by the assessing health professional and lodged at MND NSW. This form contains information about the requested equipment and contact details for the member, the assessing health professional and an alternate contact person, such as another family member or friend.

Once equipment is delivered, it should not be used by a member or carer unless the requesting health professional has:

- instructed the member and carer on the safe use of the equipment
- set-up the equipment ready for use.

It is for this reason a yellow cover letter is also included with the equipment delivery paperwork. This letter asks the member to contact the health professional who requested the equipment so that they can make an appointment for instruction and set up of the loaned equipment. Members also receive a copy of the equipment loan form when the equipment is delivered.

Before an item of equipment is delivered by MND NSW, one of the MND NSW equipment staff will contact you. We need to contact you prior to delivery because someone has to be at the member's residence to receive the item. The equipment staff will let you know what equipment is being delivered, which courier will be doing the delivery and contact details of the courier. This is so that you can contact the courier if you need to change the delivery or retrieval day. Sometimes, delays occur with delivery because we have trouble contacting the member or their carer.

To return equipment, the member or carer need only contact MND NSW and speak to one of the equipment staff who will be happy to arrange a suitable time for retrieval.

If you have any concerns or queries about the MND NSW Equipment Loan Service, please do not hesitate to contact me.

Maree Hibbert
Equipment Services Coordinator

Support Group News



Chris and Silvia Pecar at the Northern Beaches support group.

Kingswood

Our March meeting was extremely well attended due to interest in the latest MND research about TDP-43. On this occasion Lorel Adams from the Australian DNA Bank, which is supervised by Professor Roger Pamphlett, was in attendance. Lorel spoke about the latest research into the possible genetic causes of motor neurone disease and the ramifications of this. Carolyn Cecere, who is the research assistant with Professor Garth Nicholson at the ANZAC Institute, was also at the group. It was a lively and interesting discussion.

Jenny Judd
Regional Advisor

Newcastle

We warmly invite you to attend the Newcastle based support group. We meet at Charlestown on a Wednesday between 10-12pm every second month. The accessible cottage that we meet in has facilities for carers to meet with one regional advisor while members meet with the other regional advisor. You can expect a friendly welcome, a delicious morning tea and a safe environment to share your feelings and ask your questions. Our only complaint so far is that we don't meet more often! We look forward to catching up with you at our next meeting on 18 June.

Eileen O'Loughlen and Noelle Smith
Regional Advisors

Northern Beaches

The Northern Beaches support group meets bi-monthly on the first Thursday at the Palliative Care Cottage, Mona Vale Hospital. Future meetings will be held in June, August, October and December. The group membership continues to grow as newly diagnosed people in the area come along to see what happens and join the group. Our members and their carers benefit from learning how others cope with motor neurone disease. They also benefit from the information given to them by the area health service palliative care team and community care team, who are often present at the meetings. At our April meeting Mark Newlan and Lisa Duffy, both from Community Care (Northern Beaches), spoke about the need to plan ahead, the services their organisation provides and how to access services. If you have never been to our support group, we challenge you to come along. Contact me on 8877 0909 for further information.

Jo Fowler
Regional Advisor

*Walk to
D'Feet MND
2008*

*Sunday
9 November*

Mailbag

How important is the MND logo? On the back of my car there is an MND *Never Give Up* bumper sticker and I often get a toot and a wave. When I send a note it's a cornflower card or MND Christmas card. MND shortbread and cornflower seeds are always handy as small gifts.

Recently however, my MND cornflower shirt and MND socks were the cause of my introduction to Merle and David Jackson. David spotted my attire on the second morning of my Cherry Blossom Cruise around South East Asia and introduced himself and his wife Merle, who has MND.

We grabbed a corner overlooking the rolling sea and I learned of their odyssey as Merle busily wrote answers to my questions, with David filling in when necessary.

Merle is from New Zealand and several years ago began losing her power of speech. Her condition was finally diagnosed 15 months later in 2002. Adjusting to the lifestyle Merle must now live, has been something they have done with dignity, humour and courage: Merle uses medication to control her saliva and can only eat very small amounts of food. David assists Merle with her PEG tube.

During the Cherry Blossom Cruise Merle participated in the land tours - often sitting in the hot sun or cold. She daringly ventured up a crowded tower to get a good view and rode rough roads to see a volcano.

While I thought it impressive that these two would attempt the Cherry Blossom Cruise, I was soon to discover that last year they went to South America, Machu Picchu, Iguazu Falls and the Antarctic. David had booked the Cherry Blossom Cruise for Merle's special leap year birthday. After they returned to Sydney they were going straight off on a gruelling tour of South Africa. Many people on board were certainly aware of the Jacksons, and for me, I have deep admiration for their pluck. I am pleased that by wearing my MND polo shirt I have gained two wonderful friends.

Shirley
North Turramurra



Merle (l) with Shirley, both wearing their MND socks on the cruise

Iola and I would just like to give our heartfelt thanks, through the letters page of the newsletter, to all at MND NSW for the wonderful support we have received since my diagnosis with this hideous disease.

Particularly, many thanks to Maree Hibbert and the Equipment Team. You have been life savers from the start. I receive care under a Department of Health and Ageing Extended Aged Care at Home (EACH) package. We were told our EACH provider had to supply all equipment we needed. However, they neglected to tell us that they would be hiring it all and that the cost of this would be taken out of the funding for our available hours, leaving only seven hours a week for anything else! Maree came to the rescue, supplying us with a lifter, shower chair and wheelchair.

Just recently another emergency arose. When my condition deteriorated to the point that I needed an electric wheelchair, we bought one, being assured that it was the best we could buy. Ha! It did serve well until I could no longer use the hand controller. We were assured that a chin or sip and puff controller could be fitted. We opted for a chin controller, it was ordered and some parts were sent.

Weeks went by and the local agent finally rang the supplier only to be told, 'Oh no, you can't fit a chin controller to *that* model chair'. We could not believe it. We contacted the American parent company who referred us to the Australian subsidiary. They told us that they do not deal directly with the public. All further communication with America was totally ignored! Great customer service! Anyway our occupational therapist contacted Maree. Who says miracles don't happen: a chair was available and wonder of wonders, it had chin control. So after a few courier problems, I am now mobile again.

We cannot thank the Association enough. I don't know how we would have coped with this monstrous disease without you and the Ozpals Forum.

To all at MND NSW, thank you!

Chris and Iola
Coffs Harbour

The OzPals Forum was created by a person living with MND specifically for others dealing with the disease, their families and friends. It is designed for those living in Australia, New Zealand and South Pacific countries to share their thoughts, experiences and knowledge with those in similar situations. For more information see www.hotkey.net.au/~ozpals/index.html

For Sale

1997 Ford Falcon 140 000kms. Push/pull hand controls. Engineering Certificate approved by RTA. \$4,750. Call Katie on 9531 2103 or 0402 246 180.

Email or write your letter to the editor of Forum

See back page for contact details

Mailbag (cont'd)

In February this year I was fortunate to attend a Neuro-Immune Program at the Petrea King Quest for Life Centre at Bundanoon, New South Wales. I was assisted in funding my attendance by the MND NSW FlexiRest program and the Centre itself.

Set in 3.6 hectares of tranquil gardens, the Centre is a place of calmness and peace. The environment is chemical free and the food is fresh and delicious. The staff was very helpful and empathic. These things, along with philosophies I was introduced to during the course, revived my spirit and body and helped me to feel confident to meet the challenges I face living with a life-threatening disease.

Along with relaxation, visualisation and meditation techniques, we were made aware of the causes of stress and ways to manage it. Practical strategies for increased health using complimentary therapies and diet were discussed, as was the importance of removing all toxins and chemicals from your life: better to use natural products and what are regarded as old fashioned methods. For those with sleep disorders, suggestions were made but fortunately I'm not worried by that problem.

As a group, we were encouraged to regain a sense of control over our response to our life (as different to reaction); be committed to living and challenge our meaning in our lives; and to find what gets our 'juices' flowing. We were also encouraged to be aware of anger and stress, how our body reacts to it and ways of managing it.

With much laughter and some tears, we all learnt ways to develop a positive attitude for our journey to a more joyful and fulfilling life. I know that as a group we all left after a week, looking healthy, happier and more receptive to the world.

From my point of view, the program was very positive and my family also had some respite knowing I was being well looked after.

If this is of interest to you, do have a look at Petrea King's books *Quest for Life* and *Your Life Matters* at www.questforlife.com.au. I also like Christine Miserandino's personal story and analogy of what it is like to live with sickness or disability, *The Spoon Theory*, at www.butyoudontlooksick.com

Margaret
Valley Heights

Did you know you can receive Forum by email and reduce our printing and postage costs? Email admin@mndnsw.asn.au

If you and/or your carer need a break and cannot get the type of respite you need from existing services, ask your regional advisor about **FlexiRest**.

Family Support Calendar

- 17 June Information Evening**
For people recently diagnosed with MND and their families and friends MND NSW Centre Gladesville
- 3 July Bereaved Carers Group**
12-2pm at the MND NSW Centre at Gladesville. Lunch will be provided.
- 4 August Ask the Experts and Donor Drive for the MND DNA Bank**
Members, families, friends and carers come along and ask the experts questions about MND and hear about the latest research

For more information contact
MND NSW Info Line 1800 777 175

If you would like assistance with travel to attend family support sessions or would like us to organise an MND information session in your region, please speak to your regional advisor.

Support Groups

METROPOLITAN

Ph: MND NSW 1800 777 175

Gladesville

Caroline Gleig - carolineg@mndnsw.asn.au

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

Jo Fowler - josephinef@mndnsw.asn.au

Western Sydney

Jenny Judd - jennyj@mndnsw.asn.au

REGIONAL AND RURAL

ACT and Southern NSW

Iva Plessnitzer Ph. 6286 9900

ivap@mndnsw.asn.au

Broken Hill

Jamie Mitchell Ph. 08 8088 7123 (bh)
or 08 8088 1333 (ah)

Central Coast

Audree Dash Ph. 4384 2907
Sheila Holmes Ph. 4392 5513

Central West

Jenny Judd Ph. 1800 777 175
jennyj@mndnsw.asn.au

Illawarra

Cindy Cleary Ph. 4223 8000

Newcastle and Hunter

Noelle Smith or Eileen O'Loughlen Ph. 4921 4157
noelles@mndnsw.asn.au
eileeno@mndnsw.asn.au

Northern Rivers

MND NSW Ph: 1800 777 175

Research

MND NSW and Research

The Motor Neurone Disease Association of NSW is a strong advocate and funder for the advancement of research into MND. In 2006-07 and 2007-08 MND NSW contributed \$100 000 each year towards MND research. In 2008-09 the Board of MND NSW is planning to increase this amount. It is only through the generosity of our volunteers and donors that this will be possible. Thank you for your continued support.

Getting involved

In Australia there are several ways in which you can actively participate in research into MND. While MND NSW supports research into MND, individuals need to carefully consider and determine if participation is right for them. MND NSW has an information sheet available for people who are considering participating in MND research. Contact your regional advisor for more information.

ANZAC/Concord MND Research Group



Professor Garth Nicholson and a research team at Concord Hospital are carrying out research to locate new genes causing MND. If your family has had more than one person with MND (even a distant relative, for example, second cousin) you can help their research. Participation involves the donation of a blood sample to be stored indefinitely and included in current and future DNA research into motor neurone disease. *Contact: Carolyn Cecere, The ANZAC Research Institute, Concord Repatriation Hospital, Hospital Road, Concord NSW 2139. Ph. 9767 7016 email ccecere@anzac.edu.au or see www.anzac.edu.au*

Australian MND DNA Bank



The MND DNA Bank has been set up to look for genetic and environmental susceptibility to MND. If you agree to contribute to the Bank, you will be asked to consent to blood and other samples being taken. DNA and protein from your blood will be stored at the University of Sydney. In addition, you will be asked to complete a questionnaire to assess your possible exposure to harmful environmental agents. The MND DNA Bank has ethics approval from the Sydney South West Area Health Service (RPAH Zone) and The University of Sydney. *Contact: Ms Lorel Adams, Manager, The Australian MND DNA Bank, Discipline of Pathology, Blackburn Building D06, University of Sydney, Camperdown NSW 2006. Ph: 9036 5456 email dnamnd@med.usyd.edu.au or see www.dnamnd.med.usyd.edu.au*



Australian MND Registry (AMNDR)

The Australian Motor Neurone Disease Registry is a clinical database that provides a means to facilitate the collection and analysis of MND patient data such as demographics, site of onset, diagnosis data, treatment type, changes in functional capacity, complications related to disease progression and the impact of new treatments and interventions for MND. *For more information speak to your neurologist at your next visit or contact MND Australia Inc Ph. 9816 5322 or email carolb@mndaust.asn.au or see www.amndr.org*

FANS Study - Phase II Clinical Drug Trial



Scientists at the Prince of Wales Hospital hope to show that a neuroprotective agent is able to slow disease progression in MND.

Eligibility criteria apply, so some people may be excluded from participating. Since the study drug has serious side-effects, especially in relation to the heart, all potential participants will undergo full assessment by a cardiologist. Therefore you will only be informed of your eligibility once you have established contact with the trial coordinators. Free parking is available. This study has approval from the South Eastern Sydney Illawarra Area Health Service (Eastern Sect) Human Research Ethics Committee. *Contact: Jennica Winhammar or Ben Cheah Ph. 9399 1046.*

Using our Brains



This program is designed to collect and store brain and spinal cord tissue after death from a broad cross-section of the community for distribution to leading neuroscience researchers, including MND researchers. The Using our Brains program has ethics approval from the Sydney South West Area Health Service (RPAH Zone) and The University of Sydney. *Contact: Using Our Brains, Discipline of Pathology, Blackburn Building D06, University of Sydney, Camperdown NSW 2006. Ph: 9351 2410 or see www.braindonors.org*

The Australian New Zealand Clinical Trials Registry (ANZCTR)

ANZCTR is an online register of clinical trials being undertaken in Australia and New Zealand. The ANZCTR includes trials from the full spectrum of therapeutic areas of pharmaceuticals, surgical procedures, preventive measures, lifestyle, devices, treatment and rehabilitation strategies and complementary therapies. See www.anzctr.org.au for more information.

MND ALS Clinical Trials Register United States

ClinicalTrials.gov is a registry of government and privately supported clinical trials conducted in the United States and around the world. See www.clinicaltrials.gov/ct2/results?term=amyotrophic for more information.

You should let your neurologist or general practitioner know if you are thinking about participating in research

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Lithium and MND

From the UK Motor Neurone Disease Association
www.mndassociation.org/

The results of a small Italian clinical trial of the drug lithium carbonate have recently been published in the journal *Proceedings of the National Academy of Sciences*.

During the 15 month trial, 16 people with MND took lithium carbonate in addition to riluzole. The progress of their disease was compared with that of 28 people taking riluzole alone. The Italian researchers reported that the lithium carbonate significantly slowed the progression of MND.

Consider With Caution

Whilst the results of this trial may be encouraging, they do need to be considered with some caution and should not be seen as conclusive evidence that lithium is an effective treatment for MND.

Sixteen people are an inadequate number in which to establish with confidence that a drug is beneficial. The methods used in the trial also had other significant weaknesses that make the results less reliable:

- The participants in the trial knew whether they were taking the trial treatment or whether they were in the comparison group. This can produce bias in the way participants report how they feel and also means that the placebo effect can have an influence.
- A larger proportion of the participants given lithium had disease characteristics (e.g. age and site of disease onset) that tend to be associated with slower disease progression.
- The participants were not put into the treatment and comparison groups at random - they were chosen for each group by the researchers. Random selection is usually performed by a computer and prevents bias in choosing which patients go into each group.

In addition, adverse events (possible side effects) were not described by the researchers, which is extremely unusual for a clinical trial report.

More Trials Needed

Laboratory studies have shown that lithium can have a protective effect on motor neurones, and it has demonstrated positive effects in the mouse model of MND. The data from this research may well warrant further large-scale clinical trials of lithium carbonate in people with MND. Such trials, if rigorously conducted, could eventually provide the evidence that is needed to prove whether or not the drug is effective.

However, until such trials are completed, lithium should not be regarded as a proven treatment. It is also important to remember that lithium carbonate is known to have side effects. If you have MND and are considering taking lithium now, discuss the matter with your neurologist.

The Italian lithium carbonate clinical trial paper is available in full text at www.pnas.org/cgi/content/short/105/6/2052

Research Glossary

From www.informedhealthonline.org

Abstract

A very brief summary or digest of the study and its results. It should tell you what the study tried to show, how the researchers went about it, and what they found.

Clinical Trial

A clinical trial involves administering a treatment to test it. It is an experiment. Clinical trial is an umbrella term for a variety of health care trials, whether controlled or uncontrolled. Types include uncontrolled trials, controlled clinical trials (CCT), community trials, and randomized controlled trials (RCT). A clinical trial is also sometimes called a 'therapeutic trial'.

Control

The people in a 'control' group or arm in a controlled trial or a case-control study (also called the comparison group). In a trial, people who are the 'controls' represent the status quo (current standard treatment) or placebo (dummy) treatment, against which the effectiveness of a treatment is tested.

Critical Appraisal

The process of assessing and interpreting evidence, by systematically considering its validity, results, and relevance.

Peer Review

A refereeing process, used to check the quality and importance of reports of research. An article submitted for publication in a peer reviewed journal is reviewed by other experts in the area. It aims to provide a wider check on the quality and interpretation of a report.

Systematic Review

A review of studies in which evidence has been systematically searched for, studied, assessed, and summarised according to predetermined criteria. Systematic reviews often use meta-analysis to summarise results of comparable studies.



Are you planning to run for MND
in the 2008
CITY2SURF?

We can provide you with a special T-shirt and you can ensure your sponsors are able to support you easily through **Everyday Hero**. This organisation has been appointed the official sponsorship site for people entering the CITY2SURF event this year.

If you would like people to sponsor your effort in the CITY2SURF just go to www.everydayhero.com.au for more information. For your T-shirt contact Kym Nielsen, Fundraising Manager MND NSW ph. 8877 0999 or email kymn@mndnsw.asn.au.

Is there a particular topic you would like to see featured in Forum?
Let your regional advisor know or contact the Editor at info@mndnsw.asn.au or ph. 8877 0999

MND FORUM

Annual Food Service Industry Golf Day

On 5 April, the annual Food Service Industry Association golf day was held at the lovely Carnarvon Golf Club at Lidcombe. The weather was kind and the golfers enjoyed a spectacular day with over 40 golfers participating in this year's event. Thank you to the organisers and the Food Service Industry members for your continued support.

MLC Advice Solutions Ambrose Golf Tournament, Hyatt Coolum



(l-r) Peter McNeil, David Clark, Chris Browne, Cameron Forbes at the MLC Advice Solutions Ambrose Golf Tournament.

On 9 March, the PGA course Hyatt Coolum on the Sunshine Coast was a stunning venue for a charity golf tournament for MND NSW. David Clark, of Goldram Financial Services, nominated MND NSW as the recipient of MLC's inaugural Risk

Specialist Network Charity Golf Tournament. David knew about MND due to the personal experience of Hamish Pearce, a financial adviser with Goldram's. Our thanks to MLC Advice Solutions, Lena Ridley from MLC, David Clark for nominating MND NSW and, of course, to all those who participated in the golf tournament making this a great fundraiser.

Newcastle Basketball Tribute for Elliot Jay

An exciting fundraising event for MND NSW was held on 10 May in Newcastle, when the Basketball Association of Newcastle hosted an exhibition match between the Newcastle Hunters ABA Women's team and Australia's under 19 women's team, the Gems. It was a nail-biting match with over 400 people in attendance. Helen Crooks, Operations Manager, Newcastle Basketball said, *'Newcastle Basketball would like to acknowledge the match referees, score bench people, statisticians, game announcer and staff from Newcastle Basketball who all volunteered their time. One of our local sons, Elliott Jay, died of MND on Monday 14 April, aged just 19 years. Elliot had only just finished participating in the under 18 men's representative team at the end of 2006, and was looking forward to trying out for the Youth League team for 2007, when he was diagnosed with the disease'*. MND NSW thanks Helen, Newcastle Basketball, the volunteers and also the event sponsor, Ross Lewis MGA Insurance Brokers.



Basketballers from the Newcastle Hunters Women and the Australian under 19 Gems.

Hit It for MND in Batemans Bay

Where would we be without people like Melissa Love who decided to hold a charity golf day on 7 March supporting motor neurone disease after hearing about the disease at a 'Women in Business' presentation?



Kirsten and Cindy at Hit It for MND.

Melissa worked very hard to put the day together and was well supported by her employer WIN Television. MND NSW is extremely grateful to both Melissa and WIN for their support, and also to the Catalina Country Club for providing such a lovely venue. By all accounts it was a most enjoyable day and we thank Melissa and the individuals and companies who supported the day through playing golf, making a donation, contributing a raffle or auction prize, or volunteering to assist in any way possible.

Scoring a Goal for MND

One of our wonderful members sold MND merchandise on 10 May at Curl Curl netball courts. Laraine sold everything she took along on the day which was a fabulous effort: 100 cornflowers, 170 pairs of socks and 600 wristbands! Thank you Laraine.



Laraine and Andrew Hunter with daughter Lisa.

Lindsay Butler and Shaza Leigh Show

More than 150 attendees were treated to a great night of country music at Cessnock Ex-Services Club on 5 April. Lindsay Butler on guitar and Shaza Leigh on vocals put on a great show together with two guest artists, Greg Bain and 'The Last of the Travelling Showmen', Brian Young. This event was run by Shirley and Stephen Peters to honour Shirley's brother Ron who lost his battle to MND in 2007. The night included a live auction and a raffle with 35 prizes, made possible through wonderful support received from businesses in the local and surrounding districts. Congratulations and thanks to Shirley and Stephen.



(l-r) Brian Young, Greg Bain, Greg Williams, Shaza Leigh, Stephen Peters, Shirley Peters and Lindsay Butler.

To volunteer for MND NSW contact Roslyn Adams ph. 1800 777 175

MonStar Cup is a Monster Effort Again!



Hamish Pearce (l) with John Morris and the 2008 Tigers Jersey at the MonStar Cup

On 18 March a very successful MonStar Cup golf day was held at the Pennant Hills Golf Club. For the second consecutive year, organisers

Hamish Pearce, Mark Golding and Greg Hargreaves planned this fabulous day to assist two charities – the STaR Association and MND NSW.

Starting at 6.30am the enthusiastic golfers were joined by MND NSW Vice Patron, Melinda Gainsford-Taylor. The day was capped by the evening events which included a scrumptious buffet, dancing to Jelly Bean Jam, auctions and a raffle. John Morris from Wests Tigers joined us and held up a Tigers jersey for auction which, needless to say, sold well.

As usual, our volunteers were terrific in selling merchandise during the day and in assisting with the 'financials' of the auction and raffle in the evening. Thank you to Sue and Bob Ballinger, Diane Openshaw, Joy Pogson, Pat Rogers and Liz Sandwith; we are grateful for your ongoing support. We would also like to extend our thanks to the Pennant Hills Golf Club for their support on the day. Our thanks must also go to the family and friends of Mark, Hamish and Greg who gave such wonderful support to this event.

The financial outcome of the day was again an incredible result. The cheque presentation took place at the Goldram Financial Services office where both Mark and Hamish work. We are most grateful to Hamish for his commitment and contribution to MND NSW.

Wests Tigers Players Dinner



MND NSW board member Alex Green (r) with John Morris

Wests Tigers rugby league players and Club have continued their support of MND NSW through 2008, with MND NSW named as a joint recipient of proceeds from

the Wests Tigers players' dinner at Balmain Leagues Club on 9 May. Wests Tigers half-back John Morris has been a great supporter of MND after losing his father to the disease in 2002. Team-mate Bryce Gibbs has lost an uncle to MND, so MND NSW is an organisation very close to the hearts of the team. We thank Wests Tigers and the players most sincerely for their ongoing support.

Blue Week at ANZ Bank Springwood

MND NSW was fortunate to be chosen as the ANZ Bank Springwood Blue Week charity this year. Events included a sausage sizzle, raffle and guessing competition. Our sincere thanks go to Margaret, Des, Lyn, Aris, Dane, Beck and especially Karen who initiated the event.



Karen and Margaret at the ANZ Bank Springwood.

Thank you for your continued support

Dates for the Diary

12 July	Balance Health Club Annual Black Tie Ball 7pm at Western Suburbs Leagues Club. Tickets \$80. This event is in memory of Elliott Jay who died of MND at age 19 in April 2008. Contact Donna Young ph. 49036213 or d.young@balancehealth.com.au
19 July	Black Tie Ball at Panthers \$10 from each ticket will be donated to MND. Contact Maree Dolbel ph. 6330 0603.
10 August	City2Surf 'Women with Issues' are a group of motivated women who are walking for MND. They have registered with Everyday Hero, the online fundraising site at www.everdayhero.com.au.
9 Nov	Walk to D'Feet MND 2008 This event is not just for Sydney-siders - we would love some of our country connections to walk on the same day in their home town. Contact Roslyn ph. 8877 0908.
21 February 2009	St Valentine's Day Ball Illawarra Combined Seniors' Dance Group, Ribbonwood Centre, Dapto. Ticket includes supper and soft drinks. BYO. Evening dress. Contact Betty Davies ph. 0412 819 833.
2 and 3 May 2009	Open Garden at 'Homeleigh' The home of Suzanne and Bob Ballinger, 17 Linden Avenue, Pymble through the Open Garden Scheme. 10am-4.30pm. \$5 admission to OGS. Morning, afternoon tea and lunch available. MND merchandise, plant and Mother's Day stalls.
2 to 28 August 2009	Kokoda Challenge for MND If you would like to find out more contact Roslyn on 8877 0908 or World Expeditions www.worldexpeditions.com.au

Noticeboard

What Can I Say, What Can I Do?



Palliative Care Australia

During Palliative Care Week 2008, Palliative Care Australia launched three new publications: *What Can I Say*, *What Can I Do?* provides information and advice on how to support someone diagnosed with a terminal illness; *What is Palliative Care?* outlines basic information about palliative care; and *Asking Questions Can Help* is a booklet for people seeing the palliative care team. For more

information see www.palliativecare.org.au or speak with your MND NSW regional advisor.

Workplace Modifications Scheme



This Australian Government scheme helps employers of people with disability to cover the costs of purchasing special equipment and modifying the workplace. To qualify

for assistance, the worker must have a disability that is likely to last two years or more and be employed or have a formal offer of employment for at least eight hours a week in a job that is expected to last for at least thirteen weeks. Large, medium and small business, government and community organisations are able to apply for assistance. The Scheme is administered through JobAccess who aim to respond to all applications within two business days. The Scheme can provide reimbursement of pre-approved costs for vehicle modifications; wheelchairs for work; adaptive technology; automatic doors; ramps; customised laptops; voice recognition software; alert systems; modification of existing equipment; disabled toilets; and fixtures. For more information see www.jobaccess.gov.au or ph. 1800 464 800.

Insurance Law Service for individuals



Consumer Credit Legal Centre NSW

The Insurance Law Service, launched in February 2008, is a free New South Wales legal service available to individuals who would like advice on insurance law or help to solve a problem or resolve a dispute

with an insurer. This new service is part of the Consumer Credit Legal Centre, which also provides free telephone advice about credit, debt and banking matters to NSW consumers. For legal advice phone 1300 663 464 Monday to Wednesday. For credit and debt advice call 1 800 808 488. For non-English speakers, the service will work with the Telephone Interpreter Service, available on 131 450. For more information see www.cclcnsw.org.au

Understanding Younger Onset Dementia

Understanding Younger Onset Dementia

Dementia is a brain disorder causing progressive change and degeneration in cognitive mental functions, such as memory, language, rational thinking and social skills, as well as behaviour, emotion and personality. Most brain disorders causing dementia occur in the elderly. Sometimes, dementia can occur in people with motor neurone disease. Alzheimer's Australia have produced a new booklet called *Understanding Younger Onset Dementia*. The booklet provides information about aspects of the various dementias that can occur in adults under 65 years of age. The publication is available for free download from www.alzheimers.org.au

Companion Card for NSW



In April 2008 the NSW Government announced the introduction of a Companion Card scheme for people with disabilities in the State. The Companion Card will be a free wallet-sized card issued to people with a severe or profound disability who require attendant care support from a companion to access the community, everyday services and events. Cardholders who present their Companion Card to a participating organisation will not be required to pay an admission fee for their companion who is providing attendant care. The scheme is expected to commence later this year, with further details to be provided over the coming months. For more information see www.companioncard.org.au

Carer Bonus 2008



The 2008-09 Federal Budget provided additional assistance for carers. The Carer Bonus continues and, by the end of June, Carer Payment recipients will receive a \$1,000 payment and Carer Allowance recipients will receive \$600.

Medicare Australia's Online Services



You can now view, update and request information about you from Medicare Australia by using the Medicare Australia Online Service. To access this service you will need to register with Medicare and a password will be mailed to your current Medicare address. For more information see www.medicareaustralia.gov.au

You can write to the Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675

ACKNOWLEDGEMENT

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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.

Editor: Penny Waterson