THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW
March 2010
mnd New South Wales
FORUM

The 20th International Symposium on ALS/ MND and Allied Health Professionals Forum

At the beginning of last December, I travelled to Berlin, Germany to present a poster at the 20th International Symposium on ALS/MND and a paper at the International Allied Health Professionals Forum.

It was a great privilege to attend this combined international event which is singularly concerned with motor neurone disease: causes, treatments, best care practices and efforts to find a cure. The conference attracted well over seven hundred delegates, including leading researchers, medical specialists and health care professionals from all over the world. The International Symposium is presented in two concurrent strands, one based around the biomedical research being carried out worldwide and the other, the clinical strand, focused on advances in care and the management of MND.

Attendance at the Symposium afforded me the opportunity to co-present a paper at the Allied Health Professionals Forum with Kristina Dodds from Home Hospice. The Allied Health Professionals Forum is a one-day seminar specifically for allied health and social care professionals working with people living with motor neurone disease. It is structured around four separate, but interconnected, segments - collaborative models of care and multidisciplinary care networks; communication options for people with MND; caregiver pathways of support at end-of-life; and issues around familial MND and what families know and what they may want to know.

There were just fifteen speakers at the Forum and four of these were from Australia, including Carol Birks, National Executive Director, MND Australia. We were very proud to see Australia playing such a prominent role in international MND arena.

The paper I co-presented with Kristina was titled *'A Better Approach for End-of-Life Care: Community Mentors for Caregivers'*. Kristina and I spoke about the alliance our Associations have formed to provide ongoing psychosocial support for caregivers, reduce caregiver burnout and present a viable alternative to death in a health care facility. We also presented this new model of care as one that could be easily replicated globally to engage wider communities to assist caregivers caring at home through the use of volunteer community mentors.

The poster Kristina and I co-presented at the Symposium was about the same approach and it generated a great deal of interest. This resulted in a wide distribution of our supporting brochure.

For me personally, attending this international event was a wonderful opportunity to see firsthand the global interest and determination of so many researchers and health professionals trying to find the multi-factorial causes of MND and ultimately a cure. Additionally, it gave me the opportunity to network with other health professionals from around the world, deepen working relationships, take home salient points about best care practices and to share ideas and contact details. It is encouraging to see so many people sharing the common goal of doing everything possible to improve the lives of people and their families who are affected by MND.

Jo Fowler
MND NSW Regional Advisor

Conference registration at the Maritim Hotel

L-R: Jo Fowler (MND NSW), Carol Birks (MND Australia) and Kristina Dodds (Home Hospice)

Jo Fowler and Kristina Dodds with poster presentation (above) and presenting at the Allied Health Forum (below)

MND WEEK 2010

Can you help support MND Week by selling merchandise at your local shopping centre, railway station or school? We're looking for people with lots of enthusiasm and drive to help us raise awareness about motor neurone disease. Friday 7 May is Cornflower Blue Day and we want to make this the biggest event yet, with MND merchandise all over NSW and ACT. All merchandise is delivered to you on a consignment basis with unsold stock returned to MND NSW. If you have a few spare hours and would like to help, please contact Kym or Ayse to find out more on ph. 8877 0999 or email kymn@mndnsw.asn.au or aysed@mndnsw.asn.au.

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.

Port Macquarie Workshops

Left: from L-R: Bev Smith, Christine Harvey, Roberta Skinner and Lorel Adams.

Right: Directions in Care session.

Being able to attend the recent workshops in Port Macquarie after only being in the role of Family Support Information Line Advisor for three weeks was such a fantastic experience. The workshops were held over two days in December, the first day was for members and their families, and the second day was for health and community care professionals.

To meet and talk to our members, their carers and families as well as many of the health and community care professionals working with them, and hearing about their experiences was not only incredibly informative but also inspiring and humbling.

Our members deal with the challenges and issues they face with MND every day with such courage, energy, optimism, character and humour and whether they are aware of it or not, they are continually informing us about the work that we do by attending these types of workshops.

The health and community care professionals, who work with our members, have amazing dedication, commitment and passion for their work. They have a real desire to continually enhance their knowledge on MND.

The feedback and comments we received after the workshops indicated how valuable the two days had been for everyone and how much people had enjoyed the opportunity to get together at both forums and learn from each other. So a big thank you again to everyone involved, to those who attended the workshops and the presenters!

David Wallace
Information Line Advisor

Barbara Everitt and Anne Smith

Kylie Fletcher

Bev Smith with Brian and Debbie Hanson

Information Evening for those recently diagnosed with MND, their family and friends 26 May at MND NSW Centre, Gladesville.

You and your family and friends are warmly invited to

A Day of Hope and Remembrance

Tuesday 4 May 2010
1.30pm to 4pm

Soka Gakkai International Centre
3 Parkview Drive
Sydney Olympic Park

This is an afternoon of hope and remembrance for all those whose lives have been touched by motor neurone disease; people living with MND, family, friends, supporters, volunteers and those working with MND.

Associate Professor Roger Pamphlett of the Stacey MND Laboratory, University of Sydney, will talk about hope for the future in MND research. This will be followed by a candle lighting ceremony to represent the hopes of people affected by MND and to remember those who have lost their life to MND. Afternoon tea and light refreshments will be served giving everyone a chance to mingle.
The March of MND Faces banners will also be on display.

Please RSVP by phoning 02 8877 0999, freecall 1800 777 175 or email annej@mndnsw.asn.au by Friday 30 April.

This venue is close to public transport and has limited free parking and disability parking.
There is a metered car park next to the venue and another close by.

A Message from the CEO

I hope you have had a peaceful Christmas and New Year.

At MND NSW we are already in full swing for 2010. Nationally, preparations for MND Week, 2 to 8 May, are well underway. Our *Call to Action*, in which we ask members, families and friends to write to their local Federal and State Members of Parliament, will focus on the push for a National Disability Insurance Scheme (NDIS). A link to the NDIS website with full details of the scheme can be found on the MND NSW website. We will be sending out *Call to Action* templates and further information to members in early April.

MND Week is also a major fundraising event for MND NSW. We are only able to achieve our target of $70,000 through the efforts of you, the MND supporter. Funds raised will go to much needed family support services, equipment and research. If you would like to help throughout the week please call Kym Nielsen, Fundraising Manager, ph. 8877 0912.

Living Better for Longer is a national project that will endeavour to provide best practice, coordinated multidisciplinary MND care, timely interventions and appropriate referrals for all people with a diagnosis of MND. It will be a web based resource aimed at health professionals and community care providers with a special focus on regional and remote areas of Australia. Funded by the Federal government and state MND Associations, we hope to have it up and running in the latter part of 2010. We'll keep you informed.

Tuesday 4 May marks our Day of Hope and Remembrance, full details can be found on page 2.

A key aspect to our work over the last three to four years has been a focus on services in regional and remote areas of New South Wales. To this end, support from Ageing, Disability and Home Care at the Department of Human Services has been crucial. The development of strategic partnerships, particularly with other neurological disease organisations, is also an integral part of our work. Developmental work in this area is ongoing and we'll keep you informed as we move forward with more of these partnerships.

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

Watch your mailbox for the MND Call to Action. Support the National Disability Insurance Scheme.

Vale

Jack Davey
MND NSW Board Member
November 1993 - November 2000

Died 14 December 2009

MND NSW

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Regional Education Project Officer
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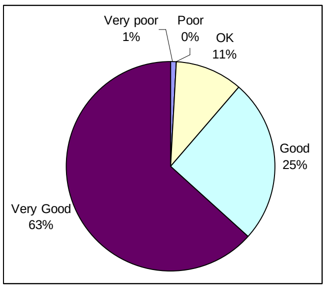
And…..*many valued volunteers*

Family Support Team

For 2010 we have planned a number of education programs both around Sydney and in some regional areas. The purpose of our education program is to provide people with MND and their family and friends with information on the supports and services available and also to answer some of the questions they may have. As the saying goes, *knowledge is power* - if you don't know what is available you don't know what to ask for. So I encourage you to attend if you can.

Of course your regional advisor is also a valuable source of information and will link you to the services you may require, but they may not be able to be in contact with you as often as we might ideally like. Providing you with knowledge through our education programs will support you to be resourceful in planning for your needs. Please do look through the programs on page 5 of this edition of *Forum* and if you need more information before you decide to attend contact your regional advisor or the Family Support Team ph. 8877 0999 or Freecall 1800 777 175.

The overall support and information provided by MND NSW is:



Volunteer Massage Program

Following a survey sent to our members in 2009 about the role of volunteers at MND NSW, we have decided to develop a volunteer massage program. We are currently recruiting and training volunteers to provide head and foot massage to our members with MND. This program will be piloted in the Sydney region and if successful we will look for opportunities to extend it to other regions.

Contact your regional advisor if you are interested in having a massage. If you know anyone that would like to volunteer for this program please contact Ayse Dalkic ph. 88770999.

Satisfaction Surveys

At the end of 2009 we conducted a survey of our members and, for the first time, a survey of health and community care professionals involved in MND care. We had an amazing response with 158 members (over 40%) and 171 professionals taking part in the surveys and I would like to thank everyone for taking the time to complete the questions.

These surveys are important as they provide another source of feedback on how well we are meeting the needs of our members, help us understand what members require and assist in planning future services.

We are currently completing the analysis of the results but overall satisfaction level was high. Here are some highlights:

- 94% of respondents would recommend MND NSW to others living with MND
- 92% responded either very good (69%) or good (23%) about loaned equipment meeting their needs.
- 93% responded either very good (68%) or good (25%) about personal manner and competence of MND NSW staff.
- 92% responded either very good (69%) or good (23%) about the ability of their regional advisor to offer support and information as needed.

There were a number of suggestions for improvements with some comments relating to limited access to services and frequency of contact from regional advisors with more visits and consistent contact desired. One person commented, *'the workload of our regional advisor appears to be too heavy and covers too much territory. More RAs perhaps?'.*

This reaffirmed the value of the role of the regional advisor and we will continue to look for opportunities to fund these positions in order to provide more contact between members and regional advisors, particularly in regional areas.

Other suggestions from several respondents were for counselling and information about complementary therapies.

Suggestions such as these help us to get a greater understanding of what our members want and to look for ways to assist members access services and information they need.

We received many comments from respondents indicating that they were very satisfied with the service we provide, including:

'We knew very little about MND until attending an information night which was very helpful. Also the support and help from the outreach team has been excellent'.

'Just keep doing the friendly approachable good work you do'.

'The support I have received has been helpful. I always feel there is someone I can turn to for help and advice'.

Thanks again to everyone who completed the survey. We undertake this survey every two years but you are welcome to provide us with feedback about our services at any time so please don't hesitate to contact me.

In our next edition of *Forum* we will provide a summary of the results from the health and community care professionals satisfaction survey.

Gina Svolos
Manager, Family Support

You are welcome to provide us with feedback about our services at any time. Ph. 8877 0999.

Equipment

Increase in the number of items available for loan

Over the past 18 months, the number of items loaned from the equipment pool has increased by 32% to 1542 items.

Our focus continues to be on purchasing items suitable for and in demand by our members, with some newer items added to keep up with changes in technology. For example, In 2008 we had 54 raiser recliner armchairs in the equipment pool and now we have 79. Over the same period, powered hoists have increased from 41 to 51 and Smart Nav hands-free computer mouses have increased from 6 to 11. Of our new purchases, just under one quarter cost between $1000 and $12,500 each.

Powered wheelchair charging

Powered wheelchairs run on two large batteries that require regular charging to keep them operating. Charging should be done every night even if the chair is not being used - otherwise the batteries will deteriorate and cannot to be used when required. Replacement batteries cost over $400. The battery should be left on charge for as long as possible. For safety reasons, only the charger provided with the powered wheelchair should be used.

If you are using a powered wheelchair please check the charging instructions provided with your chair to ensure the maximum use of the batteries.

Wheelchair tyre inflation

Some of our manual and powered wheelchairs have tyres that require occasional inflation. Changes in temperature can decrease the air pressure inside a tyre and, if not corrected, can damage the wheel of a wheelchair or cause the tyre to come off the rim.

Tyres that require inflation have a small air valve on the inside of the wheel similar to a car tyre air valve. There is a recommended air pressure level – PSI or Bar – marked on the rubber edge around the outside of each tyre and it is advised to check this information before inflating a tyre as pressure levels may vary. Inflation should be done when the chair is unoccupied.

Signs of low air pressure include flattening of the tyre when a person sits in the chair and an increased difficulty in manoeuvring. Over inflating can lead to a large BANG and a blowout of the tyre, and replacement of the inner tube would be required.

Maree Hibbert
Equipment Services Coordinator

Do you live near Tamworth or Berry? Look for events in your area in the Family Support Calendar.

Family Support Calendar

Monday 22 March	**Information Afternoon for Members and Families** *Tamworth* An afternoon to talk about the general management of MND. In the morning there will be an education program for health and community care professionals to assist them in caring for people with MND. See page 8 for more details.
Sunday 28 March	**Sailing on Sydney Harbour** This is a very popular day out for our members. See page 9 for more details.
Tuesday 4 May	**Day of Hope and Remembrance** *Sydney Olympic Park* This day is held during MND Week and is a time when the MND community come together to celebrate hope while also remembering those who have died from motor neurone disease. We hope that you will be able to join us. See page 2 for more details.
Tuesday 11, 18, 25 May and 1 June	**Care for Carers Program** *Gladesville Centre* This program is for carers of people with MND. It is a practical program and will give you additional skills to care for someone with MND. Help with respite is available. Contact 1800 777 175 to register.
Wednesday 26 May	**Information Evening for people recently diagnosed with MND, their family and friends** *Gladesville Centre*
Thursday 13 – Friday 14 May 2010	**Link and Learn** *Berry, Southern NSW* A program for carers of people with MND is being planned for southern New South Wales. This two day workshop, to be held in Berry, involves an overnight stay and a chance for carers to relax as well as to learn. Carers can register interest now by contacting Robyn Petersen, or Gina Svolos, ph. 1800 777 175.

For more information contact
MND NSW Info Line ph. 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.

Report on the 17th Annual Meeting of the International Alliance of ALS/MND Associations and 20th International Symposium on ALS/MND

Carol Birks

National Executive Director, MND Australia

David Ali, Vice President MND Australia, and I attended the 17th meeting of the International Alliance of ALS/MND Associations in Berlin, Germany on 5 and 6 December 2009 as the MND Australia delegates. 21 member Associations from 22 countries were represented by a record number of 89 delegates and observers.

The meetings commenced with the AGM chaired by the President Gudjon Sigurdsson from Iceland, followed by 14 presentations from nine countries including Australia. There were some very powerful and moving presentations. Denmark highlighted their active welfare system that allows people with disabilities, including those living with MND, to remain in control of their own lives with assistance from full time helpers. Also from Denmark were presentations on ‘Speaking with the eyes’, demonstrating that communication using a letter board can be very quick and effective, and another highlighting inequities related to access to non invasive ventilation in Scandinavia. Associations from the USA, Scotland, Japan and Italy provided an overview of care initiatives developed during the year.

The Muscular Dystrophy Association ALS Division reported that they had allocated US$38 million to ALS research and that this funding was available worldwide. They are currently funding 350 research projects. Steve Perrin, Chief Scientific Officer at ALS Therapy Development Institute (ALS TDI) highlighted the background to ALS TDI and gave an update on the Institute’s research efforts. He also spoke of the process and progress being made toward the development of therapeutics for ALS patients, which is available at www.als.net.

Innovative awareness and fundraising initiatives were reported. In Spain the Association has produced a video based on the daily life of a 34 year old man living with MND entitled ‘4000 screams’ to represent the 4000 people living with MND in Spain. ALS Canada presented a background to their ‘Heads and shoulders, knees and toes’ public service announcement which was very successful and won a number of industry awards. ALS Israel presented on ‘Fundraising out of the Box’, with which it had raised funds by using the ‘paperclip effect’ of auctioning one object for another. This campaign had started with auctioning, via the website, underwear for a guitar, the guitar, for a climbing adventure, the climbing adventure for computer lesson and so forth until $50,000 had been raised!

In my presentation I shared the Australian initiatives undertaken in 2009 and included a short excerpt from the film ‘Glass half full living with motor neurone disease’. I made a request for Alliance members to support the new national project to develop a care pathway website for health and community providers scheduled for 2010.

Presentations continued the next day with an update from Professor Kathy Mitchell from Canada on her work in Eastern Europe, followed by updates from Taiwan and Brazil. The morning ended with a presentation from Jeffrey Deitch, the Executive Director of the ALS Hope Foundation who led a discussion on the topic of how to answer the question, 'Is there any progress in finding a cure?'. The discussion highlighted the difficulties in reporting the progress in research, and tempering these breakthroughs and how they relate to people living with MND now, whilst still providing hope.

Attending these Alliance meetings is invaluable in hearing about how other countries support people living with MND and while some of them may not be applicable to Australia thoughts are stimulated and ideas are shared. This all helps us to understand and put into context achievements and constraints in supporting people living with MND in Australia.

The International Alliance of ALS/MND Associations promotes both care and research internationally. This is confirmed by the two awards presented annually at the Symposium Dinner.

Professor Christopher Shaw of the UK was awarded the Forbes Norris Award 2009. As a physician Professor Shaw’s dedication to patient care, his visionary approach to research and his tireless promotion of the interests of people with the disease are an inspiration to the whole ALS/MND community.

Professor Kathy Mitchell was awarded the Humanitarian Award 2009. Kathy has invested her time, energy and resources to improving the education of allied health and nursing professionals in Eastern Europe, Turkey and Peru about ALS/MND. Kathy is a true humanitarian and a valued member of the International ALS/MND Alliance.

Once again an Australian living with MND, Mr Tony Hynes, was included in this year’s International March of Faces Banner. There is one Australian featured on most of the banners so if you would like to be included on the banner for 2010 please contact me as soon as possible.

MND Australia is a very active member of the International Alliance of ALS/MND Associations.

Report on the 7th Annual Meeting of the International Alliance of ALS/MND Associations and 20th International Symposium on ALS/MND (cont'd)

The Allied Professionals Forum, on the day preceding the Symposium, as always attracted many health professionals and quality presentations related to care and management of MND. This forum provides unique opportunities for networking and discussion with colleagues from overseas. Presentations from Australia included two from Maryanne McPhee, Speech Pathologist from Calvary Health Care Bethlehem, who spoke about the Victorian Pathways Project and communication options for people with MND.

A joint paper from Kristina Dodds, HOME Hospice and Josephine Fowler, MND NSW, discussed their partnership whereby carers of people with MND are matched with a HOME Hospice Community mentor. I also presented on the Confident Caring Project conducted in Queensland during 2008/09. If you would like more details on these presentations, abstracts are available on the International Alliance website at: www.alsmndalliance.org/index.php?page=74

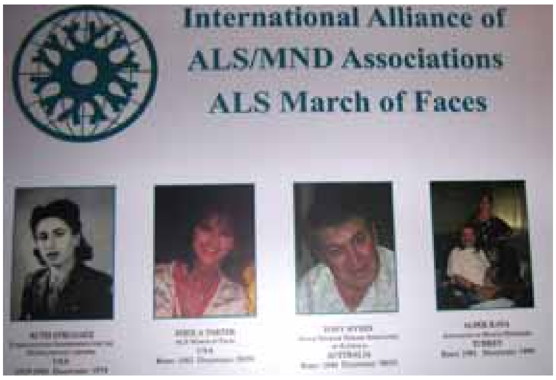
The 2011 ALS/MND Symposium will be held in Australia.

The 20th International Symposium on ALS/MND was held from 8-10 December and hosted by Deutsche Gesellschaft für Muskelkranke of Germany and organised by the MND Association of England, Northern Ireland and Wales. It presented latest research related to clinical care and science. There were many interesting presentations and all the abstracts are available at the following link:

www.mndassociation.org/research/for_researchers/international_symposium/20th_international_symposium_on_alsmnd/abstract_book_2009.html

The symposium attracted a record number of 900 delegates with 33 Australians in attendance. Dr Robyn Ray, of James Cook University, Queensland, spoke about '*Managing death in ALS/MND: identifying carers perspectives of the final days of life*'; Professor Matthew Kiernan from Prince of Wales Hospital and University of NSW presented on '*Understanding the pathophysiology of ALS*', Adam Walker and Julie Atkin from Howard Florey Institute, University of Melbourne presented their current research and many other Australian researchers and clinicians presented posters on their work.

Although there were no major breakthroughs this year, the depth and breadth of research undertaken was astounding. There were reports on two drugs that have shown to slow the progression of the disease that are now advancing to phase III trials in North America and Europe. There was a general air of hope and excitement about the future of MND care and research.



The closing session was very hopeful. Dr Meyer summarised the clinical sessions and listed the following themes he saw at the 2009 conference: a trend in the evidence for symptomatic treatment and care; an improvement in palliative care; progress in clinical trials and trial management; an integration of information technology in trials, patient management and home care as well as the empowerment of patients and their families.

Dr Van den Bosch, who summarised the scientific sessions confirmed that it is exciting times for MND research. He stated that fifteen years ago, we learnt about a mistake (mutation) in a gene called SOD1 that causes 20% of the inherited, familial form of MND (the familial form accounts for 10% of all cases of MND). He said that a few years later, riluzole was developed, the first and only treatment for MND. In the past two years we have learnt about two new causes of inherited MND, the TDP43 and FUS gene mutations; further knowledge was gained at the symposium about the role that genes play in MND as well as the development of a number of new and exciting animal models. He concluded that we are constantly adding to our current knowledge.

It was an intense three days which highlighted the commitment, collaboration and passion of researchers, clinicians and care providers in finding the cause, effective treatments and better management strategies and ultimately a cure for this disease. It is only through sharing this knowledge and collaborating internationally that we can find a new treatment for MND and improve care and quality of life for all who are living with the disease.

The 2010 International ALS/MND Alliance Meetings and Symposium will be hosted by ALS America (ALSA) from 8-13 December in Orlando, Florida.

The 2011 ALS/MND Alliance Meetings and Symposium will be held in Australia in early November hosted by MND Australia.

Support Groups

Central Coast

We were pleased to welcome back our members for the first meeting of the year. Jo Fowler shared with us some of the highlights of the recent International Symposium on MND/ALS in Berlin, Germany.

Thank you to everyone involved for their support of the Rotary Community Raffle. We are thrilled with the results and raised $1000 which will go towards the MND NSW Equipment Loan Service. We are already looking forward to the MND Awareness Week activities which will take place from 2-8 May. Our Support Group will be involved in a Bunnings barbeque sausage sizzle. Please contact Audree Dash ph. 4384 2907 if you would like to offer assistance.

Our next meetings will take place on 13 March and 17 April at the Gosford Senior Citizens Hall, Albany Street, Gosford. The building is wheelchair friendly and there is plenty of street parking close by. We look forward to seeing you there.

Audree Dash

Support Group Coordinator

Western Sydney

The Western Sydney Support Group will continue meeting bi-monthly in 2010 at the Kingswood Neighbourhood Centre, on the second Tuesday of the month, from 1pm to 3pm. This is an opportunity to meet with others who are travelling the MND journey as well as their families, friends and carers. These are social gatherings and very informal. We share afternoon tea and have guest speakers. The first meeting will be held on 9 March and the guest speaker is a representative from Companion Card, which provides free access to venues and events for the companion of a person with a disability. Details about the scheme will be explained and the speaker will take completed applications on the day. She will also ask for suggestions of venues and events that you would like added to the scheme. So come along and share in this unique social support network. If you have any questions contact Jenny Judd ph. 8877 0906.

Jenny Judd

Regional Advisor

Northern Sydney (Hornsby)

This lunch time support group meets bi-monthly from 12-2pm at the Thornleigh Community Centre, which is right next to Bunnings and McDonalds.

There is plenty of parking close by and the building is wheelchair friendly. There is a drop-off zone and turning circle at the front of the building. Our next meeting is on 8 April. We hope to see you there.

Jo Fowler

Regional Advisor

Support Group Contacts

METROPOLITAN

Ph: MND NSW 1800 777 175

Campbelltown
Robyn Petersen - robynp@mndnsw.asn.au

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

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ivap@mndnsw.asn.au

Broken Hill
Jamie Mitchell ph. 08 8088 7093 (bh)
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Central Coast
Audree Dash ph. 4384 2907
Jo Fowler ph. 1800 777 175

Central West
Jenny Judd ph. 1800 777 175
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Illawarra
Robyn Petersen ph. 1800 777 175
robynp@mndnsw.asn.au

Newcastle and Hunter
Noelle Smith or Eileen O'Loghlen ph. 4921 4157
noelles@mndnsw.asn.au
eileeno@mndnsw.asn.au

Northern Rivers
MND NSW ph. 1800 777 175

Do you live within travelling distance to Tamworth?

An Information Afternoon for Members and Families will be held from 1.30-3.30pm in the Heritage Room of the Community Centre (Cnr Peel and Dowling St), Tamworth on Monday 22 March.

You are welcome to join Noelle Smith, MND NSW Regional Advisor Lake Macquarie, Hunter and New England, and Anita Richter, MND NSW Regional Education Officer for afternoon tea and a chat. You can discuss any questions you may have about living with MND or general care management. A representative from the New England Carer Support Service will also be present to provide information on carers needs and services.
There is no charge to attend this event. For catering purposes please RSVP by 15 March to:

Noelle Smith
Ph. 4921 4157or Freecall 1800 777 175
noelles@mndnsw.asn.au

Make sure you request your complimentary MND Volunteer t-shirt when ordering merchandise to sell during MND Week

Noticeboard

AIDER Programme Assistance for Infirm, Disabled and Elderly Residents

The AIDER Programme is designed to reduce bush fire hazards on bush fire prone property of infirm, disabled and elderly residents.

Residents can receive once off assistance with many services, including clearing gutters, thinning vegetation, removing leaf or tree debris, trimming branches and mowing grass.

For more information contact the AIDER Programme on ph. 02 8741 4955.

Lithium - Interruption of Italian lithium carbonate trial in ALS due to lack of efficacy and serious concerns about toxicity

On February 2008, a paper by Fornai and collaborators was published about the use of lithium carbonate in a small series of 16 patients with amyotrophic lateral sclerosis (ALS). According to that study, lithium carbonate showed positive effects on disease progression and patients' survival, with few or no adverse events. On the basis of these extremely promising results in a disorder with a severe progressive and disabling course, a double blind, randomized trial started on May 2008. The study involved 20 Italian ALS centres and was planned to last 15 months.

A total of 171 patients were recruited. The interim analysis, **performed in October 2009**, has found that 60% of patients did not complete the trial (37 due to death/tracheostomy; 35 for severe adverse events; 29 for discontinuation due to lack of efficacy and 2 for lack of compliance). The very high level of trial discontinuation (about 2.5 times higher than that observed in any other trial on ALS), and the elevated toxicity of the drug prompted the steering committee to stop the trial immediately.

Monica Cattani, AISLA (Associazione Italiana Sclerosi Laterale Amiotrofica)

Stem Cell Handbook

The Australian Stem Cell Centre (ASCC) receives many enquiries about the status of stem cell research, clinical trials and therapies in Australia and overseas.

The Patient Handbook is designed to help individuals understand what stem cells are, which stem cell treatments are considered safe and effective by specialists, which are considered experimental and which are unproven and the safety of the treatment is unknown. The Handbook does not seek to advise patients, evaluate individual treatments, or comment on an individual's reasons for travelling for treatment, but aims to provide the patient with the necessary information prior to considering any therapy.

The Patient Handbook can be viewed or downloaded online at www.stemcellcentre.edu.au. If you have trouble viewing or downloading the booklet, contact the ASCC on ph. 03 9271 1100 to receive a copy by email.

Order your MND NSW 2010-2011 Entertainment Book before 12 April to receive over $200 in bonus vouchers!

A picture from the last cruise

Sailing on Sydney Harbour with Sailors with disAbility

Sunday 28 March at 11 am

Enjoy some time out on Sydney Harbour with the friendly volunteer sailors on this magnificent boat. One person said he had never sailed before and that he felt privileged to be part of the group. He said the day was ‘sensational’.

Regional advisors Robyn Peterson and Caroline Gleig will be with you on the day. The boat is moored at Rushcutters Bay. This has been popular in the past and numbers are limited to 12 people so call the MND NSW office on 8877 0999 for more details and bookings.

The cruise lasts approximately 3 hours and there is no charge to attend.

MND NSW needs Massage Team Volunteers

Massage can offer people with MND the benefit of a compassionate and caring touch. Massage can provide some relief from the stress people living with MND may experience and, if only for a short time, also provide a break from usual daily routine.

Are you interested in volunteering several hours a month to provide hand and foot massage for people living with MND?

An initial two-day weekend training will be held at the MND NSW Centre at Gladesville. A massage kit and ongoing support will be provided to participants who successfully complete the training.

MND massage volunteers are required all over Sydney. Your interview and first massage appointment will occur during business hours. All massages are provided in the home of the person with MND you are matched with.

To obtain the Massage Volunteer Registration Form visit www.mndnsw.asn.au or contact Ayse Dalkic at MND NSW ph. 8877 0999 or email aysed@mndnsw.asn.au.

Thank you to Melrose Health, 4 Redland Drive, Mitcham, Victoria for their kind donation of the H2Oil massage oils www.melrosehealth.com.au

Unproven therapies for MND and the internet

With the internet being as accessible and unregulated as it is, MND Associations often receive calls and e-mails from people regarding treatments being offered both here and overseas that claim to treat or cure MND. Often, these treatments are promoted on websites that feature in internet search results when people search for information about MND. It is very difficult for people living with MND and their families, desperate for effective treatments and a cure, to distinguish fact from fiction, or paid advertising from good quality health information.

Stem cell research in particular is still considered a relatively new form of science, and with the range of claims being made every day about new cures, it's not surprising people are confused. There are many success stories related to unproven therapies, including stem cell therapies, posted on the internet. Unfortunately there are just as many stories where these therapies have not been successful or where the improvement is for a very short time only. This highlights the need for properly conducted research trials to assess the effectiveness of any therapy offered.

Information about current research and alternative and unproven treatments will help people to make informed decisions regarding any treatments being offered via the internet. Talking to your doctor, neurologist or MND association will also help you to make informed decisions.

There are a number of resources available on the MND Australia website to help you decide about any claims being made about treatments or cures for MND. These include:

The International ALS/MND Alliance Statement on Alternative and Unproven Treatments and the MND Australia Research Policy: www.mndaust.asn.au/policies

Links to the Australian Stem Cell Centre Patient Handbook and Latest Research Updates: www.mndaust.asn.au/latest-research

Treatments for any health conditions can be:

- beneficial or
- have no effect or
- cause harm through side-effects, adverse events or life-shortening effects.

There are many steps that must be taken before any treatment or medication can be offered to people living with MND. It is imperative that any intervention is proven to be safe and proven to improve outcomes for people living with MND. At present we know that there is no evidence to suggest that the therapies, such as the stem cell treatments being offered by various clinics, improve outcomes for people with MND and they could in fact be harmful.

MND Australia keeps abreast of the latest research and will support and promote any new treatments that have been proven through research and scientific peer review to improve survival or symptom management for people with MND. The volume of research has increased and improved dramatically over the last few years and many researchers both in Australia and overseas are working collaboratively to better understand MND so that effective treatments and ultimately a cure will be discovered.

Contact your MND Association for more information.

Carol Birks
National Executive Director, MND Australia

Dates for the Diary

13 March	**Harrington Grove MND Dinner** *Harrington Grove Country Club* *Contact Terry Goldacre at terry@harrington.com.au or ph. 4631 3200*
19 March	**MonSTaR Cup** **Charity Gold Day and Dinner** *Pennant Hills Golf Club* *Contact Amanda Stubbs at amanda.stubbs@monstarfoundation.com.au or ph. 0416 112 085*
7 May	**MND Mothers' Day Raffle** *Griffiths* *Contact Margaret Lorenzi* *ph. 6962 1758*
27 June	**Walk to d'Feet MND** **Fundraising Walk around ACT** *Around Lake Burley Griffin* *Contact Kym Nielsen at kymn@mndnsw.asn.au or ph. 8877 0912 for more details.*
21 August—3 September	**Kokoda Trek** **14 Day Trek on Kokoda Track** *Contact Kym Nielsen at kymn@mndnsw.asn.au or ph. 8877 0912 for more details.*
October/ November (TBC)	**Walk to d'Feet MND** **Fundraising Walk** *Sydney location to be confirmed.* *Contact Kym Nielsen at kymn@mndnsw.asn.au or ph. 8877 0912 for more details.*

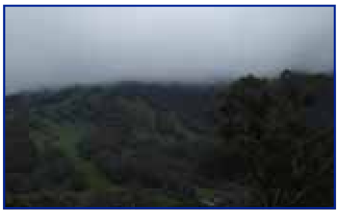
Are you selling merchandise or asking for donations in support of MND NSW? Check your ID badge is up-to-date today.

Raising Hell on the Mountain Top for MND

While Sydney sweltered under record heat conditions during December, the brave souls who turned up in Thredbo to participate in Raising Hell on the Mountain Top for MND found a very different story. A huge thank you to Penny Leemhuis who put heart and soul into organising this weekend.

Stephen shares his journey.

Bob Seger once wrote ‘I woke last night to the sound of thunder, how far off I sat and wondered’. Our version would be ‘I woke Sunday morning to the sound of thunder, pretty much right above my bed’. Another crack of thunder raised me from my bed to look out the window to see not the majestic mountain that we had seen the night before, but a stunted version completely covered by cloud. This was matched with rain coming down sideways, thunder, lightning and wind: the like I have never seen before in my life.



The next day we found the MND staff and tried to register for the climb, only to be told that the climb had been cancelled due the bad weather. Jan and I decided to go anyway. A brave group of 14 set off on the chair-lift to the start of the walk. During the first 100m on the lift, the rain got heavier, the temperature dropped a few more degrees, the wind rocked the chair and the cloud around us thickened. We disembarked at the top of the Snowgum run and proceeded to walk the 500m up to Sallees. By this time nine people, including a group with small children, decided to head back to Thredbo, whilst Jan and I decided to 'give it a go', leaving the remaining three under cover.

The first part walk of the walk was relatively easy (if you consider 100 km per hour plus head winds and driving rain easy - but it was like a walk in the park compared to what came later) winding through some of the most beautiful scenery in Australia (so we guessed as visibility was down to approx 20m). As we continued the path ended to be replaced by snow and ice.

At this point a man who camped overnight on the summit appeared and advised that the weather was worse higher up, but that if we took it easy we could get across the snow and back onto the track at the other side. The trick was to know where the track was on the other side of the snow. We pressed on, and to our complete surprise found the track again. On and on we walked. We must have been in a valley because the wind had dropped and the conditions were acceptable until we arrived at the top of a hill where the winds picked up to 120 km per hour and the hail began. This is when we found a use for the hats we had been reminded by the organisers to bring as protection against UV!

We had been instructed to stay on the metal walking track but to get off if we saw lightning. The track ended again in another snow drift, then we heard thunder (but not the lightning) and decided to head back. We were very inexperienced (we really are beach people), under dressed for the weather, cold, wet and still two kilometres from the summit.

Metal walking track on the mountain

The descent was even harder than the climb as the wind was now behind us, pushing us faster than we wanted to go. Also, parts of the metal track had iced over and we kept slipping. Jan executed the perfect slide and called herself safe while I hit the deck hard (no slide involved) bruising my bottom and hands and breaking a nail.

While continuing to tip toe down, we had the funny sensation of walking with a wind so strong behind us - the hood of the jacket flapping against your ears causing you to hear different things. Jan kept looking around the see where the horses were and I kept hearing the chopper that was coming in to rescue us. The creek under the bridge we had crossed earlier had turned into a river that was only half a metre below the bridge (we think that half an hour later the bridge would have been covered) and headed down towards the chair lift.

With a sense of relief we got onto the chair lift and shivered down the mountain, and watched in amazement as Thredbo Village appeared out of the mist in front of us. We quickly changed, got a coffee and headed off back to Melbourne. I think we had passed Corryong before we thawed out.

Thank you to my beautiful girlfriend Jan - for letting me join her on this adventure and adding this walk to our diary of experiences (next time let’s walk sand dunes).

A huge thank you to all the staff at MND for organising this event - you can control everything but the weather.

Stephen Lindsay on behalf of Team Lilian

If you would like to receive Forum by email contact Petra by emailing your name, address and email address to admin@ mndnsw.asn.au

Community Events

The end of 2009 saw some very interesting and exciting events held for MND NSW. The annual **MND Charity Golf Day** was held at the lovely Cooma Golf Club on Saturday 14 November. This event is run annually by a very dedicated team of volunteers lead by the lovely Val Young. Thanks ladies for all your hard work.

The **James Kemsley Memorial Cricket Day** was held in sweltering conditions on Sunday 22 November at the historic Bradman oval in Bowral. James was from the Bowral area, and lots of friends and family turned up to remember him and support this special day. Money was raised by entry fees and lots of merchandise sales. Thank you to all who attended and help raise much needed funds for MND NSW.

The patrons at the **Hampton Halfway Hotel** decided on a very novel way to raise funds for MND NSW and held yabby races. A great night of fun was had by all. Good work folks and thanks for your support.

Overturn Motor Neurone was organised by Gillian Beakey and Kim Gregory to support a close friend with MND. The event was held on Saturday 5 December at the lovely Camden Haven Golf Club in Kew. Patrons enjoyed a fabulous dinner with raffles and auctions. Congratulations on such a great evening.

Shazaleigh and Lindsay Butler at the concert at Kurri Workers Club

The annual **Country Music Concert** was held on Sat 12 December at Kurri Kurri Workers Club. The event boasted a star studded line-up including international recording star Wayne Horsburgh, the master of country guitar Lindsay Butler, female vocalist Shaza Leigh and bush ballad recording star Greg Bain and the Butler Boys. The night was well supported with over 200 in attendance. Thank you to Shirley and Stephen Peters who put in so much work to create this wonderful evening.

A great night was had by all who attended the wonderful evening at the **Blackbutt Hotel** in New Lambton in late December. The evening was a great success and included a monster raffle held with loads of prizes for everyone. A big thank you to Terry and Kerry from the Blackbutt Hotel.

The members of the **Junction Inn Fishing Club** recently held a fishing competition to raise money for MND NSW. There was some tall tales of 'the fish that got away' and a great day of fishing enjoyed by all.

Once again, a heartfelt thank you to everyone for their enthusiasm and hard work to raise awareness and support for those living with MND.

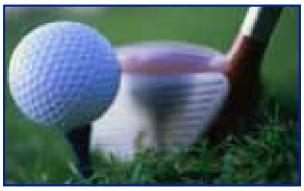
Kym Nielsen
Fundraising Manager

Danny Bergan Memorial Golf Day

The 3rd Danny Bergan Memorial Golf Day was held (in yet again sweltering conditions touching 40 degrees) on Friday 22 January 2010 at Carnarvon Golf Club. There were 112 starters on the day; about one-third more than in the inaugural year. Many of the new starters were new to both golf and the lunch! Thanks for joining us!

The day was an overwhelming success and I would like to take the opportunity to thank our major sponsors of the 2010 event:

- Lion Nathan
- Tooheys
- Schweppes
- St George Bank
- Club Rivers
- Stykris



These sponsors have been with us since the beginning and all that was achieved could not have been made possible without their continued support.

Many others also contributed, by either supporting the day by playing and/or donating raffle prizes and memorabilia. The day was a huge success and the funds raised surpassed those from previous years.

A big thank you also to the board of directors, management (Trevor and Michelle) and staff of Carnarvon Golf Club for the part they played in the running of the day. Without their support this remembrance and charity day would not have been as successful.

The support of all involved was truly appreciated. The next golf day will be held in 2011 and we hope to again go one better.

Danny Bergan was a much loved husband, father and friend who sadly lost his battle with MND on 10 March 2007.

Stuart Jamieson ACCM
Operations Manager, Club Rivers

Register today
MonSTaR Cup
2010
Tee off on
19 March
See page 11
for more.

ACKNOWLEDGEMENT
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Editor: *Penny Waterson*