



FORUM

Information Day in Tamworth March 2010

North west support group established

It is always rewarding to spend time with members and families in regional areas, especially when it provides an opportunity to experience the goodwill demonstrated by health and community care professionals who work with families living with MND.

On Monday 22 March, Noelle Smith, Regional Advisor for New England area and I experienced a great day in Tamworth. In the morning a workshop was held for health and community care professionals. The workshop content included information about MND and its various symptoms, and the role of the MND NSW Family Support Service including the Equipment Loan System. Evidence based best practice in MND care and the team approach to managing MND was also discussed in the session entitled *Working Together to Manage MND*. The workshop also provided the opportunity for care providers to share ideas about MND management, to meet each other and to become more familiar with Noelle as Regional Advisor for the area. Twenty two care providers attended and evaluation of the workshop indicated that participants were very pleased to attend such a workshop within their own health area.

"Very informative, interactive presentation! Thank you so much for coming up here to Tamworth" (care provider).

The *Information Afternoon* session for people living with MND and their families was well attended with everyone showing great enthusiasm for meeting and sharing ideas with others in a similar situation.

We had planned to explore the viability of establishing a regular support group in the Tamworth area. This was endorsed by those attending the afternoon session and we are very fortunate that staff from the Northcott Disability Services in Tamworth have offered to provide a venue and coordinate a regular support group.

We are very grateful to Ruth Loseby and her colleagues from Northcott for their interest and commitment to assist, and to members and their families who showed such enthusiasm for participating in a support group.

"It was good to hear other people's stories" (person living with MND).

"A support group would be good. I believe there are a lot of resourceful people here that could benefit from sharing their knowledge" (person living with MND).

Our day in Tamworth provided another wonderful example of everyone *working together to manage MND*.

For more information about the New England Support Group contact Noelle Smith, Regional Advisor ph. 4921 4157 or Ruth Loseby at Northcott ph. 6762 4902.

Anita Richter

Regional Education Project Officer



Les and June Shaw of Quirindi



L-R: Ruth Losbey (Northcott Disability Services), Hana Janssen (OT HACC and Disabilities Dept. HNE Health), Charissa Stewart (OT HNE Health), and Jasmine King (COPS)



Members Gordon Elliott (left) and Gary Lee from Tamworth



City 2 Surf

Run, Jog or Walk for MND

Be part of the MND Team for the Sun-Herald City 2 Surf Sunday 8 August.

All MND Team members will receive a MND T-Shirt to proudly show their support.

Register today at

city2surf.sunherald.com.au.

TREAT YOURSELF TO HAND AND FOOT

Massages

We have enthusiastic and accredited volunteers who are keen to visit people with MND in the Sydney region to provide hand and foot massages. Contact your regional advisor or call 1800 777 175 if you are interested in having a massage. We look forward to hearing from you.



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.

Day of Hope and Remembrance



Day of Hope and Remembrance



John Englefield



Kym Nielsen representing MND board and staff

As part of MND Awareness Week, a Day of Hope and Remembrance was held at the Soka Gakkai International Centre, in Sydney Olympic Park on 4 May. Over 90 people attended in the celebration of hope whilst remembering those who had died from MND.

Our guest speaker this year was Associate Professor Roger Pamphlett from The Stacey MND Laboratory, University of Sydney, who talked about hope for the future in MND research. He thanked all members of MND Associations for their ongoing contribution to research. Roger also spoke of his genuine hope that a cure for MND will be found in the near future as so much research is being carried out globally. He added that with advances in the range of support services available to people with MND and improvements in symptom management in the last few years, people living with MND now have more reason to be optimistic than ever before.

MND NSW would like to acknowledge and thank those who were part of the candle lighting ceremony that honoured all those involved with MND - the people living with MND to their families, support groups, health and community professionals, researchers, MND NSW board, staff and those involved in the global fight for a world free from MND.

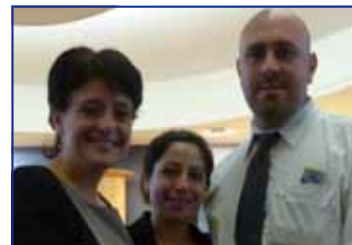
MND..... brings home the importance of familywe find out how strong we are. And whilst we can never walk in their shoes and understand what they are truly going through, we walk with them, holding their hand, wiping their tears and loving them.

Zakhia Aoun, dedicating a candle to family and friends of people living with MND

Gina Svolas
Manager, Family Support



Alexander, Elizabeth and Emma Sandwith who took part in the candle lighting ceremony



Zakhia, Charbel and Yasmin Aoun

Information Evening for those recently diagnosed with MND, their family and friends 24 August at MND NSW Centre, Gladesville.

Ask the Experts Forum and MND DNA Bank Donor Drive

Monday 2 August 2010

Ryedale Room, Ryde-Eastwood Leagues Club
117 Ryedale Road, West Ryde

Come and quiz the experts. Ask the Experts Forum is a popular day when you, family members, carers and friends can bring your questions about MND and have them answered.

For those who are shy about talking in public, have a query you would rather someone else ask or have difficulty speaking, you can pass your question(s) to any MND NSW staff member and they will ask for you. Remember your question may be just the one others want to ask! Put the date in your diary.

We will also run a donor drive for the MND DNA Bank where you can give blood samples for genetic research. Lunch will be provided.

Ask the Experts will take place from 10.30am to 3.15pm. Registration is at 10am for 10.30am start but you need to RSVP to attend. For more information see insert in this edition of *Forum* or contact the MND NSW Info Line on 1800 777 175 or 02 8877 0999.

A Message from the CEO

Another MND Awareness Week has come and gone and this year the media response, particularly in regional and remote papers across NSW and Australia, has been outstanding.

Our Day of Hope and Remembrance was well attended and a full story can be found on page 2.

This year our merchandise orders have exceeded previous years and, as you return your funds, we'll keep you updated on how much has been raised.

MND NSW has recently undergone a major transformation in its business operations.

Our new database went live mid-May and merged four different databases which will help in streamlining services. This has taken a great deal of time and planning by our Information Resources Coordinator Penny Waterson who has worked tirelessly to complete this project.

While on information technology, in the last issue of Forum I mentioned the development of a national web based pathway project.

The presentation of the website will take place in Canberra on 21 June. Our Canberra Walk to d'Feet will take place on Sunday 27 June and you can visit our website for more information on both these events.

On the international front we have been informed that Sydney will be the venue for the 22nd International Symposium on ALS/MND in December 2011.

The symposium provides the opportunity for MND researchers and health and social care professionals worldwide to contribute to the growing body of research about the causes, effects and treatments for MND.

Several satellite meetings will be held just before the symposium. These include the annual general meeting of the International Alliance of ALS/MND Associations, Ask the Experts and the Allied Health Professionals forums.

This year, our own Ask the Experts will be held in August at Ryde. For more information see page 2 of this edition of Forum.

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

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

New! Dog Leads



Why not get your pooch one of the classy new MND dog leads? They are a heavy duty lead with a strong clip, comes in blue with MND logo and the wording 'Walk to d'Feet MND'. They work well and look great! These leads are selling fast so don't miss out. Each costs \$10 + postage. Contact Kym ph. 8877 0999 or

Very handy for Walk to d'Feet MND. See page 12 for event details in Sydney and ACT

MND NSW

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Equipment Assistants

Matthew Fowler

Michael Walker

Information Resources Coordinator

Penny Waterson

Regional Education Project Officer

Anita Richter

And.....many valued volunteers

Family Support Team

The Family Support team has had a very busy few months with our membership continuing to grow as an increasing number of people find out about the support and services we provide. Through our focus on providing more information to both members and service providers more people have become aware of MND NSW. Our website provides another way for people to find out about us.

Due to the work involved with increased memberships, we have had some delay in responding in some areas - particularly with request for equipment. Our Equipment Services team – Maree, Michael and Matthew – do an amazing job in distributing the equipment and while we try to meet our members' needs, we do at times have difficulty in keeping up with the demand. So if you have experienced any delays we do apologise and will continue to work towards meeting your needs.

Volunteer Massage Program

Thirteen people attended our two day massage training on a sunny weekend in April. Wilma Davidson, a massage therapist from Canberra who has worked with many people with MND, volunteered to train our volunteers in massage techniques. The volunteers were very enthusiastic and the training was well received.

The massage volunteers are now all accredited and keen to visit people with MND in the Sydney region to provide hand and foot massages. Contact your regional advisor if you are interested in having a massage.



Wilma Davidson (second from left) and volunteers at the training

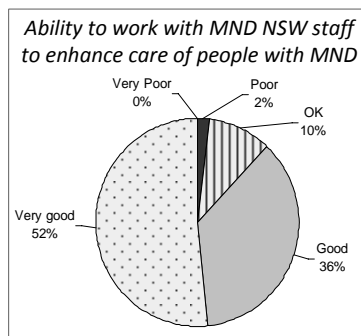
Health and Community Care Worker Satisfaction Survey

In the last issue of Forum, we reported on the results from the satisfaction survey of our members and their families. At the same time, a survey of health and community care workers was undertaken as a way to help monitor our services, identify areas that are working well and others that may need improvement.

The electronic survey drew a fantastic response, with 272 health and community workers participating.

Overall, the results indicated that the health and community care workers felt a high level of satisfaction with our services. Here are some highlights:

- 93% responded either very good (52%) or good (36%) about the competence of MND staff they have worked with.
- 84% responded either very good (40%) or good (44%) about the quality of the information they received.
- 89% responded very good (55%) or



'good' (36%) to the overall support provided by MND NSW to people living with MND.

Many positive comments included:

○ *MND have always been incredibly supportive to me as a clinician and to all the clients I have been involved with. I have yet to hear anything negative about the service since I moved to NSW and started with an MND caseload in 2003.*

○ *What a fabulous service!! I would particularly like to commend the regional advisor for all her dedication, genuine concern for patients and collaboration with our team!*

There were also many useful suggestions for improvement that we will consider further for addressing issues such as:

- *Advocate (for) more funding for equipment to be available and efficiently delivered (less waiting lists for common equipment such as attendant control units).*
- *The workshops and education sessions are always really useful. Please have more of these, and make them free or minimal cost, as many workplaces don't pay for our learning and development anymore.*

I would like to thank all the very busy health and community workers who participated. The results are very affirming of the work of MND NSW as well as full of great suggestions on how we can further enhance our services.

Gina Svolos
 Manager, Family Support

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

Equipment

Couriers and Equipment Delivery or Retrieval

Pick up on 'this day' at 'this time' cannot always be the case for MND NSW equipment delivery or retrieval but we do endeavour to be as accurate as possible.

MND NSW uses a number of courier companies to deliver and retrieve equipment. The Equipment Loan Service staff are responsible for selecting and arranging the courier for delivery or pickup. This decision is made based on the weight and size of the item and/or locality.

For example, if a large raiser recliner armchair weighing 75kg is being delivered to Dubbo, the armchair must be packed by MND NSW Equipment Loan Service staff onto a pallet for easier and safer maneuvering during the delivery process. The equipment staff will book a courier company that can provide a truck with a tail lift and delivers to the Central West area. The equipment staff may have arranged a date with the member or family for delivery but occasionally in some regional areas, courier runs may only occur once or twice a fortnight on a set day. If this does happen the courier company will contact the member or family to arrange another suitable day.

Depending on the courier company used, but usually for large equipment items and all regional deliveries, the member or family is given the courier company's contact details and also the unique booking number for the shipment. The member or family is asked to contact the courier if:

- 0 circumstances change and they are unable to be home for the courier driver on the day of the booking, or,
- 0 on the morning of the booking, they wish for a more specific time frame for the drivers arrival. This can only be given on the booked day, and usually a three hour time frame is specified.

Most metropolitan couriers are able to give a four hour time frame for delivery or retrieval on a specified day. This is discussed when the delivery or retrieval is being arranged by MND NSW Equipment Loan Service staff with the member or family.

The cost of all equipment shipments are met by MND NSW. It is important to contact MND NSW equipment staff when an item of equipment is to be returned.

Maree Hibbert

Equipment Services Coordinator

Don't forget to RSVP if you are planning to attend Ask the Experts 2010 on 2 August at Ryde. Contact 1800 777 175 for more information.

Family Support Calendar

Monday 2 August	Ask the Experts and MND DNA Bank Donor Drive <i>West Ryde</i> Ask the Experts is a popular day when you, family members, carers and friends can bring questions about MND and have them answered. You can also give blood samples for genetic research. Lunch will be provided.
Tuesday 24 August	Information Evening for people recently diagnosed with MND, their family and friends <i>Gladesville</i> These informal information evenings are for people who are newly diagnosed with motor neurone disease, and their families and friends. It provides the opportunity for you to ask questions about MND and to meet others in a similar situation.
Mondays 8 and 15 November	Learn Now Live Well <i>Gladesville</i> A two-day education and support workshop for people living with MND, their family and friends.
Tuesday 23 November	Information Evening for people recently diagnosed with MND, their family and friends <i>Gladesville</i> See information for 24 August above.

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.

It's your website too!

Have you had a look lately at the MND NSW website? For example, are you aware that if you're having problems with reading the text on the website you can increase the font size by clicking the A+ symbol in the top right hand corner of the page?

The website is a great resource for information on services available for members, carers and health professionals. The calendar is updated regularly with the latest fundraising and family support event details. News updates are posted as they become available.

We warmly invite our members to have their say on what other information they would like to see on the MND NSW website. So take a look today and let us know what you think!

Wrapping up.....MND Awareness Week 2010

Report from the Fundraising Manager

First of all, I would like to say a very big thank you to everyone who sold merchandise and helped raise awareness for MND during the MND Awareness Week. This year has been our busiest to date.

Michael Fernandez and his group of hardy volunteers braved the cold and the rush hour at Circular Quay train station and ferry terminal. Jackie and Doug Mears spent the morning at Wynyard train station selling puppies and cornflowers to commuters. Our intrepid group of volunteers led by Michelle Paton once again coerced and cajoled the many travelers landing at the Qantas International terminal. Paula Pelligrini, Tanya Brabrook and Ann Marie Keogh had a stall at the Royal Randwick Shopping Centre, and Di Openshaw and friends held a stall at Carlingford Court.

The Illawarra Support Group led by Jacqui Cousins held stalls at Port Kembla Hospital and Warrawong Shopping Centre. Also in Illawarra, Raylene McLaughlin had a stall at Albion Park and Sharon Bresciano at Westfields Figtree. We had a lot of support from regional areas with Rebecca Prior from Tumut selling lots of merchandise and also helping out Howard and Annemarie Young at their stall in Tumut. Pat O'Hara helped out by selling wristbands in Wagga Wagga and Deidre Jones held her annual stall in Batemans Bay. Margaret Lane was a very busy lady in Springwood while Isabella Spalding also had lots of merchandise sales at Minto. Penny Grace kept them busy with merchandise in Bulladelah and Kerrie Skeffington made sure the Raymond Terrace area didn't miss out on puppies.

Michelle Edwards of Kotara and Kathy Curran from Canley Vale also helped with merchandise sales this year. Thank you to Francis Miceli of Nepean Hospital, Emma-Kate Dewhurst of St Josephs Hospital and Kerry Fischer from Orange Neurology Centre for your support in raising funds and awareness. Many thanks also to the Aberdeen Rugby League Football Club and the Muswellbrook Football Club for their support. Students from University of Newcastle led by Ashleigh Worldon raised funds by holding a Blue Cupcake day as well as selling merchandise throughout the university. Carol Fort did a great job in the ACT this year and Mary Murphy once again kept the Oakdale area supplied with merchandise. Trish Saladine sold merchandise at University of Western Sydney in Penrith and David Harradine from Lismore also sold merchandise this year.

A big thank you also to the many ANZ branches in the Erina region who sold puppies, cornflowers and pens from their branches this year. Many thanks to Roger Wood of St George bank who also supported us with merchandise sales through St George bank branches. Thank you also to HCF for continuing their support with merchandise sales throughout their branches.

A very special thank you to Janet Gooddy who not only sold merchandise but also very generously shared her story of love for her son, Bruce, who had MND. Janet's moving words have been used this year for our winter appeal.

Kym Nielsen
Fundraising Manager

Thank you for your support during MND Awareness Week 2010.

Media Coverage

As Graham Opie already mentioned, there was a high level of media interest during this year's MND Awareness Week. Shown below are some of the media coverage: stories from Illawarra Mercury, Macarthur Chronicle, Sydney Observer, Muswellbrook Chronicle, and Area News Griffiths.



MND Awareness Week 2010 (contd)

A Volunteer's Tale

Doug Mears writes about his experience of working as a volunteer for MND Awareness Week, selling merchandise and raising awareness on MND amongst commuters at a busy Sydney train station.

I left home at 6am, picking up a fellow volunteer Jackie along the way. On arriving at Wynyard Station at 6.50am we got ready by putting up posters around the station and setting up a display table with the merchandise. More volunteers joined us for the morning - Kevin Johnston, Catherine McNeale, Sinead Brady and Sarah Marriott. We spread ourselves out across the Wynyard Station concourse and began to spruik. Initially our voices were a little quiet and unsure, but before long we were loud and proud. Simple phrases such as 'Help support motor neurone disease', 'MND week, raising awareness for motor neurone disease' and 'Buy a pen for \$2, only \$2!!!' were voiced across the station until 10am. A packet of Butter Menthols was a big help for the dry throats we developed.

A lot of people who bought items or donated money had been affected by MND in some way, although there were also many kind-hearted people who did not know what the 'cause' was, but supported it regardless. One of the funnier moments for me was the man who wanted to buy a pen, but told me that '\$2 was a rip off' when I gave him the price - each to their own. There was one faithful supporter who purchased a handful of pens almost as soon as we got there, then when we were packing up he returned to buy some more: thanks mate. Puppies were the hottest sellers with our stock gone in only 30 minutes, and the torches and socks were also gone before the morning was over. All in all, it was an exhilarating morning and the joy of knowing we are helping in a small way made us look forward to doing it again next year (with more puppies!).

Doug Mears

Volunteer

Mailbag

Dear Editor,

My sister Jacqueline who lives in Los Angeles was diagnosed with motor neurone disease 3 years ago at the age of 47. During my phone conversations with her, I had concerns about the quality of information she was receiving in terms of available treatments and support. I contacted MND Association of NSW for advice. Jenny Judd, Regional Co-ordinator for Central Western NSW, provided information that proved vital for my visits to LA during key milestones in my sister's illness.

I was equipped to ask critical questions of doctors, nurses, and social workers. I was also able to source equipment for Jacqueline and counselling for her 3 young children. Fortunately, my sister can afford to fund the resources and equipment for her care; unfortunately she does not have the support of an organisation like MND NSW. I am indebted to Jenny and the staff of MND NSW for their support to me personally and for providing me with information that enabled me to advocate on behalf of my sister in LA.

Gemma Cooney

Dear Editor,

At a recent MND support group meeting in Thornleigh, participants were asked if they knew of a cheap thickener for water or drinks. Helen, an MND sufferer with a nursing background, had a recipe that uses gelatine which is very cheap per serve.

Moderately thick water that is colourless and tasteless

The basic ingredient is Davis Gelatine (clear and unflavoured), available in 250g packets from supermarkets. Each packet yields about 30 serves.

- 0 Dissolve 2 teaspoons of Clear Unflavoured Gelatine in 200ml hot water.
- 0 Add cold water to make up 1 litre.
- 0 Refrigerate for a minimum of 2 hours.

The brew is tasteless, but you can add juice or cordial for flavour. Store in refrigerator.

Adding gelatine powder to produce thickened cold dishes is also an option.

Malcolm

MND NSW support group member

Do you have a tip to share with other members? Send it to the Editor of Forum today. See page 12 for more information.



John, Patricia and Sally Perryman and Jaya as we sailed out through the heads

Sailing on Sydney Harbour with Sailors with disAbility

On 28 March the sun was shining and the day was just perfect for a sail on magnificent Sydney Harbour. A big thank you to Sailors with disAbilities who once again gave people with MND the opportunity to sail with them. As sailing conditions were so good we were able to up the sails and head out beyond the heads. Everyone was given an opportunity to take a turn at the helm as others relaxed and enjoyed the thrill of the day.

Thanks to our wonderful volunteer crew who always go out of their way to make sure everyone has a great experience.

Caroline and Robyn

Support Groups

ACT

At our February meeting we had guest speakers from Community Options who discussed their services and support, and how they can be accessed. Our April guest speaker was from the Falls Clinic and we were shown ways to keep safe even though leg strength, balance or mobility may be reduced. We were 'walked' through a house and garden scenario and potential hazards were identified.

If you have any ideas for guest speakers or topics for talks for meetings please don't hesitate to call me.

The date of our June meeting has been changed to Sunday 27 June and it will be held at Lake Burley Griffin to coincide with 'Walk to d'Feet MND' in the ACT. Graham Opie and Kym Nielsen will be travelling down from the MND NSW Centre at Gladesville to join us. Your invitation will be in the mail soon if you live locally, but if you live in Southern NSW and you will be in Canberra on that day let me know and I will forward you the details. I hope to see many of you at the event. Remember though, if you are planning to attend please do let me know.

Iva Plessnitzer

Regional Advisor

Gladesville

Despite heavy rain, we had a great group of people at the April meeting. We welcomed some new faces who soon felt at home and joined the general chatter as people caught up with news and events of the last two months. Kevin Langdon told an interesting story of when he was President of the MND Association, he was invited to an audience with The Duchess of York at Buckingham Palace. He spoke of feeling like a celebrity as he rode in a limousine with the window wound down and waved to passers by.

Helena Karnolz is a very gifted botanical artist amongst whose creations are the beautiful MND gift cards and writing paper we have on sale. Helena brought some of her other botanical works to share with us at the meeting. Some of these were on sale and Helena donated 30% of what was purchased to MND NSW.

The next meeting will be on 2 June. New and visiting members are always welcome to drop in.

Caroline Gleig

Regional Advisor

Northern Beaches

Our morning tea support group meeting continues to flourish. People living with MND, their families, carers and friends come together to learn more about MND from guest speakers and each other. Recently Loral Adams and Carolyn Cecere spoke about the latest MND research taking place around the world. Meetings are held at the Palliative Care Unit at Mona Vale Hospital. All are welcome. If you would like more information, ph.1800 777 175.

Jo Fowler

Regional Advisor

Support Group Contacts

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North West

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New MND Support Group in Tamworth

The North West Motor Neurone Support Group meets bi-monthly at Tamworth. Run jointly by MND NSW and Northcott Disability Services, the support group meets between 10am-12pm and morning tea is provided. Planned meeting dates for this year are 19 July, 20 September and 15 November.

If you have any questions, contact either Ruth Loseby at Northcott Disability Services ph. 6762 4902 or Noelle Smith at MND NSW Hunter Office ph. 4921 4157 on Mondays or Tuesdays.

Visit
www.mndnsw.asn.au to view
upcoming
support group
meeting dates.

Noticeboard

Accessing Allied Health and Dental Services through the Enhanced Primary Care Program



Allied Health Services

The Enhanced Primary Care (EPC) Program can provide access to a range of allied health services under Medicare, including physiotherapy, osteopathy, chiropractic, podiatry, chiropody and counselling. Through the program you can have up to five appointments with each service in a calendar year. To access the EPC program, your GP is required to create a care plan for you, and make the referral. It should be a very straightforward process involving little or no cost to you.

The cost will depend on whether the individual service provider/practitioner bulk bills, so you should always check first. More information on the EPC is on the web at: www.health.gov.au/mbsprimarycareitems

For further information about the EPC program, talk to your regional advisor or call the MND NSW Info Line ph. 8877 0999 or Freecall 1800 777 175.

Dental Services

Funding is available to provide up to \$4,250 over two years in Medicare benefits for dental services. These services include dental assessments, preventive services, extractions, fillings, restorative work and dentures.

Check with your dentist about whether he or she will receive referrals under this scheme. If not, check with other dentists in your area. Also check whether they bulk bill, as if they don't you may need to pay an amount that is not covered by Medicare. Your GP will also need to refer you to the scheme by completing a care plan—check even if you already have a care plan to access allied health services.

More information is on the Department of Health and Ageing website at www.health.gov.au/dental. Alternatively call Medicare Australia Patient Enquiry Line on 132 011, or talk to your regional advisor or call the MND NSW Info Line on ph. 8877 0999 or Freecall 1800 777 175.

Lithium

Extract from Australian Neurology Update

Despite promising results from a small pilot study, new research shows that lithium does not delay disease progression in patients with amyotrophic lateral sclerosis (ALS). The double-blind randomised study of 84 patients with ALS found no evidence that lithium, in combination with riluzole slowed disease progression more than riluzole alone. The primary endpoint of the study was the time to an event, defined as a decrease in revised ALS functional rating scale (ALSFRS-R) score by at least six points or death.

The trial was stopped for futility at 6 months 'because of sufficient evidence that a large effect of lithium would not be seen by enrolling more patients, or by assessing patients already enrolled in the trial for longer'.

Lancet Neurology 2010; published online before print. www.neurologyupdate.com.au/article/time-to-close-the-door-on-lithium-in-als/514882.aspx

FUS clumps found in majority of cases of MND



Chicago MND researchers led by Dr Han-Xiang Deng and Professor Teepu

Siddique have for the first time been able to make a connection between a biochemical pathway recently implicated in the rare, inherited form of MND (known as familial MND) and sporadic MND. The research, published in the journal 'Annals of Neurology' found clumps of the 'FUS' protein in motor neurones of people with familial MND, AND in motor neurones of people with sporadic MND. Deposits or clumps of proteins are common to many neurodegenerative diseases, and the main difference between the diseases is which proteins are found. By studying brains and spinal cords donated from 78 people who had ALS (the most common form of MND) and 22 controls, the researchers found FUS deposits sitting alongside TDP-43 deposits in motor neurones of most of the people who had ALS.

There will now be a focus on confirming these exciting results which will take us closer to understanding the causes of MND. Read more at www.mndassociation.org/research/news_in_research/fus_clumps_found_in.html

Smoking may now be considered an established risk factor for ALS



While previous studies have indicated a "probable" connection

between smoking and ALS, a new study published in the 17 November 2009 issue of *Neurology*[®], the medical journal of the American Academy of Neurology, states that smoking may now be considered an "established" risk factor for Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease. The findings come from neurologist Dr. Carmel Armon, an ALS researcher and neuroepidemiologist, who came to this conclusion using evidence-based methods to perform a rigorous analysis of studies examining the link between smoking and developing ALS. Dr Armon noted that focusing on processes at initiation of sporadic ALS, and close to it, may provide new avenues to treatment to stop its progression. Read more at www.alsa.org/news/article.cfm?print=1&id=1567&

Your general practitioner can help you access the Enhanced Primary Care Program.

Never Give Up - MND 100km Challenge - what a success!

Scott Richmond took part in a 100km race in the Blue Mountains on 15 May in memory of Elliot Jay, his cousin who died of MND. Through the race he raised over \$10,000 for MND.

Hello again to all my awesome sponsors,

Well, it's two days since I finished the run and I'm still on the biggest high! After 15 hours and 19 minutes on the most gruelling and unforgiving terrain I have ever run, I crossed the finish line at about 10.30pm on Saturday night, 2 hours 40 minutes ahead of my target time of 18 hours! I managed to finish 95th out of 553 competitors and exceeded any expectations I had for this event.

The course presented more stairs and steep hills than I have ever imagined, pushing my physical and mental capacity to the absolute limit. At times I did ask myself 'why the heck am I putting myself through this?', but the answer wasn't far away in my mind and the inspiration and strength I sought from Elliot and my experiences with MND help me remain strong and push through.

I couldn't have completed this 100km run without



What a feeling!

so many people getting behind me and with 138 people coming on board as sponsors, there was no lack of

support and encouragement. Together we managed to blow all of my goals out of the water and exceed any expectations I had when I committed to this event 11 weeks ago. We managed to raise a total of \$10,680 for MND and for that I thank each and every one of you. It was amazing to exceed my goal of \$10,000.

Some think that running is a solo event, but in this case it was a huge team that made it happen and specifically the Support Crew that gave up their weekend to keep me fed, clothed and motivated for the duration of the run. Thank you to mum, dad, my sister Kass and her boyfriend Chris, my auntie Leah and life saving 'physio' uncle Geoff - without you I seriously doubt I would have had the strength to finish.

To Kev and Jill, I still can't believe you drove from Sydney to the Blue Mountains on Saturday morning to wish me luck at the 7am start! And to the most important person in this event, my beautiful girlfriend Kate, who headed the Support Crew, organised all the food and drink, and has been amazingly supportive throughout my preparations for the run.

Overall, this experience had given me some of the highest highs and the lowest lows I've ever experienced. To complete the run itself was one of the most amazing and satisfying achievements of



The amazing Support Crew

my life and that I will never forget. But to raise so much money for MND as well is the most satisfying thing I have ever done.

I am truly thankful for your support.

Never Give Up.

Scott Richmond

Dates for the Diary

21 June	MND Global Awareness Day <i>21 June is a solstice - a turning point - and each year the ALS/MND community undertake a range of activities to express their hope that this day will be another turning point in the search for cause, treatment and cure of motor neurone disease.</i>
27 June	Walk to d'Feet MND Fundraising Walk Canberra <i>Around Lake Burley Griffin Contact Kym Nielsen at kymn@mndnsw.asn.au or ph. 8877 0912 for more details.</i>
28 August - 1 September	Art Exhibition <i>Mosman Contact Jennifer Mattiussi at www.space4art.com.au for more details.</i>
11-12 September	Open Gardens <i>Warrawee Contact Stephen Daymond at daymond.gardens@gmail.com or ph. 94874828 for more information.</i>
19 September	Sydney Marathon <i>Suzi Heaton is running in the Sydney Marathon for MND. Contact shea7660@uni.sydney.edu.au for more information.</i>
7 November	Walk to d'Feet MND Fundraising Walk <i>Blaxland Park, Sydney Olympic Park. Contact Kym Nielsen at kymn@mndnsw.asn.au or ph. 8877 0912 for more details.</i>

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

Community Events

The Central Coast Support Group is a very active group that works tirelessly to raise funds for MND NSW. Over the recent long weekend in April group members held a sausage sizzle at Bunnings Tuggerah. The bbq was manned by Lyn and Wayne Towers, Sheila Holmes, Pat Powell, Noleen Lake and Audree Dash. The day was a great success with the group having to send out for more sausages and bread. Thank you folks, for all your hard work.

MonSTaR Cup Golf Day



Letter from the MonSTaR committee

Dear MonSTaR Supporters,

We are writing to express a heartfelt thank you for making the 4th Annual MonSTaR Cup such a success.

The Golf.....It was yet again a picture perfect day that over 170 golfers enjoyed from dawn to dusk.

Unfortunately no one was lucky enough to find the hole in one at the 18th - so the Alto Audi A4 will have to stay in the shed for another year. A few golfers came close and the opportunity no doubt provided an added incentive for all.

The **Fiona Pearce Memorial Trophy** was won by deserving sponsors, long time supporters and a group of fine gentlemen. **Jackson Industries** took the MonSTaR Cup this year on a count back from Craig Sweeney's group. The Jackson Industries Team comprised of the flamboyant Ross Jackson, Jeff Locke, Russell Main and Greg Thompson - well done chaps!

The Dinner/Party.....Our Patron Peter Overton got things underway by introducing Dave Burke. Dave lost his wife of 54 years, Sybil, to MND only 2 years ago and is therefore as hungry as anyone to find a cure for this debilitating disease. Aside from this great misfortune, Dave has a great talent as comedian and had us crying into our mains with his repertoire. Thank you Dave for your contribution to our evening.

Jason Keen, our new auctioneer (courtesy of Ray White NSW) for this year's Live Auction, did a fantastic job in selling the auction items and we thank him for being such an integral part of the evening. Of course many of you left with some great holidays, electronic equipment and a few outstanding money-can't-buy experiences.

The Silent Auction was also incredibly successful. We trust the AV equipment and rolling bid updates aided in the enjoyment and ease of participating in the evening. The Spank Town Trio kept those that needed a dance going well into the next day.

We would like to thank Pennant Hills Golf Club for providing undoubtedly the finest service and food we have had in four years, thanks to Chef Kate and her team.

The Results.....Your generosity resulted in us netting our highest figure yet at \$140,000. This was around 40 per cent increase on what we raised for MonSTaR 2009! We will be presenting cheques for \$70,000 to MND Association of NSW and the STaR Association. Over MonSTaR's 4 year history we have given our charities a total of \$492,500; \$245,250 to each charity.

We are extremely pleased with the success of this year's event and sincerely hope those who participated had a great experience.

Finally, thank you to all our volunteers, attendees and sponsors as none of this would be possible without you. As Peter Overton suggested, the MonSTaR Cup has a great community feel about it and we think that this is a big part of what makes it so special.

Wishing you all the very best,

The MonSTaR Committee

Harrington Park Event

After seeing the devastating effects of motor neurone disease when his sister-in-law was diagnosed with the disease, Terry Goldacre, Managing Director of Harrington Estates, decided to call on a few of his friends in the land development and building industry to lend a hand and raise funds for research into this cruel disease.



Terry Goldacre presents a cheque for \$100,000 to MND NSW Chief Executive Officer Graham Opie.

Movers and shakers from across south-west Sydney dug deep into their pockets at a recent fundraising dinner hosted by Mr Goldacre and his team. Over 400 people attended the gala evening held at the beautiful Harrington Grove Country Club.

The evening produced an amazing result, raising \$100,000 for MND NSW and another \$75,000 for the Prince of Wales Medical Research Institute.

Are you thinking about organising a community fundraising event for MND? Speak with Kym Nielsen ph. 8877 0912 about your plans.

Community Events (cont'd)

Win a beautiful handmade quilt



Quilts and Coffee group members presenting the flower quilt to Kym Nielsen, Fundraising Manager

Members of the Quilts and Coffee group of the Ladies Probus of the Upper Blue Mountains presented a beautiful handmade quilt to Kym Nielsen, Fundraising Manager of MND NSW. The quilt will be raffled to raise funds for MND NSW. If you would like a book of raffle tickets to sell to friends and work colleagues please email Aysed@mndnsw.asn.au. Tickets are \$2 each and the raffle will be drawn on Sunday 27 June at the Walk to d'Feet MND in Canberra to celebrate MND Global Awareness Day.

Kym Nielsen
Fundraising Manager

March of MND Faces

These banners feature a photographic display of people with motor neurone disease. MND NSW will soon be producing an eleventh 'March of MND Faces' banner. If you have MND and want to be included in the new banner you need to complete a permission form and submit a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish. Family members are also able to submit a photograph in remembrance of a person who has died from MND. For more information ph. 8877 0999 or email Penny Waterson at info@mndnsw.asn.au.



MOTOR NEURONE DISEASE

Australia's March of MND Faces



Motor Neurone Disease Association of New South Wales
Phone: 1800 777 175

Walk to d'Feet MND 2010

Walk, run or ride for a cause in ACT and NSW this year.

Please join MND NSW, MND Australia and the MND community worldwide to acknowledge and create awareness of this serious illness affecting many Australians. The Walk to d'Feet will be held in two locations this year, in NSW and in the ACT.



CANBERRA

Join us in Canberra on **Sunday, 27 June**.

The walk will commence at **10am** at the Captain Cook Globe on the edge of Lake Burley Griffin (access via Barrine Drive). The walk is a 5.5km walk/run/bike ride doing the Lake's 'Bridge to Bridge'.

Contact Kym Nielsen ph. 8877 0912 or kymn@mndnsw.asn.au for information and to register your attendance.



SYDNEY

If you can't make it to Canberra, why not join our walk in Sydney along the picturesque Parramatta River on **Sunday, 7 November**? The event will start at **10am** from Blaxland Riverside Park, at Sydney Olympic Park, Homebush.

Contact Kym Nielsen ph. 8877 0912 or kymn@mndnsw.asn.au for information and to register your attendance.

Registration and fundraising has been made easy - just click the Walk button on our website to register and create your own fundraising page.

In the event of poor weather conditions on the day, ph. 02 8877 0999 from 7am for a recorded message to confirm the day's event.

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

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

Editor: Penny Waterson