



# FORUM

## A Message from the CEO

The new year has passed and already we are well into 2011. The next two months are full of events to help raise funds to:

- support MND NSW
- raise awareness of the impact of motor neurone disease.

It is only through the support of donors and voluntary event organisers that we can continue to provide much needed equipment, regional advisor services and advocacy on behalf of people living with motor neurone disease.

Our goal is to increase services to all areas of regional NSW and with only 20% of our recurrent income from the Department of Health there remains a lot of work to help finance this goal.

Upcoming events, organised by our supporters to raise funds for MND NSW and community awareness about MND include the MonStar Cup on Friday 18 March, a 100 km cycling event on 10 April and a cocktail evening. During MND Week we have our annual Day of Hope and Remembrance on 3 May and Cornflower Blue Day on 6 May. The details of these events and more can be found in this edition of *Forum* and at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

Why not consider running an event in your community? We can help guide you and provide all the paper work to help your event run smoothly. If you are interested please contact Kym Nielsen, Fundraising Manager, ph. 8877 0999.

In October and November last year we encouraged your support of a campaign for the continuation of the NSW State Government's *Stronger Together*. Over the past five years many members of MND NSW have benefited from *Stronger Together* by getting better access to case management, attendant care and high needs pool packages. Additionally, FlexiRest, the MND NSW Info Line, some items in our Equipment Loan Pool and many of our 2009-10 regional information and education programs have been funded under this Program. The Program required a funding commitment from the NSW State Government for it to continue past 2010-11.

Thank you to all those who wrote to their local state member and/or attended the rally in Sydney in support of *Stronger Together* in November. Your voices were heard!

We are pleased to let you know that in December the NSW State Government announced a further \$2 billion funding for the second phase of *Stronger Together*.

We will continue to work with Ageing Disability and Home Care at the Department of Human Services to further enhance services for people living with MND.

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

**Graham Opie**  
Chief Executive Officer

## MND Week 2011

1 to 7 May

**Help needed.....join with others to raise awareness of MND**



### Railway stations

We will be selling wristbands, pens, puppies and other merchandise at city and metropolitan railway stations on Wednesday 4 May. This is a great way to spend several hours volunteering for MND NSW. Permits are required so please let us know your preferred location so we can secure the relevant permit.

### Shopping centres

Do you have a shopping centre near home where you could sell merchandise and collect donations? How about Cornflower Blue Day Friday 6 May? Permission would need to be sought from the shopping centre management and we would be happy to assist with this.

### Other activities

Are you a member of a tennis club, gym or golf club? Are you involved with a local school? You could sell our wonderful MND socks or puppies through your club or our 'Never Give Up' wristbands through schools. You could ask your local chemist, hairdresser or your place of employment if you could place a box of merchandise at their business for MND Week.

We would love to have your support. Contact Kym Nielsen, Ayse Dalkic or Anne Jones ph. 8877 0999 or email [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au), [aysed@mndnsw.asn.au](mailto:aysed@mndnsw.asn.au) or [annej@mndnsw.asn.au](mailto:annej@mndnsw.asn.au) for more information.



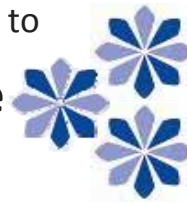
**Order your MND NSW 2011-12 Entertainment Book by 31 March** and get over \$140 in bonus vouchers! See insert in this edition of *Forum* or visit [www.mndnsw.asn.au](http://www.mndnsw.asn.au) for more information.

*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.*



You and your family and friends are warmly invited to

## A Day of Hope and Remembrance



Tuesday 3 May 2011

1pm to 3.30pm

### 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.

Our guest speaker for 2011 is the insightful, compassionate and informative Frank Brennan, Palliative Care Physician. Frank will speak about hope and MND.

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 MND March of Faces banners will also be on display.

Please RSVP by phoning 02 8877 0999, freecall 1800 777 175 or email [annej@mndnsw.asn.au](mailto:annej@mndnsw.asn.au) by Friday 29 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.

*If you would like to receive Forum by email let Petra Sammut know by emailing your name, address and email address to [admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au)*

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*Penny Waterson*



*And.....many valued volunteers including Colleen, Helen and Heather.*

## Family Support Team

It's a busy time of year for us all in the Family Support team. We are currently organising a number of events and education programs for our members, carers and service providers that will hopefully ensure that people with motor neurone disease get the best possible care and support.

This month we are conducting two *Information Days* for members and families. The first will be held on 10 March for people living on the Central Coast, and the second will be held on 25 March in Ballina. These days are a great opportunity to learn about managing with motor neurone disease, to have your questions answered and to share your ideas and experiences with those in a similar situation. On 24 March we are conducting an Information Day for health and community professionals in Ballina.

In May, the four day education program for carers, *Care for Carers*, will be held at the MND NSW Centre at Gladesville. Carers attend for one day a week, over four weeks, starting on the 9 May. The program is a great opportunity for carers to meet others and learn more about caring for someone with motor neurone disease. Those who attend this program often continue to remain in touch, offering support and guidance to each other.

Our annual *Day of Hope and Remembrance* will be held during MND Week on 3 May. This is an opportunity for everyone whose lives have been touched by motor neurone disease to join together for an afternoon of remembrance and hope for the future. I encourage you all to be a part of this. It's an opportunity to spend an afternoon with people who have motor neurone disease, family, friends, supporters, volunteers and those working with people living with MND. Our guest speaker this year is Frank Brennan. See page 2 for more.

Our new MND NSW support group has started in Port Macquarie and the ACT support group has recommenced. Support groups offer a comfortable, informal setting for the exchange of information and support for people living with motor neurone disease, their family and friends. Meetings can provide a valuable opportunity to gain practical knowledge about dealing with MND. They also provide an opportunity to share experiences and learn from each other.

More information about all these events can be found in the newsletter. If you would like any further information please don't hesitate to contact your regional advisor or contact the MND NSW Info Line ph. 1800 777 175.

**Gina Svolos**  
Manager, Family Support

*Do you live near Port Macquarie? You might be interested in the new MND NSW support group in your area. See page 6 for more.*

## Equipment

Demand for equipment loaned through MND NSW has continued to be high and we have received 310 equipment item referrals since 1 December 2010. Items most requested have been shower commodes, hoists and cushions. During this time we have received 23 referrals just for electric medical beds. For many items, demand has remained higher than availability and waitlists are unfortunately continuing to occur.

To assist in decreasing waitlists for this equipment MND NSW has spent over \$27000 purchasing equipment items in high demand during the past two months. For example, the MND NSW stock of electric medical beds has now increased to a total of 46 beds, with six beds purchased last year and another five beds purchased already this year.

Loans of equipment are made on a priority of need basis; not on the date the referral is received. It is important for members who are waiting for equipment to keep their regional advisor updated with any change in their need for equipment as this information assists when decisions on allocation of equipment are made.

Purchase of new and replacement items of equipment for inclusion in the MND NSW Loan Pool would not be possible without the continued financial support of the community. Thank you.

### Reminder on charging batteries

Replacing batteries for equipment is expensive. For example, to replace a set of batteries for a powered wheelchair can cost from \$250 to \$500. You can help us save on the cost of expensive replacement batteries by looking after the existing battery in the equipment item. For members who are using powered wheelchairs, hoists and Lightwriters, it is best to charge the equipment overnight when it is being used, or to charge it every 3rd day when it is not being used. This helps extend the item's battery life.

**Maree Hibbert**  
Equipment Services Coordinator



*This year, we will be welcoming MND researchers, clinicians, and health and community care providers to Sydney for the 22nd International Symposium on ALS/MND, Allied Professionals Forum, International Ask the Experts and other satellite meetings to be held in November and December 2011. We will update you in Forum about plans for these events as more information becomes available.*

## To drive or not to drive?

One of the most difficult things to accept with advancing age, medical condition or disability, is the prospect of no longer being able to drive. Getting behind the wheel of a car can give us a great measure of personal independence – it allows us to meet up with friends and family; get to and from work; go shopping; and keep medical and other appointments.

If someone else thinks you might need to stop driving because of your MND you may feel like you are having an important part of your life taken from you, whilst you are already adjusting to other losses.

Some of the most commonly asked questions are:

- who makes the rules?
- how will your driving ability be assessed?
- will your general practitioner notify the RTA?
- what are your legal responsibilities?
- is your insurance cover affected?
- where can you go to get the right advice and information?

In summary, if you have a long term injury or illness that may affect your ability to drive safely, the law requires you to notify the NSW Roads and Traffic Authority (RTA) as soon as possible. This applies to all licence holders. The RTA needs to ensure that all drivers are medically fit and competent to drive. Older drivers and people who have a medical condition can be asked to have regular medical examinations. Some drivers also need to have a periodical driving assessment.

Whilst it is not mandatory, it is also preferable that you inform your insurance company of any diagnosed health condition. Failure to disclose this information may result in invalid insurance cover.

Listed below are some of the organisations that you can contact to get the most relevant advice if you are facing the prospect of having to stop driving or if you are concerned about the safety of a family member or friend who is still driving.

Licensing rules and regulations - *NSW Roads and Traffic Authority* ph. 132 213 or [www.rta.nsw.gov.au](http://www.rta.nsw.gov.au). Useful RTA factsheets include: *Medical and driving tests and Vehicles Modified for People with Disabilities*

Driver assessment services - *Commonwealth Rehabilitation Service (CRS)* ph. 1800 277 277 or [www.crsaustralia.gov.au](http://www.crsaustralia.gov.au) or you can arrange your own driving assessment with a suitably qualified occupational therapist (OT). Contact *Australian Association of Occupational Therapists NSW* ph. 02 9648 3225 or [www.otnsw.com.au](http://www.otnsw.com.au)

Driving and vehicle modifications - *Wheels within Wheels Revisited - a guide to safe vehicle travel for wheelchair users*. Contact *Eddie Wheeler, NRMA ACT Road Safety Trust* ph. 02 6207 7151 or [eddie.wheeler@act.gov.au](mailto:eddie.wheeler@act.gov.au)

Alternative transport options - *Government transport concessions* ph. 131 244 or [www.seniorsinfo.nsw.gov.au](http://www.seniorsinfo.nsw.gov.au) or *MND NSW Family Support Team* ph. 1800 777 175

Wheelchair accessible vehicles for sale - [www.e-bility.com/classifieds/vehicles.php](http://www.e-bility.com/classifieds/vehicles.php)

**David Wallace**

*Information Line Advisor, MND NSW*

(Adapted from 'Driving with a disability' MND News Victoria Nov-Dec 2010 and other sources).

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

## Are you a family member, relative or friend caring for someone with motor neurone disease?

### Care for Carers Program

9, 16, 23 and 30 May at the MND NSW Centre at Gladesville

If you are keen to gain some extra information and support, this program may be ideal for you. It is suitable for those new to the caring role and also those who have been caring for some time.

You will have the opportunity to hear from a range of health professionals with expertise in MND, who will answer your questions in a relaxed and informal setting.

You will learn how to prepare your home, manage symptoms including swallowing, communication and respiratory symptoms, and also how to access services and equipment.

Those who have attended previous *Care for Carers* tell us that they especially valued the opportunity to take time out for themselves and to share their ideas and experiences with others in similar situations.

This program runs from 10am to 3.30pm over four consecutive Mondays at the MND NSW Centre at Gladesville, commencing on 9 May. Morning tea and lunch are provided each day. There is no cost to attend, but we do ask that you to commit to attending all sessions.

If you have any questions or need support in arranging care for your family member contact the MND NSW Info Line on 1800 777 175 or speak to your Regional Advisor.

## Mailbag

### *Hidden Youth*

*When I look at aged people,  
I think where they've been,  
Not in terms of travel  
But things they've done and seen  
Beyond the frailty of body  
There's a story to be told  
Of a time that is long gone  
When they were young and bold  
A tale of love and laughter  
And the many things they've done  
Of dreams and aspirations  
And battles lost and won  
I look beyond the greying hair  
And through the wrinkled skin  
To see the young, vivacious person  
I know is there within.*

**A Van H**

*Member, MND NSW*

### **Would you like to participate in letting health and community care professionals in NSW know what it is like to be living with motor neurone disease?**

Over the next few months MND NSW will be developing content for a new set of online training modules for health and community care professionals, including case managers, involved in the care of people living with MND.

We will be using photos, audio, short video and stories within the modules to show real-life situations and real-life people. We won't be hiring film crews, but will be seeking your mobile phone videos, audio and stories of what MND is like for you.

We want the training materials to show how people live with MND and the impact MND has on people's lives.

If you, your family or your friends might be interested in sharing just 60 seconds with us of how you live with MND, contact Penny Waterson, Information Resources Coordinator, MND NSW, ph. 8877 0915 or email pennyw@mndnsw.asn.au

Thinking about attending a Family Support workshop in 2011? Speak with your regional advisor for more information

## Family Support Calendar

<b>24 March</b>	<b>MND Directions in Care for health and community professionals - Far North Coast   Ballina</b>
<b>25 March</b>	<b>Information Day for people living with motor neurone disease, their family and friends - Far North Coast   Ballina</b>   If you have MND or are close to someone who has MND and you live on the Far North Coast or Southern Queensland, you are invited to learn more about MND, assisting people to live well with MND, accessing important services and benefits and maintaining independence at home. You will also be able to ask your questions to health and community care professionals from the local area. There is no charge to attend. For further details and to RSVP contact MND NSW ph. 1800 777 175 or e-mail kristinad@mndnsw.asn.au
<b>3 April</b>	<b>Sailors with disAbility Harbour Cruise   Rushcutters Bay</b>   This has been a very popular event in the past and numbers are strictly limited to 12 people. So don't delay! There is no charge. Contact MND NSW ph. 1800 777 175 to reserve your place and we will provide more information about what to bring and where to meet. (A wheelchair can be accommodated if required).
<b>12 April</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends   Gladesville</b>   Informal information evening for people who are newly diagnosed with motor neurone disease, and their families and friends
<b>3 May</b>	<b>Day of Hope and Remembrance   Sydney Olympic Park</b>   See page 2 for more information
<b>9,16,23,30 May</b>	<b>Care for Carers   Gladesville</b>   See page 4 for more information
<b>14 June</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends   Gladesville</b>   Informal information evening for people who are newly diagnosed with motor neurone disease, and their families and friends
<b>25 July</b>	<b>MND Directions in Care for health and community professionals - Hunter</b>

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.

## Support Groups

### Central Coast

Our 13th year of involvement with the Rotary Club of The Entrance Community Raffle raised \$900 for MND. Thank you to all for selling tickets and for generously supporting the raffle.

At our first meeting of 2011, Donna, of Red Cross, spoke about free Telecross service that provides a morning call to check the wellbeing and safety of those living alone.

Our next meeting will be held at 1.30pm on 7 April at Niagara Park Community Centre in Washington Avenue, Niagara Park. This venue should provide more accessible parking for members. Looking forward to seeing you all.

**Audree Dash**, Coordinator

### Northern Sydney (Hornsby)

Our group meets every two months from 12-2pm in the Thornleigh Community Centre on the corner of Phyllis Street and Central Avenue. The building is next to Bunning's and there is plenty of off-street parking. A light luncheon is supplied. If you require more information about the group, please call 8877 0999, or 1800 777 175.

**Jo Fowler**, Regional Advisor

### Port Macquarie

Members living with motor neurone disease from the Port Macquarie area, and their family and friends, recently attended several coffee mornings during which they shared a common interest in meeting regularly as an MND NSW support group. Also attending the coffee mornings were several

local health and community care professionals who all showed great support and interest in having an MND support group in the area. Thank you to Rosemary Mann, palliative care nurse, Kylie Ballantyne, community physiotherapist and Kylie Fletcher, community occupational therapist, for your support and encouragement in forming the group.

I am pleased to let you know the Port Macquarie support group has now commenced, meeting bi-monthly on a Thursday, from 10am to 12pm, at 53 Lord Street Port Macquarie (next to the ABC building). Meetings are facilitated by myself and Rosemary Mann. Rosemary has kindly volunteered her time to assist and it is envisaged that I will be present at every second meeting, with Rosemary facilitating the group when I am unable to attend.

Meeting dates for 2011 are 28 April, 30 June, 25 August, 27 October and 8 December. For more information please contact me.

**Eileen O'Loghlen**, Regional Advisor

### Western Sydney

Our meetings are held bi-monthly on the second Tuesday from 1-3pm at Kingswood Neighbourhood Centre, 19 Bringelly Road, Kingswood. The group provides people living with motor neurone disease the opportunity to share tips and experiences, and to understand and support each other. Meetings are always very casual and informal, and afternoon tea is supplied. Everyone is welcome.

**Jenny Judd**, Regional Advisor

Visit [www.mndnsw.asn.au](http://www.mndnsw.asn.au) to view upcoming support group meeting dates.



**Have you thought about FlexiRest lately?** FlexiRest funds a range of services offering in-home or out-of-home respite that cannot be met by existing community and respite services. Ask your regional advisor for more information.

## Support Groups

**METROPOLITAN** Contact MND NSW ph. 1800 777 175 for more information

Campbelltown - *Robyn Petersen* | [robypn@mndnsw.asn.au](mailto:robypn@mndnsw.asn.au)

Gladesville - *Caroline Gleig* | [carolineg@mndnsw.asn.au](mailto:carolineg@mndnsw.asn.au)

Northern Beaches (Mona Vale) and Northern Sydney (Hornsby) - *Jo Fowler* | [josephinef@mndnsw.asn.au](mailto:josephinef@mndnsw.asn.au)

Western Sydney - *Jenny Judd* | [jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)

### REGIONAL AND RURAL

ACT and Southern NSW - *Gail Ferguson* | 6286 9900 | [gailf@mndnsw.asn.au](mailto:gailf@mndnsw.asn.au)

Central Coast - *Audree Dash* | 4384 2907 or *Jo Fowler* | 1800 777 175 | [josephinef@mndnsw.asn.au](mailto:josephinef@mndnsw.asn.au)

Central West - *Jenny Judd* | 1800 777 175 | [jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)

Illawarra - *Robyn Petersen* | 1800 777 175 | [robypn@mndnsw.asn.au](mailto:robypn@mndnsw.asn.au)

Newcastle and Hunter - *Noelle Smith* | 4921 4157 | [noelles@mndnsw.asn.au](mailto:noelles@mndnsw.asn.au) or  
*Eileen O'Loghlen* | [eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au)

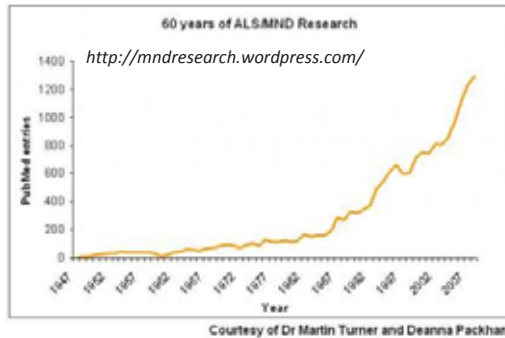
North West (Tamworth) - *Noelle Smith* | 4921 4157 | [noelles@mndnsw.asn.au](mailto:noelles@mndnsw.asn.au)

Port Macquarie | *Eileen O'Loghlen* | 4921 4157 | [eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au)

## 21st International Symposium on ALS/MND

I attended the Symposium held in Florida, USA, in December 2010, as a recipient of the MND Australia Travel Grant and with support from MND NSW.

There are many researchers world-wide working tirelessly to find causes and treatments for MND. Dr Brian Dickie, MND Association (UK), uses this image to illustrate the growth in MND research over the past 60 years.



Do you care for a family member or friend with MND? Hear from a range of health professionals with MND expertise at Care for Carers. See page 4 for more.

### Respiratory care for people with ALS/MND: 6th Annual ALS/MND Nursing Mini-Symposium



Respiratory care for people with ALS/MND was the focus of this mini-symposium held on 10 December 2010 in conjunction with

International Symposium on ALS/MND. Keynote speaker, Dr Lisa Wolfe (pictured above), Pulmonary, Sleep and Critical Care Specialist, Assistant Professor, Northwestern University Feinberg School of Medicine, USA, presented the latest in MND respiratory research, treatment and clinical care.

Dr Wolfe highlighted a study by Just and others (2010) that showed the Borg dyspnoea score gives a good assessment of diaphragmatic strength in people with ALS when compared to traditional measures of diaphragmatic strength such as the sniff nasal inspiratory pressure (SNIP) and vital capacity tests. The Borg dyspnoea score is a self-rated assessment, can be carried out in the home and needs no equipment. This finding could be especially useful for people who may have difficulty travelling for respiratory assessment or who live some distance from a centre that undertakes respiratory assessments.

Airway clearance and clearing bad bacteria from the airway (including the mouth) decreases the risk of complications from pneumonia. Dr Wolfe suggests that good oral hygiene, encouraging mouth opening and working early with a dentist to make sure there are no cavities in the teeth can all be helpful for people with motor neurone disease.

Masks used for non-invasive positive pressure ventilation, which has been shown to improve quality of life and length of life for people with MND (Lou and others, 2010), can cause discomfort.

At the Symposium, there were several interventions, known to make a positive difference to people with MND, mentioned time and time again by researchers. These included:

- riluzole
- multidisciplinary care
- good respiratory and nutritional management
- social support and access to equipment.

I report below on two Symposium satellite meetings: the 6th Annual ALS/MND Nursing Mini-Symposium and the Cochrane Neuromuscular Disease Group meeting. Both of these meetings focused on research about interventions that can help people living with MND to live better for longer. Also included in this Forum Symposium feature are selected articles from the MND Association UK and the American ALS Association.

#### Penny Waterson

Information Resources Coordinator, MND NSW

Dr Wolfe's tips included:

1. to reduce skin breakdown around where the mask sits on the face, try:
  - using a thin gel pad on the bridge of the nose
  - starting air flow first
  - replacing head gear regularly
  - using strap guards.
2. to reduce air leaks try:
  - supporting the hose with a hose support
  - using a 'cut-out' pillow so the pillow doesn't get in the way of the mask
  - using an under-chin mask
3. to reduce non-invasive ventilation humidity try:
  - avoiding windows
  - tubing wraps and heaters
  - using a saline based nasal gel

Dr Wolfe also provided an overview of the American Academy of Sleep Medicine best practice guidelines for sleep center adjustment of non-invasive positive pressure ventilation (Berry and others 2010). These guidelines cover in detail areas such as careful mask fitting, acclimatisation to the NIPPV machine through the use of an initial low pressure and recommendations for the setting of the equipment.

#### References

- Berry RB, Chediak A, Brown LK, Finder J, Gozal D, Iber C, Kushida CA, Morgenthaler T, Rowley JA, Davidson-Ward SL, NPPVTTF of the American Academy of Sleep Medicine 2010. Best clinical practices for the sleep center adjustment of noninvasive positive pressure ventilation (NPPV) in stable chronic alveolar hypoventilation syndromes, *J Clin Sleep Med* 6(5), 491-509.
- Just N, Bautin N, Danel-Brunaud V, Debroucker V, Matran R, Perez T 2010. The Borg dyspnoea score: a relevant clinical marker of inspiratory muscle weakness in amyotrophic lateral sclerosis, *Eur Respir J* 35(2), 353-360.
- Lou, JS, Moore D, Gordon PH, Miller R 2010. Correlates of quality of life in ALS: Lessons from the minocycline study, *Amyotroph Lateral Scler* 11(1-2), 116-121.
- Wolfe L 2010. 6th Annual ALS/MND Nursing Mini-Symposium, Orlando, Florida, 10 December. Full text online with audio - follow the link at [www.mndcare.net.au](http://www.mndcare.net.au)

## 21st International Symposium on ALS/MND (cont'd)

### The Cochrane Collaboration - Neuromuscular Disease Group



#### THE COCHRANE COLLABORATION®

The Cochrane Collaboration is an international, independent, not-for-profit organisation of over 28,000 contributors from more than 100 countries. These contributors work together to produce systematic reviews of healthcare interventions, known as Cochrane reviews, which are published online in The Cochrane Library. Cochrane reviews are intended to help providers, practitioners and patients make informed decisions about health care, and are the most comprehensive, reliable and relevant source of evidence on which to base these decisions.

Cochrane Reviews are systematic studies of good quality research, designed to allow conclusions to be made about an effect, lack of effect or adverse effect of a health treatment or intervention. For example the Cochrane review on riluzole (Miller and others 2009), examined the evidence from four randomised clinical trials involving 1477 patients with amyotrophic lateral sclerosis and found that patients taking riluzole probably survive longer than patients taking placebo. By pulling all the evidence together, they also found that adverse effects from riluzole are relatively minor.

Through Cochrane reviews, providers, practitioners and patients can easily identify treatments that:

- are likely to do more good than harm
- are likely to do more harm than good
- need more research before they can be determined as effective, ineffective and/or harmful.

A finding in a Cochrane review that more research is needed before it can be determined if a particular treatment is effective, ineffective and/or harmful does not mean the review was a waste of time. It is these reviews that highlight to governments, funders and health researchers the areas which should be given research funding priority.

The Cochrane Neuromuscular Disease Group looks after all Cochrane Reviews relating to treatment of MND/ALS. The group met at a satellite meeting of the International Symposium on ALS/MND in Orlando, Florida on 12 December 2010. The Group editor for MND/ALS is Dr. Robert Miller, of the California Pacific Medical Center and the Forbes-Norris MDA/ALS Research and Treatment Center (San Francisco, USA). He advised that as at October 2010 there were 15 full systematic reviews published that related to MND/ALS, three further reviews were in editorial process and a further three reviews were ongoing. At the meeting, plans

were made for the preparation of several more reviews.

You can find out more about the Cochrane Collaboration at [www.cochrane.org](http://www.cochrane.org) and access the Cochrane Database of Systematic Reviews at [www.thecochranelibrary.com](http://www.thecochranelibrary.com). Cochrane reviews about MND are also included on the Australian MNDcare website at [www.mndcare.net.au](http://www.mndcare.net.au)

*Miller RG, Mitchell JD, Lyon M, Moore DH 2009. Riluzole for amyotrophic lateral sclerosis (ALS)/motor neuron disease (MND). Cochrane Database Syst Rev(1), CD001447.*

### Hot topics from the Symposium

#### TDP-43

*Extract from article by Robert Goldstein, ALS Therapy Development Institute<sup>1</sup>*

This year's meeting opened with the introduction of Dr. Merle Weinberg, the President of the National Health Council as well as the International Alliance of Health Organizations. Weinberg used her opportunity to open the Symposium by introducing the goals of those two organizations. She encouraged researchers in the room to become involved and described the mission of the Council as striving to get therapeutics "at the right time, to the right patients, in the right place and at the right price." One of the themes from the meeting this year which stood out to me was the inclusion of researchers from other fields of neurodegeneration and disease intervention.

Highlighting this from the beginning was the invitation of a very well-known Alzheimer's researcher, Dr. Virginia Lee of the University of Pennsylvania (Philadelphia, USA), to present the opening remarks on science, specifically on TDP43. Lee was a co-author on a much read report in 2006 which identified the link between TDP-43 mislocalization in both a neurodegenerative disease (ALS) and a form of dementia (FTLD) (Lee et al., 2006). According to Dr. Lee, TDP-43 is an RNA binding protein, but beyond that researchers know little about its specific function in the body. However, she reported the mislocalization or aggregation of TDP-43 in the cytoplasm is a common pathology associated with a spectrum of diseases, including frontotemporal lobar dementia (FTLD) and amyotrophic lateral sclerosis (ALS). FTLD is the second most common form of dementia among people in the US under the age of 65. In addition, it is known that 30% of FTLD is caused directly through a mutation in the expression of TDP-43 (familial FTLD). Lee reminded us that TDP43 pathology is thought to be present



*International  
Ask the  
Experts  
at the 22nd  
International  
Symposium on  
ALS/MND  
Sydney  
28 November  
2011*



## 21st International Symposium on ALS/MND (cont'd)

in at least 90% of all ALS cases – sporadic and familial. According to Lee, her work suggests that RNA processing may, in fact, be a primary cause of ALS. Lee closed her plenary by suggesting that FTLN-TDP43 and ALS are syndrome variants of a clinicopathological spectrum of the same neurodegenerative disease.

### Vallicin-Containing Protein (VCP)

*Extract from article by Kelly Johnstone, MND Association UK<sup>2</sup>*

Dr Bryan Traynor, who is a genetic researcher based at the National Institute for Health, Maryland, USA... described his recent findings. The gene is called VCP, which stands for 'Vallicin-Containing Protein'. It was first discovered by Bryan's group in a family affected by inherited (familial) MND and was soon verified as a cause of the disease for other people with familial MND. They speculate that VCP is the cause of MND for 2% of cases of familial MND. For more information on what this finding means to people affected by MND, please read our press release on our website.

Through Bryan's talk, we also heard that this particular gene is found on chromosome 9. A chromosome is an organisational structure for our genetic code – as humans, we have 23 pairs numbered 1 to 22 with the final pair being the sex chromosomes (XX or XY). The news that VCP is on chromosome 9 is an interesting one given that earlier this year a study, led by Prof Ammar Al-Chalabi – an MND Association funded researcher, at King's College London found a region of DNA within chromosome 9 that contains three genes that may be associated with the randomly occurring sporadic form of MND; a condition called 'fronto-temporal dementia' (FTD) that affects behaviour, emotional response and language skills; as well as a rare inherited form of MND called MND-FTD.

However, it is important to note that the genetic regions are not the same, they are just found on the same 'street' of the chromosome.

### Glia

*Extract from article by Belinda Cupid, MND Association UK<sup>2</sup>*

MND isn't just about motor neurones going wrong in an otherwise perfectly functioning nervous system. A group of cells called glia, which surround motor neurones and normally provide them with support and nourishment, can dysfunction too. It's likely that they even hold most of the cards when it comes to determining how MND progresses, so they're not to be overlooked. Don Cleveland, opened this session with an overview of how each type of glial cell contributes to the cause of MND. He concluded this part of his talk by

saying that the toxicity within different cell types come together to kill motor neurones. Work has now begun on the development of therapies utilizing what we know about these support cells, including plans for an early safety study (phase 1) of a stem cell astrocyte therapy in 2014.

### Studying the risk of developing MND

*Extract from article by Kelly Johnstone, MND Association UK<sup>2</sup>*

The study of environmental and lifestyle factors that may predispose people to disease is known as epidemiology. Sporadic MND is thought to result from the cumulative effects of numerous risk factors, in people whose overall genetic make-up makes their motor neurones particularly vulnerable to damage.

The trouble is, identifying these factors with any certainty is extremely difficult. Ettore Beghi from Milan discussed why studies that aim to assess environmental and lifestyle contributors consistently fail to generate conclusive evidence. For instance, studies on heavy metal exposure, diet, head trauma and statin<sup>3</sup> use were concluded as not having enough reliable evidence to suggest a possible risk. He did however note, that it is unlikely that statin use increases the risk of somebody developing MND as he said that "despite a 10 fold increase in statin use (in recent years), there has not been the same pattern for cases of ALS".

He also suggested that researchers need to bear certain key considerations in mind when designing epidemiological studies, including how they select their study participants and how they should be unbiased when defining the risk factors themselves.

### References/Notes

1. 21st International Symposium on ALS/MND - Day 1 Recap by ALS Association (USA) at [www.als.net/News/Article.aspx?id=5381](http://www.als.net/News/Article.aspx?id=5381)
2. Short updates from various sessions written by MND Association (UK) ) at [www.mndassociation.org/research/for\\_researchers/international\\_symposium/21st\\_international\\_symposium\\_on\\_alsmnd/my\\_symposium/index.html](http://www.mndassociation.org/research/for_researchers/international_symposium/21st_international_symposium_on_alsmnd/my_symposium/index.html)
3. cholesterol lowering medications

### Other sites of interest

- International ALS/MND Meetings 2010 - Overview from Carol Birks MND Australia* <http://www.mndaust.asn.au/news/international-als-mnd-meetings-2010-overview-from-mnd-australia/>
- 21st International Symposium on ALS/MND Symposium abstracts at [www.mndassociation.org/research/for\\_researchers/international\\_symposium/21st\\_international\\_symposium\\_on\\_alsmnd/abstract\\_book\\_2010.html](http://www.mndassociation.org/research/for_researchers/international_symposium/21st_international_symposium_on_alsmnd/abstract_book_2010.html)
- 21st International Symposium on ALS/MND - Days 2 and 3 Recap ALS Association (USA) at [www.als.net/News/Article.aspx?id=5382](http://www.als.net/News/Article.aspx?id=5382)

*If you not have internet access and would like a print copy of articles referred to in Forum contact the MND NSW Info Line ph. 1800 777 175*

## Noticeboard

### Australian Motor Neurone Disease Registry



The Australian Motor Neurone Disease Registry (AMNDR) was established

in 2004 to collect data about people diagnosed with MND in Australia. It is a way for people diagnosed with MND in Australia to actively contribute to research.

AMNDR is a clinical database that provides a means to facilitate the collection and analysis of MND patient data such as demographics, site of onset, diagnosis data, treatment type, changes in functional capacity, complications related to disease progression and the impact of new treatments and interventions for MND. The goals of the registry are to improve patient care and to form significant scientific research collaborations with organisations and individuals to further the understanding of MND.

Most people who wish to be involved in AMNDR are registered by neurologists associated with MND multidisciplinary clinics. Registrations can, however, be made by individual neurologists.

If you are not registered with AMNDR and would like to contribute to this valuable research please talk to your neurologist. If you have registered but have since moved and been referred to another neurologist please make sure he or she knows that you are registered so that they can continue to provide updates on your condition to AMNDR.

#### Latest News

Recruitment continues and to date 1067 people have been registered (NSW 418, Vic 361, Qld 202, WA 59, SA 34, Act 4, NT 1). The steering committee meets annually and consists of neurologists from most states, and MND Australia. The committee is currently looking into how to increase registrations overall and in Tasmania in particular. The registry has already provided a lot of valuable information on phenotypes (the different types of MND), region of onset, age and gender distributions and survival associated with the different phenotypes. The steering committee is currently developing papers on end-of-life issues and the clinical phenotypes of MND. If you would like more information on AMNDR please talk to your Regional Advisor or visit [www.amndr.org](http://www.amndr.org)

#### Carer Life Course



This new Australian online resource identifies six phases of caring that most carers go through, and provides information, support and resources for carers. Developed for carers by Carers NSW, the Carer Life Course can help break down common feelings of isolation and fear by providing a map of what other carers have gone through. Visit [www.carerlifecourse.org.au](http://www.carerlifecourse.org.au).

### ALS Untangled



People with motor neurone disease (known as amyotrophic lateral

sclerosis or ALS in some parts of the world) often consider alternative treatments, based on information gleaned from the internet. These can be expensive and some are potentially harmful. Moreover, the evidence presented for the efficacy and safety of these treatments is often sketchy and frequently inaccurate.

ALS untangled investigates these alternative treatments. Goals for each investigation are to clarify exactly what is on offer, how much it costs, the scientific and ethical basis of the treatment, and the potential benefits and risks. Reports from ALS untangled provide timely, accurate and scientifically valid analysis of alternative treatments. They are prepared by clinical scientists who are members of the World Federation of Neurology Research Group on MND or the International ALS Research Group.

To date, investigations produced ALS untangled include:

- *Lyme Disease and Iplex*
- *Investigating The Hickey Wellness Center*
- *Investigating stem cell transplants at the Hospital San Jose Tecnologico de*
- *Investigating the XCell-Center*
- *Investigating the Stowe/Morales ALS Protocol*
- *Investigating Marty Murray's Method*
- *Hyperimmune Goat Serum for ALS*
- *Low dose naltrexone for ALS*
- *Blue-green algae (Spirulina) as a treatment for ALS*

Open investigations include:

- *Even Better Now*
- *Stem Cell Rejuvenation Center*
- *Ampyra, Ursodiol, Nepsis, Methylcobalamin*
- *Brainstorm-cell*
- *Dr. Geeta Shroff at Nu Tech Mediworld in India*
- *Perlmutter Clinic in Naples Florida*
- *IV Glutathione*
- *Stem Cells via TCA Cellular, Stem Cells at Cell Medicine*
- *Dr. Zhu Ming at Huaihua Red Cross Hospital*
- *Beike Clinic*
- *Curious Case of Dr. Martz*
- *Regenocyte Clinic run by Dr. Grekos*
- *Eric is Winning (diet)*
- *Dr. Zannos Grekos Stem Cell Clinic*
- *Equilibrium Therapy*
- *The Bronx Project*
- *International Center for Cell Therapy and Cancer Immunotherapy*
- *The Healing Code Solution*
- *BuNaoGao (BNG)*
- *Dean Kraft*
- *Dr. Shahriar Vaziritabar*

View the reports at [www.alsuntangled.com](http://www.alsuntangled.com), where you can also register alternative treatments for investigation.

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*Order your MND Week merchandise today. Contact Anne Jones ph. 8877 0999 for more information.*

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## Noticeboard

### Every Australian Counts



NDIS | Revolutionising disability services

Every Australian Counts is the campaign for the introduction of a National Disability Insurance Scheme. The NDIS will revolutionise the way people with a disability, their families and carers are supported in this

country. The NDIS will be a new support system for people with a disability, their families and carers. It will transform the way services are funded and delivered, ensuring people are better supported and enabling them to have greater choice and control.

Over the next few months the Productivity Commission will report to the Government on the findings of its inquiry into a long-term disability care and support scheme.

We need every Australian to stand up and say that people with a disability, their families and carers in this country deserve better and that it's time for change. We need every Australian to say that people with a disability, their families and carers are Australians too, and that their hopes and dreams count.

We need to show the government that there is widespread community support for change – and that the time for action has come. You can support the campaign, by taking action to make every Australian count. Visit <http://everyaustraliancounts.com.au> or ask your MND NSW Regional Advisor for more information.

### Fellowships for research into spinal cord injury and other neurological conditions including MND

NSW researchers are being encouraged to apply for a share of \$1.2 million in funded fellowships available to undertake research into spinal cord injury and related neurological conditions, including the Paul Brock Fellowship for Cross Disciplinary Research which will support research projects that will inform research outcomes in related neurological conditions such as Motor Neurone Disease and Parkinson's Disease. The Fellowships are part of the NSW Government's Spinal Cord Injury and Related Neurological Conditions Research Grants Program, established in 2003 following a visit to Sydney by the late Christopher Reeve. Medical researchers, graduates, nurses and other allied health professionals with an appropriate doctorate or post doctorate degree are encouraged to apply for the fellowships. Fellowship applications close on 31 March 2011. For more information see [www.business.nsw.gov.au/innovation-and-research](http://www.business.nsw.gov.au/innovation-and-research)

### MND Cooks



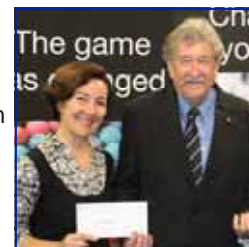
In 2009 we sought your contributions for a recipe book - MND Cooks.

We didn't receive enough recipes to go to print, but have published those we did receive on the MND NSW website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au). You can contribute your recipe for web publication - just send in your recipe, photo and several lines about why the recipe is important to you to [info@mndnsw.asn.au](mailto:info@mndnsw.asn.au) or by mail to Penny Waterson, MND NSW Locked Bag 5005 Gladesville NSW 1675.

## Community Events

### Bowled over by Royal NSW Bowling Association

The Royal NSW Bowling Association recently held a funds distribution event and MND NSW were invited to meet their board members. It was a lovely event and representatives from the chosen charities were each presented with a cheque. MND NSW would like to thank Royal NSW Bowling Association for their donation.



*Ayse Dalkic, MND NSW, with Ian McKnight, State President of the Royal NSW Bowling Association*

### Rotary Club of Carlingford

In January the Rotary Club of Carlingford Inc. held a Robbie Burns evening, celebrating the birthday of the Scottish poet. At this event, a donation for MND NSW was presented to Ayse Dalkic by Carlingford Rotary Club President 2010-11 Pamela Lawrance and Community Service Director Norrie Boorman. MND NSW is grateful for the continued support of Carlingford Rotary who also supplied and operated the yummy barbeque for the 2010 Walk to d'Feet MND.



*Pamela Lawrance (left) and Norrie Boorman of Rotary Club of Carlingford President with and Ayse Dalkic, MND NSW (centre)*

*The NSW Electoral Commission has a new online and telephone voting system, called iVote, for people with a disability. Register by 23 March. Ph. 1300 248 683*

## Dates for the Diary

18 March	<b>5th MonSTAR Cup</b>   Pennant Hills Golf Club, Pennant Hills   For more details contact Amanda Stubbs ph. 0416 112 085
19 March	<b>Tas Run Motorcycle Ride</b>   Wagga Wagga   Contact Wagga Wagga Motorcycles ph. 6922 7777
10 April	<b>MND Cycle Race</b>   Fun 100kms or 50kms - Windsor to Wiseman's Ferry and return   Contact Gemma Cooney ph. 0411 160 700 or gemma.cooney@dhs.nsw.gov.au
14 May	<b>MND Trivia Night</b>   Trivia, auctions and raffle at Warilla Bowling Club   Contact Annamaree Gasparri djaspo69@spin.net.au
14 June	<b>Charity Golf Day</b>   NSW Golf Course   Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
19 June	<b>Walk to d'Feet MND Canberra</b>   5km Walk around the lovely Lake Burley Griffin   Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
3-11 September	<b>Larapinta Trek</b>   7 day walking trek along the Larapinta Trail in Central Australia   Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
25 September - 10 October	<b>China Bike Trek</b>   10 day cycle trek through Shangri-La China   Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
6 November	<b>Walk to d'Feet MND Sydney</b>   5km walk Sydney Olympic Park   Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au

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

### Don't miss out!

**MonSTAR Cup**  
Friday 18 March 2011  
Pennant Hills Golf Club  
[www.monstarfoundation.com.au](http://www.monstarfoundation.com.au)

For the keen golfers we have the annual Monstar Cup at the lovely Pennant Hills Golf Course. The Monstar Cup will be held on Friday 18 March. There are still some spots available for the morning field so don't miss out on enjoying a great day of golf. Go to [www.monstarfoundation.com.au](http://www.monstarfoundation.com.au) for further details.



The NSW Golf Course is rated in **the top 50 golf courses** in the world. The character of the course is unique, a links style course set amongst the hills and valleys that hug the rugged Pacific Ocean coastline boasting magnificent ocean views as backdrop. Few layouts can offer such a diverse range of challenges over the course of a single round; even fewer can change so dramatically according to the vagaries of the weather.

On Tuesday 14 June we have a very special Golf Day at the wonderful **NSW Golf Course at La Perouse**. Surrounded by national parklands, NSW Golf Club is located at Cape Banks on the northern headland of Botany Bay approximately 20 minutes from the Sydney CBD.

The day will feature 18 holes of golf, and food and drinks in the magnificent club house with entertainment, auction items and silent auction items. Numbers are limited. We have some great sponsorship packages available.

Contact Kym Nielsen at [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au) for further details.



The desert landscape of the Larapinta

Join the 7 day **Larapinta Trek** for MND or the 10 day **China Bike Trek** for MND. See insert in this edition of *Forum* for more information.



Yunnan suspension bridge, Shangri-La China

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

Editor: Penny Waterson