



FORUM

MND Week 2013

5 to 11 May

MND Week is just around the corner and we are looking for your help so we can make this the biggest MND Week yet. There are lots of ways for you to become involved. You could:

- organise an event
- organise a *Drink tea for MND* at your office or with friends
- sell merchandise at a railway station, your local shopping centre, your work or sporting club

Authorities are required for all of the above activities so for more information contact Anne Jones, MND NSW Fundraising Assistant, ph. 02 8877 0999 or annej@mndnsw.asn.au



A Message from the CEO

We are well in to 2013 and 'flat chat'. Our information evenings are already bursting at the seams and we have been able to clear up backlogs in equipment loans thanks to funding from NSW Ageing, Disability and Home Care.

The trial sites for the National Disability Insurance Scheme (NDIS) kick off in July and you can get all the information and updates from the NDIS at www.ndis.gov.au. There is still a long way to go to ensure that the NDIS does become available to all Australians and I encourage you, your family and friends to go to the Every Australian Counts website, everyaustraliancounts.com.au and make sure you have registered your support. In an election year it becomes all the more important to ensure bipartisan support.

MND Week is Sunday 5 May to Saturday 11 May and a variety of events are planned across the ACT and NSW. Our annual Day of Hope and Remembrance will be held on Saturday 11 May at Sydney Olympic Park, full details can be found on page 2. For up-to-date information on community events in your area see www.mndnsw.asn.au.

We have been working with the NSW state government on our equipment loan pool and the increasing costs involved. Last year our loan pool cost over \$500,000 to run and we loaned over \$1.6million worth of equipment, free of charge. Soon we will be contacting members who have had items of equipment for over 12 months who will need this equipment for longer, asking them, with the help of their occupational therapist, to apply through EnableNSW (the NSW government equipment service) for the supply of this equipment.

Once equipment has been supplied by EnableNSW we will retrieve our equipment so it can be loaned to other MND NSW members. The equipment you currently have from MND NSW will NOT be retrieved until Enable NSW has delivered their equipment. Our priority has always been and will always be to ensure that no one in NSW or the ACT with MND goes without short to medium term essential equipment supplied in a rapidly responsive manner.

Our two new regional advisors, Deb and Lisa, have settled in well and with this increase in RAs the workload for our other regional advisors has decreased from massive to slightly less than massive. Lisa's base is at our new Penrith office, sharing with Multiple Sclerosis Limited.

Our ability to increase the number of equipment and regional advisor services, particularly in regional areas, has come about because of increased community support and fundraising events. 80% of our recurrent funding comes from donations and event fundraising. From March this year we will have five Walks to d'Feet MND in what seems like every corner of the globe. Stay tuned to mndnsw.asn.au for information about these and other fundraising events for 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



A long-time supporter of MND NSW, **Snap Printing North Ryde** is offering to donate 10% from all print jobs when MND NSW is mentioned. For total printing referrals over \$20,000 annually Snap will donate 15%. Simply mention the Motor Neurone Disease Association of NSW when placing your order. All money received will help enhance our equipment, regional advisor services and research.

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, your family and your friends are warmly invited to



Day of Hope and Remembrance

Saturday 11 May 2013

1.30pm 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 2013 is **Assoc Prof Ian Blair**, from the Australian School of Advanced Medicine at Macquarie University, who will speak about hope for the future of MND research.

This will be followed by a candle lighting ceremony to represent the hopes of people affected by MND and to remember those who have lost their life to MND.

The MND March of Faces banners will also be on display.

Afternoon tea and light refreshments will be served. **Please RSVP by ph. 02 8877 0999, Freecall 1800 777 175 or reg@mndnsw.asn.au by Tuesday 7 May.** The venue is near public transport and offers free parking and disability parking.



Getting involved and helping MND NSW raise much needed funds and awareness is easy through our *Drink Tea for MND* campaign.

Contact MND NSW now for your Drink Tea for MND information pack and registration form ph. 8877 0999 or fundraising@mndnsw.asn.au



Blue Cornflower Day
Luncheon Cruise
10 May 2013



4 hr luncheon cruise on Sydney Harbour aboard Captain Cook Matilda 3
\$90 per person includes canapés, buffet lunch, and Tyrells wines, beer, sparkling wines and soft drinks. This is a private charter for MND and numbers are limited. Invite your friends and register at www.online.mndnsw.asn.au or contact Anne Jones, MND NSW ph. 8877 0999 or annej@mndnsw.asn.au



318 people and 35 dogs @
Walk to d'Feet MND Illawarra
on 25 February 2013 raising \$30,990 for MND

Motor Neurone Disease Association of New South Wales

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Equipment Service Coordinator

Maree Hibbert

Equipment Assistants / Support Officer

Tom Giardina, Michael Walker / Ellen Hibbert

Information Resources Coordinator

Penny Waterson

And...many valued volunteers

including Rod Nielsen selling MND merchandise at Walk to d'Feet MND



Family Support Team

Having recently attended the National Disability Services State Conference with the aim of trying to keep abreast of changes that are occurring in service provision, I started to reflect on just how complex our care system is and just how confusing it can be for people who need the support of these services. It started me thinking about the role of our family support team in helping people to navigate this complex system and I just wanted to remind all our members and their families that we are here to help you make some sense of these services.

MND NSW is committed to supporting our members and their families through this system. It can feel at times like trying to find your way through a maze, but once you can understand what is available and what can assist you, these services can be invaluable to you and your family. So we really want to help you to understand how it works. We do this in a number of different ways including:

- *Regional advisors...* Although they are not case managers and aren't able to be in constant contact they do understand MND and the support that may be available and are there, sometimes in the background, but available to help you to work out what it is that you might need to assist you on a day-to-day basis. They also help the service system understand MND by providing them with education about MND. So please contact your regional advisor if you have any questions about services and supports.
- *MND NSW Info Line...* If you are unable to contact your regional advisor then you are welcome to ring our information line. Usually you will talk to David Wallace, but at times you may also hear my voice or one of our other family support staff members. We are also able to answer your questions or help you to sort out what it is that you might need to assist you at any point in time.
- *Information Evenings for people recently diagnosed with MND, their family and friends...* These evenings are a good introductory session to attend to find out more about MND, our Association and the services and supports that are available from us and also from service providers. They are held every two months. Contact David on our Info Line for further information.
- *Education programs such as Learn Now, Live Well and Care for Carers...* These programs are designed to provide you with information about what's

available and what might assist. The first such program for the year will be held in May - *Care for Carers*. It is never too early to attend this informative and enjoyable program, which enables carers to hear from a range of allied health professionals with expertise in MND. Previous participants in this program have told us that they found the practical knowledge they gained from attending this program gave them much greater confidence in their capacity to care for others. Another valued aspect of *Care for Carers* is the opportunity to meet others who have a family member, partner or friend with MND and some lasting friendships have been forged as a result. Registrations are now open for our *Care for Carers* program to be held in May, so please contact our Info Line if you would like to attend.

Another role of MND NSW is advocating for service improvements so that service providers better meet the needs of people with MND. This includes advocacy at a very local level, where a regional advisor may assist you by speaking to a service and explaining about MND, through to discussions with federal and state government services.

We are always happy to receive your feedback about how the service system is working for you. One area that we are currently interested in hearing about is people's experiences of accessing EnableNSW services. EnableNSW is the equipment service provided by the NSW Government. As some of our members are currently accessing or will be accessing this service we would appreciate any feedback about your experience. This includes the provision of non-invasive ventilation such as BiPap and CPap machines. We are encouraging our members to apply through EnableNSW for this equipment as it is not provided through our current equipment loan service, although we do offer a subsidy for anyone who does have to hire one of these machines. Please send any feedback to me by email ginas@mndnsw.asn.au or if you prefer, contact me at the MND NSW Centre at Gladesville ph. 02 8877 0999 or 1800 777 175.

We farewelled Gail Ferguson, Regional Advisor for ACT and southern NSW, on 20 February. We wish her all the best and thank her for her work with people with MND. We have advertised this position and hope to recruit as soon as possible.

Gina Svolos

Manager, Family Support

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

MND NSW cruise with Sailors with disAbility Sunday 7 April

Enjoy some time out on Sydney Harbour on this 3 hour cruise with the friendly volunteer sailors. This event has been popular in the past, is wheelchair accessible and numbers are limited to 12 people. MND NSW staff will sail with you on the day to assist. There is no charge to attend so if you are interested, contact the MND NSW Info Line 1800 777 175 or 8877 0999 to book your spots.



Family Support Team (cont'd)

Equipment

During the past 12 months MND NSW has received 1708 referrals for equipment and we have been able to loan 1482 items to our members. This is an increase of 15% and 22% respectively on the previous year's referrals and loans. Some of the key items loaned include:

- 124 cushions - gel and Roho
- 114 manual wheelchairs - self propelling, transit and tilt in space
- 90 mattress overlays - alternating air and Roho
- 80 shower commodes
- 67 raiser recliner armchairs
- 66 electrical beds
- 58 hoists
- 51 powered wheelchairs
- 32 Lightwriters
- 27 Headmaster Collars

Since July 2012 we have also loaned 23 iPads preloaded with communication Apps to members.

Additionally, 17 health professionals have used our HP Trial iPads with preloaded communication Apps for short term loan to assist in assessment of their MND clients.

Loans of equipment to our members are made on a priority of need basis and not on the date the equipment referral has been made. For members who are waiting for equipment through our service, it is very important that you let your regional advisor know if you have had a change in need for that equipment. This information assists us to make decisions when there are waitlists for certain items of equipment and limited stock available.

Purchases of equipment for inclusion in the MND NSW Equipment Loan Service would not be possible without the continued financial support of the community. Thank you.

Maree Hibbert
Equipment Services Coordinator

Support group meeting dates are at www.mndnsw.asn.au or contact the MND Info Line 1800 777 175

Were you bereaved in 2012 after caring for someone with MND?

MND NSW likes to acknowledge those who have cared for someone with MND. One of the ways that we do this is through hosting a lunch for our bereaved carers and family twice a year at the MND NSW Centre at Gladesville. The next lunch is on **25 March** and it will provide an opportunity for you to reconnect with old friends from MND NSW and to meet others who have had similar experiences. After lunch there will be a short talk and discussion about some of the experiences you may be facing through bereavement. If you have not yet had an opportunity to attend one of these lunches and have cared for someone with MND during the last 12 months, RSVP by Thursday 21 March ph. 8877 0999 or reg@mndnsw.asn.au

Family Support Calendar 2013

25 Mar	Lunch for bereaved carers Gladesville
27 Mar	Hope and Remembrance Gathering Tamworth
7 Apr	Sailors with disability MND NSW cruise Sydney Harbour
16 Apr	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
11 May	Day of Hope and Remembrance Sydney Olympic Park
13, 20, 27 May and 3 Jun	Care for Carers Gladesville To enable you to care for a person with MND at home, while still taking care of yourself.
18 Jun	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
22 July	Ask the Experts West Ryde You, family members, carers and friends can bring your questions about MND and have them answered
20 Aug	Information Evening for people recently diagnosed with MND, their family and friends Gladesville

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.

Mailbag

From **John** "I was diagnosed in 2004 and have the flail arm type MND. I thought you might like this - this is my first experience on a Jetski. It was fantastic and I cannot wait to go again. I encourage all 'MND people' to try something different, always think positive, never give up and to set yourself goals."



On 27 January **Dawn and Albert** Davies celebrated 50 years of marriage by renewing their vows. A close friend, Brother Bruce Paul, officiated together with another great friend, Reverend Lu Piper. Dawn and Alby's daughter and son stood beside them on the big day, and it was absolutely perfect, with many tears. Alby was diagnosed with MND about four years ago. He says that the support they received from MND NSW and the other local services has been second to none and they are very grateful. "When you have a disease such as this, it completely changes not only your life but the lives of everyone around you, especially your spouse. But you must continue to fight to the best of your capability".



Write to the
Editor of Forum
MND NSW
Locked Bag
5005
Gladesville
1675 or email
info@mndnsw.
asn.au

Care for Carers

13, 20, 27 May and 3 June
MND NSW Centre Gladesville

**ARE YOU A FAMILY MEMBER, RELATIVE, OR
FRIEND CARING FOR SOMEONE WITH
MOTOR NEURONE DISEASE?**

This program runs from 10am to 3pm over four consecutive Mondays at the MND NSW Centre at Gladesville.

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.

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.

A complimentary lunch and morning tea is provided each day. There is no cost to attend, but we do ask that you be willing to commit to attending all sessions. If you have any questions or need support with travel or arranging care for your family member, please contact the MND NSW Info Line ph. 1800 777 175 or speak to your regional advisor. Places are limited, so RSVP by 29 April by ph. 8877 0999 or 1800 777 175, or to reg@mndnsw.asn.au

Support Groups

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

Campbelltown - *Ann McCutcheon* | annm@mndnsw.asn.au

Gladesville - *Caroline Gleig* | carolineg@mndnsw.asn.au

Liverpool - *Ann McCutcheon* | annm@mndnsw.asn.au

Northern Beaches (Mona Vale) - *Jo Fowler* | josephinef@mndnsw.asn.au

Northern Sydney (Hornsby) - *Jo Fowler* | josephinef@mndnsw.asn.au

Western Sydney - *Lisa Dowling* | lisad@mndnsw.asn.au

REGIONAL AND RURAL

ACT and Southern NSW - Contact MND NSW ph. 1800 777 175 for more information

Central Coast - *Audree Dash* | 4384 2907 or *Deb Ward* | 1800 777 175 | debw@mndnsw.asn.au

Central West - MND NSW Info Line | 1800 777 175 | davidw@mndnsw.asn.au

Griffith and Region - Contact MND NSW ph. 1800 777 175 for more information

Illawarra - *Ann McCutcheon* | 1800 777 175 | annm@mndnsw.asn.au

Muswellbrook (Upper Hunter) - *Kim Sinclair* | 4985 5022 | kims@mndnsw.asn.au

Newcastle and Hunter - *Eileen O'Loughlen* | 4921 4157 | eileeno@mndnsw.asn.au or
Kim Sinclair | 4985 5022 | kims@mndnsw.asn.au

North West (Tamworth) - *Kim Sinclair* | 4985 5022 | kims@mndnsw.asn.au

Port Macquarie - *Eileen O'Loughlen* | 4921 4157 | eileeno@mndnsw.asn.au

Gold Coast Carers - *Chris Carroll* | 0421 252 455 | chrisc@mndnsw.asn.au

International ALS/MND Meetings 2012 Chicago, USA

The global MND community met in Chicago from 2 to 7 December 2012 for the annual International ALS/MND Meetings organised each year by the MND Association of England, Northern Ireland and Wales and hosted by a member of the International Alliance of ALS/MND Associations. Experts from research and medical communities as well as MND association members, and people living with MND come together each year with the common goal to improve the lives of people touched by MND.

The Symposium is preceded by the International Alliance annual meeting, an Ask the Experts session and the Allied Professionals Forum. Carol Birks, National Executive Director, MND Australia; Kristina Dodds, Education and Carer Support Coordinator, MND NSW; and Dr Bradley Turner, The Florey Institute, Victoria have provided these updates from the meetings.

20th Meeting of the International Alliance of ALS/MND Associations 2-3 December 2012

by Carol Birks - MND Australia

The International Alliance welcomed new delegates from Russia and Latvia who expressed the camaraderie and warmth they felt in joining the Alliance.

The 50 delegates from 18 countries shared initiatives and developed strategies for fighting ALS/MND. The meeting program was interesting and varied covering topics such as 'Promoting research to your membership', 'Partnerships and Cooperation', 'Supporting family members of people living with ALS/MND' and 'Incorporating people living with ALS/MND into advocacy, education, fundraising and funding decisions'.

Carol Birks provided an update on the progress of the MND Australia Asia Pacific outreach program and partnership with the China ALS committee.

Kathy Mitchell (Canada) highlighted the role of the Alliance as the bridge between countries and ALS/MND organisations worldwide and confirmed the need to set flexible goals and be culturally aware when developing outreach programs and partnerships.

Ask the Experts 3 December 2012

by Kristina Dodds - MND NSW

I was very privileged to be able to attend the International Symposium, representing MND NSW and presenting at the Allied Professional Forum, the day before the Symposium, on the MND Aware online and face-to-face training for frontline staff. One of the highlights of being in Chicago was to attend 'Ask the Experts' (ATE) which is held each year in conjunction with the International ALS/MND Symposium. It is an opportunity for people living with ALS/MND, their family and friends to ask international experts about the latest developments in ALS/MND research and care. The theme for ATE this time around was respiratory care in ALS/MND. I will give an overview of what was presented by each of the four speakers.

Brian Dickie, PhD. Director, Research and Development, MND Association, UK spoke about 'Research today – implications for tomorrow'. He said there is still much to do to make genuine

progress in the path to developing treatments, in particular to find the remaining causes of ALS and the genetic factors that underpin the disease. New laboratory models, that more faithfully reflect 'real world' events occurring in the patient, need to be generated. Also, the speed of diagnosis needs to be improved to predict disease progression more effectively. He stressed the need for closer international collaboration.

Dr Dickie also spoke about stem cells that can now be made from skin cells and they have been able to reduce the effect of TDP43 and the aggregates that it forms in the cells. There has also been interesting research with zebra fish that contain the SOD1 gene and a coral gene that glows in the dark, so that when the cells become sick those cells start to glow and this seems to happen very early in the life of the fish. Scientists are able to measure how drugs such as riluzole reduce the glow.

Dr Dickie spoke of ALS/MND as a multifactorial disease, something tips the balance in favour of the disease. What moves the scales? Age, gender, susceptibility and environment? Dr Dickie also made the point that we also need to start identifying the protective factors that slow down the progression of the disease in some people.

Noah Lechtzin, MD, MHA, Associate Professor of Medicine, Johns Hopkins University spoke about 'Diaphragm pacing in ALS'. Diaphragm pacing has now received FDA approval in the USA because it is considered a safe procedure and there could be probable benefit. However, there are no definitive answers as to whether it works or not and more research is needed. Diaphragm thickness measurements are encouraging but it is not a cure to respiratory muscle problems in ALS and controlled studies are lacking

Pamela J Shaw, MBBS, MD, FRCP, Professor of Neurology and Head of Neuroscience Department, University of Sheffield, England spoke about 'Ventilation in ALS – where we are and where we are going?'. Non-invasive ventilation (NIV) is a way of improving symptoms arising from weaknesses of breathing muscles and is, generally, well tolerated by patients. Studies have proved that NIV increases life expectancy and improves quality of life,

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Put it in your diary

Ask the Experts
2013

West Ryde
22 July

International ALS/MND Meetings 2012 Chicago, USA (cont'd)

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especially if the patient has a strong bulbar function. NIV assists respiratory muscles by improving levels of O₂ and CO₂ in the blood and helps to prevent collapse of the small airways at the lung base. NIV is a standard treatment in ALS. Further research is now taking place to investigate the:

- best way of detecting weakness of the breathing muscles
- best time to start NIV.

She spoke of the TOSCA 500 machine to measure CO₂ in the blood rather than take blood from the radial artery. It is a non-invasive procedure that clips to the earlobe. This is now being used in the UK enabling simple and efficient screening for respiratory failure. Dr Shaw also said that secretion accumulation can cause difficulty for the patient in tolerating NIV. Various strategies can be used to augment the person's ability to cough effectively, including the use of a technique called breath stacking or a cough-assist machine. Trials of these measures are still being conducted to establish whether they prevent or speed recovery from chest infections, reduce hospital admissions, and whether they improve well-being and quality of the life of the patient.

Lisa F Wolfe, MD, Associate Professor in Medicine (Pulmonology), Northwestern University Feinberg School of Medicine spoke about 'Airway Clearance – options and strategies'. Dr Wolfe stressed the importance of airway clearance in preventing and treating respiratory infections using strategies such as:

- using nasal drips and nasal gels, that are saline based, to keep the nasal passages open
- having good oral care and hygiene – important to prevent downstream pneumonia
- airway clearance and saliva – when to use the nebuliser
- chest secretions – cough assist, NIV, oscillation therapy and the importance of body positioning. She suggested that for sleeping, elevate the shoulders, head and neck by 40-45 degrees.

Dr Wolfe also made an excellent point about constipation and that it can reduce the capacity of the lungs and the ability to cough, so it needs to be managed.

You can access the slides and audio from Ask the Experts by following the link at www.mndnsw.asn.au

Allied Professionals Forum 4 December 2012

Carol Birks - MND Australia

The Allied Professionals Forum enables the sharing of ALS/MND care and support innovations to help guide practice worldwide. A record 340 delegates attended to hear 18 presentations covering topics as varied as caring and supporting people touched by MND, palliative care, training for frontline staff and new technologies.

Highlights included the presentations from Beth Stephens and Susan Walsh (USA) on the impact of caregiving. Beth discussed a rapid screening tool developed to guide support and interventions for carers, and to identify those at high risk. Susan presented an intervention program for carers of people with cognitive change.

Kristina Dodds from MND NSW presented the MND Aware workshop program which uses innovative training for health and community workers to augment the MND Aware online training resources.

You can view the slides and audio from the Allied Professionals Forum online by following the link at www.mndnsw.asn.au

23rd International ALS/MND Symposium 5,6,7 December 2012

by Carol Birks - MND Australia

A record 900 delegates attended the joint opening session of the 23rd International ALS/MND Symposium. The Symposium runs concurrent 'scientific' and 'clinical' streams. I attended the clinical stream which included sessions on cognitive change, autonomy and decision making, carer and family support, clinical trials, registers and epidemiology, multidisciplinary management and respiratory support. The session on carer and family support confirmed the need to start the process of working with carers to develop interventions to meet their specific needs from diagnosis onwards. Interventions to support carers should include information actively provided at diagnosis, ongoing empathic emotional support and bereavement support that includes a chance to say goodbye to the care team.

by Dr Bradley Turner - The Florey Institute

The meeting opened with an excellent presentation from Ammar Al-Chalabi (UK) who delved into the mysteries of what causes MND. He proposed that factors determined by nature (genetics), nurture (lifestyle) and chance are all likely involved and therefore inseparable in MND. Although we have a solid handle on genetics and growing suspicion of lifestyle risk factors (smoking and intense exercise were proposed, although still

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*Cruise Sydney
Harbour on
Blue
Cornflower Day
10 May*

*See page 2 for
more
information*

International ALS/MND Meetings 2012 Chicago, USA (cont'd)

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unproven), it is the random nature of MND which is the least understood and most difficult to study. He used an analogy of the Great Fire of London where wooden houses were vulnerable and stone houses were resistant to fire, however the destruction was largely determined by the chance element of wind which helped fan the fire easterly. While we cannot predict or control chance, genes offer us new treatment targets and lifestyle risks suggest certain behaviours we should avoid in MND. Ammar pleased the crowd using incredible real-time animations of genes and the molecular world they encode inside our cells, generated by the Walter Elisa Hall Institute, to emphasise that genes offer real tangible targets for potential intervention studies in MND.

Rosa Rademakers (USA) provided a much anticipated update on the latest genetic player in MND called 'C9ORF72', nicknamed C9. She led the co-discovery of C9 which is the largest genetic defect accounting for around 40% of hereditary MND. While most gene defects result from a single mistake in the genetic code, C9 becomes massively expanded in MND. Rosa outlined a diagnostic test used to detect abnormal C9 in blood which is being rolled out by Quest Diagnostics for MND patients. She also showed that C9 was most abnormal in the brain compared to other organs, consistent with a role in MND. The challenge now is to determine how C9 misbehaves in MND and whether correcting this gene expansion can be beneficial.

The accumulation of misshapen proteins inside nerve cells is a common theme in MND. Kai Ying Soo (VIC) presented new findings that multiple MND genes attack a cell compartment called the 'ER' inside motor neurones which is important for quality control of misshapen proteins. A defective ER causes a backup of proteins inside cells causing 'ER stress'. Excitingly, she boosted ER function and cleared misshapen proteins using a small molecule called 'Rab', offering practical insights into treating ER stress in MND. Neil Cashman (Canada) showed evidence for a spread of misshapen protein pathology in MND, suggesting that the disease can be transmitted between motor neurones by a released 'infectious particle', similar to mad cow disease in people. He presented collaborative work from Justin Yerbury (NSW) and our lab showing an image of the proposed infectious particle using an electron microscope, generating fervent question time and discussion afterwards. Our combined

efforts are now aimed at targeting this infectious particle as a potential treatment approach.

In a session devoted to genetics, Kelly Williams (NSW) presented findings from next generation DNA sequencing of Australian MND patients, allowing her group to pinpoint a novel MND gene – the identity of which is highly anticipated in the Milan meeting perhaps! Jeffrey Rothstein (USA) explored the biology of C9 using 'iPS cells' which are Nobel Prize-winning technology. Motor neurones were 'reprogrammed' from iPS cells isolated from MND patients with abnormal C9 and faithfully reproduced MND pathology in the petri dish. Rothstein then applied 'antisense' technology to C9 whereby the offending gene is switched-off and reversed pathology in motor neurones, generating a very vigorous question time, but perhaps offering a glimpse into the first C9 therapy.

In the poster session, my fellow lab members Bec Sheean, Nirma Perera and I fought off the masses interested in our presented work. Nirma showed new findings implicating a stress molecule called 'AMPK' which is triggered by energy depletion in MND mice. Bec and I performed a double act on twin posters describing a block in cell transport critically involved in protein disposal and

recycling in MND called 'autophagy' that could explain why protein junk piles form in MND. We also perused many other excellent posters on display, providing and receiving insightful feedback and invitations for collaboration.

One of the intriguing aspects of MND is that nerve cells controlling eye movements (oculomotor) are spared, while those affecting limbs are not. The reason for this selective pattern of vulnerable nerve cells is unclear. Georg Haase (France) addressed this question by growing oculomotor and limb nerve cells in the petri dish, revealing that these motor neurones have different shapes and response to added growth factors. Pamela Shaw (UK) continued this theme by genetically profiling oculomotor and limb nerve cells extracted from human tissue for the first time, revealing a wealth of genetic differences. Her main finding was that oculomotor nerve cells were less susceptible to electrical overstimulation (also called excitotoxicity) than limb nerve cells, which may explain why they are spared in MND.

Serge Przedborski (USA) outlined his self-confessed obsessive quest in the last five years to identify the toxic substance released by support cells in MND

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Australian researchers
Bradley Turner and
Justin Yerbury

Would you like
to receive
Forum by
email?
Let us know at
admin@
mndnsw.asn.au

International ALS/MND Meetings 2012 Chicago, USA (cont'd)

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called astrocytes. His lab and others have demonstrated that astrocytes turn rogue in MND and secrete factors that damage nerve cells. By careful process of elimination, Serge identified that a protein called 'DR6' which triggers death of motor neurones is the culprit factor released by astrocytes in MND. This is an exciting development and opens up new treatment approaches aimed at blocking DR6 in MND.

In a closing session dedicated to MND mice, an astonishing number of new and emerging mice were unveiled for the first time. Han-Xiang Deng (USA) presented on genetically engineered mice carrying defects in UBQLN2 linked to MND only last year. These mice develop brain pathology similar to MND and will complement existing MND mice as lab tools to find treatment targets. Remarkably, he continued to present on mice with two other MND genes, OPTN and C9, which are still under scrutiny,

but like the audience I was gasping. Other speakers followed armed with new and improved mice carrying defects in another important MND gene, FUS. Lastly, Catherine Blizzard (TAS) revealed her unique mouse where delivery of a toxin chemically related to MSG at the spinal cord killed nerve cells, while application at the muscle end did not, providing a clear demonstration that MND pathology proceeds from the central nervous system outwards.

In summary, the Chicago meeting provided an unprecedented showcase of translation of explosive discovery of MND genes in the last few years, namely C9, into useful diagnostic tools and laboratory animal models for MND. I look forward to their worldwide uptake and implementation in the next year leading up to the Milan conference. My only disappointment was that my notepad could barely keep up with all the developments presented this year!

The 24th ALS/MND International Meetings will be held from 2-8 December 2013 in Milan, Italy.

Noticeboard

'Patient experience' websites

When diagnosed with a particular health condition, people often find it helpful to link with others in a similar situation. Frequently this linking-up occurs in person, at a meeting or event; but it is now becoming more common for people to be provided with opportunities to link with others online. One such online meeting place is PatientsLikeMe, a privately owned website run by a company in the USA. People can use the site to track and share their disease history online. It is a 'patient experience' website and just one of several similar sites that encourage people to provide information about themselves, often for a world-wide audience.

If you are thinking about contributing to a 'patient experience' website you should consider the following points before you provide information about yourself.

Details you provide can make you identifiable to others, even though you may not intend this. There is nothing to stop others from providing false or misleading information about themselves. If anyone can become a registered member of the website, setting your profile as 'visible' to only registered members of the site provides you with no additional protection.

Some particular questions you might seek answers for are:

- Will I receive unwanted information to my email account from your site or related companies?
- Is there a way for me to have my information removed if I change my mind?

- Will my information still show up in an internet search even if it is removed?
- Are my personal details or any other information about me being sold for private profit?

Sometimes you will read information on a site about another person's medications or treatments. It is always important to remember that another person's situation or medication, as they describe it, may not be their actual situation. They may have other conditions, medications or treatments that you don't know about.

Experimental medications or treatments have three potential health outcomes. They may:

- have harmful effects, including a reduction in lifespan and/or quality of life
- have beneficial effects
- have no effect.

Other conditions, medications or treatments can interact with experimental medications or treatments. Also, there may be significant costs involved. Your doctor is always the best person to talk with about medications and treatments. If you come across a medication or treatment of interest to you, chat to your doctor about it and seek his or her advice.

References:

- www.staysmartonline.gov.au
- www.patientslikeme.com
- Goetz, T. 2008. 'Practicing patients', The New York Times. March 23.

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Noticeboard (cont'd)

(Continued from page 9)

Puncture in your wheelchair tyre?

NRMA Motoring and Services (NRMA) provides a courtesy service for unregistered motorised mobility scooters and wheelchairs. Service is limited to minor permanent or temporary repairs including tyre punctures and minor electrical or mechanical issues. NRMA patrols do not carry spare tyres or parts. For more information contact NRMA roadside assistance ph. 13 11 11. Members using MND NSW loaned wheelchairs must also report the puncture to MND NSW equipment staff on the next business day ph. 02 8877 0999, 1800 777 175 or equipment@mndnsw.asn.au. If further repairs are required MND NSW equipment staff must be informed so they can arrange the appropriate repairer.

National study seeks conversation with carers

Associate Professor Debbie Horsfall and a team of researchers from the University of Western Sydney, Calvary Centre for Palliative Care Research ACT, CSIRO and Cancer Council NSW are conducting research with carers in order to better understand what happens when people come together to care. If you have cared for someone who died at home in the past two years the researchers would be interested in talking with you about your experience of being supported by friends and family. For more information contact Niki Read ph. 02 4736 0368 or n.read@uws.edu.au or visit www.caringatendoflife.wordpress.com. This study has been approved by the University of Western Sydney Human Research Ethics Committee and will be recruiting participants until mid 2013.

Generic brand of riluzole now available

There are now two brands of riluzole available in Australia. *Rilutek* is manufactured by Sanofi and the generic version *APO-Riluzole* is made by Apotex. These medications are interchangeable and bioequivalent meaning they are, for all intents and purposes, the same. For more information about riluzole see the updated Fact sheet EB4 Riluzole at www.mndnsw.asn.au or contact your regional advisor.

Young Carer E-News

The Carers NSW Young Carer Program sends out a monthly young carer e-newsletter which gives information about upcoming events and useful resources. Visit www.youngcarersnsw.asn.au to subscribe.

Travel Insurance

Travel insurance falls into two categories:

- non-medical cover, covering unforeseen events such as cancellation of trips or flights, theft or damage of luggage, and
- medical and disability cover. This covers overseas hospital and medical expenses and loss of income due to injury or illness.

Individuals with pre-existing medical conditions may have had the experience of being denied medical and disability cover when purchasing travel insurance. This can be a frustrating process and while some companies have a total exclusion policy for anyone with a known pre-existing condition, this is not the case with every company. Some insurers will provide coverage to people with pre-existing conditions.

It is important to do your research when considering purchasing travel insurance to find a policy that best suits your individual and family's requirements. For more information contact the MND NSW Info Line ph. 02 8877 0999 or 1800 777 175.

Source: Genetic Support Network of Victoria and MND Vic

Beware of scammers asking for NDIS fees

People are being warned to beware of contact from anyone claiming to work for the government, requesting an administration fee to access the National Disability Insurance Scheme (NDIS). These claims are false. There is no need for people to pay a fee to join the NDIS.

The NDIS Launch Transition Agency will deliver the first stage of the NDIS. In the lead up to the launch date, the agency will communicate with people with disability in the launch sites. However, the agency will not be seeking fees from anyone to participate in the scheme. People should be very wary of anyone asking for payments for government schemes, including the NDIS.

If a person is concerned that their privacy has been breached or they have provided personal details as a result of one of these calls, they should report it to the police. You can also report a scam and get further information at www.scamwatch.gov.au, or call the hotline on 1300 795 995. For more information about the NDIS see www.ndis.gov.au



Would you like more information but don't have access to the internet? Contact the MND Info Line ph. 1800 777 175



Need a break? FlexiRest funds a range of services offering in-home or out-of-home respite that cannot be met by existing community and respite services. FlexiRest provides respite funding for MND families to have some 'time-out'. Ask your regional advisor for more information.

Community events

Murwillumbah Golf Club

In November 2012 the ladies of the Murwillumbah Golf Club held a fundraiser for MND NSW. There were raffles and merchandise sales and together with donations a wonderful total of \$2327 was raised. Thanks for all your hard work.

Numero Uno Hair Studio

Gary Batchelor from Numero Uno Hair Studio in Queanbeyan held a fundraising event in the salon throughout the month of November 2012. \$5 from every cut and colour combo was donated to MND NSW. Gary also had merchandise available for sale throughout the month. Thanks to Gary and the staff at Numero Uno Hair Studio.

Basketball 4 a Cure Carnival

The annual Basketball 4 a Cure Carnival was held on the first weekend in December 2012 at Bomaderry. Coordinated by Scott Balsar from the Shoalhaven Basketball Association, the event is now in its seventh year, attracting teams from across NSW and ACT. Silent auctions, chocolate wheel, bar and BBQ raised \$3000 for MND NSW. We really appreciate your ongoing support.

Picture Thousand Words

Lara Pasternak has been a great supporter of MND for many years raising funds by participating in events such as the City2Surf and the Sydney Half Marathon. But in December last year Lara and her friend Alexis decided that a more sedate way of raising funds was at their 'Picture Thousand Words' photo exhibition, held at Café Newtown. During the exhibition Lara and Alexis held a raffle and sold MND merchandise. Thanks for your great support.

Berridale Xmas Fair

The Christmas spirit was alive and well at the Berridale Xmas Fair on 21 December 2012. Darrell Worley had lots of help from local primary school kids to hold a cake and second-hand toy stall to raise money for our Association. Well done and thanks for all your help.

Expressions Hair Studio and Indulge Beauty



Expressions Hair Studio and Indulge Beauty kicked off 2013 with a lovely VIP Ladies Body Shop Party with plenty of pampering for the ladies, auctions and lucky door prizes. The day raised \$2500 in memory of Greg Porich, who passed away

from MND on 26 May 2011, and was organised by Rebecca Brown, Kate Lawrence and Louise Porich. Sounds like a lovely afternoon and a great way to raise funds for MND, a very big thanks to all.

Ron Browne Centenary Cricket Match



On Christmas Eve 2012, June and John Henry of West Kempsey hosted a fundraising cricket match at their farm. It was called the 'Ron Browne

Centenary Cricket Match' and acknowledged the 100th 'birthday' of the family home and the passing of Ron Browne, their son-in-law, who died from MND in February 2009. The oval was a closely mowed section of the cow paddock near the house and the pitch was a length of carpet flooring. Ron's daughters, Karen and Rochelle, captained the teams that consisted of June and John (both 85 years young), their seven children, grandchildren and even two great-grandchildren. Trophies were organised to mark the occasion and all participants signed a mini-bat. At the post-match presentation, a Santa hat was passed around and money collected was donated to the Association. Ron would have said that "cricket was the winner".

Stringers busking for MND



The students of musician Michelle Tesoriero formed a performance group called the Stringers and worked hard busking for MND in the days preceding Christmas 2012. More than \$300 was raised by Michelle and her students - Thomas, Savio, Travis, Alexandra, Bella, Adam and Daniel. Thank you for your ongoing support.

GOLD CHARITY ENTRIES

The Sun-Herald
CITY2SURF



MND NSW now has a limited number of Gold Charity entries available for the Sun-Herald City2Surf on 11 August 2013

Gold entrants start in the second tier behind the red group of runners, with plenty of space and freedom to move. As a Gold Charity entrant, your race pack will be available for collection from the exclusive Gold Charity booth at the City2Surf Event Expo. Gold entrants will also wear a unique gold bib, making other competitors and spectators aware that you are supporting a charity for your run. All Gold Charity entrants will be listed on the online Global Wall of Fame for the City2Surf. To get your gold charity entry

MND NSW requires a minimum fundraising guarantee of \$1,000. For more details contact Kym Nielsen ph. 88770999 or kymn@mndnsw.asn.au.

Be quick numbers are limited.



Walk to
d'Feet
MND

Canberra
24 Mar

Hunter
7 Apr

Tweed Heads
5 May

Port Macquarie
15 Sept

Sydney
10 Nov

New merchandise items available for MND Week 2013



MND Keyring
Foot shaped keyring with 'Walk to d'Feet MND' on front and contact details on reverse. \$4



MND Keyring
Cornflower shape in Association colours with contact information on reverse. \$4



The new black and white soft plush puppy is the third dog in our litter. Choose also from cream and tan/cream. \$5

Buy online at www.onlinemndnsw.asn.au or complete and return the enclosed MND NSW Merchandise Order Form. Or, you can contact Anne Jones at MND NSW ph 02 8877 0999 to place your order.

Dates for the Diary 2013

24 Mar	 Walk to d'Feet MND - Canberra Commonwealth Park, Lake Burley Griffin ACT Register at www.online.mndnsw.asn.au or contact Kym Nielsen, MND NSW ph. 8877 0999
24 Mar	Pedal Car Show - Wagga Wagga With raffle and barbeque Contact Shirley and Keith Wheaton ph. 0421 047 199
6 Apr	Tas Ride - Motorcycle Ride - Wagga Wagga Motorcycle ride to honour Tasman O'Hara Contact Chris Anthony canthony57@yahoo.com.au
7 Apr	 Walk to d'Feet MND - Hunter Speers Point, Warners Bay Register at www.online.mndnsw.asn.au or contact Ashleigh Worldon ashleigh.n.worldon@gmail.com
5 May	 Walk to d'Feet MND - Tweed-Coolangatta Jack Evans, Boat Harbour Register at www.online.mndnsw.asn.au or contact Kym Nielsen, MND NSW ph. 8877 0999
10 May	Blue Cornflower Day Luncheon Cruise - Sydney Harbour 4 hr luncheon cruise aboard Captain Cook Cruise's Matilda 3, see page 2 for more information Register at www.online.mndnsw.asn.au or contact Kym Nielsen, MND NSW ph. 8877 0999
24 May	Riddla MND Golf Fundraiser 2013 - Luddenham Twin Creeks Golf Country Club Register at www.online.mndnsw.asn.au or contact Ann Ridd aridd@live.com.au
26 Jun	Reverse The Curse State of Origin Fundraising Dinner and Auction - Ultimo Sydney Aerial UTS Function Centre Contact Gavin Turnbull gavin@bchild.com.au
29 Jun	Lighthouse to Lighthouse Fundraising Run - Wollongong to Kiama Contact Shelly-Anne Demirov shellyannedemirov@gmail.com
11 Aug	Sun-Herald City2Surf 2013 Get a team together and support MND NSW Contact Kym Nielsen, MND NSW ph. 8877 0999
15 Sep	 Walk to d'Feet MND - Port Macquarie Westport Park Online registration available closer to the date Contact Bev Smith bebbie45@hotmail.com
12 Oct	Gundaroo Music Festival Bands playing on mobile truck stage at Gundaroo. Contact Scott Harding ph. 0459 231 743
10 Nov	 Walk to d'Feet MND - Sydney Blaxland Riverside Park Homebush Online registration available closer to the date Contact Kym Nielsen ph. 8877 0999 kymn@mndnsw.asn.au

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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

Our community events for MND would not be possible without our supporters who volunteer to organise events. Thank you for your support.