THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

December 2012

mnd New South Wales

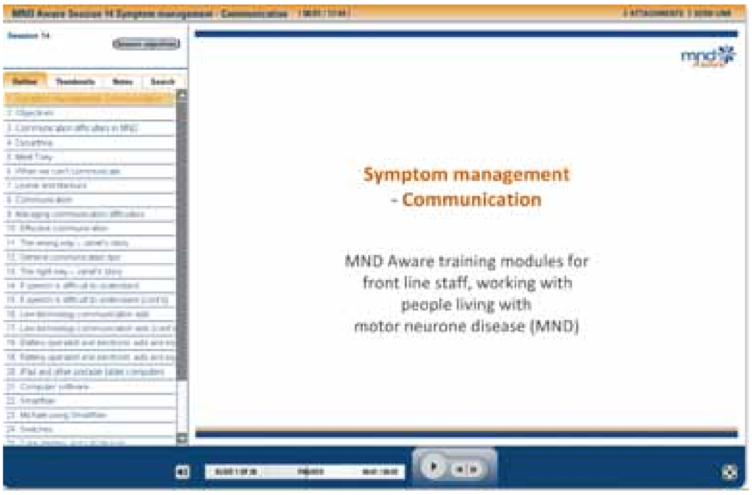
FORUM

MND Aware Free Online Training

In November, Minister for Ageing and Disability Services Andrew Constance launched the MND Aware training program. This free online program about MND was developed by MND NSW with the support of NSW Government Ageing, Disability and Home Care (ADHC).

MND Aware provides health and community professionals with the opportunity to access training about motor neurone disease via the internet, anytime. It contains information on caring for someone with MND including managing symptoms and looking after the wellbeing and support needs of the person living with MND and their carer, family and friends.

Please let your health and community service providers know about this new free online program as it will help them to understand the needs of people with MND. They can just type MND Aware into their web browser search engine or locate the training at www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware.



Symptom management
- Communication

MND Aware training modules for
front line staff, working with
people living with
motor neurone disease (MND)

(above) Minister for Ageing and Disability Services Andrew Constance with Michael Lee, who contributed many photos and videos about living with MND for MND Aware and (below l-r) Paul Armstrong, who narrates several of the MND Aware sessions, Jayasooriah who assisted with video cutting and Kristina Dodds MND NSW Education and Carer Support Coordinator.

Are you interested in becoming an MND Ambassador to help raise awareness of motor neurone disease in the wider community?

In 2012 we are introducing the MND NSW Ambassador Program. Our volunteer Ambassadors will be contacting their local service clubs (such as Apex, Lions, Probus and Rotary) and other interested groups to talk about motor neurone disease. If you are interested in participating in this program you will be provided with an Ambassador Kit containing up-to-date information about MND and information about the mission, history and funding of MND NSW.

For further details on MND NSW Ambassador Program or to register your interest contact Ayse Dalkic ph. 8877 0908 or aysed@mndnsw.asn.au.

MND NSW will be closed from 12pm Friday 23 December 2011 until 9am Tuesday 3 January 2012.
If help is needed during the Christmas break, please consult your doctor.

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.

Member's Christmas Party 2011

We launched into the Festive Season with our Member's Christmas Party on 12 November at the Ryde Eastwood Leagues Club. Everyone enjoyed a delicious afternoon tea and the engaging entertainment provided by Rosanna Gallo, before Santa and his tall elf Ahmet made a surprise visit to deliver gifts. These were excitedly received by some wide-eyed children; including one who claimed his Dad had told him Santa had parked his reindeer in a 'No Standing Zone'. Despite the threat of a parking ticket, Santa kindly stayed to assist in drawing the raffle and the enviable lucky door prizes which had been so generously donated by Entertainment Book Publications of Australia Pty Ltd and Sydney Harbour Tall Ships.

It's always great to have an excuse to celebrate and I think that everyone who attended this years Member's Christmas Party would agree that it was a most enjoyable day.

Kate Maguire
Education and Carer Support Coordinator

It's on again!
MonStar Cup
2012

23 March
Pennant Hills
Golf Club
www.monstar
foundation.
com.au

Corporate Volunteering Day at MND NSW by YES OPTUS

A team of Optus staff committed to a day of volunteering with MND NSW on 22 November 2011, as part of their corporate social responsibility. The day was a fast paced one where the team helped in preparations for the 22nd International Symposium on ALS/MND. The delegates attending this Symposium will be receiving their written material, pre-packed for them by Optus volunteers. Corporate volunteering is important as it assists in building employee skills and loyalty and helps raise the company profile in the community. It was a win–win situation and MND NSW greatly appreciated the assistance we received from Optus staff.

A Message from the CEO

What a hectic few months! Walks to D'feet in Port Macquarie and Sydney (p. 12) and a visit to the Broken Hill Walk, our (very early) member's Christmas party (p. 2), another visit from the Minister for Disability, Andrew Constance to launch the MND Aware online training (p. 1) and our Annual General Meeting. Currently we are preparing for the co-hosting of the International Symposium and Allied Professionals Forum which will be occurring as we go to print. A full report from the Symposium will be published in the next issue of *Forum*.

The MND NSW Board for 2011-12 is:

President - Phil Bower
Vice Presidents - Alex Green, Roger Henshaw
Secretary - Janice Scheinecker
Treasurer - Bob Howe
Members - Phil Brady, Michael Perry,
Ralph Warren

A copy of the Association's Annual Review is available at www.mndnsw.asn.au. Alternatively, if you would like a hard copy of the 2010-11 Annual Review or Financial Report please contact us ph. 8877 0999 or admin@mndnsw.asn.au

MND NSW Vice Patron Dr Paul Brock AM spoke at the National Press Club in Canberra on 23 November. Paul's topic, along with two other speakers, was on the National Disability Insurance Scheme - Every Australian Counts, a topic well known to members of MND NSW. Thanks to the advocacy of our members, and people such as Paul, the NDIS is closer to reality; but to ensure it does happen the campaign still needs your support. If you haven't joined the Every Australian Counts campaign or if your friends and neighbours haven't, you'll find a link from the MND NSW website.

We wish you a peaceful and safe Christmas and New Year. Thank you to our volunteers and donors for their support in 2011. Our office will be closed from 12pm Friday 23 December and will reopen on Tuesday 3 January. If help is needed during the Christmas break, please consult your doctor.

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

For more information about the National Disability Insurance Scheme visit www.everyaustraliancounts.com.au

International Symposium on ALS/MND

As this edition of Forum *goes to press, the International Symposium on ALS/MND is happening in Sydney. A Symposium update will be published in the March edition of* Forum.

Motor Neurone Disease Association of New South Wales

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Equipment Service Coordinator
Maree Hibbert
Equipment Assistants
Tom Giardina, Michael Walker
Information Resources Coordinator
Penny Waterson

And…*many valued volunteers including Suzanne Ballinger and Diane Openshaw at the Ryde EXPO*

Family Support Team

As I write this we are preparing for the International Symposium on ALS/MND that MND NSW is co-hosting with MND Australia from the 28 November. We have four project posters on display at the Symposium about the work of MND NSW including MND Aware and the volunteer massage program. Staff at MND NSW will be attending part or all of this four-day event. We have provided a report in this edition on the Ask the Experts session that many of our members and family have attended and in the next newsletter we will provide reports on the rest of the Symposium for your information. These events are such a great opportunity to find out what is happening around the world in both research on MND and care of people with MND.

I am excited to be presenting a paper on the first day at the Allied Professionals Forum on MND Aware, our new online training program for health and community professionals. We are very proud of this new training and I would like to take this opportunity to thank the members and carers who contributed to this training through their videos, photos and stories. Health and community professionals really learn from your stories so thank you for the contribution you made to this project. A big thank you also to Penny Waterson who is our information coordinator who worked tirelessly to develop this program. We also had many volunteers working on the project including a team of professional voice over artists and our regular office volunteers, Debra, Jaya and Joy. Without everyone’s contributions and efforts this project would not have been possible.

Planning Day

The Family Support team had a planning day in November to look at our plans for 2012. These days are important for us to reflect on the year and plan for the coming 12 months. This includes planning our education and support programs to our members including programs such as *Care for Carers* which is scheduled for May and *Learn Now Live Well* scheduled for October. We are also planning days in regional areas for members and carers with a two-day residential program for carers in Port Macquarie called *Link and Learn* probably in March and, for the first time, we will be running a members education day on the Gold Coast in late 2012.

We will also be conducting a series of education programs during 2012 for home and community care workers in NSW to enhance our MND Aware online training program. So we will be keeping all our staff very busy with these programs and in particular Kristina Dodds, one of our Education and Carer Support Program Coordinators, who will be organising these.

Bi-Annual Member Satisfaction Survey

Every two years we undertake a satisfaction survey of all our members to assist us in evaluating our services and identifying areas that we could enhance our services. Members will receive a survey in February and we would really appreciate your feedback as to how you would rate our services and any suggestions you might have to improve these.

By the time you receive this edition of *Forum* it will almost be Christmas. It’s a time of year when family and friends come together to enjoy each others company. It can also be a time of mixed emotions as we reflect on the past year; sharing our happy memories, achievements and our hopes, as well as remembering our losses and times of sadness. We wish you all a happy and peaceful Christmas and New Year.

Gina Svolos
Manager, Family Support

Thinking about attending a Family Support workshop in 2012? Speak with your regional advisor for more information

Family Support Calendar - 2012

21 February	**Information Evening for people recently diagnosed with MND, their family and friends** | *Gladesville* |
15 and 16 March *(to be confirmed)*	**Link and Learn** | *Port Macquarie* |
26 March	**Lunch for bereaved carers** | *Gladesville* |
17 April	**Information Evening for people recently diagnosed with MND, their family and friends** | *Gladesville* |
14, 21, 28 May and 4 June	**Care for Carers** | *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.

Family Support Team (cont'd)

Equipment

This year has seen the MND NSW Equipment Service provide over 1106 items of equipment to 261 of our members throughout NSW and the ACT. Recently, demand has been high again for power wheelchairs and specialised cushions which has resulted in waitlists for these items.

Demand has also been high for other items and through the generosity of our supporters we have been able to purchase 59 new items including 8 beds, 13 armchairs, 11 shower commodes, 11 hoists, 11 mattress overlays and 5 Smart Nav hands free computer mouse. Thank you.

Many of our members have been purchasing iPads to assist with communication. Popular iPad communication applications, known as Apps, that have been used successfully by our members include Verbally and SpeakIt, which are available for download from iTunes for no or very little cost, and Proloquo2go which is more expensive but can be trialed at most Apple stores on demo iPads.

Thank you to members who completed and returned the MND NSW equipment stocktake letter that was posted in September to all members with equipment. This is done every two years so we can keep track of our loaned equipment and confirm our database records are correct. If you haven't replied yet we will be contacting you over the phone to follow up.

I can't believe it but Christmas holidays are nearly upon us. Couriers will be busy over the coming weeks due to the increased demand on their services so delays may occur with equipment delivery or return. Where possible MND NSW staff will give a time-frame for delivery of an equipment item but this may be changed by the courier due to circumstances in the delivery area. I ask that everyone be patient during this time. If you do experience any delivery or return problems contact MND NSW and we will assist in solving the problem if possible.

MND NSW will close for the short period between Christmas and New Year from 12pm Friday 23 December 2011 to reopen Tuesday 3 January 2012.

If during that time you have any urgent equipment breakdowns please either contact your occupational therapist or speech pathologist to assist you in arranging a repair or, if they are not available, contact your local hospital.

On behalf of the equipment team - Michael, Tom and myself - I would like to wish everyone a very safe and very happy holiday.

Maree Hibbert
Equipment Services Coordinator

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

MND Directions in Care - Newcastle, Canberra

Over 70 health and community care professionals attended the MND Directions in Care seminar held in Newcastle on 15 September. This day is part of the MND NSW Regional Education Project, and aims to educate health and community care professionals on motor neurone disease including symptom management, facilitating independence and planning coordinated care for people living with MND. All the presenters had extensive MND knowledge and worked in the local area. They freely gave of their time. A special thank you to Dr David Williams (neurologist, John Hunter Hospital), A/Prof Peter Wark (respiratory physician, John Hunter Hospital), Alex Tait (speech pathologist) and speakers from community health, palliative care and Community Options – we learnt so much. Comments from participants included 'very informative presenters, very sensitive approach and very comprehensive', 'I can really see the benefits of a multidisciplinary team approach to care' and 'I feel more knowledgeable about MND'.

On 20 October over 80 health and community care professionals attended the MND Directions in Care seminar held in Canberra. Participants came from far and wide. It was great to see a strong contingent from Wagga Wagga, the Eurobodalla, Cootamundra and Albury as well as the locals. The Queen was also visiting Canberra and while she didn't attend we could hear the 21 gun salute she received that briefly interrupted the presentation from Olivia Tough on 'Coordination of client care'. A very big thank you to Dr Andrew Skeels and the ACT MND Clinic team who planned and presented on the day.

Gail Ferguson, Eileen O'Loghlen** and **Kim Sinclair
*Regional Advisors, and **Kristina Dodds**, Education and Carer Support Coordinator*

Learn Now, Live Well

In October the MND NSW *Learn Now, Live Well* program ran over two consecutive Mondays. This program is designed to provide education and support for people living with MND and their family. Those who attended this year expressed their appreciation of the opportunity to expand their understanding of the best ways to maintain energy, independence, communication and good nutrition. As always the group expressed how much they gained from meeting others in similar situations. The magnificent catered lunches enjoyed in the spring sunshine helped to make these two days a relaxed and enjoyable experience for all. If you haven't already attended this program, put it on your calendar for 2012!

***Kate Maguire**, Education and Carer Support Coordinator*

Support Groups

Gladesville

Our September meeting was in the café at Eden Garden's Nursery at North Ryde and we were joined by Graham Opie, our CEO and Jo Fowler, Regional Advisor for Northern Sydney Area and Central Coast. We all enjoyed a wonderful morning tea, which was funded by a grant from the Gladesville RSL and Community Club. After morning tea, those of us who were keen gardeners inspected the beautiful gardens and nursery.

The Gladesville Group meets at the MND NSW Centre at Gladesville every second month from 10.30am to 12.30pm. Our next meeting is on 1 February and new and visiting members and their families are always welcome. Contact the MND NSW Infoline Freecall 1800 777 175 if you would like to be added to the mailing list for the support group.

***Caroline Gleig**, Regional Advisor*

Newcastle and Hunter

In 2012 we will continue to run our MND carer support group and our MND NSW member support group, both commencing at 10am, on the 3rd Wednesday of every second month commencing 15 February. Meetings are held in rooms provided by Make Today Count Inc at 44 Dudley Road, Charlestown. We are grateful to Sue Deamer and Annie Laurie from Make Today Count for allowing us to use their venue. If you would like further information about the meetings contact MND NSW regional advisors Kim Sinclair or Eileen O'Loghlen ph. 4921 4157 or MND NSW Infoline Freecall 1800 777 175.

***Kim Sinclair** and **Eileen O'Loghlen**, Regional Advisors*

Northern Beaches

Our group has continued to grow both in knowledge and members throughout the year. We have been busily learning about navigating our way through health and community care services provided on the northern beaches. These include those based at Mona Vale Hospital such as community care providers, the palliative care team and the aged care team; and also the case managers at Community Care Northern Beaches.

We also learnt about the importance of symptom management by a multidisciplinary care team and how people with MND can benefit from close monitoring of their health status and early detection of problems as they arise. Sandra Erjavec told us about the new Macquarie Neurology MND clinic that opened at the Macquarie Neurology Hospital in August this year. You can find out more information about this clinic at www.macquarieneurology.com.au

Our support group meetings continue to be held at the Palliative Care building at Mona Vale Hospital every second month. Light refreshments are provided and free parking is available. Don't forget to pick up a free parking voucher from Sue on the reception desk at the cottage.

So 'carpe diem' – seize the day! Come along, learn more about MND and meet up with others who may be experiencing some similar symptoms to you. People with MND, their families and friends are all welcome. Hope to see you there.

***Jo Fowler**, Regional Advisor*

Western Sydney

Our November meeting doubled as our Christmas get-together. We enjoyed lots of yummy food and cool drink and fantastic music from Karen Lynne and Pat Drummond. Both Karen and Pat live in the Blue Mountains and give of their time to entertain us each year. Karen has a beautiful voice and has won many accolades for her singing and song writing. Pat is often heard on ABC Country and at Country Music Festivals around the country and he has the most extraordinary sense of humour. So there was a great assortment of music, some sad, some truthful, and some very funny. The 'Sao' song truly brought the house down. Although it was a really hot day it was a great afternoon.

The first group for next year will be on 13 March. At this meeting we can catch up with each other and plan what we would like to do at our meetings during 2012 - such as topics for discussion, guest speakers and outings.

The group is a very friendly and relaxed, and provides you and your family with a great way to connect with other people experiencing similar challenges. Afternoon tea is provided and everyone is welcome.

***Jenny Judd**, Regional Advisor*

John and Trish Graham at the Western Sydney Support Group Christmas get-together and (below) entertainers Karen Lynne and Pat Drummond

Planning a break? FlexiRest provides respite funding for MND families to spend relaxing time together

Support Groups (cont'd)

Illawarra

In October Robyn Petersen, MND NSW Regional Advisor, and I hosted an MND Morning of Remembrance in the lovely Botanic Garden, Wollongong. We were fortunate to have perfect springtime weather, which allowed us to enjoy the dappled sunlight in the secluded woodland area we had reserved for the occasion.

Participants had been invited to bring along a photo of their family member to be placed on the memorial table. Before the ceremony commenced they also had the option of decorating a river rock to represent the person they had come to remember. Both young and old enjoyed this activity and these creations looked beautiful arranged amidst the photos.

Following the ceremony we all feasted upon a fabulous lunch including an array of sandwiches, wraps, cakes, scones and cream along with a fruit platter that was like a work of art. Carers NSW kindly provided funding for this lavish spread as part of Carers Week, in recognition of the commitment and courage required by those caring for someone with MND.

Kate Maguire*, Education and Carer Support Coordinator*

The decorated river rocks were arranged amidst the photos at the Morning of Remembrance

Support group dates for 2012 are available at www.mndnsw.asn.au

Mailbag

From Rita

As my mother died when I was 5, and my father when I was 22, I had no expectancy of a long life. When the book 1984 came out in the fifties I thought I will never live that long! And when the new millennium came when I was 63 I was amazed.

Two years ago I was diagnosed with pseudo-bulbar palsy and now I cannot talk at all or eat by mouth - I have a PEG in my stomach for nutrition and hydration.

I feel I have had a good life, with five children and eight grandchildren, even though the first six years was in WWII through bombing in England. My life has been full of interest and I have no regrets and am a positive thinker.

I had some computer knowledge but on recent respite (my husband Alan died this year from leukemia and prostate cancer after a 54 years marriage, so I do get lonely living alone), I purchased myself an iPad. I have learnt from scratch how to use it in the last four weeks or so.

It is excellent for those like me with MND. I can send emails, take pictures, play music. Doodle, play games like UNO, solitaire, buy things on eBay, and lots of other things I have not tried yet. It operates by touch of one finger and I charge it up each night.

You need a young person to show you what to do, like grandson or granddaughter; I even picked the brains of the young nurses in my care facility, they find it easy. And get a thrill from showing how to do it.

From groovy granny Rita
Far northern NSW

Support Groups

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

Campbelltown - *Robyn Petersen | robynp@mndnsw.asn.au*

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

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

Western Sydney - *Jenny Judd | jennyj@mndnsw.asn.au*

REGIONAL AND RURAL

ACT and Southern NSW - *Gail Ferguson | 6286 9900 | gailf@mndnsw.asn.au*

Central Coast - *Audree Dash | 4384 2907 or Jo Fowler | 1800 777 175| josephinef@mndnsw.asn.au*

Central West - *Jenny Judd | 1800 777 175 | jennyj@mndnsw.asn.au*

Illawarra - *Robyn Petersen | 1800 777 175 | robynp@mndnsw.asn.au*

Newcastle and Hunter - *Eileen O'Loghlen | 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'Loghlen | 4921 4157 | eileeno@mndnsw.asn.au*

International Ask the Experts

On 28 November, more than 200 people attended the INTERNATIONAL Ask the Experts session held in Sydney. We briefly report on the session below. You can view the session webcast by following the links at www.mndaust.asn.au/sydney-2011.

***Penny Waterson**, Information Resources Coordinator*

What do we now understand about ALS/MND compared to 5 to 10 years ago? How has clinical and scientific research impacted on current clinical care for people living with ALS/MND? ***Kevin Talbot, Nuffield Department of Clinical Neuroscience, University of Oxford, UK***

Kevin described motor neurone disease as a failure of the very complex neuromuscular system. Each person has a 1 in 500 lifetime risk of getting MND, so it is not as uncommon as people often think. MND is a disease associated with ageing, and understanding the ageing brain is a key factor in understanding MND. It is a complicated condition clinically because MND has a highly variable clinical course - the disease progresses differently for each person, although there are some patterns of disease progression that can be common across individuals. This is further complicated by the lack of markers of disease activity and this makes research into treatments difficult.

Research science is still trying to understand the basic biology of the disease. Is it a disease in which the motor neurones degenerate over many years until a certain 'threshold' is reached resulting in the MND symptoms; or is it a disease in which the motor system is completely normal and then, within a short time, things start to unravel? What is known is that first there is a phase during which people are 'susceptible' and their nervous system is 'primed'. This is followed by a pre-clinical phase when the system is becoming stressed and things are starting not to work, but this is not noticed by the person with the disease. Finally, once the disease is established, the person starts to develop weakness.

There have been genuinely exciting advances in MND basic science research. To translate these advances into treatment we need to better understand the disease process (who gets MND, when and why does it start at that time, how do the cells die), improve monitoring (biomarkers that can be used to measure disease process or indicate earliest possible changes) and we need better disease models for laboratory testing (mice, tissue and human).

Over the past decade we have found that the genetic contribution to neurodegeneration has been grossly underestimated. Ten years ago we knew there was at least one gene (SOD1) that, if it was mutated, led to MND. Now, we know a lot more about the genetics of MND and have found that there is a significant genetic contribution to what is called 'sporadic' MND. These people don't have a family history of MND and don't necessarily have a significant chance of passing the disease on. However because of the way they are made up genetically, is one of the most important reasons of why they are susceptible to MND. We also have a huge amount of information about how the motor neurone cells are vulnerable in a person with MND, but we do not know what cell processes are occurring as a consequence of the disease, or which are involved in the causation. The UK BioMOx study is following pre-symptomatic people over five years to discover more about what is going on inside the nervous system.

Good care and good research go together. People with MND are our key partners in research and research into the care of people with MND. Over the past ten years we have learnt that non-invasive ventilation works, can give people good symptom control and can also increase life expectancy. Multidisciplinary care is also very important. MND is a technical problem that can be solved and we can only get there in partnership with people with MND.

How might stem cell research lead to a cure for ALS/MND? ***Kevin Eggan, Harvard Stem Cell Institute, USA***

Kevin explained that stem cells are any type of cell that can both make more of itself (self-renewal) and differentiate into a variety of different cell types (giving rise to other cell types). There are many different stem cells in the body and these are critical in humans. The three primary types of stem cells are pluripotent stem cells that can make all cell types in the body; cord blood stem cells, from the neonatal umbilical cord that can make the blood cell types in the body; and adult stem cells that can make only the same cell types from their tissue, for example lung stem cells make new lung cells every month. MND research focuses on pluripotent stem cells because they can be grown infinitely in culture in the laboratory and because they have the potential capacity to make motor neurones.

Although media about stem cells often focuses on stem cell transplantation, the very exciting aspect of stem cell research often overlooked is that motor neurone cells can be made in the laboratory from pluripotent stem cells or adult stem cell lines. We can now even see the electrical activity of our laboratory motor neurones as they connect to laboratory muscle cells. This allows us to replay in the laboratory many events that we think are

(Continued on page 9)

International Ask the Experts (cont'd)

(Continued from page 8)

related to motor neurone degeneration and come to understand MND at a cellular level. We can compare motor neurones from different people with the disease to see if the same thing goes wrong in each of them. The laboratory motor neurone cell lines are like 'flight recorders' for the disease and can allow us to do drug discovery directly on a cell that is affected by degeneration.

These stem cell derived motor neurones have already been used to show how they can be 'attacked' by another cell of the motor system - glia (glue-like) cells from an MND affected mouse. In some unpublished research we have found that there are some drug compounds that may be able to mitigate this effect. This is, of course, just cells in a dish so the next step is to research these compounds further. However, it is a new aspect of MND biology that we haven't really been able to investigate before.

Stem cells also provide us with a window in MND genetics, which increases our understanding of the disease. Although the mouse models are useful, they do take up to two years to grow. Recently we have been able to show in the laboratory that motor neurones from people who have the SOD1 mutation grow 'more poorly' than motor neurones from people without the SOD1 mutation. This indicates that there might be something fundamentally wrong inside these motor neurones from the very beginning. We have also been able to find that motor neurones from people with the SOD1 mutation are more 'excitable' than motor neurones that are from people not affected.

Right now we are using stem cells to really understand a lot more about MND. The motor neurone stem cell lines we have in the laboratory really are providing us with a 'flight recorder' for the disease.

You can view the full video of Ask the Experts, including the Question and Answer session. Visit www.mndaust.asn/sydney-2011

Lessons from ALS/MND Genetics ***Robert Brown Jr, Harvard, NEALS, USA***

Bob provided a brief overview of the factors that probably interplay in the development of MND - genetic susceptibility, environmental factors, behaviour and chance. These are overlayed by another factor - ageing. About 10% of people with the disease inherit it as a dominant trait and there are now about 20 MND genes that have been identified, whereas 20 years ago we didn't know this. Several of these families of genes are telling us new things about the disease. One of the burning questions is how much can we learn from the 10% of people with MND who have inherited it. Bob thinks that what we are learning from the genetics of the disease will teach us much about the disease overall and will probably help us in the development of therapy.

There is a fundamental disturbance of protein biology in MND. In people with the disease motor neurones are susceptible to protein misfolding which can trigger toxic events for the neurones. Other cases of MND can arise because of a disturbance of ribonucleic acid (RNA) in the cell nucleus, for example FUS and TDP43 are RNA binding proteins implicated in MND. In people with these mutations FUS and TDP43 can be mislocalised resulting in them being retained outside the cell nucleus in the cell cytoplasm, causing problems for the motor neruone. C9orf72 is another kind of RNA defect. Some forms of MND are associated with motor neurone axonal transport problems, for example we can show that the SOD1 mutation definitely affects axonal function. There are also gene defects that suggest that MND results from a lack of defence against environmental toxins.

There are new technologies around us that enable us to do more and better and faster genetic research. Genetic sequencing we can do now in 8 weeks at a cost of $10000, took 12 years and cost more than $1 billion a decade ago. Over the next two years we expect to do the same type of sequencing in one week at a cost of $1000. This will help us identify rare variants with high impact and as we accumulate this information it will help us understand how subtle variants can trigger MND. Each one of the genes we have found to date has led to new insights into the pathology of the disease. Now we can screen drugs in the petri dish which has the great potential to speed up the search process.

Clinical Trials in ALS/MND: Past, Present, Future
Orla Hardiman, Clinical Professor of Neurology, University of Dublin

Orla explained that for many illnesses and diseases drugs have been found through pre-existing knowledge (eg white willow/aspirin, belladonna/atropine), a prepared mind (eg penicillin), serendipity (warfarin for blood anticoagulation) or targeted development; with targeted development now most often used the search for MND drug treatments.

Targeted development of drugs includes a pre-clinical phase, which is laboratory-based investigation using animal models. In this phase, scientists seek to understand, manipulate and change animal model disease pathways through the use of drug compounds. We now know that MND is a very complex disease and taking a targeted approach does not take into consideration the complexity of the human nervous system. Translating from the research bench into the human setting needs us to show

(Continued on page 10)

International Ask the Experts (cont'd)

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that, when taking a particular drug, the person with the disease stops deteriorating; that the effect can be reproduced on other people with disease; that the placebo effect can be excluded; and that the bias of observers (clinicians and researchers) can also be excluded. To do this we have clinical trials. There are four phases of clinical trials. Phase 1 is the safety phase during which healthy animals, then people, are given the intervention drug to see if there is any unexpected drug toxicity. Phase 2 is a proof of concept phase where the drug is tested on a small number of people with the disease, looking for a signal of the effect of the drug and the doses that are most effective. Phase 3 is the most costly phase and is where the drug is tested on large numbers of people with the disease and is usually required for regulatory approval. A current Phase 3 trial of one drug has a cost of $40 million. Phase 4 is a surveillance phase that occurs after the drug is released.

Problems with this process include that the animal models used to date are limited in that mice and other animals are different to humans. Also, the TDP43 pathology of the SOD1 mouse model is different to the TDP43 profile of people with MND who do not have the SOD1 MND mutation. Drugs may fail because they don't work; there can be poor trial design; the wrong dose may be selected for the trial; or the drug may not get to the right target.

Clinical trials are not just about drugs. Clinical trials are also undertaken to evaluate the effectiveness of therapeutic interventions for people with MND such as non-invasive ventilation, diaphragmatic pacing and for other symptom management areas such as nutrition, salivation, emotional lability and cramp.

We now have more efficient screening for better drugs. As researchers, we have been paying particular attention to clinical trial design in the past few years. We are working more closely with pharmacology colleagues. We are looking at the development of biomarkers for MND and recently a large European Consortium was funded to look specifically for MND biomarkers. Also with the new developments in MND genetics we have better ways to group 'like' people with MND during our research.

View the full video of Ask the Experts, including the Question and Answer session. Visit www.mndaust.asn/sydney-2011

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

Noticeboard

Australian MND Registry (AMNDR) Update

AMNDR has been collecting information on patterns of disease and interventions used in MND since 2004. It is a way for people diagnosed with MND in Australia to actively contribute to research. Over 1200 people with MND have registered with AMNDR and at least 10 major centres from around Australia have been contributing information on a regular basis on behalf of people with MND. AMNDR remains one of only a few active MND registries world-wide and this is a testament to people with MND and their carers, along with the dedicated staff around Australia that keep the registry running. If you would like more information talk to your regional advisor or visit www.amndr.org

Stem Cells Australia

A consortium of Australia's leading universities and research organisations headed by The University of Melbourne and led by Professor Martin Pera, are the recipients of funding totalling $21 million under the Special Research Initiative in Stem Cell Science. The consortium, known as Stem Cells Australia, will become the main dedicated stem cell research organisation in Australia. Two of the investigators are involved in MND research. Find our more at www.stemcellsaustralia.edu.au

Climate Change Household Assistance Package

The Government recently announced the details of the Climate Change Household Assistance Package. This package will be implemented during 2012 and has some specific payments for people receiving Centrelink payments, self-funded retirees and those using essential medical equipment. See www.cleanenergyfuture.gov.au for more details.

CareSearch

CareSearch provides trustworthy, evidence-based information for patients, carers, families and friends who are affected by a terminal illness.

When you are caring for someone who has an illness that can't be cured, it can be a confusing time. You might feel overwhelmed or like you need some help to know the best way to provide care. CareSearch can help, 24 hours a day, free of charge.

Find specific, easy to understand information on a variety of topics that you want to know about, including how to care, managing medications, managing daily life, bereavement, grief and loss

CareSearch can also help you learn how to find quality information and point you to services.

Visit www.caresearch.com.au for more information or speak with your regional advisor.

walk to d'feet MND

Bowral

18 March

Community events

Training Workshop for Volunteers

In October Ryde Council kindly sponsored a training workshop titled Speak Up! Speak Out! facilitated by Dale Rees-Bevan. This workshop aimed to further develop the participant's public speaking skills. Several MND volunteers were invited to attend this workshop. The volunteers received many opportunities to brush up their public speaking skills throughout the workshop and in so doing raised awareness of MND within the audience. These volunteers have expressed their interest in wanting to become an MND Ambassador. They will be delivering their speeches with confidence.

Ryde TAFE – Lifestyle and Leisure EXPO

MND NSW participated in the Health, Lifestyle & Environment Expo at Ryde TAFE on Wednesday 19 October. Suzanne Ballinger and Diane Openshaw volunteered on the day to raise the profile of MND in the local community. There were over 30 other stall holders and the EXPO was well attended by students, teaching staff and members of the local community. Thank you Suzanne and Diane for your assistance.

MND volunteers recognised for their outstanding efforts.

Debra Larizza (left) was awarded a certificate in recognition of her nomination for the 2011 Sydney North Volunteer of the Year Award. Also, Joy Pogson was recognised with a nomination in the 2011 Sydney Hornsby North West Volunteer of the Year Award Ceremony.

The MND NSW massage volunteers were also presented with a certificate, in appreciation of the contribution they make to the lives of those living with MND. Thank you MND volunteers for you kindness and generosity.

Colouring our World

'Colouring our World' was the latest exhibition held by Ruth Aldrich and Judy Brownlie of Oakville. Ruth and Judy have been painting together for more than 20 years. Art lovers were invited to attend the exhibition over two consecutive weekends in October. Judy kindly donated a painting for the raffle and the exhibition raised public awareness of motor neurone disease and funds for MND NSW.

My Nearest & Dearest

Sisters Jennifer Mattiussi and Christine Farkas hosted an opening night event and art exhibition called 'My Nearest & Dearest' during October and November at The Arthouse Hotel in Sydney

The intention was to raise awareness and funds for those nearest and dearest to us who are touched by MND; as they have been following the recent death of their nearest and dearest big sister, Sue Quinn.

The opening night was an entertaining night with music performed by friends from the Fairlight Folk Acoustic Lounge: Penny Rankin Smith, Rosie McDonald and Jeremy Rankin Smith; ably assisted by Rod Nielsen. There was also performance artist The Dirt (aka Jamie Preisz) whose artwork was auctioned on the night, together with other major items - an original artwork by established Australian artist Euan Macleod, a notebook computer kindly donated by ASI Computers, and a private cocktail party for 50 at Hugo's Lounge Kings Cross.

Over 90 original small canvases of artworks and gift vouchers were donated and auctioned. All the auction items, large and small, sold along with several major artworks throughout the course of the exhibition.

Jennifer and Christine would like to thank all involved – and there were many! – in making the Opening Night event and exhibition a great success as their intention was realised!

Wagga's new Bachelor of the Year

Southcity rugby league player Brent Merritt was awarded the Bachelor of the Year crown in Wagga in November. Organised by Lauren Fifield, whose grandfather died of MND, the event raised awareness about MND as well as $3000 of much needed funds for the Association.

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

Community events

In June I visited our support group in Port Macquarie and this produced an unexpected bonus with members of the support group deciding to hold a Walk to d'Feet MND in Port Macquarie on Sunday 9 October. Bev Smith led the way and, with support from Margot and Janice, a new walk was born. And what a Walk it was - just three months later over 400 people walking, wheeling and pushing prams (and assorted puppies) headed out along the beachside track for the inaugural Port Macquarie Walk to d' Feet MND. A gorgeous setting, loads of support from the local community and some generous corporate donations from Suncorp and Essential Energy made it a resounding success. Thank you to all of the wonderful volunteers who worked so hard to make it such a great day. The fact that many of these volunteers are also full time carers, speaks volumes for their commitment. Congratulations to all involved, I look forward to next year in Port.

Not to be outdone for sunshine and supporters Walk to d'Feet MND Sydney was held on Sunday 6 November, with sausage sandwiches provided by Carlingford Rotary. With so many wonderful supporters hoping for sunshine, I think we may have overdone it. Sunday morning shone brightly and as the morning progressed so did the temperature. We had temperature reports of 33 degrees and more as walkers headed off for the start of the Walk. It's quite an inspiring sight with over 500 people in their Walk to d'Feet MND t-shirts heading off in-mass. Both Walks helped us raise funds for research. Sydney's Walk was a new record for participation and funds raised. Thank you

We will have a new Walk to d Feet MND happening in Bowral in March 2012. Keep an eye on our website for more details. If you are keen to organise a Walk in your area or would like to volunteer to assist at one of our existing Walks why not give us a call ph. 02 8877 0999.

2011 has really flown, but what a wonderful year it has been. A very big thank you for all of the amazing community events held this year by our supporters. Funds raised by these events help us to support our members with MND and raise much needed funds for research. We couldn't do it without your help.

Kym Nielsen
Fundraising Manager

If you would like more information about leaving a gift to MND NSW in your Will, contact David Dubin ph. 02 8877 0917 or davidd@mndnsw.asn.au

Dates for the Diary

18 March	**Walk to d'Feet MND Bowral** | Fundraising Walk | Contact Alan Spence alan@arygleengineering.com
23 March	**MonStar Cup** | Pennant Hills Golf Club | enquiries@monstarfoundation.com.au or www.monstarfoundation.com.au

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