



# FORUM

## Learning to Dance in the Rain

On 29 June, Penrith High School Year 11 drama students performed *Learning to Dance in the Rain*, an original production about life with motor neurone disease. The performance was an initiative of The GroundSwell Project, a local non-profit organisation that uses the arts to promote wellbeing. The story started several months earlier at the MND NSW Nepean support group meeting when Kerrie Noonan visited the support group to talk about the project and to ask for volunteers. The response was so positive it got going straight away. Members Walter and Barbara tell of their involvement,

"When we first heard from Kerrie Noonan, the friendly and enthusiastic representative from the GroundSwell Project, that she would like MND volunteers for a drama project working with students at Penrith High School, we wondered how our contribution could benefit such a group. Five of us volunteered and our initial visit was a welcoming and enlightening meeting with the students and Nicole, their teacher. What followed were a number of weeks where we were placed in groups and asked questions about motor neurone disease, MND symptoms and our feelings about MND. We were also asked how we coped and lived with the disease.

Those sessions were very interesting, entertaining and extremely therapeutic for my wife, who has MND, and me. Sometimes it would be a sad reality for what is to come and other times it was just a hoot to share with those students our thoughts and memories. Week after week we would talk about what happened during those sessions to our friends and family.

Opening afternoon came for our students to perform their work. We were encouraged to invite our family and friends and, to them, it was an honour to see what we were involved in. For us, it was a proud moment - one filled with achievement, inspiration, emotion and a feel-good feeling. Our input and support were showcased as a fine production that incorporated all aspects associated with dealing and living with MND.

Congratulations to the students of Penrith High School and a big thank you to Nicole, Kerrie, MND NSW and to the GroundSwell Project for delivering a great production promoting the highs and lows of this disease. It would be nice to see each year the legacy from this production reproduced to continue the advocacy for MND."

**Walter and Barbara Lachmund**



*Emma Riches, 16, performs (top) and the Penrith High School students involved in the project. Pictures: Matt Sullivan Penrith Press reproduced with permission.*

*Students and MND volunteers (below).*

### Sydney Olympic Park Homebush

10 am  
Sunday  
7 November



Registration and fundraising has been made easy. Visit [www.mndnsw.asn.au](http://www.mndnsw.asn.au) to register and create your own fundraising page. Or contact Kym Nielsen ph. 8877 0912 or [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au) for information.

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



*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.*



## MND Global Day acknowledged at Parliament House, Canberra on Monday 21 June

Politicians wore cornflowers during question time and Senator Guy Barnett hosted a parliamentary afternoon tea to mark Global Day in Australia on Monday 21 June. Over 50 people attended the afternoon tea including board and staff from MND Australia, MND Australia ambassadors, politicians, representatives from a number of peak bodies and health professionals involved in MND care.

## Helping People Living with Motor Neurone Disease to Live Better for Longer

MNDcare at [www.mndcare.net.au](http://www.mndcare.net.au) is a new 'one-stop shop' website about motor neurone disease for primary, allied health, palliative, aged, disability and community care professionals.

MNDcare provides access to latest evidence based and best practice MND symptom management and support information. Help us promote [www.mndcare.net.au](http://www.mndcare.net.au) by letting your doctor and allied health, palliative, aged, disability and community care professionals know about this new Australian website about motor neurone disease.



*Information Evening for those recently diagnosed with MND, their family and friends 23 November at MND NSW Centre, Gladesville*

## Introducing...



### Kristina Dodds

*Education and Carer Support Coordinator*

Hello everyone. I am delighted to be working for MND NSW after working closely with the organisation over the last 18 months, introducing the Community Mentoring Program with HOME Hospice to carers of people with MND. I am also thrilled to be sharing my role with Kate Maguire. Kate and I job-shared in our last

position, so we know how to work and laugh together.

I have a background in education, training and volunteer management and as well as working at HOME Hospice, have also worked at Cancer Council and the Spastic Centre. I have been a carer and I now have two beautiful children, Gabriella who is eight and Sebastian who has just turned six, and Victor my husband!

I look forward to meeting with many of you over the next little while.



### Kate Maguire

*Education and Carer Support Coordinator*

A warm hello to you all. I feel honoured to join the team of MND NSW, an organisation that I have long admired for its caring and professionalism. I'm also delighted to have the opportunity to continue my working relationship with Kristina Dodds, who I enjoyed working closely with at HOME Hospice.

In my shared role as Education and Carer Support Coordinator, I hope to draw upon my personal experiences of being my parent's primary carer, along with my professional experiences of conducting educational programs for those living with disabilities and life limiting illness. I look forward to meeting many of you in the months ahead.

My teenage daughter Georgia Rose and I share our home with two dogs, two cats and two rats. Contrary to popular rumour, we are not building an ark in our spare time!



### David Dubin

*Bequest Officer*

I have been fundraising in the area of planned giving and bequests for the past three years and am very happy to have just recently joined MND NSW. I am in a committed relationship with one dependent child; a 17 year old boy who reminds me daily that life

happens very quickly and not to take anything for granted. I just recently acquired my Australian citizenship, a very proud and personal achievement for me and a testament to the wonderful opportunities this great nation has to offer. I am very excited about our efforts here at the Association and look forward to meeting our members, their families, friends and all of the wonderful individuals and groups who support this very important cause.

## A Message from the CEO

Over half-way through 2010 and hopefully the weather is warming up for you.

The past three months have been hectic with MND Global Day 2010 on 21 June, marked by the presentation of the national MNDcare website at Parliament House in Canberra. This event was well attended by politicians from across the political spectrum.

The following week we held our second Walk to d'Feet MND in Canberra and, despite the freezing conditions, over 300 people attended.

The end of June marked the end of the financial year. As can be seen from this and previous editions of *Forum* (see [www.mndnsw.asn.au](http://www.mndnsw.asn.au) > *information resources*) during the previous two years we have had a dramatic increase in demand for our services. This is due to a large increase in membership with a 13% increase from 2008-09 to the end of 2009-10.

Just over 400 people with motor neurone disease are members of the Association and this places a greater workload on services. Between 2008-09

and 2009-10 family support visits have increased by 11%, support calls and calls to our Info Line by 6% and referrals to our equipment service by 48%.

Due to this increase and our desire to expand and consolidate services in regional and remote areas of New South Wales we have commenced work on our first Major Gift Campaign. The goal is to raise \$750,000 over the next year. MND NSW has never embarked on such an ambitious campaign and we hope that motor neurone disease awareness in NSW corporate circles will be a major outcome. Please let me know if you have a contact that you think we should make.

We have had several staff changes during the past three months. Jane Barrett and Iva Plessnitzer have left and we all wish them well. Kristina Dodds, Kate Maguire and David Dubin have joined MND NSW.

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

**Graham Opie**

*Chief Executive Officer*

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

*Watch your mailbox for more details*

### MND NSW Members'

#### Christmas Party 2010

Saturday 20 November 2010

2.30pm to 4.30pm

Ryedale Room, Ryde Eastwood Leagues Club,  
117 Ryedale Rd West Ryde NSW 2114

## MND NSW

### PATRON

*Her Excellency Professor Marie Bashir  
AC Governor of New South Wales*

### VICE PATRONS

*Paul Brock AM*

*Melinda Gainsford Taylor*

*Kevin Langdon OAM*

*The Hon. Mr. Justice Peter W. Young*

### Auditor

*C.M.Pitt & Co.*

### Solicitors

*Mallesons Stephen Jaques*

### MND NSW BOARD

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#### Secretary

*Bob Howe*

#### Treasurer

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#### Board Members

*Phil Brady, Alex Green, Gary Jacobson,  
Ralph Warren*

Motor Neurone Disease Association  
of New South Wales

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[www.mndnsw.asn.au](http://www.mndnsw.asn.au)

ABN 12 387 503 221

### Chief Executive Officer

*Graham Opie*

### Office Coordinator

*Petra Sammut*

### Administrative Assistant

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### Accountant

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### Fundraising Manager

*Kym Nielsen*

### Fundraising Assistant

*Ayse Dalkic*

### Bequest Officer

*David Dubin*

### Family Support Manager

*Gina Svolos*

### Regional Advisors

*Chris Carroll, Jo Fowler, Caroline Gleig, Jenny Judd,*

*Eileen O'Loughlen, Robyn Petersen, Noelle Smith*

### Information Line Advisor

*David Wallace*

### Education and Carer Support Coordinators

*Kristina Dodds, Kate Maguire*

### Equipment Service Coordinator

*Maree Hibbert*

### Equipment Assistant

*Michael Walker*

### Information Resources Coordinator

*Penny Waterson*



*And.....many valued volunteers including Nadheera (above) who has catalogued the MND NSW library resources*



## Family Support Team

It was great to see some of you at our recent Ask the Experts Forum. It was a successful day, valued by those attending, with comments on the evaluation forms such as, 'Thank you for providing this forum. Educational, inspiring and motivating.' Distance, lack of mobility, other commitments and tiredness are just some of the barriers that can make attendance at events such as Ask the Experts impossible for some members and their families.

For those who were unable to attend we have included a summary of the day in this edition of *Forum*. Also, we have audio recorded the speakers and placed these podcasts on our website.

One of the difficulties for many people with MND is accepting help in the home. This might be because none of us want to be a burden on others or because we feel others are more in need than ourselves. While this is a very positive approach it can result in just the opposite. Suddenly a person can experience a change in their situation and if there are no services involved and there has been no pre-planning it is really difficult to get assistance at short notice. This can then become an even bigger burden on family than if someone had said yes to some help in the first place. So I encourage people to take up the opportunity of attending education programs such as Learn Now, Live Well (see next page) or to talk to their regional advisors to find out more about what might be available to assist them and their families in living well with MND.

### Quality of life and experiences of chronic illness

Amanda Dean is looking for people with motor neurone disease to participate in her PhD project to voice their views on the disease. She is travelling to Australia for a period of three months from 13 September 2010 and will be able to meet and interview individuals in Sydney who wish to contribute to this research. She also provides an e-mail correspondence option if you live too far away or have speech difficulties.

You may be eligible to participate if you:

- Have received a confirmed diagnosis of MND from a certified medical practitioner.
- Have a current or past undertaking of regular physical activity, a minimum of three times per week - the specific activity is not important, for example, recreational joggers, hikers, commuter cyclists as well as competitive or non competitive athletes of individual or team sports are free to participate.

This project has ethics approval from the University of Exeter. For more information contact Amanda Dean, PhD Researcher, University of Exeter, acd205@ex.ac.uk.

It's also good to plan some fun times with family and we have an opportunity coming up for people to go sailing on Sydney Harbour on Sunday 17 October. This is always a fun day and, with limited numbers, fills up really quickly. For further information see page 6.

And don't forget that FlexiRest funding is still available to give carers a break from caring. Sometimes 'change is as good as a holiday' and through this funding carers can have a break and make time for themselves. This may be time away for the carer with or without the person they are caring for. We received four years funding for this program and this is the last year of the funding. During last financial year more than 100 people, caring for someone with MND, used this funding to have a break. We are currently preparing an evaluation to send to the Department of Human Services; Ageing, Disability and Home Care Services to report on the value of this service and the FlexiRest program coordinator, Julie Becke may be in contact with some of you to get your feedback. You are also welcome to send us your feedback to assist us in gaining further funding to continue the FlexiRest program. For further information on how to apply for FlexiRest please contact your regional advisor.

### Staff Changes

There have been a few staff changes recently. During August we said farewell to Iva Plessnitzer, Regional Advisor for Southern NSW and ACT, and we have just appointed a new person to this role.

We also farewelled Jane Barrett and recruited Kristina Dodds and Kate Maguire to job-share the Education and Carer Support Coordinator role. They will be looking after the education and support programs that we conduct for people with MND, their carers and service providers. Kristina and Kate introduce themselves on page 2.

### Volunteer Message

This new volunteer initiative has been met with great enthusiasm from our members and is proving to be a much appreciated service. We now need to train some more volunteers to help us keep up with the demand as all the volunteers from our last training group are now fully occupied providing massages to our members in the Sydney region. If you know anyone who might like to be a volunteer ask them to contact Ayse Dalkic at MND NSW ph. 8877 0908 or aysed@mndnsw.asn.au for further information. In the meantime our apologies to anyone who is waiting for a massage volunteer to visit.

**Gina Svolos**

*Manager, Family Support*

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

## Equipment

Between January and July 2010 there were 1078 equipment referrals made to the MND NSW Equipment Loan Pool. This is an increase of 48 per cent on last year. During the same period over 773 loans were made, which is an 18 per cent increase on last year. The increase in referrals has outweighed our ability to meet demand.

This has meant delays in the loan of some types of equipment including medical beds, powered wheelchairs and roho cushions. For some referrals we have asked healthcare professionals to access equipment through other services.

Loans are made on a priority of need basis rather than on the date the equipment referral was received. If you are on the waitlist for an item of

equipment through MND NSW it is best to keep in contact with your healthcare professional, usually your occupational therapist or speech pathologist, regarding any changes to your needs. Also, notify your MND NSW regional advisor if you feel your need for the equipment has become urgent.

One of our equipment assistants, Matthew Fowler, who has been with us for the past three years, will be leaving in early September. Matt has recently completed his university degree and is now moving on to expand his experiences. All of the team at MND NSW wish Matt a fond farewell and the best of luck for the future.

**Maree Hibbert**

*Equipment Services Coordinator*

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

## Learn Now Live Well

10am to 3pm **Monday 8 November and Monday 15 November**  
*For people with motor neurone disease, their family and friends*

Learn about:

- living well with MND
- health and community services you can access
- the roles of various health workers
- services offered by MND NSW

*Have your questions answered and meet other people who know what it is like to be living with MND*

For further information contact MND NSW ph 1800 777 175

## Support Groups

### ACT

The ACT and Southern NSW support group will recommence regular meetings in early 2011. For more information contact Gina Svolos, Manager, Family Support Services ph 1800 777 175.

### Western Sydney

At our recent meeting we welcomed quite a few new people who were interested to hear our speakers from the Anglicare Community Options Program in Penrith and the Commonwealth Carer Respite Service. Jessica spoke about what a case manager can offer people with MND to help them live as independently as possible in their place of choice. This includes help with domestic services, personal care, shopping, transport and social support. Case managers are also available to assist

people to sort out issues with other agencies with whom you may be involved. The Commonwealth Respite and Carelink Centres also assists people to live as independently as possible by connecting people to services they may need as well as providing emergency or short term respite care.

The next Support Group will be on 14 September. Lorel Adams from the Australian Motor Neurone Disease DNA Bank and Carolyn Cecere from the Molecular Medicine Laboratory at Concord Hospital are the guest speakers. Our meetings are very casual and we share numerous sweet treats and cups of tea and coffee. You are most welcome to attend.

**Jenny Judd**

*Regional Advisor*

**METROPOLITAN** Ph. MND NSW 1800 777 175

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

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

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

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

### REGIONAL AND RURAL

**ACT and Southern NSW** | Gina Svolos | 1800 777 175 | [ginas@mndnsw.asn.au](mailto:ginas@mndnsw.asn.au)

**Broken Hill** | Jamie Mitchell | 08 8088 7093 (bh) or 08 8088 1333 (ah)

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

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

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

**Newcastle and Hunter** | Noelle Smith | 4921 4157 | [noelles@mndnsw.asn.au](mailto:noelles@mndnsw.asn.au) or

Eileen O'Loughlen | [eileenno@mndnsw.asn.au](mailto:eileenno@mndnsw.asn.au)

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

## Mailbag

MND NSW member Robbi Skinner forwards her FlexiRest holiday journal...

**Day 1...** Our trip was good, we found the Dolphin Sands quite readily. It wasn't what we were expecting, only seven cabins. Very quiet. Clean pool and spa. We got a very warm welcome by the owner. Our disability cabin was big and clean. The bathroom was great. Bev unloaded the car. She worked like a pack horse and then we went to Aldi to get supplies for the week, and I forgot my pillow so I bought a magnetic one from Aldi...woohoo!!!



then we walked to the Bowling Club for lunch. Walked home and had tea and watched a DVD.

**Day 5...** Went to Grafton. After looking at the gardens we went to the information centre to find out where this big new shopping complex was. They said 'over the bridge on the right you can't

**Day 2...** Cold but lovely sitting on the front verandah. My shower lady arrived and she was lovely, gentle and kind. She got me all dressed up and smelling like a rose...lol, lol. Bev and I went to Sawtell, street shopping, an al fresco cafe and a quaint old cinema. I couldn't shop there because I don't have a millionaire sugar daddy.

**Day 3...** My shower lady came in all smiles. We became friends - she had personality plus. After she left I lay on the bed till 11am. Then up and had lunch at the Pet Porpoise pool and then the show. I got kissed by a seal and fed the blue penguins. The place was wonderful... They take the Companion Card too. I nearly fell in the cabin, Bev saved me, I had bought new slippers and tripped.

**Day 4...** Here comes smiley.. lol. She told me I had to buy new clothes because mine were too big on me. Bev went on errand and I had a cup of tea and

miss it'. NO you can't when you find the bloody bridge. We drove around and around asking people 'where was shopping centre 'over the bridge''. We stopped asking that question and asked, 'where was the bridge'. Half an hour later we found it.

**Day 6...** We had a lovely day yesterday, a little tired today. We went to the Clog Barn, where they make clogs and they have a miniature Dutch Village and a restaurant. Excellent. They take the Companion Card as well. We spent three hours there then went home. I was in pain. Was okay by teatime so we went to the club for dinner and a show. Went home and to bed.

**Day 7...** I was in a great deal of pain. MND didn't like me having so much fun. Packed up and drove home.

We are so thankful that we had the break and we'd like to thank everyone that made it possible.

Thank you

Your friend  
Robbi Skinner

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

The next MND NSW cruise with **Sailors with disAbility** will be on **Sunday 17 October**



leaving at 11 am from Rushcutters Bay.

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. Regional advisors from MND NSW sail with you on the day to assist. There is **no charge** to attend so if you are interested, **contact the MND NSW Infoline 1800 777 175 or 8877 0999 to book your spots**. You will be sent further details about parking, access and what to bring.

### Family Support Calendar

<b>Sunday 17 October</b>	<b>Sailors with disAbility Harbour Cruise</b>   <i>Rushcutters Bay</i>   See above for more
<b>Thursday 28 October</b>	<b>MND Special Interest Group Workshop for health and community care professionals</b>   <i>West Ryde</i>
<b>Mondays 8 and 15 November</b>	<b>Learn Now Live Well</b>   <i>Gladesville</i>   A two-day education and support workshop for people living with MND, their family and friends
<b>Saturday 20 November</b>	<b>Members' Christmas Party</b>   <i>West Ryde</i>   See page 3 for more
<b>Tuesday 23 November</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   <i>Gladesville</i>   Informal information evening for people who are newly diagnosed with motor neurone disease, and their families and friends

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.

## Update from Ask the Experts 2010

*The annual MND NSW Ask the Experts Forum, held during August, was once again a very well-attended and informative day. The speakers generously took time out of their busy schedules to attend and provided interesting presentations that stimulated much discussion. The following is a brief summary of the key points discussed during the day. Penny Waterson, Information Resources Coordinator.*

### About MND - Professor Dominic Rowe, Macquarie MND Neurology Service

Professor Rowe reviewed what is known about motor neurone disease (MND) and provided strategies that can be used when you are trying to separate MND facts from MND fallacies. When considering a therapy or treatment for MND you can use the four-question test to sort the wheat from the chaff -

1. What is the premise behind the proposed therapy?
2. How is the therapy going to help me?
3. How might the therapy hurt me – physically, psychologically and/or financially?
4. What is the person gaining by offering the therapy to me?

Some questions posed to Professor Rowe included:

*Q. What is the proven benefit of exercise in MND?*

A. It is unlikely that sport causes MND. Exercise is important for mood, pain management and mobility but does not improve survival. Never exercise to fatigue or pain.

*Q. Are the glia important in MND?*

A. Glia are the supporting cells to neurones and are thought to be important in how MND spreads through the nerve system.

*Q. Is there any new research on riluzole?*

A. By the time MND is diagnosed most people will already have about 70 per cent motor neurone cell loss in affected areas. Riluzole reduces glutamate and may also have other effects. We do know that people who take riluzole earlier will stay in the mild/moderate stages of MND for longer. Riluzole is best taken with doses about twelve hours apart on an empty stomach, but this can cause stomach upsets. Dose should be discussed with your neurologist because weight/dose may impact tolerance. Good nutrition and maintenance of weight is also very important for people with MND.

*Q. Does the body have the capacity to regenerate motor neurones?*

A. There is limited capacity for nerve cells to regenerate and repair to take up the slack created by motor neurone disease. If MND is not moving very rapidly, the body can slow down the advancing of the disease through natural repair, but eventually the neurones will fail.

*Q. Can a neurologist tell you how advanced your MND is and how long you have to survive?*

A. No. There are some observations such as if you are breathless when lying down and don't have treatment for nocturnal hypoventilation then you won't do as well. If you have swallowing problems,

and we don't look at good nutrition, you won't do as well as a person with MND who does have good nutrition and hydration. Often with MND you don't get high temperatures (with respiratory infection), so if you think your breathing has changed it is often a good idea to start antibiotics empirically so see your GP or neurologist to get a script to have on hand.

*Q. Do you need to lie on your back if you are using bi-level positive pressure ventilation?*

A. No.

*Q. How do you know when the person with MND needs to progress from continuous positive airway pressure ventilation to bi level positive pressure ventilation?*

A. Continuous positive airway pressure ventilation is not usually used in MND. It produces a gentle blast of air at a continuous pressure that keeps your throat open for breathing while you are asleep. Bi-level positive pressure ventilation delivers one level of air pressure when you breathe in and another level of air pressure for breathing out. A respiratory physician can give you advice about ventilation and MND.

*Q. Is there any research looking for other drugs that are an improvement on riluzole?*

A. In the UK, France and the USA they are researching anti-Nogo<sup>(1)</sup> therapy; there is another trial looking at VEGF<sup>(2)</sup>. The problem is that the mouse model used for testing for MND hasn't been effective in testing drugs for humans. Also there is a lack of acknowledgement of the different forms of motor neurone disease within drug trials but we are getting better at this.

*(Cont'd overleaf)*

<sup>(1)</sup> GSK1223249 is a new drug developed by GlaxoSmithKline that targets a protein called Neurite Outgrowth Inhibitor A (Nogo-A). Nogo-A impairs neurone regeneration and is found at higher than normal levels in people with MND. GSK1223249 mops up Nogo-A and may therefore help limit the loss of connections between motor neurones and muscles. GlaxoSmithKline has begun a Phase I trial in the UK, France and America, involving around 70 people with MND, in which GSK1223249 will be given to humans for the first time

<sup>(2)</sup> SB-509 is a newly synthesised gene therapy drug created by Sagamo Biosciences. It works by increasing the level of the neurotrophic factor VEGF. An 18 month Phase II clinical trial to test the safety and efficacy of SB-509 is expected to be complete in 2010. sNN0029 is a drug sponsored by the pharmaceutical company NeuroNova and contains the "nerve nourishing" neurotrophic factor VEGF. In MND animal model studies, direct administration of VEGF into the fluid filled cavity of the brain via a catheter and pump improved the animals' muscle strength and prolonged survival. A three-month, Phase I and Phase II trial will soon begin in one centre in Belgium and will enrol up to 28 people with ALS. It is estimated that this trial will be complete in late-2010.

Extracts from [www.mndassociation.org](http://www.mndassociation.org)

*Do you want to know more about stem cells? Visit [www.closerlookatstemcells.org](http://www.closerlookatstemcells.org)*



## Update from Ask the Experts 2010 (cont'd)

### What's New in MND Research? - Dr James Burrell, Neurologist and Research Fellow, Neuroscience Research Australia

Dr Burrell reviewed the pathophysiology of MND and reminded us that MND is not a genetically inherited disorder for the majority of people with the disease. However, for five to ten percent of people with MND, the disease is genetically inherited and of these, one in five people will have an abnormality that is detected in the SOD1 gene. Recently, abnormalities in the TARDBP gene and the FUS gene have been found to account for another small minority of this already small group of people who have genetically inherited MND.

These findings are relevant because they open up new areas for research related to both genetically inherited and non-inherited MND. For example, the abnormalities in the TARDBP gene lead to an accumulation of the protein TDP-43 within nerve cells. This protein is also identified in non-inherited MND. Understanding how this gene and protein works could be crucial for our understanding of MND. Similarly, the abnormalities in the FUS gene lead to an accumulation of a protein called FUS. Both TDP-43 and FUS are normal proteins, but when there is an abnormality of the gene the proteins are found in areas of the cell they are not usually found in and the cell seems to die. It is not clear whether the cell dies because of the loss of the normal function of these proteins or because the accumulation of these proteins is toxic to the cells, but either way, once the cell dies we start to see the features of MND.

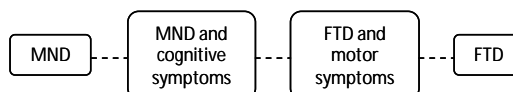
Continuing research in areas such as these may also help us, in the future, to make accurate early diagnosis of MND.

Now, there is often a long delay for most people between the symptom process and the diagnosis being made. But we know that early diagnosis provides the opportunity for earlier symptom management by a multidisciplinary team, earlier treatment and earlier entry into clinical trials.

An area of MND research underway in Sydney is contributing to the search for a biomarker for MND. Biomarkers are an objective measurement that act as an indicator of a normal or abnormal biological process, disease progression or treatment response. Professor Matthew Kiernan and Dr Steve Vucic at Neuroscience Research Australia are investigating a neurophysiological technique using transcranial magnetic stimulation technologies. They are using magnetic pulses on the part of the brain that controls hand function and looking at response differences in the muscle in the hand.

Overlaps between MND and the condition known

as fronto-temporal dementia (FTD) are a focus of Dr Burrell's research. There has been some overlap in the two conditions noted clinically – some people with MND will show cognitive symptoms and some people with FTD will show motor symptoms that are usually associated with MND. If the right types of tests are administered subtle cognitive change can be found in up to 50 per cent of people with MND, and as many as 15 to 20 per cent of people with MND may actually meet the criteria for FTD. This can be illustrated:



This is important because cognitive symptoms can be significant contributors to quality of life and carer stress and are difficult to treat.

Understanding and acknowledging these symptoms is important. Also, the group of researchers looking at FTD and the group of researchers looking at MND have started to pool their resources to the benefit of learning more about both conditions.

Other local research includes research at Prince of Wales investigating a sodium channel blocking agent. This medication has already proven to be safe and not toxic to humans, so this speeds up the research process and the focus of this research is

on the effect of this existing medication on MND. Recruitment has finished and we are looking forward to the results of the trial. Overseas, another agent being studied is talampanel. Talampanel has some similarities to riluzole but the research is in early days.

*Q. Can the plasticity of the brain compensate for the disease process of MND?*

A. The deterioration caused by MND is ongoing. There is some compensation but the capacity for compensation is limited.

*Q. Is there any evidence of vitamins being beneficial or is there any interaction of vitamins with riluzole, or paracetamol and riluzole?*

A. There are probably no significant interactions that we need to worry about with riluzole and other medications. If you have a well-balanced diet you usually cover most of your vitamin requirements.

*Q. Would you suggest a person stop taking riluzole to take a 'cocktail' of other things?*

A. No. There is a proven benefit for riluzole, albeit a minor benefit for some. We don't recommend stopping riluzole for a product that has no evidence of benefit.

*Q. What conclusions and results have you found in your studies of FTD and MND?*

A. FTD is a specific type of dementia that is uncommon. It presents in ways that are different to



*Astrid and Diana Starmer at Ask the Experts*

*Audio recordings from Ask the Experts can now be listened to on demand or downloaded from the MND NSW website [www.mndnsw.asn.au](http://www.mndnsw.asn.au)*



## Update from Ask the Experts 2010 (cont'd)

the typical Alzheimer's disease. It can cause changes in personality and behaviour, and people might lose motivation and interest in the things they would normally like to do. Sometimes their behaviour may be embarrassing to others. Specific tests are used to pick up these changes and these are not the same tests used for people with Alzheimer's disease. My research is primarily looking at the motor changes in people with FTD. No results have been published yet but changes in motor function have been found.

*Q. Are you aware of any therapies for reverting MND or extending life expectancy of people with MND?*

A. We have rigorous proof for riluzole, good respiratory management and nutrition. The best way for us to evaluate treatments is by clinical trials run by people who have a good reason for thinking the agent may be helpful. These trials also have a good support system for monitoring side-effects.

### Breathing Under Pressure - Dr Amanda Piper, Coordinator Respiratory Failure Service, RPAH

Dr Piper explained that the main muscles used for inspiration (breathing in) are the diaphragm and intercostals, with the stomach and neck muscles becoming involved when the diaphragm and intercostals are weak. If the diaphragm is weak and you are lifting or carrying items in your arms, then you can become breathless.

Changes in breathing are usually noticeable at first during sleep. Signs include snoring, pausing in breathing during sleep, rapid shallow breathing, restless sleep, insomnia, daytime sleepiness, morning headaches, feeling groggy in the morning or weight loss

Tests that can be done include:

- oximetry - testing the oxygen levels in the blood, although it can take several months for problems with night oxygen levels to show up during daytime testing
- arterial blood gas - can show if the person has been under-breathing for a short time or a longer time
- respiratory capacity - vital capacity shows how many litres of air a person can blow out in one breath
- sleep study

Treatment includes bi-level positive pressure ventilation delivering one level of air pressure when you breathe in and another level of air pressure for breathing out

Some people with bulbar MND symptoms may have trouble using bi-level positive pressure ventilation. Also, some people find the mask too uncomfortable or may find it difficult to manage the mask during sleep. Individual need and suitability can be discussed with your neurologist or respiratory physician.

*Q. Where can I get more information about a cough machine?*

A. They are expensive and you would need some training. They will not work with everyone but can be good to clear secretions. A clinic in a larger hospital can provide individual assessment because your suitability depends on which muscles are affected.

*Q. What is the normal range for oxygen?*

A. Absolutely normal is 80 to 100 mm measured through blood gas. Using oximetry it is 95 to 100 per cent.

*Q. Any comment about large inhalations (sighing) at rest?*

A. Sighing is like a lung stretch and is often much more noticeable if you have a breathing problem. If your breathing pattern is monotonous, sighing can open up the lungs while you are at rest, so if you are not moving around much you may sigh more frequently.

*Q. How do you prevent respiratory infection?*

A. Prevention of respiratory infection in people with respiratory muscle weakness is very important. Keep away from people with infections and have flu and pneumococcal vaccines. There are also some manual techniques that can be used to help clear secretions.

### Planning Ahead - John Berrill, Lawyer, Maurice Blackburn Pty Ltd

John Berrill explained that the two key superannuation issues are usually who gets the money and whether there are any disability benefits.



*Helen and Nick Baker at Ask the Experts*

Usually superannuation goes to your dependents and often it is the superannuation trustees who determine who your dependents are, irrespective of your nomination of dependents on your superannuation forms or in your will. The only way you can ensure the

people you nominate will receive your superannuation is through a binding nomination. This is a formal process and involves completing binding nomination documentation however some funds do not offer binding nominations and pay all superannuation funds into your estate. When you do make a binding nomination it needs to be renewed every three years and if you have a change in circumstance (such as remarriage) you also need to resubmit it. There may be tax benefits if you organise for your superannuation to go to your estate so it is important to seek advice about your superannuation plans.

Some superannuation funds offer death and disability benefits as part of the standard policy and you may be able to access these. So if you do have a superannuation account find out what you might be entitled to before you close a superannuation account. Even if you left your job a while ago, you may still be entitled to claim if

*Learn more at the MND NSW Learn Now Live Well two-day educational program about MND on Monday 8 and 15 November. See page 5*

**Update from Ask the Experts 2010 (cont'd)**

benefits exist and the policy is current. Self-managed superannuation funds generally have no insurance cover.

An up-to-date will is also very important if you want to know who gets your money. You can nominate beneficiaries in your will, but this can be challenged in courts before your estate is distributed. Having proof of competency could be important so you can prepare for this by having a doctor sign a certificate or record in his/her notes saying you are of sound mind.

If you are worried about decisions that may be made about you in the future you can appoint a financial power of attorney, an enduring power of attorney, a general power attorney or appoint people to be your guardian. There is a process that you need to go through but it is important to get your state-specific information. The Office of the Protective Commissioner in NSW has this information. It is not a very complex process.

*Q. I took a continuation option with my fund when I stopped work but the premiums have now escalated and are difficult to afford.*

A. Some funds have continuing cover for death and total and permanent disability (TPD).

Some have account based cover. As long as there is enough money in the account they continue to deduct your insurance premiums. Be careful when amalgamating or consolidating superannuation funds as this may affect your insurance cover and if you have more than one fund, you may be able to make more than one claim for death and TPD. If you are still in the workplace, don't change superannuation funds when MND is diagnosed because you may lose insurance cover.

*Q. Can you take out travel insurance online?*

A. Yes you can, but if you have MND then you would only be covered for everything except a claim related to your MND, which would be considered to be a pre-existing condition. For example, if you are travelling overseas and you get hit by a bus in London then you would be covered, unless the cause was MND-related, for example, a loss of mobility. However, the insurance company needs to prove that your pre-existing condition was the/a cause. If you wanted travel cover that included your MND then you would need to apply several months earlier by completing an application, getting a certificate from your doctor saying that you have a pre-existing condition but that you are not an adverse risk of becoming sick overseas, and submitting it to your insurer and seeing if they will cover you. The chance of them saying yes is probably not great, but is not impossible. A key factor is leaving enough time, between your application and the planned travel, to negotiate with the insurer.

*Q. Can I access super tax-free without having stopped working?*

A. If you do access all your superannuation you may lose all your insurance cover that may be associated with it. There may be ways you can steer around this.

*Q. Where can I get more information?*

A. You can get free advice, particularly on superannuation, from Maurice Blackburn Pty Ltd. Contact details are available from MND NSW.

**How Commonwealth Respite and Carelink Can Assist with Support and Services - Ann Mannix, Northside Community Forum Inc**

Commonwealth Respite and Carelink Centres are information centres for older people, people with disabilities and those who provide care and services. These centres provide free and confidential information on community aged care, disability and other support services available locally, interstate or anywhere within Australia. In every area of NSW and the ACT there is an agency in your local area funded by the government as a Commonwealth Respite and Carelink Centre.

At Ask the Experts, Ann Mannix from Northside Community Forum spoke of the services offered by Commonwealth Respite and Carelink Centres. In addition to offering information and links to other services, Commonwealth Respite and Carelink

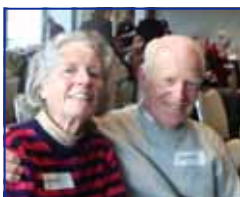
centres can help you arrange respite, when carers need to take a break from caring. They do this by acting as a single contact point for information needed by carers and by organising, purchasing, or managing respite care assistance packages for carers. Examples of respite care assistance include in-home respite care; support workers to assist you when you are taking a break away from home;

and residential respite care. Centres also provide information on many types of assistance, from personal care and domestic help to accommodation in nursing homes and hostels. Your local Centre can also let you know which services are available in your area. All information is free of charge and provided in confidence.

*Q. How do I contact the Commonwealth Respite and Carelink Centre in my area?*

A. You can call your nearest Centre using Freecall 1800 052 222. Deaf, hearing impaired or speech impaired callers may call through the National Relay Service using their modem or TTY by dialling 1800 555 677 then asking for Freecall 1800 052 222. Speech impaired callers may also call through Speech-to-Speech Relay by dialling 1800 555 727 then asking for Freecall 1800 052 222. If you prefer once you have called to locate your local agency, you can visit them in person.

*MND NSW thanks the speakers who generously gave their time to present at Ask the Experts 2010*



*Patricia and Warren Ball at Ask the Experts*

*Contact your Commonwealth Respite and Carelink Centre Freecall 1800 052 222*

## Community Events

### Safe workers at Sydney Water



Graham Opie, CEO, MND NSW, recently attended a cheque presentation with staff from Sydney Water. A Sydney Water staff member had nominated MND NSW as chosen charity for the Giving Through Safety program. This program provides incentives for staff to adopt safe work practices by linking safety targets to charity donations. Thanks to Tom McLoughlin and the staff at Sydney Water.

*Thank you to  
MND NSW  
supporters  
and friends*

### City 2 Surfers never gave up



*Sandra O'Brien with  
her sister Deborah  
Hunter*



This year saw a record field of 80,000 participants line up for this great event. Amongst them were 192 keen supporters of MND NSW all decked out in their blue MND T-shirts, which sport the "Never Give Up" slogan on the back. What a great way to raise awareness and funds for MND. A very big thank you to everyone who chose to support MND NSW by participating in this gruelling event. You are truly

inspirational and your support will give comfort and hope to those touched by MND.

### Walk to d'Feet MND - ACT

The second Canberra Walk to d'Feet MND held on Sunday 27 June was a great success. A cold but bright and sunny morning greeted the 300 participants who turned out to walk the 5km track around the lovely Lake Burley Griffin. Many had created their own hero page and raised much needed funds for research into MND. The Canberra Times gave us great support with a team of 23 walkers and front page coverage. To everyone who participated or sponsored a participant for this event a very big thank you. This event was once again held jointly by MND NSW and MND Australia.



### Supporters tee off at the Kerrie Cripps Memorial Golf Day

The Kerrie Cripps Memorial Golf Day was successfully held at Cronulla Golf Club on 30 June 2010. Approx 120 ladies competed for the trophy and congratulations to Noeline Shaw who won the event. MND merchandise was sold on the day and donations were received for research into motor neurone disease.



*(l-r) Jayden  
Cripps, Noeline  
Shaw, Michael  
Cripps, Lois  
Longhurst  
(President), and  
Suzie Wilson  
(Captain)*

### Thoughtful students at Cheltenham

At a school assembly held on 10 June the student representative council of Cheltenham Girls High School presented MND NSW fundraising manager, Kym Nielsen, with a the proceeds of their fundraising efforts towards MND. The students had chosen MND NSW to support after several families at the school had been touched by this terrible disease. Thank you to Cheltenham for their wonderful support.

### Dinner with a purpose

On Saturday 17 July, the Freemasons of Bathurst held a dinner dance in support of motor neurone disease at the Bathurst RSL Club. The night was well supported by the local members with raffles, silent auctions and other fundraising activities helping to raise much needed funds. A great evening was had by all. Patrons danced the night away to the rhythms of local band 'Session'. Thank you to the many local businesses who supported this event and to the hard working members of the Bathurst Masonic Club for organising such a wonderful event.

### Sandra 'I never win anything' Tosolini takes home the quilt

The lucky winner of the beautiful quilt donated by the Ladies Probus Club of the Upper Blue Mountains was Sandra Tosolini (pictured right with husband Paul). Congratulations Sandra. Thank you to everyone who supported this raffle.





## Dates for the Diary

11-12 September	<b>Open Gardens</b>   14 Davidson Avenue, Warrawee   Contact Stephen Daymond at daymond.gardens@gmail.com or ph. 94874828 for more information.
18 September	<b>Greta-Branxton Colts Over 35s Gala Day</b>   Greta Oval, Greta   For more information contact Glenn George 0412 215 912 or email g.george008@bigpond.com
19 September	<b>Sydney Marathon</b>   Suzi Heaton is running in the Sydney Marathon for MND   Contact shea7660@uni.sydney.edu.au for more information
5 November	<b>Gala Fundraising Evening at Le Montage</b>   Le Montage, 38 Frazer St, Lilyfield   Beautiful four-course meal with wine, silent auction and giant raffle. Tickets only \$150 per head. Contact connie@theplanet.net.au for more information.
7 November	<b>Walk to d'Feet MND Fundraising Walk</b>   Blaxland Park, Sydney Olympic Park   Contact Kym Nielsen at kymn@mndnsw.asn.au or ph. 8877 0912 for more details
6-7 December	<b>Wakehurst Golf Club Senior Pro-Am</b>   Wakehurst Golf Club, Seaforth   Contact Glen Hickey ph. 9949 3188 glenhickey@wakehurstgolf.com.au for more information
19 March 2011	<b>5th MonSTAR Cup</b>   Pennant Hills Golf Club, Pennant Hills   For more details and registration www.monstarfoundation.com.au

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



**Don't forget to  
order your  
MND NSW  
Christmas  
Cards**



See the insert to this edition of *Forum* for your order form. For more information contact MND NSW ph. 8877 0999 or visit [www.mndnsw.asn.au](http://www.mndnsw.asn.au)

### Your support to the Motor Neurone Disease Association of NSW will have an impact

*Please tick as many of the boxes as you wish.*

- ☐ Please send me a copy of the booklet *Preparing for the Future*.
- ☐ I have already put MND NSW in my Will. Please enrol me as a member of the Blue Cornflower Society.
- ☐ I have a question. Please have a Bequest Officer call me.

Name (Mr, Mrs, Miss, Dr,) \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Here is an additional gift for the work of MND NSW \$ \_\_\_\_\_

*MND NSW Locked Bag 5005 Gladesville NSW 1675*



#### ACKNOWLEDGEMENT

We wish to thank  
Snap Printing, North Ryde  
for their generous support.

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*Editor: Penny Waterson*