



# FORUM

## A Message from the CEO

Happy New Year

The International Symposium on ALS/MND and Allied Professionals Forum held in late November last year and co-hosted by MND NSW was a huge success. Over 600 researchers, neurologists, doctors, allied health and disability workers from around the world attended. It was a chance to share expertise and knowledge and drive research, care and support for people with MND.

As reported in the December 2011 edition of *Forum*, Ask the Experts was broadcast through the internet allowing people from around Australia and the world to view the presentations and ask questions of the presenters. If you missed this you can catch all the presentations on the link from our website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

The national push for a National Disability Insurance Scheme (NDIS) has gained significant support with over 100,000 signatures through the Every Australian Counts campaign. If you, your family or friends have not added your name to the growing list of supporters you can do so through the Every Australian Counts link on the MND NSW website. Throughout January and February I have been speaking at several of the MND NSW support groups, encouraging people to sign on to the campaign.

The NDIS will be the national focus during MND Week, which this year will be held from Sunday 6 May through to Saturday 12 May.

Our push is to make sure that people over the pension age who acquire a disability (over 40% of people with MND), receive the same care and support as those aged under the pension age. As the NDIS proposal currently stands, people over the pension age will be excluded from the NDIS. MND NSW, Australia and all state and territory MND

Associations believe that access to appropriate disability services should be based on need, not age.

From February of this year, in partnership with the NSW Government Ageing, Disability and Home Care (ADHC) and the Cerebral Palsy Alliance (CPA), we will be looking at the personal and wider community communication needs of our members. This has significant implications, particularly for regional and remote areas of NSW where access to services and allied health and disability expertise is limited. We'll keep you updated as we progress.

Throughout 2011 the number of cities and towns in NSW and the ACT hosting Walk to d'Feet MND events has grown and for 2012 there are already four Walk events planned to take place in regional NSW, the ACT and Sydney. They are a fantastic community event and a great way to spend the morning with family and friends. If you would like to hold a Walk to d'Feet MND in your community or participate in any of the Walks to be held around the state check our events calendar at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) or contact Kym Nielsen or Ayse Dalkic at the MND NSW Centre at Gladesville ph. 8877 0999.

Our biannual survey, to members and allied health professionals, has been sent and we hope you will take the time to participate. It is the best way we have of getting a broad picture of the impact of our services on you, the member and helps us to develop new programs and refine old.

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

You and your family and friends are warmly invited to

### A Day of Hope and Remembrance

Saturday 12 May 2012  
1.30pm to 3.30pm

**Soka Gakkai International Centre**  
3 Parkview Drive, Sydney Olympic Park

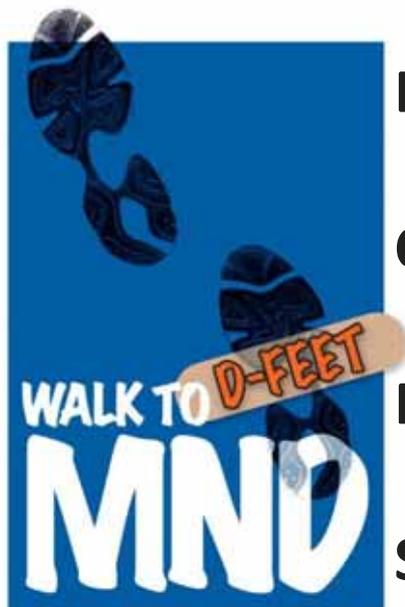
Our afternoon of Hope and Remembrance is for people whose lives have been touched by motor neurone disease; people living with MND, family, friends, supporters, volunteers and those working with MND.

A candle lighting ceremony will follow to represent the hopes of people affected by MND and to remember and celebrate the lives of those who have lost their life to MND. Afternoon tea and light refreshments will conclude the day.

This venue is close to public transport, has disability parking and a metered car park next to the venue. Children are most welcome.

Please RSVP to MND NSW ph. 02 8877 0999 or freecall 1800 777 175 or email [familysupport@mndnsw.asn.au](mailto:familysupport@mndnsw.asn.au) by Monday 7 May.

*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.*



**Bowral 18 March**

**Canberra 24 June**

**Port Macquarie 7 October**

**Sydney 4 November**

If you'd like to organise a Walk to d'Feet MND in your local area contact Kym Nielsen on [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au) or ph. 8877 0999.

## Introducing...



### Alysha Borg

#### Equipment Support Officer

Hello everyone. I am delighted to join MND NSW as the Equipment Support Officer and look forward to working with you all. I am currently studying a Masters of Occupational Therapy and am also working as a support worker for people with acquired brain injuries. I have a background in education, teaching PDHPE in a high school. I have always had a strong interest in health and in working in jobs that aim to improve others' quality of life. I am looking forward to learning about the assistive devices that people with MND have available to them and working on the communications project with Maree and Gina. I look forward to meeting you.

## Motor Neurone Disease Association of New South Wales

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AC Governor of New South Wales*

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### MND NSW

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

ABN 12 387 503 221

### Chief Executive Officer

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### Fundraising Assistant

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### Family Support Manager

*Gina Svolos*

### Regional Advisors

*Chris Carroll, Gail Ferguson, Jo Fowler, Caroline Gleig, Jenny Judd, Eileen O'Loughlen, Robyn Petersen, Kim Sinclair*

### Information Line Advisor

*David Wallace*

### Education and Carer Support Coordinators

*Kristina Dodds, Kate Maguire*

### Equipment Service Coordinator

*Maree Hibbert*

### Equipment Assistants / Support Officer

*Tom Giardina, Michael Walker / Alysha Borg*

### Information Resources Coordinator

*Penny Waterson*

And...many valued volunteers including Liz, on a golf buggy, volunteering at the MonStaR Cup.



## Family Support Team

In the last 12 months the number of support groups we have in both metropolitan and regional NSW for people with MND and their family has grown, with new groups in Liverpool, Muswellbrook, Port Macquarie and the Gold Coast. We are also planning another group in the Griffith area to commence later in 2012.

One of our regional advisors, Jo Fowler, commented that,

*"There is huge value attending a support group. Support groups offer opportunities to meet with others who are sharing a similar journey. Group participants have reported increased knowledge about MND and the many support services that are available to them in the community. Through interactions with others, group members have not only gained confidence in handling their care needs, but have also acquired a better understanding of themselves and others."*

We are grateful to the health and community professionals who give of their time to either help conduct these groups or come along as a guest speaker to share their knowledge with those who attend. Without their support we wouldn't be able to hold as many groups as we currently do. I encourage anyone who hasn't attended a support group to perhaps attend a meeting in their area as often people report that they didn't think a support group would help them but then realise that through meeting others in a similar situation they learn more about how to live with MND. See page 6 for your local support group meeting.

### Carers courses

Another way to learn more about MND is through attending our education programs. During 2012 we will have several of these for people with MND and their families. First up this year are two programs for carers, one in Port Macquarie and one at our Gladesville office. The Care for Carers program offers family and friends who are caring for someone with MND an opportunity to learn more about MND and the needs of the person living with it as well as opportunity to share ideas and experiences and have a break away. Following many of these courses carers remain in contact with each other and continue to support each other as they do understand what it's like to care for someone with MND. For more information see page 4.

### Day of Hope and Remembrance

This annual event is held during MND Week each May. MND Week is a time to raise awareness about MND in our community and various events are held throughout Australia. Following requests from some of our members that they would like the Day of Hope and Remembrance to be held on a

Saturday so that family and friends can attend we have scheduled it this year for Saturday 12 May. We hope that you are able to attend this MND NSW community event. See page 1 for further details

### Member survey

Just a reminder to return the survey that was posted to you in early February. MND NSW asks members living with MND to give feedback about the services and support provided by our organisation. This important information will assist us with future planning. We value your thoughts so if you haven't returned your form yet please do so as soon as possible. I will write a report in the next Forum to share some of our findings with you.

### Farewell to Robyn Petersen

Robyn Petersen, our regional advisor who has worked in south western Sydney and the Illawarra over the past four and a half years, is retiring from her position. Robyn has worked very hard to develop services in her area and has formed great relationships with members, their families and the service providers. Her caring nature, compassion and her willingness to advocate locally for people living with MND has been a great asset and she will be very much missed. We thank her for her hard work and dedication and wish her all the best.

We are currently recruiting to this position and will write to the members in this area when a new regional advisor commences.

**Gina Svolos**

Manager, Family Support

## Free computer skills workshop for 'beginners'

MND NSW Centre Gladesville

Monday 25 June

10.30am to 2.30pm

Are you someone who never learnt how to use a computer, or have very limited skills?

Would you like the opportunity to learn:

- how to use basic computer equipment
- introduction to the internet
- setting up an email account
- communicating by email

Carers NSW are offering this light-hearted introduction to computers for carers, on Monday 25 June at the MND NSW Centre at Gladesville. Numbers are limited to 10 participants.

To reserve your place phone 8877-0999 or 1800 777 175 or email [katem@mndnsw.asn.au](mailto:katem@mndnsw.asn.au)

Still have your 2012 Family Support Member Survey hanging around? Send it back today to MND NSW Locked Bag 5005 Gladesville 1675

## Family Support Team (cont'd)

### Equipment

#### Equipment referrals and loans

MND NSW has received 1481 referrals for equipment in the 12 months to February 2012. We have been able to loan 1224 pieces of equipment, including the hire of 16 electrical beds for members in regional or hard to access areas.

Unfortunately the demand for powered wheelchairs has been very high. We have only been able to loan 77% of the referrals made for these items, with 65 referrals received for powered wheelchairs but only 50 loans made.

MND NSW has spent over \$121,000 on purchasing new equipment during the past year to better meet demand.

When we have high demand and long waitlists for particular items we may ask the referring occupational therapist to also apply for the item through the NSW government equipment loan service EnableNSW. We do this because sometimes the item may become available through that service. Recently we have had to make such requests for the more specialised tilt-in-space mid-wheel drive powered wheelchairs, which we have had great demand for.

#### Purchasing your own equipment

Sometimes, members will purchase their own equipment. Before going ahead with an equipment purchase it is recommended that you contact your occupational therapist so their knowledge and expertise can be used to make sure the correct features are included and the equipment is suitable and safe for you to use. This may take a little longer but it will save money and most importantly ensure your safety when the correct equipment is purchased and used. Your community or hospital occupational therapist is there to assist you so talk to them about your plans before entering into purchase agreements with private equipment suppliers. The community and hospital occupational therapists are not aligned to any specific brands of equipment.

#### Welcome to Alysha

Alysha Borg has commenced in the role of part-time Equipment Support Officer, working 8 hours per week, focussing on communication equipment. Alysha introduces herself on page 2 of this edition of *Forum*. Welcome Alysha.

#### Maree Hibbert

Equipment Services Coordinator

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

### Care for Carers

**14 May, 21 May, 28 May and 4 June  
MND NSW Centre Gladesville**

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

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

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

- You will have the opportunity to hear from a range of health professionals with expertise in MND, who will answer your questions in a relaxed and informal setting.
- You will learn how to prepare your home, manage symptoms such as swallowing, communication and respiration. You will also learn about eating well with MND, accessing services and equipment and caring for yourself as you care.

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

A complimentary lunch and morning tea is provided each day. There is no cost to attend, but we do ask that you be willing to commit to attending all sessions. If you have any questions or need support with travel or arranging care for your family member, please call MND NSW Infoline or speak to your Regional Advisor.

Places are limited, so please RSVP by Monday May 1 by ph. 8877 0999 or email [katem@mndnsw.asn.au](mailto:katem@mndnsw.asn.au)

*"I was initially quite reluctant to attend this course, yet I am so glad that I did. The knowledge I gained during the program was invaluable for me and I really enjoyed attending each week and seeing my new friends. It's been wonderful to get to know others who understand what it is like to have a family member with MND."*

*"Things are so much easier for me now. I feel stronger. I've learnt there's a lot of support available for my partner and myself, I have learnt what to expect and I am no longer afraid."*

## Support Groups

### Northern Sydney (Hornsby)

Our first meeting for 2012 was very well attended and we are looking forward to another action-packed calendar of events this year. A record number of members and their carers turned up to hear from Graham Opie, CEO MND NSW. Graham outlined the pivotal role the government is taking in transforming disability services through its 'National Disability Insurance Scheme' (NDIS). He encouraged everyone to get behind the scheme and link up with the 'Every Australian Counts' website. If you missed the details, go to [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au).

The group extends a warm welcome to new members, their families and carers. Our lunchtime meetings are bi-monthly and the next meeting will be held at the Thornleigh Community Centre, on Thursday 12 April. There is plenty of parking nearby and the building is wheelchair friendly. For more information, feedback or suggestions, contact the MND NSW Infoline ph. 1800 777 175 or me on ph. 0408 803 789.

*Jo Fowler - Regional Advisor*

### Port Macquarie



Our December meeting was held at Rose's Vineyard at St Innes.

We enjoyed a lovely morning tea, keeping our fingers crossed, hoping the rain would stay away. Fortunately,

Mother Nature looked after us, and we were able to enjoy the beautiful ambience of the vineyard. Thank you to our volunteer Janice Campbell for suggesting and organising this beautiful venue.

Kym Nielsen, MND NSW Fundraising Manager, was able to join us to personally thank members and their families for their wonderful support of the recent Port Macquarie Walk to d'Feet MND

In 2012 the Port Macquarie Support group will continue to be held at the Rotary Community Hall in Hastings River Drive. The meetings are held bi-monthly on the fourth Thursday from 10am to 12pm and our next meeting is on 26 April. Morning tea is provided and our volunteer Rosemary Mann co-facilitates the meetings. If you would like further information contact me ph. 4921 6357 or the MND NSW Infoline ph. 1800 777 175.

*Eileen O'Loughlen - Regional Advisor*

### Central Coast

The joy of Christmas filled our late November meeting. The decorations and festive food set the scene and Jane Darby led the carols with her famous guitar. We also drew the beautiful Christmas wall-hanging raffle. Members participated in the lucky dip, which is always lots of fun. Janice donated some of her handmade cards which raised \$100. Also some executive pens, puppies and, of course, MND NSW socks went home for Christmas.

Our meetings for 2012 will be held on the first Thursday, bi-monthly at Niagara Park Community Centre at 1pm. This earlier time allows people to travel at a less busy time traffic-wise.

Graham Opie, CEO, and 'our Jo' (Jo Fowler, Regional Advisor) joined us for our February meeting as we welcomed in the new year. Graham spoke on National Disability Insurance Scheme and brought us up to date with what's going on. Lots of questions were asked. Jo discussed the Ask the Experts Forum held in November and together we dissected the contents of December Forum.

What a difference a great group can make. Our group is very friendly and paves the way to connect and learn from others experiencing similar challenges. Good speakers, great food and excellent company.

See you at our next meeting on Thursday 5 April. For more information contact Audree Dash ph. 4384 2907 or Jo Fowler, MND NSW ph. 1800 777 715.

*Audree Dash - Coordinator*

*Jo Fowler - Regional Advisor*



*Don and Ros at the Central Coast Support Group*

*(Continued on page 6)*

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

### Support Groups (cont'd)

*(Continued from page 5)*

#### Western Sydney

The support group continues to be well attended and popular with members and our first meeting for 2012 will be on 13 March. It will be a social occasion where we can decide what we would like to do for the remainder of the year.

We meet at the Kingswood Neighbourhood Centre, 19 Bringelly Road, Kingswood from 1pm to 3pm. Bring along any questions, challenges, solutions you have found to difficulties and anything else related to the MND journey.

The group is a great way to connect with other people experiencing similar challenges. Afternoon tea is provided and the group is convivial and relaxed. Everyone is welcome.

*Jenny Judd - Regional Advisor*

#### Upper Hunter - Muswellbrook

The inaugural gathering of the Upper Hunter Support Network (Muswellbrook) occurred in early February and was well attended by both those affected by MND and their loved ones. The atmosphere was casual and relaxed, with everyone feeling comfortable in the surroundings and with each other. Conversation was warm and free

flowing to the point that the chat continued well after our official finish time of 12.30pm! Everybody had the opportunity to meet Sorin Timis and Amanda Ing, social workers from Muswellbrook Community Health, who will be co-facilitating this group together with me on an alternating basis.

We discussed how members would like this group to run and the decision was made to have the opportunity to chat informally with each other for the first hour of the meeting and then to have a guest speaker do a short presentation with questions and answers for the second hour of the meeting.

The Muswellbrook Community Health speech pathologist is already booked in to speak at the June meeting and I am working on a guest speaker for the next gathering which is on the 11 April.

We meet in the Pegasus room of the Pegasus Day Centre located in the grounds of the Muswellbrook Hospital, from 10.30am to 12.30pm. Please contact me if you would like further details ph. 4985 5022 or 0413 977 053. We would warmly welcome more attendees.

*Kim Sinclair - Regional Advisor*

*Support group dates for 2012 are available at [www.mndnsw.asn.au](http://www.mndnsw.asn.au)*

#### Were you bereaved in 2011 after caring for someone with MND?

MND NSW likes to acknowledge those who have cared for someone with MND. One of the ways that we do this is through hosting a lunch for our bereaved carers and family twice a year at the MND NSW Centre at Gladesville. The next lunch is on **26 March** and it will provide an opportunity for you to reconnect with old friends from MND NSW and to meet others who have had similar experiences. After lunch there will be a short talk and discussion about some of the experiences you may be facing through bereavement. If you have not yet had an opportunity to attend one of these lunches and have cared for someone with MND during the last 12 months, RSVP by Thursday 22 March ph. 8877 0999 or [familysupport@mndnsw.asn.au](mailto:familysupport@mndnsw.asn.au)

### Support Groups

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

Campbelltown - MND Infoline | [davidw@mndnsw.asn.au](mailto:davidw@mndnsw.asn.au)

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

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

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

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

#### REGIONAL AND RURAL

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

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

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

Illawarra - MND Infoline | 1800 777 175 | [davidw@mndnsw.asn.au](mailto:davidw@mndnsw.asn.au)

Muswellbrook (Upper Hunter) - Kim Sinclair | 4985 5022 | [kims@mndnsw.asn.au](mailto:kims@mndnsw.asn.au)

Newcastle and Hunter - Eileen O'Loughlen | 4921 4157 | [eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au) or  
Kim Sinclair | 4985 5022 | [kims@mndnsw.asn.au](mailto:kims@mndnsw.asn.au)

North West (Tamworth) - Kim Sinclair | 4985 5022 | [kims@mndnsw.asn.au](mailto:kims@mndnsw.asn.au)

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

Gold Coast Carers - Chris Carroll | 0421 252 455 | [chrisc@mndnsw.asn.au](mailto:chrisc@mndnsw.asn.au)

## Carers - taking a break

Taking a break from caring is a realistic and important thing to do.

It offers carers a chance to restore their energy and find time for important things like:

- catching up with friends
- having a rest
- going out
- attending to business
- taking a holiday.

Breaks are also important for the person you care for. It gives them an opportunity to socialise, meet other people and have some independence. It also helps them get used to other people providing support and caring for them.

### What stops carers from taking a break?

There may be many reasons why carers don't take a regular break.

Sometimes carers forget that it is just as important to look after themselves so that they can better cope with the demands of caring.

Carers may not know what help is available to them, or how to get help organising a break, or they may even feel that they don't deserve or need a break.

Or the carer may want a break, but the person being cared for doesn't. This can make carers feel guilty about leaving the person they are caring for.

### Who can help?

Other family members and friends may be happy to help out by giving you a break from caring. Often it's just a matter of asking.

### Respite services

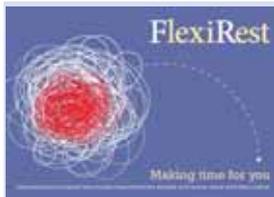
There are many organisations that will help you take a break. These are usually called respite services.

The NSW and Australian governments fund a number of respite programs that give carers regular, occasional and emergency breaks.

One of these programs is the FlexiRest program.

FlexiRest provides respite funding for MND families to spend relaxing time together.

Would you like to receive Forum by email? Email your details to Petra Sammut - petras@mndnsw.asn.au



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



## MND Week 2012

### 6 - 12 May

MND Week is just around the corner and we are looking for volunteers to help us make this the biggest MND Week yet.

There are lots of ways you can help. You could

- organise an event
- organise a *Drink tea for MND* at your office or with friends (see page 11)
- sell merchandise at a railway station
- sell merchandise at local shopping centre
- sell merchandise at your work or sporting club.

Current railway stations available are Town Hall, Wynyard, Circular Quay, St James, Edgecliff Station, Martin Place, Parramatta, Campbelltown, Eastwood, Wollongong, Penrith, Epping, Macquarie Uni, Macquarie Park, North Ryde, Chatswood and Miranda.

Authorities are required for all of the above activities so contact us now to let us know your plans.

Contact Kym Nielsen [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au), Ayse Dalkic [aysed@mndnsw.asn.au](mailto:aysed@mndnsw.asn.au) or Anne Jones [annej@mndnsw.asn.au](mailto:annej@mndnsw.asn.au) or alternatively ph. MND NSW 02 8877 0999.

## Noticeboard

### Planning Ahead Tools



Have you been thinking that you would like to make some plans for your future, but aren't quite sure what you need or where to start?

This new New South Wales Government website provides some of the tools, information and resources that you require to make your own decisions about your future. This site will guide you in how to write your will, how to communicate your wishes about your preferred future medical care and treatment and how to appoint a power of attorney or enduring guardian.

Visit [www.planningaheadtools.com.au](http://www.planningaheadtools.com.au)

### INSPIRED STUDY - Improving Service Provision for Early Onset Dementia



Early onset dementia is when a person has an onset of memory loss and/or other cognitive problems prior to the age of 65. These symptoms may occur due to a range of conditions such as

Alzheimer's disease or frontotemporal dementia, or they may result from medical conditions such as multiple sclerosis, motor neurone disease, Huntington's disease, or the long term effects of alcohol misuse. The numbers of people with early onset dementia seem to be increasing however there is little known about this group.

The INSPIRED study, led by Professor Brian Draper and Dr Adrienne Withall from the Dementia Collaborative Research Centre at the University of New South Wales, recently won funding from the National Health and Medical Research Council (NHMRC). The study will determine accurate information about the numbers of people affected, their different conditions, their experiences and those of their family members. Consumers will be interviewed across the South Eastern Sydney, Illawarra and Shoalhaven regions over the next two years. Importantly, the results of the study will inform service planners about the health and support service needs of younger persons with dementia and their carers, and will allow the development of training packages for health professionals working with these clients.

The INSPIRED study is a collaboration between researchers at the University of New South Wales, the University of Sydney, and at the Prince of Wales, St Vincent's, Sutherland and Port Kembla Hospitals. If you wish to seek more information about participating in the INSPIRED study contact the research co-ordinator Dr Prasad Nishtala on 9385 2617 or [inspiredstudy@unsw.edu.au](mailto:inspiredstudy@unsw.edu.au), or visit [www.inspiredstudy.org](http://www.inspiredstudy.org).

### Child and adolescent experiences and support needs



Curtin University

Researchers at Curtin University are currently recruiting parents or grandparents and their children or grandchildren (aged 12 to 25 years) who have, or have had, a parent or grandparent with MND.

This study aims to identify and explore child and adolescent experiences and support needs. This research has been approved by the Human Research Ethics Committee at Curtin University. The Chief Investigator is Dr Moira O'Connor. If you would like to participate in the study or would like more information contact Moira on Ph. 08 9266 1763 Mob. 0415 338 546 or [m.oconnor@curtin.edu.au](mailto:m.oconnor@curtin.edu.au)

### Free after hours GP helpline



The Australian Government has introduced a new after hours GP helpline. People who require after hours medical advice, who cannot access their usual GP and are not sure what they should do, can now speak to a GP over the telephone, when necessary.

### How will people use the helpline?

When a person calls the new helpline, their call will be answered by a registered nurse who will triage the caller. If necessary, the nurse will transfer the person to a GP on the telephone. The GP will talk with the person, assess their condition, make a diagnosis and provide medical advice.

When people calling the service are advised by either the telephone nurse or GP that they need to see a health professional immediately, they will be referred to the most appropriate face-to-face after hours services in their local area.

If at any point during the caller's conversation with either the nurse or the GP, the call is deemed to be an emergency, the caller will be immediately transferred to '000' with the nurse or GP staying on the line.

With the caller's permission, the patient's usual GP, will be able to obtain a record of the consultation with the telephone GP.

People living in the ACT, NSW and NT are able to access the helpline by calling 1800 022 222. Calls to this number are free from a landline.

*(Continued on page 9)*

*Volunteer to help out during MND Week between 6 and 12 May 2012.*

*Contact MND NSW ph. 8877 0999 for more information*

**Noticeboard cont'd**

*(Continued from page 8)*

**Guy Barnett announced as MND Australia Ambassador**



MND Australia has appointed Guy Barnett as an MND Australia Ambassador. Mr Barnett recently retired as a longstanding Tasmanian Senator and is a past President of MND Tasmania and a past national board member. In responding to the invitation by MND Australia to become its Ambassador, Mr Barnett expressed his commitment to continue his work on behalf of people living with MND and their families, both in Australia and internationally.

**Calling all creatives**



The theme of the 2012 Aurora Community TV Short Film Festival is 'Make Something'. And as long as it's under 10 minutes, Aurora don't mind what it is. It could be an animation, drama, documentary, music video,

anything. The point is to just 'Make Something'. So if you're after cash prizes, industry recognition, or you're just in it for the love of the craft, then get those creative caps on and enter the 2012 Aurora Short Film Festival. Entries close 30 April 2012. For more information visit [www.aurora.tv](http://www.aurora.tv)

**ALS/MND Webinars**

Sydney-sider Judith Lydia Mercure, whose brother has MND, has let us know about several MND related webinars organised by the ALS Association USA (ALSA) and ALS Therapy Development Institute (ALS TDI), also in the USA. Registration is free and the topics range from scientific research through to aspects of care for people living with MND. Past webinars are also accessible.

*ALSA research webinars:*

[www.alsa.org/research/research-webinars.html](http://www.alsa.org/research/research-webinars.html)

*ALSA care webinars:*

[www.alsa.org/als-care/resources/webinars.html](http://www.alsa.org/als-care/resources/webinars.html)

*ALS TDI webinars:*

[www.als.net/Events/Webinars/](http://www.als.net/Events/Webinars/)

Write to the Editor of Forum MND NSW Locked Bag 5005 Gladesville 1675 or email [info@mndnsw.asn.au](mailto:info@mndnsw.asn.au)

**Lorna's Homemade Memories**

By Lorna Jamieson

This cookbook came about after Lorna was diagnosed with MND. She has always been a good cook with a love of food. She sorted through her collection of recipes which were then typed by family and friends. The cookbooks are \$20 + \$6.50 postage and can be purchased by writing to Nola Trembath, PO Box 54 Barellan NSW 2665.



**Family Support Calendar**

|                                 |  |
|---------------------------------|--|
| <b>15-16 Mar</b>                | <b>Link and Learn</b>   <i>Port Macquarie</i>   To support you to give the best possible care at home for the person with MND  |
| <b>26 Mar</b>                   | <b>Lunch for bereaved carers</b>   <i>Gladesville</i>   For those who have experienced a bereavement through MND in the past twelve months   |
| <b>17 Apr</b>                   | <b>Information Evening for people recently diagnosed with MND, their family and friends</b>   <i>Gladesville</i>   |
| <b>14, 21, 28 May and 4 Jun</b> | <b>Care for Carers</b>   <i>Gladesville</i>   To enable you to care for a person with MND at home, while still taking care of yourself - see page 4 for more information.                                    |
| <b>19 Jun</b>                   | <b>Information Evening for people recently diagnosed with MND, their family and friends</b>   <i>Gladesville</i>   |
| <b>14 Aug</b>                   | <b>Ask the Experts</b>   <i>West Ryde</i>   You, family members, carers and friends can bring your questions about MND and have them answered  |
| <b>22 and 29 Oct</b>            | <b>Learn Now Live Well</b>   <i>Gladesville</i>   For people with MND, their family and friends. Two day educational program covering living well with MND and services available for people living with MND |

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.*

## Community events

Well the year has certainly started with some fantastic support with community events and Walk to d'Feet MND events planned right across NSW and the ACT. Currently we have Walks to be held during 2012 in Bowral, Canberra, Port Macquarie and Homebush, and planning for Walks in the Tweed Heads and Yass areas is underway.

Check out our events calendar on the back page of this edition of *Forum* or online at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) for some exciting events coming up in the next few months. There are some great golf days, soccer days, fight nights, trivia nights, motor cycle rides. Or maybe a grand Ball is more your style. Whatever your interest, there is an MND fundraising event for you to support. Thank you to all of the event organisers for their hard work in organising these great events for MND.

You can also support MND NSW by nominating MND NSW as your charity when you participate in **Channel Ten's 1 Million Kilo Challenge**, the **Sun Herald Surf/Swim** at Dee Why Beach on 18 March or the **Canberra Times Canberra Marathon** to be held 14 and 15 April.

Also, if you are thinking about organising a local event for MND you can create your own Everyday Hero Community Event fundraising page with MND NSW as your 'Cause' by following the links at [www.everydayhero.com.au](http://www.everydayhero.com.au). Do let us know about your ideas and plans so we can help you promote your activity or event for MND in *Forum*, the newsletter of MND NSW and on our website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

### **Kym Nielsen**

Fundraising Manager

[kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au)

Ph. 8877 0912



*(above) MND Fundraising Manager Kym Nielsen receives a cheque for \$1600 from Bill Eyles of the Blue Liners Motor Cycle Club. The money was raised on the Club's recent Iron Bark Motorcycle Ride.*

## Lorrie's story



Lorrie and Noel built their house in 1975 – a home that has been filled with laughter and tears. Perched high on a ridge north of Sydney, they look out over the beautiful Ku-ring-gai Chase National Park.

Lorrie loved to dance. In fact, she taught drama and dance to thousands of students over the years. But that all stopped when she started getting muscle cramps and losing movement in her arms and legs. Lorrie was diagnosed with MND.

*"Noel and I have two choices," said Lorrie. "We can laugh at the small things or we can feel sorry for ourselves. We choose to laugh".*

*"MND NSW has been wonderful; lending me an electric bed and other equipment which otherwise we would have had to purchase. And there is also the help at the end of the phone on the days when I just cannot find something to laugh about".*

*"If only there was more money available for research. I pray that one day there will be a cure – not for me, for I know it is too late, but for all those who come after me."*

*Lorrie MacGregor*

To honour Lorrie and the hundreds of people living with MND in NSW each and every day we ask you to make a difference.

Where there's a Will, there's a way! Leaving MND NSW a gift in your Will can make all the difference to people living with motor neurone disease. Your valuable gift will form a key part of the Association's long-term income and help us to continue providing essential equipment, information, support and advice for people living with MND, their families and carers and help fund research.

Make a world of difference to someone living with MND and be remembered for something incredible!

For more information about leaving a gift to MND NSW in your Will, please contact David Dubin on (02) 8877 0999, Freecall 1800 777 175 (NSW only) or mobile 0431 525 372 for a confidential discussion.

Alternatively, David can be reached via email at: [davidd@mndnsw.asn.au](mailto:davidd@mndnsw.asn.au).



It's on again!  
MonStar Cup  
2012

23 March  
Pennant Hills  
Golf Club  
[www.monstar  
foundation.  
com.au](http://www.monstarfoundation.com.au)

## Community events

### Christmas cheer

Well before Christmas I discussed with my adult children a desire this year to give a charitable donation instead of exchanging Christmas gifts. They all thought it was a grand idea and gave it their wholehearted support.

I also decided I would send out home produced Christmas cards instead of purchasing commercial ones and that for each card I would give a donation to MND. I have included the card with the thought that maybe MND might like to promote the concept. Production of the card was a family affair. Designed to be simple to make, it only involved folding a single sheet of A4 paper that was printed on one side. Created by my daughter Kate, I asked that it include on the cover a picture drawn by my eldest granddaughter, Heidi. All the work was done on a computer so that it could be reused, or become a free template for others to work from.

Please continue your good work.

**Malcolm**  
Epping



### Landcom Social Club

The Landcom Social Club donated the proceeds for the February Valentine's Day event to MND NSW. They organised a chocolate fountain morning tea during which they raffled a beautiful gift-boxed bottle of Moet champagne (that had been donated). The raffle raised \$282, which was then rounded up to \$300 using Social Club funds and sent MND NSW. Thanks Landcom Social Club.



### Stringers busking for MND

Students of guitar teacher Michelle Tesoriero, of Padstow, hit the streets before Christmas, busking for MND and raising \$331. Thanks Thomas, Savio, Jack, Travis, Pullock, Alexandra, Tim, Bella, Daniel, Jacinta and Michelle!



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

*Thank you to all of the volunteer event organisers for their hard work in organising great events for MND*



## What is Drink Tea for MND?

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

All you need to do is to host a *Drink Tea for MND* event!

*Drink Tea for MND* events can be hosted anytime, anywhere.

*Drink Tea for MND* is an event that knows no boundaries, so everybody can be involved.

Any event (big or small), any activity, any act, can be a part of raising awareness about Motor Neurone Disease.

Encourage your friends, family, colleagues, local community groups, schools and local businesses to get involved by holding a morning or afternoon tea and make a gold coin donation collection.

**Contact MND NSW now for your *Drink Tea for MND* information pack and registration form ph. 8877 0999 or email [fundraising@mndnsw.asn.au](mailto:fundraising@mndnsw.asn.au)**

**Dine with Professor Dominic Rowe**

**MonSTAR Foundation Auction**

**Bid Now** to enjoy the fine cuisine of Professor Dominic Rowe.

You will enjoy the ultimate long Sunday lunch or dinner prepared by one of Australia's leading authorities on MND.

Submit your bid to [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au) before 22 March 2012.

**High Tea for MND  
6 May 2012**

**2pm - 4.30pm**  
Shelly Beach  
Surf Life Saving Club  
(1 hour north of Sydney)

**Enjoy a High Tea and help raise funds for motor neurone disease. There will be an array of stalls for you to shop for your Mother's Day gifts as well as a Raffle and Lucky Door Prizes!**

For more information visit [www.eventswithpizazz.com.au/events/high-tea-for-motor-neurone-disease-sun-6th-may-2012/](http://www.eventswithpizazz.com.au/events/high-tea-for-motor-neurone-disease-sun-6th-may-2012/)



**Dates for the Diary**

|           |  |
|-----------|--|
| 18 Mar    | <b>Walk to d'Feet MND Southern Highlands - Bowral</b>   Fundraising Walk   Register online at <a href="http://www.mndnsw.asn.au">www.mndnsw.asn.au</a> or contact Alan Spence <a href="mailto:alan@arygleengineering.com">alan@arygleengineering.com</a>   |
| 23 Mar    | <b>6th MonStar Cup</b>   Pennant Hills Golf Club   <a href="mailto:enquiries@monstarfoundation.com.au">enquiries@monstarfoundation.com.au</a> or <a href="http://www.monstarfoundation.com.au">www.monstarfoundation.com.au</a>  |
| 24 Mar    | <b>Tas Run</b>   Motorcycle Run - Wagga Wagga   <a href="mailto:Chris Anthony canthony57@yahoo.com.au">Chris Anthony canthony57@yahoo.com.au</a>   |
| 9 Apr     | <b>The Masters Breakfast Tournament</b>   Golf Day Camden Lakeside Golf Club, Catherine Field   Brian Brown <a href="mailto:Brian@chamberdevelopments.com.au">Brian@chamberdevelopments.com.au</a>   |
| 13 Apr    | <b>Corporate Fight Night</b>   University of NSW Roundhouse   Josh King <a href="mailto:Josh@corporatefighter.com.au">Josh@corporatefighter.com.au</a>   |
| 21 Apr    | <b>Football to d'Feet MND</b>   Charity Football day Yerrinbool Oval, Yerrinbool   Danny Josipovic <a href="mailto:joscoe@bigpond.net.au">joscoe@bigpond.net.au</a>  |
| 28 Apr    | <b>Trivia Fundraiser for MND</b>   Cromer Community Centre   Pauline Jones and Barbara Barden ph. 0422 964 217   |
| 6-12 May  | <b>MND Week 2012</b>   |
| 6 May     | <b>High Tea for MND</b>   Shelly Beach   <a href="http://www.eventswithpizazz.com.au/events/high-tea-for-motor-neurone-disease-sun-6th-may-2012/">www.eventswithpizazz.com.au/events/high-tea-for-motor-neurone-disease-sun-6th-may-2012/</a>  |
| 20 May    | <b>Tilligerry Motorama</b>   Car Show & Shine, Market Stalls, Live Entertainment, Kids amusements at Tilligerry RSL Sports Club, Tanilba Bay   Don Barrett <a href="http://www.Tilligerrysports.com.au">www.Tilligerrysports.com.au</a> or <a href="https://www.facebook.com/pages/Tilligerry-Motorama/162957833817115?sk=info">https://www.facebook.com/pages/Tilligerry-Motorama/162957833817115?sk=info</a> |
| 12 Jun    | <b>Champers &amp; Pampers</b>   Cardiff South   Heidi Smith <a href="mailto:divineebeauty@live.com.au">divineebeauty@live.com.au</a>   |
| 24 Jun    | <b>Walk to d'Feet MND - Canberra</b>   Kym Nielsen, MND NSW ph. 8877 0999  |
| 22 Sep    | <b>Spring Ball</b>   Rydges Lakeside Canberra   Karin Van Leeuwen ph. 0419 694 313.  |
| 29-30 Sep | <b>Open Garden</b>   17 Linden Ave Pymble - call for volunteers to assist with refreshments   ph. MND NSW 8877 0999  |
| 7 Oct     | <b>Walk to d'Feet MND - Port Macquarie</b>   Bev Smith ph. 0411 335 104 or 6583 8345, or Kym Nielsen, MND NSW ph. 8877 0999  |
| 19 Oct    | <b>Illawarra Golf Day</b>   Wollongong Golf Club   Bryan Wells <a href="mailto:BryanWells@mcgrath.com.au">BryanWells@mcgrath.com.au</a>  |
| 4 Nov     | <b>Walk to d'Feet MND - Sydney</b>   Kym Nielsen, MND NSW ph. 8877 0999  |

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

*Editor: Penny Waterson*

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