



# FORUM

## City2Surf 2013

48 brave participants competed in this year's City2Surf on behalf of MND NSW raising over \$54,000 - an amazing effort. Thank you to each and every one of you; we have been touched by your wonderful stories and pictures and wish we had space to publish them all. *Kym Nielsen, Fundraising Manager*



**Heidi...** "I lost my adored Dad to MND almost seven years ago...I am certainly not a natural athlete. The MND Association was able to provide Dad with a Lightwriter. It made it possible for Dad to communicate with us all after speech for him became impossible."



**Ethan and Nadine...** "Here is a photo of my son, Ethan, and I finishing the City2Surf. Ethan wore the t-shirt that you sent. We were very proud to be supporting MND NSW as we

have a special connection. I have lost my grandfather, mother and uncle to MND - so having a genetic form of this disease in our family we like to support this very worthwhile charity. I know that Mum was walking with us the whole way...I'm pretty sure she was cheering Ethan on! What was even better was as we passed groups they would comment on the 'Never Give Up' on the back of Ethan's t-shirt - a great motto!"



**Jodie...** "Last Sunday a small group from Cooma travelled to Sydney and participated in the City2Surf 14km fun run to raise funds and awareness for MND. A close friend and

family member was diagnosed with MND last year inspiring the team to raise some much needed funds for this low profile disease to advance research and to raise awareness for the MND Association who do a wonderful job providing support to people with MND, their families and carers dealing with this disease which has no cure."



**Lara...** "My father was diagnosed with MND in 2004. I ran the City2Surf to raise funds for the MND Association. They provide wonderful support and assistance to people with MND and their families."

**Ian...** "The starter's gun fired and off I ran, in 'the zone', determined to do my best for my father-in-law Claudio and everyone who sponsored me. It was an honour to run in the MND blue shirt, representing those living with MND, and their carers and families."



**Lynda...** Lynda's mother Joyce was diagnosed with MND in January this year and despite the prognosis she said her mum remained a "cheerful bugger". Lynda has proven that an optimistic attitude runs in the family and took on the City2Surf to raise money and awareness for MND. Lynda named her campaign "rejoyce" as a dedication to her mother.



**Martine...** Running for her mum who was recently diagnosed with MND to raise awareness of MND in the hope that it can be better understood and that a cure could be found or, at least, treatment.



**Matt...** "Late last year my dad was diagnosed with MND. It is probably important to point out that not only is he my dad, but he is my best friend also. Dad has now finished work on his own terms and is enjoying the quality of life he still has, presently gallivanting overseas with my mum. I saw this run as an opportunity to not only raise much needed funds for a cause so close to my heart, but also raise much needed awareness in the wider community as many aspects of MND are still very much an unknown. I suppose on top of everything, I see this as an opportunity to show my love and support by completing the run on his behalf."



**Tony Abbott...** joined the crew for Team MND and ran as guide for visually impaired athlete **Nathan Johnston**, with **Nathan Shoemark**, **Glen Gorrick**, **Paul Smith** and **Murray Johnstone** all turning

in a decent time for the City2Surf and raising much-needed



awareness for MND .... and during July **Nathan Johnston** and **Glen Gorrick** also competed in the Sutherland 2 Surf in their MND NSW lycra, leading off the field of 8,000 competitors.



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

*Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries. The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.*

## Ambassador Volunteer Program

Would you like to become a volunteer Ambassador for the Motor Neurone Disease Association of NSW? Are you interested in delivering inspirational speeches/presentations to community groups such as schools, service clubs, fundraising groups or any other interested parties to help raise awareness of motor neurone disease; and informing people about the wonderful work our Association does?

If so, we will provide you with an Ambassador Kit containing up-to-date information about MND, and information about the mission, history, activities and funding of the Association. We will provide you with training and support.

For further details on MND NSW Ambassador Program or to register your interest contact Anne Jones ph. 8877 0999 or [annej@mndnsw.asn.au](mailto:annej@mndnsw.asn.au).



*Dee Doughty (right), Sydney metropolitan Ambassador, accepting a donated quilt from Betty Bird, Hunters Hill Quilters Association in April.*



*Dee Doughty (right) after a presentation to Forestville RSL Club in August, with Pat Shearer, MND NSW volunteer (left) and Ladies Aux President, Barbara Chisnall.*



*Ambassador for the Newcastle area, Don McMurray (centre) accepting a cheque for \$800 from the Rotary Club of Adamstown/New Lambton in June. The Club has invited Don to do a full presentation in the near future.*



*Joanne Crouch (left) from Dubbo accepting a donation cheque on behalf of MND NSW from Sharon Doick at Dubbo RSL fundraiser in June.*

100% of  
proceeds to  
MND NSW



\$34.95  
[www.mndnsw.asn.au](http://www.mndnsw.asn.au)

## Introducing...



### **Arja Aladjajian - Admin Assistant/Receptionist**

Hello everyone. I have a Finnish background but have lived in the (much) sunnier and warmer climate of Australia for many years. I am very pleased to have joined such an enthusiastic team here at MND NSW. I'll be working Monday to Thursday as admin assistant/receptionist at the MND NSW Centre at Gladesville and look forward to meeting many of you on the phone or in person if you visit.

## A Message from the CEO

The past few months have heralded some major changes. Some immediate and some that will take a while to implement.

DisabilityCare Australia kicked off in launch sites across Australia on 1 July. In NSW the launch site was Newcastle with people gradually being moved across to the new scheme. This will take a while and Lake Macquarie, Maitland and the ACT will move to DisabilityCare throughout 2014. Full details can be found at [www.disabilitycareaustralia.gov.au](http://www.disabilitycareaustralia.gov.au).

In July, the roll-out of our new equipment website FlexEquip.com.au happened (almost) without a hitch (it is IT after all). It will help streamline some of the processes for health professionals who make referrals to MND NSW for equipment (see page 5 for more information).

Also in July we heard that MND Aware, the MND NSW online and face to face training program for disability, community and health workers, had been selected as finalist for the 2013 National Disability Awards. You can find out more in the Family Support report on page 4.

We welcome Arja Aladjadian who has joined the staff at MND NSW.

This year our supporters participating in the 2013 City2Surf raised over \$54 000 and, just as importantly, much-needed awareness of MND in the community (see page 1). Thank you for your tremendous efforts.

For our supporters who might prefer a leisurely stroll with family, friends and other MND NSW supporters, our Walk to d'Feet MND Port Macquarie will be held on Sunday 15 September, Wagga Wagga on Sunday 20 October and Sydney on Sunday 10 November. Come along and join the sea of blue. See you there! You can keep up to date on Walk to d'Feet MND and other events supporting MND at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

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

## VALE

### Colin Thew

MND NSW Life Member

Joined MND NSW not long after its inception in 1981. In the early years of MND NSW Colin helped get the Association firmly on its feet.

### Dr Roderick Mackenzie

MND NSW Board Member - 2002 to 2003

## Motor Neurone Disease Association of New South Wales

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### MND NSW

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ABN 12 387 503 221

### Chief Executive Officer

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Eileen O'Loughlen, Kim Sinclair and Deb Ward*

### Information Line Advisor

*David Wallace*

### Education and Carer Support Coordinators

*Kristina Dodds, Kate Maguire*

### FlexEquip Coordinator

*Maree Hibbert*

### FlexEquip Assistants

*Tom Giardina, Michael Walker*

### Information Resources Coordinator

*Penny Waterson*

### And...many valued volunteers

including our 'Monday'

administration volunteer

*Jennifer Miles*





## Family Support Team

### Ask the Experts

Our Ask the Experts Forum was held in August with 120 people attending. It was great to see so many of you on the day. The Forum provided an opportunity to listen to the five speakers and have questions answered, and also the opportunity to meet others whose lives have been affected by MND. The feedback from the day was very positive with comments such as "it was wonderful, so many positive people to hear and to learn from them" and "it exceeded my expectations. The staff were very helpful and friendly".

Thank you to our great speakers - Professor Dominic Rowe, Dr Bradley Turner, Dr Frank Brennan, Rachelle Baldock and Sharon Lowe – without whom such a day would not have been possible. We have included a summary of the day for those of you who were unable to attend (see page 8). You can also access videos of the presentations at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

### Register your interest in Learn Now Live Well

Our next education program, *Learn Now Live Well* for people with MND and their family will be held on 11 and 18 November. See below for further details. People who attend these programs gain a lot of information that helps them to feel more able to deal with MND in their life and access the supports and services that they require.

### Information evening for people recently diagnosed with MND, their family and friends

A reminder also that we hold a regular information evening for people recently diagnosed with MND, their family and friends. These are held every two months at the MND NSW Centre at Gladesville. The next one will be on 22 October. If you would like us to organise an MND information session in your region, please speak to your regional advisor.

To register for any of these events please contact us on 1800 777 175 or email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au)

### 2013 National Disability Awards Finalist

MND NSW has been selected as a finalist for the 2013 National Disability Awards for its MND Aware training program for health and community professionals. This award recognises our MND Aware online training program and the MND Aware face-to-face training. To date over 650 professionals have attended this training with many more accessing the online training. These programs have been developed by Penny Waterson and Kristina Dodds with assistance from all of the Family Support team so we are very proud to have been selected as a finalist. Kristina Dodds and I will be travelling to Parliament House in November to attend the Awards Ceremony.

### Gina Svolos

Manager, Family Support

Follow the link  
at  
[www.mndnsw.asn.au](http://www.mndnsw.asn.au) to  
watch the  
Ask the  
Experts 2013  
videos



## Learn Now, Live Well

**11 and 18 November 2013**

10am to 3pm

MND NSW Centre, Gladesville

*A two day educational program to assist people to live well with MND.  
For people living with MND, their family and friends.*

Although there is currently no cure for motor neurone disease, it is not true to say that 'nothing can be done for the person with MND'. A great deal can be done to maintain quality of life and to address many of the effects of MND.

*Learn Now, Live Well* provides a range of strategies to live well with MND and to maintain independence. It also provides the opportunity for you to have your questions answered by a range of health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.

This venue is wheelchair accessible with parking available on site.

Lunch and refreshments will be provided each day. Let us know if you have dietary requirements.

There is no charge to attend this event.

To book your place or for financial assistance with travel arrangements contact

Kate Maguire Ph. 8877 0999 or 1800 777 175, or [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au)

## Equipment

### FlexEquip and MND NSW



The MND NSW Equipment Service has had a name change and is now known as FlexEquip. This service is provided by MND NSW to assist adults diagnosed with rapidly progressive neurological conditions to get equipment to meet short to medium term needs.

Stocked equipment is provided after assessment is made by an appropriate health professional - an occupational therapist, a physiotherapist or a speech pathologist. Following the assessment, the health professional completes an online referral to FlexEquip for the equipment.

The equipment service remains the same so please contact the FlexEquip staff - Maree Hibbert, Michael Walker or Tom Giardina - if you have any repair issues with your MND NSW provided equipment or if you are no longer using an item and would like to have it returned. We are more than happy to assist.

For more detailed information on equipment available and how FlexEquip operates please go to the FlexEquip website [www.flexequip.com.au](http://www.flexequip.com.au) or contact us at FlexEquip Ph. 02 8877 0999 or [flexequip@mndnsw.asn.au](mailto:flexequip@mndnsw.asn.au)

### Equipment referrals and provided equipment

Since 1 June 2013 FlexEquip has received 432 referrals for equipment and has been able to provide 353 items of equipment. This is an increase of 39% for referrals and 24% for provided equipment items compared to same period last year.

We have over 1800 items of equipment in the FlexEquip Equipment Library. Items are continually updated and reissued as required. The ability to provide this equipment could not be achieved without the generous efforts from our supporters who donate their time and/or money to MND NSW. Thank you.

**Maree Hibbert**  
FlexEquip Coordinator

Put it in your  
diary

Christmas  
Party for  
family support  
members,  
their family  
and friends

23 Nov

## Family Support Calendar 2013

|               |  |
|---------------|--|
| 16 Sep        | Lunch for bereaved carers   Gladesville  |
| 22 Oct        | Information Evening for people recently diagnosed with MND, their family and friends   Gladesville                 |
| 11 and 18 Nov | Learn Now Live Well   Gladesville   For people with MND, their family and friends. See page 4 for more information |
| 23 Nov        | Christmas Party for family support members, their family and friends   West Ryde                                   |
| 10 Dec        | Information Evening for people recently diagnosed with MND, their family and friends   Gladesville                 |

For more information contact the 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.



You, your family and friends are invited to

## MND NSW Family Support Members' Christmas Party

Saturday 23 November 2013

Ryedale Room, Ryde Eastwood Leagues Club,  
117 Ryedale Road, West Ryde

There is no charge to attend this event. For catering purposes, please  
RSVP

by 18 November ph. 8877 0999 or Freecall 1800 777 175, or [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au).

Let us know if you have dietary requirements.

We look forward to seeing you there!

## Around the support groups

### North West (Tamworth)

We continue to meet bi-monthly to provide participants with an avenue for support and information sharing. Meetings are facilitated by the wonderful Ruth Loseby from Northcott Disability Services and a guest speaker is usually in attendance. It is a relaxed and friendly atmosphere with new members often finding to their surprise that their thoughts of the stereotypical 'support group' are de-bunked, giving rise to a warm and safe sense of support. Attendees can contribute as much or as little as they feel comfortable with, which adds to the informal atmosphere. New members are always welcome. From our next meeting, Monday 14 October we will meet from 10.30am to 12.30pm. For more details contact Kim Sinclair ph. 4985 5022.

#### Kim Sinclair

*Regional Advisor*

### Newcastle and Hunter

This year our group had a venue change and we now meet in the relaxed setting at the Alzheimer's Association building in Hamilton. The new venue has excellent facilities and access, including a comfortable lounge area and a tranquil garden setting. We have seen this support group grow from strength to strength this year, with an increase in participants. It is an informal group gathering, with guest speakers only organised when requested and as deemed appropriate by the group. Our usual format, with our two group facilitators present, is to divide into two separate support groups for some of our time together; one group for people living with MND, and one group for the carers/family members of people with MND. This enables participants a genuine opportunity to confide in each other and speak to others who truly understand the challenges of dealing with MND, and there is great value in that. It is humbling to witness the bonds people have forged, and the way new attendees are welcomed into the group.

The next meeting will be held at Hamilton on Wednesday 16 October from 10am to 12pm. For more details contact Eileen O'Loughlen ph. 4921 4157 or Kim Sinclair ph. 4985 5022.

#### Eileen O'Loughlen and Kim Sinclair

*Regional Advisors*

### Northern Sydney (Thornleigh)

Our lunch time meetings at the Thornleigh Community Centre continue to flourish. Many new members have joined us this year and we have learnt much from each other through sharing ideas and useful tips about caring for loved ones at home. We have also benefited from some very informative health professional guest speakers this

year and especially would like to say thanks to our most recent guest speakers Lorna Hutchinson, Occupational Therapist, Hornsby Hospital and Julia Murphy, Senior Speech Pathologist, Ryde Community-based Rehabilitation Service. Lorna showed us ways to make access to the home environment safer with assistive devices such as toilet surrounds, ramps, and hand rails. She introduced us to a range of assistive devices such as personal alarms, chair and bed raisers, transfer benches and swivel bathing chairs. Julia covered many issues surrounding communication and swallowing difficulties. She demonstrated simple strategies that can assist swallowing. Additionally, Julia introduced us to a range of augmentative and alternative communication solutions for iPad and iPhones such as 'Proloquo2Go' and the free predictive app 'Verbally'. Our next meeting is on Thursday 10 October. If you would like to join this inclusive group and learn more about MND please contact Jo Fowler on 8877 0999.

#### Jo Fowler

*Regional Advisor*

### Muswellbrook (Upper Hunter)

Our group, which commenced at the start of last year, continues to be a success as a forum for information sharing and support. The first hour of the meeting is used as an informal catch up and it is wonderful to witness how easily the conversation flows and how supportive all participants are of each other. It is particularly warming to see how new members are welcomed into the group and how quickly they feel comfortable and at ease. The second hour of the meeting has a guest speaker in attendance to discuss a topic area relevant to MND. So far we have had our CEO, Graham Opie, as well as the local community health speech pathologist, dietitian and social worker; Carelink volunteer organisation; and a massage therapist. All speakers have been an invaluable source of information. The relaxed atmosphere has enabled the group participants to add their comments and questions relevant to the specific guest speaker topic and this has led to a great sense of feeling 'well-supported'. We will continue with this format with participants directing what they wish to get out of the gatherings. New members are always welcome. Our next meeting will be on Wednesday 9 October from 10.30am to 12.30pm at Muswellbrook Hospital Campus. For more details contact Kim Sinclair ph. 4985 5022.

#### Kim Sinclair

*Regional Advisor*

*(Continued on page 7)*

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

## Around the support groups (cont'd)

(Continued from page 6)

### Port Macquarie

We get together bi-monthly at the Rotary Community Hall in Hastings River Drive. The support group provides a safe, informal and relaxed environment, and provides the opportunity to meet other people living with MND, their family and friends. The meetings are full of support and friendship; ensuring new members feel welcome. We are very fortunate to have volunteer Rosemary Mann assist with facilitating the support group, and thank the Rotary Club of Port Macquarie for covering the cost of hiring the community hall for our meetings. The next meeting will be held on Thursday 24 October from 10am to 12pm. For further information contact Eileen O'Loughlen ph. 4921 4157

**Eileen O'Loughlen**  
Regional Advisor

### Central Coast

Our support group continues to meet bimonthly on the first Thursday afternoon on the Central Coast. We have been very lucky to have great guest speakers visit the group this year with a focus on carer support and services available to the local community via the Carer Support Unit at Gosford Hospital and Commonwealth Carer Respite Service. We were reminded of the excellent support

provided through LifeCircle at our last meeting, along with some flowery fun composing small posies from a beautiful collection of flowers.

This year we also said a big thank you to Sheila Holmes and Pat Powell who have both supported the group over many years. Both these ladies have moved home. Members of the group have put in huge efforts attending shopping centres, selling tickets and making quilts, not only raising awareness but also raising much appreciated funds in support of MND NSW.

Our next meeting will be on Thursday 3 October from 1-3pm at our shiny new venue! We will be meeting for at least the rest of this year at the Gosford/Narara Neighbourhood Centre 2 Pandala Rd Narara. It is a lovely spot with very welcoming atmosphere and our group is fun, relaxed and with a strong sense of local community. We hope to see you there.

**Audree Dash**

Coordinator

**Deb Ward**

Regional Advisor



Support group meeting dates are at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) or contact the MND Info Line 1800 777 175

## Support Groups

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

Campbelltown - Ann McCutcheon | [annm@mndnsw.asn.au](mailto:annm@mndnsw.asn.au)

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

Liverpool - Ann McCutcheon | [annm@mndnsw.asn.au](mailto:annm@mndnsw.asn.au)

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

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

Western Sydney - Contact MND NSW ph. 1800 777 175 for more information

### REGIONAL AND RURAL

ACT and Southern NSW - Dianne Epstein | 6286 9900 | [diannee@mndnsw.asn.au](mailto:diannee@mndnsw.asn.au)

Central Coast - Audree Dash | 4384 2907 or Deb Ward | 1800 777 175 | [debw@mndnsw.asn.au](mailto:debw@mndnsw.asn.au)

Central West - MND NSW Info Line | 1800 777 175 | [davidw@mndnsw.asn.au](mailto:davidw@mndnsw.asn.au)

Griffith and Region - Dianne Epstein | 6286 9900 | [diannee@mndnsw.asn.au](mailto:diannee@mndnsw.asn.au)

Illawarra - Ann McCutcheon | 1800 777 175 | [annm@mndnsw.asn.au](mailto:annm@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)

## Ask the Experts 2013

*The 2013 MND NSW Ask the Experts Forum was attended by 120 people, which makes it our largest Ask the Experts Forum yet. All were keen to listen to and learn from the five professionals who kindly agreed to share their expertise and knowledge about MND.*

*Our experts this year were Professor Dominic Rowe, Dr Bradley Turner, Dr Frank Brennan, Rachelle Baldock and Sharon Lowe. We are most grateful to each of them for their willingness to participate and be videoed on the day. If you were unable to attend Ask the Experts this year, or if you would like the opportunity to hear these experts speak again, videos of the presentations are now available by following the link at [www.mndnsw.asn.au](http://www.mndnsw.asn.au). We also have several copies on DVD available for free loan to members and their families through the MND Info Line ph. 1800 777 175.*

### About MND - an overview

**Dominic Rowe**

**Professor of Neurology, Macquarie University  
Australian School of Advanced Medicine**

Dominic explained that there is much more that we don't know than we do know about MND. He acknowledged that often the person with MND is the expert and their family are the expert observers.

No two people with MND have exactly the same signs and symptoms and this presents challenges for researchers seeking to understand more about MND. MND is a difficult disease to diagnose because diagnosis needs history-taking and careful physical examination supported by neuro-physiology and imaging. However, about one in five people with MND never fulfil the criteria for the disease - the El Escorial Criteria - but it is the best criteria we have.

There is a relative selective vulnerability of motor neurones in MND. Each person is initially affected differently to another. By the time a particular muscle weakness is noticed by the person with the disease, about 70% of lower motor neurones involved in activating that muscle have been affected. When exploring the pathogenesis of MND - the mechanism that causes the disease - it is becoming clear that the cause of MND is multifactorial and most likely includes a complex interaction of genetic and environmental factors; glutamate excitotoxicity; oxidative stress and the role of glia; abnormal calcium homeostasis; abnormal mitochondrial function; and abnormal trafficking proteins.

Current therapies for MND include the drug riluzole, which was identified in the 1990s and has been shown to slow down the momentum of the disease, and extend survival for an average of three months. Multidisciplinary care has also been shown to be beneficial. It is a team approach providing integrated, timely, reactive and patient-centric care. Non-invasive ventilation can also improve quality of life.

*Q. Is the non-invasive ventilation machine like the CPAP machine used for obstructive sleep apnoea?*

A. Very similar. Obstructive sleep apnoea is a

condition where the throat closes down when people go into REM sleep and people snore. With MND the central drive to breath can be affected and indications of this include a person not snoring when previously they did; and morning tiredness. The non-invasive ventilation (NIV) machine used in MND uses bi-level ventilation (BiPAP) rather than continuous positive airway pressure (CPAP).

*Q. What about daytime sleep and hypoventilation?*

A. Anytime you are in REM sleep cycle, breathing can be affected so it's ok to use NIV during day sleep.

*Q. Who is responsible for checking on progression of condition? Who monitors? GP? Clinic?*

A. Be your own advocate. The point of an MND clinic is to monitor. A GP may only see a couple of people with MND during their career. Be 'a squeaky gate'. Get attention by making a noise if you have to.

### What's new in MND research?

**Bradley Turner**

**Research Fellow, Florey Institute of Neuroscience  
and Mental Health, University of Melbourne**

Bradley explained that the drug riluzole is a symptom modifying treatment for MND. However the search continues for disease modifying treatments and, ultimately, a cure for MND. It is a very complex disease - MND has different subtypes (heterogeneous nature) which progress differently and have different cellular pathology.

A biomarker is an indicator that can be measured and shows if a condition (eg MND) is present in a person.

Two images presented by Bradley (page 9) showed the importance of finding a biomarker for MND.

Because there is no biomarker to show the presence of MND early on, current drug trials are conducted on people with MND who have disability and many affected motor neurones (Fig 1).

If we had a biomarker that showed when early disease was present (Fig 2) then perhaps drugs, that are showing little or no effect later in the disease process, may be effective when administered earlier.

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receive Forum by  
email?*

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mndnsw.asn.au](mailto:admin@mndnsw.asn.au)*



## Ask the Experts 2013 (cont'd)

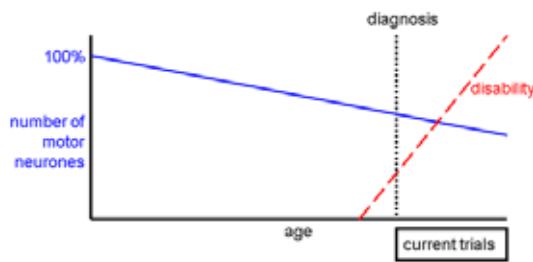


Figure 1

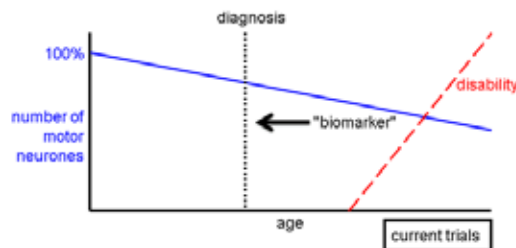


Figure 2

There have been huge advances in MND genetics knowledge during the past 10 years (Fig 3).

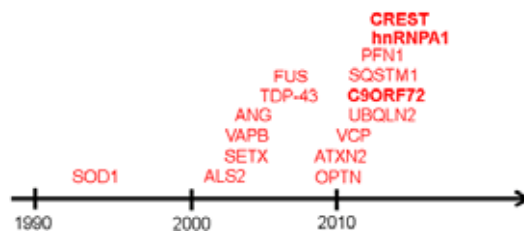


Figure 3

Exome sequencing, introduced in 2010, has enabled the DNA sequencing of an individual to be done within a week. As a result, many new MND genes have been identified and this is building a much larger body of research about MND.

**Maintaining quality of life**

**Frank Brennan**

*Palliative Physician, Calvary Health Care*

MND is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in the USA. Frank started by telling the story of Lou Gehrig, a famous US baseball player, who died from ALS in 1941. Lou Gehrig called his diagnosis with ALS his 'bad break'.

Frank spoke about how a person can maintain their 'sense of life' in the face of MND and suggested that all of a person's needs need to be attended to for this to occur. These needs include physical (symptom) needs, psychosocial needs and spiritual needs.

Getting good multidisciplinary care and good care coordination allows a person to get symptom relief so that 'living' can happen. Referral to palliative care is not just for the 'dying patient' because

palliative care teams can offer specialist symptom management advice, and provide help and advice with emotional and spiritual needs from the time of diagnosis with MND.

Q: How was Lou Gehrig diagnosed?

A: it was a long process. He thought he was just getting burnt out with playing.

Q: How can we encourage a family member to seek advice such as palliative care advice, when they don't want it?

A: This reluctance can come from a place of fear. Respect that but empower them with knowledge and contact numbers. Give them lots of reassurance. First visit could be from a palliative care nurse rather than palliative care doctor.

**Communication: it matters**

**Rachelle Baldock, Occupational Therapist, and Sharon Lowe, Speech Pathologist**

**TASC (Technology Solutions for Access, Seating and Communication), Cerebral Palsy Alliance**

Sharon spoke about how MND may affect a person's ability to participate in any or all communication modes including speech, facial expressions, and hand movements needed for writing, or using a mouse or keyboard.

There are aids and equipment items available that can be used for communication and the speech pathologist and occupational therapist often work together talking to the person about their needs, assessing the barriers to communication (for example, reduced hand function), trialling various solutions and knowing the options available for accessing aids and equipment. They also provide installation, setup, followup support and ongoing review to ensure a person's communication needs are met.

Key considerations include: thinking about issues early; being open to using several different communication devices to meet your needs; and being willing to trial equipment. The right solution for any one person will be based on that person's communication needs, environmental factors and methods for access.

Rachelle and Sharon then provided a hands-on demonstration of many devices and solutions available. These ranged from no-tech or low-tech devices including communication charts and call bells and alarms for gaining attention; through to medium-high tech items such as bluetooth or wired switches for operating devices such as iPads with communication apps, and eye gaze systems. There are also many solutions available for mounting and positioning devices for use.

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

## Community events

### Australian Government Solicitor Canberra Social Club

Kylie Bailey from the Australian Government Solicitor Canberra Social Club organised a morning tea raising \$472. Thanks Kylie.

### ICAP Annual Global Charity Day donation

ICAP's Annual Global Charity Day raises money for different charities. Thank you to ICAP client Cameron Simmons and his wife Marissa for nominating MND NSW to receive a donation of \$2500.

### Baptist Community Services Coffee Shop fundraiser

Linda Dimmock, Activities Officer from Baptist Community Services, Macquarie Park organised two fundraising events that raised \$1720 - a wonderful effort considering that the skies opened up on the day of the Mini Fete. Thank you also to Di Openshaw, MND NSW volunteer for assisting on the day.

### Cessnock Rugby League Charity Luncheon

Dave O'Brien raised \$4000 from a charity luncheon in July. MND NSW was chosen following the diagnosis and death of one of their former players, Greg Redgrove. Newcastle Knight's coach Wayne Bennett was the keynote speaker for the event.

### Chocolates fundraiser for MND NSW

Jacki Griffiths raised \$305 as the first donation from proceeds of chocolate sales at her work at Rural Press North Richmond. Thanks Jacki.

### Lorraine's Walk

Karlie Stringer's event in May included a walk around the Peel River in Tamworth followed by a picnic lunch. Donations, raffles and merchandise sales on the day raised \$885.

### Cumberland-Prospect Commonwealth Respite and Carelink Centre

Commonwealth Respite and Carelink Centre Office Admin coordinator, Christine Taylor, organised a Drink Tea for MND event in May at the Cumberland-Prospect Centre's Office in Seven Hills raising \$320.

### Soccer 2013 Annual Darby Day in memory of Brian Floyd




Marissa Floyd organised a very successful soccer fundraising event in July. Soccer players from the Ladies Belrose and Wakehurst Clubs got together to raise money in memory of Marissa's dad, Brian who died in December 2011. A total of \$1348 was raised.

(Continued on page 11)

MND merchandise gets conversations about MND started.

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

## Dates for the Diary 2013

|        |   |
|--------|---|
| 15 Sep |  <b>Walk to d'Feet MND - Port Macquarie</b>   Westport Park   Online registration at <a href="http://www.mndnsw.asn.au">www.mndnsw.asn.au</a>            |
| 21 Sep | <b>Illawarra Seniors Dance Group Charity Ball</b>   Dapto   Contact Betty Davis ph. 4283 1886   |
| 29 Sep | <b>Lighthouse to Lighthouse Fundraising Run</b>   Wollongong to Kiama   Contact Shelly-Anne Demirov <a href="mailto:shellyannedemirov@gmail.com">shellyannedemirov@gmail.com</a>  |
| 12 Oct | <b>Gundaroo Music Festival</b>   Bands playing on mobile truck stage at Gundaroo. Contact Scott Harding ph. 0459 231 743  |
| 13 Oct | <b>Social Ballroom Dancing Fundraising - Hurstville</b>   Contact Frank McQuade ph. 0407 237 326  |
| 13 Oct | <b>Donald Lai - Melbourne Marathon</b>   Contact Kym Nielsen <a href="mailto:kymn@mndnsw.asn.au">kymn@mndnsw.asn.au</a>   |
| 18 Oct | <b>Brewery Fest MND Fundraiser</b>   Rouse Hill   Contact Ben Waters ph. 9679 4555  |
| 20 Oct |  <b>Walk to d'Feet MND - Wagga Wagga</b>   Online registration at <a href="http://www.mndnsw.asn.au">www.mndnsw.asn.au</a>                               |
| 25 Oct | <b>Financial and Media Markets Charity Regatta Racing</b>   Sydney Harbour   Contact David Brocklehurst <a href="mailto:david.brocklehurst@thomsonreuters.com">david.brocklehurst@thomsonreuters.com</a> ph. 9373 1984 or 0412 411 366      |
| 27 Oct | <b>Burgh2Beach 2013 Fun Run</b>   Helensburgh to Stanwell Park Beach   More information and online registration <a href="http://www.burgh2beach.com.au">www.burgh2beach.com.au</a>  |
| 10 Nov |  <b>Walk to d'Feet MND - Sydney</b>   Blaxland Riverside Park Homebush   Online registration at <a href="http://www.mndnsw.asn.au">www.mndnsw.asn.au</a> |
| 7 Dec  | <b>Ride to the Reef</b>   Leura to Port Douglas   Contact Bob Montgomery via <a href="mailto:jenny@corpak.com.au">jenny@corpak.com.au</a>   |

## Community events (cont'd)

### Judy Dwyer Quilt Raffle

Judy was diagnosed with MND early 2012. Thanks to her combined talent for both quilting and fundraising, a staggering \$2763 was raised from the proceeds of the quilt raffle drawn in July.



### High Tea for MND

Helen Cook from Merimbula hosted a Drink Tea for MND event raising \$400 in July, following the diagnosis of the daughter of one of her good friends.



### Mufti Day for MND at Lake Munmorah Public School

Chris Knight and children in year 4 from Lake Munmorah Public School organised a very successful mufti day in July raising \$1020. Freda Pooley, who has MND, has been a volunteer in their library for 12 years.



### Christmas street party for MND honouring Lisa Perini

Kathy Hill worked tirelessly to organise this day in honour of Lisa Perini who has MND (Lisa is pictured with Northern Beach Social Riders) raising \$2730.



Last year, Lisa's friends raised over \$6000 at a Melbourne Cup High Tea at St Rose Primary School, Collaroy Plateau.

### Dubbo RSL Club High Tea and Fashion Parade

Sharon Doick (left), Events Manager at Dubbo RSL Club, organised a High Tea and Fashion Parade at the Club during June in memory of her mother, Elaine, who died in 2011. The room looked stunning themed in blue and pink: blue for MND and pink because it was her mother's favourite color. Over \$3700 was raised.



### Narromine We Run, Walk or Ride for MND

Over \$11,000 was raised for MND NSW at this May event in Narromine. Both Susan Orchard-Barber and Jacqui Schofield have lost family members to

MND in the last 12 months and together with close friend Odette Halbisch, decided to organise an event that anyone could be involved in regardless of age or physical capacity. Odette, Susan and Jacqui are pictured on the right.



### Movie Night 'I Am Breathing'

Nicci Riley organised a screening of the movie 'I Am Breathing' during August. This movie features the inspiring story of Neil Platt who died aged 34; 14 months after being diagnosed with MND.



### Riddla MND Golf Fundraiser

Twin Creeks Golf & Country Club in Luddenham was the venue for the second very successful Riddla



MND Golf Day raising over \$10,000 in May. The event was organised by Ann Ridd on behalf of her son Nathan (pictured above in the black shirt with the red-shirted winners of the golf day) who was diagnosed with MND in March 2011. Each year the event gets bigger. There were 92 starters this year and 111 people for lunch. Pictured above is Nathan's nephew with his favourite Bulldogs rugby league player, Christian Iru, who played courtesy of Heartland Holden.



### Drink Tea for MND

In July, Sylvia Pecar raised \$1000 from her second Drink Tea for MND event in memory of her husband Chris Pecar who died in July 2010 from MND. Thanks also to Sylvia's very supportive co-workers at the Department of Human Services Centrelink Office at Brookvale for their continued support.



### Kerrie Cripps Memorial Golf Day

This golf day is held annually in July at Cronulla Golf Club in memory of Kerrie Cripps who died ten years ago. An amount of \$728 was raised from merchandise sales and donations. The Trophy was won by Sharon Holt (pictured).



(Continued on page 12)

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



## Community events (cont'd)



### Donation from Kenneth Marcure Memorial Luau and Artwork Auction

In Avalon, a memorial luau and artwork auction honouring Kenneth

Marcure, who died in 2012, raised \$2000 to help purchase equipment for MND NSW. Pictured is Kenneth's sister, Judith Lydia Mercure, with Jo Fowler, Regional Advisor, MND NSW.



### Rory Chapman - World Championship Paddle Boarding

Congratulations to Rory Chapman of Floraville who not only came 6<sup>th</sup> overall in the World Championship Paddle Boarding in Hawaii

during July, but used his participation in this event to raise almost \$7500 for MND, with most of the money coming from advertising on his page through social media. Rory said, "I had always wanted to do this race as a personal goal. However, Emily (friend) had told me about her brother and his battle with MND and I had never really heard about this disease. I was very touched by Emily's story and felt that with my ambition to train and do the Molokai race, I could also raise awareness and money for MND NSW."



### Siedonea Rees – Nothing Cuter than Kids and Puppies!

Siedonea has recently been diagnosed with MND. To support and thank MND NSW

Siedonea sold MND NSW plush puppies at two local preschools in Lismore where she previously worked. Pictured are Siedonea's granddaughter and nephews.



### Netball fundraiser in memory of Keith Sparkes

Emily Gorham, a member of St Andrews Netball Club organised a

Netball Fundraiser in memory of her father, Keith Sparkes who died in July. The event raised \$1278.

### Reverse the Curse for MND

This fabulous event was the idea of self-confessed football tragic, Gavin Turnbull



who wanted to raise money for our Association following his father's diagnosis nearly three years ago. Close to 100 people attended the event which was a fundraising dinner and auction based around watching the second State of Origin rugby league match. 'Reverse the Curse' is a play on words referring to both the curse of MND and the curse of NSW's poor performance in not winning a State of Origin series in seven years. Held at the Aerial UTS Function Centre Ultimo, the event raised \$10800 from auction items, ticket sales, raffle proceeds and donations.

### Cromer Golf Club Ladies Charity Day

Over \$7100 was raised at the Cromer Golf Club Ladies Charity Day in August. The weather



was great and the 96 ladies in attendance went home after a fabulous day of golf with loads of prizes, a sense of camaraderie and a deeper awareness of MND.

On the 'signature hole' overlooking Narrabeen Lagoon, the ladies were offered a champagne while they paid a gold coin donation to have the Club golf professional hit their tee shot across the water (which they all do willingly)! Thank you also to Debra Larizza (MND NSW volunteer) for assisting on the day. The Club's continuing support is very much appreciated.



**Order your 2013 Christmas cards from MND NSW**

online.mndnsw.asn.au or

complete and return the enclosed Christmas card order form.



**Walk to d'Feet MND**

**Port Macquarie**  
15 Sep

**Wagga Wagga**  
20 Oct

**Sydney**  
10 Nov

### ACKNOWLEDGEMENT

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

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Editor: Penny Waterson