



FORUM

Regional education and training

During the last couple of months we have been out and about in regional areas conducting regional education and training for people living with MND and their families, as well as for service providers.

Link and Learn

In March, 24 family carers attended 'Link and Learn', a two day MND NSW program held in the vineyards of the Hunter Valley. This workshop is aimed at supporting carers to feel confident in caring for their family member with MND at home and also highlights the importance of carers taking time out to care for themselves. This is what some of the participants shared:

"I feel Link and Learn is the best thing that has happened to me (in the time) since my husband was diagnosed. So much information and support from everyone, thank you."

"Thank you so much for the two days - (it) gave me time to get my head around MND and how I can seek support to cope."

"....meeting others in the same situation, making connections, feeling that what you feel is normal and that others feel it too!"

"....have fun, remember to laugh and cry and follow the KISS principle, embrace every day."



MND Aware

Over March, April and May MND NSW conducted five MND Aware face-to-face training days for case managers and allied health staff working with people with MND. We travelled to Kempsey, East Maitland, Forbes, Eastern Sydney and the Gold Coast. MND NSW was very fortunate to secure funding from Community Options Australia to run the workshops in NSW and from the Gold Coast Medicare Local in Queensland. The aim of MND Aware is to educate service providers so that they learn more about MND, the impact on people living with the disease and how they can make a difference. Here is a taste of what the participants wrote:

"Interactive nature of the workshop allowed me to debrief at some level and it was great to mix with different professional backgrounds."

"Comprehensive information and strategies will assist me with people diagnosed with MND. I had limited knowledge of this disease."

"Enjoyed the case management component as it was very relevant to my role."



Illawarra Support Group

To celebrate MND Week the Illawarra Support Group were invited by the Illawarra Health and Medical Research Institute (IHMRI) to attend the open day at the Research Unit at the University of Wollongong which is headed by Dr Justin Yerbury. Our members joined health professionals, researchers and MND NSW staff to hear Justin's presentation outlining the research focus at the unit. Everyone then had an opportunity to ask questions and view the laboratories. One of the research goals is to understand how and why motor neurones die in MND, using skin cells to develop MND stem cells.

Louise Pearson, MND NSW member, with Dr Justin Yerbury.

Photo used with permission: Australian Broadcasting Commission Library



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.

MND Awareness Week 2014

Day of Hope and Remembrance

This year we started MND Week with our annual Day of Hope and Remembrance. Over 120 people attended this event on 3 May and it was good to catch up with many of our members and their families.

Thank you again to everyone involved especially to those who wrote and read dedications and those who lit candles. This is such a special part of the day and an opportunity to acknowledge everyone involved in MND including the researchers, health and community professionals, volunteers and of course, those living with MND and their families.

Thank you also to our musician Zoltan Szabo and our guest speaker, Carol Birks, National Executive Director, MND Australia. Carol spoke about the development of the MND NSW Family Support Service and the involvement of Australia in the international MND arena. You will find an excerpt from her talk on page 8 in this edition of *Forum*.

Gina Svolos

Manager, Family Support



Cornflower Blue Day

A huge THANK YOU to our volunteers for their outstanding contribution to MND Week. Eighty volunteers represented MND NSW at 12 railway stations raising a staggering \$17,000 by 10am on Cornflower Blue Day, 9 May 2014. There were also 20 volunteers at nine regional shopping centres around NSW and the ACT and they have raised \$5,042 to date.

We were very fortunate this year to be supported by University of NSW Volunteer Army (David Chan volunteer coordinator). This dedicated group of 25 university students spend their free time volunteering for charities and we would like to thank them for supporting our Association on Cornflower Blue Day at Martin Place.

HCF continues to play a significant role during MND Week by selling merchandise throughout their 55 branches and head office.

Thank you to our supporters who contributed to MND Week through selling merchandise to their family, friends and work colleagues. Thanks also to our volunteers who organised local fundraising events during MND Week.

Anne Jones

Supporter Liaison Officer



Make your donation to MND research count!

If you are thinking about raising funds or donating money towards MND research make your research donation to MND NSW. All funds donated to MND NSW for research are used by MND Australia's research arm the MND Research Institute of Australia and grants are awarded only following a transparent process overseen by MND Australia's Scientific Research Committee. The Research Committee comprises eminent clinicians and scientists from all over Australia and their combined expertise covers all fields of motor neurone disease research. You can make your donation at www.online.mndnsw.asn.au

**Entertainment
Book
2014-15**

*now available
at
[www.mndnsw.
asn.au](http://www.mndnsw.asn.au)*

A Message from the CEO

The winter solstice, 21 June, is MND Global Day. A day of recognition of MND around the world. In previous years federal, state and territory politicians have worn blue cornflowers in parliament and we hope this year they will continue that tradition.

On Global Day we encourage people to get involved - organise a Drink Tea for MND event, wear a blue cornflower or let your imagination run wild - anything to raise awareness about MND in your community. For ideas or to tell us about your event why not email Kym Nielsen kymn@mndnsw.asn.au.

MND Week 2014 - what a great effort. Thank you to our supporters for their work during MND Week at railway stations, shopping centres and local community events (see page 2). Also, our Day of Hope and Remembrance, held during MND Week,

was much appreciated by those who attended (see page 2 and 8).

Over the past three months Walks to d'Feet MND have been held on the Central Coast, in Canberra and at Tweed Heads. These events are incredibly popular and are seen as a great way of showing your support for people with MND and their families as well as raising much needed funds for care and research. It is not too late for you to join in - Walks will be held during 2014 in Dubbo, Port Macquarie, Wagga Wagga and in Sydney. More details can be found on the back page of this edition of *Forum*. I hope to see you there.

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



See page 12
for more

MND NSW Ask the Experts Forum

Monday 21 July 10.30am to 2.30pm

Ryde Eastwood Leagues Club, West Ryde

Hear from and pose questions to experts in the fields of both neurology and research. There is no charge to attend but registration is essential and includes lunch and afternoon tea. Email reg@mndnsw.asn.au or ph. 02 8877 0999 or the MND Info Line ph. 1800 777 175.

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Maree Hibbert

FlexEquip Assistants

Tom Giardina, Michael Walker

FlexEquip Support Officer

Julie Becke

Information Resources Coordinator

Penny Waterson

And...many valued volunteers

including Justine Calvert from the ACT (pictured on right) who has provided valuable support at fundraising events since 2011 and her mum, Joan Davison (left), who has recently started volunteering at the MND NSW Centre at Gladesville.



Family Support Team

Care for Carers

We commenced our annual Care for Carers program on 12 May at the MND NSW Gladesville Centre with 18 carers in attendance. It's great to see carers have a bit of time out from caring and also to see them getting to know other carers. The participants learn about caring for someone with MND through speakers such as occupational therapists, physiotherapists and speech pathologists. However a lot of learning comes from sharing and talking with each other. Many people walk away from this course with new ideas to assist them and the person with MND live their lives.



Getting to know other carers at the MND NSW Care for Carers program held during May at the MND NSW Centre at Gladesville.

Register now for Ask the Experts - 21 July

This forum is held at West Ryde and provides an opportunity for people to hear from experts in the field and ask questions about MND. This year our guest speakers will include Associate Professor Steve Vucic from Westmead Hospital, Professor Roger Chung from Macquarie University and Dr Ken Rodgers from University of Technology Sydney. For further information see enclosed flyer.

Each year we video this event so that those who are unable to attend are able to view the speakers. The recording of this year's Ask the Experts will be available early August 2014 from our website at www.mndnsw.asn.au, where you can currently view recordings from 2012 and 2013.

Farewell to Caroline Gleig

Caroline Gleig, regional advisor, who has been with MND NSW for 14 years, is retiring from her position here at the Association. Caroline was one of the first regional advisors employed and she has watched MND NSW grow to see us now employ nine regional advisors around NSW, ACT and the Gold Coast. She has contributed to the development of the regional advisor service, our publications and education programs. Thank you Caroline for the contribution you have made. We wish you every happiness in your retirement. Caroline will leave her position once we have employed another regional advisor.

Gina Svolos

Manager, Family Support

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

Living well with MND - Hunter - *A day for people living with MND, their families and friends*

You will be provided with a range of strategies to live well with MND and to maintain independence. You will also have the opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.

When: 10am to 3.30pm Wednesday 25 June

Where: Charlestown Bowling Club

There is no charge for you to attend this program but you need to reserve your place by 18 June. Lunch and refreshments will be provided (let us know if you have any special dietary requirements). To register email reg@mndnsw.asn.au or contact Kristina Dodds Ph 8877 0999 or Freecall 1800 777 175.

Coffee morning for people with a slowly progressive form of MND

Following a suggestion from an MND NSW member, the first informal coffee morning meeting for people with slowly progressive MND was held on 5 March at the MND NSW Centre at Gladesville.

I attended with my partner Helena and the morning provided the opportunity for people with a slowly progressive form of MND and their carers, to come together in an informal way and have an open conversation about many topics ranging from managing difficulties through to new and helpful ideas.

Further coffee mornings are planned for Wednesday 9 July, Wednesday 10 September and Wednesday 12 November, and Helena and I are already looking forward to the next one. Sharing

ideas in such a relaxed setting brings people closer. We get to know others with a slowly progressive form of MND better and are able to support each other.

As it is not always possible for everyone to be there at every meeting, if there is enough interest we will arrange for valuable suggestions to be emailed to people unable to make the meeting in person.

If you are interested in receiving this information or in finding out more information about the coffee mornings contact Gina Svolos, Manager, Family Support Services, by email ginas@mndnsw.asn.au or ph. 8877 0999.

Kevin Langdon OAM

Vice Patron and Member MND NSW

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



FlexEquip

Colder weather and equipment batteries

Just a reminder with the onset of colder weather - if you are using an item of equipment that has chargeable batteries please ensure that the batteries are adequately charged. This could be a power wheelchair, a hoist or a communication device. The rule of thumb is that if you are using the item frequently every day then the batteries should be charged overnight. If the item is only being used infrequently or every other day then the item should be charged overnight at last once every three days. Batteries are expensive to replace and if they are looked after the inconvenience and expense of replacing them can be minimised.

Equipment provided and returned

FlexEquip has over 1,960 items of equipment. These items are only provided after an assessment has been made by an appropriate health

professional and the health professional has submitted a written referral. During the past 12 months FlexEquip has provided over 1,800 equipment items. Some of the items provided include 249 bathroom aids, 93 home care beds, 112 pressure mattress overlays, 163 pressure cushions, 86 electric wheelchairs, 120 manual wheelchairs, 77 hoists, 95 other transfer aids and 453 communication and computer access devices. FlexEquip staff have also arranged over 1,540 returns of equipment during this same period.

No longer using FlexEquip equipment?

If you have been provided with an equipment item from FlexEquip and you are no longer using it, contact FlexEquip staff so we can arrange for the item/s to be collected. This helps us in reissuing the equipment to other people if required. FlexEquip staff can be contacted by email at flexequip@mndnsw.asn.au or ph. 02 8877 0999 or fax 02 98162077.

Maree Hibbert

FlexEquip Coordinator

Noticeboard

What do you want to know to be prepared for the next phase of MND?

People living with MND and/or their carers (present or past) in NSW and the ACT are invited to take part in a research project about preparing for the changes brought about by the disease processes and being prepared for end of life. The study is being conducted by Dr Robin Ray from James Cook University and Ms Anne Kavanagh from Queensland Health. Both Robyn and Anne have experience working with people with MND. Taking part in the research may increase your ability to ask your healthcare practitioners for the specific information you need to manage your care and prepare for the next stage. If you agree to participate the researchers will organise a telephone interview with you. During the interview you will also be asked to answer a short questionnaire. This study has ethics approval from James Cook University. Contact Dr Robin Ray Ph. 07 47814474 or robin.ray@jcu.edu.au

Disability Access Facilitation Plans

Many domestic and some international airlines and airport operators in Australia publish Disability Access Facilitation Plans (DAFPs). The aim of each plan is to provide detailed information on how they (the airlines and the airport operators) intend to meet the needs of customers with disabilities. By knowing what help airlines and airports can provide may help you plan your journey in relation to managing departure, transfer and arrival processes including check in; security screening; and using wheelchairs in airport and on board.

To access the DAFP for Sydney airport visit www.sydneyairport.com.au/prepare/quick-links/special-assistance.aspx

ANZAC/Concord MND Research Group

ANZAC Research Institute at Concord is studying variations in familial motor neurone disease genes. They are keen to obtain DNA samples from all people with motor neurone disease (familial and sporadic MND) and control samples from spouses. By collecting samples they aim to examine the contribution of gene variations to the underlying causes of MND and increase understanding of the genes which may make someone susceptible to familial MND. This in turn may provide insight into the causes of sporadic forms of the disease, and may lead to the development of new treatment strategies for all forms of MND. Contact Jody O'Connor ph. 02 9767 7016 or jody.oconnor@sydney.edu.au

Do you provide unpaid care or support to a family member or friend?

Carers NSW (in conjunction with university partners) is conducting a survey of informal care in New South Wales. They do this every two years so they can stay up to date with the issues that matter to carers. Have your say about what matters to you most as a carer and the support that you need. Visit www.carersnsw.org.au by 30 June 2014.

www.start2talk.org.au

Information to help you plan ahead for your future healthcare, lifestyle and financial decisions.

Mailbag

Each Day

*Each day is a challenge
But the passing hours are still precious*

*Each day brings restrictions
But inner victories propel us to the skies*

*Each day pushes us to the limit
But our love soothes and protects*

*Each day finds our weak spots
But our very best wins out in the end*

*Each day brings frustrations
But patience always finds a way*

*Each day is precious
Whilst you are still by my side*

JML 26 March 2014



Family Support Calendar

17 June	Information Evening for people recently diagnosed with MND, family and friends Gladesville
25 June	Information Day for people living with MND, family and friends Hunter
21 July	Ask the Experts West Ryde
19 Aug	Information Evening for people recently diagnosed with MND, family and friends Gladesville
15 Sep	Lunch for bereaved carers Gladesville
20 and 27 Oct	Learn Now Live Well Gladesville
22 Oct	Information Day for people living with MND, family and friends Central West
22 Nov	Christmas Party for family support members, their family and friends West Ryde
9 Dec	Information Evening for people recently diagnosed with MND, 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.

Support group meeting dates are at 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

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

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

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

Western Sydney - Melanie Oxenham ph. 4731 6168 | melanieo@mndnsw.asn.au

REGIONAL AND RURAL

ACT and Southern NSW - Dianne Epstein | 6286 9900 | diannee@mndnsw.asn.au

Central Coast - Deb Ward | 1800 777 175 | debw@mndnsw.asn.au

Central West - Melanie Oxenham ph. 4731 6168 | melanieo@mndnsw.asn.au

Griffith and Region - Dianne Epstein | 6286 9900 | diannee@mndnsw.asn.au

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

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

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

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

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

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

To live is to hope

At our annual Day of Hope and Remembrance, held on 3 May, our guest speaker, Carol Birks, National Executive Director, MND Australia, spoke about the development of the MND NSW Family Support Service and the involvement of Australia in the international MND arena. Here is an excerpt from her talk.

Each year we come together at the start of MND Week to collectively hope for a future free from motor neurone disease and to remember those who have died – people we have loved, cared for, undertaken research for and supported through their journey and who will remain forever linked with our community.

Today I have been asked to talk about hope. But what is hope – just think for a minute what it means to you, to your loved ones, your colleagues, friends and family. The word hope will probably paint a different picture in each person's mind depending on what stage of life they are at, what is happening in their life, their faith and their state of health. We all have hope - hope is integral to what it means to be human - to live is to hope.

It is a driving force for many of us and is summarised beautifully by the words of Martin Luther King - 'Everything that is done in this world is done by hope'.

So what is the essence of hope for people in this room and indeed all people impacted by MND?

When I think of hope and MND I think of people living with MND and the work that needs to be done to improve care and support so that they can live as well as possible for as long as possible. I think about the MND community worldwide working together to get things done to achieve that one hope we all share for the future - a world free from MND.

I first became involved in MND in January 2000 when I took on the role of Family Support Manager at MND NSW. I had had very little exposure to MND during my career as a registered nurse and only remember caring for one person with MND. However, she made a huge impression on me and I can still clearly remember her laboriously typing out her needs on the only device available at that time – the Canon communicator - as I tried to make her comfortable each night. My nursing career had included experience in oncology, palliative care, rehabilitation, aged, community and research nursing and this role at MND NSW seemed to bring together many of those skills. So I was excited about this new direction my career was taking. Little did I know back then that, in the words of my colleague, Sally Light, CEO of the MND Association in England, 'There is something about MND and the people who live with it that sucks you in and steals your heart. Once you join this fight it's hard to leave it....'.

At that time the MND NSW Family Support Service consisted of four regional advisors including Anita Richter and Caroline Gleig; the information, IT and equipment officer (and everything else) Janet Nash; and the family support admin assistant Carole Leone.

At that time I also took on the role of regional advisor for west of the dividing range and our hope was to reach out and create a service that covered all of NSW and that was able to reach at least 80% of the estimated population of people living with MND. I look

back on those days travelling around country NSW with great fondness. It was the people with MND and their families I met, many of whom I still remember so well, who inspired me, fed my spirit and sucked me in. It was also the people involved in the associations at that time and remain involved still – including MND NSW founder Marjorie Harrap, Kevin Langdon, Bob and Suzanne Ballinger and Petra Sammut. There was a sense of being a part of something special, something worth fighting for and a commitment to never give up.

Our other hope was to improve access to care and support to assist people with MND and carers to maintain their quality of life. We worked to support best practice and to promote a coordinated multi and inter disciplinary approach to the management of MND state wide. We initiated meetings for health and community care professionals around the state entitled 'Towards multidisciplinary care and support for people living with MND'.

As we travelled around Sydney and country NSW and met with health and community care professionals involved in caring for people living with MND in their town or region, time and time again we were struck by the impact of MND on a community.

There was, and still is, a unique commitment from those involved in the care of people living with MND. Despite the barriers, cut backs and changing goal posts, Association family support staff and most health professionals and community care workers do their utmost to try and cobble together the right care in the right place and at the right time for each individual living with MND and their family.

They seek to work together to coordinate care and to get informed about MND. And of course there are many champions, those prepared to go the extra mile, those who have created MND clinics and local models of care, with little support from the government, because they care and know that until an effective treatment or cure for MND is found, care is the key and that it is up to them to try and make a difference.

This dedication and commitment gives many people living with MND and their families hope and reassurance that they will receive the best possible care and support throughout their journey and that they will not be abandoned or alone.

The foundation for the current MND NSW Family Support Team was laid in 1998 by Anita Richter and Janet Nash based on a NSW needs assessment and on models established by other associations in Australia and overseas. How has the care and support available for people living with and their families changed since then? I left MND NSW in late 2006 and the Association's Family Support Service has continued to grow and develop under Gina Svolos' expert management, supported by Graham Opie MND NSW

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

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CEO, the board of MND NSW and staff and volunteers.

Today we estimate that at least 90% of people diagnosed with MND in NSW are members and receiving support from the Association; there are nine regional advisors covering the whole state as well as the ACT and the Gold Coast; a dedicated information line; the equipment service has grown considerably; we no longer talk about 'towards' multidisciplinary care because this has become standard practice wherever possible; there are specialist MND multidisciplinary clinics in Sydney; and a wide range of information and education available for health and community care professionals.

We now have strong MND associations with well established family support services in most states, we have neurologists and many other health professionals with expertise in MND and we have better informed governments and a more engaged community. Many, not all, people now have access to interventions that have been proven to improve quality and length of life including riluzole, multidisciplinary MND clinics, non-invasive ventilation and nutritional support.

But there is still much work to do. Each person diagnosed with MND will have their own hopes and goals and they need us to continue to work together to get things done to ensure that their needs are met. With constant changes to the health, aged and disability sectors, the role of the MND associations and the health and community care professional champions is as important as ever.

In October 2006 I walked down the corridor at the MND NSW Gladesville office to what is known as the 'blue cornflower room' and took on the then recently established role of National Executive Director for MND Australia. I joined Janet Nash who had done the same walk the year before to take on the role of running the MND Research Institute of Australia.

We all know that research is the only way that we can change the future of MND. But until an effective treatment or ultimately a cure is found, access to optimal care and support is the only way we can impact quality and length of life for people living with MND and their families.

MND Australia is the national peak advocate for MND and, together with the state associations, we work to advance, promote and influence local, national and international MND care and research with a vision to achieving a world free from MND.

In 2010 MND Australia and the MND Research Institute of Australia amalgamated operationally to form one national body promoting MND care and research. The staff of both organisations are employed by MND Australia and are governed by one board.

Under this new structure the grants allocation procedure remains unchanged. The MND Australia Research Committee reviews grant applications and determines the distribution of funds within the set policies, and according to the criteria for scientific assessment. Our aim is to ensure that every dollar received for research is invested in research that has the best chance of understanding the causes,

developing effective treatments, establishing evidenced based care management and finding a cure for MND.

In 2010 \$1 million was donated for research and allocated to fund new research projects commencing in 2011. This was almost double the funds awarded in the previous year. In 2012 the amount doubled once again and we have been able to award just over \$2 million dollars for new research grants commencing in 2013 and 2014!

This is a remarkable achievement and has eventuated due to the amazing support of people impacted by MND in some way in Australia. This is a prime example of the MND community working together to get things done and to get involved because they have that hope for a future world free from MND.

You may be wondering what difference this funding has made or what difference Australian researchers can make and why there is still no effective treatment.

Over the last few years there has been a steady increase in the number, diversity and quality of the research grant applications we receive. This year we allocated slightly more research funds than those allocated by the federal government to MND research, with many MND researchers missing out on NHMRC funding. This highlights the urgent need to continue to have sufficient funds available to support the increasing number of Australian researchers choosing to focus on MND research so that they remain focused on MND and don't move to another area of research or another country due to lack of funding.

The past two years have been ground-breaking for the MND Research Institute of Australia. Not only were more funds than ever before distributed but also in 2012 a major project grant was awarded for the first time. The MND Australia Leadership Grant 2013 – 2016 was awarded to Associate Professor Ian Blair at the Australian School of Advanced Medicine at Macquarie University who was judged as an MND research leader by eminent international MND researchers.

This year our donors are funding 36 top MND researchers from across Australia who are hard at work in areas as diverse as genetics, cell biology, environmental research, translational research and health care research. We believe this multifaceted approach will give us the best chance of making a better life for people with MND and stopping this fatal disease.

Australian researchers have been involved in a number of recent significant research discoveries. For example so far this year there have already been a number of papers published by Australian researchers including one from Dr Justin Yerbury, from University of Wollongong and Dr Bradley Turner from the University of Melbourne, in collaboration with colleagues in Canada, who have discovered how a neurodegenerative 'seed', misfolded SOD1, spreads from neurone to neurone in MND. Another from Mary-Louise Rogers and colleagues in South Australia who have identified that urinary levels of a protein called

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Visit us
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at
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**Register now
for
MND NSW
Ask the
Experts
West Ryde**

**Monday
21 July**

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for more)*

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neurotrophin receptor p75 are increased in patients with MND. This research is a promising development in the search for an MND biomarker to identify disease stage and facilitate improvements in the way MND is diagnosed and treated.

The MND research community worldwide is growing and the pace of research is increasing rapidly. MND was first identified in 1869 but it wasn't until the 1990s that the first research breakthroughs were made. In 1993, mutations in the SOD 1 gene were discovered in some families with familial MND.

Then, in 1994, riluzole was identified as a drug that could have a positive effect in extending life expectancy for people with MND. Subsequent development of the mouse model of MND incorporating the SOD1 MND gene mutation opened a whole new field of research with an animal model of MND available to test potential treatment drugs.

It wasn't until 2008 that another significant gene mutation was discovered. Since then more and more genes have been discovered that are implicated in both the familial and sporadic forms of MND and with the new technologies now available, genetic research is developing rapidly.

Treatments remain elusive however with a number of promising recent trials showing no effect on slowing the disease down. There are an unprecedented number of potential therapies in the pipeline, though, with many therapeutic clinical trials targeting a range of disease mechanisms and symptoms, currently underway.

Each year the global MND community gathers to share new understanding about MND and work together to improve the lives of all people with MND and move us closer to finding a cure. Each year the sense of optimism grows as more pieces of the puzzle are put together. These international meetings occur annually and the programs for all meetings continue to be full of new developments and initiatives. They are unique in that they bring together people living with MND, carers, associations, health professionals, neurologists, scientists and researchers from around the world all United in working towards a world free of MND

A record 950 delegates were in attendance at the International ALS/MND Symposium in Milan last December all focused on discoveries towards treatment and cure. The three-day Symposium was brimming with researchers who discussed a wide range of research from protein processing and degradation to development of a patient and carer centred model of care to aid decision-making. The Australians, most funded by MND Research Institute of Australia, were in such numbers that the organiser Dr Brian Dickie tweeted: "Great turnout - and great science - from Australia. Thanks for coming!".

Many who attend the Symposium have spent decades of their lives dedicated to this cause. It is inspiring to witness these committed researchers networking together, sharing their research and initiating national and international collaborations. Even more inspiring is seeing some of the brightest young researchers from around the world presenting their work, learning,

networking and getting feedback and encouragement from their research heroes and this can only be a good sign for the future.

Each year, just prior to the Symposium, the International Alliance of ALS/MND associations has its annual meetings. Last year 80 people from 23 countries attended - all sharing ideas, information and initiatives to improve outcomes for people living with MND in their respective countries. As one of the MND Australia delegates to the International Alliance I have been a board member of the Alliance since 2010 and worked with the board during this time to develop a clear strategic plan. I was honoured to be elected by members as the chairwoman of the International Alliance of ALS/MND associations at the AGM last year and I am looking forward to working with the Alliance coordinator, the board and members over the next three years, to progress the objectives we have set.

One of the cornerstones of the Alliance is the partnership program which encourages and supports the establishment of partnerships within and between Alliance members and also between Alliance members and key MND professionals. Over the last four years MND Australia has focused on reaching out in the Asia Pacific Region as there are a number of countries in our region that do not have an MND association and have very little support for people living with MND. Our aim is to share information, experience and resources to promote the best possible care and support for everyone affected by MND.

Another focus for the Alliance is to be more active on social media and to create opportunities for the MND community worldwide to work effectively together and to raise awareness globally. On Global Day, 21 June, this year we will launch the One Global Team One Goal campaign which aims to engage the many notable sportsmen and women, who have shown their support for people living with MND worldwide, to help us raise awareness and funds on and around this key date in the MND calendar.

The Alliance meetings inspire and motivate and no matter the size or maturity of our organisations we all learn from each other. The passion and commitment of people living with MND, carers, past carers, volunteers and association staff to make a difference to the lives of people living with MND worldwide is truly amazing.

Hope could be viewed as one of the miracles of life and something intrinsic to what it means to be human. Each and every one of us in this room shares the global hope for a future without MND and together during this MND Week and beyond we will work to ensure that all people living with MND get the right care in the right place and at the right time and together, ultimately, we will find a cure.

I thank you for the opportunity to give the keynote address today and I would like to conclude with a quote from the American poet Emily Dickinson:

*"Hope" is the thing with feathers--
That perches in the soul--
And sings the tunes without the words--
And never stops--at all.*

Carol Birks

National Executive Director, MND Australia

Community events

Tas Run for Motor Neurone Disease - Wagga Wagga to Cabramurra (Australia's highest town) 10 May 2014

The now annual motorcycle ride to raise funds for MND was, for the first time, a testing affair. A cold change was predicted to travel across the Riverina and Snowy Mountains during the day, but riders were determined to complete what turned out to be a memorable ride of over 440km.

The ride commemorates a friend and relative of many, Tas O'Hara, who was involved in motorcycle sport in the 70s and 80s and later go-karting in his adopted town of Wagga Wagga, where he grew to love the people, the climate and lifestyle. After Tas' death in 2010, his many friends and relatives were determined to continue the battle to find a cure for MND, within the true meaning of the slogan "Never Give Up".

With poor weather looming, organisers were delighted when at least fifty participants signed on for the ride. Warmed by hot breakfast and coffee, the ride took us through the picturesque mountain village of Tumbarumba, a quick refuel then off to the very supportive Tooma Hotel for a sausage sizzle morning tea. By then the fog and mountain mist started to roll in, so it was a more subdued ride to Australia's highest town of Cabramurra, for a welcome soup and hot meal for lunch. Fortunately for riders, not only had Snowy Hydro Ltd offered their support for the charity, but also their bistro and chefs who did a great job. As the temperature had dropped into single figures, and steady rain falling, the freshly made potato and leek soup was very popular, especially for those with Irish ancestry! Although the views were lost in the mist, we still enjoyed the ride along the Elliot Way and return via the historic Tumblong Pub for afternoon tea in front of two splendidly raging open fires.

The Wagga Wagga MND family remain committed to assisting and supporting the MND Association, and we thank Chris Anthony (Budgie), Les Gray, Trevor Argus and Pat O'Hara for their tremendous work in arranging the sponsors, donations and route planning through some of the most beautiful scenery in the country (without the mist). AVIS Rental Cars always loan us a 20 seater bus for the day, so if next year you feel like a day tour of the Snowy's western slopes, put it in your diary!!

We are planning to have the **TAS RUN 2015** in March next year to catch the good weather. A big thank you to all our sponsors and especially the riders who make it such a great day.

Lake Macquarie Rugby Club - MND Awareness Day

A great day of rugby was enjoyed at the LMRC MND Awareness Day in May. The game was played between Lake Macquarie and Waratah rugby clubs, with the Waratahs winning 28-11. The day was organised by Mark Mitchell whose friend Neil McEwan was diagnosed with MND. Thank you to Mark and everyone involved in organising this event which raised around \$780. Mark said, "It definitely had people talking about this disease. What this has taught our club in particular is to enjoy your life now. It is surprising once you talk to people about MND you hear of other people who know someone that has or has had MND. Neil McEwan played over 200 club games for Lake Macquarie Rugby Union club (Boolaroo). In September last year, on the day he turned 50, Neil made a guest appearance on the field showing the same tenacity as he did in his heyday. Neil also served on the Rugby Union Committee during his playing days and is still a member of the old boys club which actively supports the improvement of all teams from Lake Macquarie Rugby Union." Pictured (right) Neil with the players, and also with his daughters.



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Community events

Hunter Raffle

Thank you to Julie Smith who organised the very popular Smithy "Ian Smith" Raffle for our Walk to d'Feet MND Hunter held in February, raising \$300.

Musical Charity Night



A fantastic night of musical acts and a huge raffle was held during March in Wickham raising \$1648. The night featured 'The Cut' with special guests Ian Henry, Peter Wood and other artists. Thank

you to Allan Worlin who organised the night.

Wagga Wagga Pedal Car Show



A big thank you to Shirley and Keith Wheaton for again organising the annual Pedal Car Display and raffle in Wagga Wagga in March. The event showcased

collectable items such as pedal cars, trikes, scooters and bikes and was held in memory of Brian Barklem, one of the founding members of the Pedal Car Club. Through ticket sales and raffle proceeds a wonderful \$3,354 was raised.

Narooma Oyster Festival



Linda Kluske again organised a fundraising stall at the Narooma Oyster Festival which was held this year on 5 April. It was a very wet day however Linda managed

to stay dry with the help of George Delac who put up the gazebo and strung tarpaulins, and \$519 was raised through merchandise sales and donations. Pictured is local MND Ambassador Kathryn Ratcliffe with her children Stella and Marcus, promoting MND Awareness and selling merchandise on the day.

EGOs Cut and Barefoot Bowls Day

Thank you to Rebecca and Andrew Egan who organised a Barefoot Bowls Day followed by the big chop! The day was enjoyed by all who attended and raised \$2,763 for MND NSW. Rebecca said, "The bowls day was such a success. We had 62 bowlers and the wet weather held off. There were people attending of all ages from babies to Andrew's granny, who is soon to be 100! After the morning of bowls we all headed inside for some high tea, followed by the drawing of the raffle, bowlers prizes and a charity auction. Then came the part all of Andrew's friends had been waiting for, seeing his curly locks finally cut off!! So after all his friends had a cut and even his granny, Andrew took to the chair and finally has NO hair, which might be a bit chilly with winter coming on!"



Musical Concert for MND



A very talented group provided a wonderful evening of musical entertainment at the

Grace Evangelical Church in Newcastle during April in support of MND. Most of the musicians who performed knew Don's wife June who died from MND three years ago. Thank you to Don McMurray and all who helped to organise the event. A fantastic \$2,746 was raised.

Bethany College Hurstville

A big thank you to the Year 12 students and school community from Bethany College Hurstville for their fundraising efforts for MND. Steve Donlan, Year 12 Coordinator, explains, "On 30 April, the Bethany College, Hurstville Year 12 community collaborated together to raise money for a worthy cause supporting one of our own, whose family has been touched by the brutal effects of MND. In honour of the 10th anniversary of the film Mean Girls which fell on a Wednesday, the famous line "on Wednesdays we wear pink" inspired the theme for our fundraiser. Our Year 12 girls added a 'touch of pink' to their day and held a bake stall where the school community contributed donations and bought food. The day was a great success, raising an immense \$2,061, supporting a valued member of the community and allowing further research into a cure for the disease. We thank Year 12 and the school community for their support in helping those who have felt the effects of this disease."

Musical Performance

In October last year a musical performance by the Avalon Quartet was held at Mona Vale House, a nursing home where Inge Courtney-Haentjes and Ulli Courtney-Beck's mother spent the last few months of her life in late 2013. Inge said, "The concert consisted of popular classical and baroque pieces and was very well received, with lively audience interest and participation. A very satisfying and touching experience for all of us." Thank you for the funds raised for MND NSW.

Anzac Day Two Up Charity Day at Putney Tennyson Bowling and Community Club

Thank you to Lesley and Lindsay Maher from Putney Tennyson Bowling and Community Club for their ongoing support. This year \$680 was donated taking the total donations from this event to \$4,633 over the past six years.

HELPING THROUGH YOUR WILL

For more information contact Anne Jones,
MND NSW Supporter Liaison Officer
ph. 02 8877 0928 or annej@mndnsw.asn.au

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



Walk to d'Feet MND

We have been overwhelmed with the wonderful support we have received for our Walks to d'Feet MND. The Illawarra Walk was held this year on Sunday 2 March and although the rain was very heavy we still had over 300 people attending. It was such a great atmosphere of families, friends

and supporters all there to help make a difference in the lives of people with MND, raising more than \$30,000 - a fantastic achievement. To our local volunteer Walk coordinator Shelly-Anne Demirov and the Bulli Surf Club and Woonona Lions Club, thank you. Without your support this event would not be possible.

Our next stop for a Walk to d'Feet was the lovely Central Coast on Sunday 23 March. This was our first Walk to d'Feet MND on the Central Coast and what a great roll up we had. The sun was shining and there were plenty of supporters with smiling faces ready to start at the lovely Memorial Park in Woy Woy. Congratulations to Belinda Matthews our local volunteer Walk coordinator for organising such a great day with 168 participants and over \$7,500 raised.

From the warm Central Coast we headed south to the chilly weather of Canberra for our Walk on Sunday 6 April. We had a great new venue for the Walk this year and what a great spot it was. The morning dawned bright and chilly, but it was a beautiful day for a Walk beside the picturesque Lake Burley Griffin. Thank you to everyone who walked in memory of a family member or friend, or in support of a person in their family or a friend living with MND. Know that your support really does make a difference. Thank you to Marc Cusack and Dasher for the great music after the Walk, and thanks also to the Gungahlin Rotary for their great sizzle. A big thank you also to all of our wonderful volunteers without whose help we could not hold our Walks.

From the chilly weather in Canberra we headed north to the lovely Tweed Heads for our Walk on Sunday 4 May. We are spoilt with some gorgeous venues for our Walks and this venue is no exception. Walk to d'Feet MND Tweed is held around the stunning Jack Evans Boat Harbour and attracts people from many areas, including the



Gold Coast. This was our largest Walk in the Tweed to date, with over 200 participants raising more than \$10,500 to support research and people living with MND. After the Walk we enjoyed great music of April Collection and a yummy sausage sizzle from our long-time



supporters at the Tweed/Coolangatta Lions Club. A huge thank you to our major sponsor Ray White Coolangatta/Tweed Heads who also entered a team and provided free water for all participants. Your support is greatly appreciated.

If you haven't had a chance to attend a Walk to d'Feet MND this year, don't worry we still have another four Walks to go.

Our first Walk in the Central West will be held **Sunday 15 June in Dubbo**, then off to **Port Macquarie on Sunday 14 September, Wagga Wagga on Sunday 26 October** and to finish off the year the **Sydney Walk to d'Feet MND will be held on 9 November**. We hope to see you at one of our Walks.

Community events Dates for the Diary 2014

15 Jun	Walk to d'Feet MND Dubbo
19 Jul	Kogarah Mayoral Ball Museum of Contemporary Art Sydney
2 Aug	Trivia Night for MND Muswellbrook RSL Club Muswellbrook
14 Sep	Walk to d'Feet MND Port Macquarie
21 Sep	MND Charity Day Shellharbour Bowling Club Shellharbour
11 Oct	Gundaroo Music Festival Gundaroo
26 Oct	Walk to d'Feet MND Wagga Wagga
26 Oct	Burgh2Beach Fun Run
1 Nov	Greg Redgrove Memorial Fundraiser Kitchener Pub Kitchener via Cessnock
9 Nov	Walk to d'Feet MND Sydney

For more information see www.mndnsw.asn.au or contact MND NSW ph. 02 8877 0999

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Editor: Penny Waterson

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ph. 8877 0912
about
supporting
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