



FORUM

Record funding for MND research in Australia in 2013

People touched by motor neurone disease can hope for a better future with the announcement by MND Australia of a record \$2,014,000 to fund MND research in 2013.

Thanks to your donations to MND NSW towards motor neurone disease research, the MND Research Institute of Australia (MNDRIA) offers many grants to MND researchers in Australia. MNDRIA announced 22 new grants for 2013. The funds will support researchers in their quests to understand the causes, provide better care, control the symptoms or find a cure for MND. This is the third year in a row that MNDRIA can contribute over \$1million to MND research.

New powerhouse of MND research at the Australian School of Advanced Medicine at Macquarie University

Associate Professor Ian Blair has been awarded the inaugural Motor Neurone Disease Australia Leadership Grant to build a new powerhouse of motor neurone disease research. Assoc Prof Blair will lead a team of MND scientists who will work together to further research in inherited forms of MND, which account for about 10% of MND cases.

The Leadership Grant will provide the impetus to further research newly discovered MND genes and investigate how defects in these genes lead to the death of motor neurones. Assoc Prof Blair will use the grant to build a talented, multidisciplinary team specialising in genetics, cell biology, biochemistry, proteomics and animal disease models. He will begin his appointment with the Australian School of Advanced Medicine at Macquarie University in mid-December.



Associate Professor Ian Blair

Carers Week 2012

During Carers Week 2012, 60 carers from across the state were awarded a NSW Carers Award. Carers who accept an award help create awareness of the important and valuable role of all carers. Congratulations to Nita Walkom of Brandy Hill who was presented with a NSW Carers Award for the outstanding care she provided for her husband Glen, who died recently from MND. Congratulations also to Graham Frunks, an MND NSW member with MND, who was presented with a NSW Carers Award for the outstanding care he provides for his wife Kath, who has multiple sclerosis.

Also during Carers Week, through a grant from Carers NSW, members of the Campbelltown support group celebrated over lunch at Melaleuca House, a beautiful restaurant at the Mt Annan Gardens.

Even though it was a very hot day the group managed to enjoy a beautiful meal and pay tribute to the wonderful carers who attended.



(L) Nita Walkom (on left), accepting her award from The Hon Robyn Parker, MP and (R) Graham Frunks (on left) accepting his award from The Hon Geoff Lee, MP

(Below) Ann McCutcheon, Regional Advisor (left), members of the Campbelltown support group and Graham Opie, CEO (second on right) at the Carers Week lunch



MND NSW will be closed from 5pm Friday 21 December 2012 until 9am Wednesday 2 January 2013.
If help is needed during the Christmas break, please consult your doctor.



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

Members' Christmas Party 2012



The Members' Christmas Party at the Ryde Eastwood Leagues Club was a great success. By all accounts, everyone enjoyed the opportunity to catch up with old friends and to make some new connections. The highlight of the afternoon was undoubtedly a surprise visit from Santa, who took leave from the North Pole to give gifts to all the children who attended. Before flying off on his sleigh, he also assisted by drawing the winning tickets for the fabulous lucky door prizes and raffle.



Thank you lunch for our volunteers

During October MND NSW took the opportunity to thank the many volunteers who support our Association by hosting a BBQ lunch. Unfortunately, due to gale force winds and torrential rain on the day, the garden theme had to be abandoned but nothing could dampen the spirits of the staff or the volunteers. A great day was had by all as they were able to catch up and swap stories in a very relaxed and happy atmosphere with delicious food, entertainment and an atmosphere of camaraderie. Special thanks to Robert and Debra Larizza for their hard work on the day, Rowlanda Orchiston for providing the music and David Radford (our accountant) who donated and cooked all the seafood on the outdoor BBQ in the rain and under an umbrella.



If help is needed during the Christmas break, please consult your doctor or local hospital

Introducing...

Lisa Dowling



Regional Advisor for Western Sydney, Central West and Western NSW

My name is Lisa and I am delighted to be working for MND NSW. I have

worked in Western Sydney, the Central West and Western NSW before and am really looking forward to getting out and about and meeting with our members.

I have a background in rehabilitation counselling and training and have two lovely children, Liam and Grainne who are aged six and five. We also have a beautiful Kelpie cross, who rounds us all up when needed.

Adrian Gilchrist

Admin Assistant



I'm Adrian and, aside from spending three of my teenage years in Hong Kong, have lived in Gladesville my whole life. I was born with spina bifida and have had diverse experience in retail customer service, education support and administration. I am particularly interested in supporting not for profit services and am a Life Member of the World League for Protection of Animals, where I have been a volunteer since 2009. I love music, social media, friends and family (including a Jack Russell terrier and a tabby). I am excited about having the opportunity to make a difference at MND NSW.

Deb Ward



Regional Advisor for Inner West, Hills District and southern Central Coast

I'm Deb and I'm very pleased to be joining the Family Support Team

based at the Gladesville office. I have worked in the health system for many years, originally as a physiotherapist in neuro-rehab, but most recently in policy implementation for government. I am an inner-westie, have a partner and a gorgeous ten year old daughter. Our family also includes two geriatric dogs, a yabbie and a fish. I love to play golf, garden and knit – but have yet to work out a way to do all three at once! I look forward to meeting you soon.

A Message from the CEO

It seems repetitive, in fact it is, as I say it in each Forum. What a hectic 3 months! An Information Evening, Learn Now Live Well Workshop, MND Aware workshops, Members' Christmas party, open gardens, two Walks to d'Feet MND (Port Macquarie and Homebush – our biggest yet), the Burgh2Beach fun run and our AGM.

The MND NSW Board for 2012-13 is listed below. A copy of the Association's Annual Review is available at www.mndnsw.asn.au. Alternatively, if you would like a hard copy of the 2012 Annual Review or Financial Report please contact us ph. 8877 0999 or admin@mndnsw.asn.au.

The National Disability Insurance Scheme Launch Transition Agency has been established to implement the first stage of the NDIS starting July 2013. This will impact MND NSW members in the local government areas of Newcastle, Lake Macquarie and Maitland and the entire ACT. To stay up to date with changes go to www.ndis.gov.au where you can sign up for updates.

As reported in the last edition of *Forum* Jenny Judd, Regional Advisor Western Sydney and Central West NSW has left MND NSW for a colder, more genteel lifestyle (Tassie) and in her place we have employed not one but two new RAs, Lisa Dowling and Deb Ward. This will enable us to increase services in the Central West, Western Sydney and the Central Coast and alleviate some of

the RA workload in other areas. Ayse Dalkic has also moved on to greener pastures (not in Tassie) and we have employed Adrian Gilchrist in the FUNdraising area. Lisa, Deb and Adrian introduce themselves on page 2.

On behalf of the Board and staff of MND NSW we wish you a peaceful and safe Christmas and New Year. Thank you to our volunteers and donors for their support in 2012.

Our office will be closed from 5pm Friday 21 December and will reopen on Wednesday 2 January 2013. If help is needed during the Christmas break, please consult your doctor.

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

Graham Opie
Chief Executive Officer

MND NSW
will be closed
from 5pm
Friday
21 December
2012 until 9am
Wednesday
2 January 2013



Illawarra
24 February

Southern Highlands
10 March

Canberra
24 March

Motor Neurone Disease Association of New South Wales

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Kym Nielsen

Fundraising Assistant

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Administrative Assistant

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Bequests Officer

David Dubin

Family Support Manager

Gina Svolos

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Chris Carroll, Lisa Dowling, Gail Ferguson, Jo Fowler, Caroline Gleig, Ann McCutcheon, Eileen O'Loughlen, Kim Sinclair and Deb Ward

Information Line Advisor

David Wallace

Education and Carer Support Coordinators

Kristina Dodds, Kate Maguire

Equipment Service Coordinator

Maree Hibbert

Equipment Assistants / Support Officer

Tom Giardina, Michael Walker / Ellen Hibbert

Information Resources Coordinator

Penny Waterson

And...many valued volunteers including our wonderful massage volunteers, some of whom are pictured below



Family Support Team

It's hard to believe that this is our last newsletter for 2012 and we are already looking ahead to next year with planning underway for our support groups and education programs. See page 6 for some advance dates for your calendar.

We hope you will be able to attend some of these programs as those who do attend often come away being very positive about what they have gained whether it be what they learned from the speakers, or what they learned from others who attended, or just meeting others who are in similar situations to themselves. Dates of all our programs are regularly updated on our website www.mndnsw.asn.au, so keep an eye out.

The Christmas season is upon us and for many it is a time to enjoy the company of family and friends and to share meals and exchange gifts. Christmas can also be a time of very mixed emotions, as we reflect on memories of the past year: shared happiness, shared sadness, love, loss, achievements, joy and hope. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

Report on 6th National MND Conference

In September Family Support Staff attended the 6th National MND Conference in Adelaide with over 180 health and community care professionals from all corners of Australia and New Zealand. It is always great to see the enthusiasm and interest of these professionals in the work that they do, whether it be direct care and support to people with MND or research to help find a treatment or cure. MND Australia Ambassador, Guy Barnett, gave the welcome address and introduced the themes of *Care, Advocacy and Research*.

The conference was then officially opened by Hon Ian Hunter, South Australian Minister for Disabilities. Minister Hunter confirmed that research is a priority for people living with MND and their families, and noted that the National Disability Insurance Scheme (NDIS) will provide personalised support packages and a safety net for people diagnosed with MND.

There were many speakers on the day who generously shared their work with others in attendance. This included the keynote speakers who all gave really interesting and informative talks.

The first speaker was Sue Craig who lost her husband Derek to MND in 2011. Sue's presentation

was entitled *There's nothing you don't go through.....* and Sue spoke with poignant honesty about the issues faced by people with MND and their carers to give the professionals in the audience insight into this. She spoke about the mixed feelings, including guilt and isolation, often experienced by carers, and identified a need for greater awareness by psychologists regarding palliative care. Sue also called upon neurologists to refer families to the MND Association at diagnosis, to better enable early support, information and care for people with MND and their families.

In the next session, Dr Peter Allcroft, Respiratory and Palliative Care Physician from Daw Park Repatriation Hospital, Adelaide, spoke about symptom management for people with MND. Dr Allcroft focused on respiratory care including non-invasive ventilation, advance directives and care at the end of life.

Dr James Burrell from Neuroscience Research Australia provided a summary of the latest research relating to links between MND and frontotemporal dementia (FTD). This research group is focusing on the incidence and characteristics of cognitive and behavioural disturbance in MND, and he discussed the complexities of cognitive assessments, including eye movement tracking tools.

The day concluded with Dr Bradley Turner from the Florey Neuroscience Institutes at the University of Melbourne, who captivated the room with his summary about research regarding MND causes and potential treatments. Dr Turner likened motor neurones to the roads in large cities, and highlighted the complexity of the disease that has many types and disease courses. He finished the day with hope about the future of research into MND noting that the pace of research increasing and concluding that some current trials were showing promising results for people with MND.

On the day following the conference we met with staff from other MND Associations from around Australia to once again share our knowledge and experience. We always come away from these meetings with lots of information and ideas as to how we can best support people who are affected by MND.

Gina Svolos

Manager, Family Support

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

Information on accessing enteral nutrition supplies (PEG and RIG)

MND NSW has a new information sheet about accessing enteral nutrition supplies such as feed delivery syringes and pumps, feed delivery tubes and enteral feeding formula. It explains how people with MND can get their supplies at a substantial discount through several government programs. For your copy contact the MND NSW info Line 1800 77 175, your Regional Advisor or see www.mndnsw.asn.au

Family Support Team (cont'd)

Equipment

This year we have provided over 1377 items of equipment to 298 of our members throughout NSW and the ACT - an increase of 24% from 2011.

There have been some highs and some lows for the Equipment Service during 2012.

The new technology devices we can now loan for communication, such as iPads loaded with communication apps, have been very popular with members and supporting healthcare professionals. Comments received from members and their families include, 'life changing' and 'a huge difference to her quality of life'. However, a definite low point during the past year has been the delay in providing power wheelchairs for loan. The combination of limited stock and continued high demand resulted in us not being able to meet demand quickly enough, even though we did purchase an additional three power wheelchairs in an effort to alleviate delay in supply.

During 2012 we were able to purchase other items of equipment including 26 pressure cushions, 14 manual wheelchairs, 7 armchairs, 41 bathroom equipment items, for example shower commodes and over toilet aids, 20 slings, 10 mattress overlays, 20 iPads and 100 other communication items including switches, communication software, adapted door chimes and environmental controls. Thank you to our supporters for their generosity during 2012 - making the purchase of many of these items possible.

Learn Now, Live Well 2012

The Learn Now, Live Well workshop recently held over two Mondays at the MND NSW Centre at Gladesville was both an enjoyable and informative experience for all involved. We offer this program once a year and it focuses on the many things that can be done to enhance the quality of life for those living with MND.

The opportunity to hear from a range of professionals with experience in MND and to meet others in a similar situation, were rated very highly by all. The delicious morning teas and lunches were certainly an added bonus!

There were twenty six participants over the two weeks, including a number of our members accompanied by family or a close friend. We were also joined by our two newest regional advisors Lisa Dowling and Deb Ward, who attended as part of their orientation and introduction to the Association.

Many thanks to our speakers Christie Allen, Ross Black, Nina Brodaty, and Monique Covey who gave so generously of their time.

With the holiday season nearly here, courier companies become increasingly busy and delays may occur with equipment shipping or collection. Where possible we will give a time frame for a delivery of an equipment item but this may be changed by the courier due to circumstances in the delivery area. I ask that everyone be patient during this time but if there are any problems to contact MND NSW and we will assist in solving the problem if possible.

The MND NSW Equipment Service will close from 4pm Friday 21 December 2012, for the short period between Christmas and New Year, reopening Wednesday 2 January 2013.

What if your equipment breaks down during the Christmas break?

If during this time you have an urgent equipment breakdown please either contact your occupational therapist or speech pathologist to assist you in arranging a repair or if your local occupational therapist is not available then contact your local hospital. Remember if you are using a battery operated piece of equipment every day, power wheelchair, hoist or communication device, then the battery needs to be charged overnight.

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

Maree Hibbert

Equipment Services Coordinator

Book Review

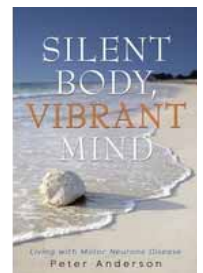
Silent Body Vibrant Mind Peter Anderson

Reviewed by Chris Carroll and David Wallace, MND NSW

This is a memoir of Peter Anderson's life as a teacher, a father and a husband. He began writing so that his daughter, who was only just over a year old when he was diagnosed with MND, would have something to remember him by.

Peter has not let MND define him. Rather MND has allowed him time to reflect on what is important in his life. He has written from the heart and it is a book that many people living with MND or who know someone living with MND will be able to relate to.

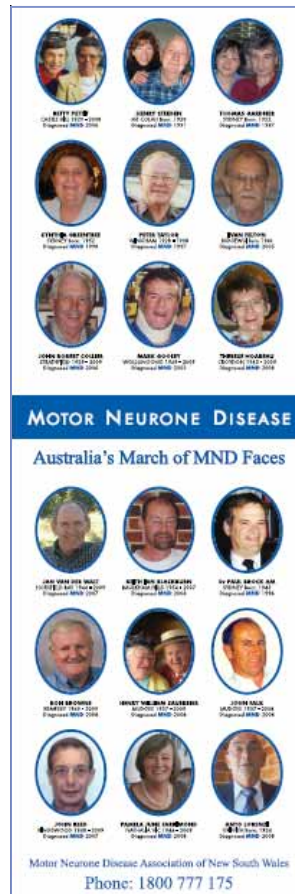
MND NSW have a copy of the book in their resource library available to members and their families to borrow at no cost for up to a month. For more information about Peter and the book see www.peteanderson.org



Get more information about communication apps for people with MND at www.mndnsw.asn.au

March of MND Faces

The MND NSW March of MND Faces banners



feature a photographic display of people with motor neurone disease. We will soon be producing another 'March of MND Faces' banner.

If you have MND and want to be included in the new banner you need to complete a permission form and submit a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish.

Family members are also able to submit a photograph in remembrance of a person who has died from MND.

For more information ph. 8877 0999 or email Penny Waterson info@mndnsw.asn.au.

Family Support Calendar 2013

19 Feb	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
25 Mar	Lunch for bereaved carers
16 Apr	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
11 May	Day of Hope and Remembrance
13, 20, 27 May and 3 Jun	Care for Carers Gladesville To enable you to care for a person with MND at home, while still taking care of yourself.
18 Jun	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
22 July	Ask the Experts West Ryde You, family members, carers and friends can bring your questions about MND and have them answered

For more information contact
MND NSW Info Line ph. 1800 777 175.
If you would like assistance with travel to attend family support sessions or would like us to organise an MND information session in your region, please speak to your regional advisor.

Support group dates for 2013 will be available at www.mndnsw.asn.au after 15 January

Support Groups

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

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

Gladesville - Caroline Gleig | carolineg@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 - Lisa Dowling | lisad@mndnsw.asn.au

REGIONAL AND RURAL

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

Central Coast - Audree Dash | 4384 2907 or Deb Ward | 1800 777 175 | debw@mndnsw.asn.au

Central West - MND NSW InfoLine | 1800 777 175 | davidw@mndnsw.asn.au

Griffith and Region MND Information and Support - Gail Ferguson | 6286 9900 | gailf@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

Communication technology and MND

In 2012 MND NSW was approached by four Master of Occupational Therapy students from the University of Sydney who needed to undertake a final year project that involved partnering with a community organisation. MND NSW wanted to know about how our members use technology and we were very fortunate that the students agreed to investigate this.

During the course of the project, the students spent more than 160 hours each working on the project. They reviewed existing research in this area and worked with several MND NSW staff to develop their own research plan. Many of our members agreed to complete a survey about their technology use or to be interviewed by the students by phone. Once all the information was collected, the students analysed it and compiled a final report.

The project was a great success with lots of new information gained. We are grateful to the students, Parthna Bhuta, Janet Devine, Anna Love and Kim Rusten for their commitment to the project and their real interest in learning about how people with MND use communication technology. Below is an excerpt from their presentation at the 6th National MND Conference in Adelaide in September 2012.

Thank you to the MND NSW members who participated in the Communication technology and MND project

...Why do a project on communication technology for people with MND? A few quotes from our qualitative data express this better than we ever could... *"The biggest thing for me is that MND stops a person from being independent but with the computer, my sister was able to communicate, interact and be very much a part of our life - we're so grateful that she had this equipment".*

And "The difference technology has made to my life is unbelievable. It has brought such joy and given me back my independence. I may not be able to speak and swallow but I still keep my sense of humour, love to travel, play bingo and make the most of each day".

However not everyone feels the same way... *"I have never done that, I have never seen that and I don't think my computer is sophisticated enough to do that. I don't think the doctors would want me to do that. If they wanted me to then I guess, maybe, but it would have to be them asking me."*

Through close consultation with MND NSW it was decided that our team could provide a snapshot of MND NSW member use of communication technology, their needs and their aspirations.

Firstly, to the literature. Research is very limited on communication technology use and preferences for people with MND.

Devices for communication

- The inconsistency of symptoms and speed of progression of the disease means that many people with MND are unprepared for the reality of using AAC.

- Each person with MND progresses differently, and this complicates decisions firstly about intervention, and secondly, places great learning demands on those with MND who need to get their head around new technology at an extremely challenging time.

- Useful lifespan of devices can be short, because many devices fail to support the necessary adaptive equipment. No one communication device 'does it all', and supports the various

assistive devices that are required as speech and hand function deteriorates.

A number of studies highlighted that early intervention and decision-making around communication technology is crucial when working with people with MND, due to the speed of progression and likely need of high technology support.

However consumer resistance may be the biggest challenge. One study identified that people with MND may see the use of these devices as 'giving in'. Communication hardware may provide one more very visible reminder of what a person has lost as a result of MND.

Internet use

It's not surprising that the internet is a crucial source of information regarding MND. However, the studies that have looked at the information available raised concern that much of it is unreliable, offers false hope, and at the worst end of the spectrum, is potentially harmful.

Survey of MND NSW members

Next we come to the survey for MND NSW members about their use of technology for communication. 93 people gave consent to be contacted. Of those, 79 participated in the final project which is about 20% of the total members of MND NSW.

Results

What are people using or accessing? 85% of respondents own a desktop or laptop, therefore 15% have no access to a computer in the home. 48% owned or were borrowing a tablet computer (eg iPad). 39% of tablet computers were gifts whereas virtually all desktop computers were self-bought.

What about the internet? Here is a quote from a respondent, *"It's a pretty big part of filling my week now. I'd be pulling my hair out with boredom without it"*. 88% of respondents had access to the internet, with virtually all on broadband even

(Continued on page 8)

Communication technology and MND (cont'd)

though 50% of respondents lived in regional or rural areas. 59% use the internet to find out about MND which corresponds with findings in the literature. Nearly all, 91%, use email at least some of the time. And finally, 42% use the internet for technology advice.

Who else do people turn to for technology advice and ideas?

Family and friends are the most popular sources of advice about technology. Around 30% ask health professionals - speech therapists and the MND Association. One quote from a respondent: *"I ask my kids. Our age group is pretty illiterate about this stuff, they're useless".* And, *"I get the cleaning lady's 14 year old son to help me out with the iPhone".*

Our findings about support needs in the area of technology are limited. We didn't specifically ask whether people wanted more support, because this would have been a leading question, so it was left open-ended. However, five respondents self-identified as requiring assistance such as, *"I am very keen to get some accessibility solutions... I wish there was a one stop shop or some gurus I could easily access... and have an applied consultation".*

Four respondents expressed an avoidance of seeking support. *"All the help would have been available had we needed it but he wasn't keen to use it. He finds it hard to accept his diagnosis".* And on a similar theme, *"I think the thing is it is very early in my diagnosis so I have my head in the sand."*

I sort of hope they have made a mistake".

How confident are people with technology?

Overall, members were more confident than not across all technology forms. For example, 84% were at least reasonably confident with using a laptop computer. Confidence levels dropped with:

- text messages (32% are not confident)
- tablet computers (35% are not confident),
- internet video phone eg Skype (48% are not confident)

Finally

One aspect that became clear was that people with MND don't seem to anticipate the need for communications technology. Many are not prepared for any decline in their ability to speak and move their hands, *"I'd be a great advocate for people to start learning technology immediately, because that's the only type of communication you're going to have... One of the things I'd push is for the MND Association to give information from day one".*

The comments also made clear the difference technology has made to many respondents, *"Without email, typed notes and text messages I would be unable to communicate my thoughts and wishes, and would be unable to take care of my own affairs."*

This study highlights the need to raise awareness about communication technology in the earliest stage after diagnosis for people with MND and their carers.

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

Research participants wanted

National study seeks conversation with carers

Associate Professor Debbie Horsfall and a team of researchers from the University of Western Sydney, Calvary Centre for Palliative Care Research ACT, CSIRO and Cancer Council NSW are currently conducting research with carers in order to better understand what happens when people come together to care. If you have cared for someone who died at home in the past two years the researchers would be interested in talking with you about your experience of being supported by friends and family. Please contact Niki Read for more information ph. 02 4736 0368 or email n.read@uws.edu.au. The project website can be found at www.caringatendoflife.wordpress.com. This study has been approved by the University of Western Sydney Human Research Ethics Committee and will be recruiting participants until mid 2013.

Stem cell tourism research project

Have you travelled abroad for stem cell treatment - as a patient or a carer? Have you considered travelling abroad but perhaps decided against it? If so, researchers at Monash University would like to capture your story via an interview. At the moment there are very few conditions where stem cell treatments are routinely offered in Australia. However clinics and companies overseas are promoting stem cell treatments for many conditions including MND*. You will be able to participate if you contact the researcher before end of June 2013. This project has been approved by the Monash University Human Research Ethics Committee. For more information visit: <http://artsonline.monash.edu.au/stem-cell-tourism-research-project/> or contact Claire Tanner ph. 0433 817 048.

* At present we know that there is no evidence to suggest that the therapies, such as the stem cell treatments being offered by various clinics, improve outcomes for people with MND and they could in fact be harmful (MND Australia position statement Unproven Therapies and the Internet, February 2010)

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

Research roundup

View the MND Australia webinar held 11 October 2012 with ALS TDI

The MND Australia webinar with the ALS TDI research institute was held on 11 October. If you missed the discussion about MND research in the USA, updates about MND Association activities in Australia and the research update from Dr Bradley Turner - you can view the Webinar at www.als.net/Archive/10102012/Webinars/

Report on The ALS Association's Drug Discovery Workshop available online

In early March 2012, over 120 researchers, drug developers, government officials, and clinicians met in Washington DC, for three days of discussions focused on advancing drug discovery for ALS. The report on that meeting, published in the journal *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* was posted online in October 2012. The workshop, hosted by The ALS Association, examined the barriers and opportunities for translating basic science discoveries into therapeutics, with special emphasis on biomarkers, alternative targets, and clinical trial development. View the Report on The ALS Association's Drug Discovery Workshop 2012 at the ALS Association <http://t.co/AWIRQZKe>.

Profilin 1 is the twelfth MND causing gene to be identified in MND

About 10% of MND is 'familial'; that is, there is or has been more than one affected person in a family. The researchers are chipping away at identifying MND related genes.

- In 1993 the first genetic mutation related to MND was discovered in the superoxide dismutase 1 gene (SOD1). About 20% of familial MND is caused by mutations in the SOD1 gene.
- In 2008 mutations in the TAR DNA binding protein (TDP-43) gene code were found to cause TDP-43 to become toxic, causing MND in a small percentage of MND families. Researchers are yet to find out how and why TDP-43 behaves abnormally to cause MND.
- In 2009 a gene mutation that causes a rare inherited form of MND, FUS (Fused in Sarcoma, a protein) was discovered. Researchers have found that genetic mutations of FUS are a cause of MND for a small number of familial forms of MND and account for between 3% - 5% of MND families.
- In 2011 the discovery of mutations in the C9ORF72 gene was announced and has since been found in about 40% of all families with familial MND.
- In 2012 Profilin 1 is identified as the twelfth MND related gene, associated with about two per cent of cases of familial MND.

Findings on environmental toxins and the risk of sporadic motor neurone disease (SALS)

Associate Professor Roger Pamphlett of the Stacey Motor Neuron Disease Laboratory, The University of Sydney, has been collecting blood samples and asking people to complete a very long questionnaire over the past decade. He has been investigating environmental toxins and MND and in June his findings were published in the *European Journal of Neurology*.

Using questionnaire data from 787 people with sporadic MND and 778 non-related controls Dr Pamphlett found that:

- men who reported that they worked with metals and chemicals or solvents, or who had been exposed to herbicides or pesticides, had an almost twofold increased risk of acquiring SALS
- women who had worked with chemicals or solvents also appeared to have an increased risk of SALS.

Dr Pamphlett concludes: "Although a mechanism by which these toxins could cause motor neurone death has not been definitively demonstrated, the generation of oxygen radicals is a favoured hypothesis. One unanswered question in the MND-toxin field is that men, rather than women, are much more likely to be exposed to toxins during their working life, whereas the incidence rates for SMND usually show only a slight preponderance of men. This could be because women are for some reason more sensitive to lower doses of toxins than men, or that domestically located toxins are equally important in the pathogenesis of SMND to those found in workplaces. However, no convincing explanation for this apparent paradox has so far been put forward. In conclusion, this large case-control study adds weight to the hypothesis that environmental toxins play a role in some patients with SMND."

Yeast and TDP-43

A collaborative American research group, led by Prof Aaron Gitler from Stanford University School of Medicine in California, has identified a potential therapeutic target for MND using yeast. The toxic activity of the MND-linked protein TDP-43 was suppressed when a gene called DBR1 was deleted from yeast and mammal cells. The study marks the first steps in the identification of a treatment that can target TDP-43, which is found to clump together in many people with sporadic MND who have no familial MND history. Read more on the MND Research Blog at <http://mndresearch.wordpress.com> and at <http://alsn.mda.org/news/als-briefs-serotonergic-neurons-and-counteracting-problematic-proteins>

Noticeboard

Cane and Able

Cane and Able Travel is a website developed by travel writer Ian Heydon, who has multiple sclerosis. The site contains info on getting around, great places to visit, events and attractions, entertainment and accessible accommodation. See www.caneandable.com.au

Accessible transport website for inner west Sydney

Transport Connect provides information on accessible transport options for the inner west Sydney area. Find out about community transport, accessible public transport and taxi services. Transport Connect also provides ideas for accessible transport service users in Sydney. See www.transportconnect.org.au
SOURCE: Carers NSW July 2012

NSW Home Power Savings Program

The NSW Home Power Savings Program can help you reduce your power and water bills. To be eligible for the program you must live in NSW and contribute to the power bills for the property and:

1. Where one person in your household has a Pensioner Concession, Low Income Health Care or Veterans' Affairs card or is an energy utility hardship customer you can access a free:
 - 1 hr home power assessment
 - Power Savings Kit including a stand-by saver power board, energy efficient light globes, showerhead, tap aerators, thermometer, draught proofing strips and seals, door snakes and a shower timer
 - personal Power Savings Action Plan
 2. Other households who do not meet the above criteria can visit savepower.nsw.gov.au and
 - subscribe to the Save Power e-newsletter
 - register to receive free SMS power saving tips
 - download Save Power fact sheets
 - create your own Power Savings Action Plan
- For more information ph. 1300 662 416 or see www.savepower.nsw.gov.au

Assist Infirm Disabled and Elderly Residents (AIDER)

The NSW Rural Fire Service AIDER Program is a one-off free service, supporting vulnerable residents to live more safely in their home on bush fire prone land. AIDER services can be provided to older people, people with disabling conditions and people who are already receiving community assistance and services. AIDER work is one-off and includes clearing gutters, thinning vegetation, removing leaf and tree debris, trimming branches from around and overhanging the home, mowing or slashing long grass. For more information ph. 02 8741 4955 or see www.rfs.nsw.gov.au/aider

National Disability Abuse and Neglect Line

National Disability Abuse and Neglect Line is a telephone service for reporting cases of neglect and abuse of disabled members of the community. Anyone can contact the Hotline and you can contact the Hotline if you are unsure what is happening is actually abuse or neglect and they can help clarify the situation. The Hotline also accepts anonymous reports. For more information ph. 1800 301 130 or see www.disabilityhotline.net.au

E-books and audiobooks

Many local councils are now offering e-books and audiobooks for free download loan directly to you at home. You can read e-books on a special e-book reader, or on your computer, tablet or phone. You can listen to audiobooks on your computer, tablet or phone. Contact your local library for more information.

National Public Toilet Map

The National Public Toilet Map shows the location of more than 16,000 Australian public and private public toilet facilities. Useful information is provided about each toilet, such as location, opening hours, accessibility for people with disabilities and details of other nearby toilets. You can also download the iPhone National Public Toilet Map App. See www.toiletmap.gov.au

Master Locksmiths Access Key System (MLAK)



The Master Locksmiths Access Key (MLAK) enables people with disabilities to gain 24/7 access to a network of public facilities including elevators at railway stations and

accessible toilets in Council municipalities and National Parks. You can purchase an MLAK master key which will open facilities which are fitted with the MLAK lock. For more information ph. 1800 810 698 or see www.masterlocksmiths.com.au/mlak.php

Law handbook now available online

The 12th edition of The Law Handbook, which provides a plain English practical guide to the law in NSW, is now free on the State Library website at www.legalanswers.sl.nsw.gov.au

Advance Care Planning Community Workbook

The Advance Care Planning Community Workbook explains terminology, who should be involved in drawing up an Advance Care Directive and answers many of the 'why' questions that people can ask. For more information see www.nscchealth.nsw.gov.au/carersupport/cc/acp.shtml or speak with your general practitioner or neurologist.

Thanks to Malcolm for the tip about e-books (see left). If you have a tip for Forum email Penny Waterson at info@mndnsw.asn.au

Community events

Moree Sky Gold Cup



The committee for Moree Race Club had a very busy first weekend in September raising money for MND - a golf tournament on the Friday afternoon followed by the B&W Rural and Farnoz dinner and auction on the Saturday night and finishing with the Crop Care and Croplands

Moree Cup race day on Sunday 2 September.

Kerry O'Keefe - the well-known, past test cricketer and current cricket radio commentator, attended all of the events, garnering enthusiasm. He was in superb form at the dinner and auction and delivered one of the funniest speeches ever delivered in Moree. The events were extremely well supported by generous local sponsors and the local community and raised a staggering \$34,686.

Burgh2Beach



In December 2011 local Helensburgh sight-impaired athlete, Nathan Johnston came up with an idea of a charity run from Helensburgh to Stanwell Park Beach. Nathan believed such a run would be challenging but in turn showcase the truly wonderful features of

Helensburgh, Otford and Stanwell Park communities. A committee of local residents was established soon after and Nathan's dream started to take shape. On Sunday 28 October, the first Burgh2Beach charity run for MND was run.

Organisers were overwhelmed with the turnout of almost 300 runners. All runners made it safely to Stanwell Park Beach for a BBQ at the Surf Club - the top 3 very fast, but slower runners still beat the cut-off by 15 minutes. Over \$10,000 was raised for MND NSW and all had a cracking day out. Thank you to Nathan Johnston, Nathan Shoemark, Paul Smith and the hard working committee. They are already planning for 2013.

Hunter Valley Traditional Archers



Hunter Valley Traditional Archers held a Charity shoot for MND NSW on 29 and 30 September. The event was attended by MND local

Ambassador Don McMurray, who spoke about his experience with MND and the work of the MND NSW Association. Don received a great reception from the archers and their families.

Sausages and merchandise at Port



With the support of her boss and colleagues at First National Real Estate Port Macquarie, Alison Williamson held a fundraising and awareness raising sausage sizzle during November. Alison writes, "My association with MND began in October 2011 when my husband Rob was diagnosed. At the time I was working at First National Real Estate and gave up my job so we could enjoy what time we had. Sadly Rob passed away in January this year, three months after being diagnosed. Without the help and support of MND NSW, family and friends our journey would have been so much harder. I then went back to work at First National and this is one way of raising awareness of what this disease does and funds towards research and loan equipment."

Photos: courtesy of Port Macquarie News

Puppies galore



In November at my school, Manly Vale Public School, my mum helped me sell MND puppies. My family knows how awful MND is because my Nanna had it. We had checked with the principal and set up a table at the school gate to sell the puppies as the kids went home. It was a great success! We sold all 90 puppies and have ordered more to sell next week. I have really enjoyed selling the puppies and am very happy we could raise money for the MND Association. From Georgia Wyatt (9)

Open Garden at Yerami



Visitors to Jenny Stannard's garden at Yerami, Lindfield on 3 and 4 November were generous in their support for MND. Yerami is a garden for all seasons created around a restored historic house with many roses, irises and seasonal plantings. The weekend was a great success with warm weather and 394 keen gardeners through the gate. More than \$1800 was raised - a great effort by everyone who helped with the weekend.

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

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

Community Fundraising

Walk to d'Feet MND – Port Macquarie 7 Oct

The folks of Port Macquarie didn't disappoint again this year and turned up in their hundreds to support the Walk. Mother Nature had decided to give us a beautiful sunny day, but with high winds that are usually unheard of in Port Macquarie. This didn't deter the wonderful local support of families and friends who made it such a great day. A big thank you to Suncorp Port Macquarie who helped promote the Walk through their branch and to the staff who attended on the day to volunteer. A very big thank you also to the wonderful local committee who worked so hard to make this such a great event again this year.

Walk to d'Feet MND - Sydney 4 Nov

What a great day on Sunday 4 November at the Sydney Walk to d'Feet MND. Sydney really rose to the challenge. Congratulations and a huge thank you to everyone who raised funds for this event through Everyday Hero. And a huge thank you to our supporters who attended the event. A new record for a Walk to d'Feet MND with 491 people and 31 dogs and (to date) \$50,661 raised. Thank you all for this fantastic support and especially to those families and individuals who created an Everyday Hero page in total these pages contributed \$39,089.



*Woof woof
New MND
puppy
arriving
in
2013
...watch
this space!*

Dates for the Diary 2013

24 Feb	Walk to d'Feet MND - Illawarra Bulli Surf Club Shelly-anne Demirov shellyannedemirov@gmail.com
10 Mar	Walk to d'Feet MND - Southern Highlands Bowral Kym Nielsen, MND NSW ph. 8877 0999
15 Mar	Battle of the Bacon Charity dinner and rugby league match organised by Griffith Police Peter Parslow Pars2pet@police.nsw.gov.au
24 Mar	Walk to d'Feet MND - Canberra Commonwealth Park, Lake Burley Griffin ACT Kym Nielsen, MND NSW ph. 8877 0999

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

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