



FORUM

Thank you to our volunteers

Local recognition

On 22 May 2012 President Mike Morgan and the members of the Rotary Club of Carlingford held an evening to recognise the efforts of volunteers. On this occasion Diane Openshaw and Rosemary Walker, longstanding MND volunteers, were presented with an award for their services to the community and building goodwill. Diane and Rosemary have volunteered for MND NSW for a total of 24 years. They have volunteered during MND Week at shopping centres and railway stations, packed *Forum*, assisted with mailouts and been available for general administrative support when required.

Thank you Diane and Rosemary for your continued contribution to the Association and it's services. Thanks also to the Rotary Club of Carlingford for organising this evening.



Pamela Lawrance (L), Volunteer Co-ordinator, Foundation Director and past President, Carlingford Rotary; Rosemary Walker and Diane Openshaw, MND Volunteers; Mike Morgan, President, Carlingford Rotary.

Corporate volunteers – Johnson & Johnson at MND NSW

Staff from Johnson & Johnson chose to spend a day of corporate volunteering with MND NSW on 22 June. Some of the Johnson & Johnson team had volunteered previously and brought along a few more colleagues this time.

The Johnson & Johnson team assisted the Association by packing this year's Christmas cards and completing the stocktake of merchandise plus various other tasks. We appreciate the assistance provided by local corporations large or small, so if you think that your business can assist the Association please don't hesitate to contact MND NSW.



Ayse Dalkic (L), MND NSW Fundraising Assistant, with the Johnson & Johnson corporate volunteers.

Judith Durham concert at the Opera House

Judith Durham held concerts at Sydney Opera House on 13 and 14 July and on each evening nine MND volunteers were able to take part in fundraising for MND. They reported they had 'an amazing time whilst volunteering'. They were visible in their bright blue volunteer t-shirts and received donations totalling \$5,818 for their efforts. MND NSW would like to thank these volunteers for donating their time so generously.

Volunteering with MND NSW

If you are thinking about volunteering for MND NSW but feel that you have limited time, you can still register your expression of interest in volunteering by contacting Ayse Dalkic, on aysed@mndnsw.asn.au or ph. 8877 0999.



Our volunteers with their fundraising buckets at the Judith Durham Concert.

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.

City2Surf - What a result!

The City2Surf seems to grow each year and so does the wonderful support we receive from participants. This year we had 38 participants raising money for MND NSW and what an amazing job they did: not only did they brave the elements and the crowds but they also raised a grand total of \$31,926 for MND NSW. Thank you to everyone who took part this year.

Here is Jayde's story



Yesterday was THE BIG DAY! Though leading up to the race, the weather (as usual) was not looking in my favour! The wind was blowing a gale days before the event and I was afraid that if it didn't stop in time for the run, I would get blown from the top of Heartbreak Hill into the ocean! I wasn't too sure what to wear temperature wise (apart from the great MND NSW T-shirt) but in the end the air settled



and it turned into pretty decent running conditions. There were lots of people dressed up in funny costumes including some apes, Jamaicans, Smurfs, pink fairies and ARMY dudes! We were determined not to let any 'Pram-pushers' overtake us during the run and made it to Heartbreak Hill with minimal injury (no blisters) but with a few sore knees!



After Heartbreak Hill (which luckily was smaller than I dreamed of) we were half way and pumped to get through to the finish line under 2 hours! Bondi Beach was in sight and I was giving all the gas I had left in my tank! By this point, I thought my stitch was about to explode but my mates held my hands as we sprang over the FINISH line! We did it in about 1 hour and 45 minutes! ...Not the best time, but in the end - we were not there to win! Just to stick together, have fun and raise money for MND NSW!

MND NSW
Infoline

1800 777 175

9am - 4.30pm

Monday
to
Friday

For people living with MND, their family and friends

Learn Now, Live Well

A two day educational program to assist people to live well with MND

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

Learn Now, Live Well is a two day educational program for people living with motor neurone disease, their families and friends. It provides a range of strategies to live well with MND and to maintain independence. It also provides the opportunity for you to have your questions answered by a range of health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.

WHEN: **Monday 22 October and Monday 29 October from 10am to 3pm.**

WHERE: **MND NSW Centre Gladesville**

Lunch and refreshments will be provided each day. Please RSVP by 17 October, 2012. To book your place or for financial assistance with travel arrangements contact Kate Maguire ph. 8877 0999 or Freecall 1800 777 175, or email familysupport@mndnsw.asn.au

It is **almost** time to celebrate the start of the Festive Season!

You, your family and friends are invited to the
MND NSW Family Support Members' Christmas Party



Saturday 24 November, 2012

2.30pm to 4.30pm

Ryde Eastwood Leagues Club
117 Ryedale Road, West Ryde

Contact MND NSW to reserve your place
Ph. 8877 0999 or Freecall 1800 777 175, or email
annej@mndnsw.asn.au. Kindly RSVP by 19 November

A Message from the CEO

Well the National Disability Insurance Scheme is on its way. Trial sites have been announced and the two that affect members of MND NSW are the ACT and the Hunter. The pilots are to start in July 2013 and will allow nearly 16,000 people with disability in the Hunter (the Local Government Areas of Lake Macquarie, Newcastle and Maitland) and ACT access to "...increased flexibility and innovation, so many people will be able to access different types of support."

A Frequently Asked Questions info sheet can be found at www.ndis.gov.au/ndis-launc/launch-faqs/. There is also an NDIS Hotline ph. 1800 800 110 if you have further questions.

As always, we will still need all the support we can muster to ensure that the NDIS progresses beyond the trial sites. If you, your family or friends haven't already done so register your support by going to the MND NSW website at www.mndnsw.asn.au and click on the Every Australian Counts link or go directly to www.everyaustraliancounts.com.au.

To highlight Motor Neurone Disease Global Awareness Day during June, Mr Harry Jenkins, Member for Scullin, and Mr Kevin Rudd, Member for Griffith, both spoke about MND in the House of Representatives, and Senator Sue Boyce (Qld) spoke about MND in the Senate. All highlighted the need for support for people living with MND and we thank them for raising awareness about MND in these very public arenas.

Judith Durham, MND Australia's Patron recently embarked on a national tour and during her concerts encouraged the audience to support motor neurone disease. In Sydney over two nights at the Opera House an army of volunteers turned out with collection buckets. Over \$11,000 was raised nationally.

We congratulate Professor Dominic Rowe AM, Chairman, Motor Neurone Disease Research Institute of Australia, on his mention in the 2012 Queens Birthday awards.

Professor Dominic Brock ROWE, Macquarie University, NSW. For service to medicine in the field of neurology through contributions to people with motor neurone disease and Parkinson's disease as a clinician, researcher, educator and administrator.

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



Port Macquarie

7 October

Sydney

4 November

If you'd like to organise a Walk to d'Feet MND in your local area during 2013 contact Kym Nielsen on kymn@mndnsw.asn.au or ph. 8877 0999.

Motor Neurone Disease Association of New South Wales

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Maree Hibbert

Equipment Assistants / Support Officer

Tom Giardina, Michael Walker / Ellen Hibbert

Information Resources Coordinator

Penny Waterson

And...many valued volunteers including Eric - one of our volunteer packers for Forum



Family Support Team

We had our *Ask the Experts Forum* in August and our speakers covered a lot of ground - talking about MND, current research and legal issues (see page 8). For those of you who were unable to attend you will be able to watch videos of the presentations by following the link on the home page at www.mndnsw.asn.au.

Our next program for members will be *Learn Now, Live Well* to be held on 22 and 29 October. This is a program that aims to give people living with MND and their family or friends information that will help them to live well with MND. We encourage you to attend. See details on page 2.

MND Aware Face-to-face training for community and health care professionals takes off around the state!

MND Aware face-to-face training is a four and a half hour training day developed by MND NSW for people working with people with MND. During 2012 we have conducted nine MND Aware training days to date with almost 250 service providers attending. Further training days are already scheduled for Northern Sydney, Wagga Wagga, Griffith, Port Macquarie and Coffs Harbour this year. Next year we travel to the ACT, Western Sydney, Southern NSW, Southern Sydney and more.

Each MND Aware training day is facilitated by two MND NSW staff: a Regional Advisor and one of our Education and Carer Support Coordinators. You

may be able to tell that Jenny Judd and Kristina Dodds have been in Parkes, where they not only met up with almost 55 service providers (over two days in Orange and Parkes) but someone very famous.

The aim of MND Aware face-to-face training for health and community care

professionals is to increase their awareness of MND and to educate these care providers about the experiences of people living with MND, their families and carers. We also discuss the importance of care coordination in symptom management, well-being and support needs, how service providers can make a difference and where they can find further information. The day adds to the online MND Aware training that was launched by MND NSW in November last year.

Some of the feedback has included "very well presented and wonderful, frank discussion around MND issues and care", "very comprehensive, good use of examples", "feel welcome to hold a day in Dubbo".



Jenny Judd (L) and Kristina Dodds (R) in Parkes

A new model of care for Port Kembla Hospital for people with MND.

In June MND NSW facilitated a workshop at Port Kembla Hospital, *Motor Neurone Disease – working together, the value of multidisciplinary care for health and community care professionals*. This workshop was very well attended by local health and community professionals eager to learn about MND. Congratulations and thank you to the local health professionals who helped organise this day and thank you to staff from Prince of Wales and Calvary Hospital who travelled down to share their knowledge and expertise with those on the South Coast. The day provided an opportunity for health professionals to think about how they can work together to improve the care of people with MND and we look forward to hearing how this progresses.

We thank all the health and community care professionals for taking time out of their very busy days to attend these workshops. We know this will result in better care for people with MND.

Farewell to Jenny Judd, Regional Advisor, Western Sydney and Central West NSW

We were very sad to farewell Jenny who worked tirelessly with MND NSW for almost six years. Jenny is moving interstate and we wish her all the best in her new location. Those who know her will be aware of her extreme dedication.

We will be recruiting two new regional advisors to

replace Jenny and also to cover some other areas to help relieve the growing workload of our regional advisors. We also plan to set up a regional office in the Penrith area so that it will be easier to visit people living in the Blue Mountains and Central West. This is in response to

the 12% increase in membership we have experienced since last year that I highlighted in the June edition of *Forum*.

We are encouraged that more people are aware of our Association and can gain the benefits of accessing our services.

For those members who live in Jenny's areas we will be in touch once we have recruited to these positions. We hope it won't be too long. In the meantime please don't hesitate to contact our Information Line on 1800 777 175 if you require any information or support.

Gina Svolos

Manager, Family Support

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

Family Support Team (cont'd)

Equipment

New staff

I would like to welcome the newest member of the MND NSW team, Ellen Hibbert, who is working in the role of Equipment Support Officer. Ellen is working eight hours a week assisting with the *MND Assess Support Communicate* Project.

MND NSW Equipment Loan Pool lists

A reminder that there are two lists of items stocked in the MND NSW Equipment Pool on the MND NSW website: (1) Standard items and (2) Communication, computer access and environmental control items. To view these lists go to www.mndnsw.asn.au > For healthcare professionals > Equipment loan referral. The list can also be posted, faxed or emailed upon request. The lists do not provide details on currently available equipment as this can change daily but gives an idea on the type of equipment available for loan. Items are loaned on a priority of need basis after assessment and request by a health professional.

Couriers

During the past three months we have arranged 361 loans and 354 returns of equipment. Due to the size, weight and destination of our loaned equipment MND NSW uses a number of courier companies to deliver and retrieve equipment. Equipment staff are responsible for arranging the most suitable company for shipping and return and where possible delivery and pickup dates are arranged to suit members first preferences. Sometimes in the more regional areas, set courier runs may occur only once or twice a fortnight on a set day. If you are not available to accept a delivery or pickup, a representative from the courier company will contact you to arrange a suitable day.

For regional deliveries and large item deliveries the courier requires a minimum of three working days from booking to delivery. Large items require a tail lift equipped vehicle to load and unload. Unfortunately this timeline is sometimes restrictive but it is out of our control.

The cost of all equipment shipments booked by MND NSW are paid for by MND NSW. It is important to remember MND NSW equipment staff are to be contacted when an item of equipment is to be returned.

If you have an item of equipment from the Equipment Loan Pool that you no longer use please contact MND NSW and we can arrange for it to be collected. This will free up space in your home and also allow the equipment to be available for loan to other members.

Healthy batteries

Replacement of batteries for equipment is expensive. For example, a replacement set of batteries for a powered wheelchair costs from \$250 to \$500. Members using battery powered equipment (such as powered wheelchairs, hoists and Lightwriters) are advised it is best to charge the equipment overnight if you are using it every day, and every third day if you are not using the equipment every day. This helps maintain battery life. For safety reasons, only the charger provided with the equipment should be used for charging the battery. However, if you currently are using a powered wheelchair please check the charging instructions provided with your chair to ensure the maximum life of the batteries.

Raiser recliner electric armchairs, have two 9V batteries connected to the power pack in case of a power blackout. It is recommended that you store a spare set of batteries in the armchair side-pocket so they can be easily found just in case they are needed. When the chair draws power from the batteries and not the power outlet, the chair will operate very slowly for approximately one or two lifts and then stop. If this happens when there is no power outage it is an indication that (a) the power cord is disconnected and (b) the 9volt batteries will need to be replaced.

The Independent Living Centre of NSW (ILC NSW)

ILC NSW has moved to Level 4, Shop 4019, Westpoint Blacktown, 17 Patrick St, Blacktown NSW 2148. This service is a great reference point where you can find information about equipment and retailers. There is an online product database and trained staff to assist with any queries. There is also an extensive show room of medical equipment for demonstration purposes only. You can contact the ILC ph. 1300 885 886 or email help@ilcnsw.asn.au or visit www.ilcnsw.asn.au.

It is always best to work with your occupational therapist to assess what equipment is required and what features of equipment are suited to your individual needs, before looking at any equipment purchase. Your occupational therapist can assist with sourcing equipment as well.

Please feel free to contact MND NSW staff if you have any concerns or queries.

Maree Hibbert

Equipment Services Coordinator



Put it in your diary

Family Support Members' Christmas Party Saturday 24 November, 2012 at West Ryde

Mailbag

My mum Jean Pascoe was diagnosed with MND in 2008. When she first told me, I didn't know what it was. I thought it was some kind of problem to do with her nerves, but didn't realise it was an actual disease. Then she handed me a leaflet to read. As I read, I felt increasingly numb with shock. Over the following weeks and months after much reading and talking to people, we became experts in the subject.

As the months went by, I felt I had quite a bit of support around me. The strong shoulders of my husband, who always made sure I could be with Mum during the week (a very difficult task as his work schedule was full on, plus we live in the country and I don't drive); the love and care of friends (sometimes providing food and accommodation); the advice and medications from doctors, the care and practical help from allied health professionals; Mum's army of friends (so many that Mum needed a diary where friends could write in their next visit); and the sense of community, knowledge and relevant advice from MND NSW (not to mention introducing me to LifeCircle and the volunteer mentor, who I never thought I needed...)

I don't need a mentor

My life at that time was all about looking after Mum and making sure she had everything she needed to lead a safe, comfortable and as happy a life as possible. So when my Regional Advisor Jo Fowler told me about LifeCircle and how they were offering volunteer mentors for carers, I brushed it aside.

To be honest, I felt that I didn't even have the time or energy to consider it. "Thanks Jo, appreciate the suggestion, but I don't need a mentor".

If you know Jo, then you know one thing about her, and that is she's persistent. Every time Jo saw me I was looking a little more tired. The wearier I became, the more she encouraged me to consider a mentor. Finally I relented and LifeCircle introduced me to my mentor...

She understood

When I spoke with my new mentor over the phone it just felt right. When we met for coffee, I took one look at her and I knew it was a perfect match. Her name is Caroline.

It was so easy and comfortable. We chatted, we shared, we laughed. We also talked about one another's life experiences. We chatted about how we'd communicate with one another. I was comfortable with the occasional catch up for

coffee when I was up seeing Mum, with our main communication being phone calls, emails and texts, as I lived so far away. Caroline told me to feel free to contact her any time... that being a mentor wasn't a 9 to 5 relationship. If she couldn't answer straightaway she'd contact me when she could. Perfect! I felt very special and spoilt.

In the beginning, we weren't in contact all that much, but I still appreciated knowing she was there, just in case. That in itself was reassuring. As time went on and Mum's condition deteriorated, our contact increased accordingly.

Have you thought about...

Our chats went from being just chats to conversations peppered with some helpful info. I noticed Caroline would pick up on any issues I brought up and then ever so gently she'd say "Have you thought about..." and a little pearl would drop out. She never told me to do anything, she had great ideas and I was happy to follow them.

There were times when things went wrong or I was frustrated or feeling down I would contact her and just burble. Being once removed made it easier...



Oxana with her mum, Jean Pascoe

Where friends and relatives were more emotionally involved and worried about me, Caroline was cool and calm when I was upset or ranting. She'd listen patiently and say I was doing a great job, to keep up the good work and make sure I was looking after myself.

They say knowledge is power, and when Mum was nearing the end of her life, I found it also gave me peace of mind. In Mum's

final months and weeks, I had so many questions. LifeCircle were able to provide me with some wonderful written resources which helped me to understand the changes that were occurring. That meant I could stop panicking and just be a loving daughter doing everything I could to have the best possible relationship and time with Mum. We were able to say our good-byes, enjoy our special time together and to appreciate it for the precious time that it was.

Oxana Paschuk-Johnson

Your Regional Advisor will be happy to discuss how a LifeCircle Mentor may benefit you in your caring role.

Or, to arrange a Mentor, contact LifeCircle ph. 1300 364 673.

Support group dates for 2012 are available at www.mndnsw.asn.au

Mailbag (cont'd)**The Ms**

*We hear of the marvels of mankind's achievements
we're mesmerised by moments of milestones done
milli-seconds of timing pursuing Olympic medals
mere mortals in feats of such magnitude
mind boggling and masterful all rolled into one.*

*An amazing spectacle in recent decades
a walk on the moon in marvellous giant strides
now to be matched with another marvel
a robot on Mars measuring the magnitude
the jigsaw of our universe well and alive.*

*Is it too much to hope for an MND breakthrough
to mellow and sooth the moments of madness
as the twitching muscles remind us of none?
A miracle for dedicated neuros and scientists
who strive and research in their unwavering quest.*

*Can we not look into the eyes of our loved ones
before our time on this earth is done
to share a marvellous magnificent moment
and say with conviction*

'The cause is now known and the cure will be won'

Carol Notter

9 August, 2012

Recipes for
people with
swallowing
difficulties

New 2012
edition
available free
for members.

MND NSW
Infoline
1800 777 175

Family Support Calendar

16 Oct	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
22 and 29 Oct	Learn Now Live Well Gladesville For people with MND, their family and friends. Two day educational program covering living well with MND, and support and services available for people living with MND
24 Nov	Christmas Party for family support members, their family and friends West Ryde
11 Dec	Information Evening for people recently diagnosed with MND, their family and friends Gladesville

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.

For people living with MND, their family and friends - Learn Now, Live Well

A two day educational program to assist people to live well with MND

Monday 22 October and Monday 29 October from 10am to 3pm at Gladesville. See page 2 for more information.

Support Groups

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

Campbelltown - Ann McCutcheon | 1800 777 175 | 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 - MND NSW InfoLine | 1800 777 175 | davidw@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 Jo Fowler | 1800 777 175 | josephinef@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

Ask the Experts 2012

The annual MND Ask the Experts Forum is always widely anticipated by members and those attending the 2012 Ask the Experts at Ryde were not left disappointed. This year we extended the time allowed for questions at the end of each presentation and there was ample time for all questions to be addressed.

Our opening speaker, **Professor David Williams, Neurologist, John Hunter Hospital**, weaved an engaging explanation about the 'science' behind the classification of types of MND. Classifying types of MND is not only useful to people with MND. Doctors, researchers and scientists use classifications to look for patterns and commonalities that can open treatment development research pathways for this complex disease. David highlighted current avenues of investigation and explained the scientific thought behind these avenues of investigations.

Q: Statin drugs and evidence in MND?

A: Needs more research, evidence slim at present

Q: Is Botox helpful for leg movement?

A: Botox is a powerful toxin that blocks messages to muscles. If muscle weakness is due to upper motor neurone deterioration then Botox may reduce stiffness. This would need to be determined on an individual basis.

Q: Sleep apnoea and MND

A: Not aware of any evidence that sleep apnoea makes MND more likely. Because MND often affects their breathing muscles investigation of sleep breathing for people with MND is usually recommended.

Q: Can MND cause discolouration/swelling of lower limbs?

A: Human beings are designed to move and this can be caused by inactivity. Muscles have diminished capacity to squeeze blood back around the body resulting in swelling and fluid leakage to the tissues. Not specific to MND but a secondary impact. Treatment: lymphatic massage, elevation, stockings more useful for preventative measure than treatment. Deep vein thrombosis does not seem to be a common problem in MND.

Q: It taking riluzole going accelerate the progression of MND

A: All medications have side-effects and a person considers the risks and benefits. Were riluzole not effective then we wouldn't have results from trials showing that riluzole can slow MND progression.

Q: Where is the Phase 3 trial of Dexpramipexole at? When will it be available to rest of population?

A: Professor Kiernan is expecting an announcement soon. Can't give specific timeframe for release due to regulatory procedures, but this can take several years.

Q: If you are slowly progressive does that mean you'll progress slowly all the way through?

A: Yes in general that is the expectation

Q: What are the causes of MND that aren't genetic, for example, environmental?

A: Over 100 years many environmental factors have been investigated. Nothing as yet absolutely identified as a cause. A blood test can rule out lead as a possible factor for neurological problem

Q: Personality changes and MND and are there any treatments?

A: Any significant diagnosis has a potential impact on people - emotionally and on their way of coping. A diagnosis can therefore have an impact. However, there are some people with MND who have changes in memory and cognition.

Q: Because of the hereditary nature of MND what should we tell relatives?

A: Yes, some forms are inherited. Generally if your MND has been diagnosed as sporadic, then to the best of our knowledge it does not have a familial link, so there is no particular need to talk about familial MND with your relatives. If the MND is familial then people usually do discuss this with their children, depending on the age of the children. It is important not to overlook that, with familial MND, any risk to children is usually 20-30 years down the track by which time we will know much more about MND.

Q: I have sporadic MND and will soon have a new grandchild. Should cord blood be stored for research or future use?

A: Individual decision - at this stage there is not any useful way cord blood could be helpful therefore it could be difficult to justify the cost of storage.

Dr Ian Blair, ANZAC Research Institute, Concord, spoke about What's New in MND Genetic Research identifying the dramatic increase in MND research and over the past two decades. As a result of this scientific knowledge about MND has increased greatly, primarily as a result of the human genome project and advances in technology. We can now use genes to create disease models that mimic features of MND for study in the laboratory. We are coming to understand that MND is caused by genetic risk factors that are interplaying with environmental risk factors.

Q: Is it possible yet to test at risk family members for C9ORF72?

A: Yes, after genetic counselling

Q: I have sporadic MND but just found out that my uncle died of MND. Should my classification be changed or is it coincidence?

A: Strongly suspect that we would be looking at unrecognised familial MND.

You can watch the Ask the Experts presentations by following the link on the home page at www.mndnsw.asn.au.

Ask the Experts 2012 (cont'd)

Q: Is there a relationship between the size of a C9ORF72 repeat expansion and age of onset of MND?

A: It is a technically difficult repeat to find and currently methods are being devised to determine the full size of the repeat. At this stage we don't know.

Q: Would it be possible to answer questions in research with a 'trio' set of DNA (ie DNA from parents of/and a person with sporadic MND)?

A: Yes, very useful and would appreciate people who have sporadic MND who still have both parents alive making contact with the ANZAC Research Institute.

Q: What is the state of the MND DNA Bank?

A: We are about to start gearing up collection of DNA again. Samples already held in the DNA Bank are currently being used in Australia and all around the world in research studies related to MND.

Q: Are there pockets of MND in certain areas in Australia?

A: Not to my knowledge. More cases sometimes appear in areas where people have access to neurologists and are therefore diagnosed appropriately, but there are no causative clusters in Australia that I am aware of.

Dr Megan Munsie, Stem Cells Australia spoke on Hope, Hype and Reality: The Facts about Stem Cell Research. Megan explained that headlines about stem cells are often sensational and oversimplify where research is at. Present use of cord blood and bone marrow stem cells is limited to diseases of the blood – 'like for like'.

Over the last 20 years researchers have been able to identify stem cells in the kidney, heart and brain, but these cannot be effectively harnessed for treatments yet.

There is often a great focus on the potential therapeutic use for stem cells, but where stem cells are currently making a great scientific contribution is as a research tool for finding out more information about the disease itself, for example we can now look at how MND develops using stem cells in a petri dish.

There is currently a long list of stem cell treatment companies even though treatments are yet unproven. A person considering stem cell treatment should speak with their neurologist first to better understand the context of the proposed treatment because the neurologist will be more impartial than a company 'selling' the treatment.

Booklets are available through Stem Cells Australia at www.stemcellsaustralia.edu.au to help with right questions to ask.

Q: If you are using someone else's stem cells is there a risk of rejection?

A: Embryonic, fetal and donor stem cells generally carry a risk of rejection. Mitochondrial stem cells are generally thought to not have a risk of rejection.

Q: In your opinion are we looking at numerous types of stems cells that are needed to treat MND?

A: We are looking at numerous type of stem cells, and in time some will look better for MND treatment than others. Perhaps a particular stem cell might have a protective factor whereas another for another purpose. Often clinics offering unproven treatment are offering the same type of stem cell to treat many very different conditions – like a magic bullet. It doesn't make a lot of sense when you consider the pathology of the different conditions.

Q: In the 16 people that you studied who went overseas for stem cell treatment what was the follow up? Did they deteriorate after a period of time?

A: We saw that not everybody had a physical improvement after treatment in the first place but they felt better in themselves for trying it.

Q: What about cord blood banking?

A: Cord blood banking is good for blood and immune system disease treatments but the jury is still out on its relevance to MND. Private cord banking costs about \$3000. People need to understand that they are not necessarily buying 'insurance'. There are public cord banks for treatments of some diseases, but not MND.

Josh Mennen, Lawyer, Maurice Blackburn Pty Ltd, spoke about Planning Ahead: Wills, Powers of Attorney, Advanced Care Directives, Superannuation. Josh advised that benefits available through superannuation, including total and permanent disability cover, often go unclaimed. It is important not to roll multiple superannuation accounts together when you are diagnosed with MND unless you have already sought advice to make sure that you are not closing off accounts that may have associated life or disability insurance cover.

Q: If I don't have a Will does that mean my assets would not go to my partner?

A: Not having a Will means that your estate could be more easily challenged and that extra steps need to be taken to distribute your assets. These involve placing newspaper advertisements and applying to the Court for an administrator, greatly increasing the stress on your loved ones.

Thank you to our speakers for giving up their time to be with us on the day.

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

Noticeboard

After hours GP helpline

You can get free health information and assistance from a registered nurse, or medical advice from a GP after hours on the Australian Government GP helpline. The helpline is available from 6pm to 8am Monday to Saturday, 12pm Saturday to 8am Monday, and 24 hours on public holidays. Ph 1800 022 222.

Smoke Alarm and Battery Replacement

The Smoke Alarm and Battery Replacement program assists NSW seniors and people with a disability who are vulnerable in the case of a fire because they are not able to install and/or maintain their smoke alarms. Firefighters can visit your home to install a battery-operated smoke alarm or replace smoke alarm batteries at no cost. The resident must supply the battery-operated smoke alarm or batteries. For more information contact your local fire station or ph. 1800 151 614.

NSW Government Life Support Electricity Rebate

If you have an electricity account in your name and you or someone else in your household use medical equipment such as non-invasive ventilation or an enteral feed pump you may be entitled to a rebate on your electricity bill. The rebate for an NIV machine is about \$0.16 per day and an enteral feed pump about \$.20 per day. You can get the Life Support Rebate application form at your electricity retailer or from www.trade.nsw.gov.au/energy/customers/rebates/life-support-rebates-questions

Australian Government Essential Medical Equipment Payment

The Essential Medical Equipment Payment is an annual \$140 payment to people who have a Commonwealth concession card who experience additional increases in home energy costs from the use of essential medical equipment in their home for themselves or others, such as non-invasive ventilation, alternating air pressure mattresses and enteral feed pumps. This payment must be claimed. For more information see www.humanservices.gov.au/customer/services/centrelink/essential-medical-equipment-payment or ph. 132 717

SOURCE: NDS June 2012

Lifeline Online Crisis Support Chat

Short-term support for people who are overwhelmed and having difficulty coping or staying safe is now available using 'chat' technology from Lifeline Online. Visit www.lifeline.org.au/Find-Help/Online-Services/crisis-chat from 8pm to midnight or ph. 13 11 14.

Source: MND Victoria

Information on accessing non-invasive ventilation (NIV)

MND NSW has a new information sheet about accessing non-invasive ventilation (NIV). It explains how MND NSW members may be able to get a NIV unit and mask(s) when these items have been prescribed by a respiratory physician. For more information contact the MND NSW info Line 1800 77 175 or your Regional Advisor.

24hour Mental Health Line

The NSW Government has established the 1800 011 511 Mental Health Line to ensure that people with a mental health problem, their families and carers can access the care they need whenever and wherever they need it. The Mental Health Line operates 24 hours a day, seven days a week and provides a telephone triage assessment and referral service staffed by mental health clinicians.

SOURCE: Carers NSW July 2012

Carer Allowance

The Carer Allowance is a small fortnightly payment that is not income and asset tested and is tax free. It is for carers who provide daily care and attention for an adult with a disability, severe medical condition or who is frail aged at home. Carer Allowance may be paid on top of Carer Payment or other payments, such as Age Pension. For more information about Centrelink payments visit www.humanservices.gov.au or phone 132 717. In July, the Australian Government paid the annual \$600 Supplement to people who receive Carer Payment, Carer Allowance and Department of Veterans' Affairs Carer Service Pension.

RESEARCH - Do you care for someone with MND?

Lauren Brockie is researching specific factors that may contribute to quality of life and the development of depression in carers of those with MND. Charles Sturt University's Human Research Ethics Committee has approved this study. The questionnaire takes 15-20 minutes to complete at www.surveymonkey.com/s/MNDCarers.

RESEARCH - Blood samples needed

ANZAC Research Institute at Concord is studying variations in the familial MND genes to determine if a combination of the variants increase the risk of developing sporadic MND. They are keen to obtain DNA samples from people with sporadic MND and control samples from spouses. To assist this research a single blood sample is required together with permission for the researchers to obtain a copy of clinical information from your clinical carers. People interested should contact the research group via Michelle Edwards ph. 02 9767 7016 or michelle.edwards@sydney.edu.au

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

Community events



Graham Opie CEO MND NSW accepting a donation from Killara Golf Club

Killara Golf Club
The charity luncheon for MND at Killara Golf Club (KGC) during June was the culmination of a year's hard fundraising for MND. With the support of Marie

Nesbit, Charity Manager KGC, and Chris Briggs, Event Manager KGC, over \$11000 was raised. Brenda Straton, KGC member who has MND said in her luncheon speech:

I'd like to express my gratitude to Graham and his team at MND for being so supportive as I travel downhill to complete paralysis with this terminal illness. When I was diagnosed with ALS it was a shattering experience and a roller coaster of emotions not only for me, but my family, friends and work colleagues.

Within days we were visited by the MND Family Support Regional Advisor who gave us lots of information and organised home visits by other health and community care services. We were reassured that they would always be there for us and would organise the supply of equipment. The most amazing part of this is that it is all supplied at no cost. My electric wheelchair is just one of the many items we have been loaned. To realise that we were only a phone call away from help and would not be financially ruined by this disease was a huge relief. The funding comes from the generosity of people like yourselves who donate to this very supportive charity. Thank you everyone for raising money for MND.



The Gageler Family in a sea of blue

Muswellbrook MND Trivia

The Muswellbrook MND Trivia night fundraiser was held on 28 July and was a huge success.

Many thanks go to Rachel Gageler and her team of organisers who made it such a successful and enjoyable night due to their hard work and commitment. What a fun night!! A packed hall that was a sea of blue, and a great sense of the enormous generosity and community essence that is legendary of the Muswellbrook locals. From the young lads of the community right up to the elder statesmen and women, everyone was into the spirit of the evening to raise much needed funds for MND. A very big thank you to you all.

Champers and Pampers

In June, Heidi Smith of D'Vine Tan & Beauty in the Hunter, held a Champers & Pampers fundraising event for MND.



Even the children were up for a treat at Champers and Pampers

On arrival guests were given a gift bag which included donations from Pure Fiji and ASAP Skin care, other products and vouchers. During the afternoon they were able to shop around at stalls and have their hair, nails and makeup done. There was face painting for the kids and a raffle, the major prize being one night's accommodation, breakfast and massage for two at the Crowne Plaza Hotel in the Hunter Valley. Over \$6000 was raised for MND. Heidi was inspired to run the event after meeting Jennie Morgan-Jones Austin in September last year soon after Jennie had been diagnosed with MND. Thank you to Heidi and her family and friends, including Mel Charters, Ali Morgan Jones, Liz Goodwin, Robyn Knight, Phoebe Knight and Zoe Palmer.

RayLee

Nathan, Ric and Gordon, friends of Raylee, who died from MND, set up a display and collected donations for MND at the Macleay Auto



Spectacular at Kempsey Racecourse and at the All GM Day at Cundletown run by the Mid-Coast Old Holdens Car Club. The displays were positioned in spots where Raylee's pride and joy would have been parked and raised much needed awareness about MND.

Vega Disco

A fun 70's and 80's disco was attended by over 500 guests on 26 May 2012 at the Lantana Palace Bonnyrigg NSW. The fundraising event was organised by the Vega family (pictured above with Anne Jones, [third from left] MND NSW), in memory of Amaro Vega who died from MND on 10 February 2011.



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

Community Fundraising

Woolworths Norwest Office



Ian Kingham (L) with organiser Colette McKenna at the Beer night for MND

During the Month of May, Woolworths Norwest Head Office raised an amazing \$23,575 for MND NSW. The fundraising was co-ordinated by Colette McKenna, whose good friend Nathan Ridd is

living with MND. Lots of events were held with raffles, cake sale, merchandise sales and a beer night held at Castle Hill Tavern. What a fantastic effort.

Thanks Jonno!



Jonno getting the chop

At his 21st birthday, Jonathan Hart raised \$1,536 for MND in memory of his Uncle Tas who died from MND. Jonno bravely had his beloved mullet cut to raise these funds.

Pub 2 Pub

Running from Dee Why Beach to the Newport Arms Hotel was no problem for Christine Harrison who participated in the 2012 Pub2Pub fun run for MND, running a personal best time. Christine was one of four MND runners in this event who together raised over \$2,600 for MND.



Christine Harrison (L) and friends at the finish line in the 2012 Pub2Pub

*We hope many members will visit and bring their friends to **Bob and Suzanne Ballinger's Spring Garden Opening at 17 Linden Avenue Pymble 29 and 30 September from 10am to 4.30 pm.** Helena and Kevin Langdon will be there with Helena demonstrating and selling her stationery. There will be an MND merchandise table. Refreshments and lunch will be available and a knife and tool sharpening service will sharpen your knives and tools for \$6 each on Saturday morning from 10am to 1pm.*

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

Dates for the Diary

29-30 Sep	Open Garden 17 Linden Ave Pymble - call for volunteers to assist with refreshments ph. MND NSW 8877 0999
29-30 Sep	Hunter Valley Traditional Archers Charity Shoot Hunter Valley Archers Range, Tarro Nick Lintern and Trish Ford kandpford@bigpond.com
7 Oct	Walk to d'Feet MND - Port Macquarie Bev Smith ph. 0411 335 104 or 6583 8345, or Kym Nielsen, MND NSW ph. 8877 0999
26 Oct	McGrath Wollongong Golf Day Wollongong Golf Club Bryan Wells BryanWells@mcgrath.com.au
27 Oct	Illawarra Country Music Club Live music, face painting and car show at Albion Park Showground Donnamaree Gasparrini ph. 0414 608 859
28 Oct	Burgh to Beach 8-10km Fun Run Helensburgh to Stanwell Park Nathan Johnston nathan@finsolutions.com.au
4 Nov	Walk to d'Feet MND - Sydney Kym Nielsen, MND NSW ph. 8877 0999

ACKNOWLEDGEMENT

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

Editor: Penny Waterson