



FORUM



Walk to d'Feet MND 2011 - CANBERRA

Join us in Canberra on **Sunday, 19 June**. 5.5km walk/run/bike ride along the RG Menzies walk to the Carillion and returning back through the gardens with a Gunghalin Rotary barbeque at the finish. Merchandise on sale on the day.

Come along. Run, walk or wheel with your family, friends and dogs.

For more information and to register your attendance visit www.mndnsw.asn.au or contact MND NSW ph. 8877 0999.

Tas Run - motorcycle ride for MND

by Tas' great mate, Greg Roberts, aka 'Jaws'

Tas O'Hara was a character who had a huge influence on many people's lives. He had a mad sense of humour, a generous nature and a 'never-sit-still' lifestyle. He had competed in motorcycle racing since he was a teenager, finishing runner up in NSW and Australian titles in the late 70's. On moving to Wagga Wagga, he continued involvement in sport at the local Go-kart club. Everyone knew Tas as a man of great generosity with his time and engineering skills.

Tas' MND brought many of them back to his side. Chris (Budgie) Anthony, a former work colleague, was motivated to create a fundraiser that included Tas' first love – motorcycle riding. Over 120 riders signed up for the ride which started from Wagga Motorcycles, Wagga Wagga, through Gundagai, the Snowy Mountains towns of Tumut and Tumbarumba and back to Wagga. Through generous support from local businesses and individuals, a back-up vehicle, a bus, a coffee van and prizes for raffles were donated for the ride. The bus was to hold anyone not wanting to ride, and finished up full of relatives and friends as well as supporters who have been affected by MND.



Riders wore their 'Never Give Up' wristbands and were extremely generous in their support of raffles and auctions. During the day we heard lots of conversations about Tas, but especially about MND. By that night, at least 120 people were now aware of the disease and became committed to assist in fundraising events like this in the future. The special needs and equipment required by people with MND was also a topic of conversation. That was an amazing achievement.

Tas' wife Pat, family and friends worked flat out all day running the fundraising side, and were overwhelmed by the support for the event. Budgie believes this one event made over \$7,000 for the Association, and a huge boost for MND awareness. There is now interest in making the event an annual affair. Tas would have loved the ride, but perhaps not the attention.

Tas' family and friends wish to thank all involved in making it a great day. Next year, if you see a group of smiling bike riders running through the Riverina with blue wrist bands - they are supporting the MND Association, so give 'em a wave. Never give up.



Michael Gay (son-in-law), Ryan O'Hara (son) Front: Julie O'Hara (daughter-in-law), Pat O'Hara (Tas' wife), Skye Gay (daughter), Sue Wales (Tas' sister).



Tas O'Hara who died from MND in 2010. Tas on the cover of two wheels April 1971.

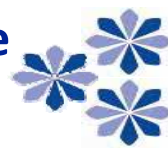


Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries. The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.



Our Day of Hope and Remembrance

Tuesday 3 May 2011



During MND week over 100 people from the MND community gathered at the Soka Gakkai International Centre, Sydney Olympic Park, to celebrate hope whilst remembering those who had died from MND. Our vice-Patrons Paul Brock AM, Melinda Gainsford Taylor and Kevin Langdon OAM were present and our guest speaker this year was Frank Brennan, Palliative Care Physician, Calvary Hospital, Sydney. Frank spoke about the meaning of hope for people progressing with MND and those supporting them. We have included an excerpt from his talk on page 4 of this edition of *Forum*.

MND NSW would also like to acknowledge all those who were a part of the candle lighting ceremony to honour all those involved in the MND community – the people living with MND, their family and friends, support groups, volunteers, supporters, health and community professionals, researchers, the MND NSW Board and staff as well as those involved in the global fight against MND.

"This candle is being lit in honour of people living with MND. As light and fire are hidden in every candle, may we find love and hope in hard times; may we never give up." Michael Lee, dedicating a candle for people living with MND.

"People with MND and their families undertake a journey that is filled with many emotions, trials and tribulations. It tests our very being of who we are, who we would like to think we are, but remarkably at different times we find a strength that we never knew we had or were capable of..." Gemma Cooney, in her dedication for those involved in support groups.

It was a very special day allowing opportunity for reflection and a chance to catch up, mingle and share experiences over afternoon tea. Thank you to those who made the day so memorable.

Kristina Dodds, Education and Carer Support Coordinator



Colleen Sanderson (above)
Gemma Cooney (below)



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



Phil Brady, Phil Bower and Michael Perry (above) and Frank Brennan, Kym Nielsen and Jenny Mattiussi (below)



Michael Lee, Joanna Mawson and Margaret Lee



Noelene Lake (left) with our most recent March of Faces banner

Introducing...



Kim Sinclair

Regional Advisor - Lake Macquarie, Hunter and New England

I am pleased to be joining the MND NSW team as a regional advisor. My background is in nursing,

predominantly in the aged care and high dependency sectors. I also currently teach in aged care, disabilities and palliative care.

Nursing provided me with fantastic opportunities for travel and I have worked in Edinburgh and in Guernsey in the Channel Islands.

I met my husband through nursing and we have two young children who are a delight - most of the time! We have now settled back into the Aussie way of life and have returned permanently to the region I grew up in.

I'm looking forward to getting to know members and their families in the Lake Macquarie, Hunter and New England areas of NSW.

A Message from the CEO

Thank you to those who participated in MND Week 2011. We had a great start to this special week with a near capacity crowd attending our Day of Hope and Remembrance on Tuesday 3 May (see page 2 of this edition of *Forum*).

It is only through our supporters getting out and beating the MND drum that we are able to cut through the media clutter and let people in the street know about motor neurone disease. This year, some of our members provided their personal stories about MND for MND Week media promotion. Many thanks to those who contributed in this way - it is these stories that media outlets find so compelling.

In national media we were well represented with over 1.5 million 'banner ads' on an assortment of websites. Thanks to PostClick for donating these spots and for their creative input into this project. As well as great coverage in print and radio, the blue cornflower also featured on an episode of Master Chef. An overview of all the national media coverage for MND Week can be found at www.mndaust.asn.au.

The subject of our national call to action during MND Week, the support of a National Disability Insurance Scheme (see page 8) has been getting a lot of support from media following the release of the Productivity Commission's draft report in February. Submissions and public hearings closed on 30 April with the final report to be delivered to the Government on 31 July. To follow the progress of the NDIS and to register your support on the Every Australian Counts follow the link on the home page at www.mndnsw.asn.au.

We have had a change in staff over the past month with Noelle Smith leaving the Association and Kim Sinclair taking up the role of Regional Advisor Lake Macquarie, Hunter and New England. Kim introduces herself on page 2. Welcome aboard Kim.

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



International
Symposium on
ALS/MND and
Ask the Experts

International Symposium on ALS/MND **Ask the Experts** SYDNEY, 28 NOVEMBER 2011

Every year MND researchers and clinicians from around the world meet together to share their research investigations into the care of people with MND and treatments for MND.

In 2011 they are meeting in Sydney. **Ask the Experts** is your opportunity to hear directly from experts from around the world. You, your family and friends are invited to ask any questions you have about MND. Mark the date in your diary now!

Motor Neurone Disease Association of New South Wales

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Education and Carer Support Coordinators

Kristina Dodds, Kate Maguire

Equipment Service Coordinator

Maree Hibbert

Equipment Assistants

Tom Giardina, Michael Walker

Information Resources Coordinator

Penny Waterson

And.....many valued volunteers
including Annemarie Young who, with



the assistance of her husband Howard, holds a stall for MND every year in Tumut.

Hope and motor neurone disease

Our guest speaker at our Day of Hope and Remembrance on 3 May was Frank Brennan, Palliative Care Physician, Calvary Hospital, Sydney. Frank spoke about the meaning of hope for people progressing with MND and those supporting them. Following is an excerpt from his talk.



**Frank
Brennan**

What is it about Motor Neurone Disease that marks it as so unique? We are all mortal, after all, and we shall die of some cause. Why is this cause so hard? Why does this disease test us to our limits and beyond? Firstly from diagnosis it is an incurable illness. So immediately that commandeers hope. Secondly,

it takes so much away. Their strength, their capacity, their swallowing, their breathing, their precious voice. And finally for those of us who love them, it takes them away from our lives.

Hopelessness is a natural response to the diagnosis of Motor Neurone Disease. It is also a natural response to the unfolding of this disease. Indeed, hopelessness may be the only response. We cannot banish it. We cannot embargo it. And we cannot ask each other to not feel it. Like shadows falling across a river on a grey day it settles on patients and their families at points along this illness. Hopelessness is an emotion that is both natural and authentic. But it is not the only response.

Is something else happening through those years? Is there another voice? Another sense of things? Where does hope lie in this story?

Ultimately hope is an act of the imagination. We are forever moving from a past, into a present and towards an imagined future. We have always done this. MND does not suddenly bring hope into focus. Hope is always there. Hope is intrinsic to us. And it won't go away. In an illness like MND it may seem so, where there is despair or depression or a stripping away of all sense of dignity, but it won't go away. It lies within us.

And so herein lies the challenge for all of us as patients, as carers and as clinicians – how do we imagine the future?

The onset of MND cuts through the present like a knife. It also cuts through the imagined future. That future is so different to the past that it almost unrecognisable. Repeated visits to health professionals. Speaking to family, friends, employers. "What is this?" they ask "What does this mean?" The long wait for change, for some good news. For some it involves the slow calibration of hope from cure to comfort, from victory to a negotiated truce on its terms, always on its terms.

Hope is a form of homesickness – for the past, a country where you were, if not happy, then you were, at least, healthy. You travel like Ulysses away

from your home through the most difficult waters. Reports come back to you of what it was like to be well, you look to a better future when you will return home, you dream of release, you hope.

Hope is the imagined future. Of course it is more than simply imagination that is passive. I could imagine sitting on a bench. Here there is content to that imagined future. There is yearning associated with hope.

In my care of patients with MND repeatedly I have found hope within them. No it is not hope, writ large, the hope for cure or of a normal life returned. It is hope in human things. Of a life that is. And a life that could be. That I feel less cramps tomorrow, that I will breathe more easily, that my mouth is not so awash with saliva, that my son will visit tonight. And in their eyes I see this: even though I cannot do that I will do this. The man with the lightwriter, who when I would lean over and anticipate the finishing of a sentence, would look at me disapprovingly as if to say it was his sentence and he would complete it....

...And hope can vest in many things. A man, living alone brought to an Emergency Department late one night. Later in the hospice he said he felt desolate there, fearing that he would die alone, in the Casualty surrounded by strangers. We talked about this at some length. He hoped for better days ahead. A week or so before he died he looked at me with great warmth to whisper that he had said goodbye to everyone now, that he had reconciled with a family member, that he had passed on whatever wisdom he had and that now he was ready. The past had been attended. The future was more secure.

That secure future may lie on another plane. When the disease is sweeping all before it, I find it vital to say to patients words to the effect – yes this disease has done many things to you and will continue to do so. But it cannot take away who you are, your core, your centre. Equally it cannot take away your past, whom you have been for everyone, especially the good things and what you will leave behind for them. Yes your family will remember these years. But they will also remember the sum of your life. A sense of legacy may be as powerful as the sense of loss it accompanies.

Frank Brennan

*Palliative Care Physician
Calvary Hospital, Sydney*

Sections of this talk appeared in: Brennan FP. A Short Talk on Hope. *Illness, Crisis and Loss* 2010; 18(3):259-261

*Back issues of
Forum are
available at
[www.mndnsw.
asn.au](http://www.mndnsw.asn.au)*

Family Support Team

It was great to be able to meet many of you at our Day of Hope and Remembrance held in MND Week. Thank you to all who participated on the day, especially those who wrote the dedications that acknowledged all whose lives have been touched by motor neurone disease.

Most of our events and programs would not be possible without the assistance of others. This includes our education programs. As I write this we are in the middle of our Care for Carers program. This is an educational program for carers with guest speakers who are health professionals who share their knowledge about caring for someone with MND. These professionals are very generous in providing their time and knowledge and somehow fitting this into their busy work schedules. Without them we would not be able to run these programs.

This extends to our regional education programs where our guest speakers once again devote time to preparing and attending our programs. Their commitment to support people with MND and their carers is astounding.

March was a busy month. On 10 March we headed to the Central Coast for a day of information and sharing for people with MND, their family and friends, with 35 people attending. Comments about the day included, "I am so grateful for all this thoughtful advice and help. There were services I didn't know about. The speakers explained every detail".

On 24 and 25 March we had two education days in Ballina. We were very fortunate to secure part funding from the Far North Coast Commonwealth Carers Respite Centre, enabling both days to go ahead with good food and a great venue. Thirty members and carers attended on 24 March. One person commented, "I don't feel alone in coping with Dad's future – I am now well informed regarding support". Fifty health and community care professionals attended on 25 March to learn more about MND and directions in care. The highlight was the presentation given by Bangalow Consulting Physician, Dr Robert Lodge on the role of the GP/neurologist. We had so many great speakers, thanks to you all.

Gina Svolos
Manager, Family Support

Jo Fowler (on right), MND NSW Regional Advisor for Northern Sydney and Central Coast, presented at the Carers NSW Conference in March this year with Kathy Lee from Home Hospice. Their presentation was about the value of linking carers with volunteer mentors who support them in their caring role. This provided a great opportunity for more people to hear about MND and also about the support available to carers through Home Hospice which many of our carers have found to be extremely beneficial.

Equipment

The MND NSW Equipment Loan Service assists in providing equipment for loan, free of charge to members, when an assessment has been made by the appropriate healthcare professional. Unfortunately MND NSW has limited funding and is not able to purchase new equipment for every referral made for members.

Since March approximately 320 new loans of equipment have been made to members throughout NSW and the ACT. However waitlists have still occurred for some key equipment items and to reduce this delay we have spent just on \$20,000 on new beds and hoists for the MND NSW loan pool.

If you have an item of equipment from the equipment loan pool that is no longer required please contact MND NSW and we can arrange collection. This will free up space in your home and also allow the equipment to be available for loan to other members.

With the weather getting colder even some pieces of battery operated equipment, for example powered wheelchairs, hoists and some communication devices, can be reluctant to get going in the morning. Extra power is required of the battery and it is recommended to charge the batteries every night if they are being used daily and every third night if they are not being used as frequently. This keeps the batteries in good condition.

For raiser recliner electric armchairs, which have two 9V batteries connected to the power pack in case of a power blackout, it is recommended to store a spare set of batteries in the armchairs side pocket. This way they can be easily found just in case they are needed.

If a problem does occur with any MND NSW equipment item you have on loan contact us to let us know so we can arrange repair as soon as possible. MND NSW only covers the cost of repair if we have authorised it with the authorised repairer.

Maree Hibbert
Equipment Services Coordinator



Thinking about attending a Family Support workshop in 2011? Speak with your regional advisor for more information

Support Groups

Gladesville

In April Ashlea Williamson, of Kimberly-Clark, spoke to the group about PEG tubes. It was helpful to see what the tubes looked like and Ashlea explained how the tubes are inserted and answered many questions. There was also plenty of time for a 'cuppa' and a chat. People with MND, their family and friends are most welcome to attend – some great friendships have formed out of support groups. The group also give you the opportunity to exchange ideas and connect with others in similar circumstances. We meet every second month at the MND NSW Centre at Gladesville.

Caroline Gleig, Regional Advisor

Newcastle

The Newcastle group continues to meet bi-monthly at 44 Dudley Road Charlestown. The aim of our support group is to provide an opportunity to meet other members, their family and friends, in a relaxed informal environment and to provide support, information and to share ideas. Noelle Smith, our previous MND NSW Regional Advisor, was greatly missed at the April support group, but we all look forward to welcoming Kim Sinclair, Regional Advisor for Lake Macquarie, Hunter and New England at our meeting on 28 June.

I would like to thank Gary Hodges, one of our members, and his wife Sue who spoke at our April meeting about Newcastle Mater Palliative Care Program and the Fig Tree Day Program. Gary provided information and discussed the support that he and Sue have received from the palliative care team. This information was warmly received by families at the support group.

Eileen O'Loghlen, Regional Advisor

Northern Beaches

Although numbers have been down a little this year, our group continues to meet bi-monthly, at the Mona Vale Palliative Care Cottage, Mona Vale Hospital. This group is for members and their carers and the next meeting is on Monday 18 July. We extend a warm welcome to new members and their families to come along and see what a support group can offer you.

Jo Fowler, Regional Advisor

Western Sydney

The Western Sydney Support Group continues to be well attended and popular with members. Our informative guest speaker at the last meeting, a speech pathologist, spoke about swallowing and communication. There were lots of questions and discussion around this topic which was relevant to many people's circumstances.

Our speaker for our meeting on 12 July will be from the Independent Living Centre. She will bring many items and information on products and services that may be of practical use to people living with MND. Later in the year we are hoping to have a luncheon outing – our outings in previous years have been fun and relaxing.

These groups are a great way to connect with other people experiencing similar challenges. Afternoon tea is provided and the group is convivial and relaxed.

Jenny Judd, Regional Advisor

For more information about attending an MND NSW support group contact the MND NSW Info Line on 1800 777 175

Visit
www.mndnsw.asn.au to view
upcoming
support group
meeting dates.

Support Groups

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

Campbelltown - Robyn Petersen | robypn@mndnsw.asn.au

Gladesville - Caroline Gleig | carolineg@mndnsw.asn.au

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

Western Sydney - Jenny Judd | jennyj@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 - Jenny Judd | 1800 777 175 | jennyj@mndnsw.asn.au

Illawarra - Robyn Petersen | 1800 777 175 | robypn@mndnsw.asn.au

Newcastle and Hunter - Eileen O'Loghlen | 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'Loghlen | 4921 4157 | eileeno@mndnsw.asn.au

Top 10 tips for wheelchair etiquette

1. Speak directly to the person, not to someone else nearby
2. If a conversation lasts for more than a few minutes consider sitting down
3. When greeting a person, it is appropriate to shake hands. If they are unable to shake hands, a touch, a nod or a similar gesture is fine
4. Focus on the person first not the disability
5. Don't shout, speak patronisingly or force enthusiasm. Forget the 'speed limit' jokes.
6. Always ask the person if they would like your assistance
7. Accept "no" for an answer and don't hover. People using wheelchairs have their unique way of achieving everyday tasks
8. If unsure, ask and follow instructions
9. A wheelchair is part of a person's body space, don't push it, lean on it or tap it—respect the wheelchair as you would another person's limbs
10. In a work environment people using wheelchairs require turning and circulation space. Keep pathways and corridors clear
And most importantly RELAX and BE YOURSELF!

From ParaQuad www.paraquad.org.au

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

Learn Now Live Well

For people with motor neurone disease, their family and friends

10 and 17 October

MND NSW Centre, Gladesville

Learn Now Live Well is a two-day educational program held over two weeks on consecutive Mondays. It covers living well with MND and the services available for people living with MND.

This program is available to people with motor neurone disease, their families and friends.

During the program you will learn about:

- living well with motor neurone disease
- health and community services you can access.

You will also learn about the roles of various health workers such as the occupational therapist, physiotherapist and speech pathologist and the services offered by MND NSW.

You will have the opportunity to:

- have your questions about motor neurone disease answered
- meet other people who know what it is like to be living with motor neurone disease.

There is no charge to attend this program but bookings are essential.

For further information about the program, to book or for assistance with travel arrangements contact MND NSW ph. 1800 777 175 or email familysupport@mndnsw.asn.au

Family Support Calendar

14 June	Information Evening for people recently diagnosed with MND, their family and friends Gladesville Informal information evening for people who are newly diagnosed with motor neurone disease, and their families and friends
9 August	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
10 and 17 October	Learn Now Live Well Gladesville For people with motor neurone disease, their family and friends. Learn Now Live Well is a two-day educational program held over two weeks on consecutive Mondays. It covers living well with MND and the services available for people living with MND. This program is available to people with MND, their families and friends. See above for more information.
11 October	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
12 November	Christmas Party for family support members, their family and friends
28 November	International Ask the Experts Hilton Hotel, Sydney Ask the Experts Forum is a popular day when you, family members, carers and friends can bring your questions about MND and have them answered. This year, Ask the Experts is being held at the 22nd ALS/MND International Symposium 2011 in Sydney.
13 December	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.

A Chance at Real Reform - A National Disability Insurance Scheme

The current disability system is “underfunded, unfair, fragmented and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports”, according to the Productivity Commission’s recently released draft report on Disability Care and Support.

The Report contains proposals for a National Disability Insurance Scheme (NDIS), and forms part of a comprehensive inquiry conducted by the Productivity Commission into Australia’s disability supports and services.

Under the current system, there are insufficient resources and many gaps in service delivery across all jurisdictions. The development of a disability insurance scheme will enable significant reform for people with a disability and their carers.

The Productivity Commission report indicates there are a variety of models available to implement a national disability insurance scheme. One of the options is to substantially increase disability funding within the current structure. While an increase in funding would provide benefits, it would not address the recognised need for certainty of support and early intervention, nor empower beneficiaries to make the decisions which affect their lives.

The Productivity Commission favours a model which provides disability-related services and supports to the community at large, with a particular emphasis on funded supports for people with significant disabilities and their carers.

Among the report’s recommendations is the implementation of family-based assessment – a process which would focus on carers’ needs as well as the needs of those with a disability.

These needs would be assessed by NDIS-appointed local assessors, which would lead to individualised support packages. These support packages would fund long-term high quality care and would also be portable across state and territory borders.

Carers Australia President Tim Moore said, “Australians who care for someone with a disability have been waiting many years for an opportunity to develop a system which truly meets their needs, as well as those of their carers and families. The NDIS is an opportunity to make transformational change.”

The proposed NDIS will target three different groups, referred to in the draft report as Tiers:

Tier 1: Everyone

The Productivity Commission considers the NDIS a reform for all Australians as it will provide insurance against the costs of support should they or a family member acquire a disability.

Tier 2: People with, or affected by, a disability

Under the proposed NDIS anyone with, or affected by, a disability could approach the NDIS for support, information and referral services. This would include providing links with relevant services for which the NDIS was not directly responsible, such as main-

stream services and community support groups. The scheme would also provide general information about the most effective care and support options. However, it will be critical to provide any referral and information services cost-effectively, with strict cost limits.

Tier 3: Access to publicly-funded individualised small groups

Tier 3 would be targeted at the much smaller group of people whose needs could not be met without taxpayer funding. Such a focus is consistent with the fact that risk-pooling through insurance tends to focus on higher costs, less frequent events (like early death or serious injury) and property loss. Many families and individuals have an ability to bear some risks themselves, and this is often a more efficient and flexible way of addressing smaller and more common risks than formal risk pooling through insurance.

The Commission is also proposing a National Injury Insurance Scheme (NIIS) to run in tandem with the NDIS, addressing catastrophic injuries from accidents, such as quadriplegia and multiple amputations.

The NDIS will provide greater choice for those in need, with beneficiaries able to choose their own service providers, ask an intermediary to assemble the best package on their behalf, or ‘cash out’ their funding allocation and direct it to areas of need they think are most important.

The Productivity Commission recognises that under an NDIS, funding for disability would be much greater, providing strong incentives for innovation. The Commission has proposed the creation of an ‘innovation fund’, which would be made available to service providers, encouraging the development of new approaches to disability services.

Carers Australia recognises that Australians who care for someone with a disability have been waiting many years for an opportunity to develop a system which truly meets the needs of Australians with a disability, their carers and their families.

The needs of family carers are linked to the needs of the person with the disability but carers also have individual needs including accurate and timely service information, emotional and social support, counselling, practical assistance, financial security, respite, opportunities to engage in employment, retirement planning as well as the need to have services that acknowledge their expertise and include them in decision making as far as possible.

If a national disability insurance scheme is implemented it would have the potential to deliver real benefits over generations for people with a disability, their families and carers. Emphasis needs to be placed on the whole picture of care provision and on making caring a shared community responsibility.

Reprinted with permission from Carers Australia Carers National News 2011 First Quarter

*International
Ask the
Experts
at the 22nd
International
Symposium on
ALS/MND
Sydney
28 November
2011*

Noticeboard

Adaptive clothing

Adaptive clothing is clothing that is designed and made for people with limited mobility or other disability. Designs usually include features that have side or back openings and fasteners that include press studs, hook and loop and buttons. You can view adaptive clothing suppliers listed in the Independent Living Centre product database at www.ilcnsw.asn.au or for more information contact the MND NSW Info Line ph. 1800 777 175.

Advance care planning

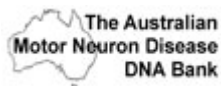
Advance Care Planning Community Workbook

It's all about talking, and making your voice heard!

The time for advance care planning is now, no matter what your

age or health. An advance care plan will only be used if ever a time comes when you are unable to make decisions or communicate for yourself. Advance care planning involves discussing your choices with your health care providers, your family and other important people in your life. The Northern Sydney Central Coast Health Carer Support Unit Advance Care Planning Community Workbook aims to assist you with additional tools and strategies to 'get the planning started for you and your family'. You can download it free at www.ccdgp.com.au > Resources > Document Library > Programs > Advance Care Planning or for more information contact the MND NSW Info Line ph. 1800 777 175.

MND DNA Bank



The MND DNA Bank has been set up to look for genetic and environmental susceptibility to MND. The first phase of the DNA Bank, the collection of samples, ceased during May 2011, when NHMRC funding of sample collection ceased. The Bank has now moved to into its second phase, the promotion of collaborative research projects with national and international teams who need access to DNA samples from people with MND. There are now over 2,700 MND and control samples in the Bank. Ongoing projects using DNA from the Bank include a group at the ANZAC Research Institute at the University of Sydney looking for new genetic mutations that underlie familial MND and a group at the Pathology Department at the University of Sydney looking at the possibility that too many or too few copies of genes may underlie sporadic MND. They are also looking (with collaborators at Washington University) for newly-arising mutations that may underlie sporadic MND, by comparing the DNA in people with MND with that of their parents, as well as between twins. Visit www.dnamnd.med.usyd.edu.au/

Stem Cells



The 2011 edition of the Australian Stem Cell Centre Patient Handbook has now been

released. The Handbook is designed to help individuals understand what stem cells are, which stem cell treatments are considered safe and effective by specialists, which are considered experimental and which are unproven and the safety of the treatment is unknown. The Handbook does not seek to advise patients, evaluate individual treatments, or comment on an individual's reasons for travelling for treatment, but aims to provide the patient with the necessary information prior to considering any therapy. For more information see www.stemcellcentre.edu.au or contact the MND NSW Info Line ph. 1800 777 175.

Controversial stem cell clinic closed

One of the largest and most controversial stem cell clinics in the western world has closed. The XCell-Center at the Institute for Regenerative Medicine, based in Germany, ceased operations on April 21, due to what the Center claims is "a new development in German law". In October 2010, the UK's Daily Telegraph reported that the XCell-Center was operating in Germany under a regulatory loophole. It would now appear that the German authorities have evaluated the Center under more rigorous rules.

Source: Stem Cell Network Canada 4 May 2011 <http://www.stemcellnetwork.ca/index.php?page=about-us&hl=eng>

Working Carers Gateway



The Working Carers Gateway website has been created to

help people who are juggling working AND caring roles. Who is a working carer? - A working carer is a person who is in paid employment and who cares for a relative or friend who is ill, frail, has a disability or is ageing. They may work full-time, part-time, casually or have a business of their own. Visit www.workingcarers.org.au or contact Carers NSW ph. 1800 242 636.

FOR SALE



2004 Holden Commodore executive station wagon, metallic green, excellent condition, fitted with a Carony manual wheelchair with turn swivel seat base, new rego, 147000kms, \$14000. Contact Jenny 02 6628 4435.

If you not have internet access and would like a print copy of articles referred to in Forum contact the MND NSW Info Line ph. 1800 777 175

When it's too late to say thank you

Martin Gillan was a wonderful and valued supporter of MND NSW. His support for the Association started after his wife, Anne, was diagnosed with motor neurone disease and became a member of MND NSW in 1991. She died from MND in 1994.

Following Anne's death, Martin continued supporting MND NSW. He would give at every opportunity. He also attended most events when he was able.

Almost two decades later Martin died. We were notified that he had left a gift to MND NSW in his Will. However, because we didn't know that Martin was planning to leave a bequest to the Association, we were unable to thank Martin during his lifetime for his wonderful gift that will enable MND NSW to continue to help so many people living with MND.

It is not uncommon for the Association to find out about a person's bequest after they have died. Although bequests are one of the largest and most important gifts that anyone will give in their lifetime, they are generally not known to the charity which ultimately receives the gift until it is too late to thank the person making the bequest.

A bequest is a valuable gift. It helps form a key part of the Association's long-term income. Bequests enable MND NSW to continue to provide essential information, support and advice for people with MND, their families and carers. Bequests also help to continue the search for better treatments and ultimately a cure.

If you have already made a gift to MND NSW in your Will, please do let us know. We would like the opportunity to acknowledge and thank you during your lifetime for the eventual gift that will change so many lives!

MND NSW invites people who make a bequest to the Association in their Will to join our Blue Cornflower Society. The Blue Cornflower Society, named after the symbol of hope for people living with motor neurone disease, was formed to recognise benefactors who support the vital work of MND NSW. All Blue Cornflower Society members are invited to annual lunches, special events and functions throughout the year.



If you would like more information about leaving a gift to MND NSW in your Will, please contact David Dubin on 02 8877 0917 or 0431 525 372. Alternatively, David can always be reached at davidd@mndnsw.asn.au.



Order your
MND NSW
2011-12
Entertainment
Book.
Contact Anne
Jones ph. 8877
0999 for more
information.

Dates for the Diary

19 June	Walk to d'Feet MND Canberra Starting at the National Exhibition Centre, Barrine Drive, proceeding along the RG Menzies walk to the Carillion and returning back through the gardens. BBQ by Gunghalin Rotary at the finish. Merchandise on sale on the day. Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
21 June	MND Global Awareness Day 21 June is a solstice - a turning point - and each year the ALS/MND community undertake a range of activities to express their hope that this day will be another turning point in the search for cause, treatment and cure of motor neurone disease.
14 August	City2Surf Be part of the 2011 MND Team for the Sun-Herald City2Surf from the city to Bondi. All MND team members will receive a MND T-Shirt to proudly show their support. Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
28 August	Pub2Pub Be part of the 2011 MND Team for Pub2Pub from Dee Why to Newport. All MND team members will receive a MND T-Shirt to proudly show their support. Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
3-11 September	Larapinta Trek 7 day walking trek along the Larapinta Trail in Central Australia Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
10 October - 12 November	My Nearest and Dearest Art Exhibition Arthouse Hotel Contact Jennifer Mattiussi ph. 0417 437900 or jmatt@bigpond.net.au
6 November	Walk to d'Feet MND Sydney Blaxland Park, Sydney Olympic Park, Homebush 5km Fundraising Walk Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au

Community events

Oakville to Kenthurst Bike Ride

On Sunday 10 April a 50km fundraising bike ride was held by a group who call themselves the Friends of MND. Riding between Oakville and Kenthurst in the Hills District of Sydney, 27 cyclists participated, with two cyclists, Stephan and Michelle Glennan, coming from Nowra to join the ride.



(l-r) Brigid Murphy, Kathleen Kirwin, Anne-Marie Moloney with Gemma Cooney on the bike.

The event has raised \$9500 to date but this figure is expected to reach \$10,000 when all sponsorship is finally collected. A very big thank you to the volunteers who assisted Gemma Cooney organise the event including Mary Brehony, Kathleen Kirwin, Anne-Marie Moloney and Brigid Murphy. The Lions Club of Riverstone supported the event by undertaking traffic control and providing signs. A special thanks to Wal, Lorraine and Kevin from the Lions Club.

The event was undertaken in memory of Jacqueline Kane Melott who died from MND in December 2010. It was great to see so many who had never met Jacqueline take part in the event, although many of the participants and volunteers had been touched by MND in some way through family or friends. Their generosity and the generosity of their families, friends and work colleagues resulted in a very successful day. Thank you all. (Yes, feedback indicates this should become an annual event so no excuses - get into training now for next year).

Gemma Cooney

Thanks Amelia and Charlotte



After Christmas each year my family go on holidays to Seven Mile Beach at Gerroa in our caravan. Every year, my two eldest girls Amelia and Charlotte, aged seven and five, like to hold a stall where they sell things they have made and donate any money they make to charity. Mid-2010 my girlfriends' mother, Sue Quinn, died from MND and the girls felt that the MND Association would be their choice for donation this year. So on 8 Jan 2011 they held their stall selling home-made jewellery, pet rocks and mosaic pictures. All items were made by the girls (with just a little assistance). They walked around the caravan park advertising their stall and handing out MND information pamphlets to raise awareness and managed to raise \$120.

Troy and Claire Beahan



Michelle Hayward supporting MND NSW in the 10km Canberra Times Fun Run

From the MonStar Foundation

Well MonSTaR 2011 has been and gone, and we would like to express our heartfelt thanks to all of you who came along and made the event a huge success. There was widespread acclamation for the running of the night, with food, comedian and band all receiving high praise. We are very pleased to announce that we raised in excess of \$150,000 on the day and night, and we will soon be in a position to distribute funds to our respective charities.

The golf event was contested by over 200 players, and the 2011 winner of the Fiona Pearce Memorial Trophy was the team from Bing Lee: Olly Sunstrum, Gary Lee, Brian Taylor and Alex Turner. Runners up were the JALaw Team: James Antonenas, Troy Trisley, Robert Trisley and John Harris.

Nobody managed to ace the 18th which would have yielded an Audi A1, however Craig Stubbs gave it a big scare by finishing one metre from the pin after rolling across the front of the hole. Special mention to Pennant Hills Golf Club Assistant Professional Geoff Black who did manage an ace on the day on the 6th, which yielded Geoff a more modest prize of a Crystal Decanter and bottle of Dewars scotch.

Wakehurst Golf Club (WGC)



WAKEHURST GOLF CLUB

WGC held a Senior's PRO-AM Golf

Tournament hosting both senior professional as well as amateur male and female golfers over two days in December 2010. Lion Nathan and Cadbury Schweppes were the two main sponsors, as well as other local community businesses. Proceeds totalling \$2,500 were presented to MND NSW by Glen Hickey, General Manager of WGC. MND NSW thanks WGC member and MND volunteer Margaret Orr and her many dedicated helpers for their continued support.

War on the North Shore 15

On 17 April Daniel Roberts competed in the 'War on the North Shore 15' in the Muay Thai super heavyweight division. This was a four man eliminator fight. Dan won the first fight via KO in the second round. Dan then went through to the main event and he won via TKO in Round 3. Dan has been fighting for four years now. He fights for the Bulldog Gym in Manly. Dan donated half of his prize money (\$250) to MND. Thank you Dan.

Newly released 'Mother and Daughter' rose, raising funds for MND research

See www.rankinsroses.com.au or www.melissaking.com.au



Wrapping up MND Week 2011



Linda Kluske at the MND stall held at Narooma Plaza

Well what a week it was! Thank you to our wonderful volunteers for selling merchandise on railway stations, in shopping centres and through their friends and businesses. We had great coverage. Once again HCF sold merchandise through its branches and, this year, Berrima District Credit Union also sold merchandise at four branches. A big thank you also to our corporate volunteers from Optus who sold merchandise at Macquarie Shopping Centre, Macquarie Park Railway Station and at the Optus offices at Macquarie Park.



At Circular Quay with (top) Greg Corr and Tony Brcic and (below) Therese Fernandez, Elizabeth Sandwith and John Nicolson (with Gail Thomas peeking behind Liz)



Thank you

Arthurville, Dubbo
Belrose Park Bowling Club
Camden Hospital
Carlingford Court
Circular Quay
Edgecliff Station
Griffith Central Plaza
Macquarie Park Railway Station
Macquarie Shopping Centre
Martin Place
Mittagong Market Place
Mudgee
Narooma Plaza
Optus, Macquarie Park
Port Kembla Hospital
Royal Randwick Shopping Centre
Ryde Council
St James Station
Tumut
Wagga Wagga Marketplace
Warringah Mall
Westfields Warrawong
Woollahra Council
Wynyard Station
Wyong Council

Write to the
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MND NSW
Locked Bag
5005
Gladesville 1675
or email
info@mndnsw.
ans.au

Recognition for our volunteers

The annual Ryde City Council Volunteer Recognition Awards acknowledge the outstanding contribution made by volunteers to the local community. Shohreh Nourouzi, MND NSW administration volunteer was nominated in the Individual Category and our team of massage volunteers, represented by MND NSW massage volunteer Doby Gardner was nominated in the Group Category. They were presented with their respective nomination certificates at a celebration held in their honour at the Civic Centre Ryde on 9 May.



Vic Dominello MP (Member for Ryde) Shohreh Nourouzi, Doby Gardner and Artin Etmekdjian (Mayor)



Join the 7 day **Larapinta Trek** for MND see www.mndnsw.asn.au for more information



The Sun-Herald
CITY2SURF

Run, Jog or Walk for MND

Be part of this years MND Team for the Sun-Herald City2Surf Sunday 14 August. All MND team members will receive a MND T-Shirt to proudly show their support. Register today at city2surf.sunherald.com.au.

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