



FORUM

It is now several weeks since the roads re-opened in Stanwell Park after the running of the 2nd **Burgh2Beach Charity Fun Run and Walk** on 27 October, and what a huge



success it was! Traffic control was great, safety was paramount, fundraising was sensational and, notably, the little man on the sand was able to build his leg-burning finish.

There was a lot of anticipation and interest building up to the 2013 event, after the success of the event last year, when over 250 people took to the streets of Helensburgh, Otford and Stanwell Park. We were looking to do our bit to ensure funds raised for MND were improved on the \$10000 raised last year and Nathan Johnston's \$4000 during his Port Macquarie Ironman campaign. This was

aided by the inclusion of walkers and individual fundraising for the 2013 event and 400 registered to participate. It is still an educated guess but our on-the-day estimated donation amount of around \$25000 stands. Importantly, the Michelle Moore Memorial Trophy went to Tanya Bailey (\$3455 and still climbing with Everyday Hero still open).

The official gold sponsor for Burgh2Beach 2013 was QBE, silver sponsor was GU Energy and bronze sponsor was Illawarra Credit Union. Other sponsors supporting the event were Helensburgh Stanwell Park SLSC, Snap Printing, Runner's World Mag, Innovative Body Works, Dorian Cobb Photography, Tall Poppy Designs, Sydney Adventures, Sydney Hang Gliding Centre and Wollongong City Council.

The fundraising is paramount but we had some 'flying' times this year in the racing side of things. Erin Hargrave won the Sarah Turk Memorial with a time of 32.57 and in the open men James Tunbridge set a blistering 26:01 and race record to take out the Glenn Watts Memorial. You can link to the full results at www.burgh2beach.com.au.

The 2013 Burgh2Beach organisers have done a great job in doubling not only the participation, but the \$'s raised. Can't wait for next year's Burgh2Beach!

During October 2013 the **MND NSW Campbelltown Support Group** celebrated Carers Week 2013 with a 'pampering day' under the Carers NSW 2013 Carers Week grants program. There were massages and manicures all round and it was a great session by all accounts.

This group has both carers and people with MND who attend. The day was a great opportunity to acknowledge the amazing caring role that many of the group perform and turn the tables and pamper them instead. It was appreciated and enjoyed by all. Thank you to Janell Mahoney and Louise Findlay from Macarthur Community Options who coordinated the day.



Carrathool Public School has just nine students and their Student Representative Council decided to raise money for MND NSW after their principal had been speaking to a local fellow whose wife has MND. Here they are at their crazy hair day on Monday 4 November.



Donald Lai ran in the Melbourne Marathon for MND and also organised other runners to participate in this event because he wanted to raise money for our Association following the death of his dad from MND. Donald's aim was to "...raise funds which can make a difference in helping other families living with MND...". Over \$14000 was raised with donations still being received. Thanks Donald.



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

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

Lighthouse 2 Lighthouse for MND



In September Shelly-Anne Demirov ran from Kiama Lighthouse to Wollongong Lighthouse to raise money for MND, fulfilling a promise she made to her dad, Jim, who died from MND in 2010. Shelly started her gruelling 48km run at 3.30am from Kiama and was joined by running buddy Trent Tame (whose mum has MND) for the final 20km, before finishing at Wollongong Lighthouse at 1.15pm. Many supporters cheered them across the line having enjoyed a great family fun day including a jumping castle, live music, stalls, a kids petting zoo and sausage sizzle. More than \$10000 was raised for MND. Thanks to Shelly-Anne and Trent. Thanks also to Donnamaree and Zac and the other volunteers who sold MND NSW merchandise, and to the many sponsors who supported the day.

Walk to d'Feet MND



Port Macquarie - A beautiful sunny day on Sunday 15 September greeted our supporters for the 3rd Walk to d'Feet MND in Port Macquarie. What a great roll-up and a gorgeous venue for the Walk! More than 250 people participated this year with over



\$29000 raised. Local dynamo Bev Smith was the driving force behind the event - selling raffle tickets, collecting raffle prizes and generally making sure that all in Port knew the Walk was on. A big thank you to the local sponsors for their support including Suncorp Port Macquarie, Travel World Port Macquarie, Essential Energy and Port Macquarie Council. Thanks also to Port Macquarie Lions Club who made sure the walkers are well fed and to Carol Philpott for the photos.



Wagga Wagga - Sunday 20 October, saw the inaugural Walk to d'Feet MND in Wagga Wagga around the gorgeous Lake Albert. Loads of families and friends lined up to show their support for MND, with over 180 people participating in the Walk. The



Rotary Club of Wagga Wagga fed the hungry bunch with a sausage sizzle at the end. Over \$25000 was raised with many participants supported by friends and family through their 'Everyday Hero' pages. A big thank you to Pat, Renee and Les, the students from Riverina Anglican College and the other wonderful volunteers for making this such a great day. A special thank you to Riverina MP Michael McCormack and to Councillor Rod Kendall, Mayor of the City of Wagga Wagga, for their support for this event. Thanks also to the event sponsors Les Gray Plumbing, Wagga Pole Studio and Pirtek.



STOP PRESS Sydney - Thank you to everyone who braved the cold and rain at Homebush on Sunday 10 November for Walk to d'Feet MND Sydney. Despite the rain we had a great roll up and a wonderful day. Our supporters outdid themselves this year, with over \$64000 raised to date. The full Walk coverage will be in the next edition of *Forum*.

**MND Week
2014
4 to 10
May**

Introducing...



Julie Becke - FlexEquip Support Officer

I am thrilled to be joining MND NSW after working very closely with people living with MND for the past seven years coordinating the FlexiRest program. During my thirteen years in the disability sector I have become passionate about supporting families and carers as best I can and, having had a family member with MND, I particularly understand the impact this can have on families. No doubt I will have contact with many of you as I get into the swing of my FlexEquip Support Officer role. I have a teaching background and enjoy a busy life surrounded by family and friends (and cats!).

A Message from the CEO

Christmas is just around the corner and things are speeding up.

Our Walks and other community fundraising events have happened in quick succession; MND Aware training of health, disability and community professionals is in full swing; our equipment service, FlexEquip is busier than ever; the first people with MND are moving onto the National Disability Insurance Scheme (NDIS) in the Hunter; and our regional advisors have been travelling across the State visiting families.

We have appointed a new regional advisor who will be based at Penrith covering Western Sydney, Blue Mountains and Central West NSW. Full details will follow.

Our AGM was held in late October. Three dedicated board members: Phil Brady, Michael Perry and Janice Scheinecker resigned from the board and three new board members were elected.

The new board is:

Phil Bower - President
 Alex Green - Vice President
 Roger Henshaw - Vice President
 Anita Richter - Secretary
 Lara Kirchner - Treasurer
 Ralph Warren and new members Amy Critchley, Kirsten Harley and Nick Shaw.

A brief overview of the board members will appear in the next issue of *Forum*.

Life membership was awarded to Janice Scheinecker and Bob Howe who have served over 17 years and 14 years respectively on the board.

From all at MND NSW we wish you and your family a happy and safe Christmas and new year.

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

Graham Opie

Chief Executive Officer

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

MND NSW will be closed from 12pm Tuesday 24 December 2013 until 9am Thursday 2 January 2014.
If help is needed during the Christmas break, please consult your doctor.

*Would you like to receive Forum by email? You can save MND NSW postage costs.
 Let us know at admin@mndnsw.asn.au*

Motor Neurone Disease Association of New South Wales

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MND NSW

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*Information Line Advisor
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*Education and Carer Support Coordinators
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*FlexEquip Coordinator
 Maree Hibbert*

*FlexEquip Assistants
 Tom Giardina, Michael Walker
 FlexEquip Support Officer
 Julie Becke*

*Information Resources Coordinator
 Penny Waterson*

*And...many valued volunteers
 including Deidree Jones of Batemans Bay who has raised much needed
 funds and awareness of MND by selling merchandise and organising
 raffles at monthly stalls at her local shopping centre and markets.*



Family Support Team

In October we met in Melbourne with other state MND association family support services to share our work and experiences. These meetings are always valuable because we learn from each other and come back with good ideas for developing our services and supports. It's also good to hear what issues and concerns other state associations are experiencing.

For example we talked about the National Disability Insurance Scheme (NDIS) and how it is progressing in the launch sites in Victoria and NSW and there were many common areas of interest. Like any change, there are many issues that have to be considered and new ways that we need to think about things. However we know that the NDIS will be of such benefit to our members under 65 years of age that it is worth some of the uncertainty that we are currently experiencing. We talked at the meeting about how we can best support our members through the process of assessment and planning and shared some ideas that we hope to develop. If anyone who has been through this process has any insights on what might assist we are very happy to receive your suggestions.

The main premise of the NDIS is that the person with the disability has choice and control over their life and the supports they require to assist them to live in the community. Some of our members who live in the Newcastle area launch site have been assessed and had their planning meetings. It seems that this process is fairly streamlined but at the moment isn't available to all in the launch sites of the Newcastle, Maitland and Lake Macquarie local government areas. Some people who already receive NSW Government services such as home care and other packages of care may not be assessed for the NDIS until early in 2014.

However, if you live in the launch sites and are uncertain as to what to do next don't hesitate to contact your regional advisor: Eileen O'Loughlen or Kim Sinclair. They are available to assist and at this stage are developing their understanding of the process more and more each day.

We are currently planning dates for our education programs and support groups for 2014. This year we have had good attendance at all our events although we do realise that most of our courses are run at our MND NSW Centre at Gladesville and many are unable to attend. Whenever we have the funding and resources available we do conduct educational events in regional areas and for 2014 we are planning some regional area education programs for members and their families. Keep an eye out in future editions of *Forum* for dates.

Our last event for the year will be our Information Evening for people recently diagnosed with MND, their family and friends on 10 December from

6.30pm at the MND NSW Centre at Gladesville.

These nights offer an opportunity to learn more about MND and supports available, including our services at MND NSW. It is also a time to meet others who are in similar situations to yourself.

We have employed a new regional advisor for Western Sydney, Blue Mountains and Central West NSW who will be based at Penrith. For those living in these areas you will be receiving some further information soon. In the meantime don't hesitate to contact the MND NSW Info Line ph. 1800 777 175 if you require any information or support. David Wallace, Information Line Advisor, will assist you.

As Christmas approaches it is good to remind ourselves that it can be a special time to spend with others. I would like to wish you and your families all the best during the festive season.

Gina Svolos

Manager, Family Support

Special Interest Group Workshop September 2013

Our Special Interest Group workshop for health and community care professionals who have an interest in, or already work with, people with MND is held every two years. The theme this year was on symptom management and care coordination.

There was great interest in the workshop and we reached our registration maximum capacity some weeks before the event.

We had 125 people attend with occupational therapists forming the largest allied health discipline group, followed closely by speech pathologists, physiotherapists, nurses and case managers.

Four people with MND consented to be filmed for the workshop and we shared their journey with MND via pre-recorded video.

We showcased different models of coordinated care from across NSW with the aim of motivating the health and community care professionals to meet locally with each other regularly to discuss care and the coordination of their services for people with MND.

One comment from the evaluation was, *"It was one of the best education days I have been to ... particularly in terms of integrating evidence based care, practical implementation and patient perspectives - rarely achieved in workshops"*.

Providing education and opportunities for professionals to network and brainstorm ideas on how to work better for the benefit of people living with MND and their families is an ongoing priority of MND NSW.

Kristina Dodds

Education and Carer Support Coordinator

*Sailors with
disAbilities*

*Sunday
19 January
2014*

*More info on
page 9*



FlexEquip

Welcome to Julie Becke who has joined the MND NSW FlexEquip service as

our new Equipment Support Officer working Monday to Thursday at the Gladesville Centre.

During the past 12 months there has been a 21 per cent increase in the number of equipment items shipped by FlexEquip with over 1660 items provided throughout NSW and the ACT. If we were to purchase again each item of equipment provided during this time the cost would be over \$1.9 million. To help meet the demand and to minimise wait lists we purchased 237 new equipment items during the same period with a total value of over \$297000. This would not be possible without the ongoing effort from all of our hard working supporters. A very big thank you to everyone.

The equipment purchased included more iPads, power wheelchairs, specialised pressure relieving cushions, mattress overlays and many other items. We currently have 35 iPads preloaded with specialised apps to assist with communication and all are currently in use.

We also have seven iPads specifically for short-term two week trial for health professionals to use when assessing a person with communication needs.

The holidays are fast approaching and our couriers will become increasingly busy, with more deliveries and shipments and increased traffic on the roads. Delays can sometimes occur that are out of our control. Therefore I would like to ask everyone to be patient during this time but please do not hesitate to contact us if there is a problem. Where possible, we will provide you with a time frame for delivery or pickup but this may be changed by the courier due to circumstances in your local area.

This year MND NSW will close between Christmas and New Year from 12pm Tuesday 24 December 2013 until 9am Thursday 2 January 2014.

Staff from the MND NSW FlexEquip service - Maree, Michael, Tom and Julie - wish you a very safe and very, very, happy memorable holiday.

Maree Hibbert

FlexEquip Coordinator

You can view the MND NSW MND Aware online training about MND at www.mndcare.net.au



Christmas close - equipment breakdown

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



It's a record! 864 health and community care professionals have become MND Aware

Kristina Dodds, MND NSW Education and Carer Support Coordinator, and the MND NSW regional advisors have been busy educating health and community care professionals across the State. With funding from NSW Government Ageing, Disability and Home Care (ADHC) 31 MND Aware

sessions have been run since April 2012. In total 864 health and community care professionals have attended MND Aware. The MND Aware face-to-face training was developed to complement the MND Aware online training at www.mndcare.net.au

The aim of this training is to facilitate an awareness of the impact of MND; inform and resource front line staff on effective ways of responding to people with MND; and enhance the capacity of existing services to more appropriately meet the needs of people with MND. Of the 864 participants, 99% have rated the day as good (20%) or excellent (79%), with some feedback including:

- *great balance of information on MND and how to actually apply this information when providing care to a person with MND and their family*
- *thank you - making a challenging subject interesting, informative, thought provoking in a gentle environment*
- *thankyou for the brilliant opportunity, it will be exceptionally helpful in all areas of care for my clients with MND*
- *great resources provided, feel less helpless in helping people with MND*
- *this is an excellent workshop. I'll definitely recommend to my colleagues to read through the online training material that complements this training.*

Around the support groups

Northern Beaches

Our group continues to meet bi-monthly at the Mona Vale Hospital Palliative Care Unit from 11.30am to 1.30pm. Reflecting back over the year we have learnt a great deal from each other and the many health professionals who spoke to the group. Nicole Ellis from Flavour Creations taught us about dysphagia, safe swallowing techniques and how thickening up fluids with preparations like xanthan gum can help prevent liquids ending up in the lungs. Nicole spoke about 'three different levels of thickener' and brought with her a variety of tasty samples for us to try. There were fruit juices, 'fruits with attitude' and different flavoured puddings and custards. I think we will be asking Nicole back again.

Graham Opie, MND NSW CEO, spoke to the group about many of the changes currently taking place due to roll-out National Disability Insurance Scheme (NDIS). Other guest speakers this year were Carolyn Robertson, Social Worker, Mona Vale Palliative Care, and Sandy Cozens, Case Manager, Community Care Northern Beaches (CCNB). Carolyn's topic was carer support and ways to help with the caring journey. Sandy spoke about the many services CCNB offers and how to access these and other services in the community.

For the latter part of the year the group's attention focused on the presentations from 'Ask the

Experts' by specialist neurologist, Professor Dominic Rowe; Melbourne researcher, Dr Bradley Turner; and palliative care specialist, Dr Frank Brennan. If you would like to learn more about MND, come along to the group or ph. Jo Fowler 1800 777 175 or 8877 0999.

Jo Fowler

Regional Advisor - Northern Sydney and Central Coast

Gold Coast Carers

We meet bi-monthly the first Wednesday of the month at the Italian Club at Clear Island Waters. This is a wonderful partnership with Carers QLD.

This year we have welcomed folk from the deep south, as far away as Lismore. Our informal, friendly meetings start with good coffee from the barista and we enjoy the company of other carers and learn through sharing ideas and stories over a sandwich. Guest speakers have included a range of allied health professionals who assist people living with MND. Twice a year we open the meeting to include members and families. Our next meeting is on 4 December and we will recommence our meetings in February 2014. All MND carers are welcome and for more details contact Chris Carroll ph. 0421 252 455 or 6672 7722.

Chris Carroll

Regional Advisor - Far North Coast

Support group meeting dates are at www.mndnsw.asn.au or contact the MND Info Line 1800 777 175

Support Groups

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

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

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

REGIONAL AND RURAL

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

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

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

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

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

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

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

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

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

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

Mailbag

From Pam - Living with MND

Fred and Jane are walking through the jungle of life when a very hungry, vicious wolf is attracted to them. The reasons why the wolf is attracted to our friends remains a mystery. It might be the clothes they wear, their particular human scent, or maybe the way they walked through life's jungle. Nobody knows why them. Anyway, the vicious, hungry wolf sees them and gives chase. They panic and run, looking for some escape.

They are running very fast and come to a hole in the ground, a well. They instinctively jump in the well to escape from the wolf. This is their lifeline. Well, it is and it isn't. The well does not contain water. It is empty of water but it does have a viper at the bottom which means sudden death. Our friends manage to cling to some tree roots growing through the sides of the well, Jane on one side and Fred on the other, just out of reach of the vicious wolf at the top and the viper at the bottom. And there are mice in the well, one black, called Night and one white, called Day. These mice nibble away at the tree roots supporting them. As Day follows Night, our friends' grip on life becomes more fragile. But still they hold on to all the support they can reach out and grab.

Fred reaches for something that looks like it might save him to find that it crumbles away from his grasp. Jane uses her imagination to make clinging to the wall less stressful, although the viper still is writhing at the bottom. Overhanging the well is a beehive laden with honey. Sweet honey drips into the well, past the open mouths of Fred and Jane. As she is thinking of possibilities to make her life sweeter, Jane put out her tongue to capture the drips of honey, making some of her moments clinging to the side of the well, just out of reach of the vicious wolf and the viper, somehow sweeter. I don't think Fred noticed the honey, in his fear and panic. Or is it Jane in a panic and Fred catching the honey on his tongue?

This is something like the position all people with MND find themselves, clinging to the wall of the well, holding on to all the support structures available. The hungry wolf is ever present and the viper is below. Medical science is looking for a stick to beat off the vicious wolf, but at the moment he is still there at the top of the well. Medical science can offer supports at the side of the well so Fred and Jane can hold on a bit longer but the viper is still at the bottom of the well. It is a struggle for all concerned, for Fred and Jane and all those who provide the supports. One benefit Jane or Fred has, despite being between the wolf and the viper, they are still able to capture the drips of honey as they come their way.

Pam

From Clare and her sister Kate



This poem was written by Kate, the daughter of Graeme McIlwain (pictured left) on the second anniversary of his death. Kate wrote the poem in the perspective of her dad. Graeme died from MND on 8 September 2011, aged 51. Clare,

Kate's sister, was touched by the poem and sent it in to us. Clare and Kate hope the message touches other families who have lost a loved one to MND and can take comfort in relating to the similar journey their loved ones went through.

I couldn't move a muscle,
you wanted someone to hold,
it was strange, it was fearsome,
I felt numb, I felt cold.

I had left my earthly body,
and been sent to Him above,
I was their rock, their world, their daddy.

They cried, they whispered,
how much I meant to them,
if only I could let them know,
I am fine, I am your angel, I will always be part of them.

When I look at your face,
I see mine,
and I want you to know,
I'm looking down and I am fine.

I watch you face your day,
I kiss your cheek goodnight,
I know it is a struggle,
I understand your fight.

Please know right now,
I am always so very proud,
that you are able to stand so tall,
my songs I sing for you are loud.

Kate

Identical twins project



Associate Professor Roger Pamphlett, Pathology, School of Medical Sciences, Bosch Institute, The University of Sydney is looking for DNA samples from identical twins. Identical twins, one with and one without sporadic MND, are having their genes sequenced to see what the differences might be. Currently, five sets of twins are part of this study and genetic differences could show the cause of motor neurone disease. If you and your twin are identical twins, one with and one without MND, and are interested in participating in the project please contact Roger Pamphlett ph. 02 9351 3318 or roger.pamphlett@sydney.edu.au

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

Superannuation

Early access to super

If you've stopped work, you might be going through a period of financial difficulty. Most superannuation funds have a policy of allowing you to apply for access to some of your super so you can help yourself through those times. However, the rules for access can be complicated and can affect your other entitlements.

If you access your superannuation on the grounds of 'financial hardship' and are younger than the 'preservation age' – between 55 and 60 – you might pay a significant amount of tax on any benefit you withdraw. The amount of tax can be up to 21.5 per cent. If you've ceased work as a result of illness or injury, however, you might be able to access your super because of 'permanent incapacity'. A superannuation benefit that's released for that reason is taxed at a concessional rate, and a significant portion of the benefit is tax free.

Any amount you've taken out of your super fund won't usually count towards the income test for Centrelink payments, and in most cases, your payments won't cease because you have that amount. Any amount you take out of the super fund does count towards the 'assets test', and if you access an amount that's larger than \$192,500*, you might be above the Centrelink assets threshold, and Centrelink will cease your payments for a time.

Insurance benefits

You might also be entitled to claim some significant insurance benefits. Most superannuation funds offer automatic 'death and disability' insurance benefits that can be very valuable, especially if you have a long-term illness or injury. You need to note that often, because fund members have accessed their super, their insurance cover under the policy ceases.

It's extremely important you obtain advice about this aspect before you decide to access your super. In most superannuation funds, the insurance cover comes in the following two forms:

- Death cover, which can sometimes be claimed if you're diagnosed as having a terminal illness
- Total and Permanent Disability, and Income Protection. Income Protection – or Total and Temporary Disability insurance, as it's sometimes called – usually entails a monthly benefit that's payable for two years from the date you ceased working, but minus the waiting period. Some Income Protection policies are payable for five years, until you turn 65, whereas others are payable until you die.

Redundancy

Many people believe that if they ceased work because they were made redundant, they're not entitled to claim a disability benefit, but that belief isn't necessarily sound. Many people who are sick or injured when they're made redundant are entitled to lodge a claim for disability benefits through either their superannuation fund or their insurance policy. If you think you might be made redundant, you should obtain advice about your superannuation entitlements, because the way in which you cease work, as well as any agreements you sign when you cease working, might affect your super or insurance. Some insurance policies have a rule whereby you're prevented from claiming a disability benefit if you've accepted redundancy. Although that rule is unusual, before you sign any agreement or accept redundancy, you should have an expert examine the agreement so you can be sure that your superannuation entitlements won't be affected.

Terminal illness

Under the legislation, super-fund members who've been diagnosed as being terminally ill are eligible to access all their superannuation tax free. 'Terminal illness' means that the member has fewer than 12 months to live.

In many superannuation funds, terminally ill members can also claim the insured death benefit even though they're still alive. The insurance benefits are also tax free.

Do you need help?

Maurice Blackburn Lawyers has set up a free advice service. If you'd like to speak to an expert before you access your superannuation, or if you have any other questions about superannuation or insurance, call 1800 810 812 to access the free advice and help.

*This figure (\$192,500) is for single people who own their home. Other figures are applicable in the case of couples and people who don't own their home. The figure was current as at July 2012.

This article was supplied by Josh Mennen, Senior Associate in Maurice Blackburn Lawyers' superannuation and insurance practice. It is an extract from an article first published in Spring 2013 Intouch, the magazine of MS Australia – ACT/NSW/VIC.

Disclaimer: Individuals shouldn't use the information in the article as legal advice; they should seek professional advice as they require.

Do you have a question about living with MND?

*Contact the MND Info Line
ph. 1800 777 175*

18 Feb 2014

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

Ahoy, me hearties! ..yes, you

The next MND NSW cruise with **Sailors with disAbilities** will be on **Sunday 19 January** leaving at 12pm from Rushcutters Bay. If you live or are visiting Sydney at this time why not take this opportunity to sail on a specially modified yacht that would have just returned from the Sydney to Hobart yacht race.



This 3 hour cruise with experienced and friendly sailors has been popular in the past. It is wheelchair accessible and MND NSW staff will sail with you on the

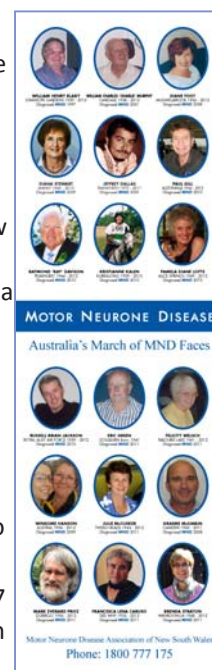
day. Numbers are limited and we encourage family and friends to join you. There is **no charge** to attend so if you are interested, **contact the MND Info Line ph. 1800 777 175 or 8877 0999 or reg@mndnsw.asn.au to book your spots.** You will be sent further details about parking, access and what to bring.

March of MND Faces

The MND NSW March of MND Faces banners feature a photographic display of people with motor neurone disease. We will soon be producing another 'March of MND Faces' banner. If you have MND and want to be included in the new banner, you need to complete a permission form and submit a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish.

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

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



Are you a family member, relative or friend caring for someone with MND?

If you are keen to gain some extra information and support and you would like some time out for yourself, our **Link and Learn** program may be ideal for you. It is suitable for those new to the caring role and also those who have been caring for some time. You will have the opportunity to hear from a range of health professionals and MND NSW staff with expertise in MND, who will answer your questions in a relaxed and informal setting. You will learn how to prepare your home, manage symptoms such as swallowing, communication and breathing and also how to access services and equipment.

Those who have attended Link and Learn tell us that they especially valued the opportunity to take time out for themselves and to share their ideas and experiences with others in similar situations.

This program is residential and will run over two days and a night in the **Hunter Valley on 13 and 14 March 2014.**

Participation in the program, including meals and accommodation is free of charge for people caring for someone with MND, but we do ask that you commit to attending the two days. If you might be interested in attending contact the MND Info Line ph. 1800 777 175 or speak to your regional advisor.

Family Support Calendar 2014

19 Jan	Sailors with disAbilities see above on this page for more information
18 Feb	Information Evening for people recently diagnosed with MND, their family and friends Gladesville
10 Mar	Lunch for bereaved carers Gladesville
13 and 14 Mar	Link and Learn Hunter Valley To support you to give the best possible care at home for the person with MND - see above on this page for more information
12, 19, 26 May and 2 Jun	Care for Carers Gladesville To enable you to care for a person with MND at home, while still taking care of yourself.
3 May	Day of Hope and Remembrance Sydney Olympic Park

For more information contact the MND NSW Info Line ph. 1800 777 175.

If you would like assistance with travel to attend family support sessions or would like us to organise an MND information session in your region, please speak to your regional advisor.

Noticeboard



Disability Care now National Disability Insurance Scheme

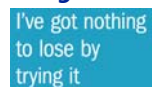
On 28 October Disability Care was named back to the National Disability Insurance Scheme (NDIS). However, current printed materials with the 'Disability Care' branding will be used until stock runs out. The scheme is a new way of funding individualised support for people with disability that involves more choice and control. It will support people with permanent and significant disability, their families and carers and is currently being piloted in NSW in the Newcastle local government area. To be eligible you need to meet specific age and locality restrictions. For more information visit www.ndis.gov.au or speak with your MND NSW regional advisor.



Australian Stem Cell Handbook 2nd edition 2013

With so much discussion about stem cells and their potential benefits, it is often difficult to determine if stem cells can really help you, your friend or family member. This free handbook has been developed by the National Stem Cell Foundation of Australia and Stem Cells Australia to help you in your quest for information. It discusses what makes stem cells so special; how they are currently used in research and in the clinic; and raises concerns about unproven stem cell treatments that are currently being offered in Australia and overseas. Use this handbook as an aid to critically analyse information you gather. Available for free download at www.stemcellsaustralia.edu.au

I've got nothing to lose by trying it



2nd edition 2013

Every month there are dozens of news reports about medical breakthroughs and wonder drugs. The internet is cluttered with adverts and chat-room conversations testifying to 'amazing' benefits.

These stories offer hope of finding something that will do more than conventional medicines can. But the evidence for many of these treatment claims is unreliable. This leaves people unsure about what to try and where they can draw the line. How can we make sense of 'cure' stories? How can we tell the beneficial from the bogus, the likely from the doubtful?

Living with a debilitating condition is difficult, particularly if there is no cure or current treatments aren't providing relief. When people feel that their doctors don't have enough time or concern, alternative therapies can seem appealing. While there is no easy way to know what to believe, there are questions you can ask. Available for free download at www.senseaboutscience.org



NSW Government planning ahead campaign

Take control of your future and make decisions about your financial, legal and health needs by making a Will and ensuring that critical pre-planning documents are in place. A Will, Power of Attorney and Enduring Guardianship are documents that are straightforward to make, but many of us do not even know why we need them. A NSW Government campaign 'Get it in black & white' is encouraging everyone - whether they are 33 or 83 - to make sure they have their Will and pre-planning documents in place. Four in every ten adults do not have a Will and in recent research only one in twenty people could correctly identify the purpose of all three pre-planning documents. The website www.planningaheadtools.com.au has useful information written in plain, easy to understand English. The website also includes plenty of videos as well as fact sheets in a number of languages.



New website - AbilityHouse

Having a disability means it can be difficult to operate

appliances in your home such as doors, the bed, lights, windows, the telephone, TV, music system, curtains, blinds, air conditioner, heater and fans. The AbilityHouse website is designed to provide you with information about alternative methods to operate appliances in your home. When you enter the virtual AbilityHouse, you can select the appliance you have difficulty with, to find out about Home Control Solutions that meet your needs. You can filter information according to your disability. AbilityHouse does not sell equipment. It is a web based project that provides information about solutions, services and suppliers that may be able to assist you. Visit <http://abilityhouse.org.au>

Ed. Before you make any decisions about getting equipment MND NSW recommends that you first contact your local allied health professional for the correct prescription of equipment needed. Your local allied health professional will also know about programs that may provide you with the items you need at no (or reduced) cost to you. Allied health professionals include the occupational therapist, speech pathologist and physiotherapist. They are usually based at a local community health centre, hospital or rehabilitation centre; or may have their own private practice. If you do not know how to contact an allied health professional, your MND NSW regional advisor can help you get in touch with one.

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

Community events

Country Music Fundraiser

Frankie T and the crew from 2MCR 100.3FM put on an afternoon of country music. Fans were spoilt for choice with some great artists performing at Campbelltown RSL on Sunday 18 August to raise funds for MND. The auditorium was full and spirits were high with everyone enjoying the music of Adam Harvey, Christie Lamb, Stuie French Band and many more, raising \$7500 on the day. Pictured above (L-R) Adam Harvey, Kym Nielsen, MND NSW Fundraising Manager and Frankie T.



Schubert Recital

Ross Penglase (singer) and Robert Schmidli (piano) combined their medical careers with their musical careers to raise money for MND by arranging a Schubert Recital on 17 August at the Wesley Music Centre, Forrest ACT. Everyone had a great night and \$1800 was raised for MND. A big thank you also to the MND NSW volunteers assisting at the event: Colleen and Henrik Nielsen, Sandra and Ewan Elliott, and Michael Phoenix.

Kings of Swing social ballroom dancing

Frank McQuade and Graham Cotter are veteran musicians and performers. When Frank's partner Jennifer was diagnosed with MND, they decided to rally their contacts in the music industry and put on a show to raise money for MND. This culminated in a fun-filled afternoon at the Marana Auditorium in Hurstville on 25 August. An 18 piece swing band provided the music for the audience to dance the hours away with \$1600 raised on the day. Thank you to MND NSW volunteers Mark Jones, Jenny Miles and Beverly Whiteford who assisted on the day.

Breakfast for MND

Thank you to Jana Lorenzi who organised a workplace breakfast for MND during September at Recreational Aviation Australia Inc raising \$285.

Illawarra Seniors Dance Group Charity Ball

Betty Davies has been organising this annual MND fundraiser since 2008 and almost \$12000 has been raised to date, with \$2400 of this raised in September at the 2013 event. Thank you Betty for your hard work and ongoing support. Pictured above are Donnamaree Gasparrini, MND NSW volunteer (right), accepting the cheque on behalf of MND NSW with Betty Davies.



Fundraiser in Honour of Keith Sparkes

Keith Sparkes died from MND in July and his daughter, Amanda, organised a workplace fundraiser at QBE Parramatta on 12 September. Amanda said, "I wanted to raise money so the good work that MND NSW does can continue for other families going through what we went through". The staff were treated to a tasty sausage sizzle lunch and paid a gold coin donation to wear 'mufti' clothes to work. The \$1790 raised on the day was matched by a donation from QBE Foundation, raising a total of \$3580 for MND. Pictured above are Amanda with volunteers from QBE.



POPAI Gala Awards Dinner

POPAI is a global not-for-profit retail sector shopper marketing industry association. MND NSW was invited to their annual awards gala dinner in September and CEO Graham Opie delivered a presentation and MND NSW volunteer Suzanne Ballinger guided the guests through a fundraising game of 'heads and tails' for MND. Thank you to Kristen Gadd, POPAI Administration and Events Coordinator, and to our fabulous volunteers assisting on the night raising \$3450 for MND.

Brewery Fest MND Fundraiser

The Australian Hotel and Brewery at Rouse Hill chose MND NSW to be the charity of the month for October, holding a fundraising beer hall dinner on 18 October. Ticket sales, a raffle and silent and live auctions, with Ray Hadley as the guest auctioneer, resulted in \$4200 raised on the night. A big thanks to Ben Waters and Kylie Murphy for choosing MND NSW to be the charity for the month and to our volunteers Jeffrey Lord and Ben McNally who assisted at the event.

Community Market Stalls in the Northern Territory

A big thank you to our first registered volunteer in the Northern Territory, Jennifer Armour and her team of volunteers for organising community market stalls to raise money and awareness of MND by selling merchandise and running raffles in various locations. The first event was at Coolalinga in October. Good luck for your future endeavours and thank you for your hard work. Pictured above at Coolalinga (L-R) - Maerwen Taylor, Scott Franklin and Jenny Armour.



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

(Continued on page 12)

Community events (cont'd)

Murwillumbah Women's Golf 4 Person Ambrose

Thank you to Eve Wheeler from Murwillumbah Women's Golf Club for organising a golf day fundraiser in October. CEO Graham Opie represented MND NSW on the day with \$1500 raised through registrations and raffle ticket sales.

Kfarsaroun Charity Dinner Dance

Many thanks to Elie Nassif, Kfarsaroun Charity Association President and volunteers for organising a fun-filled night on 17 August raising an astounding \$15000 for MND NSW. Guests enjoyed the platters of



delicious food and the entertainment before dancing late into the night. Thank you to the Georges family of Condell Park for initiating the fundraiser and to our MND NSW volunteers Zakhia Aoun, Lacey Aoun and Yasmin Aoun (pictured left) for doing such an amazing job selling raffle tickets and assisting on the night. Pictured (right) are Mary and Abraham Georges with MND NSW Supporter Liaison Officer Anne Jones (L).



Dates for the Diary 2014

16 Feb	 Walk to d'Feet MND - Hunter
Feb	Illawarra Seniors Valentine's Day Ball
20-21 Feb	ASX Thomson Reuters Charity Golf Tournament
2 Mar	Tour de Hills - Castle Hill Rotary
2 Mar	 Walk to d'Feet MND - Illawarra
Mar	MonSTAR Cup - Pennant Hills Golf Club
23 Mar	 Walk to d'Feet MND - Central Coast
Apr	Tas Run for MND Wagga Wagga
6 Apr	 Walk to d'Feet MND - Canberra
Apr	Masters Breakfast Tournament - Camden Lakeside Golf Club
4 May	 Walk to d'Feet MND - Tweed
4-10 May	MND Week
16 May	Riddla MND Golf Day - Penrith Golf Club
15 Jun	 Walk to d'Feet MND - Dubbo
14 Sep	 Walk to d'Feet MND - Port Macquarie
19 Oct	 Walk to d'Feet MND - Wagga Wagga
Oct	Lighthouse2Lighthouse
26 Oct	Burgh2Beach
9 Nov	 Walk to d'Feet MND - Sydney

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

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

ACKNOWLEDGEMENT

We wish to thank
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Editor: Penny Waterson

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