



# FORUM

## Wrapping up MND Week 2013

What a great week we had with 140 of our fabulous volunteers selling merchandise at railway stations and shopping centres or through their friends and businesses; or organising a 'Drink Tea for MND' event at home or at work. Letting other people know about MND during MND Week increases community awareness about the disease and around \$30,000 has been raised. Once again, we received wonderful support from our corporate volunteers. MND NSW merchandise was available through HCF branches and was also sold by Optus staff volunteers at Top Ryde Shopping Centre and at Macquarie Park railway station. On behalf of all of us here at MND NSW, a huge THANK YOU for your massive contribution to MND Week!

*Kym Nielsen, Fundraising Manager and Anne Jones, Fundraising Assistant*



### Tumut

The Young family has been long-time supporters of our Association selling MND merchandise for many years. Pictured here at their Tumut stall

are Annemarie Young (right) and her daughter Caroline Bujaroski. Caroline lives in Queanbeyan and sold merchandise at her work as well as volunteering at the Seekers Canberra concert and at Walk to d'Feet MND Canberra.



### Central Coast

Wendy Whitmore was out and about on the Central Coast at Deepwater Plaza Woy Woy, Stockland Bay Village, Westfield Tuggerah and at

Erina Fair during MND Week.



### Goulburn

Eric Green is a member with MND and he organised the stall at Centro Goulburn. Eric (left) was assisted by

wife Judy and volunteers Oxana Paschuk-Johnson (right) and Paul Johnson.



### Miranda

Jill Johnston and Heidi Dopson fundraised at Westfield Miranda during MND Week. They were assisted by Kevin Johnston, Kate Richmond and Scott Richmond and

they also organised a stall at Sutherland railway station.



### Castle Hill

Mishelle Klar (pictured) and Dee Doughty had a stall at Castle Towers Shopping Centre.

### Frenchs Forest

Pat Shearer (right) organised the MND Week stall at Forestway Shopping Centre and was assisted by Linda Maddock and Tony Maddock. Pat is a regular administration volunteer at the MND NSW Centre at Gladesville and also sells MND merchandise throughout the year.



### Circular Quay

Supporter Michael Fernandez organised the MND Week volunteers at Circular Quay railway station.



### Narooma

Linda Kluske organised a stall at the Narooma Oyster Festival and was assisted by Ken Barklem, Val Brooks and Matthew Ratcliffe.



### Drink tea for MND

This mouth watering morning tea was organised during MND Week by Danni Anderson in memory of her Nan who died from MND just over ten years ago. Danni says, "MND NSW was wonderful in offering support and loaning equipment. Our morning tea was an excellent opportunity for us to raise money to continue researching this disease, educating others and gaining support."



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.*

On 27 March the **Tamworth Hope and Remembrance Gathering** was held in the tranquil setting of The Pavillion Function Centre. After a touching and humbling dedication and candle lighting ceremony in honour of those living with MND and those who have died from MND, we gathered together for a relaxed morning tea. It was inspiring to see so many in attendance whose lives have been touched by MND; coming together to share, connect, honour and discuss the many forms that hope can take on a journey with MND, even in bereavement. Special thanks to Gina Svolos, MND NSW Family Support Manager, and Phil Bower, MND NSW President, for their valued presence. Also thanks to Clubs NSW and Northcott Disability Services for their generous contributions towards funding this event, without which it would not have been possible. Most of all, thank you to the members, past carers, health professionals, families and friends who attended, lit candles, gave dedications or were there to support others. You were the ones who made the day the precious and affirming experience that it was.

*Kim Sinclair, MND NSW Regional Advisor*



*Alan Fullbrook  
(above) and below  
with Mike Fittler (L)  
and Phil Bower (R)*



Over 140 members of the MND community came together at Sydney Olympic Park on 11 May for our

annual **Day of Hope and Remembrance**. We had an inspiring talk from Dr Ian Blair from the Australian School of Advanced Medicine, at Macquarie University. Dr Blair's research career has focused on determining the molecular basis of a variety of neurological disorders including MND. His research group has also played a key role in several critical MND gene discoveries. Ian shared his interest in MND research and updated us on what was currently happening in MND research.



*Cheryl and Tim  
Goodwin*



*Georg and Janice  
Ludstock*



*Juanita Englefield*

We would like to thank everyone who attended and especially those who read out dedications to those whose lives have been affected by MND and also those who lit candles as part of these dedications. This is a very special part of the day and we appreciate your willingness to be involved. And as usual we couldn't have managed without our volunteers who help the day run smoothly and take care of us all by helping with food and cups of tea.

*Gina Svolos, Manager, Family Support*

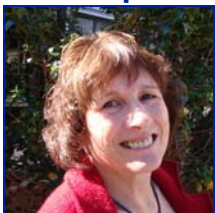


*Talented musicians  
Megan and Alex Cronin*

*DisabilityCare  
Australia  
and you -  
see page 8*

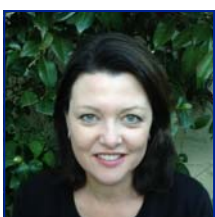
## Introducing...

### **Dianne Epstein** - Regional Advisor for Southern NSW and ACT



Hello everyone. I am pleased, honoured and excited to be one of the newest regional advisors on the Family Support team at MND NSW. I have a background of working with people with disabilities and their families as a case manager and advisor, with many years' experience working in the ACT and southern NSW area. I really enjoy country driving! I look forward to meeting each of our members and their family in my region.

### **Amanda O'Farrell** - Administration Assistant

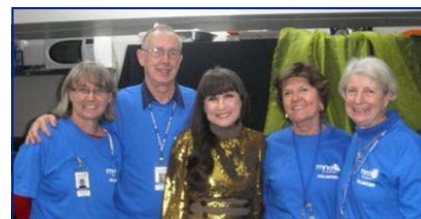


A very warm hello to everyone. I am very happy to have recently joined MND NSW. I am working with the Fundraising team providing data entry and administrative support. I have worked in the areas of administration and finance for many years. At home I have two children and a husband who all keep life busy, and I enjoy spending time with family and friends. I look forward to working for the Association and helping to make a difference for all those living with MND.

## A Message from the CEO

MND Week has been huge.

Our Day of Hope and Remembrance, held during MND Week, continues to grow with over 140 people present at this year's event at Homebush. The Seekers managed to coincide their 50<sup>th</sup> anniversary tour with MND Week and kindly invited MND NSW to collect donations at their concerts in the ACT, Sydney, Newcastle and Wollongong raising nearly \$30,000. Judith Durham is the Patron of MND Australia and between Judith and our tireless volunteers the message about MND reached a broader audience. Judith was admitted to hospital during a latter part of the tour and we wish her well.



*Judith Durham (centre) with  
our MND volunteers*

Blue Cornflower day proved a great day for the sale of merchandise across the state. From railway stations to shopping malls, volunteers turned out to raise funds to support people with MND and get the word out. This year volunteers raised an amazing \$30,000 during MND Week.

So far in 2013, Walks to d'Feet MND have taken place in the Illawarra, Hunter and Tweed Heads with great turnouts for all. A report can be found on page 12.

The National Disability Insurance Scheme, DisabilityCare has now been agreed on by seven states and territories. A 0.5% increase to the Medicare Levy from July 2014, to support DisabilityCare, has passed through both houses of Parliament. More information about DisabilityCare can be found on page 8 of this edition of *Forum* and at [www.ndis.gov.au](http://www.ndis.gov.au).

Our Equipment Loan Service will now be known as FlexEquip. This is a change in name only and it will take some months to update all of our publications and website with the new name for this service.

We welcome Dianne Epstein and Amanda O'Farrell who have joined the staff at MND NSW and they introduce themselves on page 2. In May we farewelled Lisa Dowling.

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*

## Motor Neurone Disease Association of New South Wales

### PATRON

*Her Excellency Professor Marie Bashir  
AC Governor of New South Wales*

### VICE PATRONS

*Paul Brock AM  
Melinda Gainsford Taylor  
Kevin Langdon OAM  
The Hon. Mr. Justice Peter W. Young*

### Auditor

*C.M. Pitt & Co.*

### Solicitors

*Mallesons Stephen Jaques*

### MND NSW BOARD

#### President

*Phil Bower*

#### Vice Presidents

*Alex Green, Roger Henshaw*

#### Secretary

*Janice Scheinecker*

#### Treasurer

*Lara Kirchner*

#### Board Members

*Phil Brady, Michael Perry,  
Anita Richter, Ralph Warren*

### MND NSW

*Building 4 Gladesville Hospital  
Gladesville NSW 2111*

*(Locked Bag 5005*

*Gladesville NSW 1675)*

*Phone: 02 8877 0999*

*or 1800 777 175*

*Fax: 02 9816 2077*

*Email: [admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au)*

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

*ABN 12 387 503 221*

### Chief Executive Officer

*Graham Opie*

### Office Coordinator

*Petra Sammut*

### Accountant

*David Radford*

### Fundraising Manager

*Kym Nielsen*

### Fundraising Assistant

*Anne Jones*

### Administration Assistant

*Amanda O'Farrell*

### Bequests Officer

*David Dubin*

### Family Support Manager

*Gina Svolos*

### Regional Advisors

*Chris Carroll, Dianne Epstein, Jo Fowler,*

*Caroline Gleig, Ann McCutcheon,*

*Eileen O'Loughlen, Kim Sinclair and Deb Ward*

### Information Line Advisor

*David Wallace*

### Education and Carer Support Coordinators

*Kristina Dodds, Kate Maguire*

### FlexEquip Coordinator

*Maree Hibbert*

### FlexEquip Assistants / Support Officer

*Tom Giardina, Michael Walker / Ellen Hibbert*

### Information Resources Coordinator

*Penny Waterson*

*And...many valued volunteers  
including administration volunteer,  
fundraising volunteer and  
Ambassador, Dee Doughty*



## Family Support Team

### Sailors with disAbilities

Each year Sailors with disAbilities offers MND NSW members and their families a Sunday afternoon sail free of charge. On 7 April we had a wonderful sail on the maxi yacht *Kayle* on Sydney Harbour with two families attending. Neither family had ever sailed on the Harbour before, so it was a real treat to have the two sails hoisted for our journey. Everyone had a go at the helm, ably instructed by our skipper David Leslie and crew. We are often struggling to get the numbers for this sail day and yet every year we have a wonderful time. The yacht is specially designed to take wheelchairs and people with limited mobility on board, so when we advertise next year please consider coming along and inviting your family as well.

### Care for Carers update

Care for Carers commenced on 13 May and is held over four Mondays. This year we have about 16 carers attending the program which aims to support carers in their role through guest speakers, discussion and sharing of experiences. Every year when we run this program we find that carers really do get a lot out of meeting together, swapping handy hints and sharing their experiences with the aim of providing the best possible care for the person with MND.

Guest speakers, such as occupational therapists, physiotherapists, speech pathologists and others, provide information and ideas on how to provide care and support to someone with MND in their day to day living. Each year friendships are formed and supports are gained making this a very popular program to attend.



*Carers at Care for Carers enjoying their lunch*

*Have a  
question  
about  
MND?*

*MND Info Line  
1800 777 175*

### Ask the Experts – 22 July 2013

Our next major event for members and family is our Ask the Experts Forum to be held at West Ryde on 22 July. Professor Dominic Rowe from Macquarie Neurology will be providing an overview of MND. Dr Bradley Turner from Florey Neuroscience Institutes will speak about what's new in MND genetic research and other speakers will present on communication matters and quality of life. There will be plenty of time for audience questions so come along and bring your questions. If you would prefer someone else to ask your questions MND NSW staff will be available to do this. We hope to be able to video record this day so that people who are unable to attend will be able to watch it on our website at a later date. It is essential that you register for this event. See below or the enclosed flyer for further details.

### Gina Svolos

*Manager, Family Support*



## MND NSW 'Ask the Experts' Forum

**22 July 2013**

Ryedale Room, Ryde-Eastwood Leagues Club

117 Ryedale Road, West Ryde

10.30am-3.15pm (registration at 10am)

Come and quiz the experts! This forum is an opportunity for people living with MND, their family, carers and friends to bring their questions about MND and have them answered.

Our experts will speak about MND, what's new in MND research, maintaining quality of life and information on communication solutions.

For those who are shy about talking in public, have speech difficulties or have a query they would rather have someone else ask, you can pass your question onto any MND NSW staff member and they will ask the question on your behalf. Remember your question may be just the one others want to ask!

This venue is wheelchair accessible with parking available on site.

Lunch, morning and afternoon tea are provided.

There is no charge to attend this event but please RSVP for catering purposes.

Email: [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) or ph. 02 8877 0999 or 1800 777 175

## Equipment

The MND NSW Equipment Loan Service is now known as FlexEquip.

### Loans and referrals

FlexEquip has provided 274 items of equipment for loan in the past two months. Loans include 43 bathroom aids, 22 armchairs, 20 manual wheelchairs, 14 homecare beds and 8 powered wheelchairs. During this time 323 items of loaned equipment have been returned.

### The health professional and equipment

Before we provide an item, a qualified health professional (usually an occupational therapist, physiotherapist or speech pathologist) makes an assessment to determine the most suitable item for you, taking into account your individual situation, physical needs and goals. Once this assessment has been undertaken, the health professional sends an equipment referral to FlexEquip for the item/s required. FlexEquip staff arrange the delivery of the requested equipment but it is the responsibility of the referring health professional to set up the equipment and instruct the person and their carers on the safe use of the item. With every delivery of FlexEquip equipment you receive a letter listing the item/s delivered and contact details for the health professional who made the equipment referral. You are asked to contact that health professional so they can come to your home and show you how to setup and use the item.

## Changing equipment needs

A person's use of and need for equipment changes throughout the progression of MND. The equipment being used should be reviewed regularly especially if there have been noticeable changes in your strength. FlexEquip has a large range of equipment available and a qualified health professional can make referrals to FlexEquip to assist you to have the right items of equipment when you need them in your home. For example: John is using a walking stick but is getting very tired walking longer distances. John enjoys going out and socialising but because it is so tiring he is reluctant to do so and as a result is going out less frequently. John's occupational therapist can assess what equipment John might now need. This could be a different type of walking aid or even a manual wheelchair that John could use for longer distances thereby saving his energy for the social activities he enjoys.

Equipment needs change as your needs change. However MND is unpredictable and sometimes changes in need may happen more quickly than expected. If this does happen then contact your health professional to let them know. The health professional and you can review what equipment may now be most useful. It is important to keep the health professional and your MND NSW regional advisor up-to-date as your needs change.

**Maree Hibbert**

*FlexEquip Coordinator*

*Put it in your diary*

*Ask the Experts  
2013*

*West Ryde  
22 July*

## Family Support Calendar 2013

<b>18 Jun</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   Gladesville
<b>22 July</b>	<b>Ask the Experts</b>   West Ryde   You, family members, carers and friends can bring your questions about MND and have them answered
<b>20 Aug</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   Gladesville
<b>16 Sep</b>	<b>Lunch for bereaved carers</b>   Gladesville
<b>22 Oct</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   Gladesville
<b>11 and 18 Nov</b>	<b>Learn Now Live Well</b>   Gladesville   For people with MND, their family and friends. Two day educational program covering living well with MND, and support and services available for people living with MND
<b>23 Nov</b>	<b>Christmas Party for family support members, their family and friends</b>   West Ryde
<b>10 Dec</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   Gladesville

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

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

## Mailbag

### From Judy

Eighteen months ago my world was turned upside down when I was diagnosed with MND.

One of my bucket list items was to go on a hot air balloon ride. This activity was something that I have wanted to do for the past 20 years but never got around to doing it.

I contacted an operator in the Hunter Valley and soon realised that I wouldn't be able to get into the basket as one had to climb in!!! Not to be defeated I asked the operator if there was any place in Australia where a disabled person could get to ride in a balloon. Remarkably, I was told that there was a business in Melbourne that had an easy access basket. Yay, a little holiday in Victoria!

So after contacting the business, I booked my place in the easy access basket for my birthday. How lucky was I to go up in the balloon (flights are dependent on weather conditions) on my birthday, where my husband and I floated over the Yarra Valley which was followed by a champagne breakfast.

The staff were very professional and nothing was too much trouble to give me the joy of hot air ballooning.



*Judy on her very special balloon flight*

Photo courtesy of Global Ballooning Australia Pty Ltd

### From Louise's Mum

In June 2007, my 36 year old daughter asked me to go with her to receive the results of some neurological and other tests she had undergone. This was two weeks before she was to leave on a trip to Mongolia.

We set out on a beautiful morning, she excitedly talking about her upcoming trip and me feeling happy for her. The day came to a blinding halt when the neurologist told us that he thought she had motor neurone disease and our world turned upside down. The next days passed in a blur, she cancelled her trip on the advice of the neurologist

and we had the difficult task of letting family (including her brother who lives in the USA) and close friends know of the news we had received. Further tests were performed and the diagnosis was confirmed.

In the five years since, Louise's condition has gradually worsened, but my husband and I are so proud of the way she has handled things. She returned to work as a clinical psychologist and continues in this job although she has had to cut back to working four days per week. There she is surrounded by the most wonderful colleagues who help her in so many ways. She also continues to live in her own home which she purchased a few months before the diagnosis. Naturally she could not have done this without the great support she has received from family and friends, and particularly her wonderful neighbours. A couple of years ago, her neighbour Ella, came in one day and said "Louise, when your mum and dad go home, I'm going to take you shopping each Saturday morning". She has been doing this ever since. Family members and a friend who live close have been there for her when she has had falls, some of which needed visits to the emergency department at the local hospital, and her friend visits at least once a week. This is such a comfort to my husband and I as we live on the far south coast, and although we visit regularly can't be there all the time. This is at Louise's request as she is so determined to live independently for as long as possible.

Twelve months after the diagnosis she decided that even if she didn't get to Mongolia, she still wanted to take an overseas trip which she did, travelling first to Belgium to meet up with a friend she made while travelling through Europe in 2003. She was then a surprise guest at my aunt's 80th birthday in Scotland, travelled to Turkey where she spent two weeks, returned to Scotland and then spent another two weeks in Ireland meeting up with friends she made while working there in 2002. The following year she, together with two friends, took a trip to the Northern Territory and Western Australia visiting Darwin, Kakadu, Broome and places in between.

Louise continued driving for a few years and then early last year, it was felt that it would not be wise for her to continue. At this stage, we felt that she would have to give up work and come to live with us, but no, not Louise, she investigated public transport and found that provided she could get to the station she could continue working. This is where her neighbours really came to the fore when one volunteered to take her to the station

*(Continued on page 7)*

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

## Mailbag (cont'd)

(Continued from page 6)

each morning and collect her each evening. Incidentally, Louise lives on the south coast but works in southern Sydney.

Until early this year, Louise was using a walker to get about, but she found that this was getting very tiring. Once again, we thought it was time for her to give up work and come to live with us, but once again SHE was not ready and has now purchased a fold up electric wheelchair so that she can continue working. She talked this over with her neighbour Jim who went with her to look at wheelchairs to see if he could get it in and out of his car. Not only is she getting on and off the train each day, she is also getting on and off a bus which takes her to her workplace. The wheelchair has actually given her back some independence, as she is able to go up to the shops near work on her own and with the help of the wheelchair taxi, travel into town to meet up with friends.

Each year since 2007, Louise, my husband and I have taken a holiday together which we have all enjoyed. She also spends time with us at our home which is in a lovely rural area and where she will ultimately live IF she ever decides it is all too much.

Although we all know there is no cure, we are living our lives as normally as we can, keeping involved with other interests. Louise is a keen

photographer and has recently purchased equipment which will enable her to have her camera mounted on her wheelchair. She loves to read, but found it hard to hold a book so she invested in an e-book reader. She also loves TV and working on the computer and has compiled some beautiful photo books. Louise also loved to cook, but unfortunately that is now too difficult, so she now relies on me to fill up her freezer each time I visit, but she likes to be involved and gives me quite a bit of advice, as well as looking for interesting recipes on the internet.

I am sure that it is her positive attitude to life that has helped her continue on for so long, and we hope that she will continue to do so. Her mantra is "I am living WITH motor neurone disease, NOT dying from it". Our visits to the MND Clinic are also positive experiences where the staff are so helpful and encouraging, always trying to find ways to make life easier for those with MND and their carers. There is no feeling of doom and gloom, and there is a lot of joking and laughing.

Throughout this time we have come to realise that there are some wonderful people in the world who are happy to go that extra mile to make things easier for people with a disability.



Support group meeting dates are at [www.mndnsw.asn.au](http://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](mailto:annm@mndnsw.asn.au)

Gladesville - Caroline Gleig | [carolineg@mndnsw.asn.au](mailto:carolineg@mndnsw.asn.au)

Liverpool - Ann McCutcheon | [annm@mndnsw.asn.au](mailto:annm@mndnsw.asn.au)

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

Northern Sydney (Hornsby) - Jo Fowler | [josephinef@mndnsw.asn.au](mailto: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](mailto:diannee@mndnsw.asn.au)

Central Coast - Audree Dash | 4384 2907 or Deb Ward | 1800 777 175 | [debw@mndnsw.asn.au](mailto:debw@mndnsw.asn.au)

Central West - MND NSW Info Line | 1800 777 175 | [davidw@mndnsw.asn.au](mailto:davidw@mndnsw.asn.au)

Griffith and Region - Dianne Epstein | 6286 9900 | [diannee@mndnsw.asn.au](mailto:diannee@mndnsw.asn.au)

Illawarra - Ann McCutcheon | 1800 777 175 | [annm@mndnsw.asn.au](mailto:annm@mndnsw.asn.au)

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

Newcastle and Hunter - Eileen O'Loughlen | 4921 4157 | [eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au) or  
Kim Sinclair | 4985 5022 | [kims@mndnsw.asn.au](mailto:kims@mndnsw.asn.au)

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

Port Macquarie - Eileen O'Loughlen | 4921 4157 | [eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au)

Gold Coast Carers - Chris Carroll | 0421 252 455 | [chrisc@mndnsw.asn.au](mailto:chrisc@mndnsw.asn.au)

## DisabilityCare Australia and you

### Quick guide for MND NSW members

DisabilityCare is the name for the new national disability insurance scheme (NDIS). The scheme will deliver a life-long approach to support people with disability through individualised funding. This means rather than providing support based on the number of places in a limited number of programs, the scheme will provide funding so people can get the care and support they need, based on their individual support needs, goals and aspirations.

DisabilityCare Australia starts on 1 July 2013, but is being rolled out in stages based on local government areas. It is expected that the NSW rollout will be completed by July 2018 and the ACT rollout will be completed by July 2019.

To be eligible for DisabilityCare a person needs to have acquired their disability before they turned 65, and be aged under 65 at the time the scheme starts. You cannot enter the scheme until it commences in your area. You can meet the disability requirements if you have a permanent impairment and you:

- cannot join in activities or do things without assistive technology, equipment (other than commonly used items such as glasses) or home modifications or
- usually require help from other people to join in or do things.

For people with MND, this means being diagnosed with MND before the age of 65 and being aged under 65 at the time the scheme starts.

Governments have agreed how existing clients of disability programs will gradually enter the new scheme, and your current support arrangements will continue with your current providers until you enter the scheme.

#### New South Wales

DisabilityCare for people living in the local government area of *Newcastle* starts from July 2013, *Lake Macquarie* from 2014 and *Maitland* from 2014. By July 2016, about 10,000 Hunter area residents with a permanent and significant disability will be covered by the scheme. By July 2018, all NSW residents with permanent and significant disability will be supported by the scheme.

#### Australian Capital Territory

DisabilityCare starts for some people living in the ACT from July 2014. By July 2019, all ACT residents with permanent and significant disability will be supported by the scheme.

#### When the scheme comes to your area

DisabilityCare Australia staff will meet with you to discuss ongoing support needs when you are scheduled to enter the scheme. Once you enter the scheme, you will be able to choose whether you want to manage your funding package yourself, or have it managed by a family member, DisabilityCare Australia or an organisation providing plan management services. DisabilityCare Australia can also connect people with community services and mainstream supports and services such as health, transport, education and housing. If you are currently receiving care and support these arrangements will continue. The Agency, participating governments and service providers will discuss how best to transition your support into DisabilityCare.

#### What do I need to do now?

You don't need to do anything right now because DisabilityCare Australia does not start until 1 July 2013. In June, you will be able to use the My Access Checker tool on the website to see whether you may be able to access assistance from DisabilityCare Australia after 1 July 2013.

#### More information

For more information about DisabilityCare Australia and the rollout of the scheme from 1 July 2013:

- visit [www.ndis.gov.au](http://www.ndis.gov.au)
- email [NDISEnquiries@fahcsia.gov.au](mailto:NDISEnquiries@fahcsia.gov.au)
- call 1800 800 110.

To stay up-to-date with the rollout of the scheme, visit [www.ndis.gov.au](http://www.ndis.gov.au) and click 'sign up now'.

#### I was diagnosed with MND after I turned 65

Your existing supports stay in place. MND NSW, other state MND Associations and MND Australia are continuing their advocacy for DisabilityCare to cover all Australians.

SOURCE: Edited extract from Participating in DisabilityCare Australia FAHCSIA 12525 9 May 2013 <http://www.ndis.gov.au/wp-content/uploads/2013/05/Participant-fact-sheet-Hunter-area.pdf> and National Disability Insurance Scheme Launch Locations <http://www.ndis.gov.au/ndis-launch/launch-locations/>

*Would you like  
to receive  
Forum by  
email?*

*Let us know at  
admin@  
mndnsw.asn.au*

## Noticeboard

### Home Modification and Maintenance Services

The Home Modification and Maintenance Services (HMMS) can provide modifications and some maintenance work for eligible residents of NSW, so that they can live more independently in the community and remain in their homes for longer. People living with MND are considered to be eligible. HMMS provides both minor and major modifications. Minor modifications include the supply and provision of grabrails, handrails, hand held showers, access modifications such as ramps, step wedges and paths to suit individual needs, lever taps; and widening doorways. Major modifications include access modifications such as ramps, bathroom and kitchen modifications and safety modifications. All modification work must be referred by an occupational therapist. Generally the client is asked to pay for the cost of all materials plus a subsidised hourly rate. Wherever possible, materials are at discount prices. If you have difficulty paying your account, assistance is available and can be negotiated with staff at your local HMMS - each HMMS sets its own fee policy. Contact the Commonwealth Respite and Carelink Centre freecall 1800 052 222 or visit <http://www9.health.gov.au/ccsd/index.cfm>

### Talking with Young People about MND

An Australian information pack for parents, Talking with Young People about MND, is available from MND NSW. Written for families making the difficult journey with MND, the pack includes booklets for parents, 8 to 12 year olds, teenagers, young friends, schools and health professionals who may be working with the family.

The booklets include suggestions from parents and children who wanted to share their experience of living with MND with other families. There are suggestions for ways of talking with your children following a diagnosis of MND, and ideas about how to keep communication strong as time goes by. If you have children or teenagers and would like to receive a copy of the Talking with Young People information pack please contact your MND NSW regional advisor or the MND Info Line ph. 1800 777 175.



### My Choice, My Control, My Future: DisabilityCare Australia conference

23 and 24 June 2013 at the Melbourne Convention and Exhibition Centre - registrations now open. This conference will take place one week before DisabilityCare Australia commences. It will bring together more than 1,000 people with disability, carers and people from the disability and community sector to discuss the scheme, how it will work and how the Government will help them transition to this new system of support. See [www.ndis.gov.au](http://www.ndis.gov.au) for more.

### Hoyts Cinemas



Hoyts Cinemas is offering \$1 movie tickets for carers who come accompanying the person they care for. Carers simply need to present either a Healthcare Card with a CD or CP code noted in the payment type section or a Centrelink Pension Card with CAR or DSP noted on the reverse side of the card to be eligible. All Hoyts cinemas are accepting this special offer until 31 March 2014.

### Olympic gold medallist, Brittany Elmslie champions people with motor neurone disease



Olympic gold medallist, Brittany Elmslie is the new Young Ambassador for Motor Neurone Disease Australia (MND Australia).

"We feel privileged that Brittany has chosen to advocate on behalf of people living with motor neurone disease (MND) and that she

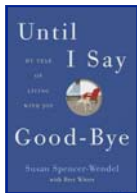
shares our vision of a world free from this devastating disease," says Mr Ralph Warren, President MND Australia. "Brittany's vitality and outstanding swimming record are inspirational. Her humility and sunny disposition will be particularly appreciated by young people who are living with MND or caring for a loved one with the disease."

Ms Elmslie approached MND Australia after learning of the widespread repercussions of MND. "I hope that my profile as an Olympic gold medallist can help raise awareness about MND and those affected by it."

Ms Elmslie burst into the Australian public's sporting conscience at the 2012 London Olympic Games when she won a gold and two silver medals in the pool at just 18 years of age.

"As an Olympian I felt totally empowered knowing that the nation was behind me. I want all Australians to get behind people living with MND to give them the strength to tackle their personal challenges."

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



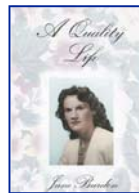
## Book Review

**Until I Say Good-Bye**  
Susan Spencer-Wendel

After two years of symptoms, Susan Spencer-Wendel, an American journalist, was diagnosed with MND.

Married, 44 years old and with 3 young children, she was told she had perhaps only one year of good health remaining. So she decided "to live that year with joy" and travel around the world with her family and friends. She went to California to find her birth mother; to New York, where her teenage daughter tried on wedding dresses for a glimpse of a day they'll never share; to Budapest, where she and her husband retraced footsteps of an earlier life; to the Yukon, in a vain attempt to see the Northern Lights with her lifelong best friend; to the Caribbean; and to Cyprus. This book is uplifting and inspiring, especially because Susan wrote it in just four months typing with one finger on iPhone.

*Reviewed by David Wallace, MND NSW*



## Book Review

**A Quality Life**  
June Burdon

June's family describe the book *A Quality Life* as June's great gift to them. It is however a gift to all

interested in the human experience. June tells us about growing up in South Australia, teenage life during the war years, travel and work in the United Kingdom, marriage in Canada, raising a family in northern Tasmania in the 1960s, a move to Sydney in 1979 and about travels to Egypt, Europe, North America, Turkey and China. June had her first symptoms of MND in late 1999 and describes the difficult period of investigations and doctor visits before her diagnosis in 2001 as, 'a new time-consuming and obsessive hobby, but it was nowhere as pleasant'. June wrote her memoir with engaging candor during the year before her death in 2003. Her story provides insight into Australian life and June's experience with MND. Sale proceeds will be donated to MND NSW.

*Reviewed by Penny Waterson, MND NSW*

**Entertainment Book 2013-14**  
now available at  
[www.mndnsw.asn.au](http://www.mndnsw.asn.au)



## Dates for the Diary 2013

22 Jun	<b>Cooinda Court Mini Fete - Macquarie Park</b>   Contact Linda Dimmock <a href="mailto:ldimmock@bcs.org.au">ldimmock@bcs.org.au</a>
26 Jun	<b>Reverse The Curse State of Origin Fundraising Dinner and Auction - Ultimo</b>   Sydney Aerial UTS Function Centre   Contact Gavin Turnbull <a href="mailto:gavin@bchild.com.au">gavin@bchild.com.au</a>
29 Jun	<b>Lighthouse to Lighthouse Fundraising Run - Wollongong to Kiama</b>   Contact Shelly-Anne Demirov <a href="mailto:shellyannedemirov@gmail.com">shellyannedemirov@gmail.com</a>
30 Jun	<b>MND High Tea and Fashion Parade - Dubbo</b>   Contact Sharon Doick <a href="mailto:functions@dubborisl.com.au">functions@dubborisl.com.au</a>
26 Jul	<b>Cessnock Rugby League Charity Luncheon - Cessnock</b>   Contact Dave O'Brien <a href="mailto:daveo33@bigpond.net.au">daveo33@bigpond.net.au</a> ph. 0419 281 121
11 Aug	<b>Sun-Herald City2Surf 2013</b>   Get a team together and support MND NSW   Contact Kym Nielsen, MND NSW ph. 8877 0999
17 Aug	<b>Kfarsaroun Charity Association Dinner Dance - Granville</b>   Contact Elie Nassif <a href="mailto:ctcquakerscourt@ctcgroup.com.au">ctcquakerscourt@ctcgroup.com.au</a> ph. 0425 230 649.
23 Aug	<b>Tee Off to d'Feet MND Charity Golf Day - Maitland</b>   Contact Dr Malcolm Buck <a href="mailto:drmdbuck@dodo.com.au">drmdbuck@dodo.com.au</a>
25 Aug	<b>Social Ballroom Dancing Fundraising - Hurstville</b>   Contact Frank McQuade ph. 0407 237 326
15 Sep	 <b>Walk to d'Feet MND - Port Macquarie</b>   Westport Park   Online registration available closer to the date   Contact Bev Smith <a href="mailto:bebbie45@hotmail.com">bebbie45@hotmail.com</a>
12 Oct	<b>Gundaroo Music Festival</b>   Bands playing on mobile truck stage at Gundaroo. Contact Scott Harding ph. 0459 231 743
13 Oct	<b>Social Ballroom Dancing Fundraising - Hurstville</b>   Contact Frank McQuade ph. 0407 237 326
20 Oct	 <b>Walk to d'Feet MND - Wagga Wagga</b>   Online registration available closer to the date   Contact Kym Nielsen ph. 8877 0999 <a href="mailto:kymn@mndnsw.asn.au">kymn@mndnsw.asn.au</a>
10 Nov	 <b>Walk to d'Feet MND - Sydney</b>   Blaxland Riverside Park Homebush   Online registration available closer to the date   Contact Kym Nielsen ph. 8877 0999 <a href="mailto:kymn@mndnsw.asn.au">kymn@mndnsw.asn.au</a>

## Community events

### Chamber Developments Charity Golf Day

The Camden Lakeside Country Club was again the venue for the annual Chamber Developments Charity Golf Day on 15 April. 'The Masters Breakfast Tournament' raised \$2418 for MND and players gathered at the Camden Lakeside clubhouse early in the morning to watch the end of the US Masters on the big screen while enjoying a delicious breakfast, before heading out to the course for a Stableford golf competition. A big thank you to Brian Brown and Chamber Developments for their continued support.

### TAS Run for MND

The 'Tas Run' is a fundraising motorcycle ride that starts in Wagga Wagga then takes in the sights of Gundagai, Tumut and Tumbarumba before returning back to Wagga Wagga. The event is organised by Pat O'Hara and Chris Anthony with the help of many family and friends in memory of Tas O'Hara who died from MND in October 2010. Held this year on 6 April, over \$7000 and much awareness about MND was raised. Tas O'Hara was a keen competitor in motorcycle racing and was runner up in several NSW and Australian titles during the late 70's. Pat and Chris would like to thank the many race and personal sponsors for making the day such a huge success and hope to be able to make the event even bigger next year.

### Football to d'Feet MND - Yerrinbool Bargo Soccer Club

This is the second very successful year that Yerrinbool Bargo Soccer Club has hosted a football fundraising event to raise money and awareness for MND. Close to \$5000 was raised and we thank Danny Josipovic and the many other event organisers for their continued support of our Association. The event was held at Yerrinbool on the 6 April in honour of one of their members who has MND.

## Need a keyring?....



MND Keyring  
Cornflower shape in  
Association colours with  
contact information on  
reverse. \$4



MND Keyring  
Foot shaped keyring with  
'Walk to d'Feet MND' on  
front and contact  
details on reverse. \$4

[www.online.mndnsw.asn.au](http://www.online.mndnsw.asn.au) or contact Anne Jones at  
MND NSW ph 02 8877 0999 to place your order.

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



Photo courtesy of TWT  
on-the-spot PHOTO

Thank you to Lesley and Lindsay Maher from Putney Tennyson Bowling and Community Club for their ongoing support. This year they donated a

record \$1040 taking the total donations to \$3953 over the past five years. Lindsay says, "What a frightening disease MND is. I am truly touched by the courage of those diagnosed and their families. Visiting the MND NSW Centre at Gladesville each year with the proceeds I have come to realise that even small donations can make a difference. How wonderful it would be to have a world without MND. To be able to help, even in a small way is rewarding. We look forward to breaking the record donation again next year."

### Wagga Wagga Pedal Car Show



A big thank you to Shirley and Keith Wheaton for organising the Wagga Wagga Pedal Car Show for MND on 24 March.

Through ticket sales, a barbeque and raffle proceeds a grand total of \$3333 was raised. The event showcased gorgeous collectable items such as pedal cars, trikes, scooters and bikes and was held in memory of one of the founding members of the Pedal Car Club.

Get your team together and  
pick **MND NSW** as your charity for

The Sun-Herald  
**CITY2SURF**

[www.city2surf.com.au](http://www.city2surf.com.au)

For more information about supporting  
**MND NSW** speak with Kym Nielsen  
ph. 8877 0912 or  
[kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au)

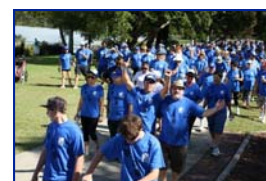
*Our community events for MND would not be possible without our supporters who volunteer to organise events. Thank you for your support.*

## Walk to d'Feet MND



Wow - we are already half way through the year and we've had some great Walks to d'Feet MND. In February we had the inaugural Walk to d'Feet MND Illawarra. In March we had Walk to d'Feet MND Canberra followed by the inaugural Walk to d'Feet MND Hunter held in April. In May our supporters were at Walk to d'Feet MND in Tweed Heads. Thanks to our local coordinators Shelly-Anne Demirov from the Illawarra and Ashley Worlton from the Hunter who worked so hard to make the inaugural Illawarra and Hunter Walks such a success - having a local coordinator makes a lot of difference, so if you are in the Tweed or Canberra areas and might be interested in coordinating these Walks in 2014 please do let us know. All of our Walks have been well supported with lots of *Everyday Heroes* adding to the funds raised at these events. To date our Walks have raised over \$85,000 for MND. It is not too late to Walk to d'Feet MND. You can join us in

**Port Macquarie** on  
**15 September**, **Wagga Wagga**  
on **20 October** and in **Sydney**  
on **10 November**.



## Seekers Concert - A Night to Remember

For those of you too young to remember, The Seekers were the first Australian pop group to achieve major chart sales in UK and USA. They formed in Melbourne in 1962 and were very popular during the 1960's with many hits in the Top 10 including *Georgy Girl* and *I'll Never Find Another You*. Lead singer, Judith Durham has had a close association with MND since her former husband Ron Edgeworth died from MND in 1994, and is the National Patron of MND Australia. The Seekers very kindly allowed MND NSW volunteers to collect donations from patrons at their 50th Anniversary Golden Jubilee National Tour concerts in NSW and the ACT. A staggering amount of \$29,853 was raised. A big thank you to the Seekers and our best wishes to Judith who fell ill towards the end of the tour. Also a big thank you to the many volunteers who helped collect donations on the various nights and to Suzanne and Bob Ballinger who were the volunteer coordinators for the four Sydney concerts, to Pete McMurray and the McMurray family for their hard work for the Newcastle concert and to our ACT volunteers who braved the cold weather at the Canberra concert.



MND volunteers on duty at the Seekers  
Sydney Concert on 6 May

### ACKNOWLEDGEMENT

We wish to thank  
Snap Printing, North Ryde  
for their generous support.

**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



Walk to  
d'Feet  
MND

**Port Macquarie**  
15 Sept

**Wagga Wagga**  
20 Oct

**Sydney**  
10 Nov