



### **In this edition**

Reflecting on a decade of change - Gina Svolos, Manager Support Services MND NSW... Planning for MND Week 2017... Thanks Hunter... review of Acuscope therapy... Upcoming Government information sessions about the NDIS in NSW, ACT and NT... Familial MND families... MND education, support groups and coffee mornings... and more.

### **A Message from the CEO**

In early May a group of eight MND NSW supporters will be tackling the Inca Trail. Over five days they will hike to Macho Pichu, battling altitude sickness and blisters, all to raise funds and awareness in support of motor neurone disease. Also next month, MND NSW supporter Bob Montgomery will be cycling from Darwin to Perth in his Darwin2Perth4MND ride raising funds for MND NSW and Huntington's NSW. Watch the MND NSW Facebook page for updates from both these events.

We have included in this edition of e-news some photos from Walk to d'Feet MND Hunter, which was held on a rare sunny day in March. As is always the case in the Hunter, there was a large crowd with over 800 people and nearly as many dogs. Make sure you keep your eyes open for a Walk near you.

*Graham Opie*  
CEO



## Saturday 6 May 2017 Day of Hope and Remembrance

This is an afternoon of hope and remembrance for all those whose lives have been touched by motor neurone disease. More information [here](#).



# MND Week | 7-13 May 2017

What will you do to raise awareness this MND Week?

**Blue Cornflower Day** on Friday 12 May is the perfect day for your event!

Email: [fundraising@mndnsw.asn.au](mailto:fundraising@mndnsw.asn.au) or phone: (02) 8877 0999 to discuss your plans, order merchandise and list your event on our website.



How will you BLUE? #MNDblue #MNDweek

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

## Advocating for the best outcomes for people with progressive neurodegenerative diseases

Ten national peak not-for-profit health organisations (making up the Neurological Alliance Australia (NAA)) are calling for the National Disability Insurance Scheme (NDIS) to transform the lives of over 850,000 Australians living with progressive neurological or neuromuscular conditions that have no known cause and no cure. The Joint Position Paper, *People with progressive neurodegenerative diseases in the NDIS*, was launched 22 March 2017 at Parliament House Canberra.



To ensure the best outcomes for people with progressive neurodegenerative diseases under the NDIS, the NAA recommends:

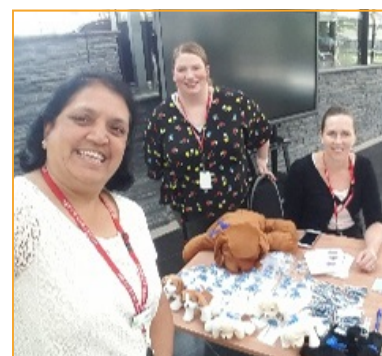
- Improved pre-planning support for people with a progressive neurodegenerative disease;
- NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease;
- Mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease; and
- The needs of people with a progressive neurodegenerative disease be addressed in the Productivity Commission's upcoming Review of NDIS Costs.

Read the full paper [here](#)

## Woolworths Head Office Charity of the Month

MND NSW was chosen as the Charity of the Month by Woolworths Head Office in Bella Vista. Throughout March, various fundraising events were run with \$6,221 donated to the Association.

A big thank you to Megan Moore who was the coordinator of the events, and to the staff at Woolworths Head Office for their generosity.





## Walk to d'Feet MND Hunter ...

26 March, Croudace Bay

Walk to d'Feet MND Hunter has always been our biggest Walk and our Hunter supporters didn't hold back this year. Hundreds of participants turned out to show their support for people living with MND on Sunday 26 March. What a great morning it was, with plenty of sunshine and lots of family groups, teams of friends and supporters.

A big thank you to Leah Jay property management specialists who were our major sponsor again this year. Thank you also to our wonderful volunteers and the team from Warners Bay Lions Club for the yummy sausage sizzle. If you missed the Hunter Walk we still have plenty of Walks this year. Check out our website for venues and registration.

You can view more pictures from the day on the MND NSW Facebook page. <http://fb.me/mndnsw>

*Thank you to our Walk  
to d'Feet MND Hunter  
event  
sponsors*



## Save the date

Join us at a 2017 Walk to d'Feet MND. The name of this event reflects the hope and inspiration these special days provide for the MND Community. Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with MND.

You can create your own online fundraising page to raise funds in an individual name or a team name.

30  
Apr

### Walk to d'Feet MND Forbes

Lions Park  
Forbes

Supported by



We Serve

Register now

21  
May

### Walk to d'Feet MND Tweed Heads

Chris Cunningham Park  
Tweed Heads

Supported by

KATE NUTT  
photography

Register now

25  
June

### Walk to d'Feet MND Canberra

Patrick White Lawns, Parkes, ACT

17  
Sep

### Walk to d'Feet MND Port Macquarie

Westport Park, Port Macquarie

Supported by



22  
Oct

### Walk to d'Feet MND Wagga Wagga

Apex Park, Wagga Wagga

Supported by



Les Gray Plumbing



5  
Nov

### Walk to d'Feet MND Sydney

Blaxland Riverside Park, Olympic Park Homebush

Supported by



For more information see <http://www.mndnsw.asn.au/get-involved/walk-to-dfeet-mnd.html>.

## Newcastle Italian Film Festival

This is the third year that a donation to MND NSW has been made from the Newcastle Italian Film Festival. This popular event is held annually in November, and we would like to thank organiser Nick Moretti for his fantastic support. Our thanks also to the sponsors of the event and to Don McMurray who attended on behalf of the Association at the recent presentation where a donation of \$13,500 was made from the 2016 Festival.



## Upcoming Government information sessions about the NDIS in NSW, ACT and NT

Run by the Australian Government, NDIS information sessions are designed to help people with a disability, as well as their families and carers, learn about the National Disability Insurance Scheme (NDIS).



The sessions will cover topics such as:

- What is the NDIS and how does it work?
- Am I eligible for the NDIS?
- What will happen if I am made eligible?
- What kind of support can I access through the NDIS?

The information sessions are also a perfect opportunity to bring your questions along and have them answered by experienced NDIA staff members.

Information sessions are scheduled from time to time in various areas of NSW, ACT and the NT. You can find out when sessions are scheduled here:

NSW: <https://www.ndis.gov.au/news/events/nsw>

ACT: <https://www.ndis.gov.au/news/events/act>

NT: <https://www.ndis.gov.au/news/events/nt>

## Independent Living Centre of NSW now called Assistive Technology Australia

Assistive Technology Australia at <http://at-aust.org/> is the new name for the Independent Living Centre of NSW. Assistive Technology Australia is a not for profit, community based organisation and it continues to provide impartial information, advice and training on assistive technology (aids and equipment).



## ALSUntangled review of Acuscope therapy

ALSUntangled reviews alternative and off-label treatments for people with ALS/MND. In their latest review they evaluate Acuscope therapy for ALS (in response to 395 requests).



Acuscope, also known as Electro-Acuscope, is a device that can deliver very low amplitude (micro-Amp) electrical stimulation to muscle.

The review found there is no clear mechanism of action that would be useful to people with ALS/MND and that, following the ALSUntangled review of trials and cases, Acuscope could not be endorsed for use to slow, stop or reverse ALS progression. You can read the full paper [here](#) and find out more about ALSUntangled here <http://www.alsuntangled.com/>

## Concert to support MND NSW

Thank you to Don McMurray who has again organised a musical concert to support MND NSW. The enjoyable afternoon included a variety of musical items and performances, with this year's concert raising \$2,223. Thank you also to MND NSW Ambassador, Patti Conway, who attended the event.



### Care for Carers Program commencing 16 May

*Care for Carers* is a supportive educational program conducted by MND NSW for those caring for a family member or partner with motor neurone disease. It is never too early to attend this informative and enjoyable program, which runs once a week for four weeks - Tuesday 16 May, Tuesday 23 May, Tuesday 30 May and Tuesday 6 June at the MND NSW Centre at Gladesville. There is no cost for you to attend but you will need to reserve your place. For more information and to read what last year's participants said about the program see <http://www.mndnsw.asn.au/all-events/living-with-mnd/183-care-for-carers-2017-wk1.html>.



### Living Well with MND Information Day - Forbes, Newcastle, West Ryde and Wollongong in 2017

*Living Well with MND* is an informative day for people living with motor neurone disease, their families and friends. You will be provided with a range of strategies to live well with MND and to maintain independence. You will also have the opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND. During 2017 you can attend *Living Well with MND* at the following locations:



18 May - Forbes

21 June - Newcastle

12 September - West Ryde

17 October - Wollongong

There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.

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## Upcoming Support Service events

Click to find out more.

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6

May

### Day of Hope and Remembrance

Homebush

This afternoon of hope and remembrance marks the beginning of MND Awareness Week.

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10

May

### Supporting NDIS participants Living with MND - South West Sydney for allied health professionals and care workers

Bossley Park

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16

May

### Care for Carers

Gladesville

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18

May

### Living Well with MND

Forbes

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8

Jun

### Supporting NDIS participants Living with MND - Western Sydney/Blue Mountains for allied health professionals and care workers

Springwood

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13

Jun

### Information Evening for people recently diagnosed with MND

Gladesville

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21

Jun

### Living Well with MND

Newcastle

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25

Jul

### MND Aware for health and community care professionals

Wagga Wagga

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15

Aug

### Information Evening for people recently diagnosed with MND

Gladesville

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See <http://www.mndnsw.asn.au/all-events.html> for all 2017 events.

### Familial MND families: Researcher wants to hear from you

Around 10% of people with MND have familial MND, and two-thirds of these individuals will carry a genetic fault in a currently known MND gene, such as C9orf72 and SOD1. If you are from a family with familial MND and there is a known genetic fault in the family, you are invited to participate in an interview with researcher Ashley Crook from Macquarie University who is undertaking a study investigating experiences of familial MND, receiving genetic information, and any subsequent decisions made such as whether to speak to a genetic counsellor or to have genetic testing. It is hoped that information from this research can guide the MND care and genetic counselling community on best practice guidelines for familial MND. See [here](#) for more information. This study has been approved by the Human Research Ethics Committee, Macquarie University.

### Exploring voice banking and message banking

A team of business students from the UTS Shopfront Community Program are working with MND NSW to explore voice banking and message banking technology, costs and complexity. The aim of the project is gather information that can be used to assist people with MND make choices about communication options. MND NSW had a very productive kick-off meeting on Monday 3 April with student consultants (L to R): Han, Tanushree, Hongbo, Harpreet and Yvette.








### Carnarvon Charity Golf Day

The Carnarvon Golf Club in Lidcombe hosted a Charity Golf Day in March with \$7,737.25 raised from the event donated to MND NSW. Despite the rain it was a fantastic day enjoyed by all who attended. Thank you to the organisers, the many sponsors, the Carnarvon Golf Club and everyone who attended and provided their support. Special thanks to Sharon Honeybrook and Kathy Knevitt (pictured) for their generosity of their time and talent.



## Upcoming community fundraising events

Click to find out more.

1 May	<b>Trek Together for MND NSW</b> Peru	
6 May	<b>Run MND</b> Sutherland 2 Surf	
7 May	<b>MND Week 7-13 May</b> Various across NSW and ACT	
14 May	<b>Darwin2Perth4MND</b> Bob Montgomery cycling from Darwin to Perth	
21 May	<b>Mid North Coast Open Charity Dice Run</b> Ride open to all makes and models of roadworthy bikes	
26 May	<b>Riddla Golf Day</b> Twin Creeks Golf & Country Club	
30 May	<b>High Tea for MND</b> Quakers Hill Veterinary Hospital	
21 Jun	<b>Fund Raiser</b> Woy Woy Leagues Club	
22 Jun	<b>Fashion Parade</b> Northbridge, Mosman and Macquarie Centre	

**BINGO with BALLS - 7.30pm every Tuesday night at STONEWALL**  
175 Oxford Street, Darlinghurst. Charity donation to MND NSW.

Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? Read here about how to get involved <http://www.mndnsw.asn.au/get-involved/fundraise.html>

### Introducing... Monica Fabiani

#### Supporter Liaison Officer

Hello. I am excited to be joining the team at MND NSW Gladesville. I have many years' experience in the customer service industry, including several years as carer and am very passionate about people and life. I am looking forward to providing quality support for those who support our Association in any way I can. I'm also looking forward to meeting our supporters on this journey for such a special cause.



### Introducing... Anna Fisher

#### Coordinator of Support - Western Sydney and Blue Mountains

Hi everyone. I am delighted to be working with members to implement and coordinate their National Disability Insurance Scheme (NDIS) plans. I have recently moved down from the North Coast of NSW (where there is usually lots of heat and sunshine, but of late there has been terrible floods) to live in the Blue Mountains. I have over sixteen years of experience working in disability, aged and community services in a variety of roles including case manager, support coordinator and support planner. I am originally from New Zealand (hence I love mountains) and have qualifications in psychology and physical education.



### Positive results for PMX205 in mice with SOD1

A study published in the British Journal of Pharmacology in March, led by University of Queensland researchers Associate Professor Trent Woodruff and Dr John Lee, found the drug PMX205 extends the life of mice with a SOD1 mutation, when administered before or during very early disease onset. Studies are now underway to determine the safety of PMX205 before human testing. More information [here](#).



## A decade in review

by Gina Svolos

Manager Support Services, MND NSW

Welcome to this edition of e-news. Late last year I celebrated my ten years of working at MND NSW. Such a milestone has caused me to reflect on the changes that I have seen occur over this time, both within MND NSW and in the wider

MND community. I do recall being told when I started in 2006 that, following the discovery of the SOD1 gene in the early 1990s, there had been very few new findings about motor neurone disease in the 15 years following. However, since then we have heard about multiple genes discoveries that are informing researchers about MND. There are now also many drug trials around the world and researchers are very hopeful the findings will assist in the clinical management of MND.



MND NSW has also continued to develop over this time. The Association provides more and more targeted information in print, web and video formats and is active on social media platforms such as Facebook. We have greatly increased the range and stock of assistive technology items the Association provides at no charge to members (we used to call this 'equipment' a decade ago!) and we have increased our MND Advisor staff as the number of people joining MND NSW has increased. We continue to offer support groups and education programs for people living with MND and we work hard to keep up with the continuing changes that occur in services provided in the community. From a service perspective, the biggest changes in the past ten years are those currently occurring in both aged care services and disability services through government restructure.

In February this year there was a further change to how aged care services are delivered. Home Care Packages are now centrally managed and once a person has a package allocated they are able to

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select the provider they prefer. In the past the provider actually had the package and there wasn't any choice when one became available. For further information about aged care services see the My Aged Care Website [www.myagedcare.gov.au](http://www.myagedcare.gov.au) or phone 1800 200 422.

For people under 65 years, the National Disability Insurance Scheme (NDIS) continues to roll out. From July 2017 the second half of the State will start to transition to the NDIS. This includes Illawarra Shoalhaven, Mid North Coast, Murrumbidgee, Northern NSW, South East Sydney, Sydney, Western NSW and Far West NSW.

We have been working with government to try to ensure that the needs of people with MND are catered for in their NDIS plans. Our MND Advisors are available to assist you prepare for your planning meeting and may also be available to attend the planning meeting in person or over the phone. We encourage you to contact your MND Advisor as soon as you have been contacted by NDIS staff to discuss the best way to approach this planning process. We have learned a lot from this first year and are happy to share with you what we know to help you ensure a smooth transition to the NDIS.

MND NSW is a registered provider with the NDIS for Support Coordination and, through FlexEquip, Assistive Technology. For NDIS participants MND NSW offers:

- Coordination of Support - this service provides people with assistance to implement their NDIS plan and includes assisting them to find services, addressing any issues with their plans and assistance to work with the NDIA to review their plans as their needs change. We will be extending the areas we provide this service to the Illawarra, South East Sydney and Sydney from July 2017. We currently have Coordinators of Support working in the Hunter, Central Coast, Western Sydney, South West Sydney and Northern Sydney areas. This service needs to be funded in your NDIS plan if you would like to access it.

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- FlexEquip rents either individual equipment items (quarterly or yearly) or a bundle of equipment items. The bundle allows for the provision of the range of items available from FlexEquip for a 12 month period. Our assistive technology provides for the general needs of people with MND. Any individualised equipment will need to be sourced elsewhere. Once a bundle has been included in a person's plan the referring therapist can continue to request equipment through our website [www.flexequip.com.au](http://www.flexequip.com.au). If you currently have equipment from MND NSW FlexEquip service you will need to have this provided for in your NDIS plan.

With so much change happening all the staff at MND NSW continue to strive to ensure that people with MND receive the supports and services they need. We are here to assist you directly with this process and also continue to work behind the scenes to represent the needs of people with MND to government.

We appreciate your feedback to help us continue to do this in these changing times.

*Gina Svolos*

*Manager, Support Services*

### **MND support groups and coffee mornings**

MND support groups and coffee mornings provide the opportunity for people living with motor neurone disease to meet together regularly to chat and learn from each other. Often, a guest speaker is invited to the meeting. Guest speakers include health workers who know about motor neurone disease or a person with expertise in a topic that may be of interest to the members of the group.

Support groups and coffee mornings are located in city, regional and rural areas of NSW, in the ACT and on the Gold Coast Queensland. Find out more [here](#) or speak with your MND Advisor.



# Motor Neurone Disease Association of New South Wales

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**Information Resources  
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**...and many valued  
volunteers**