THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

March 2015

mnd New South Wales

FORUM

Around the regions

In the country's capital

> *"I appreciated the session on learning how to get the house ready and changes that need to be made"*
>
> *"Not having to travel to Sydney was a bonus"*
>
> *"I was made aware of all the help available"*

On Thursday 19 February MND NSW held a *Living well with MND* day, in Canberra, for people living with MND, their family and friends. Almost 50 people attended from the ACT and southern NSW.

Dianne Epstein, MND NSW Regional Advisor for southern NSW and the ACT, did a great job of encouraging members and their families to travel the distance to attend the event. They were rewarded with excellent speakers, many from the ACT Multidisciplinary MND Clinic. Thank you to Andrew Skeels, Medical Director, Clare Holland House; Rachel Heatley and Trang Nguyen, Speech Pathologists, Canberra Hospital; Teena Bacon, Occupational Therapist and Jasmin Jamieson, Physiotherapist, Community Rehabilitation, ACT Health; Jenny Cahill, Clinic Coordinator, ACT Multidisciplinary MND Clinic; and Rosanna Doherty, Nurse Specialist, Goulburn Community Health Centre. The last session of the day was interactive, with participants sharing tips and tricks on managing symptoms. The whole day was a great success.

Our next regional *Living well with MND* day for people living with MND, their family and friends will be held in the Illawarra on Thursday 17 September.

Link and Learn - 26 and 27 March in Berry

Link and Learn is a two day residential program that aims to support carers to give the best possible care at home for the person with MND, while taking some time out for themselves and meeting others in a similar situation. Participation in the program to be held in Berry on 26 and 27 March, including meals and accommodation, is free for carers living in southern NSW. If you are interested in attending contact the MND Info Line ph. 1800 777 175 or speak to your regional advisor.

Talk-Link Grief and Loss by telephone - 21 April

Carers NSW and MND NSW have partnered to offer the *Grief and Loss Talk-Link* program to former carers of someone with MND. This is a six-week telephone program (one hour per week), for adults, facilitated by professional counsellors. Registrations for the program commencing 21 April, close on 16 April. Register early as places are limited. For more information or to register contact the Carers NSW Carer Line ph. 1800 242 636.

MND Week 2015

3 May to 9 May 2015

Cornflower Blue Day - Friday 8 May 2015

MND Week is fast approaching and we are looking for lots of volunteers to sell merchandise and to collect donations at designated venues such as railway stations and shopping centres on Cornflower Blue Day, Friday 8 May 2015.

You can also support MND NSW by selling merchandise at your work place, or at a venue such as your local sporting or social club; or by organising a fundraising event during MND Week.

Please help in any way you can. Together we can make this the biggest and best MND Week yet!

For more information contact Kym Nielsen (Fundraising Manager) or Anne Jones (Supporter Liaison Officer) ph. 02 8877 0999 or kymn@mndnsw.asn.au and annej@mndnsw.asn.au

Reports and research update from the International Alliance and the 25th International Symposium on ALS/MND

.......see pages 8-10

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.

You, your family and your friends are warmly invited to

Day of Hope and Remembrance

Saturday 2 May, 2015

1.30pm to 3.30pm

Soka Gakkai International Centre, 3 Parkview Drive, Sydney Olympic Park

This is an afternoon of hope and remembrance for all those whose lives have been touched by motor neurone disease, people living with MND, family, friends, supporters, and volunteers and those working with MND.

There will be a candle lighting ceremony to represent the hopes of people affected by MND and to remember those who have lost their life to MND.

The MND March of Faces banners will be on display.

Afternoon tea and light refreshments will be served.

For catering purposes RSVP by 28 April
by contacting reg@mndnsw.asn.au or Ph. 02 8877 0999 or Freecall 1800 777 175

Walk to d'Feet MND
See page 12

Introducing...

Nicole Smith - FlexEquip Equipment Assistant

Hello everyone. I have led a varied work life: everything from a taxation officer, commercial real estate agent, through to running my own wedding car company (only the best with Rolls Royces thank you). A few years ago though, a friend of mine was diagnosed with MND, and it led me on a whole new career path starting as a volunteer and then as professional home carer. When the work opportunity at MND NSW came up I had to try and grab it as I had already met some of the wonderful people from the Association and had attended some MND NSW courses. I have two dogs, a cat, a husband and a precocious daughter aged six years, so life is busy. I have greatly enjoyed my first month at the Association and look forward to meeting many of you on the phone.

Motor Neurone Disease Association of New South Wales

PATRON
His Excellency General The Honourable David Hurley AC DSC (Ret'd)
Governor of New South Wales

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

Auditor
Walker Wayland NSW

Solicitors
Mallesons Stephen Jaques

MND NSW BOARD

President
Phil Bower

Vice Presidents
Alex Green, Roger Henshaw

Secretary
Anita Richter

Treasurer
Lara Kirchner

Board Members
Amy Critchley, Kirsten Harley, Nick Shaw and 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
admin@mndnsw.asn.au
mndnsw.asn.au

ABN 12 387 503 221

Chief Executive Officer
Graham Opie

Office Coordinator
Petra Sammut

Admin Assistant/Receptionist
Arja Aladjadjan

Accountant
David Radford

Fundraising Manager
Kym Nielsen

Supporter Liaison Officer
Anne Jones

Fundraising Assistant
Amanda O'Farrell

Fundraising Assistant
Ellen Hibbert

Family Support Manager
Gina Svolos

Regional Advisors
Madeleine Bowman, Chris Carroll, Dianne Epstein, Jo Fowler, Ann McCutcheon, Eileen O'Loghlen, Melanie Oxenham, Kim Sinclair and Deb Ward

Information Line Advisor
David Wallace

Education and Carer Support Coordinators
Kristina Dodds, Kate Maguire

FlexEquip Coordinator
Maree Hibbert

FlexEquip Assistant
Nicole Smith

FlexEquip Support Officer
Julie Becke

Information Resources Coordinator
Penny Waterson

***And…many valued volunteers** including Kevin Langdon OAM, MND NSW Ambassador and past President of the Association. Kevin has advocated, fundraised and raised awareness of MND, since his diagnosis with a slowly progressive form of the disease in 1988.*

A Message from the CEO

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

It's February, and already we are well into 2015. Our education and information activities are underway and a full update of what has happened can be found throughout this edition of *Forum*. What is on the horizon can be found at mndnsw.asn.au.

In a recent equipment report we provided to NSW Ageing Disability and Home Care I was astonished at the number of items of equipment we have provided since July 2012. 5,742 items were loaned to over 700 people, all free of charge. If each item was to be bought, the cost would be over $6.2million to individuals. Maree Hibbert, MND NSW FlexEquip Coordinator and her staff do an outstanding job and work extremely hard to get equipment to people in the shortest possible time.

The Association's services are made possible through donations and fundraising events such as our Hunter Walk to d'Feet MND which took place in early February. A record 1050 people turned up and raised over $53,000. Thank you for your support. The 2015 Walk to d'Feet MND calendar is on page 12. Encourage your family, friends and colleagues to participate in this worthwhile cause.

Bequests are another key area, where people we have come into contact with, have made a provision for MND NSW in their Will. For further information see page 11.

Government disability and aged sector reforms affecting many people living with MND

Government reforms in the disability and aged care sectors are happening across Australia:

- On the disability front, the National Disability Insurance Scheme (NDIS), for people aged under 65 years, commenced in the Hunter in July 2013, and in the ACT in July 2014. For most people, the timeframe for moving to the NDIS is several years away, with full-scheme rollout across NSW expected between 2016 and 2018. However, changes to services, in anticipation of the full roll-out, are already happening across NSW and in the ACT.
- On the aged care front, affecting people aged 65 years and over, government changes to funding of services commenced in 2012. Of particular interest to people living with MND are changes to services that enable a person to continue to live at home with community support (for example personal, home and respite care services) and with access to equipment items. The Home Care Packages Programme commenced on 1 August 2013, replacing the former packaged care programmes – Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) packages and Extended Aged Care at Home Dementia (EACHD). On 1 July 2015, the new Commonwealth Home Support Programme (CHSP) will begin, encompassing two programs that have previously funded services frequently accessed by people living with MND and their carers - the Commonwealth Home and Community Care (HACC) Program and the National Respite for Carers Program (NRCP). Further changes are planned in the coming years.

Aged and disability organisations do not get much notice of changes, for example, sector briefings the for aged care funding changes that commenced on 1 July 2014 were only held five weeks before implementation (from 27 May 2014). Sector briefings for the changes to take effect from 1 July 2015 will only commence from 3 March 2015.

Underpinning this structural change is a 'conceptual' and practical move to individualised funding (NDIS) and consumer directed care (aged care). Essentially, this provides the person with the disability or the person aged 65 years and older with more choice and flexibility in what supports they access and in who provides the services. This would be a good thing for people living with MND, **but only if the funding packages for people with the disease are adequately funded, responsive and flexible to meet changing needs, including care coordination and equipment needs**.

As a result of the structural change in disability and aged care, the local services commonly accessed by people living with MND, including local health, community and aged care services, are already undergoing significant change. These include changes to the service provided, who the services are provided to and how those services are funded. This is occurring now, across NSW and the ACT, even before the full NDIS roll-out and the planned aged care changes are implemented.

Most unfortunately, there are already some reasonably large gaps and road bumps that need to be ironed out. One such road bump that affects many people with MND is the current rapid reduction in case management services (see page 4 of this edition of *Forum*).

We are already advocating with State and Federal governments and we will keep you updated with our progress.

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

Family Support Team

During the past decade MND NSW has developed strong working relationships with local Community Option case management services, often forming multidisciplinary teams that are able to respond to the quickly changing needs of a person with MND in a timely manner. Because of the current changes to disability and aged care funding happening now across NSW and the ACT (see page 3) we are experiencing a rapid reduction in the availability of case management services. The changes to the availability of case management services will have a particularly adverse effect on people with MND aged 65 years and older as government reforms to aged care roll-out.

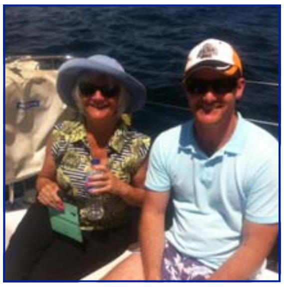
Additionally, as a result of the disability and aged care structural change, other local services commonly accessed by people living with MND, including local health, community and aged care services, are already undergoing significant change. Our regional advisors work hard at keeping up with these changes so they can help guide you to the most appropriate services. However, information about changes is often scant and sometimes we only find out about eligibility changes to a local service, or in fact, if the service is still providing services, when we make a referral to that service.

Our regional advisors pride themselves in doing their job well and are committed to getting our members access to the best quality of care possible. However, with the changes in both the aged and disability sectors, our regional advisors will be spending much more time than previously needed guiding people through these changes and helping them connect with appropriate services as well as keeping up-to-date with changes to these local services. So if your regional advisor has not been in touch with you this may be the reason why. If you need to talk with your regional advisor please contact them to let them know. You don't need to wait for the regional advisor to be in touch with you. You can also contact the MND Info Line if your regional advisor is unavailable as the Info Line may be able to assist in the meantime ph. 1800 777 175 or email infoline@mndnsw.asn.au

Members rights, responsibilities and feedback

Just a reminder that we do value your feedback whether this is a compliment or a complaint. MND NSW has a brochure that informs you about your rights when using MND NSW services and also your responsibilities. Information is also provided on how you can give us feedback. See our website for further information or contact the MND Info Line ph. 1800 777 175 and ask for a copy of the brochure to be sent to you.

Events and programs



Nine of our carers and past carers (including Suzanne Gooley and Benjamin Gooley pictured right) had a lovely day sailing Sydney Harbour on 15 February. Carers came from as far away as Newcastle for the day. Each year Sailors with disABILITIES offer a sail day to MND NSW for carers and past carers.

Also in February, we had a *Living well with MND* day in the ACT for 50 of our members and families. Some excellent speakers were a part of this day and we thank them for their time.

Our *Link and Learn* for carers in southern NSW will be held in Berry in March and our *Care for Carers* program at the MND NSW Centre at Gladesville commences in May.

Once again we will be having our *Day of Hope and Remembrance* to mark the beginning of MND Week and we hope many of you will be able to attend at Sydney Olympic Park on Saturday 2 May.

There are also several events for our past carers in March and April. We have a lunch on 23 March on the Central Coast and another one at Gladesville on 30 March. These lunches are for family members or friends who have faced the unique challenges of caring for someone with MND who has died in the last 12 months. Please contact us if you would like more details or would like to attend. We also are working with Carers NSW to have a *Grief and Loss Talk-Link* for past carers staring on 21 April. All of these events provide our past carers with the opportunity to meet others who have also been carers.

MND NSW also has a commitment to educating health and community care professionals about MND. In June we are running two workshops for these professionals. The *CommSPOT* workshop on 17 June is specifically for speech pathologists and occupational therapists who support people with MND with their communication and computer access goals. The bi-annual *MND Special Interest Group* workshop will be held on 18 June. At this event, clinicians and community care professionals will be updated with practical information and network with fellow practitioners. The theme of the day is 'engage'.

For more information about events, visit mndnsw.asn.au, speak with your regional advisor or contact the MND Info Line ph. 1800 777 175 or email infoline@mndnsw.asn.au

Gina Svolos
Manager, Family Support

If your regional advisor is unavailable the MND NSW Info Line may be able to assist ph. 1800 777 175 or email infoline@mndnsw.asn.au

FlexEquip

Referrals and loans update

During the past 12 months FlexEquip received 2081 referrals for equipment from health professionals. Of these referrals, FlexEquip had been able to provide and ship over 1820 items of equipment throughout NSW and the ACT.

Purchases

This year FlexEquip has spent more than $238,000 on new equipment and now has 1985 items in the FlexEquip Equipment Pool. New purchases throughout the year were made to help reduce the waitlist for high demand items including power wheelchairs, iPads preloaded with communication applications, raiser recliner armchairs and hoists. However, demand for power wheelchairs continues to be very high and extended waitlists remain for these items.

During this time FlexEquip has also paid for the hire of 81 homecare beds, with 17 of the beds hired every month reserved for regional areas.

Return or repair of equipment

If you are no longer using a FlexEquip equipment item or if your equipment needs repair please contact FlexEquip so we can make arrangements for return or repair - phone 02 8877 0999 or Freecall 1800 777 175 or you can email flexequip@mndnsw.asn.au

Staff changes

Just after Christmas, Nicole Smith commenced in the role of FlexEquip Equipment Assistant. Nicole will be arranging for equipment to be delivered and picked up from you so you may receive a call from her if you have a referral for equipment. Nicole works Tuesday to Friday and you can read more about her on page 2 of this edition of *Forum*. Also in January we farewelled Tom Giardina, who resigned from the other FlexEquip Equipment Assistant position after four years with the Association. We wish Tom well for the future and will fill this position in the coming weeks.

FlexEquip equipment range lists online

FlexEquip equipment range lists are now available for viewing or download at flexequip.com.au under the Equipment Range tab. There are two lists; one for standard equipment and one for communication and computer access equipment. Requests for equipment are not processed until a written referral is received for the item from a health professional who has assessed your needs and requirements.

Provision of equipment is made on a priority of need for members. This information is obtained from the health professional who has assessed your needs and submitted the referral. However, if your needs change while you are waiting for equipment to be provided, contact your assessing health professional or your MND NSW Regional Advisor to let them know so they can follow up with FlexEquip staff.

What is a raiser recliner armchair?

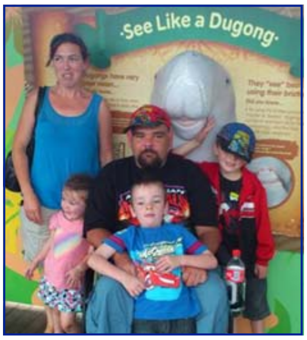
A raiser recliner armchair or lift chair is an upholstered electric armchair. The legrest will return to its tucked in position when the armchair is the upright position. In the raised or standing position the armchair lifts the user upwards and slightly forward to a near upright position which helps the user to the standing position.

These armchairs can be placed in the main living area of the home. They can be used for naps rather than always using a bed or power wheelchair. The armchairs come in different sizes and it is recommended that an occupational therapist show you the correct and safe use of the armchair before you use it, so as to minimise the risk of any falls or injury to you or others.

If you think a raiser recliner armchair would assist you please contact your health professional for more information.

Maree Hibbert
FlexEquip Coordinator

If you would like more information about flexible respite funding speak with your MND NSW regional advisor.



The Teasdale family (pictured left) - Tina, Brenton and their children - travelled to Sydney and had a fabulous and memorable day at the Sydney Aquarium. This was a special break away for the family with flexible respite funding assistance from MND NSW.

Lunch for bereaved carers

From time to time MND NSW hosts a lunch and get together for people who have experienced bereavement during the last twelve months. These lunches offer an opportunity for you to reconnect with old friends from MND NSW and to meet others who have had similar experiences. After lunch there is usually a short talk and discussion about some of the feelings you may be experiencing during bereavement and ways that you may choose to manage these. See the Family Support Calendar page 7 for upcoming dates.

Around the support groups

Central Coast

Our group meets on the first Thursday afternoon of every second month at Narara. We are very fortunate to have a great line up of guest speakers willing to share their knowledge with the group and help with any queries. Recently, Lauren Curtis, physiotherapist from the CORT team spoke about the importance of falls prevention and provided the group with some very helpful and practical advice. CORT is a community-based Allied Health Team working for Central Coast Health and is available for people living at home on the Central Coast who have been diagnosed with a progressive neurological disorder, and who require therapy from two or more allied health professionals.

We have also met Dr Sian White from the Carer retreat at Gosford Hospital. This wonderful local resource is available to all carers visiting the hospital who need a quiet, supportive space to take some time out away from a hospital bedside. At our January meeting Gina Svolos, Manager Family Support, provided an update on Association activities including progress of the NDIS in the Hunter area.

The group maintains a focus on supporting people living with MND and their carers on the Coast, so we ensure there is plenty of time to share ideas, information and helpful tips and tricks over a casual cuppa and afternoon tea.

Meetings for the rest of this year will be on 4 April, 4 June, 6 August, 1 October and 3 December from 1pm till 3pm at Gosford/Narara Neighbourhood Centre. It is a lovely spot with a very welcoming atmosphere and our group is fun, relaxed and with a strong sense of local community. We hope to see you there.

Deb Ward
Regional Advisor

Western Sydney

During 2015 we will be meeting on Tuesday afternoons from 1.30-3.30pm at Kingswood and members and their families are most welcome to attend. We have a small but committed group who are very friendly and supportive. This year we plan to have a mix of guest speakers and topics for discussion. Our first meeting in February will explore ways of creating a personal history or life story. Coming up later in the year we have an occupational therapist coming to talk about managing at home, and we will cover other topics such as the role of palliative care teams and research updates. Every meeting is also a chance to hear news from the Association and to spend time catching up with each other and sharing experiences of living with MND. The venue at Kingswood is easy to access and has plenty of parking. If you would like to know more about the group you can contact me on the details below.

Melanie Oxenham
Regional Advisor

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

Support Groups and Coffee Mornings

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

Campbelltown - *Ann McCutcheon | annm@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 - *Melanie Oxenham ph. 4731 6168 | melanieo@mndnsw.asn.au*

REGIONAL AND RURAL

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

Central Coast - *Deb Ward | 1800 777 175| debw@mndnsw.asn.au*

Central West - *Melanie Oxenham ph. 4731 6168 | melanieo@mndnsw.asn.au*

Griffith/Wagga Wagga - *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'Loghlen | 4921 4157 | eileeno@mndnsw.asn.au or*
Kim Sinclair | 4985 5022 | kims@mndnsw.asn.au

North West (Tamworth) - *Madeleine Bowman | 8877 0905 | madeleineb@mndnsw.asn.au*

Northern Rivers - *Chris Carroll | 0421 252 455 | chrisc@mndnsw.asn.au*

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

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

Noticeboard

ALS Quest

You are invited to participate in a new research project that is looking for risk factors that might precipitate motor neurone disease (MND). An online anonymous questionnaire asks a series of questions about you that may give clues as to what factors trigger MND. Both people with the sporadic form of MND and people without MND are eligible to complete questionnaire. This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. The questionnaire, designed by Dr Roger Pamphlett at the University of Sydney, and instructions on how to complete it can be found at alsquest.org

Understanding health apps

Health Apps- a Toolkit to Help You takes a comprehensive approach to helping people find and use tried-and-tested health apps. It walks the reader through each step of a journey towards getting started with health apps. The Toolkit identifies the main pitfalls with health apps and educates on how to overcome these problems. Available at myhealthapps.net/

CareSearch: My Information Kit

CareSearch is an online resource providing relevant and trustworthy information and resources about palliative care, including information for carers. *My Information Kit* is a new feature of the CareSearch website. It allows you to choose your own individualised set of factsheets for printing out or for reading online. The factsheets provide information on a range of issues typically faced by people living with a condition such as MND. The website has been funded by the Australian Government as part of the National Palliative Care Program and developed by Palliative Care Australia. caresearch.com.au/caresearch/tabid/1594/Default.aspx

Voting from home for the NSW State Election 28 March 2015

The iVote system is a form of voting using a telephone or the internet at a location of your choice. It is managed by the Electoral Commission NSW and is available to people who:

- have literacy needs
- have a disability
- live more than 20km from a polling place; or
- will be outside NSW on election day.

To use iVote you must register between now and 1pm Saturday 28 March. Your iVote number will be sent to you.

You can then use the iVote system to vote at a time convenient to you between 8am Monday 16 March until 6pm Saturday 28 March. For more information visit votensw.info or phone 1300 135 736.

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

CARE FOR CARERS - Register now
Tuesday 12, 19, 26 May and 2 June

Once a year we offer *Care for Carers* at the MND NSW Centre at Gladesville. It is never too early to attend this informative and enjoyable program, which provides the opportunity for carers to hear from a range of allied health professionals with expertise in MND.

> *"So what did I take from this valuable time? I met and have remained friends with other carers travelling my journey. I learnt to feel confident and good about being a carer for my husband. I learnt the importance of taking care of myself. I learnt to be proactive in putting in place all the support available to my husband and myself, which enabled us to have the best quality time together. I learnt there is so much support available within my community and being too proud to ask or accept it was not life-giving to this illness. I learnt there is still beauty and joy to travel the uncertain road of MND, when you are equipped to traverse this journey with support and knowledge."*
>
> Dianne Vogt Care for Carers 2013

To find out more about this program ph. 02 8877 0999 or Freecall 1 800 777 175 or email reg@mndnsw.org.au

Family Support Calendar

26-27 Mar	**Link and Learn** | *Berry*
23 Mar	**Lunch for bereaved carers** | *Narara*
30 Mar	**Lunch for bereaved carers** | *Gladesville*
21 Apr	**Grief and Loss Talk Link, week 1** | *by phone*
28 Apr	**Information Evening for people recently diagnosed with MND, family and friends** | *Gladesville*
2 May	**Day of Hope and Remembrance** | *Sydney Olympic Park*
12, 19, 26 May, 2 Jun	**Care for Carers** | *Gladesville*
16 Jun	**Information Evening for people recently diagnosed with MND, family and friends** | *Gladesville*
17-18 Jun	**CommSPOT and MND Special Interest Group workshops for health and community professionals** | *West Ryde*
27 Jul	**Ask the Experts** | *West Ryde*

For more information contact the MND NSW Info Line ph. 1800 777 175. or infoline@mndnsw.asn.au

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.

International Meetings, Brussels, December 2014

The annual International ALS/MND meetings are organised by the MND Association of England, Wales and Northern Ireland in partnership with the International Alliance of ALS/MND Associations. Experts from research and medical communities as well as ALS/MND associations and people living with ALS/MND come together each year to share new understandings about ALS/MND to improve the lives of all people living with ALS/MND. All share a common goal to move us closer to finding effective treatments and ultimately a cure. The Symposium is preceded by the International Alliance annual meeting, an Ask the Experts session and the Allied Professionals Forum. In 2014 the meetings were held from 2 to 7 December and hosted by Alliance member ALS Liga Belgium in Brussels.

22nd Meeting of the International Alliance of ALS/MND Associations

(extract) by Carol Birks, National Executive Director MND Australia and Chairwoman International Alliance of ALS/MND Associations

Over 100 delegates from 26 countries across six continents gathered for the 22nd meeting of the International Alliance of ALS/MND Associations to share initiatives and strategies for supporting people living with ALS/MND. In 2014, the worldwide social media phenomenon known as the ALS/MND Ice Bucket Challenge created global awareness of the disease and boosted the fundraising income of many member organisations. Rachel Patterson, General Manager of the Alliance, reported that Alliance members alone received a total of US$164 million! As a result, the first topic of discussion at this year's meeting was how this action began, how it spread, and what next steps the Alliance and its members could take to leverage the challenge in the future. Rob Goldstein from ALS Therapy Development Institute kicked off the discussion with his presentation *How Water and Ice Made Supporting ALS Research "Cool'.* Rob suggested that the number one reason why the Ice Bucket Challenge was so successful was that it was a truly organic movement with no organisational ownership. It was about the people; easy, fun and involved a video that lived on in social media.

Awareness, Advocacy, and Service Challenges

Where to invest funds and how the decisions are made was a key theme of the Alliance meeting. According to Sally Light, CEO, MND Association of England, Wales and Northern Ireland, received £7 million from the Ice Bucket Challenge so they decided to survey clients and seek input from board members to assist with decision making. 88% of clients who responded said they felt the funds should be spent on research, care services and educating health professionals.

Yumiko Kawaguchi from the Japanese ALS Association (JALSA) gave a talk on their decision-making process, which also included outreach to its donors and clients. In total the organisation received the equivalent of US$318,000 and similar to others, the feedback they received was to invest primarily in ALS/MND research.

Challenges to Providing Services

Many considerations impact on Alliance member association ability to reach and provide support services to all people living with ALS/MND such as lack of awareness, delay in diagnosis, access to services and the cultural, language, ethnic and other differences between people within their country's borders.

Steve Bell, MND Association of England, Wales and Northern Ireland, presented on *Red Flags for MND: A Step Towards Earlier Diagnosis and Efficient Referral* a new information tool for GPs and the primary healthcare team to help reduce inaccurate referrals and therefore reduce the time to diagnosis.

According to Efrat Carmi, CEO of IsrALS (Israel), only 4% of the people living with MND they support are ethnic Arabs. Reaching the large Arab population in Israel has been a major focus over the last few years. They engaged an Arab social worker who can "literally walk from town to town" within the Arab community. Now as a result of this effort, IsrALS is supporting twice as many people living with MND who are Arab as it was before it began its new outreach effort. In addition IsrALS recently launched a version of its website and corresponding social media channels written entirely in Arabic.

National and Regional ALS/MND Registries

Craig Stockton, MND Scotland, and Janet Nash, MND Australia presented on the role of registries, appropriate ways to set them up and how to ensure optimal registrations. In Scotland, they found that applying a comprehensive approach of auditing medical records and reaching out to people living with MND was the most effective approach to optimal registrations. Janet reported on the success of implementing an opt-out registration process in Victoria and the plans to extend this nationally. She also highlighted that data from registries supports research, informs advocacy and provides hope to people living with MND and their families.

Partnerships Update

The cornerstone of the Alliance is its partnership and mentoring program. Kiki Qu, MND Taiwan,

(Continued on page 9)

If you are caring for someone living with MND on the South Coast, why not join us for Link and Learn at Berry on 26 and 27 March. (See page 1)

International Meetings, Brussels, December 2014 (cont'd)

(Continued from page 8)

reported on preparations for an inaugural Asia Pacific ALS/MND Conference to be held in Taiwan in April 2015. The aim of the meeting is to increase the communication and exchange of information between existing ALS/MND organisations and encourage and support the development of new ALS/MND associations in the Asia-Pacific region.

Links - 22nd Meeting of the International Alliance of ALS/MND Associations
PDFs of presentations from the meeting
alsmndalliance.org/2014-meetings

Ask the Experts

The International Meetings offer the host organisation a unique opportunity to invite international ALS/MND experts to provide updates to people living with ALS/MND in their region. ALS Liga Belgium invited three renowned experts to present on three very different topics and to take questions from the audience. The program included:

- Professor Orla Hardiman, Ireland - Clinical Trials from Mouse to Man: The Many Pitfalls of Translating Promising Studies
- Professor Leonard Van Den Berg, Holland - Update on Project MinE – 'Make it yours' initiative
- Dr. Lucie Bruijn, ALS Association, USA - Research Opportunities as a Result of the Ice Bucket Challenge

Links - 2014 International Ask The Experts
Video of the session youtube.com/user/mndnsw

12th Annual Allied Professionals Forum

The Allied Professionals Forum enables the sharing of ALS/MND care and support innovations to help guide practice worldwide. Over 250 delegates attended to hear 18 presentations covering a wide variety of topics.

Links - 12th Annual Allied Professionals Forum
Videos of the session youtube.com/user/mndnsw

Report on scientific highlights of the 25th International Symposium on ALS/MND, Brussels

by Dr Bradley Turner, Florey Institute of Neuroscience & Mental Health, University of Melbourne

Recipient of the Zo-ee MND Research Grant, 2014

The international MND community assembled at the capital of Europe to present, share and debate the latest and greatest in MND research progress in December 2014 over a Belgian hot chocolate and waffle. The scientific program involved a classic mix of genetics, cell biology, therapeutics in development, while new insights into C9ORF72 and iPSCs dominated the scene.

The conference was opened by Alfred Sandrock (Biogen, USA) who shared some interesting lessons learnt from the recent dexpramipexole trial in MND. He pointed out 4 challenges for MND drug trials: substantial clinical variability, underlying biological variability, inability to measure response to drug and limited measures of disease progression. Alfred then proposed 4 potential solutions to conduct better clinical trials in MND: using software to predict disease progression and grouping patients accordingly, grouping according to genetics, grouping according to biomarkers (although lacking validation) and accelerating the drug testing pipeline from the Petri dish straight to patient. The importance of biomarkers (biological markers used to track MND onset and progression) was nicely affirmed when our own Matthew Kiernan (Sydney) received the prestigious Forbes Norris Award for his contributions to developing the TMS test for MND, working together with Steve Vucic. Congratulations Matthew!

In sessions dedicated to C9ORF72 or C9, the most common MND gene, fascinating new biology was unravelled. In MND, the C9 gene becomes massively repeated and it is presently unclear whether the gene is: "switched off" or "turned on", leading to toxic gene products such as RNA or protein. The consensus from speakers was that abnormal C9 proteins build up in nerve cells in MND. Laura Ranum (USA) outlined that C9 pathology in MND resembled other diseases such as spinocerebellar ataxia and myotonic dystrophy in which "gene therapy" is excitingly close. Thus, gene therapy to correct abnormal C9 is likely to be a realistic pathway to potential treatment in MND. In the world-wide race to generate a relevant C9 mouse, Clotilde Lagier-Tourenne (USA) revealed her mouse developed some mild symptoms at 1 year of age, suggesting C9 mouse models are imminent and should drastically speed up development of C9 gene therapy for MND.

On the hot topic of Autophagy, a protective process which breaks down cellular garbage in motor neurons, Nirma Perera from our lab presented new findings on a drug which boosts autophagy. Surprisingly, treatment of MND mice with this drug hastened disease progression and build-up of garbage proteins, suggesting that manipulating autophagy has complex effects in animal models of MND. Kai Ying Soo (Australia) continued this theme by showing that autophagy is defective in Petri dish models of MND which can be corrected by an upstream protein called

(Continued on page 10)

Report on scientific highlights of the 25th International Symposium on ALS/MND, Brussels (con'td)

"Rab1". These results therefore warrant more development of approaches to manipulate autophagy in MND.

Kevin Eggan (USA), a legend of the stem cell field, made a strong case for the promise of iPSCs (MND patient-derived motor neurons programmed from stem cells) for drug discovery for MND. Using these cells, he identified an existing drug for epilepsy (retigabine) as a lead drug candidate for MND and a clinical trial is presently underway. Ruxandra Mutihac (UK) elegantly demonstrated that motor neurons grown from MND patients carrying abnormal C9 develop pathological signs of MND, suggesting they are tools to rapidly screen drug libraries in a high-throughput manner to find therapeutic agents. Manal Farg (Australia) concluded this session showing that abnormal C9 leads to nuclear stress and DNA damage in cells. This session illustrated further strides into C9 pathology and exciting progress in potential treatment targets resulting from application of iPSCs.

Francisco Barelle (Italy), perhaps considered the godfather of TDP-43, an important factor that causes MND, launched a session on Cell Biology and Pathology. He supported evidence that abnormal TDP-43 depletes motor neurons of proteins that build connections to muscle using fly models of MND. Clearing abnormal TDP-43 restored its function in flies, further validating approaches targeting TDP-43 in MND therapy development.

John Hardy (UK), a pioneer in the genetics of Alzheimer's disease, opened a session on Genetics. He outlined the wealth of genetic discoveries in MND in the last 7 years and importantly, how this established the link between MND and FTD (a common form of dementia sometimes occurring with MND). He proposed that motor neuron vulnerability in MND results from defects in breakdown of cellular garbage as informed by MND and FTD genes and this process should continue to be targeted in therapy development. Also noteworthy in the closing session, two new gene players in MND were announced: TUBA4A and an autophagy gene, reinforcing that defects in structural scaffolds and breakdown of garbage proteins play roles in MND.

In a session on Mouse Models, an impressive line-up of new and sophisticated genetically engineered mice carrying human MND mutations in profilin 1, FUS, TDP-43 and VAPB were unveiled. These mice faithfully replicate aspects of MND, including adult-onset muscle weakness and motor neuron pathology, and should complement existing mouse models for testing of potential treatments for MND. Barney Bryson (UK) presented ground-breaking findings on a novel approach to restore muscle function using light. He showed that transplantation of modified stem cell-derived motor neurons, whose electrical activity is controlled by light, into nerves of paralysed mice remarkably restored connections to muscle and movement, simply by shining a light on motor neurons! This approach overcomes the block in electrical signals from the brain and spinal cord in MND by replacing motor neurons with optical control of electrical activity. He speculated that such an approach could be used to keep the diaphragm muscle working in MND patients when coupled to a pacemaker-like device and further development of this tool is eagerly awaited. Although this technique poses many questions and needs to be adapted to people, the clinical implications of this concept are thrilling and this presentation was my personal highlight from the Symposium.

Lastly, in a session about SOD1 Therapy, there were 4 talks outlining promising approaches under development to target toxic SOD1 protein in MND. These approaches ranged from injectable viruses to "turn off" the SOD1 gene, small molecules to massage misshapen SOD1 back to shape and copper delivery to make SOD1 "more mature". Les Grad (Canada) presented encouraging results that fluoro-uridine (a chemo agent) blocks the spread of SOD1 pathology, in the Petri, which is linked to MND progression. Further evaluation of fluoro uridine in MND mice and patients is highly anticipated.

In summary, this conference clearly demonstrated the explosive pace of genetic discoveries in MND is being met by rapid translation of these findings into new Petri dish and animal models of MND, in particular C9. These new models should complement existing ones and continue to spur on discoveries about the fundamental biology of MND to continue to guide identification and testing of promising candidate drugs.

(Published with the kind permission of MND Australia and Dr Bradley Turner)

Links - 25th International Symposium on ALS/MND
Find out what was discussed during the three day symposium and read the research blog, delegate twitter posts, the peer to peer reports and view audio clips at mndassociation.org/research/International+Symposium/Past+symposia/abstracts2014.htm

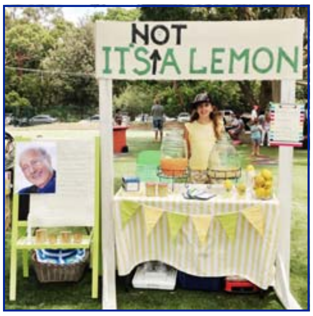
Would you like to receive Forum by email? You can save MND NSW postage costs. Let us know at admin@mndnsw.asn.au

Community events

Greg Redgrove Memorial Fundraiser

The Greg Redgrove Memorial Fundraiser was held at the Kitchener Pub in November raising $7,731. A very big thank you to Sue Redgrove for organising this event which included a sausage and steak sizzle, entertainment, auctions and raffles. We would also like to thank Jessica Fairlie, Scott Redgrove, Aleena Creek, Denise Schilko, Jen McKay, Brianna O'Neil and Glen George who helped Sue with organising a very successful and enjoyable day.

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



It's not a lemon

My name is Claudia, I'm Juliette's mum. My family and I are terribly proud of Juliette (pictured left) and her efforts to raise money and awareness through her lemonade stand. She is inspirational to us all. It was my dad who had MND; I cared for him in the last year of his life, alongside my mum. His name was Sam Frasca, and he was a very special man to say the least.

During this time, Juliette felt so helpless. She wanted to do something to help her Nonno, like her mum was, but didn't know how one little girl could make a difference. To her it seemed impossible, until she saw people taking the Ice Bucket Challenge on social media and TV. Seeing individuals taking the challenge, she saw first-hand how just one person could actually make a difference. It planted a seed, that grew into an idea, that started a conversation, that turned into action, that became a reality and eventually gave the gift of healing to all of us. We were doing something to help everyone who suffered from this cruel disease.

Her idea was to start a business at our local market to help raise money to find a cure for MND. Today, that tiny seed has grown into her own lemonade stand. She came up with her own recipe, her own branding, the name of the stand and recruited her own volunteers to help. Her profits and donations are given to the MND Association of NSW and as of last Saturday she has raised over $1,000.

Her stall is at Ramsgate Organic Foodies Market, Ramsgate Public School, Chuter Ave Ramsgate, every Saturday from 8am-2pm. She is amazing us with her tenacity and how people are being affected by her. She has the support of our local Mayor, Stephen Agius, and she has our hearts and 100% support for all she is doing for MND NSW. We are so very pleased for our beautiful Juliette.

MND Golf Day

Thank you to Eve Wheeler from Murwillumbah Women's Golf Club who again organised a golf day fundraiser, held in October. Chris Carroll from the Far North Coast office of MND NSW attended the event and enjoyed spending time with a lovely group of ladies. On the day $1,614 was raised through registrations, raffle ticket and merchandise sales.

Winter Wonderland UBall 2014

A winter wonderland was created for the University of Technology, Sydney Ball bringing students together to enjoy an elegant evening. Thank you to Rebecca Nguyen and all those who assisted raising $605 for MND.

Charity Concert

In Telarah an entertaining Charity Concert was held at the beginning of December. The concert was organised by Stephen Peters (pictured above on right with Ron Watkins who helped on the day) with $1,600 raised from tickets and donations. Stephen said, "the benefit concert raising funds for motor neurone was a large success. We had an array of artists who were all fantastic on the day and the audience all had a wonderful time". Thank you Stephen for organising this wonderful event.

Spring Fashion Parade

An lovely afternoon Spring Fashion Parade was held at the Ettalong Beach Tourist Resort in August raising $2,250. Guests enjoyed the latest fashions from Clara Boutique and CoralBlu along with champagne and nibbles. A special thank you to Noelene Lake who spoke at the event on behalf of MND NSW.

Charity Bowls Day

Nambucca Heads Bowling Club was the venue for a Charity Bowls Day in November organised by Suzanne McInnes. It was a very enjoyable day for all who attended and raised $800. Thank you Suzanne.

Bequests

Leaving a Gift in your Will

Making a Will is an important way to secure the future of your loved ones and to make known your wishes to those you leave behind. Leaving MND NSW a gift in your Will (a bequest) is a tremendous and thoughtful way of supporting the work that we do. For a confidential discussion, contact our Supporter Liaison Officer, Anne Jones ph. 02 8877 0999 or annej@mndnsw.asn.au

Walk to d'Feet MND

Wow! What an amazing start to the year. Sunday 15 February was Hunter region's third *Walk to d'Feet MND* in as many years and a new Walk record was set when 1,050 people came out in force to show their support for people with MND and help raise funds for research and care. It was a stunning Sunday morning. Speers Point Park was covered in a sea of blue t-shirts, lots of happy faces and a great atmosphere. Great food and wonderful music from Bel Enks finished off the day.

Many of the Walk participants created an 'Everyday Hero Page' and people they knew made donations towards their Walk participation, with over $53,000 raised.

A special thank you to our Hunter Walk sponsors - KOFM, Leah Jay, Altus Traffic and Hollydene Estate Wines. Thanks also to Danielle Richards, our Hunter Walk to d'Feet MND volunteer Walk Coordinator, who put in an enormous effort for this event.

During 2015 Walk with us to d'Feet MND and show your support for people living with the disease. More information at mndnsw.asn.au

Visit us on Facebook at www.facebook.com/mndnsw

Seeking volunteer MND NSW ambassadors

Our Ambassador Program has been very successful in raising awareness of MND in local communities.

In 2014, MND NSW ambassadors attended 20 events in NSW, the ACT and the Gold Coast. We have had a fabulous start to 2015 with eight confirmed appointments to date.

Kevin Johnstone accepting a donation to MND NSW at Sans Souci Leisure Centre in 2014

If you are a member of a club or organisation and would like to organise a speaker for an upcoming event or if you are interested in becoming a Volunteer Ambassador in your area contact Anne Jones ph. 02 8877 0999 or annej@mndnsw.asn.au

2015 GOLD PASSES

Calling all our gym junkie and fitness freaks. Would you like to run the City2Surf 2015 on 9 August and raise funds for MND NSW? This year MND NSW has Gold Pass tickets that will put you in the 2nd tier of runners, in front of all the crazies!! Email our Fundraising Manager Kym Nielsen at kymn@mndnsw.asn.au to find out how you can get a Gold pass ticket. Don't delay we only have 15 places.

Community events
Dates for the Diary 2015

28 Mar	**Dale's Day** | Lambton Park
29 Mar	**Walk to d'Feet MND** | Illawarra
11 Apr	**Corporate Fighter 14** | Hilton Hotel Sydney | corporatefighter.com.au
19 Apr	**Walk to d'Feet MND** | Forbes
3 May	**Walk to d'Feet MND** | Lismore
3-9 May	**MND Week**
10 May	**Riverwood Downs Mother's Day Lunch** | Monkerai
21 Jun	**Walk to d'Feet MND** | Canberra
25-26 Jul	**34th Liverpool Doll Fair** | Liverpool
9 Aug	**Walk to d'Feet MND** | Central Coast
13 Sep	**Walk to d'Feet MND** | Port Macquarie
10 Oct	**Gundaroo Music Festival** | Gundaroo | gundaroomusicfestival.com
25 Oct	**Walk to d'Feet MND** | Wagga Wagga
8 Nov	**Walk to d'Feet MND** | Sydney

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

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

Editor: *Penny Waterson*