



FORUM

Ride to the Reef

Bob Montgomery decided to celebrate his 70th Birthday by raising money for MND NSW. He rode his pushbike from Leura in the Blue Mountains to Port Douglas in Far North Queensland. Leaving Leura on 1 December 2013, Bob cycled over 3000 kilometres in 30 days, arriving in Port Douglas on 30 December. Bob's 'Ride to the Reef' raised more than \$23000.



Day 1 - Bob (L) leaving the Blue Mountains!



End of Day 4 - Arrived in Kempsey and Bob is tired but strong



End of Day 6 - First stop the Grafton Hotel where Bob can be seen sipping a cold ale with the publican Peter Herden



End of Day 11 - Arrived in Toowoomba



Day 28 - Innisfail



Day 30 - Arriving in Port Douglas

You, your family and your friends are warmly invited to

MND NSW

Day of Hope and Remembrance

Saturday 3 May, 2014

1.30pm to 3.30 pm

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. This venue is wheelchair accessible, near public transport and with ample free and disability parking.

For catering purposes RSVP by 28 April

ph. 02 8877 0999 or Freecall 1800 777 175 or reg@mndnsw.asn.au



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.

Dear Editor,

Here is a photo of me with my 'local support team'. I think it's a nice photo to go in the MND NSW Forum to show off these good people.

We had a 'case management meeting' on 18 December with these good people gathering to 'pro-actively' consider how they can support myself and my wife as my MND advances.

Left to right are **Kim Sinclair** (Regional Advisor, MND NSW), **Sharon Frith** (Occupational Therapist, East Maitland Community Health Centre), **Deborah Veness** (Case Manager, Maitland Community Options), and **Daniel Buck** (no relation) (Physiotherapist, Therapy at Home).

I can only be very thankful that these folks have my wellbeing in mind.

Malcolm Buck - member, MND NSW



Introducing...

Melanie Oxenham - Regional Advisor - Western Sydney, Blue Mountains and Central West



I'm really pleased to have joined the Family Support team. I am based in Penrith and work on Mondays, Tuesdays and Wednesdays. I am a long term 'westie' and have family living near Orange so it is great to be able to work in my 'patch'. Just a bit about myself: I am married with 3 children and a cat (guess who gets the most attention!). On the weekends you will find me bushwalking, kayaking, scuba diving or playing netball. Professionally I am a social worker and have worked in the health

and disability sectors for the past 20-odd years. I am enjoying meeting members in my area; if I haven't been in contact yet I soon will be! In the meantime you can contact me ph. 0431 471 734 or melanieo@mndnsw.asn.au

...and new MND NSW board members elected at the 2013 AGM

Amy Critchley

Amy Critchley is a public sector professional based between the Australian Capital Territory and the Mid North Coast of NSW. Amy has worked over a decade in public policy and governance across numerous levels of government, predominantly in the criminal justice and health sectors. Amy is also a committed carer for her mother who was diagnosed with MND in 2011 and is a strong advocate for people living with MND, in particular the ACT and rural and regional members of the Association.

Kirsten Harley

Kirsten Harley is a sociologist who works as a lecturer in the Faculty of Health Sciences at the University of Sydney, researching in areas including health care choice and the history of sociology. She has a PhD in sociology (University of Sydney, awarded the inaugural Rita and John Cornforth Medal for PhD Achievement, 2011), an honours degree in sociology from University of New England (University Medal) and a science degree from Sydney. She has previously worked in policy, government relations and audience research positions at the ABC, as a researcher with RMIT (Vic) communications policy group, Network Insight and in various university teaching positions. Kirsten joined the board of the MND Association NSW in 2013, following her diagnosis with MND early that year, and greatly appreciates the wonderful support provided by the Association to herself and her young family.

Nick Shaw

Nick joined Coopers & Lybrand (now PriceWaterhouseCoopers) in 1983 straight from high school as a cadet, graduated from UNSW with a BCom in Finance, Audit and Systems in 1986 and was admitted to the Institute of Chartered Accountants in 1989. Married with two children and a dog, Nick is keen on all sports, but especially tennis and golf. Nick is Chief Financial Officer for Guide Dogs NSW/ACT covering finance, IT, infrastructure and HR, a position he has held for seven years.

MND Week
2014
4 to 10
May

Cornflower
Blue Day
Friday 9 May
2014

A Message from the CEO

It is March already! It seems like 2014 has only just arrived and yet we are nearly a quarter of the way through the year.

Keeping us very busy are:

- an increase in new memberships due to our outreach in regional areas - we currently have 513 members living with MND
- our first Walk to d'Feet MND for the year, held in the Hunter - with a record 774 walkers who didn't let the rain stop them. And, by the time this edition of *Forum* goes to print, the Illawarra Walk to d'Feet MND, to be held on 3 March, will also have taken place
- MND Aware training for health and community care workers to be run on the Gold Coast
- our first Information Evening for 2014
- planning for our Link and Learn program for carers to be held 13 and 14 March in the Hunter.

As always MND Week will be in the first week of May (Sunday 4 May to Saturday 10 May). Our Day of Hope and Remembrance will be held on Saturday 3 May. You can find out more about our upcoming events on pages 10 and 12 of this edition of *Forum*.

The move to a National Disability Insurance Scheme is progressing in the Hunter, with the ACT to start in July 2014. Progress is slow and we are still advocating strongly for the inclusion of those people over 65 diagnosed with MND to be included or given greater support through aged care.

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



See page 12
for more

MND Week

4 May to 10 May 2014

Cornflower Blue Day - Friday 9 May 2014

MND Week is fast approaching and we are looking for lots of volunteers to sell merchandise and collect donations at busy railway stations on Cornflower Blue Day, Friday 9 May 2014. You can also help by purchasing MND NSW merchandise or by organising a fundraising event during MND Week.

Full details are provided on the yellow Expression of Interest form enclosed.

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

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

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

Email: admin@mndnsw.asn.au

www.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

*Chris Carroll, Dianne Epstein, Jo Fowler,
Caroline Gleig, Ann McCutcheon, Eileen
O'Loughlen, Melanie Oxenham,
Kim Sinclair and Deb Ward*

Information Line Advisor

David Wallace

Education and Carer Support Coordinators

Kristina Dodds, Kate Maguire

Information Resources Coordinator

Penny Waterson

FlexEquip Coordinator

Maree Hibbert

FlexEquip Assistants

Tom Giardina, Michael Walker

FlexEquip Support Officer

Julie Becke

And...many valued volunteers

*including Bev Smith who has worked tirelessly in the Port Macquarie area
organising very successful Walk to d'Feet MND events.*



Family Support Team

In preparing this report I was reflecting back on events that have occurred since our last newsletter and was reminded of the MND NSW Members Christmas Party that was held in late November. It was good to see so many people attend especially our younger visitors who really enjoyed seeing Santa.

We are now well into planning events for 2014. We have a carers program, Link and Learn, in the Hunter on 13 and 14 March which has been fully subscribed. We are also planning some other education programs in regional areas this year so keep an eye out for dates.

The Care for Carers Program will be held at the MND NSW Centre at Gladesville during May and June and registrations are currently being taken for this. See page 5 for further details.

Our Day of Hope and Remembrance is on 3 May at the Sydney Olympic Park precinct to launch MND Week. Each year we ask for volunteers who can assist with our candle lighting ceremony by either lighting a candle or reading a dedication. If you would like to be part of this please contact David Wallace, Information Line Advisor, who will be organising this part of the day. See page 1 for further details.

Quality Improvement

As part of our commitment to providing high quality services MND NSW is currently undergoing a quality management accreditation program. This accreditation is granted to organisations that successfully meet the Health and Community Services Standards and the Disability Services Standards, and demonstrate ongoing continuous quality improvement.

The accreditation process involves an audit by external reviewers who will be looking at all aspects of our organisation to ensure we meet the quality standards. This may include speaking to some of our service users to get their views on how our services are meeting these standards and we will be in touch with some people later in the year to ask if they are interested in taking part in this process.

As part of our accreditation and to improve the quality of the services provided by MND NSW we have recently introduced home visit risk assessments and care action plans. Both of these are designed to ensure you gain the most out of your visit from your regional advisor.

The home visit risk assessment requires the regional advisor to ask you a series of questions prior to their first visit so that they have all the information necessary to find your home no matter where you live. This will help to ensure the safety of our regional advisors when they are in unfamiliar

areas. The care action plans are designed to keep you informed about the progress of the actions the regional advisor has said she will undertake on your behalf. You will be provided with a copy of a plan of actions agreed upon and also a follow up letter outlining the outcome of the actions. We hope that you will find this written record useful because there are often many health and community care professionals involved when a person has MND.

We will be undertaking a Member Satisfaction Survey in 2014 to gain feedback from members about their experience of our services. Our surveys are undertaken every two years and they assist us in the ongoing development of our services. These will be sent to members in March and we would appreciate you completing the survey. We do really value your feedback. We also survey health and community professionals to get their feedback about their experience of our services as well.

National Disability Insurance Scheme (NDIS)

Following the launch of the NDIS in the Hunter, MND NSW has become a registered provider of support. This includes our regional advisor service and equipment service.

Currently MND NSW members aged less than 65 years who live in the Newcastle local government area are being transitioned to NDIS. Transitioning members are choosing the MND NSW regional advisor service and equipment service as part of their NDIS plan, which is developed by the member and the NDIS planner. Regional advisors are able to assist members in developing their plans by attending the NDIS planning meeting with them if requested. Please let your NDIS planner know if you would like your regional advisor to attend.

MND NSW continues to maintain its current referral processes for all people living with MND in NSW, ACT and the Gold Coast.

Gina Svolos

Manager, Family Support

**Information Day
for people
living with MND, family and friends**

Charlestown Bowling Club

Wednesday 25 June 2014

10am to 3.30pm

Dr David Williams, a neurologist with extensive experience in MND from John Hunter Hospital, will be one of the speakers on the day. Lunch is provided and bookings are essential
reg@mdnsw.asn.au or ph. 1800 777 175.

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

MND NSW Training - finalist National Disability Awards 2013

The MND NSW MND Aware online and face-to-face training for frontline staff was nominated as one of three finalists for a National Disability Award 2013 in the category of "excellence in improving health and wellbeing outcomes for people with disabilities". The awards were presented in December to coincide with the International Day for people with disabilities. MND NSW was honoured to have been selected as one of three finalists from a field of over 200. Finalists across all nine categories were invited to attend the ceremony in the Grand Hall at Parliament House Canberra.

MND Aware was nominated for this award because of the quality, presentation and reach of these two training resources. In 2012 and 2013 over 880 health and community care professionals attended 31 MND Aware face-to-face training sessions across NSW. Just under half of all current MND NSW members have had at least one of their service providers attend the MND Aware face-to-face training. The MND Aware online training modules have been accessed a total of 6920 times across Australia, with 3815 of these views from NSW and the ACT.

MND Aware is aimed at improving the coordination and quality of care for people with MND and their families. As one participant wrote, the training provided a "great balance of information on MND and how to actually apply this information when providing care to a person with MND and their family".

Kristina Dodds - Education and Carer Support Coordinator

The conditions were superb

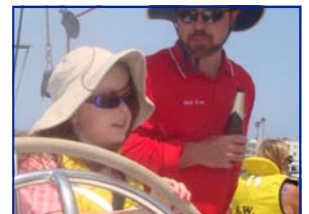
On Sunday 19 January the Sailors with disABILITIES yacht, Kayle, slipped its mooring at Rushcutters Bay and, with 13 MND NSW members and family members aboard, headed out into Sydney Harbour for a thrilling three hour sail. The conditions were superb – there was not a cloud in the sky, the wind was up and there was plenty to eat and drink on board. Kayle is a 52ft Lyons grand prix offshore racing yacht and was designed "to be ergonomically sensitive to the needs of the disabled, yet in every sense of the word to be an ocean racer". Indeed she had just returned from Hobart having come third in her division and the crew, with help from our members and their families, put her through her paces again. It was a thoroughly enjoyable time for everyone and we cannot thank Sailors with disABILITIES enough for giving everyone an afternoon to remember. This sail has become a regular fixture in our calendar of events each year, so if you think it is something you and your family would like to be a part of, keep an eye out for the date of the next sail.

David Wallace - Information Line Advisor



Award finalists (L-R) Susan Race (who won the Award for her work in discharge planning), Kristina Dodds, representing MND NSW, Naomi Snell, Paws for Purrfect Patient Pet Therapy

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



Kimi at the helm!

CARE FOR CARERS at MND NSW Centre Gladesville - Register now Four consecutive Mondays 12, 19, 26 May and 2 June 2014

Once a year we offer the 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.

Dianne Vogt attended Care for Carers in 2013 and this is what she has to say about her experience of the program.

"I have had the wonderful opportunity to participate in MND Care for Carers. Unsure of what to expect I attended with an open mind which soon became a sponge to completely absorb and take on board all the valuable information that was professionally and positively given to me.

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."

Care for Carers runs over four consecutive Mondays on 12, 19, 26 May and 2 June.

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



FlexEquip

MND NSW FlexEquip Service received 2015 referrals for equipment in the past 12 months and this is an increase of 16% on same period last year. We have provided over 1720 items of equipment to our members, which is an increase of 17%. Demand on the equipment service was particularly high in December 2013 with over 175 equipment referrals received during the month.

Maree Hibbert - FlexEquip Coordinator

Around the support groups

Central Coast

We continue to meet bi-monthly on the first Thursday afternoon at Narara and over recent months have had a great range of guest speakers including Charlotte Adams, Social Worker from CORT and Jacqui Swindells, Continence Nurse from Erina Community Health Centre. Also, Nicole Ellis from Flavour Creations provided the group with a very interesting session on nutrition options available.

One of the most useful and beneficial aspects of our group, however, continues to be the practical sharing of information, tips and tricks which sometimes only those living with MND and their carers know about!

We are all looking forward to being active participants in the Walk to d'Feet MND Central Coast, planned for 23 March at Woy Woy. Members of our group have put in huge efforts to raise awareness of MND and also raise much needed funds in support of MND NSW. The walk will be a chance to join together in the sunshine and will be another great community event.

Our next meeting will be from 1pm-3pm on Thursday 3 April at Gosford/Narara Neighbourhood Centre 2 Pandala Rd Narara. Our group has a very welcoming atmosphere and is fun and relaxed, with a strong sense of local community. We hope to see you there.

Deb Ward - Regional Advisor

Western Sydney

Western Sydney support group has kicked off again for the year at Kingswood Neighbourhood Centre. This year we are meeting in the afternoons, as some members found the mornings a bit of a rush. The group will meet every second month, and we are planning to have a mix of guest speakers and fun activities over the year. Each meeting will also have time for informal chat and sharing of ideas and experiences. We have some wonderful longer term members in the group who welcome new members wanting to learn more about living with MND. If you are not sure what a support group is like, contact me and come along and give us a try!

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

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

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

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

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

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

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

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

24th International Symposium on ALS/MND

In December 2013 I attended the 24th International Symposium on ALS/MND and Allied Professionals Forum in Milan, Italy, with the support of a MND Australia travel grant and MND NSW. These annual events draw clinicians, researchers and MND Associations from around the world. Here is a brief summary of some of the key presentations. Penny Waterson - Information Resources Coordinator, MND NSW

ALS in a world of multiple phenotypes

In the Symposium opening address, Dr Stan Appel, Methodist Neurological Institute, Houston, Texas, USA, observed that the different familial genetic mutations so far associated with ALS/MND can produce a single clinical phenotype (or form) of ALS/MND with signs and symptoms that do not look different; yet individuals with the same genetic mutation can present with different clinical phenotypes of the disease, showing different signs and symptoms, even though each mutated gene has a distinctive 'signature':

Mutation in	Pathway affected
Dynactin, PFN1, EphA4	Cytoskeletal function, axonal transport
TDP43, FUS/TLS, C9orf72	RNA and chromatin
SOD1, TDP43, FUS/TLS	Misfolded protein, aggregation
Ubiquilin-2, p62	Protein digestion: proteasome, autophagy

Additionally, these familial ALS/MND phenotypes are indistinguishable from sporadic ALS/MND phenotypes which have marked variability in sites of onset, ages of onset, rates of disease progression and cognitive involvement. Therefore an important goal for researchers is to identify factors that contribute to this diversity.

To test or not to test

Professor Orla Hardiman, Trinity College Dublin, Dublin, Ireland, discussed the dilemmas, generated by advances in genetics, now increasingly faced by some people affected by ALS/MND and their doctors. It is known that some forms of ALS/MND are familial which implies that some people with ALS/MND may have one or more genes that greatly increase their risk of developing ALS/MND. For guidance about testing, European neurologists look to the European Federation of Neurological Societies (EFNS) guidelines for testing which state that testing should only be performed in people with a known family history of ALS/MND following appropriate genetic counselling. The first dilemma is that there is no universal definition of familial disease: familial disease can be difficult to detect in small families and the risks of two people in the one family developing ALS/MND by chance increases in larger families. The second dilemma is whether to have any testing given there is a lack of disease modifying treatments for people with ALS/MND. And, is a person tested for all known genes or just one at a time? This is important because people with reported variants do not always

produce disease; ALS/MND may be oligogenic (have several genes involved in producing the disease); the frequency of known genes is not uniform across populations (for example no SOD1 or TDP-43 in Ireland); and there is a cost implication for the testing. The third dilemma is the impact of testing on other family members. Professor Hardiman suggests that ultimately, genetic testing for ALS/MND needs to be standardised by modifying existing guidelines established for other diseases, supported by ongoing research in clinical and genetic epidemiology and governed by a robust ethical framework.

In her research on genetic testing in practice in ALS/MND clinics in North America, Europe and Israel, Professor Stacy Rudnicki, University of Arkansas for Medical Sciences, Little Rock, Arkansas, USA, found that about 6% of clinics had a genetic counsellor/geneticist available at every clinic visit, 20% had a genetic counsellor/geneticist available at selected clinic visits and 75% did not have a genetic counsellor/geneticist in their clinic but could readily make an appointment locally. However, 83% of clinic neurologists were willing to discuss and send a person for genetic testing without the person having a consultation with a genetics counsellor/geneticist first. The challenges of genetic testing as identified by the clinics included uncertainty of meaning following a positive test when a person had a negative family history; limited knowledge of newer genes; lack of gene-based therapy; cost; phenotype variability; complexities of explaining results to people and their families; and lack of a genetic counsellor/geneticist. The survey highlights the need for developing guidelines around testing for MND related genes.

Quality of life, depression and perceived social support in the course of ALS/MND

Two researchers presented the results of their studies into how people with MND felt about their quality of life. Dr Dorothee Lule of the University of Ulm, Ulm, Germany, explained that some commonly used quality of life measures focus on physical function and abilities, while other quality of life measures focus on a person's feelings of satisfaction and happiness. Dr Lule presented research findings from her study which was based on interviews of 93 people who had, on average, been diagnosed with MND for around 35 months.

(Continued on page 8)

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

(Continued from page 7)

Generally, the people interviewed felt their quality of life was good (scoring greater than 70 on a 0-100 scale) and they had a low depression rate. These findings were independent of the decline in the person's actual physical function.

In the second quality of life presentation, partial results from the Trajectories of Outcome in Neurological Conditions study (TONIC) conducted in the UK, were presented by Hikari Ando, Liverpool Hope University, Liverpool, UK. Semi-structured interviews of 19 people with MND were used to explore an individual's perceived quality of life with MND, and factors which negatively or positively affect quality of life. Three core factors were found: enjoyment of life, significant others and self-identity. For an individual, these factors could be influenced either positively or negatively by the following:

- half full/half empty approach
- the person's locus of control (the extent to which individuals believe that they can control events that affect them - they were not able to change the trajectory of MND, yet they felt able to control its impact)
- spirituality
- support that included practical help, professional input and encouragement, that promoted independence, confidence, a positive attitude and an increased sense of security
- environmental factors including accessibility of places and/or tools to retain independence and social activities.

Getting enough energy from food or food supplements

Dr Rup Tandan from the University of Vermont, Burlington, Vermont, USA explored *Assessment and management of caloric needs in ALS/MND*. Under-nutrition in ALS/MND largely results from decreased food intake or increased energy expenditure or both. Malnutrition in ALS/MND is associated with poorer outcomes for those people with the disease and has also been thought to negatively affect general motor and respiratory function and quality of life. Many people with ALS/MND have a resting metabolic rate that is higher than in the general population and standard equations used by dietitians to calculate caloric need are not effective in taking this into account. Additionally, there is little research available on other causes, directly related to ALS/MND, that may cause increased caloric use by people with the disease, such as muscle weakness, spasticity, cramps, fasciculation and emotional lability. Dr Tandan's research group followed 80 people with ALS/MND and found that 73% had an energy intake that was less than their daily expenditure resulting in malnourishment or under-

nourishment. This is important because although ALS/MND can cause muscle atrophy, malnutrition can also worsen muscle atrophy for a person with the disease. The research group also found that fasciculation, spasticity, cramps, emotional lability and laboured breathing all increase caloric expenditure. The group has developed an ALS/MND specific equation that can be used by dietitians to determine a person's total daily energy expenditure and their caloric needs.

Lumping and splitting

Lumping and splitting was an often heard phrase at the Symposium and the concept behind lumping and splitting and the relevance to MND clinical trial research was explained by Dr Michael Strong, Robarts Research Institute, London, Ontario, Canada in his presentation *ALS/MND as a disease spectrum: time to leave the lumpers behind?* ALS/MND has been traditionally described as a single disease process although it is clear this has never been the case. Most researchers are agreeable that ALS/MND represents the final expression of a broad range of pathological processes and although any given individual will show a largely predictable disease course, there is little consistency amongst individuals: individuals may have only upper motor neurones affected, or only lower motor neurones affected, or have bulbar involvement or have cognitive symptoms. Some people will have a 'fast' progression and others will progress much less quickly. The use of these clinical differences could suggest different underlying pathologies.

Treatments that have shown much promise in the laboratory have not shown the same positive effect during large clinical trials, where individuals with ALS/MND are often 'lumped' together notwithstanding their individual ALS/MND differences. Yet by 'lumping' people together both positive and negative effects of proposed 'treatments' may be cloaked, or hidden, by the natural variation a researcher could expect based on individual characteristics. Conducting clinical trials on targeted groups or 'splits' of people with ALS/MND is a challenge that needs to be translated into clinical trial design. 'Splitting' or stratifying people with ALS/MND into defined groups based on age at onset; bulbar or respiratory onset; behavioural impairment; cognitive involvement; length of time to diagnosis and several other characteristics will, amongst other benefits, better reflect the syndromic nature of ALS/MND, allow for a decrease in the number of people needed for individual clinical trials and reduce the cost of trials by increasing the ability to detect a clinical benefit in a shorter time-frame.

(Continued on page 9)

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

<p><i>Date for your diary</i></p> <p><i>Monday 21 July</i></p> <p>MND NSW</p> <p>Ask the Experts</p> <p><i>West Ryde</i></p>	<p>(Continued from page 8)</p> <p>Quality measures in ALS/MND care</p> <p>The America Academy of Neurology (AAN) Practice Parameters for ALS (2009) are an evidence-based review of symptom management strategies for ALS/MND. The Parameters highlight symptom management strategies that have been shown to be effective however many of these evidence-based treatment recommendations are still underutilised by people living with ALS/MND. These gaps in care led the AAN to develop ALS Quality Measures that can be used to facilitate quality improvement in the care offered to people with the disease.</p> <p>The ALS quality measures were published in November 2013 and presented to the International Symposium on ALS/MND by Dr Robert Miller, Forbes Norris MDA/ALS Research Center, San Francisco, California, USA. The measures were determined following a review of 378 guidelines and consensus papers by the AAN ALS quality measure work group. The final 11 measures were selected based on clinical importance, evidence base, gaps in care and implementation feasibility. They were posted for a 30-day public comment period and 222 comments were received from physicians, people living with MND, insurers and other interested stakeholders from the United States and Canada. Finally the measures were approved by the AAN and will be revised periodically.</p> <p>The AAN ALS/MND Quality Measures identify that a person living with MND needs:</p> <ol style="list-style-type: none"> 1. an ALS multidisciplinary care plan developed or updated. Frequency: at least once annually. 2. a discussion about the disease-modifying pharmacotherapy (riluzole) to slow ALS disease progression. Frequency: at least once annually. 3. screening for ALS cognitive and behavioural impairment screening. Frequency: at least once annually. 4. symptomatic therapy treatment offered for pseudobulbar affect, sialorrhea and ALS-related symptoms. 5. a discussion about any symptoms of respiratory insufficiency (awake or associated with sleep) and referred for pulmonary (respiratory) function testing (eg vital capacity, maximum inspiratory pressure, sniff nasal pressure or peak cough expiratory flow) Frequency: at least once every three months. 6. a discussion about treatment options for non-invasive ventilation support including non-invasive ventilation and assisted cough, if they have respiratory insufficiency. Frequency: at least once annually. 7. screening for dysphagia, weight loss, and impaired nutrition and results are documented in the medical record. Frequency: at least once every three months. 8. nutritional support (dietary or enteral nutrition support via percutaneous endoscopic gastrostomy or radiographic inserted gastrostomy) offered for people with dysphagia, weight loss, or impaired nutrition. Frequency: at least once annually. 9. ALS communication support (speech pathology) referral for an augmentative/alternative communication evaluation for people who are dysarthric. Frequency: at least once annually. 10. ALS advance care planning. Frequency: at least once annually. 11. ALS falls querying (have you had any falls?). Frequency: all visits. <p>It is hoped that through the development of the measures that the standard of care for all people with ALS/MND will be raised, increasing life expectancy and enhancing quality of life.</p> <p>You can access more information about the AAN ALS Quality measures here: https://www.aan.com/uploadedFiles/Website_Library_Assets/Documents/3.Practice_Management/2.Quality_Improvement/1.Quality_Measures/ALS%20journal%20article.pdf</p> <p>And from the Allied Professionals Forum....</p> <p>Mel Holmes, Occupational Therapist, Victorian Respiratory Support Service, Australia, spoke about Practical and cost effective solutions for enabling independence in MND patients requiring non-invasive ventilation (NIV). This service has found that early discussion and trial of NIV provides the time and opportunity to allay people's fears, provide answers to questions and to work through potential problems such as getting a good mask fit, managing pressure points on the face and back of the head, and how to get out and about with NIV. Mel highlighted some solutions for people with MND including the attaching of loops to the mask straps and resting your elbows on a table while using your hands and the loops to put on and take off the mask; having a means of calling for assistance with your NIV when needed such as a switch adapted door chime; trying on different masks to find a comfortable fit; having one mask for night and a different style for other times to provide relief for night time mask pressure areas; using the right dressing (type and fit) for pressure points; using sheepskin on the back of the head to reduce pressure from mask straps; adapting the bed pillow by cutting out some of the centre pillow foam and replacing it with lighter material so the mask doesn't push onto the head; using a satin pillowcase to reduce friction; using a ventilator tray on your wheelchair for the NIV machine and ensuring you have extra batteries when going out; trying a mouthpiece for NIV during the day. However, if thinking about this, you also need to consider how the mouthpiece will be setup and</p> <p>(Continued on page 10)</p>
--	---

(Continued from page 9)

the movement of the person and their wheelchair. Gastrostomy (PEG or RIG) is a medical procedure during which a short, permanent tube is placed into the stomach through the abdominal wall. You can have enteral nutrition (liquid feeds) and fluids through the tube, directly into your stomach, bypassing your mouth and throat. People sometimes delay making the decision to have a gastrostomy however respiratory muscle weaknesses can affect a person's recovery from the procedure or prevent them from having a gastrostomy. The **'Traffic light' approach to assessing respiratory risk and guiding decision-making for enteral nutrition in ALS** used at the Oxford MND Care and Research Centre, UK was presented by Mel Lord, Speech Pathologist from the Centre. Using a range of respiratory assessments, people referred for gastrostomy are evaluated against a pre-determined respiratory function criteria and classified into one of three groups - green, amber or red - each with a different 'action' path. The low risk green group has their gastrostomy as 'routine', with standard respiratory management during the procedure; the moderate risk amber group has the procedure performed by a specialist with experience in the care of patients with potential respiratory compromise; and the high risk red group is

provided with NIV for extra respiratory support before and during the procedure. This system has enabled clear identification of people with respiratory compromise.

The National Institute of Clinical Excellence in the UK is looking to develop guidelines for facilitating and managing the process of withdrawal of non-invasive ventilation. To find out more about how doctors 'manage' communication with a person with MND when the person has decided to stop using NIV, Dr Christina Faull, Palliative Medicine Consultant, UK, asked 20 specialist doctors to talk about their "last or most memorable patient" and presented the results in the paper **Withdrawal of NIV at the patient's request in MND**. When recalling the events the doctors remembered explicit details, even over time. The emotionality of the situations were especially vivid. The doctors spoke about the weight of responsibility they felt in correctly determining a person's wishes when the person had communication difficulties; the need for several conversations with the person and also the need to allow enough time during the conversation for the person to communicate their wishes to the doctor.

You can find links to all of the presentations on from the Allied Professionals Forum at <http://www.alsmndalliance.org/alsmndmeetings/past-meetings/2013-meeting-archives/>

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

Noticeboard

Selling Houses Australia

Selling Houses Australia (SHA) Series 7 - Episode 4 aired during the week of 26 February featured Kym Kovan and her friend and business partner Fiona Austen. Kym and Fiona kindly donated computer items from their business to MND NSW before they moved to northern NSW.

Independence Expo

Spinal Cord Injuries Australia is hosting Australia's second Independence Expo on Saturday 5 April at Australian Technology Park, Sydney, from 10am to 5pm. The Expo will showcase an extensive range of products, services and resources to promote independence. See www.scia.org.au/expo

Holiday News

Great feedback from one of our members who travelled late last year to Far North Queensland for a much needed break with family.

The family took advantage of a Quicksilver tour to the Outer Barrier Reef. Although our member is confined to a wheelchair, nothing was too hard for the crew. The entire family had a wonderful day out which included snorkelling on the reef, and our member was accompanied by an experienced guide. See www.quicksilver-cruises.com

Family Support Calendar 2014

29 April	Information Evening for people recently diagnosed with MND, family and friends Gladesville
3 May	Day of Hope and Remembrance Sydney Olympic Park (see Page 1)
12, 19, 26 May and 2 June	Care for Carers Gladesville (see Page 5)
17 June	Information Evening for people recently diagnosed with MND, family and friends Gladesville
25 June	Information Day for people living with MND, family and friends Hunter (see Page 4)
21 July	Ask the Experts West Ryde

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.

Community events

Drink Tea for MND

Thank you to Danielle Richards who organised a workplace morning tea for MND in November at Southern Cross Austereo. Danielle explained, "My uncle's name is John Goodenough (pictured) and he was 53 when he died from MND in 2011. He was my Mum's baby brother, and he was a



very energetic and wise man. He left behind a 3 year old son, my cousin Arthur, who is now 5. He is basically Dennis the Menace and one of the main reasons I am trying to raise awareness and money for MND NSW is that I want Arthur to know how strong his father was and that when he grows up he too can help out by doing the same kind of thing by fundraising".

Morning Tea for MND

An enjoyable morning tea was attended by about 65 people on 16 November hosted by the Rotary Club of Forbes Ipomoea. The president of the Club, Julie Simpson, was diagnosed with MND in July and the event was held to help raise awareness of MND. Thank you to Therese Newell for organising the morning tea and everyone who assisted. The morning tea included a guest speaker, entertainment and raffles raising \$2355.



Gundaroo Music Festival

Thank you to Scott Harding and the organising committee of the very successful Gundaroo Music Festival held in October which raised \$20000 for MND research. The large crowd enjoyed 12 hours of live music from some of the finest national talent available, two fireworks displays, food and produce stalls, local arts, handcrafts and various other entertainment. The Festival was the vision of a very talented local musician, Scott Windsor, who was recently diagnosed with MND. Friends rallied around Scott to make his dream a reality. It was a great family atmosphere with lots of fun for all. Due to the success of the day the Gundaroo Music Festival is again being planned for October 2014.

Crazy Hair Day

Warrawee Public School held a Crazy Hair Day in November with students able to wear a crazy hair style to school for a gold coin donation. Crazy biscuits and MND puppies were also sold on the day. An amazing \$6767 was raised!

MND Walk Virginia, USA

Lauren Groom (pictured) held our very first walk in the USA raising \$1225. Lauren said, "It was very cold that day (-1°C) but no rain which was good. My husband and I (and the dog) walked 16.1km in a little under three hours. I had all my MND gear on and my Nan's blue jacket. I was hoping to hand out brochures to people along the way however there were not many people out!".



Salamander Bay Merchandise

Thank you to Clara Reis Dos Santos for her ongoing MND fundraising activities. Pictured at one of her fundraising stalls is Clara with her daughter Nicole and goddaughter Delilah.



Canberra Raffle

Siobhan Mayo helped Mischa (pictured) raise funds and awareness for MND by running a raffle in Canberra raising \$1400. Both Mischa's grandfathers have died of MND. Thank you Mischa and Siobhan.



Young Open Garden Day

Karen Curtis kindly opened her garden at her property in Young for viewing by the public. Karen's husband, Vincent Curtis, has MND and the event was held to raise funds for MND NSW. The day went well despite the rain, with around 200 people attending. Morning tea, lunch, a plant stall and a raffle were organised with \$2570 raised on the day.

Spring Morning Tea

Thank you to Helen Martin from Bowral for hosting a Spring Morning Tea for MND in November. The event went very well and \$6550 was raised.

Council and Staff of Great Lakes Council

Thank you to the Council and Staff of the Great Lakes Council for their donations to MND NSW.

Seeking volunteer MND NSW ambassadors

Are you interested in becoming a Volunteer Ambassador for MND NSW and raising awareness of MND in your local area? Contact Anne Jones on 02 8877 0928 or email annej@mndnsw.asn.au for further information.

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 Hunter Sunday 16 Feb 2014

With over 525 pre-registrations, we knew this Walk was going to be big. However, little did we know how motivated people in the Hunter really were. Sunday morning dawned grey and overcast with light rain and as we started registrations the queue started to form! So many wonderful families and supporters turned up to support or honour a relative or friend with MND. As our walkers headed off along the path in a sea of blue, the atmosphere was electric.

A big thank you to Ashleigh Worldon who was the local coordinator for a second year running. The Warners Bay Lions Club made sure that everyone was fed whilst they listened to some great live music. Thank you to our wonderful sponsors KO.FM, Lowe Winery, EGO Sunsense and Anytime Fitness. Congratulations Hunter for the largest participation in any Walk held by MND NSW. We had 774 participants (and let's not forget the 28 dogs) and to date we have raised \$45970 with more donations still coming through the 'Everyday Hero Pages'.



*Team Jodie (above) and
Team of 50 for Richard and Brad (below)*



Team of Strength

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.

Community events Dates for the Diary 2014

21 Mar	MonSTAR Cup Pennant Hills Golf Club
23 Mar	Pedal Car Display Wagga Wagga
23 Mar	Walk to d'Feet MND Central Coast
(tba) Apr	Tas Run for MND Wagga Wagga
6 Apr	Walk to d'Feet MND Canberra
6 Apr	EGOs Cut and Barefoot Bowls Day Scone
26 Apr	Musical Concert for MND Glendale, Newcastle
(tba) Apr	Masters Breakfast Tournament Camden Lakeside Golf Club
4 May	Walk to d'Feet MND Tweed
4-10 May	MND Week
9 May	Cornflower Blue Day
16 May	Riddla MND Golf Day Penrith Golf Club
15 Jun	Walk to d'Feet MND Dubbo
14 Sep	Walk to d'Feet MND Port Macquarie
11 Oct	Gundaroo Music Festival Gundaroo
19 Oct	Walk to d'Feet MND Wagga Wagga
26 Oct	Burgh2Beach Fun Run
9 Nov	Walk to d'Feet MND Sydney

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

HELPING THROUGH YOUR WILL

Your Will can be a convenient way of making a charitable gift of lasting value.
Please consider MND NSW as a living memorial for a loved one. Join those who support the work of MND NSW through bequests from their Estates.
For more information contact Anne Jones,
Supporter Liaison Officer
ph. 02 8877 0928 or annej@mndnsw.asn.au

For more
photos of our
wonderful
supporters visit
our Facebook
page

www.facebook.com/mndnsw

Editor: Penny Waterson