

## December 2008

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## Walk to D'Feet MND



This year's Walk to D'Feet MND on 9 November at Sydney Olympic Park was an absolute success with regards to the number of participants, the venue and the funds raised.

Although there was some uncertainty about the weather, we were certain of the sincere support of the people who walked to raise funds for research into motor neurone disease.

We had four marshals on bicycles to assist throughout the day. Most participants completed the walk regardless of age or fitness levels by noon, with some groups staying on to relax over a barbeque. We also received donations from people passing by who happened to be at the park but had no involvement with motor neurone disease. What a great way to broaden awareness and meet others in a relaxed atmosphere.

The Walk to D'Feet MND course needed to be completed twice for the full 5 km circuit. This did not pose a concern to the adults who wished to stop at the playground and have fun climbing ropes. The children, however, were determined to complete the Walk without any diversions.

The winner of the lucky door prize of a wonderful gift basket was M. Fairlie. Congratulations and we hope that you enjoy your early Christmas gift.

Thank you to all who participated in the event, as organisers, walkers or sponsors. We appreciate your generosity, dedication and efforts.



*Therese Aoun (centre) and family*



*Jacqueline Mears assisting at the registration desk with MND staff Matthew Fowler, Jenny Judd and Gina Svolos*



*The local playground was a bit of a distraction for some of the adult participants*



*Some four-legged (above) and two-legged supporters (below)*



MND NSW will be closed from 2pm Wednesday 24 December to Monday 5 January. If help is needed during the Christmas break, please consult your doctor.



*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.*

## A Message from the CEO

Our Walk to D'Feet MND, held on 9 November at Sydney Olympic Park, was a spectacular success. A great crowd and great weather made for a very special event. Our team of dedicated volunteers and staff were there to provide drinks and steer people towards the straight and narrow. Thank you to these people and also to everyone who came along. The venue was excellent. However, due to Sydney Olympic Park requirements, we needed to limit the number of registrations. We will be reviewing our venue options for the 2009 Walk to D'Feet MND.

Since the last edition of *Forum* our annual general meeting has taken place. The MND NSW Board for 2008-09 is:

<i>President</i>	Phil Bower
<i>Vice President</i>	Janice Scheinecker
<i>Vice President</i>	Roger Henshaw
<i>Secretary</i>	Bob Howe
<i>Treasurer</i>	Bob Templeman
<i>Members</i>	Alex Green, Gary Jacobson, Nick McLoughlin, Ralph Warren

If you would like to receive a copy our 2007-08 Annual Review and 2007-08 Financial Statement contact the MND NSW Centre at Gladesville ph. 8877 0999.

The 19<sup>th</sup> International Symposium of ALS/MND was held in Birmingham in early November. Maree Hibbert, our Equipment Service Coordinator, attended and will report on her impressions in the next edition of *Forum*. In this edition we have an update about the event from Carol Birks, National Executive Director, MND Australia, who also attended.

Also in November, the Motor Neurone Disease Research Institute of Australia (MNDRIA) and MND Australia held their annual general meetings. At the MNDRIA meeting, a vote to amalgamate MNDRIA with MND Australia as a single national entity was taken and passed. A single national entity will enhance the impact of these separate organisations. We expect a positive effect on the promotion of research into motor neurone disease and on the profile of our national advocacy on behalf of people living with motor neurone disease.

During the past few weeks we have welcomed Ayse Dalkic, Fundraising Assistant, and Greg Colby, Family Support Volunteer Program Coordinator, who introduce themselves below. You can read more about the Family Support Volunteer Program on page 3 of this edition of *Forum*.

We wish you a peaceful and safe Christmas and New Year. Thank you to all our donors for their support in 2008. Our office will be closed from 2pm Wednesday 24 December and will reopen on Monday 5 January. If help is needed during the Christmas break, please consult your doctor.

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*

*Thank you for  
your support at  
Walk to D'Feet  
MND 2008*

## Introducing...

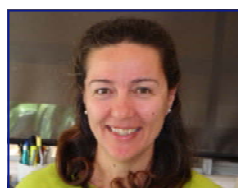


**Greg Colby**  
*Family Support Volunteer  
Program Coordinator*

Hello everyone. It can be difficult introducing yourself to people via a newsletter.

What would people want to know about me? What information would help them get to know me and the sort of person I am? So I thought I'd start with the most important things to know; my birthday is 28 April and I have a fondness for hummingbird cake! I feel much better now that's out of the road.

I have worked with and managed volunteers for most of the past 16 years and have developed a passion for engaging people in what I think is the single most important part of living in community – supporting one another through acts of volunteering. I have managed volunteer programs in a variety of settings including health, youth, aged care and community action groups. I never tire of seeing the changes brought about by volunteers in not just their communities, but in themselves as well.



**Ayse Dalkic**  
*Fundraising Assistant*

I have been working in marketing, finance and educational associations for a very long time and I am delighted to now be at MND NSW. At home I have two teenage children, a supportive husband, a demanding terrier and a docile tabby cat, so home life is quite hectic at times. My hobbies include cycling, making jewellery, painting and bushwalking with friends.

During the past few weeks I have already had the pleasure of meeting many supporters at Walk to D'Feet MND and the Premium Wealth Management MND Charity Golf Day. I've also spoken by phone with most of our fundraising volunteers. If I haven't been able to reach you and you would like to introduce yourself, please do contact me on ph. 8877 0908.

## Family Support

### Christmas

As we approach Christmas life can, at times, get very busy. On pages 8-9 of this edition of *Forum* we have included some suggestions for carers that may help you deal with the emotional and physically demanding aspects of being a carer during this time. Exercising, eating well, taking a break and the other suggestions in the *Carers Survival Guide* are all good ideas and are a timely reminder for you to take care of yourself over Christmas.

For many people, Christmas is a time to meet up with family and friends to enjoy each others company, share meals and exchange gifts. But Christmas can often be a time of very mixed emotions, as we reflect on memories of the past year: shared happiness, shared sadness, love, loss, achievement, joy, hope. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

### Family Support Service Staff Planning Day

As we come to the end of 2008, staff of the Family Support Service will be meeting together for their annual planning day. It is a day for us, as a service, to reflect on our activities of the past year. We will look at what we have achieved, what we might do differently and what we want to achieve in the future. If you have any suggestions about how we could improve our services please don't hesitate to give me a call or send me an email at [ginas@mndnsw.asn.au](mailto:ginas@mndnsw.asn.au).

At the planning day we will also be finalising the calendar for our support group meetings and education programs for the next twelve months. We will include these dates in future editions of *Forum* and on our website as they become available.

### Welcome

I would like to welcome Greg Colby, our new Family Support Volunteer Coordinator, who is working with us one day a week to develop volunteer programs that will support our members living with MND.

### Reminder

In October we mailed out a letter to all members from Professor John Hodges from the Prince of Wales Medical Research Institute, inviting people to be a part of his research, *Emotion and Cognition in MND*. Professor Hodges has been very happy with the response he has received from our members interested in taking part in this research. These members will be completing questionnaires that are designed to evaluate changes in aspects of cognition, especially judgement, problem solving and alterations in emotions. It is not too late to participate. If you have not responded you can still send in your forms or contact Dr Patricia Lillo ph. 9399 1138 or email at [p.lillo@powmri.edu.au](mailto:p.lillo@powmri.edu.au) for more information.

### Gina Svolos

Manager, Family Support

### Family Support Volunteer Program

MND NSW has, since its inception, been a volunteer including organisation - in fact in its early days it was created, staffed and run entirely by volunteers.

In July 2003 the Association began a pilot project in the Hunter, Newcastle and Central Coast areas looking at the benefits of a volunteer visitor program in supporting people with motor neurone disease. The project developed a range of resources for training and recruiting volunteers. This foundation and culture of volunteering is now being built upon by my employment, for one day per week, as the Family Support Volunteer Program Coordinator.

Volunteering is often overlooked as a pathway to social inclusion and as a builder of social capital (the glue that holds communities together; the networks and individual connections between people). It will be my job (actually, my joy) to develop the Family Support Volunteer Program by drawing upon people's needs to belong to and contribute to their communities.

So what will our Family Support Volunteer Program look like? A great question and I'm glad you asked it. During the course of the next few months I will be calling together a working party to look at the shape of the Family Support Volunteer Program. If you would like to participate contact me ph. 8877 0999 Freecall 1800 777 175 or [gregc@mndnsw.asn.au](mailto:gregc@mndnsw.asn.au)

I have identified a range of potential roles for volunteers including:

- transport - to and from appointments
- shopping (either for or with)
- short term respite (a few hours) for carers
- assisting at support groups
- visiting - assisting with meals, reading to, or simply turning pages for members
- housekeeping - lawns, gardens
- writing up life stories - interviews, photos, putting together in a booklet
- foot and hand massages

Another area I think we could explore is that of volunteers assisting MND NSW members to volunteer themselves, either with MND NSW or in a separate area of interest. The personal rewards are numerous.

I'm looking forward to seeing what we can build together.

### Greg Colby

Family Support Volunteer Program Coordinator

### Do you know someone in the media?

MND NSW is looking for volunteers who can assist with organising interviews, prepare media press releases and gain publicity for MND NSW events, issues and volunteer recruitment drives. If you know of someone and would be willing to provide an introduction, we would really appreciate your help in doing so. Contact Kym Nielsen or Greg Colby at MND NSW ph. 8877 0999.

Interested in knowing more about the Family Support Volunteer Program? Contact Greg Colby, MND NSW ph. 8877 0999



## Special Projects and Carers News

### MND NSW Special Interest Groups' Workshop 2008

When a health or community worker cares for someone with motor neurone disease, they bring many skills to the task. However if this is their first encounter with MND, there are a number of additional areas they need to know about to provide optimal care for the person living with motor neurone disease, their family and carers.

A few years ago MND NSW established the Special Interest Groups (SIGs) as an informal e-network of health and community professionals to enhance knowledge about MND and to support workers caring for people living with MND.

This year, the annual SIG Workshop was opened up to include all health and community professionals who are in contact with the Association. It was held on Thursday 6 November at Ryde and was a great success, with over 90 people attending. Thanks to the financial support of the Sacred Heart Palliative Care Service we were able to contribute towards the travel costs of thirteen regional and rural workers.

The day began with Margie Zoing, CNC and MND Clinic Coordinator, Prince of Wales (PoW) and Calvary Hospitals providing an overview of MND and current research at PoW Hospital. Gina Svolos, MND NSW, gave a short talk about working with the Association – a timely presentation due to the number of new faces in the audience. Patricia Reynolds, Clinical Nurse Consultant, Royal North Shore Hospital, spoke about the role of non-invasive ventilation in MND, an area many workers find complex to manage.

After lunch a panel, made up of professionals very experienced in the MND field, discussed how to manage aspects of MND based on a case study written by Margie Zoing. Pamela Hennessy, who cared for her husband with MND, took on the role of family representative and gave her perspective throughout the discussion.

This was followed by Professor John Hodges from the PoW Research Institute, who spoke about an under-recognised association between cognition and behavioural changes in MND. Michael Farrell-Whelan, Bereavement Coordinator, finished off the day looking at the complexities of caring for someone with MND and how to deal with work-related burnout.

Workers who care for people with MND need to be supported and connected with others in the field. We, at MND NSW, seek to facilitate this process. It benefits both the professionals and our members.

If the professionals who are working with you need or want more information about MND, ask them to give us a call to see how we can help them.

### Why not plan a break away (respite) for the New Year?

Feeling a bit tired and overwhelmed with all the Christmas preparations? People with MND and their carers may experience added stresses, some emotional, physical and financial around this time. Planning respite (taking a break), can help you get through this crazy time. Even just having something planned to look forward to in the New Year can bring peace of mind and some added relief.

FlexiRest is funding provided by the Department of Ageing, Disability and Home Care for respite that is not available through existing services and programs.

With this program the person with MND, their family/ carer have a say in what sort of break they need and want. Have a talk to your regional advisor. Taking 'time out' in whatever way that suits you can make a huge difference, helping to diminish built up stresses and strains as well as supporting and nurturing the caregiver relationship. Make a New Year resolution – plan a break!

### Keeping in touch by teleconferencing

Participants from our most recent *Care for Carers* course decided they want to keep in touch with one another after the course, so MND NSW coordinated a teleconference they could dial into for a chat.

Getting busy carers together is a major achievement but was well worth the efforts of all involved. It was great to hear familiar voices again. It felt a bit strange not being able to see one another, but after a while we hardly noticed and talked as though we were back in same room at the *Care for Carers* course. A further *Care for Carers* course is being planned for 2009. If you are interested in finding out more, your regional advisor can provide some information.

**Jane Barrett**

*Family Services Coordinator*

*Need a break?  
Speak with your  
MND NSW  
regional advisor  
about FlexiRest*



*Participants (left) and panel members (right) at the MND NSW Special Interest Groups' Workshop 2008*



## Equipment

During the past few months we have reviewed the operations of the Equipment Loan Service, with the aim of providing a more informative and streamlined service to members and health professionals who access the equipment loan pool.

These changes include:

- an email confirmation from MND NSW to the health professional requesting the equipment for the member, once the request is received at MND NSW.
- the inclusion of a more detailed letter for members with each equipment delivery. This letter informs the member about what is included in the delivery. It also includes details of the health professional the member needs to contact for instruction about the set-up and use of the item.
- an email advising the requesting health professional when an item of equipment is shipped to the member.

Although only implemented in late October we have already seen improvements in communication between members, health professionals and the Equipment Loan Service.

As mentioned elsewhere in *Forum*, the MND NSW office closes for a short period around Christmas. Requests for equipment loan can be made until 24 December, but deliveries around this period can be delayed due to courier and postal schedules.

If an equipment breakdown or emergency does happen during the time the Association office is closed, contact your health professional, for example your occupational therapist or physiotherapist. They will be able to assist in arranging repairs during this time.

The MND Equipment Loan Service staff - Michael, Matthew and myself, wish you all a very safe, memorable and happy holiday.

**Maree Hibbert**  
Equipment Services Coordinator

MND Week  
4-8 May  
2009

## 'Patient experience' websites

When diagnosed with a particular health condition, people often find it helpful to link with others in a similar situation. Frequently this linking-up occurs in person, at a meeting or event; but it is now becoming more common for people to be provided with opportunities to link with others online.

One such online meeting place is *PatientsLikeMe*, a privately owned website run by a company in the United States of America. People can use the site to track and share their disease history online. It is a 'patient experience' website and just one of several similar sites that encourage people to provide information about themselves, often for a world-wide audience.

If you are thinking about contributing to a 'patient experience' website you should consider the following points before you provide information about yourself.

- Details you provide can make you identifiable to others, even though you may not intend this.
- There is nothing to stop others from providing false or misleading information about themselves.
- If anyone can become a registered member of the website, setting your profile as 'visible' to only registered members of the site provides you with no additional protection.

Some particular questions you might seek answers for are:

- Will I receive unwanted information to my email account from your site or related companies?
- Is there a way for me to have my information removed if I change my mind?
- Will my information still show up in an internet search even if it is removed?

- Are my personal details or any other information about me being sold for private profit?

Sometimes you will read information on a site about another person's medications or treatments. It is always important to remember that another person's situation or medication, as they describe it, may not be their actual situation. They may have other conditions, medications or treatments that you don't know about.

Experimental medications or treatments have three potential health outcomes. They may:

- have harmful effects, including a reduction in lifespan and/or quality of life
- have beneficial effects
- have no effect.

Other conditions, medications or treatments can interact with experimental medications or treatments. Also, there may be significant costs involved.

Your doctor is always the best person to talk with about medications and treatments. If you come across a medication or treatment of interest to you, chat to your doctor about it and seek his or her advice.

**Penny Waterson**  
Information Resources Coordinator

For more information see:

- PatientsLikeMe: [www.patientslikeme.com](http://www.patientslikeme.com)
- Internet and online safety: [www.netaert.gov.au/advice/risks.html](http://www.netaert.gov.au/advice/risks.html)
- Article discussing the issues: Goetz, T. 2008. 'Practicing patients', The New York Times. March 23.

## Mailbag

**A**round 1972 the Lions Club of Warners Bay commenced a motor neurone disease support group after a member of the club was diagnosed with MND. In 1986 I was asked to join the Lions Club and participate in the MND support group as a 'Supporting Lion' and in later years took on the position of Secretary.

In 1996, ten years later, I noticed that when I was doing ballroom dancing, my legs got very tired. Then in 1997 my speech became very nasally. A trip to the doctor and I was told it was sinuses that were causing my speech problem. As things were getting a bit worse I decided to go to another doctor for acupuncture as it was mentioned that this might help my sinus problem. I did not get the acupuncture but was referred to a neurologist who did a nerve test on my legs and arms, plus a blood test. It was confirmed that I had a form of motor neurone disease called Kennedy's disease. Never at any stage as a supporter to the MND group did I think I would become a patient.

It was very hard to accept the news but I was grateful to find out just what was wrong with me. I was the only person with Kennedy's disease in NSW at the time I was diagnosed (that I knew). After a few years I learnt there were five patients just like me. I contacted each one by email or phone and set up a communication between us all giving an insight as to how we were all going each week.

My greatest contact, who is now a personal friend, was from Queensland. I contacted him in the early days and he gave me great information on Kennedy's disease as he has had it for about twenty years. Today, we are great friends and communicate by email every day. Most importantly, when time permits, I call in to see him and have a chat. Over time I was given information about a Kennedy's Disease Association in America, which I contacted. The help I received from the members was fantastic to say the least.

More recently, I have been connecting with others who have Kennedy's disease through the *PatientsLikeMe* website. I have added bits of information about myself and about the effects of Kennedy's disease. Others with Kennedy's disease can learn about how I am going. I like being in contact with people from around the world and often receive emails thanking me for my support and for giving information about myself.

I have a disease that is not going to go away and there is no medication to stop the progression. I live each day to the fullest. To people living with motor neurone disease, God bless.

**Alistair**  
Warners Bay

*For more information about the PatientsLikeMe website, see 'Patient Experience' Websites on page 5 of this edition of Forum.*

**R**ecently, my husband and I had a great holiday in Fiji where we stayed at The Warwick Resort. It was the first time in my life that I've actually had an aromatherapy body massage and it was great. My husband had a hot spa which helped his muscles afterwards.

Thanks to FlexiRest and the respite program, we had a memorable holiday which I will cherish. The financial assistance was most appreciated.

**Sylvia**

*For more information about FlexiRest speak with your MND NSW regional advisor.*



### Support Group Contacts

#### METROPOLITAN

Ph: MND NSW 1800 777 175

#### Gladesville

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

#### Northern Beaches (Mona Vale) and Northern Sydney (Hornsby)

Jo Fowler - [josephinef@mndnsw.asn.au](mailto:josephinef@mndnsw.asn.au)

#### Western Sydney

Jenny Judd - [jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)

#### REGIONAL AND RURAL

#### ACT and Southern NSW

Iva Plessnitzer Ph. 6286 9900  
[ivap@mndnsw.asn.au](mailto:ivap@mndnsw.asn.au)

#### Broken Hill

Jamie Mitchell Ph. 08 8088 7123 (bh)  
or 08 8088 1333 (ah)

#### Central Coast

Audree Dash Ph. 4384 2907  
Sheila Holmes Ph. 4392 5513

#### Central West

Jenny Judd Ph. 1800 777 175  
[jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)

#### Illawarra

Cindy Cleary Ph. 4223 8000

#### Newcastle and Hunter

Noelle Smith or Eileen O'Loughlen Ph. 4921 4157  
[noelles@mndnsw.asn.au](mailto:noelles@mndnsw.asn.au)  
[eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au)

#### Northern Rivers

MND NSW Ph: 1800 777 175

*Email or write  
your letter to  
the editor of  
Forum*

*See back page  
for contact  
details*

## Support Groups

### Central Coast

We have enjoyed another wonderful year of fellowship at our bi-monthly meetings with our new and old friends, family members, carers and regional advisor, Jo Fowler.

During MND Week in May we were out in the community, raising awareness and funds for the continued good work of the Association through stalls and well-placed boxes of cornflowers. In spring, a painting donated by our own artist, Louise Grant, proved a popular and profitable raffle. The lucky winner was D. Matthews. If you missed out, Louise is preparing another painting, so make sure you get a ticket.

For the tenth consecutive year we are running a Rotary Community raffle. First prize is \$3000 worth of travel. Tickets at \$2 each are selling until January 2009 and are available from Audree Dash, ph. 4384 2907. All profits go to MND NSW.

I am so proud of our little group. We have laughed and cried and shared pain and joy together. Great friendships have formed through love and support of each other. My best wishes for the New Year.

### Audree Dash

*Coordinator*

### Kingswood

The group was very well attended in September as we had a speaker from Carers NSW who addressed the often challenging and largely unsung work that carers do for those living with motor neurone disease. This generated much discussion and was a great way for people to share their experiences, wherever they may be on their journey of living with MND. It was great to see new people at the group feeling more fortified for the road ahead.

The next meeting at Kingswood will be our last for the year. We will have singer Karen Lynne providing some light entertainment, and Kym Nielsen, Fundraising Manager, MND NSW will speak about her role at the Association. Kym will also have merchandise available for sale.

These meetings provide a casual opportunity to meet others who are facing similar challenges. Everyone is always warmly welcomed.

### Jenny Judd

*Regional Advisor*

### Orange

At our October meeting we all enjoyed a lovely lunch, made possible through a donation from Carers NSW towards our Carers Week activities. It was an excellent opportunity to relax and continue our meeting chat and was most appreciated by everyone!

### Jenny Judd

*Regional Advisor*

### Northern Beaches

Our group held its last informal meeting for the year in October. Rather than meeting again on 4 December, our members and carers collectively decided to attend the members' Christmas party and join in with the fun and festivities at the MND NSW Centre, Gladesville. We look forward to catching up with each other there.

Thank you to all our group members and the supporters who regularly attend and help make the meetings so worth while. Many thanks also to the service providers and speakers who have contributed so much help and information to us throughout the year.

We have been asked to change our meeting day at the Palliative Care Cottage from a Thursday to a Monday. So I will keep you posted when dates for next year have been finalised.

May we all look forward to Christmas and the coming New Year with hope and love in our hearts.

### Jo Fowler

*Regional Advisor*

### ACT and Southern NSW

Our group has met twice now and while our numbers have been small the members have found it beneficial to discuss and share information with each other. Jill Pearce from the Carers Association came to speak to us during November. That led to a discussion about how people have accessed respite and which services in the ACT offer respite.

New people are always welcome: members with MND and/or their carers so please ring me for more information. I hope that you all have an enjoyable time over Christmas with family and friends.

### Iva Plessnitzer

*Regional Advisor*

### Learn Now Live Well Workshop MND NSW Centre, Gladesville

Regional advisors, Caroline Gleig and Robyn Peterson, facilitated the MND NSW *Learn Now Live Well* workshop during November.

The workshop provided a great opportunity for members and families to meet with other people who know what it is like to live with motor neurone disease.

There was always lots to talk about during the workshop, as well as around the lunch table.





## EATING WELL

Eating a healthy, well balanced diet is just as important for you, as it is for the person you support. A balanced diet, including fruit and vegetables will provide you with the energy you need for caring, build your immune system and reduce the chances of you becoming unwell.



## SLEEPING WELL

Regular exercise and a healthy diet will help you to get a good night's sleep. Try to go to bed and rise at the same time every day. Ensure your bedroom is comfortable and your bed provides good support for your back. Cut down on tea and coffee in the evening and try not to eat late at night. A warm bath may also help.



## KEEPING WELL

Have a regular check-up and let your doctor know that you are a carer. They will be an invaluable source of help and advice. As a carer you will most likely carry on regardless through coughs and colds or stomach upsets, but it is unwise to put off seeing your doctor. Even with a minor illness it is important to take some time out to rest to speed up your recovery.



## BACK CARE

Helping the person you support may place strain on your back. See your doctor if you currently are experiencing back pain. It may be impossible to avoid lifting so you need to learn how to lift in ways that reduce the risk of harming your back. There is equipment that can minimise the strain on your back. This includes lifting equipment, mobility aids, motorised bath seats and walk-in showers suitable for wheelchairs.



# The Carers' Survival Guide

**Being a carer can be immensely rewarding, but it can also be emotionally and physically demanding.**

There are an increasing number of services out there for you and the person you support, although it will vary from area to area.

### Services include:

- Carer Support Groups
- Respite
- Counselling Services
- Community Health Centres
- Food Services
- Personal Care
- Domestic Assistance
- Neighbour Aid
- Home Modification and Maintenance
- Home Nursing
- Palliative Care
- Transport Services

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## STRESS

There are simple things you can do to help reduce stress and cope with its effects. Try to work out what is making you stressed. Allow yourself some breathing space. Take a break from caring, even for a couple of hours each week and treat yourself to something you enjoy. Take up a physical activity, eat sensibly and get enough sleep. Find someone you can talk to and use their support to talk through your feelings.



## FEELING DOWN

There are useful steps you can take if you are feeling down. It often helps to talk things over with someone else. Get outdoors and do some exercise, even if it is only for a walk. Treat yourself or do something you find really interesting. Eat a balanced diet. Remember, other people have gone through what you are experiencing and may be able to help you.



## TAKING A BREAK

Everybody needs some time off to recharge the mind and body. Taking a break from caring is a realistic and important thing to do - a chance to do all the things you can't do while caring, such as catching up with friends, family or achieving your personal goals. It is also a good opportunity for the person you support to experience and communicate with others.



## EXERCISE

Exercise and a good night's sleep gives you a lift if you are feeling down. A brisk walk, gardening or dancing are easy ways to keep active and healthy. Swimming, if you have arthritis, is an excellent activity. Tai Chi can improve posture, balance, flexibility, strength and reduce stress. Yoga and meditation leads to increased relaxation and physical fitness. If you can't leave the person you support, try an exercise video.

**The better your physical and emotional wellbeing, the better you are able to cope with the demands of caring.**

To find out what services can help, call the *Commonwealth Carer Resource Centre on Freecall 1800 242 636*.

Your nearest Commonwealth Carelink Centre can provide you with information about community care and other disability and aged care services available in your local area. *Commonwealth Carelink Centre Freecall 1800 052 222*.

Other information services:

*Commonwealth Carer Respite Centres Freecall 1800 059 059*

*Translating and Interpreting Service 131 450*

*Aged and Community Care Information Line 1800 500 853*

*Carers NSW 02 9280 4744 [www.carersnsw.asn.au](http://www.carersnsw.asn.au)*

*Carers NSW Young Carer Project Freecall 1800 242 636*

## International Update



The **International Symposium on ALS/MND** is an annual event bringing together leading international scientists, health professionals and others to present and debate key innovations in ALS/MND research, treatment and care.

Each year, during the days just before the Symposium, two other important international meetings are conducted. These are the:

- **Annual Meeting of the International Alliance of ALS/MND Associations**, which brings together ALS/MND Associations from around the world to share initiatives and develop strategies for fighting ALS/MND
- **Allied Professionals Forum**, which focuses on practice and experience for health professionals in the care and support of people living with ALS/MND.

In November 2008, **Carol Birks, National Executive Director MND Australia**, attended the International Alliance meeting, the International Symposium, the Allied Health Professionals Forum and a local **Ask the Experts** session in Birmingham, England. This is her report.

### 16th Annual Meeting of the International Alliance of ALS/MND Association

At the Alliance meetings, there were 63 delegates representing 49 organisations from 40 countries.

The meetings commenced with the annual general meeting where Rod Harris, CEO MND Victoria and MND Australia delegate, stood down as the Chairperson and handed over to Gudjon Sigurdsson from Iceland. Rod's achievements in growing and developing the Alliance were formally recognised and acknowledged by the board.

### International overview of care and information developments

Presentations on the first day provided an overview of care and information developments in Iceland, Taiwan, Italy, Slovenia, Australia, Israel and Spain. Contrasting awareness films from the United Kingdom and Canada were shown which engendered much discussion. There was a short introduction to the film 'Living with Lew' presented by Dee Holden Norris. This film follows a young Hollywood writer and director who received funds to direct one of his films after being diagnosed with motor neurone disease. The film follows his life as he directs the film from his wheelchair. Hopefully this will be shown in Australia one day!

The theme of the day was the promotion of global research and collaboration. The Paulo Gontijo Institute provided information to those present about their PG Award. Researchers or scientists from anywhere in the world can apply for this funding in 2009. The Israeli Association (IsrA.L.S) was inspiring in outlining its achievements and goals since it was founded just four years ago. Three years ago there was no amyotrophic lateral sclerosis research in Israel and now the Association is funding 20 researchers. It has been instrumental in initiating a national research program of neurodegenerative diseases and has secured matched funding from its government. IsrA.L.S is keen to promote combined global research efforts.

### Partnership Program and Needs and Offers

The next day provided updates on two Alliance initiatives - the *Partnership Program* and *Needs and Offers*. Supported by the *Alliance Support Grant Program*, the *Partnership Program* provides monetary assistance to support new or less well

resourced associations around the world. Some 37 support grants have been awarded since it was established five years ago.

Kathy Mitchell from Algonquin College in Canada has been working closely with the ALS/MND Association in Serbia/Montenegro over the last five years educating and supporting health professionals caring for people with motor neurone disease. The ongoing partnership between the ALS Hope Foundation, USA and ABrELA, Brazil, has been further strengthened through exchange visits to promote sharing of information and ideas. A new partnership was established during the year between England and Turkey. Turkey has limited resources for people living with motor neurone disease and the professionals caring for them. Two nurses from England visited Turkey to provide education and support to the nurses there. They plan to remain in contact via email and to visit the Turkish Health Minister to discuss their project and the model of care in the United Kingdom.

*Needs and Offers* was established last year to promote sharing of resources, information and ideas. During the year Iceland identified the need for a database to organise information about people with motor neurone disease in Iceland. The ALS Hope Foundation offered to provide theirs and an exchange visit facilitated further sharing. At the meeting in 2007 IsrA.L.S offered a DVD, featuring Professor Stephen Hawking, to all Alliance members. MND Australia needed a community service announcement to support the MND Week 2008 theme *Living Better for Longer* and used the DVD to fill this need. The UK/Turkish partnership grew from the Turkish need for health provider education and support and the offer from the UK nurses to provide support. This program, along with the Alliance itself, continues to grow and develop.

### Ask the Experts

An *Ask the Experts* session was held that afternoon for people living with motor neurone disease and this year a new format was trialled based on speed dating!! Over 80 attendees sat at tables and the researchers moved every ten minutes to a new table to talk about their research and to answer questions.

(Continued on page 11)

*MND Australia is a very active member of the International Alliance of ALS/MND Associations*

## International Update (cont'd)

(Continued from page 10)

### Allied Professionals Forum

The Allied Professionals Forum, hosted by the International Alliance, precedes the Symposium and, as always, attracted many health professionals and quality presentations related to care and management of motor neurone disease. There were 15 presentations, including three from Australia.

Management and care issues covered included: care pathways, a fast track diagnosis program, volunteers and the multidisciplinary team, nurse-led clinics, compassion fatigue, support needs of people with motor neurone disease, palliative care, the computer and communication, guidelines on percutaneous endoscopic gastrostomy placement and diaphragm pacing to assist breathing. Abstracts will be available soon on the International Alliance website. If you would like more details on these presentations see [www.mndassociation.org](http://www.mndassociation.org).

### 19th International Symposium on ALS/MND

The Symposium, hosted and organised by the MND Association of England, Northern Ireland and Wales, was held on the following three days and included plenary sessions, concurrent scientific and clinical sessions and a room filled with research posters! As Brian Dickie, Director of Research at MND England, Northern Ireland and Wales commented, "after more than 60 years of research ALS/MND research around the world is now exploding". There were many interesting presentations and all the abstracts are available at [www.mndassociation.org](http://www.mndassociation.org).

I attended the clinical sessions and there were many useful presentations which will help to strengthen our quest to promote the best possible care and support for people living with motor neurone disease in Australia.

Work being done to identify the different types of motor neurone disease is progressing. This research is vital in ensuring an early and accurate

diagnosis for people with motor neurone disease, to guide treatment, to develop disease markers and to assist physicians to provide a more accurate prognosis to their patients. The increasing need for evidence based research related to motor neurone disease care management was highlighted and the difficulties discussed. Although evidence based treatment trials are the 'gold standard', the presenter argued that there should be an opportunity to also share the experiences of pro-active multidisciplinary teams that commonly utilise non-evidence based, symptomatic treatments to improve quality of life and comfort.

The diagnosis of motor neurone disease can sometimes take a long time, delaying the initiation of support and treatment. A motor neurone disease care centre in the United Kingdom implemented a fast track referral process for people suspected of having motor neurone disease. The median time from referral to diagnosis for the fast track patients was 51 days compared to 104.5 days for others. The most important barrier to early diagnosis is the ability of the general practitioner to identify motor neurone disease as a potential diagnosis.

The importance of ALS/MND registries in defining clinical characteristics and care provision was discussed by a researcher from an ALS centre in Italy. Their register of ALS/MND patients has shown no increase in incidence since 1995. A significant decrease in the time from symptom onset to diagnosis indicates that physicians in the area are more aware of ALS/MND. Please talk to your neurologist about registering with the Australian MND Registry (AMNDR) [www.amndr.org](http://www.amndr.org) if you are not already registered and want to contribute to Australian research.

A Spanish survey of patient experiences of diagnosis and care identified considerable delay in diagnosis. Together with the way the diagnosis was given, this delay impacted on the emotional distress of the patients. The need to raise awareness of motor neurone disease and to educate health professionals was confirmed.

### Cognitive and psychological change

There was a whole session on cognitive and psychological change, demonstrating that research related to these symptoms has progressed considerably.

The prevalence of frontotemporal dementia in the ALS population is estimated to be up to 50 per cent. How this manifests in individuals, however, varies considerably from very minor and subtle behavioural changes or word-finding difficulties to, in a very few cases, a marked dementia. Evaluation and screening is therefore important but often very difficult. The development of concise and practical assessment tools to assist multidisciplinary teams to improve care planning and support with the patient

(Continued on page 12)

*Talk to your neurologist about registering with the Australian MND Registry (AMNDR) if you are not already registered*



(l-r) At the Symposium (l-r) Rod Harris, Chief Executive Officer, MND Vic, and immediate past Chairman of the International Alliance of ALS/MND Associations; Lesley Burcher, Regional Advisor, MND Vic; Maree Hibbert, Equipment Service Coordinator, MND NSW; Miranda Rodriquez, Clinical Nurse Consultant, Calvary Health Care Bethlehem Victoria; and Carol Birks, National Executive Director, MND Australia.



## International Update (cont'd)

(Continued from page 11)

and the family is progressing.

The need to better understand the impact of cognitive change on the quality of life of the person with motor neurone disease and the carer and to invest in appropriate information and clinical resources was also discussed.

### Respiratory management

The respiratory management session discussed the need for optimal timing of this intervention based on ventilatory insufficiency and also the issue of compliance. The presenters highlighted that we know that non-invasive ventilation extends survival and improves quality of life but many people do not tolerate this intervention or refuse it when offered. It has been suggested that early initiation may assist with compliance, but there is no standardised method for initiation to guide practice.

A number of trials are looking at these issues. One study suggests that males with a higher level of income and education and good upper limb function are more compliant. The importance of education and support to manage non-invasive ventilation machines and to address issues was highlighted.

A new technology to stimulate the diaphragm to assist respiration being trialled at eleven sites worldwide was presented. Diaphragm pacing involves the insertion of pacing wires into the diaphragm to stimulate contraction of the diaphragm in patients who are experiencing diaphragmatic weakness which impacts their breathing. This trial has found that the technology is safe, has a positive effect on diaphragm function and enhances non-invasive ventilation use. It was found to be most useful for people with increased upper motor neurone involvement.

### Scientific highlights

The final joint closing sessions included the scientific highlights. In this session research advances related to axonal transport and new genes were discussed. The potential for research advances to be further investigated using new animal models, including a fly model, was highlighted. Results of a randomised control phase II trial for coenzyme Q10 showed a decline in function for those participants who were given the drug. Delta 9Tetrahydrocannabinol was found not to be effective in treating cramps. A two-year multicentre trial to assess the efficacy of subcutaneous insulin-like growth factor type 1 (IGF-1) found no difference between treatment groups. Current drug trials are focusing on testing drugs that can get into the cerebral-spinal fluid and a couple of preliminary drug trials are looking promising.

It was a positive end to a very intense few days for all delegates to note that a new genetic cause has been identified that we knew nothing about twelve months previously resulting in a whole session on

TDP 43 related research. There are now increased insights into the genetic causes of sporadic ALS and the mutant SOD 1 mouse model is being refined to be a more effective research tool.

Although there were no major breakthroughs related to treatments for people living with motor neurone disease today, the increased understanding of many of the mechanisms related to MND provides hope that we are getting closer to that breakthrough. In the meantime clinical research confirms the positive effect of early diagnosis, comprehensive multidisciplinary care and management interventions to assist nutrition, ventilation and communication on quality and length of life for people living with motor neurone disease.

### Awards

The International Alliance of ALS/MND Associations promotes both care and research internationally. This is confirmed by the two awards presented annually at the Symposium Dinner.

The Forbes Norris Award, first presented in 1994, was inaugurated by the International Alliance of ALS/MND Associations in memory of Dr Forbes (Ted) Norris, a neurologist dedicated to helping people with ALS/MND. The Award is to encourage a combination of two major qualities; management of, and advances in understanding ALS/MND, to the benefit of people living with ALS/MND. The recipient this year was Canadian researcher Michael Strong.

The Humanitarian Award was inaugurated in 2000 by the International Alliance of ALS/MND Associations to recognise non-scientific contribution to the fight against ALS/MND. The award recognises and encourages individuals from a non-scientific background whose work makes, or has made a contribution of international significance for people affected by ALS/MND. I am very pleased to report that this year an Australian, Rodney Harris, CEO MND Victoria and outgoing chair of the International Alliance, was presented with this prestigious award in recognition of his work both nationally and internationally.

Once again this year an Australian with MND, Mr Phil Brady, was included in the International March of Faces Banner. There is one Australian featured on most of the banners, so if you would like to be included on the new International March of Faces banner next year please contact me as soon as possible.

**Carol Birks**

National Executive Director, MND Australia

*"....we know that non-invasive ventilation extends survival and improves quality of life..."*





## MND Research Institute of Australia Grants 2009

*Congratulations to the recipients of the Motor Neurone Disease Research Institute of Australia research grants for projects commencing in 2009.*

### Grant-in-Aid

**Dr Julie Atkin** *Motor Neuron Disease Research Team, Howard Florey Institute, University of Melbourne.*

**New therapeutic approaches for MND based on ER stress inhibition**

We recently showed that a cellular pathway called 'ER stress' triggers the death of motor neuron cells in MND. We wish to determine if new compounds that reduce the ER stress response could be used to delay disease onset and progression of this disease in animals that develop MND. These studies would establish whether these or related drugs might be effective in humans with the disease.

### Peter Stearne Grant for Familial MND Research

**Dr Ian Blair** *ANZAC Research Institute, NSW*

**Identifying novel genetic loci for familial motor neuron disease**

The aim of this project is to use genetic screening strategies in a subset of our MND family cohort to identify one or more chromosomal regions that harbour new MND genes. Identification of the genes causing MND will lead to a greater understanding of the biology of motor neurons and the basis of familial and sporadic motor neuron degeneration.

### Mick Rodger Benalla MND Research Grant

**Dr Anna King** *Menzies Research Institute, University of Tasmania*

**The role of distal axonal degeneration in ALS**

Nerve cells are highly specialised cells, which have long processes (axons) that are necessary for the conduction of the nerve impulse to the neuro-muscular junction. It is still unclear whether this disease is caused by a dying back from the nerve terminals in the muscles, or a dying forward from the cell bodies in the nervous system. This proposal will seek to answer this question using animal and cell culture models.

### MND Victoria Research Grant

**Dr Fiona Fisher** *Clinical Neuropsychologist, Calvary Health Care Bethlehem, VIC*

**Cognitive and behavioural changes in MND: exploring the impact on caregivers.**

The proposed research aims to explore the impact of cognitive and behavioural changes on caregiver burden and psychological wellbeing, in a large Australian sample of persons with MND and their caregivers. It is anticipated that subsequent research will focus on the development of interventions and education programs to support caregivers to better manage the cognitive and behavioural difficulties, to promote improved quality of life for both the care recipient and caregiver.

### Charles & Shirley Graham Family MND Research Grant

**Dr Marina Kennerson** *ANZAC Research Institute, NSW*

**Finding genes causing familial motor neuron degeneration**

We have mapped and refined a locus for distal spinal muscular atrophy on chromosome Xq13.1-q21 (DSMAX). In this application we aim to identify the gene by targeting the DSMAX region in an affected individual in the family and undertaking high throughput sequencing.

### Henry H Roth Charitable Foundation MND Research Grant

**Professor Nigel Laing** *Western Australian Institute of Medical Research*

**Genome-wide mapping of modifying loci in familial ALS**

Whilst the mapping and identification of some genes responsible for FALS has been successful, other genes remain to be found and modifying factors that influence the phenotypical variation remain to be elucidated. Further understanding of these modifying elements in *SOD1* FALS would be of great benefit in predictive genetic counselling of unaffected relatives and diagnostic testing.

### Zo-eè MND Research Grant

**Dr Louisa Ng** *Rehabilitation Physician, Royal Melbourne Hospital, VIC*

**Disability in motor neurone disease**

This study aims to paint a holistic profile and health care needs for persons with MND in an Australian sample, and in doing so identify gaps in knowledge and in service provision to enable recommendations for future development of health care services to best meet the needs of the identified priorities.

### Mick Rodger Benalla MND Research Grant

**Dr Robyn Wallace** *Queensland Brain Institute, University of Queensland*

**Identifying biomarkers for MND using flow cytometry**

We will attempt to identify biological markers from MND patient blood samples, using modern technologies. These studies have the potential to identify markers that can be used to track progress of disease and that may give information about what causes MND. This could highlight potential targets for drug development.

### Bill Gole MND Postdoctoral MND Research Fellowship (2009 - 2011)

**Dr Justin Yerbury** *Centre for Medical Biosciences, University of Wollongong*

**Probing molecular mechanisms of microglial and astrocyte activation in ALS**

This project combines unique expertise to perform truly pioneering studies to determine how a genetic defect in a protein, superoxide dismutase, affects immune processes implicated in motor neuron disease. Novel approaches will be used to study relevant molecular interactions, both in the test tube and in animal models. The outcomes will provide a new understanding of these processes and may contribute towards the ultimate development of new therapies.

## Support from the Southern Highlands



Kym Nielsen (r), Fundraising Manager, MND NSW, accepting a donation from Helen Kemsley at the Bradman Museum.

In the past few months two fundraising events have been held in the Bowral area to honour the memory of Ginger Meggs cartoonist, James Kemsley, who lived with motor neurone disease until December last year. The first was the local premiere of the movie 'Sex in the City', held at the

Empire Twin Cinema in Bowral. Lots of local residents came along to support this great night and enjoy a glass of champagne and nibbles.

On Sunday 14 November a dedicated group of friends held the James Kemsley Memorial Cricket match at the Bradman Oval in Bowral. Half of the proceeds from the match fees were donated to MND NSW, with the other half put towards a student cricket scholarship at Chevalier College where James was a former student. A great day was had by all and a very enthusiastic group of cricketers has decided to do it all again next year. Thank you all for your support.

## Wonderful Charity Weekend at South West Rocks

The annual Ray McDougall-Margaret Burge Charity Weekend at South West Rocks was held over 25-26 October and what a huge weekend it was, with lots of local support. This is the eighth year of this great fundraising event which includes a sports memorabilia auction, golf game and a wonderful raffle to raise much needed funds for MND NSW. We'd like to thank Bruce and his committee for their continued support.

## Singles masquerading at BBQ

A Singles Masquerade Ball held for MND NSW was transformed into a barbeque evening for friends at the last minute due to the lack of single guys.

The barbeque fun night was held on 25 October, at Coogee Surf Life Saving Club. Over 50 people attended the night with great lucky door prizes, raffles and a fabulous barbeque feast catered by Swiss Paulies catering. The night was a great success with lots of dollars raised for MND NSW. Our thanks to De Bortelli Wines and Speedboats on the Harbour who donated raffle prizes. Thanks to the hardworking committee of Vicky Kasunic, Julie Werda, Kathy Lasan, Colin Coates, Sasha Faint and Christina Pettorino.

## Style is more than fashion

Elizabeth Walter from Ms Elizabeth Hair Studio of Epping recently held a fundraiser for MND NSW at Boronia Grove Epping.

Over 95 women enjoyed a night of bubbles, nibbles and loads of fashion and makeup tips. A very big thank you to Elizabeth and all involved with this great fundraising night.

## Reaching fundraising goals

by Laraine Hunter of Sydney's northern beaches

During November, the Harbord Diggers Club played host to a wonderful fundraising event for MND NSW. This evening was organised by Beacon Hill Youth Club Netball (BHYC) and supported by Manly Warringah Netball Association (MWNA). I have been involved with netball in varying capacities for the past 14 years and was diagnosed with motor neurone disease over Christmas last year. This year has been a bit of a struggle, especially being an umpire and coach with the loss of my speech. However through all of this my netball friends have been a tremendous support.

My club, BHYC, asked if they could help in a special way. What better way than to raise money for MND NSW to use for their services and to support research into this disease in the hope of finding a cause and cure? I am overwhelmed by the effort of the group of organisers from BHYC and MWNA who put together such a fun night - where 230 people gathered, where one-third were in their twenties, and many others, well let's say were more senior, and every one of them enjoyed themselves and donated freely to the cause.

## Premium Wealth Management MND Charity Golf Day

by Roz Kaye of Premium Wealth Management



The winners of the Golf Day with Graham Opie, CEO MND NSW (l-r) Tony Cooper, Richard O'Flynn, Sean Leong, Graham Opie and Ben Tallentire.

The inaugural Premium Wealth Management MND Charity Golf Day started out with sunshine and blue skies. We had 61 players registered for the day and 62 players turned up (which I think you will agree was an outstanding success). Special guest on the day was Mark Bylsma, Australian long drive champion, who put on a wonderful display (smashed the ball so far - most participants couldn't find it on the golf course). Mark spent the day auctioning his golf shots off to the players. Thanks Mark.

All agreed that the day was a wonderful success and the participants enjoyed fantastic facilities at Killara Golf Course. In the evening we had a barbeque dinner and charity auction. Many thanks to Indy Singh from Fiducian who was our Auctioneer for the night who made sure everybody bid. The day was a great success. A big thank you to our sponsors on the day:

- |                         |              |
|-------------------------|--------------|
| - AGC Premium Insurance | - Challenger |
| - AMP Capital           | - CommSec    |
| - APN Funds Management  | - Instreet   |
| - Aspen Group           | - Macquarie  |
|                         | - Principal  |
|                         | - Skandia    |

Thank you for your continued support



**MND Week 2009****4-8 May**

**Just a reminder that MND Week 2009 will be upon us before we know it.**

Volunteers are needed on Sydney's streets - and elsewhere. The prime time is between 7-9am at one of your local train stations.

So, why not join a team or organise to sell some merchandise at your office?

No previous experience needed - just a big heart.

To volunteer or for further details contact Ayse Dalkic at MND NSW ph. 8877 0908 or email [aysed@mndnsw.asn.au](mailto:aysed@mndnsw.asn.au)

*Join us in raising community awareness of motor neurone disease during MND Week 2009*

# Tuesdays with Morrie

The Ensemble Theatre has offered MND NSW this exciting opportunity for the final night performance of this fabulous play starring Glenn Hazeldine as Mitch Albom and Warren Mitchell as Morrie Schwarz.

**Date** Monday 16 February 2009

**Place** Ensemble Theatre Kirribilli

**Time** 7.30pm

**Tickets** \$54 Seniors \$49 Pensioners \$45  
Full-time students under 26 \$23

**Bookings** Through the theatre ph. 9929 0644 and mention that it is the charity night event for MND NSW on Monday 16 February.

We would like to acknowledge Mitch Albom, Jeffrey Hatcher, Dramatis Play Services and Hal Leonard Australia for giving us permission for this very special fundraising evening.

**ensemble  
theatre**

**Dates for the Diary**

16 Feb	<b>Tuesdays with Morrie</b> <i>MND NSW Charity Night</i> <i>Ensemble Theatre Kirribilli</i> 7.30pm. Book through the theatre on 9929 0644. Tickets \$54, Seniors \$49, Pensioners \$45, Full-time students under 26 \$23.
21 Feb	<b>St Valentine's Day Ball</b> <i>Dapto</i>
March	<b>Third MonStar Cup</b>
11 Mar-10 May	<b>A Drive for A Cure</b> <i>In memory of Norman George Jones</i>
2-3 May	<b>Open Garden at 'Homeleigh'</b> <i>Pymble</i>
4-8 May	<b>MND Week</b>
8-21 Aug	<b>Kokoda Challenge for MND</b>

**kokoda** Charity Challenge.

The Motor Neurone Disease Association of NSW and World Expeditions are excited to offer the MND Association Kokoda Challenge.

**8-21 August 2009**

One of the great treks of the world, the Kokoda Track crosses the Owen Stanley Ranges in Papua New Guinea. A journey through Australian history, the track stretches 96 kms through what is arguably some of the most rugged and wild jungle in the world. This is a trek that you can feel proud to say you've completed; as a mark of respect to Australian wartime history, and of course, as a physical challenge.

## challenging trek

## expert guides

*with an indepth historical knowledge*

## no local payments

*international airfares*

*all meals on trek*

*track fees*

*donation to assist with local community projects*

## unique accommodation

*a combination of rest houses and camping*

**\$6500 fundraising target**

This trip is limited to the first twenty people registered. **For further information contact Kym Nielsen at MND NSW ph. 8877 0912.**

## Noticeboard

### NSW Companion Card Update



The Companion Card Program currently being implemented in New South Wales will allow people who have a significant and lifelong disability to take a carer on public transport and to recreational activities and events for the price of a single ticket. The Department of Ageing, Disability and Home Care (DADHC) is expecting the first cards to be issued in March 2009. If you would like more information about the program, would like to register your interest to receive an application kit when it becomes available, or would like to suggest an organisation to recognise the Companion Card, contact DADHC ph. 02 8270 2000 or email [companioncard@dadhc.nsw.gov.au](mailto:companioncard@dadhc.nsw.gov.au)

### Australia ratifies Convention on the Rights of Persons with Disabilities



During 2008 Australia became a signatory to the United Nations

Convention on the Rights of Persons with Disabilities, making it one of the first Western countries to do so. The Convention marks a paradigm shift in attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as subjects with rights, who are active members of society capable of claiming those rights and making decisions for their lives based on their free and informed consent. The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorisation of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. For more information see [www.un.org/disabilities](http://www.un.org/disabilities) source: [www.un.org/disabilities](http://www.un.org/disabilities)

### For Sale



Chrysler Grand Voyager 2005, reg. to Apr 2009, Khaki. Auto, approx, 36000km. Five-seater plus wheelchair front passenger, or six-seater. Certified electronic side-ramp and doors. \$75,000 ono. Contact Annette ph. 99087128.

### Thank you Huhtamaki Australia Limited



Thank you to Khalid Ali, Tony Clark and Huhtamaki Australia Limited for their kind donation of plates, cups, glasses and cutlery for the MND NSW Members Christmas Party.

### Planning ahead



A new fact sheet about planning ahead has recently been released by the NSW Seniors Information Service. Covering issues such as wills, power of attorney, guardianship and advanced care directives, the fact sheet is available in English, Arabic, Chinese, Greek, Italian, Polish and Spanish. For more information speak with your MND NSW regional advisor or see [www.seniorsinfo.nsw.gov.au](http://www.seniorsinfo.nsw.gov.au)

### CityRail Guide to Accessible services



CityRail's Guide to Accessible Services provides tips advice and information about:

- planning your trip
- transport connections
- tickets and fares
- passenger information
- wayfinding
- boarding the train
- your train
- wheelchairs and scooters
- animals and pets
- toilets

For more information see [www.cityrail.nsw.gov.au/facilities/accessible\\_services.jsp](http://www.cityrail.nsw.gov.au/facilities/accessible_services.jsp)

### March of MND Faces

These banners feature a photographic display of people with motor neurone disease. MND NSW will soon be producing a ninth 'March of MND Faces' banner.

If you have MND and want to be included in the new banner you need to complete a permission form and submit a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish. Family members are also able to submit a photograph in remembrance of a person who has died from MND. For more information ph. 8877 0999 or email Penny Waterson at [info@mndnsw.asn.au](mailto:info@mndnsw.asn.au)



*You can write to the Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675*

### ACKNOWLEDGEMENT

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**DISCLAIMER** All care has been taken in the preparation of this newsletter. The MND Association of New South Wales disclaims any liability for its content. The information contained within is of a general nature. For medical advice, consult your doctor.

**Editor:** Penny Waterson