



# FORUM

## March 2008

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## 18th International Symposium on ALS/MND

In November last year I had the privilege of attending the 18th International Symposium on ALS/MND in Toronto, Canada. Over 550 people attended the conference and this included researchers, clinicians, support groups, MND associations, carers and people living with MND. There were many interesting presentations and it was inspiring to see the level of collaboration and sharing amongst health professionals involved in MND.

Many very committed clinicians and researchers presented their work and this gave me an international perspective on what was happening in MND around the globe. This included programs that helped reach people in isolated areas, supportive care programs established for people living with MND and their carers, the development of neurological and clinical care pathways for people with MND, developments in assistive technology and partnerships formed with other services such as an ambulance service and a faith community.

There were also many presentations on research into MND including cognitive and psychological change, quality of life, respiratory function, nutrition, medical and supportive care. Papers were also presented about research into the causes and treatment of MND and, while there is still a long way to go to finding the answers, there seems to be much hope that we are getting closer. For myself, having worked in many different areas of health care, I was inspired by the level of commitment that health professionals had towards working in MND that I had not experienced before in other areas of health care, whether it was about finding a cure or providing excellence in care.

It was also exciting to see posters from several Australian researchers and to see some of our health professionals in attendance at the conference even though it was held a long way from the Australian summer in snowy and cold conditions. I left the conference feeling privileged to be part of such a passionate group of researchers and care providers. Further updates from the conference can be found on pages 7-9 of this edition of *Forum*.

### Gina Svolos

*Manager Family Support*

## CPA Australia President's Charity supports MND

Alex Malley, whose mother died from motor neurone disease (MND), has been a friend of MND for a number of years. He has recently become the President of CPA (Certified Practising Accountants) Australia and he has initiated a President's Charity whereby the President personally selects a charity to support for the duration of the presidential term. The CPA Australia board has approved this initiative and CPA Australia members will be asked to get involved in raising awareness and funds to support people living with MND over the next twelve months.

The President's Charity has been launched via the President's blog. There will be a two page spread on MND in the March edition of the CPA Australia magazine 'In the Black'. You can visit

the CPA Australia website to view or comment on the blog and to access the feature article at [cpaaustralia.com.au](http://cpaaustralia.com.au)

CPA Australia has 117,000 members and it is hoped that members of CPA Australia, their employers and their employees will get behind the idea. The MND Australia board has approved the proposal and thanks CPA Australia and Alex for choosing MND Australia as the inaugural President's Charity.

During the year CPA Australia hopes to interview CPA members who have MND or who have had a family member or friend with MND. If you are a member of CPA Australia and would like to tell your story please contact Carol Birks, National Executive Director, MND Australia Ph. 02 9816 5322.

*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

The year has started with some good news from the New South Wales Department of Ageing, Disability and Home Care (DADHC). DADHC have decided to provide funding of \$450,000 towards the administering of the MND NSW equipment pool. This is in addition to the one-off grant we received from DADHC two years ago. As with the previous funding, this new funding is expected to be expended within a two to three year period.

We are currently in discussion with the New South Wales Department of Health, who have long been a supporter of MND NSW, regarding the next round of recurrent funding.

We have several reports in this edition of *Forum* about the 18th International Symposium on ALS/MND which was held in Toronto in late 2007. This is an important event on the international MND Calendar. It provides the opportunity for researchers, health professionals, MND Association volunteers, staff and members from all over the world to meet and hear the latest news and developments about motor neurone disease.

After nearly five years at MND NSW, Allison Pearson, Regional Advisor for ACT and Southern NSW, has resigned from this position. We wish Allison well and thank her for her commitment to her position and the Association.

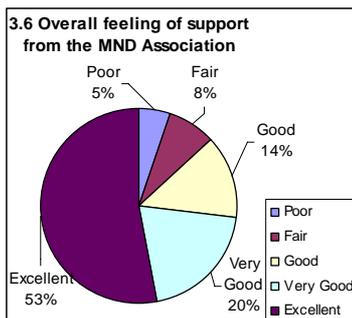
MND Week is just around the corner. Information about the launch of MND Week on 1 May is on page 3 of this edition of *Forum*. This year's theme is **Living Better for Longer** and as part of our **national call to action** we will be asking members to contact local federal, state and territory politicians to address inequity of services nationally. More detailed information will follow.

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

*During April we will let you know how you can support the National Call for Action*

## Member Survey



A big thank you to those who responded to the satisfaction survey we sent to people living with MND in November last year. Surveys were returned by 126 people and

We received many comments from respondents that indicated that they were very satisfied or grateful for the service, such as, "Extremely happy with all the services provided", "Your staff are very helpful, easy to talk to - makes one feel like you belong" and "Our experience with these people has been most pleasing. A wonderful lot of competent, compassionate and friendly people - it has been a pleasure to know them". Many respondents also acknowledged a particular regional advisor for her good work.

the results will assist us to plan services for the future. The location and membership duration of survey respondents reflected the membership as a whole.

Overall satisfaction was high and it was good to see that 93% of respondents would definitely recommend the MND Association to others living with MND and 6% would probably recommend MND NSW. The mean score for most of our services was at least 4 out of 5. Our highest ranked activities were the Equipment Loan Service, Carers Kit, information provided when contacting the Association, such as the Info Line, and the *Forum* newsletter

When comparing metropolitan and rural/regional members, those from Sydney rated the following slightly higher than our rural/regional members: information and education, referral to other services, quality of information, value of support and overall feeling of support from the MND Association.

Some respondents highlighted their limited access to services (15%), and that they would like more contact from the regional advisors (12%).

The main issues and concerns identified by several respondents related to not enough contact with regional advisors and inability to get to groups/ events or programs due to distance. Comments about this included, "Very little country support", "Regional advisors have changed a lot", and "Living outside of Sydney we feel very isolated, since travel to Sydney is not an option for most of us".

These comments will help us to look at our future directions for family support services. If you would like a copy of the report emailed or posted to you, please phone me on 1800 777 175 .

There were 37 people who were happy to be contacted by us and we have been in touch with some but unfortunately have not got onto everyone. If you are keen to discuss your responses or want to provide any additional feedback please do not hesitate to contact the Association.

**Gina Svolos**  
Manager Family Support

## Family Support

I would like to welcome our new members to this edition of *Forum*. We have had an increase in membership over the last few months and this has kept the Family Support Team very busy.

Our regional advisors aim to meet new members as soon as possible. For people located in rural and regional areas of New South Wales this can take a bit longer than we would like, even though every effort is taken by your regional advisor to meet you as soon as this can be arranged. It is hoped that once you can put a name to a face then it might be easier for you to phone your regional advisor for information and support when you need it. However, whether you have met your regional advisor or not, you can make contact with us by calling the MND NSW 'Info Line'. This telephone service is attended by a Family Support Team member five days a week, 9am-4.30pm, phone freecall 1800 777 175.

### 4th National MND Conference, Melbourne 24 June 2008

The theme for the National MND Conference 2008 is 'Living better for longer - pathways for the future'. This is the fourth year this conference has been held and it is building momentum each year. This is an opportunity for Australian health and community workers to learn more about MND and to share their work. People living with MND are also welcome to attend. If you would like any further information please contact the MND NSW Centre at Gladesville on ph. 8877 0999 or 1800 777 175.

### Regional advisor for the ACT and southern NSW

Our regional advisor for the ACT and southern New South Wales, Allison Pearson, finished working for MND NSW in February. Allison has been instrumental in developing and providing MND specific support services for people in southern NSW. Allison is to be commended on her efforts, commitment and achievements.

We are currently advertising for a new regional advisor and will be establishing an office in the ACT for this person. We have also increased the hours allocated for this role from 18 hours per week to 24 hours a week in the hope that we can provide more direct support to our members in the ACT and southern NSW. Members in this region will be informed once a new regional advisor is appointed. In the meantime, please call the MND NSW 'Info Line' on 1800 777 175 for support and information.

**Gina Svolos**  
Manager Family Support

## Equipment

The MND Equipment Loan Service has been operating for over ten years. Loans are made free of charge to members of the Association who have a confirmed diagnosis of MND.

A loan of equipment is made after an assessment by a health professional - usually an occupational therapist, physiotherapist or speech pathologist. This assessment is important as it ensures that the correct type of equipment is requested. For example, the width of a hallway can be measured to assist in determining if a wheelchair or shower commode can fit or turn into a room. Also, access to a house may be difficult and this can hinder the use or delivery of equipment.

It is important for members to plan ahead because there can be delays in obtaining an assessment by a health professional. Delay can also occur because there may be a waitlist for certain items of equipment.

Once an item is loaned, it is a MND NSW requirement that a health professional demonstrate the safe and correct use of the loaned item in the member's home environment.

Not all items are available all of the time and waitlists do occur. It is best to have an assessment earlier rather than later and to have the equipment request form lodged with MND NSW by the assessing health professional. This helps to prevent delays with the loan of equipment when it is needed. At present there is a long wait for Lightwriters; demand for these has remained high even though there are 35 Lightwriters in the loan pool, including five new Lightwriters purchased by MND NSW during the last six months at \$6100 each.

Prior to the delivery of MND equipment, the member or carer is contacted with an estimated delivery date. In some areas, especially where courier services are limited, this may only be possible on one particular day a week. A copy of the original equipment request form is sent with the equipment, together with any necessary instructions and a letter requesting the member or carer contact their health professional to arrange a time for the equipment to be demonstrated.

If any problems occur, MND NSW Equipment and Family Support staff are available to answer your concerns on 1800 777 175.

**Maree Hibbert**  
Equipment Services Coordinator

The MND NSW Info Line is attended by a Family Support Team member five days a week, 9am-4.30pm, phone freecall 1800 777 175



Let's launch MND Week together!

Thursday 1 May 2008

2pm to 4.30pm

Waterview Convention Centre, Bicentennial Park

Circle the date on your calendar and watch your letter box for more information

## Special Projects and Carers News

It is time to get out your diaries and pens to jot down some dates for activities and programs for 2008.

### Care for Carers Program

Are you a new carer or one who has been caring for a while? The Care for Carers Program is for both the experienced and less experienced carer. It runs over four Tuesdays, 20 May to 10 June from 10am-3.30pm. You will not only learn practical skills to care for someone with MND, but you will also meet others in the same situation. Four days is a big commitment but the evaluations from the last program showed that getting to know other carers was a very important aspect of the program, one that made people come back week after week. Unfortunately it is not possible to attend the odd session or day. Attendees need to commit to the four Tuesdays as this allows people to get to know one another and feel part of the group. We can help you to access respite if you wish to attend the program.

### Ask the Experts

Monday 4 August is a long way off I know, but Ask the Experts is a popular day. Members, families, friends and carers come along and ask the experts - MND specialists, any questions about MND and hear about the latest research. We also run a donor drive for the MND DNA Bank where you can give blood for genetic research into MND. For those who are shy about asking questions, have a query you would rather someone else ask or have difficulty speaking, you can pass your question(s) to any staff member from MND NSW and they will ask for you. Remember, your question may just be the one others want to hear about. Lunch is provided.

### FlexiRest

You have probably read about FlexiRest in the last edition of *Forum*. To date nine people have successfully applied for and received funding for respite services giving either the carer, the person with MND or both some sort of break. Such a break is short-term and time limited. FlexiRest provides funding for services that cannot be obtained through existing community respite services.

Funding to date has provided financial support towards short holidays, for overnight accommodation while a member was undergoing respiratory tests, for massages and to help support a member take a break to attend a course on managing a complex disease. Talk to your regional advisor if you, your carer or both want some respite.

### Talking to Young People Project

The Talking to Young People project is going well as a joint venture between MND NSW and MND Victoria. Anita Richter, former MND NSW Special Projects and Carers Coordinator, is managing the NSW side. To date nearly 100 parents, teachers, children, health professionals and counsellors have contributed their experience and ideas.

When completed, the five booklets and a fact sheet will be for recently diagnosed parents and their children, their friends, their children's schools and health professionals who may be assisting the family. They will be available in NSW initially, throughout Australia and then finally internationally.

At the moment the booklets and the fact sheet are being sent to people with MND and their children for review.

### Past Carers

Past Carers has been running at Gladesville for several years. However numbers have gradually dwindled. At the end of last year I discussed the direction of Past Carers with some of the more regular attendees and sent letters to others. The group initially ran for carers who had been bereaved at least six months. We would meet up, have a chat and enjoy the food brought along by participants. It would be great to hear from past carers about what sort of support you would like. Please contact me with your thoughts and ideas.

To find out more about any of the above, please phone me on 8877 0902 or 1800 777 175.

### Jane Barrett

*Family Services Coordinator*

**Care for Carers Program**

MND NSW Centre, Gladesville  
20 May  
27 May  
3 June  
10 June

### How many volunteers does it take to stuff the *Forum* envelopes?



Actually quite a few. Every three months a dedicated group of volunteers

and some MND staff form a working bee to get *Forum* out. With 1800 copies to send, several flyers to insert, addresses to check; it's a huge task.

We are looking for volunteers to join us on this quarterly marathon. Benefits are clear – no pay, a 'free' lunch, great team mates and at the end of the day, job satisfaction seeing *Forum* in boxes ready to take to the post office. Seriously, we do need your assistance.

If you can spare some time during the week and want to join our team to stuff the *Forum* envelopes – for a half or whole day, please contact Roslyn ph. 8877 0908. We would love to have your company!

### AHOY! Sailors

#### Sailors with disABILITIES

will be taking people out on **Sunday, 13 April**, 1-4pm.

This is a great day out sailing on the harbour for people with MND, their families and friends and for those who are past carers. The boat can take both electric and manual wheelchairs. We have to have a minimum of ten people and a maximum of 14 including two MND NSW staff. Contact Jane at MND NSW 1800 777 175.

## Support Group News

### Northern Sydney (Hornsby)

The focus of our next meeting on 10 April will be nutrition and safe eating strategies. Other meeting dates for this year are 12 June, 14 August, 9 October and 11 December. We are always glad to welcome new members to the support group and appreciate any feedback or new ideas on how we can improve the meetings and make them more enjoyable and meaningful. Light refreshments are provided by MND NSW. To help cover the cost of our tasty luncheons, a gold coin donation would be appreciated. If you would like to join the group, learn more about what happens at our meetings or if you require assistance, please contact me.



*Joy and Maurice Battaglia at the Northern Beaches group*

**Jo Fowler** - Regional Advisor

### Central West

By the time you read this we will have had our first support group meeting and hopefully had lots of ideas as to what you would like to hear/do throughout 2008. I have tentatively arranged Lorel Adams from the Australian MND DNA Bank to come to the meeting on 17 June. She will speak about the research at the University of Sydney and about organ donation. There will be the opportunity to donate blood to the Bank, if you so choose. The MND DNA Bank has been set up to look for genetic and environmental susceptibility to MND.

Thank you to those who sent their feedback about the support group. It was greatly appreciated. I would encourage you to contact me, however, any time, with suggestions, queries or just for a chat.

**Jenny Judd** - Regional Advisor

### Gladesville

In February at our first meeting of the year conversations flowed as people shared information about themselves and about their own experiences with MND. This is the true value of support groups; we all help each other and support each other and learn from others in the group. Our next meeting will be at the MND NSW Gladesville Centre at 10.30am on 2 April. Graham Opie, MND NSW CEO will come and talk with the group about what is happening in the organisation and future directions. I am sure you will have questions of your own.

The Gladesville group welcomes visitors; indeed we had some overseas visitors at the last group. If you are passing through Sydney and have a spare couple of hours please drop by. Meeting dates for 2008 are 2 April, 4 June, 6 August, 1 October and 2 December. You can enjoy the surrounds and there is a very nice coffee shop in the grounds where you may enjoy lunch following the meeting.

**Caroline Gleig** - Regional Advisor

## Support Group Contacts

### Metropolitan:

Ph: MND NSW 1800 777 175

### Gladesville

**Caroline Gleig**  
carolineg@mndnsw.asn.au

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

**Jo Fowler**  
josephinef@mndnsw.asn.au

### Western Sydney

**Jenny Judd**  
jennyj@mndnsw.asn.au

### Regional and Rural:

#### ACT and Southern NSW

MND NSW Ph: 1800 777 175

#### Broken Hill

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

#### Central Coast

**Audree Dash** Ph: 02 4384 2907  
**Sheila Holmes** Ph: 02 4392 5513

#### Central West

**Jenny Judd** Ph: 1800 777 175  
jennyj@mndnsw.asn.au

#### Illawarra

**Cindy Cleary** Ph: 02 4223 8000

#### Newcastle and Hunter

**Noelle Smith** or **Eileen O'Loughlen** Ph: 02 4921 4157  
noelles@mndnsw.asn.au  
eileeno@mndnsw.asn.au

#### Northern Rivers

MND NSW Ph: 1800 777 175

## Family Support Calendar

- 13 April** **Sailors with disABILITIES**  
*Sailing on the harbour for people with MND, their families and friends and for those who are past carers.*
- 20 May** **Care for Carers Program (4 days)**  
*MND NSW Centre Gladesville*
- 27 May**
- 3 June**
- 10 June**
- 17 June** **Information Evening**  
*For people recently diagnosed with MND and their families and friends*  
*MND NSW Centre Gladesville*
- 4 August** **Ask the Experts and donor drive for the MND DNA Bank**  
*Members, families, friends and carers come along and ask the experts questions about MND and hear about the latest research*

For more information contact the MND NSW Info Line  
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.*

**Ask the Experts**

Monday 4 August

## Mailbag

When my mum Sally was diagnosed with MND in May 2005, I had a fairly vague idea of what this meant. After reading up on it a little, I realised how devastating it could become and how difficult and sad it would be for her. Over the following year or so, I went through periods of denial and sadness and eventually came to terms with the diagnosis as best I could. My mum and dad both have such a lovely sense of humour about it all and I think this has really helped the whole family get through the more trying times.

Last year, I was reading *Forum* online and read about the Care for Carers program. I thought it would be a good way for me to learn as much as I could about how best to help take care of Mum. Dad and I attended together and I was so impressed by everyone involved with it.

Jane Barrett had done a brilliant job of co-ordinating the program. We had health professionals (physiotherapist, occupational therapist and speech therapist) talk to us about different things to expect as carers for people with MND and they taught us important skills I would not have otherwise known. Learning about all the equipment available to people with MND and techniques to help make life easier for them was so interesting and I took so much knowledge away with me. A lot of what I do on the days I am with Mum includes the tips and procedures I learnt at Care for Carers.

One of the things I feel I particularly benefited from was meeting other carers. Talking with people who are living with similar circumstances to my own was a great support and participating provided all of us with a confidential forum in which we could speak openly about our fears, hopes and experiences.

I would truly recommend Care for Carers to any family member or friend looking after a loved one with Motor Neurone Disease. You learn so much as well as building up a most important and great support network for yourself.

**Claudia**  
Sydney

May I through your newsletter share with other MND people my enthusiasm for my recently acquired stairlift?

I started three years ago to seriously consider getting a stairlift for our home but decided, with scant information to back up the view, that it would be too expensive, unwieldy and inconvenient. All the usual excuses for procrastination. At the same time I put far too much time and effort into thinking it would be easier to move house! That's even better for procrastination. Even this letter has taken me ten months to 'get around to'.

However, I'm sharing my story because having a stairlift has given me such a thrill and taken away the two burdens of physically tackling the stairs and the emotional exhaustion of the fear of calamity.

The stairlift was easily installed and poses very little inconvenience to others using the stairs (unless they are fit enough to want to hurl themselves willy nilly up or down!). I thought, wrongly, that it would be too scary sitting on a moving seat. However, it is amazing how often able-bodied people are too scared to try it out!

**Margaret**  
Faulconbridge

*While some people find stairlifts invaluable, for many others they are unsuitable. A person with a condition that causes their function to deteriorate should consider and seek individual advice on the best solution for them. Before you go ahead with home modifications such as the installation of a stairlift or bathroom modifications, MND NSW recommends that you discuss the suitability of your plans with an occupational therapist who will give you professional, non sales-based, advice.*

Gina Svolos, Family Support Manager

Email or write your letter to the editor of Forum

See back page for contact details

## Do you have a great photo?

Forum readers and supporters of MND NSW are invited to participate in the **2008 Christmas Card Photo Competition**.

All you need to do is to email or post your favourite photograph, taken by you of course, of an Australian scene that you love.



The photographs will be judged independently and the photo deemed to be the best will feature on the **2008 'MND NSW Australian Christmas Card'** which will form part of our 2008 Christmas Card Selection\*.

To enter, simply post your entry by **30 April 2008** to:  
MND NSW, Locked Bag 5005, Gladesville NSW 1675  
or email to [roslyna@mndnsw.asn.au](mailto:roslyna@mndnsw.asn.au)  
with your name, address, phone number, email address, age, gender and details of where the photo was taken.

For more information phone Roslyn Adams on 8877 0908

*\*your publication consent is a condition of entry*

## 18th International Symposium on ALS/MND

The following report was written by Carol Birks, National Executive Director MND Australia, as the recipient of the MND Victoria Nina Buscombe Award. This Award provided financial assistance for Carol's attendance at the International Alliance Meetings, Allied Professionals Day and International ALS/MND Symposium in Toronto in 2007.

The **International Alliance Meetings** kicked off on Wednesday 28 November with the AGM where Gudjon Sigurdsson from Iceland was appointed the Chair elect. Highlights included the presentation from IsrA.L.S introducing the Stephen Hawking DVD which is available for use by all MND Associations and will be the focus for **MND Week 2008** in Australia. The Scottish MND Association highlighted the success of their coordinated political Care Service Campaign which has provided ideas for augmenting the MND Australia Call to Action plan. ALS Canada presented their resources for parents and young people. Copies of booklets were obtained and forwarded to the people involved in the Young Peoples Project here in Australia. In 2008 the parents and young people's project in Canada, ALS411, will become an interactive website which will be of interest to the Australian project team.

The Key Issues presentations highlighted that in Japan 30% of people with MND used mechanical ventilation and that this has driven recognition of patients' rights including the need for government funded 24 hour care. The International Alliance presented a draft position statement on **Patients Rights** for discussion. The document will be adopted at the next meeting and will be an important influencing tool for MND Associations in Australia when available. The **Statement of Good Practice for the Management of ALS/MND** was adopted unanimously. This was developed following review of the International Alliance Baseline of Services (1999) and will also provide a tool for influencing in Australia.

The papers presented at the **Ask the Experts**, the **Allied Health Professionals Day** and the **International Symposium Clinical Stream** were all interesting and most provided new and relevant information. In February, together with Gina Svolos, Family Support Manager MND NSW, I presented an overview of the highlights of these sessions at a MND NSW staff education day.



(l-r) Nicole Hutchinson, Carol Birks, Jennica Winhammar, Dr Helen Herz, Gina Svolos at the Symposium dinner

The whole experience was very worthwhile and gave me:

- an increased awareness and understanding of how ALS/MND Associations operate internationally
- ideas for future developments in Australia
- opportunity to promote MND Australia, national information and the bid to host the International Symposium in 2011
- networking and friendship opportunities
- affirmation and inspiration to continue to work collaboratively nationally and internationally to improve care and services for people living with MND and their families and to promote research.

There are also a number of potential benefits to people living with MND and their families in Australia through:

- promotion of best practice care based on international evidence
- future service development in Australia
- potential partnerships and collaborations through the networking opportunities
- dissemination of latest care and research through the MND Association networks
- evidence and international guidelines to support influencing nationally.

Toronto was very cold and Niagara breathtaking, literally at that time of the year! The people, however, were very warm and friendly and willing to share experiences and resources. I look forward to ongoing contact with many of them.

**Carol Birks**  
MND Australia

**Abstracts of all presentations and some full presentations from Toronto are now available for free download on the internet**

Abstracts from 2007 Symposium presentations and posters

[www.mndassociation.org/research/for\\_researchers/international\\_symposium/18th\\_international\\_symposium/abstract\\_book.html](http://www.mndassociation.org/research/for_researchers/international_symposium/18th_international_symposium/abstract_book.html)

Abstracts from Ask the Experts – Toronto 2007

[www.alsmndalliance.org/uploads/Ask%20the%20Experts%20for%20website.pdf](http://www.alsmndalliance.org/uploads/Ask%20the%20Experts%20for%20website.pdf)

PowerPoint presentations of the Allied Professionals Day – Toronto 2007

[www.alsmndalliance.org/index.php?page=74](http://www.alsmndalliance.org/index.php?page=74)

MND Week  
4-10 May  
2008

Cornflower  
Blue Day  
9 May 2008

## 18th International Symposium on ALS/MND (cont'd)

From *MDA/ALS Newsmagazine* January 2008 v13  
[www.als-mda.org/publications/als/als13\\_1.html](http://www.als-mda.org/publications/als/als13_1.html)

by Margaret Wahl

Some 750 conferees, mostly ALS clinical and scientific experts, gathered in Toronto Dec. 1-3 for the 18th International Symposium on ALS/MND, sponsored by the British MND Association.

Michael Strong, a professor of neurology at the University of Western Ontario, presented the increasingly compelling evidence that ALS is not one disease, but many.

The evidence includes the wide range of survival times; variability in the parts of the brain affected, including nonmotor areas in some people but not others; and the lack of a single genetic factor leading to ALS.

The failure of mouse studies to predict human responses to experimental treatments may be due to the lack of a single cause of ALS among human patients, compared to the uniformity of disease causation (usually, a mutation in the SOD1 gene) in lab mice.

ALS patients typically are grouped by whether their disease is familial or sporadic, by the site of symptom onset and by rate of disease progression. However, these categories aren't sufficient to reflect the wide variation seen in ALS.

Results of several specific trials were presented, as follows.

### Large-scale minocycline trial showed drug is harmful in ALS

Paul Gordon, until recently an assistant professor of neurology at Columbia University in New York and a co-director at the Eleanor and Lou Gehrig MDA/ALS Center at Columbia, presented the results of a 412-person, phase 3 trial of minocycline, a drug that had shown promise in ALS-affected rodents and in phase 1 and phase 2 studies in patients. (Gordon is now at the Hôpital Pitié Salpêtrière in Paris.)

Minocycline is an antibiotic used to treat certain types of infections. It also has the ability to prevent a cell "suicide" program (apoptosis) and to dampen inflammation.

Participants at 31 US centres were randomly assigned to either minocycline in escalating doses up to 400 milligrams per day, or to a placebo, for nine months, following a four-month lead-in phase during which patients' untreated rate of decline in the ALS Functional Rating Scale (ALSFRS) was observed.

ALSFRS scores deteriorated 25 percent faster in the minocycline group than in the placebo group, although survival was the same in the two groups. The rate of ALSFRS decline wasn't dependent on the dose of minocycline, or if people also were taking riluzole (Rilutek).

Gordon said these disappointing results demonstrate the need to improve both the reliability of animal studies in predicting human responses to treatments, and the ability to use early-phase trials to select potentially beneficial compounds and eliminate useless or harmful ones.



### Celecoxib and creatine combination may warrant further testing

Gordon also reported on a trial conducted at Columbia to compare two drug combinations against a historical control group (a similar group of ALS patients, previously observed and not treated with either combination).

Patients were randomly assigned to take either creatine plus minocycline or creatine plus celecoxib (Celebrex) for six months and were evaluated using the ALSFRS each month.

Of 60 people, 58 completed the trial. Average ALSFRS decline in the creatine plus celecoxib group was 5.27 units; in the creatine plus minocycline group, 6.47 units; and in the historical control group, 5.82 units.

The creatine-celecoxib combination was selected for further study.

### Ritonavir eliminated, but hydroxyurea may be worth closer look

Catherine Lomen-Hoerth, who directs an MDA/ALS centre at the University of California at San Francisco, reported on phase 1 trials of Ritonavir, a medication used for HIV/AIDS, and hydroxyurea.

Ritonavir reduces levels of two compounds involved in cellular waste disposal that are elevated in ALS. Hydroxyurea, which is used to treat leukemia, may prevent damage from astrocytes and microglia, two types of nervous-system support cells. Anecdotal reports from three people with ALS suggested possible benefit.

Participants were randomly assigned to receive either low-dose Ritonavir, high-dose Ritonavir, hydroxyurea or a placebo for six months, followed by an additional six months of observation.

Among 24 enrolled patients, investigators found no significant improvements over placebo among the low- and high-dose Ritonavir groups. However, the hydroxyurea group did slightly better than the placebo group on tests of strength and on the ALS Functional Rating Scale (ALSFRS), and their respiratory scores were better than the placebo group.

Lomen-Hoerth said they're considering a phase 2 study of hydroxyurea.

Scientists at the Prince of Wales Hospital in Sydney hope to show that a neuroprotective agent is able to slow disease progression in MND. See back page for more information.

## 18th International Symposium on ALS/MND (cont'd)

### Dutch study warns against Chinese stem-cell treatments

Leonard Van Den Berg, a neurologist at University Medical Centre in Utrecht, Netherlands, reported on followup studies of patients who went to China for treatment with a type of stem cell found in human fetal nasal lining (olfactory ensheathing cells, or OECs).

At Beijing West Hill Hospital and Rehabilitation Center, OECs are injected into the brains of ALS patients, at a cost of approximately \$25,000.

A Dutch study followed 12 patients who went to Beijing. Seven reported very short-term improvement in functioning or an increase in strength immediately after the injections, lasting less than a day. Three saw no change, and two said they deteriorated.

ALSFRS scores, respiratory measurements and strength tests resumed a downward course in all cases. Of the 10 patients who later died, median survival time was 2.9 years. One person developed a serious blood clot, and another developed pneumonia.

Van Den Berg recommended that people not seek stem-cell treatments in Beijing. He also reported that the West Hill center has since closed, because the Chinese government considered it too "mercantile."

### Strenuous lifestyle may increase ALS susceptibility

Agnes Gonzalez, a research nurse at an ALS center in Montpellier, France, described her team's study, in which preliminary results suggest that consistent strenuous activity over decades may increase one's risk of developing ALS.

When Gonzalez and her colleagues studied 51 ALS patients and 40 people with other neurological diseases, matched by age and gender, they found that those with ALS had expended significantly more energy in their daily lives over the course of three decades, starting at age 20.

Gonzalez said it appears that regular and intense daily activity is a more common way of life for people who develop ALS than for those who don't. She hypothesized that decades of heavy work or other strenuous exercise could create a deficit of blood flow or oxygen in relation to nerve cells' demands. Gonzalez emphasized that a final analysis will include many more people with and without ALS.

### Nose may provide window to brain

There was general agreement at the meeting about the need for more convenient and precise ways to measure ALS progression and response to treatment.

Jeffrey Rothstein, an MDA research grantee and director of the MDA/ALS Center at Johns Hopkins University in Baltimore, reported on a new technique involving biopsies of nasal tissue that may provide better information about how nerve cells respond to experimental treatments.

Rothstein found cells that he believes are the same as nervous-system astrocytes in the nasal lining and says the new technique might be useful in testing drugs that modify astrocyte activity.

### Portable device might make trials easier for participants

Edward Kasarskis, professor of neurology at the University of Kentucky in Lexington, presented his group's study on the use of a lightweight, portable device called an accelerometer that provides quantitative information about muscle movements.

Thirty-four people with ALS and ten without strapped Actical accelerometers to each limb and went about their daily activities. Data from the devices were compared with muscle-mass measurements, manual muscle-testing measures and self-ratings of movements.

Investigators concluded the accelerometers have the potential to be used for outcome measures in trials and could minimize participants' travel and reduce dropout rates.

Order your merchandise now for MND Week 2008

## Merchandise available for MND Week 2008



See insert for other products and order form



or visit

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

or phone MND NSW 02 8877 0999



# WANTED

## Volunteers for MND Week 2008

Come and have some fun for a good cause!

### Railway Stations

We will be selling merchandise around metropolitan railway stations on **Cornflower Blue Day, Friday 9 May from 7-9am**. It is a great way to spend a couple of hours volunteering for MND. Permission has been granted for us to collect at the following stations so please nominate which one you would like to collect at: Wynyard, Town Hall, St James, Circular Quay, Martin Place, Beecroft, Edgecliff, Emu Plains, Epping, Hornsby, Penrith, Roseville, St Leonards, Seven Hills, Turrumurra, Wahroonga, Warrawee and Westmead or if there is a station close to you that has not been mentioned contact Roslyn Adams on 8877 0908 to see if we are able to gain permission.

### Outdoor Areas in Sydney City

Permission has also been granted for us to sell merchandise and collect donations in **Pitt Street Mall** and the **Queen Victoria Building Forecourt** on **Cornflower Blue Day, Friday 9 May**. So, if you work in the city and would like to get together with some work-mates and have a bit of fun why not get a team together and you can set up a roster as we have permission to collect for the whole day, alternatively you could have a roster for the peak pedestrian hours. Just give Roslyn a call on 8877 0908.



is a terrific fundraiser and we are very grateful to both our volunteers and to Qantas for granting permission for this to take place.

### Shopping Centres

Do you have a shopping centre near home at which you could sell merchandise and collect donations? You wouldn't have to spend all MND Week there, just one day would be great, for example, **Cornflower Blue Day on Friday 9 May**. Permission would need to be sought from the Shopping Centre Management and we would be happy to assist with this.

### Other Activities

Are you a member of a tennis, squash, gym or golf club? Are you involved with a local school? You could sell our wonderful MND socks through your club or a selection of merchandise through schools. You could ask your local pharmacist, doctor, newsagent, delicatessen or hairdresser if you could place a **box of merchandise** in their business for a week to promote MND Week.

We would love to have your support

Please contact Roslyn Adams at MND NSW on 8877 0999 if you would like to be involved in MND Week

### Qantas Terminal

Each year a wonderful family together with friends and their children take over Qantas T3 on **Cornflower Blue Day, Friday 9 May** selling MND merchandise to commuters flying all over the country. It

For the 6<sup>th</sup> year in a row HCF will host our MND merchandise boxes in their HCF branches. Throughout NSW from 28 April to 6 May. Thanks HCF!

### Volunteers' T-Shirts

The round necked white cotton MND NSW Volunteer T-Shirts have the MND logo and VOLUNTEER printed on the front and NEVER GIVE UP printed on the back. Complimentary for all volunteers ordering merchandise to sell this year. Please make sure you indicate on the form your size(s) when you place your order for merchandise.

Thanks to Lorna Lever for the photo

### Volunteer ID - Is yours up to date for 2008?

Anyone selling merchandise or asking for donations on our behalf must, in keeping with the Office of Charities requirements, wear ID issued by MND NSW. If you need a new badge please call us on 8877 0999 or email roslyna@mndnsw.asn.au for a form. If you had an ID last year this will be automatically renewed when you send in your merchandise order form.

**Christmas Lights Still Twinkling in Cowra**

Once again the Oliver and Tarrant families, and parents, Sue and Bob Dunn put together a wonderful Christmas light display for the people of Cowra. Though still in drought but with some good news of the abattoir being up and running again for a few months, the community graciously put their hands in their pockets and donated a considerable amount of money to buy needed equipment for people living with MND. The children handed out lollies and jollied along the visitors; the children love to do this to help their 'Pop' who has MND. We really do appreciate this great effort and support from the Dunns, Olivers, Tarrants and people of Cowra.

**Peter Hammerman's 60th Birthday Celebration**

Peter Hammerman and his wife Kitty decided that instead of Peter receiving lots of lovely gifts for the special occasion of his 60th Birthday that they would invite their guests to make a donation to MND NSW. Their guests thought this was a wonderful idea and between them all raised \$2,592. We thank Peter and Kitty very much for thinking of MND NSW and their guests for supporting their wishes. This really is a most worthwhile fundraising activity and people are doing this for weddings, wedding anniversaries, birthdays etc so why not think about it for your next milestone.



*Peter Hammerman (wearing cap) with his wife Kitty and other family members*

**White Christmas**



*Isaac Greenall and Vanessa Juresic*

On 21 December, Isaac Greenall and Vanessa Juresic organised a motor neurone disease charity event. They planned the event around the Christmas period and had it themed for their annual event at the Hunters Hill Club - 'The Hunters Hill White Christmas Party'. On the entertainment list there were caricaturists, DJ's, barefoot bowls, fabulous raffles and silent auctions.

Despite the horrific weather of the night, the event was a huge success raising money to be directly donated to research. When asked what inspired them to include MND as the charity to donate to, they responded with a heartfelt, "One of our very close friends is a carer for her mother who has MND. We see the struggle and pain first hand; we really wanted to do something to help prevent this in the future." The Association is most appreciative of Vanessa and Isaac's fundraising efforts raising \$2,000 for research and thank them for their contribution.

**Singleton Lawn Bowls Charity Day**

Greg Cleary, whose wife Sandra has MND, organised a Lawn Bowls Day on 23 September 2007. Greg organised this event single handedly to raise money as a way of 'giving back' to



*Peter Ford, Greg Cleary and Judy Ford Singleton Lawn Bowls Charity Day*

the Association as he knows that this helps to keep loved ones with MND as comfortable as possible through the facilities of the Equipment Loan Pool. It was a great day with 68 people attending and \$6,800 was raised which was a wonderful effort. Greg said that he was overwhelmed with the support he received however there are too many people and businesses to thank individually but he particularly wanted to thank Coal & Allied H.V.O Operations, Mortgage House, Wests Tigers Football Club, Club Singleton, Retired Coal Miners Federation, Judy and Peter Ford, with a special thank you to Isobella Bailey. We thank Greg most sincerely for his time and fundraising efforts!

**Got the Blues**

Was it the attraction of the blue flowers, our blue sign or was it just knowing that blue is our colour that brought this sleepy blue tongue lizard out for a bit of sun?



**Dates for the Diary**

18 Mar	<b>MonStar Cup</b> <i>Pennant Hills Golf Club, Beecroft Golf Day and Dinner</i> <a href="http://www.monstarcup.com">www.monstarcup.com</a>
5 April	<b>Lindsay Butler and Shaza Leigh Show</b> <i>Country music concert at Cessnock Ex-Services Club. Contact Shirley and Stephen Peters Ph. 4991 4571</i>
1 May	<b>Launch of MND Week</b> <i>Lake Room, Waterview Convention Centre, Bicentennial Park</i>
4-10 May	<b>MND Week</b>
9 May	<b>Cornflower Blue Day</b>
9 Nov	<b>Walk to D'Feet MND 2008</b> <i>This event is not just for Sydney siders - we would love some of our country connections to walk on the same day in their home town. Contact Roslyn ph. 8877 0908.</i>
2009	<b>Kokoda Challenge</b> <i>If you would like to find out more contact Roslyn ph. 8877 0908.</i>

To volunteer for MND NSW contact Roslyn Adams ph. 1800 777 175

## Noticeboard

### Economic Impact of MND on Well-Being

In 2006, MND NSW members were invited to participate in a research project looking at the economic impact of neurological illness (including MND) on well-being. The final report has been released by the study's authors - Professor Marita McCabe, Elodie O'Connor and Candice Roberts of Deakin University and Dr. Lucy Firth of the University of Melbourne. Key recommendations related to MND arising from the report include:

- Attempts should be made to reduce the economic pressures related to these illnesses, possibly by increasing levels of support available in this area; for example, raising awareness in the professional community as to the economic pressures experienced, in order for them to provide support and assistance to individuals and families living with neurological illnesses.
- Patients and carers require assistance in learning to cope effectively with economic pressures. This requires identification of effective coping strategies utilised by individuals or families who have managed to successfully adjust to the economic pressures of living with a neurological illness.
- Intervention programs to improve the quality of life of people with these illnesses need to draw on the findings from the current study, and be designed to address the particular concerns of respondents from each of the illness groups.
- The lack of difference between patients and carers in mood and quality of life suggests that information and support programs are required for carers of people with neurological illness as much as for the patient. Further, programs need to be developed to help carers better cope with the demands of this role. This will then assist them to improve both their mood and levels of quality of life.

Overall, patients had significantly higher levels of social support satisfaction than carers. Increased awareness of carers needs by health professionals working with people with chronic degenerative neurological illnesses, in addition to the provision of support groups for carers may increase carers overall quality of life and satisfaction with their marital relationship. This may then allow carers to cope with the burden of caring for their spouse for a longer period of time, limiting the time the person with the illness needs to spend in other forms of supported care, such as in a residential care facility.

If you would like a copy of the final report contact Penny Waterson at MND NSW Ph. 1800 777 175 or email [info@mndnsw.asn.au](mailto:info@mndnsw.asn.au)

### Phase II Clinical Drug Trial Prince of Wales Hospital, Randwick

Scientists at the Prince of Wales Hospital hope to show that a neuroprotective agent is able to slow disease progression in MND. It is projected that this study will run over the next three years. What you will need to do if you volunteer:

- Attend the Prince of Wales Hospital up to 10 times over approximately 13 months.
- Each visit to hospital will take up to 3 hours. Free parking will be available.

*N.B. Eligibility criteria apply, so some people may be excluded from participating.*

If you are keen on participating, contact:  
Jennica Winhammar Ph. 9399 1046 Mob. 0411 432 887 [jennicawinhammar@yahoo.com](mailto:jennicawinhammar@yahoo.com) or Ben Cheah Ph. 9399 1046 Mob. 0421 641 484 [bccheah@optusnet.com.au](mailto:bccheah@optusnet.com.au)

This study has been approved by the South Eastern Sydney Illawarra Area Health Service (Eastern Sect) Human Research Ethics Committee Ph. 9382 3583

### Early Release of Superannuation Benefits

Superannuation is generally 'preserved' in your fund or retirement savings account (RSA) until you retire from the workforce after age 55. Subject to the governing rules of the fund/RSA, early release of preserved superannuation benefits is permitted in certain restricted circumstances. Recent changes now enable tax free release of funds under specified compassionate grounds including medical treatment, medical transport, palliative care and home or motor vehicle modifications. For more information contact the Australian Prudential Regulation Authority on 1300 13 10 60.

### March of MND Faces

These banners feature a photographic display of people with motor neurone disease. MND NSW will soon be producing a banner for 2008.

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



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*Editor: Penny Waterson*