

September 2004

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## *Making a difference*

The MND Association has been instrumental in making a noticeable difference through advances in services provided for people with MND in recent years. This includes the care that is now available through specialised multi-disciplinary MND clinics, education of service providers (page 3), provision of disability aids and much more. This all adds up to better quality of life for people living with MND.

Although provision of the best possible care is the prime concern of the MND Association of NSW, without research there can be no discovery that will lead to the long-awaited cure. Research provides hope for the future and 2004 has seen a large increase in the funds available for MND research in Australia.

Congratulations to three post-doctoral scientists who, through the MND Research Institute of Australia, have been awarded Fellowships to further their projects in research that could make the difference we all hope for. Dr Roger Chung (Tasmania) and Dr Valerie Hansen (NSW) have been awarded the inaugural Bill Gole MND Research Fellowships. These grants have been made possible by the generosity of an anonymous donor from NSW. Dr Julie Atkin (Victoria) has been awarded the MND Research Institute Fellowship. (Page 9)

The MNDA NSW Clinical Scholar Research Scholarship (page 8) is directed to medical graduates working in clinical research of MND in NSW. Applications close on 15 Oct 2004 ([www.mndresearch.asn.au](http://www.mndresearch.asn.au)).

2004 has also seen the launch of the MND Registry (page 8) which aims to collect information about every person diagnosed with MND in Australia, to identify treatment gaps and areas for further research.



*Dr Roger Chung, Neuro Repair Group, University of Tasmania.  
Supported by the Bill Gole MND Research Fellowship through  
the MND Research Institute of Australia.*

*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*

## A message from the CEO

The search for new accommodation for the Association is producing positive leads and discussions are taking place with the NSW Health Department. I hope to give members more definitive advice in the next edition.

The MND Association has received financial support this year from the Baxter Trust, United Way, Ryde Eastwood Leagues Club and Campsie RSL specifically to purchase much needed disability aids.

Links have been forged with the Rotary Club of Carlingford and Chatswood Chamber of Commerce, both of whom will strongly support the Association over the next year, for which we are extremely grateful.

I am proud to confirm that the Constellation Hotel Group, through its Country Comfort Hotel properties throughout NSW will donate to the

MND Association of NSW \$1 from every "Country Fare" meal purchased during the months of November, December and January. So, when travelling over that time, please stay Country Comfort and support your Association.



Regrettably, Elizabeth Herbert resigned as Fundraising Manager from 30 June last after three years of dedicated service. Elizabeth will be sorely missed.

A review of directions and strategies in the area of fundraising has been undertaken and I anticipate the appointment of a new staff member in the near future.

*Bruce Fraser*  
Chief Executive Officer

### Christmas Cards form MND NSW

Proceeds go to further the work of the MND Association so we encourage you to write lots of cards. If you require a large number of cards, call the office. There are limited stocks available so please place your orders early.

### MNDA NSW CONTACT DETAILS

**Email:** [admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au)  
**Internet:** [www.mndnsw.asn.au](http://www.mndnsw.asn.au)

General enquiries and Family Support and Info Line:  
Phone 9743 5872 or Freecall 1800 640 144.

To call a particular person, dial the number listed below.  
If the person you have called is not available, you will be transferred to their voice mailbox where you can leave a message.

Roslyn Adams	8765 5118 <a href="mailto:roslyna@mndnsw.asn.au">roslyna@mndnsw.asn.au</a>
Carol Birks	8765 5115 <a href="mailto:carolb@mndnsw.asn.au">carolb@mndnsw.asn.au</a>
Bruce Fraser	8765 5111 <a href="mailto:brucef@mndnsw.asn.au">brucef@mndnsw.asn.au</a>
Maree Hibbert	8765 5114 <a href="mailto:equipment@mndnsw.asn.au">equipment@mndnsw.asn.au</a>
Carole Leone	8765 5117 <a href="mailto:carolel@mndnsw.asn.au">carolel@mndnsw.asn.au</a>
Janet Nash	8765 5116 <a href="mailto:janetn@mndnsw.asn.au">janetn@mndnsw.asn.au</a>
Petra Sammut	8765 5110 <a href="mailto:admin@mndnsw.asn.au">admin@mndnsw.asn.au</a>

**The Annual General Meeting of the Motor Neurone Disease Association of New South Wales Inc will be conducted at Sydney Rowing Club at 11.30 am**

**on Saturday 4 December 2004. All members are invited to attend.**

**The AGM will be followed by the MNDA Christmas party for members and their families.**

**The party will be a Christmas luncheon from 12.30 pm until 2.30 pm at Dedes Restaurant Sydney Rowing Club 613 Great North Road Abbotsford.**

To assist with catering, if you would like to attend the Christmas luncheon, please call Petra Sammut at the office on 9743 5872 by Friday 26 November.

## Family Support: Making a difference

### Information and education for health and community care providers -

the role of the MND Regional Advisors in promoting best practice coordinated multidisciplinary care for people living with MND.

A 1998 survey indicated that people living with MND and their carers wanted to be cared for by health professionals and service providers from their local community who understood MND. Since then MNDA NSW Family Support has focused on promoting best practice coordinated multidisciplinary care through the development and delivery of information and

education for a variety of service providers. The importance of MND education for health and community care providers was again confirmed in the survey distributed to members with MND in 2002, where 71% of respondents rated this aspect of Family Support as **extremely** important.

#### What is best practice coordinated multidisciplinary care?

Care of people living with MND requires a **multidisciplinary approach**, which means that they need the expertise and care provided by some, or all, of the following providers:

Allied health (occupational therapists, speech pathologists etc), nurses, specialist doctors, HomeCare, volunteers, palliative care, aged care, General Practitioners and sometimes nursing home staff. In order to minimise the impact of being seen by all these providers it is imperative that the providers **coordinate care** to prevent duplication and to ensure ongoing communication regarding care needs. MND specific information and education for all potential providers, many of whom may not have had previous experience of caring for a person with MND, helps to promote **best practice care** and support. For most people with MND their local providers, who are encouraged to implement a coordinated multidisciplinary approach within existing teams, provide this type of care. Increasingly MND Specific Models of Care and/or MND Clinics are providing multidisciplinary care in collaboration with the local community teams.

MNDA NSW has a range of printed information including the GP Booklet, which outlines symptom and medical management of MND. This is sent to the GP of all new members, with their permission. All new providers who contact the "info line" for

information or who the Regional Advisors have contact with, or refer people with MND to, are asked if they would like an information pack posted to them. This pack includes a variety of information including, if applicable, the GP booklet and discipline specific information. They are encouraged to contact the Association for further information as the needs of the person with MND change. The number of information packs distributed throughout NSW has risen each year since 1998. Approximately 600 packs were sent out in 2003-2004.

Each Regional Advisor is responsible for providing a consultancy service, individual case advice and face-to-face education sessions for providers in her region as required. Family Support staff aim to be flexible in their approach to education sessions to fit in with the needs of the group. In-services may last from 30 minutes to three hours and may consist of an informal question and answer session or formal presentations including tailored PowerPoint presentations and videos. The audience may include medical, nursing, allied health, Home Care, volunteers, aged care, palliative care, nursing home staff etc. As few as three people to as many as 60 may attend. This year, for the first time, a videoconference education session was held linking Family Support at Concord with health professionals in Dubbo. The aim of the sessions is to provide timely education and support for providers caring for an individual with MND. Each year the capacity of the Regional Advisors to provide this type of education has increased resulting in more in-service education sessions, a larger audience and a wider geographical reach.

On a larger scale, Family Support has annual/bi-annual education and information events for service providers including:

- Rural and Regional Seminars
- Equipment Expo
- Conference for Health and Community Care providers.

Annual Rural and Regional Seminars provides the opportunity for more in-depth education and information on MND care and management in areas that may have had an increase in the incidence of people living with MND. These seminars focus on the integrated

**During the year ending 30 June 2004, MNDA NSW Family Support provided 54 in-service education sessions. 900 health and community care providers are now better equipped to make a difference for people with MND.**

(Continued on page 4)

## Family Support: Making a difference (continued from previous page)

care of people living with MND and invited speakers are included to cover a range of issues associated with MND. This year, a Rural and Regional Seminar was held in Canberra and 55 health providers from the ACT and surrounding areas attended. Since 2000, seminars have also been held in Coffs Harbour, Tamworth, Wagga Wagga and Newcastle. A seminar is proposed for Orange in 2005.

The Equipment Expo is now held bi-annually and provides information and hands on experience on the latest technology and equipment. The next MND Equipment Expo will be held in August 2005.

This year's Conference for Health and Community Care Providers broke all records with 160 providers from NSW and some from ACT, Victoria, Tasmania, Qld and New Zealand attending. Researchers, doctors, nurses, MND Clinics, allied health and MNDA Regional Advisors provided abstracts relating to the theme of the conference "Advances, Initiatives and Challenges". We were overwhelmed by the interest shown and the abstracts received. The program covered different aspects of MND care and management including advances in research, management initiatives and care challenges. The Conference was very well received and evaluated by all who attended. The response has prompted the Association to build on this increasing interest from professionals working with MND by co-hosting future Conferences with the MND Association of Victoria. Next year's conference will therefore be held in Melbourne where we hope that professionals from NSW will present and share their experience and expertise. MNDA NSW will next host the conference in 2006.

The Annual Conference included a session to launch MND Special Interest Groups. Again Family Support was overwhelmed by the interest shown by the health professionals, 110 of whom have joined one of the three special interest groups formed. These groups will be coordinated by Family Support staff in the first instance and will provide an opportunity for health professionals with similar interests to keep in touch, receive relevant up to date information and to meet on a regular basis.

Presenting at Conferences hosted by other organisations is another means of disseminating information regarding MND care and management to a wider audience. In 2003, a poster on the Carers Kit was presented at the

National Palliative Care Conference in Adelaide. Three abstracts from MNDA NSW Family Support have been accepted for the NSW Palliative Care Conference in November 2004. This has resulted in a concurrent session devoted to MND.

Over the last few years Family Support has provided information, case advice and education to many health and community care providers throughout NSW and ACT. It is hoped that increased interest in MND and the increase in MND Clinics and Models of Care corresponds to an increased knowledge and *makes a difference* to the care and treatment that people living with MND receive.

### The Future:

The revised MNDA NSW Business Plan 2003 – 2006 reflects continued commitment to this aspect of Family Support, with three of the seven Family Support objectives focusing on improving and further developing advocacy, information, support and education for providers. The objectives which focus on health and community care providers include:

- to increase family support and advocacy for all people with MND and to respond effectively to their individual needs
- to further develop education programs for health and community care providers, as well as for palliative care, general practitioners and specialists, in order to promote best practice and MND models of care
- to develop interest groups for a range of health professionals to encourage sharing of expertise in MND.

The need for Regional Advisors to advocate for people with MND and their carers at the grass roots level in each region will continue and we will aim to respond effectively to this need. Information and education will continue to be revised and reviewed as symptom management and treatments improve and change and health professionals who do not traditionally seek information and education will be targeted. Developing and supporting the newly established Special Interest Groups will be a focus over the next few years to encourage the sharing of ideas and expertise and to facilitate peer support.

*Carol Birks  
Manager Family Support*

*If you would like us to organise an education session that could 'make the difference' for the people providing your care, speak to your Regional Advisor or contact the MNDA office on 9743 5872.*

**LINK AND LEARN****An Educational, Support and Self care Program for Rural and Regional MND Carers**

MNDA NSW succeeded in obtaining a grant through the NSW Health's Carers Program (Local Carers Grants) to provide Carers Workshops followed by Tele-link support for Carers in three areas of NSW over three years.

The regional areas that will be the focus of this Program are:

- Southern NSW - based in Wollongong 2005-2006
- Riverina and South West Slopes - based in Wagga Wagga 2006-2007
- Northern NSW - based in Newcastle 2007-2008.

This funding provides us with a valuable opportunity to extend the reach of our Family Support Service into regional NSW - a primary aim of the current MNDA NSW Business Plan.

As a result of previous funding through the NSW Health

Department Carers Projects we have been able to establish regular Programs of Carers Workshops in the Sydney metropolitan area and to develop the Carers Kit, which has proved to be a very valuable resource for MND carers and professional health care providers.

With this new round of funding we will be able to adapt these resources with a more regional focus.

*Anita Richter  
Special Projects/Carers Services*

**FAMILY SUPPORT DIARY DATES****Community Care Awareness Week  
13 - 19 September**

If you would like postcards to send to Mr Howard and Mr Latham to highlight the importance of community care in supporting people with MND and their carer at home please contact the office.

**Learn now/Live well Program at Concord  
Tuesdays 19 and 26 October**

A two-day education and support program for people with MND and their family to assist them to live well with MND.

Please contact Carol Birks at the MND office for further information or to express your interest in attending.

**Information Evenings for people  
recently diagnosed with MND their  
families and friends.**

If you have been recently diagnosed with MND and have a family and friends who would like to learn more about MND, please speak to your Regional Advisor about organising an information session in your area.

**Info Line**

**Phone 9743 5872  
or 1800 640 144**

**Roster:**

Monday *Ruth Quaken*  
Tuesday *Mary Butcher*  
Wednesday *Caroline Gleig*  
Thursday *Ruth Quaken*  
Friday *Ruth Quaken*

Plus *Carol Birks* on Tuesday,  
Wednesday and Thursday

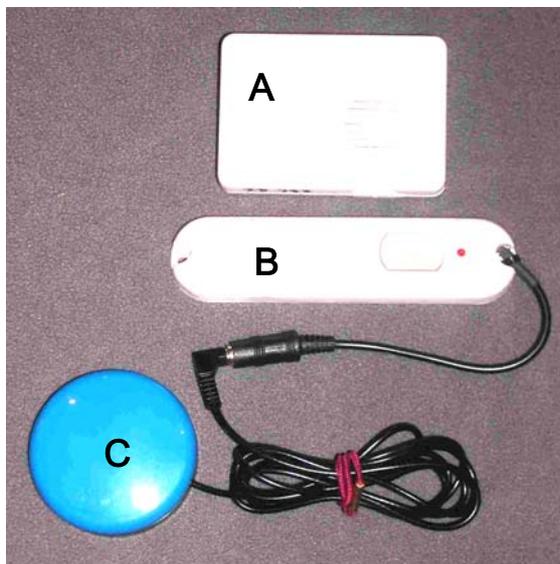
**Carers**

*I recently attended a course for Carers with my sister Jenny who has been caring for her husband Bill who has had MND for seven years.*

*The course was held by the MND Association at Concord and was a great help to us both in learning more about caring. It was also helpful to meet other carers.*

*Our thanks go to Anita Richter and all the staff at MNDA and especially to all the carers who face living with MND every day.*

*Ann Best  
Baulkham Hills*

**A call for help is only a buzz away.**

A cordless door chime can provide a simple solution when a call for attention is needed. The two part chime is available through retail outlets for about \$30. The battery operated chime (A) can be carried around the house or out into the garden by the carer while the door button (B) is conveniently placed for the person who may need help. For someone with little hand function, a switch adaptor (C) can be added. Switch-adapted door chimes are available for loan from the MND Association with the request of an occupational therapist. The large button control can be positioned so the chime can be activated by any simple movement.

## Making a difference in regional NSW & the ACT

### Link and Learn Southern NSW 2005

In March to May 2005 we will be running the first of our **Link and Learn Programs** for carers of people with MND in the Illawarra area and Southern NSW.

This program will provide MND carers with education/training in caring for people with MND along with support and pampering activities.

The program will consist of a two-day (one night) residential workshop at the Novotel in Wollongong. Experienced local health care professionals will provide education on managing MND during the two-day workshop. It is hoped that carers from a broad geographic area will be able to attend this two-day "live in" workshop. This will be followed by six weekly sessions of telephone group link ups allowing participants to continue to share ideas and ask questions without the need to travel. Funding will be provided for pampering activities for participants throughout the duration of the Program.

Ruth Quaken, Regional Advisor for the area will be the key member of the Family Support team working with me on this

Project. We will liaise with local Carers Respite Centres to provide respite care in the home to enable MND carers to participate in the workshop and, wherever necessary, the tele-link program that follows. Costs for this Program including additional staff hours are funded through the grant.

Previous Carers Programs have demonstrated the value of support and education for MND carers. This benefit ultimately flows on to the person with MND being cared for. We hope that many MND carers in Southern NSW will take advantage of this great opportunity.

MNDA NSW is grateful to the NSW Health Department for the funding to establish this Program, which would not be possible through our regular resources. We will be notifying carers in southern NSW of more specific details later this year. If you would like more information please contact Ruth Quaken or Anita Richter at the office.

*Anita Richter  
anitar@mndnsw.asn.au*

### For sale

2003 Holden Combo - fully modified mobility vehicle. Approximately 1500 kms. Silver. Registered till November 04. Wheelchair ramp width 710 mm. Price \$42,000. Contact Jim Parish on 4951 2379 or 0422 178 406.

### Northern NSW

During the last week of June, I travelled north to Coffs Harbour and visited people with MND living on the mid-north coast. This was a good opportunity to meet with people who have recently been diagnosed in the area and to put faces to voices on the phone. It was also a time for people with MND and their carers to have a more personalised discussion about the issues affecting them, and the support that is available to them throughout the progression of the disease.

I also delivered MND education to Macksville and Coffs Harbour Palliative Care Services, Coffs Harbour Community Health Service, and a nursing home in Bellingen. Providing education and information to service providers and community health services is just one of the ways that I am able to make a difference to people with MND.

During October I will be travelling to the far-north coast and the Queensland border. If there are any service providers in that region, for whom you would like me to provide education and information, please phone me on (02) 4952 4492 and I will contact them.

*Christina Jason*

### ACT

As a result of the "multi-disciplinary" message of the MNDA NSW Rural and Regional Seminar held in Canberra, a move has been made to improve care for those with MND in the ACT region. Felicity Rust, Head Speech Pathologist at The Canberra Hospital, attended the conference and has initiated regular meetings between the health professionals involved in the care of those with MND.

The group includes speech pathologists, occupational therapists, a palliative care specialist, social workers, a palliative care nurse, representatives from the volunteer program and myself.

We will meet monthly at Clare Holland House and hope to improve the care of those with MND by approaching each case in a co-ordinated manner. We will also have a system of communicating any pertinent information to the whole group so that we can keep in touch between meetings.

Thankyou Felicity for this very positive move.

*Allison Pearson*

## Support Groups

### Newcastle & Hunter

The group held its AGM on Tuesday the 10 August. Paul Kentwell was re-elected as president after his first year doing an excellent job. Christine and Alistair Fyfe returned as treasurer and secretary, as did our fundraiser Neta Cassidy. John Cassidy is publicity officer and Jean Brown assistant treasurer.

The group continues to support those living with MND and also the research program, hoping that a cure will be found.

*Alistair Fyfe*

### Southern Highlands / Monaro

Canberra turned on a glorious winter day for our August meeting in the Botanic Gardens where eight of us enjoyed the sunshine and chat on the terrace of the café. We welcomed a new face and I hope our group will be a source of on-going support and help for all who attend.

Among matters discussed was our willingness to have a "roving" group. We are willing to travel in the Canberra region so those who find it difficult to get here might enjoy the opportunity of meeting other members. Let me know if you are interested in our group coming to you.

We also discussed a change of name for our group as I found there was some confusion with the "A.C.T." in our name and that of the ACT MND Association. By deleting any reference to our capital, we hope it will be clearer that anyone who lives from approximately Mittagong south to Eden, and all directions out (!), is welcome to come to our meetings. It will also clarify any activities undertaken by both groups.

Our next meeting is at 1 pm on Saturday 6 November at the Goulburn Workers Club. Steve Shackel from Goulburn has developed an MND website at [www.goulburn.net.au/shack](http://www.goulburn.net.au/shack). Steve will talk about his insights at the meeting.

*Allison Pearson*

### Southern Sydney

*(Panania)*

The next meeting will be on Tuesday 5 October at 11 am till 1pm at the Uniting Church Hall, Marco Avenue, Panania.

*Caroline Gleig*

### Western Sydney

*(Penrith & Blue Mountains)*

Anyone who is interested is welcome to attend meetings held on the third Tuesday of each month at the Kingswood Community Health Centre. Enquires to the MNDA office on 9743 5872.

*Ruth Quaken*

### FOR INTERNET USERS

- **OZPALS** is a group of people in Australia and New Zealand with an interest in MND who keep in touch by email. To subscribe go to [www.hotkey.net.au/~ozpals](http://www.hotkey.net.au/~ozpals) or email [ozpals-subscribe@yahoo.com](mailto:ozpals-subscribe@yahoo.com).
- **Internet Chat - Living with MND** Every Tuesday at 1pm & Thursday & Sunday at 8pm EST. Go to [www.mnd.asn.au/](http://www.mnd.asn.au/) then click on the chat room link. For a chat room which is open 24 hours per day, try <http://neuro-mancer.mgh.harvard.edu/echat42/ALS/>.
- Visit the MNDA NSW website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) for information, news and links to other sites.

## SUPPORT GROUP CONTACTS

### Central Coast

Audree Dash  
Phone: 02 4384 2907

### Central West

Mary Campbell  
Phone: 02 6851 4403

### Coffs Harbour

Lily Jenkins  
Phone: 02 6652 2571

### Illawarra

Pam Van Den Hoogen  
Phone: 02 4223 8000

### Newcastle & Hunter

Alistair Fyfe  
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### New England

Robyn Barton  
Phone: 02 6766 6065

### Northern Rivers

Helen Gates  
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### Port Stephens

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[christinaj@mndnsw.asn.au](mailto:christinaj@mndnsw.asn.au)

### Riverina & S W Slopes

Wes Russell  
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### Southern Highlands/ Monaro

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### Northern Sydney

*(Hornsby)*  
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and

### Southern Sydney

Caroline Gleig  
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and

### Western Sydney

Ruth Quaken  
[ruthq@mndnsw.asn.au](mailto:ruthq@mndnsw.asn.au)

are coordinated through the MNDA office.  
Phone: 02 9743 5872

## Research

### MNDA NSW

#### Clinical Research Scholarship

The MND Research Institute of Australia invites applications for a prestigious Clinical Research Scholarship.

This Scholarship is directed towards medical graduates wishing to enrol in a PhD or MD in clinical research into MND in a sponsoring institution in New South Wales.

Applications should include a detailed research plan for an innovative 2-3 year project that involves evaluation and/or improvement of the clinical care of people with MND.

**Closing date: 15 October 2004.**

Further details are available from [www.mndresearch.asn.au](http://www.mndresearch.asn.au) or by email to [info@mndresearch.asn.au](mailto:info@mndresearch.asn.au).

#### Letter to the Editor of Forum

*The proposal of the NSW MND Association to allocate a clinical research scholarship to the MND Research Institute of Australia is an exciting and important initiative. It is one that I strongly support, both as a public health researcher and a person married to someone now living with MND.*

*As the national consumer representative on the National Health and Research Council (NH&MRC) 1984-1992, I and others working on behalf of health care consumers became very concerned at the imbalance between funds allocated to laboratory research as compared with studies directed towards improving clinical care and quality of life. We were glad that NH&MRC brought out strong guidelines that remedy this imbalance in 2001. The guidelines give a priority to research that is a collaboration between researcher and health care consumer, and able to inform clinical practice. The MND Clinical research grant appears to be exactly what these guidelines are meant to encourage.*

*While the majority of research resources are being understandably directed towards prevention and cure, this has been at the expense of several generations of MND patients. While we wait for an effective treatment or cure, we live with our quality of life dependent on the clinical capacity to respond to our immediate needs. While we are so grateful for the marvellous support services, our experience is that rigorous research findings that allow optimal support of people with MND would be welcomed. This new research funding will provide much needed support both for those practitioners and for the rest of us living with MND.*

*Congratulations to the MND Association NSW, and the generous donors on making this possible*

Valerie A. Brown AO, BSc Med PhD  
Canberra

## Australian Motor Neurone Disease Registry (AMNDR)

On 21 June 2004 the Australian Motor Neurone Disease Registry was launched at the MNDA NSW Conference on MND. This date is significant, as 21 June is the international day of recognition of ALS/MND, and this initiative has international significance for people diagnosed with MND, neurologists and scientists.

The Registry is an initiative of a group of neurologists, scientists and MNDA to record basic information about the diagnosis, management and progression of MND in Australia. Funded by an unrestricted educational grant from Aventis Pharma, the Registry is a unique attempt to capture information about every person diagnosed with MND in Australia.

The Registry will collect and analyse MND patient data, including demographics, site of onset, diagnosis, treatment type, change in functional capacity, complications, impact of new treatments and new interventions. The goal of the Registry is to improve patient care through continuous evaluation of patient management and associated outcomes. This will provide Australian neurologists with an opportunity to identify treatment gaps and compare management strategies with associated outcomes at a national level. This will, in turn, generate novel hypotheses for further research.

To be successful, the Registry needs people with MND to participate. Without people diagnosed with MND, the Registry will simply be a collection of interesting information. It needs every person with MND to tell their neurologist that they want to be a part of the Registry.

Participation may be the most important contribution a person with MND can make to research. Recruitment of people living with MND is expected to begin in late August, following ethical approval from hospitals and clinical centres.

Your MND Association has a question and answer leaflet on the Registry. Further information is available at [www.amndr.org](http://www.amndr.org) or from the MND Association in your State.

Rodney Harris  
AMNDR

AMNDR is endorsed by:

The MND Association of Australian

The Australian Association of Neurologists

The International Alliance of ALS/MND Associations

*Three new research fellowships have been awarded by the MND Research Institute of Australia.*

## Bill Gole MND Research Fellowships

### Dr Roger Chung

NeuroRepair Group, School of Medicine,  
University of Tasmania.

#### **Excitotoxicity and cytoskeletal alterations in the pathogenesis of Motor Neurone Disease**

Glutamate is the key chemical involved in transmitting signals between nerve cells within the brain. Changes caused by injury or disease lead to abnormal cell functions and ultimately to death of neurones. The sustained exposure to glutamate which leads to death of neurones is termed *excitotoxicity*.

*Excitotoxicity* is thought to be involved in the development of MND, but it is not clear if over-activation of glutamate receptors leads to the specific patterns of nerve cell changes that are seen in MND, and in particular the changes involving neuronal *cytoskeletal proteins* (proteins responsible for maintaining the structure and shape of neurones). Furthermore, it is not entirely clear why motor neurones are particularly susceptible to excitotoxicity.

This project will determine whether excitotoxicity can directly or indirectly cause the changes in cytoskeletal proteins that are seen in MND, and whether the specific cytoskeletal composition of motor neurones contributes to their selective vulnerability.

Finally, we will explore whether a protein that we have developed that promotes brain healing may also have a neuroprotective role in MND.

This project will be undertaken primarily by Dr Roger Chung, supported by the Bill Gole MND Research Fellowship, under the supervision of Professor James Vickers, who has world-renowned expertise in the study of neurodegenerative disease.

Dr Chung completed his PhD in Biochemistry & Molecular Biology at the University of Tasmania in

2003. His primary research focus is understanding how the brain responds to injury or disease. He has a great interest in promoting medical science research to the local community. In recognition of his efforts, Dr Chung has been nominated as a Tasmanian finalist in the Young Australian of the Year Awards for 2004. He was the winner of the TEMCO Science & Technology Young Achiever of the Year and the overall winner of the Tasmanian Premier's Young Achiever of the Year Award for 2004.

### Dr Valerie Hansen

Department of Pathology, University of Sydney.

#### **Susceptibility to enteroviral infection: a cause of motor neuron disease?**

In 90% of cases MND affects one family member only. This sporadic form of MND is very similar clinically and pathologically to the hereditary form. There is therefore a strong suspicion that genetic defects also underlie the sporadic form of MND.

Sporadic MND may arise in people who are exposed to an environmental agent that is usually harmless. We aim to show that people with sporadic MND have a genetic difference that allows a group of viruses to kill their motor neurons. In this project Valerie Hansen, a recently graduated PhD researcher from the UK, will examine genes that if abnormal could predispose to motor neuron viral infection. She will use DNA samples from the Australia-wide MND DNA Bank.

Any gene differences found would enable identification of people at risk of MND and set in train preventative strategies, for example vaccination against the responsible viruses. For people who already have the disease, the agents could be directly targeted with antiviral therapy. Furthermore, with these findings research in gene therapy for MND could be planned.

## MND Research Institute Fellowship

### Dr Julie Atkin

MND Research Laboratory, Howard Florey Institute, University of Melbourne.

#### **Human ALS linked to SOD1 mutations:**

#### **Mechanisms of toxicity in motor neurones and creation of novel zebrafish models.**

In some people with inherited ALS, the disease is linked to defects, or mutations, in the gene called SOD1. SOD1 is an anti-oxidant protein that normally protects all our cells from damage caused by free radicals. We propose to examine how an inherited defect in the human SOD1 gene converts this normally helpful protein into a harmful protein that leads to the degeneration of motor neurons.

**In the first part**, we genetically engineer different defective human SOD1 genes into motor-neuron-like cells. Using this approach we can ask why one mutation (called A4V) in the SOD1 gene is particularly lethal in human ALS while another mutation (D90A) is relatively harmless. Once we know how differential toxicity occurs, we can begin to identify therapeutic targets and drugs to inhibit or reduce the harmful effects of such mutations and may eventually evolve into therapies for the treatment of inherited ALS in humans.

**In the second part**, we join with a biotechnology company that was spun out from Cambridge University in the UK that specialises in making zebrafish models of human neurodegenerative diseases. We have supplied them with defective human SOD1 genes generated in our laboratory. Through this collaboration we are creating "transgenic" zebrafish and screening those that can pass the defective human SOD1 gene to future generations just like humans with familial human ALS. Such "ALS" fish will become an invaluable tool for studying disease processes and for screening tens of thousands of potential drugs for the treatment of MND.

## Ask the expert

**Q** *I was diagnosed with MND 18 months ago and am being looked after at home, with regular visits to my GP. He mentioned that a new treatment called Rilutek is now available in Australia. Will it help me and how can I get it?*

**A** Rilutek (riluzole) has been used worldwide for a number of years in the treatment of MND, but was only listed by the Pharmaceutical Benefits Scheme (PBS) here in Australia in June 2003. In clinical trials Rilutek increased life expectancy by up to 9 months, although more recent analyses suggest perhaps greater benefit. Rilutek is generally well tolerated by MND patients and can be taken in combination with other treatments. It is probably best used in the early stage of the disease in the expectation that it will delay the onset of further symptoms. Rilutek is an 'Authority' medication, meaning that it is generally prescribed by a neurologist or other specialist and is reserved for MND patients aged under 75 years. There are a few further criteria that need to be satisfied, including an assessment of respiratory function. These issues are best addressed through further discussion with your neurologist.

**Q** *I am having problems swallowing my saliva. Sometimes I can't stop dribbling which is embarrassing when I am out. Also, my voice is becoming weaker. Is there anything I can do?*

**A** Problems with saliva are common for people with MND. Either they seem to have too much or not enough! It is generally not that saliva production is increased but rather that there has been deterioration of the actual swallowing mechanism, as muscles become weaker. The problem may be worse if you have difficulty keeping your head upright. There are no easy answers but here are a few options:

- As a first step, consciously remember to swallow and try to keep your lips closed as much as possible to prevent the saliva escaping.
- Use head supports and collars to prevent the head falling forward.
- Try medications that can reduce salivary production (e.g. atrobe, amitriptyline). But be aware that they may cause a 'dry' mouth and saliva substitutes are sometimes required.
- Suction equipment may be helpful.
- Some people with MND have trialed injections of botulinum toxin (Botox) into their salivary glands to reduce secretions, with variable benefit.

Regarding changes to your voice, most people with MND develop weakness in the tongue, face, throat and larynx at some stage, and as respiratory function becomes affected,

may notice difficulties in loudness of their voice. You could try voice therapy, although this often results in fatigue. A simple voice amplifier is often a good substitute. Ask your Speech Pathologist for the best options for you.

**Q** *I am having problems with cramps in my legs, which are very painful, particularly at night time. Can I take anything to reduce the pain?*

**A** Muscle cramps, spasms and stiffness are common symptoms of MND, particularly early in the course of the disease. In fact, cramps are present in about 10% of patients at the time of their initial consultation. The causes of cramp are varied in MND, some related to muscle breakdown, others possibly to over-activity or over-excitation of the nerves supplying the symptomatic muscles.

In terms of treatment, physical therapies including massage may be of benefit. Some people with MND have also reported benefits with calcium, magnesium and manganese supplements. A number of medications can also help. Quinine sulphate is a common over-the-counter preparation that can be trialed. Tonic water contains small amounts of quinine, which may be a more pleasant and equally effective way of preventing or reducing cramp. Medications used for epilepsy are also effective, particularly carbamazepine and gabapentin. If stiffness is also an issue, baclofen may be effective. These latter medications require prescription and should be discussed with your physician.

**These questions have been answered by Dr Matthew Kiernan, Multidisciplinary MND Service, Prince of Wales Hospital, NSW. He received additional input from Claire Quinn, Director of Speech Pathology at POW Hospital and Tracey Kelly, Speech Pathologist, POW Hospital MND Service.**

Do you have a question about Motor Neurone Disease? Send it to "Ask the Expert" and they will ask their panel of medical experts to answer your query. Send your question to:  
 Email: asktheexpert.mnd@omnus.com.au  
 Fax: 02 9418 9681. Please mark it "MND"  
 Mail: MNDA Ask the Expert  
 Reply Paid 82782  
 Locked Bag 2067  
 Lane Cove NSW 2066

***Please remember that these answers are not intended to replace your usual medical contact and advice. A physician or another healthcare professional should always be consulted for any health problem or medical condition.***

# Make a difference by supporting the Association

## Finding Funding

Like any charity, the MND Association depends mainly upon the generosity of individual and corporate donors to maintain a sustainable income stream with which to acquire equipment for people with MND and also fund research into the cause and cure.

We cannot afford to rely upon Government grants in the climate of resource reduction in that sector and, most importantly, we are

competing with all the better known charities for public attention.

It is the Association's objective to increase community awareness of MND and attract greater financial support. We are asking for your help!

The majority of our fundraising comes from people who have been touched by MND. You as members of the Association are our most valuable asset as your legacy is your time and your contacts. It makes such a difference when we contact organisations if they know of

someone who has been affected by MND as opposed to when we cold call organisations seeking support for events who have no affinity with MND - this is when we are usually met with a polite 'no'.

If you know of any individuals or companies who might respond to our plea for support through sponsorship or donations in kind, and especially if you are able to 'open any doors', please contact Roslyn Adams or Bruce Fraser on 9743 5872.

## Fundraising update

On 3 July, the Misso family held a fundraising event for around 130 people. Jann Karp completed the Gold Coast Marathon on 4 July and held a PhD completion party on 15 August. The Seekers performed in Wollongong on 5 July and in Sydney on 6 July and with collections for MND after the concerts. The opening night of the Charity Art Exhibition held at the Dale Thomas Gallery in Artarmon was held on 15 July with the exhibition running for 5 weeks. On 31 July, Central West Support Group held a Trivia Night in Condobolin. Chatswood Rotary Club held a fundraiser at Pymble Golf Club 30 August.

Thank you to all of the wonderful individuals and organisations who so generously gave their time to manage these events with the proceeds coming to MNDA NSW.

## MND WEEK 3 - 9 April 2005

The launch of MND Week is planned for Government House on Wednesday 30 March 2005. Cornflower Blue Day will be on WEDNESDAY 6 April (Friday 8 is the first day of the school holidays and therefore not a suitable day). Already we have our invaluable supporters and volunteers planning ahead.

Golf Days are marked on the calendar for April at Manly, Shellharbour, Mollymook and Cronulla. Any other events, small or large, would be welcomed to coincide with MND Week!

During MND Week 2005 we are contemplating holding a **service of Hope and Remembrance** for all those people whose lives have been touched by MND over the years. Our thoughts at this stage are to hold the service in Bicentennial Park, Homebush. If this is something you or other members of your family and friends would like to participate in, please call Roslyn Adams at the Association on 9743 5872 or email [roslyna@mndnsw.asn.au](mailto:roslyna@mndnsw.asn.au).

### HELPING THROUGH YOUR WILL

*Your Will can be a convenient vehicle for making a charitable gift of lasting value.*

*Please consider the MND Association as a living memorial for a loved one.*

*Join those who support the work of MNDA NSW through bequests from their Estates.*

To make a donation to support the vital work of the Association, please complete this form and send to: Motor Neurone Disease Association of NSW Inc., Concord Hospital, Hospital Road, Concord NSW 2139

**All donations of \$2 and over are tax deductible**

**Please do not send cash in the mail**

Title ..... First Name ..... Surname .....

Address ..... Postcode .....

Phone Numbers ..... Email .....

Please accept my donation of \$ ..... I enclose my cheque  or Charge my credit card

BC  MC  Visa  Amex  Card number                     Expires

I authorise MNDA NSW to charge the sum of \$ ..... to my credit card (details above) on the 20th day of each month as a donation to the Association. I understand that this contribution can be changed or cease at my instruction at any time.

Cardholder's name (BLOCK LETTERS) ..... Signed ..... Date ...../...../.....

I am remembering ..... with this donation.

Please send me more information more information about:

Becoming a member of the MND Association  Becoming a volunteer  Making a bequest in my will



## MND FORUM

### Race for a Cure

Following the success of the inaugural Motor Neurone Disease Villiers Race Day at Royal Randwick in December 2003 we will be racing again this year on Saturday 18 December and would love you to join us. The Association is looking for six sponsors to buy a race on the day. The cost is \$10,000 (inclusive of GST) and it includes TV coverage on Foxtel and Sky, radio and newspaper coverage, signage on the course and a page in the racebook. It is a great day out and the sponsor of each race will be able to make the presentation to the owner and sash the winning horse. Sponsorship includes a party of ten to be accommodated in the Oaks Lawn Marquee with a delicious buffet lunch, wine, beer, admission and program.

We hope you will support us again this year by coming along for this fun day out, sporting cornflowers. Individual tickets are available at \$130 per person or why not gather a group of friends or colleagues together to make a table of ten for \$1300.

Volunteers are needed for a range of things from helping with wheelchairs to shaking a bucket (near those who are collecting their winnings) and assisting the Fundraising and

Awareness Committee during the event.

The first year was a great success and we want it to be a regular feature in the calendar to raise awareness about MND. For those of you who are further afield, think about having a party – at home or at your local hotel. Run a sweep. Have fun and make sure people in your area know more about MND (leaflets, posters and balloons supplied).

### Dinner Dance & Charity Auction

This MND research fundraiser is being held in memory of Brett Gemmill at the Sutherland Entertainment Centre on Saturday 30 October.

Please contact Leanne Clare on 0414 951 400 if you would like to attend. Tickets are \$65 per head.

In conjunction with this function, Laing & Simmons Miranda agents Michelle and Peter Green have come up with a wonderful initiative 'Commission to Cure MND' by donating their full sales commission from a Shire property listed with them to raise funds for research into finding a cure for MND. Please contact Michelle on 0417 047 062.

*Roslyn Adams*  
Promotions Coordinator

**Walk to d'feet MND**  
*A reminder to all our members that we have ladies and mens socks available for \$6.00 per pair. They are extremely comfortable and of 'Jag' quality and would make excellent gifts for Christmas.*

### What's happening?

23-24 October	South West Rocks Fundraising Weekend - Raffles, Auctions, Golf and BBQ
Friday 29 October	Fashion Parade in Orange
Saturday 30 October	Dinner Dance & Charity Auction in Memory of Brett Gemmill - MND research fundraiser at Sutherland Entertainment Centre
Saturday 30 October	Melbourne Cup Dinner and Auction for Research at Cootamundra
Saturday 13 November	Memorial Golf Day for Tony Young at Cooma Golf Club
Tuesday 16 November	Chatswood Chamber of Commerce Golf Day (proceeds to MNDA NSW and Humpty Dumpty Foundation)
Saturday 27 November	Charlestown Golf Club Charity Day
Friday 3 December	Financial Planners Association Australian Christmas Party - donations during the function to come to MNDA NSW
Saturday 4 December	MNDA NSW Annual General Meeting followed by MNDA NSW Annual Christmas party—all members are invited
Saturday 18 December	Motor Neurone Disease Villiers Race Day at Royal Randwick (call Roslyn Adams at the MNDA Office on 9743 5872 for details)
3 - 9 April 2005	MND Week 2005
Wednesday 6 April	Cornflower Blue Day 2005
Saturday 18 June	Cornflower Blue Ball, Westin Hotel, Sydney

**NB This list is not exhaustive. Call the MNDA Office if you have something to add.**

#### ACKNOWLEDGEMENT

We wish to thank Snap Printing, Artarmon for their generous support.

#### DISCLAIMER

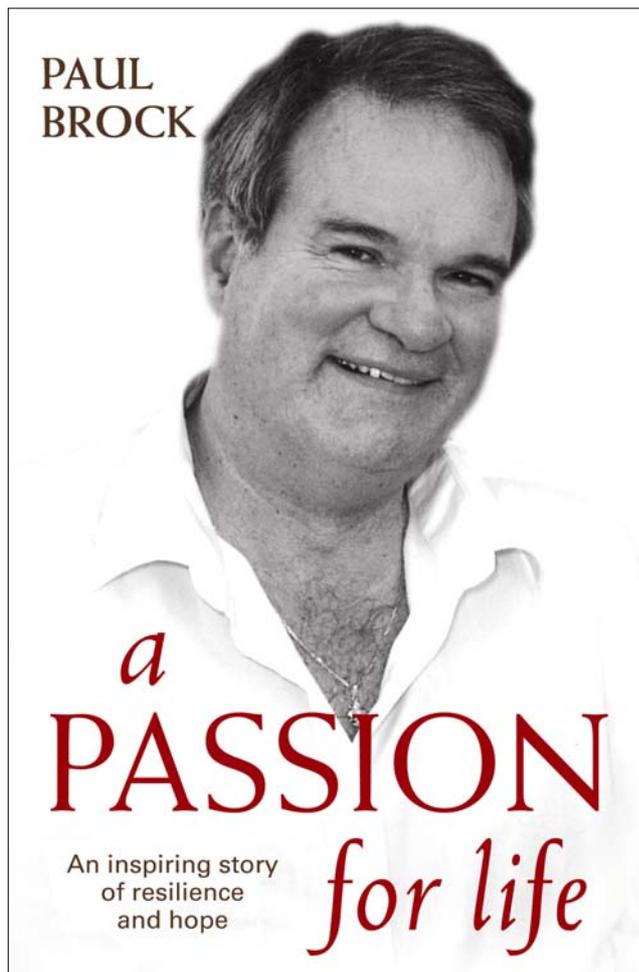
All care has been taken in the preparation of this newsletter. The MND Association of NSW disclaims any liability for its content. The information contained within is of a general nature and to be used as a guide.

**Editor:** *Janet Nash*

## *A Passion for Life* by Paul Brock -

available from selected booksellers from 6 September 2004.

Dr Paul Brock has been a member of the Board of the MND Association of NSW since May 2002.



At fifty-three years of age, Paul Brock, a happily married man with three children, was at the peak of an illustrious career and a bundle of energy - except for a weak right forearm. Out of the blue, he was diagnosed with Motor Neurone Disease and given three to five years to live.

Paul is now sixty. As he says in his new book, *A Passion for Life*, "I can no longer walk, play the piano, scratch my nose, cuddle my wife, hug my kids, drive, wipe my backside, play sport, dress myself, sign my name, swim, play the guitar, turn on a light switch, drink without a straw, wear my wedding ring, get in and out of bed without being hoisted or clean my teeth."

But he can still think, talk, propel himself by motorised wheelchair, love, be loved, laugh, cry, feel, work, dream, get cranky, watch his beloved cricket, empathise, hope, feel the touch of a hand, taste the warmth of red wine, hear the bellbirds and

the kookaburras sing, exercise professional leadership in education, help his daughters with their schooling, stay in touch with his eldest daughter, deliver keynote addresses at major conferences and write. Despite it all, says Paul, "I retain my passion for life. And for telling stories."

Over the past seven years, Paul Brock has had time to reflect on his life. Having spent 15 years of monastic life as a Marist Brother, he wonders to what extent and where he can draw spiritual sustenance. He asks whether his experience of what he calls his 'guts and glory days' in ALP politics was worth it. He questions whether education has changed a little or a lot after his thirty-nine years as a teacher, academic, ministerial staffer, member of State and national boards and statutory bodies, and public servant. Has his passion for public education, for English literature and language, for establishing professional teaching standards in Australia, for authentic research, made a difference? What now of his passion for cricket and music?

*A Passion for Life is Paul Brock's incredible and remarkable story – a celebration of the courage and tenacity of the human spirit.*

### **About Paul Brock**

Paul Brock has had a distinguished career in education. He worked first as a school English Teacher and Deputy Principal, then as a Senior Lecturer in English and as Chair of the Teacher Education program at the University of New England, Armidale. He was the Australian Labor Party candidate in the 1990 Federal election for the seat of New England. From 1990 – 1996 Dr Brock lived in Canberra, working as an advisor to John Dawkins, Kim Beazley and Simon Crean, as each filled the role of Minister for Employment, Education and Training. In 1996 he took up the position of Director of Strategic Policy in the then NSW Department of Training and Education Coordination. He is now the Director of Professional Practice, in the NSW Department of Education and Training.

**A Passion for Life - rrp \$29.95 – Published by ABC Books and available from selected booksellers. Also available from MND NSW at \$20 per copy (plus packing and postage). Phone 02 9743 5872.**