



FORUM

March 2006

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MND Week 2-8 April 2006

An Invitation

All members of the MND
Association of New South Wales
are invited to attend the launch of
MND Week by Her Excellency
Professor Marie Bashir AC,
Governor of New South Wales and
Patron of the Association
in The Lake Room
at the Waterview Convention Centre
Bicentennial Park

on Tuesday 28 March 2006
at 11am

*If you would like to attend, please phone the
Association on 8877 0999 as soon as possible
because seating is strictly limited.
An invitation card will be required for entry.*

The office of the Motor Neurone Disease Association of New South Wales
will be closed for Easter from 5pm Thursday 13 April to Monday 17 April.

Normal office hours will resume on Tuesday 18 April 2006. If help is
needed during the Easter break, please consult your Doctor.

*Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's
disease in some countries. The Blue Cornflower has been adopted in most countries as the
symbol of hope for people living with motor neurone disease.*

A message from the CEO

Planning is well underway for MND Week 2006 and we hope to see many members, supporters and friends of MNDA NSW at all of the events. The planned activities include the formal launch of MND Week by **Her Excellency Marie Bashir AC** Governor of New South Wales and Patron of the Association on Tuesday 28 March, the **MND March of Faces** on Saturday 1 April and **Cornflower Blue Day** on Friday 7 April.

Also during MND Week 2006, MND Associations in all states and territories are asking their members to be a part of a coordinated Australia-wide **Call To Action**. The focus of Call to Action 2006 is the discrepancy of treatment and funding for those over 65, who are Commonwealth funded; and those under 65, who are state and territory funded. The Call to Action will be seeking a unified and fair approach.

Additionally, Call to Action 2006 will seek a concerted effort by federal, state and territory governments in the provision of a more appropriate alternative to the placing of young people in aged care facilities – an issue recently highlighted at the Council on Australian Governments (COAG) meeting. An insert in this edition of *Forum* provides full details about how to become involved in Call to Action 2006 and MNDA NSW encourages your participation.

On a sad note, Regional Advisor **Mary Butcher** has resigned from her position after just over two years with the Association. We will miss Mary and her commitment to people with MND. Her farewell message is on page 6 of this edition of *Forum*.

MNDA NSW membership numbers have risen dramatically during the past six months and this has placed increasing pressure on Family Support resources.

In response to this, two new Regional Advisors have commenced at MNDA NSW – **Jo Fowler** and **Fern Linden**. Both Jo and Fern bring a wealth of experience with them to the Association and they are introduced on page 6 of this edition *Forum*.

On behalf of the board and staff of MNDA NSW I would like to congratulate our Vice President, **Dr Paul Brock**, who was awarded an Order of Australia in the 2006 New Year's Day Honours List. The award specifically recognises his service "... to people with Motor Neurone Disease" and further details appear on page 11.

Heading towards **MND Week 2006** it would be great to hear from people willing to be involved in advocacy, awareness raising and FUNdraising efforts. If you are interested please call **Judy Ford** or **Roslyn Adams** at MNDA NSW or, if you are in the neighbourhood, why not drop in for a cuppa.

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
Executive Director

PS. Regular readers of Forum will know that my children, Tom and Molly (pictured below), have been eagerly awaiting the appearance of blue cornflowers from the seeds we planted



during 2005. Thank you to all who responded to my calls for advice regarding cornflower 'husbandry' in the last edition of Forum. Here are Tom and Molly with their beautiful 'crop'.

Fundamental to the success of the National Call to Action is the involvement of members, supporters and friends of MNDA NSW

Call To Action

The Association has been working hard for some time now to advocate for adequate personal care for people with MND to enable them remain at home. We hope that you will all join us in the Call to Action to further highlight the current inadequacies and inequities.

You can become involved in the Call to Action by sending a letter or email to your Commonwealth MP or Senator. A sample letter you may wish to send is included in this edition of *Forum*. Adjust the text or needs as you see fit and **send it to your Commonwealth MP or Senator by the end of April 2006**. If you need advice about where or to whom you should direct your particular concerns, or if you need assistance in writing your letter, please contact MNDA NSW. A link to locate your local member and an electronic version of the letter are available at www.mndnsw.asn.au



International Symposium

In December 2005 I was very fortunate to attend the **16th International Symposium on ALS/MND** in Dublin. I was presenting a paper 'Respiratory management: a view from the field' during the **Allied Health Professionals Forum held at the event**. The three day International Symposium was attended by 953 people, demonstrating world-wide interest in the challenging area of ALS/MND

*It was through the generosity of **Cathay Pacific Australia** that **Ruth Quaken**, MND NSW Regional Advisor, was able to attend the 16th International Symposium on ALS/MND in Dublin*

The **Allied Health Professionals Forum** focused on care pathways, ventilation and psychosocial aspects of care. Some 350 health professionals attended and the speakers represented eight countries, with two other speakers travelling from Australia to present. These included Robin Ray, a nurse researcher from Melbourne, who spoke about the use of 'ecomaps' to identify gaps in supportive care networks for people living with MND, and Jennene Arnel, Family Support Manager, MND Association of Victoria, who spoke about the Living On Program, developed for past carers by the Victorian Association.

The three day **International Symposium** was divided into two concurrent strands - Research and Clinical Practice. The research strand included presentations on research from around the world: motor neurone biology and pathology; lessons from other motor neurone disorders; cellular transport and trafficking; inflammation; protein



Ruth Quaken, MND NSW Regional Advisor with **Sumana Gopinath**, Neurologist, Sydney at the 16th International Symposium in Dublin

folding and degradation defects; imaging and neurophysiology; therapeutic strategies; genetics and mitochondria. It was very rewarding to see that research is underway and that there is such commitment and interest world wide.

The clinical practice strand included presentations on clinical trials and trial design; quality of life and palliative care; nutritional care and functional independence; clinical phenotypes; carer support; cognition; population genetics and epidemiology and respiratory management.



*At the Symposium, there were also several poster presentations from New South Wales, including one from **Christina Jason**, MND NSW Regional Advisor, about the Volunteer Visitor Program conducted in this State.*

The Symposium provided the opportunity to present and share experiences of working with people living with MND, learn from overseas experience and to further develop relationships with other Australian and international MND professionals.

For me personally, the Symposium offered the chance to develop as a health professional working with people living with MND. It also enabled me to confirm that the care and support for people living with MND in Australia is up there with the best in the world.

Ruth Quaken
MND NSW Regional Advisor

MARCH OF FACES

Saturday 1 April 2006

Come and hold the banners high and tell people about MND!



Families and friends of people who have been touched by MND are invited to gather at the Northern end of **Hyde Park** at **11.30 am on 1 April 2006** for a **Multi Faith Reflection** followed by a **March** through Hyde Park concluding with **Sausage Sizzle** provided by Strathfield Rotary Club or, if you prefer, a BYO Picnic.

This **Research Update** was prepared following the Symposium by the Motor Neurone Disease Association UK.

Is MND one disease?

A better understanding of the different forms of motor neurone disease based on their physical characteristics or 'phenotype' may help unravel the mystery of what causes the disease and how to treat it.

A clinical perspective

Prof Nigel Leigh from King's College Hospital, described the symptoms and physical characteristics of motor neurone disease. Since it was first described in 1869, many different forms have been identified. He concluded that biomedical researchers and clinicians around the world needed to pool their knowledge to understand how different forms of MND occur at a molecular level, to help in the search for effective treatments.

A pathological perspective

Prof Paul Ince, a neuropathologist from Sheffield University, continued this theme, describing the variations in dying motor neurones, as seen under a microscope. By looking at patterns of motor neurone damage in different parts of the brain and spinal cord, he could relate this to the physical characteristics of disease seen in these people.

Clinical trials

The disappointing results of two clinical trials were balanced by the hope of a better outcome of two ongoing trials.

TCH346

The results of the trial of the drug known as TCH346, conducted at 42 different clinics in Europe and North America, including centres in the UK, found that it did not delay disease progression in people with MND.

Creatine

Describing the results of the chemical Creatine, Dr Rosenfeld (Carolinas Medical Center, USA) commented that "the patients felt better on creatine but it is hard to understand why". Unfortunately he and his colleagues found no statistical differences in disease progression or muscle fatigue in this very preliminary analysis of the trial results. They are currently investigating whether creatine may be beneficial in a sub-group of ALS patients.

More hopeful trials

Dr Bob Miller (California Pacific Medical Centre, CA) and Dr Paul Gordon from Columbia University, New York presented more positive results on two preliminary trials of AEOL 10150 and Glatiramer Acetate respectively that have an anti-inflammatory action.

AEOL 10150 was found to be safe and well tolerated in the small number of patients receiving this novel drug. The results will allow the researchers to calculate the optimum drug concentration for larger trials in the future.

The aim of the Glatiramer Acetate (GA) study was to determine whether the drug was safe, and how frequently the drug should be given. Dr Gordon concluded that GA was safe and well tolerated given either daily or twice weekly and that the results supported plans for a larger study.

Are cells' 'power houses' the key to MND?

The importance of mitochondria, the compartment within the cell that provides its energy, emerged as a hot topic at the Symposium. In addition to the production of energy for the cell, mitochondria have several other functions, including maintaining a biochemical balance within the cell and triggering cell death.

Mitochondria are a unique as they contain their own DNA – known as mitochondrial DNA. This is entirely separate from the rest of the DNA within the cell, which is held in a compartment known as the 'nucleus'.

A closer look at mitochondrial DNA

In his overview of this area of research Dr Douglas Wallace (Irvine, California) explained that mitochondrial DNA has many roles in the body, ranging from determining lifespan (the lifespan of many species can be determined by looking at the level of damage in mitochondrial DNA), to evolving protective genetic variations to different environmental conditions. Specific variations in mitochondrial DNA have also been shown to be risk factors for other neuro-degenerative diseases. Their role in MND remains to be understood.

The International Symposium on ALS/MND is a unique annual event, bringing together leading international researchers and Health and Social Care Professionals to present and debate key innovations in their respective fields.

The 17th International Symposium on ALS/MND Symposium will be held in Yokohama, Japan from 30 November to 2 December 2006. For further information see www.mndassociation.org





International Research Update

Quality of life for people with MND

The important topics of quality of life and palliative care came under the spotlight in one session of the meeting.

Developing palliative care for people with MND

Dr Normand of Trinity College, Dublin explained that due to the origins of palliative care, which, he said “owes much to the vision and commitment of some extraordinary people”, research on its effectiveness has been limited. His evaluation of palliative care found that the healthcare providers tried to ‘protect’ their patients. Patients’ rating of different aspects of the services were different to those perceived by healthcare providers.

Monitoring quality of life for people affected by MND

“Quality of life is what people say it is”, explained Dr O’Boyle, based at the Royal College of Surgeons in Ireland, adding that we need to consider this when developing methods to assess quality of life in people with MND. He presented a number of studies that used the ‘SEIQoL’ measure of quality of life, which allows patients to choose the areas of their lives that are important to them. Dr O’Boyle also illustrated the importance of hindsight in assessing quality of life: Although rated highly at the time, comparison with improvements made in the interim may cause people to alter their initial opinion. Quality of life measurements are an aspect of many clinical trials, so it is important to consider all of these factors in the overall assessment of a drug or new clinical intervention.

Preventing cell death

One theory is that the body’s system for cell death, an essential and necessary part of healthy tissues, is over-triggered in MND. Dr Jochen Prehn of Royal College of Surgeons in Ireland, presented some work investigating the effects of genetically modifying the pathways leading to this cell death trigger and how this would affect motor neurones in MND. His preliminary work suggests that such an approach may delay motor neurone degeneration in animal models of MND.

Following many careful and painstaking years of research work, Dr Wood-Allum of Sheffield University, suggested that in MND there may be lower than normal levels of the protective mechanisms to prevent cell death from being triggered. By restoring these to their normal level, the effects of motor neurone degeneration may be reduced.

Hope for the future?

In addition to the more conventional method of drug therapy – what other approaches may be used in the future to treat MND?

Gene therapy

Dr Linda Greensmith described the effects of the neurotrophic factor IGF1 (known commercially as Myotrophin) gene therapy, using a form of this protein known as ‘MGF’. MGF was injected into the muscles of a mouse model of MND, when they first started to show symptoms. Improvements in muscle strength and motor neuron survival were found in treated animals in comparison to controls (untreated animals).

Dr Brian Kaspar has previously shown that gene therapy of the more common form of IGF1 is beneficial in animal models of MND. In his latest study he has taken the seemingly counter-intuitive step of combining this gene therapy with an exercise regime. (There are reports, both suggesting that high levels of exercise is a risk factor for MND, and also that exercise may be beneficial). Dr Kaspar’s results showed that the combination of IGF1 gene therapy and exercise improves the survival of these mice more than the effects of the gene therapy alone. Further study is required to understand the underlying cellular mechanisms causing these effects.

Stem cells

There were no presentations demonstrating the effects of stem cell therapies at this year’s International Symposium. However, Prof Vincenzo Silani presented some laboratory-based research showing that it is possible to turn human stem cells extracted from the bone marrow into a type of support cell for motor neurones called astrocytes. “These data, combined with the recent hypothesis on the essential role played by astrocytes, may open a new prospect for stem cell therapy in ALS, although further investigations and pre-clinical data are needed” he concluded.

*Motor Neurone Disease (MND)
Association UK
www.mndassociation.org
Reprinted with Permission*

Quality of life measurements are an aspect of many clinical trials.

Family Support

There have been some changes to Family Support as we sadly farewell Mary Butcher but gladly welcome **Jo Fowler** and **Fern Linden** to the team. Mary has been a very professional and empathic Regional Advisor and made a significant contribution to the capacity of the Association. We will all miss her and wish her and her family all the best for the future. Regional Advisor boundaries have changed slightly with the two new appointments. Jo Fowler will cover Northern Sydney and Central Coast and Fern Linden will cover South West Sydney/Central West and New England.

The 2nd National MND Conference will be held on Tuesday 20 June at the Wesley Centre, Sydney. Everyone is welcome to attend; however, this Conference is aimed at health professionals in order to promote the best possible care and support for people with MND in Australia and New Zealand. Please let the health professionals and community care providers involved in your care know about this conference

*Carol Birks
Manager, Family Support*

Adieu from Mary Butcher....*I would like to say goodbye to everyone involved in MNDA NSW, as I have resigned from my position as Regional Advisor for the Northern Sydney, Central Coast and New England Areas. I have met many remarkable people during my time in this role and it is with sadness that I leave, due to illness in my own family. I have so valued all the relationships I have developed, friends I have made, my wonderful colleagues and the incredible volunteers of the Association. My very best wishes to everyone living with this wretched disease, to those working to support people living with MND and to those involved in the search to find a cure. Mary.*

Introducing.....

Jo Fowler - Regional Advisor
Northern Sydney/Central Coast

I am very excited about taking on this new role and getting to know the members of MNDA NSW and the health professionals working with members in the Northern Sydney and Central Coast Areas.

As a registered nurse, I have worked in post operative cardiac care, midwifery, health promotion, women's health and dermatology. Following completion of my Bachelor of Arts and Diploma of Teaching Nursing I have taught in several Schools of Nursing in Sydney.

It is a privilege to join the team and I am looking forward to working as a Regional Advisor.



Jo Fowler and Fern Linden, new MNDA NSW Regional Advisors

Gladesville

The first support group to be held at the MNDA NSW Gladesville Centre was held in February and it was attended by a great group of people with MND, their families and friends. We got to know each other a little with general discussion. Judy Ford, MNDA NSW Fundraising Manager, showed us the variety of Association merchandise available and talked a little about fundraising activities.

The next meeting at Gladesville will be held on Wednesday 5 April at 10am, Carol Birks, MNDA NSW Family Support Manager, will introduce Enza Velasi from Commonwealth Carelink and Carer Respite Services. Enza will talk about the services offered and this will be followed by a general discussion about community services available to people living with MND. Everyone is welcome but it would be helpful if you could call the office to let us know if you are planning to attend.

*Caroline Gleig
Regional Advisor*

Fern Linden - Regional Advisor
South West Sydney/Central West/New England

My background in teaching and interest in community work has led me to this position at MNDA NSW which I consider myself fortunate to have found.

I have Bachelor of Arts and Diploma in Education, a Master of Education in Adult Learning and a Bachelor of Social Science

in Psychology. My employment history is varied, and includes work in universities, spending a decade in the public service and teaching in both city and rural areas. I am looking forward to meeting members and their families, working with support groups, volunteers and health professionals.

MND Charity Golf Day

Sunday 2 April

Waratah Golf Club

All golf levels welcome, wear your brightest shirt for a great day.

Heaps of prizes, music and fun for all!

Phone 1300 667 873
or 49427476

Carers News

Lunch for Past Carers

MNDA NSW is very aware of the tremendous contribution of those who have cared for a loved one with MND. A lunch and get together for past carers was held at the Gladesville Centre on 20 February to acknowledge this contribution. This was a good opportunity for past carers, particularly those who had lost

a loved one with MND during the last 12 months, to renew acquaintances and share thoughts and experiences. Interest in a regular past carers support group was flagged at this meeting and more information about the next meeting appears below.

Past Carers Support Group

The date for the **next meeting of past carers** is from 12-2pm

Monday 8 May at the MNDA NSW Centre in Gladesville.

Participants have suggested bringing a plate or a small contribution of food for lunch. This will be an informal gathering and **all past carers are welcome**. If you would like further information please contact Anita Richter on 8877 0999.



From left, Gweneth Taggart, Anne Paterson with daughters Skye Paterson and Tina MacKander, Margaret Hoare, and Diane Gordon at the past carers lunch held at the MNDA NSW Gladesville Centre on 20 February.

Link and Learn – Reaching Out to Regional Carers

Nine carers from the Riverina, South West Slopes, Central West and the ACT attended the **Link and Learn** residential workshop in Young on 6-7 March. Local health professionals and MNDA NSW Family Support staff

provided education on managing many aspects of MND. Funding through the NSW Health Local Carers Program also allowed the participants to enjoy a little pampering and to relax and have fun. Now that everyone has returned home, Link and Learn continues with six weeks of telephone group support so that participants can continue to keep in touch with each other.

Information Resource for MND Families

For some time MNDA Victoria and MNDA NSW have been aware that there has been insufficient information to support families when a parent has MND. A successful joint submission for funding under the Australian Government, Local Palliative Care Grants will enable both Associations to work together to develop a Resource Kit: **'Talking to Young People about MND'**. This Kit will include guidelines for young people, parents, teachers, counsellors and palliative care providers. MNDAV will lead this project and we look forward to working with our Victorian colleagues on this project during the next three years. We are sure it will make a difference.

MND Carers Kit

Knowing what to do at the right time can make a tremendous difference when you are caring for someone with complex needs resulting from MND. The **MNDA NSW Carers Kit** was developed with the assistance of NSW Health Department funding. While primarily designed for carers of people living with MND, a variety of health and community care professionals have also found the Kit to be helpful. The Kit is available in separate sections, which can be ordered as they are needed. For more information or for a checklist for the Carers Kit contact MNDA NSW on 8877 0999.

*Anita Richter,
Special Projects/Carers Coordinator*

Support Groups

Central Coast

Audree Dash
Phone: 02 4384 2907

Central West

Fern Linden
Phone: 02 8877 0999
fern1@mndnsw.asn.au

Coffs Harbour

Lily Jenkins
Phone: 02 6652 2571

Illawarra

Pam Van Den Hogan
Phone: 02 4223 8000

New England

Robyn Barton
Phone: 02 6766 6065

Newcastle & Hunter

Barry Harrison
Phone: 1300 667 873

Northern Rivers

Helen Gates
Phone: 02 6621 4018

Riverina & S W Slopes

Wes Russell
Phone: 0408 692 127

Southern Highlands/Monaro

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and

Western Sydney

Ruth Quaken
ruthq@mndnsw.asn.au

are coordinated through the MNDA office.
Phone: 02 8877 0999

The 2nd National MND Conference 'MND: Advances, Initiatives and Challenges' will be held in Sydney on 20 June. For more information see www.mndnsw.asn.au

Equipment

One of the most challenging aspects for staff of the MND Association of NSW is the ongoing necessity to apply for funding to assist us in providing a good service for our members. Funding applications are regularly made to various Government departments, private foundations, clubs and private companies. Most of these applications are very involved and they take a considerable amount of time to complete. For every application, a particular project or equipment need must be identified. Also, a final report which demonstrates the member benefit is often required.

Some applications are unfortunately unsuccessful but with others, all the effort is worth it. Equipment purchases over the last 12 months directly attributable to these successful applications include:



MNDA NSW Equipment Assistant Trevor Rakuraku with the fifteen manual light weight wheelchairs which were purchased through funds raised by Barnwell Park Golf Club

- Three powered tilt-in-space wheelchairs
- Two electronic page turners with sip-and-puff and scanning switching, and three hands free laser computer mice for hands free access to computers
- Six high profile alternating air mattress overlays. These mattresses improve care and comfort as well as relieving some of the burden on carers
- Fifteen manual light weight wheelchairs which have quick release wheels for easy transport and solid/tubeless tyres for use where the region may be remote and the inflation of tyres is difficult.

Planned future purchases include:

- Ten switch activated remote controlled door chimes that enable a member to remotely contact a carer with the press of a special switch. Five laser/cap head pointers used for infrared pointing in communication. All specifically built for MNDA NSW by Technability with funding from **The Ross Divett Foundation**.
- Bathroom and lounge room equipment , for example, toilet aids that are height adjustable for different members to use and armchairs that are either electric raiser recliner in style or just height adjustable to assist in mobility. Funding, from various local Leagues and RSL clubs, make these purchases possible

These generous contributors have answered our ongoing calls to action and have enabled the MND Association of NSW Equipment Service to respond to calls of need from our members.

*Maree Hibbert
Equipment Officer*

After careful discussion with the Regional Advisor and the requesting Health Professional, equipment loans are allocated by the equipment officer on a 'need' priority basis.



The Australian Motor Neurone Disease Registry (AMNDR) is an initiative of Australian neurologists, scientists and MND Associations to record basic information about the diagnosis, management and progression of MND in people living in Australia. It is funded through an unrestricted educational grant from Sanofi-aventis. The Registry is a unique attempt to capture information about every person diagnosed with MND in Australia.

The Registry collects information about people with MND, 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 care through continuous evaluation of clinical 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.

Participation in the Registry may be the most important contribution a person with MND can make to research. Further information is available at www.amndr.org, your MND Association of NSW Regional Advisor or from your neurologist.



Congratulations to researchers receiving grants from the **Motor Neurone Disease Research Institute of Australia Inc** for MND research in 2006.

All grants distributed by the Motor Neurone Disease Research Institute of Australia are made possible through donations and bequests from individual supporters and contributions from MND Associations across Australia.

A total of **\$327,564 has been allocated**, with **\$100,000** of this amount provided by an anonymous donor towards two concurrent Bill Gole MND Fellowships. It was not possible to meet requests for an additional \$340,000 from researchers around Australia who are trying to advance the cause of MND research.

MND Research Institute of Australia 2006 Research Grants

MNDRIA FELLOWSHIP

(Year 2 of 2) **\$69,188**

Dr Julie Atkin, MND Research Laboratory, Brain Injury and Repair Group, Howard Florey Institute, University of Melbourne, Victoria

Human ALS linked to SOD1 mutations: Mechanisms of toxicity in motor neurons and creation of novel zebrafish models

BILL GOLE MND FELLOWSHIP

(Year 2 of 2) **\$69,188**

Dr Valerie Hansen, Department of Pathology, University of Sydney, New South Wales

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

BILL GOLE MND FELLOWSHIP

(Year 1 of 2) **\$69,188**

Dr Ian Blair, Northcott Neuroscience Laboratory, ANZAC Research Institute, Concord, New South Wales

Identification of novel genes involved in motor neuron degeneration

MND NSW CLINICAL RESEARCH SCHOLAR

(Year 2 of 2) **\$75,000**

Dr Steve Vucic, Prince of Wales Medical Research Institute, New South Wales

Site of origin and patterns of neuronal degeneration in motor neurone disease

GRANT-IN-AID

\$15,000

Dr Mark Bellingham, School of Biomedical Sciences, Dept of Physiology & Pharmacology, University of Queensland, Queensland

Glutamate receptors and ion currents controlling in vivo excitability of motor neurons resistant and susceptible to death in ALS

GRANT-IN-AID

\$10,000

Dr Robert Henderson, Department of Neurology, Royal Brisbane Hospital, Queensland

Assessing disease progression in motor neurone disease

GRANT-IN-AID

\$5,000

Dr Wayne Murrell, Eskitis Institute for Cell and Molecular Therapies, Griffith University, Queensland

Adult stem cells from patients with ALS: culture of motor neurons, proteomics and functional analysis

GRANT-IN-AID

\$15,000

Dr Roger Pamphlett, Department of Pathology, University of Sydney, New South Wales

Somatic mutations in motor neuron disease

For more information see www.mndresearch.asn.au

NHMRC funds Australia-wide DNA Bank for Motor Neuron Disease

Congratulations to Dr Roger Pamphlett of the University of Sydney who has successfully secured a National Health and Medical Research Council (NHMRC) Enabling Grant for the Australian Motor Neuron Disease DNA Bank. Dr Pamphlett is a Neurologist and Neuropathologist at Royal Prince Alfred Hospital. He also teaches undergraduate and postgraduate Neuropathology and Neurology at the University of Sydney and Royal Prince Alfred Hospital. His main research interest is MND, and he runs a regular MND Clinic for people with MND.



Dr Roger Pamphlett

For most people with MND it is thought that the disease occurs as a result of a genetic susceptibility to an environmental agent, such as a toxin or a virus, which enters and destroys the motor nerve cells of susceptible individuals. To see if people with MND have a genetic susceptibility to environmental agents, the Australia-wide MND DNA bank has been set up. People both with and without MND are encouraged to contribute blood samples. Comparisons will be made between people with and without MND and it is hoped that genetic differences will be found between these groups. With this new funding it is planned to increase the numbers of people with MND in the Bank to over 1,000.

For further information contact the Australian Motor Neuron Disease DNA Bank, Department of Pathology, Blackburn Building D06, University of Sydney NSW 2006, phone 02 9351 3318 or email rogerp@med.usyd.edu.au.

Dates for the Diary

28 March	MND Week Launch <i>Waterview Convention Centre, Bicentennial Park</i>
1 April	March of Faces <i>Hyde Park, Sydney</i>
2 April	Charity Golf Day <i>Waratah Golf Club</i>
7 April	Cornflower Blue Day
8 May	Past Carers Support Group <i>MNDA NSW Centre Gladesville</i>
20 June	2nd National MND Conference <i>Sydney</i>
21 June	<i>ALS/MND Global Awareness Day</i>
<i>Contact MNDA NSW on 8877 0999 or 1800 640 144 for further information</i>	

Research Project: Financial Impact of MND

YOUR HELP IS NEEDED!

As part of a collaborative research project between Deakin University and MNDA NSW, Professor Marita McCabe and Dr. Lucy Firth are undertaking a research project looking at the **financial impact of MND on the quality of life of people with MND and their families**. In March, members of MNDA NSW with MND should have received a cover letter and consent form asking for assistance with this research.

WHY YOU SHOULD HELP:

Firstly, there has been limited research conducted in Australia looking at the relationship between financial strain and quality of life in people with MND. So, your information will assist in understanding this relationship as well as educating others on this issue. Also, your information will be essential when lobbying policy making bodies responsible for providing benefits for people with MND. Lastly, we need this information so adequate intervention programs assisting with financial strain can be implemented for people with MND and their families

For further information contact Candice Roberts at Deakin University on 03 9251 7258 or via email candice.roberts@deakin.edu.au.



2006
MND Week
Help Needed...

Railway Stations

We will be selling wrist bands, pins, cornflowers and other merchandise around metropolitan railway stations on **Friday 7 April from 7-9am**. It is a great way to spend a couple of hours volunteering for MND. Permits are required so please let us know for which station you would like us to gain permission for you to collect.

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 7 April**. 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 our 'Never Give Up' wristbands 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.

*Contact Judy Ford or Roslyn Adams at MNDA
NSW on 8877 0999.*

Join with
others to
raise
awareness
of MND

Australia Day Honours 2006

Congratulations to Dr Paul Brock, recipient of the Member in the Order of Australia (AM) in the Australia Day 2006 Honours List. Diagnosed with MND in 1996, Paul is a member of the Board of Directors of MNDA NSW. He is a strong advocate for stem cell research and therapy, and is a member of the MND Research Institute of Australia.

Paul is currently Director, Professional Learning and Research, NSW Department of Education and Training. His citation reads: *"For service to public education, particularly as an adviser and author in the areas of strategic policy development, to maintaining high standards of teaching and professionalism, and to people with Motor Neurone Disease."*



Dr Paul Brock AM

**MND
Week
2-8 April
2006**

Fire Brigade Graduates Choose MNDA NSW

Each time a class from the New South Wales Fire Brigades State Training College in Alexandria graduates, they show their community spirit by collecting for a chosen charity. **Class 7/2005 chose MNDA NSW as their charity** as some of the recruits had been touched by MND.

For both the graduates and onlookers the day was exciting. After the Class Parade, inspection and presentation of Graduation Certificates by Commissioner Greg Mullins, the new fire officers put on a magnificent display of their firefighting skills.



After watching a car explode, a building burst into flames and firefighters rescue people trapped on the top floor, **MNDA NSW CEO Graham Opie** had a difficult act to follow when he accepted the cheque for **\$2,000**. He thanked the new firemen for choosing motor neurone disease as their charity and assured them that the money would be used to support people with MND and make their lives more



MNDA NSW CEO Graham Opie accepting a cheque from the Firefighters of Class 7/2005

Better Homes and Gardens Raising MND Awareness

Confirmation has been received that **Bob and Suzanne Ballinger's** garden, featured in the December edition of *Forum*, will be shown in a segment of the Better Homes and Gardens program to be broadcast on Channel 7 (Prime) at **7.30 pm on Friday 24 March** (assuming there are no late program changes). There will also be a short article in the April edition of the Better Homes and Gardens magazine which is distributed to newsstands in late March. Thank you to Bob and Suzanne for opening their garden and the MND awareness raising this has generated.

MNDA NSW 25 years 2006

We are seeking volunteers who may be interested in working with others to review and further develop historical information about the Association. A meeting of interested people is planned for April at the MNDA NSW Centre Gladesville. If you are interested in participating contact Penny Waterson, MNDA NSW Information Officer by 10 April 2006, phone 8877 0915 or pennyw@mndnsw.asn.au

Mailbag

To the Motor Neurone Disease Association of NSW

Dear Maree

I am writing this letter to confirm that the beach chair has been donated, in Dennis Vickery's memory, to the Motor Neurone Disease Association, to use as they wish. He would love to think that other people with this condition could get some fun and enjoyment from the use of this chair.

We used this chair when we stayed at our caravan at Lake Burrill, which is down the South Coast, during the Christmas break 2004 and Easter 2005. Den could no longer walk or move his arms, he could still use his right hand enough to drive an electric wheelchair. We would transfer Den from his wheelchair to the beach chair, then the boys: Todd and Shaun (our sons), Brett (son-in-law), Chad and Bob (friends), would take turns in pushing Den across the lake's entrance to the surf. To do this we had to travel across two channels and a sandbar. The chair would float in the channels if they were deep and we needed a person each side as well as at the back to guide it across. When we reached the beach, the boys would push the chair into gentle surf and catch small waves in with Den in the chair. Den loved it, though he didn't really trust us!



Dennis Vickery, in his beach wheelchair, setting off for the beach with family and friends.

When we took Den for a swim, we would have an entourage taking him across to the beach. Each time was like an adventure and it gave him a chance to have a swim and share in part of our holiday. I hope this chair will give many happy memories!

Yours sincerely

*Kerry Vickery
Engadine.*



The Freewheeler recently donated to MND NSW Equipment Pool in memory of Dennis Vickery

Would you like to participate in updating the Travel Information held by MND NSW?

Do you like searching the internet and have an interest in travel? We are seeking a volunteer who may be interested in updating the Travel Information Resource Sheet published by MND NSW. Travel information is provided by MND NSW to people living with MND who are seeking 'MND friendly' accommodation, transport, agencies and tours.

You will need to use email and the internet to make sure that the information held by MND NSW is up to date, and also do some internet searching to find new 'MND friendly' travel destinations. The task can be undertaken at home if you have access to the internet, or at the MND Centre Gladesville.

If you are interested in assisting with updating the information, contact Penny Waterson, MND NSW Information Officer by 10 April 2006, phone 8877 0915 or pennyw@mndnsw.asn.au

POSITIONS VACANT

We need volunteers to take responsibility for the Reception area at our Gladesville Centre. Based at the hub of the organisation, you will meet and greet visitors, answer the phone and carry out many useful tasks throughout the office.

Volunteers have always formed the backbone of the Association and are always needed to help with the many aspects of running the Association. Special times, such as MND Week, can require large numbers of volunteers for a short time, but people who can commit a regular day or half day to help are always needed too.

If you could help out for a few hours, a day or even longer we would be most grateful.

Please contact Roslyn Adams phone 8877 0908 if you can offer assistance

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 New South Wales disclaims any liability for its content. The information contained within is of a general nature. For medical advice, consult your doctor.

Editor: Penny Waterson