



June 2006

Advance

NEWSLETTER OF THE MND RESEARCH INSTITUTE OF AUSTRALIA

The Motor Neurone Disease Research Institute of Australia Inc

was established in 1986 with the following objectives:

- To promote medical and scientific research into MND
- To determine the relative merits of research proposals for the study of MND for the receipt of research grants
- To administer research grants for the study of MND
- To facilitate the exchange of information about MND
- To affiliate with other bodies, either national or international, as will advance the cause of research into MND
- To be an Approved Research Institute by meeting the conditions of the Income Tax Assessment Act Section 73A (including assessment of applications by suitably qualified members of a medical/scientific research committee)
- To raise funds for MND research.

The Research Institute's constitution was amended in 2005 to allow the MND Associations in Australia to become members. All MND Associations have chosen to take up membership and it is hoped that they will now have a more active role in establishing policy for the Institute and raising funds to support research.

The Medical/Scientific Research Committee

comprises experts from all States of Australia who are leaders in their fields in medical and scientific research and also have a special interest in MND. These people give their time to review all grant applications and make sure that the limited funds that are available for distribution each year are given to the most worthy applicants. We welcome Associate Professor Matthew Kiernan (NSW) and Professor James Vickers (Tasmania) as new members of the committee.

The Committee is the strength of the Institute and it is a fitting tribute to MND research that these eminent researchers are willing to give their time to promote MND research in Australia. There are always more requests for funding of grants than there are funds available, so it is essential that each project is carefully assessed to ensure that the maximum benefit will be obtained from the funding. Brief profiles of committee members are on pages 2 & 3.

Funds allocated to grants in 2006

\$361,164 has been provided for three post doctoral research Fellowships, a clinical PhD scholarship and five grants-in-aid.

New grants awarded for 2006:

BILL GOLE MND RESEARCH FELLOW 2006-2007

Dr Ian Blair ANZAC Research Institute, NSW
Identification of novel genes involved in motor neuron degeneration

GRANTS-IN AID

Dr Mark Bellingham University of Queensland
Glutamate receptors and ion currents controlling in vivo excitability of motor neurons resistant and susceptible to death in ALS

Dr Robert Henderson Royal Brisbane Hospital, QLD
Assessing disease progression in MND

Professor Alan McKay-Sim and Dr Wayne Murrell
Griffith University QLD

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

Associate Professor Roger Pamphlett

Department of Pathology, University of Sydney
Somatic mutations in MND

Grants continuing from previous years:

BILL GOLE MND RESEARCH FELLOW 2005-2006

Valerie Hansen University of Sydney
Susceptibility to enteroviral infection: a cause of MND

MND RESEARCH INSTITUTE FELLOW 2005-2006

Dr Julie Atkin MND Laboratory
Howard Florey Institute, University of Melbourne
The mechanism by which SOD1 mutations induce degeneration of NSC-34 motor neurons

MND NSW CLINICAL RESEARCH SCHOLAR 2005-2006

Dr Steve Vucic
Prince of Wales Medical Research Institute, NSW
Site of origin and patterns of neuronal degeneration in MND

GRANT-IN AID

Dr Dominic Rowe

Royal North Shore Hospital & Prince of Wales Medical Research Institute, NSW
Mechanisms of nocturnal hypoventilation in MND/ALS

Closing date for applications for grants for 2007 is Friday 25 August 2006.

For details go to www.mndresearch.asn.au.

Office Bearers of the MND Research Institute of Australia in 2006

Executive

CHAIRMAN

Dr Dominic B. Rowe, NSW

BSc(Med) MBBS (Hons) FRACP, PhD (UNSW)

I am the Director of the Multidisciplinary MND Clinic at RNSH, that has been operating since August of 1999. My interest in MND was ignited at Baylor College of Medicine, where I was a Huffington Scholar on Ageing from 1996 until 1998 under the supervision of Professor Stanley H. Appel. Infected by Professor Appel's drive and enthusiasm to identify the cause(s) of MND, I was also overwhelmed by the excellence of clinical service that he provided for patients with MND. Excellence in clinical service provision and research must go hand in hand. It is imperative that our current patients with MND have access to the best therapies that are available. In addition, clinician-scientists must be involved in phrasing the two major questions relevant to MND: why and how. It is only by understanding 'why and how', that science will provide the therapies that will slow and stop MND.

I am married to Sally, and have three children now aged 15, 13 and 9 years. I enjoy cooking, music and pottering in the garden.

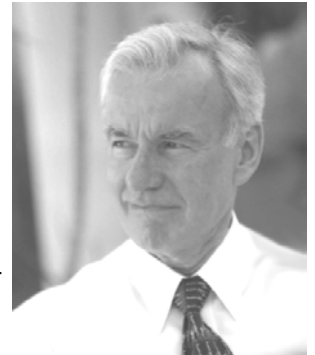


I previously worked at Royal North Shore Hospital where I established the Research Office. My ambition is to raise the profile of the MNDRIA, promote awareness and improve funding for MND research.

PUBLIC OFFICER

Professor John Pollard, NSW

Bushell Professor of Neurology at the University of Sydney and co-director of the Nerve Research Foundation and the Brain & Mind Research Institute. He is a member of the Steering Committee for the Neuromuscular Group within the World Federation of Neurology, and a past board member of the Peripheral Nerve Society. Professor Pollard is on the scientific advisory board of the Australian Association of Neurologists, the National Multiple Sclerosis Society, and is a corresponding member of the American & British Association of Neurologists. His major research interest is in neuromuscular disorders, particularly in the field of neuroimmunology.



TREASURER

Mr David Lamperd, Victoria

I have enjoyed a strong involvement with the MND community, including volunteer roles within MNDRIA, since my father-in-law passed away from the disease in 1999. This has provided me the opportunity to meet many hardworking and inspirational people who are passionate about finding the cause and a cure for MND.



Medical/Scientific Committee Members

Professor Perry Bartlett, QLD

Foundation Chair in Molecular Neuroscience at The University of Queensland in August 2002, and Director of the newly established Queensland Brain Institute in 2003. Professor Bartlett previously headed the Neuroscience division at the Walter and Eliza Hall Institute in Melbourne, where his group gained an international reputation in the field of cellular and molecular neurobiology, a fact highlighted by his election as a Fellow of the Australian Academy and the awarding of the highly prestigious ARC Federation Fellowship. His group's work on the production of neurons in the adult brain was published on the front covers of Nature and Journal of Neuroscience. Professor Bartlett is continuing his research into how the production of new neurons influences the function of the adult brain, a program of discovery which has led to several paradigm shifts in our understanding of the nervous system. The most recent work has implications for how memory and learning are regulated and underpins the new concept that the brain has the capabilities of repairing and replacing damaged or diseased neurons. Finding the mechanisms that regulate these processes is the primary focus of QBI and will lead to a new generation of therapeutics to treat the avalanche of neurological and mental illness.



SECRETARY

Mrs Paula Trigg, NSW

After my cousin-in-law's husband died of MND I volunteered to help at the 1999 MND Ball in Sydney at which Dr Roger Pamphlett gave an inspirational speech about MND. I have been volunteering in numerous ways ever since: selling cornflowers; taking photos of cornflowers for fundraising and promotion purposes; helping with mailouts etc. I have been Convenor of the MNDA NSW Fundraising Committee, a member of the Board of MND Association of NSW and am currently Convenor of the MNDA NSW Research Sub Committee.



Associate Professor Matthew Kiernan, NSW

Associate Professor in Neurology, Faculty of Medicine, UNSW, Senior Scientist, Prince of Wales Medical Research Institute, Consultant Neurologist, Institute of Neurological Sciences, Prince of Wales Hospital. A/Prof Kiernan is Honorary Secretary of the Australian Association of Neurologists and a member of the steering committee that developed and launched the Australian Motor Neurone Disease Registry. He runs a multidisciplinary MND clinical service at Prince of Wales Hospital. In addition to this clinical interest in MND, he supervises a number of MND-related research projects.



Professor Frank Mastaglia, Western Australia

Consultant neurologist at the Queen Elizabeth II Medical Centre in Perth since 1970. He is the Director of the Centre for Neuromuscular and Neurological Disorders at the University of WA and of the Clinical Research Unit and Neuromuscular Clinics at the Australian Neuromuscular Research Institute (ANRI). He is also Medical Director of the Muscular Dystrophy Association of WA and is on the Advisory Panel of the MND Association of WA. The Neuromuscular Clinic at the ANRI provides a diagnostic and multidisciplinary management service for patients with MND.



Associate Professor Pamela McCombe, QLD

Associate Professor McCombe is a Consultant Neurologist and Visiting Medical Officer at the Royal Brisbane Hospital and holds the position of Associate Professor, Department of Medicine at the University of Queensland where she is a member of the Neuroimmunology Research Centre team. The main focus of the Centre's work is the investigation of immune mediated diseases of the nervous system. She is also Chair of the Wesley Research Institute Research Committee and Chair of the Scientific Program Committee of the Australian Association of Neurologists.

Professor Robert Rush, South Australia

Head of Department of Physiology, School of Medicine, Flinders University. The focus of our research has primarily been an analysis of the role that one family of growth factors, the neurotrophins, plays in sculpting billions of undifferentiated cells into a functional nervous system and then to continually modify their connections as the organism reacts to its internal and external environments. Most recently we have used this basic knowledge gained to investigate a number of clinical situations where abnormalities of growth factor production result in disturbances of function. These have included studies in blood pressure control, arthritis, spinal cord injury and motor neuron disease. The focus of the laboratory is currently on a novel system to introduce growth factor genes into the nervous system, with a view to understanding further the role of neurotrophins in the mature nervous system and thereby identify ways to treat or prevent neurodegenerative disease.



Professor Norman Saunders, Victoria

University of Melbourne
Member of Australian Society for Clinical and Experimental Pharmacology and Toxicology, Australian Medical Association, Physiological Society (UK), Society for Neuroscience (USA)

Professor James Vickers, Tasmania

I completed a BSc(Hons) at the University of Tasmania and PhD at the Flinders University SA. Following postdoctoral studies at the Mt Sinai Medical Centre (New York), I returned to Tasmania to establish a laboratory in 1994. I am now Professor of Pathology and Associate Dean (Research) in the Faculty of Health Science. Our laboratory is part of the cross-Discipline NeuroRepair Group at the University of Tasmania. Our main focus is on the cellular basis of the degeneration and regeneration of the nervous system. We are involved in studies related to Alzheimer's disease, Parkinson's disease, motor neurone disease, glaucoma and brain trauma. We apply a variety of modern cell biology techniques to human brain studies as well as experimental models related to human brain disorders. Our overall aims are to contribute towards an understanding of how disease and injury affect the brain as well as to develop therapeutic agents that may inhibit the degeneration of nerve cells.



Reports from the MNDRIA Annual General Meeting held on 30 November 2005

Chairman's Report

This year has been a year of change for the Motor Neurone Disease Research Institute of Australia. I was honoured to be asked to take up the role of Chairman at last year's AGM. Following Perry Bartlett in any task is surely a very difficult role to assume. I am very grateful to Janet Nash, Paula Trigg and David Lamperd for their efforts in their roles in the MNDRIA. It is essential to the fundraising task that the mechanisms of the MNDRIA are completely transparent, and that funds raised for research are distributed with probity and equity. It is imperative that the MNDRIA is able to get the biggest impact from the money donated for research in MND.

Another change is the formal involvement of the state MND associations in the MNDRIA. I thank each delegate nominated from each state in giving their time and effort. I thank the assessors from the scientific committee for giving their time to evaluate the grant. I would like to note the death of Professor Peter Gage, who for many years assessed grants for the scientific committee.

Currently there are only two sources of revenue for the MNDRIA: money given by each of the state MND Associations and donations from the public. The MNDRIA has been able to award post-doctoral fellowships in honour of Bill Gole from a generous donor, but it is important that money continues to be available for grants-in-aid to seed research. This year we will only be able to fund a small proportion of the research proposals submitted for consideration. I urge the state MND Associations to take up the challenge of funding research at a national level. While there are many differences between the UK and Australia, we can learn a great deal from how the MND association in the UK is the prime mover of both the clinical care and the research effort in that country. I am aware of the state support that occurs to drive the research effort locally in each state. However, it is also important to adopt a federal approach to drive the research effort, as enthusiasm and collegiality is able to improve this effort.

I have several wishes for the next year for the MNDRIA, and I hope we can achieve them together. To raise the profile of the MNDRIA so that donors, past present and future can see that their valuable donations are used carefully. To increase the exchange with the state MND associations, so that a sense of shared purpose is further developed. To continue the funding of young scientists and clinician-scientists so that the best and brightest Australian minds are attracted to this field, with funds to perform research that will uncover the biology and lead to a cure for MND.

Dominic B. Rowe

Treasurer's Report

Audited Financials show a satisfactory financial position for the Institute for the 12 months to 30th June 2005. These Financials also reveal increased activity for the Institute in comparison to previous years.

Some brief points to help summarise the financial year:

- Total revenue of \$402,142 represented a 202% increase from revenue to 30th June 2004, influenced by strong support from MNDA Vic and MNDA NSW (particularly the latter). Direct individual donations of \$19,499 were not as high as previous years but nevertheless an excellent effort considering the amount of change within the Institute during this period.
- Total expenditure of \$419,602 exceeded our income (contributing to the loss of \$17,460), however this was due to a timing issue to ensure payment of grants prior to the end of the financial year. Research Grant expenditure rose to \$408,488 – a 76% increase from a record high of \$231,704 to 30th June 2004.
- Remaining expenditure of \$11,114 (3% of total income raised) comprised primarily of expenses relating to the establishment of a new donor database (from a very antiquated system) and also the

payment of salary for much invaluable administration help from Janet Nash.

- Cash reserves of \$340,948 comprised a good spread of strong financial institutions.

Notwithstanding the continued support from the State Associations and ongoing fund raising activity, only \$40,000 is available for 2006 Grants-in-Aid. This is to ensure the Institute has sufficient funds to meet all budgeted commitments (outstanding 2004 & current 2005 Research Grants, Bill Gole & MNDRIA Fellowships and MND NSW Clinical Scholarship) for the period ending 31 December 2006 of approximately \$468,000. Fundraising activity and State Association contributions for the current financial year will be directed towards the 2007 Research Grants.

In summary, the increased financial activity again highlights the improved role of MNDRIA within the MND community as a provider of substantial monies to Australia's researchers.

David Lamperd

Secretary's Report

As a result of changes to the Executive after the last AGM, a meeting was convened on 20 June 2005 in Melbourne. In summary it was agreed that:

- The financial administration of the MNDRIA should move from Victoria to NSW at the end of the financial year.
- MNDA NSW has agreed to provide office space and equipment for a nominal rent of \$50 per week.
- Proposed changes to the Constitution were discussed & finalised.

A revised MNDRIA Constitution was circulated to all MND Associations and members in June and all changes were approved at a Special General Meeting on 5 August. Subsequently, all the State MND Associations were invited to become members and asked to nominate up to 2 delegates. In addition, all previous members were invited to renew their membership for 2 years.

The following have been nominated as delegates:

MNDA Aust - Helen Sjardin & Bob Howe; MNDA ACT - Helen Christiansen; MNDA NSW - Paul Brock & Paula Trigg; MNDA QLD - John Wearne & Lesley Taylor; MNDA SA (no delegates nominated); MNDA TAS - Tim Hynes & Lyn Willis; MNDA VIC - Rodney Harris & David Lamperd; MNDA WA - Marie Macdonald & Emanuel Manolios. Renewing members: Mavis Galliène, Graham Lang, Kevin Langdon.

Consideration must be given to:

- How we can raise more funds and encourage more donations for research. Currently, future budgeting and planning is made difficult because it is impossible to predict the expected annual income.
- It has come to our attention that there is a perception among the different State Associations that giving funds to the MNDRIA may incur a tax penalty. Legal advice was sought by MNDA NSW and it is hoped that this perception can be clarified and ratified by the MNDAA for all States.
- Grants-in-aid awarded in the last few years did not include a "use-by" date. Consequently, in chasing up reports etc for previous grants, it has been found that funds that were thought to have been expended have not been and some claims are still being made from 2003 and 2004. The terms and conditions of acceptance of grants must be reviewed and clarified.

Paula Trigg

The Bill Gole MND Research Fellowship will be offered again for 2007-2008.

The Fellowship is directed towards postdoctoral scientists with a track record in areas of neuroscience related to motor neurone disease. Closing date for applications is Friday 25 August 2006. For details go to www.mndresearch.asn.au.