



FORUM

March 2004

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Introducing the President

It was with a sense of purpose, and a tinge of trepidation, that I accepted the Board's nomination to the office of President of the MND Association of NSW in December last year. I was at that time, and I remain, well aware of the tireless effort contributed by Kevin Langdon in the role of President since 1993. They are large "shoes" to fill – I will do my best.

For those of you who don't know me, I continue to be blessed with a wonderful supportive wife and three children who remain at the centre of our focus, though they have all now "flown the nest". We live at Port Stephens, approximately sixty kilometres north of Newcastle and my work takes me both to Newcastle and on a very regular basis to Sydney.

I became aware of the insidious and non-discriminatory disease, which gives us our purpose, some years ago and joined the Board of this Association in 1998. My aim was then and continues to be, to in some way contribute to the support of those brave people, and all those whose lives they touch, who live daily with MND. The Association will continue with its principal dual aims, to support those living with MND, and to continue to sponsor those dedicated researchers whose work we all wish will make our organisation redundant.

The Motor Neurone Disease Association of NSW is entering a new phase in our growth with talented and dedicated staff who are ably assisted by a band of volunteers, whose selfless work we could not do without. I am fortunate to work with a Board experienced in the needs of our members and who can be relied upon to put in such effort as is required to ensure this Association continues to meet its objectives.

Ralph Warren

President MND Association of New South Wales

Motor Neurone Disease Week 28 March - 3 April 2004

Many activities are planned for this week of opportunities to raise awareness of MND, and also to raise funds to support the work of the MND Association. A full program appears on the back page.

Cornflower Blue Day on Friday 2 April will promote the symbol of hope for people living with motor neurone disease.

Paula Trigg's photographs of cornflowers appear on our posters and were the inspiration for our cornflower logo. Please buy your cornflower and wear it to spread awareness and show you care. Cornflowers will be on sale at selected shopping centres, railway stations, newsagents, HCF branches and many other outlets.

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

MND Week is almost upon us, with the official launch by Margaret Throsby, Morning Presenter on ABC Classic FM, at Government House on Wednesday, 24 March. The following week will be eventful throughout the State, with activities to raise funds and awareness.

The major activity is the BNZA Blue Ball on Friday, 2 April, organised by Mr Ray Haddad.

Donations are essential to the Association. I was privileged to receive cheques from graduates of the NSW Fire Brigades 2003 Class and also the APEX Club of Pennant Hills, totalling \$4,940.

Events will dominate the calendar in the next twelve months, as we continue to raise awareness and increase our income stream.

The Board has authorised negotiations with the AJC to conduct further Race Days following the outstanding success of the Motor Neurone Disease Villiers Race Day at Royal Randwick in December. Net proceeds from that event were \$25,000.

I am confident that other significant events, now in the planning stage, will produce great benefits to the Association.

The Corporate Sector will be invited to form alliances with MNDA NSW and already the Constellation Hotel Group has offered to donate \$1 from every Country Fare dinner meal sold through Country Comfort Hotels in NSW during June, July and August. More details in next Forum.

If any readers know of other companies wishing to be "good corporate citizens" and support a charity, please let me know.

Corporate and significant personal generosity will be acknowledged by Awards at the MND Week Launch at Government House on 24 March.

Kevin Langdon OAM has accepted an offer from the Board, of appointment as a Vice Patron of the Association. This appointment will enable Kevin to continue to represent MNDA NSW at functions and to increase awareness with the aim of generating support for the work of the Association.

Kevin has also been granted Life Membership of the MND Association of NSW in recognition of his contribution.

*Bruce Fraser
Chief Executive Officer*

Forum, the quarterly newsletter of the MND Association of NSW, is available as a brief 4 page letter, or a full 12 page newsletter. If you have not received the full newsletter, you might consider becoming a member of the Association to get all the news.

All members of the Motor Neurone Disease Association of NSW are invited to
**the official launch of MND Week at Government House
on Wednesday 24 March at 12.00 pm.**

Speakers will include

Margaret Throsby, Morning Presenter on ABC Classic FM and
Dr Matthew Kiernan, Senior Lecturer in Neurology
Prince of Wales Medical School.

Registration is from 11 am and guests are invited to stay for a light lunch.

If you would like to attend, please telephone the office before Friday 12 March.
Numbers are strictly limited so be sure to reply early.

MND Support Groups

There are many volunteers throughout NSW supporting the MNDA NSW in a variety of ways. MNDA NSW will officially acknowledge the important role of volunteers at the MND Week Launch at Government House. On this occasion the focus will be on acknowledging volunteers involved with the MND support group network. These presentations will provide the opportunity to identify interest in establishing annual MND Support Group Network meetings. These meetings would give support group volunteers the opportunity to share ideas, learn more about MND research, treatments, services and care and would provide an opportunity for ongoing peer support and regular contact with each other.

Carol Birks, Manager Family Support

Family Support and MND Support Groups

The primary objective of Family Support as identified in the revised Business Plan 2003–2006 is:

To provide and enhance equal access to family support and to promote best practice multidisciplinary care for all people in NSW living with MND and their families.

The regional advisor role is a diverse one aimed at supporting people with MND, their carer, family, friends and health and community care providers. This support is basically provided through small group support, information, education, advocacy and referral.

In view of the forthcoming MND Week Launch, which will focus on support group volunteers, this edition of Forum will discuss the role of the regional advisor and volunteers in facilitating the small group support available through the MND Support Group

Network.

There are currently eleven support groups affiliated with MNDA NSW. The six regional advisors are responsible for different regions of NSW and ACT and within those regions there may be one or more support groups who meet on a regular basis. The regional advisor may facilitate the group, attend each meeting as a member or attend sporadically in the course of an annual field trip to the region. The regional advisor may have been instrumental in establishing the group and organising the meetings, or may have simply provided some information and support to enable the volunteers interested in starting up a group to get going. A number of support groups were established years ago by volunteers who continue to run the groups successfully today.

Support groups are a collection of people with similar needs who meet regularly. They are designed to support their members by meeting their needs and enhancing a sense of well being by providing social support. Many people find that joining a support group normalises their experiences, gives them a sense of control and an opportunity to come together to share and solve problems. For many people with MND there is an initial

reluctance to meet others who may be more affected by MND than themselves. However, this initial discomfort is soon offset by realising how much they have in common. Support groups offer a supportive caring environment in which to learn more about MND, develop personal skills and raise awareness of MND in the local community.

Each support group is different, depending on the needs and interests of its members. Some focus on fundraising and awareness, others prefer to learn more about MND through guest speakers and education sessions and some simply meet for a chat and a cup of tea. Some support groups meet monthly, some bi-monthly and one in a different town each meeting! Some last for years and some for just a few months whilst there is a need for one in that particular region.

One of the roles of the regional advisor is to identify and respond to a need for a support group in an area based on the wishes of the people living with MND, their carers, family members or past carers. If people express a desire for a support group in their area, the regional advisor may organise a seminar or an education-based meeting to launch the group and to foster interest from the wider community. Alternatively, the regional advisor may simply establish the most suitable time and place to meet and invite people living with MND and their families to attend the first meeting to discuss how they would like the group to develop. Some new groups are instigated and facilitated from the outset by volunteers whilst for others the regional advisor will facilitate the group until a willing volunteer steps forward. The relevant regional advisor will continue to attend meetings if distance allows or support the group as required.

Two new MND support groups are being launched in 2004:

- **ACT and Monaro MND Support Group** on 29 March — ring the South West NSW/ACT regional advisor Allison Pearson on 6238 3769 for further details.
- **Port Stephens and Great Lakes Group** on 6 March — ring the Northern NSW regional advisor Christina Jason on 4952 4492 for further details.

(Continued on page 4)

Family support comprises of regional advisors, equipment personnel and the special projects/carer services coordinator. Over the coming editions of Forum, the roles and responsibilities of these people will be outlined.

Family Support

DATES FOR THE DIARY IN 2004

Volunteer Visitor Education Program

Commences Monday 5 and Tuesday 6 April – Hunter/Newcastle/Central Coast
People interested in becoming an MND volunteer please contact the office as soon as possible.

Inaugural meeting of the Port Stephens and Great Lakes Support Group

Saturday 6 March 2 pm – Raymond Terrace

29 March - Canberra

Seminar for Health and Community Care Providers -

Morning session

Meeting for People Living With MND and their families – Canberra

Afternoon session

ACT and Monaro Support Group Meeting

Following afternoon tea

DNA Donor Drive – Canberra

Dr Roger Pamphlett will be collecting samples for the MND DNA bank from 12 midday to 2 pm.

Information Evenings

For people recently diagnosed with MND their families and friends.

The next meeting will be on Tuesday 25 May at Concord.

Care for Carers Course - Concord

Thursday 10 June

Four-week education and support program commences for family carers of people with MND.

Annual MND Conference for Health and Community Care Providers

Monday 21 June – North Ryde RSL, Sydney

Learn now/Live well Program - Concord

Tuesday 19 and Tuesday 26 October

An 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 MNDA office for further information or to express your interest in attending any of the programs or sessions above.

(Support Groups—Continued from page 3)

Volunteers coordinate and run eight of the eleven support groups and are integral to their continued success. Some of these groups have been running for a number of years and are the “face” of the MND Association of NSW in their local community. These support group volunteers include people living with MND, family members, friends and past carers all of whom are passionate about helping to support people living with MND in their local community, raising awareness and raising much needed funds for care, equipment and research into the cause and a cure for MND. For people living with MND in rural and regional NSW, knowing that there is a support group in their region gives them an immediate sense of relief that they are not alone and that there is someone nearby who understands what they are facing on a day-to-day basis. These support group volunteers are a vital link in the chain in supporting people living with MND, carers, past carers and family and friends.

*Carol Birks
Manager Family Support*

Reference: Kellehear, Allan (1999)
Health Promoting Palliative Care, Oxford University Press

A new telephone system has been installed in the MNDA office. You can still phone us on the regular numbers:

02 9743 5872 and Freecall 1800 640 144.

If you want 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
Carol Birks	8765 5115
Bruce Fraser	8765 5111
Elizabeth Herbert	8765 5113
Maree Hibbert	8765 5114
Carole Leone	8765 5117
Janet Nash	8765 5116
Trevor Rakuraku	8765 5114
Petra Sammut	8765 5110

Family Support and Info Line

02 9743 5872 or Freecall 1800 640 144

HOPELINE

*The telephone counselling service linking patients and families facing all potentially life-threatening illnesses with survivors and family members who've been through a similar crisis.
Call 1300 364 673
www.can-survive.org.*

Carers news

Are you caring for a family member with MND?

Living with MND places very special demands on family and friends.

If you are helping to support someone with MND you may be required to learn many new skills. Practical knowledge can help you to manage.

Would you like to learn more about:

- useful aids and equipment
- techniques to assist with mobility
- how to manage communication and swallowing difficulties
- handy hints for every day care
- emotional aspects of living with MND
- support services that can be of assistance?

Would you like to meet other MND carers and share ideas and handy hints with them?

If so, come along to the MND NSW **Care for Carers Workshops 2004**.

Four full day workshops will be held at Concord Hospital on **Thursdays June 10, 17 & 24 and July 1 with a short reunion meeting on August 1**.

MNDA NSW has been running Care for Carers Workshops since 2000 and feedback received from participants has been very positive.

Attendance at **all** the workshops is important and our family support staff will work with your local Carers Respite Centre to provide care for your loved one with MND while you attend the workshops.

Attendance at the workshops is free.

Lunch and refreshments are provided and MNDA NSW will reimburse bus and train fares.

Flyers providing details of the Care for Carers Workshops will be available in April.

If you would like to enrol before then or would like more information please phone 9743 5872.

*Anita Richter
Special Projects Coordinator*

Australia's March of MND Faces Banner

The fourth banner of NSW MND Faces will be completed in time to be displayed at Government House at the launch of MND Week. This presentation of eighty faces of people in NSW with MND is a touching and compelling awareness-raising exhibit. The four banners will move from Government House to Parliament House where they will be exhibited throughout MND Week.

The fifth NSW March of MND Faces Banner should be ready for display at the MND Conference for Health and Community Care Providers on MND Global Day, June 21.

If you would like to contribute a photo to be included on the banner, please phone the MNDA office on 9743 5872 to ask for details.

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
- **Internet Chat - Living with MND** Every Tuesday at 1pm & Thursday & Sunday at 8pm EST. Go to www.mnd.asn.au/ then click on the chat room link.. Also try <http://neuro-mancer.mgh.harvard.edu/echat42/ALS/> for a chat room which is open 24 hours per day.
- Visit the MNDA NSW website at www.mndnsw.asn.au for links to many useful and interesting sites.

Visit the Guardianship Tribunal's new website at www.gt.nsw.gov.au for useful information and links to assist with planning ahead.

Support Groups: people helping people throughout NSW

Penrith & Blue Mountains

At our February meeting, one of the things the group discussed was what the members felt the support group offered. For some the first visit to the group was a bit daunting but all agreed that the group offers support and friendship. A place where people come together to meet others living with MND, it allows people to share their stories, learn and even gain strength from each other. All agreed that it was definitely worthwhile to put the time aside to attend.

Ruth Quaken



Newcastle & Hunter

We have regular meetings attended by people with MND and carers and families and we all support one another. Christina Jason is always there to help answer any questions we might have. We have all become good friends and past carers stay on as members of the group.

If you can't do anything to physically help people, you feel you are doing your best if you help by raising funds to provide the help. The people in the coalfields are fantastic when it comes to raising money - they have already taken all the pens I had in readiness for MND Week. Our group wants to do everything they can to help people with MND and their families.

Neta Cassidy, Maitland

Coffs Harbour

Being part of a group helped us a lot when Bob was first diagnosed with MND.

Talking to other people and sharing experiences has helped us to accept living with MND.

Bob and Lily Jenkins

Hornsby

Following my husband John's initial diagnosis 4 years ago, we decided it might be beneficial to join the MND Association to get information as our future seemed so uncertain.

John has gradually withdrawn from most social activities due to his difficulty with speech. The inability to communicate has changed our life considerably as we no longer spend hours chatting with friends at a BBQ or over drinks.

The bi-monthly meetings initially were only attended by myself until John's acceptance of his condition. It is obvious now that he feels comfortable in the group, as we rarely miss a meeting and it adds a dimension to our limited activities. The meetings provide much more than information, they also give me the opportunity to talk to other members facing similar and often more challenging problems.

I look forward to the meetings to hear the latest news about MND, to renew friendships and meet new members, all with a common interest.

Eileen Ellis, Glenhaven



Riverina & SouthWest Slopes

We started out as strangers and now we are all the best of friends. We've shared losses as well as swapping ideas - it's like having a second family where you can say things to one another that can't be said to anyone else.

MND sets you aside so everyone makes a huge effort to get to all the meetings because everyone there is on the same level.

Everyone feels supported by the group and there is also an opportunity for like-minded people to get together in smaller groups.

Susan Chambers, Cootamundra

Panania

After 18 months of deteriorating health, a confirmed diagnosis was given a week prior to Christmas. A shock it was, however, a relief too. What next - after perusing two brochures on MND given to us by the Neurologist, we made contact with the MND Association in the New Year to seek guidance.

Our initial meeting with our MND Regional Advisor at home gave us valuable assistance. As a family member, I attended the first Support Group meeting at Panania with a little apprehension. However, I soon realised we were not alone and the open discussions between people with MND and those still grieving the loss of a loved one was stimulating.

The simple act of communication and friendship was my reward.

We thank you for a great life line.

Anon.

SUPPORT GROUP CONTACTS**Illawarra**

We emphasises fun and education at our monthly meetings. Interesting speakers provide helpful information to our members, their families and carers. We welcome new members and aim to help them with their challenges. We have the regular participation of a nurse and a social worker and our guest speakers will include a physiotherapist, occupational therapist, speech therapist and dietitian, as well as a psychologist, who managed to put some of us to sleep during the relaxation session last year!

Come along to our group on the second Tuesday of every month at 10.00 am and make new friends, get some extra support and enjoy a cuppa with us all.

It's at Port Kembla Hospital in the Diversional Therapy room.

Pam Van Den Hoogen, Port Kembla

Central Coast

I can't believe the amount of help we have been given. We try to get to all the meetings at Gosford and always feel very welcomed by the group. Someone always comes up to have a chat. There is usually a guest speaker and afterwards we have afternoon tea. There is always someone who you can call if you need them.

Betty Bruckard, Toukley

Northern Rivers

There is a good feeling of camaraderie in our group - of people helping people. We have been well informed of all the support services in our area and sometimes we have speakers who come to talk to us. Most of the members are people who have lost someone in their family to MND and they have already experienced what we are experiencing now. We have all exchanged phone numbers so, if you have a problem, you know there is always someone who can help.

MND can isolate you but in this group you know that problems that may seem trivial to others will be understood - how to use a cup or scratch an itchy nose if you can't use your arms.

The group has made our journey with MND a lot easier.

Pat and Peter Murphy, Alstonville

Central West

About six months after my dad was diagnosed with MND, we went to an information session run by the MND Association. It helped my family to meet other families, and just to know that there were other people not only going through similar things, but also feeling as lost as we were. Knowledge is power, and learning about MND and meeting other families and other people with MND took away some of that fear.

It wasn't only **my** family that had a need for support in this area, so I started the Central West MND Support Group. We held our first meeting in Forbes, and since then we've had meetings in Molong and Condobolin. Our next meeting will be in West Wyalong. We meet bi-monthly, but between meetings my father and I talk to members on the phone. Of course many of the other members talk to each other by phone too. In this way we provide ongoing support.

We now have a great pool of knowledge, and I'm constantly learning about new services, and finding solutions to problems I hadn't even thought of. There is no shortage of help from other members of the support group - we really work as a team.

We've had many different health professionals involved in the group and they have been a great asset in assisting with organising meetings. I have noticed that by being involved in the group, the health professionals have also gained the support and information they need. Ultimately this means better treatment and services for people in the Central West with MND.

Mary Campbell, Forbes

Port Stephens & Great Lakes

The first meeting for members, their family and friends, in the Port Stephens and Great Lakes regions will commence at 2 pm on Saturday 6 March, at 59 Port Stephens Street, in the Raymond Terrace Community Care Centre.

This will be an informal get-together, where friendship, support, ideas and information can be shared between people with similar experiences.

Please join us.

Christina Jason

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

Phone: 02 4947 1983

New England

Robyn Barton

Phone: 02 6766 6065

Northern NSW

Phil Bower

Phone: 02 6743 4218

Northern Rivers

Helen Gates

Phone: 02 6621 4018

Port Stephens & Great Lakes

Christina Jason

Phone: 02 4952 4492

Riverina & South West Slopes

Wes Russell

Phone: 0408 692 127

Hornsby

(Mary Butcher)

and

Panania

(Caroline Gleig)

and

Penrith & Blue Mountains

(Ruth Quaken)

are coordinated through the MNDA office.

Phone: 02 9743 5872

Research

Dr. Mark C. Bellingham University of QLD
Functional differences in glutamate receptor responses of motor neurones resistant and susceptible to death in MND.

One reason why motor neurones may die selectively in MND is exposure to excessive amounts of glutamate, the main excitatory neurotransmitter released by brain synapses. Glutamate is thought to trigger motor neurone death by activating certain types of glutamate-sensitive receptors, which then allow calcium ions to flow into the motor neurone in excessive amounts. This project will improve our understanding of MND.

Dr Michel Guipponi, Dr Hamish S. Scott
Walter & Eliza Hall Institute, Victoria.
Gene expression profiling in mouse models of neurodegenerative diseases. Looking for common genetic pathways involved in neurodegeneration.

Researchers have suggested that the risk of developing sporadic MND is likely to involve a combination of a wide variety of genetic and environmental risk factors, perhaps occurring years, or even decades, before the onset of symptoms. Advances in our understanding of molecular mechanisms have led to the discovery of susceptibility genes and the construction of animal models of the disease, which have allowed researchers to unravel processes and to screen new therapies more rapidly.

We will take advantage of the existing animal model for ALS to identify genes and genetic pathways affected at the early stage of the disease. The identification of such genes involved in motor neuron degeneration should contribute to development of new therapeutic drugs designed to significantly slow or ideally stop progression of MND and other neurodegenerative diseases.

Dr Christine Hawkins Murdoch Children's Research Institute, Victoria
Does the Spinal Muscular Atrophy gene SMN inhibit apoptosis?

Spinal muscular atrophy (SMA) is an inherited disease characterised by muscle wasting and weakness. Its more severe forms are fatal. SMA is caused by death of nerve cells in the spinal cord. A gene mutation is responsible for the disease. However the way in which mutations in this gene lead to death of the nerve cells is not known.

In this project we will extend our recent findings of a link between the SMA gene and cell death. We anticipate this project will contribute important information for the future development of treatments for this serious disease.

Dr Robert Henderson Royal Brisbane Hospital
A new method of Motor Unit Number Estimates (MUNE). The aim of the project is to use statistical and electrophysiological techniques to determine the number of motor nerves (motor units) that supply a muscle. A means of

objectively measuring the pathology of MND is needed because the only available methods of assessing progression and treatment efficacy in MND patients are survival and manual muscle strength testing. A reliable method of determining the number of motor units supplying a muscle could potentially be applied in the diagnosis and treatment trials in MND.

Prof Garth Nicholson, Dr Sumana Gopinath
ANZAC Research Institute, NSW. *Finding new pathogenic genes affecting motor neurones.*

It is likely that motor neurone disorders are caused by many different factors, some of which are genetic. The genetic forms of hereditary motor neurone disorders range from rapidly progressive to slowly progressive forms. For example, MND is a fatal adult-onset neurodegenerative disorder characterised by death of motor neurones in the brain and spinal cord causing progressive muscle weakness and wasting. Hereditary motor neuropathies are slowly progressive, non-fatal disorders of motor neurones with onset in the first or second decades. Genes involved in hereditary motor neuropathies and slowly progressive motor neurone disorders clearly affect the lifespan of motor neurones. These genes may also be involved in MND.

Identification of new gene mutations responsible for disorders affecting motor neurones will increase understanding of the biology of motor neurones, reveal mechanisms underlying motor neurone disorders and may provide insight into familial and sporadic forms of MND.

Prof Garth Nicholson, Dr Vadim Dedov
ANZAC Research Institute, NSW.
A possible short cut to find new drug treatments for MND.

The exact cause of the dying-off of motor neurones in MND is unclear but increasing evidence suggests that it is caused by 'junk protein', where the accumulation of damaged or abnormal protein pollutes the cell, squeezing out normal protein and leading to cell death.

Trying to identify drugs that might help by preventing protein accumulation and subsequent cell death is difficult because it can only be done very slowly, as it takes a long time for the cells to become affected and can generally only be done in animals. We propose a method that if successful will both accelerate protein accumulation and enable screening of potentially useful drugs in cell culture rather than in an animal. This will make the drug screening process vastly more efficient and enable screening of many more potential drugs, thus a much greater chance of finding a drug that makes a real difference to MND.

**In December 2003
the MND Research
Institute of
Australia
approved grants to
fund these eleven
projects around
Australia during
2004.**

Dr Roger Pamphlett University of Sydney.
Gene-environment interactions in motor neuron disease.

Recent findings of traces of enteroviruses in the spinal cords of people with MND has rekindled interest in the possibility of a viral cause for sporadic MND. Enteroviruses are a family of viruses that include poliovirus as well as a number of viruses that commonly infect humans. In MND, motor neurons may be susceptible to either infection or persistence of one of these enteroviruses. It has been shown that persistence

of poliovirus in cells is related to mutations in the gene for the poliovirus receptor. We will therefore look for differences in a range of enteroviral receptor genes to see if these make people susceptible to MND.

This study hopes to identify genetic differences that allow certain viruses to attack motor neurons. Once these differences are found, further studies can be carried out to find out ways to avoid or prevent viral attack. In this way we hope the disease will be able either to be prevented or treated.

Dr William D. Phillips University of Sydney
Role of the acetylcholine receptor-associated protein, rapsyn, in the mature nervous system

This project will investigate the role of two proteins, rapsyn and agrin, in maintaining a healthy interaction between motor neuron and muscle cell in adult life. Rapsyn and agrin are essential parts of developmental pathways that lead to the formation of nerve-muscle connections in the embryo. The project will allow us to inactivate the genes for these proteins in mature mice to clarify their role. A deeper understanding of the mechanisms that underlie the nerve-muscle interaction is likely to be important in helping to clarify the early stages in the causation of MND.

Dr. Dominic Rowe, Dr Matthew Kiernan
Royal North Shore & Prince of Wales Hospitals, NSW
Mechanisms of Nocturnal Hypoventilation in ALS/MND

Although disordered breathing during sleep is a common and serious problem in MND, the mechanisms that are involved are not known.

This study aims to determine whether problems in the pathways that connect the cortex of the brain with the breathing centres lower in the brain are involved in the production of sleep disordered breathing in MND.

A better understanding of the mechanisms involved in nocturnal hypoventilation in ALS/MND is critical in the ongoing assessment and therapy.

Dr Bryce Vissel

Garvan Institute of Medical Research, NSW.
Adeno-associated virus mediated delivery of genes to study and treat spinal cord disorders.

A study in the USA showed that, by injecting a virus carrying a nerve growth factor, insulin growth factor I (IGF-I), directly into the limb muscles of SOD1 mice (a mouse model of ALS/MND), disease progression in the mice was delayed, and the mice survived significantly longer than untreated mice. The study was important because it showed that the virus could deliver the growth factor from the muscle directly to the nucleus of the motor neurons. The growth factor was then able to protect the neurons from degeneration and prolonged mouse survival.

Our start-up project will establish the techniques, tools, collaborations and approaches used successfully in the USA for delivering recombinant adenoassociated virus (rAAV) to the spinal cord and brain. This will allow us to expand our work through NH&MRC and other funding sources to explore the effects of delivery of viruses with other growth factors that may have therapeutic potential in mouse neurodegenerative models. Further, we hope we will be in a position in the next five years to explore clinical trials.

Professor Jeffrey Zajac

University of Melbourne

The neuroprotective capacity of IGF-I in Kennedy's disease.

Kennedy's disease is a debilitating neurodegenerative disease causing a progressive decline in muscle function. It is one of a number of inherited motor neurone disorders. The genetic cause is a type of gene which is similar to mutations that cause Huntington's disease and some other neurodegenerative disorders. To date, the reasons that nerve cells die in these diseases is poorly understood, and there is no treatment.

Our research is trying to understand the causes of the degenerative processes, with the long-term aim of developing appropriate therapies to either stop or slow the progression of the disease. In particular, a potential therapy that we are testing in our studies is a type of growth factor that promotes the survival of nerve cells. This growth factor will be tested in both cells in culture dishes and in a mouse in which Kennedy's disease was created by introducing the genetic defect that causes the disease. This "Kennedy's disease mouse" will enable us to study aspects which we are currently unable to do in humans, and to test potential therapies such as growth factors.

We anticipate that our studies will demonstrate that this growth factor therapy will improve the life quality of people with Kennedy's disease.

Increased availability of funds for MND research has attracted applications for funds for projects representing both scientific and clinical research from both new and established researchers.

Dear Editor

My Dad (Charles Scroggy) has slowly progressive MND and my Mum (Janice) has been his carer for many years. Sometimes Mum has had to call for assistance because she was having difficulty getting Dad out of bed or from his chair, and of course she always knew if it was an emergency, she could call an ambulance. What we didn't think about was the possibility of Dad having to access emergency assistance if Mum became sick or had a fall.

It's for this reason that I am sharing with you the situation Mum and Dad faced when Mum was hanging curtains up and fell and broke her hip. Mum was in her bedroom, Dad was in the lounge room and food was cooking on the stove. The kitchen is at the other end of the house from the bedroom. The telephone is in the lounge room, opposite the wall where Dad sits and so it's useless to him. Mum had to get herself from her bedroom to the kitchen for fear that a fire would start. It took her about half an hour to drag herself along the floor to the kitchen. She managed to pull herself up and was able to turn the stove off. She was in a lot of pain after having to move with a broken hip and felt like she was going to faint, so couldn't attempt to move again to reach the phone. Luckily, Dad was able to lean over from his chair and managed to reach the power point to turn his computer on. Also very lucky that Dad did not fall out of his chair attempting to do this. He connected the internet and entered the MND chat room (www.mnd.asn.au/ then click on the chat room link).

Fortunately someone was in the chat room at the time (thank you so much to Jill and Roly from New Zealand), as Dad was able to type his message to Jill and then Roly called my sister to let her know that Mum needed an ambulance. One and a half hours

after Mum broke her hip, an ambulance arrived at her house. She is now recovering well after a hip replacement and Dad is being cared for by my brother.

It's very upsetting to know that Mum and Dad needed help urgently and it was unavailable to them. The truth is, we didn't imagine such a situation, but we should have had something set up for Dad to be able to get help if Mum needed it. I think my Dad is a very strong person. He has a lot of determination and will-power to not let MND beat him, but I think my Mum is the most caring, loving, devoted person I know. She has cared for Dad for years, and it's so important that we also care for her and think of her needs. I think all carers are very special people. They are always there when their loved one needs assistance and we need to make sure, someone will be there for them, if they too need assistance.

There are a few different devices a person with MND could have access to if they found themselves in a situation such as my parents were in. I'm sure many of you already have such access devices in place, but for any of you who might not have, I hope that my parents' story will make you aware of the importance of the person with MND also being able to get help if needed.

If they are able to use a telephone, make sure that it is in reach to call emergency services. Telstra (1800 068 424) also offer certain services that may assist people with certain disabilities.

For people who cannot walk, use their hands or talk, there are suitable devices available: Care Call (1300 130 100) and Vital Call (1300 360 808)

Kim Wallace
Lurnea

When help is needed for the carer, call the Carer Respite Centre on 1800 059 059 to ask for assistance.

To all Newcastle fishermen

We are seeking good Samaritans interested in fishing outside Newcastle. Our boat is a 6 metre marlin broadbill catamaran which has a special winch to lift a person aboard. We usually go to sea at 5-6 am—through the week is best as it is less crowded at the boat ramp. My husband (who is fun loving with a great sense of humour) has MND and we need a capable person to help us.

We need a caring person who is fit and kind, likes fishing and is free on week days who could help us by either driving the boat or backing the trailer.

Please email mgrennan@bigpond.net.au or phone 02 4950 0939.

Ray & Margaret Grennan
Maryland

We welcome your ideas - Forum is your voice - so if you would like to contribute to the next issue, please write to the Editor.

Fundraising

MIXING WITH STRANGERS

This edition of Forum cannot go to press without acknowledgement of the tireless efforts of Alex Malley. Alex lost his mother, Irene, to MND at Concord in 1997. He has now found time to mastermind the most spectacular event at Parliament House on 6 April where he has the Speaker of the Legislative Assembly, the Hon John Aquilina MP, as host and Alan Jones as Guest Speaker. Besides that he has found

almost all the guests – and a bevy of sponsors led by the CPA – to fill the **Stranger’s Dining Room.**

There are places left at \$180 per person but hurry!

GIVING CARE AND GIVING HOPE

Gifts have been received from such a wide range of individuals and organisations that it is difficult to thank them all. It is a real pleasure to be able to acknowledge the generosity of so many. Tamworth

again displayed its great fundraising skills through the Farrer Memorial Agricultural High School where funds were raised in memory of Albert Otte. A very generous donation for equipment was received from the Ryde-Eastwood Leagues Club and APEX of Pennant Hills. In addition, special thanks must go to Naomi Yerbury for getting her class of trainee firefighters to raise funds for MND.

Great gifts were received from Brian Bowles and Joan Schmeising, and the second installment of a major grant has been received from the Baxter Foundation. Many thanks.

FIRST PAST THE POST

The Motor Neurone Disease Villiers Race Day could not have happened without people putting their money on the ‘Race for a Cure’. Special thanks to those who bet on the MND Association – especially Rene and Leon Symon, Christie’s and the team led by Stephen Cambridge; Cripps & Cripps; the MFS Group and PriceWaterhouseCoopers.

IN THE WARS

Australian manufacturer and style-setter, Christie’s Pty Ltd is now backing the association at many levels following the Royal Randwick debut. The company specialises in striking medals (as well as making a host of fashion items and flags and banners). It is currently producing an unique collection of medals issued to Australian ‘Women at War’ and the edition has been limited to one thousand frames. One interesting fact to emerge is that the women who served in the Boer War were given bunches of cornflowers on their return home. This series equally features the cornflower which MND has, subsequently, made its own. Part of the profit will come to the Association to help generate funds to enable the Association to further its work and a magnificent lunch is also scheduled for Parliament House on 7 June which will also generate funds to enable the Association to meet its goals.

NICK’S PARTY ON SATURDAY 27 MARCH

Tickets are now available at the MND Association as well as direct from Nick McLoughlin (9922 3333). It is being held at the Kirribilli Club just before the Club closes

(Continued on next page)

QUILT RAFFLE
We all want to win this priceless, beautiful quilt that will become some lucky person’s heirloom. Raffle tickets are available through the MNDA office and at Thornleigh Community Centre from 14 - 16 May.

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 1st 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/...../.....

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

(Continued from previous page)

for renovations. Tickets cost \$35 and include finger food. Drinks are available at the Bar. There's something for everyone as early birds can arrive at 6.30 pm but the festivities go on till midnight.

MND WEEK

If you have not received a copy of the MND Week flyer, do call and you will be sent a copy in the post. And, more importantly, if you know any journalists – print, radio or TV – do call the office as it is so much easier to attract coverage through personal connections. Of course, if you prefer to make contact yourself, just call the office for the latest press release and media fact sheets.

SUPPORTING MND IN 2004

- 11 March Lions of Frenchs Forest Golf Day, Wakehurst Golf Club
21 March Newcastle Christian Center Service at 6.30 pm
24 March Government House launch of MND Week
26 March Bankstown Golf Club fundraiser for Ian Fuller & MND
27 March Nick's Party at Kirribilli - Nick McLoughlin
28 March - 3 April MND WEEK 2004
28 March Art in the Garden in Hay - Maggie Clark
1 April Shellharbour Golf Day - Clare Bull
2 April Cornflower Blue Day
2 April 'The Blue Ball' at La Montage, Leichhardt
3 April Country & Western night in Orange
3 April Sydney Conservatorium concert & reception
4 April St Andrews Cathedral special service for MND 10.30 am
6 April Evening at Parliament House hosted by Speaker of the Legislative Assembly, guest speaker Alan Jones
29 April Russell Vale Golf Club - Carolyn Woods
14 - 16 May Quilt for MND raffle at Thornleigh
19 June Five Dock Auction & Dinner - Angie Helmers
7 June Christie's 'Women at War', Parliament House
21 June ALS/MND Global Awareness Day
3 July Charity Auction & Dinner - Charmaine Misso

CORNFLOWER BLUE DAY - Friday 2 APRIL

A magnificent BNZA Blue Ball at Leichhardt is another innovation. Created by the Haddad family and friends, this special event is being held at 'La Montage'. Call Ray Haddad for tickets on 9687 9222.

Call the MNDA on 9743 5872 if you can join collection teams on Circular Quay; North Sydney; Town Hall or Martin Place for the early morning shift 7 am - 9 am. Other locations are also available.

Elizabeth Herbert

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.

GENEROUS DONATIONS SUPPORT MND RESEARCH.

Motor Neurone Disease Research Institute of Australia Inc.

Bill Gole MND Research Fellowship MND Research Institute Fellowship

The MND Research Institute invites applications for two prestigious research Fellowships. These Fellowships are directed towards scientists with a track record in areas of neuroscience related to motor neurone disease. Salary will be funded in the NH&MRC postdoctoral Research Fellow range for a 2-year period.

Applications should include a detailed research plan for a 2-year project (which will be relevant to the cause, treatment or cure of MND) a full curriculum vitae, including the names of three academic referees who must provide their reports before the deadline, and a covering letter from a sponsoring institution in Australia confirming that laboratory space and consumables will be provided for the project.

The starting time will be negotiated with the successful applicants.

Closing date: 2 April 2004. Further details regarding the application process are available from www.mndresearch.asn.au or by email to info@mndresearch.asn.au

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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