



# FORUM

December 2002

*Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries.*

## **PATRON**

Her Excellency Professor Marie Bashir AC  
Governor of New South Wales

## **VICE PATRONS**

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Lady Yvonne Leonard  
Mr. Roderick H. McGeoch AM

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### **SOLICITORS**

Mallesons Stephen Jaques

and

### **MANY VALUED VOLUNTEERS**

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## **Working together to make a difference for MND**



*New South Wales delegates at the 13th International Symposium on ALS/MND in Melbourne in November included doctors, scientists, the Royal North Shore Hospital MND Clinic team and the Motor Neurone Disease Association of NSW Family Support team.*

The Symposium was convened in Australia for the first time and approximately 100 Australian delegates had the opportunity to meet one another and the 300 delegates and speakers from around the world.

Scientists, neurologists, health workers and many others met with a common vision - the vision of a world without MND.

A brief report on pages 4 & 5 outlines the highlights of the Symposium with clinicians continuing to work towards provision of better care for people living with ALS/MND, and researchers uniting in the race towards understanding the mechanisms that underly the disease process and finding agents to more effectively treat the disease.

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## **Merry Christmas**

At Christmas time we reflect on memories of the past year: shared happiness - shared sadness - loss, love, achievement, joy, hope.

Christmas is a time of mixed emotions, particularly when motor neurone disease is involved. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

## **Happy New Year**

The MND Association of NSW office will be closed for Christmas from Tuesday 24 December to Wednesday 1 January inclusive.

Normal office hours will resume on Thursday 2 January 2003.

If help is needed during the Christmas break, please consult your Doctor.

## From the CEO

I am writing this message on behalf of our President, Kevin Langdon, who is going through a very sad and difficult time at the moment. Ry, Kevin's son, tragically broke his neck in an accident and is likely to be in hospital for a prolonged period. Kevin has been at Ry's bedside since the accident and has asked me to thank everyone for their support, messages of comfort and the kind words received from the MND family and friends around the globe.

Despite this tragic event Kevin has found time to appeal to MP's and Senators of the Federal Government, including the Prime Minister and the Minister for Health and Ageing, for PBS registration of Rilutek. The application is due to be heard by the Pharmaceutical Benefits Advisory Committee on 13 December 2002.

**Annual General Meeting.** The AGM was held on 7 December prior to our annual Christmas party at the Concord RSL Club. Board members and office bearers were elected as listed on page 1.

Many thanks to retiring committee members Pamela Hennessy and Alan Kincade, and a very warm welcome to Gary Jacobson.

**Annual report** is included in this mailing.

**MND Family Resource Centre.** The MND Association of NSW has been working towards acquiring a home. The Centre will be a place where members can meet and share their

experiences, liaise with the family support staff, obtain up to date information or just have a chat and a cup of tea. We have been working with the Concord Hospital authorities for a parcel of land or a suitable building since 1998. Good progress has been made recently and it appears that we will have land for construction of our MND Family Resource Centre in 2003. A special appeal will be conducted next year to raise additional funds for this project.

**Business Plan.** The existing Business Plan will be due for replacement in July 2003. The review process has commenced with a survey to our members with MND. Among other things, they have been asked to tell us what we might do to improve the existing services provided by the Association. Board member, Mr Bob Howe of Strategic Consulting Solutions Pty Ltd, is heading a review committee consisting of Carol Birks, Dr Paul Brock, Janet Nash and Paula Trigg. The consultation process will begin in the New Year and we will work with you to plan our future.

We wish you all a Merry Christmas and a Happy New Year.

*Hari Singh*  
Chief Executive Officer

*All readers will join with us to send best wishes to Ry Langdon and his family.*

*There is a long road ahead to a different life, but, with the support of his family and many friends, Ry's courage and determination will get him there.*

*Editor*

### MND EQUIPMENT LOAN SERVICE



The MND Equipment Loan Service aims to provide, at no cost, equipment (wheelchairs, communication aids, medical beds, etc.) to all people living with MND in NSW as soon as the need for a particular item arises. Equipment needs change constantly with progression of the disease and increasing dependency.

Equipment for people with disabilities is usually accessed through government loan services (PADP) but, as PADP loan applications can take considerable time to be processed, the MND Association fills the gap for needs that cannot wait. Some people with more slowly progressive motor neurone diseases will need assistive devices for a long period. A therapist will assess their needs and make an application to PADP for the appropriate equipment. In the interim, the equipment may be borrowed from the MNDA loan pool. When the requested equipment is received from PADP, the items borrowed from the MNDA loan pool can be returned for recycling to other users.

All requests for equipment loans require a written prescription from an occupational therapist (physio/speech pathologist etc), so please try to plan well ahead for your needs. It is a good idea to have an OT assessment early so the therapist can explain the use of the particular aids that will make your daily living easier.

### EQUIPMENT OFFICER

The MND Equipment Service has grown and now needs a full time equipment officer to run it.

This full time position will be shared between two half-time people, and Linda Hager needs someone to join her in this rewarding role.

If you are a practical person with an allied health or nursing background, have some experience with medical equipment and computer record keeping and would like to join our team, please phone Hari Singh on 9743 5872 for more details.

## Family Support

*Thank you to all who have responded to the survey of members with MND. Please send your response as soon as possible if you have not already done so. If you have mislaid the survey form, contact the office for another.*

*Your responses will help guide us in providing comprehensive support for people with MND in the future and assist with the review of the Business Plan.*

### **Do you have access to the internet?**

Would you like to receive information from us by email? Send an email to [info@mndnsw.asn.au](mailto:info@mndnsw.asn.au) to register your address. For information and links to other sites, visit our website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

It has been an exciting time for the family support team over the last couple of months with much learning, networking and sharing of experiences. We were fortunate to receive a visit from Tricia Holmes, Director of Care Development MNDA UK, in early November. Tricia was very generous in sharing knowledge and information relating to the MND Association in the UK and the services they provide. It was interesting to observe that the problems faced by people living with MND in the UK are similar to

problems in Australia, despite the larger numbers of people with the disease, and the smaller area to cover. Tricia was very interested in the challenges in providing support to people over the wide geographic area of New South Wales.

The International Symposium was a wonderful experience for all family support staff and a unique opportunity to learn about current research. It was most rewarding to see and meet so many people committed to the care of people with MND and share ideas and experiences with them. Carol and Anita gave presentations at the International MND Nurses Forum on the

MNDA NSW Information Sessions for people recently diagnosed with MND and the Care for Carers Program. Posters on these initiatives were also displayed. The interest in care related issues, and the depth and range of posters relating to care and support, has prompted the Symposium organisers to include an extra day dedicated to care related presentations at next year's Symposium in Milan.

### **Australasian family support day**

Following the Symposium, 33 family support staff from NSW, Victoria, South Australia, Western Australia, Tasmania, ACT, New Zealand and the UK met for a day of discussion and problem solving at the headquarters of the MND Association of Victoria. The meeting was very lively and interactive with everyone keen to share information and learn from one another.

Tricia Holmes gave the opening address talking about current services and planned service development in the UK. Again it was encouraging to learn that in Australia and NZ we face many issues common to the UK experience and that our services are heading in the same general direction.

The group split up into five small groups to discuss equipment, information, volunteers, family support – clients/carers and family support – service providers. These groups reported back on their discussions and identified a key priority issue for more in-depth discussion.

The meeting concluded with each State reporting on recent highlights.

The day was a great success and the sharing with peers was a highlight of the year for all participants. We hope to be able to organise a similar meeting in 2003.

*Carol Birks  
Manager Family Support*

### **SPECIAL MEETINGS – 2003**

#### **Meeting for members in the Hunter and Central Coast region – Tuesday 11 February**

Speakers will include Dr Roger Pamphlett who will talk about the DNA bank and latest research.

#### **Former carers meeting – Monday 17 February - Concord**

Get together for people who have lost a loved one to MND over the last couple of years.

#### **Care for Carers Course – June/July**

A six-week education and emotional support program for family and friends caring for a person with MND. We are thinking of holding the sessions in Hornsby to make them accessible for people in the Central Coast and Hunter. To assist with planning, please let us know if you would be able to attend sessions at Hornsby (instead of Concord).

#### **Living with MND –**

##### **An education and support program for people with MND, their family and friends**

Following the success of the pilot program, this two-day program will be held at Concord in May and November.

#### **Meetings for people recently diagnosed with MND their family and friends**

Evening meetings will be held every three months at Concord in 2003.

Please contact the office if you would like to attend any of these meetings or if you would like further information.

# 13th International Symposium on ALS/MND

The International Symposium on ALS/MND brought together scientists, clinicians and health professionals from around the world to provide a cross-disciplinary interaction between experts with diverse interests.

For the delegates from the MND Association of NSW (all seven members of our family support team), this was much more than an opportunity to increase our knowledge from presentations at the main meetings plus the poster session and the International Nurses' Forum. It was also the opportunity to meet and share ideas with members of 'the MND family' from around Australia and the rest of the world.

The MND Association of Australia admirably hosted the meeting and the MND Association of Victoria is to be congratulated on the magnificent role played in welcoming everyone to their State. Their many volunteers were attentive to everyone's needs and clearly recognisable in their green and gold shirts.

The Symposium was run in two parallel strands - one on biomedical research and the other on advances in the care and management of people with ALS/MND - with joint sessions at the start of each day. There was not always a clear distinction between scientific and clinical areas, particularly in the case of development and trial of new treatments. It was often difficult to choose which session to attend as all presentations were of such high standard and great interest to all.

The **SCIENTIFIC PROGRAM** included presentations and posters in areas which were wide-ranging and overlapping. These included: advances in genetics, mouse models of MND, cellular biology, cell death mechanisms, protein aggregation, neuroprotection and functional repair and stem cells.

The international community of ALS/MND investigators is small, dedicated and cooperative, with multinational input on many projects.

The basic science of MND aims to identify the cause of the disease through an understanding of what initiates death of motor neurones and what is needed for their survival. This knowledge will lead to the development of the most appropriate treatments to prevent neuronal death and stimulate neuronal repair.

## **Advances in genetics**

The discovery of the first gene mutation (SOD1) responsible for some families with inherited MND in 1993 was the first major breakthrough in MND research. This allowed the development of genetically modified mice with a defective SOD1 gene as a model of MND. Scientists in the UK

and USA are now close to identifying another gene that causes familial MND.

Other genetic research seeks to identify risk factor genes in sporadic cases of MND.

## **Mouse models of MND**

Transgenic mice with SOD1 gene mutations have, since 1994, formed the basis of research in neurodegeneration and have served as an excellent model for preclinical screening of potential treatment agents. Discovery of new human MND gene mutations will allow the development of new mouse models and thereby broaden the base of this research.

## **Stem cells**

There is, as yet, little real evidence of clinical benefit from stem cell therapy in humans but stem cell research holds great promise for the future.

Transplanted stem cells can be surgically inserted into the spinal cord to provide a focal treatment, or infused into the fluid surrounding the spinal cord. Injection of stem cells into the spinal cord of patients with MND showed that the procedure was well tolerated and safe.

Infusion into the intrathecal space in rats showed widespread migration of the cells.

Future pathways of research will focus on

- transplantation of stem cells to replace missing motor neurones or to introduce pharmacological products to support existing motor neurones
- reactivation of endogenous stem cells, i.e. finding a way to 'switch on' cells that are already present.

(It is encouraging to note that on December 5 2002, Australian Senators voted nearly two to one to allow scientific research on surplus IVF embryos, after lengthy debate on this controversial issue).

## **The CLINICAL PROGRAM**

included: development of new treatments, clinical trials, palliative care, respiratory support, quality of life, quality of care, cognitive and psychological changes, genetic counselling and new methods of monitoring disease progression.

## **Treatments and trials**

Not all results presented at the Symposium were positive. Several agents that had shown promising results in trials in transgenic mice showed no effect in human trials, e.g. creatine.

Continual refinement in methods of selecting appropriate agents for use in future trials has led to new trials with promising agents e.g. celebrex (inhibits glutamate and oxidation) and minocycline (an antibiotic with high central nervous system

## **SCIENTIFIC TOPICS**

*Advances in genetics*

*Mouse models of MND*

*Cellular biology*

*Cell death mechanisms*

*Protein aggregation*

*Neuroprotection*

*Functional repair*

*Stem cells*

(Continued on page 5)

## 17—19 November 2002 Melbourne, Australia

(Continued from page 4)

penetration and thought to inhibit some enzymes that contribute to motor neurone death). Both of these drugs have shown beneficial effects on survival and strength in mice, and human trials are now in progress. (Please note that people with MND are cautioned not to take minocycline because of potential serious side effects which will be carefully monitored in those who are included in trials in the USA).

Symptom control was the subject of a number of studies, with reports of

improvement in emotional lability (dextromethorphan in conjunction with quinidine sulfate) and benefits in insomnia, appetite and spasticity using Marinol (a medicinal form of marijuana).

**Quality of life** is the prime objective of medical care in MND.

**Palliation** is best provided by development of specialised multidisciplinary MND centres in which continuity of care is provided from rehabilitation to palliation.

**End of life issues** are complex and controversial, with ongoing discussions driven by advances in life sustaining treatments, right to die associations and palliative medicine.

Use of **non invasive respiratory support** continues to increase survival and quality of life but in one report was shown to reduce the vitality of carers. This emphasises the need to monitor and

improve help for carers.

**Cognitive and neuropsychological impairment** in MND is more common than has previously been reported, indicating that dysfunction can extend beyond the cerebral motor cortex.

Development of **surrogate markers of disease progression** could help with more accurate prognosis, which is important in anticipating needs. Advances in brain imaging techniques will aid earlier diagnosis in people with upper motor neurone loss. Techniques of motor unit number estimation (MUNE) and the Neurophysiological Index provide methods for estimating loss of lower motor neurones. The loss of motor units continues at a regular rate with a corresponding loss of muscle strength, and has been demonstrated to precede onset of symptoms by only a few months.

To conclude, Professor Nigel Leigh (UK) declared the Symposium to be the most successful ever. There was a feeling of excitement and hope at the rate of change in research and advancement of care. More cases of MND are now recognised, probably as a result of better diagnosis, and people with MND are living longer - almost certainly as a consequence of better treatment and care.

Abstracts from the Symposium are available on the internet at [www.mndassociation.org](http://www.mndassociation.org).

Janet Nash  
Information Officer

### CLINICAL TOPICS

*New treatments & trials*

*Palliative care*

*Respiratory support*

*Quality of life*

*Quality of care*

*Cognitive changes*

*Genetic counselling*

*Markers of progression*

### Charcot Young Investigator Prize

The Motor Neurone Disease Association (UK) has awarded this year's Charcot Young Investigator Prize to Dr Robert Friedlander of Boston, USA. Dr Friedlander, a 34-year-old Associate Professor in Surgery (Neurosurgery), is based at the Harvard Medical School in Boston. He was awarded the prize for his research work based on the impact of apoptotic (programmed) cell death in neurodegenerative diseases, with a particular interest in Motor Neurone Disease (MND).

The prize was presented on the closing afternoon of the 13th International Symposium on ALS/MND in Melbourne, Australia, which took place from the 17 - 19 November. The annual award is made by the MND Association and Aventis Pharma, to an outstanding young investigator whose research is judged to have contributed to scientific understanding or advances in patient treatment and care in MND and related disorders.

Dr Brian Dickie, Director of Research at the MND Association, said: "Dr Friedlander's work has been central to our understanding of the

various mediators of cell death that become activated in MND. It has allowed specific pathways to be targeted using inhibitory drugs, some of which have been effective in delaying disease progression in mice with the disease."

Dr Friedlander's work as a post-doctorate fellow has increased understanding of the key role of the "cell death cascade" that occurs among people with MND, and is also evident in other neurological diseases. His research results have provided valuable information about the nature of cell death pathways in neurodegenerative diseases.

The prize, which is valued at 20,000 pounds and includes The Charcot Prize Trophy, will be used by Dr Friedlander to advance his research into MND or related disorders.

Marion Reichle  
Research Administrator  
MND Association, PO Box 246  
NORTHAMPTON NN1 2PR

Reprinted from Bob Broedel's ALS DIGEST  
20 Nov 2002

## Regional News

### SUPPORT GROUP CONTACTS

#### Central Coast

Audree Dash  
Phone: 02 4384 2907

#### Central West

Mary Campbell  
Phone: 02 6851 4403

#### Coffs Harbour

Lily Jenkins  
Phone: 02 6652 2571

#### Illawarra

Lyn Bedford  
Phone: 02 4223 8239

#### 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

Noelene Kidd  
Phone: 02 6624 4684

#### Riverina & Sth West Slopes

Wes Russell  
Phone: 0408 692 127

#### Hornsby

(Anita Richter)  
and

#### Panania

(Caroline Gleig & Ruth Quaken)  
and

#### Penrith/Blue Mountains

(Ruth Quaken)  
are coordinated through  
the MNDA office.  
Phone: 02 9743 5872

#### Central West

I am pleased to announce the formation of a new support group for people in rural and regional NSW.

Members in the Central West expressed a desire for a support group in their area during a field trip I conducted in July. This small but lively group got together, appointed a very willing coordinator and invited me back to the region to launch the group in Molong in November. An education morning for people with MND, family, friends and interested service providers was incorporated into the day. This session was very well attended and the MND Association is grateful to the service providers who gave up their time to come and talk about their service and role in supporting people living with MND. Following a delicious lunch prepared by the Molong Bakery, the support group was officially launched.

People with MND in this region are quite widespread and the group has therefore decided to meet in a different town bi-monthly. The first meeting will be on Saturday 15 February in Molong and thereafter in Forbes, Molong or Dunedoo depending on the wishes of the group.

If you live in the Central West and would like to find out more about these meetings, contact the coordinator, Mary Campbell, on 6851 4403.

*Carol Birks*

#### Hornsby

Would you like to know about the latest research into MND?

Would you like to learn about fundraising initiatives planned by MNDA's fundraising committee and Development Manager?

An open invitation is extended for

all who have an interest in MND to attend the first meeting of the Hornsby Support group for 2003 at 11 am on Wednesday 12 February at Thornleigh Community Centre.

Janet Nash, MNDA Information Officer, will talk about research presented at the 13th International Symposium on ALS/MND, and answer questions on recent research.

Elizabeth Herbert, MNDA Development Manager, will give an update on exciting fundraising initiatives and plans for MND Awareness Week 2003.

Other meeting dates for 2003: April 16, June 11, Aug 13 & Oct 15.

*Anita Richter*

#### Panania

The group celebrated its final meeting for the year with a Christmas party and lunch at the Revesby Workers Club.

A number of health professionals have addressed the group during the year and membership has remained strong.

The first meeting for 2003 will be on Tuesday 4 February and we will have a speaker from Carers NSW.

Once again we thank Janelle and Ross Wilson and Dave Robinson for their continuing assistance

*Caroline Gleig*

#### Penrith/Blue Mountains

After years of coordinating this group, Judy Stringer has stepped aside so she can spend more time with her family. Many thanks to Judy for her caring support of so many people in this region.

I will now be coordinating this group, with all enquiries directed to the MNDA office.

*Ruth Quaken*

***There are now eight MND support groups in rural and regional NSW. If you are unable to access one of these groups and are interested in forming, or attending, a support group, please contact Carol Birks to discuss the feasibility of developing a group in your area or arranging phone contact with people in your region.***

### FOR INTERNET USERS

**OZPALS** is a group of people in Australia and New Zealand with an interest in MND who keep in touch by email. To subscribe go to [www.hotkey.net.au/~ozpals](http://www.hotkey.net.au/~ozpals)

#### Internet Chat - Living with MND

Every Tuesday at 1pm & Thursday at 8pm DST.

Go to [www.mnd.asn.au/](http://www.mnd.asn.au/) then click on the chat room link.

Also try <http://neuro-mancer.mgh.harvard.edu/brainchat/classic.shtml> or [www.alschat.com](http://www.alschat.com) for chat rooms which are open 24 hours per day.

Visit the MNDA NSW website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) for links to many useful and interesting sites.

## Fundraising

### It has been eventful ....

Over the past couple of months, there have been the most wonderful series of fundraising events taking place around NSW. This has been hugely successful in raising the profile of MND as well. "Magnificent and heart-warming" are some of the words used. If anyone is interested in planning an event, don't think twice, call 9743 5872 and speak to Elizabeth Herbert.

### Many Manly golfers

Andrew Paxton has some very good friends. On 3 October, over two hundred turned out on the most successful day

which raised a staggering \$105,000. The Committee worked tirelessly to make it a success. Led by travel agency guru, David Broit and his wife, Rene, and aided and abetted by Andrew and Sue Paxton, they were Ric Holm, Ross Hale, John Mater, Rob Simeon, Steve Patrick, Richard Turner, Bob Orth and Gordon Smith,

It is hoped that they enjoyed themselves enough to volunteer to repeat the whole thing in 2003.

### Young at heart

Young turned blue on 9 November. The whole town took part in a magnificent fundraiser organised by Roz Smith and friends. Even the local hairdressers turned up for work in blue wigs and every business contributed to the day. Roz had previously raised a magnificent \$12,000 for another charity but, this time, she broke all records.

Young raised over \$20,000 and warmed the hearts of a local family who have familial MND and recently lost three cherished members of the family to MND.

### Go Go Golf at Cooma

While Young turned blue, in Cooma Valma Young was organising the annual Golf Day in memory of her husband, Tony. The family ensured that there were first-class prizes available in Thredbo and raised substantial sums to help people with MND.

### Go Go Golf at South West Rocks

Bruce MacDougall is making it an annual event. He has two very good reasons for helping to fund the Association's work. His son Ray MacDougall was a popular policeman and a good friend of the family was Margaret Burge. The day is a memorial to these two great people and Bruce ensures it is a great success. This year he presented a cheque for \$15,000 to help the MNDA's work.

### Cootamundra's vintage debutantes

Great fun was had on 16 November when Susan Chambers and her sister, Gillian Galvin, brought out some debutantes who had been on the shelf for a while. Twenty ladies and their partners made their debut and they have banked over \$8,000 for the Association to invest in making life easier for people with MND and their families. This event was a great innovation by the Riverina and South West Slopes Support Group, which is jointly led by Wes Russell in Wagga Wagga and Susan in Cootamundra. What a fundraising 'debut' for this group which has already held several smaller events in town.

### VOLUNTEERS -

#### A VALUABLE PART OF THE TEAM

I have recently joined the team at the MND Association of NSW as a volunteer, in the new and challenging role of Coordinator of Volunteers. I am excited by the opportunities that exist to build upon the hardworking group of volunteers that we currently have. Our volunteers are important team members who can help with mobilising community support and extend the reach of the Association's staff in providing services.

It is important that we understand "who" our volunteers are and how best we can utilise their particular skills. Hopefully, all volunteers would have received by now the short questionnaire which was sent out in October. Your help in completing and returning the form will assist in establishing a database which will be invaluable for planning, not only for MND Awareness Week, but for other activities throughout the year. If you are a volunteer (or would like to be one) and have not received the form, please contact Elizabeth Herbert at the MNDA office. The questionnaire is also seeking to tap into all those great ideas you have on how to increase funds raised and also increase awareness of MND in the community.

Ensuring that all volunteers are kept informed of developments in MND and are well informed of the services that the Association provides is extremely important. An "orientation manual" will be developed for all new volunteers and we will hold briefing workshops for volunteers taking part in MND Awareness week 2003.

The dedicated work that volunteers perform varies from person to person, but it's all-important and cannot be underestimated! In recognition of this, we are looking into ways to acknowledge each volunteer's contribution and will hopefully be able to announce this new initiative shortly.

*Coty Cortese  
Coordinator of Volunteers*

**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. Many people support the work of MNDA NSW through bequests from their Estates. We can arrange for a solicitor to draft a standard will for you free of charge.*

(Continued on page 8)

**Fundraising** (Continued from page 7)

**Thanks for keeping the MNDA going**

Since the last edition of *Forum*, the Association has received a substantial bequest from the estate of the late Mary Margaret Hill; an anonymous donation of \$50,000 and welcome support from Class 5 of New South Wales Fire Brigade, the Bulldog Leagues Club and Lidcombe Catholic Workers' Club, ING Foundation and the United Grand Lodge of NSW & ACT.

**Forward planning**

MND Awareness Week dates are 6-12 April with Cornflower Blue Day on Friday 11<sup>th</sup>. Shopping Centres need manning, as do street collections and help is needed with all sorts of odd jobs. Anyone fancy restocking the shopping centres with merchandise this year? Last year, it was difficult to restock quickly enough and a mobile unit would be a great advantage. We could also do with people prepared to hang the banners over the motorways. Looking for a job? We're looking for you.

*Elizabeth Herbert  
Development Manager*

**IDREAM**

Getting dressed in a beautiful red gown and dancing to a romantic Strauss waltz.  
Relaxing in a luxurious bubble bath, drinking champagne.  
Strolling along golden sands with the water lapping at my feet.  
Watching the seagulls and the boats bobbing up and down.  
Entering the water slowly and swimming in total relaxation in the cool blue waters.  
Sitting on a bench under a shady tree turning the pages of a captivating book.  
Writing down my thoughts as they come to me.  
Scratching my nose when it itches.  
Baking my favourite apple cake and sharing it with my family and friends.  
Spending leisurely hours painting pictures and moulding clay into interesting shapes.  
Playing games with children and hugging them tight.  
Putting my arms around a loved one and feeling them close.

I wake with tears trickling down my cheeks,  
I can no longer do these things.

I am angry, frightened and sad, but I have to be strong to get me through the day and put a smile on my face until night comes and sleep wraps me in her arms and I can dream once more.

*Renee Symon  
Bondi Junction*

**Carers news**

**The MNDA NSW Carers Kit is now available.**

The Kit was developed through funding we received from NSW Health Department's Care for Carers Demonstration Projects, and information derived from the Care for Carers workshops we have held during the last two years.

This project has enabled us to compile a comprehensive information resource on managing different aspects of MND. We will be able to further develop this over time for application in different contexts, e.g., information for professional carers and health professionals.

Due to the quantity of information contained in the Kit we recommend that people request the Kit section by section, as the topics apply to their particular need and situation. A folder, an index, introduction and a request sheet will be issued with each new application.

We are currently looking into other ways of issuing the Kit including CD Rom and email.

A Carers Kit index and check list accompanies this edition of *Forum*. Please select sections and return the request sheet to the office.

Feedback from our members and carers is important to help us improve our information resources as well as our other activities. We have consulted with present and past carers during the development of the Carers Kit but would appreciate other suggestions regarding the information contained and the format. Please let us know what you think!

**Support Groups and the Carers Kit**

Videos taken during the Care for Carers workshops and accompanying information are now available to regional support groups wishing to hold sessions on managing different aspects of managing MND. Support Group Coordinators can phone Carol at the office to obtain further information.

**Carers Workshops**

Following the success of our previous Care for Carers workshops, we will be holding a six-week series of workshops offering education and emotional support for MND carers in June/July 2003. See the next edition of *Forum* for further details.

*Anita Richter  
Coordinator Carers Services*

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

**ACKNOWLEDGEMENT**

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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.

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