

December 2003

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Governor of New South Wales

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and

**MANY VALUED VOLUNTEERS**

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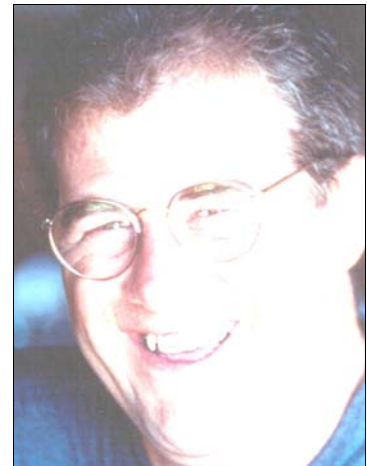
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**Kevin Langdon, OAM**

Kevin Langdon joined the MND Association of NSW in 1988 after being diagnosed with MND. He had a difficult time coming to terms with diagnosis of a disease that doctors told him would end his life within two to three years but he is still very much with us despite his decision to step aside from his role as President of the Association.



Amongst people living with MND, Kevin is comparatively lucky. He has a slowly progressive form of the disease and, although weakened by progressive motor neurone loss, he is still able to live a very meaningful life. In the sixteen years since diagnosis, he has worked constantly to do what he can to make a better world for people living with MND.

Kevin was elected as a member of the Board of the MND Association in 1990, became Vice President in 1992 and played a very active role as President from 1993 until December 2003. He has also been a delegate to the MND Research Institute of Australia and is a past Vice President of the MND Association of Australia. Kevin was awarded the OAM in 1999 in recognition of his service to people living with MND.

Throughout all of this time, Kevin has been everywhere - not only travelling extensively around New South Wales but also frequently representing the Association overseas at the annual International ALS/MND Symposium. It was at an international meeting in the UK in 1990 that Kevin befriended the Duchess of York, Patron of the MND UK Association, and they have remained firm friends since that time.

Kevin has always gone out of his way to make contact with people living with MND, attend support group meetings, stimulate awareness of MND in the community, generate funds to help with the work of the MND Association and generally provide first hand information from the perspective of a person living with MND.

*(Continued on page 3)*

*The MND Association of NSW office will close for Christmas from Wednesday 24 December to Friday 2 January inclusive.*

*Normal office hours will resume on Monday 5 January 2004.*

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

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

*The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.*

## A message from the CEO

### Changes on the Board

The Association has just conducted its Annual General Meeting, at which the Board was elected for the next twelve months.

It is with some regret that four members of the Board did not seek re-election, including the President, Kevin Langdon OAM. Special testimony to Kevin appears elsewhere in Forum and he will be sorely missed by all. As CEO, I have been privileged to benefit from Kevin's wisdom and advice.

Paula Trigg and Norman Minton did not nominate for election and Dr Roderick Mackenzie resigned from the Board in October.

I thank them for their contributions to MNDA NSW and wish them well.

### A new President

Ralph Warren has been elected by the Board as President for 2003/2004. A member of the Board since November 1998, Ralph was Chair of the Staff Committee and most recently has been instrumental in fully revising the Constitution of the MND Association of NSW.

The staff and I congratulate him on this appointment and look forward to working closely with him.

Other Office Bearers for 2003/2004 are:  
Vice-Presidents:

Dr Robert Marr and Phil Bower

Treasurer: Robert Templeman

Secretary: Suzanne Ballinger

Katrina Horman is welcomed as a new member of the Board.

### Constitution is updated

The membership, at a Special General Meeting, has endorsed the Board's recommendation that the Constitution of MNDA NSW be revised to bring it into line with the Model Rules of the Department of Fair Trading.

The most significant changes are the reduction in the size of the Board from 15 to 11 Members (with a further reduction to nine effective December 2004) and the elimination of the Office of Chairman.

### Advances in communications

The Office now has a new telephone system which will soon provide each staff member with a direct extension and voicemail facility. Internet and email access are also now available to all staff.

### CEO settles in

I am grateful for the confidence shown in me by the Board after what has proven to be an eventful three month period of settlement.

Having visited all active Support Groups and met people with MND, I have a greater appreciation of the disease and its effects upon one's life and significant others. I am, more than ever, determined to increase public awareness and support for the Association.

On behalf of all staff at MNDA NSW, please accept my warm wishes for a very Merry Christmas, a happy and prosperous New Year and a safe holiday period.

*Bruce Fraser  
Chief Executive Officer*



*MNDA NSW President  
Ralph Warren*

## Christmas and MND

The MND family is growing - for every person who is diagnosed with MND, another fourteen will live with it forever. These people are families and friends and people who provide all the care and services throughout the course of the disease. They also include the researchers who are collaborating in their efforts to understand the cause and find a treatment and a cure that will lead to a world without MND. This is our extended MND family.

Since 1981, the Association has gathered its family members together in December to celebrate the Christmas season. The annual MND Association Christmas party means different things to different people - for some it is an opportunity

to meet other members and MNDA staff; some come to share experiences, others to remember and to catch up with old friends.

Some things never change. Each year Norma Hughes prepares a wonderful Christmas basket as a raffle prize, and Lyn and Alex Henderson contribute a bottle of Scotch whiskey. Santa (aka Bob Ballinger this year) distributes gifts, songs are sung and everyone has a happy time.

If you could not get there this year, we hope to see you next year.

Many thanks to all who helped and particularly to Marjorie Harrap and Petra Sammut for their planning and organisation.

We wish all readers a Happy Christmas and a new year that is filled with hope for the future.

## Support

### Snap Printing, Artarmon

The MND Association's quarterly newsletter *Forum* provides a way of keeping people up to date with the world of MND: the workings of the MNDA, information about MND, handy hints, regional news, the latest in research, letters from members and more. The newsletter is mailed each quarter to all members of the MND Association and many people choose to become members so they can be included on the mailing list.

Karen Scheinecker has had a long-term work relationship with Rob Christie at Snap Printing, Artarmon. When Karen's father, Gus, died from MND, she asked Rob if he could help the MND Association. He agreed and, since 1995, Rob and the always helpful Tony Kerr have printed the newsletter as a gift to the Association. With a current print

run of 1,700 copies, this is truly a generous gift.

The MND Association is extremely grateful for this on-going support which allows precious funds to be used where they are most needed - funds to provide care and support for people living with MND today and, through research, funds to provide hope for a future.

Thank you Snap Printing.

*Editor*

### Volunteering

...is something I have done for 24 years.

My first position was as a "Pink Lady" in the aged care ward at Deniliquin Hospital in country NSW. Subsequent to that, I have volunteered as a part-time teachers' aid at a Primary school in Canberra, done diversional therapy at an aged care facility in Sydney's Inner West and have also been a client interviewer with the Smith Family for people requiring assistance.

One and a half years ago, I came full circle by again becoming a "Pink Lady" but this time at Concord Hospital in an aged care ward where I do the flowers, manicures, odd jobs for the staff and chat to the patients.

One day while at the Hospital and after my uncle had been diagnosed with MND, I walked into the MNDA NSW office and asked if they needed volunteers. The answer was a resounding yes and I commenced the following week.

The best way to describe my role is as a "Girl Friday". Given that technology challenges me, it has been interesting coming to terms with computers, photocopiers, fax machines and a telephone with more than one line. I suppose things are going well because I haven't been sacked yet which is great because I really enjoy what I do and look forward to my day at the office.

I can highly recommend volunteering to anyone who has the time or inclination.

*Debra Larizza  
Concord*

*(Continued from page 1)*

Kevin's long-term knowledge of MND and the workings of the Association have helped with building the team which now collectively supports people living with MND throughout NSW. Kevin has always been solidly supported by all of his family who are regular participants in MNDA NSW gatherings. In more recent times, the shining light in Kevin's life has been Helena Karnolz. Helena has been there to help Kevin through the tragic accident last year in which Kevin's teenage son, Ry, broke his neck and is now quadriplegic. There is now a long and difficult path ahead but things can only get better.

In the immediate future, Kevin plans to spend more time supporting spinal injury research.

We will miss Kevin's extremely active input to the Association. He has done so much to raise awareness of MND and has lived through the years of growth of the Association to the proactive organisation that it is today.

Thank you Kevin. We wish you well.

*Janet Nash  
Editor*

#### **MNDA Volunteer Visitor Pilot Program**

**Recruitment of volunteer  
visitors has commenced.  
If you live in the Hunter,  
Newcastle or Central  
Coast Regions and are  
interested in becoming a  
MND Friendly Visitor  
please contact the  
MNDA NSW office.**

## Family Support

### The year in review

2003 was a very busy year for the Family Support Team. We have gone through another period of re-structure and grown yet again with the addition of four new members of staff. We have been fortunate that the Association has been in a strong position to enable Family Support to respond to increasing demands and provide extra resources to fund more hours for the equipment service, a new Regional Advisor position for Southern NSW and ACT and the Special Projects and Carer Services Coordinator position. Family Support continues to provide an increasing level of service with statistics over the past 12 months showing an increase in the number of home visits, equipment loans, phone follow up, "info line" calls, education for health and community care providers and information sent out to people living with MND, carers and health and community care providers.

The Carers Kit has proven to be a very valued resource for MND carers and health and community care providers. The Care for Carers course, Information Evenings for people recently diagnosed with MND, Past Carer and Bereavement meetings, Learn now/Live Well Program and Rural and Regional Members/Service Provider meetings and seminars have all been very well attended and will continue to be incorporated into the Annual Calendar. The commencement of the Volunteer Visitor Pilot Program in July was very exciting and we look forward to seeing this project through to completion in 2005.

### Palliative Care

Christina Jason and I attended the National Palliative Care Conference in Adelaide in September. This was a wonderful opportunity to hear the latest palliative care related research, network with palliative care teams and present Anita Richter's poster on the 'Care for Carers Project'.

A number of the presentations and papers provided confirmation of the commitment of MNDA NSW to providing and promoting support and education for carers of people living with MND, integrated care, volunteer visitors and referral to palliative care on an as needs basis rather than length of life basis.

A paper entitled *Assessment of the effectiveness of Australian models of palliative care delivery in four neurodegenerative disorders* discussed a study looking at the care needs of people with Parkinsons, Huntingtons, Multiple Sclerosis and MND.

Preliminary results indicate that:

- Associations are excellent sources of support
- Health care providers need specialized skills
- There is a need to define the role of palliative care in MND particularly in regards to counselling, planning, end of life and symptom management.

The emerging shift away from cancer-focused Palliative Care towards Palliative Care for all people with life threatening illnesses on an as needs basis was gratifying.

One of the highlights of the Conference was the inaugural MND Special Interest Group Meeting. The attendance was very good, indicating a strong interest in MND and a desire to learn more about how to support and care for people living with MND. To maintain this interest, the MND Association of Australia has instigated an MND Palliative Care Special Interest email group. Rod Harris, CEO MNDA Vic, will distribute nationally, MND related papers and information via email to palliative care providers with an interest in MND.

Regional Advisors are able to refer people to a number of Palliative Care services in NSW and the ACT, with their permission and if applicable, from diagnosis onwards. This enables people living with MND and their family to become acquainted with the team and to access palliative care throughout the course of MND and through their bereavement.

The Conference gave Christina and me the opportunity to participate in a **National Family Support Network meeting** with family support staff from the MND Associations of Victoria and South Australia. These meetings offer a unique opportunity to share ideas and resources and to support each other.

### New Staff

I am very happy to introduce to you two new family support staff members. Elizabeth Milsom decided not to continue as Equipment Coordinator and Trevor Rakuraku has taken on the role of Equipment Assistant.

Trevor has experience with equipment loan services in New Zealand and has very quickly taken up the challenge of assisting Maree with the very busy equipment loan service.

*Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.*

*World Health Organisation definition*

Mary Butcher has just commenced work as the new Northern Metropolitan/New England Regional Advisor. Mary will assume responsibility for Anita Richter's members on the North Shore and Northern Beaches and also members in North West Sydney and the New England region. Mary is a Registered Nurse with a wealth of experience in a variety of areas and her expertise will further strengthen the Family Support Team.

Anita will take on her new position as Special Projects and Carer Services Coordinator in January and I look forward to working with Anita on new initiatives to better meet the needs of people living with MND, their families and health care providers.

### The year ahead

Running programs and courses to meet the needs of special groups as above is important and allows Family Support to increase their depth of knowledge and expertise. The priority for Regional Advisors,

however, continues to be support of people with MND and their families through home visits and regular telephone follow up, as well as the promotion of best practice care and support from their local health and community care providers. The aim of the recent restructure of Regional Advisor areas is to enable Regional Advisors to better meet the needs of the people living with MND in their region.

New initiatives in 2004 currently being developed or planned include greater liaison with GPs, development of Special Interest Groups for health care providers, extending a modified Care for Carers program to rural and regional NSW and the implementation of a Bereavement protocol. A Seminar is being organised in Canberra during MND Week and the Annual Conference for Health and Community Care Providers will be on 21 June, MND Global Awareness Day. If you have any ideas on how we could better meet your needs and the needs of your local health and community care providers, please contact me at the office – your ideas and feedback are always important.

*Carol Birks*

*The family support team  
wish you all a  
Happy Christmas.*

*If you need help during  
the Christmas break,  
please consult your  
Doctor.*

*The MNDA office  
will reopen on  
Monday 5 January 2004.*

I have worked in both the hospital system and community care as a Registered Nurse. I worked for many years in Sydney's Northern Beaches area in service provision for community based aged clients.

I have most recently worked as a consultant to the Commonwealth Dept of Veterans' Affairs involved largely with welfare, aged care and health promotional activities. I am also a Community Member of the Guardianship Tribunal.

I live on the Northern Beaches and look forward to meeting all the people involved with MND in my region.

*Mary Butcher*



### FAMILY SUPPORT DIARY DATES FOR 2004

#### **Tuesday 10 February - Concord**

Research Update – Dr Roger Pamphlett.

**Thursday 18 March – Hunter/Newcastle/Central Coast** Volunteer Visitor education course commences.

#### **Monday 29 March - Canberra**

Morning session - Seminar for Health and Community Care Providers followed by an information afternoon for people living with MND and their families and the inaugural Canberra and Monaro Support Group meeting.

**May/June - Concord** Care for Carers course.

#### **Monday 21 June - North Ryde RSL**

Annual Conference for Health and Community Care Providers.

#### **Mondays 18 & 25 October - Concord**

Learn now/Live well program.



I worked with occupational therapists in the equipment service at Wellington Hospital, NZ for a couple of years.

I recently came to live in Australia because my family are here.

I am looking forward to working on this side of the Tasman and helping Maree with the MND Equipment Service.

*Trevor Rakuraku*

## Research

### BODY PARTS: MOTOR NEURON DISEASE **Delivery of messages a matter of life or death**

Our nerves operate with a buddy system, not unlike that which gives our kids a helping hand when they start school. The cells surrounding our nerves seem to play a role in keeping our nerve cells healthy; in guiding, nourishing and removing toxins from neurons. In the case of some forms of motor neuron disease, these surrounding non-neuronal cells even appear to prevent the degeneration of the nerves associated with the debilitating disease.

The body relies on nerves to transport the message from our brains to the various parts of our bodies. The nerves responsible for movement are among some of the longest in the body, travelling from one extremity to the other to enable us to walk.

Motor neurons are situated in the brain, brainstem and spinal cord.

Messages from motor neurons in the brain are transmitted to motor neurons in the spinal cord and from there to particular muscles.

Motor neuron disease refers to a collection of disorders in which the neurons degenerate or die.

The muscles are no longer able to receive the electrical messages from the brain and unable to move, gradually weaken and waste away.

In many forms, eventually even the muscles that control breathing fail and many patients die from respiratory failure.

The latest issue of Science reports a study by scientists from six US research institutes into the most common form of inherited motor neuron disease, amyotrophic lateral sclerosis, (ALS), sometimes called Lou Gehrig's disease after a legendary baseball player who died of the condition.

The scientific team bred 65 mice that were mixtures of normal cells and cells with a defective gene known to cause ALS, the superoxide dismutase gene (SOD1).

The aim was to determine whether ALS was caused by defects in the motor neurons themselves or whether other cells were causing the motor neurons to degenerate.

The researchers found that the non-neuronal cells surrounding the motor neurons, called glia and astrocytes, can protect the neurons from the damaging effect of the gene.

These surrounding cells have been thought of as a supportive framework for the neurons - the word glia comes from the Greek for glue. But scientists now realise these cells can play other important roles.

Glia have been shown to keep the brain free from injury by digesting damaged neurons and to make the myelin sheaths that insulate and protect neurons.

The scientists found that in the mice, if the genetic mutation was in the non-neuronal cells, these cells could pass on the disease to normal motor neurons.

If the non-neuronal cells were healthy, they were able to protect the motor neurons from degenerating, extending the life of the neurons, the life of the animals and sometimes even preventing the disease from taking hold.

The scientists hope the findings offer an avenue for treatment for all types of motor neurone disease by inserting healthy non-neuronal cells to protect motor neurons, a simpler task than trying to replace a metre-long motor neuron.

*Justine Ferrari*

*This article which sheds new light on the possibilities for stem cell research and MND is reprinted from The Weekend Australian 11-12 October 2003*

## The Australian MND DNA Bank

A DNA bank has been set up in Sydney for research into the causes of motor neurone disease. The bank is a joint project between the University of Sydney and Royal Prince Alfred Hospital. We would like to obtain DNA samples from people with both the sporadic form of MND (in which only one person in a family is affected) and the familial form of MND (in which more than one person in a family is affected). We also need samples from people who do not have MND, e.g. relatives, spouses or friends of people with MND. You will be asked to fill in a lifestyle questionnaire so that we can assess what possible toxic agents you have been exposed to.

The DNA bank, which gathers blood samples from people all over Australia, has been set up to provide researchers in motor neurone disease with large enough numbers of DNA samples to look for

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## *A postcard from Milan*

### **The 14th International Symposium**

**on ALS/MND** was held in Milan in November. A record number of registrants (over 700) were present, which indicates the intense research activity into MND at the moment. Milan was a little short of tourist sites in November, with the Duomo under renovation and La Scala closed. So the meeting was well attended at all times.

Attendants had to choose between two, and sometimes three, concurrent sessions. This made things difficult for those of us who are interested in both the clinical and scientific side of MND. I went mostly to the scientific sessions, and to a few of the clinical ones. There was an interesting contrast in atmosphere between the two sites: the scientific sessions were sober and cautious, the clinical ones more outgoing and cooperative.

Questions at the clinical sessions were very vigorous and enthusiastic.

There was a good contingent from Australia at the meeting. At the scientific sessions, Dominic Rowe from Sydney and Surindar Cheema from Melbourne had members of their teams with them, and I had two students attending. The work presented by the Australian scientists was of a very high standard.

No major advances were presented at the meeting, though there is a lot of very interesting work in the pipeline that we will hear about soon. This meeting is unusual in being held every year, so the chances of a breakthrough being presented every year is slight.

### **Some highlights of the meeting were:**

1. Work presented on the MND mouse model that showed that the chemical porphyrin extends survival in these mice to a greater extent than virtually all other agents so far. I'm sure we'll be hearing more about this agent soon.
2. The growing realisation that mitochondria, the energy packets within cells, could be the target of the disordered protein in the familial forms of the disease.
3. The discovery of new ways to deliver drugs, especially via harmless viruses, could mean that agents previously found to be ineffective in MND could be tried again using these viral carriers.
4. The enthusiasm for international collaborative efforts in looking for interactions between environmental agents (such as toxins or viruses) and genetic susceptibilities to these agents. Australia is well placed to join these efforts with the Australian MND DNA bank.
5. By screening a huge number of therapeutic agents, a big USA research effort has judged that two types of antibiotic, a cephalosporin and a tetracycline, may be worth further testing in animals. 15 other compounds have also been identified as being of potential use. This work has not yet been published and we are all awaiting the results with great interest.

Next year's meeting is in Philadelphia and I would encourage as many Australian MND workers as possible to attend.

*Roger Pamphlett*

*Dr Roger Pamphlett will present a research update at Concord Hospital in lecture Theatre 2, Clinical Sciences Building at 2.30 pm on 10 February 2004. The talk will be preceded by lunch and blood collection from 1 pm. If you would like to attend/contribute, you must phone 9743 5872 to RSVP before 3 February.*

*(Continued from page 6 - MND DNA Bank)*

causes of the disease. We are particularly interested in looking to see if people with MND are genetically susceptible to certain toxins or viruses. The response from all states has been excellent, and we now have 500 DNA samples in the bank. However, we need many more samples for the type of high-level genetic testing that we are doing.

If you would like to contribute your DNA to the bank, the MND Association of NSW is organising a collection day at Concord Hospital on Tuesday 10 February 2004. Please contact Carol Birks or Janet Nash at the MND Association on 9743 5872 if you would like to attend. Dr Roger Pamphlett will be giving a talk on research progress in MND on the day. This talk (and blood collection) will be repeated in Canberra on 29 March at the MND meeting.

For more information, you can contact the MND Association at any time or Dr Pamphlett *after 12 January 2004* (he is at present in the UK doing fulltime MND research) at the Department of Pathology D06, The University of Sydney, NSW 2006. Phone 02 9351-3318, fax 02 9351-3429, email [rogerp@med.usyd.edu.au](mailto:rogerp@med.usyd.edu.au).

## Fundraising

### A MAGNIFICENT LEGACY

A telephone call to the MNDA announced that a bequest nominating the Motor Neurone Disease Association of NSW as a significant benefactor is being finalised. The Solicitor estimates that this Will adds about \$400,000 to the Association's funding.

This is a legacy from Mrs Madeleine Brown. During the last years of her life, Mrs Brown made several anonymous gifts to the Association. Her final gift will make a substantial difference when plans are being drawn up for future of the Association. It is with great regret that the MNDA is unable to thank Mrs Brown in person for her generosity.

During this period, the estate of Mrs Gwynyth Alice Lindsay was finalised adding another \$10,000 to the Association's funding and another major gift was received in memory of Vic Ramsden.

If you are thinking about making a Will, do not forget what a difference a legacy can make to the work of the MNDA.

### RAFFLES

Libby Sharp put her Fridays to good use at Liquorland in October to raise more money for the MNDA.



A

*This beautiful quilt has been made by the Fairholme Quilters and will be raffled for MND in May 2004. Raffle tickets are available at the MNDA office.*

### BIG THANK YOU

for funds raised to: Bellbird Club Inc; Brisbane Water Bridge Club Inc; Cabramatta High School; Coogee Beach Dolphins Sports Inc; Croydon Industries; John Eades; the Ionian Club Sydney '84 Inc; the Rotary Clubs of Ballina and Silverwater-Homebush Bay and Waverley Council Staff Charitable Trust.

### GARDENS

Suzanne and Bob Ballinger raised a lot of awareness (and funds) by opening their garden for MND in September. *Bruce Fraser, Roslyn Adams and Jillian Michie* were among the many garden enthusiasts who gave their support on the day.

Mr and Mrs Overton of Blackville also sent the proceeds from their Open Garden to the Association.



### HAPPENINGS

**Golf Days** are now happening throughout the State. Bruce McDougall is more successful each year in raising money in memory of his son, Ray McDougall and, his good friend, Margaret Burge. South West Rocks banked almost \$16,000 this year. Cooma's day was 8 November and Valma Young worked tirelessly backed, yet again, by the whole family. The Windsor Golf Club must also be thanked for its contribution.

A newcomer to the scene is Carolyn Woods who organised a golf day for MND at Russell Vale Golf Club in October and plans another after MND Week on 29 April.

And Lions of Frenchs Forest Golf Day will be held at Wakehurst Golf Club on 11 March. Interested? Phone 9416 1335.

### CHRISTMAS SHOPPING HELPS MNDA

Shoppers at **Ashfield** using the wrapping service will be given the option of making a gold coin donation to the MNDA.

### A BIG BLUE BALL

The Haddad family and friends have formed a committee which is creating a major new annual event in Leichhardt.

The 'Blue Ball' is being held at La Montage in Sydney's Leichhardt on Cornflower Blue Day (Friday 2 April).

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### UNITED WAY

Special thanks to United Way who have provided the funds that are needed for us to upgrade our website so we can provide the latest information and links to other sites and, hopefully, receive donations via the internet.

### MND WEEK VOLUNTEERS NEEDED

From Monday 29 March to Saturday 3 April, help will be needed to man the myriad shopping centres which kindly allow a stall to be set up in MND Week.

If you are able to give up half a day; a whole day (or more), do please telephone the office and give your name, preferred shopping centre and the time you have available.

Obviously, it is early days, so if you need to change anything at a later date, that will not be a problem – this just gives the MNDA an opportunity for early planning.

Happy Christmas

*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.*

## 2004

11 March	Lions of Frenchs Forest Golf Day, Wakehurst Golf Club
24 March	Government House launch of MND Week
26 March	Bankstown Golf Club fundraiser for Ian Fuller & MNDA
27 March	Nick's Party in Sydney - Nick McLoughlin
<b>28 March - 3 April MND WEEK 2004</b>	
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
6 April	Evening at Parliament House hosted by the Speaker of the Legislative Assembly with guest speaker, Alan Jones
29 April	Russell Vale Golf Club - Carolyn Woods
14 - 16 May	Quilt for MND raffle at Thornleigh Community Centre
19 June	Five Dock Auction & Dinner - Angie Helmers
<b>21 June</b>	<b>ALS/MND Global Awareness Day</b>
3 July	Charity Auction & Dinner - Charmaine Misso

### WANTED: PHOTOS - MAKE A DIFFERENCE FOR MND

**The ALS March of Faces Banner** is a travelling exhibit in the USA that features a 170-foot photographic display of people with ALS from all over the world. It represents the courageous men and women who have been stricken with the brutal disease known in America as Amyotrophic Lateral Sclerosis (ALS), and in Australia, New Zealand, Britain and Canada, as Motor Neurone Disease (MND). Visit the ALS March of Faces at <http://march-of-faces.org>.

This idea was introduced to Australia by MNDA VIC member Jackie Williams, as the "Australia's March of MND Faces" Banner. It is a touching and compelling awareness-raising exhibit.

Australian State banners, each displaying twenty photos, are used throughout each State and can also be brought together for events such as the MND/ALS International Symposium in Melbourne Nov 2002.

Banners completed so far:

NSW 3, QLD 2, SA 1 & WA 1. TAS contributions total 7, so we are spreading the word there! VIC has just completed banner number 8 and NSW only needs 7 photos to complete number 4. Jackie is still collecting photos, so please keep them coming in! It's not too late for you to be a part of this exceptional photographic project to advance MND Awareness.

### How to participate in the MND March of Faces Project

Contact the MNDA office on 9743 5872 and ask for a form to send with a photograph of yourself (or your PALS), any size, color or black and white is fine. You are welcome to include family or caregivers in the photo if you wish.

Your photo will be returned to you after it has been copied for printing on the banner.

Only seven more photos are needed to complete the fourth NSW banner which will be displayed with the other three at NSW Government House at the MND Week launch.

## Handy hints

### The MNDA NSW Carers Kit

Approximately 100 kits have been sent out this year to carers of people with MND and another 40 have gone out to health professionals. It is available either printed as sections that can be placed in a folder, or on a CD for the computer.

The Carers Kit, which contains useful information about all aspects of living with MND, has proved to be an extremely popular resource. Individual sections can be requested at the time they are needed, rather than being swamped with too much information.

The Carers Kit is free for carers of people living with MND in NSW, and \$50 (printed version) or \$25 (CD) for health professionals.

### Taxi Transport Subsidy

Taxi subsidy is available for people who are unable to use public transport because of a qualifying severe and permanent disability. Application forms must be completed by your Doctor.

If your taxi subsidy has been coded 'M50' for a wheelchair accessible taxi, you must call the Central booking office on 02 8332 0200 within Sydney, or 1800 043 187 (free call outside the Sydney metropolitan area).

If you have complaints about the quality of a taxi service, call the NSW Ministry of Transport's Taxi Complaints Hotline 1800 648 478.

### *For that long day out ...*

*The Uribag is a discreet, pocket-sized, leakproof urinal for men. Alternatively, a leg bag strapped inside the trousers is a secret no one would notice.*

*The Uribag F for women can be used with minimal need for privacy and fits into a handbag.*

### EZ KEYS

I would like to share this information with anyone out there who's facing difficulty using a computer mouse and keyboard. As a compulsive chatterbox, I feel literally tongue tied with my speech now ridiculously reduced to mmm and uhuh. My typing ability isn't much better with my arms as weak as they are. I find typg like th nt v gd bec no 1 new wat I ws sayg. And then along came EZ KEYS, a computer program used by Stephen Hawking to write his books on the black holes and the universe. So the sky's the limit and much more. EZ KEYS for WINDOWS is available through the Spastic Centre of NSW and what's more, they'll come out to your home and install it for you and show you how to use it. What could be Ezier? The software is free but the adaptive hardware costs around \$1000 but, hey, it's Christmas.

Firstly, you don't have to handle a mouse and yet you can open documents and files, select parts of a document, copy and paste, print and scan, write emails and surf the net like anyone else. All you need is a small switch (I use a jellybean switch which can be bought at Dick Smith for \$90) which you can place anywhere and you click it with any part of your body. I hold it in my left hand and click with the ball of my right hand but you could place it on the bed and click with your arm or place it on the floor and click with your foot, etc. A line moves down the screen and you click where you want it to stop. Then an arrow moves across the screen and you click again when it reaches the thing you want. There are functions for left and right clicks, double click, etc but you only press the switch once for each one.

Secondly, you don't need a keyboard or even an onscreen keyboard. Instead you have four rows of letters efficiently arranged according to frequency of use. Each row is briefly highlighted so you click the one you want. Then each letter is highlighted so you click the one you need.

Thirdly it predicts words so you rarely have to type the whole word. And if it doesn't know the word you type in full, it will learn it so it can predict next time. The program also predicts word order and learns the sentences you type. For example when I type 'for', 'example' will also come up and when I type 'home', 'care' will appear on the side so you click it if you want it.

Other useful features include prefixes such as er, ly, tion, ful, ing, ment, ed, 's. And like all keyboards it has numbers, punctuation, shift key, CAPSLOCK, tab key, etc. You can also store useful words and phrases for your daily communication such as thank you, please help me to....., could you bring me the....., my hovercraft is full of eels!

All in all, EZ KEYS enables you to use the computer in full as if you can operate a mouse and keyboard but all you have to do is press a switch.

And the bottom line is, next time you get those visitors with their tea and biscuit and their small talk, you can quietly type out "I'm very sorry but I feel tired all of a sudden and have to rest now." As soon as they're out the door you can go back to what you were doing on your computer.

*Zana Abdul Rahman  
Croydon Park*

**Hornsby**

The next meeting will be held at Thornleigh Community Centre on Wednesday 18 Feb at 11 am.

Speakers will be Elizabeth Herbert (MND Week 2004 activities) and Janet Nash (MND research). The meeting will also provide an opportunity to meet Mary Butcher, the new Regional Advisor for the Northern Metropolitan Area who will take over the role as coordinator of the support group.

*Anita Richter*

**Newcastle & Hunter**

The group has had three recent successful fundraisers with another one planned right after our Christmas break. First off the rank was our fun night at Abermain Bowling

Club which was a good money maker. Then it was our annual Christmas Fete at Weston Workers Club, with 27 stalls there was plenty of variety. Then it was a mini garage sale with plenty of onlookers arriving long before the designated time.

Our next project is our annual bowls day held at the Abermain Bowling Club. This is always a terrific day with Bowls then lunch, then more bowls.

Already steps are in place for MND Week in March/April.

To all readers and other support groups we wish you a safe Merry Christmas and a Happy New Year.

*Alistair Fyfe*

**Panania**

This year's Christmas party at Revesby Workers Club was a relaxed and happy event with Janelle again running the hilarious games and we all enjoyed lunch together.

Sadly the group is going to lose the wonderful support we have had from Ross, Janelle and David. Ross and Janelle are moving to the country where they will take up new job positions. We all would like to thank them for their great support in the last two years and wish them great success in their future lives.

Next meeting will be February 3.

*Caroline Gleig*

**Riverina & South West Slopes**

Support Group meets bi monthly in Wagga Wagga and I had my first trip to join them for this in October. It was an opportunity to meet members and families from Wagga, Junee, Cootamundra and Griffith whom I would normally only see once a year.

Guest speakers are present at occasional meetings but it is mostly seen as a chance to spend a couple of hours with people drawn together by a common experience. Attending the support group enables people to talk about how they are managing and a chance to share tips with each other. It was obvious that strong friendships have been made and members often phone each other between meetings.

I would like to thank the Support Group for welcoming me and hope it won't be too long before I get there again.

*Allison Pearson*

**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 EST. 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> for a chat room which is 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.

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**Riverina & South West Slopes**

Wes Russell  
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**Hornsby**

(Mary Butcher)  
and

**Panania**

(Caroline Gleig)  
and

**Penrith & Blue Mountains**  
(Ruth Quaken)

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

**Northern Rivers**

*Changing Faces - Helen Gates has taken over the reins as president of the group and secretary, Noelene Kidd, is heading off to a new life in sunny Queensland. Welcome Helen, and thank you Noelene for all your care and time.*

**Dear Editor**

Travelling is still fun.

Annette, my wife, and I have been keen travellers for many years. In 2000, and some time after I had been diagnosed with MND, we were in Europe and I thought that would be the last time I would visit British shores. That has certainly not been the case and we have been overseas each year since, despite the increased difficulty with mobility. So this article I hope will provide both information and encouragement to those who may be a little hesitant in setting out.

For a start, you simply cannot rely on what hotels describe as

'handicapped facilities'. You need to be very specific in what your particular requirements are, and if they are not available, be prepared to improvise. The most important thing to check on is whether they have a portable shower hose. If so

you can generally cope one way or the other. I have showered sitting on the loo, the edge of the bath and in an assortment of plastic chairs.

We have found, particularly in Europe, the cheaper, newer hotels have the best facilities. Holiday Inn Express for instance are mainly modern purpose built hotels with excellent facilities, including a flat floor open shower. They are often not in the most scenic places but they are always conveniently located. EU regulations require all places offering accommodation of hotel standard to provide handicapped facilities by 1.1.2004. I could not find out what exactly those standards have to be but at least it is a step in the right direction.

The same applies to some extent in Australia. Earlier this year we drove to Broome and back. We did 14,000 kms in all and travelled via northern NSW and on to Longreach, Mt Isa to Kakadu. Then to Katherine, Kununurra to Broome and back via The Centre, Coober Pedy, Port Augusta and back to Sydney via Broken Hill and Dubbo. A fantastic trip over six weeks and I showered comfortably every single night! There was very little I could not do. They got me on boats at Yellow Waters in Kakadu, and another day trip out of



Kununurra up the Ord River, into a light aircraft to fly over the Bungle Bungles and the Argyle Lake and diamond mine, to the 'Sounds of Silence' dinner at Uluru and in a tented camp at Western Plains Zoo at Dubbo which has excellent disabled facilities.

I should explain we now have a portable hoist which packs easily into two bags. We have found it invaluable and it got me into a Cessna at Kununurra airport to fly over the Kimberly. It gets me in and out of bed etc although next time we will be more diligent in checking that the bed is high enough off the ground, or that the hotel will make

it so.

Which brings me to flying long distances. The airlines are pretty good and give good support on the ground

and on the aircraft. We take our manual wheelchair to the bridge to make sure it is put in the hold last. We take the cushions and footrest with us on the plane to make sure they don't get lost. You are then transferred onto a small aircraft wheelchair, by slide board or manhandling, which gets you to your seat. Better to have a seat on the aisle.

Toileting on the aircraft can be a problem of course but is manageable. On Cathay Pacific this year the cabin attendants were very worried that I seemingly had not 'been' and when Annette eventually told them how I coped they were not only relieved but highly amused. I won't go into details here but equipment is available!

The most important piece of advice I can pass on however is to plan very thoroughly and pre-book everything so you are not caught short. We still drive everywhere, but there are tour companies here and overseas who specialise in helping people with mobility problems.

As that fellow says on TV, "go on - get out there !"

*Malcolm Hodgkinson  
Neutral Bay*

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

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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*