THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

mnd New South Wales

FORUM

December 2006

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Ten years of dedicated service

The Board and staff of MNDA NSW celebrated ten years of service by Janet Nash and Anita Richter at a special function in October. Former Family Support Manager, Carol Birks spoke about the achievements both have had over the years.

"**Janet Nash** started working at MNDA NSW in 1995 as the Patient Care Coordinator. Janet was the first professionally employed person providing information and assistance to people with MND. She turned her practical and hardworking nature to addressing the equipment needs of people with MND running the service single handed for many years with very little room and resources. The way she developed the service was instrumental to the support we have received in recent years to grow and maintain the service. The Newsletter became a professional publication as Janet took on the role of editor.

Janet's research background and scientific skills ensured that MNDA NSW could be confident that information given had a sound basis and of course she was always able to answer those tricky questions! Her contribution to the growth of the MND Association has been immense and it is only fitting that Janet is now using all her valuable skills to grow the MND Research Institute of Australia and is still working tirelessly towards hope for a future without MND

For over a year Janet was the only paid person providing support for people all around NSW; in other words the only regional advisor, equipment and information officer!

Janet Nash (left) and Anita Richter at the celebration of their ten years dedicated service in October 2006

Anita Richter was employed in October 1996 to conduct a needs survey of people with MND and their carers. The results of this survey formed the framework of a fledgling family support service. Over the next two years, regional advisors and admin staff were employed, regular newly diagnosed evenings commenced, the annual conference and rural and regional seminars for health providers were established, there were field trips using the Royal Flying Doctor Service, and the first MND model of care in NSW was established at Neringah and Hornsby Hospitals.

It was Anita's passion, skills and absolute commitment to people living with MND and their carers that drove these programs and the continuing development of family support. Over the last few years Anita has been instrumental in driving the objectives of a very ambitious strategic plan - to establish and develop the Care for Carers program, the Carers Kit and a spectrum of care, education and support for MND carers.

Anita and Janet should be proud of their contribution to this Association. I know that all the staff, volunteers, board members, patrons, people with MND, carers past and present have truly appreciated their hard work, commitment and passion and most importantly have enjoyed their friendship."

The office of the Motor Neurone Disease Association of New South Wales will be closed for Christmas from 4pm Friday 22 December to Monday 1 January. Normal office hours will resume on Tuesday 2 January 2007. 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

Christmas is almost upon us and brings with it the end of an extremely productive and busy year. In the past few months we have welcomed **Gina Svolos**, Family Support Manager, and **Jenny Judd**, Regional Advisor, to the Association. Gina and Jenny introduce themselves on page 4 of this edition of *Forum*.

The decision by MNDA NSW to support the recommendations of the **Lockhart Review** during the Senate Inquiry into the Review and, in particular, board member Paul Brock's efforts in pushing for that support, has helped keep motor neurone disease in the national media.

As stated in the MNDA NSW submission to the Inquiry, *"Whilst we understand that there are a broad range of views within our membership we believe that the only way to fulfil our vision of a world free from MND is to investigate all legal and ethical research avenues……The Lockhart Review Committee's recommendations dramatically broaden avenues for scientific research into spinal cord injuries and diseases such as motor neurone disease, particularly options relating to somatic cell nuclear transfer."*

During October, MNDA NSW was invited to appear before the Inquiry. At the time of this edition of *Forum* going to press the Lockhart recommendations had been passed by the Senate with just two amendments and were due to be put to the House of Representatives.

The **17th International Symposium on ALS/MND** in Japan starts on 29 November. A representative from MNDA NSW, Anita Richter, will be presenting to the Allied Health Professionals Forum run in conjunction with the Symposium (see page 6). This is the second year our Family Support staff have had papers accepted, demonstrating a growing interest in the innovative work being undertaken by MNDA NSW.

As part of our advocacy campaign the State government through the Department of Ageing, Disability and Home Care (DADHC) has established a **Motor Neurone Disease Advisory Group**. The Terms of Reference include: improved response to meet the needs of people with MND; an allocation of $200,000 to Community Options to pilot a case management model; review pathways to care; report to the Minister on outcomes of current initiatives; consider any specific matter referred to the Group by the Minister and identify emerging systemic issues for people with MND.

This initiative marks a year of **outstanding support** for people with MND by **DADHC** and we thank the Minister, John Della Bosca for his ongoing interest and support.

By the time you receive this newsletter our Annual General Meeting (AGM) will have been conducted and our Members Christmas Party will have been celebrated. I will provide an update from the AGM in the next edition of *Forum*.

To all those who have lost loved ones and friends to MND I extend, on behalf of the Board and Staff, our deepest sympathy.

We wish you all a happy and safe Christmas and New Year. Thank you to all our donors for their support during 2006.

Graham Opie
Chief Executive Officer

3rd National
Motor Neurone
Disease
Conference

19 June 2007

Esplanade
Hotel
Fremantle

www.mndawa.iinet.net.au

The MonStar Cup is an exciting event being being organised by MNDA NSW supporter **Hamish Pearce.** It will be held on **20 March** at **Pennant Hills Golf Course**, and half the proceeds from the day will be donated to MNDA NSW.

Chat to your golfing friends and invite them to register with you for the Cup. For more information see **www.monstar.com** or contact MNDA NSW on 8877 0999.

BiPAP rental assistance from MNDA NSW

The MND Association of NSW has recently received a very generous one-off payment from the Department of Ageing, Disability and Home Care. This money will be used to develop a new package to better support members with MND who are experiencing respiratory symptoms.

The package will include increasing the current monthly BiPAP rental assistance from $50 to $100 per month, assisting with the purchase of masks (up to 50 per cent of the cost of masks) and purchase or rental of hospital beds and tilt-in-space shower commode chairs for use by members following respiratory assessment.

For BiPAP rental assistance, Mayohealthcare have been asked to reduce the invoice price for people currently renting by $100 from 1 August 2006 and to invoice the MND Association for that amount each month. If you are renting from another company please continue to send us a copy of your receipt and you will be eligible for reimbursement of $100 per month from 1 August.

Please do not hesitate to contact Gina Svolos on 8877 0904 if you would like more information.

MND Week
2007

6-12 May

Tips for Assessing Health Information

The Internet can be a valuable source of health information that can help you understand your health issues as well as those of your friends or families.

Health information on web sites should not take the place of your health provider/patient relationship and should not be used for self-diagnosis. There are many factors that need to be considered in relation to your health and the diagnosis of any condition. You should use the Internet as an information resource and ask a health professional about any issues raised by the information or anything that you don't understand, such as medical terms. You should also avoid any online health practitioner who proposes to diagnose or treat you without a proper physical examination and a full consultation regarding your medical history.

The following questions may help you to decide if health information on the Internet is of good quality:

1. Why was it created (purpose)?

- does the site state why it was developed?
- who developed the site? Can you find any apparent bias or conflict?
- who is it aimed at and pitched for - health professionals, general public, young people, children?

2. Who is responsible for the information (authority)?

- is it clearly stated who is responsible for the information content?
- what are the author's qualifications and can they be verified?
- are there contact details such as email, postal details, phone numbers, including toll free? Is feedback and interaction encouraged?
- is the publisher a reputable one?
- does the site provide details of the quality assurance process used to ensure that information on the site meets a high standard?
- what are the qualifications of the authors and people who approve information for the site?
- do the producers of the site have a commercial interest, for example, companies often have good information but only about their products?
- is information provided on the site's privacy policies and are there appropriate disclaimers?

3. Is the information up-to-date?

- how often is the site updated?
- is the date clearly visible?
- are there other features to indicate that information is kept up-to-date?
- is all of this information clear and easy to understand?

4. Is the subject coverage complete and in-depth?

- does it include links to other reputable sites?
- for diseases or conditions, does it indicate:
  - the causes
  - how to prevent it
  - how to recognise it
  - how it is diagnosed
  - treatments/procedures (and alternatives)
  - after care and quality of life issues associated with the disease or condition
- does it provide balanced and unbiased information without being opinionated?
- does it have good coverage of topics?
- is it clear what sources of information were used to develop the page/study/publication?
- how extensive is the coverage?
- for information on treatments, does it cover:
  - how treatments work
  - what are their benefits and risks
  - what are the effects on quality of life, and
  - what is the likely effect of non-treatment?
- are there alternatives for obtaining the information, such as phoning or having reports posted to you?
- is there help available, either by instructions on the site or via email?

5. How easy is the site to use?

- is it easy to navigate the site and find information?
- is it carefully laid out and are there any additional features such as images to enhance the information?
- is it easy to know where you are in the site and to find additional information on the topic?

From Health Insite, the Australian Government
gateway to reliable health information at
www.healthinsite.gov.au

***Dr Dominic Rowe** from the Multidisciplinary MND Clinic, Department of Neurology, Royal North Shore Hospital, Sydney suggests a **Four Question Test** for deciding whether or not to undertake a particular therapy or treatment:*

What is the premise (or fact) behind the proposed therapy?	**How is the therapy going to help me?**
How might the therapy hurt me?	**What has the person got to gain by offering the therapy to me?**

Family Support

Gina Svolos
Manager,
Family Support

I commenced working as the Family Support Manager on 6 November 2006 and since this time have managed to meet some of you and hope to meet many more of you over the next few months. I have replaced Carol Birks who was in this position for almost seven years.

I know I have '*big shoes to fill*', as has been said to me on more than one occasion, and I look forward to continuing to develop and enhance the services offered by Family Support.

Prior to commencing at MNDA NSW I worked at Royal Prince Alfred Hospital developing support services for people with cancer. I have also worked at the Sacred Heart Hospice where I had contact with people living with MND. I am a social worker and have worked mainly in hospitals and community services with people who are experiencing illness and disability so I hope that this experience will be useful in my role with MNDA.

Dates for the Diary

13 February	Information Evening for People Newly Diagnosed and their families and friends *MNDA NSW Centre Gladesville*
19 February	Living on after MND *MNDA NSW Centre Gladesville*
5-6 March (commencing)	Link and Learn - Hunter Region *Hunter Resort*
20 March	MonStar Cup *Pennant Hills Golf Course*
6-12 May	MND Week
11 May	Cornflower Blue Day
21 June	MND Global Day *Drawing day of the MND Global Day Raffle*

If you would like assistance with travel to attend any of the family support sessions or would like us to organise an MND information session in your region, please speak to your Regional Advisor.

Beach Wheelchairs / All Terrain Wheelchairs
Life Without Barriers, in partnership with Gosford City Council, have all terrain wheelchairs at various Central Coast beaches. Contact Gosford City Council Lifeguard Services 4385 8106 (m-f) or Leanne Reading, Life Without Barriers 4353 0126.

On my first day I had the privilege to attend the **Learn Now Live Well** program held at Gladesville along with 20 of our members and carers. This was a really good introduction and provided information about many aspects of living with MND. I learnt a lot from the speakers which included a physiotherapist, occupational therapist, speech pathologist, registered nurses and MNDA Family Support staff who gave many hints and tips on managing with MND. I also learnt a great deal from the people who attended the day as they asked questions and shared information about their own experiences. The program was held over two consecutive Mondays and I would recommend it to others. We will be running another program in 2007.

I have also had the opportunity to visit some of the Multidisciplinary MND Clinics where I again met many of our members who allowed me to sit in on their discussions with various health professionals. The staff who work in these clinics are extremely dedicated and I was impressed with their level of knowledge about MND. Having worked in other hospital clinics I found the MND clinics very well developed and I am sure they are a great service to people with MND.

I would also like to welcome our newest Regional Advisor, Jenny Judd who is replacing Ruth Quaken. From what I hear Ruth will be sadly missed by many but it is great that we have replaced her with another experienced health professional. Jenny will be in contact with members previously supported by Ruth once she settles in and completes her orientation.

I would be happy to hear from anyone who has any comments, thoughts or ideas about Family Support. I will be working full-time at the Gladesville Centre.

Gina Svolos
Manager Family Support

Introducing Jenny Judd

Jenny Judd
Regional Advisor

I've started working at MNDA NSW after twelve years as a diversional therapist in palliative care at Neringah Hospital. I also have degrees in psychology and literature and have a varied work history including working in pathology and running a large specialist medical practice.

I am the proud mother of two, now grown up, daughters and live in the lower Blue Mountains on a acre of lovely land. Here I have my first ever garden - so gardening advice is always gratefully received.

I look forward to a long and fruitful association with MNDA NSW.

Jenny Judd
Regional Advisor

Link and Learn
Hunter
Region

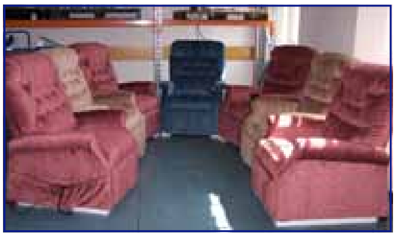
5-6 March
2007

Equipment

The MNDA NSW Equipment Stocktake for 2006 has finished and I would like to thank the members and families who replied. I received 71 per cent feedback from the letter that was sent out in September.

New Purchases

The equipment pool has recently taken delivery of ten new raiser recliner armchairs purchased with funds donated by **City Tattersalls**. Three were sent out within 18 hours of delivery to members needing them urgently, whilst the other seven were sent out over the next week. These chairs assist people to remain independent and sometimes, when the thought of going to bed for a short sleep seems too difficult, the chair can be reclined and used as an alternative.



Seven of the ten new raiser recliner armchairs purchased with funds donated by City Tattersalls

Photos needed

On that note, I would like to ask anyone who has photos of themselves or their loved one using a raiser recliner armchair whether it be having a nap, celebrating a special occasion or just normal life activities to forward a copy to me by post or by email. I am hoping to do a talk in the near future regarding the use of these chairs and as everyone is aware, a picture says a thousand words. I would also need signed permission to use the photo but do not necessarily need to state names. My email address is equipment@mndnsw.asn.au.

Holiday Closing Dates

Finally, a reminder to all that the equipment service will only be closed from 23 December 2006 until 2 January 2007.

There may be delays due to couriers being busy during Christmas or suppliers closing over this period but we hope to have as little disruption as possible during this time.

Merry Christmas

Trevor and I would like to wish everyone a very safe and happy Christmas and New Year holiday.

Maree Hibbert
Equipment Services Coordinator

Information Evening for People Newly Diagnosed and their families and friends
MNDA NSW Centre Gladesville
13 February 2007

Farewell and thank you from Carol Birks, Manager, Family Support (to October 2006)

Carol Birks

It was with mixed emotions that I moved down the corridor to my new office at Gladesville in early October to take on the role of National Executive Director with MND Australia. Delighted to have the opportunity to remain within the MND family and to face new challenges but sad to say goodbye to the NSW team and people living with MND in NSW.

I enjoyed almost seven years as Manager Family Support and have had the privilege of working with some very special and dedicated people during that time. It has been a time of great change and growth for MNDANSW. The Board, staff, volunteers and members have embraced that change and grown too. The family support team has always been a great source of inspiration to me as we worked together to develop new initiatives to better support people living with MND, their families and the health care providers involved in their care. I thank them, and of course Graham and all staff and volunteers, for their dedication and support.

More importantly I have met so many inspiring and special people living with MND during that time. Their strength, courage and often humour in the face of a disease that has such a devastating impact on all facets of life have always been the driving force for me. I take this opportunity to say farewell and to thank you all.

It is with confidence that I hand over to Gina, the new Family Support Manager, who has skills and experience to further develop and enhance family support. I am confident too that you, the MND community in NSW, will continue to teach and guide Gina as you did me.

….and from Ruth Quaken, Regional Advisor

Ruth Quaken

I have enjoyed my time working at the MND Association and I will take with me very fond memories of working here as I have had the privilege to meet and work with some truly exceptional people.

Watching the Association grow has been very rewarding and I will continue to read the Forum with anticipation as the Association continues to grow and develop, and hope that it will not be too long before an effective treatment for MND is developed. I would like to take this chance to wish everyone well and say thank you for a very rewarding six years.

Carers News

Living on after MND - February 2007

Have you lost a loved one with MND during the last 12 months? Do you feel you would like to talk with others who are in the same situation?

Caring for a loved one with MND involves unique challenges.

MNDA NSW would like to acknowledge the unequalled support that carers dedicate to the care of their loved one with MND throughout the course of the disease by offering a lunch and get together for former carers.

This lunch will provide an opportunity to meet old friends from MNDA NSW and others who have shared a similar experience. After lunch there will be a short talk and discussion about some of the feelings you may be experiencing through bereavement.

Invitations will be sent to carers who have lost their loved one through MND in 2006.

Where: MNDA NSW Centre, Building 4, Old Gladesville Hospital, Gladesville
Date: Monday **19 February 2007**
Time: 12 noon for lunch until 3pm
RSVP: Would be appreciated by 12 February for catering purposes. There is no charge for lunch or parking. Contact MNDA NSW ph 8877 0999 or Freecall 1800 777 175

Living on after MND - an opportunity to meet others who have shared a similar experience

19 February 2007

Link and Learn - March 2007

Hunter Region - An Educational, Support and Selfcare Program for Rural and Regional MND Carers

We are pleased to announce that arrangements for **Link and Learn Hunter Region 2007** are now in place.

The Hunter Resort in Hunter Valley will be the venue for the two-day (one night) residential workshop. The workshop will be held on **5-6 March** and will provide education to carers of people with MND. This Program also includes pampering activities and the opportunity to share ideas with others in the same situation. MNDA NSW staff and experienced local health care professionals will provide education on managing MND during the workshop. This two-day 'live in' workshop offers an opportunity for carers from a large geographic area to come together.

The workshop will be followed by **six weekly sessions** of telephone group linkup of approximately one hour duration each. This enables participants to continue to share ideas and ask questions without the need to travel. Both the workshop and the telephone group linkup are provided at no cost to participants.

Christina Jason, Regional Advisor for the area will be the key member of the family support team involved with this phase of the project. She will be working with Regional Advisor, Allison Pearson.

Christina and Allison will liaise with local Carers Respite Centres to provide respite care in the home to enable carers of people with MND to participate in the workshop and, wherever necessary, the telephone linkup that follows. Costs for this Program, including additional staff hours, are funded through a grant from the NSW Health Care for Carers Projects. It would not be possible through our regular resources. **Link and Learn** provides the opportunity for MNDA NSW to extend better service to rural/regional carers.

Previous Carers Programs have shown the value of support and education for carers of people with MND. This benefit ultimately flows on to the person with MND being cared for. We hope that many carers of people with MND in the Hunter and surrounding areas will participate in this Program.

We will be sending out flyers to carers in the region early next year. However, we invite carers in the region to register their interest now by contacting Christina Jason, phone 4921 4157 or Gina Svolos, Family Support Manager, on Freecall 1800 777 175.

MNDA NSW at the 17th International Symposium on ALS/MND

Government funding received by MNDA NSW during the past five years has been instrumental in developing the resources of the Association. Two rounds of funding through the NSW Health Carers Projects have enabled the development of Carers Workshops, the Carers Kit and the Link and Learn Program.

The Carers Kit has become an important resource not only for people living with MND, but also for health and community care professionals involved in their care. It has also been integral to the development of other programs.

The Link and Learn Program funding has enabled training in telephone group support for the family support team and these skills will be used to develop future programs.

I will be presenting a short paper with the theme – 'Building a Spectrum of Support for Carers of People with MND' at the Allied Health Professionals Forum, a satellite meeting of the 17th International Symposium on ALS/MND to be held in Yokohama from 29 November to 3 December. I will also be giving a short presentation on the development of MND Special Interest Groups for health and community care professionals at another satellite meeting of the Symposium.

The program for the Symposium is most interesting and I am sure I will come back with ideas and materials to help in the future development of services for MNDA NSW.

Anita Richter
Special Projects/Carers Services

Carers News (Cont'd)

Cruising Sydney Harbour with Sailors with DisABILITIES

On 22 October a merry band of people with MND and their families embarked on a lovely sailing boat for a cruise and sail around Sydney Harbour and up to the Heads. It was a good day for sailing and the crew from Sailors with DisABILITIES made everyone welcome.

If you are interested in cruising Sydney Harbour at a future MND Sailors with DisABILITIES sailing day call MNDA NSW on 8877 0999

Carers Workshops

Our last Carers Workshop for 2006 was held during September. The Workshop consisted of four sessions, held weekly, and was well received by the carers participating.

The Carers Workshops provide the opportunity to learn about strategies to help with caring, equipment and services that can help with caring at home and to share ideas, feelings and the support of others in the same situation. The next Carers Workshop will be held during 2007.

Support Group Contacts

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Coffs Harbour
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Illawarra
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and

Northern Sydney *(Hornsby)*
Jo Fowler
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and

Western Sydney
Jenny Judd
jennyj@mndnsw.asn.au

are coordinated through the MNDA office.
Ph: 02 8877 0999 or
Freecall 1800 777 175

Support Groups

Central West Support Group Visits Dubbo Zoo

As reported in the September edition of ***Forum***, the Central West Support Group held its October meeting at the Dubbo Zoo. Those interested in a tour of the zoo met at 10am and drove independently through the grounds, which for a few of us was a first visit. We were able to linger in front of enclosures where our favourite creatures were lolling around in the sun, enjoying the gorgeous spring weather.

Everyone gathered at midday in the function centre where we were joined by members of the Rotary Club of Dubbo Macquarie for a very enjoyable lunch and a talk on MND. Members, their carers, extended family and guests came from Dubbo, Orange, Mudgee, Young and Cowra.

Sincere thanks go to the Rotary Club of Dubbo Macquarie for sponsoring this event. It was a great way for a support group to get together and certainly was a meeting with a difference. The food and the venue were excellent and a very pleasant day was had by all. It is always a special treat to see animals like elephants, giraffes, lions, zebras in such close proximity and it was extra special to end our day with a coffee on the terrace outside the function centre where for an hour the spider monkeys put on a great display for us. Congratulations and thanks also to **Vivienne Nichols** of Dubbo who organised this special day.

Fern Linden
Regional Advisor

Northern Sydney Support Group

It is only a few weeks until Christmas so we would like to take this opportunity to wish everyone peace and happiness together at this festive time of year. Also we would like to say thank you to all group members and our guest speakers this year for their continuing interest and support and making our meetings so successful.

As this edition of *Forum* is going to press, we are planning our final meeting of the year for early December. We are having our own Christmas get-together where we will share some happy times around the table.

Bi-monthly meetings will continue next year. Morning tea is provided, usually there is a guest speaker and there is time for interaction with others. Dates for next year's meetings are yet to be confirmed. So don't forget to check in *Forum* or on the website for the latest information and other important dates for your diary. We are always glad to welcome new members to the group. If you would like to join or learn more about what happens in a Support Group, contact Jo Fowler, Regional Advisor on 8877 0909 or the 'Info Line' at the Gladesville Centre on 8877 0999.

Jo Fowler
Regional Advisor

Flat Chat with an Etran Board

by Annie Woodger

(For Ken Woodger and with grateful thanks to the Warragul JayCees who manufacture Etran Boards)

It arrived with none of the fanfare of the hugely expensive computer communication aides. There were no training sessions, big boxes, manuals or dire warnings about battery charging.

A flat Perspex frame, the Etran Board was a scarcely noticeable addition to our family's collection of aides – electric recliner, wheelchairs, hoist, commode chair, urine bottles and all the normal accoutrements of the gourmet peg feeder.

In fact, 'the Board', as it came to be known, was so unobtrusive, it lay unused for some days, until someone picked up the short but adequate instructions and we gave it a go.

For my dad, 'the Board' became a crucial communication tool. His form of motor neurone disease meant he could not speak or use his hands and arms. He could not write so we relied at first, on huge homemade alphabet boards to converse with him. He also used a code for yes and no by moving his foot.

Later he tried an electronic Lightwriter that was sophisticated but exhausting and hugely frustrating when operated via scanner and foot pedal.

My father and I had some very mundane and, very profound, interchanges using the simple Etran Board - from where to find a particular key in his sock drawer to fundamental questions about his treatment and his death.

Never a great talker, my dad was not prone to lengthy Etran messages. He looked for the shortest and most effective way to communicate his meaning. Some of the scribbled notes of our conversations have the pithy elegance or anguished brevity of a Haiku poem. When each letter is an effort, you do not waste them.

When my dad was in palliative care we continued to use the Etran Board, although it became harder as even his eye movement deteriorated. During these days, he asked me, (using the Board) to write an article about the Etran Board for this MND Newsletter.

He was always puzzled why so few people used this very simple and relatively cheap communication board.

It surprised him that often health professionals treating or caring for him in hospitals or in home care had not seen or heard of Etran Boards before.

He wanted the Etran Board to be better understood and used by more people so he and those in his situation could communicate directly with more friends and professional carers.

How It Works

The Etran Board is methodical and slow - but was effective both for dad and me. The Etran system is simple and the instructions take about 10-15 minutes to read and absorb. This is the *only* training required.

The Board is a flat, clear Perspex frame about 50 x 40cm. Each corner is marked with a square of colour (blue, orange, green or red). Each segment has letters and numbers, which are colour coded. (see photograph) The Board is held so that the person who cannot speak (the 'Etranner') reads the letters backwards. The Etranner and the speaking person look at each other through the space in the middle of the Perspex frame.

To indicate a letter, the Etranner looks at the segment that the letter is in. If it is a blue coloured letter, he/she then looks at the blue corner. The speaker then knows that the Etranner is indicating the blue letter in that particular segment.

Whilst there are some refinements to this process, that is the nub of it. Check the instructions for the details. The process speeds up as the Etranner becomes more familiar with the position of the back to front letters.

I also found it vital to write down each letter as we went. It is important to concentrate on getting each new letter, rather than remembering the one before.

Dad's much used Etran Board, the letters slightly rubbed off and the corner broken after an altercation with a Recliner Rocker, now hangs on my wall.

It doesn't remind me of his inability to speak. Rather, it reminds me of the conversations – ordinary, funny, frustrated and close - that we continued to have without speech.

Like Dad, I have puzzled over why people might be reluctant to use this simple device. Using an Etran Board may be confronting or uncomfortable because you have to sit closer than you normally would in conversation. It also means that you have to look the person in the eye in a very direct way.

For me, using 'the Board' was actually a way for me to be closer to my dad but I can understand why the closeness that the Board necessitates could be a challenge for others.

However, if you can overcome the initial discomfort, read the short instructions and give the Etran Board a go, you will probably end up communicating with an incredibly grateful person with a great deal to tell you.

Reprinted with permission from MND NEWS, the newsletter of MNDA Vic

Etran Boards and sample communication charts are available from MNDA NSW

Motor Neurone Disease Research Institute of Australia Inc

The Motor Neurone Disease Research Institute of Australia Inc (MNDRIA) was established in 1986 to promote medical and scientific research into motor neurone disease to work towards a world without MND. All funds available through MNDRIA come from contributions from Australian State MND Associations, bequests and donations.

Each year, grants are advertised and applications are assessed by the Medical/Scientific Committee to determine which projects have the greatest merit.

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After careful consideration, the Committee has allocated a total of $370,000 for distribution by MNDRIA for MND research in Australia in 2007. $185,000 will go to grants in aid, $175,000 to postdoctoral Fellowships, and $10,000 will support the Australian MND Registry (AMNDR). AMNDR will also be supported in 2008 and 2009.

Congratulations to the successful recipients.

Grants in aid

Dr Gilles Guillemin
St Vincent's Hospital, Sydney
Involvement of the kynurenine pathway in ALS

Professor Nigel Laing
West Australian Institute for Medical Research
Whole genome amplification and PCR screening of a WA cohort of 97 familial and sporadic ALS patient DNA samples

Professor Grant Morahan
West Australian Institute for Medical Research
Discovery of novel genes causing MND

ZO-EE MND RESEARCH GRANT
Professor James Vickers
Menzies Research Institute, University of Tasmania
Unravelling the cellular pathology underlying neuronal degeneration in MND

Dr Bryce Vissel
Garvan Institute of Medical Research, Sydney
The Effect of Kainate Receptor RNA editing in excitotoxic cell death of motor neurons in MND.

Dr Robyn Wallace
Queensland Brain Institute, University of QLD
Assessing therapeutic peptides in a mouse model of MND

MND VICTORIA RESEARCH GRANT
Professor Kate White
Faculty of Nursing & Midwifery, University of Sydney
Letter on future care: development of an individualised disease specific future care plan for MND

Three MND Fellowships will be funded by MNDRIA in 2007

BILL GOLE MND RESEARCH FELLOWSHIP 2007-08
Dr Julia Morahan
Department of Pathology, University of Sydney
Somatic mutations in motor neuron disease?

Continuing Fellowships

MND RESEARCH INSTITUTE FELLOWSHIP
Dr Julie Atkin
Howard Florey Institute, University of Melbourne
The mechanism by which hSOD1 mutations induce degeneration of NSC-34 motor neurons
The initial funding provided by MNDRIA has led to the award of an NH&MRC project grant of $514,500 over three years (2007-09) to continue this study.

BILL GOLE MND RESEARCH FELLOWSHIP 2006-07
Dr Ian Blair
ANZAC Research Institute, Concord, NSW
Identification of novel genes involved in motor neuron degeneration

For more details about MNDRIA, phone Janet Nash, MNDRIA Executive Officer on 02 8877 0990, email info@mndresearch.asn.au or visit www.mndresearch.asn.au

From *Advance*: The Annual Review of the MND Research Institute of Australia, December 2006.

MNDA NSW

Introducing our
Global Day Raffle
To be drawn on Thursday 21st June 2007

1st prize: Beautiful hand-made quilt for double bed with autumn tones (215 cm x 215 cm) donated by the Hunters Hill Quilters : Value $2,000

2nd prize: 1 dozen 2005 Sauvignon Blanc donated by Blue Metal Vineyard and a set of 4 Trace Flute Waterford Crystal Glasses donated by Janice Scheinecker : Value $400

3rd prize: Bessemer 34 cm Baking Dish Base and 34 cm Lid : Value $350

Order your tickets today!
Phone 1800 777 175

All tickets
$5 each

Special prize of a **Techline MP3/ MP4 Multi-audio Player** for the person who sells the most books. (Each book has 10 tickets)

MND Week 6 - 12 May 2007
Cornflower Blue Day 11 May 2007

MND Week next year has moved to May and this gives us a little longer for planning.

However, once the New Year comes and goes it will be time to really think about what we can do to make MND Week 2007 a success.

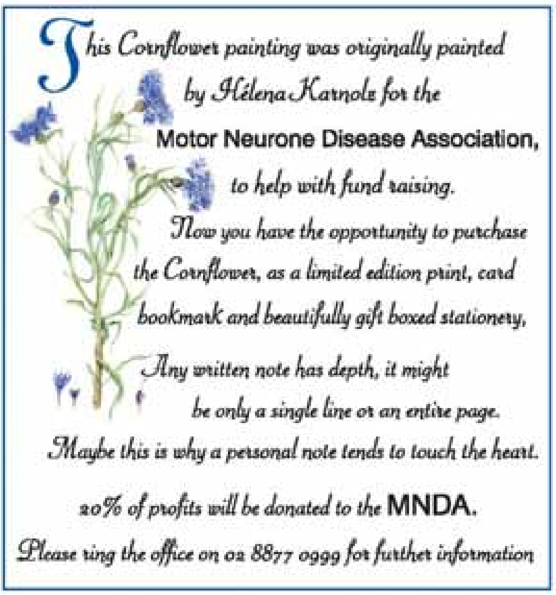
We are looking at a few changes next year and would appreciate your input. Some ideas that have been suggested include:

Combining the day of the Launch with the March of Faces

Having the Launch on a weekend day so that people who work can attend.

Having a fundraising event called 'Walk to D'Feet MND' which has been held successfully in other states and overseas

I am also interested in ideas for speakers at the Launch and any other ideas for ways to create more public interest. If you have any comments to make then please email me: *judyf@mndnsw.asn.au* or drop me a line in the post.



This Cornflower painting was originally painted
by Hélena Karnolz for the
Motor Neurone Disease Association,
to help with fund raising.
Now you have the opportunity to purchase
the Cornflower, as a limited edition print, card
bookmark and beautifully gift boxed stationery,
Any written note has depth, it might
be only a single line or an entire page.
Maybe this is why a personal note tends to touch the heart.
20% of profits will be donated to the MNDA.
Please ring the office on 02 8877 0999 for further information

There are a number of ways you can help during MND Week….

….Merchandise

No matter where you live – town or country – selling merchandise during MND Week is a great way to spread the word and also make some money for the organisation. If you would like to participate you can order merchandise on consignment. This means we send you your order with an invoice which states how much your order will sell for. When you have sold as much as you can you return the unsold merchandise and deposit the money collected in the bank. Instructions are sent with the merchandise order. Judy Ford will again visit country areas in April and deliver your orders and, at the same time, take the opportunity to get to meet you and say thank you.

….Railway Stations

We plan to concentrate our selling of wrist bands, lanyards, cornflowers and other merchandise around the main railway stations on Friday 11 May from 7 to 9 am. We need station coordinators to organise small teams to cover these stations. If you can help please contact either Judy or Roslyn.

….Shopping Centres

We plan to concentrate our efforts with the independent shopping centres this year. If you are one of our keen shopping centre coordinators and would like to continue this year or if you have a shopping centre near home and would like to help sell merchandise and collect donations there, please let us know.

….Schools

Do you know, or have contact with, a school that might be keen to help raise money during MND Week? Students might hold a Mufti Day with a gold coin collection. Or they might be allowed to wear something blue for the day. Perhaps the Students' Association would like to sell our wrist bands or socks. Please let us know and we will make contact with the school.

….Events

Do you have an idea for an event we could hold during MND Week that would help create awareness and raise funds for the organisation? If so, please let us know. Call Roslyn Adams or Judy Ford on 8877 0999.

The Sloane family have donated the lovely quilt displayed in the reception area at the MNDA NSW Centre Gladesville

New Volunteer Positions Vacant

We are looking for enthusiastic volunteers to join a team and form a Fundraising Support Group in city and country areas, particularly in the **Central West**, **Central Coast** and **South Coast** (Nowra and beyond).

For each group we will need a Group Coordinator, Treasurer and Secretary to lead each group in fundraising. We are also looking for new volunteers for each support group. These groups can be part of the current Support Groups for members and carers or they can be totally new.

To fill these positions we are looking for dedicated enthusiastic volunteers with an outgoing personality, who enjoy having a good time whilst raising funds for a dedicated organisation.

For more information on the positions contact Judy Ford, Fundraising Manager, phone 8877 0912 or 1800 777 175.

City to Surf 2006

Thank you to all of our wonderful supporters including the family and friends of Mark Gooley and Margaret Pinch who made it such a special day.

Look again - fun at the gallery

The Inverell Art Gallery was the place to be back in June when Nola Turner and her friends from the Mercy Associates held a wonderful fundraiser for MNDA NSW. Those who attended were treated to a variety of fun activities and at the centre of the event was the beautiful quilt made by Nola.

Sister Coral Headley introducing Sam Cox who provided a demonstration of the popular hobby of scrapbooking at the Inverell event for MND

After a short talk about the Motor Neurone Disease Association of NSW by Judy Ford the guests were given a talk and demonstration of the popular hobby of Scrapbooking by Sam Cox. This was followed by Kate Jorgenson talking about skin care and nails. In case people were feeling a bit sleepy Nick King got everyone up on their feet and showed them a few moves in Tai Chi.

Lunch was typical of Aussie Country Fare - a smorgasbord of the most delicious home cooked dishes you could imagine and far too much to choose from. They ranged from hearty soups to sandwiches, slices and savouries. Yum!

After drawing the major prize raffle – the quilt – local health educator Denise Pickett spoke on Women's Health. Local wine producer Rae Thomas from New England Estate Wines told us about her life and travels and Fran Harris ended the day with ideas about hair care.

The beautiful quilt made by Nola Turner.

It certainly was a day full of treats and we are most grateful for the time and effort given by Nola Turner and Sister Coral Headly in particular.

Camel caravan seen at Port Kembla Hospital

The Illawarra Support Group had to blink twice to check that they were still sitting in the Activities Room at Port Kembla Hospital and not in the middle of the Sahara Desert when the Flaming Phoenix troupe joined them in September.

This group of drummers and dancers arrived in a long colourful line led by the head of a camel and accompanied by many camel noises! Then, with the use of some African drums, a graceful belly dancer and audience participation, these amusing ladies took us on a trip over the desert complete with memories of Rudolph Valentino.

A night of razzle dazzle to remember

Fundraising manager, Judy Ford was invited to attend the 6th Annual Bar Awards Gala Dinner at the Hilton Hotel in September. Why? Because the organiser, David Spanton of Spanton Media Group was to donate $10 from every ticket sold to MNDA NSW. Judy was there to collect the cheque and say a few words about motor neurone disease to the packed ballroom. "It was like attending the Oscars", she said. "The women were dressed in the most amazing outfits and it was obvious that if you were a top bartender then you had to wear a hat!".

David Spanton presenting cheque to Judy Ford at the Bar Awards

Judy had a great time meeting people from the industry and was very grateful to David, whose uncle has motor neurone disease, for making this donation possible.

Hugo's sets the scene for a fun night

Hugo's Bar in the heart of Kings Cross was a most suitable venue for the MNDA NSW Cocktail Party and Art Auction. Guests were greeted at the door with a delicious passionfruit based cocktail as they moved in to the cosy and intimate bar. Seventeen original paintings were displayed ready for a fun silent auction. Justine Mossman, whose partner died twelve months ago from MND, organised the complimentary venue and food.

This was a special night in more ways than one because it was the inaugural joint effort of MNDA NSW and MND Australia. It is hoped that this will be the first of many combined fundraisers.

Hugo's organiser and volunteer Debra Larizza (right), assisted by Roslyn Adams (left), said she was delighted with the evening. "It was lovely to see so many new faces and watch as people participated in the auction."

Disco inferno is a blazing success

In October marketing staff at American Express had a wonderful night living it up in the 70s style and at the same time raising money for MNDA NSW. The party 'Disco Inferno' was held at Darling Harbour and guests, clothed in fancy dress danced to a DJ, and had fun with a silent auction. Thank you to Lesley Longley who organised the whole event.

Mailbag

Dear Editor,

Recently, Bob Delaney, who has motor neurone disease, challenged the elements to ride 100km to support the Northern Rivers Support Group of the MND Association of New South Wales. This disease has affected his speech and swallowing, but, so far, his limbs are not greatly affected. He is an experienced bike rider and loves nothing better than to get out in the country with his friends and ride his bike. Let us hope he can continue to do this for a long time.

He and three friends, Kim Evans, Debbie Melino and Zelinda Brown headed off from Trinity College, where Bob is a teacher, at 9.45am on 12 September, through a 'guard of honour' of students, staff and friends. With rain and wind threatening, they were suitably attired in wet weather gear. The ride took them from Lismore to Jiggi, The Channon, back to Lismore, then on to Woodlawn, Numulgi and home. During their ride, Bob managed two flat tyres and an angry magpie.....twice. The rain cleared to only one shower, but the wind was a real challenge.

They riders arrived back at Trinity at around 1.30pm to the welcome of students and staff, after riding 75 km - had a short break and a coffee and then headed off to finish their journey.

Brother Peter, Principal, Trinity Catholic College Lismore, with Bob Delaney.

They rode 103km and raised over $3000.

Recently, a cheque for money raised by the students and staff of Trinity College was presented to Bob and me to a standing ovation for Bob's courageous effort. This was a very moving experience. We were both overwhelmed by the response from the students and staff of Trinity and the wider community, who also supported the ride. We would like to thank everyone from the bottom of our hearts.

I wish Bob and his family well for the future.

Helen Gates,
Northern Rivers Support Group

Send in your letter for mailbag to The Editor, Forum, MNDA NSW, Locked Bag 5005, Gladesville NSW 1675

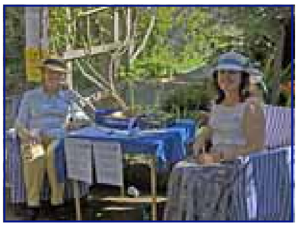
Blooming garden attracts visitors

The beautiful garden of Suzanne and Bob Ballinger was again open to the public one weekend in September. Visitors were plentiful and, unlike the year before, the weather was kind on both days.

Open Garden Weekend Garden party volunteers Jennifer Foster and Michelle Paton

The garden was open to the public through the Open Garden Scheme with proceeds from the day going to MNDA NSW.

We had some familiar faces helping to make the day a success including Helena Karnolz, botanical artist; Heather and Bernard Pryor from Iris Haven with plants and gift items; Alex Hearl, hand-made cards; and Kim Smith with products from Lavendilli-Blue. Other stalls included MND merchandise, a huge selection of second hand books, a plant stall, a sausage sizzle for a quick snack and a delicious afternoon tea and sandwiches for those who wanted to sit for a while and enjoy the delightful surroundings.



Open Garden Weekend Garden party volunteers Gail Busuttil and Kerry Gilmore

It was wonderful to see so many volunteers helping on both days including some of our own staff and a very big thank you to the Ballinger Family for this wonderful opportunity to raise awareness and funds!

ACKNOWLEDGEMENT
We wish to thank
Snap Printing, Artarmon
for their generous support.

Editor: Penny Waterson