



# FORUM

September 2006

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## New communication devices...

### ...with thanks to the Ross Divett Foundation

The MND Association of NSW has just taken delivery of specifically adapted communication devices by Technability, purchased with funding from the **Ross Divett Foundation** (see *Forum March 2006*). This Foundation is an initiative by Centrelink Staff to support the Australian community.

The new devices include **nine** switch adapted remote controlled door chimes that enable a member to remotely contact a carer with the press of a special switch and **five** laser/cap head pointers which can be used for infrared pointing in communication.

Thank you to the **Ross Divett Foundation** for enabling MNDA NSW to be increasingly able to lend specialised aids, free of charge to people living with MND, at the time when they are needed.

*Maree Hibbert  
Equipment Service Coordinator*



## The yummy smell of a sausage sizzle grabs Bunnings shoppers

Member Pat Ball and her husband Warren organised for MND to run a BBQ at Thornleigh Bunnings early in July.

Bunnings very kindly provided the BBQ and gas, Pat and Warren organised the sausages and onions, and MNDA NSW provided the rest including staff members Roslyn Adams, Caroline Gleig and Judy Ford. Judy's husband Peter also assisted and together with Warren, cooked some very yummy sausages.



*(l-r) Roslyn Adams, Warren Ball, Caroline Gleig,  
Peter Ford and Pat Ball*

Luckily the weather, although cool and crisp, was sunny and the strong smell of onions cooking enticed the shoppers over for a quick snack before going home. Over three hundred sausage sandwiches were sold as well as the great MND socks and cornflowers.

Thank you Pat and Warren for a great idea!



The charitable organisation *Sailors with disAbilities* have invited people with MND to cruise Sydney Harbour with their volunteers on **Sunday 22 October** from 1-4pm. Places on board will be limited, so please contact Anita Richter on 8877 0999 as soon as possible if you would like to 'join the crew'.

*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

Welcome to the September edition of *Forum* which, to my reckoning, puts us well and truly over the winter hump. The past few months have been fairly dramatic (as it always seems of late) for MNDA NSW with the initiating of new programs and an upswing in our **advocacy** efforts, particularly around the continuum of care and respite.

Additionally, on a national front, there has been a strengthening of a coordinated approach to literature and the development of a **new national logo**.

The logo, which features prominently on the front cover of this edition of *Forum* was recommended to MNDA Australia for adoption by the **Executive Management Group (EMG)** as a way of presenting a unified look for MND across Australia. Members of the EMG represent the management of MND state, territory and the national associations. Each member of the EMG agreed to put forward the new logo to their respective boards for adoption and the MNDA NSW Board agreed to move to the new image in June 2006. It will be phased in as existing printed stocks are depleted.

Also over the past few months, the **Lockhart Review** has been debated vigorously and thanks largely to the efforts of MNDA NSW board member Dr Paul Brock AM we have been able sift through the facts and fallacies enabling all people with MND their families and carers the opportunity to make informed decisions. More information about the Review and reasons behind the recent media coverage is included on page 3 of this edition of *Forum*.

During September we will be saying farewell to **Carol Birks**, our Family Support Manager, who has accepted a position with the Motor Neurone Disease Association of Australia as the National Executive Director. Carol has worked for MNDA NSW for almost seven years and we will be sorry to see her go, however she is not going far (geographically) and will still be based at Gladesville in her new role. A farewell to Carol from the Family Support Team appears on page 7. I'm sure that you will all join me in wishing Carol well.

In the last edition of *Forum* I mentioned that we were undergoing the Quality Improvement Council (QIC) Standards and Accreditation Program. We have received their initial report and the next step will be to report on the implementation of recommendations. If you would like to know more about this process please call me.

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

*Graham Opie*  
Chief Executive Officer

## Thank you! Our equipment loan pool is growing

I would like to thank all those wonderful people who responded to my letter in June for financial help to purchase much needed equipment. I promised I would let you know in this newsletter what we have been able to purchase and our plans for future purchases.

MNDA NSW has recently been able to purchase four electric hi lo medical beds, three alternating air mattresses, specialised pressure cushions and a variety of bathroom equipment for loan to its members through the Equipment Loan Pool.

All items are presently out on loan to members and, to help meet continued demand for equipment, future purchases will include large items such as raiser recliner armchairs and electric hoists. Smaller items to be purchased for use in bathrooms will include shower commodes and shower chairs.

All equipment purchased has been given a unique identification number and is available for loan to members of the Association with MND free of charge, after a health professional assessment.

Thank you again from all of us for your contribution.

*Judy Ford*  
Fundraising Manager

## Introducing Anne Jones

Hi, my name is Anne Jones and I am very excited about taking on the new position of Receptionist/Administration Officer with MNDA NSW. Chances are you will talk to me when you ring so I would like to introduce myself.

I am married with two children and have been living locally for 15 years. I will be working part-time between the hours of 9.30am and 1.30pm Monday to Friday. I have a strong background in administration and office management.

My employment history is varied, and includes working in the market research industry for nine years, working for a major financial institution for 17 years, being a registered Family Day Carer for two years as well as doing many and varied temping roles prior to taking on this position in June 2006.

I love my new role here and look forward to hearing from you in the future.

*Anne Jones*  
Receptionist/Administration Officer



*Anne Jones, MNDA  
NSW Receptionist /  
Administration Officer*

Congratulations  
to  
**Nick  
McLoughlin**  
on his  
appointment to  
the Board of  
MNDA NSW

## Recent parliamentary and media interest in stem cells

### Legislation Review Committee

On 17 June 2005, the former Minister for Ageing, the Hon Julie Bishop MP, appointed a six-member committee to conduct independent reviews of Australia's *Prohibition of Human Cloning Act 2002* and the *Research Involving Human Embryos Act 2002*.

The committee was Chaired by retired Federal Court judge, the late the Hon John Lockhart AO QC and was known as the Legislation Review Committee. Other members are Professor Loane Skene, a lawyer and ethicist; who was Deputy Chair and has become Chair of the committee following the death of Justice Lockhart; Associate Professor Ian Kerridge, a clinical ethicist; Professor Barry Marshall, Nobel Prize Winner for Medicine who is a specialist gastroenterologist and community advocate; Professor Peter Schofield, a neuroscientist; and Associate Professor Pamela McCombe, a clinical neurologist.

The Lockhart Review recommended that the existing ban on human reproductive cloning be maintained by legislation. It also recommended that somatic cell nuclear transfer (SCNT), which is sometimes described as 'therapeutic cloning', should be legalised in Australia.

Consequently, much of the recent media interest has focused on Recommendation 23 of the Legislation Review Committee:

*Human somatic cell nuclear transfer should be permitted, under licence, to create and use human embryo clones for research, training and clinical application, including the production of human embryonic stem cells, as long as the activity satisfies all the criteria outlined in the amended Act and these embryos are not implanted into the body of a woman or allowed to develop for more than 14 days.*

**The Board of MND NSW supports this recommendation**

**MNDA NSW and CAMRA strongly support a ban on human reproductive cloning but strongly support therapeutic cloning.**

### Coalition for the Advancement of Medical Research Australia

The Coalition for the Advancement of Medical Research Australia (CAMRA) was created in 2001, to advocate for the advancement of breakthrough research in regenerative medicine in order to cure disease and alleviate suffering.

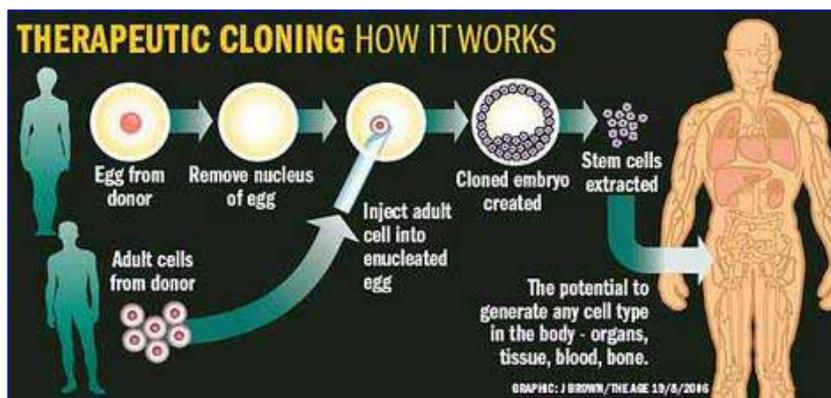
CAMRA comprises nationally-recognised patient organisations, universities, scientific societies, foundations, and individuals with life-threatening illnesses and disorders for which there are currently no cures. MNDA NSW is a member of CAMRA.

CAMRA endorses and encourages research with both embryonic and adult stem cells into the cause, treatment and prevention of diabetes, Parkinson's disease, spinal cord injury, motor neurone disease and many other neurodegenerative and neuromuscular disorders.

### Human somatic cell nuclear transfer

MNDA NSW and CAMRA strongly support a ban on human reproductive cloning but strongly support therapeutic cloning.

Therapeutic cloning is the term used to describe the transfer of the nucleus from an adult cell into an empty egg in order to generate self-compatible stem cells, also known as embryonic stem (ES) cells.



(Brown 2006)

This kind of research is variously referred to as Therapeutic Cloning, Somatic Cell Nuclear Transfer (SCNT) (see illustration), or Cell Nuclear Replacement (CNR).

CAMRA prefers the term 'Patient-specific stem cell research' (PSS cells).

### **References**

Brown, J. 2006. Therapeutic cloning how it works, *The Age*, 19 August.

Coalition for the Advancement of Medical Research Australia (CAMRA) <http://www.camra.org.au/>

The Legislation Review Committee of Australia's *Prohibition of Human Cloning Act 2002* and the *Research Involving Human Embryos Act 2002* <http://www.lockhartreview.com.au>

## Recent parliamentary and media interest in stem cells (cont'd)

### Stem cells, cloning and related issues

*Extract from Stem cells, cloning and related issues - the basics (National Health and Medical Research Council 2006).*

#### What are stem cells?

- Stem cells are 'unspecialised' cells that have the unique potential to develop into 'specialised' cell types in the body (for example blood cells, muscle cells or nerve cells). This can be either for growth and development, or for replenishment and repair.
- Stem cells occur at all stages of human development, from embryo to adult - but their versatility and numbers tend to decrease with age.
- Given the right conditions in the body or the laboratory, stem cells (unlike muscle cells, nerve cells and or blood cells) can replicate themselves many times over.
- When a stem cell replicates, the resulting cells can either remain as stem cells or can become specialised cells.

#### Why is stem cell research important?

Doctors and scientists believe that stem cell research has the potential to revolutionise medical treatment in two main areas:

**Better understanding of diseases such as cancer.** By understanding how stem cells transform into the specialised cells that make us what we are, we can better understand and cure diseases such as cancer. Cancer is a major example of where this process has gone wrong.

**Making cells and tissues to replace or regenerate tissues that are either diseased or have been destroyed.** Organ transplants can be used for this in some cases, but the demand for suitable donated organs exceeds supply. Stem cells offer the possibility of a source of replacement cells that could be used to treat diseases and conditions from Parkinson's disease to heart disease, spinal cord injury, diabetes and arthritis.

#### What are embryonic stem cells and adult stem cells?

##### Embryonic stem cells

- Embryonic stem cells, as their name suggests, are derived from human embryos. They have the potential to develop into all cell types in the body.
- In Australia, embryonic stem cells are derived from human embryos that are left over from assisted reproductive technology (ART) treatment programs and have been donated to research by the couple for whom they were created. They are not derived from eggs fertilised in a woman's body.
- As part of a couple's infertility treatment these ART embryos would have been placed in cold storage within 2–6 days of fertilisation.

##### Adult stem cells

- Adult stem cells (often called somatic stem cells) are found in many organs and tissues of the body, where their main function is to replace cells that have died in the tissue or organ where they are located.
- Adult stem cells extracted from the bone marrow of patients or compatible donors are used routinely in treating diseases such as leukaemia. (All blood cells in the body are manufactured in the bone marrow).
- Umbilical cord blood, extracted from the umbilical cord and placenta when a baby is born, is a rich source of adult stem cells. These cells may be useful for medical research or therapeutic use in the future. In the USA in particular, a whole industry has developed where people are having cord blood frozen for possible use later in life.

#### Embryonic and adult stem cells in medical research

Most experts think that research involving both embryonic and adult stem cells will lead to a new understanding of, and new therapeutic treatments for, injury and disease.

- The advantages of embryonic stem cells are that they can be grown in the laboratory for long periods and be made to change into most types of tissue found in the human body.
  - Some people have concerns with the use of embryonic stem cells because deriving stem cells from embryos destroys the embryo.
  - Adult stem cells are present in the body in low numbers, and, with the exception of bone marrow, are difficult to obtain.
  - Although adult stem cells are currently difficult to grow in the laboratory and cannot develop into every kind of cell, recent developments in this field are promising.
- The regulation of stem cell research in Australia**
- The use of human or animal cell lines in health and medical research is covered by guidelines and other statements issued by the National Health and Medical Research Council (NHMRC).
  - The use of human embryos to derive human embryonic stem cell lines for research is governed by the Research Involving Human Embryos Act 2002.
  - Only excess ART embryos can be used in such research. Embryos cannot be created purely for the purposes of research.

**A Date for  
Your  
Diary**

MND Week  
2007

6-12 May

## Recent parliamentary and media interest in stem cells (cont'd)

### What about cloning?

Human cloning, in any form, is banned in Australia under the Prohibition of Human Cloning Act 2002.

### Types of human cloning

There two main types of human cloning: reproductive cloning (for the purposes of creating a cloned child); and what is commonly termed 'therapeutic cloning' (cloning for research purposes). Both begin in the same way, which is a process known as somatic cell nuclear transfer (SCNT).

SCNT involves obtaining a woman's egg cell in the same way eggs are obtained for ART treatment, then removing the genetic material (DNA) from it and replacing it with DNA from a cell from a person's body (e.g. a skin cell). With the right triggers this new cell can be turned into an embryo.

Reproductive cloning would involve placing the resulting embryo into a woman's uterus. If the clone implants and develops to birth, a new human being is created whose nuclear DNA is identical to one person (the original body cell donor) instead of from two people, as happens with natural fertilisation. There is no scientific evidence that a human being has ever been cloned. Furthermore, attempts to

clone other primates have been unsuccessful. Many people find reproductive cloning completely unacceptable.

With 'therapeutic cloning' the resultant embryo is allowed to develop in the laboratory for a few days, after which stem cells would be harvested from it and encouraged to develop into human tissue or (possibly in the future) a complete organ for transplant.

Extracting stem cells from a cloned embryo would result in the death of the embryo, which has the same ethical implications noted earlier for harvesting stem cells from excess ART embryos.

The main theoretical advantage of 'therapeutic cloning' is that it overcomes the 'rejection' hurdle that exists with current organ or tissue transplants.

The Prohibition of Human Cloning Act 2002 does not distinguish between reproductive and 'therapeutic' cloning.

### Reference

National Health and Medical Research Council, 2006. *Stem cells, cloning and related issues - the basics*, Accessed 29 August 2006, <http://www.nhmrc.gov.au/embryos/stemcells/index.htm>

The Art Auction and Cocktail Party on 2 November will raise funds for MND

### What are you doing on Friday 11 May 2007?

This is next year's Cornflower Blue Day and we are looking for volunteers to help sell merchandise at railway stations and shopping centres. Can you please help? Phone Roslyn today and put your name down so that we can start planning for the best MND Week yet! Phone 02 8877 0908 or email [roslyna@mndnsw.asn.au](mailto:roslyna@mndnsw.asn.au)



*Participants of the Spring Luncheon at the Star Room, Darling Harbour had spectacular views, a wonderful lunch and lots of information about creating a picture story of their lives (l to r) Susie Knowles, Wendy Hunter, Bev Hoddinott, Scott Hoddinott and Roslyn Adams*

## M.N.D.A ART AUCTION AND COCKTAIL PARTY

Thursday 2 November 2006  
at Hugo's Lounge Sky Bar  
33 Bayswater Rd  
Potts Point  
6.30 pm - 9.00 pm  
\$75 p.p.  
(includes food and drinks)

An interesting and diverse collection of original paintings will be auctioned silently.

Don't miss out on this worthwhile fundraising event for MND NSW and MND Australia. As space is limited tickets will only be available for 100 guests.

For further information or to book your tickets please phone Judy Ford or Roslyn Adams on 8877 0999.



**Open Garden for MND**  
16-17 September

**Suzanne and Bob Ballinger's Open Garden for MND at Homeleigh, 17 Linden Avenue, Pymble**

## Family Support

One of the major objectives of family support is to promote best possible care and support for people living with MND and their families through advocacy and by providing information and education for health and community care providers.

### 2006 National MND Conference

The annual National MND Conference is a unique opportunity for MNDA staff, researchers and health and community care providers from Australia and New Zealand to come together to exchange ideas and to hear about the latest MND developments. The Conference is always preceded by a National Family Support Meeting to provide an opportunity for the extended MND 'family' from each State and New Zealand to get together. This year, the meeting was as vibrant as ever with 26 MNDA staff from New Zealand, Western Australia, South Australia, Victoria and New South Wales exchanging ideas and new initiatives.

The 2006 National MND Conference was held in Sydney and attracted 175 delegates. The presentations were varied and interesting and demonstrated an increasing commitment to providing the best possible care and support for people living with MND.

The Conference entitled '**Advances, Initiatives and Challenges**' commenced with an inspiring presentation from Dr Dominic Rowe, neurologist, director of the MND Clinic at the Royal North Shore Hospital and Chairman of the MND Research Institute of Australia. His presentation **Fact and Fallacy** set the scene by giving an overview of MND. This presentation not only highlighted therapies available that do make a difference to survival and quality of life for people living with MND, but also highlighted treatment fallacies. The **Advances** session included a presentation from Dr Steve Vujic, who gave an overview of the research he is conducting at the Prince of Wales Hospital into the site of origin and patterns of neuronal degeneration in MND to assist with early diagnosis. Jennica Winhammer then gave an overview of the research she is undertaking together with Dr Dominic Rowe at the Royal North Shore Hospital and Associate Professor Matthew Kiernan at the Prince of Wales Hospital looking at the mechanisms of nocturnal hypoventilation in MND.

The **Initiatives** session included an overview of **Treatment Options for Excessive Saliva**, a common problem for many people with MND, by

Anita McKinstry from Austin Health, Melbourne. The presentation confirmed that Botox injections into the parotid glands (the glands that supply the salivary glands) can be beneficial if more traditional medications do not address the problem. Associate Professor Roger Pamphlett, Royal Prince Alfred Hospital, presented preliminary results on **Risk Factors for MND** from his work with the Australian MND DNA Bank, to which many of you have contributed. The next presentation, **Enhancing Social Support to improve quality of life for patients and caregivers**, by Robin Ray from Latrobe University, Melbourne, explored the effect of social support on quality of life. It confirmed that social support was essential, especially for the carer, to enable people with MND to be cared for at home throughout their journey with MND. Peer support was found to be particularly beneficial. This confirms the importance of the MNDA NSW support programs designed specifically for carers and I would encourage all carers to consider attending the carers activities and workshops.

The final presentation was a moving and inspiring talk from Leida Williams and Jenny Fuller from the Hospice Care Association of Southern Tasmania entitled **A brush with life**. The presentation highlighted the important role of volunteers in helping people with MND with the emotional impact of the disease. The case study described how support for a woman with MND from volunteers to develop a new painting skill helped her to focus on her abilities and lifted her mood and sense of self worth.

The **Challenges** session in the afternoon opened with a thought provoking presentation from Dianne McKissock from The Bereavement Care Centre, Sydney, on **MND Families – Holding it all together: emotional challenges and helpful strategies**. A presentation from Lesley Burcher a Regional Advisor from MNDA Victoria entitled **Palliative Care it's all about perception** discussed the varied perceptions the community has about palliative care. The take home message highlighted the importance of palliative care from diagnosis onwards, for organisations to promote and make links with palliative care services and for people with MND and their families to promote their positive palliative care experiences - maybe you could send in your positive experiences with your palliative care service for inclusion in the next Forum!



A plenary session at the MND National Conference held in Sydney in June 2006 (above), and a group of participants viewing the poster presentations (below).



The 2nd National MND Conference Book of Abstracts can be downloaded from the website at [mndnsw.asn.au](http://mndnsw.asn.au)

## Family Support (Cont'd)

Roxanne Maule, speech pathologist, Calvary Health Care, Melbourne presented **PEG: What difference will it make?** highlighting the benefits of PEG and the importance of timing. Finally Nicole Hutchinson nurse coordinator of the MND Clinic in Brisbane presented **The Queensland Experience** demonstrating the expansion of MND multi-disciplinary clinics nationally and their benefits to people living with MND.

The Conference included workshops for the three MND Special Interest Groups: Independent Living; Communication, Swallowing and Nutrition; and Psychosocial and Supportive Care. These enabled health professionals to get together to discuss latest interventions related to their area of expertise. The Conference had a truly national feel with delegates networking and sharing their MND experiences during breaks where they continued to learn by viewing the Trade and Poster Displays. The 2007 National MND Conference will be hosted by MND Western Australia and will further promote the exchange of ideas nationally.

### **Non-invasive Positive Pressure Ventilation**

One of the most powerful overall messages repeated in a number of presentations was that non-invasive positive pressure ventilation (NIPPV or BiPAP) can have a positive effect on survival. It is well documented that it has a positive effect on quality of life contributing towards better sleep, more energy during the day and possibly clearer thinking. Now there is increasing research that NIPPV is likely to increase length of life.

NIPPV delivers room air at some pressure via a nose mask similar to the machines and masks used by people who snore. People with MND need to be assessed prior to accessing this form of treatment so a referral to a respiratory physician is required from the general practitioner or neurologist. All the MND Multidisciplinary Clinics have links to a respiratory team and most local

hospitals have a respiratory physician. It is a good idea to be referred fairly early for baseline measurements of respiratory function followed by regular reviews. An overnight stay in hospital may be necessary to assess respiratory function during sleep.

If the respiratory doctor recommends NIPPV a suitable machine and mask will be recommended and organised. Some people may be eligible to access the machine through the government funded Program of Appliances for Disabled People (PADP) scheme and we recommend that you discuss this with the prescribing doctor. Others may have to buy the masks and pay a monthly rental for the machine, as the machines are expensive to purchase and a rental agreement ensures cover for repairs.

MNDA NSW recently received a very generous one-off payment from the Department of Ageing, Disability and Home Care and has decided to use this money to develop a new package to better support people with MND who are experiencing respiratory symptoms. The package will include increasing the current monthly NIPPV rental assistance from \$50 to \$100 per month, assisting with the purchase of masks (up to 50 per cent of cost) and purchasing or renting hospital beds and tilt-in-space shower commode chairs for use by people with breathing difficulties if required.

Not everyone chooses to use NIPPV, however, for those who do we hope that this package goes some way to relieving financial burden and improving quality of life.

If you would like further information on respiratory symptoms and/or NIPPV please ring the MNDA NSW 'info line' or speak to your regional advisor.

*Carol Birks  
Manager Family Support*

## Thank you Carol from the Family Support Team

On 27 September Carol Birks will leave her position as the Manager of Family Support Services MNDA NSW to become the National Executive Director of the Motor Neurone Disease Association of Australia (MNDAA). Carol will bring to her new role the many skills she has used so effectively to develop the Family Support Service in NSW since 1999. She leaves the Association in a strong position for the future.

Under Carol's guidance Family Support has seen many positive developments including an increase in the number of Regional Advisors to improve support for people with

MND and their families throughout NSW and the ACT, a more effective equipment loan service and improved information technology support for service delivery.

Carol has also been successful in sourcing government funding for projects that have developed the capacity of the Association to improve information and support for its members.

Carol's skills and attributes include a genuine concern for and commitment to people with MND and their families, experience and knowledge of the needs of the MND community, an efficiency in management and a

capacity to liaise with government and non-government organisations.

Carol is well regarded by her team for her warmth, patience, support and encouragement. As a manager she encouraged the personal strengths and capabilities of individual staff members, blending these to form an effective and committed team.

Although we are sad that Carol will no longer be our Manager of Family Support Services we are very pleased that Carol will continue to use her skills in the best interest of the MND community. Good luck Carol!

The 3rd National MND Conference will be hosted by MNDA WA in Perth in 2007

## Carers News

### Talking with Young People About MND

*Have you been diagnosed with MND and have young or adolescent children?*

*Have you cared for a person with MND as well as having young or adolescent children in the family?*

*Did you help care for a parent with MND when you were in your teens?*

*If so....*

Please contact Anita Richter on 8877 0999 if you would like to be involved in interviews or focus groups to help us to plan the Resource Kit:

**'Talking with Young People about MND'**. We are working on this project with the MND Association of Victoria. This Kit will include guidelines for young people, parents, teachers, counsellors and palliative care providers.

## Equipment Loan Pool Stocktake 2006

The staff of the MND NSW Equipment Loan Pool will be conducting their annual stock take during the week commencing 9 October 2006. Disruption to the usual loan service will be kept to a minimum but there may be delays on equipment deliveries around this time.

Members who currently have equipment loaned to them by the Association will receive a **letter in the mail on about 20 September** which will include an **Equipment Loan List**.

The MND NSW identification number, equipment description and loan date for each piece of equipment will be included on this list.

Members or their carers are asked to check the Equipment Loan List. Any discrepancies can be marked on the list.

The list needs to be **returned** to the Equipment loan pool staff by post or fax 02 9816 2077 by **9 October**.

Contact Maree Hibbert or Trevor Rakuraku on Ph 1800 777 175 or 02 8877 0907 if you have any queries.

### Past Carers Meeting - Correction

Please note that the date for the Past Carers Meeting is **29 September**. It will be held at the Gladesville Centre between 12-2pm. A small contribution of food towards lunch would be appreciated. MND NSW CEO, Graham Opie, will give a short talk **'Future Directions for the MND Association of NSW'**. If you would like further information contact Anita Richter on 8877 0999.

### Counselling for Carers

Short term Counselling for carers is available through the Commonwealth Carer Resource Centre. Fees are based on need, not the ability to pay. Phone 1800 242 636 to discuss your particular needs and circumstances.

### Counselling for carers of someone with a genetic disability

For carers of the **small** percentage of people diagnosed with Familial ALS. Help may be available through the 'Filling the Void' project of the Association of Genetic Support of Australasia (AGSA). This project supports carers of people with a genetic condition. Seminars are arranged in rural areas and sibling workshops, telegroup and face-to-face counselling. For further information, phone Laurie Taylor, AGSA Project Officer, on 02 9211 1462, email [projects@agsa-geneticsupport.org.au](mailto:projects@agsa-geneticsupport.org.au) or visit [www.agsa-geneticsupport.org.au](http://www.agsa-geneticsupport.org.au)

### Young people

Young people who have a parent living with MND may benefit by visiting the following website: [www.youngcarersnsw.asn.au](http://www.youngcarersnsw.asn.au)

### MND NSW Regional Advisors

Remember that your MND NSW Regional Advisor is also available to 'talk things through' or to help you to link in with services in your area including counselling.

### Farewell and congratulations to Joan Hughes, CEO of Carers NSW

During the last 10 years MND NSW has worked closely with Carers NSW through the NSW Carers Coalition. During this time we have seen many developments in government and community awareness of the needs of carers. In NSW, this change has been largely driven through the leadership of Joan Hughes CEO of Carers NSW. After 13 years in the role, Joan is moving on to assume the role of CEO of Carers Australia where she will continue to advance the needs of carers nationally. MND NSW would like to thank Joan for the support and assistance extended to our organisation – good luck Joan!

For more information on the NSW Carers Coalition see [www.carersnsw.asn.au](http://www.carersnsw.asn.au)

The Past Carers Meeting will be held on **29 September** at the Gladesville Centre between 12-2pm. All past carers are welcome.

## Carers News (Cont'd)

### Advance Notice for Link and Learn

Preparations are now underway for the **Newcastle/Hunter/Northern New South Wales** phase of the Link and Learn Program. This is the third phase of the Link and Learn Project which was held in the Illawarra/Southern NSW in 2005 and in the Riverina and South West Plains in 2006.

Link and Learn is an initiative to offer better support to regional and remote carers. Funding for the Program comes from a grant to MND NSW through the **NSW Health Carers Projects**. Participation in the program is therefore **free of charge** for carers of people with MND in the target area.

Link and Learn is a two day program during which carers learn about managing the physical aspects of care for the person with MND, useful equipment, services and emotional aspects of caring. The right knowledge and planning ahead can help carers to manage better and this can ultimately benefit the person living with MND. The Program will provide an opportunity to meet others and share ideas and experiences.

The two day residential workshop will be held at the beginning of **March 2007**. Following this, carers will keep in touch by means of weekly telephone group sessions of one hour duration each, over six weeks.

Christina Jason and Allison Pearson will be the Regional Advisors involved in the next phase of the Program. For more information contact your Regional Advisor or MND NSW.



(l-r) Noelene Nadalini, Vivien Anderson, Lucy Lee, Annette Hodgkinson, Sue Fairley, Anita Richter (MND NSW), Margaret The and Adrianna Filiopulos watch while massage therapist, Margaret Erdmanis demonstrates neck massage with Con Filiopulos (seated) at the **Carers Pampering Day** held 24 July.

## Dates for the Diary

4, 11, 18, 25 September	Care for Carers Course (1 day per week for 4 weeks commencing 4 September) <i>MNDA NSW Centre Gladesville</i>
16-17 September	Suzanne and Bob Ballinger's Open Garden for MND <i>at Homeleigh, 17 Linden Avenue, Pymble</i>
29 September	Past Carers Meeting <i>MNDA NSW Centre Gladesville</i>
3 October (commencing)	Field Trip - Allison Pearson, Regional Advisor: Riverina area including Griffith, Cootamundra, Temora and Binalong
9-13 October	Equipment Pool Stocktake Week
12 – 14 October	Field Trip – Allison Pearson, Regional Advisor: Young, Boorowa and Cowra
16 October (commencing)	Field Trip – Fern Linden, Regional Advisor: Central West New South Wales including support group visit to Dubbo Zoo 17 October
October (commencing)	Field Trip – Christina Jason, Regional Advisor: Far North Coast
2 November	Cocktail Party and Art Auction <i>at Hugo's</i>
6 and 13 November	Learn Now/Live Well Information and Education program for people with MND their families and friends (1 day per week for 2 weeks commencing 6 November) <i>MNDA NSW Centre Gladesville</i>
9 December	Annual General Meeting
9 December	Christmas Party for members and friends
<p>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, particularly during field trips, please speak to your Regional Advisor.</p>	

Participants at past Link and Learn events have found them to be a great experience.

## Support Groups

### Central Coast

Hello from the Central Coast Support Group where it's all happening. The love, caring and sharing basis on which we provide the functioning of our happy group is flourishing as we have welcomed new members this year.



*Mrs Goody, Judy Ford, Ken and Jenny Winter at the Central Coast Support Group*

We were sorry to say goodbye to Mary Butcher, our Regional Adviser in January. However, we were delighted when Judy Ford, MND Fundraising Manger, visited in March, bringing with her our new Regional Adviser, Jo Fowler.

Awareness Week proved very successful both financially and in strengthening public awareness of MND. The individual support of every member, together with Umina High School and Narara Lions Club, was inspirational. This wonderful support was also very evident in the achievement of record fundraising by our group through our involvement with the Rotary Club of The Entrance Community Raffle.

The recognition of the work and dedication of our Sheila Holmes as a life member of the Association during Awareness Week was very exciting for the group.

We enjoy a variety of guest speakers at our meetings. However, it is agreed that the impromptu discussion triggered by a simple question during our July meeting, where Jo Fowler provided an excellent information session on the latest in care and treatment and promising research, was the best ever.

On 30 September we are privileged to have Professor Roger Pamphlett to speak to our meeting at 2pm. We extend an invitation to interested members and friends. During the day, Professor Pamphlett will be conducting a DNA Donor Drive. It is hoped that the Drive will be helpful with his research into MND.

If you would care to join us please contact either Audree 4384 2907 or Sheila 4392 5513.

**Audree Dash**

### Northern Beaches

The Northern Beaches Support meets bi-monthly on a Thursday morning at the Palliative Care Cottage, Mona Vale Hospital. Refreshments are provided, there is easy wheelchair access to the building and a drop off zone at the door.

This informal gathering is attended by people with MND, their family and friends and some former carers. The meeting affords the opportunity to develop new friendships, share experiences to gain insights into how best to cope with motor neurone disease, to be proactive in management decisions and to plan ahead. Some local service providers such as physiotherapists, social workers and the palliative care physician regularly attend the meeting and are on hand to chat with clients and their carers and lend support.

There have been some very interesting speakers at the last three meetings. In April Kevin Langdon OAM, Vice-Patron and Past President of MNDANSW was our guest speaker and spoke about his role as an Ambassador in raising awareness of MND and the profile of the MND Association, Dr Helen Gillespie from the Aged Care Emergency (ACE) Team at Mona Vale Hospital addressed the June meeting and gave us strategies to aid health and well being in our later years. Jane Hauser, Manager, Community Care, Manly/Pittwater/ Warringah

talked about the services available in the Northern Beaches area and how to access them.

The next meeting is on 12 October and we will be learning some relaxation techniques and how to manage stress wisely.

Please contact Jo Fowler on 8877 0909 if you need any further information regarding the Support Group or if you would like to offer some ideas to enhance the meetings.

**Jo Fowler**

*Regional Advisor*



*Peter Ellwood and Ron McNally at the Northern Beaches Support Group in August 2006.*

### Southern Highlands/Monaro

Spring has sprung! To celebrate the return of warm weather, our group will meet for afternoon tea in the cafe at the Botanic Gardens in Canberra on Saturday, 7 October. This is the third year we have met at the Gardens and on our prior occasions we have enjoyed the spring sunshine while catching up with new and old acquaintances. The cafe is accessed from the main entrance on Clunies Ross Street and has disabled access via a path from the car park (pay parking). We will meet at 2pm and welcome those with MND, their families and friends.

Our thoughts are with Helen Christianson (President of the ACT Association) as she recuperates from surgery in late August. We wish her a speedy and complete recovery.

For information on our support group please ring me on 6238 3769.

**Allison Pearson**

*Regional Advisor*

MNDA NSW Christmas Cards are now in stock. See the flyer enclosed in this edition of Forum, or call 8877 0999 for more information.

## Support Groups (Cont'd)

### Central West to visit Dubbo Zoo

The Central West Support Group is having its October meeting at the Dubbo Zoo on Tuesday 17 October. The meeting is generously being sponsored by the Rotary Club of Dubbo/Macquarie. The support group is to meet at the front entrance at 10am and will undertake a tour of the zoo by car, after which they will join the members of the Rotary Club for lunch at 12pm.

Members and their carers are coming from Orange, Cowra, Mudgee, Young and Dubbo.

The meeting will also be attended by Fern Linden, Regional Advisor for the Central West area and Judy Ford, Fundraising Manager for MNDA NSW. Both are looking forward to attending the meeting in such gorgeous surroundings - taking tea with the tigers and chatting with cheetahs is certainly different to most of the meeting venues we've been to in the past!

This novel idea, hatched by Vivienne Nichols of Dubbo, became a reality when financial support was offered by Past President Steve Cowley and the members of the Rotary Club of Dubbo/Macquarie.

Should anyone else in surrounding areas wish to join the group please call Vivienne Nicholls on 6882 3232 or Fern Linden on 8877 0919. We look forward to seeing you all then.

**Fern Linden**  
Regional Advisor

### Illawarra

The Illawarra MND Support Group has continued well this past year with our focus remaining on education, support and of course fun. Our meetings vary monthly ranging from enjoying lunch out for Christmas in July celebrations, to having Dr Roger Pamphlett speak about the MND DNA Bank, and we are currently looking forward to a local belly dancing troupe coming to entertain us all next month. At the end of each meeting all members thoroughly enjoy taking the opportunity to catch-up and share information, stories and the odd joke while enjoying a light lunch. The group meets on the second Tuesday of every month at Port Kembla Hospital in the Activities Room and everyone is welcome.

**Erin Hiesley**



Wheelchair access to the spectacular views of Blue Mountains is now available on the Fairfax Walking Track

## Learn now Live well

Monday 6 and Monday 13 November  
10am-3pm at Gladesville

**Held** over two Mondays, this is a program where people with MND plus family members and friends can come together and learn more about living with MND.

**It** will include information about exercise, managing difficulties and maintaining independence. There will be plenty of time to ask questions and learn from others living with MND.

**Call** MNDA NSW on 8877 0999 to register your interest and a brochure will be sent with more information.

## Support Group Contacts

### Central Coast

Audree Dash  
Ph: 02 4384 2907

### Central West

Fern Linden  
Ph: 02 8877 0999  
fern1@mndnsw.asn.au

### Coffs Harbour

Lily Jenkins  
Ph: 02 6652 2571

### Illawarra

Pam Van Den Hogan  
Ph: 02 4223 8000

### New England

Robyn Barton  
Ph: 02 6766 6065

### Newcastle & Hunter

Barry Harrison  
Ph: 1300 667 873

### Northern Rivers

Helen Gates  
Ph: 02 6621 4018

### Riverina & SW Slopes

Wes Russell  
Ph: 0408 692 127

### Southern Highlands/ Monaro

Allison Pearson  
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### Gladesville

Caroline Gleig  
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and

### Northern Beaches

Jo Fowler  
josephinef@mndnsw.asn.au  
and

### Northern Sydney (Hornsby)

Jo Fowler  
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and

### Western Sydney

Ruth Quaken  
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are coordinated through  
the MNDA office.  
Ph: 02 8877 0999

## Mailbag

Dear Editor,

My husband Gordon was diagnosed with motor neurone disease five years ago. His gentle acceptance of the diagnosis, and his concern for the needs of his family were an inspiration to all who knew him. Whilst still in Sydney, he resolved to come home and keep doing the things he loved doing for as long as he could.

He did just that, going to his beloved workshop, doing the beautiful woodwork and furniture restoration that he loved, for the last two years from a wheelchair. He completed his last job, a set of dining chairs for friends, in early May this year

We were able to keep him at home comfortably until his death on 18 July. This was made possible largely by the support we received, especially from the Motor Neurone Disease Association. One of the nurses at St. Vincent's, where Gordon was diagnosed, gave us the Association's contact details and after we came home and settled down I rang.

In the later stages, it didn't matter what our occupational therapist asked for, Maree and



*Gordon Turner in the recliner rocker he said was the most comfortable chair he had ever sat in.*

Trevor, who look after the MNDA NSW Equipment Pool, seemed to be able to supply it. Every piece of equipment made a difference, especially the beautiful green recliner rocker in which he spent all of his waking hours for the last month of his life. He said it was the most comfortable chair he had ever sat in.

We were blessed indeed for the whole five years, meeting each problem as it arose and finding solutions to most of them. I was able to continue in my part time job until one month before his death. His final stage was just that month and it was a blessed family time for us all, the children and their families coming and going. He was able to rise and be showered and sit in the living room, being a part of whatever was going on until the last two days of his life. He died as he had always lived, quietly and peacefully in his sleep in the early hours of 18 July.

I am writing this letter to express our gratitude to the Association for all the help you provided on our MND journey. Thank you from us all

*Nola Turner and her family*

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

## Three ways to get up Heartbreak Hill

It's not everyone who relishes the thought of getting to the top of Heartbreak Hill in the City to Surf and for Mark Gooley in a wheelchair it was daunting. However he had his three very supportive children, Melinda, Ben and Marcia, and their friends to push him up and over to the finish line.

Mark was no novice when it came to the City to Surf. He had previously competed ten times, but in his words, "this one was the most satisfying". Although confined to a wheelchair now due to his progressing motor neurone disease, Mark was able to enjoy the fun day and get a great sense of achievement out of completing the event.



*Mark with his daughters Marcia and Melinda*

Mark's family and friends ran with him wearing MND T-shirts. Through sponsorship and donations collected before and after the race, they managed to raise \$5,000 for MND.

Mark said, "I am continually amazed at the generosity of people and it made me proud to see the efforts of my children so well rewarded."

Thank you to Mark, his family, their friends and the many other participants in the City to Surf who promoted MNDA NSW in August 2006.



*Mark with family and friends at the finish line*

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

**DISCLAIMER** All care has been taken in the preparation of this newsletter. The MND Association of New South Wales disclaims any liability for its content. The information contained within is of a general nature. For medical advice, consult your doctor.

*Editor: Penny Waterson*