



# FORUM

December 2005

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and

## **MANY VALUED VOLUNTEERS**

## **ADDRESS**

Building 4 Old Gladesville Hospital  
Gladesville NSW 2111  
(Locked Bag 5005 Gladesville NSW 1675)  
Phone: 02 8877 0999 or 1800 640 144  
Fax: 02 9816 2077

## Linking Up



Christmas is often a time for reflection on the memories of the past year: achievement, shared happiness, shared sadness, loss, joy, hope and love. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

Christmas is also often a time of *linking up* - with friends, family, neighbours and other members of the community. During early December, MNDA NSW members, friends and staff linked up at two wonderful events - the Annual General Meeting and Christmas Party.

Our Christmas Party this year was a great opportunity for members, carers, staff, and volunteers to catch up with familiar faces and to make new acquaintances. At the AGM, held just prior to the Christmas Party, we were able to reflect on the achievements of the Association during 2005.

MNDA NSW will continue to provide opportunities for members, carers and others to *link up* in 2006. Plans already include a new support group at Gladesville (see below), a Link and Learn Program for carers in Southern New South Wales and a lunch for former carers (see page 6). Planning is also underway for a variety of MND Week activities (see page 11). Your participation is warmly welcomed.

*Penny Waterson, Editor*

### ***New Support Group at Gladesville***

To take advantage of our wonderful new MNDA NSW Centre, we will be commencing a new support group for all members, their families and friends at the Centre in Gladesville during 2006. Regional Advisor, Caroline Gleig, will be the contact person for this group.

It is planned to meet on a Wednesday morning from 10am-12pm with the first meeting on 1 February. Please come with your ideas for how you would like the group to proceed through next year, for example, particular topics you might like covered, or perhaps whether you might like to have an invited speaker attend every second meeting. At the first meeting you will also be able to meet our newer members of staff - Judy Ford, Graham Opie and Penny Waterson, and hear about their roles.

The meeting will be informal and morning tea will be provided. It would be most helpful if you could call the MNDA NSW Centre with an expression of your interest in attending and I will send a reminder and further information by post nearer to the day.

*Caroline Gleig, Regional Advisor*

*The office of the Motor Neurone Disease Association of New South Wales will be closed for Christmas from 5pm Friday 23 December to Monday 2 January. Normal office hours will resume on Tuesday 3 January 2006. 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

Well it has been over three months since the last *Forum* which means that it also has been over three months since Tom and I planted our Cornflower seeds. And still no blue! Is it the increased Sydney rainfall, are they planted too close together, is my notorious 'brown thumb' at work? Tom and I would really appreciate your suggestions or tips so that I can report the appearance of blue in the next *Forum*.

This edition is dedicated to 'linking up'. A key function of the Motor Neurone Disease Association of NSW (MNDA NSW) is linking up members, families, volunteers, health professionals and communities. Additionally, MNDA NSW links up with other associations and organisations. At the Motor Neurone Disease Association of Australia Annual General Meeting in October, the links and ties forged with other MND Associations across Australia and New Zealand were clearly evident. Bob Howe, MNDA NSW Secretary and MNDAA Vice President, has provided us with an update from the meeting on page 3.

As reported in the last edition of *Forum*, Janet Nash has taken up the role of Executive Officer of the Motor Neurone Disease Research Institute of Australia. Although she is in a new role, Janet will undertake her work for the Institute from the MNDA NSW Centre at Gladesville and, I dare say, will contribute to *Forum* on a regular basis. Hari Singh, past CEO of MNDA NSW and well known to all, on hearing of Janet's move, felt compelled to write to acknowledge Janet's outstanding achievements at the Association. Hari has kindly agreed to allow us to print the letter (see page 12).

The launch of our bequest program, the Blue Cornflower Society, took place in October. It was an outstanding success and linked up like-minded people over a casual lunch. It also provided the opportunity for Society members to catch up with old friends. Janice Scheinecker, a long-time member and current Director of MNDA NSW, attended and her report on the event is on page 9.

Our next Blue Cornflower Society lunch is planned for Tuesday February 28, 2006. The Blue Cornflower Society lunches are open to all people with the common connection of MND. And they are free, thanks to Perpetual. If you are interested in finding out more information about the Society contact Roslyn Adams at the MNDA NSW Centre.

I would like to make special mention of the effort of our support groups across the State. These groups provide the opportunity for those living with MND to link up, not only within metropolitan areas of Sydney, but also within regional and rural areas of New South Wales. Groups such as the Newcastle and Hunter Region Group have been invaluable in creating and maintaining local links within a regional community.

Our membership has been increasing gradually and we currently have 319 members with MND. This has prompted us to increase our capacity around Family Support and we have advertised for a new regional advisor who will hopefully start at the end of 2005.



David Radford



Penny Waterson

During the past three months we have welcomed several new staff members to the Association - Judy Ford, Fundraising Manager; David Radford, Accountant; and Penny Waterson - Information Officer and new editor of *Forum*. Judy, David and Penny have a wealth of experience in their respective fields and we are extremely excited to have them here as part of the MNDA NSW team. Why not drop in to our new Centre at Gladesville and say hi?

Finally, I'd like to wish all members of MNDA NSW a merry Christmas, happy holidays and a happy New Year.

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

*If you would like a copy of the MNDA NSW 2005 Annual Review contact us at 8877 0999 or visit [www.mndnsw.asn.au](http://www.mndnsw.asn.au) where it can be downloaded.*

### MNDA NSW 2005 Annual General Meeting

*At the MNDA NSW 2005 Annual General Meeting, Gary Jacobson and Robert Marr were farewelled from the Board. Robert has been involved since the Association's inception and both Robert and Gary have served the Association well - guiding MNDA NSW through some difficult circumstances.*

*If you would like a copy of the MNDA NSW Annual Review 2005 contact us at 8877 0999 or visit [www.mndnsw.asn.au](http://www.mndnsw.asn.au) where it can be downloaded.*

## 2005 Christmas Party

In early December MNDA NSW members, families, friends, staff and Board members enjoyed a great afternoon together at the Sydney Rowing Club at the Association's 2005 Christmas Party.

The water views provided a spectacular backdrop to the wonderful carol singing of the U3A Sydney Choir, who generously entertained us on the day. Santa and his reindeer dropped in to

hand out some gifts and to draw the names of the raffle winners, including the prize won by a staff member of the Rowing Club.



*Santa Ian Birks - 'Never Giving Up'*



*Family Support Reindeer Anita Richter assisted Santa with his work*



*Judy Saladine (above) helping her grand-daughter, Olivia Cauchi, with some important Christmas decision-making*



*Kerry Gilmore and Kim Smith*



*George and Helen Kaldas*



*Barry Harrison and Jim Simpson (above), and Pamela Walker, Noel and Val Simpson (left) all try very hard to convince Santa that they really have been good.*



*Molly Opie enjoying some fine food*



*Francis Cassa-Trigonna*



## Motor Neurone Disease Association of Australia

*...1989 saw the first Australian conference with Motor Neurone Societies ... in November 1991 came the formation of a National Body with an interim committee of one representative from each of the seven founding societies - the six state organisations and the Newcastle and Hunter Region (which later became the Newcastle Hunter Regional Support Group).*

*(Extract taken from the history compiled by John Wearne and Mavis Gallienne in May 2005)*

The links and ties envisaged by those involved in the formation of the National Peak Body for MND in 1991 were further advanced in October 2005 during the Annual General Meeting of the Motor Neurone Disease Association of Australia (MNDAA). At the meeting, it was unanimously agreed to adopt the new five year National Strategic Plan and to advertise the position of National Executive Director for MNDAA.

When appointed, our new National Executive Director will work closely with the state and territory

MND Associations to develop the 2005-2010 MNDAA Business Plan. This will help us to work together at a national level to inform policy, raise awareness, attract funding and to encourage and support research into MND.

These activities all take us closer towards to a national response and voice and ultimately, our vision of 'A world free from the impact of MND'.

*Bob Howe, MNDAA Vice President*



## Family Support - Linking Up

The system of health and community care services in NSW can be very confusing and it is often difficult for people to *link into* services which might be helpful.

Most people with MND will already be *linked in* with a neurologist and a general practitioner when they become members of the MND Association. Some will have been linked in with an **MND Clinic** (see below) or the relevant local multidisciplinary allied health team - some will not have been. The regional advisors will talk to new members about the services they have in place and will advise them about services that may be of assistance depending on the symptoms they are experiencing at the time.

There are many health and community care providers who may be involved in providing services. These can be accessed from a variety of services depending on a number of criteria such as the person's age, the services available, or the stage of the disease. Understanding the role of the various health care providers and how to access them helps people with MND to remain in control of their disease and plan their future care and support. The following is a brief overview of some of the health and community care providers that a person with MND may be linked to by their regional advisor.

For most people with MND in NSW their local medical, nursing and allied health services provide ongoing care. A case manager or key worker may be appointed to coordinate care and ensure that the various health care providers involved in caring for the person with MND share information and liaise with one another.

**Allied health** is the term given to a number of therapists who have a specific role and work closely together as part of a multidisciplinary team. They may be accessed from an MND Clinic or local hospital aged, rehabilitation, palliative care service or community health centre. Allied health providers include occupational therapists, dietitians, physiotherapists, speech pathologists and social workers.



*A person with MND and their carer may link in with a variety of health and community care services.*

### Occupational Therapist

- Undertakes home visits to assess home environment
- Recommends home modifications
- Recommends and prescribes equipment, such as small aids, rails, seating and devices to assist computer use.

### Dietitian

- Assesses current dietary intake
- Advises on maintaining weight
- Advises on modified foods and fluids
- Supports people who are planning a PEG and assists with sourcing feeds

### Physiotherapist

- Advises on and provides exercises, hydrotherapy, splints and some equipment
- Instructs the carer on safe lifting and transfer techniques
- Advises on assisted cough techniques
- Assists the person with MND with breathing exercises

### Speech Pathologist

- Assesses and monitors speech and swallowing
- Advises on diet modification
- Advises on communication devices and helps develop a suitable means of communication with the person with MND

### Social Worker

- Provides financial advice
- May help organise Centrelink payments
- Gives emotional support
- May provide short term counselling

The MND NSW Regional Advisor has a pivotal role in providing information about local services.

### Specialised MND Clinics and Programs

MND Multidisciplinary Clinic, Royal North Shore Hospital, St Leonards  
 MND Multidisciplinary Clinic, Prince of Wales Hospital, Randwick  
 MND Multidisciplinary Clinic, St Josephs Hospital, Auburn

MND Service Calvary Hospital, Kogarah  
 Clare Holland House, Canberra  
 Sacred Heart Hospice, Darlinghurst  
 Port Kembla Hospital, Port Kembla  
 Community Outreach Team (CORTS) Central Coast

*For more information on these clinics or programs please speak to your regional advisor.*

## Family Support - Linking Up (cont'd)

Registered **community nurses** may be accessed through the local hospital, home nursing service or community health centre. Community nurses:

- Identify and review nursing needs
- Support the carer and review their needs
- Monitor pressure areas
- Provide nursing care, for example, care of PEG and continence needs
- Liaise closely with other service providers
- Offer support for the whole family
- May provide short term personal care such as showering.

Palliative Care Australia defines **palliative care** to mean:

*"a concept of care which provides coordinated medical, nursing and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional and spiritual support for patients, and support for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient and continuing after death."*

As there is still no cure for MND, palliative care services may be accessed from diagnosis onwards and, depending on the service, may provide:

- Expert symptom management and support, in consultation with the general practitioner and/or specialist
- Monitoring of disease progression
- Emotional and social support to people with MND and their family in their own home
- 24 hour support
- Day hospice
- Alternative therapies such as massage and aromatherapy
- Volunteers
- Respite care in hospice or palliative care unit
- Bereavement support

There are a variety of **community services** and packages of care jointly funded by the New South Wales and Commonwealth Governments to provide assistance to people in their own home to enable them to remain independent. Most services charge a proportion of the cost of the service to users.

Community services may provide assistance with:

- Personal care
- Respite
- Meal preparation
- Shopping
- Home modifications
- Housework
- Gardening
- Transport

Depending on where you live, **volunteers** may be available from MNDA NSW, palliative care services or your local council. They may be able to provide:

- Companionship
- Respite
- Assistance with activities, such as writing stories
- Help around the home and garden
- Transport

There are many **MND support groups** around the State that can offer the person with MND and their family and friends:

- Peer support
- Information and education from guest speakers
- Help with problem solving
- Companionship
- An opportunity to be involved in fundraising and advocacy and raising awareness

**Carers Respite** has a freecall number, **1800 059 059**, available for carers to call if they would like assistance with all types of respite care including:

- Emergency
- Holiday
- Overnight
- Personal care for the person with MND to support the carer in their caring role (in some regions).

For information on services in your area speak to your MNDA NSW regional advisor or call the Commonwealth Carelink Centre **1800 052 222**

Most people with MND are well supported at home and receive a level of care that enables them to live well with MND. Sometimes, however, people may experience difficulties in obtaining services or may have to wait a long time for an assessment from service providers. **MNDA NSW Family Support** constantly advocates at all levels to promote optimal care and support for people living with MND. Please let your regional advisor know if you are experiencing any difficulties in obtaining services.

Carol Birks  
Manager, Family Support

Thank you to the members who have returned their **member survey** form. Your comments are greatly appreciated. If you haven't returned your form yet, it is not too late. Post or fax it in as soon as possible.

## Carers - Linking Up

### Link Up for Counselling

Ideally, if counselling is desired, it should be available for people with MND and their families at the time of diagnosis and as the situation changes with the progress of the disease. Unfortunately, counselling may not be easy to access for those who seek it.

The following links may be helpful to MND families seeking counselling support.

### Your GP

New rebates are now available for the chronically ill through Medicare. This can be arranged by referral from the GP if the patient is on an **Enhanced Primary Care Plan**. Medicare rebates are available for up to five allied health consultations including social workers and psychologists. For more information contact your GP.

### Relationships Australia

Relationships Australia provides affordable counselling for families dealing with serious life changes. For more information call 1300 364 277.

### Carers NSW

The **National Carer Counselling Program** provides short term counselling through professionally qualified counsellors. The carer can

'talk over' issues including grief and loss, stress management, coping skills and health and wellbeing. This program is delivered through the Carers NSW Commonwealth Carer Resource Centre and is subject to the Home and Community Care (HACC) Program fees policy. However, there are safeguards to allow fees to be reduced or waived in accordance to the carer's capacity to pay. For more information phone the Commonwealth Carer Resource Centre 1800 242 636.

Carers NSW **Talk-Link Program** is a type of teleconferencing where a group of six carers and two trained facilitators get together on the telephone at the same time. The main focus of Talk-Link is to explore the emotional impact of caring and identify ways of managing every day life. For more information phone the Commonwealth Carer Resource Centre 1800 242 636.

### Palliative Care

Local Palliative Care Services may offer a very real level of emotional support.

If you would like more information regarding access to counselling contact your MND Association regional advisor or Info-line.

Anita Richter

Special Projects/Carers Services

On 16 October a merry band of MND carers and kids embarked on the good vessel Kaz for a sail on Sydney Harbour. See page 12 for more.

### Linking Up for Past Carers 12-3pm 20th February 2006 MNDA NSW Centre Gladesville

*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 2005. However, this meeting is open to **all** past carers.

**RSVP** would be appreciated by 14 February for catering purposes. There is no charge for lunch or parking. Contact Anita Richter on 8877 0902.

### Link and Learn Program for Carers 6-7 March 2006 Young

*Do you live in Central or South-Western NSW or the ACT? Are you caring for a loved one with MND? Do you feel the need to learn more to help you to look after the person with MND?*

This two day residential program addresses some of the physical and emotional aspects of caring for a person with MND. The program will provide an opportunity to meet others and share ideas and experiences. There will also be some time for a little relaxation and pampering. Participation in the program is free of charge for those currently caring for someone with MND.

It is difficult for MND carers to take 'time out' from caring and MNDA NSW Family Support staff will help liaise with Carers Respite Centres to help provide respite care (including overnight), in the home if necessary, for carers to participate in the program.

For further information contact Ruth Quaken on 8877 0906 or Allison Pearson on 6238 3769.

## Equipment

The Equipment Service at the Motor Neurone Disease Association of New South Wales provides medical equipment to help maintain independence, comfort and safety, at no cost to its members.

Medical equipment is very expensive and the Association would not be able to continue to provide the range of equipment it does without the generous contributions from a number of different organisations. Often, contact with donors occurs through links established by members and others

wanting to improve access to relevant and current equipment for people living with MND.

Recent financial contributions for equipment have been received from:

Honda Foundation - through the Honda Waitara Dealership  
Newman's Own Foundation Inc  
Canterbury Hurlstone Park RSL Club  
United Way  
City Tattersalls Club  
Rooty Hill RSL Club  
Ryde-Eastwood Leagues Club

The equipment purchased with this funding includes electric wheelchairs, bathroom and bedroom equipment as well as new communication devices. It is all very much needed and greatly appreciated.

*Maree Hibbert*

## Dates for the Diary

23 January	Volunteers Meeting <i>Gosford</i>
20 February	Linking Up for Past Carers <i>12-3pm. MND NSW Centre Gladesville</i>
28 February	Blue Cornflower Society Lunch <i>Sydney</i>
28 February	Information evening for people recently diagnosed and their family and friends <i>6.30-8.30pm. MND NSW Centre Gladesville</i>
6-7 March	Link and Learn Program for Carers <i>Young</i>
2-8 April	MND Week
20 June	2nd National MND Conference <i>Sydney</i>
Contact the MND NSW Centre on 8877 0999 or 1800 640 144 for further information	

## Health Professionals

### Linking Up with Health Professionals

#### MND NSW Special Interest Groups

Membership of the MND NSW Special Interest Groups (SIGs) has now risen to 185 and two SIG Workshops were held at the MND NSW Centre in early November.

Approximately thirty health professionals attended the first workshop held on 3 November. Topics covered included augmentative communication, research and care update, specialised equipment used in the care of people with MND and seating issues in MND.

Dr David Oliver, acclaimed specialist in motor neurone disease and palliative care in the United Kingdom, was a keynote speaker at the second workshop held for fifty health professionals on 9 November. Professor Kate White, of the University of Sydney, challenged those present to consider research projects involving specific areas of managing care of people with MND. We are grateful to David, Kate and the other health professionals who gave generously of their time and expertise to present at these workshops.

There was a great response to these workshops and the SIGs provide a means of sharing information and promoting best practice care. E Bulletins are circulated to SIG members every two months and these include news updates, journal articles and other information relevant to the care of people living with MND.

Planning is well underway for the 2<sup>nd</sup> National MND Conference - 'MND: Advances, Initiatives and Challenges' to be held in Sydney on 20 June. The Call for Abstracts is currently being finalised and will be available during December. The Conference will focus on advances in MND research and clinical practice, initiatives in the care and management of people living with motor neurone disease, and challenges to best practice. For further information see [www.mndnsw.asn.au](http://www.mndnsw.asn.au) or call 8877 0999.

### Have Your Say...

*... Carers NSW is doing research on respite and short breaks for carers and they are conducting an online survey so that **carers and service providers** can have their say. The survey can be accessed from [www.carersnsw.asn.au](http://www.carersnsw.asn.au) until mid-January 2006.*

The 2<sup>nd</sup> National MND Conference - 'MND: Advances, Initiatives and Challenges' will be held in Sydney on 20 June. The Call for Abstracts will be available at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) in December.



## Support Groups

### Central Coast

Audree Dash  
Phone: 02 4384 2907

### Central West

Carol Birks  
Phone: 02 8877 0999

### Coffs Harbour

Lily Jenkins  
Phone: 02 6652 2571

### Illawarra

Pam Van Den Hogan  
Phone: 02 4223 8000

### New England

Robyn Barton  
Phone: 02 6766 6065

### Newcastle & Hunter

Barry Harrison  
Phone: 1300 667 873

### Northern Rivers

Helen Gates  
Phone: 02 6621 4018

### Riverina & S W Slopes

Wes Russell  
Phone: 0408 692 127

### Southern Highlands/ Monaro

Allison Pearson  
Phone: 02 6238 3769  
allisonp@mndnsw.asn.au

### Gladesville

Caroline Gleig  
carolineg@mndnsw.asn.au  
and

### Northern Beaches

Mary Butcher  
maryb@mndnsw.asn.au  
and

### Northern Sydney

(Hornsby)  
Mary Butcher  
maryb@mndnsw.asn.au  
and

### Western Sydney

Ruth Quaken  
ruthq@mndnsw.asn.au

are coordinated through  
the MNDA office.  
Phone: 02 8877 0999

### Southern Highlands/Monaro

Our little group has continued meeting on a regular basis despite lower numbers attending this year. It is the nature of groups, particularly those based on MND, to have varying numbers attending as it is often difficult to travel due to lack of mobility and also fatigue. As well as physical barriers, some people are just not keen on the idea of 'support groups' and the thought of having to get to know strangers can be off-putting. Many people who attend these groups enjoy not just sharing the common practical and emotional experiences of MND, but also enjoy socialising with others who have an unspoken understanding of what they are going through. All are welcome on a 'once-only' or a regular basis - those with MND, their families, carers and past-carers.

Meetings are held every second month, usually at Clare Holland House, Menindee Drive, Barton, ACT. The next meeting is planned for 2pm Saturday 4 February. If you have any queries please contact me directly on 6238 3769.

Allison Pearson

### Western Sydney - Kingswood

The bi-monthly meetings have been well attended throughout 2005 with speakers from Kingswood Community Health Centre, the Independent Living Centre, Carers NSW and the local Bereavement Service providing very helpful information. At each meeting the group also enjoys a 'cuppa and a chat'. We are planning to continue our meetings next year in a similar bi-monthly format and if you would like to be added to the support group contact list please call me at MNDA NSW. Everyone is welcome.

Ruth Quaken

### Illawarra

We have had another lovely year together in friendship and support, however, we have also lost some members and they are dearly missed by all. Guest speakers in 2005 have included a solicitor, a Centrelink Financial Information Services Officer and several informative presenters from our local palliative care service. We have enjoyed other activities such as 'Christmas in July', 'scrap-booking', a golf day and MND Week events. Thank you to our members who organised these activities. We wish everyone a wonderful Festive Season.

Pam Van Den Hogan

### Central Coast

During 2005 our group met on a bi-monthly basis, with guest speakers including Therese and Rose from the Central Coast Community Outreach Team. We enjoyed recipe swapping, a 'chat and share' day and involvement in MND Week and other awareness raising and fundraising activities. In 2006 we will continue our meetings over afternoon tea at the Gosford Senior Citizens' Centre, commencing at 2pm on Saturday 28 January. All are welcome.

Audree Dash

### Central West

We are pleased to announce that the Central West support group was re-formed recently. The group will meet bi-monthly on the first Tuesday commencing in February. Meetings will be at the Orange Ex-Serviceman's Club and will combine informal get-togethers with guest speakers. If you would like to join the group, or would like to be informed of the program for 2006, please contact me at MNDA NSW.

Carol Birks

*The first meeting of the Gladesville support group will be on Wednesday 1 February. The meeting will be informal and morning tea will be provided. For more information phone Caroline Gleig on 8877 0999.*

## For Sale

Holden Combo 1998. Manual. Wheelchair accessible with hydraulic floor rear door access and restraints. 25,000kms. Reg 09/06. \$13000. Ph. Robyn 4267 2223.

Mazda E2000 Van 1993. Auto. RTA approved rear hydraulic wheelchair hoist. 104,000kms. Reg 12/05. \$13200 ono. Ph. Lorraine 4423 1327.



## Recent Events

### Open Garden Weekend 29-30 October

Much planning and preparation over many months was rewarded when we woke up to a glorious Saturday morning. Suzanne had an early interview with Jennifer Stackhouse on 2UE to promote the opening which was organised under the auspices of the Open Garden Scheme. There were also mentions on both ABC702 and 2GB.

The event, organised to be an MND fundraiser, was also

publicised in the local paper and in the Open Garden national book although the latter does not publicise the garden owner's chosen charity.

Roslyn Adams from MNDA NSW office did a great job of coordinating a roster of MND volunteers and our friends to work on the two days and to

support and organise the various stalls, most of which were set up along the drive. There was a plant stall, book stall and a display of MND merchandise and information.

Paula Trigg displayed her hand-made cards. Kim Smith came with lovely lavender products and Lindy McLeod had beautiful French baskets. On the back balcony refreshments stocked with yummy cakes, biscuits and sandwiches were served throughout the day. Helena Karnolz, botanical artist extraordinaire, added class and interest in the front garden as she demonstrated her skill in precisely drawing an

aquilegia. The raffle, with several excellent prizes, was also popular.

Our half acre block is predominantly a semi formal cottage garden created under huge turpentine. Suzanne is a self-confessed plant collector and Bob has used sandstone flagging and blocks to create winding paths and sandstone walls to retain the garden beds.

Roses were blooming on the rose arches. The cascades of the Japanese influenced pond added a soothing sound to the fragrances and colours of the flowers. There is also a more tropical feeling foliage garden under tree ferns.

Over 100 people visited on Saturday but unfortunately it rained heavily during all of Sunday and our fundraising was really curtailed as only about thirty people braved the weather and it was far too wet to contemplate setting up the various stalls and an artist.

However, as a flow on from the opening, Better Homes & Gardens program on Channel 7 have televised and

photographed the garden for their TV show and magazine. They have agreed to promote MND Week nationally when the segment goes to air and the magazine is published in the first few months of next year. If you weren't able to see the garden at the opening, we hope you will have the opportunity to see it then.

*Bob and Suzanne Ballinger*



*Lindy's French baskets at the Ballinger's Open Garden Weekend for MNDA NSW*

### Blue Cornflower Society Launch

On Tuesday 11 October I attended the launch of the Blue Cornflower Society in Sydney.

At first I was apprehensive of the concept but attended the lunch determined to keep an open mind. I was pleasantly surprised as it was not a lunch whereby the push was to raise funds through bequests even though this was the reason for launching the Society.

The lunch that was held included many people that I had not seen for a while and so it was a fantastic opportunity to catch up. It was also, as I found out, a terrific way of sharing time with like minded people and a great opportunity to share common experiences.

I certainly plan to attend again next year and hopefully will invite friends to join as I feel confident it will be up to the individuals if at any stage they decide they would like to include the MND Association in any bequests in the future.

The Society itself, while focusing on bequests left in Wills, has a focus on common values and is a great way to show support for MNDA NSW and the work that the Association does.

Special thanks to Roslyn Adams and Graham Opie for organising such a lovely warm atmosphere on the day.

*Janice Scheinecker*

The next Blue Cornflower Society lunch is planned for Tuesday, 28 February. Contact Roslyn Adams at the MNDA NSW Centre on 8877 0999 for more information.

## Fundraising and Volunteers

*Hello, my name is Judy Ford and I am delighted to introduce myself as the new Fundraising Manager for MNDA NSW. I am looking forward to meeting and getting to know you over the coming months.*

*Prior to starting in my new role here, I was working in the rescue helicopter world for Westpac Life Saver Rescue Helicopter and before that, Telstra Child Flight. Having lost a very good friend a few years ago to MND, I was keen to come and work for this organisation. I am enjoying working alongside Roslyn Adams and I hope that, between the two of us, we can continue to do the good work already in place.*

### Volunteers Meeting 21 November

It was terrific that ten volunteers were able to attend the tri-monthly volunteers meeting at the MNDA NSW Centre at Gladesville. It was an opportunity for everyone to meet the new fundraising manager, Judy Ford, and hear about some of the plans for the coming year.

Judy explained that there was a need to meet Department of Gaming and Racing regulations while undertaking fundraising activities, for example, all volunteers need to be provided with photo identification which is to be worn whenever MNDA NSW fundraising activities are taking place. Photographs were arranged for those present and those unable to attend will have their photo taken when they next visit the Gladesville Centre.

Lively discussion took place about MND Week. It was decided that for Blue Cornflower Day 2006 there would be less emphasis on collecting at shopping centres and more on collecting at railway

stations. It was suggested that volunteers wear polo shirts and be issued with 'bum bags' to help with money handling.

Ideas for events for next year included a fete or family day at Gladesville, 'Pack a Pub' where young people (and the not so young) would invite friends to visit a pub where they would pay an entry fee to listen to a band, and 'Jog a Dog' where dog owners would bring their dogs for a fun run or walk. Everyone liked the idea of running a raffle - so we are looking for donations for prizes, please.

It was also discussed that volunteers living out of Sydney found it difficult to attend meetings at Gladesville, so the next meeting will be held in Gosford on Monday 23 January 2006. We hope to see you there and more details will be sent to volunteers. If you would like your name added to the contact list, please let us know.

*Judy Ford and Roslyn Adams*



*Welcome to  
Judy Ford,  
Fundraising  
Manager,  
MNDA NSW*

## Invitation

**Would you like to be more involved with our Association?** Whether you live in town or country we would like to involve more people with our organisation by forming groups of **'Friends of MND'** to help with fundraising.

Already some wonderful work is done by members of our Support Groups, especially for MND Week. But, we would like to give more people an opportunity to be involved all year round. We are looking for enthusiastic volunteers to form 'Friends of MND' groups in both city and regional areas.

You may, for example, live in a country town and would like to spread the word about MND by organising or taking part in various fundraising activities. You might have a great idea but need people to help you get it going.

We are creating new groups called 'Friends of MND' which will meet regularly to look at fun and enjoyable ways to raise extra funds for MNDA NSW and help raise awareness.

**Who can join?** Anyone who is keen, enthusiastic, with an outgoing personality who enjoys having a good time whilst raising funds for a worthy cause can join a 'Friends of MND' group. You may have been touched by MND or volunteering may be something you enjoy doing. Either way you would be most welcome. For more information and a volunteer's pack contact Judy Ford, Fundraising Manager, MNDA NSW on 02 8877 0999.

*Each **'Friends of MND'** group will need a Group Coordinator, Treasurer and Secretary, and as many others as possible. These groups can be part of current Association support groups or they can be totally new. Once a group is formed it will be given advice on how to proceed, ideas to get started and lots of support and visits from the MNDA NSW fundraising team.*

## Links for Fundraising

### ... Golf links that is!

In recent years Charity Golf Days have become very popular. They give people a chance to participate in a fun day, whilst raising funds for their favourite charity. Fortunately many people have chosen to support MNDA NSW in this way and we are most grateful to the groups, service clubs and golf clubs that have, over the year, held special days for us.

The benefits of having a Charity Golf Day include:



*Valuable funds are raised*

*It's fun for the supporters*

*It raises awareness in your community*

*It's a great excuse to get out on to the golf course!*

A Charity Golf Day is more than a day playing a few rounds of golf. It can include a putting competition, a hole-in-one competition, a sausage sizzle lunch, or a dinner and auction after the event. Usually the game is played according to the Ambrose rules where players compete in teams.

The advantage of Ambrose play is that it allows golfers of all standards to participate in the day and takes the pressure off the less skilled golfers. It also promotes teamwork as every player has a chance of contributing towards the team score.

Would you like to organise a Golf Day for MNDA NSW? Please contact the Fundraising Team and we will give you all the help you need.

Our NEVER GIVE UP wristbands for MND have sold like hot cakes. Place your order now for the new stock which will be arriving in the New Year.



### Great Christmas Gift Ideas



As a special offer, the **Blue Metal Vineyard** in the Southern Highlands is offering wine to MNDA NSW members at 10% discount with a further 10% contribution to the Association.



The **imsmaat Breathanalyser** is a great Christmas gift. In addition to allowing you to monitor your blood alcohol level, it has a timer, flashlight and built in key chain. MNDA NSW will receive \$8 for every Breathanalyser ordered through the Association.

*See the insert in this edition of Forum for more information.*

## MND Week 2-8 April 2006

*Proposed MND Week Activities*

**Launch at Government House**  
Wednesday 29 March 2006

**March of Faces**  
*Venue to be advised*  
Saturday 1 April 2006

**MND Week**  
Sun 2-8 April 2006

**Blue Cornflower Day**  
Fri 7 April 2006

### Help needed...

It may seem a few months off, but once we head into the new year, MND Week will be just around the corner! Now is the time to start planning for this important event and I am asking all members and friends to think about how they would like to see the Week progressing, pass on any ideas for the Week and also let me know if you are able to assist in any way. There are a number of ways you can help during MND Week.

#### **Railway Stations**

We plan to concentrate our selling of wrist bands, pins, cornflowers and other merchandise around the main railway stations on Friday 7 April from 7-9am. We need station coordinators to organise small teams. 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 a 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 wristbands 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.

Judy Ford

## Mailbag

**Dear Graham,**

Having read the article about Janet's departure in the latest *Forum* I am compelled to write this short note to acknowledge her outstanding contribution to the Association. Let me enlighten you about her arrival and affairs of the Association in 1995. Soon after my appointment in 1993, the Board of Management asked me to carry out an audit/review of the services and prepare a plan of action for future development of the Association. In the wash up, we came to the conclusion that we needed to employ a professional person to provide information and assistance to people with MND. NSW Health provided us with an annual grant of \$10,000 to employ a Patient Care Coordinator and Janet Nash joined us in this role in July 1995.

Janet was a God given gift to the Association because no other person with her qualifications and experience would have taken on such a challenging role for the very basic wage and conditions associated with the post. She has been a true friend of people with MND and I am sure that those who have known her will miss her very much.

Janet has given ten years of dedicated service to MNDA NSW. During this time she was personally responsible for establishing the very valuable and efficient Association equipment pool, which continues to be so important in providing an improved quality of life to those with MND. She excelled in the provision of information to our members and, as Editor of the newsletter, Janet has done a sterling job with the style, presentation and content of each edition of *Forum*.

Janet has a 'hands on' approach and always demonstrated a willingness to turn her hand to many activities, both at work and at home. A particular occasion I recall is when, after a full day at work preparing the newsletter, she spent the evening tiling her terrace. No wonder she did an excellent job spearheading the relocation of the MNDA NSW office from Concord to Gladesville.

During the past decade, Janet's contribution to MNDA NSW has truly been outstanding. I enjoyed working with Janet, and Tara joins me in wishing her good health and happiness.

*Hari Singh*

*Former CEO, MNDA NSW.*

**Dear Caroline, Anita and all at MNDA NSW,**

Just a brief note to again express sincere thanks on behalf of myself and our daughter, Karen, for the Carers' Sailing Day aboard the 52' racing yacht *Kaz* on Sunday 16 October.

Whilst the weather was perhaps a 'titch' unkind to those who might have preferred a little more sunshine, the breeze was, for my part (as a multi hull sailor of many years past), a far more important element. Following the leisurely cruise under power to Sydney Harbour Bridge, we were indeed fortunate, with the breeze building to 10-12 knots, to have the headsail hoisted off the Zoo and an opportunity for those who wished to briefly take the helm of *Kaz*.

It's not often one gets the opportunity to take the helm of a thoroughbred racing yacht of the calibre of *Kaz*. How sweet it was to feel *Kaz* heeling on the wind under a stiffening breeze, taking advantage of the numerous wind shift 'lifts' and bearing away with the 'knocks' as we sailed up Harbour toward the Heads.

Exhilarating stuff. Karen and I both enjoyed ourselves immensely, as I'm sure did the other MND Carers. It certainly helped provide a refreshing change to our daily MND Carer routine.

I would be most grateful if you would please extend sincere thanks to the yacht's owner (whose book 'Life Without Limits' we both read recently), for the opportunity to sail aboard *Kaz* and also to the *Kaz* crew members for their generosity in providing their time and good humour on the day. It was great.

Kind regards,

*Jim Simpson and  
Karen Simpson  
Five Dock*



*Jim at the helm of the 52' racing yacht Kaz, at the MNDA NSW Carers' Sailing Day*

MNDA NSW thanks **Sailors with disAbilities** for making our Carers' Sailing Day possible.

### ACKNOWLEDGEMENT

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### DISCLAIMER

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