THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MND MOTOR NEURONE DISEASE

FORUM

June 2006

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Governor of New South Wales

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Many valued volunteers

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Recognition of Our Volunteers

The Fundraising Institute of Australia held a special presentation and luncheon for volunteers during Charity Awareness Week in May. Charities were invited to bring one volunteer to accept an award on behalf of all the volunteers for that organisation.

Joy Pogson with The Honourable Grant McBride, Minister for Gaming and Racing, at the Fundraising Institute of Australia presentation for volunteers during Charity Awareness Week.

Mrs Joy Pogson, who regularly helps in the MNDA NSW office on Fridays, accepted the certificate from The Honourable Grant McBride, Minister for Gaming and Racing.

Following the presentation of the award, Joy was joined by Association volunteers Libby Gole and Marge Harrap and our new Regional Advisor, Fern Linden, for a luncheon in the Strangers' Dining Room at Parliament House Sydney for 250 other volunteers and charity workers.

We are very grateful for the work all our volunteers perform and thank them most dearly.

Judy Ford
Fundraising Manager

Fern Linden, Regional Advisor, with MNDA NSW volunteers Libby Gole, Joy Pogson and Marge Harrap at the Volunteers Luncheon in the Strangers' Dining Room at Parliament House during Charity Awareness Week in May.

MND Week 2006

In April during MND Week many wonderful volunteers gave up their time to sit or stand at Railway Stations, in shopping centres, in clubs or out on the streets to sell cornflowers, wristbands, shortbread, pens and other merchandise. Some took boxes to work and others sold to their families and friends. It was a fantastic effort by everyone and we are extremely grateful for your efforts.

Articles, interviews and stories about motor neurone disease appeared in local, state and national media, and included print, radio, television and electronic features.

It was a time for those touched by MND to renew acquaintances and meet new friends as members, supporters and friends of MNDA NSW raised awareness right across the State. See pages 3, 10 and 11 inside for more.

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

Winter is almost upon us and it has been a year since we moved into new premises at Gladesville. After a year of settling in it is time to see how and where we are going as an organisation, review our services and find out what you, the member, would like to see us doing in the coming years.

MND Week 2006 was a sensation. We exceeded all expectations when it came to media exposure and publicity and our national call to action ensured all State and Territory Associations were 'singing from the same hymn sheet'. The response from members and the general public from across New South Wales was outstanding. Thank you.

Even the NSW Government got in on the act with a generous pledge of $500,000 to enhance our equipment pool. A special thanks must go to the Minister for Disability Services, John Della Bosca and the Department of Ageing, Disability and Home Care (DADHC). Full details of how we will utilise this grant will be published in the next issue of *Forum*.

On page 4 in this edition of *Forum* we publish an excerpt from the results of the Member Satisfaction Survey that was conducted late last year. Thank you to those members who responded.

The year 2006 marks the end of our current Strategic Plan and in the coming months we will be contacting all stakeholders for input into the direction they would like to see the Association moving through to 2010. We would encourage you to get involved as it is your organisation.

On advocacy, we have been lobbying DADHC for greater access for people living with MND to home and respite care funding programs including the Attendant Care Program and the High Needs Pool. The Department has since reviewed the assessment protocol and we have been encouraged to advise case managers to apply for Attendant Care Program and the High Needs Pool as soon as the need is identified. We are currently working with Community Options to develop a partnership approach which appears to be in line with DADHC's new *Stronger Together* initiative.

We have also been lobbying the Minister for Health on funding for MND Clinics with slightly less success. This is a work in progress.

Members were recently invited to take part in a study conducted by Deakin University, entitled *Study on the Economic Impact of Motor Neurone Disease on Well-Being* (see page 9). Initial feedback has shown members from MNDA NSW as enthusiastic participants. We hope to gain valuable information with which to lobby state government departments on the true economic impact of MND on families.

As part of the review process we have recently participated in the Quality Improvement Council (QIC) Standards and Accreditation Program. This has involved an internal review conducted by the staff of the Association and the completion of a Quality Journal to assess how well MNDA NSW meets the QIC quality standards. The QIC team visited the Association over three days where staff, management and board members were interviewed by QIC external reviewers. Stakeholders also provided feedback to reviewers about their experiences with MNDA NSW and relevant documents were inspected. The reviewers are currently preparing a report to provide feedback about our strengths and areas for improvement. Initial feedback was positive and we will be able to report back in more detail on the outcomes in the next *Forum*.

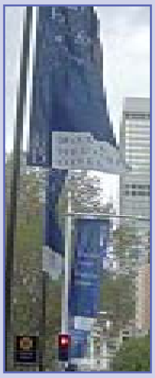
Global MND/ALS Awareness Day will be celebrated around the World on 21 June to coincide with the summer and winter solstices. In Australia the day will be marked by a Parliamentary Briefing at Parliament House in Canberra.

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
Executive Director

In the coming months we will be contacting all stakeholders for input into the direction they would like to see the Association moving through to 2010

Adil Nariman raised over $2,500 when he shaved his head in May, sharing his sponsored money between MNDA NSW and the Leukaemia Foundation based on sponsors' preferences. This resulted in a contribution of around $1,500 for MNDA NSW. His donation will go towards finding a cure for MND



MND in the Media

MND Week 2006 media coverage and publicity ensured that awareness about motor neurone disease was raised in New South Wales local communities and regional areas. Additionally, state MND Association cooperation ensured a united effort was directed towards national media. Thank you to all involved.

Newspapers

- 31 March, North Shore Times
- 5 April, Daily Liberal and Macquarie Advocate Dubbo
- 6 April, Daily Liberal and Macquarie Advocate Dubbo
- 11 April, Armidale Express
- 11 April, Central Western Daily Orange

Television

- 24 March, Channel 7 Better Homes & Gardens
- 30 March, Ch 10 Morning Show
- 3 April, Ch 7 Sunrise
- 7 April, NRL Footy Show
- 7 April, Sky News

Johanna Griggs (Channel 7 Better Homes & Gardens) with Suzanne and Bob Ballinger

Radio

- 28 March, 2UE Lunch time interview
- 28 March, 2SM Morning show
- 1 April, ABC 702 Interview with Kevin Langdon OAM, Vice Patron and past President MNDA NSW
- 4 April, 2SM Morning show with national syndication
- 4 April, 2GB Alan Jones interview with Barry Harrison, Newcastle Support Group

Magazines

- Better Homes and Gardens April issue and website
- Woman's Day magazine website

MND Banners

Monday 27 March to Sunday 9 April 2006

- Footbridge over Sydney Road east of Manly Road, Balgowlah
- Pacific Highway Bridge over Sydney-Newcastle Freeway (F3), Wahroonga
- Coleman Street over M4 Motorway, Mays Hill
- Pennant Street junction with Kissing Point Road over James Ruse Drive, North Parramatta
- Kent Road Bridge over M4 Motorway, Orchard Hills

City of Sydney MND Banners

Sunday 26 March through to Sunday 9 April

- Elizabeth, Park, Pitt, Bathurst and Phillip Streets.
- Wynyard Park, Belmore Park and outside the Town Hall.

The Blue Cornflower Society

The Blue Cornflower Society, named after the symbol of hope for people living with motor neurone disease, has been formed to recognise those friends who have remembered the Motor Neurone Disease Association of NSW in their Wills.

All too often we hear about a bequest only after the benefactor has passed away. The Blue Cornflower Society provides the opportunity to celebrate the support of benefactors with them, and at the same time encourage others to consider this form of support.

Membership of the Blue Cornflower Society is open to anyone who confirms in writing that they have left a bequest of any nature to the MND Association of NSW. It is not necessary to give details of the bequest, just to let us know that you have remembered us. Members will be invited to lunch regularly to hear interesting speakers and learn what their support can make possible.

If you would like more information or a brochure please contact Judy Ford at the MNDA NSW Centre Gladesville on 02 8877 0912 or email judyf@mndansw.asn.au

Family Support

A heart felt thank you to those who responded to the satisfaction survey we sent to people living with MND at the end of last year. Surveys were returned from 80 people and the results analysed to assist the Association to plan services for the future.

The graphs below are an example of the answers to some of the questions about respondents satisfaction with the services the Association provides.

Satisfaction generally was high with all aspects of the family support service and it was very gratifying to note that 91 per cent of respondents would definitely recommend the MND Association to others living with MND.

The comments received highlighted the need for:

- better care in nursing homes
- more contact from the MNDA Regional Advisor
- more support in rural and regional NSW
- more funding from the government
- national retail outlets to sell merchandise
- more home care hours
- more respite care beds
- access to counseling
- more research

Positive comments directly related to the MND Association included:

“As far as I am concerned the MND Association is doing a great and excellent job”

“I feel as though all types of support and service that you have provided to us have been very professional, friendly and I have always felt I could approach staff with any problems or issues. Thank you”

“We think the MND Association is doing an amazing job and would be quite lost without them, Thank you. You are very much appreciated”

“Our family members are overwhelmed by the support and care given by the staff at MND Association and will be forever grateful. We cannot think of any negative comments”

Negative comments directly related to the MND Association included:

“I would appreciate more contacts from a regional advisor”

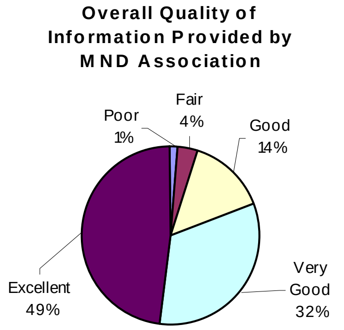
“MND have not done anything but send monthly reviews which doesn't help with the care of [name]. I, as a carer of [a person with] MND, would love some information on anything to do with MNDA”

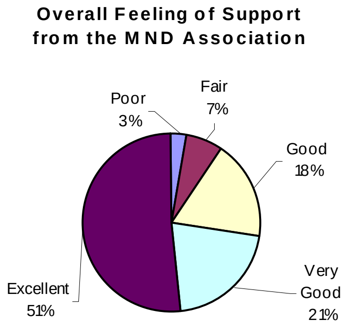
“Inform members directly of equipment available so that MND [Association] and the patients and the family can work out what equipment is needed rather than going for a prescription from an OT”

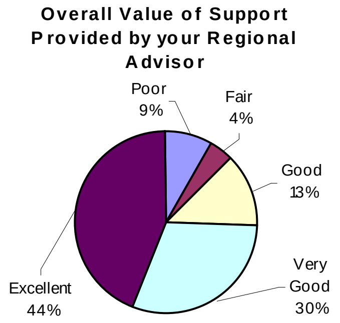
“Equipment officer needed full time. Better support for young carers. Lobby for increased home care hours for people with MND. More support groups for people with MND and carer. Safe lifting education for carers. Linkage with MS Society for respite care accommodation”

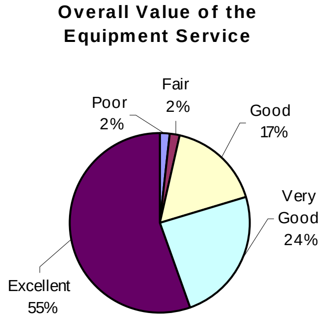
If you would like to see the full analysis of the results please give me a call and I will send you a copy. Alternatively if you would like to provide any feedback on the services we provide, or comment on the above results, please do not hesitate to contact the Association.

Carol Birks
Manager, Family Support









If you would like to provide any feedback on the services provided by MNDA NSW contact the Association on 1800 640 144 or 8877 0999

Family Support

Since the satisfaction survey (see previous page) there have been some changes to MNDA NSW Family Support which we hope will help to address some of the issues highlighted.

Maree Hibbert, Equipment Officer, has increased her hours recently and she is now working 8-3pm Mondays to Thursdays to better meet the equipment needs of our members. Recent changes to the **Regional Advisor boundaries** aim to provide an enhanced and more equitable Regional Advisor service for members throughout New South Wales and the Australian Capital Territory.

Also the **'Speaking to Young People'** project has commenced. This project seeks to address the support needs of young people who have a parent with MND. More information about the project is included on page 6 of this edition of *Forum*.

Information about education and support for **MND Carers** is included in Carers News in each edition of *Forum*. Additionally, the *Carers Kit* is available from MNDA NSW. Please do not hesitate to contact Family Support if you are a carer and would like more information or support.

The Association constantly advocates on behalf of people with MND and their carers to promote optimal care and support. Anita Richter, Graham Opie and I have met on a number of occasions with representatives from the **Department of Disability, Ageing and Home Care** (DADHC) to discuss the need for rapid response packages of care in the home for people with MND. Discussions are ongoing, but in the meantime if you are experiencing difficulties accessing a meaningful level of care and support in the home, please let your Regional Advisor know.

The new Regional Advisors **Jo Fowler** and **Fern Linden** have recently completed their orientation program. All members with MND in their areas have been handed over to them and they are currently working hard on contacting each member. If you have not yet heard from Fern or Jo please do not hesitate to contact them in the office. The toll free number is 1800 640 144.

If you would like to discuss any of these changes or your current needs please do not hesitate to contact me on 8877 0904 or 1800 640 144.
Carol Birks
Manager, Family Support

The 2nd National MND Conference **'MND: Advances, Initiatives and Challenges'** will be held in Sydney on 20 June.

MNDA NSW Revised Regional Boundaries	Regional Advisor	Contact Details
Sydney Metropolitan	Caroline Gleig *MNDA NSW Centre Gladesville*	Mon, Tues, Wed *MND office - Wed* 8877 0905 0409 577 225
Western Sydney and Illawarra *Blue Mountains, Parramatta, Blacktown, Penrith, Wollongong, Kiama*	Ruth Quaken *MNDA NSW Centre Gladesville*	Mon - Fri *MND Office - Thurs, Fri* 8877 0906 0419 225 594
Northern Sydney and Central Coast *North Shore, Northern Beaches, Gosford, Wyong*	Jo Fowler *MNDA NSW Centre Gladesville*	Mon, Tues, Thurs *MND Office - Tues* 8877 0909 0408 803 789
South Western Sydney, Western NSW and New England *Cambelltown, Camden, Liverpool, Orange, Dubbo, Broken Hill, Tamworth, Armidale, Inverell, Northwest NSW*	Fern Linden *MNDA NSW Centre Gladesville*	Mon, Wed, Thurs *MND Office - Mon* 8877 0919 0408 899 863
Southern NSW and ACT *Nowra, Batemans Bay, Eden, Albury, Griffith, Wagga Wagga, ACT, Bowral, Goulburn*	Allison Pearson *Canberra*	Mon, Wed, Fri 6238 3769 0400 701 133
Northern NSW *Lake Macquarie, Newcastle, Hunter, Port Stephens, Taree, Port Macquarie, Coffs Harbour, Ballina, Tweed*	Christina Jason *Newcastle*	Mon, Tues, Wed, Thurs 4965 4406
Family Support *MNDA NSW Centre Gladesville*	Carol Birks *Manager, Family Support*	Mon - Thurs 8877 0904 M. 0408 461 932
	Anita Richter *Carers and Special Projects*	Mon and Thurs 8877 0902
	Maree Hibbert *Equipment Officer*	Mon - Thurs 8877 0907

Carers News

Carers' Workshops

For carers who would like to learn more about managing different aspects of MND our annual **Carers' Workshops** will be held at the Gladesville Centre during **September** this year. The workshops consist of four full day sessions held on consecutive Mondays. Health professionals and members of the family support team will talk on:

- Managing physical aspects of MND
- Aids and equipment
- Managing communication swallowing and nutrition
- Services to assist people with MND and their carers
- Emotional aspects of MND and the caring

For more information contact your Regional Advisor

Speaking to 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: '*Speaking to 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.

Carers Pampering Day

Carers are invited to 'take a break' and share some fun and relaxation at a **Carers Pampering Day** from 10am-3.30pm on **24 July** at our Gladesville Centre. The day will include:

- Self care for carers of people with MND
- Relaxation
- Head and neck massage
- Managing stress with humour

Numbers will be limited, so if you would like to attend, please call Anita Richter on 8877 0999.

Link and Learn Newcastle/Hunter Area March 2007

Following the success of the recent Link and Learn Program conducted in Young for carers from the Riverina, South West Slopes, Central West and ACT areas, a Program for **Carers** in **Northern NSW** has been planned for March 2007.

The two day MNDA NSW Link and Learn Program is followed by six weeks tele-link. It is particularly valuable for remote and regional carers to learn and to share thoughts and ideas on caring.

Carers from **Northern NSW** are invited to attend next year's Link and Learn Program to be held in the **Newcastle/Hunter area in March 2007.**

For more information contact your Regional Advisor or MNDA NSW.

Anita Richter
Special Projects and Carers Services

Meetings for Past Carers

A meeting for past carers was held at the Gladesville Centre on 8 May. A small group of past carers gathered to share experiences and learn about aspects of volunteering.

The next meeting for **past carers** will be held from 12-2pm on **22 September** at the Gladesville Centre.

The suggestion of bringing a plate or a small contribution of food for lunch worked well for our last meeting.

This will be an informal gathering and **all** past carers are welcome. Our CEO Graham Opie will also give a short talk on **'Future Directions for the MND Association of NSW'.** If you would like further information please contact Anita Richter on 8877 0999.

Working Carers Support Gateway

The Working Carers Support Gateway is a website aiming to assist low-income and isolated carers who have both caring and workplace responsibilities. Developed by the Lismore-based Disability and Aged Information Service Inc, the website provides information for working carers. The vision for the Gateway is that working carers are valued, respected and supported to achieve balance in their work and home life.

The Gateway hosts a monthly chat room on the second Tuesday of the month between 8pm and 9pm. The chats are hosted by high profile guests with expertise in areas including finances, relationships, equipment, and health and are an opportunity for working carers to ask questions of experts in these areas. For more information see www.workingcarers.org.au

Carer Respite Centres may be able to help with access to respite care, personal care, equipment and support for younger carers 1800 059 059

Carers News

Link and Learn – Reaching out to Regional Carers Young, March 2006

Thanks to NSW Health for funding to help support Regional MND Carers through the Link and Learn Project.

Carers from Dubbo, Orange, Lithgow, Cowra, Albury, Binnalong, Goulburn and the ACT enjoyed taking ‘time out’ to attend the two day workshop at in Young and were very happy to keep in touch through the six week Tele-link that followed.

(L-R) Ruth Quaken (Regional Advisor), Tereza Cooney, Paul Walker, Fiona Beavan, Vivienne Nicholls, Robyn Gargan, Allan Wilson, Heather Frantzen, Helen Severin, Allison Pearson (Regional Advisor) and Sue Dunn at the Link and Learn Program in Young. Christina Jason, (Regional Advisor) was taking the photograph.

From Sue in Cowra

Just taking this opportunity through the Forum to let other carers of people living with MND know that if they have the opportunity to go to a Link and Learn Seminar, please go, as it is sure to be as rewarding the one I attended in Young in March.

I met some very nice people and we all got on great. It was really good to be able to talk with people who are going through and have the same feelings as you do and to know you are normal.

There were tears and lots of laughs (thanks Heather) and we also enjoyed some pampering which was really nice.

I would like to thank Ruth, Allison and Christina for a memorable couple of days.

Sue Dunn
Cowra

The Link and Learn Program will be held in the Hunter area in March 2007

My Feeble Attempt

The Federation Motel at Young was our destination
We were there as guests by nomination
The proposers were our special half parts
Suffering Motor Neurone Disease were their painful tasks.
Both spouse and ‘spice’ were there to learn
How to manage and cope with the pain of infirm
The frustrations and joys of outdoing the enemy
Were the hopes and handicaps of people with MND.

Day One began at nine, we were showered and dressed to toe the line
Another coffee before we proceed, minties supplied to cater for our need
Bottles, ‘uridomes’, ‘inconti’ pads and walking frames
Something to edify and keep us entertained.
How to lift, how to lower without hurting the ‘caree’
Taught to be cheerful as we dropped to our knee.
How will we ever learn all this stuff
Learning how to whinge and when to bluff.

A hearty lunch hit the spot then back to learning at the trot.

We lifted Ruth on a mammoth contraption
And were told we could have one at home with adaption
Move out a wall and a door as well
A lifting machine will add to your ease and give you a spell.
Any heavy weight can be handled by one
As long as you tighten the girth so it won’t come undone.
Make sure the harness is not tangled or shred
Or your dear luggage will fall on its head.

We went to the club for strawberry stomach liner
Then off to a quaint little cottage with Royal Doulton china
We feasted on pheasant and fish as well
The laughter and merriment broke the spell.
We all trooped home in awkward fashion
And gave the ‘4D doubles’ a score for imagination.
The roads were wide and gutters steep
But we made it home to bed and sleep.

How many days has it been? Only one so far and we’re still keen
We jumped out of bed, rested and with anticipation
We hurdled the pool and made the entrance with expectation.
Allison, Ruth and Christina were there
Again to tell stories and fill our heads with heavy air.
Pampered and puffed, face massage and toes touched up
Even the sandwiches walked around to the salon
Where we were happy and delightfully waited on.
The staff were patient and gave us big smiles
They said come back real soon and we’ll work on your dials.

The trip home was difficult with me on my knees
Pleading with Alli to have one more night please.
The two furrows made by my heels
Are proof that I enjoyed myself and the meals.
No wombat eggs to take to my lover
But hide in euphoria and stay undercover.

The days in respite taught me much
How to be patient with myself and learn to laugh.
The beds were comfy, the rooms divine
The tea and coffee and bickies supplied
Gave me a new aspect of clearing my mind.

Thankyou MND for having tolerance with me
I will never forget the people I met
And all the staff at Federation need a big hooray
For the services they gave along the way.

Heather Frantzen, O’Connor, ACT

Support Groups

Central Coast
Audree Dash
Phone: 02 4384 2907

Central West
Fern Linden
Phone: 02 8877 0999
fernl@mndnsw.asn.au

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
Jo Fowler
josephinef@mndnsw.asn.au
and
Northern Sydney
(Hornsby)
Jo Fowler
josephinef@mndnsw.asn.au
and
Western Sydney
Ruth Quaken
ruthq@mndnsw.asn.au

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

Central West

The Central West support group is going along really well. We have formed really great relationships with each family and find one another's support a great help. It's really nice to talk face to face with others in the same situation. We usually meet on the first Tuesday of every second month at 11am in Orange at the RSL Club… and we 'the carers' know we are only a phone call away from one another and often keep in touch between meetings.

On Tuesday **10 October** we are going to meet at **Dubbo Zoo** for our support meeting, have some lunch together and to just enjoy a good day. So if anyone out there would like to join us they are more than welcome.
Sue Dunn, Cowra

Riverina and South West Slopes

MND Week was the topic of the day at the April meeting of the Riverina and South West Slopes support group. Those from Wagga reported a good response inside the shopping mall where they had set up but the cold weather in Cootamundra and Junee meant that not too many people were out and about.

Meetings are held every second month on Saturdays at The Commercial Club in **Wagga** and are attended by those with MND, their families and also past carers. Anyone interested in attending this group would find a warm welcome and lively conversation.

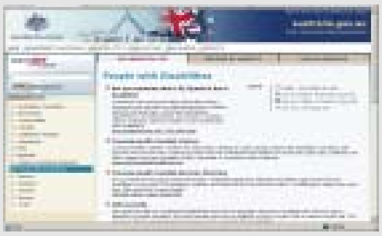
Meetings commence at 12.30pm and dates for the rest of the year are as follows: 5 August, 30 September and 2 December. For further details about this group please contact Wes Russell on 0408 692 127 or Allison Pearson, Regional Advisor, on 6238 3769.

Western Sydney - Kingswood

The support group continues to meet bi-monthly and is attended by people with MND their families and friends. The meetings are an informal get together, with a speaker or group discussion, followed by afternoon tea.

We are lucky to have **Janet Nash**, Executive Officer MND Research Institute of Australia, as guest speaker on the **27 June.** Janet will give us an update on recent projects funded by the Institute. All interested people are welcome to attend. For further information please contact Ruth Quaken, Regional Advisor, on 8877 0906.

Disability Web Portal



A national disability internet portal is now part of the Australian Government's website australia.gov.au. The website links to information and services on over 700 Australian Government websites as well as selected state and territory resources.

The disability portal provides coordinated access to a range of online disability-related information and resources including Centrelink, Carelink Centres and Directory, the Australian Government Department of Families, Community Services and Indigenous Affairs, Disability Rights, HealthInsite and information for individuals and communities.
For more information see www.australia.gov.au/367

MNDA NSW will pay ATO rates per kilometre for people who travel more than 100kms, round trip, to attend their nearest MDNA NSW support group

Equipment

Have you ever wondered what happens to our retired equipment?

Over the years the MNDA NSW Equipment Pool has been operating, many pieces of equipment have been donated and purchased. A recent internal review of the items in the Equipment Pool found that some items had reached their 'used by date', due to advances in technology or because of changes to Australian occupational health and safety laws.

With the assistance of **Hari Singh**, former MNDA NSW Chief Executive Officer, the Association recently retired 27 items of equipment for a well-earned permanent holiday in sunny Fiji at the **Fiji Crippled Children's Society**.

It is great that this equipment, which has helped so many members of our Association, will be used to continue to provide assistance to others. Thanks Hari, for arranging the contact and shipping details.

Maree Hibbert
Equipment Officer

Biotechnology Australia has assembled an information kit containing publicly available information on stem cells - see www.biotechnology.gov.au

Research Project: Financial Impact of MND

Reminder… Earlier this year members of MNDA NSW were sent cover letters and consent forms providing information about a research project looking at the **financial impact of MND on the quality of life of people with MND and their families**. This is a **reminder** note to all members; please make sure you return consent forms or questionnaires (if you have received one) to Deakin University. Your information is needed so that others can be educated about the relationship between financial strain and quality of life in people with MND. Also, your information is needed to **lobby policy making bodies** responsible for providing benefits for people with MND. If you have not yet received a consent form please contact Candice Roberts at Deakin University on 03 9251 7258 or email candice.roberts@deakin.edu.au

Anyone for Tennis?

Darren Rowley and his wife Vanessa decided they would like to raise some funds for MNDA NSW so they got a few friends around for an afternoon of tennis. It was a perfect sunny day and everyone had a great time. The Ku-Ring-Gai Council donated the courts for the event and over $800 was raised. Thank you Darren, Vanessa and friends. We really do appreciate your help.

Maybe you are thinking of holding an event to raise funds for MNDA NSW? We have a great little booklet called *'So You Want to Raise Funds for MND?'* with lots and lots of ideas of ways anyone can do some fundraising and at the same time have a lot of fun! If you would like a free copy of this booklet please call Judy Ford on 02 8877 0912 or email her for an electronic version judyf@mndnsw.asn.au

Volunteering for the Motor Neurone Disease Association of NSW can be a rewarding experience

There are two ways you can become involved:

- *Join a fundraising group.*
- *Come in to the Gladesville Centre to help with administrative duties.*

You will be required to fill in an application form, apply for an authorisation badge and be prepared to have a police check performed if necessary.

If you would like to be involved in either of these roles please contact Judy Ford on 02 8877 0912.

Fundraising Group

Throughout the State we have groups of people getting together to find ways to promote MNDA NSW and raise funds.

Such ways include:

- Selling merchandise during MND Week
- Putting together prizes for a raffle and selling raffle tickets in local areas
- Holding a special event such as a Trivia Night, Auction Dinner, Sausage Sizzle, Card Night or 'Walk to d'feet MND'

Help at the MNDA NSW Centre

We are always looking for volunteers to help with office duties. These include:

- Reception work answering the phones
- Data entry and filing
- Open and logging the mail
- Photocopying and preparation of materials for meetings
- Packing boxes with merchandise to send to other volunteers
- Folding newsletters and inserting them in envelopes
- Other office duties as they occur

MND Week 2006

Launch of MND Week - 28 March

MND Week 2006 was launched on Tuesday 28 March at the Waterview Convention Centre in the grounds of Bicentennial Park. On this very warm, sunny day members and friends gathered to meet with Her Excellency Professor **Marie Bashir** AC, Governor of NSW and to commemorate the start of another week of promoting awareness of MND.

Ralph Warren, President MNDA NSW welcomed those present and the Governor. Her Excellency congratulated the volunteers and staff of the Association for their work assisting people living with MND and spoke passionately and empathically about the impact of MND and of the need for MND research. **Graham Opie**, Chief Executive Officer MNDA NSW focused his address on 'Looking Forward for MNDA NSW'; people living with MND who sometimes "slip through the system", for example people who speak languages other than English, and those of Aboriginal and Torres Strait Islander descent; and of the need for a National co-operative approach for MND. **Janet Nash**, Executive Officer MND Research Institute of Australia, provided an update on MND research in Australia.

Christina Jason, MNDA NSW Regional Advisor, spoke about the Volunteer Visitor Pilot Program and congratulated the first recipients of the MNDA NSW Volunteer Visitor medal **- Ronnie Blennerhassett, Libby Blennerhassett, Lyn Champion, Richard Dash, Sharyn Morris, Brian Schrader, Dianne Toschack and Jenny Way.** Both **Richard and Sharyn** were able to be at the presentation to receive their medals from the Governor and Ralph Warren.

Mrs **Sheila Holmes** and Dr **Robert Marr** were honoured with **life membership** of MNDA NSW and received a special gift presented by the Governor. Sheila is a foundation member of Central Coast Support Group and has organised many local promotional events for the group, including sreet stalls; served as coordinator for the group and more recently, been involved in the Volunteer Visitor Program. Robert's involvement with MNDA NSW started prior to 1982 and he has been instrumental in the growth and development of support services for people with MND in New South Wales.

Malcolm Hodgkinson (front) with Annette Hodgkinson (L), Mark Rosenburg and Dierdre Tebbut at the Launch of MND Week 2006

Our guest speaker, **Mark Rosenberg**, Executive Director of Marketing and Communications for the Sydney Olympic Park Authority spoke about the future of the Park and of some of the newer attractions for visitors. Mr Rosenberg had been instrumental in helping secure our access to the lovely venue for the Launch.

Judy Ford
Fundraising Manager

The Port Kembla crowd traveled together by bus to attend the Launch. (L-R) Tina, Anne, Shirley, Ted, Ron, Michelle and Erin (Port Kembla Rehabilitation Hospital), Angela, Gwen, Ruth (Regional Advisor) and Vi

(L-R) Richard Dash and Sharyn Morris, recipients of the Volunteer Visitor Medal with MNDA NSW Patron and Governor of NSW Her Excellency Professor Marie Bashir AC

A Date for Your Diary

MND Week 2007

6-12 May

Sail with Sailors with disAbilities

The charitable organisation *Sailors with disAbilities* have invited people with MND to cruise Sydney Harbour with their volunteers on **Sunday 22 October** from 1pm to 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 crewe'.

MND Week 2006

March of Faces – 1 April

Once again the City of Sydney was awash with blue and white as the MND Week flags flapped in the autumn breeze. Driving down Elizabeth Street, George Street, Bathurst Street and across Martin Place one could not help but be impressed with the flush of colour and the strong awareness of motor neurone disease.

A glimpse of sunlight for the those walking through Hyde Park on 1 April for March of Faces 2006

The March of Faces was a quieter affair than last year. We assembled in Hyde Park ready to present to passers-by the faces of loved ones who have been touched by MND. The strong winds made it difficult to keep the banners from falling over but the walk through the park still created a sense of commonality. The Rotary Club of Strathfield put on a very welcoming BBQ on this unusually cool day and we are most appreciative of their continuing support.

Bring your friends to the Spring Luncheon on 1 September and help to raise funds for MND research

Other Events

It was easy to think one was playing golf in Hawaii at the Golf Day organised by the Newcastle support group when all players turned up for **A Loud Shirt Day**. It was a lot of fun and ended with a most successful dinner and auction. Well done to the organisers.

Mary and Michael Wilson at the MND March of Faces Hyde Park 1 April

Thank you to all those magnificent people who contributed to the week. We hope you will all mark your diaries for 6-12 May 2007 for MND Week 2007.

Judy Ford

Fundraising Manager

Motor Neurone Disease Charity Golf Day

On Monday 1 May one of our keen volunteers, **Matt Grant**, organised a charity golf day and auction at the Cronulla Private Golf Club to help raise funds for our association. Matt lost his 56 year old mother, Diane Grant, to Motor Neurone Disease four years ago.

The charity golf day helped to raise awareness and also to raise funds to help pay for research into the disease. The day started with a BBQ lunch and 18 holes of golf followed by a two course dinner at the Fairview Restaurant in the Golf Club. "We were really pleased with the number of people who supported the day", Matt said. "We acquired some wonderful items for auction including sporting memorabilia, a bridge climb and special restaurant dinners and these were all snapped up quickly."

Another great supporter of MNDA NSW, Michael Cripps, was a major sponsor of the day and filled three tables with friends and associates at the dinner. The day was very successful and raised a large amount of money.

star room
Sydney's best kept secret

SPRING LUNCHEON

Start the new season with a fun filled afternoon and luncheon learning about creating beautiful memories through the art of Scrapbooking. In addition, stalls displaying beautiful hand made cards, writing paper and other lovely crafts will be available at which to make purchases.
(Only 116 days to Christmas!)

Bring your friends and make up tables of eight and help to raise funds for MND research.

Date: Friday **1 September 2006**
Time: 12.30pm
Venue: Star Room, above the Imax Theatre, **Darling Harbour**
Cost: $75 per person including 3 course meal and drinks
To book tickets please phone Roslyn on 02 8877 0999
Payment can be made by credit card or cheque

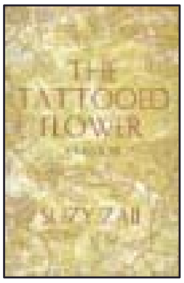
Guest Speaker: Susan Chisholm
"Photo Preservation and Album Making using Scrapbooking Techniques"

If you would like to have a stall at this function or know someone who would, please phone Roslyn Adams on 8877 0908 for details.

Book Review

The Tattooed Flower. A Memoir by Suzy Zail

213 pages, paperback.
Scribe, Melbourne, 2006. ISBN: 1920769765



This is a touching, well written and cleverly constructed book written about a family's journey of discovery after the author's father is diagnosed with Motor Neurone Disease.

It is the story of Emil Braun's extraordinary life as a child growing up in an anti-Semitic town in Czechoslovakia in the 1930s and his survival during WWII, his numerous brushes with death in the concentration camp at Birkenau and his escape to a better life in Australia. Here he settled, worked hard, married and ensured that his much loved children were happy and secure and that their carefree childhood provided them with the opportunities their father had been denied. When his illness cast a shadow over their lives, his daughter Suzy became aware that there was much she didn't know about her father's early years. So the family gathered to hear the story of his childhood, the devastation brought upon his own family and his amazing survival against all odds.

As Emil's story unfolds, Suzy Zail takes us on the other journey in her father's life, that of the progress of the disease which will eventually take her beloved father from her. It is an inspirational story about how one person can overcome adversity, deprivation and tragedy, yet remain positive and strong, enjoy life and show what can be achieved through hard work. Emil's strength of character shines through the story, reminding us that life is better if it is filled with love and hope.

There is no happy ending for Suzy and her family, but there is no doubt that Emil will live on in the memories of those who read The Tattooed Flower. It is an easy book to read and while sad at the end, cannot help but leave the reader enriched by Emil's story.

Fern Linden

Regional Advisor

Dates for the Diary

7 June	DNA Donor Drive and Information Session *Armidale*
20 June	2nd National MND Conference *Sydney*
21 June	*ALS/MND Global Awareness Day*
24 July	Carers Pampering Day *MNDA NSW Centre Gladesville*
24-28 July	Regional Advisor Visit *Gundagai, Wagga Wagga, Tumut Tumbarumba and surrounding areas*
8 August	Information Evening for people recently diagnosed their families and friends *MNDA NSW Centre Gladesville*
1 September	Spring Luncheon *Star Room, Darling Harbour*
4, 11, 18, 25 September	Care for Carers Course (1 day per week for 4 weeks commencing 4 September) *MNDA NSW Centre Gladesville*
16-17 September	Suzanne and Bob Ballinger's Open Garden for MND *at Homeleigh, 17 Linden Avenue, Pymble*
29 September	Past Carers Meeting *MNDA NSW Centre Gladesville*
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) *MNDA NSW Centre Gladesville*
2 December	Christmas Party for members and friends

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

Contact MNDA NSW on 8877 0999 or 1800 640 144 for further information about any of these events

Australian Government 2006-07 Budget

During May 2006, the Commonwealth Government Budget included:

- A Carer Payment bonus of $1,000 and a bonus of $600 for recipients of the Carer Allowance
- An additional $5 M a year for the National Adult Stem Cell Research Centre
- Continued funding for a range of national palliative care in the community initiatives

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