

## December 2007

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**F**or many people Christmas is happy and joyous time to celebrate with people we care about. However it can also be a difficult time for some people who are experiencing changes in their life and who can feel overwhelmed by the Christmas preparations.

With a few simple changes, realistic expectations and some planning you can still have an enjoyable time without the high levels of stress that can be felt without appropriate planning.

The following is an excerpt from an article I found on the internet recently called 'Coping with Christmas' by Clair Wavell at [www.changeworksunlimited.co.uk](http://www.changeworksunlimited.co.uk)

**Gina Svolos**  
*Family Support Manager*



### So what can you do to make this Christmas as stress free as possible?

- ✳ Be honest about the type of Christmas you want. Would you like a day with just your immediate family? Maybe you would like to be with your friends or perhaps going away appeals? Everyone can be accommodated in some way but it's about finding a balance.
- ✳ Be aware about what causes you stress and think of ways to minimise this before hand. Stay focused on the solution rather than the problem and talk openly about it if it helps.
- ✳ Take control of your time and plan ahead. List everything that needs doing and decide when you will fit it all in. Ask family members for help and be realistic, if you don't have time to make your own mince pies it's not the end of the world.
- ✳ As you are in control of your time, allow a few hours for some fun and relaxation. It could be as simple as a haircut, a nice walk or an afternoon reading a book.
- ✳ Take time to work out your budget before you start shopping and be sensible. Take into account the number and cost of gifts, food and drink, parties, new outfits and any travel and stick to it.
- ✳ If you don't have the money cut back and be honest with people telling them upfront, they will appreciate your honesty and may even follow your lead.
- ✳ Look after your health; drink plenty of water, eat well, get enough sleep, exercise regularly.
- ✳ Try to be more assertive; ask for help before and on the day, know you have the right to decline invitations if you don't want to go out night after night, and remember Christmas does not mean having to please everyone around you.
- ✳ Be realistic about people, they don't change just because it's Christmas. Try to think ahead about who or what causes tension in the family and work together to find a compromise.
- ✳ And last of all make sure you have the essentials in the house like tin foil for the turkey and batteries for the new toys, these small things can make a big difference to the enjoyment of the day!



*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**

In late October MND NSW, MND Australia and the MND Research Institute of Australia held their annual general meetings at Gladesville. After four years as President of MND NSW, Ralph Warren has been elected President of MND Australia. Although stepping down from his role as President of MND NSW, Ralph will remain on the Board. During his tenure as President of this Association membership has grown dramatically; we moved to our Gladesville Centre and our family support services have expanded.

The 2007-08 MND NSW Board is:

President	Phil Bower
Vice Presidents	Roger Henshaw Janice Scheinecker
Secretary	Bob Howe
Treasurer	Bob Templeman
Members	Alex Green, Gary Jacobson, Nick McLoughlin, Ralph Warren

It is fitting that, following the annual general meetings of both MND Australia and the MND Research Institute of Australia, we take some moments to look back at the development of the MND Association. Marjorie Harrap, a founding member of MND NSW provides us with an interesting account on page 8 of *Forum*.

Our Association has had an active role in the inception and development of the MND Research Institute. In 2006-07, MND NSW directed over \$100,000 of funds to MND research. We are grateful for the generosity of our donors and commend our supporters for their fundraising efforts towards understanding the causes, finding effective treatments and discovering cures that will lead to the ultimate eradication of motor neurone disease.

Our inaugural *Walk to D'Feet MND* took place at Sydney Olympic Park on Sunday 4 November (see page 11). More than 260 walkers attended despite the atrocious weather leading up to the event. The day itself turned out to be a cracker and I would like to thank the intrepid band of volunteers and staff who helped run the event so smoothly. It is a fantastic event that can be run easily in any community. If you would like information about how to run *Walk to D'Feet MND* in your community please call Roslyn Adams, Fundraising Coordinator on 8877 0908.

Over the past few months we have had several staff changes. We farewelled Karen Kemp and Fern Linden, Regional Advisors, in September and October. Judy Ford, our Fundraising Manager, moved to Canberra in December. Our new regional advisors, Eileen O'Loghlen (based in Newcastle) and Robyn Petersen (at Gladesville) introduce themselves below. Welcome Eileen and Robyn.

Our office will be closed over Christmas from Monday 24 December and will reopen on Wednesday 2 January. If help is needed during the Christmas break, please consult your doctor

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

We wish you a peaceful and safe Christmas and New Year.

**Graham Opie**  
*Chief Executive Officer*

*MND NSW will be closed from Monday 24 December and will reopen on Wednesday 2 January.*

## **Introducing...**

**Eileen O'Loghlen**  
*Regional Advisor  
Greater Newcastle and Mid  
North Coast.*



I feel privileged to have been given the opportunity to join the family support team as a regional advisor. In my few weeks of employment, staff members of MND NSW have made me feel very welcome. I have attended the Special Interest Groups Workshop and Learn Now /Live Well Program and gained valuable knowledge through meeting people with MND and hearing from invited speakers.

I am a registered nurse and I have worked most recently as a home care nurse assisting clients with complex medical needs. I have recently moved from Victoria to Newcastle with my family. I have four sons and we have all settled well and enjoy the Newcastle lifestyle. I look forward to meeting all members and their families in my region.

**Robyn Petersen**  
*Regional Advisor  
South West Sydney, Illawarra  
and Far North Coast*



I am enthusiastic about commencing in my regional advisor role and applying my past professional experience to the position. I trained as a nurse at St Vincent's Sydney and have completed post graduate study in operating theatre, management, gerontology and palliative care.

My main nursing experience has been in community health. This encompassed an involvement in nursing, healthy lifestyle community programs and setting up support groups.

I am looking forward to the challenge and the logistics of visiting members living with MND in South West Sydney, Illawarra and the Far North Coast

## Family Support

It's hard to believe that end of the year is almost upon us. This year we have seen the start of some new projects that will continue into 2008.

### FlexiRest

Our new FlexiRest program has now commenced. This is a flexible respite program that provides funding to members to assist with respite.

This new initiative operates with funding from the Department of Ageing, Disability and Home Care (DADHC) and is run by a consortium consisting of the Muscular Dystrophy Association of NSW, Motor Neurone Disease Association of NSW and the MS Society of NSW/VIC. These three organisations worked together to apply for this funding that will assist members from these organisations when they need it.

FlexiRest funds respite and by this we mean anything that is a break for you and your family and/or carer. FlexiRest aims to be flexible and responsive to your individual needs. The word 'flexible' is used to describe the FlexiRest program because it is for funding respite that cannot be funded through existing government funded services or programs. More information about FlexiRest is included in this edition of *Forum* on page 5. For further details contact your MND NSW regional advisor or the Info Line on 1800 777 175.

### Volunteer Visitors Program

We have also received funding through the Lord Mayors Fund to extend the Volunteer Visitors Program (VVP). In 2005-06 a pilot VVP program was established in the Newcastle area and we now have several volunteers assisting in the Hunter region. This new funding will enable us to extend the program to the Sydney area through the employment of a VVP Coordinator.

### Community Options Program

Another program that you may hear about from your regional advisor or NSW Government Community Options Program (COPS) case manager is MNDPacks. Specific money has been allocated to NSW COPS following submissions from MND NSW and NSW COPS to fund a pilot project for one year. This pilot provides assistance to people with MND whose circumstances have changed causing a need for additional services which may not be immediately accessible because there is a waiting list, such as home care. The funding aims to provide rapid service response to people with MND in the interim period, while they are on a waiting list, until they can be provided the 'wait listed' service.

As part of this project NSW COPS will be



At Christmas time we reflect on memories of the past year: shared happiness - shared sadness - loss, love, achievement, joy, hope.



Christmas is a time of mixed emotions, particularly when motor neurone disease is involved. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

If you have not already returned your member survey please complete and return it. The results will be used to help us plan and develop MND NSW services.

interviewing some members to look at their service provision and the impact this has on people living with MND. You may be approached by your COPS case manager or your regional advisor to participate in this study and I encourage you to participate. The study is seeking information about what life is like for people with MND and whether people living with MND get the services they need. If you are interested in participating, contact your regional advisor. There will also be an online survey that all members can complete. This will give you the opportunity to contribute your story about the experience of living with MND and for this to be used as data when more funding is needed. We will let you know when this is ready.

### New Regional Advisors

Two new regional advisors have been employed following the resignations of Karen Kemp and Fern Linden. We would like to thank Karen and Fern for the work they have done for people living with MND and we wish them well for the future.

We welcome our new regional advisors, Eileen O'Loghlen and Robyn Petersen, to the Association.

Eileen, who commenced in October, is working in the Hunter and Mid North Coast areas and is based at our Newcastle office at the John Hunter Hospital. Robyn commenced in November and is based at Gladesville. She will be working in the Illawarra, South West Sydney and Far North Coast areas. Robyn will also be working as the Volunteer Visitors Co-ordinator one day a week from early next year and will be extending this program to the Sydney area. Eileen and Robyn will be in contact with members from their areas once they complete their orientation programs.

### Member Survey

All of our members with MND should have received a membership satisfaction survey during the middle of November. This survey will help us know what you think about how we provide services to you. If you have not already returned your survey I would encourage you to complete and return it as we use the results of this survey to help us plan and develop our services. We really want your feedback about how we are doing and also suggestions for improvements.

### Gina Svolos

*Manager Family Support*

**Carers News**

At the end of the Care for Carers program, many of us, participants and myself as one of the facilitators, felt we had been on a journey together. It was a journey that started off by getting to know one another. For the carers it meant meeting others in similar situations, sharing experiences, voicing some of their fears, giving practical advice, offering support as well as giving comfort to one another when things got difficult. It was also about learning the practicalities of caring for someone with MND with sessions on a wide variety of topics.

It's a big commitment for carers to come along for four Mondays for the program. However I think it is the focus on the carer as well as the person with MND and the process described above that makes people come back each week.

We looked at self care including taking time out and nurturing relationships. To finish the program we went to the building opposite the Association - the Gladesville Pottery Studio based in the historic bakehouse, where, thanks to the support from the studio and time given freely by two Sydney potters, we were able to get creative molding anything from leaves to pears, plates, tiny animals and objects that defied classification!

Carers need knowledge to deal with the day-to-day issues and to plan for future events. They also need government recognition and support. A new report 'The Wellbeing of Australians - *Carer Health and Wellbeing*, by Carers Australia, Australian Unity and Deakin University, reports that carer wellbeing is well below other groups studied in Australia including the unemployed, low income earners and those who live alone. Caring comes at a huge cost to carers and affects other household members as well.

An astounding figure about the cost of carers contribution to society comes from a campaign called 'if you don't care...why should we?' launched before the election by Carers Australia, the national voice for carers. If service workers replaced carers it would cost the government over \$30.5 billion per year. Perhaps that figure is not so outstanding to most of us. We know the value of carers.

**Jane Barrett**

*Family Services Coordinator*



*Care for Carer participants Sylvia Herrera and Jean Lee relaxing and getting creative at the Gladesville Pottery Studio guided by skilled Sydney potter Barbara Taggart*

**Equipment**

We have recently purchased, through funds raised at the 'Spring into Action' event (see page 10), one Lightwriter and two shower commodes. In the near future we will be purchasing an electric wheelchair, an additional Lightwriter and a page turner with specialised switches. A further two Lightwriters have been purchased with funds generously donated by the Robert Topfer Family Trust. Thank you.



*Recently purchased Lightwriters*

The few weeks leading up to Christmas and the New Year are busy for everyone including the MND NSW Equipment Service. Requests for equipment loan usually increase during this time as everyone likes to get organised before Christmas and be settled well before the Association closes for the short break over the holiday season.

The MND NSW Equipment Service will remain operating during the last week before Christmas but deliveries may be delayed due to this being a very busy time for our courier companies.

A reminder that if an equipment breakdown or emergency does happen during the time the Association is closed please contact the health professional, for example, your occupation therapist, for assistance.

I would like to take this opportunity on behalf of the MND Equipment Service, Trevor, Matthew and myself, to wish everyone in the MND family a safe, memorable and happy holiday season.

**Maree Hibbert**

*Equipment Services Coordinator*

**MND Australia Travel Grant**

In September 2007 Maree Hibbert, MND NSW Equipment Service Coordinator, was successful in applying for the first MND Australia Travel Grant.

Maree will be reviewing the equipment services of both existing and developing state MND services in Australia. Outcomes include the sharing of information between state associations; looking towards standardising and improving service to people living with MND; and to further develop specific equipment information for health professionals working with people with MND. MND NSW will also contribute special project funding towards the project.



*As one of her last official duties, the outgoing MND Australia President, Helen Sjardin presented Maree Hibbert with the Travel Grant Certificate*

*2008  
Care for  
Carers  
Program*

*MND NSW  
Centre,  
Gladesville  
20 May  
27 May  
3 June  
10 June*

### Learn Now Live Well

This two day educational workshop for people with MND, their family and friends was held at our Gladesville Centre on 12 and 19 November. On the first week an occupational therapist spoke about maintaining independent living at home and tips and tricks to use around the house. This was followed by a physiotherapist who spoke about the value of exercise. The second week focused on speech, swallowing and breathing.

Participants found the workshop valuable. ...

*"It gives me less fear about the future knowing I am now prepared for what may come."*

*"Meeting other people with MND is most important and informative."*

*"...enlightening, informative and instructive. (We) derive a great deal of benefit and support from these activities and all the seminars and programs which are arranged and provided by MND NSW. "*

*"I think the MND Association does a wonderful job. Knowing that they are there and all the services they offer is reassuring."*

*"(I) gained a lot of information re MND and where to go for help."*

**Caroline Gleig and Jenny Judd**  
Regional Advisors

There is an e-network based at MND NSW which



Regional Advisors Jenny Judd (l) and Caroline Gleig (r) with the Learn Now

### MND Workshop for Health Professionals

extends across NSW and further a field, made up of healthcare professionals - occupational therapists, physiotherapists, nurses, dietitians, speech pathologists, social workers and case managers with an interest in MND. The members are part of three main Special Interest Groups: Psychosocial, Swallowing, Nutrition and Communication and Independent Living, commonly just abbreviated as 'the SIGs'. The SIGs were set up following the 2005 National MND Conference in recognition that health professionals need support in their work. Every two months I send out an e-bulletin with the latest MND news plus key research articles.

Health professionals involved with people with MND also need to get together to talk to others. Isolation is not just geographical but comes from working with an uncommon but complex disease. With the help of representatives from the SIGs I organised the third annual MND SIG workshop. A good venue, time to network plus great speakers made for a highly productive day. There was excellent feedback with many suggested topics for the next workshop. Thanks to sanofi aventis for their support.

**Jane Barrett**  
Family Support Coordinator



Workshop presenter Patsy Pynn, Calvary Hospital, with Lauren Thompson and Rebecca Anderson, occupational therapists from Port Kembla Hospital



Nina Brodaty, physiotherapist from Prince of Wales Hospital spoke about exercise and MND

*Respite means providing carers and people with MND with a break from their usual routines and caring responsibilities. Depending on the needs of the individual and their carer, respite can be offered in many different ways.*

### Flexible Respite Program – FlexiRest

MND NSW offers a new flexible respite program called 'FlexiRest'. FlexiRest funds a range of respite-related services either in-home or out-of-home for people with progressive neurological disorders, their families and carers. Some examples include:

- In-home respite where the respite is provided in your home for a nominated period of time
- Short breaks, for example support for the whole family to go on a short holiday together
- Peer support respite involving leisure and recreation activities with people of similar age and interests
- Transport support for you to access respite services

This new initiative operates with funding from the Department of Ageing, Disability and Home Care (DADHC) and is run by a consortium consisting of the MS Society of NSW/VIC, Muscular Dystrophy Association of NSW and the Motor Neurone Disease Association of NSW.

**Members of MND NSW who have a demonstrated need that cannot be met by existing respite services can apply.**

*For further information contact your regional advisor or the MND NSW Info Line 1800 777 175*

Email or write your letter to the editor of Forum. See back page for contact details

## Support Group News

### Central Coast

We meet bi-monthly and we have had a variety of interesting speakers this year. It was good to welcome some new members to the group and sadly, again, we have lost some of our friends. Our thoughts and love are extended to these families, as the festive season approaches. Once again, the year has flown.

Just a timely reminder that the Rotary raffle needs to be finalised by early February. So please bring along booklets and tickets to go into the draw. There are some wonderful prizes this year. Thank you to all those who have so generously given their time, their money and their energy to our fundraising pursuits. It is through these endeavours that we are able to continue to provide support for those with motor neurone disease.

We would like to extend our thanks to our members and carers for their continuing support. It is you who make our meetings so rewarding. We look forward to the coming new year with hope. Our first meeting next year will be held on 2 February. Hope to see you there.

### Audrey Dash

### Kingswood

The final meeting for 2007 was enjoyed thoroughly as we were entertained by musicians Pat Drummond and Karen Lynne. They were warm, talented and funny. It was a privilege and a pleasure to have them along for our enjoyment. We hope that they might come again sometime. Next year the group will be meeting from 1-3pm on 29 Jan, 25 Mar, 27 May, 29 Jul, 30 Sept and 25 Nov at Kingswood Neighbourhood Centre, 19 Bringelly Road, Kingswood.

*Jenny Judd - Regional Advisor*



(l-r) Margaret, Frances, Bregetta and Jean at the Kingswood Group (left) and the Central West Group at the October meeting (right)

### Northern Sydney (Hornsby)

Our members and carers have all benefited from the knowledge and expertise of the guest speakers at our meetings throughout the year. Dates for 2008 meetings are still to be finalised.

We meet at Thornleigh Community Centre. If you would like to join the group or would just like to come along to see what happens at a meeting, we would make you most welcome. Merry Christmas to all. Ho Ho Ho!

*Jo Fowler - Regional Advisor*



*Jue and Thomas Gardiner at the Hornsby Group*

### Central West

On 15-16 October, I drove to Dubbo, Orange and environs visiting rural members living with MND. I also met with Community Options Program staff who are working energetically to assist people living with MND on a daily basis. While I was in Orange the Central West Support Group was held at the Orange Ex-Servicemen's Club. Three allied health professionals from Orange Base Hospital spoke about their roles in assisting people living MND. After the group, a lovely lunch was provided courtesy of Carers NSW (and the Ex-Servicemen's Club who always look after us very well), as this meeting coincided with Carers Week. This was a small way of acknowledging the amazing work done by people caring for those living with MND. The next group will be on 18 December and will be a Christmas get-together. Meetings next year will be held on 19 Feb, 15 April, 17 June, 19 Aug, 21 Oct and 16 Dec.

And my advice for anyone driving at night in these areas is to watch out for killer moths! They were everywhere.

*Jenny Judd - Regional Advisor*



## Support Group Contacts

### Metropolitan:

Ph: MND NSW 1800 777 175

#### Gladesville

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Northern Beaches (Mona Vale) and Northern Sydney (Hornsby)

Jo Fowler

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Jenny Judd

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### Regional and Rural:

#### Central Coast

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#### Central West

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#### Coffs Harbour

Lily Jenkins Ph: 02 6652 2571

#### Illawarra

Cindy Cherry Ph: 02 4223 8000

#### New England

MND NSW Ph: 1800 777 175

#### Newcastle and Hunter

MND NSW Ph: 1800 777 175

#### Northern Rivers

Helen Gates Ph: 02 6621 4018

#### Riverina and SW Slopes

Susan Chambers

Ph: 02 6942 3970

#### Southern Highlands/Monaro

Allison Pearson Ph: 02 6238 3769

allisonp@mndnsw.asn.au

MND Week  
4-10 May  
2008

Cornflower  
Blue Day  
9 May 2008

## Mailbag



Looking down from our room at Victoria Falls Safari Lodge we could see the water hole a few hundred yards away.

Around it were gathered malibu storks, smaller birds, wildebeest and zebra, the latter drinking warily. During the night we had heard the sounds of buffalo and lions roaring.

We (my friend Joan Walker and I) had been in Kenya visiting several National Parks to see the animals in the wild. We saw the big five - elephants, lions, leopards, rhinos and buffalo, as well as various types of antelope, giraffes, baboons, monkeys and numerous other creatures. One monkey invaded our room and ran off with a muesli bar. He had opened the plastic container and was about to rifle the suitcase further when he was disturbed.

We were in Zimbabwe to see the Victoria Falls. We had a helicopter ride over the Falls as well as walking around the baboon inhabited tracks to view them from the ground.

We had flown to South Africa, landing at Johannesburg, from which we went first to Durban on the East Coast, then to Kenya to see the animals, then Victoria Falls and finally Capetown - a very attractive city with several places of interest. We visited the Kirstenbosch Gardens, the Waterfront complex of shops and boats in port, Table Mountain with its extensive views of the city and, of course, the Cape of Good Hope, the most southerly point in Africa. We saw seals and penguins which, unlike our Australian penguins, were scattered on rocks and sand in the sun.

In all, we had ten plane trips, returning to Johannesburg before each destination. The three weeks went all too quickly but our photos will serve to keep the pleasant memories alive.

**Betty** - Member MND NSW  
Castle Hill

My wife June was diagnosed with MND in February this year. I would like to congratulate MND NSW for the wonderful assistance she has received from your organisation.

June's father, Arnold Bridge passed away with MND over twenty years ago so her disease is hereditary.

Some of the help June has received includes guidance from MND staff and the loan of equipment including a folding wheelchair, electric lounge chair, Polyanna computer, shower chair and a Jet 7 electric wheelchair. We have received literature and a carers handbook provided by MND NSW

Also, I attended a two day MND Carers seminar in the Hunter Valley with all costs provided by MND NSW and participated in a carers 'ring around' for six weeks. This has proved very beneficial to both June and myself.

All of these were not available to June's father and his family twenty years ago. We both congratulate your organisation for its wonderful progress.

**Col and June** - Members MND NSW  
Forster

MonStar Cup  
18 Mar 2008  
Pennant Hills  
Golf Club,  
Beecroft  
Golf Day and  
Dinner

## Family Support Calendar 2008

- 19 Feb**      **Information Evening**  
*For people newly diagnosed with MND  
and their families and friends*  
MND NSW Centre Gladsville
- 4 Mar**        **Living on after MND**  
MND NSW Centre Gladsville
- 20 May**      **Care for Carers Program (4 days)**  
**27 May**      MND NSW Centre Gladsville  
**3 June**  
**10 June**

For more information contact the MND NSW Info Line  
1800 777 175

*If you would like assistance with travel to attend family support sessions or would like us to organise an MND information session in your region, please speak to your regional advisor.*

## HUNTERS HILL ANNUAL WHITE CHRISTMAS PARTY<sup>3</sup>



**Where** | Hunters Hill Bowling Club  
**When** | Saturday 22nd December @ 2.30pm - 9pm  
**Dress** | Crisp White

Come and join the Christmas celebrations with generous raffles, barefoot bowls, music, fabulous bistro and entertainment

All money raised going to the Motor Neurone Disease Association Gladsville

Tickets/Donation \$10 - sold at the door on the night  
Enquiries/Donations - please call  
Vanessa 0412 307 675 or Isaac 0410 404 290

## Looking Back

*Mrs Marjorie Harrap is a founding member of MND NSW, having been actively involved in the Association since 1981. She is now a life member, and continues to work in the office one day per week as a volunteer.*

"I think the organisation began in much the same way as other similar organisations have begun - a family member, relative or friend is diagnosed as having a rare or uncommon disease - information and literature is very difficult, almost impossible, to obtain - and the need for a support group becomes obvious.

In 1981, my husband Bill was diagnosed as having amyotrophic lateral sclerosis (ALS), the most common motor neurone disease by Dr Brian Somerville at the Neurological Centre, Westmead. Bill was eager for information and, after answering some of his questions, Dr Somerville gave us some literature he had recently obtained from the ALS Society of America.

On one of our visits Dr Somerville mentioned his concern for the plight of people with MND and their carers and asked us how we felt about "getting something going" - a support group providing information, advice and possibly equipment.

And so we approached family and friends - we knew no one with MND at this time - and the Amyotrophic Lateral Sclerosis Society of Australia (renamed the Motor Neurone Disease Association of NSW Inc in May 1994) was formed on 9 December 1981 by a group of seven volunteers who became the management committee - Dr Dawn Thew, Don Thew, Colin and Denise Grundwell, Alex and Lynette Henderson and myself with Dr Somerville as our very active medical advisor.

Our aim was to provide emotional support and to disseminate information concerning specialised medical and paramedical services, equipment and other supportive measures available to people living with MND and to promote an interchange of ideas concerning patient management.

Volunteers served on the management committee, maintained the day-to-day running of the Association and organised meetings and workshops



*Marjorie Harrap at Roselands Shopping Centre in the 80's - raising MND awareness and funds for the Association*

for people living with MND. In city and country areas they participated in all sorts of fundraising ventures - street stalls, concerts, balls, fun runs, raffles, bowls and card days - to support the work of the Association.

During the 80's the Association organised several very successful seminars and workshops. Important events included the 1982 'Seminar on ALS' when Eames Bishop (the then President of the ALS Society of America) was guest speaker. The Neurological Centre at Westmead was full to overflowing with about 200 people in attendance and the Association really 'took off'. In 1983 the seminar 'ALS and Research' brought together members and researchers for the first time.

The Association created a special account for research into MND and regularly set aside funds for this purpose. In 1986 a separate entity was created, the ALS Research Foundation (since renamed ALS - Motor Neurone Disease Research Institute Inc., and then the Motor Neurone Disease Research Institute of Australia). The funds raised in NSW for research were transferred to the new entity. Dawn Thew became the inaugural Honorary Chairperson of the Research Institute.

In 1989 Australian MND Associations came together for the first time. Although this meeting was organised and hosted by the NSW Association, it was held in Adelaide. There was a very worthwhile exchange of ideas and it was decided that the first National Awareness Week would be held from 1-8 April in 1990. In 1991 the Motor Neurone Disease Association of Australia was formed."

### **Marjorie Harrap**

Ed. In 2000-07 MND NSW received more than 3,200 Info Line calls, loaned 1048 equipment items, conducted 49 information/education sessions for service providers and community groups and directed over \$100,000 of funds to MND research. Thank you Marj and Dawn.

*Isaac (the camel), Marjorie Harrap (1st Honorary Secretary 1981) and Dawn Thew (1st Honorary President 1981). Marjorie said, "On a recent trip to Broome, Dawn said to me that a camel ride on Cable Beach was a must. I wasn't at all sure about this nevertheless... - the most challenging part was getting on. Otherwise I quite enjoyed the ride on Isaac and felt quite chuffed about it all when, on seeing the photo, my granddaughter Lois said, "I'm proud of you Grandma!"*



Marjorie said, "With MND it is 'take one day at a time'. With the Association it is 'from little acorns oak trees grow'"



## Members Christmas Party 2007

While the rest of Australia was thinking about the election on 24 November, MND NSW members, staff and volunteers were having a fabulous time at the Members Christmas Party 2007.



Jean Lee and Janice Berg



MND NSW Vice President Janice Scheinecker with (l-r) Olivia Cauchi, Tara Perkins and Leah Perkins



MND NSW Vice President, Roger Henshaw, led the carols



"Which one will I pick?" Caroline Gleig (l) helping Debbie Fotiadis choose her prize



Renewing old acquaintances and making new ones



(l-r) Gerri McCurtayne, Andrew Connell and Sally Rust



Trish Saladine and Jennifer Cauchi



Matt Fowler and Jillian Henshaw

Warren and Pat Ball



Cathy Loughlin



Santa Matt Fowler was generous - pictured here with MC Jo Fowler (l) and Debra Larizza

### With thanks to...

About Life Rozelle  
 Entertainment Publications of Australia  
 Cornucopia Café Gladesville  
 Marjorie Harrap  
 Lynette and Alex Henderson  
 Debra Larizza



Joy Pogson  
 David Radford  
 Liz Sandwith  
 Gwenanne Taggart  
 Members and Staff

### Book Review - Losing My Voice by Barbara Frances Williams



Barbara Williams is from Auckland in New Zealand and has obviously always been a very active, energetic woman. She is also highly accomplished in her personal life and equally accomplished in her professional and academic endeavours. In 2003 her children were independent

adults and she was very keen to further her career and to travel which, apart from her family, were two things that she was quite passionate about.

In 2004 an ongoing cough and huskiness in her voice led Barbara to seek some medical advice. Along with her family, friends and colleagues she was understandably shocked to be diagnosed with motor neurone disease. The following couple of years have led Barbara on a journey of discovery about the world around her.

Each page of Barbara's book takes us through the frustrations and anger she often felt, embarrassing episodes and the distress caused by her slowly diminishing independence. Despite the difficulties there are also some amusing moments. Sometimes readers will shake their heads in disbelief that people can be so ignorant and insensitive to the needs of others. In reality many of the difficulties have resulted in tears and feeling quite overwhelmed. However, Barbara's strength and tenacity, her determination and her marvellous sense of humour have carried her through the immense challenges and some fairly dark days. It is to her great credit that she can still laugh at herself and that she so generously continues to think of others.

**Fern Linden**  
 Past Regional Advisor

*Losing My Voice can be purchased online see [www.losingmyvoice.com](http://www.losingmyvoice.com) for more information.*

Information Evening  
 19 Feb

For people newly diagnosed with MND and their families and friends

MND NSW Centre  
 Gladesville

## MND FORUM

### Getting Out to the Clubs

Volunteer Joy Pogson, CEO Graham Opie and fundraising manager Judy Ford have been visiting **Rotary** clubs in Sydney and rural areas telling people about motor neurone disease and the work we do here at the Association. Clubs as far west as Parkes and Dubbo, as far south as Bateman's Bay and as far north as Mudgee have been visited in the past few months. It is interesting to note that no matter where a presentation is made, there is always someone who has known a person with MND. But there are always many who know little about this disease and this is the purpose of the talks - to create awareness.

### Melbourne Cup at Pymble Golf Club

A wonderful group of very committed ladies got together to raise funds for MND at a Melbourne Cup Luncheon on 6 November at **Pymble Golf Club**. It was a 'no go zone' for the men (with the exception of our CEO who spoke on the day) and 185 women had a great time. There were raffles, sweeps and a tombola. They also ran a raffle during September and the prize was a NZ holiday. The holiday raffle and the money raised on the day totalled over \$18,000 which was a terrific effort. The luncheon was in memory of Fiona Pearce who lost her fight with MND earlier this year. Our sincere thanks to all the women on the committee who worked so hard and to all those individuals and businesses who donated raffle and tombola prizes.



*The organisers of the Melbourne Cup Luncheon*

### Spring Into Action Cocktail Party

Sue Whereat and Meg Tudehope organised a cocktail party at the home of Meg and Aidan Tudehope on Saturday 15 September which was a wonderful evening. The generosity of their friends and colleagues has been outstanding and the evening raised over \$50,000 with the pledge of more donations to come. About 140 guests enjoyed catering by **Birriga Café** and lovely wines donated by **Printhie Wines** and **Bunamagoo Wines**. There were very generous donations of raffle and auction items which were well received by the guests. Funds raised go to much-needed equipment and family support programs. It is through the hard work and dedication of supporters such as Sue and Meg that we are able to maintain our support for people with MND, their families and carers.



*Aiden Tudehope, Meg Tudehope and Sue Whereat.*

### Hats Off to the Best Bars

Fundraising co-ordinator, Roslyn Adams was invited to attend the 7th Annual Bar Awards Gala Dinner at the Hilton Hotel in September.

As he did in 2006, the organiser, David Spanton of **Spanton Media Group**, whose uncle has MND, donated \$10 from every ticket sold to MND NSW. Roslyn accepted the cheque for \$7,000 and said a few words about MND to the very excited guests. "They were all having such a great time and it was obvious that they all respect each others talent which is wonderful." MND NSW is very grateful to David for making this donation possible. The recipient of the Bar of the Year, **Golden Monkey** Melbourne also made a donation of \$1,000 to MND NSW for which we are most appreciative.



*Roslyn Adams accepting \$7000 for MND from David Spanton*

### IBM Connects Regional Advisors

As part of the **IBM** Corporate Citizenship Program, MND NSW has received two refurbished computers. They have been used to connect MND NSW regional advisors located in Newcastle and Canberra to the MND NSW computer network at Gladesville. Thanks IBM! Thanks also to John Fortey for letting us know about the program.

### Fundraiser at Food Festival

On Sunday 18 November the Hills Gourmet Food and Wine Festival was held at Castle Hill. Organised by **Castle Hill Rotary**, an invitation was extended to MND NSW to have a stall. MND NSW Fundraising Manager Judy Ford, also a member of Rotary, and her daughter Susan managed the stall serving a delicious chicken dish. A good time was had by all!



*Judy and Susan*

### ... and goodbye from Judy Ford

*It is with a sad heart that I say goodbye to all my friends at MND NSW. Over the two years I have been with the Association I have got to know so many people facing challenges that require enormous strength and I applaud all of you. Visiting support groups and many of our wonderful volunteers have been the highlights of my time with MND NSW. I could not have asked for a happier bunch of work mates and I have been humbled by the courage of members, their carers and families.. Driving out to rural towns and meeting with you has been an honour which I will not forget. I am leaving Sydney to live in Murrumbateman and I will be working with Anglicare in Canberra. I look forward to reading future issues of Forum and keeping in touch with you all.*

We are grateful for the generosity of our donors and commend our supporters for their fundraising efforts



**What a Walk!**

We held our inaugural Walk to D'Feet MND on Sunday 4 November at Sydney Olympic Park leaving from Wentworth Common. It was a wonderful day with 265 registered walkers in very smart red t-shirts and 26 registered pooches resplendent in MND bandanas!



*Molly Murray with Buddy (above) and Registration (below)*



The atmosphere was very happy, the sun shone and the walk was an easy five kms. Strathfield Rotary Club put on a very tasty sausage sizzle for the weary walkers and Cadbury Schweppes donated Cool Ridge bottled water to quench our thirst. Thank you to the volunteers and staff who helped on the day and to those who participated and made it a special MND get-together (and to the pooches for being so well behaved)! It was lovely to have groups walking in memory of family members and friends. Participants gathered afterwards for picnics, making the most of the day.



*(l-r) Melissa Unmack, Liz Sandwith, Liz Segreto, Jenni Lincoln and Deb Sunarhra (above) and the Strathfield Rotarians (below)*



Some of our walkers raised sponsorship money through the *Everyday Hero* website and others in the traditional way. Sponsorship money totalled \$5415 at the time of printing, however donations are still being received. Congratulations to our sponsored walkers for such a wonderful effort. Next year there will be a prize and/or trophy for the most sponsorship! By the way, the date is Sunday 9 November 2008 so please put it in your diary. Thank you for joining us on this fun day out with all proceeds going to research - in the hope of finding a cause and cure for motor neurone disease.



*Jack and Charlie (above) and setting off (below)*



*MND NSW Patron Melinda Gainsford-Taylor (standing with child) with the Matthews family group (above right) and walkers cooling off in the fountain (right)*



To volunteer for MND NSW contact Roslyn Adams ph. 1800 777 175

**Planning Ahead**

**MND Week 4 - 10 May 2008**  
**Cornflower Blue Day 9 May 2008**

It may seem like a long way off but MND Week 2008 will be upon us before we know it. I am already in the planning stages and would love to know that help is at hand. So, if you have any ideas about something new and different or something tried and true we could do please let me know.

I would also love to hear from volunteers for railway stations, shopping centres, schools, hospitals, anywhere you can think of where there is an audience to purchase our merchandise!

To volunteer for MND Week contact Roslyn Adams ph. 8877 0908 or email [roslyna@mndnsw.asn.au](mailto:roslyna@mndnsw.asn.au)

**Dates for the Diary**

22 Dec 2007	<b>Hunters Hill Annual White Christmas Party</b> Hunters Hill Bowling Club, 2.30-9pm. Dress: Crisp White. Organised by Vanessa 0412 307 675 and Issac 0410 404 290 Tickets at door: \$10
18 Mar 2008	<b>MonStar Cup</b> Pennant Hills Golf Club, Beecroft Golf Day and Dinner
4-10 May	<b>MND Week</b>
9 May	<b>Cornflower Blue Day</b>
9 Nov	<b>Walk to D'Feet MND 2008</b>

## Noticeboard

### Seniors Card Discount Directory

The 2008 New South Wales Government Seniors Card Discount Directory includes more than 7,200 special deals and discounts from businesses throughout New South Wales. The Discount Directory is broken down into five regions:

- Sydney and Surrounds
- Central Coast and Hunter
- Northern NSW
- Southern NSW
- Western NSW



Seniors Card members should have received their free copy of the Discount Directory for their region in the mail throughout November. To obtain a directory for other regions, phone 1300 364 758 or email [info@seniorscard.nsw.gov.au](mailto:info@seniorscard.nsw.gov.au). A complete list of the discounts available to NSW Seniors Card members can also be found at [www.seniorscard.nsw.gov.au](http://www.seniorscard.nsw.gov.au)

### ANZAC/Concord MND Research Group

Professor Garth Nicholson and a research team at Concord Hospital are carrying out research to locate new genes causing MND. If your family has had more than one person with MND (even a distant relative, for example, second cousin) you can help their research. Participation in the project is likely to benefit future generations rather than provide any immediate benefit to any family member currently affected. Participation involves the donation of a blood sample to be stored indefinitely and included in current and future DNA research into motor neurone disease. For more information contact Carolyn Cecere ph. 9767 7016 or email [ccocere@anzac.edu.au](mailto:ccocere@anzac.edu.au)

### Hunter Hydrotherapy

Hunter Valley Private Hospital offers casual hydrotherapy pool hire. Disability access is provided by abundant free general and disability parking. There is a level entry from the car park and main entry with a choice of steps or seated hoist lift into the pool. For more information contact Kate Godfrey Physiotherapist, Hunter Valley Private Hospital on ph. 4944 3715.

### HealthInsite



HealthInsite is an Australian Government online initiative, funded by the Department of Health and Ageing. It aims to improve the health of Australians by providing easy access to

quality information about human health. For more information see [www.healthinsite.gov.au](http://www.healthinsite.gov.au)

### Living Caring Working

Living Caring Working is a



website which provides a range of information for people living with a life threatening illness, their carers, and work colleagues. Resources include tip sheets covering issues such as:

- Thinking about questions and answers for your health care providers
- Thinking about your needs
- Understanding your work colleague who is living with a life threatening illness
- Thinking about your needs as a carer
- Ideas for helping your friend or family member with a life threatening illness

See [www.livingcaringworking.com](http://www.livingcaringworking.com) or if you would like a copy of a resource sheet mailed to you contact the MND NSW Info Line on 1800 777 175.

### Australian Motor Neurone Disease Registry



The Australian Motor Neurone Disease Registry (AMNDR) collects information on people

diagnosed with motor neurone disease. The registry has been designed by a steering committee of neurologists from around Australia. This registry provides you with an opportunity to actively contribute to research.

AMNDR has been developed to collect information on MND diagnosis, treatment, management and outcomes from all over Australia. For more information talk to your neurologist or visit [www.amndr.org](http://www.amndr.org)

### March of MND Faces

These banners feature a photographic display of people with motor neurone disease. MND NSW has already produced seven 'March of MND Faces' banners and will soon be producing an eighth.

If you have MND and want to be included in the new banner you need to complete a permission form and submit a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish. Family members are also able to submit a photograph in remembrance of a person who has died from MND.

For more information ph. 8877 0999 or email Penny Waterson at [info@mndnsw.asn.au](mailto:info@mndnsw.asn.au)



*You can write to the Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675*

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**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*