THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MND MOTOR NEURONE DISEASE

FORUM

September 2005

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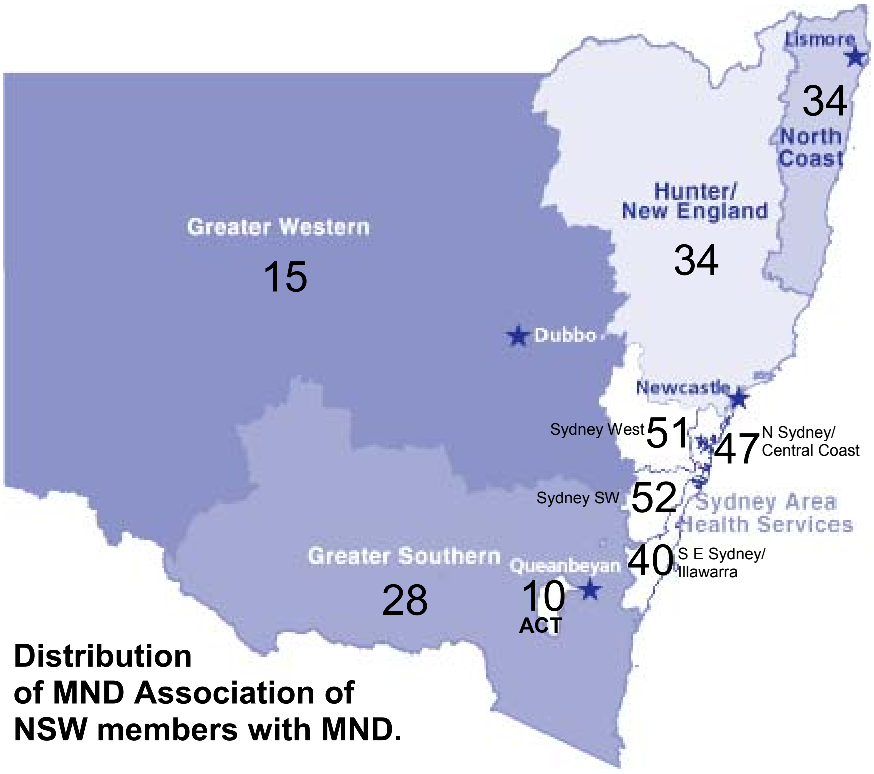
Reaching out
across New South Wales and the ACT



Distribution of MND Association of NSW members with MND.

Motor neurone disease has no boundaries - it strikes people in all countries of the world with approximately 1 in 37,500 people being diagnosed each year.
The MND Association of NSW is helping over 300 people with MND, their families and carers throughout NSW and the ACT. MND Association Regional Advisors work with service providers in nine different Health Service Areas to ensure the best possible care wherever people are living.

Would you like to receive your copy of Forum by email?

For ten years, Snap Printing at Artarmon has provided a gift to the MND Association by printing the quarterly newsletter free of charge. However, there is still the cost of paper and envelopes and postage, with over 1,200 newsletters sent out each quarter. Although this is money well spent in providing information and news to members, you can help save trees and help the Association to save money by receiving your copy of Forum by email.

If you have access to the internet and would like to receive future editions of Forum by email, please send a message to admin@mndnsw.asn.au to request listing on the Forum electronic mailing list. The current edition of Forum, and back copies, are always available on the website at www.mndnsw.asn.au, but if you are on the email list you will receive the latest news as soon as it is available.

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

September is already upon us which means I have been CEO of MNDA NSW for three months.

It has been a rapid and thoroughly enjoyable learning curve for me. Getting out to some support group meetings, clinics, a new budget and still I had time to buy some cornflower seeds for my 5 year old son and helped him plant them. Come Spring we'll be awash with blue.

This edition of FORUM is dedicated to "reaching out". It emphasises the work of volunteers, the Association and support groups across NSW and our impact internationally, underlining our common mission - to provide the best possible support for people living with motor neurone disease, their families and carers, to advance research and to raise awareness.

Across NSW the numbers of people with MND approaching MNDA NSW are increasing. Coinciding with this is the increased emphasis and value in support groups, offering a forum for people to speak to and hear from people who really know what each person and family are going through.

The family support work done by MND Associations across Australia is starting to have an impact on international events such as the 16th International Symposium on ALS/MND to be held in Dublin, Ireland. Regional Advisors Ruth Quaken and Christina Jason have had papers and posters accepted at this prestigious event. An outstanding achievement.

I would like to take this opportunity to thank Debra Larizza and Roslyn Adams and the Cornflower Blue Ball steering committee for organising what could only be described as an extravaganza. Over 350 people attended the Ball and approximately $75,000 was raised for the Association.

With 2006 just around the corner, our 2003-2006 Strategic Plan will be up for review. We are looking to you for input into the next phase of development of MNDA NSW. Over the next few months we will be asking members and supporters for their input into the planning process for 2006 and beyond.

As part of this new phase we would like to call on members to participate in advocacy at the local level. We are developing a state-wide advocacy plan and will be calling on you to contact your local MP. Particular issues that have been identified include attendant care packages, timely access to services and innovative care. We'll be in touch.

Janet Nash, who has been an integral part of MNDA NSW for over 10 years will be moving on in October. Janet is not going far, based at the MNDA NSW office Janet will be the driving force of the MND Research Institute of Australia.

Throughout her time with MNDA NSW Janet has taken on a variety of roles supporting people living with MND and has been vital to the growth of the Association. Committed and an expert voice, Janet has often been the first point of contact for people calling the Association. Janet has been responsible for the editing, production and often the writing of FORUM, the Annual Report, our website and the knowledgeable voice of research information for the organisation.

More recently Janet coordinated the building committee and it is largely due to her efforts that we now enjoy our new office and surrounds.

On behalf of the staff, volunteers and the wider MND community I would like to thank Janet for her long standing dedication and commitment to the MND Association of NSW and the care and support of people living with MND and their families.

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

NEVER GIVE UP wristbands have proved a real hit across the State. Schools and community groups have jumped on board to help raise awareness of MND and funds for family support and research. If you haven't ordered yours yet, don't worry, we have a few as emergency stock!

MNDA NSW is seeking applicants for two positions based at our Gladesville office:

Information Officer

We are seeking a person who will be responsible for the oversight of information, both printed and electronic, that is sent to members and the general public and that is used internally by staff. The position is for 2 ½ days per week.

Bookkeeper

We are also looking for an experienced bookkeeper to work two days per week.

For more information on either of these positions please call Graham Opie on 8877 0999.

Family Support – reaching out

We will soon be surveying and engaging with members to develop future objectives for the MND Association of NSW. It is timely, therefore, to evaluate the family support objectives as identified in the Strategic Plan 2003 – 2006. In particular I would like to review the objectives as they relate to the theme of "Reaching Out".

The primary objective for family support is:

To provide and enhance equal access to family support and to promote multidisciplinary care for all people in NSW living with MND and their families.

Ten strategies were identified to ensure that this objective was met. All strategies relate to the whole of NSW, however, three strategies specifically target rural and regional NSW and ACT:

1. To increase family support and advocacy for all people with MND throughout NSW and to respond effectively to their needs.
2. To develop family support and advocacy for people with MND in the ACT in partnership with MNDA ACT.
3. To pilot a sustainable volunteer visiting program and extend to other regions in the future.

Association membership of people with MND has increased by almost 20 % in the past six years.
We believe this increase is largely due to the increase in assistance the MND Association has been able to give to people in rural and regional areas.

1. To increase family support and advocacy for all people with MND throughout NSW and to respond effectively to their needs.

In order to implement the first strategy, objectives were set related to increasing family support hours for people living with MND in rural and regional NSW. The aim of this increase in hours was to dedicate more family support hours to rural and regional NSW and to ensure optimal and equitable hours for each regional advisor to better support people living with MND. Over the last few years Country NSW has been divided into three regions supported by three regional advisors: New England, Central West and Southern NSW. This restructure has enabled family support to fulfill the aim of all regional advisors having 24 hours per week to support 60 people living with MND, or equivalent. During 2004/5 the restructure enabled regional advisors supporting people living outside of metropolitan Sydney to reach out and provide:

- 11 rural and regional field trips
- 144 home visits
- 20 education sessions for health and community care providers.

This has led to more opportunities to increase advocacy and to promote multidisciplinary care in these regions.

Forthcoming Field Trips include Cowra/Boorowa in late September and the Central West, Far North Coast and Riverina and South West Slopes in October. Unfortunately, due to the size of NSW, there are some regions that are more difficult to access due to time and budgetary constraints. The Royal Flying Doctor Service has helped regional advisors to make flying visits to some of the more remote areas which is very much appreciated. Telephone and email enable family support to keep in touch with people we are unable to visit or visit on a one off basis only.

2. To develop family support and advocacy for people with MND in the ACT in partnership with MNDA ACT.

The second strategy was successfully implemented through the employment of Allison Pearson in June 2003. Allison works in partnership with MNDA ACT to support people living in the ACT. Since June 2003 Allison has organised a seminar for members and health professionals held in Canberra in 2004 and established a support group. She has also been instrumental in supporting health and community care providers in Canberra to meet on a regular basis to ensure coordinated, multidisciplinary care in the ACT.

3. To pilot a sustainable volunteer visiting program and extend to other regions in the future.

The third strategy was initiated in July 2003 thanks to funding from the Australian Government Palliative Care Caring Communities Program. Christina Jason, Anita Richter and I recruited and educated volunteers to visit people living with MND in the Newcastle and Hunter region. There are currently five volunteers visiting people in the region. This pilot project has enabled family support to reach out and fill a gap in support in this region. The project has also enabled family support to develop a manual to

(Continued on page 4)

Family Support: reaching out

(Continued from page 3)

educate palliative care volunteers and MND volunteer visitors in other areas in the future.

Family support staff have highlighted elsewhere in this issue other ways the team have reached out recently by providing information and support for MND carers, particularly through the **Link and Learn** program for carers living in rural and regional NSW. The **Learn Now Live Well** program has been adapted for rural and regional NSW and has provided information and support for people living with MND, family members and health professionals in New England and the Hunter over the last 12 months. The **MND Special Interest Groups for health professionals** has proven to be a very effective way to reach out regularly to health professionals via email and there are currently 150 group members from around NSW and the rest of Australia.

Disseminating information on MND care and management to a variety of audiences is a significant way of reaching out. Over the last 12 months family support staff have given presentations on respiratory support, communication and MND palliative models of care at the NSW Palliative Care Conference and the role of the regional advisor at the National MND Conference in Melbourne. A poster on the Volunteer Visitor Program was also presented at the conference in Melbourne and Christina Jason gave an oral presentation on this program at the National Palliative Care Conference in Sydney in August. Anita Richter chaired a concurrent session dedicated to MND care and management at this Conference confirming that people living with MND are a well-recognised client group for palliative care.

At the international level, Ruth Quaken will be presenting at the Allied Professionals Forum in Dublin, which is an integral part of the International ALS/MND Symposium. She will also be taking Christina Jason's poster on the Volunteer Visitor Program which has been accepted for presentation at the International Symposium itself. The acceptance of these abstracts at an international level is a great achievement and offers family support a unique chance to present to a large international audience. It also provides a vital opportunity to learn more about current international practices to help family support to continue to promote and provide the best possible care and support for people with MND, their families and the health and community care providers involved in their care.

The Equipment Service reaches out to all regions to ensure help is provided

Carol Birks
Manager Family Support

Dates for the Diary

Mondays September 5, 12. 19 and 26 Gladesville	**Care for Carers Course** Four weekly education and support sessions for family or friends caring for a person with MND
Tuesday October 4 10am Gladesville	Inaugural **monthly drop in meeting** and a chance to donate a drop of blood to Dr Roger Pamphlett's MND DNA Bank. Please phone 8877 0999 if you want to participate.
Tuesday October 11	Meeting for people with MND, their families and friends in Orange
Sunday October 16	Carers Sailing Day
Saturday October 29 2-4pm	**Newcastle Afternoon Tea for MND** Edgeworth Neighbourhood Centre, Cnr Minmi & Main Road, Edgeworth. For people living with MND, their family, carers and friends - informal get together with others who have been touched by MND. Phone 1300 66 7873.
Thursday November 3 - Gladesville	**Special Interest Group Workshops for Health Professionals**
Saturday December 3	MND Association of NSW AGM and Christmas Party
March 6 & 7, 2006	**Link and Learn Workshops** Riverina and South West Slopes

Please contact the MNDA NSW office on 8877 0999 or 1800 640 144 for further information or to express your interest in attending any of the programs or sessions above.

Reaching out to provide assistive equipment

The MND Association of NSW continues to supply members with much needed equipment, free of charge, throughout the State.

In the past 12 months, the MND NSW Equipment Service has lent 871 items of assistive equipment. The service has also arranged the hire of 17 medical electric Hi Lo beds to members in remote areas or wherever there has been an urgent need. The distribution of equipment loans closely follows the pattern of distribution of members, with 66 percent of loans going to members in the Metropolitan area (68 percent of all members) and 34 percent of loans going to members in rural and regional areas (32 percent of all members).

All equipment loans from the MND Association Equipment Loan Service require assessment and request by a health professional.
If you need help in getting an assessment, contact your MNDA Regional Advisor.

Provision of equipment at the time it is needed can be difficult in remote areas, but with our ongoing relationship with Cope Sensitive Transport and local medical bed hire services, the MND Association is able to assist those members when the need arises. Hire of larger equipment items in more remote areas has proved to be a better option to ensure there are no delays and to offset the high costs of delivery and maintenance.

Not all equipment needs are provided by the MND Association. Some regional areas have access to other equipment service providers who work with the Association to better support members with MND.

Maree Hibbert
Equipment Officer

FOR SALE

Pair of king size electric Hi Lo beds with massage and pocket spring mattresses by Simmons.
As new. $2,500 for the pair or $1,500 each.
Phone Campbell on 02 4446 4762

Wheelchair accessible vehicle
Ford Falcon 1994 LPG. Auto. Air. Record. Engine 67,000 kms Reg: 12/05 $18000 ono
Phone Lubica Marusevski on 02 9546 1758

Angel Flight reaches out to help people living with MND. Angel Flight Australia is a charity that co-ordinates non emergency flights for financially and medically needy people.
All flights are free and may involve patients or compassionate carers travelling to or from medical facilities anywhere in Australia.
Angel Flight works to particularly assist those in isolated areas. Recently one of our members benefited from the care and generosity of Angel Flight who enabled a family member from a geographically isolated area to attend one of the Sydney education sessions. This was very meaningful to the person and part of a most successful day.
Thank you to the people and pilots who work so tirelessly to assist people in need.

Mary Butcher

Girrawheen – Central Western NSW

Of all the places I have been
There's none can conquer Girrawheen
Set amongst the bushland trees
Scented from the gentle breeze
All nature's gifts they can be seen
When you live with me at Girrawheen.

John K. Cross

This short excerpt from John's poem "Girrawheen" evokes the beauty of the Australian bush and the strong ties country people have with the land. These are the aspects of field trips that the Regional Advisors who reach out to the bush always comment on and enjoy. I am looking forward to visiting John (who was diagnosed with MND in 2004) at Girrawheen during my field trip to the Central West of NSW in the week starting 10 October.

Carol Birks

Reaching out to carers

Link and Learn - March to May 2006

This program for carers of people with MND in the Riverina and South West Slopes region, will start in March 2006. The program will provide MND carers with education/training in caring for people with MND along with support and pampering activities.

The program will consist of a two-day (one night) residential workshop in a hotel in Young. Experienced local health care professionals will provide education on managing MND during the two-day workshop. It is hoped that carers from a broad geographic area will be able to attend this two-day "live in" workshop. This will be followed by six weekly sessions of telephone group link-up allowing participants to continue to share ideas and ask questions without the need to travel. Funding will be provided for continuing pampering activities for participating carers throughout the duration of the Program.

Allison Pearson, Regional Advisor for the area, will be the key member of the Family Support team involved with this phase of the project. She will be working with Ruth Quaken. They will liaise with local Carers Respite Centres to provide respite care in the home to enable MND carers to participate in the workshop and, wherever necessary, the tele-link program that follows.

Previous Carers Programs have demonstrated the value of support and education for MND carers. This benefit ultimately flows on to the person with MND being cared for. We hope that many MND carers in Southern NSW will take advantage of this opportunity.

Costs for this Program including additional staff hours are funded through a grant from the NSW Health Carers Program. The Association is grateful to NSW Health for the funding to establish this Program, which would not otherwise be possible.

Carers in the Riverina and South West Slopes area will be notified of more specific details later this year. In the meantime if you would like more information please contact Ruth Quaken or Anita Richter at the office.

Seminar Series for parents and guardians responsible for the care of bereaved children.

Seminars with Dianne McKissock OAM
National Centre for Childhood Grief
14 Hollis Ave, Eastwood.

Cost $25 includes light refreshments

1 – DAYTIME 10.30am – 1.30pm
Friday 23 September
RSVP by 12/9/05

2 – EVENING 6.00pm - 9.00pm
Tuesday 25 October
RSVP by 10/10/05
Spaces are limited so phone or fax
1300 654 556 or email
dianne@childhoodgrief.org.au
if you are interested in attending.

Drop in Day at Gladesville
First Tuesday of every month - 10.00am – 12.00 midday, commencing Tuesday 4 October 5

Now that we are settled into our lovely new facility at Gladesville Hospital we would like to extend an open invitation to members and their families to "**drop in**" on the first Tuesday of each month to meet MND Association staff and share a cup of tea and a chat.

MNDA "drop in" day will be launched with a DNA donor drive. Please "drop in" on Tuesday 4 October to meet Dr Roger Pamphlett and to donate a "drop" of blood to help with research through the MND DNA Bank.

Carers Sailing Day - October 16, 2005

Carers and children of people living with MND are invited to cruise Sydney's magnificent harbour. ***Sailors with disAbilities*** are offering a complementary sailing day for carers and kids. MND Association Regional Advisors can help arrange respite for the person with MND. Don't miss this great opportunity - respond quickly as numbers are strictly limited (phone 8877 0999). The boat departs from the Royal Cruising Yacht Club, Rushcutters Bay, Sydney at 11.00 am and cruises for approximately 3 hours.

Anita Richter
Special Projects/Carers Services

Education Sessions for Health Professionals

MND Association Family Support staff are happy to organise education sessions anywhere in NSW.
If health professionals involved in your care would like an MND specific education session ask them to contact Carol Birks on 8877 0904 or 1800 640 144.

Research

How can YOU help with research?

Many researchers are dependent on participation of people with MND to gather the information they need as the basis of understanding the disease. In Australia there are currently several ways in which you can actively contribute to research into MND.

1. Contribute to the MND DNA Bank

Dr Roger Pamphlett from the University of Sydney will have his next collection day at Gladesville on Tuesday 4 October. The MND DNA Bank now has a large number of samples from people with sporadic MND and also normal controls (often another family member without MND). The DNA Bank can be used by Australian researchers to investigate various genetic factors that may contribute to understanding the cause of MND.

The Coalition for Advancement of Medical Research Australia supports changes to the Prohibition of Human Cloning Act 2002 to allow therapeutic cloning (also known as somatic cell nuclear transfer) research which is NOT reproductive cloning. Have your say at www.lockhartreview.com.au or write to your State or Federal MP.

2. Using our Brains

People often think it may be useful to leave tissue to research after they die. If you are interested in donating your tissue, phone the *Using our Brains* donor program on 02 9351 2410.

3. Dr Steve Vucic needs volunteers with sporadic MND, those belonging to families with mutations in the SOD1 gene, and people with Kennedy's disease. His study uses transcranial magnetic stimulation and electrical stimulation of a nerve at the wrist to assess motor neurone function. It is hoped that the test will not only prove to be of diagnostic value in the future, but that it will also become a means of monitoring motor neurone function during treatment. If you have a few hours to spare and would like to participate in this study at the Prince of Wales Medical Research Institute, please contact Dr Steve Vucic on 0415 833 811 or 02 9382 2413.

4. The Australian MND Registry (AMNDR) is the only **national** study in the world investigating the incidence and prevalence of MND. Contact your Neurologist to make sure that you have been enrolled in this Registry which aims to improve patient care through continuous evaluation of management to find the most effective treatments for the disease.

Funding for MND research

There are many dedicated researchers in Australia who are collectively working towards understanding the causes and finding effective treatments and cures for MND. As well as grants provided annually through the MND Research Institute of Australia, significant funding is provided through other sources.

The University of Queensland's Brain Institute (QBI) recently received a $3 million donation as part of a bequest to further research into MND. This bequest was left by Peter Goodenough, who died in Cairns in November 2004 from MND. Additional funding for MND at QBI comes through the family of the late Ross Maclean who are sponsoring an MND Research Fellowship. Dr Robyn Wallace, the inaugural Ross Maclean Fellow, is working on a project seeking to find novel genes that cause MND.

The MND Laboratory at the Howard Florey Institute, University of Melbourne, receives funding from various sources including the NH&MRC and the MND Research Institute. The team, lead by Dr Julie Atkin, aims to understand the early mechanisms that trigger degeneration of motor neurones.

16th International Symposium on ALS/MND, Dublin, Republic of Ireland 8 - 10 December 2005

This exciting annual gathering brings together researchers and care providers from around the world - all reaching out to make a better world for people with MND.

The MND Association of NSW will be represented at the Allied Professionals' Forum by Regional Advisor, Ruth Quaken, who will present her paper *Respiratory Management – view from the field*. Ruth's travel to Dublin has been made possible by the generosity of Cathay Pacific Airways.

Northern NSW Regional Advisor, Christina Jason, will send her poster presentation *New Partnerships to Improve the Quality of Life of People with Motor Neurone Disease and their Carers*. This poster has been accepted at the Symposium under the theme: **Research to improve standards of care**.

Volunteers

Volunteer day Monday 21 August
Launch of the MND Ambassador Program

Monday 21 August saw much laughter at the MND Volunteer Day. It was the launch of the 'Ambassador Program', a program for volunteer speakers committed to promoting awareness of MND and the Association. We were fortunate to secure Natasha McNamara, a Tutor from the Corporate Program at NIDA, well experienced in assisting potential public speakers to hone their presentation skills. Natasha created much fun by giving us voice and movement exercises, feedback on presentation, and ideas about the role of the presenter. Thank you to those who were able to attend and to Kevin Langdon who continues to be the driving force of the Ambassador Program.

Anyone who may be interested in representing the Association as an Ambassador, where ever you may be located, please do contact the Association as we would welcome and support you in this role.

'Ambassadors in the making'

We need YOU

Volunteers have always formed the backbone of the Association and are always needed to help with the many aspects of running the Association. Special times, such as MND Week, can require large numbers of volunteers for a short time, but people who can commit a regular day to help are always needed too.

Regular volunteers are still needed to take responsibility for the Reception area at our Gladesville Centre. Based at the hub of the organisation, you will meet and greet visitors, answer the phone and carry out many useful tasks throughout the office. We have been fortunate to have a commitment for alternate Tuesdays and Wednesdays and every Friday. This leaves Mondays and Thursdays open for volunteers.

Please contact Roslyn Adams on 8877 0908 if you think you can help.

If you have special skills that you can offer as a volunteer, your offer will be welcomed.
There are always countless office jobs to be done but you might be able to suggest other ways to help.
Please phone Roslyn Adams on 8877 0908.

The next volunteer workshop and lunch is scheduled for **Monday 21 November**. This will be a planning day for MND Week which runs from 2 to 8 April next year so we will welcome your input on the day.

Open Garden at 17 Linden Avenue Pymble
Saturday 29 & Sunday 30 October 10am - 4pm.

Once again, Suzanne and Bob Ballinger will open their beautiful garden to support the Open Garden Scheme and the MND Association.

An attractive lych-gate entry frames a pretty cottage garden of rose-covered arches, perennial borders, hedges and sandstone walls. The cottage theme blends into a Japanese influenced back garden with a stone bridge and water feature. The garden is on a battleaxe half-acre block with wheelchair access to a good part of it.

Refreshments and merchandise, including books and plants, will be available. We invite you to participate by holding a stall with perhaps a garden, craft or art theme – suggestions welcome.

Please contact Roslyn Adams on 8877 0908 if you would like to hold a stall, donate paperbacks or garden books in good condition, volunteer for a few hours during the weekend or make some home made goodies.

Support groups

Newcastle and Hunter

The AGM of this group was held in August and new office bearers were elected.
President: Paul Kentwell
Vice President: Barry Harrison
Secretary: Linda Bower
Treasurer: Sandy Klein
Many thanks to outgoing office bearers, particularly Christine and Alistair Fyfe, who have worked long and hard to raise funds and help people with MND living in the area.

Christina Jason

> *Many thanks to Christine and Alistair Fyfe who have given many dedicated hours over many years to the Newcastle and Hunter Support Group.*
> *They have stepped aside to make room for others but there is no doubt their support will continue.*

New England

A 'Learn now Live Well' two day workshop recently held at Armidale to meet the current need for people living with MND within the New England area was well supported by members, family, carers and the local health services.
The evaluations of the workshop identified the value that the participants placed upon meeting others living with MND, the benefit of companionship and humour and the sharing of ideas.
There has been subsequent interest in establishing a support group.
It may be a travelling group which meets at different places around the New England area.
Anyone who may be interested in attending or supporting such a group, please contact me at the Association and I will contact participants of the workshop who have indicated interest in arranging this group.

Mary Butcher

Northern Beaches

This group continues to grow as more newly diagnosed people in the area join the group. Happily this area is very well supported in terms of health services and support networks. Recently the group had Trish Reynolds, Respiratory Clinical Nurse Consultant from Royal North Shore Hospital as the guest speaker. She provided an interesting presentation leaving us with much to think about.
Thank you to the Northern Beaches Palliative Care Team who continue to provide care, support and commitment for everyone they work with.

Mary Butcher

South West Sydney (Panania)

Numbers attending this group have recently reduced and we have decided to close the group down for now due to lack of new members in the geographical area. The group has been very supportive to many families in the last three years. The next scheduled meeting date was Tuesday 4 October. In place of this we will be holding the first drop in day for all members at Gladesville on that day.
It is hard to see a support group wind down but it is acknowledged that support groups need to be responsive to changing needs. We will be looking at the possibility of a new support group in the Sutherland Shire area or the Eastern suburbs area. Please contact the Association and let us know if you would like to be connected with a support group, and also if you have any suggestions for a good location.

Caroline Gleig

FOR INTERNET USERS

- **OZPALS** is a group of people in Australia and New Zealand with an interest in MND who keep in touch by email. To subscribe go to *www.hotkey.net.au/~ozpals* or email *ozpals-subscribe@yahoogroups.com*.
- **Internet Chat – Living with MND** Every Tuesday at 1pm & Thursday & Sunday at 8pm EST. Go to *www.mnd.asn.au/* then click on the chat room link. For a chat room which is open 24 hours per day, try *http://neuro-mancer.mgh.harvard.edu/echat42/ALS/*.
- Visit the MNDA NSW website at *www.mndnsw.asn.au* for information, news and links to other sites.

SUPPORT GROUP CONTACTS

Central Coast
Audree Dash
Phone: 02 4384 2907

Coffs Harbour
Lily Jenkins
Phone: 02 6652 2571

Illawarra
Pam Van Den Hogan
Phone: 02 4223 8000

Newcastle & Hunter
Barry Harrison
Phone: 1300 667 873.

New England
Robyn Barton
Phone: 02 6766 6065

Northern Rivers
Helen Gates
Phone: 02 6621 4018

Port Stephens
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and
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Ruth Quaken
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are coordinated through the MNDA office.
Phone: 02 8877 0999

Fundraising

City to Surf for MND

There was a brave band of MND supporters who 'never gave up' on the 14 km fun run/walk City to Surf on the morning of Sunday 14 August. It was a mixed bunch of young and not so young, the fit and the not so fit, family members, carers, friends and staff. We came from far and wide, with Helen Butcher (UK) supporting her sister, Liz Sandwith and family, and Ken Rowles remembering his brother. Our goal was to reach out in promoting awareness of MND whilst raising money (over $3,000!) and having fun. We joined the thousands of participants in the surge to Bondi Beach where we enjoyed a picnic lunch arranged by our trusty support team.

Bequests

Blue Cornflower Society

The launch of our new bequest program, the Blue Cornflower Society, will take place on Tuesday 11 October. The Society's purpose is to recognise and thank those who have left a bequest in their Will. If you would like to know more please contact Roslyn Adams at our office.

The reason for this initiative is the higher levels of support and increasing number of members with MND requiring family support and equipment. Increased income will also allow us to increase levels of funding for research.

Leaving donations through Wills has become an increasingly popular way for Australians to help fund organisations they care about. Importantly, bequest programs cost less to run than traditional fundraising events leaving more money for the delivery of services to people with MND, their carers and family members.

Graham Opie

HELPING THROUGH YOUR WILL

Your Will can be a convenient vehicle for making a charitable gift of lasting value.

Please consider the MND Association as a living memorial for a loved one.

Join those who support the work of MNDA NSW through bequests from their Estates.

March of Faces Banner

Jackie Williams was the champion of the MND March of Faces Banners in Australia. Jackie gained support around the country for this project and each State now has a collection of Banners which have a very moving impact as a tribute to the people who live with MND. Sadly, Jackie lost her fight with MND earlier this year, but the Banner project lives on to advance awareness of MND.

New South Wales has completed its sixth Banner, each carrying photographs of 20 people with MND.

To see the Australian banners go to http://march-of-faces.org/community/oz/oz.html.

If you would like to contribute a photograph to the next NSW March of Faces Banner, information and a consent form can be sent to you. Please contact Janet Nash on 02 8877 0901 or 1800 640 144.

Supporting the work of the MND Association

The Dunn/Oliver family of Cowra have raised a sizeable amount for the MND Association firstly through accepting donations for the display of Christmas lights in their street and now, by promoting MND socks for sportspeople who want to win!

A friend who had purchased a pair of socks won his regular game of squash the first time he wore them. The next week he was looking for his "lucky" MND socks and, like most of us, could only find one after they had been through the wash. He had to wear ordinary socks to the game that night and suffered a defeat! He contacted the Dunn family and purchased four more pairs and has had a winning streak ever since!

Word has it that MND socks are also popular at the girls' netball competition in Cowra. These lucky socks are growing in reputation so if you are a sportsperson who *has* to win, or someone who simply enjoys comfort, these may be the socks for you!

Allison Pearson

Socks to d-feet MND are walking out the door at $6 a pair - available in large size for men and medium for women. To help raise funds by selling MND merchandise, call 8877 0999 or 1800 640 144 for socks, cornflower seeds, brooches and badges, pens, shortbread and wristbands.

NEVER GIVE UP

Wristbands have been taken up as the charity rage around the world. Blue NEVER GIVE UP wristbands for MND have been available in Australia since early July and are selling like hot cakes. They come in two sizes (adult and child). At $2 each, you can get on the **bandwagon** and plan your **band days** to support MND in schools, shopping centres, sporting groups and any other location where you can have some impact.

Phone the MND Association on 8877 0999 or 1800 640 144 so we can send wristbands to you.

A year ago we were told my Aunty has Motor Neurone Disease. I didn't know what to think or even what it was, most kids my age have no idea. I felt helpless and wanted to do something.

I was in Newport one afternoon when I saw my friend who was wearing a blue wristband. I liked the look of it and bought one from the chemist, then I realised it was for MND and thought my cousin Emma and I could sell them at school to raise money and awareness of this little known disease.

We spoke at assembly and most of the kids were shocked to find out about MND and that at this time there is no cure. Emma and I were able to sell over 100 wristbands within a few days. We also bought the socks because they are really comfortable.

Hopefully our small effort will help research into MND so other families don't have to go through this.

Angie Lovett
Newport

Dear Editor

Recently my husband Gordon and I took the opportunity to attend a two-day Learn Now - Live Well Seminar in Armidale, a town about two hours drive from our home in Inverell. Gordon has been diagnosed with MND since June 2001. I had read about these seminars in Forum and jumped at the chance to attend when it was offered in our area.

The seminar was organised by Mary Butcher, our Regional Advisor from the MND Association in Sydney and she had gathered together speakers from a number of services who could offer help to people with MND and their carers. All of these health professionals were excellent, their talks well prepared and very helpful and practical.

I thought I was fairly well informed about what was available, but I found information about services I didn't know existed, particularly Commonwealth Respite Care, based in Tamworth but easily accessible by phone to our area. I particularly enjoyed the talk by Kate McCrea, a naturopath based in Armidale and I really enjoyed the neck and shoulder massage her young assistant provided. All talks were down to earth, practical and delivered happily and with a very obvious willingness to help in any way possible to make our lives easier. Another aspect was the fact that even though we don't live in Armidale, a lot of the services offered there are also available to us, just with a phone call.

All of the above was great, but the biggest plus for us was meeting other MND families, hearing their stories and realising that human beings are a wonderfully resilient lot. We laughed a lot, talked seriously on a one to one basis with each other, shared our stories and resolved to stay in touch. It was a very uplifting part of the two days.

Thank you to Mary, for all her work. I know these events don't come together on their own volition. Thank you also to the MND Association, not just for providing the Seminar, but also for all the help and support they provide for us all.

I would recommend attendance at one of these gatherings to anyone with MND and their carers. It was a wonderful two days, full of laughter, useful information and fellowship.

Nola Turner
Inverell

To Graham Opie, CEO

I am writing this letter as a thank you to your organisation for the help and assistance my sister (newly diagnosed with MND) and myself (as her advocate and guardian) have received.

I am a member of the following organisations: Down Syndrome Association (9 years), Parkinson's Association (20 years), Arthritis Association (15 years), Alzheimer's Association (10 years), Carers Association (15 years).

In all my years of having been involved with these many organisations I have never found one that has been as helpful and enlightening as yours. You have offered immeasurable support in the form of aids and mobility assistance to my sister, the likes of which I have never seen. Your field officer visited my sister at her Hostel in Wauchope within weeks of my contacting your office.

Once again thank you for the assistance and support your organisation has provided.

Mrs Jean Paterson
Buff Point

We welcome your ideas - Forum is your voice - so if you would like to contribute to the next issue, please write to the Editor.

From the Editor

In recent years, the MND Association of NSW has grown from strength to strength. From a small organisation run largely by volunteers, it has become a well-coordinated professional team providing outstanding support and services to all people involved with MND throughout NSW and the ACT.

After ten years at the MND Association of NSW and nine years producing Forum, it is time for me to move on. But I am not leaving.

Research is the hope for the future and it is to the MND Research Institute of Australia that I am headed. From 1 November I will focus my attention on my role as Administrator for the Research Institute. The Institute is based at the MND Association's office at Gladesville so I can look forward to a continuing relationship with the 'MND family', and the hope that research will soon find the answers we are all seeking.

Janet Nash

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Editor: *Janet Nash*