THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MND MOTOR NEURONE DISEASE

FORUM

June 2004

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Care for today – Hope for a future

The message for Motor Neurone Disease Week 2004 was prominent on banners in Sydney city streets and around Circular Quay for ten days at the end of March and beginning of April.

MND Week each year is the culmination of a year of awareness and fundraising events that together provide the majority of the running costs of the MND Association (see details on page 3).

Countless people throughout New South Wales work to support the Association's mission to provide and promote the best possible support for people living with motor neurone disease, their families and carers, to advance research and to raise awareness.

This year, a fantastic $334,000 was raised from activities and special events around MND Week. Congratulations and thank you to everyone who contributed to this wonderful support for the work of the MND Association.

Membership renewal

June is the time to remind members that they need to renew their membership for 2004/2005 by 30 June. Forms for new and renewing membership are available from our new website at www.mndnsw.asn.au.

Investing in a new website also brings the MND Association the ability to receive donations online. Before the end of the financial year, you may like to think of making a gift which will help people with MND to stay at home and enjoy the company of family and friends as the disease takes its toll.

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries.
The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.

A message from the CEO

Well, the efforts of the team at MNDA NSW have certainly borne fruit through significant monies raised at major events. The Association has been most fortunate to attract the support of some influential and generous people. Read more about that elsewhere in this edition. I sincerely congratulate and thank everyone involved.

I expect that our relationship with the Constellation Hotel Group which I mentioned last edition will commence in the next couple of months so if you are planning to travel, stay Country Comfort and support MNDA.

People living with MND and their carers are the real winners in the Association's Budget 2004/2005, which provides for significant enhancement of care support services, through increased hours for the Regional Advisors. The team will now be able to provide even better quality assistance and support.

Furthermore, our support of MND Clinics at Royal North Shore, Prince of Wales and St Joseph's (Auburn) Hospitals will continue and financial support to the Calvary Hospital MND Service will enhance services in Sydney's South East Health Area.

It is indeed satisfying to see the benefits of such valuable healthcare partnerships.

Bruce Fraser
Chief Executive Officer

Socks helping d-feet motor neurone disease.
$6.00 per pair (plus $2.50 postage per order).
Phone 9743 5872 or shop at www.mndnsw.asn.au.

MNDA NSW CONTACT DETAILS

Email: **admin@mndnsw.asn.au**
Internet: **www.mndnsw.asn.au**

General enquiries and
Family Support and Info Line:
Phone 9743 5872 or Freecall 1800 640 144.

To call a particular person, dial the number listed below. If the person you have called is not available, you will be transferred to their voice mailbox where you can leave a message.

Roslyn Adams	8765 5118	roslyna@mndnsw.asn.au
Carol Birks	8765 5115	carolb@mndnsw.asn.au
Bruce Fraser	8765 5111	brucef@mndnsw.asn.au
Elizabeth Herbert	8765 5113	elizabethh@mndnsw.asn.au
Maree Hibbert	8765 5114	equipment@mndnsw.asn.au
Carole Leone	8765 5117	carolel@mndnsw.asn.au
Janet Nash	8765 5116	janetn@mndnsw.asn.au
Petra Sammut	8765 5110	admin@mndnsw.asn.au

For regional contact details, see Support Group contacts on page 9.

ALS/MND Global Day
Monday 21 June 2004

Global Awareness Day takes place each year on 21 June. This date, the Solstice, was chosen by the International Alliance of ALS/MND Associations as a symbolic turning point or time of change.

This year, the MND Association of New South Wales will convene a conference for health and community care providers at the North Ryde RSL Club on ALS/MND Global Day. Over one hundred registrations have already been received, with people coming from most Australian states.

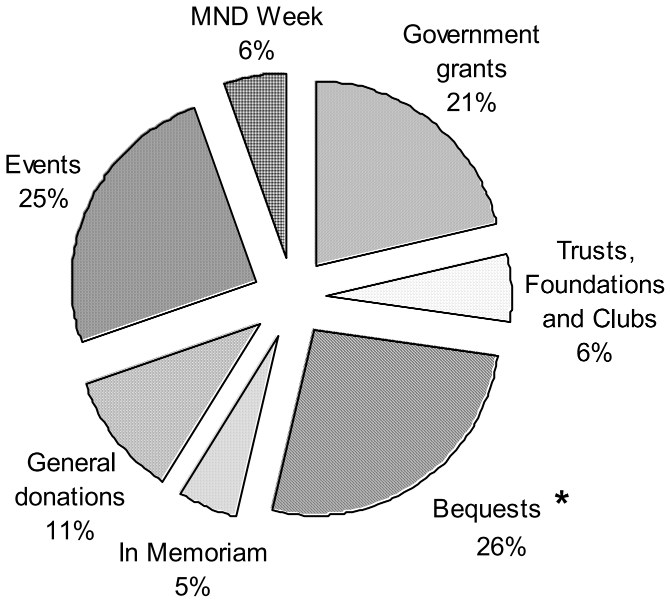
The conference program offers insights into MND research in Australia and many recent management interventions.

For registration details, go to
www.mndnsw.asn.au/htmdocs/press_room.htm
or phone Carol Birks on 02 8765 5115.

Funds to support the work of the Association

As the financial year comes to a close, members may be interested to learn the source of the Association's funding. The figures speak for themselves. The Association depends on government for approximately 20% of its income but the rest comes from the enormous range of activities undertaken by individuals.

A big thank you to each and everyone who has worked to ensure a bumper year which will enable more funds to be put into supporting people living with MND and research in the year ahead.



Income 1 July 2003 - 31 May 2004

***Bequests** are an unpredictable source of funds and it is not possible to know when this windfall will provide the funds that can make such a difference to the level of services that are provided. This year the Association has been fortunate to be the recipient of one large bequest and this has really made a difference.

HELPING THROUGH YOUR WILL

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

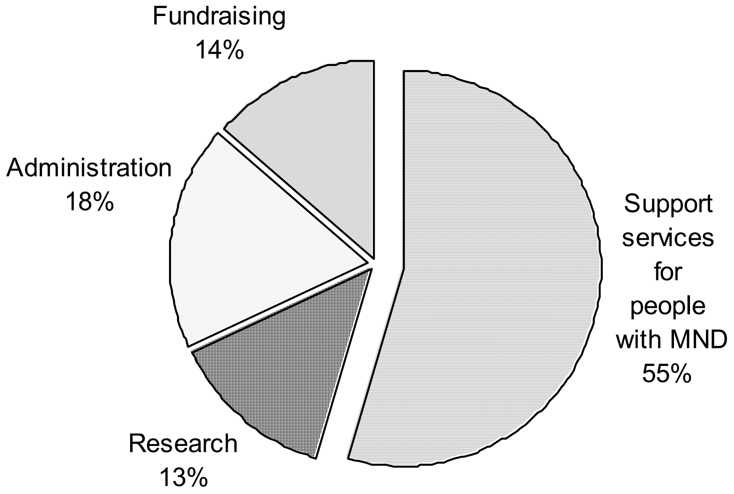
Please consider the MND Association as a living memorial for a loved one.

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

Care for today

The majority of the expenditure of the MND Association goes directly to support of people living with MND and their families and carers. This is provided through information, education, home visits, liaison with health service providers, equipment loans and much more.

To ensure that people with MND have access to the best possible care, MNDA NSW is now providing financial support for three specialised MND clinics in Sydney and to the MND Service at Calvary Hospital.



Expenditure 1 July 2003 - 31 May 2004

Hope for a future

This year MNDA NSW has been able to provide greater support for motor neurone disease research in Australia. Working closely with individual donors and the MND Research Institute of Australia, the increased allocation of funds for research will encourage investigations that will find the cause, better treatments and a cure for MND.

Motor Neurone Disease Week 2004

Wow. It was bigger. It was better and more successful than any previous MND Week. Thank you everyone who contributed their time and energy to making it all work. There are so many stories it is hard to know what to mention first.

MND Week … and still counting!

Boxes and merchandise have been coming back from all corners of New South Wales. Countless cornflowers and pens have been counted. This year, it is estimated that an extra 25% were dispatched and we prefer to count the money rather than the merchandise! The Association has banked $91,286 from the support groups, shopping centres, merchandise and street collections – and that excludes the substantial input events have made. The very grand total for the Week is a massive $334,000.

A classical launch..

Government House was the scene, on 24 March, of a truly representative launch of MND Week. A mini-bus came from Port Kembla and Newcastle & Hunter Region's support group turned out in force. Officiating was Classic FM's Margaret Throsby who had interviewed MNDA NSW Board member, Dr Paul Brock on her show last October. He reciprocated by introducing his interviewer to the assembled crowd. Afterwards, the audience listened attentively to Dr Mathew Kiernan's talk about living with MND and the day presented an opportunity for the new President, Ralph Warren, to meet many members of the Association.

For the first year of presentation of medals to a few of the many, wonderful volunteers who keep the Association going, the criteria was "those who had been instrumental in the development of the support groups" but the innovation was a huge success and, next year, different criteria will be used. Plaques were given to major donors in recognition of their contribution to people with MND.

The classical theme continued with a concert at Sydney's Conservatorium of Music with, conductor, Harry Lyth, joining the post-concert reception for MND supporters.

Two special events each netted over $100,000 for MND.

A dinner at **Parliament House** brought together the family and friends of Alex Malley to remember his mother, Irene, who died of MND. Alex has a lot of friends and filled the Strangers' Dining Room without any help from anyone. Among his friends he counts Mr Speaker, John Aquilina, who hosted the evening and Alan Jones spoke passionately about the need to ensure that everyone with MND gets the help they need.

The BNZA Ball at Leichhardt was organised by the Haddad family and their friends and the evening was a huge success (see story on page 5).

Bluebeard

Well, it is in fact not 'Bluebeard' but 'Bluehair'. Nick McLoughlin's hair turned a wonderful shade of cornflower blue as he marketed his party at the Kirribilli Club. From his wheelchair, Nick masterminded an array of events for the Association. He organised a cruise on his vintage ferry, the Emerald Star – which seats eighty - as well hosting the party and convening a motley crew of friends who all outdid each other obtaining auction and silent auction items to sell on the night. Nick, wife Naomi, son Tom and friends raised a magnificent $10,500 during MND Week.

> ***Next year MND Week can be even more successful than this year.***
>
> ***Start planning early and please let us know how we can help you to help us.***

The West goes Western

The fantastic team of Kerry Pippin and Sam Vennard are well on their way to raising sufficient money to buy an electric recliner chair. Working at neurologist Dr James Gordon's rooms in Orange, they have first-hand experience of the difference a chair can make to the life of someone with MND. They have the whole town sewn up and acquired the services of well-known Country music band 'Southbound'.

Since MND Week, golf days have taken over with Clare Bull organising her second event at Shellharbour Golf Club and the Beasley's giving ongoing support through Mollymook Golf Club. On 29 April, Russell Vale held another MND Golf Day. The second Herbie Haas Memorial Golf Day took place on 7 May at Asquith followed by a memorial day for Kerrie Cripps at Cronulla Golf Club on May 26.

Other activities have included the raffle, at Sydney's Thornleigh Community Centre, of a truly beautiful quilt created by the friends of Annette Furlong.

Elizabeth Herbert

Northern Rivers

I would like to thank the northern Rivers community for their overwhelming support during MND Week. In just three days we raised selling MND merchandise and there were also many generous donations over $2,200. A big, big thank you must go to all the volunteers who helped in many ways to make our awareness week so successful.

Helen Gates
Lismore

Helen Gates must take out the prize for scoring the record number of 'hits' in getting stories about MND into the local newspapers in her area. Of particular note was the heart-warming story of Peter Murphy (who has MND) and his wife Pat, whose positive attitude is uplifting: "Just look outside. It is like paradise here. There isn't a time of year when the landscape isn't alive with colour. Life should be about making the most of each moment." *Ed.*

> ***It is the people who are living with motor neurone disease who benefit from the proceeds of the great effort of so many generous people.***
>
> ***A warm thank you to each and every one who has helped.***

The BNZA Blue Ball was held at Le Montage in Leichhardt with 666 supporters attending. We are very grateful to the Bank of New Zealand Australia for their generosity as the major sponsor. The evening was very exciting with a Citroen C3 being raffled; live and silent auctions items to bid on and a total of $101,000 raised.

The driving force behind this event was Raymond Haddad whose mother Evelyn was diagnosed with MND in May 2003.

Thank you to everyone who gave so generously of their time and to individuals and companies who gave so wholeheartedly for the auction items.

Roslyn Adams

Cromehurst Special School, Lindfield

Please find enclosed a cheque for $82 which was raised by the children at this school on 2nd April as part of 'Blue Day'. The school had a 'Blue breakfast' which consisted of lots of blue food, everyone wore blue clothes and our primary school had a swimming carnival in our 'blue pool'. Everyone had a great time.

Ms Sue Dennett
Principal

What's happening?

21 June	**ALS/MND Global Awareness Day**
3 July	Charity Dinner & Dance at Blacktown- Charmaine Misso
4 July	Jann Karp runs Gold Coast marathon for MND Association
6 July	Collection after Seekers' Concert at Sydney Opera House – volunteers needed – call Roslyn Adams at MNDA NSW
15 July	Dale Thomas Gallery – Opening night for exhibition in aid of MND
21 July	Condobolin Lions Club Trivia Night
TBA	Five Dock fundraiser (postponed from June)
29 October	Fashion Parade in Orange
30 October	Auction in Memory of Brett Gemmell – MND fundraiser in Sutherland Shire
18 December	Motor Neurone Disease Villiers Race Day at Royal Randwick (call the MND Office on 9743 5872 for details)

NB This list is not exhaustive. Call the MNDA Office if you have something to add!

Australia's March of MND Faces Banner

Four NSW banners were on display at Government House and Parliament House throughout MND Week.

The fifth banner of NSW MND Faces will be completed in time to be displayed at the MND Conference for Health and Community Care Providers on MND Global Day, June 21.

This presentation of one hundred faces of people in NSW with MND is a touching and compelling awareness-raising exhibit.

If you would like to contribute a photo to be included on the next banner, please phone the MNDA office on 9743 5872 to ask for details.

Family Support: The MND Info Line

For many people recently diagnosed with MND and their family and friends, the first contact with the MND Association is by phone. At this stage the provision of accurate information and support is vital. The phone is also a convenient and quick way for people living with MND, family members, friends and service providers involved in caring for a person with MND, to obtain ongoing information, support and advice.

One of the many roles of the MND Association's regional advisors is to provide support through the *MND Info Line.*

The *Info Line* is available five days a week from 9.00 am to 4.30 pm. Phone the MND Association office on 9743 5872 or the freecall number 1800 640 144. Each day one of the Sydney based regional advisors comes to the office specifically to cover the *Info Line* .

The regional advisors are people with specific knowledge and experience related to MND who have a commitment to providing professional and appropriate support. They are all qualified health professionals, and are able to draw on their past experience and knowledge when discussing various management issues.

Through the *Info Line* the regional advisors are able to:

- provide information about MND – when people are newly diagnosed, and also on specific issues as they arise
- assist people to understand the information they have been given
- provide a consultancy service for service providers working with people living with MND
- provide a backup for other regional advisors, all of whom work part time, so that there is access to support, information and advice five days a week
- pass on information about *Info Line* contacts to the relevant regional advisor to ensure follow up of specific issues
- refer equipment queries on to the relevant equipment personnel or take messages regarding equipment.

In the last member survey, distributed towards the end of 2002, specific questions were asked regarding the *Info Line* . The results confirmed the importance of this form of support for people living with MND and their carers.

The results indicated that of the people who responded:

- 55% had used the info line in the last six months
- 85% rated the info line as important to extremely important
- 73% rated the information and support received as good to excellent.

When asked to nominate what had been the most helpful thing about their contact with MND Association, access to telephone support from people with an understanding of MND featured highly. Comments received included:

- Definitely the equipment but also the phone service. Knowing that someone is there to listen and who understands.
- The support that's at the end of the phone, particularly just after diagnosis.
- Being able to talk with someone directly with total understanding of my needs and possible expectations.
- Knowing I can pick up the phone to ask if something is worrying me.
- Knowing that someone is always there to give assistance if required.
- The phone support made us feel very welcome.

The *Info Line* also provides a set day each week for people to contact the Sydney based regional advisors in the office. This is particularly beneficial for service providers wishing to discuss aspects of MND management.

Since July 1 2003 there have been 1506 calls to the *Info Line* . The breakdown of the calls indicates that:

- 494 were from allied health professionals and nurses
- 329 from carers
- 259 from family members
- 215 from people with MND and
- the rest from a range of other providers, doctors or people associated with people living with MND.

The *Info Line* service not only provides support directly to people living with MND and their families but it also facilitates best practice care and support from service providers assisting people living with MND in NSW and the ACT.

Feedback from you about the *Info Line* – both good and not so good, would be welcomed. All feedback provides opportunities to learn and improve the service. If you would like to provide feedback about the support you receive please contact:

Carol Birks
Family Support Manager

Info Line
Phone 9743 5872
or 1800 640 144

Roster:

Monday	*Carol Birks*
Tuesday	*Carol Birks*
Wednesday	*Caroline Gleig & Mary Butcher*
Thursday	*Ruth Quaken*
Friday	*Carol Birks*

Carers

ASSISTANCE FOR CARERS

Carers Allowance – A small fortnightly allowance for carers available for carers who are looking after a loved one at home. This is not subject to income and assets test.

Carers Payment - is income and asset tested and availability is dependent on assessment of full-time care needs.

Federal Budget 2004-2005 brings good news for carers. A payment of $600 will made to carers who are receiving the Carers Allowance. A payment of $1,000 will be made to carers who receive the Carer Payment. If the carer is in receipt of both the Carer Allowance and the Carer Payment, they will receive $1,600. These are one-off payments and will be sent directly to carers this month.

Carers Respite Centres – provide one-off, short term and emergency respite for carers. Carers Respite Centres have been of great benefit to MND carers since their introduction through Commonwealth funding in 1998. Contact your local Carer Respite Centre on 1800 059 059.

Angel Flight
Coordinates free air transport for medical patients and family members for those who cannot access such transportation by ordinary commercial means.

For information, visit www.angelflight,org.au or phone 07 3262 4300.

Remember to apply for **Disabled Parking permits** and **Disabled Taxi Subsidy**.

Someone to talk to – it is very important that MND carers have the opportunity to talk to professionals who have an understanding of issues involved with managing MND and caring generally.

Who can carers contact when they need advice or just to talk?

- Remember your Regional Advisor is available to talk through any concerns you may have.
- Contact the MND Info Line (between 10.00am and 4.00pm Monday to Friday).
- Contact Carers NSW to find out about the National Carer Counselling Program on 1800 242 636.

Carers Kit - speak to your regional advisor about the MNDA NSW Carers Kit which has printed information on many aspects of caring. The kit is available in separate sections which can be requested as they are needed.

Care for Carers Course - commences Thursday 10 June - Concord Hospital
A four-week education and support program for family carers of people with MND.

Anita Richter
anitar@mndnsw.asn.au

COMMUNITY CARE COALITION

The coalition has been established by Aged and Community Services Australia as part of a National Community Care Awareness Program. Members of the coalition include many peak national bodies.

A Community Care Summit held in 2003 identified three aims:

1. to raise the awareness of the need of people with a disability, people with chronic and complex needs and carers
2. to raise awareness of demand
3. to lobby in the lead up to the election.

The National approach includes sending postcards and letters to leaders of all political parties and local members to highlight community care issues. Each State will also develop a strategy to lobby and raise awareness. In NSW a Community Care Awareness Week will be held in August. During the week there will be a media campaign focussing on the needs of different groups of people each day. The needs of people with neurodegenerative diseases such as MND will be the focus on one day that week.

If you would like to:

- send postcards to John Howard and Mark Latham
- speak to the media to highlight how important community care is to you or the difficulties you have experienced in accessing this type of care
- invite your local MP along to your support group meeting

please contact Carol Birks at the MND office for more details including the dates as soon as they are available.

FAMILY SUPPORT DATES FOR THE DIARY 2004

Monday 21 June - North Ryde RSL, Sydney
Annual MND Conference for Health and Community Care Providers

Tuesday 14 September – Concord Hospital
Information Evenings for people recently diagnosed with MND their families and friends
For people outside the Sydney Metropolitan Region, please speak to your Regional Advisor about organising an information session in your area.

Tuesday October 19 & 26 – Concord Hospital
Learn now/Live well Program
A two day education and support program for people with MND and their families, to assist them to live well with MND.

Support groups

Coffs Harbour

We had another successful MND Week even though we are no longer allowed to sell merchandise at the shopping plaza. But thanks to all the willing helpers, we managed to collect $3,392 from the surrounding area - Sawtell, Toormina, Bellingen, Woolgoolga and Coffs Harbour. Special thanks to the families and my good friends who gave so much help, and also to the Support Group for their effort.

Lily Jenkins

Northern Beaches

Seventeen people attended the first meeting of the Northern Beaches MND Support Group on the 13th May at the Northern Beaches Palliative Care Cottage, in the grounds of Mona Vale Hospital. It was great to see the interest and support offered to both carers and people living with MND. Dr Peter Moore and the rest of the Palliative Care team popped in to say hello. It is intended that the group will meet on a bi-monthly basis.

Mary Butcher

Panania

April: Janet Nash; MND Association Information and Research Administrator, spoke to the group about some recent advances in research followed by a lively general discussion and question and answer session.

June: Margie Zoing is Clinical Nurse Consultant for MND service for St George/ Sutherland /Calvary areas and also for the new Motor Neurone Disease multi disciplinary clinic operating at Prince of Wales Hospital Sydney. Margie spoke to the group about her role and how she assists people with MND.

The next meeting of the group will be in August.

Please call the office if you are not sure whether you are on the mailing list for the Panania Support Group.

Caroline Gleig

Newcastle set the scene for MND Week with a special church service at the Newcastle Christian Centre. This was a very moving experience for the many MND supporters who were present.

ACT/Monaro

The ACT/Monaro Support Group had its first meeting on Saturday 1 May in Canberra. This group has been formed to complement the meetings and activities organised by Helen Christiansen, the President of MND ACT. It is hoped that those who live in the surrounding regions of NSW will feel free to come along and meet the local members and enjoy the friendship and support. Anyone who lives in towns near Cooma, Boorowa and Goulburn are most welcome and we would also love to see those from further afield if in Canberra for the weekend.

At our first meeting the members decided they would like it to be a social group with the occasional guest speaker or other activity. It was evident by the amount of chat that everyone appreciated the opportunity to share experiences, swap hints and enjoy the fellowship of those in a similar situation.

Meetings will be held on the first Saturday of each month. Please phone to confirm this if you are travelling any distance as it may vary occasionally. This is because MND ACT meets approximately every 3 months (Saturdays) and Helen arranges a speaker or lunch that local members attend. In this case the ACT/Monaro S.G. would not meet as we would be MND'd out!

Meetings for the ACT/Monaro Support Group are held at 1 p.m. in the lounge room at Clare Holland House, Menindee Drive, Barton.

For any further information please ring me on 6238 3769.

Allison Pearson

Working together: Helen Christiansen (MNDA ACT) and Allison Pearson (MNDA NSW) at the inaugural meeting of the ACT/Monaro Support Group

Port Stephens and Great Lakes

The support group was set up in response to discussions with members in those regions expressing interest in and their need for a support group. So far there have been two bi-monthly support group meetings held at the Raymond Terrace Community Care Centre on a Saturday afternoon. There hasn't been many in attendance, so the meetings are postponed until further notice. I'll be sending a survey to members to determine who is interested in attending the support group, where the best place to hold it is, and what days and times are most suitable.

Support groups are a great opportunity to get together with people who have an understanding of living with MND and with similar experience. Guest speakers such as Occupational Therapists, Speech Pathologists, or Neurologists, may be arranged to talk about managing specific difficulties or to provide more general information about MND.

If you are unable to attend because of transportation, please phone me on 4952 4492. I hope to see you at the next meeting.

Christina Jason

Two members have wheelchair accessible vehicles for sale:

1995 Ford EF Flashcab
12 months rego
Good condition
85,000kms LPG.
Phone 9449 2767

A second vehicle is advertised at www.wheelchair-car.com or phone 9489 2708

IDEAS EXPO 2004 On Common Ground
Dubbo Showground18 – 20 September 2004

IDEAS Inc provides information about disability to the people of Rural NSW, as well as other parts of Australia. More than 80 exhibitors at the Expo will include mobility & other equipment suppliers, government departments, assistive technology suppliers and major peak organisations.

For more information, phone 1800 029 904.

Do you have time on your hands?

Have you talents which you are longing to use?

Are you interested in helping a worthy cause?

VOLUNTEER FOR MNDA !!!

The Association is searching for volunteers to assist in various activities, ranging from computer and administrative issues, to helping out at special fundraising events and packing and dispatching merchandise. We would love to hear from you and would be grateful for your time.

Please contact Roslyn Adams, Promotions Coordinator, on 8765 5118 or roslyna@mndnsw.asn.au to register your interest.

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*
- **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.. Also try *http://neuromancer.mgh.harvard.edu/echat42/ALS/* for a chat room which is open 24 hours per day.
- Visit the MNDA NSW website at *www.mndnsw.asn.au* for links to other sites.

SUPPORT GROUP CONTACTS

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

Central Coast
Audree Dash
Phone: 02 4384 2907

Central West
Mary Campbell
Phone: 02 6851 4403

Coffs Harbour
Lily Jenkins
Phone: 02 6652 2571

Illawarra
Pam Van Den Hoogen
Phone: 02 4223 8000

Newcastle & Hunter
Alistair Fyfe
Phone: 02 4947 1983

New England
Robyn Barton
Phone: 02 6766 6065

Northern Rivers
Helen Gates
Phone: 02 6621 4018

Port Stephens
Christina Jason
Phone: 02 4952 4492
christinaj@mndnsw.asn.au

Riverina & S W Slopes
Wes Russell
Phone: 0408 692 127

Hornsby and
Northern Beaches
Mary Butcher
maryb@mndnsw.asn.au
and

Panania
Caroline Gleig
carolineg@mndnsw.asn.au
and

Penrith &
Blue Mountains
Ruth Quaken
ruthq@mndnsw.asn.au

are coordinated through the MNDA office.
Phone: 02 9743 5872

Research

Scientists may have developed a gene therapy treatment for the most common form of motor neurone disease (MND).

In lab tests on mice the therapy slowed onset and progression of Amyotrophic Lateral Sclerosis (ALS). It also extended life expectancy by 30%.

Writing in the journal Nature, the research team at biopharmaceutical firm Oxford BioMedica stressed the work is at an early stage.

MND affects about 5,000 people in the UK and there are 1,000 new cases a year.

The disease is caused by the death of cells - called motor neurones - that control movement in the brain and spinal cord. There is currently no known cure.

ALS is a form of the disease which affects adults, leading to paralysis and death within five years for most patients.

Key gene The new treatment - called MoNuDin - essentially consists of a gene which triggers production of a chemical called a vascular endothelial growth factor (VEGF).

The gene is injected into the muscles, but stimulates VEGF production in the nerve cells of the spine.

ALS has been linked to reduced levels of VEGF in both mice and humans. It is thought that the chemical plays a key role in protecting nerve cells from damage.

Tests on mice showed that a single shot of the new therapy was enough to produce a significant beneficial effect.

Professor Alan Kingsman, Oxford BioMedica chief executive, said: "Although these results published in Nature are still at a preclinical stage, the data suggests that VEGF gene therapy could provide an effective treatment for ALS."

Dr Brian Dickie, of the MND Association, welcomed the findings.

He said: "These findings reflect current optimism amongst researchers that gene therapy represents a viable strategy for the treatment of ALS and other neurodegenerative diseases, overcoming problems of access of drugs to the central nervous system, which can occur with more conventional approaches to treatment."

The Oxford BioMedica team worked on the treatment in collaboration with the Center for Transgene Technology and Gene Therapy in Belgium.

Story from BBC NEWS: http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/3750125.stm
Published: 27/05/2004

Blood on the Deck

- research can be fun!

Dr Roger Pamphlett from the University of Sydney took to the high seas when Nick McLoughlin offered a cruise on his vintage ferry, the Emerald Star, to people willing to give a small blood sample for inclusion in the MND DNA bank. Thirty volunteers (mostly yachtsmen) turned up on Saturday 5 June and Mary Jenkins had a very busy morning extracting blood from them.

Dr Pamphlett's research is investigating gene/environment interactions to try to find some clues to the cause of MND.

The 15th International Symposium on ALS/ MND will take place in Philadelphia, USA from 2-4 December 2004. Researchers and clinicians will meet to share their common interest of working towards a world without MND.

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.
There is a website for further information at www.braindonors.com. Offers of brain tissue are sought from everyone - not only people with MND.
Please note that if you have previously sent an autopsy request form to the University of Sydney, the *Using our Brains* program has superceded previous requests. You will have to resubmit your request on the above phone number.

MND Research Institute of Australia

Applications for grants-in-aid to support research in the calendar year 2005 close on Tuesday 31 August 2004.
This year, as well as the usual funding for small projects, funds have been made available through the MND Association of NSW specifically to support scientifically assessable **clinical** research in NSW.
For application forms, go to the MND Research Institute's website at www.mndresearch.asn.au.

Volunteer visitors for people living with MND

The recently run Volunteer Visitor Pilot Project Education and Orientation Program was a great success. The sessions were held one day per week over five weeks and provided prospective volunteer visitors with information about motor neurone disease, and volunteer policies and procedures. A manual was provided to each participant for future reference.

Of the thirteen people who attended the program, six were volunteers from Palliative Care Volunteer services in the Port Stephens, Singleton and Central Coast regions. They were invited along to receive some specific knowledge about motor neurone disease, to enable them to share that knowledge with others in their service and use that knowledge themselves when they visit people with MND who have been referred to palliative care. Three of the palliative care volunteers were so impressed by the information they were provided with and the professionalism of the presenters, they decided to become volunteers for the MND Association as well as for their local palliative care volunteer service. Add to these three another seven people who specifically expressed interest in becoming MND volunteers, and we now have ten educated volunteers waiting to visit people with MND in the Hunter and on the Central Coast.

Volunteer visitors *are good listeners, are caring, reliable people from many different walks of life who work with sensitivity and understand the need for confidentiality. They offer support to people with MND on a regular basis.*

Forms to determine the need or desire for a volunteer have already been sent to some people with MND and their carers in the Hunter, Newcastle, Port Stephens, and Central Coast regions. These forms will help to match people with MND with a suitable volunteer. If you haven't received a form and you feel that you would like a volunteer visitor and you live in one of these regions, please phone 4952 4492.

I would like to thank everyone who has supported and had input into the development of the education and orientation program and manual. I look forward to working with the new volunteer visitors and running the education and orientation program again.

Christina Jason
Regional Advisor, Northern NSW

I attended this course as a volunteer and I am happy to report that it was very professionally run. It was obvious that a lot of preparation had been done by Christina Jason, Carol Birks and Anita Richter.

All the volunteers who participated put their hearts into it and were very interested and a lot wiser afterwards. They were all excellent contributors so there was a lot of input from the group.

After a long-term involvement with the Central Coast MND Support Group, I thought I knew everything about motor neurone disease, but I learnt much more by attending this course.

I am now looking forward to the next stage of being a volunteer visitor and making regular visits to people with MND in my area.

Sheila Holmes
Gorokan

To make a donation to support the vital work of the Association, please complete this form and send to:
Motor Neurone Disease Association of NSW Inc., Concord Hospital, Hospital Road, Concord NSW 2139

All donations of $2 and over are tax deductible **Please do not send cash in the mail**

Title ……….. First Name ………………………….. Surname ……………………………………………………..

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☐ I authorise MNDA NSW to charge the sum of $ ……………… to my credit card (details above) on the 20th day of each month as a donation to the Association. I understand that this contribution can be changed or cease at my instruction at any time.

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Please send me more information more information about:

☐ Becoming a member of the MND Association ☐ Becoming a volunteer ☐ Making a bequest in my will

Dear Editor

Thank you for a very interesting information evening for people newly diagnosed with MND. It helps when you realise there are others feeling like we do but all trying to carry on as normally as possible. I would like to share with your readers my story of trying to carry on as normally as possible

My husband and I have always danced - modern ballroom and latin - and I had been teaching for eight years when I was diagnosed with MND. We thought this would end our social life and also our trips to restaurants, but we found I could still dance; we improvised in some dances which gave us a few laughs. Although I needed to wear a collar everybody accepted me and we were treated just the same.

We used to go out with groups of friends to restaurants which was something we thought we wouldn't be able to do any more, especially when I was told I needed to puree all my food, but we found all we had to do was ring wherever we were going and they made sure we were near a power point, so we would take our mixer and jug to puree whatever I chose. In one place they even took the mixer and jug and washed them for us. We have found every person is willing to cater for us and we have some laughs when I say my meal is tastier when it's pureed.

We often have a Sunday dance which includes a smorgasbord lunch. No one ever passes a comment when we take out our mixer; they have all accepted what we have to do.

We have planned a holiday to Las Vegas in August but we will make sure we can manage it, the eating part, and check in case I might have to have a PEG tube put in before we go.

Ivy Byrne
Narellan

A great escape

Mary Butcher must be congratulated for the great escape weekend she organised for three couples from Northern Sydney. My husband, Noel, has MND and is in a wheelchair. For us, the weekend started when Mary's husband, Peter, arrived on a Friday afternoon in May in a rented van to collect us and take us to O'Carrollyns at One Mile Beach on Port Stephens.

Peter was just wonderful. From the outset he was so willing to help Noel that I was free to enjoy myself. We arrived at O'Carrollyns to see this place that is so green and lovely. Our accommodation in so called 'huts' came complete with a lounge/dining room, kitchen, master bedroom and bathroom with disabled facilities, and upstairs in the loft there were four more beds. This would be perfect accommodation for a whole family but it was just for the two of us.

Mary had brought all the ingredients for a delicious barbecue dinner which she and Peter cooked for us in an undercover BBQ area beside a pond. Afterwards we went back to out 'hut' where we were cosy and warm with the reverse cycle air conditioning and the TV.

The next morning, a nurse helped Noel with showering and Mary had prepared a breakfast package with everything we needed. We then set out on a day touring the area – Nelson Bay, Shoal Bay, Fingal, Salamander Bay and Soldiers Point. In the afternoon while our husbands were resting, I had coffee by the beach with one of the other carers and we had a wonderful chat about all sorts of things.

Dinner on Saturday night was at the Soldiers Point Bowling Club and the next day we were up bright and early and off to the wharf at Nelson Bay for a dolphin watching cruise. Mary was absolutely fantastic. She had planned everything very thoughtfully and we were able to get the wheelchairs on and off the boat without mishap.

Thank you Mary and Peter for this thoughtfully planned weekend.

Val Simpson
Eastwood

BBQ by the pond at O'Carrollyns

Many thanks to the Northern Area Carers Respite for the special initiative of funding for this Great Escape Weekend. Ed.

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

ACKNOWLEDGEMENT
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Editor: *Janet Nash*