THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MOTOR NEURONE DISEASE

FORUM

June 2005

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MND in the spotlight

Sydney March of MND Faces - Hyde Park to Parliament House - 2 April 2005

A huge thank you to everyone who turned up for the March of MND faces on Saturday 2 April at the start of MND Week. It was kind of the Footy Show, Alan Jones and Column 8 to broadcast the event and attract some extra foot soldiers. Equally, the Police, Maxi Taxis and the City of Sydney have to be thanked for giving the necessary permissions and backup.

But the most important people were those who came from as far afield as Holland (Len!), the Illawarra and Newcastle. People were able to carry the banners with a photograph of their loved ones and the event attracted a lot of children and grandchildren who don't normally get involved with MND. It was great to see them. The television coverage came thanks to Sharyn Morris from Scone, whose son John brought along his mates from Parramatta Eels.

Strathfield Rotary have to be thanked for sizzling those sausages too.

It was a major achievement. Almost 250 people turned up. The prayers that followed, in a very informal environment, were heartfelt *(see page 5)*. The chance to meet with others afterwards was something that people have told us should be repeated.

Elizabeth Herbert

Chief Executive Officer

On behalf of the Board and members, I am very pleased to announce the appointment of Graham Opie as the new Chief Executive Officer of the Association. Graham brings a wealth of experience and expertise to this critical position, having spent time both here and abroad in similar roles. Most recently, Graham was the CEO of the Heart Foundation in the Northern Territory where he successfully grew the organisation and substantially enhanced its reputation.

Graham returns to Sydney with his young family and we feel very confident that he will bring renewed energy to the Association and provide both leadership and innovation as we continue to build the Association and provide the highest quality of service to our members.

Ralph Warren
President

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 Acting CEO

It has been an exciting and fulfilling period for staff at the Association since the last newsletter. The new MND Centre at Gladesville continues to provide new possibilities; people with MND and family members have popped in for a chat from around the State, health professionals have visited to look at equipment and resources available, and more volunteers have joined the team as receptionists, office assistants and envelope stuffers. There is a definite feel that this is now home for the MND Association of NSW.

MND Week was a flurry of activity as always and, considering its proximity to the move, staff changes and big media stories breaking during the week, was a great success in raising awareness. Elizabeth Herbert managed the whole process admirably encouraging and supporting the army of MND volunteers across NSW who were out in force at shopping centres, airports, railway stations, Circular Quay, schools and in the streets marching. We thank you all for keeping **MND in the spotlight**.

The Association aims to raise awareness of MND at every level and this has certainly been achieved in the last few months. The interest in the inaugural scientific meeting exceeded all expectations and has engendered new and invigorated opportunities for networking. Another new initiative **The March of Faces** was a great success and will certainly become an annual event during MND Week highlighting the impact of MND to a wide range of people. Interest and attendance at Ask the Experts and MND DNA donor drive, Link and Learn and Learn Now Live Well sessions during this period confirms the need for the Association to continue to look at the best ways of meeting the needs of all people affected by MND. Raising awareness of the personal care needs of people living with MND and their families at government and Department of Ageing Disability and Home Care (DADAC) level has also been a focus during this period and will continue to be so. The lead up to the Cornflower Blue Ball has opened opportunities to raise awareness at many levels when seeking sponsorship, prizes and donations. There have been many people who have donated generously time, money, prizes and commitment to make this major event a success and I thank them all.

One of the most effective ways to raise awareness is through the sales of merchandise. In this issue of Forum we are launching a new product the **NEVER GIVE UP** wristbands. These bands have been very popular in the USA and we ask all our members to get behind this initiative and encourage friends, family, schools and any contacts you have in the sporting and media world to buy them and wear them **now**. This product will be sold in a number of States in an effort to keep MND in the spotlight throughout the year across Australia.

It has been a privilege to take on the role of acting CEO over the last few months and I have enjoyed extending my knowledge and working more closely with all staff, board members and volunteers. On behalf of the staff I welcome the new CEO, Graham Opie, and as I hand over the reins I would like to take this opportunity to thank the extended MND family for your continued support.

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

Carol Birks
Acting CEO

NEVER GIVE UP

Wristbands have been taken up as the charity rage around the world. Michelle Rozzen took up the concept with NEVER GIVE UP wristbands to support people living with MND in memory of her father, David Rozzen, who died from MND in the USA on 16 June 2004.

Blue NEVER GIVE UP wristbands for MND will be available in Australia in early July.

At $2 each, you can get on the **bandwagon** and plan your **band days** to support MND in schools, shopping centres, sporting venues 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 as soon as they are available.

Chief Executive Officer

As the new Chief Executive Officer of the Motor Neurone Disease Association of NSW, I would like to introduce myself.

My family and I have recently moved back to Sydney from the Northern Territory where I was CEO of the National Heart Foundation. Before joining the not-for-profit sector I worked in a variety of industries including catering, building and the media.

In 1995 I moved to New York City where I took up a role as Director of school health for the American Cancer Society. Upon returning to Sydney I worked with UNICEF Australia, the Association of Childrens Welfare Agencies and as a consultant restructuring several youth refuges.

I have always held a deep commitment to both health and social welfare but it wasn't until I embarked on a career with the American Cancer Society that I discovered my niche. Since taking this path I have found each position fascinating and personally rewarding.

During my time in the Territory I worked closely with the NT Council of Social Services and was chair of a joint government/non government Homelessness Task Force, allowing me to look more broadly at the social determinants of health and work across government, non government and the corporate sector.

Starting my working life with a trade as a pastry cook (always comes in handy and no, I will not be baking fabulous cakes and pastries at Gladesville), I hold a Bachelor of Sports Science from the University of NSW, a Graduate Diploma of Management with the University of Technology, Sydney and have embarked on a Graduate Diploma of Applied Corporate Governance.

I would like to thank Carol Birks for her work as Acting CEO. From what I have heard Carol and the staff have done a fantastic job and I am looking forward to working with them and getting to know the members and volunteers of the MND Association of NSW.

Graham Opie

MEMBERSHIP RENEWAL ON THE INTERNET

Application for new membership and membership renewal can now be made using a credit card at our website www.mndnsw.asn.au. Just click on the membership tab.

Donations can also be made online by clicking the donations tab.

MND ASSOCIATION OF NSW CONTACT DETAILS

Postal address: Locked Bag 5005 Gladesville NSW 1675 Fax: 9816 2077

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

General enquiries, Family Support & Info Line: Phone 8877 0999 or Freecall 1800 640 144.

To contact a particular person at Gladesville, dial the number listed below or send an email:

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Caroline Gleig	8877 0905	carolineg@mndnsw.asn.au
Maree Hibbert	8877 0907	equipment@mndnsw.asn.au
Michelle McGrath	8877 0910	michellem@mndnsw.asn.au
Janet Nash	8877 0901	janetn@mndnsw.asn.au
Graham Opie	8877 0914	grahamo@mndnsw.asn.au
Ruth Quaken	8877 0906	ruthq@mndnsw.asn.au
Trevor Rakuraku	9816 2644	trevorr@mndnsw.asn.au
Anita Richter	8877 0902	anitar@mndnsw.asn.au
Petra Sammut	8877 0903	admin@mndnsw.asn.au

MND Week 3 - 10 April 2005

How can we thank all those people who helped during MND Week? This is the one week of the year when people all around Australia are out in force to do whatever they can to raise awareness about MND and to raise funds to support the work of their MND Association.

Funds flowing in from around NSW account for $67,000 so far and we are still counting. The money is still coming in from all those people who gave up their time to sell merchandise and do whatever else they could think of to support people living with MND. This has been a fantastic effort by many people. Thank you.

One person who deserves special mention is Nick McLoughlin who once again held Nick's Party at Kirribilli to raise an impressive sum to support the MND Association and also the MND Clinic at Royal North Shore Hospital.

Cornflower Blues

Once again the streets of the city of Sydney were adorned with blue MND banners bearing the slogan - **Care for Today, Hope for a Future**. Banners were displayed on RTA bridges around Sydney and media around the State gave their support. This all made an impact and helped support the collectors on the ground. At Town Hall, the students from St Andrew's Cathedral School were again excellent ambassadors for MND under the auspices of their Head of House, Sam Blanche.

Many people gave generously of their time and many early birds were seen clutching bucketfuls of cornflowers around train stations and, at Qantas Domestic Terminal, Megan and Michelle Paton and their team were indefatigable.

Talking about MND

The Association was pleased to have ongoing support of some very caring media personalities. Simon Marnie spent half an hour talking to Vice Patron, Kevin Langdon, on his Sunday morning show at the beginning of MND Week and Angela Catterns, Ray Hadley, John Laws and Chris Smith all featured Cornflower Blue Day on Wednesday 6 April. ABC TV also ran a news item at the end of the week featuring Professor Garth Nicholson and Helen Hall.

Thanks to all those who badgered their local radio stations and newspapers or called and 'talked back' about MND. Between you, the coverage was excellent, even though there were many major news stories competing for attention at the time.

Schoolies *Millie Brock wrote the most poignant letter about her father's battle with MND and this was circulated by the Dept of Education to heads of all schools in NSW. Schools throughout the State raised both funds and awareness for MND.*

Shopping around

Your feedback would be appreciated. Several people have reported that positions given to the in shopping centres were unfavourable. Let the office know if you think it is time to look for a new type of fundraising venue. Call 8877 0999 or 1800 640 144 or email admin@mndnsw.asn.au

Elizabeth Herbert

21 JUNE – ALS/MND GLOBAL DAY

Every year, since 1997, the International Alliance has celebrated 21 June as the global day of recognition of ALS/MND – a disease that affects people in every country of the globe.
21 June is a solstice – a turning point - and each year the ALS/MND community undertakes a range of activities to express their hope that this day will be another turning point in the search for the causes, effective treatments and cures for this disease. This one day allows us to recognise that we are not alone in our fight against ALS/MND, and that people with MND, carers, former carers, scientists, health care professionals, volunteers and many, many others, all of whom care, are all part of this fight.

What can you do on ALS/MND Global Day?

- Join the Global Chat session at www.alsmndalliance.org/chat.shtml
- Tell ten people you meet about MND
- Have a party to raise funds for the MND Association
- Contact your local newspaper or radio station and tell them your story about MND
- Make a donation to support the work of the MND Association
- Contact the MND Association of NSW on 02 8877 0999 or 1800 640 144 for even more ideas.

Service of remembrance

Saturday April 2 Hyde Park, Sydney

"Did you hear about the priest, the imam and the rabbi?" No, it's not one of those jokes, but it's what happened between the MND march and the sausage sizzle.

Words and prayers were said in English, Arabic and Hebrew. We remembered and prayed for those who have MND, their families, their carers, the stirrers and activists who agitate on their behalf, and the doctors and scientists who must find treatment and a cure for this disease.

Led by Father Peter Brock (brother of MNDA NSW Board member, Dr Paul Brock), the Association was honoured to have Sheikh Chami and his prayers for Islam before Leon Symon arrived with Rabbi Kastel to conclude the formal proceedings.

April 2, 2005 would become historic some hours later, with the death in Rome of Pope John Paul II. But a small piece of history was made on a beautiful sunny autumn day in Sydney, as men of three great (but often antagonistic) religious traditions joined together to offer prayers and support for those dealing with MND.

Father Peter Brock
Canberra

Dear brothers and sisters

I am very proud to be with you on this occasion. I was not aware of motor neurone disease until the Motor Neurone Disease Association contacted me. In one way I was sad that I was so unaware of this disease but I am happy to help you and share with you the work to help those who are suffering from MND.

This disease is not limited to one group or another; rather it affects every one and anyone. It should be our aim to cure it permanently and of course the first step is research. This is where the government can give financial assistance.

But today do pray to God that all who suffer find a cure very quickly. I hope you join with me in this prayer to the Almighty God –

> Oh Almighty God we ask you for your protection in this life and the hereafter.
> Oh Almighty God we ask you to pardon and protect our faith, our life and wealth.
> We seek refuge in your greatness to help save our land and us from any disease that may affect our families or us.
> Oh Almighty God with your great mercy we surround ourselves and to your help we turn our hearts to make us feel for those who have been suffering.
> We believe that you are the only one that can help.
>
> Oh Almighty God we ask you to guide our scientists and researchers to find a cure for this disease. Amen

Sheikh Khalil Chami
Minister for Moslem Religion

Heal us, O Lord, and we shall be healed; save us and we shall be saved, for You are our praise. Grant a perfect healing to all our ailments, for You are a faithful and merciful God, King and Healer. Blessed are You – the Lord, the Healer of the sick. We pray for all those afflicted with motor neurone difficulties. May it be God's will that you know of no suffering or difficulty and may the doctors be given the tools to be able to find the cure. May God find in His great mercy healing for all the sick. Amen

Rabbi Mendel Kastel
The Great Synagogue, Sydney

Family Support

For the final instalment in the series outlining the various roles within Family Support Maree Hibbert the Equipment Officer has provided an overview of the equipment service.

Equipment is an integral part of Family Support and we are fortunate to have two dedicated staff members running this service. It has been very gratifying over the last few months to see the reaction of the people who have been involved with this Association for a long time when they visit the new equipment store at the MND Centre at Gladesville. They understand the significance of the huge expansion of the equipment service over the last few years and now having the room to store, clean and maintain equipment on site.

We hope that members and health professionals will take advantage of the MND Centre and pop in to view equipment and meet with staff.

Carol Birks
Manager Family Support

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.

MND equipment loan service

Since the MND Association of NSW started in 1981 there has been a need for equipment loans to help maintain comfort, independence and support wherever possible. Starting out with three manual wheelchairs stored in a spare bedroom, the Equipment Loan Pool of the Association has expanded to 1,139 items ranging from large items (e.g. electric beds, hoists, and shower commode chairs) to small, high tech communication devices. A majority of these items are on loan at any one time. At the time of writing there have been 661 items sent out on loan since July 2004.

As Equipment Officer I work three days during the week, usually Monday to Wednesday, but there are occasions when my days of work have to be altered due to meetings or workshops. I liaise with health professionals e.g. Occupational Therapists, Speech Pathologists, regarding equipment requests, and the MND Association regional advisors to help ensure the right equipment is being loaned. I am also responsible for sourcing new types or pieces of equipment that would be suitable for use by our members in the equipment loan pool.

There are never enough minutes in the day working at the Association and I am lucky to have an assistant, Trevor Rakuraku, who works four days a week from Tuesday to Friday. Trevor is responsible for transport and maintenance of equipment and usually has the job of contacting members when deliveries or pick up of equipment are needed.

Now that the equipment loan store and our offices are on one site, members and Health Professionals are welcome to visit so please feel free to contact me or the Association to make an appointment.

The MND Association of NSW continues to provide this service free of charge to its members as equipment costs can be very high and place undue strain on families and their carers. It continues to expand and keep up to date with new developments so as to maintain a high standard of care.

Maree Hibbert
Equipment Officer
Phone: 02 8877 0907
Email: equipment@mndnsw.asn.au

The MND Association has purchased two hands free laser computer mice, called a SmartNav Mouse, to be used with a computer by members with limited hand function.

This new technology can give independence for people to access computer programs and emails and maintain communication with limited assistance. Both SmartNav mice are presently out on loan but the feedback from the members using them is very positive. (*See letter on following page*).

SmartNav mouse (for hands free computer access)

Dear Maree

Firstly, my thanks to you and all at the MND Association of NSW for the ongoing support you provide for my wife Leonie who was diagnosed with MND/ALS in February 2002. I don't know where we would be today without your assistance, not the least of which is your most recent item of IT equipment, the Claytons Mouse (ie the Mouse your having when your not having a Mouse!).

Leonie has been unable to speak normally for more than a year now and the use of alternate communication methods (like picture boards, Scanning LightWriter and computer) are essential for her day to day care and inner well being.

Whilst Leonie is still managing to 'click' with a normal PC Mouse (*together with screen based keyboard Click & Type software)* to operate her computer to produce letters and exchange emails with her friends and family, her ability to do so is becoming more difficult.

Thus, your latest leading edge SmartNav (Claytons) Mouse is a most useful hands free enhancement to Leonie's future communications capability.

Installing the associated Smart-NAV CD-ROM software into Leonie's PC (running Windows 2000 Professional Operating System) was easy. It was then a simple matter to attach the Smart-NAV unit onto the top of Leonie's PC, plug it into the PC's USB port and focus the unit. This only took a few minutes and the unit worked first go.

Leonie's still getting used to its functionality. I've tried it too. Strange feeling at first, operating your computer hands free! But it does work! We attached the small grey reflective 'dot' on the bridge of Leonie's glasses *(though this could well be located anywhere, even on the end of your nose or finger providing you have control over where to point it).*

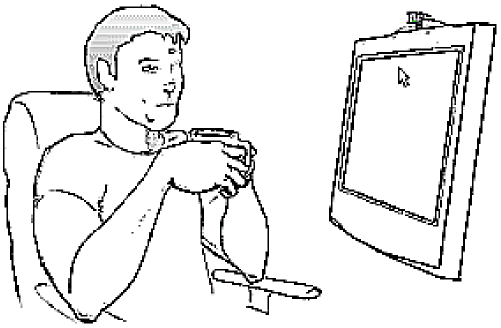
The grey 'dot' then reflects the infrared signal back on to the screen where it instantly becomes the cursor replacing the normal hand held Mouse functions. Controlling head movement (up/down/sideways) is something of a challenge made easier for Leonie by using a neck brace (collar) to provide additional support.

Whilst the Claytons Mouse will take Leonie some time to become fully comfortable with, we're grateful to have it now so she can familiarise herself with the technology in advance of any further change in her ability to use a normal PC Mouse.

Again, our sincere thanks to the MND Association for your assistance. I believe the SmartNav hands free mouse is definitely a very worthwhile addition to the MNDA's armoury of support equipment for Members of the MND Association of NSW.

Kind regards

Jim Simpson
Five Dock



VEHICLE FOR SALE:
Wheelchair accessible vehicle
1995 automatic
Ford Flashcab
registered to May 2006
86,500km
LPG/petrol.
Price to be negotiated.
Phone 02 9449 2767

Carers news

Carers Kit

The second edition of **the MND Association of NSW Carers Kit** is now available. The Carers Kit has proved to be a valuable resource for MND carers and a variety of care providers. Since its inception in April 2002, 202 complete Kits have been issued to carers and over 43 to health professionals. The recent amendment ensures up to date information as small details change over time.

We recommend that MND carers order the Kit in sections concerning symptoms that are currently affecting the person they are caring for with MND. Further sections can be ordered as needs change. This can help to avoid information "overload". For more details speak with your Regional Advisor or phone Info Line on 8877 0999 or Freecall: 1800 640 144.

Link and Learn Program –Southern NSW

This program was well received and gave us the first opportunity to trial the concept of telephone group support. We appreciated the enthusiastic participation from our first group of carers who helped the whole project to run smoothly, (see Mailbag on page 12 for comment). The second phase of the Link and Learn Program for MND carers in the Riverina and South Western Slopes NSW will be run early next year. Thanks to NSW Health for supporting this program.

Carers Workshops

will be held in our Gladesville Centre during **September.** These workshops will be run over four full day sessions and offer education in techniques for caring as well as emotional support for carers. If necessary, family support staff will help interested carers to make any respite arrangements to attend the workshops. Feed-back from carers who have attended previous workshops confirm that MND carers find great benefit in the opportunity to share learning and ideas with others in a similar situation.

Anita Richter

If you have been recently diagnosed with MND and have a family and friends who would like to learn more about MND, please speak to your Regional Advisor about organising an information session in your area.

Learn Now Live Well workshop

was held in Newcastle in May for people with MND and their carers. Some came from as far as Forster and the Central Coast. Local health professionals spoke about exercise and MND, maintaining independent living at home, tips for living well, eating well with MND, monitoring changes in swallowing and communication, monitoring respiratory function, and services available to support people with MND and their families. If you would like a Learn Now Live Well workshop to be held in an area near you, please contact the Association.

Christina Jason

Family Support Dates for the Diary in 2005

Tuesday July 26 2 pm - 4 pm Building 4 Old Gladesville Hospital Gladesville	**Past Carers Meeting** **Have you lost a loved one through MND?** **Would you like to meet with others in the same situation?** We are aware that there may be past MND Carers who would like to keep in touch with the Association and with others in the same situation. Now that MND Association NSW has settled into the new Gladesville Centre we have the room and the opportunity to reach out to the wider MND community. We are therefore holding an informal "get-together" for past carers: This will be the first of regular Past Carers meetings to be held bi-monthly on the last Tuesday of every second month. **RSVP for this meeting by Friday 22 July**
Monday August 22 at 10.30am - Gladesville	**Volunteer education and lunch** Kevin Langdon will talk about his role in the MND Ambassador program. All prospective and existing volunteers welcome. Please phone 8877 0999 if you would like to attend.
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

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.

Support Groups

Southern Highlands/Monaro

Six of us met at a Braidwood café on Saturday, April 16th to have lunch and enjoy a chat about various topics from wheelchairs to soup recipes! Robyn and Matt Gargan, who had run a cafe and owned a property in the Braidwood district before his diagnosis with MND, enjoyed seeing some familiar faces in town. After lunch we drove out to Ailsa Korten's home, a 400 acre bush retreat, the serenity and beauty of which made us all very envious. Thank you Ailsa for opening your home and allowing us to enjoy your little bit of heaven.

> ***Central Western NSW meeting in Orange week beginning 10 October 2005. This will be the first meeting for our members to be held in Orange. Please contact Carol Birks on 1800 640 144 if you would like to attend.***

Our May meeting was held at The Independent Living Centre in Weston, ACT. One of the occupational therapists gave us a comprehensive tour of the building which has a large range of equipment on display for people to try and compare. Equipment to help with all daily activities such as cooking, eating, showering, toileting, sitting, reading, dressing and mobility is displayed…to name just a few! Equipment is not for sale but advice is given as to how to access it.

Anyone is able to drop in to the ILC to look around on their own between 12-2pm. Monday-Friday. If you require detailed advice you are able to make an appointment to see an O.T. by ringing 6205 1900 or emailing ILCACT@act.gov.au. Advice can also be given over the phone and is not limited to ACT residents.

We do not have a meeting in June but will meet again on Saturday, 2 July at Clare Holland House, Barton at 1pm. Julie Kulikowski, a social worker at CHH, will speak on the personal issues confronting those diagnosed with MND and their carers.

Allison Pearson

Afternoon Tea for MND Newcastle

People living with MND, their family, carers and friends, are welcome to share their experiences and friendship with understanding. Join us at our informal get together and meet others who have been touched by MND.

Guest speakers will lead informative discussions on relevant topics.

Edgeworth Neighbourhood Centre
Cnr Minim & Main Rd, Edgeworth (wheelchair accessible) at 2pm on Saturdays 25 June, 27 August, 29 October and 17 December.

For more info phone 1800 640 144.

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

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

Volunteers

The MND Association was formed in 1981 by a group of dedicated volunteers and, 24 years later, **v**olunteers are still invaluable to the Association. As well as helping with ongoing activities in the office, volunteers help to increase community awareness of MND, elicit interest in research for a cure, promote member and carer support whilst informing the public about the work of the Association.

If you would like to become a volunteer, you will be invited to participate in volunteer support meetings and ongoing education offered by MNDA NSW; you will be invited to attend volunteer functions and participate in the appraisal of your role and an evaluation of the provision of support to the Association and to seek support from relevant staff members.

Volunteer Education Day

MNDA NSW was delighted to be able to hold the inaugural Volunteer Education Day in the new Centre at Gladesville on Monday 23 May. The day was well attended and it was an excellent day of exchanging ideas. The positive feedback made staff aware of the value placed on our service and the Association.

The program covered the following:

- Volunteer Role Descriptions
- Volunteer Policies and Procedures
- Introduction to the MND Ambassador Program
- MND Week – Review 2005, moving forward 2006
- Launch of Support Group Guidelines.

Those attending agreed it was a worthwhile day and decided to meet on a regular basis every 3 months. Everyone who is interested in volunteering or currently a volunteer is invited to attend.

The next volunteer meeting will be held on **Monday 22 August from 10.30 am – 12.30 pm**. Kevin Langdon has been invited to talk about the Ambassador program. We will have an open forum for discussion and then have lunch together. Please us know if you will be attending.

Roslyn Adams, Phone: 8877 0908

Bequests

In the past year the MND Association of NSW has been fortunate to be the beneficiary of two very significant bequests. People who are touched by MND at some stage during their life and have had the foresight to make a bequest to support MND are the people who can really make a difference. We are very grateful for all the bequests we have received, but must make particular mention of the late John Greenhill who left a bequest of approximately $500,000 to support the work of the MND Association of NSW. In an organisation that is so dependent on donations, it can be difficult to budget to support the many aspects the Association's work. The generosity of a bequest such as this allows provision of support that could not otherwise be given.

The Association is also extremely grateful for the recent bequest of over $100,000 from the Estate of the late Daphne Toohey. This money will go to MND research, directed through the MND Research Institute of Australia to fund projects in 2006.

In Queensland, research into the causes of MND has also received a fantastic boost from the Estate of the late Peter Goodenough who left $3 million to the Brain Institute at the University of Queensland. This is **really** putting MND research **in the spotlight**.

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.

What's happening?

Saturday June 18 Westin Hotel, Sydney	**Cornflower Blue Ball** – Fundraising auction and dinner. Black Tie. Wine, dine and dance to Galapagos Duck. $175 per person
Tuesday June 21	**MND Global Day** *(see page 4)*
Saturday June 25 Saturday August 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.
Friday July 29 8.30am Asquith Golf Club	**Herbie Haas Memorial Day Classic** $110 per player includes golf and lunch. All money raised to be donated to MND Association of NSW. For enquiries contact Marten Clark on 9477 1266.
Saturday 29 and Sunday 30 October 10am – 4pm	**Open Garden Scheme** at the garden of Suzanne & Bob Ballinger, 17 Linden Avenue, Pymble. Wheelchair accessible, refreshments available.

Please contact MNDA NSW on 8877 0999 or 1800 640 144 for further information in any of these events.

Research

MND Research – Hope for a future 30 March 2005.

This scientific meeting showcased researchers supported by the MND Research Institute of Australia, and others working in the field of MND research.

The meeting of Australian MND researchers at the new premises of the MND Association of NSW engendered a spirit of cooperation and urgency to further research into MND.

Researchers funded by MNDRIA at MNDA NSW in March

Dr Julie Atkin	MNDRIA Research Fellow 2005-2006
Dr Steve Vucic	MND NSW Clinical Research Scholar 2005-2006
Dr Roger Chung	Bill Gole MND Research Fellow 2005
Dr Valerie Hansen	Bill Gole MND Research Fellow 2005-2006
Dr Elizabeth Coulson	MND Sealey Research Fellow 2001-2003

The MND Association of NSW supports research funded through the MND Research Institute of Australia.

Funding decisions for MNDRIA grants for 2006 will be made by the Institute's scientific review panel in November 2005.

Motor Neurone Disease Research Institute of Australia
Grant applications for MND research in 2006 – closing date: 26 August 2005

The Bill Gole Fellowship will be offered again for 2006-2007

The MND Research Institute invites applications for this prestigious research Fellowship for motor neurone disease research in Australia. The Fellowship is directed towards scientists with a track record in areas of neuroscience related to motor neurone disease.

Salary will be funded in the NH&MRC postdoctoral Research Fellow range for a two-year period.

Grants-in-Aid for Research into Motor Neurone Disease

The MND Research Institute of Australia regards its role as one of providing seed-funding for research that is innovative and having a clear relationship to the causes and cures of MND, or the support of people living with MND. Accordingly, researchers working in fields that are relevant to motor neurone disease are invited to apply for grants-in-aid to support research in the calendar year 2006. In recent years, grants have ranged from $15,000 to $34,000, with an average of around $25,000.

Further details and application form are available from www.mndresearch.asn.au

Opal Cove Resort Coffs Harbour

Dear Editor

Recently our family gathered for a weekend to celebrate my husband Gordon's 70th birthday. He has been diagnosed since June, 2001 and has recently started to use a wheelchair.

I am writing to let other MND families know that Opal Cove Resort, just north of Coffs Harbour is extremely wheelchair friendly. We were in the resort itself and the rooms. bathrooms etc. were quite spacious. There was a disabled parking space quite close to the main entrance and gaining entry to all parts of the resort, including the pool, was very easy. There wasn't one area we could not go to. To add to all of this, the staff were very friendly and helpful.

Nola Turner, Inverell

Dear Editor

My husband and I have just recently returned from a very restive sorjourn at O'Carrollyns which is situated at One Mile Beach, Port Stephens. It is about a two hour drive from Sydney. I was initially drawn to O'Carrollyns because they offer 'accessible' accommodation for people with disabilities. We were so pleasantly surprised and it extended beyond our expectations. So many times you are let down by places stating accessibility, especially in the bathroom, only to find that perhaps it a designed by an able-bodied person.

O'Carrollyns offer self contained villas on a 5 acre property that is set in bushland and across the road from One Mile beach. The cabins have facilities for a carer if needed. They have an undercover BBQ area which looks onto a lake. We spent quite a few nights under the fairly lights cooking our dinner looking out over the lake. The highlight of the holiday for me was that they have a beach wheelchair in which Steve, one of the team at O'Carrollyns, took me to the beach and I was able to go into the surf on the chair. It floats on the water and it was just such a wonderful experience to have the waves lapping around my feet.

The best thing about O'Carrollyns is that they provide everything from shower chairs to toilet chairs (thus taking out the hassle of organising such things yourself) and the staff are so warm and helpful. They also put us in touch with a dolphin watch cruise that had a ramp for wheelchairs. I can honestly say it has been the most memorable holiday I have had since living with MND.

I would highly recommend O'Carrollyns at
36 Eucalyptus Drive, One Mile Beach NSW 2316
Ph: +61 2 4982 2801 www.ocarrollyns.com.au

Cynthia Cameron
Marrickville

Link and Learn Program
– a carer's perspective

Thank you so much to all involved in organising this very worthwhile program held recently in Wollongong. I was fortunate enough to attend this 2 day residential workshop for carers despite my hesitancy at leaving my husband in the hands of a task force of friends, relatives and overnight respite service providers. (I was delighted when I returned home after 3 days to be greeted by my husband saying that I should do it more often).

Some of the issues dealt with included suitable equipment, managing/planning ahead, emotional/mental health, available support and palliative care. The program was well balanced with pampering sessions, yoga, laughter therapy, lots of lolly sucking and camaraderie taking place throughout the 2 days. Friendships developed and strengthened as we all relaxed, held hands or passed tissues and I am sure we all found strength in one another and in the fact that we are not alone in what we are going through and what we are feeling.

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

Ruth Quaken and Anita Richter were great facilitators and ran the course with such sensitivity and empathy that despite some of the tough issues we were discussing, I felt protected yet more confident as a carer.

The residential program was then followed up over six weeks with a weekly telelink conference call in which we discussed on-going and newly arisen issues. Lots more laughter and support! I came away from the program feeling not as isolated in my role as carer, far more informed and very aware of the need to look after myself as well as my husband.

If you are given an opportunity to attend this program then I cannot recommend it highly enough. Take care of yourselves and take time to smell the roses - don't worry that they need pruning and the grass around them is getting long.

Robyn Baldwin
Thirroul
(Gary was diagnosed end of 2000)

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Editor: *Janet Nash*