

September 2003

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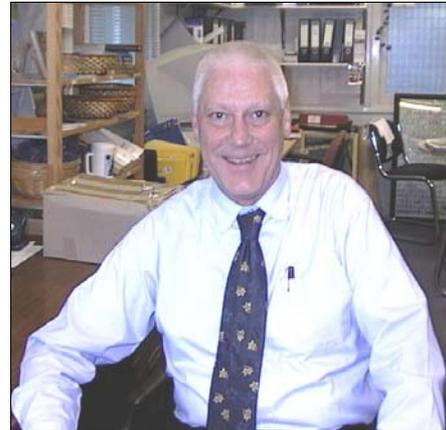
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A new CEO for MNDA NSW

Mr Bruce Fraser has been appointed Chief Executive Officer of the Motor Neurone Disease Association of New South Wales Inc.

Bruce started in this position on 30 July following the retirement of Hari Singh.

Bruce brings with him a wealth of experience from a background well-suited to enable him to steer the Association through the coming years.



- Bruce has worked in the Not-for-Profit sector for a total of around fourteen years, most recently as Business Operations Manager at Diabetes Australia-NSW since 1994.
- He has extensive senior management experience, having spent almost twenty years in the NSW Health system including the Minister's Office, Northern Metropolitan Regional Office and Royal North Shore Hospital.
- Bruce also served as Executive Officer of Chatswood Community Care Association and was later appointed to the Board of Directors, becoming Chairman for four years.
- For nine years in the late 1970s and 1980s, Bruce was an elected Member of Lane Cove Council, representing Council on several community Committees.
- He has qualifications in Association Management and is an Associate Fellow of the Australian Society of Association Executives (AUSAE), the Australian College of Healthcare Executives (ACHE) and the Australian Institute of Management (AIM).

On behalf of the Motor Neurone Disease Association of NSW Board Members, staff and all of our members, I extend a warm welcome to Bruce and look forward to working with him to provide the best possible future for people living with MND.

*Kevin Langdon
President*

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

A message from the CEO

Since joining MNDA NSW as CEO I have come to realise the high level of professionalism and dedication which Hari Singh has instilled into a great staff team.

I trust that I can follow well in Hari's footsteps and justify the confidence already shown in me by a most supportive Board.

My extensive experience in the not-for-profit sector and NSW Health (some 35 years) as well as involvement in local government politics should assist me.

My immediate priorities, as reflected in the draft business plan 2003-2006, are to relocate the Association's office and equipment pool to more appropriate accommodation and to increase support for our objectives from community, corporate and government sectors, enhancing and sustaining a realistic income stream.

It feels great to be a member of a quality organisation providing services to people with MND.

Please feel free to contact me through the office at any time.

Business Plan

After extensive consultation with Board, staff and other stakeholders, the Association has produced a Draft Business Plan for the period 2003 to 2006.

Objectives have been identified for family support, research, fundraising, information, awareness and advocacy, and the identification of and relocation to a new resource and administration centre.

The next step is the formulation of strategies, timeframes and responsibilities to achieve these objectives.

Accommodation

High priority is being given to finding suitable premises to house our equipment pool and office accommodation together.

The present situation is far from ideal and any new facility will also include adequate space for meetings and volunteer workers.

The family support team in particular will enjoy facilities conducive to managing situations requiring privacy and confidentiality.

Staff

Anita Richter moves to a new position as Family Support Special Projects Coordinator. In this role she will research, develop and implement programs to assist family support to fulfill the strategies identified in the Business Plan.

Since the last edition of Forum, the family support services have gained two new staff members.

Allison Pearson joins MNDA as Regional Advisor for Southern NSW/ACT. Allison is a registered nurse with extensive experience in caring for people with progressive illnesses.

Elizabeth Milsom is our new Equipment Coordinator and is an occupational therapist, having many years experience in the health system.

Both Allison and Elizabeth have quickly made themselves at home with MNDA and we welcome them to the team.

Board Decisions

The Board has adopted a budget to June 2004 which provides the resources needed to progress the Business Plan in its first twelve months.

Priority will be given to family support services and reducing administrative overload.

The Future

The image of MNDA NSW in the wider community will be enlivened through greater exposure in the many forms of media.

It is proposed to foster partnerships with relevant organisations to achieve mutual benefits, which ultimately will provide even better support services to people with MND.

*Bruce Fraser
Chief Executive Officer*

Melinda Gainsford Taylor has played a very active role in supporting the work of the Association since becoming the first Friend of MNDA NSW in 1999. The Association welcomes Melinda as a Vice Patron.

The Annual General Meeting of the MND Association of NSW Inc. will be held at the Concord RSL Club on Saturday 6 December 2003 at 1.00 pm. All members are invited to attend.

The AGM will be followed by the MNDA Christmas party at 2.00 pm.

MNDA NSW Equipment Service

The Association aims to help people with MND to live as comfortably as possible by providing assistive equipment as soon as the need arises. The equipment loan service continues to expand to meet the needs of members and last year a record 717 equipment loans were made to MNDA



With MND there is no time for waiting lists so a large storage area is needed to keep a supply of all commonly requested items, as well as providing space for cleaning, repairing, packing for dispatch and receiving returned equipment.

The **MND Equipment**

Expo held at Concord Hospital in August provided an excellent opportunity for members, allied health professionals and MNDA staff to get some new ideas from the many equipment suppliers who were present.

Equipment Service wish list:

Volunteers to help with cleaning and maintenance

A sewing machine to help with small repairs

A clothes dryer for rainy days.

If you can help, please phone us on 9743 5872.

members throughout NSW & the ACT. Requests for equipment loans are made after assessment and referral by a health professional (e.g. an occupational therapist).

A day in the life of the MNDA Equipment Officer

- Purchase of new equipment - this requires getting quotes from suppliers, assessing suitability to our needs, allocating ID numbers and recording all new equipment on arrival (and balancing costs of purchases against available budget).
- Tracking all equipment movements with database entry which provides instant access to information on who has what, how long they have had it, age of each item, maintenance history and detailed listing of items available for loan.
- Maintenance - ensuring that all equipment is clean and in good working order. This means washing, scrubbing, steaming, sterilising and organising repairs and service checks. Arrangements are made to 'retire' older equipment through, for example, Rotary or overseas aid services.
- Allocation of equipment involves constant contact with health professionals and the MNDA regional advisors to ensure that

everyone's needs are met as soon as possible.

- Dispatch means arranging couriers and meeting them for pick-ups (the Equipment Cottage is 5 kms away from the MNDA office) after protective wrapping and labelling and contacting recipients to make sure they will be at home to receive the requested items.
 - Retrieval of equipment is the whole process in reverse, with arrangements for couriers and wrapping and many hours on the telephone.
- The plus side of all of these tasks is knowing that I am helping people. I have been Equipment Officer at the Association since February this year and, in that time, have got to know many of our members, countless occupational therapists and other health professionals, equipment suppliers, service technicians and lots of courier drivers.

It is a very time consuming job but also a very rewarding one.

Maree Hibbert



Equipment Coordinator. I am an occupational therapist with many years of experience across a wide range of areas of occupational therapy practice. I have most recently been working in Newcastle and am still commuting from there on a weekly basis but plan to move to Sydney in the near future.

Since joining the staff at MNDA NSW as the equipment coordinator, I have been very impressed by the dedication of this hard working team. A three-week orientation program has given me the opportunity to meet the regional advisors and their support groups, visit some members at home and attend the MND clinic at Royal North Shore Hospital. I have also had a 'crash course' in the intricate workings of the MNDA Equipment Service. These weeks have provided me with an excellent overview of the work of the MNDA Family Support Service.

I look forward to working with Maree Hibbert in maintaining the high standards of the Equipment Service and to meet the ongoing needs of our members.

Elizabeth Milson

Family Support

Overview of the 2002 member survey

MNDA NSW has continued to expand and restructure its family support service. Towards the end of 2002, the MND Association of NSW distributed a questionnaire to all members who were living with MND to evaluate family support and to ensure that the service continues to meet the needs of people currently living with MND and their families. It was anticipated that the results of the survey would assist with planning services for the future and the development of the Business Plan 2003 – 2006.

The survey was designed to evaluate the various aspects of the family support service, which includes: information, support, equipment, advocacy/lobbying for better care and support for people with MND.

A total of 290 questionnaires were distributed and 86 returned constituting a 30% response rate. In view of the fact that the questionnaire was 11 pages long this is a very acceptable response rate and we thank you for taking the time to fill in the questionnaire and respond so thoughtfully with your comments.

The majority of respondents felt the **information received on membership** was easily understood and met their needs at the time. Almost all respondents felt that they received the right amount of information after initial contact and 65% had consequently requested more information. All respondents who had received a copy of **Forum** rated it as good to excellent.

The **information and support** received at their initial contact with the Association was rated as good to excellent by 93% of respondents. 81% had received at least one home visit from their MNDA Regional Advisor (47% had received more than one home visit) and 53% stated they would like more home visits. The home visit was rated as important to extremely important by 78% of respondents. The “info line” had been used by 55% of respondents in the last 6 months. 85% rated the existence of the “info line” as important to extremely important and 73% felt that the information and support they had received had been good to excellent. 50% of respondents were attending or had attended an MND support group.

The **MNDA equipment loan service** has always been an important aspect MNDA NSW family support. The results of the survey indicated that this service continues to be a very valued and much used service with 86% rating the availability of equipment as important or extremely important. 57% were currently borrowing equipment from MNDA NSW

and 90% reported that the assistance they had received had ranged from good to excellent. 70% were borrowing equipment from other sources indicating the importance of liaising closely with other equipment loan services to meet the individual needs of members.

The questions relating to advocacy and lobbying for better care and support for people with MND were aimed at determining:

- The importance of educating health and community care providers about MND
- Whether they were linked in with an MND multidisciplinary clinic or program
- Where MNDA NSW should concentrate lobbying efforts
- The importance of raising community awareness

Education of health and community care providers was rated as *extremely* important by 71% of respondents with the remainder rating this aspect of family support as important or very important.

15% were linked in with an **MND clinic or program** and 58% would like to be able to access one in their area.

Respondents were asked to select three things on which we should concentrate **lobbying efforts** from the following:

Care related issues: community care, more allied health, home nursing, palliative care, respite care, private health funds, counselling, funding for MND clinics, equipment.

Research/treatment related issues: research in general, stem cell research (in the news when questionnaire distributed), availability of Rilutek (not available through PBS at the time).

The results were evenly split between concentrating lobbying efforts on care related issues and lobbying for research and treatments.

Raising community awareness was rated as extremely important by 76% of respondents with others rating this issue as important or very important.

The comments received were particularly valuable and will assist us to review our current practice. The draft Business Plan 2003 – 2006 has been developed and the objectives identified closely reflect the importance placed on care, support, equipment, information, education, research, advocacy and awareness by people living with MND.

The Sacred Heart MND Service covers Eastern Suburbs, Darlinghurst & some inner city suburbs. The service is coordinated by Jenny Talbot RN in conjunction with Dr Philip McCauley. Referrals are made to the service through St Vincent's Community Health.

Carol Birks

MEETINGS AT MNDA NSW CONCORD

There are a number of meetings scheduled for members at the MNDA office at Concord Hospital in the coming months. In an effort to contain the cost of postage and minimise the number of letters you receive we have outlined details of those meetings below. Please contact the office or speak to your regional advisor if you would like to attend any of these meetings. Further details will then be forwarded to you nearer to the time.

Congratulations to Dr Helen Herz on the birth of her baby boy in August. Dr Herz has been instrumental in setting up the MND Service at Calvary Hospital, Kogarah and will continue to coordinate the program after her maternity leave.

The **Learn now/Live well program** is a two-day course for people living with MND, their family and friends. The program will include presentations from MNDA family support and relevant guest speakers to provide education, emotional support and information to assist people to live well with MND.

The **MND Bereavement Support Group** is outlined in

Carer News.

Information evenings for people recently diagnosed with MND are held approximately every three months and offer people recently diagnosed, their family and friends, the opportunity to meet MNDA NSW staff, discuss the impact of the diagnosis of MND and to meet others in a similar situation.

HANDY HINTS

for people who have weak arms and hands:

- **Rocker knives** use a rocking motion to cut, which keeps food steady when cutting. The **Queens rocker knife** has a built up handle and allows better grip. For more information on this and other useful gadgets contact the Independent Living Centre NSW ph 02 9808 2233 or 1800 800 525 or visit their website www.ilcnsw.asn.au.
- **Hands-free telephones** can be a great help for those who have difficulty picking up and holding the telephone handset. For more information contact 1800 068 424.
- **For computer users** – voice activated software, special keyboards (including on-screen) and special mice are available to help with access. For more information contact your Regional Advisor or the MND Info Line 9743 5872 or 1800 640 144.

CARERS NEWS

Feeling Stressed? Talking through issues can be a great help for carers who are feeling particularly stressed. Remember your Regional Advisor is available to help you talk through issues related to caring for a loved one who has MND and to help you access essential services, counselling and respite care.

Carers Australia National Carer Counselling Program can provide one-off or short-term counselling sessions (face to face, telephone, internet and/or group based) for carers who are feeling particularly stressed. For more details contact Commonwealth Carer Resource Centres on 1800 242 636.

Carers Respite Centres assist carers to obtain emergency, short-term respite. Even though you may not need their assistance now it is useful to ring your local Carer Respite Centre on 1800 059 059 to register with them and enquire about ways in which they can help you.

Bereavement Support

No one can be prepared for the intensity of feelings caused by the death of a loved one. Grief is a normal reaction to this loss and the depth and duration of this experience is different for everyone. Losing a loved one with MND has a particular impact following the complexities of looking after the person with MND. Carers in this situation have indicated the need to talk with other people who have lost a loved one through MND.

MND Bereavement Support meetings will be held during the next twelve months. The first MND Bereavement Support Group will be at Concord Hospital on Monday 10 November, starting with lunch at 1.00 pm in Lecture Theatre 2, Clinical Sciences Building.

If you would like to attend this group, please contact the MNDA office.

Anita Richter

DATES FOR THE DIARY:

Monday 20 October 10.30 am –3.00 pm

Learn now/Live well – Day 1

Monday 27 October 10.30am – 3.00 pm

Learn now/Live well – Day 2

Monday 10 November 1.00 pm

MND Bereavement Support Group.

Tuesday 11 November 7.00 pm

Information evening for people recently diagnosed with MND.

Research

The article reproduced below was developed and written at the request of the International Alliance of ALS/MND Associations and published on their website at www.alsmndalliance.org on 27 August 2003.

ALS/MND: The Dangers of Unproven "Therapies"

All of those involved in ALS/MND, be they health professionals, care-givers and, most of all, patients with ALS/MND are only too aware of the grave significance and implications of the disease. This results in a variable degree of desperation which makes all three vulnerable to "try anything" for "what is there to lose"?

There are several categories of drug therapy. They include:

1. Conventionally approved drugs. For ALS/MND there is presently only one - Rilutek.

2. Therapies that have shown promise in ALS/MND animal models, in particular SOD1 mutant mice. Numerous examples of such medications can be quoted (complex Q10, celebrex, minocycline, creatine are just a few). Thus far none of these and others have translated into the same efficacy in the human disease. I would recommend an excellent web site <http://www.als-tdf.org> which is dedicated to analysis and discussion of these animal model therapies.

3. Off-label drugs. Off label drugs are drugs that have been approved for treatment of other diseases that may have some rationale in ALS/MND. In some respects these are the most problematical since they are readily prescribed by family physicians and others not always familiar with ALS/MND. The problem with off-label medications is that there is no knowledge of the correct dose or of interactions with other medications used in ALS/MND. Combination poly-therapy for ALS/MND is very much an accepted approach but it remains to be seen what are optimal combinations and drug doses. Other off-label medications, such as the "AIDS cocktail" are potentially dangerous and extremely expensive. Even in countries where there is subsidized provision of pharmacological products it is invariably for medications specifically directed.

4. Non-conventional (alternative medicine) medications. These list in the hundreds and they too are readily available over the counter,

without a prescription. There is thus far no evidence that any are beneficial for ALS/MND. However, there have been few formal trials involving these medications. Most ALS/MND patients take some or many of these. For the most part they do not appear to do harm, which is important. However, many are expensive and there is no regulation as to their exact content or concentration of compounds that they contain.

5. Stem cell therapy. Hardly a day goes by without a press release on some form of stem cell therapy. The whole science of stem cells is extremely complex apart from the ethical issues raised in some forms of stem cell treatment. The diffuse nature of ALS/MND raises particular difficulties of stem cell therapy in this disease. A recent, excellent, article by Silani and Leigh "STEM CELL THERAPY FOR ALS: HOPE and REALITY" highlights the problems.

Uncontrolled, non-approved stem cell therapy is offered in certain parts of the world. One has to be extremely cautious about these. They usually make false and ridiculous claims.

In recent years, the pressure to treat has been heightened and hyped by the popular press (newspapers, TV and the internet). They, increasingly and vigorously, report news regarding health, medical therapies and indulge in disorders that are much rarer than ALS/MND such as mad cow disease (Bovine spongiform encephalopathy). The increased dispersion of medical news has not necessarily been matched by an increase in competent professional "health" news writers and broadcasters. The combination of growing demand for health information by the public and an almost vertical drop in the skill base in the media called upon to meet this request, can be very detrimental in its effect. At best it raises "false hope" but worse is the pressure placed on physicians by ALS/MND patients and their families who with very good reason demand access to the new "cure".

However, the worst portrayer of misinformation, information taken out of context and plain quackery, is to be found on the internet. Even if one limits an internet search to ALS/MND using a popular search engine no less than 732,000 sites

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Researchers from all round the world will gather to present the latest findings and share ideas at the 14th International Symposium on ALS/MND in Milan in November 2003.

(Continued from page 6)

are available, many have link-outs to other sites. The vast amount of internet information on ALS/MND is anecdotal and it certainly cannot be assumed that it was produced by a patient with ALS/MND or even anyone interested in the disease. However, there are a few reputable, well-organized sites that are educational. It is important for ALS/MND health care workers and ALS/MND Societies to direct patients and their families to such sites.

The World of ALS/MND health professionals is rather small (less than 1000) but very dedicated and communicates frequently and well. ALS/MND patients should be assured that they will not miss out on meaningful therapy as long as they maintain membership of or contact with a recognized ALS/MND clinic or ALS/MND Association or Society.

Unfortunately there are those who prey on the vulnerability of people with serious disease. Their ethics

are questionable or non-existent and the up-front fees they charge underscores the scam in which they are involved. One of the roles of the ALS/MND team and ALS/MND Associations is to protect patients from this totally unacceptable behavior.

Let me conclude by plagiarizing a small section from an excellent article published in the Italian newspaper IL SOLE24ORE "The Scientific Journalists" that resulted from the Di Bella "debacle" claiming to treat numerous types of cancer in the late 1990's "Every piece of information concerning a scientific issue relating to ALS/MND must clearly indicate the factual elements and the sources it refers to, favouring as much as possible the distinction between existing data and opinions. Information must not confuse science with faith and hopes with facts, which is the essence of journalism. And this also applies to opinion leaders".

Information to make patients fully aware of all the details of treatments cannot be minimized!

*Andrew Eisen MD, F.R.C.P.C
Professor Emeritus, Director of the ALS Clinic
Vancouver General Hospital and the University of
British Columbia.
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What forms does MND take?

MND takes several forms. In some cases the symptoms are widespread from the onset, but usually MND begins in a localised fashion, affecting a single limb or aspect of motor function, become more generalised as the disease progresses. There is usually evidence of wasting and weakness in some muscles and twitching (fasciculation) of parts of the muscle may be visible under the skin.

Fasciculation is a sign of damage to lower motor neurones. Involvement of upper motor neurones results in stiffness of muscles (spasticity) and slowed movements; sometimes the muscles will spasm or spontaneously jerk.

Patients may have only lower motor neurone or only upper motor neurone signs early in the illness but typically develop a combination of the two as the disease progresses. Depending on the pattern of motor neurone involvement and the part of the body where the symptoms begin, the disease can be classified into four main types.

Amyotrophic lateral sclerosis (ALS) is the most common form, characterised by muscle weakness and stiffness, over-active reflexes and rapidly changing emotions. Upper and lower motor neurones are both affected; the limbs cease to work properly. ALS is the term most commonly applied to MND in the USA, where it is also known as Lou Gehrig's disease, after a famous baseball player.

Progressive muscular atrophy (PMA) is characterised by muscle wasting and weakness, loss of weight and muscle-twitching, and is caused by damage to the spinal (lower) motor neurones.

Progressive bulbar palsy (PBP), mixed bulbar palsy and pseudo-bulbar palsy are forms that involve the muscles of speech and swallowing. The nerves that control these functions are located in the bulb (the lower part of the brain), hence the term bulbar palsy (paralysis).

Primary lateral sclerosis, in which upper motor neurone damage results in stiffness and spastic paralysis of the limbs. This is a very rare form of the disease.

Other diseases affecting motor neurones:

Kennedy's disease (bulbo-spinal muscular atrophy) is a disorder of motor neurones which is not motor neurone disease. It is much more benign and is an inherited disorder affecting adult males. It causes slowly progressive weakness and wasting of muscles.

Other forms of *spinal muscular atrophy* include wasting diseases of varying severity, usually inherited and often with onset in childhood.

Information derived from the booklet 'Motor Neurone Disease - More Facts', produced by the MND Association of Australia and approved by the Australian Association of Neurologists.

**MND Research
Institute of Australia**
Closing date for
applications for 2004
Grants-in-Aid is Friday
17 October 2003.
Applications are to be
sent by email to
info@mndresearch.asn.au
For details, go to www.
mndresearch.asn.au

Fundraising

FINDING FUNDING

2002/3 was the most successful year for the Association – thanks to all the wonderful support received from around the State. The plan is to go from strength to strength and there is already a commitment from the Perpetual Foundation for another \$20,000 in 2004 to match the \$20,000 received at the end of the last financial year (thanks to Richard Atkinson's hard work).

Special mention is overdue of the fantastic role the Support Groups play in fundraising for the Association. Their constant support is the backbone on which all else hangs.

Race for a Cure

Royal Randwick on Saturday 20 December will be the **Motor Neurone Disease Villiers Race Day**. The Association is looking for six sponsors to buy a race on the day. The cost is \$8,000 but it includes TV coverage on Foxtel and Sky, radio and newspaper coverage, signage on the course and a page in the race book for the day. It will be great fun and the sponsor of each race will be able to make the presentation to the winner and present the sash. (Provision has been made to include a party of ten to be accommodated in the Vista Room – with full buffet, wine, beer, admission and program - in the Queen Elizabeth II Stand and additional tickets are available at \$125 per person).

What a day it will be. It is hoped that supporters will come along on the day, sporting their cornflowers and volunteers are needed for a range of things, from helping with wheelchairs to shaking a bucket (near those who are collecting their winnings).

Let's make a great success of the day so it will become a regular feature in the calendar and raise awareness about MND. Equally, for those of you who are further afield, think about having a party – at home or at your local hotel. Run a sweep. Have fun and make sure people in your area know more about MND (leaflets, posters and balloons supplied).

For more – see www.raceforcure.org.au.

The MNDA Christmas Party

Start writing to Santa Claus. He'll be putting in his annual appearance at the Concord RSL on 6 December. Put the date in your diary and let the office know that you want to join in the festivities after the Annual General

Meeting. Let us know if you would like to attend the AGM too.

Don't forget to check out the enclosed flyer with this year's **Christmas cards**. As ever, they are extremely good value and the proceeds go to further the work of MNDA NSW. If you want a large number of cards, call the office. There are limited stocks and it would be a pity to disappoint you. Order early.

MND WEEK 2004 DATES

It's official. Next year, the launch at Government House is on Wednesday, 24 March.

The week will run from 28 March through to 3 April with Cornflower Blue Day on Friday 2 April.

The telephone has been ringing. People have been planning ahead. Already Clare Bull has organised her golf day at Shellharbour on 1 April (she's nobody's fool!) and Nick McLoughlin is planning another function following the success of Nick's Party this year. He's booked 27 March – while, in Hay, Maggie Clark is organising Art in the Garden for 28 March. The intrepid Kerry and Sam in Orange have already started planning their event to coincide.

Elizabeth Herbert

Volunteers needed for reception work at the busy MND Office at Concord – answer the phone, help with mail outs and much more.

Do you have a regular day once each week or fortnight that you can give to help us?

Phone 9743 5872 – your call will be welcomed.



Janace and Peter Holmes took time out from fundraising in Dunedoo to visit their son Mark in Sydney and to check out the MND Equipment Expo at Concord Hospital.

Midwinter magic

The midwinter solstice falls on 21 June and, each year, this is the global ALS/MND Awareness Day. In 2003, in Blacktown, nearly 200 people attended a fundraising event held by the Misso family.

In the City centre, the solstice was marked by a magnificent ball at the Four Season's Hotel. The event was professionally managed by Sally Gole with a hardworking team of supporters led by Suzanne and

Bob Ballinger.

Megan Paton and her friend, Manar Fawzi, raised the standards to new heights. There was wonderful support from both the sponsors – ASX, Adcorp and Macquarie Bank and the other table takers. The Deb Bailey Foundation took a table as did KPMG, Rilutek

suppliers, 'Aventis', Gresham Partners, Nautica, the Premier's Department, Telstra and JB Were. The auction bids reached record levels and James Morrision's music was superb. Special thanks must go to Villeroy & Boch who gave a complete 'cornflower' set to be auctioned but there were so many generous gifts and the committee gave unstintingly of its time – Ros Adams, Coty Cortese, Pamela Hennessy, Roger Henshaw, Noelani Reardon, Janice Scheinecker and

Paula Trigg left no stone unturned in finding enough prizes for 250 balloons as well. Another major contributor was Malcolm Hodgkinson who organised a party of fifty people while he was on holiday in Europe.

The whole night was a wonderful accolade to Bill Gole, with special thanks to his daughter, Sally, and her friends Laura and Sherryn.

The Ball raised a record-breaking \$100,000.



ABC presenter Simon Marnie who generously acted as MC at the Cornflower Blue Ball.

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?

- | | |
|-----------------|--|
| 22 September | Movie Premiere at Blacktown for the Ian Fuller Foundation (with a contribution to MNDA) www.caring4ian.4t.com |
| 25 September | Cabramatta High School Draw
Caringbah Rotary dinner at Woollahare Golf Club |
| 27 September | Abermain Bowling Club Fun Night |
| 27/28 September | Bob & Suzanne Ballinger's open garden for MND at Pymble |
| October | Liquorland: Libby Sharp masterminding a raffle at head office |
| 11/12 October | South West Rocks Golf Day – organised by Bruce McDougall |
| 23 October | Business Breakfast, Bankstown for the Ian Fuller Foundation and MND |
| 8 November | Newcastle Christmas Fete at Weston Workers Club |
| 20 December | MND Villiers Race Day, Royal Randwick www.raceforacure.org.au |
| 24 March 2004 | Government House launch of MND Week |
| 27 March | Nick's Party in Sydney (Nick McLoughlin) |

28 March - 3 April MND WEEK 2004

- | | |
|-------------|--|
| 28 March | Art in the Garden in Hay organised by Maggie Clark |
| 1 April | Shellharbour Golf Day |
| 2 April | Cornflower Blue Day |
| 3 April | Country & Western night in Orange |
| 14 - 16 May | Quilt for MND to be raffled at Thornleigh Community Centre |

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

FOR SALE
\$33,000

VW transporter van fitted with wheelchair ramp and restraints. Perfect condition, only 18 months old, very low mileage. Phone the MNDA office for contact details.

Regional News

Southern NSW & ACT



Since taking on my new role as MND Regional Advisor for the Southern NSW & ACT, I have been slowly getting to know members through phone-calls and visits.

I am a registered nurse with most of my experience being in

oncology and home nursing. In the last few years I have also been a volunteer and employee at The Australian War Memorial in Canberra, which allowed me to indulge my interest in Australian war history.

Two years ago I decided I wanted a position that included the “caring” aspect of nursing without being confined to that profession. I applied to the University of Canberra as a (very!) mature-aged student and am now half way through my Bachelor of Community Education, specialising in counselling studies.

I live with my husband and three children between Canberra and Bungendore - a good base for travelling throughout the southern region.

I look forward to the new experiences and friendships and will do my best to serve MND NSW/ACT.

Allison Pearson

Far North Coast

I will visit the far north coast between Dorrigo and the border in the week 15 - 22 October and will be contacting members in the area to arrange home visits.

The Northern Rivers Support Group will meet on 18 October at Summerland House With No Steps, Alstonville and I will speak there on my role as Regional Advisor and the role of the MND. I will also be speaking to allied health members of the Northern Rivers Area Health Service on the effects of MND and symptom management.



Christina Jason
Northern NSW Regional Advisor
Ph: (02) 4952 4492

Central West

I visited members in the Central West of NSW during a field trip at the end of July. The trip provided the opportunity for an in-service education session for health and community care providers in Orange, and contribution to a meeting organised by the Central West Support Group for members and health and community care providers in Forbes.

The morning session comprised presentations from MND family support in conjunction with Mary-Lou Kemp, Occupational Therapist, from Forbes Community Health and Judith Schmalkuche, physiotherapist. Following lunch, the group chatted and exchanged tips and techniques to assist with living well with MND.

Members from Forbes, Molong, Grenfell and West Wyalong attended the meeting but distance prevented people from further afield from attending. The group's response was to organise the next meeting in Condobolin!

Carol Birks

Central West Support Group

Meeting for people living with MND, their family and friends, past carers, health and community care providers living in the Central West

Friday 19th September 11 am – 1 pm

Condobolin Community Health Centre (behind the hospital).

The meeting will be an informal get together with no obligation to attend future meetings.

Emma McRae, Social Worker from Condobolin, will talk about the services available locally to support people living with MND.

Lunch will be available at \$5 per person.

Please RSVP by 15 September to Mary Campbell, support group coordinator, on 6851 4403 or Carol Birks at the MND Association on 1800 640 144.

MNDA NSW has submitted a report to the 'National Inquiry into the Social Impact of Caring for the Terminally Ill' to highlight the unique experiences of MND carers. If you would like to include your experiences of caring for a loved one with MND, contact the office.

Newcastle & Hunter

The Newcastle group has lost two very good friends. Both will be sadly missed.

Hari Singh, past CEO of MNDA NSW, has retired after a ten years of dedicated service to MNDA NSW.

Also it is sad to announce that our former Newcastle President, Mathew Taute, has lost his battle

with MND. Over the years our group has lost many people to MND, but we will continue to support those still affected by this insidious disease, and also to raise awareness to help to find a cure by raising funds for research.

Our annual general meeting was held in August and we were pleased to have Mr

Bruce Fraser, the new CEO of MNDA NSW, attend our meeting. We wish Bruce all the best and look forward to giving him our support.

Office Bearers for the Newcastle & Hunter MND Group elected at the meeting are: *President*, Paul Kentwell who has spinal muscular atrophy (SMA); *Secretary*, Alistair Fyfe (Kennedy's Disease); *Treasurer*, Christine Fyfe; *Fundraiser*, Neta Cassidy; *Publicity Officer*, Barbara Brown (Past Carer).

The combined experience of this group provides a lot of knowledge about many aspects of living with MND (*and some of*

its many forms, see page 7, Ed.)

The group has already taken steps for planned fundraising activities. On 27 September there will be a fun night at Abermain Bowling Club, and on 8 November the Christmas fete day will be held at Weston Workers Club.

Following the Christmas break we will go right into action in February with our bowls day at Abermain Bowling club. Over the past three years, this has been a tremendous bowls day full of fun and meeting old friends and gaining new friends who support the group.

Why not make a day of it and join in. You don't have to be a professional bowler - you will believe me when you see some of the players!

Alistair Fyfe

MNDA Volunteer Visitor Pilot Program

Recruitment of volunteer visitors will commence soon.

If you live in the Hunter, Newcastle or Central Coast Regions and are interested in becoming a MND Friendly Visitor please contact the MNDA office on 1800 640 144 and a flyer and application form will be sent to you.

The volunteers will be caring, practical people who are good listeners and understand the impact of MND on a family.

A comprehensive training program will be implemented and ongoing support provided.

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 at 8pm EST. Go to www.mnd.asn.au/ then click on the chat room link.. Also try <http://neuro-mancer.mgh.harvard.edu/brainchat/classic.shtml> for a chat room which is open 24 hours per day.
- Visit the MNDA NSW website at www.mndnsw.asn.au for links to many useful and interesting sites.

SUPPORT GROUP CONTACTS**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 Hogen
Phone: 02 4223 8000

Newcastle & Hunter

Alistair Fyfe
Phone: 02 4947 1983

New England

Robyn Barton
Phone: 02 6766 6065

Northern NSW

Phil Bower
Phone: 02 6743 4218

Northern Rivers

Helen Gates
Phone: 02 6621 4018

Riverina & South West Slopes

Wes Russell
Phone: 0408 692 127

Hornsby

(Anita Richter)
and

Panania

(Caroline Gleig)
and

Penrith & Blue Mountains
(Ruth Quaken)

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

Hornsby Support Group

Thornleigh Community Centre

at 11.00am on

Wednesday 15 October.

An open invitation is extended to all in the area to meet guest speaker, Bruce Fraser, new CEO at MNDA NSW. Phone the office for details.

MAILBAG

Dear Editor

The **MND Equipment Expo** gave us a great opportunity to get some tips for things that Noel will need in the future. Although we know we can get equipment from the Association, it was very educational to meet all the suppliers and get some tips about how to use their gadgets. We saw many things that we had never heard about that will be very useful for Noel. These included:

- a spoon with a curved handle that makes it much easier to get food into your mouth without bending your wrist
- a 'handybar' which you attach near the door lock on your car and you hold onto it to help get out of the car
- an electrically operated armchair that not only lets you lie back with your feet up while you watch TV, but also raises you almost to standing position when you want to get up
- a ramp system that works a bit like hollow Lego blocks - you can clip square sections together to build up the floor of a shower recess, and you clip sloping sections together to get up over the hob. The result is no shower hob to get over and no money needed for rebuilding the bathroom.

We also enjoyed catching up with our friends at the Association. Thank you.

Val and Noel Simpson, Eastwood

Dear Editor

I was diagnosed with MND 18 months ago. The MND initially affected my legs and now has started on my speech.

I have recently acquired a **HandyBar** which is very useful for assisting you to get into or out of motor vehicles if you still have strength in your arms. The one I have fits many but not all motor vehicles and is easy to use. The bar is locked into position against the striker plate.

With the bar in position, one hand on the arm of the wheelchair and one on the bar, I can raise myself out of the wheelchair, to standing against the motor vehicle. I then turn around and lower myself into the car seat with the bar providing support and increased confidence.

When getting out of the vehicle I use the bar to assist me to stand and then to help lower myself into the wheelchair.

I have only recently been introduced to the HandyBar and wish I had known of it months ago. It has given me much more confidence in getting in and out of the vehicle and I'm sure it will delay the use of a slide board.

John Campbell, Forbes

Dear Editor

Australia's Open Garden Scheme

17 Linden Avenue, Pymble

Saturday 27 and Sunday 28 September.

We are opening our garden and hope some of you might be able to come along to see it. Our garden is on a battleaxe half-acre block and has wheelchair access to a good part of it. There is no on-site parking on the open days. However, this can be organised if advised in advance but is strictly limited to those people with MND.

The Open Garden Scheme's guide describes the garden as follows:

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.

As I write this I wonder what will be out – the prunus, daffodils and tulips are already blooming. No doubt they will be finished but I do hope the display of hellebores will be lovely at the end of September.

There is a \$4.50 per adult entry fee set by the Open Garden Scheme (children are free), thirty-five percent of this will be given to MND, the balance goes to the Open Garden Scheme for administration and other gardening charitable projects.

Our aim is to make the weekend an MND awareness and fundraising occasion. The MND fundraising committee will be serving refreshments with all proceeds going to MND and would really welcome contributions of help in serving on the days, in baking or making sandwiches.

Please call the MNDA office prior to the weekend on 9743 5872 if you can help or if you require parking.

Suzanne and Bob Ballinger, Pymble

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

We wish to thank Snap Printing, Artarmon for their generous support.

DISCLAIMER

All care has been taken in the preparation of this newsletter. The MND Association of NSW disclaims any liability for its content. The information contained within is of a general nature and to be used as a guide.

Editor: Janet Nash