THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MND
MOTOR
NEURONE
DISEASE

FORUM

December 2004

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Merry Christmas

At Christmas time we reflect on memories of the past year: shared happiness – shared sadness – loss, love, achievement, joy, hope. Christmas is a time of mixed emotions, particularly when motor neurone disease is involved. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

Happy New Year

Working together

Board members of the MND Association of NSW, staff, volunteers, doctors, health professionals, community service providers, scientists, government – the boundaries are not defined – all are working together to provide the best possible life for people living with MND, their families and carers. All are working towards a time when an effective treatment and a cure will be found.

The board members of MNDA NSW are a dedicated group of volunteers who work together to ensure that the Association can maximise the opportunities that are available. They bring diverse fields of expertise together to provide the framework that is needed to support the work of the Association and plan for future needs. Brief profiles of Board Members appear on pages 3 and 4. Alex Malley is welcomed as a new board member, and thanks go to retiring member Suzanne Ballinger for the time she have given, particularly in her role as Secretary of the Board. Bob Howe takes over this position for the coming year.

In 2005, the MND Association will move to new premises at Gladesville. There will be ample space for meetings, equipment and offices in the gracious old sandstone building. Help from new volunteers will be gratefully welcomed as the MND team grows to meet the many demands of the fight to defeat MND.

MNDA NSW CONTACT DETAILS

General enquiries & Family Support & Info Line:
Phone 9743 5872 or Freecall 1800 640 144.
To call a particular person, dial the number listed below:

Roslyn Adams	8765 5118	roslyna@mndnsw.asn.au
Carol Birks	8765 5115	carolb@mndnsw.asn.au
Bruce Fraser	8765 5111	brucef@mndnsw.asn.au
Maree Hibbert	8765 5114	equipment@mndnsw.asn.au
Janet Nash	8765 5116	janetn@mndnsw.asn.au
Petra Sammut	8765 5110	admin@mndnsw.asn.au
Anthea Siow	8765 5113	antheas@mndnsw.asn.au

The MND Association of NSW office will be closed for Christmas from Friday 24 December to Monday 3 January inclusive.

Normal office hours will resume on Tuesday 4 January 2005.

If help is needed during the Christmas break, please consult your Doctor.

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

What is the Association's Focus?

The focus of the MND Association of NSW is, and always will be, the provision of quality care and support services for people living with MND, their families and carers. We are also focused on research into the cause and finding an effective treatment for MND. That is why MNDA NSW exists.

I am aware of some concerns surrounding our drive for a sustainable income stream for the Association and, as management leader, I assure all stakeholders that the quest for more funding, whilst necessary to ensure the continuation of these services, will never be at the expense of caring.

This edition of Forum is dedicated to care and support services and research, with issues relating to fundraising commented upon in "Fundraising Chatter" – an insert. I commend this new format to all readers and would welcome any feedback.

Fundraising Manager

I am delighted to welcome Anthea Siow to the team, as Fundraising Manager. Previously employed as Fundraising and Events Coordinator with St Vincents and Mater Health, Sydney, Anthea will start with the Association early in January 2005. Anthea brings much experience, ideas and enthusiasm with her and I am confident that she will succeed in the position.

Volunteers

Volunteers are the backbone of any not-for-profit organisation and the MND Association of NSW depends upon and greatly values the many hours of time given by our volunteers, including members of the Board.

The impending relocation of our offices and equipment pool to the Gladesville Hospital site early in the new year will provide much improved accommodation which will be attractive to those of you who wish to spend time assisting with various projects.

We are always keen to see both current and new volunteers, so please contact the office to register your interest.

The Year Past and the Year Ahead

- The last 12 months have been quite exciting. Whilst the Annual Report has full details, some achievements are summarised here:
- As a commitment to the focus on care and support, the Board approved increases in hours for Regional Advisors, facilitating more home visits and field trips, especially in the more remote areas of NSW.
- This has also enabled better access to our telephone Info Line service.
- The Board now provides funding towards Nurse Co-ordinator positions at four MND Clinics – Royal North Shore, Prince of Wales and St Joseph's Hospitals, as well as the Calvary MND Service at Kogarah. MNDA NSW is proud to be associated with these state-of-the-art facilities.
- After years of searching, new accommodation has finally been offered to us by NSW Health, on the site of the former Gladesville Hospital. The Association will relocate early in 2005.

To all those who have lost loved ones and friends to MND in the past year, I extend on behalf of the Board and staff our warmest sympathy. Please be assured that we will continue to be here to support you through these difficult times.

I take this opportunity to wish you all the very best for a safe and happy holiday season.

Bruce Fraser
Chief Executive Officer

Thank you to Suzanne Ballinger who has retired from the Board after five dedicated years. Suzanne served as Secretary of the Board, having made a commitment to helping people with MND after the loss of her Mother to MND in 1983. Suzanne remains an active member of the Fundraising & Awareness Committee.

Changes to the Constitution of the MND Association of New South Wales Inc accepted at the Annual General Meeting held on 4 December 2004:

Article 2 a) "To provide benefits for and services to ***members of the Association*** with Motor Neurone Disease, their families and carers, without discrimination."

Rule 8 *3)* ***"A member of the Association shall, upon payment of an amount of not less than $500, be eligible for admission by the Board as a Perpetual Member at certain levels of membership to be determined by the Board from time to time. Such members will not be required to pay further membership fees."***

Rule 14 5) "At the AGM 2004 and thereafter the ordinary members elected to the Board in Rule 14 1)b. ***shall reduce to 4. To implement this Rule, casual vacancies will not be filled until the total number of Board members is less than 9."***

Motor Neurone Disease Association of New South Wales Inc. Board Members 2005

Ralph Warren PRESIDENT

I have practised as a barrister for the past twenty years.

I became aware of this insidious and non-discriminatory disease some years ago and joined the Board of the MND Association of NSW in 1998. My aim was then and continues to be to contribute in some way to the support of those brave people who live daily with MND, and all those whose lives they touch.

Phil Bower VICE PRESIDENT

My late wife, Laurie, died with MND in 1997 after we fought hard for three years to no avail. During that time we spoke at many information sessions, raised funds and did interviews for awareness. Since her passing, I have delivered equipment for members from Wagga Wagga to Casino at my expense. I have been available to speak with people with MND or their families anywhere in NSW. Having lived with a person with MND I have found I am able to offer practical assistance to the MND community at large.

I have been a member of the MNDA NSW Board for ten years, Vice President for about five years and a delegate to the MNDA Australia for five years.

My background is veterinary and livestock nutrition. I am a Past District Governor of Lions International and am the Lions spokesman for Cord Blood, Spinal Cord and Stem Cell Research in District 201N1.

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.

Robert Marr VICE PRESIDENT

I have been a member of the MNDA NSW Board for twelve years. I am a general medical practitioner and I have a special interest in MND because my father died from MND.

Bob Howe SECRETARY

I became a Board member of the MND Association of NSW in 1998 as a good friend of mine (Colin Mills) had MND. Prior to his death, Colin had encouraged me to assist him to establish a new Business Plan for the MND Association.

I have been a management consultant for 20 years, specialising in business planning and organisation development.

My background is Economics (Sydney), MBA (USA) and I am a fellow of the Society of Certified Practising Accountants. Other interests are mainly youth related (swimming and soccer) and I will be the Rotary District 9680 Youth Adviser in 2005.

Robert Templeman TREASURER

After a career in banking and accounting, primarily as cost accountant and then as chief accountant of Speedo Knitting Mills , I progressed into small business proprietorship, involved in newsagencies and hospital patient television services. I have been a member of the Rotary Club of Strathfield for over 25 years, active at both club and district level. I am a past president and Paul Harris Fellow. For some years I was on the Board of the Trinity Grammar School Foundation, and a member of the school council at the Chalmers Road Public School (a school for physically and mentally challenged children) Strathfield.

I have been a member of the Board of the MND Association of NSW for the past six years, initially as assistant treasurer, and then treasurer. This has given me an opportunity to assist those who are living with this disease, and their families.

Paul Brock

I have been involved in Education for nearly forty years: as a school teacher; an academic in Australian, British and North American universities; a member of staff or policy advisor to a succession of Commonwealth Government Ministers of Education; a member of State and national boards and statutory bodies; and, for most of the past decade, a senior executive in the NSW Department of Education and Training.

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MNDA NSW Board Members 2005 *(Continued from previous page)*

My principal area of research, and scholarship is in the field of English Literature, Language and Literacy. I spent the first fifteen years after leaving high school as a Marist Brother - a Religious Order within the Catholic Church. I am now the Director of Professional Practice in the NSW Department of Education and Training. I am also an author: my most recent work being my autobiography, *A Passion for Life*.

I attempt to bring to the Board of the MND Association of NSW a perspective based on my experience of life and, in particular, my having lived with MND for nearly eight years since initial diagnosis.

Roger Henshaw

My first encounter with MND was via Colin Mills, my then General Manager at Marrickville Council. Colin was an outstanding individual and mentor and took the time to ensure my development as a manager in library services despite his living with MND. At the time I was President of the Rotary Club of Marrickville and my presidential year project was a fundraiser for the MND Association. We raised about $40,000 and on the strength of that I became involved with the Association's fundraising committee and subsequent election to the Board.

It has been five years now since Colin died and my commitment to his memory and to others living with MND hasn't subsided. I am committed to making a difference to those living with MND, and their carers, family and friends.

Katrina Horman

My background is Occupational Therapy and I am currently working with the Northern Sydney Commonwealth Carer Respite Centre, on a special project for ageing carers. Through my work, and especially in my previous position as a Community Options case manager, I have worked closely with many people with MND and their families. I continue to advocate strongly for the development of flexible and creative service provision to meet their unique and significant care needs.

Gary Jacobson

I have been involved with the Association for two years, having become acquainted with MND when both my parents-in-law passed away from the disease. Having seen the issues that beset someone caring for their loved one with MND, I am dedicated to raising awareness and funds to support people with MND and their carers and hopefully play some small part in finding a cure.

I have a background in general management and Human Resources, with specific focus on the not-for-profit sector.

Alex Malley

I am Associate Dean in the Division of Economic and Financial Studies at Macquarie University, a member of the board of CPA Australia and consultant within the private and public sectors.

My mother passed away from MND in 1997. Since that time I have made a personal commitment to assist in any way I can those whose lives have been touched by the disease. We desperately need to continue to raise awareness and funding to provide the appropriate practical care for those in need.

I commit my persistent character to the cause.

Alex Malley was elected as a new member of the MNDA NSW Board at the AGM on 4 December. Alex brings a wealth of experience, and his commitment is welcomed by all in the extended MND 'family'.

Janice Scheinecker

My background is in Financial Management, having worked as an Accountant now specialising in Payroll. I was first introduced to the MND Association in 1993 when my late husband was diagnosed with the disease. The Association was in a one-room office at Bankstown, manned by Hari Singh (past CEO) and volunteers headed by founding member, Marjorie Harrap. Sadly my husband passed away in March 1995.

It was at this time Karen, our eldest daughter, joined the MNDA NSW Board. When Karen went to live overseas early in 1996, I was asked to join the Board in her place and gladly accepted. I believe I can contribute to the Association as a past carer who has lost a loved one to MND. I believe it is important that we remain focused on the Association's objective to provide the best possible care to those living with MND, including support to carers of loved ones living with the disease.

Family Support: Working together

Regional Advisors — people living with MND — carers — family members.

Continuing this year's theme for *Forum* outlining the role of family support, in this issue I will describe how the Regional Advisors ***work together*** with people living with MND and families in their regions to assist them to live well with MND and to maintain their quality of life.

The major focus of the Regional Advisors role is to support people living with MND, their carer and families by providing ongoing regular contact, either face to face or by telephone. One of the key principles of MND care and management, however, is that the care provided should be determined by the needs of the person with MND and their carer and that their autonomy be respected. With this in mind Regional Advisors endeavour to ***work together*** with the person with MND and their carer to facilitate access to relevant information, support and services as and when requested.

Home Care is in the news. If you, too, are having problems obtaining adequate access to Home Care, please let your Regional Advisor know. We can then work together to lobby for access to the care you need.

The Regional Advisor makes telephone contact with the person with MND as soon as possible following membership – usually within two weeks. During this contact the Regional Advisor outlines the services provided by MNDANSW family support, the information available, support groups in the region, relevant local services and how much, or how little, future contact the person with MND or their carer would like. A home visit is offered to most people and the appointment time negotiated. For people in more remote areas a home visit may not be possible until the Regional Advisor conducts her next field trip, however, regular contact can be maintained by phone. Nine field trips were conducted in 2003/4 and more recently, courtesy of the Royal Flying Doctor Service, a couple of day trips have been conducted to more remote areas in the New England region to visit people recently diagnosed with MND and to provide in-service education to the community health care providers.

The frequency and mode of contact following the initial phone call and home visit varies dependent on the needs and wishes of the person living with MND and their carer, and the capacity of the Regional Advisor. Some people may have contact with their Regional Advisor weekly others only once or twice a year, however, most people have some form of contact with Family Support every two to three months. Regular contact helps to facilitate the other key principles of MND care and management, which include:

- Flexible, timely and responsive referral to health and community care providers
- Continuity of care and support throughout the progression of the disease
- Coordination, communication and cooperation between service providers and MNDA Regional Advisors
- Regular review and ongoing assessment.

During 2003/4 the Regional Advisors made 1,960 individual contacts to people living with MND, carers and/or family members. These contacts included home, nursing home, hospital and office visits, attendance at MND Clinics and phone calls.

In addition to these contacts Regional Advisors ***work together*** with people living with MND and their carer through the "info line", the support group network and special group meetings.

Facilitating links with others in a similar situation for people with MND and their carers and families through the support group network is an integral part of the Regional Advisors role. The Regional Advisors actively ***work together*** with the local communities in the regions they cover to develop support groups when a need is identified. They also continue to ***work together*** with existing support group coordinators and volunteers maintaining links through attending meetings as able and referring people recently diagnosed in their region to the support group coordinator. During 2003/4 three new support groups were established by Regional Advisors. Support Groups do wax and wane, however, depending on the needs of people with MND, past carers and group members. At the moment 11 of the 14 groups around the State continue to meet regularly.

Special group programs and/or meetings are organised by MNDA Family Support and these provide an opportunity for Regional Advisors to ***work together*** with health professionals, people living with MND, carers, families and friends to facilitate sharing of information and support. These meetings and programs connect people living with MND and carers with others in a similar situation, promoting peer support and the sharing of frustrations, triumphs and ideas. These meetings provide timely and relevant information and education enhancing a person's individual ability to manage the disease and

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Family Support: Working together

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to assist them to live well with MND.

Special Group meeting held during 2003/4 included three Information Evenings for people recently diagnosed with MND, a Care for Carer Program Reunion Meeting, a four week Care for Carer program, a two week Learn Now/Live Well program a Regional Members Meetings in Canberra, a Research Update Meeting, an Equipment Expo and a Past Carers Meeting. Family Support planning for 2005 has begun in earnest and some of the special group meetings planned are outlined in this issue of Forum.

The benefit of education and support for carers is well recognised and the Association has a range of programs specifically for carers which have been developed and implemented by Anita Richter, Special Projects and Carers Coordinator whose role, in ***working together*** with carers, will be outlined in more detail in the next Forum.

Carol Birks
Manager Family Support

A Thank You Lunch for Former Carers
Monday February 21 2005
The Riverside Room, Medical Library,
Concord Hospital Commencing 12.00 noon

Former Carers who have lost a loved one are invited to a special lunch to acknowledge the unequalled support that carers dedicate during the course of MND.

Come along and meet old friends from MNDA NSW and others who have shared a similar experience. There will also be an opportunity to learn about some of the feelings you may be experiencing. After lunch there will be a short talk on the experience of bereavement and an opportunity to share feelings with others.

If you would like to attend, please RSVP by 14 February 2005.

Many thanks to Carole Leone who will retire at the end of this year after providing invaluable administrative assistance to Family Support for six years. We wish her inspiration and enjoyment in her retirement.

Family Support Dates for the Diary in 2005

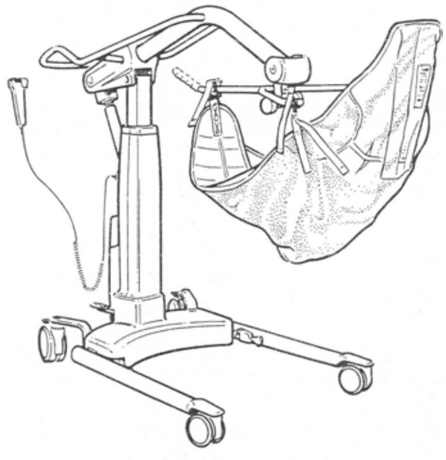
Tuesday February 15 - Concord	**Information Evening** for people recently diagnosed with MND their families and friends If you have been diagnosed with MND and have family and friends who would like to learn more about MND, please speak to your Regional Advisor about organising an information session in your area.
Monday February 21 - Concord	**Lunch and get-together for past carers** See details at top of page
Tuesday and Wednesday March 1 and 2 - Wollongong	**Link and Learn** See details on page 8.
March 9,10,11 - Rosehill, Sydney	**Daily Living Expo** A three-day expo to showcase the latest equipment available in Australia from equipment suppliers and manufacturers. In place of the MNDA NSW Equipment Expo this year, MNDA Staff will be on hand on the Thursday to assist people with MND and their families in looking at equipment suitable for their needs.
Friday March 11 - Concord	**Ask the Experts** and **MND DNA Donor Drive** A new initiative – experts in MND research, neurology, MND care and management and palliative care will be invited to give short presentations and to answer questions from the audience. Further details in the New Year.
Wednesday March 30 - NSW Government House	**Launch of MND Week**
Thursday May 5 and 12 - Central Coast, Newcastle and Hunter Region (venue to be announced)	**Learn now/Live well Program** A two-day education and support program for people with MND and their family to assist them to live well with MND.

Please contact the MNDA NSW office for further information or to express your interest in attending any of the programs or sessions above.

Annual Report 2003—2004 errata
Despite careful checking, two important digits went missing without being detected. On page 14, MND Clinic Visits for 2002/2003 should be 37 (not 3) and on page 16, the number of equipment loans in 2002/3 should be 717 (not 71).

Equipment loan pool

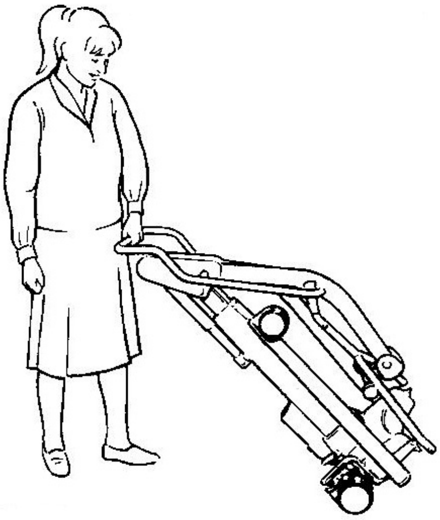
Trixie Lift - the compact lifting hoist that folds and rolls away.



At more than double the price of a standard electric lifter, the Arjo Trixie Lift is not a standard item in the MND equipment loan pool. However, one Trixie Lift has been purchased as a 'portable' lifter available to members for short-term loans.

The advantage of the Trixie Lift is that it can be folded up and taken in the car. For people who require a lifter for transfers, the Trixie Lift opens up endless possibilities for weekends or holidays away from home that would otherwise not be possible. Not only can the Trixie Lift be used for transfers into and out of the car, but it is also available for use at the destination. When transferring to the car, the tilting spreader bar allows positioning over the car seat, before lowering into a good sitting position without suffering uncomfortable knocks.

With a total weight of 43.5 kg (which can be reduced by 2.25 kg by removing the battery pack) the Trixie Lift will require some determination (and space) to get it into the vehicle. Undoubtedly, people who require a lifter to transfer will also need a host of other aids when planning to be away from home, so a vehicle with adequate luggage space will be needed.



The Trixie Lift is not available for permanent loan as it is hoped that many people will be able to borrow it for special occasions. Planning ahead will be needed to ensure availability if you are planning an outing or holiday, have had a health professional's referral for a lifter, and want to take the opportunity to have a break away from home. For more information, contact your Regional Advisor or Equipment Officer, Maree Hibbert.

Stock take:

The 2004 equipment stock take has just been completed. It is now time to ask anyone who has equipment that they are not using or no longer have a use for, to notify MNDA NSW to arrange return as soon as possible.

In particular, if you have a LIGHTWRITER that is not being used, please note that we are unable to meet the high demand for these communication devices. If you are not using the lightwriter could you please post (by registered mail) or return to the MNDA office.

If in the future, you require any of the items that you return, your referral will remain active and your request will be given a priority. Our limited supplies are intended to be used by someone who needs them now, and not just stored away in case you will need them one day.

Please contact Trevor Rakuraku ph 8765 9966 or Maree Hibbert ph 8765 5114.

Go for it! *(Continued from page 12)*

Anyone with MND/ALS will understand the profound tiredness that comes with this affliction.

The beauty of the e-chair is that one can travel great distances with the minimum expenditure of energy, without becoming tired, the only limiting factors being the distance between disabled toilets and the inconsiderate behaviour of motorists who block access to street ramps! The sense of freedom is palpable as I zoom along, wind on face and hair.

There is much joy amidst sorrow in facing the inevitable. I am grateful for all the support given, mindful of the fact that in less developed parts of the world such service would not be available.

Helen Hall
Woollahra
hhall@bigpond.net.au

Working together in regional NSW and the ACT

Working together with NSW Health

Link and Learn – an educational, support and self care program for carers of people with MND in Southern NSW.

The Novotel at Northbeach, Wollongong is the venue for the two-day (one night) residential workshop. The workshop will be held on 1 & 2 March 2005 and will provide MND carers with education/training in caring for a person with MND. It also includes pampering activities and the opportunity to share ideas with others in a similar situation. MNDA NSW staff and experienced local health care professionals will provide education on managing MND during the two-day workshop. This two-day "live in" workshop provides an opportunity for carers from a large geographic area to come together.

The workshop will be followed by six weekly sessions of telephone group link up (approximately 1 hour duration) allowing participants to continue to share ideas and ask questions without the need to travel. Funding will be provided for continuing pampering activities for participants throughout the duration of the Program.

We realise that taking "time out" from caring is always difficult for MND carers and we will work with local Carers Respite Centres to provide respite care in the home to enable MND carers to participate in the overnight workshop and, where necessary, the tele-link program that follows.

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

MNDA NSW is grateful to NSW Health Carers Program, Local Carers Grants, for providing the funding to establish the Link and Learn Program. It would not be possible through our regular resources. Link and Learn will be run in two other areas of NSW during the next three years and provides the opportunity for MNDA NSW to extend better service to rural/regional members and their carers.

Flyers will be sent to members/carers in the southern region early next year. For earlier information, phone Ruth Quaken at the MNDA office on 9743 5872 or Freecall 1800 640 144 – numbers are strictly limited.

Anita Richter & Ruth Quaken

Goulburn meeting

Fifteen people gathered in Goulburn in November to hear Steve Shackel speak about his experience with MND. Steve is a powerful speaker with a deep understanding of MND and has devoted much of the last ten years to "asking questions" and developing a website at www.goulburn.net.au/~shack. This meeting provided an opportunity to ask questions and discuss the merits of different approaches to the treatment of MND.

Two members had recently been to the "Neuro Recovery" course with Petrea King and Jonathon Coleman at Bundanoon which they had found uplifting. It was good to see some new faces from various parts of the region at the meeting and we welcomed the family of one member who had flown from New Zealand the night before! It was also a pleasure to have Helen Christiansen (President of the MNDA ACT) joining us.

I would like to thank Steve for the time and effort he put into the day, and particularly acknowledge his nephew Kim and the management at The Goulburn Workers Club for providing the venue and afternoon tea free of charge. Generosity like this makes it easy to ensure regular contact for all members.


Steve Shackel presents his theories of MND at www.goulburn.net.au/~shack.

Cowra region

An informal information meeting is planned for Cowra in late January/early February for all members in this area. Those of you who enjoy the contact may decide to continue seeing each other as a form of mutual support. There will also be an education session for local health providers.

Allison Pearson

MND Special Interest Groups – working with health professionals to achieve best practice care for people living with MND and their families.

MNDA NSW strives to increase links with health professionals who have an interest in MND and to support them with up to date information on what is considered to be best practice MND care and management. Links between MNDA family support staff and MND specific Programs and Clinics are now well known to our members. However, the MND Special Interest Groups for health professionals presents a new opportunity for information on MND care and research to be disseminated and shared.

112 health and community care professionals have registered since the groups were formed in June 2004, and the second bi-monthly round of emailed/posted information was issued this month.

Anita Richter
Special Projects/Carers Services

Support Groups

Central Coast

The Central Coast Group has enjoyed informal meetings on a bi-monthly basis, usually with a guest speaker, followed by general discussion and fellowship.

Through donations and sale of goods we provide support for research and MNDA NSW. Hopefully these amounts will help towards finding a solution and making a difference. A particular thank you to Kanwal Public School and to our dedicated crew who make a difference, especially during MND Week.

We are saddened to say farewell to many friends this year. Our love and prayers are extended to their families.

> ***In 2004, medals were presented to volunteers who had been instrumental in the development of MND support groups. If you would like to nominate a volunteer to be considered for an award in 2005 in recognition of their support, please write to the CEO.***

We are all here in support of MND and without the help of our members it would be impossible. Thank you to the Sydney crew, our members, friends and supporters, Christina Jason and my right hand, Sheila Holmes. May we look forward with hope to the New Year.

Audree Dash

Newcastle & Hunter Region

Our group held its last meeting for the year and the Christmas party on 14 December. The next meeting will be on 8 February, followed by our annual bowls day at the Abermain Bowling Club on 13 February. All are welcome to come along and join in the family fun day.

As a group we give support not only to the person living with MND but also to the family members.

This year we have achieved our goal by donations to research, equipment and care provision. This is only achieved by the support of our members and our dedicated fundraiser who keeps the group busy and is always looking towards new fundraising activities.

We are looking forward to next year with health professionals attending our meetings as guest speakers. Our remembrance church service is planned for April next year and hopefully it will be as moving as the 2004 service.

A Merry Christmas to all and a Prosperous 2005.

Alistair Fyfe

Southern Highlands/Monaro

Naming a support group based on geographical location can make those who live outside that area feel reluctant to attend meetings. When we named the Southern Highlands/Monaro group it was a very broad title with very blurry edges! New faces are always welcome, even if just visiting Canberra for the weekend.

Meetings are usually held at Clare Holland House, Barton, ACT on the first Saturday of most months but the location and time can vary depending on the planned activity.

Allison Pearson

FOR INTERNET USERS

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

SUPPORT GROUP CONTACTS

Central Coast
Audree Dash
Phone: 02 4384 2907

Central West
Carol Birks
Phone: 02 8765 5115

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
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Research

CELEBREX SHOWS NO BENEFIT IN ALS
Researchers Want to Know Why

A one-year study of the anti-inflammatory medication celecoxib (Celebrex) in people with amyotrophic lateral sclerosis (ALS) has failed to show benefit, according to the Northeast ALS Consortium, which conducted the trial with support from MDA and Pfizer Inc., makers of Celebrex.

The trial involved 300 people, two-thirds of whom received Celebrex and one-third of whom received a placebo (inactive substance), at 25 medical centers across the United States.

Basing their hypothesis on laboratory studies of cells in culture and in mice with ALS, the researchers had hoped to demonstrate a slower rate of ALS progression with the drug.

Celebrex has been shown to interfere with COX2, part of the chemical pathway that leads to inflammation and to damage from glutamate, a natural central nervous system chemical that is toxic in excess amounts. It has been proposed that elevated levels of prostaglandin E2, one of the chemicals involved in inflammation, may increase secretion of glutamate in the nervous system.

"Celebrex worked in two laboratory models," said MDA clinic director and research grantee Dan Drachman, a neurologist at Johns Hopkins University Medical Center in Baltimore and a principal investigator on the Celebrex study. "There was more than enough reason to translate the research to humans, and it was a very well done study. It didn't produce any clinical benefit at the dose used, and our efforts now are to try to figure out why."

Drachman added that the trial took a "tremendous amount of coordination among the investigators in all 25 institutions" and that "everybody did everything that they should have."

Celebrex or a substance very similar to it provided significant protection against poisoning of motor neurons (the nerve cells that die in ALS) when rat spinal cords in a culture dish were subjected to glutamate-related toxicity and when mice with genetic ALS were given the drug.

The treated mice developed ALS later, lived longer, lost strength and weight more slowly, and showed less damage in their spinal cord motor neurons, when compared with their untreated counterparts.

The statement from the Northeast ALS Consortium, released yesterday, says:

"At 800 milligrams per day, Celebrex was safe and well tolerated. Celebrex did not have any demonstrated beneficial effects on ALS disease course. Studies are under way to assess whether Celebrex as used in this study had the predicted pharmacologic [drug-related] effects in the treated subjects. The study results will be presented at the International ALS/MND Symposium in Philadelphia on Dec 3 2004."

Drachman said the challenge now will be to see whether the failure of celecoxib in ALS was due to "an inherent flaw in the theory, or to a difference between mice and men, or to a dosage effect, or to lack of penetration of the drug into the nervous system."

MDA Medical Advisory Committee member Merit Cudkowicz, a neurologist at Massachusetts General Hospital and a principal investigator and coordinator on the Celebrex study, said she and the NEALS group were committed, with MDA, to "understanding why Celebrex at 800 milligrams a day did not work and to finding other therapies."

Published at www.mdausa.org/research
(Muscular Dystrophy Association USA) 26.10.04

Pathways to Hope
The State of Research into Amyotrophic Lateral Sclerosis.

This report from the ALS Association (USA) is available on the internet at www.alsa.org/research/resources.cfm.

International Alliance of ALS/MND Associations www.alsmndalliance.org

Congratulations to Rodney Harris, CEO of the MND Association of Victoria, who has been elected as Chairman of the International Alliance for a three year term. Rodney is the second Australian to hold this prestigious international position — the Alliance was chaired by fellow Victorian, Mavis Gallienne in the late 90s.

The International Alliance of ALS/MND Associations was founded in November 1992 to provide a forum for support and the exchange of information between the worldwide associations. More than 50 national patient support and advocacy groups from over 40 countries worldwide have joined together to form the International Alliance.

The Alliance's objectives are:

- to increase awareness of ALS/MND worldwide
- to exchange and disseminate information
- to improve the quality of care
- to stimulate and support research
- to provide an international identity.

Members of the International Alliance meet each year prior to the International Symposium for researchers and health and social care professionals. This year, the meetings were held in Philadelphia, USA from 2-4 December.

Making Connections with Parkinson's Disease, Multiple Sclerosis and Motor Neurone Disease

A scientific symposium was held at NSW State Parliament House in September 2004 to celebrate 25 years of service provision by Parkinson's NSW. The symposium was presented by Parkinson's NSW, the MS Society of NSW and the MND Association of NSW.

The link between these three diseases that affect the central nervous system is that the body's immune system must be responding to the damage caused by the disease. Altered immunity has been well recognised in contributing to MS and recently different immune responses and inflammation have also been linked to Parkinson's disease and MND.

Eminent US researcher, Prof. Stanley Appel, Chairman of the Department of Neurology at Baylor College of Medicine, USA joined leading Australian researchers as they explored possible connections between current research into Parkinson's Disease, MS and MND. Prof Appel's work in MND is world-renowned. Australian neurologists who have worked with him at Baylor include Prof. Garth Nicholson and Dr Dominic Rowe.

Pathways to Hope
Published in August 2004, this report is an up-to-date overview of research into ALS/ MND around the world. If you do not have access to the internet and would like a copy of the report, please phone the office.

An audience of 75 scientists, medical researchers, students and interested supporters had the opportunity to listen, learn and share their ideas throughout the very full day.

The main themes of the program were:

Genetic/environment interactions in which inheritance and exposure to particular aspects of the environment can influence the likelihood of developing disease.

Dr Roger Pamphlett spoke about the Australian MND DNA bank which now has 781 DNA samples and provides the basis of research looking for abnormalities in a variety of candidate genes including *paraoxonase 1* (responsible for organophosphate breakdown). A particular form of this gene is more common in people with sporadic MND who were exposed to pesticides. The cause of sporadic MND could be a combination of ageing, environment and gene interactions.

Immune mechanisms and the interactions between inflammation and degeneration of nerves. Dr Dominic Rowe raised the question of whether inflammatory mechanisms are a response to the disease process in MND, or are involved in the predisposition, precipitation or pathogenesis of the disease.

Prevention and treatment strategies which provide the hope for the future we are all seeking. Dr Matthew Kiernan presented findings of increased survival in MND for people attending multidisciplinary clinics – probably through institution of a combination of disease modifying and symptomatic therapies.

Continued research into understanding what happens during the course of a disease will allow the development of better treatment. Current research suggests that future therapies in Parkinson's Disease and motor neurone disease should be targeted both to enhancing neuroprotection and also to inhibiting cell death. While many therapies to modify the effects of MS have been trialled, future MS treatment should be aimed at reducing inflammation and promoting remyelination.

The enthusiasm of all the presenters in exploring **why** people are susceptible to these diseases, **how** the nerve cells are affected in the course of the disease, and **what can be done** for people living with Parkinson's Disease, MS and MND left all participants with a positive feeling that research will make a difference.

Experimental therapy

A recent television feature on A Current Affair highlighted the work of Dr Dan Milder who has trialled a combination of drugs (azathioprine and interferon beta 1a) in the treatment of some people with MS. He suggested that this treatment could also be beneficial for people with MND and other neurological conditions. Further, he recommended on the website posting of the program, that people should contact their relevant disease Associations to encourage them to discuss the merits of 'pilot' trials with their Medical Advisory Boards.

The MND Association of NSW took up the suggestion and asked the seven Medical Advisors to comment. The overwhelming response was that there is no reason to support trials without good evidence that they are safe and likely to be beneficial. This evidence should be obtained through properly constituted clinical trials with appropriate ethics approval, and the results published, after peer review, in a recognised scientific/medical journal.

Janet Nash
Information & Research Administrator

Dear Editor

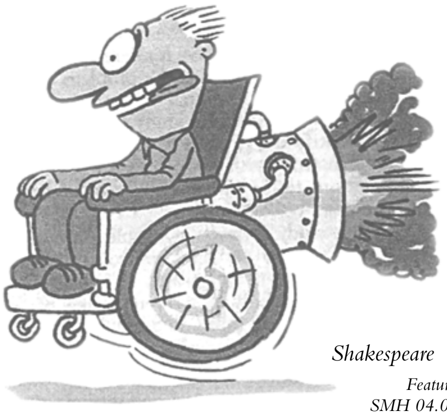
Go for it!
Get out there in the electric wheelchair!

'While you are able', said my friend, 'prepare your home, gather all the equipment, be sure to register for assistance and, most important, make sure you have level access to the street!' Her husband had recently died from MND/ALS and as his dominant carer these matters were fresh in her mind.

So began months of planning; bedroom and bathroom reconstruction as well as visits from an endless stream of health-care professionals, laden with clip-boards and a wealth of knowledge, who eased me into the system. In addition, mechanical aids galore arrived. I thought that none of these items would be needed for some time. Their presence silently spoke of a life of diminishing returns that had to be faced. 'Oh, and don't forget to ask for an electric wheelchair!' said my friend in passing. All these items were quickly dismissed from my mind, especially the monstrous electric wheelchair, because of the future they represented.

All this paraphernalia is now in use, a necessary adjunct to my life. My life has changed considerably and so has my attitude which includes deep gratitude for all the care given by a host of professionals from the Palliative Care Group, Home Care, MND Association, respite for my husband as well as support from friends and family. Most important, the e-chair has given me a restored sense of independence. In it I have travelled alone many times to the city and back, eight kilometres each way. It takes me to the local park to contemplate the beauty of this earth, business meetings, grocery shopping, the movies and much more – so much so that recently a new set of tyres was necessary to replace the old which had become bald with all my gallivanting around town.

(Continued on page 7)



Shakespeare

Featured in SMH 04.09.03

What does the future hold for all of us?

The future of people with MND is in our own hands and in the hands of the people involved in our care. We cannot rely on the Government to provide the funds that are required for the running of the MND Association and other organisations involved in our care.

What will become of us and the people who will follow?

The answer to the question is in our hands! We must take a more proactive role in the raising of funds for the Association. The involvement of people with MND will help to create and further the awareness in the community and the corporate environment. This is a necessity forced on us by the number of charities in the marketplace competing for the State and Commonwealth Governments' and the public's dollar.

Every one of us knows people, or people who know people, who will donate to our charity whether it be by purchasing raffle tickets, in the giving of prizes for the raffles or coming to fundraising events. We must take the promotion of the charity into our own hands and every time we are able to speak and explain what MND is we must seize the opportunity and explain that not only does it affect us but also our family and friends. Also explain that we are supporting ourselves with our fundraising and what a cost it would be if we were just dropped into the pool known as the public hospital system.

It is a very simple equation. If there are seven million people in NSW, surely we are able to accept the challenge of raising $1.00 per person from 2 million of these people. If this was possible it would benefit all of us, whether it be for more equipment, family support workers, better disease management or the research that will find a cure.

So we are all in the same boat. It needs a good strong captain (leadership) and a crew that works together to achieve the desired goal (better lifestyle, cure or respite for our carers and loved ones).

We can best raise the awareness because **we** know what it is like to live with the disease and what toll it takes on the people we love. The best legacy that we can leave for the people with MND who will follow is to be sure that the Association is healthy financially and therefore in a secure position to continue with the work that they do for us.

Barry S Harrison
Eleebana

Do you agree with Barry Harrison's view?

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

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Editor: *Janet Nash*