



FORUM

September 2002

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries.

PATRON

Her Excellency Professor Marie Bashir AC
Governor of New South Wales

VICE PATRONS

The Hon. Mr. Justice Peter W. Young
Lady Yvonne Leonard
Mr. Roderick H. McGeoch AM

BOARD OF MANAGEMENT

PRESIDENT

Kevin Langdon OAM, J.P.

VICE PRESIDENTS

Phil Bower Norman Minton

CHAIRMAN/SECRETARY

Dr. Robert Marr

TREASURER

Robert Templeman

COMMITTEE MEMBERS

Suzanne Ballinger Dr Paul Brock
Pamela Hennessy Roger Henshaw
Robert Howe Alan Kinkade
Dr Roderick Mackenzie
Janice Scheinecker Paula Trigg
Ralph Warren

CHIEF EXECUTIVE OFFICER

Hari P. Singh J.P.

FAMILY SUPPORT

MANAGER

Carol Birks

INFORMATION/EQUIPMENT

Janet Nash

OUTREACH

Caroline Gleig Christina Jason
Ruth Quaken Anita Richter

EQUIPMENT OFFICER

Linda Hager

EQUIPMENT STORE

Mario Bianco

ADMINISTRATIVE ASSISTANTS

Carole Leone Petra Sammut

DEVELOPMENT MANAGER

Elizabeth Herbert

AUDITOR

Bullivant & Flynn Pty Ltd

SOLICITORS

Mallesons Stephen Jaques

and

MANY VALUED VOLUNTEERS

BUSINESS ADDRESS

Concord Repatriation General Hospital
Hospital Road

CONCORD NSW 2139

Ph: 02 9743 5872 Fax: 02 9743 0526

FREECALL 1800 640 144

E-mail admin@mndnsw.asn.au

Internet www.mndnsw.asn.au

ABN 12 387 503 221

Lobbying to make a difference for MND

The Editor has asked me to provide readers of this Newsletter with an account of my 'lobbying' for stem cell research and its potential application to those of us with MND, our families, our friends and our colleagues. In particular, in recent months I have been involved in lobbying Members and Senators of the Australian Parliament in relation to the human cloning and embryonic stem cell legislation which was introduced into the Parliament in the week commencing August 19th and which was subsequently divided into two Bills: that dealing with banning human cloning was passed unanimously; that dealing with embryonic stem cell research has been postponed for a fortnight.

Why? Ever since the significant developments into embryonic stem cell research took off in 1998, I have been convinced, and have done my best to convince others, that embryonic stem cell research holds out a real hope of slowing or even curing this wretched disease. In advocating this, I have also encouraged adult stem cell research - even though in approximately 40 years of adult stem cell research I believe we have yet to see any significant therapeutic impact of this research upon neurodegenerative diseases. Furthermore, I also strongly support all of the other scientifically reputable avenues of research for cures, such as 'growth factors', as well as all the other research being undertaken on a variety of fronts to try to understand the causes of MND.

An allied focus of my activism has been a determination to make Australian scientists, politicians, public opinion shapers, and the wider Australian community understand that stem cell research offers hope to those of us suffering with MND. I became increasingly irritated by the fact that whenever the diseases or incapacities for which stem cell research offered such opportunities were mentioned - e.g. Parkinson's, Alzheimer's, diabetes and spinal cord severance - MND was nearly always ignored.

My campaign has been conducted on a number of fronts.

First of all, every time I read an article in the press which addressed embryonic stem cell research and ignored MND, I personally rang up the journalist, 'educated' them about MND, briefed them on the scientific, ethical and moral issues, and urged them not to exclude us in future. Following such phone calls, subsequent articles by these journalists have virtually always included reference to MND.

My second tactic has been to write articles (as distinct from 'letters to the editors') in both *The Sydney Morning Herald* and *The Australian* in defence of embryonic stem cell research from a moral and ethical perspective and to oppose earlier articles in the press which had condemned this research. The first of these appeared in *The Sydney Morning Herald* last December in response to an earlier article by a bioethicist from South Australia, Dr. Gregory Pike. I was also invited by *The Australian* to write a piece in a double page supplement focussing on embryonic stem cell research from the perspective of one having MND.

Earlier this year *The Australian* published an "Open Letter" of opposition to embryonic stem cell research, signed by a number of leading Australian ecclesiastical figures and some Australian scientists. Incidentally, the Anglican Primate of Australia, Archbishop Peter Carnley, a notable public supporter of embryonic stem cell research, was conspicuous by his absence from the list of signatories.

(Continued on page 2)

Lobbying for MND *(continued from page 1)*

In my subsequent reply, published in *The Australian*, I once again drew attention to MND and focused particularly on the moral and ethical issues involved in embryonic stem cell research using surplus IVF embryos which, otherwise, must be discarded and destroyed in accordance with Australian law. In doing so I drew upon my own five and half years of formal theological and philosophical studies during my 15 years as a member of a Roman Catholic Religious Order.

My third strategy was to set out to make Australia's leading embryonic stem cell researchers aware of the possibilities for MND arising from their research. To this end I attended a research conference at Concord Hospital and had discussions with Dr Martin Pera from the Monash Institute of Reproduction and Development, who is internationally renowned for his research in this field. I then arranged to meet Professor Alan Trounson, who heads up Dr Pera's Department and who is not only Australia's premier researcher in this field but one of the world's leading scientists in embryonic stem cell research. I pointed out to Prof Trounson that not once had MND been mentioned in the prospectus that he and his Monash colleagues had prepared in what turned out to be their successful bid for the \$46M National Centre of Excellence. Every other disease and disability for which embryonic stem cell research holds out so much hope was mentioned – but not MND. To Prof Trounson's great credit, he undertook immediately to redress this situation. He asked me to provide him with a short list of International research centres that are focussing on MND/ALS and assured me that he would attempt to set up linkages with them. He has been absolutely true to his word. For example, I know that he has already been in touch with the prestigious ALS research centre at Johns Hopkins University. Subsequently at the National Press Conference in Parliament House, Canberra, on August 19th he publicly referred to our conversation and recommitted himself to seeking a cure for MND through his research and that of his colleagues.

My fourth strategy has been a somewhat more 'political' one. I have been impressed by Premier Bob Carr's national leadership of unswerving support for embryonic stem cell research. But, once again, not once had I seen any reference to MND in the Premier's campaign. So I contacted his senior advisor on this matter and set up a meeting with him to advance the cause of MND. Since then whenever Mr Carr has spoken about embryonic stem cell research, he has consistently included

reference to MND. Furthermore, I met with a few ALP Members and Senators whom I knew well. Subsequently Darryl Melham, a Member of the ALP Shadow Cabinet, referred to MND in general and to my situation in particular in his moving speech to the House in support of the Legislation on August 27th.

CAMRA

Among others, I was approached by a representative of the Junior Diabetes Research Foundation to see whether the MNDA NSW would be prepared to join the Coalition for the Advancement of Medical Research Australia (CAMRA), set up to lobby for stem cell research in general, and the passing of the Bill that was eventually presented to Parliament recently, in particular. I approached Kevin Langdon and Hari Singh who agreed that we should be involved. Kevin, Paula Trigg and I have attended subsequent meetings. The other members of CAMRA are as follows: Australasian Spinal Research Trust; Australian & NZ Society for Cell and Developmental Biology; Australian Society of Medical Research; Diabetes Transplant Unit of the Prince of Wales Hospital/University of New South Wales; Juvenile Diabetes Research Foundation; Monash Institute of Reproduction and Development; Paraplegic and Quadriplegic Association of NSW; Prince of Wales Medical Research Institute; and the Rett Syndrome Association of Australia.

Under the auspices of CAMRA we have lobbied Federal Parliament and the national media on two separate occasions. In June a small delegation of us spoke individually to over 20 Members and Senators – including strident supporters, those still undecided, and some of our most vociferous opponents. On the 19th August, Kevin Langdon and I were invited to be part of a small delegation, led by Premier Carr, to return to Parliament House where the Premier presented to the Parliament a statement in support of the Bill signed by a very large number of prominent Australians. I was one of four speakers who joined the Premier and Simon Crean in addressing a National Press Conference on these issues. This received Australia-wide coverage in the evening TV News on the ABC, 7, 9 and 10 Networks, SBS and the Sky Channel. I was interviewed by a most supportive Mike Carleton on 2UE that afternoon.

(Continued on page 7)

The determination of Dr Paul Brock has really made a difference in raising the public profile of MND.

This is what is needed to attract the research funding that will lead the way to a world without MND.

Services to support people with MND and their carer

There are a number of services available in the community that assist people with MND to manage their symptoms and to remain as independent as possible. Accessing these services and navigating the often complex care provision network, however, can be difficult. MNDA Family Support outreach workers play a pivotal role in putting people with MND in touch with care providers in each area or, with their permission, making the referral to the relevant services and health care providers.

For information on services in your area:

- MNDA Family Support
- Commonwealth Carelink Centre 1800 052 222 for details of all local services.
- Carers Respite Centre 1800 059 059 for emergency, holiday and overnight respite.

There are many health care providers who may be accessed from a variety of services depending on the services available in a particular area or the stage of the disease. Understanding the role of the various health care providers and how to access them helps people with MND to remain in control of their disease and plan their future care and support.

Medical support

A *Neurologist* will have made the diagnosis of MND and will usually review people with MND every six to twelve months, depending on the

rate of progression.

Your *General Practitioner* provides ongoing care and support, monitors medications and provides symptom management.

A *Rehabilitation Specialist* or *Geriatrician* can provide expert advice on certain aids and equipment and strategies to maintain mobility.

A *Palliative Care Physician* from the local hospital/hospice/MND clinic or program can provide expert symptom management and support, particularly in the later stages of the disease.

A *Respiratory Physician* will be able to discuss the management of breathing difficulties as they arise.

For most people with MND in NSW, care is provided by the local medical, nursing and allied health providers. A case manager may be appointed to coordinate care and ensure that the various health care providers involved in caring for the person with MND share information and liaise with one another. In some areas there are MND specific clinics or programs of care.

Allied Health Services – therapists who have a specific role and work closely together as part of a multidisciplinary team.

Occupational Therapist : Home visit to assess home environment, home modifications, equipment needs, seating etc.

Physiotherapist: Exercise, hydrotherapy, splints, equipment, safe lifting techniques, assisted cough and breathing exercises.

Speech Pathologist: Assess and monitor speech and swallowing, advise on diet modification,

prescribe communication devices.

Dietitian: Assess dietary intake, maintaining weight, modified foods and fluids, PEG feeds

Social Worker: Financial advice, Centrelink payments, emotional support and short-term counselling.

Access to Allied Health is available through a number of services:

Aged Care Assessment Teams or *Aged and*

Rehabilitation Teams are located at most local hospitals within the aged care department.

Community Health Centres -

Palliative care teams may be accessed through local hospitals, hospice or community health centre with a referral from a GP or specialist.

Nursing Services

Registered Community Nurses (accessed from the local hospital, home nursing service or community health center) identify and review nursing needs, support the carer and review their needs, monitor pressure areas, provide nursing care (e.g. continence needs), liaise closely with other service providers, offer support for the whole family and advise on symptom control. *Palliative Care Nurses* provide expert symptom management in consultation with GP/specialist, monitor progress of disease, provide emotional and social support to people with life threatening illness and their family in their own home.

Services to assist with personal care

Personal Care Assistants provide assistance with showering, toileting, feeding, respite, housework.

Access to this service is available through *Home Care Service of NSW* - Part of the Home and Community Care Services (HACC). HACC Services are jointly funded by the NSW and Commonwealth Governments. Most services charge a proportion of the cost of the service to users, but no person is denied services if they cannot afford to pay.

Anyone may refer to Home Care. Services are provided depending on need. Following the referral an initial home assessment is arranged. It is advisable to be referred to Home Care early, as it is easier to increase services once they are in place. Personal care assistance may be provided from a couple of hours a week to, in some instances, up to one to two hours per day.

Community Care Packages

Care packages enable people to deal with only one person who arranges all the care. To be eligible to receive a community aged care package, needs must first be assessed by an Aged Care Assessment Team. These packages are aimed at older people who have a variety of care needs which are not all available from other services and whose needs are changing.

(Continued on page 4)

The 13th International Symposium on ALS/MND

will be held at the Carlton Crest Hotel, Melbourne from 17 – 19 November 2002. The Symposium is designed to enable scientists, clinicians and health and social care providers to meet and discuss current and future issues relating to ALS/MND. Areas of common interest will be covered in the joint sessions, and the separate scientific and clinical sessions will be of particular interest to delegates from different disciplines. The MNDA NSW family support team will be attending the Symposium and, while in Melbourne, they will also have a one day meeting with all other Australasian MND family support workers.

MNDA NSW will also send three young scientists to the symposium. The scientists chosen by MND researchers Prof David Burke, Prof Garth Nicholson and Dr Roger Pamphlett are: Cindy Lin, a PhD student; Stella Christodoulou, BSc, familial MND research coordinator and Julia Morahan, BSc (Hons). Julia's poster on the role of metallothionein 3 in MND has been accepted for presentation at the Symposium.

MNDA NSW Board of Management and Staff are fully committed to working with the international community for achieving optimal care for people with MND and to find the causes and a cure for MND.

*Kevin Langdon
President MNDA NSW*

**MND Association
Family Support Service**
*can identify who to
contact for assistance,
provide contact details,
make referrals, liaise with
care providers, follow up
referrals and assessments,
organise education sessions
for care providers, give
information packages to
care providers and
lend equipment.*

(Continued from page 3) Services to support people with MND and their carer

Community Options

An individual case management service to assist people of any age to continue to live at home. Community Options project officers will assist people in obtaining a full range of services where their needs are complex and fluctuating. Individual care plans are developed in consultation with the consumer, carer and service provider. The project officer monitors ongoing needs, liaises with the family, friends, doctor and service providers.

What if you are unable to access services that meet your needs?

There are a number of private agencies that can provide nursing, personal care, allied health, podiatry, alternative and complementary therapies. Check with your private health fund.

*Carol Birks
Family Support Manager*

Australia's March of MND Faces

The ALS March of Faces Banner is a travelling exhibit in the USA that features a 170-foot photographic display of people with ALS from all over the world. It represents the courageous men and women who have been stricken with the disease known in America as Amyotrophic Lateral Sclerosis (ALS), and in Australia, New Zealand, Britain and Canada, as Motor Neurone Disease (MND). Visit the ALS March of Faces at <http://march-of-faces.org>.

This idea was introduced to Australia by MNDA VIC member Jackie Williams, as the "Australia's March of MND Faces" Banner. NSW and QLD were able to complete their first banners, and VIC their fifth, by the launch of MND Week 2002! It is already a touching and compelling awareness-raising exhibit. NSW needs 13 more photos to complete NSW Banner No.3 so please keep them coming in! All States will bring their banners together at events such as the MND/ALS International Symposium in Melbourne Nov 2002.

It's not too late for you to be a part of this exceptional photographic project to advance MND Awareness. To find out how you can be included on the Banner, phone MNDA NSW on 9743 5872 or send an email enquiry to Jackie at jbw@ruralnet.net.au.



MOTOR NEURONE DISEASE ASSOCIATION

Australia's March of MND Faces



Fundraising

Who needs friends?

We do! A very successful evening was hosted at the Royal Sydney Yacht Club on ALS/MND Global Day 2002. Bob Howe welcomed new members of the 'Friends of Motor Neurone Disease' and lamented that there were not more of them. The 'Friends' are a group of people happy to commit a regular donation to the MNDA. They can be counted on for all sorts of support.

If you would like to become a 'Friend', contact Elizabeth Herbert on 9743 5872.

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. Many people support the work of MNDA NSW through bequests from their Estates. We can arrange for a solicitor to draft a standard will for you free of charge.

Special thanks to volunteers Peter and Janice Stuart whose techno-wizardry has updated our computers and our equipment store. We could not continue without the help of our volunteers and the generous donations received from so many wonderful people and organisations.

We had a Ball

Sydney University students, Nicole Hall, Matthew Gibbs, India Hardy and Ben Godwin are four young people who managed to organise a very successful ball *within three months* and raise nearly \$8,000 for MND.

It was Nicole who took the initiative and persuaded her colleagues from St Paul's and the Women's College that MND should be the charity nominated for their student ball. An early coup was the acceptance of Women's College alumni, the Governor, Her Excellency Professor Marie Bashir (who also is Patron of MNDA NSW). It was not only a great evening but it was also hugely successful as a fundraiser.

Paul Cookson was determined to make a difference for MND. He took to the skies over Gloucester in August to raise funds in memory of a friend lost to MND.

go-go-go-golf at Manly

Andrew Paxton is a golfer with a problem. Andrew has MND. However, his mates have all rallied round and created an outstandingly successful event on 3 October. David Broit works with Andrew at the Travel Bureau and he has been calling in all sorts of favours. There is a tournament in the morning followed by lunch. Not satisfied with that, David and Andrew's other mates have also organised a full round in the afternoon followed by dinner and auction at the Club. The Master of Ceremonies is Channel 9's Richard Wilkins. Rumour has it that they are going to raise more money than went down with the 'Titanic'.

MND Awareness Week 2003 will run from 6-12 April with Cornflower Blue Day on Friday 11th. We are planning to do bigger and better things next year - with *your* help. Plans are afoot to ensure that volunteers get the red-carpet treatment and there will be lots of new opportunities. For example, thanks to help received from Lisa Wherrett, MNDA NSW will be collecting at Sydney Airport on Cornflower Blue Day. The object is to **DOUBLE** the income achieved in 2002. The goal for MND Week in 2003 is **\$200,000.**

VOLUNTEER NOW. We need you!

*Elizabeth Herbert
Development Manager*

0 0 0 0 0 0 0 0 0 0

MOTOR NEURONE DISEASE ASSOCIATION

Australia's March of MND Faces

0 0 0 0 0 0 0 0 0 0

Regional News

SUPPORT GROUP CONTACTS

Central Coast

Audree Dash
Phone: 02 4384 2907

Coffs Harbour

Lily Jenkins
Phone: 02 6652 2571

Illawarra

Lyn Bedford
Phone: 02 4223 8239

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

Noelene Kidd
Phone: 02 6624 4684

Penrith/Blue Mountains

Judy Stringer
Phone: 02 4736 3346

Panania

(Caroline Gleig & Ruth Quaken)

and

Hornsby

(Anita Richter)

are coordinated through the MNDA office.

Phone: 02 9743 5872

Wagga Wagga

Wes Russell
Phone: 0408 692 127

Central Coast

We are happy to welcome Christina Jason to the team. Christina has been making contact with everyone in our area and is very popular.

We are holding an 'Equipment Afternoon' at 2pm on 19 October with the help of David Craddock from Alpha Rehab. Equipment will be on display at Gosford Senior Citizens Club and we extend an invitation to anyone visiting the Coast to join us.

Audree Dash

Hornsby Support Group

meets bi-monthly at the Thornleigh Community Centre. A big vote of thanks to Eileen and John Ellis for their help in organising the Group during the last twelve months. Their assistance has been invaluable. We enjoy a range of activities, e.g. a Trivia Contest at our August meeting and a talk from the Northern Sydney Carers Respite Centre at our next meeting on 9 October.

Anita Richter

Illawarra

Monthly meetings coordinated by social worker, Lyn Bedford, are usually held at Port Kembla Hospital, with an occasional lunch at Dapto Leagues Club. There is often a guest speaker followed by a 'cuppa and a chat'. The group comprises people living with MND, their family, friends, past carers, health professionals and anyone else who would like to attend.

Ruth Quaken

Newcastle & Hunter

Mathew Taute has been elected as our new president. Matthew has MND and travels with his wife Brenda from Singleton for our monthly meetings. Noelene Heggert, our new publicity officer, is a past Lions District Governor who has won awards for work in

media and promotion. All other Board positions were taken on by past board members and we look forward to working together for another busy year.

Alistair Fyfe, Secretary

Northern Rivers

Barbara Moston, President of our group, received a cheque for \$2,500 from Lismore Workers Golf Club ladies' president, Thea Warren.

The money was raised at the club's charity day in July.

Our group was formed in 1997 when Barbara's sister, Christine, was diagnosed with MND. At that time they knew nothing about MND and there was no local support so they contacted the MND Association and started their own group.

Noelene Kidd

Panania Support Group

meets at Panania Uniting Church, 206 Marco Ave, Panania on the second Tuesday of every second month starting at 11am. Support can be given to help with taxi expense - phone the MNDA office for more details.

We appreciate the continued support of Janelle and Ross Wilson and Dave Robinson who set up and help with running the group. Meetings have been well attended during the year. New members are most welcome to come along. The next meeting will be on 8 October.

Caroline Gleig & Ruth Quaken

BED FOR SALE \$1,700 o.n.o.
Electrically operated adjustable bed with head and knee bends and 5 zone massage in mattress.
Phone Peter on 02 9452 4696.

If you would like to be on the mailing list for a local MND support group, please phone the office on 9743 5872 and let us know which support group is the most convenient for you.

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 <http://ozpals.8m.com>.

Internet Chat - Living with MND

Every Wednesday & Sunday 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> or www.alschat.com for chat rooms which are open 24 hours per day.

Visit the MNDA NSW website at www.mndnsw.asn.au for links to many useful and interesting sites.

Research

Detectable motor neurone loss in familial amyotrophic lateral sclerosis

Ten percent of amyotrophic lateral sclerosis (ALS) cases are familial and 20 percent of these families have point mutations in the superoxide dismutase 1 (SOD1) gene. We have been performing an electrophysiological study to examine the pattern of motor neurone loss in a group of people who are SOD1 mutation carriers but who do not have symptoms of the disease. The study aimed to determine whether gradual life-long loss of motor neurones precedes clinical disease or whether sudden, catastrophic loss of motor neurones occurs at the onset of the disease.

Using a special technique to estimate motor unit numbers, we found that there was no detectable difference in the number of motor neurones in SOD1 mutation carriers compared to people without the gene mutation. This implies that symptomatic ALS is not the end result of a slow loss of motor neurones, as mutation carriers have a normal survival of motor neurones until rapid and widespread cell death of motor neurones occurs, coinciding with the onset of clinical features.

We followed 19 SOD1 mutation carriers over a period of three to four years. During this time, a sudden reduction in the number of motor neurones several months prior to the onset of weakness was

seen in four of our subjects. This suggests that this technique has the ability to detect pre-clinical loss of motor neurones in familial ALS and that there may be some form of trigger initiating rapid cell loss and death of motor neurones just prior to the onset of symptoms.

Arun Aggarwal

Department of Neurology, Concord Hospital

Clinical Trials Centre

St. Vincent's Hospital, Sydney

PROPOSED TRIAL OF MEDICINE TO TREAT ALS

St Vincent Clinical Trial Centre is planning to undertake a company sponsored study to assess the safety and effectiveness of medication for treating ALS.

Adult patients with a clinical diagnosis of definite or probable sporadic ALS and of no more than 5 years duration may be eligible for the study.

The study will last 3 months. There will be a 50% chance of being on the test medicine or on placebo (inactive, "dummy" medication). However, after the initial 3 months study period, patients who were on placebo will be given the option of taking the study medication for 3 months.

The St Vincent's Research Ethics Committee has approved the study.

For more information please contact the Clinical Trials Centre or Professor Bruce Brew on 02 8382 2233

If it is possible to identify factors causing motor neurone loss prior to the development of symptoms, it may then be possible to develop effective preventions for familial ALS and possible treatments for sporadic ALS.

Lobbying for MND (continued from page 2)

To Sum Up

Irrespective of the outcome in Parliament – and I remain confident of a positive result – I feel some satisfaction from having made a contribution to highlighting this devastating disease and of paying tribute to the wonderful supporting network of family, friends, colleagues, scientists and professional caring organizations such as MNDA NSW. No longer do scientists, journalists, politicians and others routinely ignore MND when identifying those who stand to benefit from any significant therapeutic breakthroughs that may come from embryonic stem cell research.

If I had to sum up in a few words what I have been trying to do, I would quote from the speech I made at the National Press Conference in Parliament House on August 19th.

I urge our federal parliamentarians, therefore, to look at the facts and not be swayed by irrational hype or irrelevant distractions. In making their decision, Members and Senators are faced with an essentially simple decision. Either agree that all of those excess IVF embryos ought to be destroyed – as, by law, they eventually must be. Or enable these excess IVF embryos to be used in research that could eventually help hundreds of thousands of Australians recover from what currently are incurable diseases or injuries.

Finally, let me put all of this into that intensely personal context within which all of us live our lives. Could I ask those parliamentarians who honestly, sincerely and conscientiously still remain undecided as to how to vote, to please imagine looking fair square in the eye my wife, my young daughters, and my elderly mother, and being able to say to them “I voted to use rather than to destroy the surplus IVF embryos for stem cell research – which could eventually heal your husband, your dad, and your son – because it was the right thing to do.”

Dr Paul Brock

Member MND Association of NSW Board

Dear Editor

I just wanted to say thanks for having your photo banner (see pages 4 & 5, Ed.). It was very hard and very emotional for us to see it, but at the same time I am very proud to have known, loved and cared for the wonderful man who was and still is and always will be my father, my dad, Colin Grant.

Thank you for your support, it has been appreciated and welcomed.

Jeanne Brannolte

Dear Editor

My husband, Herb, was diagnosed with MND 12 months ago. This had an enormous impact on our lives and resulted in the happy go lucky sporty workaholic I married reduced to life in a wheelchair and unable to do anything for himself.

Then the Flocon Car Hoist came into our lives. It has made a tremendous difference, enabling us at a moment's notice to pop out to visit friends, the beach, the cinema or even just to go shopping.

I have a rather tiny car, a Ford Festiva Trio. The Flocon sits on roof racks located above the front seats and is operated by means of a hydraulic jack. When he gets up in the morning, Herb is hoisted onto a denim sling which fits neatly in his wheelchair. He then stays sitting in that sling ready to go out. When we are ready to go, a steel bar is released from the roof rack and an attachment with a hook fitted. The wheelchair is then positioned at the passenger's open door and the hook is located through clips on the denim harness. With a few easy pumps of the hydraulic jack, Herb is lifted into the air, his chair is pulled back and he is ready for the transfer to the car seat.

I must confess it took me a couple of goes to get it down pat but now I can have him in and out of the car in a matter of minutes. The hook attachment is stored in the boot of the car together with the wheelchair and off we go.

Herb loves to go out in the car. It gives him a chance to stretch his legs out straight and relieves the pressure of sitting on his bottom and back.

We have had many enjoyable outings since the arrival of the Flocon Car Hoist and expect many more in the future.

Julie Haas, Lindfield

VAN WITH WHEELCHAIR LIFT FOR SALE

1990 white Toyota LiteAce 1.8 litre, two seats, 48,000 km, automatic with Tieman chair lift installed. Very good condition. Unregistered. \$6,000 o.n.o.
Phone Dorothy Cork on 02 9489 6716.

COMING TO LIFE

In his book *COMING TO LIFE*, David Mackenzie shares his personal journey with MND. He takes us from his 'watershed day' - an unwelcome turning point in his life, moves us through what he calls his 'darkest tunnel', where he faces a gamut of emotions - anger, fear, frustration and embarrassment, and shares with us his inward journey. Here he travels into his own mind, where he has gone through a process of re-discovery, by questioning his faith and beliefs and searching for healing. As a consequence of having a terminal disease and going through this process of self-discovery, David feels that he has moved closer towards liberation of the spirit and a greater tolerance of others.

David says - 'there's also been a positive side, a sense of destiny and a determination to make the rest of my life count for something...to live each day to the full, especially the weekends with the kids'. And that is what David's journey can teach all of us, to make every day count, and to take time out for reflection on what we do have that brings us joy and what is really important to each of us.

Christina Jason

MNDA Northern NSW Outreach

Rev Tim Costello writes in the book's foreword: *This is both beautifully written and deeply moving. It opens up within the reader emotions and feelings that we scarcely knew were there. I have been privileged to read it and I hope my privilege is now enjoyed by thousands of others.*

I've always wanted to write a book. When I was told I had MND I knew it was now or never. In writing *COMING TO LIFE*, I look at every aspect of my challenge with terminal illness. I look at my physical journey, my emotional journey and my spiritual journey. I put my marriage under the spotlight, I talk about how parenthood has changed, I look at the role of friends, I ask myself what sort of a legacy I'll be leaving and I write a letter to my grandchildren. So the reader should get a fairly comprehensive idea of how I have tried to cope with pretty much every aspect of the challenge of MND.

David Mackenzie, Wallsend

COMING TO LIFE is published by Harper Collins and is available in bookstores now. For further information, and for the opportunity to purchase the book on-line, visit David's website at www.comingtolife.biz.

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*