



*Motor Neurone Disease Association of NSW*

ANNUAL REVIEW 2005

# Board Members

The Board Members of the  
 MOTOR NEURONE DISEASE ASSOCIATION of NSW INC  
 at the date of this report are:

## EXECUTIVE

Ralph Warren	President
Dr Robert Marr	Vice President
Phil Bower	Vice President
Robert Templeman	Treasurer
Bob Howe	Secretary

## MEMBERS

Dr Paul Brock	Roger Henshaw
Katrina Horman	Gary Jacobson
Alex Malley	Janice Scheinecker



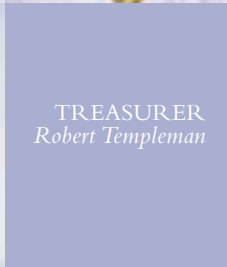
PRESIDENT  
 Ralph Warren



VICE -  
 PRESIDENT  
 Phil Bower



VICE-  
 PRESIDENT  
 Dr Robert Marr



TREASURER  
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SECRETARY  
 Bob Howe



MEMBER  
 Katrina Horman



MEMBER  
 Dr Paul Brock



MEMBER  
 Roger Henshaw



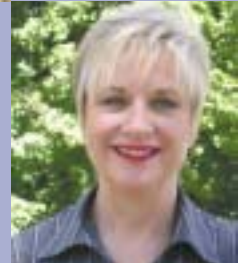
MEMBER  
 Janice Scheinecker



MEMBER  
 Gary Jacobson



MEMBER  
 Alex Malley



## **Mission Statement:**

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*To provide and promote the best possible support for people living with motor neurone disease, their families and carers, to advance research, and to raise awareness.*

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Motor Neurone Disease (MND) is the name given to a group of progressive neuromuscular diseases in which the nerve cells (neurons) controlling the muscles that enable people to move around, speak, swallow and breathe, fail to work normally.

With no nerves to activate them, muscles gradually weaken and waste and paralysis ensues. The patterns of weakness vary from person to person. Some muscles can fail in a few months, while the decline of others may take years. Intellect remains unaffected in most cases, so an active mind is trapped in an inactive body.

The most common form of MND is amyotrophic lateral sclerosis (ALS).

MND can strike anyone - most commonly people in their 50s and 60s.

The cause of MND is not known, except in about ten percent of cases when it is hereditary.

Average survival time after diagnosis is two to three years.

In New South Wales, at any point in time up to 400 people have been diagnosed as having MND, with approximately 140 new cases diagnosed annually.

It is estimated that for every person diagnosed with the disease another fourteen, including their carers, families and close friends, will live with it forever.

In Australia, more than one person dies every day from MND.

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## *Motor Neurone Disease Association of NSW*

*Care for today  
Hope for a future*



# Executive Report

2004/05 heralded dramatic change for the Motor Neurone Disease Association of NSW. The increase in our outreach work involving support groups from across the state and the strengthening of a national voice for people with MND have been key features of the past financial year.

A new office, staff changes and a record number of people seeking support, advice and equipment have been the focus for internal changes that have strengthened the organisation and ensured its relevance and viability into the future.

The Association moved from our “shoe box” in Concord into what could only be described as a “palatial” residence courtesy of the NSW Department of Health and helped along by MNDA NSW Board member Alex Malley. Based at the Old Gladesville Hospital grounds, the building has sweeping river views and ample room for equipment storage and office space.

Significant advances in 2004/05 included:

- increased delivery of effective information, support, assessment and referral services to people living with MND to ensure that they are able to access the services they need to live well and independently in the accommodation of their choice
- continued work with the three MND Clinics and the Calvary MND Palliative Care Service to ensure that more people with MND in NSW have access to expert health care and support
- development and growth of the MND Special Interest Groups
- development and delivery of year one of a three-year *Link and Learn* program. This is a new project funded by the NSW Health Carers Program (local grants). This program offers practical and emotional support to rural and regional carers.
- submission to the Senate Inquiry into Aged Care-Younger People in Nursing Homes and the Future Directions DADHC Policy Statement
- establishment of MND Volunteer Visitor Program in the Newcastle/Hunter region
- development of Education for Palliative Care volunteers through the Volunteer Visitor Program

- extension of the *Learn Now/Live Well* program for people living with MND and their families to rural and regional centres to assist them to live well with MND
- the move to the new premises at Gladesville which continues to open new possibilities to better support people living with MND, their carers and health and community care providers
- the inaugural scientific meeting following the MND Week Launch which was very well received and promoted interest in the research being conducted in Australia
- the inaugural Volunteer Education Day and launch of MND Ambassador Program
- the MND March of Faces during MND Week which attracted many people who wanted to get together as a united voice to publicly raise awareness of MND
- the presentation of three papers by Family Support at the NSW Palliative Care Conference
- Making Connections with Parkinson’s Disease, MS and MND - a Scientific Symposium
- the move towards a formal Bequest program
- another successful Cornflower Blue Ball and
- the launch of *Never Give Up* wrist bands.

## MND Week

MND Week was a flurry of activity as always.

Considering its proximity to the move, staff changes and big media stories breaking during the week, MND week was a great success in raising awareness.

Elizabeth Herbert managed the whole process admirably encouraging and supporting the army of MND volunteers across NSW who were out in force at shopping centres, airports, railway stations, Circular Quay, schools and in the streets marching! We thank you all for keeping MND in the spotlight.

A focal point for MND Week in 2005 was the March of Faces. Banners displayed the human impact of MND by putting names to faces, personalising the impact of MND on individuals and families.



Our returns to the Motor Neurone Disease Research Institute of Australia increased to nearly \$300,000 in the last financial year. Contributions from NSW and other state and territory Associations are helping to drive MND research in Australia. Whilst a cure and prevention are a fair way off, an increased public interest in research and a larger budget will allow a greater input in 2005/06.

Our membership stretches across NSW to all regional areas and support groups have again proved a great means of support for people with MND, their family and carers. Support Groups hold the key to help reach out to people with MND across NSW.

The dramatic changes that have occurred in 2004/05 have highlighted the work over the past two decades of board, volunteers, management and staff: our ability to manage the increasing numbers of requests for family support, equipment and assistance; our increased support of the Motor Neurone Disease Research Institute of Australia; the coordinated push from all states and territories to put forward a strong national voice for people with MND, their families and carers; and increased focus on advocacy to state and federal government, is testament to the hard work that goes on behind the scenes.

Several Board and staff changes took place at the last Annual General Meeting and throughout the year. We would like to bid a fond farewell to Suzanne Ballinger. Suzanne is a long term supporter of the Association and has given her time freely both as a board member and a volunteer at many events throughout the years. Suzanne will still be involved with the organisation in a voluntary capacity. Joining the Board is Alex Malley. Alex is the Associate Dean in the Division of Economic and Financial Studies at Macquarie University and a member of the board of CPA.

Staff changes in 2004/05 include the farewell of Elizabeth Herbert, MNDA NSW's highly dedicated Fundraising Manager, CEO Bruce Fraser and Administration Assistant Carole Leone. We would particularly like to thank Carol Birks who took on the added responsibility of acting CEO and welcome our new CEO Graham Opie.

**PATRON**

Her Excellency Professor Marie Bashir AC  
Governor of New South Wales

**VICE PATRONS**

Melinda Gainsford Taylor  
Kevin Langdon OAM  
Mr Roderick H. McGeoch AM  
The Hon Mr Justice Peter W. Young

**HONORARY SOLICITOR**

Mallesons Stephen Jaques

**AUDITOR**

C. M. Pitt & Co  
Chartered Accountants

**Medical Advisors**

**Dr Paul Clouston**

Department of Neurology  
Westmead Hospital

**Dr Helen Herz**

Calvary Health Care, Sydney

**Associate Professor Matthew Kiernan**

Prince of Wales Medical Research Institute  
& Prince of Wales Clinical School  
University of New South Wales

**Professor Garth Nicholson**

ANZAC Research Institute  
Concord Hospital &  
University of Sydney

**Dr Roger Pamphlett**

Department of Pathology  
University of Sydney

**Dr Dominic Rowe**

Department of Neurology  
Royal North Shore Hospital



# Family Support

## Living with MND



Two years ago my life, thought process and measurement of success were changed forever. I had tripped and fallen while walking. This just did not happen. I was a very fit human being who surfed, ran and swam every day. I lived life to the maximum by the high standards I had set myself after my father had died young and very early in my life. That was not going to be me!

But I was to find that my life had changed forever; the trip was motor neurone disease.

Let me tell you about this life changing event. MND is

terminal but so is life, the only difference is I know what I will die from. The benefit I have is that, unlike my father who died suddenly, I can leave my imprint on my family, friends, people living with MND and society in general. I am now on a very steep learning curve. I need to be strong for my loved ones and there is so much to do to make things better for those who will follow or are on the same journey. This brings me to the MND Association of NSW - what a tower of strength, information and knowledge these people are to us who are living with MND and our carers. Where would we be without our Regional Advisors and their intimate knowledge of our ridiculously complex Community Health System and the education which the Association has to offer. Not to mention the equipment loan pool at our disposal.

The Association continues to grow and change and we can participate in this growth. We have to rise to this challenge; nobody can do it better or with more passion than us. But with one voice. If we do not speak up we will not be heard.

I have turned my knowledge and effort to our Regional Support Group for fund raising, support for others with MND and raising awareness of MND.

We are all able to do something positive and become involved, even if it is in some small way, which could be just saying thanks to the people who care for us.

We need to learn to appreciate life as it is, not as we want it. Remember that the greatest events are not the loudest but the quietest moments in our life. Take the time to see the moon, stars and sunshine, feel the breeze on your cheeks and don't say no when somebody asks you for help.

Barry S Harrison

Family Support includes regional advisors, information, equipment, volunteers and groups.

Family Support aims to provide and promote the best possible care and support for people living with MND, their families and carers, helping to ensure they receive care for today. The Family Support team, led by Carol Birks, includes nine people, most of whom work part-time. The team has a special projects and carer services coordinator, five regional advisors (including an "info line" coordinator), an equipment officer and an equipment assistant. The team members continue to be guided in their practice and inspired by the people living with MND and their families.

The past year has once again seen many changes for the Association. The major change has been the move to the new premises at Gladesville and the whole team is now together on one site. This has offered new opportunities for people living with MND, their families and their service providers to come to the Association to gather information and obtain support.

Family Support continues to work closely with the MND Clinics and MND services in NSW and ACT. During the year more people were able to access an MND specific multidisciplinary service.





MND is now widely recognised by Palliative Care teams throughout NSW and ACT as a target group for their services, often from diagnosis onwards. In November 2004, Carol Birks, Anita Richter and Ruth Quaken presented papers on MND at the NSW Palliative Care Conference in Sydney. The first National Annual MND Conference was hosted by the Victorian MND Association in June 2005. Staff members from MNDA NSW attended the



conference: Ruth Quaken presented a paper on the role of the regional advisor and Christina Jason presented a poster on the Volunteer Visitor Pilot Project. Family Support staff from Australia and New Zealand also met to discuss the issues they face in addressing the needs of people living with MND. Presenting at conferences such as these promotes recognition of MND and the needs of people living with this disease. It also helps to develop partnerships to address the unmet needs of the people with MND and their families

and demonstrates and enhances the breadth and depth of knowledge of Family Support.

## Regional Advisors

Regional advisors are at the forefront in supporting people living with MND. Their objective is that all people living with MND and their families are well supported throughout their journey with MND and have access to relevant information to help guide their decision making. Regional advisors aim to ensure that no person living with MND has a high level of unmet need. This usually means that people whose needs are high and changing rapidly receive frequent contacts from their regional advisor. Others who are relatively stable, and linked in to appropriate services, have less frequent contact.

During the year 150 people with MND registered as members of the Association. Over 50 percent of these new members contacted the Association within one month of diagnosis. Early contact with the Association is a key factor in acquiring timely, relevant, high quality information, the early referral to MND clinics or services and the appropriate health and community care providers.

During 2004/05 the Association was advised of 126 people who lost their fight against MND. Bereavement is the final loss in a series of losses experienced by carers, family and friends and our thoughts are with them.

At 30 June 2005, services were being provided to 310 people living with MND plus their families and carers in NSW and the ACT. This number is slowly increasing, up from 295 at 30 June 2004. During the year regional advisors provided support for 466 people living with MND plus their family, carers and friends.

Regional Advisors:	2004/05	2003/04
<b>New members</b>	<b>150</b>	<b>165</b>
<b>Deaths</b>	<b>126</b>	<b>152</b>
<b>Home/hospital/office visits</b>	<b>309</b>	<b>363</b>
<b>MND Clinic contacts</b>	<b>250</b>	<b>95</b>
<b>Support phone calls</b>	<b>1378</b>	<b>1502</b>

NSW is a large State and there are many people living with MND in rural and regional NSW and the ACT. Five regional advisors support people living outside the Sydney Metropolitan region and two of these are based regionally to provide a more responsive service. The other regional advisors support rural and regional people through regular field trips, "flying visits" courtesy of the Royal Flying Doctor service, the telephone and emails to promote the best possible care wherever people are living.

Regional advisors continue to forge links with service providers who provide care and support for people living with MND in their regions. Regional advisor knowledge of the services available locally helps



to prevent people living with MND falling through the gaps of service provision. A wide variety of health and community care providers may be involved in the care and support of the person with MND and their family throughout their journey with MND. It is these people who deliver the services essential to ensure care for today and hope for a future.

Advocacy continues to be a focus for the family support team in order to promote the needs of people living with MND at the grassroots and government planning level. Service providers are increasingly aware of the progressive nature of MND and the need to respond accordingly. Support from NSW Health and the Australian Government continues through recurrent funding and funding for special projects.

## Information

Good quality information is essential for people to self manage the progression of MND. It is also important for health and community care providers, many of whom may not have had experience of MND before, to assist them to provide best practice care and support. A wide range of quality information is constantly researched, developed and disseminated covering a wide variety of topics. Information is sourced from people working in relevant areas, peer-reviewed literature, conferences, other MND organisations around the world and the internet. Gathering and reviewing the information and making this available to people living with MND helps empower them to seek information as and when the need arises.

For many people recently diagnosed with MND and their family and friends, the first contact with the MND Association is by phone. The provision of accurate information and support is vital. The phone is also a convenient and quick way for people living with MND, family members, friends and service providers involved in caring for a person with MND to obtain ongoing information. The family support "info line" is available five days a week from 9am to 4.30pm and can be accessed by ringing the MNDA office on either 8877 0999 or the freecall number 1800 640 144.

Information:	2004/05	2003/04
"Info Line" calls	2118	1741
Information provision	632	600
Information sessions	50	57
Newsletters	4x1100	4x1100
Special Interest Group e-bulletins	6x154	nil

The provision of information and education to service providers is a high priority for regional advisors. During the year Family Support conducted 50 information/education sessions for service providers and community groups with an audience of 1319. Printed information was disseminated to a wide range of health providers at these sessions and also posted to providers requesting information.

The formation of three discipline specific special interest groups has presented a new opportunity for the regular dissemination of up to date relevant information electronically. The special interest groups formed at the Annual MND Conference in Sydney in 2004 have continued to grow and flourish throughout the year, demonstrating an increasing interest in MND information and research.

The website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) is regularly reviewed and updated and continues to provide accessible information about MND and a means of communication with the Association for internet users.

## Group Programs

The *Learn Now/Live Well* program continues to assist people living with MND and their families to prepare for the future and to live as well as possible with MND. This program was delivered in Sydney and in Newcastle during the year thereby extending the program to people living outside the Sydney metropolitan region.

The *Ask the Experts* session was the last event to be held at Concord Hospital and was very well attended. Experts in the field gave an update on the current trends in research and care management and Dr Roger Pamphlett took blood samples from many willing DNA donors.





Carers of people living with MND have specific needs relating to their care for their loved one. Carers also need support. The annual four week Care for Carers Program was held in Sydney and continues to give carers the chance to learn about MND and gain much needed mutual support. NSW Health Carers Grants funded a new program for carers in rural and regional NSW. This two day residential program held in Wollongong was followed by six weekly tele-link sessions and was highly valued by the participants. This program will be held in South West NSW in 2006 and the Newcastle/Hunter region in 2007.

## Equipment

The equipment service is essential in assisting people living with MND to maintain their independence and communication for as long as possible, and to enhance their comfort and quality of life. This service encompasses sourcing and purchasing new equipment, liaising with therapists prescribing the equipment, seeking further funding, lending, delivering and picking up equipment, developing relationships with equipment hire companies and couriers, and maintenance and cleaning. There is no charge for this service to people living with MND.

Equipment loans:	2004/05	2003/04
Number of equipment items	1147	1124
New items acquired	183	190
No. of items - loaned	888	865
No. of items - returned	373	301



## A carer's story

I lived a blissfully ignorant life. If you work hard you get rewards. Do your best because you get what you deserve. All the cliches applied to my life. Health was not a consideration when all of your family and everyone you know are healthy. News reports on families struggling with sick children or people dying with unpronounceable diseases were sad, but did not have any relevance to my life and were quickly forgotten. Then, one day my partner and I were on our afternoon walk and he fell over. Tripped, clumsy, age was catching up, not fit enough, tired and over worked. Soon the excuses didn't work.

MN what? What on earth is Motor Neurone Disease? Where is the pill he can he take to cure it? How soon will he get better? When can we get back to our old life?

The illusion of my world came crashing down around me and I learnt some life altering lessons. Hard work did not guarantee success (my original, financial based definition of success). Bad things can happen to good people. Health is a priceless commodity.

Through all of the turmoil, the 'what did I do to deserve this', the re-adjustment, lowering of expectations, I have come out the other side a different person. I now cherish my time on this planet. I appreciate the small things that I would have previously overlooked. I am grateful for what I have. I have faith that things will be OK. So many things really don't matter. I want to help make a difference. I am inspired by my partner's inner strength. I have learnt to be compassionate.

In a strange way, I am happy.

An MND carer.

## Research - Hope for a future

### Research

Research was a high priority in 2004/05. The MND Association works closely with the MND Research Institute of Australia to support world-class Australian research in working towards understanding the causes of MND and finding effective treatments and cures. Without research there would be no hope for a future so it is essential that a proportion of the Association's resources be directed to research. In 2004/05, the Association forwarded \$296,000 to the MND Research Institute of Australia for MND research projects that will be carried out during 2005 and 2006.

The driving force behind the upsurge in support for research has been the ongoing private sponsorship of the Bill Gole MND Research Fellowships. Inaugural Bill Gole Fellows, Roger Chung from the University of Tasmania and Valerie Hansen from University of Sydney, outlined their projects at a special Scientific Meeting held at Gladesville in conjunction with the launch of the Association's new Centre for MND. This meeting brought together MND researchers from around Australia and showcased researchers supported by the MND Research Institute of Australia, and others working in the field of MND research. The meeting engendered a spirit of cooperation and urgency to further research of MND.

Some researchers have spent many years in research dedicated to MND. In March 2005, MNDA NSW presented awards to Dr Roger Pamphlett from the University of Sydney and Professor Garth Nicholson from the ANZAC Research Institute in recognition of their long commitment to MND research. These two NSW researchers have led their teams in the true spirit of 'Never Give Up' in trying to trace causes of MND.

Many generous people who dedicate the funds they raise for the MND Association of NSW to research have contributed to the funding of the MND NSW Clinical Research Scholarship, which commenced in January 2005. This scholarship, administered through the MND Research Institute, was established to encourage young doctors to MND research in the hope that this will engender a lifelong dedication to MND.

The MND Association of NSW is also actively supporting the MND Research Institute by providing office space for administration of the Institute.



### Dr Steve Vucic, Neurologist, MND NSW Clinical Research Fellow in 2005 and 2006.

Motor neurone disease was described in 1865 by JM Charcot, but the cause of MND remains unknown. Furthermore, the site of disease onset and the pattern of nerve cell death also remain unknown.

Brain hyperexcitability has been proposed as a possible mechanism of motor neuron cell loss. Such a process can be investigated by using a novel technique called transcranial magnetic stimulation (TMS). In addition, we wish to use TMS to investigate where the motor neurones are affected first and how the motor neuron loss progresses over time. TMS will be combined with electrical stimulation of a specific nerve at the wrist so that the excitability of nerves outside the brain can be assessed and therefore compared to brain excitability. We hope that the test will not only prove to be of diagnostic value in the future, but that it will also become a means of monitoring motor neuron function during treatment.

I was awarded the clinical fellowship by the MND Research Institute of Australia to undertake this research, and I am working with the multidisciplinary MND service at Prince of Wales Hospital. All the testing will be performed at the Prince of Wales Medical Research Institute (PMRI), Randwick. Dr Matthew Kiernan, Director of the MND service at Prince of Wales Hospital, is supervising my clinical and research activities.

Steve Vucic



## Volunteering

My introduction to MND came through my involvement with Carlingford Rotary when a fellow Rotarian developed MND. As his disability increased, club members became aware of the needs of his wife and worked out a roster to provide respite care and support for the carer. I had just retired and was looking for something worthwhile to do, so after Jim died I approached the MND Association to find out how it works to help people. I have discovered that there is much to do 'behind the scenes' to provide the resources that are needed for the many aspects of helping people with MND.

Volunteering for me has been lots of fun – correction – is lots of fun because I intend to continue with my 'Friday job'.

I was lucky enough to begin just after the move to Gladesville so I did not know the previous cramped conditions. Instead I look out on a harbour view and work in a modern stylish office.

I am stationed at reception to answer all your Friday calls but that is not the extent of my work. I have become proficient at counting – counting pens, cornflowers, seeds and most recently – wristbands. I package orders and am now very creative in the shape of the parcels I send. There are many varied jobs I have learned to do to help in the running of our office.

I have also been fortunate to meet some of the other volunteers at the training days or at 'mail-out' days. It is great to work for an organisation which values each person's contribution.

I look forward to my Fridays. I enjoy the varied work and I also enjoy interacting with the terrific staff at Gladesville.

Joy Pogson

Founded by volunteers, the backbone of the MND Association is still its volunteers. Volunteers are people from many walks of life. Some are former carers of people with MND who know first hand how much help is needed. Some have had friends with MND – and others are friends of friends. Some have special skills, others are happy to do anything that needs an extra pair of hands. Some help by raising funds, others give assistance in the office, some serve as members of the Board. The one thing they all have in common is the willingness to give their time to help the Association – they are people helping people.

Special awards were given to long serving volunteers Suzanne Ballinger and Neta Cassidy at the launch of MND Week this year. MND Week is the one time of the year when our volunteers come out in force, but since the Association's move to more spacious accommodation at Gladesville, volunteers are sharing in day to day office tasks. Regular volunteer education days have commenced, offering the opportunity to learn more and to get together socially. The increasing help from a growing team of dedicated generous people is greatly appreciated.

Support groups continue to grow and thrive throughout NSW. They are the "face" of the Association in local communities, raising awareness and supporting the people with MND in their community. Volunteers are highly valued coordinators of the majority of these groups.

The MND Volunteer Visitor Pilot Program in the Central Coast, Newcastle and Hunter regions, funded through the Dept of Health and Ageing 'Caring Communities Program', has thrived during the year. Volunteer visitors have been placed with people with MND who they visit regularly. The education program developed through this pilot has also increased capacity to provide education to Palliative Care volunteers throughout NSW.

# Bequests and in memoriam donations

## Why Anyone?

I often wondered why John, the girls and I never asked the questions: 'Why John?' 'Why us?' 'Why our family?' It was only looking back that I understood that with motor neurone disease the question is 'Why anyone?'

Sadly I know from our journey with MND, (October 1996 to February 1999) that the courageous, inspirational spirits living with MND, and their families, need special care. They also need hope for the future through research that will develop treatments and find a triumphant cure. I also know we would all do anything to prevent precious people dear to us from finding themselves locked into the relentless journey dictated by the progress of MND. There are important ways we can all help turn the tide on motor neurone disease.

We can keep in touch with our unique MND Family by getting together and supporting one another. We can also consider giving now or making a future bequest in our will to benefit MND care, support and research. Like each drop of rain in our water catchment, each contribution to the MND Association makes an impact.

WE can indeed MAKE A DIFFERENCE! Please join our growing group of donors, take care, we care!

Pamela J Hennessy



## Donations received in memory of:

Eileen Adam	Bill Gole	Heather Oldroyd
William Adams	Lester Good	Alistair Orr
Audrey Ahrens	Bruce Goodydy	Ronald Owen
Graeme Alchin	James Gordon	Val Parish
Phyllis Allars	Colin Grant	David Paterson
Mrs Ascot	John Greenhill	Harold Paterson
Peter Asimakopoulos	Edward Gregory	Andrew Paxton
Alec Bailey	Herb Haas	Hazel Penno
Veronica Ball	Kenneth Haydon	Rene Prior
Alfred Bates	Philip Heath	Barbara Ramsden
Bert Bayley	Paul Heffernan	Victor Ramsden
Sylvia Benavente	Benjamin Darcy Henry	Dr John Riley
William Blair	Nina Maxine Hickman	Beverley Robertson
Stanley Blyden	Norma Hitchen	Alan Ross
Brian Bowles	Barbara Hottes	Thomas Saladine
Margaret Burge	Terry Howe	Jennifer Sandstrom
Stuart Butterworth	Myrtle Hoy	Annie Seymour
Ivy Byrne	Joan Hubbard	Marie Shaw
Selwyn Byrne	John Huegill	James Shearer
John Campbell	Wendy Jarvis	Joyce Shelley
Graham Chalker	Judith Jeske	Helen Sidoti
John Cherry	Beula Johnson	Keith Simpson
Joan Clemens	Graeme Kelly	Tony Simpson
Donald Ross Collins	Richard Kenyon	Kenneth Skarratt
Eunice Corby	Cecilia Khursigara	Desmond Smith
Clarence Cornish	Joan Kramer	Noelene Smith
Leonard Cusack	Naomi Kronenberg	Christine Stevens
Paul D'Arcy	Gladys Lever	Dr Monica Stewart
Michael Dennison	Betty Lewandowski	Rene Symons
Vincenza Di Francesco	Thomas Lynch	Eddie Symonds
Robert Dowling	Paul Lynne	Geoffrey Taylor
Terry Driscoll	Oliver Males	Julie Thomson
Robert Duckworth	Bianca Marangon	Kathleen Thurgood
Richard Dunham	John Markovina	Doreen Tonkin
Michael Fennamore	Lola McDonald	Nanette Vella
Jospeh Ratnam	Kathleen McGlin	Norm Wakeham
Fernandopulle	John McGregor	Jean Warner
Maria Finocchiara	Anthony McKenna	Carmel Watson
Heinz Fischl	Mary McLean	Phyllis Weeks
Beryl Fleming	Patricia McNeale	Michael Wilmont
Paul Forrester	Joan Messaris	Allan Worrall
Neal Freeling	Stephen Milliss	Lance Wotton
Annette Furlong	Allan Morrissey	Graham Wyllie
Barry Gemmell	Alan Muir	Pauline Yerbury
Dorothy Gentle	David Newlyn	Anthony Young
Alexis Goh	Malcolm Newport	Joyce Zito



## Donors

### Bequests

Over 80 percent of the Association's income comes from donations, special events and bequests. All are vital to our continuing work, increased commitment to research and, in particular, greater support of individuals with MND, their families and carers and equipment.

2005 saw our first tentative steps towards a recognised bequest program, The Blue Cornflower Society.

This Society has been set up to recognise those who have left gifts in their Will while they are alive, and provides a chance to honour those touched by our work. As a charity, the pressure is always on to keep our overheads low and bequests offer a cost effective way of fundraising with greater returns to programs and less to overheads.

### Trusts & Foundations

AMP Foundation  
 Annie Danks Trust  
 Baxter Charitable Foundation  
 Bill and Patricia Ritchie Foundation  
 Honda Foundation  
 Ian McNair Charitable Foundation  
 Macquarie Bank Foundation  
 Microsoft Unlimited Potential  
 Nick's Foundation  
 PricewaterhouseCoopers Foundation  
 Promina Foundation

### Clubs

Alexandria Erskinville Bowling Club  
 Batemans Bay Women's Bowling Club  
 Beta Sigma Phi Gamma Master Chapter  
 Campsie R S L Sub-Branch Club  
 Chatswood Chamber of Commerce  
 Chatswood Legacy Widow's Club  
 City Tattersalls Club  
 Cronulla Golf Club  
 Five Dock Park Womens Bowling Club  
 Galston District Garden Club  
 Gerringong Women's Bowling Club  
 Gladesville Bowling & Sports Club  
 Inner Wheel Club Of Norwest  
 Kuringai Amateur Swimming Club  
 L.U.S.C. Ladies Social Golf  
 Lioness Club Of Camden  
 Lions Club of Carlingford-Dundas  
 Lions Club of Condoobolin  
 Lions Club of Frenchs Forest  
 Lions Club Of Nambucca Heads  
 Lions Club of Parramatta  
 Lithgow Country Women's Association  
 Macquarie Golden 'A' Club  
 Manly Golf Club Limited  
 Manly-Warringah Master Builders Club  
 MBT Group Social Club  
 Mount Beulah Chapter No. 5  
 Northbridge Cammeray Masonic Hall  
 Order of the Amaranth  
 Pymble Golf Club  
 Randwick Coogee Social  
 Swimming Club  
 Rotary Club Of Bankstown Inc  
 Rotary Club of Chatswood  
 Rotary Club Of Concord  
 Rotary Club Of Granville  
 Rotary Club of Strathfield  
 Russell Vale Golf & Social Club  
 Ryde-Eastwood Leagues Club  
 South Sydney District Junior Rugby  
 Football League  
 South West Rocks Country Club  
 Windsor Country Golf Club

### Major Supporters

Amgen Australia  
 Associated Planners Ltd  
 Australian Dept of Health and Ageing  
 Nevil Barlow  
 Meg Basser  
 BNZA  
 Boots Healthcare Australia Pty Ltd  
 Monica Cooney  
 Cripps & Cripps Real Estate  
 Jill Driscoll  
 Elite Fresh Produce Pty Ltd  
 Eventide Homes (NSW)  
 Fairholme Quilters Inc  
 Fisher & Paykel  
 Jean Hale  
 Henson Park Hotel  
 Malcolm Hodgkinson  
 Independent Living Specialists  
 Ailsa Korten  
 Vernon Kronenberg  
 David Maxwell  
 Mr R I McBroom  
 Gail McKenna  
 Craig & Tisha McTavish  
 MND Support Group  
 Newcastle/Hunter Region  
 Helen Molesworth  
 Nautica  
 NSW Department of Health  
 Lyn Pennock  
 George Ramsden  
 Ian & Sue Rodwell  
 Mrs J Schmeising  
 Brian Sheils  
 Leon Symon  
 Thomas Hare Investments Ltd  
 Thompson Health Care Pty Ltd  
 Shane Tiernan  
 Victoria Turnbull  
 United Way Sydney  
 John Walsh  
 Whelan Project Co Pty Limited  
 Karin Zandvliet

*and many loyal friends of the MND  
 Association who contribute year after year*

# Year in review



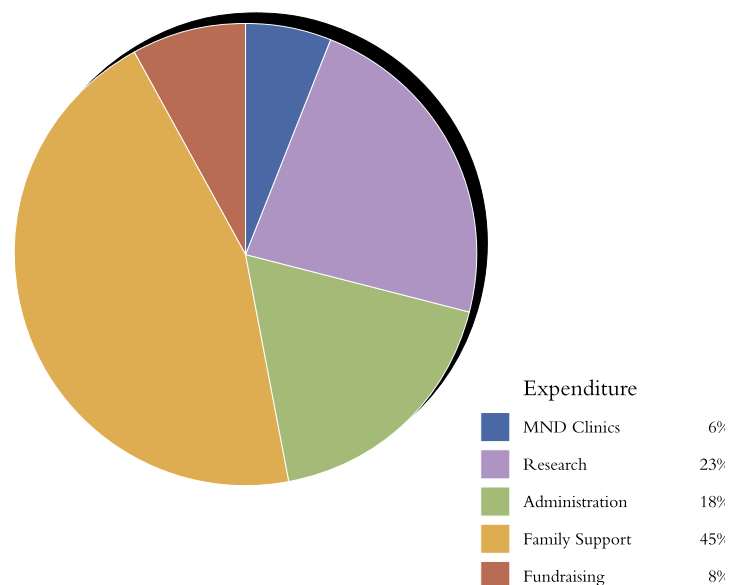
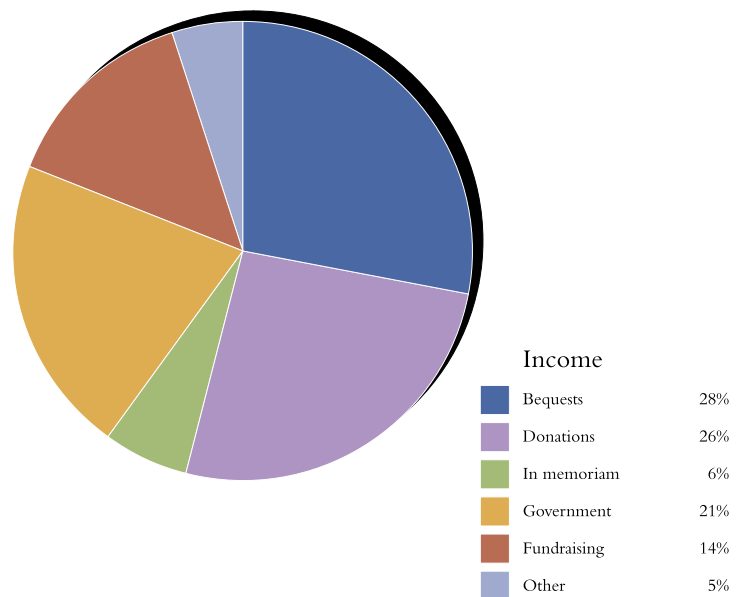
## 2004/2005 Year in review

The 2004/05 audited financial statement shows revenue of \$1,759,486 and expenditure of \$1,534,512.

The increase in revenue was due mainly to our Winter Appeal, an increase in donations for research and government funding. Expenditure increased in Family Support Services by over \$87,000 and research expenditure increased by nearly \$64,000. Fundraising costs decreased by \$50,000. Administration expenses increased from 16% of total expenditure in 2003/04 to 19% in 2004/05 due to recruitment costs.

Total equity retained by the Association increased by 11% due to an increase in fixed assets with the move to our Gladesville office.

For a copy of the full 2004/05 audited Financial Statement, please contact our office.



# Staff

*CHIEF  
EXECUTIVE  
OFFICER  
Graham Opie*



*Manager  
Family Support  
Carol Birks*



*Information &  
Research  
Administrator  
Janet Nash*



*Events & Bequests  
Coordinator  
Roslyn Adams*



*Office Coordinator  
Petra Sammut*



*Regional Advisor  
Mary Butcher*



*Regional Advisor  
Caroline Gleig*



*Regional Advisor  
Christina Jason*



*Regional Advisor  
Allison Pearson*



*Regional Advisor  
& Info Line  
Coordinator  
Ruth Quaken*



*Special Projects  
Coordinator  
Anita Richter*



*Equipment Officer  
Maree Hibbert*



*Equipment  
Assistant  
Trevor Rakuraku*





*people helping people*

The Motor Neurone Disease Association of NSW Inc.

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