

ANNUAL REVIEW

2006-2007



A World Free From the Impact of MND

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About Motor Neurone Disease

Motor neurone disease (MND) is the name given to a group of diseases in which the nerve cells (neurones) controlling the muscles that enable us to move around, speak, swallow and breathe fail to work normally. With no nerves to activate them the muscles gradually weaken and waste. The patterns of weakness and rate of progression vary from person to person.

MND was first described by Jean-Martin Charcot in 1869 and there is still no known cause or cure for this devastating disease and treatment options are very limited. Effective management of the disease by a variety of specialist health professionals is vital to maintaining quality of life and assisting with symptom control.

Recent data around the incidence of mortality demonstrate an increase in the number of deaths from MND in Australia during the last decade (Australian Institute of Health and Welfare). The ageing population and interventions that improve life expectancy in MND are likely to result in a steady increase in the number of people living with MND in Australia.

- Each day at least one person dies from MND and another is diagnosed
- Average life expectancy is 2-3 years from diagnosis
- 1400 people are living with MND in Australia at any given time
- 971 people are currently registered with MND Associations
- 2187 items of equipment were loaned by MND Associations in 2006/07

For every person diagnosed with MND it is estimated that a further 14 members of their family and their friends will live with MND forever. Due to the rapid progression of MND and the spiralling series of losses MND has a significant impact on the physical and emotional well being of the carer.

MND carers are a specific client group with specific needs related to training and support from diagnosis and through bereavement. Health professionals and community care providers, who may have only limited knowledge of MND, also have special needs related to information, education and support.

Until a cure or an effective treatment for MND is discovered care and research must go hand in hand.

Care based on the needs of people living with MND and their families no matter where they live in Australia or their age.

And

Research, which is adequately funded and supported, to give people living with MND today hope that a cure will one day be found.

Care Research Cure



About MND Australia

VISION:

A world free from the impact of MND

GOAL:

No person diagnosed with MND will experience high levels of unmet needs

PURPOSE:

By providing a national peak body for MND in Australia, MND Australia is committed to:

- Lobby for excellence in all services provided to all people affected by MND
- Facilitate and coordinate dissemination of information
- Create reciprocal supportive and informative links with research organisations.
- Ensure increased awareness of the issues facing people living with MND
- Enhance the quality of life for people living with MND

VALUES:

- Our service is to people with MND above all else
- We can expect effective communication, openness, trust and respect of the individual and expect a fair hearing within our Association
- We support, encourage and value innovation that improves opportunity and quality of outcomes



Strategic objectives, initiatives and achievements

MND Australia, in its Strategic Plan 2006-2011, provides the framework for endeavours over the next five years to ultimately enhance the quality of life for people living with MND. The following outlines the main initiatives and achievements of the past 12 months and the future directions related to the five identified key strategic objectives.

1. Gain recognition as a viable, effective and sustainable PEAK body for MND in Australia

Initiatives and achievements 2006/07:

- Involvement in three key Senate Standing Committee inquiries
- Monthly EMG meeting to remain up to date on areas of relevance and to identify national issues to be supported through influencing
- Meetings and contact with relevant government ministers/senators/advisors
- Meetings with other key peak bodies in Canberra
- Business Plan Dec 06 – June 08 prepared and finalised
- Support provided to MND Q to effect change and to access funding
- Paper related to baseline services of care developed

Future Directions:

- Further establish links with other similar national NGO's
- Explore synergies and partnerships
- Further develop web site
- Continue to respond to relevant Federal issues
- Establish a panel of experts

2. Inform policy that impacts on people living with MND nationally and internationally

Initiatives and achievements 2006/07:

- Membership of National Disability Services established
- Annual Statistics collated
- Membership of International Alliance maintained
- Information received via International Alliance reviewed for content and distributed to members
- MND Australia update distributed through International Alliance newsletter
- Awarded a Nina Buscombe grant to support attendance at International ALS/MND Symposium and International Alliance meetings in 2007
- Visit to MND UK, ALSA Greater New York and Beth Israel MND Clinic

Future Directions:

- EMG to continue to identify national agenda issues
- To continue to maintain and develop links with relevant Federal Government ministers and departments
- Maintain and develop links with other MND Associations Internationally

3. Raise awareness of the issues faced by people living with MND

Initiatives and achievements 2006/07:

- New logo adopted by most state Associations and MNDRIA



- National branding policy implemented
- Website updated regularly with:
 - Media releases, position statements, National Conference, Annual Review and strategic plan
- National literature reviewed and revised through shared services
- National Annual MND Conference guidelines for future hosting developed
- MND Week and Global Day communication maintained through EMG
- Visits to MND SA, Tas, Qld, WA

Future Directions:

- Maintain regular contact with State Associations through directors and EMG
- Develop national Call to Action for MND Week 2008

4. Attract funding at a national level to achieve our mission

Initiatives and achievements 2006/07:

- Financial support from the State Associations confirmed for 2007/08
- Three national projects identified by EMG at face to face meeting June 2007
- Revised funding proposal written to assist with submissions for funding from national corporate organisations
- Opportunities for Federal Government funding identified and applied for
 - Funding for Confident Caring Project in Queensland
- Joint fundraising event conducted with NSW
- Contact maintained with sanofi aventis and national support given to their successful submissions to lift restrictions related to:
 - PBS access to Rilutek for people aged 75 and length of disease

Future Directions:

- Continue to identify government, sponsorship or corporate philanthropy opportunities to support MND Australia to become independent of State funding and to build capacity
- Seek funding to support the national projects and the National Conference

5. Encourage and support research into MND

Initiatives and achievements 2006/07:

- MND Australia representation on AMNDR
- MND Australia representation on MNDRIA
- Research information received and distributed regularly
- Visits to The Stacey DNA laboratory at Sydney University and the Western Australian Institute of Medical Research
- Nina Buscombe award information distributed
- Bid submitted to MND UK to host the International Symposium in Sydney
- Inaugural MND Australia Travel Grant for MND Association staff launched at National Conference
- Background papers related to possible MNDA/ MNDRIA alignment prepared with MNDRIA Executive officer and presented to boards of MND Australia and MNDRIA
- MNDRIA invited to become a full member of MND Australia

Future Directions:

- Attend International Symposium and International Alliance Meetings annually
- Prepare to host International Symposium if bid successful



Patrons:

Sir Gustav Nossal AC, CBE

Judith Durham OAM

Auditor:

CM Pitt and Co

Chartered Accountants

Officers:

President

Helen Sjardin-Howard

Vice President

Ralph Warren

Secretary

Tim Hynes

Treasurer

Bob Howe

Public Officer

Mavis Gallienne

Directors:

Australian Capital Territory

Kaye Radovanovic

Helen Christiansen



Helen became involved with MND ACT in 1997 after she moved to Canberra to help her sister care for her husband who had been diagnosed with MND. After he passed away at the end of 1998 she started to volunteer in the office and during awareness week.

She became President of MND ACT in 2000 and has been instrumental in promoting the sale of MNDA merchandise in all Capital Chemists, other shops and offices in the ACT and also her church. She has had to slow down over the last 18 months or so, as have many of the older helpers, but she plans to continue to support

MNDA as long as she is needed

New South Wales

Ralph Warren



Ralph was educated at Narrabeen Boys High School (as it then was), studied law at Macquarie University, worked in private industry for a time, travelled O/S with his young family for some time, then settled back down in Australia. Ralph was admitted to the Bar in NSW in 1985 and is a member of chambers in Newcastle and Sydney. He has been on the Board of MND NSW for nine years and on the MNDA Board since 2005.



Bob Howe



Bob has been on the NSW Board since 1999 through his friend Colin Mills, a NSW Board member who had MND. Colin asked him to help with the development of a business plan for NSW and he has been heavily involved since then. Bob is a Director of a consulting firm specialising in planning and organisation. Prior to this he worked for many years in Qantas and on the consulting side of Coopers & Lybrand. He is a qualified accountant. He has many outside community interests including soccer, learn to swim, Australian Maths Olympiad and Rotary.

Queensland

Lesley Taylor



Lesley's involvement with motor neurone disease began in 1981 with the diagnosis of MND given to Charles Graham (her father). Following the formation of the Queensland Association in 1983 her roles within the Association have been many and varied, volunteer, family support, fundraiser, Queensland representative to MNDRIA, office manager. With a background in Education, Lesley looks to the future with the hope that tomorrow's children will never experience motor neurone disease

John Wearne AM



Following the diagnosis of his Father-in-law with MND in 1981, John helped him and other family members form the Queensland Association in 1983, becoming the Association's inaugural President, a position which he held for 17 years. John now is the Queensland Association's Education Support Officer and gives talks on MND at nursing homes, hospitals and community service organisations. John has a banking background retiring from the National Australia Bank as a District Commercial Manager in 1995. He has been involved with MNDA since its inception

South Australia

Steven Warren



Stephen joined the South Australian Committee of Management as Treasurer in 2000 and was appointed Chairperson in May 2004. Stephen has a Bachelor of Arts in Accountancy and a Master of Business Administration. Stephen is the Chief Financial Officer at Michell Pty Ltd. He is a fellow of CPA Australia.



Peter Whitehouse



Peter was appointed as Executive Director and a member of the Committee of Management of MND South Australia in April 2006. He has extensive management experience and prior to his appointment as the Executive Director, he was the Chief Executive Officer, the Multiple Sclerosis Society of SA & NT Inc from September 1996 to April 2006.

Tasmania

Tim Hynes



Tim became involved with MND Tasmania shortly after moving to Tasmania from Brisbane with his wife. Tim's father was diagnosed with MND in 2003. In March 2007 he was elected President of the MND Tasmania association. Tim studied Health Information Management at the Queensland University of Technology and currently works in the Department of Health and Human Services as a project manager.

Denis Lyne



Denis has been Secretary of MND Tasmania since 2005. For the past 20 years he has worked in Local Government, managing recreational facilities. Denis was a keen runner and football umpire until he was diagnosed with Spinal Bulbar Muscular Atrophy (Kennedy's Disease) in 2003.

Victoria

Mavis Gallienne AO



Mavis has been involved with MND associations since 1981, the year her sister died from MND. She has served on local, state, national and international boards. Her particular interests are in seeing that good governance is applied to organisations, the sharing of information and ideas to ensure we can provide the best possible care and support for people with MND wherever they live. Mavis is Social Welfare trained.



David Ali



David was invited to join the MND Victoria State Council in 2000 through his Fellowship of Leadership Victoria. David values his contribution since 2000 (less one year leave of absence) to working towards a world without MND. David is currently State President. He is also a senior executive in the Victorian public service, President of a non-government school, board member of a community health service, Member of the Australian Institute of Company Directors and Member of the Institute of Public Administration Australia. David has a broad mix of skills including governance, strategic policy development, analysis and advice; organisational development and review; and government relations.

Western Australia

Manny Manolios



After graduating from Curtin University of Technology, Western Australia in 1990 with a Bachelor of Engineering Degree, Manny travelled and worked overseas for 18 months spending most of his time in the UK. Shortly after returning to Perth in 1992 he commenced employment at Royal Perth Hospital in the Department of Medical Engineering & Physics as a Rehabilitation Technologist and in 1996 his post altered to Rehabilitation Engineer. Manny's role in this position encompasses designing and/or modifying assistive technology to aid clients with communication and motor impairments. Approximately 60% of his workload is dedicated directly to helping people with MND.

In 1996 Manny was invited by Stephen Brown to join the board of the MND Assoc. of WA and he became a state representative to the National Board in 2005.

Helen Sjardin-Howard



Helen's early education was in Tasmania. She studied at the Australian College of Speech and Hearing, Melbourne, graduating in 1965. After working in Hobart for several years as a Speech Pathologist Helen moved overseas living and working in Holland. She worked for the Royal Hobart Hospital from 1971 until 1984 when she was appointed Chief Speech Pathologist at Royal Perth Hospital. Helen held this post for 15 years before turning her focus to private practice.

Helen's interest in working with people with MND dates back to recognising the imposed powerlessness and generally poor community understanding about this devastating disease. Her driving force was the many inspirational connections she made with people living with MND, more recently Dr. Paul Brock in NSW and Stephen Brown in WA who invited her to join the board of MND WA about twelve years ago. Helen was President of MND WA from 2001 to 2003. Since then she has also worked on the national board with a focus on equity and excellence, culminating in three years as National President in 2005-2007.



President's Report

This review reflects achievement of organisational and personal enrichment due to careful planning and the cooperative work of a skilled team.

It was some years since the National Presidency had the continuity of a three year term - now a recommendation incorporated in our Constitution. This has enabled longer term planning, following through to effective implementation in relation to support of member organisations and building relations with relevant peak bodies and federal ministries.

The key to increased effectiveness with demonstrable outcomes has been the now well established role of National Executive Director. Carol Birks in her .6FTE position has leveraged this time and budgetary allocation with flexibility and utilisation of other personal travel plans to benefit MND Australia's cause at minimal cost. With a focus on strategic goals, Carol has visited overseas and interstate to build valuable networks and offer support and advice to member associations as well as procuring hearings with a range of politicians whose arena significantly impacts people living with MND.

Structural changes affecting the lines of communication and delineation of operational aspects, as the realm of the Executive Management Group (EMG), have contributed to a newly emerging culture of the National Board. The board now has its focus appropriately on National policy, influence, awareness, maintenance of standards of care and equity of service.

The fact that the new name of MND Australia, along with the revised logo has now been officially registered reflects the revitalised and streamlined organisation.

Once again appreciation is expressed to MND NSW for their three year contribution of \$30,000, completing this year to support the establishment of a more professional association. This, together with an

increased subscription from all Members has allowed MND Australia to move beyond volunteerism to a small corporate structure with an enhanced image and impact. Beyond this stage, the scene is set to refine recruitment to the Board of Directors with a focus on appropriate skills-mix and to further develop national projects and themes identified in conjunction with the EMG.

Adoption of guidelines for the National Conference and an Annual Travel Grant of \$5,000 reflect the role of MND Australia in fostering professional development and dissemination of quality information about MND. These initiatives, along with the development of a National Call to Action, are examples of how the EMG and the Board of Directors (MND Australia) have emerged with complementary yet clearly defined roles. The National Executive Director acts as an effective conduit between the two groups.

The most challenging target identified in last year's report remains the need to secure national funding. MND Australia is mindful that any national funding sourced should not impinge on Members' current priorities to fund care services. A specific paper addressing this has been developed identifying opportunities and reporting on approaches made to date for corporate, community and government support. In addition to this, through further discussion with the EMG, the potential for a National Fundraising event will be explored.

As the successful recipient of the Nina Buscombe Award, funded and awarded by MND Victoria, Carol Birks will attend the International Alliance Symposium in Toronto, Canada, in November, 2007. This should be an opportunity to further build links with overseas organisations and return with new information on research and care.

This past year has afforded many valuable exchanges with the MND research Institute of Australia including Janet Nash, (Executive Officer, MNDRIA)



accompanying Carol Birks to an arranged meeting with The Federal Minister for Health and Ageing's Advisor in Canberra and a subsequent invited written submission for funds.

As part of its vision to create "A world free from the impact of MND" MND Australia has continued to explore ways of working closely to support and promote research, recognising the mutuality with MNDRIA. The possibility of aligning these two organisations on a formal basis has been thoroughly explored, following an initiative in 2002 and during this last year much wider consultation. Resulting proposals are to be voted on at the forthcoming AGM's of the two Associations and MNDRIA has been invited to be a full member of MND Australia.

Our policy on research stood the test of time during the Federal debate on the use of SCNT (embryonic stem cells) and there

was a measurable increase in the references to people with MND being one of the potential beneficiaries in both National and State publicity.

On reflection over the three years of my term, I feel satisfied and rewarded to see an association that is now poised to strongly represent the needs of people with MND around Australia in a more timely, strategic and professional way. The support of the Board, and particularly the executive, has been the key component of the personal reward and enrichment referred to. My confidence in the continuing effectiveness of MND Australia is strongly founded on the demonstrated competence of our National Executive Director and the value added by establishing this pivotal role.

Helen Sjardin-Howard,
National President, MND Australia



National Executive Director's Report



I took on the role of part time National Executive Director for MND Australia in October 2006. As the establishment of this role heralded a new phase for MND Australia one of my first tasks was to work with the President to finalise the draft Strategic Plan 2006-2011 and to then develop an 18 month Business Plan. The Business Plan December 2006–June 2008 sets out clearly actions and outcomes for that period. Many of the strategic aims have been achieved or are currently being developed. The main achievements over the last 12 months are listed on the pages 6 and 7.

Influencing the Federal Government to improve care, services, support and research related to MND is a primary objective of MND Australia. A number of Senate inquiries of relevance were conducted during 2006/07. It was therefore fortunate that MND Australia was in a position to respond effectively. MND Australia appeared as a witness at the Senate Inquiry into the Commonwealth State and Territory Disability Agreement (CSTDA) last October.

MND Australia highlighted issues related to:

- the high level of unmet needs of people with MND
- the difficulties related to people aged 65 moving from disability to aged care
- the impact of a confusing disability services system on outcomes
- the complexity of the needs of people with MND and their carers
- the need for flexible assessment options for people with diseases like MND where needs change rapidly

- the need for people with MND to access timely equipment

Each of these issues is addressed within the 29 recommendations made by the bipartisan members of the Senate committee in their subsequent report. The primary recommendation of this report, released in February 2007, was that all governments jointly commit to **substantial additional** funding to address **identified unmet need** for specialist disability services. The fourth CSTDA was due for renewal by July 1, 2007 but to date agreement has not been reached.

MND Australia and MND NSW made submissions to the Senate Inquiry into the Legislative responses to Recommendations of the Lockhart Review. MND NSW was particularly active on this issue through their involvement with the Coalition for the Advancement of Medical Research Australia (CAMRA) and the tireless campaigning of Dr Paul Brock. MND NSW appeared as a witness during the Senate Inquiry. MND Australia recognised that the Stem Cell debate was a sensitive issue. However, the vision of the Association is a world free from the impact of MND. It is therefore imperative that we support research which is legal, has sound scientific rationale and has the potential to bring us closer to finding the cause, treatment or cure for MND. MND Australia wrote to all Senators and MPs prior to the vote on this issue in each house urging them to support the recommendations of the Lockhart Review. Following the decision by the House of Representatives to implement the recommendations of the Lockhart Report, lifting the ban on therapeutic cloning or somatic cell nuclear transfer (SCNT), MND Australia distributed a media release immediately congratulating the government. This resulted in over 17 television and radio interviews in the following 48 hours.

In January a submission was made to the Senate Inquiry into changes to the Private Health Insurance Act. MND Australia was invited to appear as a



witness in February. MND Australia highlighted that any enhancement of private health insurance products must encompass the needs of people living with MND and should include case management, equipment, flexible respite and education programs to help keep people living with MND out of hospital. Influencing private health insurers to provide products relevant to people living with MND and their carers will be a focus for the coming 12 months.

Meetings with key ministers, shadow ministers, advisors and relevant departments have taken place during the last 12 months to raise the issues related to people living with MND nationally and to influence government policy. Regular visits to Canberra for these meetings also provide the opportunity to make links with other national peak not for profit organisations. These meetings assist in developing a national presence and in exploring synergies and opportunities for working together to strengthen lobbying and to influence policy.

Other influencing opportunities during the past 12 months have included involvement in the ALP Conference fringe event *Health Policy Challenges – Long term strategies for chronic illness in Australia* organised by MS Vic/NSW and Chronic Illness Alliance (Vic). MND Australia and a past MND Carer highlighted the needs of people living with MND. The panel included, Nicola Roxon - Shadow Minister for Health, Senator Kate Lundy - Shadow Minister for Sport, recreation, health promotion and local government, Dr Ken Harvey and Dr Sally Cockburn.

MND Australia collaborates fully with its members, the State MND Associations, who remain committed to supporting a national body through annual subscriptions. This commitment ensures the viability of MND Australia in the short term.

At an operational level MND Australia works with the State CEO's via monthly executive management group (EMG) meetings. This guarantees regular communication between all State senior

managers and MND Australia. State Associations provide services and it is vital therefore that the national body is informed about the current needs of people with MND. Similarly State Associations must be aware of the direction and objectives of MND Australia. During 2006/07 the EMG developed a paper comparing, anecdotally, the services available in Australia with the International Alliance Baseline of Services for People with ALS/MND. This paper confirms that, although there have been improvements in most states related to diagnosis and care, inequities remain.

Following the CSTDA senate report the EMG formed a CSTDA campaign committee. This issue was the focus of the MND Week 2007 National Call to Action urging governments to provide sufficient funding during the fourth CSTDA to support the recommendations of the Senate Report and to meet unmet need. We continue to monitor this issue.

At the annual face to face EMG meeting in June the group identified three areas of need to focus on during 07/08. These three priority areas include:

1. An audit of people with MND and the development of National MND Standards of Care
2. Development of online information resources
3. A national awareness campaign.

Priorities 1 and 2 will require additional funding to progress. Philanthropic and federal government funding opportunities are currently being explored. A national awareness campaign group has been formed to progress this concept and to ensure a coordinated national approach to MND Week and Global Day in 2008.

Visits to all States during the year have assisted with developing a national overview of issues. These visits have also helped to review the capacity of each Association and to promote partnerships to assist the less well resourced Associations. An application for funding through the Australian Government



Department of Health and Ageing Local Palliative Care Grants Program round four has recently been approved. This will fund The Confident Caring Project which includes the employment of a project officer in Brisbane to conduct education programs for MND carers, palliative care volunteers and health and community care providers to support home based care.

During the year Jennene Arnel, Manager Family Support Services, MND Vic worked with MND Australia to develop the National MND Conference Guidelines. These guidelines outline the process of application to host the Conference, the roles and responsibilities of the State and National organisations and a timeline. We also finalised documentation related to launching a Staff Travel Grant. This grant was approved by the board and included in the budget for 2007/08. The recipient of the inaugural MND Australia Staff Travel Grant will be announced in September 2007.

The 3rd National MND Conference was hosted by MND WA in Fremantle on 19 June. The conference was very well attended and the program varied and relevant to the audience. The number of delegates was testament to the increasing interest in the care and support of people living with MND and their carers in Australia. I adapted a paper on carers which Anita Richter, former Carer Support Services Coordinator MND NSW presented at the International ALS/MND Symposium in Yokohama in December 2006. This presentation provided a national overview of carer support.

Developing national sponsorship and funding opportunities within the corporate sector continues to present a challenge. A funding proposal document has been developed and a number of corporate funding opportunities followed with little success to date.

Internationally, visits to the MND Association in the UK, the ALS Association Greater New York Chapter and the Beth Israel ALS Clinic during an overseas holiday in June were highly valuable. I thank the staff in Northampton,

UK and in New York for their time and hospitality. With the assistance of MND NSW and the Sydney Convention and Visitors Bureau an application has been submitted to host the International MND/ALS Symposium in Sydney in 2011. The successful bids will be announced later this year.



Visit to the ALS Association Greater New York Chapter.

Jacqueline Reinhard, Executive Director, Carol Birks, MND Australia and Adele Marano, Director of Patient Services

During the last 12 months MND Australia has met regularly with Janet Nash the Executive Officer of the MND Research Institute of Australia to review and update past SWOT analyses related to amalgamating the two organisations. A comprehensive background paper was produced which was presented to both boards. To further strengthen links with MNDRIA the MND Australia Board have extended full membership to MNDRIA.

I sincerely thank the outgoing President Helen Sjardin-Howard for her support and wisdom. Her passion and vision have been instrumental in establishing a professional organisation. I also thank the MND Australia board and the State and Territory Associations and I look forward to continuing to work collaboratively towards our vision of a world free from the impact of MND

Carol Birks



Member Highlights during 2006 – 2007

New South Wales

Achievements in advocacy seemed to be the recurrent theme for MND NSW in 2006/2007.

The year kicked off with a \$500,000 one off grant from the Department of Ageing, Disability and Home Care (DADHC). The grant provided for equipment and is to be spent over 3 years.

MND NSW became heavily involved in the human embryonic stem cell debate both at a federal level in late 2006 and at a state level in May and June 2007 when the mirror legislation was passed.

MND NSW has been working with Community Options, who were awarded a \$200,000 grant by DADHC to look at a continuum of care model proposed by MND NSW. A Motor Neurone Disease Advisory Group comprising of senior DADHC staff, Palliative Care, Community Options and MND NSW has been formed. The Group have completed a report to the Minister for Disability Services who plans to work with the Minister for Health to better cater to people affected by MND.

MND NSW approached Multiple Sclerosis NSW/VIC and Muscular Dystrophy NSW to form a consortium to look at common advocacy issues. An immediate outcome has been the awarding of \$1 million to the Consortium to initiate a flexible respite care program.

Our member numbers continue to grow and during the year, support has been provided to 494 people living with MND, as well as their carers, family, friends and workmates. This necessitated an increase in family support staff and an injection of new equipment to help ease the waiting times.

MND Week 2007 was dominated by a national push by MND Australia and all state and territory MND Associations to

forward the stalled Commonwealth State Territory Disability Agreement and for both state and federal politicians to understand the huge unmet need and inequity in disability services across Australia. Members of MND NSW were asked to write to their local federal members and all senators asking them address this issue. We thank all members for taking part and helping to drive the MND agenda.

Through his tireless efforts advocating for people with MND Paul Brock, who retired from the MND NSW board in late 2006 was appointed Vice Patron of MND NSW. Paul was presented this award at the launch of MND Week.



*The MND NSW MND Week Launch
Carol Birks, Assoc. Professor Roger
Pamphlett, Dr Paul Brock, Janet Nash*

Our team of volunteers were out in force across Sydney and NSW on Cornflower Blue day and media within NSW focussed more on regional areas than has happened in the past.

As always we would have been unable to achieve all that we have without our volunteers and the support of the NSW community as a whole. Through the tireless work of members, particularly in regional areas, there appears to be a much wider understanding of MND and its impact on individuals, families and the community.



Queensland

2006 - 2007 has proven to be a time of changes and challenges for the Queensland Association, however with our committed Executive, staff, community development officer and volunteers these challenges have been met and the Association has gone from strength to strength.

An Information evening was held with the aim of attracting interested people to form the new Board, followed by a strategic planning day and the revision of the Constitution by the new Board.

The MND Clinic at the Royal Brisbane Hospital continues to grow from a monthly to fortnightly clinic to support our MND families. Dr Henderson, Dr McCombe, Dr Douglas and the Palliative care team assist families through their journey, by providing support and information in a caring and professional environment. Dr Henderson provides MND people with the opportunity to participate in research, and recently received a grant of \$150,000 from the Queensland Government, for research into the diagnosis and treatment of MND.



*The Blue Ball
Noni Hazelhurst and Casey Donovan*

With so many needy and worthwhile causes in Queensland, fundraising as always, is a challenge however this financial year has been kind and the people of Queensland very generous. The Blue Ball was a great success, attended by Brisbane's social set and attracting performers Glenn Shorrock and Casey

Donovan. We have received wonderful support from AMP, the Brisbane Broncos and many organisations, having lost members to MND, Lions, Rotary, RSL clubs, Golf Clubs and small community groups.

As always one of our main objectives is to inform the public about motor neurone disease, and with the assistance of our Support Groups and volunteers many avenues were explored and opportunities seized. Awareness was created through, posters and merchandise in Medicare offices throughout Queensland, collections at Bronco's home games, Doomben races, information stalls, concerts, combined charity card shop, collectors in the city and Royal Show. Many of these activities were undertaken by the Associations volunteers, people who give so freely of their time and expertise.

Queensland is a large area for the provision of services. We are fortunate to have Support Groups on the Sunshine Coast, Gold Coast, Darling Downs, North Brisbane & Caboolture, and contact people throughout the State all assisting the MND families in their areas. We are pleased to welcome Robin Ray, as the contact/support person for North Queensland. Robin has recently moved to Townsville, is a past family caregiver, nurse and researcher. Robin will provide information services to health and social care workers as well as support for family members.

As we grow, develop and refine our services the challenges will vary, however with a strong Board, dedicated staff and volunteers we are well prepared for what awaits us in 2007 – 2008.

South Australia

During the past year while the Association was able to maintain services at existing levels and in some cases provide new/additional services, its income streams did not generate sufficient income to cover expenditure. The Association suffered a debilitating operational loss of \$59K that seriously depleted reserves.



South Australia together with Queensland, remain the only mainland State MND Associations not funded by their respective State Government. Although we have met with the Office for Disability and Client Services on numerous occasions to discuss funding support, our applications so far have been declined. Per capita, disability funding in South Australia remains the lowest in the country.



Marjorie Coats and Tia Schubert at their 2007 Awareness Week stall in the Barossa.

The focus of the Association is to provide services and support to clients and their families. It is most gratifying to report the Association enjoys a highly regarded reputation in the healthcare sector together with the appreciation of clients and families. Our dedicated Client Services staff can take well deserved credit for this. In addition to providing direct services to clients, the Association acts as a facilitator of services by arranging support/equipment from Government agencies and palliative care services. To achieve improved outcomes, significant effort has been made during the year to establish closer working relationships.

As a result of the very successful speech pathology project conducted in conjunction with the Repatriation General Hospital, the Hospital provided funding to establish a specific MND Swallowing Disorders Clinic.

The Association acknowledges the support provided by the Hospital.

The Committee of Management finalised a Strategic Plan to develop the association over the next three years. The Plan contains four key objectives and which there are a number of strategies with set timelines for completion. The success of a number of strategies is very much contingent upon the Association achieving the required levels income to ensure the strategies can be implemented

Tasmania

MND Tasmania has had a busy year of change and fundraising in 2006-07. Our most exciting change has been the successful initiation of a new 1800 number supported by MND Victoria. This has provided the association with a telephone support service that includes dissemination of key information. Our newly created volunteer care advisor liaises regularly with the MND Victoria office should a referral be made from the telephone support service.

During 2006-07 the association has continued to receive kind donations from organisations and individuals enabling us to purchase speech assistance devices for our equipment pool. These devices are high cost items that are generally unavailable through government equipment schemes.

A successful awareness week campaign was held across the state. MND merchandise boxes were again placed in a number of pharmacies and other retail outlets in the Launceston area raising hard earned funds for the association. In the north-west and south of the state volunteers pounded the pavement during awareness week to raise funds. A number of radio interviews were conducted also discussing MND and how it affects those with the disease.

MND Tasmania is proud to announce that it is one of seven organisations that form the Neuro-Muscular Alliance of Tasmania (NMAT). In August 2007 the NMAT held a successful fundraising art auction in Richmond raising just under



\$10,000. NMAT will be a strong lobby organisation representing the common needs of the seven member organisations.

Future Directions

Throughout 2006 the association is hoping to form an alliance between (Multiple Sclerosis) MS Tasmania and Parkinson's Tasmania. It is hoped this alliance will seek to identify the synergies between the organisations leading to an agreed sharing of resources where possible.

In late November 2007 MND Tasmania is conducting a strategic planning day to investigate the future directions of the organisation in meeting the needs of those living with MND in Tasmania.

MND Tasmania has been working on developing a new more user friendly website for members and those with and interest in our organisation. It is hoped that this will be complete prior to Christmas 2007.

Victoria

MND Victoria has continued to deliver high quality services to people living with MND to assist them to retain and maintain their independence and to live well while fighting MND.

During the year, support has been provided to 364 people living with MND, as well as their carers, family, friends and workmates. While the Association delivers four key services – information, equipment, case coordination/case management and volunteers – it works with over 600 other providers within the community to ensure that people living with MND are able to access the services they need to maintain their independence and address their unmet needs.

Some key outputs were:

- Volunteers - 15 new; 4820 hours of support to the office; 162 special event hours; five training sessions
- Information –1298 requests met; 25 community awareness sessions conducted; 1300 newsletters every two months

- Regional Advisors – 140 new clients; 5,410 hours of support provided; 747 face to face visits with clients and families; 82 meetings to “influence” outcomes
- “Living Well” and “Living On” presentations; 16 telelinks with 74 participants
- Equipment – 744 loans; \$194,500 spent on new equipment; \$62,000 spent on deliveries and repairs
- Income - Fundraising (39%); Government (23%); Donations/Bequests (23%)
- Expenditure – Services (71%); Fundraising (12%); Research (6%); Administration (11%)

The key outcome was to support 364 people with MND, their families and friends to live well while fighting MND.

The introduction of the Disability Act 2006 is a significant step forward to people with disabilities in Victoria. This Act does not include any restriction on people over the age of 64 receiving services funded under the Act. We will need to see this actually happen. There was significant support by members for the MNDA call to action regarding the Commonwealth State Territory Disability Agreement



Living Well - Staff and Participants

MND Week is a focus for people with MND, their carers and families, and former carers. The “Service of Hope and Remembrance”, “Ask the Experts” session and Blue Cornflower Day were well supported. The Association also held its first “MND – Our Community Responding” event, aimed at bringing together all of the



services being provided in a Region. Our aim is to develop common understanding of the services in a Region and to enhance their capacity to work together and support people with MND.

The “Walk to d’feet MND” continues its growth and success, with over 600 walkers raising over \$27,000 for research.

MND Victoria has established a strategic relationship with MND Tasmania and is providing information by telephone and newsletter to Tasmanian members. Support and information is provided to people who are newly diagnosed. Further discussions are in hand to enhance this relationship and support for people with MND in Tasmania.

MND Victoria looks forward to working with MND Australia and its members in the fight against MND.

Western Australia

Awareness Week activities – Support from many schools, businesses and the wider MND family meant many awareness and fundraising functions were held during MND Awareness Week in 2007. The launch of the week commenced with a packed out gala dinner at “Friends at the Hyatt” Restaurant in Perth which was well supported by the Board of MNDWA Inc., other members, supporters and VIP’s. The theme for the week was “Care, Research, Cure.” Entertainment was provided by Mr. Keith Potger of the Seekers fame and a great night out was enjoyed by all present. The inaugural Eleanor Mounsher medal was awarded to Marie Macdonald in recognition of her many years of service to the association. Murdoch Community Hospice held its annual Cornflower Blue Day function with its usual festivities which was a great success. Several schools supported the week with different functions and many of our volunteers manned stalls throughout the week in shopping centres. We had promotions at Sir Charles Gairdner Hospital and the Western Australian Trotting Association and the Fremantle Trotting Club also supported MND during the week. Our regional

contacts in Quairading, Albany, Geraldton, Broome, Lancelin and Dandaragan all contributed to a great awareness week. The media were also very supportive with interviews and press articles and many, together with our State politicians wore cornflowers during the week to promote MND to the wider community.

3rd National MND Conference – Western Australia hosted the national conference for the first time at The Esplanade Hotel in Fremantle.

160 delegates from across Australia and New Zealand were rewarded with an excellent array of presentations from experts in the care and research of people living with MND in Australia.



*3rd National MND Conference
Helen Sjardin Howard (President MNDA)
Jim Benson (CEO MNDA WA), Carol Birks
(MNDA)*

A tour of the Western Australian Institute for Medical Research was incorporated into the conference and was also a highlight for those who attended. The family support meeting the day prior to the conference was again a great success and well supported by support staff from associations across Australia.

Care Advisory Service – The growing demand for our services across the State has meant that our team of care advisers were very busy keeping up with the demands of supporting PLWMND. They provide an excellent care advisory service to all of our clients.



Equipment Library – Thanks to a breakthrough grant of \$165,000 from the Disability Services Commission PLWMND are being better serviced with new equipment from our loan library. The association has been able to purchase 7 new cough assist machines which are a welcome addition to supporting our clients' quality of life living with MND. We have also been able to replace many of our electric wheelchairs which had come to the end of their economic life. Thanks to an agreement with TADWA Inc. we are also better able to service our equipment at economical prices.

Global MND day – A function was held at the Anchorage Restaurant at Hillary's Marina for members and friends of MNDWA to commemorate Global MND day around the world.

National Volunteers Week – A thank you morning tea was held at Zamia café in King's Park to recognise and thank all of our dedicated volunteers for their support throughout the year.

Palliative Care Focus Group – This focus group has continued to foster understanding of the special needs of PLWMND in relation to palliative care. The group provides a forum for health and allied health professionals to network issues and suggest solutions for better care of PLWMND in W.A.

Stem cell debate – After much lobbying by many people associated with MND

throughout Australia, the Federal Parliament passed legislation to allow Somatic Cell Nuclear Transfer to proceed in Australia with many safeguards and sanctions in place. Hopefully all State Parliaments will pass enabling legislation to allow vital research to go ahead with the hope of finding a cure for MND and other related diseases.

Research – A draft report on “An Investigation into the Home support Needs of Adults Living with MND” and three other major neurological diseases has been released. MNDWA Inc. is involved with this vital research and hopes the final findings will be helpful in gaining more support from Government and other agencies in caring for people living with MND.

Neurosciences & Senses Clinical Network – An MND subcommittee of the Neurosciences Network has been formed and will report soon on its findings. The focus has been on the major issues of care and clinical pathways for people living with MND (PLWMND). The committee of eminent health and allied health service providers have been presented with a range of issues facing MND clients and hopefully their final report will lead to better outcomes for PLWMND



MND Research Institute of Australia

The vision to understand the causes, find effective treatments and discover cures that lead to an ultimate eradication of MND is the driving force that propels the MND Research Institute of Australia.

MNDRIA continues to establish a firm financial base so a steady flow of funds for research can be assured. With an ultimate aim of providing a minimum of \$1 million annually for MND research in Australia, it is necessary to have prudent financial planning and seek ways to attract more funds. As funds for research have grown, an Audit & Finance Committee has been established to support the Executive Committee.

Since the amendment of the MNDRIA constitution in 2005 to allow the Australian MND Associations to be members of the Institute, a closer relationship has been established. With the aim of contributing to a unified image for MND in Australia, MNDRIA has adopted the new logo used by the Associations. For the first time, the MNDRIA newsletter, *Advance*, has been sent out nationally through the Associations. Attendance at the Annual MND Conference in Perth in June and the associated MND Australia meetings provided an opportunity to meet with national delegates and generate a greater level of understanding of MND research funding in Australia. All funding for MNDRIA currently comes from the MND Associations and individual donors.

Significant contributions for research projects from MND NSW and MND VIC came with the request that a proportion of the funds be allocated to health care research projects. This initiative from the Associations resulted in health care applications being considered separately from the biomedical research projects and the inaugural MND Victoria Research Grant was awarded to Professor Kate White from the Faculty of Nursing and Midwifery at the University of Sydney. Funds were also allocated to support the Australian MND Registry over three years.

A major role of MNDRIA is provision of seed funding for the initial research that will allow researchers to achieve the results they need in order to attract major funding from other sources such as the National Health & Medical Research Council (NHMRC). In the past two years, three projects supported by MNDRIA have resulted in significant grants being awarded by the NHMRC: Dr Julie Atkin (Howard Florey Institute, University of Melbourne) \$514,500 for 2007-2009, Dr Peter Noakes (University of Queensland) \$513,000 for 2007 - 2009 and Assoc. Prof Roger Pamphlett (University of Sydney) received \$750,000 for 2006 – 2010.

The incredible generosity of an individual donor continues to sponsor two concurrent post doctoral research fellowships. Bill Gole Postdoctoral MND Research Fellowships are currently held by Dr Ian Blair and Dr Julia Morahan, both from the University of Sydney. Professor Nigel Laing at WAIMR is supported in his MND project by The Henry H Roth Charitable Foundation.

This year a partnership has been established with NHMRC and a PhD Scholarship in MND research will be jointly funded by MNDRIA and NHMRC. The increased exposure for MND through NHMRC will ensure a wider range of applicants. Meetings with the Australian Rotary Health Foundation and MS Research have also been helpful in finding new avenues for funding.

Thanks must go particularly to Paula Trigg for her untiring support as Honorary Secretary, to our Chairman, Dr Dominic Rowe for his dedication and passion, and to all members of the Research Committee who give their valued time to select grant recipients.

It is only through research and discovery of the mechanisms that produce MND, that therapies that slow and stop MND will be available.

Janet Nash, Executive Officer



International Alliance of ALS/MND Associations

Delegate's Report

The Yokohama meeting of the International Alliance, and the International Symposium on ALS/MND were great successes.

The Alliance attracted over 80 attendees, with a significant number from Japan, Taiwan and other Asian countries. 186 people attended the Allied Professionals Forum. Eighteen presentations describing new or different care and support initiatives were discussed, exposing the audience to initiatives from 7 countries.

The Annual Meeting of the Alliance was held in Yokohama, Japan, in November 2006. The Annual Meeting plays a key and enduring role in facilitating the exchange of information. 80 people attended the meeting representing 22 members. Presentations were made by 22 people representing 16 members on a wide range of topics, including:

- The year in review highlighting activities in seven countries
- Detailed presentations about services for people living with ALS/MND in Belgium and Turkey
- Health Care and end of life decision making in Japan
- Patient's rights policy, including the process of informing and decision making in Japan
- Terminology and end of life decision-making
- Alliance Support Grant and outcomes achieved
- Partnership Program
- Standards of Care
- Investing in research

A summary of the meeting was included on the Alliance website.

Following on from the Yokohama meeting, the Board of Directors has met to plan the year, and begin preparation for the Annual Meeting in Toronto.

Two key documents will be presented:

- The Cameron/Fleeson document on patient's rights will be finalised and represented to members for consideration, deliberation and decision. This comprehensive document highlights the key issues the majority of the Alliance believes should be available to every person diagnosed with ALS/MND. They are highlighted in the attached Update 18.
- The Holmes/Matland document reviewing the Baseline of Services and providing some underpinning standards will be presented for adoption. This was reported in Update 18

Both of these documents will present challenges for MND associations in Australia. They will affirm positions we have already adopted, or have protected in legislation, particularly with respect to patient's rights. The Baseline document and its associated standards will sit well with work being undertaken by MNDA, and will put pressure on state associations to enhance service delivery and service options. For some, these standards will affirm their current practices, for others they will create a challenge. This has been recognised as an international issue, with many countries looking to use the standards as tools to improve their response to ALS/MND.

The balance of the meeting will follow a usual pattern, with individual countries reporting on their initiatives and successes, new members telling of their country and organisation, and an opportunity to identify the future direction of the Alliance through either a rapid fire strategic planning session or a brain storm (like last year).

Denise Figlewicz, Director of Research ALS Canada will be presenting an update on research for Alliance Members. The Alliance and ALS Canada will host Ask the Experts, and an interesting panel of experts is being recruited.



Alliance Support Grant

The Alliance has called for submissions for assistance from the Alliance Support Grant, and a number of grants have been awarded to either travel to another Association, attend the Alliance Meeting or help a fledgling or emerging Association.

Following negotiations between the Alliance and a significant donor, the Alliance has established the Sepulveda Grant. This has been funded at \$US5,000 per year and will be used to fund travel by allied health professionals to other countries to undertake education and skills transfer in ALS/MND. There has been genuine recognition of the contribution by MND Australia to the Support grant. The Grant is now funded by a number of countries, and it has been encouraging that the number and quality of applications has been improving.

Alliance Resources Library

The resources Library continues to be a significant tool for sharing printed resources between members of the Alliance and for ensuring that people can access quality information from around the world. The key reason for having the Resources Library is to prevent reinventing the information wheel.

The Future

I believe it is essential that MND Australia be represented at every annual Alliance Meeting and Symposium. This view was supported by Helen Sjardin, Chairman, in her report on attending the Dublin meetings in 2005. I also believe that it is important that MNDA members make a commitment to have a representative attend the Alliance Meeting and Symposium.

Exposure to overseas experience is a significant element in affirming our existing practice and in identifying new opportunities for service delivery.

Rodney Harris

Alliance Delegate



The Annual Meeting of the Alliance Yokohama, Japan, November 2006



The Australian Motor Neurone Disease Registry

The Australian Motor Neurone Disease Registry is a clinical database that provides a means to facilitate the collection and analysis of MND patient data such as demographics, site of onset, diagnosis data, treatment type, changes in functional capacity, complications related to disease progression and the impact of new treatments and interventions for MND. The goals of the registry are to improve patient care through continuous evaluation of patient management and associated outcomes and to form significant scientific research collaborations with organisations and individuals to further the understanding of MND. The registry has been designed by a steering committee of neurologists and patient representatives from around Australia.

In 2007 sanofi aventis awarded AMNDR a further unrestricted educational grant of \$40,000 per annum for three years. The Motor Neurone Disease Research Institute of Australia (MNDRIA) also confirmed funding for three years to support AMNDR and to assist in maintaining the registry.

During the past year the provider for the data management service has changed from Quintiles to Infoxchange Australia. The web site has been redeveloped –

www.amndr.org and is constantly being updated.

As at February 2007 there were 564 patients registered with AMNDR and there are currently 47 participating clinical sites. MND Associations have reported a total of 959 people with MND registered as at 30 June 2007 and registrations of 461 during the year. There is speculation that excess workload delays enrolment, as does the fact that not all people with MND attend MND clinics. Registration continues to be a key issue.

Paul Talman has continued to extend his analysis of the data from the registry and enhance the implications of the MND phenotypes for progression and survival patterns. Matthew Kiernan is continuing his use of the Registry data for publication.

AMNDR is a valuable tool for research and is an organisation which requires ongoing participation by MND Australia and its members. MND Australia will continue to inform members about AMNDR and to encourage them to drive participation of their neurologist in registering people living with MND.

Carol Birks
MND Australia representative



Finance Report

The results for our first full year with a National Executive Director have ensured that we now are in a position to understand our financial requirements for the future. The results for 2006 / 2007 were as forecast and we have approximately \$34,000 in equity as at 30 June 2007.

During the year we were fortunate to be supported by all State Organisations to provide the necessary revenues required by the National Peak Body. Unfortunately it will be necessary to continue this arrangement as there is limited external funding available for administration of national organisations. The National Executive Director has advised that MND Australia has been awarded \$89,000 through the Department of Health and Ageing local palliative care grants to conduct a project in partnership with MND Queensland. Other opportunities for grants and funding are actively being sought.

MND NSW is to be commended for its provision of a donation of \$30,000 pa to MND Australia over the last three years. This has been very much appreciated. MND NSW is providing accommodation and accounting assistance at a nominal rate.

We have almost divested ourselves of merchandise and this has now become the responsibility of the State Associations. The only unusual expenditure item was the one-off final payment for the Secretariat carried over from 05/06 paid in July 2006.

The accounts have been audited by Charles Pitt & Associates and no matters of significance have been brought to our attention. A copy of the audited accounts is available on request*. We remain solvent based on the agreement by all State Associations to pay their agreed fees on a pre paid quarterly basis.

Bob Howe
Treasurer
2006 2007

* If you would like to receive a full copy of the audited Financial Statements, please contact Carol Birks, MND Australia

National Statistics
1 July 2006 to 30 June 2007

State Association	Total no. registered with MND as at 30/6/07	No. of people with MND registered 06/07	No. of deaths 06/07	No. of active volunteers as at 30/6/07	No. of FTE Staff as at 30/6/07	No. of info packs distributed 06/07	No. of presentations delivered 06/07	Estimated total audience	No. of items of equipment provided 06/07	No. with MND receiving equipment from MNDA	Total income (% of income recurrent state government funding)
NSW/ACT	348	164	151	260	11.85	460	65	700	1048	254	\$1,599,193 (22%)
Queensland	148	52	73	59	2.1	280	10	279	151	73	\$463,457 (0%)
South Australia	90	47	45	50	2	80	49	540	40	30	\$173,806 (0%)
Tasmania	12	10	9	50	0	4	0	0	14	6	\$15,998 (0%)
Victoria	255	145	110	133	11.63	1298	78	1000	850	186	\$2,097,268 (19%)
Western Australia	118	53	33	45	3.5	92	27	609	84	63	\$329,752 (31%)
TOTAL	971	471	421	597	31.08	2214	229	3124	2187	612	\$4,679,474

Membership:

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