

Motor Neurone Disease Association of NSW

ANNUAL REVIEW 2006



Board Members

The Board Members of the Motor Neurone Disease Association of NSW Inc. at the date of this report are:

EXECUTIVE

President	Ralph Warren
Vice President	Phil Bower
Vice President	Paul Brock AM
Secretary	Bob Howe
Treasurer	Robert Templeman

MEMBERS

Roger Henshaw, Katrina Horman, Janice Scheinecker, Nick McLoughlin

Ralph Warren <i>President</i>		Phil Bower <i>Vice President</i>		Paul Brock AM <i>Vice President</i>	
	Bob Howe <i>Secretary</i>		Robert Templeman <i>Treasurer</i>		Roger Henshaw
Katrina Horman		Janice Scheinecker		Nick McLoughlin	



Motor Neurone Disease Association of NSW

Mission Statement

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.

Motor Neurone Disease (MND) is the name given to a group of progressive neuromuscular diseases in which the nerve cells (neurones) 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 for most people with MND 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, family and close friends, will live with it forever.

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

Never Give Up



Executive Report

2005/2006 can only be described as 'HUGE!' Dramatic changes have occurred in the world of the MND Association of NSW and the voice of MND nationally.

Our new office space (now 15 months old) has allowed: an increased equipment pool; access to people with MND their families and carers; an increase in the number of Regional Advisors; and given volunteers the opportunity to participate in the day to day operations of MNDA NSW. In 2005 we signed a 20 year lease giving us a permanent operation, centrally located and close to the city.



Staff in December 2005

The Department of Health has been a key player in these changes and we thank them. DoH has again contributed to the running of MNDA NSW - our ongoing non government organisation grant as well as a grant to progress Link and Learn. Funding from the Australian Government has allowed us to complete our Volunteer Visitor Pilot Project (VVPP). Thanks also to the Newcastle Hunter Support Group who has provided funding to keep the VVPP going.

The Department of Aging Disability Home Care (DADHC) has been integral to our advocacy efforts in broadening access to Attendant Care and High Needs Pool Packages to help people with MND access these services in a more timely manner. DADHC has also been extremely generous in providing a one off grant of \$500,000 for equipment.

Conferences this year have included the 16th International Symposium on ALS/MND in Dublin, Ireland where Regional Advisor Christina Jason had a poster accepted and Ruth Quaken presented a paper at the Allied Health Professional Forum.

In June 2006 MNDA NSW hosted the 2nd National MND Conference in Sydney. The Conference has allowed people from across Australia to meet, hear of new research and treatment and share innovative service delivery models.

Nationally the Motor Neurone Disease Association of Australia was given a huge boost by the employment of a National Executive Director. All state and territory MND Associations have now agreed on a national logo and to work cooperatively on common areas such as national literature and national fundraising.

MND Week was again a great success in terms of fundraising but, more importantly awareness raising. Unprecedented media across NSW and Australia created saturation of both electronic and print media. Across NSW volunteers turned out at railway stations, in schools and in their community to support people with MND.

Congratulations to Shiela Holmes and Robert Marr who were awarded life membership of MNDA NSW.

Congratulations to Board Member Paul Brock on his Order of Australia for service to public education, particularly as an advisor and author in the areas of strategic policy development, to maintaining high standards of teaching



CEO Graham Opie at launch of MND Week in April 2006

and professionalism, and to people with motor neurone disease.

During 2005 our Board decreased in size. Long standing Board Member Robert Marr stepped down. Robert has been a member of the Board and helped guide the organisation virtually from its inception. In recognition of his service he was awarded a Life Membership. Alex Malley and Gary Jacobson, two Board Members who helped guide and were integral to the move to the Gladesville premises and recent administrative changes also stepped down from the Board. In April 2006 we welcomed Association member and supporter Nick McLoughlin to the board.

Some staff changes have also occurred. We said farewell to Regional Advisor Mary Butcher. Janet Nash accepted a new role as Executive Officer of the Motor Neurone Disease Research Institute of Australia. We welcomed Fundraising Manager, Judy Ford; Accountant, David Radford; Regional Advisors Fern Linden and Jo Fowler; and Information Resources Coordinator, Penny Waterson.

Patron

Her Excellency Professor Marie Bashir AC
Governor of New South Wales

VICE PATRONS

Melinda Gainsford Taylor
Kevin Langdon OAM
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

Associate Professor Roger Pamphlett

Department of Pathology
University of Sydney

Dr Dominic Rowe

Department of Neurology
Royal North Shore Hospital

Family Support



From left, Gwenanne Taggart, Anne Paterson with daughters Skye Paterson and Tina MacKander, Margaret Hoare, and Diane Gordon at the past carers lunch held at the MNDA NSW Gladesville Centre on 20 February.

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 MND their families and carers and to promote research.

The Association has enjoyed its first full year at the premises at Gladesville which continues to offer opportunities to better meet the needs of people living with MND and their family members. The Gladesville support group, Information Evenings for People recently diagnosed their families and friends, Care for Carers workshops, Special Interest Group workshops, family support meetings, staff education days and past carers meetings have all been held on-site over the past 12 months.

Family support continues to work closely with the MND Clinics and MND services in NSW and ACT. Over the last 12 months there has been an increase in the number of local multidisciplinary teams meeting regularly with regional advisors and other involved health professionals to discuss the care and management of the people living with

MND. This helps to ensure a seamless service for people with MND and their carer and minimises duplication of service.

The 2005 International MND/ALS Symposium was held in Dublin last December and family support was very proud to be represented by Ruth Quaken. Ruth presented a poster by Christina Jason on the Volunteer Visitor Program at the Symposium and presented the paper on 'Respiratory Management – A view from the field at the Allied Health Day'.

This year the 2nd National Annual MND Conference was hosted by the NSW Association with a record number of 175 delegates from around Australia and New Zealand. The day before the Conference Family Support staff from Australia and New Zealand met to discuss the issues they face in addressing the needs of people living with MND.

Presenting and hosting 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 professionals with specific knowledge and experience of MND and are at the forefront in supporting people living with MND. Their objective is to ensure 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 ensuring 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 173 people who were newly diagnosed with MND became members of the Association. During this period the Association was advised of 128 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 2006, services were being provided to 346 people living with MND registered as members plus their families and carers in NSW and the ACT. This number has steadily increased from 295 at 30 June 2004 and 310 last year.

Regional Advisors:	2004/5	2005/6
New members	150	173
Number of deaths	126	128
Home/hospital/office		
Visits	309	387
MND Clinic contacts	250	313
Regional Advisors		
phone calls	1378	1182

As part of our commitment to rural and regional NSW a new Regional Advisor position was created in early 2006 to support people living with MND in Western NSW and New England. This new position has ensured that the number of people with MND allocated to each regional advisor remains equitable. Regional Advisor hours have increased by 24 hours per week to a total of 138 hours per week. Five Regional Advisors support people living outside the Sydney Metropolitan region and two of these are based regionally ensuring 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, telephone and email to ensure

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 people with MND and their families throughout their journey with MND. It is these people who deliver the essential services needed by people living with MND.

Advocacy continues to be a focus for the family support team in order to ensure that the needs of people living with MND are promoted 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 relevant 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 families and friends, the first contact with the Association is by phone. At this stage 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 02 8877 0999 or the freecall number 1800 777 175. All forms of information distribution and dissemination have increased during the year. Calls to and from the 'info line' have increased dramatically demonstrating the importance of this vital service.

Information:	2004/5	2005/6
"Info Line" calls	2118	3490
Information provision	632	902
Information sessions	50	92
Newsletters	4/1100	4/1400
Special Interest Group E-Bulletins	6/154	6/202

The provision of information and education to service providers is a high priority for Regional Advisors. During the year Family Support conducted 92 information/education sessions for service providers and community groups with an audience of 1333. A wide range of printed information was disseminated to health providers at these sessions and also posted to providers requesting information including:

- The Carers Kit
- Information Packs for Service Providers
- G P Booklets
- Recipe Books
- Special Interest Group Starter Packs

Membership of the three discipline specific special interest groups continues to grow and there are now 202 health professionals who receive the bi-monthly bulletins and invitations to annual workshops.

These groups are:

- Communication, Swallowing and Nutrition
- Psychosocial and Supportive Care
- Independent living

The website at www.mndnsw.asn.au is regularly reviewed and updated, continues to provide accessible information about MND and a means of communication with the Association for Internet users.

Equipment

The equipment service is essential for people living with MND to maintain independence and communication for as long as possible and enhance comfort and quality of life. This service encompasses sourcing and purchasing new equipment, liaison with therapists prescribing the equipment, loans, arranging equipment hire, seeking further funding, delivery and pick up, developing relationships with equipment hire companies, maintenance and cleaning. There is no charge for this service to people living with MND.

Equipment Pool	2004/5	2005/6
Equipment items	1147	1177
New items acquired	183	159
Items loaned	888	938



Equipment assistant Trevor Rakuraku with new wheelchairs to add to our diverse equipment pool



Support Groups

Support groups continue to grow and thrive throughout NSW they are the 'face' of the Association in local communities raising awareness of the disease and supporting people living with MND in their community. Volunteers coordinate the majority of the groups and their contribution is highly valued. Family support staff coordinates some groups and attends many of the others regularly to support them and recognise their valuable work.

During the year new support groups were established in Orange and at the MND Centre in Gladesville. There are now 14 active support groups throughout NSW and in ACT which meet monthly or bi-monthly.

In the last two and a half years, I have had several clients with motor neurone disease. In community occupational therapy, I discovered that there was limited expertise in regard to understanding the disease and its progression due to two main factors. One of these is that each of us may only see one to two of these clients a year and there is often staff turnover. The second is the fact that no two clients exhibit the same symptoms and progression. MND is one of the most stressful conditions for clients to deal with, and its rapid progression can leave most clinicians feeling somewhat helpless in relieving the client and family's grief. We rely on the MNDA NSW to provide ongoing support through and in between services, and know they will call therapists in again when required.

I have often sought the expertise and resources offered by MNDA NSW. I have not found any other support organisations as helpful and as well run as this association. My questions have always been answered in a timely fashion, and MNDA NSW was more than happy to run workshops for the local occupational therapists. These have been very informative. Other OTs have had joint home visits with MNDA NSW Regional Advisor Ruth Quaken, which were helpful for all concerned.

The most useful service offered by MNDA NSW is the equipment loan pool. Due to the fast progression of the disease and the severe lack of finances (that many have due to loss of income and medical expenses), buying equipment is out of the question. A lot of equipment may be required by an individual to avoid institutionalisation, and being able to borrow a wide range of equipment from the Association is very beneficial to all concerned. Local hospital equipment pools can be costly, have only limited specialised equipment, or may not exist at all.

My only concern is that due to the increase in need, the equipment in the last six months is now not always there to be borrowed. This equipment directly prevents institutionalisation, and is cost effective as it is reused over and over and having the correct equipment also reduces the potential for carer back injury. It is my hope that this service will be well funded as it is saving the community money on many levels.

Trish Farmer
Occupational Therapist
Lawson Community Health Centre





Volunteer Visitor Pilot Program



(L-R) Richard Dash and Sharyn Morris, recipients of the Volunteer Visitor Medal with MND NSW Patron and Governor of NSW Her Excellency Professor Marie Bashir AC

The MND Volunteer Visitor Pilot Program in the Central Coast, Newcastle and Hunter regions funded through the Australian Government Department of Health and Ageing 'Caring Communities Program' ended in March 2006. Volunteer Visitors continue to visit

people living with MND in those regions on a regular basis. The Volunteer Manual developed through this pilot was launched at the 2nd National Conference and will be an invaluable resource for educating future MND Volunteer Visitors and palliative care volunteers.

in August 2005 thereby extending the program to people living outside the Sydney metropolitan region.

Associate Professor Roger Pamphlett took blood samples from many willing DNA donors at DNA donor drives around the State.

These DNA Donor Drives are a unique opportunity for people with MND, their families, friends and interested health and community care providers to learn more about the latest MND research.

Carers of people living with MND have specific needs related to caring for their loved one and the support they need in their role as carer. The annual four week Care for Carers Program was held in Sydney in September 2005 and continues to demonstrate its relevance for carers to learn about MND and gain much needed mutual support.

Four meetings for past carers were held during the year at the MND Centre offering an opportunity for carers to share with others who understand their experiences of loss.

Round two of the Link and Learn project funded through the NSW Health Carers Grants commenced in March 2006. The two day residential program was held in Young and was aimed at carers living in the Riverina, ACT, South West and Central NSW. This was followed by six weekly tele-link sessions which were highly valued by the participants. This program will be held in the Newcastle/Hunter region in 2007.

This year marked the end of the MND NSW Business Plan 2003-2006. It was a very ambitious plan and we are very pleased that family support has had the support and resources to enable them to achieve the identified objectives.

Group Programs

People who have been recently diagnosed, their families and friends have specific information needs and information evenings have been held regularly at the MND Centre in Gladesville. These have been very well attended over the last 12 months demonstrating the relevance of providing information and an opportunity to meet others in a similar situation at this time.

The annual two day 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 the New England area





The Australian MND DNA Bank

The Australian MND DNA Bank has been able to substantially increase the number of samples collected over the past year. A major contribution to this achievement has been the many successful donor drives organised through the MNDA NSW.

We have collected blood samples, hair samples and questionnaire data in many country centres: Orange, Armidale, Port Kembla, Gosford and Coffs Harbour' and at the Gladesville Centre in Sydney. Many thanks to Regional Advisors, local volunteers and the many people with MND, their carers, family and friends who came to donate on these days. The participants appeared to be very interested in the presentations on our research, and enjoyed meeting each other and strengthening support networks.

Using this data, Ms Julia Morahan, a PhD student, has shown that regular exposure to herbicides or pesticides appears to increase the risk of MND.

As a result of the promotion of these donor drives, we were contacted by many people who were

geographically isolated, or unable to travel, but still wished to donate to our research. We have been able to communicate via mail or email, and organise local GPs or pathology services to send the samples and data to us. We now have links throughout the state to be able to have donors contribute from their homes.

We now have over 1,300 DNA samples and environmental data from people with MND and from controls. Using this data, Ms Julia Morahan, a PhD student, has shown that regular exposure

to herbicides or pesticides appears to increase the risk of MND. An analysis of 179 SALS patients and 179 controls showed that SALS was associated with herbicide/pesticide exposure. These findings, on an Australian population, support northern hemisphere studies on exposure to environmental toxins as a risk factor for MND.

Studies in progress using DNA samples from the bank that are looking at susceptibility to MND are examining:

- viral receptor genes
- the metallothionein family of heavy metal protection genes
- the glutathione synthetase toxin protecting gene
- epigenetic changes to genes
- tissue differences in the SOD1 gene
- introns in the SOD1 gene
- a whole genome approach to somatic mutations

We look forward to ongoing donor drives and being able to present results arising from the MND DNA bank.

Lorel Adams
(Manager, Australian MND DNA Bank)
Roger Pamphlett
(Neurologist)

Research

Ian Blair

Bill Gole Research Fellow

My research career has focussed on determining the genetic basis of a variety of neurological disorders including motor neuron disease (MND/ALS), hereditary sensory neuropathy (HSN), Charcot Marie Tooth disorder (CMT), the spinal cerebellar ataxias (SCA), Joubert syndrome, and bipolar disorder.



My early career was under the guidance of Prof Garth Nicholson at Concord Hospital, where I learnt the skills of my “trade” as well as experienced the trials and tribulations of genetic research. This was before the completion of the Human Genome Project, when identifying disease genes was a much slower process and a true test of patience. Thankfully, I was part of a dynamic group that was working to identify the gene responsible for a sensory neuron disease, HSN (hereditary sensory neuropathy). We were finally successful in mapping the location of the responsible gene, an exciting breakthrough. This quickly led to the development of effective prenatal diagnosis, a real and tangible benefit for the affected families. Around the same time, I was also researching the biological basis of CMT1A, a degenerative disorder of motor and sensory neurons. Amongst various studies to better understand the causes of CMT1A, I was fortunate enough to discover specific genetic “markers” that led to one of the first gene based diagnostic tests for this disease. The culmination of my work during this period was the completion of my PhD.

After this fortunate apprenticeship, I travelled the USA where I began my first foray into motor neuron disease research. Again, I was lucky enough to join a well respected group at the University of Washington who were searching for the gene that causes a juvenile form of MND (ALS type 4). After many frustrating false starts, we eventually managed to identify the responsible gene (Senataxin). This was exciting as it was one of the major breakthroughs that identified a shared genetic link among motor neuron disorders.

I returned to Australia in 2000 to take up a position in the Neurobiology Program at the Garvan Institute of Medical Research. My goal was to gain extensive experience in the genetic analysis of complex genetic diseases. At the Garvan, I focussed on identifying risk genes for bipolar disorder. Bipolar is a complex genetic disorder caused by a complex interplay between inherited genetic risk factors and environmental exposures. This work led to the successful identification of a risk gene for bipolar disorder, a significant breakthrough.

With support from the MNDRIA (Bill Gole Research Fellowship) I moved to the ANZAC Research Institute to establish a research group focussing on identifying genes involved in MND. This research is in direct association with Prof Garth Nicholson, who for over 10 years, has identified and recruited MND families for genetic studies. Our goal is to identify genes that cause the disease among MND families and investigate how these may confer a risk to the disease among sporadic MND cases. Little understanding of the biological basis of MND was known until a major breakthrough came from the finding that around 20% of families with familial MND showed mutations in the SOD1 gene. Investigation of SOD1 related MND has been the major source of our current understanding of disease biology. We hope to identify the unknown genes that cause the disease among the 80% of families for which no mutation has yet been found. It is increasingly being shown that sporadic MND can also be caused by some of the same genes that cause familial MND. Identification of genes causing familial MND will lead to a greater understanding of the biological basis of both familial and sporadic forms of the disease. This knowledge is a prerequisite to effective diagnosis, treatment and prevention of MND.



Fundraising and Volunteering

Launch of MND Week

MND Week 2006 was launched on Tuesday 28 March at the Waterview Convention Centre in the grounds of Bicentennial Park. On this very warm, sunny day members and friends gathered to meet with Her Excellency Professor Marie Bashir AC, Governor of NSW and to commemorate the start of another week of promoting awareness of MND.

Ralph Warren, President MND NSW welcomed those present and the Governor. Her Excellency congratulated the volunteers and staff of the Association for their work assisting people living with MND and spoke passionately and empathically about the impact of MND and of the need for MND research. Graham Opie, Chief Executive Officer MND NSW focused his address on 'Looking Forward for MND NSW'; people living with MND who sometimes 'slip through the system', for example people who speak languages other than English, and those of Aboriginal and Torres Strait Islander descent; and of the need for a National co-operative approach for MND. Janet Nash, Executive Officer MND Research Institute of Australia, provided an update on MND research in Australia.

Christina Jason, MND NSW Regional Advisor, spoke about the Volunteer Visitor Pilot Program and congratulated the first recipients of the MND NSW Volunteer Visitor medal - Ronnie Blennerhassett, Libby Blennerhassett, Lyn Champion, Richard Dash, Sharyn Morris, Brian Schrader, Dianne Toschack and Jenny Way. Both Richard and Sharyn were able to be at the presentation to

receive their medals from the Governor and Ralph Warren.

Mrs Sheila Holmes and Dr Robert Marr were honoured with life membership of MND NSW and received a special gift presented by the Governor. Sheila is a foundation member of Central Coast Support Group and has organised many local promotional events for the group, including street stalls; served as coordinator for the group and more recently, been involved in the Volunteer Visitor Program. Robert's involvement with MND NSW started prior to 1982 and he has been instrumental in the



Port Kembla Support Group at Launch of MND Week

growth and development of support services for people with MND in New South Wales.

Our guest speaker, Mark Rosenberg, Executive Director of Marketing and Communications for the Sydney Olympic Park Authority spoke about the future of the Park and of some of the newer attractions for visitors. Mr Rosenberg had been instrumental in helping secure our access to the lovely venue for the Launch.

MNDintheMedia



MND Week 2006 media coverage and publicity ensured that awareness about motor neurone disease was raised in New South Wales local communities and regional areas. Additionally, a cooperative approach by all state MND Associations ensured a united effort was directed towards national media. Thank you to all involved.

Newspapers

31 March, North Shore Times
5 April, Daily Liberal and Macquarie Advocate Dubbo
6 April, Daily Liberal and Macquarie Advocate Dubbo
8 April, Border Mail Albury Wodonga
11 April, Armidale Express
11 April, Central Western Daily Orange

Television

24 March, Channel 7 Better Homes and Gardens
30 March, Ch 10 Morning Show
3 April, Ch 7 Sunrise
7 April, NRL Footy Show
7 April, Sky News



Radio

28 March, 2UE Lunch time interview
 28 March, 2SM Morning show
 1 April, ABC 702 Interview with Kevin Langdon
 OAM, Vice Patron and Past President MNDA
 NSW
 4 April, 2SM Morning show with national
 syndication
 4 April, 2GB Alan Jones interview with Barry
 Harrison, Newcastle Support Group

Magazines

Better Homes and Gardens April issue and
 website
 Woman's Day magazine website



MND Banners

Monday 27 March to Sunday 9 April 2006
 Footbridge over Sydney Road east of Manly
 Road, Balgowlah
 Pacific Highway Bridge over Sydney-
 Newcastle Freeway (F3), Wahroonga
 Coleman Street over M4 Motorway, Mays Hill
 Pennant Street junction with Kissing Point
 Road over James Ruse Drive, North
 Parramatta
 Kent Road Bridge over M4 Motorway, Orchard
 Hills



City of Sydney MNDA Banners

Sunday 26 March through to Sunday 9 April
 Elizabeth, Park, Pitt, Bathurst and Phillip
 Streets.
 Wynyard Park, Belmore Park and outside the
 Town Hall.





Participants at the March of Faces



Beautiful Cornflower quilt made and donated by the Sloane Family of Molong in memory of Cecil (Toby) Sloane.



L to R: Audrey Dash (Coordinator of the Central Coast Support Group), Jo Folwer (Regional Advisor), Judy Ford (Fundraising Manager), Sheila Holmes (Life Member)

March of Faces

Once again the City of Sydney was awash with blue and white as the MND Week flags flapped in the autumn breeze. Driving down Elizabeth Street, George Street, Bathurst Street and across Martin Place one could not help but be impressed with the flush of colour and the strong awareness of motor neurone disease.

The March of Faces was a quieter affair than last year. We assembled in Hyde Park ready to present to passers-by the faces of loved ones who have been touched by MND. The strong winds made it difficult to keep the banners from falling over but the walk through the park still created a sense of commonality. The Rotary Club of Strathfield put on a very welcoming BBQ on this unusually cool day and we are most appreciative of their continuing support.

Once again we were blessed with the presence of our spiritual leaders to conduct a multi faith service. Father Peter Brock, Sheik Shami and a Rabbi gave moving addresses to those attending. We appreciate their time to join us on this special day.

Other Events for MND NSW

During the year many people have worked hard to raise money for the Association in various ways.

- City to Surf on 14 August attracted a number of people who ran to support MND including Helen Butcher supporting her sister, Liz Sandwith and family and Ken Rowles remembering his brother.
- Blue Cornflower Society Launch on 11 October in Sydney attended by members and friends of MNDA NSW.
- Open Garden at the home of Bob and Suzanne Ballinger in Pymble on Saturday 29 and Sunday 30 October.
- Display of Christmas Lights during December at the home of the Dunn/Oliver family in Cowra.



- MND Week 2 – 8 April was supported by many volunteers selling merchandise to family, friends and the general public.
- Fire Brigade Graduates collection for MND was held 16 February where members of the Class 7/2005 collected donations from the general public in the city.
- Tennis Day held by Darren and Vanessa Rowley in March at the Ku-Ring-Gai courts donated by the Council.
- Carlingford Seniors' two groups had a collection for the Association after a presentation by Judy Ford.
- 'Cocktails and Dreams' was the name of the event held at the Paddington Bowling Club in honour of the Pearce Family and raising funds for MND.
- A Shaved Head was a method used by Adil Nariman when he decided to raise money for MND in May.
- Students at the Star of the Sea in Wollogong held a fundraising event in memory of the husband of one of their teachers.
- Golf Day in May, organised by Matt Grant and held at Cronulla Private Golf Course.
- A Loud Shirt Golf Day organised by the Newcastle Support Group as part of MND week.
- Nola Turner, Sr. Coral Hedley and their friends held a wonderful day full of raffles and different speakers on a variety of subjects at the Inverell Art Gallery in June.
- A fundriaser was held by the National Council of Jewish Womens Association and the money presented to the Association in June.

- Many individual members of the Support Groups have sold merchandise throughout the year.

Volunteers

Founded by volunteers, the backbone of the MND Association is still its volunteers. Volunteers are an integral part of the MND family, they help to fulfil our commitment to people with MND, their families, friends and carers and they come to us from many avenues. Those who have been former carers of people with MND and those who have had a friend with MND all know how valuable their assistance can be. Their help comes in many forms; some help by assisting in the office, some serve as members of the Board, others help by raising funds. The common thread with our volunteers is their willingness to give their time to help the Association either with their special skills or to do just whatever needs to be done – they Never Give Up.

The ambience of our location at Gladesville inspires our volunteers to want to come and share the workload where they can enjoy the company of others and have room to go about their many and varied tasks. The ongoing help we receive from our dedicated team of volunteers is invaluable and greatly appreciated.



L to R: Regional Advisor Fern Linden with MNDA NSW volunteers Libby Gole, Joy Pogson and Marj Harrap at a luncheon at Parliament House in May to acknowledge the wonderful work done by volunteers



InMemoriam,Trusts,Foundations,Clubsand General Donations

We are most grateful for the continuing support which we receive from the community. Thank you.

Donations received in memory of:

Joseph Ackerman
Eric Adams
Leonard Akhurst
Annie
Julie Asher
Peter Asimakopoulos
Aunt Patty
Robin Balsdon
Ruth Barlow
Leslie (Roy) Baxter
Mary Beavan
Charles Bevk
Mr Brady
Thelma Brunner
Sandra Burnes
Georgette Buttie
Murray Carse
Ken Carver
Mary Cash
Kim Cheah
Joan Clemens
Clarence Cornish
Lucy Cross
Paul Cunningham
Paul D'Arcy
Patricia Joy Davey
Florence Dell
Terry Driscoll
Minnie Everett
Joyce (Corrie) Falkingham
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Hartley, Ms Claire	Joannou, Mr & Mrs George and Dora	Laureti, Mr & Mrs S	Marsh, Mrs Pam	MND Association of Tasmania Inc
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Harvey, Mr & Mrs R & L	John Smith Building & Design	Lawrance, Mr & Mrs P & C	Marshall, Mr Peter	Moffitt, Mr Brian Arthur
Harvey, Mr B	Johnson, Mr & Mrs Brian and Ann	Lawrance, Ms Leanne	Marshall, Mrs Suzy	Mogg, Mrs Margaret
Harvey, Mrs Gladys	Johnson, Mr Charles	le Bas de Plumetot, Ms Amanda	Martin, Mr & Mrs Barrie and Robyn	Moir, Mr & Mrs Brian and Carolyn
Harvey, Mrs Jan	Johnson, Mr Norman	Lean, Mr & Mrs Jim and Elaine		Monkhouse, Mrs Irene
Haslam, Ms Elizabeth	Jones, Fay, Col, Michael and Glenn	Leclerc, Mrs M		Monteith, Ms Yvonne
Hastie, Mrs Ona				
Haswell, Mr Kevin				
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Moore, Mr Ken
Morgan, Mr & Mrs Geoffrey & Betty
Morgan, Mr & Mrs Howard & Beverly
Morgan, Mr Michael
Moroney, Mr K
Morris, Mr David
Morris, Mrs Sharyn
Morrison, Mr Don
Morrison, Mr Ian
Morrow, Ms Corrina
Morse, Ms Joan
Mortimer, Mr & Mrs R & Z
Moses, Mr Jason
Mossman, Mrs Moya
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Mr & Mrs Catherine and Matt
Mr & Mrs Charles & Melissa
Mr & Mrs Ecka & Glenda
Mr & Mrs John & Jean Cooper
Mr Pailas & Ms Venning
Mrs G Bosi and Family
Mrs R Gibson, Mrs H Lees, Mrs
W Taplin, Mrs N Thorn and Mrs J
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Ms Susan Lupica and Mr Roland
Sdiani
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Mula, Mrs Rosemary
Mulley, Mr & Mrs Graeme And Helen
Munday, Mrs Annette
Munro, Mrs Robin
Murray, Mr & Mrs John & Joan
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Muston, Ms Jenny
Myers, Mr & Mrs John and Barb
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Nakayama, Ayano
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Norris, Mr Graeme
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Nrma Insurance Australia Ltd
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O'Connor, Mr & Mrs Geoffrey &
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Oddie, Ms Nola

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Olby, Miss Susan
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O'Neill, Mr Graham
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Chapter No. 39
Order Of The Eastern Star
Wollongong Chapter No. 59
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Orel, Mrs Ann
Orr, Mr Cameron
Orr, Mr Derek
Orr, Mr Graham
Orr, Mrs Debi
Orr, Mrs Margaret
Orr, Mrs Olive
Orton, Mr & Mrs Margaret and Norm

Parmenter, Mrs Majella
Parr, Mrs Wendy
Parsons, Mrs Janet
Paterson, Mrs Anne
Paterson, Mrs Jean
Patrick, Mrs Elspeth
Payne, Mr & Mrs Alan & Thelma
Payne, Mrs
Payoe, Mr Chris
Pearce, Mr Hamish
Pearce, Mrs Helen
Pearson, Mrs Allison
Pecar, Mrs Patricia
Pena, Mr Luis
Pennfather, Mrs Jean
Pennings, Miss Jenny
Perera, Ms Maryann
Perkins, Mrs Jill
Perks, Mr Geoffrey
Pero & Ivo Polouineo

Pope, Mr & Mrs G & B
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Committee
Porter, Mr Garth
Porter, Ms Leslie
Portland Branch Country Women'S
Association Of Nsw
Portland Central School
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Potter, Mr Stewart
Potter, Mrs Kathleen
Potter, Mrs Lesley
Poulos, Mr Jim
Poulos, Mrs Nina
Powditch, Ms Elizabeth
Powell, Mrs Patricia
Powney, Ms Maryann
Pring, Ms Ellen
Prinsen, Ms Eve
Prior, Mr Kingsley

Ridd, Mrs Gladys
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Robertson, Mr & Mrs Mike & Janice
Robertson, Mr E
Robertson, Mrs Donna
Robinson, Mr & Mrs Phil and Sue
Robinson, Mr Dave
Robinson, Mrs June
Robinson, Ms Wendy
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Rockliff, Mrs Jann
Rodgers, Ms Julie
Rodoreda, Ms Louise
Rodrigues Holding Pty Ltd
Rodwell, Mr Ian
Rogers, Ms Val
Rogut, Mr Shawn
Rojo, Mrs Karla
Roland Clark & Associates
Rose, Mr Athol
Ross, Mr & Mrs E & L
Rourke, Mr & Mrs John and Eileen
Rowley, Mr & Mrs Darren & Vanessa
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Royal North Shore-Merchandise
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Rumsey, Mr Neville
Ruscio, Mr & Mrs S & M
Russell, Ms Suzanne
Ryan, Mr & Mrs Noel and Sandra
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Ryan, Mr & Mrs T & C
Ryan, Mr Barry
Ryan, Mr Matthew
Ryan, Mrs Fay
Ryan, Ms Louise
Saladine, Mrs Shirley
Sams, Miss Muriel
Samuels, The Hon. Gordon
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Santer, Mr & Mrs David & Eleanor
Saunders, Mrs Helen
Savva, Mr & Mrs Con & Dora
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Scenic Tours
Scheinecker, Mrs Janice
Schmeising, Mrs
Schneider, Mrs Margaret
Schouten, Mr Pieter
Schwertner, Mr & Mrs Lothar & Inge
Scipioni, Ms Nina
Scully, Mr & Mrs Laurie and Josie
Searle, Mrs Annette
Semple, Mrs Deborah
Sen, Mrs Archana Roma
Sergi, Mr F
Seven Hills Station
Severin, Mr Reginald
Sewell, Mrs Di
Seymour, Miss Carol
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Shattles, Mr & Mrs G & B
Shaw, Mr J P
Shearer, Miss Alison
Shearer, Mrs Patricia
Shiels, Mr & Mrs Gary and Vicki
Shrivell, Mrs C A
Sibbald, Ms Leanne
Siciliano, Mr & Mrs M & M
Siddall, Mr & Mrs Carl and Rhonda
Sidoti, Mr V
Simiana, Mrs Agnes
Simich, Mr Martin
Simon, Mrs Susan
Simpson, Jim
Simpson, Mr & Mrs David & Penny
Simpson, Mrs Val
Simpson, Ms Lorraine
Sinclair, Ms Linda
Singer, Mr & Mrs David and Marilyn

A year ago we were told my Auntie has Motor Neurone Disease. I didn't know what to think or even what it was, most kids my age have no idea. I felt helpless and wanted to do something.

I was in Newport one afternoon when I saw my friend who was wearing a blue wristband. I liked the look of it and bought one from the chemist, then I realised it was for MND and thought my cousin Emma and I could sell them at school to raise money and awareness of this little known disease.

We spoke at assembly and most of the kids were shocked to find out about MND and that at this time there is no cure. Emma and I were able to sell over 100 wristbands within a few days. We also bought the socks because they are really comfortable.

Hopefully our small effort will help research into MND so other families don't have to go through this.

Angie Lovett
Newport



Osborn, Mrs Beverley
Oswald, Mr Phillip
Owen, Mr Matthew
Owen, Mr Nev J
Owen, Mrs Doreen
Owen, Mrs Joan
Owens, Ms Davina
Oz Labels
Packer, Mrs Jenny
Padovan, Ms Belinda
Page, Meredith
Pailas, Mr & Mrs
Pakainiskis, Mrs C F
Pallis, Mr Bill
Pallis, Mr Bill
Pallis, Mr Cecil
Palmer, Leslie
Palmer, Ms Novah
Palmerone, Mr & Mrs Vera and
Laurie
Pamphlett, Dr Roger
Paol, Ms Robyn
Papadopoulos, Mrs Sofia
Pappas, Mr Peter
Paranomos, Mr Andrew
Parker, Mr Neville
Parkes High School
Parkes, Ms Vicki

Perry, Mr Chris
Petersen, Ms Natalie
Peterson, Mrs Kelly-Anne
Peterstiles Associates
Petterson, Janet
Pettiford, Mrs Irene
Pfafflin, Mr Robert
Pfennigworth, Mr & Mrs Ian And
Elizabeth
Philipp, Mr & Mrs Don And Joy
Phillips, Mr & Mrs S
Phillips, Mr K S
Phillips, Mrs Dorothy
Phillips, Ms Connie
Phillips, Ms Judi
Phillips, Ms Lynne
Pinna, Mrs G
Piper, Mrs Thelma
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Pitty, OAM, Mrs Doris
Plane, Mr & Mrs H J & E A
Platt, Mr & Mrs Michael And Pamela
Pogson, Mrs Joy
Pola, Mr & Mrs Ron and Shirley
Pollard, Ms Maryann
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Ponder, Mr & Mrs G & S
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Pursell, Mr & Mrs Robert and
Rosemarie
Qasabian, Mr & Mrs Vic & Chris
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Quist, Mrs Jennifer
Rainaldi, Ms Anna
Raisin, Mr Louis
Rajola, Miss Rosemary
Ramsden, Mr George
Rann, Ms Yazmin
Rantucci, Ms Maria
Recreational Aviation Australia
Redding, Mr John
Reed, Mr John
Rega, Miss Maria
Regal, Mrs Vi
Rego, Ms L S
Reid, Mr R
Rendalls, Mr Shane
Reymond, Mr & Mrs R F
Reymond, Ms Claire
Rice, Mr & Mrs Malcolm & Carolyn
Richard, Kristen and Travis

Singer, Mr Arnold
Single, Mrs K D
Singline, Mr Vernon
Skal International Sydney North
Skinner, Mr & Mrs Peter and Sue
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Slack, Mrs Betty
Sloane, Mrs Olive
Smallwood, Mrs Doreen
Smaniotto, Ms Iuana
Smirniotis, Mr & Mrs J & C
Smith & R M Morris, Mr M E
Smith, Dr. David
Smith, Mr & Mrs Gary & Maura
Smith, Mr & Mrs Tony and Prue
Smith, Mr Frank
Smith, Mr Geoff
Smith, Mr Gregory John
Smith, Mr J A
Smith, Mrs J
Smith, Mrs L
Smith, Mrs Maria
Smith, Mrs Marion
Smith, Ms Barbara
Smith, Ms Catriona
Smith, Ms Kim
Smith, Ms Sandra
Snow, Mr P J
Snow, Mrs E A
Southam, Mrs Judith
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Spitzer, Mr & Mrs Allan & Madeleine
Squadrito, Mr & Mrs J & M
Squires, Mrs Colleen
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St John Ambulance Australia
St Mary Star Of The Sea College
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Staff At Macquarie Bank
Stankowski, Ms Judith
Statis, Mrs Elizabeth
Stavra, Mr Antonios
Steele, Ms Bonnie
Stenning, Ms Felicity
Stevens, Dr. Robert
Stevens, Ms Catherine
Stevenson, Mr Norman
Stewart, Mr John
Stewart, Ms Shirley
Stirzaker, Mrs Clare
Stobo, Mrs Margaret
Stock, Mr & Mrs K H & S N
Stockland Bay Village
Stojkovic, Mrs Tereza
Stollwitzer, Mr & Mrs Andy and Elaine
Stuart, Ms Lindy
Stuart, Ms Verity
Sullivan, Mrs M
Summerell, Mr P
Sundar, Ms Bevika
Swain, Mrs N
Swansea High School
Sykes, Mrs Tuula
Symonds, Mrs Dorothy
Taggart, Mrs Janet
Taggart, Mrs Nancy
Taggart, Ms Gwenanne
Tait, Ms Maree
Tam, Ms Alice
Tarento, Mr & Mrs David And Fiona
Tatarelli, Mr & Mrs Giovanni & Luciana
Tatarelli, Mr & Mrs Pasquale
Tatarelli, Mr Nazzareno
Taylor, Mr & Mrs J & S
Taylor, Mr & Mrs Robert and

Beverley
Taylor, Mr Wayne
Taylor, Mrs Beverley
Taylor, Mrs L J
Taylor, Mrs Lorna
Taylor, Mrs Rosemary
Teasdale, Miss Julia
Tebbutt, Mrs Diedre
Telstra
Templeman, Mr Robert
Templeton, Mrs Deborah
Tester Porter Services
The Affleck Family
The Department Of Health
The Dowdall Family
The Ellison Family
The Espitalier-Noel Family

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Ticehurst, Mr Benjamin
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Tippett, Mr & Mrs Phil and Margaret
Tobias, Ms Tania
Todman, Mrs Lorraine
Tomasi, Miss Sandra
Toner, Ms Ronda
Tooher, Ms Elizabeth
Torrelli, Mr Frank
Torrelli, Mr R.E.
Town Hall
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Van Weije, Mr Len
Varley, Ms Jenny
Vennard, Ms Samone (Sam)
Venn-Brown, Mr Ian
Vincent, Mrs
Virginie, Mrs G
Vittoriano, Doriana and Dana Ciacca
Waddington, Mrs (Gwen) Florence
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Walker, Mr Glen
Walker, Mrs Lorraine
Walker, Mrs Margaret
Walker, Mrs Pamela
Walker, Mrs Rosemary
Walker, Ms Kristy
Wallace, Mr & Mrs Gordon and Vicky

White, Mr & Mrs George and Marilyn
White, Mr Norm
White, Mrs Joan C
White, The Hon, Justice M J
Whitford, Mrs Judy
Whitton, Miss G
Whitty, Mrs Joanne
Wiles, Mrs Lianna
Wilkinson, Mr Robert
Wilkinson, Ms Fay
Wilkinson, Ms Judith
Williams, Mr Grant
Williams, Mrs Christine
Williamson, Ms Anna
Williamson, Mr Grant
Williamson, Mrs Gwen
Williamson, Ms Coral
Willoughby Public School
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Wilson, Mr & Mrs Michael & Janelle
Wilson, Mr & Mrs Ron and Bev
Wilson, Mr John
Wilson, Mr Philip
Wilson, Mrs Margaret
Wineera, Mr & Mrs R
Wink, Mr & Mrs A & S
Winkler, Mr Eric
Wintle, Mrs Nancy
Wise, Mrs Judith H
Withers, Mr & Mrs R
Witte, Mr & Mrs Harry And Barbara
Witte, Mr David
Witt-Roney, Mrs Erica
Wong, Mrs I
Wood, Mr & Mrs Glen & Joyce
Wood, Mr J
Wood, Mr Robert
Wood, Mr S
Woodcock, Mr & Mrs George & Bev
Woods, Mr Rowley
Woodward, Ms Charlotte
Woolley, Mr Matthew
Woolley, Mrs Una
Worrall, Mrs Lesley
Wright, Mr & Mrs D R & T A
Wright, Mr & Mrs S & P
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Wyllie, Mrs Leone
Wyong Public School
Wyrallah Public School
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Xu, Ms Linda
Yeatman, Mr Fae
Yeomans, Mrs Bev
Yexley, Mr Roger
Yip, P
Young, Mr & Mrs Howard & Annemarie
Young, Mr Timothy
Young, Mrs Valma
Young, The Hon. Justice Peter
Yu, Mr & Mrs Vince & Norma
Zanella, Mrs C
Zavvos, Mr & Mrs
Ziedan, Ms Josephine



Early in 2006 Pauline Marcus joined the Association when she was diagnosed with MND. Until being forced to give up work she had been a highly successful business woman with an appetite to see the world.

Her passion for photography and her excellent creative skills meant that each of her many trips to the four corners of the world has resulted in some magnificent pictures.

She has an ability to make a photograph look like a view from a window. Animals come alive in her photographs and she has been able to capture them in their natural habitats – places most of us will never see.

Soon after making contact with her Regional Advisor, Jo Fowler, Pauline made a wonderful offer and gave us permission to use some of her photographs in our 2006 Christmas card selection. Playful polar bears and cheeky seals compliment some wonderful scenes of glaciers in the North Pole region. Although Pauline has lost the use of her hands and arms her amazing photography skills will continue to delight many of us. We are most grateful for her generosity.

The Golfin Family
The Grandchildren of Bianca Torrelli
The Irvine Family
The Morrison Family
The National Council Of Jewish
Women Of Australia
The Pick Family
The Rigney Family
The Schools Chapter
The Walker Family
The Waythe Family
Thearle, Mr Tim
Theoharous, Mr & Mrs D
Thomas, Mr & Mrs Peter & Mary
Thomas, Mrs Ann
Thomas, Mrs Patricia
Thomas, Rev. Warwick
Thompson, Miss Joanne
Thompson, Mr Philip
Thomsett, Ms Jan
Thomson Legal & Regulatory Ltd
Thomson, Mr Graeme
Thomson, Mrs J
Thomson, Ms Jo
Thorley, Mr Barrie
Thorpe, Mr & Mrs Trevor and Jo

Tuckwell, Mrs Jeanne
Tuesley, Mr William
Turnbull, Mr & Mrs John & Julie
Turner, Mr & Mrs Richard & Deborah
Turner, Mrs Nola
Turnock, Mr & Mrs Doug
Turvey, Ms Aileen
Twin City Hire Service
Twynham, Mr & Mrs Paul And Raewyn
Tyler, P
Tyson, Mr Dennis
Tzavellas, Mr & Mrs Con & Kay
Ullett, Mr & Mrs Richard & Shirley
Underhill, Mr & Mrs S
Unilever Foods
United Airlines
United Services Union
United Way Sydney
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Uther, Ms Hannah
UWS School of Law
Valden, Mr John
Vamos, Mr & Mrs
Van Cornewal, Mr Peter
Van Grootel, Mrs Hazel

Wallace, Mrs Angela
Walsh, Mrs P
Wane, Mrs Dorothy
Warden, Ms Amy
Warners Bay Uniting Church Aid
Warren, Mr Ralph
Waterhouse, Mr & Mrs John & Ruth
Watkins, Mr Michael
Watkins, Mrs Helen
Watson, Mr Grant
Watson, Mrs Audine
Watson, Mrs Gwen
Watson, Ms Christine
Webster, Mrs Helen
Wee, Mr Kenneth
Wes Russell Real Estate Pty Ltd
Westpac Community Involvement
Wetherill Park TAFE
Wheeler Garden Chinese Restaurant
Wheeler, Miss Michele
Whelan Project Co Pty Limited
Whitaker, Mrs Sue
Whitbread, Mr & Mrs Don And Barbara
White, Miss Linda
White, Mr & Mrs Eric And Shirlee



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Graham Opie
CEO



Carol Birks
Family
Support
Manager



Judy Ford
Fundraising
Manager



Anita Richter
Special
Projects
Coordinator



**Maree
Hibbert**
Equipment
Coordinator



Petra Sammut
Office
Coordinator



Ruth Quaken
Regional
Advisor &
Infoline
Coordinator



**Penny
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Information &
Resources
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**Roslyn
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**Allison
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Regional
Advisor



Jo Fowler
Regional
Advisor



Caroline Gleig
Regional
Advisor



**Christina
Jason**
Regional
Advisor



Mary Butcher
Regional
Advisor



Fern Linden
Regional
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**Trevor
Rakuraku**
Equipment
Assistant



Laura King
Office
Assistant



**David
Radford**
Accounts





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