MND | MOTOR
NEURONE
DISEASE

Motor Neurone Disease Association of NSW

ANNUAL REPORT 2004

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 in most cases, so an active mind is trapped in an inactive body.

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

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

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

Average survival time after diagnosis is two to three years.

In New South Wales, at any point in time up to 400 people have been diagnosed as having MND, with approximately 120 new cases being diagnosed annually.

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

In Australia, ten people die each week from MND.

Motor Neurone Disease Association of NSW
Making a difference

Care for today
Hope for a future

Executive Report

Care for today

The majority of the expenditure of the MND Association goes directly to support people living with MND and their families and carers. This is provided through information, education, home visits, liaison with health service providers, equipment loans and much more.
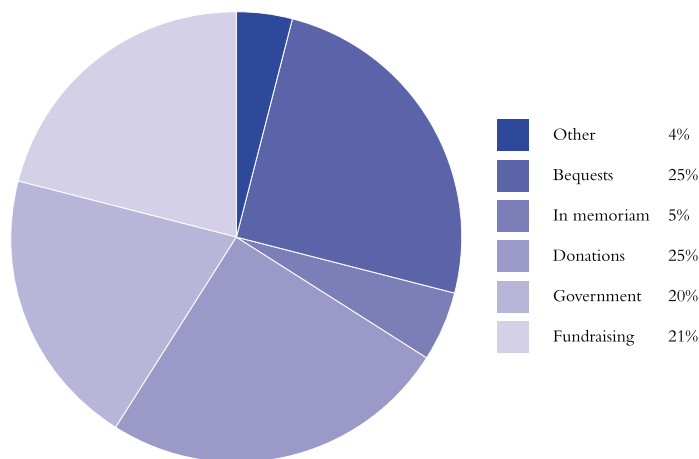
To ensure that people with MND have access to the best possible care, the MND Association of NSW is now providing financial support for three specialised MND clinics in Sydney and to the MND Service at Calvary Health Care, Sydney.

Hope for a future

This year, the MND Association of NSW has been able to provide greater support for MND research in Australia. Working closely with individual donors and the MND Research Institute of Australia, the increased allocation of funds for research will encourage investigations that will find the cause, better treatments and a cure for MND.

Revenue 2003 – 2004

Other	4%
Bequests	25%
In memoriam	5%
Donations	25%
Government	20%
Fundraising	21%

The Association depends on government for approximately 20% of its income but the rest comes from the enormous range of activities undertaken by individuals.

In 2003 – 2004 the Association received grants totalling $320,100 from NSW Health for equipment and services. A further $17,250 was received from the Australian Government Department of Health and Ageing for the Volunteer Visitor Pilot Program.

The remainder of the revenue for 2003 – 2004 came largely from the generosity of people in the community. The year saw a major boost to funds through a significant bequest and two highly successful events which collectively contributed $621,960 to support the work of the Association.

Bequests, give a greatly welcomed boost but are an unpredictable source of funds. It is not possible to know when this windfall will give the funds that can make such a difference to the level of services that can be provided. This year the Association has been fortunate to be the recipient of a very large bequest that has really made a difference.

Also, it is not possible to predict when major donors will choose to give their financial support, but whenever it happens it is always welcomed as a lifeline for the Association.

Ralph Warren — President

Robert Templeman — Treasurer

Bruce Fraser — Chief Executive Officer

There are many people, too numerous to name, who have worked to ensure another financially positive year which will enable more funds to be put into supporting people living with MND and research in the year ahead.

However, special mention must be made of the families of Ray Haddad and Alex Malley who are to be congratulated and thanked for the fantastic results of the fundraising events that they each held in support of the Association

Race for a Cure was an initiative of Scott Gale and his family in 2003 –2004, which is hoped to be repeated as an annual event to support research into MND.

Expenditure 2003 – 2004

MND Clinics 5%

Research 18%

Administration 16%

Fundraising 12%

Family Support & Information 49%

In 2003 – 2004, 49% of the Association's expenditure went to Family Support, including equipment and information provision. The main focus during 2003 – 2004, and indeed the focus into the next year, was and will be the provision of care and support services for people living with MND, their families and carers.

Additional hours were approved for Family Support facilitating more attention being given to those in greatest need and those in more remote areas of the State. This initiative also enables the office Info Line to be more efficiently and effectively managed, providing easier access to the information and support services. The Manager Family Support is now more available to actively assist and support the Regional Advisors in their local areas through accompanying them to in-service education sessions, support group meetings and home visits.

A further 5% of expenditure was allocated to patient care through support of specialised MND clinics in Sydney.
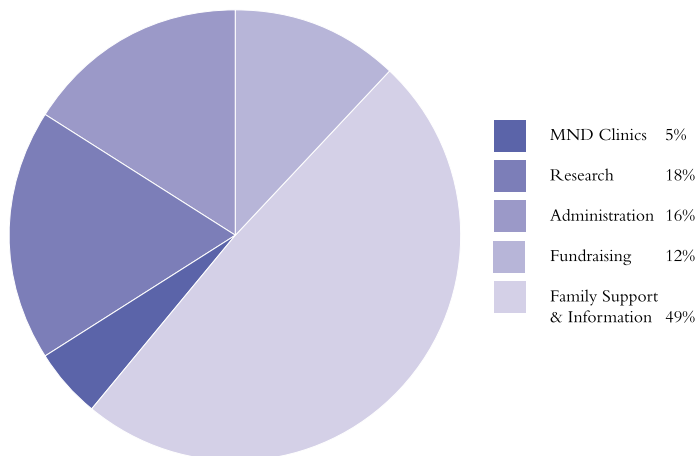
Support for research saw a boost to 18% of total expenditure in 2003 – 2004, up from 7% in the previous year. This increase was not only due to one very generous research donation, but also due to a decision of the Board to provide greater support for research.

Costs of administration remain at a low rate of 16% of outgoings, and fundraising 12%.

Condolences are extended to all those who have lost loved ones to MND. The Association remains committed to its mission of providing the best possible support for people living with MND, their families and carers, to advance research and to raise awareness.

The work of the Association would not be possible without the support of its volunteers, support groups, individual supporters, staff, Board members and many others. Thank you to all who contributed in the past year to the Association's vision of *Care for today* and *Hope for a future*.

Board Members

Board Members submit the financial statements of
MOTOR NEURONE DISEASE ASSOCIATION of NSW INC
for the financial year ended 30th June 2004.

The names of Board members at the date
of this report are:

EXECUTIVE
Ralph Warren   President
Dr Robert Marr   Vice President
Phil Bower   Vice President
Robert Templeman   Treasurer
Suzanne Ballinger   Secretary

MEMBERS
Dr Paul Brock   Roger Henshaw
Katrina Horman   Robert Howe
Gary Jacobson   Janice Scheinecker

PRESIDENT
Ralph Warren

VICE -
PRESIDENT
Phil Bower

VICE-
PRESIDENT
Dr Robert Marr

TREASURER
Robert Templeman

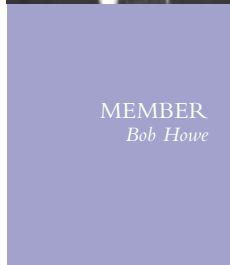SECRETARY
Suzanne Ballinger

MEMBER
Dr Paul Brock

MEMBER
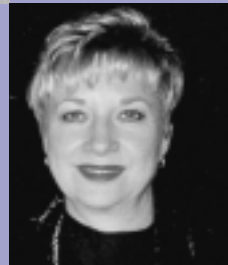Roger Henshaw

MEMBER
Katrina Horman

MEMBER
Bob Howe

MEMBER
Gary Jacobson

MEMBER
Janice Scheinecker

Board's Report

PRINCIPAL ACTIVITIES
The principal activities of the Association during the financial year were support and assistance to people with MND, their carers and their families.

SIGNIFICANT CHANGES
No significant changes in the nature of these activities occurred during the year.

OPERATING RESULTS
The net surplus of operating and non-operating activities for the year was $317,405.
Signed in accordance with a resolution of the Members of the Board.

Ralph Warren
President

Robert Templeman
Treasurer
Dated this 21st day of October 2004.

MOTOR NEURONE DISEASE ASSOCIATION of NSW INCORPORATED STATEMENT BY MEMBERS OF THE BOARD

The Board has determined that the Association is not a reporting entity.

The Board has determined that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the accounts.

In the opinion of the Board, the financial statements as set out on pages 6 to 9:

1. Present fairly the financial position of MOTOR NEURONE DISEASE ASSOCIATION of NSW Inc. as at 30th June 2004, and the results of the Association for the year ended on that date.

2. At the date of this statement, there are reasonable grounds to believe that MOTOR NEURONE DISEASE ASSOCIATION of NSW Inc., will be able to pay its debts as and when they fall due.

This statement is made in accordance with a Resolution of the Board and is signed for and on behalf of the Board by:

Ralph Warren
President

Robert Templeman
Treasurer
Dated this 21st day of October 2004.

Auditor's Report

INDEPENDENT AUDIT REPORT TO THE MEMBERS OF MOTOR NEURONE DISEASE ASSOCIATION of NSW INCORPORATED

SCOPE

We have audited the financial statements, being a special purpose financial report comprising of the Statement by Members of the Committee, Statement of Financial Performance, Statement of Financial Position and Notes to and forming part of the Financial Report of MOTOR NEURONE DISEASE ASSOCIATION of NSW Inc. for the year ended 30 June 2004.

The Committee is responsible for the financial report and have determined that the accounting policies used are appropriate to meet the needs of the members. We have conducted an independent audit of this financial report in order to express an opinion on it to the members. No opinion is expressed as to whether the accounting policies used and described in Note 1, are appropriate to the needs of the members.

The financial report has been prepared for the purpose of fulfilling the requirements of the Associations Incorporation Act of N.S.W. We disclaim any assumption of responsibility for any reliance on this report or on the financial report to which it relates to any person other than to the members, or for any purpose other than that for which it was prepared.

Our audit has been conducted in accordance with Australian Auditing Standards. Our procedures included examination, on a test basis, of evidence supporting the amounts and other disclosures in the financial report and the evaluation of significant accounting estimates. These procedures have been undertaken to form an opinion whether, in all material respect, the financial report is presented fairly in accordance with the accounting policies described in Note 1 so as to present a view which is consistent with our understanding of the Association's financial report, and performance as represented by the results of its operations and its cash flows. These policies do not require the application of all Accounting Standards and other mandatory professional reporting requirements in Australia.

The audit opinion expressed in this report has been formed on the above basis.

AUDIT OPINION
In our opinion, the financial report of MOTOR NEURONE DISEASE ASSOCIATION of NSW INC. presents a true and fair view of the financial position of MOTOR NEURONE DISEASE ASSOCIATION of NSW INC. as at 30 June 2004, and the results of its operations and its cash flows for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements.

CM PITT & CO
Charles M Pitt
Units 6 & 7, 2 Philip Street
STRATHFIELD NSW 2135
Dated this 21st day of October 2004.

Statement of Financial Performance
for the year ended 30 June 2004

			2004		2003
REVENUE					
Bequest			418,966		67,817
Donations –	Equipment		128,816		96,732
Donations –	General		191,098		308,705
Donations –	in Memorium		87,414		62,399
Donations –	Research		119,835		48,380
Grant –	State Government		320,100		311,067
Grant–	Volunteer Visitor Program		17,250		19,250
Income –	Conference		5,555		–
Income –	Other		5,264		7,215
Income –	Expo		564		–
Income –	MND Clinic		2,912		–
Interest received			39,079		33,557
Raffles			536		7,493
Subscriptions –	Membership		8,428		5,302
Fundraising					
MND Week –	Donations	28,807		52,190	
	Merchandise	78,167		63,682	
	less: expenses & cost of sales	– 2,081	104,893	– 31,444	84,428
Christmas Appeal			–		6,690
Cornflower Blue Ball –	Revenue	3,317		149,502	
	less: expenses	– 13,679	– 10,362	– 54,989	94,513
Donations –	Clubs		16,050		13,850
Employee Giving Partnership			323		–
Friends of MNDA			4,909		4,488
Parliament House Dinner			102,472		–
The Blue Ball			100,522		–
Women at War			– 1,273		–
Special Event: Golf Day –	Revenue			99,205	
	less: Expenses			– 63,750	35,455
Special Event: Race Day			35,850		–
Sales –	Merchandise	25,614		37,178	–
	Less cost of sales	– 30,704	–5,090	– 18,358	18,820
Total Revenue			**1,649,111**		**1,226,161**

	2004	2003
EXPENSES		
Care Support Expenses		
Advertising	736	3,082
Conference Attend-Local/Overseas	2,801	11,838
Equipment-Assistive Devices	38,518	44,609
Equipment-Depreciation	73,152	71,268
Equipment written off	26,188	4,659
Equipment-R & M	10,323	11,188
Equipment - Rental	688	–
Equipment-Cartage	37,854	24,108
Grant-MND Clinic coordinator	75,000	25,000
Insurance	6,159	4,015
Electricity/Water	420	233
Literature,Printing,Stationery	6,742	14,133
MND Week-Annual Conference	5,327	3,386
MND Week-Official Launch	6,610	4,932
MND Week-Publicity	–	5,530
MV/Expenses-Family Support	17,488	15,991
Newsletter (Forum)	5,002	2,732
Office Equipment	805	1,054
Office Maintenance	–	1,367
Patient Care	770	608
Patient Care Meetings	2,520	3,246
Postage	3,227	5,185
Rent-Office/Shed	16,812	13,020
Subscriptions, Books, Journals	919	2,142
Telephone-Field Workers	11,766	11,088
Training-Field Workers	700	180
Travel & Accom-Field Workers	6,454	3,095
Salaries-Field Workers	269,034	232,467
Salary Sacrifice Cost-Field Workers	–	7,340
Superannuation-Field Workers	25,320	22,212
W/Comp. Ins-Field Workers	9,000	8,254
Volunteer Expenses	30	80
Provision for Holiday Pay	17,382	–
Provision for Long Service Leave	–	5,568
Total Care Support Expenses	**677,747**	**563,610**
Care for Carers		
Care for Carers	466	7,799
Total Care for Carers	**466**	**7,799**
Volunteer Visitor Program		
Salaries	14,464	1,267
Postage	122	–
Printing & Stationery	581	–
Travel	4,357	–
Volunteer Training	2,318	–
Total Volunteer Visitor Program	**21,842**	**1,267**
Administration		
Annual Report	5,018	5,695
Annual Return	74	72
Audit fees	4,000	2,750
Bank Charges	5,311	7,010
Board Expenses	1,647	352
Insurance-Directors & Officers	–	759
M/V & Telephone-KL	1,158	4,090
MNDAA Fee/Meeting Expenses	7,494	4,096
Books, Manuals, Journals	181	55
Conference-Travel & Acc.-local	635	444
Computer–Software	2,820	–
Courier-admin.	4,677	185
Depreciation-Admin.	16,835	7,464
Insurance-Public Liability & General	5,500	1,154

	2004	2003
M/V Expenses	292	4,237
M/V-Fuel	2,022	775
M/V-Registration & Ins.	1,498	1,425
Office Expenses	2,066	934
Office Equipment	5,151	734
Office Repairs & Maintenance	922	1,730
Postage	2,417	1,106
Printing & Stationery	3,137	2,667
Rent	3,289	2,456
Subscriptions	1,856	580
Telephone	3,322	2,160
Salaries & Wages	108,736	72,576
Salary Sacrifice Cost- Admin.	10,000	21,972
Superannuation-Admin	13,314	33,833
Workers Comp.Insurance	1,500	1,893
Staff Recruitment Avert.	–	2,610
Provision for Holiday Pay	9,860	8,500
Provision- Long Service Leave	661	6,905
Volunteer Expenses	250	295
Total Administrative Expenses	**225,643**	**201,514**
Information & Research		
Conference/ Travel Accommodation	1,627	–
Journals/ Subscriptions	634	–
Office Equipment	364	–
Postage	1,412	–
Printing / Stationery	2,559	–
Telephone	1,692	–
Salary	19,492	–
Salary Sacrifice	8,040	–
Superannuation	2,523	–
Workers Comp Insurance	1,741	–
Provision for Holiday Pay	1,389	–
Research Reserve	119,835	71,093
MNDRIA Research Scholarship	75,000	–
Research Donations	48,380	–
International Symposium	–	3,413
CAMRA Support	–	1,007
Total Info & Research Expenses	**284,688**	**75,513**
Fundraising		
Administrative Expenses	133	1,355
Advertising / Display	24,853	4,839
Conference etc.	343	145
Consulting Fee	15,188	–
MND Week	–	3,029
Motor Vehicle Exps-Fundraiser	1,884	2,488
Postage	3,174	1,828
Printing/Stationery	5,747	3,591
Rent-Fundraising	2,481	2,682
Subscriptions	2,431	401
Telephone/Fax	2,690	1,904
Salaries & Wages	89,205	39,096
Superannuation	8,029	4,242
Provision for Holiday Pay	3,314	–
Insurance-general	1,810	1,013
Workers Com.Insurance	2,082	859
General Expenses/Courier	2,750	2,450
Volunteer Expenses	180	210
Wizquiz	26	7,503
Total Fundraising Expenses	**166,320**	**77,635**
Total Expenses	**1,376,706**	**927,338**
Net Surplus / (Deficit)	**317,405**	**298,823**

Statement of Financial Position
as at 30 June 2004 Balance Sheet

	Notes	2004	2003
CURRENT ASSETS			
Cash Assets	2	1,400,478	981,691
Inventories – at cost		22,619	22,619
Prepayments		13,500	–
Debtors		6,067	–
Total Current Assets		**1,442,664**	**1,004,310**
NON CURRENT ASSETS			
Fixed Assets	3	517,117	509,595
Total Non Current Assets		**517,117**	**509,595**
TOTAL ASSETS		**1,959,781**	**1,513,905**
CURRENT LIABILITIES			
Creditors		141,243	21,377
Provision for Employee Entitlements		43,078	34,473
TOTAL CURRENT LIABILITIES		**184,321**	**55,850**
NET ASSETS		**1,775,460**	**1,458,055**
EQUITY			
Retained Income	4	1,775,460	1,458,055
TOTAL EQUITY		**1,775,460**	**1,458,055**

		2004	2003
2 CASH ASSETS			
Cheque Account		162,731	182,772
Cash on Hand		550	300
Family Resource Centre	– Term deposit	532,006	506,870
	– Term deposit	160,892	153,496
	– Term deposit	400,000	–
Patient Care Equipment	– Term deposit	32,376	31,173
	– Term deposit	111,923	107,080
TOTAL CASH ASSETS		**1,400,478**	**981,691**

		2004	2003
3 FIXED ASSETS			
Patient Care Equipment	– at cost	774,252	738,639
Less: Provision for depreciation		(310,910)	(255,124)
		463,342	**483,515**
Furniture and Fittings – at cost		18,178	15,178
Less: Provision for depreciation		(12,750)	(12,157)
		5,428	**3,021**
Office Equipment – at cost		71,628	58,590
Less: Provision for depreciation		(46,971)	(35,531)
		24,657	**23,059**
Motor Vehicle at cost		28,492	–
Less; Provision for depreciation		(4,802)	–
		23,690	**–**
TOTAL FIXED ASSETS		**517,117**	**509,595**

		2004	2003
4 RETAINED INCOME			
Retained Income at beginning of year		1,458,055	1,159,232
Add:	Current Year Surplus	**317,405**	**298,823**
Retained Income at the end of the year		**1,775,460**	**1,458,055**

RELATED PARTIES

There were no Related Party transactions during the year.

1 SUMMARY OF SIGNIFICANT ACCOUNTING POLICY

(a) These financial statements are a special purpose financial report prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Act of NSW. The Committee has determined that the Association is not a reporting entity.

The statements have been prepared in accordance with the requirements of the Associations Incorporation Act of NSW and the following Australian Accounting Standards and other mandatory professional reporting requirements:
AAS 5 Materiality
AAS 6 Accounting Policies
AAS 8 Events Occurring After Reporting Date.

No other Australian Accounting Standards or other mandatory professional reporting requirements have been applied. The statements are prepared on an accrual basis. They are based on historic costs and do not take into account changing money values, or except where specifically stated, current valuations of non-current assets.

(b) Depreciation
Depreciation is calculated on the straight line basis so as to write off the net cost of each asset over its effective life.

(c) Employee Entitlements
(i) Annual Leave
Provision is made for the Association's liability for annual leave for employees at the reporting date.
Liabilities have not been discounted to their present values.

(ii) Long Service leave
A liability for long service leave is recognised, and is measured as the current value of expected payments.

(iii) Superannuation
Contributions are made by the Association to an employee superannuation fund and are charged as expenses when incurred. The Association has no legal obligation to provide benefits to employees on retirement.

(d) Income Tax
The Association is exempt from income tax.

(e) Maintenance, Repairs and Replacements.
Maintenance, repairs and minor renewals are charged as expenses when incurred.

(f) Comparatives
Where necessary, comparative information has been reclassified to achieve consistency in disclosure with current year amounts and other disclosures.

2003 - 2004

The start of the year saw the availability of Rilutek, the only drug that has been shown to have an effect on slowing the progression of MND, approved for prescription through the Pharmaceutical Benefits Scheme.

The close of the year saw the launch of the Australian MND Registry at the MNDA NSW annual conference for health and community care providers. The registry will attempt to gain information about every person diagnosed with MND in Australia with the goal of improving patient care.

MND Awareness

Through awareness of MND in the community, more people have an understanding of the plight of people affected by MND, and more funds are attracted from the community for making the difference that is needed for their support.

Much was achieved in creating added awareness of MND in 2003 –2004.

For the first time, MND banners were seen throughout the streets of the City of Sydney during MND Week.

Radio National's Margaret Throsby interviewed indefatigable campaigner and MNDA NSW Board member, Dr Paul Brock. This interview was broadcast nationally twice as it generated such a wide response. Dr Brock's story of living and working with MND has also been produced on DVD.

The ABC kept MND in the spotlight with a half-hour Health Report program on MND for Norman Swan produced by Aviva Ziegler.

Every extra bit of publicity helps, and many people throughout the State have contributed to increased awareness of MND in their communities.

While researchers race to find a cure for MND, the past year has seen great sadness with the Association receiving reports of 152 people lost to MND.

Although research is the way to provide hope for the future, the major focus of the Association must continue to be the promotion of the best possible care for people who are living with MND now.

MND Multidisciplinary Clinics

People diagnosed with MND today will live longer than those diagnosed with the disease only decades ago. The two known factors contributing to longer life expectancy are better care provided through multidisciplinary teams and medication (Rilutek) that can help to add months to life expectancy.

Dr Dominc Rowe, Neurologist, and Dr David Joffe, Respiratory Physician, together with a team of health professionals, set up the first specialised MND multidisciplinary clinic in NSW at Royal North Shore Hospital, St Leonards in 1999.

The MND Association of NSW has advocated for the development of MND specific models of care since 1997. In 2003 – 2004, the Association encouraged the establishment of MND clinics to cover other areas of Sydney. The Association now supports three state-of-the-art MND multidisciplinary clinics in the Sydney Metropolitan Area – at Royal North Shore, Prince of Wales and St Joseph's Hospitals and a unique MND Service at Calvary Health Care, Sydney.

Limited funding from MNDA NSW is allocated towards the salaries of a Nurse Coordinator at each clinic, without which the high quality of care provided would not be possible.

MND Clinic
Royal NorthShore Hospital,
St Leonards.
Patients at the clinic are seen by Neurologist,
Dr Dominic Rowe and Clinic Coordinator,
Sandra Erjavec and other members
of the multidisciplinary team.

MND Clinic
Prince of Wales Hospital, Randwick.
The multidisciplinary team is lead
by Neurologist, Dr Matthew Kiernan.

Prince of Wales MND Clinic Coordinator,
Margie Zoing, – with patients at the MND Clinic.
MNDA NSW contributes to funding for the
Prince of Wales MND Clinic Coordinator, who also assists
Palliative Care specialist, Dr Helen Herz (bottom right above)
with the special MND Service at Calvary Health Care, Sydney.

MND Clinic
St Joseph's Hospital, Auburn.
Dr Joseph Sandanam, Rehabilitation Specialist,
St Joseph's Hospital, and Dr Paul Clouston,
Neurologist Westmead Hospital, lead this
multidisciplinary MND team.

Funding for these special MND clinics is supported
by the MND Association of NSW.
MNDA NSW CEO, Bruce Fraser, congratulates
Dr Paul Clouston and Dr Joseph Sandanam
at the launch of the MND Clinic at St Joseph's Hospital.

2004 - 2005

Relocation of the Association

After years of searching for appropriate space, the Association will relocate to the former Gladesville Hospital site early in 2005.

The Association is grateful to the NSW Health Department for offering suitable accommodation for the office and equipment pool together at Gladesville, which will be a vast improvement upon our present situation.

When MNDA NSW moved from Bankstown to Concord Hospital in July 1995, space was only needed for Executive Officer, Hari Singh, part-time Care Coordinator, Janet Nash, and a band of volunteers lead by Association founder, Marjorie Harrap.

In 2004, MNDA NSW has a staff of 15 people and a band of volunteers (still lead by Marjorie Harrap) and the space available at Concord Hospital was outgrown years ago.

There have been many advantages to being co-located with Central Sydney Area Health and Concord Hospital. The Association acknowledges their support in provision of lodgings over the last nine years, but it is time to move on.

Website – mndnsw.asn.au

2004 paves the way ahead for the revised and revamped website for the Association.

The website provides
- **information about motor neurone disease**
- **information about the services and support provided by the Association**
- **links to other sites**
- **on-line membership**
- **on-line donations**
- **merchandise orders.**

Forum, the quarterly newsletter of the MND Association of NSW, is available on-line and back copies are also available, The site is updated regularly to give news of Support Group meetings and events.

While the website is a valuable source of information, one of its aims is to attract new members to the Association so they are not trying to navigate the maze of information on their own.

Our home for the future.

The complex of wonderful old stone buildings at Gladesville Hospital is shared by health services including Sydney Home Nursing, the Cochlear Implant Centre and the Schizophrenia Fellowship of NSW.

When renovations have been completed, it will be possible to accommodate all Sydney staff, equipment stores and volunteers under one roof. There will also be ample space for meetings on site and we look forward to sharing these premises with many visitors

Research

Research is a high priority in 2004 -2005. The MND Association works closely with the MND Research Institute of Australia to support world-class Australian research into understanding the causes of MND and finding an effective treatment and a cure. Without research there would be no hope for a future so it is essential that a proportion of the Association's resources be directed to research. In 2003 -2004, the Association forwarded $269,835 to the MND Research Institute of Australia for MND research projects during 2004 and 2005.

A major boost to funds available to support MND research in 2004-2005 comes from a very significant donation from an anonymous supporter to sponsor the inaugural Bill Gole MND Research Fellowships. Funded through the MND Research Institute of Australia, two postdoctoral research scientists will each be funded for two years in work that could engender a lifelong dedication to finding the answers that will make a difference for MND.

Many other generous people who dedicate the funds they raise for the MND Association of NSW to research, have contributed to the funding of the MND NSW Clinical Research Scholarship, commencing in January 2005. This scholarship will allow a young neurologist working in NSW to complete a PhD through a project involving the clinical care of people living with MND.

Smaller grants by the MND Research Institute provide start-up funds for projects that need a boost to attract funds from other sources. Eleven grants-in-aid are funded around Australia in 2004.

Making Connections with Parkinson's Disease, MS and MND was a 2004 initiative in which the three organisations worked together to showcase cooperative research. The enthusiasm of all the presenters in exploring **why** people are susceptible to these diseases, **how** the nerve cells are affected in the course of the disease, and **what can be done** for people living with Parkinson's Disease, Multiple Sclerosis and Motor Neurone Disease left all participants with a positive feeling that research will make a difference.

Research - the hope for a future.

Dr Roger Chung, Bill Gole MND Research Fellow, working on a project that may lead to understanding a cause of MND. Dr Chung works with the NeuroRepair Group, School of Medicine, University of Tasmania.

Will this be the work that will make a difference for MND?

Dr Valerie Hansen will take up her Bill Gole MND Research Fellowship at the University of Sydney early in 2005. Dr Hansen will work with Dr Roger Pamphlett on a project investigating enteroviral infection as a possible cause of MND.

Family Support Report - making a difference

Family support comprises of the manager, special projects/carer services coordinator, regional advisors, equipment officer, equipment assistant and an administration assistant. The primary objective of Family Support as identified in the revised Business Plan 2003-2006 is:

To provide and enhance equal access to family support and to promote best practice multidisciplinary care for all people in NSW living with MND and their families

This year 165 people newly diagnosed with MND from NSW and ACT registered with the MND Association of NSW to seek support. People living with MND join the Association to access relevant information, MND specific knowledge and experience, key services and peer support to enable them to live well with MND for as long as possible.

Regional Advisors

The Regional Advisor role is a diverse one aimed at supporting people living with MND their carer, family, friends and health and community care providers. This support is provided through ongoing contact, small group support, information, education, advocacy and referral. The Regional Advisors are people with specific knowledge and experience related to MND who have a commitment to providing professional and appropriate support.

At 30 June 2004, services were being provided to 295 people living with MND, their families and Carers in NSW and ACT. During 2003-2004, Regional Advisors provided support for 430 people living with MND plus their family, carers and friends.

During 2003/4 the Association was advised of 152 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. Regional Advisors contact carers following the death of their loved one and maintain support during the initial bereavement period if required.

The main thrust of the Regional Advisor role is to support people living with MND, their carer and families by providing ongoing regular contact, either face to face or by telephone. This communication *makes a difference* by giving people a regular and familiar point of contact and ensuring timely referral to the relevant health and community care providers. For people living in Rural and Regional NSW, face to face contact is maintained by annual field trips to the regions. In 2003/4 nine field trips were conducted making a difference for more people living with MND throughout NSW.

	2003/2004	2002/2003
New members	165	144
Home/hospital/office visits	363	337
MND Clinic visits	95	3
Phone calls to families	1,502	1,358

Facilitating links with others in a similar situation for people with MND and their carers and families through the support group network is an integral part of the Regional Advisor role. During 2003/4 three new support groups were established by Regional Advisors bringing the total number to 14 groups around the State.

Group programs have *made a difference* for people living with MND by connecting them with others in a similar situation, promoting peer support and the sharing of frustrations, triumphs and ideas. These meetings provide timely and relevant information and education enhancing their own ability to manage the disease and to enable them to live as well as possible with MND.

People attending group programs in 2003/4:

Information Evenings	25
Learn Now/Live Well Program	32
Care for Carers Program	25
Regional Members Meetings in Canberra	65
Research Update Meeting	40
Equipment Expo	60
Past Carers Meeting	10
TOTAL	**257**

Family Support team members demonstrate assistive aids at a Learn Now/ Live Well meeting.

Carol Birks -
Manager Family Support

The benefit of education and support for carers is well recognised and the Association has a range of information and programs specifically for carers. More recently the role of the Coordinator of Carer Services has been expanded to one of Special Projects and Carers Coordinator to enable Family Support to progress the objectives identified in the revised Business Plan 2003-2006 and to better meet the needs of people living with MND, their carers and their families.

Each Regional Advisor is responsible for providing a consultancy service, individual case advice and education sessions for providers in each region. Audiences include medical, nursing, allied health, Home Care, volunteers, aged care, palliative care, and nursing home staff. Each year the capacity of the Regional Advisors to provide this type of education has increased resulting in more in-service education sessions, a larger audience and a wider geographical reach.

During 2003/4 the Association held **57** in-service education sessions, a Rural and Regional Seminar in Canberra and the MND Annual Conference, which were attended by **1134** health and community care providers.

Annual Rural and Regional Seminars provide the opportunity for more in-depth education and information on MND care and management in areas that may have had a recent increase in the incidence of people living with MND. These seminars focus on the integrated care of people living with MND.

This years Conference for Health and Community Care Providers broke all records with 160 providers from NSW and some from ACT, Victoria, New Zealand, Tasmania and Queensland attending. For the first time, researchers, doctors, nurses, MND Clinic teams, allied health and MNDA Regional Advisors provided abstracts relating to the theme of the conference "Advances, Initiatives and Challenges". The program covered different aspects of MND care and management including advances in research, management initiatives and care challenges. The Conference was very well received and evaluated by all who attended. The response has prompted the Association to build on this increasing interest from professionals working with MND by co-hosting future Conferences with the Victorian MND Association.

The Annual Conference included a session to launch MND Special Interest Groups. Again family support was overwhelmed by the interest shown by the health professionals, 110 of whom have joined one of the three special interest groups formed. These groups will provide an opportunity for health and community care providers with similar interests to keep in touch, receive relevant up to date information and to meet on a regular basis.

Presenting at Conferences hosted by other organisations is another means of disseminating information regarding MND care and management to a wider audience. In 2003 a poster on the Carers Kit was presented at the National Palliative Care Conference in Adelaide.

Health and community care providers attending MND education in 2003/4:

In-service (Metropolitan)	575
In-service (Rural & Regional)	344
Regional Seminar	55
Annual Conference	160
TOTAL	**1,134**

Over the last few years Family Support has provided information, case advice and education to many health and community care providers throughout NSW and ACT. It is hoped that increased interest in MND and the increase in MND Clinics and Models of Care corresponds to an increased knowledge and makes a difference to the care and treatment that people living with MND receive.

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 Federal Government continues through recurrent funding and funding for special projects.

Involvement in a number of groups and peak bodies serves as an information sharing mechanism and provides opportunities for group lobbying on common issues. Links with Carers NSW and Carer Respite Centres have provided opportunities for highlighting the specific needs of MND carers and increased options to meet their needs.

Information

Family support makes a difference through collecting and providing information. The collection of information is vital to promote the needs of people living with MND and those working with them and to add value and depth to the knowledge of the family support team. The aim of family support is to provide quality, relevant information to people to empower them to make informed decisions about MND care and management.

For many people recently diagnosed with MND and their family 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 to obtain ongoing information.

The "info line" is available five days a week from 9am to 4.30pm when one of the Sydney based Regional Advisors covers the service. During 2003/4 there were **1741** calls to the "info line". These calls were predominantly from allied health professionals and nurses, carers, family members and people with MND. It is hoped that this service not only provides support directly

Family Support Report

to people living with MND and their family but also facilitates best practice care and support from health and community care providers assisting people living with MND in NSW and ACT.

Family support continues to identify, review and develop relevant and accessible information in a variety of formats in collaboration with the Information & Research Administrator. Information is provided to health and community care providers, residential care staff, general practitioners and neurologists to assist them to deliver quality care and support to people with MND in their community.

During the past year over **600** information packages were sent to members, carers, family members, general practitioners and health and community care providers. The newsletter *Forum* was distributed to over a **1,000** people quarterly. The Carers Kit continues to be a valuable resource for MND Carers and health and community care providers. The Internet website at www.mndnsw.asn.au, recently renewed, provides accessible information about MND and a means of communication with the Association for Internet users.

	2003/2004	2002/2003
Loan pool equipment items	1,124	1,000
New items acquired	173	160
Number of loans	865	71

Referrals from the appropriate Health Professional must be received before an item of equipment can be sent. This process ensures that the equipment borrowed is the most appropriate item for the individual. It also ensures that the person living with MND and their carer are given training in the correct use of the item and ongoing instruction in its use.

Developing links and partnerships with service providers, equipment suppliers, equipment rental services, delivery services and repairers throughout NSW is a vital part of the equipment staff roles and responsibilities. The quality and efficiency of the service ensures better value for each dollar invested in equipment from the funds received through donations, bequests, clubs, Government and fundraising.

Equipment

The most tangible way that family support *makes a difference* is through the provision of assistive aids and devices *as soon as the need arises, wherever possible.* Aids and equipment enable people living with MND to maintain their independence and communication for as long as possible and enhance their comfort and quality of life.

Equipment may be sourced through the Government run PADP scheme, local services and/or the MNDA NSW Equipment Service. Links with allied health and equipment providers ensures that the most appropriate equipment is available with the shortest waiting time.

Equipment borrowed from MNDA NSW is free of charge and once returned is rapidly reallocated Without this service members could expect to purchase equipment costing up to $40,000 during the course of the disease. The capacity of and the demands on the Equipment Service continue to grow. Running the service includes maintenance and repairs, delivery, wages, purchasing new items, rental of equipment items, insurance and depreciation of equipment.

Volunteers

Volunteers have been the backbone of the Association since its inception. The ability of Family Support to train and support volunteers to provide extra support to people living with MND and their carer, however, has been limited. Funding was approved through the Australian Government Department of Health and Ageing 'Caring Communities Program' to develop and implement an MND Volunteer Visitor Pilot Project in the Central Coast, Newcastle and Hunter regions in June 2003. This funding has increased the capacity of the Association to provide MND volunteer visitors for people living with MND in these regions. The project has also provided the opportunity to educate existing Palliative Care volunteers about the specific needs of people living with MND and their family.

Regional Advisors work in partnership with a number of volunteers involved in the support groups they attend. Support Groups are the face of the Association in the wider community. Most of the 14 groups meet regularly to support people living with MND and to raise funds and awareness in their community. Regional Advisors coordinate or attend seven of the groups and visit other groups in more remote areas in the course of their field trips. Other staff members visit groups throughout the year ensuring that links are maintained and enhanced between all facets of the Association and these valuable groups.

Northern Sydney Support Group meeting at the Thornleigh Community Health Centre. The group has bi-monthly meetings, alternating between general discussions and guest speakers.

Central Coast
Bi-monthly meetings at North Gosford.

Central West
Roving meetings different towns depending on location of MND members: Condobolin, Dunedoo, Forbes, Molong, Orange, Parkes, West Wyalong

Coffs Harbour
Bi-monthly meetings at the Neighbourhood Centre Earl Street, Coffs Harbour.

Illawarra
Monthly meetings at Port Kembla Rehab Hospital.

Newcastle and Hunter Region
Monthly meetings at Warners Bay.

New England
Support contact for people in the Tamworth area.

Northern Beaches, Sydney
Bi-monthly meetings at Mona Vale Hospital.

Northern Rivers
Bi-monthly meetings at Alstonville.

Northern Sydney (Hornsby)
Bi-monthly meetings at Thornleigh Community Health Centre.

Port Stephens & Great Lakes
Informal meetings at Raymond Terrace.

Riverina & South West Slopes
Bi-monthly luncheon meetings at The Commercial Club, Burwood Street, Wagga Wagga.

Southern Highlands/Monaro
Monthly meetings at Clare Holland House, Canberra.

Southern Sydney (Panania)
Bi-monthly meetings at Panania Uniting Church.

Western Sydney (Penrith)
Bi-monthly meetings at Kingswood Community Health Centre.

Bequests

Bequests

In 2003 - 2004, four bequests totalling $419,000 were received by the Association. The Association is extremely grateful for the consideration and generosity of these Estates. The financial support provided in this way comes 'out of the blue' and makes the difference in providing better resources for the Association and extra support that would otherwise not be possible.

Your Will can be a convenient vehicle for making a charitable gift of lasting value. Please consider the MND Association of NSW. Join those who support the work of the Association through bequests from their Estates. Your legacy, as a living memorial for a loved one, would also help to ease the burden of people who are living with MND.

There is something about the way in which motor neurone disease touches people that inspires the willingness to give to support others. As the MND Association extends its reach to help more people, the help that is given back has also grown.

Many people give donations in memory of a loved one, a tribute that ensures continuing support for others.

The MND Association thanks the many people who contributed to providing and promoting the best possible support for people living with MND, their families and carers, to advance research and to raise awareness during 2003 –2004.

Donations received in memory of:

James Bailey	Catherine Glossop	Patricia Middleton
Veronica Ball	Bill Gole	Boguslaw Mikunda
Robin Balsdon	Bruce Gooddy	Stephen Milliss
Geoff Bath	Malcolm Gorham	Sherwin Misso
Mike Beams	Laurie Grant	Garry Newman
Charles Bevk	Colin Grant	Marguerite O'Brien
Harry Bousfield	Peter Green	Alistair Orr
Mabel Breckenridge	Gloria Greer	Albert Otte
Christopher Brennan	Edward Gregory	Ronald Owen
Betty Irene Broadfoot	Herb Haas	Patricia Page
Vivienne Brogan	David Hastie	Ellen Pangas
June Burdon	Philip Heath	Harold Paterson
Margaret Burge	John Edmund Hennessy	Andrew Paxton
Winifred Campbell	Geoffrey Wallace Hickson	Scott Pennefather
Carmel Carter	Janace Holmes	Mira Poljak
Rosemary Carver	Kenneth Howarth	Raymond Prasad
Michele Castiglione	Peter Howe	Rene Prior
Marie Cheney	Terry Howe	Victor Ramsden
Allan Clark	John Huegill	Rona Rayner
Jeremy Clarke	Mary Jago	Garry Regal
Joan Clemens	Hugo Jaimes	Sue Riley
Anne Cockerill	Wendy Jarvis	Bernard Robb
Donald Cook	Anita Jenner	Elie Sahyoun
Leslie Coombes	Gordon Johnson	Joyce Irene Sandry
Clarence Cornish	Alan Johnston	Colin Schneider
Kerrie Cripps	Bramod Kelkar	Marie Silvester
Margaret Cross	Betty Kennedy	Keith Simpson
Gordon & Grace Douglass	Cecilia Khursigara	Jenny Sladden
Robert Dowling	Naomi Kronenberg	Cecil (Toby) Sloane
Terry Driscoll	Helen Levy	Mrs A Smith
Robert Duckworth	Margaret Livermore	Sylvia Smith
Shirley Dumbrell	Myra Locke	Christine Stevens
Lorna Eagles	Clifford Looney	Helen Stroud
Keith Edgar	Ray Lucas	Eddie Symonds
Leith Ellem	Kevin Luff	Kathleen Thurgood
Peter Evans A.M.	Paul Lynne	Phillip Tran
Jill Evans	Allan Lyons	Norm Wakeham
Chrissie Fairweather	Harrison Macardle	Felicity Walker
Heinz Fischl	Anders Malmquist	Phyllis Weeks
Arthur Foley	Betty Mansell	Robyn Wilkinson
Richard Frost	Ken Marlin	Bonnie Willis
Ian Fuller	Lola McDonald	Kerry Worldon
Scott Gale	John McGregor	Joyce Zito
Angela Gauci	Patricia McNeale	
Richard Geersen	Doug McPhee	

Donors

In 2003 – 2004, only 20 percent of income to the Association came from Government funding. The rest of the funds that are needed to support the work of the Association came from many generous donations from many generous people and organisations. These donations provide the majority of the funds that are needed to make the difference in supporting specialised care for people living with motor neurone disease.

There are many ways of making a difference through donations.

Some people organise special fundraising events

Some enlist the help of club members in a group effort to raise funds for their special cause.

Numerous people, both individually and through Support Groups, work tirelessly to raise awareness that generates financial support from people throughout the community. MND Week is a major focus for these activities each year.

'Friends of MND' commit to making a regular monthly donation to the Association. This helps to create a predictable income stream for planning financial commitments of the Association.

Every donation, no matter how small or how large, is received with great thanks and contributes towards making the difference that is needed for the best possibly care for today and the hope for a future that can only come through research.

Major Donors

Brian Bowles
John Campbell
Eventide Homes (NSW)
Chris & Margarita Goumas
Hare & Forbes Pty Ltd
Mrs Gwynyth Alice Lindsay
Mallesons Stephen Jaques
Mrs Eileen McDonnell
MND Newcastle/Hunter Region Support Group
Ian & Sue Rodwell
Mrs Joan Schmeising

Trusts & Foundations

Baxter Charitable Foundation
The Bill Ritchie Foundation,
Leighton Holdings Limited
Paul Newman Foundation
Reserve Bank of Australia
United Way Sydney
Whelan Project Co Pty Limited

Clubs

Apex Club of Pennant Hills
Australian Order of Old Bastards
Bankstown & Districts Lapidary Club Inc
Batemans Bay Women's Bowling Club
Bathurst RSL Club Ltd
Bayview Golf Club
Bellbirds Club Inc
Beta Sigma Phi Gamma Master Chapter
Blacktown Workers Club Ltd
Brisbane Water Bridge Club Inc
Bulldogs League Club Limited
Campsie RSL Sub-Branch Club Ltd
Carlingford Rotary Club
Five Dock RSL Community Club Ltd
Gerringong Women's Bowling Club
Hornsby RSL Club
Inner Wheel Club of Lismore
Lioness Club of Camden
Lions Club of Carlingford-Dundas
Lions Club of Frenchs Forest
Lions Club of Parramatta
Northbridge Golf Club
Pittwater RSL Club
Raymond Terrace Women's Bowling Club
Rotary Club of Ballina Inc
Rotary Club of Bankstown Inc
Rotary Club of Chatswood
Rotary Club of Gunnedah
Rotary Club of Scone
Rotary Club of Silverwater-Homebush Bay
Russell Vale Golf & Social Club
Ryde-Eastwood Leagues Club
St Marys Bridge Club
The Ionian Club Sydney '84 Inc
Toukley Women's Bowling Club
Windsor Country Golf Club
Wiseman Park Wollongong City Bowling Club

Volunteers

Supported by NSW Health

Founded by volunteers, the backbone of the MND Association is still its volunteers. Today, the Board is a dedicated group of volunteers that meets every month. Between meetings, a very substantial amount of work is done by the Executive: President, Ralph Warren; Treasurer, Bob Templeman and Secretary, Suzanne Ballinger. Board subcommittees give extra time for special planning needs of Finance, Research, Fundraising, Staff and a special task force to find alternative accommodation for the office and equipment stores. In 2003 – 2004 the Building subcommittee assisted the CEO in investigating many potential sites for a new home for the headquarters of the Association, and will continue to assist with plans for the move to Gladesville in 2005.

Volunteers are people from many walks of life. Some are former carers of people with MND who know at first hand how much help is needed. Some have had friends with MND – and others are friends of friends. Some have special skills, others are happy to do anything that needs an extra pair of hands. Some help by raising funds, others give assistance in the office. There are countless ways in which volunteers provide help. The one thing they all have in common is the willingness to give their time to help the Association to help other people – they are people helping people.

Support Groups not only extend the reach of the Family Support team through their volunteers, but also do wonders with raising awareness and funds in their local community.

The one time of the year when our volunteers come out in force is during MND Week. They sell cornflowers and other merchandise, contact local media to raise awareness and generally participate in creating a widespread network of support. If you took the volunteers away, the Association would soon grind to a halt.

Thank you all for caring.

Marjorie Harrap
Volunteer
Founding Member of MNDA NSW

Staff

CHIEF
EXECUTIVE
OFFICER
Bruce Fraser

Manager
Family Support
Carol Birks

Manager Fundraising
& Membership
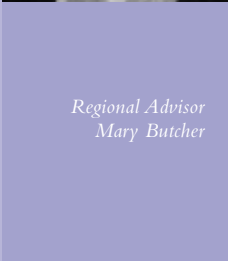Elizabeth Herbert

Information
& Research
Administrator
Janet Nash

Promotions
Coordinator
Roslyn Adams

Office Coordinator
Petra Sammut

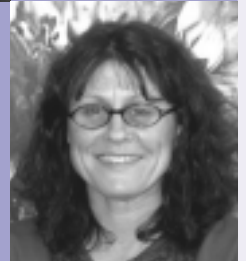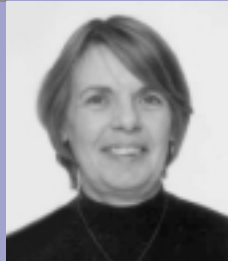Regional Advisor
Mary Butcher

Regional Advisor
Caroline Gleig

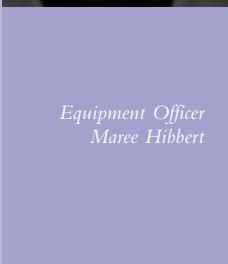Regional Advisor
Christina Jason

Regional Advisor
Allison Pearson

Regional Advisor
Ruth Quaken

Special Projects
Coordinator
Anita Richter

Equipment Officer
Maree Hibbert

Equipment Assistant
Trevor Rakuraku

Administration
Assistant
Carole Leone

people helping people