



MOTOR NEURONE DISEASE ASSOCIATION
OF QUEENSLAND INCORPORATED

ANNUAL REVIEW 2014

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Motor Neurone Disease

Motor Neurone Disease (also known as ALS - Amyotrophic lateral sclerosis or Lou Gehrig's Disease), is a devastating and incurable neurological disease affecting more than 1900 people in Australia at the present time.

The term 'motor neurone disease' (MND) describes a group of related diseases affecting the nerves in the brain and spinal cord. These nerves are known as motor neurones. As the nerves become damaged the muscles they control weaken and waste.

The nature of the disease is that it affects different people in different ways. In other words there are no clear-cut definitive symptoms that immediately indicate a diagnosis of MND.

Early symptoms can be mild, indicated by problems with walking, difficulties holding objects due to weakness of the hand muscles, slurring of speech or a swallowing difficulty due to weakness of the tongue and throat muscles. The senses remain intact. Recent research has shown that cognitive changes occur in up to 50% of cases. A key feature of the disease can be its rapid progression creating a significant burden of adjustment for individuals, carers and families responding to complex care needs.

This terminal illness takes the life of at least two Australians every day with a life expectancy of 2—5 years after diagnosis.

At present there is no known cure or treatment for MND. Although many symptoms can be managed effectively with multi-disciplinary care.

Research in Australia and throughout the world is ongoing – it is a journey.



MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

OUR VISION

A world free of the impact of motor neurone disease.

OUR MISSION

Our mission is to help reduce the impact of motor neurone disease on people living with MND, their families and carers. We do this by:

- Providing information, education and support;
- Raising awareness of MND and its impact; and
- Supporting efforts to find the cause and a cure for motor neurone

OUR CORNFLOWER

The cornflower is the symbol of hope for people living with MND—hope for finding the cause; hope for development of treatments, and for a cure. The cornflower represents positive hope for the future—a future without MND.

OUR CURRENT POSITION

Membership

From twenty one members in 1983 to a current membership in 2014 of over 300.

Support Groups

From one support group established in Brisbane in 1983, we currently have four active support groups throughout Queensland.

Staff

When MND Queensland was established in 1983 it started with one permanent part-time staff member and a team of dedicated volunteers. We now have two part time and two full time staff members with one full time vacant position.

Patron, Board and Staff

PATRON

His Excellency the Honorable Paul de Jersey AC, Governor of Queensland

VICE PATRONS

Dr Robert Henderson, Neurologist

Dr Pamela McCombe, Neurologist

Mrs Karen Malcolm, Speech Pathologist



GOVERNANCE STRUCTURE

The Governance of the Association in 2013 was the responsibility of the volunteer Management Committee (Board) and its two standing sub committees, the Audit & Finance Committee and Governance & Review Committee, composed of Board members and other members of the Association with relevant expertise and experience.

BOARD SUB-COMMITTEES

AUDIT & FINANCE COMMITTEE

Allan Morrison

GOVERNANCE & REVIEW COMMITTEE

David Schwarz

Graeme Holyer

John Wearne AM

Jacqueline D'Alton

OUR STAFF

Cheryl Miller, Chief Executive Officer

Anna Thompson Fundraising & Communications Manager to March 2014

Telisa Sekona, Administration Coordinator

Denise Plunkett-Mansell, Information & Referral Officer/Equipment Services

Christine Carroll, Regional Advisor, Gold Coast (under contract with MND NSW)

Kate Hudson, Regional Advisor, Brisbane to Sept 2014

Dr Amanda Pavey, Senior Regional Advisor from Sep 2014

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

OUR BOARD



Ray Currie PSM
President from December 2014

I hold a Diploma of Local Government Administration and a Queensland Local Government Clerk's Certificate. I have been a Qld Justice of the Peace (Qualified) for over 40 years. I am a Fellow of Local Government Managers Australia, and am a life member. I was a Member with the Australian Institute of Company Directors, and a Fellow with the Australian Institute of Management, until I resigned on 30 June 2008.

I received a Public Service Medal (PSM) in 2005 for outstanding service to Local Government, and a Meritorious Service Medal in 2006, for service to the Qld State Emergency Service.

I was a Divisional Councillor on the Qld Division of Local Government Managers Australia, and held the position of State President, and a Federal Councillor. I was a representative and also served as Chairperson of BIEDO. I completed two four year terms as a Government Appointed Director on the South Burnett District Health Council, and held the position as Chairperson, for the second term.

I am patron of the Kilkivan Swimming Club, and have previously served many terms as Captain/Handicapper for the Kilkivan Golf Club, and I am a life member of the Kilkivan & District Historical Society Inc.

I worked in Local Government for over 40 years, with the last 22 years as a Chief Executive Officer and then 18 months as a Regional Director with the Dept of Infrastructure & Planning.

My wife was inflicted with "Motor Neurone Disease", and for the last years of her life I cared for her on a full time basis, until her passing on 14-February-2014. Sue was also honoured to receive an Order of Australia Medal (OAM) in the 2013 Queens Birthday Honours, for outstanding service to the Kilkivan community.



Elizabeth Holyer
Vice President

Elizabeth has worked extensively in clerical & financial positions government and in private companies. Married to Graeme, with two daughters, Elizabeth ran Grace Primary School tuckshop for 8 years then became Bursar/Business Manager's assistant of the school's extensive charity work includes Rural Youth, Leo, Rotaract & Lions clubs. She became involved with MND in 1993 when a neighbour was diagnosed with MND and has served as President and Secretary of North Brisbane & Caboolture Support Group, as well

as managing the finances.

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND



Allan Morrison B.Ec., B. Bus.

Treasurer

Allan holds a Bachelor of Economics and a Bachelor of Business, and for 11 years worked in government (including as Director – Trade and Investment within the Queensland Premier’s Department). He then established a successful business management consultancy and then BSD Robotics, a company designing, manufacturing and supplying high tech scientific laboratory instruments to world niche markets which he sold to a US based public company. Allan then continued as General Manager in Brisbane. Allan retired in July 2012 but has since acquired two bakery businesses to be run by family

members.



Jackie D'Alton

MAppFin, BCom, FAICD, SF FINSIA

Secretary

Jackie is a Fellow of AICD and a Senior Fellow of FINSIA, holds a Master of Applied Finance, Bachelor of Commerce and is a Graduate from the Securities Institute of Australia and of the AICD Directors Course Directors Update Course and Nexus Course; Jackie has over 15 years’ experience on government boards including QLeave and the Major Sports Facility Authority, in roles including Board Chair and Chair of Audit Risk & Compliance

Committee and finance committee as well as other committee roles. Also Chair of “Topology”, a Queensland contemporary classical music ensemble. Jackie has been a member of the MND Qld Governance & Review Committee since 2012 and was appointed a Board Member in May 2013.



Deborah Teeboon

Board Member

In July 2013, 16 years after being diagnosed, our son David passed away from MND. Although we struggled through most of those years, supporting David financially with equipment, medication, vehicle conversions and house renovations with little to no assistance, the last 10 months were the most difficult as Grant gave up his career of 33 years with the RAAF to look after David. It has and continues to be a long journey.

I am a CPA specialising in cost and management accounting with the ability to focus on short and long term goals. My speciality is as a successful trouble-shooter, specialising in policy, procedures and systems taking teams through change management processes to achieve a lean, efficient and effective operations with significant cost saving. My ability to see not only currently in the final stages of double masters: MBA (Business Strategy/Human Resource speciality)/Master of Commercial Law

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND



Peter Denham
Board Member to May 2014

Peter Denham, Peter served 26 years as an officer of the Australian regular Army, both in Australia and overseas. Following his military career, Peter worked for Legacy and then as the Executive Director of the Muscular Dystrophy Association of Queensland, an association which Peter guided from a small voluntary organisation to a charity with income of more than \$3million per year offering aid to some 4000 people in Queensland with muscular dystrophy. Peter has served as President of MND Qld since 2011.



Karen Mowles
Board Member from May 2014

I am married with three daughters and two grandchildren. I first became aware of Motor Neurone Disease when my grandmother Annette Hosking was diagnosed with the disease in the late eighties and subsequently passed away in 1993. MNDAQ played a large role in keeping my grandmother in her own home with her husband as long as possible through access to hoist, bed and wheelchair and also providing information on what to expect and where to access medical help etc.

My second personal encounter with the disease was with my mother Anne Dunstan who also died from MND two years ago. Once again MNDAQ was there for my mother and her family, providing equipment along with the most valuable of all a machine that spoke for her. Without this she would have been like my grandmother and not able to communicate, which was very distressing.

With this in mind I feel the need to give back to the organization that has given so much to my family.

On a professional level, for the majority of my adult life I have worked in family business. Firstly for and with my husband in our trophy shop I am also a director of the company. I mainly focus on the accounting side of the operation.

I have also worked for my mother in her fundraising company (Fundraising Services) since 1992. I took over as proprietor in 2004 upon her retirement. During my children's schooling years I was involved in many aspects of their school including fundraising.

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

STATE FORUM 2014

Official opening and Inaugural Charles Graham Oration by Her Excellency
Ms Penelope Wensley AC Governor of Queensland, Patron, Motor Neurone Disease Association, Queensland

National Executive Director, Motor Neurone Disease Australia, Ms Carol Birks,
MND Queensland President, Mr Peter Denham, Secretary, Ms Jacqueline D'Alton,
Acting Treasurer, Mr Allan Morrison, Board Members, Elizabeth and Graeme Holyer, and CEO, Ms Cheryl
Miller, CEO, Endeavour Foundation, Mr David Barbagello, Executive Officer, Research, MNDA Ms Janet Nash,
Special Guest, MNDQ Foundation and Life member, Mrs. Shirley Graham OAM, Ladies and Gentlemen,

An extract from the recent address by the Governor General, Her Excellency Ms Penelope Wensley AC
Governor of Queensland, Patron, Motor Neurone Disease Association, Queensland at the recent MND
Queensland State Conference.

"When faced with the grim reality of this devastating condition that has, still today, no clear cause, no cure, and very little treatment, those MUST remain our core goals never to give up helping and never to give up hoping that we can do more to penetrate and manage its puzzling complexities, we are living in an age of rapid advances thirty-three years in calendar time from Charlie Graham's initial quest for information, but light years on, in terms of technological gains, giving new impetus, surely, to the 'hope' part of the equation. We are not there yet, but MND research has accelerated quite dramatically in recent years and here in Queensland, we are especially well placed to contribute to this research. We have an exceptional constellation of medical research institutes, including The Brain Institute at the University of Queensland established in 2003, one of the largest MND laboratories in the world and now with a decade of development behind it I have little doubt that there are many Queenslanders, in 2014, who, like Charlie in 1981, have never heard of Motor Neurone Disease which is why we need the Society to "take a leaf from his book" and resolve at this State Conference (and the national MND conference that Queensland will host in September) to reaffirm and intensify efforts to pursue that vital founding goal of promotion and publicity, honoring not only the memory of Charles Graham but his activism."



State Forum
Left to Right:
President Peter Denham, Shirley Graham,
Her Excellency Penelope Wensley AC and
Cheryl Miller

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

PRESIDENTS REPORT 2014

It was a momentous year for the Association as the Ice Bucket Challenge found supporters around the World who raised millions of extra dollars to find a cause, find a cure, and give everyone with this insidious disease a better life. Our thanks go out to Peter Frates and his supporters in the USA who created this challenge.

2014 will be remembered as the year that MND found a new beginning and a new symbol of hope for the future. Here in Queensland the Association and the MND and ME Foundation raised more funds for Medical Research and Services. Very quickly your Association placed a Regional Advisor in North Queensland. Our senior Regional Advisor Doctor Amanda Pavey increased the Associations capacity for personal contact, services, and home visits. In the coming year we will see a further increase in Regional Advisors.

Then a second surprise came to us as a benefactor left us a gift in his Will. This bequest has strengthened the Association and provided state wide services. We urge everyone to consider helping the Association through their Will as my wife and I have done so. It is a lasting gift that brings hope and strength to everyone fighting this disease.

The year began with an amazing State Conference and our previous Governor of Queensland Her Excellency Penelope Wensley AC opened the conference in Caboolture. In October the seventh Bi-Annual National MND Conference was held on the Gold Coast and was well attended and enhanced our understanding and knowledge of MND. On the national scene David Ali President MND Australia and CEO Carol Birks gave our Association terrific support and encouragement throughout the year and we thank them for their dedication and service to the MND Community throughout Australia.

People living with MND face daily challenges and their families face dramatic change as the disease progresses. Our Association has stood beside men and women who have been diagnosed with MND and supported their families since its inception in 1983. Likewise everyone has stood with the Association and your membership has enabled our Association to grow and face the future with courage and determination. This year we have made great steps forward as we strive to bring everyone together.

The MND and ME Foundation Limited began in Queensland in 2010 and was founded by the late Scott Sullivan. The Foundation and its supporters raised the profile of MND as well as funding research. This year we have continued to work with the Foundation to combine our supporter strength and bring better services to people with MND. In 2015 we are aiming at integrating the two organisations into one and provide everyone with MND throughout Queensland with better services and stronger representation.

In December I handed over the position of President to Ray Currie to continue the good work and lead the Association into 2015.

Taking over the role of President give me the opportunity to see that the future is very bright for MND research and the MNDRIA is closing the gaps on the unknown causes of this disease. Our National President, David Ali, and the National CEO, Carol Birks, continue to support and assist us. Their involvement in MND Australia provides us with up to date information on all aspects of the disease and we thank them for their dedication and taking time to visit us. As President I have the privilege of representing Queensland on the National Board.

During the year we continued to organise events and also assist our many support groups to raise funds and awareness of MND and we are very grateful for their support.

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

I place on record my appreciation to our hard working, wonderful CEO, Cheryl Miller, and her team of staff for their enduring service during this year. An organisation like ours cannot service without good and supportive staff, members, amazing volunteers and our financial supporters, donors, sponsors and stakeholders and the support we continue to receive from the State Government of Queensland.

I also wish to pay tribute to the Management Committee for their support and in particular to the Secretary Jackie D'Alton for her hours of dedicated work.

Lastly in the words of our founder Charles Graham (1925-1983) we ask everyone to "Never Give UP"

Peter Denham
President to November 2014

Ray Currie
President from December 2014

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

TREASURES REPORT'S 2014

ALLAN MORRISON

1. Overall.

In retrospect, 2014 was a watershed year for the Association from a financial viewpoint.

By way of background, the previous year -2013 - saw a loss for the Association of approx. \$161,000. But as reported at the 2014 AGM, the Association's Management Committee was committed to achieving at least a break-even position in 2014. At the start of the 2014 year, the Management Committee expected that in order to achieve a break- even position, based on a forecast income of approx. \$550,000, the Association would only be able to offer a very modest expansion in services, including our services outside SE Queensland. It was also recognised at the time that our ability to raise additional donations during 2014 would also be limited by the extent of the resources that we could direct at that fundraising function.

Today, however, I am very pleased to be able to report that the Association's financial position as at 31 December 2014 was much stronger than had been anticipated at the start of 2014 and foreshadowed at the 2014 AGM.

This favourable position was reached with the assistance of two major bequests during the year, totalling \$215,000, and donations of more than \$206,000 received as a result of the Ice Bucket Challenge (IBC), in the second half of 2014.

While it is intended and envisaged that bequests will become a more familiar feature of the Association's income stream, and that the Ice Bucket Challenge will be repeated in 2015, if these large contributions to 2014 income were excluded, 2014 income was still approx. \$585,000. This is still significantly better than 2013 income of \$503,426, and better than the forecast for the year of approx. \$552,000, as reported in the 2014 AGM Treasurer's Report.

When all amounts are included, the Association's income for the 2014 year exceeded \$1 million - a great milestone.

As a result of this strong income stream during 2014, Net Assets as at 31 December 2014 reached approx. \$1.34 mill.

The watershed effect of the additional income received during 2014 has been to allow the Association to accelerate its plans to expand its services, and, amongst other things, to expand its fundraising capacity. Only some of these accelerated plans were able to be put in place before the end of 2014, with an expansion of the Association's services and activities continuing in 2015. The additional funds will allow the Association to maintain this higher level of services into the future and generate additional donations to support these services.

The 2014 outcomes from a services viewpoint are reported on elsewhere as part of the 2014 Annual Review.

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

2. Asset Position.

The following table summarises the assets and liabilities of the Association as at 31 December 2014, and provides equivalent 2013 information for comparison purposes.

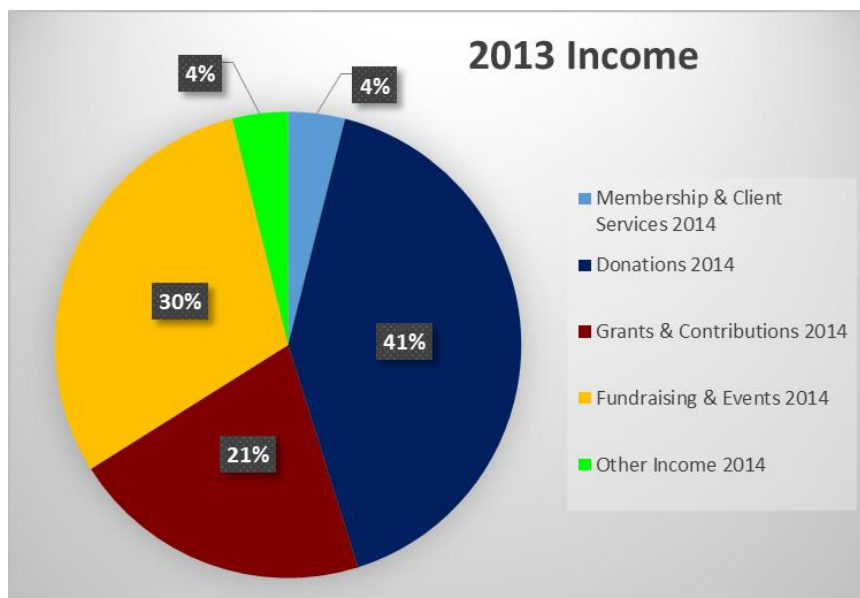
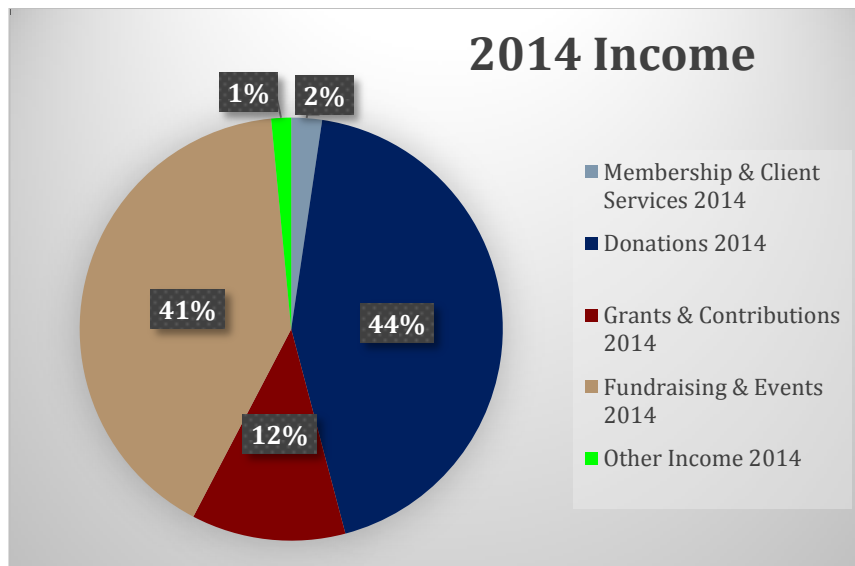
Balance Sheet Item	2014	2013
TOTAL ASSETS	\$1,425,236	\$985,722
Current Assets	\$867,213	\$390,582
Bank Deposits	\$808,098	\$328,961
Inventory	\$19,735	\$12,727
Barter Card/BBX	\$34,652	\$33,382
Other	\$13,728	\$15,512
Non Current Assets (deprd)	\$549,022	\$595,139
Property	\$319,860	\$324,278
Office Equipment/ vehicle	\$29,688	\$28,755
Patient Aids	\$191,325	\$232,532
Intangible and Other	\$8149	\$9567
TOTAL LIABILITIES	\$85,576	\$54,964
Payables	\$47,195	\$18,429
Financial/Tax Liabilities	\$19,079	\$20,212
Provisions	\$19,302	\$16,322
NET ASSETS	\$1,339,659	\$930,757

The above table confirms the sound nature of the financial position of the Association at this time. Note that the values for Non-Current Assets represent the depreciated value of those assets. By way of example, during 2014 the Association acquired additional Patient Aides, with a value of more than \$25,000. But over the year, accounting policies are such that the Association was able to depreciate its stock of aides by approx. \$66,600, resulting in a decline in the depreciated value of the total Aides stock.

3. Sources and Uses of Funds.

Tables and Pie Charts for 2014 have been included below to portray the sources of the Association's income during 2014, and the uses to which those funds were put. Pie charts for 2013 have also been provided for purposes of comparison.

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In relation to sources of funding, the following table shows the actual amounts in these income categories for 2013 and 2014.

Year	Membership	Donations	Grants etc	Fundraising etc	Other	Total
2014	\$23,543	\$437,901	\$118,490	\$410,614	\$15,283	\$1,005,833
2013	\$19,268	\$202,202	\$102,516	\$158,710	\$20,909	\$503,426

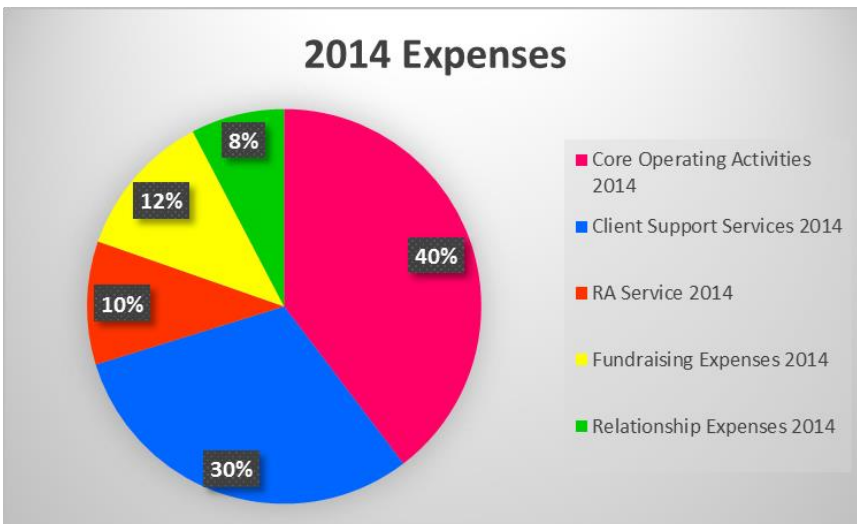
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Members will note the importance of Donations, and of Fundraising and Events to the 2014 Income stream (44% and 41% respectively). The bequests and the Ice Bucket Challenge referred to earlier have obviously contributed to this position.

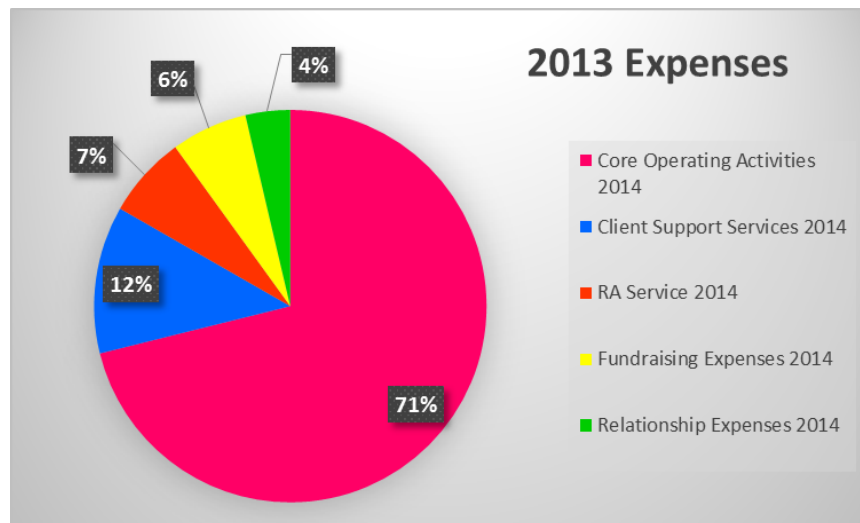
Members should also note that in 2014, as in previous years, there has been a relatively low percentage of the Association's income received by way of Government grants. The heading 'Grants and Contributions' includes not only Government grants, but also contributions received from other Community Benefit Funds. In 2014, some \$70,160 was received from these various Community Benefit funds as a result of applications for funding made by Association staff. (Note that Association staff also continue to actively pursue all available sources of funding from a variety of Government agencies). The fact that the Association has been able to continue to offer services and expand, without a high percentage of Government funding, may yet be to our advantage in the years to come, when traditional Government funding models may be replaced by new models under the national disability scheme, as are currently being trialled.

In relation to uses of funds, Members will be aware that in 2014, the Association adopted a new approach by which we would review and examine our expenditures. That new approach saw our expenses broken into 5 broad categories, where each category was related to one or more Objects, as set out in our Constitution. A listing of those 8 Objects is attached to this Report for ease of reference. These 5 expenditure categories are as follows:

- a) Client Support Services
- b) Fundraising and Awareness Services
- b) Regional Advisory Services
- c) Relationship Expenses and
- d) Core Operating Expenses.



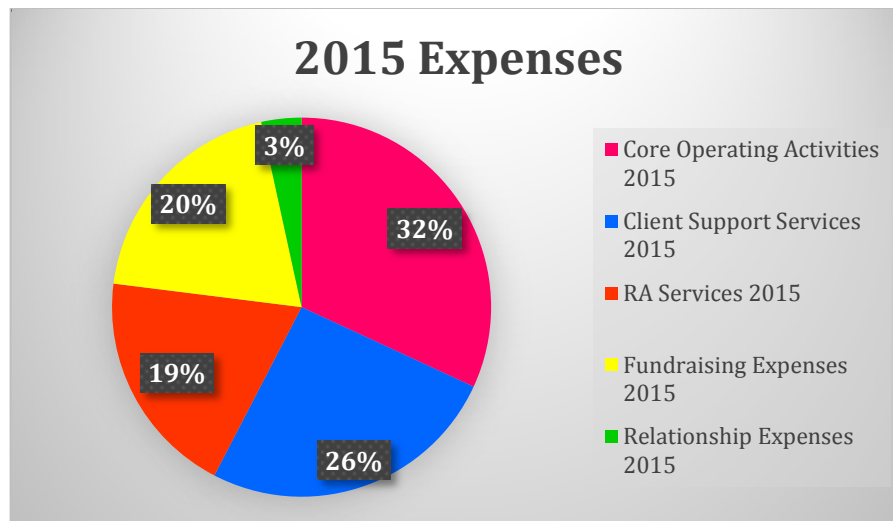
MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND



Total expenditures in 2014 amounted to \$596,932 – a fall of more than 8% on the 2013 figure.

The 2014 Pie Chart clearly shows the relative significance of each of the expenditure categories during 2014. Compared to 2013, it is clear that increased levels of service are now being provided in relation to Client Support Services and Regional Advisor Services. The Association is also investing more into the task of fundraising, and this investment is already showing positive returns.

Note that “Core Operating Expenses” cover Object 8 of the Constitution, involving all expenditures that are required to allow the other Objects to be pursued (eg the costs of operating a telephone system, and a computer system, of employing an administrative assistant and a bookkeeper, auditing the accounts, maintaining a certified Quality System, etc). Many of these costs are fixed ie as the income of the Association grows, these Core Operating Expenses do not grow proportionally, meaning that they decline as a percentage of total expenditures as Income grows. This is apparent when comparing the Pie Charts for 2013 and 2014, where Core Operating Expenses fell from 71% to 40% of total expenditures over that period. As indicated earlier, the Association is providing even higher levels of service during 2015. For the year, the Association has established a budget with expenditures amounting to more than \$878,000. The following Pie Chart has been included to show the extent of 2015 expenditures to the end of April. For this period, expenditure on Regional Advisor Services is already higher than the total 2014 period, and on Client Support Services is already nearly 44% of the 2014 total.



4. Conclusion.

At the end of the 2014 year, the Association was in a considerably stronger position than at the end of the previous year. The additional income received in 2014 has been invested, amongst other things, into additional Client Support Services and Regional Advisory Services for Members and for people living with MND in Queensland. It has also been invested into building a stronger fundraising capability within the Association - a step which will have a compounding beneficial effect into the future.

The investment made by the Association in previous years in establishing its core operating systems, such as its quality system and its donor software system, now places it in a good position to convert additional income into expanded services for Members.

The Association's greatest assets - its Members, staff and its other supporters, also deserve recognition for their great efforts in 2014 which have contributed in no small way to the Association's current position.

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

An Extract from the Constitution (Rules) of

The Motor Neurone Disease Association of Queensland Inc. (2010)

OBJECTS

3. The objects for which the Association is established are:-
- (1) To provide a range of services and support to benefit and assist all people living with motor neurone disease, their families and carers in Queensland.
 - (2) To undertake and promote fundraising activities to fund the provision of services and support by the Motor Neurone Disease Association of Queensland Inc to people living with motor neurone disease, their families and carers in Queensland.
 - (3) To provide information, education and resources about motor neurone disease to people living with motor neurone disease, their families and carers, health care professionals, and the public.
 - (4) To foster relationships and connections between the Motor Neurone Disease Association of Queensland Inc and its members, other organisations and service providers to help to reduce the impact of motor neurone disease on people living with MND, their families and carers.
 - (5) To raise community awareness of motor neurone disease and its impact on the lives of people living with MND, their families and carers.
 - (6) To support research efforts by raising awareness of research into motor neurone disease, encouraging and contributing to fundraising activities, and informing members and the public about research being undertaken in Australia and overseas.
 - (7) To encourage people living with motor neurone disease, their families and carers, health professionals, community supporters and members of the public to become members of the Motor Neurone Disease Association of Queensland Inc.
 - (8) To do all other things as may be necessary or desirable to achieve the above mentioned Objects.

In this Rule 3, “people living with motor neurone disease” includes those diagnosed, and those yet to be diagnosed having symptoms consistent with motor neurone disease as well as, where the context permits, any person whose life is affected by a diagnosis of motor neurone disease.

The MND Support Service

Our aim is to ensure that no person living with MND has a high level of unmet need created by the disease. The service aims to achieve this outcome using two complementary strategies:

1. The delivery of key services by MNDAQ
2. Supporting other service sectors by providing information and education about MND and its impact

These strategies are delivered through the provision of three key services:

1. Information
2. Regional MND Advisors
3. Aids and Equipment

The MND Support Service works closely with health care professionals and service providers to discuss care and management of people living with MND. This helps to ensure a seamless service for people with MND and their carer and minimises duplication of services.

Senior Regional Advisor Dr Amanda Pavey, 2014

Having been in the post for just a few months it is difficult for me to fill a report full of statements of impact and growth just yet. However, reviewing and getting to grips with all the workings of the association it seems clear projecting forward that we are on the verge of exceptional growth for The Motor Neurone Disease Association of Queensland (MNDAQ). Approval is in place for two new staff members to join the Regional Advisory team in the New Year. One appointment will help share the very busy workload in the Brisbane area, and the other, for the first time in MNDAQ history, we will be appointing to cover North QLD. Our vision for this staff growth is to reach more clients in person than ever before, spanning the breath of Queensland. This is no easy task given the vast geographical area involved! The direct impact of having more staff on the ground, is we will be able to increase our scope of areas where we can travel, and offer face-to-face time with our rural and remote clients, meeting and talking with their families, and delivering education to health professionals in the area. I recognize there is much we can learn from our rural and remote colleagues, and have yet to fully engage with this rich resource. Seeing first hand how healthcare is managed and delivered under far more challenging circumstances, without the luxury of large well equipped hospitals found in the metropolitan regions, is important to the future development of our service. Understanding the diverse needs of our clients, influences the way we go about our work, the development and delivery of our services, and how we provide and purchase equipment.

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Gathering in popularity and momentum is the use of multidisciplinary meetings between the regional advisor service and health professionals within hospital and community environments. Since my appointment the provision of MND education to health professionals in our community has increased, and collaborative links with many different community healthcare providers are going from strength to strength. As a consequence, the awareness of our organization and services we offer has begun to grow exponentially. Examples are emerging throughout my work demonstrating how this approach is improving the quality of care and the timely deliverance of services to people living with MND and their families. Feedback from clients speaks to this collaborative style of working going further than functional service provision, it crosses the boundaries into the feeling of being socially supported by a team that communicates with each other and cares for all involved. My mission within the RA service is to continue building relationships with our colleagues in all health related fields, to further encourage cohesive partnerships, and nurture new ones. I will often remind people that MND is not a condition one person, or even a family lives in isolation with. It is a condition that encapsulates all who come into contact with it on a day to day basis, and while I am wholly committed to client centered care, I am also always aware of the ripple affect MND can have.

As our team here at MNDAQ goes from strength to strength it is difficult to predict quite what we will have achieved by the next annual review! However, all eyes shall be peeled, ears will be pinned back, and opportunities will be taken and sought as we endeavor to work cohesively as a team to reduce the impact of life with MND.

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, to have information 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 and other MND organisations from around the world. 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. This is ongoing.

Contact

For many people recently diagnosed with MND, their families and friends find that 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 to obtain ongoing information.

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND

Our Information and Referral Services position is funded through a service agreement with the Department of Communities (Disability Services). This is the only source of regular operational government funding MND Queensland receives.

Information distribution and dissemination has continued to be a focus of our work and calls to our office continue to increase in numbers with longer times spent on the phone with each individual person this demonstrate the importance of this fundamental and crucial service.

Regional Advisor– Gold Coast Chris Carroll FNCNSW & GC QLD

The Regional Advisor role on the Gold Coast continues to be challenging and rewarding. During 2013 families living with MND have been supported in a variety of ways. This includes home visits, meeting people in hospital, residential care facilities, referrals, in-service for health professionals and our Carer Support Group which meets bi- monthly. Phone support and email have become popular as the number of people registered with the association continues to increase. I think this is mostly due to the fact that the allied health professionals have become more aware of the services provided by the MND Association and therefore referring clients to us.

I have been working closely with Jenny Stofmeel, a nurse practitioner at the Gold Coast Hospital Neurology Department. We identified that families would be better supported with the implementation of multi-disciplinary team meetings. Our first meeting was in November with health professionals from many different services attending. The aim is to ensure that families are linked with all the supports possible in a timely fashion.

Natalie Setz from Carers QLD is a fantastic support with our Carer Group that meets at the Italian Club. Twice a year families are invited to attend this group. Guest speakers are very informative, covering a variety of topics. Our December Support Group had a jolly 37 people attend; it was a terrific few hours.

In my role I also support people living with MND as far south as Woolgoolga in NSW in this 3 day per week position. Families have travelled from as far as Lismore to participate in the Gold Coast Carer support group. This year the Murwillumbah Hospital Rehab Unit has started a MND clinic.

I would like to thank the dedicated teams at MNDNSW and MND QLD who support me in my work. As always it is the families I wish to thank most sincerely for welcoming me into their homes to ensure that together we can locate the best supports possible.

Client Services Service Advisor Denise Plunkett – Mansell

Reflection is a great exercise in many circumstances and as I reflect back on 2014 there are many things that remain the same. Our focus continues to be the clients living with MND and their families, and providing the best possible outcomes.

We do this by providing good quality up to date information, this year we have seen through MND Australia the release of another fact sheet called Planning Ahead, this joins the library of others available to be downloaded from MND Australia web page and is included in our initial information pack.

This information also talks about the importance of having an advanced health directive which is important for us all to consider. We have also seen the release of research done on cognitive changes experienced by some people with MND. We have also reviewed several processes with MND Qld. In November we started a new process of referral for equipment from the Allied Health professionals which allows us to manage the equipment in a timelier manner. The process has allowed a quicker turnaround from request to delivery and client get faster results.

Over the last twelve months our equipment library has grown thanks to the successful application for several grants. The Ford Burnett Grant allowed us to purchase new raiser recliners, a new bed with extension for a tall person. Repair to several pressure relieving mattresses and new shower commodes. The Walter and Eliza Hall Trust gave us the ability to increase the number of both electric and manual tilt in space wheelchairs, shower commodes with tilt and a verity of pressure reliving cushions an again raiser recliners. The Podd Family fundraising efforts allowed for the purchase of more raiser recliners and more pressure relieving cushions.

Keeping clients engaged in their life. Being able to do normal everyday things safely is important for both the client and their family. The biggest issue we have in providing the equipment is maintenance and transport. We send equipment from one end of Qld to the other. Clients and families are grateful to be able to access the equipment from us; as in most circumstances getting it for MASS (Medical Aids Subsidy Scheme) is lengthy. And not everyone is eligible for MASS. 2014 saw our equipment used, in some cased several times over with four hundred pieces of equipment being sent to approximately one hundred and eighty clients.

We provide clients and their families with face to face visits. This service is imperative in guiding clients and their families through the maze that can be our health system. With the changes the government has for us in the future with the National Disabilities and our Aging population it is a service which will grow. We are already seeing the increase in requests for the face to face contact from our Regional Advisors, as we now have several working out in the field. This also coincides with the increase in Neurology clinics dealing with MND clients across the State. Over the past twelve months we have provided Motor Neurone education to many, nursing homes, and care agencies. We have also been invited by the Department of Human Services to talk with Centrelink staffs who are involved in decision making around their clients living with MND and accessing a disability pension. This invitation arose from the many complaints by clients of the lack of understanding around MND when trying to access disability pensions and allowances. I presented to one hundred Centrelink employees at length about the difficulties people living with this disease and the effect

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on families. We also had several lunches and morning teas with clients and their families in a peer environment to discuss current issues. These were very well attended and gratefully received. We continue to try and identify all people living with this awful disease and in 2014 fifty two new clients joined with us and seventy five passed away. The number remains about the same every year and our thoughts go out to those who have and are experiencing Motor Neurone Disease. My hope is that the researchers never tire in their quest to find the answers that MND will one day be eradicated from the world and until that happens; we do our best to support those on the journey.

Equipment Services

Our equipment service is essential for people living with MND to maintain their independence and communication for as long as possible and enhance their comfort and quality of life.

This service encompasses sourcing and purchasing new equipment, liaison with therapists prescribing the equipment, loans, arranging equipment hire, delivery and pick up, developing relationships with equipment hire companies and couriers, maintenance and cleaning.



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Fundraising at MND QLD takes many and varied forms and without them we could not exist. The peer to peer platforms are growing rapidly with sites like Every Day Hero and My Cause raising millions for Charities. Appeals at tax time and end of year are promoted, with soft asks throughout the year through a range of communication. Twitter and Face book are reaching out to thousands and our third party fundraising has also grown. The Cornflower Newsletter is morphing into a nice contemporary read that raises awareness about the need for support.

Our generous volunteer fundraisers are the foundation of the association they passionately arrange fundraising opportunities and events for us, from painting themselves blue to riding on a Harley they care! From Hervey Bay to Townsville they are spreading the word.

Fundraising activities are varied and too many to mention but to name a few like Drink Tea for MND, Walk to D-Feet in three locations now, Harley Davidson (HOG) motorcycle rides, horse rides have now become annual events. These third party community fundraisers are the backbone of MND Queensland.

Left to Right Top photo: HOG Ride, Stacey Rowe-Zoch Gold Coast Marathon, Ice Bucket Challenge, Brisbane Volunteers



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Government, Trust and Foundation Grants

We are very appreciative of the funding support received in 2014, and the current and future expansion of our service provision it has enabled Funding applications for specific projects will continue to be sought in 2015

Thank you to - John Villiers – Funding, Ford Burnett Foundation, Walter and Eliza Hall.

The Association also has a regular giving program available through our website and the support of Give Now online, whereby donors are able to establish a regular weekly, fortnightly or monthly giving program. This regular commitment and dedication by donors is truly appreciated and beneficial to the MND community we support.

General Donations, In Memoriam and Tribute Gifts

Throughout the year, MND Queensland receives unsolicited donations from current and new donors. These donations come from many sources including tribute gifts (donations in lieu of gifts) to recognize a birthday, anniversary or personal celebratory event as well as in-memoriam donations and in lieu of flowers at funerals. The generosity of people at these times is incredible generous and is always greatly appreciated

Bequests

The Association has a low profile bequest program aimed at assisting people recognize the importance of the Association's work by leaving a gift in their Will. In particular, the Association wishes to recognise this year, the generosity, foresight and commitment to the fight against MND by people who have left a gift to MND after they have passed.

Regardless of the size of the bequest it is a reflection of how deeply people care about the need to find a cure and to continue supporting those people who are living with MND .

Ice Bucket Challenge

The Ice Bucket Challenge has provided both a boost of hope and funds to the MND community. Over 60,000 Ice Bucket Challenge supporters raised more than \$3 million for MND Australia and the State Associations It was the latest viral craze spiraling through social media networks, but people were left wondering why people are pouring ice water over their heads. When the Ice Bucket Challenge first started blowing up our social media feeds there was a little confusion as to what it was all about. By now, most people know the Ice Bucket Challenge is a digital campaign to raise funds and awareness for a neurodegenerative disease called Amyotrophic Lateral Sclerosis (ALS) — here in Australia, we know it as Motor Neurone Disease (MND).

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Merchandise

At every community event and fundraising opportunity we are able to provide a variety of MND merchandise for sale. Each item sold, whether it's a pen, socks, cuddly toy or badge, it highlights awareness in the community of MND and raises much needed funds for MNDAQ. We are then able to continue to provide information, services and equipment to our clients, their carers and their families with this support.

Volunteers

Volunteers are at the backbone of the Association. Volunteers started the Association, created its vision and mission and developed the underlying belief that we can all make a difference in the fight against MND. No matter what the task, or what the event, volunteers are at the forefront.

Volunteers help to fulfil our commitment to people with MND, their families and carers and they come from all walks of life. Some serve as members of the Board, some help by assisting in the office, some help by selling merchandise through their work place.

Fundraising events such as Drink Tea for MND and Walk to D-Feet are successful thanks to the involvement, contribution and dedication of our volunteers. The common thread with our volunteers is their willingness to give up their time to help the Association either with their special skills or to do just whatever needs to be done—they Never Give Up.

Conclusion

MND Queensland is only able to deliver its services and support for people living with MND because of the generosity of our donors, supporters and members. As highlighted in the introduction of this report, they contribute the major portion of the Association's total operating budget. It goes without saying that without them, the Association would not be able to carry out its service delivery mission and achieve the ultimate objective, support and a better quality of life for Queenslanders living with MND.

Your support in the past is so much appreciated but now more than ever, as we continue to extend our service delivery via our Regional Advisor service. We endeavour to raise further awareness in the community of Motor Neurone Disease so your support means so much in meeting not only our objective, but our responsibility to our clients, their families and their carers.

Looking forward Motor Neurone Disease in Queensland, will continue to assist people with MND in the community & support research into a cause and cure for Motor Neurone Disease

We dedicate ourselves to working alongside our members, carers, families and health care professionals.

Your support is greatly needed and appreciated if you would like to support Motor Neurone Disease Association of Queensland contact Donna Tunbridge at fundraising@mndaq.org.au your support is vital in enabling us to continue to raise awareness in the community and in providing information, equipment and services to those living with MND, their families, carers & support workers.

Support Groups

Support groups continue throughout Queensland and are the “face” of the Association in local communities, raising awareness about the disease and supporting people with MND.

Volunteers coordinate the majority of groups and there are groups meeting monthly throughout Queensland. These groups are often actively involved in fundraising as well as providing support and information to those with MND, their families and carers in their own communities.

Their support and tireless efforts are invaluable to MND Queensland.

The Support Group manual is currently under revision to assist members in establishing and maintaining a strong support group while abiding by the Association Regulations. It is an invaluable resource in strengthening those groups.

North Brisbane & Caboolture Support Presidents Graeme Holyer

We have farewelled the year of 2014. Again, I am so impressed by the commitment and friendship shown at our meetings that makes this such a special support group.

At the 2013 MND Qld. AGM, Elizabeth again was elected to the board on MND Qld. as a Director, and has served as Vice President for most of the year. Life in our home is busy and never boring!

Several of our group members are living with MND, and are now unable to attend our meetings. Although we miss them, we try to keep in touch with them and their families. I am reminded each time we meet of the importance of support groups and the value of mentors and friends for those on the MND journey. Each year we have several 'referrals' of people who have been diagnosed with MND so the vital role of groups like ours is undiminished.

We were again supported financially by our group patron Councillor Allan Sutherland, Mayor of Moreton Bay Regional Council, and we wish to thank him for this. We also supported the Peter Barwick Memorial Sports Award, which is presented to students by the Lakes College, Northlakes. Again I had the honour to attend their presentation evening with Sue Barwick and present the awards on behalf of MND Qld. and our support group.

We have enjoyed the company of some special people at our meetings, including Peter Denham and our (then) local State MP, Trevor Ruthenberg. Trevor was a great champion for the MND cause and I wish to record our appreciation for his interest and friendship. He will always be welcome at our meetings. We look forward to welcoming any board members or MND staff members at our meetings whenever you are able spare some of your valuable time.

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We received funding again from the Latown Dance Group in Victoria. They have supported us over a number years with fund raising and the sale of their dance DVD's. Thank you to these great people who have now raised over \$10,000 in support of research funding. Without their support the battle to find a cure for MND would be more difficult. We appreciate the efforts of Dawn and Bill Noy to keep us in touch with their dance group. We do not see Dawn and Bill very often at our meetings, but they are special to us and contribute in large part to the spirit that makes our support group very special.

We carried out an awareness and fundraising day at the Seekers Decades Festival sponsored by Moreton Bay Regional Council with our Queensland CEO, Cheryl Miller. A big thank you to all of our supporters.

Several of our members took part in the 'Ice Bucket Challenge', and we also held a great fund raiser at the Burpengary Community Hall. This took the form of a Fashion Parade and High Tea, which was very well supported by the community and was a great afternoon of fun. We enjoyed the company of Cheryl Miller and Trevor Ruthenberg for the afternoon. At the end of the function, Trevor responded to my challenge to do the 'Ice Bucket Challenge', and auctioned off the right to dunk him. This auction was won by one of our members, Kay Jackson who sadly lost her son to MND last year, and carried out the dunk in memory of him. We raised over \$2,300.00 for the afternoon, which was a great reward for the work of our members and Elizabeth's organising efforts.

Our last fund raiser for the year was again the Christmas gift wrapping at Northlakes Shopping Centre. At first I was upset that center management had moved our wrapping table well away from Santa, but I was proved wrong when we raised over \$2,500.00, so it was the best gift wrapping year for us so far. It's busy and sometimes hard work, but it's fun and we look forward to doing it again next Christmas. Thank you to our loyal members and helpers for your time and effort.

Thank you to our Secretary Elizabeth and to our Vice President, June Logan for your efforts during the year, there is no doubt that I need your help to keep me on track. Thank you to all the members of the North Brisbane and Caboolture Support for the opportunity to again serve as President. It has been a busy year for the group and for myself. The successes we have achieved were due to your hard work and efforts, and to the friendship and support you have given each other and myself.

Townsville Support Group President Robin Ray

The Townsville based support group continues to meet monthly with varying numbers attending depending on their need to be involved at that time. Alternate months we meet socially at Tumbetin Tearooms for coffee/lunch and the other months we have a more formal meeting at Kirwan Health. During the last half hour of this meeting, the Allied Health team join us, providing an opportunity for members to ask questions or engage in a consultation.

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During the year we welcomed new members to the group and took time to remember with thanks the contributions of the members who had died. We welcome the support of Sharon Gray as our local regional advisor for MNDAQ

Darling Downs Support Group Judith Maker-Field

As per usual the members of the support group had another busy year starting with Toowoomba having its first Walk to D-Feet around Queens Park. The day was a huge success with the help of West Toowoomba Lions who put on a sausage sizzle for us and Mr Owen Ray – Musician who kept the crowds entertained. We were also fortunate this year to get some lovely donations from the Toowoomba city golf club and from the Toowoomba Lions club – ladies auxiliary.

The Toowoomba Rotary Club also held a lovely garden party with fashion parade with the brave models being dashing males dressed in ladies attire. Very entertaining.

In June the Coolaroo Football club held a day to commemorate two of their past members Russell Roser and Darling Downs Lawrie Tessman. This will be an annual event and by all accounts was very successful.

Cheryl Miller visited and presented an informative talk to a group from the CWA who held a fundraising luncheon for MND in July.

In August Toowoomba participated in the global Ice Bucket Challenge with a few notables getting dunked on not so warm days. On November 1st we held our annual Remembrance Day luncheon at the Winery at Kingsthorpe, apart from a very hot day and a few flies this day was also a great success. At the end of the day seventy balloons were released to remember those who are no longer with us.

We also celebrated the achievements of one of our members who has been dubbed the Teddy/Puppy selling queen. She was honoured with a tiara and our own certificate of appreciation from the group.

Our final meeting of the year in December had a touch of sadness as the group had decided to discontinue having support group meetings and we acknowledged all the people who over the years have helped us out. I had one of our original members Delly's Kelly present some certificates of appreciation and gifts and I presented Delly's with a gift thanking her for introducing me to this organisation on February 1991 and meeting some of the most wonderful people I have had the pleasure of calling my friends. However in saying that the group now do the coffee and cake thing every second Saturday and we now have more people attending than ever before.

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Gold Coast Support Group President Lorraine Lovatt

The Gold Coast MND Support Group / Cornflower Social Group continued to meet on a monthly basis at the Italo-Australian Club who make available their meeting rooms and offer a friendly and easy accessible place to meet, and we give our sincere thanks for their continued support.

Our focus continues to be that of social support group meeting, offering a friendly place to get together each month for not only a chat and catch up but for social and emotional support for those with MND as well as their family and friends with a few regularly now catching up for lunch or a coffee before our official meeting time of 2pm to 4pm.

Again our Christmas get together was a fabulous day and a time to catch up with members and their family and friends.

We have a strong commitment to continue to offer our assistance to those who are or have been affected by Motor Neurone Disease including their family members and/or friends; we will continue to offer a friendly welcome as well as to those who too have been personally touched by the loss of someone very dear.

We celebrated our 25th Anniversary of the Gold Coast Support Group, the Gold Coast being the longest running Support Group for Motor Neurone Disease Association in Queensland. The Gold Coast group was first established by MNDQA in October 1989 and continues to offer valuable assistance to the community.

We now also have our own Facebook page called MND Gold Coast Support Group <https://www.facebook.com/MNDGoldCoastSupportGroup?ref=hl> Our group is run entirely by volunteers who have a very personal experience with MND.

I would also like to take this opportunity to thank all our volunteers, friends and family members for their assistance during the year. The common thread with our volunteers is their willingness to give up their time to help the Association either with their special skills or to do just whatever needs to be done—they 'Never Give Up.'

SUPPORT GROUP INFORMATION

TOWNSVILLE

Contact Robin Ray
Phone 07 4781 4474
robin.ray@jcu.edu.au

SUNSHINE COAST

Contact Rod Downes
Phone 0417 043 095

CAIRNS

Contact Anne Kavanagh
Phone 0400 739 674
Anne_Kavanagh@health.qld.gov.au

GOLD COAST

Meet monthly, 2nd Saturday,
2pm Italo Australian Club,
18 Fairway Drive Clear
Island Waters
Contact Dianne Brauer
Phone 0411 742 265

NORTH BRISBANE & CABOOLTURE

Meet monthly 4th Saturday,
9.30am Pine Rivers
Community Health Centre,
568 Gympie Road, Strathpine
Contact Graeme Holyer
Phone 07 3888 1783

MARYBOROUGH

Contact Evelyn Jacobs
Phone 07 4122 2575

ROCKHAMPTON

Contact Anne Thompson
Phone 0407 116 367
Or Gillian Truelson
Phone 4934 0493

DARLING DOWNS

We are currently looking for volunteers to re-start our Darling Downs group. If you can help or know of someone please call our office. 07 3372 9004

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Foundation Members

Charles Graham
Shirley Graham
John Wearne
Margaret Wearne
David Taylor
Lesley Taylor
Anne Martin
Frank Soos
Vera Stevens
Evelyn Moore
Stan Douglas
Barbara Douglas
Eddie Kudzius
Vida Kudzius
Peg Herbert
Mr F Herbert
Mrs. F Herbert
Desley Atkinson
Mrs. D V Atkinson
Ray Underwood
Alex Underwood

Life Members

1987 Shirley Graham
1990 John Wearne
1991 Evelyn Jacobs
1991 Violet Leggat
1993 Norman Isdale
1993 Patricia Fahey
1994 Margaret Wearne
1994 Lesley Taylor
1995 Frank Rough
1996 James Lawson
1996 Dawn Mahoney
1996 Muriel Roser
2001 Bill Dixon
2004 Judy Maker –Field
2005 Fr Malcolm Bell
2006 Keith Brown
2008 Rod Downes
2008 George Taylor
2009 Dianna Robinson
2009 Beris Milburn
2010 Johanna Dinon
2011 Lyn Sharp
2014 David Schwarz
2014 Vicki Forrest

Honorary Members

1987 Dr. Jack Schlink
1995 Roy Colquhoun
1995 Dr. Kerry Larkin
1998 Fr Malcolm Bell
2006 Yvonne Herbert
2008 Paul Coogan



Established in 1983 and founded by Charles Graham (1925-1983)

Motor Neurone Disease Association

Incorporation of Queensland

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