



**MOTOR NEURONE DISEASE
ASSOCIATION OF QUEENSLAND
INCORPORATED**

ANNUAL REVIEW 2015

Motor Neurone Disease Association of QLD INC

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.

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.

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

GOVERNANCE STRUCTURE

The Governance of the Association in 2015 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.

OUR BOARD

- | | |
|--|---|
| ● Peter Denham | ● Moya Denham |
| ● Elizabeth Holyer | ● David Graham (resigned 24 November 2015) |
| ● Jackie D'Alton | ● Trent Daly (resigned 08 December 2015) |
| ● Stephen Gifford (resigned 23 November 2015) | ● Luke Jeffrey (resigned 23 November 2015) |
| ● Deborah Teeboon (resigned 01 December 2015) | ● Graeme Holyer (appointed 10 December 2015) |
| ● Ray Currie (resigned 24 November 2015) | ● David Schwarz (appointed 10 December 2015) |

OUR STAFF

- | | |
|--|---|
| ● Cheryl Miller , Chief Executive Officer –
Departed September 9, 2015 | ● Christine Carroll , Regional Advisor, Gold Coast (under contract with MND NSW) |
| ● Donna Tunbridge , Acting Chief Executive Officer September through to the year end;
Fundraising & communications Manager | ● Brad Miller , Regional advisor, Brisbane |
| ● Telisa Sekona , Administration Coordinator | ● Dr Amanda Pavey , Senior Regional Advisor |
| ● Denise Plunkett-Mansell , Information & Referral Officer/Equipment Services | ● Mark Whitely , Regional Advisor |
| | ● Sharon Grey , Regional Advisor |

President's report 2015

Peter Denham

It is with great pleasure that I report to you on our 33rd year. It is many years since Charles Graham and others worked hard to found this Association and to raise awareness of motor neurone disease. He founded a membership based Association that would focus its efforts on the people and families of Queensland with MND.

The founders called a meeting on Saturday 26 February 1983 and 21 people gathered at the Oxley CWA hall to form an organisation that would provide practical help and hope to others.

We gather today to do the same thing around Queensland at support group meetings, carers groups, research seminars, and general meetings. Our Association is about helping others and is focused on its membership. Our membership of over 180 people includes clients, families, professionals, and supporters. Each member agrees to act by our code of conduct and objects of the association that were set out in those early years.

2015 was no exception as we have provided support to over 200 families who have loved ones with the disease. Our regional advisors and other key staff provide a professional service to each person with MND and assist their families with the provision of advice, local agency support, aids and equipment, and a link with other carers. We are today delivering what is called client centric services.

This year we also held discussions with the MND and Me Foundation Limited and it is hoped that we may be able to continue these talks and work collaboratively during 2016. The NDIS will soon be a reality and provide enhanced services, aids and equipment's, and new technologies. NDIS agencies and contractors will provide services to 60% of our clients under the age of 64 years. We have a broad outline plan for the NDIS but we are seeking the help of our national body MND Australia for strategic direction so that we deliver the same services as other state MND associations.

The film "The Theory of Everything" has again focused the attention and awareness of MND as it tells the life story of Stephen Hawkins. Many of us who have watched the movie are inspired by it and of course admire the Professor.

We pay tribute this year to our 2015 president Mr Ray Currie, PSM who led the association for part of the year and furthered relationships with the MND and me Foundation limited. Ray has now taken up a position with his local council and we wish him every success.

The finances of the association are healthy and in 2015 we continued to consolidate our regional services and budgeted for a loss. The attached audited financial reports will reflect this result. In 2016 we will continue to provide these valuable services in preparation of the NDIS.

The introduction of the NDIS in Queensland will occur over the next few years and will gradually broaden its coverage. We will also maintain strong client services for those aged over 65 years who will not be eligible for the NDIS. Our plan for the NDIS is flexible so that we can meet the challenge of change and it will include the maintenance of current services until the introduction of the NDIS, participation in

a neurological group venture called Neurocare led by MS Queensland, and continue to support clients who are eligible for services under the new scheme. We are attending the many planning sessions so that we are ready for the introduction. We will keep you updated with the changes and progress.

We thank our patron His Excellency the Governor of Queensland the Honourable Paul de Jersey AC and Mrs Kaye de Jersey for their kindness and patronage throughout the year. Also we thank our members, supporters and volunteers for their wonderful support and commitment and I personally wish to thank on your behalf our Management Committee members who give so freely of their time.

We farewelled our 2015 CEO – Cheryl Miller in early September who took up a new business challenge and moved further north and we welcomed Bruce Milligan who joined us in March 2016. We wish to thank Donna Tunbridge for acting in the CEO role while we recruited to fill the position.

We thank all our staff for their dedication, as their challenge is always to make a difference and create the future for the Association in these challenging times.

We face the future together so that we can make a difference to each person with MND and their family and in the words of the late Charles Graham we promise to 'NEVER GIVE UP'.

Treasurers Report

Elizabeth Holyer

It is with pleasure that I submit the 2015 audited financial statements to you. As mentioned in the other reports, 2015 was a very busy year with the consolidation of the Regional Advisor Service throughout Queensland as well as maintaining other vital services to clients and families.

Our fundraising events, general donations and appeals raised vital funds and donations with over \$100k from the WANTZ dinner dedicated to Dr Keith Woodhead, this was a wonderful success. Also our support groups have all worked hard in 2015 to raise funds in many different ways from including colorful fashion parades, Christmas present wrapping, and morning teas.

Once the funds are raised it is then important to allocate them to our many services and projects that include information and referral, aids and equipment, regional advisors, and member services.

During 2015 the income for the Association exceeded \$983,000 and our costs were in excess of \$988,000 leaving us with a small deficit of \$4,116. This was in line with the budget and enabled the Association to consolidate the Regional Advisor Services.

We have over recent years improved our chart of accounts and the MYOB accounting and tracking systems. Several years ago we were budgeting for an income of \$300,000 gross and this year we have an income well in excess of this amount. Our fundraising and sources of income continue to develop and are not reliant on any one type of activity such as feature events. This broad business base will enable the income of the Association to continue to grow and meet the challenges of the future.

I sincerely wish to thank our previous treasurer, Deborah Teeboon, CEO Cheryl Miller and acting CEO Donna Tunbridge, bookkeepers, Noela & Jan for their diligence and accounting during 2015. I recommend the 2015 Audited Financial statements to you and move that they be accepted.

Annual Financial Summary

Item	2015	2014
Total Income	\$983,911	\$1,005,833
Total Expenditure	\$988,027	\$596,932
Annual Result Profit or (Loss)	\$(4,116)	\$408,901
Total Assets	\$1,425,142	\$1,421,356
Total Liabilities	\$89,599	\$81,697
Net Assets	\$1,335,542	\$1,339,659
Total Member's Funds	\$1,335,542	\$1,339,659

SOURCE OF OUR INCOME BY %

Income Source	%
Membership Fees	0.51
Client Service Fees	3.59
All Fundraising Activities	89.04
Local Government	0
State Government	5.45
Commonwealth Government	0
Other	1.41

Acting CEO & Fundraising & Communications Manager

Donna Tunbridge

2015 saw some changes within the business. With Cheryl Miller leaving us to take on an 'adventure' in Hervey Bay, and myself taking on the role of Acting CEO until the right person could be found to head the organisation.

With the NDIS on our doorstep much time was spent in research and meetings to consider how we will operate under this new scheme.

FEWER Australians are donating money to charity but they are handing over **larger amounts**.

A **News Corp Australia** analysis of new data from the Australian Taxation Office shows that 35.3 per cent of individuals made tax-deductible donations to charities in the 2014 financial year, down from 38 per cent five years earlier. (38% of people gave a tax deductible donation in 2009 five years later its 35.3%. That is a 7.10% drop)

The raw number of donors in Australia also dropped, from 4.65 million to 4.54 million, but total donations climbed from \$2.09 billion to \$2.62 billion, a 25 per cent rise to an average \$577 per donor.

The dwindling donor numbers come as official government aid was cut by a **third** in the past two years, aid agencies say. (Source: *Anthony Keane News Corp*).

This year MNDQ received just over \$50,000 from the State Government, we need to fundraise the rest to reach our \$1million budgeted target, and this includes bequests, corporate grants and general donations. Easily the majority of these donations come from people who have known someone who has passed away from motor neurone disease or currently know of someone **living** with this disease.

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 financials of this report, they contribute the major portion of the Association's total operating budget through fundraising. 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, we need you, as we head into a new area of health service delivery with the commencement of the NDIS.

Our fundraising covers many different areas including direct mail, merchandising, grants, trust and foundation's, bequests, third party fundraising events held by generous individuals and groups and of course our own events that we manage in house. These events not only raise vital funds for our association but help raise awareness of MND and those living with MND. The diversity of events in 2015 and the amazing financial outcomes are a **tribute** to our supporters.

MND Week 2015 saw an enthusiastic response across all areas, with the Story Bridge being lit up in Cornflower blue on Mother's day which was the perfect backdrop for the Channel seven weather report that evening.

Our annual fundraiser The Walk to D'Feet MND 2015 was held in Toowoomba, Hervey Bay and Brisbane all three of the walks saw an increase in participation, media and income.

The Brad Drewett Tennis PRO AM was developed and held by, the Australian Tennis Academy Hope Island Gold Coast. Brad Drewett was a strikingly handsome pin-up boy and a former great Australian Tennis Player who at the age of 17 was the youngest player to win The Australian Open Junior Championships since Ken Rosewall and John Newcombe. Brad became a valued member in Australia's Davis Cup Team in the 1980's whilst breaking into the World's top 50. Upon retirement as tennis professional Brad went on to become a leading administrator and then Executive Chairman and President of The ATP. Brad passed away from MND 2013.

This event allowed 'you' in for a price, to play centre court against a Tennis great.

The number one Australian broadcaster **Mr Alan Jones OAM** was our MC. (Alan graciously gave his time to travel to the Gold Coast for this fundraiser)

The event included participation from tennis greats, John Alexander, Ken Rosewall, Wally Masur, Sandon Stolle, Lesley Downey and many others. This was a large scale event and took many months to organise. The valuable awareness' and the monies raised were a great start to the fundraising year. Although on the day a massive storm hit and flooded many of the courts. All were true champions and played on!

- The 2015 Gold Coast Marathon was a great success.
- The annual HOG Gasoline Alley ride was held on a cold day in July but everyone rugged up and took up the challenge.
- WANTZ Ball was held in August at the GOMA and again a huge event to manage for a small organization. But it was a great success and raised just over \$132,000.
- Blind Man Running. Getting up at midnight is tough. Starting a run in the dark leaving the Gold Coast at 2am is tough. Running 100 km up and down hills to raise money for Motor Neurone Disease Queensland is amazing. Doing this **totally blind** was extraordinary. Damien Williams achieved his personal best time and raised vital funds for MND Qld.
- Ride for a Cause Charters Towers. Horses and riders raising funds for MND QLD.
- Golf Days, dances, balls, school events, morning teas, lunches and race meetings are just some of the many third party fundraising events helping to raise funds for MNDQA in 2015.

Government, trusts and foundations grants

We are appreciative of the funding/grant support we received in 2015 and the current and future expansion of our service provision it has facilitated. Funding applications for specific projects will continue to be sought in 2016.

GENERAL DONATIONS, BEQUESTS, IN MEMORIAM AND TRIBUTE GIFTS

Throughout the year, MND Queensland receives unsolicited donations from current and new donors. These donations come from many areas 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. Bequests fall into two categories the **known-bequest** and **the un-known** bequest, bequests provide financial sustainability for any charity and we are extremely grateful to the bequests we receive.

Volunteers are the backbone of the MND Association QLD. Volunteers founded the Association, created its vision and mission and developed the underlying belief that we can all make a difference in the fight against Motor Neurone Disease. 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 on our board, some help by assisting in the office, many 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.

Gold Coast Support Groups – Presidents Report

Dianne Brauer

MND Gold Coast Support Group gatherings in 2015 were attended by a small group of carers and clients. Sadly two of our clients passed away in the last year, they eventually lost their brave battle with motor neurone disease but they Never Gave Up. I've always said 'we don't want new members' but we know they are out there. We are all volunteers who have been touched by MND through loved ones and friends, we are there to offer our support to those who feel that they need some help. We had a large gathering for our Christmas lunch at The Italo Club, Carrara, thoroughly enjoyed by all. Unfortunately we are unable to have future meetings at the Club due to a change in their opening times.

We have found a new home for our gatherings at Surfers Paradise Golf Club, Fairways Drive, Carrara, just across the road, and will be meeting every second month. We welcome anyone to join us for lunch and a chat in 2016.

Best wishes to everyone for 2016.

North Brisbane and Caboolture Support Group – Presidents Report

Graeme Holyer

Best wishes to everybody for a happy and fulfilling 2016. The past year was a busy one for the North Brisbane and Caboolture Support Group, and we wouldn't have it any other way. Attendance at our meetings has fluctuated throughout the year, but I don't think it dropped below six, and support from group members remains high. Elizabeth and I have the honour of being foundation members of the group, which was formed in Caboolture in 1993. I am very grateful for the loyalty and support of our members, and reminded again of the importance of support groups such as ours, and the reasons for the formation of MND QLD.

I am also reminded of how far MND QLD has come since it formed so many years ago in 1983 by Charles Graham. It was, and still is, the foremost champion of people with MND in Queensland and their families. All members of MND QLD can be proud of the organisation, the progress it has made, and the services and support we are able to extend to our clients. We have a very hard working President, board and staff, and they need and deserve full support from all members.

Several of our group members are living with MND, and are unable to attend our meetings. However, their carers are usually present, and we will do our very best to extend our support to them. We are also supported regularly at our meetings by board members or Brad Miller, who is the RA for north Brisbane and Caboolture. We also supported Lakes College with our contribution for the Peter Barwick Memorial Sports Award, with funds received from Councillor Allan Sutherland, Mayor of Moreton Bay Regional Council, who is patron of our group.

On June 20, Elizabeth and I were honored to attend the wedding of one of our members, David Masters. Congratulations to David and his lovely bride, Beverley. We enjoy your company at our monthly meetings.

The major activities of our group in 2015 were:

- May – Brisbane Walk to D-feet, Roma St. parklands. Attended by several of our members and friends.
- May – Charity stall (information and merchandise) at Morayfield shopping center. Run by several of our members for the whole day.
- July – HOG ride (Harley Owners Group) in support of MND QLD. Elizabeth and I both went. What an unforgettable day that was!
- September – Fashion in the Gardens day, hosted by Marie and Lindsay Jones. Thank you for your support and for allowing us to use your beautiful home and gardens for this fundraiser. We raised nearly \$3,000.00.

- December – Gift wrapping at Northlakes Shopping Centre. We were allocated four days for wrapping gifts. Donations for wrapping are matched dollar for dollar by shopping center management. This is lots of fun and (sometimes) hard work. We raised just \$618.00, which is a little disappointing as it is the smallest amount we have raised in five years with gift wrapping.

We held our group Christmas party late in November, attended by nearly all our group members and our guests, Peter Denham and our RA, Brad Miller. Thank you to everybody for making it such a relaxed and enjoyable afternoon. It was a great way to finish the year.

I have again enjoyed the year as president of the North Brisbane and Caboolture Support Group. Thank you to all members for your confidence, friendship, and loyalty. My sincere thanks also goes to our Vice President, June Logan and our Secretary (and my lovely wife) Elizabeth. I really enjoy and rely on your support, and the success of our group and our functions is due to your hard work, organization and commitment. Best wishes for 2016.

Services team 2015

Denise Plunkett-Mansell

2015 saw the services team grow with the employment of extra Regional Advisors, Sharon Grey in Townsville in late 2014, Brad Miller for the Upper Gold Coast region and parts of Brisbane and the Sunshine coast. Mark Whitley now looks after the Fraser Coast. Chris Carroll is still with us in the southern end of the Gold Coast. Amanda Pavey looks after the Brisbane, Ipswich and Toowoomba regions. The other regional areas are shared by Amanda or Brad. With the increased numbers in communities our client numbers have increased; we are now providing services to well over 200 clients across the large State of Queensland. With the increased numbers of RA's in the community the awareness about our Association is growing and we are receiving more and more requests for support. The increased numbers also equate to more equipment being transported to clients across the state. For the first time in eight years we have waiting lists for beds and hoists, and eye gaze communication equipment. This is not a good thing. We have been very fortunate this year winning a few grants, along with generous donations of funds and equipment from supporters; however we need to raise more funds in the next few years to be able to manage our clients effectively. 2015 saw an increase also in the number of education sessions we were requested to provide to nursing homes and multi-disciplinary teams who engage with our clients. These education sessions enable health professionals to remain up to date with the latest information on MND. Sadly we lost 118 brave people in 2015, to motor neurone disease. As you are aware more are diagnosed to take their place.

2015 also saw the start of our **Carer Support Groups**. These groups have been successful in bringing carers together to talk and support one other as they negotiate the MND journey, this peer support is vital in preventing isolation.

Thank you to everyone who has supported us and encourages us.

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 – Lesley Taylor

2015 – Marian Schwarz

HONORARY MEMBERS

1987 – Dr Jack Schlink

1995 – Roy Colquhoun

1995 – Dr Kerry Larkin

1998 – Fr Malcolm Bell

2006 – Yvonne Herbert

2008 – Paul Coogan



Motor Neurone Disease Association Incorporation of Queensland

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

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