

**MOTOR NEURONE DISEASE ASSOCIATION  
OF QUEENSLAND INCORPORATED**

# ANNUAL REVIEW 2017



**mnd**   
*Queensland*

# ABOUT MOTOR NEURONE DISEASE

Every day in Australia two people are diagnosed with Motor Neurone Disease (MND) and two people pass away. As a result, this fatal and debilitating disease has a massive impact on hundreds of lives.

It turns the world upside down for not only the person who is diagnosed, but their family, friends and colleagues. They become carers, helpers, and backup support crew and those who are closest often leave their jobs and homes to move in with their loved one because of the intense care that is eventually required. While they wouldn't have it any other way, these dedicated and passionate people are changed forever. Their hearts break as they watch their loved one lose their capacity.

## WHAT IS MOTOR NEURONE DISEASE?

Motor Neurone Disease is the name given to a group of diseases in which motor neurones progressively die. Motor neurones are nerve cells that control the movement of voluntary muscles, that is, muscles that are under conscious control. These include all the muscles of the arms, legs, back and neck and of speech, swallowing and breathing. With no nerves to activate them, muscles gradually weaken and waste, and paralysis ensues. Weakness is often seen first in the hands or feet, or the first sign may be swallowing difficulty or slurred speech. Muscle twitching and/or cramps may also occur.

MND affects each person differently in respect of initial symptoms, rate and pattern of progression, and survival time. There are no remissions. The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND, an escalating burden on carers and families, and a challenge to health, disability, aged and community care professionals involved in meeting the variable and complex care needs.

## KEY FACTS

- MND is a rapidly progressive, terminal neurological disease
- There is no known cure and no effective treatment for MND - yet
- Each day in Australia two people die from MND
- Each day in Australia two people are diagnosed with MND
- People with MND progressively lose the use of their limbs and ability to speak, swallow and breathe, whilst their mind and senses usually remain intact – this is why the effect of the disease is sometimes described as “locked-in”
- Average life expectancy is 2.5 years from diagnosis. While some people live for 5 years or more there are others that may only live for 5 months.

## 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 support to people living with MND, their carers and families
- Delivering information and education
- Raising awareness of MND and its impact
- Supporting efforts to find the cause and a cure for Motor Neurone Disease

## THE 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 a future free from MND.

Cover image - By Payge Kerman from [www.pngtree.com](http://www.pngtree.com)



# PATRON, BOARD AND STAFF

## PATRON

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

## VICE PATRONS

Dr Robert Henderson, Neurologist

Dr Pamela McCombe, Neurologist

## PRESIDENT EMERITUS

John Wearne AM

## GOVERNANCE STRUCTURE

The Governance of the Association in 2017 was the responsibility of the volunteer Management Committee (Board).

## OUR 2017 BOARD MEMBERS

- President—Peter Denham
- Secretary/Vice-President—David Schwarz
- Treasurer—Elizabeth Holyer
- Board Director—Moya Denham
- Board Director—Jackie D'Alton  
*(resigned 30 August 2017)*
- Board Director—Fiona Hudson-Langham  
*(elected at 2017 AGM and resigned 4 August 2017)*



## OUR STAFF

Lisa Rayner  
**Chief Executive Officer**

Jason Russo  
**Fundraising and Communications Manager**

Telisa Sekona  
**Administration Coordinator**

Mal Farrow  
**MND Equipment Officer**

Denise Plunkett-Mansell  
**MND Support**

## MND ADVISORY TEAM

Eirlys Pijpers  
**Senior MND Advisor**

Sharon Edwards  
**MND Advisor (North Queensland)**

Mark Whitley  
**MND Advisor (Central Queensland)**



## HONOUR BOARD

We acknowledge the wonderful contributions of our Foundation Members along with our Life and Honorary Members.

### 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 Talyor  
2009 Dianna Robinson  
2009 Beris Milburn  
2010 Johanna Dinon  
2011 Lyn Sharp  
2014 David Schwarz  
2014 Vicki Forrest  
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

# PRESIDENT'S REPORT

## Peter Denham

As we celebrate our 35<sup>th</sup> Anniversary we wish to thank you all for your continued support. We pay tribute to the Founders and members of our Association who established this great organisation in 1983 and we thank them for their dedication and service. Our work throughout Queensland is vitally important to every local community and to each person with Motor Neurone Disease. With your support we continue to assist people with MND, their families, and carers. Today, our work is not possible without the support of thousands of generous Queenslanders.



Each year we deliver support services to more than 200 people with MND. Together, with other State Associations we fund vital research programs around Australia and support education, information, and wellness programs to improve the life of each person with MND. We collaborate with many other agencies and government services so that we can provide the very best support and services to each person wherever they may reside in Queensland.

Our MND Support Groups throughout the State play a vital role in providing a link to the community and local service providers as well as the wellbeing of the carer.

With the introduction of the National Disability Insurance Scheme (NDIS) the task of coordinating the new services will be a priority. Local NDIS Area Coordinators will work closely with our MND Advisory Service to get the best outcomes for our clients and members. In regional areas we are well aware of the importance of access and equity and we continue to explore new ways to deliver services.

This year we have worked closely with other Accredited Service Providers and Allied Health Professions so that we can deliver the very best outcomes for people with MND.

One of our most important services is the short-term equipment loan service available to our members and clients. With the introduction of the NDIS the service will be modified to meet future needs. We thank the Cure for MND Foundation (Fight MND) for their significant grant of new equipment to this important service.

Our sponsors and supporters provide the vital gifts, donations, and bequests to enable the Association to continue its great work and we wish to thank everyone for their kindness and generosity. We thank the Service Clubs and local community Clubs around Queensland for their amazing support.

May I personally thank our Patron His Excellency the Honourable Paul de Jersey, The Premier of Queensland Anastacia Palaszczuk, and Vice Patrons for their continued patronage and kindness. Also, may I thank the members of our Management Committee and Support Groups, our CEO and staff team for their hard work and dedication to the Association throughout the year. We are a member-based charitable organisation and I thank all our financial members for their support and wonderful work.

To you all may I again thank you for your kindness and dedication to this wonderful Association. I have pleasure in presenting this report to you.

# TREASURER'S REPORT

## Elizabeth Holyer

It is with pleasure that I submit the 2017 audited financial statements to you.

This year has been challenging, as it has in previous years, however we have managed to reduce our deficit although not as quickly as we had hoped. Our fundraising income was reduced by approximately \$27,000 on last year's figures due to varying factors, including loss of income from the HOG Bike Ride which was cancelled due to bad weather, ongoing competition with other Foundations and staff changes which interrupt the flow of planning and setting up of events.

On the positive side we received wonderful support from the Chill Factor Challenge & Ball in Mackay in conjunction with major sponsor Rio Tinto; our annual Walks to D-Feet MND in Brisbane and Toowoomba (these are being expanded this year), direct mail appeals, a range of fundraising activities organised by dedicated supporters, and street collections through Karen Mowles' Fundraising Services.

The Financial Statements for 2017 are representative of the focus upon providing and funding the delivery of our MND Advisory service, Equipment Hire and Information services as well as Fundraising and Administration functions.

I would like to thank our retiring Bookkeeper Noela Slattery for her assistance and dedication to maintaining our finances, as well as my fellow board members for the invaluable assistance. Also, to our auditors, Dickensons Accountants for their continued support over the years.

I recommend the 2017 Audited Financial statements to you and move that they be accepted.

### Annual Financial Summary

Item	2017	2016
Total Income	\$714,375	\$741,340
Total Expenditure	\$856,185	\$935,878
Annual Result: Profit or (Loss)	\$(141,210)	\$(194,538)
Total Assets	\$1,065,765	\$1,283,877
Total Liabilities	\$59,660	\$142,873
Net Assets	\$1,006,105	\$1,141,004
Total Member's Funds	\$1,006,105	\$1,141,004

### Source of Income by %

Income Source	%
Membership Fees	0.68
Client Service Fees	4.17
All Fundraising Activities	77.6
Trust & Community Foundations	-
State Government	7.42
Commonwealth Government	-
Bequests	8.22
Other	1.92



## CEO'S REPORT

### Lisa Rayner

MND Queensland, your State Association is proud to provide support, information, equipment and care for people living with Motor Neurone Disease. Our aim is to provide the most expert and informed support that we can, and offer clients and their families the understanding and information about the disease which may not be as readily available in other areas of the health system.

Being part of a national network of State Associations, headed by Motor Neurone Disease Association of Australia (MNDAA) along with Motor Neurone Disease Research Institute of Australia (MNDRIA) helps us to deliver this standard of support, along with our highly qualified and experienced staff, extremely committed Board and our dedicated supporters and donors.



In 2017 we pursued our ethos with vigour despite some setbacks in the second half of the year. A number of staff changes impacted on our capacity to service clients in South-East Queensland while we undertook a recruiting process in order to find the most experienced staff possible. We are very grateful to our outgoing staff for their contribution, as well as existing staff who took up the slack so we were able to connect with clients in all areas.

Towards the end of 2017 I moved from my role as Fundraising & Communications Manager to take over the role of CEO after the departure of Mark Hosking. Thank you Mark for your contribution during your tenure. In December we recruited for my replacement and welcomed Jason Russo as our new Fundraising & Communications Manager in early January. Jason comes with excellent experience in his field, in a number of health and disability not-for-profits, and was the start of restoring our quality team.

Our Equipment Service continues to provide equipment and aids that are crucial to the comfort and wellbeing of clients, helping to improve mobility, respiration, sleep and communication. Mal Farrow our Equipment Officer worked hard during the year to support clients as efficiently as possible and upgraded the service to an online system which has helped allied health professionals to identify suitable equipment, check availability and order more efficiently. We hope to continue refining this system, funds allowing, so we can better serve clients and also to be as compatible as possible with the NDIS system.

The Equipment Service is expensive to run, as our fees are set to be affordable for clients. The fee does not cover the cost of staff wages, or anywhere near the full cost of warehousing, sanitising and maintaining the equipment, let alone replacing items which are past repair. As Equipment is crucial for people living with MND, this aspect of our service requires substantial fundraising income to allow it to continue. We are very grateful to Fight MND for their generous Care Grants in this regard, the many individual donors to our appeals, the service clubs who provide ongoing support, and to those who have donated wheelchairs during the year.

Financially, in 2017 we were able to reduce our deficit but not to the extent we would have liked. Some of the challenges were, and continue to be that the number of charities running events

vying for funding and asking for donations has increased over the last 10 years to around 55,000 in Australia. The environment in Queensland is increasingly competitive in a health and disability sector that is under strain due to the implementation of the NDIS and the deficiencies of the aged care system, particularly for people with MND. This is a time where the support of donors, including philanthropists, bequestors and third party event organisers is especially important.

Fundraising activity for 2017 included Walks to D-feet MND in Brisbane and Toowoomba, the Chill Factor Challenge and Blue Tie Ball in Mackay, and three very successful fundraising appeals at Easter, tax time and Christmas. The Walks to D-Feet remain a very significant part of our events calendar, not only raising substantial funds but providing a way for families affected by MND to join together on one special day. The Chill Factor Challenge and Ball in Mackay was a new event for us, initiated by Mackay Magpies AFL Club and sponsored by Rio Tinto Hail Creek Mine. Funds from this incredible event, which recently won a Rio Tinto Award for best community partnership, allowed us to introduce regular support groups in Mackay organised by Sharon Edwards. We were also fortunate in 2017 to receive generous support from the Queensland Trefoil Guild, the Gasoline Alley Harley Owners Group (HOG) in a number of ways including their regular barbecues, and from a substantial number of kind supporters, social groups and sporting clubs who ran events, ran marathons and took up collections on our behalf.

The NDIS continued to rollout in 2017, with Bundaberg, Toowoomba and Ipswich commencing. During this time we applied for NDIS Registration for our Equipment Service however our NDIS preparation was slowed due to staff changes and we are currently undertaking further work to fine-tune our Registration and the details of our pricing structure and policies for both NDIS eligible clients as well as clients over 65. As the NDIS is a new national system there are still many issues to be ironed out, and we are working with MNDAA and our counterparts in other states to advocate for the changes we feel are necessary to provide the best deal for our clients. Our partnership with Spark Neurocare continued, and as the NDIS rolled out a Neurocare centre was opened in Toowoomba in December, allowing MND clients in the region to access support more readily.

In 2018 we were excited to recruit Eirlys Pijpers as our new Senior Advisor. Eirlys is extremely qualified and experienced and comes to us from a highly regarded neurological clinic in the Netherlands where she developed a strong interest in working with people with MND. Her substantial knowledge across the board is proving invaluable for clients, and for working with her team to provide the best service possible. Looking ahead we are focussing on continuing to look for ways we can better serve our clients and their families. We are hoping to introduce some “Coping with the Diagnosis” sessions in Brisbane later in the year, expand our support groups in regional areas, add to our equipment options, and advocate for better support for those over the age of 65. As our client list is growing we hope to be able to employ an additional Advisor in Brisbane in late 2018 or early 2019.

I would like to thank all of our extremely hardworking staff, our wonderful volunteers and our dedicated members and donors who are all part of making MND Queensland the leading provider of support for people living with MND in Queensland. Your support is invaluable as we meet the challenges ahead and remain as a strength in the lives of those we serve.



# MND ADVISORY AND EQUIPMENT SERVICE INSIGHTS

## Eirlys Pijpers

In 2017 both the Advisory and Equipment service have undergone a number of major revisions. These planned changes, which we highlighted in the 2016 Annual Review, were aimed at providing a more streamlined service in preparation for the NDIS.

The rollout of the NDIS started in 2016 with the Townsville and Mackay areas. In January 2017 Toowoomba followed; and later in the year the NDIS rolled out in Ipswich and Bundaberg. This provided new challenges for our MND Advisors in these regions. Firstly to help our clients join the NDIS as a participant, but the bigger challenge has been to get plans in place that meet clients' needs. The Advisors in these areas have provided training and education for NDIA planners and the NDIA local area coordinators (LAC's); and have had additional discussions with the planners and LAC's in regards to individual clients. Feedback from our advisors shows that after these discussions and presentations, more clients get a plan in place that actually meets their needs. However, it still remains a challenge and will continue to be a challenge with NDIS rollout in most of Queensland in 2018.

Our Equipment service underwent major changes in 2017, the most important being the publication of the equipment stock list on our website. The online list is kept up-to-date showing the pieces of equipment available. This provides our clients and their allied health team the opportunity to see whether the equipment they need is available before they make a request. This is of huge benefit to our clients, the health care professionals, and our Equipment Officer, providing a clearer and more streamlined service. We have received ongoing positive feedback on the current system. The aim for 2018 is to provide more details of each piece of equipment, such as photos and dimensions, making appropriate equipment selection even easier.

In preparation of NDIS rollout, in 2017, we started the registration process with NDIA for our equipment service. Once we become a registered provider, our clients with an NDIS plan can use their equipment budget to pay for the equipment they receive from MND Queensland. So far we have been approved as a registered provider for '*personal mobility equipment*' (including walkers, wheelchairs and hoists). We are now working on the process to have our full range of equipment registered ('*assistive products for personal care and safety*' and '*communications and information equipment*'). Another aim for 2018 is to amend our pricing for equipment hire. Our equipment service is low-cost to clients, but there is now the potential to charge higher rates for clients with an NDIS plan (where the NDIS pays for the equipment), enabling us to offer our equipment at a lower rate to those without funding. This will bring financial relief to our clients, already facing large expenses due to their disease.

In 2017 we also saw a number of staff changes in the Advisory team, where some of our full and part-time Advisors left the organisation to pursue other projects and devote more time to family. We are grateful for their valuable service to clients. I would like to express a big thank you to the Advisory and Equipment staff that have covered during the recruiting and rebuilding of our team. Mal Farrow for taking many phone calls along with running a demanding equipment service; Mark Whitley and Sharon Edwards for providing advice to Brisbane clients over the phone and email, while continuing to serve the clients in their regions; and Denise Plunkett-Mansell for providing support and keeping in touch with clients.

Despite an absence of advisors in the Brisbane area for some months we can still be proud of the numbers of phone calls, emails, home visits and support group visits undertaken by staff.

The following figures reflect the minimum output for 2017 *(due to staff changes some figures are incomplete so the real output will be slightly higher)*

### **MND Advisors Client Support 2017**

Phone Calls - 1315

Emails sent or answered - 1607

Home Visits undertaken - 239

Support groups facilitated - 28 *(This does not include those facilitated by volunteers)*

### **Equipment Officer Client Support 2017**

Calls and emails - 1740

For 2018, I hope to continue improvements in our Advisory and Equipment Service and provide figures that reflect that. The MND Advisors will continue their great work, providing advice and support to people living with MND, and facilitating the support groups for our clients and family members, as well as Advocacy that will help improve outcomes for both NDIS eligible clients and clients over the age of 65. Our Equipment Officer will continue to work on improving the online equipment system, including a detailed audit to help identify ongoing needs. We will continue to adjust our services in line with the state-wide NDIS rollout. Let's hope that the NDIS will have a positive impact on our clients (under 65) that are eligible for NDIS funding.

## **MND SUPPORT GROUPS**

In 2017 regular support groups were organised for clients, carers and family members. The groups varied in format and type, reflecting client needs. They give participants the chance to meet others in a similar situation to exchange information, ideas and experiences, and ask questions about the disease and related topics.

Guest speakers were invited to some support groups, with most groups coordinated by an MND Advisor and others run by volunteers. In Brisbane, Ipswich and the Sunshine Coast, groups were jointly organised with the MND and Me Foundation.

Support groups in 2017 were held in Bundaberg/Childers, Brisbane North and South, Gold Coast, Ipswich, Cairns, Mackay (sponsored by Rio Tinto through the Chill Factor fundraising event), Sunshine Coast and Townsville. We are very grateful to the volunteers who run some groups, and would like to make special mention of the Gold Coast Support Group, coordinated by Lorraine Lovatt and Dianne Brauer, which was formed in October 1989. The North Brisbane & Caboolture Support Group is another long-running group which reaches their 25<sup>th</sup> Anniversary in 2018. This group still has three original members attending since the inception, Lorraine Blanch and Graeme & Elizabeth Holyer.

Support groups continue in the above regions in 2018, with the North Brisbane & Caboolture Group holding anniversary events throughout the year. We also hope to add some new support groups in the Central Queensland area: Gladstone, Gympie, Maryborough and Rockhampton.



## 2017 FUNDRAISING EVENT PHOTOS

### Walk to D-Feet MND Brisbane



### Walk to D-Feet MND Toowoomba



### Mackay Chill Factor Challenge



### Mackay MND Blue Tie Ball







CAUSE

CARE

CURE

**MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND INCORPORATED**

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

ABN: 75 990 922 939

35 Wedgetail Street, Inala QLD 4077

PO Box 470, Inala QLD 4077

Phone: 07 3372 9004

Fax: 07 3278 9871

[info@mndaq.org.au](mailto:info@mndaq.org.au)

[www.facebook.com/mndaq](https://www.facebook.com/mndaq)

Twitter @MNDQueensland

[www.mndaq.org.au](http://www.mndaq.org.au)

**Never Give Up!**