

Motor Neurone Disease Association of Queensland Inc.

2019 ANNUAL REVIEW



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GOVERNOR OF QUEENSLAND

Message from the Governor of Queensland

As Governor and Patron, I am delighted to provide this foreword for the MND Queensland 2019 Annual Review.

In the early 1980s, brave visionary, Charles Graham resolved to support fellow Queenslanders living with the disease that sadly ended his own life. Now, 37 years later, the Association he helped form has grown from its modest beginnings to become multi-faceted and far-reaching, working with commitment to help those living with and affected by MND.

Providing valuable information and education, and championing the cause through advocacy and ongoing research form the backbone of MND Queensland's activities. This year has also seen the Association expand its mission to embrace the provision of occupational therapy, and support coordination under the National Disability Insurance Scheme (NDIS). MND Queensland's deep understanding of the disease and its impacts are a tremendous positive for the implementation and management of effective NDIS plans.

I applaud efforts in 2019 to diversify revenue sources. However, I was intrigued to note the year also saw record-breaking funds raised through 'Walk to D-Feet MND' events in Brisbane and on the Gold Coast. Queenslanders are evidently eager to help the Association deliver its valued services to ever more regions.

These achievements place the organisation in good stead to continue to support Queenslanders in challenging times. On behalf of the wider community, I commend MND Queensland management and its dedicated team of staff and volunteers, together with loyal members and supporters, who so wonderfully embody "Charlie's" ethos, "Never Give Up!".

A handwritten signature in black ink that reads "Paul de Jersey".

His Excellency the Honourable Paul de Jersey AC
Governor of Queensland

PATRON, BOARD & STAFF

PATRON

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

VICE PATRONS

Dr Robert Henderson, Neurologist

Dr Pamela McCombe, Neurologist

The Hon Henry Palaszczuk, former State Government Member for Inala

PRESIDENT EMERITUS

John Wearne AM

GOVERNANCE STRUCTURE

The Governance of the Association in 2019 was the responsibility of the volunteer Management Committee (Board).

OUR 2019 BOARD DIRECTORS

- President - Peter Denham
- Vice-President - David Schwarz
- Secretary - Megan Peach
- Treasurer - Elizabeth Holyer
- Board Director - Moya Denham
- Board Director - Graeme Holyer
- Board Director - Dean Palmer



Pictured (L-R) - Graham Holyer, Elizabeth Holyer, Megan Peach, Peter Denham, Dean Palmer, Moya Denham & David Schwarz.

OUR STAFF IN 2019

Chief Executive Officer (Commenced July 2019)
Ian Landreth

Fundraising and Communications Manager
Jason Russo

Events Coordinator (Commenced June 2019)
Georgia Railton-Stewart

Membership and Community Liaison Coordinator
Leigh Gilbert

MND SERVICES TEAM

Director of Services (Commenced May 2019)
Stacey Thorpe

MND Advisor (North Queensland)
Sharon Edwards

MND Advisor/Support Coordinator (Commenced July 2019)
Shaun Gannon

MND Equipment Officer (departed February 2019)
Ricardo Brule

MND Equipment Officer (commenced February 2019)
Sue Wells

MND Equipment Delivery Driver (commenced April 2019)
Seth Lauder

MND Support (departed September 2019)
Denise Plunkett-Mansell

Senior MND Advisor (departed March 2019)
Kylie Kellalea

MND Advisor (Toowoomba) (April - October 2019)
Tamara Silvester

Services Support Role (April - August 2019)
Beth Sanderson

MND QUEENSLAND'S HONOUR BOARD

We acknowledge the wonderful contributions of our Foundation Members who first built MND Queensland along with our Life and Honorary Members who have given so much serving and growing our organisation to better meet the needs of people impacted by Motor Neurone Disease.

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 OAM
1990 John Wearne AM
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
2018 Margaret Graham
2018 Graeme Holyer
2018 Liz Holyer
2018 Lorraine Lovatt
2018 Lorraine Lynch
2019 Anne Thompson
2019 Jane Milward

HONORARY MEMBERS

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

INTERIM PRESIDENT PETER FORDAY'S REPORT

It is with gratitude I present the MND Queensland Annual Review for 2019.

These are unusual times we live in, not least as demonstrated by this publication being shared in November 2020. This is an opportunity to review 2019 and also encourage our Members and community to learn more about the exciting developments afoot for our Association.

Whilst our Constitution instructs that I will Chair the forthcoming AGM, we have invited Peter Denham to contribute comment by way of the President's report and Elizabeth Holyer to submit the Treasurer's report in this Annual Review document, as they were the President and Treasurer respectively of the Association throughout the reporting period, January to December 2019.



I would like to thank Peter and Elizabeth for their contribution over this period as well as David Schwarz, Moya Denham, Graeme Holyer and Dean Palmer who have also served on the Management Committee over the period as well as previously. Serving on a not-for-profit board is never easy and demands considerable passion, commitment and an ability to balance one's work, family and community commitments. On behalf of the interim Board that has been in place since June 2020, I sincerely acknowledge their contributions.

I would also like to thank Megan Peach (Director and Management Committee Secretary) for her ongoing service to the Association and her commitment and support as she continues in that role. Megan has contributed an extraordinary amount of her time and skills since being appointed to the role and I have no doubt that our organisation would not be as strong as we are without her presence and active commitment.

I also recognise and commend my fellow Board Directors, Gaylene Coulton, Elyse Maberley and Evan Nunn. Accepting their respective voluntary roles as interim Directors for our organisation has taken significant time, effort and skill to ensure that we have maintained a very high level of governance and oversight for our client service delivery, staff engagement, performance and culture and finances. I am particularly pleased that along with Megan, all three of these outstanding individuals are willing to continue to remain on the Board, subject of course to their election by our Members.

The achievements of the past two years would be too long to list in this report. However if I had to list my top three they would be as follows:

1. Securing office accommodation that honours the professionalism of our staff and supports our current and future client service delivery.
2. Finalising the new Strategic Plan to provide priority foci and accountabilities for the next few years
3. Strengthening governance processes and practices required to provide the necessary levels of confidence for our members and other stakeholders, in our capacity and capabilities in operating an impactful and trustworthy not-for-profit organisation.

In conclusion, I believe the Association can be proud of its many developments and achievements throughout the period and I draw everyone's attention to the Board News section of the MND Queensland website, via the homepage, to learn of new activities as they happen.

www.mndaq.org.au/About-us/Board-News.aspx

Peter Forday
Interim President (June - November 2020)

PAST PRESIDENT PETER DENHAM'S REPORT

It is with great pleasure that I report to you that your Association during 2019 had another year of strong growth and achievement.

Together, we have maintained strong membership and increased the number of our families applying for membership. The Association is very different from other MND organisations in that we are membership based and work for the people of Queensland with MND and their families as well as supporting our national medical research programs.

Another great and enduring strength is your participation in helping others and joining activities and events. Your participation this year has made a remarkable difference.

I wish to make special mention of the Wolters' family from Bundaberg that cycled around Australia in 2018/2019 and raised over \$60,000 for the MND cause and lifted the profile and awareness of MND wherever they went. We thank them for their amazing effort and achievement.

Our Association is a member of the national body - MND Australia. We thank the National President David Ali and now his successor David Lamperd and all the national board for their support and kindness. Our Associations around Australia are much stronger working together to find a cure and deliver national programs to support everyone living with MND.

Every year we cannot thank enough our Management Committee members, volunteers, support groups and staff team for their continuous dedication and service to not only our Association but to our Queensland communities.

I wish to mention the amazing service of David Schwarz who has served the Association since 2007. His wise counsel and guidance on the Management Committee has made the Association what it is today. Also, I wish to pay tribute to Graeme and Elizabeth Holyer who have served the Association for over 28 years and their dedication to our Association has made an amazing difference to people with MND living in the northern districts of Brisbane, and the growth areas of Caboolture and Burpengary. Special thanks go to all our Committee members - Moya Denham, Dean Palmer, and Megan Peach for their valuable contribution throughout 2019.

This year of 2020 is remarkably different as I write to you. What unprecedented times we are living through today and I sincerely hope you and your families are keeping safe during the lockdown brought about by the COVID-19 pandemic.

Rest assured that your Association is here for you and your family every day and every week. We are in a strong position and with the continuing support from everyone we will continue to provide the services and support that you need.

Sadly this will be my last report as I have taken the difficult decision to step down as your President after 10 years of involvement. It has been an absolute pleasure and honour to serve our Association in this role. We have seen a lot of change and advancement over recent years for which I extend a heartfelt 'thank you' to you and our committee for the effort you have all put in.

I know you will join with me to thank our Patron, The Governor of Queensland, His Excellency The Honourable Paul De Jersey and to all our Vice-Patrons. I wish the new committee and staff team every success for the future and I would like to thank you all for your support of the Association. I look forward to hopefully seeing many of you again at future events, and I hope you all remain safe during these difficult times.

Lastly, I wish to thank my wife and family for their support over the last ten years in helping me to serve you. *Never Give Up!*

Best wishes
Peter Denham

FORMER TREASURER ELIZABETH HOLYER'S REPORT

As former Treasurer, I'm pleased to present you with my 2019 report. The financials illustrate a very successful year of trading as a result of the wonderful support from members and their families and various communities around Queensland.

As at the close of 2019 our financials were strong and sound and this has enabled the Association to deliver excellent services.

We thank everyone for their amazing fundraising efforts and donations as well as the support of the Queensland Government and the Gaming Commemorative Grant and other grants to support our services. The financial support from the NDIS is increasing thus it is enabling the Association to provide new and innovative services.

My personal thanks must go to David Sneesby of Merrots (Accountants), bookkeepers and staff for their wonderful help in assisting with the preparation of this report. I also would like to thank Board members Peter, David & Dean and CEO Ian for their support and guidance during 2019.

I believe MND Queensland has a bright future and I am sure they will continue to support the people and their families living with MND.

On a sad note I made the difficult decision to resign as a Board member after serving for 7 years and have also stepped away from supporting the North Brisbane & Caboolture Support Group after 27 years. The changes my husband, Graeme, and I have seen in the advancement of research into MND and the growth of our Association over these years has been truly amazing. Lots of fun, tears and hard work, wonderful friendships and farewelling so many lovely people – I thank you all and will miss you.

Thank you
Elizabeth Holyer

Annual Financial Summary

Item	2019	2018
Total Income	\$1,108,017	\$887,176
Total Expenditure	(\$1,036,851)	(\$869,952)
Annual Result: Profit or (Loss)	\$71,166	\$17,224
Total Assets	\$1,245,644	\$1,153,832
Total Liabilities	(\$98,089)	(\$77,443)
Equity	\$1,147,555*	\$1,076,389

**N.B. Almost 80% of the 2019 Equity is Equipment and Property*

Source of Income by %

Income Source	2019 %	2018 %
Donations	49.5%	53.5%
Fundraising	37.8%	31.0%
Sale of Merchandise	1.2%	1.4%
Services	4.5%	4.9%
Government Grants	4.8%	6.0%
Other Grants	1.4%	1.9%
Other (inc Membership Fees)	0.8%	1.3%
TOTALS	100%	100%

CEO IAN LANDRETH'S UPDATE

The year began with Peter Denham, the Association President, in the role of Acting CEO. He undertook that role in a voluntary capacity with the agreement of the Management Committee until a new CEO was recruited to the role at the end of July.



Throughout the year, change has been a focus toward a new direction.

What has not changed is:

- The recognition of our history
- The respect for tradition
- The commitment to those with MND and those who care for and support them
- The dedication of skilled and compassionate staff to support Care until there is a Cure.

What has changed is a drive to establish a sustainable future for the Association through:

- Enhancing its reputation in service delivery
- Establishing best-practice business and community support systems
- Building on our relationships with other organisations throughout Australia who are working in the field of MND including the support of a search for a cure
- Benefitting from and contributing to a strong National Alliance of MND Associations and alignment to MND Australia

The registration as a provider of NDIS services this year has been a turning point for the organisation. It has been discussed for many years but is now in place and financially the goal is to see a diversification of our funding base. Historically the Association has benefited from the generous donations and philanthropy of its members and supporters with 80-90% of our revenue coming from that source. With the professionalisation of our service delivery, we are aiming to generate about 50% of our revenue from Service delivery and 50% from grants, donations and fundraising. If we can achieve that, we will be more robust in facing the challenges of an uncertain revenue stream.

The historical home that we have enjoyed at 35 Wedgetail St, Inala for 17 years, has been a testament to the generosity of many people and has placed us well to consider our next home. We have grown the Association and its business so much that particularly in the last 6 months of 2019, it was no longer able to hold our staff, or our equipment and resources and so as the year closed, we were already searching for our next home.

I would like to thank the Management Committee for the opportunity to work within this wonderful MND Community. I would like to thank our MND Community in Queensland for their ongoing generosity and the trust that they show in engaging us in their journey. I would like to thank my amazing staff for the dedication they show every day, where they give so much more than what is asked of them. The growth we are experiencing is in the largest part due to the excellent work they are doing.

Financially we have increased our revenue. Reputationally we have received more referrals from more clinics and Allied Health Professionals, supported research and delivered more services to more people. We have increased our standing in Queensland as the only MND-exclusive provider of services from within our own team. We have some exciting plans for 2020 and beyond to share with you if you join us on that journey.

MND QUEENSLAND SUPPORT SERVICES REPORT

2019 was a year of change for MND Queensland's Support Services. There were a number of staffing changes including the arrival of Stacey Thorpe in May in the newly formed role of Director of Services. Her focus on service delivery saw additional staff recruited in the second half of the year and the development of new processes to professionalise and enhance the delivery of those services.

The Equipment Service, which has traditionally been outsourced in terms of storage, inventory management and deliveries was brought fully inhouse. This was made possible due to the generous donation of a van that was able to be used for deliveries. This has allowed us to identify efficiencies, improve quality and more effectively distribute our equipment to those who need it, in a timely manner.

These improvements in our Equipment Service translate directly into increased income with 73% of Services income being received in the six months from July to December and 50% of the annual total in the final quarter alone.

There was also increased focus on transitioning the Equipment Service to provide NDIS funded hire. This led to 56% of 2019's total equipment hire income being NDIS funded. This figure is even higher at 71% based on the second half of the year alone. Maximising income generated from NDIS funded services allows us to maintain very low-cost hire arrangements for those people who are not entitled to NDIS funding.

We were very fortunate to be able to invest in a number of new equipment items thanks to generous grants from the Gambling Community Benefits Fund, Mazda Foundation and The Lord Mayor's Charitable Trust. These were used to purchase a number of electric beds, cough assists, hoists and slings, sit-to-stand recliners and a power wheelchair.

Additionally, the generous support of our community resulted in donations of two brand new NeuroNode communication devices, a number of eye gaze devices, power wheelchairs, manual wheelchairs, shower commodes, hoists and wheelie walkers. These items allow us to maintain a plentiful supply of equipment to provide to our client base and even led to us being able to support our colleagues in South Australia by providing them with some of the excess items for the benefit of people with MND there.

Another big change that occurred in 2019 was our successful registration with the NDIA to deliver Support Coordination services to NDIS-funded clients. We believe strongly in the value of people with MND receiving such supports from a specialist MND service and so our MND Advisors are best placed to provide this. This is a key growth area for MND Queensland and will significantly enhance the quality and scope of the supports that we can provide.

Whilst delivering NDIS funded services is vital given the disability sector has moved almost entirely into an individualised funding model, we are still committed to growing our supports for the clients aged over 65 that are not able to access the NDIS. Our MND Advisors continue to support this cohort of clients and we are particularly proud to have been able to assist a number of those clients access high priority, top level Home Care Packages through the My Aged Care system. This was achieved through attendance and advocacy at the ACAT assessments.

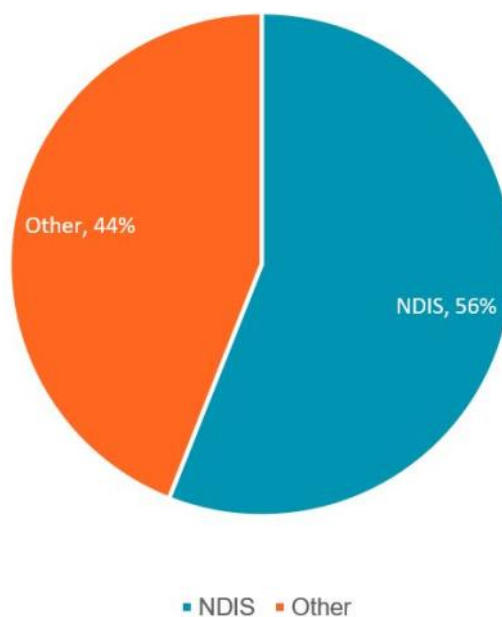
Towards the end of 2019 it became clear that the changes that the Support Services team were implementing were not well supported by the existing IT systems. Statistics were being captured manually which creates concerns about accuracy and reliability. To address this, research was undertaken to identify a cost effective client management system that would fully support all Support Services activities and reliably capture relevant client data for provision of services as well as reporting purposes whilst also maintaining capacity for continued growth. This led to investment in a new database and migration of client data completed by the end of 2019.

Throughout 2019, the Support Services team continued to provide supports to people living with MND across 147 different Queensland postcodes from as far north as Thursday Island, down to the Tweed border and out to Charleville. These services consisted of face to face visits, phone and email support as well as the facilitation of Support Groups. Additionally, the Support Services team continued to provide MND specific information to health professionals as required.

2019's activities and changes in the Support Services team has laid the groundwork for continued growth in 2020 with a focus on broadening the services on offer to our community whilst maintaining the high quality supports that are vital to people impacted by MND.



Equipment Hire by Source



Registered Provider



FUNDRAISING & COMMUNICATIONS ACTIVITIES

During the 2019 calendar year, MND Queensland enjoyed a boost in our fundraising income. This was due to several factors including appointing an Events Coordinator to manage our walks and introduce some other activities such as the Motor On for Motor Neurone Disease Car Rally.

2019 saw very strong community support with our third-party fundraising efforts bringing in over \$200,000! Some of the major fundraisers included the Wolters family 'One Year on Our Bike' campaign, 100 Miles for MND, Ice Bucket Challenge participants, a dinner at MODA hosted by two of our Board members (David and Dean) Mackay events such as the Chillfactor Challenge and MND Blue Tie Ball along with the inaugural Moranbah to Mackay Ride for MND, plus we had a large group participating in the Bridge to Brisbane. A stand-out competitor in the Bridge to Brisbane was Jared Ashcroft who ended up being the third-highest fundraiser overall for the event and went to a great deal of effort raising funds for MND Queensland including hosting a drag bingo night in Maleny. We appreciate each person who took the time to increase awareness on MND in the community and raise vital funds at the same time.

We were also successful in securing a major grant from the Gambling Community Benefit Fund's Commemorative Grant Round as well as grants from The Mazda Foundation, QUT Staff Welfare Fund and a grant from the Brisbane Lord Mayor's Charitable Trust. These grants allowed us to purchase vital equipment to make available to our clients.

There were four 'Walk to D-Feet MND' events during 2019. Walks were held on the Gold Coast, Brisbane, Toowoomba and Redcliffe. Combined income from all of our walks totalled over \$140,000 (this includes registrations, donations, merchandise sold on the day as well as raffle income). We appreciate every participant and donor who contributed to the walks along with all of the volunteers who helped them run so smoothly.

Four donor appeals were conducted throughout the year (Easter, Tax, Spring and Christmas) asking our supporters to support our work by making a donation. The 2019 Tax Appeal netted an amazing total \$87,605 from our donors which beat the previous year's record income of \$86,575. Thank you all for believing in our work and being on this journey of support with us.

As previously mentioned, this year we hosted our very first Moranbah to Mackay Ride for MND. The event was the concept of Michael Scholer who is a local in the area and had been very supportive of our previous Chillfactor Challenge and MND Blue Tie Ball events over the years. This new event gathered a bunch of riders to take up the task of riding 234KM from the mining centre of Moranbah to Mackay in just one day. It was a great success with many sponsors coming on board and we look forward to helping Michael host the event again in the future.

Three newsletters were created in 2019 and sent to clients and supporters in with editions of 'The Cornflower' released in autumn, spring and summer. Three electronic newsletters were also emailed to our clients and supporters who choose to receive email communications.

Social media followers and engagement have grown with Facebook being our main form of engagement with our supporters, but we have also seen growth in our Twitter and Instagram following. Every post that is shared helps us get our messages out, so thank you to everyone for liking and sharing our posts.

FUNDRAISING EVENT PHOTOS

Moranbah to Mackay Ride for MND



Chillfactor Challenge and MND Blue Tie Ball at Magpies Sporting Club, Mackay



Wolters Family 'One Year on Our Bike' Challenge



Motor On for Motor Neurone Disease Car Rally



FUNDRAISING EVENT PHOTOS CONTINUED

Walk to D-Feet MND Gold Coast 2019



Walk to D-Feet MND Toowoomba 2019



FUNDRAISING EVENT PHOTOS CONTINUED

Walk to D-Feet MND Brisbane 2019



Jared's Drag Queen Bingo Fundraiser - Maleny





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

Motor Neurone Disease Association of Queensland Inc.

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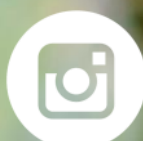
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Phone: 07 3372 9004

ABN: 75 990 922 939



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Never Give Up!