



2021 ANNUAL REVIEW

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND INC.



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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



MND Queensland Staff - (L-R) Standing: Jason Russo, Sonia Dziewierz, Ian Landreth, Stacey Thorpe, Hannah Woods, Jeremie Alexis, Sandra Biffin & Leigh Gilbert. Kneeling: Simone Morison, Jason Russell, Caitlin Mulcahy, Salma Charania & Sue Wells



2021 editions of The Cornflower



PATRON

His Excellency the Honourable Paul de Jersey AC, Governor of Queensland (until retiring in 2021)

VICE PATRONS

Assoc Prof Robert Henderson, Neurologist

Prof 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 2021 was the responsibility of the volunteer Management Committee (Board).

2021 MANAGEMENT COMMITTEE

President - Gaylene Coulton
(departed in 2021)

Secretary - Julia Rollston
(commenced in 2021)

President - Diana Melham
(commenced in 2021)

Treasurer - Evan Nunn

Vice-President - Elyse Maberley

Board Director - Suzanne Graham
(departed in 2021)

Secretary - Megan Peach
(departed in 2021)

Board Director - Jacqui Williams
(commenced in 2021)



Diana Melham



Elyse Maberley



Julia Rollston



Evan Nunn



Jacqui Williams

OUR STAFF IN 2021

Chief Executive Officer
Ian Landreth

Office Administrator
Sonia Dziewierz

Equipment Support Officer
Don Moyle

Director of Services/CEO
Stacey Thorpe

MND Advisor/Support Coordinator
Jason Russell

Occupational Therapist
Jeremie Alexis

Client Services Manager
Lisa McIlroy

MND Advisor/Support Coordinator
Sandra Biffin

Occupational Therapist
Peta Stimson

Fundraising and Communications Manager
Jason Russo

MND Advisor/Support Coordinator
Simone Reid

Occupational Therapist
Hannah Woods

Events & Fundraising Coordinator
Caitlin Mulcahy

MND Equipment Officer
Sue Wells

Speech Pathologist
Salma Charania

Membership & Community Liaison Coordinator/Client Services Coordinator
Leigh Gilbert

Equipment Support Officer
Andrew Parker



We acknowledge the contributions of our Foundation Members who built our organisation along with our Life and Honorary Members who have given so much serving and growing MND Queensland 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
2020 Louise Stanford
2020 Wayne Stanford

HONORARY MEMBERS

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



It is a privilege to present the 2021 MND Queensland Annual Review to our members, clients and supporters, particularly given our success, and continued growth.

I joined the Management Committee in July 2021 having already worked with the existing members for some time. In October I was honoured to be appointed President when Gaylene Coulton stepped down. The dedication and professionalism of the Management Committee and staff inspired me to want to contribute more to the organisation and its very important cause. As my involvement has grown, I can definitely say MND Queensland's most valuable asset is its amazing people.



While MND Queensland has experienced exceptional growth and considerable change over the last couple of years, none of this would have been possible without the strong foundations laid by our original members. The efforts of these individuals as well as our Life and Honorary members and every person that has served on our Management Committee, is the reason MND Queensland is in the strong position that it is today.

I wish to acknowledge the contributions of Megan Peach, Sue Graham, and Gaylene Coulton during 2021 and to thank Jacqui Williams and Julia Rollston who joined us part way through the year. I'd like to give particular thanks to Evan Nunn as Treasurer and Elyse Maberley as Vice President and MNDA Board member for their dedication and constancy throughout the year, and since they joined in 2020. At MND Queensland, we are very fortunate to have benefitted from the expertise of these individuals and I am sorry to announce that Evan and Jacqui have decided to resign from the Management Committee at the AGM. Their contribution has been invaluable, and we will miss their knowledge and steady guidance. It is sad to say goodbye, but their commitment to MND Queensland and our cause remains. Any organisation will always benefit from different perspectives and experiences, so we look forward to welcoming new colleagues.

I would like to commend the staff on their immense effort. Each gives considerably of themselves and their dedication to our community is unparalleled. We farewelled Ian Landreth in December, retiring after two and half years as CEO. Ian will long be remembered for his impact on the organisation and as the driving force behind the improvements that occurred during his tenure. It is a sign of a strong and resilient team when an existing staff member can step into the leadership role, with the full endorsement of the outgoing CEO and Management Committee, so we were very fortunate to have Stacey Thorpe, formerly Director of Services, take over as CEO. Stacey has brought her drive and passion to the role and in the past six months has continued to drive the organisation's success.

2021 saw a significant increase in fundraising events from the previous year and we are always grateful for the effort, creativity, and humour our community puts into third party events. I thank each and every person that was involved in organising and attending these events. Particular acknowledgement goes to the wonderful Jo Boon and her family for their spectacular hosting of JoJo's Glitter Gala. From all reports, it was an amazing, and very emotional event that raised a massive \$51,000!

We also benefited from some very generous individual and corporate donations. Each of these contributions is vital for our continued success and I want to specifically acknowledge Fight MND who provided us with an incredibly generous grant exceeding \$400,000, for investment in purchasing mobility aids and operating our equipment hire service.

Lastly, but most importantly, the people that really shape MND Queensland are those that are currently, or have been impacted by MND. It is for you that MND Queensland exists, and we thank you for letting us be part of your journey and for trusting us to support you at such a difficult time. We seek to repay that trust with our steadfast focus on quality service and on finding new and innovative ways to meet our community's needs, such as launching Australia's first MND specific Speech Pathology service.

Diana Melham, MBL, GAICD, AGIA
President



Sadly, this will be my last report as Treasurer of MND Queensland as I have made the very difficult decision to resign from the Management Committee. I joined the Management Committee in 2020, initially as an interim director, and committed to supporting the organisation through a strengthening of governance practices and transitioning to a sustainable and resilient operational model focussed on Service delivery. Those goals have been realised and this is reflected in 2021's financial results.

It was another year of record revenue despite the Government COVID supports ceasing in 2020. Whilst the impact of COVID continued to be evident in terms of lockdowns and gathering restrictions limiting planned events, we did see a partial recovery of our fundraising and events revenue. Services continued to be the main source of revenue and whilst services growth comes with increased costs, mostly in relation to wages, this translates directly into increased assistance for people impacted by MND.

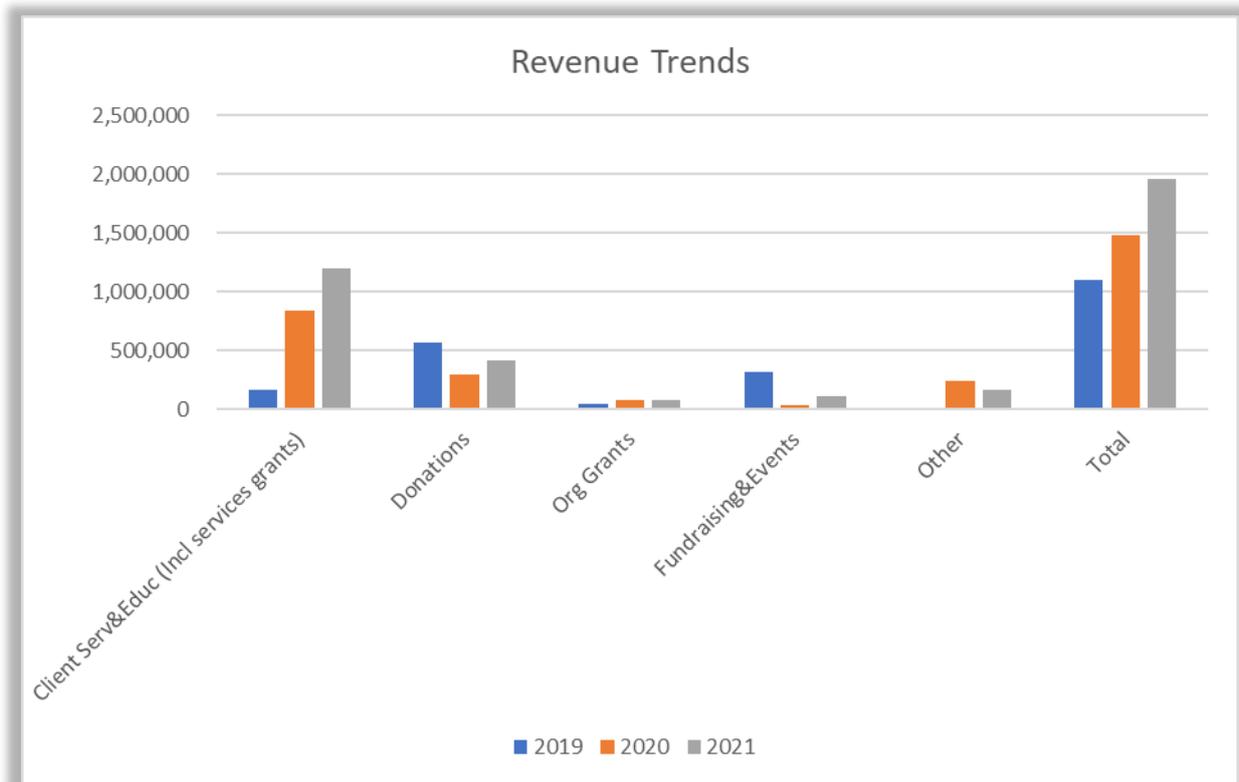
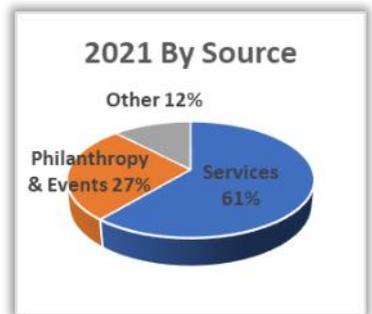
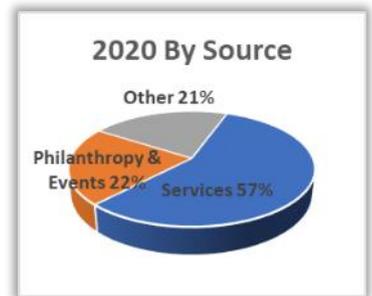
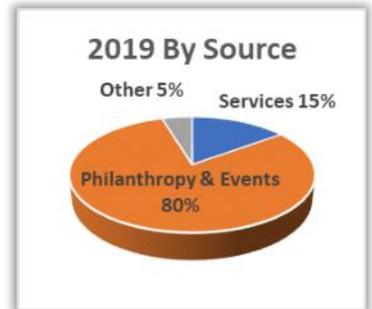
Our asset base increased due to donations and purchases of equipment, and the investment in 3 new vehicles as well as through maintaining our cash reserves.

Overall, 2021 financial results are really encouraging and demonstrate steady and consistent growth, and I am delighted to be able to leave the organisation in such a strong position as well as with an established reputation as a provider of quality MND specific services. All these factors provide for a very positive outlook where future diversification and continued growth can be supported through existing resources.

I am delighted to see that by focussing on supporting our members in as many ways as we can, Stacey Thorpe and her Team are leading this very important Queensland focussed organisation in a viable direction.

I would like to thank my fellow Directors, the staff and Ian Landreth the former CEO. Each one of them made a significant and vital contribution to the organisation's success. My decision to resign my post was made much easier by the knowledge that the organisation is in good hands, and I will continue to be a strong and active supporter of MND Queensland.

Thank you
Evan Nunn, BBus Man. Acc. CPA, AGIA, GAICD, AFAIM





Whilst I have the pleasure of providing the update for 2021, which was another year of exceptional growth amidst numerous challenges, it was Ian Landreth that occupied the CEO role for the year. Ian would be the first to say that no organisations performance can be attributed entirely to one individual, but Ian's contribution was immense. He joined the organisation at a time of uncertainty and was the driving force behind what is likely, the biggest period of change and growth in MND Queensland's history. He left an organisation that has established itself as a provider of a range of quality MND Specialist Services which has demonstrated its resilience during unprecedented times.



At MND Queensland we always ask ourselves “*what more can we do for the Queensland MND Community?*”

In 2021 we answered this question with “more events, more fundraising, more awareness raising, more staff, more equipment, more vehicles, more volunteers, more interactions, more collaborations, more online activity, more innovation and, to achieve all this, more revenue”

But what it really comes down to is being able to deliver services to *more people* in *more ways* and that certainly happened in 2021.

There was no reprieve in the disruption caused by the COVID 19 pandemic but we didn't let that slow us down because, just as our community will 'never give up', neither will we! In a world where many charities have struggled just to survive, we have gone from strength to strength!

I would like to personally thank the Management Committee for putting their trust in me to lead this amazing organisation and for their tireless support of the cause. I would also like to thank my fantastic team who show their dedication, determination and compassion every single day.

One of our highlights for the year was being awarded the Voice Project Workplace of the Year Award. This shows that, despite the many challenges that the staff have faced, they take great pride in what they do and who they work for. And whilst MND Queensland might be the employer, it is the Queensland MND Community that we really work for. It is you that inspires us to want to be the best we can be. We get to see the very best of humanity in endless acts of care, kindness and generosity both within families and between them, in times of personal hardship. This is incredible and the fact that it is done with such grace and humour is humbling.

Thank you all for not just letting us be part of your journey but for making it possible for us to support others now and into the future. 2022 will see us do *even more*. More of what we currently do, and more new offerings so watch this space!

Stacey Thorpe
Chief Executive Officer





Our services offering improved in 2021 and we continued to find new ways to provide support, not only to our clients but also their families.

MND Queensland is the only organisation in the State providing a range of specialist support services to people living with MND. 2021, being another year of growth saw us expand our services in the areas of Speech Pathology and the Life Stories Program. Our Speech Pathology Service is Australia's first MND-specific service of its type. Our Life Stories Program is managed by a group of dedicated volunteers headed by Miriam Cafer, who stayed on as a volunteer at MND Queensland after leaving her position as an Occupational Therapist for personal reasons, which really reflects her commitment to the cause and the organisation.



The income generated through Support Services was significantly higher in 2021 than 2020. In fact it was significantly higher than ever before in MND Queensland's history with Services revenue increasing by 43% from 2020. This is the result of our continued focus on quality service delivery and increasing the capability of the support services team. Whilst income generation is vital to the sustainability of the organisation, what continues to be the most impressive measure is the quantity of engagements the team has with people impacted by MND. In 2021, the team had more than 9873 interactions with 293 MND sufferers, this represents an increase in engagements of 46% from 2020.



We pride ourselves on the services we provide and our Equipment Hire Service is second to none. In 2021 our service grew to meet the needs of the MND community and we delivered hundreds of items of mobility and assistive technology to clients all over Queensland. This service grew by 44% from 2020.

The MND Advisors were responsible for the vast majority of client engagements delivering over 3784 hours of specialist support across both NDIS and non-NDIS funded clients, an increase of 160% from 2020. MND Queensland Advisors continue to provide quality support to our non-NDIS clients despite no funding to do so. Whilst the lack of funding makes this increasingly challenging, we are committed to supporting the whole MND Community and will continue to advocate for this inequality to be addressed.



The Speech Pathology Service was established in August and the decision to implement this much needed service was due to our specialist knowledge of MND and its progression and therefore the impacts of MND on voice/speech and swallowing. The Occupational Therapy Service continues to go from strength to strength and together with our Support Coordination makes MND Queensland the only provider of integrated multidisciplinary MND-specific services.





In 2021 we continued to gather online using video conferencing technology, what started as a COVID-19 initiative has continued, making it easier for both clients and carers to join and take part in these support groups and educational presentations. These presentations are made available to everyone impacted by MND and the MND community via our website.

MND Queensland support services benefited again in 2021 from a significant grant from Fight MND, the grant provided by Fight MND was in excess of \$400,000 towards the purchase of a range of equipment together with the operational costs of the Equipment Hire Service. This resulted in the purchase of much-needed equipment including a number of electric beds, power wheelchairs, recliners, and cough assist machines.

Our Equipment Hire Service has also received many generous donations from families all over Queensland that have lost loved ones to MND, linking people with MND to vital equipment support. We would like to take this opportunity to thank all the families that have generously donated equipment that we continue to use to support those living with MND and their families and carers.

MND Queensland continued to work closely with the other State Associations at all levels of the organisation. From a Services perspective, this collaboration has led to shared knowledge and expertise as well as the development of high quality resources for our community such as the End of Life guide.

In 2022 MND Support Services will continue to grow in an effort to provide a broad range of services to the MND community and in response to the people we serve.

Lisa McIlroy
Client Services Manager

- ### SERVICES DELIVERED
- MND Advisory Service
 - Support Coordination
 - MND Support Groups
 - Equipment Hire Service
 - Occupational Therapy
 - Speech Pathology
 - Life Stories Program
 - Education



'What I do really like is getting online and talking to the other people when we have the group sessions because we get to talk and I've made friends with them.' - Liz

'We couldn't ask for a better advocate to speak on our behalf and work in the background.' - Marjorie

'Myself, as a carer, have had nothing but support from MND Queensland... MND Queensland have been absolutely fantastic.' - Lesley



Life Stories Program Volunteer Training



Flowers received to say 'thanks' for our work



Andy delivering equipment



It was fantastic to see our events return in 2021 after we saw almost every event cancelled in 2020 due to COVID-19 although we did still experience some event postponements and cancellations due to lockdowns. Our fundraising income also bounced back a little in comparison to 2020, but still not to pre-pandemic levels.

Our four annual appeals continued to perform well and 2021 saw an appeal income of over \$144,000, our highest appeal income in the organisation's history. The Spring Appeal - which asked for support for our Voice Banking Clinic - performed particularly well with an income of around \$59,000.

We received generous sponsorship from Hello Mobility to set up our Therapy and Learning Centre which will be used to host meetings (both in-person and online using state-of-the-art video conferencing equipment) and will be used as a client consultation space for our allied health services as well as a recording space for our Voice Banking Clinic.

One of the biggest programs that MND Queensland offers is our Equipment Hire Service and we took on the warehousing, delivery and maintenance of our equipment in 2020 and were able to do this thanks to the generous donation of a commuter bus. Unfortunately the bus wasn't designed for this purpose so we needed to get a dedicated delivery van. Commercial Mine Recyclers in Mackay heard about our need and made a generous donation which allowed us to purchase a new delivery van.

MND Queensland works with MND associations in other States on fundraising and awareness activities and we continued this strong partnership in 2021. A national Drink Tea for MND week and day were planned which worked very well in Queensland raising well over \$16,000, but unfortunately other States experienced COVID lockdowns and didn't do as well as Queensland did. Together we also held our first national Walk to D-Feet MND day with Springfield being the venue for the Queensland event.

A new event that we introduced in 2021 was the Blue Cornflower Tribute Ceremony which was held during MND Awareness week to watch the Story Bridge light up in blue and pay tribute to those battling MND and remember those that we have lost. It was a touching ceremony that was positively received by the community so we will add it to our annual calendar.

We also saw third-party fundraising return in 2021 as COVID restrictions eased and our supporters were more confident that they could host fundraisers. A major gala event, JoJo's Glitter Gala was hosted by the Boon family in November and raised over \$51,000 for MND Queensland.

Other major third-party fundraisers included Spiecapag whose Brisbane Marathon team raised over \$10,000, and the Scody MND Over Matter bike ride from Brisbane to Wynnum and back which raised over \$9,000. We appreciate everyone who supported us including those that put on events year after year including the Bundaberg Early Holden Owner's Club and the Thuringowa Bowls Club in Townsville.

Ray Graham sadly lost his wife, Alison to MND and he was determined to do something to pay tribute to her, so he raised \$5,000 and then approached The Freemasons charity, Hand Heart Pocket who matched Ray's fundraising effort which saw \$10,000 go towards MND research.

Grants are an important source of funding support for MND Queensland. Along with the generous Fight MND grant previously mentioned in this review, we were also successful with a grant from Brisbane City Council which allowed us to replace our photocopier. Our one fleet vehicle was in high demand with our growing team, and we were delighted to be awarded a grant from the Gambling Community Benefit Fund which allowed us to purchase two Kia Picanto hatchbacks which means we can be mobile for the MND community. The CommBank Staff Foundation heard about our fantastic work and we were invited to submit a grant application which was successful and they awarded \$10,000 to MND Queensland to support us.

MND Queensland receives no recurrent government funding. The support of the community is very important for us to continue providing services and support to those impacted by MND, so we genuinely appreciate every donation, fundraiser, event participant, volunteer or social media share. Thank you.

Jason Russo
Fundraising, Marketing and Communications Manager



Blue Cornflower Day Tribute Ceremony



Various Walk to D-Feet MND Events



New Delivery Van & Fleet Vehicles



Various Third-Party Fundraising





ABN: 75 990 922 939
1/89 Factory Road
Oxley QLD 4075
PO Box 470
Inala QLD 4077
Phone: 07 3372 9004
Email: info@mndaq.org.au
Web: www.mndaq.org.au



until there is a cure, there is care