

ANNUAL  
REPORT  
2023



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## ACKNOWLEDGEMENT OF COUNTRY

MND Queensland acknowledges the Traditional Custodians of the lands and waters on which we live and work, and pay our respects to Elders past, present and emerging.



Left to right: Julia Rollston, Diana Melham, Paul King Koi, Katie Choi, Stacey Thorpe

# PRESIDENT'S REPORT

I am pleased to provide my 2023 report to our members, clients, and supporters for MND Queensland's 40th Anniversary year.

For 40 years MND Queensland has been working hard to make it that little bit easier for people with MND and their loved ones. We have grown to the point where we now provide a wide range of vital, MND expert services in several locations across the State. Our integrated multidisciplinary model of care is backed by research and recognised internationally as best practice.

In September, my fellow Management Committee members along with CEO Stacey spent two days strategising on how we can make our Mission (*to ensure access to best practice care and support for every Queenslander impacted by MND and contribute to finding a cure*) a reality; looking at innovative ways of expanding care and support services so Queenslanders with MND, no matter their location have access to services within their own communities.

Our strategy has five core pillars and deeply embeds our values of excellence, community, inclusiveness, innovation, and integrity. In January, we shared our strategy with members, and it was very pleasing to receive such positive feedback from the community that we are committed to supporting. If you haven't seen it yet, the 2024 - 2026 Strategic Plan is available on our website.

## Strategic Pillars:

1

Enhance and expand *care and support* for clients, their families, friends, and carers.

2

Build and sustain *connection and community*.

3

Deliver *education*, build *awareness*, and provide *advocacy*.

4

Promote and support research into care, cause, and cure for MND.

5

Ensure *sustainability* and enable growth.

Part of my role as President of MND Queensland includes serving as a director of MND Australia. Working with my state counterparts and fellow independent directors, we have overseen significant change in the past 12 months to ensure our national body is sustainable, relevant and a united voice representing Australia's MND community. Changes include

development of a new fit for purpose constitution which facilitates transition to a company limited by guarantee and providing a robust governance structure, and the appointment of a new CEO, Clare Sullivan, to lead the organisation into its next exciting phase. It is pleasing to see the positive working relationships and shared passion of Stacey, Clare and their State colleagues which provides enormous benefit to our MND organisations and communities. The national network is extremely valuable and brings a unique strength built on collective expertise, collaboration, and mutual respect.

During the year we received some much-needed financial support. The \$250,000 State Government donation was a welcome endorsement of our organisation, the care we provide and the vital role we play in the lives of Queenslanders with MND. FightMND provided us with a \$250,000 community capacity building grant which is being used to enhance both our volunteer program and education services, as well \$150,000 for care packages for clients not eligible for NDIS funding.

I would like to acknowledge our founding President John Wearne and his fellow founders of MND Queensland for their vision 40 years ago, and the Management Committee members who have served over the past 40 years.

This year, we welcomed Paul King Koi and Eric Holgate to the Management Committee who, along with Keith Malpress, enable increased input from individuals with lived experience, as well as enhancing the diversity of skills and experience brought by fellow Committee members Elyse Maberley, Julia Rollston, and Katie Choi. I would like to express my appreciation to Elyse,

Julia, Katie, Keith, Paul and Eric for their time, effort and support throughout the past year. I feel privileged to be part of a professional, committed, and collegiate leadership group.

MND Queensland's Values:

**Excellence:** Our commitment to people impacted by MND is the fundamental basis for all we do and drives our high quality, person-centred, care and support.

**Community:** We foster positive and supportive relationships by enabling connection, sharing resources, and advocating for the interests of people impacted by MND.

**Inclusiveness:** We respect and value each and every member of the MND community.

**Innovation:** We seek to be at the forefront of best practice and opportunities that improve the quality of outcomes.

**Integrity:** We are ethical in all our practices.

The compassion and commitment of our fantastic MND Queensland team continues to inspire; the dedicated staff who provide highest quality support and care and develop innovative ways to raise funds and awareness of MND itself and MND Queensland, our volunteers who work tirelessly to ensure the success of our events and activities, and our CEO Stacey whose transformational leadership continues to drive our organisation forward.

Finally, to our members, clients, and the wider MND community, you are the reason MND Queensland exists. It is a privilege to be part of the team committed to supporting you through such an extremely challenging time.

Diana Melham, MBL, GIACD, FGIA  
President





# TREASURER'S REPORT

I am pleased to present the Treasurer's report for the 2023 financial year. I have had the pleasure of holding the role of Treasurer throughout the financial year and am delighted to see the organisation continuing to grow for the benefit of Queenslanders impacted by MND.

In 2023, MND Queensland achieved another record year for revenue in both service delivery and fundraising.

During 2023, MND Queensland has increased its MND Advisory staff which sees us extending our service into regional Queensland. Whilst the increase in number of staff has not immediately resulted in a proportionate increase in revenue, this is largely due to the increased focus on delivering quality services to those people who are not entitled to NDIS funding, who therefore have no means to pay for the supports we provide. Additionally, we had introduced free equipment loans for people with MND over the age of 65, who are either without funding or have fully utilised it for other vital services.

From a fundraising perspective, we were very grateful to receive a generous donation of \$250,000 from the Queensland State Government that contributed to us achieving a new record for fundraising revenue in our 40th anniversary year.

We are strongly advocating for the State Government to provide recurrent funding to support us to continue to deliver services outside of those funded by NDIS plans.

We are also grateful for two very generous grants provided by Fight MND that allowed us to further enhance the supports we provide to the MND community. These funds totalled \$400,000 and cover the 2023 and 2024 financial years. The entirety of the funds are not fully reflected in our 2023 results.

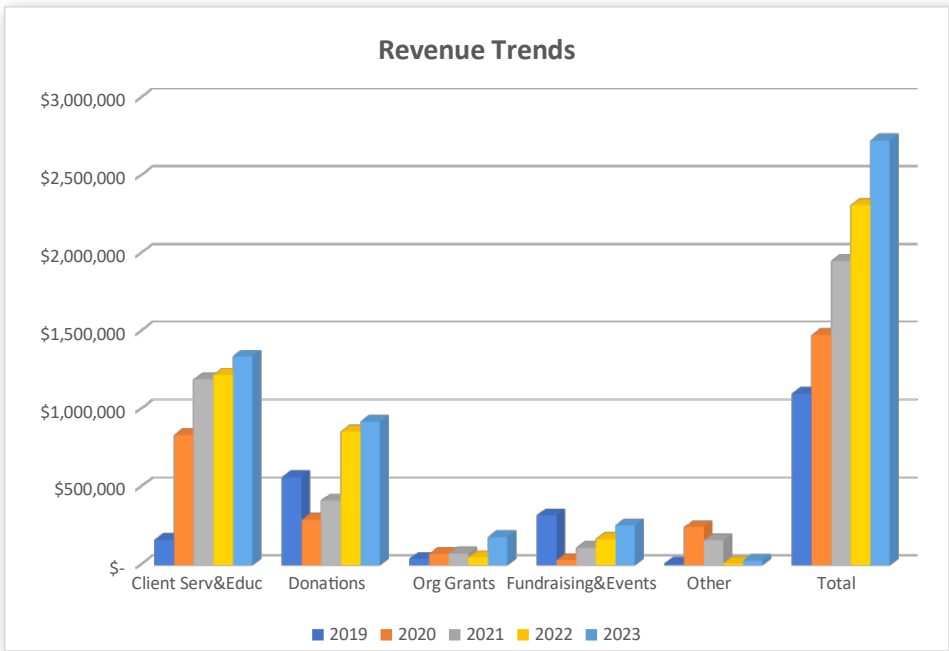
MND Queensland did experience a loss of \$268,736 for the 2023 financial year. It should be noted that this reflects our services growth strategy to establish a presence in the regions, the long-term benefits of which may not be immediately recognised.

The deficit for the year can be largely attributed to depreciation on our equipment assets and lease value, which are non-cash expenses, as well as the increase in free services for our clients over 65 and a reduction in donations in

kind, as our warehouse is at capacity for mobility equipment.

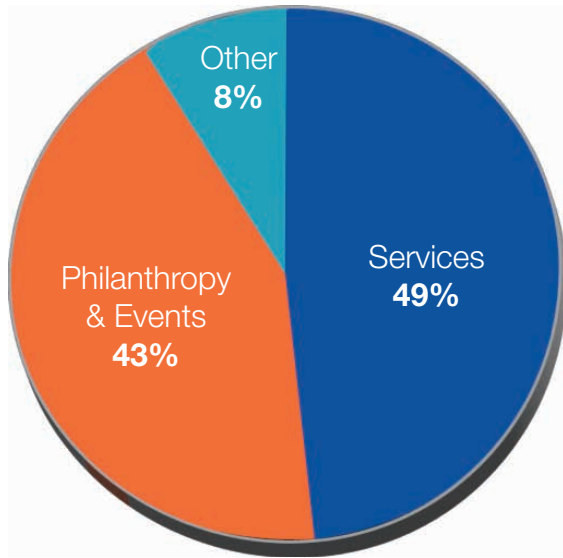
Notwithstanding the above, we maintained a positive cashflow, despite increased expenses on salary costs. Our members funds remain substantial, and we are confident that we have sufficient funds to continue to invest in our ambitious 2024-2026 strategy.

Katie Choi,  
BEc, LLB, LLM, GradDipAppFin, GIACD, FGIA,  
FCG (CS, CGP)  
*Treasurer*

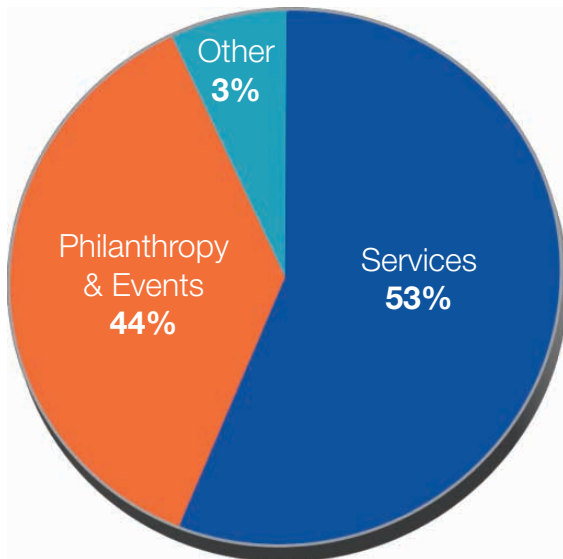


\*Excludes donations in kind

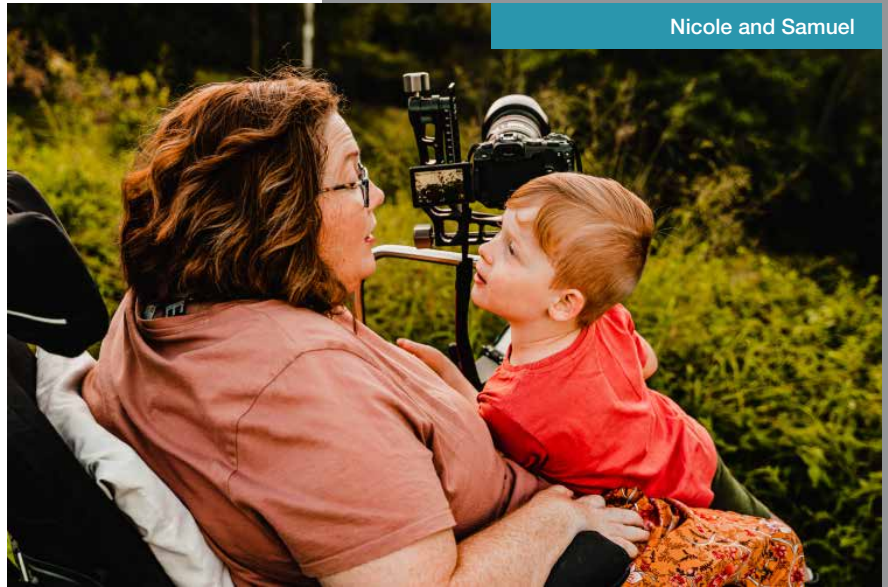
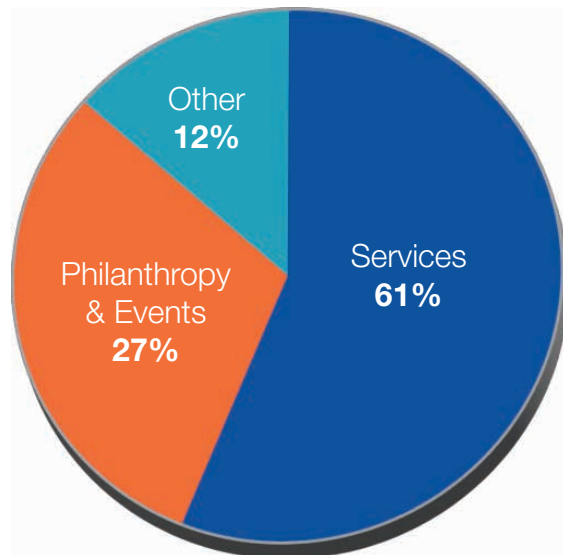
### 2023 By Source



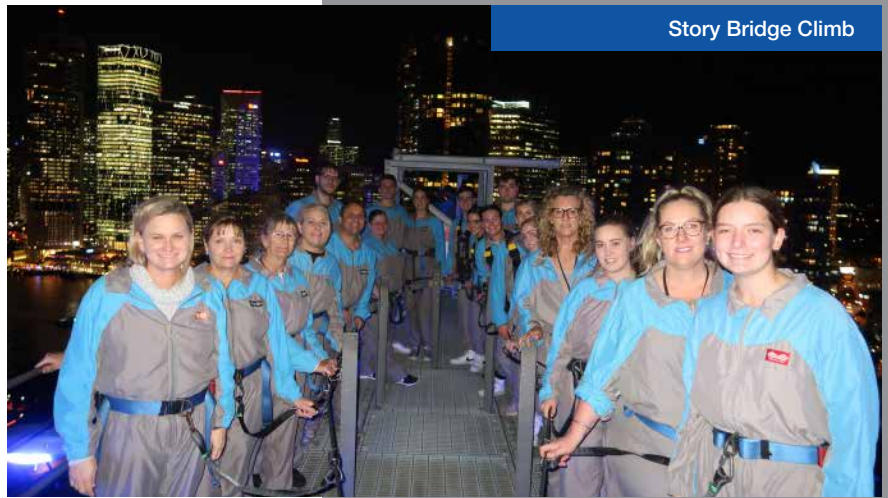
### 2022 By Source



### 2021 By Source



Nicole and Samuel



Story Bridge Climb



Craig and Sandy



# PATRONS & BOARD

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 OAM  
John Wearne AM  
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

## HONORARY MEMBERS

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

## 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  
2022 Karen Mowles

## VICE PATRONS

Assoc Prof Robert Henderson, Neurologist  
Prof Pamela McCombe, Neurologist

## PRESIDENT EMERITUS

John Wearne AM

## GOVERNANCE STRUCTURE

The Governance of the Association in 2023 was the responsibility of the volunteer Management Committee (Board).

## 2023 MANAGEMENT COMMITTEE

**President:** Diana Melham  
**Vice-President:** Elyse Maberley  
**Secretary:** Julia Rollston  
**Treasurer:** Katie Choi  
**Board Director:** Keith Malpress  
**Board Director:** Paul King Koi  
*(commenced in 2023)*  
**Board Director:** Dr Eric Holgate  
*(commenced in 2023)*



Julia Rollston



Diana Melham



Elyse Maberley



Keith Malpress



Katie Choi



Paul King Koi



Dr Eric Holgate

# CEO'S REPORT

**2023 was without doubt, our biggest year yet at MND Queensland. It is difficult to believe that we managed to fit so much in! I have an immense amount of pride in what we've achieved as well as eternal gratitude to every person that played a part in those achievements.**

But before I get into the positives, I want to acknowledge every person lost to MND during that time and the pain and heartbreak of the loved ones left behind. I also want to recognise each and every person that received an MND diagnosis in 2023 and the families and friends that have stepped up to offer their unwavering support. For those that have trusted us to be part of that journey, please know that we never take that trust for granted. I want our members and supporters to know that we take the time to mark the passing of every Queenslanders lost to the disease, to remember who they were as a person and the impact they made on the world. It is a regular reminder of our 'why' and ensures that every member of our team is connected to the cause.

It is this connection to our community that makes us so passionate about supporting every Queenslanders impacted by MND and providing the best quality service possible. And so, when I reflect on our accomplishments in the last year, it is really difficult to pick out just one so instead I'm going to go with a top 3!

Firstly, we grew our team from 16 at the start of the year to 26 at the end of it. Our primary purpose is to deliver MND expert services to Queenslanders and in order to do that, we need enough people with the right skills and expertise to be able to provide the extensive supports a person with MND requires. This staff growth is critical for us to be there for EVERY Queenslanders impacted by the disease.

Secondly, we expanded our MND Advisory Service into the regions. We have heard our clients tell us that they want local services so we established ourselves in Cairns and Townsville and grew our capacity on the Sunshine Coast. We know there is more to do in this respect but it is a fantastic start!

And thirdly, we received a \$250,000 donation from the Queensland Government. This demonstrates that our State Government recognises the importance of MND expert supports for Queenslanders and MND Queensland as the leading provider of those supports. This was a one off so we need to continue to advocate for recurrent funding but the donation was an important first step in achieving that.

These are just some of the amazing things our team achieved and I would be remiss not to mention the many wonderful events and opportunities for connection that our fantastic fundraising team coordinated. The annual Blue Cornflower Tribute night is my favourite event on our calendar and last year was the best one yet. Our gala was also a wonderful celebration of our 40 years of dedicated service to the MND community.

But none of what we have achieved would have been possible without the support of that MND community and so I want to thank you all. Our Management Committee give so generously of their time and expertise to ensure we maintain the standards that our community deserve. Our staff and volunteers are so passionate and capable that it is a privilege to be part of the team. Our colleagues in the MND clinics and community health roles are genuine partners in MND care.

Our colleagues at MND Australia and the other state MND associations share the same vision of best practice care for all Australians with MND and are generous in their support and advice and consistently collaborative in their approach. Our supporters and donors are some of the most generous and genuinely caring people that exist.

Jo Boon, Stacey Thorpe, Anastacia Palaszczyk, Hon Shannon Fentiman MP



And our clients and their families are inspiring. They challenge us to be the best we can be, they motivate us to do more and they go out of their way to show their gratitude despite having so many more things they could be thinking about instead of thanking us!

Until there is a cure, there is care and thanks to each and every one of you, MND Queensland will continue to contribute in every way we can to helping Queenslanders with MND live better for longer!

Stacey Thorpe  
*Chief Executive Officer*

A world free of  
Motor Neurone Disease.



# SUPPORT SERVICES REPORT

**The services team continues to focus on delivering responsive, client-centred care to all Queenslanders who have been diagnosed with MND.**

Whilst I may not have been part of this amazing team in 2023, I have stepped into the role at the beginning of 2024 and have already seen the significant impact that MND Queensland's Services Team has on our clients and their families. The passion and commitment our team has is awe-inspiring in the face of this dreadful disease. Our team supported 399 clients in 2023, and I'd like to acknowledge their resilience in the face of having lost 123 of our clients to this disease in the same period of time. I offer my sincerest condolences to our clients' loved ones and want to reassure you that MND Queensland continues to be here for you.

The 2023 year saw the MND Queensland Services Team work towards furthering our mission of ensuring access to best practice care and support for every Queenslanders impacted by MND. This was firstly evident through the expansion of our MND Advisory & Support Coordination Services beyond the metro areas of South-East Queensland and into the regional areas of Townsville and Cairns. We are excited to be able to offer "on-the-ground" support to our clients in these regions and also provide a more local service to clients in other regional areas in North Queensland. In 2023, our MND Advisory & Support Coordination Team delivered almost 1,000 more hours of support to clients than in 2022 – an 11% jump in 12 months.

Secondly, MND Queensland were successful in obtaining a grant through FightMND to support the development and rollout of educational programs for people with MND and their loved ones. As an organisation, we understand that best-practice care includes improving the health literacy of our community. A dedicated Education Program Manager was hired in 2023 and work began to develop our initial education offering. This included a Newly Diagnosed Workshop and a practical, hands-on Manual Handling Training Session for informal carers.

It is hoped that 2024 will see these sessions be held regularly across the state (and online) with further education topics to be added through a co-design process with our clients.

We continue to acknowledge the significant inequity experienced by our clients who are over 65 at time of diagnosis and are therefore unable to access the NDIS. With clients over 65 receiving less than a quarter of the funding their younger counterparts received, MND Queensland worked hard to reduce the inequity. In July of 2023, we received a FightMND grant enabling us to provide short term care packages to clients to access free allied health, advisory, and equipment. This saw us provide these clients with 2,469 episodes of advisory support, 269 client interactions with our allied health services, and 308 pieces of equipment were provided free of charge.

We are keen to look at ways we can support our over 65's across regional areas in 2024, including exploring the viability of telehealth services and through supporting regional practitioners.

Unfortunately, MND Queensland was not immune to the significant workforce shortages and challenging operating environment experienced right across the disability sector nationwide in 2023 (NDS 2023). Staff turnover in the latter part of 2023 had a negative impact on our capacity, and subsequently our revenue, with both allied health and advisory services affected.

Our commitment to ensuring that Queenslanders with MND receive the care and support they need in a responsive manner meant that we referred several clients to external providers to ensure our clients received the supports needed whilst we managed the recruitment process.



Don and Sam

MND Queensland's strong reputation enabled the organisation to successfully recruit new team members quite quickly when compared to both State and National data specific to the disability industry. Whilst we understand that change in team isn't ideal for our clients, we ended 2023 strongly and commenced 2024 with a highly skilled and experienced team.

Following a period of significant growth and expansion in 2022 and 2023, we are looking forward to 2024 being a year of consolidation, where we will focus on enhancing efficiency, drive service growth and improve our financial position. We will do this whilst continuing to work closely with our clients, their families, and our members to ensure that the services we deliver meet the needs and expectations of the MND community.

Alicia Edwards  
*Director of Care Services*





# SERVICING THE COMMUNITY

Total distance travelled by our team in 2023

78,632 kms

## Allied Health Team



37,966kms

## Equipment Team



34,799kms

## MND Advisors - Support Coordinators



Janet & Graham



## QUICK FACTS

140



New client registrations

45



Support Groups were held

49



People preserved their voice via our Voice Banking Service

48



Enquiries for Coordination of Supports & NDIS Access were received

Support Group



Glen and Jenny



Hydrotherapy Session



Simone





# FUNDRAISING & EVENTS REPORT

Thanks to our amazing community supporters, 2023 was a record fundraising year for MND Queensland!

We celebrated 40 years of care and support, paying respect to those who laid our foundations and enabled support for thousands of people impacted by MND. On 23 September around 120 people gathered at Crystalbrook Vincent, Brisbane to mark the occasion and help raise funds. It was wonderful to have our President Emeritus, John Wearne join us to speak about the founding of MND Queensland.

We held Walk to D-Feet MND events at the Gold Coast, Brisbane, Toowoomba and Redcliffe, and for the first time, we held a walk at the Sunshine Coast which was a massive success and raised almost \$32,000. We also worked on a rebrand of the Walk to Defeat MND with our national counterparts to be rolled out in 2024.

Community-driven fundraising has been instrumental throughout our four-decade journey. We extend heartfelt appreciation to all our community champions who raise essential funds while spreading awareness about Motor Neurone Disease. Notable efforts include Bev Kraft's coordination of a Walk to D-Feet MND event in Biloela, raising over \$10,500, and outstanding contributions from initiatives such as The Johnny McCowan Cup, generating over \$51,000, and the Suzuki North Brisbane 4 x 4 Club, raising \$5,000. Annual events like the Bob Ford Memorial Day, Ipswich Eagles MND Game Day, and efforts by groups like Thuringowa Bowls Club, McLai Pipes and Drums, have also been invaluable.

Grants are an important part of the fundraising mix for MND Queensland as they are a source of major funding. In 2023 we were successful in securing grants from the Commonwealth Bank Staff Foundation, the Dalwood-Wyllie Foundation, and Star Entertainment Group.

We expanded our small fundraising and events team in 2023 welcoming Susie Longman in the role of Relationships

Manager. This strategic development is focused on gaining more corporate support for MND Queensland.

Our much-loved newsletter The Cornflower, was produced seasonally throughout the year and ran alongside our four donor appeals. We have seen a decline in donations to our appeals over the last few years and know that times are tough for many, the MND community is small, and we ask a lot of you, but hope that you'll continue to donate to the cause.

We introduced the Cornflower Club, a regular giving circle and conducted a telemarketing campaign to recruit more monthly donors with the \$40-for-40 campaign. A special cornflower badge has been designed for our Cornflower Club members.

A major one-off \$250,000 donation from the Queensland Government was presented at the Walk to D-Feet MND Brisbane in May. The event saw Premier Anastacia Palaczszuk, Health Minister Shannon Fentiman and Grace Grace MP in attendance. The Premier also spoke in Parliament the following day about Motor Neurone Disease. While this donation was greatly appreciated it's only a fraction of what is required to provide basic services and we continue to advocate to government for ongoing funding as Queensland remains the only state association not to receive funding from its State Government.

New fundraising programs were introduced into the 2023 calendar. These included our virtual event, Mates Move for MND which was held in February and raised over \$19,000 and saw people moving in whatever way they chose, whenever and wherever they liked. The other new program was a tasty fundraiser, Snag Ya Boss which aimed at getting workplaces to host barbeques for their staff and raise funds, with the aim that the boss, or company would also dollar-match what was raised.

## QUICK STATS



**INSTAGRAM**  
Instagram reach –  
14,166



**FACEBOOK**  
Facebook reach –  
589,396



**WEBSITE**  
Visits – 31,916



**GOOGLE**  
Impressions – 1,451  
Ads clicks – 1,451

We were really pleased with the uptake of this new program and it raised over \$13,000. Its secondary goal was to increase corporate support for MND Queensland and it was wonderful to have so many companies involved. The success of both programs means that they have again been incorporated into our calendar in 2024.

We partnered with Inspired Adventures on our first adventure fundraiser and had a team of ten supporters trek through the Scenic Rim over three days. Together this group raised \$23,385.

Our gratitude goes to our donors, sponsors, and fundraisers, whose unwavering support positively impacts Queensland families facing the challenges of MND. Without their generosity, our vital services would not be possible. Thank you to everyone who contributed to making life a little easier for hundreds of Queenslanders living with MND in 2023.

Jason Russo  
*Fundraising, Marketing & Communications Manager*





# EVENTS

Snapshots of some of the amazing events held throughout the year!

## Blue Cornflower Tribute Ceremony



## MND Queensland Staff



## Community Fundraising



## Walk to D-Feet



## 40th Anniversary Gala





# OUR VISION

A world free of Motor Neurone Disease

# OUR MISSION

Our mission is to ensure access to best practice care and support for every Queenslanders impacted by MND and contribute to finding a cure.

# CONTACT US



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