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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.







mnd 🔆

the cornflower

### PRESIDENT'S REPORT

I am delighted to present the President's Report for 2024: a year of growth, innovation, and continued commitment to our mission at MND Queensland. As we enter our fifth decade of service, our guiding principle remains constant **until there is a cure, there is care.** 

This was the first full year under our 2024–2026 Strategic Plan, which set out five clear pillars: expanding care and support, building community, educating and advocating, supporting research, and ensuring sustainability. I'm pleased to report that we've made strong progress in each area thanks to the leadership of our team and the dedication of our community.

### **Strategic Progress in 2024**

Rather than catalogue each initiative, I want to focus on the broader significance of what we've achieved. We have **broadened our footprint**, reaching more Queenslanders in more communities, including rural and remote areas, and responded to longstanding unmet needs with creativity and compassion. We've strengthened our workforce, both in skill and structure, and invested in staff wellbeing and development. We've deepened our community ties through the growth of peer support and volunteer programs, and contributed to national research efforts that hold promise for future care models and, ultimately, a cure.

Importantly, this year we reached a key organisational milestone: MND Queensland is now classified as a **large charity**. This shift reflects not just our scale, but the increasing trust placed in us by the people and partners we serve.

### **Leadership Transitions and Appreciation**

We begin by acknowledging the profound loss of **Eric Holgate**, who joined the Management Committee in December 2023 and sadly passed away in September following the progression of his MND. Eric brought wisdom, authenticity, and lived experience to his role. His presence was powerful, and his legacy will remain part of the fabric of MND Queensland. We hold his family and loved ones in our thoughts and offer our deepest condolences.

This year also saw the departure of Elyse Maberley, who stepped down from the Management Committee after serving with great distinction as our Vice President and as the longest-standing member of the Committee. Elyse's contributions over many years have been both considerable and lasting, from her work shaping strategic direction to her unwavering commitment to the people we serve. On behalf of the Committee and the wider organisation, I extend our sincere thanks to Elyse for her extraordinary service and support.

### **Closing Thoughts**

I wish to thank my fellow Management Committee members, Julia, Katie, Keith and Paul for their insight, stewardship, commitment and care. I also extend sincere thanks to our CEO, Stacey Thorpe, for her visionary and compassionate leadership. Stacey continues to guide our organisation with professionalism and a relentless focus on improving outcomes for those impacted by MND.

To our staff, volunteers, supporters, and most importantly, to the people and families living with MND, thank you for your trust and partnership. Everything we do is in service of you.

We remain steadfast in our mission and inspired by the community we serve. Together, we are making a difference, and we will continue to do so until that difference is no longer needed.

Warm regards,
Diana Melham
President, MND Queensland

### Just Some of Our Many Valued Volunteers



#### 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.



### TREASURER'S REPORT

I am pleased to present the Treasurer's Report for the 2024 financial year on behalf of the Management Committee. This report reflects a year of continued service delivery, targeted investment in strategic initiatives, and careful financial management, all undertaken within a challenging funding landscape.

MND Queensland concluded the 2024 financial year with an operating deficit of \$183,634. While this marks the second consecutive year of deficit, it is important to note that the result represents a significant reduction from the previous year's deficit of \$268,736 and is in line with budgeted expectations.

The modest cash surplus originally forecast in our 2024 budget was primarily absorbed by non-cash depreciation expenses, which remain substantial due to our portfolio of lease and equipment assets. These depreciation expenses — particularly related to our premises and mobility equipment — are a regular and expected part of our financial model. Unlike other expenses, they are non-cash in nature and do not reflect ongoing operational overspend.

Despite the reported deficit, the Statement of Cash Flows demonstrates a modest net positive result from operating activities. There is an overall reduction of cash and cash equivalents from the previous year and this decrease in cash holdings can be attributed to two specific activities.

Firstly, the Management Committee made strategic decisions to fund several key initiatives in 2024 using our reserves, these include our pre-election advocacy campaign and the purchase of a vehicle. Secondly, advance grant funding received at the end of 2023 was utilised in 2024. These funds, previously recorded as liabilities, were appropriately expended on designated programs throughout 2024, reflecting both good financial stewardship and full delivery on our funding commitments.

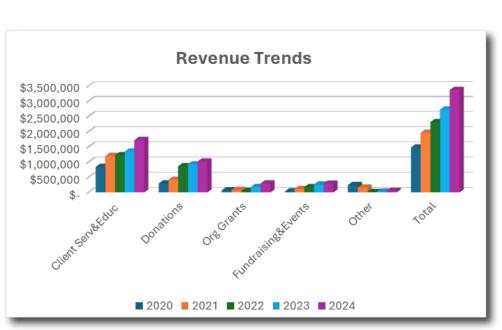
We have entered 2025 with a revised and strengthened budget that fully incorporates non-cash items, providing a more transparent view of our financial performance. The approved budget forecasts a surplus, and while it is still early in the year, emerging developments suggest that our actual performance may exceed expectations.

Our financial outlook remains cautious but positive. We continue to pursue additional funding streams, including new grant opportunities and State Government support, to ensure we can sustain and grow our services for every Queenslander impacted by MND.

I would like to thank our Accounts Team and CEO for their diligent management throughout the year, our auditors for their oversight, and the Management Committee for their ongoing support and strategic guidance. Most importantly, I thank our members, donors, and partners—your continued support and contributions ensure that we can remain focused on delivering high-quality, client-centred care and advocacy across the state

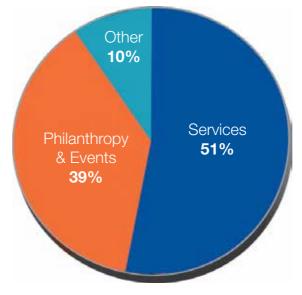
Katie Choi, BEc, LLB, LLM, GradDipAppFin, GIACD, FGIA, FCG (CS, CGP) Treasurer



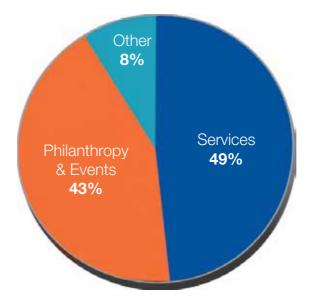


### \*Excludes donations in kind

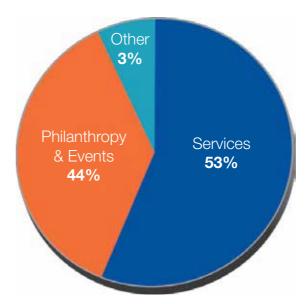
### 2024 By Source



### 2023 By Source



### 2022 By Source







### 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 John Wearne Margaret Wearne **David Taylor** Lesley Taylor Anne Martin Frank Soos Vera Stevens Evelyn Moore Stan Douglas Barbara Douglas

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 Fahev 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**

Eddie Kudzius

Vida Kudzius

Peg Herbert

Mr F Herbert

Assoc Prof Robert Henderson, Neurologist Prof Pamela McCombe, Neurologist

#### PRESIDENT EMERITUS

John Wearne AM

#### **GOVERNANCE STRUCTURE**

The Governance of the Association in 2024 was the responsibility of the volunteer Management Committee (Board).

#### 2024 MANAGEMENT COMMITTEE

Diana Melham President: Vice-President: Elyse Maberley Julia Rollston Secretary: Katie Choi Treasurer: Board Director: Keith Malpress Board Director: Paul King Koi

Board Director: Dr Eric Holgate (deceased)



Julia Rollston

Diana Melham Elyse Maberly

Keith Malpress



Katie Choi

Paul King Koi Dr Eric Holgate

CEO, Stacey Thorpe & MND Australia CEO, Clare Sullivan

with UQ researchers

Our Vision, a world free of Motor Nurone Disease

### CEO'S REPORT

As I reflect on 2024, I feel an overwhelming sense of pride—not only in what MND Queensland has achieved, but in the unwavering heart and dedication of our people. This has been a year of thoughtful growth, operational strength, and deep connection with the community we serve.

#### **Expanding Reach and Strengthening** Services

Our mission—to provide best-practice care and support for every Queenslander impacted by Motor Neurone Disease has continued to guide every step we take. In 2024, we expanded both the breadth and depth of our services:

- We extended our Advisory Service into **Toowoomba**, enhancing access for individuals and families in the Darling Downs. This was supported by our new regional road trips, which have become an important bridge to people in remote and rural communities.
- We introduced regular educational workshops tailored to both people recently diagnosed with MND and the informal carers who support them. These practical sessions are improving safety, confidence, and connection for those navigating a complex and often isolating diagnosis.
- Our support groups expanded in number and reach—now available in Cairns, Townsville, Sunshine Coast, Gold Coast, and Brisbane offered both in person and online. These groups have been a lifeline for many, creating connection, fostering belonging and shared understanding.
- Our allied health, support coordination. and equipment services remained central to our care model, with an ongoing focus on equity for those over 65 who do not qualify for NDIS funding. We have done everything possible to meet those gaps with compassion and creativity, enabled by philanthropic grants and community support.

### **Investing in People and Culture**

Behind every service stands an extraordinary team. In 2024:

- We launched a staff wellbeing strategy to strengthen resilience and
- A monthly professional development program supported continued learning and knowledge-sharing across disciplines.
- We began building a comprehensive staff induction and onboarding program to ensure every new team member is confident, supported, and equipped to deliver expert care.

We are privileged to work with people who consistently go above and beyondbringing professionalism, empathy, and heart into every interaction with our clients and families.

### **Commitment to Quality and Research**

We continued our involvement in the MiNDAUS national registry, ensuring the voices and experiences of Queenslanders are represented in research and policy development. Our partnership with the University of Queensland's Save Our Speech study is helping build a clearer picture of how to preserve communication for people living with MND.

Foundational work was also undertaken to establish a Clinical Governance Framework, which will be implemented in 2025 to ensure service quality, safety, and continuous improvement remain central to our operations.

#### **Volunteers and Community** Contribution

One of the most inspiring developments in 2024 is the substantial growth of our volunteer programs. Through the introduction of structured recruitment strategies and targeted initiatives, we have been able to connect more community members with meaningful roles that directly enhance the lives of people living with MND.

These programs are a vital part of our community impact. Our volunteers now support people with everything from emotional connection and peer-based engagement to practical help that addresses the ongoing unmet needs that persist across the MND landscape. Their contribution is not only generous—it is essential.

### **Sustainability and Growth**

Thanks to sound financial stewardship, our organisation ended 2024 in a stable position despite ongoing sector-wide funding pressures. While a modest deficit was recorded, it was in line with our expectations and largely driven by non-cash depreciation. Importantly, MND Queensland has now reached a new milestone in its evolution—we are formally recognised as a large charity, reflecting both the scale of our operations and the impact of our services statewide.

This growth would not be possible without our supporters, donors, and the tireless work of our fundraising team, who have continued to foster vital community and corporate partnerships.

#### **In Memory and Honour**

This year, we said goodbye to many Queenslanders whose lives were cut short by Motor Neurone Disease. Every individual we support leaves an imprint on our hearts, and every loss is felt deeply across our team.

We remember not only the challenges they faced, but the strength, warmth, and humanity they shared with us. In our work, we do not simply track numbers—we remember names, faces, families, and moments. It is our honour to walk alongside people with MND, and we never take for granted the trust that families place in us. That connection between clients, staff, and supporters—is what drives everything we do.

Among those we lost was Eric Holgate, a member of our Management Committee, a valued colleague, and a deeply respected member of our MND community. Eric brought both insight and lived experience to his role, and we are grateful for the time we shared with him. His voice continues to guide our thinking and remind us why this work matters.

#### **Gratitude and Acknowledgement**

To our dedicated staff: thank you. Your knowledge, your compassion, and your commitment are the heartbeat of MND Queensland.

To our **volunteers**: your time and energy have created real moments of joy, relief, and comfort.

To our Management Committee: thank you for your trust, guidance, and unwavering support for me and the entire team throughout the year.

And to our clients, families, and supporters: thank you for letting us walk beside you. You are the reason we exist and the reason we strive to be better, every day.

As we enter 2025, our work is far from done—but our purpose is clear. We will continue to innovate, advocate, and deliver high-quality care to ensure that every Queenslander impacted by MND feels supported, empowered, and never

#### Until there is a cure, there is care.

Warmly Stacey Thorpe Chief Executive Officer, MND Queensland



### SUPPORT SERVICES REPORT

MND Queensland's Services Team has worked tirelessly throughout 2024 to provide compassionate and client-focused care to Queenslanders impacted by Motor Neurone Disease. Every day, our team is inspired by the resilience of those we support, and we remain committed to ensuring that no one faces this journey alone.

This year, we supported more than 440 clients, a meaningful increase from the 399 people we assisted in 2023. We delivered over 10,100 hours of support through our Advisory, Support Coordination, and Allied Health services. This growth reflects not only the increasing demand for our services but also our commitment to expanding our reach and deepening the level of care we

Our Advisory and Support Coordination team has been a pillar of connection for many. With new staff joining us in key regions; including the Darling Downs, we were able to offer more localised, specialised support than ever before. Throughout the year, our MND Advisors facilitated more than 60 support groups both in-person and online—which have been essential spaces for people to connect, share, and feel heard. These groups continue to offer both practical assistance and emotional reassurance for our clients and their loved ones and we hope to see as many of you as possible ioin these in 2025.

That sense of connection carried through into our Allied Health services, where we saw significant growth across all streams. Voice banking, too, continued to be in high demand, with 86 individuals preserving their voice in 2024. This service, often deeply emotional and empowering, remains one of the most meaningful ways we help people hold onto part of their identity.

As both our clinical and advisory work grew, so too did our Equipment Hire service, which provided more than 640 pieces of equipment to people living with MND across Queensland. The appointment of a dedicated Equipment Team Leader played a vital role in improving service responsiveness, reducing wait times and enhancing the client experience. We have seen firsthand the difference that timely access to equipment can make in maintaining independence and comfort.

Our commitment to supporting Queenslanders no matter where they live was evident in the distance our team travelled to provide in-person care. Over the course of the year, our staff collectively drove more than 111,000 kilometres to reach people across the state. Whether in metropolitan centres or remote regional towns, our team remained dedicated to delivering care where it was needed most.

In addition to these supports, education remained a central focus of our efforts this year. We continued to run Newly Diagnosed and Manual Handling workshops to equip individuals and families with the knowledge and confidence needed to navigate life with MND. Our involvement in national health professional education initiatives further demonstrated our commitment to sharing best-practice care strategies beyond our immediate community.

In order to deliver such a broad range of services effectively, we've worked hard behind the scenes to strengthen our systems and infrastructure in 2024. We have implemented an IT strategy for services and moved the Advisory and Support Coordination service to a new client management platform. In doing so, this has helped reduce administrative tasks, freeing up more time for direct care. Our other service streams will be moving to different platforms in 2025 with further efficiencies expected. The release of our new Client Service Handbook, now included in all Welcome Packs, ensures that clients start their journey with us feeling informed and supported. Our regional outreach efforts also expanded, with the launch of our "Regional Road Trips" enabling us to connect with people living in remote communities who may otherwise be unable to access face-toface support.

MND Queensland continues to be focused on delivering high quality services that align with best practice and are based on evidence. In 2024, we were

ecstatic to pass our NDIS audit with flying colours; having no recommendations or non-conformances and receiving a best practice nod for our Quality Management

Our 2024 year saw us overcome many challenges and we were incredibly proud to see the services teams exceed budget targets in Q4. Despite not having any ongoing funding to support us, we were still able to launch our Short-Term Allied Health Supports Program, which provides heavily subsidised allied health services to people over 65—an important step toward addressing the inequities faced by those who are ineligible for NDIS funding. We are continuing this program into 2025 and are continuing to fight hard for financial support to ensure its sustainability.

I wanted to conclude by acknowledging each and every member of our services team for the enormous impact they have had this year. The compassion. dedication, and professionalism shown by our team every single day has made a real and lasting difference in the lives of people living with MND and their loved ones. To the individuals and families who have welcomed us into their livesthank you for your trust. Please be reassured that MND Queensland remains committed to walking alongside you in 2025 and beyond, continuing to deliver care that is responsive, person-centred, and grounded in best practice.

Alicia Edwards Director of Care Services



### SERVICING THE COMMUNITY

Our Biggest Travellers in 2024 94,416 kms

**Allied Health Team** 

50.850kms

**Equipment Team** 43,566kms

Speech Pathologist, Physiotherapist and Occupational Therapist



### **QUICK FACTS**



10,000 hours of support in 2024



111 newly diagnosed individuals



Helped 86 people bank their voices



Supported 55 people download and use their banked voice









Our Volunteer-Led Lifestories Program





# FUNDRAISING & EVENTS REPORT

2024 was MND Queensland's most successful fundraising year yet, driven by amazing community participation, generous philanthropic gifts, and a growing recognition of our mission to support Queenslanders living with motor neurone disease. It was a year marked by growth, collaboration, and a deepened connection with those who share our vision of a future where no one faces MND alone.

This success was especially evident in our events and community fundraising programs. Our Walk to Defeat MND events expanded significantly, drawing over 1,768 participants across Brisbane, Gold Coast, Sunshine Coast, Toowoomba, Redcliffe, Gladstone and Bundaberg. Collectively, these walks raised more than \$228,500. Each event was not just a fundraiser but a heartfelt tribute featuring stories of courage and loss. Brisbane's walk brought in a record-breaking \$74,000, while regional walks demonstrated the increasing reach and passion of our grassroots supporters. The Gladstone and Bundaberg walks were led by community volunteers who wanted to bring the walks to their region and make a positive difference for MND by raising funds and awareness.

Our major events also gained strong traction. The Tennis Legends Breakfast, featuring icons John Alexander and Ken Rosewall, raised \$30,000 and delivered an inspiring morning for over 200 guests. Meanwhile, the Gold Coast Rugby Lunch saw a guest panel of former rugby stars sharing stories and raised over \$26,000. The High Tea for MND at the Imperial Hotel on the Gold Coast saw 130 glamorous ladies enjoying an afternoon of fun and fashion and raised over \$30,000.

Community fundraisers continued to shine in 2024. From bake sales, trivia nights and golf days to livestreaming events and international challenges, our supporters demonstrated incredible passion and creativity. Long-time supporters like elFarqo brought his online communities together once again to raise awareness and funds during his livestream, while the McLai Pipes and Drums group continued to busk regularly in support of our mission. Ipswich Eagles held their annual MND day and the Caboolture Snakes continued their support.

Other notable efforts included morning teas, lunches, merchandise sales and the bi-annual Phil Rogers Golf Day, which raised more than \$25,000. Our appeals delivered modest results in terms of direct donations, but donors continued to show their support in other ways. Many contributed through regular giving, event attendance, and major gifts.

One of the most meaningful and significant contributions in 2024 came through Gifts in Wills. Bequests formed a substantial part of our income, enabling long-term planning and sustainable service delivery. These final acts of generosity are powerful reflections of our donors' values, and we honour the trust they placed in us. Every legacy gift makes a lasting difference in the lives of people impacted by MND.

Grants continued to play a crucial role in diversifying income. In addition to multi-year support from the Eastern Star Foundation we were grateful for project-based funding from the James Frizelle Charitable Foundation, the Intelligent Foundation and Lord Mayor's Charitable Trust. We were pleased to receive \$34,999 from the Gambling Community Benefit Fund. This grant enabled us to purchase a Hyundai Staria van so we can stay mobile and visit clients in their homes and facilitate the delivery of smaller equipment items.

While our corporate partnerships program is still maturing, we continued to receive valuable support from several committed businesses through sponsorships, workplace giving and awareness-raising activities. We received wonderful support from Brendan O'Donnell Fencing, Chempro, Star Casino, Treasury Casino and CPA Sunshine Coast. We are optimistic that this area will continue to grow with targeted relationship-building.

As we reflect on 2024, we do so with immense gratitude - for the generosity of our supporters, the trust of our community, and the shared determination to make a difference.

Whether through a donation, hosting a fundraiser or a leaving a legacy gift, every act of giving helped ensure that Queenslanders with MND received the care, support and advocacy they deserve. We thank you for being part of this journey.

Lastly, sincere thanks go to the fundraising team and our incredible volunteers for your passion, creativity, and unwavering commitment. Your energy and dedication played a crucial role in making 2024 our most successful fundraising year on record and more importantly, in making a meaningful difference in the lives of Queenslanders living with MND.

Jason Russo Fundraising, Marketing & Communications Manager



### **EVENTS**

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





High Tea for MND











A world free of Motor Neurone Disease

## **OUR MISSION**

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

## **CONTACT US**



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