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### Welcome

The 2019-20 financial year encountered a global challenge that saw great change in a short period of time.

Our organisation quickly adapted to the shifting needs of those living with multiple sclerosis and other neurological conditions during the COVID-19 pandemic. The incredible commitment and innovation of our team through this change has laid the foundation for MS Queensland's future strategic direction.

For the first time, our service coordinators and physiotherapists could be accessed via Telehealth video calls. We launched a seven-week Virtual Wellness Program that guided physical and mental wellness activities in the home and connected our community for World MS Day.

Our fundraising team encouraged thousands of our valued supporters to ride independently for our first virtual MS Brissie to the Bay bike ride. Our employment support service was also expanded to overcome the significant impact MS can have on participating in paid employment. By working hard to adapt these aspects of our services and fundraising to a virtual environment, MS Queensland was able to see a continued customer growth of 9.3%.

To consistently provide world-class homes for people living with a disability, we confirmed partnerships for the delivery of services on Specialist Disability Accommodation sites in Caboolture, Robina, and Palm Beach as well as opened our Southport site. We also invested in our communities in Toowoomba and on the Sunshine Coast by opening wellness centres and began early stages of development for two additional, MS Queensland built, Specialist Disability Accommodation sites in both locations.

MS Queensland strived to be the best at saying 'thank you', which encouraged the launch of our first annual Thankathon. This saw staff, board members, and volunteers come together for a few hours to call our

supporters and donors to say 'thank you', as without their immense support we wouldn't be able to provide the highest quality of services to Queenslander's living with MS and other neurological conditions.

This year, we farewell our Chairman, Roger Burrell, who will be stepping down following the AGM. We thank Roger for his tireless work for MS Queensland since joining our board in 1996. Roger has been incredibly generous with his time, his legal knowledge, and his commitment to our cause over the last 24 years.

I would like to acknowledge that under Roger's leadership, MS Queensland has seen growth in the budgeted revenue from approximately \$3 million to over \$30 million and has become a leading provider of Supported Independent Living and high-quality Specialist Disability Accommodation in Queensland. I also wish to acknowledge the wonderful leadership and contribution provided by Karen Quaile our Executive General Manager, Service Delivery who will be leaving us in December 2020. Karen's passion, experience, and enthusiasm has been a critical factor in the growth and success of our organisation. I extend a special thanks to both Roger and Karen from all of us across the wider MS Community.

David Curd

David Curd
CEO, MS Queensland



# Impact of MS



**2.8** million people globally

**25,600+** Australians

**3,970**Queenslanders

live with MS

77

MS varies significantly from person to person. For some, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others, it means a progressive decline over time. For all, it is life-changing.

MS Australia



It is a roller coaster ride living with MS. Not one day is the same. I have days that I cannot see, feel a thing in my body, stop the room from spinning, get out of bed, or swallow well. I have days that I have pins and needles stabbing parts of my body.

Gail Harbott



MS makes up part of the neurological conditions picture

850,000+ Australians & 54,249 Queenslanders

live with chronic, progressive conditions that affect nervous system



3 out of 4 people living with MS are women



10+ Australians are diagnosed with MS every week



30
is the average age of a MS diagnosis



31% less than other Australians is the affect MS has on quality of life



Every 5 minutes someone in the world is diagnosed with MS



\$1.75 billion is what MS costs the Australian community annually

## Support services

Our services have helped people living with MS and other neurological conditions get the best out of life.

We've strived in 2019-20 to be an organisation that continually changes to meet the needs of our community and their families.

We embraced technology to deliver sustainable services that create positive impacts to the lives of those living with MS and other neurological conditions.





Webinars & wellness

people watched topics on MS services & treatments, as well as wellness & self-care



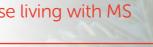
**Support groups** 

34 more than



support groups with

members to share information & connect those living with MS





1,295

people spoke with our service coordinators to coordinate care & receive NDIS information & referrals

**NeuroPhysio** 

9,840

hours of physio & exercise therapy delivered to improve & maintain customer mobility & function

Wellbeing centres

centres brought a range of expertise & services under one roof Family & carer support

1,440

calls to our NeuroAssist line aided carers, family & friends of those living with MS

MS nurse support

856

NEUROLOGICA

consultations saw patients informed on MS symptom management & treatment

**Employment support service** 

workers were empowered in their current role or helped to find new employment

Peter

## **Customer impact**

#### **Amanda**

Amanda Bennetts manages her strength, range of movement, and balance through neurological physiotherapy sessions. After being diagnosed with MS at just 25, Amanda contacted MS Queensland to better understand her condition and find services that would help her maintain independence. Physiotherapy has become part of Amanda's weekly routine on the Sunshine Coast, since we opened our wellbeing centre in the area at the end of 2019.

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MS Queensland takes a holistic approach and once you connect with them, you'll find out about all the options you have to help manage your individual symptoms and needs.

Amanda Bennetts



Since having MS Queensland's assistance with my NDIS plan, I've been leaps and bounds ahead and through being linked with a skilled occupational therapist I've been able to get all of the modifications and equipment I need installed in my home. The team have made a real effort to help me understand what support I can get access to.

Peter Law



Peter Law is from Murgon (regional

Queensland), which has meant that in order

with a neurologist, he's had to travel three

to access expert care or attend appointments

hours to Brisbane. Peter was supported by MS

Queensland in purchasing a tablet through his

to easily keep in contact with MS Queensland's

NDIS package. This now allows Peter access

support coordinators through Telehealth

appointments in the future.

and the ability to have virtual physiotherapy

>> Peter used his new tablet to have his very first Telehealth session with us via Zoom. This has assisted him in maintaining his essential NDIS funded supports.

#### **Snapshot of our customers**







## **Best Life Project**

To provide a solution to the current disability housing crisis in Queensland, we've continued developing Specialised Disability Accommodation (SDA) and delivering Supported Independent Living (SIL) services on site through our Best Life Project.

#### **Accommodation**

Our accommodation has seen people living with MS, other neurological conditions, and high support needs live full and independent lives.

This year, we introduced a specialised team to assist customers in navigating the NDIS housing pathway, provide support with tenancy matching, link with services available while ensuring customers have the correct customisations, modifications, and equipment needed to live as safely and independently as possible in their new homes.



#### Our accommodation partners

Choosing to partner with developers and organisations that shared our vision to end the disability housing crisis has seen a more immediate impact with several additional sites due to open to residents in 2021. A huge thank you to our partners LifeBright, KTQ Developments, Upinvest, and Accessible Homes Australia for working with us to provide world-class, purpose-built independent housing to those living with MS.

David Curd and Roger Burrell with Toowoomba MS Support Group convenor and advocate Joanna Leane.





occupancy on average over 12 months



sites opening in 2021 in Caboolture, Robina, Toowoomba, & on the Sunshine Coast



sites open in Albany Creek, Annerley, Springfield, Robina, Southport, Bundall & Lutwyche



residents are supported with 24/7 onsite care



#### Best Life Project plan

MS Queensland's Best Life Project is our plan to build better lives for those living with MS, other neurological conditions, and high physical support needs by investing in specialist disability housing and providing 24-hour on site care.

Australia's disability housing crisis has seen young people with MS and other neurological conditions forced to live in aged care, hospital, or other inappropriate circumstances because

homes simply can't adapt to a person's changing needs and where a family's ability to cope is stretched to breaking point.

In Queensland, 1716 people with a disability still desperately need Specialised Disability Accommodation (SDA).\*

\*Summer Housing Report March 2020

# Creating freedom of choice

Gary Madden will have the choice to move closer to his family thanks to the Chancellor Park apartments that MS Queensland are planning to build on the Sunshine Coast.

Gary moved into our Springfield apartments when he was no longer able to care for himself and staying at home was a risk to his safety.

WINDER NEW MANAGEMENT
SSS &



Gary Madden and his mother Fay who lives on the Sunshine Coast with the rest of Gary's family, including his children and grandchildren. Here, he received 24/7 support from our specialist staff to manage the complex high-care needs that come with his MS, but he was away from his family. Gary is excited to move back home to the Sunshine Coast where he can be with his children, grandchildren, and his 91-year-old mother Fay.

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MS. He doesn't have a choice about having MS. He doesn't have a choice about everything that's been taken from him because he has MS, but he should have a choice about where he lives, and he shouldn't have to live so far from the people that love him.

Amy Madden (Gary's daughter)



## Community & awareness

MS Queensland's strong and passionate community connects customers, supporters, and staff to our cause and remind us of the importance of our work.

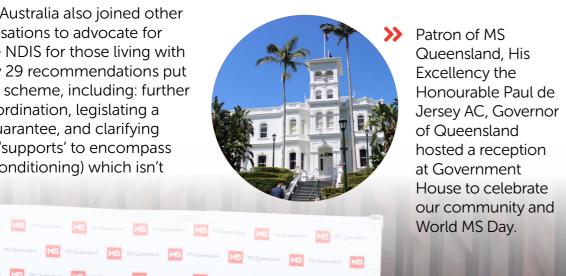
Throughout the year our 16 ambassadors shared their experiences parenting, working, and dealing with the ups and downs of life – all while living with MS.

### **Advocacy**

MS Australia advocates for MS Queensland through regular representations and submission responses to the Australian Government. As a result, several treatments for MS were added to the pharmaceutical benefits scheme. MS Queensland and MS Australia also joined other peak disability organisations to advocate for improvements to the NDIS for those living with MS. This support saw 29 recommendations put forward to better the scheme, including: further enabling support coordination, legislating a participant service quarantee, and clarifying terminology around 'supports' to encompass equipment (like air-conditioning) which isn't consistently funded.

#### World MS Day

The theme of World MS Day for 2020-2022 is Connections. The aim is to break down social barriers as well as raise awareness of the loneliness and isolation people living with MS can feel. To bring our community together to connect at a disconnected time, MS Queensland launched a seven-week Virtual Wellness Program that brought topics on self-care to the homes of our customers. To promote topics on health, wellness, and managing the everyday symptoms of MS we shared webinars to our social media channels.



## **Fundraising**

The sky was the limit this year when it came to raising essential funds for those living with MS.

MS Queensland would like to thank our donors, fundraisers, event participants, volunteers, and staff for continuing to ensure no one faced their neurological condition alone through uncertain times.



2020 Winner of the Fundraising Institute Australia's Fundraising Impact through Creativity award.

Kaitlyn Sapier faced her << fears with partner Ryan and plunged 14,000ft (with 24 others) in a naked skydive raising \$19,111 for MS.



**Donate** 1800 841 922 msqld.org.au/donate



**Philanthropy** 

\$550k

raised for capital, research & special projects

Grants

\$377k

raised through successful grants

Lotteries

\$4.7mil

lotteries

gifted by

14 people

through

their will

\$98k \$512k

> raised from generous donors

raised though the selling of 80,465 tickets across 10

Gifts in wills Individual giving



### MS Brissie to the Bay

The 30th anniversary MS Brissie to the Bay bike ride looked a little different in 2020. The annual event went virtual, encouraging participants to set a daily distance goal for June to celebrate our 30 years of riding to fight MS.

Ø₹®

986 virtual riders

> \$580k raised

**390,641** km's travelled across the state

#### **MS Swimathons**

Diving into fundraising saw MS Swimathons hosted in Gladstone, Mt Gravatt, Redcliffe, Rockhampton, the Sunshine Coast, Toowoomba, and the Gold Coast. Unfortunately, our Cairns, Mackay, and Townsville events were cancelled due to the pandemic.



relay swimmers

\$170k raised

events across regional and metro areas

#### **MS** Readathon

MS Readathon inspired kids all over Australia to read throughout the month of August to

support people living with MS



4,604

Queensland kids

\$206k raised

281,562

books read nation wide

#### **MS Moonlight Walk**

To celebrate its 21st year, MS Moonlight Walk illuminated Davies Park in West End with supporters walking courses that encapsulated the best parts of the Brisbane city. The sea of lanterns illuminated our belief that no one should face MS alone.



4,577 lunar walkers

\$445k

raised

216

people who took part live with MS

### **Community Fundraising**

Our amazing community bring innovative, quirky, and inspiring ideas about how they would like to fundraise for MS. In 2019 fundraisers climbed mountains and jumped out of planes all to support our cause.



Over **64** fundraising champions

> \$164k raised

innovative ideas that supported our cause

22



### MS research

#### **Championing Queensland-based** research

MS Queensland increased our contribution to promote and support cutting-edge research by providing \$169,962 to MS Research Australia as part of our ongoing commitment to the national research initiatives. A further \$453,991 supported the University of Queensland and the Royal Brisbane Women's Hospital, who are working in collaboration to undertake cuttingedge clinical trials for MS, led by Queensland's Professor Michael Pender MD.

Thanks to this funding, and the success of the world-first clinical trial of adoptive immunotherapy for MS, Professor Pender, Dr Zara loannides and their team can participate in an international phase two clinical trial. The therapy works by targeting the Epstein-Barr Virus (EBV) infected cells in the central nervous system linked to MS. The first clinical trial into adoptive immunotherapy has seen less fatigue and neurological improvements in patients living with MS. This has given participants a great amount of hope for the future.



\$623,953

contributed to MS research



MS Queensland CEO David Curd. Dr Zara A Ioannides, and Professor Michael Pender MD

>>> Professor Pender won MS Australia's 2019 John Studdy Award in recognition of his outstanding achievements in research into MS. He and his team have also received approval to offer further adoptive immunotherapy to patients in the study, as well as enrol new patients. They are currently following up with patients two and three years after treatment to document further results.

### Our people

MS Queensland is focused on ensuring we have the right people, with the right skills to take our organisation into the future and deliver quality customer outcomes.

The expertise and resilience of our people continues to be the key to our success, both as an organisation, and in delivering on our vision to see a world free of MS. This year more than ever has seen a renewed focus on our employees' health, wellbeing and safety both within the workplace and outside of work.



To see more staff working from home, we offered new digital platforms and accelerated roll out to increase flexible work practices, conducted online learning and development, as well as recognised employees for their commitment. We also established a health and wellbeing program that kept staff connected and engaged, a COVID-19 communications hub to stay informed on restrictions and extended our Employee Assistance program to include immediate family members of staff.



#### **Accessible**

there when and how you need us

#### **Flexible**

understanding that situations change

#### Authentic

approachable and real

#### Connecting

giving you the support you need



#### Volunteer with us

07 3840 0888

volunteer@msqld.org.au



team members



20% growth in

workforce



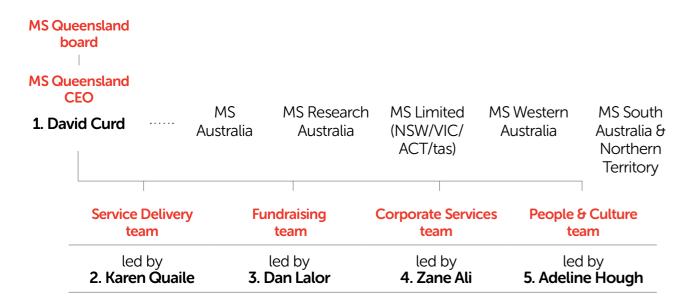
eager volunteers



## **Board & governance**

Our board performs a very important governance function, establishing the organisation's strategic direction and monitoring progress towards the achievement of our strategic objectives.

### MS Queensland organisation chart













MS Queensland is an iconic organisation with a proud history of helping people living with MS to get the best out of life, of advocating for change and supporting the search for a cure. I look forward to ensuring our continued growth as we expand our services across the state and deliver on our promise to put our customers' wellbeing at the centre of everything we do.

David Curd, CEO

#### **Farewell**

I have had the honour and privilege to represent our members as a director on the MS Queensland Board for 24 years, including 12 years as Deputy Chairman and the last six years as Chairman. I joined when the gross revenues were approximately \$3 million. This year, revenues are estimated to be in excess of \$30 million. I have seen and been involved in many changes. including the broadening and deepening of services provided as well as the move away from institutional accommodation and care at one location to dignified independent living in a variety of communal settings, realising the previously undreamt-of opportunities emanating from National Disability Insurance Scheme (NDIS) and Specialist Disability Accommodation (SDA).

During my time with MS Queensland, I have championed substantial funding of the MS Clinic and Professor Michael Pender's research, and supported growth in lotteries, MS Brissie to the Bay bike ride, and MS Moonlight Walk fundraising events. I was fortunate to be involved in the start-up of the national Society, MS Australia and served on its Board for 18 years, including as Vice President. I was also involved in the start-up of MS Research Australia and am thrilled at the myriad of helpful drugs now available to help members live well with their conditions. My fervent hope and true belief is that it will be possible in my lifetime to stop and even reverse many of the conditions members currently face. We are so close.

Thank you to the various Boards, CEOs, staff, volunteers, and members who have worked so hard for the cause during my tenure and who are helping change hope into reality. I pass the baton knowing that there is more work to do, but the future for members is bright, and thank you for indelibly enriching my life.

Roger Burrell

















1. ROGER BURRELL, CHAIR Member since 1996

2. TRACEY PARKER, SECRETARY Member since 2011

3. JOHANNA ROCHE, TREASURER Member since 2010

4. WENDY LOVELACE, MEMBER Member since 2008

5. BRETT BASSETT, MEMBER Member since 2017

6. CARMEL MACMILLAN, MEMBER Member since 2013

7. VIVIENNE JOHNSON, MEMBER Member since 2017



## Financial summary

First and foremost, we would like to take a moment to say thank you to our members, donors, philanthropists, fundraisers, and supporters for their unwavering dedication to our organisation through a particularly tough year.

For more than 60 years, MS Queensland has been dedicated to helping people with MS get the best out of life, advocating for change, and searching for a cure for MS. The 2019-20 financial year has been a challenging one for MS Queensland with the organisation incurring a deficit of \$1.5 million. The impact of the COVID-19 global pandemic was profound; having several implications for the organisation including reduced fundraising activity, temporary closure of services, and increased equipment costs.

We made some difficult decisions during the financial year to prioritise the safety of our customers, community, and staff. This saw the cancellation of physical fundraising events. The sudden closure of wellbeing centres resulted in limited face to face physiotherapy and exercise therapy services being offered and a transition to virtual service coordination during the peak of the pandemic. Heightened visitor restrictions were in place at all of our accommodation sites, and costs of personal protective equipment was increased. We're proud to report that these decisions have seen our customers and staff remain safe throughout these unprecedented times.

The agility and innovation to ensure that no Queenslander faces their neurological condition alone is a testament to the culture of our organisation that has been forged over our rich history. We strengthened our commitment to providing high-quality housing by building accommodation to Platinum Liveable Housing Design standard compliant with NDIS Specialist Disability Accommodation. Our new projects in

Toowoomba and Sunshine Coast will become homes for 24 people with high physical support needs and are expected to open in 2021. The MS Readathon was also reinvigorated with over 10,000 students across Queensland participating and a seven-week Virtual Wellness Program kept our community connected in lockdown.

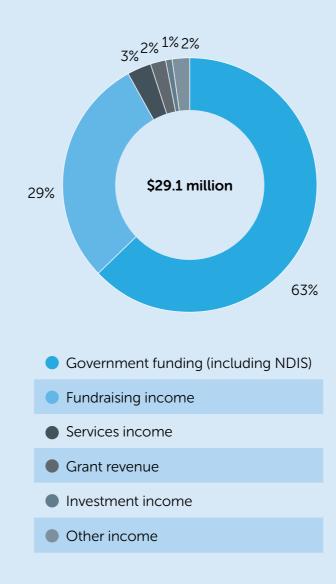
As a result of these initiatives and the continued growth of the NDIS, MS Queensland's underlying revenue (excluding the sale of Dutton Park) grew from \$24.4 million in 2018-19 to \$29.1 million in 2019-20 (19.4% growth). Our financial position remains strong with net assets of \$26.1 million and \$13 million in cash and financial assets that will serve as a foundation for future success. Some of these funds will be invested in Specialist Disability Accommodation and 24/7 Supported Independent Living onsite care and service growth initiatives to continue delivering quality outcomes to our customers.



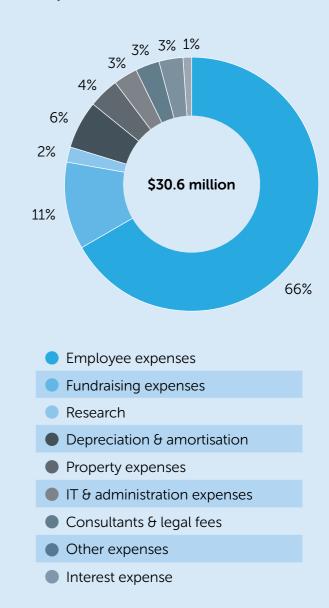
## Cash & financial assets

2020 \$12,990,655
2019 \$16,302,600
2018 \$5,199,376
2017 \$6,761,301

### Where our funding comes from (Revenue)



### How we spend our funding (Expenses)





19.4%

growth in underlying revenue



\$26.2

million net assets



\$3.3

million capital expenditure

Mark's ride with MS

Mark Elvery has been living with MS for 27 years.

It began with numbness in his feet after a game of soccer when he was 17. Mark thought it was just because of his cold and damp boots. When the numbness had reached his knees, Mark told his parents. After what seemed like hundreds of x-rays over three years, doctors found a tiny spot on his spine. He had multiple sclerosis. Since being diagnosed with MS in 1993 (when he was 20) Mark is so thankful to be able to live a full and happy life. He's been with his wife Adrienne for over 20 years and together they've had two sons.

Mark has used a wheelchair since 2001 and claims it's been almost impossible for his family to take a break since then, yet he's adamant his determination to live life to the fullest has helped them through. To help give others like Mark a sense of a independence and support a cure for MS, Mark's sons Nathan (15) and Matthew (10) have taken part in MS Queensland's MS Brissie to the Bay since 2013. Although Mark had planned to ride this year for the very first time with thousands of other riders in his wheelchair bike, he embraced the 30 for 30 virtual challenge and rode his wheelchair bike around his neighbourhood. Team Elvery raised over \$3,000 in 2020 to support our cause and Mark's bike has given him a new lease on life.

"I don't resent MS. After I was diagnosed, someone told me 'don't give in. Keep doing as much as you can, for as long as I can.' And I have." My children love riding, and although I can't take them for a ride, there is still hope that we can find a cure for this disease and that one day I will be able to.

Mark Elvery



