



Queensland



Impact **Report**

2020-2021



Queensland

Here for *your* journey



If you or someone you care for is living with MS, or a similar neurological condition, you are not alone—the passionate and caring people of MS Queensland are here for you. Here for the journey you're on. Here for *your* journey.

Acknowledgement of Country

Our organisation is committed to engaging with Aboriginal and Torres Strait Islander peoples in the communities we work with. As one of the world's oldest living cultures, we recognise that Australia always has been and always will be Aboriginal and Torres Strait Islander land. We who come from many places pay our respects to Elders throughout all time and commit to learning from the knowledge, traditions, stories, spirituality and experiences of Aboriginal and Torres Strait Islander people as we learn to live on their land. We walk together in solidarity in the shared pain of the past and the shared hope for the future. We would like to take this opportunity to thank the traditional owners for welcoming us on the land we gathered on across Queensland.

Our strategy & impact

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Financial information

Our 2020-21 Special Purpose Financial Report is available in full on our website msqld.org.au



Message from our Chair & CEO

The 2020-21 financial year saw many challenges as restrictions and outcomes of the COVID-19 pandemic affected different aspects of our lives.

MS Queensland, like many organisations across the world, continued to innovate and be agile in its approach to support working from home, online and Telehealth services, as well as managing restrictions on events and visitors to our disability accommodation sites. Despite these key challenges, our organisation saw an 8.1% growth in our customer base, increased fundraising to support our services, and \$588,792 contributed to finding a cure for MS. These achievements are a testament to our rich 60 years+ history and our dedication to ensure no Queenslanders face MS and other neurological conditions alone.

Providing innovative and accessible supported accommodation

To strengthen our commitment to reduce the shortfall in high physical support disability housing, MS Queensland worked with philanthropic and commercial partners to build apartments in Toowoomba and start the design of apartments at Chancellor Park on the Sunshine Coast. Designed and built to Liveable Housing Australia's platinum standards and compliant with NDIS Specialist Disability Accommodation (SDA) – both accommodation projects will collectively provide homes for 24 people living with high physical support needs. This year, we introduced our Living Well initiative, which has established three regional hubs with direct access to leadership for staff and specialised support for residents. Throughout the year, we've been proud to continue partnering with specialist disability accommodation providers who share our vision to see no one with MS and high physical support

needs in an unsuitable living arrangement. The overwhelming commitment from our supporter and commercial partners over the year has ensured that we are working towards this vision in a tangible way.

Connecting services to regional Queensland

To better service all regions of Queensland throughout the pandemic and into the future, we are continuing to expand our service offering into virtual wellbeing programs, allied health, Telehealth, and other digital services. This contributed to 7,400+ hours of physio and exercise therapy and 35,000+ hours of support coordination delivered over 12 months, and 1,300+ people registered for our webinars and wellness programs. In April 2021, we partnered with National Head Contractor CoAct to now offer employment support to 130+ people living and working with MS. These services will underpin the strategy for our expanded Allied Health service offering, which will better service people living with MS

in regional parts of our state through Telehealth and partnerships. Telehealth technology enables our team to deliver physiotherapy and exercise therapy, employment support, and a growing range of services in 2022 virtually.

Keeping our community safe

We are proud that throughout these uncertain times, we continue to keep our customers, supporters, and staff safe. As we head into 2021-22, our Board and Executive Leadership team are committed to delivering our strategic priorities of know, engage, impact, people, and sustainability – whilst bringing our stated values to life.



Brett Bassett
Acting Executive Chairman



David Curd
Chief Executive Officer

Thank you & farewell

We want to say a well-deserved thank you to both Johanna Roche and Tracey Parker who we farewell this year from our MS Queensland Board. Both Johanna and Tracey have been valuable members of our Board and provided crucial strategic direction and oversight that's seen MS Queensland mature our property, financial, and services strategies. During their time on our Board, they've overseen the development of our Albany Creek, Springfield, and Toowoomba Apartments; the organisation's transition to the National Disability Insurance Scheme (NDIS); and been actively involved in the extension of our services into the other neurological condition services. We will miss their passion and dedication to ensuring no Queenslanders face MS alone. We would also like to thank Nick Wells for his service on MS Queensland Board over the last 12 months. We wish Nick, Johanna, and Tracey all the best for the future.



Our strategic direction

Our passionate team are here to be a partner on your journey.

This strategy relies on us keeping our strong community and customers at the heart of our decision making. MS Queensland will strive to know, engage, and be impactful in the lives of those living with MS and other neurological conditions regardless of where they live in Queensland. This includes their families, friends, and supporters. Please enjoy this year's Impact Report, which will start to bring this strategy to life.

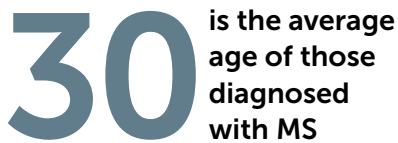
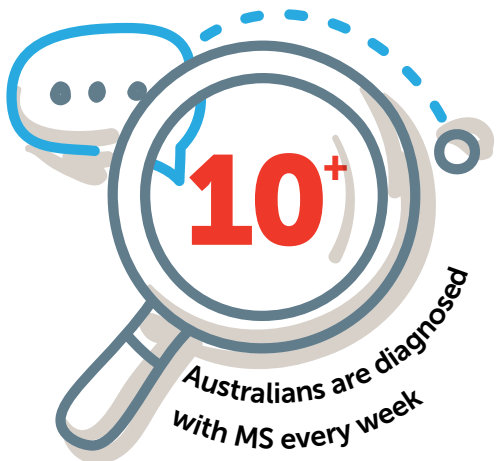
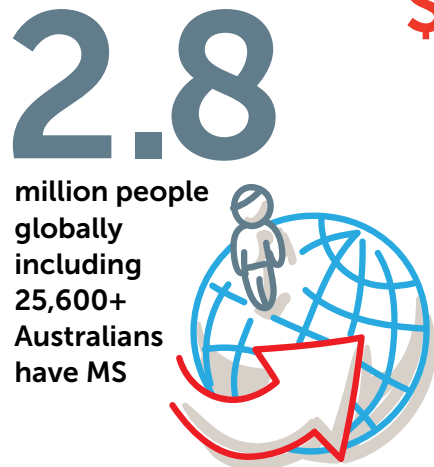
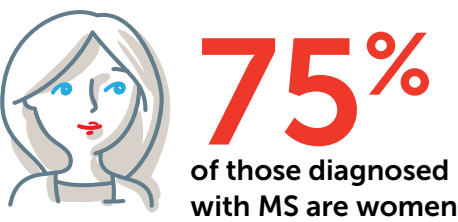


Know



We are dedicated to learning from the experiences of the 3,970+ Queenslanders living with MS and getting to know everyone in our state living with MS, so they don't face this condition alone.

Key facts about MS



Other neurological conditions
54,249+ Queenslanders live with chronic, progressive conditions that affect the nervous system

Sources: MS Australia: Key facts and figures about multiple sclerosis (September 2020). Department of Health. Burden of disease and injury in Queensland: Summary results for Queensland (November 2017).



Meg's story

"MS Queensland is like a warm hug when you need one." – Meg

Meg Mill is an effervescent mother of two beautiful girls who was diagnosed with relapsing-remitting MS in 2018 at 32 years old. When she was first diagnosed, she was devastated. Neither Meg nor her husband Andrew knew much about MS, except that it was a chronic disease for which there is no cure. Meg had experienced symptoms of MS for three years prior to her diagnosis including numbness in her shoulders, arms and feet as well as vertigo, blurred vision, extreme fatigue, and loss of memory.

Despite being able to manage her symptoms, lesions on Meg's brain and spinal cord have been progressing with each MRI. Meg stays brave in her fight, yet fears the next lesion could introduce a symptom that will heavily impact her quality of life. When she was first diagnosed, Meg called MS Queensland giving her access to important information, support networks and services including newly diagnosed workshops and webinars, psychology, physiotherapy, and fundraising events.

NeuroConnect

In 2021, we launched phase 1 of our NeuroConnect program to help get to know more of the people living with MS in Queensland. NeuroConnect is designed to strengthen the partnership between neurologists, MS clinic specialists, and MS Queensland by providing personalised support at every stage of the MS journey. NeuroConnect ensures people receive the right kind of personal connection and support on their MS journey.

Engage

Connecting with the community we support. We are committed to meaningful engagement with all Queenslanders living with MS.

Our community

The insights of our spirited community have seen our organisation remain integral and able to provide services to those living with MS and other neurological conditions. Throughout the year, MS Queensland has taken feedback from a range of customers, supporters, and long-term community members to inform every part of our future strategy and direction. We were also able to help those with MS connect and support each other when needed.



World *MS* Day

28



accessible
yoga events
hosted



24

landmarks
lit up red in
support

46



attended
Government
House
reception

Advocacy

This financial year, MS Queensland supported the Building Better Homes campaign to fight for more accessible housing options for those living with MS and high physical support needs. This campaign successfully saw mandatory minimum accessible standards included in the National Construction Code, Australia's primary set of technical design and construction provisions for buildings for all new residential buildings in Queensland built after September 2021. MS Queensland and our National body MS Australia also advocated for all people living with MS to have access to a full range of safe, effective and affordable treatments to help manage their individual symptoms. Thanks to the ongoing work of MS Australia, Siponimod (Mayzent) a medication to treatment of secondary progressive MS (SPMS) was added to the Pharmaceutical Benefits Scheme (PBS). This is the first ever medication listed on the PBS specifically for the treatment of SPMS. MS Australia's efforts also saw Ozanimod (Zeposia) approved for PBS listing for relapsing remitting MS.



Awareness

In 2020-21, we worked with our Ambassadors and supporters to increase awareness of the symptoms and chronic effects MS has on the body and to share the stories of those recently diagnosed with MS. Social and traditional media stories focused on the real impact MS has on someone’s life, how scary it can be to be diagnosed, as well as explored how symptoms vary for the individual. We also celebrated another successful World MS Day that again focused on the Connections theme, which continued to challenge social barriers that can leave people affected by MS feeling lonely and socially isolated, and advocate for better services, celebrate support networks, and champion self-care. Accessible yoga events held all over Queensland on World MS Day and the weekend following brought the MS community together and focused on the importance of meaningful connections. Despite COVID-19 restrictions, a group of key community members also attended Queensland’s Government House with His Excellency the Honourable Paul de Jersey AC.

Thank you & farewell

This year, we say farewell to His Excellency the Honourable Paul de Jersey AC and thank him for his commitment and courage to support those living with MS in Queensland over the last seven years as Patron of MS Queensland. Since his term began, the Governor has hosted a reception at Government House every year to mark the importance of World MS Day and has supported MS Queensland in its accommodation initiative and awareness campaigns. We wish His Excellency all the best in his future endeavours and look forward to the possibility of working with Dr Jeannette Young.



Kate’s story

Kate Casey was 18, attending university, and an active teenager who played squash and loved travelling when she started experiencing chronic dizziness and lethargy. Then Kate received a shock diagnosis of MS. Kate’s positive attitude meant she learnt as much as she could about MS, which changed the way she looked at her diagnosis and how she managed her symptoms. Kate wanted to provide peer support for other young people with MS in Townsville, so she created a targeted support group with the help of MS Queensland. More than 15 years since diagnosis, she has a successful career and is happily married.

“I have a positive approach to living with MS and I don’t let it rule my life.” – Kate

Throughout this last challenging year, Kate’s support group got together and lit up The Strand in Townsville for the MS Moonlight Walk to support each other and others living with MS. They also joined another Townsville support group to raise awareness for World MS Day.

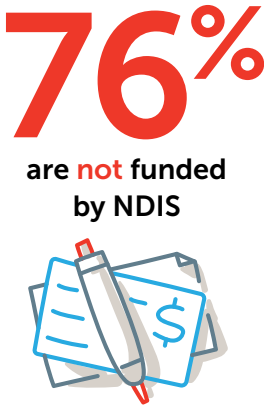
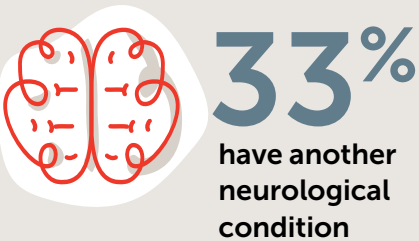
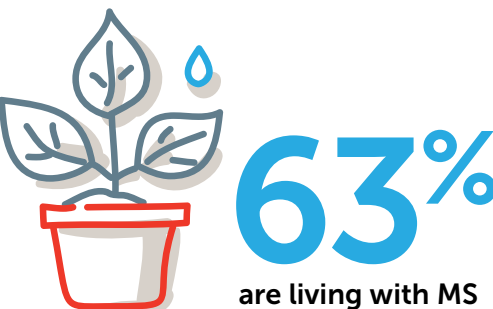
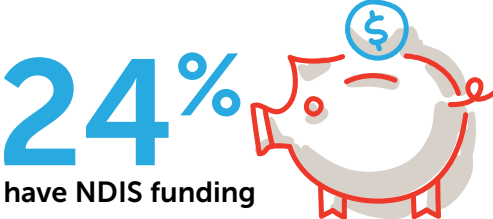


Impact



We strive to positively impact the lives of those affected by MS, so they live well and achieve their goals.

Our customers



Andrew's story

Andrew is a Nurse Unit Manager in a busy hospital department. On a day-to-day basis he oversees 60+ staff and faces many challenges including managing doctors, nurses, bed allocations, budgets, and the impacts of COVID-19 – all while living with Primary Progressive MS.

"The only reason I can continue in full-time work is because of MS Queensland's Employment Support Service. If it wasn't for my consultant, my MS may have forced me to drop back to part-time."
– Andrew

MS Queensland's Employment Services Support (ESS) team has been working with Andrew for 18 months, providing him with advice on symptom management and other support to handle his MS at work. Our team visited his workplace to educate his staff and managers on

his MS and helped Andrew access the National Disability Insurance Scheme (NDIS). His consultant also sourced specialised work equipment through Job Access including chairs, a mouse, a keyboard, and monitors – which support Andrew when working at the hospital and at home. Andrew's NDIS package has also seen him begin physiotherapy. Andrew's ESS consultant has been instrumental in supporting his MS journey.



Our services

MS Queensland is committed to delivering a wide range of specialist supports for MS and other neurological conditions. Our services include those funded by the Government and the National Disability Insurance Scheme (NDIS) as well as services funded by fundraising and donations to MS Queensland. Our supporter funded services are focused on filling the gaps and meeting the unmet need within the community including information, education, wellness programs, community connection, as well as NDIS access and pre-planning.

Supporter funded services

Wellness programs



24 webinars saw 1300 people register for topics on how MS effects pain, bone health, bladder management, and driving

Specialist nursing



phone and clinic consultations helped 738 patients understand MS symptom management and treatments

NeuroAssist



calls aided those living with MS and their families and helped 100+ people access the NDIS

Support groups



groups gave members a network that makes them feel connected and supported through sharing their experiences

NDIS and Government funded services

Employment support



people were supported in managing their MS at work or given assistance in seeking new employment

Physio and exercise therapy



hours of therapy were delivered to improve client's movement and mobility to maintain greater independence

Support coordination



hours of support saw 600+ people connect with services for MS and other neurological conditions



Brooklyn's story

Brooklyn Downes is 27, works in social media marketing and in May this year received a shock MS diagnosis. Brooklyn had double vision for a week and couldn't figure out what was wrong.

"It's a huge relief having someone to call that can answer all your questions when you're coming to terms with your MS diagnosis."
– Brooklyn

As her vision wasn't improving, Brooklyn went to the Emergency Department where she was rushed in to have blood tests and MRI scans – confirming she had relapsing remitting MS.

Before being discharged from hospital, Brooklyn was visited by an MS Nurse from MS Queensland who explained that he was there to talk anytime if she had questions. Nursing support has given Brooklyn a sense of reassurance, addressing any concerns from treatments to relapses or even how to approach pregnancy. Brooklyn now writes down questions as she thinks of them to ask her MS nurse next time they speak. Since diagnosis, Brooklyn has received intravenous treatment for her MS and is feeling good. Armed with support on how to manage her MS in everyday life, Brooklyn is excited to get married to her supportive partner Alyse and continue living her life.



MS Queensland's Toowoomba Apartments



MS Queensland's Springfield Apartments



"I knew I could be much more independent if I had the right accommodation. I'm so thankful I found MS Queensland's apartments."
- Barbara

Accommodation

In the 2020-21 financial year, we continued engaging and partnering with developers, philanthropists, and organisations who share our vision to end the disability housing crisis. This saw our organisation continue to provide world-class, purpose built independent apartments built to platinum Liveable Housing Australia standards for those with MS and high physical support needs. A big thank you to all of our accommodation partners.



Perry Cross, MS Queensland's Zane Ali, and the team from Accessible Homes Australia at the ground breaking of the East Palm Beach apartments which opened in September 2021



Living Well

MS Queensland is committed to ensuring all current and future residents have the best opportunity to live well and are supported by committed staff, experienced leaders, and positive community partnerships. Our Living Well initiative was introduced in 2021 to better align our commitment with resident's experiences. To achieve this, we have established three regional hubs to provide leadership resources across locations to resolve issues and create opportunities, deliver a sustainable and consistent service model, as well as enhance experience for residents through relevant and local community partnerships.

From SOD to reality

Construction is now complete on our Toowoomba Apartments and we're now working to ensure 12 people with high physical support needs can soon call these beautiful apartments home. We're excited to open this Supported Disability Accommodation on Hume Street after the project was made possible by local philanthropic support. These apartments are a key steppingstone in our commitment to contribute to solving the disability housing crisis in Queensland and creating amazing homes that are genuinely inviting, modern and bright, as well as practical for those living with MS and other neurological conditions. We hope to soon share good news stories about some of the residents living in Toowoomba and news of breaking ground on our next apartment project on the Sunshine Coast.

Fundraising

2021 was a big year for fundraising as the constant unpredictably of COVID-19 restrictions continued to shift in parts of Queensland.

Despite this, our team was excited to see the return of many of our major events under approved COVID Safe plans and our campaigns see dedicated support to change the lives of those with MS. The team also won Queensland’s Best Pivot Campaign for MS Brissie to the Bay – 30 for 30 Challenge, with our very own Clancy Feuerriegel nominated for Australia’s Young Fundraiser of the Year. We thank all our loyal and generous supporters who continued to support MS Queensland even through times of uncertainty and change.

Thankathon

To continue being the best at saying thank you, MS Queensland held its second annual Thankathon seeing the below done to thank all our supporters.



Philanthropy

\$1,566,657
raised from major gifts from generous donors

Grants

\$355,097
raised through grants for capital, services, and research

Lotteries

\$4,637,950
raised through the selling of
79,759 tickets across all lotteries

Gifts in wills

\$424,751
gifted by **10** people through their will

Individual giving

\$552,703
raised from **3,475** generous donors



Donate
msqld.org.au/donate
07 3840 0888

Nicole's story

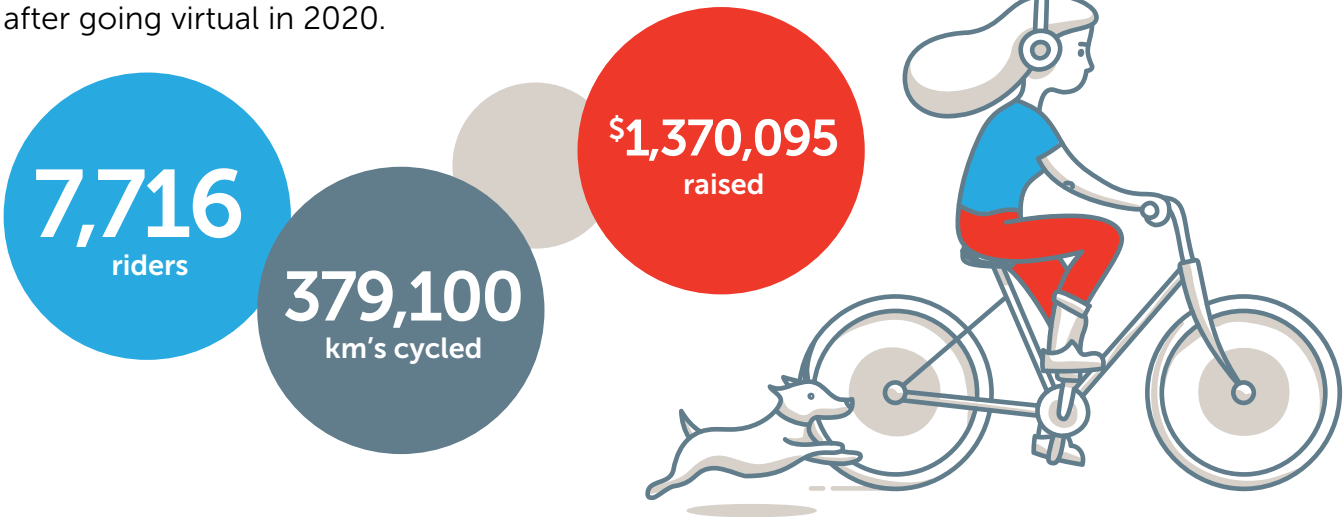
Nicole Zell is 38, a Dealers Assistant at Shaw & Partners, and living with relapsing remitting MS. Nicole's first MS episode saw the entire right side of her body go numb and she was admitted to hospital where they took an MRI of her spine. She wasn't diagnosed until the following year at 28, after the numbness returned and scans of her brain showed lesions. Nicole has now managed her MS symptoms for over 10 years. She believes MS has made her a stronger person able to fight for what she believes in as well as appreciate her family, friends, life, and health much more than before. Nicole and her Shaw & Partners team raised over \$130,000 in this year MS Brissie to the Bay. Since Nicole's boss, Rick Terpstra, learnt of Nicole's diagnosis he's been overwhelmingly supportive and the team cycle in the ride to fight MS every year.

"MS Brissie to the Bay is a phenomenal opportunity to raise awareness of MS and vital funds for support services and research. We look forward to many more years of the ride."
- Nicole



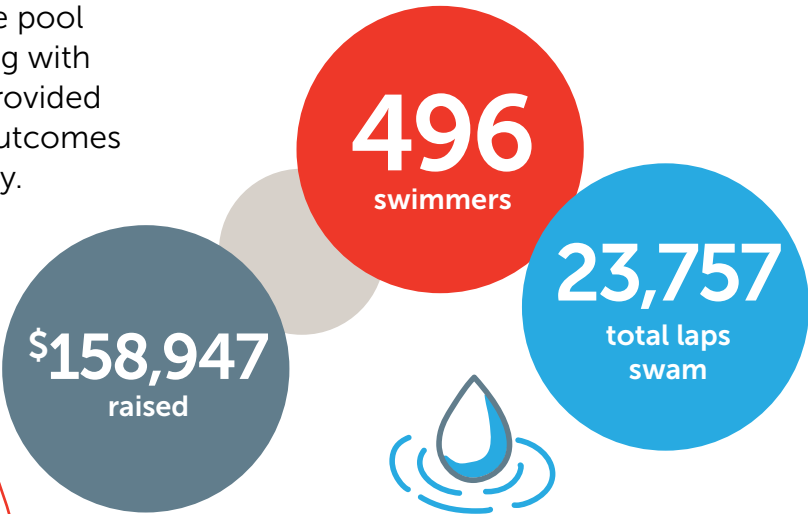
MS Brissie to the Bay

The ride to fight MS was welcomed back to South Bank. Its 31st year saw one of our biggest ever MS Brissie to the Bay events after going virtual in 2020.



MS Swimathons

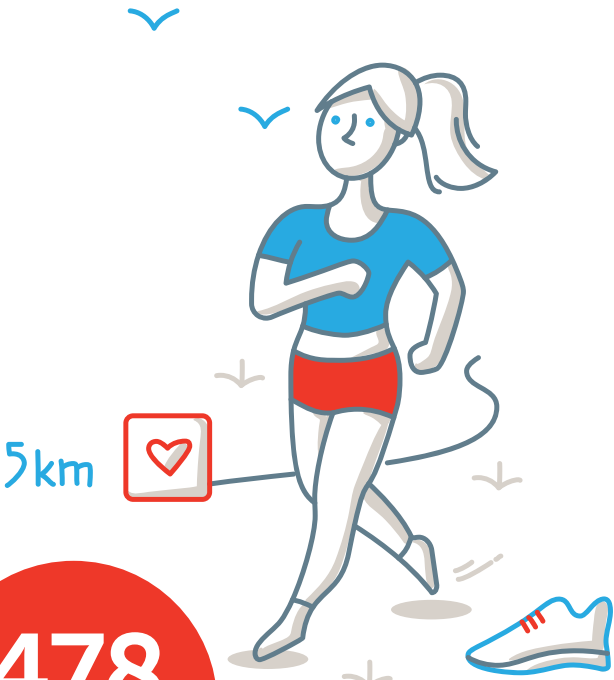
Townsville, Redcliffe, Toowoomba, and the Sunshine Coast dove into the pool and made a splash for those living with MS at the MS Swimathons and provided connection, engagement, and outcomes for those living with MS regionally.





MS Moonlight Walk

Illuminating our belief that no one should face MS alone, the MS Moonlight Walk returned to West End after the height of the COVID-19 pandemic, engaging supporters across the state in a physical and virtual walk.



MS Readathon

With many families in lockdown, kids all over Australia picked up books and read as many as possible in August to support families affected by MS.



Community fundraising

In 2021, supporters inspired us with their creativity and rode 100kms on horseback and trekked the Larapinta Trail for our cause.



Aimee's story

Aimee Segal is a passionate 16-year-old and aspiring performer with a love of acting, singing, and bassoon who hopes one day to study performing arts. Since seven, Aimee has swum in the Townsville MS Swimathon, raising over \$30,000 for MS Queensland's support services seeing her nominated for 2021 7NEWS Young Achiever Awards QLD. On the morning of Christmas eve 2020, Aimee was flown to Townsville University Hospital after she was temporarily unable to speak and the right side of her body had shut down. After 10 days in hospital, Aimee was diagnosed with MS and is now undergoing treatment that requires her to get infusion medication every 28 days. Aimee is one of the youngest to be diagnosed with MS in Australia! Since December, Aimee has been committed to raising awareness that young people can develop MS and that MS is more prevalent in young people than any other neurological condition. With her family's support, Aimee is living well and teaching her school in Townsville how to support students with neurological conditions.

"MS has taught me to persevere and not let the illness define me as a person. I'm excited for what my future holds and happy I can still do the things I love – while knowing my family, friends, and MS Queensland will always be there to support me when I need it!" – Aimee



MS research

MS Queensland contributes annual funds to MS Australia and its national research body, which runs grant programs throughout the year.

In addition to this research contribution, it has been eight years since MS Queensland and Queensland philanthropists began supporting Emeritus Professor Michael Pender from The University of Queensland to undertake adoptive T cell immunotherapy treatment research. It's also been three years since adoptive T cell immunotherapy treatment was shown to be safe in a small clinical trial group of 10 people with progressive MS. This cutting-edge treatment – which targets the Epstein Barr virus (EBV) – saw four participants have some sustained improvement, including reduced fatigue and disability.

Thanks to these encouraging results, a further clinical trial has commenced, led by Principal Investigator Dr Zara Ioannides following Professor Pender's retirement. This follow-up trial will differ from the first trial which involved taking cells from a person with MS, boosting their EBV-killing capacity, and then reintroducing those cells to the same person. In the new trial, researchers are using EBV-targeted cells collected from a healthy unrelated donor instead of the person themselves. This is important research as it targets progressive MS which has very few treatment options.

Farewell & thank you



We are honoured to congratulate Emeritus Professor Michael Pender as he retires after 40 years of dedicated MS research and recognise his successful career.

Professor Michael Pender has devoted his life to understanding MS and finding a cure. In his work, Michael researched how to alleviate and stop the progression of the debilitating and crippling effects of MS. Under Michael's leadership, the team has made huge progress in understanding the causes and progression of MS. From hypothesising that Epstein-Barr Virus (EBV) has a role in the development of

MS, to testing this with clinical trials to identify possible treatments for stopping and potentially reversing the neurological damage in those patients with progressive MS. We welcome and acknowledge the work of Dr Zara Ioannides in taking this important research into the future, and look forward to the outcomes for people living with MS and other neurological conditions.

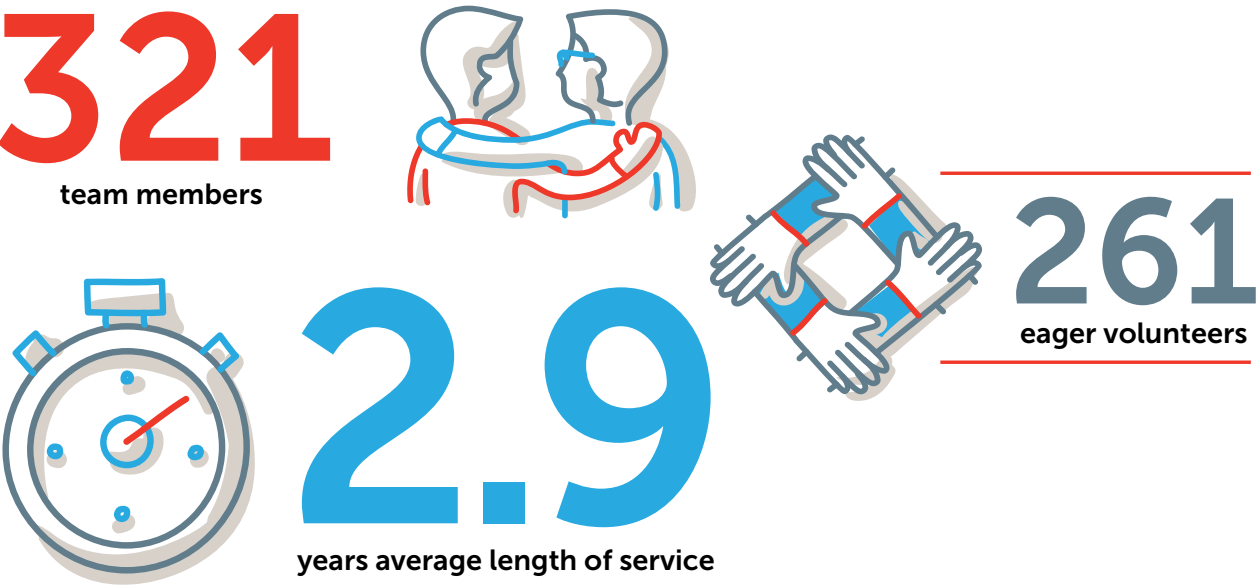


People



Connecting people with people. Our compassionate team is committed to building lasting and rewarding relationships that achieve quality outcomes for customers.

Our team



Focusing on health & wellbeing

We’ve helped connect our team with our cause, so they can see how their quality services impact the lives of those living with MS through events, stories, and communication. Staff programs including virtual trivia, yoga sessions, and bake-offs – focused on wellbeing and brought people together in a disconnected time. The Employee Assistance Program (EAP) also gave staff someone else to talk to if they were struggling. Other programs also connected staff such as our Greatest of all Time (GOAT) app, which saw staff post appreciation and thank you messages to each other. To support our staff’s health and wellbeing, we added provisions to see those impacted by domestic violence receive the needed leave, introduced paid paternity leave, funded flu immunisations and continued providing health fund discounts.

COVID-19 response

Throughout the challenging and unpredictable changes of the COVID-19 pandemic, leaders across our team worked together to best support customers, residents, and staff. The COVID-19 working group optimised working from home processes, introduced special leave provisions when work was impacted by COVID-19 as well as digitalised reporting (including temperature checking), provided personal protective equipment (PPE) in accordance with Queensland Health guidelines for all sites, as well as

communicated COVID-19 changes to staff and customers through intranet sites, emails, town halls, and our website. The wellbeing of staff was also supported through connecting them with our Employee Assistance Program to discuss any difficulties and concerns they may be having, and care packages were given to staff diagnosed with COVID-19 to help with their recovery journey. This additional support was provided despite MS Queensland not receiving Federal Job Keeper funding assistance.

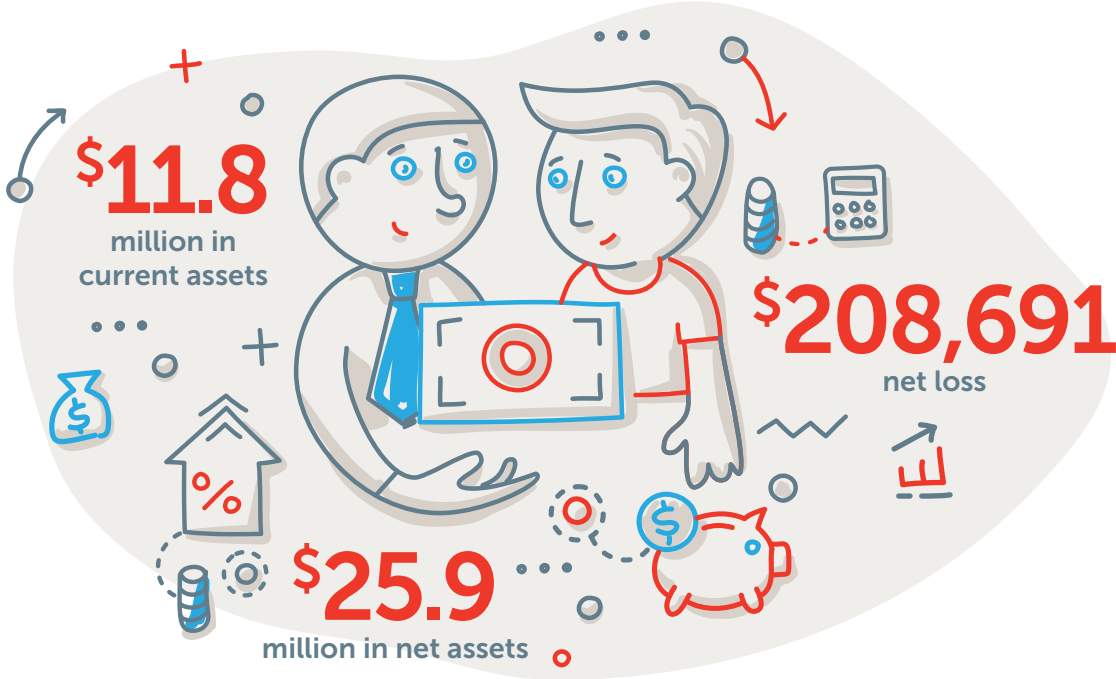


Volunteer with us
volunteer@msqld.org.au
07 3840 0888



Sustainability

We aim to support continued growth through valuing transparency and accountability. Our sustainable business, service, and governance model relies on being transparent about the use of funds.



Board, leaders & financials

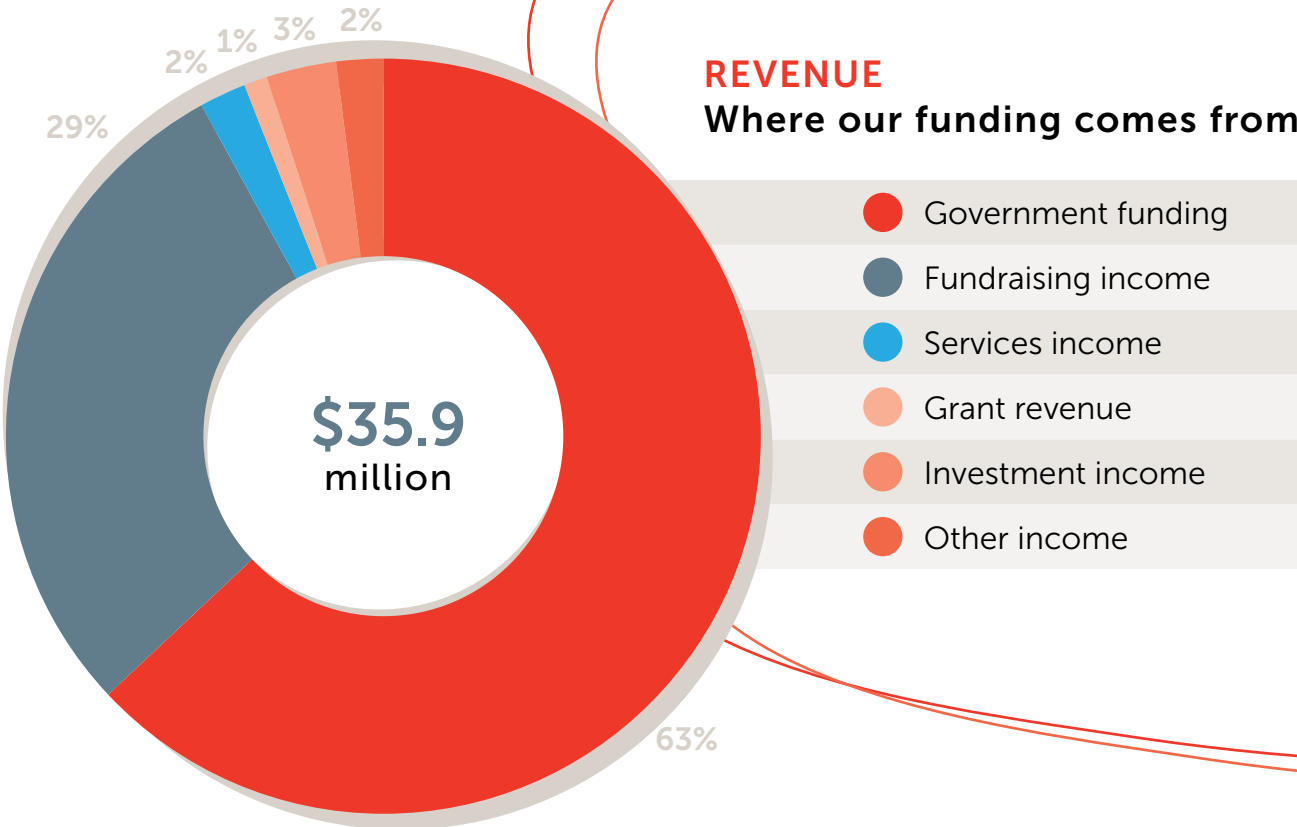
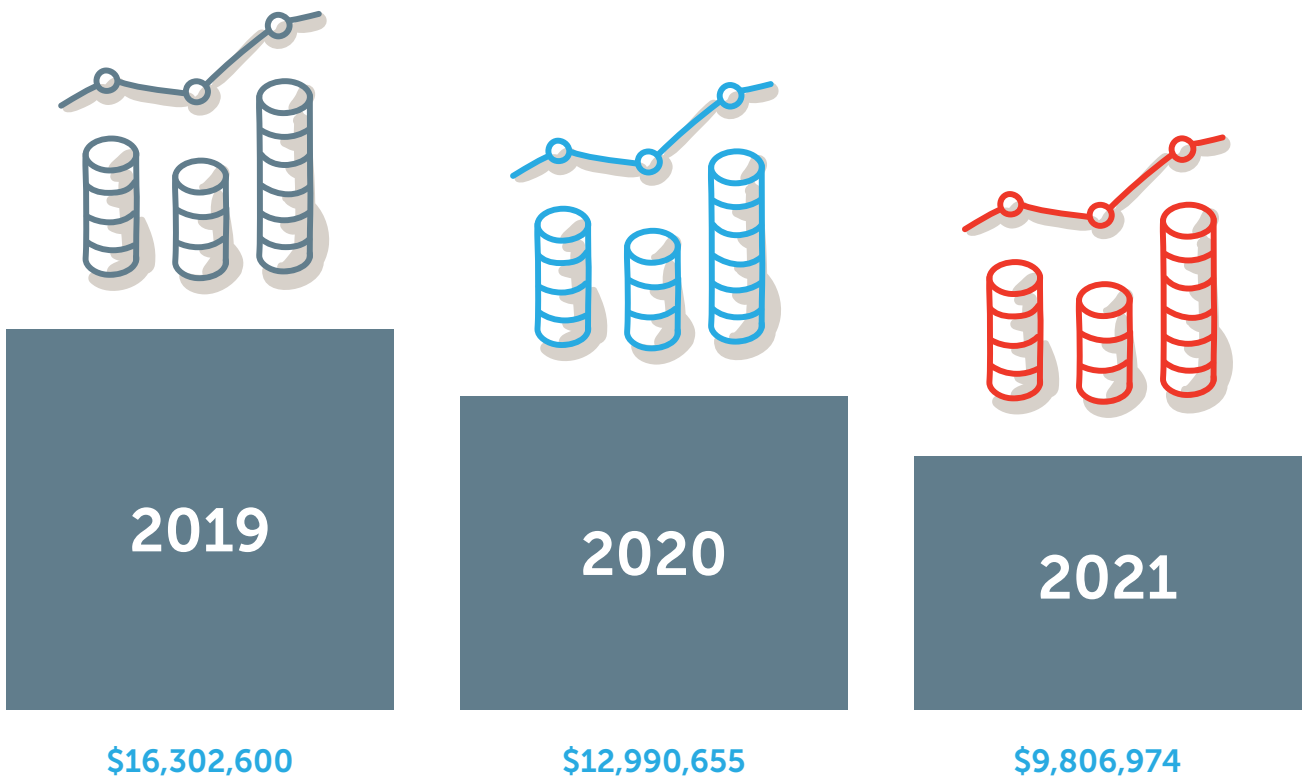
The Board and executive leadership team play a critical role in establishing and executing our organisation’s strategic direction. Learn more about our Board and leaders and see the full financials here.

Financial summary

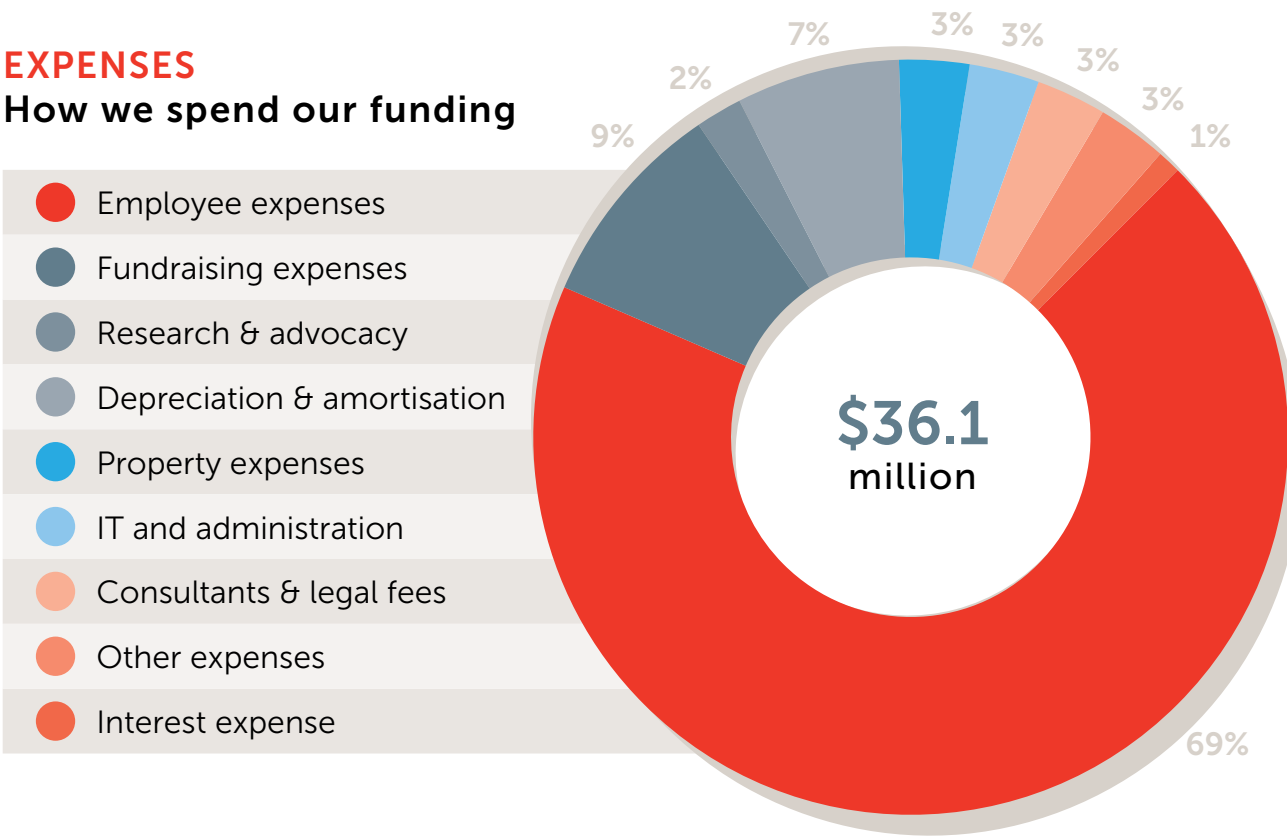
The 2020-21 financial year has been a challenging one for MS Queensland both financially and personally for our customers, supporters, and staff with the COVID-19 global pandemic continuing to impact us in unexpected ways.

The year again saw reduced fundraising activity, the closure of wellbeing centres, a shift to more virtual support coordination sessions, limited face-to-face physiotherapy and exercise therapy services, heightened restrictions for our accommodation sites and visitors, and an increase in costs of Personal Protective Equipment (PPE). Despite these challenges, the organisation grew its customers by 8.1%, reduced our net loss on the previous years performance, and maintained a strong cash and financial asset position.

Cash and financial assets



EXPENSES How we spend our funding





Janine's story

Janine is a talented athlete who was diagnosed with MS at 25. Janine refuses to let MS define her. This year, Janine made history as the first Australian to compete in Para taekwondo at the 2020 Tokyo Paralympic Games where she won bronze! Janine is an MS Queensland Ambassador and also holds several titles across taekwondo, sparring and poomsae, as well as wheelchair tennis. Before diagnosis, Janine was having visual disturbances when she was exercising (including blurred and double vision) for six months. She thought it was just sweat in her contact lenses, until she lost complete sight and knew something was wrong. After a series of trips between her hometown of Chinchilla to Brisbane and Toowoomba, Janine was diagnosed with MS.

"Rather than focusing on what MS is taking away from me and worrying about what could happen in the future, I decide to concentrate on what I still have and what I can do."

– Janine

Thank *you* for your support



Queensland



NeuroAssist
1800 177 591



msqld.org.au



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