

2020 - 2021 ANNUAL REPORT



**Multiple Sclerosis
New Zealand**

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Multiple Sclerosis
New Zealand

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OVERVIEW OF 2020/1 OUTPUTS

At Multiple Sclerosis New Zealand (MSNZ) we are passionate about supporting over 4000 New Zealanders and their loved ones nationwide to have access to the best information, services, treatments and supports they need to live well with their diagnosis, maintaining and improving their life-long brain health. Since 1967, we have supported our members, 18 independent Regional Societies, to meet the needs of people with MS, their families and carers through national leadership, advocacy, communication, and national and international collaboration.

Our organisation:

- Advocates on national issues impacting the MS community;
- Raises awareness for MS as a chronic condition affecting New Zealanders and highlighting the needs of those impacted by the condition;
- Provides free information on understanding, managing and living well with MS;
- Offers a free helpline and online tools to connect those looking for support.
- Funds scholarships to keep people with MS in paid employment;
- Provides member organisations with operational and governance support;
- Provides leadership to model best practice to improve outcomes for people with MS;
- Organises educational training opportunities for community-based support staff;
- Works collaboratively with relevant partners to identify and develop tools to support effective self-management of MS;
- Collaborates with other organisations to increase opportunities for positive engagement and living well with MS.

3

Major projects
underway

141

Website
stories

2

Education
scholarships
awarded to
people with MS

23

Community Support Workers funded
to attend annual training

778

Calls received via our Helpline

122,505

Website
page views

2

Fundraising and
Awareness
Campaigns

2

Public
Webinars
held

4

Events
organised in
collaborating
with other
organisations

9

Alliances, organisations and
networks engaged with

3

Meetings and
webinars held
for member
organisations

68,589

Website views from 51,579
unique visitors.

1462

Information
resources
supplied to
member
organisations
and general
public

29

Meetings, submissions, OIA request, letters to
MP's, Committees, PHARMAC or Ministry of
Health Officials, DHBs

42

Intranet post to
members

135

Information
requests via our
website

17

Information
requests for
Regions via our
website

A MESSAGE FROM MSNZ'S PRESIDENT



Since joining the National Committee in 2011 I am inspired by how far the organisation has come to achieve our vision of “A world without MS”. The dedicated National Committee and office staff are working hard to achieve our mission of “Collaborating with member organisations to provide a voice for people with Multiple Sclerosis (PwMS), their families and carers through leadership, advocacy, communication, and national and international collaboration.”

Having been Vice President since October 2021, I was elected as President of the National Committee. It has been a challenging year with Covid adding to the myriad of challenges small not-for-profit organisations were already facing. MSNZ has despite this, has had a very productive year.

We have made substantial progress in stabilising the financial position of the organisation. In the last 7 years we have increased our Equity from a deficit of \$256,000 to a surplus \$467,000 and income from \$469,000 to \$674,000. As expected, expenses have increased mirroring how our organisation and impact has grown. I am pleased to report a \$58,000 surplus for the year, a position we are extremely pleased with despite the unprecedented year faced.

A huge thank you to the Rotary Club of Half Moon Bay for their continued support of our organisation, and our Regions nationwide. Once again, we were one of two masthead charities for Bangers to Bluff. For the first time we entered a team “Keep S’myelin.” Myself along with fellow National Committee Members Jeff Silvester and Graham Walker took the opportunity to further engage with the Club and participants. Not only does the event raise vital funds for our organisation, but also provides opportunities to meet Regional Societies along the way and raise well received national press coverage and awareness for MS. We look forward to travelling with the team next year in our “new” VW Beetle.

Of highlight to me has been the major milestone we achieved in March 2021, improving access to MS disease modifying therapies (DMTs). I have been involved with the Advocacy Subcommittee since the beginning of the process 6 years ago. This development is testament to the persistence and commitment of MSNZ in advocating for changes to improve the health and well-being of New Zealanders with MS. As we move forward with our advocacy, we are hoping to share the final ‘Cost of MS Study’ report which will provide a further springboard to get improved access for drugs for MS which is after all a treatable chronic disease.

A major concern for several years has been the dire state of the neurology workforce in New Zealand especially neurologists and nurses who specialise in MS. It is encouraging to see some signs that there has been an increase in registrars enrolled in Neurology. We continue to advocate for more neurology resources, both independently and alongside allied organisations such as the New Zealand Multiple Sclerosis Research Trust and the Neurological Alliance.

MSNZ is a member of the NZ Carers Alliance, a grouping of about 40 organisations whose members rely on family members and other carers to provide support for people with disabilities. The challenges of Covid has exposed the failure of governments over a long period of time to provide a comprehensive and consistent approach to the estimated 400,000 people affected in this way. It is disappointing to report little progress has been made in this area.

The NZ Health Sector is currently undergoing the most comprehensive reforms in over 20 years. These reforms are set to be in place from 1 July 2022. At time of writing, it is unclear where organisations like ours will fit. One issue for me is the current split between Health and Disability. This allows people with chronic health conditions and inevitable disabilities, such as MS, to fall between the cracks that exist. People with MS, especially those with advanced disease need a comprehensive, integrated response from the health care professionals. Currently this care is fragmented and the PwMS, or their partner/carer or MS Community Support Worker needs to be the coordinator and advocate. It is unclear at this stage that the proposed reforms will address these issues.

While the past year challenged on many levels, on balance I believe MSNZ has emerged from it in good shape having achieved a lot despite the extreme disruption Covid caused. We look forward to the future, confident we have the ability and resilience to weather whatever challenges are thrown our way.

Neil Woodhams
President

NATIONAL MANAGER'S ROUND UP



Multiple Sclerosis NZ (MSNZ) has come a long way in the last nine years since I joined the organisation and no more so than in this last twelve months. Despite the challenges that we have been confronted with we have shown ourselves to be a resilient and flexible organisation. We have been able to meet increasing demands, change working practices to meet needs, increase outputs and make great strides to achieve our strategic plan. All this would not be possible without such a dedicated team of staff which I am proud to lead, supported by an engaged volunteer Executive Committee.

A particular highlight of the year to me was in our Advocacy. After 6 years of hard-fought advocacy, it was a huge relief to finally see changes made to the access criteria for MS treatments. There is still some way to go but progress has been made. The 'Cost of MS Study' and 'Good Service Project' have also progressed well. Both are due for completion next year. Further information about our advocacy can be found on pages 14 to 24 of this report.

At the end of 2020 we began working with Advocacy Answers to seek an independent review of our organisation, in particular our fundraising. The review highlighted several areas for development which we have either actioned, are in progress or in review. Following this we redeveloped our Strategic Plan through to 2025 to ensure that MSNZ is staying focussed and on task. I am excited about the direction that strategy is taking us in.

We have significantly increased our communication outputs this year, restarting our monthly e-newsletter and regularly posting on our internal intranet. Our intranet ensures our regional member staff and committees are informed in a timely manner with information that may be relevant to their governance, operations or service provision.

Our MS Conference, held in Christchurch in October 2020 was well attended and encouraged Regions to begin looking forward in this time of change. As 19 independent organisations we must look towards how we can best collaborate. As our organisations vary in size, capabilities, and capacities, ensuring resources are targeted and duplication across the network reduced, will increase efficiencies for the benefit of people impacted by MS. I am pleased to see some of our clusters addressing these issues and developing opportunities for collaborative working and fundraising.

After a year of limited face-to-face contact, and no meeting in 18 months, we were pleased to bring together Community Support Workers once again from across the country for their

meeting and educational opportunity in May 2021. While learnings can be delivered online, the benefits of engaging in person are invaluable, particularly for those working in remote rural regions. The sessions covered in the programme closely followed the theme of self-management. MSNZ promotes and encourages resiliency, self-management, preventative services and principles of living well with a chronic treatable condition. We do this by providing evidence-based information that supports and encourages people to take control of their diagnosis and condition. Positive attitudes and life-style modifications can have a profound effect on symptom management and maximising opportunities for long-term health outcomes. With thanks to Merck, Roche, Novartis and Biogen we were able to fully fund attendance, reducing barriers for our Regions.

While in-person opportunities allow for deeper engagement, the increased use of technology to provide services and engage with our members and the wider MS community has been invaluable. We have facilitated 3 webinars this year for our member organisations and the wider MS Community which means as a national organisation we are able to engage nationwide effectively but at reduced costs. We are also able to utilise the skills of international speakers.

MSNZ prides itself on ensuring information we provide is evidence based. We are always grateful for the support provided by the Neurology experts and our friends at MS Australia who regularly provide advice and input on matters of interest. Their expertise ensures we are confident in the advice and information we provide our members and the MS Community.

Covid continued to have an impact on NZ, the MS Community and our services. This year saw a particular focus on vaccines and how these impact people with MS. We were fortunate to engage the skills of Professor David Tschärke, Head of the Department of Immunology and Infectious Diseases at the John Curtin School of Medical Research, the Australian National University. Professor Tschärke is also a person with MS. Via a webinar for World MS Day, clear and well researched evidence was shared about how the Pfizer Covid-19 vaccine impacts the immune system and interactions with MS treatments available in NZ. We had an excellent response to the webinar which answered questions that were of concern for people with MS in making decisions about whether to get vaccinated. The event was co-hosted by the Ministry of Health and included a presentation about their roll out plan to the disability community.

This year we began a major project reviewing our suite of information resources. A long-planned project, we have received good engagement and feedback from service providers, people with MS, carers and whānau. While the feedback has showed the value of the information, it has highlighted key areas for change and development both in content and format. A larger project than expected, this will now be completed in the next year.

With the cessation of cheques from July 2021 we are cautious about the impact this will have on us financially. We realise this is a big change for many in the community and have endeavoured to work with our donors providing support to make the transition smooth. Time will tell what impact these changes imposed by banks will have on Charities nationally. We have seen an increase in funding from trusts and grant providers this year. However, we remain vigilant that lockdowns cause delays in funding and often a reprioritisation of funding by providers. We are actively remaining on top of these changes and work with funders to ensure we secure much needed income to progress our work.

A huge thank you to those individuals, organisations and businesses who have supported us over the last 12 months. In particular, the Rotary Club of Half Moon Bay, Allen and Clarke, Merck, Roche, Novartis and Biogen. Their continued support of our organisation is invaluable for ensuring we are able to deliver on our strategy.

Thank you to Emily, Sam and Louise in the National Office for your continued dedication and passion. Our innovative team is always looking at new opportunities and ways to improve services. Thank you Jan, Malcolm, Graham, Lyn and Jeff for your commitment to the organisation. The National Committees support, direction and oversight is always valued.

Lastly congratulations to Neil Woodhams, on his New Zealand Order of Merit, received this year. A well-deserved award recognising his long-standing services to the MS community. In his first term as President, he has made tremendous headway, increasing communications with Regional Members, presenting at local meetings on request and pushing the organisation to achieve our goals.

Amanda Rose
MSNZ National Manager

VISION

A world without Multiple Sclerosis

MISSION

Collaborating with member organisations to provide a voice for people with Multiple Sclerosis, their families and carers through leadership, advocacy, communication, and national and international collaboration.

PURPOSE

Delivering advocacy, information, awareness, education so people living with MS can independently live their best lives.

VALUES

We endeavour to deliver our services with understanding, collaboration, clarity, purpose and trust.

DELIVERING NATIONAL LEADERSHIP



OBJECTIVES

- Build MSNZs capacity to support regional accountability and sustainability
- Leadership to model best practice to improve outcomes for people with Multiple Sclerosis
- Promote evidence-based concepts of optimal self-management practices
- Model effective leadership in Governance
- Strengthen leadership capabilities through deliberate focus and role clarity
- Work collaboratively with other organisations in New Zealand and overseas.

KEY OUTPUTS OF 2020/1 MS CONFERENCE

Our annual Conference in October 2020, attended by 24 representatives from 13 Regions, encouraged opportunities for learning, networking, collaboration and innovative thinking to address the needs of our communities. Attended by volunteer Committee Members and management staff, content was designed to support members to run effective organisations in their local communities. The event provided the opportunity to provide feedback, and points for discussion in an open, honest and regulated forum. MSNZ subsidised the costs for members to attend.

STANDARDISED POLICIES

As our organisations vary in size, capabilities, and capacities, we must ensure resources are targeted and duplication across the network reduced. MSNZ ensures to provide regions with templates of standardised nationally approved policies to reduce duplication and promote consistency. Thank you to Allen and Clarke who provided their pro bono skills and expertise to develop a standardised national Privacy Policy and supporting documentation in line with the new Privacy Act.

INFORMATION EDUCATION AND AWARENESS



OBJECTIVES

- Optimise communications to ensure accurate and current information is available.
- Raise awareness nationally for Multiple Sclerosis as a chronic condition affecting New Zealanders and highlighting the needs of those impacted by the condition.
- Creating a strong recognisable brand that people know and trust.

KEY OUTPUTS OF 2020/1 INFORMATION

MSNZ provides evidence-based information that supports and encourages people to take control of their diagnosis and condition. Promoting positive attitudes and lifestyle modifications which can have a profound effect on symptom management and maximising opportunities for long-term health and brain health outcomes. An extensive review is underway of all our inhouse resources, including booklets and our website. Feedback from the MS Community has been sought through surveys and workshops. The review will ensure our information and the formats meet the varying needs of the MS Community

EDUCATION

The annual Community Support Worker Meeting held across 3 days in May 2021, provided opportunities for education and networking. Education was provided on a range of topics to encourage resiliency, self-management and principles of living well with a chronic condition. The meeting aims to improve national standards of service and information provided to people impacted by MS through regional supports. With thanks to Merck, Roche, Novartis and Biogen we were able to fully fund attendance, reducing barriers for our Regions.

AWARENESS

MS is a chronic, treatable condition affecting 4000 New Zealanders, their carers and whānau. Each year Multiple Sclerosis NZ looks to raise national awareness MS, which is common yet often misunderstood. By highlighting the experiences and needs of those impacted by the condition we aim to generate empathy and understanding to reduce isolation and increase inclusivity for the MS community.

Having noticed an increase in people with MS becoming more open about sharing their life and experiences with their condition, we launched the first year of our 'Faces of MS' campaign. Through the campaign we introduced a range of people diagnosed nationwide, highlighting the diversity of MS, in age, gender, cultures and abilities. By sharing a range of unique and personal stories, the campaign emphasised MS is a condition that can impact anyone, at any time of life and has many unseen symptoms.

We also reached out to the public to support MSNZ and our Regional Societies with donations to continue the provision of vital MS support. With a Covid-19 lockdown period being lifted just prior to our Awareness Week, some Regions had to make the difficult decision to cancel, delay or scale back their Street Appeals and associated events. While disappointing, our campaign fundraising platform gave each Regional Society an online opportunity to introduce their local communities to their 'Face of MS' to raise awareness. A library of digitally branded resources were supplied to further assist their fundraising efforts.

Despite the impacts of the pandemic, \$118,411 was raised nationwide. Most notably, MS and Parkinson's Canterbury collected over \$47,000, MS Wellington in excess of \$10,000 and MS and Parkinson's West Coast Craft Fair raised a fantastic \$16,500 after being postponed to a later date.

Thank you to everyone who donated their time or money to support Multiple Sclerosis in the 2020 Awareness Week. We and our Regional Societies are deeply grateful for the 361 volunteers, 17 schools and 64 service organisations who dedicated over 1514 hours of their time at 126 locations to support their local MS organisations. With this support, Regional Societies were able to raise much needed funds and can continue to provide services in their communities



OBJECTIVES

- National voice for people impacted by Multiple Sclerosis
- Seek meaningful engagement and input on the needs of the MS Community to establish advocacy priorities.
- Work with the government and key agencies to address the needs of those living with MS.

KEY OUTPUTS OF 2020/1

The most recent estimates are that over 4100 people are diagnosed with MS in New Zealand. This has increased from 2917 in 2006. Incidence data shows an average of 134 people are diagnosed with MS each year, and an additional 94 people will experience their first symptom, which may result in an MS diagnosis.

Through our Advocacy we aim to:

- Recommend internationally recognised strategies to maximise lifelong 'brain health'.
- Advocate for international consensus recommendations on diagnosis, therapeutic strategies and improving access to treatment in MS.
- Recommend the goal of treating MS early to preserve tissue in the central nervous system and maximise lifelong brain health by reducing disease activity.
- Call for major policy changes aimed at achieving the best possible outcomes for people with MS and those who care for them.
- MSNZ works to break down barriers to treatment and care for people living with MS.

PRIORITIES 2020/1

Our agenda of advocacy priorities is based on the expressed needs of the MS community, supporting not only those diagnosed but also their whanau, carers and other support networks. Input is received from a wide range of networks including people with MS, our members, allied organisations and health professionals.

In 2020-21 our Advocacy Programme has focussed on 8 key areas:

01

ACCESS TO MS TREATMENTS

Widening the access criteria for funded disease modifying therapies (DMTs), beginning earlier and continuing for longer based on evidence

02

FUNDING FOR NEW TREATMENTS

Funding for treatments which have shown benefits for MS, particularly interested in options for SPMS and PPMS due to high unmet need

03

AHSCT

Ensuring Autologous Haematopoietic Stem Cell Transplant (AHSCT) is available and funded in NZ for those who would benefit

04

PHARMAC REVIEW

Engaging with the ongoing PHARMAC review and advocating to increase the PHARMAC budget to fund life improving and saving medicines

05

UNDERRESOURCED NEUROLOGICAL SERVICES

Advocating for increased resourcing for neurological services to improve access to diagnosis, treatment and on-going care

06

THE COSTS OF MS

Improving the understanding of the costs of MS to the NZ economy, those diagnosed, and their families

07

COVID-19 RESPONSE

Ensuring people with MS are informed about Covid-19 and MS as well as ensuring the needs of the MS Community are addressed by relevant agencies

08

FAMILY CARERS

Working with the Carers Alliance to improve funding and support for NZ Carers

TREATMENTS



2021 HIGHLIGHT PROLONGING ACCESS TO TREATMENTS

Advocacy is a long-term commitment for our organisation. Since 2014 MSNZ has advocated for improved access to disease modifying therapies (DMTs). During that time, we have made multiple submissions, held education webinars and events and brought over international experts to best present the evidence and arguments. After 6 years of relentless advocacy, some of the changes we have been advocating for were approved in March 2021. **Now over 1900 people, and those newly diagnosed, will stay on treatment for longer, improving their long-term health and brain outcomes and supporting them to live well with MS.**

We have been advocating for these changes that will keep people on treatment for longer, thereby improving their brain-health, keeping them in work longer, active, and able to support their families and themselves. These changes will also help to speed up the approval process and relieve the pressure on New Zealand's under-resourced neurology workforce.

Further to patients no longer being prematurely cut off from treatment, they will no longer have to undergo the commonly named "walk of shame". The annual 500m walk was an ordeal one world-leading neurologist described as 'inhumane'. It placed undue physical and emotional toll, with the pressure of having to complete it leaving many distraught, fearful and tearful for far too long.

Webinars have helped us this year to ensure we receive considered and informed input from the MS community, including those diagnosed, carers and health professionals.

Feedback received from the MS Community about our efforts confirm for us the value of our persistence in pushing for these changes:



JOSIE

“These changes will give me the ability to continue to be the mother, wife and future entrepreneur I want to be. They give me hope that at 45 years old I can use all my wisdom and experience to start my own business, to live, rather than just survive. They will help with my dignity, for without these changes I am overshadowed with fear of the future, with tears in my eyes, I am fearful of my ability to be the wife, mother, grandmother, entrepreneur, person I want to be.”

NICKI

“Hi, I really wanted to get in touch and say a huge thank you, I have just received the information from the Nelson Marlborough DHB that I am now eligible to apply for Pharmac funded disease modifying therapy again, two years after I had to stop because I couldn't do the walk required. I am so grateful for your lobbying for this change to happen, I don't have enough words, but your hard work is so appreciated.”

ANON

“I am forever grateful to just hear that I have been approved for MS treatments. I have a family and feel that having treatment will give me a better chance to lead as normal life as possible and slow down the rate of disability and progression for me.”

EARLIER ACCESS TO TREATMENTS

While we are pleased to see this extended access, MSNZ is still very disappointed and concerned patients will continue to be denied or delayed in starting these treatments until they have a second MS episode/relapse. Insisting on a second 'attack' risks some patients suffering permanent serious disability before therapies are made available to them – disability they may never recover from.

MSNZ continues to advocate that PHARMAC adopt the internationally-accepted 2017 McDonald Criteria which many other countries follow. This allows an MS diagnosis based on a wider range of clinical factors. There's credible research that MS treatments work best when they're prescribed to patients as soon as they are diagnosed to improve long-term brain outcomes, yet Pharmac appears reluctant to acknowledge the international evidence around this.

FUNDING FOR NEW TREATMENTS

MSNZ supports access to all proven treatment options being made available to people with MS in NZ. A wide range of treatment options enables Neurologists and patients to find the most effective, and best suited treatment, for an individual's circumstances. With 8 treatment options now available for Relapsing MS we are still significantly below the number available in Australia (16). MSNZ has been advocating for funding for Mavenclad (cladribine). However, PHARMAC's funding and policy decisions are frustratingly delaying this approval.

Lack of treatments for those with Secondary Progressive MS (SPMS) and Primary Progressive MS (PPMS) is a primary concern. With limited options available to them they often feel isolated and forgotten. Changes we successfully advocated for, applied in March 2021, now accessible for those with active progressive MS.

We continue to advocate for the Ocrevus (ocrelizumab) for PPMS. PHARMAC announced in February 2021 it had received a low priority funding recommendation. We are pleased to see acknowledgement that there is supporting evidence for the use of Ocrelizumab for those with PPMS and recognising the high unmet health need. However, there is still substantial work required to progress the recommendation higher up the priority list.

AUTOLOGOUS HAEMATOPOIETIC STEM CELL TRANSPLANTS

MSNZ has been advocating to the Ministry of Health (MOH) for the funded availability of autologous haematopoietic stem cell transplants (aHSCT) for people with MS since 2017. We have continued to put pressure on the Ministry of Health, Minister of Health and DHBs to understand why it is still not available. We have worked closely with Neurology and Haematology experts who are supportive of this treatment option for those that the evidence shows would benefit.

We have received, via Official Information Act, requests information now under review from the MOH, Auckland DHB and the Minister of Health regarding their perspectives and actions to date. MSNZ is disappointed to understand that no further progress, or independent research has been made by the Ministry in the 4 year since our initial approach in 2017. Further to this the comprehensive report by the Haematology and Neurology Special Interest Group presented end of 2019 has received no further consideration. From our analysis of the OIA information received, the Ministry has limited Neurological expertise providing it with advice. MSNZ is committed to continuing to make aHSCT available in NZ.

PHARMAC REVIEW

The NZ Health Sector is currently undergoing the most comprehensive reforms in over 20 years. These reforms are set to be in place from 1 July 2022. At time of writing, it is unclear where organisations like ours will fit.

We made a submission to the independent Pharmac Review Panel raising key issues of transparency, issues with processes. Our submission was based on our extensive experiences with PHARMAC over the last 7 years.

We are disappointed this review was not held in conjunction with the wider health system review. Health and disability continue to be separated despite being intrinsically linked. Separation often allows people with chronic health conditions and inevitable disabilities, such as MS, to fall between the cracks. PwMS, especially those with advanced disease, need a comprehensive, holistic care. Currently this care is fragmented and the PwMS or their partner/carer needs to be the coordinator and advocate. It is not clear at this stage that the proposed reforms will address these issues but we will continue to advocate for the MS community.

ACCESS TO SERVICES



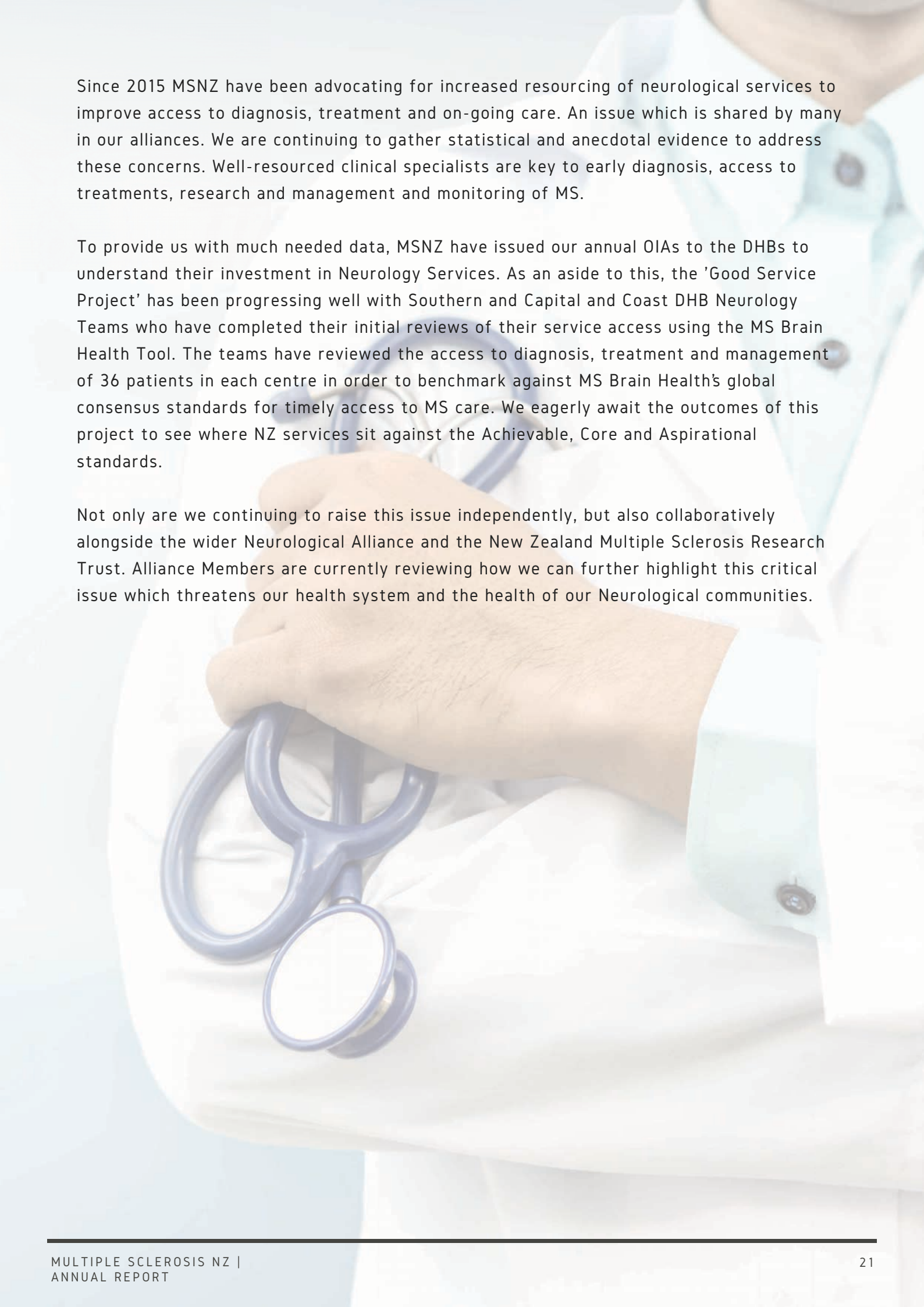
NATIONWIDE UNDER RESOURCED NEUROLOGY SERVICES

An issue that not only impacts the MS community, but also a wider health system. It has been well documented that for several years New Zealand has been building up to a crisis in terms of the shortage of key clinical staff. Further heightened by the pandemic, New Zealand is now at this crunch point.

Best international practice requires people with MS to be seen by a MS specialist neurologist. In New Zealand there is a critical shortage of these as well as shortage of specialist MS nurses. Under resourcing of health care professionals is resulting in an overwhelmed and overburdened health system. Compounding issues with underfunding of the health services, post code lotteries, poor immigration policies, movement towards private practice and specialisation means the health of New Zealanders with MS is at risk.

Delayed access to specialist Neurological care, primary health carer services (GPs) and Allied Health Services add to the premature increase in disability, a higher risk of falls and increased pressure for ED departments. The latest data from the MS Incidence Study (2012-14), funded by MSNZ, shows an almost 5-year delay from the presentation of first MS symptoms to diagnosis. This is due to a combination of delayed access to services due to an overwhelmed health system, strict out-dated Pharmac diagnostic criteria, complexity of MS symptoms and a lack of in-depth understanding of these by GPs often delaying referrals.

International best practice recommends annual reviews for all people with MS. While this happens in NZ for those on DMTs, those not, or with more a progressed condition rarely, if ever, see a neurologist again following diagnosis or stopping treatment. With new treatments being researched all the time, we risk patients, particularly those with PPMS or SPMS, being unable to access due to an overwhelmed system that has no record of their suitability for a treatment.

A background image of a doctor in a white lab coat, holding a blue stethoscope. The doctor's face is partially visible at the top right, and their hands are holding the stethoscope in the center. The image is slightly faded to allow text to be read over it.

Since 2015 MSNZ have been advocating for increased resourcing of neurological services to improve access to diagnosis, treatment and on-going care. An issue which is shared by many in our alliances. We are continuing to gather statistical and anecdotal evidence to address these concerns. Well-resourced clinical specialists are key to early diagnosis, access to treatments, research and management and monitoring of MS.

To provide us with much needed data, MSNZ have issued our annual OIAs to the DHBs to understand their investment in Neurology Services. As an aside to this, the 'Good Service Project' has been progressing well with Southern and Capital and Coast DHB Neurology Teams who have completed their initial reviews of their service access using the MS Brain Health Tool. The teams have reviewed the access to diagnosis, treatment and management of 36 patients in each centre in order to benchmark against MS Brain Health's global consensus standards for timely access to MS care. We eagerly await the outcomes of this project to see where NZ services sit against the Achievable, Core and Aspirational standards.

Not only are we continuing to raise this issue independently, but also collaboratively alongside the wider Neurological Alliance and the New Zealand Multiple Sclerosis Research Trust. Alliance Members are currently reviewing how we can further highlight this critical issue which threatens our health system and the health of our Neurological communities.

COST OF MS

MS can have a significant impact on a person's income. Particularly so for those with highly active disease not responding well to DMTs, or progressive forms with limited treatment options. In 2006, when the Prevalence Study was undertaken, MS has a direct influence on the working abilities of those diagnosed and their income. In 2006, 54.6% were not working despite 90% having a work history (NZ overall average 22%). At least 67% changed their work status due to the effects of MS, most within the first 4 years of diagnosis. The median annual personal income was NZ\$20,000, compared with NZ\$34,750 for the general NZ population.

Anecdotally, we are seeing the positive impacts of our advocacy work with reports people are staying in paid employment for longer. However, as shown by the COMPANZ Study (published July 2021), policy decisions have delayed access to DMTs. Disappointingly, but expected, this has resulted in reduced quality of life of New Zealanders with MS compared to Australian counterparts, and increased premature disability.

Many PwMS are living on low incomes with significant rates of unemployment and underemployment. Reduced income create stress, poorer living conditions and reduced quality of life. The low-income threshold for the Community Services Card through WINZ means many earn just over the threshold to be eligible for benefits.

Housing in New Zealand is becoming unaffordable for many, particularly those with health conditions and disabilities that might reduce income, such as MS. Regional Community Support Staff across the country provide advocacy to individuals and in some instances have helped clients find appropriate housing where they otherwise would have been homeless. Advocacy with WINZ has ensured that people are receiving their correct entitlement.

MSNZ is initially addressing this through our 'Cost of MS Study' to develop the Economic Burden of MS in NZ Report. Commissioned out of the New Zealand Institute of Economic Research the report is scheduled for release at the end of 2021. This vital study will provide key data to support our claims that the financial impact of MS to individuals and the economy is undervalued. It will also demonstrate the value of treating people earlier in their disease course in order to maximise working years to generate personal income and tax for the economy, whilst reducing premature reliance on government benefits.

OUR COVID-19 RESPONSE



IMPACTS OF COVID

The impacts of Covid have been huge for the MS Community. Many have seen reductions in services, or poor services, incomes and employment opportunities reduced, and increased social isolation. This has, for some, seen heightened barriers due to poor telephone or internet access if living in remote rural areas.

COVID and lockdowns brought to the forefront issues with residential care facilities and in-home caregivers. Issues include poor communication, untrained support staff, late or no-shows, low standards of care or service, lack of coordination to cover staffing shortages and leave. Several reports of in-home caregivers declining to be vaccinated have interrupted services.

There has been confusion and variability reported in access. Complexities in the roll out and concerns over how it will impact those who are immune compromised and on treatments have heightened concerns and anxiety in the community.

To address this, MSNZ provides regular information on COVID-19 and vaccinations. We collaborate with internationally renowned Neurologists and relevant NZ agencies to provide the best available advice. On the 2nd June we hosted an educational webinar on the vaccine for PwMS and the Ministry of Health's Disability Roll Out Plan. We are also represented on the Ministry's Disabled People's Engagement Group, ensuring the MS Community's needs are heard and receive considered input.

Despite the issues, impacts and challenges there have been numerous positive outcomes for PwMS across the country. Regional Societies report they have adapted in the face of a global pandemic, becoming more agile and IT savvy. Across the country many use telehealth options, virtual visits with video conferencing, increased use of email and social media to share and impart information. Support groups and social events have continued, both during and out of lockdowns via video conferencing to maintain communication networking and support amongst PwMS. The increased use of technology has enabled a wider group of clients to be reach, particularly those who may be working or live remotely.

WHERE TO FROM HERE

As we head into the next year, and progress has been made in some key priorities, we have been looking at the future direction of our advocacy.

As the needs of those impacted by MS are wide ranging, while we can advocate for priorities at a national level, there is tremendous value in community-led programmes to increase knowledge and provide tools and resources to enable self-advocacy to improve the long-term health outcomes and well-being of individuals impacted. As our Advocacy Programme moves forward, we are strategically planning to increase our focus on encouraging and supporting people with MS taking control of their own health and being the CEO of their own body by:

- 1) Educating people with MS and carers across the country, to be advocates in their local area to address national and local priority issues.
- 2) Developing the necessary tools and resources, to ensure people with MS have the necessary information and tools to be their own advocates for their health and well-being.

A particular area of concern is the increasing mental health issues that a large portion of PwMS face in their lifetime. From digesting a diagnosis, through to coming to terms with MS progression, it is a very challenging time. Mental Health concerns result in people becoming isolated, unable to retain paid employment, broken relationships and poorly managed comorbidities. Many PwMS require, or could benefit from, effective mental health services. However, public funded referrals for psychiatry and counselling are slow to progress or refused if not deemed a 'crisis' and private low-cost services are hard to come by.

MSNZ is investigating opportunities to improve the awareness of the mental health impacts of MS and how to address this growing concern.

KEEPING PEOPLE WITH MS IN EMPLOYMENT



For over 35 years the Dorothy L Newman Trust and Multiple Sclerosis NZ have co-funded a scholarship programme which supports and encourages people with MS to remain in paid employment. Two awards were funded this year.

DAVE

During 2019 I came to realize my MS was making my management career no longer sustainable. I decided to change my life entirely and study Personal Training at Polytech. I had been working with a PT for some time, and found my physical health and well-being improved as a result. As a PT, I hope to help others with MS or other disabilities, thus making MS the focus of my career, in a positive way.

Being awarded the Dorothy L Newman Scholarship has made this change of direction possible. As a single parent with two dependent children it was a big decision to give up a well paid job to become an impoverished student for a time. The scholarship enabled me to do this without needing a huge student loan. I am so grateful for the financial assistance allowing me to change my life.

I am now in my second year of study, training four clients under supervision. One of my clients has MS, and working with this person has confirmed my desire to help people with a range of health problems, through targeted exercise programmes.

I'm also working part-time for Healthcare NZ as a caregiver for a disabled person, and as a trainer in a gym programme 'Iron Warriors', catering for people with physical disabilities. This work is fulfilling and enjoyable, and definitely what I want to do with the rest of my working life. As a trainer with MS myself, I am in a good position to be able to help others with MS, together with others with disabilities.

As a fully qualified PT, I hope to work alongside such agencies as Healthcare NZ, the Neurology Department of Dunedin Hospital, and the MS Society, training people with MS. I feel working in this way is a small way to give back to those who helped me both in treatment and enabling my study through the scholarship.

BANGERS TO BLUFF 2021



Multiple Sclerosis NZ, alongside HopeWorks NZ, has been fortunate to be the Masthead Charity for the Rotary Club of Half Moon Bay's iconic event 'Banger's to Bluff' for the past 5 years. The 2021 event was the first year we entered our own donated 'banger', 'Keep Shmyelin', taking in the sights, whilst also spreading the message about MS and fundraising across the length of the country. The event provides a unique opportunity for MSNZ to also meet and connect with our member organisations on route.

We are extremely grateful to the Rotary Club of Half Moon Bay, the event participants and all the sponsors and donors of the event. Thank you

RIDING FOR A CAUSE

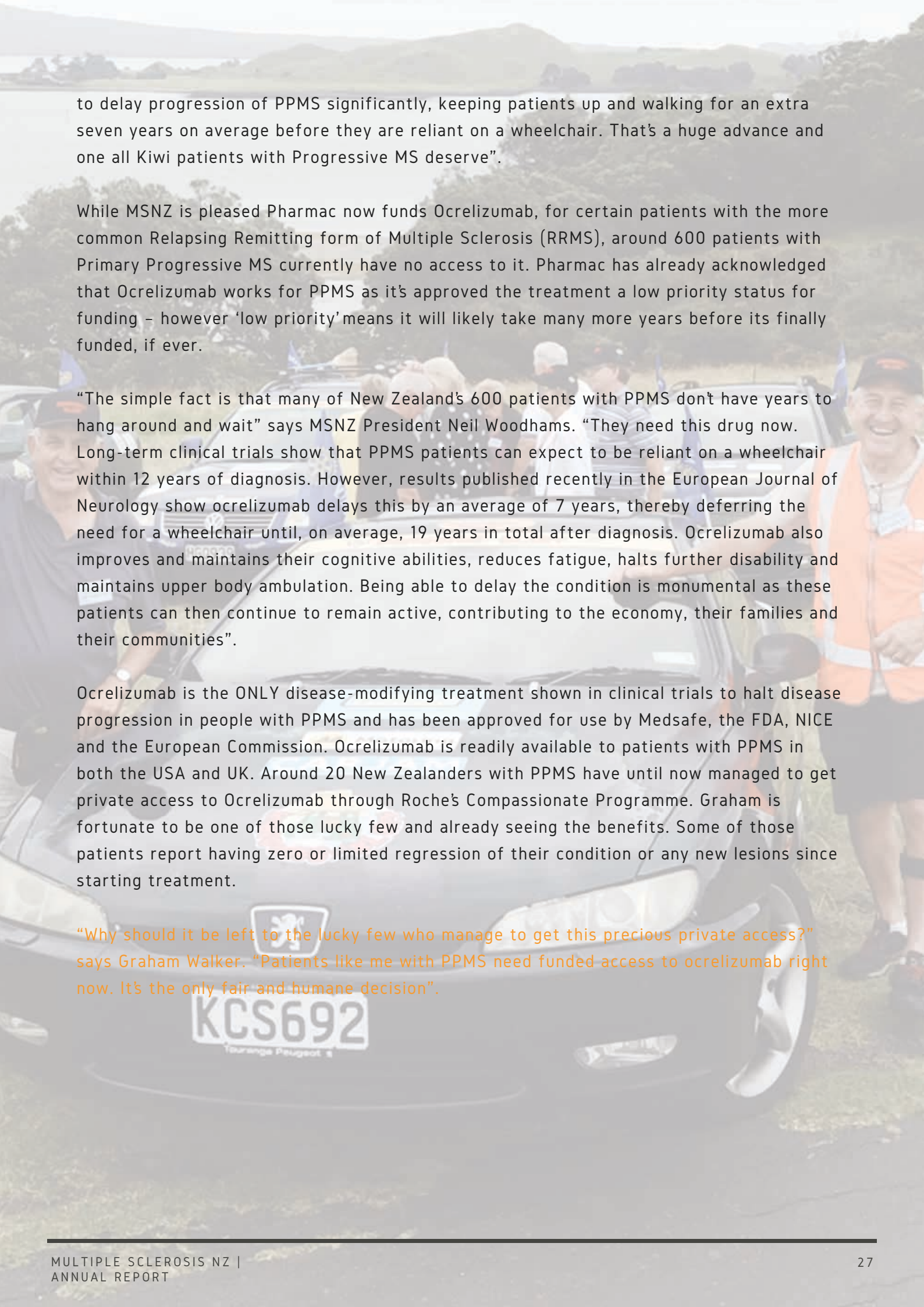
For most, the annual Rotary Club of Half Moon Bay 'Bangers to Bluff' event is a chance to drive from Auckland to Bluff on roads less travelled to raise funds for charity. But for one man, taking part was a personal crusade to help his fellow people with multiple sclerosis (MS) remain on their own two feet for as long as possible.

Graham Walker was diagnosed with Primary Progressive Multiple Sclerosis (PPMS) 8 years ago. Despite the fact the former competitive cyclist now struggles to walk, he currently rides close to 200km per week.

"I do feel fortunate that I am currently able to manage my condition well" says Graham, President of the Taranaki MS Society and Committee Member of Multiple Sclerosis New Zealand (MSNZ). "Because of this I feel duty bound to help others with PPMS, and am taking part in this year's Bangers to Bluff event, both on my bike and in our 'old banger' car, showing others with the disease that regular exercise is vital to staying healthy for as long as possible".

Graham went above and beyond, setting out early every day to ride 20-40kms on his bike before being picked up to drive the rest of the way. Through Graham and the teams efforts we used the event as an opportunity to draw attention to Pharmac's continued delays in funding Ocrevus (Ocrelizumab) for those with PPMS.

"There's huge unmet need for over 600 New Zealanders like me with Progressive MS who have never been able to access any treatments" says Graham. "Ocrelizumab has been shown



to delay progression of PPMS significantly, keeping patients up and walking for an extra seven years on average before they are reliant on a wheelchair. That's a huge advance and one all Kiwi patients with Progressive MS deserve".

While MSNZ is pleased Pharmac now funds Ocrelizumab, for certain patients with the more common Relapsing Remitting form of Multiple Sclerosis (RRMS), around 600 patients with Primary Progressive MS currently have no access to it. Pharmac has already acknowledged that Ocrelizumab works for PPMS as it's approved the treatment a low priority status for funding – however 'low priority' means it will likely take many more years before its finally funded, if ever.

"The simple fact is that many of New Zealand's 600 patients with PPMS don't have years to hang around and wait" says MSNZ President Neil Woodhams. "They need this drug now. Long-term clinical trials show that PPMS patients can expect to be reliant on a wheelchair within 12 years of diagnosis. However, results published recently in the European Journal of Neurology show ocrelizumab delays this by an average of 7 years, thereby deferring the need for a wheelchair until, on average, 19 years in total after diagnosis. Ocrelizumab also improves and maintains their cognitive abilities, reduces fatigue, halts further disability and maintains upper body ambulation. Being able to delay the condition is monumental as these patients can then continue to remain active, contributing to the economy, their families and their communities".

Ocrelizumab is the ONLY disease-modifying treatment shown in clinical trials to halt disease progression in people with PPMS and has been approved for use by Medsafe, the FDA, NICE and the European Commission. Ocrelizumab is readily available to patients with PPMS in both the USA and UK. Around 20 New Zealanders with PPMS have until now managed to get private access to Ocrelizumab through Roche's Compassionate Programme. Graham is fortunate to be one of those lucky few and already seeing the benefits. Some of those patients report having zero or limited regression of their condition or any new lesions since starting treatment.

"Why should it be left to the lucky few who manage to get this precious private access?" says Graham Walker. "Patients like me with PPMS need funded access to ocrelizumab right now. It's the only fair and humane decision".

OCEANS OF HOPE CHALLENGE NZ 2021



Oceans of Hope Challenge NZ was successfully completed for the third year in April 2021, sailing the Hauraki Gulf. The event is a collaborative effort between Oceans of Hope Challenge NZ, the New Zealand Sailing Trust and MS New Zealand. It is a pleasure for MSNZ to be a part of this unique and life changing event which gives hope, inspiration, friendships and a huge sense of achievement to the participants. Due to the pandemic, this year was a restricted crew of 25 New Zealanders as overseas participants were unable to visit. Crew Member Linda perfectly sums up how Oceans of Hope Challenges can help people to get their magnificence back:

‘The most inspiring experience I have been part of, is my instant reply when asked about my Oceans of Hope Challenge. I was thrilled, (but slightly pensive) when accepted for the trip but there were the little voices in my head, what will it be like, how will I manage, what will it be like spending 5 days with 20+ people I have never met before, how many toilets for all those people, how will I manage the bunks!? To name but a few.

All those thoughts completely disappeared when we boarded the iconic Steinlager II. The sense of excitement, chatter, and reassuring words from those who had previously completed a trip was amazing. I would never have believed how well everyone, crew included gelled together into a team that worked so well.

Forming connections with like-minded people, listening to their experiences, and finding out how many were shared made the trip so special. I met such wonderful, inspiring people and as we sailed back under the Auckland Harbour Bridge all of us felt a little sad this was coming to an end. I would highly recommend anyone with MS joining the challenge, don't worry about what you can't do, but focus on what you can!

Loved ones have also reported seeing momentous changes in participants following their involvement: “He has come back inspired, joyful, passionate, relieved, happy, fulfilled and most of all, in a different space regarding his MS. The week away with you was completely life changing for him”

MSNZ is proud to be a partner of the Challenge events helping New Zealanders to dream bigger and achieve their goals. We look forward to begin a part of changing more people's lives in the November 2022 event sailing to the Bay of Islands.

OUR GRATEFUL THANKS



Annually, MSNZ must raise over 90% of our income from donors, fundraisers, trusts and grants and bequests to continue our work. Each year we are amazed by the support we receive. This has never been more so than this year when we know so many have been impacted by the COVID-19 pandemic in their personal and business lives. Thank you to all those who have continued to support our work. We are extremely grateful for any donations, or funds raised. A particular thank you to the following for their support this year:

TRUSTS AND GRANT FUNDERS

Lottery National Community Grants, Air Rescue Services, Ministry of Health, The Dorothy L Newman Charitable Trust, The Southern Trust, Society of Mary Board, Four Winds Foundation, Pub Charity Ltd, Rata Foundation, Aotearoa Gaming Trust, Mainland Foundation

BUSINESSES

Rotary Club of Half Moon Bay, Allen & Clarke, New Zealand Institute of Economic Research, Roche Products (NZ) Limited, Merck Healthcare Pty Ltd, Sanofi New Zealand, Biogen NZ Biopharma Limited, Novartis, Printable, Nexia Christchurch Ltd., Lorelei Mason Health Communications, Mortlock McCormack Law.

DONORS

Thank you to all our wonderful donors who have supported MSNZ throughout the year. Particularly in what has been a difficult year for many. Your generosity and encouragement is greatly appreciated.

BEQUESTS

Thank you to those who bequeathed generous gifts in their will this year and to the families and friends who made donations in memory of loved ones:

Estate of Jean Una Benson

Estate of Dawn Dorothy Sare

Estate of Janice Thelma Garbutt

Estate of Ian Douglas Smith.

FANTASTIC FUNDRAISERS

We are constantly inspired by the passion and dedication of community fundraisers who support our work. Often these are people with MS who value our work, or their friends and families, inspired by the challenges their loved one's face. Here are just some of this year's amazing fundraisers.

KYLIE'S "MS FRIENDRAISER"

Kylie and her friend's organised an online auction giving supporters the opportunity to bid on a selection of lovely, donated items, raising a fantastic \$2,260. Our friend Iskra is the most generous, kind, hilarious, and all round gorgeous person. She has had MS since she was fifteen and our group of friends wanted to do something to show her how much we love her. We could think of no better way than to contribute to an awesome cause, that supports people with MS in Aotearoa

LUKE "OFF THE SAUCE FOR MS"

"Early this year, I decided to go 'off the sauce' (zero alcohol) for March, and post a daily workout video on Facebook. The idea was to set up a Givealittle page for people to donate and share, which would help keep me accountable as well as raise some funds (\$1,250) for the MS Society of NZ. Almost two years ago, my Dad was diagnosed with MS which came as a huge shock to all of us. With the help of his local MS society he has been able to receive the support and information to be able to start living with his condition and moving forward with his life. This was an opportunity for us to raise some money and give back to make sure that others are able to receive this support. Thank you guys for your work!"

THE MILKMEN "MAKING MONEY FOR MS"

Four Glenavy dairy farmers were all enjoying a beer together, mainly to complain about all their aches and pains from years of hard graft on the farm, when one of them threw out the idea they should do the Challenge Wanaka Triathlon 2021. All in the twilight of their sporting careers, thought it was a 'great idea', with the aches and pains of 40 years of farming slowly disappearing with every beer drank, it was settled.

The dairy farmers Hamish M, Allan, Andrew and injury replacement Hamish E, were successfully managed by Paul. Took on the challenge, raising \$11,650 for two charities "close to their hearts" MSNZ and Blind Low Vision NZ.

FINANCIAL OVERVIEW

REVENUE

2020/1

2019/20

Donations, fundraising and other similar revenue	331,802	299,544
Fees Subscriptions and other revenue from members	9,228	9,478
Revenue from providing goods or services	285,246	282,620
Interest, dividends and other investment revenue	48,094	24,307
Other Revenue	-	3,069
Total Revenue	674,370	619,018

EXPENSES

Expenses relating to public fundraising	55,940	11,162
Volunteer and Employee related costs	243,992	221,697
Costs related to providing goods or services	288,210	270,309
Grants and donations made	6,381	7,011
Other expenses	22,048	26,913
Total Expenses	616,571	537,092
Surplus/(Deficit) for the Year	57,799	81,926

ASSETS

Current Assets	126,578	131,829
Total Non-Current Assets	408,255	359,164
Total Liabilities	67,689	81,648
Net Assets	467,144	409,345

SUMMARY AUDIT OPINION

The accounts have been audited by Nexia Audit Christchurch. All summary figures have been extracted from the full unmodified audited Performance Report which has been prepared in accordance with Public Benefit Entity Simple Format Reporting - Accrual (Not-For-Profit) issued in New Zealand by the New Zealand Accounting Standards Board.

The Performance Report for the year ended 30 June 2021, authorised for issue on 27 September 2021 by the President and a Committee Member of the Society has been audited by Nexia Audit Christchurch. An unqualified audit opinion was issued on the Performance Report for the year ended 30 June 2021.

The presentation currency of the Summary Financial Statements is New Zealand dollars. The financial information presented has been rounded to the nearest whole dollar.

The Summary Financial Statements do not include all the disclosures provided in the performance Report and cannot be expected to provide as complete an understanding of the financial affairs of the Society as the Performance Report. The Performance Report and full audited accounts of the Society can be obtained on our website www.msnz.org.nz

Annual Report 2020-21

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