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Multiple Sclerosis
New Zealand

Annual Report
2019 – 2020

MSNZ Strategic Plan 2020 – 2025

Aims & Objectives

1) How we work together

- » Build MSNZs capacity to support regional accountability and sustainability

2) Communication

- » National voice for people impacted by Multiple Sclerosis
- » Seek meaningful engagement and input on the needs of the Multiple Sclerosis Community to establish advocacy priorities
- » Work with other Multiple Sclerosis organisations on leadership and advocacy opportunities
- » Seek out opportunities to work with other organisations on key priorities for the benefit of MSNZs priorities

3) Advocacy

- » Support Regional Societies with nationally consistent, relevant and evidence-based resources
- » Provide (on request) examples of exemplary policies and procedures to support Regional Societies to develop their own quality manuals
- » Inform Regional Societies of any legislative changes that may have an impact on their business and service delivery
- » Work with Regional Societies to design and implement a service delivery model that is focused on outcomes for individual people with MS

4) Awareness

- » Raise awareness nationally for Multiple Sclerosis as a chronic condition affecting New Zealanders and highlighting the needs of those impacted by the condition

5) Leadership

- » Provide leadership to model best practice to improve outcomes for people with Multiple Sclerosis
- » Work collaboratively with relevant partners to identify and develop tools to support self-management of Multiple Sclerosis

- » Model effective leadership in Governance

- » Strengthen leadership capabilities through deliberate focus and role clarity

6) Sustainability

- » Develop a succession plan
- » Develop and sustain funding ratios appropriate to the organisation
- » Ensuring organisational preparedness and having the scope to change
- » Develop a risk mitigation plan for responding to crisis
- » Explore opportunities for alternative sources of revenue generation

7) Credibility

- » Work collaboratively with the New Zealand Multiple Sclerosis Research Trust on areas of mutual interest
- » Increasing the brand awareness of the organisation
- » Continue to grow credibility nationally and internationally
- » Increase visibility through presentation, communication and networking opportunities
- » Build relationships with MS Australia and other international counterparts
- » Optimise opportunities for international speakers





Our
vision:
a world
without
MS

Our mission:

- » Working with member organisations to meet the needs of people with Multiple Sclerosis, their families and carers through national leadership, advocacy, communication, and national and international collaboration

Our Role and Impact



At Multiple Sclerosis New Zealand 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, Multiple Sclerosis New Zealand has been supporting 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.

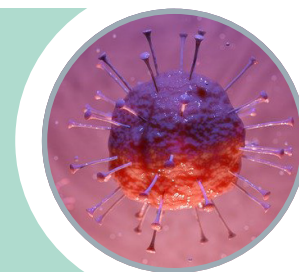
Our organisation:

- 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 with their local providers;
- Funds scholarships to keep people with MS in paid employment;
- Supports 18 independent MS organisations providing 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.

2019/20 Outputs

- Sent 31 submissions, OIA requests, letters to MP's, Pharmac and Government Departments and Officials;
- Approved 2 Dorothy L Newman Scholarships, 1 funding still to be spent;
- Supported the administration of 3 Mastering Mountains Grant;
- Held 1 Field Worker Annual Meeting attended by 21 regional support staff;
- Held 1 MS Conference attended by 29 regional member representatives;
- Provided 193 books on MS;
- Received 742 calls via our Helpline;
- Received 134 information requests via our website, 22 were for Regional Societies;
- Had 60,251 unique visits on our website for information on MS with 45,152 unique users and 105,118 page views;
- Shared 67 news items on our internal intranet with our membership;
- Placed 73 news items on our website;
- Supported the NZ MS Research Trust to organise their annual MS Research Day, attended by 167 people and livestreamed;
- Collaborated with Oceans of Hope and the New Zealand Sailing Trust on Oceans of Hope Challenge NZ 2019 attended by 40 people.

Leading Through COVID



Information

MSNZ worked with MS specialists to develop specific information about COVID-19 and Multiple Sclerosis which was not available elsewhere.

Advocacy

During the pandemic lockdown MSNZ wrote to MPs and Government Departments regarding issues impacting the MS Community and our organisations to deliver services.

Internal communication systems

An internal intranet system was set up to improve the way MSNZ communicates with its membership and sharing the most up to date information to support the MS community.

Pandemic planning

Pandemic Plan templates were developed to support our members at governance and operational levels, to ensure long term sustainability and support clients.

Cluster groups

Cluster Groups stepped up their level of interaction, connecting regularly, developing a supportive collegial network.

Improving knowledge and understanding

By connecting with international counterparts particularly in Italy, the USA and through our International Federation, we increased our understanding about how COVID-19 impacted their Multiple Sclerosis communities, to provide the most relevant information to the NZ MS Community.

Health and wellbeing

Working with specialists we provided informative resources to support health, nutrition, exercise and well-being during isolation.

National President and Manager's Report



This last year has been one like no other, not just for MSNZ, but nationally and globally. What started out with a growth in the team, plans for increased investment in fundraising, advocacy, awareness and communications were halted by the onset of the global pandemic. Despite the challenges, the National Office has stepped up to increase support and information for our members and the MS Community. While several plans, such as Bangers to Bluff and our information review were postponed, the resiliency of the organisation has been possible due to strong governance and management, alongside a passionate and proactive team in the office.

The National Office re-established itself in its new premises within the Deaf Society of Christchurch building early in the financial year. During the Pandemic, Level 3 and 4 saw all staff set up home offices, putting their energy into making sure information, that changed daily in some cases, was provided to Regional Society members, supporting them to continue delivering appropriate services.

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Despite the challenges, the National Office has stepped up to increase support and information for our members and the MS Community.

A key resource, the Intranet, was set up immediately to ensure swift and regular provision of, and access to information. From feedback received our support was well received by the membership.

Thanks to the Government Wage Subsidy we supported staff 100% without having to reduce numbers, hours, or impact. Since returning to the

office the staff continued to focus on members support and ensuring the sustainability of the organisation.

The National Office has continued to fulfil its contract of service for the New Zealand Multiple Sclerosis Research Trust, supporting in areas such as administration, event organisation and communications. While the needs of both organisations are growing, we need to ensure we have the capacity within MSNZ to meet these in the long and short term. Ensuring MSNZ has the necessary resourcing to support our members will be a core focus for the National Executive this next year.

As seen in the outcomes in our Performance Report there is a need for the work of our organisation supporting both our members and the wider MS Community. It is interesting, and not unexpected, that there is a movement towards information delivery in electronic form rather than physical resources.

Despite the pandemic impacting some income sources, other opportunities arose. Our \$81,926 surplus is due to several factors including movements in liabilities to the next financial year for grants received for projects and salaries. Thanks to a growth in investments and bequests our Total Assets have grown to \$490,993 meaning the Society is in a reasonable sound financial position. The Executive Committee are committed to seeing 12 months income in reserves to ensure the long-term resiliency and sustainability of the organisation. With predicted upcoming financial impacts in the next year, such

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It is imperative to see how we can ensure our viability and develop sustainable income streams.



as the cancellation of cheques, reprioritisation of many grant funders, and the unknown long term impacts of the pandemic, it is imperative to see how we can ensure our viability and develop sustainable income streams.

Throughout the year several members asked for increased support and involvement in areas outside of our current Constitution. Our national structure, with 18 independent societies, has many positives, touchpoints in communities and localised support. However, it also creates issues such as duplication, lack of consistency and financial competition. With over 27,000 charities in NZ, the highest per capita worldwide, could this be the time to review and explore alternative ways of working to maximise investment of resources, to improve impact and outcomes for people with MS?

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We are pleased to see the Clusters regaining momentum. With increased use of Zoom most

now meet on a more regular basis to connect and collaborate more efficiently. While still a new way of working for many, it is certainly the way of the future, and was an asset during lockdown.

The Cost of MS Study is currently being undertaken by the New Zealand Institute of Economic Research and due to be completed later in 2020. From preliminary data presented, the economic burden of MS on people living with MS as well as the national economy justifies our calls to adopt the recommendations of MS Brain Health, targeting earlier diagnosis, intervention and monitoring.

We are proud as an organisation to see the immense positive impacts that the disease modifying treatments, which we have and continue to advocate for, have brought to people's lives. With reduced relapses, and delayed progression or onset of disability, we are seeing people remaining in the workplace, contributing to the economy and seeing a reduced impact of MS. We must ensure our services are meeting the current needs of the MS Community whilst also offering levels of community support for those less impacted by these advancements. The work of MS Brain Health continues to be a guiding tool for MSNZ. We will continue to support Regions to review how the recommendations can be implemented.

Thank you to the National Executive Committee for your commitment to MSNZ this past year. We have a Committee that is growing in skill and direction, a team helping to guide MSNZ into a positive direction, focussed on being progressive and proactive.

Happy reading,

Malcolm Rickerby
President

Amanda Rose
National Manager

Field Worker Representative Report



18 independent MS Regional Societies continue to provide information, support and advocacy for people diagnosed with MS, family members, carers, friends, colleagues, and employers. While services may vary across the country, both within the public health system and in the community, Regional Societies provide a local source of information, guidance and support for anyone looking for assistance with MS related matters.

The work that Regional Societies do within their communities to release pressures on the public health system has never been formally recognised. While we are grateful the Ministry of Health has continued our DIAS contract for a further 3 years, the services and support Regional Societies provide are much wider than purely information provision, for which we are minimally funded. Regional Societies are finding that while community needs and impact is increasing, resourcing to support this isn't. Financial sustainability is the main concern impacting Regional Societies moving forward.

It is well accepted that earlier diagnosis, treatment and access to supports, improves outcomes for people with MS. Despite this, access to services in the public health system continues to be one of the main concerns for many local support staff and their clients. Rural areas have extended wait times due to the lack of Neurology and allied services available, and in the main centres, the departments are often overloaded and under resourced. Many Regions also report continued lack of respite beds to support their clients and their families. Many respite services are not age appropriate for those under 65.



Community needs and impact is increasing, resourcing to support this isn't.

COVID-19 has had a significant impact this year, both positively and negatively. In the early days, supported by the information supplied by MSNZ, Field Workers, Nurses and Community Advisors provided up to date information to clients, particularly in terms of what might be expected, theoretically, in terms of risk and severity of impact people with MS might experience with COVID-19. Evidence internationally is demonstrating on the whole people with MS have not been more impacted than the general population. Those at higher risk are those with comorbidities, who are older, and less mobile.

Across the country regional support staff, and Committees, kept up regular communications with their members, checking in on their mental and physical health and well-being. The pandemic presented an opportunity for support staff to touch base with members who had not made use of their services in a while



Access to services in the public health system continues to be one of the main concerns for many local support staff and their clients.

due to lack of need, or because they worked or had other commitments. This was a great opportunity to connect or reconnect with those members. Many groups went virtual, using technology such as Zoom.

Technology has enabled greater connection with other MS organisations or providers in the community. We expect the use of technology to become a regular part of practice as it allows greater reach. The personal interaction cannot be fully

replaced in many situations, particularly as not all people with MS have access to phones, computers or the internet. Many also find technology creates a barrier to building strong relationships, empathy and trust often required.

In the main, people with MS managed this unprecedented time very well. However, concerns regarding employment, finances, family and isolation increased issues with mental health, particularly depression and anxiety. Isolation and loneliness were particularly difficult and Regional Societies endeavoured to keep up

“People with MS who are accessing treatment early are managing their lives well and independently, reaching out for support only when needed.”

communication and connection, particularly for their most high-risk clients. Employment has been a long-standing issue for people with MS and disabilities alike, and the pandemic has further heightened this.

Treatments continue to change member needs. Those able to access treatment early are managing their lives well and independently, reaching out for support only when needed. We expect this to

continue and services will need to adapt to the needs of our clients, whilst also ensuring that those with more complex needs continue to receive the well-rounded supports they require to live well with MS.

Diana Hay, Field Worker Representative, Field Worker for MS Rotorua and Districts

Regional Societies provide a range of services locally (may vary based on location)

Support	Personal support identifying client needs and developing individualised management strategies.
Education	Courses for newly diagnosed, living well with MS, fatigue, symptom management, residential care training, specialist and allied health professional education.
Information	Printed publications, websites and social media.
Advocacy	Employment support, attending appointments, WINZ, power of attorney etc.
Service Co-ordination	Referrals to allied health and other disability support services.
Support Groups	Co-ordination and facilitation of support groups, including peer support, newly diagnosed, younger persons, men's and working people's groups.
Exercise	Co-ordination of exercise opportunities, including walking groups, swimming classes, fitness classes, gyms, and loaning of Alinker walking bikes.
Awareness and fundraising	Increasing MS awareness and generating vital funds for service provision.
Carer Support	Support groups, information and service co-ordination.
Library	Informative resources on relevant topics.
Newsletters	Regional newsletters providing relevant information about living with MS.
Social Events	Organising social networking opportunities for members.
Transport	Transport to key appointments and Total Mobility assessments.

Actively Advocating

Increasing Access to MS Treatments



Advocacy Priorities for 2019–2020:

1. Widening the access criteria for all Disease Modifying Treatments (DMTs)
2. Addressing the critical shortage of Neurologists and Neurology Nurses in New Zealand
3. The underfunding of community health services such as MS organisations
1. Funding of Ocrelizumab for RRMS and PPMS - APPROVED October 2019 for RRMS, continuing to advocate for PPMS
2. Access to Autologous Haematopoietic Stem Cell Transplant (AHSCT) in New Zealand
3. Fair payments for carers
4. Lack of prompt access to critical diagnostic services such as MRIs
5. The urgent need to place more value and importance on allied health services for managing chronic conditions
6. Supporting issues with immigration for people with MS unfairly denied a visa or residency due to their diagnosis.

More information about our advocacy work not covered in this report can be found on our website at www.msnz.org.nz

How We Have Actioned These Priorities:



Submissions

Letters

Campaigns

Media Releases



Meetings with MPs

Meetings with Ministry of Health

Meetings with Pharmac



Official Information Act requests



Engaging the support and advice of national and international experts



Funding independent research projects

Widening the Access to MS Treatments

In February Pharmac published the minutes of the Pharmacology and Therapeutics Advisory Committee's (PTAC) November 2019 meeting. The minutes reported the outcome of the meeting at which MSNZ's submission to widen the Special Authority (SA) access criteria for disease modifying treatments (DMTs) was reviewed. The submission had originally been made in June 2018 but was not fully reviewed at the time. MSNZ pushed for a full review of the evidence presented.

In our June 2018 submission, MSNZ requested and provided evidence to support:

1. expanding the stopping criteria to EDSS 6.0 or 6.5;
2. removing the gradient scale;
3. removing the starting criteria of EDSS 0-4;
4. widening the starting criteria to change the requirement of needing a second relapse AND new MRI activity to be OR.

MS TREATMENTS SPECIAL AUTHORITY ENTRY CRITERIA

The minutes reported that PTAC have *"recommended amending the entry criteria such that access to funding for MS treatments would be from EDSS 0 to EDSS 5.5, with funding ceasing should an EDSS of 6.0 be reached, regardless of the EDSS score at entry, with a high priority. This was based on the high health need of people with MS and their carers, the financial impact of widening access, the possible QALY gains from widening access and the practicalities of clinically measuring disease progression."*

*November 2019 PTAC Meeting Minutes

Multiple Sclerosis NZ is pleased that PTAC have made this decision and given it high priority however, we are conscious that this is only the first step as funding still needs to be approved, which could still take some time.

From the Medicines NZ June 2019 report, the mean waiting time between PTAC recommendation to Pharmac funding for high priority treatments was 2.46 years, ranging between 0.35 to 6.92 years. Further delays continue to deny access to treatments, or risk people stopping treatment too early, increasing their risk of relapse, disease progression and disability. MSNZ will continue to advocate to Pharmac for urgent approval of the recommendations.

In April 2020, as part of Patients Voice Aotearoa, MSNZ signed an open letter to Prime Minister Jacinda Ardern to immediately provide a significant funding boost to Pharmac, with an instruction to purchase more medicines for some of the most vulnerable in our community, including funding as per the PTAC recommendations.

MSNZ wrote to PHARMAC separately, requesting a review of the Special Authority application process to reduce the expenditure of valuable Neurologist time on applications.

MS TREATMENTS SPECIAL AUTHORITY ENTRY CRITERIA

"The Committee recommended the application to widen access to Multiple Sclerosis treatments for the treatment of CIS be declined. This was based on a lack of good quality evidence that earlier treatment, at the stage of CIS, improves long-term health outcomes. However, the Committee noted that it would be happy to review a funding application again in the future that included new evidence (not previously considered) that supports long-term health outcomes from treatment of CIS."

*November 2019 PTAC Meeting Minutes

MSNZ is disappointed PTAC continue to confuse Clinically Isolated Syndrome (CIS), where a person is suspected of having MS but not confirmed due to the lack of clinical supporting evidence on MRI, with clinically definite MS (CDMS) using the most up to date internationally recognised criteria. The McDonald Criteria was updated in 2017 and has been recognised worldwide. PTAC however, in their misunderstanding, claim there to be a lack of evidence to support adopting this new diagnostic method.

The lack of acceptance of the internationally recognised criteria mean that people with clinically definite MS are missing out on timely access to treatment.

MSNZ is continuing to advocate for earlier access to DMTs for patients with diagnosable MS according to the 2017 McDonald Criteria.

Drastic Under Resourcing of Neurology Services

One of our primary concerns is the continued drastic shortage of Neurologists and Specialist Neurology Nurses that New Zealand is facing. NZ has approximately one third the number of Neurologists in comparison with Australia and half the number recommended by international studies. This shortage creates problems with extensive wait periods, delayed access to DMTs and overburdened Health Professionals.

MSNZ submitted OIAs to the District Health Board's (DHBs) nationally. Results reported that there are currently 54 Neurologists or Physicians seeing neurology patients in NZ totalling 44.5 FTE, 13 of which have undertaken additional sub-specialist training in MS or is considered an area of expertise. There are also currently 16 MS Specialist or Neurology Nurses across 20 DHBs covering 9.55 FTE.

This under resourcing is not solely an MS issue. MSNZ is an active member of the Neurological Alliance which has agreed that this is the primary concern we are collectively facing. The Alliance will be addressing this issue as a network.

Fair Payments for Family Carers and Community Organisations

The pandemic lockdown period clearly demonstrated the vital role that Family Carers and Community Organisations, such as MSNZ and our Regions, have in New Zealand. Both, reduce the impact on Government funded services. However, both continue to be significantly under-funded.

MSNZ will continue to raise these issues as part of alliances and networks we are members of, in particular the Carers Alliance, the New Zealand Disability Support Network and the NGO Council.

Cost Of MS Study:

- » It is well known that a diagnosis of MS places a significant health burden on individuals, families, carers, and the public health system. According to international research, this comes with substantial costs. Relapses, worsening symptoms and disease progression generate multifactorial financial costs.
- » There is no current or up-to-date research on the economic toll that a diagnosis of Multiple Sclerosis takes on individuals, families and communities in NZ.
- » As a result, Government agencies make funding decisions based on insufficient information.
- » MSNZ has contracted the NZ Institute of Economic Research to undertake the Cost of MS Study.
- » Evidence will be used to support our advocacy for more resourcing, better access to treatments and provide the Government with the data needed to make informed decisions.
- » The Study will measure the economic impact of MS in NZ on the person diagnosed, families, carers, Government and society, considering the direct and indirect costs of MS quantifying the:
 - Health burden of MS on the individual
 - Economic cost of MS on the individual, their families and community
 - Impact on the health system and other Government services
- » Where possible, the Cost of MS Study will attempt to specify expenses according to the stages of the disease and the personal circumstances of individuals.
- » The results are expected later in 2020.

Good Service Project:

- » Expert consensus standards for timely MS care were developed by a panel of global MS Specialist Neurologists. An online, modified Delphi process was followed to define 'core', 'achievable' and 'aspirational' time frames reflecting minimum, good and high care standards, respectively. A multidisciplinary Review Group (MS Nurses, people with MS, allied healthcare professionals) provided insights to ensure the recommendations reflected perspectives from multiple stakeholders.
- » These quality standards for care provide MS teams with a three-level framework for service evaluation, benchmarking and improvement. If implemented, they could revolutionise the care of people with MS.
- » The Good Service Project will fund selected Neurology DHB Departments to use the MS Brain Health tool to review and benchmark their services across the country for people with Multiple Sclerosis. Our project will use the benchmarking templates developed by MS Brain Health and see where New Zealand sits in relation to the three standards of access to care relative to international recommendations, 20 other international centres, and each other nationally.
- » The project is expected to begin later in 2020.

MS Awareness Week

15 - 21 September 2019



Awareness Week 2019 continued the 2018 'My Story: My Strength: My MS' digital campaign, sharing real life stories of people living their lives well with MS.

Due to overwhelming interest, 7 stories quickly grew to 17, with people sharing their MS journey to inspire others and increase awareness about MS and the impacts it has on individuals and their families lives. These stories were shared on our website, Facebook, Instagram and Twitter.

Sam Baxter, from the More FM Breakfast Club, also recorded a new video as an update on her MS journey, shared by More FM Breakfast Club.

Regional Societies recorded varying success for their Street Appeals and associated events. \$159,115 was raised nationwide. Most notably, MS and Parkinson's Canterbury collected over \$54,000 and MS West Coast held yet another successful Craft Fair raising a fantastic \$15,000.

Thank you to everyone who donated their time or money to support Multiple Sclerosis in the 2019 Awareness Week and Street Appeal. We and the Regional Societies are deeply grateful for the 934 volunteers, 29 schools and 41 service organisations who dedicated over 1690 hours of their time at 129 locations to supports their local MS organisations. With this support, the Regional Societies were able to raise much needed funds and can continue to provide services in their communities.

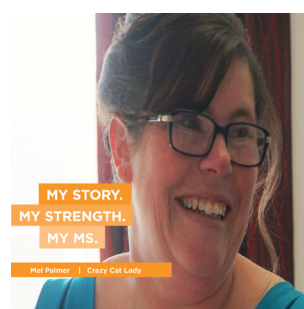
Outputs

1. 67,329 people were reached through our social media coverage.
2. 47,505 items of fundraising collateral were provided to support Regional Street Appeals and other events.
3. 27 posts were made on social media with 4 being paid boosted posts and generated 7,880 engagements.
4. 17 stories about people impacted by MS were shared.



MY STORY.
MY STRENGTH.
MY MS.

Nicole Jupp | Regional Member



MY STORY.
MY STRENGTH.
MY MS.

Mel Palmer | Crazy Cat Lady



MY STORY.
MY STRENGTH.
MY MS.

Daniel Debono | HSCT Advocate



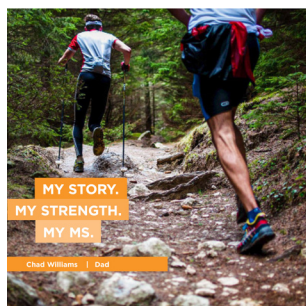
MY STORY.
MY STRENGTH.
MY MS.

Hiliana Hickox | Advocate



MY STORY.
MY STRENGTH.
MY MS.

Tracey Hall | Influencer



MY STORY.
MY STRENGTH.
MY MS.

Chad Williams | Dad



MY STORY.
MY STRENGTH.
MY MS.

Geniee Hunt | Teacher Aide

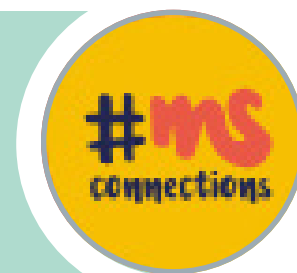


MY STORY.
MY STRENGTH.
MY MS.

Cath Barr | Desktop Publisher

World MS Day

30 May 2020



Outputs

1. 104,00 people were reached through our month of social media coverage.
2. 23 posts were made on social media throughout the month with 4 being paid boosted posts generating 8,000 engagements.
3. 3 stories about people with MS were shared.
4. 4 unique videos were created (3 by MSNZ and one by MS International Federation using supplied content).

World MS Day is the only global awareness campaign for MS, led by the MS International Federation (MSIF) Every year, on 30 May, the MS movement comes together to provide the information about MS and how it affects the lives of 2.8 million people around the world.

The theme for World MS Day 2020 - 2022 is 'MS Connections', focused on community connections, self-connection and connections to quality care. It challenges social barriers that leave people feeling lonely and socially isolated. It is an opportunity to advocate for better services, celebrate support networks and champion self-care.

Thanks to funding from MSIF, we created three short videos based on the focus angles of Stigma, Communities and Self. Annie McManis (Advocate), Sam Smith (Comedian, Writer, MS Auckland Ambassador) and Sam Baxter (Radio Announcer, More FM Breakfast Club) shared how the stigma of MS impacts them, and the importance of community connections and self-care to live well with MS. The videos were posted on Facebook, Instagram, Twitter and on our YouTube channel.

#Stigma

"The best way to help people is to talk about it."

- Sam Smith (Comedian)

#Communities

"My illness ... wasn't going to stop me from making friendships."

- Annie McManus

#Self-Care

"Self-care is... doing things that I enjoy."

- Sam Smith (Comedian)

Our Impact

Thank you to Barkers of Geraldine for donating a delicious hamper, and Sam, Sam and Annie for sharing their stories.

Dorothy L Newman Scholarship



For 35 years the Dorothy L Newman Charitable Trust has co-funded the Dorothy L Newman Scholarship Programme assisting people with MS who are unable to continue in their present employment and must need to retrain to stay in paid work. In that time over \$128,500 has been donated by the Trust to support New Zealanders with MS. Our grateful thanks goes to Sue Clothier and the Dorothy L Newman Trust for their continued generosity and support of the MS Community helping people like Sarah:

"I thought going back to study after 6 years would be one of the more challenging things I did in 2020, but distance learning through a pandemic while undergoing Cladribine (oral chemotherapy) is something else!

At the start of this year, I was lucky enough to be awarded the Dorothy L Newman Scholarship, and have gone back to university to get a Bachelor of Social Work. Being able to receive the scholarship has helped out immensely this year, and with the pandemic, there was no work from my part-time job which obviously was very stressful.

I've since started my second year of Cladribine (an oral chemotherapy used to treat Leukaemia and MS).

The fact I have been able to complete my courses from home has meant when I'm having a bad MS day, I can just write my essays on the couch, in my favourite track pants, with no worries about having to start my student loan for my course until next year, which I am so grateful for. Studying from home also means my 2 cats appear on my Zoom lectures a lot too!

Being given the opportunity to go back to study, and after completing semester one, it's only further cemented the idea that this is what I want to be doing for the rest of my life.

I would highly recommend to anyone who's been thinking of wanting to retrain due to MS impacting their career to apply for the Dorothy L Newman Scholarship and take that leap of faith to pursue something you love and something that is kinder to your body. I would like to thank the amazing individuals again at MSNZ who have made this year possible for me.

Thank you"

Sarah

For more information about the Dorothy L Newman Scholarship and the criteria visit:
www.msnz.org.nz/scholarships-and-grants



Oceans of Hope Challenge NZ



Between 2-5 December 2019, 40 people with MS headed out onto the Hauraki Gulf from Auckland Harbour, to prove that MS won't stop them. Participating in the 2019 Oceans of Hope Challenge NZ, these adventurous people hoisted the rigging, worked the grinders and scrubbed the deck aboard the legendary Whitbread Maxi yachts, Steinlager 2 and Lion New Zealand.

The five-day challenge encouraged people with MS to push themselves beyond their perceived physical and mental limits and build comradery and resilience.

"Facing the challenges the event presents, with people who truly understand what you are going through, gives you the strength and encouragement you need," said Oceans of Hope NZ organiser, and person with MS, Ingrid Robertson. "Coming together, meeting like-minded people and realising that we're not alone is hugely empowering."



For many with MS, the thought of sailing on these iconic yachts seemed like an impossible task. "This event is sure to be our toughest to date due to the sheer pedigree of the boats," commented Oceans of Hope Managing Director, Robert Munns.

Robert also has MS and has witnessed the transformational impacts of the Challenge: "I've been privileged to see people walking for the first time in years without their sticks or jumping from their wheelchairs into the water, all because their participation has challenged their own beliefs about their abilities."

It's not just the general public's preconceived ideas about MS that we want to change, but the mindset of those diagnosed. MS is a chronic condition, but it is not a life sentence. People with MS are living well due to advances in knowledge, research, treatments and events like Oceans of Hope make people realise that MS doesn't stop them. They are more than their MS.

MSNZ was pleased to work with Oceans of Hope Challenge and the NZ Sailing Trust to make this opportunity possible. For information about the 2021 event visit: www.msnz.org.nz/oceansofhopechallengenz



Mastering Mountains and Expedition Grants



The Mastering Mountains Charitable Trust (MMCT) provides funding to help people with MS pursue local and international adventures. MSNZ is proud to work alongside the Trust to provide administrative support for their two grants on offer, helping to make people's dreams a reality. We hope that these adventures encourage a healthy lifestyle and change the perceptions of MS. During the year 3 grants were awarded.

The Mastering Mountains Grant was awarded in 2019 to Bryce MacKenzie. Bryce, a keen cyclist approached MMCT with the goal of completing this year's Around Taupo Cycle Challenge. The Trust awarded money to fund the personal trainer and gym costs needed to support him as he worked to increase his fitness. Mastering Mountains also made a contribution toward a new bicycle that better suited his needs. Working towards the goal alongside his trainer, Bryce made excellent progress. However, the Taupo Cycle Challenge got cancelled this year, due to COVID-19, but Bryce will still complete the course with a number of friends early in December.

Despite a diagnosis of MS, Aucklanders Sam Smith and Rachelle Becker will redefine what's possible with MS and to inspire others to pursue healthier lifestyles. Supporting their aspirations, Mastering Mountains Charitable Trust with Multiple Sclerosis New Zealand awarded grants to the pair, so that they can pursue outdoor adventures overseas.

Two Expedition Grants were awarded in 2019. Sam Smith, a well-known comedian at TV3, was diagnosed with MS in 2015 will walk 107km along King Ludwig's Way in Bavaria, Germany. Rachelle who works in marketing was diagnosed in 2017 and will bike and hike across South-East Asia. As members of MS Auckland, both plan to use their trips as a platform for inspiring others. Due to COVID-19 both trips have been put on hold but Sam and Rachelle are eagerly awaiting their adventures.

Sam feels motivated to accomplish his mission. "My two young boys are big balls of energy," Sam says. "I want to run around with them without wanting to take a nap every 5 minutes. ... This trip has really given me the impetus to train up, get active, get fit and take charge of this part of my life." For Rachelle, her upcoming cycling adventure is about regaining "the light and confidence that I had before I was diagnosed." She also wants to redefine what MS looks like for her: "I want to prove to myself that I can achieve whatever I put my mind and body to."

Mastering Mountains Charitable Trust and MSNZ along with grant sponsors Macpac, MitoQ and World Expeditions are proud to get behind Bryce, Sam and Rachelle.

For more information about the Mastering Mountains Grants and how to apply visit:
www.msnz.org.nz/scholarships-and-grants



Our Grateful Thanks



Every year MSNZ is amazed by the dedication and passion of the fundraisers that choose to support us by helping us raise vital funds. Inspired by the challenges their loved one's face daily, they take on their own. Without these fundraisers, we could not advocate for the needs of people impacted by MS in New Zealand. Thank you.

Bangers to Bluff



Our deepest gratitude to the Rotary Club of Half Moon Bay for once again selecting Multiple Sclerosis New Zealand to be one of the two masthead charities for Bangers to Bluff 2020.

Unfortunately, this fully subscribed, and much anticipated event had to be cancelled at the last moment due to COVID-19.

Despite this, many of the wonderful participants and donors continued to show their support for our work and donated an incredible \$8000 to MSNZ.

Thank you to all the supporters and donors who continue to show your support for our work in the Multiple Sclerosis Community. We are looking forward to 2021 when we will have our own car and team participating in the journey.



Fantastic Fundraisers



Trish

"I was diagnosed with Multiple Sclerosis early in 2019 and my family and friends have been an amazing support since my diagnosis. At the same time, a work colleague was diagnosed with breast cancer so a few of us at work brainstormed and came up with the idea of a local bike ride to raise some funds for both charities.

My brother was to ride the 'Sydney to Gong' ride in Australia in support of Multiple Sclerosis so picking the day of the ride was easy, we would ride on the same day.

On the day 20 of our work colleagues and friends braved the hot weather, slapped on some sunscreen, and came together to show their support for us.

After much research, we chose to donate all the funds to Kiss Goodbye to MS as the funds are going to the right thing. Our work matched our donation with a donation to Breast Cancer."

Our Impact

Fundraising



Amber

"My goal of 100km wasn't to prove anything to anyone other than myself; it was a distance I thought would be extremely challenging mentally and physically. Those living with Multiple Sclerosis struggle with mental and physical challenges daily. If any of you have sat in a kayak for a few hours (not to mention 13 hours) you will know that your toes and legs go numb, your fingers start tingling, and if not well distracted your sole focus becomes those pains – much similar to MS symptoms.

When I was completing the last 1-2 km I felt refreshed and quite emotional but mostly grateful for my life and my achievement, because the paddle in fact had nothing to do with me, it was a representation of the challenges and trials that a person with Multiple Sclerosis must face every single day. It taught me gratitude for my mobility and freedom to move.

I celebrated my mother and everything she has done, with every single stroke of that paddle. My mother is the strongest woman I know.

My hope is that others will feel inspired to think outside the box, be creative, be selfless and struggle if you must, show compassion and support to others."



(Fight Night images courtesy of Gravity Events)

Hannah

"Getting punched square in the nose by one of your close friends is truly the strangest feeling.

My father was diagnosed with Multiple Sclerosis just after I was born. I grew up learning about the effects of the disease and observing the slow progression that consumed my father.

In 2016, after a hard battle with both MS and bowel cancer, my father passed away. It was a very sad and drawn out process watching my dad slowly develop the symptoms MS presents, from increasingly unstable gait, to speech impairments, to severe memory loss. It is a debilitating disease.

This is what motivated me to work, fundraise, and most importantly WIN my fight! Throughout the 10-week training course, participants were encouraged to gain sponsorship to cover the costs of training and I was lucky enough to get a fantastic sponsor – Electric Kiwi. They not only paid for my training fees but donated \$1,000.00 outright to my cause! Awesome! In the end, I managed to raise almost \$2,000 for Multiple Sclerosis New Zealand, a figure I am immensely proud of."



Sarah and Amy

"I feel fortunate to have support from my family and friends. In particular, I feel overwhelming gratitude towards my sister-in-law, Amy, who ran a full marathon in Queenstown to raise awareness and over \$2700 for Multiple Sclerosis.

Having loving, understanding people like Amy to provide both emotional and practical support gives hope that I can cope with any curveballs Multiple Sclerosis throws at me. As I know through my clinical psychology research, this connection is the most important element contributing to happiness and life satisfaction.

Thank you to all those caregivers and friends who support us. We are not alone."



Natasha

"The impact this condition has had on my Mum's life is heart breaking and something I never wish for anyone to go through. If I could take it all away I could. I want to do everything I can to help the MS society and to raise awareness. I feel like it isn't spoken about enough on how serious this disease is. Especially how much it impacts a person."

Over the month of May Natasha walked 500kms, including around the house due to COVID-19. "It's encouraging me to get out of the house more and enjoy fresh air. I'm trying to find a positive to come out of this situation the world is going through and support something that is very close to me."

Funders and Supporters:

A huge thank you from MSNZ to the following for your support of our work:

Trusts and Grant Funders

Lottery National Community Grants, Air Rescue Services, Ministry of Health, Ministry of Social Development, The Dorothy L Newman Charitable Trust, The Southern Trust, Society of Mary Trust Board, Multiple Sclerosis International Federation.

Businesses and Organisations

Rotary Club of Half Moon Bay, Roche Products (NZ) Limited, Merck Healthcare Pty Ltd., Sanofi New Zealand, Biogen NZ Biopharma Limited, BNZ, Printable, Nexia Christchurch Ltd., Nexia Audit Christchurch, Lorelei Mason Health Communications, Mortlock McCormack Law, Canon Medical Systems ANZ Pty Limited, Barkers of Geraldine.

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 support, generosity and encouragement is greatly appreciated.

Bequests

Thank you to the below for bequeathing generous gifts to the Multiple Sclerosis Society of New Zealand in their will this last year:

Estate of Ronald Ivan Sare

Estate of Dawn Dorothy Sare

Estate of Jean Una Benson

Estate of Ernest R Robinson

Estate of Diane McDonald

The Nicolaas and Hendricus Van Teeffelen
Charitable Trust

Thank you to the families and friends who have made donations in the memory of loved ones who have passed away this year.

Financial Overview



Revenue

	2019/20	2018/19
Donations, fundraising and other similar revenue	\$299,544	\$448,683
Fees, subscriptions and other revenue from members	\$9,478	\$0
Revenue from providing goods or series	\$282,620	\$282,619
Interest, dividends and other investment revenue	\$24,307	\$25,741
Other revenue	\$3,069	\$0
Total Revenue	\$619,018	\$757,043

Expenses

Expenses related to public fundraising	\$11,162	\$6,844
Volunteer and employee related costs	\$221,697	\$156,326
Costs related to providing goods or services	\$270,309	\$307,016
Grants and donations made	\$7,011	\$111,844
Other expenses	\$26,913	\$27,427
Total	\$537,092	\$609,457
 Surplus/(Deficit) for the Year	 \$81,926	 \$147,585

Assets

Current Assets	\$131,829	\$118,104
Total Non-Current Assets	\$359,164	\$263,269
Total Liabilities	\$81,648	\$53,954
Net Assets	\$409,345	\$327,419

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 ("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 2020, authorised for issue on 21 September 2020 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 2020.

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 of the Society can be obtained on our website **www.msnz.org.nz**

MSNZ Directory

(As at 30 June 2020)

President	Malcolm Rickerby
Vice President	Neil Woodhams
National Executive Committee Members	Jeff Silvester
	Graham Walker
	Jan Hollway
	Lyn Lindsay
	Melanie Stanton
	Mark Etheridge (term ended October 2019)
	Dr Caroline Allbon (co-opted term ended February 2020)
National Manager	Amanda Rose
Fundraising Coordinator	Emily Smith
Communications and Information Coordinator	Nick Allen
Administration Coordinator	Sam Barber
Accountant	Nexia Christchurch Ltd
Auditor	Nexia Audit Christchurch
Life members	Gloria Hunt
	Anne McAuley
	Jim Millar
	Dr Ernie Willoughby
Society Registrations	Charities Number: CC10861
	Incorporated Society Number: WE/217036
Registered Office	80 Fitzgerald Avenue
	Central Christchurch
	Christchurch 8011
Postal Address	PO Box 1192 Christchurch 8140
Phone	0800 67 54 63 / 03 366 2581
Email	info@msnz.org.nz
Website	www.msnz.org.nz
Instagram	@MSNewZealand
Facebook	@MSSNZ
Twitter	@MSSocietyNZ

“ Where there is charity and wisdom,
there is neither fear nor ignorance.”

– St. Francis of Assisi.

Annual Report
2019 – 2020

ms.

Multiple Sclerosis
New Zealand

PO Box 1192, Christchurch 8140
Phone: 0800 67 54 63
Email: info@msnz.org.nz
Website: www.msnz.org.nz