

Multiple Sclerosis New Zealand

2021 - 2022
ANNUAL REPORT



TOGETHER WE ARE
STRONGER

ms.
Multiple Sclerosis
New Zealand

DIRECTORY

President	Neil Woodhams ONZM
National Executive Committee Members	Jeff Silvester (Independent) Jan Hollway (Upper North Island Cluster Representative) Graham Walker (Lower North Island Cluster Representative) Malcolm Rickerby (Upper South Island Cluster Representative) Allan Teviotdale (Lower South Island and Cluster Representative) Kathryn Marshall (Independent) Jan Campbell (Co-opted)
National Manager	Nicholas Cowie
National Advocacy Manager	Amanda Rose
Fundraising Coordinator	Emily Smith
Administration Coordinator	Sam Barber
Communications Coordinator	Louise Mckinlay
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 Societies Number: WE/217036
Registered Office	80 Fitzgerald Avenue Central Christchurch Christchurch 8011
Postal Addresss	PO Box 1192, Christchurch 8140
Phone	0800 67 54 63 / 03 366 2581
Email / website	info@msnz.org.nz / www.mznz.org.nz
Instagram / Facebook	@MSNewZealand / @MSSNZ
Twitter / TikTok	@MSSocietyNZ / Multiple.Sclerosis.NZ

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OVERVIEW OF 2021/2 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.

Communications support for
submission of aHSCT petition to
Parliament

83

Website
news stories

23

Community Support Workers funded
to attend annual 2 day training
conference

696

Calls received
via our Helpline

10

MS Voice
newsletters
published

133,588

Website
individual
page views

Attended MS Nurse
conference in
Queenstown

Joined the
global World
MS Day series
of events,
helping to raise
awareness

Collaborated with Oceans of
Hope for their 2022 sailing event

60,215

Website visitors.

11,000

Signatures
obtained for
aHSCT petition
presented to
Parliament

453

Information
resources
supplied to
member
organisations
and general
public

Lobbied Pharmac to provide
access to MS treatments
earlier than ever before

130

Information
requests via our
website

26

Information
requests for
Regions via our
website

260

Intranet post to
members

PRESIDENTS REPORT TO THE 54TH ANNUAL GENERAL MEETING OF MULTIPLE SCLEROSIS NEW ZEALAND INC.



It is my pleasure again to provide my report to members for the 54th AGM here in Christchurch. It will be great to meet with so many of you in person for the first time in two years. Hopefully the disruptions of Covid, which impacted on so much of what we set out to do in the last year, are behind us. This was the same hope I expressed in my report last year! But it was not to be.

So, 2022 was again a challenging year for not-for-profit organisations like ours. Covid just added to the challenges of access to health and disability services already severely stretched by staff and resource shortages. As we try and anticipate what the major changes of the health and disability services will mean for services for people with MS, I remain seriously concerned at the severe lack of critical staff in the public sector. MS is a multi-faceted disease which needs a multi-disciplinary approach, yet we continuously get reports of difficulty for PwMS accessing neurologists, specialist MS nurses, physio therapists, occupational therapists, respite care, etc. There are no short-term fixes for any of these issues but we will continue to advocate for improvements for the benefit of PwMS. In the same vein, we await with interest the impacts of a separate Ministry for Disability. This split complicates our approach as we now will need to deal with two ministries in Wellington instead of just one.

MSNZ has, despite these challenges, had a very productive year. Nicholas Cowie came on board in October to assume the role of National Manager in the absence of Amanda Rose on maternity leave. He has steered the ship admirably through some pretty difficult times and at the same time has led effectively our small but dedicated team of Sam, Emily and Louise. We are indebted to Nicholas and the team for the effective and friendly way they have maintained support and services through very challenging times.

Through these challenges we have managed our finances effectively reporting a surplus for the year of \$24,000. Income for the year reduced by \$33,000 being the effect of a reduction in our investments of \$83,000 offset by the one off MoH Covid contract of \$50,000 and the effective management of our costs. We are now in a sound financial position and can plan with more confidence for the future.

Some of the highlights of our activities mentioned elsewhere in this report include:

- A successful submission to the PHARMAC independent review
- The acceptance by PHARMAC of the 2017 McDonald criteria which increased access to MS drugs sooner for PwMS

- Major progress on the availability of stem cell treatment in New Zealand with our support for Joan Perry's petition to Parliament which contained more than 11,000 signatures. This must surely be evidence of the success of our sustained advocacy campaigns over the last 8 years
- A very successful in person conference for MS regional community advisers.

The Executive Committee has been reviewing our strategic direction in the coming years and delegates to our conference will have an opportunity to make a major contribution to this review. The need for the review has been highlighted by several factors:

- The restructuring of the health and disability sector
- The change in our advocacy focus, away from access to new medicines. Although that will remain a focus, it is time to address the other needs of people with MS. These include access to respite care, long term residential care for young disabled, access to support for those living in hardship, and support for partners and families of PwMS.
- The improved financial position of MSNZ.

A key focus in the last year has been an effort to improve and increase our ties and involvement with other organisations who advocate for the same issues as we do. This is important because MSNZ simply does not have the resources to be able to be effective across the whole spectrum of issues faced by the whole MS community. As a result, our links with the New Zealand Multiple Sclerosis Research Trust, New Zealanders for Health Research, The Neurological Alliance, the NGO Council, the Disabled Persons Assembly and the Carers' Alliance are very important.

Looking internally, it will be important that any future strategy builds on the strengths that lie within our organisation. We have within MSNZ and the member regions both the institutional knowledge, the capacity, and the ability to make major differences to the people we serve. At times I believe we have failed to capitalise on that capacity. The organisation of MSNZ into clusters is intended to provide some of this support and knowledge from other societies nearby. Making the clusters work effectively needs the support and commitment of all members. As President along with other members of the executive, I rely on the reports of the cluster representatives to keep up-to-date with the issues you are facing. The interaction of the regions with their clusters is an important way for the regions to influence the direction and activities of MSNZ. If you take away one thing of importance from this annual general meeting, it is the need for all regions to participate in their cluster and to make them as effective as possible.

I have been blessed with a hardworking and effective Executive Committee who have willingly given of their time to make my job easier. Jan Hollway and Graham Walker have been my two very effective Vice Presidents. Malcolm Rickerby, Jeff Silvester, Kathryn Marshall, Jan Campbell and Alan Teviotdale as committee members, have all made a very real commitment to the success of this year. In saying that I must single out Malcolm Rickerby for special mention. Malcolm has been involved with MSNZ since the 1980's when he was on the executive and Vice President to President Esme Tombleson in 1980-1981. Since that time, he has for at least 20 years been the delegate for MS and Parkinsons Canterbury. He was National President from 2012- 2020. Malcolm is retiring from the Executive Committee at this meeting.

Our thanks to Malcolm and the rest of the Executive is richly deserved.



Neil Woodhams
President

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.

NATIONAL MANAGER'S ROUND UP



The MSNZ financial year opened with COVID-19 continuing to have affect across New Zealand's Multiple Sclerosis community. However, despite the operational challenges to working in a COVID-19 environment, MSNZ and Regional Societies continued to successfully provide their essential services to people with Multiple Sclerosis.

Significant efforts were made to interpret and apply Government mandates in relation to COVID-19 vaccinations and infection control management. Correspondingly, national policies, procedures, and advice was developed and shared to Regional Societies for engagement with the community.

MSNZ undertook a specialist contract with the Government to develop, publish and share COVID-19 vaccination information to people with Multiple Sclerosis. We are grateful to the Regional Societies for their assistance in this. We were pleased to see funding support come from the Ministry of Health to offset this increased workload in addressing concerns from the community. We continued to engage with the Ministry's Disability Engagement Group to ensure that the needs of the Multiple Sclerosis community were heard.

National and regional lockdowns meant the most logical decision was to postpone the annual conference in lieu of an online AGM. Successfully completed, MSNZ once again proved itself to be an agile organisation, adapting to maintain its operational services.

MSNZ National Office staff set up their work-from-home offices during lockdown periods to ensure continuity of service through:

- The 0800 free phone MS information line;
- Provision of information publication booklets;
- Maintaining response to website information requests;
- Delivering on the Ministry of Health DIAS contract;
- Grant applications;
- National administration including, receipting, and responding to donations, providing grant accountability information, and
- Liaison with the National Executive Committee and Regional Societies.

MSNZ made a submission to the independent Pharmac review. Based on its extensive experience working with Pharmac in advocacy for disease modifying therapies (DMTs), MSNZ raised process issues, the need for greater transparency and more meaningful patient group engagement.

We are pleased to see positive outcomes from the review, with Pharmac reaching out to MSNZ for feedback on their review of Siponimod for Secondary Progressive Multiple Sclerosis.

The release of the COMPANZ paper highlighted how Australia's more open and aggressive approach to treatment has meant patients have achieved far better outcomes over the last 10 years compared to New Zealand counterparts. While the organisation grappled with the hard truths of this paper, and were mindful of how it would be received, this important Trans-Tasman research paper provides valuable data to further propel our advocacy endeavours, continuing to advocate for early access to treatments.

The New Zealand Institute of Economic Research (NZIER) was commissioned by MSNZ to research, assess and report on the social and economic burden of Multiple Sclerosis to New Zealand. The published report shows that earlier intervention of Multiple Sclerosis will not only save New Zealand's health system millions of dollars per year, but it will also contribute millions back into the economy through individual income related earnings by people with Multiple Sclerosis able to remain actively engaged, working, and contributing to the New Zealand economy.

Although challenged by COVID-19, it has been an excellent time for shoring up projects and processes for the organisation, completing great initiatives and strengthening our operational support programmes and tools.

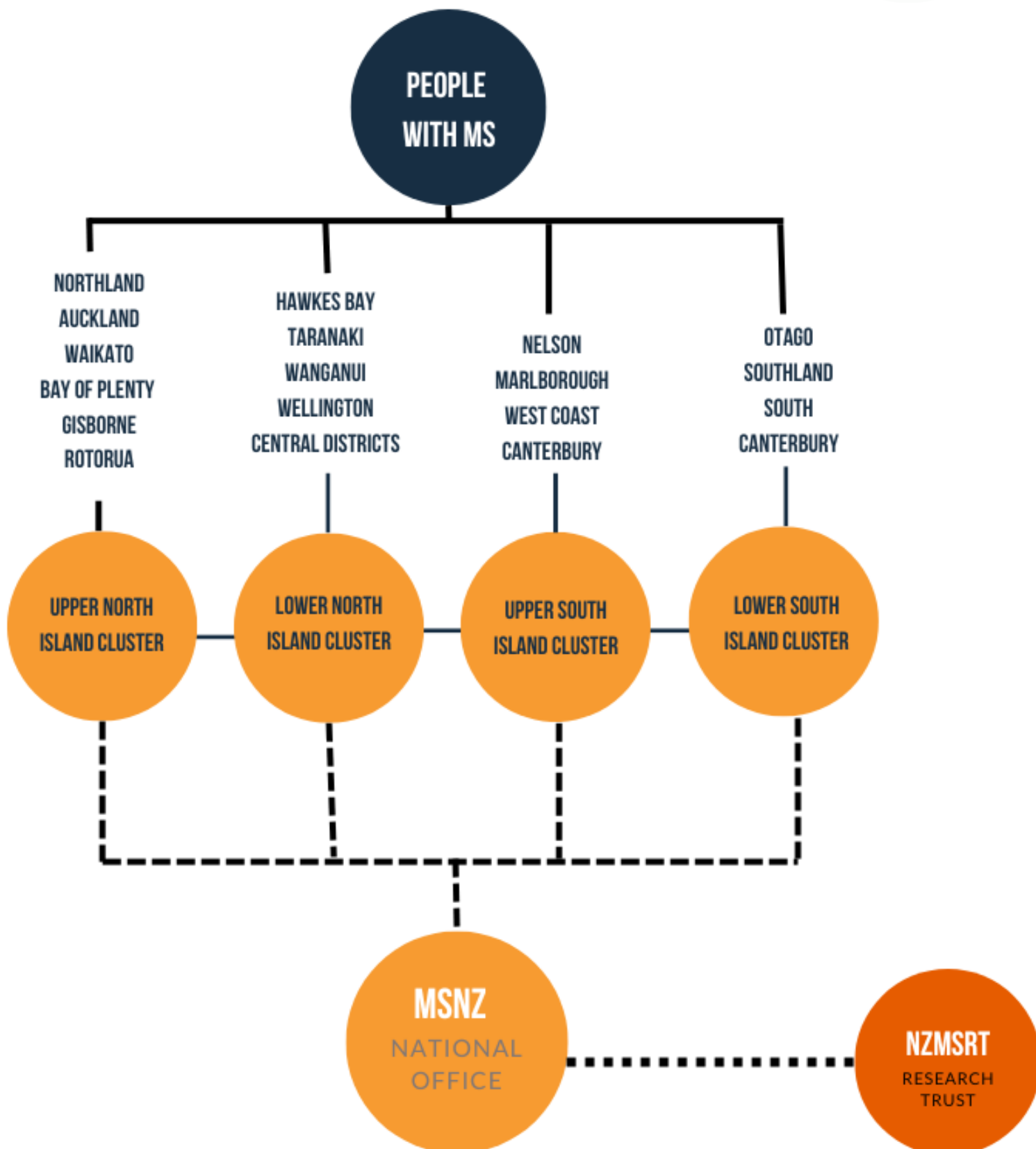
As the National Manager I have full gratitude for the people of the MSNZ National Office, for their professional abilities and their great attitude to getting things done. The skills they bring to the team and their unified drive in supporting the Regional Societies and the Multiple Sclerosis community. Specifically, they are (in alphabetical order):

- Amanda Rose – National Advocacy Manager
- Emily Smith – Fundraising Coordinator
- Louise McKinlay – Communications Coordinator
- Sam Barber – Administration Coordinator

The close of the financial year sees the organisation in a firm position, with a great National Office team, and with confidence to manage the new year ahead.

Nicholas Cowie
MSNZ National Manager

WE'RE HERE FOR YOU



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 2021/2 MS CONFERENCE

Our annual Conference in October 2021 was held online and attended by 38 representatives from 18 Regions, which 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.

INFORMATION, EDUCATION AND AWARENESS



OBJECTIVES

- To increase public awareness of MS, highlighting it as a condition of which a lot is unseen
- To increase public empathy of MS so they have a better understanding of what living with MS means
- Encourage people to donate and support MS societies who provide vital support, not found elsewhere in the community

KEY OUTPUTS OF 2021/2 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 2 days in June 2022, 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. Funding from Roche, Novartis and Biogen helped to achieve the education meeting and reduce barriers for our Regions.

While there is a lot we do know about Multiple Sclerosis, the feedback that we continuously receive from those impacted, shows it is still relatively unknown and misunderstood by the public. This is largely due to the complexities and variances of the symptoms, many of which are unseen, and the unknown course that the condition may take for each person.

Each year Multiple Sclerosis NZ looks to raise national awareness of MS and in September 2021, we ran our 'Face of MS' national campaign. Designed to increase the knowledge and understanding of Multiple Sclerosis within society, to heighten the understanding of the condition, encouraging empathy and support, thereby increasing the quality of life for those diagnosed.

Our 'Face of MS' campaign was developed further, introducing new faces and their unique personal stories, which emphasised MS as a condition that can impact anyone, at any time of life and has many unseen symptoms. By highlighting the experiences and needs of those impacted by the condition we aimed to generate empathy and understanding, reducing isolation and increasing inclusivity for the MS community.

We also reached out to the public to support MSNZ and our Regional Societies with donations to continue the provision of vital MS support. The pandemic had a huge impact causing the cancellation of many Regions 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 was supplied to further assist their fundraising efforts.

The cancellation of Street Appeals and events seriously impacted the opportunities to connect with our supporters to raise much needed funds. Nationwide, we raised \$35,098, a significant difference to the \$118,411 raised in 2020.

MSNZ and our supporters are deeply grateful for the support received in such hard times. This funding will support Regions to continue to provide services in their communities.





THE BIG TICK

New Zealand currently has 8 Disease Modifying Therapies (DMTs) funded by Pharmac, which MSNZ has made significant efforts to advocate for. Unfortunately, these have always been accompanied by an extremely restrictive criteria for access, unique in the world, and not based on research data. After 8 long years of continued pressure on Pharmac, including presentations, submissions and bringing over international experts, we now have access that is in line with overseas comparative countries and the internationally accepted diagnostic criteria.

This is a huge step forward for people diagnosed with MS, and those yet to be. The length of time it has taken certainly highlights the longevity of our commitment to ensuring the best outcomes for the MS community. We have been resilient in our position to ensure optimal access to treatments, improving life-long brain health outcomes.

ADDRESSING THE UNMET NEED

Only 1900 of the over 4130 people diagnosed with MS are able to access the funded DMTs. In particular, those with progressive forms of MS, Secondary (SPMS) and Primary Progressive MS (PPMS), are unable to access any treatment currently. In August 2021 we made a submission to the Independent Pharmac Review in which we raised the need for greater patient lobby group consultation. We are pleased to report this has been heard, with Pharmac requesting our feedback on Siponimod (Mayzent), a treatment for SPMS. We sought the input of the SPMS community. Their feedback highlighted several key issues we shared with Pharmac.



AUTOLOGOUS HEMATOPOIETIC STEM CELL TREATMENT (AHSCT)

AHSCT is a life-improving treatment halting the disease and disability in its tracks. A person receiving aHSCT will potentially need NO further treatment. aHSCT is already routinely performed across NZ as a treatment for blood cancer. Despite the clinical evidence and high-level clinical support for its use, patients in NZ with active relapsing MS are still being denied access to this proven, cost-effective treatment.

Since 2017 MSNZ has been advocating for the availability of aHSCT for patients with highly active MS that are not responding to current treatments. Our efforts have included commissioning an independent evidence review, meeting with the Ministry of Health, and bringing in specialists from overseas. On 26th July 2022 we supported Joan Perry, a mother who's daughter has MS, in submitting her 11, 903 signature petition to Parliament to make aHSCT a treatment option for MS, here in New Zealand. Thus removing the heavy financial burden currently placed on individuals wishing to access this treatment, and the need to travel overseas for it.

We have since made a submission to the Petitions Committee further detailing the benefits of making aHSCT an available treatment option and eagerly await the outcome of this.



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. 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, Esme Tombleson, Society of Mary Trust Board, Four Winds Foundation, Pub Charity Ltd, Rata Foundation, Aotearoa Gaming Trust, The Lion Foundation.

BUSINESSES

Rotary Club of Half Moon Bay, New Zealand Institute of Economic Research, Roche Products (NZ) Limited, Biogen NZ Biopharma Limited, Novartis, 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 Ronald Ivan Sare

Estate of Lesley Alexander Pollard

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.

BLAKE "TE ARAROA FOR MS AWARENESS"

"If you google MS you'll find that for every story of hope, there are 100 more stories of despair. This isn't a fair representation of the MS community! I wish I had known that as I scrolled through endless stories showing nothing but wheelchairs and disability. Hopefully, through sharing this journey, we can highlight a story of hope especially for those newly diagnosed and their loved ones."



Hopefully, through sharing his journey, we can highlight a story of hope especially for those newly diagnosed and their loved ones. Blake raised \$7,571 hiking the South Island along Te Araroa.



DANIEL "TAKING ON TE ARAROA"

"I know that there are many people who suffer from reduced mobility and the loss of independence that can come from living with a chronic neurological or pain condition. My mum was diagnosed with Multiple Sclerosis around 20 years ago, and after a number of relapses has lost most of the mobility in her legs. She has had to adjust to many challenges, but remained optimistic throughout. She taught me a lot about resilience in the face of adversity and I plan on channeling this energy during the grueling 3000km journey."

Daniel raised \$1,300 walking the length of New Zealand.

MADDY "JUMPING FOR MS"

"In 2001, at the age of 40, my mother was diagnosed with Multiple Sclerosis. I was only 5 years old at the time. For my mum, it has now gotten to the point where being mobile is becoming a struggle due to minimal feeling in her legs and feet. This is also accompanied by memory loss and easy frustration. Our family has lived with the effects of MS for the last 20 years."

Maddy raised \$4,300 by facing her fears and skydiving.



FINANCIAL OVERVIEW

REVENUE

2022

2021

Donations, fundraising and other similar revenue	336,739	331,802
Fees Subscriptions and other revenue from members	2,307	9,228
Revenue from providing goods or services	338,943	285,246
Interest, dividends and other investment revenue	(36,187)	48,094
Other Revenue	-	-
Total Revenue	641,802	674,370

EXPENSES

Expenses relating to public fundraising	27,184	55,940
Volunteer and Employee related costs	244,978	243,992
Costs related to providing goods or services	334,776	288,210
Grants and donations made	0	6,381
Other expenses	13,924	22,048
Total Expenses	620,862	616,571
Surplus/(Deficit) for the Year	20,940	57,799

ASSETS

Current Assets	112,291	126,578
Total Non-Current Assets	426,844	408,255
Total Liabilities	51,065	67,689
Net Assets	488,070	467,144

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 by the President and a Committee Member of the Society at the Annual General Meeting. Accounts have 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

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Multiple Sclerosis
New Zealand

PO Box 1192, Christchurch 8140

Phone: 0800 67 54 63

Email: info@msnz.org.nz

Website: www.msnz.org.nz