

MULTIPLE SCLEROSIS NEW ZEALAND

2022/3 ANNUAL REPORT



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FINANCIAL REPORT

ON THE PATH TO EXCELLENCE

Multiple Sclerosis New Zealand (MSNZ) is a non-profit organisation, established in 1967. We are striving towards our vision of being the National Leader for Service Excellence for people impacted by Multiple Sclerosis.

To achieve this, we are on a mission to coordinate and lead the advances in best practice multiple sclerosis care. We do this by providing national leadership, advocacy, information, education and raising awareness.

We work with 18 member organisations nationally to meet the needs of people with multiple sclerosis, their families, carers and whānau across Aotearoa. We promote internationally recognised MS Brain Health principles and recommendations for living well with MS.

We encourage resiliency, self-management, preventative services. By providing evidence-based information and advocacy we encourage people to take control of their diagnosis and condition. Positive attitudes and lifestyle modifications, which we encourage, can have a profound effect on symptom management and maximising opportunities for long-term health and brain health outcomes.



To achieve our mission we:

- Support 18 MS regional organisations with operational and governance support;
- Provide leadership to model best practice to improve outcomes for people impacted by MS;
- Advocate on national issues impacting the MS community;
- Raise awareness for MS as a chronic condition affecting New Zealanders and highlighting the needs of those impacted by the condition;
- Provide free information on understanding, managing and living well with MS;
- Offer a free information line and online tools to connect those looking for support with their local MS Society;
- Fund scholarships to keep people with MS in paid employment;
- Organise educational training opportunities for community-based support staff;
- Work collaboratively with relevant partners to identify and develop tools to support effective self-management of MS;
- Collaborate with other organisations to increase opportunities for positive engagement and living well with MS.



NATIONAL PRESIDENT'S REPORT

At the beginning of the financial year MSNZ took time to reset and re-focus its direction and strategy. Our vision to be “The National Leader for services for People affected by Multiple Sclerosis” is a challenging one, but MSNZ’s National Executive Committee are inspired to drive the organisation forward into the future for the betterment of the MS community.

To maintain our focus, our priorities are defined by 4 key pillars: 1) National Leadership, 2) Advocacy, 3) Information, Education and Awareness and 4) Future-Proofing.

The current health and disability system is falling short in terms of meeting international MS Brain Health recommended standards. We continue to feel the impacts of the extreme pressure placed on our health and disability services. Shortages of specialist MS neurologists and MS nurses, long waiting times for first specialist assessments, the lack of access to neurology services for people with advanced MS who have no access to disease modifying therapies (DMTs).

Alongside this, MS is a multifaceted Health and Disability issue. People impacted by MS require the support of multi-disciplinary teams including neurologists, nurses, physiotherapists, occupational therapists, and psychotherapists. In most cases, access to public services is one dimensional and people are left to navigate services on their own. This means it is important that MSNZ continues to take leadership on National issues and create an environment where the Regions and people impacted by MS can be strong self-advocates.



Our relationships with allied organisations with similar objectives and issues to ours, are a key part of our activity. Our links with the Neurological Alliance, Carers Alliance, NGO Council, Patients Voice Aotearoa, Disabled Persons Assembly and MS organisations around the world, enables us to amplify our voice on matters of collective issue.

You will read further in this report, the strides we have been taking with our advocacy. A cornerstone of our success has been ensuring decision makers have had the latest and best clinical evidence to support our case. This has been recognised and acknowledged by Pharmac. The highlight this year was the MS Brain Health international award received for our advocacy efforts in widening access to DMTs.

One of the four pillars of our strategy is Future Proofing. For most of this financial year at least we have been able to operate in a more normal environment and we can look to the future with confidence. Key to this is ensuring the on-going financial viability of the Society. From a position 10 years ago when the Society was essentially insolvent, we have built up our finances to a position where we can look to the future with some confidence. Historically this represents the best position for well over 15 years.

The Executive are comfortable with our level of reserves when weighed against the following factors: less than 10% of our budget is from Government contracts, the reliance on community fundraising, recent global and national crises and changes to legislation impacting community organisations, the need to ensure a balance between ensuring future financial stability, the needs of the organisation now.

Our grateful thanks to the Rotary Club of Half Moon Bay for once again selecting us to be a masthead charity for Bangers to Bluff. The event has a warm collegial spirit, that is full of fun and laughs. It is a highlight of our calendar and provides opportunity for members of the Executive to meet with Regional Societies in their localities.

We would not have achieved what we have in the last year without the efforts of Vice Presidents Jan Hollway and Graham Walker and Committee Members Jeff Silvester, Jenny Woods, Allan Teviotdale and Jan Campbell. I owe you all thanks for a major effort this year and a job well done.

In the same way Amanda and the staff Emily, Sam and Louise have made a major contribution to what we have been able to achieve. Theirs is not an easy job working constantly under the pressure of tight deadlines high expectations and limited resources. My personal thanks and the thanks of the Executive Committee to you all.

Neil Woodhams
President

NATIONAL MANAGER'S REPORT

After 11 years at Multiple Sclerosis NZ, I am more inspired than ever with the direction we are heading. Our new vision and purpose will see us striving over the next 10 years to be the National Leader for Service Excellence for people impacted by Multiple Sclerosis. This is a long-term vision change the way that people living with MS across Aotearoa will experience services to improve their health and wellbeing.

Over the next three years we will focus on coordinating and leading advances in best practice Multiple Sclerosis care. This will be no easy feat. It will require the collective understanding, support, and work of all MS organisations, striving towards wanting to improve services and experiences for their clients nationally. MSNZ's focus will be on providing national leadership, advocacy, information, education and continuing to raise awareness nationally. We know that success can't be achieved alone, it will take us all working symbiotically together, and focussing on our areas of strength.

Internally, we have identified several critical initiatives that will determine our success to achieve this vision and mission. We look forward to bringing these to fruition. At the forefront of our focus, is how we can relieve our hard-working and stretched Regions of their pressure points. This will enable Regions to maintain their focus on local service delivery, based on recommended standards of excellence.

MSNZ was proud to award three Dorothy L Newman Scholarships and two Esme Tomblason Awards this year. Joan Perry and Ingrid Robertson are both shining examples of New Zealanders who have gone above and beyond to inspire and change the lives of people impacted by MS. We look forward to following the progress of our three Scholarship recipients as they undertake their new courses of study to improve their employment prospects and futures, while navigating MS.



Spending three days with 25 of our community advisors from across the country at the annual meeting highlighted the strength in our network. This knowledgeable, skilled and passionate team of go above and beyond to improve the lives of their clients. To support their professional development, MSNZ has launched a new webinar series for community advisors on issues impacting their clients.

2022 was a stand-out year for our advocacy. Momentum built over the last 8 years came to fruition in many priority areas. Not only does it mean we achieved huge leaps forward in the treatment of MS but can now redirect our focus to other areas. Changes in the health and disability systems, critical workforce shortages in vital health, carer and respite services, and the cost-of-living crisis are being felt by the MS community and organisations. Later in this report you can read more about our recent successes and future directions.

Much of our advocacy is long-term, requiring years of persistence, commitment and significant resources. It was an honour to receive the Oxford Health Policy Forum Team Award in the 2023 MS Brain Health Awards – for "creating a better future for people living with multiple sclerosis and their families". We happily share this award with the clinicians, people with MS and their whānau, international experts, donors and supporters who all contributed to our 8-year campaign.

We are pleased to see the impact of our work, people living their lives well, continuing in employment, supporting their families and communities, and having improved long-term brain health outcomes. However, we appreciate improvements impact regional services. Many report the availability and success of disease modifying therapies, changing how newly diagnosed and younger clients use their services.

We continue to navigate a crowded funding space with many worthy causes vying for community donations. Thank you to all those who chose to support MS either nationally or regionally, your support does not go unnoticed and is vitally needed.

MSNZ is fortunate to have passionate and committed staff who are focussed on making a positive impact. Our dedicated National Executive Committee also contribute countless volunteer hours to achieve our mission. Thanks to our interns Isabella, Mia and Indica for their support over this past year from the University of Canterbury. MSNZ is a small organisation, but together we strive for big steps.

As we head into this next year, we look forward to setting the pathway for our new strategy as we remain focussed on seeing service excellence in MS care nationally for all those impacted by MS. We hope you will join us.

Amanda Rose
National Manager

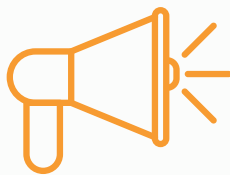
ADVOCACY



OUR IMPACT IN NUMBERS

1

International Award received - MS Brain Health Team Award recognising our advocacy to improve the lives of people impacted by MS.



14

Official Information Act Requests and Letters sent to Ministers and government departments to advocate on critical issues.

1

Petition with 10,903 signatures delivered to Parliament calling for the funding and availability of aHSCT as a treatment option.



1

New major project was funded reviewing how Pharmac costs MS treatments.

1

Presentation made to the Health Select Committee to present the evidence to support the funded availability of aHSCT for people with MS.

1

petition launched with the Carers Alliance the Carers Alliance to protect the physical, mental and financial wellbeing of family and whānau carers.

5

Media releases, articles, and advertisements commissioned to increase the awareness of critical issues facing those impacted by MS.

TIME MATTERS IN MS

On the 1st of July 2022 we saw the results of eight years of hard fought, and persistent advocacy, come to fruition when Pharmac widened the disease modifying therapy (DMT) access criteria. The adoption of the McDonald 2017 criteria now means those clinically diagnosed with relapsing MS can begin treatment on diagnosis and not have to risk disability and further relapses. This is a huge step forward in the treatment of MS in NZ, prioritising the importance of early intervention as critical for preserving long-term brain health, reducing the likelihood of premature disease progression or disability. Importantly, these changes will help to relieve some of the mental stress and fear of the waiting game.

MS BRAIN HEALTH TEAM AWARD

MSNZ's work to widen the Special Authority Criteria was awarded the UK's Oxford Health Policy Forum Team Award in the 2023 MS Brain Health Awards – for "creating a better future for people living with multiple sclerosis and their families". It was an honour to have our courage, determination, care and pride recognised with this award. The team award acknowledged all the support we received over the 8-year campaign from clinicians, people with MS and their whānau, international experts, donors and supporters. This could not have been achieved without our commitment to developing positive and beneficial relationships.



"Those newly diagnosed are now able to access funded treatments earlier than ever before, and we are now seeing people staying on treatment significantly longer."

**Neil Woodhams,
MSNZ President**

"This award reflects the power and value of the collective voice. We thank everyone who was involved over the years for their contribution."

**Amanda Rose,
MSNZ National
Manager**



AUTOLOGOUS HEMATOPOIETIC STEM CELL TREATMENT (AHSCT)

Overseas aHSCT has been a safely managed and effective treatment for MS for over ten years. In studies comparing clinical outcomes of aHSCT to available DMTs, aHSCT outperforms conventional treatments. In most cases, aHSCT is a one-off intensive treatment. At a time when NZ is under critical health and financial pressures, aHSCT has clear clinical and financial benefits to the health sector, other government agencies and to those diagnosed and their whānau.

On the 26th July 2022, following a year of campaigning and collecting signatures, one of MSNZs 2022 Esme Tombleson Award winners, Joan Perry, her daughter Anne Besley, and representatives from MSNZ, and the MS community presented 10,903 signatures to ACT Deputy Leader Brooke van Velden outside of Parliament in Wellington. The petition called on the Government to make aHSCT an available treatment option in NZ. Following this, a written submission was made to the Petitions Committee in August and an oral presentation made to the Health Select Committee in November.

On 30 May 2023, World MS Day, we were excited to introduce on our webinar the first MS patient to receive aHSCT for MS in New Zealand. Specialists became interested in aHSCT in 2017 after MSNZ brought aHSCT specialist Dr Riccardo Saccardi to New Zealand. Neurologists nationally have since established an access criteria and committee to review potential candidates for treatment. MSNZ continues to work with Te Whatu Ora to ensure equity of access for patients nationally.

A BEACON OF HOPE

In June 2023 Pharmac opened public consultation to fund Ocrelizumab for those with primary progressive MS (PPMS) and have since approved to fund access from 1 October 2023. 10-15% of those diagnosed with MS have PPMS who, until now, had little hope of slowing and delaying the progression of their condition and disability. PPMS causes symptoms to worsen gradually and consistently. Ocrelizumab has been proven in trials to maintain mobility and independence, allowing people to continue working, supporting their families and whānau, and living well. This momentous decision follows a seven-year advocacy battle to bring hope to hundreds of people diagnosed with the most progressive form of MS and their whānau. While Ocrelizumab is available in 26 other countries, New Zealand will be the first in the Asia-Pacific region and one of only four English speaking countries with funded access.

CARING FOR THE CARERS

Carers play a crucial role in our society, providing essential support and care for their loved ones. However, their invaluable contributions often go unrecognized and unacknowledged. Despite their immense value, carers are facing a burnout crisis. It is crucial to recognise the invaluable work they do and provide them with meaningful support and access to adequately resourced respite and financial security.

Taking a stand, MSNZ and the Carers Alliance are spearheading a petition calling for the establishment of a Minister or Commissioner for family and whānau carers, as well as the development of protective legislation, programs, and services to sustain carers physically, mentally, and financially. This petition aims to address the pressing needs of carers, ensuring they receive the recognition and support they deserve. Alongside the petition we have run a campaign to highlight the issues facing MS carers specifically.

"This disease has been so cruel, causing a great deal of pain for my husband, disturbed sleep, mood swings, physical disability, loss of work and has destroyed our 50's. We would be so grateful if it didn't destroy our 60's as well."

Gail and Murray

"I am exhausted because in the past six years, I have only had about 20 days when I wasn't a full-time carer, and 14 of those were when I was in hospital with an ankle broken in eight places."

Maxine

"It would give me some hope for the future. I could get back some of my old lifestyle and make plans. I would have something positive to focus on."

Anonymous

"When you've been told repeatedly there's no cure, no medication, no therapies, and no indication for your future... the light of hope, a chance, an opportunity... essentially, that's like a miracle!"

Anonymous

THE UNMET NEED FOR THOSE WITH SECONDARY PROGRESSIVE MS

In 2022, as part of their assessment of Mayzent (siponimod) for Secondary Progressive MS (SPMS), Pharmac reached out to us to understand more about the unmet need.

As part of our consultation, we launched a snap survey and were overwhelmed with the responses which were used to support our submission. The stories were deeply personal and, in many cases, heart-breaking experiences.

In November 2022 we were advised that Pharmacology and Therapeutics Advisory Committee (PTAC) recommended listing Siponimod with low priority requesting further specialist input.

Pharmac also advised us that they "found the MSNZ submission incredibly valuable. Having the voice of those with SPMS included and the real-life experiences was both moving and important for us to receive to consider in the assessment of siponimod. Thank you again for providing this to us."

While pleased the severe unmet health need has been recognised, there is still substantial work to be done to progress the recommendation higher up the priority list.

The feedback is continuing to be used by MSNZ in reviewing our advocacy priorities as it highlighted multiple areas of need within the MS community.

FUTURE DIRECTIONS

Having ticked off many of our advocacy campaigns which have taken substantial time and resources, we can now reprioritise and address inequities in access to services and health and wellbeing. We are currently focussed on:

01

SPECIALIST WORKFORCE

The whole health system is in crisis with under resourcing. We are raising how this is impacting the MS community and how the crisis is impacting the access to diagnosis, treatment and ongoing management which in turn impacts health and wellbeing outcomes.

02

ECONOMIC BURDEN OF MS

In the current world of high inflation and cost of living crisis, the economic burden of MS has never been more alarming. Of particular concern for MSNZ are the barriers for accessing Community Services Cards and the range of services that this makes more attainable.

03

CARING FOR CARERS

Addressing the impact of MS on family and whānau carers both economically and on their health and wellbeing.

04

DISEASE MODIFYING THERAPIES

Treatments continue to be a priority with particular focus on addressing the unmet needs of those with progressive MS. We are currently advocating for Siponomod (SPMS) and Cladribine (RMS).

05

AHSCT

Ensuring the progress being made with making aHSCT an available treatment option continues.

NATIONAL LEADERSHIP



OUR IMPACT IN NUMBERS

25

Community Advisors funded to attend our Annual Meeting

to support their professional development enhancing their service delivery regionally.



3

Dorothy L Newman Scholarships awarded to support people with MS to undergo courses of retraining to gain or retain paid employment, where MS may have had an impact.



33

Attendees funded or subsidised to attend our Annual Conference

to connect, network, collaborate and learn from other MS organisations in our network.

2

Esme Tombleson Awards

presented to people who have provided outstanding services to the MS community nationally. The award recognises the impact these individuals have had on the lives of New Zealanders impacted by MS..



MS CONFERENCE

In October 2022 we brought together 33 representatives from MS organisations across NZ to connect, share and learn from each other at our annual conference in Christchurch. Despite the second day of the event being impacted by Covid, the first day was pivotal for the future direction of the organisation. Valuable time was spent workshopping and exploring the specific pain points for our members and how this impacts the delivery of service to their clients. The information gathered during these sessions paved the way for the development of MSNZ's new 10-year strategic direction which will set us on the path towards establishing national excellence in MS care and supporting regional service delivery. At the dinner, departing Committee Member and ex-president Malcolm Rickerby was awarded life membership for his outstanding contribution to MSNZ and MS in New Zealand. Our thanks to Lottery and Roche Products NZ for their funding support of this important event in our calendar.

COMMUNITY ADVISORS MEETING

At the end of June 2023, MSNZ hosted our annual Community Advisors Meeting in Christchurch. 25 community advisors from across Aotearoa participated in two and a half days of workshops, presentations, networking and collective learning to improve their knowledge and education to deliver services in their local communities. Workshops covered issues on Men's Mental Health and Family Violence, and presentations addressed issues such as relapse, working with NASCs and WINZ, service planning. This event was made possible thanks to funding from the Ministry of Social Development's Care in the Community Fund and Aotearoa Gaming Trust.

2022 ESME TOMBLESON AWARD WINNERS

JOAN PERRY

Mother of a person with MS, wife and passionate advocate, Joan Perry was tired of sitting by and watching the continued delays being faced by New Zealanders in accessing aHSCT. Inspired by her strong and incredible daughter Anne, Joan wanted others to have the same opportunities she and her family had been afforded by the treatment, to have her daughter back. After talking with MSNZ about the continued frustrations, Joan was motivated to start a petition to call on the Government to progress the availability of the treatment. Over the next 14 months Joan took every opportunity to gather signatures from within her community and worked closely with MSNZ to promote the petition. By the end of June 2022, 10,903 had signed the petition which was received and read out in Parliament on 26th July 2022. Following this, Joan worked with MSNZ to make a written submission to the Petitions Commission and an oral presentation to the Health Select Committee.



INGRID ROBERTSON

Cantabrian Ingrid Robertson was diagnosed with MS in 1999, but has never let that hold her back in achieving her dreams, inspiring and supporting others by being an advocate not only in her local community, but also nationally. Since 2018 she has organised four Oceans of Hope Challenge NZ events, taking over 120 people with MS on sailing adventures. She is inspired to help others with MS to find their magnificence. Ingrid organises the sails to provide opportunities for others with MS to meet people also diagnosed, learn from each other, feel empowered, and push the limits of what they think they can achieve. Ingrid is an inspiration to everyone she meets, encouraging people to “Believe in yourself.”

DOROTHY L NEWMAN SCHOLARSHIPS

For over 35 years the Dorothy L Newman Trust and Multiple Sclerosis NZ have co-funded a scholarship programme supporting and encouraging people with MS to remain in paid employment. Three scholarships were awarded this year to worthy recipients including Sarah and Haley who share their stories.

SARAH

Sarah was awarded a scholarship to study a NZ Diploma in Psychology. MSNZ was pleased to be able to support Sarah to follow her passion, while also providing a future for herself and financial security for her family.

“Being a creative person, I studied Sociology and Art then worked within the fashion industry for 30 years. I travelled to various countries, always creating. Now, I am Lecturing Level 5 Diploma in fashion technology. I love working in the fashion industry, designing, dressmaking coordinating and teaching.”

Sarah has journeyed with MS for 11 years, struggling with Uvietis, inflammation, neuropathic nerve pain. A steroid injection has unfortunately resulted in cataracts developing in both eyes. These health issues necessitated a reduction in work hours to prioritise her well-being and be there for her four children, providing for them to the best of her abilities.

This ignited a strong desire to retrain in psychology, a field that has long fascinated her. Her passion for mental health, awareness, and psychology has continued to grow over time, she states that “art therapy, psychology and counselling support that awareness to be kind to ourselves and show us a way through these times, to see the courage it can take to ask for help or to learn something new.”



HAYLEY

“Currently I am studying full time, working on a casual basis as an Emergency Medical Technician (EMT) for St. John and running my own business. I have a real passion for helping people in the community with health-related issues, which has led me to this career choice and studying to become a Registered Nurse.”

“Unfortunately, as my MS is progressing, I am starting to find these 12-hour shifts, especially night shifts more and more difficult to maintain due to fatigue. I chose to complete my nursing degree, so when I am no longer able to do 12-hour shifts, I will still be able to provide meaningful help and support to others.”

At MSNZ, our mission is to be a supportive force for those with MS, fostering their ability to remain in paid employment for as long as possible. We firmly believe that sustained work not only provides financial security but also enhances overall quality of life, well-being, and self-reliance. By nurturing a sense of purpose and strength, we enable individuals to maintain their independence despite the challenges they face.

So, it was heartening to hear that Hayley has already devised a plan. On completing her training, she will look to transitioning into community health as a Registered Nurse (RN), ideally at a GP practice or as a community nurse. Additionally, completing this qualification could provide opportunities for delivering tele health should her MS progress. “This qualification will give me a lot of flexibility to be able to continue to work, regardless of the level of disability I end up with due to MS. Nurses continue to be in high demand throughout New Zealand so I believe there will be no possibility of not obtaining employment in this field for years to come.”



INFORMATION, EDUCATION AND AWARENESS



OUR IMPACT IN NUMBERS

6

Webinars were organised by MSNZ on critical issues impacting the MS community.



11

E-newsletters were delivered to our subscribers containing information to support people to live well with MS.

448

Copies of MSNZ's publications were distributed providing information on MS, living well with MS and managing MS symptoms.



142

Information requests received via www.msnz.org.nz.

709

Calls for information and support were received via our 0800 MS LINE.



137

Information posts shared with our member organisations on our internal intranet system, keeping them informed, updated and providing resources to support their members.



SOME OF THE MANY FACES OF MS

MULTIPLE SCLEROSIS AWARENESS

Help us to support those impacted by MS

MS is a complex condition which presents itself differently in everyone. No two people have the same symptoms or experience and that can make MS hard to understand. Combined with the range of symptoms, many of which are unseen, people diagnosed with MS often feel isolated and misunderstood.

Multiple Sclerosis New Zealand aims to raise national awareness of MS through two main campaign periods, World MS Day annually on 30 May, and Awareness Week in September. Through our campaigns we aim to increase the knowledge and understanding of MS within society and encourage empathy and support, thereby increasing the quality of life for those diagnosed.

MS AWARENESS WEEK 2022

Thanks to the support from Pub Charity Limited, we ran our annual 'Face of MS' national campaign between 12 - 18 September 2022. Through the campaign we share real stories, of real people diagnosed with MS, demonstrating that MS can impact anyone, at any time of life.

We provided a fundraising platform with personalised toolkits to each of our 18 member organisations to support their local fundraising efforts while maintaining brand consistency. To reach the wider public we sought the support of an external digital marketing firm to increase our reach through social media, digital news sites and on radio. With the support of one of our University of Canterbury interns we developed several education videos for social media. Our digital and social media advertising achieved above average industry benchmarks, delivering over 5 million impressions.

MS Awareness Week is a critical time for fundraising for many MS organisations. While improving, the pandemic did continue to impact the opportunities for MS organisations to connect with supporters in person to raise much needed funds. Nationwide, MS organisations raised \$86,000, an improvement of the \$35,098 raised in 2021 but still a way to go to meet the \$118,411 raised in 2020.

We are deeply grateful for all the support received over the appeal. Funds raised by MSNZ support us to continue our advocacy efforts. All funds raised regionally enable local organisations to positively impact the lives of their local MS communities.

WORLD MS DAY, 30 MAY 2023

World MS Day is a day to celebrate global solidarity and hope for the future. The 2020-2023 World MS Day theme has been 'connections'. MS Connections is all about building community connection, self-connection and connections to quality care. We are challenging social barriers that leave people affected by MS feeling lonely and socially isolated. Together, we advocate for better services, celebrate support networks and champion self-care.

On 30 May 2023 we celebrated the day with our aHSCT webinar, announcing the first successful transplant on an MS patient in NZ. This was a momentous moment that had been long awaited and hard fought for by MSNZ, clinicians and people with MS and their whānau. Additionally, we were also able to announce our international honour of the Team Award in the MS Brain Health 2023 awards, recognising our advocacy efforts and impact these have had on the lives of New Zealanders with MS.

It is pleasing to see the momentum, globally and nationally, building behind World MS Day. It presents an opportunity to work with international partners and NZ Regional Societies to raise awareness for MS.

"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 my journey, we can highlight a story of hope especially for those newly diagnosed and their loved ones." **Blake**



ENHANCING KNOWLEDGE

For people diagnosed with MS, or supporting someone with MS, improving knowledge enables them to take control of their condition and future, make choices about treatments and lifestyle changes that will positively impact the course of their condition, and feel more informed when new challenges present themselves.

Importantly, at MSNZ, we want people to know that there are avenues for seeking information that is evidence based, approved by specialists and keeps the needs of the MS community at the forefront of mind.

Our website has seen a huge uptake in users and views. It is pleasing to see how well used it is as a critical resource for those seeking information about MS.

MS Voice, our monthly e-newsletter is well received with a growing audience.

Our social media following continues to grow, and thanks to our University of Otago interns we tested out new platforms to increase our reach to younger demographics.

WEBSITE VISITS

117,266

WEBSITE PAGE VIEWS

207,351

FACEBOOK FOLLOWERS

5.5K

PLATFORMS USED





Behind the scenes at MSNZ the team has been working hard over the last year to develop a suite of new resources to be launched late 2023. We thank the Ministry of Social Development's Care in the Community Fund for supporting this work, as well as our team of external reviewers for their feedback and guidance. Creating information that was well received by those with MS, their families, community advisors, MS nurses, neurologists and specialist allied health workers is critical to ensuring the information will be valued resources. We are well on the way to achieving this and look forward to launching our new resources which we make freely available online and in print direct from MSNZ or through our regional societies.



Early diagnosis is critical to ensuring optimal brain health outcomes. However, one of the most reported issues we receive calls about at MSNZ is the difficulty those going through diagnosis have at being heard and understood. Symptoms are often treated in isolation, or because many MS symptoms are unseen, those seeking diagnosis struggle which impacts their disease and disability progression, careers, families and mental health.

MS is a complex condition and with approximately 4100 people diagnosed in NZ, most health professionals will see a small number of MS patients, if any, during their career. To improve the understanding and knowledge of MS in the health sector we have embarked on a three-year programme to increase the awareness of MS and the early symptoms, with an aim to reduce the current 4.5 year delay between onset of symptoms and diagnosis. We are targeting key sectors of the health profession who may come into contact with patients experiencing early symptoms. While only in the early stages, we have begun our campaign with a series of articles in key sector publications, including the front page story of the Pharmacy Guild Magazine, Contact.



OUR GRATEFUL THANKS



As a not for profit, 90% of our income comes from our generous supporters who choose to gift their time and support to help us raise the funds needed to continue helping those impacted by MS. The majority of our funds are raised from trusts and grants, bequests, donations and fundraisers. We appreciate the support of every gift, monetary, in-kind, pro bono, discounts or the donation of your time through volunteering. We are grateful for the support of those in the community who choose to support Multiple Sclerosis New Zealand and the work we do. Thank you.

Volunteers

A huge thank you to all our volunteers for choosing to give their valuable time and skills to our mission. As a small organisation, volunteers are the backbone of our work and incredibly valued. A special thanks to our three interns, Isbella, Mia and Indica from the University of Canterbury for your time and contributions.

Trust and Grant Funders

Whaikaha/Ministry for Disabled Persons, Ministry of Social Development Care in the Community Fund, Rotary Club of Half Moon Bay, The Lion Foundation, Lottery National Community Grants, Air Rescue Services Ltd., 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

ABC Photosigns NZ Limited, Craigs Investment Partners, Crowne Plaza Queenstown, Cycle Inn, David Trim and Associates, Emerson McLaughlin Ltd, Ironman NZ, Lorelei Mason Health Communications, Mainfreight, Marshall Batteries, Mortlock McCormack Law, NES Hire, NPD, Oceanbridge Shipping Limited, Panasonic NZ, Permobil, Printers Inc, Roche Products (NZ) Limited, The Bike Dude, Williams Auto Electrical.

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.

Gifts in Wills

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 Murray Stoughton Rider
Estate of J H Yeoman
Estate of Janet L Pollard
Estate of Leslie Alexander Pollard
Estate of Roger M Mackie
Estate of Robert McHattie
Estate of Alan David Anderson

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, families or whānau inspired by the challenges their loved ones face. Thank you for choosing to support MSNZ.





BANGERS TO BLUFF

MSNZ was delighted to be chosen again as one of two masthead charities for Bangers to Bluff 2023, a 12-day car rally, organised by the Rotary Club of Half Moon Bay.

Between 21st March and 1st April 2023, after a hiatus due to Covid, 18 cars and support crews were excited to be on the road once again. Participants drive a 'banger' costing less than \$2000 from Auckland to Bluff. Ultimately, the challenge is whether the cars will make the finish line. The rally is well supported by MS Regions on route, who welcome the crews into their communities to show their appreciation.

Our team Keep S'myelin (MSNZ National Committee Members Neil Woodhams, Graham Walker and Jeff Silvester) participated, this time in a 2002 silver VW Beetle. Despite missing a few crucial elements like a heater, which certainly would have come in handy when they reached snowy Tekapo, the team and car made it safely to the finish line (thanks to a new cambelt it needed before it even left Auckland).

Team cyclist, Graham Walker, steamed ahead of the cars for 20-40km each day before they caught up with him. Diagnosed with Primary Progressive MS 10 years ago, Graham is an inspiration showing what people with MS can do with exercise, perseverance, a positive mind-set, and access to treatment.

The cars were auctioned in Invercargill at the end of the rally on 1st April, with the proceeds being donated to charities the Rotary Club of Half Moon Bay supports, including MSNZ and MS Regions they meet on route. A huge thanks to the Rotary Club of Half Moon Bay, the organisers, participants and donors for your support.



Ellie



Alysha

FANTASTIC FUNDRAISERS

Spurred on by New Zealanders impacted by MS, and one person in particular, her mum, **Ellie** challenged herself to complete the Taupo 70.3. in December 2022. Ellie swam an incredible 1.9km, biked 90km and ran 21.1km to reach the finish line in under 6 hours and raised \$3550 for MSNZ.

Alysha sadly lost her grandmother in August 2022 “after battling the cruel incurable disease from a young age.” After brainstorming ideas on how she could help others in “their fight with MS”, Alysha decided to climb the Eiffel Tower every day on the stair master machine to help raise \$1500 to support our work. That’s 129 stories every day!

*“Every little bit of funding helps and for me it's a small choice to push myself to the edge of exhaustion however for those living with MS, they have to deal with this level of fatigue each day.” **Ellie***

*“I hope that one day there will be enough research and funding to find a cure for this terrible disease many suffer.” **Alysha***



Ken



James and City Fitness Nelson

Ken knows from experience how challenging having a young family can be “from juggling work commitments and family time to finding time and motivation to prioritise your own health” even without a chronic health condition like MS. After learning more about the challenges people living with MS experience on a day-to-day basis, and how it impacts on the quality of life for not only those diagnosed but also their loved ones he decided he wanted to do more to help and completed the Taupo 50km Ultramarathon in October 2022 raising \$1785.

*“I’ve been incredibly inspired by some of the positive stories - a great reminder not to take my own ability to run (no matter how amateur) for granted.” **Ken***

To inspire club member James to “Chop that Mullet” **City Fitness Nelson** decided the best way would be with a fundraiser. With a few members with MS, they chose to support MSNZ for the work we do to improve the lives of those impacted. After raising \$1852 the mullet was chopped!

*“We want to show our support to these amazing people and hope that it can even make a small difference in their lives.” **City Fitness Nelson***

REVENUE

2022/3
2021/2

| | | |
|---|------------------|----------------|
| Donations, fundraising and other similar revenue | 660,355 | 336,056 |
| Fees Subscriptions and other revenue from members | 9,228 | 2,307 |
| Revenue from providing goods or services | 373,125 | 339,625 |
| Interest, dividends and other investment revenue | 32,624 | (36,187) |
| Other Revenue | 0 | 0 |
| Total Revenue | 1,075,332 | 641,801 |

EXPENSES

| | | |
|--|----------------|---------------|
| Expenses relating to public fundraising | 60,780 | 27,185 |
| Volunteer and Employee related costs | 317,785 | 244,390 |
| Costs related to providing goods or services | 371,711 | 335,874 |
| Other expenses | 20,926 | 13,412 |
| Total Expenses | 771,203 | 620,861 |
| Surplus/(Deficit) for the Year | 304,130 | 20,940 |

ASSETS

| | | |
|--------------------------|----------------|----------------|
| Current Assets | 408,549 | 350,552 |
| Total Non-Current Assets | 670,004 | 346,639 |
| Total Liabilities | 286,353 | 209,121 |
| Net Assets | 792,199 | 488,070 |

SUMMARY AUDIT OPINION

The accounts have been audited by PKF Goldsmith Fox Audit. 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 2023, authorised for issue on 5 October 2023 by the President and a Committee Member of the Society has been audited by PKF Goldsmith Fox Audit. An unqualified audit opinion was issued on the Performance Report for the year ended 30 June 2023.

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 2022-23

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