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Multiple Sclerosis
New Zealand

Annual Report
2016–2017

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MSNZ Directory

As at 30 June 2017

President	Malcolm Rickerby
Vice President	Neil Woodhams
National Executive Committee Members	Mark Etheridge Jane Heywood Jeff Silvester Ian Chadburn Tony Kerr
National Manager	Amanda Rose
Communications and Administration Coordinator	Emily Smith
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MSNZ Strategic Plan 2017-20

VISION

A world without MS

MISSION

To advocate for people with MS in New Zealand to have access to first world treatment, resources and services to improve their well-being and quality of life

To reduce the burden of MS on those diagnosed, their carers and families

AIMS AND OBJECTIVES

1) *Advocacy*

- > Effective Advocacy on behalf of:
 - **Systemic:** National advocacy to improve the lives of people with Multiple Sclerosis in New Zealand
 - **Collaborative:** Working with other organisations and health professionals on common issues
- > Raise awareness nationally for MS as a chronic condition affecting New Zealanders and highlighting the needs of those living with the condition

2) *Work collaboratively with Regional Societies to help people with MS to self-manage their lives*

- > Work collaboratively with Regional Societies to gain a clear understanding of the diverse needs of PwMS
- > Work collaboratively with Regional Societies to determine the scope of evidence based service responses that support PwMS to improve their well-being and self-manage their quality of life
- > Manage a workforce development programme that is progressive and supports PwMS to self-manage their lives
- > Provide relevant, evidence based, up-to-date information on MS

3) *Consistent and equitable level of care and services wherever you are across the country*

- > 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 impact on their business and service delivery
- > Work with Regional Societies to design and implement a service delivery model that is focussed on outcomes for individual PwMS

4) *Agreed National Data Set*

- > Report nationally consistent data that is relevant; informative and supports effective future planning for PwMS in New Zealand and meets contractual requirements

5) *Research*

- > Support the work of the New Zealand Multiple Sclerosis Research Trust, including its fundraising efforts

6) *Recognised national voice of Multiple Sclerosis in New Zealand*

- > Provide advice and input into all national issues related to MS

7) *Viable and successful organisation*

- > Ensure MSNZ has future viability and delivers on its Strategic and annual Business Plans

President's Report to the 2017 AGM



The 2016-17 financial year has been as forecasted, which is fantastic in today's not-for-profit health sector funding climate. However, balancing the budget is just one element in the life of MSNZ. It is exciting to walk into the National Office these days as it is always buzzing. We welcomed Emily Smith in late 2016, and since then, she and Amanda have had several projects on the go at one time including; the advocacy programme, new website, new database system, communications programme and working with NZ and International MS organisations.

Over the last five years, thanks to Amanda, the whole concept of the National Office has changed dramatically, most of all the enhanced relationships with Regional Societies. In our efforts to increase our rapport with Regions there has been a marked increase in circulated communications regarding MSNZ and MS developments. Advocacy is where the National Office has put in a huge amount of time and energy this year on behalf of all people with MS (PwMS) and their carers in New Zealand.

Advocacy

With 2017 being election year the advocacy team met with major political parties in Wellington, as well as the Minister of Health, PHARMAC, Lotteries, and the Ministry of Health. Our discussions were focussed around the lack of neurologists across the country, waiting times for MRI scans, delays in receiving MRI reports, the need for changes to the entry and exit Special Authority Criteria for new treatments and funding for charities. A full report on our advocacy is provided later in this Annual Report.

Regional Support

At the 2016 AGM, a report reviewing the current and future opportunities facing MS organisations in NZ was accepted. Regional Societies were consulted and support expressed for Stage Two, developing projects based on collaboration to reduce expenditure, increase capacity and capabilities and ultimately improve services for PwMS. Funding for Stage Two is still being sought.

The Field Worker Training was held in Auckland, coinciding with MS Auckland's Research Day on the Saturday, which were both well organised and attended.

Several regions have experienced issues over the year that have required support from the National Office. This always take time and energy away from our core focus of advocating for the needs of people with MS.

Finance

As you can see from our Annual Accounts we had a small surplus for the year.

Our income was ahead of budget with good results from our donor mail, sponsorships and trust applications.

However we have struggled to keep some of our costs under control, hopefully as we move through 2017-18 these will be rectified with most of our administration being in-house, our upgraded website and the donor mail software being converted to a more user-friendly, cloud-based system.

I would like to thank David Hackston and his team at Nexia NZ for their support and professional help in the changes made with our financial administration of MSNZ.

Ministry of Health Funding

Our contract with the Ministry of Health has now been extended to 31 July 2020. Over the years, the MSNZ Committee has always agreed that some regions are allocated far more per PwMS than others. In 2005 a complex model was agreed at the AGM but never implemented and the anomalies not addressed. The National Executive Committee has begun the process of reallocating funds to a more equitable model. We hope to begin to make these changes, steadily, over the next three years.

Research

The New Zealand Multiple Research Trust increased its capital base over the last year and is reviewing the feasibility of a major project which will benefit PwMS, clinicians, regulating bodies and researchers.

The need to achieve its goal of \$5 million in five years is always in front of the Trustees. As a Trustee, it is a mission of mine that the Trust work more closely with MSNZ and the Regional Societies to increase the awareness and capital for MS Research which has long-term and wide-reaching benefits for PwMS across NZ.

Committee

I would like to thank Neil Woodhams, Mark Etheridge, Jeff Silvester, Ian Chadburn, Jane Haywood and Tony Kerr for the contribution in improving the delivery of information and awareness of MS to the regions and across the country. Their work with their regional Cluster groups is key to providing a collaborative MS community and ensure that the needs of our members and their clients feed into the work of the National Office.

Malcolm Rickerby
President

National Manager's Report to the 2017 AGM

2016-7 was a productive year for MSNZ particularly in terms of defining the direction of the organisation, our advocacy work and increasing our awareness.

National Office

Notably we welcomed Emily Smith to our small team who has taken on the role of Communications and Administration Coordinator with great enthusiasm. This past year has seen a review of our communications processes and we have been developing new tools to enable us to better provide our services. The next financial year will see this work come into fruition with the launch of a new website, fundraising database and communication strategy which will enable us to improve the service we provide for our members and people impacted by MS in NZ. I wish to thank Emily for her time, dedication and passion in these projects and we look forward to reaping the benefits in streamlining our processes and improving further our communications and information provision. Emily's employment also saw us bring more of the daily financial administration of the organisation in-house, working closely with our new Christchurch based accountants Nexia.

Review Project

With changes occurring in the health and disability sectors, the ever-growing competition for charity funding and imposition of more demanding legislation, MSNZ, supported by our Regional Societies, and funded by the Working Together More Fund, contracted Helen Brownlie and Helen Eastwood of Brora Ltd to undertake a 'Review of current and future opportunities' project. The purpose of the project was to ensure MS organisations understand and maximise opportunities and review the range of options and potential pathways for change and development in terms of the structure, functionality, productivity and outputs. In July and August 2016, the Project Managers provided several consultation tools to staff and Committees and visited the four Clusters for further consultation. At the October AGM the report was presented and highlighted several concerns and opportunities and provided a pathway for 3 options; either maintaining the status

quo in terms of organisation and service, working more collaboratively within Cluster Groups and with the support of MSNZ whilst remaining independent, or undergoing a full service and organisation review. The membership approved the middle road and funding is currently being sought by MSNZ to further Stage 2 of the project

'Developing Capability and Capacity to Respond Effectively to the Future.'



...MSNZ distributed 3,318 information and educational resources to the public and our Regional Societies for distribution.



Following the review report the Committee agreed to redefine the strategic direction of the organisation to ensure clarity about the role and purpose of MSNZ. Our current Strategic Plan is on Page 4 and as office staff we have found this, alongside our Constitution, influential in directing what we as a National Office with independent member organisations, can achieve, where we can support our members, and how our organisation can address the needs of people with MS (PwMS).

Advocacy

Emily's employment has allowed me to focus more time on our advocacy programme supported by Neil Woodhams and Malcolm Rickerby. At the end of 2016 we convened in Auckland to begin developing our 2017 advocacy agenda. After reviewing the feedback from the 2016 MS Care Survey, listening to our members who raised concerns about issues on-going in their communities, and examining international best practices for the optimal care of PwMS, the advocacy team agreed

to priorities several key issues. Priorities included the drastically under-resourced neurology services across the country and widening of the Special Authority Criteria for MS treatments.

MSNZ strongly believes our advocacy work for treatments should be supported by a robust research base. As such, MSNZ commissioned two independent research review reports on three key areas; the limitations to the current funding criteria for MS treatments, the benefits of Sativex as a symptom management treatment, and the evidence to support the use of Autologous Haematopoietic Stem Cell Transplant (AHSCT) as a treatment option. These reports are available on our website.

After many months of preparation, and in the lead up to the 2017 General Election, we met with MPs, the Ministry of Health and PHARMAC to present our cases. A full report on our advocacy is found on page 8.

We encourage PwMS and our members to report issues impacting the quality of life and well being of PwMS to direct our future advocacy agenda. Our advocacy is driven by the expressed needs of those we work to support and engagement is always welcomed.

Incidence Study

This year we made our final payment for the MS Incidence Study with the receipt of the final report, see Page 11. We continue to engage with the researchers about plans to continue to a five-year review to understand participants progress post-diagnosis. The findings have helped guide and support our advocacy work regarding the need for increased funding for neurology services and the importance of early interventions. The study reported the average age of first symptom development was 37.8 years. This is older than the average age recorded in previous studies and notably those with Primary Progressive are diagnosed at a later age. The mean age at diagnosis was 42.2 years indicating that there is a significant delay, almost 4 and a half years, between the onset of first symptoms and diagnosis. Improvements must be made to ensure that symptoms are reported and diagnosis made earlier to enable the initiation of treatment to prevent further accumulation of disability and disease progression.

Regional Support

Between July 2016 and June 2017 MSNZ distributed 3,318 information and educational resources to the public and our Regional Societies. MSNZ endeavours to provide nationally consistent and evidence-based resources available free of charge.

Every 6 months our Regions report their statistics for MOH reporting. During this year the statistics clearly showed that there is a continued demand nationally for information and support by MS organisations with:

- 10,667 email requests for information
- 5241 face-to-face meetings for information
- 8733 telephone requests for information

MSNZ continues to deliver our annual Field Worker Training that is progressive and supports PwMS to self-manage their lives. We are also increasing the circulation of relevant, evidence-based and up-to-date information on MS to our Regions to support their clients.

Awareness

Our efforts to raise awareness for MS focussed on two key periods; MS Awareness Week and Red Lab Coat Day. For Awareness Week we created three short videos to help improve the understanding of the condition and enabled those living with MS to tell their story. We worked closely with MS Auckland on this project and are proud of the quality products created which continue to be used in our communications.

On 1st May 2017 we held our first Red Lab Coat Day in collaboration with the NZ MS Research Trust (NZMSRT) and MS Research Australia. The day launched Kiss Goodbye to MS for the year and is an opportunity to highlight and recognise the work that researchers in NZ are doing into understanding more about MS. The day was an opportunity to work closely with the NZMSRT and we look forward to further developing this relationship.

Fundraisers

During the year we were extremely fortunate to engage with several fundraisers looking to raise funds and awareness for MS and the work we do. Fundraisers make a huge impact helping us to raise public awareness and we are seeing a marked increase in PwMS, or those who have a loved one affected, looking to make a difference. We hope this is a consequence of our efforts to raise awareness for the condition. As with most charities in New Zealand, we struggle with funding and the ever-increasing competition for the dollar.

MSNZ requires more than 90 per cent of our income to be raised through fundraisers, sponsorship, donations, grants and bequests. We are extremely grateful to all our donors and funders for their encouragement and commitment enabling us to continue to advocate to improve the quality of life and wellbeing of those affected by MS. Thank you to everyone who has contributed to us in any way, big or small.

Ministry of Health

At the end of the financial year, following the renewal of our Ministry of Health (MOH) contract for a further three years, the National Executive Committee approved reviewing the current funding allocation to our Regions. This project will begin in the first quarter of the 2017-8 financial year through an independent contractor and aims to ensure that Regional Societies are equitably funded for the work they do, providing information about MS to those in their communities.

National Executive Committee

I would like to thank particularly thank Malcolm Rickerby and Neil Woodhams who both invest a huge amount of time and expertise into the work of MSNZ. As a small resourced organisation we need and value the support of our dedicated volunteer base. Thank you.

I would also like to thank our other National Executive members Jeff Silvester, Mark Etheridge, Jane Heywood, Ian Chadburn and Tony Kerr for their guidance and support of Emily and myself in the National Office.

Happy reading and kind regards,



Amanda Rose
National Manager

Actively Advocating

MS New Zealand's mission is to advocate for people with MS(PwMS) in NZ to have access to first world treatments, resources and services to improve their well-being and quality of life and to reduce the burden of MS on those diagnosed, their carers and families.

MSNZ strives to achieve this through 3 pathways:

- **Systemic advocacy:** National advocacy to improve the lives of people with Multiple Sclerosis in NZ.
- **Collaborative advocacy:** Working with other organisations and health professionals on common issues
- **Awareness raising:** Working to raise awareness nationally for MS as a chronic condition affecting New Zealanders and highlighting the needs of those living with the condition

Our advocacy is driven by the expressed needs and concerns of those living with MS. While we would like to advocate for all issues affecting PwMS in NZ, the small advocacy team annually chose key issues which we feel that a positive and meaningful impact can be made with the best chance of success within our resources.

After reviewing the feedback from the 2016 MS Care Survey, listening to our Regions who raised concerns about issues on-going in their communities, and examining international best practices, MSNZ's advocacy team agreed to prioritise several key issues.

MSNZ met with several MPs, the Ministry of Health and PHARMAC to address these issues, present our informed concerns and request improvements.

MS Treatments

Review of the Special Authority Criteria

The criteria imposed on disease modifying treatments (DMTs) available in NZ is much more restrictive than in other countries and not supported by current research. MSNZ contracted an independent researcher to compile an evidence-base to substantiate a review. With this evidence, MSNZ met with PHARMAC and presented our report and recommended changes to the Special Authority Criteria for DMTs for Relapsing Remitting MS (RRMS). MSNZ has since made an official submission, which is currently under review, requesting:

- The widening of access to funded DMTs for those with Clinically Isolated Syndrome (CIS) that fulfil the McDonald 2010 criteria for the diagnosis of MS.
- Amending the stopping criteria to EDSS 6.5 for all patients irrespective of EDSS score at entry.
- Amending the definition for 'significant relapse' in the Special Authority criteria for all MS treatments to 'must last at least 24 hours' in line with the McDonald 2010 criteria.

- Use of an alternative measurement scale to assess effectiveness of treatment as EDSS scoring ignores improvements to fatigue and cognitive function.
- Review of the position of MSTAC (MS Technical Advisory Committee) and the need to review every application for DMT funding.

PHARMAC provided us with statistics based on an Official Information Act request (18 April 2017) regarding the uptake of the treatments advocated for in recent years. The data clearly demonstrates the success and demand of DMTs and we hope our current advocacy work will continue to increase access for those who research shows would benefit. In the 28 months since the first treatments became available there have been:

- **901** applications for Fingolimod (Gilenya®), Natalizumab (Tysabri®), dimethyl fumarate (Tecfidera®) and teriflunomide (Aubagio®), or where treatment has not been decided
- **865** successful applications
- **889** individuals have claimed their treatment
- **25** pending applications
- **8** deferred applications
- **11** declined applications

A breakdown of data by treatment shows the following.

- Fingolimod (Gilenya®): there have been **431** applications, **417** approved **9** pending and **5** declined
- Natalizumab (Tysabri®): there have been **261** applications, **250** approved **7** pending and **4** declined
- Dimethyl fumarate (Tecfidera®): there have been **188** applications, **177** approved **9** pending and **2** declined
- Teriflunomide (Aubagio®): there have been **21** applications, all have been approved
- **16** applications were declined where no treatment was specified
- **14** applications were initially declined and then subsequently approved
- **4** applications for renewal were declined, **2** were subsequently approved

A breakdown of successful applications based on the District Health Boards is set out on the following page.

In order to protect patient privacy the numbers have been provided to us as a range when the number of patients is five or below:

DHB	Approved Applications	Supporting Regional MS Society
Auckland	82	Auckland
Bay of Plenty	29	Bay of Plenty
Canterbury	129	Canterbury
Capital & Coast	91	Wellington
Counties Manukau	48	Auckland
Hawkes Bay	23	Hawkes Bay
Hutt Valley	44	Wellington
Lakes	19	Rotorua
MidCentral	43	Central
Nelson Marlborough	28	Nelson & Marlborough
Northland	21	Northland
South Canterbury	19	South Canterbury
Southern	102	Southland & Otago
Tairāwhiti	0-5	Gisborne
Taranaki	23	Taranaki
Waikato	64	Waikato
Wairarapa	9	Wellington
Waitematā	118	Auckland
West Coast	6	West Coast
Whanganui	13	Wanganui

Ocrelizumab (Ocrevus)

We have received a significant amount of interest in Ocrelizumab since it was approved by the FDA in March 2017. Ocrelizumab is the first treatment that not only shows benefits to those with RRMS but also Primary Progressive MS (PPMS). MSNZ has reviewed the research and been in discussions with the pharmaceutical company Roche, regarding the treatment since 2016. In August 2016 Roche applied to Medsafe for the registration of Ocrelizumab. This is still under review and we hope to receive further information later in 2017.

In May 2017 Roche applied to PHARMAC for funding for Ocrelizumab for RRMS under the pre-existing MS treatments Special Authority Criteria. MSNZ wrote in support of this application. Applications for the inclusion of Ocrelizumab for PPMS are being made in August/September 2017. Should this be successful, we hope it will begin to address the currently unmet medical need of those with PPMS who have no alternative option for treatment currently available.

While Ocrelizumab is not currently registered with Medsafe, PHARMAC processes do not allow for a treatment to be considered for funding. This highlights the issue of delayed access to treatments in NZ due to the lengthy Medsafe and PHARMAC approval processes.

Sativex

Sativex is the only cannabis-based product that has made a therapeutic claim and is only approved by Medsafe for “use as an add-on treatment for symptom improvement in patients with moderate to severe spasticity due to Multiple Sclerosis who have not responded adequately to other anti-spasticity medication and who demonstrate clinically significant improvement in spasticity related symptoms during an initial trial of therapy”. In 2015 PHARMACs Pharmaceutical Technical Advisory Committee (PTAC) reviewed the evidence to potentially fund Sativex but concluded that the evidence was not conclusive enough.

MSNZ funded an independent research review this year to bring together the supporting evidence for the use of Sativex for people with both MS related pain and spasticity. We have presented this evidence to PHARMAC and requested a review of the current non-funded status of Sativex for PwMS. MSNZ has requested funding where evidence shows the treatment would be clinically appropriate to a PwMS and on the recommendation of a GP.

Autologous Haematopoietic Stem Cell Transplant (AHSCT)

With growing interest in AHSCT and the increasing numbers of PwMS in NZ going abroad for treatment, MSNZ funded an independent researcher to review the current evidence base. Our report demonstrates that there is increasing evidence to support the safety and efficacy of AHSCT. Evidence demonstrates that AHSCT primarily benefits those with active relapsing MS, who have tried, but are not successfully responding to, currently funded DMTs. As a result, MSNZ can no longer maintain our previous position on AHSCT that it is an experimental treatment. MSNZ has presented our report to the MOH and offered to work together to develop a process for approved access in NZ, for those for who the research shows would benefit from the treatment, under an observational study protocol.

Improved access to MS care and services

There are several key barriers impacting access to MS care and services. Early intervention is vital to ensure better outcomes for people with MS, improved quality of life and brain health. Our work in this area has been influenced by the excellent work of an international multidisciplinary group of experts: “Brain Health: Time matters in multiple sclerosis”. This internationally endorsed report provides research-based recommendations on diagnosis, therapeutic strategies and the need to improve access to MS treatment with the aim of maximising lifelong brain health by reducing disease activity. MSNZ has used this to help guide our areas of advocacy to achieve the best possible outcomes for PwMS and those who support them.

Early intervention

In NZ the average age of symptom onset is 37.8 years while the mean age of diagnosis is 42.2 years. This indicates a significant delay between the onset of first symptoms and diagnosis. Early intervention is crucial for limiting and managing the irreversible, progressive deterioration that people with MS experience. Increased funding for neurology services, improved education among the public and GPs about the symptoms of MS and earlier access to treatments will all be vital in addressing this issue.

Under resourced neurology services

The NZ health system is seriously short of neurologists and the position will worsen without further investment. Based on international standards NZ should have 74 FTE neurologists for our population size. However, currently there are 50% of this recommended number in the public health system, impacting access to services.

MSNZ is advocating for increased funding for DHBs to address critical staffing deficits in neurology services for specialists, such as neurologists and MS nurses. Appropriate staffing will alleviate increasing pressure on the system and ensure timely and equitable access to diagnosis and treatment. MSNZ presented the issue for the second time to MPs in Wellington and followed this with a media campaign which was successfully picked up. We will be continuing to make demands for a review of this issue following the 2017 General Election.

Access to specialists within a reasonable timeframe

Currently PwMS experience substantial waiting times for first and follow up appointments in many DHBs. Delays risk people being unable to qualify for DMTs by the time they apply. MSNZ highly concerned about this nationwide problem in delays and inequitable access to specialist services. MSNZ is advocating for timely and equitable access to MRI scans, reduced waiting times and annual reviews so that people with MS can access an MRI scan every year regardless of whether on treatment. Regular monitoring allows for future planning based on an individual's recorded progression. Should the NZMSRT's work on establishing an MS registry be successful this will be an invaluable tool for patients, practitioners, researchers and regulating bodies in improving the management of the condition in those diagnosed.

MS guidelines and pathway

MSNZ is advocating for the development of nationally consistent guidelines to provide a pathway and expected level of care and service for PwMS. Such guidelines exist in the UK providing a consistent pathway and ensure PwMS receive the same service, information and support, irrelevant of locality. Guidelines encourage patient centred care and their inclusion in decisions. MSNZ has met with the Minister of Health and the MOH to advocate for this need and will continue to do so.

Integrated multidisciplinary care

DHB services need to be better integrated internally and work more cohesively with services available in the community, including MS Regional Society Field Worker Services, to support people with chronic conditions. MSNZ has been advocating for the need to address the lack of coordinated services within DHBs and between DHBs and primary and community services to best support those with long-term chronic conditions.

Residential care in age appropriate facilities

There is a lack of respite and long term residential care facilities for young people with chronic conditions. This is a long-standing issue which is not widely addressed. MSNZ has questioned the political parties on this matter and whether they intend to address the issue.

Funding for charities

With over 27,000 charities and a reduction in funders, we are steadily seeing the pool of funds from traditional sources shrinking. Funding for NGOs that fulfil functions that are not supported by central government is increasingly difficult to come by. Organisations such as ours heavily rely on the private sector to fund and support our work. While our MOH contract has been renewed for a further three years, work is being undertaken by the Ministry to redevelop the disability sector with changes that will likely impact our current contract in the long term. MSNZ is continuing to advocate for the need for continued, and increased, government support for the role our MS organisations provide in the community, a role which centrally funded DHBs cannot provide internally. We are also staying abreast of the Disability Transformation Strategy to understand how this will impact our organisations and ways the service may need to adapt.

Mid 2016, we undertook an extensive review of current and future opportunities for MS. The final report delivered to the AGM in October 2016 offered three potential scenarios for the future. The Regions approved a lean thinking, collaborative approach.

Phase Two aims to build capacity of MS organisations through a lean thinking approach designed to reduce operational expenses by collaborating and utilising the skills and resources within the 4 MS Cluster Groups. By reducing operating expenses and streamlining processes overarching aim is to ensure clients receive better outcomes due to funding being better directed and with a consistent and equitable level of care and services provided nationwide. MSNZ aims to achieve this by working with Regional Societies to design and implement a service delivery model focussed on outcomes for individual PwMS. There is a consensus that changes are required to ensure clients receive the best service possible, while maintaining regional identity and independence.

Regions have expressed their support and MSNZ is currently seeking funding for Phase Two.

MS Incidence Study

The study began recruitment in 2012 with the aim of identifying all persons throughout NZ who were either diagnosed with multiple sclerosis or, who experienced an episode of neurological symptoms caused by demyelination, between 1st June 2012 and 31st May 2014. During the study period, 464 participants were identified and recruited, 277 of whom had received a diagnosis of MS and 187 who had experienced a single episode of demyelination known as a clinical isolated syndrome (CIS). In addition, 317 notifications were received of persons who did not meet the study criteria either because their symptoms occurred outside of the study period or because an alternate diagnosis was made during follow-up. The following information was gathered from participants:

- the nature and onset date of their first demyelinating symptoms
- the nature of and number of attacks or relapses participants experienced
- in those diagnosed with MS we recorded the date at which they received the diagnosis, the type of MS (relapsing-remitting or progressive) and the level of impairment the participant experienced
- participants were also invited to complete a comprehensive questionnaire

The primary aim of the study was to determine the incidence (number of new cases per year) of MS in NZ. The age-standardised incidence (ASI) was 3.3 (95% CI 2.9-3.7) per 100,000 population for the entire country. For males the incidence was 1.6 (95% CI 1.2- 2.0)/100,000 and for females 4.8 (95% CI 4.2- 5.5)/100,000 with a male to female ratio of 1:3. The results confirm that NZ continues to be a high risk country with around 134 people diagnosed annually.

A total of 238 (86%) patients responded to the survey questionnaire. A full analysis of the questionnaires has yet to be completed but analysis of the ethnicity data identified 15 persons who self-identified as Maori. The ASI for Maori was lower than the overall population at 1.3 (95% CI 0.7-2.1) per 100,000 population. Of the non-Maori population, 198 self-identified as NZ European, 25 reported other ethnicities of whom two were of Pacific Island ethnicity. 19% percent of the cohort were overseas born migrants with a mean age at migration of 24 ± 14 years.

In those diagnosed with MS the disease onset was of the relapsing-remitting type in the majority (88%) whilst in the remaining 12% disease onset was of the progressive type. The average age at which people developed their first symptoms was 37.8 ± 11.8 years. This is older than the average age recorded in previous studies. The mean age at diagnosis was 42.2 years indicating that there is a significant delay between the onset of first symptoms and diagnosis.

The mean EDSS at diagnosis was 2.3 ± 1.6 .

35% of the 277 participants were originally recruited as CIS but later diagnosed as MS in the study period.

A further objective of the study was to calculate the number of new cases (incidence) of MS by region in order to investigate the relationship between the incidence of the disease and latitude. Residential data obtained at the time of diagnosis showed a 3.8-fold increase in ASI between the northern (36.70S) and southern (45.80S) region of the country. As shown in Figure 1, MS incidence for the total population increased by 0.68 ± 0.12 per 100,000 population per degree of latitude ($p < 0.01$).

This rate is higher than found in the 2006 Prevalence Study. This is likely to be because incidence studies are generally a more accurate way of assessing risk factors such as the influence of latitude. This study however confirms that the presence of a latitudinal gradient is a robust finding. These findings will help form the basis of future work to better understand why incidence differs between the Northern and Southern regions of NZ and to identify specific risk factors for MS both genetic and environmental.

In addition to the incidence data, information was gathered via 6 monthly calls. Where available, information from clinic visits is collected as we continue to be interested in determining how many people subsequently go on to develop MS after a first demyelinating episode. For those diagnosed with RRMS we wish to determine the numbers who start treatment and assess the benefits gained from the new medications over time. To date we have completed the 6 and 12 month follow-up of the majority of participants and two year follow-up in 90%. Once all patients have completed 5 years of follow-up we will be able to provide more information about MS and its course in New Zealand as well as the benefits and uptake of the new medications for PwMS.

There was a great response to the study and questionnaires with over 80% of participants returning their completed forms. Once analysed this will provide more valuable information about how MS affects a person's socioeconomic status including employment and income, as well as information about how a diagnosis of MS affects each person's quality of life.

Thanks to MSNZ and the NZBRI for their generous support for Dr Alla, without which none of these projects would be possible. The support by participants of this study has also been incredible and the information we have collected is beginning to draw international attention. We believe this will lead to increasing collaborations that will continue to extend the research work of the MS research group.

Report by the MS Study Group's Dr Deborah Mason on behalf of: Dr Sridhar Alla, Dr John Pearson, Professor Ann Richardson and Professor David Miller.

New Zealand Multiple Sclerosis Research Trust

The New Zealand Multiple Sclerosis Research Trust (NZMSRT) for the year ended March 31, 2017, was preparing the terms of reference and initiating a feasibility study into the establishment of a national registry for all persons with multiple sclerosis (PwMS) in New Zealand.

The NZMSRT, in discussion with other interested parties including Multiple Sclerosis New Zealand, MS specialist neurologists, MS researchers, and the Neurological Foundation, identified establishing a national registry as a priority foundation project for the Trust. As a result, the NZMSRT agreed to fund and undertake a feasibility study to examine the introduction of a national MS patient registry in all New Zealand Neurological units that hold records of PwMS.

Having a national registry will have multiple benefits including being able to accurately monitor the progress of PwMS and the effectiveness of different treatments as well as providing an invaluable database that could be utilised and leveraged by researchers here and overseas.

Several grants were received to help fund the feasibility study which was completed post balance date. The NZMSRT is now evaluating the feasibility study with the aim of finalising the next steps in the project.

As at the end of March 31, 2017, the NZMSRT had total accumulated funds of \$1,217,244.



Red Lab Coat Day 2017

On Wednesday 1 May 2017, MSNZ and the NZMSRT collaborated to celebrate Red Lab Coat Day. This day recognised the work of MS researchers in New Zealand and marked the launch of our 2017 Kiss Goodbye to MS campaign year.

NZ MS researchers swapped their regular white lab coats for red lab coats, kindly donated by MS Research Australia, to highlight some of the outstanding work taking place in NZ. Red Lab Coat Day involved more than 14 NZ researchers.

Red Coat Lab Day is a social media event that aims to raise awareness of the significance of ongoing research into MS and is part of the wider @kissgoodbyetoms and @kissgoodbyetomsglobal campaign.

NZMSRT Chairman Tim Preston said “Red Lab Coat Day is an important initiative to raise awareness and puts a face to some of the many MS researchers we have working to better understand MS.

“It is an opportunity for our fundraisers, donors and supporters to say thank you to the wonderful MS researchers in New Zealand, who have dedicated their careers to accelerating research into MS. Thanks to them, finding a cure for MS is a matter of ‘when’ not ‘if’.

“With the help of our MS researchers and supportive community, together we will Kiss Goodbye to MS once and for all!”

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Multiple Sclerosis

**life-long &
life-changing**

No known cause. No known cure.
People with MS can lead fulfilling lives.
Your support helps.

VISIT MSNZ.ORG.NZ TO LEARN MORE ABOUT MS

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MS Awareness Week 2016

The 2016 Multiple Sclerosis Awareness Week took place across the country between 29 August and 4 September. With funding from Pub Charity Limited, three videos, plus a 30 second silent short of video 1, were created using Attitude TV as the producers. MSNZ, MS Auckland and Attitude TV all worked together to develop the themes and intentions of the videos. They were all designed to be true, honest, from the words of people with MS and while they discuss the fact that MS is life-long and life-changing, these people do not let MS define or stop them living their lives, and supports help to achieve that.

Video One showed four people with MS from different demographics talking about what life with MS is like for them, how they first experienced MS, how they live their lives with it and the importance of support.

Video Two provided key facts about what MS is from those who live with the condition in New Zealand. It followed the same four people with MS but was more factual and direct to the viewer. This video addressed the fact that there are so many myths and unknowns about MS. Many have heard of the name multiple sclerosis, or MS, but do not know what it means, what are some of the symptoms and how it impacts the lives of those diagnosed.

Video Three followed Julie, a young Tongan woman with MS living in Auckland. Her experiences with her first symptoms, how she manages her life and condition and how the support that her family and MS Field Worker provide help. Julie also discussed how MS does not define her nor will it stop her achieving her dreams.

The three videos reached over 70,000 people on Facebook and were viewed over 17,000 times on Facebook, Youtube and on websites.

MSNZ was also able to support our 18 Regional Societies in raising much-needed funds with Street Appeal resources. Around \$164,377 was collected in the 2016 Street Appeals, a 17.4% increase from 2015.

Thank you to everyone who donated their time and money to support our Regions with their MS Street Appeals. With our organisations having to raise the majority of funds direct from the community, each and every person's support is greatly valued.

Mastering Mountains Grant

In 2015 MSNZ was approached by MSeer Nick Allen to establish the Mastering Mountains Grant, by financially assisting people who have been diagnosed as having multiple sclerosis to overcome a specific obstacle so that they can achieve a specific outdoor pursuit.

With this grant, Mastering Mountains and MSNZ hope to help people with MS pursue adventures that encourage a healthy lifestyle and change the perceptions of MS. Getting outdoors has therapeutic qualities and MS can hinder people from the fullest experience of this. The Grant hopes to overcome this obstacle.

MSNZ has had the pleasure of working with Nick for the last two years and we look forward to further developing this relationship and growing the Grant in the future. The Mastering Mountains Trust are the primary funders of the Grant and MSNZ supports with the administration and promotion. For more information about the Trust visit www.masteringmountains.org

Sue

The inaugural Grant was awarded in November 2016 to fund a personal trainer to help Sue achieve her dream of tramping over the Maungatautari Mountain. The 11km track has a 500m ascent which Sue estimated would take five hours to complete. "It's a big mission! My MS and my current lack of fitness are the only reasons I have not yet done this," said Sue when applying.

Sue works as the Administration Manager at the Maungatautari Ecological Island Trust in Pukeatua. "I love the role and I often get called into the Visitor Center, where I talk with visitors and tell them about the sanctuary and its tracks. The only problem is that I had to rely on second-hand information."

The Panel were encouraged by Sue's determination and reasons for wanting to complete this challenge; "I am looking forward to that feeling of achieving something that is out of reach with the support and encouragement of others. To me, it's also really important to make memories with my young daughter. She is very active and I want to be able to participate in outdoor activities with her. Walking over Mt Maungatautari will help me achieve this and I believe that it will set me up for future adventures."

Sue initially struggled with the additional exercise, thinking she never be fit enough. However, she soon overcame her initial fears and was off to a flying start managing to treble the amount of daily walking, building in daily bush walks at work and going to the gym once a week. "Every morning before I start work, my boss lets me go for a power walk for 35 minutes on the mountain tracks, I also climb the 16m tower three times a week, if not 4, which is 91 steps." Despite an injury mid-way she was soon back on track with a renewed determination planning base to mountain peak training walks.

"Thanks to the personal training and regular exercise I am much fitter, my balance has improved and I have

so much more confidence in myself, to not only get out more, and by myself, but also confidence that I can achieve this goal I have set myself." Sue set herself a second challenge to lose 10kgs. "I started training and following the Overcoming MS diet in early January. Boy, does it feel good having shed those extra pounds and I feel much healthier."

Before the walk, Sue admitted, "I am a little scared but very excited – scared as I know it will be no mean feat with my MS, but excited that I have every chance of achieving my goal due to all the support I have been given to get me there!"

Sue's challenge took place on the 24th September 2017. "It was amazing, I was nervous as anything, however excited that the day had finally come." Sue was supported by a team of 21 including staff from MS Waikato, other PwMS, her personal trainer, colleagues, Maungatautari Trust volunteers, friends and even a surprise visit from her Neurologist.

"I must admit the first two hours were hard going, steep uphill rises, however with such a big support group, encouragement and laughter we made it to the top of Maungatautari." Following a lunch stop in the saddle, enjoying the rare birdlife and views, they reached the Visitors Centre where staff and Trustees had tea, a dairy free birthday cake and flowers waiting.

"I walked down the final slope towards the Visitors Centre to clapping and cheering. I was elated and overwhelmed with my achievement, thankful for the support I had from so many people and to be surrounded by such positivity. I inspired a few PwMS to do the walk with me and they achieved their goal too, an awesome effort! I feel honoured to have inspired others to push past MS and kick MS in the butt and say I can do this even with MS. MS may slow me down but it will not stop me! We all achieved something. I was smiling all the way and I am still smiling. I achieved. I met my goal. I lived my dream."

"A huge thanks to the support I received from the Mastering Mountains Grant, sponsors, my trainer, friends and family. It would not have been possible without such amazing support."



Dorothy L Newman Scholarships

The Dorothy L Newman Scholarship supports people with MS who, as a result of their condition, are unable to continue in their present employment. Recipients are provided with financial support, to undergo a course of retraining in order to gain new employment.

In November 2016, MSNZ awarded Scholarships to three worthy recipients. One recipient unfortunately did not begin her course; however, two successful applicants, and a third continuing from a previous year, rose to the challenge with great success.

The Selection Panel were particularly inspired by those who showed a strong commitment to their future employment, and understood the practicalities of managing a career and their chronic health condition.

Thank you to Sue Clothier and the Dorothy L Newman Trust for financially supporting half of the Scholarships.

Genevieve

"I applied for a Scholarship because my job as a nurse was becoming increasingly physically demanding and stressful. My passion for elder care was not diminished so I sought another area of healthcare that would still allow me to work in the industry I am passionate about.

Healthcare auditing was something that had always interested me so I began to research the possibility of retraining as an auditor. That same day I received an MS magazine in the mail that featured an article about the Dorothy L Newman Scholarship. I filled in the application with increasing excitement and was thrilled to be accepted for both the course and Scholarship.

In February I underwent an intense week of training in Healthcare Auditing, with homework every night and a presentation to give to the group. On the last day we sat an exam requiring 100% to pass. Fortunately we were allowed to repeat any questions we missed the first time.

Finally I had my certificate of achievement and began applying for jobs with auditing agencies. I was accepted by an agency, have completed my observation audits, and am waiting to complete two training audits where I will be given increasing responsibilities. Then I will undergo an appraisal to ensure I am competent before signing a contract with the agency and being nominated for registration with the Ministry of Health.

I am so grateful to have been a recipient of the Dorothy Newman Scholarship and to have had this opportunity to retrain into a job that is more manageable and allows me to continue to fulfil my passion."

Julian

"For most of my career I was a musician and sound engineer however, after 20 years with MS, I was experiencing decreasing dexterity and numbness in my hands, hindering my abilities to work. My symptoms mean that I now find it increasingly difficult to play instruments, control mixing desks and audio equipment. The late hours, a common condition in the industry, were also taking their toll in terms of fatigue.

When I applied I was completing my second year of Music and History at Canterbury University and achieving excellent marks but needed financial help to complete my third year. As you can imagine studying coupled with a chronic condition has had an impact. I have found my memory and cognition has been an issue with the progression of my MS. Allowing time for rest to recuperate is important for memory retention and combating fatigue.

I am interested in venturing into research of audio engineering and electro acoustic composition or a career in teaching music or history if I continue to get good grades. I am applying for a research position over summer with the Human Interface Technology Lab in Canterbury looking at the effects of realistic soundscapes upon virtual reality users. This research ties in well with my interests in composition and audio engineering and should hopefully lead to employment that is less taxing upon my health.

I would like to thank Multiple Sclerosis New Zealand for awarding me a Dorothy L Newman Scholarship and for the opportunities this has provided me."

Anthony

"In 2014 I was awarded a Scholarship to complete the New Zealand Institute of Management Certificate aiming to improve my chances of getting a job and eventually give me the tools to start up my own business. I had experience as a manager in the entertainment business but no formal qualification. This coupled with the difficulties I experience with walking and balance, symptoms of my MS, meant I needed to upskill. This course would help open up more employment opportunities for me as an office-based employee.

My studies went extremely well, receiving A's and A+'s in all my modules. As an online study programme I was able to work from home and not have to travel into town.

Being proactive and getting back to studying and working to achieve a goal has had an INCREDIBLE effect on me and my job prospects! I have recently been given a position with The Royal New Zealand Ballet based in Wellington. Because of doing this study course, I now have marketing and HR knowledge and I was able to discuss these topics with confidence at my interview and landed the role! I couldn't be happier.

I have only encountered one problem during the time, being that is that the study took longer than I originally anticipated, but this was due to other obligations rather than my MS. I am inspired to study further after I get more qualifications to progress in my career.

I recommend anyone with MS looking to change their career to better suit their lifestyle to apply for the Scholarship which has been life-changing for me. I hope I am proof that people with MS are valued members of society, that we can contribute and have the same goals as everyone else."

Esme Tombleson Person with MS of the Year 2016

Christine O'Sullivan was diagnosed with Secondary Progressive MS in 2005 and always had a positive view about her diagnosis choosing to focus on helping others. Christine has lobbied and worked in the community, for PwMS, and disabilities, for many years. Leading by example she is an inspiring role model in the community. Christine sat on the MS Wellington Committee in 2011, and on the Wellington City Council Accessibility Advisory group since February 2014.

In the early days, Christine decided to accept that she couldn't control MS, but could take charge of the ongoing changes and focus on what she could do.

Resulting from her proactive work, Christine was invited to speak at the GPCME Conferences in Rotorua and Christchurch in 2015. Christine presented on 'Taking Charge of Change – my adventures with MS' and was part of a panel speaking on 'Living with Disability'. The other panel members all had congenital disabilities which gave Christine a different perspective to present as being comparatively 'new' to being disabled.

Christine's most recent initiative has been developing "Sing for MS", held on World MS Day in May in Wellington for three years running. This wonderful event brings people together and provides a fun, supportive and encouraging environment. The events have been thoroughly enjoyed by all. There is a lot of work that goes into organising the event; from securing the singers/facilitators through to liaising with the Council to promote the event and secure parking permits.

The MS Wellington Committee and Field Workers wholeheartedly supported Christine's nomination for the Esme Tombleson Award and thank her for all her contributions to the MS Community.



Alinker #keepmoving

In May 2017 MSNZ was advised we are to be the recipients of generous donation of a new and innovative mobility device called "The Alinker". The donation is thanks to the Li Ka Shing Foundation. 40 Alinkers will be available in NZ, 10 allocated to selected rehabilitation centres and 30 to MSNZ to allocate to our Regions. Later in 2017 MSNZ we will be developing the #keepmoving programme to be implemented across the country. The programme aims to provide people with the opportunity to try an Alinker to see how it can benefit their lives in terms of social engagement, mobility and overall health.

Since her award Christine O'Sullivan has become the NZ Alinker Ambassador and helped spread the word about staying positive, active and engaged in the community with a disability, like MS.

About the Alinker

The Alinker is a non-motorized walking-bike without pedals designed in the Netherlands. It is for everyone who wants to maintain an active life regardless of their movement abilities/disabilities. It is designed to be so cool that it overcomes the uneasiness towards disabilities that is felt by mainstream society. When you are using the Alinker you are the person with that cool bike rather than someone who is overlooked or ignored. The Alinker is challenging assumptions about people with disabilities and is striving to build a more inclusive community.

We look forward to receiving this donation, seeing how it can improve the lives of PwMS and reporting on the outcomes next year.

Esme Tombleson Carer of the Year 2016

Originally from Wellington, Peter Wood is the husband and caregiver of Maureen Wood, a member of MS Auckland. Maureen was diagnosed with MS in 1995 and joined the Bay of Plenty MS Society at that time. She was Treasurer for a number of years and Peter assisted her in this role.

Their combination of Accountant and Pharmacist worked very well when Maureen purchased her first pharmacy in Titahi Bay, Wellington in 1973. When MS struck in 1995 she was forced to sell her pharmacy “Chemist Maureen Ltd” in Papamoa, Bay of Plenty. Going from ‘full on’ to ‘full stop’ overnight was devastating.

A trip to Medjugorje in Croatia meant purchasing a manual wheelchair in 2004. In Croatia the roads were full of potholes – it was just not long after the war ended – and this day it was raining so Peter was pushing faster. There was a large puddle in the road but no sign of the pothole in the middle of it - oh Dear! The wheelchair came to an abrupt stop and Maureen fell headfirst into the puddle, handbag and all. She was unhurt but the bystanders were gasping. Maureen couldn’t stand being pushed so swapped the wheelchair in London for a small scooter and has driven scooters ever since.

Maureen has always had a positive outlook on managing her MS and Peter has always been encouraging and supportive of this. Maureen often acts as a mentor for others with multiple sclerosis.

Peter is frequently a volunteer at fundraising events and has been a tireless supporter of MS Auckland for the past 5 years as Treasurer, Trustee of the MS Auckland Regional Trust and more recently as a Trustee on the NZ MS Research Trust.

One of the first things he did as Treasurer of MS Auckland was to challenge the auditor’s interpretation of the tax laws around fringe benefit tax, which the Society had paid for a number of years, and which resulted in the Inland Revenue Department paying back \$26,000 to the Society.

While quietly encouraging Maureen to be as independent as possible, Peter has always been there to assist Maureen, when required, with activities of daily living. Alterations have been made in the bathroom and they have had a lift installed so that Maureen can access the house from the basement garage.

Peter does most of the cooking, shopping, laundry and has transported Maureen to various therapy sessions and other social activities over the years. They have a cleaner to assist them in the home.

Fortunately, Maureen has remained on a stable plateau for at least 8 years, probably due to the fact that she

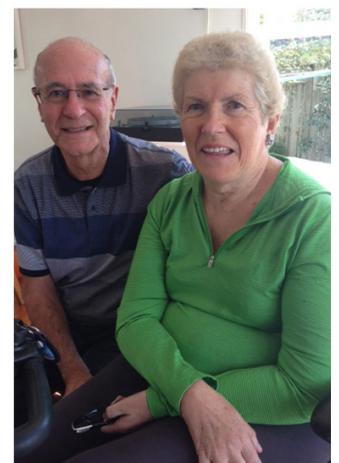
is a great believer in exercise. Peter takes Maureen to two Conductive Education sessions a week and three intensive neurophysiotherapy sessions a week. They both attend a Support Group regularly and are frequent attendees at MS Auckland functions, fundraising events and seminars.

Maureen says that Peter is always willing to help others and that his care and support and “a shared sense of humour is important and she couldn’t live without him”.

Peter is always willing to look at new treatments and innovations to support Maureen in her quest for better health and management of her MS. They travelled to India in 2016 for Maureen to undergo HSCT which has been most successful.

His care, devotion and support for Maureen over the years has been without any fuss and at times putting his own interests aside.

MS Auckland was delighted to put forward Peter Wood’s nomination as Carer of the Year and present the award in November 2016.



Fantastic Fundraisers

“Thanks to all these fundraisers MSNZ has been able to continue to advocate for better access to treatments, resources and services to improve the well-being and quality of life of New Zealander’s affected by MS. As a non-profit organisation that has to fundraise 90% of our annual income, we are extremely grateful for this support.”

- Malcolm Rickerby, MSNZ President

Aileen

“My name is Aileen Robinson and I’m 72 years old. I knew very little about multiple sclerosis until my sister Edna and niece Claire, who both live in England, were diagnosed. It is very difficult living so far away from family and not being able to help.

I’ve always done a lot of walking and when I retired I got into race walking and competitions. I’ve entered Wellington Around the Bays Half Marathon many times, the major spot prize was a trip to the London Marathon, which unfortunately I never won. But the idea was hatched that I’d like to do the London Marathon and to make it worthwhile I would also raise awareness and funds for Multiple Sclerosis NZ, my way of helping Edna and Claire.

The trouble was I wasn’t sure if the old body was up to it, so I did the Wellington Around the Bays Marathons in 2015 and 2016 to see how I’d go. Then in 2017 I would do the London Marathon. I trained 5 out of 7 days. My basic walk was 12 km, then slowly I built up my distances until I could cover the 42.2 km. I knew that I had to this training or I wouldn’t make it on the day.

Well I’m happy to say I walked the London Marathon on the 23rd April in 5 hours 29 minutes and the icing on the cake was that I more than doubled my fundraising target for MSNZ and made Edna and Claire very proud.”

Clare

“Over the past two and a half years, since one of my nearest and dearest was diagnosed with MS, I’d been racking my mind thinking of ways I can help. Emotional and physical support come with the day-to-day life of being great friends but I always felt like I could do more.

A half marathon is something from my own personal bucket list but also a way I knew I could help by fundraising. Because I am far from a ‘runner’ this physically draining and tough mental challenge was my own way of trying to understand the discomfort PwMS live with. There were days I felt my legs would fall off!

As I walk through life with my best friend I am thankful for what MS has taught me. To be kinder, show patience, be more caring, open-minded, generous, to be thankful and most of all how important time is.

Take a leap, don’t be scared of the outcome because everything will teach you a lesson for the better.

I never imagined I would reach my fundraising target of \$5k, it was almost just a cheeky wish to start with but this truly proved to me the power of generosity, love and selflessness. There are so many people who I don’t know and may never know who helped me reach this.

On Sunday 30th October 2016 I achieved my goal of running a half marathon - 21.2km in 2 hours and 44 minutes. I was absolutely terrified as I started the run and the week leading up to the event I was incredibly nervous, had a lot of self doubt and honestly wasn’t sure if I’d be able to do it. But then I reminded myself of the strength and determination I see in my best friend ... if she can be positive then why can’t I?

The event was amazing with stunning views and so rewarding. I hope next year I will return to raise more for MSNZ and better my time to under 2 hours 30 minutes.

To everyone who supported me or supports someone with MS, thank you!”

Julie

In October 2016 Julie Collier and her team of 21 supportive women took part in the New Plymouth Joggers and Walkers Club Half Marathon to raise funds and awareness for MS.

For Julie, who was diagnosed with MS in 2013, the challenge involved training for many months to walk the course and finishing the event was a goal in itself. “It’s very exciting. I just hope I can complete the course.” Never one to shy away from a challenge Julie who had already smashed her fundraising target was determined. “I did it six years ago in just under three hours, this year I would like to beat that time,” she said.

“I am one of the lucky ones, as my symptoms are relatively mild compared to some people. However, I am aware my circumstances could change at any time. I decided that I wanted to raise more awareness about MS as my experience showed that my knowledge, along with my family, and friends was very limited.”

Brett

Wellingtonian Brett chose to 'Cut or Keep' for MS. Brett was inspired to Kiss Goodbye to MS by his wife Catherine who was diagnosed with RRMS in 2014 and the work of MSNZ. On the 3rd December 2016 Brett let his friends, families and colleagues vote whether to 'cut or keep' his beloved 18 meters of dreadlocks with a donation. With a total of 89 votes - 22 to keep 'em and 67 to cut 'em, Brett was in for a mop chop! More than doubled his fundraising target and 800grams of hair lighter Brett was a new man, with a very happy wife.

exceed

Auckland-based IT distribution company *exeed* entered 30 staff in the Auckland Half Marathon on 30 October 2016. Exeed staff wanted to help in some way after the wife of a long-standing colleague, Account Manager Simon Bell-Booth, was diagnosed with MS in 2016.

"My wife and I are truly humbled by the support shown by exeed and its staff," says Simon. "It is testament to the great people who work within this organisation."

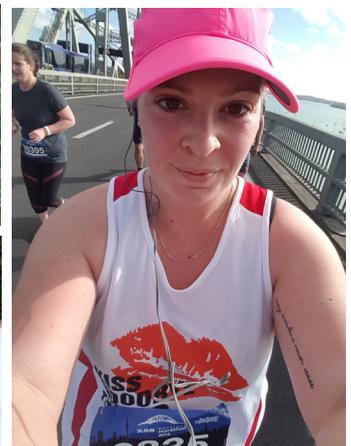
Exeed's Managing Director Justin Tye says that the firm normally has five or six staff who enter the marathon each year, said he was amazed by the number of people inside the business that have signed up. "I'm really thrilled with the way the team have rallied around. The support for Simon and his wife is testimony to how much the team both appreciates the work that he does and wants to help the couple." Justin himself entered and was really happy that members of his team are achieving increased fitness as a by-product of their fundraising dedication.

Felicity

In September 2015 Felicity began her year-long challenge to run 12 races in 12 countries in 12 months, "a Sufferfest of epic proportions" as she put it. Felicity was inspired to fundraise for MSNZ from seeing the gradual decline of "one of the most loving, welcoming and inspirational" women she says she was fortunate to meet, her oldest and dearest friend's mother, who had been diagnosed with MS for over 10 years. "Seeing first-hand the effects MS has had on her family and what she's having to battle with every single day has really hit home. What is more than that is that I know she has a loving, supportive family and the means to get the help she needs. But the fact is that there are people out there with MS that don't have the support and the means they need."

In August 2016 Felicity ran her final race on home turf in NZ at the The Great Naseby Water Race, 50 miles (80km). The average race distance over the 12 events was 48km with 1750m of vertical ascent.

"It is a sobering thought that while I get the choice to push myself to the edge of exhaustion and beyond. People living with MS have to deal with that sort of fatigue each day and still have the courage to carry on."



Field Worker Training 2017

On 31st March MSNZ held our annual Field Worker Training. This year we collaborated with MS Auckland to coincide the training with their Research Day. The collaboration enabled the Field Workers to participate in both opportunities while allowing our organisations to reduce expenditure and share speakers. We are endeavouring to continue this in 2018 due to the success of this year. The Research Day had an excellent turn out with 214 PwMS, their families, carers and our MS Field Workers.

The interest in developments into the condition is evidence that there is a continued demand and need for this element of the service provided by MS organisations, to provide information about the condition. Inspired by the huge turn out we are looking at further opportunities to provide education sessions for both Field Workers and people with MS in the upcoming year.

As with previous years we ensured to provide a programme that was diverse in topic choice whilst also covering issues that are pertinent to the expressed needs of the Field Workers through their engagements with their clients.

Topics covered over the two days included:

The importance of good record keeping, Ria Sapsford, MS Central Districts Field Worker

Advanced Care Planning, Ian d'Young, Auckland DHB, Service Improvement Manager

When helping others hurts, Tricia Hendry

MS Treatments, Various presentations on the available disease modifying treatments, benefits and side effects

How to take the power back, Gilly Davy, Connect Neuro Physiotherapy, Neurophysiotherapist

Using food choices to stabilize and reverse neurodegenerative disease processes - Dr Terry Wahls M.D., creator of The Wahls Protocol

Update on new drug treatments - Dr Ernie Willoughby, Neurologist, Auckland DHB

Thank you to all our speakers and to Sanofi, Roche, Novartis, Biogen and Seqirus for their continued funding towards the educational development of our Field Workers and supporting the Auckland Research Day.



“ I gain so much knowledge and affirmation from being with the other Field Workers. The content of this training was relevant and each session focussed on most important aspects of working with PwMS.



Field Worker Representative's Report to the 2017 AGM



With the introduction of the newer treatments DHB staff have often utilised the additional support of MS Field Workers which is resulting in a more wrap around approach to provide a better outcome for PwMS.



As the new Field Worker Representative, elected in April at the annual Field Worker Training, I have collated the feedback from the Regions to report on the common trends impacting people with MS (PwMS) across the country as seen by the Field Worker network.

Firstly, all Field Workers are reporting a rise in numbers on their databases, with a notable increase in the number of younger PwMS requesting information and support. Field Worker hours in comparison are not noted to have increased.

There appears to be a trend of DHBs being under staffed with both neurologists and allied specialist staff. In more provincial areas people are often left without a resident neurologist and must see a different person every time. This does not provide consistency of care and people with limited resources are often left struggling to travel to their appointments when they do eventually get one.

The regions that do have resident neurologists report a developing relationship with the neurology teams and a more collaborative approach resulting in improved support for PwMS in their communities. With the introduction of the newer treatments DHB staff have often utilised the additional support of MS Field Workers which is resulting in a more wrap around approach to provide a better outcome for PwMS.

I highlight the fact that this may reflect the general trend of a growing gap in our society between the 'haves' and the 'have-nots'. Several Regions report seeing an increase in people needing support with housing and food parcels due to lack of access to financial resources. There is certainly plenty of advocacy work being undertaken by Field Workers in these areas. There is a lack of residential facilities for under 65 year olds as well as an issue with shortage of respite beds in some areas.

Most regions are providing a range of group activities for both social and physical support. The regions that have access to a registered Minimise Fatigue Maximise Life facilitator are also providing several groups addressing fatigue management. These groups are proving to be popular and successful in their outcomes. There appears to be a growing trend of employing volunteers to assist at the various groups.

There is also a report of continued struggle for funding to facilitate their programmes as well as funding for Societies in general. Most Field Workers have reported being very involved in fundraising activities as well as raising community awareness.

In general, we have a few newer Field Workers on the team now and they have reported being very grateful for the support they have received from their cluster groups as well as from the wider peer group nationally.

Amanda and I have had discussions around the Field Worker Training for 2018. I am working on collecting feedback from the Field Workers in the regions to ensure the training provided is of benefit and relevance to the role in supporting clients.

Cheryl Standing

Registered Social Worker, MSNZ Field Worker Representative

Regional Reports 2016-7

Upper North Island Cluster

Northland

Our past year in the Northland region had some unforeseen interruptions with service, but our general support activities and fundraising events all continued.

In July this year, I resigned as the Field Worker, due to long term ill health over the previous 5 months, and took up retirement. The new Field Worker is looking to start in October to continue the service to clients.

In June we held a seminar presented by Dr Nicole McGrath, senior Physician at Whangarei Hospital. The seminar was very well attended and all MS members, families and healthcare providers who attended found the talk very beneficial.

It is quite exciting to know that of our 100 or so PwMS in Northland, over 20 of them have been started on one of the four new disease modifying treatments. Only one so far has had to withdraw from the initial treatment and all the rest are doing very well.

I would like to take this opportunity to thank the Executive Committee of MSNZ, Amanda Rose, National Manager and her office staff over the years, all my fellow Field Workers throughout NZ, and all the various Regional Committee Members and supporters that I have been involved with over the past 22 years. Your support, friendship and collegiality has been wonderful, and it has been great meeting you all and working with you. I wish MSNZ and all the Regional Societies all the very best for the future, with all the great work you do for our PwMS and their families in New Zealand.

Gay Dickie, NZRN, Ex MS Field Worker

Auckland

Four Field Workers cover the region estimated to have 1,000 people living with MS. Each Field Worker covers a specific area. Andrea our newest team member, came on board July 2016 to cover the West and Rodney area. She settled in quickly and is enjoying her new role.

Field Workers provide a range of support, including home visits, assessments, referrals and of course a listening ear. We work collaboratively with our hospital based MS Nurse Specialists with the aim of providing integrated hospital and community care. Regular meetings with the hospital nurses have supported good communications and an effective and efficient working relationship. Almost all newly diagnosed people are now seen by one of MS Auckland's four Field Workers.

This year, due largely to a gradually declining 'membership' over the years, we have changed the way we talk about the MS Society. Financial memberships

are still available but for those who don't want to join, they are encouraged to be part of the community and, if they can, give a donation. This enables them to continue to get our news, invites, information and keep in touch with what is going on. As Field Workers this has been a wonderful change. We don't have to concern ourselves with who is a member and who is not and are able to support all in need. It has also helped our MS network to grow. The Society is also seeing people choosing to donate back at a rate that amounts to more than the membership fee was.

Regular activities included:

- 14 Active Support Groups, meeting monthly across the different areas each week.
- 6 Hydrotherapy groups in 6 different pools across Auckland each week, conducted by Rope Neuro Rehabilitation employees
- Quarterly Wellness Workshops
- Quarterly magazine, Multiple News, which the Field Workers contribute to with articles relevant to clients

Last year our Central Auckland Field Worker, Carol Andrews, trained to facilitate the Minimise Fatigue, Maximise Life Course. She runs the programme twice a year, one mid-week session of six weeks and the other on a weekend for those who work. It has been very well received by participants.

We organised a Counselling Course which proved to be very popular and worthwhile. The Society employed a counsellor and had 8 of our clients attend in a group session from South Auckland in 2 hourly sessions over 6 weeks. The group decided that it was so worthwhile that once the group sessions ended they decided to continue to meet regularly and at this stage have met twice now. We have another group now running in the northern area.

The MS Research Day was attended by 214 people with MS, their families and MS Field Workers as part of their Training days. The day proved to be very well accepted with informative speakers and a lot of networking.

There are a number of issues which the Auckland Field Workers find difficult to work around with the big one being the lack of funding for neuropsychological services. We would like to see more psychological help for our newly diagnosed clients. There remains a lack of suitable care facilities for people under 65 years of age, transport services for people with mobility issues, and regular access to neurologists and MS nurses – due to the demand exceeding current resources. There also seems to be a delayed access to some of the Community Health Services in some areas of Auckland.

Dianne Bartlett (South); Carol Andrews (Central); Diane Hampton (North) and Andrea Kortas (West and Rodney)

Waikato

Another good year at MS Waikato (MSWT), staff have been kept busy with a steady stream of new clients reaching out for information and support and of course caring for our existing clients. At the present time we have 283 people with MS living between Whitianga and Taumarunui.

The number of clients having infusions has steadily risen over the year and staff have enjoyed supporting them at the infusion centre. The MS Clinic continues on a fortnightly basis, it was set up by our specialist MS neurologist Mr Jan Schepel and is a collaborative clinic with Clinical Nurse Specialist Karen Thomas, Jan and a MSWT staff member working together. Weekly client meetings continue between MSWT and CNS Karen providing an invaluable sharing of information and care.

The annual MS Education Evening where we invite neurologists to present was, as always, well attended and enjoyed.

Staff continue to provide in-service education as required in the wider community, Waikato hospital and other care providers as required.

We have added a new support group for clients with MS, based in Hamilton which has been well received and complements the groups in the smaller towns.

The exercise class, run in collaboration with Parkinson's continues to be worthwhile on many levels, physically, emotionally, and socially.

We have enjoyed fundraising highlights including the annual golf tournament, the 'Kawhia Cruise' car event, a movie night fundraiser and of course our Awareness Week stalls. The Christmas lunch is always a happy fun event to finish the calendar year on.

Client Services Staff, Waikato

Bay of Plenty

We continue to provide a diverse range of exercise and social activities to ensure our members have choice in what activities appeal to them.

Both Field Workers are becoming known for their pro-active approach in providing a client-centred service. We have received positive feedback from allied health professionals. Cheryl has continued to develop the relationship with the neurology team at the DHB, this provides a more robust support for PwMS by utilising a collaborative approach.

We continue to develop skills to enhance the service. Max completed the 'NZ Certificate in Health and Wellbeing (Support Work)' and is continuing his study in Autism, providing transferrable skills and strategies that are useful in MS work. This upskilling benefits our members increasing self-empowerment, independence and quality of life.

Cheryl was appointed as Field Worker Representative at the MSNZ Field Worker Training this year.

The office was closed as a cost reducing measure and staff are now all homebased.

A number of key trends have been noticeable in the region:

- Western BOP continues to see member numbers growing due to the trend of people moving here from other regions and referrals from the DHB. Member numbers in the Eastern BOP remain consistent.
- Homelessness continues to grow in Tauranga. Cheryl utilises community agencies to source accommodation for members in desperate need. There is a real shortage of suitable affordable housing in this region.
- Employment issues for PwMS are becoming more prevalent.
- With only one Neurologist at the DHB in BOP there is a waiting list and extra travel expenses for members in the EBOP who are often challenged financially.
- There is no Community Response Team or Neurology Nurse in the EBOP.
- Lack of funding continues to be an issue in providing services.

Max Hollis and Cheryl Standring, MS Field Workers

Gisborne

We have 23 clients with MS and other related neurological conditions. All our clients participate in the society activities.

The Field Worker Service is provided over a 10-15 hours per week with supports for clients including; regular visits, phone follow-ups with clients, referrals to GPs, occupational therapists, physiotherapists and speech therapists. I liaise with other groups such as Stroke, the Volunteer Centre and Parkinson's. Monday afternoons I am office based and Tuesday's to Thursday's in the field.

We have two groups, the working persons with MS group who meet at a restaurant in the evening every two – three months. They enjoy this time to socialise and talk about MS. The physiotherapist attended one evening and this was well received. The morning group enjoy morning teas held in a café every six weeks.

Other client and member engagement activities include the Mid-Winter Christmas Lunch, Christmas Dinner and a summer garden party. All events were well attended and greatly enjoyed.

We offer pool therapy, horse riding, pilates and exercise classes to all our clients.

We offer health supplements to our clients free of charge; deer velvet capsules, uri cleanse capsules, flaxseed oil and omega-3 fish oil capsules and liquid. A record is kept and recorded of each client who use these products.

Christine Beard, MS Field Worker

Rotorua

My sixth year as Field Officer for MS Rotorua has seen another good year for the Society with all going well. We currently have 83 Clients covering Rotorua, Taupo and Turangi. We have 58:25 females to males and 20 people currently on the new disease modifying treatments and 2 continuing on beta-feron. Our numbers have increased not because of newly diagnosed PwMS but ones moving from the cities to Taupo and Rotorua

Our Rotorua support group is held twice monthly, and our Taupo and Turangi clients meet in Taupo the last Friday of each month. We held our Mid Year and End of Year lunches in June and November which are fully funded by the Society, enabling clients to attend this social occasion for free. We held an enjoyable morning tea at Blue Berry Farm in September. We have also found our members actively organising social events as our Taupo clients enjoyed a 'pot luck lunch' at one of their homes in May.

Highlights this past year have included two presentations on "What is MS" and the "Caring for the disabled in the home" at Taupo and Rotorua Healthcare Providers NZ.

I have also attended 8 training opportunities in the past year to keep informed about the developments in MS and to ensure I am providing an informed service to MS clients in the region.

Diana Hay, MS Field Officer, Registered Nurse

Lower North Island Cluster

Hawkes Bay

Once again it has been an interesting year for us here in Hawkes Bay, with the fundraising events we have had sausage sizzles and quiz nights along side our 'Multiple Steps for Multiple Sclerosis' event which once again improved on the previous year. We really appreciate the numbers of volunteers who assist us and those who participate. Watching the faces of those who achieve the goal of the 'Gut Buster; or 5k course (10 or 5 kilometres of hills and steps over Napier Hill) or those who prefer the flat walk along the Napier foreshore and seeing the members with MS cross the finish line is amazing.

The Kiss Goodbye to MS sausage sizzle's held at Mitre 10 Mega in both Napier and Hastings were well patronised. We really appreciated Napier Mitre 10 Mega inviting us to be the Charity of Choice for their Mitre 10 Ladies night an excellent and easy fundraiser.

We noticed a decline in takings for our appeal week, but have put a lot of this down to the water crisis in Havelock North and Hastings, here's to a better year this year.

The Society was visited by MSNZs Vice President, Neil Woodhams, who spoke to a group of our members about what National MS is doing with PHARMAC, disease modifying treatments and Sativex. The National MS advocacy agenda was also discussed and how our members can assist with information relevant on the different issues present to MP's.

We have managed to continue our swimming, pilates and Monday Group through funding from different funding agencies which we really appreciate. Our members participate regularly in these groups.

Robyn Coyle, MS Field Worker

Taranaki

It has been busy in Taranaki with new MS referrals and we continue to see a slow increase in our client numbers. We are now looking after those with Motor Neurone Disease as the group here felt they needed a Field Worker based in Taranaki not in Waikato.

We still have the ongoing issues due to not having a resident neurologist and extensive waiting times. With a visiting neurologist, there is no guarantee a client will see the same neurologist at each appointment so consistency of care is also an issue.

Funding is always a challenge but our wonderful Treasurer/Secretary Jeannette is chasing up lots of groups and schools to make maximum effort with the Street Appeal this year. We held a quiz night and will hopefully have another before the year ends. Our Patron was organising an art auction but it was decided that a fresh approach was needed so she is now organising a garden party to be held at the beginning of next year.

Our committee is so wonderfully proactive and so supportive of me in my role as Field Worker that it makes my job so much easier and a happy environment for the clients when they attend morning teas and groups.

Our President, Graham Walker and I went down to Palmerston North on the 31st July to see the Alinker bike demonstration and we were both absolutely blown away. What a wonderful piece of equipment and we are so hoping that we get some here to be able to show people how they could benefit from one.

Moira Paterson, MS Field Worker

Wanganui

Kia ora koutou katoa

I started as the new Field Worker for MS Wanganui in December 2016 and have been busy building relationships with clients, their families, GPs and staff, support networks, community supports and the DHB.

I have maintained continued support for clients with their care plans as well as supporting clients with their GP and/or Neurologists.

I have started several new groups including; a Coffee Club for newly diagnosed clients, an MS Art group, an MS Friendship group and a closed Facebook page for my clients only.

All the new groups have been met warmly by our clients and members have shown enthusiasm to participate in our new groups. I run these groups once a month as my hours are part time. We also have a long running members luncheon that was started by a previous Field Worker some time ago. We have revitalised this from

3-4 members attending to now having on average 15 clients attending.

We have been without an Office Manager since March however our committee has been working together on administrative duties until a new administrator is appointed. Our President, Veronica Kapaiwai, has been kept very busy, being available at all times for Board, managerial, administration and Field Worker support.

Field Worker Training in Auckland was fantastic and I thoroughly enjoyed meeting all the Field Workers. My fellow Cluster Field Workers have been outstanding in continued support and advice. There have been times when I have been met with uncertainty around a client's concerns and issues, ranging from complications with MS and pregnancy. I need to acknowledge Ria Sapsford from Palmerston North for her excellent knowledge and support. This networking is so valuable to my role.

I have also been in the community doing community presentations to raise awareness for MS. The feedback has been really positive.

Thank you to MSNZ, and all the MS Field Workers for their assistance and support.

Nga Mihi Nui

Michelle Chapman-Cullen, MS Field Worker

Central Districts

MS Central Districts has had another busy year. A trend towards referrals from younger people diagnosed with MS as well as the DHB, the new drugs and more complex problems with the progression of MS, has kept the two Field Workers busy in their respective areas (one covers the northern Mid Central area, the other the south). This has provided good overall support for our 200 plus clients.

There has been a resurgence of interest in the maintenance therapy programmes with the increase in client numbers. Alongside the regular client and carer peer support groups, art and yogalates, we also now offer a regular practical session on managing MS and the Minimise Fatigue, Maximise Life programme twice yearly. There has also been keen interest in the Massey personal training programme run by the School of Sport and Exercise students.

The 2016 Annual Appeal was a very successful appeal raising almost \$8000. Presentations to several Lions Clubs resulted in more of their members boosting our volunteer numbers which certainly contributed to the efforts.

Finding sufficient funding for our services remains an ongoing challenge. This year Lotteries provided an annual grant which was substantially lower than the previous two-year grant from Lotteries.

Philippa Russell and Ria Sapsford, MS Field Workers

Wellington

MS Wellington covers Wellington, Porirua, Kapiti Coast, Hutt Valley, and the Wairarapa comprising of one full time, and two part-time Field Workers. The team consists of Sue Johnston (in excess of 20 years in the role, Nursing background); Gillian Fry (in the role for 5 years, Naturopathic and HR background); and we are pleased to welcome Katherine Jourdain who started in February 2017 (Dental Therapy and Research background).

We work on client request due to the large number of clients, at a place that suits them. We hold 6 monthly support groups and clients can access a weekly yoga group in Johnsonville. We have extended our profile by having a monthly 'hot seat' at The Upper Hutt city Library and the Kapiti Community Centre. Another recently diagnosed workshop is planned for September 2017.

Field Workers receive referrals from Neurology departments, PwMS and other medical and allied health teams. We maintain good working relationships with Neurology and allied health teams to focus on providing appropriate and effective support for PwMS and their families and whanau in the community.

Over the past 12 months we have worked with a number of clients who have experienced a housing crisis. It is no surprise this reflects the national issue for a large number of people with limited financial resources. Advocacy especially with the likes of WINZ and Housing New Zealand is one of the ways where we can provide a level of help along with letters of support for funding applications to the likes of the Lotteries Commission. Local food banks do an amazing job and have certainly provided help to a number of our clients this year. We have supported many grants applications and clients have been successful in receiving grants for mobility scooters and vehicles.

Gillian Fry, Sue Johnston and Katherine Jourdain, MS Field Workers

Top of the South Cluster

Marlborough

We finished our year with a Christmas High Tea Garden Party which was attended by over 50 clients and then started the year with a generous donation from our local Suzuki dealer, Wadsco, of a car with a lease for 2 years provided by Redwood Trust.

MS Marlborough clients have been well supported this past year by the addition of a Neurology Nurse Specialist employed by NMDHB who follows up clients with our only Neurologist in the region Dr Desiree Fernandez on disease modifying treatments. Clients on Natalizumab now receive their infusions in Nelson as opposed to Wellington.

Support groups include a weekly exercise group, monthly brunch and monthly coffee group run by the Committee.

A 2-day assessment clinic was organised by myself in March this year and held by Neurophysiotherapist Gilly

Davy from Auckland. Our clients had the opportunity to receive a subsidised specialist assessment. This was subsidised by grants and we extended the offer to the general public and other neighbouring Societies. We had one client from the West Coast MS Society travel to Blenheim for this opportunity. An evening presentation about MS and exercise was well attended by 45 people and the exercise class was reviewed to ensure best evidence based exercise principals.

An opportunity in June to raise awareness of MS in our community was achieved when we were selected by the Marlborough District Council Major and Councillors to speak at their 'Cuppa for a Cause'.

Janine Ready, Community Nurse Educator

Nelson

Nelson continues to remain busy with a membership of over 100 clients covering the Tasman Bay area. In the past year, we have had 6 client referrals from other regions and 6 new PwMS join our Society. We also support people with Huntington's and Parkinson's who have their own Community Educator also employed by the Nelson Multiple Sclerosis Society.

I continue to organise all the support groups for both MS and Parkinson's including; Golden Bay MS, Motueka MS, Nordic walking, Victory Boxing, MS Mums group, Young MS group, Coffee & chat group, Parkinson's ladies and men's carer groups and various other Parkinson groups. All these are well attended.

We have a wonderful physio at the Nelson Hospital who successfully co-ordinated an 8 week MS Exercise programme using the Rehab gym with 5 clients attending at a time. She hopes to get funding to further these classes for others with MS who are interested and also for those with Parkinson's.

I attended the National MS Field Worker Conference in Auckland this year. There was a good source of learning, networking and professional development. I have continued to have professional supervision which is paid by the Society.

Pam Grey, MS Field Worker

West Coast

The past year has seen MS West Coast Inc. go from strength to strength.

In September 2016, a Special General Meeting was held due to the 3 remaining Committee Members stepping down. At this meeting, it was put to our members that we shut up shop or receive help to form a new Committee and right the ship. Urged on by our local Mayor and Patron, people stepped forward, as the thought of such a vital support system to people on the West Coast dissolving was not an option. This committee, with the assistance from MSNZ and Parkinson's NZ, proceeded

to work tirelessly to get everything back on track. A new Office Manager was employed and brought a bright, cheery hope back to the Society as she and our President has written numerous funding applications.

2017 has seen us not only with secure finances but new opportunities for our members. Our membership has grown and we now have double the number of members than in 2014. Our Field Worker has commenced a Younger Members support group, has held two Minimise Fatigue: Maximise Life groups, completed teachings to rest homes and continued coffee morning support groups which are now very well attended with regular speakers. We are also preparing for the annual craft fair that is now bigger and better than ever.

Our name in the community is now well known and respected and we continue to assist and support our ever-growing number of people living with MS on the West Coast.

Belinda Butterfield, MS Field Worker

Canterbury

In 2016/17 we had 36 new referrals of people with MS and our MS nurse had 1764 contacts. 1653 attendances were made at 353 exercise/gym/yoga sessions.

Our nurse developed a self management programme with the input of a focus group of people with MS. Living Well With MS runs twice a year for two hours once a week for 6 weeks. This has attracted good interest, attendance rates and very positive feedback. The interactive programme specifically focuses on managing different aspects of MS, differentiating from Minimise Fatigue, Maximise Life.

Several members with complex social/medical issues have required intervention and advocacy by the nurse e.g. a long term client requested extra help as MS symptoms had worsened. We referred the person to Housing NZ and Accessible Housing, organised for modifications to the wheelchair and home environment, ordered a driving assessment and referred to a speech language therapist. This person moved from private rental accommodation to an accessible Housing NZ house, which is much more suitable and safer for their level of disability.

Workplace and employment issues were a focus with advocacy and education provided by our nurse giving employers a greater understanding of MS and how to help and support an employee in a work place situation.

Our three regional peer support groups (Ashburton, Christchurch and Rangiora) and MS monthly lunches continue, with attendance over the 12 months at 340.

As our World MS Day event we held an informal meet and greet event with Cheryl Hile, the American marathon runner with MS who participated in the Christchurch marathon.

Our nurse was actively involved in the Christchurch Neuro Nurses Group's Education Day (Neurology

Through The Ages) in September attended by 90 health professionals from across South Island. In the last 12 months our nurse has attended an MS nurse education day in Wellington, a conference in Sydney and the MSNA conference in Hobart.

Robin Furley, Manager

Lower South Island Cluster

South Canterbury

MS South Canterbury have had a very good year. We currently have 96 clients with 9 new this year.

Timaru has the largest number of senior citizens per capita in NZ putting a strain on resources but also making this a more accessible region, benefitting many clients. The biggest problems are the long waiting lists for occupational therapist, physios and specialists due to a shortage of staff and large numbers using these services. With no resident neurologist and visiting neurologists on rotation every 6-8 weeks clients often don't always see the same specialist.

Respite Care is extremely bad. Respite beds are so limited that many clients travel 2 hours to Christchurch for a break. We have no age appropriate beds for younger clients.

We have two regular social groups which meet each month, attendance for these varies depending on the weather. Awareness Week was very successful with many different displays and boards set up, one of the local schools helped with collection day. We have our Awareness Week to align with World MS Day in May this suits us better as not so many other groups are collecting then.

Fiona Pierce, MS Field Worker

Otago

The Otago region continued collaborating with allied health professionals throughout our community. We have various support groups in Dunedin, the surrounding areas and outlying areas of South Otago, North Otago and Central.

Over the past year we have had various fundraising events. Mitre 10 Mega have had two nights where all the proceeds raised were given to us. These were their annual Gardening and Ladies nights. This enabled us to get a higher profile about our service in the public. We also had a Ricon Golf Tournament raising funds and awareness.

This year our Wobbly Art Event returned after 7 years. This was a long running event at Otago and its revival has given our members who contributed a way of expressing their artistic abilities in a valued way. This was evident through the high calibre of the art which was presented at the event. We are looking forward to the next 12 months.

Maree Darling, MS Field Worker

Southland

This year we benefitted from having our Manager Nicki Kitson support the functioning of both the operational and governance roles of the Society. Our members have seen improved efficiency in the operation of our service. Alongside of this we were happy to welcome Jo McIntosh to our team. Jo is a Registered Nurse and has replaced our long serving rural Field Worker Doreen MacManus.

A key highlight has been the improved access to tertiary services (SDHB) evidenced by the numbers of members now reporting regular appointments with specialist neurology services. Our members are reporting improvements in symptom management with the advent of the new medications and appear more hopeful with the additional treatments now available. The result of this in practice is some reduction of the need to refer to SDHB Allied Health services for our members but we continue to refer in cases where our members are in need.

Meanwhile we continue to support and to respond to identified need and to support our people with progressive neurological conditions.

Viv Gillan, MS Field Worker.

Our Grateful Thanks

Bequests

Thank you to the following for bequeathing generous gifts to the Multiple Sclerosis Society of New Zealand in their will in recent years:

- Estate of David Reid Currie
- Estate of Gillian Ann Brockie
- Estate of Phyllis Jose Cottle
- Estate of Margaret Allan Ralston
- Estate of Pamela Mary McKenzie
- Estate of Ernest Robert Robinson
- Estate of Shirley Mullooly
- Estate of Rayner Vincent Dixon
- Estate of Joyce Olive McKay
- Estate of Jeanette Procter
- Estate of Mary Anne Worth
- Estate of Gordon Francis Anderson
- Estate of Alan John Morris
- Estate of Raymond George Druce
- Estate of Frances Margaret McNish
- Estate of Angela Carolyn Savory
- Estate of Margaret Richmond Stevens
- Middleton 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.

Funders and Supporters:

MSNZ would like to thank the following for their support in 2016–7:

Trusts and Grant Funders

Des and Olive Walker Charitable Trust, Lottery National Community Grants, Ministry of Health, Pub Charity Limited, Community Post, Working Together More Fund, Trillian Trust, Four Winds Foundation, The Dorothy L Newman Charitable Trust, Society of Mary Trust Board, Li Ka Shing Foundation

Businesses

Pharmacy Retailing (NZ) Limited, exceed, Slipstream, WaltersPR, The Spark Foundation, BNZ, Oceanbridge Shipping Ltd, Printable, Nexia, Roche, Novartis, Sanofi, Biogen, Seqirus, The Alinker

Thank you to all our donors who have supported MSNZ throughout the year. We greatly appreciate your generosity and encouragement of our work in advocating for the needs of people with MS nationally.



Annual Financial Statements

Multiple Sclerosis Society of New Zealand Inc

Financial Statements as at 30 June 2017

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- 32. "What the entity owns" and "What the entity owes"
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Summary Audit Opinion

These Summary Financial Statements comprising the Statement of Financial Performance, Statement of Financial Position, and Statement of Cash Flows are those of the Multiple Sclerosis Society of New Zealand Inc.

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 full financial statements for the year ended 30 June 2017, authorised for issue on 26 September 2017 by the President and Vice President of the Society, have been audited by Nexia Christchurch Limited (known as Nexia New Zealand). The unqualified audit opinion included an emphasis of matter paragraph drawing attention to the fact that the Multiple Sclerosis Society of New Zealand Inc. continues to be reliant on fundraising, donations, grants and government funding and that the Committee is committed to the on-going financial viability of the Society.

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 full Performance Report and cannot be expected to provide as complete an understanding of the financial affairs of the Society as the full Performance Report. The full Performance Report of the Society can be obtained by contacting the National Office.

Multiple Sclerosis Society of New Zealand

Statement of Financial Performance
 "How was it funded?" and "What did it cost?"
 For the year ended
 30 June 2017



Multiple Sclerosis
 New Zealand

	Note	Actual This Year \$	Actual Last Year \$
Revenue	1		
Bequests, Donations, fundraising and other similar revenue		250,941	384,295
Fees, subscriptions and other revenue from members		7,640	4,987
Revenue from providing goods or services		258,735	258,753
Interest, dividends and other investment revenue		12,677	23,807
Other revenue		2,044	9,804
Total Revenue		532,037	681,646
Expenses	2		
Expenses related to public fundraising		17,982	37,871
Volunteer and employee related costs		148,734	111,179
Costs related to providing goods or services		326,582	275,435
Grants and donations made		8,402	224,224
Other expenses		29,553	22,862
Total Expenses		531,253	671,571
Surplus/(Deficit) for the Year		784	10,075

Multiple Sclerosis Society of New Zealand

Statement of Financial Position

"What the entity owns?" and "What the entity owes?"

As at
30 June 2017

ms.

Multiple Sclerosis
New Zealand

	Note	Actual This Year \$	Actual Last Year \$
Assets			
Current Assets	3		
Bank accounts and cash		28,435	81,247
Debtors and prepayments		20,931	17,307
Total Current Assets		49,366	98,554
Non-Current Assets			
Property, plant and equipment	4	6,979	2,421
Investments		162,395	150,190
Total Non-Current Assets		169,374	152,611
Total Assets		218,740	251,165
Liabilities			
Current Liabilities	3		
Bank overdraft		-	-
Creditors and accrued expenses		21,489	55,245
Employee costs payable		7,807	7,261
Total Current Liabilities		29,296	62,506
Non-Current Liabilities			
Other non-current liabilities		-	-
Total Non-Current liabilities		-	-
Total Liabilities		29,296	62,506
Total Assets less Total Liabilities (Net Assets)		189,444	188,659
Accumulated Funds	5		
Accumulated surpluses or (deficits)		130,582	132,649
Reserves		58,862	56,010
Total Accumulated Funds		189,444	188,659

President



Vice President



Multiple Sclerosis Society of New Zealand

Statement of Cash Flows

"How the entity has received and used cash"

For the year ended
30 June 2017



Multiple Sclerosis
New Zealand

	Actual This Year \$	Actual Last Year \$
Cash Flows from Operating Activities		
Cash was received from:		
Donations, bequests, fundraising and other similar receipts	252,985	400,664
Fees, subscriptions and other receipts from members	8,276	4,987
Receipts from providing goods or services	258,735	261,300
Interest, dividends and other investment receipts	5,604	11,750
Net GST	(9,046)	(3,649)
Cash was applied to:		
Payments to suppliers and employees	538,086	426,177
Donations or grants paid	20,812	244,224
Net Cash Flows from Operating Activities	(42,344)	4,651
Cash flows from Investing and Financing Activities		
Cash was received from:		
Receipts from the sale of investments	43,650	88,803
Cash was applied to:		
Payments to acquire property, plant and equipment	5,338	-
Payments to purchase investments	48,780	10,000
Repayments of loans borrowed from other parties	-	26,028
Net Cash Flows from Investing and Financing Activities	(10,468)	52,775
Net Increase / (Decrease) in Cash	(52,812)	57,426
Opening Cash	81,247	23,821
Closing Cash	28,435	81,247
This is represented by:		
Bank Accounts and Cash	28,435	81,247



**Make visible what, without
you, might perhaps never
have been seen.**

– Robet Bresson.

ms.

Multiple Sclerosis
New Zealand

Annual Report
2016–2017

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