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Multiple Sclerosis  
New Zealand

Annual Report  
**2017-2018**



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# MSNZ Directory

**As at 30 June 2018**

President	Malcolm Rickerby
Vice President	Neil Woodhams
National Executive Committee Members	Dr Caroline Allbon (from 30 Jan 2018) Ian Chadburn Mark Etheridge Jane Heywood Tony Kerr Jeff Silvester Graham Walker (from 30 Jan 2018)
National Manager	Amanda Rose
Communications and Administration Coordinator	Emily Smith
Project Coordinator	Regan De Burgh
Accountant	Nexia New Zealand
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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 2018 AGM



The 2017-18 financial year has ended with a small deficit which is not how we had forecasted. With the changes in the National office and the extensive Advocacy programme we have undertaken over the last few months it is not a surprise to find a deficit for the year.

## National Office

Amanda has led the team exceptionally well which has expanded by one staff member. Our Advocacy programme took a huge amount of her time, the results will come through over the next year. Working with Lottery after a visit to their Wellington office resulted in a positive outcome. Two excellent workshops were held, one on fundraising and the other the Fieldworkers annual conference, thanks to Amanda they were very well put together.

Regan De Burgh joined the national office in April as Project Coordinator to heighten the awareness of MS, through campaign management and fundraising.

Emily Smith has managed various changes to our communications and internal systems.

## Advocacy

MSNZ has started on an extensive advocacy programme to bring long lasting changes to how Pharmac manages the supply of drugs to people with multiple sclerosis (PwMS). The need to change the entry and exit criteria of MS drugs is critical, based on international research. This year we brought Professor Helmut Butzkueven, a prominent world-renowned MS Researcher and Director of MS Services at the Royal Melbourne and Box Hill Hospitals in Melbourne to speak at MS Research Day in Auckland. This was very well attended, and he gave a very interesting talk to a large group of PwMS and their carers in Christchurch, and then to Wellington to head our advocacy team to Pharmac on the need to change the criteria. We should know the outcome in November. The urgent need to increase the numbers of Neurologists, MS Nurses and to reduce the waiting time for MRI scans within hospitals are our primary drivers for the 2018-19. To make the changes needed for PwMS across a number of health areas we need the support of Regional Societies to have their members telling their stories of living with MS.

## Regional Support

'Bangers to Bluff' was a great fundraiser for MSNZ as well as some of the regions where the 'bangers' drove through on their way from Auckland to Bluff. This event is being held again in April 2019 with a different route to Bluff.

A fundraising seminar was held in Christchurch, attended by several regions with the emphasis on Awareness Week.

The Field Workers annual meeting was held in Auckland which coincided with their research day on the Saturday and was well organised and attended.

## Finance

As you can see from our Annual Accounts, we have a deficit for the year.

Our income was ahead of budget but with the increase in staff numbers and our drive to advocate for change in the lives of PwMS also means using technology in the most appropriate way to increase the awareness of MS in the communities throughout the country, and therefore our costs have increased as well. Our goal this year is to have a small surplus.

## Ministry of Health Funding

Our contract with the Ministry of Health has now been extended to 31<sup>st</sup> July 2020. Over the years, the MSNZ committee has always agreed that some regions are allocated far more per PwMS than others and the committee have addressed this issue which started in January and will take three years to completely implement.

## Research

The New Zealand Multiple Sclerosis Research Trust (NZMSRT) has increased its capital base over the last year. MS Base an international software product which is being used in 33 countries, and 127 clinics to house information on PwMS has 61,700 patients records already in the system. MS Base is being used in Waikato and Canterbury hospitals.

It is a concept of mine that the NZMSRT should work with regions to help to increase the capital, which in the long term will help PwMS in New Zealand. \$5 million is the goal.

## National Management Coimmittee

To Neil Woodhams, Mark Etheridge, Jeff Silvester, Ian Chadburn, Jane Haywood and Tony Kerr along with Dr Caroline Allbon and Graham Walker who joined the committee after the 2017 AGM as independent members I thank you all most sincerely for the contribution you have made over the last year to improve the delivery of information and awareness of MS to the regions and across the country.

Malcolm Rickerby  
President

# National Manager's Report to the 2018 AGM



The 2017-18 year marked the 50<sup>th</sup> Anniversary for the Multiple Sclerosis Society of New Zealand (MSNZ), a huge milestone for the organisation and an opportunity to celebrate the successes of the past and to present our future direction. Several events were held to mark our 50<sup>th</sup> year of supporting people with MS (PwMS) and the Regional Societies.

## Advocacy

The year saw our advocacy programme continue to pick up pace. Key areas of focus have been:

- continuing to advocate to PHARMAC to increase access to MS funded treatments by widening the entry and exit criteria;
- supporting and participating in the work of MS Brain Health;
- developing the Good Service Project;
- advocating to the Ministry of Health for the introduction of HSCT as a treatment option in NZ;
- advocating to the Health Select Committee for the inclusion of people with MS related pain and spasticity to have safe, free and legal access to pharmaceutical grade medicinal cannabis;
- advocating to PHARMAC for the inclusion of Ocrelizumab on the Pharmaceutical Schedule as a treatment option for people with both Relapsing Remitting and Primary Progressive MS;
- collaborating with allied organisations to lobby for better access to toilets for people with bladder and bowel issues.

A full report of our advocacy work can be found on page 8.

## 50<sup>th</sup> Anniversary

On the 16<sup>th</sup> October 2017, as part of MSNZ's 50<sup>th</sup> Anniversary and Annual General Meeting, a lecture evening was hosted on 'The future of MS treatments' in Christchurch. The event was well attended by 80 people with MS, carers, families and health professionals.

Associate Professor Tomas Kalincik, of Melbourne University, addressed the importance of early diagnosis and treatment as being crucial for limiting and managing the often irreversible, progressive deterioration that people with MS experience. The session supported MSNZ's position that it had been advocating to PHARMAC treatments need to be made available earlier to targeting and preventing disability.

With thanks to the support of MS Research Australia, Roche and Novartis, MSNZ brought internationally renowned Stem Cell Transplant Haematologist, Dr

Riccardo Saccardi, of Careggi University Hospital in Florence, Italy to Christchurch. Dr Saccardi presented the growing evidence to support Haematopoietic Stem Cell Transplantation (HSCT) as a viable treatment option for New Zealand to consider. MSNZ also supported the travel of Dr Saccardi to speak in Auckland the following evening to an audience of 90 in Auckland.

## MS International Federation Welcome

In November Peer Baneke, CEO of the Multiple Sclerosis International Federation (MSIF), visited New Zealand. We understand this is the first visit of an MSIF CEO to NZ. A welcome function was held with invited guests. The National Executive Committee and Trustees of the New Zealand Multiple Sclerosis Research Trust (NZMSRT), also had the opportunity to discuss ways in which our organisations can be more involved in the international MS network.

## Life Memberships

MSNZ awarded two Life Memberships this year to Dr Ernest Willoughby and Jim Millar. Dr Willoughby, MS Neurologist at Auckland DHB, is well known and respected in the MS community both in NZ and internationally and has provided guidance to MSNZ since 2001, officially undertaking the role of Medical Director between 2001 and 2008. Jim Millar was also recognised for his support of MSNZ as Vice President between 1981-1986 and the outstanding guidance he has provided to MS South Canterbury over the years as both President and Patron.

## 2017 Election

In the wider NZ landscape, 2017 was an election year which saw the introduction of a new three-party government. In the lead up to the election MSNZ provided materials through the Regional Societies for people to ask questions of their local candidate, regarding how they intend to support their constituents with MS as well as people impacted by MS across the country.

## Ministry of Health Funding

Mid 2017 MSNZ contracted Helen Eastwood to undertake a review of the how the Ministry of Health funding received is allocated. While this project had been of interest to the Committee for some time, funding has been under constant threat of being cut with the Ministry undertaking systemic reviews of how to fund support organisations. On receiving a renewed contract for a further three years the Committee saw this as an opportune time to review and reallocate the funding and ensure equity.

It was decided that funding should be allocated based on a PwMS basis. The Committee accepted that some regions cover larger distances however with improved technology there are various ways Regions can communicate and provide information to members and clients. The reallocation was approved at the 2017 AGM and the new distribution began in January 2018. The estimated numbers for the reallocation were based on the numbers of people in the region for the 2006 Prevalence Study, measured against the 2012-14 Incidence Study numbers and mortality data. The Committee is confident that the new allocation is more equitable nationwide.

## **Alinker**

In May 2017 MSNZ was advised we were to be the recipients of generous donation of a new and innovative mobility device called "The Alinker". The Alinker is a non-motorized walking-bike without pedals and is for people who want to maintain an active life regardless of their movement abilities/disabilities. The Alinker can benefit the lives of people with MS in terms of social engagement, mobility and overall health. In August, creator Barbara Alinker visited NZ to travel around the country, to meet many of the Regional Societies, to demonstrate the walking bike and the opportunities it could offer to people with walking difficulties. 40 Alinkers will be available in NZ, 10 allocated to selected rehabilitation centres and 30 for MSNZ to allocate to the Regions. The donation from Alinker Inventions Ltd was made possible thanks to the Li Ka Shing Foundation.

To understand how best to utilise the Alinkers, this year Multiple Sclerosis and Parkinson's Canterbury and Life Unlimited in Hamilton held pilots of the Keep Moving Programme. The Alinkers are now in the process of distribution to the remainder of Regional Societies who wish to have the Alinker's available for their members. Our grateful thanks to Mainfreight for their support with distribution.

## **NZMSRT**

As of the 1<sup>st</sup> June MSNZ and the NZMSRT signed a contract of service. The Trust has grown to a size where reliance on the Trustees for day-to-day administration is untenable, and it has therefore entered into a contractual arrangement with MSNZ, who are to provide specific administrative services to NZMSRT. MSNZ looks forward to providing administrative, communications and fundraising support to the Trust, assisting in its efforts to stimulate, co-ordinate and support New Zealand-based research into the cause, prevention, treatment, alleviation and cure of Multiple Sclerosis (MS), and to obtain and disseminate research findings.

## **Communications**

Thank you to Emily Smith for her continued passion she brings to MSNZ. Her dedication to the organisation and the work she does in ensuring that people with MS and the Regional Societies are receiving relevant and up to date information has been invaluable this year. Emily has been integral to reviewing and reviving our Communication Programmes including; launching our new website,

improving our Social Media strategy, relaunching our electronic external newsletter MS Voice, and introducing the new internal newsletter, 'In the Loop' to improve our communication with our members, the Regional Societies. The enhanced and increased communications are helping to elevate people's awareness and engagement with our organisation.

## **Fundraising and Campaigns**

This year saw a continuation of our fundraising programmes. Thank you to our fantastic donors who have supported us through a variety of ways including donor mail, fundraisers, donations, bequests and payroll giving. We are grateful for any donation and appreciate the wide range of options donors are faced with in this current environment.

A warm welcome to our newest team member Regan De Burgh. Regan joined us at the end of April taking on the role of Projects Coordinator with a focus on fundraising and campaigns. With a dedicated fundraiser on the team we are now able to ensure that all areas of the organisations key functions; advocacy, communications, regional support and fundraising, are given full attention. We look forward to Regan steering our Kiss Goodbye to MS fundraising campaign and MS Awareness Week into the future.

## **National Executive Committee**

Thank you also to the National Executive Committee for all the support and guidance you have provided this year. Mark, Jeff, Jane and Ian thank you for your continued involvement and we welcome Graham and Caroline to the team who both bring with them personal knowledge of living with MS.

Finally, thank you to Malcolm and Neil for both of your continued dedication and passion. The countless hours you both invest regionally and nationally for MS is an invaluable asset. The support and guidance provided particularly to the advocacy programmes and office staff is greatly appreciated. We look forward to the 2018-19 year and continuing to advocate for the needs of people living with multiple sclerosis across New Zealand.

We look forward to the 2018-19 year and continuing to advocate for the needs of people living with multiple sclerosis across New Zealand.

Happy reading and kind regards,



Amanda Rose  
National Manager



# Actively Advocating

## Increasing access to MS Treatments

In February 2018 the minutes of PHARMAC'S PTAC meeting were released and were not favourable to a submission made by MSNZ in July 2017, but requested further supporting evidence.

Following the commissioning of an independent report on the evidence to support widening the entry and exit criteria for MS treatments, MSNZ met with PHARMAC again in May 2018 to present the findings. An official submission to request widening the access was made a week later.

With the expert support of Professor Helmut Butzkueven, of Monash University in Melbourne, MSNZ met with members of PHARMAC staff to discuss our continued concerns with the very restrictive access criteria for MS disease modifying treatments (DMTs). Following this meeting we made a further official submission to PHARMAC.

Following advice and further research evidence from Professor Butzkueven, we chose to concentrate on the two areas that research shows will have the most impact and benefit for people with MS (PwMS);

### Stopping Criteria

1. Expanding the stopping criteria to EDSS 6.0 or 6.5 (there is evidence to support both potential endpoints)
2. Removing the gradient scale

### Starting Criteria

1. Removing the starting criteria of EDSS 0-4
2. Amending to include the acceptance of relapse activity demonstrated by clinically confirmed relapse OR new MRI activity in line with modern definition of RRMS instead of the current requirement for both.

### Current Criteria

Currently the primary intent of the current criteria is to restrict access to DMT to PwMS who:

1. Have not transitioned from relapsing remitting MS (RRMS) to secondary progressive MS (SPMS). Currently there is no funded treatment for SPMS.
2. Definitely have RRMS rather than a clinically isolated syndrome (CIS), which may not progress to RRMS (starting criteria). This avoids misdiagnosis and inappropriate treatment for PwMS who do not have MS at all, but another disease such as migraine with some white matter lesions on MRI and fleeting sensory symptoms (starting criteria).

However, both the stopping and starting criteria are not based on any evidence to support them.

### Stopping Criteria

Evidence we presented disputes the stopping criteria in two key areas.

1. The requirement to stop treatment following a 6-month disability progression event. New evidence shows that this is not indicative of treatment failure or SPMS, which is usually classified at EDSS 6.0 and with the absence of a relapse and further progression.
2. Strong evidence exists to support DMTs being effective for people with RRMS beyond the current two step deterioration on the EDSS scale and up to 6.5, compared currently with a maximum of 4.5.

Historically it was thought that once EDSS 3.0 was reached, progression was uniform. However, newer studies have shown this to be incorrect and the range of progression trajectories for individuals after EDSS 3.0 is in fact very broad particularly with continued use of high efficacy treatments. The disease course after EDSS 3.0 has little to no relationship to the disease course up to EDSS 3.0. It also cannot be assumed that EDSS progression after EDSS 3.0 is uniform or indicative of SPMS. The current requirement for 6 months to improve does not allow enough time for improvement to be truly visible and we have requested that this criterion be altered.

We also highlighted the risks that stopping treatment prematurely is highly likely to cause further and accelerated relapse-associated disability worsening for the individual. In this case, a person is denied access to DMTs when research shows continued access will improve outcomes of disease stability. Their MS is inflammatory (relapse-driven) and thus highly modifiable by DMTs.

### Stopping Criteria

MSNZ submitted further evidence to support the widening of the starting criteria for those who clearly have clinically defined and relapsing MS but do not fit the current starting criteria of having a second episode or relapse from the initial presenting symptoms.

The key areas we provided evidence for reconsideration in relation to the starting criteria are:

1. Removal of EDSS Score 0-4
2. Starting criteria be amended to include the acceptance of relapse activity demonstrated by clinically confirmed relapse OR new MRI activity in line with modern definition of RRMS

MSNZ has urged PHARMAC to remove EDSS 0-4 from the criteria as people with RRMS who would benefit, are being denied treatment. According to the PHARMAC criteria, a patient with severe early RRMS, which, following a single relapse, could elevate their EDSS to a point which would not qualify for treatment. This is the type of patient who would benefit most from early treatment.

There is strong evidence, which MSNZ supports, that a person should not begin treatment until confirmation of MS has been confirmed, and not CIS. The criteria in NZ are designed to eliminate the risk of people being prescribed DMTs when they do not in fact have MS. However, the PHARMAC criteria are not in line with the international consensus for the diagnosis of MS as defined in the 2010 and newly revised 2017 MacDonald Criteria. These accept a relapse/second episode OR new MRI activity as the diagnosis of MS. In NZ the requirement is for both.

MSNZ is also aware that there are significant issues nationwide with access to MRIs. While the delays in MRI access are not the responsibility of PHARMAC, the criteria impose serious disadvantages for PwMS who may have to wait up to six months for a second MRI. MSNZ will also be advocating later in 2018/2019 to the Ministry of Health, Government and DHBs to address this issue as a priority.

Evidence from the New Zealand MS Incidence Study, funded by MSNZ, showed that there is a significant delay of 4.4 years between the onset of first symptoms and diagnosis. This demonstrates that people in New Zealand are missing the opportunity to be treated when it is shown to matter. The earlier that treatment is initiated the higher the likelihood of treatment success.

MSNZ hopes that PHARMAC will look favourably on our submission and that we can work together to make positive changes to benefit the lives of people with MS in New Zealand. We expect to hear the outcomes of both meetings later in 2018 when we will provide an update of the outcomes.

A media campaign in late 2018 using the testimonies of people impacted by the restrictive criteria resulted in the greatest uptake by most major media outlets of the issue and we were able to convey our message to politicians and the wider public.

## **Improved access to MS Services and the Good Service Project**

Earlier in 2017 MSNZ issued OIAs to the 20 DHBs nationwide regarding specialist neurology clinical staffing numbers and wait times. The results showed that the NZ health system is seriously short of neurologists and MS Nurses, a position which 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 began in 2017 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 help alleviate increasing pressure on the system and ensure timely and equitable access to diagnosis and treatment. Repeat OIAs have been sent to the DHBs to review the progress or

otherwise in the past 12 months at rectifying the issues.

After speaking at several Regional Society events, Vice President Neil Woodhams, discovered that many people with MS do not realise that the service they are receiving is sub-par, nor do they know how to ask for this, or make a complaint. As a result, MSNZ developed the Good Service Project 'MS New Zealand: Guidelines to delivering and receiving a good MS service in New Zealand'. The project's objectives are to educate people with MS by providing tools and resources, to be their own advocates for their health needs. The project will compare NZ to international best standards demonstrating what a good service looks like and how the needs of people with MS in New Zealand are not being met.

The project aims to have to key outcomes:

1. Evidence to support MSNZs advocacy approach to relevant stakeholders to elevate and improve the health services PwMS in NZ are currently receiving;
2. Provide a tool for PwMS to feel empowered to be their own advocates for receiving a good service.

The project is not intended to criticise or find fault with the excellent work that neurologists and MS nurses are providing across the country but to highlight the need for further resourcing by decision making authorities in order to achieve international standards.

The project has been made possible with funding support thanks to Roche and Sanofi.

## **MS Brain Health**

In 2017 MSNZ officially endorsed MS Brain Health, an initiative that has emerged from an evidence-based international consensus report, Brain health: time matters in MS, which recommends a strategy to maximize lifelong 'brain health'.

MS Brain Health is an international multidisciplinary group of leading world experts in MS and is calling for a radical change in the management of MS because time matters at every stage of the disease.

Brain health: time matters in MS presents consensus recommendations on diagnosis, therapeutic strategies and improving access to treatment in MS. Its core recommendation is that the goal of treating MS should be to preserve tissue in the central nervous system and maximize lifelong brain health by reducing disease activity. The report calls for major policy changes aimed at achieving the best possible outcomes for people with MS and those who care for them.

MSNZ has used the principles to direct and provide international support for our advocacy work into improving the access to treatments and services for people with MS in New Zealand.

MS Brain Health are currently developing an international baseline for a satisfactory MS service. The first step in the project, the MS Brain Health Survey, aims to understand what are the barriers to achieving optimal outcomes for people with MS across the globe. In June

2018 MSNZ participated in this project and circulated the response to our networks. We received several responses from NZ patients, carers, neurologists, MS Nurses and other health professionals and support staff. We await the results of the survey and project which are expected later in 2018.

MSNZ's Good Service Project is currently on hold as we await the outcomes of the project to provide the international recommendations as the comparator.

## Ocrelizumab

Currently the only treatments funded in New Zealand are for those with Relapsing Remitting MS (RRMS). However, there is a high unmet need for those with more progressive forms of the condition. Ocrelizumab (Ocrevus®) is a treatment shown in clinical trials to provide benefits to both those with RRMS and Primary Progressive MS (PPMS). It is the first FDA approved treatment for PPMS and is the only approved disease modifying treatment (DMT) to slow the progression of the condition in clinical trials. Currently Ocrelizumab is providing benefit to over 40,000 people worldwide.

In May and September 2017 MSNZ made two submissions to PHARMAC to request the funding of Ocrelizumab for Relapsing Remitting MS (RRMS) and Primary Progressive MS (PPMS). Medsafe approved the registration for both indications of MS in December.

MSNZ participated in the Roche organised Ocrelizumab Advisory Group held in Wellington in March. Attended by a select group of MS Nurses, MS Field Workers, MSNZ representatives and Roche staff, the day was extremely beneficial, bringing together sectors of the support networks looking at how to best provide information to patients and health professionals regarding the treatment.

In May 2018 the minutes were released from PHARMAC's Pharmacology and Therapeutics Advisory Committee (PTAC) meeting held earlier in the year, in February. At this meeting applications for funding from Roche and supporting submissions from MSNZ were reviewed.

The minutes concluded that PTAC support the funding of Ocrelizumab for RRMS on the guarantee that this will be cost neutral to other currently available MS Treatments. They also requested further information from the Neurological Subcommittee and MS Technical Advisory Committee (MSTAC) on the risks of using Ocrelizumab in patients who are JCV positive, potential fiscal risks of adding an additional therapy, and views of sequencing options of Ocrelizumab. Ocrelizumab has not shown through its trials to cause PML, a life-threatening brain disease, or present a risk as a treatment option to those who test positive for the JC Virus.

Further information has been provided to PTAC on these matters and we expect these to be considered by PTAC later in 2018. MSNZ is very pleased with this result and hope to see Ocrelizumab on the Pharmaceutical Schedule for RRMS in the near future as a first-line treatment option.

PTAC unfortunately declined the request to fund Ocrelizumab for PPMS patients. MSNZ is disappointed with this outcome. PTAC accepted that there is a high unmet need for those with PPMS but have questioned the evidence and outcomes of the ORATORIO clinical trial as well as its use in combination with other immunosuppressive treatments. Further evidence has been provided to PTAC for review later in 2018.

Whilst some may consider the successes "modest", for those New Zealanders living with PPMS, the most aggressive, disabling and life altering form of the condition the trial outcomes provide hope that Ocrelizumab may potentially slow or halt the progression of disability, reduce their fatigue and improve their mental quality of life.

MSNZ was pleased to be able to assist in promoting the Ocrelizumab Global Compassionate Programme which has enabled 20 people nationwide with PPMS to receive access to the treatment. MSNZ is committed to continuing to advocate for Ocrelizumab being made available for those with RRMS and PPMS in New Zealand who would benefit from access.

Graham Walker was diagnosed with Primary Progressive MS five years ago and is one of 20 New Zealanders receiving Ocrelizumab as part of a Compassionate Programme.

**“It's incredible the improvements I have found to my daily life and mobility, particularly in ways I didn't expect. I can now clap my hands palm to palm when previously my right palm clapped the back of my left hand, and I no longer drag my foot when I walk.” - Graham Walker**

Walker is optimistic but also realistic about the treatment. “I hope ocrelizumab will continue to halt the progression of my condition and disability. I know it is not a cure but I hope it will enable me to stay active doing the things I love for longer like playing with my young grandchildren and cycling. I'm an optimistic person usually but this treatment has given me so much more hope for a bright future and will hopefully do the same for many more New Zealanders.”

## HSCT

On the 16<sup>th</sup> October 2017, as part of MSNZ's 50<sup>th</sup> Anniversary and Annual General Meeting, a lecture evening was hosted on 'The future of MS treatments' in Christchurch. Internationally renowned Stem Cell Transplant Haematologist, Dr Riccardo Saccardi of Careggi University Hospital in Florence, Italy, addressed the growing evidence to support Haematopoietic Stem Cell Transplantation (HSCT) as a viable treatment option for New Zealand to consider.

Dr Saccardi presented evidence to support the use of HSCT for those who are early in their disease course, have highly active relapsing MS and tried and failed at least one, if not two, of the treatments currently funded by PHARMAC. The criteria for observational studies in Europe and Australia follow these criteria and MSNZ would like to see the same opportunity made available here in New Zealand. This information and position had been presented earlier in 2017 to the Ministry of Health and the Society intends on continuing this push to see access made available in NZ. The regulated availability of treatment in NZ would reduce the numbers of patients fundraising and travelling abroad for treatment and improved monitoring and safety for patients.

Following Dr Saccardi's presentation MSNZ publicly confirmed its support for the introduction of HSCT, within a clinical trial setting under established international protocols, as a viable treatment option for people with MS. MSNZ worked with the Sunday programme to raise the public awareness of HSCT and our position.

MSNZ acknowledges that the treatment still comes with risks and that there are some people who have not achieved successful outcomes. However, there is an identifiable, and growing, group of people with MS who are doing extremely well following treatment.

Dr Saccardi highlighted the need for continued robust research and clear information to help clinicians, patients and regulating bodies make decisions based on the proven evidence. MSNZ supports patient choice has requested the Ministry of Health review introducing HSCT as a treatment option based on the latest research available, offering its support in the process.

## Misuse of Drugs (Medicinal Cannabis) Amendment Bill

With the increasing interest in Medicinal Cannabis for managing pain and spasticity in MS and other chronic conditions MS NZ and Motor Neurone Disease New Zealand jointly commissioned independent researcher Kerry Walker to provide a written report on:

1. The current research on the use of medicinal cannabis for MS (MS) and motor neurone disease (MND) symptom management;
2. The risks and the risk/benefits of using medicinal cannabis; and

3. The current international recommendations for the safe use of medicinal cannabis for MS and MND symptom management.

The report is designed to contribute to an informed debate about the information and research into the benefits that cannabis can provide medicinally. The information is intended to allow the reader to formulate their own informed decision as to their support or otherwise for use.

Following this, in January 2017, the Government approved First Reading a Bill to make changes to the Misuse of Drugs Act 1975 with the Misuse of Drugs (Medicinal Cannabis) Amendment Bill. The bill currently aims to:

- introduce an exception and a statutory defence for terminally ill people to possess and use illicit cannabis and to possess a cannabis utensil; and
- provide a regulation-making power to enable the setting of standards that products manufactured, imported, and supplied under licence must meet; and
- amend Schedule 2 of the Act so that cannabidiol (CBD) and CBD products are no longer classed as controlled drugs.

The Bill is now being reviewed by the Health Select Committee. As MS is a chronic condition, not a terminal one, it is not covered under the proposed new legislation and cannabis use for medicinal purposes would still be illegal under the law.

In response, MSNZ wrote a submission supporting regulated, pharmaceutical grade medicinal cannabis products being made available, free and legally, to people with MS for the management of pain and spasticity, on prescription from their GP or neurologist. Medicinal Cannabis products are currently unfunded in New Zealand and expensive to access. We are following the progress of this review with interest and will be continuing to advocate for the inclusion of people with MS to be within the legal parameters.

There is a strong interest among the MS community for funded access as available options currently cost patients between \$300 and \$1,200 per month. MSNZ also participated in a health professional education day to help improve the understanding and benefits of Sativex for people with MS.

## I Can't Wait

Crohn's and Colitis NZ approached MSNZ in late 2017 to request support for its campaign 'I Can't Wait', advocating for the needs of those with bladder and bowel issues. The campaign aimed to support those with medical conditions with immediate access to toilets on business premises where no public facility is available.

Bladder and bowel problems affect approximately 50% of people with MS, as well as many expected unreported cases. These symptoms of MS can be concerning and isolating and the fear of not being able to access a toilet in the necessary time can exacerbate these feelings.



They can have an impact on a person's well-being and mental health.

Crohn's and Colitis NZ presented the oral petition to the Health Select Committee on the 21<sup>st</sup> March 2018 in Parliament. Their request recommended legislative changes which would see that a person with an approved medical need to urgently access the toilet facilities of a business (e.g. the employee bathroom) should no patron services be available.

MSNZ wrote in support of this petition with the request that people with MS be included in the list of those with a medical need to use the bathroom urgently.

It was reported that the Health Select Committee appeared sympathetic and interested in the needs of those with crohn's, colitis, MS and other health conditions which have an impact on the bladder and bowel. We await their response and indications of whether this petition will be successful in bringing about legislative changes for those in need.

## End of Life Bill

MSNZ was approached to advocate in support to the End of Life Bill proceeding through Parliament. As the topic is hotly debated with support for both sides the National Executive Committee agreed that MSNZ would not take a position on this Bill but encourage individuals to make personal submissions at their own choosing.



# New Zealand Multiple Sclerosis Research Trust

On the 25<sup>th</sup> May 2018 the New Zealand Multiple Sclerosis Research Trust along with invited guests welcomed Professor Helmut Butzkueven, the Managing Director of MSBase, to New Zealand to officially launch MSBase, New Zealand's first MS patient registry. Professor Butzkueven was in the country to speak on behalf of MSNZ at three advocacy meetings regarding the importance of preserving brain health and particularly the need to access disease modifying drugs (DMTs) earlier than is currently allowed by the New Zealand specific criteria. More information about this can be found on page 8.

In October 2016 the Trust funded its foundation project, "A Feasibility Study on the Introduction of a National MS Patient Registry", conducted by Dr Caroline Allbon. The final report was submitted in July 2017 and concluded with the recommendation to introduce MSBase to New Zealand.

MSBase is a longitudinal, strictly observational MS database open to all practicing Neurologists and their teams, worldwide. There is now the anonymised data of over 60,000 PwMS from 33 countries in the database. In collaboration with participating Neurologists, MSBase has established a unique web-based platform dedicated to sharing, tracking and evaluating 'real world' data outcomes. The ability for the front-end platform iMed to interface with existing hospital records has the potential to reduce duplication for under resourced neurology departments and reduce time spent on administrative tasks.

MSBase encourages global research and observational studies using 'real world' data. With consent, MSBase enables people with MS to participate in global collaborative research using non-identifiable data, which would otherwise be difficult to achieve.

Since the completion of the feasibility study, the Trust has been working to establish two pilot sites in Canterbury and Waikato. Professor Butzkueven officially launched the two pilot sites at the Auckland function expressing his excitement that New Zealand was now joining this important MS database.

"Since the Trusts initiation our primary focus has been to establish a national database of all people with MS in New Zealand. We are proud to be leading the way and look forward to New Zealand playing its part on the global stage, participating in life improving research and improving our understanding of research needs and outcomes through real world data" commented Trust Chairman Doug Haines.

As the next stage, the Trust has continued its commitment and is now funding the implementation of MSBase at the two pilot sites. The pilot teams of Dr Deborah Mason alongside Nurse Specialist Heather Brunton in Canterbury, and Dr Jan Schapel and Nurse Sophie Wills in the Waikato are now beginning the processes in their respective DHBs. Following expressions of interest, the Trust is hopeful that other DHBs will join in the near future.

Attendees also thanked departing Trust Chair Tim Preston who has successfully spearheaded the organisation since its launch in 2015. The Trustees thank Tim for his dedication to elevating the importance of MS Research and laying the groundwork for the future direction of the organisation.

The Trust continues to strive to reach its goal of raising \$5 million by 2020. Vital funds will support more centres around the country to join the MSBase patient registry as well as stimulating other MS research projects in the coming years.



Professor Helmut Butzkueven, Dr Deborah Mason, Dr Ernie Willoughby



# MS Awareness Week 2017

The 2017 Multiple Sclerosis Awareness Week took place across the country between 28<sup>th</sup> August and 3<sup>rd</sup> September. With the support of Pub Charity Ltd funding, MSNZ was able to support the Regional Societies to raise much needed funds by supplying fundraising resources and raising awareness nationally for MS as a chronic condition affecting New Zealanders by highlighting the needs of those living with the condition.

The goals of Awareness Week and this project were three-fold:

1. To increase public awareness of MS, highlighting it as a chronic, unpredictable, life-changing, disease with currently no known cause or cure;
2. To increase public empathy of MS so they have a better understanding of what living with MS means and;
3. To encourage the public to choose to donate and support MS Regional societies supporting people with MS.

In 2016 Pub Charity Ltd funding supported the development of three short videos to assist us with raising awareness of what MS is and what life is like with MS from the perspective of those diagnosed and living in NZ. These were well received however our budget only allowed for marketing within our networks and on Facebook. To reach the wider public we used the same video content in 2017 with an investment in online marketing to encourage people to watch the video, drive traffic to our website and encourage people to learn more about MS and donate.

We promoted MS in a variety of mediums to capitalize on the reach and target multiple demographics including;

- Launching our new website at the beginning of the week;
- A series of digital advertising on Stuff.co.nz resulting in 434,118 impressions during the week, 2,007 views and 189 click throughs;
- 92 short 7-9 second radio Adlets across four radio stations to encourage people to donate to MSNZ online or by giving to Regional Societies through their Street Collectors;
- Two weeks of promotion on Health TV in hospital and GP waiting rooms.

For the 2017 Street Appeal and associated events MS Regional Societies recorded varying success across the country. \$140,000 was raised nationwide with notable successes by Multiple Sclerosis and Parkinson Canterbury experiencing a record year collecting over \$60,000 and MS West Coast holding a successful Craft Fair collecting over \$10,000 from the local community. Over 548 volunteers, 19 schools and 67 Service organisations dedicated over 2,439 hours of their time at 235 locations to support MS organisations across the country to raise much needed funds to continue to provide services in their communities. THANK YOU to everyone who donated their time or money to supporting Multiple Sclerosis in the 2017 Awareness Week and Street Appeal.



# Mastering Mountains Grant

MSNZ is proud to continue working with the Mastering Mountains Trust to provide a range of opportunities to assist people diagnosed with MS, to overcome a specific obstacle so that they can achieve a specific outdoor pursuit. This year we were able to award three grants in two categories, the Mastering Mountains Grant, awarded to Marlene Hessing and Michelle Gerrits to reach their goals to be more active in their daily lives, and the new Mastering Mountains Expedition Grant, to encourage people to achieve their dreams further afield, on an overseas adventure awarded to Tracey Hall.

## Marlene Masters her Mountains with Pride

On 6<sup>th</sup> May Marlene Hessing proudly achieved her personal mission of completing the Tiri Tiri Matangi Walk, following an Anzac Day walk on the Leigh Coastal Walkway on Goat Island. While the one-and-a-half and three-hour walks respectively, may be easily achievable for some, for Marlene who was diagnosed with relapsing remitting multiple sclerosis (RRMS) in 1999, and then a few years later secondary progressive MS (SPMS), this was a goal she thought not possible.

That was until she saw an advert for the Mastering Mountains Grant and was awarded the opportunity to work with Lisa Gombinsky, of Counter Punch Parkinson's in Auckland, to help her build her strength, balance, coordination and stamina for her to achieve her goals.

On Marlene's first walk the combination of the narrow track of the Leigh Coastal Walkway on Goat Island, its steep drops to the side, loose gravel underfoot, and her balance issues from her MS, made the walk a challenge. However, Marlene took it in her stride "it was also exciting as the greater the challenge the sweeter the reward for having completed it."

Supported by her personal coach Lisa, Marlene completed her second challenge, the Tiri Tiri Matangi Walk. Despite the predicted bad weather Marlene chose to not let this stop her. "We took a longer route, just in case, and walked nearly an hour and a half reaching the light house and joining other people." Fortunately, the weather was on Marlene's side, as the rain stayed away with the sun even peeking through the clouds as they reached the summit. Marlene relished the lovely views, great bush and tree canopies, as well as listening to the host of native birds who were cheering her along as they merrily chirped away.

Marlene, a self-described survivor doesn't let MS and her mobility issues hold her back. Despite having to give up a successful career with Air New Zealand as her condition progressed, Marlene's strong, independent and determined personality empowered her to fight back against the odds. Even before being awarded the Mastering Mountains Grant, Marlene attended the gym three times a week, as well as yoga and water walking

classes run by MS Auckland, to keep mobile.

Regardless of the changes in her mobility, Marlene's love of walking and the outdoors never wavered and so she leapt at the chance of applying for a Mastering Mountain's Grant provided through the collaborative efforts of the Mastering Mountains Trust and MSNZ. "Walking is the best medicine" commented Marlene "it's good for body and mind."

Impressed by Marlene's determination and goals, she was awarded a grant for personal training sessions with Lisa at Counter Punch Parkinson's. "I knew that if I trained with a professional, they would help me to be consciously aware of using the correct technique while improving my gait, posture, arm movements, weight transferring and everything else that goes with safe and correct walking. I have lost these skills and need to retrain."

"With Lisa's training and my diligent efforts to do just about everything and more, we achieved an amazing result. This has now given me the confidence and tools to keep going. I have already joined a walking group that do between an hour to an hour and a half each week. This will be good for me to keep up and build strength, endurance, balance, speed and fellowship."

Mastering Mountains Trust founder Nick Allen said he was blown away with Marlene's dedication and passion and how quickly she was able to achieve her goal by putting her mind to it. "Marlene is exactly the type of person this grant was developed to support."



## Michelle Gerrits achieving her dreams one step at a time

Michelle Gerrits was tired of explaining to her grandchildren that the reason she could not join them on family walks was because "Nanny's legs don't work properly." Determined not to let her MS stop her from doing things that she values the most, making memories with her grandchildren, Michelle applied for a Mastering Mountains Grant to purchase an Alinker with the aim of eventually completing a nine kilometre section of the Great River Ride, from Ngaruawahia to Horotiu with her



family. The Alinker, a walking bike, is designed to support people with mobility issues to remain active physically and socially, while being balanced and comfortable.

Since being diagnosed six years ago, Michelle suffered from severe numbness, tingling, balance and mobility issues. Finding work and social occasions hard, Michelle would need to sit down, struggling to stand for long periods of time, “sometimes it is hard to mix and mingle.”

Michelle believes that one of the best things she can do is to be proactive. “Don’t give up,” she says, “try and try again.” With the support of the Alinker she was able to focus on building the strength and stamina she needs to go the distance and achieve her goal, “now that I have the Alinker Bike, not only can I do the track with my family and grandchildren, but I can join them in doing so much more.”

The gift of the Alinker bike means that Michelle is no longer confined by distance and disability. The possibility of doing more and getting active has not only improved her physical wellbeing, but her outlook on life has brightened as well.

Michelle described how “disheartened”, she felt when she was first diagnosed, especially when thinking about the future, but now, she has a firm belief: “Don’t let the bad times get you down!”

## Mastering Mountains Expedition Grant

In 2018 MSNZ and the Mastering Mountains Charitable Trust awarded the inaugural Mastering Mountains Expedition Grant to MS Central Districts member, Tracey Hall. An avid adventurer she applied for funding to help her achieve her dream of mastering the famous trek along the Inca Trail to Machu Picchu. Tracey isn’t one to let anything hold her back from achieving her dreams, let alone her MS diagnosis.

The Mastering Mountains Trustees were inspired by her dedication not only to overcoming her MS, but also her love of the outdoors and strong sense of community. The trustees, MSNZ and the Grant sponsors, World Expeditions and Macpac’s Fund for Good, are excited to support Tracey as she pursues her goal on the 11-day trip.



# Dorothy L Newman Scholarship

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.

## Bronwyn

“I had been working as a civil litigator for 9 years when I was diagnosed with multiple sclerosis. My main symptoms were a permanent loss of central vision in my right eye due to optic neuritis, and fatigue. I continued working as a lawyer for another year, but ultimately the amount of reading required, high pressure and long hours meant it was unsustainable long term. I initially took a role in a different area of work that was manageable but not at all stimulating or utilising my skills.

With the support of the Dorothy Newman scholarship, I was able to enrol in a post-graduate diploma in international development which I am completing by distance study through Massey University. The scholarship has transformed how I feel now and my optimism for the future. It has made me believe that I am still capable and can still contribute to society and also set a good example for my children. Additionally, it has made me feel less isolated socially as I have made many new friends in my course. This would not have been possible without the support of the Multiple Sclerosis Society.”

## Christine

“After being diagnosed with M.S, I realised I needed to start to have a look at other options for my future when it came to my teaching career. I’d always assumed that after having my children and taking some time off to raise them, I would enter back into full time teaching. I had started out slowly after having kids doing Reading Recovery teaching in a part time position and then I got my MS diagnosis and started to suffer from overwhelming fatigue. This was when I realised that full-time classroom teaching was probably no longer going to be in my future and that I needed to see what else was available. Training to become a SPELD NZ teacher working one to one with children suffering from dyslexia and similar disabilities, was something that allowed me to continue teaching but to decrease my hours and workload. As I was considering this, I discovered the Dorothy Newman scholarship. I applied and was so lucky to be successful. Having the scholarship has been a big financial help. It has meant I was able to cut my teaching back to one day a week and study on the other days, which I have been really grateful for. I have really loved all of the learning – even the assignments although my family wouldn’t say the same when I’m writing them!”

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



# Bangers To Bluff 2018

In April, the Auckland Rotary Club of Half Moon Bay traversed the country making the long journey to Bluff in their annual fundraiser 'Bangers to Bluff'.

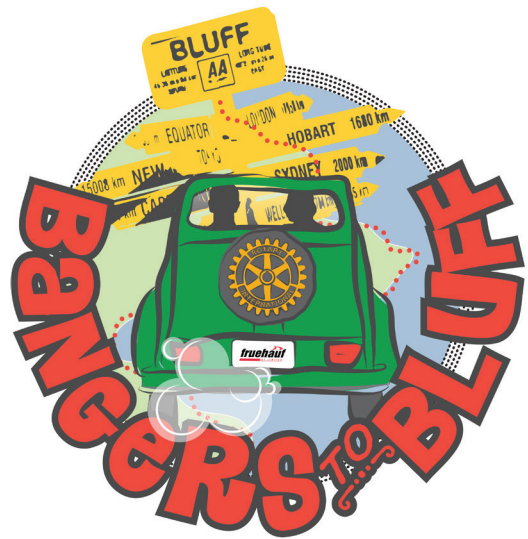
Every year competitors buy 'Bangers' (cheap cars under \$2,000) and drive on 'roads less travelled' from Auckland to Bluff, over an 11-day period. After the last photo stop in Bluff the cars are sold off at auction to help raise funds for their chosen charities. The cars certainly were 'bangers', ranging from an Audi with very broken suspension to a Toyota with a range of horn sounds that delighted the children.

This year, MSNZ and Hopeworks NZ (who provide support to people with head injuries) were fortunate to be the chosen charities and MSNZ were delighted to have an opportunity to meet the full crew in person.

When Kirwee resident, Glenn Sparrow, found out about the fundraiser he got in touch with the organisers and offered the friendly town as a stop off on their trip. Monday the 16<sup>th</sup> May saw the arrival of twelve cars at the Kirwee Reserve for a morning tea to fuel them up for their journey on the great divide from Christchurch to Greymouth. "I think the part they were most excited about was the cheese toasties," laughed Sparrow. "They couldn't praise them enough."

The strong community spirit from the Kirwee residents, MSNZ staff and members of the local MS and Parkinson's Society of Canterbury, made the Bangers crew feel genuinely welcome and appreciated for what they are doing. The morning tea was not about fundraising for clubs or charities it was about expressing our gratitude for everything they are doing for people with MS and neurological conditions, with some true Kiwi hospitality mixed in.

After a couple of hours and multiple plates of cheese toasties, the Bangers left Kirwee with blasts of their horns and headed off to the next stop on their trip, a photo at the Springfield donut.





# Fabulous 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

## Cherie

“My mum’s resilience living with MS has inspired me to raise awareness and financial assistance towards further research into this illness.

My beautiful mum was diagnosed with the disease over 20 years ago yet manages to stay active in the community and extremely positive despite her disability.

There’s no point in worrying about things you can’t change” is Mums go to saying. Witnessing her determination and courage when faced with a challenge has taught me the true power of mental strength. She is an absolute inspiration in my life and I wouldn’t be who I am without her today.

Mum has shared with me, that being diagnosed with a disease that doesn’t have a cure or much awareness can be difficult as there is a lot of uncertainty about your future. Now older, I am able to understand the effects of MS and feel responsible for spreading awareness about the illness and doing my part towards helping others.

Raising much needed funds for MS will help towards finding a cure so that individuals in the future can manage their disease more effectively in the early stages without experiencing as many debilitating symptoms.”

## Kathy

“We had a great day and I’m still blown away by everyone’s generosity ~ I’m so lucky to have such a wonderful group of supportive and caring friends. My mum and I both have MS, and people we’ve known for years were of course more than happy to donate.

My event was a picnic then walk and talk at the beautiful Trentham Memorial Park in Upper Hutt. It’s a park we go to often as it has a great playground which our little girl, Georgia, loves and its dog friendly which our pooch, Sarge, loves! So my invite encouraged people to bring themselves, their kids, and their dogs for an arvo of ‘gentle exercise and socialising’.

To say thank you, I set up a table with a bit of food and some drinks. My darling mum made two types of muffins, my sister made a delicious brownie, and my husband made some yummy little sandwiches, plus we had a few hot savouries. It all went down very well!”

## Emily

“In mid-2017, I wanted to challenge myself with something well outside of my sphere of experience. Running has never been a natural strength of mine, despite overall living a healthy and active lifestyle. So, I decided to bite the bullet and sign up for the Auckland half marathon which took place in October. I wanted to make myself accountable – so decided to run for charity.

However, I wanted to pick a charity that I connected with, as there are many deserving ones out there. I’d recently watched an amazing video by Nic Chapman, a famous YouTuber about her diagnosis with MS. Also, a close friend of mine’s mother has MS which results in her being in a wheelchair and highly dependent on her family and carers.

There were many dark mornings and evenings in the middle of the Wellington winter, that made me wonder what on earth I was doing. But, the feeling at the finish line made it worthwhile – relief, pride, elation. I successfully ran the half marathon in just over two hours, and smashed my initial \$500 target by almost three times. This was all thanks to the generosity of family, friends and colleagues at Kiwibank. Almost exactly a year to the day, it’s still an achievement that I look back on with pride, not only for the physical and mental challenge, but also that I was able to do something that some people with MS cannot do – move my body freely and push it to its limits.”

## Meghann

“Everyday I feel fortunate and grateful to be able to move and run. So I thought what better way to honour my dear Aunty that lived with MS, then to contribute to a worthy cause and continue to do what I love by taking part in Kiss Goodbye to MS with my running to help raise awareness and funds for MS.

Over the past 12 months I have raced at the World Masters Athletics in Denmark and New Zealand Masters Athletics. I’ve had a few set backs, but what I’ve always said to myself “it’s how you deal with it, that makes the difference”. I enjoy having a goal, I believe in staying consistent and being patient. I’m looking forward to seeing what the rest of 2018 will bring.”

# Field Worker Training 2018

The 2018 Field Worker Annual Meeting was held in Auckland on the 24<sup>th</sup> and 25<sup>th</sup> May in collaboration with MS Auckland's Research Day on Saturday 26<sup>th</sup> May. The educational two and a half days were attended by 22 Field Workers from across the country. By providing nationally consistent, relevant, evidence based and up-to-date information on MS, the meeting is a core service provided by MSNZ to assist the Regional Societies in their endeavours to support people with MS to self-manage their lives. The meeting endeavours to cover a range of topics which support the Field Workers and prepare them for often challenging situations and difficult discussions they may encounter supporting their clients.

Topics this year included:

- Bladder incontinence;
- Exercise for the arms, from the wheelchair and in front of the computer;
- Spasticity and MS;
- Alinker;
- De-escalation;
- And presentations on the range of treatments available in NZ.

MSNZ was also able to support the MS Auckland Research Day attended by over 200 people with MS, their families, carers and Field Workers, to learn more about the progress being made. MSNZ was delighted to bring key note speaker Professor Helmut Butzkueven to present at the meeting on Brain Health: Time Matters in MS and the changes to treatment criteria that MSNZ would be advocating to PHARMAC. Guest speakers

also included Dr John Davison who discussed the role of cognition and MS, and Dr Mark Craig who presented the benefits that plant based diets can have.

Thank you to the event sponsors for their support of the Field Worker Annual Meeting and MS Auckland Research Day. Without the funding support from the Multiple Sclerosis International Federation, Roche, Novartis and Biogen these days would not be possible.



## MS Fundraisers Workshop

On the 16<sup>th</sup> May 2018, MSNZ held a Fundraisers Workshop attended by 15 participants from 10 MS Regional Societies across the country (Southland, South Canterbury, Canterbury, West Coast, Wellington, Central, Hawkes Bay, Waikato, Bay of Plenty and MSNZ). The workshop was an informative day, hearing from a variety of speakers from both within and external to the MS Network.

The event was organised in response to the expressed need of our members looking for opportunities to collaborate and learn. For many, attending larger fundraising conferences can be beyond the financial reach and beyond what is applicable to their needs. Many of the MS Regional Societies often work in silos from a fundraising perspective so the ability to network, share ideas and experiences was a key priority of the workshop.

From a National Office perspective, it was interesting to hear about the innovative and often unique events that are happening nationwide including; Southland's successful blank envelope auction, West Coast's Craft Fair and the opportunities this brings to engage with the wider community and the continued growth and success of Hawkes Bay's "Multiple Steps for Multiple Sclerosis" event.

Thank you to Kate Russell (Canterbury Medical Research Foundation), Lynne Trowbridge (Multiple Sclerosis and Parkinson's Canterbury) and Vimbayi Chitaka (Rata Foundation) for supporting our MS Organisations and volunteering your time to speak to our MS Fundraisers.



# Field Worker Representative's Report to the 2018 AGM



I feel really privileged to be asked.

After eight years in my role covering Rotorua and Districts I was given the privilege of being elected as Field Worker Representative (FWR) at the Field Worker (FW) Training in Auckland in April of this year.

My first official task was to request from all regions their yearly report for this AGM which proved to be a challenge when some regions needed three reminders and a forth from National. It was interesting reading each report and I felt for the most, each region was doing really well for their PwMS. Because of this task it gave me the opportunity to have one on one contact with all the FW's around the country either by phone or e-mail and ensuring them of my support if needed

I became aware that our new Field Worker from Bay Of Plenty may need a hand to settle into her new role so as FWR I initiated a get together where we were able to look at all the aspects of our responsibility to our PwMS, our committee and National which was greatly appreciated. Fortunately, we are only 45 minutes' drive apart.

Other than these two tasks my job as FWR certainly hasn't been arduous and I do really feel privileged to be asked.

*Diana Hay*

*MS Resource Nurse for Rotorua & Districts, MSNZ Field Worker Representative*



# Regional Reports 2017-18

## Upper North Island Cluster

### Northland

MS Northland continues to remain busy with a membership of over 100 plus their families covering an area east/west of Wellsford to Cape Reinga. In the past year we have had eight new PwMS join our society, most of them newly diagnosed but over a wide age group.

This past year has seen ongoing events such as yoga classes, our newly formed exercise group, ten pin bowling and coffee groups continue. We were fortunate enough to have an afternoon cruising on the Whanagarei harbour which was well attended.

Recently we held a Health and Wellness seminar for our members. We had three speakers, a Homeopath, a Craniosacral therapist and a Life Coach. These were all very interesting with tips on how to incorporate their various practices into everyday life for an improved sense of wellbeing.

Here in Northland, we are very lucky that there are a range of organisations providing a Disability Information Advisory Service known as the Northland Collective DIAS. Tiaho trust supports these organisations, to which MS Northland belongs. We meet every 2 months to share ideas, work collaboratively & support each others organisations, which works very well.

*Renee Cains, Field Worker*

### Auckland

The Auckland Region extends from the Bombay Hills in the south to Wellsford in the north. Four fieldworkers cover the region estimated to have just over 1,000 people living with MS. Our database of people we make contact with currently has 720 people.

We encourage people to be part of the MS Auckland community even if they do not wish to make current use of any of our services. We continue to accept donations rather than promote membership (though this is still available). This is working well and has helped our community reach to grow. We also field a number of requests through our website from people with MS who are looking to travel to Auckland and are seeking information.

About 60 people in Auckland are diagnosed with MS each year. We are developing a seamless service between the hospital and community to enable all newly diagnosed people to be referred to our services. Regular catch ups and contact with the MS Nurses help to ensure people in Auckland are well supported. The complexity of cases has increased over the years requiring us to also work in closely with a number of other government and

social service agencies.

Aside from the Field Worker education, information and advocacy provided, we also have a number of activities, workshops and seminars throughout the year. Core activities each year include:

- 15 Active Support Groups - two popular new groups include a Men's group and a West Auckland group.
- 6 Hydrotherapy groups, led by neurological physiotherapists or educators in 6 different pools across Auckland each week.
- Quarterly workshops covering a range of topics. This year we looked at including practical workshops, with the first one on Resistance Training proving very popular.

Other activities and services are listed on our website.

*Dianne Bartlett (South and East); Catherine Glover (Central); Diane Hampton (North) and Andrea Kortas-Ray (West and Rodney)*

### Waikato

MSWT has had another busy year, client numbers have continued to grow, and services have continued to expand to meet needs. We have started two new groups, Hamilton support group which meets monthly and a walking group that meets weekly. The new groups are in addition to the existing groups and activities including the gym class that operates twice a week, the existing support groups in the outlying areas and the annual MS education evening where we invited neurologist Jan Schepel to address our clients.

A highlight this year was the MS family camp at Totara Springs, it is over a weekend and brings families from around the greater Waikato together for a weekend of fun, friendship and learning.

We also have fundraising activities including The Kawhia Cruise car rally, The Michael Ford Golf tournament, a movie night and Entertainment book sales.

We are thrilled to have had two recipients of the Mastering Mountains award, Sue Dela Rue achieved her dream of walking across Maungatangi Mountain where staff, clients and supporters enjoyed being part of the day and walking with Sue. Michelle Gerrits was delighted to be awarded the grant earlier this year; she has purchased an Alinker and is training to walk a section of the Waikato walkway with her family and supporters. We are also looking forward to hearing of Jody Butler's adventures after she sails away with Oceans of Hope.

MSWT continues to enjoy a close working relationship with the neurology department at Waikato hospital with regular contact at the MS clinic, infusion centre and

regular meetings with neurologists and nursing staff.

*Liz Hogan, Karen Bird, Field Workers, Waikato*

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## Bay of Plenty

The society continues to provide information, advocacy and support to PwMS whilst providing a diverse range of exercise and social activities to ensure our members have choice in what activities appeal to them. This has resulted in members increasing their self-empowerment, independence and quality of life.

Circumstances have dictated that both the WBOP Fieldworker and Office Manager have moved on from their respective roles. Both these roles have since been filled by experienced professionals who will continue to be homebased (as is the EBOP Fieldworker). Staff work with a pro-active approach in providing a client centred service.

The Society is now running two MS Awareness campaigns annually. These events are based around World MS Day in May and MS Awareness Week in September. Both these activities are proving successful with regards to raising awareness in the community about MS, informing of the support that is available for PwMS and raising much needed finance in being able to provide information, support and advocacy services to PwMS.

### Key Trends

- WBOP continues to see member numbers growing due to the trend of people moving here from other regions and referrals from the DHB. These people need support in managing their diagnosis and to establish themselves in a new community.
- Member numbers in the EBOP remain consistent.
- Homelessness continues to grow in Tauranga. There is a real shortage of suitable affordable housing in this region.
- Employment issues for PwMS are becoming more prevalent.
- There is no Community Response Team or Neurology Nurse in the EBOP.

*Max Hollis and Cheryl Standring, MS Field Workers*

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## Gisborne

We have 27 clients with MS and other related neurological conditions. All but one, take part in all activities offered.

We have a morning tea group every six weeks approximately 16-20 members attend. Then we have the evening group. These members work and so we meet at a restaurant every two months approximately 12-16 attend. This is a great way to keep in touch and discuss any issues or concerns they may have with follow up from the field officer.

Last December we had a Christmas Lunch at a winery with 25 members attending and in June we had a Mid-Winter Christmas party with 30 members attending.

Health products are available to clients free of charge providing they have a letter from their GP.

Horse riding for the Disabled, pool therapy, Pilates and exercise classes are offered to clients. Only two clients accepted the offer of horse riding and Pilates.

The Executive Committee have been very supportive and this year I am required to attend for 15 minutes at their meeting to keep them updated and for any requests that I may have on behalf of the clients.

I spend Monday afternoons in the office. Tuesday to Thursday I visit clients, and make numerous phone calls. I also refer to physiotherapists, Speech therapists, GPs and Occupational Therapists and liaise with other support groups e.g. Stroke support, head injury, age concern, Volunteer Centre and NASC and CCS. We also do fundraising throughout the year.

My hours of work are Monday-Thursday 10-15 hours per week. The area covered is from Te Araroa/Ruatoria to Mahia/Wairoa approx. 460 kms around trip.

*Christine Beard, MS Field Worker*

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## Rotorua

This is my 8<sup>th</sup> year in this role with 85 clients on the data base. My work load has shifted mainly to client request/demand, to manage volume. Each member on the data base has had some contact in a six-month period.

Rotorua has two support groups per month, meeting at cafes and Taupo has a Pot Luck Lunch at one members home per month. Taupo and Rotorua started an extra support group for their younger PwMS. Rotorua and Taupo have a mid-year lunch and an end of year lunch, paid for by the local MS Society for financial members.

Our fund raiser this year was a Garden Garage Sale in cooperation with Rotorua Garden Festival weekend. Those on the committee, those who helped with fundraisers and organising support groups enjoyed a special morning tea at Mamaku Blue Café.

This last year I have presented a presentation to the Field Worker's in my cluster group on medicinal cannabis and one to Taupo Health Care NZ for the Carer Workers. I have attended conferences in Melbourne by Roche drug company launching Ocrelizumab, MS Winter Meeting in Queenstown and Field Worker's Training and MS Research day. A 'Meet and Greet' meeting was arranged for four members who were very interested in SCT to discuss established options and create a support system.

*Diana Hay, MS Field Officer, Registered Nurse*

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## Lower North Island Cluster

### Hawkes Bay

Fundraising events such as 'Multiple Steps for Multiple Sclerosis' again increased in numbers, appeal week was a case of "steady as she goes" with a slightly larger amount being raised than the previous year. A ladies clothes swap event raised \$2,500.

Over time we have established a working relationship with different departments at HBDHB which is now enabling us to have speakers such as the Continence Advisors, Dietitians, Physiotherapist and Occupational Therapist come and talk to small groups of our members who are able to ask questions that are relevant to them. Also, we have run two Fatigue Management Courses over the last 12 months, these certainly make people look at how they are doing things and make changes that conserve energy.

Our three Coffee mornings are all well attended, and the Monday Group is an informative group giving peer support to all who attend. We enjoyed a High Tea for Hawkes Bay's Art Deco weekend, a lunch and Domino/Card session at Napier RSA and getting out and about in our community.

The swimming group available to financial members of the society is a group proving very beneficial as members use the pools at times appropriate for them especially if they are still in the workforce.

Due to work we have been doing raising awareness of the HBMS Society, we are making a number of new contacts and supporters. We've been encouraging our members to speak on our local community radio station Radio Kidnappers about their journey with MS, this has proved very successful and of interest locally. We have also established a MS Hawkes Bay Facebook page which is a closed member only group which allows our members to chat and be informed of relevant local events.

*Robyn Coyle, MS Field Worker*

### Taranaki

Everything is working really well in Taranaki with the committee gearing up for Awareness Week which they aim to make bigger and better. We now have a Facebook page other than the closed one for clients, and it is proving already to be of great benefit to contact members about functions etc. It will no doubt be beneficial for fundraising as well.

We are now looking after some Motor Neurone Disease (MND) people who request our help. I keep in contact with the MND Fieldworker who is based in Waikato, they feel more comfortable having local support.

We have a nurse at the hospital who is looking after all the members who are on drug treatments, but we have no nurse to work with the neurologists when they are visiting.

I feel totally supported by the MS Taranaki committee and this makes my role as field worker so much easier.

*Moir Paterson, MS Field Worker*

### Wanganui

Kia Ora Koutou Katoa

During the past 12 months I have been kept busy with my usual support and advocacy to our MS clients.

I have had a surge of newly diagnosed clients in between the ages of 20 and 45.

I have been doing community presentations to raise MS Awareness and to raise our little MS Societies profile. This includes, newspaper articles, radio announcements with MOREFM, representing MS Wanganui in Community events, invitations to speak about MS and what our society is all about (Whanganui Girls High School, Hospice, Freemasons, network meetings etc.) We are looking in the near future to do clinical presentations for GPs and nurses to help PwMS.

We have no Neurologists or MS Nurses in Wanganui. Clients go to Palmerston North to see their Neurologist. However due to Palmerston North being overwhelmed and over committed already, they are declining new clients from Wanganui. We currently have five clients with no MS clinical support due to their GP referrals being declined. We unfortunately also do not have a specialist clinician at WDHB outpatient department.

I attend monthly WDHB and Community Network meetings to keep up-to-date with everything.

I absolutely love our group events/sessions. It is an opportunity to watch all our clients shine and relax knowing they are in a safe and accepting environment.

Hosting our education workshops with local guest speakers specialising in the workshop topic, and the interactions our members have before, during and after the sessions, it is rewarding seeing our members participate and learn from the workshops.

Bangers to Bluff was amazing, we had such an awesome time with the group and community. The morning was thoroughly enjoyed by all and the energy was fantastic.

I do wish we could have more fieldworker cluster meetings, I treasure and value them in every possible sense.

*Michelle Chapman-Cullen, MS Field Worker*

### Central Districts

MS Central Districts has had another busy year dealing with complex cases and constant new referrals, as well as adjusting to only one Field Worker in the field. Philippa has undertaken to be the part-time Field Work Support helping in the office, organising education sessions and making sure all the Health centres and GP's are aware



of our services. Overall, new clients are well provided for though still some frustrations with waiting times for DHB services.

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 offer regular practical sessions on managing MS. These sessions offer practical information such as getting up from a fall, dealing with brain fog and non-medicinal management of pain. There have been two Minimise Fatigue, Maximise Life programmes this year. There has also been keen interest in the Massey personal training programme run by the School of Sport and Exercise students. We have jointly developed a pathway where by clients are able to continue with their rehabilitation at other gyms.

The 2017 Annual Appeal was a very successful appeal raising almost \$8,000. Presentations to several Lions Clubs resulted in more of their members boosting our volunteer numbers which certainly contributed to the efforts.

Other activities include our now regular Christmas shopping expeditions which is growing year by year and much anticipated by ladies who have husband carers. Bimonthly evenings where we have an outside speaker such as Janet Thakray from continence NZ, and we have a volunteer developing our new database which we hope will not only be of invaluable help to the society but also as a fundraising option.

*Ria Sapsford, MS Field Workers*

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## Wellington

The MS Wellington Field Worker Service comprises of one full time, and two part time Fieldworkers. We hold around 450 client files so work on client request to manage the volume.

Seven regular monthly support groups are held, and clients can access an adapted weekly yoga group. We have extended our profile by commencing a Wellington City coffee group in August 2017. A 'recently diagnosed' research day was held in September 2017.

Working with our Committee, Executive Officer and Professor Anne La Flamme, information Roadshows will be delivered in different locations throughout Wellington later in 2018 for anyone with MS.

Field Workers receive referrals from, PwMS, Neurology and medical and allied health teams. We maintain good working relationships with health teams to focus on providing appropriate and effective support for PwMS and their families and whanau in the community. We provide a wide range of advocacy services, some of these include advocacy with WINZ, Residential Care facilities, GP's, Social Workers, MP's, Mental Health teams, and NASCs. Considerable interest has been received from clients regarding HSTC, Ocrelizumab and Medicinal Marijuana. We provide sites with information and can put people

in touch with clients who have experienced a certain treatment so direct feedback can be gained.

A Disability Parking App that was trialed in Wellington last year has been awarded as the Most Innovative Technology Award at the NZ Disability Support Network Conference. The app allows users to see the known locations of mobility parks on a map in real time, so they can find a park when they need it. It also allows people to make reports of parking abuse. For those with smart phones, this app may provide greater confidence for our clients who use mobility parking to make Wellington more accessible.

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

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## Top of the South Cluster

### Marlborough

The Society currently supports 125 clients with Multiple Sclerosis and Parkinson's disease with the Community Educator service throughout Marlborough with home visits.

Exercise classes are held once a week, currently 25 regularly attending with a mix of those with MS or Parkinson's with a monthly brunch held after exercise class. This class has been ACC tick accredited which means it meets a set of evidence-based criteria to ensure it is safe and effective for older adults. A weekly Dru yoga group is also running weekly. Every two months a carers group meet.

In May we invited Gilly Davy for a return visit. Gilly is an Expert Neurophysiotherapist who specialises in MS and Parkinson's. Twenty individual assessments and an evening talk on Neuroplasticity and Exercise which was partially funded by Churchill Private Hospital.

The society partially funded a Maximise Life Minimise Fatigue Course held by Belinda Butterfield, West Coast MS Society Educator and Facilitator for this course. Five members with MS benefited from a small group exploration of fatigue factors and self-assessment over three weeks.

The Society also fully funded to have the Huntington's Nurse Advisor Jeanette Wiggins visit from Wellington, to provide a study day when it was identified that we needed education to support workers involved in the care of our four Huntington's clients and families in Marlborough. A two-hour presentation was held at Wairau Hospital to staff and NASC assessors followed by a targeted presentation to support workers and a family.

Speaking opportunities to create awareness of the service included: Hospice Marlborough, Blenheim Rotary Club, Rehabilitation Unit - Wairau Hospital, Marlborough District Council - Older Persons Forum, Primary Health Organisation - Marlborough, Seniors Expo - Marlborough Convention Centre.

*Janine Ready, Community Nurse Educator*

## Nelson

MS Nelson continues to remain busy with a membership of over 115 PwMS. New clients are enrolled by appointment in their own homes, we look at referrals and then other visits are arranged according to client needs.

Currently, we have 11 support groups running at varying intervals (i.e some weekly and others monthly). We also provide Nordic walking and Victory Boxing for both MS and Parkinson's clients. We are very excited to begin a new weekly group 'FunFriday'. This is a wonderful opportunity for any isolated clients to meet up on a regular basis (45 min with trained exercise instructor, 15 min cup of tea, 45 min with a variety of entertaining activities, something new each week). This is proving to be very popular and something we have noticed is it is drawing some of our younger clients.

Recently we have been meeting up with other organisations to share ideas, work collaboratively, and support each other's organisations, which works well. We hope in the future to raise awareness in the community and fundraise together.

The challenges for our clients are varied and we believe the largest missing resource here is under sixty-five care. Sometimes carers find it difficult to obtain career relief for their relative in the rest home of their choice.

I continue to enjoy my work with people that constantly inspire me. I count it a privilege to enter their homes and be a part of their journey.

*Pam Grey, MS Field Worker*

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## West Coast

Over the past year we have seen an increase in our client base with not only newly diagnosed members joining the society but also people who have been living with MS for many years who are reaching out for more support, to have an avenue to assist them to reengage with the health system and to discover whether they are eligible for disease modifying therapies.

We continue to hold our three-monthly support group morning teas and have seen an increase in numbers attending as we have held these in conjunction with having a guest speaker on relevant neurological topics. Our newsletter is put out every three months and is widely viewed across the West Coast and is very well received by members and others in the community. Newsletters are distributed to members, supporters, medical practices and widely throughout Buller and Grey Base Hospitals.

*Belinda Butterfield, MS Field Worker*

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## Canterbury

We have had a lower number of new referrals this year (22) compared with 36 last year. Our nurse had 1755 face to face and phone contacts with clients.

We moved to new premises in March and have seen increased attendance at exercise sessions since then. An Open Day we held in June prompted people to reconnect with us and our services.

Members attended various exercise, gym, yoga and dance sessions. Social connection is an important part of group exercise and some clients go for coffee/lunch together after their exercise.

Our self-management course, Living Well With MS, which runs twice a year on Saturday mornings, has been very well received, with positive feedback. Many of those members have been keen to go on and participate in Minimise Fatigue, Maximise Life, which is facilitated by our physio.

Regular groups include peer support in Ashburton, Christchurch and Rangiora. Our regular MS lunch has reduced in frequency due to low attendance, and we now have this every three months instead of each month.

We surveyed younger people with MS (20-40) and found that 14 are keen to join a group for support. This is under way.

Our members enjoyed a visit and talk by Dr Helmut Butzkueven at the end of May, for World MS Day.

Referrals continue to be complex, with people struggling with common issues of pain, anxiety, depression and employment. Our nurse is involved extensively in advocacy and intervention.

She is working on a project on MS and Pregnancy with a midwife who herself has MS.

She attended an education day in Wellington, the Atlas conference, MSNA Conference in Brisbane, and the NZ MS Nurses meeting.

*Robin Furley, Manager*

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## Lower South Island Cluster

### South Canterbury

There have been a number of highlights in the last 12 months. Our Patron, Jim Millar was awarded Life membership to MSNZ at a presentation in Auckland. Jim who is still very active in our committee is a great support and a wealth of knowledge, congratulations go to him.

We were also recognised by our community with South Canterbury Toyota donating a sum of money to support us as did the IMPACT club with a donation of \$9,700. This is a newly formed club and the fact we were there first recipients makes it even more rewarding.

We continue to run social groups and coffee groups with a good response to these and many discussions on many different topics, some of these even being about their

MS. As we are a small community several clients have formed good relationships with each other and catch up outside these meetings giving support to each other.

At present we have 98 clients on our books and 25 whom call in for support without being clients. I have noticed a larger number of family and whanau calling into the office for support of their family members who live elsewhere often overseas. I see this as very important as it gives a lot of relief and support to upset parents', friends etc. I also find that more clients call to my office than in the past, as many of them are still working and will fit it in their work day.

We live in an interesting time of change, we have to keep up with these changes or get left behind. We need to focus on the future ahead and how we support those people with MS in the best way that we can.

*Fiona Pierce, MS Field Worker*

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## Otago

Statistics show that 578 phone calls were made with 641 emails sent and 97 home visits carried out. 56 groups were held with 413 clients participating. During the same time frame working with other agencies included 270 phone calls, 160 emails and 28 meetings. Referrals came to 15 across this time.

We have close relationships with several of the tertiary education providers within Dunedin which our members enjoy. The schools of Nursing, Physiotherapy, Occupational Therapy and Medicine are all involved. Benefits of this are two-fold, encouraging wider knowledge of MS within these environments and allowing our clients to actively encourage on-site learning.

Celebrating with a client when she purchased a A-linker, this was an amazing event in her life and I was very privileged that she let me be part of the excitement.

Meeting and connecting with our clients in Otago is an ongoing pleasure.

Listening to clients talk about how they beat the earlier 'heatwave', was interesting and a variety of cooling methods were shared around Otago due to these conversations.

Celebrating small 'wins' and achievements within our community is an ongoing way to encourage our clients.

Promotion of the Bangers to Bluff event and our clients/ community participation in this was great, a way to raise awareness of MS and a fabulous social outing for several of our members.

Seeing how the members took ownership and control of their own exercise event when the students were on holidays, a great display of our community in action.

Starting up our radio show and getting input from our clients about who they would like to hear from is ongoing and has led to some lively debate.

*Valerie Wilson, MS Field Worker*

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## Southland

I have been in this role since March 2017, I cover both MS and Parkinson's, I have a client base of 62 MS. I work 35 hrs per week. All my clients are visited or contacted at least six monthly, (except for those clients that decline visits).

- My time is spent on support to clients and their families/ whanau
- Advocacy to external agencies
- Resource information and Education
- Referrals to external agencies

My role includes

- Road wise mobility vouchers, for general half price use for clients
- Disability parking sign for disability car parks. (in some situations, we fund this).
- Equipment loan service
- Monthly support group
- Appointment support
- Gore and Districts community liaison meeting (monthly)

Southland has three support groups Invercargill, Te Anau, Gore and working on interest for my other areas.

We also have fortnightly physiotherapy at the Invercargill centre.

Invercargill, Gore, Te Anau all had mid-winter luncheons.

We have had several fundraisers this year with our biggest being Bangers to Bluff.

Our committee continues to look at all applications for financial support, for those who apply.

Community Education

- DHB neurological study day
- Lions and Rotary clubs throughout Southland and Districts
- Southern Institute of Technology Massage student's presentation

I have attended the MS conference and MS research day. I also try and attend as much professional development as I am able.

*Jo McIntosh, 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

**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 2017-18:

### Trusts and Grant Funders

Lottery National Community Grants, Ministry of Health, Pub Charity Limited, Community Post, The Dorothy L Newman Charitable Trust, Society of Mary Trust Board, Li Ka Shing Foundation

### Businesses

Pharmacy Retailing (NZ) Limited, WaltersPR, The Spark Foundation, BNZ, Printable, Nexia, Roche, Novartis, Sanofi, Biogen, 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 2018

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28. Summary Audit Opinion

#### Statement of Financial Performance:

- 29. "How was it funded" and "What did it cost"
- 30. "What the entity owns" and "What the entity owes"
- 31. "How the entity has received and used cash"

## 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 2018, authorised for issue on 11 October 2018 by the President and Vice President of the Society, have been audited by Nexia Christchurch Limited (known as Nexia New Zealand). An unqualified audit opinion was issued on the full financial statements for the year ended 30 June 2018.

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

For the year ended 30 June 2018

'How was it funded?' and 'What did it cost?'

Account	Notes	2018	2017
<b>Revenue</b>	<b>1</b>		
Donations, fundraising and other similar revenue		234,746	250,941
Fees, subscriptions and other revenue from members		7,750	7,640
Revenue from providing goods or services		262,616	258,735
Interest, dividends and other investment revenue		30,235	12,677
Other revenue		6,775	2,046
<b>Total Revenue</b>		<b>542,122</b>	<b>532,039</b>
<b>Expenses</b>	<b>2</b>		
Expenses related to public fundraising		13,731	17,982
Volunteer and employee related costs		171,578	148,734
Costs related to providing goods or service		327,075	326,584
Grants and donations made		9,261	8,402
Other expenses		30,087	29,552
<b>Total Expenses</b>		<b>551,732</b>	<b>531,254</b>
<b>Surplus/(Deficit) for the Year</b>		<b>(9,609)</b>	<b>785</b>

## Multiple Sclerosis Society of New Zealand

### Statement of Financial Position

As at 30 June 2018

'What the entity owns?' and 'What the entity owes?'

Account	Notes	2018	2017
<b>Assets</b>			
<b>Current Assets</b>	<b>3</b>		
Bank accounts and cash		82,498	28,434
Debtors and prepayments		19,376	20,931
<b>Total Current Assets</b>		<b>101,874</b>	<b>49,365</b>
<b>Non-Current Assets</b>			
Property, Plant and Equipment	5	5,889	6,979
Investments	3	156,425	162,395
<b>Total Non-Current Assets</b>		<b>162,314</b>	<b>169,375</b>
<b>Total Assets</b>		<b>264,189</b>	<b>218,740</b>
<b>Liabilities</b>			
<b>Current Liabilities</b>	<b>4</b>		
Creditors and accrued expenses		32,702	21,489
Employee costs payable		10,104	7,807
Unused donations and grants with conditions		41,549	0
<b>Total Current Liabilities</b>		<b>84,355</b>	<b>29,296</b>
<b>Total Liabilities</b>		<b>84,355</b>	<b>29,296</b>
<b>Total Assets less Total Liabilities (Net Assets)</b>			
		<b>179,834</b>	<b>189,443</b>
<b>Accumulated Funds</b>			
	<b>6</b>		
Reserves		60,851	58,861
Accumulated surpluses or (deficits)		118,983	130,582
<b>Total Accumulated Funds</b>		<b>179,834</b>	<b>189,443</b>

President

Vice President






## Multiple Sclerosis Society of New Zealand

### Statement of Cash Flows For the year ended 30 June 2018

‘How the entity has received and used cash’

	2018	2017
<b>Cash Flows from Operating Activities</b>		
Donations, bequests, fundraising and other similar receipt	283,071	252,985
Fees, subscriptions and other receipts from members	7,750	8,276
Receipts from providing goods or services	259,593	258,735
Interest, dividends and other investment receipts	5,033	5,604
GST	4,578	(9,046)
Payments to suppliers and employees	(526,193)	(538,086)
Donations or grants paid	(9,261)	(20,812)
<b>Total Cash Flows from Operating Activities</b>	<b>24,571</b>	<b>(42,344)</b>
<b>Cash Flows from Investing and Financing Activities</b>		
Receipts from the sale of investments	60,838	43,650
Payments to acquire property, plant and equipment	(1,679)	(5,338)
Payments to purchase investments	(29,666)	(48,780)
<b>Total Cash Flows from Investing and Financing Activities</b>	<b>29,493</b>	<b>(10,468)</b>
<b>Net Increase/ (Decrease) in Cash</b>	<b>54,064</b>	<b>(52,812)</b>
<b>Cash Balances</b>		
Cash and cash equivalents at beginning of period	28,435	81,247
Cash and cash equivalents at end of period	82,498	28,435
Net Change in cash for period	54,064	(52,812)



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

*– St. Francis of Assisi.*

**ms.**

Multiple Sclerosis  
New Zealand

**Annual Report  
2017-2018**

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