



KISS  
GOODBYE  
TO MS

**ms.**

Multiple Sclerosis  
New Zealand

Annual Report  
**2015–2016**

# MSNZ Directory

**As at 30 June 2016**

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# Contents

1	MSNZ Directory
2	Contents
3	President's Report to the 2016 AGM
5	National Manager's Report to the 2016 AGM
6	MSNZ Strategic Plan 2016–2020
7	National Advocacy
10	MSNZ Care Survey 2016
12	Field Worker Training
13	NZ Multiple Sclerosis Research Trust
15	MS Awareness Week 2015
16	BNZ Community Partnership
16	World MS Day 2016
17	Kiss Goodbye to MS
18	Mastering Mountains Grant
19	Dorothy L Newman Scholarships
20	Esme Tombleson Person with MS of the Year 2015
21	Fantastic Fundraisers <ul style="list-style-type: none"><li>• Tramp For MS</li><li>• Shave For MS</li><li>• Walking A World Of Friendship For MS</li></ul>
23	Field Worker Representative's Report to the 2016 AGM
24	Regional Reports 2015–6
29	Our Grateful Thanks
30	Annual Financial Statements

# President's Report to the 2016 AGM



It is always challenging to follow an outstanding year, such as the one we had in 2014–5 and reach the same incredible heights. While 2015–6 may not have been quite as spectacular, we do have some very exciting achievements and advances worthy of celebration:

- our advocacy with PHARMAC regarding implementation of the drugs Tecfidera® and Aubagio®
- engagement in Wellington with Members of Parliament regarding MSNZ concerns and a forward discussion plan
- official launch of the New Zealand Multiple Sclerosis Research Trust
- BNZ Community Partnership commenced September 2015 with ongoing support to raise funds and awareness
- Dorothy L Newman Scholarship received a significant increase in applications
- development of the Mastering Mountains Grant, a scholarship run by the Mastering Mountains Charitable Trust and MSNZ to help People with MS (PwMS) pursue adventures that encourage a healthy lifestyle and change the perception of MS. The grant will be launched later in 2016
- Field Workers' Training, attended by 24 MS Field Workers, with a variety of informative speakers
- planning and implementation of the project 'Review of current and future opportunities facing MS organisations' in response to on-going funding concerns due to complete October 2016
- implementation, completion and external review of the MSNZ Care Survey 2016.

## Advocacy

- Our advocacy with PHARMAC came through again with two more drugs released into the market on 1 February 2016. We are still working on growing this relationship and advocating for changes to the criteria, to make the treatments more accessible. Recently released statistics, available later in this report, show the higher than expected uptake of all four first-line treatments.
- As 2017 is election year, advocacy with all parties' Members of Parliament began in early 2016. Our discussions included funding for charities, lack of neurologists within the hospital systems, waiting times for MRI scans for PwMS, the changes that need to be made to the criteria (both entry and exit) for the new treatments.

- The launch of Kiss Goodbye to MS, an international brand that has huge opportunities for MSNZ and Regional Societies to use as a fundraising tool to generate extra funds. Increased resources will enhance the full potential of this campaign as it grows in the future.

## Regional Support

- The Field Worker Training was well organised and received.
- The relationship between MSNZ and the Regions is continuing to grow. Confidence in the MSNZ team has been shown by approaches to the National Manager to discuss a number of varied issues.
- Some Regions have experienced issues that have required advice and support from the National Office. MSNZ has been careful to work within the confines of our Membership Agreement and has provided support where possible. In some cases, this has taken many unscheduled hours to work through, resulting in unplanned resources being used that had been allocated to other projects. This has meant that some projects the National Office had planned to undertake could not happen.

## Finance

As you will see from our Annual Accounts we have achieved our budget for the year ending 30 June 2016 of \$10,075.00, which is surplus and very gratifying. In order to further improve our position, whilst also increasing resource capacity, the Committee has made a number of decisions that will come to fruition in the next financial year:

- In 2016–7 we are changing our accountants to Nexia New Zealand, with the majority of the monthly administration being completed in-house at the National Office. This will reduce our accounting costs.
- A new staff member, working 30 hours per week to support Amanda, will enhance our delivery of services and capitalise on funding opportunities to grow the income for the National Office. Throughout the 2015–6 period we only had one staff member, which limited achievements.
- The National Office has moved to the New Zealand Brain Research Institute where there is room to accommodate a new staff member.



- The national computer system, which over a number of years has cost many dollars to maintain, will be dispensed with. MS and Parkinson's Canterbury will take over the complete system and continue to provide the same support to those who are currently using it. The database and the computer system were initially purchased for all of the Regions to use, in a collaborative effort to reduce costs. This has not happened for various reasons, and MSNZ is unable to maintain the cost.
- Our goal, as per our budget for 2016–7, will be to have a more positive financial result.
- Our BNZ Community Partnership is a fantastic opportunity that still needs more work. Just like all nationwide business sponsorships it's about building relationships, which takes time to reach its full potential.

I would like to thank David Collis and his team at Bennett Curie Accountants of Palmerston North for all the support, professional information, and timely delivery of monthly accounts over the last six years. It has been great working with you.

## Research

This has been a really important year and a change of direction for MS research in New Zealand. The New Zealand Multiple Sclerosis Research Trust (NZMSRT) was officially launched in Auckland at the end of 2015. The Trust has been established to fund research and projects that benefit PwMS in New Zealand. A sum of \$600,000 was transferred to the Trust last year from our Investments account and the Trust is working on growing this with other seed funding and fundraising opportunities.

## Legislation Changes

It is vitally important that MS Societies fully understand all the legislative changes and complete their implementation within stated timeframes. These are the changes that are essential to the not-for-profit sector:

- new Financial Reporting Act 2013 and the development of XRB standards
- outcome service reporting in Annual Reports
- Health and Safety at Work Act 2015 regulations and the Committee/Management responsibilities
- governance within the societies, particularly where there are remunerated staff
- proposed Incorporated Societies Bill requiring constitutional changes.

## National Management Committee

Neil Woodhams, Mark Etheridge, Jeff Silvester, Ian Chadburn and Jane Heywood, thank you all for the contributions that you have made over the last year to the National Society to improve the delivery of information, support to the Regions and raising of the awareness of MS across New Zealand.



Malcolm Rickerby  
President



# National Manager's Report to the 2016 AGM

This year we have once again made steps in working towards positive changes for people living with and affected by MS in New Zealand. The information provided throughout this report should provide a snapshot of the achievements and struggles of an extremely busy year. Our new 2016–20 Strategic Plan truly defines the work we do and the direction in which we intend to take the organisation in these coming years.

As with most charities in New Zealand, we struggle with funding, requiring more than 90 per cent of our income from donations, grant funders and bequests. We are extremely grateful to all our donors and funders for their encouragement and commitment to our cause. Funding for core operational costs and salaries is becoming increasingly difficult to secure and a number of funders are choosing to prioritise regional rather than national organisations. There is some work that the sector needs to do in raising awareness of the needs of core service funding.

These difficulties have, however, raised opportunities, since we have needed to look at where else we can seek funding. Primarily this year, we have focused on corporate and peer-to-peer fundraisers. I see some real opportunities for MS in these areas. We are very conscious of the limited awareness that the general public have of MS and our activities, but as awareness increases, we are reaching more people with a passion and drive who want to fundraise for the cause, mainly due to personal connections.

This year MSNZ distributed 3996 information resources about MS to our Regional Societies and those requesting information from us. MSNZ continues to provide these resources free-of-charge thanks to donations from the community. We continue to receive positive reports about our resources, particularly the Knowledge is Power Programme aimed at those newly diagnosed. We are looking to undertake a review of our literature this coming year.

MSNZ continued to fund the MS Incidence Study in 2015–6. After identifying 185 people with Clinically

Isolated Syndrome (those who have had their first episode or symptom), and 274 with clinically definite MS, as reported last year, the routine follow ups have continued. These figures were achieved after reviewing

more than 800 cases of people who were diagnosed between 1 July 2012 and 30 June 2014. This means that, on average, there are 130–230 new cases of MS being diagnosed in NZ every year. Each of these people will require information and support about their diagnosis, as may their families, carers and their other support networks. A number of papers have been published this year on the Study. As at the beginning of April 2016 the MS Incidence Study is on hold due to staffing changes. Efforts are being made to continue this work in the very near future, and to ensure the valuable information gathered continues to be researched. New Zealand is in a unique position to be able to study this information due to our relatively small population and NHI number recording system.

I would like to thank Malcolm Rickerby and Neil Woodhams who both invest, on average, 30 hours per week to their MS commitments, both regionally and nationally. While driven by personal motives, they demonstrate the true value of volunteers and with only having one employee at the organisation this year they have been an invaluable help to me and my role. Thank you.

I would also like to thank Jeff Silvester, Mark Etheridge and Ian Chadburn who continue to provide considered and measured advice and direction, and Jane Heywood for her valued contributions in her first year on the Committee.

Happy reading and kind regards,



Amanda Keefe  
National Manager

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# MSNZ Strategic Plan 2016–2020

## I VISION

A world without MS

## I 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

## I AIMS AND OBJECTIVES

### 1) *Advocacy*

- > Effective Advocacy on behalf of:
  - Individuals: Field Workers and Regional Societies advocating on behalf of their clients
  - 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
- > Raising awareness nationally for MS as a chronic condition affecting New Zealanders and highlighting the needs of those living with the condition

### 2) *Supporting Regional Societies to help people with MS to self-manage their lives*

- > Working collaboratively with Regional Societies to gain a clear understanding of the diverse needs of PwMS together with ensuring they are provided with choice and access to services
- > Providing training for regional staff to encourage consistent and professional services
- > Providing relevant, evidence-based, up-to-date information on MS, its management and available services

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

- > Providing Regional Societies with nationally consistent resources and policies to deliver programmes and services in their communities. Ensuring Regions are supported to successfully implement these
- > Working with Regional Societies to establish a minimum level of service, model of care and delivery to achieve successful outcomes

### 4) *Agreed National Data Set*

- > The development and implementation of an agreed nationally consistent, relevant and accurate reporting of data to inform services, advocacy, Regions, government agencies and other funders

### 5) *Research*

- > Working collaboratively together to benefit people with Multiple Sclerosis
- > Supporting the work of the New Zealand Multiple Sclerosis Research Trust, including supporting its fundraising efforts

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

- > To be seen as the spokesperson on all national issues related to MS

### 7) *Viable and successful organisation*

- > Ensuring MSNZ has the funding and other resources to deliver on its Strategic Plan and its annual Business Plan

# National Advocacy

## MS Treatments

In 2014, MSNZ led a successful advocacy campaign in which two new treatments, Tysabri® and Gilenya®, were funded for relapsing remitting MS. MSNZ, as the spokesperson on all national issues related to MS, led the campaign and made submissions on behalf of our membership and People with MS (PwMS). Interested parties were consulted for feedback and input into the submission, including PwMS, carers, health professionals both in New Zealand and abroad, and our MS Regional Societies.

New Zealand finally funded these treatments eight years after other First World countries, meaning that people no longer have to show a level of disability before receiving treatment, but are able to be treated from diagnosis. Data from the MSNZ-funded MS Incidence Study, regarding the numbers of people diagnosed and their localities, were used by PHARMAC to calculate the potential uptake of these treatments—estimated to be 400 in the first 12 months. At the one-year mark of 30 November 2015, 514 applications had been submitted for funding, of which 485 were accepted, nine pending, 14 deferred and eight declined.

In December 2015 it was announced that two further treatments, Tecfidera® and Aubagio®, were to be funded and made available under the same funding criteria. MSNZ once again submitted to PHARMAC (in October 2015) in support of this move and advocated for extensions to the entry and exit criteria. We again sought support and input through consultation with our membership and networks. These treatments were made available from 1 February 2016. Some changes were made to the criteria; however, we feel there are still improvements to be made, and are continuing to discuss our concerns and suggestions with PHARMAC. We are particularly concerned about the strict entry and exit criteria: there are a number of PwMS who do not fit the criteria at entry, but for whom early access would be highly beneficial. With advice from medical professionals we have continued to raise our concerns with PHARMAC and are hopeful that, as the treatments become better understood in New Zealand, there will be flexibility within the system. We thank PHARMAC for its continued willingness to engage with us to ensure that people with MS receive the best access to services and treatments. We are pleased to see the growing commitment to ensuring that PwMS are receiving the best First World treatments available.

We are receiving extremely positive feedback from people accessing treatment, with people returning to work and being able to manage their lives with fewer relapses, hospital admissions, and less need for support.

Anne from Auckland writes:

*"I used to be a nurse educator. However, due to the progression of my MS I was out of work for almost six years. I was considering retraining in Psychology, and the MS Society offered me support under the Dorothy L Newman Scholarship to do this. The MS Society successfully advocated for funding for two new drugs, and I was able to commence on one of them—Gilenya® (Fingolimod)—in January 2015, and my health improved immensely. I was able to walk for long periods and remain on my feet without the use of a crutch for the first time in eight years. In fact, I improved so much that the Nursing Council supported me in returning to nursing, and I am back at work two days a week. I know my treatment is not a cure, but now I am able to provide for my family and have a sense of purpose. These treatments have changed my world."*

The older treatments, Avonex®, Betaferon® and Copaxone®, continue to be well used and are the preferred option for those for whom the new treatments may not be suitable. PHARMAC has provided us with statistics based on an Official Information Act request about the uptake of the new treatments. The figures show that at 19 August 2016 (in the first 18 months of treatments being available) there have been:

- **762** applications for Fingolimod (Gilenya®), Natalizumab (Tysabri®), dimethyl fumarate (Tecfidera®) and teriflunomide (Aubagio®), or where treatment has not been decided
- **698** successful applications
- **32** pending applications
- **8** deferred applications
- **24** declined applications

A breakdown of data by treatment shows the following.

- Fingolimod (Gilenya®): there have been **387** applications, **373** approved and **14** pending
- Natalizumab (Tysabri®): there have been **201** applications, **195** approved and **6** pending
- Dimethyl fumarate (Tecfidera®): there have been **123** applications, **114** approved and **9** pending
- Teriflunomide (Aubagio®): there have been **11** applications, **all** have been approved
- **5** applications have been approved but treatment is undecided
- **3** applications are pending where treatment is undecided
- **8** applications have been deferred
- **24** applications have been declined



A breakdown of successful applications based on the District Health Boards is set out below. Please note that in order to protect patient privacy the numbers have been provided as a range when the number of patients is five or below:

DHB	Approved Applications	Supporting Regional MS Society
Auckland	61	Auckland
Bay of Plenty	22	Bay of Plenty
Canterbury	93	Canterbury
Capital & Coast	63	Wellington
Counties Manukau	39	Auckland
Hawkes Bay	22	Hawkes Bay
Hutt Valley	30	Wellington
Lakes	15	Rotorua
MidCentral	32	Central
Nelson Marlborough	21	Nelson & Marlborough
Northland	19	Northland
South Canterbury	15	South Canterbury
Southern	85	Otago & Southland
Tairāwhiti	0–5	Gisborne
Taranaki	18	Taranaki
Waikato	46	Waikato
Wairarapa	6	Wellington
Waitematā	91	Auckland
West Coast	0–5	West Coast
Whanganui	9	Wanganui

## Ongoing Concerns

In May, Amanda Keefe, Malcolm Rickerby and Neil Woodhams visited MPs in Wellington to discuss a number of matters of concern for MS Societies and the MS Communities. The primary aim was to introduce Members of Parliament to our concerns: MSNZ has not engaged with the government for many years. We received a largely positive response and are now developing the next stages of the advocacy plan. We would like to thank the Members of Parliament who made themselves available to discuss issues affecting MS organisations and people with MS. We appreciate their support and guidance, and look forward to discussing these points further. Our key areas of concern are the state of the neurological workforce and the funding of charities:

## Neurological Workforce

A major concern that we foresee with MS and other neurological conditions is the distinct lack of Neurologists in New Zealand, and particularly those specialising in MS. An article published in August 2015, 'New Zealand's Neurological Workforce', in the New Zealand Medical Journal shows that:

- Currently there are 34 FTE Neurologists in New Zealand. By international standards there should be 74, based on current productivity.
- Nearly half the current workforce will reach retirement age within the next 12 years.
- There are nine approved training posts for Neurologists but only six or seven in training currently.
- Some parts of rural New Zealand have one Neurologist per 700,000 head of population. This compares with best practice of a ratio between 1:50,000 and 1:70,000.
- Over the past five years, only five new Neurologists have started employment in NZ.
- In some areas, Neurology is becoming a speciality of sub-specialists.

We see the key impacts this will have on MS as:

- Many of our smaller Regions report having visiting Neurologists only every few months, while larger centres are experiencing long waiting times. Some areas are experiencing up to four-month waiting times for appointments to MS Neurologists for semi-urgent cases.
- There has been no increase in the specialist MS Nurse capacity in most centres, despite the increasing prevalence of MS, and new treatments becoming available that require increased specialist nursing input. Acute admissions through A&E could be treated in the community if caught earlier.
- There is limited capacity for people with Secondary or Primary Progressive MS to be seen by a Neurologist. Both PwMS and their GPs have largely given up trying to have referrals accepted. People with these more progressive forms of MS are often told there is nothing that can be done for them, and may never see a Neurologist again. Should treatments become available for progressive forms of MS, this will have an even greater effect on the neurology demands in NZ.
- There are waiting lists of up to six months for MRI scans in some areas—scans that are essential in the diagnosis and treatment of MS.

- Since the recently available treatments are very new to NZ, and some come with high risks, such as progressive multifocal leukoencephalopathy (PML), there is an increased demand on the system as a whole, as more tests and monitoring are required. Infusion clinics have also needed to accommodate these new treatments.
- The funding criteria require annual reviews and regular renewals of special authorities. This requirement will only increase in the future, as more people begin treatment, significantly increasing the time demands on Neurologists and specialist MS Nurses.

There are clearly some key issues that need addressing, for people not only with MS, but all neurological conditions.

## Funding of Charities

A major concern for most charities in New Zealand is their funding. Government funding of MSNZ and its 18 Regional Societies is approximately \$350,000 from the Ministry of Health. For MSNZ our allocation is a minimal amount of our budget—less than 10% of our total income. Our contract is currently under review by the Ministry, with a decision expected at the end of September 2016 when this report was being prepared. The review is looking to move funding from organisations and reallocate to individuals. While early reports are showing that no major change is expected for the next few years, MSNZ is extremely concerned about the long term availability of funds.

In response, MSNZ has been engaging where possible in the review process, as well as taking a proactive approach by planning our own project entitled ‘Review of current and future opportunities facing MS organisations’. This environmental scan began its initial consultation with our Regional Societies and Field Workers in June and is due to be completed in October 2016. We hope the review, coordinated by external contractor Helen Brownlie of Bora, will:

- provide an overview of the current landscape with an environmental scan of information, services and resources available to MS Organisations
- identify and report the current structure of MS organisations in terms of functions, productivity, and the alignment of these to the MSNZ Strategic Plan 2016–20
- identify and report potential opportunities for collaboration with other organisations including within the MS Societies’ Membership
- report potential options for change and development
- and finally, identify and report any potential funding streams.

We thank the Working Together More Fund for their support and generous funding of this project.

The activities of MS Societies undoubtedly keep people living with their families in their own homes for longer, and provide them with MS-specific support. This saves money for the Government and DHBs, but MS Organisations see no recognition of that. Keeping people in the community is specifically in line with the 2016–26 New Zealand Health Strategy. MS organisations across the country receive no DHB funding to do the community-based work their nurses cannot do, because of their restriction to working within the hospital.

The ongoing erosion of traditional sources of funds to organisations such as MSNZ is of great concern. Charities funded by gaming organisations have less funding to distribute. Some of our organisations are seeing a 50–75% reduction in funding from grant providers because of an increase in applications, decrease in funds available, and changes to processes and criteria. Some funders who have declined applications note they are receiving requests that are three to four times greater than their allocation. With one of the highest ratios of charities per population in the world, there are huge risks for New Zealand charities, particularly with the increase in individuals’ fundraising for personal causes.

We are also concerned that some of the changes to legislation are imposing punitive and unreasonable demands on the governance of small charities, which are in general staffed by unpaid volunteers giving major amounts of their time to causes they are passionate about. The new Health and Safety legislation, for example, imposes criminal liability on committee members for the actions of others. We are already seeing committee members questioning whether the risks merit the benefits, and our Regional Societies struggle annually with finding new committee members and holding onto existing ones.

MSNZ is continuing to work through these concerns and issues with relevant parties and we thank those who have engaged with us so far.

# MSNZ Care Survey 2016

## Background

Multiple Sclerosis New Zealand undertook the first MS Care Survey in 2016 in order to obtain information from People with MS (PwMS) about the state of MS care in New Zealand and how PwMS experience health care services.

## Aim of Survey

The aim was to seek responses from PwMS that will help to better inform MS New Zealand about their experiences of health services, the needs within the MS community, and how MSNZ can work or advocate to improve these specialist MS care services in New Zealand.

## Participants' Profiles

PwMS were sent an invitation to complete an online survey. The backgrounds of those completing the New Zealand MS Care Survey were either PwMS, or a nominated person completing the survey on their behalf. The survey was distributed electronically through Regional Societies to their membership, to the MSNZ database, on Facebook and on the MSNZ website.

The survey captured a wide range of responses in relation to learning more about PwMS, their life with MS, their views and how they experience health care services in New Zealand.

## Responses and Engagement

The online survey was answered by 422 people.

MS Auckland also asked their membership the survey questions in their annual membership survey. There were 155 responses which were used as a measure to see the comparisons and contrasts between the national responses and an individual region, in this case the region with the largest MS membership, population numbers and DHBs servicing the community.

Respondents were able to skip questions if the questions were not applicable or they were unable to answer.

## Comments from the Reviewer

MS is one of the most common debilitating neurological diseases, and despite measures to improve awareness of the considerable impact of MS, there has been a lack of information on the state of MS care in New Zealand. Even if no cure as yet exists for MS, identifying the key issues that need addressing will help to alleviate the information deficit about MS care in New Zealand and will improve the quality of life for PwMS and others affected by the MS condition.

Overall, respondents who took part in this survey viewed it positively. Some respondents found some aspects of the questions unclear or challenging.

The summary recommendations provided from analysis of the MS Care Survey will go a long way to significantly inform MSNZ of key issues it needs to address to improve the accessibility and availability of specialist MS care services in New Zealand.

## Major Issues Identified by the NZ MS Care Survey for PwMS

Responses showed that the major issues were **diagnosis**, **information**, and **support services**.

### Diagnosis

- The availability and accessibility of information services/diagnostic services such as MRI varied widely between regions.
- Response times from onset of symptoms to diagnosis varied widely and in some cases was often drawn out over many months or years.
- Many viewed the Expanded Disability Scale Status (EDSS) as a blunt instrument that was not equitable in regard to care services required for their MS at time of confirmed diagnosis or when a PwMS transitioned to Secondary Progressive MS.
- In many cases the provision for care services and the gap between information required and received for PwMS lessened over time since diagnosis.

### Information

- There is a lack of information and education for health professionals about MS, including research into MS issues.
- There are inequalities in the provision of information and research for PwMS who have Relapsing Remitting MS compared with those who have Primary Progressive MS or Secondary Progressive MS.
- In many cases, the provision of care services and the gap between information required and received were vastly different for people with Progressive MS, Secondary Progressive MS and Relapsing Remitting MS.
- Lack of information/education on disease modifying drugs for PwMS from health professionals.
- MS is being managed in a medical, not social, model of care, and that there is a general lack of well-qualified MS Nurses to provide care, answers to their questions/queries from PwMS after their confirmed diagnosis.
- Inequalities in the provision of research information for PwMS who have these types of MS: relapsing remitting MS, primary progressive MS and secondary progressive MS.

## Support Services

- Non-specialist health professionals are not receiving any or enough training post-registration to help them better identify MS symptoms and treat PwMS.
- Inadequate information, education, advice and care support for PwMS, as PwMS are sometimes unaware of how best to cope with their MS diagnosis, and how to remain physically active, in education or employment.
- PwMS actively seek and sometimes use complementary or alternative remedies or therapies as ways to care for themselves and live with their MS.
- The financial cost and access to self-funded Disease Modifying Drugs (DMDs) is prohibitive for many PwMS eg. Fampyra® and Sativex®.
- There is a need for PwMS and health professionals to better understand DMD options and MS care with treatment modalities.
- PwMS report issues related to length of time to see specialists, receive a diagnosis and begin the process of accessing support and care services.
- Waiting times are also long for appointments with a Neurologist or specialists for follow-up MS care.
- In some rural areas there are few mutual support groups, MS related health services or centres.
- More regular assessments are required with better access to see Neurologists and MS Nurses.
- There is no register for PwMS so that monitoring of access and care services options can be better identified and enacted.
- Accessibility issues to services with the need for more disability-friendly access to buildings
- With isolation being an issue for many, peer-to-peer support systems to share information and provide support are limited, despite being highly valued.

## Changes Required

The survey showed that major changes are needed to improve MS care:

- enact recommendation of a proposed New Zealand MS Registry or an MS Database to record all PwMS and their progression and treatment plan
- invest in more resources for MS care and rehabilitation services to make MS care services accessible and available
- provision of regular annual follow-up assessment of PwMS, and standardised care services
- improve and expand research into MS issues for health professionals and PwMS
- strengthen and support MS care service structures to ensure better access to information for PwMS

- increase general awareness of medical conditions and types of MS with medical and allied health professionals, PwMS, general public, key stakeholders, funders, researchers
- identify better delivery systems of MS care information and support services, focussing on the medical profession and significant others
- enact service provision processes to ensure equity, accessibility and availability for the delivery of health care and support services for PwMS who have progressive MS, secondary progressive MS and relapsing remitting MS
- provide better MS care information, education structures and access to health professionals for PwMS who transition to secondary progressive MS
- better response time for enquiries from PwMS about their care, or changes to their care from DHBs

## Conclusion

The New Zealand MS Care Survey highlighted considerable discrepancies between levels of care, information and support, and in the availability of access to care services for people affected by MS. In many cases the gap between information required and received was vast, especially for information about diagnosis, and information choices about therapy or treatment with DMD that could help to alleviate and modify the course of the disease.

Overall, the data from the two surveys was consistent in the feedback themes and information. The MS Auckland Survey particularly highlighted the lengthy waiting times in the region for PwMS to see Neurologists, Specialists or MS Nurses. This significant issue was noted to add to the stress of living with and managing a chronic, degenerative illness.

It is intended that results from this survey will better inform policy makers, health professionals and PwMS. If organisations, Regional Societies and government agencies act on these major changes needed to improve MS care, they will have it in their power to significantly improve the quality of life for PwMS.

## Closing Remarks from MSNZ

MSNZ would like to thank Dr Caroline Allbon for reviewing the New Zealand MS Care Survey data and providing a comprehensive and independent report of the information received. The information gathered will be used to support and direct our advocacy work for the coming year, help suggest improvements in the provision of care and support by MSNZ and our Regional Societies, as well as push for changes in the services available from DHBs.



# Field Worker Training

On 23 and 24 June, 24 Field Workers attended the annual Field Worker Training in Christchurch. The programme provided training in a variety of areas that are pertinent to a Field Worker's role, covering interesting, challenging and new topics.

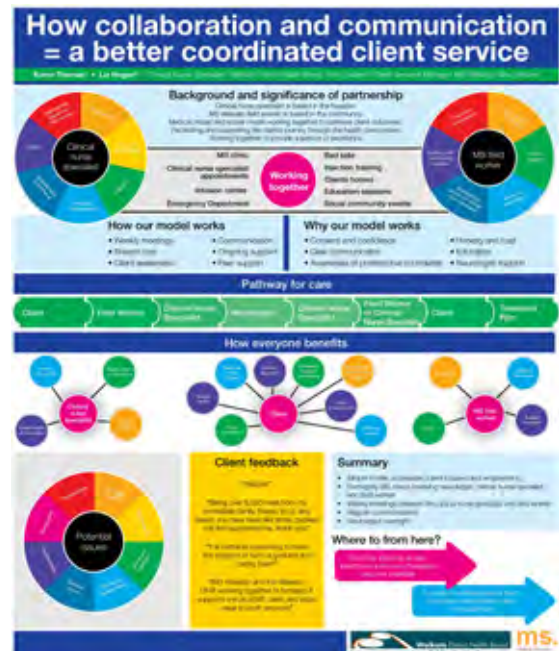
The day also provided Field Workers with an opportunity to collaborate and network. Most Field Workers are working in isolation in their areas, and the training provides a forum to share new ideas and discuss both the common trends they experience in working with MS, and how they can best support their clients.

Thank you to all of the engaging and informative speakers who gave their time, and helped to increase the education and skills of our Field Workers in their community.

- **Enduring Power of Attorney**, Penny Arthur, Canterbury Community Law
- **Cognitive Behavior and changes in MS**, Dr S. Bharathan, Consultant Psychiatrist and Psychogeriatrician, SCDHB
- **The Elephant in the Room: Anxiety, depression and suicide, and the impact of MS on relationships**, Frances Young, Counsellor and Psychotherapist
- **Sex and MS**, Glenda Wallace, Clinical Psychologist
- **Supervision/Mentoring**, Gay Dickie, Field Worker Representative
- **MS Nurse Specialist**, Helen Lloyd, MS Nurse Specialist, CDHB
- **How Collaboration and Communication = a better coordinated client service**, Liz Hogan, Client Services Manager, MS Waikato
- **MS and Physiotherapy**, Rachel Bladon, Physiotherapist, MS and Parkinson's Canterbury

Thank you to Sanofi, Novartis, Biogen and Seqirus for their funding support, without which we would not be able to provide this training for MS Field Workers—a core service of our organisation. Thank you also to the BNZ for providing the venue without charge as part of our BNZ Community Partnership.

“The standard of this last training was excellent. It was helpful to Field Workers who have been in the job some time and to newer Field Workers.”



“How collaboration and communication = a better coordinated client service” presented by Liz Hogan, Client Services Manager for MS Waikato, at the MS Nurses Australasia Conference, in Wellington in August 2015, and MS Field Worker Training, June 2016

## THE QUESTION OF SEXUALITY FOR PEOPLE WITH MULTIPLE SCLEROSIS

MS+PD Canterbury

Judy McKeown RN · Bronnie Alexander RN · Helen Stone RN · Trudy Keer RN · Gail Walton RN · Jane Eagle RN

<sup>1</sup> The Multiple Sclerosis and Parkinson's Society of Canterbury (Inc), Christchurch, New Zealand  
<sup>2</sup> Department of Neurology, Christchurch Hospital, Christchurch, New Zealand

### INTRODUCTION

Sexuality impacts on identity, relationships and quality of life. Up to 80% of people with multiple sclerosis (PwMS) have some form of sexual dysfunction<sup>1,2</sup>. Living with multiple sclerosis (MS), individuals and couples can under-rate the dimension of sexuality<sup>1</sup>.

The Canterbury Neurology Nurses Group meets to reflect and improve on nursing practice through peer support, education and networking. The Group raised the question, how can we as nurses introduce or start a conversation regarding sexuality and what resources are available for people with MS.

### PROJECT GOALS

- Raise awareness of addressing sexuality in PwMS
- Identify a tool that health professionals can use
- Present a case study that highlights a sexuality concern

### LITERATURE REVIEW

- Searched CINAHL, PubMed, Cochrane Library data bases for articles published from 1983 until May 2015.
- Assessed all peer reviewed articles under the major headings of "multiple sclerosis and sexuality" combining with key words "sexual dysfunction", "intimacy", and "body image".
- 18 publications were found to have a relevant and potentially useful discussion on the subject, most articles were medically based. The combined literature served to inform the group.

### CASE STUDY

- Marget<sup>3</sup> is in her late 30s with MS, married to Martin<sup>4</sup> for four years.
- They report a loving and caring partnership.
- Marget raised concerns regarding their sexual relationship.
- She reported low libido and loss of sensation and felt Martin was becoming frustrated.
- They tried to find solutions such as creating an intimate environment without success.
- Marget's medications were reviewed and other illnesses were excluded.
- The MS nurse referred the couple to a sex therapist.
- The therapist introduced the couple to Sensory Body Mapping.

### EVALUATION

After one month Marget felt the use of the body map had increased communication with her husband, they felt closer and experienced more times of intimacy. At three months Marget felt there continued to be improvement in communication, and intimacy. They were spending more planned time together and had a better understanding of each other's needs.

### SENSORY BODY MAPPING

A Body Map is a tool using an outline of a body to indicate areas of sensitivity that can be shared as a couple. Colour is used to illustrate how touch is experienced.

Touch me here anytime.  
 Yellow: It depends — sometimes I like this, sometimes not.  
 Red: No! Stop! I don't want to be touched here anytime.

Body Maps often change due to health or major life events. Revisiting the map is essential to its long term success. The body map encourages communication between couples and may enhance intimacy.

### DISCUSSION

Sexual dysfunction often appears in the early stage of MS, although 63% of PwMS have never talked to a health professional about sexual problems<sup>1</sup>. Nurses are in a prime position to ask the question: "MS can sometimes affect people's sexuality and relationships. Has this had an impact on you?" This question helps to normalise a taboo subject and makes people aware that it can be related to MS symptoms.

A body map is a personal tool that promotes communication, and enables PwMS to redefine their sexuality. Limited nursing research and literature on this subject highlights the need for future enquiry.

### REFERENCES

1. Basso DM, Basso DM, Basso DM. Multiple sclerosis and sexual dysfunction. *Neurology*. 2011; 76(10): 1011-1012.
2. Basso DM, Basso DM, Basso DM. Multiple sclerosis and sexual dysfunction. *Neurology*. 2011; 76(10): 1011-1012.
3. Marget. [Personal communication with the author].
4. Martin. [Personal communication with the author].

“The question of sexuality for people with Multiple Sclerosis” presented by Judy McKeown, MS Resource Nurse for MS and Parkinson's Canterbury, at the MS Nurses Australasia Conference, in Wellington in August 2015. This poster won the award for 'Best Poster'





# NZ Multiple Sclerosis Research Trust

It was a significant year for MS research in New Zealand with the establishment in late 2015 of the New Zealand Multiple Sclerosis Research Trust (NZMSRT).

The Trust received a substantial kick-start in funding with \$600,000 transferred from MS New Zealand and \$300,000 from the MS Auckland Region Trust. By 31 March 2016, together with investment gains and further donations, the Trust's funds had grown to \$1,150,000.

NZMSRT's target is to raise \$5 million by 2020 to provide a sustainable income base to fund research and projects that benefit people with MS in New Zealand. By having a single point of focus for research funding, the Trust believes there will be better coordination, focus and allocation of resources to research.

Memorandums of Understanding have been signed between the Trust, MSNZ and MS Auckland Region

Trust, setting out the respective roles and responsibilities of the organisations as regards MS research in New Zealand.

As one of its initial focuses, NZMSRT has identified the establishment of a national database of all people in New Zealand with MS. This is seen as a key priority in tracking and identifying research needs and outcomes.

A special funding push during May and June this year to kick off this initiative resulted in nearly \$50,000 being raised for the project. Scoping is currently underway to undertake a feasibility study on how best to implement a national database and ensure it is kept current.

The Trust has seven Trustees and its patron is Sir William Gallagher. More information on the NZMSRT can be found on its website at [www.msresearch.nz](http://www.msresearch.nz)









# MS Awareness Week 2015

The 2015 Multiple Sclerosis Awareness Week took place across the country between 29 August and 5 September. With funding from Pub Charity Limited, MSNZ was able to support our 18 Regional Societies and more than 1700 volunteers in raising much-needed funds, due to the increased visibility that the resources provided.

- **1,124** posters were printed and placed by Phantom Billstickers in prime outdoor locations across New Zealand. These were placed in two runs to ensure posters were kept fresh and visible in the week leading up to and during the campaign period.
- **300** posters were placed in retail and café locations in Auckland, Hamilton, Wellington, Christchurch, Dunedin, Queenstown and Wanaka.
- **11,000** flyers were placed in retail and café locations in Auckland, Hamilton, Wellington, Christchurch, Dunedin, Queenstown and Wanaka.
- MSNZ also printed and funded **1000** extra posters for our Regional Societies.

Our Regional Societies largely reported a decline in funding in 2015. Common concerns were finding sufficient volunteer numbers, and larger organisations' collection weeks directly preceding our own.

Around **\$140,000** was collected in 2015 (a 25% drop from 2014); **300** locations were used (the same as 2014); 1,700 volunteers supported the collections (25% lower than 2014); **66** Service Groups and **12** schools participated, and an estimated **2,500** volunteer hours were donated. Thank you to all the incredible people in the communities who donated their time and money to support the MS Street Appeal. With our organisations having to raise the majority of funds from the community, each and every person's support is greatly valued. Thank you.

MSNZ also funded collection buckets and promotional resources for all 173 BNZ stores nationwide, and created and displayed digital advertisements on BNZ store screens and on Health TV screens found in hospitals and GP waiting rooms. Thank you BNZ and Health TV for allowing us to use these spaces to promote our cause.



# BNZ Community Partnership



In 2015, MSNZ and our Regional Societies entered into a Community Partnership with BNZ. During September, collection buckets were placed in all 173 BNZ stores across New Zealand and their customers could also donate through their online banking system. Due to the Nepal Red Cross Appeal in September, the MSNZ online donations remained open during October. In total \$9773.35 was raised for Multiple Sclerosis organisations through the BNZ: MSNZ raised \$5184.44 through online banking donations, and \$4588.91 was collected in stores and distributed to Regional Societies.

The MSNZ membership benefits package was also launched by BNZ in 2015, providing financial members and employees of MS organisations with discounts on home loans, waived account fees, competitive interest rates and insurance discounts.

Thank you, BNZ, for your support of MSNZ, for recognising the work we do, and helping us to raise vital funds and awareness for MS.

## World MS Day 2016

On Wednesday, 25 May 2016, MSNZ celebrated World MS Day with Christine O'Sullivan and the Wellington MS Society in 'Sing for MS'. The second annual event, organised by Wellington Member Christine and her friend Christine Richardson, was a joyous, welcoming community occasion held at the Wellington City Library.

Led by Julian Raphael of Community Music Junction, more than one hundred very happy people with MS or other disabilities, and people in the community who enjoy singing, came together to raise the roof in song on a wet and windy Wellington day.



# Kiss Goodbye to MS

In May 2016, MSNZ held the first Kiss Goodbye to MS campaign in New Zealand. The campaign began in Australia in 2012 where it has raised more than AUD 3.5 million since its inception. MS Research Australia expects to reach AUD 4.5 million by the end of 2016. In 2015, the MS International Federation established an international group of MS organisations seeking to bring the campaign to their countries. Each country was to be responsible for the activities in its own country, with the group to be used as a support network for advice and idea sharing. MSNZ joined this group after a number of years of discussion with MS Research Australia.

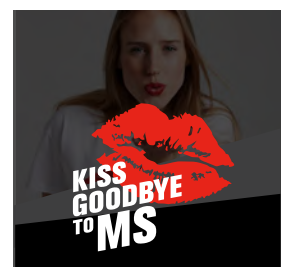
In May 2016, MSNZ asked supporters to WEAR, DARE and SHARE for MS. Fundraisers were encouraged to be sponsored to wear red lipstick, take a dare or do a challenge, and share their support on social media. Importantly, fundraisers were encouraged to have fun and do what they wanted to show their support and raise funds for MS.

Six Regional Societies, Taranaki, Marlborough, Northland, Hawkes Bay, Central Districts and Otago, held events in their communities to raise funds for their local work. Seven individuals and teams signed up to a fundraiser under the campaign, raising \$5,433 by the end of June. Donations are still coming in as a team of 21 women prepare to run the New Plymouth half-marathon, two individuals and a corporate team of 30 from Exeed are training for the Auckland full- and half-marathons and a bowls day is being held in Christchurch, all in October.

Funds raised have enabled MSNZ and our participating Regions to capture a new audience of fundraisers to help us continue our work nationally and in local communities. MSNZ, as an organisation that has to find 90% of our income annually, has been able to continue to deliver key services such as providing information through educational resources on MS, advocating for better services and treatments for those affected, and supporting our Regional Society staff through training.

While engagement from Regional Societies and fundraisers was limited, this was expected since MSNZ intentionally started small in 2016 due to the restricted resources available to us. However, the potential of peer-to-peer fundraising as a future fundraising stream for MSNZ has been shown, since people are able to engage those within their own networks and not only raise funds but also raise the profile of MS among those who may know little about the condition.

Thank you to our incredible and dedicated fundraisers: Clare, Kathy, Bec, Julie, Tom, Stewart and Team Exeed, as well as our Regional Societies for their support. We hope to be able to grow this campaign in future years.





# Mastering Mountains Grant

MSNZ and the Mastering Mountains Charitable Trust have come together to offer people diagnosed with MS the Mastering Mountains Grant. Since October 2015 the two organisations have been working together to develop the grant, which will launch later in 2016. Applications for the annual Mastering Mountains Grant will open 1 August and close 31 October.

The purpose of the grant is to assist people who have been diagnosed as having Multiple Sclerosis to overcome a specific obstacle so that they can achieve a specific outdoor pursuit.

With this grant, Mastering Mountains and MSNZ hope to help people with MS pursue adventures that encourage a healthy lifestyle and to change the perceptions of MS, in accordance with the Trust's purposes. The Mastering Mountains Charitable Trust was established in 2015, and exists to enrich the lives of people affected by MS, by helping them to get outdoors. Getting outdoors has an incredible therapeutic quality. MS can hinder people from the fullest experience of this, and Mastering Mountains hopes to overcome this obstacle.

The Trust was set up by Nick Allen, an active young Kiwi who was diagnosed with MS at the age of 25. Nick grew up climbing, tramping and mountain-biking, until he was diagnosed with MS and found himself living in a wheelchair. Nick decided to fight back, and through the support of his family and friends, he changed his diet and lifestyle, and in 2015 summited Island Peak (6,189 metres) in the Himalayas. Nick is passionate about helping others and so created the Mastering Mountains Charitable Trust and the Mastering Mountains Grant to help others living with MS to overcome obstacles that prevent them getting outdoors. Nick approached MSNZ to assist with the administration and promotion of the grant through our networks. MSNZ has had the pleasure of working with Nick this past year and we look forward to further developing this relationship in the future.

Mastering Mountains Trust will be the primary funders of the Grant. For more information about the Trust visit [www.masteringmountains.org](http://www.masteringmountains.org)



# Dorothy L Newman Scholarships

In October 2015, MSNZ awarded Dorothy L Newman Scholarships to four worthy recipients. The Dorothy L Newman Scholarship assists people who have been diagnosed with MS and who, as a result, are unable to continue in their present employment; it allows them to undergo a course of retraining in order to change their employment. Applications are open solely to people with MS needing to retrain for paid employment. The Selection Panel members are particularly inspired by those who are able to show a strong commitment to their chosen course of study and future employment, and an understanding of the practicalities of managing a career and their chronic health condition.

The number of applications in 2015 was the highest received for a number of years, and the decision-making by the Selection Panel was extremely difficult. Thank you once again to Sue Clothier and the Dorothy L Newman Trust for financially supporting half of the Scholarships provided. One recipient unfortunately did not begin her course; however, we have had three very successful applicants rising to the challenge with great successes, despite battling their own difficulties.

## Chelsea

I applied for the Scholarship so I could have the opportunity to finish my Diploma without adding to my student loan. I had never heard about the Scholarship before my Field Officer, Gay Dickie, talked to me about it and helped me submit my application. I am on the last paper for the Information and Library Studies Level 5 Diploma with The Open Polytechnic of New Zealand and will finish mid-October.

I am looking at moving to Hamilton in the next six months and hope to get a job in a library, but I am finding it hard as most library jobs already want you to have the Diploma that I am currently studying. I had to pull out of two papers last year due to problems with my health, but the Scholarship is giving me the push I need to finish my Diploma. I am hoping to continue on with my studies next year, as this Diploma crosses over into the Bachelor's Degree of Information and Library Studies.

## Rachael

In 2015, I was fortunate to be awarded \$2000 from MSNZ, through the Dorothy L Newman Scholarship. It was a long-held (20 year) dream to be able to study naturopathy and I felt I was in a good position with my health.

I am currently in my first year of three, studying naturopathy at the Naturopathic College of New Zealand. I have really stepped outside my boundaries this year, as I have needed to remain focused on my studies and to attend the New Plymouth workshop. It was a big hurdle physically and mentally to have been without my family supports, performing and being assessed on therapeutic

massage, and attending the tutorials for the week. I enjoyed most of it, but afterwards spent a couple of weeks recovering.

I have learnt a lot about natural therapies this year and realise there are definitely some areas which I feel more drawn to than others. It has cemented my idea that diet and other complementary therapies are excellent to assist healing from not only MS, but also many other health issues.

I have passed all of my work so far this year but sometimes it has been hard dealing with extra stress in my day-to-day life, having days when I feel particularly fatigued.

After I have qualified, I intend to be self-employed and appropriately I feel compelled to work with people who have an autoimmune disease. I have been surprised at the lack of understanding from many people, including those within the health industry, who have no idea how this diagnosis can affect people.

Thank you very much for the Scholarship. I really appreciate that you agree I am worthy of receiving this.

## Rachel

I was diagnosed with relapsing remitting MS in 2008. I was 23 at the time, studying law and music at university.

After graduating, I worked as a lawyer in Wellington for four years, until it became clear that my health was significantly impacting my ability to work in this profession. When I was first diagnosed I sought counselling for assistance in coming to terms with my diagnosis, and since then it was always in the back of my mind to help others in a similar way. Prioritising my health, I left my job as a lawyer in December 2014, and commenced studying a Diploma of Professional Counselling in January 2015.

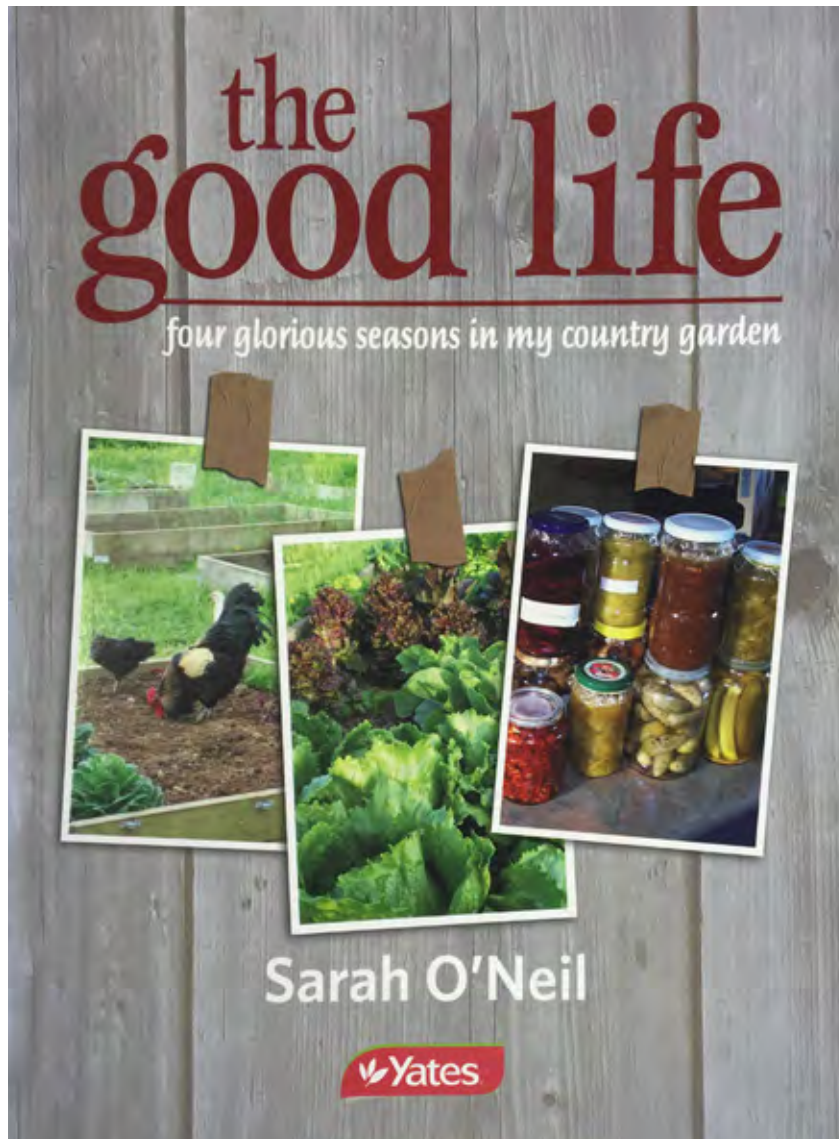
As the first year of counsellor study was in fact my seventh year of requiring a student loan, I applied for the Dorothy L. Newman Scholarship for help in paying my 2016 course fees, 2016 being the final year of this Diploma.

After completing all theory and practical components of this course with an average mark of 92%, I have now achieved my Diploma, and I am working as a counsellor at a women's centre. Once I gain more experience, I ultimately want to specialise in working with people struggling with health and grief, and support people in the same way I was assisted all those years ago.

I am immensely grateful for the MS Society and the Dorothy L Newman Scholarship's assistance with my course fees this year; it has been a great help, thank you!



# Esme Tombleson Person with MS of the Year 2015



Diagnosed with relapsing remitting MS, Sarah is a mother, wife and author who has dedicated her life to showing people that there is life beyond MS. The panel members were extremely impressed by Sarah's sense of community action and her strong focus on promoting a healthy lifestyle to the youth of today.

Since her diagnosis, Sarah and her family have moved from Auckland City to the country, to live a happier, healthier lifestyle. Due to fatigue and other problematic MS symptoms, returning to the workplace did not seem a viable option. Prompted by her lifestyle change, Sarah progressed into writing about her gardening and has now written two books: one documenting the journey from city slicker to country bumpkin, and the other to encourage families to get out into the garden and grow fresh food together. Sarah also writes for the New Zealand Herald in their Bite and Plus supplement, has a column on the Go Gardening website, and contributes to their paper magazine. In articles in the Natural Parent magazine and on [Kiwifamilies.co.nz](http://Kiwifamilies.co.nz), Sarah encourages families to grow their own food.

Sarah doesn't just sit behind her words, however; she has her own YouTube channel, is a Yates Brand Ambassador, speaks to groups about the benefits of growing food, has been on TV and helps out at her local school garden, mentoring and teaching others who want to garden.

**At the 2015 AGM, MSNZ presented Auckland member Sarah O'Neill with the Esme Tombleson Person with MS of the Year award.**

# Fantastic Fundraisers

## Many Steps for MS—Rachel Kirkbride

In November 2015, Rachel Kirkbride, from Christchurch, began the tremendous challenge of tramping the Te Araroa Trail, a 3000km journey down the length of New Zealand to raise awareness for MS. Fundraising for MSNZ and the NZMSRT, Rachel walked in memory of her brother Ian who had passed away five years before from progressive MS that had left him wheelchair—and bed-bound for 15 years. Seeing the impact MS had on her elderly parents was particularly difficult for Rachel, and she wanted to do her part to ensure others didn't have to go through the same thing.

“Think about all the places that you’ve been to, how many sunrises and sunsets that you have seen, how many hands you have held, how many plans for the future you have made in the last 15 years. Then stop and imagine that for these 15 years you were in a wheelchair or a bed, needing help with every movement of your body that you take for granted.”

Despite being an ultra-marathon runner and endurance racer, the 24-week-long tramp was her greatest challenge, both mentally and physically. During the adventure, Rachel managed to make time to speak at the launch of the MSNZ Research Trust, sharing snippets of her adventures so far and the friendly people she had met along the way. MSNZ and a number of our Regional Society staff and members were fortunate to meet with Rachel on her journey, providing a friendly face, supplies and even a warm bed for the night. MSNZ is extremely grateful to Rachel for the incredible effort she made in raising both awareness for MS and \$2146 in donations.

Read more about Rachel's journey at [www.ms-trampnz.com](http://www.ms-trampnz.com)

## Shave for MS—Joanna Judge

Joanna's older sister had just started university when she was diagnosed with MS, but it wasn't until Joanna herself helped out as a carer for another PwMS that she realised how the disease was going to affect her sister and the family.

“By 2015 I felt compelled to support the cause of the disease my sister is learning to live with (it shouldn't have taken me this long!) ... The previous year saw me attend two cancer funerals and witness my sister experiment with different medications, encounter symptoms, and relapse, due to financial obstacles making her then current (and effective!) drug unattainable. I become conscious of the fact that most of us take everyday life for granted (if not complain about it) and acted on my opinion that we have a duty to ease the unfair challenges that others face.”

Joanna realised that MS is relatively unknown, although most people know about the effects of cancer. She decided to shave her head and donate her hair to increase awareness of MS, and to raise funds for Multiple Sclerosis NZ and the Child Cancer Foundation. Joanna's efforts raised an impressive \$4500 for the two organisations.

“Being bald provided the perfect opportunity to raise awareness, as most people would ask if I shaved for cancer. I would reply, educating them about MS and the debilitating effects it has on the lives of people with MS and their families. I maintained the bald look for five months to broaden the scope of people I was able to enlighten, and—I have to admit—I also loved the look!”

## Walking a World of Friendship for MS—Angela Kirby

Turning 70, and still mobile twenty years after her first MS exacerbation, was Angela Kirby's incentive to celebrate in style. As a regular participant in the Canadian Walk for MS, and with enough travel points to complete a world tour, she had the idea to combine multiple fundraising walks with trips to friends and family abroad. It didn't take long to plan the tour:

“Starting with six walks in North America, then I would fly out, visiting five continents, do a further 24 walks, and end with a final walk with my husband in the Arizona desert for my 20th anniversary.”

During the tour, Angela completed three walks in New Zealand; the first was in Feilding with 17 supporters; the second in Christchurch Airport between flights, where other fundraisers, including Amanda Keefe, MSNZ's own National Manager, joined her; and the third in Queenstown.

“This I did solo, managing to leave the terminal and enjoy the snow-capped peaks and wonderful air that were everywhere!”

During the long tour, Angela completed 31 walks in 13 countries on five continents, bringing in over CAD 12,200 for MS internationally.





Rachel Kirkbride



Joanna Judge



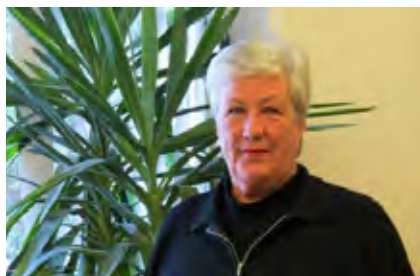
Angela Kirby



# Field Worker Representative's Report to the 2016 AGM



Many of us work in isolation, and this chance to learn from other colleagues is very beneficial.



This year it was back to beautiful Christchurch again for our annual Field Worker Conference in June. For those of us who arrived the night before, we were treated to local tastes and drinks, thanks to the South Canterbury Committee. This was very much appreciated by those fortunate enough to attend.

Our Conference material, topics and presentations were excellent, with interesting and talented presenters. I know that all the Field Workers gained a lot of knowledge and tools to take home and help us further in our profession, as well as supporting those with MS, and their families. This opportunity to continue our education is extremely important to us all. Many of us work in isolation, and this chance to learn from other colleagues and to share ideas and different case scenarios is very beneficial. The conference was very well organised and ran smoothly. A special thanks to Amanda Keefe and to the MSNZ Executive Committee for allowing us the two days together for this important ongoing education.

Between September and March many of the Field Workers throughout New Zealand met up with Rachel Kirkbride of Christchurch, who was walking the Te Araroa Trail (from Cape Reinga to Bluff) to raise awareness of MS. This was a magnificent, and brave effort by Rachel, and anybody who has read her blog site would readily understand the difficulty and hardship that she put herself through to help PwMS in NZ. For those of us who met Rachel, it was a humbling experience, and also a pleasure to be able to assist her by providing food supplies, a hot shower, occasional clothing items, a warm, dry, comfortable bed, and arranging for other trampers to accompany her on short parts of her marathon walk.

To all Regional Committees and Societies: I sincerely hope that you continue to use the knowledge, expertise and experience of your Field Workers. We all work very hard, and are passionate, professional and committed to delivering the best quality of care to PwMS, their families, carers, other medical staff and the general public.

On behalf of all the Field Workers, I would like to pass on our sincere thanks to all the Regional Societies and the MSNZ Executive Committee. Special thanks is owed to Amanda Keefe for all the work that she does behind the scenes on our behalf.

*Gay Dickie NZRN —MSNZ Field Worker Representative*



# Regional Reports 2015–6

## Upper North Island Cluster

### Northland

Northland MS continues to be busy and active and to grow in many ways. This year has seen another 12 PwMS join. Most are newly diagnosed but some have come from other areas; some have conquered their fear of seeing others with MS who are worse than they are, and decided that MS Northland is able to offer professional and personal help.

It is gratifying to know that we now have at least 19 PwMS on new treatments, with more awaiting the approval process or still deciding which is right for them. Few side effects have been reported, and many PwMS are very excited to take a medication that does not require regular injections. Improvements in clients' conditions are being reported. The numbers of PwMS on Tysabri® in Northland seem low, with most opting for the oral form of medication. Our Whangarei Hospital resident Specialist Physician, Dr. Nicole McGrath, has set up a good team at the hospital to deliver the infusions of Tysabri® as required, and they keep in good contact with the PwMS on the various, new DMDs. I continue to receive a lot of enquiries from others with MS, and their families, about the new drugs.

The past year has seen us continue with various activities from yoga, 10-pin bowling, 'Operatunity' concerts, coffee groups, and so on. However, many clients are quite apathetic about attending. I think that some of it is possibly due to a mix of low socio-economic situations, vast travel distances, younger clients being disinterested, and some not wanting to acknowledge their disability. Whatever the reason, it offers a challenge to me as a Field Worker that I am sure will be ongoing.

Fundraising continues as a daily routine; we held a very successful auction last October.

*Gay Dickie NZRN, MS Field Worker*

### Auckland

The Auckland Region covers a large area from the Bombay Hills in the south to Wellsford in the North. Four Field Workers (three FTE) cover the region, which is estimated to have one thousand people living with MS. About 560 people were members of MS Auckland during this period, receiving support from Field Workers, including home visits and assessments. We aim to see all people that are diagnosed with MS to provide them with free books and information on the community. While some decide not to join MS Auckland and take up the Field Worker service initially, we find that many will change their mind over time and call on us when they have a relapse or when their condition deteriorates.

In March 2016 the Field Worker covering West Auckland and Rodney resigned after eight years of service. The other three Field Workers worked extra hard to maintain a continuity of service for people until Andrea joined the team in July 2016.

Regular activities include:

- 14 Active Support Groups, meeting monthly
- six hydrotherapy groups in six different pools across Auckland each week, conducted by Rope Neuro Rehabilitation employees
- quarterly wellness workshops, covering a wide variety of topics.

In April, we brought back a month of yoga classes that were well received. MS Auckland is now looking at establishing regular yoga classes for people with MS.

The main issues experienced by the Auckland Field Workers include lack of funded neuropsychological services, lack of suitable care facilities for people under 65 years of age, transport services for people with mobility issues, and regular access to Neurologists and MS nurses because the demand exceeds current resources.

*Dianne Bartlett (South), Carol Andrews (Central), Diane Hampton (North) and Georga Forgac (West, until March 2016)—MS Field Workers*

### Waikato

It has been a busy and successful year for MS Waikato. Highlights for the year include our Golf Tournament fundraiser held in Lochiel in March and we marked World MS Day with our annual appeal in Hamilton and outlying areas. Other fundraisers included the 'The Inheritance' movie night and 'The Kawhia Cruise'—a fundraiser held in November and organised by one of our clients; this was a great day out for car enthusiasts that raised awareness and funds for the Trust.

An Education Evening was held in May for MS clients and their families, led by Neurologist Dr. Jan Schepel who spoke about diet, exercise, medication and meditation. MS monthly support groups at Momatawa and Te Awamutu continue to be well attended. The exercise class has been held twice a week with a good turnout. It is a collaborative initiative with the Parkinson's Society, whose members also attend. Totara Springs camp for MS clients and their families was held in March, an amazing weekend for families to be together, have fun, challenge themselves and form support networks. Christmas Lunch will be held at the Hamilton Workingmen's Club for all clients.

In June, Client Services staff attended the MSNZ Field Worker training in Christchurch, where a presentation was given on 'How collaboration and communication = a better-coordinated client service'. A poster version of this of this session was also presented at the MS Nurses Australasia conference by the Client Services Manager and Clinical Nurse Specialist at Waikato Hospital.

The MS Waikato website was redeveloped to be more user-friendly.

*Client Services Staff, Waikato*

## Bay of Plenty

The Western Bay of Plenty is now part of the 'golden triangle' and, as such, has seen five members relocating from Auckland. MS Field Workers in this region have advised that more members are on their way. This creates additional work, as not only do these people have MS but they also need support in establishing themselves in a new community and building new support networks.

Cheryl Standring received training to facilitate 'Minimise Fatigue, Maximise Life' workshops. Funding was obtained to subsidise workbooks, making it affordable for participants. In the period of this report, one workshop has been completed, with members expressing noticeable increases in the quality of their lives. Both Field Workers continue their professional development.

We have a diverse and complementary range of exercise activities on offer and our members are fortunate to have a choice as to what activities they attend. The Society is becoming known for our proactive approach in providing a client-centred service to our members.

There is only one Neurologist in the Bay of Plenty, located in Tauranga. This creates a waiting list and extra travel expenses for members, who are often challenged financially. There is no Community Response Team in the Eastern Bay of Plenty, nor a designated MS Nurse, but only a Neurological Nurse to support all conditions. Both Field Workers are challenged in providing services to members under their contract hours. A lack of funding continues to be an issue.

Worryingly, we have a number of homeless people amongst our own members. The housing crisis has reached Tauranga, and there is an urgent need for more, affordable housing in our region.

*Max Hollis and Cheryl Standring, MS Field Workers*

## Gisborne

We have 21 clients with MS and other related conditions.

Our two social groups meetings occur bi-monthly (with one targeted at employed people) and are well attended. We rely on the Sunshine bus (volunteer service) and taxis to transport those clients with wheelchair requirements.

Last November, we held a Garden Party—an event enjoyed by all, with perfect weather, good food and plenty of socialising. Other Society events included Christmas and Mid-Winter lunches.

We offer health supplements to all clients free of charge: Deer Velvet capsules, Uri cleanse capsules, flaxseed oil capsules, and flaxseed oil and Omega 3 fish oil capsules. A record is kept for each client who uses these products.

Pool therapy, horse riding, Pilates and exercise classes are on offer, but many clients are either working or too unwell to use these opportunities regularly. Services such as pool facilities, physiotherapy and Occupational Therapists have been arranged for clients when requested.

*Christine Beard, MS Field Worker*

## Rotorua

It has been another good year for the Society with much progress made. We have 76 clients throughout Rotorua, Taupo and Turangi.

The new treatments are progressing well in the region, with four clients on Tysabri®, eight on Gilenya® and three on Tecfidera®. Currently we do not have any using Aubagio®. Fourteen clients are still in the process to commence treatment soon and we have had four clients declined by PHARMAC.

The Rotorua Support group meets fortnightly, with the Taupo and Turangi groups catching up monthly. The Mid-Year Lunch for all three Regions was in June, and an End-of-Year lunch is subsidised by the Society.

Highlights for the year included a social gathering at Wai-O-Tapu for a free morning tea. Everyone was able to either walk or be pushed around the park. In April, we enjoyed a Gondola ride on the Skyline Skyride for morning tea, thanks to a donation that was given to the Society.

Members enjoyed yoga classes for a while but these had to cease due to unforeseen circumstances. We are researching Chairiobics to see if that might be viable. Our office has moved to the Pollards Building, which is more suitable for our purpose.

This year I attended a number of training opportunities: MS Nurses Australia Annual Conference, Biogen's in-service day on Tecfidera®, Loss & Grief study days, MS Auckland's Research Study Day, Biogen's MS Atlas 2016, MSNZ Field Worker Training and Biogen's MS Winter Meeting.

*Diana Hay, MS Field Officer*

## Lower North Island Cluster

### Hawkes Bay

MS Hawkes Bay celebrates its 40th year in 2016, and we will be having a celebratory lunch in November.

We had an excellent response to Multiple Steps for Multiple Sclerosis, increasing participation numbers once again. Our new flat course enabled participation by those less able, resulting in 366 people taking part, climbing more than 950 steps over Napier Hill. We also had the first Kiss Goodbye to MS event this year with an 'Ultimate Workout' at a local school. Trivial Pursuit nights, raffles and a 'Good in the Hood' month at a local Z Station all helped with fundraising.

Our first 'Minimise Fatigue, Maximise Life' course proved successful, with interesting results. Our Monday Group which is a social/peer support brain gym has been running for well over 35 years and is a great resource for many of our knowledgeable members discussing MS symptoms and life. We would also like to acknowledge our volunteers for this group who turn up every fortnight without fail; they and their work are greatly appreciated by everyone attending the group.

Our swimming group is going from strength to strength, and due to new funding, it now also supports people in Central Hawkes Bay. We have also been lucky to receive funding for a Pilates group that started in May. We hope to continue this next year, depending on funding. The Society is very appreciative of Hawkes Bay District Health Board and the team at Neuro-Physio who have worked and fought to retain our Neuro Gym Group at the Hospital Gym.

Our community radio programme is into its tenth year, informing people about life with MS and passing on relevant information to the local community.

*Robyn Coyle, MS Field Worker*

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## Taranaki

Taranaki is continuing to see a slow increase in our client members, though I continue to hear of many PwMS who are not members of our Society. I feel it is hard to get an accurate picture of the numbers of PwMS in our region based on our records alone.

Due to low numbers, we are currently not holding exercise classes or Society lunches and only have a morning tea every three months. The fact that our members are spread out around Taranaki could be a factor. I feel technology plays a positive part as clients can communicate online; our Society has a closed Facebook page, which is a great tool for enabling clients to ask questions and communicate freely.

I have had great success in communicating with the visiting Neurologists at Taranaki District Health Board; they have been very helpful, and complete referrals when able. We also now have a nurse who looks after those on the new treatment drugs; she is of great benefit to them.

We have had a good response with all referrals for equipment, although at times it is slow. Physiotherapy and occupational therapy referrals are usually dealt with promptly.

With our wonderful, proactive committee we have been very successful in our fundraising ventures, and though they may not raise huge amounts, we are certainly bringing attention to the challenges faced by those living with MS.

*Moiria Paterson, MS Field Worker*

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## Wanganui

It has been a year of change at MS Wanganui. Following Carol Hammond's retirement I was employed in June 2016 and my main focus has been meeting our clients in their homes. I have been providing support, referrals to appropriate agencies, and advocacy for MS clients. Home visits are necessary to keep in touch with clients and to assess their requirements for services such as personal care, housework support (or alterations), and to keep them informed on up-to-date knowledge of MS and its management.

The support group meets monthly at Caroline's Boat Shed for a meal and a chat. This is a great way to socialise with our clients and find out their expectations from the MS Society as a whole. I have supported members' applications to the Lotteries Commission, and completed assessments to Horizon for taxi vouchers. Most of our members are doing reasonably well, and they tell me they really appreciate the help the Society gives them.

I liaise with allied agencies and attend the monthly Assessment, Treatment and Rehabilitation meetings at the hospital. The MS Field Worker Cluster meets three times a year in Palmerston North, and I attend relevant training opportunities. I had the pleasure of attending the MS Field Workers' Training, which was very informative. Being so new to this role, it was great to meet other Field Workers to network and learn more about the role.

I would like to thank the members who have supported me this past year. Also thanks to Gary Buckley, Carol Hammond and Jody Tapa for their support since I started.

*Travena White, MS Field Worker*

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## Central Districts

MS Central Districts has had another busy 12 months of referrals from newly diagnosed patients and clients seeking more support as their MS progressed. Thanks to a successful multi-year funding application to Lotteries, a second part-time Field Worker joined our staff in February 2016. This has resulted in better overall support for our clients, particularly in the area of symptom management.

Attendance at our maintenance therapy programmes fluctuates, but overall there is generally a strong demand for these groups (client and carer peer support, art, yoga and fatigue management). Two 'Minimise Fatigue, Maximise Life' courses have been held in the last year, ably facilitated by a volunteer health professional. Our newsletter is now a quarterly edition, covering local MS news, events and research, and is well received by members.

We had several opportunities to raise awareness of MS in the community with presentations to Lions and Rotary Clubs alongside a successful Street Appeal and art exhibition in September 2015. As a result, we have more volunteers on board and several Lions Clubs have offered to assist with our 2016 street appeal.

Funding our services remains an ongoing challenge as the supply of community funding diminishes and Ministry of Health funding undergoes a revamp.

*Philippa Russell and Ria Sapsford, MS Field Workers*

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## Wellington

MS Wellington covers Wellington, Porirua, Kapiti Coast, Hutt Valley and Wairarapa.

Field Worker training, local community courses and regular supervision keep learning fresh and current. Last August, Wellington Field Workers were invited to attend the Australasian Nurses Conference in Wellington, which was very beneficial and informative. A regional Dementia network and education sessions have also been invaluable.

We hold five monthly support groups and a weekly yoga group. The Laura Fergusson Trust has a specialised and adapted gym in the Hutt Valley, and in Kapiti we link people to localised community activities.

Field Workers work with the Committee and a variety of other organisations, including Neurology and Community Health teams. Together we developed and facilitated a 'Recently diagnosed' education workshop, designed to provide information, facilitate clients and their support persons in discussions, and assist with establishing support networks. Feedback has been excellent and there is likelihood of a further workshop next year, should numbers be high enough.

Clinical trials of MIS416 through P3 Research continue, and we receive feedback from our clients. The trial of clozapine and risperidone for the treatment of secondary progressive multiple sclerosis (CRISP), instigated by Associate Professor



Anne LaFlamme in Wellington, is now recruiting candidates. It is exciting to have two trials in Wellington, both targeting secondary progressive MS.

*Gillian Fry and Sue Johnston, MS Field Workers*

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## Top of the South Cluster

### Marlborough

Marlborough MS and Parkinson's Society has a steady number of existing and new clients using the service. Referrals are being received through different channels such as the Nelson Marlborough District Health Board and other agencies that are becoming aware of the service through networking.

We are encouraged by the appointment of a Nelson-based Neurology Nurse who assists our only Neurologist, Dr. Desiree Fernandez, with those who choose to take the MS disease modifying drugs. This has meant that Tysabri® infusions are now offered in Nelson, previously requiring a trip to Wellington. Only a small number of our clients with RRMS have chosen to use these medications, preferring to use lifestyle and dietary changes, with good results. The appointment has also increased our collaboration with the medical staff of NMDHB, and care has been timely and optimal when required at hospital level.

Community Educator Support is provided by reviewing clients' needs and, when symptoms change, identifying ways to enhance each individual's health outcomes in a way that empowers each client to self-manage. We are planning to bring expert speakers to Marlborough, and have Dr. Louise Parr-Brownlie from the Brain Health Research Centre speaking to members in October.

We continue to offer social opportunities by organising regular morning teas and lunches, and Society events such as a recent mid-winter lunch held at Nelson Marlborough Institute of Technology in Blenheim.

Fundraising continues with regular sausage sizzles, 'Good in the Hood' with Z Petrol, MS Awareness Week and street appeals increasing our local awareness and profile to the public.

*Janine Ready NZ RCpN, MS Field Worker*

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### Nelson

Looking back, the past year has been challenging yet rewarding, providing information, support, advocacy, education, home visits, hospital and rest home visits. In addition, I run support groups for our members and carers with the main aim being to help them maintain as normal a lifestyle as possible, to provide practical help, relief, and to decrease the feelings of isolation.

I continue to have a good relationship with hospital social workers, speech therapists, rehabilitation physiotherapists, occupational therapists and all other allied health care providers. The highlight for Nelson is that we now have a MS Neurological Nurse in the hospital, and our clients on medications can have direct contact with her.

During the year we took part in MS International Day and MS Awareness week in our region. We have also set up monthly information tables in the community, giving the public easy access to pamphlets and information on MS.

I have attended a number of local training sessions in our region, and attended staff meetings and supervision on a regular basis. I have a very supportive committee and I consider it a privilege to enter into the personal lives and homes of each client.

*Pam Grey, MS Field Worker*

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### West Coast

The past year has seen the West Coast Society struggle with staffing issues and the retention of a functioning committee. It has been difficult; however, things are now improving and we are looking to the future with excitement and with the intention of building a bigger and stronger Society than before.

As Field Worker, I have continued to follow up with existing clients and have added a few more newly diagnosed people to our client base. Time has been spent liaising with other health professionals in the community, to widen awareness of our Society on the Coast. I have also performed many education sessions both to other health workers and community groups; these have been really well received, and are also a fantastic way of raising awareness of MS across the board.

Our annual Craft Fair was held in September 2015. It was a great success, as always, and even though hampered by the West Coast weather, was well attended by the locals and tourists alike. Our Craft Fair is a well-known annual event on the Coast and great for getting our name out there and advertising the Society to all as well as raising much-needed funds.

*Belinda Butterfield, MS Field Worker*

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### Canterbury

The 2015–2016 year has seen an 'onwards and upwards' increase in referrals, contacts and services. Judy's caseload increased by 55 new referrals bringing it to just under 400. Nurse contacts numbers were 1869, making a total of 3000 contacts, including gym and exercise class attendances.

During the year we started two new peer-support groups in Christchurch and Rangiora. Our three groups, including Ashburton, are well attended, with different speakers and themes. Gym sessions, exercise groups, yoga and Nordic Walking, overseen by our physiotherapists, all help to keep members fit and as active as possible. Our monthly lunch group continues with a core group of 7–10.

At the MS Nurses Australasia Conference at Te Papa last August, Judy McKeown, our nurse (along with the Christchurch Neuro Nurses Group) won the award for best poster on MS and Sexuality. Judy also presented a case study as a podium session, and physiotherapist Jessie Snowden presented a session on Minimise Fatigue, Maximise Life.

Our public event for World MS Day featured international speakers Brett Drummond and Travis Stiles, who spoke about stem cells, science communication and Novoron Bioscience, Inc. to 75 attendees.

*Robin Furlley, Manager*



## Lower South Island Cluster

### South Canterbury

On 25 February 2016, MS South Canterbury celebrated our 50-year anniversary. When reading back through reports and notes from the mid-sixties, the focus of the new Society back then was much the same as it is today: to empower people with MS to lead independent, active and fulfilling lives, and to encourage them to be active members in their communities. We celebrated with an invitation to all our clients to attend a lovely meal and an inspirational talk by our guest speaker Graeme Sinclair. We had several special guests, including MS National President Malcom Rickerby and his wife, and our Patron, Mr Jim Millar, and his wife. The evening was enjoyed by all.

MS South Canterbury has, for several years now, organised our MS Awareness Week to coincide with World MS Day at the end of May. The reason is that Timaru is a small town and there are just far too many groups with their awareness days in August and September. It works very well for us, and, with the help of several of the local high schools, which use it to help with their service awards, we have a very successful collection day. With displays at various places around Timaru and a large manned display table in the centre of town, there was no escaping the wonderful bright orange that is the trademark colour of MS in NZ.

We continue to run a number of different support and social groups with varying numbers attending depending on where, when, what and weather.

I have noticed how well my clients on the new drugs are keeping, and of course this has made a difference to my workload. I am hoping that we will continue to notice this trend.

*Fiona Pierce, MS Field Worker*

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### Otago

The Otago region remains strong and continues to work closely with other allied healthcare professionals. This has been reflected in the number of people who have started treatments. The Otago Multiple Sclerosis (MS) Society has been able to work collaboratively with the MS neurology personnel within the Southern District Health Board.

The Field Worker Service provides visits to our members in the community. Some members have engaged with our 'MS Momentum' community radio show and talked about their own experiences. This is one area where we have been able to provide support and education.

When covering such a large area, we have to consider that location can cause problems. We aim to reduce barriers that adversely affect a person's treatment options and support them by exploring transportation options. After discussions with the Neurology team we plan to include day-stay units in more remote areas in the future.

This is a time when a difference can be made for our people, potentially changing the long-term prognosis for many.

*Maree Darling, MS Field Officer*

### Southland

We have, as always, been kept busy supporting our members over the year. We are fortunate to now have a Centre Manager: Nicki Kitson took the helm in December and is a welcome addition to MS Southland.

One of the highlights of the year has been a generous donation to the direct welfare of our members from the Masonic Charitable Trust. Funding from the Trust has enabled our members to get out and about, to access community activities more freely and, most importantly, independently.

We continue to appreciate and benefit from the Southern District Health Board Neurology team, and are constantly being told by members that they are benefiting from treatment with the recently available disease modifying drugs. This is great progress for PwMS and a huge relief for Field Workers to have such excellent medical interventions available.

The Centre continues to offer support, activity groups and social outings for our members, but many of our PwMS are in the workforce and so unable to attend daytime meetings.

Our main frustration is the length of time it takes for our clients to be assessed by the occupational and physiotherapy departments in Southland. This is due to staffing shortages at the hospital.

We would like to thank Amanda at MSNZ for putting together a very informative, interesting and fun Field Worker Training conference in Christchurch in June this year. We look forward to next year's training! Thank you.

*Doreen McMannus and Viv Gillan, MS Field Workers.*

# Our Grateful Thanks

## Bequests

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

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

**Thank you to the families and friends for their donations in memory of:**

Late Mrs Isabel Magnussen  
Late Mrs Patricia Doreen Steffensen  
Late Georgia Maureen Whittaker  
Late Mrs Elsa Victoria Lambert  
Late Mr Gerard Bracken  
Late Mrs Elaine Jessie Holden  
Late Mrs Carolyn Harper

## Funders and Supporters:

MSNZ would like to thank the following for their support in 2015–6:

### Trusts and Grant Funders

Lottery National Community Grants, Ministry of Health, Pub Charity Limited, Community Post, Working Together More Fund, The Dorothy L Newman Charitable Trust

### Businesses

Pharmacy Retailing (NZ) Limited, Health TV, Slipstream, WaltersPR, Servcorp NZ, Aspire Canterbury, The Spark Foundation, BNZ, Oceanbridge Shipping Ltd, Printable, Bennett Currie, Novartis, Sanofi, Biogen, Seqirus

### Major Donors

Society of Mary Trust Board, Wildermoth Family Trust, Goodman Foundation, Rainer Huebner, Robert Lawford, John Judge, David and Sarah Crofoot, Hampden Street School, Maurice Collins, Cunningham Lindsey, WJ & JA Plimmer, WG Going, RS and V Fox, David Dunham and Alexandra Carter.





# Annual Financial Statements

## Multiple Sclerosis Society of New Zealand Inc

Financial Statements 30 June 2016

### 30. Summary Audit Opinion

#### Statement of Financial Performance:

- 31. “How was it funded” and “What did it cost”
- 32. “What the entity owns” and “What the entity owes”
- 33. “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 2016, authorised for issue on 28 September 2016 by the President and Vice President of the Society, have been audited by Nexia New Zealand. The audit opinion noted that except for the possible effects of the Basis of Qualified Opinion, in all material respects the financial position as at 30 June 2016, the financial performance and cash flows for the year ended 30 June 2016 were presented fairly, and included the following paragraphs:

#### Basis for Qualified Opinion

- 1. As is common with organisation of a similar nature, control over revenue collected in cash (e.g. donations and appeals), prior to being recorded, is limited and there are no practical audit procedures to determine the effect of this limited control.

#### 2. Emphasis of Matter

Without further qualifying our opinion, we drew attention to Note 10 (of the full Performance Report) which records that Multiple Sclerosis Society of New Zealand Inc. continues to be reliant on fundraising, donations, grants and government funding and that the Committee is committed to the on-going financial viability of the Society.

#### 3. Other Matter

The financial statements of Multiple Sclerosis Society of New Zealand Inc. for the year ended 30 June 2015 were audited by another auditor who expressed a qualified opinion on those financial statements date 31 August 2015.

The presentation currency of the summary financial statements is New Zealand dollars. The financial information presented has been rounded to the nearest whole dollar. The summary financial statements do not include all the disclosures provided in the full Performance Report and cannot be expected to provide as complete an understanding of the financial affairs of the Society as the full Performance Report. The full Performance Report of the Society can be obtained by contacting the National Office.

# Multiple Sclerosis Society of New Zealand

## Statement of Financial Performance

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

For the year ended

30 June 2016

	Actual This Year \$	Actual Last Year \$
<b>Revenue</b>		
Bequests, Donations, fundraising and other similar revenue	384,295	195,949
Fees, subscriptions and other revenue from members	4,987	5,164
Revenue from providing goods or services	258,753	258,753
Interest, dividends and other investment revenue	23,807	94,500
Other revenue	9,803	25,009
<b>Total Revenue</b>	<b>681,645</b>	<b>579,375</b>
<b>Expenses</b>		
Expenses related to public fundraising	37,871	42,332
Volunteer and employee related costs	111,179	139,298
Costs related to providing goods or services	273,981	268,228
Grants and donations made	224,224	687,574
Other expenses	24,315	31,256
<b>Total Expenses</b>	<b>671,570</b>	<b>1,168,688</b>
<b>Surplus/(Deficit) for the Year</b>	<b>10,075</b>	<b>(589,313)</b>



**Multiple Sclerosis Society of New Zealand**  
**Statement of Financial Position**  
**"What the entity owns" and "What the entity owes"**

As at  
30 June 2016

	Actual This Year \$	Actual Last Year \$
<b>Assets</b>		
<b>Current Assets</b>		
Bank accounts and cash	81,247	23,821
Debtors and prepayments	17,307	26,625
<b>Total Current Assets</b>	<b>98,554</b>	<b>50,446</b>
<b>Non-Current Assets</b>		
Property, plant and equipment	2,421	2,912
Investments	150,190	190,909
<b>Total Non-Current Assets</b>	<b>152,611</b>	<b>193,821</b>
<b>Total Assets</b>	<b>251,165</b>	<b>244,267</b>
<b>Liabilities</b>		
<b>Current Liabilities</b>		
Bank overdraft		
Creditors and accrued expenses	55,245	55,244
Employee costs payable	7,261	7,864
<b>Total Current Liabilities</b>	<b>62,506</b>	<b>63,108</b>
<b>Non-Current Liabilities</b>		
Other non-current liabilities		2,575
<b>Total Non-Current liabilities</b>	<b>-</b>	<b>2,575</b>
<b>Total Liabilities</b>	<b>62,506</b>	<b>65,683</b>
<b>Total Assets less Total Liabilities (Net Assets)</b>	<b>188,659</b>	<b>178,584</b>
<b>Accumulated Funds</b>		
Accumulated surpluses or (deficits)	132,649	122,906
Reserves	56,010	55,678
<b>Total Accumulated Funds</b>	<b>188,659</b>	<b>178,584</b>

President



Vice President



**Multiple Sclerosis Society of New Zealand**  
**Statement of Cash Flows**

"How the entity has received and used cash"

**For the year ended**  
**30 June 2016**

	Actual This Year \$	Actual Last Year \$
<b>Cash Flows from Operating Activities</b>		
<b>Cash was received from:</b>		
Donations, bequests, fundraising and other similar receipts	400,664	210,258
Fees, subscriptions and other receipts from members	4,987	5,164
Receipts from providing goods or services	261,300	258,768
Interest, dividends and other investment receipts	11,750	39,120
Net GST	(3,649)	(3,554)
<b>Cash was applied to:</b>		
Payments to suppliers and employees	426,177	505,768
Donations or grants paid	244,224	648,211
<b>Net Cash Flows from Operating Activities</b>	<b>4,651</b>	<b>(644,223)</b>
<b>Cash flows from Investing and Financing Activities</b>		
<b>Cash was received from:</b>		
Receipts from the sale of investments	88,803	635,335
<b>Cash was applied to:</b>		
Payments to acquire property, plant and equipment	-	1,845
Payments to purchase investments	10,000	-
Repayments of loans borrowed from other parties	26,028	-
<b>Net Cash Flows from Investing and Financing Activities</b>	<b>52,775</b>	<b>633,490</b>
<b>Net Increase / (Decrease) in Cash</b>	<b>57,426</b>	<b>(10,733)</b>
<b>Opening Cash</b>	<b>23,821</b>	<b>34,554</b>
<b>Closing Cash</b>	<b>81,247</b>	<b>23,821</b>
<b>This is represented by:</b>		
Bank Accounts and Cash	81,247	23,821







**Alone we can do so little.  
Together we can do so much.**

*—Helen Keller.*

**ms.**

Multiple Sclerosis  
New Zealand

Annual Report  
**2015–2016**

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