

New Zealand Multiple Sclerosis Research Trust



research that really makes a difference

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ms. New Zealand
Multiple Sclerosis
Research Trust

Charities Registration number: CC51849

New Zealand Multiple Sclerosis Research Trust

OUR AIM:

- ▶ To stimulate, co-ordinate and support New Zealand-based research into the cause, prevention, treatment, alleviation and cure of Multiple Sclerosis (MS), and to obtain and disseminate research findings.

WHAT DOES THE TRUST DO?

- ▶ Collaborates with partners to fund research that helps people with MS;
- ▶ Informs people about research findings;
- ▶ Uses fact-based research findings to improve the lives of people with MS.

WHY IS THE TRUST NEEDED?

- ▶ A single point of focus is needed for funding MS research. In the past, research for MS has been one of only a number of research strands within organisations that deal with a wide range of neurological or other health conditions.
- ▶ To make a real difference to New Zealanders living with MS, MS research needs a stand-alone Trust that can initiate MS research or collaborate with research partners to fund research opportunities.

HOW MANY KIWIS HAVE MS?

The true number of people with MS in New Zealand is currently unknown. The most accurate figures from the 2006 New Zealand National MS Prevalence Study showed:

- ▶ **2,917** people diagnosed with MS in New Zealand;
- ▶ The overall prevalence of MS in NZ in 2006 was 73.1 per 100,000 population;
- ▶ Of the 2,917 people with MS, 2,189 (75%) were women and 728 (25%) were men, making the female to male ratio of illness as 3:1;
- ▶ Since 2006, **the numbers of New Zealanders with MS has continued to grow** due to a number of new cases being diagnosed every year.

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WHAT WILL WE DO WITH THE RESEARCH?

- ▶ Co-operate, collaborate and share information with other research organisations or individual researchers, within New Zealand and overseas, in the interests of advancing the research undertaken by the Trust;
- ▶ Consult and share information with the MSNZ or other organisations within New Zealand representing or supporting people with MS;
- ▶ Initiate, encourage and facilitate research into the application and use of clinical research outputs in establishing, supporting or maintaining practical programmes for the alleviation of the medical, psychological, physical, social, employment or other effects of MS in New Zealand;
- ▶ Obtain, publish and disseminate papers, articles and other forms of information containing or reporting on research findings;
- ▶ Provide research results to health professionals and their organisations with the aim of attracting, educating, and retaining high quality health professionals to work with people with MS in our hospitals and in the community;
- ▶ Educate people with MS, their families, carers and members of the wider community on the outcomes of research;
- ▶ Make submissions or representations to Government, health authorities or other agencies in support of legislation, regulations, funding programmes or practices designed or intended to prevent, treat, cure or alleviate the effects of MS.

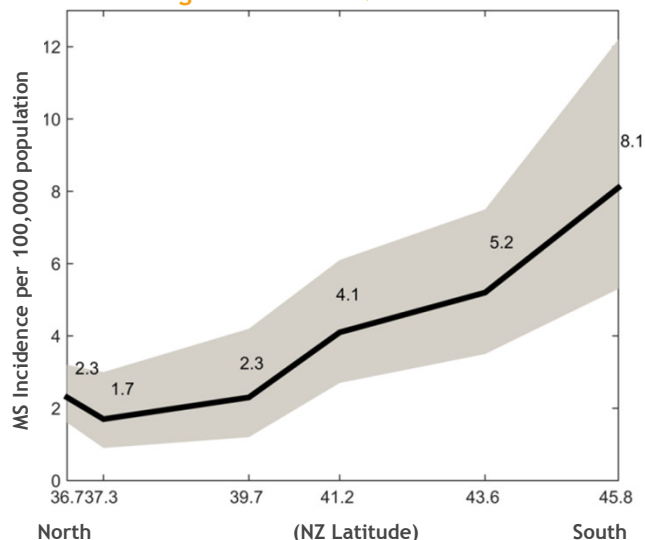
WHY DOES NEW ZEALAND NEED TO DO RESEARCH?

- ▶ New Zealand provides unique opportunities for MS researchers. There is so much about MS in New Zealand that is unknown. The opportunity to make life better for people with MS in our

country is enormous and the need is pressing.

- ▶ A strong research community underpins a strong medical and clinical workforce, and New Zealand needs to attract and retain key clinical doctors and nurses with an interest in MS.
- ▶ Through its research and by strengthening international links with other MS organisations, the Trust is aiming to build a strong and respected NZ-based research capability that will make a real difference to the lives of people with MS here.
- ▶ The MS Community in New Zealand strongly supports the establishment of the Trust, with MSNZ giving an initial \$600,000 and the MS Auckland Region Trust giving \$300,000 as founding capital for the Trust. Both organisations have indicated an intention to continue to support the Trust with additional funds as these become available.
- ▶ All money raised by the trust will be professionally invested and a percentage of the income will be made available for approved NZ-based MS Research. The Trust is a registered charity under the Charities Act 2005 (Reg no CC51849) and donations to the Trust are eligible as deductions for tax purposes.

Latitude gradient with NZ Incidence



Source: MS Research Group Incidence Study 2015

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HOW DOES MS AFFECT PEOPLE'S LIVES?

- ▶ People with MS suffer physically, emotionally and financially - and so do their families as it most often affects young adults in their most productive years.
- ▶ The 2006 Prevalence Study reported significant levels of disability and its deleterious effects on work status within the MS community:
 - ▶ 1,659 people experienced moderate to severe disability, of which more than 400 were confined to a wheelchair or bed;
 - ▶ MS profoundly and negatively influences work force status of New Zealanders within the working age group (25-64 years);
 - ▶ Over 90% of people with MS in the working age population had a work history, however more than 54% were not working in 2006 due to MS;
- ▶ At least 69% of the working age MS population changed their work status as a consequence of the disease process, most within the first four years of diagnosis. The strongest predictor of not working was age, with those above 35 years and over more likely to report that they are not working. The loss of work status also appears to be greater for women and those with progressive type of disease;
- ▶ The median annual personal income for the MS working population was \$20,000, which is significantly lower compared with the median income of the New Zealand population of \$34,750;
- ▶ Income sources showed that more than 30% were receiving an Invalid's benefit compared with just 3% of the general population in New Zealand;
- ▶ Burden of illness studies have identified loss of work as the major cost driver with some studies reporting the cost of MS to an individual to be as much as 40% of their lifetime earnings.

WE NEED YOUR HELP

There is much that the Multiple Sclerosis Research Trust can do but we need your help. Our aim is to build the Trust from its initial funding of \$900,000 to \$5,000,000 within five years. Income from the Trust will be used to fund qualifying research.

YOU CAN HELP US BY

- ▶ Making an initial donation;
- ▶ Committing to a regular annual donation;
- ▶ Providing services on a 'pro bono' basis;
- ▶ Agreeing to underwrite the annual operating costs of the trust;
- ▶ Making a specific bequest to the Trust in your wills Act 2005 (Charities Registration number CC51849) and donations to the Trust are eligible as deductions for tax purposes.

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