

# Issue 40 Autumn 2014

ms  
voice



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## Multiple Sclerosis New Zealand

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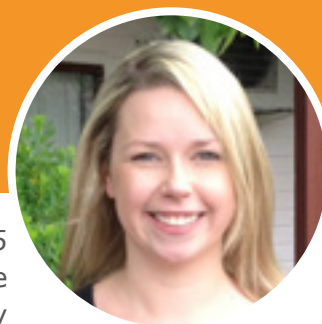
Glenn  
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## We want to hear from you

With a refreshed design and story approach, we would like to offer more content on research, living well and experiencing life with Multiple Sclerosis, and we want to know what you think and even share your own story! Email to **[info@msnz.org.nz](mailto:info@msnz.org.nz)** or post to PO Box 32124, Christchurch 8147

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# News from National



What a busy start to the year it has been!

Firstly, MSNZ would like to express a huge thank you to BDO for nominating the Society as the event charity for the **2014 BDO Wellington to Auckland Cycle Challenge**. The event took place over 7 days from 9th – 15th February and raised over \$20,000 for Multiple Sclerosis.

In March MS Fundraisers from our Regional Societies came together in Christchurch for the inaugural **Fundraisers Workshop**. The event was fantastic in bringing together people who are passionate about raising the profile and awareness of MS in their region sharing ideas and advice. MSNZ was proud to be able to support our Regional Societies with this workshop, helping to create unity and strengthen the skills of fundraisers across the country.

At the beginning of April 23 Field Workers from across New Zealand came to Christchurch for their annual training. This educational workshop is an invaluable opportunity to hear from specialised speakers, providing them with further knowledge, information and skills to assist their clients in their regions. MSNZ organises and funds the **Field Workers Training** with thanks to bioCSL, Biogen Idec, and Bayer for supporting the training as well as BNZ for the use of their Partners venue.

Between March and May the next stage of the **“Minimise Fatigue, Maximise Life. Creating a balance with Multiple Sclerosis”** research

programme takes place in 5 centres across the country. The results are looking extremely positive and we look forward to being able to take the programme across the rest of the country within the coming year.

The MS Incidence Study funded by MSNZ is nearing its two year recruitment period on 31 May 2014.

If you have been diagnosed with MS since 1st June 2012 and are not part of the study please contact **msstudy@nzbri.org** or **0800 MS STUDY**.

We hope to bring you the first results later this year.

MSNZ is aware that there is considerable interest and frustration in the non-availability of Government funded access to the drug Tysabri. MSNZ has written recently both to the Minister of Health and to PHARMAC. Copies of those correspondence are available on our website at [www.msnz.org.nz](http://www.msnz.org.nz). We are aware also that a number of individuals supported by their Neurologists have made their own submissions for funding to Pharmac without success. More information on the work of MSNZ on this matter, how to be a part of the Tysabri Steering Group and recent research into Tysabri can be found on Page 7. MSNZ is committed to advocating for choice for people living with Multiple Sclerosis.

## In this edition of MS Voice:

- ◆ We will have more updates and stories from the BDO Wellington to Auckland Cycle Challenge
- ◆ Get to know your Field Workers. Who are the Field Workers out there working in the community, what do they do and what motivates them?
- ◆ Employment – how can simple changes in the workplace benefit you?
- ◆ The Dorothy L Newman Scholarship applications are open. The Scholarship assists people with MS who need to change their employment and undergo a course of retraining in order to do so.

We welcome any feedback or suggestions for future issues. If you have a story that you would like to tell please contact us on **info@msnz.org.nz** or call 0800 MS LINE (67 5463).

With warm regards,

Amanda Keefe  
National Coordinator

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Multiple Sclerosis  
New Zealand

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When MS was announced as the nominated charity for the **2014 BDO Wellington to Auckland Cycle Challenge** we did not expect to be handed over a giant cheque for \$20,297.20 that was raised from the event. Not only were we elated with the generous funds raised but also the increased awareness of the condition across the country that the event enabled us to provide.

Funds raised from the event will go towards supporting MSNZ to provide information and education about the condition to those who need it. Over 3000 people in New Zealand are diagnosed with the condition and support and education is required by all who are touched by the condition including those diagnosed, their families, carers, employers and health professionals.



With the support of our Regional Societies and their members, riders on the challenge were able to engage with the people their hard work and fundraising was going to support.

“So, over the course of the last few days, the boys seem to have been enjoying the ritual of Sarah’s ham & avo sammies at the end of every morning leg, but today something completely topped this. We got to Hunterville and a couple of lovely local ladies who suffer from Multiple Sclerosis (the charity we are riding for) were there to support, just Freshmax, laden with a wee box of homemade curried pies and fruit cake. It was a special moment for the boys.”  
(Extract from the Freshmax NZ Team blog)

**Thank you to all those who came out to support and help tell your story.**

**Thank you** to everyone that donated, **BDO New Zealand** for nominating MS as the charity of choice and **Dynamo Events** for putting on such a successful event.

It has been an incredible event to be a part of and we are blown away by the support from all involved including **Team Xero** and **Freshmax NZ Ltd** who rode for MS.



David O’Connor, partner and Chairman of event sponsor BDO took part in the event, completing each and every kilometre of the journey alongside his BDO team mates.

“The BDO challenge saw Corporates and their staff taking time away from the office along with associated clients and suppliers to cycle together for a common purpose, building team spirit and camaraderie, all in all the BDO Wellington to Auckland Challenge was a huge success.”

Dynamo Events Director and former Olympic Games cyclist Stephen Cox was thrilled with the success of the event and the chance to make a difference with two deserving charities.

“I have to thank all of those who participated; the vast majority of them are just everyday normal Kiwi people who love taking on a challenge. Our solo riders are just fantastic, as well as riding every day, many of them fundraised and contributed during the week to raffles and our official auction night at Ohakune for MS.”

Over \$6500 was raised at the Auction night in Ohakune for MS. Prizes for auction included box seats for two at the Bruce Springsteen Concert donated by ASB and won by John O’Brien. Also on the auction table was a bottle of Chateau d’Yquem sold for \$1000 which has been designated to go towards MS Research.



“It is all of our participants who are the stars; they inspire us with their riding and the money raised all goes to MS.” commented Stephen.  
(Quotes from dynamoevents.co.nz)

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MSNZ would like to express **a special thank you to MS Auckland Fundraising and Marketing Manager Pam Smith** for the incredible effort she put into the challenge. Pam rode the entire event for MS Auckland raising \$3010. Pam became a key figure at the event and was pivotal in ensuring that everyone she met was aware of MS.

## Pam's final blog post

Day 7 update, final stages 12 & 13. TOTAL KMS 875.

**“**Phew what a day to finish, stunning weather and awesome riding. We left Hamilton early with a brief stop at Glen Murray before heading to the finish at Pukekohe.

What a ride it was. Team Xero were out for redemption and we were racing for PRIDE. I have never ridden so fast in my life!! I really didn't think my legs had anything left. Team mates Richard and Carl pushed me through the tough rises and



*we finished ahead of Team Hynds and Freshmax. Unbelievable!!*

*I really didn't think I had anything left in my legs however as soon as I hopped back on the bike for the final stage we were off!!! From the start of those final 37kms we were game on. Another great effort from total Team Xero and again we redeemed ourselves with our best result for the entire week coming in 5th from 11. Our last 2 stages were exceptional and my legs have never moved so fast!*

*As I crossed the finish line it was great to see so many people from MS Auckland there to see me finish. I thank you all so much for your support. Thank you Malcolm for making the journey from Christchurch to be there at the end. A huge thank you to Neil Woodhams who was my support crew all week.*

*Its been one helluva ride.”*

**Thanks Pam and all the riders for your hard work!**

## Good Sort

Ray Hyndman (Lower Hutt) was one of the remarkable stories of the event, the 79 year old was the oldest in the race and overcame the tough conditions early in the week and some long days in the saddle to cross the line to a great reaction from the waiting crowd, whereupon he was presented with his finisher's medal.

“That was tougher than I thought it was going to be to be honest. I knew it was a big challenge but with the weather the way it was early in the week, it was hard going at times.

“But I have finished and met some great people along the way. That is the best thing about this ride, as well as the roads we travelled down, it was the people you meet along the way and shared a few stories with once you crossed the finish line.

“I am not finished yet though, I am going to spend a week in Auckland resting up and then plan to ride up to Cape Reinga with a group called the ‘Geriatric Cycle Club’ so that will be fun as well.”

Thank you to the [Scenic Hotel Group](#) for the fantastic prize donated that we were able to give to Ray as a thank you for all his efforts in helping to support MS and raising \$739! What an inspiration and keep peddling Ray!



**SCENIC HOTEL GROUP**  
HEARTLAND HOTELS & SCENIC HOTELS  
NEW ZEALAND OWNED & OPERATED

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# Dorothy L. Newman Scholarship

The Dorothy L Newman Scholarship assists people who have been diagnosed as having MS and as a result are unable to continue in their present employment, who need to change their employment and undergo a course of retraining in order to do so. Applications are open solely to people with MS needing to retrain for paid employment.

Applicants will be required to explain in a statement in their application the reasons why they chose their course of study, how they intend to use their qualification on successful completion of their course and the likelihood of employment following the course.

Applications for the Dorothy Newman Scholarship fund are now open. To receive a copy of the guidelines and application form email [info@msnz.org.nz](mailto:info@msnz.org.nz). Applications close 30th June 2014.



// Once again I have a dream of a bright future, a future where I can support myself and have a career. Through MSNZ it has been feasible for me to return to university and acquire a new qualification that will allow me to return into the workforce, a workforce where I may be able to help myself and others with multiple sclerosis. Without that wonderful Dorothy Newman Scholarship the dream would be tainted with expense that in my condition it would be hard for me to fathom. So thanx you to MSNZ for the fantastic work they are doing, reminding us that we still control our future." Katarina, 2012/13 recipient

## Entertainment Book - Help us fundraise!

The new 2014 | 2015 Entertainment™ Memberships are available now and packed with thousands of up to 50% off and 2-for-1 offers. This year you have the choice between the Entertainment™ Book Membership and the new Entertainment™ Digital Membership!

From every Entertainment™ Membership we sell, \$12 goes towards our fundraising to provide information, education and support for people with Multiple Sclerosis in New Zealand! The more Entertainment™ Memberships we sell, the more we raise - so please forward to your family and friends! To purchase visit [www.entertainmentbook.co.nz/orderbooks/106n247](http://www.entertainmentbook.co.nz/orderbooks/106n247)



Auckland - \$65  
Dunedin, Invercargill and Queenstown - \$55  
Waikato and Bay of Plenty - \$60  
Wellington - \$60  
Christchurch, Canterbury and Nelson - \$65

A number of our regions are also fundraising with the Entertainment Book.  
If they are and you would like to donate to your Regional Society please contact them first.

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# TYSABRI/ NATALIZUMAB

**B**iogen Idec made a submission to Pharmac over 2 years ago to include Tysabri on the schedule of funded medicines. **We are still waiting on any decision.** Since 1st July 2013 no new patients have been able to start treatment with no known reason. Currently there has still no criteria for access to funding been released. Numerous NPPA (Named Patient Pharmaceutical Assessment) Applications have been made to PHARMAC to try and gain access to Tysabri for patients. All of them have been declined. Currently there are around 2000 people receiving Tysabri in Australia and about 25 in NZ.

**M**SNZ is aware that there is considerable interest and frustration in the non-availability of Government funded access to the drug Tysabri. MSNZ has written recently both to the Minister of Health and to PHARMAC. Copies of those correspondence are available on our website at [www.msnz.org.nz](http://www.msnz.org.nz). We are aware also that a number of individuals supported by their Neurologists have made their own submissions for funding to Pharmac without success.

**T**o ensure that the very best case is put to the Government and Pharmac, Neil Woodhams, a member of the National committee and President of MS Auckland is coordinating a National response and establishing a Steering Group that will prepare suitable material for regions and individuals with in those regions to speak with their MPs and other parliamentary candidates in the run up to this year's elections.

To receive further information or to notify your interest in being a part of the Steering Group please email [info@msnz.org.nz](mailto:info@msnz.org.nz) or call 0800 MS LINE (67 5463) with the following details:

- 1** The names, contact numbers and email addresses of those interested in being part of this process
- 2** Copies of any correspondence that may have been written to Pharmac, the Minister or local politicians and their replies
- 3** Details of any verbal contact in respect of Tysabri that members have had with politicians Pharmac etc.

## Submissions made by MSNZ in 2014

1) 13 February 2014 MSNZ wrote to the Minister of Health, Hon Tony Ryall requesting support in this matter. [See the letter here](#)

On the 14th March 2014 MSNZ received a reply from the Minister. As per the letter we encourage you to keep an eye on the PHARMAC website [www.pharmac.health.nz](http://www.pharmac.health.nz) for any updates about Tysabri in the recent meetings. [See the letter here](#)

2) 22nd April 2014 MSNZ submitted an response to the request by PHARMAC for feedback on the Named Patient Pharmaceutical Assessment Policy (NPPA). [See the letter here.](#)

3) 22nd April 2014 MSNZ submitted feedback to PHARMAC's proposed Decision Making Criteria.

## MSNZ is committed to advocating for CHOICE for people living with Multiple Sclerosis

## TYSABRI RESEARCH UPDATES

### Efficacy and safety of Natalizumab in multiple sclerosis: interim observational programme results

*H Butzkueven et al. 14 Feb 2014 - JNNP Online*

**Background** Clinical trials established the efficacy and safety of natalizumab. Data are needed over longer periods of time and in the clinical practice setting.

**Objective** To evaluate long-term safety of natalizumab and its impact on annualised relapse rate and Expanded Disability Status Scale (EDSS) progression in patients with relapsing-remitting multiple sclerosis (RRMS).

**Methods** The Tysabri (natalizumab) Observational Program (TOP) is an open-label, multinational, 10-year prospective study in clinical practice settings.

**Results** In this 5-year interim analysis, 4821 patients were enrolled. Follow-up for at least 4 years from natalizumab commencement in 468 patients and at least 2 years in 2496 patients revealed no new safety signals. There were 18 cases of progressive multifocal leukoencephalopathy reported, following 11–44 natalizumab infusions. Mean annualised relapse rate decreased from 1.99 in the 12 months prior to baseline to 0.31 on natalizumab therapy ( $p < 0.0001$ ), remaining low at 5 years. Lower annualised relapse rates were observed in patients who used natalizumab as first MS therapy, in patients with lower baseline EDSS scores, and in patients with lower prenatizumab relapse rates. Mean EDSS scores remained unchanged up to 5 years.

**Conclusions** Interim TOP data confirm natalizumab's overall safety profile and the low relapse rate and stabilised disability levels in natalizumab-treated patients with RRMS in clinical practice. [Read more](#)

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## Natalizumab in progressive MS: Results of an open-label, phase 2A, proof-of-concept trial

*Neurology. 2014 Mar 28. [Epub ahead of print]*

This study shows that natalizumab (tysabri) treatment in progressive MS reduces central nervous system (CNS) inflammation and tissue damage. Changes in certain MRI parameters indicate an improvement in myelin integrity. These results support the role of systemic immune cells in the pathogenesis of progressive MS. This may encourage the initiation of placebo-controlled clinical trials with natalizumab for progressive MS patients. [Read more](#)

## JC virus reactivation during prolonged natalizumab monotherapy for MS

*Ann Neurol. 2014 Mar 31. doi: 10.1002/ana.24148. [Epub ahead of print]*

This study looks at getting a better understanding of the virus which causes PML (Progressive Multifocal Leukoencephalopathy) in patients treated with natalizumab (tysabri). The study shows that after more than 18 months of treatment with natalizumab, a high viral load was found in specific T cells (CD34+) and monocytes. The virus may reactivate in the cerebrospinal fluid without new clinical or MRI findings in patients. This helps to improve our understanding of the virus and further research is needed to improve PML risk stratification.

[Read more](#)

## Reduced sick leave in multiple sclerosis after one year of natalizumab treatment

*Mult Scler. 2013 Dec 30. [Epub ahead of print]*

Natalizumab is used for the treatment of relapsing remitting MS and it acts by inhibiting lymphocyte migration across the blood-brain-barrier. This study group looked at the amount of sick leave in subjects with relapsing remitting MS (RRMS) before and one year after treatment with natalizumab (Tysabri). They found that the initiation of natalizumab treatment in RRMS may be associated with improved ability to work. Both younger age and improvement of walking ability correlated with decreased sick leave. [Read more](#)

## Neurofilament light antibodies in serum reflect response to natalizumab treatment in MS

*Mult Scler. 2014 Feb 10. [Epub ahead of print]*

This study group looked at certain components/proteins of neurons, and the role of antibodies against these proteins (neurofilament light protein (NF-L)), as biomarkers for monitoring response to treatment (with natalizumab/tysabri) and their correlation with the different types of MS. Overall, the results support the potential use of serum autoantibodies to these proteins (NF-L) as a good indicator of disease activity in MS. There was also an association between treatment with natalizumab/tysabri and lowered levels of these proteins (NF-L) in the blood. [Read more](#)

## MiR-126: a novel route for natalizumab action?

*Mult Scler. 2014 Mar 5. [Epub ahead of print]*

This study shows the potential role of a particular type of protein (miR-126), which control gene expression and are involved in immunity. This particular protein was found to be down-regulated in patients treated with natalizumab, while the protein was up-regulated during relapse. This provides us with a better understanding of how natalizumab works on MS activity as well as helping us understand specific side-effects associated with the drug. [Read more](#)

### DISCLAIMER

MSNZ advises that you do not simply rely on the information in these pages to imply any diagnosis or course of treatment for any particular individual. You should not rely on this information in place of a visit, call, consultation or the advice of a physician or other qualified healthcare provider.

Content neither indicates nor reflects the views of MSNZ. Any research, study, clinical trial, event, news or other item included in this MS Voice is not intended to imply endorsement or approval of it by the Society.

Although we have made a conscientious effort to provide high quality information, MSNZ disclaims any implied guarantee about the accuracy, completeness, timeliness or relevance of any information.

We choose our research news items according to the following criteria:

- » The source is identified, and valid
- » The research reports meaningful, interesting, and/or controversial results, or indicates a useful development for future research on MS.
- » The study is described in a straightforward manner, is in the English language and balances scientific information with coherent and accessible language for layperson.



# BECOME A REGULAR DONOR

Regular donations make a big difference to our work, enabling us to plan more effectively for the future. There is no minimum donation and your donation will help ensure that people with MS are provided with the information, education and support they are required whether they are newly diagnosed or have lived with the condition for many years. Setting up an automatic payment enables MSNZ to plan for the future effectively and efficiently, ensuring that we achieve our goals and commitments to the supporting New Zealanders with MS.

*"The support from the MS Society and the information I have received has made the transition of acceptance that much easier - I'm very grateful for that - thank you everyone."*

Giving by direct debit or automatic payment is an agreement between you and MSNZ to have regular donations taken from your bank account. To make a regular donation to MSNZ as an automatic payment complete the form below and return by Freepost to the address. A receipt is automatically provided on an annual basis as at 31 March for the total amount donated that year, for tax purposes. All donations of \$5 or more are tax deductible.

**The Multiple Sclerosis Society of New Zealand (Inc) is a registered charity (CC10861) under the Charities Act 2005**



Multiple Sclerosis  
New Zealand

Send completed forms to:

**Freepost 241789**

**MS New Zealand**

**PO Box 32124**

**Linwood**

**Christchurch 8147**

## Automatic Payment Authority Form

To the Manager

Name of Bank

Branch Address

Please start/amend the following Automatic Payment ☐ New Payment  
☐ Change Existing Payment

Name of  
Account

Account  
Number

Payer Reference

**I P D O N**

(to appear on statement)

SURNAME (Required)

Amount

Start/Change Date

Pay to:

**Multiple Sclerosis Society of New Zealand Inc.**

Account Number:

**02 0500 0355668 00**

Payee Reference:

(completed by MSNZ)

Regular Gift ID Number:

(completed by MSNZ)

Signature

Date

Signature

Date

### Contact Details

Name

Address

Telephone

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# Our regions – supporting you in your community

There are 18 regional MS Societies across New Zealand providing support to most corners of the country. Each Regional Society has skilled and experienced Field Workers who, if required, can assist you in finding the services you need. Our Field Worker Service has developed from humble beginnings into a vital, high profile service, staffed by well-qualified people who are required to have a prior qualification and experience in such areas as teaching, nursing or social work.

## **MS Society Field Workers provide on-going support to people with MS by:**

- working with people newly diagnosed with MS on a one-to-one basis
- offering up-to-date knowledge of MS and its management
- providing advocacy and support
- offering counselling or referrals to appropriate agencies
- supporting partners, carers, families, friends, health professionals, employers and workmates
- facilitating groups for people newly diagnosed and their partners, carers, children, workmates
- offering assessment facilitation
- providing social contact, for those who want it, with other people with MS, on either a group or individual basis
- liaising with other services such as home-based care providers, community health services, counsellors, professionals Work and Income to coordinate client needs
- carrying out mobility assessments
- Some also offer physiotherapy, yoga classes, hydrotherapy at local pools and access to Riding for the Disabled, as well as assistive devices for daily living.

## *North Island*

### **Northland MS Society**

PO Box 1555  
WHANGAREI 0140  
Phone: 09 438 3945  
Email: nthlndms@xtra.co.nz

### **Wanganui MS Society**

PO Box 102  
WANGANUI 4540  
Phone: 06 345 2336  
Email: mswanganui@xtra.co.nz

### **MS Waikato Trust**

PO Box 146  
HAMILTON 3240  
Phone: 07 834 4740  
Email: mswaikato@mswaikato.org.nz  
Website: www.mswaikato.org.nz

### **Bay of Plenty MS Society**

PO Box 15309  
TAURANGA 3144  
Phone: 07 571 6898  
Email: admin@bopms.co.nz  
Website: www.bopms.co.nz

### **Hawke's Bay MS Society**

PO Box 3136  
NAPIER 4142  
Phone: 06 835 8542  
Email: officehbms@paradise.net.nz

### **MS Auckland**

PO Box 40524  
AUCKLAND 0747  
Phone: 09 845 5921  
Email: info@msakl.org.nz  
Website: www.msakl.org.nz

### **Gisborne East Coast MS Society**

PO Box 50  
GISBORNE 4040  
Phone: 06 868 8842  
Email: Lynne.smith@msnz.org.nz

### **Taranaki MS Society**

PO Box 791  
NEW PLYMOUTH 4340  
Phone: 06 751 2330  
Email: info@mstaranaki.co.nz  
Website: www.mstaranaki.co.nz

### **Rotorua & District MS Society**

PO Box 811  
ROTORUA 3040  
Phone: 07 346 1840  
Email: ms.society.inc@mail.com

### **Central Districts MS Society**

PO Box 194  
PALMERSTON NORTH 4440  
Phone: 06 357 3188  
Email: mmss@inspire.net.nz  
Website: www.mscentral.org.nz

### **Wellington MS Society**

PO Box 15 024  
WELLINGTON 6243  
Phone: 04 388 8127  
Email: info@mswellington.org.nz  
Website: www.mswellington.org.nz

## *South Island*

### **Marlborough MS Society**

PO Box 31  
BLENHEIM 7240  
Phone: 03 578 4058  
Email: mmss@xtra.co.nz

### **Nelson MS Society**

PO Box 2158  
NELSON 7041  
Phone: 03 544 6386  
Email: nelsonmss@ts.co.nz

### **West Coast MS Society**

PO Box 76  
GREYMOUTH 7840  
Phone: 03 768 7007  
Email: westcoastms@paradise.net.nz

### **MS & Parkinson's Society of Canterbury**

PO Box 32 135  
CHRISTCHURCH 8147  
Phone: 03 366 2857  
Email: support@ms-pd.org.nz  
Website: www.ms-pd.org.nz

### **South Canterbury MS Society**

PO Box 231  
TIMARU 7940  
Phone: 03 687 7375  
Email: mssouthcant@kol.co.nz

### **Otago MS Society**

PO Box 2293  
DUNEDIN 9012  
Phone: 03 455 5894  
Email: tania@msotago.org.nz  
Website: www.msotago.org.nz

### **Southland MS Society Inc.**

PO Box 1561  
INVERCARGILL 9840  
Phone: 03 218 3975  
Email: info@mssouthland.org.nz

# Meet Our Fieldworkers

## Diana Hay



Hi,

my name is Diana Hay and I am the Field Officer for the Rotorua & District MS Society. I've been with the Society for three years now and cover the area around Rotorua, Taupo and Turangi.

I am also a Registered Nurse working three days a week at the Outpatient Clinic at the Rotorua Hospital.

What I like best in my job is that it gives me opportunity to make a difference for my patients and clients. The best part of my work days are the home visits and support groups that we run for our members.



**If you can change one thing today that will have huge impact on your job – what would it be?**

It would be great if our region had better funding and be able to provide our members with needed equipment and private assessment, rather than the long slow process of going through Occupational Therapists, Physios, applying for grants etc.

**What would you like to see happening in your job more in the next couple of years?**

Many of our members have to cope with a low income and to buy coffee and muffin at support group is just too much. I would like there to be a way to support morning teas for our members.

**What is your vision for your work?**

I don't think there will ever be a world without MS, but I would like to see all who need medication being able to get it – not as it is at present, where they need to fit a certain criteria. I would like Rotorua Hospital to recognise the need to have our own Neurology Nurse based at the hospital to support all neurology patients (and I would like that nurse to be me).

**What trends do you see emerging in the work you do?**

I have an increased number of family members developing MS - Father / Son, Brother / Sister, Cousins.

**Note: The risk of siblings being diagnosed with MS is 3 % and 2% risk for children**

**What do you think your clients need most at the moment?**

A listening ear. Referrals to be dealt with immediately – not months down the line when it's too late.

**Your favourite success story...**

When I first started in my role as Field Officer, one young woman with MS I visited, was living in a situation totally unsuitable for her disabilities.

Talking to her, I came to realise she had no idea she was entitled to access to any health care service providers and didn't have to pay for their input. She seldom went to the doctor as she could not afford it.

She was relying on a friend to buy her disposable undies and all her groceries from the corner store as she could no longer walk the short distance or drive. She was washing at the sink as she could no longer hop into the bath for a shower. She had no rails in the bathroom and toilet or steps at front and back door which made her virtually house bound. She was very thin. Fell often. Loved gardening but couldn't do anything now.

Life wasn't much fun.

With her permission I sent one referral after the other to every health care provider I could think of. To cut a long story short, she now has a safe home environment with all the gadgets needed and ongoing checkups with orthotics and the dietician. Life Unlimited store kindly provided free-of-charge their private Occupational Therapist who left no stone unturned. Our local CCS were also fundamental in this ladies change of life providing



her with a computer plus lessons and a raised garden.

**So for those who think the field officer just drinks lots of coffee as she attends support groups and does the odd home visit think again. Your field Officer can make the difference.**

When I first started this job I said to Annette at Life Unlimited that I didn't know who I could or could not write referrals too. Her reply was – Diana - you are the Field Officer. You can write referrals to anyone you want. So I do and am amazed at what I have been able to get away with.

If the above person sounds like you I encourage you to contact your local Field Officer – She too can write any referral to anyone as well.

**What is the first thing you notice about people?**

If they are suffering or not.

**Would you bungee jump?**

Definitely not.

**What is one of your favorite quotes?**

**"Treat others as you would want to be treated"**



# Christine Beard



Hello, my name is Christine Beard and I am the Field Officer for Gisborne & East Coast MS Society. I cover the area from Te Araroa to Mahia/Wairoa.

I was born in Liverpool and trained as a State Enrolled Nurse in Liverpool, England. Over the years I worked as Teachers Aide and ANZ Bank Officer in Tolaga Bay, Gisborne. Since 1993 I have also worked at Gisborne Hospital as a divisional therapist on the nursing pool as an enrolled nurse for the Acute Psychiatric Ward.

I've been with the Society for 5 and a half years now. I love working with people and helping them achieve their goals and making life easier for them. And that is the best part of my job – people contact!



**If you can change one thing today that will have huge impact on your job – what would it be?**

A car with a hoist. So that people in wheelchairs could come out for a drive with no planning ahead or cost for taxis.

**What would you like to see happening in your job more in the next couple of years?**

Transport for those who cannot

get out so easily and isolating themselves because of it. More public awareness and affordability for disabled persons. Improvements for wheelchairs on sidewalks, restaurants and shops.

**What is your vision for your job/work?**

I would like to see more awareness, more support groups. There is a need for more funding to help people stay warm in the winter and cooler in the summer e.g. air conditioning in their homes but without the huge bills they receive monthly. Maybe this could be subsidised?

**What trends do you see emerging in the work you do?**

Younger people being diagnosed with MS. Now that we have MRI scans MS has become easier to diagnose.

**What do you think your clients need most at the moment?**

Financial support - most of them can't afford good heating and travel costs.

**Your favourite success story...**

I think one of our success stories as a group are the monthly morning teas we have at a local café. Everyone, enjoys the friendly atmosphere, the chatter and laughter and the non-judgemental support they get from each other. It's something we all like doing together.

We also had a pontoon trip on the Waimata River a few years



ago. It was a super day, and everyone sat around a big table with lots of food and drinks. The river is beautiful and it was a great day out. Unfortunately the pontoon no longer goes up the river.

### What cheers you up?

Lots of things, I am a positive person and think myself extremely fortunate. Gardening and floral art is a passion.

### What is the first thing you notice about people?

Smiling, friendly, posture, eye contact, or shy, introverted nil eye contact.

### Would you bungee jump?

No!

### It wasn't funny when it happened, but...

The whole family, we were riding our bikes down country road. I felt so proud of my little boys in front of me. Until one of them stopped suddenly and we all ploughed into each other. After being bruised in places you can't see, I did think it funny!



MS Field Workers at the 2014 Training organised by MSNZ. Training was held in Christchurch on 1st and 2nd April and was attended by Field Workers from our Regional Societies across the country.

MSNZ is committed to ensuring the best level of care for people touched by MS wherever they are in New Zealand through our Field Workers working within the community.

## DONATE TODAY!

Your donations make it possible for MSNZ to fund research and develop and support new programmes to improve the quality of life of those affected by Multiple Sclerosis.

By becoming a regular donor you allow us to plan better and be more proactive with those initiatives. To become one you can fill and send us the form on **page 4**.

Or you can set up regular payments to MSNZ through your online banking using:

Name: **National Multiple Sclerosis Society of New Zealand Inc**

Number: **02-0500-0355668-00**

Reference: **IP DON & your surname**

For single donations or to set up a page to fundraise for MSNZ, please visit:

<http://givealittle.co.nz/org/msnz>

## THANK YOU!

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# MS Volunteer Stars Needed!

**V**olunteers are essential for non-profit organisations such as your MS Society who rely on the support of helpful volunteers to provide them with resources to be able to provide services to those living with MS in their community. Everyone has their own reasons to volunteer. Volunteers are very special people united by the desire to help a cause in a way that is challenging as well as rewarding.

The **"Where volunteering begins" YouTube campaign** tells five inspirational stories from ordinary people doing extraordinary things.

*"Remember,  
if you ever need a helping hand,  
you'll find one at the end of your arm...  
As you grow older you will discover  
that you have two hands.  
One for helping yourself,  
the other for helping others."  
Audrey Hepburn*



## Volunteering Defined:

**Voluntary work is done of one's own free will, unpaid, for the common good.**

**Aroha ki te takata a rohe**

## Why volunteer and what can it do for you?

- ◆ Provide opportunities to make friends and widen social contacts
- ◆ Family circumstances (sports, hobbies, family concerns etc.)
- ◆ A desire to play an active part in the community
- ◆ A desire to be involved in a special issue – to further a cause
- ◆ A search for personal growth/development/experience
- ◆ A means of "paying back" for benefits received. Give something back to an organisation that has impacted on a person's life, either directly or indirectly
- ◆ A way of gaining valuable work experience
- ◆ To spend time doing something worthwhile
- ◆ Make a difference to other peoples lives
- ◆ Help others less fortunate or without a voice
- ◆ Feel valued and part of a team
- ◆ Spend quality time away from work or a busy lifestyle
- ◆ Gain confidence and self-esteem

## Why does your local MS Society need your support?

Your Regional MS Society requires volunteers throughout the year for a number of events, appeal collections or support within the office with tasks such as putting together newsletters and helping with social groups.

Most of our Regional Offices have a small office staff that without the support of wonderful volunteers wouldn't be able to provide the services needed by its clients.

**MS Awareness Week  
30 August - 6 September 2014**

In 2013 **over \$200,000** was raised for MS across the country during MS Awareness Week and this wouldn't have been possible without the support of over **1000 volunteers**. MS Regional Societies are already preparing for the 2014 Awareness Week so contact them today and let them know if you will be available to be an MS Volunteer Angel and show your support.

## How to register your interest?

Contact your local MS Society ([contact details on page 10](#)) today to see how you can help. If you have a specific skill that you think your region can benefit from let them know.

## How else can I show my support if I can't volunteer?

If you can't volunteer but would still like to show your support how about making a donation?

Or could you organise your own fundraiser?

*"We make a living by what we get.  
We make a life  
by what we give."  
Winston Churchill*



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[www.msnz.org.nz](http://www.msnz.org.nz)

0800 MS LINE

[info@msnz.org.nz](mailto:info@msnz.org.nz)

Facebook

LinkedIn

**Donate Online**



## The Incidence of MS in New Zealand

Since 1st June 2012 MSNZ has been funding the National Incidence Study of MS in New Zealand. The aim of the study has been to identify all persons with a new diagnosis of MS as well as anyone presenting with a CIS (their first symptom of MS) between 1st of June 2012 and 31st of May 2014. The study looks at the natural history of MS in NZ. It is an observational study with follow-ups at 6, 12 and 24 months.

### Why is an Incidence Study significant?

The expected outcomes of the study are that MSNZ, health professionals and decision making bodies will have more evidence to make to make more informed decisions. The results will enable:

- ◇ Cost benefit analysis of early intervention strategies
- ◇ Risk-benefit ratios of newer high-risk Rx interventions
- ◇ Understanding of how rapidly cases have been occurring in NZ (how many each year and where)
- ◇ Indicates present and future burden on each

DHB's and country

- ◇ Doctors to make decisions about treatment and provide improved advice on prognosis
- ◇ Doctors will be able to make informed decisions about initiation or cessation of disease modifying drug treatments
- ◇ Patients will be able to see a clearer idea of their risk and prognosis

### Follow up

6, 12 and 24 month questionnaire results will provide information regarding:

- ◇ Change in Employment and or Job status
- ◇ Effect of Smoking on progression
- ◇ Quality of Life and its change overtime
- ◇ Changes in Disability
- ◇ Role of latitude in disability progression

The MS Incidence Study now is nearing its two year recruitment period on 31 May 2014.

If you have been diagnosed with MS since June 2012 and are not part of the study, for more information, please contact **msstudy@nzbri.org** or **0800 MS STUDY (6778839)**

## MS Information Series

can be

downloaded at:

<http://bit.ly/1jBDSG2>



## Latest Publications on MS in NZ

### The Increasing Prevalence of Multiple Sclerosis in New Zealand

*Sridhar Alla, John Pearson, Laëtitia Debernard, David Miller, Deborah Mason*

**Background:** New Zealand (NZ) has a high prevalence of multiple sclerosis (MS). Worldwide, the prevalence of MS appears to be increasing.

**Objectives:** To review all published prevalence studies undertaken in NZ to determine whether the prevalence of MS in NZ is increasing.

**Methods:** PubMed, Medline, Scopus, Web of Knowledge, EMBASE, AMED and CINAHL were searched to identify studies reporting the prevalence of MS in NZ. Prevalence rates from the National MS Prevalence study in 2006 were compared with earlier prevalence rates for the same regions using Poisson regression.

**Results:** Prevalence rates reported in the earlier regional studies ranged from 23.6 to 68.5/100,000 population; in the same regions in 2006, the range was 47.6–134.2/100,000 population. Prevalence rates were significantly increased in all regions studied except for the Bay of Plenty. The increase in prevalence was seen in both sexes. The sex ratio remained constant over time.

**Conclusions:** In studies spanning almost 40 years (1968–2006), the prevalence of MS within the same regions of NZ has significantly increased whereas the sex ratio and latitudinal gradient have remained stable.

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[Read the full research paper here](#)

# Multiple sclerosis in New Zealand

Sridhar Alla, New Zealand Brain Research Institute, University of Otago and Deborah F. Mason, Department of Neurology, Christchurch Hospital

New Zealand is a high risk country for multiple sclerosis with an overall age and sex standardised prevalence of 73.1 per 100,000 population. The age and sex standardised prevalence within the Maori population is substantially lower at 24.2 per 100,000 population. A latitudinal gradient exists with MS prevalence increasing threefold from the North to the South of NZ. Over 1600 (56.8%) persons with MS experience moderate to severe disability. Despite the high prevalence of MS and the significant degree of disability experienced by people with MS, the availability and prescribing guidelines for MS disease modifying treatments are more restrictive in NZ than in other developed nations.

[Read the full research paper here](#)

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## Tell a friend about the MS Voice

MS Voice (electronic version) goes out to a rich and varied group of subscribers. It endeavours to meet the needs of health professionals as well as people with MS and their support networks. It includes both technical research and more accessible studies.

If you know of anyone - whether it be in your MS Society - its committee members, staff members, people with MS and their carers, family members, health professionals, your GP... then tell them about MS Voice and suggest they subscribe by following the link below:

<http://eepurl.com/KkmiP>

.....  
If you require the full text of any research article referred to above, you may be required to pay for it online. If you do not wish to do so, you can always take the reference to your nearest public library. They should be able to access it for you. There might be a slight charge for this service.  
.....

## CURRENT RESEARCH INVOLVEMENT OPPORTUNITY

### Take part in a NZ based study looking into the use of mobile technology

Researchers at Auckland University of Technology are carrying out a questionnaire survey which is looking at mobile technology use by people with multiple sclerosis, such as phones or iPads.

The information from the survey will be used to help them design a mobile application that people with multiple sclerosis could use to help manage their fatigue or other key MS related symptoms.

To make sure they design a mobile application that is of use, they want to find out what mobile devices people use or would consider using.

They also would like to get a better understanding of how severe people's MS-related fatigue is (in New Zealand), what impact it has on their lives and strategies that work best for them.

If you would like to find out more about the survey please go to

<http://www.synapseproject.org/ms-survey>

The actual survey itself can be found here:  
<https://www.surveymonkey.com/s/PLLNCN3>

## Research in Wellington

The Neurological Foundation have awarded Associate Professor Anne La Flamme a grant of \$124,017 towards her project "Identifying the mechanisms by which clozapine reduces central nervous system inflammation."

Current FDA-approved disease modifying treatments are limited in terms of efficacy, mode of administration, availability due to cost, and concerns regarding side-effects. Therefore there is an urgent need for more effective and more easily tolerated treatments and for therapies that not only halt disease progression but also may reverse the neurological damage sustained.

Determining how the psychoactive drug clozapine can reduce central nervous system inflammation and damage will provide novel insights into immune dysfunction and its contribution to disease pathogenesis will emerge. It is also anticipated that the results of Associate Professor La Flamme's study will contribute to the understanding of the cause of MS, which remains unknown.



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# Research News from around the globe

## Lower urinary tract symptoms and urodynamic dysfunction in clinically isolated syndromes suggestive of MS

*Eur J Neurol.* 2014 Jan 28. doi: 10.1111/ene.12370. [Epub ahead of print]

Urinary tract symptoms are common in MS, with a significant negative impact on quality of life. This study demonstrated that patients with clinically isolated syndrome (CIS) had a higher prevalence of urinary symptoms. The urinary symptoms were associated with lower scores on certain quality of life domains, especially in females with obstructive symptoms. This highlights the importance of early identification and treatment of urinary symptoms in individuals who may be at the very early stages of MS. **[Read more](#)**

## Hemodynamic evidence linking cognitive deficits in clinically isolated syndrome to brain inflammation

*Eur J Neurol.* 2013 Dec 26. doi: 10.1111/ene.12338. [Epub ahead of print]

This study looked at changes in cerebral blood flow and volume on MRI in subjects with a clinically isolated syndrome and they then looked at the relationship between these changes on MRI and memory function. The researchers found that there was an inverse correlation between verbal memory and cerebral blood volume in areas of the brain involved in memory. These changes seen in memory function are likely due to widespread brain inflammation, present at the very early stages of MS. **[Read more](#)**

## Safety and efficacy of ofatumumab in relapsing-remitting MS: A phase 2 study

*Neurology.* 2014 Jan 22. [Epub ahead of print]

This clinical trial looked at ofatumumab in patients with relapsing remitting MS (RRMS), to assess both the safety and the efficacy of the drug. Overall, the results demonstrated that ofatumumab, administered twice, at a two week interval, did not produce any unexpected safety concerns, was well tolerated and showed a reduction in MRI lesion activity. **[Read more](#)**

## Naive CD4 T-cell activation identifies MS patients having rapid transition to progressive MS

*Neurology.* 2014 Jan 22. [Epub ahead of print]

Many patients with relapsing remitting MS (RRMS) eventually go on to develop a progressive accumulation of neurological disability, termed secondary progressive MS (SPMS). This study looked at particular types of immune cells (T cells), which are known to cause injury to the central nervous system in RRMS, although their role in SPMS is not clear. The researchers found that there were differences in the cell biology of these T cells, which identified patients with MS having different rates of development of secondary progression. Further research is needed in this area but these findings may help determine long-term prognosis in MS in the future. **[Read more](#)**

## Effect of high-dose simvastatin on brain atrophy and disability in secondary progressive MS (MS-STAT)

*Lancet.* 2014 Mar 18. pii: S0140-6736(13)62242-4. doi: 10.1016/S0140-6736(13)62242-4. [Epub ahead of print]

This phase 2, placebo-controlled trial showed that statins (simvastatin) in secondary progressive MS were safe, well tolerated and reduced progression of annualised brain atrophy over two years. Statins are widely used and well tolerated in the treatment of high cholesterol and for secondary prevention of myocardial and cerebral ischaemia. The exact mechanism of action needs to be determined, but may be due to an effect on vascular function or cell protection. Further investigation is needed in a larger phase 3 trial. **[Read more](#)**

## Epstein-Barr virus-specific adoptive immunotherapy for progressive MS

*Mult Scler.* 2014 Feb 3. [Epub ahead of print]

A lot of evidence to date indicates that infection with Epstein-Barr virus (EBV) (which causes glandular fever) has a role in the causation of MS. This study demonstrated that immunotherapy with EBV-specific T cells was associated with an improvement in patient symptoms and there was a reduction in disease activity on MRI with no side-effects. A clinical trial is needed to evaluate the therapeutic effect of this treatment across the clinical spectrum of MS. **[Read more](#)**

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## Major stressful life events in adulthood and risk of multiple sclerosis

*J Neurol Neurosurg Psychiatry.* 2014 Mar 7. doi: 10.1136/jnnp-2013-307181. [Epub ahead of print]

This study looked at the risk of developing MS following exposure to well-defined indicators of severe stress as a result of divorce or loss of a close family member. The results demonstrated that there was no association between these stress measures and risk of developing MS. **[Read more](#)**

## Core outcome measures for exercise studies in people with MS

*Mult Scler.* 2014 Mar 17. [Epub ahead of print]

Exercise in MS patients can have many benefits including improvements in muscle power, physical and psychosocial functioning and quality of life. Regular exercise may also have an important role to play in the management of fatigue, which negatively affects quality of life, mental alertness and cognitive processing. This research article presents the results of a meeting of a group of international experts, which recommended the most appropriate outcome measures for use in exercise-based research as one step in the process toward the application, and evaluation, of exercise in people with MS. **[Read more](#)**

## Interaction between adolescent obesity and HLA risk genes in the etiology of MS

*Neurology.* 2014 Feb 5. [Epub ahead of print]

This study looked at the potential interaction between adolescent obesity and the genes most strongly associated with MS. The researchers found interactions between adolescent obesity and two potent MS risk genes. **[Read more](#)**

## Intervention for increasing self-directed exercise behaviour and improving important health outcomes

*Mult Scler.* 2014 Jan 13. [Epub ahead of print]

This study demonstrates improvements in self-directed exercise behaviour, health related quality of life and fatigue in a tailored programme of both supervised and home-based exercises in individuals with MS with different physical abilities. **[Read more](#)**

## Modest familial risks for MS: a registry-based study of the population of Sweden

*Brain.* 2014 Jan 17. [Epub ahead of print]

MS is a complex disease with more than one hundred risk associated genes identified to date. This study looked at the familial recurrence risks of MS. Overall the results demonstrated lower risk ratios than most previous studies of familial recurrences in multiple sclerosis to date. **[Read more](#)**

## Brain atrophy and disability progression in MS patients: a 10-year follow-up study

*J Neurol Neurosurg Psychiatry.* 2014 Feb 19. doi: 10.1136/jnnp-2013-306906. [Epub ahead of print]

This prospective study looked at the association between MRI measures of global and tissue-specific damage and disability progression in a group of patients with MS. Overall the results showed that atrophy of the whole brain and two specific areas of the brain (the cortex and the putamen) were associated with disability progression five years after MS diagnosis while, at 10 years, whole-brain atrophy showed better association with disability progression than tissue-specific or regional damage. **[Read more](#)**

## Memory in multiple sclerosis is linked to glutamate concentration in grey matter regions

*J Neurol Neurosurg Psychiatry.* 2014 Jan 15. doi: 10.1136/jnnp-2013-306662. [Epub ahead of print]

Glutamate is the main excitatory neurotransmitter in the brain and it is involved in normal brain function. In this study the researchers quantified this neurotransmitter (glutamate) in specific regions of the brain and investigated if there was a relationship between the concentration of this neurotransmitter and memory performance in subjects with relapsing-remitting MS. They found that patients had worse visual and verbal memory than controls. There was also a relationship between memory and the neurotransmitter (glutamate) concentration, which is unique to MS. This helps us to understand the mechanisms involved in memory problems in MS. **[Read more](#)**

## Colour vision impairment is associated with disease severity in multiple sclerosis

*Mult Scler.* 2014 Jan 7. [Epub ahead of print]

Abnormalities in colour vision are common in patients with multiple sclerosis (MS), especially after optic neuritis. It is thought that impaired colour vision occurs mainly due to injury to the anterior visual pathway. This interesting study showed that impaired colour in the eyes of MS patients who have not previously suffered optic neuritis is associated with increased clinical disability. The impaired colour vision was not associated with inflammatory activity but with the neurodegenerative activity measured by clinical disability. **[Read more](#)**

## Websites that publish new research

The [Multiple Sclerosis Discovery Forum](#) (MSDF) is an online resource that aims to accelerate progress toward cures for multiple sclerosis and related disorders & aspires to facilitate researchers' abilities to conceive and execute well-informed, innovative, and feasible experimental tactics.

MSDF is a joint project of the Accelerated Cure Project for MS (ACP), which creates the site's content and directs its outreach activities; the MassGeneral Institute for Neurodegenerative Disease (MIND), which developed and supports the site's platform; and the Max Planck Institute for Molecular Genetics, which curates MSGene.

<http://www.msdiscovery.org>

There is also a **blog section** that may be of interest <http://www.msdiscovery.org/news/blogs/>

[Multiple Sclerosis and Related Disorders](#) is a wide ranging international journal supported by key researchers from all neuroscience domains that focus on MS and associated disease of the central nervous system. The primary aim of this new journal is the rapid publication of high quality original research in the field. Important secondary aims will be timely updates and editorials on important scientific and clinical care advances, controversies in the field, and invited opinion articles from current thought leaders on topical issues. <http://www.msard-journal.com/>

[Vitamin D research stream on PubMed](#)

<http://1.usa.gov/OqzSfJ>

## Multiple Sclerosis Resource Centre

This MS Resource Centre aims to provide clinicians with open access to the latest literature on MS. The site is hosted by MS and Related Disorders and sponsored by a donation from EMD Serono, Inc., a subsidiary of Merck KGaA, Darmstadt, Germany.

Open access article collection, videos, lectures & teaching cases. If you subscribe for E-alerts you will get access promo code.

<http://multiplesclerosis.elsevierresource.com/>

## Living with MS

[MS Patient. Ph.D.: MS and Vitamin D: What's a Patient to Do?](#)

My levels struggle this way even though my mother, who has some crunchy tendencies, poured cod liver oil down our throats and had us swallowing vitamin D supplements every day of our childhoods.

In fact, she still offers me cod liver oil whenever I visit. Add to this that I wear sunscreen only on my face, a habit I developed just recently. I get substantial sun on all my other body parts. I drink milk and eat cheese and yogurt and sour cream.

My greatest aquatic protein weakness is fatty fish, and I eat eggs at least on the weekends. Sure, my cholesterol might suffer (actually, it's fine), but vitamin D-wise, my lifestyle should have left me well stocked without the need for supplements.

<http://bit.ly/1evOcNQ>

## MultipleSclerosis.net: 'You Can't Compare'

*Posted by Ashley Ringstaff—April 16th, 2014*

Okay – I've had this on my mind for a while... but it's really started to bother me more and more lately. What am I referring to? What I'm talking about is when healthy individuals try to compare what I go through with my MS with something they have dealt with in the past.

Let me just get one thing straight about this... Notice how I said that people try and compare what we go through every day with something that they have dealt with in the past. That plays a big factor, when you're trying to compare two completely different situations.

So, here are some things that I have had people try and compare 'symptoms' with me in the past...

<http://bit.ly/1tMzARh>

[MS Mentoring: 'No One Should Have to Face MS Alone'](#)

MS mentorship programs match people who've been given a new multiple sclerosis diagnosis to people who have been living with the condition for years. A mentor can help the newly diagnosed person in ways that family, friends, and doctors cannot, said Nancy Law, executive vice president of programs and services at the National MS Society. <http://bit.ly/1fVxFnt>

[New Studies Look at Lifestyle Factors in Terms of Who Get MS and Improving the Daily Lives of People with MS](#)

Exercise and memory, fatty fish and MS, Looking at Lifestyle <http://bit.ly/1qe4PSC>

# Stem Cell Therapies

## (Australian) NHMRC publishes new resources to assist people contemplating stem cell treatments

(Article from MS Research Australia) 7th January, 2014

Stem cells are considered by many to hold the ultimate promise for repair and cure for a variety of chronic and degenerative conditions.

While great progress is being made in understanding how stem cells work and how they may be used to treat a variety of illnesses, there is still a considerable way to go before they become part of standard treatment. Despite this, many people travel overseas or visit private Australian clinics to undergo untested and unproven stem cell treatments.

In a statement released in December, the National Health and Medical Research Council (NHMRC) warned that unproven stem cell treatments available in Australia and overseas could pose risks to the health and well-being of patients.

The NHMRC have released two documents, 'Stem Cell Treatments – a Quick Guide for Medical Practitioners' and the patient-targeted document 'Stem Cell Treatments – Frequently Asked Questions'. These documents inform medical practitioners and their patients about the stem cell treatments that are available, and the risks associated with unproven treatments.

Stem cell treatments for MS are currently limited to autologous haematopoietic stem cell transplants (stem cell transplants from the

patient's own bone marrow). This treatment is regarded as a highly aggressive and experimental form of therapy and is generally only considered in specific cases at a limited number of hospitals.

Other forms of stem cells are being intensively researched in the laboratory for their properties to calm inflammation and encourage repair and regeneration in the central nervous system in MS, however, they are yet to reach the clinical trial stage. Despite this, some private Australian and overseas clinics offer autologous stem cell treatments to people with MS with no evidence for their safety or efficacy.

The NHMRC encourages patients considering stem cell treatments to seek additional information from a trustworthy source other than the clinic or practitioner offering the treatment. Patients should also speak to their general or specialist medical practitioners about their decision. The patient resource document also provides a list of questions to ask treatment providers when considering a specific treatment.

'Our resources provide information to support practitioners and patients in their discussions about stem cell treatments, and ultimately to assist people to make informed choices about their medical care,' said NHMRC Chief Executive Officer, Professor Warwick Anderson. **END**

**For a comprehensive review of the current status we recommend watching Associate Professor Bronwen Connor's presentation on 'Stem Cells and the Brain' at Brain Day 2013 in Christchurch. [See the video here](#)**

## Advice from MSNZ

Stem cells have generated a lot of excitement because the potential therapeutic benefits are so vast. There is real hope that stem cell transplants may assist in remyelination and may help protect the nervous system from immune attacks.

Unfortunately this interest has also generated unsubstantiated reports of stem cell transplantation "curing or improving" a wide variety of neurological conditions. Unfortunately the details around many of these claims have rarely been subjected to scientific scrutiny and most, when subjected to such scrutiny may have been found wanting.

At this stage the ability for stem cell transplantation to reduce damaged cells, particularly axons, within the nervous system is not scientifically confirmed.

The majority of therapies are at a very early stage of development, and in most cases a number of scientific and technical hurdles need to be resolved before clinical application can progress.

Based on a review of the most current information available on Stem Cells the Stem Cell in Multiple Sclerosis Consensus Group (STEMS) has published a paper with the following recommendations;

- 1.** Exploratory trials using MSC's and NPC's to treat patients with early secondary progressive MS that is refractory to conventional treatments should now be considered.
- 2.** Relapsing/remitting disease should continue to be treated with conventional therapies.
- 3.** Stem cell treatments should only be done in established centres that strictly adhere to the International Society for Stem Cell research guidelines and should be done in the context of a clinical trial where benefits can be measured and patients closely monitored for adverse outcomes.

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# Carer's Corner

## Family Care Magazine

Produced every 3 months by Carers New Zealand, Family Care is packed with inspiring stories, advice and helpful articles to help you self-manage common caring issues at home.

To request a free sample copy, phone Carers NZ's National Carer Resource Centre on 0800 777 797 from Monday to Friday during business hours, or email

[flightdeck@carersair.net.nz](mailto:flightdeck@carersair.net.nz)

For more information and details about subscriptions visit the [Carers Net Website](http://Carers Net Website)

## Funded Family Care Scheme Feedback

There has apparently been a low uptake of the new payment for carers since its launch in October 2013.

Carers NZ would like to hear from carers who have inquired about or been assessed for the payment: has it been an easy process, did you encounter any barriers, if you decided not to pursue being considered for the payment what were your reasons?

**Click here** to give your feedback via the online survey.

They would also like to hear from carers who are now receiving the payment so they can monitor how it's working for you; send comments to [sara@carers.net.nz](mailto:sara@carers.net.nz) or phone 0800 777 797.

## A Guide for Carers

An updated version was published in 2013. It includes information on the government-funded services and supports available for family carers, such as financial help, travel, assessments, help at home, special education needs and more.

You can **download the Guide here**, or obtain a hard copy by phoning *Work and Income* 0800 559009.



## New Zealand Carers' Strategy Action Plan 2014 to 2018

The New Zealand Carers' Strategy Action Plan for 2014 to 2018 was launched at Parliament on 18th February by the Minister for Senior Citizens, the Hon Jo Goodhew.

Developed in consultation with whānau, aiga and carers, the new Action Plan builds on the results and lessons of the previous Carers' Strategy Action Plan from 2008 to 2013.

Click here <http://bit.ly/1IEMNqv> to download your own copy in either PDF or Word format (on the right sidebar). You can also read the Hon Jo Goodhew's launch speech by clicking here <http://bit.ly/1jRQoSi>.



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# Summertime and the MS is easy... Not!

A Good MS Husband Blog

\*\*\*\*\*

by Roy Burgoyne

**W**e managed to make it through winter without a cold or flu (touching wood frantically as writing this). It does help when you banish everyone with the slightest dribble, or runny nose and you just hide yourself away. Some people call it hibernation, we call it survival. Not that I had the chance to feel the cold as the air conditioning was on 23 degrees all winter and I managed to swan around in shorts and t-shirt most of the time.

Now spring has sprung and the days are warmer and longer and I managed to squeeze in a few days down the mountain for some spring skiing and much needed, but often delayed respite.

When it was first raised that everyone around me thought I needed a break, I laughed it off saying that I was fine and that I didn't need a break and if I did go away, who was going to step into my role. After all I am indispensable. No one can do what I do, can they?

Turns out they can and sometimes a bit better.

It took two years to finally get me out of the house and when the time came it was like I was going away for ever, not just for three nights.

**T**he four hour drive was a combination of guilt-ridden

excitement and guilt-ridden relief giving way to excitement and relief. I found out that I didn't need to worry, she was in good hands and being cared for by someone close to us both, so at last I was on my own for the first time in 3 years.

I found myself having little flash backs of bum wiping, sheet changing and all the other endless tasks that fill a large part of my day. I didn't have to think of those things for 4 days, but still couldn't get them out of my head. Were they being done right, was the right shower gel being used, was the bed put up to the right angle at night, what if the wrong drugs were given.



**M**y mind came back to these places many times over my time away, but when I stood at the upper part of the mountain and saw what was below me and realised that I was about to have an uninterrupted long ski, everything else just faded away. It was just me and the mountain and it was all downhill from here.

There are few things that fill my soul full to bursting, one is the muffled sound of the nothingness at the top of a mountain and the sound of carving the snow, the other is the feeling of the cool breeze on my face when skating fast, damn I miss skating!

**N**one of these come close to pulling up in the driveway and seeing the look on her face when I came through the door, that smile, those words:

**"What are you doing here, you're early".**

Ah yes reality strikes. It seems I wasn't the only one who enjoyed my time away.

**Y**ou see, respite is a vital part of caring for someone, for as much as we do what we have to and as much as they love that its us looking after them and not some stranger, we all need a break, we all need time for ourselves and we need to do it as non guilt ridden as possible.

**O**ur time as a carer is not one of choice, but while we are given the responsibility of looking after the person we love, their way of looking after us is to wave us on our way as we take a break.

"So what's summertime got to do with this?", I hear you ask.

Well nothing really, its only spring and summer will be a whole different story \*

[www.agoodmshusband.blogspot.com](http://www.agoodmshusband.blogspot.com)

If you write a blog about your experiences living with MS or read one that you want to recommend, please write to us at:

[info@msnz.org.nz](mailto:info@msnz.org.nz)

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# Small workplace changes help people with multiple sclerosis keep their job

SPECIAL REPORT from **euractive.com**

**W**hile many people who suffer from multiple sclerosis are highly skilled, 50-60% can expect to be unemployed after receiving their diagnosis despite the fact that only little adaptation in the workplace is needed to keep them employed, experts say.

The economic burden of healthcare costs related to brain diseases such as multiple sclerosis has increased from €386 billion in 2004 to €798 billion in 2010 across 30 European countries, according to the European Brain Council (EBC).

Aside from the drastic increase in healthcare costs, Europe is also losing a highly-educated group of young workers as many lose their jobs shortly after being diagnosed. This happens although employers only need to make small adjustments in the workplace to hold on to a young employee with multiple sclerosis. Around 70% of Europe's 600,000 people with multiple sclerosis are diagnosed with the disease in their 20s and 30s.

Shoshana Pezaro, who was diagnosed with multiple sclerosis at the age of 28, though she had lived with the symptoms of the disease for years, has a university degree in theatre and film and landed a job in television immediately after graduating. As a production coordinator, she sometimes worked two days without stopping though she would lose the feeling in her arms and would need help to get dressed in the morning and be taken to work.

**E**ventually, Pezaro decided it would be better to become self-employed in Brighton, England, and set up her own business with 13 employees teaching piano, singing, dancing and drama, to control her working hours.

**H**owever, Emma Rogan, who works as a project coordinator at the European Multiple Sclerosis Platform (EMSP) in Ireland, said that people living with the condition have different symptoms that vary in type as well as severity.

This means that some might be able to work full-time with only small adaptations at work.

Fatigue is a symptom for many people with multiple sclerosis, me included," Rogan said in an interview.

"However, a planned rest period during the day means I continue my work and complete tasks. To facilitate this my employer last year put a reclining chair in the building. For others it's about having their lunch hours extended so they go home and take a rest."

Multiple sclerosis is a potentially disabling disease, which strikes the white matter of the brain and spinal cord and affects the rest of the nervous system. It has great consequences for society as more than one million people are affected indirectly through their role as carers and family members, according to the EMSP.

**Y**ounger people between 20 and 40 are the ones who are the most often diagnosed with multiple sclerosis, and women are diagnosed twice as often as men. Both Pezaro and Rogan were diagnosed in their 20s.

## Focus on SMEs and self-employment

**P**ezaro cited the example of a friend with multiple sclerosis who was able to keep her job at a large energy company because the firm had been "fantastically supportive". For example, the company has ensured flexible working hours for her and has made sure she could sit close to the toilet and a window to prevent her from overheating.

"She doesn't need physical adaptation, but she knows that if she did need a large screen that they understand her needs and are willing to talk about it. She doesn't even fear of losing her job. She feels like her work is valued," Pezaro stressed.

Rogan added that keeping an employee with multiple sclerosis isn't only good for the person concerned.

"When word gets out that you are an employer who takes such considerations, it's great for business and it opens up a whole new market," she said.

**B**ut while a large energy company in Britain was able to keep an employer with multiple sclerosis, Pezaro said that the real issue in the EU is the lack of government support for SMEs which employ around 80% of the EU's workforce.

While the EU has also established a youth unemployment scheme where national governments can apply for funding, it remains to be seen how much money trickles down to young people with disabilities.

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"If one of the people working for me had multiple sclerosis and was suddenly off, I would have really struggled financially to keep the business running. There's no financial support in place for small businesses if someone is off," Pezaro stated.

**S**elf-employment is another way for people with multiple sclerosis to get to do what they are passionate about, according to Pezaro. But had she been diagnosed with the disease before she set up her business, she wouldn't have succeeded to get business insurance, loans or overdraft.

"The banks would just have said 'no'," she said. "So I think to support people to be able to work independently and set up their own enterprises, we really need to look at how that can be funded and where the grants could come from so that people could have equal opportunities."

Source - <http://bit.ly/1IQ6yix>

# Employment Information & Resources

## To find out more about Advocacy you can:

- ◆ Ring Works4Us on 0800 40 40 49 (Employment Advocacy Service)
- ◆ Talk to IHC Advocacy 0800 442 442
- ◆ Talk to People First New Zealand 0800 206070
- ◆ Ring the NZ Council of Trade Unions (CTU) on 04 385 1334

## To find out what other services are in your area talk to:

- ◆ The Association of Supported Employment in New Zealand (ASENZ) on 06 343 3669
- ◆ Talk to Workbridge 0508 858 858

To find out what benefit you are entitled to, ring:

- ◆ Work and Income NZ (WINZ) on 0800 559 009

## To talk to Labour Inspector phone

- ◆ The Department of Labour on 0800 20 90 20

## Or ask your Field Worker!



**Workbridge** is a non for profit organisation that has been operating since 1990.

Consultants work with jobseekers and employers to match people to the right job. Services provided to jobseekers or employers are free of charge.

## For people looking for work:

- ◆ Identifying your current job skills, training needs, and developing a career goals action plan
- ◆ Help with job interviews and writing Cv
- ◆ Arranging work experience, if appropriate
- ◆ Helping you look for job opportunities
- ◆ Working with the employer to make the job match successful
- ◆ Assisting you to access appropriate support funding, if necessary
- ◆ Providing you and your employer with support after you start work

## For people in work

If you are worried that your disability, injury or illness could affect your job, we can provide practical workplace advice and support.

**Services for employers:** cost-free, hassle-free service for organisations of all sizes and from every industry, who are looking for talented, reliable employees.

Workbridge has staff at 27 locations throughout New Zealand.

Phone toll free on **0508 858 858**

<http://workbridge.co.nz/>

The 2006 Prevalence Study (Taylor et al) funded by MSNZ and the Health Research Council\* showed that MS directly influenced the work force status of New Zealander's within the working age (25-64 years) population living with the diagnosis.

- 54.6% were not working despite 90% having a work history (NZ overall average 22%)
- At least 67% changed their work status due to the effects of MS, most within first 4 years of diagnosis
- The effect is significantly greater for females
- The median annual personal income was \$20,000 compared with \$34,750 for the general NZ population
- Income sources showed that over 30% were receiving an invalid's benefit compared with 3% of the NZ population

Read more

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# Members helping members: How to cope with Fatigue

## Glenn Sparrow

In January 2010 I woke up one sunny, summer morning in Hamilton. My one job for the day was for my wife and I to photograph my sisters wedding. Suddenly having double vision and a munted equilibrium made a difficult job just all the more harder. I swore I would never drink Waikato Draught again. A few weeks later I was officially diagnosed with MS.

Four years later and with our son a matter of weeks away from starting school I am fortunate enough to be still working, but the everyday fatigue is hardest part of the battle.

One of my work mates has recently had brain surgery and has been struggling with coming back to work and asked for advice.

I am sharing here some of the things I have learnt about managing it, that I was able to pass on to her. It's amazing what you know when it comes time to write it down. It's not definitive list by any means but those things help me.



### EAT

The human metabolism requires regular feeding. A healthy **breakfast** is critical. It will help to provide you with energy throughout the whole day. I also find that having **healthy snacks** during the day helps.

When I'm at work I also use the times when I am eating these to have a "**micro break**" to help me "catch my breath" and recharge a bit.

As much as it sucks – avoid the quick sugary fix to give yourself an energy boost. Its false energy and in the long term you feel worse.

### DRINK

...plenty of **fresh water** as well. It helps to cleanse the body.

Avoid energy drinks (Red Bull, V, etc.) as tempting as they are all they give you is a quick 5 minute boost and will leave you drained for a long time afterwards.

### SLEEP

Another no brainer (so to speak) but sleeping is critical for brain health. There are a number of solutions to getting to sleep.

**Breathing exercises** help me sometimes. There are times when I'm on strong doses of steroids and on those occasions my Doctor has prescribed sleeping pills. I hate using them but I know I have to.

If you having issues with sleep – talk to your doctor.

The other horrible E Word. No, not "drugs" ...**EXERCISE**

I'm not talking about running till you puke or ending up built like a Professional Wrestler. Soft simple and manageable exercise. It might only be a 5 minute walk on the first day but slow and gradual increases coupled with rests is hugely beneficial. Something as simple as ten minutes gardening can make a huge difference.

### KNOW YOUR LIMITS

This is probably the hardest thing to do, I know I certainly struggle with it. Your limits may change from day to day but you do need to know what your limits are at that day.

### and then... STICK WITHIN THEM

That's the hard part – I suck at this. I am always trying to push myself and do what I used to. MS is incredibly frustrating like that and I get frustrated I don't have the energy I used too but I am always trying to stick within my body's limits.

### BREAK IT DOWN

There will be things that you can and things that you cannot do. The dishes might need doing, the lawn mowing, the washing needs folding and the cat needs patting. Break it down into individual tasks and do them when you can. But don't forget to pat the cat or they will poo in your slippers.

### RECOGNISE YOUR SIGNS

You will learn that you have certain signs of having overdone it – or you are approaching your limit. I get vague, dizzy and my legs feel like they are wrapped in concrete. You will be completely different.

## TURN YOUR BRAIN OFF

I find that there are times during the day when I need to turn my brain off and just sit still for a few minutes. I am lucky I can do that at home or in the evening, sitting on the deck listening to the birds.

## THE WITCHING HOUR

My witching hour is from 3 till around 5:30. I feel like complete crap then so I avoid scheduling anything to mentally taxing during that period. Learn when you feel most tired and work with it. I also try to have a lie down for ten minutes when I get home from work.

Don't forget the chocolate:

## REWARD YOURSELF

If you have set yourself a goal and achieved it, be proud of it and it is ok to reward yourself. No-one else will ever truly know how much of a struggle it may have been for you. It could be something as simple as a piece of chocolate.

## COTTON WOOL

All this aside don't make the mistake I have over the last four years of wrapping myself in cotton wool. I have missed so much of my son's first four years by not doing anything instead of doing what I can.

## DON'T BEAT YOURSELF UP

There are days that I get really frustrated that I can't do everything I want to. But you know what, my health is more important. I often ask myself when struggling with something "is it really important?"

## TALK

It is critical that you let those close to you know what is going on. They can help you in a way that no-one else can.

Above all else remember IT IS NOT YOUR FAULT. You got sick.



**Minimise Fatigue, Maximise Life: Creating Balance with Multiple Sclerosis,** is a recently developed programme for people experiencing MS related fatigue. It has been developed in Christchurch by a team of health professionals and people who live with, and manage, MS related fatigue.

It is currently being rolled out across NZ and is part of an on-going research project run by the Multiple Sclerosis and Parkinson's Society of Canterbury (Inc.) and University of Otago. It is also supported by the NZ Brain Research Institute and local Neurologists.

The programme runs for 6 weeks and involves a 2 hour session each week. It is currently in 5 centres, run by a licensed health professional such as a Physio, OT or Nurse and there are 4-6 people in each group.

For more information or to find out future course dates visit [www.msfatigue.org.nz](http://www.msfatigue.org.nz).



**WEDNESDAY 28 MAY 2014**

**'ONE DAY...'**

World MS Day is held on the last Wednesday in May annually for the past 5 years. The aim is to raise awareness globally about MS and to strengthen the network of people living with MS across the world.

The Theme for 2014 is 'Access'. The global campaign is aimed to educate and inform people across the globe of the different issues to access faced by people with MS or touched by MS.

The campaign is for all those touched by MS whether you are diagnosed, a carer, a parent or a child.

Read more about the campaign at [www.worldmsday.org](http://www.worldmsday.org) and see how you can get involved. MSIF will be sharing stories from people with MS about their 'One Day' hopes for access.

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# Are You Ready For Winter?

## Are you eligible for free insulation?

**W**arm Up New Zealand: Healthy Homes projects provide free ceiling and underfloor insulation for low-income households occupied by people with health needs related to cold, damp housing. Availability will be through regional projects.

Home owners or tenants may be eligible if they have a Community Services Card and are at risk of a health issue linked to cold damp housing - such as a respiratory condition. Children under 17 years or people over 65 will be prioritised because they are most likely to benefit from insulation.

Although insulation will be free for eligible homeowners and tenants, landlords of the eligible tenants may be asked to make a contribution.

Not all regions will be covered and there may be some areas within regions without coverage.

There is a list on the website of service providers with funding to offer insulation through Warm Up New Zealand: Healthy Homes but please be aware funding is limited. Visit <http://bit.ly/1e06oSl> or <http://bit.ly/1qcEjZA> for more information.

Take a look also at this **Ministry of Social Development guide** for ideas about 'Keeping Warm and Healthy This Winter.' <http://bit.ly/1jj2GCi>



## Flu Shots

**A**s winter approaches many may be thinking about whether to have a flu shot. The flu vaccine is one option available to individuals to prevent the spread of the flu virus.

MSNZ advise that you consult with your doctor to determine if getting a flu shot is appropriate for you. If your doctor is unsure ask them to contact your Neurologist or Neurology Nurse for guidance.

## Influenza and MS Research latest

Immunotherapies influence the influenza vaccination response in multiple sclerosis patients: an explorative study

*Mult Scler. 2014 Jan 16. [Epub ahead of print]*

The researchers in this study demonstrated that MS patients receiving immunomodulatory therapy (glatiramer acetate, natalizumab and mitoxantrone) had a reduced rate of protection to the seasonal influenza vaccine. Patients receiving interferon therapy did not demonstrate reduced protection. This raises the question of whether MS patients receiving immunomodulatory therapy may require a second dose of the vaccine if they have insufficient protection after the first dose. The safety issue in relation to MS patients receiving two doses of an adjuvant vaccine has not been fully investigated to date and further studies are needed to look at this.

[Read more](#)

## 5 TOP TIPS FOR KEEPING WARM AND WELL THIS WINTER

**1** Get your free flu jab if you are aged 65 or over, pregnant, have certain medical conditions, live in a residential or nursing home, or are the main carer for an older or disabled person.

**2** Keep warm. By setting your heating to the right temperature (18–21°C or 65–70°F), you can keep your home warm and your bills as low as possible.

**3** Layer your clothing and wear shoes with a good grip if you need to go outside.

**4** Food is a vital source of energy, which helps to keep your body warm. Try to make sure that you have hot meals and drinks regularly throughout the day and keep active in the home if you can.

**5** Get financial support. Are you eligible for free insulation to help lower your heating bills? It's worthwhile claiming what you are entitled to before the winter sets in.



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# The Good Life: Four Glorious Seasons In My Country garden

Seven years ago I was living in the heart of Auckland with my husband Tom, a toddler and a baby on the way and had my world turned upside down when I found out I had this thing called MS. After the initial shock wore off and I realised that what doesn't kill you can only make you stronger, we decided the city and its traffic pollution couldn't be good for my health or that of our young kids and made the big move into the country so we could reap the benefits of its fresh air and more relaxed lifestyle.

Having a whole lot of land, it only seemed natural to start a small veggie garden to provide us with fresh veggies that I knew where they had come from and what hadn't be sprayed onto them. But unexpectedly the garden gave me so much more. I found the time spent in the garden improved my health and wellbeing as well as the benefits from eating food so fresh.

My fatigue was always my biggest bugbear, and once the kids went to school, going out and getting a "real" job seemed impossible as I couldn't predict the fatigue. So I continued to garden, and the garden grew and grew. At this time I also discovered a love of writing as the good people at Yates ran a gardening blogging competition on their website and I felt compelled to enter. It took a couple of attempts at the competition to come up

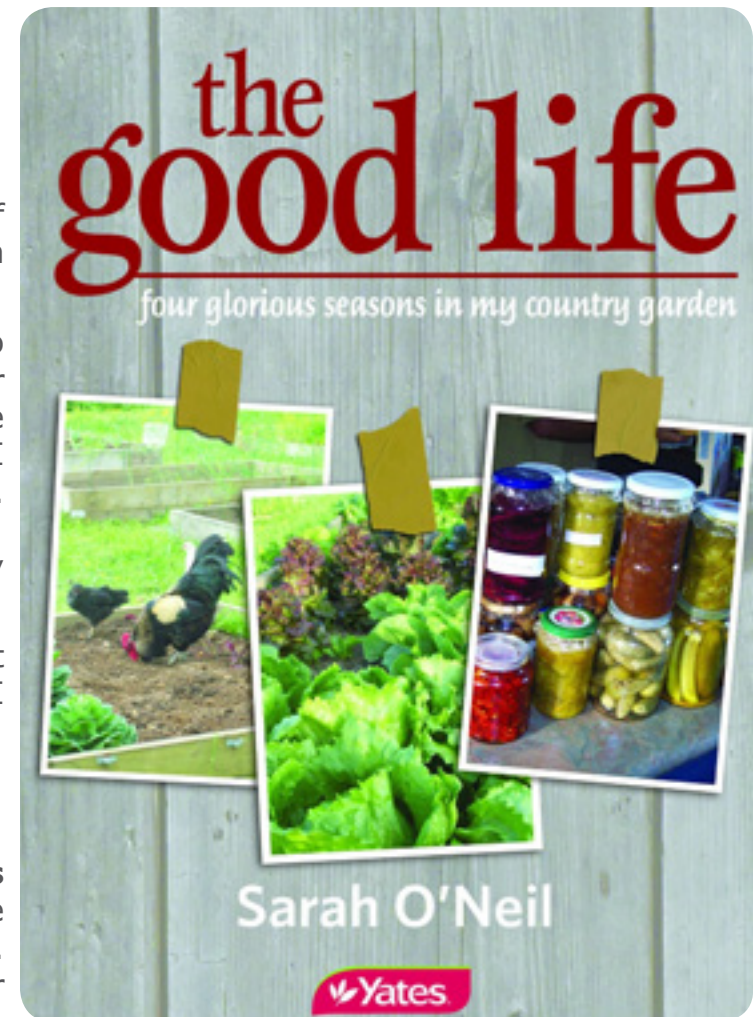
with a win, but in the meantime the love of writing was growing as fast as my garden was.

Yates recognised all the work I had put into the blogging and introduced me to their publishers. It was suggested the blogs to be turned into a book, which was something I had never imagined was ever a possibility. But here I am with my very own book: *The Good Life, four glorious seasons in my country garden*.

Having MS hasn't held me back, it's just given me a new way to do life and I couldn't be happier.



You can buy Sarah's book **"The Good Life: Four Glorious Seasons In My Country Garden"** at discounted price \$30.00 (RRP \$40.00) from MS Auckland. Please phone 09 845 5921 to place your order or email [info@msakl.org.nz](mailto:info@msakl.org.nz)



'The shift from summer to autumn is a subtle one. If it wasn't for the calendar to remind us we probably wouldn't even notice. How awesome would that be to not have a moment when summer officially ends? We could bask in the warmth of an Indian summer without realizing we are on borrowed summertime.

But the shortening days, a creeping chill in the air, leaves falling off the trees and summer plans no longer in their prime would quickly shatter the illusion. Besides, if we had an endless summer we wouldn't be able to grow all the wonderful cold-season vegies.'

(Extract)

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# Boccia New Zealand

## What is Boccia?

A cross between lawn bowls and petanque, Boccia is a non-contact target sport that is played indoors on a smooth rectangular court and can be played as individuals, in pairs or teams of three.

For those who dream of reaching the pinnacle of the sport and who want to compete at the Paralympic Games, Boccia is a sport that requires a significant amount of skill and strategy. The top athletes in the world work hard to perfect their game, and display a high degree of muscle control, accuracy, concentration, and tactical awareness.

Whether you participate for pure enjoyment, social interaction, the thrill of a challenge, or you have ambitions of becoming a Paralympic Games champion, Boccia may well be the sport for you!

## Who can play Boccia?

Boccia is a truly inclusive sport for all. It is a very skilful, strategic and exciting sport in which men and women of all ages can compete and play together – with or without a disability. Although people of all abilities can play, participants are required to be seated while competing.

At the social level, Boccia is a fantastic sporting opportunity that is suitable to people of any age, gender or disability. However, to take advantage and gain the benefits of the competitive pathways available in the sport and compete at the national and international levels, athletes must display movement difficulties in all four limbs. This may be the result of a number of conditions, including multiple sclerosis.

## Participation opportunities and pathways

Boccia can be played recreationally in someone's garage, or competitively at the local hall or gymnasium – making it easy to get a local group started. Different levels of events take place all year round to cater for a range of goals – whether you want to socialise with friends, develop new skills or compete to the highest level of competition.

Opportunities to participate in the sport of Boccia are readily available across New Zealand, so please do not hesitate to contact us to find out how you can join the action!

For more information please contact:

## Boccia New Zealand

**Email:** [boccia@boccia.org.nz](mailto:boccia@boccia.org.nz)

**www:** [www.boccia.org.nz](http://www.boccia.org.nz)

## WHERE THERE'S A WILL, THERE'S A WAY

### A LASTING LEGACY

We all have a different way we want to leave our mark on the world. As little as 1% of your estate will make a difference and will help support our many essential services. A gift in your Will is one way to leave a lasting legacy that continues long after you are gone.

### HOW DO I MAKE A BEQUEST?

A bequest is made through your Will. If you already have a Will, all you need to do is add a codicil (supplement), which amends part of that Will. You are able to place conditions on any bequest, but since your bequest is likely to be received far into the future, it is more beneficial if its terms are as general as possible. We recommend that you seek legal advice from your Solicitor when adding a bequest to your Will.

Simply make a bequest to the:

**Multiple Sclerosis Society of New Zealand Inc (CC10861)**

For more information, or to make a donation, contact

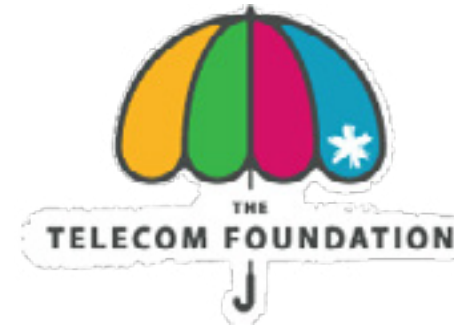
**0800 MS LINE (67 5463) or**

**[info@msnz.org.nz](mailto:info@msnz.org.nz)**

**[www.msnz.org.nz](http://www.msnz.org.nz)**



Thank you to the following organisations and businesses for their support



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