

Issue 39 Summer 2013

ms
VOICE



VOICE

VOICE

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Multiple Sclerosis New Zealand

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Tania McGregor (MS Otago)

Ian Chadburn (MS Central Districts)

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Dr. Debbie Mason

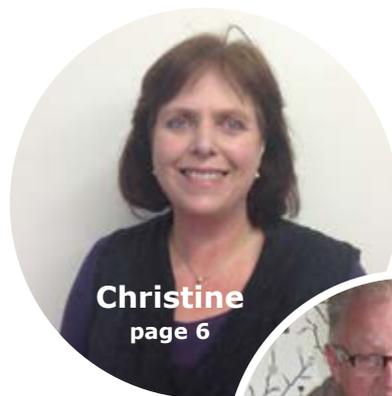
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We want to hear from you

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 or post to PO Box 32124, Christchurch 8147

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News from National



Welcome back to MS Voice. We are pleased to be bringing you the first electronic edition of the new look MS Voice which you will be receiving quarterly in your inbox. While MS Voice has been on hold for a while, MSNZ has still had a busy and interesting year with many changes.

MSNZ has been working hard over the past year beginning with the relocation of the National Office to Christchurch and changing the dynamics of the organisation. Throughout the changes MSNZ has still continued to provide support, information and education to benefit people touched by Multiple Sclerosis in New Zealand. We have been working to best support our Regions, planning the way to heighten the awareness of Multiple Sclerosis across New Zealand communities as well as bringing the National Office closer to other Multiple Sclerosis Research bodies within New Zealand and Australia. As many charitable organisations are aware funding is always difficult and MSNZ is happy to report that we are now on a positive track towards managing at a sustainable level.

Thank you to the National Executive Committee (Malcolm, Mark, Jenny, Neil, Tania, Jeff) for the time and effort that you all have contributed towards the changes that we, as a National Society, need to make for the future to deliver the best support and information to people with MS across New Zealand. We look

forward to welcoming Ian Chadburn (MS Central Districts) to the Committee and receiving his input. A special thank you also to Robyn Coyle for the assistance she has provided as the Field Workers Representative, now in her second term.

Iwould like to thank those who attended our recent AGM held on the 16th October in Hamilton. A very successful meeting and we look forward to working closer with our Regions towards a positive future ensuring people with MS in New Zealand are provided with the same level of care, information and support wherever they are in the country.

Our gratitude also goes to Professor David Miller, our guest speaker at the 2013 AGM. Professor of Clinical Neurology at the Institute of Neurology, at the University College London, he is also the head of the MS Incidence Study in Christchurch and works closely with Dr Mason on the Vitamin D Study. Professor Miller gave a very interesting and optimistic presentation regarding 'The Current Status and Prospects for Treating Relapsing Remitting and Progressive MS.' Positively to note, there are a number of drugs currently being trialed which for both Progressive and Relapsing Remitting MS. While there is no current proven effective treatment for Progressive MS, it is hoped that in the future these new

treatments may provide neuroprotection and repair. Professor Miller also presented interesting research being undertaken at the New Zealand Brain Research Institute, in Christchurch, on Perfusion Imaging of Grey Matter with MRI scanners. The study looks at the role that grey matter plays in progressive MS and eventually it is hoped that perfusion MRI will help detect those at risk of progressive MS. We look forward to working closely with Professor Miller and the team at the NZBRI as we step into the future.

We hope you enjoy this edition of MS Voice and we welcome all feedback and suggestions of topics for future editions. Please send all feedback to info@msnz.org.nz.

Wishing you a very Merry Christmas and a Happy New Year

Amanda Keefe
National Coordinator

ms.

**Multiple Sclerosis
New Zealand**

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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 gift will help ensure that people with MS are provided with the information, education and support they require 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

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Branch Address

Please start/amend the following Automatic Payment

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 Change Existing Payment

Name of Account

Account Number

Payer Reference

(to appear on statement)

I P D O N

SURNAME (Required)

Amount

\$

Start/Change Date

Frequency Weekly Fortnightly Monthly Quarterly Annually

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Date _____

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WELLINGTON TO AUCKLAND CYCLE CHALLENGE

ON YER BIKE - ACCEPT THE CORPORATE CHALLENGE - 9th - 15th February 2014

We challenge you to form a corporate team with your workmates and battle it out with other firms for the grand prize of \$100,000 of products and services gifted to your business's chosen charity! Riders will cycle a combined 700kms in this truly unique 13 stage event. Riders of all ability from Weekend Warriors to international competitors will feel a sense of personal accomplishment as they cross the finish of each stage.

PRIZES

The winning Corporate Challenge team - along with bragging rights - will win \$100,000 of products and services for the charity of their choice!

The prize consists of a car for a year (only available to Auckland-based charities), accounting, legal and advertising services and software. A bonanza for any charity kindly donated by the companies listed below.

The fastest teams on each stage will get points and the team finishing with the most points overall wins.

THE COURSE

- Departing from the main street in Lower Hutt.
- 13 stages over 7 days, each day is divided into one or two stages covering anywhere from 38km - 122kms - riding a total of over 700kms.
- Finishing in Pukekohe.

CYCLING AND SUPPORT TEAM

- Your team must have a minimum of 3 riders per stage and a maximum of 6.
- The riders may be changed every stage if you wish or some may choose to do multiple stages or ride the whole week!
- You could have as many as 42 riders take part over the week riding one stage or multiple stages.
- You will need a support person/vehicle or hook up with another team to share support duties.

WHO CAN RIDE IN YOUR TEAM?

Your team can be made up of employees, customers or invited guests of your organisation. Get together for training rides, mentor riders starting out make it fun whilst getting fit and improving your company's corporate social responsibility.

SOCIAL EVENTS

Its not just all cycling, there will be spot prizes, dinners, drinks and social events to enjoy with your fellow cyclists

- Daily prize giving and dinners
- Spot prizes for tenacity, sportsmanlike behaviour and hilarity!
- On the last day at the finish line there will be a BBQ and cold drinks waiting.

A great chance to relax, put your feet up and congratulate all who have taken part in the challenge that should be on everyone's bucket list.

ENTRY COSTS

The cost per corporate team is \$3,000. There are other costs such as accommodation, meals and transport for your team. These can be arranged through Dynamo Events if required.

REGISTER NOW!

Go to www.wellingtontoauckland.co.nz for more information and to register your team for this amazing event.



Multiple Sclerosis
New Zealand

Multiple Sclerosis New Zealand is the nominated charity of the BDO Wellington to Auckland Cycle Challenge 2014

Dynamo Events is a sports events delivery company that has a commitment to excellence across all facets of the event experience



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The Esme Tombleson Awards: Person with MS of the Year

At the 2013 MSNZ AGM held on Wednesday 16th October in Hamilton the Esme Tombleson Awards for Person with MS and Carer of the Year were awarded to two members of MS Auckland. Christine (Person with MS of the Year) and Roy (Carer of the Year) were both very humbling and gracious in their acceptance of the awards.

Christine Ball

Christine was diagnosed with Multiple Sclerosis at the age of 18 and has had MS for 30 years. She joined MS Auckland in 2002. Christine is married to Rob and has two daughters Kate and Ellice.

During her early years with MS, Christine was focused on raising her 2 daughters, as well as working with her local church and community. As her daughters have become older and since joining the Society in 2002 Christine has become more involved with the activities of the Society and is a loyal and supportive member.

Christine has collected for the Society for many years at the Annual MS Appeal. For the past 2 years Christine has been the Team Leader, collecting on the Friday and Saturday of Appeal Week at Glenfield Mall, one of the main collection points in Auckland.

Christine manages her MS symptoms very well and is always interested in new developments in the management of MS. She has been on Disease Modifying Drugs for 9 years and is very conscientious about her treatment.

Despite setbacks at times, Christine is always positive and an inspiration for other members. For several years now has been the organiser of a monthly support group. One of the support group attendees, says that Christine not only organises the meetings but is also in regular contact with the members through texts and phone calls. She always goes around each member of the group when they meet to see how everyone is managing and is always thinking of others first. Auckland Fieldworker Diane Hampton commented, that "I have found Christine over the years to be a positive role model and mentor for other PwMS."

At the beginning of this year Christine finished her employment with an Early Childhood Centre to provide support to family members. "I have been impressed by her calm and measured way of dealing with this extra stress. She has also found the time to work regularly in the MS Auckland office this year as a volunteer, often at short notice." praised Diane. Despite personal setbacks Christine is now investigating what field of work she would like to be in next.

"What strikes me about Christine is the length of time that she has had MS and her positive attitude and concern for others"



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The Esme Tombleson Awards: Caregiver of the Year

Roy Burgoyne



Roy is the husband and caregiver of Tina French, Life Member of MS Auckland. Tina was diagnosed with MS in 1995 and joined the Society in 1998.

From 2000 she worked in the North Shore Office firstly as a volunteer and then on the committee as Secretary/Treasurer and later was appointed Office Manager. Instrumental in advocating for a merger of the 2 Societies, when they merged in 2008 Tina became the Grants Coordinator for MS Auckland.

For many years, Tina was the recognisable face of MS in Auckland on radio, TV and in print. Over the years Roy has been supportive of Tina with her interests in raising the profile of MS and fundraising for the Society, helping her where needed.

In 2008, 2009 and 2011 Roy was involved as an organiser for the MS Auckland Art Shows and was a member of MS Auckland Committee in 2010 and 2011.

Tina left her position as Grants Coordinator in April 2011 and worked briefly in the same role for Mobility Dogs until she was unable to carry on because of her deteriorating MS.

Because of her deterioration in June 2010 Tina became the proud owner of a 2 year old Golden Retriever Mobility Dog called 'Ezra'. Ezra made quite a difference to Tina's life by assisting her with various tasks, fetching items such as mobile phones, TV remote etc and opening the door. Roy took on the role of playing with 'Ezra', exercising him and attending to his needs.

For the past 4 years as Tina's MS continued to progress Roy became more involved with Tina's care and assisted her with personal cares as well as doing the cleaning, shopping, cooking and laundry. Tina was no longer driving and required Roy to drive her to appointments and on outings.

By mid 2012 it was obvious that more assistance was required as Roy was juggling the demands of his job which he fitted in around caring for Tina. Auckland Field Worker Diane Hampton referred Tina to Taikura Trust (NASC) for a needs assessment. Personal care hours were provided over lunchtime and Tina and Roy's friends also visited and assisted where they could.

It was also obvious that the unit they were renting was unsuitable for Tina's needs and was too small for equipment required such as a hoist. So, they bought a suitable unit and moved there in early March 2013. The bathroom needed to be made disability friendly but there were long delays and extra expenses if Tina and Roy proceeded with this through the Ministry of Health.

Roy's solution was to do it himself - gutting the bathroom (with some help from the concrete cutter) and then building a wonderful new bathroom over the next few months, saving considerable time and money. After 4 months of 'bedbaths' Tina had her first shower and luxuriated in it for an hour.

Individual Funding has meant that Roy and Tina can be flexible with her caregiving needs. Roy showers Tina on Tuesdays, Thursday and weekends. Caregivers do this on Mondays,

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Wednesdays and Fridays. Roy goes to work early at 5am and can be back for meetings, appointments and liaising with carers later in the morning or attend to Tina's needs. Caregivers come in to prepare lunch and feed Tina and Roy is home by mid afternoon. Supportive friends continue to be involved and call in on a regular, rostered basis and read the news to Tina. Because of her poor sight she listens to talking books and the sound on TV. 'Ezra' remains a much loved, working companion dog to Tina.

Recently, Sue, one of Tina's friends and caregivers moved in for 3 days to look after her while Roy had 3 days away skiing. Sue said she now realised the extent of Roy's commitment to Tina, his patience and the amazing job he does balancing his work schedule with Tina's needs which always come first. Sue said Tina required attention several times during the night with severe leg spasms, repositioning of her upper body, putting the head of the bed up with coughing/choking episodes and catheter emptying and management. She said this is what Roy would be doing on a nightly basis. Sue says that Tina requires everything to be done for her and feeding her is a slow process. On a good day Tina may be able to hold her drinking cup and finger food but other days this isn't possible.

Roy has a great interest in ceramics and has converted the garage into a studio so that he can be at home with Tina but still follow his passion. Roy is half way through a Diploma in Ceramics (on hold) and is currently Treasurer of Auckland Studio Potters. Roy is a Trustee of the Orewa Estuary Arts Charitable Trust and is about to have an exhibition of his work there.

Roy says one thing that he has found comforting is writing his journal in the form of a blog. He says he has an appreciative audience from around the world who identify with what he is saying.

His blogsite is

www.agoodmshusband.blogspot.com

Roy's unswerving commitment to caring for Tina means that she can remain at home in the surroundings that she loves. ♦

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

Have you visited Carers Air?

CarersAir is a wellbeing and learning space for family caregivers and friends.

It's a place for you to unwind, catch your breath, discover who's out there to help ... a place to park up and be soothed, or entertained, or shown how to safely carry out common caring tasks.

What's behind the name CarersAir?

It was inspired by carers who told Carers NZ the

Carers - Have your say!

Family carers are being asked to take part in the country's first longitudinal study of caregiving, being undertaken by Tracey-Lee Dalton of Auckland University. So far about 500 carers have undertaken the survey and it is hoped that this number will be increased by several hundred more before the study finishes at the end of January. The study will be repeated each year for a period of at least three years to give a picture of the impacts of caring over time.

The survey is important because it looks at carer wellbeing, the financial cost of health/disability on households, how caring affects paid employment, and other topics we don't know enough about in New Zealand.

We would like to ask any carers to take part in this Survey through the link below. Your participation in this is important as it allows you to have a voice in your community. Your input can be heard in this important work.

The survey link can be found at

<https://www.surveymonkey.com/s/7L3N9Q2>

place they really feel free is on an airplane, after the hatch has closed: whatever's happening on the ground, they have no option but to let go; to sleep, read, watch a movie, hang out, reflect without interruption, and have someone else bring the drinks and nibbles.

CarersAir ... it means whatever it means to you. Sit back and enjoy!

www.carersair.net.nz



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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: liz@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

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MS AWARENESS WEEK

MSNZ supports 18 Regions across New Zealand. During Awareness Week (31st August - 7th September 2013) each Regional Society holds its own Annual Collection with all proceeds going to support people with MS in their region.

In 2013 Regional Societies collected **over \$200,000** for MS through street appeals and fundraising events held throughout the week. This money will go a long way to support people with MS in NZ.

Over 1000 fantastic volunteers helped make this possible and without their support many Regions would struggle.

Thank you to all the volunteers, donors and businesses for your support of MSNZ and our Regional Societies this MS Awareness Week!

DATES FOR THE DIARY
WORLD MS DAY 2014

Wednesday 28th May

AWARENESS WEEK 2014

30th Aug - 6th Sept

To find out more about volunteering for your Regional Society visit page 9 for contact details.



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To All Our Volunteers - Thank You!

Huge thank you to each and every one of you who contributed your time, energy and expertise to help our regional societies provide services and raise money for programmes!

Have a great holiday season and we hope we can partner with you again next year!



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Research Round Up

Over the last two years there have been an increasing number of research projects undertaken on Multiple Sclerosis within the country, a number of which MSNZ have been involved in. Over the next year or so we will start to see the results of these projects and we would like to acknowledge your generous support without which many of these projects would not have been possible. MSNZ would also like to thank all those involved in MS Research in New Zealand.

MS Incidence Study

The MS Incidence Study is being undertaken throughout the country and collated by Dr Sridhar Alla, who is funded by MSNZ. Recruitment began in July 2012 and will continue until 30th June 2014. To date 127 patients have been recruited with CIS and 122 patients with MS.

The team continues to work to ensure all eligible patients are recruited including liaising with MRI centers around the country to identify any patients that may have been overlooked.

Dr Alla will report on the MS Incidence Study data collected in early 2014. A number of medical papers are also due to be published during the

coming year. We await these papers with interest.

Dr Mason presented the current recruitment numbers to the yearly Multiple Sclerosis meeting in Queenstown in August.

These were very well received by Neurologists across the country and it was felt that these numbers will be extremely useful to those presenting the case to PHARMAC for high cost medicine use in Multiple Sclerosis.

Prevalence Study

Dr Sridhar Alla has also completed analysis of previous Prevalence Study data which has resulted in the acceptance by the Journal of Clinical Neurosciences of a paper entitled "Multiple Sclerosis in New Zealand".

Dr Alla presented two submissions atECTRIMS in Copenhagen in October. One a poster containing a systematic review of the increasing prevalence of MS in New Zealand since 1968. The other submission was accepted for a prestigious platform presentation the title of which is that "Latitude is Not Associated with Multiple Sclerosis Disability in New Zealand."

PrevANZ Vitamin D MS Prevention Trial

MSNZ Medical Director and Clinical Neurologist Dr Deborah Mason heads the New Zealand portion of the MS Research Australia led 'PrevANZ

Vitamin D MS Prevention Trial'. This world-first clinical trial is testing to see whether Vitamin D supplementation can prevent MS in those at risk of developing the disease following a person's presentation with a first episode of symptoms (people with CIS or clinically isolated syndrome).

This three to five year study is currently recruiting people in Auckland, Hamilton, Wellington, Christchurch, and Dunedin. To read more about this study see **page 19** for The Listener article.

Perfusion Imaging of Grey Matter

With the use of MRI scanners the study headed by Professor Miller and Dr Debernard looks at the role that grey matter plays in progressive MS.

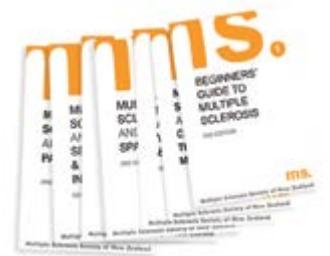
The data from these studies has provided very valuable information and the MS Study Group has just had a publication accepted for the Journal of Neurology, Neurosurgery and Psychiatry entitled "Reduced Grey Matter Perfusion Without Volume Loss in Early Relapsing Remitting Multiple Sclerosis".

MS Information Series

can be

downloaded at:

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



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CuroNZ wins support from National MS Society (USA) to develop NRP2945 as potential therapy for stopping MS progression

Media release from CuroNZ

CuroNZ, an Auckland biotechnology start-up company developing treatments for progressive multiple sclerosis, has been awarded funding of US\$ 540,000 from the National Multiple Sclerosis Society through Fast Forward to support preclinical studies needed to develop CuroNZ's NRP2945 candidate as a potential therapy to protect the nervous system from MS damage.

Current therapies available for treating multiple sclerosis do not adequately treat progressive stages of the disease or directly protect the nervous system from that damage that leads to progression.

The funding will enable CuroNZ to undertake pre-clinical proof of concept, pharmacokinetic and toxicity studies to bring the drug candidate lead NRP2945 closer to an investigational new drug (IND) application. As part of the project, CuroNZ will collaborate with leading research organisations including the University of Auckland and Monash University in Melbourne.

With its unique mechanism of action and a pristine safety profile to date, NRP2945 has the potential to act as a neuroprotective agent which might eventually be developed into a product that can help patients with progressive MS, worldwide.

Finding ways to stop MS progression is a strategic priority of the National MS Society's research program. A key



Frank Sieg (left) and Aki von Roy have a \$650,000 grant for CuroNZ's multiple sclerosis drug. Photo Dean Purcell

aspect of the Society's comprehensive approach to driving research progress is the support of promising research discoveries - such as NRP2945 - toward commercial drug development.

About CuroNZ:

CuroNZ was founded in 2009 by Dr. Frank Sieg who discovered the drug candidate portfolio called Neural Regeneration Peptides (NRPs) in Germany. He subsequently brought them to New Zealand with the hope of being able to eventually develop products that could benefit patients suffering from the debilitating effects of progressive MS.

For more information, please visit

www.curonz.com

DISCLAIMER

MSNZ's advise 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.

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minimise fatigue maximise life

CREATING BALANCE WITH MULTIPLE SCLEROSIS

“Multiple Sclerosis fatigue is hard to explain to other people as they can not see it. Fatigue is a feeling that overwhelms you. It randomly zaps all energy from you. There is no escape from it and I thought nothing you can do about it.”

When MS first reared its ugly head for Marijke in 2003, the doctors originally thought her double vision was a tumour, then nerve palsy, only to finally be diagnosed with Multiple Sclerosis in 2007 after sensory loss in her arm and hand.

After the diagnosis she felt confused and helpless about the fact that there was no cure. ‘We as a society are so used to a quick fix and realising that was not going to happen made me feel quite desperate,’ says Marijke.

Only after the symptoms thankfully resided and she began educating herself, did she adjust to her diagnosis and begin to get on with her life. The thing that she was never able to get rid of though, was fatigue.

Then Marijke came across the Minimise Fatigue, Maximise Life: Creating Balance with Multiple Sclerosis course, offered by the Canterbury MS Society. This six-week course was created and run by the Canterbury Society’s Physiotherapist, Jessie Snowdon. Jessie had worked with people

with MS for almost a decade and she saw first-hand how fatigue could worsen all the other MS symptoms.

Marijke enrolled in the Fatigue course and the small group started going over all the aspects of their fatigue, how it affected them and what could be done about it. ‘It was re-assuring that we were all in the same boat and learned so much from each other,’ says Marijke.

‘I’ve learned to manage or let go of (often unnecessary) stress. I’m eating super healthy, do yoga, plan my days, I also exercise and meditate. This was the total opposite of my initial approach of dealing with fatigue, which was being frustrated and sleeping.’

Through the course, Marijke has evaluated her life and took action. ‘I now know what to do to revitalise and make it a priority to minimise my fatigue in order to make the most of life. I recommend it to anyone with MS!’

Marijke’s story was first published in Good Health Choices, October issue, 2013

Research Progress

The Multiple Sclerosis and Parkinson’s Society of Canterbury has just completed the second stage of their research programme Minimise Fatigue, Maximise Life, New Zealand’s first MS Fatigue Management Programme where six trained health professionals across the country held six-week courses.

We now await outcomes from the Research Team analysis and are pleased to announce they have received funding for the next stage of the research from Otago University. The MS Study Group will be providing support for Jessie Snowdon and Dr Hilda Mulligan for validation of this programme.

To watch the video presentation from the launch held on World MS Day (29th May 2013) visit

http://www.youtube.com/watch?v=j0Ghrz_W95E

The 52 minute video include a presentation by Dr Mason on the topic of “Disability and the Socioeconomic Effects of MS in New Zealand” followed by a presentation by Jessie Snowdon describing the course, its origins and future.

The Minimise Fatigue, Maximise Life: Creating Balance with Multiple Sclerosis course is now available in 6 centres throughout New Zealand.

For more information or to find out future course dates visit

www.msfatigue.org.nz.

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HEALTH
by Margo White

The sun and MS

People living at higher latitudes have a greater chance of developing multiple sclerosis. Now a long-awaited study aims to find out whether a lack of sunlight could be the problem.

Strange but true; the further you live from the equator, the greater your risk of developing multiple sclerosis (MS). This is thought to be as a result of the lack of sunlight – or more precisely, lack of vitamin D, which we synthesise from sunlight. Does this mean those living above a certain latitude should take vitamin D supplements?

Researchers in New Zealand and Australia have joined forces to try to find out, and are now recruiting for the first large, placebo-controlled, randomised study designed to investigate whether taking daily vitamin D supplements affects those at risk of developing the disease. “This is the leading-edge hot topic in MS research,” says Deborah Mason, the Christchurch-based neurologist leading the New Zealand arm. “It’s the trial that everybody has been waiting for.”

MS is a disorder in which the immune system starts to attack the myelin that coats the nerve fibres, interfering with communication between the brain, spine and other parts of the body. There are many different types of MS, but it’s typically characterised by intermittent episodes of demyelination, or attacks, causing symptoms including visual disturbances and limb weakness that may worsen over time.

Vitamin D receptors are found throughout the body – in the bones, brain, heart, for example, and where there is a receptor, vitamin D affects function. In recent years low vitamin D levels have been implicated in numerous health problems including bone disease, colds and flu, tuberculosis and even Alzheimer’s. And in the development and severity of MS.

For some decades it has been known that populations living at higher latitudes have greater rates of the disease – it’s significantly more common in countries such as New Zealand and Canada than in the Mediterranean countries or Central America, and it’s three times more common in Southland than it is in northern regions of New Zealand. This geographic relationship “has been shown worldwide”, says Mason.

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“There are much higher rates in Hobart than in the Gold Coast and northern parts of Australia, for instance.”

The theory that this could be a result of reduced sunlight exposure and lower levels of vitamin D was mooted early on, and gained traction as researchers found that people with MS seem to have lower vitamin D levels than those who didn't. Also, that genetic changes that affect vitamin D regulation were more common among people with MS.

Which might be enough to persuade most people with MS to take it, but it's not enough for a clinician to recommend it, says Mason.

“This is still an association – nobody knows the mechanism by which it might work, or even if it's the answer.”

The study will involve more than 300 people from New Zealand and Australia who have had a single episode of demyelination, but haven't been diagnosed with MS. Participants will take vitamin D supplements of one of two strengths, or a placebo, and be observed for three years.

As the evidence of a link is so strong, some researchers have questioned whether it is ethical to withhold vitamin D in the placebo patient groups. However, Mason says they simply don't know if vitamin D supplementation is effective, or even safe, and they need to find out. After all, it wasn't that long ago women were told to take calcium supplements, because there was good reason to believe it would build bone density – before New Zealand researchers discovered that taking calcium supplements increased the risk of heart attacks.

It's not entirely clear what constitutes an optimal level of vitamin D, but New Zealanders are showing low levels of it compared with people in the United Kingdom and the US.

This could be the result of cultural factors – our fear of the sun, or less fortification of vitamin D in our food. “But one of the problems is that in winter sunlight across southern parts of New Zealand there isn't enough of the right UVB wavelength to make vitamin D – even if it's a sunny day, unless you're sitting on top of a mountain, you're not getting the right amount of sunlight to make vitamin D.”

Mason says she has no idea what results the trial will produce, but of course it would be nice to find out supplementation makes a difference.

“In winter sunlight across southern parts of New Zealand there isn't enough of the right UVB wave length to make vitamin D.”

“If we could prevent just 10% of people getting this disease just by increasing their vitamin D, that would be amazing.”

This article first appeared in The Listener, August 17, 2013 and is reprinted here with their permission.

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 services and allow essential programmes to continue. 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

www.msnz.org.nz

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Research News from around the globe

» **Quality of life outcomes with BG-12 (dimethyl fumarate) in patients with relapsing-remitting multiple sclerosis: The DEFINE study**

<http://bit.ly/1gTccu2>

» **New data published from Canadian CCSVI prevalence study**

<http://bit.ly/1fdFWB7>

» **Reduced grey matter perfusion without volume loss in early relapsing-remitting multiple sclerosis**

<http://bit.ly/1hIB7TP>

» **Disclosure of diagnosis of multiple sclerosis in the workplace positively affects employment status and job tenure**

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

» **Natalizumab affects the T-cell receptor repertoire in patients with multiple sclerosis**

<http://bit.ly/19wHwJO>

» **Sex as a determinant of relapse incidence and progressive course of MS**

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

» **MS drug sales lift Biogen 3Q net income climbs. Biogen Idec 3rd-quarter net income rises 22 percent on sales of MS drugs Tysabri and Tecfidera**

<http://yhoo.it/J7N9rP>

» **Ectrims Website – visit the library to see Podcasts, e-posters and presentations from the 29th European Conference for Treatment and Research In Multiple Sclerosis held 2-5 October 2013 in Copenhagen, Denmark.**

<http://bit.ly/1f26TXJ>

» **New imaging research shows increased iron in the brain in earliest stages of MS**

<http://bit.ly/1cl8i8M>

» **Clinical Trial – Stem Cell Clinical Trial For Multiple Sclerosis Approved**

<http://bit.ly/1bS0JLD>

» **Cognitive Dysfunction in MS: New Insights and Clinical Management**

<http://prn.to/18PrJvc>

» **Isolation of Clostridium perfringens Type B in an Individual at First Clinical Presentation of Multiple Sclerosis Provides Clues for Environmental Triggers of the Disease**

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

» **TB vaccine 'could help prevent MS**

<http://bbc.in/IJFjUx>

» **An eye test for MS**

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

Note: Visit our website www.msnz.org.nz for regular updates of news articles from around the globe related to MS. These can be found on the right hand side of the home screen.

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.

Tell a friend about the MS Voice

Our quarterly 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>

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Atlas of MS 2013 launched with staggering global statistics on the condition



Global statistics released about Multiple Sclerosis which affects 2.3 million people worldwide highlights the improvements that New Zealand must make in the access to high cost medicine use in MS.

The Multiple Sclerosis International Federation launched the 'Atlas of MS 2013: Mapping Multiple Sclerosis Around the World' at the 2013 European Committee for Treatment and Research In Multiple Sclerosis (ECTRIMS) in Copenhagen on 2nd October.

"MS is one of the world's most common neurological disorders and the leading cause of non-traumatic disability in young adults," comments Professor Alan J Thompson, Chairman of the MSIF International Medical and Scientific Board and Peer Baneke, MSIF Chief Executive in the published report.

The Atlas of MS 2013 enables MS Organisations around the globe to provide policy makers, governments and health professionals with "Reliable data concerning the worldwide distribution of MS provides useful insights about the disease... to campaign for better support and quality of life for people with MS."

"We are extremely excited to receive this report and to have been a part of it," commented Multiple Sclerosis Society of New Zealand National Coordinator Amanda Keefe.

"With the results from the National Incidence Study that is taking place across the New Zealand at present we hope to use the findings, due to be released early next year, alongside these global statistics to be able to lobby PHARMAC and Government for both better funding for more high cost medicine use, many of which are available and often fully funded in other countries and receive better funding for research."

Over 3000 New Zealander's are diagnosed with MS which is one of the most common neurological conditions in the country with women three times more likely than men to be diagnosed.

More information about The Atlas of MS 2013 is available online at:

www.atlasofms.org

Download the full report as .pdf file at:

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

View the promotional video:

<http://www.vimeo.com/74305546>

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Atlas of MS 2013 Stats

Global Key Findings

- ◆ The estimated number of people with MS globally has increased from 2.1 million in 2008 to **2.3 million in 2013**
- ◆ MS is found **in every region of the world**
- ◆ The 2:1 ration of women to men with MS has not changed significantly since 2008. **(In NZ the ratio is 3:1, higher than the global average)**
- ◆ Support and healthcare services have improved but substantial global inequalities remain.
- ◆ **There are substantial inequalities in the availability of and access to disease modifying therapies**
- ◆ The number of MRI machines in emerging countries has doubled in five years with a global statistic of 0.31 increased to 0.46 per 100,000) and an increase in the number of neurologists around the world from 1.01 in 2008 to 1.32 per 100,000 in 2013.
- ◆ High income countries have 100 times more neurologists per head than low income ones
- ◆ **One in five countries has no organisation** providing support to people with MS

- ◆ **More research is needed in relation to quality of life and experiences of people with MS**
- ◆ More research is needed to measure indirect costs of MS
- ◆ **8 out of 10 people who are diagnoses with relapsing-remitting MS develop secondary progressive MS**
- ◆ The average age of MS onset is 30 years
- ◆ Physiotherapy is available is almost all (99%) of the 100 countries that provided data on rehabilitation services.
- ◆ Cognitive rehabilitation was the least available of the rehabilitation services worldwide, being available in only 48% of countries, even though **cognitive problems can affect 40-70% of people with MS.**
- ◆ The most common presenting symptoms were found to be sensory (40%) and motor (39%), and least common were pain (15%) and cognitive issues (10%).

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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Janette's Story: Nothing is Unsurmountable

1980 I was a busy housewife and mum to 8 year old Matthew and 6 year old Louise. I was working part time, helping out at our local library and made myself available for school outings.

Sport had been enjoyed by me and I went back to playing hockey in a team with other mums for our local club. I loved dribbling the ball up the field. Out of the blue, my legs started giving up on me and I would end up on the ground; I would pick myself up and keep on running.

My GP gave me a thorough general check-up, could find nothing untoward and told me he thought I was just not physically fit and suggested I enroll at a gym. Our coach moved me to play as a back with little running to do and I managed to stay vertical!!

This was to be the pattern over the following seven years; I gave up hockey, started a full time job, worked out at the gym several times a week, was taxi driver to both children with their activities and carried on, busy as ever.

As a family, we were into doing bush walks and often I would find after walking a couple of hours, my legs would feel 'rubbery' and weak; I would need to sit down to rest before I could continue.

I remember at one of my visits to the doctor, he said that if my problem was MS, some other symptoms would have shown up. That comment stayed with me for many years.

1987 Finally, on 12 May, I got a diagnosis - Multiple Sclerosis. The nurse handed me a manila folder with several articles on MS and the phone number of the local field officer of the MS Society. Judy was a registered nurse with a sunny disposition.

✿ Her advice to me on her first visit was to read up, eat lots of green vegetables then forget I had MS and get on with living. Even now, I feel that was excellent advice and the bit on green vegetables still stands today. ✿

Over the ensuing years I saw many health professionals in an effort to arrest the progression of my MS.



✿ Janette Keown: As a child I was very healthy and fit; played hockey and soccer. Diagnosis at 39 was a devastating news but I am always looking for ways to help my health.

Apart from tingling and numbness intermittently in my hands, the only symptom that gradually got worse was the strength in my legs. I started tripping, then falling suddenly. My balance became affected so I used a walking stick.

2000 I had been open and honest with my employer right from my diagnosis and the company and my workmates supported and helped me for many years until at the age of 52 the fatigue got the better of me and I retired on medical grounds.

Life became lonely after retiring and giving away driving. My left foot was dropping and I needed to wear a splint which meant saying goodbye to my many beloved high-heels. After quite a few falls, the physiotherapist decided I would be safer with a walking frame – and I was. My doctor arranged for someone to come each morning to help me. Gradually, my bladder became overactive. Trying to get to the toilet in a hurry is no laughing matter when one has Multiple Sclerosis!

At that stage I was struggling to get a meal on the table at night. Cooking had been a passion of mine so I doggedly carried on – I found that by starting at 2pm, the meal would be ready by 6.30pm. My tingling fingers and poor co-ordination meant spending 20 minutes chopping just two onions (I timed myself on one occasion, just out of curiosity!).

2005 The exhaustion was completely taking over my life and I made the decision to move to an environment where trained and caring staff could look after me.

I am now in a power chair and try to get out often and have lots of friends and family who visit or meet me for lunch somewhere. Since 1996 I have had a small shares portfolio and keeping abreast of the share market has been a hobby. I also enjoy studying extramurally, with psychology being my main interest.

✿ **A positive outlook on life has been with me all my life and I firmly believe we are all responsible for our own health. I believe we can all help ourselves by way of what we put in our mouths.** ✿

I have tried to stay true to a food regime that helped me to stop taking hypertension pills; my fatigue has lessened and I have an improved sense of well being.

2013 It was in about March of this year that I was lying in bed one night thinking about how I had always wanted to travel. The next day I rang a caregiver that I had befriended and that was the start of many hours of planning!

In June we flew to Dubai for a couple of nights to break our journey. We then flew to Venice where we met up with our cruise ship. From then on, we cruised at night arriving at a different port each morning. We visited Split and Dubrovnik (Croatia), Corfu (Greece), Naples, Civitavecchia (Rome), Livorno (Florence), Monaco, Marseilles ending the cruise in Barcelona. We spent a further three nights there, then flew home, stopping in Dubai



again. We were away for 22 days and felt that was long enough.

I rented a lifting hoist which was in our room when we arrived and was collected after we left. I had found another company that organized three separate one-day tours for our three Italian ports. A van with a ramp to transport me in my power chair as well as an English speaking guide was provided with each tour. I felt that the money spent on these individual tours was well worth it.

✿ **The whole experience has given me such a boost and I am now thinking about where I might like to go next year! My strong message to anyone with a disability is 'where there's a will, there's a way' – in other words, don't allow Multiple Sclerosis to stop you from traveling. Find a good travel agent, take a reliable caregiver, and do your homework. It is worth the effort and you will have the memories for your lifetime.** ✿

Janette Keown ~

Huge Thank you to Gillian from MS Wellington for putting us in touch with Janette and making possible for her story to appear in North & South magazine October Issue as part of our 2013 Awareness Week Campaign.

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Special Feature: Travel

Recommended by Janette

Special Needs at Sea is dedicated to fulfilling the special needs requirements for persons who want to travel but may need mobility aides, oxygen or other equipment.



We make travel easy, comfortable and accessible. Our trained delivery agents in 55 cities across 20 countries around the globe help us fulfill this

mission.

<http://www.specialneedsatsea.com/>



Sage Traveling is committed to providing customized accessible holiday travel for our clients. We make it our job to understand all the challenges that disabled travelers may encounter and how to overcome them. Sage Traveling offers comprehensive, detailed, and organized disabled travel information on accessible European tourist attractions, hotels, and transportation.

www.SageTraveling.com

Here are some useful information and recommendations from fellow travellers

Southland MS Society Holiday Home in Frankton



The holiday home is situated at 106 McBride Street, Frankton. It is close to the main road for bus services, airport, hospital. The home is about 1 km from Frankton's main shopping centre. There are concrete footpaths between the holiday home and shopping centre.

RATE: MS persons from outside Southland and disabled people from other organizations:

\$25.00 per night, Carer - \$5.00 per night

MS Southland members: \$20.00 per night, Carer - \$5.00 per night

All other adults \$30.00/night or \$120.00/night maximum. No charge for children

BOOKINGS AND ENQUIRIES:

Phone: (03) 218 3975 or (03) 218 4673

Kaikoura Holiday Home



Situated approximately 5 km from the centre of Kaikoura, 2 km from the beach, this fully self-contained studio unit has disabled friendly features including wet floor bathroom, handrails, flat access and room to move within the unit.

Situated on our 2 acre property, enjoy the peaceful rural views to Mt Fyffe and proximity to town, yet well within walking distance of the supermarket and beach.

RATE: \$125.00 per night (2 persons)

\$15.00 / night each extra person (Maximum of 4)

Minimum stay 2 nights

BOOKINGS AND ENQUIRIES:

Email: redbarn@xtra.co.nz

Phone: 027 497-2133

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Useful links for travel information in NZ

For more information about accessible holiday homes, places to visit and things to do in your region of choice for holidaying, good places to start are the local branches of:



<http://www.newzealand.com/int/visitor-information-centre/>



<http://nzfdic.org.nz/>



<http://www.doc.govt.nz/>



<http://www.ccsdisabilityaction.org.nz>

To hire equipment or check the services available in the area:



<http://www.weka.net.nz>



<http://www.aspirecanterbury.org.nz>



<http://wheeliesvanrentals.co.nz>

If you know other sources of useful information, please share those with us by emailing info@msnz.org.nz.

If you have used services that you want to recommend to others, we would love to hear from you as well. Thank you!

Touching MS *Poetic Expressions*

Seeds of Hope

Orange Cosmos, in all your glory
you hold your head high,
using your strength wisely,
gently with bugs, butterflies.

Your planting was on purpose,
a beautiful gift from afar.
Through your stem flows hope,
so confident you are.

Dew-kissed petals spun with lace
bathed in a yellow gleam.
Branches thick and far reaching,
send the stars our precious dreams.

Storms will pelt, rays will burn,
your focus may lean off track.
But you laugh at the rain, and from
the wind you always bounce back.

Let us pull out the weeds, carefully
tend to the garden's needs.
We must plan for tomorrow
when we sow more seeds.

© 2013 Jennifer Evans

You can read more poems written by Jennifer Evans and other people with MS or order the full collection @ www.touchingms.com

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Six Years On: The Silverlining In The MS Cloud



🍷 2007: The Dream. The Nightmare

I was dreaming that I couldn't roll over. Something was holding me down, something was terribly wrong. My anxiety penetrated my conscious. I realised I could feel my right side at all. I called out to my husband, Peter. In the darkness I felt, rather than saw Pete leaning over me, asking what was wrong. Thank goodness he was a light sleeper.

🍷 The Hospital: Escape Denied

At a loss of what to do, Pete phoned an ambulance.

The doctors in ED thought it could be a stroke, even though I didn't fit the profile – wrong age & gender, non-smoker. Until the blood clot was ruled out, I was sure I would never see my children again.

The frantic activity around me slowed, and I realised my toes could move just a little. Unfortunately my hopes of going home were dashed. Instead, I was formally admitted for testing.

The improvement was short lived and I was issued a walking frame and ordered to use it whenever I was out of bed.

Nothing in my life had prepared me for this. My childhood had been idyllic, and I had been a healthy child. I was only 34. It felt like my life was over.

🍷 Testing Begins

My first scheduled test was an MRI. I was feeling anxious about it, but it turned out it was the most peaceful I had felt since arriving in hospital.

The next procedure was a lumbar puncture.

I could feel the needle pushing into the bones of my spine, tapping the bone, and scraping along it.

After 10 excruciating minutes, the procedure was over. I felt so raw and violated.



Susan Kitson - a wife, a mum, an author of "In Search Of Health", a yoga teacher, a customer service manager... MS does not define her

🍷 The Diagnosis: MS

Two days later the neurologist came to show me the pictures of my brain. I had a number of lesions, which showed up as dark blotches on the MRI scans.

The lesions, combined with slightly elevated levels of protein in my spinal fluid, provided the diagnosis.

The doctor explained, "You are young and very likely to make a full recovery." Fear had been joined by something else – hope.

His advice allowed me to believe I could get

better. Without it I may not have embarked on the journey that brought me to where I am now. Words, especially from people in authority, are powerful and should be wielded with care.

With that, I was quickly discharged. I was certainly glad to see the back of the hospital.

A Holiday Before the Fear

The possibility of MS had been rattling round in my brain since our trip to Fiji two weeks earlier. It took me ages to complete the departure cards, as I could not connect my vision with my hand. Blaming the bright lighting I dismissed my difficulty and focused on the kids.

A few days later I began having problems with simple tasks such as buttering toast. The journal I wrote while away looked like it had been completed by a 5 year old.

Over a cocktail we had joked about the possibility of MS, never imagining that we could be right. All I knew about MS was what I had seen on TV or read in books.

Facing Reality: Learning to Walk

A walking frame was provided and physiotherapy appointments scheduled.

Walking from my bedroom to the kitchen would exhaust me to the extent that I would need to have a nap for a few hours.

I detest being helpless so I worked hard. She began to call me her star patient.

An occupational therapist was also assigned to me, a young girl. She set me my hardest task, that of using my right hand again. Placing Play-Doh in my palm I would attempt to squeeze it. Sweat would break out and I would have barely made an imprint.

The night I peeled the potatoes for dinner was a huge for me – it had taken me half an hour, but I had done it all on my own without ‘cheating’ with my left hand.

The Road to Health

We employed a nanny and the children were finally able to come home.

It was both lovely and difficult to have the kids back, and made me even more determined to get better.

Within a month I was driving again. Oh the sweet relief of being able to move around under my own steam

The research I was undertaking on MS was very depressing and I realised I was looking in the wrong place for the right answers.

Placing a ban on ‘negative’ research I started to explore how to become healthy.

Starting with yoga, along with physiotherapy, my manual dexterity continued to improve. I explored different ways of eating and living, and discovered it is possible to bring back the vitality to your mind, body, and soul.

I have learned a lot about being grateful over the last five years and I continue to be amazed and appreciative of my husband’s ability to see past the bad times and know that good times will return.

Namaste (the light in me recognises the light in you)

Susan 

Susan’s story first appeared in Australian Woman’s Weekly New Zealand edition in their September Issue as part of our Awareness Week campaign.

You can read more about Susan’s experiences in her blog posts on www.msnz.org.nz where she talks about coming to terms with her diagnosis and rebuilding her life:

<http://bit.ly/18NCm1C>

And, of course, huge thank you to Robyn Coyle from Hawkes Bay MS Society for putting us in touch with Susan and making those articles possible.

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Drinking your nutrients is a great way to have them absorbed into your body without much effort by your digestive system. Juicing or blending food breaks the molecules down into tiny bits, which means much of your bodies digestive work is done already. I aim to drink some nutrients most days.

Since introducing these delicious smoothies into my daily eating routine I have experienced a heightened immunity and increased energy levels.

Green leafy vegetables are a great source of iron and vitamin C. Iron, specifically non-heme iron found in the plant world, requires Vitamin C to enable it to be fully absorbed. Green leafy vegetables are perfectly positioned to provide the Vitamin C necessary for the iron absorption.

The high levels of Vitamin C will boost your immune system and drinking a Green Garden Smoothie makes it possible to consume sufficient green leafy vegetables to beneficially increase iron levels.

Green Garden Smoothie

SERVES 2-3

Ingredients

6-9 large leaves of silverbeet (chard), spinach, kale, or cavalo nero (approx 2 cups, chopped)

1 peeled lemon

1 pear or apple

2 cups fresh water

Optional Extras: Chia seeds, cinnamon, cocoa, coconut oil, Tahini, ginger root, ground flax seed, parsley, sprouts, or anything else tasty and delicious you would like to include.

Method

1. Use organic produce where possible.
2. Wash and roughly chop everything. The more industrial the blender the less the ingredients will need to be chopped.
3. Blend together thoroughly and enjoy.

Excess can be refrigerated and consumed over the next 24-48 hours. If the flavour is too strongly green vegetable tasting, try adding less green leaves and more fruit. Gradually add less fruit and more green leafy vegetables each time it is made.

For children, start with one leaf of silverbeet or spinach and three pieces of fruit (apple, pear, orange, banana, kiwifruit). Each time you give it to them, increase the quantity of leafy greens. Eventually they will be drinking the same as you.

Mix up the type of leaves you use as different leafy greens have slightly different Vitamin and mineral contents.

Silverbeet is one of the easiest year round vegetables to grow, and what could be better than home grown vegetables picked just before you consume them?

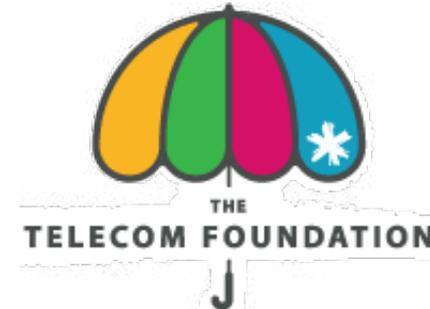
Enjoy!

Susan 

You can find Susan's book **In Search of Health – 21 Steps to Glowing Health** on [Amazon.com](https://www.amazon.com)

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