

# multiple news

*The bi-monthly newsletter from Multiple Sclerosis Auckland*

## Kiss Goodbye to MS



## BDO W2A CYCLE CHALLENGE 2015

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# A few words from the CEO...

We are off to a busy start and holidays seem like a life time ago! Multiple Sclerosis celebrates turning 50 this year and to be very precise – on 5th March 2015. What an incredible journey it has been and continues to be. After receiving a special grant from the Lotteries Commission, we have engaged the services of historian writer Ruth Greenway to record the history of our Society which will be available on our website later in the year. If you have a great recall of our 50 years or know someone else who does, please contact the office and let us know. We have compiled a list of people to interview however we are very likely to miss someone important off our list, so your help would really be appreciated.



Last year we said goodbye to Pam Smith and last month we welcomed Gabrielle McNaughten to our Team. Gabes is currently under a three month contract with us, however has already proved to be 'awesome' and we hope we don't lose her. Our event systems have never looked so good. Gabes comes from an extensive career of organising events both in the corporate world and with many charities, so she knows how we operate.

Nicholas Kearns from Auckland Council contacted us at the beginning of this year to introduce us to his fundraising initiative **Lift Free February**. Nick has an uncle, a nephew and a friend that have MS and he wanted to raise awareness and funds for us – hopefully on an annual basis.

See the article later in this edition about how **HUNCH, HELL and MS Auckland won Gold** in the New Zealand Post Direct Marketing Awards. It was certainly a really innovative way to create awareness about Multiple Sclerosis.

In this edition we are giving People with MS an opportunity to sail around Auckland Harbour on **Oceans of Hope**. Please register your interest immediately as numbers will be limited.

You will also read later in this publication how we have spaces available for children of a parent with MS that would like to go away at Easter time on a camp. We were very fortunate to be chosen by Auckland Airport as a Charity they wanted to help which involved giving parents a rest and children some fun. You may have seen the article in the New Zealand Herald last December. If not you can see it here [http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11376468](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11376468)

We have planned many ways to celebrate our 50th this year and we hope you will partake in some of the activities scheduled (see details later in the issue).

Please mark your diaries:

AGM	Wednesday 15th April, 7.30 at MS Auckland offices
Oceans of Hope	6th – 12th May
Research Day	Saturday 16th May
Life Buoy for MS	Friday 26th June
Street Appeal	4th & 5th September
Bike the Bridge	Sunday 15th November

This issue is packed with news on upcoming events, the latest research and a great 'read' in our library. Grab a cup of tea, put your feet up and enjoy Multiple News...

THÉRÈSE RUSSEL  
Chief Executive Officer

## DISCLAIMER

Please don't rely on the information in these pages to imply any diagnosis or course of treatment. 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 MS Auckland. Any research, study, clinical trial, event, news or other item included in Multiple News 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, MS Auckland disclaims any implied guarantee about the accuracy, completeness, timeliness or relevance of any information.

**ms.**  
Multiple Sclerosis  
AUCKLAND

# Notice Board

## Smart Phone App

I came across a smart phone app that I found quite useful as a resource. Here is a link [https://play.google.com/store/apps/details?id=com.bbi.national\\_multiple\\_sclerosis\\_society&hl=en](https://play.google.com/store/apps/details?id=com.bbi.national_multiple_sclerosis_society&hl=en). It is easy to install and operate although some content is US specific. It might be of interest to some people in the MS community.

Regards, Klaus Benz,  
MSAkl member

## Happy 50th Birthday MS Auckland

Please join us in the many celebrations we have planned this year to honour turning 50 on 5th March. Events are advertised in this publication. 2015... something to be really proud of!

## DREAMs

Do you have a reasonable "Dream"? Tell us about it and we will see if we can make it happen. No promises and don't make it huge. Email [therese@msakl.org.nz](mailto:therese@msakl.org.nz) or phone 845 5921.

## Honorary Life Members

Always appreciated,  
never forgotten

David Ashton  
Jo Smith  
Ken Wadham  
Judy Wear  
Tina French  
Barbara Broome  
Nancy Caughie  
Judith and Rob Linton  
Bruce Cameron  
Ken Hall

## Calendar

## Important dates to remember...

**5th March**

**MS Auckland's  
50th Birthday**

**7th March**

**The Amazing Race**

(see details later  
in this issue)

**15th April**

**AGM**

7.30pm at the offices of  
MS Auckland, Mayfield  
Centre, 5 Mayfield Road,  
Glenfield

**16th April**

**Conversations That  
Count Day**

(see MS Nurses article)

**6th-12th May**

**Oceans of Hope  
Yacht in Auckland**

(see details later  
in this issue)

**16th May**

**Research Day at  
Alexandra Racepark**

(see details later  
in this issue)

**26th June**

**Life Buoy for  
MS Charity Luncheon**

## From the field...

## Our Field Workers



Diane Hampton, North Shore



Carol Andrews, Central



Georga Forgac, West



Dianne Bartlett, South

**N**ero Rehab Results (a private practice specialising in Neurological Rehabilitation) are currently running a Balance-Fit class and a Move it class, on the North Shore (where they are based), for people with Neurological conditions, including Parkinsons and MS.

The Balance-Fit class focuses on strength, balance and flexibility. You can find further information on these classes on their website at [www.neurorehab.co.nz](http://www.neurorehab.co.nz)

A reminder too, about our Support/Coffee Groups which are held once a month throughout the Auckland area. There are 13 groups in total.

**What is a Support Group?** A gathering, where people experiencing similar problems or life transitions come together to offer each other support and encouragement.

**Benefits of Support Groups:** Regardless of format, in a support group, you will find people with problems similar to yours. People can share their personal experiences and offer one another emotional comfort and moral support. They may also offer practical advice and tips to help you cope with your situation.

### Benefits may include:

- Feeling less lonely and isolated
  - Improving your coping skills and sense of judgement
  - Talking openly and honestly about your feelings
  - Getting practical advice or information about treatment options
  - Comparing notes about resources, such as doctors and alternative options.
  - Forming new friendships
  - Just enjoying a cuppa and a chat with like minded people
- Partners, family and friends are welcome to attend these groups. By attending, they may learn how to be more understanding and supportive.

**If you would like further information about these groups, please contact your Field Worker, 09 845 5921**

Remember, you do not have to wait for us to contact you we are just at the end of the phone so please call us if you have any queries or just want to have a chat.

*Take care, from Carol, Diane, Georga and Dianne*

## Rope Neuro Rehabilitation

**R**ope Neuro Rehabilitation is excited to present to you Online Neuro Physio; an online hub where you can access 1:1 client consultations and condition specific educational Webinars all lead by the Physiotherapists from Rope Neuro Rehab and in the comfort of your own home.

Our First Webinar is 'Fatigue Management in Multiple Sclerosis' where we explore the fundamental principles of fatigue management. By the end of the Webinar you will be able to differentiate between mental and physical fatigue, know the primary and secondary causes, know the basics of resting, including preventative resting, being energy efficient and have access to tips and tricks from other people with MS.

The best tool to manage fatigue is knowledge. Don't underestimate the power that small changes can make to your everyday life and fatigue levels.

To sign up for this WEBINAR head to [www.onlineneurophysio.co.nz](http://www.onlineneurophysio.co.nz) to reserve your spot! (under neuro education)



**Tuesday 17th of March 2015 10.00am-11.30am OR 7.00pm-8.30pm**

**Cost: \$40**

On another note, welcome back to all the pool groups, and a special welcome to all of our new hydro members!! We hope that you are getting back into the swing of your exercise timetable. It will be time for some outcome measure testing in the next couple of months, so keep going to the pool regularly to keep those endurance levels up! All pool groups have returned to normal times, please contact your physiotherapist if you have any questions.

*Stephanie, Julie, Sarah, Jess and Alisha*

*[Stephanie@ropeneurorehab.co.nz](mailto:Stephanie@ropeneurorehab.co.nz) 021 109 947*

## From the MS Nurses

### Conversations that Count Day is April 16th 2015

*Many of you will be encouraged to learn that we at the hospital and those at PHARMAC have nearly processed the initial deluge of referrals for the new MS medicines.*

*It is still an exceedingly busy time, however the robust systems that we have developed to ensure patient safety on these medicines are now in place. I am sure you will agree that it is better to ensure these cornerstones are laid before rushing people onto new medicines.*

*Our thanks to those of you who have been or are currently going through the approval and screening process, for your patience and understanding.*

*We recognise that it is frustrating to know a treatment is available and to not be able to start it immediately.*

*We are finding our response time to your emails and phone calls is slower than usual which we hope will not be a long term concern however if you have called or emailed and have not had a response please make contact again.*

#### CONVERSATIONS THAT COUNT DAY

Talking about death and dying is hard. Most of us will not die suddenly. We all potentially have lots of time to think, talk and plan for our future and end of life care. Yet for most families this conversation does not happen, or if it does, then only when someone is very unwell. Many people don't spend their last weeks and months doing what they value in a place they call home. They are undergoing treatments they would not have chosen given the choice, away from their homes in a hospital or high care facility, isolated from their families by visiting hours or distance.



Many don't get to say what they want to the important people in their lives, don't get to say I love you, thank you, sorry and goodbye.

Advance Care Planning helps us think about and share what is important, it helps us think about and plan what treatments we do and don't want, it helps us clarify how we want to be cared for as we approach the end of our lives.

This year 16th April will be **Conversations that Count Day**, a national initiative led by a co-operative of hundreds of people across New Zealand's health system that is encouraging us to have a 'Conversation that Counts'. That is, talk to those we care about and with those who will care for us as the end approaches about what we would want for ourselves.

The theme will be 'Start a Conversation'. The aim is to encourage people to start having conversations with their family, friends and wider social networks. The hope is that people feel confident to start conversations about what matters to them and what care and treatment they would want in the future. Visit the website at [www.conversationthatcount.org.nz](http://www.conversationthatcount.org.nz) to find out more, download the poster or email one of our postcards to someone you care about to help to get the ball rolling.

To find out more about Advance Care Planning, access our e-Learning modules or watch the moving and very informative film *Living for Today, Planning for Tomorrow*, visit [www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz).

*Take care and all the best from Fiona and Nazila  
09 307 4949 ext 25885*

## Donations

### Regular Monthly Donors

**January and February winners were David and Gay Compton and they donated the winnings back to the Society. We are so grateful and value their continued support.**

Our objective is to increase our regular donors list and our monthly earnings, so if you are keen to be a donor, please call the office. It is a great way for your friends and family to support your Society and the donation can be \$10.00 or more (the cost of two cups of coffee).

**Please phone Kirsty on 09 845 5921 to register as a Regular Monthly donor.**

### Please join us on Facebook

Please go to [www.msaki.org.nz](http://www.msaki.org.nz) and like our Facebook page. We regularly post up to date MS information and news so that you are in the know!

It was only two weeks ago we had 465 followers and since our new postings we now have 2,500 followers. So don't be misinformed or miss out – simply 'like' our page.



## Recipe Hummingbird Cake

**Serves 4 to 6**

### Ingredients

- 2 cups self raising flour (can use half white and half wholemeal)
- 2 egg whites
- 1/3 cup sugar
- 1/2 cup apple puree
- 1 teaspoon bi-carb soda
- 3/4 cup drained canned crushed pineapple (in natural juice)
- 1 cup mashed banana
- 1/4 cup (25g) walnuts - chopped
- 1 teaspoon mixed spice

### Method

Keeping the juice for the icing if you wish. In a large mixing bowl beat egg whites and sugar for 1 minute using an electric beater. Stir bi-carb into apple sauce (it will froth up) and add to bowl. Mix in mashed banana, walnuts, drained pineapple and mixed spice. Blend ingredients together well. Gently fold into mixture in one go. DO NOT



BEAT as this will make the cake tough. Pour mixture into a round 19 cm cake tin that has been lined with baking paper. Bake for 35 - 40 minutes or until firm to touch in centre. Allow cake to sit for 5 minutes in tin before turning out onto a wire rack to cool. Ice if you wish to.

**Sandra Perry** Dip.Nutrition  
Nutritionist



55 Bushlands Park Drive Albany 0632  
p: 09 415 2676 m: 021 1546999 e: nutrition360@clear.net.nz

## Carers' Corner Carer Support

If you're the unpaid full-time carer of a disabled person, then Carer Support is available for you.

Carer Support provides reimbursement of some of the costs of using a support person to care and support a disabled person. This means you can take some time out for yourself.

A full-time carer is the person who provides more than four hours per day unpaid care to a disabled person, for example the parent of a disabled child.

Carer Support is a subsidy funded by the Ministry of Health. The number of hours or days that carer support is funded for depends on your needs and those of the person you care for.

### Getting Carer Support

You can be assessed by a Needs Assessment Service Coordination organisation (NASC) or, in some circumstances, by a doctor. They will then allocate your Carer Support days and undertake a review with you, usually after a year.

You can find out more about claiming Carer Support by reading the pamphlet How to Claim Carer Support (PDF, 93 KB). You can also see a sample copy of the Carer Support Claim Form (1.4 MB). Talk to your local NASC to find out more.

### Who can provide support care

Carer Support is designed to be flexible. You can use it to pay:

- Friends, some family members or neighbours who provide relief care
- People who provide relief care in a formal setting, for example a rest home.

### Carer Support cannot be used:

- While the full-time carer is at work
- To pay a parent or partner of the disabled person
- While the disabled person is in hospital
- To pay a carer who lives at the same address as the full-time carer.

If you're unsure about how you can use your Carer Support, please contact the person or agency who has allocated your carer support.

### What are Carer Support payments regarded as?

Carer Support payments may be subject to income tax. This will depend on your individual circumstances. You may wish to seek advice regarding tax issues from the Inland Revenue Department or, if you receive a benefit, from Work and Income New Zealand.

**Source:** Ministry of Health Website <http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respite-and-carer-support/carers-support>

*People need to be assessed by a Needs Assessment Coordination Organisation (NASC) which will be either Taikura Trust or Older Adults Health Services (DHB's) for People with MS. Your Field Worker may be able to advise you, so please contact her.*

**NEW**



# Invacare "Alber Twion"



**Twion power assist offers new freedom and maximum independence.**



The electric motors equipped with leading-edge digital electronics provide you with extra power for every propelling movement. The sensor fitted to the hand rim calculates precisely the right amount of support.

The silent direct drive ensures high agility and simple handling. You are actively on the move and reach your destination quickly, efficiently and calmly.



## Lightweight

In the selection of materials, particular attention was focused on weight. High-tensile aluminium alloys, high-tech plastics and the latest digital motor technology have been used.



## BlueDrive

The innovative BlueDrive function allows wheelchairs equipped with twion drive wheels to be remotely controlled by Smartphone\*



## Efficient energy recovery

The efficient energy recovery system feeds energy back into the batteries during braking, providing a 10% range extension for greater freedom.

\* For safety reasons, the BlueDrive function may only be used without wheelchair occupants for free wheelchair positioning.



0800 INVACARE | [www.invacare.co.nz](http://www.invacare.co.nz)



**Yes, you can.**

MS Members and Volunteers had a real treat at our Christmas Lunch last year. We were entertained by the simply amazing **Frances McDonald and Friends**.

They were the highlight of the day and everyone enjoyed their performance. If you have an event coming up and you need a very professional band then go to their Facebook page <https://www.facebook.com/pages/Frances-McDonald-Friends/475063615963360>

I promise you, you won't be disappointed.

Thanks so much to the band and maybe we can book you in again next year!

Members, volunteers, our Ambassadors and staff enjoyed a fabulous lunch at the Commerce Club in Remuera to celebrate Christmas (a distant memory now) and were spoilt with fabulous company, food, raffle prizes and outstanding entertainment.



Our entertainment – Frances McDonald and Friends



Our Ambassadors, John and Lorraine Street



Honourary Life Member, Nancy Caughie



Members with Field Worker Carol Andrews



## Events

# Oceans of Hope (OOH)

The Sailing Sclerosis project, **Oceans of Hope (OOH)**, will change the perception of multiple sclerosis by showing what is possible when people with a chronic disease are empowered to conquer their individual challenges, by engaging those whose lives are touched by MS and developing networks as a foundation for life changing behaviours.

This project aims to broaden the horizons of those who perceive themselves as trapped by their condition, either physically or mentally, and inspire them to realise that they still have potential to achieve great things.

*Go to this link to see what OOH is all about: <http://www.sailing-sclerosis.org/oceans-of-hope/about-oceans-of-hope/>*



## YOUR CHANCE TO SAIL AROUND AUCKLAND HARBOUR

We are delighted to announce that Oceans of Hope will sail into Auckland city during May and be stationed here for six days. Oceans of Hope in conjunction with MS Auckland would like to give you the opportunity to crew this yacht for special sailings around Auckland Harbour. No experience is necessary and the vessel is wheelchair friendly. This is your chance for an experience of a life time. Email [therese@msakl.org.nz](mailto:therese@msakl.org.nz) and advise her that you are interested.

## NOW FULLY FUNDED HELP STAY ACTIVE<sup>1</sup>

TYSABRI is indicated and now fully funded for the treatment of relapsing remitting forms of multiple sclerosis (MS) to slow the progression of physical disability and reduce the frequency of relapse in patients who meet the Special Authority criteria.<sup>1,2</sup>

**TYSABRI**  
(natalizumab)

TYSABRI® is a Prescription Medicine containing natalizumab 300mg/15mL in a sterile single use vial for IV infusion. Approved Use: TYSABRI is used for the treatment of patients with relapsing remitting multiple sclerosis (MS) to delay the progression of physical disability and reduce the frequency of relapse. Do not use if you are being treated with an interferon or glatiramer acetate. Like all medicines, TYSABRI has risks and benefits. Ask your doctor if TYSABRI is right for you. If your symptoms continue or you have side effects, see your doctor, MS nurse or other health professional. Side Effects: There have been reports of a rare brain infection called progressive multifocal leucoencephalopathy (PML) occurring in patients who have been given TYSABRI. PML is a serious condition and can cause severe disability or even death. The risk of PML increases the longer you are on treatment, especially beyond 2 years. Common side effects include: pain or stinging when passing urine, sore throat, runny or blocked up nose, shivering, itchy rash (hives), headache, dizziness, nausea, vomiting, joint pain, fever, tiredness. Serious side effects include: signs of an infection, psychological or intellectual changes, yellowing of the skin or eyes, signs of a severe allergic reaction, difficulty breathing or chest pain. Serious side effects are rare. Further Information: For further information see the TYSABRI Consumer Medicine Information available at [www.medsafe.govt.nz](http://www.medsafe.govt.nz) or by calling 0800 852 289. Biogen Idec NZ Ltd, 54 Carbine Road, Mt Wellington, Auckland. Revision Date: Oct 2014. TYSABRI is a funded medicine – a prescription charge and Special Authority criteria will apply.

**References:** 1. TYSABRI® (natalizumab) Data Sheet (Date of Preparation 24 March 2014). 2. PHARMAC - [www.pharmac.health.nz/news/notification-2014-10-10-mstreatments/](http://www.pharmac.health.nz/news/notification-2014-10-10-mstreatments/) Accessed 13th October 2014.

**biogen idec**

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# LIFE BUOY FOR MS

MS AUCKLAND 50th ANNIVERSARY 1965-2015



**TIME:** 12.00PM - 4.00PM

**VENUE:** Royal New Zealand  
Yacht Squadron  
Westhaven Marina  
AUCKLAND

**TICKETS:** \$200.00 per ticket  
\$1,500.00 table (10 pax)

*For more information please  
Phone: Gabrielle on 09 845 5921 OR  
Email: [Gabrielle@msakl.org.nz](mailto:Gabrielle@msakl.org.nz)*

## good sorts TEA PARTY

It's **SIMPLE** and  
it's **EASY** and we will  
**HELP YOU**



All **YOU** need to  
do is **HOST** a  
**TEA PARTY**

Make it a morning, afternoon or evening Tea Party, depending on what you and your friends like to do. The options are endless!

We will supply you with a Good Sort kit including; plunger coffee from Columbus, a raffle, an MS apron for the hostess & some recipe ideas to get you going.

*If you would like to become an MS Good Sort  
and host a Tea Party - please contact:  
Gabrielle on 09 845 5921 OR [gabrielle@msakl.org.nz](mailto:gabrielle@msakl.org.nz)*

# Nick steps up for MS

Nick Kearns will be thinking twice before buying lunch at work next month. His pledge to ditch the lift in favour of the stairs will have him trekking up and down 390 steps to his 26th floor office as part of **Lift-Free February**.

The Titirangi resident works in the Auckland Council building, formerly the ASB Tower, and is taking part in the fundraising initiative to raise money for Multiple Sclerosis Auckland.

"I should give the credit to my wife actually," he says, "It occurred to us that there must be a way to maximise the utility of that iconic building and to raise funds for a cause that is close to my heart," Kearns' uncle has advanced MS and his cousin was diagnosed with a neurological condition in his late 20s. His uncle and cousin both live in Ireland but Kearns says the situation in New Zealand is not too dissimilar.

"We have a history of neurological conditions in the family and seeing the level of support people with MS get, I think we can do better," he says. "If we can build a bit of groundswell this year and raise the profile of the work MS Auckland does and help their efforts, I'd be pretty happy with that."

The father of three will have completed around 31,000 steps by the end of February. "It's amazing how many people say 'where is the stairwell?'" he says. "I've also found a lot of people saying MS is close to their hearts too."

A lot of people are indirectly or directly affected by MS. "It's great, we can band together as a sort of little community and show our support to all those people living with MS." MS Auckland chief executive Thérèse Russel says there are around 1000 people living with the condition in the region. "You don't only deal with the people with MS, you deal with their families and their carers," she says. "What Nick is doing for us is just so invaluable. We need good initiatives like this to help us with fundraising. MS Auckland receives 8 per cent of its funding from the Government, which is around \$58,000, with the rest coming from grants, bequests, donations and its own fundraising."



Nicholas Kearns, Jordon Milroy and Deputy Mayor Hulse



Nick and Jordon

Jordon then went on to climb Melbourne's tallest building (1800 steps). Jordon has the climbing bug now and intends to travel the world climbing the tallest buildings as he goes. Jordon helped raise \$350 when he walked the 26 floors in Nick's building with lots of support and cheering as he achieved yet another milestone in his 'climb for life' goals.

The month of February has now come to an end and Nick's **Lift Free February** campaign has raised an amazing \$2,134. Nick is fitter and slimmer for partaking in this innovative fundraiser and when asked this morning 'how was the lift', he replied "it is absolutely wonderful not to feel sweaty and flustered on a Monday morning"! Well done Nick and a big pat on your back for raising funds for MS Auckland. We look forward to working with you next February and raising more awareness and money.



Jordon surrounded by Auckland Council staff



"We don't waste any of our money. We operate out of very small premises so when people raise money for us it does go straight back into providing services and benefits for MS." Kearns approached MS Auckland with the idea of **Lift Free February**.

The idea has already been pitched to other regions around the country and the response has been overwhelmingly positive. "It would be fantastic if next year the other regions picked it up so we will take our learnings out of this year and see what happens," Kearns says.

The event comes just before MS Auckland celebrates its 50th anniversary of helping people with the condition. Visit [givealittle.co.nz/event/liftfreefeb](http://givealittle.co.nz/event/liftfreefeb) to become a fundraiser or to donate. The page will remain open so that people can still donate in March.

Nick was lucky enough to have some serious support from Jordon Milroy. Jordon who was born with Cerebral Palsy (CP) and wanted to set himself a personal challenge of climbing the Auckland Sky Tower (1029 steps) and then bungee jump off the top, which he achieved in 2012. Jordon's aim was to bring awareness to being physically disabled but not weak!

Our special thanks goes to BDO for another successful Wellington to Auckland Cycle Challenge organised by Dynamo Events. MS New Zealand was the chosen charity of BDO's event and we were extremely grateful for this opportunity. BDO (Accountants) are very special partners of MS and they have created great awareness for Multiple Sclerosis throughout the North Island thanks to this event.

As you could imagine this challenge is not for the faint hearted and the stars of the cycle challenge had to be our very own team **KISS GOODBYE TO MS** (KGBTMS). Our amazing cyclists were Tim Jones, Mark Gray and his son Taylor Gray and his wife Suzanah Gray, Adam Clark, Geoff and Hillary Currie, and Russell Watts (Person with MS).

The Society's president, Neil Woodhams, shepherded the team on the week-long trip from Wellington. Following are brief extracts from the colourful email reports Neil sent out to friends and supporters at the end of each day's long ride:

Travelling south, I picked up Russell Watts in Taupo. It was good to meet him and to discuss his journey with traumatic brain injury and then being diagnosed with MS. The previous six days Russell had been tramping in the Kaweka Ranges. To meet me he had left his group and completed a three-day tramp in two days. His determination and drive never ceased to amaze me.

**DAY ONE:** An early start! We eventually got everyone to the start line on time and all the gear in the car. Just as well I wasn't needed to take any passengers because the boot, the whole of the back seat and the passenger seat were all packed with the team's gear.

The weather in Wellington was miserable. The climb to the top of the Rimutakas was cold and wet and by the time the team got to Featherston everyone was very cold. We came fourth out of eight teams and Hillary was the

fastest woman. The afternoon ride was in slightly better conditions, but it still rained. I realised that in all my efforts to get everyone to the start line on time with all the right clothes, I had left my computer in my room, so I made a

quick return trip to Lower Hutt. This meant I missed the finish in Masterton, but Hillary Currie was the first woman home again.

I note we have now raised \$10,000 on the Everyday Hero website (EDH).

**DAY TWO:** The ride from Masterton to Paihia is one of the longest, about 75km, and unfortunately two of our best riders had punctures and were effectively out of the running. Russell Watts stepped up and finished fourth with the rest of the bunch – a truly courageous ride. At lunch there was a furious effort of swapping wheels and tyres and a trip to the bike mechanic to get ready for the 35km ride from Paihia to Palmerston North, over the Paihia Track. I'm glad I was driving! The hills were steep and the road winding. The team finished really well, fourth or fifth.

The corporate teams are fiercely competitive, especially as both 2 Degrees and ASB have two teams each, and the competition between the two teams internally is as fierce as the competition with the rest of the field.

I see the funding on the EDH page has now exceeded \$12,000. The team talks about how much money they have

raised all the time and every time they get an email saying they have another donation there is great excitement in the camp.

**DAY THREE:** The stop at Huntville is outside the local primary school and we had use of their facilities, as well as the PTA putting on a barbeque for the riders and supporters. The race was a bit of a triumph for us. Mark



Gray was second home. He was clocked at 85kph going down one of the hills. His sister Hillary was again the first woman home, by a country mile. Both of them are unbelievably competitive.

The afternoon was more problematic. Mark missed the start, answering the call of nature, and things went downhill a bit from there on. Russell blew a tyre, along with about five others, so there was a long wait for assistance. He turned up tired and frustrated. I was really pleased to meet three of the Whanganui MS team at the finish – the president, office manager and field worker. They looked great in their orange volunteer tee shirts. The team really appreciated it.

**DAY FOUR:** After packing the car, I noticed one of my rear tyres was almost flat. Three garages later, I found one with a working pump and an emergency tyre kit in case it went flat before Ohakune. I was then tasked with finding another jar of high powered recovery food, but obviously life in Whanganui is such that it is not needed, as the bike shop and two gyms did not stock anything remotely like what I was looking for.

Up the Paraparas they go! I knew the team would be hot and tired when they arrived for lunch. We stopped at a little school where this day is their major fundraiser and the whole community brings a plate and pitches in. The team, were able to wade in the swimming pool to cool off, which was appreciated. Tempers were getting frayed over the tactics of some of the other teams and apparently words were spoken. Not sure what the problems were, but they included blocking our team at times and physically pushing riders up the hill to conserve energy for the ride home!!

Last night the prize giving and auction was at the local rugby club. The auction raised about \$3300 and the raffle

\$1095. The mobile EFTPOS machine worked a treat.

**DAY FIVE:** A great day in every way. The weather was glorious and the drive around the mountain to Turangi provided great sights of the mountains. It's a reasonable

ride as there is more descending than climbing. The long descent into Turangi saw some high speeds generated. Two Turangi PwMS met us during the lunch break – as there are only three PwMS in Turangi, a 66% turnout was the best so far. The afternoon stage was a team time trial. Our team decided that as Taupo is Russell's home town they would all support him and finish as a team of six.

This meant some of them waiting for Russell at the top of the Hatepe hill and then all riding together. There were earthworks at the bottom of the hill, with one rider getting badly cut in a crash and being carted off to Waikato Hospital and one rider not finishing – the first incidents of this nature so far. Our team maintained sixth place.

I see on the website we have now raised over \$15,000 and closing in on our budget of \$20,000.

**DAYS SIX AND SEVEN:** The ride from Taupo was over 120km. Next year it would be great if MS Rotorua and Waikato could man a drinks station at the 65km mark, as several riders arrived in Te Awamutu dehydrated. The team decided before the start to release Adam from any responsibility of getting the fourth rider over the line, as he had been steering the team and had not had a chance to

stretch his legs. So he and an ASB rider broke away after only about 5km and rode the whole leg as a two. In the end he was just beaten at the post by about half a wheel. A truly magnificent feat of stamina and power. The rest of the team rode well, however were very glad there was no afternoon stage. Dynamo [the event organisers] and BDO



## Events Kiss Goodbye to MS

supplied a barbeque at the end with a gold coin donation to MS. We raised nearly \$500.

At the end of the stage the riders had a 35km ride to the hotel in Hamilton. We had a team dinner at a great restaurant near the river.

The riders set off at 8 o'clock from the centre of Hamilton. When the first of the riders came in to the Glen Murray Community Centre they reported that Tim Jones (Novartis and our team captain) had had an attack of severe kidney pain and pulled out at Huntly. He was picked up by the first aid van that accompanies the riders. Hillary, the GP in our team, swung into action and provided first class care. Tim went off to Auckland Hospital in my car and I cadged a ride to the finish from another supporter. This meant Taylor Gray, who had been riding as an individual to get fit, swapped into the team event as our fifth rider.

While all this was going on I managed to catch up with Bindi Ground who I had noticed was raising funds for us. He is a pig farmer from Pirongia, out of Hamilton and a client of ASB, so he was riding in their colours. He has two friends with MS and was doing the ride as part of his therapy to stop smoking. He had challenged 20 of his friends to sponsor him. His funding page should top out at over \$3200 before it closes.

Once again we gave Adam the freedom to ride out in front and see what he could do. It was a thrill to see the KGBTMS jersey sweep down the road at the finish second once again. Even better was to see Taylor, who had been having fun all tour riding out the back with a group of three riders, come in ahead of both his father and uncle. We have already booked him for next year!



It was great to have the support of the MS Auckland team at the finish and I know the riders really appreciated it. Helena Watts, Russell's wife, had driven up from Taupo to see him come over the line. An awesome effort. Russell is a great example of living life with a disability to the full. He finished every stage of the event and was always competitive, never finishing at the tail of the corporate teams.

If you want to read an excellent account of the ride from a rider's point of view and see some great photos, go to Tim Jones's website and scroll down – <http://bdowellingtontoauckland2015.everydayhero.com/nz/tim>.

I've spoken to Tim this morning. He is at home having passed a large kidney stone into his bladder. He was a bit the worse for wear but incredibly grateful for the help and support he received.

At this stage the overall funds raised looks something like:

Everyday Hero	\$17,928.75
Auction	\$3200.00
Raffle	\$1035.00
Barbeque	\$500.00
<b>Preliminary total:</b>	<b>\$22,663.75</b>

A special mention must go to our top fundraisers for this event, Bill Fowler and Doug Haines – thank you so much for your great efforts here, you both did incredibly well. Check out how much everyone raised by going to this link: [http://www.everydayhero.co.nz/event/BDOWellingtontoAuckland2015/top\\_ten](http://www.everydayhero.co.nz/event/BDOWellingtontoAuckland2015/top_ten)

A fantastic result and the Society thanks everyone involved in this exciting event. I would be fairly confident that our KGBTMS team rested for a couple of days before getting into training for next year's BDO W2A Cycle Challenge.



# Free Camps for Children of a Parent with MS

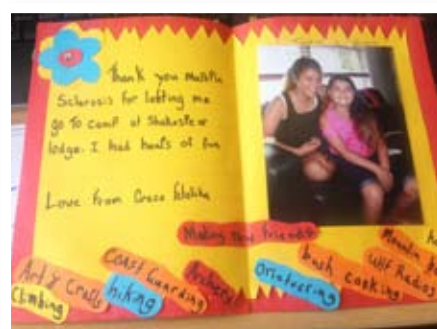
We would like to offer parents a wee break and your children a bit of fun. We were the lucky recipients of a grant from Auckland Airport to send some of our children to camp.

The flyer outlines where and when and the age ranges for each camp.

We want to send your child/children away at Easter and if you would like to know more about this fantastic opportunity please email [therese@msakl.org.nz](mailto:therese@msakl.org.nz) and we can register your child/children, without it costing you a cent.

We are so grateful to Auckland Airport.

The photos and comments are from children that attended at Christmas time.



**Easter Holiday Camp**

**Auckland Airport** **YMCA** **ms. Multiple Sclerosis AUCKLAND**

Discover Outdoors  
Age: 9-11 yrs  
YMCA Shakespear Lodge  
7 to 10 April 2015  
Tue 2pm – Fri 3.30pm

Jump Outdoors  
Age: 6-8 yrs  
YMCA Shakespear Lodge  
7 to 10 April 2015  
Tue 2pm – Fri 3.30pm

Ultimate Adventurers  
Residential Camp  
Age: 11 to 13 Yrs  
YMCA Camp Adair  
7 to 10 April  
Tue 4pm – Fri 12pm

Young Adventurers  
Age: 8 to 10 Yrs  
YMCA Camp Adair  
7 to 10 April  
Tues 4pm – Fri 12pm

Discover Outdoors  
Age: 9-11 yrs  
YMCA Shakespear Lodge  
12 to 17 April 2015  
Sun 2pm – Fri 3.30pm

Outdoor Adventure  
Age: 12-14 yrs  
YMCA Shakespear Lodge  
12 to 17 April 2015  
Sun 2pm – Fri 3.30pm

Ultimate Adventurers  
Age: 11-13 yrs  
YMCA Camp Adair  
12 to 17 April 2015  
Sun 4pm – Fri 3.30pm

Young Adventurers  
Age: 8-10 yrs  
YMCA Camp Adair  
12 to 17 April 2015  
Sun 4pm – Fri 12pm

If you are interested  
in any of the camps  
please contact  
MS Auckland  
on 09 845 5921

Hi Therese

I am writing to say a very sincere thank you... My two boys had such a fantastic time at Camp Adire. This opportunity to have some time out for all of us was an awesome start to the year. My boys were able to experience things I am just not capable to do with them anymore without their worrying about me. A week with no worrying if mum needs quiet, a week when they could just be teenage boys...

From the bottom of my heart,  
thank you!

*Leda Waite*

**Auckland Airport**

## Events

## Research Day

This year we are conducting our Research Day independent of our AGM (see details of AGM on the calendar of events on page 3). We intend bringing you a first class line up of keynote speakers to present the latest research pertaining to Multiple Sclerosis.



Our first confirmed speaker is Dr. Wallace Brownlee. Wallace completed his training as a Neurologist in Auckland and then was offered Neurological Foundation Scholarship in the UK. Wallace is now 18 months into a research project and about half way through his study. Wallace has been researching about 150 people who had their first attack 15 years ago and in particular analysing the MRI scans taken in the first five years with special emphasis on the spinal cord. His area of interest in the spinal cord is because most of the long term problems People with MS face, e.g. poor mobility, spasticity, bladder/ bowel problems and pain are all directly related to spinal cord damage.

Wallace will be presenting his findings at our Research Day, on Saturday 16th May 10.30am – 2.30pm at the Alexandra Race Park. Please mark your diaries now, so that you don't miss out.

## We Need Volunteers

We are so reliant on volunteers for many of the tasks we undertake here at the Society.

Volunteers are like gold and we appreciate the wonderful volunteers that our Society currently have.

Good volunteers are very hard to come by and we are always on the look out. If you have a spare day a week to assist us in the office with administrative duties, or helping us organise events, we really want to hear from you. We are all stretched to capacity in the office and if you have a talent that we could use, please contact us urgently.

We can always do with more volunteers to help out at our Hydrotherapy classes, so if you have a couple of hours to spare on any given day and own a car, would like to help then please contact the office.

Prospective volunteers, please contact Gabrielle at [gabrielle@msakl.org.nz](mailto:gabrielle@msakl.org.nz)



# MS & FIREFLY

# A M A Z I N G

# R A C E

A fundraiser developed from the CBS show 'The Amazing Race'. Teams to complete mental and physical challenges at locations throughout West Auckland.

This is a fundraising event with 100% proceeds benefiting both the Multiple Sclerosis Society of New Zealand and Firefly Children's Home, an orphanage based in Kathmandu, Nepal.

Entry Fee: \$15 per person

## 10 Challenges

Teams in costume gain extra advantage

Team size: Min 3, Max 5.

## 1 Finish Line

Part brains, Part brawn and Heaps of FUN

## SATURDAY, 7 MARCH 2015

## RACE BRIEF STARTS: 10.30AM

@ The car park area opposite Whenuapai School  
(14 Airport Road Whenuapai, Auckland)

Winners will be announced once all the teams have returned to the finish line.  
Sign up your team by Friday 6 March. Register @ [Melissa.Mikaere@nzdf.mil.nz](mailto:Melissa.Mikaere@nzdf.mil.nz)  
or ring 021 2046202 for further information.

Last year during our Awareness Week we worked closely with **HUNCH** (Advertising Agency) and **HELL Pizza** to try and bring a creative message of awareness to corporates. Well it worked and we won GOLD at the NZ Post DM Awards last week. MS Auckland was sad not to have been able to attend on the night, due to the ticket price being way too much for our budget! However the HUNCH team were there in force - Michael Goldthorpe - Director, Matt Watts - Senior Copywriter (Matt's mum has MS) and Natalie Cole - Account Manager. It was such an exciting night and a well-deserved award for HUNCH and the team.

HUNCH came up with the idea of delivering HELL pizzas to corporates that had not even placed an order for the pizza. The campaign was to bring about confusion – a symptom experienced by some People with MS. The concept was all about the brain's messages not going to the right places in the body at times. It was indeed a very novel approach and one that captured the attention of NZ Post judges of the awards. It was very much a team effort at HUNCH and was designed by Vic Skinner (Designer at HUNCH).



Ge



Matt, Michael and Natalie



HELL's New Zealand Marketing Manager, Jason Buckley loved the whole approach and was more than delighted to donate all the pizzas for free. HELL have been a partner of MS Auckland for the last two years now, helping to increase awareness of MS during our Awareness Week and Street Appeal. MS Auckland received \$14,800 from HELL in 2013 and in 2014 they donated \$13,200 to us. We are extremely

grateful for their support and look forward to another successful year this year.

We are so proud of HUNCH and their great achievements. The **Wrong Delivery** campaign was a winner on many levels – awareness, HELL Pizza sales and awards. MS Auckland was invited to a Pre-Awards night at the Pullman Hotel to view the work of all the finalists. I can assure you HUNCH was up against some very big 'guns', so to bring GOLD home was an awesome achievement for a job well done.

Huge thanks to **HUNCH** and **HELL**! What on earth are you going to come up with this year to beat **Wrong Delivery**?



Martin Shepherd's mother-in-law has MS and he decided to raise some funds for MS Auckland. With the help of other staff and students, from the University of Auckland's Faculty of Education, Martin received a rude awakening when ice cold water was poured over him.

"All for a good cause" said Martin as he silently, but theatrically screamed at the reality of ice cold water being poured over him by the highest bidder on the day. We were delighted that so many people wanted to support Martin and his Ice Bucket endeavour, which raised nearly \$900.

Well done Martin and all the wonderful bidders and a huge thanks from us all here at MS Auckland.

If you would like to raise money for the Society and be as adventurous (or not) as Martin, please feel free to contact Gabrielle at [gabrielle@msakl.org.nz](mailto:gabrielle@msakl.org.nz) and let her know how we can help you help us.



## Auckland District Health Board needs your help

**Do you have Relapsing Remitting Multiple Sclerosis (MS) and live in Auckland?**

As part of an improvement project, Auckland District Health Board is interested in hearing from people with Relapsing Remitting Multiple Sclerosis who have little or no contact with their neurology team.

We will be holding a small interactive workshop where people will have the opportunity to share their experiences and make suggestions that may help shape future service development.

Details are still being finalised but the workshop will be held in central Auckland in early March. Jelinek diet based refreshments will be provided.

**To register your interest in attending please contact:**

Hilary Boyd, Project Manager,

Auckland District Health Board

Email: [hboyd@adhb.govt.nz](mailto:hboyd@adhb.govt.nz)

Ph 307-4949 x21960 (Tuesday to Thursday)

With less than four months to go to **World MS Day 2015**, the new multilingual World MS Day site is now live.

The site includes up-to-date information on this year's campaign, the latest resources for people to download, plus stories and photos from the last six years.

The resources include everything you need to organise your own World MS Day event for 2015. It also includes links to MS International Federation's member organisations and others around the world, most of which will be taking part in World MS Day. Last year, World MS Day was celebrated in 77 countries.

### Access

The World MS Day theme for 2015 will be access, and the campaign will celebrate people and organisations that have made less difficult for people affected by MS.



Sophie Paterson, Communications Manager at MS International Federation, says: "We will be running the campaign across social media and sharing stories of strength and teamwork used to break down the barriers to living with MS."

Within the next few weeks the website will also include a map to

which people can add their own World MS Day events.

The campaign will be launched to the public in April, starting the build-up to World MS Day itself on 27 May.

The site and all its resources are available in Arabic, English, French, Portuguese and Spanish. It has been designed so it works equally well on mobile phones and tablets.

For World MS Day 2015 the World MS Day team is looking for stories about how people have broken

down the barriers to access all over the world. If you want to share a good-news story from your country, get in touch with the team.

*See more at: <http://www.msif.org/news/2015/02/03/world-ms-day-website-goes-live/#sthash.HXanUojN.dpuf>*

## Jack takes message online

The son of legendary rock and reality TV star Ozzy Osbourne, Jack Osbourne, has decided to start educating people about multiple sclerosis.

The 29-year-old, who has been diagnosed with relapsing remitting MS, has launched an online video series whereby he asks people what they know about the condition.

You Don't Know Jack About MS is an online series of short films aimed at the newly-diagnosed and those who have friends and family who are diagnosed. The show features his wife Lisa and daughter Pearl and his father and mother, Ozzy and Sharon, as well as sister Kelly.

The free web series is produced in partnership with Teva Neuroscience. In a note on the website, [youdontknowjackaboutms.com](http://youdontknowjackaboutms.com), Jack says "You first got to know me



as a teenager on MTV more than ten years ago. For starters, I am a bit different now than when I was a teen. I've started producing my own reality TV shows, got married to Lisa and last year we had a beautiful baby girl named Pearl. Two years

ago, I was diagnosed with relapsing remitting MS".

"It's not just women or older people who get it, and it's not a death sentence. I thought, 'Why don't more people know about this?' I decided to create the You Don't Know Jack About MS campaign to show people that, while relapsing remitting MS is a major part of my life, it doesn't control my life. I want to change the way people think and talk about MS."

The site also features a self-help quiz about MS and important information about support systems available to people with the condition in the US.

*If you are in Auckland and would like to know more about MS please phone the office 09 845 5921 and speak to Kirsty.*

# At last! Something can be done about fatigue...

Most people with MS, around 85% in clinical studies, experience fatigue; for many, this is the most disabling symptom they have. People often ask on forums and social media, what can I do about my fatigue?

To date, there has been little to offer people with MS to counter fatigue, including no effective medications, although many have been tried. This major international study from the HOLISM investigators of two thousand people with MS, published in the world's biggest medical journal, PLOS One, changes all that.

We found that around two-thirds of our sample (65.6%) had clinically significant fatigue. This is considerably lower than in other big studies, probably because so many of our HOLISM sample were following the OMS approach, and therefore had fewer of the adverse lifestyle factors that we later identified as predicting fatigue in our study. We showed that fatigue is markedly lower in those people with MS who adopt healthy lifestyles.

In particular, we found people with progressive types of MS complained of significant fatigue 2-3 times more commonly than those with relapsing-remitting disease. We also found increased fatigue in people with MS who ate a poor diet high in saturated fats (95% more likely), were obese (84% more likely to be fatigued), or took commonly used disease-modifying medications (83%



more likely), and reduced fatigue for those who exercised more (66% reduction), supplemented with vitamin D (38% reduction) and omega 3 fatty acids (37% reduction for flaxseed oil, no reduction for fish oil), consumed fish frequently (34% reduction), or drank alcohol in moderation (24% reduction).

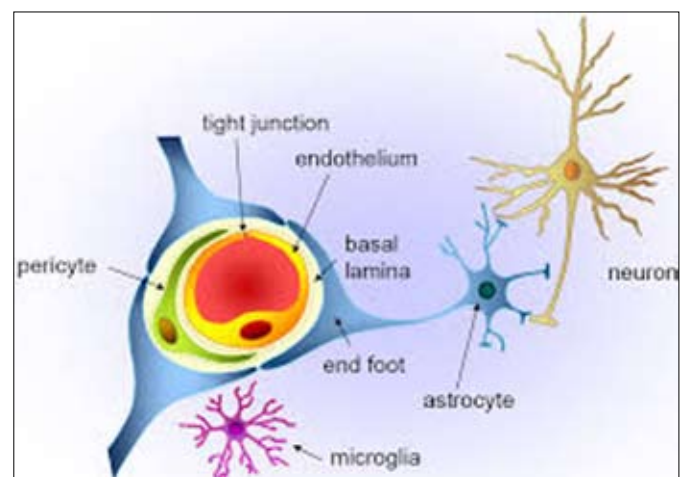
These findings are simply extraordinary! Many PwMS attending our retreats report back that their fatigue has lifted after they embrace the OMS Recovery Program. What we found is that the very lifestyle changes that we teach in the retreats aimed at stabilising the illness and reducing relapse rate and disease progression, are exactly those that are associated with less fatigue. It is no wonder those going to the retreats start to feel better, as their fatigue lifts.

Our results fit well with a preventive medicine approach to managing MS; other HOLISM papers show that such healthy lifestyle behaviours are also associated with better quality of life and reduced risk of MS relapses and depression. So adopting the OMS Recovery Program is a win-win situation all round! Doctors and people with MS everywhere will be heartened to know that fatigue need no longer be such a disabling problem.

Find the paper online at <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0115541>

## MS Fatigue strongly associated with Vascular Irregularities

The cause of MS fatigue, while not well understood, is frequently believed to have strong neurological/immune associations. Understanding the involvement the vascular system in this process is an emerging issue. Since 2009 details of the prevalence of vascular irregularities in PwMS have increasingly appeared in the literature. Studies are showing that while more than 80% of the overall MS population identify extreme fatigue as one of their major issues the same population percentage has vascular irregularities. Many patients treated for these vascular irregularities, experience significant improvements in fatigue related conditions simultaneously with the restoration of normal blood flow. These improvements are reported by some as being akin to those associated with hypoxia, a condition in which the body as a whole or a region of the body is deprived of adequate oxygen supply.



Continued page 21

*Continued from page 20*

During 2014 there were a number of research outcomes that strikingly illustrate the physiological foundation whereby the vascular system plays a critical role in regulating the supply of oxygen and other essential nutrients. For the first time, and described as a missing link, it was demonstrated that the vascular endothelium plays a critical role in the regulation of blood flow in response to stimulation in the living brain.

This is extremely important, as neurons need adequate blood flow to provide glucose and oxygenation. A healthy lining of the blood vessels would normally respond to circumstances of inadequate blood flow by widening vessels and allowing for more blood to flow to the brain. Without this response the brain will not function properly, and neurons can potentially die.

One study reported that patients with MS had a significant decrease of cerebrovascular reactivity compared with controls. Another showed a significant derangement of the endothelial layer as compared to controls whereby no endothelial cells were found in the defective internal jugular veins of MS patients. This new research appears to go a significant way in validating the first hand experiences of the tens of thousands treated for CCSVI conditions across the globe as well as providing a strong clinical foundation to build upon.

*Find out more at*

<http://www.msnetwork.org/roadmap/issues.htm#impact>

Peter Sullivan. On behalf of Multiple Sclerosis Network of Care, Australia

## An invitation to participate in an international study on lifestyle factors

Australian Professor George Jelinek (a person with multiple sclerosis) and the Overcoming MS group are conducting important international research into lifestyle factors in MS. On 10 February 2015 they invited "people with multiple sclerosis (MS) to participate in a large online international study on lifestyle factors in MS!" and went on to say 'At Overcoming Multiple Sclerosis (OMS), we are committed to determining what lifestyle factors contribute to the progression of MS.

In 2012 we commenced a major international research project to examine this, recruiting approximately 2,500 people with MS (PwMS). The study is approved by St Vincent's Human Research Ethics Committee in Australia. Many scientific articles have been published from the 2012 survey, showing interesting associations between lifestyle interventions and health outcomes. You can find more information about these publications and the study on our Facebook page <https://www.facebook.com/HOLISMresearch>.

We intend to follow this group every 2.5 years to see if there is a relationship between changes in these lifestyle factors and the health of the group. We will analyse this information to determine which factors best predict the health of PwMS and share this information with the scientific and MS communities. In addition, we seek to enrol more PwMS to expand our group size.

If you have completed the survey in 2012 we encourage you to do so again (unless you have already completed your 2014/15 follow up in the last three months).



Prof George Jelinek

If you have not completed the survey before and have been diagnosed with MS, and are over 18 years of age we invite you to participate in this important research."

To complete the survey please follow the link: <https://www.surveymonkey.com/r/HOLISM2NEW>

You may need around 40 minutes to complete your responses.

Peter Sullivan. On behalf of Multiple Sclerosis Network of Care, Australia

See also <http://www.msnetwork.org/bookmarks/lifestyle.htm>

George's book **Recovering from MS**, received a really good review in the 'Medical Journal of Australia', Australia's most prestigious medical journal and the latest papers from the HOLISM Study were accepted for publication in some medical journals. Keryn Taylor's paper from the HOLISM study on Depression was recently published in the BMC Psychiatry. The paper was the 'Editor's Pick' of the papers published in BMC Psychiatry this week! The MS Society of the United Kingdom, in a blog on the BMC Journal website, described the research as 'crucial'. The next paper from the study on fatigue has just been accepted for publication in PLOS ONE, the biggest journal in the world! All this latest news was sent to me from Gary – CEO of Overcoming MS (UK).

Fatigue is one of the most common and disabling symptoms of multiple sclerosis (MS) occurring in up to 90 per cent of people with MS.

MS-related fatigue occurs on a daily basis and gets worse during the day. Heat and humidity make it worse.

Fatigue is not directly linked to depression or degree of neurological disability, and may occur first thing in the morning even if the patient has slept well.

There is no medication approved specifically to treat MS-related fatigue.

Amantadine was the first medication used to treat fatigue, although most studies have not shown evidence of benefit. Modafinil was studied recently, also showing inconsistent results.

Several non-drug interventions have also been proposed including aquatic exercise training, occupational therapy, and internet-based programs.

Combating MS-related fatigue is of importance to those affected by MS, as it interferes with daily living, work, family life and socialising.

## Researchers find that Alfacalcidol is a safe and effective treatment for fatigue

### Study findings

The Multiple Sclerosis Journal recently published the results of a study by researchers from Israel who measured the effect of vitamin D analogue, Alfacalcidol, on MS-related fatigue. In this study, 158 MS patients with significant fatigue received Alfacalcidol or a placebo.

The researchers found that Alfacalcidol is a safe and effective treatment for fatigue among patients with MS.

These findings suggest that Alfacalcidol, a drug similar to vitamin D, should be considered a safe treatment option for MS-related fatigue.

See more at: <http://www.msif.org/news/2014/11/17/new-treatment-fatigue/#sthash.QQgW6aap.dpuf>

## Stem Cell Study Findings Revealed

A **Phase 1 Trial**, unique in the United States, has been testing the safety and feasibility of treating MS patients with a dose of their own adult mesenchymal stem cells, or MSCs, reports Cleveland.com.

Found in the bone marrow, MSCs are being tested in more than 150 clinical trials worldwide - including in England - as a way to treat a variety of other conditions such as osteoarthritis, diabetes, emphysema and strokes.

Dr. Jeffrey Cohen, director of the Cleveland Clinic's Mellen Center for Multiple Sclerosis Treatment and Research, presented the findings at the MSBoston2014 convention.

Dr. Cohen worked with a team at University Hospitals Seidman Cancer Center and Case Western Reserve University on the trial, which was completed in January. A total of 24 patients with relapsing forms of MS received injections of their own MSCs. "We really encountered no practical issues and there really were no safety issues," said Dr. Cohen.

While the study was not designed to measure for benefits it did not have a comparison group and involved a small group of patients. Cohen said the researchers were encouraged by what they saw. "We didn't see any dramatic changes in anybody, but looking at the results as a whole there really were some encouraging trends, which is really as much as you hope to see in this kind of study," he said.

Dr. Cohen and his team are now planning a larger **Phase 2 Trial**. While at the MS Boston convention, Dr. Cohen also presented the results of another trial the GATE trial (Efficacy and Safety of GTR in Comparison to Copaxone) - which

may pave the way for the approval of the first generic version of an MS drug.

Eleven drugs have been approved by regulators to treat relapsing-remitting MS. Copaxone, a drug that is injected either once a day or three times a week, was approved in 1997 to reduce the frequency of relapses.

"Some of the initial MS medications are going off patent, so that gives us the opportunity to get approval for generic drugs," Dr. Cohen said. Generic forms of currently approved medication would provide serious savings to patients and here in Britain - health authorities.

Dr. Cohen stressed that the drug manufacturers and the Food and Drug Administration needed to make sure that the generic versions equally as effective as the drugs, such as Copaxone, that were already in use.

"Some minor changes in how you manufacture the medication could have significant changes in safety or the efficacy," he said, "so it's sort of a balance. For the generic it can't be too expensive in order to make it attractive to pharmaceutical companies, but if you cut corners, the medication may not work or have unexpected side effects."

Source: *New Pathways News, MS-UK (01206) 226500, [www.ms-uk.org](http://www.ms-uk.org)*



Dr Jeffrey Cohen

## Brain Day 2015 Your Life: Your Brain

Saturday 28 March - 9 am - 4 pm  
University of Auckland Business School  
Owen G Glenn Building, 12 Grafton Road  
(off Symonds Street)

Free Entry • Wheelchair access • Cafe facilities  
Parking under the Business School - \$6.00 per day

### Lectures in the Fisher & Paykel Appliances Auditorium

The timetable features scientific, clinical and community experts speaking around the theme "Your Life: Your brain". All lectures will be made available in audio format on our website following the event at [www.cbr.auckland.ac.nz/brainday](http://www.cbr.auckland.ac.nz/brainday)

9:00am	Welcome - Distinguished Professor Richard Faulk, Director Centre for Brain Research
9:15am	<b>Protecting babies' brains</b> Professor Alastair Gunn, Centre for Brain Research The idea that mild cooling could have a protective effect on an infant's brain was first suggested more than three thousand years ago. This talk will discuss how New Zealand researchers helped to turn that old idea into a treatment which is now used around the world.
10:15am	<b>Music &amp; Dance: Jazzing up your brain</b> Professor Ngaira Kerse, Centre for Brain Research, Associate Professor Ralph Buck, Centre for Brain Research, Carlene Newall, PhD candidate, Centre for Brain Research Hear about the ways in which music and dance can be a critical part of the toolkit in dealing with the challenges of life with dementia, and see some real-life evidence of its effectiveness!
11:15am	<b>Older persons' pain: assessment and management</b> Professor Stein Husebe and Associate Professor Bettina Husebe, University of Bergen, Norway Visiting Norway-based pain specialists Professor Stein Husebe and Associate Professor Bettina Husebe will discuss assessment and treatment options for the elderly person in pain.
1:30pm	<b>The Inside Story: Imaging the brain</b> Dr Andrew Smith, Auckland Radiology Group, Dr Ben McGuinness, Trinity MRI, Dr Gerard Dieb, Centre for Brain Research Imaging the young brain, including fetal and pediatric development. (Dr Andrew Smith) Imaging the brain in adulthood, with a focus on diagnosis and treatment of stroke. (Dr Ben McGuinness) Imaging the mature brain, looking at causes of cognitive impairment. (Dr Gerard Dieb)
2:45pm	<b>Exciting Research Developments around Alzheimer's Disease in New Zealand</b> The vision for dementia research - Distinguished Professor Richard Faulk The Brain Research New Zealand Dementia Research Clinics: An exciting partnership between scientists, clinicians, and the community - Associate Professor Lynette Tippett, Dr Christina Ilse, Karen Smith
4:00pm	Close and Award Presentation



**10:00 am and 2:30**  
**Children's Learning Activities: Caseroom 2**  
Hear about what happens when we damage our brain, and take part in some simulations of this (9-12yrs).  
**Presenter:**  
Sarah Schenberger

**11:00 am and 1:30**  
Enjoy learning about how the brain produces sound, complete with activities about speech mechanisms (9-12yrs).  
**Presenter:**  
Rose Kalathotsukaren

**12:30**  
**CeleBration Choir: Caseroom 3**  
The CeleBration Choir is a community music therapy initiative for people with communication problems caused by brain disorders.



### Panel Discussions in OGG84

Benefit from our speakers' experience and expertise in a relaxed and informal atmosphere - questions welcome!

10:15am	<b>The Wandering Mind</b> Emeritus Professor Michael Corballis A conversation with Professor Michael Corballis, professor of psychology and author of popular books 'From Hand to Mouth' and 'The Wandering Mind: What the brain does when you're not looking'.
11:30am	<b>Minds for Minds: Recent research developments in autism</b> Professor Russell Snell, Centre for Brain Research, and Dr Rosamund Hill, neurologist
12:30pm	<b>The teen brain: Puberty, drugs and rock'n'roll</b> Associate Professor Karen Wokoski, Centre for Brain Research In this session we will explore some of the most common questions about the teen brain. Are kids undergoing puberty at a younger age? What happens to the brain during puberty and the teenage years? What is the evidence that marijuana use is bad during adolescence? Do kids grow out of ADHD - what does medication do to the brain? How prevalent are depression and other mental health concerns during adolescence?
1:30pm	<b>Living well with dementia</b> Choir: Associate Professor Paul Corballis, Centre for Brain Research In this session, you will have the opportunity to hear first-hand from those working and living at the 'front-lines' of dementia - family members, community support and field workers for various advocacy groups, will convene to share their experience and answer your questions.

We receive updates from this organisation and they are always interesting, take a look and get on their database to receive regular newsletters. <http://www.msif.org/>

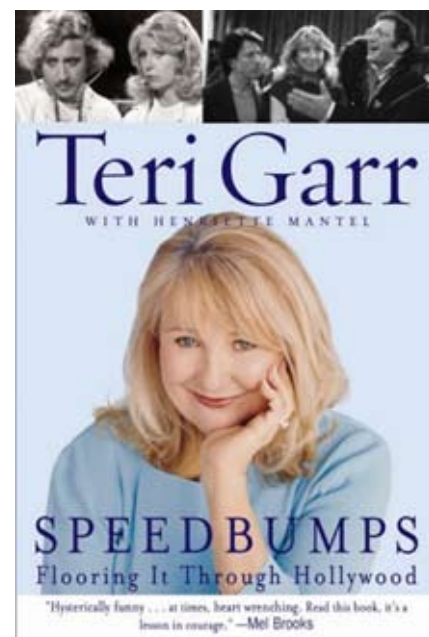
## Library Speedbumps by Teri Garr

In this laugh-out-loud funny and inspiring autobiography, one of Hollywood's best-loved comedienne muses about movies, men, motherhood, and MS In a book that is at once Hollywood hilarious and personally moving.



Teri Garr, star of such classic films as Young Frankenstein, Oh God!, Close Encounters of the Third Kind, Mr. Mom, and Tootsie, for which she received an Academy Award nomination, writes about her life with the same wit and warmth that have won the hearts of fans for over three decades.

From sipping Cokes with Elvis Presley to hangin' with the Beatles; from her secrets to succeeding in Hollywood without losing her sanity, to dealing with the fear, anxiety, and denial of being plagued by mysterious physical problems that eluded diagnosis for over twenty years - the insights in Speedbumps, while always couched in Garr's trademark humour, are honest, heartfelt, and often profound.



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Jordon Milroy • Nicholas Kearns  
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