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ISSUE 30

# multiple news

*The bi-monthly newsletter from Multiple Sclerosis Auckland*



We are extremely grateful to the Sir John Logan-Campbell Trust, who fund the publication of this newsletter. It is a well-read publication and a service we provide to our Members.

**ms.**  
Multiple Sclerosis  
AUCKLAND

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# A few words from the CEO...

Hi again everyone,

It has been manic here at MS Auckland, we have achieved so much since our last Newsletter. However we have all 'burnt' out and have been sick, probably like several of you during this cold winter snap!

I hope many of you were lucky enough to see [Sky Tower](#) lit up orange for [MS World Awareness Day](#). We were very fortunate to have Graeme Sinclair and his family 'flick' the switch!

The front cover is proof that it did actually happen. It is the first time SkyCity agreed to light the Tower up to raise awareness for Multiple Sclerosis in New Zealand.

Many of you had the great privilege of sailing on the [Oceans of Hope](#) yacht when she was in Auckland – see what some of our MS sailors had to say about the experience later in this issue. At this time we also celebrated [MS Auckland's 50th Anniversary](#) and Biogen helped with funding as we celebrated this milestone at the Royal New Zealand Yacht Squadron. We were very grateful for Biogen's funding because we were able to bring past and current staff and Committee Members together and thank our many corporate partners. It was a really special luncheon.

We were also proud to announce the launch of the [MS NZ Research Trust](#) at this luncheon and MS Auckland Region Trust presented the Chairman of the Research Trust, Tim Preston with a \$300,000 portfolio. See more about this later in this edition.

We are thrilled to inform you that our recent '[Life Buoy for MS](#)' Charity Luncheon raised \$94k and the event was a huge credit to the team that put it together. We have only had positive feedback and already tables have been sold for next year. One lucky punter paid \$8.5K for a personally signed copy of Graham Norton's latest book, plus two front row seats to his show in London, drinks in the 'Green Room' with the celebrities and Graham himself. But wait, there's more... five night's accommodation and dinner for two at one of Peter Gordon's famous London restaurants.

We had another wonderful supporter who paid \$14K to have drinks with the Prime Minister. We really had some awesome auction items. Get in early and book your table for Friday 8th April next year!

After our very successful [AGM](#), we have been lucky to secure four new Committee Members and their profiles will be up on our website very soon. We welcome Maureen Wood (PwMS), Michael Duggan, Julie Rogers (PwMS) and Kerri Hoy.

If you missed our [Research Day](#), you really did miss a 'winner'. The largest turnout ever, with over 120 Members attending. No one was disappointed with the information that was presented, it was interesting, informative and up to date research. See notes from our three presenters later in this issue.



*Continued bottom of page 3*

# Notice Board

## 1. Bike the Bridge

The opportunity to ride over the Auckland Harbour Bridge is back! This time Bike the Bridge [www.bikethebridge.co.nz](http://www.bikethebridge.co.nz) will be an over and back course – doesn't get better than that. Sign up to ride and open an Everyday Hero Fundraising page to help raise funds for MS Auckland.

## 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  
Milton Jennings  
Graeme Sinclair

## 2. Bike the Bridge For Non-Bikers

If you are not a cyclist (like me), you don't have to cycle the Bike the Bridge event, but you can come along on the day and help us get into the Guinness Book of Records for the most people at a breakfast. We are going to have some fun at Smales Farm in Takapuna.

## 3. Open a Fundraising Page

Irrespective of whether you cycle over the Harbour Bridge or not, won't stop you opening an Everyday Hero Fundraising page.

Email [Kirsty@msakl.org.nz](mailto:Kirsty@msakl.org.nz) to find out how or donate to my fundraising page already created <https://bikethebridge2015.everydayhero.com/nz/therese>

## Important dates to remember...

## CALENDAR

29th August -  
5th September  
MS Awareness  
Week

4th/5th September  
Street  
Appeal

17th October  
Members' Lunch -  
South

15th November  
Bike the  
Bridge

13th December  
Members'  
Christmas Lunch

Our next [Wellness Workshop](#) is not to be missed. Come along to listen to our Patron – Dr Jennifer Pereira speak about the new drugs being offered to People with MS and how to 'talk' to your Neurologist. More details in this edition.

Another coup for MS in New Zealand is that Chairman of MS Auckland and Vice Chairman of MS NZ, Neil Woodhams' is now an advisor on the Pharmac Consumer Advisory Committee. Neil is also a regional finalist for the 2015 Pride of NZ Awards in the lifetime achievement category for services to MS – we can't think of a more worthy recipient for this award.

Right put your feet up, grab one of Marlene Hessing's 'tea sensations' and enjoy your magazine.

THÉRÈSE RUSSEL  
Chief Executive Officer



Diane Hampton, North Shore



Carol Andrews, Central



Georga Forgac, West



Dianne Bartlett, South

We hope you are all managing to keep warm during these colder months. It can be a challenge to maintain exercise programmes and other out of house activities as it feels like hibernating weather.

Our **MS hydrotherapy** classes continue to run throughout the year in various locations across Auckland. We encourage you to attend if you can as it is a very beneficial exercise. If you look on our MS Auckland website [www.msakl.org.nz](http://www.msakl.org.nz) under "We Can Help" and "Exercising with MS" you will find some information on hydrotherapy and our class locations and times. You can then contact your Field Worker for further information.

This is an enjoyable way to keep fit plus an opportunity to meet others living with MS.

Our **MS Awareness Week** (MS Warrior Week) is fast approaching, so once again we are looking for collectors for our annual street appeal. The collection days are Friday 4th and Saturday 5th September.

If you, your family or friends can spare an hour or two please email your interest to Lisa at [streetappeal@msakl.org.nz](mailto:streetappeal@msakl.org.nz)

While collecting it is a great way to talk to the general public about what MS is, so this has the ongoing effect of raising awareness of MS.

Lastly we'd like to finish with a few quotes, as they can help to provide a focus for thought, contemplation and motivation.

**Self-Discovery:** "Learn to get in touch with the silence within yourself and know that everything in this life has a purpose" - Elisabeth Kubler-Ross.

**Opportunity:** "Do not wait for extraordinary circumstances to do good; try to use ordinary situations" - Jean Paul Richter.

**Optimism:** "I am an optimist. It does not seem too much use being anything else" - Winston Churchill.

Cheerio, Georga, Dianne, Carol and Diane.

## DONATIONS

### Regular Monthly Donors

June draw was won by Mary Harding, thank you for regularly giving.

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.

### WE ARE ON THE MOVE...

MS Auckland has outgrown its office space and Auckland Council have kindly leased us some larger premises. We are shifting mid-September to offices above Takapuna Library. We are so excited and look forward to you popping in to say 'hi'.

## Please join us on Facebook



We have been trying to engage People with MS in the Auckland region (and of course around the world) to join us on Facebook. Do you know we have gone from 456 likes to nearly 2,600. Our followers are loving our posts and really engaging with our Society. If you haven't joined up yet it's easy, click on this link <https://www.facebook.com/multiplesclerosisakl?ref=hl>

Every day you will receive posts of information, research updates, inspirational messages, funny stories or Member's stories, you will be kept up to date and informed. It's as easy as a 'click'

See you on Facebook.



# Focusing on MS relapse

## FROM THE MS NURSES

New Zealand has now had 9 months of access to the two novel disease modifying medicines for relapsing remitting MS – Fingolimod (Gilenya) and Natalizumab (Tysabri).

At Auckland hospital 50 people are now established on Fingolimod with many more going through the lengthy work-up process for this. There are 40 people now established on Natalizumab given by IV infusion once per month. As these treatments have a high level of efficacy it is our hope that over time we will see less people reporting MS relapses. However, for now, our main focus, outside of the safe management of the people on these treatments, is to look at helping you manage your relapse in the best, most effective way possible.

With help from MS Auckland and a group of people who have MS we have undertaken a large piece of work looking specifically at MS relapses. The project focused on what it feels like physically and emotionally when you have a relapse, the services people in Auckland use for assistance and advice when they are relapsing and for those people who call the MS team at ACH, what works and what doesn't about the current system.

From the amazing feedback we received from our workshops and interviews we are changing the way we educate people about their relapses and are developing a visual reminder of what steps we recommend you take when experiencing what you think may be a relapse.

A version of this for GP's is also underway, and will be issued to GP's who have a person with MS on their books. We recognise that in some GP's practices there may only be one or two people with MS so assistance is required to help these GP's more effectively manage their patients.

Additional information for GPs is to be added to our health point website [www.healthpoint.co.nz](http://www.healthpoint.co.nz) Auckland-DHB- MS- Nursing team, along with the details about new treatments and MS relapse management.



If you are someone who's GP does prescribe steroids for MS symptoms, could you please ensure you ask them to let your neurologist or MS nurse about this.

If your specialist team is not aware you are having a relapse we can't arrange a follow up review for you nor can we give you the information you require to make an informed choice about starting the new medicines.

At your next appointment you may be given a short questionnaire to complete in the waiting room that will ask you to list your major concerns about your MS, and enquires about your mood and bladder function. The form will also give you an option to indicate that you want your MS Field Worker to be copied into your clinic letter. We hope that focusing your neurologist in to what you feel is having the biggest impact on your daily life will make better use of your appointment.

This has been a hugely exciting and challenging time for us, if you have experienced delays in your queries or phone calls being processed please bear with us. Non-urgent enquires are taking considerably longer to be answered. If you are experiencing new or troublesome symptoms please mention this in your phone message or email so we can prioritise getting back to you. The other option is to contact your Field Worker.

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

Do you know the difference between physical and cognitive fatigue?

#### Physical Fatigue:

- Also known as motor fatigue
- Body feels tired and does not have the energy to go any further
- Legs might start to give way
- Co-ordination can suffer
- Speech might begin to slur



Resting: Watching TV, reading, computer, sitting doing tasks

#### Cognitive Fatigue:

- Also known as cognitive fatigue
- Difficult to follow a thought plan
- Reduced concentration
- Overwhelming desire to close your eyes and sleep
- Struggle to find the right word



Resting: NO electronics. Sleeping, relaxation techniques, meditation breathing

It is important to identify what type of fatigue you are experiencing as the type of resting for each is different! Ensure that you are resting correctly for the type of fatigue you are experiencing

Due to overwhelming demand at our last evening talk, Rope Neuro Rehab is pleased to host another educational evening :

**Multiple Sclerosis and Exercise Prescription**  
Tuesday 22<sup>nd</sup> September 2015 6.15pm - 7.15pm  
Tickets available from [www.onlineneurophysio.co.nz](http://www.onlineneurophysio.co.nz)

## ROPE NEURO REHABILITATION



## RECIPE

# Vegetable & Bacon Slice

Serves 4 to 6

6 eggs  
1 large zucchini, grated  
1 carrot, grated  
1/2 onion, finely diced  
1/2 cup grated cheese  
300g thinly sliced bacon  
Pinch of nutmeg and baking powder  
Salt and pepper to taste

Beat the eggs in a large bowl then add nutmeg, salt, pepper and baking powder. Then softly stir all ingredients together. Place in lined tin and bake for 25 mins at 180 degrees. Then slice for lunch boxes.

Source: yum.glutenfree

info @yumglutenfree.com.au



## CARERS' CORNER

### MeetUps: Learning, Sharing, Fun for Carers!

Would you like to meet other carers in your community? If you would like to find carers in your community to host your own MeetUp, just set up an account at the MeetUp website and enter details about your event. Then let Carers NZ know about it by phoning the National Resource Centre (0800 777 797) or emailing [centre@carers.net.nz](mailto:centre@carers.net.nz). We'll help to promote your MeetUp to our network of almost 50,000 individual carers, professionals, and supporting organisations! The MeetUp website will also promote your event(s) to people in your community who have a MeetUp account: there are thousands of users in New Zealand.

#### **Not sure how to organise a successful MeetUp that carers will enjoy?**

Download our MeetUps toolkit, designed to help carers self-organise get together in their communities... and for organisations that want to host a special event for family carers in their communities.

#### **Are you willing to act as a facilitator for a Carers NZ MeetUp in your community?**

Please get in touch with us, and we'll organise and promote the event, and provide coaching to help you prepare for your carer meeting. We may even be able to contribute to catering costs!

We know that many family carers find it difficult to attend events for learning, sharing, and fun ... but no one understands a carer like another carer. Give a MeetUp a try!

Carers NZ is able to provide free infopacks for carers attending MeetUps and can assist in other ways.

If you or your organisation would like to host a MeetUp, please contact us to arrange delivery of resources all carers should know about, and to discuss how we can help you host a successful event for carers.

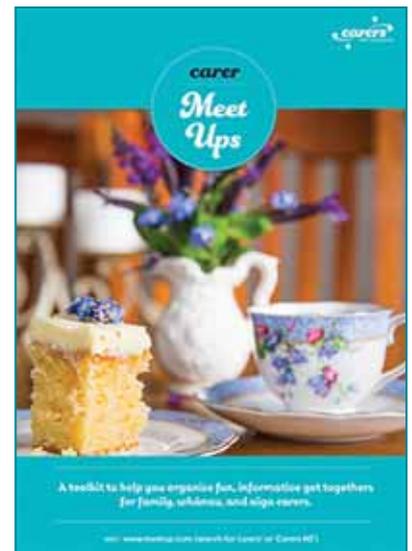
#### **Our Carers MeetUps Toolkit**

We have prepared a PDF containing more information about MeetUps. You can download it here (PDF 450kb)

#### **MeetUps in your Area**

Watch for events in your area in the MeetUps section of our Blog!

<http://www.carersair.net.nz/information/meetups-learning-sharing-fun-carers>



**P**ET First Aid & Training (NZ) Ltd was started in 2014 when we noticed a lack of education regarding companion animals in New Zealand.

Working with Multiple Sclerosis we are setting out to educate New Zealanders and encourage stronger relationships between people and their animals.

Over the month of September PET First Aid & Training (NZ) Ltd will donate \$10.00 for every person who attends a course to The Multiple Sclerosis Society.

Joanna (Director) is a qualified Veterinary Nurse with an Animal Care certification; she has trained across Australia and New Zealand.

Laura (Director) is qualified in Canine Care and Behaviour and is currently sitting a degree in Canine Psychology. Both are qualified PET First Aiders and PET First Aid Instructors.



After extensive research into what various companies across England, America, Canada and Australia offer we decided that courses written specifically for New Zealand were required.

### Courses available

- PET First Aid
- Canine Body Language

Each course is designed to be interactive, educational and fun.

### PET First Aid Course: \$179.00 per person

Did you know... 1-out-of-4 pets would survive if just one PET First Aid technique was applied prior to getting emergency veterinary care.

This 6-hour course is designed to give you the confidence and skills to enable you to help an animal in need. Over the 23 modules a fully qualified instructor will give you hands on training on how you can preserve life, prevent deterioration and promote recovery. Each attendee receives a 64-page full colour manual, poisons sheets, emergency response plan and a certificate once the course is completed.

### Canine Body Language Course: \$75.00 per person

Did you know... in 2014 there were over 230 dog bites reported per week, over 12,200 that year and it is estimated that only one third of dog bites are ever reported.



This course is designed for anyone

- Who has a dog
- Who would like to get a dog
- Who has friends who have dogs
- And anyone who has children



### The Canine Body Language

Course is designed to help people to better understand their own dog and other dogs around them.

Over the two hours attendees will gain an insight into Dog World and learn how to read a dog's body language.

The course is fully interactive and provides an entertaining and educational way to learn about dogs through videos and discussions.

### Testimonials

"Best money I've spent all year although I hope it will be 'unnecessary' "

*Clare, Dog Owner - Pet First Aid Course*

"I found the Pet First Aid & Training (NZ) course to be invaluable. It has given me a good knowledge base to be able to deliver first aid techniques with a confidence that I would not have achieved prior to taking the course.

I loved the hands-on training, a manual that was very clear, with awesome hand-outs and an approachable instructor"

"This made for a great course that i would totally recommend to any person looking to know how to be of help to pets in need."

*Lyn, Dog Owner - Pet First Aid Course & Canine Body Language Course*

### Additional Courses:

- Dog Safe in the Work Place
- Kid Safe with Dogs

To book you can email: [info@petfat.co.nz](mailto:info@petfat.co.nz)

Call: 0508 PET First Aid

Or via our website: [www.petfirstaidandtrainingnz.co.nz](http://www.petfirstaidandtrainingnz.co.nz) or [www.petfat.co.nz](http://www.petfat.co.nz)

Facebook: [PETFirstAidNZ](https://www.facebook.com/PETFirstAidNZ)



Saturday 29th August

## What Questions Do You Ask Your Neurologist?

Speaker: Dr. Jennifer Pereira

We are delighted to present a Wellness Workshop hosted by our Patron and Neurologist Dr. Jennifer Pereira, who specialises in Multiple Sclerosis.

Jennifer works as a Neurologist at Auckland City Hospital, and is also employed by the University of Auckland where she works as a Senior Lecturer in Neurology.

She has a special interest in immune therapies for the treatment of Multiple Sclerosis. Jennifer completed her neurology training in Auckland and then with the Therapeutic Immunology Group in the Department of Clinical Neurosciences in Cambridge, UK.

This Workshop will offer you an insight into important questions that you should ask your Neurologist and many other important factors about MS:

- Important questions to ask your Neurologist
- Getting your Neurologist to tell you what type of MS you have and your EDSS score
- New Drugs available
- Reassessment for the new drugs
- Identifying a relapse

We are expecting a large attendance to this Workshop so **BOOKINGS ARE ESSENTIAL**.

TIME: 1.30pm – 3.30pm

Cost: Members \$10.00/Non-Members \$20.00

Includes afternoon tea

Venue: Commerce Club, 27 – 33 Ohinerau Street, Remuera

RSVP: [Kirsty@msakl.org.nz](mailto:Kirsty@msakl.org.nz) or phone the office 09 845 5921 and make your booking directly with Kirsty.

## WILL you help us?

When did you last update your WILL?

A bequest to MS Auckland would mean so much to us. It would help us provide our beneficial services to people with Multiple Sclerosis for another 50 years.

If you would like to remember MS Auckland in your WILL contact our office and speak to Thérèse 845 5921 or email me with your questions

at [therese@msakl.org.nz](mailto:therese@msakl.org.nz)



### HAPPY 80TH BIRTHDAY MAVIS

Mavis Ulrich, turned 80 on 15th July and celebrated this wonderful occasion with family and friends.



# Good Sorts Tea Party *Hosted by Fran Watts*

EVENTS

Fran hosted a Good Sorts Tea Party at her local church and invited members and friends along to promote the work MS Auckland does and raised funds at the same time. Fran and her friends raised \$748 and had a fun time doing it.

If you would like to host a Good Sorts Tea Party please contact [kirsty@msakl.org.nz](mailto:kirsty@msakl.org.nz) and she will help you organise it.



## 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 Coffee, tea from Tea Total, 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)

COLUMBUS  
COFFEE

**ms.**  
Multiple Sclerosis  
AUCKLAND



**S**ome lovely comments from our members who enjoyed a wonderful day out with Oceans of Hope.

*"Thankyou so much!!!!!!!! Tammy had the most amazing time, we met lovely people and were truly impressed with the beautiful scenery and fantastic sun and yacht. The crew made us feel very safe and were very engaging. Thanks again"*

**Lorraine**

*"Hi Kirsty & MSAKL team*

*A BIG thank you from Pip & I for such a lovely day on the harbour yesterday with some of the OOH crew. What a great bunch of guys, so helpful & friendly. And nice for me to meet some of the fellow MS people that I've heard of from Mum & Lou.*

*Even though Pip was physically exhausted by the end of the time out on the water she really enjoyed the variation to her usual daily routine."*

**Melanie**

*"Of course, I enjoyed the taster sailing, but more importantly, I was able to gain appreciation for the OOH voyage, its goals and met with key OOH staff/crew. The highlight being my confirmation for a OOH crew position. It was good that Helena was able to come with me so she can see what I've committed too (she's still laughing about the tight bunk space!)"*

**Russell**

*What a lovely way to spend a morning sailing on the Oceans of Hope with fellow MSer's enjoying fellowship and participating in an activity that I've never experienced before, yet felt perfectly safe and empowered to achieve the tasks asked of me. My favourite duty was pulling up the main sail and not feeling at all disabled! What a great crew and a wonderful memory to cherish.*

**Fran**

Take a look at these links involving our Honorary Life Member, Graeme Sinclair

<http://www.sailing-sclerosis.org/oceans-of-hope/news/2015/150630-oceans-of-hope-news-team/>

[http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=151535](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=151535)

## Sailing Around the World

**W**e were lucky enough to have the Oceans of Hope yacht arrive in Auckland waters in May for a week. Several of our Members were fortunate to get an experience of a life time and enjoy a two hour sail around our Auckland Harbour.

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.

We have one Member who leaves this month to sail a week on the yacht and his report will be in the next newsletter. If you want to follow the rest of the journey, here is the link [www.sailingsclerosis.org](http://www.sailingsclerosis.org)

# Volunteer for Street Appeal

EVENTS

We are looking for people to help us shake buckets on Friday 4th and Saturday 5th September. This year we are aiming to raise \$80,000 in our National Street Appeal and we need your help to do it!

During the past year MS Auckland have supported over 4,000 people whose lives have been touched by Multiple Sclerosis in some form, it doesn't just affect the person living with it, it has a huge impact on their families and carers.

Our Field Workers provide personalised information, assessments, education, referrals, support, advocacy and social integration that promote behaviours which are essential to maintaining and improving the quality of life for people with Multiple Sclerosis.

To provide this service we only receive 8% of our funding from the Government so we need your support for our annual Street Appeal.

Collect for MS Auckland and make a difference in your MS community. The money raised will go towards helping us grow the services that we provide directly to the community. This will mean reaching and helping more people with Multiple Sclerosis and their families.



*To volunteer a couple of hours at a venue near you please email [streetappeal@msakl.org.nz](mailto:streetappeal@msakl.org.nz) and HELP STOP MS.*



PUT YOUR  
HAND UP  
FOR MS

**Help us help people with MS**

Can you spare 2 hours to help us collect during Street Appeal on Friday 4th or Saturday 5th September?  
Signup online, email [streetappeal@msakl.org.nz](mailto:streetappeal@msakl.org.nz) or call 09 845 5921.

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



## Proud supporters of Multiple Sclerosis Auckland

**Multiple Sclerosis is one of the most common neurological diseases in New Zealand.**

Fidelity Life are proud to support the outstanding work that Multiple Sclerosis Auckland does for New Zealand families.

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### **Protecting the NZ way of life**

[fidelitylife.co.nz](https://fidelitylife.co.nz) | 0800 88 22 88  
[clientservices@fidelitylife.co.nz](mailto:clientservices@fidelitylife.co.nz)









**A GREAT RESULT**



# Tea, anyone?

by Marlene Hessing

**M**y name is Marlene Hessing, and like most of you reading this article, I have MS and have had this condition for a number of years now.

In 2012 I had to step down from my job, as the fatigue and stress was making it very hard to cope day to day. I have been looking to find a part-time job but have had no luck finding one. My son suggested to start an online business based on one of my passions, tea.

Why tea? Well tea is the most popular drink in the world after water, yet is a distant cousin to coffee for most Kiwis. As long as I can remember, tea has been a staple in my daily routine, but only recently have opened my eyes, and taste buds, to the wonderful unique flavours of tea leaves from across the globe.

The only problem was that to try these teas I would have to buy large quantities and therefore ended up wasting the teas that did not appeal to my taste palate. To solve this problem, I have recently started Tea Samples, a business where you receive 6 small sachets each month, containing premium tea leaves from around the world.

This box is sent to your doorstep and each month you will receive a new set of premium tea leaves chosen by myself. The tea is a mystery until you open the box,



and therefore we ensure you get to taste different teas offering variety and choice you may have never tried before. Included in the box is some information on the tea's and brewing instructions to get the most flavour out of each cup.

If this sounds like you, or better yet, have a friend that may get excited finding a mysterious tea box each month in their letter box, then head over to [www.teasamples.co.nz](http://www.teasamples.co.nz) and sign up! I would love to offer anyone reading this magazine a 20% discount on your first order. Please use the coupon code 'MS' at the checkout to join me in tasting the unique tea flavours from around the world.

# Meet my Liquorice...

by Michelle Rankin



**L**iquorice was born on the 5 January 2014, a Gisborne girl who made her way to Animates in Albany. This is where we first met and I never realised the change she would have on my life.

My intention was to buy a dog for my daughter, niece and nephew, something they had wished for a long time, to say a big thank-you for the past 12 months I had been in a wheelchair. Although she is everyone's dog, she soon built a special relationship with me, going everywhere with numerous appointments at Auckland, North Shore and Waitakere hospitals she was a real hit and was even mentioned in a hospital letter!

We are well known in Birkenhead, with people drawn to me to say what a cute dog, what breed is she which leads to many conversations about the dog they had once owned. They can't believe she's not tied down to the wheelchair, she just sits on my lap and wouldn't have it any other way, never once jumping off. This has led to the wider North Shore with people coming up to me at Glenfield, Albany and Takapuna shopping centres and saying "Hello Liquorice, I met you at Birkenhead".

I used to hesitate going out in the wheelchair because people would stare and quickly look away when I caught their eye. I have pushed myself to go out and now it's really nice to know the barriers have been broken down by Liquorice, it's amazing what one little dog can do for a person, I'm so lucky to have her.

I recommend a little dog like Liquorice who stands at 25cm, 30cm long and has the personality of "Look at me, come and pat me."



# Maree's Big Week

by Maree Perkinson

Maree has some great mates, Nicolette and Craig, who wanted to spoil Maree and so they arranged a week away at the Novotel Tainui Hamilton, where Nicolette is the HR Manager. Between them they gave her a fantastic week. Nicolette arranged for some wonderful hotel workers, Jasmine, Malia and Tati to care for Maree. Maree wishes to thank all of the amazing staff at Novotel and Ibis Tainui Hamilton and to Freedom Mobility for the use of the van that was so comfortable and great people to deal with. And of course, her mates Nicolette and Craig for "making it happen."

You all rock!!!

This is her story.

It all started one Sunday afternoon when my friends from Hamilton came to visit, one conversation lead to another and the next thing I knew we were planning a trip to see the Waikato...

A dream come true topped off with a sheer miracle is all I could think of as I hadn't been on holiday for over 11 years since my mum and dad were alive. My MS has deteriorated over this time so an average day for me is a carer in at 7am, hoisted out of bed, showered and shampoo'd and put in my wheelchair in front of the TV with a glance or two out of my lounge window.

I have limited movement in one hand so if there is nothing on TV1 I have to wait for the next carer to arrive or fall asleep as that movement in my hand just isn't enough to push the buttons on the TV remote.

OK enough of that doom and gloom about me. It was 10am on Saturday morning and my carer had packed my bags, hoist, commode and box of belongings were out on the porch and 'nek minit' beeping up the drive were the McGregors in the freedom Mobility van coming to pick me up. We stopped off

at the Gordonton semi rural home of the McGregors and it was just as amazing as they had described to me over the years.

Freshly cut green grass, paddocks of cows chewing their cud, real cold wind blowing and of course Craig whinging

and moaning as he puts back in the van my entourage of equipment wondering again what the hell he had got himself into....

Next stop and final destination was the Novotel Tainui Hamilton, looked like a mansion to me, like something I'd seen on the living channel. Nicolette's place of work was fully equipped for disabled clients so it was out of the



van on the chair lift, into the hotel lift and up to my room with a view. WOW this is really happening I thought to myself with the biggest grin from ear to ear. So much to see, people to meet, places to go, "If only I could pinch myself."

The next five days consisted of full buffet breakfasts,



homemade soups for lunch on the balcony and my personal barista that had my flat whites perfectly brewed each day (how funny since instant is all I get at home)

We had trips to the lake and walks along the Waikato River enjoying the simple things in life like sun shining on my face and the colourful autumn leaves falling from the trees.

The staff were amazing as Nicolette had handpicked carers for me. One was the partner of one of the Managers at the Ibis, Jasmine, and two beautiful ladies as Room Attendants, Malia and Tati who cared for my every need before and after their shifts. I was even treated to massages something I had forgotten even existed. Nothing was ever a problem and we laughed

so much my face hurt as they called me 'Queen Maree', spoilt me with gifts and without knowing it, made me feel like one of the team - moments in time I actually forgot I had MS.

Coming to the end of my dream come true was sad especially having to say goodbye and not finding words that really could explain how grateful I was. But thanks to Craig being Craig and putting things back into perspective like always as he has known me for over 20 years.

"Stop ya bloody blubbering and stop being a sook or you wont be going again on a holiday."

God I love him, down to earth he is! A true friend who married an angel and between them both they remind me to concentrate on the things you can do AND not dwell on what you can't do.

# Jenny's in control...

This is me, Jennie, with my new car. I had been finding it difficult to drive using the pedals and so with funding from the Lotteries Commission I was able to purchase this new car which has been fitted with hand controls. This has made my life much easier and now I feel confident driving on the Auckland roads and motorways.

There are some people I would like to say a HUGE thank you to for helping me through the process.



For the wonderful support letters from my amazing MS Field Worker Dianne Bartlett, Dr Rebecca Thompson, and Kate McLaughlin of CNS.

To Rod Milner Motors for tips and hints on points to include in my personal letter and my daughter Ashley for helping me write it.

Also a big thank you to David Morris the OT assigned to my case. David helped with organising the modifications at IKON and then arranged a lesson in a car with hand controls. Scary as my first drive alone was, I am now mobile again!

To Gary Cox, the auto broker recommended by David, for finding me the car and organising viewings at my home.

Thanks a million to all of you. I couldn't have done it without your help, and of course a HUGE thank you to The Lotteries Commission who have given me a whole new sense of freedom. And last but not least, a big thanks to my wonderful family for encouraging me to apply for the grant and helping with the application.

## Rick and David need your help...

Two of New Zealand's outstanding sailors have turned frustration into inspiration after been dealt a rough card in life.

America's Cup sailors, and Multiple World Champions Richard Dodson and David Barnes have both had Multiple Sclerosis for the last 18 years.

Richard and David have been professional sailors since the early 1990's - between them they have competed in 9 Americas Cup Regattas, winning two.

Collectively they have won 8 World Championships and a long list of New Zealand National Championships.

When the opportunity arose to harness their undoubted talent in disabled sailing they took some convincing they could campaign to the high standards they have set in the past.

Unfortunately David's health took a turn for the worse last year and regrettably he has had to step down from the sailing crew.

Rick is now joined by Chris Sharp and Andrew May, both experienced yachtsmen and paraplegics due to road accidents.

The Team have now set sail to try and qualify for the 2016 Paralympics in Rio, Brazil. However to make it to Rio they first have to qualify at the International Disabled World Champs in Melbourne in November, and they need a further \$26,500 to get there.



Kiwi Gold Sailing has been approached by the Givealittle fundraising organisation who have set up a 'Crowd funding' webpage for them.

Any donations would of course be really appreciated, but also we would like your help in circulating the website, as this is how crowd funding is successful. So we would also appreciate if you would share our link on social media, or if you're not into that, just email it to anyone you think might be interested in supporting the boys and their quest for Gold.

### The boys need your assistance...

By donating to <http://givealittle.co.nz/cause/kiwigoldsailing> you are part of a special group of people, who are helping Rick, Andrew and Chris realise a dream – to campaign for Paralympic.

NOW FULLY FUNDED<sup>2</sup>



# ONE PILL ONCE A-DAY<sup>1</sup>

Ask your doctor about GILENYA.



Gilenya<sup>®</sup> (fingolimod) 0.5mg is a prescription medicine available as capsules for the treatment of patients with relapsing multiple sclerosis to reduce the frequency of relapses and to delay the progression of disability. Gilenya is a fully funded medicine under Special Authority Criteria. Normal doctor visit fees and prescription charges apply. Out-patient monitoring will be necessary for administering the first dose. You should avoid becoming pregnant while taking Gilenya and for two months after you stop taking it. It is important not to stop taking this medicine without your doctor's advice. Gilenya has risks and benefits. Cautions are infections, vaccinations, visual disturbances, decrease in heart rate, signs of liver disorders, sudden onset of severe headache, nausea, and vomiting, pearly nodules, patches or open sores of the skin. Talk to your doctor right away if you experience any of these. Side effects can include headache, liver enzyme increased, diarrhoea, cough, influenza, sinusitis, and back pain. Refer to consumer medicine information at the website [www.medsafe.govt.nz](http://www.medsafe.govt.nz) for full details. Ask your doctor if Gilenya is right for you. Use strictly as directed. If symptoms continue or you need further information or you have side effects see your doctor. Gilenya is the registered trademark of Novartis AG. Novartis New Zealand Ltd, Auckland.

**References:** 1. Gilenya Consumer Medicine Information available at [www.medsafe.govt.nz](http://www.medsafe.govt.nz) 2. Pharmaceutical Schedule available at [www.pharmac.health.nz](http://www.pharmac.health.nz)

## New leadership

Wellington smoking cessation advocate Shane Bradbrook has been appointed chair of PHARMAC's Consumer Advisory Committee.

Shane Bradbrook, a member of the Committee since 2010, will succeed Kate Russell when her term on the Committee ends on 31 July.

The Consumer Advisory Committee is a statutory advisory committee to PHARMAC, with members appointed by the PHARMAC Board.

Chief Executive Steffan Crausaz says the transition to the new Chair will be among several changes in the Committee's membership over coming months.

As well as Shane Bradbrook's appointment, Auckland mental health consultant David Lui has been appointed as Deputy Chair.

And four new members have been appointed to fill vacancies that become available this year and next. The incoming members are:

- **Stephanie Clare** – acting Chief Executive of Parkinsons NZ, Wellington (appointed from 1 August 2015)
- **Francesca Holloway** – Northern Regional manager of Arthritis NZ, Auckland (appointed from 1 August 2016)
- **Adrienne von Tunzelmann** – Board member of Age Concern NZ and Osteoporosis NZ, Tauranga (appointed from 1 August 2015)

## TPPA implications raise serious concerns

The Multiple Sclerosis Society of New Zealand (MSNZ) is extremely concerned by the potential implications of the proposed Trans-Pacific Partnership Agreement for people with multiple sclerosis.

"The TPPA could undermine PHARMAC's buying power and its right to choose the most appropriate and cost-effective drugs. It could also impede its ability to negotiate confidentially to gain the best price. This could have devastating consequences for people with MS and their families," said Multiple Sclerosis New Zealand President Malcolm Rickerby.

"Many people with MS are from low income households or are beneficiaries, due to an inability to work caused by their MS symptoms. Many of their partners and family members are also on a low wage or are carers. This makes them extremely vulnerable to any increases in prescription charges, which we see as a very likely consequence of the TPPA's impact on PHARMAC."

Mr Rickerby said that if New Zealand agrees to a situation where pharmaceutical patents are extended from five to eight years, as speculated by some commentators, this will have a serious knock-on effect

- **Neil Woodhams** – vice-president of Multiple Sclerosis NZ (appointed from 1 August 2015).

Neil Woodhams is the vice-president of Multiple Sclerosis New Zealand and the President of the Multiple Sclerosis Society of Auckland. His nomination is supported by Multiple Sclerosis NZ.

Neil has an extensive career in senior healthcare management at a governance and senior management level. He is a former senior executive of the Midland RHA and was Chief Operating Officer of Auckland DHB 2000-2002. He has also held many positions in management and governance in community and not-for-profit organisations, including Māori and Pacific organisations.

Neil's core interest area is in multiple sclerosis and people with disabilities, both as an advocate and as a carer.

"PHARMAC is delighted to have such high quality people being appointed to the Consumer Advisory Committee," says Steffan Crausaz. "They will bring new perspectives to the already diverse and highly experienced people on the Committee."

"The new people appointed will continue to provide PHARMAC with high quality advice on its consumer engagement."

Steffan Crausaz paid tribute to the outgoing chair Kate Russell, and to Maurice Gianotti of Taupo, whose terms end on 31 July after both served on the Committee for six years.

"The Committee has encouraged PHARMAC to engage with the community and this was seen in the two rounds of Community Forums that were held around the country," he says. "That has helped to build stronger relationships between PHARMAC and consumer groups."

and constrain PHARMAC from funding new drugs in the future.

"New Zealanders will pay higher costs for patented drugs for longer unless the Government increases PHARMAC's budget to offset that change to patents. What we are seeking is a firm commitment from the Government that the extended patent protection resulting from participation in the TPPA will not limit or constrain access to the next generation of MS drugs.

PHARMAC funding for the latest generation MS drugs is already seven years behind Australia due to Government funding constraints, said Mr Rickerby. "Only the latest MS drugs are shown to have clinical efficacy. In the case of MS treatment, there is no scope for substituting generics."

Since PHARMAC negotiated the best price for bringing two important new MS treatments to New Zealand last year there has been a strong demand for the new treatments, he said.

"The number of people applying for those treatments has already exceeded the number PHARMAC expected to be approved for treatment for the whole of 2015."

For further information contact our office.

# Official launch of the New Zealand Multiple Sclerosis Research Trust

**\$900,000 in grants kick starts Trust dedicated to New Zealand-based Multiple Sclerosis research**

The New Zealand Multiple Sclerosis Research Trust (NZMSRT) has announced it has received a combined \$900,000 investment portfolio as founding capital for the Trust.

A \$600,000 portfolio has been transferred from the Multiple Sclerosis Society of New Zealand and a \$300,000 portfolio from the Multiple Sclerosis Auckland Region Trust. The Research Trust has been established to stimulate, co-ordinate and support New Zealand-based research into the cause, prevention, treatment, alleviation and cure of Multiple Sclerosis (MS), and to obtain and disseminate research findings.

NZMSRT Trustee Neil Woodhams said: "We are delighted to have secured this substantial initial funding. This is an important first step to securing much

needed capital for the many New Zealand-based MS research projects that need our help. With the Trust now established, we will be looking at further opportunities to increase the capital base of the Trust."

The Trust has a target of raising a minimum of \$5 million in the next 5 years and will use income generated from its investments to collaborate with partners to fund research that improves the lives of people with MS.

With the rate of MS on the increase in New Zealand, there is a need to centralise the autonomous research being undertaken by numerous different organisations throughout the country.

"A single point of focus is needed for funding MS research. In the past, in many cases research for MS has been one of only a number of research strands within organisations that deal with a wide range of neurological or other health conditions," Mr Woodhams said.

Because of its size, geographic spread of population and the ability through the health system to accurately track individuals, New Zealand provides an ideal environment for MS research. Recent research has revealed that the incidence of MS for people living in Otago and



*From left to right, Peter Wood and Graham Wear, Trustees of the Auckland Region MS Trust, present NZMS Research Trustees Neil Woodhams and Tim Preston a \$300,000 Investment Portfolio to establish funding for the Research Trust. Peter Wood is also a Trustee for NSZMSRT.*

Southland is four times that of people living in Auckland or Northland.

According to figures from the 2006 New Zealand National MS Prevalence Study, 2,917 people have been diagnosed with MS in New Zealand with the female to male ratio of illness at 3:1. The number of people with MS has continued to grow since then due to the number of new cases being diagnosed every year.

The Trust is registered under the Charitable Trusts Act.

About New Zealand Multiple Sclerosis Research Trust: The New Zealand Multiple Sclerosis Research Trust was established for the purpose of stimulating, co-ordinating and supporting New Zealand-based research into the cause, prevention, treatment, alleviation and cure of Multiple Sclerosis (MS), and to obtain and disseminate research findings. Registered under the Charitable Trusts Act, the NZ MS Research Trust collaborates with partners to fund research that helps people with MS, informs people about research findings and uses fact-based research findings to improve the lives of people with MS. See: [www.msresearch.nz](http://www.msresearch.nz)

23 June 2015

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Dear Amanda

## REQUEST FOR INFORMATION

Thank you for your request dated 28 May 2015 under the Official Information Act 1982 (OIA) for information relating to natalizumab and fingolimod treatment. You asked for the:

1. Number of applications submitted for Gilenya (Fingolimod)
2. Number of applications submitted for Tysabri (Natalizumab)
3. Number of successful applications for both
4. Number of people who have begun treatment for both
5. Number of those waiting to begin who have had their applications successful
6. Number of unsuccessful applications for both treatments
7. Number of people who have been accepted but not taken up the treatment
8. Breakdown of successful applications based on DHB region
9. Current waiting time for application processing and approval/non-approval

All data queries relating to your OIA request were run on 16 June 2015 so reflect data held by PHARMAC as at that date.

- 1, 2 & 3. There have been a total of 392 applications made for fingolimod, natalizumab or where treatment hasn't been decided.
  - there have been 239 applications for fingolimod – 183 approved and 56 pending
  - there have been 120 applications for natalizumab – 100 approved and 20 pending
  - there are a total of 33 other applications: 11 approvals where treatment isn't decided, 5 pending where treatment isn't decided, 12 deferrals where the committee has requested additional information and 5 declined applications.
- 4 Claiming data, which indicates where a prescription has been dispensed for an individual and submitted by the claimant (pharmacy) for reimbursement, has been received for 209 individuals. It is important to note that this data may indicate if a patient has had prescription dispensed but it does not tell us if that patient has started the treatment. In addition there is a delay in PHARMAC receiving the data from the pharmaceutical claim system, as well as a delay in claimants (pharmacies in the community and in hospitals) submitting a claim, so it is likely that more people have started on these pharmaceuticals but we do not have claims for them yet. There can be a delay of up to 3 months before full information is available.
  - 5 We do not have this information available. As noted above it may be possible to estimate this based on claims data; however, the delay in receiving the claim information can be a limiting factor. Also, there may be people who have had a successful application but decide that they do not want to start on treatment.
  - 6 There have been 5 declined applications in total since 1 November 2014..
  - 7 As with question 5 above, we do not have this information.

## 8 Breakdown of successful applications based on DHB region

DHB	Successful applications
Auckland	23
Bay of Plenty	10
Canterbury	46
Capital Coast	30
Counties Manukau	20
Hawkes Bay	6
Hutt Valley	10
Lakes	3
Mid Central	11
Nelson Marlborough	8
Northland	4
South Canterbury	5
Southern	39
Taranaki	7
Waikato	22
Wairarapa	1
Waitemata	34
West Coast	2
#N/A	2

Highlighted areas apply to Auckland Region.

This information is based on what clinicians record in their applications as to which DHB region they have been allocated to.

9 The Multiple Sclerosis Treatment Assessment Panel meets every fortnightly to discuss applications received in the previous fortnight. Sometimes the panel will request more information for an application and defer resolving an application until the following meeting.

We trust that the provision of this information answers your queries, if you have any further questions please feel free to contact us again.

Yours sincerely

Jude Ulrich  
Director of Engagement & Implementation

## Risk Factors

by Simon Broadley

**M**ultiple sclerosis (MS) is a demyelinating disease of the central nervous system (CNS) which if left untreated results in significant disability over a 20-30 year time frame for the majority of people.

We know that the Epstein-Barr virus that causes glandular fever, relative vitamin D deficiency, smoking and obesity are all risk factors for the development of the disease. These environmental factors cause an autoimmune attack of the myelin component of the brain and spine in people who have a genetic predisposition.

Over 100 different genes and loci contributing to MS susceptibility have been identified so far. Thankfully the past 25 years has seen the introduction of 10 therapies that are effective in reducing the risk of relapses and disability progression in MS with more to come in the coming years. These therapies all act on various components of the adaptive immune system.

The injectable therapies of beta-interferon and glatiramer acetate are only modestly effective in terms of relapse rates and disability accumulation over 2 years, but have proven to be very safe over 20 or more years and seems to adequately control the disease over this time frame in perhaps 30-40% of patients. The effectiveness of beta-interferons appears to be similar across several stages of MS including the first initial presentation, relapsing remitting MS and the secondary progressive stage in terms of relapse rates and MRI activity at least. The oral drug teriflunomide has similar efficacy to the interferons and is generally well tolerated.

Fingolimod and dimethyl fumarate are two further tablets that have slightly greater efficacy in terms of relapses and prevention of disability progression. Both have some minor practical issues with their use but are generally well tolerated. Both of these medications have now been associated with single cases of progressive multifocal leukoencephalopathy (PML). This complication has been a particular problem with the monoclonal antibody natalizumab where there have now been over 500 cases of PML.

PML is caused by the JC virus which lives quietly benignly in the kidneys of about half the adult population. Unfortunately, when immunosuppressed or immune surveillance of the brain is prevented with natalizumab, which blocks lymphocytes trafficking into the brain, PML can emerge in a small number of people. This typically takes more than a year. Thankfully it is now possible to test for the JC virus using an antibody assay developed in Denmark and it is recommended that this be tested in those taking natalizumab every 6 months.

In those who are, or become positive, then a difficult decision as to whether to start or continue natalizumab therapy needs to be made.



Another monoclonal antibody, alemtuzumab, has recently completed phase III clinical trials and is now available in many parts of the world. This antibody identifies and destroys circulating lymphocytes that normally fight infection but in MS cause CNS inflammation. The drug is administered as a series of infusions over 5 days initially and then another 3 days 12 months later.

In up to half of patients no further infusions are required in the first 5 years. If further relapses or MRI lesions occur then further courses of 3 infusions can be administered. This is a very effective therapy and essentially reboots the body's immune system.

A significant number of patients actually improve in terms of disability, but sadly as with all the above therapies this treatment does not prevent or reverse established progressive disease later on. The infusions are associated with moderate adverse reactions (rashes, lethargy, nausea) but these are transient.

Surprisingly, with the exception of herpetic infections which can be avoided through the prophylactic use of acyclovir, opportunistic infections have not been a significant issue. The immune system reconstitutes itself from the bone marrow within 1 – 3 months.

The commonest adverse effect is the development of autoimmune disease including thyroid (30%), low platelets with a risk of bleeding (2%) and a rare condition of the kidneys and lungs (0.5%). The risk of these appears to be within the first 5 years and therefore necessitates month blood and urine screening. When detected early in this way these conditions are generally easily treated without long term problems.

Autologous haematopoietic stem cell therapy or bone marrow transplantation has shown considerable promise for severe relapsing remitting MS in uncontrolled observational studies but carries a risk of death which in the largest recent review of studies and registries across Europe was as high as 3.8%. Further controlled trials are proceeding and hopefully these will clarify the exact role of this therapeutic approach. At this time this is an option worth considering in early aggressive MS where other treatments are failing.

All of the above therapies are aimed at relapsing remitting MS and evidence is now emerging that treatment at this early stage even with moderately effective therapies such

as beta-interferon and glatiramer acetate does reduce the likelihood of disease progressive over the longer term. Thus in relapsing remitting disease the target of treatment is to ensure no evidence of disease activity (NEDA) in the forms of relapses, disability progression or new lesions on MRI.

Many treatments are also now showing clear benefits in reducing brain atrophy. The most difficult task for neurologists now is to judge what level treatment is appropriate for each person with MS. There are two broad options, start with safer more modestly affective treatments and then escalate if further disease activity occurs, or start with the most effective therapy whose risks are acceptable to both the person with MS and the neurologist. All decision will need to be individual and take into account personal expectations in life and perceived balance of risks and benefits.

There have now been at least 14 major clinical trials in progressive MS, unfortunately these have been largely negative, although two trials of beta-interferon were positive for their primary disability outcome measure. Simvastatin showed a positive effect on brain atrophy but no clinical benefit. A recent small phase III trial of high dose biotin (300 mg), a B vitamin that may reduce

oxidative stress, in progressive MS was positive for its primary outcome measure (sustained improvement). This result ideally needs to be confirmed in a second trial, but this is clearly a very promising development. A trial of vitamin D in people with their first demyelinating event is currently underway across Australia and New Zealand.

In summary, we now have a range of effective therapies for MS which in the majority of people with relapsing remitting MS are having a significant impact on improving the medium term outcome. More data is needed with regards to long term safety and long term outcomes with the newer therapies but the current trends are all very encouraging. Treatment decisions need to be tailored to the individual. Some in-roads into the pathology and treatment of progressive MS and the recent announcement of a global research fund of €22 million through the Progressive MS Alliance is to be applauded.

Through the concerted efforts of many around the world the outlook for those diagnosed with MS is improving all the time.

## How Important is an MRI?

by Wallace Brownlee

**M**RI is the key investigation that neurologists use to diagnose multiple sclerosis (MS). In the past 15 years there have been major changes to the diagnostic criteria for MS that incorporate the results of MRI scanning.

Using MRI we can now diagnose and ultimately treat MS at an earlier time point.

Although the MRI scans we use in everyday practice are a powerful tool for diagnosing MS they only provide limited information about prognosis. This is important because relapsing-remitting MS is a variable condition and people can have very different experiences in the longer term.

Some people with relapsing-remitting MS develop permanent disability either because of poor recovery from relapses or because the course of their MS changes as a result of secondary progression. However, in other people MS is a much milder illness resulting in little physical disability in the longer term.

I'm conducting a research study to try and understand the reasons why

some people with relapsing-remitting MS become disabled in the longer term and other people stay relatively well. We are following up a group of people who had their first symptoms of MS on average 15 years ago.

We refer to this very first attack as a clinically isolated syndrome (CIS). At the time of their CIS the people we are following up agreed to take part in an MRI research study. For the first 5 years after CIS they came for regular MRI scans, irrespective of how they were keeping.

We hope that by looking back at the MRI scans that were done over the first 5 years we can determine what MRI changes are most strongly associated with disability in the longer term.

In a preliminary analysis we have found that early spinal cord changes detected on MRI (spinal cord lesions and atrophy) may be a better predictor of long term disability than brain MRI measures.

We are also obtaining a new research quality MRI scan as part of the long term follow up. In addition



to the standard sequences we are also investigating a number of new, advanced MRI sequences. These include scans that detect grey matter lesions that we don't see on a standard MRI.

We are also looking at new techniques that can measure levels of sodium (salt) in the brain and the density of nerve cells in the grey and white matter, both potential measures of neuroaxonal (brain cell) loss that may be the underlying cause of long term disability in MS.

The long term follow up study will be completed in September 2015 and we hope to present our results in mid 2016.

# 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<sup>®</sup> 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 apply.

**References:** 1. TYSABRI<sup>®</sup> (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**<sup>®</sup>

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# Pharmac and MS Treatment in NZ

by Ernest Willoughby

The new regulations approved in Nov 2014 by Pharmac for MS treatments in NZ represent a substantial step forward, although there are still significant restrictions in use of the new medications.

More effective medications are now available and access approved for patients with less disability, earlier in the course of the disease. At the same time approval is more limited for patients with more severe disability, as evidence is lacking that the treatments are effective in later stages of the disease, particularly where there is low grade progressive worsening.

The main value of the treatments is in preventing relapses. There is the reasonable expectation that early effective reduction of relapses will help prevent later progressive disease, but that is not established.

Since March 2000 we have had access to beta-interferons (Avonex and Betaferon), with glatiramer acetate (Copaxone) added as an option in Dec 2005. At the same time some changes were made to the clinical criteria for approval, giving access to patients with less severe disability. However treatment was still restricted to patients with frequent relapses and significant residual disability.

The new regulations give access to treatment also to patients with active relapsing MS without residual disability, but still not to patients with very early disease after only one clinical attack. The upper limit of disability is now limited to an Expanded Disability Status Scale (EDSS) score of 4.0 or less – essentially that requires the ability to walk 500 m without support and without stopping.

The basic process for accessing MS treatment has not changed, with applications made by neurologists on patients' behalf to the MS Treatment Assessment Committee (MSTAC), with defined criteria for qualifying relapses. There is annual review of progress on treatment, also monitored by MSTAC, with strict criteria for stopping treatment if progress is not satisfactory.

The new treatments are natalizumab (Tysabri) which is given by monthly iv infusions, and fingolimod (Gilenya) which is taken as a daily capsule. Both require more intensive monitoring than the older (self) injected treatments and have a small risk of serious side-effects.

Approval may still be given for beta-interferon and glatiramer acetate if the new treatments are considered to be contra-indicated. Patients already established on the old treatments can continue under the previous regulations, or may switch to one of the new treatments if disability is not severe – in essence an EDSS score of 4.0 or less.



Over the 15 years of Pharmac funded MS treatment to date, about 1150 patients have been approved for beta-interferon or glatiramer acetate (of a total of about 3000 MS patients in NZ). At the introduction of the new treatments, about 680 patients were still on the older injectable treatments. It was expected that most would switch to the new treatments, and that has been the case, but many, who have been doing well and have not had problems with the injections, have opted to continue on their current treatment.

There is still the hope that, in the future, access to treatment will be extended to patients after the first clinical attack, if it is clear that MS is the cause and active inflammation continues on MR scans. There is also concern that some of the criteria for stopping treatment if disability increases may be too strict.

Application of the new regulations in applying for and selecting the appropriate new treatment, has substantially increased the workload for neurologists, with delays also related to extra MR scans and other tests required, plus access to facilities for natalizumab infusions and the first dose of fingolimod, which requires closely monitored observation for a day, because of a small risk of slowing of the heart rate.

Those issues have led to a good deal of frustration for patients. The problems should ease over the year, as suitable arrangements are more widely established and co-ordinated, but, in most areas extra funding from DHBs to support the process will not be available.

## LIBRARY

We recommend you follow this site as it always has very informative information and research on MS

<http://multiplesclerosisnewstoday.com/>

And for the most up to date research and treatment follow this blog page:

<http://multiple-sclerosis-research.blogspot.com/>

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