

multiple news

The bi-monthly newsletter from Multiple Sclerosis Auckland

Bike the Bridge 2015



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A few words from the CEO... for the last time, from me...

Hi everyone,

I hope you are getting into the Christmas spirit. Not long now until the jolly man in red visits your homes. The year has flown!

This is my last newsletter to all you wonderful readers. I have been with the Society three and a half years now and have loved every minute of it – learning about Multiple

Sclerosis; meeting so many of you; working with a great team of staff; assisting with fundraising and hopefully raising the level of the Society. It is now time for some fresh ideas to help MS Auckland grow further.

What now for me? I am going to enjoy some family time! I won't sit still for too long, however, my family needs me right now and they must come first.

I am delighted to announce the new General Manager of the Society, Ingrid Minett. Read about Ingrid later in this issue.

We survived another Street Appeal last September – sadly we didn't reach our \$65,000 target. However we had many wonderful volunteers on the street all spreading awareness of MS, and raised \$45,000, which will certainly help us continue providing our services to the MS community. You might like to note that MS Auckland will be asking for your help again next year, when Street Appeal takes place on Friday 2nd September and Saturday 3rd September, 2016.

I hope some of you took the opportunity to 'Bike the Bridge' – what a great occasion that was. It is the only chance to cycle over the Auckland Harbour Bridge and back again. MS Auckland was the chosen charity and we were able to raise some much needed funds and support from this unique event. One of our Members had the rare experience of completing the course in a Tri-shaw. See photos later in this edition.

This year has been a very special year for MS Auckland – there are not many organisations and very few charities that celebrate being in business for 50 years. We are very proud of this achievement and our goal is to keep going for another 50 years - although I am sure that a cure will be found before then!

If I can take a moment to reflect back on this year and remember some highlights... Our great 'Kiss Goodbye to MS' cycling team that rode from Wellington to Auckland raising awareness and funds for MS along the way; March 5th, when MS Auckland turned 50; May, when the Sky Tower was lit up orange especially for MS Auckland; and the yacht 'Oceans of Hope' arriving in Auckland allowing many of our Members the opportunity to enjoy a sail around our Harbour. Some of our Members actually sailed part of the world journey which would have been a dream come true.



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ms.
Multiple Sclerosis
AUCKLAND

Notice Board

Congrats to Nancy!

Congratulations to our Honorary Life Member, Nancy Caughie, she has become a proud Great Grandmother in the past few months, to two Great Grandsons Harrison and William.



Come in and see us!

We are loving our new premises, please come and visit us any time at the Top floor, 5-7 The Strand, Takapuna (above Takapuna Library). We have so much space now!

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

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 ingrid@msaki.org.nz or phone 845 5921.

Australian MS Longitudinal Study

The Australian MS Longitudinal Study (AMSLS), also known as the MS Life Study, is an ongoing research project designed to provide data of practical use for improving the lives of Australians living with MS. It includes information about the employment impact of MS and the disclosure of MS to employers.

Although it's Australian there are useful pieces of information for people with MS in NZ.

www.msra.org.au/AMSLS

Important dates to remember...

CALENDAR

23rd December
MS Auckland
office closes for
2015

11th January
MS Auckland
office opens

8th April
Life Buoy
for MS



Other fond memories include the extremely successful Research Day we presented with leading international speakers discussing current research programmes and the latest drugs available for people with MS; the wonderful 50th celebration, with past Committee and Staff Members, Honorary Life Members and Corporate Partners; and our major fundraiser, Life Buoy for MS, at the Royal NZ Yacht Squadron where we nearly raised \$100k. It's been a very busy year. Time to rest!

Thank you so much for allowing me into the MS community, I am going to miss it. I wish you all a very happy, healthy, safe and cool Christmas. God Bless.

Thérèse Russel

THÉRÈSE RUSSEL
Chief Executive Officer





Diane Hampton, North Shore



Carol Andrews, Central



Georga Forgac, West



Dianne Bartlett, South

Christmas is almost upon us and another year has gone by so quickly. This year seems to have had its share of global tragedies with conflict in many areas and the greatest number of refugees seen since the end of World War Two. So while we spare a thought for these people we can be grateful that we live in New Zealand. Christmas and the New Year gives us the chance to relax, have fun and enjoy the company of family and friends.

Our thanks to those of you who have attended our support groups over the year. We hope you have gained support and friendship from doing so. Others belong to the hydrotherapy groups and have gained great benefit from exercising in the water and forming friendships.

Our thanks to the volunteers who are involved in the various groups and particularly hydrotherapy. We couldn't manage without you.

This busy time of the year can be quite stressful for PwMS so do take care of yourself. With El Nino weather predicted (it is already starting to get warm) do pace yourself and have rests to prevent fatigue. It's often a good idea to plan activities early in the morning or later in

the evening when it is cooler. Remember to keep drinking water, make your shower a cool one and eat easily prepared food.

Try and keep Christmas simple and share the chores with family and friends to lighten the load on yourselves so you can enjoy the festivities. While most New Year's resolutions are broken it is a chance to think about what you would like to achieve in 2016. Perhaps join a support group, attend a hydrotherapy group or look at lifestyle changes. If you would like to explore these ideas or have other ideas, we would love to discuss them with you.

As we close for the holidays the Field Workers farewell Thérèse Russel, our outgoing CEO with our warm wishes for the future and welcome Ingrid Minett, our incoming General Manager.

Our offices close on Wednesday 23rd December and reopen on Monday 11th January 2016. If you have a health problem during this period please see your GP or dial 111 in an emergency.

Merry Christmas and a Happy New Year from Carol, Diane, Dianne and Georga

DONATIONS

Regular Monthly Donors

Every month we do a draw to see which of our regularly donors will win the monthly cash prize. The following people were all winners and all donated the cash back to MS Auckland. We are very grateful for your generosity.

July	David Compton
August	Judith Herbert
September	Heather & Roger Hawthorne
October	Thérèse Russel
November	Thérèse Russel
December	Carol Lichkus

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.

Please phone Kirsty on 09 845 5921 to register as a regular monthly donor.

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 2,874 likes? 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/multiplesclerosisaki?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.



Greetings from the new GM...

Greetings! I am delighted to be joining the MS Society of Auckland community and look forward to meeting you all over the coming months. I'm writing this on my second official day of work and I have to say already that I am very impressed by the hard work and the dedication of the team in the office and the volunteer committee under the leadership of Neil Woodhams. I feel very fortunate to be joining such a dynamic and caring organisation.

Therese has asked that I write a bit about myself, so here it is:

I'm originally from Vancouver, Canada and came to New Zealand in 1987 with my husband, Paul, and our baby, Pamela. We came via Botswana, Africa where Paul and I had been volunteering for the past two and a half years. We immediately fell in love with New Zealand and thought we would stay here for a couple of years. Well that was 28 years ago now so needless to say we are feeling very settled here and now call New Zealand home. In 1988 our second child, Vincent was born. Our daughter is now married and we are delighted to have two beautiful grandchildren.

I have a background in management, particularly with the not-for-profit and health sector. In the past I have managed a women's health and social service centre, Diabetes Auckland, and a community health and social service centre in Otara. I have also worked in smokefree and managed smokefree pregnancy contracts in Auckland for a number of years before joining Counties Manukau District Health Board and leading their District

Tobacco Control Plan. My last position was with the University of Auckland where I managed two contracts both involved with supporting New Zealand in reaching its goal of being smokefree by 2025.

I have a degree in Communications and did post graduate studies in Public Health. This year I also completed a certificate course through Cornell University on Plant Based Nutrition. I follow a whole food plant based diet and am very interested in nutrition. My other main interest is yoga, which I have been doing regularly for about 10 years now, although I'm still not very flexible! My husband and I love going to the theatre and movies and connecting with family and friends, especially over good food and wine. We also have a little dog and enjoy long weekend walks with her and exploring different parts of Auckland.

Please feel free to phone or e-mail me at any time. I would love to hear from as many people as possible as I familiarise myself with all aspects of MS and explore further opportunities for MS Auckland to continue to serve the needs of the community.

Yours in peace and good health and with best wishes for Christmas and the New Year,

Ingrid Minnett



Your bequest can help beat MS

From time to time the Society benefits from provision made for it in Wills of deceased testators.

MS Auckland appreciates receiving these bequests and puts them to good use. Sometimes the bequests are for a specific purpose, such as research, or the money can be used for general purposes.

If you wish to assist MS Auckland by leaving it a sum of money or a share of your estate, you need to consult your lawyer who can prepare a Will for you that makes such provision for the Society.

Remember no matter how large or small the bequest is that you decide to leave to the Society, it will be greatly appreciated and wisely used.

If you have any questions or require any further information regarding this matter please contact Michael Duggan duggan@orcon.net.nz or Michael Cole michael@michaelcole.co.nz who are members of the MS Auckland Committee.

The committee wants to recognise in a permanent way those generous individuals who left legacies to the Society in their wills. We intend to erect a board in our new premises listing all known legacies. At this stage we do not believe we have a complete list of bequests and seek your help in making this list as complete as possible. At this stage we have records of the following bequests:

2013 – Dawn Carrington
2013 – Frederick Eklund
2011 – Marjorie McDonald
2010 – Colin Armishaw
2010 – Gertrude Mary Terry
2010 – Hope Isabel Stemson
2007 – J Perkins
2006 – Jean Everitt
2006 – Violet May Pyper
2006 – Joan Ethel Rudall
2006 – Helen Jean Coles
2006 – Mary Lois Masters
2005 – Lorna Blanche Biglin
2004 – Frank Martin Lomas
2003 – Gilbert De Las Rivas
2003 – Irene McChesney Dodson

If you have details of any bequests not listed above would you please provide details to Mark Blackie at the office; Mark Blackie mark@msaki.org.nz

BEQUESTS



Hello and Happy Christmas everyone.

It's such a frantic time of year so I hope you are all managing the increased humidity and the lead up to Christmas as best you can.

After a very busy year we are feeling a bit fatigued as I'm sure many of you are also!

Fatigue is one of the most common and difficult MS symptoms to manage. If you want to discuss your fatigue and ways of managing it with us please get in touch with your Field Worker or the MS Nurses. The BFASS (Brief fatigue and associated symptoms scale) designed by a group of NZ and Australian MS nurses is now available to us. The people I have asked to complete it recently have found it has helped them pinpoint the areas in their life causing the greatest amount of fatigue.

There are medicine-based ways of managing fatigue, which have limited effectiveness. Good ways to get started on managing this symptom are to think about your sleep pattern. Do you wake to go to the toilet throughout the night? What time of day do you feel most fatigued? Can you identify triggers for your fatigue?

Should you want to read more about fatigue management and medicines the MS Trust have a wonderful information booklet available to download or read online www.mstrust.co.uk <http://support.mstrust.org.uk/file/living-with-fatigue.pdf>

Thank you for bearing with us over the past 12 months. Due to the introduction of new therapies, it has been



by far the busiest year that we have ever experienced at Auckland District Health Board. Please take time to review the Recognising an MS Relapse Guide (in the Member's Section of this newsletter) which we have developed. Remember to make contact with your Field Worker or the MS Nurses, if you feel you are experiencing new symptoms.

Our office will shut from the 23rd of December and reopen on the 7th January so speaking to your GP about potential MS relapses over this time will be vital.

Wishing you all the best for 2015
Fiona and Nazila

ROPE NEURO REHABILITATION

There has been a lot of new exciting research coming out over the past couple of years about Multiple Sclerosis and Exercise Prescription.

It has been commented within the research that high intensity exercise (working at approximately 80%) increases the anti-inflammatory agent within the body and slows disease progression! A recent study by Platta et al., (2015) noted that there was a 27% reduced risk of relapse with exercise training, and that people with MS should not be deterred from exercise from the fear of relapse. It is important to note that during and up to 2 hours post exercise it is completely normal to experience an increase in symptoms, especially sensory symptoms.

Thinking about a safe way to exercise is key and by incorporating the 7 principles of neuroplasticity into your training, regardless of your ability is important to reach maximum benefit of exercise training. Now that the warmer months are coming, it is also important that you think about heat regulation and how to keep yourself cool. Have an ice cold drink with you, and exercising in the water is always a good option.

MS and Exercise Prescription



Good Luck! If you would like access to the MS and Exercise webinar recently recorded by Stephanie Kurtovich, please email us for more information:

stephanie@ropeneurorehab.co.nz

We hope you have a wonderful Christmas with family and friends, and we hope to see many of your lovely faces again next year.

Merry Christmas from Steph Kurtovich and the team at Rope Neuro Rehabilitation



Christmas Puddings!



RECIPES

Gluten Free Christmas Pudding

Ingredients:

1 c currants
¾ c sugar
¾ c prunes (pitted and chopped)
1 tsp vanilla essence
¼ c dried apricots (chopped)
1 tsp cinnamon
1 c raisins
¼ tsp nutmeg
¼ c ground almonds
¼ tsp all spice
2 apples (grated) ¼ c melted butter
3 eggs 1 c Brandy (optional)
1 dtsp golden syrup 1 c GF breadcrumbs
½ c GF flour



Directions:

1. Combine all the dried fruit and apples in a large bowl. Add the eggs, sugar, spices, brandy and golden syrup and mix to combine. Add the breadcrumbs and flour and mix. Finally, add the melted butter and combine.
2. Pour the mixture into a well-greased pudding basin lined with baking paper. Cover the basin tightly. If it doesn't have a lid, cover with baking paper and tie securely on with string. Place into a pot and add boiling water to the point where it comes halfway up the side of the pudding basin.
3. Place on the stove, covered with the pot lid on a low simmer for 2 hours. Check the water level regularly. Remove from the heat and allow to cool.

Gluten-free Dark Chocolate Bread Pudding

Christmas means bread pudding for my family. Rich, dense and delicious, this gluten-free bread pudding recipe can be served as a dessert topped with whipped cream or do double duty as a hearty breakfast dolloped with yogurt. Serves 8



Ingredients:

8 eggs
1 (400gm) can coconut milk (shake before opening)
1 cup milk ½ cup granulated sugar
½ cup firmly packed brown sugar
1 tablespoon ground cinnamon
1 teaspoon freshly grated nutmeg
1 tablespoon gluten-free vanilla extract
6 cups whole grain gluten-free bread, cut into chunks
1 cup coarsely chopped dark chocolate

Directions:

1. Preheat oven to 180 degrees c and grease a 9 x 13-inch baking dish.
2. In a large bowl, whisk together eggs, milks, sugars, cinnamon, nutmeg and vanilla extract.
3. Add bread and toss to coat. Let sit for five minutes so bread absorbs some of the liquid.
4. Pour bread mixture into prepared baking dish and sprinkle with chocolate, stirring lightly to combine.
5. Bake for 45 minutes or until custard is set and top is lightly browned. Serve warm.

Why respite matters

You're probably used to looking at life in terms of the needs of the person or people you support. So let's start with the reasons why you taking a break is important to them.

"Find time for yourself. Even if it's having a bath, reading a book or making yourself a cup of tea."

Having a break away from you can benefit their health and wellbeing. It can encourage independence, build self-esteem, and provide a broader range of social interactions. When you get back together again, you'll have different things to talk about. If you support an adult family member or friend, they may feel concerned that they need your help. If you take a break, it may help them overcome any sense of guilt they may feel.

For more ideas of how to look after yourself (the carer) please take a look at this link:

http://www.carers.net.nz/sites/default/files/documents/TIME_OUT_Guide-2.pdf

CARERS' CORNER





Over 300 volunteers took to the streets around Auckland for our annual Street Appeal collection on Friday 4th and Saturday 5th September.

We didn't reach our target however we raised \$45,000 which was a great effort.

When you consider the many charities that are always out in the public collecting you can understand 'donor fatigue'. Our appeal sadly comes one week after Daffodil Day and one week before Breast Cancer appeal – two of the biggest charities in New Zealand, so we didn't do too bad.

A special thanks to our Street Appeal Coordinator, Lisa Kent, who did a superb job at organising the collection days, volunteers, banking and logistics. Not an easy job!

A huge thanks to all our special volunteers that give up valuable time during this appeal to support Multiple Sclerosis and raise much needed funds and awareness. Thank you to you all.



Bike the Bridge 2015

EVENTS

In the early hours of Sunday morning 15th November, approximately 3,800 people gathered at Smales Farm in Takapuna to prepare to cycle over the Auckland Harbour Bridge and back again. Certainly an occasion worthy of been ticked off your 'bucket list'.

Multiple Sclerosis Auckland was the chosen charity associated with this event. Spare a thought for MS Auckland staff that were up at 4.00am to set up our hospitality tent, collect a gold coin donation from riders that parked their cars at Smales Farm and we were there at the finish line awarding medals to all finishers.

It's a great event to be involved in, the atmosphere was

electric and seeing the excited faces of the cyclists crossing the finish line is something not to be missed. A great achievement by young (12 and over) and wise (we spoke to a few people in their 80's) and everyone seemed keen to do it all again next year.

Well done to the many cyclists that partook in this event and especially those with Multiple Sclerosis. We even had one lucky person with MS that experienced the whole journey in a Tuk Tuk, kindly ridden by Miss World, Miss North Harbour and one of the members from the famous dance group Jgeeks. It doesn't get better than that!



Spreading the word

Everone received a finisher's medal on the day



Miss World being serenaded by super heroes



Erin handing out medals



Four very happy finishers



Martin Cooper of Harcourts Cooper & Co with Deborah Lambie, Miss World



Fundraisers Billie and Monte cross the line



Tracey (person with MS) sitting next to Eru from Jgeeks, being driven by Brooke (Miss North Harbour)



Miss NZ Tourism speaking with MS Auckland Committee Members Louise Reed and Neil Woodhams



Our great sign at the back of the tuk tuk



BNZ OFFERS MEMBERS A SPECIAL DEAL



Special benefits to help you be good with money.

As an employee or member of Multiple Sclerosis Auckland you can get special deals from BNZ with Your Association Benefits Package.

Home Loans¹

Fixed home loans (excludes BNZ Classic rates)
0.25% discount on the advertised fixed home loan interest rate for the length of your fixed term. Available on all new or rolling fixed home loans.

Variable home loans

0.25% off the Standard Home Loan variable rate including Rapid Repay.

Receive up to

\$1,000 towards legal/valuation costs when purchasing a new home or refinancing to BNZ. We'll also waive establishment fees.

For these discounts a minimum 20% equity required. Rates differ where lending is greater than 80% LVR.

HomeAdvantage²

With a BNZ home loan, you could get a credit card at a variable mortgage rate for the life of your loan.

Rate excludes cash advances. Ongoing 25% equity required.

Insurance⁴

Your big assets in life are worth protecting. Whether it's your ability to earn an income, your home, car, or the things you own, we can make it easy to get the financial protection you and your family need. **LifeCare** can cover you if you are unable to work due to illness or injury, suffer a major illness, or worse.

PremierCare can cover you for accidental loss or damage to your home, car and contents.



Also, get 1 Fly Buys point for every \$20 premium.⁷

Personal loans⁸

\$0 FACILITY FEE We'll waive the loan facility fee and get a low interest rate (the advertised rate for YouMoney tertiary)

Investments

Receive a **50%** discount off plan fees and a **30%** discount off portfolio fees for all retail wealth model portfolios.

Transaction accounts

\$0 MONTHLY ACCOUNT FEE Open a YouMoney⁵ transaction account and we'll waive the \$5 monthly base fee. You'll also get access to our internet banking experience that works like your brain does. Plus you can drag and drop money, personalise your account with names and pictures and use predictive search to find past transactions quickly.

BNZ KiwiSaver Scheme³

Open a BNZ KiwiSaver Scheme account and get 150 bonus Fly Buys points.



Convert your Fly Buys points into BNZ KiwiSaver Scheme contributions.⁷

Bonus offerings

BNZ is the only bank to offer Fly Buys Points⁶ with various credit card, insurance and home loan options. Take out any three products and in addition you could get:

- › Flexi Debit Visa Card – account fee waived for the first 12 months⁶
- › Plus, 100 Fly Buys Bonus Points⁷



Credit cards

\$0 ACCOUNT FEE We'll waive the annual account fee for the first 12 months on all new credit cards⁹, including BNZ Low Rate MasterCard.

Term deposits

Come and talk to us today to see what great rates we are able to offer.

Some things to note:

1. You must be a member or employee of an eligible organisation.
2. Your salary/wages must be direct credited to a BNZ account.
3. The package is reviewed at an organisation/association level every six months and can be altered or removed at any time at the discretion of BNZ.
4. Please present this flyer at your local store when taking up any offers.
5. This cannot be used in conjunction with any other offer. The package discounts are not proactively or retrospectively applied.

Banker Name: Rob Noble-Beasley

Phone: 021 833 181

Email address: Rob.Noble-Beasley@bnz.co.nz

We're ready to help you be good with money.

Ask in store 0800 275 269 workperks@bnz.co.nz

Not for business purposes. Please see reverse for qualifying information.

Confitex Lingerie Show

Very Absorbing *by Diane Hampton*

MEMBERS' STORIES

It's not every day that MS Auckland Field Workers get an invitation to Fashion Week so Georga and I went along to the Confitex Show wondering what to expect.

This was a first for Fashion Week with Confitex being the world's first fashion show for incontinence lingerie.

Their lingerie is stylish and sexy and makes use of a patented fabric technology which makes it reusable so it's not like the bulky, plastic incontinence wear that we currently know.

The catwalk display brought a standing ovation for Frantisek Riha-Scott.

While more women than men have incontinence issues Mr Riha-Scott has also designed a range for men.



The highlight of the after-party function was Mr Riha-Scott emptying his champagne flutes onto the underwear to demonstrate their absorbency capabilities.

To find out more about Confitex products visit their website www.confiteX.nz

“Beauties with a Purpose help People with MS”

by Monique Bradley

Bike the Bridge is a unique event giving Auckland cyclists the opportunity to ride across the iconic Harbour Bridge, while raising money for a disease with no cure: Multiple Sclerosis.

MS is an autoimmune disease of the central nervous system, affecting the brain, spinal cord, and the optic nerves, impairing vision, balance, muscle control, and other basic body functions. MS Auckland supports both its members and their families and caregivers with education, field worker visits, support groups, research days and in some cases rehabilitation and advocacy. Bike the Bridge supports MS awareness with many riders choosing to create fundraising campaigns to raise much needed funds to help those with this disease.

This year, two special 'Beauties with a Purpose' have decided to jump on board and do their bit to support people with MS (PwMS).



Brooke Houia (17, pictured left) in her final year at Orewa College, was recently crowned 'Miss North Harbour' and knows the effects of MS first hand, having been there at her mother Tracey's diagnosis when she was just 10.

'Brooke noticed that I started falling over a lot or having really wobbly legs and having experienced the effects of MS through her Auntie Ann - also a person living with MS - she knew at the age of 10 that something was wrong.' Tracey said.

'It was when Mum started to talk to me as I got older that everything fell into place and I understood what was going on. Since then I've worked to help her and MS Auckland in any way that I can, collecting for appeal week, speaking about living with MS at my pageant and continuing to be an ambassador for MS awareness moving forward.'

Brooke has opened her own fundraising page via the Everyday Hero official fundraising website and hopes to achieve her goals of raising both awareness and monetary support for MS Auckland through the Bike the Bridge event.

Another 'Beauty with a Purpose' - Deborah Lambie (23, pictured right), is preparing to travel to China to represent NZ at the Miss World Pageant - on the same day she graduates as a Doctor. As an Ambassador for education and health, as well as having personal first hand experience with people living with MS, Bike the Bridge is to be a special event for her also, having a very auspicious part to play.



'My job is to pedal over Auckland Harbour Bridge in a Tuk Tuk, carrying a person with MS! I'm really looking forward to this. It's going to be a great event, for a fantastic cause!'

© www.starlightmediahouse.co.nz

Multiple Sclerosis

Recognising a relapse



Occasional Symptoms can be caused by...



Increased body temperature



Infection



Stress

Watch and wait

These symptoms come and go and may not require treatment.



Symptoms Lasting more than 48 Hours



Weakness



Dizziness



Changes in vision



Altered sensation

Contact your GP and MS Nurse:

09 307 4949 extn 25885

You may need an appointment with your GP, they can contact your neurology team to discuss your symptoms



Seek Urgent Advice



Falls with injury



Sudden loss of vision



Severe balance issues



Problems breathing



Inability to walk



Seek urgent medical advice

Blenheim mates turn scrap metal into masterpiece

by Jennifer Eder/Stuff.co.nz

Marlburians Pete Rickerby and Gordon Forshaw have built a classic 1973 Yamaha 650 motorbike from scrap metal.

Two mates from Marlborough, one with Multiple Sclerosis and the other Parkinson's Disease, say rebuilding a classic motorbike from scrap metal was like the "blind leading the wobbly".

Pete Rickerby and Gordon Forshaw started work on the 1973 Yamaha 650 motorcycle in November last year.

The project was a welcome distraction from their illnesses, but also taught them about each other's daily struggles.

Rickerby, who suffers from Multiple Sclerosis, said rebuilding the entire engine was a gruelling task.

"It did take longer [for us], but not hugely longer," he said. "We had to do things twice occasionally, or Gort [Forshaw] would have a fit, and that'd be it for the day. I didn't know a lot about Parkinson's before I met him. It's terribly cruel."

Gordon Forshaw, left, and Pete Rickerby say building a classic motorbike from scrap metal was "challenging but rewarding".

Rickerby's own illness caused him much frustration. He would never be able to ride the bike because he had only a third of his sight, and the degeneration of the brain and spinal

cord affected his mobility.

Forshaw could not ride the bike unless he was having a good day, he said.

"I get too anxious now with the Parkinson's to ride it. But I repainted the tanks the other day, and jumped on it to put a new tyre on, and I got all my confidence back.

"I'm going to take it for a ride today and get a warrant for it," Forshaw said.

Rickerby and Forshaw kept each other in good spirits during the rebuild. They had been friends for nearly three years, after meeting at

a pub where Forshaw played the harmonica in a band.

"It's been a lot of fun," Forshaw said.

The pair could no longer "work to a clock", so projects like the Yamaha kept them busy, Forshaw said.

"It keeps my brain active."

The Yamaha was Rickerby's first mechanical project, but it was Forshaw's fourth.

But they had already

moved onto their next project together, Forshaw's old mobility scooter.

"Mobility scooters are great, but I really hate them with the basket on the front, so I got a grill," Forshaw said.

"I'm looking for an Alfa Romeo grill for Pete.

"I'm trying to build this thing that's like a little car, so it'll have a little roof for when it rains. It'll be a two-seater. We'll get to town at a better speed. It's gotta be comfortable, and it's gotta look cool."

The Marlborough Express



Photo: Scott Hammond, Fairfax NZ

PRESS RELEASE

MS Auckland welcomes PHARMAC's release of a consultation document that proposes to list two new treatments for Multiple Sclerosis (MS) – dimethyl fumarate (Tecfidera) and teriflunomide (Aubagio) and to make amendments to the Special Authority criteria relating to MRI requirements for all MS treatments. In summary, the proposals would, from 1 February 2016 result in:

- dimethyl fumarate (Tecfidera), supplied by Biogen NZ Biopharma Limited ("Biogen"); and
- teriflunomide (Aubagio), supplied by Sanofi-Aventis

New Zealand Limited ("Sanofi") being funded in the community and in DHB hospitals subject to the same restrictions that apply to natalizumab (Tysabri) and fingolimod (Gilenya); and - changes to the Special Authority criteria for MS Treatments relating to MRI requirements, to ensure clarity and better reflect the intent of the criteria. The proposed changes to the Special Authority criteria relating to MRI requirements are not dependent on the proposals to list dimethyl fumarate or teriflunomide.

"I'm sure that's a giraffe down there!" I shouted above the loud drone of our little Cessna aeroplane's engine as we came in to land on a dusty airstrip in the middle of the Selenkay Conservancy, Amboseli, Kenya. A lone jeep was waiting to meet me, my 16 year old daughter Billie and two other New Zealand women at the beginning of our 8 day safari adventure with Gamewatcher Safaris. Our Maasai warrior guides, Wilson and Melita, resplendent in traditional red robes and laden with silver and beaded jewellery, welcomed us and calmly announced they'd just had to chase a pride of lions off the runway so our plane could land!

This was truly a "trip of a lifetime", that I would recommend to anyone. You may think that a trip to Africa sounds way too difficult for someone with MS or a disability, but the truth is

quite the opposite. The great thing is that a safari is vehicle based – all that is required is to be able to get in and out of the 4 wheel drive (and the guides are really helpful) and then sit back and enjoy the amazing scenery and wildlife. The only walking you really need to do is the few metres from the dining tent to your sleeping quarters. We went in early July at the beginning of the season, and the weather was quite cool – there was only one really hot day when we travelled to the Masai Mara national park. In Kenya we stayed

in the Maasai-owned wildlife conservancies adjacent to national parks, where there are only a few camps and tourist numbers are limited. The money earned from tourism here goes straight to the Maasai people so it is a real incentive to protect habitat and wildlife and it creates employment. Because tourist numbers are strictly limited, unlike the national parks,

when we went out on morning and afternoon game drives we very rarely saw another vehicle and we could get right up close to the animals, going off road and even out at night. What an amazing experience to be just metres away from a pride of lions or a herd of elephants in a small open-sided Toyota! The wonderful and welcoming camp staff went out of their way to cater to our every need, cooking amazing

meals, even catering to my OMS (Jelinek) diet out in the wilderness with fish from Lake Victoria and delicious salads and tropical fruit.

We stayed in an Adventure camp, in domed tents, which might be a little tricky for those with more limited mobility, but there are



also the more luxury tented camps complete with proper double beds and ensuite bathrooms. After Kenya we spent 8 days in Tanzania staying in lodges – but these often had lots of steps so in some ways the tents were easier. And the Cessna plane was a bit of a squeeze to get into but you can choose a road-based trip instead (like we did in Tanzania). My travel agent at African Safaris (www.africansafaris.co.nz), was amazing and organised everything with people to meet us every step of the



way after I explained my limitations. Another great travel tip when flying is when you book your flights to ask for travel assistance. This is especially important if you have to change planes in big unfamiliar airports – you are met at the plane door with a wheelchair and then taken via all

the shortcuts straight to the front of the security queues and then straight to your next departure gate. I would get exhausted very quickly traipsing along those endless airport corridors otherwise, and some airports like Dubai or Singapore are just huge.



People ask me what were the highlights but I can't honestly pick any out – every day I would look at Billie and say “we can't possibly top that!” and then something else amazing would come into view – jackals and vultures devouring a dead giraffe, lion cubs playing

at dusk, a leopard up a tree, a giraffe drinking at the waterhole, a visit to a Maasai village, lions roaring outside our camp at night, stopping on the road as a herd of elephants parted and went either side of us, waiting for half an hour as a mother and baby elephant refused to get off the road, sundowners as the sun set over the Masai Mara ...

So if you've ever dreamed of Africa – I would really encourage you to do it. It's certainly given me the confidence to know that travel is not in the too- hard-basket for someone with MS. Now where to next?

MEMBERS' STORIES



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Kiwi Gold aiming for the Paralympics

by Dana Johannsen

The three members of disabled sailing team Kiwi Gold have all had tough roads to travel, and now must conquer some rough seas to reach the Rio Olympics. They tell Dana Johannsen about their quest for the next year's Paralympics.

Rick Dodson won't let up. Pitted against the Australians, one of the top-ranked disabled sailing teams in the world, in a series of training races in Melbourne, the former Team NZ strategist's competitiveness surges like a spring swell as his Kiwi Gold crew race bow to stern with their opposition.

Multiple sclerosis has wreaked havoc with some of Dodson's internal wiring, slowing the transmission of messages between his brain and his nervous system. His eye-sight, balance and co-ordination aren't what they used to be, but his tactical awareness remains as sharp as ever.

He tacks and gybes right on top of the Australians, never allowing any breathing space as he tailgates them across the course.

"You could almost see Richard's eyes glaze over and the old America's Cup strategy kicking in," says Don Cowie, the coach of Kiwi Gold Sailing and a veteran of three America's Cup campaigns himself.

For the past 18 months, however, most of Dodson's battles have been fought off the water.

He's seen his former Team NZ crewmate and Kiwi Gold original, David Barnes, who also suffers from MS, forced to quit the campaign after his health rapidly declined. He's gone through the months of uncertainty while the team remained in a holding pattern as they searched for a replacement for Barnes.

And he, with the help of a small but committed group of supporters, has battled through funding shortfalls that kept the team from competing in any international regattas this year.

Having endured all these setbacks, this week's para world sailing championships in Melbourne will be the Kiwi Gold team of Dodson, Andrew May and Chris Sharp's last chance to qualify for the 2016 Paralympics in Rio.

Now is not the time to be letting up.

Two greats from New Zealand sailing's golden era - Dodson and Barnes - both, by some cruel coincidence, diagnosed with MS at around the same time in the late-90s. After gentle coercion by some of the big-wigs at Yachting New Zealand, they decided to band together to give the Paralympics a crack and recruited May, a two-time Paralympian who has been wheelchair bound since a car accident in his teens, to join them in the Sonar class.

High profile supporters were also quick to jump on board. It took a 30-second conversation between team manager Mike Clark and Neville Chrichton for the automobile tycoon

to write out a cheque for \$60,000 to buy the team's first boat, while Sir Michael Fay is a mentor for the campaign.

The team were confident of success ahead of their first opportunity to qualify for Rio at last year's world championships in Halifax, Nova Scotia. Having placed eighth the year before in Ireland in their first international, a podium finish looked well within their grasp.



Rick Dodson and David Barnes

That confidence unravelled on day one of the regatta, when Barnes' health took a drastic turn.

"He had an MS attack and it completely wiped him out," recalls Celia Snedden, Dodson's sister and chief wrangler. "He sent us an email on that first night and said, 'I don't know what's happened, it feels like I've been hit by a bus'."

Without the time or money to get their reserve crew member, Wanaka-based Quentin Smith, to Halifax, the team had no choice but to take the ailing Barnes, who was barely able to move, out on the water with them each day in order to comply with the class rules.

It was to be Barnes' last regatta with the team. After stepping onto the plane in Auckland, he returned home in a wheelchair.

The loss of Barnes nearly spelt the end for Kiwi Gold, says Snedden.

"I had sleepless nights thinking, 'How on earth are we going to find someone?'"

Not only did the team need a good yachting to replace the experienced Barnes, they needed someone that fit the complicated Paralympics classification matrix.

With Paralympic sailing, the athletes are classified 1-7 depending on their level of impairment. In the three-person sonar class, the team must have a collective total of 14.

Dodson is classified a six, May a four, so they needed to find another four.

But their four was in hiding, still getting to grips with becoming, well, a four, after a split-second mistake.

It took the persistence of a close family friend, Andrea Kendall, who had heard of Kiwi Gold's predicament, to convince Sharp to get back into sailing.

"She rang me every day for three weeks until I just gave up and said, 'Okay, I'll come down and have a sail with them.' It was the best thing I ever did."

The team's psyche was in a bad place when they returned from Halifax down a team member and having failed to qualify the boat for Rio. But Sharp's enthusiasm and willingness to get stuck in has helped reinvigorate the team.

With a building background and a practical bent, Sharp took it upon himself to take a leading role in boat maintenance and was soon appointed as the "on-land skipper", with

Dodson remaining the "on-the-ropes skipper".

Dealing with the fatigue that comes with MS - not just tiredness, but chronic, debilitating exhaustion - means Dodson often struggles to motivate himself, let alone the team.

Snedden says having Sharp manage the gear and getting the team on the water in time has been a godsend.

The hours upon hours the team have spent out on the Waitemata Harbour in Maserati, their aspirationally named boat, has put them in good nick heading into the world champs, where they must finish in the top seven to qualify for Rio.

Having been unable to pull together the funds to compete overseas this year, there is some uncertainty over what

MEMBERS' STORIES

happens if and when the team qualify for Rio.

Achieving the qualifying standard is no guarantee they will be selected for the Games - that lies in the hands of the Yachting New Zealand selectors. The national body have so far kept their distance from the Kiwi Gold campaign, offering encouragement, but little in the way of tangible support.

The crew will likely need to demonstrate over the next week they are capable of medalling in Rio, but this is assumed - as yet Kiwi Gold has had no official word of what they need to achieve results-wise in Melbourne.

It's that last proviso that keeps Snedden awake late at night. She estimates the team will need to find \$175,000 if they are to compete in a full regatta programme before Rio.

Money may be in short supply for Kiwi Gold, but goodwill is not.



Kiwi Gold Sailing para-sailing members Rick Dodson (left), Andrew May (centre) and Craig Sharp (right). Photo: Nick Reed

Dodson, who has won just about every major prize in yachting - as well as his success in the America's Cup he's skippered teams to One Ton Cup and Admirals Cup victories - can't fathom how New Zealand leads the way in virtually all forms of sailing, yet don't feature in disabled sailing.

"We want disabled sailing to have a profile here, but to do

that we have to go out and win regattas," he says.

He's interested to know what I, the writer, have learned from my time out on the water with the team. Had I noticed anything different about the way they sailed the boat compared to others?

"Not really," I say, "you guys seem to have a workaround for everything."

"That's right," he says. "Nothing is insurmountable, there's always a way - you just have to want to look for it."

**Dana Johannsen (edited by Thérèse Russel)
NZ Herald 26 November 2015**

HOT OF THE PRESS – The boys have qualified for the Paralympics in Rio!

Hydrotherapy – Why every Member should be enjoying this activity

All Hydrotherapy (Water Walking) sessions are run by Rope Neuro Physiotherapists. All Water Walking sessions are 1.5 hours with the exception of Saturday which runs for an hour. The benefits include:

- Water Walking focuses on a whole body work out, rather than isolated areas of the body. By using both the lower and upper body Water Walking covers both strength competencies and cardiovascular components.
- Water Walking provides a supportive environment where fatigue levels are able to be monitored on an individual basis.
- Group dynamics are more motivating. The group provides a social component where people suffering from the same condition can connect to each other.
- For those with balance difficulties, there is a risk involved with exercising on land and this can be challenging. Exercising in water removes that challenge and reduces the risk.
- Where a person with MS is not mobile on land they are more likely to be able to keep up in a group situation in water.
- Decreased weight bearing is beneficial especially in the older population as Water Walking allows joint stiffness to be released.
- Water Walking is very good for pain, especially those with chronic pain, providing a non-weight bearing situation.

Call Kirsty at the office 845 5921 and find out where you can attend classes near where you live.



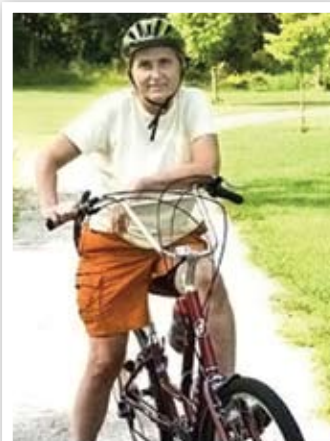
Who follows Terry Wahl's programme?

One of our members has got in contact with us to see if anyone gets Terry Wahl's regular emails and would be prepared to forward them onto her?

She is about to embark on the Wahls Paleo Plus programme and went to register on the site to receive her encouraging emails which she used to get a year or two ago.

You now have to pay a yearly subscription fee for them which is out of reach for her. Is there someone who gets these newsletters who might be happy to forward them on to her?

If so please contact the office and we will give you her contact details.



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Gilenya® (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, or experience worsening of your MS symptoms. 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 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 2. Pharmaceutical Schedule available at www.pharmac.health.nz



Funding brings MS clinical trial closer

The journey to deliver a new (and first-ever) treatment for secondary progressive MS has been bolstered by a \$1.2 million grant to Dr Anne La Flamme, a long-time associate of the Malaghan Institute, who was recently awarded the funds through the Ministry of Business, Innovation and Education's 2015 Science Investment Round.

MS can be broadly categorised into four basic clinical patterns. While there is no cure, disease-modifying drugs are available but are only effective in the relapsing remitting form of MS. There are no long-term therapies for the secondary progressive form that causes patients the greatest reduction in quality of life.

Anne's plan is to build on her experimental models and trial the use of low doses of two commonly prescribed anti-psychotic drugs, risperidone and clozapine, in people who have secondary progressive MS.

"These drugs have been used for decades to treat patients with various mental health disorders, but to

adapt them to treat MS; we must balance the possible side effects with the drugs' potential therapeutic benefits. Many people assume incorrectly that because a drug has been through clinical trials at a dose specific for one disease, investigations for another purpose would be rudimentary.



Dr Anne La Flamme

But taking a higher dose to treat an episode of psychosis is a long way from taking a drug at smaller doses over many years and MS patients may live with their disease for several decades. The ultimate aim for MS researchers worldwide is to find a way to prevent MS. The next best option is to stop the disease progressing and to restore function lost especially in people with the progressive forms of MS. Finding

new treatments for this group of patients will make a huge difference to many lives," says Anne.

The trial is planned to take three years to complete. The ultimate aim of this clinical trial is to determine which drug is more acceptable and shows therapeutic promise.

MS Auckland Research Day



As promised we have now uploaded the speaker's presentations from our Research Day held at Alexandra Park. For those of you who would like a re-cap, please enjoy and for those of you who were unable to attend, we are sure you will find the content very interesting.

<http://msakl.org.nz/about-ms/research/>

Also on this link you will find Jennifer Pereira's presentation from the Wellness Workshop event in October.

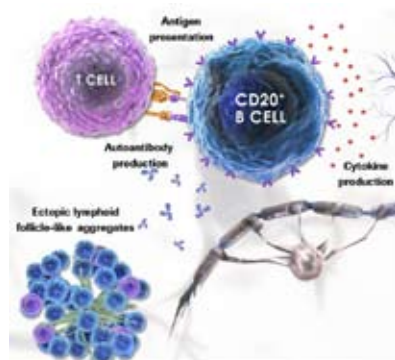
This is an extract from Roche's YTD Sales Report on all their drugs. These pages relate to great progress for PPMS. Should you wish to read their full report please click on the link below.

<http://www.roche.com/irp3q15e-a.pdf>

Ocrelizumab: First drug active in both RMS & PPMS

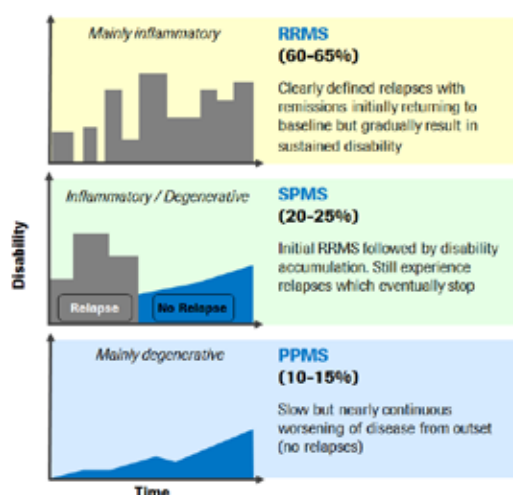
Roche

Results confirm central role of B cells in MS



Targeted product profile

- Humanised anti-CD20 antibody
- Selective depletion of a B cell subset leaving the ability to generate new B cells intact
- Administered IV twice yearly



RMS=relapsing forms of multiple sclerosis (MS) which includes patients with RRMS and SPMS with superimposed relapses; RRMS=relapsing-remitting MS; SPMS=secondary progressive MS; PPMS=primary progressive MS; Adapted from Lublin 1996, Arnold 2004

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ORATORIO: Positive results in PPMS

First positive efficacy outcome

Roche



	Study Endpoint	Relative Risk Reduction versus placebo
		ORATORIO
1 EP	CDP (12 wks)	24%
Key 2 EP	CDP (24 wks)	25%
	Timed 25-foot walk (baseline to wk 120)	29%
	T2 lesion volume (baseline to wk 120)	3.4%
	Whole brain volume (wk 24 to wk 120)	17.5%



ORATORIO

- Data establishes role of B cells in PPMS
- Significant risk reductions on primary and key secondary endpoints
- Favourable safety profile: Serious infections similar to placebo during a mean treatment duration of 3 years

PPMS=primary progressive multiple sclerosis; CDP=confirmed disability progression

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Official launch of the New Zealand Multiple Sclerosis Research Trust

On Thursday 19th November we were thrilled to launch the New Zealand Multiple Sclerosis Research Trust, here in Auckland.

The event was held at The Crew Club (highly recommended) in the Viaduct.

We were very fortunate to have Sir Robert Jones as our guest speaker, he was extremely entertaining. We also heard from Chairman Tim Preston, Trustee – Neil Woodhams and Researcher – Dr. Deborah Mason.

If you would like to donate to our Research Trust please following this link <http://msresearch.nz/>



Dr. Brian Linehan (Trustee NZMSRT)



Aleida White (Trustee NZMSRT)



Graham, Sir Robert Jones (Guest Speaker) and Thérèse Russel



Tim Preston (Chairman NZMSRT)



Neil Woodhams (Trustee NZMSRT and Chair MS Auckland Committee)



Guests



Cindy, Andrew and Amanda Keefe (MS NZ National Manager)



Graham Wear (MS Auckland Committee)



Andrew and Malcolm Rickerby



Dr. Deborah Mason (MS Neurologist CDHB) and Malcolm Rickerby (Trustee for NZMSRT)



Doug Haines from BDO (Trustee NZMSRT)

Australians are at the Multiple Sclerosis Innovation Forefront

HEALTH & RESEARCH

On 13 October 2015 CCSI Australia (also known as Neurovascular Research Australia) was announced as a finalist in Melbourne Australia's 2015 awards for "Innovative organisations, iconic institutions and outstanding individuals".

Despite receiving no government funding, their fundraising allowed them to commission an internationally recognised and endorsed medical trial of the removal of jugular vein obstructions in people with Multiple Sclerosis (MS) to relieve MS symptoms.

The trial has attracted global interest, funding and talent to The Alfred Hospital, and placed The Alfred at the forefront of medical research, with world-renowned scientists and medical specialists visiting to collaborate. While much is being achieved by the remarkable Alfred

Hospital "patient centred" innovation there is significant scope to accelerate this iconic research. Given that an estimated 200,000 Australians are associated with families living with MS better targeted government policies and programs readily spring to mind. The very recent emphasis by Prime Minister Turnbull identifying the importance of fostering Australian innovation accentuates this need

Find out more at <http://www.msnetwork.org/future/alfred-innovation-forefront.htm>

As ever your feedback and ongoing support is appreciated.

**Peter Sullivan. On behalf of
Multiple Sclerosis Network of Care, Australia**
<http://www.msnetwork.org/news.htm>

Vitamin D gives brain protection to MS patients

A new Yale co-authored study links higher vitamin D levels to possible neuroprotection for individuals suffering from multiple sclerosis.

The study, published in the European Journal of Neurology, draws a connection between higher vitamin D levels in the blood and higher gray matter levels in the brain. For individuals with MS, low vitamin D levels are linked to relapses and lesions in the brain, wrote principal investigator Ellen Mowry, neurology professor at Johns Hopkins University, in an email to the News.

The National Multiple Sclerosis Society, a funder of the research, is currently involved in many studies attempting to ascertain the exact relationship between vitamin D and the causes and symptoms of MS, according to the National MS Society website.

"Higher levels of vitamin D in the blood are associated with a lower amount of loss of brain tissue over the course of the study. If this association is true, vitamin D supplementation could be studied as a way to prevent damage to the actual brain tissue," Mowry said.

MS occurs less frequently in regions closer to the equator, where the exposure to sunlight and to vitamin D is higher, Mowry said. She added that her study aims to further validate that connection between vitamin D levels and MS. However, according to Scott Zamvil, neurology professor at the University of California, San Francisco and co-author on the paper, it is unclear whether vitamin D's connection to MS is a causal relationship or simply a correlation.

The research was conducted using data from a 2012 study for which Zamvil was the principle

investigator. From the data set collected for that study, 65 individuals were eligible for Mowry's research, Zamvil said. The MRI data for those individuals was analyzed to measure gray matter volume in the brain and brain atrophy — the loss of brain tissue over time.

"The MRI was used to identify an association between the levels of vitamin D and changes we know are happening in brains with MS," said Emmanuelle Waubant, co-author of the study and neurology professor at the University of California, San Francisco.

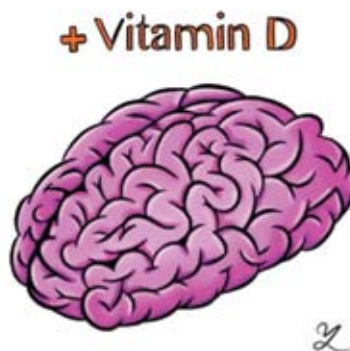
The researchers looked at new lesions in the brain, which indicate relapses, and measures of atrophy in the brain. The strongest correlation was drawn between lower vitamin D levels and high levels of brain atrophy,

Waubant said, though she added that this does not confirm causality, since there may be another factor that leads to both low vitamin D levels and high brain atrophy.

The study is one of many looking at the role of vitamin D in MS, and has implications for both the understanding of the causes of the disease and the value of vitamin D supplements in treating it, Waubant said. Vitamin D supplements are already used for MS patients with unusually low vitamin D levels, but there are currently trials ongoing to see how those supplements in different forms can be used to treat the disease overall, Waubant added.

Maya Chandra
Yale Daily News, Nov 10, 2015
Illustration: Yanna Lee

<http://yaledailynews.com/blog/2015/11/10/vitamin-d-gives-brain-protection-to-ms-patients/>





Overcoming Multiple Sclerosis Announces Expansion to United States Following Success in Australia and Europe

NEW YORK, Oct. 28, 2015 /PRNewswire/

Overcoming Multiple Sclerosis (OMS), an organisation dedicated to improving health outcomes of people with MS through its lifestyle risk modification programme, announced today its expansion into the United States. Recently, OMS unveiled a new website geared toward educating the MS community and announced the publication of two research studies in significant medical journals.

Overcoming Multiple Sclerosis promotes its OMS Recovery Programme, a well-established lifestyle programme conceived in Australia by Dr. George Jelinek – a doctor, professor of medicine, researcher and MS survivor. The OMS regimen combines diet modifications and lifestyle management to encourage health and quality of life improvements in MS patients.

“My experience with MS inspired me to study the disease and develop the OMS Recovery Programme,” said Dr. Jelinek. “My mother had MS and before she died, she was unable to care for herself. When I was diagnosed, I was determined not to have the same fate and wanted to help others living with MS improve their quality of life.”

Since 2012, OMS has conducted its HOLISM (Health Outcomes and Lifestyle Interventions in a Sample of people with Multiple Sclerosis) study, a 57-country survey of 2,500 people with MS, many of whom follow the OMS Recovery Programme. Overall, the study showed significant improvements in health outcomes and quality of life for people with MS on the OMS Recovery Programme.

In 2015, two research studies emanating from a HOLISM survey were published supporting the Programme. The first, published in Neurological Sciences, affirmed that positive outcomes are associated in people with MS who follow the OMS Recovery Programme. Another study, published in PLOS ONE, confirmed that lifestyle modifications recommended by the Programme could reduce the likelihood of fatigue and depression in people with MS and improve quality of life.

Since its inception in 1999, OMS has worked towards making its Programme available to the estimated 2.5 million people living with MS worldwide and has not accepted funding from the pharmaceutical industry. For more information, visit www.overcomingms.org.

About Overcoming Multiple Sclerosis

Overcoming Multiple Sclerosis (OMS), a pending 501 (c)(3) nonprofit organization in the U.S., is a registered charity in the United Kingdom and Australia dedicated to improving the health outcomes of people diagnosed with MS through its scientifically tested diet and lifestyle programme. The regimen, which promotes healthy living in addition to standard medical care, was developed by Dr. George Jelinek in Australia, and has since expanded into the United Kingdom, Europe and the United States.

For Media Inquiries:

Rebecca Pineiro

917-595-3032

rpineiro@cooperkatz.com

State Finalist Australian of the Year 2016

When George Jelinek was diagnosed with multiple sclerosis (MS) in 1999, he was determined that the disease would not dictate his fate.

A distinguished career as a professor in emergency medicine and a background as editor-in-chief of a major medical journal gave George the tools to examine the medical literature on MS. By enquiring deeply using scientific methods, George discovered that MS could be controlled through lifestyle factors such as good nutrition and exercise.

Initiating the world's first lifestyle MS self-help program in 2002, George has shared his findings with the world. Together with others who remain well with MS, George



has founded Overcoming Multiple Sclerosis, a charitable organisation with subsidiaries worldwide. He has written countless papers for academic journals, conducted research studies and hosts regular retreats for people living with MS.

In 2015, George was appointed Professor and Head of Neuroepidemiology at a new unit within the University of Melbourne and continues his search for evidence-based science that helps people with MS lead healthy lives.

George was a state finalist for Victoria but didn't make the final being pipped to the post by Julian McMahon a human rights lawyer.

NOW FULLY FUNDED HELP STAY ACTIVE¹

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.^{1,2}



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

biogen idec[®]

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TYSABRI is a funded medicine – a prescription charge and Special Authority criteria apply.



The following articles appeared in Issue 36 of this year's NRR.

Oral versus intravenous high-dose methylprednisolone for treatment of relapses in patients with Multiple Sclerosis (COPOUSEP)

Authors: Le Page E et al., for the COPOUSEP Investigators

Summary: This study compared the use of oral versus IV high-dose methylprednisolone for the treatment of relapses in patients with MS. 199 patients aged 18–55 years with relapsing-remitting MS who reported a relapse within the previous 15 days were randomised to receive oral or IV methylprednisolone (1000mg once a day for 3 days). Mean time from relapse onset to treatment was 7.0 and 7.4 days in the respective groups. 81% of patients in the oral group and 80% of patients in the IV group had improved by day 28 without the need for retreatment with corticosteroids. Rates of adverse events were similar between groups, although insomnia was reported more frequently in the oral group (77% vs 64%).

Comment: Steroids shorten the duration of an attack of MS, but do not alter the long-term progress of the disease. To get into the brain, very high doses are necessary, and we routinely use 1000mg of methylprednisolone. Traditionally, this has been given intravenously, which often means an inconvenient hospital admission. Oral methylprednisolone is well absorbed, and it has been the practice among NZ neurologists for some time to prefer oral to IV methylprednisolone for MS relapses. This study supports that approach.

Reference: Lancet 2015; 386(9997):974-981

Vitamin D and risk of Multiple Sclerosis

Authors: Mokry L et al.

Summary: This Mendelian randomisation (MR) study evaluated whether genetically lowered vitamin D (25(OH) D) levels influence the risk of MS. Data for 14,498 cases and 24,091 healthy controls in the

International Multiple Sclerosis Genetics Consortium study were evaluated. MR analyses found that a genetically determined 1-SD decrease in log-transformed 25 (OH) D levels conferred a 2.0-fold increase in the odds of MS. Whether vitamin D sufficiency can delay or prevent MS onset merits further investigation.

Comment: Here is more evidence for a link between vitamin D and MS. We still do not know if supplementation makes a difference, and it is possible that there is a “U” shaped curve with higher doses being harmful. Despite this many patients with MS are now taking vitamin D supplementation while they await the outcome of randomised trials.

Reference: PLoS Med 2015; 12(8):e100186

New Zealand's neurologist workforce: a pragmatic analysis of demand, supply and future projections

Authors: Ranta A et al.

Summary: This study estimated current and future specialist neurologist demand in NZ. Current demand for the neurology workforce was assessed using neuro-epidemiological data, and supply was assessed by surveying all NZ neurology departments.

Projections were based on current neurologists' anticipated retirement rates and addition of new neurologists based on current training positions. The current supply of neurologists was found to be 36 full-time equivalents (FTE), which is insufficient to meet current demand (74 FTE). Demand is likely to grow over time and the gap between supply and demand will widen. The investigators proposed a 12-year strategic approach to address their findings.

Comment: This is sobering reading. NZ has traditionally managed with a small number of neurologists. This may not be possible in the future as new and complex treatments are introduced, and neurologists are expected to participate more in the acute management of disorders

like stroke. The average age of neurologists in NZ is 52, so we are facing a workforce crisis as many of them retire over the next 10–15 years.

Reference: NZ Med J 2015; 128:1419

Independent commentary by Dr Barry Snow

Barry Snow was educated at Auckland Medical School. He spent his first house surgeon year at Rotorua Hospital where he learned to catch trout.



After his FRACP examinations in 1983, he pursued geriatrics training before changing to Neurology training at Auckland Hospital. From 1998 to 2005 he taught at the UBC Medical School, Vancouver.

There he was engaged in research into Movement Disorders, particularly Parkinson's disease; he

has published over 100 papers in the area.

He returned to NZ in 2005 to join the Department of Neurology at Auckland Hospital and is currently Director of Adult Medicine at Auckland District Health Board. In addition to his general Neurology work, he runs a Movement Disorder Clinic and research programme.

Barry Snow sends out a regular Neurology Research Review; if you would like to be added to his email list please contact him at barrysnow@researchreview.co.nz



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Some of the Group



The talented Maria made everyone a decoration to hang on their tree



One of our lovely volunteers - Jocelyn with Peta



A cheeky Peta getting into the Christmas spirit

Esme Tomlinson Award for the Person with Multiple Sclerosis of the Year 2015



Our very own Sarah O'Neil accepts the award with husband, Tom and their two boys.



Pip with volunteer Judy



Thérèse talking with volunteers, Louise and Sharon

The Epsom Pool Christmas Party

ms.

**Multiple Sclerosis
AUCKLAND**



Heather looking her usual glamorous self



Pip with her mum and MS Ambassador - Lorraine



Roger and Noel looking ready to party