

MAY/JUNE 2015

ISSUE 29

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.

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A few words from the CEO...

These are exciting times for MS Auckland as we celebrate turning 50 years. There are not many organisations, let alone charitable organisations that are still around after 50 years, so we have something to be really proud of. Many people have contributed to this milestone with their commitment, time and support in various ways and we are so grateful to each and every one of you. We are currently writing our 50 year history and it involves several people, (too many to mention) that have been involved since we started. That promises to be a very valuable manuscript which will include interviews from first Members of the Society, the first volunteer Field Worker, past Committee Members and staff. The completion of our history is due later in the year and will be available for all Members to read.



As many of you know May is the month that MS is remembered around the world and in particular 27 May is **World MS Day**. We have been busy organising some events to raise awareness of this condition with no cure (yet!). We are so privileged to have the **Oceans of Hope** yacht arriving in Auckland on 5 May and sailing opportunities have been made available to all Members – I hope you have taken this once in a life time chance to have a two hour sail around our beautiful Harbour and then lunch with the crew, at the Royal New Zealand Yacht Squadron which is being hosted by Biogen.

We are once again presenting a **Research Day** (see Agenda later in this issue) and we are thrilled with our line up of presenters. Bookings are essential! You won't be disappointed and Professor Simon Broadley has just told me he will also be speaking about Stem Cell transplant which is an interesting topic for many of our Members. You may have read in the Herald a couple of weeks ago about a young family man with MS who has mortgaged his house to go to Singapore to have the procedure done there. We will follow his progress as he was on the MS National Committee and is involved with MS Wellington. We wish him all the best.

Also on 27th May we are hoping to light **Sky City** up in orange to bring greater awareness to MS. They seem very keen to do it, so if you see an orange tower on 27th May, you know we were successful. Fingers crossed, as it would be a great talking point.

We are asking any Members who would like to host a **'Good Sorts'** morning/afternoon tea to ring the office and we will help you organise it. We encourage these get-togethers with family and friends in May so that we can concentrate on awareness month. Last year many of our Members had such a fun time hosting a 'Good Sorts' tea party and raised several thousand dollars for MS Auckland. You could combine with another friend and host one, that is what I'm doing.

Don't forget to book your table for **Life Buoy for MS** on Friday 26th June at the Royal New Zealand Yacht Squadron. This event was a sell out last year, so

Continued bottom of page 3

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Please don't rely on the information in these pages to imply any diagnosis or course of treatment. You should not rely on this information in place of a visit, call, consultation or the advice of a physician or other qualified healthcare provider. Content neither indicates nor reflects the views of MS Auckland. Any research, study, clinical trial, event, news or other item included in Multiple News is not intended to imply endorsement or approval of it by the Society. Although we have made a conscientious effort to provide high quality information, MS Auckland disclaims any implied guarantee about the accuracy, completeness, timeliness or relevance of any information.

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Notice Board

Portable Hoist

The Millennium Pool in Mairangi Bay has a brand new super portable hoist that can go anywhere in the Pool area to assist people in getting into and out of the pool.

This has been a problem in the past with only one fixed point for a hoist at the pool. If you are now interested in coming to the pool please contact Diane Hampton, North Shore Field Worker on 845 5921 ext 219.

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 or phone 845 5921.

Honorary Life Members

**Always appreciated,
never forgotten**

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

Calendar

Important dates to remember...

6th-12th May

**Oceans of Hope
Yacht in Auckland**

*(see details later
in this issue)*

16th May

**Research Day at
Alexandra Racepark**

*(see details later
in this issue)*

27th May

MS World Day

26th June

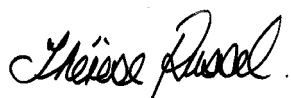
**Life Buoy for
MS Charity Luncheon**

**4th/5th September
Street Appeal**

don't leave your booking until the last minute as you may end up disappointed. We are very grateful to our partners for this event – Fidelity Life and Harcourts Cooper & Co.

Thank you very much to the many Members that offer such wonderful positive feedback about this Newsletter. We are delighted you enjoy it. We are very appreciative to Sir John Logan Campbell Estate who fund the publications so that the Society can offer an important benefit to all our Members. If you have any articles you would like included, we would love to hear from you. This is your magazine.

So take a half hour break, put your feet up, grab a cup of tea and enjoy the read.



THÉRÈSE RUSSEL
Chief Executive Officer

From the field...

Our Field Workers



Diane Hampton, North Shore



Carol Andrews, Central



Georga Forgac, West



Dianne Bartlett, South

2015 is a special year for the Auckland MS Society as we celebrate our 50th year! We have many events planned and would love you to join us to help make this year a special one.

Oceans of Hope

Oceans of Hope is the MS sail boat, coming to Auckland City during May. Manned by a crew of people with MS, the boat will be here for 6 days and this is your chance to experience either a morning or afternoon sailing. It is wheelchair friendly and previous sailing experience is not required. As part of this event, there will be a lunch between sailings for invited guests, honorary members, past committee members and for those taking part held at the Royal NZ Yacht Squadron on the 8th May.

Good Sorts

May has become the month of "The Good Sorts." This is a fundraiser whereby you host a tea party for friends and family, have a wonderful time and raise much needed funds for the Society. To get some help with running your event feel free to ring Gabrielle in the office on 09 845 5921.

MS Lunch - West Auckland

On June 20th we will be hosting a lunch to be held in West Auckland. This event is open to everyone - not just those living in the West - so if you're interested, please contact the office. More information will be sent out very soon.

Life Buoy Lunch

The Life Buoy Lunch, in celebration of MS Auckland's 50th Anniversary is happening on the 26th of July. This is our main fundraiser of the year, involving many corporate

businesses, whom we would like to thank in advance. This looks to be a fantastic event!

Get Moving!

We have recently joined a Tai Chi class in Manurewa in South Auckland. This class meets on a weekly basis and now has PwMS participating. I joined in and really enjoyed the whole experience! You can be seated for the class if you prefer and do as much as feels comfortable. We were made to feel very welcome so if you are interested in joining us, please contact your Fieldworker.

Workshops

We are also in the planning stages of offering some workshops which will be advertised shortly. A lot of consideration is taken into account when preparing topics for these workshops to ensure they are relevant and of interest, however if you have suggestions of topics you'd like covered, please let us know!

Keep In Touch

Please read your emails. We often hear from members that you are not kept informed as to what's on offer. As each Fieldworker has approximately 150 to 200 people on their books the best and most effective way to keep you up to date is via email, so please check your email regularly. We also share details through the MS website and our Facebook Page, so please check those as well. We want **YOU** to be part of what is happening at the MS Society so please make sure you keep in touch.

Hope to see you at one of our events very soon!

Dianne, Diane, Carol and Georga.

Donations

Regular Monthly Donors

March was won by John and Nora Gabriel, April won by me (Therese) and May was won by Carol Lichkus and we all said "MS Auckland you keep the money". Thank you!

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

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

Please join us on Facebook

Please go to www.msakl.org.nz and like our Facebook page. We regularly post up to date MS information and news so that you are in the know!

We want to increase our followers, so "like" us please!



From the MS Nurses

Don't forget your flu jabs!

We have certainly had very different weather patterns and real cold snaps so, it's a pertinent reminder for any of you who are undecided on getting the flu jab this year.

Auckland Hospital is readying itself, as it does every year for the significant increase in inpatients and pressure on beds that is caused by flu.

As you are no doubt aware the flu jab will not protect you from every flu out there. The most virulent strains are predicted and targeted with the jab.



We would strongly urge you to have the flu jab. If you have MS you can reasonably expect that catching the flu will hit you that bit harder than someone who does not have MS. The fever that accompanies it may aggravate your previous symptoms or make fatigue levels that bit more difficult to manage. So if you're wavering or indecisive go for it!

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

Rope Neuro Rehabilitation

It is with great excitement that we are now able to offer another round of Minimise Fatigue, Maximise Life! We would like to say a big thank-you to the Multiple Sclerosis Auckland Trust for funding this programme for the third time running!

If you suffer from fatigue, and would like to engage in a six week fatigue management programme, then this programme might be for you. Facilitated over a six week period at our premise on Dominion Road, you will be taken through the main fatigue management principles and given tools to help improve your quality of life. There is six people per group and always time to catch up and share experiences. If this sounds like something that you would benefit from, please get in contact with me to register your interest.

If you didn't manage to take part in our fatigue management webinar that we held last month, we are pleased to offer another date due to high demand. The fatigue in MS webinar will be held on Tuesday the 2nd of June. If you would like to access the webinar before this date, we have a pre-recorded fatigue webinar ready for viewing at any time.

Please head over to

www.onlineneurophysio.co.nz

to book your space now!

By the end of this webinar you will be able to....

- Differentiate between mental and physical fatigue
- Know the primary and secondary causes of fatigue
- Know the basics of resting, including preventative resting
- Energy Efficiency - being aware of how to use your energy smarter
- Have access to tips and tricks from other people with MS fatigue

Now that the warmer months are behind us, some of you may be feeling more ready to get back into your exercise programme. Remember that the hydrotherapy pool groups run throughout the year and are a great way to get involved in exercise with like-minded people. Contact the society if you would like more information on this!

Stephanie, Julie, Sarah and Jess

Stephanie@ropeneurorehab.co.nz

021 1029 947



Recipe Leek and Potato Soup

Serves 4 to 6

- 2 carrots peeled and diced
- 2 sticks of celery sliced
- 2 medium onions diced
- 400 g leeks
- 2 cloves garlic crushed
- 400 g potatoes
- olive oil
- 2 organic chicken or vegetable stock cubes
- sea salt
- freshly ground black pepper

Cut the ends off the leeks, quarter them lengthways, wash them under running water and cut them into 1cm slices.

Place a large pan on a high heat and add 2 tablespoons of olive oil. Add all your chopped and sliced ingredients and mix together with a wooden spoon. Cook for around 10 minutes with the lid askew, until the carrots have softened, but are still holding their shape, and the onion and leeks are lightly golden.

Peel the potatoes and cut them into 1cm dice. Put the stock cubes into a jug and pour in 1.8 litres of boiling water from the kettle. Stir until the stock cubes are dissolved, add to the vegetables.



Add your potatoes. Stir well and bring to the boil. Reduce the heat and simmer for 10 minutes with the lid on.

Remove the pan from the heat. Season with salt and pepper. Serve like this or blend until smooth. Divide between your serving bowls.

Sandra Perry Dip.Nutrition
Nutritionist

Carers' Corner

Carers NZ Meeting

One of our Carers attended the Carers NZ meeting last month and these were the discussion points:

- What help do carers need?
- How to link all carers needs e.g. MS, dementia, disabled children, etc. They generally all have specific needs
- Mean spiritedness of government agencies.
- No commitment from government to assist/support carers.
- Time/money allocated annually by NASC may come as one or two lump sums. It takes forever for the money to arrive after completing the paperwork.
- They have a Carers website that should be up and running shortly to help carers find respite.
- They have been unable to meet with Maggie Barry.

We are now going to meet with Carers NZ and set up a meeting with Maggie Barry to see what can be done.

We are also now on the Carers NZ Database for future meetings in Auckland – if you would be interested in attending these meetings please let me know

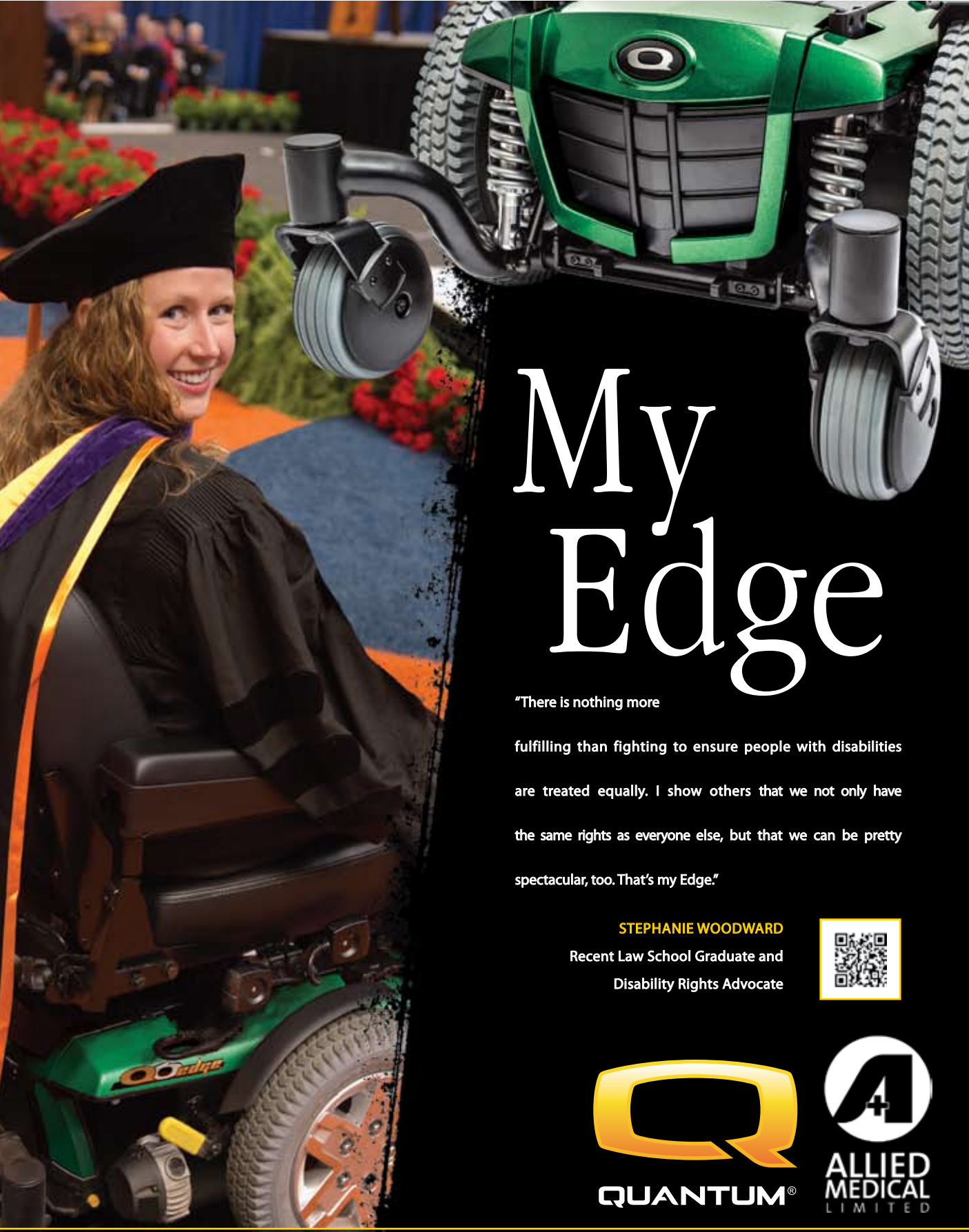
therese@msakl.org.nz

so that I can send information to you.

A Carer's Poem

Lord, bless me this morning and each one I live,
So I'll remain focused on the care I give,
Be sure I'm afforded the best tools allowed,
To serve my dearest's needs and make them proud,
Please look down upon me and offer a smile,
So, I'll always know that what I do is worthwhile,
As I continue to care for my loved one, I will need time to rest,
So that I can always give my very best,
At times it seems too much for me to bear,
Then I remember my loved one never asked to put me here,
Our journey is different to the one we first thought about,
However we love each other
and there is no doubt.





My Edge

"There is nothing more

fulfilling than fighting to ensure people with disabilities are treated equally. I show others that we not only have the same rights as everyone else, but that we can be pretty spectacular, too. That's my Edge."

STEPHANIE WOODWARD

Recent Law School Graduate and
Disability Rights Advocate



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youtube.com/QuantumRehab

Events Wellness Workshops

13 June

Connections

Speaker: Dr Nick Penney



The Connection is a feature documentary revealing the ground breaking research by world leading experts proving that there is a direct connection between your mind and body when it comes to your health.

The Connection is a film that proves we have more influence on our health outcomes than we ever thought possible. Yoga and Meditation plays an important role in aiding recovery.

Professor George Jelinek is interviewed in this documentary along with world leading scientists, pioneering medical experts and mindfulness teachers.

*I was completely blown away!
The film conveys groundbreaking
information to say the least*

msdietforwomen.com



The role of mindfulness skills training and mindfulness based stress reduction will then be discussed together with Relaxation Response Training, both of which are featured in the documentary. A short practical mindfulness exercise will be included for participants to 'take away'.

After the documentary is shown Dr Penney will be available to lead a discussion about the film and answer any questions that may arise.

TIME: 10.30am - 1.00pm

COST: Members \$10.00 / Non-members \$20.00

Morning Tea will be provided.

4 July

Who Cares for the Carers - I Need to Look After Me Too!

Speaker: Suzanne Henwood



A session using the very latest research from Neuroscience to enable people to both understand the risk of not taking care of themselves and also sharing some simple techniques to enable carers to radically reduce their own stresses related to caring for others, in short, simple, realistic bursts.

Come along to invest in your own health,
so you can continue to care....

TIME: 10.00 am - 12.00 pm

COST: Members \$10.00 / Non-members \$20.00

Followed by a light Lunch

Venue: Commerce Club
27-33 Ohinerau Street
Remuera

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

RSVP: events@msaki.org.nz OR
09 845 5921



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**12PM ON FRIDAY
26 JUNE 2015**

For a charity luncheon at the
**ROYAL NEW ZEALAND YACHT SQUADRON,
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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

COLUMBUS
COFFEE

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Events

Oceans of Hope (OOH)

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

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

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



It's a dream come true for Barbara

When we invited Honorary Life Member, Barbara Broome to sail on Oceans of Hope, this was her reply:

Dear Therese,

This trip sounds not only wonderful but would be a dream come true for me. I have always longed for a trip on the Harbour but would never have imagined I would have an opportunity to do it by sail. Already I give you a big hug I am so excited. It will mean far more to me than a world trip.

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

Barbara (middle) being presented her Honorary Life Membership Certificate by past GM Gary McMahon (right) and Committee Member Joan Thomson (left)



LAST CHANCE TO BOOK YOUR SAIL AROUND AUCKLAND HARBOUR

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

NOW FULLY FUNDED²



ONE PILL ONCE A-DAY¹

Ask your doctor about GILENYA.



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. Patient monitoring will be necessary. You should avoid becoming pregnant while taking Gilenya and for two months after you stop taking it. Gilenya has benefits and risks. Cautions are infections, vaccinations, visual disturbances, decrease in heart rate, signs of liver disorders, sudden onset of severe headache, nausea & vomiting. Talk to your doctor right away if you experience any of these. Side effects can include headache, liver enzyme increase, 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



MULTIPLE SCLEROSIS AUCKLAND RESEARCH DAY

When: Saturday 16th May 2015

Where: Rutherford Room, Alexandra Park Race Course
Cnr Greenlane West and Manukau Rd, Greenlane, Auckland

Time: 9:00am Start – 2:00pm Finish

9:00 am	Introduction	
9:05 am	Professor Simon Broadley – Dean and Head of the School of Medicine, Griffith University. He is also a Senior Staff Specialist in Neurology at the Gold Coast Hospital. Professor Broadley will speak about 'A new era in Treatment for Multiple Sclerosis'	
10:15am	Robert Irving from Rex Bionics – Robert Irving, Senior Mechanical Engineer and Co-Founder of Rex Bionics, who have developed a hands-free robotic mobility device, designed to assist with rehabilitation for people with mobility impairments. Mr. Irving will demonstrate Robot-Assisted Physiotherapy, lifting patients from a sitting position into a robot-supported standing position, allowing them to take part in a set of supported walking and stretching exercises, designed by specialist physiotherapists.	
10:30am	MORNING TEA	
10:50am	Introduction	
10:55 am	Doctor Wallace Brownlee – Neurologist and Clinical Research Fellow at the Queen Square Multiple Sclerosis Centre, part of the National Hospital for Neurology and Neurosurgery and the UCL Institute of Neurology, London. Dr. Brownlee will talk about his follow up study of a group of people who first had a clinically isolated syndrome (CIS) suggestive of MS 14 years ago.	
12:10pm	LUNCH	
12:50pm	Introduction	
12:55pm	Doctor Ernest Willoughby – Neurologist, Department of Neurology, Auckland District Health Board and Clinical Associate Professor, Department of Medicine, University of Auckland. Dr Willoughby will give an update on disease modifying treatments, especially the new medications recently approved for funding by Pharmac – fingolimod (Gilenya - Novartis) and natalizumab (Tysabri - Biogen).	
2:00 pm	FINISH	

MS Changed My Life for the Better *by Ann Glamuzina*

I remember trying to read the Sunday Star Times and watching as chunks of letters formed before my eyes. It was like reading a ticker tape waiting for the words to appear across the page. I wasn't particularly concerned. I was 36, a new mum, a bit tired and probably needed glasses.

A week later a male optometrist did a cursory check of my eyesight, told me nothing was wrong and that I needed to 'go home and get some rest'. I was tired, but as I humped off home feeling more than a little grumpy, I started to have a sense that something wasn't quite right after all.

The next week I reversed into a car in a parking lot. I had looked over my shoulder and couldn't quite believe it when I heard the crunch. I didn't understand how the other driver had manoeuvred their car behind me when I was certain it hadn't been there a second before. I was more upset at the fact that I knew I had seen no car there rather than the fact that I had reversed into someone!

I went home, and the unease I'd felt after leaving the optometrist returned. There was something happening to me that I didn't understand, so I made an appointment to see the Doctor. I explained to him that I was reading things in 'chunks' and told him what the optometrist had said. I almost begged him to believe me. He sent me for blood tests and he telephoned me when the results came back and he advised it was 'nothing sinister like cancer', but he believed me that there was something odd happening and he referred me to an Ophthalmologist.

I rang the Ophthalmologist, promptly burst into tears when the receptionist said an appointment would be 8 weeks away. After I explained I could read fine one weekend and not the next she returned with an appointment the next day. The Ophthalmologist was an amazing caring man (Dr Brian Sloan) and a standard field of vision test revealed Optic Neuritis and an MRI that same day, confirmed a diagnosis of MS.

I contacted MS Auckland and received a visit from case worker, Diane Hampton. It was a frightening world I found myself in, and I recall being grateful that I couldn't read anything as it stopped me looking at and probably fretting over all sorts of things on the Internet! Diane told me about

a session that was happening with a man called Dr George Jelinek in Auckland and I went along, not knowing then that this would show me how to keep myself well.

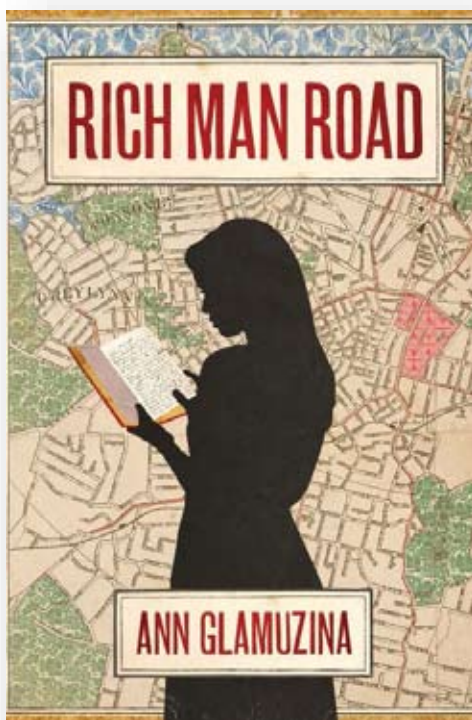
After listening to George, I signed up to a course at the Gawler Institute and after a weeks retreat in Australia, decided to never practise law / work in a corporate job again, to become a fish eating vegan and to take active control of my MS and life.

I'd always tinkered with words – in fact had note books and stories going back 25 years stashed away in suitcases and old diaries! An ad in the paper talking about a Master of Creative Writing course starting up in Auckland and I took the first step in finally writing the novel that I'd been thinking about since I was a child by signing up to do my Masters at AUT University.

In March of this year I launched that novel, Rich Man Road. I cannot describe the satisfaction I felt seeing my novel on the shelves of The Women's Bookshop and The Booklover – I had done it – I'd taken a sow's ear and turned it into a silk purse! Because of MS, I had challenged myself to not let this disease take away my future. With a loving family and support from MS Auckland I have been able to achieve my dream and now write fulltime.

I have been relatively well for the past 11 years bar a few sensory issues that now and then flare up when I get too tired and do too much. Some days I don't even think about MS, but when I do, I think how lucky I am to be so well and able to do what I do.

Available at good bookstores such as The Women's Bookshop, Unity Books, Time Out Bookstore, Paper Plus Newmarket, Poppies Remuera, The Book Lover, Dear Reader, University Bookshop and Paradox. If your local store doesn't have the book in stock they can order for you.



Before being diagnosed with MS I was 25-years-old and running my own start-up business. I was a hard worker, but also partied hard. I was putting in around 70 work hours a week and then would drink heavily in my spare time and pretty much lived on junk food. I weighed over 100kg and was generally unfit and unhealthy.

My symptoms started in early-2004 with stabbing pins and needle type headaches and a constant ache behind my right eye. I had slightly blurred vision in my right eye, but never really took too much notice of it. I guess with such long hours and late nights I assumed it was due to tiredness.

I was extremely sensitive to light to the point my eyes would water when in contact with direct sunlight. Then when I would close my eyes at night I experienced shooting stars or lightning bolts of vivid, flashing colours. It was constant.

This went on for several months. I didn't confide in anyone at the time, as I just hoped one day it would all stop. Then one day I remember walking along the street and just suddenly needing to stop. The sharp, stabbing pain behind my right eye was unbearable. That was the first time I acknowledged something could be seriously wrong. So that evening, I visited a doctor. With his flashlight, he examined my right eye and observed significant lack of pupil dilation in my right eye. He advised my eye was non-responsive to light.

He immediately referred me to Auckland hospital. I remember the exact words he scribbled on the specialist referral note: "Optic Neuritis, MRI?"

I was extremely anxious throughout my hospital appointment the next day. Doctors ran various tests. In one I was asked to nod my head forward, pressing my chin to my chest to determine whether I could feel tingling in my feet - which I did.

In another they stuck a match stick like object directly into my eye to ensure it remained open while they



shone a bright light through to examine my optic nerve. At the time I didn't know anything about the optic nerve. I later learnt it's the 1.3 million nerve fibres that connect your eye to your brain. During the test, a specialist noted there was evidence that the optic nerve was very inflamed. "Is it Multiple Sclerosis?" I asked. The doctor appeared very calm as he replied. "It may be, but whatever the case we have to get the swelling of the nerves down immediately to avoid potential blindness," he said. I was immediately put on a steroid called Methyl Prednisone for a week, to help try to bring the swelling down.

Within three days I was sent in for an MRI (Magnetic Resonance Imaging) and MS was confirmed.

From that day onwards life became pretty dark. My family were devastated, and everyone else felt "sorry" for me. At just 25-years-old I battled depression with thoughts of being wheelchair-bound within months. I felt like my whole life as I knew it was gone. I felt lost, lonely, and held little hope for my future.

I immediately shut down my business, I just didn't feel I could cope with the demands of it any longer. As much as I was struggling- both physically and emotionally- I knew I still had to work to pay the bills. So after around three months I took up a role at a finance company. I was predominantly phone based, which suited me as I didn't feel like dealing face to face with people at the time.

While still trying to mentally come to terms with my diagnosis, my physical symptoms started to increase by the day. Lethargy kicked in. Then I gradually lost my ability to walk straight as I was losing general feelings in my arms and legs. My arms started curling up to the point I could no longer write with my right hand anymore. I had to train myself to become left-handed for many day to day activities.

It was a constant mind and body battle throughout the first 12 months after my diagnosis.

Then one day, I decided that enough was enough. I was no longer going to just sit back and let this disease take over my life. I needed to gain back control in any way I could.

I started with my diet. I vowed to give up the junk food and instead stocked up on healthy fruits, vegetables and lean meats. I also bought a treadmill, setting a goal to regain control of my limbs. In the beginning I held onto the side rails, focusing on one step at a time to retrain my legs and urge myself to walk steadily again.

I took it one day at a time. With each day of improvement I felt great satisfaction, and setting goals gave me real purpose again.

After several months I could let go of the rails. Then I started to walk faster and eventually could even run!

I also set a goal to tackle the numbness and curling in my arms. I started to lift light dumbbells to try and re-establish the mind - muscle connection. The way I saw it was that at birth we develop motor skills through neural pathways. At first we can't hold a spoon and eat properly, however over time we practice and eventually get that connection. I therefore strongly believe that I could re-train my body and regain the skills I had lost.

Each day I worked hard. After about 12 months I had lost 40kg and had a whole new lease on life! I was walking steadily, the tingling and numbness had stopped, my arms were no longer curling. The overall physical symptoms that had been

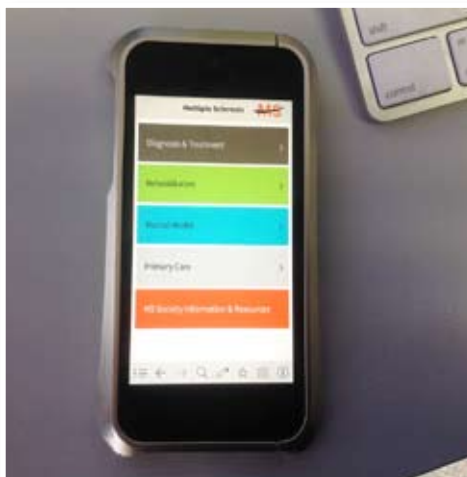
MS Diagnosis and Management App now available *by Thérèse Russel*

Last issue I put a small article on the Notice Board regarding this app. Sadly you couldn't get into the app so we went back to our Member and asked for his help. This is what he had to say:

Regarding the electronic resource app I mentioned, it is called "MS Diagnosis and Management" and is free to download. Just google 'MS Diagnosis and Management' and some links will pop up.

Other options to download: for Android phone/tablet, go to Google play store, type 'multiple sclerosis' into the search bar, click the app and install. Or use this link:

https://play.google.com/store/apps/details?id=com.bbi.national_multiple_sclerosis_society&hl=en for apple devices at itunes app store medical, here is a link <https://itunes.apple.com/us/app/multiple-sclerosis-diagnosis/id480116542?mt=8>



The application is designed for use as a resource by both professionals and patients published by nmss.org. The recently updated version is a bit harder to navigate than the previous one, but also has a lot more information. Obviously the more tech savvy generation is at an advantage when comes to using what's called interface of an application. I just swipe and click and see what happens. The basics are: > to go somewhere, + and - to expand or close, arrows to go backwards forwards, a home button to go back to start, etc. This app has got two symbols on a bar at bottom right hand side. Touch 'i' as in info button, you will then find a short menu item 'app user guide', have a look. As well the 'library' symbol will take you to a menu of resources, clinical bulletins etc. Tapping most of those will ask

'leaving app, continue? This just means your device requires to open 'adobe reader' to open a pdf. document.

Give it a go and all will become clear.

.....
Continued from page 14, Bid For a Better Life

hindering my body had disappeared. I was physically and mentally functioning again. I was back to the person I was before the diagnosis. And from there, I vowed to never look back!

After bouncing back from the worst of my symptoms I was determined to work my way up the corporate ladder. I started running teams of credit controllers, and thoroughly enjoyed my leadership role. My health was good, work was going well, I was socialising again.

Life was once again enjoyable.

In February 2014, after 10 years working at the same company, I decided I needed a change. I left my job and sat back and had a good think about my life, and where I wanted to go from there. MS was such a huge part of my life now.

So within two months I decided that I wanted to make it my life mission to assist in finding a cure for Multiple Sclerosis and to support the MS community in any way I can. I decided to start a new research foundation and knew I needed good guidance. So I researched people involved in MS

nationally to find the best fit. I came across Neil Woodhams, President of MS Auckland.

I discussed my goals and ambitions with Neil and as pointed out to me, my energy would be best suited in assisting the already established MS Auckland. He introduced me to the MS Auckland staff and I signed up as a volunteer of the organisation. We brainstormed ideas about how I could get things off the ground and I thought long and hard about a major way I could make a difference. The CEO of the organisation Thérèse Russel was a huge support and inspirational to me.

I came up with a slogan, now a registered entity, called **"Bid for a Better Life"**.

Bid for a Better Life is a global fundraising platform designed to raise funds to assist in the research, support and treatment of Multiple Sclerosis.

We are kicking off our fundraising in Auckland this May through Trademe - New Zealand's largest internet-auction website. We will implement a series of themed online campaigns throughout the year. This is a fundraising initiative

for Multiple Sclerosis Auckland. Bid for a Better Life will expand globally with its platform. Funding will be raised through global online and live charity auctions. The goal is to raise as much money possible to facilitate the construction of an Advanced Treatment and Cutting Edge Research Facility to provide better treatment for the disease and work towards putting an end to MS.

I aim to gain the support of organisations, foundations, philanthropists and the general communities around the world to help with these goals. I want to encourage as many people possible to join the Bid for a Better Life platform to share my vision to stop this debilitating disease.

My visions and goals are big, however I believe very achievable.

I am passionate, driven, and determined to fight against MS. I want to join the many people around the world who dedicate their time and efforts to raising funds and awareness towards the cure, prevention and treatment of MS.

Together I believe we can join forces, find answers, and one day beat it.

Fasting could help us cope with a number of diseases

by Liz Hunt

We usually think of fasting as a weight loss measure, but advocates say it has therapeutic benefits too.

Francoise Wilhelmi de Toledo combines a passion for her subject with a precision one would expect of a doctor and scientist with a raft of publications to her name.

"Real medicine is lifestyle. It is how we live," she says. "Drugs, any drugs, must be complementary to that."

As medical director of the renowned Buchinger Wilhelmi Clinic in Germany, she is an authority on therapeutic fasting and responsible at least in part for the current interest in its role in the management of chronic diseases including obesity, diabetes, high blood pressure, high cholesterol and cancer. And, of course, as a means of weight control made popular by the diet du jour, the 5:2.

Fasting – as part of a lifestyle – is undoubtedly a good thing, she says, but her focus is on making it part of the armamentarium available to doctors coping with an epidemic of lifestyle diseases in the West that threaten to cripple healthcare systems.

She says there is strong evidence gathered over many decades to show how it can lower blood pressure, reduce excess fat and glucose in the blood, modulate the immune system, increase the effect of the mood and sleep-regulating neuro-transmitter serotonin, boost protein repair, and reduce inflammation.

Fasting has been likened to a "reset" button that returns the human body to its – healthy – factory settings. A study published last year in the United States, drawing on animal and human trials, concluded that three days of fasting can rejuvenate the immune system, triggering the production of new white blood cells. Other studies show that fasting can enable healthy cells to endure better the toxic impact of chemotherapy while cancer cells die more rapidly. It is a fascinating area of research that draws on the body's evolutionary adaptation.

"Human beings are not programmed for abundance," de Toledo says. "Humans are programmed for loss." The capacity to fast derives from periods when our ancestors ate more than they needed and built up fat reserves and surplus nutrients, such as vitamins and minerals, in summer and autumn.

In winter and spring, when access to food was much reduced, they endured periods of fasting in which their

metabolism switched automatically from "external nutrition to nutrition taken from fat reserves".

In the absence of carbohydrates as a source of energy (glucose) for the cells, fatty acids, from fat supplies, were broken down in the liver to produce molecules known as ketone bodies which were used for fuel instead.

Of course we retain this ability to fast and exist on a ketogenic diet but rarely use it in the affluent West because food shortages are largely unknown. Nor is there much incentive to invest in fasting research, despite preliminary evidence that it may help in Parkinson's, Multiple Sclerosis and Alzheimer's. In Russia, there is a vast, largely unexplored archive built up by a psychiatrist Dr Yuri

Nikolayev, who used fasting or "the hunger cure" to treat a range of mental disorders.

This lack of interest frustrates de Toledo.

"Take type 2 diabetes," she says.

"This is a disease we know that we can cure [through fasting]. But there is an industry that sells all these drugs and devices. We have a type of medicine [in

fasting] that is highly successful but there is no return on investment."

It was as a 17-year-old in Geneva that de Toledo embarked on her first fast with the aid of a book, because she "was at odds with my weight and wanted to match the ideal of the slim beauty". She says it was a revelation, that she felt "buoyant, sometimes euphoric" while fasting.

She says people who turn to fasting include some seeking help for intractable health problems while for others weight loss is the primary goal. Many, however, are seeking respite from stress of work in the "spiritual dimension of fasting" that de Toledo claims is one of its most beneficial side effects.

She still fasts twice a year, during a 12-day annual retreat, and to counteract a severe seasonal allergy to birch pollen. She says suspicion and cynicism about fasting is still rife among doctors and nutritionists and she is determined to challenge it. "We want to document and show that fasting is therapeutically efficient, safe and enjoyable," she says.

The science, it would seem, is increasingly on her side.

<http://www.stuff.co.nz/life-style/well-good/inspire-me/67744102/Fasting-could-help-us-cope-with-a-number-of-diseases>



Cognitive Rehabilitation for Attention and Memory in People with MS

Researchers at the University of Nottingham, UK are conducting a study aimed at helping people with MS who have difficulty paying attention, learning, remembering new things and planning ahead. The research is led by Professor Nadina Lincoln, University of Nottingham, and Dr Roshan Das Nair, Nottingham University Hospitals NHS Trust. They are evaluating the benefits of a group treatment programme, which takes place once a week for 10 weeks. Participants who attend the groups are taught more efficient ways of remembering, as well as strategies to help them cope with their memory difficulties. The study will be exploring the benefits of using internal memory aids, such as mnemonics – using patterns, words and images to remember details – and external aids, such as diaries, mobile phones and cameras.

The aim is to recruit 400 volunteers, aged 16 to 69 years, from NHS hospitals, rehabilitation centres, multiple sclerosis charities, and web forums. About half the volunteers will then receive a 10-week group intervention at one of the study centres in Nottingham, Sheffield, Liverpool and Birmingham.

Previous research has indicated that people with MS have found the group programme to be helpful in enabling them

to cope with memory problems in daily life and this has also improved their mood.

This research is aiming to provide evidence of the benefits of the treatment, by comparing people who attend the groups with people who do not, in order to make a case for cognitive rehabilitation to be more widely available in the NHS. If this study confirms the benefits of cognitive rehabilitation it could lead to a change in clinical practice in the NHS and abroad. The researchers will also use questionnaires to determine the cost-effectiveness of this intervention, and to get feedback from those taking part in the trial to establish if intervention improved their quality of life.

The study is being conducted in collaboration with Swansea University, Nottingham Clinical Trials Unit, Nottingham University Hospitals NHS Trust, Sheffield Teaching Hospitals NHS Trust, The Walton Centre NHS Trust, and University Hospitals Birmingham NHS Trust.

For more information about the study please contact:

Professor Nadina Lincoln

Tel: 0115 9515315 Email: nadina.lincoln@nottingham.ac.uk



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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.

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New drug could reverse MS damage *by Sarah Knapton*

A new drug could reverse the damage of multiple sclerosis, curing balance and vision problems for sufferers, researchers believe.

The disorder occurs when myelin, the fatty material which protects nerves is damaged, exposing the nerves and causing signalling problems between the brain and muscles.

One of the earliest indicators of multiple sclerosis is a condition called optic neuritis in which the retina stops sending electrical signals to the brain, causing vision loss.

But a new drug, called anti-LINGO-1, has been found to repair myelin, radically improving nerve signalling and completely restoring function in some cases.

Although the subjects tested have not been diagnosed with multiple sclerosis, more than half of people with optic neuritis go on to acquire the disorder.

Scientists say that crucially the new results prove that anti-LINGO-1 can repair myelin, and so should help people with MS.

"This study, for the first time, provides biological evidence of repair of damaged myelin in the human brain, and advances the field of neuro-reparative therapies," said study lead author Dr Diego Cadavid, of Biogen, which is based Cambridge, Massachusetts.

- 'Miracle' stem cell therapy reverses multiple sclerosis
- Thousands of people wrongly diagnosed with Multiple Sclerosis, experts warn
- Multiple sclerosis: the facts and fictions

Around 100,000 people in Britain suffer from MS and there is currently no cure.



All patients involved in the trial were given the new drug or a placebo once every four weeks for a total of six doses.

Because optic neuritis only usually affects one eye, doctors evaluated the recovery of the optic nerve by comparing it with the normal healthy eye.

The results showed that 53 per cent of people on the drug saw their nerve signalling restored to normal or nearly normal while on average most saw signalling between the retina and the brain improve by 41 per cent.

The scientists are now following up patients to find out if the signalling improvement will restore their vision.

"More studies are needed to evaluate whether these changes

lead to clinical improvement," said Cadavid.

The drug works by targeting 'Lingo-1' a protein which stops nerve cells from developing further once the nervous system is fully formed.

By blocking that protein, the drug effectively tells the body to carry on growing the nerves, which repairs any damage.

Biogen chief medical officer Alfred Sandrock said "We believe the results are encouraging, as this is the first clinical trial to provide evidence of biological repair in the central nervous system by facilitating remyelination following an acute inflammatory injury".

The research was presented at the American Academy of Neurology's Annual Meeting in Washington.

<http://www.telegraph.co.uk/news/science/science-news/11535380/New-drug-could-reverse-the-damage-of-multiple-sclerosis.html>

<http://www.iflscience.com/health-and-medicine/new-drugs-may-show-promise-reversing-multiple-sclerosis-damage>

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

Library Research worth looking at...

I have just finished reviewing the MSAA annual RESEARCH UPDATE for 2015. It should be available for free on the MSAA Web site. You might want to share that site with the people with MS in NZ. It is comprehensive AND non commercial.

Doctors and patients give us good feedback each year. Wishing you the best.

Jack Burks, MD

Fierce Biotech Research

http://www.fiercebiotechresearch.com/story/blood-pressure-drug-looks-promising-preventing-myelin-loss-ms/2015-03-17?utm_medium=nl&utm_source=internal

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