

# multiple news

Multiple Sclerosis Auckland Magazine

June 2016 | Issue 33

## stretching out with yoga classes



inside

pamper  
parties

wellness  
workshops

food & recipe

MStranlsate

and more...

**ms.**  
Multiple Sclerosis  
AUCKLAND



## Shhhh, Aubagio at work

If you're living with relapsing MS, there is a treatment that may suit you.

Aubagio is a well-tolerated treatment that effectively delays disability progression and reduces relapses.

Aubagio, working to help quiet MS quietly.\*

A once-daily pill, ask your doctor if Aubagio is right for you.

\*Aubagio has demonstrated a significant and consistent reduction in multiple measures of disease activity in relapsing forms of MS, while its most common adverse events included diarrhoea, rashes/itchy skin, which rarely required treatment discontinuation. For full information on side effects, please read the Consumer Medicines Information available at [www.medsafe.govt.nz](http://www.medsafe.govt.nz).

Once-daily  
**AUBAGIO**<sup>®</sup>  
(teriflunomide) 14 mg tablets

**Aubagio**<sup>®</sup> (teriflunomide, 14 mg tablets) is a Prescription Medicine for the treatment of patients with relapsing forms of Multiple Sclerosis to reduce the frequency of clinical relapses and to delay the progression of physical disability. AUBAGIO has risks and benefits. For more information read the Consumer Medicines Information available at [www.medsafe.govt.nz](http://www.medsafe.govt.nz). Ask your doctor if AUBAGIO is right for you. Use strictly as directed. If symptoms continue, or you have side effects, see your doctor. AUBAGIO is a fully funded medicine. Special authority criteria apply. Normal doctors visit fees apply. **References:** Aubagio Approved Data Sheet October 2015. Additional references to support the information in this advertisement are available on request. Sanofi New Zealand. Level 8, 56 Cawley Street, Ellerslie, Auckland. GZANZ.AUBA.16.02.0009. TAPS CH4731. February 2016. GEAB10736/MSA. **SANOFI GENZYME** 

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## a few words from Ingrid.

*Our General Manager*

We are well into the winter season now. It's time to bring out the hats, scarves and woolly jumpers. I'm a summer person, preferring beaches to mountains. But over the years I have learned to appreciate what each season brings. In winter I am grateful for hot cooked meals, candle lit dinners and my woolly slippers, and look forward to curling up on the couch with a good book and a blanket.

The crew at MS Auckland has been working overtime with all the exciting things happening. As I write this, Kirsty is head down in the final planning stages of 'Life Buoy for MS', our biggest annual fundraising event. So many generous people have come forward with donations and gifts. The auction items look amazing! A big thank you to Kirsty, our events coordinator, and Carolin, our wonderful volunteer, who have certainly gone 'the extra mile' and put in many long hours to make Life Buoy happen. We will be giving more updates on Life Buoy in our e-newsletter.

Over 130 people attended Research Day on the 21st of May – mostly people living with MS and family members. We had 5 amazing presentations from around the world, showcasing the best in both local and international multiple sclerosis research. Please see our website - [www.msakl.org.nz](http://www.msakl.org.nz) - for videos and summaries of the day.

We are so pleased to welcome two new people to MS Auckland. Francesca has come on board to organise our Street Appeal this year. She will be calling for volunteers to make this year's Awareness Week and Street Appeal one of the biggest and best yet. In July we will be welcoming Andrea to our team, our new Field Worker for West Auckland.

Our AGM was held in April and we are pleased to report that all Committee members are continuing on, with Louise Reed taking up the position of Vice-President. We have also gained one new member, Carolin Perkins, who was unanimously elected.

I met up with neuro physiotherapist Gilly Davy who has returned from Sydney. She is looking at bringing the highly successful 'MS Get a Head Start' programme to Auckland. Register your interest for this 6 week course by filling out the survey on page 10.

Thank you to everyone who contributed to this Issue of Multiple News. We hope you enjoy reading it. I hope to see you at some of our regular or special events coming up over the next few months. Please keep in touch. I love hearing your stories and getting to know you.

With warm wishes for a cozy winter,  
Ingrid

## our new field worker. *Andrea Kortas*



We are very pleased to announce that we have a new Field Worker for West Auckland! Andrea Kortas will start on the 4th of July. She is very excited about joining us and will be a great addition to our team.

Andrea's training is in Speech Language Therapy. She also has extensive work in the community, having worked as an Epilepsy Information and Support Specialist. Andrea has a personal connection with MS and the chronic illness community and a real passion in working to support all people to live active and fulfilling lives.

We are most grateful to Carol, Dianne and Diane, who have worked extremely hard over the past 3 months to cover the vacancy since Georga left, and are thrilled to have Andrea on board. I'm sure you will all join in making her feel welcomed into the MS community.

# events for your calendar.

July/  
August

30th July

Wellness Workshop  
Taking Control of  
our Life Changes



14th August

Meditation and  
Yoga Workshop for  
people with MS.



28th August

MS Awareness Week  
starts

*Upcoming  
events*

2-3rd September

MS Auckland  
Annual Street Appeal



## yoga in April.

The Saturdays in April saw 18 people come to Birkenhead to participate in yoga classes under the expert guidance of Kylie. 8 attended regularly each week, and probably noticed the most benefit from the exercises. Special thanks to Auckland Council – Kaipatiki Local Board – for their support. The feedback from everyone was overwhelmingly positive, with strong requests to keep it going!

Well, we have heard you and we are working on getting more yoga for MS happening throughout Auckland. Watch this space!



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Keep up to date with all the latest  
MS. news and research.

 Like us on  
Facebook

For more information visit  
[www.msakl.org.nz](http://www.msakl.org.nz)

# from the field.

Margaret and Bruce Cameron and Margaret's Mobility Assistance Dog, Prue, attended the Manukau Support group recently. As you can imagine, Prue captured the hearts of everyone at the group, especially Ric Stewart who has started the process of applying for a mobility dog. He wanted to see Prue 'in action' to see just what she is capable of.

Prue came to Margaret through the Mobility Assistance Dogs Trust (MADT). Prue initially trained as a Guide dog but failed to meet their exacting standards. Her training was continued through the MADT's Puppies in Prisons programme.

On qualifying (Mobility Dogs are very special dogs and not all make the grade.) Prue was given further training to meet Margaret's specific requirements and Margaret was then trained to work with Prue.

Margaret and Bruce explained to the group that these dogs are trained to assist people living with physical disabilities with their everyday tasks. A lot of time, effort and money go into training these dogs.



*Ric and Prue*



*Carol Central Auckland      Dianne South Auckland      Diane North Shore*

Mobility dogs learn a variety of 'foundation skills' to assist their owners with activities such as retrieving something off the floor, getting the telephone, carrying messages, items in baskets, pressing pedestrian buttons, opening doors, and so on . If the client has a requirement for further skills the dogs are given further training to meet these needs.

This might include things like getting washing from a washing machine or collecting groceries from a supermarket shelf. Most are also trained to obtain help for their boss in an emergency by getting a phone or the attention of a designated person in either a home or work situation.

They further explained that dogs are available at various levels of training - from a basic rest home dog, through a companion dog with a few commands, to a highly skilled service providing dog that can obey over 90 commands. Prue has about 40 commands that are regularly used.

Along with companionship, which is very important for those people who spend a lot of time on their own, Prue carries out the many simple tasks we don't even think about, and this significantly reduces Margaret's level of fatigue. Also Prue seems to have an innate ability (or perhaps from her Guide Dog training) to ensure Margaret finds a safe and secure route when she is out and about in her mobility scooter.

A huge contribution that Prue makes is the breaking down of barriers between Margaret in a wheelchair and able people. Margaret told the group that what Prue provides is irreplaceable in every way.

(Written by Dianne Bartlett, Field Worker, South, and Bruce Cameron. With appreciation to Margaret and Bruce (and Prue) for a most interesting and enjoyable Support Group Session).

# from the MS nurses.

## *When to see your GP*

With the onset of winter we can all expect to have more colds and flu. It's a depressing but true fact. Have you had a flu injection yet? If not it is highly recommended for people with MS so please speak to your GP or practice nurse. In some cases the injection is free or subsidised.

People often tell me how frustrating it is to call the MS Nurses and after making contact to be told to see their GP for advice. We are able to advise and assist with a raft of things but a telephone assessment is exactly that. If you are experiencing a serious symptom nothing can substitute a face to face medical review.

There is clear evidence that infections can bring back old MS symptoms or worsen current symptoms. If you notice changes in your health – perhaps you are going to the toilet more frequently to pass urine, have a chesty productive cough or a temperature – it is vital for you to be reviewed. Many practice nurse's will dipstick urine and perform infection screens without you needing to see the GP. We will routinely ask you about infections when you call us to report the return of old symptoms, so getting into the habit of assessing yourself for sources of infections before calling us is very helpful.

If your GP is ever unsure about how to manage your symptoms or suspects you may be having a relapse they have the option to call the on-call neurologist at Auckland Hospital for acute advice.



*Fiona and Nazila*

The MS Nurse Auckland Healthpoint website has a GP relapse management section. Information on steroid dose and on-call neurology number are part of the pathway.

Directing your GP to the site may help to streamline your consultation. <http://www.healthpoint.co.nz/public/neurology/auckland-dhb-multiple-sclerosis-nursing-team/>

### **Contact Details:**

e-mail - [MSNurse@adhb.govt.nz](mailto:MSNurse@adhb.govt.nz)

Phone: 09 307 4949 ext. 25885#

The MS Nurses, Fiona and Nazila, each work part time. Together they cover Monday to Friday from 9am to 4pm. During holidays they have reduced availability. This will be reflected in their phone messages and automatic e-mail responses.

## Flu Prevention Tips

Flu Vaccination - In healthy adults aged 18 – 65 years, the flu vaccination is 73% effective in preventing flu symptoms. That's better odds than winning Lotto! Flu vaccinations are available at your GP clinic.

Free Flu Vaccines – for all pregnant women, children over 6 months, up to 64 years with a chronic health condition such as asthma on a regular preventive treatment, COPD, diabetes, rheumatic fever, heart failure, stroke, kidney disease, cancer, auto immune disease, transplant recipients, neuromuscular and central nervous system diseases. All adults over the age of 65 can have the vaccine free also. Ask your Medical Centre if you are eligible for a free vaccine.

Community Immunity - The more of us that have the flu vaccine the better our chances are of not getting the flu. By having the flu vaccination you are helping to protect not just yourself and your whanau, but everyone in your community.

# Rebecca's pamper parties for MS.



Rebecca is a gorgeous, busy, happy, talented mother, who also happens to have MS. Earlier this year she contacted the office saying that she would like to help raise money for our Annual Street Appeal through 'pamper parties and makeup classes'. She is also donating 6 beautiful fascinators (and, if you are like me and not sure what that is – fascinators are small decorative hair accessories for women, like you would see at the Races) for our Life Buoy event.

Ingrid Minett chatted with Rebecca to learn more about this very special woman. Here is the interview:

## ***Tell me a bit about yourself:***

I married Jai in 2007 and we have two daughters – Emily who is 6 and Claire who is 3. I trained as a florist and with my passion for flowers and love of Vintage I started making Vintage inspired headwear as 'madewithlovenz'.

I love the 1950s era and base most of my inspiration from there. After I was diagnosed with MS I decided to only do things that make me happy because life is too short.

I recently started my training as a makeup artist and became a Senior Consultant for Mary Kay which is where the pamper parties come in. I attend a lot of the Vintage Markets. You can see more of my creations on [www.facebook.com/groups/madewithlovenz/](http://www.facebook.com/groups/madewithlovenz/).

In August 2014 I was diagnosed with MS. I'd been attending a 6 week boot camp to lose the last of my baby weight. Our trainer took a week off to go on holiday. When we got back into our training my legs felt heavy and my balance wasn't great. I'd noticed a few other strange things like dropping my keys and missing the handle of the kitchen drawers. I went to the doctor and his first thought was I'd over done it with boot camp and to take a couple of weeks off.

But my legs got worse to the point where I couldn't feel that my right foot was on the accelerator in the car. My husband and I both have cars with hand controls, because my husband is in a wheelchair. So for the first time ever in our lives together I started driving with the hand control. Jai had a spinal cord injury from a swimming accident 15 years ago which left him a tetraplegic. This all happened before we met so I knew what I was signing up for but this lovely man didn't see this coming. Well on the bright side our whole house and cars are wheelchair accessible. So after about 6 weeks from first seeing my doctor I found myself in hospital having an MRI and being told I had MS.

## ***How did you feel when you were told you had MS?***

I was really upset! I was supposed to be the one that was fine! My GP had initially told me there was a 1 in 40,000 chance that I had MS! And my response was what is MS? He told me not to google it and that it probably wasn't MS and that I would be fine. I don't know where he got that number from, but I remember it so clearly.

## ***How do you look after yourself?***

Jai starting googling MS as soon as I got the diagnosis. He found out about the Jelinek diet and we were very interested. On my first night home, was the last night I ate a cheesy, meaty lasagna meal that we had been given, and since then I have been following the Jelinek diet. I feel great on it and have also lost the last 5kg of my baby weight that I had been struggling to lose.

My legs are still heavy and I can't run or hop but I'm ok with that. I have bad days but lots of good days too. I'm back to driving with my foot. I've got use to my new normal.

**You are being very generous with your time and donations to MS Auckland. It can't be easy running a household, a business and being a full time Mum. It is awesome the way you find ways to give back. Why do you do it?**

I have found the MS Society to be a wealth of support and knowledge and I think as well as funding for research to find a cure, we need funding for the amazing work the MS fieldworkers do. It's a great service that the Society does. I also love the magazine and read it from cover to cover.

Being diagnosed with MS can make you lose your confidence. These days I love what I am doing. Being a Mary Kay Consultant, doing make-up, and helping people with skin care. Life is too short to do stuff that doesn't make you happy. I'm happy doing what I do and I love being able to give back.

**Tell me a bit about what people can expect from a pamper party?**

Well I can cater a party to what the group wants. I come into your home and I can do make-up, teach techniques for applying make-up, do colour matchings, and teach you about skincare and facials.

Mary Kay cosmetics are all designed for sensitive skin and are not tested on animals. From sales and orders generated from these parties and classes I will be able to donate 20% back to MS Auckland.

**How do people book a party?**

They just need to ring me on 021 025 64223. They have to say that they want to book a party for MS. Any party booked between now and the 3rd of September will go towards MS Auckland.

Help Rebecca raise money for MS Auckland services, by having a pamper party in your home. Rebecca uses Mary Kay cosmetics, and together with friends you can learn and apply make-up and skin care products and learn about what colours are best for you. **20% of all products sold on the night will go to MS Auckland.** Phone 021 025 64223 and book your party today.



## awareness week and annual street appeal

28th August - 3rd September 2016

Awareness Week this year kicks off on the 28th of August. It finishes with two days of Street Appeal on the 2nd and the 3rd of September.

**We need your help!**

Please could you give us a couple hours of your time on the 2nd or the 3rd of September to help us at our collection sites?

We hope to be in many of the malls and supermarkets around Auckland. Francesca's goal is to raise over \$50,000 to support us in providing our services. This is just a bit more than the \$48,000 which was raised last year.



Mark Blackie with Francesca, and Kirsty Whitehouse

We are thrilled to have Francesca on board with us this year to help us in undertaking the mammoth task of organising the Street Appeal.

**Francesca would love to hear from you if you can help. You can e-mail her on [streetappeal@msaklorg.nz](mailto:streetappeal@msaklorg.nz) or call her on 09 845 5921.**

# Get a head start in managing your MS.

'MS Get a Head Start' is an innovative programme designed to educate and empower you with the knowledge and skills you need to help you take control of your MS.

Implementing the latest evidence based treatment approaches in multiple sclerosis combining high intensity progressive exercise and education in a six-week hydrotherapy programme. Exercise can be neuroprotective. The programme focuses on building self-management and is structured around a framework of six core principles of exercise specific to MS.



MS Get a Head Start has proven to be hugely successful at its launch site – the Advance Rehab Centre in Sydney – where results over the past 3 years have demonstrated:

100%  
of participants  
made  
improvements  
in functional  
outcomes

An average  
25%  
improvement in  
report fatigue

90%  
continued with  
regular exercise

To register your interest and to let us know when and where this programme should be delivered please go to the link below and complete the short online questionnaire. Or contact Connect Neuro Physiotherapy on the details below.

## Online Survey

*Tell us how you want to access  
this life changing programme*

[www.surveymonkey.com/r/ZQ6W6V8](http://www.surveymonkey.com/r/ZQ6W6V8)

or contact: Gilly Davy

Email: [gilly@connectneurophysiotherapy.com](mailto:gilly@connectneurophysiotherapy.com)

Phone 0220440295



[www.connectneurophysiotherapy.com](http://www.connectneurophysiotherapy.com)

# hydrotherapy.

The evidence is clear that water exercise for people with MS has many benefits. People who attend our hydrotherapy classes regularly will also tell you how much enjoyment they get from it.

If you haven't tried it yet, you can have two free classes to see if you like it. After that classes are only \$50 for 10 sessions. Payments are made to MS Auckland and can be charged to your credit card by phoning 845 5921.

To arrange your free visits contact the MS Field Worker in the pool closest to you (see contact details below).

Our hydrotherapy classes are also open to people with Parkinson's or people who have had a stroke. If interested please contact Rope Neuro Rehabilitation on 623 8433 to discuss, before attending.

Costs for non-MS people is just \$7 per session. Payment must be made in advance through the office. A trial of



2 classes is \$14, and after that payments of \$70 for 10 sessions can be made.

All Hydrotherapy classes are conducted by a Rope Neuro Rehabilitation Physiotherapist. See their website [www.ropeurorehab.co.nz](http://www.ropeurorehab.co.nz)

## 2016 Weekly Sessions

### Tuesday

#### Lloyd Elsmore Pool

Sir Lloyd Drive  
Pakuranga

11.00am - 12.00 noon

**Contact:**

**Dianne Bartlett**  
09 845 5921 Ext 220  
dianne@msakl.org.nz

### Wednesday

#### Millennium Pool

17 Antares Place  
Rosedale

10.30am - 11.30am

**Contact:**

**Diane Hampton**  
09 845 5921 Ext 219  
diane@msakl.org.nz

### Wednesday

#### Manurewa Leisure

Sykes Road  
Manurewa

11.00am - 12.00 noon

**Contact:**

**Dianne Bartlett**  
09 845 5921 Ext 220  
dianne@msakl.org.nz

### Thursday

#### Epsom Girls

Silver Road  
Epsom

10.30am - 11.30am

**Contact:**

**Carol Andrews**  
09 845 5921 Ext 222  
carol@msakl.org.nz

### Friday

#### Westwave Aquatics

20 Alderman Drive  
Henderson

11.00am - 12.00 noon

**Contact:**

**Carol Andrews**  
09 845 5921 Ext 222  
carol@msakl.org.nz

### Saturday

#### Diocesan Girls

Clyde Street  
Epsom

10.00am - 11.00am

**Contact:**

**Carol Andrews**  
09 845 5921 Ext 222  
carol@msakl.org.nz

# Gary Stephenson – my journey so far...

It all started around 2005 with numb feet which made walking upstairs quite challenging. My Doctor sent me to a Chiropractor which did little to help. During a visit to Parakai pools I found I could just walk into the very hot pool while others entered very gradually. The cool side of the pool though felt like it was red hot to my skin, not all over, just patches.

Back to my Doctor who decided to send me off to see a neurologist. After a thorough examination, she ordered an MRI of my brain. A week later we sat in her offices as she pulled out the MRI films and said, "I've found something strange. I think you have Multiple Sclerosis".

We were referred to Dr Willoughby, who diagnosed two conditions, Myotonia Congenita and Multiple Sclerosis. He ordered a full spine MRI as he was sure there were lesions there as well. At our next visit it was confirmed, lesions in the spine as well as brain. During this time, other symptoms started to appear like Lhermitte's signs, feeling of spiders crawling down my back, spasms, and restless legs syndrome. As time dragged on fatigue became more noticeable accompanied by heat intolerance.

We owned our own business with its busiest time in summer when it became all hands on deck. The activity, both mental and physical was intolerable even when we outsourced a large chunk of work. By midday I was usually on my last legs, as time went on we took the decision to sell up.

Suicidal depression became a big issue, not being able to work or cope with a high work load like I used to - going from travelling the world on business, juggling multiple roles and managing many different teams at varying locations for major international companies to running my own business - to being a PwMS and unable to cope took some mighty getting used to.

After taking anti-depressants for a long while I had Cognitive Behavioural Therapy that helped me accept my diagnosis and learn to realise that I can still do what I used to do, as well as I used to do, it just takes a lot longer. It also helped me dump anti-depressants.

At home, with less stress and less time pressure and more cognitive therapy I learned to slowly cope with my symptoms including a new lesion that affected bladder control and changes to my abilities. We joined our local café group which was refreshing.



At home we have two house rabbits which helps with stress (yes, they do have their own room kitted as a warren and freedom of the entire house). We grow our own, and the rabbits, vegetables, and make our own wine. But the issue remained of how to keep a curious and once very active mind alive.

I started writing. I self-published my first book and took a creative writing course which I passed with distinction. I started writing the second book in the series whilst making many improvement changes to the first book. Both books were taken up by a Literary Agent and subsequently a Publisher. The first book *The Charles Langham Series - The Pacific Affair* has a few twists and turns with a secondary story line, the second book *The Charles Langham Series - The Atlantic Affair* is much more complex, required much more research and took a lot of notes and memory joggers to keep the various plot and characters in my mind.

We have a film rights agreement covering both books with our Literary Agent which means we are working on the screen adaptation of the first book which is fun but hard and very tiring. It's a totally different writing style reducing a novel down to 120 pages. It entails having to decide where to cut, what to cut out, what to keep in and all the time ensuring the story line and essence of the book remains. Keeping the different time zone locations chronologically correct when scenes are cut is fun.

When finished, we then have to make some choices, writing the third book in the series, The Charles Langham Series - The Caribbean Affair, which will require a trip to the Caribbean, or work on the screen adaptation of the second book which my Literary Agent would like. But then the publisher may require the third book plus PR trips to UK and USA. Thankfully both my Literary Agent and Publisher are aware of MS and the affect it has, so how long things take is up to me.

We developed our own website and after contacting many companies received permission to use images

of their products and location for which we are very grateful. We have just commissioned a 90 second live action video trailer for the first book which will be followed by one for the second book.

Davina, my wife, is my rock. Without her strength I honestly do not know what would have happened, she looks after me so well, helping with any activity, whether in the garden, with the rabbits or my writing.

**Life after the diagnosis of MS does not mean the end, it is a new beginning.**

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## having a car and MS.

Rod Milner from Rod Milner motors has been a long term supporter of MS Auckland. For the last 34 years he has specialized in cars for people with disabilities. His interest began when his late wife needed a wheelchair and he found out first-hand how difficult it was to find cars for people with disabilities.

Today, Rod Milner motors is the largest supplier of disability vehicles in NZ. They also have the biggest range of vehicles to choose from. Or, if you like the car you have already, but need to have it adapted, they can look after that too.

Rod's son, Darren, has also joined the business. They have been growing so much that they are looking for new premises to move to.

If you are looking at buying or renting a car, would like help and advice on vehicle purchases or adaptations then speak to Rod, Darren or the team at Rod Milner Motors.

**Check out their website - [www.rodmilner.co.nz](http://www.rodmilner.co.nz) or give them a call on (09) 579 9632. And if you purchase a car and tell them you have MS, they will also donate \$500 to MS Auckland to support our work.**



# meditation & yoga workshop.

In May, MS Auckland was named the recipient of donations from people attending weekly meditation classes at the Hot Yoga Studio in Newmarket. A big thank you goes to Studio Owner, Fiona, and the yogis who gave generously to support MS Auckland.

Fiona has a real passion and gift of meditation and yoga. We were delighted to hear that in August she will be offering a workshop for MS Auckland members.

The workshop will be at the Om Yoga studio in Stonefields. There is plenty of parking outside and the room, which is one floor up is accessible by elevator.

To participate in this class people must be able to sit on the floor, or on cushions on the floor.

You will become entranced by her gentle voice and nature as she guides you through meditation, relaxation and gentle, therapeutic Yin yoga.



## *Meditation & Yin Yoga workshop*

### When:

.....  
Sunday 14th August  
1:00 - 3:00pm

### Where?

.....  
Om Yoga Studio, Shop 16,  
Stonefield's Market,  
40 Stonefield Avenue.

### Cost?

.....  
Only \$5 for members  
\$10 for non-members



### Registration is Essential

.....  
To register either e-mail us at  
events@msakl.org.nz or phone  
(09) 845 5921. Spaces are Limited.

### About the workshop

.....  
We'll start with a mindfulness meditation cultivating the attention on our relationship with the body, the emotions, the thoughts and the external space. This will be followed by therapeutic Yin Yoga practice and end with blissful Yoga Nidra into full relaxation.

Please Note: Participants must be able to sit on a mat on the floor or on cushions on the floor.

# wellness workshop.

## taking control of our life changes

### About the Workshop

People with MS are familiar with the unpredictable nature of the disease: from the expected diagnosis to the frequent changes and challenges to their body, their brain, their sense of identity, and often their lifestyle, relationships and jobs.

The uncertainties and the challenges of MS can make people feel helpless and hopeless, and potentially develop depression, anxieties and stressed relationships. However, more often than not, people with MS are able to develop effective ways for coping with change, adapting to their circumstances, and live fulfilling lives.

Dr John Davison's presentation will use concepts of positive neuropsychology to both help us recognise the potential effects of MS on our sense of well-being and, more importantly, to gain control of our life changes rather than be controlled by MS.

He will discuss evidence-based coping strategies to help improve our wellbeing and resilience in the context of living with MS, and to avert vicious cycles of depression and anxiety.

The presentation will end with time for questions and open discussion.



### About the Presenter – Dr John Davison

Dr John Davison is a senior clinical psychologist with experience in both clinical and academic positions in New Zealand, Australia and Singapore.

He currently works at Middlemore Hospital, where he provides psychological and neuropsychological assessment and rehabilitation for adults and families adjusting to medical and neurological disorders.

John completed his Doctorate of Clinical Psychology at the University of Auckland, in collaboration with Harvard University/Mass General Hospital.



## Wellness workshop

### Taking control of our life changes

#### When:

.....  
Sunday 30th July  
10:30am – morning tea  
11:00am – presentation  
12:30pm – close

#### Cost?

.....  
Only \$10 for members  
\$15 for non-members

#### Where?

.....  
Commerce Club  
of Auckland  
27-33 Ohinerau Street,  
Remuera

#### Booking is Essential

.....  
Please book by Wednesday 27  
July by e-mailing: [events@msakl.org.nz](mailto:events@msakl.org.nz),  
or calling (09) 845 5921



# food & recipe.

As the weather gets colder our cravings turn more to hot casseroles, instead of cold salads. Our recipe today has been sent in by Fran Watts. She found the recipe in Forks over Knives and adapted it slightly to suit. (Check out the Forks over Knives website for more delicious plant based recipes <http://www.forksoverknives.com/>).



## Winter casserole

This winter casserole recipe will feed 6 people. Fran says she has made it a few times and that it's delicious.

### Ingredients

#### *For the kumara and vegetable mixture:*

1 large kumara, cut into small slices  
1 small onion, peeled and diced  
2 medium carrots, peeled and cut into slices  
2 medium courgettes cut into slices  
1 red bell pepper, seeded and cut into slices  
2 cups cauliflower florets (about one head)  
1 cup green beans, trimmed (or frozen sliced beans)  
1 tablespoon dried thyme  
1 bay leaf  
3 cups vegetable broth  
2 cloves garlic, peeled and minced  
Sea salt  
Freshly ground black pepper

#### *For the mashed potato and mushroom mixture:*

8 small potatoes, cut into small cubes  
2 cups vegetable broth  
1 cup mushrooms, sliced  
2 shallots, peeled and minced  
3 celery stalks, chopped  
½ teaspoon celery seed  
¼ teaspoon white pepper  
½ teaspoon sage  
2 cloves garlic, peeled and minced  
1 tablespoon vegan Worcestershire sauce

#### *For the white bean cream:*

1 cup cooked cannellini or navy beans

### Instructions:

1. Preheat the oven to 230°C.
2. To make the kumara and vegetable mixture, place the kumara on the bottom of a large baking dish, and top with the onion, carrots, courgettes, red pepper, cauliflower, green beans, thyme, bay leaf, vegetable stock, and garlic. Season with the salt and black pepper to taste. Cover with a lid or aluminium foil. Place in the preheated oven and bake for 50 minutes, or until the kumara are tender. (Note that both the kumara and vegetable mixture and the mashed potato and mushroom mixture should be placed in the oven at the same time.)
3. To make the mashed potato and mushroom mixture, place the potatoes on the bottom of a large baking dish, and top with the vegetable stock, mushrooms, shallots, celery, celery seed, white pepper, sage, garlic, and Worcestershire sauce. Cover with a lid or aluminium foil. Place in the preheated oven and bake for 50 minutes, or until the potatoes are tender. Then coarsely mash them in the baking dish with a potato masher.
4. To make the white bean cream, place the beans and 1 cup of water in a blender, and process until creamy, adding more water as needed for a smooth consistency.
5. To assemble the stew, pour the white bean cream into the mashed potato and mushroom mixture, and mix well to combine. Spread on top of the sweet potato and vegetable mixture. Return the baking dish to the oven, and bake for another 10 minutes.



## flaxseed oil

Flaxseed oil is a healthy, Jelinek friendly alternative to butter on toast, and an excellent source of plant Omega-3 fatty acids, yet it can be hard to find a good supply of it. It is quite unstable and prone to oxidation, making it bitter and unpleasant. One of our members wrote in to tell us about a good supplier that she found based in Ashburton that will deliver straight to the door - <http://www.bio-oils.co.nz>.

She purchases a 5 litre container from which she decants 500 ml into a bottle for ease of use. Both containers should be kept in the deep freeze. Flaxseed oil can be frozen without affecting its chemical structure or effectiveness. It is the best way to store it. The cost for 5 liters is \$131.00 incl g.s.t. and courier fee.



## the role of vitamin D in MS.

### RESEARCH

The Consortium of Multiple Sclerosis Centres (CMSC) has recently held a webinar of experts discussing the role of vitamin D in MS.

The discussion was between Dr Emmanuelle Waubant, Professor of Clinical Neurology and Paediatrics at the University of California, San Francisco, and Dr Ellen Mowry, Associate Professor of Neurology and Epidemiology at Johns Hopkins University in Baltimore, moderated by June Halper, the Chief Executive Officer of CMSC.

It was interesting to note that while the experts concurred that data were not conclusive, with the inevitable caveat that more research is required, specifically randomised controlled trials of vitamin D in people with MS, Prof Waubant was very clear that he routinely checks vitamin D at diagnosis and mostly finds that it is low.

He also regularly prescribes vitamin D in doses of 2,000-4,000IU of vitamin D3 daily, but is prepared to increase it after checking the blood level at three months. The experts also concluded that supplementation should not be stopped in summer, and noted that pregnant women need 50-100% more than this dosage.

While these doses are a little lower than recommended at OMS (Overcoming MS), it is important to note the shift in mainstream neurology towards vitamin D supplementation for most people with MS.



The full webinar can be listened to by going to <https://event.webcasts.com/viewer/event.jsp?ei=1087341>.

# MStranlate – building and serving the MS. community.



*At our Research Day this year we were pleased to have Brett Drummond present to us. Brett has set up MStranlate. In the article below he explains a bit more about what MStranlate is and what they are doing.*

The growth of the Internet has produced a new wave of platforms for people to gather information. However, when it comes to scientific information, many online sources (as well as mainstream media) provide coverage that is inaccurate, overstated or misleading. For these reasons, science communication has become increasingly important to ensure that resources exist to provide research updates that are accurate and reputable.

During my time researching Multiple Sclerosis, I noticed a clear disconnect between the people doing the research and people living with MS. To me, it was obvious that this gap benefitted no one and should be fixed. After extensive planning with my brother Eric (web and social media expert), we launched MStranlate – a science communication initiative that is designed to bridge the gap between research into Multiple Sclerosis and people living with MS.

In essence, the concepts behind MStranlate are simple. We take research findings and ‘translate’ them into a form that is independent, accurate, up-to-date, easily accessible and most importantly, easy to understand for people with MS.

However, we realise that this only solves part of the problem. By using social media platforms, MStranlate seeks to connect with people with MS and engage in meaningful conversation and discussion. This ensures that while we are providing information and reducing confusion, we are also decreasing isolation and creating a community.

At MStranlate, we are extremely passionate about the work that we do and continue to find new ways to expand and grow. We are one of the few sites that provides information directly from the source by interviewing researchers from laboratories, institutions and biotechnology companies around the world.

In addition to this, our Google Hangouts have provided people with MS the opportunity to engage personally with scientists from around the globe – allowing them to learn more and ask their own questions about ongoing studies.

*The most common question that I’m asked is “Why?” The answer is actually incredibly simple – we do this because we believe it is important and the right thing to do.*

Having been involved in MS for almost a decade (in both a research and science communication capacity), helping people with MS is something I am extremely passionate about.

MStranlate believes in creating an environment where all members of the MS community (people with MS, researchers, organisations, carers) are connected and working together. It is our hope that building these networks will help advance the progress of MS research, whilst at all times making sure that the best interests of people with MS are served.

To learn more about MStranlate, visit their website [www.mstranlate.com.au](http://www.mstranlate.com.au) or



[www.facebook.com/MStranlate](http://www.facebook.com/MStranlate)



[www.twitter.com/MStranlate](http://www.twitter.com/MStranlate)



[www.instagram.com/MStranlate](http://www.instagram.com/MStranlate)

If you would like to talk to Brett directly, you can contact him by e-mail ([brett@mstranlate.com.au](mailto:brett@mstranlate.com.au)) or by phone (+61 4 3963 6279).

# support groups.

Location	Contact	Date/ Time
<b>South / East Auckland</b>		
Beachlands Support Group Pepper Jacks Café	Dianne Bartlett 021 845 903	Fridays / Six Weekly 11.30am
Pukekohe Café Group Different Venues	Dianne Bartlett 021 845 903	First Thursday / Month 11.30am
Botany Café Group Whitcoulls Coffee Lounge - Botany Town Centre	Dianne Bartlett 021 845 903	Third Thursday / Month 11.30am
Manukau Café Group Friendship House Manukau	Dianne Bartlett 021 845 903	Last Tuesday / Month 10.30am
<b>Central / West Auckland</b>		
Greenlane Café Group McCafé - Greenland McDonalds	Carol Andrews 021 959 187	Second Saturday / Month 11.00am
Newmarket Café Group Parnell Café	Carol Andrews 021 959 187	Fourth Tuesday / Month 1.30pm
Stonefields Café Group Stonebake Café - Lunn Avenue, Mt Wellington	Carol Andrews 021 959 187	Third Wednesday / Month 10.30am
Onehunga Group Frolic Café - Manukau Road, Royal Oak	Carol Andrews 021 959 187	Second Tuesday / Month 10.30am
Kumeu Café Group Different Venues	Carol Andrews 021 959 187	First Tuesday / Month 10.30am
Henderson Group BB's Café - Waitakere Mega Centre	Carol Andrews 021 959 187	First Thursday / Month 11.00am
<b>North Auckland</b>		
Mayfield Coffee Morning Kings Plant Barn - Porana Road, Glenfield	Diane Hampton 021 859 187	First Thursday / Month 10.30am
North Café Groupies Kings Plant Barn, Silverdale	Diane Hampton 021 859 187	Third Wednesday / Month 10.30am
Shore Lunch Group Different Venues	Diane Hampton 021 859 187	Second Wednesday / Month 12.00 noon
North Shore Café Group Kings Plant Barn - Porana Road, Glenfield	Christine Ball 09 444 6945	First Saturday / Month 12.30pm

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

Ask your doctor about GILENYA.



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

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

# Marvyn & Doug Smith – MS. Auckland's newest honorary life members.

At the Annual General Meeting this year Marvyn and Doug Smith were awarded Honorary Life Membership. President Neil Woodhams and General Manager Ingrid Minett, took the lovely drive up to Waipu Cove to deliver their Honorary Certificate to them. They were rewarded with delicious coffee and scones, beautiful views over the water, and of course delightful company.

## *A little bit about Marvyn and Doug Smith*

Marvyn studied to be a primary school teacher in 1961. She taught in schools around Auckland until she retired in the late 70's. In 1965 she was diagnosed with MS, although it certainly didn't seem to slow her down – even after getting diabetes as a result of the large doses of prednisone she took for her relapses. She is a lovely woman with a positive attitude that shines through as you talk to her.

Doug is an accountant and worked for Fisher and Paykel NZ until his retirement in 1995. Together they have 3 children and 5 grandchildren.

In 1984 Marvyn and Doug purchased 25 acres of land up at Waipu Cove. They gifted 4 acres of it to the QE11 National Trust. Over the years they managed to subdivide the land into 5 sections and sold off 4 lots. With some of the money they made from this they formed the Marvyn and Doug Charitable Trust.



They invested the money with Milford Asset Management, and fortunately did very well over the years, enabling the Trust to annually give to 11 different charities close to their heart, with MS Auckland being one.

This year they decided to wind up the Trust and donate the money held to their charities. MS Auckland was thrilled to receive \$48,000. This money will be invested so that we can continue to draw out money each year to assist us in our work. It is a most generous gift that will keep on giving to us for many years to come.

Thank-you, Marvyn and Doug and family!



Leaving a gift in your Will  
is an easy way to support us.

include *a charity*  
Help the work live on.



Many everyday people like to leave a gift in their will. The truth is that most gifts are made by ordinary, hardworking people who want to give lasting support to causes that are important in their lives. The good news is that including a charity in your will is just as easy as providing for your loved ones. And it can be as much or as little as you want.

Without the generosity of everyday Kiwis, the services Multiple Sclerosis Auckland provides wouldn't exist. Supporting us in this way is essential for ensuring our work continues into the future. If you would like further information about writing a will or leaving a gift to Multiple Sclerosis Auckland, or for a confidential no-obligation chat about how your bequest can make a difference please contact Mark or Ingrid on (09) 845 5921, or by e-mail on [mark@msakl.org.nz](mailto:mark@msakl.org.nz) or [Ingrid@msakl.org.nz](mailto:Ingrid@msakl.org.nz).



# Membership and/ or Donation Form



Multiple Sclerosis  
AUCKLAND

www.msakl.org.nz

Please return this form to: Multiple Sclerosis Auckland  
PO Box 33574, Takapuna, Auckland 0740  
Email: info@msakl.org.nz, Telephone: 09 845 5921

First Name: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Surname: \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_ Home ph: \_\_\_\_\_

\_\_\_\_\_ Work ph: \_\_\_\_\_

\_\_\_\_\_ Post code \_\_\_\_\_ Mobile: \_\_\_\_\_

## Membership Information

Is this a renewal membership? Yes:  No:

Date of birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Membership No. \_\_\_\_\_

### Please select one of the following:

- I have MS
- A family member has MS
- Supporter
- I am a health professional
- Other \_\_\_\_\_

### Membership Type:

- Annual Individual \$40
- Annual Individual Beneficiary \$20
- Annual Family \$55
- Lifetime Individual \$400
- Lifetime Family \$550

### For an Annual or Lifetime Family Membership, please give details of the family members you wish to include:

Name:	Address:	Email:	Phone:	Mobile:
1	_____	_____	_____	_____
2	_____	_____	_____	_____
3	_____	_____	_____	_____

I wish to give a donation: \$10  \$20  \$50  \$100  Other \$ \_\_\_\_\_

## Total Payment to MS Auckland

Membership: \$ \_\_\_\_\_ Donation: \$ \_\_\_\_\_ **TOTAL \$** \_\_\_\_\_

**Payment Options:**  Visa or Mastercard  Expiry Date \_\_\_\_ / \_\_\_\_ Name on card: \_\_\_\_\_

Card Number

I have enclosed my cheque payment of \$ \_\_\_\_\_ Please make cheques payable to Multiple Sclerosis Auckland.

Deposited into MS Account No. **12 3047 0088939 00** ASB Bank. (Please use your first and last name as reference)

I give my approval for my photo to be used in any of MS Auckland's publications: Signature: \_\_\_\_\_

# our supporters.

MS Auckland is grateful to all organisations, families and individuals who support our work. Key supporters for 2015 were:



A complete list of all our supporters is available on our Annual Report for 2015.

*Special thanks also to our wonderful volunteers who give us their time, expertise and support.*



Takapuna Community Services Building  
Top Floor, 5 The Strand, Takapuna, Auckland 0622  
PO Box 33574, Takapuna, Auckland 0740  
P: 09 845 5921 | Email: [info@msakl.org.nz](mailto:info@msakl.org.nz) | [www.msakl.org.nz](http://www.msakl.org.nz)



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(dimethyl fumarate)

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Talk to your neurologist to see  
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**References:** 1. TECFIDERA Data Sheet [18 Nov 2015]. 2. PHARMAC website – [www.pharmac.govt.nz](http://www.pharmac.govt.nz). Date accessed 4th February 2016. TECFIDERA is a funded medicine – a pharmacy charge and Special Authority criteria will apply. Normal doctors' charges will apply.

  
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