

multiple news

Multiple Sclerosis Auckland Magazine

March 2016 | Issue 32

feature story: Nick Allen

inside

Nic Miller Clendon
shares her New York
marathon story

ms. research:
brain fog explained

wellness
workshops

yoga

and more...



ms.
Multiple Sclerosis
AUCKLAND



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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.

Aubagio® (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. 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.

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our people.

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*Thank you to Susan
from Underdog Design
www.underdogdesign.co.nz
for the magazine design,
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a few words from Ingrid.

Our General Manager

The summer holidays are over and I am very quickly getting to grips with my new role here at MS Auckland. A big thank you to the wonderful volunteer committee, led by our President Neil Woodham, and the great team of staff and volunteers who have welcomed me on board and helped me to get my bearings.

I have had to hit the ground running, so to speak, because of all the things that are happening – some exciting and some sad. We have had to say farewell to two of our team – Georgia Forgac, who has been the Field Worker for West Auckland for the past 11 years, and Carolin who took on the role of Administration assistant last year.

For Georgia it means moving to the Waikato and being closer to family. We will certainly miss her and also wish her all the best with her new adventures. Carolin has been one of our valued volunteers for a long time and will continue her half day volunteer roster this year. She is also leading the volunteers for our big annual fundraising event 'Life Buoy' this year, which is a big undertaking and for which we are extremely grateful!

As we go to print, we welcome our new Administrator/Volunteer Coordinator, Becky Tucker. Recruitment for a new Field Worker continues, with our other 3 Field Workers working extra hard to ensure continuity and support for all our members.

There are lots of exciting things happening over the next few months. April will be busy with our first Wellness Workshop being held and our very popular Research Day also being planned.

There will also be an opportunity to visit the beautiful Eden Gardens and enjoy a High Tea fundraiser for MS Auckland. All the usual activities such as hydrotherapy and support group meetings are also continuing, as well as the introduction of new yoga classes with Kylie Harris every Saturday throughout April.

I hope you enjoy our new look magazine. It was lots of fun to put together. We have some lovely stories from some inspirational members – Nick Allen who features on our cover, Nic Miller Clendon who did the New York Marathon, and Megan Otto, who shares one of her favourite recipes with us.

Please feel free to e-mail, call or drop in to say hello. I love hearing from our members!

Wishing you all a wonderful year,
Ingrid

Email: Ingrid@msaki.org.nz

farewell



from Georgia.

As many of you know I am leaving Auckland and moving to the Waikato region. This decision has been made with much thought.

Sadly it means that after 11 years of working for MS Auckland that I will be leaving. But I will take with me so many outstanding memories, plus a whole 'life time' of experience (as I have shared your ups and downs, triumphs, and sadness at times).

I encourage you to keep doing what you can to stay as well as possible. Connect with others, as a support network can be a great source of strength when you feel you have little. But most of all have fun and keep smiling. Adieu.

events for your calendar.

April

2nd April	3rd April	9th April	13th April
<p>Yoga @ 11am 181 Hinemoa St Birkenhead</p>	<p>High Tea @ 10.30am or 2:30pm Eden Gardens</p>	<p>Yoga @ 11am</p> <p>Wellness Workshop @ 10.30am – 12:30pm</p>	<p>MS Auckland AGM @ 7pm 5-7 The Strand Takapuna</p>
16th April	23rd April	30th April	
<p>Yoga @ 11am</p>	<p>Yoga @ 11am</p>	<p>Yoga @ 11am</p>	
<i>Upcoming events</i>	21st May (TBC)	10th June	2-3rd September
	<p>Research Day at Alexander Park</p>	<p>Life Buoy Annual MS Fundraising @ 12:00 – 4:00pm</p>	<p>MS Auckland Annual Street Appeal</p>



welcome to Becky.

Becky Tucker joined us on the 1st of March to take on the part-time role of Administrator/Volunteer Coordinator.

Originally from the U.K. Becky came to New Zealand in 2008. Becky is the mother of three active school aged children.

When not busy looking after MS Auckland's volunteers and numerous activities, Becky likes looking after the children's soccer and netball teams and enjoying life.



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all the latest MS. news
and research.

For more information visit
www.msakl.org.nz

our field workers.

Managing heat and fatigue

Our warm sticky weather is continuing and we know many of our clients are struggling to cope with the impact our warm temperatures are having on their MS. Heat or high humidity can make many people with MS experience a temporary worsening of their symptoms. Doctors believe that this occurs because heat causes nerves (whose myelin covering has been destroyed from MS) to conduct electrical signals even less efficiently. This is different to a true relapse as, when the body's temperature returns to normal, these symptoms disappear with no damage such as inflammation, demyelination or new lesions.



Diane Hampton,
North Shore



Carol Andrews, Central



Dianne Bartlett, South

To ease these symptoms

- Decreased cognitive function
 - Numbness in the extremities
 - Fatigue
 - Blurred vision
 - Tremor
 - Weakness
- To ease these symptoms**
- Avoid extreme temperatures
 - Avoid heavy exercise
 - Use air conditioning. If hot and humid conditions worsen your MS, try to stay in cool and dry areas as much as possible.
 - Use cooling products such as vests, neck wraps and bandanas during exercise or outdoors.
 - Keep cool water from the fridge or freezer with you
 - Try running cold water over your wrists and swishing it on your face and neck.

Fatigue is often identified as the symptom that has the most affect on day to day living:



How to manage fatigue:

- Prioritise tasks. By doing this you save energy for the things you really want or need to do. It can help you plan your activities and your time to rest and recuperate.
- Be realistic about how much you can, or need to get done - don't try to take on too much.
- Organise living and work spaces. Sometimes, the simplest of changes can make the workplace or home more energy efficient.
- Healthy eating. A balanced diet can help you maintain a healthy weight which, in turn, will help you get the energy you need. What you eat can also make a difference. For example, large hot meals can make fatigue worse and caffeine or sugary snacks might have an initial 'pick me up' effect, but can leave you feeling more tired later.

- Rest when needed. It does not need to be for long periods, often a 20 minute break will be long enough to feel re-energised.
- It's possible to do too much exercise in hot weather, so balance the exercise with rest and keep cool while you exercise. Water based exercise is helpful for maintaining a steady temperature.
- Accept help from family and friends. It is not always easy to ask for help, even when it is offered. It can be useful to prepare a list of tasks that you'd like help with. That way, if someone does offer to help, you can easily tell them how they can help.

It is important to remember, that while climate may worsen the symptoms of MS, climate changes do not produce more actual nerve damage. The adverse affects of temperature and humidity are generally temporary. However, it can take longer (a few days) to recover if you get overheated.

Contact your GP, MS Nurse or Field Worker if you are concerned that your sudden fatigue, or other symptoms, could be more than heat related.

from the MS nurses.

It is amazing that in a 16 month period people in NZ with relapsing remitting MS now have access to 4 efficacious disease modifying treatments (DMTs). The acronym NEDA or 'no evidence of disease activity' is used more and more internationally and we can now hope that people with relapsing remitting MS in New Zealand will also experience this phenomenon in the coming years.

Tecfidera (Biogen) and Aubagio (Sanofi) are the newcomers for 2016, being approved for use early this month. Fingolimod and Natalizumab were approved in November 2014. Further information on these medicines can be found via the PHARMAC website www.pharmac.govt.nz. These medicines have all been used internationally for some years.



The rapid introduction of DMTs and the vital and very necessary time the MS Nursing staff spend educating and then monitoring people starting them is overfilling our working week. Unfortunately this continues to impact on the time frame in which your email and telephone queries are resolved.

To help us focus on responding to people reporting symptoms, relapses and side effects of medications in a timely fashion we would ask you seek repeat prescriptions for common medicines, such as Vitamin D, through your GP. Should you have questions about symptoms and are unable to reach us your MS Auckland Field Workers are a wealth of knowledge and will also liaise with us should you report worrying symptoms to them.

If you have recently changed address or GP your updated details are most appropriately directed to our neurology schedulers on (09) 307 4949 extension 25820. They can also update you on queries you may have about your upcoming neurology appointments.

Many people are anxious to know when scheduled MRI's might occur. Please direct queries of this variety to the radiology department of your local hospital.

Middlemore Hospital (09) 276 0169
North Shore Hospital (09) 486 8920 extn 3518
Auckland Hospital (09) 307 4949 extn 23559

Warmest regards
Fiona and Nazila

fundraising help for MS Auckland.

Only 8% of operating expenses for MS Auckland comes from the Ministry of Health. Your membership fees, donations and support therefore makes a big difference to our ability to continue to serve the needs of people in Auckland with MS and their families.

We are always extremely grateful when we hear of people initiating their own fundraising ventures. This not only raises vital funds for us, but it also helps to increase the awareness of the general public about MS.

In February Nick Kearns once again held his Lift Free February fundraising event. Auckland City Council and UniServices got behind it and entered teams to see how many people can go for a whole month using stairs instead of the lift.

While February is over, it may not be too late to donate to the cause through their Give-a-Little page: <https://givealittle.co.nz/fundraiser/nicholaskearns>

New to the MS fundraising scene is Josh. Josh is a student in sound engineering. His father has MS. Josh developed an initiative that would raise money and awareness of MS while also helping to raise the profile of local Auckland bands. He is putting a compilation album together with 8 bands participating.



Nick Kearns, Jaimee Maha from Auckland Council and Ingrid Minett from MS Auckland.

Sales of the CD and money raised from gigs to promote the CD will all go to MS Auckland. While Josh and all the artists donated their time, they had to meet costs for the sound room and the mastering of the CD.

Josh set up a Give-a-Little page to help meet those costs. Any excess funding would also go to MS Auckland. To find out more or to donate go to their Give-a-Little page: <https://givealittle.co.nz/cause/breakdownonthenorthern/>

LIFE BUOY FOR ms.

Save the Date

Friday 10th June 2016

12:00 pm - 4:00 pm
Aotea Centre
Lower NZI Room
50 Mayoral Drive
Auckland

RSVP:
Phone 09 845 5921
Email events@msakl.org.nz

Tickets:
\$ 190.00 per person
\$ 1,850.00 per table of 10

FidelityLife **ms.**
Multiple Sclerosis AUCKLAND **Harcourts**

yoga.

*For MS Auckland members
every Saturday in April 2016*

You've been asking for it and now we've got it!

Once again we are bringing yoga to MS Auckland members. If you haven't tried yoga before this is an excellent opportunity to give it a go. More MS experts are noting that for people with MS, yoga with its emphasis on relaxation, breathing, stretching and deliberate movements, is an excellent choice of exercise. If you have done yoga before then come and experience some classes under the expert guidance of Kylie Harris.

Kylie comes from a background in nursing, dance, tai chi and yoga. She has been teaching for 20 years in the area of dance and movement. Her focus the last 3 years has been on yoga and she has trained over the years with internationally renowned yoga practitioners. Kylie has gained a popular following in Auckland for her yoga workshops and group and private yoga sessions.

Kylie's father has Parkinson's disease. She has been working with him to help with breathing, coordination, balance and reducing rigidity in the body and has witnessed first-hand the powerful effects of yoga for people with neurological conditions. She is very pleased to be working with MS Auckland and hopes to be able to work with a number of members through April.



The sessions will be held every Saturday in Birkenhead for the month of April. See information below.

Numbers are limited - to reserve your place please call MS Auckland: 09 845 5921.

When:

Saturday, 2nd, 9th, 16th,
23rd and 30th of April

What time?

11am - 12:15pm
(please arrive at 10:45am)

Where?

181 Hinemoa Street, Birkenhead
(hall behind the Church)

Who should attend?

This class will be suitable for all levels of ability. If you have never done yoga before... or if you do yoga regularly, you should also come along and experience the classes under Kylie's guidance.

What to bring?

Just bring yourself. Mats will be provided, or bring your own if you have one. Wear comfortable clothing.



Cost?

only \$5 for one session or all 5 sessions!. Come every Saturday and reap the benefits of a weekly yoga session.

rope neuro rehabilitation.

By Steph Kurtovich, on behalf of the team at Rope Neuro Rehabilitation

Happy New Year to all MS Auckland members! Things are quickly back into full swing here at Rope Neuro Rehab, and we look forward to catching up with you over the course of the year at the hydrotherapy groups and in the clinic.

For those who already attend our hydro groups you will know that every three months we take outcome measures where we measure how many lengths can be completed in 30 minutes and also how many sit to stands can be achieved in 30 seconds.

I am pleased to share the positive results with you that reiterate the benefit of exercising in water. Across both outcomes:

17% of people increased by more than 50%,
25% of people increased by 25-50%
51% of people increased by 0-25%

The hydrotherapy classes are provided with the aim of focusing on whole body workouts, rather than isolated areas of the body. The water is warm and non-weight bearing so is good for pain, especially chronic pain and allows joint range of movement.

Research investigating the use of aquatic exercise in people with MS provides varying levels of support for the following benefits: improved muscle strength, improved fitness, improved gait and mobility, reduced fatigue, increased quality of life or sense of wellbeing.

This year is also a year of change for Rope Neuro Rehab, it is with sadness that we say goodbye to Jess Simms who is leaving New Zealand to return home to England. Jess has thoroughly enjoyed taking both the Millennium and Westwave groups and is currently handing over to the new hydro therapists Barbara Moore and Lauren Mason, who are looking forward to the year ahead.

On a personal note, I would like to say what an absolute privilege it has been meeting some of you either in the clinic, or at MS events, or at hydrotherapy.



I am heading to the UK in search of the next big adventure in April, and sadly leaving Rope Neuro Rehab. Special thanks to all the devoted Epsom hydrotherapy members and volunteers, you have made my job such a pleasure, and never fail to inspire me each week.

I look forward to catching up with you all in the years to come.

“As always, it is great to see new faces at the pool groups so if you are interested in coming along, please talk to your field worker who can organise two free trials for you.”



www.ropeneurorehab.co.nz

hydrotherapy.

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 noon

Contact:**Carol Andrews**

09 845 5921 Ext 222
carol@msakl.org.nz

Saturday

Diocesan Girls

Clyde Street
Epsom

11.00am - 12.00 noon

Contact:**Carol Andrews**

09 845 5921 Ext 222
carol@msakl.org.nz

Feedback from regular Hydrotherapy participants

“I am definitely fitter as a result of attending the class. I think my balance had improved too”

“I think my mood has improved because of the social aspect of the group”

“I am physically stronger all round and able to function longer before fatigue sets in”



If you haven't tried it yet make 2016 the year you give it a go! As a member of MS Auckland you will receive your **first two sessions FREE**. Costs after that for members is only \$50.00 for 10 sessions (from the 1st April 2016) that's as little as \$5.00 per session.

Please contact your Field Worker for more information. We hope to see you there!

feature story: Nick Allen.



In December of 2015 Nick Allen was the guest speaker at the MS Auckland Society Christmas luncheon. His story of how far he had come since his diagnosis of Primary Progressive MS five years earlier moved everyone in the room. He had achieved a dream that he had almost given up on – climbing a peak off the side of Mt Everest - overcoming so many obstacles along the way.

A bit about Nick.

Nick has just turned 31 and is currently living in Palmerston North. He is doing a PhD in NZ Literature, works part time for Macpac and the Manawatu Community Justice Trust, is writing a book (due to be released in September) and is the founder of the Mastering Mountains Trust and Scholarship Fund. He was named by Wilderness Magazine as one of New Zealand's 20 most inspiring outdoor personalities.

Nick kindly agreed to an interview to answer a few more of the questions for us.

What was life like for you before you had MS?

I loved the outdoors and as a child developed the goal of climbing Mount Everest. I started getting sick though when I was about 18. I started losing bladder control, had problems with my legs and was tired all the time.

I still rode my bike, but my ability to do exercise was decreasing. I continued to be unwell through my early 20's while I was living in the United States, studying on a Scholarship in South Carolina and came home after 18 months.

I was first diagnosed as having Chronic Fatigue Syndrome and then when I turned 25 they gave me a new diagnosis of Primary Progressive Multiple Sclerosis.

How did you react to your diagnosis?

My feelings were really mixed. On the one hand it was a great relief. I had been pushing to get a diagnosis for some time!

On the other hand I was devastated. There is no MS in my family but I knew of some older people that had MS. My impression was it was aggressive and debilitating. I saw it as a death sentence.

What treatment plan were you given when you were diagnosed?

There wasn't much they could give me in terms of treatment. I was given medication to help with bladder control and for the neuropathic pain. My doctor told me that physical exertion would only make things worse. I felt the situation was hopeless. MS was this big monster and I was powerless. I felt like I wanted to roll over and die. But I didn't give up completely. I did re-enroll myself into University and tried to get on as best as I could.

You made lots of changes to your diet. How did this come about?

I moved home and my parents weren't happy seeing me the way I was. They went to a workshop in Auckland where they found out about the Jelinek diet. They came back with lots of information on things I could start doing for myself.

I changed my diet and immediately started noticing good results! My parents provided huge encouragement and went on the diet with me. They did all the cooking in the beginning and I just ate what they put in front of me. We used the principles of the Jelinek diet and then, over the next few years, made our own adaptations that worked for me. My sister has coeliac disease, so even though the Jelinek diet is not gluten free, we added this to it. I feel this really helped me.

The diet changes were done in stages. My diet now is 100% diary free, gluten free and processed sugar free. I eat fish, eggs and occasionally chicken. I really noticed an improvement when I cut out processed sugar from my diet. It was amazing!

Changing my diet was very empowering, I realised that I was not entirely powerless against the disease. It is not strictly the Jelinek diet, but I think it is important for people to figure out what works best for them.

What are your favourite dishes?

My favourite dish is a potato, kumara and lentil curry. I also love stir-fries where I combine whatever vegetables are in the fridge into a wok.

What about exercise? How did you build this back into your life?

I am very fortunate that the MS Society in Palmerston North has a relationship with Massey University that provides exercise rehabilitation to people with MS. I saw a rehabilitation specialist at Massey University who was extremely helpful.

I found going to the gym hard at first. I had to learn not to be discouraged, as I couldn't do anywhere near what I could do before I had MS. I also had to learn to not overdo it. I learned to appreciate the steady, slow pace set by my trainer and saw progress happening.

My biggest battle continues to be with fatigue. Exercise and my diet help tremendously. I'm also learning to listen to my body so I can stop or slow down before I crash. It means learning how to rest properly and learning to say no. It's not easy!

I also meditate most mornings. It's my own version of meditation. I close my eyes and centre myself through prayer for about 15 minutes. I'm going to be seeing a psychologist to learn more about fatigue management and how to rest well.

What advice would you give to a newly diagnosed person?

I love this question! I wish someone had said to me "don't give up hope". Having MS doesn't mean your life is over. MS will mean change. You will learn new ways of doing things. Be happy to make changes. Don't let MS control you.

Also, let people help you. As I started asking for help and handing over stuff to people I started to make progress. I had tremendous support from my parents and friends. I couldn't have done what I did on my own. I am extremely grateful to my support network.

To find out more about Nick Allen or to donate to his Mastering Mountains Scholarship Fund go to his website: www.masteringmountains.org



Above: Breakfast Lake Pangong (4249m), Ladakh
Nicholas Allen – © Mastering Mountains, 2016

Nic Miller Clendon – New York marathon finisher!

**“If you don’t try to spread your wings
how will you know if you can fly?”**

This is the story of how I found myself in the New York marathon last year. My diagnosis of MS in 2011 finally gave a name to the episodes I had had over the previous 15 years. I went from running the half at Auckland Marathon to not being able to walk 100m. In 2014 I was using a crutch to get around and having to use a wheelchair over longer distances.

In my before diagnosis life I had run marathons. A friend from those days, Kiri Price, was just about to leave for New York with a team of disabled athletes to run the New York Marathon. This group were all members of Achilles New Zealand, a chapter of Achilles International, an organisation dedicated to providing people with disabilities the opportunity to participate alongside able-bodied athletes in main-stream events. She suggested that when they returned I should come along to a training session. I readily agreed but little did I know that Kiri had a plan. Her plan was that by November 2015 I was going to be on the start line for the New York Marathon! Kiri is one of those people who when they tell you something you just believe it and agree to do whatever she says. So my training for New York began!

On the 30th of October a team of eight Achilles New Zealand athletes and their guides and support team headed off from Auckland International Airport for New York. Having arrived on the Thursday the Sunday race day came around very quickly. We were boarded buses at 5:30am to travel to the start at Fort Wadsworth, an army base on Staten Island. Our start time of 9:55 came around surprisingly quickly.

The start is in waves beginning with the wheelchair athletes in two waves, the elite men and the first wave of disabled athletes, the elite women and the second wave of disabled athletes including us and then the general field in waves every fifteen minutes – about 51,000 runners in total! There are three routes from the start that finally merge at about mile 13.

I ran with four guides; my husband, two women from Brooklyn and a man from Florida, it seemed they gave me a guide for every disability I had. They kept me entertained, played interference every time a wave of people came through and grabbed water for me. It's an incredible course and the crowd support is unbelievable. People were four deep all along the



course. They cheered constantly and it was just a wave of noise. I was full of self doubt for about three quarters of the race but I just kept to my program of running 4 minutes, walking 1 minute, walking up the hills (mainly bridges) and always running down hills. I poured icy cold water over my head at every water stop as New York decided to have hot weather rather than the expected cold weather.

I don't remember that much of the run, just snippets. When we got to the 17 mile marker I had managed to do some calculations and thought there might be the chance that we would finish in six and a half hours, this was the point that I finally felt that I could do this.

When we crossed the finish line our time was 6:10:14! As we finished we were presented with a medal and wrapped in a foil blanket. The next step was the best. While other finishers did the zombie shuffle to the bag trucks and then out to try and find a way home we were directed through a special chute for Achilles athletes where we got gorgeous warm ponchos and the New Zealand contingent put us into hire cars to shuttle us back to our Times Square hotel. Just what was needed after such an incredible mission.

The New York marathon was an incredible experience but really for me it was the day that I realised I could help my brain and body build new connections - that was the red letter day. The marathon just proved to me that if you don't try you will never find out what you are capable of. I plan to do it again and I have set my sights on doing as many marathons as I can for as long as I can. Achilles New Zealand has been an incredible part of my



Happy Finisher!

life for a year now and we need more athletes. Whether it is you with MS or your neighbour with asthma or a stroke everyone is welcome. If you are interested in becoming an Achilles athlete please check out www.achillesnewzealand.org

There is a fortnightly one hour training session at your own pace followed by really good coffee. It's not just about running a marathon, there are athletes who have to fight to complete a circuit of the 400m track with their walker, to walk a 5k or a 10k but they are still athletes and who knows what sort of athlete is hiding within you.

Experience Accessible **SAILING** *“Give it a go!”*



Catering for all disabilities, no prior sailing experience required. Sailing in the Paralympic Sonar Yachts.

When: *Sunday 20th March 2016 at 1pm - 5pm*
(weather permitting)

Where: *Z Pier, Westhaven Marina, Westhaven Drive*
(near the Billfish Café)

To register or for further information please contact:
Celia Snedden at MS Sailors Trust: 021 320 310

Or register online www.mssailortrust.com (contact us)

*Life isn't about finding yourself.
Life is about creating yourself.*
- George Bernard Shaw

food & recipes.

Thank you for all your feedback on our recipes. The overwhelming response has been that it would be nice if our recipes were suitable to all people. Many people with MS and their families follow a whole food plant based diet, or the Jelinek diet (which includes fish and seafood and egg whites). So all our recipes now will be Jelinek friendly and hopefully will be enjoyed by all. Below is a reminder on what foods to enjoy and avoid on a Jelinek diet.

enjoy Vegetables

Fruits

Grains (pasta, rice, oats, barley)

Legumes, beans and peas

Seeds and nuts

Fish and seafood

Egg whites

avoid Dairy

Fats such as margarine, shortening, coconut oil, palm oil

Meat

Foods fried or deep fried in oil

Egg yolks



There are many milk alternatives on the market now, including soy, almond, and oat milk, and they can easily be substituted for cow's milk in recipes.

We would love to hear from our members and find out more about their favourite recipes. Please email Ingrid at Ingrid@msakl.org.nz if you would like to contribute your favourite recipe to our next magazine. Either ones you have found somewhere else, or ones you have made up or adapted.



We were thrilled to hear from Megan Otto and welcome her as our first member contributor to this section. I asked Megan to tell us a bit more about herself. Here is my interview with her:

I was diagnosed with MS in Oct 2011. I was 42 years old. A week or so later I met with an MS Auckland Field Worker who gave me the book 'Overcoming Multiple Sclerosis' by Professor George Jelinek, telling me that there was a diet that could help. At that stage I was exhausted. I had nose-to-tailed the car trying to drive to work so there was no more driving until leg and foot control resumed. Every day I felt like I walked a million unsteady miles (I dreaded the raised bumps on footpath crossings!).

I got onto the diet right away. In the early days I regularly met with nutritionist Sandra Perry and a naturopath Eva Cahill. They gave me a foundation for the diet. Now 4 years on I haven't had a second relapse. Residual numbness in the sole of my foot doesn't bother me and there is less tingling in my legs.

I still work full time work as administrator. I drive. Spare time is spent maintaining my old house, seeing friends and family. I do the lawns and adore gardening.

I go to the MS hydrotherapy class (great company!) and meditate a little. The rest of the time I'm usually cooking. I squeak in cat naps when I can.

What is your favourite meal of the day and why?

Breakfast! Early on naturopath Eva suggested I eat protein at breakfast to help with fatigue. She said I know this will sound crazy but try to have protein at breakfast, like tuna or beans on toast, even a tofu stir-fry! When I do this, I really notice how my energy levels improve.

Lately the working week breakfast is Jamie Oliver's 'Pukkolla' (constructed muesli which includes nuts for protein, soaked in almond milk or bought lemon, honey and ginger juice). Sometimes I have lentil based soup or a green smoothie (greens from the garden, chia seeds, fruit).

What is your favourite fruit and vegetable?

All fruits and vegetables! Fruit & veggie stores are like Disneyland to me...where to start?!

What do you love about your diet?

I love that it can halt the disease for some (no, not a cure). Even non-scientist me, can grasp that immune system's TH1 chemicals which promote inflammation, are fuelled by saturated fat. By depriving them of this, TH1 is held in check. I love that I have a chance to help myself.

The Jelinek programme involves extra vitamin D, meditation, massage and yoga. At yoga I used to think I've got a disease, you can't expect me to do that! Now I think, yip I can balance on one leg and tip forward... look at me now!

What are some of the challenges of following the Jelinek diet and what advice can you give for overcoming those challenges?

For me, a current challenge is explaining to strangers why I won't eat something. "It's for health reasons," works as a way to avoid fishing for sympathy.

Italian Tofu Meatballs

Megan found this recipe in the Healthy Food Guide magazine back in 2009. It is quick and easy to make. If you are gluten free, it can easily be adapted by using gluten free bread and flour. Have it with spaghetti and heat up some pasta sauce to pour over it.

Ingredients

300g tofu mashed
1 onion very finely chopped
1 clove garlic
 $\frac{1}{4}$ cup ground almonds
2 slices bread crumbled
2 tablespoons flour
2 tablespoons finely chopped parsley
2 tablespoons soy sauce
1 teaspoon dried basil or handful fresh basil,
plus extra to garnish
Oil spray to grease

Supermarket shopping can be daunting because you have to check the label of everything you buy. Grocery shopping gets faster as you get familiar with the products. Is it more expensive? My feeling is that it is not...buy fruit & veggies in season and economical grains such as lentils and carbohydrates like bread & pasta (diary free versions) are still on the menu.

Mostly I use 'normal' recipes and tweak them. 'No Eggs' powder (which you find in supermarket 'health sections') replaces eggs. Olive oil replaces butter (the ratio is bit less oil than butter). Almond or soy milk replaces milk. 'Savoury Yeast' creates a hint of cheese. With these substitutes I can cook most things and people can't tell the difference.

Why did you choose to include your Italian Tofu Meatball recipe?

The Italian tofu meatballs are a mainstay for me because they are quick and yummy. They are also good as a snack or in the lunch-box. Healthy Food Guide Lois says, "I have served these to non-vegetarians and they have not known there was no meat in these 'meat'-balls. These are a great way to have a 'meatless' meal. They freeze well and I work on four meatballs per person, so doubling the recipe goes a long way."



Preparation

Preheat oven to 200°C. Combine all ingredients, except oil in a bowl (I put all ingredients into a food processor to be chopped & combined). Mix well.

Shape into 16 – 20 balls (depending on the size) Spray a non-stick baking dish (baking tray) with oil (or line with baking paper). Place tofu balls on prepared dish and bake in oven for 15 minutes. Turn tofu balls over and bake for 15 more minutes.

Toss tofu balls with rice or pasta and your favourite tomato sauce. Serve sprinkled with fresh basil.

wellness workshops.

We are very pleased to announce that our first Wellness Workshop for the year will be held on Saturday 9 April at 10:30am.

Please put this date in your diary now.

The topic this time is often a difficult one to approach, but people are always so grateful when they have – Advance Care Planning. Our speaker is the wonderful Ian D'Young from Auckland District Health Board. Please come join us for a most interesting talk and discussions and a nourishing morning tea.

Invite along your family members as well, but please remember to book everyone in by giving us a call or e-mailing us. That way we will be sure to have enough food and chairs for all.

For all the details of this event see the information below.



CONVERSATIONS
THAT COUNT DAY

IT'S NOT EASY...

our voice
to tātou reo | Advance
Care
Planning

to talk about planning for
end-of-life care, but it's important

Many People...

don't like to talk about death and dying.
Often discussions do not happen in
families until someone is very unwell
and is unable to communicate.

Families and healthcare
providers are often left
to make difficult decisions
without knowing what
someone would have
chosen for themselves.



Join Us...

Saturday 9th April
10:30 am - 12:30 pm
Commerce Club of Auckland
27-33 Ohinerau Street, Remuera
Cost: \$ 5.00
to cover morning tea

Numbers are limited.
Please book by emailing:
events@msaki.org.nz OR
calling: 09 845 5921

Advance Care Planning...

is the process of thinking, talking and
planning for future health and end of life
care. It's about making sure that
clinicians and loved ones understand
what matters to you and what
treatments you would or would not
want.



Speaker:
Ian D'Young from Auckland
DHB



support groups.

Location	Contact	Date/ Time
South / East Auckland		
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
Manuakau Café Group Friendship House Manukau	Dianne Bartlett 021 845 903	Last Tuesday / Month 10.30am
Central / West Auckland		
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
North Auckland		
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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References: 1. Gilenya Consumer Medicine Information available at www.medsafe.govt.nz 2. Pharmaceutical Schedule available at www.pharmac.health.nz



**High Tea
in the Garden**

Supporting **MS Auckland**
We invite you to join us at Eden Garden for
High Tea

24 Omana Avenue, Epsom
Sunday 3rd April

Two Sessions:
10:30 am OR 2:30 pm

\$45.00 per person
Numbers are limited
for each session. Please
RSVP and let us know
which session you
prefer.

Tickets include:
Entry to the gardens
from 9:00 am.
Door Prizes
Music
Raffles

RSVP to: events@msakl.org.nz OR
call 09 845 5921
OR purchase your ticket at the
Eden Garden Reception

ms.
Multiple Sclerosis
AUCKLAND

NZ research investigating a new drug for the treatment of secondary progressive MS.

RESEARCH

Optimal Clinical Trials is an independent, clinical research company in Auckland, NZ. They specialize in phase II – IV trials.

They are currently conducting a clinical study investigating a new drug being developed for the treatment of Secondary Progressive Multiple Sclerosis. To be eligible to participate you must be 18-70 years and have been diagnosed with Secondary Progressive Multiple Sclerosis. The study will run for just over a year and involve weekly visits.



They are almost finished their recruitment for this study. However if you are interested or would like

to find out more it may not be too late. Please contact the friendly team on 0800 RESEARCH (0800 73 73 27).

To find out more about Optimal Clinical Trials go to their website: www.optimalclinicaltrials.com

FOR SALE

Scooter - approximately 6 years old. Needs new batteries but otherwise in good condition \$800.00

If interested please contact Annette on 09 257 4558



brain fog explained.

RESEARCH

Cognitive issues, colloquially known as 'Brain Fog', are a common complaint of people with MS, with an estimated 70% of people progressing to report problems with thinking, concentration or memory.

A recent study published in the Journal of Neuroscience sheds new light on damage caused by MS, specifically in the brain, which may help to explain this cognitive decline and consequently help researchers to target effective treatments.

Lead author of the study, neurologist Matthew Bellizzi, notes that the research identifies a new disease mechanism in MS which causes damage to neurons independent of the demyelination which normally characterises the disease. This, he explains, represents a further component of the disease and importantly, is one that is not prevented or controlled by the current range of disease-modifying immunosuppressive drugs used to treat MS.

The drugs which are currently at the disposal of physicians are effective in suppressing the attacks which lead to myelin damage, however they are ineffective in the prevention of cognitive issues. Hence, researchers speculate that there may be additional, as yet not fully understood, damage occurring in the central nervous system.

Senior author of the study, Harris Gelbard, feels that for too long MS has largely been discussed as a disease which affects sensory or motor functions, yet for many patients it is the loss of cognitive ability which has the greatest impact on their quality of life.

The research team carried out experiments in mouse models of MS, and showed that neurons in the hippocampus (an area of the brain not associated with motor control) were being damaged at the synapse, which is the point where cells communicate with each other via the transmission of chemical signals. And, responsible for this damage they report, appears to be the microglia – a cell in the central nervous system's defences.

The primary role of the microglia is to fight infection or other attacks on the nervous system, and to clean up the damaged cells, but it also serves to preserve the health of the synapse so that it functions normally and aids the hippocampus with cognitive abilities such as learning and memory.

The problems therefore occur when the immune system is over-stimulated during MS, and the microglia receive distress signals which prompt them to switch from their protective, nurturing role to an aggressive, pro-inflammatory response.

During this reaction, they release the molecule PAF (platelet-activating factor), which affects the signalling that neurons use to activate one another. High levels of PAF cause over-activation of these signals and actually serve to destroy the receiving end of the synapse. Consequently, more microglia and other immune cells rush to the site, which triggers a cycle of destruction. The researchers felt that the cumulative effect was like trying to put out a fire with gasoline.

It is this phenomenon which the researchers believe is largely responsible for the greater part of the cognitive damage and over-time decline that people with MS experience. Due to the activation of microglia being unaffected by current MS drugs, research is now focussing on potential therapies which could suppress the signalling pathways which result in nerve cells and microglia becoming overactive.

Amongst the potential candidates is a drug which is being investigated in the treatment of HIV-associated neurological disorders. It is interesting to note of course that the OMS Recovery Program works precisely through this mechanism of switching the immune system from an over-stimulated mode (Th1 response) to a more quiescent mode (Th2 response); there is every likelihood that this helps to put out the fire around the synapses in the central nervous system.

Article sourced from the Overcoming Multiple Sclerosis website.

MS AUCKLAND ANNUAL GENERAL MEETING

7pm - April 13, 2016

To be held in the Volunteering
Auckland Room beside MS Auckland
5-7 The Strand, Takapuna

All members welcome
For more information please contact
MS Auckland at info@msakl.org.nz
or phone 845 5921

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Further Information: For further information see the TECFIDERA Consumer Medicine Information (CMI) available at www.medsafe.govt.nz or by calling 0800 852 289. Biogen NZ Ltd, 54 Carbine Road, Mt Wellington, Auckland.

References: 1. TECFIDERA Data Sheet (18 Nov 2015). 2. PHARMAC website – 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.