

multiple news

Multiple Sclerosis Auckland Magazine

June 2017 | Issue 37

**Fred
Graham**
*"I always
wanted
to fly!"*

inside
.....
employment rights
food & recipe
volunteering from afar
"I've got my life back"
and more...





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 and MRI lesions.

Aubagio, working to help quiet MS.*

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


AUBAGIO[®]
(teriflunomide) 14 mg tablets

*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 November 2016. 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. February 2017. GEAB12114. TAPS MR5167.

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our people.

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For more information visit www.msakl.org.nz

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a few words from Ingrid.

Our General Manager

It is sometimes good to look back at where you came from to see how far you've come. As I sit at my desk writing this, I am reflecting on the wonderful 'Clash of the Hemispheres' event that we had last night. Last November, when the idea of having a rugby themed event in conjunction with the Lions Tour was taking shape, we really had no idea where it would lead us. I'm reminded of a quote by Ralph Waldo Emerson 'Once you make a decision, the universe conspires to make it happen.'

Thanks to a very small group of people who worked extremely hard at organising the event, and a large number of generous individuals, companies, businesses, and organisations who contributed time, money, and support and who came out on the night, MS Auckland was able to have one of its biggest events ever. We are so very, very grateful to each and every one.

The funds we raised are essential in enabling us to continue to provide support and services to people with MS and their families. There are a few photos from

the event on page 12 and 13, and we hope to get some more photos and videos up on our website over the coming weeks.

Looking ahead now, I have to say I'm quite relieved to have this event behind us. Fundraising is unfortunately a necessary part of existence for organisations like MS Auckland. However the bonus is that often with fundraising we are able to expand people's awareness and understanding of MS. Our next big fundraiser is our Annual Street Appeal, which is preceded by Awareness Week.

Even though much energy is taken up with raising funds, our Field Workers and our team work twice as hard on ensuring people affected by MS receive the information, support and assistance they need for a good life. That's the reason why we are here after all. It is always all about the people, the people, the people.

Until next time, wishing you all the best,
Ingrid

MS Auckland AGM.

At the AGM Dr Ernie Willoughby was presented with an Honorary Lifetime membership to MS Auckland by President Neil Woodhams, for his long service, commitment and dedication to Multiple Sclerosis.



Dr Ernie Willoughby – Honorary Life Membership Award

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events for your calendar.

July /
August

Upcoming events



Mondays
24th July to
28th August

Group Counselling
Whangaparaoa

27th August to
2nd September

Awareness Week

1st and 2nd
September

Street Appeal

Saturdays
9th September to
14th October

Minimise Fatigue,
Maximise Life

30th September

Wellness
Workshop

Dealing with
Cognitive
Issues in MS

Please check our website for more programmes and events as they are confirmed.

An easy way to keep up to date with programmes and events is through our monthly e-newsletter. This usually comes out during the first week of each month. You can sign up on our website – www.msakl.org.nz or contact Becky in the office at 09 845 5921.

looking back research day 2017.

April was a busy month this year! On the 1st of April over 200 people joined us at Alexandra Park for Research Day. The three speakers – Dr Ernie Willoughby, Gilly Davy, and Dr Terry Wahls (who was videoed in from her home in Iowa, USA) – were all very well received. If you would like a copy of Ernie's presentation or Gilly's presentation, please contact us at info@msakl.org.nz. If you are interested in hearing more about the Wahls protocol and news from Dr Terry Wahl, we highly recommend signing up for her newsletter on her website <http://terrywahls.com/>



Dr Ernie Willoughby with Field
Workers Dianne and Diane



The Event at Alexandra Park for Research Day.

from the field.

Employment Rights for people with MS



People with MS are often very hesitant to talk about their MS when seeking employment or even with their current employer. There is the dilemma - to disclose MS or not to disclose MS. Field Workers are often asked to support people who experience employment issues. In order for us to understand the issues better an expert was asked to speak at our recent Field Workers training day.

Olivia Kelly, from Auckland Disability Law, provided a most thorough and informative talk. We are hoping to have her, or someone else from Auckland Disability Law, at one of our Wellness Workshop next year. In the meantime, here is some information that you might find useful.

Diane Hampton, MS Field Worker, North Shore

The Human Rights Act (HRA) and Employment Relations Act (ERA) both deal with disability discrimination. Section 21 of the Human Rights Act 1993 states the prohibited grounds of discrimination relating to disability. In order to use these provisions a person must identify as disabled. Often a person does not admit that they are disabled as this is seen as a label.



Carol
Central
Auckland

Dianne
South
Auckland

Andrea
West
Auckland

Diane
North
Shore

Pre-employment - Disclosure of Disability

The HRA prohibits employers asking questions that could be understood as "indicating an intention to discriminate". However an employer can ask if you have a disability that is directly related to the tasks in the role. If you do then it is important to be honest as you can be dismissed if you lie. It also gives you a chance to discuss the possibility of accommodation of such a disability. This would need to be included in the Employment agreement. If it is not too disruptive to the workplace or not too costly this may be acceptable to the employer. Sometimes it's just about educating the employer.

Discrimination in Employment

The attitude of employers and other employees is important. People already employed can be discriminated with promotion, remuneration, training and restructuring.

Medical incapacity dismissals

The general principle is that an employer is not obliged to hold a job open 'indefinitely'. There is a need to distinguish between incapacity dismissal and medical 'retirement'. Often in incapacity situations there will be a timeframe between the initial incapacitating event and the decision to start dismissal investigations. The employer can not immediately begin the dismissal process and it is important to seek legal advice.

Dismissal process

If it looks if the return to work will take too long or the employee is having too much trouble performing the job the employer can start the dismissal process. This is not disciplinary as the employee hasn't done anything wrong. The employment agreement may outline the process. This is the start of the legal process and the employee should seek advice from a Community Law Office, an employment advocate or a private employment lawyer.

The test is whether the employer's actions and how they acted were what a fair and reasonable employer

could have done in the circumstances at the time the dismissal or action occurred. It has to be substantively justified and procedurally fair.

Dismissal – Employer's duties

In medical incapacity cases a fair and reasonable employer is expected to inform itself about an employee's condition and prognosis. This includes:

1. Asking the employee for information. They may also request an independent medical report
2. Consulting with the employee or representative – a meeting with advance notice with the right to have a support person along. The employer needs to be open minded and there needs to be information gathering for an investigation.

If the conclusion is reached that the incapacity is long term and permanent and the employee is unable to be accommodated (such as with graduated return, changed tasks, assistive technology, etc.) or unable to be covered by other leave, then a dismissal process will begin.

Dismissal – Employee's Duties

It is important that the employee engages with the process by providing information, attending meetings and keeping open the channels of communications.

Legal options for Discrimination Complaints

In all cases it is of course better to resolve issues with the employer early on. This can either take the path of ERA Mediation, then Employment Relations Authority, then Employment Court, or in cases of discrimination it will go to HRC Mediation, then Human Rights Review Tribunal, and then the High Court. Legal representation is recommended for either pathway.

The ERA is a simpler process. It takes 90 days to bring a claim with more modest pay out for loss and humiliation. Reinstatement is also possible.

The HRA process is more complex with a maximum pay out of around \$200,000. There is no reference to reinstatement but it could be negotiated, and there is a time frame of one year to bring a claim.

Important Points to consider

- You can take out a personal grievance while still in the job. It can be drastic however, as you could potentially lose your job.
- If your disability is affecting your job there is a duty of disclosure to your employer in good faith.
- For people who are newly diagnosed there is no need to disclose if there is no disability.

Medical Retirement

Medical retirement means you stop work and don't work again. There is usually a 12 week exit and pay out package.

Talk to your Field worker if you are experiencing employment difficulties. We can discuss the situation with you, offer support and give you information that may be useful.

Other resources that you may find useful include:

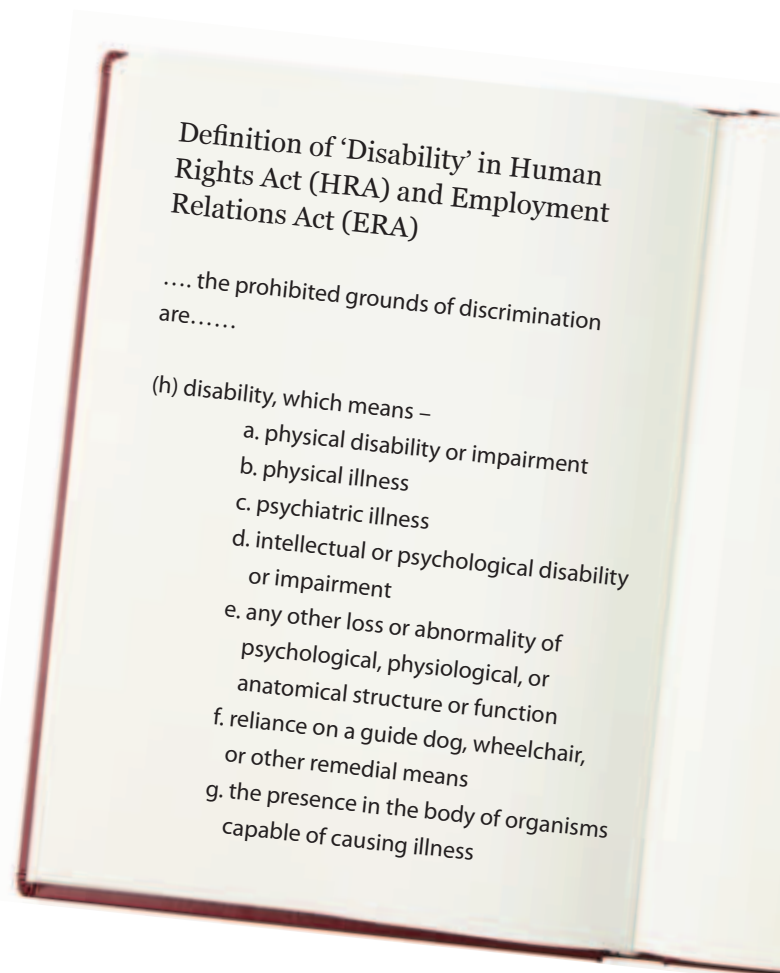
www.workandincome.govt.nz

www.era.govt.nz

www.hrc.co.nz

www.aclc.org.nz

www.aucklanddisabilitylaw.org.nz



from the MS nurses.

As you may know the recent 'cyber-bombing' hacking issue has had a huge impact on Britain's National Health System. Notes, referrals and test results were not available to clinicians. This must have made both the patients and the medical teams experience deeply frustrating. Imagine sitting in clinic with your neurologist and trying to cover important issues without access to your records.

Keeping a personal health record including your letters and MRI results is hugely valuable. Learning from the experience in NHS this is something we should all attempt to do. You should routinely be copied in to letters from your MS team that are sent to your GP. If you are not being copied in please mention this at your next appointment.

Take care and best wishes
Fiona and Nazila



Multiple Sclerosis Nurse Specialists
Auckland City Hospital
e-mail – MSNurse@adhb.govt.nz
Phone – 09 307 4949 ext. 25885#

Nancy Caughie.

08/07/1931 - 10/05/2017

Nancy was born in Scotland and came to New Zealand with her husband and 2 year old daughter in 1959. Four months after she arrived here she was diagnosed with MS.

Nancy was one of the founding members of MS Auckland in 1964 and then North Shore MS Society when it was formed in 1978. Nancy went on the committee and her husband Jim was President. Nancy was presented with Honorary Life Membership for her wonderful support of the society. She collected on MS Collection Day on the North Shore for many years, was a regular attendee of the Mayfield Coffee Morning Group since its formation in 1978 and until recently and was a regular attendee of the Members Christmas lunch.

Nancy was very independent. She lived alone and was a familiar sight tooting around Milford, Takapuna and Hauraki on her mobility scooter. Her grandchildren and great grandchildren were the joy of her life.

Her greatest wish was to remain living at home and this she achieved until hospitalised for the past few weeks following a fall.

She will be sadly missed by the Mayfield Group.



hydrotherapy.

One of the key services of MS Auckland is the Hydrotherapy programme. Classes operate in 6 pools around Auckland each week, with each session professionally led by a Physiotherapist from the Rope Neuro Rehabilitation team.

Benefits

The hydrotherapy sessions focus is on a whole body workout. The water is warm and non-weight bearing so is good for pain, especially chronic pain. Research is showing that aquatic exercise in people with MS provides a number of benefits including improved muscle strength, improved fitness, improved gait and mobility, reduced fatigue and increased quality of life or sense of wellbeing.

Cost

To encourage people in the MS community to give it a go, we offer your first two classes free. After that classes are just \$50 for a book of 10. Be sure to talk to your Field Worker if you are interested in giving it a go.

For people with other neurological conditions, it is important that they first contact Rope Neuro



Rehabilitation on 623 8433, to be assessed for their suitability to attend the classes. On the recommendation of a Rope Physiotherapist they may try their first 2 classes for \$14 (\$7/class). On-going classes can be purchased in lots of 10 for \$70.

Contact MS Auckland to arrange payment for Hydrotherapy classes on 09 845 5921.

Attendance at the pools has been steady, and we have been pleased to see numbers grow in some areas. Sometimes over winter pool numbers can drop. We hope this doesn't happen this year! With so much to gain by participating it is a shame not to attend all year round.

2017 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:

Andrea Kortas

09 845 5921 Ext 221
andrea@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

MS annual awareness week and street appeal 2017.

27th August to 2nd September

This is the week each year when New Zealand gets out in force to raise public awareness of MS and ask the New Zealand public to contribute a gold coin, or two or three, to support the MS services in our communities.

It is quite surprising to think that while Multiple Sclerosis is the leading cause of neurological impairment of young adults, there is still such little public knowledge about it. I still regularly hear stories of young people being diagnosed with it and then having to go home and look it up on google, because they have never heard of this condition.

We don't have any specific plans for Awareness Week yet, but we do know that we will be looking to get some media attention and to get people talking more about MS.

Street Appeal, which takes place on the last two days of Awareness Week, raises funds but also much needed Awareness. Last year, with your help, we were in over 50 locations in Auckland over the 2 days and raised \$60,000! Francesca led the Street Appeal campaign, ably assisted by our own Kirsty.

This year Kirsty will take the helm and lead Street Appeal for 2017. Tessa, our wonderful intern who has worked with us through our big 'Clash of the Hemispheres' event will be helping her for 10 hours a week, but we will need many more helpers and volunteers to co-ordinate this mammoth task.

WE NEED YOUR HELP!

There are many ways in which you can help us this year for our Annual Street Appeal.

Here are just a few:

1. Put aside Friday 1 September and Saturday 2 September to help us as a collector for a few hours at one of the many locations. If you have more time you may want to look at being a Team Leader at one of the sites and perhaps help organise the roster with your friends and family.
2. Be one of our Area Co-ordinators on Friday 1 September or Saturday 2 September, collecting buckets and helping out on the day.
3. Organise something special at your work place – such as a morning tea, or a collection at your work place.
4. Volunteer your time in assisting us in the office with organising the locations, contacting community groups, or helping to organise the rosters. There is always lots of work to do in the office.

Street Appeal is a mammoth task! It is only because of your help that we are able to run this each year. If you can help out this year please contact Kirsty on streetappeal@msakl.org.nz or call her on 09 845 5921.



food & recipe.

I love trying new recipes and am therefore often scrolling the internet looking for new ideas and inspiration. While scrolling recently I came across the site Letfoodbe.com. The site is run by a Dr Chloe Humphry.

I was inspired by the words on her home page which reads:

Food has the power to cure disease and reform the body. The global medical industry is now turning its attention to the power of preventative medicine. Once the domain of naturopaths, preventative medicine is becoming one of the preeminent models of health. There is no one better to manage your health than you. You have the ability to make excellent daily choices about what goes into your body.

The following recipe is taken from Letfoodbe.com, and was inspired by a recipe from the Oh She Glow website, another one of my favourite recipe sites. I like this recipe because the ingredients are all ones that I tend to have on hand. When corn isn't in season you can steam, grill or roast any other favourite vegetable.

Black Bean Burrito Bowl

Serves 3 | Prep time 25 minutes | Cook time 25 minutes

Ingredients

1 cup brown rice
2 ears fresh corn (peeled and cut into halves)

Spicy Black beans

2 Tablespoons olive oil
1 brown onion diced
4 cloves garlic minced
1 cup fresh chopped tomatoes
1 teaspoon chili powder
1 teaspoon garlic powder
1 teaspoon dried oregano
¼ teaspoon cayenne pepper (optional)
½ teaspoon sea salt (plus a pinch more to taste)
2.5 Tablespoons tomato paste
2 cans black beans (drained and rinsed)
½ cup fresh coriander (finely chopped)

Instructions

Rice – Cook the rice in plenty of boiling water until tender. This usually takes 20 to 25 minutes. In the last 5 minutes of cooking time add the corn and boil for 5 minutes. Drain the rice and corn and place on serving bowls.

Avocado-lime sauce – Put all the ingredients in a food processor and process until smooth. If you don't have one, finely chop the garlic clove then add the other ingredients and mash until smooth. Add more lime juice to taste. Set sauce aside.

Spicy Black Beans – Prepare the beans while the rice is cooking. In a large frying pan on medium heat, add the oil. Stir in the onions and garlic along with a pinch of salt. Sauté for 5 to 6 minutes until soft. Stir in the chopped tomatoes, chili powder, garlic powder, oregano and cayenne pepper and salt. Cook for another 3 to 5 minutes until the tomatoes soften. Stir in the tomato paste and drained and rinsed black beans. Cook for a few minutes until heated throughout.

To serve – Divide the rice and corn between the bowls. Top each pile of rice with a couple of scoops of black bean mixture and a large dollop of avocado lime sauce. *Enjoy!*



Avocado Lime Sauce

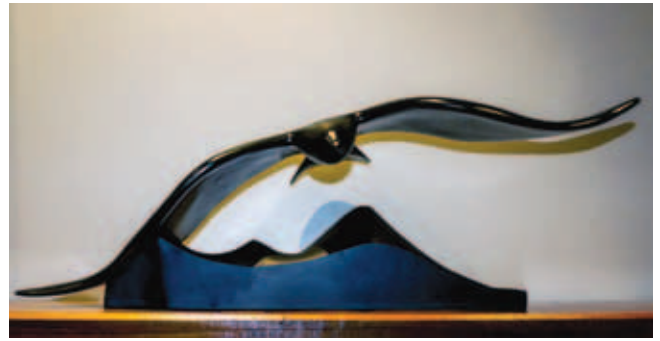
1 large garlic clove
1 large ripe avocado (or 2 small ones)
1 Tablespoon fresh lime juice (plus more to taste)
1 Tablespoon water
¼ teaspoon sea salt (to taste)

Fred Graham.

We felt immensely privileged when Fred Graham said he would do a sculpture for MS Auckland to be auctioned off at our Clash of the Hemispheres fundraising event.

Back in 1955 Fred was a Maori All Black. When asked why he stopped playing rugby, he answered “because I got smart” with one of his lovely grins, and his lovely wife Norma, nodding in agreement! He went on to develop a career in the art world and become a leading New Zealand and International sculptor.

Fred and Norma live in Waiuku. Norma is still active in the tennis club that MS Auckland Committee member, Joan plays at. It was Joan that asked Norma if Fred might consider doing something for our event. Norma thought he might be too busy, but when she asked him he was very positive about being able to help out. His sister had passed away with a neurological condition and Fred says that at 88 he feels very fortunate to still have his good health.



Black Hawk over Ngauruhoe

Fred's work can be seen throughout NZ and overseas, including the Auckland High Court building, the National Archives building in Wellington, the Burke Museum in Seattle, Washington, and the Auckland Domain, to name a few. The piece he carved for MS Auckland he named 'Black Hawk over Ngauruhoe' and is a stunning piece of work. The lucky winner of the auction now has a unique and original piece of art from one of the world's best!

Thank you, Fred for supporting Multiple Sclerosis Auckland.



Joan, Norma, Fred and Ingrid, at Fred and Norma's home in South Auckland

clash of the hemispheres 2017.



On the 6th of June 2017 at Eden Park in Auckland, 6 Rugby greats came together on stage to debate – ‘The Southern Hemisphere should be on top. The Earth is upside down’ – with MC and Referee for the evening Jeremy Corbett.

The Southern Hemisphere was represented by Captain Phil Gifford, Sir Graham Henry and Ian Jones. The Northern Hemisphere was led by Captain Stuart Barnes, Miles Harrison and Scott Quinnell. They both did amazing well at going off topic, telling hilarious stories and keeping the audience roaring with laughter. At the end they were judged by the audience – not surprisingly (given the rather biased audience) the Southern Hemisphere team was declared the winner.

MS Auckland member Judith Pullen-Burry spoke briefly and beautifully, reminding people what we were fundraising for and Martin Cooper from Harcourts Cooper & Co worked his magic at getting people to dig deep for the 11 auction items that went under the hammer. 60 more items were bid for with the Givergy silent auction system.

A huge thanks to our premier sponsor Fidelity Life, and Silver sponsors, Harcourts Cooper & Co and John Andrew Mazda, and all our other event sponsors and supporters.



“I’ve got my life back”

Michael talks about his experience with Stem Cell treatment (HSCT) in Singapore

Two and a half weeks after returning from Singapore for HSCT Michael feels like a new man. “I’m lucky” he says, “even the specialists were surprised at how quickly I responded to treatment.”

Michael was diagnosed with Relapsing Remitting MS in July of 2010. For the first four years things were okay. He could deal with the relapses when they occurred and his MS didn’t seem to interfere too much with his life and work. However in 2014 he moved to having Secondary Progressive MS and his physical decline, at only 33 years of age, became a real worry.

Michael feels that his MS was probably harder on his parents than on him. “No parent should have to go through seeing their child’s health deteriorate, as with MS”. And it doesn’t seem to matter how old that child is.

From 2014 Michael started looking into what his options were. He wrote to many clinics and was always turned down for not fitting the criteria for Clinical Trials. He feels it was because he had the Secondary Progressive MS, and most trials are for Relapsing Remitting. It seemed to Michael that HSCT was the best solution for him. At this stage what he wanted was first and foremost to stop the frightening progression of his MS.

“HSCT is not without its risks” says Michael. The worst risk is of course death. And while death is still a statistically insignificant risk, it still happens. Not long before Michael’s visit a woman had passed away undergoing similar treatment.

He first looked at going to Russia, however there was a two year waiting list, and Michael did not feel he could wait that long.

The cost of treatment in Singapore can cost up to \$120,000, which doesn’t include the airfare and accommodation. Michael feels that he cannot sing the praises enough though of the top notch care that he received. He arrived at the hospital on the 6th of February 2017 and the first step was to attend a family meeting where they were told what to expect and all the consent forms were signed. All up he could expect to stay for 3 months in Singapore. His father or his mother was there with him during his stay, so he always had some company.

During the first month Michael received a chemo trial, to see how his body reacted to the chemo. He also underwent stem cell release injections and had his stem cells harvested.



Harvest results



Michael arriving back home with Mum and Dad

During the second month he was admitted into the hospital and kept in a highly controlled environment for two weeks while he received his chemo treatment. He feels fortunate that he didn't have any severe adverse reaction to the chemo, other than extreme nausea. The last day of the chemo treatment was the worst, but Michael felt he had had worse days with his MS.

After the chemo treatment he had a day of rest before his stem cells were re-introduced. This procedure took less than a half hour. After that it was a 'waiting game'. Michael was released from the hospital under very strict conditions and was monitored regularly. When he ventured out he wore a face mask and he was given an ear thermometer to check his temperature regularly.

After three weeks Michael received permission from the doctor to fly home. Although he needs to build some strength in his body now, Michael is full of smiles and can't stop saying how fantastic he feels. "I wake up at 7:30 in the morning and I feel refreshed. I wake up with energy".

jubilee sailing trust New Zealand.

The Jubilee Sailing Trust (JST) is now operating in New Zealand! They are a very unique charity that integrates disabled and able-bodied sailors aboard its two purpose-built tall ships – Lord Nelson and Tenacious. They started in the UK more than 35 years ago and sail about 50,000 nautical miles every year. Tenacious sailed into Wellington in May 2017, seventeen months after leaving the UK on her southern hemisphere sojourn.

JST aims to provide opportunities for adventure in an all-inclusive environment. They encourage people living with a disability to challenge themselves while having an adventure that is for people of all abilities, and in doing so build their self-esteem and confidence.

The United Nations recently accredited the JST under its Convention on the Rights of Persons with Disabilities.



Voyage on Tenacious for a life-changing experience!

For a limited time only, voyages are available for \$100 per person per day

Auckland Round Trip (10 days) 27 July to 5 August 2017

now only \$1000 per person (usually \$2470)



Join Tenacious as it comes out of Auckland and explores the coast surrounding Auckland and the Northland. Tenacious sails with 9 professional crew who are assisted by trained volunteer bosun's mates, watch leaders and cook's assistants.

As well as the professional crew, Tenacious carries 40 'voyage crew', typically comprising half who are living with a disability and half who are generally able-bodied. Up to 8 wheelchair users can be taken on each voyage. The voyage crew members are buddied up and support each other throughout the voyage. Special bonds and friendships are often created through the sharing of the experiences and adventures.



Wendy Wood - volunteering from afar.

Written by Ingrid Minett

On the South Island, in a town called Murchison situated about 1.5 hours south of Nelson and 1.5 hours east of Westport, Wendy sits down each week to do a post for the MS Auckland Facebook page. Wendy is our only non-Auckland volunteer, and for this magazine we would like to acknowledge her wonderful contribution to our work.

I spoke with Wendy on the phone, as she sat in the May sunshine of their Murchison home – the Korimako Lodge. From the 1st of October to the end of April, Wendy and her husband Steve host guests in their 3 bedroom luxury accommodation. On the lodge off-season Wendy enjoys spending her time reading and tending to her garden.

Wendy was diagnosed with MS in 1998. In 2012 she went on what was sadly the last Jelinek retreat in New Zealand on the Coromandel Peninsula. (Hopefully one day we can bring it back to New Zealand). She has fully adopted the OMS diet and attributes it largely to her on-going good health. The only issue she is dealing with is balance, which means that when she leaves the house for any length of time she may take a walking stick, just for a bit of security.

Guests in their beautiful lodge are offered breakfast and dinner, which is now OMS friendly. Feedback from guests has been largely positive, with people enjoying the fresh vegetables and fruits as a welcome alternative to the heavier fried or greasy food that will often form part of a traveller's diet.

About a year ago, Wendy commented on a post on the MS Auckland Facebook page, to which I replied, and which ended up in Wendy saying to me "how can I help you?" I had been managing the Facebook page on my own, and was very keen on getting some help. Wendy had been an OMS volunteer when their website was hosted in New Zealand. Since they had moved to the UK it was no longer practical to continue volunteering for them, but Wendy was keen to continue to share stories, especially around OMS.

With her social media experience, her passion to help make a difference, and as a person living with MS, Wendy was an ideal candidate to help with Facebook.

Wendy generally posts once a week, but has helped out more frequently when I'm away. When I asked how she finds her interesting stories and articles, she said she is great at 'planning ahead'. Her love of reading comes in handy and as she comes across articles or pieces of interest she will make a note of it. When it comes time to post something she has a list of interesting things to choose from. Often Wendy's posts will be on diet or lifestyle. She is very aware on how hard it is to change habits, and hopes that she is able to make a difference to some of our readers or followers.

I feel very grateful for technology. It has allowed us to connect with Wendy and has given us a wonderful volunteer! Thank you to Wendy for being part of our MS Auckland community!



Wendy with Steve and dogs Oscar and Shadow

Wendy features in the book 'Recovering from Multiple Sclerosis, Real life stories of hope and inspiration', by George Jelinek and Karen Law, which is available from our library (<http://www.msakl.org.nz/library>). Her Korimako lodge can be viewed at - <http://www.korimako.co.nz/>

Robert Loft and his new freedom chair.



I've had MS for many years and have pretty much lost all mobility on my left side. This has been severely restrictive. I already have a large power chair and I've been using this chair for both inside the house and for outdoor trips which has certainly made my life more bearable.

However, because of its size and weight, loading this chair into our small SUV by joining three pieces of aluminium to make a ramp is time consuming and a little difficult for my wife, Sharon. Of more importance was the issue that once we arrived at our destination we needed to find parking where we had the space to install the ramps, lower the chair to the

ground and do this without impacting on those around us. When the chair is in the SUV there's only room for the two of us and this is also restrictive. The alternative was to take taxis but this was an expensive option.

I then discovered the Freedom Chair. Paul from Montec Mobility Ltd sourced the chair, trained me how to use it and has supplied other helpful extras.

I'm now FREE.

Sharon and I can go out together with ease as it only takes a few seconds for her to load the Freedom Chair into the car. In fact, we can load it into almost any vehicle. Parking is unrestricted as there is no need for a ramp. I can go to the Zoo, the movies, the waterfront and cafes. I can almost go anywhere. We can enjoy visits to family and friends without them having to come to us. I can also get picked up by friends and with very little support from them we can have an enjoyable day together.

In late July Sharon and I are going overseas to see the kids and we're all booked to fly including the Freedom Chair.

The Freedom Chair has given me my life back and the best thing I can say about it is:

"Its Life Changing"



Finding walking difficult?

***The Freedom Chair
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Ocrevus (ocrelizumab) approved by the FDA for relapsing and primary progressive forms of MS.

Taken from <http://www.roche.com/investors/updates/inv-update-2017-03-29.htm>



At the end of March the news broke that the US Food and Drug Administration (FDA) approved OCREVUS for both relapsing and primary progressive forms of MS.

This was exciting news as it is the first and only approved disease-modifying therapy for primary progressive multiple progressive. It is also a new treatment option for people with relapsing forms of MS.

Roche news released an update in which Sandra Horning, MD, Roche's Chief Medical Officer and Head of Global Product Development states "Until now, no FDA approved treatment has been available to the primary progressive MS community, and some people with relapsing forms of MS continue to experience disease activity and disability progression despite available therapies. We believe OCREVUS, given every six months, has the potential to change the disease course for people with MS, and we are committed to helping those who can benefit gain access to our medicine".

OCREVUS is administered by intravenous infusion every six months. The first dose is given as two 300 mg infusions given two weeks apart, with subsequent doses given as single 600 mg infusions. According to the paper, the most common side effects associated with the drug in all the Phase III studies were infusion reactions and upper respiratory tract infections "which were mostly mild to moderate in severity".

This FDA approval was welcomed in New Zealand, and provides some hope for people living with primary progressive MS. Currently an application is in with MEDSAFE (New Zealand Medicines and Medical Devices Safety Authority) for OCREVUS and the outcome of their decision is still pending.



About OCREVUS

'OCREVUS is a humanised monoclonal antibody designed to selectively target CD20-positive B cells, a specific type of immune cell thought to be a key contributor to myelin (nerve cell insulation and support) and axonal (nerve cell) damage. This nerve cell damage can lead to disability in people with MS. Based on preclinical studies, OCREVUS binds to CD20 cell surface proteins expressed on certain B cells, but not on stem cells or plasma cells, and therefore important functions of the immune system may be preserved.'

drug trial for Ocrelizumab – a participant's view.

RESEARCH

Jason talks about his experiences on the drug trial for Ocrelizumab

I recently attended the MS Auckland Research Day where Dr Ernie Willoughby considered the drugs that are currently available to those with MS. In his presentation there was considerable interest and questions on a drug that has received recent approval from the FDA. The drug developed is Ocrelizumab, and is now marketed as Ocrevus. Around 4 years ago I met with Dr Jennifer Pereira, this was my second opinion on my MS diagnosis. As part of my meeting with her I asked if there were any trials that I could participate in. I was keen to make myself available to make any positive steps to tackle my primary progressive MS (PPMS). She was aware of a new trial and put my name forward for testing of a drug in the Waikato for my type of MS.

The trial began with an initial assessment of my medical history and current symptoms. This was done to make sure that I met the criteria that the drug company were looking for. Having passed this hurdle I was quickly placed on the participants list. I was told there were just two people in New Zealand on the trial. Worldwide there were around 650 but it ended up being around 720. The other person in New Zealand has since dropped out of the trial meaning I am the only one in New Zealand.

The commitment is now a visit to the Waikato Hospital every three months with each alternative visit including a 2-3 hour infusion. The visits are normally a busy day (especially for the drug trial nurses!) and include neurological testing, blood and urine tests, walking and an annual MRI. The trial provides for accommodation and travel costs.

The worst part of the trial is the PASSAT testing. This testing includes hand co-ordination where you need to put small pegs into a tray with holes and then take them out again. This is timed and done twice - once for each hand. Then there is the memory testing where a CD randomly plays numbers (from 1-9) in a sequence spaced 3 seconds apart and you need to add together the last two numbers you heard. It sounds easy but it is very easy to get distracted and lose your thought process. This number testing is then done at 2 second intervals for 60 numbers each sequence. For me this is worse than the claustrophobia of the 45 minute MRIs! Previously there were more visits with the infusion doses being split over two visits in a fortnight.

The visits are set within certain 'windows' meaning I must plan for the visit with my employer and family. I am very fortunate to have an understanding boss who allows me to attend the trials. Due to trial protocol changes, sometimes the visits are at short notice. My boss, the nurses and neurologists are all great, professional people with a good sense of humour. I am very well looked after for my visits.

In November 2015 I was told that I had been allocated the drug not a placebo meaning my infusions were not just saline. This cleared up my thoughts as to whether I was on the drug or a placebo. Being on the drug meant I received it straight away and not after a 3 year delay.

To date my abilities have remained much the same as they were when I commenced the trial. Walking distances, walking speed, memory, neurological tests, and all other tests have been very consistent. I am very happy with my results and hope that when available in New Zealand the drug will be approved by Pharmac for those with PPMS. The annual cost in the US is US\$65,000, which has been described as low when compared to other MS drugs.



Jason

support groups.

MS Support Groups meet throughout Auckland. In Support Groups you are able to talk to other people who truly understand what you are going through and share the type of practical insights that can only come from first-hand experience. There are many benefits to joining a support group. If you haven't been to one yet, why not come along and see what it's all about? Talk to your Field Worker if you are unsure which group to go to, or if you are interested in having a support group set up in your area.

| 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 |
| Manukau Café Group Friendship House (Manukau) | Dianne Bartlett 021 845 903 | Last Tuesday / Month 10.30am |
| Central | | |
| City Evening Group Scarecrow Café | Carol Andrews 021 959 187 | Wednesday / Six Weekly 6.00pm |
| Greenlane Café Group Mama Rich Café (205 Great South Rd, Greenlane) | Carol Andrews 021 959 187 | Second Saturday / Month 11.00am |
| Stonefields Café Group Stonebake Café (Lunn Avenue, Mt Wellington) | Carol Andrews 021 959 187 | Third Wednesday / Month 10.30am |
| Onehunga Group Frolic Café (Manukau Rd, Royal Oak) | Carol Andrews 021 959 187 | Second Tuesday / Month 10.30am |
| West Auckland & Rodney | | |
| Kumeu Café Group Different Venues | Andrea Kortas 021 959 189 | First Tuesday / Month 10.30am |
| Henderson Garden Café Group Espresso Garden Café (inside Mitre 10 Mega, 186 Lincoln Rd) | Andrea Kortas 021 959 189 | First Thursday / Month 11.00am |
| North Café Groupies Kings Plant Barn (Silverdale) | Andrea Kortas 021 959 189 | Third Wednesday / Month 10.30am |
| North Auckland | | |
| Mayfield Coffee Morning Kings Plant Barn (1 Forrest Hill Road, Milford) | Diane Hampton 021 859 187 | First Thursday / Month 10.30am |
| Shore Lunch Group Palmers Planet Café (cnr Hugh Green Drive/Greville Rd, Albany) | Diane Hampton 021 859 187 | Last Wednesday / Bimonthly 12.00 noon |
| North Shore Café Group Kings Plant Barn (1 Forrest Hill Road, Milford) | Diane Hampton 021 859 187 | First Saturday / Month 12.30pm |

Consumer Information Gilenya® (fingolimod) 0.5mg is a prescription medicine available as capsules for the treatment of patients with relapsing multiple sclerosis to reduce the frequency of relapses and to delay the progression of disability. Gilenya is a fully funded medicine under Special Authority Criteria. Normal doctor visit fees and prescription charges apply. Out-patient monitoring will be necessary for administering the first dose. You should avoid becoming pregnant while taking Gilenya and for two months after you stop taking it. It is important not to stop taking this medicine without your doctor's advice. Gilenya has risks and benefits. Cautions are infections, vaccinations, visual disturbances, decrease in heart rate, signs of liver disorders, sudden onset of severe headache, nausea, and vomiting, pearly nodules, patches or open sores of the skin. Talk to your doctor right away if you experience any of these, or experience worsening of your MS symptoms. Side effects can include headache, liver enzyme increased, diarrhoea, cough, influenza, sinusitis, and back pain. Refer to consumer medicine information at the website www.medsafe.govt.nz for full details. Ask your doctor if Gilenya is right for you. Use strictly as directed. If symptoms continue or you need further information or you have side effects see your doctor. Gilenya is the registered trademark of Novartis AG. Novartis New Zealand Ltd, Auckland. GIL 0916-162 TAPS MR4974 essence Reference: 1. Gilenya Consumer Medicine Information available at www.medsafe.govt.nz

Model is for illustrative purposes only

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With a treatment routine as simple as one pill a day¹, Gilenya can let you focus on the life you want.

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Email: info@msakl.org.nz, Telephone: 09 845 5921

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Multiple Sclerosis
AUCKLAND

www.msakl.org.nz

MS Auckland is a charitable organisation. You may join our community by donation. A tax receipt will be issued for all donations either on receipt (annual donation), or at the end of the financial year (for regular giving).

Monthly donations of \$30 or an annual donation of \$360 or more also entitles you to free participation to our Wellness Workshops and our annual Christmas Lunch. Financial membership is also available. Please contact the office for more information.

Date: ____ / ____ / ____

Please select one of the following:

I have MS ☐ A family member has MS ☐ I am a health professional ☐ Other _____

First Name: _____

Date of birth: ____ / ____ / ____

Surname: _____

Email: _____

Address: _____

Home ph: _____

Work ph: _____

_____ Post code _____

Mobile: _____

I would like to make an annual donation of

\$30 ☐

\$50 ☐

\$100 ☐

\$360 ☐

Other _____

I would like to give a regular amount of

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\$20 ☐

\$30 ☐

\$40 ☐

Other _____

Frequency

per week ☐ per fortnight ☐ per month ☐

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☐ Visa or Mastercard ☐ Expiry Date ____ / ____ Name on card: _____

Card No.

For regular giving via credit card we will contact you to confirm details.

☐ 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)

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A complete list of all our supporters is available in our Annual Report.

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



Takapuna Community Services Building
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PO Box 33574, Takapuna, Auckland 0740
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For more information visit
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Biogen.

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