

MS Ambassadors Raewyn and Lorraine – preparing for the Life Buoy Event



inside

Michael, one year
on after HSCT

giving back

hydrotherapy

new men's group

and more...



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our people.

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a few words from Ingrid.

Our General Manager

"We make a living by what we get, but we make a life by what we give"- Winston S. Churchill

Oh my! What a busy time these past few months have been. It is often when you stop to reflect that you realise how much has been happening!

In the last issue I wrote that there were lots of changes ahead. A Committee sub-group has been meeting to discuss what these changes might look like with the end goal of course providing quality information and services to help enrich the lives of people affected by MS. This continues to be a work in progress and soon we hope to be able to communicate our ideas with the MS Community for feedback.

We were overwhelmed by the generosity of our supporters at our Life Buoy Fundraising lunch and auction. The plan was to do something small this year, and while the event was much smaller in size the amount raised through the afternoon was amazing! Check out my brief overview of the event and some of the photos on page 16.

Our other big annual fundraiser is of course Street Appeal. I keep thinking that the days of asking for donations outside supermarkets must be coming to an end soon, however New Zealand people are generous

people and the money we raise over the weekend of Street Appeal continues to help us balance our budget and provide services to people living with MS. We are always looking for more people though to help at the sites. Please if you have a few hours to spare and feel you could help give us a call. Many hands will make light work!

Unfortunately our core revenue stream continues to be grants, donations and fundraising events. With over 27,000 registered charities in New Zealand and two new charities established every day, the reliance on income from these sources is not sustainable. It would be so nice not to have to spend so much time raising money and more time in developing and providing programmes and services. This is the goal and it is very much top of mind for the Committee and Staff. If you have any ideas that might help us achieve this I would love to hear from you.

The shortest day of the year is now behind us. We are back on the uphill road to summer! Have a wonderful winter. I hope you enjoy reading this edition. Look out for the next one in November and in the meantime keep up to date with our e-newsletters and facebook.

With warm wishes,
Ingrid

MS Auckland committee.

Thank you to everyone that came out to our Annual General Meeting in April. At that meeting we had three members step down – Graham Wear, Michael Cole and Kerri Hoy – and four new people were welcomed to the Committee – Amit Abhyankar, Donald Bowie, Judith Herbert and Jan Hollway. A full list of Committee members are on page 3.



Graham Wear was our special guest speaker on the night and at the end of his talk President Neil Woodhams presented him with an honorary Life Membership for his many years of service. Graham and his wife, Judy, became active in the North Shore MS society when their son, Steven, got diagnosed with MS. Graham then went on to become president of the North Shore Society and Judy was active in many of the activities of the society. Judy received an Honorary Life Membership when she retired and Graham went on to become the vice-president of the newly amalgamated MS Societies – the North Shore and Auckland. He held that position for many years as well as being a member of the MS Auckland Region Trust.

events for your calendar.



Sunday
26th August

Titirangi Pottery Club
Fundraising Event

Titirangi Market, from 9am.
See page 13.

Upcoming events

Please refer to the information on the Support Groups on page 21 and Hydrotherapy page 19, for the on-going activities happening in your area.

Saturday
21st July

Brain Day

University of Auckland,
Owen G Glenn Building,
12 Grafton Rd (off Symonds
St) from 9am to 3:30pm.

For more information go to:
<https://www.fmhs.auckland.ac.nz/en/faculty/cbr/brain-awareness-week-2016.html>

Saturday
28th July

Save the Date

Volunteers are planning a social event out west. Everyone is invited. The venue and details are still being sorted out. More information will be available through your Field Workers or by calling Neil on 021 531 654.

Saturday / Sunday
8th & 9th September

Annual Street Appeal

Volunteers needed! If you can spare a few hours to help out please contact Charlotte or Kirsty at the office on 09 845 5921 or on streetappeal@msakl.org.nz.

welcome - Charlotte Hoonhout.

We are very pleased to welcome Charlotte to our team for the next 4 months. Charlotte has been accepted to work with us as part of an internship programme with the MSD. Her project is to work alongside our project coordinator to make this year's Street Appeal another successful fundraising event.

Charlotte studied Innovation & Entrepreneurship at the University of Auckland and has a real passion for social impact and innovation. Her other interests include equestrian and swimming. She has ridden competitively on the NZ national circuit and internationally representing NZ in Para-Dressage.

Charlotte has already been very busy booking Street Appeal sites across Auckland and contacting groups to support our appeal.

Street Appeal is on the 8th and 9th of September. If you can spare a few hours to assist with street collection, Charlotte would love to hear from you.



She would also like to hear from you if you can assist us in any other way during the week. You can contact Charlotte on streetappeal@msakl.org.nz. She can also be contacted at the office (09 845 5921) Tuesday to Friday from 9am to 4pm.

MS Auckland office is located at
5 The Strand, Takapuna

Office Hours
Monday – Friday 9am to 5pm

Phone number: 09 845 5921

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Mark@msakl.org.nz

info@msakl.org.nz

Kirsty@msakl.org.nz
Becky@msakl.org.nz

from the MS nurses.

The Process of Starting on Pharmac approved MS Medicine

I have had requests on the process surrounding starting on PHARMAC's approved medicine so thought I would take the opportunity here to outline the steps involved. There are a number of steps to go through with variations depending on your neurologist, test results and outcome of your application.

Medicines are approved for people with relapsing remitting MS only. To be eligible you must have

- A recent relapse (symptom lasting for one week)
- In some cases PHARMAC requires evidence of new inflammation on an MRI scan
- Your neurologist will be able to advise if they feel you are eligible and we encourage you to report any new symptoms to your GP or MS nurse or your Field Worker so a review can be booked.

If your neurologist is able to make an application it is then:

- Submitted to the PHARMAC review board (meets monthly)
- Your application will be approved, declined or deferred.
- Should your application be deferred your neurologist may need to provide further details
- If you are declined we will call you to discuss the reasons why.

When your application is approved you will

- Receive a letter from PHARMAC explaining this and be allocated a special authority number
- Your neurologist receives a copy of this too
- If you have already decided on a medication to start the MS nurse's will then arrange some further tests depending on your medication.

These tests are then

- Reviewed by your neurologist and prescriptions signed. As your safety is paramount your neurologist needs at least 15-20 minutes to review your tests and write to your GP informing them of the plan and your GP's role in monitoring your treatment.



Fiona and Nazila

The next steps:

- Coming in for an infusion or day stay visit for Tysabri or Gilenya or an appointment with us if you are starting Tecfidera.
- Securing a bed in the day stay for Tysabri or Gilenya is dependent on the day stay bookings.
- Over 100 people are infused with Tysabri each month so your flexibility about dates and times is appreciated.

You are required to see your neurologist annually for a reapplication of your special authority number. If the review is delayed then your pharmacy will be unable to dispense more medicine so please email or call us before cancelling or missing your appointment.

Please feel free to email us at any stage if you have questions about this process.

**MS nurses e-mail: msnurse@adhb.govt.nz;
phone: 09307 4949 ext. 25885#**





welcome to our new field worker, Catherine Glover.

Catherine joined our team early in April, taking over the work done by Carol in the Central Auckland area.

Catherine has a broad healthcare background. She initially qualified as a Registered Nurse, before completing several years work in business administration and training. For the past nine years she worked for Auckland Bone Density as DXA Operator and Head Technician. She has extensive experience working with patients, clients and customers.

Catherine has very much appreciated the support of Dianne, Andrea and Diane, our other three Field Workers, as she gets herself settled into her new role with us, and has very much enjoyed her first few months.

MS Auckland is currently undergoing a strategic review process to support future planning for the organisation.

Our Field Workers



Dianne



Diane



Andrea

Catherine's role is therefore a contract role until the end of November when we hope to have clearer direction and more certainty to enable us to make permanent positions going forward.

Catherine can be contacted on Catherine@msakl.org.nz or on 021 959 187.

Ken & Margaret's golden anniversary.

I was privileged to be invited to attend the Golden anniversary of Margaret and Ken Hall in Papakura on 14 April 2018. They were married at St James Presbyterian Church in Pukekohe on 2 March 1968. Since marrying they have lived in Papakura where they brought up their three sons. They are now also proud grandparents to their five grandchildren. A lovely gathering of Margaret and Ken's family including their three sons and their wives and grandchildren, other family members and friends and carers all came along to celebrate with Margaret and Ken.

Written by Field Worker, Dianne Bartlett



Margaret and Ken have been quite involved with MS Auckland over the years. They used to host the Papakura Support Group in their home each month for many years with Ken doing all of the baking for the group. Everyone loved to attend to see what Ken with Margaret's guidance of course, baked especially for the group.

They were also the first ones to put up their hands to organise and then collect for the annual MS Street Collection which is held in September each year. No one could get past Margaret and Ken without contributing.



These are but 2 of the special ways Margaret and Ken have given back to MS Auckland. On behalf of all of the MS Community I would like to thank them both for all they have done for us over the years and look forward to seeing them at the next Support Group at Friendship House in Manukau.



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References: 1. Data on file, Biogen. 2. Desai A et al. *Eur J Pharm Med Res* 2016; 3(5): 197–205.
3. TECFIDERA (dimethyl fumarate) Data Sheet, 2 May 2017.

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mastering mountains grant recipient 2017 – Marlene Hessing.

Marlene was one of two people who received a Mastering Mountains Grant last year from the Mastering Mountains Charitable Trust.

This grant was set up to assist 'people who have been diagnosed as having Multiple Sclerosis, to overcome a specific obstacle so that they can achieve a specific outdoor pursuit'.

The Trust was established in 2015 and aims to 'help people with MS pursue adventures that encourage a healthy lifestyle and change the perceptions of MS..... Getting outdoors has an incredible therapeutic quality. MS can hinder people from the fullest experience of this, and the Mastering Mountains Grant hopes to overcome this obstacle.'

When Marlene was diagnosed with MS she was told she would just get worse and eventually have to be in a wheelchair. Twenty years later, Marlene is proving them wrong. She has taken control of her MS and has left her wheelchair and walker and now walks unaided.

Walking and balancing is still a challenge. Marlene applied to the Trust to help her build her strength with the help of Parkinson's Counter Punch so that she could complete two walks – The Goat Island Walkway and Tiritiri Matangi island walk.

Marlene is thrilled that she has now managed to complete both the walks. She did the two hour Goat Island coastal walk with her son and daughter in law. She writes:

"The walk was narrow, steep and close to an electrical fence and some private properties. There was quite a bit of loose gravel challenging my balance and there was a deep drop at the other end. However it was also exciting as the greater the challenge the sweeter the reward for having completed it."

She did the Tiri Tiri Matangi walk with her trainer, Lisa. This walk was 7.8 kilometres and took nearly 3 hours. She experienced 'lovely views, great bush and tree canopies and a host of native birds all merrily chirping away'.

Marlene attributes Lisa's training and her diligent efforts for her good results. She writes:



Lisa and Marlene

"This has now given me confidence and tools to keep up and build on the same. I have now joined a walking group that do between an hour to an hour and a half each Tuesday. This will be good for me to keep up and continue to build on my strength, endurance, balance, speed and fellowship."

Marlene is very grateful to Mastering Mountains Charitable Trust and everyone that supported her with her ambition to master these two beautiful Auckland walks. She encourages other people to go out there and give it a go as well.

Applications to the Trust can be received between 1 September and 31 October. For more information talk to a Field Worker or visit the MSNZ website:

<https://www.msnz.org.nz/scholarships-and-grants/>

rebooting the system at seventy. By Roy Bartlett



Reaching seventy last June, I found myself thinking about how much time do I have left on the planet. As a result I set about reviewing the four pillars of good health – food, relaxation, sleep and exercise to improve my health and how I age.

I started by asking myself the questions; *“What do I want to do more of? What do I want to do less of? Who do I want to spend time with? Who don’t I want to spend more time with? Who do I want to share my heart with? What friends do I want to spend time with?”* This exercise helped remind me of what I value, what I value in myself, and what I value in others.

Next I reviewed all that I have learnt from brain science about emotional and mental health. This led me to register for an online 7-part documentary series entitled *“Betrayal, the autoimmune disease solution they’re not telling you”*; which interviewed 87 of the world’s leading doctors, scientists, researchers and patients who have reversed their autoimmune conditions.

Believing the brain is the most important organ in the body and all the other organs are there to serve it because our emotions, judgements, personality, and decisions all arise from it; I decided because everything starts from there, to provide it with the right environment by eating well, exercising, sleeping well, and having community and love in my life.

As a consequence I created a vision and timeline for myself of living to 80 with good health, vitality, energy and remaining active in the community.

Six months down the track I have made minor changes to my diet, it now being completely an anti inflammatory plant based diet. New science findings strongly indicate that inflammation is what makes a good brain go bad. Now when I raise a fork to my mouth I ask myself: *“Is this food going to love me back?”* The result of those changes has seen my bodyweight drop 10kgms and wearing clothes I haven’t been able to fit into for 3 years.

The World Health Organisation now characterises inflammatory chronic degenerative conditions that are lifestyle related as the No 1 type of cause of death on the planet. They are related to the choices we make. Primarily in our food choices, but also in the areas like the medications we take, the amount of sleep we get and the exercise that we do or do not participate in.

I have just recently completed my third marathon; the first two completed before developing MS. The main difference about the third is I completed the 26 miles by walking a mile a day with the aid of my walker and rest days in between. I’m spending more time in the garden with my wife Julie and am more proactive in suggesting activities we can do together. She has recently commented; *“It’s like having my old Roy back again”*.

volunteers profile.

*"Do it for no reward,
but because you want to"*

Our volunteer team at Millennium Hydrotherapy

Chatting to our volunteers is definitely a perk of my role at MS Auckland. Their kindness and selflessness is inspiring, giving their time and energy to help a greater cause.

I was lucky enough to catch up with Karen and Liz at our Millennium hydrotherapy group, who both have been volunteering there for the last 7 - 8 years. Karen and Liz saw a flyer at the Millennium asking for volunteers. Both were members at the gym and thought 'I can swim, I have time and I can help' – and so they did. This ethos carries through to the whole team.

We are fortunate to have 6 committed volunteers, Karen Jensen, Liz Poore, Mila Magendans, Joanne Booth, Sue Dixon and Gemma Chamberlain. Karen sets up a roster each month, having 2 volunteers attend each week.



Mila

Written by Becky Tucker



Liz and Karen

It is most definitely a team of volunteers as all are eager to help each other and over the time have become friends; this is evident from all the laughter that can be heard at coffee time afterwards!

Karen and Liz take pleasure from seeing the benefits of hydrotherapy and watching the swimmers relax in the water, becoming more able bodied. Both believe that hydro is not only important for the physical side but just as much for the social side, offering much encouragement, laughter and rapport to the group.

Mila our volunteer who has been with us for 4 years is aware of the effects of autoimmune diseases, herself having lupus and understands the importance of exercise. Mila is such an advocate for this and has become a personal trainer to help people with rehabilitation.

Thank you so much, Karen, Liz, Mila, Joanne, Sue and Gemma for all the support and commitment you give, it is invaluable.

***if you are interested in volunteering for
MS Auckland please contact Becky –
becky@msakl.org.nz or 09 845 5921.***

Ms Sassy en Blanc Lunch.

Written by Hiria Kayes

In April my good friend Nikki Davidson and I organised the “Ms Sassy en Blanc Lunch” in our local community, Manly, Whangaparaoa. More than 115 people, dressed all in white, took part and we raised just over \$5,600 for Multiple Sclerosis Auckland and the NZ Breast Cancer Foundation.

The stylish outdoor lunch, at a private residence on a sunny Saturday afternoon included white tablecloths and decorations as well as music, dancing and a silent auction. The fundraiser was based upon the successful Le Diner en Blanc, where every participant brings their own food, drinks, white table cloths, and white table and chairs. Tables were kindly provided by our local Whangaparaoa Primary School.

Our inspiration for this event has been our lovely friend Linda who has lived with MS for many years and was diagnosed with Breast Cancer late last year. Hence why this event is named after her “Ms Sassy” (“Ms” for MS and “Sassy” because we think Linda is strong, full of spirit and a little bit cheeky).

The lunch exceeded our expectations and was “a lovely spectacle and a fun gathering featuring kindness, support, friendship and bravery”.



join Titirangi potters for the next 'bowl for...' fundraiser.



Titirangi Potters' annual 'bowl for' fundraising event for MS Auckland is happening at the Titirangi Market this August.

Each year, Titirangi Potters selects a deserving local charity and furiously makes bowls, plates and mugs. At the winter market (Sunday August 26th) they host a soup operation selling gourmet, hand-made soup (by members). Buy a bowl (or mug) of soup, and take your vessel home with you. Or purchase baking delicacies, sold on hand-made plates. Bowls/ mugs or plates from \$5, including works from renowned local potters – and this year 100% of profits goes to MS Auckland.

If you would like to help out with offers to make soup or biscuits or to help on the day, please contact Suzie Beck on suehoyle123@gmail.com.

Put the date in your diary, to visit the Titirangi Market on Sunday the 26th of August to support this fundraising effort. Get in early to get the best bowls (from 9am) – the bowls and mugs sell out each year so it's a great way to support MS, and stock your kitchen with beautiful hand-made pottery.

A big thank you to all the members of the Titirangi Potters!

skincare and makeup fundraiser.

Our lovely Rebecca is doing a skincare and makeup Fundraiser to raise funds for MS Auckland. Please see her letter below.

This year for my annual MS Fundraiser I'm hosting an online Facebook Fundraiser selling Mary Kay Skincare and makeup with 20% of sales being donated to MS Auckland. If you would like to join the fun please go to <https://www.facebook.com/events/172274603623033/>

It will be a fun week of interactive videos, great offers, spot prizes, makeup tips and tricks and best of all 20% of all products sold will be donated back to MS Auckland.

I also have a gorgeous handbag and purse kindly donated from an international designer, Lynne Wambeek, up for grabs! To find out more go to the facebook link or give me a call on 021 0256 4223 for all the details.

For those of you not on Facebook and would like to take part in this send me an email to vintagemakeupartist@gmail.com or call or text me.

Look forward to see you all

Love from your fellow MS warrior
Rebecca Waite
Mary Kay Consultant



Michael one year on after HSCT.

Written by Ingrid Minett

I interviewed Mike in June 2017, shortly after he had returned from Singapore from receiving Stem Cell treatment for his secondary progressive MS. One year on I caught up with him again to see how he was doing.

We met at his workplace over a cup of coffee. Mike seemed full of life.

"I am so much better than when I travelled to Singapore for treatment. Mentally I am completely better. The brain fog and fatigue that I was having has completely gone. My physical symptoms are much improved too. I have used a stick probably about 4 times over the past year. My gait is much improved but after about 100 meters I have a slight right foot drop."

Mike had realistic expectations going in and his main objective was to halt the progression of his MS. He realised that some permanent damage may have been done that will not be undone.

"I used to love skiing and biking. My skiing days are probably behind me now, but I have been out on a bike a few times and would like to do more biking."

Mike was 30 years of age when he was diagnosed with MS. Life had taken a new normal for him. He was often sad, had no energy and was leaving work early in the afternoon feeling completely 'stuffed'.



Mike and Angela

He is now working a forty plus work week and has a fairly fast paced life. He is looking now at getting some work/life balance and doing more of the recreational activities that he enjoys so much.

He hasn't had a follow up MRI yet. The last time he had one was in November 2016, in preparation for his treatment. He is aware that his haematologist in Singapore is keen to have a follow up MRI, and while Mike isn't very keen on the procedure, he knows he will have to book one in soon.

Mike feels that his haematologist will be 'blown away' with his progress. They were quite surprised already with the progress that he was making in the short time that he was in Singapore following treatment.

We bumped into Angela, one of his co-workers as I was leaving the office building. Angela has known and worked with Mike for many years and tells me how much she has noticed the changes in Mike since his return from Singapore last year.

"He smiles all the time now and is so much happier.... and he stays at work all day."

Mike says that he is indeed a much happier person now with lots to look forward to. It was lovely to see Mike again and, along with everyone at MS Auckland, wish him all the very best.

(Mike's first interview appeared in the June 2017 issue of Multiple News.)



giving back.

Kerri Hoy resigned this year after serving for some years on the MS Auckland Committee. She reflects on her diagnoses 12 years ago and tells the story of the impact her MS Auckland Field Worker had on her life and her desire to give back.

Kerri's relationship with MS Auckland began twelve years ago when she was diagnosed with MS. Kerri describes herself as self-reliant so her first question for her doctor was "what can I do to help myself?". She replied "There's nothing you can do. Come back and see me in a year."

I was heading off to work and by the time I got to the office I was so angry. I thought "This is ridiculous!" I rang MS Auckland and relayed this conversation to a Field Worker who said "Oh, there are things you can do. Would you like to meet with me?"

*So I met up with her as soon as I could and she gave me George Jelinek's book, **Overcoming Multiple Sclerosis**, and talked me through Vitamin D and all the things you can actually do to take some control. That book was my bible from then on.*

Kerri describes herself now as "one of the lucky ones. I haven't got the aggressive form of MS which is devastating for some people".

I occasionally experience the symptoms that sent me off to the doctor years ago – but nothing like the initial frequency.

MS doesn't have any impact on my quality of life at all – in fact having the diagnosis has possibly improved it because of the extra care I have taken of myself.

That first meeting with my Field Worker has been a life-saver for me. I think I may have disappeared down a dark hole if I hadn't felt I could do anything to help myself.

As a Committee member of MS Auckland, Kerri was inspired to consider including a gift in her Will. Robyn O'Connor was talking to the Committee about her work on the Bequest programme and explained that often people hesitate to leave a gift to charity in their Will as they feel they have to leave their entire estate to their families. Since having a conversation with her own mother, Robyn suggests that a gift of 1 or 2% to a favourite charity will not usually deprive family and loved ones in any significant way but can make a big difference to a charity.

Robyn's suggestion opened my eyes. My parents had been very generous supporting different charities during their lifetimes, but when they died all their estate was left to us (their children). I had thought to follow their example but then, with the example of a gift of 1 or 2% to charity, thought "Oh, that's another way of doing it".

My family – my children and grandchildren – are my priority now and in the future. I feel happy knowing that I can look after them in the future by leaving them the bulk of my estate.

But I can't imagine my life now if I hadn't had the support of MS Auckland when I needed it. Including a gift in your Will to MS Auckland is a way of supporting others by ensuring they get the information and support that allows them to live well with MS.

The decision to leave a gift in your Will to charity is a gift from the heart. Most people who do so have been touched by the charity in some way. Often they, or a loved one, have been the recipient of the charity's support so their gift is in appreciation of that support. Also, people want to ensure that others receive information and support which has so benefited them.

If you would like more information about including a gift in your Will to MS Auckland please contact Mark or Ingrid on 09 845 5921 or mark@msakl.org.nz or Ingrid on Ingrid@msakl.org.nz. Or visit the MS Auckland website www.msakl.org.nz.



Simon, Christine and Neil



Kirsty

life buoy for MS 2018.

By Ingrid Minett

Our annual fundraising event was back at what must be our favourite venue – the Royal NZ Yacht Squadron at Westhaven Marina.

Scotty Stevenson did a brilliant job of MC, keeping the pace relaxed as people enjoyed a delicious lunch in the beautiful surroundings of the Yacht Squadron.

The sun shone and the guests gave generously as our Auctioneer Lisa called the six live auction items – including a fabulous lunch or dinner for up to 10 people at Sir Graham and Raewyn Henry's home on Waiheke Island, which was so hotly contested that they agreed to do it for two groups! A further 18 items were bid on in a silent auction.

This event was run by a small group of dedicated volunteers – MS Auckland ambassadors, Lorraine Street and Raewyn Henry, Committee members Carolin Perkins, Joan Thomson and Donald Bowie, and ex-President Christine Hart, along with Kirsty and me from the office. Mark and Becky from the office were also always on hand to help out and also volunteered their time on the day.



Harcourts guest with Fiona and Tony Blake



Lorraine, Tessa and Callum



Graham, Raewyn and friends



Lisa, our Auctioneer



There are so many people to thank, including the 12 people who volunteered their time on the day to help keep the day running smoothly, to the people and the organisations that donated the prizes, the chocolate dessert and the table centrepieces, to the musician and the photographer, to the guests that came and gave so generously, to the RNZYS staff who looked after us so well, to our MC Scotty Stevenson and to Sam Smith who shared his story of MS with us, to our corporate sponsors who stood behind us – Harcourt’s Cooper & Co., Care on Call and JUCY.

The final total is still being worked out, but it looks clear that this event will bring in over \$70,000 to go directly to support MS Auckland services. The success of this event is due to so many generous and supportive people coming together. You have made a difference to people affected by MS. I am so, so very grateful to you all.



Graham with Judith (right) and friend



Sam and Scotty

Karen reflects on having MS and enjoying hydrotherapy.

Written by Karen Blair

On St Patricks Day when I was 47 years old I had to ask my son to lift my legs off the ground for a sufficiently long time for me to get my bottom half dressed. I am not sure which one of us was more mortified. For the record, I hadn't had anything to drink. But I hadn't been feeling myself for a week, so I thought maybe I had a virus and that perhaps I had put my back out.

The next morning I could not lift my pelvic floor muscles or pull in my tummy. Lifting my legs was still an issue. I developed a sporadic tremor in my right arm. I used the walls to get to the toilet. I drank my soup because I had considerable difficulty connecting my spoon and my mouth.

A number of days in hospital and various tests later, the doctor told me that I had MS. That afternoon, the lady in the adjacent bed whispered loudly to her visiting husband, that "the poor girl next door has MS. Isn't that really awful". I wanted to tell her there were worse things in the world than MS, but while I was certain that was true, I also didn't really have much of an idea what it was. Whispers that are not meant to be heard should be written down.

I kept my diagnosis largely to myself. I still haven't told many people outside my family. To begin with it was unknown and very personal, and as time has gone on it remains a bit of a mystery and often doesn't seem entirely relevant.

I joined MS Auckland very soon after my diagnosis. I had morning tea with my Field Worker. She was awesome and answered lots of my questions. I tried not to search out the internet (too much). I went to a couple of MS Auckland events and learnt a bit more.

Before I got MS my baseline exercise was running 5 days a week for half an hour, doing 2 sessions of boot camp a week, 2 sessions of mixed level pilates and walking for 2 hours every Sunday. I also did non-competitive ocean swims, the odd half marathon (I walked – you can't get enough conversation in when you run) and cycling. You get the drift: I was fit. And my exercise was sociable – generally everything fitness-wise I did, I did with friends. After I was diagnosed with MS my fitness slumped. It wasn't that I didn't want to do those things anymore: just that my energy was required for other things and that I found that level of exercise too challenging.

Things had changed. Instead, I was going to 2 beginners pilates sessions a week – and finding them tough enough. I became curvier, less socialised and a lot less fit.



I read about the hydrotherapy classes in the MS magazine and I thought I'd give one a go. I went to the Saturday morning class at Diocesan School for Girls. I loved it. My first session I met the instructor, Tom, and he was super friendly. He introduced me to everyone and everyone introduced themselves to me. What a neat group of people: I felt right at home. Of course, I couldn't remember all their names but Tom really helpfully uses people's names throughout the class and this year I have only had to ask one person (well, maybe two people) to remind me of theirs.

The class lasts an hour. Getting in is the worst part because it always feels cold, but after you have gotten going you are glad the water isn't any warmer. This particular class is a higher intensity class than some of the other classes that are available. It is mixed ability, but everyone in this class has reasonable mobility. We all do the best we can, and we compete with ourselves not each other. Some weeks my best is different to what it is other weeks, but I get support and encouragement from the group and I get a massive sense of satisfaction at being able to get my heart rate up. We all wear a buoyancy vest and when I lose my balance or need to slow down it doesn't matter. I feel safe. I can't fall over and do myself an injury. That does wonders for my confidence and I can put more effort into my exercise. I feel that the benefits that I get from class makes my life on land safer too.

Hydrotherapy class is one of the highlights of my week. It makes me happy and helps me to feel good about myself. Sure, I am knackered after class – but I sleep soundly and happily in the afternoon.

I feel very blessed that I am able to access such a high quality professionally run class, and also that it is highly subsidised. No one knows what course my MS will take. But I believe that hydrotherapy is one way that I can help myself manage its impact: the class is good for my body, my mind and my emotions.

hydrotherapy.

Have you tried a hydrotherapy class yet? Once you do, you might be hooked! We offer the first two classes at no charge, for MS people only, and then payments of \$30 per quarter of \$60 for half a year or \$120 for the full year. Payment allows entry into any pool and as many times as desired during the period. Payment can be made directly into our bank account or on credit card. Please contact the office on 09 845 5921.

The classes are run by three contracted providers:

Rope Neuro Rehabilitation - 623 8433 - Epsom Pool and Lloyd Elsmore Pool

Physio Rehab Group - 524 0633 - Manurewa Pool, Westwave Aquatics, and Diocesan Girls pool

Neuro Rehab Results - 480 6464 - Millennium Pool

For further information on the hydrotherapy classes please contact the Field Worker listed below for each pool.



People with other neurological conditions are also welcome to participate in these sessions but must first contact the contracted provider for the pool group they are interested in joining. Joining the group may be subject to an assessment by the provider and payment must be made to MS Auckland before attending.

2018 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

Wednesday

Westwave Aquatics
20 Alderman Drive
Henderson

11.30am - 12.30 noon

Contact:
Andrea Kortas-Ray
09 845 5921 Ext 221
andrea@msakl.org.nz

Thursday

Epsom Girls
Silver Road
Epsom

10.30am - 11.30am

Contact:
Catherine Glover
09 845 5921 Ext 222
catherine@msakl.org.nz

Saturday

Diocesan Girls
Clyde Street
Epsom

10.00am - 11.00am

Contact:
Catherine Glover
09 845 5921 Ext 222
catherine@msakl.org.nz

a new men's group in South Auckland.

*Written by Dianne Bartlett
Field Worker, South and East Auckland*

I was asked by a man whom I hadn't seen for some years if we had a men's MS group. I said that we didn't but was happy to give it a try and see what reaction I get. This man was very enthusiastic about the idea. He had listened to Mike King and was inspired by him to ask about this. He felt that men today don't talk enough about anything much and he saw a group of men with MS as a way to share their experiences and to perhaps help each another cope with MS.

I sent out an email targeting the men in my area and almost immediately received 8 replies. Heartened by this I went back to the men and said "we have a group - I have had 8 replies" and within the next few days, I had received another 8 more men keen to join up!

At the first session we had 12 attendees. We met at a café. I asked them to introduce themselves, tell us how long they have had MS, if they are on any medications and whatever else they wished to share with the group. I thought women could talk! It took well over an hour to do this and by then they were chatting away to each other as if they had known each other for years.

At our second get together we had another 12 men along. This time there were a few men who had not been able to attend the first time but wanted to come along and one or two who could not make this session.

I am leaving it to the men as to how they want to run the group. There is absolutely nothing formal about it.



They just chat within small groups and then get up and talk to others across the table. I took along some information that I thought might be pertinent and have left it up to them if they take it or not. They have all suggested that they swap contact details and have an open email so that all can be contactable. They are all keen to keep this going.

I am absolutely delighted that there was one brave man who suggested this and then another 16 men who came along.

Please feel free to contact me if you wish to attend some time.

Dianne can be contacted at dianne@msakl.org.nz



Manukau support group celebrates world MS day.

World MS day is celebrated internationally on the 30th of May each year. The Manukau Support Group decided to celebrate it by wearing something orange to their May meeting. They then shared a lunch and were taken through some Tai Chi by one of their members.

support groups.

Support Groups are free and open to anyone with MS (and partner, parent, friend, caregiver or children) to attend. It's a great way to meet people, share information and make new friends. Two new Support Groups have started up recently – one in New Lynn and a men's only group in South Auckland (but open to men throughout Auckland to attend). If you are interested in starting up a support group please talk to your Field Worker.

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 Robert Harris Café (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
Men's Group Robert Harris Café (Botany Town Centre)	Dianne Bartlett 021 845 903	Saturday / Month 10.00am
Central		
City Evening Group Scarecrow Café	Catherine Glover 021 959 187	Wednesday / Six Weekly 6.00pm
Mt Wellington Café Group Coffee Club on Lunn Avenue	Maria Greenfield 021 131 6613	Second Saturday / Month 11.00am
Stonefields Café Group Stonebake Café (Lunn Avenue, Mt Wellington)	Catherine Glover 021 959 187	Third Wednesday / Month 10.30am
Onehunga Group Frolic Café (Manukau Rd, Royal Oak)	Catherine Glover 021 959 187	Second Tuesday / Month 10.30am
West Auckland & Rodney		
Kumeu Café Group Different Venues	Andrea Kortas-Ray 021 959 189	First Tuesday / Month 10.30am
Henderson Garden Café Group Espresso Garden Café (inside Mitre 10 Mega, 186 Lincoln Rd)	Andrea Kortas-Ray 021 959 189	First Thursday / Month 11.00am
New Lynn Café Group Columbus Coffee Café (inside Mitre 10 Mega, New Lynn)	Andrea Kortas-Ray 021 959 189	Second Tuesday / Month 10.30am
North Café Groupies Kings Plant Barn (Silverdale)	Diane Hampton 021 859 187	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 Palmer's 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



Only think about your MS once daily

Relapsing multiple sclerosis may be there every morning, but that doesn't mean it has to always be on your mind.

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

**Ask your doctor
about Gilenya.**

🔍 **'Multiple Sclerosis NZ'**

Reference: 1. GILENYA Consumer Medicine Information available at www.medsafe.govt.nz

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, or any abnormal skin growths or changes (e.g. pearly nodules, patches, or open sores or unusual moles). 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. NZ-00269 03/2018 TAPS MR5588 essence NV8662 WD

recipe.

Beetroot and swede soup

I can live off soups for most of the winter. This soup is so simple to make and is always a winner with family and guests.

Serves 4 (or more)

Ingredients

- 4-6 beetroot, chopped
- 2 swedes, peeled and chopped
- 1 onion, peeled and chopped
- freshly ground black pepper, to taste
- pinch salt
- 3-5 cups water or vegetable stock
(I always use stock. For a thinner soup use more.)
- Coconut yoghurt (optional)
- 1 Tbsp chopped parsley



Method

1. Place beetroot, swede, onion, pepper, salt and stock in a large heavy-based saucepan.
2. Bring to the boil, reduce heat and simmer until vegetables are soft.
3. Blend in batches until smooth.
4. Return to the saucepan and heat to steaming hot.
5. Serve with a sprinkle of chopped parsley on top, and if you wish a dollop of coconut yoghurt





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Living your life your way with MS

1. Ocrevus (ocrelizumab) Consumer Medicine Information February 2018 <http://medsafe.govt.nz/consumers/educational-material.asp>

Ocrevus is **not funded** by PHARMAC for relapsing or primary progressive multiple sclerosis. You will need to pay the full cost of this medicine. A prescription charge and normal doctor's fees may apply.

Ocrevus[®] (ocrelizumab), 300mg vial, is a **Prescription Medicine** used to treat relapsing forms of multiple sclerosis (RMS) and primary progressive multiple sclerosis (PPMS). **Do not use Ocrevus if:** you have had an allergic reaction to Ocrevus or any of the ingredients. **Tell your doctor if:** you have an infection, or a history of a recurring or long-term infection such as hepatitis B; you are taking or have previously taken medicines which may affect your immune system, such as other medicines for MS; you intend to have or have had immunisation with any vaccine; you are allergic to any other medicines or any other substances such as foods, preservatives or dyes; you are pregnant or intend to become pregnant; you are breast feeding or plan to breast feed. **Tell your doctor immediately or go to your nearest Accident and Emergency Centre if you notice any of the following;** swelling of your face, lips, tongue or throat with difficulty breathing; swelling of other parts of your body; shortness of breath, wheezing or trouble breathing; skin problems including rash, itchiness or hives; fever, flushing or chills; cough, throat irritation or pain; feeling tired; headache; dizziness or light headedness; feeling sick (nausea); fast heartbeat. **Tell your doctor, nurse or pharmacist if you notice any of the following common side effects:** signs of an infection such as fever or chills, cold sore, shingles or genital sores; stuffy nose or chest; thick mucus in the nose, throat or chest; persistent cough; difficulty sleeping (insomnia); diarrhoea, vomiting and/or stomach cramps (gastroenteritis). **Ocrevus** has risks and benefits. Ask your doctor if Ocrevus is right for you. Use strictly as directed. If symptoms continue or you have side effects, see your healthcare professional. For further information on Ocrevus, please talk to your health professional or visit www.medsafe.govt.nz for Ocrevus Consumer Medicine Information.

2018 supporter survey.

Written by Robyn O'Connor

Thank you to everyone who shared their opinions in the 2018 Supporter Survey. It is heart-warming that so many of you took the opportunity to tell us what is important to you.

Most of the people who completed the survey were people with MS. A second group have a family member or friend with MS and there was a smaller group who did not appear to know anyone with MS. We feel happy that we gained insight into the values of the people most affected by MS and will use that information to inform changes to our practises.

The thing you value most, by far, was the personal, practical support of MS Auckland Field Workers.

"The best thing is I know I can contact my Field Worker if I need any advice about MS." "The thing I value most is... the support of Field Workers for my brother." The second and third things most valued are Advocating for people with MS and Education & Research.

Most people were inspired to support MS Auckland because they felt it a worthy charity and wanted to help people in the community affected by MS. However, many may share the opinion of one person who reminded us *"I directly benefit from its services."* At present, most of the 'supporters' of MS Auckland are people directly affected by MS.

Over the past months we have been delighted to learn of many people who have included a gift to MS Auckland in their Wills or intend to do so. More people told us of their intentions in the survey and we are so grateful for these gifts which are invested to ensure MS Auckland services will be available to those who need them in future. Thank you.

Thank you also to those of you who offered your services as volunteers in varying capacities. We could not do all we do without the support of our wonderful volunteers.

Responses to our question *"What would inspire you to continue or increase your support of MS Auckland?"* were mixed with no clear preference. Perhaps opinions are best understood by a couple of comments *"No motivation is needed once a family member is affected."* *"All of the above, but I am not in a position to support MS Auckland financially."* These comments remind us that MS Auckland is an unusual charity in that our pool of supporters are mostly people affected with MS. Many charities have wider support by 'the public'



as the medical condition is more readily understood. We are considering ways to address this.

You reiterated your appreciation for MS Auckland Field Workers when we asked when you most appreciated MS Auckland. The most common responses were *"when diagnosed with MS"* or for on-going support by Field Workers. *"I most appreciated MS Auckland at diagnosis – but throughout my 16 year journey with this disease MS Auckland has been helpful with information and education that I would otherwise not get as the Health system doesn't really tell you anything because the doctors have no time."* *"When first diagnosed – talking to a Field Worker and going to events for Newly Diagnosed."* *"My partner, who has MS, regularly says MS Auckland provides much more useful medical and personal support for her, in terms of her MS, than any other source."*

Finally, we loved your Comments which reassure us that we are doing things well. *"MS Auckland is a wonderful organisation doing a great job."* *"MS Auckland means I feel less on my own. If it was not there I'd be without any real source of information and support."* *"I always enjoy your fundraising events. Well organised and very enjoyable."* *"I appreciate the time and energy that goes into providing the Research Days which are of great value and personal interest."*

Thank you all for generously sharing your opinions. We feel like we are doing some things well and know also that there are others things that we will continue to work on – including big challenges to get the funding we need so people with MS get the supportive care they need and deserve.

new research finds key players in MS progression.

The following article was taken from The Harvard Gazette – <https://news.harvard.edu/gazette/story/2018/05/new-study-clarifies-gut-brain-connection-and-ms-progression>

A new study sheds light on the connection between the gut and the brain by defining pathways that may help guide therapies for multiple sclerosis (MS) and other neurologic diseases.

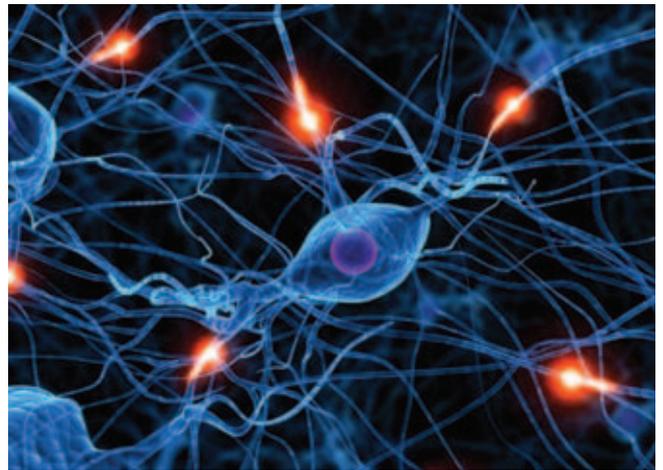
The study, conducted by investigators from Harvard-affiliated Brigham and Women's Hospital (BWH), was published this month in *Nature*. (<https://www.nature.com/articles/s41586-018-0119-x>).

Using both animal models and human cells from patients, researchers untangled the complex interplay that allows the byproducts of microorganisms living in the gut to influence the progression of neurodegenerative diseases. This enabled them to tease out the key players involved in the gut-brain connection as well as in the crosstalk between immune cells and brain cells. This current study is the first to report on how microbial products may act directly on microglia to prevent inflammation.

“These findings provide a clear understanding of how the gut impacts central nervous system resident cells in the brain,” said corresponding author Francisco Quintana of the Ann Romney Centre for Neurologic Diseases at BWH. “Now that we have an idea of the players involved, we can begin to go after them to develop new therapies.”

The new research focuses on the influence of gut microbes on two types of cells that play major roles in the central nervous system (CNS): microglia and astrocytes. Microglia are an integral part of the body's immune system, responsible for scavenging the CNS and getting rid of plaques, damaged cells, and other materials that need to be cleared. But microglia can also secrete compounds that induce neurotoxic properties on the star-shaped brain cells known as astrocytes. This damage is thought to contribute to many neurologic diseases, including multiple sclerosis.

Brigham researchers have previously explored the gut-brain connection to gain insights into multiple sclerosis. Although some studies have examined how byproducts



from organisms living in the gut may promote inflammation in the brain, the current study is the first to report on how microbial products may act directly on microglia to prevent inflammation. The team reports that the byproducts that microbes produce when they break down dietary tryptophan — an amino acid found in turkey and other foods — may limit inflammation in the brain through their influence on microglia.

To conduct their study, the research team examined gut microbes and the influence of changes in diet in a mouse model of multiple sclerosis. They found that compounds resulting from the breakdown of tryptophan can cross the blood-brain barrier, activating an anti-inflammatory pathway that limits neurodegeneration. The researchers also studied human multiple sclerosis brain samples, finding evidence of the same pathway and players.

Activation of this same pathway has recently been linked to Alzheimer's disease and glioblastoma. The Ann Romney Centre for Neurologic Diseases brings experts together to accelerate treatment for these diseases, as well as multiple sclerosis, Parkinson's disease, and amyotrophic lateral sclerosis.

“It is likely the mechanisms we've uncovered are relevant for other neurologic diseases in addition to multiple sclerosis,” said Quintana, who is an associate professor at Harvard Medical School. “These insights could guide us toward new therapies for MS and other diseases.” Quintana and his colleagues plan to further study the connections to neurologic diseases, and are also optimizing small molecules as well as probiotics to identify additional elements that participate in the pathway and new therapies.

our supporters.

MS Auckland is grateful to all organisations, families and individuals who support our work.

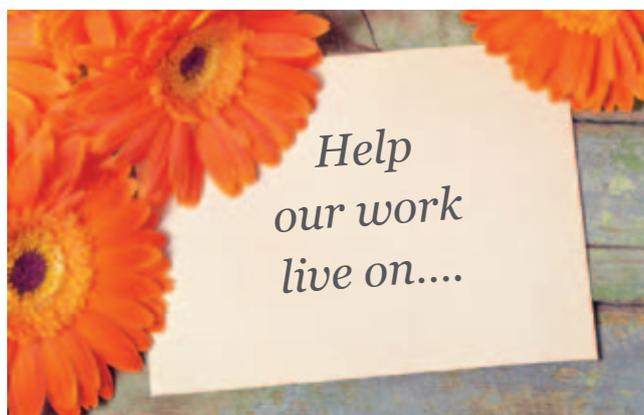
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Blue Waters Community Trust	Ministry of Social Development
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Constellation Communities Trust	North Shore Presbyterian Hospital Trust
Dragon Community Trust	Novartis Pharmaceuticals
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Four Winds Foundation	Rehabilitation Welfare Trust
Grassroots Trust	Rob Webber & Associates
Harcourts Cooper & Co	Roche
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who give us their time, expertise and support.*

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If you would like further information on writing a Will or leaving a gift to Multiple Sclerosis Auckland, or for a confidential no-obligation chat about how your gift can make a difference, please contact Mark or Ingrid on (09) 845 5921, or by e-mail to mark@msakl.org.nz or Ingrid@msakl.org.nz.



For more information visit www.msakl.org.nz

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References: 1. TYSABRI (natalizumab) Approved Data Sheet, March 2018. 2. Biogen Data on File.



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TYS-NZ-0001. TAPS No: PP2433. Date of preparation: June 2018. BIOG0504/EMBC.

