



MS Street Appeal Volunteers 2019

inside



Celebrating our
volunteers

From NZ to
Moscow for
new life

Sam Smith, new
MS Ambassador

Ratatouille
Recipe

and much more...



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our people.

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Dr. J. Pereira

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Raewyn Henry
Sam Smith

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Neil Woodhams

Vice-Presidents

Jan Hollway
Donald Bowie

Treasurer

Peter Wood

Secretary

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Louise Reed
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Maureen Wood
Maxine Pitch
Peter Tutty

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Ingrid Minett

Business Manager

Mark Blackie

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Lucy Reade
Catherine Glover
Luminita Apostol

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Liz Callinan

Administration/Volunteer

Co-ordinator
Becky Tucker

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a few words from Ingrid.

Our General Manager

Stem Cell treatment for MS is an exciting and growing field. Stephen Hawking is quoted as saying:

Stem cell research is the key to developing cures for degenerative conditions like Parkinson's and motor neuron disease from which I and many others suffer.

We know it's also an effective treatment for MS, yet in NZ it's still not available. In this issue Celia Attwood writes about her experience travelling to Moscow for HSCT, and Brett Drummond from MStranlate helps us to understand what stem cell treatment is all about. Advancement over the past 5 years in the availability of treatment options for people with MS has been encouraging. Hopefully HSCT will be another option available in NZ in the very near future.

We celebrate our volunteers in this issue's cover and

centerfold. Becky usually interviews a volunteer to profile, but felt that with the vast number that came out for Street Appeal there were just too many amazing volunteers to choose from!

Our Community Advisor Andrea has a new baby girl! While Andrea takes a year off to enjoy motherhood, we are fortunate to have Lucy and Catherine step in to cover the West Auckland and Rodney areas.

I hope you enjoy this issue as much as I have enjoyed pulling it together for you. I'm guided by your feedback so please get in touch if there is anything you would like to see in the magazine, or if you would like to contribute a story.

Christmas is just around the corner. My best wishes to you all for a peaceful and joyful holiday season.

MS Auckland community consultation.

MS Auckland is looking at developing a stronger service for those who are newly diagnosed with MS, while continuing to maintain the services valued by those living with MS for many years.

There has been much progress lately with MS and change in general that we need to stay on top of, to remain relevant to all people living with MS. Some of the key changes over the years include:

- People being diagnosed with MS earlier
- A greater awareness and understanding of MS
- More therapies being made available to manage symptoms and delay progression
- More awareness and evidence of lifestyle changes in managing MS such as diet and exercise

Survey Results

251 people responded to our survey. Of those 215 had MS, 35 cared for someone with MS and 1 was 'other'. The youngest person was 21 years of age and the oldest was 90, with the highest number of people being born between 1951 and 1960. However 55% of the people were born after 1960. People were evenly spread throughout the Auckland Region with 5 people residing outside Auckland.

Of the 215 with MS:

17 were diagnosed in the last year; 41 were diagnosed 1 to 5 years ago; 29 were diagnosed 6-10 years ago and 128 were diagnosed 10+ years ago.

What do you value about belonging to MS Auckland?

Number one response across all respondents was - *I like keeping up to date with news, information and events.*

This was followed closely by:

I enjoy being with and learning from others with MS; and it makes me feel good to belong to an organisation supporting MS.

What do you see as the most important elements of a Newly Diagnosed service?

Across all people with MS the two most important elements were:

*Access to and/or understanding of the information about MS
Access to information about support available*

A full analysis of the results and all the comments is still taking place at the time of writing. These results will help us shape our services for the coming and future years.

events for your calendar.

Upcoming events



MS Auckland office will close on Friday the 20th of December at 5pm and reopen on Monday the 6th of January.

Our warmest wishes for the Christmas and Holiday season.

From the MS Auckland Team

Round the Bays - info afternoon

MS Auckland is teaming up with Vision PT in Ponsonby for the iconic Auckland Round the Bays event Sunday 8 March 2020. This 8.4 kilometer event can be run, walked or wheeled (wheelchairs and prams, but no bikes) and is for everyone. Why not join in the fun and set yourself a goal for 2020!

If you are keen, or think you might be a starter for this event please join us for the following information session:

Round the Bays Information and Planning Afternoon

Date: Saturday 30 November
Time: 2pm
Venue: Vision PT – 4 Newton Road, Ponsonby

Come meet Dean Williams and Olivia Giles and find out more about this event, including:

- Event logistics, such as time, date, cost, transport and lunch; and
- Event preparation, such as training recommendations, individual training programmes and group training options with Vision PT

We hope to have a big group walking, wheeling or running for MS. We will have a tent set up with food and friendship after the event, so bring your family and friends along and make a day of it.

Registrations of Interest:

Please register if you are attending the session on the 30th of November by e-mailing events@msakl.org.nz or calling Liz on 09 845 5921.

If you are unable to attend on the 30th, but still interested in participating please still register your interest with us and let us know that you will need to be sent further information.

Quiz and Lawn Bowling Social Event

Come join us for a fun afternoon and evening at the Royal Oak Lawn Bowls Club.

Date: Sunday 24 November
Time: 4pm if you would like to learn how to play lawn bowls and have a go
5pm for a social mix and mingle
6pm for the quiz and pizza

Total cost for the evening is just \$40, which includes the pizza (all dietary requirements will be catered for) a raffle ticket and a drink ticket. A cash bar will also be available.

Bring your family and friends and join in the fun!

To book your tickets please e-mail events@msakl.org.nz or call Liz on 09 845 5921.

Christmas Party 2020

We hope you will be able to join us this year for our Annual Christmas Party.

Date: Sunday 8th of December
Time: 12 noon to 3pm
Venue: Remuera Club
(27-33 Ohinerau Street, Remuera)

Cost: \$25/person which includes a buffet lunch with tea and coffee. A cash bar is also available.

This is a fun, family event with an opportunity to meet old friends and make new friends.

To book your tickets please e-mail info@msakl.org.nz or call the office on 09 845 5921.



MS Auckland office is located at
5 The Strand, Takapuna

Office Hours

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from the MS Community Advisors.

Home Fire Safety Programme

Written by Luminita Apostol, MS Community Advisor

Luminita has been referring people through to the Hopeworks and Fire & Emergency NZ PREP programme and has had overwhelming response. She took the opportunity to meet up with Kate from Hopeworks and learn more about the origins of this wonderful safety programme.



I met with Kate Johns on a capricious morning of spring. Kate is the Founder and Executive Officer of Hopeworks Foundation – an organization passionate about empowering those with brain injury and neurological condition through educated choices and information. Hopeworks and Fire & Emergency NZ have developed PREP (Proactive Review and Evacuation Procedures), a comprehensive home fire safety program looking at households with significant fire risk.

Today's house fires burn 8 times faster and produce 200 times the amount of smoke than 50 years ago. This means the time for real evacuation has reduced from 8 minutes to as little as to 2 minutes! For those with disability and illnesses, that time is crucial. The PREP programme is a unique and very special service to help prevent fires and help keep people living with disability safe in case of fire.

Kate explains and describes the PREP programme as follows:

"I developed PREP following many years caring for my Dad (Motor Neuron Disease) and my Mum (Parkinson's, stroke, dementia) and the realization that there was no existing fire check or evacuation process which met their needs. Between them, they had difficulties with mobilization, communication, cognitive function, behavioral function, isolation and sensory dysfunction – all factors that I deemed to be a catastrophic fire risk.

I worked with the local fire station to develop the basis of the PREP program and over the last 6 years have continued to develop the PREP plan, alongside those with immobility related disabilities and the fire service, as well as the best resources and information I could source from international fire stations and organizations.

The most basic level is IIEE (Identify, Isolate, Eliminate and Educate).

At every house, rather than just looking at the situation as it is today, we prepare for the latest stage of the diseases, and we look at every possibility that could either prevent the fire, or enable them to get out early and safely.

From the point of view of the fire crews, they are educated in what these conditions look like, what scenarios they may be presented with and can familiarize themselves with those in their communities who have disabilities.

The crews install 10-year smoke alarms, which do not need battery replacements, in all bedrooms and throughout all living areas to increase the warning times should they be activated. This extra time can make all the difference to a family, especially where mobility is impaired – allowing extra time to get from bed to wheelchair or to be carried to safety. The check also allows the fire crews to demonstrate and practice basic fire safety education, which for most kiwi families, they have not encountered since primary school."

Checks can take up to 90 minutes, depending on size of house and number of alarms needed. Feedback from MS families that have been involved has been fantastic, as seen by what Christine writes:

Thank you so much for putting Kate Johns onto us. She and her daughter came this afternoon with two gorgeous firemen, and we have all new power boards plus ten-year smoke alarms, so I will never have to struggle replacing batteries again. We have 7 smoke detectors. They even got down and dealt with all the cords behind furniture, it was wonderful. What a service! Thank you."

Your Community Advisors



Lucy
West Auckland
Contact 021 959 189



Luminita
North Shore and
Central Auckland
Contact 021 959 187



Priyanka
South and East Auckland
Contact 021 845 903



Catherine
Rodney
Contact 09 845 5921

PREP checks are free and organized at times that suits the family. All the fire alarms and other fire prevention equipment can be supplied during the check. Families that include members with brain injuries or neurological conditions currently qualify for these to be fully funded.

While the service was set up for people with brain injury or neurological conditions, anyone who is at high risk is

able to access it. This includes the elderly or people with other special needs. For more information please visit their website www.hopeworks.org.nz.

For a referral to the service please talk to your Community Advisor or send your referral directly through to Kate at: kate@hopeworks.org.nz

welcome to Lucy & Catherine!

The newest members of our team



I'm Lucy Reade and I'll be your Community Advisor in West Auckland for a year while Andrea takes time off with her baby.

I'm from Scotland originally but after more than 20 years here I think of myself as Kiwi although my accent is apparently still a giveaway. I trained as an Occupational Therapist back in Glasgow and have come and gone from the profession over the years but always stayed registered as an OT and in roles with a whole-person approach to health and well-being. For me this means using my skills, knowledge and training not just to work with the physical or just the emotional but instead the whole person.

I turned 50 this year and with my 3 kids now teenagers I decided to indulge myself and do some of my favourite things. I bought an old converted truck and wandered around the country for 6 months at my own pace. What an amazingly beautiful, easy and relaxing country with live in! I'm happy to be home now with my family and in this awesome city but hope for more Gypsy adventures in the future.

I've always lived out West and am delighted that I'll be covering this area. I am really enjoying meeting the community and joining in with member's support groups. Getting people together, learning from each other through open and honest conversation and drinking good coffee are more of my favourite things.

I'm looking forward to meeting you all and being of service.

Warm wishes, Lucy



It is with pleasure that I return as a Community Advisor for the Rodney district while Andrea is on Maternity leave. I worked in the central area previously and met many wonderful people who face the many challenges of MS with such amazing strength and courage. I am pleased to be able to continue supporting the MS Community and look forward to meeting the people of Rodney.

Best wishes, Catherine



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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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from the MS nurses.

Measles outbreak

With the current measles outbreak the topic of vaccination in MS is very topical and for many of us potentially frightening. Most vaccinations are inactive and safe to take if you have MS. Any vaccine that is live-attenuated should be avoided if you have MS and are taking an MS disease modifying drug (DMD) or another medication that is suppressing your immune system.

The MMR is a live-attenuated vaccine which means it contains the measles virus at a low level. MS DMD's modulate the immune system to reduce MS relapses; this creates a vulnerability to contracting measles from the vaccination, which is why if you are on a DMD we ask you NOT to have it.

We would encourage you to see your GP and request a blood form for measles serology (IgG) to check this. It does incur a cost of \$48 however there is a certain piece of mind this can buy you should you find out you are positive and have some natural immunity to the measles virus. Should you find you do not have immunity you are then empowered to take steps to protect yourself to exposure, we suggest you urge your friends and family to be vaccinated so there is a reduced chance of their contracting measles and putting you at risk. Further information can be found on the Ministry of Health website <https://www.health.govt.nz>

Another commonly administered live-attenuated vaccination is for yellow fever. This is often recommended should you be planning a trip to certain parts of South America. Again it's not possible to have this if you are taking a DMD.



Fiona d'Young and Nazila Samadi

There is no high quality evidence that live vaccines pose a risk of triggering an MS relapse but we would advise if you have MS but are not taking a DMD to first talk to your MS team before having the vaccination. If you have had a recent relapse and been treated with high dose steroid treatment you should wait for 6 weeks before having a live vaccination.

Finally the good news is the annual flu vaccine is inactivated AND recommended for everyone. Having MS is no barrier to receiving this each year, in fact we would encourage you to have it.

Please do not hesitate to contact your GP with further queries on this – it's a complicated area so feeling confident about this is important.

*Fiona d'Young and Nazila Samadi
Multiple Sclerosis Nurse Specialists
Auckland City Hospital*

*Email – msnurse@adhb.govt.nz
Phone – 09307 4949 ext. 25885#*

Our office will close on the 24th of December and reopen on the 30th of December

For the month of January we will be operating a reduced service for 20hrs per week – the details of this will be reflected on our out of office email and phone message.

It can be extremely worrying to experience new symptoms and have limited access to professional advice and support. If you notice new symptoms that are lasting more than 24-48 hours that are changing your ability to go about daily life it may be that you are having a relapse. If this is the case over the Christmas break please seek advice from your local emergency service, white cross or GP, if they are open. The on-call neurologist based at Auckland hospital will be working through the holiday period and be available for urgent queries so remind your local team that they are able to make contact.



Your MS Auckland President - Neil Woodhams.

Written by Louise Reed



One person who has made a huge impact on MS in Auckland and New Zealand is the current president of MS Auckland and vice president of MS NZ, Neil Woodhams.

Neil's skills as a chartered accountant were applied to the health sector from 1993 after a successful career in the finance sector. His connection with the MS community began in 1994 when his wife Erin was diagnosed. Essentially there were no treatment options for MS at that time and Erin was told to go and "have a good life".

At that time Neil was working in Hamilton for the Midland Regional Health Authority as General Manager of Hospital and Specialist services. During this time there were significant waiting lists for elective surgery and Neil was instrumental in securing additional funding of \$25 million to reduce the waiting lists. In 1997, Neil moved to a senior position with Auckland Healthcare which later became the Auckland District Health Board (ADHB). He progressed to be Chief Operating Officer in 2000 and in 2002 was for a short time the General Manager for Starship and National Women's Hospitals.

After leaving the DHB in 2002 Neil consulted to a group of three Maori organisations who set up the first Primary Health Organisation [PHO] under the labour government's new primary healthcare strategy. Neil had grown up in Hamilton and his father had a close involvement with Princess Te Puia. Neil considers that it was his exposure to Maori tikanga during this childhood that helped him establish strong relationships with Maori working in the Health sector which continue to this day.

In 2002 Neil joined the MS Auckland committee and was elected Vice president in 2003 and then President in 2007. In 2003 Neil represented MS Auckland on the Board of MS New Zealand and in 2005 became its Vice President.

Neil noted that there was work to be done on the lack of disease modifying drugs (DMDs) available

to people with MS, and began talking to doctors, neurologists and others within the health community to find out what could be done. Neil comments that the availability of DMDs for people with MS in New Zealand began with a Labour Party election promise in 1999. They kept to their promise when elected and the first DMDs became available for people with MS – Beta Interferon (Avonex and Rebif) and later Glatirimer Acetate (Copaxone) in 2000. However, the stringent entry and exit requirements set out by Pharmac to access these drugs meant that access was denied to many who would have benefited from them. This resulted in intense lobbying by MSNZ with government and Pharmac over a number of years.

In 2013 Neil assisted with the submissions to Pharmac to widen the entry and exit criteria for patients on MS treatments. A detailed submission was then made to Pharmac in 2014 advocating for the relaxing of the arbitrary criteria for DMD use for patients with MS in New Zealand. Whilst the number of DMD available for people with MS has widened, the criteria for patients to access the treatments remains "cruelly" restrictive. Advocacy work in this area continues.

In 2004, Neil prepared a paper on the establishment of a MS research trust. This paper would later become the blueprint for the New Zealand Multiple Sclerosis Research Trust which Neil played an important part in establishing finally in 2015. A primary aim of the research trust is to help ensure clinical staff interested in specialising in treating MS are attracted and retained to work in NZ.

At the heart of Neil's involvement with MS has been Erin. Despite the progress made with MS treatment in New Zealand, Erin's MS has progressed and Neil is now Erin's full-time carer. Neil says "I am committed to Erin and therefore I am committed to helping others with MS. MS is such an encompassing illness that has such an impact on family."

There is no doubt that Neil's skills and advocacy work have made a huge contribution to the lives of people with MS in New Zealand. Thank you, Neil, for the work you have done, and continue to do to the MS community.

Sam Smith - new ambassador for MS Auckland.

Many of you will know Sam Smith as the comedian who for the past three years for MS Awareness Week has organised a comedy night at The Classic Comedy Club – a sell-out success every year! We are absolutely thrilled when Sam accepted the volunteer role of MS Ambassador, joining Raewyn Henry and long term ambassadors John and Lorraine Street. I asked Sam to write a bit about himself and how he sees this new role.

It is a great pleasure to be asked to be an ambassador for MS Auckland. MS literally makes up 67% of the name SAM, so I figure that's why I was asked.

MS has been a big part of my life. My granddad had it, so I knew about it from a young age. MS Societies were so helpful to him throughout his life, and I'm looking forward to meeting more amazing people with it. I've seen first-hand the difference in care that is available between him and myself, and once you see that, it is incredibly easy to be optimistic about it.

I was diagnosed in 2015, just a few weeks after I became a Dad. It led to me having to give up my career as a dentist as I lost feeling and control of my hands. This has since come back, but in that time I've found a new career as a writer and comedian. My main symptom that I deal with is I've lost half my eyesight. I have a blind spot in the centre of each eye, and my left eye is almost completely grey. It means I can't drive but apart

laughter is the best medicine 2019.

Sam Smith's 3rd Annual Comedy night was held on the 17th of September. Sam, and all his comedian friends donated their time and talent to raise awareness and funds for MS Auckland.

The comedians this year were Ray O'Leary and Cori Gonzalez-Maceur (Pictured) as well as Jeremy Elwood, Pax Assadi and Michele A'Court.

The event was sponsored once again by Harcourts Cooper & Co and our new partner, Allied Medical.

Written by Sam Smith

from that, I can still function pretty normally.

The MS Club is not a club you choose to be a part of, but if you have to be here we're all going to make you feel very welcome. My aim is to help people newly diagnosed with MS to come to terms with it and help them adjust and achieve their goals. I'll be here to answer questions but more importantly, remind people that this condition can change your life – for the better. I know it doesn't seem like that at times, but it really can be true.

I'm going to try and bring my connection with something I really enjoy – comedy – to people with MS. I've found it a great way to deal with trying times and I hope it can do the same for others. I just keep thinking, the more awareness we can raise about this condition, the more likely we are to find some clever science person who figures out a way to cure it once and for all.

I look forward to meeting and working with you all.

Sam



Rachel and Cameron - use it or lose it.

Written by Lucy Reade

I met up with Cameron and Rachel Ford on their visit to Neuro Connection to make use of the MOTOmed. They have a regular booking and taking a spin on the MOTOmed has become part of their weekly exercise routine. On Wednesdays they have a one on one session with their physical therapist in the gym and often finish with another spin on the MOTOmed. Robin from Neuro Connection meets them and supports them to access the machine. She has gotten to know them and their needs well.

About Rachel and Cameron

Rachel and Cameron are married. They met through a friend, who figured that having MS in common would give them plenty to talk about. They struck up a great friendship and the rest is history. Cameron was a bit of an athlete back then and into adventurous activities such as surf kayaking, climbing and bush running. Rachel, on the other hand is keen to stress that she was quite the opposite – a real bookworm.

It was the strong evidence of the benefits of regular exercise for managing MS and maintaining mobility that dragged her nose out of her books and to the swimming pool and yoga classes. Both she and Cameron also became members at West Wave gym and worked out together regularly.

Cameron and Rachel first heard of and used the MOTOmed when it was in the West Wave gym facility in Henderson. They used it when they could, as they were aware of its benefits for those with MS and its ability to be used even with limited mobility. They remember it being out of order a lot of the time however, and then it just disappeared.

Using the public equipment at West Wave gym independently and safely became less tenable for this couple as their mobility changed. Determined to keep moving, and to make the most of the mobility and strength they have Cameron and Rachel were still eager to enjoy the many health benefits of getting out and about to exercise. When they read here that the MOTOmed had been repaired and was now available to MS Auckland members to use at no cost at Neuro Connection, just a stones throw from West Wave, they made an appointment and went to check it out.

They are now among many people with MS who are regular users of the MOTOmed and have since cancelled their membership at West Wave. Seeing how relevant Neuro Connection was for their needs as people with



Motomed Rachel and Cameron

MS, they now use dollars saved from their West Wave memberships to fund an additional customised weekly session at Neuro Connection. They say that their session at Neuro Connection is a top priority for them as a couple and strongly believe that with MS it can be 'Use it or lose it' when it comes to mobility. They reckon Neuro Connection is a great place for anyone with a neurological condition to have their exercise needs met.

The MOTOmed

The MOTOmed's design offers movement to those who can't otherwise safely move or exercise. It was specifically developed to support physical therapy for people with limited mobility, and users can train sitting in a chair, wheelchair, or even from a bed.

In February this year the MOTOmed Movement Therapy Unit was moved to Neuro Connection in Henderson. It is free for people with MS to use, however it is important to book in to avoid overlapping or clashing with others.

To book call 09 836 6830 or e-mail admin@neuroconnection.org.nz.

friendship, understanding & support.

Debbie and Anu were introduced to each other by their Neurologist, Jennifer Pereira. Debbie was not responding well to any of the MS treatment medications and was considering Ocrevus. Anu, whose MS also wasn't doing well on other treatments, had been fortunate enough to be given Ocrevus through a compassionate review in the USA. While it still meant costs for flights to America the bonus was being able to see her Grandmother and other family, and of course receiving the treatment which she is responding positively to.

They met up to talk about Ocrevus but then found that they clicked on so many other levels. They both commented on how nice it is to catch up with someone 'who just gets it'. "We understand what each other is going through, but we also share experiences beyond our MS" says Debbie.

They meet up fairly regularly now and share a wonderful bond of friendship. They both follow the OMS diet. Debbie went on the Jelinek retreat in Melbourne in 2013

and highly recommends it. However a family holiday had Debbie slip off the diet, to her regret, as she felt the impact on her health almost immediately.



Anu is new to the OMS diet. She also loves her Barre classes which she feels are so important. While others might see her doing these things because she has MS, Anu is quick to comment "I'm doing it for me to get better. My MS is part of me".

Anu was diagnosed with MS in December 2015, just before her 18th birthday. She is currently studying with the goal of a future in neuroscience. Debbie is 51 and was diagnosed in February 2013 at 45 years of age. She has a daughter the same age as Anu and a younger daughter at intermediate school. The two have become the best of mates. (Anu is also featured on our front cover helping to raise awareness and funds for MS).

peer connection.

We know many people with MS that have made valuable connections like Debbie and Anu's. They've been able to share wisdom, knowledge and experience that could only have been gained from living with MS.

We are looking at formalising that a bit next year by offering Peer Connection opportunities in addition to our Community Advisor service, in particular to those newly diagnosed.

We will be interested to hear from members who would be happy to share from their own journeys with MS with the express purpose of supporting others. If you have been living with MS for more than 2 years, have a positive attitude and would consider yourself an ambassador for those with MS you might be interested in being a part of this programme.

More information on the Peer Connection programme will be coming out over the coming months. If you would like to keep in touch and learn more please e-mail Ingrid@msakl.org.nz.

Sam & Rachelle - grant recipients.

Congratulations to Sam Smith and Rachelle Becker who both were recently awarded a Mastering Mountains Expedition Grant.

Both Sam and Rachelle have chosen an outdoor adventure that will challenge them - Sam will be doing a walk in Bavaria and Rachelle will be biking in Laos.

Both Sam and Rachelle will be mentored by the Mastering Mountains Trust to become community leaders that share their knowledge, help others problem solve and create dynamic community.

We look forward to following them on their adventures next year!



street appeal 2019!

Written by Becky Tucker



Kowhai Intermediate boys helping out

Our annual Street Appeal was held this September, now hands up, I am guilty of exaggerating the truth sometimes, but not this time, when I say MS Auckland was humbled by the many, many volunteers that came out in force to help us with this vitally important week.

There were some 374 hours spent shaking buckets, 100's of balloons blown up, 100's of stickers given, and 1000's of words spoken spreading awareness of MS, along with much laughter teaching the pronunciation of Sclerosis!

A buzz could be felt at our collection sites, they were a hive of activity – It put my fears to rest about the art of conversation being lost in this era of high technology, as many people across different generations were happy to chat with us. Some people were keen to share their own stories and connections they have of MS and some had no connections and just wanted to learn more, but what remained constant was the generosity and kindness of people, allowing our appeal to be so worthy and enjoyable for all those involved.

Street Appeal takes a huge amount of organization, energy and commitment along with numerous faithful volunteers and thanks to Liz and her team, this year was a great success not only in raising funds but equally important in raising awareness. Time is so valuable and with so many volunteers giving their time during Street Appeal, I was curious to learn their reasons why, I would like to share just a few of the many with you;

'Last year I went through the various testing as my GP thought I may have MS. During that process I did a lot of MS research and made a promise to myself that if I did not have MS I would volunteer and support the MS community if I could. I don't have it and I'm more than happy to support the community in this way.' Jenny



St John's Rotary Robyn and Gonza

'My mother had MS, so I like to volunteer every year and send a selfie to my brothers back in the UK to encourage them to remember Mum and do their bit too. I live literally a street away from the collection site and love chatting with the familiar faces while collecting. People are so kind and generous. It restores my faith in humanity.' Nick

'My husband and I were blown away beyond overwhelmed at how generous people were. It wasn't hard to raise the money. Most people were very kind & we also had some people who were quite interested to know more about MS as well. Our children helped collect as well. It made them more aware of what I was suffering with.' Geraldine

'Ultimately I was very happy to be supporting the organisation and had a fun time with my friend! I will definitely be recommending it in the future to my friends. I hope to be able to volunteer next year and wish all the best with the rest of your fundraising and support efforts for Multiple Sclerosis.' Joseph

'I collect for the MS Street Appeal because the MS Society is so useful. I love what they do to support people living with MS. The Community Advisors are awesome.' Karen

I would like to take this opportunity to thank all of our volunteers that were able to help out for Street Appeal and those that have helped out all year round with our events and programmes, thank you; we couldn't do it without you!



Luminita, Matthew and Becky



Amit and family collecting at Manukau



Collecting at New World Kumeu

ms
MULTIPLE SCLEROSIS
AUCKLAND

Help for today.
Hope for tomorrow.

FACTS ABOUT STREET APPEAL 2019

**\$ 23,940 TOTAL
AMOUNT RAISED**

**116 VOLUNTEER
COLLECTORS**

**8 SCHOOLS AND
CLUBS INVOLVED**

**374 VOLUNTEER
HOURS**

**13 COLLECTION
SITES**

Thank you so much for your support
- join us again next year!

Contact us at streetappeal@msaki.org.nz

no cash? no problem.

Written by Liz Callinan

Street Appeal successfully adopts technology to combat a cashless society.

Times are changing. The New Zealand 1, 2, and 5 cent pieces are gone, you can use your Smartphone to pay at the till, and some shops and events now don't accept cash at all.

So with Street Appeal this year we knew we would hear "sorry I don't have any cash on me" from members of the public. This doesn't necessarily mean people don't want to donate; they just don't have the means...until now.

Launched on the 1st of September for one month our Text-To-Give campaign gave donors the option to donate an automatic \$3 to MS Auckland via text. This was simple, effective and really well received. We are thrilled to announce that we raised \$4,623.00 from the month long text campaign.

We will certainly look at utilising a text donation option next year but wonder, with the pace of change in technology, what other options might be available to us. Tap-n-Go consoles are already in the marketplace but currently are out of the price range for many charities. Perhaps there will be new technologies available or cash might even make a comeback – we will certainly be keeping watch, probably via a Smartphone!

From NZ to Moscow for new life.

Written by Celia Attwood

I had just turned 28 in May 2017, my son Milan was 2 and a half and we decided it was the right time to start trying to extend our family. A few months later I noticed tingling in my hands and feet, I hoped it would go away but after a few weeks it was still very much there. I went to my GP who thought it could be peripheral neuropathy and advised me to come back in a few weeks if it hadn't gone away.

It didn't go away so she referred me to a neurologist. I had a month wait to see the neurologist and during that time the tingling stopped but I got a new symptom – 'Lhermitte's sign' which is like an electric shock going through your body when you bend your neck. Google told me it was most likely MS or a brain tumor which of course completely freaked me out!

The neurologist referred me to have an MRI which was another month wait. I found out I was pregnant a few weeks before my MRI so I had to cancel the appointment. Unfortunately I miscarried at 9 weeks and as heart-breaking as it was I am a firm believer that everything happens for a reason and it was not the right time for us. So another month wait to get my MRI and then another month wait to get my results from the neurologist. In January 2018 it was confirmed I had Relapsing Remitting MS (RRMS).

Looking back I had most likely had MS for about 5 years undiagnosed. My first symptom would have been shaky vision that lasted a week. Then headaches, aching muscles, fatigue, brain fog and just never feeling 100%, but I always just thought that was 'normal' for me.

I didn't know anything about MS, had never met anyone with it and I really thought I could go on medication and everything would be okay. My neuro advised me I most likely didn't qualify for DMTs and he would see me again if or when I got worse. He told me not to google MS but of course I did. I felt like my life was over and I don't think I stopped crying for 2 weeks. I could feel myself getting worse. My partner was so amazing and supportive and after 2 weeks of crying he kindly told me it was time to stop crying and start thinking about the future. It was the push I needed.

A few days before my diagnosis I had read an article in a magazine about a girl with MS that had gone overseas

to have a hematopoietic stem cell transplant (HSCT). I didn't think much of it at the time but I suddenly remembered it and starting researching about it and never looked back. It's the only thing that gave me any hope for my future and I believe it was meant to be! I am so blessed with the most amazing parents who said they would support me with whatever treatment I decided to do. Without them it wouldn't have been possible to go as the cost is high.

I found the worldwide group on Facebook (HSCT Hematopoietic stem cell transplant – MS & auto immune Diseases). This is an amazing resource to find out about reputable clinics where you can have HSCT done, including costs, criteria, side effects, links to research papers and trial results. It is also a place to connect with others who have done it and hear about their experiences.

I had a good feeling about Dr Fedorenko in Moscow, Russia. I got in touch with them and only a month after my official diagnosis I had a date to be in Moscow for November 26th 2018. It wasn't an easy decision. There is a lot to consider, especially as one of the main side effects can be infertility and I would still love to add to our little family one day if I can. I went through a round of IVF to freeze embryos just in case. I did end up being approved for tysabri before I left but by then I had my sight firmly set on HSCT.

My parents travelled to Moscow with me. Leaving my partner and son at home was one of the hardest things I've done. By the time I got to Moscow I was relapsing and had 3 active lesions. Dr Fedorenko said that if he didn't see my walk into his office judging by my MRI he would have thought I was in a wheelchair. I am so thankful I got there when I did.

HSCT and recovery is not a walk in the park, but no road with MS is. I went into treatment expecting the worst and hoping for the best. I have made so many lifelong friends and Russia will always have a special place in my heart. Dr Fedorenko says modern medicine can only do so much and is a firm believer that having a positive attitude is a must for successful treatment and for people with MS in general. I try to live by his mantra – good food, good mood and an active lifestyle for recovery and the future.



Celia with her son Milan the day before leaving for Russia



Celia in hospital



Celia getting her new life pin from Dr Fedorenko

The first 3 months of recovery were hard but since then I'm feeling the best I have in years. I still have bad days but the good are definitely outweighing the bad. I have so much more energy and a new outlook on life. My MRI at 3 months post showed no progression and some lesions had even decreased in size. The aim of HSCT is to halt progression and any symptomatic improvement is a bonus! I will be celebrating my 1 year stem cell birthday December 12th and I'm so excited to see what next year will bring as some people are seeing improvements years following HSCT.

I really do hope that HSCT becomes an option for people with MS in New Zealand because everyone deserves the opportunity to have this life changing treatment. I am more than happy to chat with anyone considering going overseas for HSCT who would like to know more about my experience. Also if you would like more info on HSCT in Moscow visit <https://www.hsct-russia.com/>

hydrotherapy.

It is not too late to join in on Hydrotherapy classes before the year is out. People with MS are eligible to have two free sessions to 'try before you buy'.

Classes will end for the year in December and will re-open end of January or early February 2020. Check the website www.msakl.org.nz for closing and opening dates and to find out more about how to join.



The sessions at the Millennium Pool unfortunately had to be cancelled for Term 4. However we will be starting up a Friday class at West Wave in February and also hope to have a new class starting then at Millennium.

For more information please contact your Community Advisor or Liz at the MS Auckland office on info@msakl.org.nz or 09 845 5921.

2019 Weekly Sessions

Tuesday	Wednesday	Thursday	Saturday
Lloyd Elsmore Pool Sir Lloyd Drive Pakuranga	Manurewa Leisure Sykes Road Manurewa	Epsom Girls Silver Road Epsom	Diocesan Girls Clyde Street Epsom
11:00am - 12:00 noon	11:00am - 12:00 noon	10:30am - 11:30am	10:00am - 11:00am
Contact Priyanka Kumar 09 845 5921 Ext 220 priyanka@msakl.org.nz	Contact Priyanka Kumar 09 845 5921 Ext 220 priyanka@msakl.org.nz	Contact Luminita Apostol 09 845 5921 Ext 222 luminita@msakl.org.nz	Contact Luminita Apostol 09 845 5921 Ext 222 luminita@msakl.org.nz



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.**

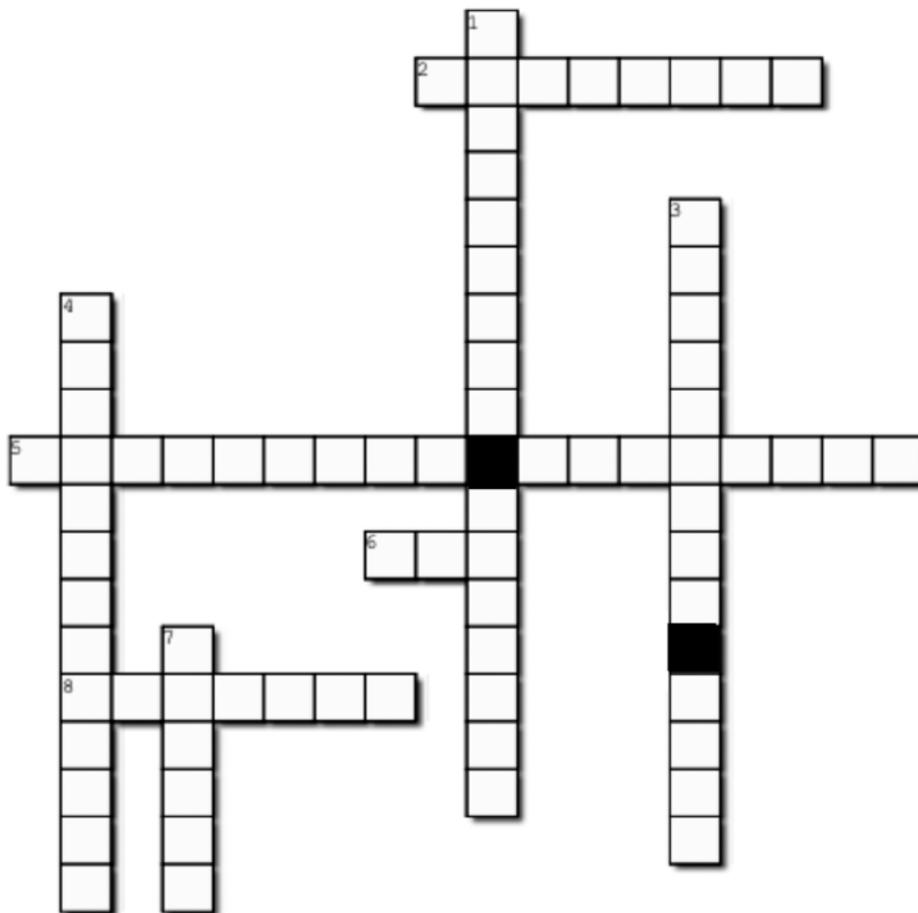
🔍 **'Multiple Sclerosis NZ'**

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 not take Gilenya if you have certain heart conditions or if you are taking some medicines that affect heart rate – check with your doctor. You should not be pregnant before you start and 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. Tell your doctor straight away, if you believe your MS is getting worse after you have stopped treatment with Gilenya, because it could be serious. 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, 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-00624 September 2019 2019 TAPS MR6438 essence NV9338A MS

it's all relative...again!

Solve the crossword puzzle below using the clues.



Across

2. An event that takes place in various locations around Auckland, hosted by MS Auckland on various topics.
5. A drug in various forms with natural properties, prescribed currently for Parkinson's and spasticity for people with MS. (2 words)
6. The dominant chemical component that is derived from the Cannabis plant commonly known as _____.
8. A New Zealand government agency that decides which medical equipment and medicines are funded in New Zealand.

Down

1. The new formal name for staff at MS Auckland that work closely with people with MS providing services and support.
3. A time for organizations to promote themselves and the work that they do among their communities, usually by engaging their community to volunteer for events the charity has organized. (2 words)
4. A weekend long event that was held in September in multiple sites across Auckland, involving volunteers and staff who took out their time to raise funds for MS Auckland.
7. A way of consuming Medicinal Cannabis safely through inhaling aerosols created by a device.

*Answers to Crossword
found on page 26.*

medical cannabis, the change is nearly here!

The government passed a bill late last year with the hopes of broadening access to Medical Cannabis in New Zealand, and allow local companies to manufacture products.

The short term fix in the bill, and quite relevant to MS is the 'Palliation Clause'. This means that with a certification from a GP or a Nurse Practitioner, anyone with an 'advanced, progressive, life-limiting condition and nearing the end of life' is protected from the law for the possession of Cannabis and its utensils. This is essentially a get out of jail free card for end-stage Neurological conditions, and if your GP is generous, could grant years of legal protection.

The political process to this point has been long-winded, yet the finish is near. For a bit of background, prior to coming to power, Labour promised to 'legalize Medical Cannabis within 100 days'. The language was then toned down to 'introduce legislation' within 100 days. Labour managed this within time for that deadline; however the caveat was that the government had no clear vision of what it wanted to do. Because of this, the legislation had very little detail, and essentially it authorized the Ministry of Health to set up a workable scheme and create an agency to administer it.

The Ministry has been working on setting up the scheme for most of 2019 and has had a very quick and quiet public consultation phase. Thanks to pressure from the Greens, there is a deadline looming mid-December for the scheme to be completed, however implementing them will take more time still.

What can we look forward to in the regulations?

Currently, GPs can prescribe a non-psychoactive extract of Cannabis - Cannabidiol or CBD for short - and Sativex for MS. Specialists are required to apply to the Ministry for every patient using a THC product other than Sativex, or Sativex for any condition other than MS, which burdens specialists with paperwork. This requirement is not the case for any other drug in NZ, up to and including medicinal cocaine! Yes that's right, currently medicinal cocaine is easier to prescribe!

The proposed regulations removed the Ministry of Health approval system but required specialists to prescribe. This would disadvantage people living in



regions with no resident specialists, an example being the lack of a Neurologist in Taranaki. Fortunately, both the GPs college, patient groups, and the fledgling medical cannabis Industry all protested this provision, and it seems highly likely that GPs, and indeed even Nurse Practitioners will be granted relatively free prescribing rights.

The second point of significance in the consultation document was setting quality standards. These have a direct impact on the capital costs to set up production, the timeframe to set up production, secondary impacts on product costs, and trust from stakeholders in the system, and finally export potential. Because of our small size as a country, (and too many companies attempting to setup) much of the industry prefer the more complex 'pharmaceutical grade' production standards that would support potential exports. This standard is also preferred by the Ministry Officials and prescribers, who feel if Cannabis is truly a medicine, it should be held to the same standards.

In short, we can expect the following;

- Prescribing will be much easier next year
- Products will likely be made to the same standards as other medicines
- Products won't be much cheaper for a few years yet
- Exports and adult-use markets could help drive prices down.

Shane Le Brun is the Coordinator for MCANZ - a Registered charity, run by a group of passionate, rational like-minded people with a personal stake in the need for Medical Cannabis in New Zealand. For more information go to <https://mcanz.org.nz/>.

recipe.

Ratatouille

Ratatouille is a traditional French Provençal stewed vegetable dish, originating in Nice. It was originally a meal made by poor farmers, and was prepared in the summer with fresh summer vegetables.

The original and simplest form of Ratatouille used only courgettes, tomatoes, green and red peppers, onions, and garlic. The recipe below includes eggplant, which has become one of my favourite summer vegetables. I generally omit the honey and, when basil is plentiful, am very generous with the basil.

Ratatouille can be served as a side dish alongside fish or other food. I choose to have it as the main meal overtop of brown rice.

Ingredients:

Serves 4-6

- 1 Red Onion, chopped
- 1 Red Capsicum, de seeded
- 1 Yellow Capsicum, de seeded
- 1 medium eggplant
- 3 courgettes
- 3 tbsp Olive oil
- 3 cloves garlic
- 2 cans tomatoes, chopped
- 1 tsp Tomato paste
- 1 tsp Honey
- ½ tsp salt and pepper
- 1 cup fresh basil leaves
- 1 tbsp olive oil



Directions:

1. Chop onions, capsicums, eggplant and courgette into equal, bite sized pieces.
2. In a large saucepan, heat the olive oil over a medium to high heat. Cook the onion and garlic until lightly golden in colour.
3. Add the eggplant and cook for a few more minutes. Next add the capsicums and cook for a further 5 minutes. Finally add the tomatoes, tomato paste and honey.
4. Cover the pan and simmer on a low to medium heat for 25 minutes. At this point stir in the courgettes. If the sauce is too thick add a dash of water. Cover the pan again and simmer on a low heat for another 20 minutes.
5. Lastly, mix through the fresh basil leaves and (if you want, but not necessary) a good splash of extra virgin olive oil. Season well with salt and pepper and enjoy!

Do you have a favourite Jelinek friendly, or plant based recipe you would like to share for the next magazine? Please send it to Ingrid@msakl.org.nz. If you can, please also include why it's your favourite and a photo.

FULLY FUNDED

from 1 December 2019 for people with RMS who meet pre-defined criteria



Get on with life,
we'll see you
in 6 months.

OCREVUS only needs to be given every six months after the first dose.¹ If you're one of the 4000 New Zealanders affected by MS, ask your doctor if OCREVUS is right for you.

OCREVUS[®]
ocrelizumab



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 a PHARMAC funded medicine from 1st December 2019 for patients with relapsing multiple sclerosis (RMS) who meet pre-defined criteria. Patients outside these criteria and with primary progressive multiple sclerosis (PPMS) 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.

Consumer Panel based on CMI dated 28 February 2018. Roche Products (New Zealand) Limited, Auckland. Phone: 0800 656 464. www.roche.co.nz. All trademarks mentioned herein are protected by law. PM-NZ-0400/NA10550/OCT2019

support groups.

There are MS Support Groups operating in venues all across Auckland every week. These groups are open to anyone with MS, their partner, parent, friend, carer, sibling, or child. There are many benefits to coming along to support groups. People tend to feel less isolated when they meet others and are able to talk openly and honestly about their feelings. They get practical advice from others who have gone through things that they are experiencing, and they can compare notes about resources, doctors, or alternative options.

You may want to go to one or two support groups to find one that is most compatible for you. Talk to your Community Advisor (listed in the contact details below) if you are unsure which one to go to or if you are going to one for the first time. They will make sure that you are met and welcomed to the group.

If you are interested in starting up a Support Group in your area, or would like to look at a different type of Support Group than what we currently have on offer (perhaps an evening group, Mum and tots group, etc) your Community Advisor would love to hear from you and work with you to help make that happen.

Location	Contact	Date/ Time
South / East Auckland		
Beachlands Support Group Pepper Jacks Café	Priyanka Kumar 021 845 903	Fridays 11.30am
Pukekohe Café Group Different Venues	Priyanka Kumar 021 845 903	First Thursday / Month 11.30am
Botany Café Group Robert Harris Café (Botany Town Centre)	Priyanka Kumar 021 845 903	Third Thursday / Month 11.30am
Manukau Café Group Friendship House (Manukau)	Priyanka Kumar 021 845 903	Last Tuesday / Month 10.30am
Men's Group Robert Harris Café (Botany Town Centre)	Priyanka Kumar 021 845 903	Last Saturday of each Month 10.00am
Central		
Mt Wellington Café Group Coffee Club on Lunn Avenue	Luminita Apostol 021 959 187	Second Saturday / Month 11.00am
Stonefields Café Group Stonebake Café (Lunn Avenue, Mt Wellington)	Luminita Apostol 021 959 187	Third Wednesday / Month 10.30am
Onehunga Group Urban Verge Café (653 Manukau Rd, Royal Oak)	Luminita Apostol 021 959 187	Third Tuesday / Month 10.30am
West Auckland & Rodney		
Kumeu Café Group Different Venues	Lucy Reade 021 959 189	First Tuesday / Month 10.30am
Henderson Garden Café Group Columbus Coffee Café (inside Mitre 10 Mega, 186 Lincoln Rd)	Lucy Reade 021 959 189	First Thursday / Month 11.00am
New Lynn Café Group Columbus Coffee Café (inside Mitre 10 Mega, New Lynn)	Lucy Reade 021 959 189	Second Tuesday / Month 10.30am
North Café Groupies Kings Plant Barn (Silverdale)	Catherine Glover 09 845 5921	Third Wednesday / Month 10.30am
North Auckland		
Mayfield Coffee Morning Kings Plant Barn (1 Forrest Hill Road, Milford)	Luminita Apostol 021 959 187	First Thursday / Month 10.30am
Shore Lunch Group Palmer's Planet Café (cnr Hugh Green Drive/Greville Rd, Albany)	Luminita Apostol 021 959 187	Last Wednesday / Bimonthly 12.00 noon
North Shore Café Group Columbus Café Smales Farm (74 Taharoto Rd, Takapuna)	Luminita Apostol 021 959 187	First Saturday / Month 12.30pm

stem cells and multiple sclerosis.

Written by Brett Drummond, Researcher, Science Communicator and Co-Founder of MStranlate

You have probably heard of the term stem cells and possibly even the acronym HSCT. Indeed, this has been one of the most interesting and talked about areas of multiple sclerosis research for the past few years. However, it is also a topic that has been the subject of much confusion and poor reporting (particularly online). In the most extreme circumstances, this misinformation has allowed for predatory medical clinics to use the promise of a 'cure' to accept large amounts of money, only to actually give unproven treatments or in some circumstances, no treatment at all. In this article, we will be explaining the basics of stem cells and stem cell treatments for multiple sclerosis, as well as providing updates on the latest trial results, as heard atECTRIMS 2019.



What are stem cells?

Stem cells are cells in the body that have the ability to divide continuously and turn into (through a process known as differentiation) a variety of different cell types. This may sound complicated, but we can picture it in a more simple way. Essentially, stem cells can be thought of as cells that are like teenagers in high school...they haven't quite worked out what they want to be when they grow up yet.

What is HSCT?

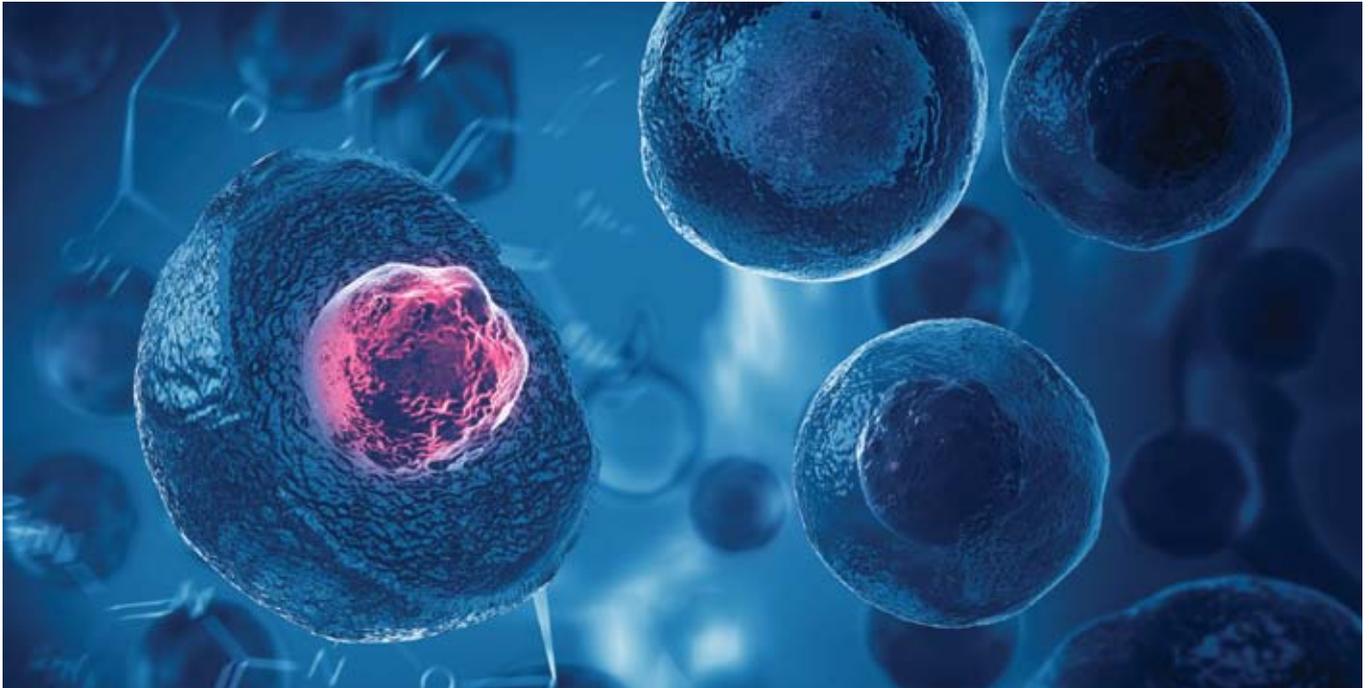
Haematopoietic stem cell transplantation or HSCT is a relatively new treatment for multiple sclerosis that is being trialled in numerous clinical centres throughout the world. Whilst it is new in the multiple sclerosis field, it has actually been used as a leukaemia therapy for a long time. There are three main steps involved in HSCT, which are:

- **Harvesting:** at the beginning of the treatment, bone marrow is taken from the individual to be used for the transplant later in the process. Currently for the treatment of multiple sclerosis, transplants are only performed using bone marrow from the same individual. In this case, it is called an autologous transplant and so you may have seen the therapy called AHSCT (autologous haematopoietic stem cell transplantation).
- **Conditioning:** this is the chemotherapy part of the process. There are many different procedures for this being used, but all of them have the goal of destroying or eliminating the existing bone marrow and the immune cells contained within.
- **Transplant:** the bone marrow that was harvest in step 1 is then transplanted back into the individual. This allows for the immune system to come back, which ensures that the person isn't at risk of infection for the rest of their lives.

What have trials shown so far?

There have now been extensive clinical trials done around the world to assess the use of HSCT as a treatment option for people living with multiple sclerosis. These trials are all aiming to do the same thing - determine whether the treatment delivers benefits to people living with MS and, if so, do those improvements outweigh any risks associated with the procedure.

The safety risks largely come from the conditioning process (step 2 listed above). This chemotherapy not only takes a toll on the body, but it also leaves the individual immunocompromised for a period of time. This makes them susceptible to infections, which considering the body can't fight back, can be very dangerous. However, results presented atECTRIMS 2019 indicate that the safety profile of HSCT has improved significantly over the past few years. This is largely due to the fact that researchers have found that less harsh chemotherapy approaches can still generate positive results, which makes the treatment safer.



There is a strong consensus now that HSCT can definitely have positive effects for some people living with multiple sclerosis. Indeed, studies have shown that many people who have participated in these trials experience long-term control of their multiple sclerosis. However, it has also been found that it is certainly not going to be beneficial for everyone living with MS. Currently, researchers think that those most likely to achieve the best outcomes are those that are early in their diagnosis and have highly active, inflammatory disease. Considering this, it is mostly people with relapsing-remitting MS that have been shown to exhibit the most benefits.

Research into this area is ongoing and is now mostly focussed on trying to identify the individuals that are the most suitable candidates for receiving this treatment. Striving to improve the safety profile and reduce the mortality rate of HSCT will also be crucial.

What other stem cells may be useful in MS?

Part of the problems with discussions around stem cells is that the term is used in a 'one size fits all' fashion and this isn't really accurate, nor appropriate. To explain this, we can extend our analogy using the high school children from earlier. While we have children that may not know exactly what they want to be when they grow up, they probably have some sort of general idea. As an example, the sporty child may know that they want to be an athlete, but isn't sure if it will be athletics, swimming, rugby or tennis. On the other hand, the child that enjoys art may not know if they want to be a painter or an illustrator or a sculptor. Stem cells are the same. The haematopoietic stem cells used in HSCT can differentiate into cells of the immune system. However, another type of stem cell (called a mesenchymal stem cell) is able to become a different range of cells when it differentiates, including ones that are important in the nervous system. For this reason, these stem cells are also being trialled as a potential treatment for multiple sclerosis. It is thought that this type of therapy would provide myelin repair potential, which means repairing the damage to the insulation of the nerves that is associated with multiple sclerosis. Currently, no existing medication is able to do this and it is thought of as the next big step in the treatment of MS.

At ECTRIMS 2019, there were two talks that presented results of clinical trials of mesenchymal stem cells for treating people living with multiple sclerosis. Interestingly, these trials had very different outcomes: one failed to meet any of the aims, whereas the other one was highly successful and generated some very exciting data. It is clear that there is significant potential for this approach to be a novel and beneficial treatment option for people living with multiple sclerosis, however, there is still much that we need to learn about the best ways to apply this therapy. There isn't time to go into the details of the successful trial in this article, however, we interviewed the lead researcher of this study at the conference and this video will appear in the near future on MStranlate. Stay tuned to our Facebook page (www.facebook.com/MStranlate) for that!

celebrating the life of Ray Wilson who remembered MS Auckland in his will.

Written by Robyn O'Connor



When we recently discovered that Raymond Wilson had left a generous bequest to MS Auckland we were keen to learn more about him and to understand how he had been touched by MS. Happily (because this is not always the case) I was able to talk to his nieces Libby and Carolin who graciously shared memories of their Uncle Ray.

Ray, and his younger siblings Elizabeth (known as Betty) and Keith, grew up in Invercargill to parents of Scottish Presbyterian background. Those missionary origins and strong values of caring for others and 'putting others first' were a big influence throughout their childhood and have been passed on to subsequent generations.

Ray married Doreen after returning from WW11 where he served in the Royal Navy and as the loving couple was not blessed with children, they became firm favorites with their nieces and nephews. Carolin remembers sitting on the fence outside her home in Hamilton, eagerly awaiting their visits.

Music and sports were a big part of the lives of this talented family and the three siblings played and competed in tennis, yachting, rugby, gymnastics, high-board diving, netball, hockey and snow skiing. Future generations of the Wilson family are very grateful that the love of these sports has been passed on to them. Libby described one of her last memories of her Uncle Ray; "in his wheelchair outside Kohimarama Yacht Club, watching the P Class races through binoculars and yelling advice to his great nieces".

As is often the case, Ray's decision to leave a generous gift in his Will to MS Auckland, was driven by his own personal experience of MS. In the 1970's Ray's beloved sister, Betty, had problems with fatigue and unsteadiness on her feet while on holiday in Vienna and on her return to NZ Betty was diagnosed with MS.

Coming from such a sporting background and with a family of four children, Betty's prognosis obviously had a serious impact on Ray which no doubt prompted his generous bequest in his Will to MS Auckland.

But this is not a family to dwell on the negative and now 46 years down the track Betty continues to inspire all her family and friends with her outstanding positive mental attitude despite the challenges of living with MS.

Over the years, MS Auckland has provided support to Betty, and Ray's bequest helps ensure that others with MS receive the support they need and deserve. The gift that Ray left in his Will to MS Auckland is a tribute to both his sister, and to his parents who inspired a lifetime of giving to help others. We believe he would be happy knowing that the gift he left in his Will to MS Auckland will provide tangible support to people living with MS.

Answers to Crossword on page 20

Across: 2. Workshop; 5. Medicinal Cannabis; 6. CBD; 8. PHARMAC

Down: 1. Community Advisor; 3. Awareness Week; 4. Street Appeal; 7. Vaping

our supporters.

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Foundation North	Rob Webber & Associates
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Furley Digital	Rod Milner Motors
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Special thanks also to our wonderful volunteers who give us their time, expertise and support.

remember us with a gift in your Will.

Most gifts are made by ordinary hardworking people who would like to give lasting support to causes that are important in their lives. A gift to MS Auckland in your Will can be as much or as little as you want.

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 Robyn or Mark in the office on 09 845 5921.



For more information visit www.msakl.org.nz



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