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and much more...

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for people with RMS who meet pre-defined criteria

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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 or your child if they were exposed to Ocrevus during pregnancy, 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); skin infections, sinus infections. **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 Version 3.

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Welcome

Kia ora koutou.

Warm greetings to all in our community, especially our new members and whānau. The team at MS Auckland looks forward to connecting with you and supporting you throughout 2022, regardless of whatever challenges the year may present.

Every day, we are inspired by the incredible people in our community. During lockdown last year, Anne decided to embark on a 10 week trip to the UK, travelling alone. A positive and pragmatic attitude combined with a collapsible scooter made it all possible! Read her story on page 7, then start making your own plans!

Claire's Dad was diagnosed with MS when she was a child. Although he has now passed away, Claire is running a half marathon in Hawkes Bay in his memory, to raise awareness of MS and funds for MS Auckland (page 14). Very best of luck, Claire!

We are delighted to bring you a series of information webinars during 2022. They will be held monthly on a Tuesday evening with a range of topics and speakers. The first was Fatigue Management and MS; an insightful session with tips and tricks for everyone to get the most out of their days and ensure you can achieve those things which are most important.

I would like to take the opportunity to acknowledge the tireless commitment of our wonderful people. Everyone representing the work of MS Auckland, whether it be employees, Board or other volunteers, is dedicated, day in and day out, to serving and supporting the MS community.

Finally, if you haven't yet seen it, read the reflection on MS by our Ambassador, funnyman Sam Smith (page 5).

Nicola Bitossi
General Manager

Knowledge is power

Bringing you MS Auckland's webinar series.

MS Auckland is delighted to bring you a series of information webinars over the course of this year. These Tuesday evening sessions will feature a range of topics and speakers, all selected to help inform and guide you. Each webinar will comprise a live presentation, followed by the opportunity for your questions to be answered. It's a well spent hour, and best of all, free of charge!

Some key points:

- Pre-registration isn't necessary, just click the event link to join!
- Your audio and video will be turned off
- Presentation and live Q&A via the chat box
- A recording will be available afterwards
- If you aren't available for the live event, feel free to send any questions in advance to info@msakl.org.nz



For more details, follow us on Facebook (@multiplesclerosisakl) or keep an eye on our website www.msakl.org.nz. Our members will be notified of all our events, including webinars, via our monthly e-news. If you're not sure if you're a member, email [Becky info@msakl.org.nz](mailto:Becky.info@msakl.org.nz) who will help sign you up (also free of charge).

See you there!

The raisin that turned out to be a dead fly

Sam Smith's story proves that MS people make great comedians and great writers!

I was diagnosed with MS in July 2015. At the time, I thought my whole world would turn upside down. I thought I would follow in the slow-plodding footsteps of my Papa. He was diagnosed with MS a few years before I was born. He had a cool walking stick with a bell on it, and an even cooler sense of humour. He would tell my Granny that maggots had got into the pasta, when really, he had sprinkled the bubbling pot with a handful of rice. He eventually traded in his walking stick for a wheelchair, and then passed away in 2008.

And here I was, just seven years later, with a one-month-old new-born to care for; when I myself had about as much control of my hands as he did. I didn't know at the time, but my paternity leave from my job as a dentist would lead to me leaving the profession – and I hadn't even paid off my bloody student loan!

I'll be honest – I was kind of looking forward to the walking stick with a bell on it. But alas! It turns out modern medication would steal my ambulatory aid from me. Curses! While I was treated with natalizumab infusions, and then later a convenient twice-daily Tecfidera pill, my Papa had been treated with a shrug and crossed fingers. But from then on, I knew things were going to be a bit easier than what I had witnessed my grandfather go through.

Now here I am, seven years on from my diagnosis, and life couldn't be better. I take my medicine, forgetting only occasionally which makes my wife mad. I now make a living through comedy and writing, and I don't have to remind twenty people a day that they need to floss.

Summer's tough, but my heat management skills have become second nature. I bought a cool electric fan that makes me feel like I'm in an 80s music video. The fuzziness in my hands and legs is still there, but only when I think about it. I used to be cripplingly ticklish, but the constant paraesthesia has kind of built up my tolerance. I can sit through my six- and three-year olds' tickle attacks like a stoic legend.



Shaky Sam takes another sip of olive oil

Vision loss is my main symptom. I am legally blind, but according to my ophthalmologist I am at the level just below being able to drive so I'm pretty good. I have about 25 percent vision in my left eye, and 75 percent-ish in my right. I said that to a friend once who pointed out that those numbers add to 100 percent so I'm all good. Not too bad. I can function pretty damn well. Sure, I've swigged some apple juice that turned out to be olive oil. Sure, I put some chewing gum in my mouth that turned out to be Bluetak. The worst one was when I ate a raisin that turned out to be a dead fly. But hey, that's protein.

MS is special because it affects a lot of people; but everyone in their own unique way. The world still doesn't know what it is, and sure we should spread awareness; but maybe not so quickly. At the moment we have a sure-fire excuse to get out of anything. Ever want to go home early from work? "Sorry, gotta go, my MS is playing up". You'll be out of there in a flash. "Can't come in next Wednesday, I've got a scan of some sort or something". It's great. Take advantage of it. Highly recommended.

So, if you have MS, or know someone with MS, talk to them about MS. It's good to talk. If you don't know anyone with MS, talk to the people at MS Auckland, talk to me! @ReelBigSmith on Twitter and Instagram. I would say find me on Facebook but my name is Sam Smith and there are 3.4 million of us. You'll never find me.

Having MS sucks, but once you've got in the gang there's no point moping around. You might as well enjoy it. There ain't no party like an MS Club party. Adjust your goals, meet some lovely new people, *and most of all; remember to floss.*



From our MS nurses

Mental Health and Exercise



Fiona d'Young & Nazila Samadi
Multiple Sclerosis Specialist Nurses
Auckland Hospital
(09) 307 4949 extn 25885

Mental health and exercise reappear in our clinic and phone conversations with people with MS on a daily basis and it's not surprising as these are on-going key areas that we all need to keep up with and areas that extend beyond our current pandemic world.

Exercise and mental health have a large role to play in keeping us on track in our current situation where self-isolation and reduced personal comfort in attending group exercise is a common theme.

We encourage you to take a hard look at where you are at with your exercise and activity regime. If you are wanting to increase your levels and move more, there are a number of options and speaking to your MS Society Community educator is a great first step.

You may have heard about the Green Prescription service via your family medical centre?

This is a free three-month service for people over 18 living anywhere in NZ provided by the Ministry of Health. There are also programs available for your whole whanau (Active Families) which is great if you and your young family are needing to self-isolate and also for pregnant women (maternal green prescriptions).

You can access this service by:

- self-referring to via the website www.sporty.co.nz or by calling 0800 ACTIVE (228483)
- via a practice nurse referral
- discussing with your community advisor at MS Auckland

Once you have been referred you will be contacted by a green prescription wellbeing consultant who will work with you to identify your needs and what sort of exercise and information is right for you.

They will provide regular reviews to track your progress and give motivational support to keep you achieving your goals and feeling good by making positive changes to help strengthen your heart and muscles.

You will also have access to nutrition and exercise information sessions/workshops alongside the regular goal setting free community exercise sessions.



If you make a commitment to the coaching and education aspect of this service your consultant can provide you with short term access to swimming pools and gymnasium/exercise centres which can often be prohibitive to people on a limited budget. It's important to note that this discount is similar to that you will receive if you have a community services card so when your three months is over you can continue to receive the discount via your community service card.

There are large bodies of evidence to support the idea that exercise improves our mental wellbeing. If you are worried about your mood or have noticed changes in your appetite, sleep pattern and/or an increase in negative thoughts, feelings of hopelessness/lack of joy, then speaking to your GP is the first and key step to take. Sharing this information with a health professional can feel to some like a mountain to climb, so taking a friend or family member with you for support can really help. So many people we speak to tell us they wish they had spoken to their GP sooner. GP's do not always default to offering anti-anxiety or antidepressant medication so it is important to note that there are counselling options available.

Please remember that if you suspect you are experiencing new MS symptoms you may be asked to see your GP in the first instance for an assessment rather than being offered an immediate appointment here in the neurology department. Short notice acute appointments are limited and we rely heavily on our GP colleagues to provide a physical assessment and the sharing of these details assist your neurologist in triaging your symptoms.

We are often told that GP's charge too much but we are reliant on their expertise to help us guide you through your issues. We can only learn so much via email and phone calls so do bear with us.

All the best and take care out there

Fiona and Nazila

The world is my oyster!

Member Anne Schofield talked to Nicola Bitossi, General Manager, about her recent 10-week trip to Europe, and her advice to others living with MS.

Anne, when were you diagnosed with MS?

I was diagnosed with MS in 2005. Medication was not available then so after a lot of research I adopted the OMS regime and have been on it ever since.

I have been a member of MS Auckland since I was diagnosed and have found the community advisors very supportive throughout, especially when my husband died in late 2020.

I regularly attend two support groups and have made some good friends.

Have you travelled since your diagnosis?

Yes. My husband and I regularly travelled abroad together but since losing him I have had to work out how I can travel alone. My daughter and family are in the UK and the motivation to see them last year was very strong! Especially my six-year-old grandson.

What made it all possible?

I was inspired by an MS friend whose folding scooter has enabled him to do so much, and he raved about it. So I thought I'd look into it. I investigated the different options and chose a folding scooter that was best for me. I gave it a good test run on a trip to Christchurch for a singing convention. It all worked well and gave me confidence to travel to the UK alone!

Tell us about your Big Trip

I arrived in the UK during August 2021, just days before NZ went into major lockdown, and settled in for a 10 week stay with my daughter and her family. It was great to spend time with them all. I enjoyed preparing their dinner while they were all out at work and school for the day to help with the 'busyness' of family life. I'm sure they enjoyed this too!

I went to three car rallies while there: just folded my scooter into the boot of the car. Once there I could be completely independent which was great. I went shopping, to parks and playgrounds with my grandson, and also shopping in local towns. A highlight was going to the seafront every day in Margate, Kent; to people-watch, smell the sea and soak up being away. I loved that I could do this alone!

How is your mobility around town?

I found that when I stopped driving, I lost my independence. So, I made an effort to get out and about as much as I could on my local scooter. Most things are possible! My neighbour with a car laughed out loud when I offered to pick up anything she might need from the supermarket!

What's next?

I don't know what's round the corner so I've already booked flights to the UK this year in August with an extra flight this time to see family in Shetland, an island north of Scotland.

Anne's travel tips:

- If you want to do something and can afford it, then just do it!
- Plan in advance. Planning is essential!
- Airlines are very helpful. European airports must provide support for disabled travellers.
- Have someone collect you at the airport
- Don't try to do too much. Enjoy the people you are with rather than trying to complete the tourist circuit. Soak up the scenery. Take time to relax.



From our CAs' corner

Assessments for the Total Mobility Scheme – one of the services offered by MS Auckland.

What is the Total Mobility Scheme?

The scheme is a nationwide initiative which supports people who cannot use public transport to travel, all or some of the time. It is intended to complement public transport services and ensure people with impairments can meet their daily needs in a safe and dignified manner. It is open to people with a permanent, temporary, or fluctuating disability that prevents them from travelling on buses, trains, or ferries, or getting to or from where the public transport starts or ends.

The scheme has no minimum fare threshold. In the Auckland region a 50 percent discount applies until a maximum \$40 subsidy is reached. Those who are eligible get a subsidised rate on contracted taxis for door-to-door transport, and an accessible concession loaded on a Total Mobility AT HOP card used to pay for discounted travel on public transport.



Eligibility

To be eligible to hold a Total Mobility AT HOP Card you must have an impairment that prevents you from undertaking any one or more of the following five components of a journey unaccompanied, on a bus, train or ferry in a safe and dignified manner:

Getting to the place from where the transport departs

Getting on to the transport

Riding securely

Getting off the transport

Getting to the destination

Assessment and steps to get a Total Mobility Card

Your Community Advisors



Tatjana
Ph 021 845 903



Luminita
Ph 021 959 187



Catherine
Ph 021 959 189



Step 1 - Contact us.

Ring MS Auckland on 09 845 5921 or email info@msakl.org.nz and request a Total Mobility assessment.

Step 2 – Conducting the assessment.

The assessment for eligibility to access subsidised transport is facilitated by one of MS Auckland's assessors. Based on that assessment, Auckland Transport will establish your eligibility for a TM card and, if successful, a TM card will be issued within 30 days.

Cost

For MS Auckland members/people diagnosed with MS, assessment is free of charge plus \$10 for issuing a TM card.

For non-members / people with other diagnoses, assessment is \$65, plus \$10 for issuing a TM card. There is no longer a two year renewal process for the Total Mobility card in the Auckland region. Once you have been assessed, you are eligible to use the Total Mobility Scheme for as long as you need to. Your Total Mobility card is yours and will remain active unless your mobility circumstance changes.

You can only use your card with taxi operators and their drivers who have been approved by AT to participate in the Total Mobility scheme. Google 'AT Total Mobility taxi providers'.

Happy travels, everyone!

Catherine Glover

New Community Advisor

MS AKL extends a warm welcome to the newest member of the CA team. Catherine Glover began her career as a registered nurse and has worked in a variety of healthcare settings including as a bone density technician.

Catherine has a keen interest in research and resource provision. If her name rings a bell, Catherine has been part of our Community Advisor team in the past and it is wonderful to have her return. Catherine's focus will be on remote support via phone, email and zoom. She can be contacted on catherine@msakl.org.nz, or 8455921 x221

Catherine says, "Thank you to the MS Society for the

warm welcome. It is my pleasure to return to the Society in the role of a Community Advisor. I look forward to meeting with past members and meeting new people who have joined the Society.

"A little about me: I like to keep up with worldwide MS News, that is, what's happening in Pharma, Lifestyle and Technology. My current interest is how climate change is affecting us all, in particular those with disabilities. How did people deal with the heat this summer? Pheew!"

"I'm so excited to be back with the team and look forward to engaging with you all."

Cumulative effects of therapies on disability in relapsing multiple sclerosis

Recently published research in France has investigated the long-term effectiveness of treatment which the authors suggest remains a key question in multiple sclerosis. They say the cumulative effects of past treatment have not been investigated so far.

The objective of the research was to explore the relationship between treatment exposure and disability risk in patients with relapsing-remitting multiple sclerosis (RRMS).

A total of 2285 adult patients from the French nationwide MS cohort were included.

Outcomes were irreversible EDSS4 (the Expanded Disability Status Scale [EDSS] is a way of measuring how much someone is affected by their MS. You might hear your neurologist talk about it or see it mentioned in reports on trials of MS drugs) and conversion to secondary progression of multiple sclerosis (SPMS). Associations between treatments and risk of disability were assessed using a novel weighted cumulative exposure model, assuming a three-year lag to account for reverse causality. This flexible approach accounts for past exposure in a 'multivariate Cox proportional hazards' model by computing a weight function.

The results at baseline, mean \pm standard deviation age of patients was 33.4 ± 8.9 years and 75.0% were women.

A 15-year continuous treatment starting 20 years ago was associated with a decrease in risk of 26% for irreversible EDSS4, and 34% for SPMS compared to a 5-year treatment starting 10 years ago. The risk of disability decreased with increasing duration of exposure to disease-modifying treatment (DMT).

In conclusion, this research suggests long-term use of treatments in RRMS has a stronger beneficial cumulative impact than only early uses and delays the occurrence of moderate disability and conversion to SPMS.



Your life changing sailing adventure is here!

You may recall Duncan Grant's uplifting article discussing five awesome days on Steinlager 2. Well Duncan's 'unparalleled' experience could be yours too!

The Oceans of Hope Challenge's aim is to help you gain self-confidence and a renewed sense of empowerment.

The camaraderie of sailing a boat with people who have similar experiences creates an environment where people can comfortably share their hopes and fears. The Oceans of Hope experience is a catalyst for creating lasting friendships and a sense of community.

There will be crew to help you learn and ensure you get everything you want from this experience. These fabulous boats are easy and safe to sail so you can learn to sail or learn new sailing skills. If you come alone, you will certainly have some fun and make life-long friends.

Whether you have sailed before or not, this is an opportunity not to be missed!



Embarking 28th November 2022
@ 09.00 Auckland Viaduct Marina

Disembarking 2nd December 2022
@ 16.00 Opua Wharf, Beechy Street, Opua

COST: \$1,454 (includes food)

For an application form,
email: oceansofhopechallengenz@gmail.com



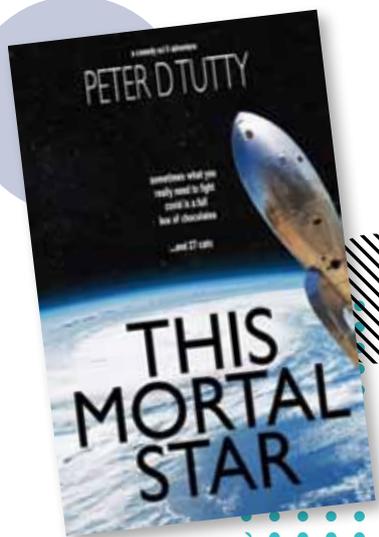
Writing a new future with MS

Peter Tutty was diagnosed with Multiple Sclerosis in 2005, while living in Sydney Australia. His marketing career for Telstra came to a sudden halt the day he woke up with his eyesight completely gone, thanks to an MS relapse overnight. Today with his sight only 20 percent remitted, Peter lives with his wife Kathie, and dog Brontë, in Riverhead, and enjoys the weird oil-painting-like sunrises, sunsets and river views his remaining eyesight has left him able to enjoy.

After returning to New Zealand, seeking the support of friends and family, Peter and Kathie spent the better part of two years readjusting to life with MS. And the fatigue! And the needles! Needing something to occupy his days, Peter returned to university, studying psychology and sociology. He had always enjoyed writing since childhood and so took a couple of English writing papers as electives, which proved to be highly successful.

“Writing gives me an escape from reality. I am pretty much home-bound these days, and with my writing I can travel the universe, without leaving my armchair. RRMS is not generally life-threatening, so it is vital I find some way to occupy my mind, even if I can only manage a couple of hours each day.”

Peter’s debut novel is *This Mortal Star*, a comedy/sci-fi story about Jack Parsons: a pizza delivery guy living in Hobsonville Point.



Peter Tutty writes as an escape

Jack’s life is turned upside down when aliens come to Earth to save the planet from an ancient enemy. And somebody is stealing all the mint chocolates! It’s a light-hearted read about Covid, aliens and cats. Lots of cats. The science shouldn’t be taken seriously, and the fiction certainly shouldn’t be.

The book was released on 22nd February 2022 and is available in digital (Kindle) format for less than a coffee and paperback on Amazon.com. Just search for ‘Peter D Tutty’. His second novel, *In Case of Emergency*, will be released on 6th July 2022, and his third novel, *Legends Live Forever* will be coming out before Christmas. A collection of short stories (*Aardvark Is a Funny Word*) will be slotted into the year somewhere too.

“If I sell a few copies, I’ll be happy, but really I write to see how the stories end. I never know where the characters are going to take it and I find the whole process fascinating. I will keep writing until MS stops me...let the battle begin!”

Peter will be donating a share of any profits from book sales to MS Auckland. The rest will be donated, one pint at a time, to his local pub Hallertau Breweries (Peter is a current board member of MS Auckland, and a life member of the Blind Society).



Volunteer Profile:

Julie Adams



Julie Adams has been giving back to the MS community for many years; previously as a board member of MS Auckland; and currently in coordinating the Manukau Support Group.

What's your MS story?

I was diagnosed with MS around 20 years ago. I was 42 years old and had just been licensed as a private investigator. Being diagnosed with MS just as I was embarking on an exciting new career felt like a slap in the face, however I pushed on and worked as a private investigator for the next ten years. After that, circumstances changed including the need to care for my elderly mother which is still my main priority today.

What's something that you've learnt along the way?

I was initially diagnosed with Relapsing-Remitting MS (RRMS) and now have Secondary Progressive MS. With my current diagnosis there is currently no medication available in NZ. Through all of this I've learnt that self-management is key to help keep control of my MS. For me that is careful attention to diet, exercising and keeping my brain active.

My regular activities include tai chi, swimming and walking. I'm slowly building up my distance with the walking. To keep my brain active, even though I have retired from professional work, I am doing a lot of work on my genealogy and family history.

What motivates you to volunteer for MS Auckland?

Some time ago, I realised that there's a real need for volunteers to help their peers who also live with MS. It's incredibly valuable and important to meet others with MS and share tips and tricks: the group recommendations, various strategies like sleeping with icepacks and lifting the bedhead; things that a specialist would never know! It's just great to have a group of people who really 'get it'.

What happens in your group?

In 'regular' times we would meet in person once a month over coffee. We've also shared some pretty fun times: we dress up for Christmas, and for World MS Day we pull out all the stops. Dressing in orange and getting into the community with our scooters and wheelchairs – it's a good chance to talk to the wider community about MS.



Julie Adams and her Manukau group at Christmas



All set to have some fun on World MS Day

COVID has been difficult for everyone but technology helps. We have been meeting more regularly during lockdowns. The online Zoom platform lets us stay connected and hear what others are doing to stay active.

Finally, if you could invite any person to dinner, who would it be?

It would have to be Stevie Nicks. I've always been a major fan! I love music and keep playing the guitar as I can.

Claim your donation rebates with Supergenerous



Make your donation to MS Auckland go even further. And it won't cost you any extra!

Did you know that if you have donated to us in the past four years, you are eligible to get 33 percent back in donation rebates? Supergenerous is a small Kiwi social enterprise helping get these rebates back to charities like us.

Their aim is to supercharge human generosity and tap into the estimated one billion dollars of unclaimed donation rebates sitting in a government bank account right now.

How it works

You sign up online with them, give them your details and the names of the charities you donated to - that's it.

They'll collect the receipts from charities, schools and religious organisations you donated to and manage the IRD side of things so you can sit back and relax.

They don't assume that you want to keep the money for yourself, they know you are already generous by donating in the first place. They give you the option to become a Supergiver by re-gifting the rebate right back to us. They handle that side of things too. The option is yours.

If they secure your rebate, they take a 10 percent fee that allows them to keep operating.

Supergenerous is a 'win-win' solution for gifters that's really growing in Aotearoa. Still have questions? Visit their website www.supergenerous.co.nz

supergenerous



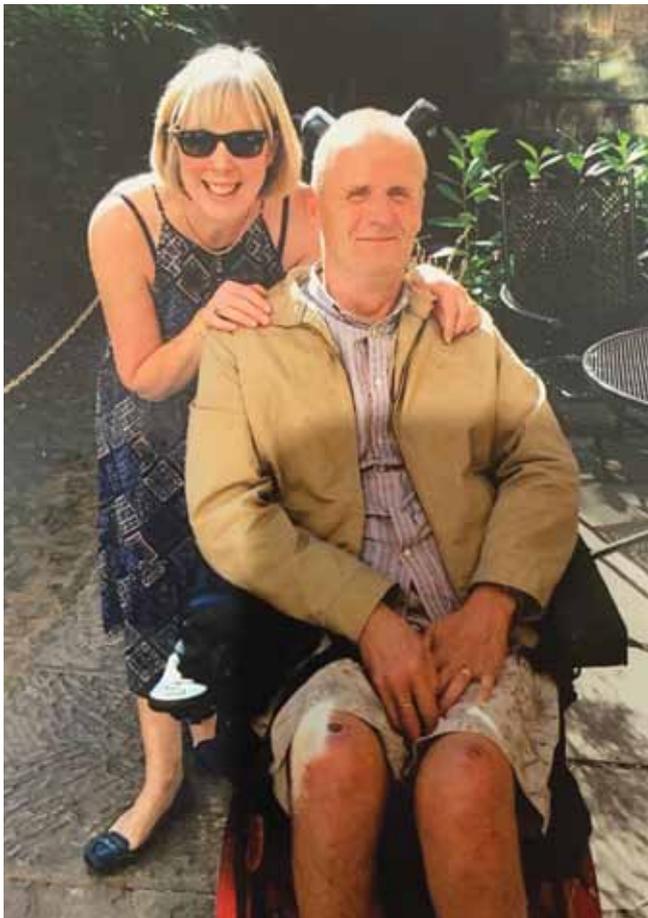
Inspiration to run for MS

Claire Percy discusses a fearless father and getting out of the comfort zone

One of my New Year's resolutions for 2022 was to put myself out of my comfort zone and embrace new opportunities when they presented themselves. So naturally when one of my good friends suggested a half marathon I jumped at the chance!

I wanted this run to be more than just a gruelling 21 kilometres, but to be also an opportunity to bring more attention to a condition that's close to my heart.

My dad was an incredible human and struggled with Primary Progressive MS for as long as I can remember. A memory that always sticks with me was a family vacation to a UK holiday resort after my dad first received his collapsible wheelchair.



Alan and Louise Percy in Lumley Castle grounds in 2014



Claire Percy and her beloved dad Alan

In his classic daredevil style on our way back from dinner he opted for a faster route to our caravan which involved an almost vertical hill, hurling himself down at full speed while we could only watch in fear! The wheels wobbled uncontrollably for what seemed like an eternity, but finally he gave us the wave to say all was fine. That was the thing about my dad - he was full of surprises and completely fearless.

It's true to say that my dad was one of the most generous people I knew, and he never let his condition hold him back. Even at his very lowest, when his stairlift broke down or he wasn't coping mentally he was always there; cooking us our favourite microwave dinners or making us toast with a ridiculous amount of butter on each slice. He was also a proud member of the MS Society back in the UK and would always joke about collecting twice as much as my mother, who also shook her tin at Christmas alongside him.

I had always hoped that he would make it to New Zealand but unfortunately that was not meant to be. But the words he would say after our daily morning call would be, "Claire, you know you can always come home. Don't forget that, and never worry about the cost", which has always stuck with me.

I know if my dad was here today, he would be just as passionate about advocating for the cause here in NZ as he was in the UK.

On the 14th May I will be running a half marathon in Hawkes Bay and raising money for the incredible Multiple Sclerosis Society, so that they can continue to provide support around Auckland.

Five ideas to support MS Auckland



“How can I help?” It is a question we (often!) feel quite humbled to hear.

Under COVID restrictions, we cannot engage these wonderful people to help at our groups, be a community friend, shake buckets or hold a sausage sizzle.

Here are some non-contact ideas of how to help MS Auckland.



If you've donated to MS Auckland over the last four years, consider maximising your impact by authorising **Supergenerous to re-donate your tax rebate** to us. Details on page 13.



Like and share our social media posts



Consider fundraising on our behalf (like the inspirational Claire on page 14). If running is not your thing, consider asking friends to donate to us in lieu of a gift on your birthday; or hold an entry-by-donation, orange-themed morning tea on World MS Day, 30th May. We would love to hear about it!



Buy a 12-month subscription to Entertainment either for yourself or for a gift, ensuring you select MS Auckland as recipient charity (see page 16). Every subscription benefits us. Also note that there are plenty of non-contact services and takeaway deals on offer.



Consider leaving us a gift in your will. Even one percent will make a significant difference in ensuring we can support whānau living with MS into the future.

Every dollar donated to MS Auckland has a measurable social impact of \$8.50. So, you can rest assured that all donations have a significant and lasting impact to Auckland whānau living with MS.

Our warmest thanks to all our incredible friends and supporters who help to spread the word, and support us, every day. Arohanui.

Entertainment

Fundraising with Entertainment

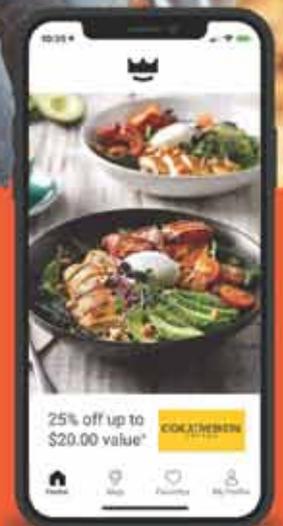
20% of every Membership we sell, goes directly to our fundraising



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MS Auckland

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*Member offers are subject T&Cs. Check individual offers on the Entertainment Membership App or www.entertainmentbook.co.nz

FATIGUE MANAGEMENT AND MS



Take control of one of the
biggest challenges of MS

with
Stephanie Kurtovich
Rope Neuro

Our new webinar series is off to roaring start

The first in our very useful new webinar for the year was Fatigue Management and MS, with very informative and helpful advice from Stephanie Kurtovich, Neurological Physiotherapist at Rope Neuro Rehab.

If you didn't attend on the night, we highly recommend that you set aside an hour to watch the recording. There are fabulous tips and tricks which could have a big impact on your abilities and your lifestyle.

For more details you can follow us on Facebook (@multiplesclerosisakl) or keep an eye on our website www.msakl.org.nz. Our members will be notified of all our events, including webinars, via our monthly e-news.

If you're not sure if you're a member, email Becky info@msakl.org.nz who will help sign you up (free of charge).

FATIGUE

'A lack of **physical** and/or **mental** energy that is perceived by the individual or the caregiver to interfere with usual and desired activities'

- Affects up to 80% of people with Multiple Sclerosis
- Misunderstood by family and friends, often as depression
- Not the same as 'tiredness'

What we do know about MS fatigue is that it is **UNPREDICTABLE** and not necessarily associated with expending energy, can come on during the morning even after a nights sleep

The Power of Self Management

- ▶ "Self management is one of the most powerful resources we have in health care. It is fundamental to assisting people better manage their health and live a fuller, healthier life, and yet, is one of the least utilised approaches to chronic disease"
- ▶ A process of increasing knowledge of the condition, symptoms and consequences, having the ability to self manage and take appropriate actions

Facilitation

Study links vegetables to MS risk reduction



A recently concluded study in Iran indicates that eating a lot of green leafy and other vegetables, beans, nuts and berries seems to significantly lower the likelihood of developing multiple sclerosis.

The findings also suggest that the chances of developing the disease may be higher in people who eat more cheese, poultry, sweets, and fried foods. The study, *“MIND Diet Adherence Might be Associated with a Reduced Odds of Multiple Sclerosis: Results from a Case–Control Study,”* was published in *Neurology and Therapy*.

The food that people eat has a profound effect on their health, and a number of studies have suggested that dietary habits may influence the development of diseases such as MS. However, the specific effect of any given diet or food type on MS risk remains poorly understood.

Here, a team of scientists in Iran were interested in assessing whether a dietary style called the Mediterranean–DASH Intervention for Neurodegenerative Delay (MIND) diet might be protective for MS. MIND takes inspiration from the Mediterranean diet, as well as a diet called DASH that is used to manage high blood pressure.

In combination, these diets promote the consumption of foods thought to benefit neurodegenerative disorders. Adherence to the MIND diet is based on the consumption of *“brain healthy”* and *“unhealthy”* foods.

Brain healthy foods include green leafy vegetables, other vegetables, nuts, berries, beans, whole grains, fish, poultry, olive oil, and wine. In contrast, unhealthy foods include red meat, butter or margarine, cheese, pastries and sweets, and fried and fast foods.

The MIND diet *“encourages natural plant-based meals and limits animal-based/high in saturated fat foods,”* the researchers wrote.

The team conducted interviews about dietary habits with 77 people with newly diagnosed relapsing-remitting MS,

and 148 controls without MS. Relative to the MS patients, the controls generally were older and had a higher body mass index (BMI). Controls consumed fewer calories and total carbohydrates, but ate more fibre and animal-based proteins than patients.

Based on each individual’s dietary habits, the researchers assigned a MIND score, basically reflecting how closely the person’s usual diet resembled the MIND diet. Statistical analyses showed that, after adjusting for between-group differences, participants in the top third of MIND score were about 90% less likely to develop MS.

“Studying the MIND diet score in this retrospective research shows that higher adherence to the overall MIND dietary pattern may protect against MS,” the researchers wrote. *“According to these findings, even a moderate level of MIND diet adherence may significantly impact the prevention of MS.”*

The odds of MS also were significantly lower among the third of participants who reported the highest consumption of green leafy vegetables, other vegetables, and beans. The researchers noted that vegetables and greens are high in antioxidants and anti-inflammatory compounds like polyphenols, which may explain these associations.

MS risk also was lower in the third of patients with the highest consumption of butter and stick margarine. These are generally considered unhealthy, and the researchers cautioned this association may be due to many different foods (e.g., soft and hard margarine) being classified as a single group.

By comparison, the risk of MS was higher among the third of participants with the greatest intake of cheese, poultry, pastries and sweets, and fried or fast foods.

“According to the present outcomes, fast fried food consumption more than once per week increased the odds of MS by 32.8 times compared to eating this type of food less than once a week,” the researchers wrote.

The team noted that these dietary trends may explain, in part, the relatively high prevalence of MS in western societies, where diets tend to be rich in salts, fats, and sugars.

Recipe

Salmon Patties

Salmon, even canned, contains Omega 3 which has been found to be beneficial to brain health.

With the added nutritional bonus of veges and white beans, these patties would go nicely with a wedge of lemon and a salad!



Serves 8

Ingredients

300g tinned salmon, drained

200g (half can) of white butter beans, mashed well with a fork

1/3 cup vegetables, such as onion, zucchini, mushroom, grated carrot etc.

1 garlic clove, crushed

1/2 fresh chilli, finely diced

1 cup parsley, finely chopped

Buckwheat flour

1-2 egg yolk lightly beaten

1 tbsp milk / soy milk

Sesame seeds

Olive oil

Method

Combine white beans, salmon, vegetables, garlic, chilli and parsley in a large bowl and mix well.

Place some flour in one shallow bowl, then combine egg and milk in a second bowl and sesame seeds in a third bowl.

Dampen your hands with water and form the salmon mixture into patties.

Dip each one into a thin layer of flour, then dip in the egg wash and then the sesame seeds.

Place on a plate and refrigerate for 30-60 minutes to firm. Heat some oil and cook the patties for a few minutes on each side so that they are nicely browned.

Serve with salad dressed with flaxseed oil.

These keep really well in the fridge or freezer for reheating.

Recipe from www.ms.org.au



MS & Pregnancy

Approximately three times as many women as men have MS. Most women are diagnosed in their mid thirties at exactly the time when they may be thinking about starting a family.

The issue of pregnancy and MS is therefore an important one. In addition, women who have been diagnosed with MS may have concerns about how the disease will affect their ability to have children and how pregnancy and delivery may exacerbate their MS.

When is the best time to have a baby?

The major factors in the decision to have children are the same for people with MS as they are for other people. The decision whether to have a family and when to start is a very personal one and needs to be made with attention to current and future emotional, financial and medical considerations.

Is MS inherited?

Although we still do not understand what causes MS, research suggests that there is a genetic component in a person's susceptibility to developing the disease. Children who have a parent with MS have an approximate 3% (3 out of 100) chance of developing MS themselves.

The risk in the general population is approximately 0.3% (that is, 3 children out of 1000 will get MS). So although having a parent with MS increases the risk, it is important to remember that the risk remains quite small.

Does MS affect fertility?

While MS does not affect a woman's fertility, men who experience MS related problems with ejaculation may need medical intervention to assist with fertility. Since the majority of couples will not experience any reduction in fertility, you will be faced with the same decisions about birth control as any other couple.

You are free to use any form of birth control that you find manageable and comfortable. However, keep in mind that some forms of contraception require more manual dexterity than others. Also, a diaphragm may increase a woman's risk of bladder infections. Because of these concerns, you may want to consider using additional birth control protection with any one of these methods. It is important to consult your general practitioner (GP) when you and your partner are deciding on the most suitable form of contraception.



How does MS affect pregnancy and childbirth?

Couples do not need to be concerned that a woman's MS will affect her ability to have a normal, healthy baby. MS has not been found to affect the course of pregnancy and labour. Neither does it increase the risk of miscarriages, complications during labour or delivery, foetal malformations or stillbirths.

Epidural anaesthesia is considered safe to use for pain relief during labour and has been found to be beneficial for women who experience spasticity. Either general or epidural anaesthesia is recommended for women requiring caesarean section.

What medications are safe for use during pregnancy and breast-feeding?

As a general rule, the use of any medications during pregnancy and breast-feeding (including ones bought over-the-counter) should be done cautiously and under the supervision of your GP. If at all possible, a woman who wishes to become pregnant should consult her GP prior to conception about any medications she may be taking.

The GP will eliminate any unnecessary medications and substitute safer ones where required. Both men and women taking Disease Modifying Treatments who wishes to start a family should review treatment options with



their neurologist or GP. A woman who becomes pregnant while taking any medications should review them with her doctor as soon as possible. Similarly, men may also need to cease use of these treatments to assist spermatogenesis (sperm production) and should seek the advice of their treating doctor.

Can mothers who have MS breast-feed their babies?

Any mother who wishes to breast-feed is encouraged to do so, provided she has the strength to do it safely and does not require any medications that might be unsafe for the baby.

It is recommended that women talk to their neurologist and GP about the best time to recommence their MS medications. Since fatigue can sometimes affect milk production, it is important for the new mother to eat well, get plenty of rest and have sufficient help available in the home.

Will having a baby make my MS worse?

Before 1950, women with MS were routinely advised by their doctors not to have children. All of the published research since has pointed to a very different conclusion.

A woman's MS is likely to be stable, or even improved, during the nine months of pregnancy. In the few months

following the pregnancy (whether the pregnancy goes to term or ends prematurely), the risk of exacerbation has been found to range from 20% to 75%.

Research suggests that a possible indicator might be related to the frequency of exacerbations experienced by the woman prior to the pregnancy. Given the increased chance of an exacerbation, it may be beneficial to arrange for some additional short-term assistance in the home.

This support may include help from family and friends. Community Support Staff from the MS Society in your region can also provide information on services available in the community.

Researchers have also concluded that pregnancy does not affect the woman's long-term disease course or level of disability. This means that a woman can make her decision knowing that becoming pregnant is unlikely to have any long-lasting impact on the course of her MS.

Further info:

MS Australia – Pregnancy and MS

National Multiple Sclerosis Society – Pregnancy and reproductive issues

MS Society – Pregnancy and birth

Overcoming MS – Pregnancy and MS

Physical activity and effective coping skills to ease anxiety

Reporting in *MS News Today*, Marisa Wexler says that a recent review study indicates that getting more physical activity and having effective ways of coping with multiple sclerosis could help to ease anxiety in patients, a review study suggests.



“The findings of this review highlight links between anxiety in MS and a number of diverse factors, all of which are amenable to change,” its researchers wrote. *“We argue that further research is needed to develop interventions that can target these modifiable factors in order to reduce the experience of anxiety in those with MS.”*

The study, *“Potentially modifiable associates of anxiety in people with multiple sclerosis: a systematic review,”* was published in *Disability and Rehabilitation*.

Living with a chronic disease like MS can be anxiety-provoking, and it’s estimated that more than 1 in every 5 MS patients has clinically relevant anxiety — a rate that far exceeds the general population.

Even though anxiety is common with MS and substantially affects patients’ life quality, little is known about the factors that influence anxiety in these people. Understanding them could aid in developing ways that would better support patients in coping with anxiety.

A pair of scientists at Maynooth University in Ireland reviewed studies published between 2015 and 2021 that examined anxiety in people with MS. Of 3,116 in total, 39 studies met the inclusion criteria and were included in the analyses.

These studies encompassed 10,779 MS patients, most with the relapsing-remitting form of the disease (RRMS). With the exception of one study, a majority of the patients were female, with mean ages ranging from 24.2 to 58.3 years.

Combing through study results and looking for patterns across them, the researchers identified several factors that were consistently associated with anxiety.

Some had to do with lifestyle habits. In particular, a number of studies indicated more physically active patients reported less anxiety, and getting more physical exercise could ease reported anxiety. In some studies, for example, patients reported feeling less anxious after taking several weeks of calisthenics (exercises that rely solely on a person’s own body weight) or yoga classes.



“Our findings serve to emphasize the importance of physical activity for the treatment of anxiety comorbidities, further strengthening the case for developing targeted exercise programs for” people with MS, the researchers wrote.

Patients with more social support — those with strong connections to family, and particularly patients who regularly spent time with friends — also tended to report lesser anxiety.

“Interestingly, in those studies that investigated different sources of social support (i.e., support from friends, family, and/or significant others), social support from friends was consistently linked to better anxiety outcomes, while evidence linking anxiety and support from family and significant others was less conclusive,” the researchers wrote.

Several psychological factors also were noted as tied to anxiety; for instance, patients with high emotional resilience (a tendency to quickly recover from stress or changes) were generally less anxious. Those with higher self-efficacy (a sense of their own capabilities) also were less anxious overall.

Disease acceptance also affected anxiety’s intensity.

“Results unanimously suggest that higher levels of acceptance, as well as related concepts such as disability identity were associated with lower levels of anxiety,” the researchers wrote.

Likewise, a person’s coping strategies had influence. Patients who used strategies like trying to manage stress, adjusting expectations, and tenaciously but flexibly pursuing goals tended to have less anxiety. By contrast, other strategies such as maladaptive emotional regulation — in essence, getting upset with yourself for the emotions you feel — was associated with more anxiety.

These findings *“suggest that a range of lifestyle, social, and psychological factors may play a role in the experience of anxiety”* among patients, the researchers wrote, and *“offer some insight into how psychological wellbeing might be improved in this group, paving the way for targeted interventions in the area.”*

As *“clear links”* were seen between *“coping strategies and anxiety outcomes, it may be pertinent for MS service providers to assess the current coping strategies that PwMS [people with MS] depend on, as well as considering how best to foster more adaptive coping strategies associated with improved anxiety outcomes,”* they added.



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“Find walking difficult?”
This power chair is designed especially for
INDOORS, OUTDOORS AND TRAVEL
That’s the Freedom Chair advantage!

For a demonstration call Paul on 0800 466 626
paul@freedom-chair.nz • www.freedom-chair.nz

A life changing experience!

The advertisement for Freedom Chair features a red border. At the top is the logo, which includes a stylized red figure and the text 'FreedomChair' with a globe icon for the 'o' in 'Chair', and the tagline 'A power chair with a difference'. Below the logo is the headline '“Find walking difficult?”' in red, followed by the text 'This power chair is designed especially for' and 'INDOORS, OUTDOORS AND TRAVEL' in bold red. Underneath is 'That’s the Freedom Chair advantage!' in black. The center of the ad shows two views of a silver and black power chair: a front-three-quarter view and a side view. At the bottom, contact information is provided: 'For a demonstration call Paul on 0800 466 626' and 'paul@freedom-chair.nz • www.freedom-chair.nz'. The ad concludes with the slogan 'A life changing experience!' in bold black text.

Ocrelizumab Clinical Trial

This is a new clinical trial to examine if an injection of Ocrelizumab under the skin, vs intravenous infusion, is a safe and effective way of treating patients with Multiple Sclerosis (MS)

Who can take part in this clinical study?

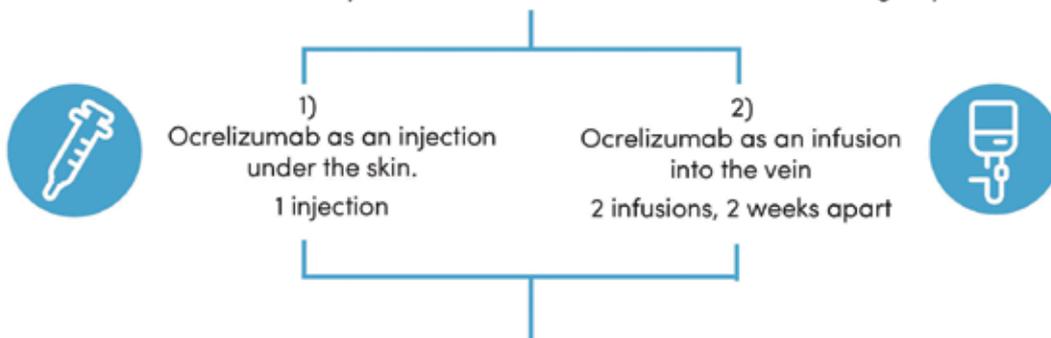
People aged 18 - 65 years who have been diagnosed with:

- a) Primary progressive multiple sclerosis (PPMS)
- b) Relapsing multiple sclerosis (RMS)

What does the clinical trial involve?

Week 1 - 24:

You will be randomly entered into one of two different treatment groups:



At 24 weeks:

Ocrelizumab as an injection under the skin.

At 48 weeks:

Ocrelizumab as an injection under the skin.

After 48 weeks:

Once you have had your last dose of Ocrelizumab you will be seen by the Doctor every 24 weeks (roughly 6 months) until 48 weeks (roughly 12 months) after your last dose.

During the clinical trial you will be seen by the Doctor and have regular tests (such as blood tests, mobility and function tests, and MRI scans) to check how you are responding to the treatment and any side effects you may be having.

For more information or to apply for this clinical trial please visit the 'Open Trials' section on our website or call 0800 737 327 to talk to one of our friendly team.

Support groups

Our groups meet virtually during COVID restrictions and in-person when they lift.

Support groups are for people living with MS as well as their spouses, partners, friends, siblings, children – basically anyone who is affected by MS.

They are fun! They are all about people coming together to connect, share stories, laugh, or shed a few tears, build each other up and make new friends.



Happy faces of our Manukau group at their January meet-up



The Community Advisor might have some news to share, or there might be a certain topic that people want to discuss. Mostly though the discussion is free flowing and moves easily from topic to topic. There really isn't anything quite as satisfying as meeting a group of people who you don't have to explain your MS to. They just 'get it'.

COVID lockdowns might be behind us but restrictions around in-person meetings have added some challenges, so we have kept these invaluable meetings on a digital platform. Everyone feels safe attending, plus there's no travel time!

Our list of groups, most of which meet virtually, is below. If you are not yet part of a group and would like to join, please contact your MS Community Advisor. They can suggest the group that fits best with you, usually based on area of Auckland.

Our groups

South / East Auckland

Pukekohe Café Group
Botany Café Group
Manukau Café Group
Men's Group

Central

Mt Wellington Café Group
Stonefields Café Group
Onehunga Group

West Auckland & Rodney

Kumeu Café Group
Henderson Garden Café Group
New Lynn Café Group
Silverdale Café Group

North Auckland

Mayfield Coffee Morning
Shore Lunch Group
North Shore Café Group

Newly Diagnosed Zoom Meetings

Date/ Time

First Thursday / Month - 11.30am
Third Thursday / Month - 11.30am
Last Tuesday / Month - 10.30am
Last Saturday of each Month - 10.30am

Second Saturday / Month - 11.00am
Third Wednesday / Month - Evenings
Third Tuesday / Month - 10.30am

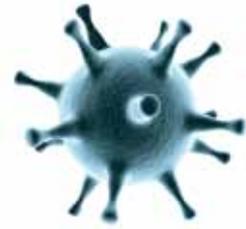
First Tuesday / Month - 10.30am
First Thursday / Month - 11.00am
Second Tuesday / Month - 10.30am
Third Wednesday / Month - 10.30am

First Thursday / Month - 10.30am
Last Wednesday / Bimonthly - 12.00 noon
First Saturday / Month - Mornings

Dates and times vary

**For more information on venues and times please contact
Tatjana on tatjana@msakl.org.nz or on 021 845 903**

EBV 'likely' main cause of multiple sclerosis



Just released ground-breaking research is suggesting that a globally common virus is also likely the main cause of multiple sclerosis and brings the potential for a cure one step closer.

Harvard academics found that the Epstein-Barr virus (EBV) - one of the most common viruses in the world - increases the chance of multiple sclerosis 32-fold.

Scientists have long speculated that the virus may be linked to the condition, but have been unable to provide any evidence to back this up.

"This is the first study providing compelling evidence of causality," said Alberto Ascherio, professor of epidemiology and nutrition at Harvard Chan School and senior author of the study. "This is a big step because it suggests that most MS cases could be prevented by stopping EBV infection, and that targeting EBV could lead to the discovery of a cure for MS."

Unpredictable symptoms

MS symptoms are unpredictable and can range from physical disabilities like mobility problems to mental health conditions, such as depression. Many people with MS report feeling an overwhelming sense of exhaustion, making simple tasks a struggle. In around a quarter of cases, the first noticeable symptom is a problem with one of the patient's eyes, including colour blindness and double vision.

In contrast, Epstein-Barr Virus infection is astoundingly common, and can be found in around 95 percent of people.

EBV infection can leave people feeling tired and sore, and is also known as mono (mononucleosis US) and glandular fever (NZ). After a person contracts the pathogen, it remains in their system forever, often without any symptoms but occasionally reactivating.

Prof Daniel Davis, professor of immunology at the University of Manchester, who was not involved with the research, said: "Well over nine in 10 people are infected with this virus worldwide, usually in childhood, and only very rarely does a problem arise.

"We already knew that this virus increases the risk of some cancer types, and now we know that it is also possibly a factor in multiple sclerosis, although it's important to note for most people that have the virus, it will not cause them any problems."

"Crucially, we do not know why only a small fraction of people infected with this virus develop a problem."

He added that other factors will be at play, such as genetics, and a cure may only be found once these have been identified.

Millions of military recruits

The US-based researchers studied the medical records of more than ten million people enlisted in the US military, of which 955 developed multiple sclerosis during their period of service.

Blood samples taken twice a year by the military were analysed by the researchers to determine if the person had the virus, and this was cross-referenced against a later MS diagnosis, which normally only begins to manifest ten years after the identification of EBV.

The risk of a person was found to be 32 times greater in people who tested positive for the herpes virus than in the minority of people who do not have EBV.

A protein and biomarker for nerve degeneration called NfL only increased in those who had been infected with the virus, the researchers write in their study, published in the journal Science.

Their findings cannot be explained by any other known risk factors for MS and suggest EBV may therefore be the leading cause.

Ascherio said:

"Currently there is no way to effectively prevent or treat EBV infection, but an EBV vaccine or targeting the virus with EBV-specific antiviral drugs could ultimately prevent or cure MS."

Once a person becomes infected with a herpes virus, the virus never leaves the body. After the first outbreak, the virus moves from the skin cells to nerve cells. The virus stays in the nerve cells forever. But it usually just stays there. In this stage, the virus is said to be dormant, or asleep. But it can become active again.



MS Auckland is grateful to all the individuals, whānau, volunteers and organisations who support our work.

We would like to acknowledge by name our current corporate partners, trusts, foundations and other supporting organisations.

Allied Medical
ASB Bank
Auckland Council
Biogen
Chenery Memorial Trust
COGS
Harcourts Cooper and Co
Hugo Foundation
Independent Living Service
IT Performance
John Ilott Charitable Trust

Lion Foundation
Lions Club of Remuera
Lottery Grants Board
Lynch and Associates
Nomad's Golf Club
Novartis Pharmaceuticals
Roche
Rod Milner Motors
Rotary Club of Newmarket
Sweep

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.

Consider leaving a 1% legacy to MS Auckland in your will; a small proportion for you, but a significant, lasting impact for Aucklanders living with MS.



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 in the office on 09 845 5921.

For more information visit www.msakl.org.nz



Life doesn't wait

TYSABRI® works fast^{1,2}

TYSABRI may reduce new lesions by >85% within 1 month¹ and reduce relapses by 87% within 3 months.² **Why wait any longer?** Talk to your doctor to see if TYSABRI is right for you.

TYSABRI[®]
(natalizumab)

TYSABRI® is a Prescription Medicine containing natalizumab 300mg/15mL in a sterile single use vial for IV infusion. **Approved Use:** TYSABRI is used for the treatment of patients with relapsing remitting multiple sclerosis (MS) to delay the progression of physical disability and reduce the frequency of relapse. **Before Use:** Do not use Tysabri at the same time as medicines that modify the activity of the immune system e.g. an interferon or glatiramer acetate. Your doctor should test your blood to check if you have antibodies to the John Cunningham (JC) virus before treatment and periodically during treatment. Like all medicines, TYSABRI has risks and benefits. Ask your doctor if TYSABRI is right for you. If your symptoms continue or you have side effects, see your doctor, MS nurse or other health professional. **During Use:** There have been reports of a rare viral brain infection called progressive multifocal leukoencephalopathy (PML) in patients who have been given TYSABRI. PML is a serious condition and can cause severe disability or even death. The risk of getting PML increases: 1) if you have been exposed to the JC virus; 2) the length of time on Tysabri, especially beyond 2 years; or 3) if you have taken a medicine to suppress your immune system (an immunosuppressant) in the past. The risk of getting PML is greatest if you have all 3 risk factors. If you have not previously been treated with an immunosuppressant and you have received TYSABRI for two years or longer, the level of your anti-JC virus antibody test results may help your doctor assess your risk of getting PML. For those with a lower risk of PML (if you do not have antibodies to the JC virus in your blood OR if you have been treated for more than 2 years and you have a lower level of JC virus antibodies in your blood) your doctor may repeat the test regularly to check if anything has changed. Some of the symptoms of PML are similar to MS. If you or your partner/caregiver thinks your MS is getting worse or notice new symptoms talk to your doctor as soon as possible. If your doctor suspects PML, they will want you to stop treatment with TYSABRI either permanently or until they can confirm it is not PML. Management of patients with PML may require removal of TYSABRI from the blood, usually by plasma exchange. This may lead to further serious complications, including worsening of brain (neurological) function. **Common side effects include:** pain or stinging when passing urine, sore throat, runny or blocked up nose, shivering, itchy rash (hives), headache, dizziness, nausea, vomiting, joint pain, fever, tiredness. **Serious side effects include:** signs of an infection, changes in your personality, thinking abilities or behaviour, yellowing of the skin or eyes, signs of a severe allergic reaction, difficulty breathing or chest pain, easy bruising, spots on your skin, heavier than usual menstrual periods, bleeding from gums or nose, bleeding hard to stop. Serious side effects are rare. **Further Information:** For further information see the TYSABRI Consumer Medicine Information available at www.medsafe.govt.nz or by calling 0800 852 289. Biogen NZ Biopharma Limited, 188 Quay Street, Auckland. TYSABRI is a funded medicine – a pharmacy charge and Special Authority criteria will apply. Normal doctors' charges will apply. **Revision Date:** January 2021.

References: 1. Rudick R *et al.* *JAMA Neurology* 2013; 70(2): 172-182. 2. Kappos L *et al.* *J Neurol* 2013; 260: 1388-1395. ©2022. Biogen® and TYSABRI® are registered trademarks of Biogen MA Inc. Biogen-150242. TAPS BG1952. Date of preparation: February 2022. BIOG00985/EMBC.

 Biogen