

AUTUMN 2024 / ISSUE 58

multipleneews

AUCKLAND / BAY OF PLENTY / ROTORUA & DISTRICTS

TOTAL
MOBILITY
FREEDOM

FABULOUS
LIFEBUOY

MASTERING
MOUNTAINS

The man with
two diseases

ms
MULTIPLE SCLEROSIS
AUCKLAND



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CONTENTS

AUTUMN 2024 / ISSUE 58



Cover story

6 The man with two diseases
Steve Keys does a little restoration

Features

8 Living a life
Clare Lawler gets outside her comfort zone

10 Living with MS
Joni Bentham finds a happy place

14 A full life
Suzanne Delores just happens to have MS

18 Life Buoy 2023
A big success again

20 So far...
Sandy Magill's 24 years with MS

Regulars

4 Welcome

5 Community Advisors

12 MSNZ Advocacy Update

13 Research

23 Volunteer Profile

24 Support Groups

26 MS Tidbits

27 Thank you

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WELCOME

Welcome to this 58th edition of *Multiple News*. This issue is bursting with inspirational and incredible stories from people just on our doorstep. Steve has always had a passion for cars, particularly collecting and restoring automotive memorabilia. His achievements are incredible for anyone; let alone considering that his biggest project was undertaken when he was dealing with the early symptoms of primary progressive multiple sclerosis.

Equally inspiring but in complete contrast, Clare is a young mum, occupational therapist, and champion wrestler! Clare lives with RRMS although she believes the major life choices that her diagnosis has forced her to make are for the better.

Are you aware of the Total Mobility programme offered by Auckland Transport? It offers discounted transport for people with mobility difficulties. Community Advisors can provide assessments. Check out the article to see if you're eligible. If you're not yet convinced, read about the difference that this little card made in Christine's life!

Both Joni and Duncan were competitive athletes prior to being diagnosed with MS. Joni describes her 'new' lifestyle; and Duncan his renewed goals with a Mastering Mountains grant, also within these pages. Suzie Deroles has been living with MS for over four decades. Think it might be slowing her down? Think again.

I'd like to acknowledge the many people and organisations who make this well-loved publication, *Multiple News*, available and free of charge. From our wonderful volunteer editor, Ross, to everyone who has generously shared their story, to our advertisers, this publication really reflects our exceptional community.

On that note, I encourage all who are affected by multiple sclerosis in some way, whether living with a diagnosis or close to someone who is, to consciously build a community around you in order to provide the right support, and understanding and robust guidance. Your local society has much to offer and is committed to identifying the little changes that make a big difference.

Noho ora mai rā
Nicola

MS Auckland team along with Ambassador Sam Smith at Paddy Gower has Issues



Total Mobility: freedom for the impaired



The Total Mobility scheme is a national scheme which supports people who cannot use public transport to travel, all or some of the time.

In Auckland, 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.

Total Mobility customers receive a 75 percent discount off taxi fares, up to a maximum fare cap of \$80 per trip. For trips over \$80, Auckland Transport will only pay a maximum subsidy of \$60 subsidy.

If you're an Auckland resident/ratepayer with an impairment that prevents you from undertaking one or more of these aspects of a journey: getting to a public transport stop; getting onto the bus, train or ferry; riding safely and securely; getting off the bus, train or ferry; getting to your final destination, then you may qualify for the Total Mobility scheme.

STEPS TO GET A TOTAL MOBILITY AT HOP CARD

- 1. Contact us.** MS Auckland is one of the agencies Auckland Transport (AT) partners with in Auckland. The Community Advisors are accredited by AT to give you accurate information on the TM eligibility criteria and to conduct full Total Mobility (TM) assessments. Ring the MS office on 098455821 to book an assessment. For MS Auckland members, the assessment and the TM card application are completely free.
- 2. Meet with one of the MS Community Advisors for a full TM eligibility assessment.** Once eligibility is established, the assessment is completed (+ photo).
- 3. Assessment is submitted to AT.** The new TM card should arrive in the mailbox in 10 working days.

Total Mobility clients will not be charged for new and replacement AT TM cards.

Please note that for MS Auckland's members there is no assessment fee. For non-members, the cost is \$70 for assessments at the MS Auckland office, and \$150 for home visit assessment within the Auckland region.

There is no longer a two-year renewal process for the Total Mobility Scheme in the Auckland region. If you have a Total Mobility card with an expiry date, it does not need replacing. New Total Mobility cards are no longer issued with an expiry date. 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.

The list of TM taxi operators and fares and guidance on how to book a taxi can be found on the Auckland Transport website: at.govt.nz

CHRISTINE JONES SAYS HER PRECIOUS WEE CARD IS GOLD

My TM card changed my life and took several stressful situations from me.

My main use of the card is getting to and from Auckland Hospital. As patients well know, the parking situation there is a nightmare. There's the huge problem of finding a park, and this involves driving round and round those tight bends from level to level, tense every moment for fear of scraping your car on the posts of the turns, as you can see many others have.

You need to go long before your appointment as you may not find a park for at least half an hour. Then there's the stress when you insert your card to pay and gaze unbelievably at the screen. \$21!! How can that be? I have regular four-hour infusions. But with my wonderful TM card I sit back relaxed in a taxi, dropped door to door.

The government has been paying three-quarters of our fare. I think the new government will reduce this shortly, but it will still be a lot cheaper than the real taxi fare. It's partly funded by councils anyway I believe.

And getting around in another city is a breeze even for those with very limited energy. Flying to Dunedin, Wellington or Christchurch? No need for a car. Use your card to go anywhere. As these places are smaller than Auckland, the trips are cheaper there. Want to go to an event in the Domain? Forget getting parking there unless you can walk a very long way. Just get a cab. That precious wee card is worth gold to me.

The man with two diseases

Steve Keys looks like a regular Kiwi guy. He sounds like a regular Kiwi guy. But he's a man with a couple of problems: one he is happy to have, the other, well, perhaps not so much.

Steve has primary progressive multiple sclerosis (PPMS), a somewhat less visible form of the disease which sees a gradual worsening of symptoms (progression) from diagnosis onwards without distinct relapses or remissions. It snuck up on Steve but by the time he got the diagnosis he had a pretty good idea about what was going on.

"I knew something was terribly wrong but wasn't sure exactly what. It was a culmination of two years of visiting doctors and asking what was wrong with my leg, but I kept getting told it was age-related weakness... it turns out it was this."

"Even after getting all the test results and receiving a final diagnosis, I thought that maybe they got it wrong. In a way, it was good to know that there was a reason for the symptoms. But I also thought it was just like a really bad cold and I'd get over it. It's obvious now that I'm not going to get over it".

Steve calls his other problem a disease too, an addiction even. But he's got his tongue firmly in the cheeky grin when he says it.

"I've been collecting automotive memorabilia probably for 40 plus years, and I feel very fortunate to have the collection in part of the house. And with the cars, it's just a wonderful hobby. I mean, I say hobby, but collecting is probably like a disease. An addiction? Yeah, I suppose it is".

Steve, ably assisted by wife Sue and sundry other local gurus, also restores old vehicles back to their former glories. There is a local and international recognition that goes with this.

More than thirty years ago, Steve started collecting the odd piece of service station memorabilia and now has an extensive collection. He does ongoing restorations on gas pumps and service station collectibles and is an avid collector.

His most recent project, achieved while dealing with the effects of multiple sclerosis, has been the long and difficult restoration of an extremely rare, original 1938 Diamond T streamlined Texaco tanker truck.

Steve has been immersed in classic and collectible cars his entire life with his late father, Les, owning vintage cars for more than four decades. Steve began building hot rods in his late teens and for the past 40 years has owned vintage, hot rod and classic cars.

In the late eighties, Steve built (and raced) a popular Mercedes 'doorslammer'; a 1986 500SEC. He has done a number of rebuilds over the years

"There must be a lot of people out there that are undiagnosed or newly diagnosed that don't want to face the music, I suppose. I'm past that stage now. I'm listening to the music."

with other projects being a 1964 Ford Fairlane Thunderbolt recreation and a 1951 Ford F5 Cabover.

The full restoration of the Diamond T was carried out over more than four years with help from a team of incredibly talented craftsmen and, in

February 2023, Steve and Sue unveiled the finished truck. They also discovered much of the tanker's history with help from locals in Newberry County, South Carolina who recognised it online.

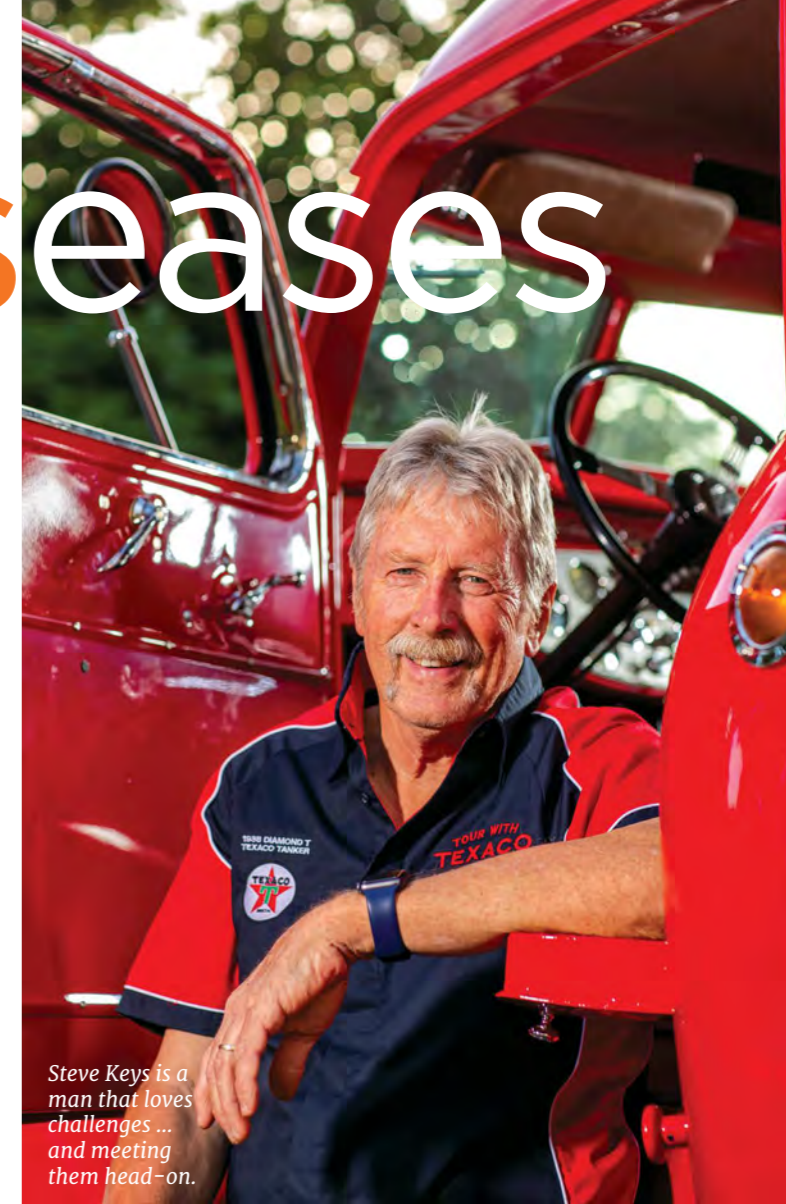
Research over five years has revealed that this truck is the only complete Diamond T streamliner tanker known to exist with a Heil tank.

Call Steve a glutton for punishment (these restorations are highly complex and demanding undertakings) but no sooner had he done with the Diamond T than an even more gargantuan undertaking came into his purview. The new restoration will actually be a recreation of the now extinct 'Doodlebug' tanker truck of which only seven were built between 1933 and 1934. Making things even tougher, there are none in existence and Steve and his team will be building from the ground up, so to speak.

"There are none left in the world, so we are going to reproduce one. It had a Diamond T chassis and a tank also made by Heil. It was a very unique vehicle, curved glass, engine in the rear and was very out there for 1933. It's going to be a big job."

Of course, making the big job even tougher also means having to deal with disease. Like all his projects, Steve deals with what is in front of him.

"I just try and brush it aside for as much as



Steve Keys is a man that loves challenges ... and meeting them head-on.



Far left: The rusted remains of the Diamond T tanker in a yard in Newberry County, South Carolina, in 2010.

Left: The next tank off the rank for Steve Keys: an iconic 1934 Texaco Diamond T Doodlebug.

Below: The restored 1938 Diamond T Texaco streamliner tanker now in pride of place at the Classics Museum in Hamilton.



possible. It's becoming increasingly harder to just ignore it and not to think about it getting a little worse. But I just keep pushing through".

Steve hasn't given up yet, but he is coming towards the end of his work on the smaller car projects he does 'in between times'.

"I've got another car that has been on my hoist out in the shed for six years. It's nearly finished and about to go on the road. And I've got a Dodge truck that I've had for years that I'm getting a guy to build out at Whitford."

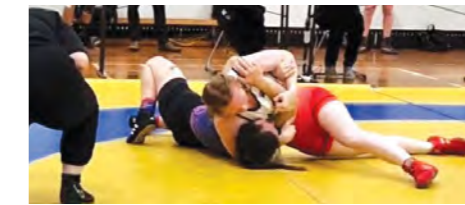
"I would like to add that I think MS Auckland does a wonderful job. Of course, you've got to get in touch to communicate your needs and ask for help. I haven't had a lot of interaction because I'm kind of independent, I think it's my problem and I'll just get through it. But I guess as time goes on, I might need to lean on them a bit but also try and help in any way I can."

"There must be a lot of people out there that are undiagnosed or newly diagnosed that don't want to face the music, I suppose. I'm past that stage now. I'm listening to the music."

If you want to know more about the exploits of Steve and Sue or dig further into the fascinating world of vehicle restoration, their website and blog is a great place to start: texacotankerproject.com



Living a life outside the comfort zone



With the power of hindsight, Clare Lawler wonders whether the complete hair loss she suffered at the age of 11 was her first symptom of multiple sclerosis.

It wasn't until more than a decade later, when she had studied health and was working as a honey production machinist, that she received her diagnosis. With no one else in her family known to have had MS, Clare felt like the relapsing remitting multiple sclerosis diagnosis she was presented with was the worst possible scenario. At least with something like cancer, she surmised, there may have been possibility of a cure.

On D-day, Clare returned home with the news, and her well-meaning partner immediately joked about wheelchairs. The year that followed, Clare's head was firmly buried in the sand. As a self-proclaimed 'functioning alcoholic', Clare, who described herself at that stage as a hermit, self-medicated in the worst way possible for her brain.

"A diagnosis of MS is make or break – I was broken for the first year. Then I decided that enough is enough. I want to do something more with my life".

With two primary school aged children at the time, as well as managing a full time career which became increasingly challenging with her MS symptoms, Clare took a step back and looked at her life. Health had always been of interest, and Clare decided to utilise her own challenges and capabilities to help others, and train as an occupational therapist. She undertook her studies during the challenging lockdown years.

Clare works 40 hours per week as a mental health occupational therapist. It's a demanding community-facing role which has intentionally forced Clare outside her comfort zone. Working days are planned a little around energy levels,

conducting demanding home visits in the mornings with office work in the afternoon. Fatigue and cognitive fog are Clare's most stable systems, together with total sensation change down her left side, and her left leg being a 'ghost limb'. She also has to deal with foot drop issues.

With her two busy children, Dominic and Natalie, and their various activities, Clare found herself supporting Dominic's new-found sport, wrestling. Natalie quickly decided to give wrestling a go too, and of course Clare couldn't just sit on the sidelines! She started joining in the warm-ups, then progressed to full training.

That was just under two years ago. Now, Clare trains six days per week. Upon finishing work and collecting her kids, she undertakes a rigorous two and a half to three hours of training. This typically involves a half hour warmup followed by fighting then strength and conditioning training.

Mobility, speed, power and strength are all key ingredients of wrestling: but the essential ingredient is psychological strength. Now, she claims to feel the best she has since diagnosis, and thinks this has to do with her fitness and the high intensity exercise she goes through. She has even lost the sensory pain when entering cold water!

Clare loves food but maintaining her weight (57kgs) is essential to her sport. She eats clean food, less carbohydrates, no sugar (a change from the old Clare!) and high protein.

Clare's opponents are able bodied which gives Clare a buzz. "Everyone has a negative, self-doubting inner voice. I love to show mine that it's wrong! And I'm in control".

Clare has just returned from Guam, competing in the Oceania Wrestling

Champs and says it was another magnificent experience. She bought back a bronze medal to go with the one she won last year and has continued to make international connections in an effort to help the next generation of wrestlers to have a

"A diagnosis of MS is make or break – I was broken for the first year. Then I decided that enough is enough. I want to do something more with my life".



better variety and future within the sport.

What's the driver? To show her kids and others that anything is possible.

Set your mind to something, and follow through with your dedication, thoughts and reasonings.

"Without MS, I wouldn't have my career in occupational therapy, my wrestling, and for making me push myself. I push myself outside my comfort zone"

Where to next? Clare's dream is to get to the Olympic qualifiers.

"If I hadn't got MS, I'd certainly have a more narrow view of the world. MS has made me see everything a couple of shades lighter. I don't take things for granted – no day is promised to us!".

"I'm glad it's me and not someone else with this diagnosis. I'm completely stubborn!"



WHY ENTER AN EVENT?

Community advisor Penelope Butler gives us some valuable pointers

There are lots of benefits of entering an event and maybe even putting yourself outside your comfort zone...

- Gives instant motivation
- Sets a challenge with a calendar date to work towards
- Online event social media groups can help with queries and event planning and give a sense of camaraderie
- Great topic to tell your friends/whanau/colleagues all about
- Social fun: you can enter with friends/whanau, can train together, motivate each other, travel to the event together, celebrate together afterwards!
- Explore new areas within Auckland or New Zealand; or further afield
- Take the opportunity to fundraise for a charity and gain further motivation to complete your event from your friends and family backing you
- Great sense of accomplishment and you may even get a medal too: finishing is winning!
- Bragging rights; you've earned them
- Inspire others with your contagious enthusiasm sharing your experiences
- Build confidence to set your next challenge or enter your next event

Finding a happy place

JONI BENTHAM ON LIVING WITH MS

It's been quite a journey since the early days of MS. I was diagnosed in May 2006, feeling afraid of the future. I was experiencing odd neurological symptoms in the legs like numbness and a feeling of being uncoordinated while running. Being a triathlete and multi-sporter, that was frustrating and unnerving. Also, there were vision problems and numbness, leg weakness and balance issues. Looking back, those first few years were rough in that I didn't know what to expect day to day and in the years to come.

When I was diagnosed, I wasn't bad and was told there's nothing to help me, go home and keep calm! Nowadays there's an abundance of medications that can help.

It was a bit of a lucky break being in Melbourne at the time, with many more funded medications than here. Though now that I'm back I'm being very well looked after by Dr Chancellor and the neuro team at Tauranga Hospital. I am on one of the latest disease-modifying therapies, Ocrevus, which slows progression, may even halt it.

I'm quietly confident things will stay as they are, and I'll avoid any further progression.

I am told multiple sclerosis is caused by your immune system mistakenly attacking the brain and nerves. It's not clear why this happens but it may be a combination of genetic and environmental factors. Patches of inflammation, which can be seen on an MRI scan, can disrupt the messages travelling along the nerves. It can slow them down, jumble them, send them the wrong way, or stop them completely. This disruption leads to the symptoms and signs of MS.

When the inflammation goes away, it can leave behind scarring of the sheath (sclerosis). These attacks can eventually lead to permanent damage to the underlying nerves.

Again, it's not clear what causes the immune system to attack the myelin sheath. It seems likely that it's partly caused by genes you inherit and partly by outside factors that may trigger the condition. I learnt that some of the factors include:

- **YOUR GENES:** MS isn't directly inherited, but people who are related to someone with the condition are more likely to develop it; the chance of a sibling or child of someone with MS also developing it is estimated to be around two to three in a hundred

- **A LACK OF SUNLIGHT** and low vitamin D levels may play a role in the condition
- **PEOPLE WHO SMOKE** are about twice as likely to develop MS
- **VIRAL INFECTIONS**, particularly those caused by the Epstein-Barr virus (responsible for glandular fever), might trigger the immune system, leading to MS in some people
- **BEING FEMALE** – women are two to three times more likely to develop MS than men; the reason for this is unclear

There's currently no cure for multiple sclerosis but treatment can help manage it. In recent years, new medications have become available to help slow the progression of the disease and relieve symptoms.

To date there's more than a dozen disease modifying therapies approved to treat MS.

Researchers continue to develop new treatments and learn more about the causes and risk factors of this disease.

Several other medications are working their way through the research pipeline, and have shown promise for treating MS. So, there is a lot to be hopeful about.

Now, back with the uncoordinated running. I spent most of my time in denial, but there were meltdowns and finally this pursuit was reluctantly deemed unsafe, the triathlons were off the list and it was time to reassess. It quickly dawned on me how valuable my swimming ability is and that I'm incredibly lucky that, oddly enough, my arms are unaffected.

To this day it's swimming that keeps me sane is the one piece of certainty in this uncertain condition. I can jump in the pool or ocean and swim, around the Mount or Pilot Bay for three or four kilometres with my other unusual and dear swimming buddies. It is my happy place, where it seems I'm without MS.

Also, I can't say enough how valuable the support and care of the Bay of Plenty MS Society was, and still is. I'm sure you've all been in a place where you've felt like the black sheep of a group, it's isolating and depressing. Having this Society was a godsend in those times, someone to talk to, reassure, advise or to put you in touch with someone who can.

Nowadays I understand the pattern of my MS, what aggravates it, what helps, I've had no new



The water sets Joni free from her MS

lesions or new symptoms for years so touch wood. I've become quite good at living life fairly simply; there's little room for stress, because that makes everything worse. I pay more attention to the good times than the bad, laughing helps.

But the other important things for life to run smoothly, something that applies to all of us I could suggest, are having purpose, direction, a bit of hope, and a lot of love!

Poem about living with multiple sclerosis by MS Bay of Plenty member Janette Barclay

Dancing Painblobs

When I've been in my bed a while,
The Painblobs come and play,
Dancing around my pelvis bones,
Things they don't do in the day!

I dread when they do star-jumps,
The pain travels up my spine,
I change the settings on my bed,
Stop them making a bee-line.

It's annoying that they wake me,
Feel the choreography of the pain,
Their dancing jigs and reels around,
I don't want their visit again!

Painblobs are unique, you know,
Each person has their own,
White-hot and sharply spikey,
Cause faces to fiercely frown!

I would like to live in a world,
Where Painblobs are forbidden,
No nasty, cruel, hurtful tricks,
On the elderly and 'bedridden'.

©Janette G Barclay

July 2008

Update from MSNZ

The new year has gotten off to a flying start and it is full steam ahead in the MSNZ office. There's lots to update you on this edition. More information about each of these updates can be found on our website at www.msnz.org.nz/latest-news.

Neurological Alliance

Multiple Sclerosis NZ is a proud member of the Neurological Alliance along with 19 other allied organisations. In 2023, the members of the Alliance came together to develop a briefing for the incoming Minister of Health, Dr Shane Reti and fellow MPs with health portfolios to highlight the common issues that our organisations and the people we support face. The Alliance has pooled its collective knowledge to identify the four most important actions Government can take to optimise brain health, reduce inequities and better serve people in our communities with neurological conditions. Our priorities are based on feedback from our members and their experiences on-the-ground supporting people with neurological conditions, their carers and whānau:

1. Address health workforce shortages to speed up diagnosis and treatment.
2. Increase funding for pharmaceutical treatment to improve quality of life.
3. Increase funding for community-based care and support services.
4. Improve data collection on neurological conditions.

We hope to meet with Minister Reti this year to be able to discuss the issues further.

The full briefing and more information about our identified collective priorities can be found on our website.

Sativex

In December 2023, Pharmac proposed to decline funding for inactive applications, this included an application to fund Sativex for MS spasticity. MSNZ has written to the Pharmac Board to ask that this application remain live, and we be permitted to present more evidence regarding the patient need. Sativex is currently unfunded and costing approximately \$300 per month. Should our request be accepted, MSNZ will be looking for stories from people with MS to highlight the burden that non-funded Sativex places on those diagnosed and their whānau. You are welcome to send your personal story to info@msnz.org.nz.

Shingrix

Pharmac announced in February it was looking to extend funded access to Shingrix, the new

vaccination for shingles, to immunocompromised people over 18 years old. However, the proposal listed specific treatments and conditions eligible. While we were pleased to see people who are pre- or post-haematopoietic stem cell transplant included, we were disappointed that MS DMT's were not. While not all DMTs are immunosuppressive, some are at varying degrees and times. Together, MSNZ and Dr Jennifer Pereira wrote on behalf of the MS patient and clinical communities to call on Pharmac to widen their proposed criteria to include people with MS, particularly those on immunosuppressive therapies.

Disease Modifying Therapies

Towards the end of 2023 Pharmac's Neurological Advisory Committee and Pharmacology and Therapeutics Advisory Committee (PTAC) each met to review applications for various upcoming MS treatments. These treatments present a potential expansion in the suite of MS treatments that clinicians and patients can choose from, introducing new administration regime options and the first potential treatment for those with secondary progressive MS.

“Offering the full range of therapies that can reduce disease activity improves the chance of finding the best option for each person with MS” MS Brain Health

In September the Neurological Advisory Committee met to review two disease modifying therapies, Mayzent® (Siponimod) for the treatment of secondary progressive MS, and a subcutaneous version of Natalizumab® (Tysabri SC) for relapsing remitting MS. Both treatments received medium priority recommendations and will now be put to the PTAC for further review.

In November PTAC reviewed the revised application for funding by Merck for Mavenclad® (Cladribine). Multiple Sclerosis NZ wrote a supporting submission to call on Pharmac to fund this treatment which is highly considered and well used overseas for RRMS. Mavenclad's® administration is different to any other treatment currently available in NZ. Administered in two treatment courses over two years, each treatment course consists of two treatment weeks. We expect to receive the minutes of the meeting in early March.



To stay up to date with our advocacy work visit www.msnz.org.nz/latest-news

MSBase: a collaborative approach to real world data

Apart from MS research projects, NZ MS Research Trust is also focussed on providing support to neurology services and clinicians within New Zealand, the setting up and maintenance of MSBase. www.msbase.org

In October 2016 the Trust funded its foundation project, a “A Feasibility Study on the Introduction of a National MS Patient Registry”, conducted by Dr Caroline Allbon. The final report was submitted in July 2017 and concluded with the recommendation to introduce MSBase to New Zealand.

Since the completion of the feasibility study, the Trust has been working to establish two pilot sites in Waikato and Canterbury. Currently the Trust has funded Te Whatu Ora – Health New Zealand Waikato to input all the clinical records of people with MS into the MSBase registry. MS Waikato has played a key part in getting patients' consent and their enrolling into the project. The Trust is looking forward to working with Te Whatu Ora – Health

New Zealand Waitaha Canterbury in a similar way, in the coming months.

MSBase encourages global research and observational studies using ‘real world’ data. With consent, MSBase enables people with MS to participate in global collaborative research using non-identifiable data, which would otherwise be difficult to achieve.

With over 97204 patient records currently in the system and 43 participating countries, New Zealand is now a global partner contributing to improving the understanding and management of MS, and ultimately a cure. Data from Waikato patients has already been used in three international studies.

The Trust continues to strive to reach its goal for vital funds to support more centres around the country to join the MSBase patient registry as well as stimulating other MS research projects in the coming years.

Less restrictive low-fat diet seen to lessen fatigue in MS

Adhering to a low-fat diet for three months was found to significantly ease fatigue among people with multiple sclerosis according to data from a pilot 16 week clinical trial. The diet, which restricted total fat intake to less than 20 percent of calories per day, had a good adherence. Unlike other strictly plant-based low-fat diets, participants were allowed fat from lean animal protein sources, such as chicken, turkey, lean fish, and egg whites.

“A low-fat diet can truly make a difference in a patient's fatigue level, even without going so far as to make it a vegan diet,” Vijayshree Yadav, MD, the study's senior author and a professor of neurology at the Oregon Health & Science University School of Medicine, said in a university news story.

Overall, according to the researchers, “this 16-week pilot study of a diet intervention that included a significant reduction in saturated fat and increased carbohydrates and fibre calories appears to [lessen] fatigue in [people with] MS.”

Fatigue is a common and disabling symptom of MS, a progressive disease characterized by inflammation and damage to healthy parts of the

brain and spinal cord.

However, medications targeting MS-related fatigue have failed to show benefits. Meanwhile, several dietary interventions (including the palaeolithic, ketogenic, Mediterranean, and intermittent fasting diets) have generated mixed results on fatigue.

“Fatigue is very disabling for these patients,” said Yadav, who also serves as the director of the OHSU Multiple Sclerosis Centre.

“There is no [U.S. Food and Drug Administration]-approved drug for fatigue, but we know that fatigue greatly affects their quality of life,” Yadav added.

Low-fat diets have been studied for weight loss and their benefits in people with cardiovascular disease. Such diets loosely have been defined as those with a saturated fat intake of less than 20 grams/day, or a total fat intake corresponding to less than 10% of daily calories.

Full details of the study, “A low-fat diet improves fatigue in multiple sclerosis: Results from a randomised controlled trial,” was published in the Multiple Sclerosis Journal.

Living a full life...



Suzanne Deroles doesn't like to muck around. There is far too much life to be lived to sit there with a woe-is-me hat on.

Suzie (like everything, she's relaxed about the name but is happy with the informal version) was diagnosed with relapsing remitting multiple sclerosis (RRMS) when she was a nineteen year old university student. She was at the Picton Youth Hostel when she woke up in the night and realised she had lost all movement on her right hand side. Attempting to get out of bed she fell flat on her face. Managing to walk with great difficulty, with uncontrolled movement and with slurred speech, she thought, "this is weird".

Diagnosis back then was no simple process. This was 1977. There were no MRI's. A local doctor was baffled. Specialists in Nelson and Christchurch figured it out through a process of elimination. A lumbar puncture some three years later confirmed the diagnosis.

Suzie has been living with MS for 41 years now. Her mother was told she would be in a wheelchair by the time she was 45. Fat chance!

While Suzie was not taking a whole lot of notice of that foreboding prognosis, she couldn't write and she couldn't think with the level of analysis required for learning. She quit university and with her then partner she joined a shearing gang and, along with other farm work, saved enough to buy a hobby farm in Takaka. She was physically active and a keen trumper so was able to keep up with the rigours of a demanding work environment. Suzie is quite proud of her wool classing certification for fine wool.

When Suzie and her then partner (amicably) decided on separate paths, she packed her bags and went travelling. Her four years of travel would provide enough material and excitement for a book.



Top: The Masters Games obstacle courses can be tough at the best of times - wearing a wig for every event doesn't help. Above: The heights of achievement and enjoyment. Left: Conquering the Great Wall is worth smiling about.

just happens to have MS

Across the USA and the UK Suzie worked her way, picking peas, grading potatoes, berries, beans, chickens, you name it. She also spent time as a 'granny nanny' in the UK and visited other countries like Iceland, Spain and Turkey: a life full with adventure, excitement and exploration.

In London, working to live and looking for something different, she answered an advertisement in a magazine to join in the delivery of some trucks and equipment to Uganda, a year-long expedition. This led to her travelling the length and breadth of that continent, visiting some 22 countries, contacting malaria and at one point being involved in a serious bus crash in South Africa.

Joining expedition company Phoenix Overland as a courier, Suzie dragged her MS along with her and didn't seriously consider anything going wrong. She didn't even have travel insurance. She will be the first to admit to a little recklessness and a good dose of luck. Apart from a few minor episodes and a fair bit of tripping over, she emerged unscathed.

By 1994, Suzie was back in New Zealand. She had previously purchased a section on a beach in Collingwood as she didn't want to come back to

nothing after her travels. She did have plans to build there but also wanted to be around family and was aiming for Taupo but ended up a block back from the beach at Mt Maunganui. She looked after her mother at her Mount house for the last three years of her life.

At the Mount her life took off on another tangent. Through the cajoling of friends and associates she re-established her love of exercise and found

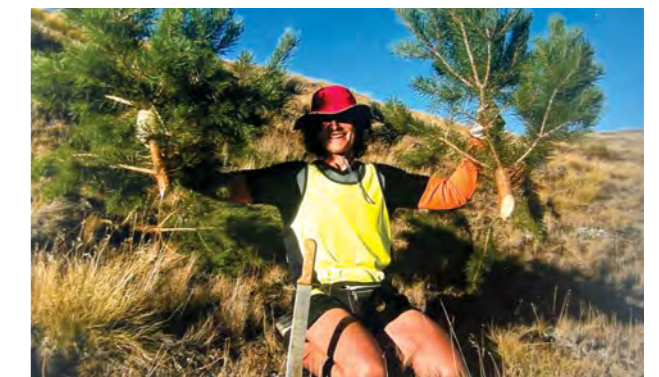
enjoyment in competitive endurance events. She joined the local triathlon club and tramping clubs which led to the challenges of off-road running, something that has stayed with her to this day.

She found the more she trained and exercised the better she felt, the less the MS seemed to impact on her and the more she could do..

She found the more she trained and exercised the better she felt, the less the MS seemed to impact on her and the more she could do: big lesson for us all! 48 kilometres has been Suzie's

longest distance. While she enters competitive events, it's not about the winning, it's about the challenge, the finishing and the camaraderie.

There have been events and walks across New Zealand and around the world as budgets permit; Antarctica, the Great Wall of China. Tri Club friend Leslie has a goal of seven marathons on seven continents and invariably Suzie has been a



Top: Suzie pictured at Slope Point was a keen participant in the Great New Zealand Trek the length of the South Island that raised some \$35,00 for MS. Left: Reach for the sky- the red hills of Richmond Forest Park. Above: Wilding pines don't stand a chance.

companion on a couple of these. She is hoping to be in Athens for a 10 kilometre event in November.

In 2017 Suzie moved to her bach on a flat section in a quiet street in Taupo to start another chapter of her eventful life. While things might be slowing down just a little bit, they're not stopping and at 66 years of age she still gives little heed to her MS.

Over the past few years she has been undertaking voluntary work clearing wilding pines on the Molesworth Station. She reckons she has been at it 13 or 14 times now and her team has cleared some 32 square kilometres using axes, handsaws, slashers and machetes. It is the outdoors, the quiet and the clean air that Suzie loves.

All her life Suzie Deroles has been inquisitive by nature. The physical activity is only part of it. Apart from the running, walking, swimming, kayaking and gardening,

For Suzie Deroles it has never been about fighting MS. It's been about living, about being someone who just happens to have MS.

there is the reading, sewing, applique and, importantly, the art. She has a double garage as an art studio and dedicated to her artistic endeavours. Most people chronicle their lives and their journeys with photography. Suzie

does it with her art. She uses whatever medium is at hand, charcoal around a campfire for example, and generally each artwork is totally different, including in style.

She doesn't have a computer. Her mobile is the most basic available and even then she's going to be hard to pin down: A "Suzie here, I'm out doing stuff" message will be the invariable result of a call. Such has been Suzie's life of experiences and adventure you feel that if she had any time left in her full days she would actually be writing that book.



She does not drive so walks everywhere. Until recently she even had a part-time role clearing overgrowth from a reserve in Turangi. She hitchhiked there when needed.

For Suzie Deroles it has never been about fighting MS. It's been about living, about being someone who just happens to have MS. When correction is needed, you do your rehab and you come right. MS doesn't influence her decisions and has never been a reason for taking any particular direction.

When *Multiple News* caught up with Suzie she had just returned from Golden Bay where she had been clearing still more wildings, helping a friend on his land, catching up with mates at the dog trials and marvelling at the light playing on the snow on the tops after a recent cold snap.

When people tell her, "You've done so well", she doesn't argue.



Top: Pine trees on the Aratiatia dam Above: Suzie gets warm on the Antarctica half marathon. Left: Autumn willows on the Otago Rail Trail



Butter bean & vegetable soup

From MS Queensland



Difficulty Easy **Servings** 6
Preparation 15 min. **Cooking** 50 min.

Ingredients

- 35ml olive oil
- 150g onion, peeled and finely diced
- 2 tsp (10g) crushed garlic
- 1 tbsp tomato paste
- 1 tsp fresh thyme, finely chopped
- 750ml vegetable stock, hot
- 500g cauliflower, stalk removed and cut into 2cm pieces
- 200g carrots, peeled and cut into 2cm pieces
- 200g mushrooms, sliced thickly
- 150g red capsicum, core removed, de-seeded and cut to 2cm cubes
- 450g frozen peas
- 2 x 410g cans butter beans
- 2 x 410g cans crushed tomatoes
- 2 stalks spring onion, thinly sliced
- Salt and freshly ground black pepper

Instructions

1. In a large pot, heat half the olive oil over a medium heat.
2. Add onions, garlic, tomato paste and thyme. Cook, stirring occasionally, until onions are soft.
3. Add in half of the vegetable stock and the cauliflower. Bring to the boil and cook for approximately 5 minutes, until cauliflower is soft.
4. Allow to cool and purée with hand blender until smooth.
5. Heat remaining olive oil in another large pan and add carrots and mushrooms. Cook for 2 minutes, then add capsicum. Cook for a further 5 minutes.
6. Add the carrots, mushrooms and capsicum into the cauliflower purée along with peas, butter beans and crushed tomatoes. Bring to a boil.
7. Add remaining stock and salt and pepper. Return to a boil and reduce to a simmer.
8. Cook for 20 minutes uncovered on a medium heat until stew has thickened.
9. Serve garnished with spring onion.



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Another fabulous success!

MS Auckland's fabulous fundraiser luncheon, Life Buoy for MS was held at a new venue, the Hyundai Marine Sports Centre in Tamaki Drive, on Sunday 12 November. It stands as another humbling success for the organisation with over \$100,000 raised for the local MS community. The generous contributions from auctioned items, pledges and donations raised in excess of \$100,000 to support people living with the challenges of multiple sclerosis.

There were some fabulous items up for grabs, every dollar raised supporting the MS community: fantastic memories could be made from a special meal with Sir Graham and Lady Raewyn Henry, a classic yacht experience, a family day out, beautiful jewellery and special sporting memorabilia.

A moving welcome address from MS Auckland general manager, Nicola Bitossi, set the tone for the event. She said, "I'm incredibly proud to be part of an organisation that makes a big difference. Because anyone can be impacted by MS, and it plays out differently for each one, MS Auckland provides a range of programmes to help everyone with MS live as full a life as possible".

Two hundred supporters enjoyed a delicious three course lunch in a stunning location with captivating views over the Waitemata Harbour, highlighted by a typically openhearted talk from Kiwi sports legend Ruby Tui. Ruby told her avid audience she only started playing rugby after she finished school. She says she wasn't the strongest player but had coaches



who believed in her, and, in a lesson for all of us, she persevered and kept going.

Ruby spoke of the connection she formed with a young fan who had recently been through extensive cancer treatment and spoke of her 'dusty eyes' when the girl gifted Ruby her favourite bead from her hospital treatments necklace after Ruby gave her her Rugby World Cup medal. Dry eyes were getting scarce on Tamaki Drive too!

A Q&A session with Sir Graham Henry and Ruby, facilitated by MC and former Black Fern Melodie Robinson, was both genuine and amusing. Especially when Sir Graham was pushed on whether he preferred coaching the boys or the girls!

MS Auckland member Shea Tagilala shared her story of total right side paralysis when first diagnosed with MS, through to relearning how to walk – and paint with her left (non-dominant) hand. During the luncheon, Shea completed her stunning painting of a huia bird. It was sold by auction at conclusion of the event for \$2,400.

In the time since the event, MS Auckland has been able to: provide personalised support plans for well over 100 people living with multiple sclerosis, advice and care for whanau and carers affected by multiple sclerosis, plan annual training for more than 30 volunteers who give regular support to people with MS in the community and offer subsidised attendance at specialised exercise classes for people with MS on low incomes.

1. The one and only Ruby Tui
2. Sir Graham Henry and Ruby Tui's 'panel' chat with MC extraordinaire Melodie Robinson
3. Ruby Tui with Nicola Bitossi, GM MS Auckland
4. Ruby Tui with the Allied Medical team
5. Shea Tagilala and Melodie Robinson
6. Sir Graham Henry and Ruby Tui
7. Shea's Huia painting
8. A full house at the Hyundai Marine Sports Centre



MS AND ME ... SO FAR

Sandy Magill's 24 years with multiple sclerosis

The year 2000 was a year of many changes...

My mother, with whom I was extremely close, was diagnosed with breast cancer for the second time, and members of the public who had specific ailments like asthma, and other debilitating illnesses were offered the flu vaccination for free from medical professionals in our communities. My daughter who was a very bad asthmatic was one of these people who was offered a free flu vaccination. When we visited our GP, my daughter feared having the injection, so I had one with her. My life changed five days after that.

We had always been a 'busy' family; children Sam, 12 and David eight (in 2000). On the Friday afternoon, after having our injections, my husband was taking part in a round Waiheke Island sailing race.

The kids and I were at Blackbridge Riding School, where Sam's horse was boarded and grazed and where we cared for her. David was playing with our friends' children who lived on the property,

one being Sam's coach. I also had riding lessons there, with an emphasis on dressage. Sam was competing at this time, and we were up at the stables every afternoon. We lived at Gulf Harbour at the time. I would pick both kids up from school five days a week and then visit the horse as we did at weekends.

On this particular day I told the kids that as Dad was away for the weekend and that I wasn't feeling 'right' I was stopping in at the doctors on the way home. At this time my feet were tingling and leaden. I saw a doctor who checked me over and told me to drive directly to North Shore Hospital as a precaution.

Of course, I drove home (30 minutes), fed the pets, rang my parents to meet us at North Shore Hospital to take the kids for a sleepover as I was becoming increasingly frightened by what was happening to me. So, the kids with their overnight bags, and I started off on our 60-minute drive.

As Samantha was sitting in the front (only 12 years old remember) I asked her to tell me if my right foot ever lifted from the pedal as I could not feel it. The paralysis was slowly moving up my body. By the time we reached the hospital at the reception area, the numbness was up to my thighs. I fell out of the car. Thankfully a security guard brought a wheelchair for me. My kids were screaming and crying and luckily my parents were there by then to help. I was taken into Emergency, had an ECG, as well as all the usual observations. I was paralysed up to my armpits. My kids went off with my parents.

I was transferred by ambulance to Auckland Hospital's Intensive Care Unit. It was there I was examined and told I had Guillain-Barre Syndrome which often starts at the feet and travels up the body before hopefully receding out of the body. I was to spend 10 days in ICU. My husband was located at sea and rushed to me at ICU.

After a few days I was told that no, I had MS, probably from the Guillain-Barre Syndrome, but no one was specific. Remember it was 2000 and MS cases were not as prevalent or as well understood as today.

It was a terrifying time for my family. The kids were told to go and say goodbye to Mummy as she was dying. There was no counselling of any description available for my husband and he just had to 'handle' everything ...Thankfully he did.

The 10 days I spent in ICU are a blur: MRI's, spinal taps, blood tests, x-rays, being fed as I couldn't feed myself, a catheter...etc.

Life changing, not life ending...

From that moment forward I began to learn about and research multiple sclerosis as much as I could. At that time (April 2000) information on Guillain-Barre and MS was scarce.

At the beginning I had relapsing remitting MS, which meant I would have an episode of MS and then it would go, and I would regain around 75 percent of my 'normal' life. At this time, as my kids grew older, they were always caring for me. I worked (had very understanding employers, but I was a good worker for them), I rode horses, supported Sam with her riding competitions and was there for David, my son and Bill, my husband. During this time and those episodes, I rested much of the time. Sometimes I could not drive so wonderful friends helped.

Over the last 20 years I have been totally paralysed, blind, deaf, had to use a crutch, had to stop horse-riding six years ago and stopped driving five years ago. My MS has progressed over the years to me now having secondary progressive MS. Mobility is now limited, there is no walking and so, I use an electric wheelchair.

Memory now fades after a short time each day. For example, I cannot follow a knitting pattern. At some stage I have suffered a stroke which has affected my right side. I was also right-handed but now, of course, I am left-handed.

I have carers in my home three times a day. I can no longer shower, dry or dress myself. I have all my meals served to me, cut up where needed, as I can only use a fork.

You may think this sounds like a very bleak existence. I say no, no, no! Everything can still be achieved. You just have to do it another way! Every day my glass starts full of energy. It just empties as the day goes on. When it's empty, I go to bed ...



I no longer go out at night or drink alcohol, but boy, my days are fantastic! I am now a published author. I have spoken to many newly diagnosed MS people and tried to help them to understand that their life is changing and not ending.

I have changed my diet to be mostly raw and whole foods. I am not sitting on my hands; my social life is buzzing. I have coffee with friends five days a week. I belong to a knitting group, meeting each week to create for charity). I belong to a discussion group and boy do we have some meaty debates! I have been on committees (I live in a retirement village). I have a new hobby propagating indoor houseplants.

I have learnt that pain killing drugs are my best friend. As I relax in my electric Lazyboy I ponder on my future.... not very long as it's a bit bleak!

However, I strive to make each day as meaningful and as full of fun as I can make it.

And laugh ...



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A life changing experience!

Mastering Mountains

BY DUNCAN GRANT. Duncan is one of MS Auckland's seven trained Peer Support Volunteers

I have always been up for a challenge in life especially in the sporting realm. Sport and fitness have been my life, albeit now slightly adjusted.

I started ocean swimming in 2011. I couldn't run anymore (little did I know at that stage this was because of MS) so my best mate threw me his old wetsuit and said there is an Ocean Swim series down at Kohimarama beach every Thursday.

I entered the smallest distance, which was 500m, I mean I could swim like any other kiwi but not distance swim. Well, what an eye opener that was as I ended up like a drowned rat after 500 metres, but I made it.

Being the stubborn person that I am I decided to conquer this ocean swimming gig. I went to the pool, got one of my top swimmers at the school I teach at to help with improving my technique.

Slowly I knocked off the 500 metres at the ocean swim series, then the 1000 metres, then the 1500 metres and finally was comfortable swimming the 2000 metre distance and so my addiction began. I have since swum numerous ocean events around Auckland and knocked off the Rangitoto to St Heliers swim of 4.6 kilometres in 2019.

When my MS diagnosis was given to me in 2020 and damage was done due to a relapse, I had to change my whole mindset on what swimming meant to me. It has taken me a few years but now swimming is about my mental health; swimming with friends and not about what time I achieved or how far I swam. More recently I have come to realise that maybe I could inspire others with MS that exercise especially as swimming has so many benefits no matter what stage of MS we may be at.



Duncan takes a breather somewhere between Rangitoto and the mainland.

I knew of the Mastering Mountains Charity (for those with multiple sclerosis and functional neurological disorders) formed and chaired by Nick Allen. I thought this would be the perfect avenue to get my love of swimming out there, so I applied for the grant with my mission to swim that 4.6-kilometre Rangitoto to St Heliers swim. You must have a challenge that is in the outdoors to be accepted.

I was lucky enough to be accepted and was granted money for a gym membership, a new wetsuit and neuro physio sessions to help me achieve this goal. The Rangitoto to St Heliers swim was in November 2023, I was granted the funding in July 2023.

So, my mission began, swimming in the ocean through the winter which I have done for several years but however this year I had two attacks on my nervous system in the cold water which scared me. Cold affects me not the heat, so I went to the pool to continue training.

The gym was a revelation which I am now totally addicted to. I started attending Les Mills Body Pump around three to four times a week. I was extremely nervous due to my left leg weakness and lack of ability to do lunges properly. But this soon passed as when looking around everyone else was as well, and they didn't have MS!

I was on track for the November Rangitoto swim. Then with seven days to go before the swim I tested positive for COVID! And it hit me hard. I couldn't believe it! All that training. I sat in my room and cried. My fifteen-year-old daughter came in and hugged me and gave me her favourite soft toy to cheer me up, which I keep on my bed.

It was time to refocus. I came up with a new plan. The plan was to swim three of the Ocean Swim Series races. The first being the Bean Rock Lighthouse 3.2 kilometres in February 2024, the second to swim the Harbour Crossing (3.2 kilometres) in March 2024 and the final swim, Swim the Mount 2.8 kilometres at Easter in 2024.

I ramped my training back up. I swim with my ocean swim group called the 'Kohi Kippers'. Some training swims included swimming Rotoroa Island, Goat Island and numerous ocean swims from Kohimarama beach to the various marker sticks out in the gulf. Even when on holiday I found pools and gyms to continue with my workouts.

The Kohi Swim Series started back up in October of 2023 and I religiously swim these races every Thursday at Kohimarama Beach. I am about to swim the first of my three ocean swims for Mastering Mountains. This is the iconic Bean Rock lighthouse swim. You can follow my journey on Instagram swim.for.ms and you can find out more about Mastering Mountains at masteringmountains.org.nz

Story to be continued in *Multiple News*...

PEER SUPPORT

Volunteer profile: Sylvia Apostol



Tell us about yourself

I really like talking to people and helping people. I find it heartwarming. It makes me feel good about myself. I'm a high school student, in year 10 at Rangitoto College.

I love playing the piano. I play every day for at least an hour. I like experiencing and trying new cultures. I'm Romanian myself so my culture is quite complex and there's a lot to learn about it.



Sylvia (centre) with the Round the Bays team

I also like other cultures. My friends are a very diverse group; Mexican, Indian – we celebrate each others' cultures and foods. I'm also learning Spanish at school.

Another thing about me is that I love to write. I have written many stories before. I also love telling my stories to my Mum, reading them to her. I find it fun to just release all my creative juices into a story and then step back and look at everything I've created. I love that. I love writing.



MS Auckland has seven trained Peer Support Volunteers who are available to talk to you on the phone or over a coffee. They provide mentoring and support from the perspective of having walked a similar path to you.

What got you into volunteering?

I think we've always been a helping family. Maybe it just runs in the genes. I like to help out wherever I can. It's really nice seeing smiles on people's faces and seeing that I put them there.

You've volunteered at most of MS Auckland's community events over the last five years. What is your favourite?

Round the Bays is so much fun. I love volunteering there and walking with people who volunteer or have MS. You meet so many new people and people from other charities.

Do you do any other volunteering?

I also volunteer for the RSA. I go to their meetings whenever I have time and make tea and coffee and help serve food. I also raise money for them whenever I can. I collect for them at the Takapuna Mall. Everybody has a different story and it's great to uncover them.

What do you think you're going to do when you leave school?

I haven't told Mum this but I might want to join MS Auckland too, alongside mum! I get to help people and go to the events. I might want to do that. But at university, I might want to study sciences.

What's your favourite place in the world?

My bed! And wherever my family is.

If you could have dinner with anyone, dead or alive, who would it be?

Freddie Mercury, for sure! I went to the Queen Adam Lambert concert a couple of years ago. Freddie, 100%!

The power of connections

Come along to the group that you never wanted to belong to! Humour, friendship and warmth are what MS Auckland's coffee and support groups are all about. It can be really positive to have regular connection with others who quite simply 'get it'!

Most of our groups meet in-person for coffee. We also have virtual group options for those who prefer to connect in this way.

Our list of groups is below. If you are not yet part of a group and are interested in finding out more, contact the Community Advisor team on info@msakl.org.nz or 09 8455921. They can suggest the group that fits best with your needs and/or where you live.

"Having the support group is the most important thing. It's interesting, some people ask me, why do you want to hang around with others with this disability? But it's just a group of people who have something

in common. It doesn't matter what it is - my husband belongs to a car club. You've got to look at it that way, rather than saying I'm going to get support... or something to do with my condition.

"It's a group of people who just come together and have a good time and enjoy everyone's company."
-Bronwyn Young

Below: North Shore group members enjoy Christmas Lunch at the Remuera Club



FIND A GROUP FOR YOU

For more information including venue/link, please contact us info@msakl.org.nz or 09 8455921

SOUTH/EAST AUCKLAND		
Pukekohe Café Group	First Thursday / month	11.30am
Botany Café Group	Third Thursday / month	11.30am
Manukau Café Group	Last Tuesday / month	10.30am
Men's Group	Last Saturday / month	10.30am
CENTRAL		
Mt Wellington Café Group	Second Saturday / month	11.00am
Stonefields & Onehunga Café Group	Third Wednesday / month	10.30am
WEST AUCKLAND & RODNEY		
Kumeu Café Group	First Tuesday / month	10.30am
Henderson Garden Café Group	First Thursday / month	11.00am
Silverdale Café Group	Third Wednesday / month	10.30am
NORTH SHORE		
Shore and Mayfield Lunch Group	Last Wednesday / bimonthly	Midday
North Shore Café Group	First Saturday / month	10.30am
NEWLY DIAGNOSED		
Zoom meetings	Dates & times vary	
Mt Eden Café Group	Last Wednesday / month	6.30pm
North Shore Café Group	Third Saturday / month	11.00am
GENERAL GROUPS		
Zoom coffee & chat (all welcome)	First Wednesday / month	10.30am
Whānau group Zoom	Fourth Monday / month	6.30pm

Bruce Cameron Honorary Life Member



Bruce Cameron comes from a family of community-minded people with voluntary involvements including Kiwanis, Coastguard, Scouts, St John Ambulance and Riding for the Disabled.

So when Bruce's wife Margaret was diagnosed with multiple sclerosis around 2000, it's not surprising that he started to become involved with his local MS society. "I wanted to show my support for Margaret" he says.

Bruce was heavily involved for more than a decade, including as Secretary of the Committee and even acting Manager of MS Auckland. Bruce was one of the top bucket collectors and heavily involved in

fundraising as well as support groups.

Bruce was nominated for the Esme Tomblinson carer of the year award in 2011. He had given up his own career in food technology to care for Margaret. They were proud recipients of one of the first mobility dogs in the country.

Bruce's extensive community involvement with MS Auckland, in addition to caring for Margaret, had to be curtailed when he experienced his own health issues, including brain cancer. Both Bruce and Margaret are currently well cared for in a retirement village with children and grandchildren close by. Bruce reflects on his relationship with MS and MS Auckland: "Margaret was diagnosed, and I've been looking over her shoulder ever since".

Bruce was made an Honorary Life Member of Multiple Sclerosis Auckland in 2013 for his extensive service.

Obituary John Street

We acknowledge the passing of former MS Auckland Ambassador, John Street. John, together with his wife Lorraine, were made MS Auckland's inaugural Ambassadors in 2013.

John and Lorraine were married for over 60 years. They had three daughters: Melanie, Louise and Philippa (Pip). Pip was diagnosed with multiple sclerosis in 1993 and sadly passed away in 2020. The family's involvement with MS Auckland has been a lengthy one, spanning 30 years.

Lorraine and John first started the Life Buoy fundraising event in 2014. These events have been MS Auckland's largest single income source, raising well over a million dollars over the years. Lorraine and John's network, organisation and generosity has ensured the success of Life Buoy and by extension, sustainability of the life-changing impact that MS Auckland can have. John and Lorraine were made Honorary Life Members in 2019 in recognition of their contribution via Life Buoy.

John's career and passion was the maritime industry. He was honoured with a Member of New Zealand Order of Merit (MNZM) for his contribution to all things marine in 1996.

John was a giant in boating circles, both when he worked in the marine industry and later in his retirement, where he devoted so much energy to preserving New Zealand's maritime heritage. Largely due to John's tenacity and hard work, New Zealand proudly has perhaps the largest classic boat fleet in the world.

Other volunteer involvements of John's included founding and chairing the Auckland Volcanic Cone Society. John was also a key supporter of Richard Dodson, assisting the former America's Cup sailor to compete in the Paralympics following his MS diagnosis.

Nicola and Jan attended his memorial service on behalf of MS Auckland and were humbled by the depth of John's reach: a person who did so

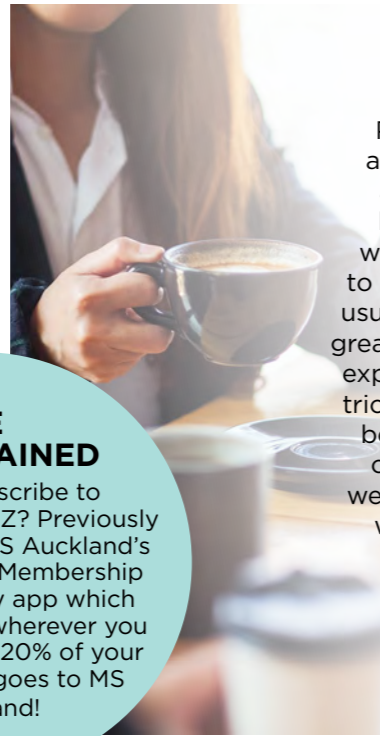
much, impacting and inspiring a great number of people and leaving a truly unique legacy. We give our utmost respect and gratitude to all that John did for MS Auckland. Our heartfelt thoughts are with Lorraine, Melanie and Louise and whānau.



Left: John Street and wife Lorraine

A SIZZLING FUNDRAISER!

Amit and friends raised more than \$1,000 for MS Auckland with a sausage sizzle and bake sale at Bunnings Mt Roskill. As well as raising funds, the event helped get the community thinking and talking about multiple sclerosis. Thank you so much Amit and crew, fabulous effort and result!



OTHERS IN THE SAME BOAT

We have a fabulous group of Peer Support volunteers who are from different walks of life and face different challenges but are all in a positive space with their MS. They are trained to provide one-on-one support, usually via phone calls. They are great at listening, validating your experience and sharing tips and tricks. If this sounds like it could benefit you, email info@msakl.org.nz or call 09 8455921 and we'll connect you with someone who fits your situation. There's nothing like connecting with someone who 'gets it'!

ORIGINS OF MS

Researchers have given insight into how the genetic risk of multiple sclerosis may have originated. Looking at ancient genome data sets, the genetic risk for MS rose among pastoralists from the Pontic steppe and was brought into Europe by the Yamnaya-related migration approximately 5,000 years ago. (Barrie, W., et al, Nature, 625, 2024 <https://www.nature.com/articles/s41586-023-06618-z>)

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MOBILITY EQUIPMENT REPAIR

Independent Living accepts applications for free repairs on mobility products from those not in a position to be able to pay ilsnz.org

MS Tidbits

Bits and pieces from the MS world



DO YOU NEED HELP WITH CLEANING?

Jim's Cleaning has a new initiative aimed at providing pro-cleaning services to people who are handicapped, disabled, or single mothers who may not have the time or resources to keep their homes/offices clean.

Their team of highly trained and experienced cleaners will ensure that homes are spotless, allowing people to focus on other important aspects of their lives. The service will be tailored to specific needs and preferences.

Individuals or families who meet the criteria and could benefit from these free of charge cleaning services, can reach out to Jim's Cleaning directly at 0211974635 to schedule an appointment or inquire further.

HIGH USE HEALTH CARD

This card helps a person with some medical costs (such as doctor's visits and prescription costs) if they have ongoing health problems that mean they often visit the doctor.

To get this card, the person needs to have made 12 or more visits to a doctor or nurse at the general practice where they are enrolled, in the previous 12 months. Getting the card does not depend on how much the person earns. The card can only be used by the cardholder and does not give benefits to the rest of the family. The general practitioner will make the application for the card on the person's behalf.

If someone already has a Community Services Card, they don't need to apply for a High Use Health Card because the discounts relating to medical costs are the same. However, for people with a High Use Health Card, there is an advantage in also having a Community Services Card because that card enables enrolled patients to get lower cost fees and gives subsidies to dependent family members.

To find out more, search for High Use Health Care, Ministry of Health.

BEQUEST

Michelle Hall

Receiving a legacy gift is always humbling. Recently, Michelle Hall left a gift to MS Auckland.

Michelle was an active member of MS Auckland for nearly 20 years and well known within our community. Michelle passed away in December 2022. MS Auckland's team of Community Advisors supported her intensively as she negotiated various health challenges and life changes. In the words of Luminita Apostol, Senior Community Advisor:

Michelle Hall loved the good life: she loved singing, a good meal, socialising, making new friends and entertaining the old ones. Her voice was clear and loud as was her mind.

No hidden agendas in her world, all honest and transparent: "I struggle with this. Can you help?", "How am I going to do this? Any ideas?"

Severely physically disabled, nothing would stop her mind from soaring above all the body's inaccuracies. Michelle took pride in her home, her relationships, her achievements... but she was also very lonely. It was a world in between the four walls of her home furnished with struggles, frustrations, ineptitudes, always trying to adapt her body to complete tasks that many people take for granted (brushing teeth, combing her hair, doing dishes, some days just simply mobilising from one room to another).

And it was another world outside her home, a world in which Michelle was courageous, loud, gregarious and fearless.

These were the two Michelles I was fortunate to know: I admired and supported both; understood them, too.

Many members are not in a financial position to donate to MS Auckland during their lifetime, but may consider leaving a legacy gift, as Michelle did. As little as just one percent can make a significant and lasting difference.

Michelle, we acknowledge your generosity in supporting people who will walk the challenging road of MS in years to come. Thank you.

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 one percent 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 8455921.

THANK YOU

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
- ARA Lodge 348
- Auckland Council
- AutoPal Vehicle Servicing
- Care on Call
- COGS
- Deloitte
- Diamonds on Richmond
- Furley Digital
- Gibbs Farm
- Harcourts Cooper & Co
- Hugo Foundation
- Hyundai Marine Sports Centre
- Lindsay Foundation
- Lions Club of Remuera
- Lottery Grants Board
- Lynch & Associates
- Rehabilitation Welfare Trust
- Milner Mobility
- Sweep
- Te Pou



PEOPLE WITH
MULTIPLE
SCLEROSIS WILL
HAVE **DIFFERENT
SYMPTOMS AT
DIFFERENT TIMES,**
AND WILL ALL
EXPERIENCE MS
DIFFERENTLY

INTERVENTION WITH
**DISEASE MODIFYING
TREATMENTS (DMT)** CAN
CHANGE THE COURSE
OF MULTIPLE SCLEROSIS

IF YOU'RE
SUPPORTING
SOMEONE WITH MS,
BE **OPEN** TO WHAT
THEY **NEED**



MULTIPLE
SCLEROSIS IS
A LIFE-LONG
**NEUROLOGICAL
DISEASE** OF
THE CENTRAL
NERVOUS
SYSTEM



**DIET, EXERCISE
AND STRESS
MANAGEMENT**
ARE IMPORTANT
IN THE
MANAGEMENT
OF MS

AROUND **1 IN 1,000**
NEW ZEALANDERS
LIVES WITH A
DIAGNOSIS OF
MULTIPLE SCLEROSIS

ms
MULTIPLE SCLEROSIS
AUCKLAND