

Issue 69 - May 2021

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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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Introducing our Patron

Kay Gregory is a familiar face to many and MS Waikato are honoured to be able to introduce her as our Patron.

Kay has been a Broadcaster for 40 years. Her roles have included being a Reporter and Weather Presenter for TVNZ and Co-host of the Breakfast programme. She is currently a Radio Newsreader for the NewstalkZB network.

Kay has had extensive involvement with charities, including Parkinson's Auckland, and Dress for Success where she was their ambassador for two years. She has served on the board of the Sky City Community Trust and the Neurological Foundation National Council.

Kay has been a Marriage and Funeral Celebrant for 20 years. She is actively involved as a volunteer for Rowing New Zealand and a very keen golfer.

Kay says she didn't hesitate when asked to become involved with MS Waikato.

"I have a friend whose daughter was



diagnosed at the age of 32, so I was already aware of the need for a big support network'.

Kay says she's looking forward to learning more about MS and helping to raise awareness of something many people don't understand.

One of Kay's first MS events was the annual Michael Ford Golf Tournament.

"That was a very fitting way to start, and of course there was no way I was just going to hand out the prizes - I had to play as well!"

The Michael Ford Memorial Charity Golf Tournament

Our golf tournament, held recently at Ngahinepouri golf club was a very successful day. The event is one of our major fundraisers and is now in its 21st year.

We had a good turnout for the tournament with many players who have supported us previously; and a few new faces on the course too. The event raised a total of \$9,382.

Overall best Stableford was awarded to Roger Neal, with Joanne Ford joining us to assist with the prizegiving ceremony.

Thank you to our generous sponsors and to the players without which the tournament would not be possible. In particular, we would like to thank the Ngahinepouri golf club who donated the course to us for the day and our Platinum sponsor MitoQ. Thank you also to our wonderful volunteers – Sue who gave up her time to assist on the gambling hole and Kay Gregory, our Master of Ceremony.

Our sponsors help in a variety of different ways, some making a monetary donation, others donating prizes or services for the day. They choose to do this to help make a difference; all funds raised remain in our region to assist with the provision of support and education services for our clients and their families.

Please do remember our sponsors and support them too.

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COVID-19 vaccination guidance for people with Multiple Sclerosis

Never in our history has there ever been such a mass vaccination program as the COVID-19 vaccination program. There is a mountain of information about vaccines out there and it is often confusing and complicated. Here we try to break down some of the basics on the COVID-19 vaccination and how it will affect people with MS.

This article is designed to complement the more clinical advice around COVID-19 vaccination for people with MS.

What is vaccination?

Vaccination is the safest way, and sometimes, as in the case of COVID-19, the only way to protect yourself against some specific infections. Vaccination aims to train your immune system against a virus or bacteria that otherwise would cause disease if you were to encounter it. In other words, vaccinations give you immunity to those bugs.

How does vaccination work?

There are many different types of vaccines, but generally, they use a harmless form of the virus, or part of the virus to train the immune system without making you sick. The immune system remembers this bug, so if a vaccinated person encounters the virus later, the immune system already knows how to mount a suitable response.

Should someone with MS have the COVID-19 vaccination?

It is currently recommended that everyone over the age of 16 years should be vaccinated against COVID-19. There is no specific data relating to the administration of any of the vaccines to a person with MS, but studies in the US, EU and Australia are currently being conducted. However, there is no theoretical reason why any of the presently available vaccines should pose any particular risk to a person with MS. The chances of developing COVID-19 are genuine, and the risks may be higher in a person with MS who also has some disability or other health conditions.

The risks in contracting the disease far outweigh any conceivable risks from the vaccines. The current advice is that people living with MS should be vaccinated **unless advised not to do so by their treating neurologist.**

What is the COVID-19 vaccination?

One vaccine has been approved by Medsafe so far for distribution to New Zealanders later in 2021. The Medsafe approved treatment is the Pfizer/BioNTech vaccine (10 m doses) and requires a course of 2 doses.

The Pfizer vaccine is what is called an mRNA virus. These vaccines use mRNA and our cells own protein manufacturing mechanism to produce the “spike” protein of the SARS-CoV-2 virus that causes COVID-19. This in turn triggers an immunological reaction against the spike protein thereby conferring immunity. This is a new mechanism for vaccination. These vaccines have proven to be 95% effective in large phase III, placebo-controlled, clinical trials. Serious adverse events were seen no more frequently in those receiving the vaccine versus those who received placebo (sham injections). The only side effects that were seen in slightly higher numbers in those receiving the vaccine were local injection site reactions, chills/fever, headache and fatigue/tiredness. These were mostly mild or moderate in severity. These vaccines do not contain eggs, preservatives or latex. From the way that these vaccines work it is not anticipated that there would be any additional risk of adverse outcomes and side effects in a pwMS, including those on treatment. It is considered that for a pwMS the risks of contracting COVID-19 far outweigh any potential risk from the vaccine. These vaccines have been authorised for use in US, EU, UK, Canada and many other countries.

The New Zealand Government has invested:

- more than \$37 million into the COVID-19 vaccine strategy, allocating funding to international and national research as well as manufacturing of vaccines.
- \$27 million in COVID-19 vaccine development through the COVAX Facility, a global initiative to distribute safe and effective COVID-19
- hundreds of millions of dollars has additionally been allocated for vaccines that are safe and effective.

Where do people with MS fit into the vaccine rollout?

The first doses of the Pfizer vaccine arrived on Monday 15th February 2021 in Auckland,

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MS COVID-19 vaccination guide

Continued from page 3

with 12,000 border workers, followed by their household contacts being the first to receive the vaccinations. Vaccinations have now progressed to the Governments group 2 – high risk frontline healthcare workers and people living in high risk places.

Limited information is currently available on the rollout plan which is expected to take place later in 2021. The vaccine rollout is expected to be based on the level of risk of contracting the disease. Multiple Sclerosis New Zealand has contacted the Ministry of Health to understand where those with health conditions such as Multiple Sclerosis are considered in the roll out strategy.

What is Herd Immunity?

Herd immunity is the idea that if a large enough percentage of the population is vaccinated, it is difficult for the virus to find an unvaccinated person to infect and spread. Not only does this limit the spread of infection but it also limits the chance of the virus mutating or changing. Herd immunity is also essential in protecting people who can't be vaccinated themselves for various reasons, such as age or immunological diseases. It is currently unknown exactly what percentage of the population needs to be vaccinated to produce herd immunity, but experts believe it to be around 75%.

How effective are the different vaccines?

Like any medical intervention, no medicine is 100% effective, but vaccines are the most effective way of preventing COVID-19, especially severe COVID-19. There are variations in people's immune systems, there are variations in the virus caused by mutations, and there are variations in the vaccines themselves. Vaccine "efficacy" is indicated by the percentage reduction of disease in a vaccinated group of people compared to an unvaccinated group.

Among the COVID-19 vaccine candidates, there have been different efficacies reported. This is varied and depends on the vaccine, the study, and the population they are being used in. But generally, they are all considered to have a significant impact on the virus responsible for COVID-19.

Previously, diseases such as smallpox and polio have been eradicated from New Zealand by effective vaccination strategies, and without any other options COVID-19, vaccination is the only line of defence we have. Vaccination protects yourself and the community around you. If you have any concerns about vaccination, it is essential to talk to your healthcare team.

For more detailed information about each of the different vaccines, visit the MS Society of NZ website.

Source - MS Society of New Zealand

AGM Updates

The MS Waikato AGM was held on the 25 March.

There have been a few changes to the board with both Marsha Marshall and William Hughes retiring. Both Marsha and William had been Trustees for several years. Our Trustees all work in a voluntary capacity and we would like to express our sincere thanks and appreciation to them for the time they gave and the knowledge they shared.

Desley Park will continue as Chairperson, our other Trustees are Keith Small – Deputy Chairperson, Mark Etheridge, Mike Tuck and Graham Derrick with Dave Cordery being co-opted to the board too.

We farewell ME/CFS and Fibromyalgia

For 12 years ME/CFS and Fibromyalgia clients have been supported under the umbrella of MS Waikato.

During this time the group has grown considerably, and had recently sought to separate itself from MS Waikato to create their own identity.

Following discussions with the Bay of Plenty organisation Complex Chronic illness Support Inc. (CCIS) an agreement was made and CCIS has welcomed the ME/CFS group into their midst. They have a great model for service, which is a much better fit for supporting those affected by ME/CFS and allied conditions than under the MS umbrella.

Tracey has transferred to CCIS where she will continue to be employed to provide support services to the ME/CFS group. Following a transition period, the group transferred on the 1st April.

CCIS is an excellent organisation! Originally established in 1981 as the Bay of Plenty ME Support Group (renamed CCIS in May 2018) it is among the longest-serving support organisations in the world for people affected by ME/CFS.

To learn more about CCIS view their website <https://ccisupport.org.nz>.

Why do our brains stop repairing myelin as we get older?

A new study has discovered a specific gene plays a major role in myelin repair becoming less effective as we age.

To stop MS from getting worse, we need to find ways **to repair damaged myelin** – the protective coating around nerves in our brains.

Although our bodies have the natural ability to repair myelin, this process breaks down in MS. Recently, researchers have discovered that ageing is a key cause of this breakdown. But they aren't sure exactly why.

A new study published this week has started unravelling what happens to cause the natural myelin repair process to stop working properly when we get older.

Genes behaving badly

We usually think about genes as the things responsible for characteristics we inherit from our parents, like eye colour. But genes do much more than that. They set in motion all the activities needed to provide our cells with instructions for what they need to do, and when they need to do it.

The study by researchers from the UK, Germany and Italy compared the brains of young and old mice to see which genes were not behaving normally. They found the genes that provide instructions to myelin-making cells were the most affected by ageing.

In particular, a gene called GRP17 played a major role in making myelin repair less effective in the older mouse brain.

Stem cells can't transition to myelin-making cells

Myelin is repaired or replaced by special cells in the brain called oligodendrocytes. These cells are made from a type of stem cell found in the brain, called oligodendrocyte precursor cells (OPCs).

GRP17 is responsible for instructions to OPCs that are in transition, on their way to becoming fully mature oligodendrocytes. The study found changes in how GRP17 gets those instructions

to the OPCs. And this made it harder for the OPCs to turn into oligodendrocytes, which meant myelin repair was less effective.

The researchers also tested a number of molecules that could potentially help older OPCs behave more like young OPCs. One molecule was able to effectively improve myelin repair in older mice.

Potential for new treatments

By uncovering the role of GRP17 in the breakdown of myelin repair as we age, the researchers have identified a potential target for treatments to slow MS progression.

One of the authors, **Dr Kasum Azim from the University of Dusseldorf said:** "This approach is promising for targeting myelin loss in the aging brain and demyelination diseases, including multiple sclerosis, Alzheimer's disease and neuropsychiatric disorders. Indeed, we have only touched the tip of the iceberg and future investigation from our research groups aim to bring our findings into human translational settings."

The interaction between ageing and myelin repair is becoming a hot topic in MS research. Just last week we announced **a commitment to raise over a million pounds in funding for research at our Cambridge Centre of Excellence which** will include a strong emphasis on understanding myelin repair over the lifespan.

Dr Emma Gray, our Assistant Director of Research, said: "We can see a future where no one has to worry about MS getting worse but, for that to happen, we need to find ways to repair damaged myelin."

"This research sheds light on why cells that drive myelin repair become less efficient as we age, and we're really proud to have helped fund it. Improving our understanding of ageing brain stem cells could have important implications for future treatment."

<https://www.mssociety.org.uk/research/latest-research/latest-research-news-and-blogs/why-do-our-brains-stop-repairing-myelin-we-get-older>

Wednesday 10 March 2021

HD Education Evening

Another successful education evening with our HD community was held in March with guest speakers, Ruth Mylchreest, Eileen McManus and Dr Matt Phillips, our HD Neurology team.

Ruth (Clinical Nurse Specialist) opened the evening speaking about her role in working with those living with HD and supporting them to be able to do the things that matter most to them. She is the link between the community, MS Waikato registrars and specialists. She facilitates and coordinates the HD cluster clinic appointments and any acute appointments when required.

When a change in medication has been prescribed, patients can contact her directly if they are experiencing any issues. Ruth can also action referrals to other departments when required, such as speech

language therapy, community dieticians, Disability Support Link and social workers. She can also coordinate family meetings for ongoing care. This enables everyone involved in your care to meet openly to discuss any issues and involves a multi-disciplinary approach. MS Waikato are very grateful to have Ruth as a contact point at neurology, this helps provide a better wrap around service for our families.

Eileen (Advanced Trainee of Neurology) spoke next. She started with a brief overview of HD, highlighting when HD creates an impact in one's life and how it can affect all areas of life – physical health, psychological health, level of independence, social relationships and spiritual wellbeing.

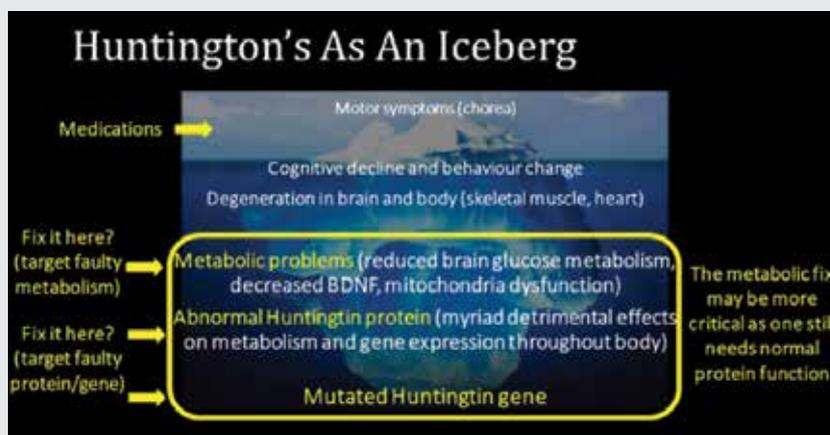
Eileen then spoke of her interest in understanding the role of mitochondria in neurodegeneration diseases such as HD. Some animal and human studies indicate that HD patients have abnormal glucose tolerance test results or elevated insulin resistance potentially resulting in metabolic syndrome. Therefore targeting metabolic syndrome in Huntington's Disease might be beneficial for

treating this disease, which forms the basis of her hypothesis. Eileen is seeking participants for her study, if you are interested, please contact her on the email detailed below.

Eileen McManus Eileen.McManus@waikatodhb.health.nz

Lastly Dr Matt Phillips, (Neurologist) spoke of HD being like an iceberg. What we typically see are the physical symptoms of chorea. Just under the surface are less obvious symptoms (at times) such as cognitive decline and behavioural changes. Drug treatments that target these issues only support the symptoms and not the disease itself. Matt is

interested in treating HD at the level of protein dysfunction via metabolic approaches, such as the ketogenic diet and strategic fasting. Keto diets are high fat and very low carbohydrate intake, which increase neuron use of fat-derived



ketones to increase energy, and in turn reduce cell and protein degeneration and dysfunction. The main goal of a keto diet is to mimic the fasting metabolic state to optimise neuron metabolism.

Matt is proposing a research study group and is interested to hear from anyone who would like to participate.

If you are interested please contact: Matt Phillips at Matthew.Phillips@waikatodhb.health.nz

It was great to see many of our families present on this night. It gave me the opportunity to say farewell and best of wishes to you as I depart MS Waikato. I have grown very fond of our HD community and have enjoyed supporting you all over the last seven years. For ongoing support please contact Liz Hogan and Karen Bird. It brings me great comfort to know that I leave you in good hands with Liz, Karen, Ruth and the Neurology team at Waikato.

Go well

Nga mihi

Tracey Larsen

NOTICE BOARD

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or are housebound due to an illness or disability. Volunteers phone clients regularly to check that everything is ok. The service is free, if you wish to enquire about receiving a regular call from a Caring Caller phone 0800 000 606.

TravelScoot

We have a TravelScoot available for short term loan for a donation. For more information contact Liz or Karen.

Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

MS Education Evening

MS Waikato warmly invites you to the annual MS education evening with Neurologist Dr. Jan Schepel.

**Thursday 27 May, 6.15pm
(for a 6.30pm start)**

The Link (corner River Road and Te Aroha Street)

This will be followed by a light supper. We would appreciate a donation towards the evening; there will be collection pots at the venue.

Please RSVP by Friday 21 May

Phone 834 4741, Text 027 428 7417 or email liz@mswaikato.org.nz

Payments

If you wish to make any payments directly to MS Waikato please pay into account number 02 0316 0488196 000.

Please remember to include your name and what the payment is for eg Subs.

Dogs in Homes

For the safety of our staff please ensure all dogs are secured when staff visit.

Phasing out of Cheques

As New Zealand banks phase out cheques, please note we will be unable to cash any after 30 June 21

Scooter Batteries

If you need to replace the batteries in your scooter we may be able to assist, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

Subscriptions

Please note 2021 subscriptions are now due. The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received. Thank you for your support.

Entertainment Book

MS Waikato are selling the Entertainment books again this year. The books are now digital and contain thousands of dollars worth of vouchers. The books can be purchased as a single city, multi city or multi year. MS Waikato will receive 20% from each book sold. For more information visit <https://nz.entdigital.net/orderbooks/1b54128> or contact janet@mswaikato.org.nz to receive this link.

Donations

Donations to MS Waikato can be made directly to the MS Waikato bank account. Receipts will be sent for all donations, if you are not a client please advise Janet of your address – janet@mswaikato.org.nz. Donation can also be made through our website www.mswaikato.org.nz, please click the link 'Donate now' and it will take you to the Spark Foundations give a little website. Alternatively, a direct link to this site is through www.givealittle.co.nz/org/MSWT, please note give a little now charge 5% commission.

Thanks to our Sponsors and Supporters



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MSWT EVENTS CALENDAR



June 2021

SUN	MON	TUE	WED	THU	FRI	SAT
		1	2 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3 MS Support Group Hamilton Venue to be advised 10.30am	4	5 MS Walking Group 9am The Veranda Cafe Hamilton Lake
6	7 Queen's Birthday	8	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10	11	12 MS Walking Group 9am The Veranda Cafe Hamilton Lake
13	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15	16 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	18	19 MS Walking Group 9am The Veranda Cafe Hamilton Lake
20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24 MS Support Group Mometewa Morrinsville 10.30am	25	26 MS Walking Group 9am The Veranda Cafe Hamilton Lake
27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29	30 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton			

July 2021

SUN	MON	TUE	WED	THU	FRI	SAT
				1 MS Support Group The Café Summerset Down the Lane 206 Dixon Rd, Hamilton 10.30am	2	3 MS Walking Group 9am The Veranda Cafe Hamilton Lake
4	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 MS Support Group Churchill Cafe Te Awamutu 10.30am	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8	9	10 MS Walking Group 9am The Veranda Cafe Hamilton Lake
11	12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15	16	17 MS Walking Group 9am The Veranda Cafe Hamilton Lake
18	19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22 MS Support Group Mometewa Matamata 10.30am	23	24 MS Walking Group 9am The Veranda Cafe Hamilton Lake
25	26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29	30	31 MS Walking Group 9am The Veranda Cafe Hamilton Lake

August 2021

SUN	MON	TUE	WED	THU	FRI	SAT
1	2 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3	4 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	5 MS Support Group Hamilton Venue to be advised 10.30am	6	7 MS Walking Group 9am The Veranda Cafe Hamilton Lake
8	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10	11 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	12	13	14 MS Walking Group 9am The Veranda Cafe Hamilton Lake
15	16 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	18 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19	20	21 MS Walking Group 9am The Veranda Cafe Hamilton Lake
22	23 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24	25 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	26 MS Support Group Mometewa Te Aroha 10.30am	27	28 MS Walking Group 9am The Veranda Cafe Hamilton Lake
29	30 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	31				

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Please cut here