

## Multiple Sclerosis Waikato

Issue 83 – November 2024

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MS Waikato Trust supports people affected with Multiple Sclerosis and Huntington's Disease: 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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## **MS Education Evening**



ur annual MS Education Evening was held early September, and we were fortunate to have a number of inspirational speakers for this.

Keith Small, our Chairperson opened the evening, welcoming our speakers and guests.

Brooke Hawker, a PHD student at the centre for brain research at Auckland University spoke about remyelination therapy for the treatment of MS.

Brooks shared "My current research is focused on how we can facilitate remyelination through the transplantation of oligodendrocytes. Our lab, led by Prof. Bronwen Connor and Dr Amy McCaughey-Chapman have developed the ability to convert human skin cells into oligodendrocytes with the potential to remyelinate nerve fibres. Our current work has shown that we can protect cell survival and enhance maturation through encapsulating cells in a 3D hydrogel that acts as a 'jelly shield'. Our next steps look to transplant these cells into animal models of MS to test therapeutic potential. I look forward to catching up with you all and sharing our new findings."

Jody Butler spoke about 'Oceans of Hope'. Oceans of Hope is a sailing experience and UK charity supporting

people affected by MS. Diagnosed with MS 9 years ago, Jody first sailed on the 'Spirit of NZ' in 2018, this was a 5 day cruise from Auckland to Tauranga. Jody shared that the participants had all been quite different, but they soon realised they were all the same too! They bonded quickly, with people doing as much or as little as they wanted to, and duties were shared. They had witnessed beautiful sunsets and people doing amazing things. The suggestion to join Oceans of Hope initially came from Liz, Jody loved it so much she has since completed several more voyages, with the exception of Covid, it has been an annual event for Jody sailing from Turkey, Greece, Australia, the UK and NZ.

Karen Clarke, our Neurology Nurse Specialist at Waikato Hospital spoke about Epidemiology. Epidemiology is the study of the determinants, occurrence, and distribution of health and disease in a defined population. It is widely viewed that Epidimiology began with John Snow who investigated how cholera spread in London in 1854. Karen spoke about MS and its prevalence. In almost all locations where MS prevalence has been measured, MS is increasing. It is likely due to changes in modifiable

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### ms.

## MS Education Evening Continued from page 1

environmental risk factor exposures over time, particularly obesity, fertility, and sun exposure. Risk factors include infectious agents like Epstein Barr Virus (EBV), environmental factors including latitude/gradient and Vitamin D, or genetic factors. Acceleration of preventative strategies including EBV vaccines may help reduce the occurrence of the disease.

Kate Ives, our Neurology Research Nurse Coordinator updated us on MSBase. The MSBase Registry (or database) is a web-based platform established to share, track and evaluate outcomes in data in MS and other Central Nervous System demyelinating diseases. We now have 287 Waikato based participants. Each participant's data will be updated at least yearly. Data will be collected during Neurology clinic appointments or via yearly phone calls. Prior to the implementation of MSBase across the country, Multiple Sclerosis New Zealand, New Zealand Multiple Sclerosis Research Trust, researchers, clinicians and health agencies relied on one-off incidence or prevalence studies.

Now, with MSBase in place, Neurology centers have access to ongoing real-time data. At the click of a button, MSBase produces the following summaries of our Waikato data:

Gender \$	Count \$	Percent \$
Male	66	23.00%
Female	221	77.00%
Age \$	Count \$	Percent \$
< 20	0	0.00%
20-29	12	4.18%
30-39	41	14.29%
40-49	56	19.51%
50-59	74	25.78%
60-69	59	20.56%
70-79	38	13.24%
>=80	7	2.44%

Waikato MSBase data is currently being used in 19 international Sub-studies. For example:

- Analysis of Gilenya/Fingolimod drug prescriptions in MSBase
- MS care in cancer survivors
- Demographic and Clinical Characteristics of Late-Onset Multiple Sclerosis
- Impact of pregnancy on the MS Brain
- Brain MRI predictors of disability progression in multiple sclerosis

Liz Hogan, our Client Services Manager also provided an overview of services provided by MS Waikato.

It was wonderful to have so many people stay behind after the presentations, to chat with one another and our speakers, and enjoy the supper.

Thank you to the SPAN Trust who supported us with funding for the event and to those who generously made a donation on the night.

### **Kawhia Cruise**



Adam Muir's Kawhia Cruise made a fantastic surprise return this month, but with a twist, the event was a car meet in Tamahere instead of Kawhia.

It's been a while since the last cruise, as an ex-rally driver, Adam established the event in 2013, but with Covid and its after affects it had taken a break for a few years.

Now organized by his daughter Ash, with the help and support of their family and friends, it was a great turnout and they were overwhelmed by the generosity of our community. With live music from the band Shotgun, auctions, raffles, face painting, spot prizes and yummy food throughout the day, the event raised \$3.800 for MS Waikato.

A huge thank you to the Muir family, the sponsors and supporters and all those who came along and joined the day.









## **Sleep and MS**

Lots of people with MS have sleep problems at some time, and the effects of MS can disturb sleep or make any difficulties worse. But there are ways to get a better night's rest - from treating MS symptoms and other conditions, to making lifestyle changes that improve our 'sleep hygiene'.

MS can cause sleep problems because of MS symptoms, and from the effects of living with MS. But sleep can also be disturbed by other conditions and our day to day lifestyle.

#### **MS** symptoms

MS symptoms that can disrupt sleep include:

- muscle spasms
- pain or unusual sensations
- bladder problems (needing to pee at night a lot is called 'nocturia')

#### Living with MS

Some of the impact of living with MS can also affect sleep, like:

- stress and anxiety
- depression
- · being less active
- dealing with lots of fatigue during the day
- side effects from some MS disease modifying therapies

#### **Other conditions**

MS might not be the only reason sleep is disturbed. People with MS can have problems sleeping well because of other conditions, including:

- · restless legs syndrome
- sleep apnoea, which affects people's breathing while they sleep
- rapid eye movement (REM) sleep behaviour disorder, when you make movements and sounds to act out your dreams

#### Lifestyle

Anyone's sleep can be upset by certain lifestyle things, like:

- noise
- not finding the time to sleep
- shift patterns
- · too much caffeine

#### **Restless legs syndrome (RLS)**

Restless legs syndrome (RLS) is quite a common reason for people with MS to have disrupted sleep. It's called restless legs because it causes unpleasant or uncomfortable feelings in your legs, and a constant

urge to move them. It's most noticeable when you're sitting or lying down, especially at night.

RLS isn't a symptom directly caused by MS, but it might be more common for people with MS. Some of the symptoms of restless legs can be similar to MS muscle spasms or 'spasticity'. So your MS team or GP will need to consider both to help you find the best treatments.

#### Does poor sleep make MS worse?

Poor sleep might make some of your MS symptoms feel worse, including fatigue, pain and memory and thinking. Finding ways to sleep better could help you manage these symptoms.

In the long term, if we don't get enough sleep it can make us more likely to have problems later in life with 'cognitive decline' - memory and thinking issues. That's true for people with or without MS.

#### Why does sleep matter?

Sleep is part of staying as healthy as possible. Lots of things go on in our body while we sleep to keep things working well when we're awake. That includes helping our mood and our memory.

Some of us need more sleep than others. To be at our best, most adults need between seven and nine hours a night. But some people are fine on less. We have to listen to our bodies to gauge if we're getting enough sleep. And health care professionals can help us look for signs we might not be.

#### Am I getting a good night's sleep?

You might know your sleep is disturbed because it's shorter than you'd like. Or if you wake up during the night. But sometimes sleep problems aren't so obvious.

For example, the breathing changes caused by sleep apnoea might disturb your sleep cycle or briefly wake you many times – but you might not be aware of waking up. If you share a bed, the other person might notice sounds or movements that show your sleep is disturbed. Or the signs might be there during the day, like:

- always feeling tired
- · feeing irritable
- · finding it hard to concentrate

Of course sometimes it can be hard to tell if these are the effects of bad sleep. Fatigue, for example, is a very common MS symptom. That's why it's really important to manage things 'holistically' – getting care support as a whole person, not just seeing one symptom separated out.

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### **Sleep and MS** Continued from page 3

### Tips for better sleep if you've got MS

#### Lifestyle changes - 'sleep hygiene'

We can get better quality sleep by having regular sleep habits. This is sometimes called 'sleep hygiene' - it's like we're keeping our sleeping time clean and tidy.

#### In the late afternoon and evening

- · avoid stress where you can
- · don't have stimulants like caffeine, chocolate or
- · try to find time to wind down and relax
- · don't exercise too close to bedtime
- · avoid big heavy meals

#### Physical activity

- through the day, try to be physically active if you can (but not so much close to bedtime)
- · avoid getting overtired with too much activity

#### **Natural sunlight**

- · aim to see some natural sunlight every day, whether indoors or outside (even on a cloudy day)
- · it might also help to avoid bright lights in the evening

#### **Establish a routine**

- · keep the same habits every night before bed
- the routine could be, for example, relaxing, having a drink of warm milk, having a bath
- · aim to get up the same time every day

#### **Instead of lying awake**

- if you can, get up and do something calming or even boring
- if getting up isn't possible, relaxation techniques could help

#### As comfortable as possible

- think about what's a good temperature for you too hot or too cold can make a difference to how well you sleep
- does your bed support your body as comfortably as possible?
- if noise is an issue, can you change or manage that, even if only with earplugs?
- if it's hard to turn and stay comfortable in bed, a physiotherapist or occupational therapist might suggest things to help - for instance, handles on the side of the bed

The above information has been sourced from the UK MS Society, they also have a Podcast on sleep with a sleep expert which you may find of interest by following the link below.

https://www.mssociety.org.uk/living-with-ms/physical-andmental-health/sleep-and-ms/sleep-and-ms-podcast-series

## Hidden Disabilities Sunflower

Some disabilities are not immediately obvious to others, perhaps people have questioned whether you have a disability because you don't look 'like you have a disability'.

The Hidden Disabilities Sunflower is internationally recognized by a growing number of organisations, to encourage inclusivity, acceptance and understanding. If you are travelling overseas, by wearing the Sunflower, you're letting people know that you might need extra help, understanding or just more time.

In NZ, the Sunflower is recognized by Air New Zealand, Qantas, Auckland Airport and Auckland University, The Sunflower can be purchased as a badge, lanyard, wristband or ID card, the items do ship from Australia so postage is additional https://hdsunflower.com/ au/shop/sunflower-wearer.html.









## Interruptions are encouraged

A CRISPR-based approach called "base editing" is being explored to develop a new potential treatment for Huntington's disease. Editing a single letter in the genetic code with base editing may be the key for delaying HD symptoms, maybe by a decade.

Scientists searching for new ways to stop Huntington's disease (HD) have focused in on the repeating C-A-G letters of genetic code that cause the disease. That's because the exact way these C-A-G letters repeat may have a big impact on when and whether someone develops HD. A group in Boston led by Dr. Jong-Min Lee recently applied a cutting-edge technology to try to change the letters of the C-A-G repeat in cells grown in a dish and mice that model HD. Were they successful? And what could this mean for future therapeutic approaches?

# Three repeating letters – and an interruption to the repeat

The genetic code of every living organism is made up of 4 letters – C, A, G, and T. They're combined in different ways to make every gene in our body, like letters on each page of a book. That's a lot of diversity for just 4 letters! HD is caused by a stretch of repeating C-A-G letters in the huntingtin gene – like three letters repeated on one specific page of the book. People who develop HD are born with 36 or more CAG repeats, one after the other at least 36 times, like this on the page: ...CAG CAG CAG CAG...

HD is caused by a long stretch in the genetic code repeating the letters C-A-G. But those CAGs are frequently interrupted by C-A-A near the end of the repeating sequence. These 3 letter "words" code for the same protein building block, so the protein made from the genetic code is the same. However, that change can make a big difference for when symptoms appear.

In most people, however, these repeating CAG letters actually have a slight imperfection near the end, which looks like this: ...CAG CAG CAG CAA CAG. Notice those three CAA letters? Scientists call this the "CAG repeat interruption", because it "interrupts" the repeating CAG letters. The CAG repeat interruption is found in the DNA of almost everyone, including people who have the gene that causes HD.

#### Two words, one meaning

Letters in the genetic code are grouped by threes to create "words" that code for building blocks to create proteins. C-A-G codes for a protein building block called "glutamine". This is why you may have heard of the CAG repeats referred to as a "polyglutamine" stretch – there's lots of glutamines in a row.

But C-A-G isn't the only word that codes for glutamine. C-A-A does as well! This means when the CAG repeat is interrupted by CAA, it doesn't change the protein word that's spelled. It still codes for glutamine.

It's noteworthy that if you get a genetic test for HD and you're told that you have a certain number of repeats, like 42 for example, that number is the pure CAG repeats. They're not including any CAG repeat interruptions you may have in your genetic code. There may be more glutamines present, but the CAG repeat stretch, uninterrupted, is 42.

#### More interruptions please

Not long ago, HD researchers discovered that some people with HD have no CAG repeat interruption – and some even have an extra interruption in the CAG repeat!

What is especially interesting about people without the CAG repeat interruption is that they develop HD much earlier than expected – about 12 years earlier. And people with an extra interruption appear to develop HD later – perhaps 5 year later. So, there may be something special about those CAA letters that interrupt the repeated CAG letters. Losing the interruption in the middle of CAG letters might make HD symptoms appear earlier – and an extra interruption in the middle of CAG letters might make HD symptoms appear later.

Could adding extra CAG repeat interruptions into the DNA of people with HD help delay or slow symptoms? Changing the DNA of a person is no easy task, but a group of scientists led by Dr. Lee decided to try a cutting-edge approach to introduce more CAG repeat interruptions into cells grown in a dish and mice, as a proof-of-concept to seeing if it would be possible in people.

#### **Changing bases**

Dr. Lee's group teamed up with Dr. Ben Kleinstiver, an expert in "base editing", to try out their idea

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## **Important Telephone Numbers**

Your Own Doctor
Anglesea Clinic
In an Emergency111
Anxiety phone line
Mental Health Helpline
Citizens Advice Bureau
Dept of Work & Income 0800 559 009
Electricity Complaints
Inland Revenue (IRD)0800 775 247
Lifeline - Hamilton 07 838 0715
Lifeline - Outside Hamilton (open 24/7) 0800 543 354
Mental Health Waikato Hospital07 838 3752
NZ Drug Foundation 0800 378 474
Police - Central Station07 858 6200
Tenancy Service
Victim Support Helpline 0800 842 846
Crisis Team (CAT Team) 0800 50 50 50
Depression Help line (open 24/7)0800 111 757
Suicide Prevention Helpline 0508 828 865
Samaritans (open 24/7)
Need to talk1737
call free or text anytime to talk to a trained councilor
Health Line
(advice from Registered Nurses, open 24/7)
Your local Rural Support Trust
Alcohol Drug Helpline (open 24/7)0800 787 797
you can also text 8691 for free
Are You OK
Gambling Helpline
Shine
Quit Line 0800 778 778 (smoking cessation help)
Women's Refuge Crisis line 0800 733 843
(0800 REFUGE) (for women living with violence, or in fear, in their relationship or family)
Youthline (open 24/7)0800 376 633
You can also text 234 for free between 8am and midnight, or email talk@youthline.co.nz

## Interruptions are encouraged

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of adding more CAG repeat interruptions. What's base editing? It's basically a new technology that allows you to change a specific letter on a specific page of the book. It's targeted to a specific letter like a homing missile. The technology is based on CRISPR discoveries that have been used to create medicines that recently received regulatory agency approval. Base editing is basically based on CRISPR.

Base editing is hot-off-the-press technology, so scientists are still working out the kinks. They don't really know which ingredients of base editing work best to change specific letters in DNA sequences. So, Dr. Lee's group tried a bunch of different combinations of ingredients to see what happened in cells in a dish that have a CAG repeat resembling the repeat in people who have the gene for HD.

In a few combinations of base editing ingredients, up to 50% of cells in a dish had CAA interruptions added to the CAG repeat sequence. That's pretty amazing! Scientists can't yet control exactly where these interruptions are added in the CAG repeat, but a few of the letter changes even looked like the extra interruption we see in people with delayed onset of HD symptoms.

### Not quite ready for prime time

Getting all the ingredients to make base editing work into people is a big task, similar to the hurdles facing CRISPR therapeutics for HD. This is really hard if you're trying to get all those ingredients into the brain, where people who have the gene for HD need them.

But scientists are a tenacious bunch of people and Dr. Lee's group was not about to let the challenge stop them from trying. His group tried the best combinations of base editing ingredients in mice that have the CAG repeat from people that have the gene for HD, with some early indicators that the approach may be working to add interruptions.

We will no doubt hear more about this work in the future, and learn more about whether adding interruptions to the CAG repeat would be a new promising approach to slow HD. Stay tuned!

By Dr Chris Kay October 14, 2024 Edited by Dr Sarah Hernandez

https://en.hdbuzz.net/383

\*CRISPR stands for Clustered Regularly Interspaced Short Palindromic Repeats



MS Waikato Trustees and staff would like to wish you all a Happy Christmas and a prosperous New Year.

## 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.

### **Eftpos**

In addition to taking payments via internet banking, MS Waikato now have an Eftpos machine, please let Liz or Karen know if you would like them to bring this with them when they visit.

#### **TravelScoot**

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

### Exercise Classes

The last exercise class before
Christmas will be on Monday 23rd
December, the classes will re-start on Monday

# Dogs in Homes

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

## **Scooter Batteries**

If you need to replace the batteries in your mobility scooter we may be able to help with the cost.

A generous gift in a will, is assisting with this, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

### CHRISTMAS CLOSURE

The office will close on Friday 20th December and re-open on Monday 20th January.

## **Wheelchairs**

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

### **Client Survey**

A huge thank you to all those who completed the recent client survey, these are currently being assessed to ensure services are meeting client needs.

## Subscriptions

Please note 2024 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.

## **Cooling Vests**

Hydro cool are again supporting us with a great promotion on cooling vests, which may help on hot summer days. They are offering a 25% discount on all orders for cooling vests, and will include a complimentary towel.

Please visit https://www.
hydrocool.nz/. After selecting
products, go to the checkout, you
will need to enter MSWAIKATO
into the promotion code area to
receive the discount.

Feedback from previous years is that it is a really good product.

## **Entertainment App**

MS Waikato are selling the Entertainment apps again, these also make a great gift. The apps contain thousands of dollars worth of vouchers. They can be purchased as a single city, multi city or multi year.

MS Waikato will receive 20% from each app sold. For more information and to view any current offers visit https://nz.entdigital.net/orderbooks/1b54128 or contact janet@mswaikato.org.nz to receive this link.

## **Payments and Donations**

If you wish to make any payments or donations directly to MS Waikato the account number is 02 0316 0488196 000. Please remember to include your name and what the

payment is for eg Subs.

Receipts are given for all donations, if you are not registered with us please email Janet with your contact details to enable us to forward a receipt – janet@mswaikato.org.nz.

Donations 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.

## Thanks to our Sponsors and Supporters























WDFF Karamu Trust • Waipa District Council • COGS- Hamilton City, South Waikato & Waikato West Rehabilitation Welfare Trust • Anytime Fitness - Hamilton Central • Gallagher Charitable Trust The Norah Howell Charitable Trust • Waipa District Council • Glenice and John Gallagher Foundation Hamilton Road Runners • Loxies • Terry Slattery • Ruth Mylchreest • Georgina Terry



## **MSWT EVENTS CALENDAR**

## December 2024

SUN	MON	TUE	WED	THU	FRI	SAT
1	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	MS Support Group Hamilton Venue and time to be advised	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	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	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19	20 Office Closes	21 MS Walking Group 9am The Veranda Cafe Hamilton Lake
22	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24	25 Christmas Day	26 Boxing Day	27	28
29	30	31				

## January 2025

SUN	MON	TUE	WED	THU	FRI	SAT
			1 New Year's Day	2 New Year Holiday	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18 MS Walking Group 9am The Veranda Cafe Hamilton Lake
19	20 MS Exercise Class 10.30am - 11.30am Office Re-opens	21	22 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	23	24	25 MS Walking Group 9am The Veranda Cafe Hamilton Lake
26	27 Auckland Anniversary	28	29 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	30	31	

## February 2025

SUN	MON	TUE	WED	THU	FRI	SAT
						1 MS Walking Group 9am The Veranda Cafe Hamilton Lake
2	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 Waitangi Day	7	8 MS Walking Group 9am The Veranda Cafe Hamilton Lake
9	10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	11	12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13	14	15 MS Walking Group 9am The Veranda Cafe Hamilton Lake
16	17 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	18 MS Support Group Orca Café Raglan 10.30am	19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20	21	22 MS Walking Group 9am The Veranda Cafe Hamilton Lake
23	24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	25	26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27 MS Support Group Mometewa Morrinsville 10.30am	28	