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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 and 60 years of service

We had a fantastic turnout for our recent education evening and celebration of 60 years service. With Neurologist, Dr Beatriz Romero Ferrando, Neurology's Karen Clark and Kate Ives and also Terry Slattery (fundraiser extraordinaire) as speakers, we learnt so much and really valued having time afterwards to chat with them over supper. Our Trustees and Patron Kay Gregory also enjoyed meeting clients at the event too.

Dr Romero Ferrando spoke about the latest treatments in MS, vaccination and access to treatment for primary progressive MS. She advised that there are currently clinical trials in possible myelin repair treatments. There is a lot of research into 'cousins' of drugs. Autologous stem cell transplants (aHSCT) are now available in New Zealand. There is a strict criteria – a young age, high inflammatory activity despite high efficacy MS treatments and benefits must outweigh the risks. One transplant has been done in Auckland.

Vitamin D may help with fatigue but the aim is to keep levels normal. The results on a Vitamin D trial demonstrated that there was no difference on low/mid doses on relapses, high Vitamin D levels are related to worse outcomes.

There is no increased risk in developing MS from vaccination; there is also no increased risk of a relapse from a vaccination. However, you need to wait 4 – 6 weeks after a relapse before receiving a vaccine. Dr Romero Ferrando



Keith & Dr Romero Ferrando

recommended receiving the flu vaccine every year. Live vaccines (MMR, Zostavax, VZV and Yellow Fever) shouldn't be administered while on MS treatment, these should be checked and immunised before treatment commences. There is reduced efficacy of vaccines while on Ocrelizumab, Dimethyl fumarate with lymphopenia or Fingolimod.

Since 1 October Ocrelizumab has been available for PPMS, it reduces relapses by 80-90% and also reduces new lesions in MRI by 80-90%, pregnancy should be avoided. If you have PPMS and are considering Ocrelizumab please send an email to Karen Clark - karen.clark@waikatodhb.health.nz .

Karen Clark, Clinical Nurse Specialist, spoke on switching disease-modifying therapies (DMTS). DMTS are designed to reduce the frequency of

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MS Education Evening and 60 years of service Continued from page 1

relapses or attacks, reduce new brain and spinal cord lesions and delay disease progression. The treatment choice must be tailored to the individual patient and a patient's safety is the priority. There are several reasons why a switch may be considered; this includes relapses or disease progression, side effects or a patient's request. Switching treatments is a discussion between a patient and the neurologist and there is always a wash out period as you cannot be on two treatments at the same time.

Kate Ives, Research Nurse / Coordinator Neurology Clinical Trials spoke about the MSBase registry. MSBase is a web-based platform established to share, track and evaluate outcomes data in MS and other CNS demyelinating diseases. It is an international registry; collecting data worldwide from 43 countries, with over 93,000 patient records, all data is anonymised. The aim is to:

- To collect long-term observational health and medical information from a large group of patients
- To enable researchers to evaluate long term effects and safety of current and future disease modifying therapies
- To enable researchers to document disease outcomes in different areas of the world

Participants are required to consent to be included on the registry. Participation began in 2018/2019 but due to Covid and staffing issues at Waikato Hospital it was put on hold and re-booted in 2022. Due to the timeframe, it is necessary for all participants to re-consent to participating in the registry.

In New Zealand, the MSBase registry data can be used for local, regional and national research. It can also be used to support the lobbying of Te Whatu Ora, PHARMAC, other government agencies for resources and funding.

We still have clients who have not re-consented to participating in MSBase; if you have not been contacted in the past 12 months please get in touch with Liz or Karen at MS Waikato for a consent form.

Terry Slattery shared his incredible journey on the tour of Aotearoa where in March last year, he cycled from Cape Reinga to Bluff in 28 days. In total he raised over \$12,000 for MS Waikato, we enjoyed watching his slide show and listening to some of the highs and lows of his journey.

Terry met Avril Proud who completed the same journey from Cape Reinga to Bluff but on horseback on the Great New Zealand Trek. With only one 7-day trek a year, Avril joked it had taken her 14 years to complete!

Our Chairperson Keith Small shared some of the history of our organisation which has been around since 1963; he then invited Dr Romero Ferrando to cut the 60th celebration cake.

We would like to express our thanks and appreciation to the Neurology team, Terry Slattery, our Trustees, Kay Gregory, April Johnson for the Karakia and to those of you who came along on the night. Thank you too to SPAN Trust for their grant to support the event.



Terry and Liz



Karen, Kate and Dr Romero Ferrando



Avril and Terry

Whangamata RSA Quiz

On Saturday 30th September the Whangamata RSA held a charity quiz evening to raise money for MS Waikato, the event was organised by Karyn Jones.

Karyn shared – “The evening was a huge success, with 30 teams of 6 people competing for the top score to take home \$300.

Quiz master Gavin opened the evening with a question game for everyone, presenting a bottle of wine to the last two standing. A picture sheet containing 40 questions to be answered was then handed out.

During the night when the theme music to Selwyn Toogood’s Money or the Bag Show went off it was spot prize time! At 8pm supper was available for all players and anyone that was in the RSA at the time.

We ended the night drawing a raffle worth \$700 and revealing the winners of the items on the auction table.

The winners of the Quiz kindly donated the \$300 prize money back to the cause.

I would like to thank everybody who participated and paid their \$25 to play, all entry fees have been donated to MS Waikato along with the auction and raffle money totalling a whopping \$6,000.

Gavin did an amazing job as Quizmaster; he kept the audience entertained and the night flowing.

Jane put a lot of work in organising the Quiz with Gavin, arranging the auction table and the bidding papers. With the help of Roxie, they marked all the quiz sheets to reveal the winners.

Peter and I approached the town’s businesses for donations for the night and were amazed with the

generosity and kindness. We had a large amount of quality products for people to bid on and were able to put together a beautiful raffle featuring a gorgeous neckless donated from Rod at Strictly Time, Smoky Pallet vouchers, Bliss haircut and blow wave, Nourish massage and Luv Coffee vouchers.

With help from Dianne, Pam, Chris and Robyn, Debra provided supper for the evening; and what a wonderful spread they provided, everyone was very impressed.

Overall the night was a huge success with many inquiring if we can do it next year, if my amazing team are up for it and local businesses get behind us again then yes, why not.”

Karyn Jones

A huge thank you to Karyn, the Whangamata RSA, all those who assisted Karyn in organising the event, the businesses that donated and to those who came along on the night. We appreciate your generosity and support.



MS Awareness Week

A huge thank you to all those who supported us during MS Awareness week.

We had stalls at Chartwell Shopping centre and Dave Cordery entertained locals with his guitar on a stall at Whangamata, thank you to all who gave up their time to assist with running these.

We also ran a digital campaign; a number of our clients very generously and bravely shared their individual journey with MS to help raise awareness and understanding. The number of shares and the reach these posts obtained blew us away, reaching 3,309 people. A huge thank you to Sean, Keith, Emma, Pam, Amanda, Julie, Ros and Sally for sharing their stories.

Our awareness week campaign raised a total of \$1,804



Kay and Heather at Chartwell

Life expectancy for people with MS significantly improved

Dr Ruth Leadbetter (NZBRI), Dr Deborah Mason (NZBRI) and co-authors have published a study on multiple sclerosis mortality in New Zealand in the *Journal of Neurology, Neurosurgery and Psychiatry*. They studied the life expectancy and risk of dying in New Zealanders with MS compared to the general population. Their results show that people with MS can expect to live a long life, close to that of the general population. The life expectancy for people with MS is expected to improve even further in the near future.

A summary of the study and an article written by Cosmos magazine on the findings can be found at <https://cosmosmagazine.com/health/multiple-sclerosis-ms-life-expectancy/>. A link to the full paper can be found at: <https://jnnp.bmj.com/content/early/2023/03/06/jnnp-2022-330582>.

The following has been written by Dr. Ruth Leadbetter:

We have recently published the results of our New Zealand Multiple Sclerosis (MS) mortality study. This showed that New Zealanders with MS can expect to live a long life with a life expectancy nearing that of the general population. This is the first nationwide study on MS mortality from the southern hemisphere in the last 30 years. Most research in this area before our study, has only looked at people with MS in Europe and North America.

In our study, we investigated the life expectancy and mortality rates (or risk of dying) in New Zealanders with MS compared to the general NZ population. We studied the survival of people with MS who had taken part in the NZ MS Prevalence study in 2006. In the Prevalence study, every person with MS living in NZ at the time of the census was recruited and there were just under 3000 participants. We obtained ethics approval for this mortality study and used anonymised data. We established which people from the Prevalence study were deceased after 15 years, in March 2021, and their ages at death. We then matched each person with MS with a hypothetical New Zealander of the same age, year of birth and sex from life table data from Statistics New Zealand. We were able to compare the life expectancy of our group of people with MS with the expected life expectancy of someone similar without MS. We also compared the numbers or rates of deaths between the two groups.

In our study, people with MS had a median life expectancy of 79.4 years compared to 86.6 years for someone similar without MS. The difference in life expectancy was only 7.2 years and this is in an

MS group who had lived most of their life before the highly effective treatments we now have for MS were available. The difference we found in life expectancy is very similar to what has been seen in recent overseas studies which report a difference of 6-9 years between people with MS and the general population. We also found that people with MS have overall, twice the risk of dying than the average New Zealander. This is also similar to other countries where the mortality risk (or overall risk of dying) is calculated to be 2-3 times the risk of the general population.

When we looked more closely at the different characteristics of people with MS, we found that those with a progressive form of the disease from the start had a lower life expectancy than those who started with a relapsing-remitting form. We also found that those people who had started experiencing MS symptoms earlier in life had a lower life expectancy and higher risk of dying than people who developed the disease later. In our study group, people with MS who first had symptoms in their 20s had a life expectancy that was almost 10 years lower than the general population.

Our data shows an improvement in the numbers of deaths (or excess death rates) in New Zealanders with MS over time. Those people who had been diagnosed in the late 1990s or early 2000s had half the numbers of deaths of those who were diagnosed in the 1960s or 70s. We believe there are a number of factors which have led to an improvement in survival for people with MS over those years, including better medical care such as treatment of infections and access to rehabilitation. Treatment of MS has improved significantly even since the Prevalence study group were enrolled. We now have highly effective treatments available which we expect will improve the life expectancy of people with MS further.

This study is an important first step in understanding the difference in life expectancy and survival of New Zealanders with MS compared to the rest of the population. We hope these results provide valuable information to help plan healthcare initiatives and resource allocation for New Zealanders with MS. Our next study will be looking more closely at the causes of death in MS to better understand what is causing this difference in life expectancy and to identify aspects of the disease that we could target to improve the survival of New Zealanders with MS.

This study was funded by the VJ Chapman grant from the Neurological Foundation and the Neurology Trust.

Source – Multiple Sclerosis New Zealand, New Zealand Brain Research Institute

Cognitive changes in people with HD

The changes in thinking (known as 'cognition') in HD are characterised by a pattern of both preserved and impaired abilities. Considerable differences occur among affected individuals in terms of the presence, severity and progression of cognitive impairment. For example, some may remain relatively untouched by memory disturbance throughout the course of their illness (certainly until the later stages) whereas others may experience memory loss very early.

Preserved Abilities

It is worth emphasising that many cognitive functions remain relatively unaffected in HD. For example, an affected person's long-term memory can remain relatively intact and they can therefore recount experiences from the past or still have a good general knowledge. Also, they are often able to remember well-learned skills and automatic actions or behaviours. Thus, if the individual has been working in a particular job for many years they will be able to continue to carry out the tasks required. However, this does become a problem if new skills are introduced and the person with HD is expected to learn new information. People with HD usually do not have trouble comprehending what you are saying to them, even until quite late in the illness, however they sometimes take a long time to respond. Their perceptual ability also remains relatively intact, for instance they are still able to recognise objects, shapes, letters, numbers, colours and persons.

Cognitive Decline in People with HD

Unfortunately, HD is characterised by specific cognitive deficits. Memory appears especially affected, with problems occurring for both verbal and non-verbal memory. For example, a person with HD may have trouble remembering what you have said to them, or story lines in TV programmes or movies. Similarly, they may have extreme difficulty interpreting maps or remembering places. They often have trouble finding their way around and frequently get lost in familiar places. Thus, they may have difficulties when transferred to a new environment, such as a nursing home and need time to adapt to their new surroundings.

Because the disease affects the frontal lobes of the brain, planning ability, judgment and decision-

making are affected. As a result, people with HD often have trouble monitoring their own behaviour and do not realise that they are making errors or mistakes. Another characteristic is that people with HD have trouble motivating themselves and others often mistake this as stubbornness or laziness. Planning and problem solving become increasingly difficult and they may, for example, now have more trouble cooking a new recipe or fixing a fuse.

Affected individuals often have difficulty changing from one idea or task to another and this is why they struggle when it comes to changing routines. They also tend to lose the ability to think in abstract terms and their thinking becomes more concrete and rigid. Consequently, their conversation becomes more simplistic and they are no longer able to discuss topics or understand complicated concepts.

Verbal fluency is often impaired, so they have difficulty recalling words from memory and expressing them. Motor functions are of course also disrupted (involuntary movements), which interferes with speech and coordination.

People with HD sometimes have trouble controlling their emotions and this can lead to inappropriate behaviour, which is often mistaken as a psychiatric disorder, particularly in the early stages when a diagnosis of HD has not been made. There are many emotional changes that occur in HD, which may be a psychological reaction to the illness or a result of physical changes in the brain, or a function of both these factors. Emotional changes include anxiety, depression, reduced motivation, apathy, irritability and rapid mood changes.

Conclusion

It is important to remember that in HD, cognitive ability does not correspond with the severity of the movement disorder. Also, the type of cognitive deficits does not 'run in families' so if an affected person had a parent with a severe memory disturbance and few movements, it does not necessarily follow that this pattern will be repeated. Individuals with mildly deteriorating conditions may be able to carry out their 'normal' life for many years and continue to function well within their job and with hobbies and activities.

<https://www.huntingtonswa.org.au/information/living-with-hd/cognitive-changes-in-people-with-hd/>

Important Telephone Numbers

Your Own Doctor	
Anglesea Clinic.....	07 858 0800
In an Emergency.....	111
Anxiety phone line	0800 269 4389
Mental Health Helpline.....	0800 505 050
Citizens Advice Bureau.....	0800 367 222
Dept of Work & Income	0800 559 009
Electricity Complaints.....	0800 223 340
Inland Revenue (IRD).....	0800 775 247
Lifeline - Hamilton.....	07 838 0715
Lifeline - Outside Hamilton (<i>open 24/7</i>).....	0800 543 354
Mental Health Waikato Hospital	07 838 3752
NZ Drug Foundation	0800 378 474
Police - Central Station.....	07 858 6200
Tenancy Service.....	0800 836 262
Victim Support Helpline.....	0800 842 846
Crisis Team (CAT Team)	0800 50 50 50
Depression Help line (<i>open 24/7</i>).....	0800 111 757
Suicide Prevention Helpline	0508 828 865
Samaritans (<i>open 24/7</i>)	0800 726 666
Need to talk	1737
<i>call free or text anytime to talk to a trained counsellor</i>	
Health Line.....	0800 611 116
<i>(advice from Registered Nurses, open 24/7)</i>	
Your local Rural Support Trust	
.....	0800 787 254 (0800 RURAL HELP)
Alcohol Drug Helpline (<i>open 24/7</i>).....	0800 787 797
<i>you can also text 8691 for free</i>	
Are You OK	0800 456 450
<i>(family violence helpline)</i>	
Gambling Helpline	0800 654 655
Shine	0508 744 633
<i>(confidential domestic abuse helpline)</i>	
Quit Line.....	0800 778 778 (smoking cessation help)
Women's Refuge Crisis line.....	0800 733 843
<i>(0800 REFUGE) (for women living with violence, or in fear, in their relationship or family)</i>	
Youthline (<i>open 24/7</i>)	0800 376 633
<i>You can also text 234 for free between 8am and midnight, or email talk@youthline.co.nz</i>	



Reduce stress at Christmas and avoid over exertion

- 1. Make a List** - It works for Santa! Checking items off a list gives a sense of accomplishment and is satisfying in itself.
- 2. Prioritise** – Attend to what is most important and set your own realistic boundaries. Avoid being caught up in the frenzy of Christmas. It is important to attend to the evergreen basics - sleep, rest and eating well.
- 3. Lower others expectations**
– Be realistic by creating your own idea of the 'perfect' Christmas that suits you and your family.
- 4. Buy online** – No need to cope with busy shopping centres but order early so they arrive on time.
- 5. Delegate** – A problem shared is a problem halved.
- 6. Learn to say no** - Learning to say no to others' demands can be a struggle at this time of year, so start thinking of your needs when family and social activities are being planned.

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



NOTICE BOARD

CHRISTMAS CLOSURE

The office will close on Thursday 21 December and re-open on Monday 22 January.

Dogs in Homes

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

KAKEPUKU 10 CHALLENGE

Saturday 18th November

Support Ruth Mylchreest, Clinical Nurse Specialist as she climbs Kakepuku Mountain 10 times in 24 hours, a total of 75km.

Come along on the day or make a donation <https://givealittle.co.nz/fundraiser/nurse-climbing-75km-for-mnd-and-hd>. Raffle tickets are also currently available. All funds raised will be split between MS Waikato (for those impacted by Huntington's Disease) and MND to provide ongoing psychological support for clients and their families.

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.

Bequest

A bequest is a gift made through your will. A gift to MS Waikato is very easy to leave in your will and is a gift that makes a difference and lives on in memory. If you would like to include a gift to MS Waikato it will help future generations living with the effects of MS and HD.

A bequest to MS Waikato can be made through writing a will or making an amendment (Codicil) to your existing will. Please ensure your will states the donation is for MS Waikato, naming our organisation ensures the donation is received by MS Waikato and remains in our region. Making a will ensures that your estate is distributed according to your wishes. We recommend talking to your family to ensure they are aware of your wishes.

TravelScoot

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

Entertainment Book

MS Waikato are selling the Entertainment apps 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 and to view any current offers visit <https://nz.entdigital.net/orderbooks/1b54128> or contact janet@mswaikato.org.nz to receive this link.

Exercise Classes

The last exercise class before Christmas will be on Wednesday 20 December, the classes will re-start on Monday 8 January.

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

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



WDFW Karamu Trust • Waipa District Council • COGS- Hamilton City, South Waikato & Waikato West Rehabilitation Welfare Trust • Anytime Fitness - Hamilton Central • Gallagher Charitable Trust Trinity Lands • WEL Energy Trust • The Norah Howell Charitable Trust • Waipa District Council Glenice and John Gallagher Foundation • Waikato Lyceum Charitable Trust • QS Plus



MSWT EVENTS CALENDAR



December 2023

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

January 2024

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

February 2024

SUN	MON	TUE	WED	THU	FRI	SAT
				1 MS Support Group Hamilton Venue to be advised 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 Waitangi Day	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 MS Support Group Churchill Café Te Awamutu 10.30am	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 MS Support Group Raglan Venue and Time to be advised	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	22	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 MS Support Group Mometewa Te Aroha 10.30am		

Please cut here

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Disclaimer: "MS Waikato accepts no responsibility for accuracy of information contained within this newsletter."