ms.
Multiple Sclerosis
Waikato

ManuScript

Working Together to Provide a Service of Excellence
Mahi tatau ki te whakawhiwhi he hapori rawe

Issue 87 – November 2025

Inside:

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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SPAN Trust

Annual MS Education Evening

Our annual MS Education Evening was held in September; we had a great turnout and learnt so much from our speakers.

Dr Beatriz Romero Ferrando, Neurologist at Waikato Hospital, shared " I reviewed the status of subcutaneous natalizumab and ocrelizumab availability in New Zealand as well as technical aspects of administration. I recommended to avoid stopping abruptly Fingolimod due to an increased risk of a relapse. I touched base on new treatments like Ofatumumab and bruton's tyrosine kinase inhibitors. A remyelination trial is likely to open beginning of next year and general inclusion criteria were discussed. I reminded briefly about vaccination status and malignancy screening in MS patients as well as the use of MS Base improving clinical practice and research."

Karen Clark, Neurology Nurse Specialist at Waikato Hospital spoke about treatments for MS. Karen reminded us there is no cure for MS yet, but treatments aim to modify the disease course through subcutaneous, oral or intravenous medication. Relapses may be managed with steroids. Physiotherapy, Occupational Therapy and pain management may be recommended to help relieve symptoms.

There are two disease-modifying therapies (DMTs) available, both are currently only approved for intravenous infusion, they work in different ways. Treatment choice is made on an individual basis between the patient and the neurology team and there are currently over 150 people on IV infusions.

- Natalizumab (Tysabri) – this is an IV infusion every 4-6 weeks. It blocks the α4-integrin (entry point that allows cells to pass into the CNS) on the surface of immune cells (mainly T-cells). This prevents those immune cells from crossing the blood-brain barrier and entering the nervous system. Blocking the immune cells from entering the CNS reduces inflammation and demyelination.
- Ocrelizumab (Ocrevus) – this is an IV infusion every 6 months. It targets CD20, a protein on the surface of B- cells (immune cell).

Speakers: Philip, Tracey, Karen, Beatriz

Continued on P2

Annual MS Education Evening *cont from P1*

It selectively depletes B-cells which play a role in driving inflammation in MS. Ocrelizumab does have an increased risk of infection or reactions to the infusion.

A few reminders from Karen were:

- Prior to an Ocrelizumab infusion - please ensure you have your bloods taken within 1 week prior to Ocrelizumab infusion. (Avoid blood tests on a Friday afternoon at Pathlab). Don't take any blood pressure medication on the morning of Ocrelizumab infusion.
- Keep note of any infections or new medications between treatments.
- If you are unwell, don't come in, call the infusion centre on 07 8396621 to reschedule.

Tracey Larsen spoke about counselling and why you would consider it, more detailed information about counselling can be found in Tracey's article below.

Our final presentation was given by Philip Burbage. Philip is a passionate surfer and lives with MS, taking part in the National surfing competition in Taranaki in January, he became the New Zealand Adaptive Surf Champion. We previously shared Philip's story in February's newsletter.

Our Chairperson Keith Small rounded off the evening introducing Trustees and thanking our speakers, sponsors and staff. Keith shared that staff are this year, collectively celebrating 50 years of service with MS Waikato.

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

Thank you to the SPAN Trust for their generous grant to support the evening,

What is Counselling and Why Would You Consider It

The topic of my talk was 'What is Counselling and Why Would You Consider It'. I spoke of how counselling is a professional practice that focuses on supporting individuals, couples, or families through personal, social, or psychological challenges. It involves forming a trusting, respectful and non-judgemental professional relationship where you can talk in confidence about matters which are troubling you.

Counsellors use a range of skills, approaches and interventions to help you explore your emotions, thoughts, beliefs and values, and behaviours to help you find clarity, understanding, meaning and purpose, and ways of coping with the stress that life's challenges bring.

So why consider it?

Learning tools to build resilience, find clarity, peace and purpose and improve overall wellbeing are some great reasons to seek counselling support. Many people invest in new cars, homes and their physical health but sadly, mental and emotional health is often overlooked. Learning how to manage difficult emotions, improve communication for healthy relationships, develop coping and stress management skills, explore trauma blocks, and increase self-awareness can help you to live your best life and achieve your life goals.

Building confidence and self-esteem is important for living a fulfilling meaningful life despite a diagnosis of MS and the limitations that may come with it. A counsellor will support you to see the MS is not your identity, but that you are someone who lives with MS. They can help you focus on what you 'can do' to find solutions to issues and dilemmas around disease management and lifestyle changes that support you to live your best life.

With disease progression, a sense of grief and loss may be felt from time to time, so it can be natural for depression to walk beside you at these times as you adjust to new ways of living. A counsellor can support you to live through these episodes as you grapple with the complexities of the disease.

Looking for a counsellor? Search online for Talking works, Psychology Today, or the New Zealand Association of Counsellors website for counsellors in your area. Many Employee Assistance Programs (EAP) are also available such as Clearhead, Vitae, Habit Health to name a few.

My details are

Tracey Larsen Counselling,

E: traceylarsencounselling@outlook.com, P: 0277706354

Tracey Larsen

Preparing for your neurologist appointment

Be prepared

Appointments may be months apart and short, so preparation is key. Wear loose fitting comfortable clothing that allows movement of your arms and legs for any clinical exams. Write down questions in advance. Ask for clarification if you don't understand something.

Bring a support person to help recall and record answers. Use the provided checklist to take notes and track your MS or HD over time.

What to discuss with your neurologist

- New symptoms: note down anything new, even if it's not caused by MS or HD
- Worsening or returning symptoms: important for understanding how your condition is affecting you
- MRI or test results: ask for and bring them; discuss their meaning. (Your neurologist should have access to a digital copy of your recent MRI's)
- Major life changes: discuss before making decisions like moving or stopping work.
- Family planning: talk early about your plans to guide treatment choices.
- Treatment questions: (for MS) ask about disease modifying therapies (DMTs), benefits, and side effects.
- Side effects: know what to look out for and how to report them.
- Other medications: always disclose everything you're taking, including over the counter and herbal remedies.

Between appointments

Know who to contact (clinic, nurse, or MS Waikato staff) if issues arise. Clarify how information will be shared between your GP and neurologist.

Living well with MS

Discuss lifestyle strategies, in particular, fatigue, nutrition, exercise and social connection. Consider creating a self-management plan with your neurologist.

Other tips

Use the checklist to record symptoms, concerns and goals between visits. Talk about plans until your next appointment – this could lead to helpful referrals.

Source: MS Auckland

NEUROLOGY APPOINTMENT CHECKLIST

Appointment Date: ____________ Time: ___________

Current symptoms

(List ongoing symptoms, even if stable)

- Weakness
- Visual disturbances
  (e.g. blurred vision, double vision)
- Numbness or tingling
- Fatigue
- Balance or coordination issues
- Bladder or bowel changes
- Cognitive changes (e.g. memory, concentration)
- Pain
- Spasticity (muscle stiffness)

Any new symptoms? (Include onset date if possible)

- ____
- ____

Any worsening symptoms? (Include how symptoms have changed e.g. increased frequency or severity)

- ____
- ____

MRI or test results – your neurologist should have access to digital copies of these but as back-up download these onto a USB stick.

Medications you are taking – including supplements or recreational drugs

____

____

Any other health issues happening for you?

____

Goals e.g. family planning, retiring, changing careers

____

What else could I be doing to help my MS or HD symptoms? e.g. physio/nutrition/counselling

____

Trial shows ocrelizumab slows disability progression in more people with primary progressive MS

The ORATORIO-HAND trial shows that ocrelizumab (Ocrevus) can slow overall disability progression and the worsening of hand and arm function in more people with primary progressive MS.

In September, researchers from around the world gathered in Barcelona for ECTRIMS – the world's largest MS research conference.

Professor Gavin Giovannoni shared the results of the ORATORIO-HAND trial. They found that ocrelizumab slowed the progression of disability and the worsening of hand and arm function in people with primary progressive MS. Including older people and those with more advanced MS.

What is ORATORIO-HAND?

ORATORIO-HAND is a phase 3 trial that tested ocrelizumab in people with primary progressive MS. Ocrelizumab is already licensed for people with active relapsing remitting MS and early primary progressive MS. ORATORIO-HAND aimed to see if it could also slow the progression of disability – including hand and arm function - in people with more advanced primary progressive MS.

The trial team recruited over 1,000 participants with primary progressive MS. The trial included people aged 18 to 65, some of whom used a wheelchair. This means that many people who were previously excluded from trials because of their age or level of disability were able to take part in ORATORIO-HAND.

Participants were randomly assigned to receive an infusion of either ocrelizumab or a placebo (a dummy drug). The researchers used measures like as the EDSS and the 9-Hole Peg Test to see whether participants' disability progressed.

What did the researchers find?

The researchers found that ocrelizumab delayed overall disability progression and slowed the worsening of hand and arm function in people with primary progressive MS. They also found it was effective in people with more advanced MS.

Why is this exciting?

Hand and arm function is important for independence and quality of life. But many previous trials have focused on walking to measure if a treatment is effective. That means we don't know if those treatments are also effective for people with more advanced MS.

The ORATORIO-HAND trial shows that ocrelizumab could help slow disability progression and the worsening of hand and arm function for people with more advanced primary progressive MS. This could mean they might have access to treatment for the first time, potentially helping them stay independent for longer.

"The results of the ORATORIO-HAND trial are incredibly positive to see. MS can be debilitating, exhausting and unpredictable, and hand and arm function is essential for helping people to remain independent. Many previous trials have focused solely on walking ability as a measure of whether a drug is effective. But trials like this are vital in helping us find treatments for everyone." Dr Emma Gray, Director of Research at the MS Society

What's next?

These results could mean that ocrelizumab is made available for even more people with primary progressive MS who don't currently have access to any treatment options to stop their MS getting worse. The next step will be for the treatment to go through approval before it could become available to this group.

We're also funding other research to find new treatments to maintain arm and hand function in advanced progressive MS, including ChariotMS. ChariotMS has recently completed recruitment, and we look forward to their first results in 2027.

Laura Ohlmeier - https://www.mssociety.org.uk/research/latest-research/latest-research-news-and-blogs/trial-shows-ocrelizumab-slows-disability-progression-more-people-primary-progressive-ms

Oceans of Hope Challenge!

In 2026, Oceans of Hope is marking a special 10-year milestone of the Oceans of Hope Challenge.

Oceans of Hope is for people with MS, led by people with MS. Their aim is to give people the chance to experience sailing as a way to build new skills, regain confidence, and share unforgettable moments on the water.

Join them aboard Lion New Zealand, for an unforgettable adventure. They'll be sailing through the breathtaking islands of the Hauraki Gulf, creating memories that will last a lifetime.

With a professional skipper and crew alongside you, you'll learn the ropes, take the helm, and discover just how much you're capable of.

DATE: 23rd to 27th November 2026

COST: $1456.00 (including food)

TO APPLY: 2026 Oceans of Hope Challenge NZ

MORE INFORMATION

Email: oceansofhopechallengenz@gmail.com

Ways to keep you and your loved ones safe from fraud

Fraud and scams are sadly becoming all too common and we’re all at risk. Here are ‘Sorted’ top tips to avoid being scammed. Stop and think: ***Is this for real?***

1. Only click on links if you’re ***100% certain they are legitimate.*** Always check the link by hovering over address with your mouse, and the return email address, too.
2. Remember that banks and other companies ***will not ask for your passwords or personal details*** by email, text or phone. If you receive a request like this, delete it or hang up.
3. ***Just hang up!*** Cold calls with investment offers are illegal in New Zealand.
4. If you’re suspicious of any caller, hang up and ***call the official number of the organisation*** they say they represent to check if the call was genuine.
5. If you’re not sure who you’re talking to, whether online, over the phone or at the door – ***end the conversation and look them up*** to confirm that they are who they say they are.
6. ***Make your passwords unique*** and hard to guess. We recommend using a password manager.
7. ***Never send money*** to anyone you don’t know or haven’t met in person.
8. ***Be suspicious*** when the love interest you met online wants to use your bank account for receiving and forwarding money.
9. ***Avoid giving personal details*** that could be used to impersonate you.
10. If you think you are being scammed, ***stop all contact and don’t send further payments.***

Here are telltale signs you’re being targeted – watch out whenever you’re:

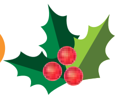
- **Contacted out of the blue**
- **Asked for your password**
- **Asked to verify your account or details**
- **Asked for remote access to your device**
- **Being pressured to make a decision quickly**
- **Asked to pay in an unusual way.**

Some notes from ‘Moneyworks’

1. Pig Butchering - is what the scammers do - fattening up the target to be scammed through flattery and other techniques.
2. When people who are being scammed are 'in the thrall' of the scam, they don't believe that they are being scammed, as the scammers are so good at pushing psychological buttons (or using psychological weapons - as it has been described).
3. The scammers are so good that people find themselves doing things they would never normally do, lying to family, friends, their financial advisers, stealing (in their minds possibly' borrowing') money.
4. There are scamming 'camps' across the world, on the border of Myanmar - thousands of trafficked people are stuck here working up to 16 hours a day to scam. If they can't scam, they may be punished.
5. There are also scam compounds in Russia, Eastern Europe, the Isle of Man, China and Asia. Some scammers participate voluntarily for the rewards that they get.
6. The scammers use Artificial Intelligence and fake pictures, profiles, videos and voices to reel their targets in.
7. It is estimated that at present the scam industry is worth between $500 billion US and $1 trillion US and is growing rapidly.
8. Crypto currency transactions are a common part of a scam, as are social media platforms.
9. Scammers will usually ask you to take your conversation onto a different platform that is encrypted so that they can't be traced.
10. It is very difficult to get your money back, but Netsafe NZ advise that www.cybera.io is a reliable site to go to to try and get your money back.
11. If you believe that you have been scammed, please let Netsafe know at www.netsafe.org.nz and lodge a complaint with the police. While they may not be able to do much, this helps the authorities with understanding what is happening with the scam industry.
12. If you have a financial adviser, we recommend that you tell them that if they believe that you are being scammed and you aren't believing them, that they have permission to contact someone (family, friend) who may be able to get you to see sense and stop.

Source: Sorted and Moneyworks.

Further information on scams can be found at www.moneyworks.co.nz



Going out for a meal or drink when you have HD

Going for a meal or a drink can sometimes be stressful when you have Huntington's. Here are some tips to help your visit go smoothly.

Before you go...

- Plan ahead to avoid busy times as these can be stressful.
- If there is a 'favourite' table, book ahead if possible so that you are able to use it - or to give time to prepare the person with Huntington's if it is going to be necessary to sit elsewhere.
- If it is possible to look at the menu online at home, then this may take some of the pressure off making decisions when you are out.
- Take your 'I have HD' card – available from MS Waikato.
- If waiting is difficult it may help to take something - e.g. game, puzzle, phone -to fill the time while waiting for food to be served.

When you are out...

- It may help to find a quiet spot in the restaurant or pub as this will make it easier for the person with Huntington's to think. Sitting facing away from a busy room may help concentration.
- If there is an extensive menu, it may help to narrow the choice down to a few options that you know the person with Huntington's will enjoy.
- A chair with arms can help make standing up easier.
- Know where the toilets are so you don't have to find them in a hurry.
- Show the information below to staff!

For the staff...

- Huntington's disease is a neurological condition which affects movement, speech, swallowing and thinking.
- Involuntary movement, balance problems and slurred speech might make me look drunk when I am not.
- I may have movement and spatial awareness problems that might appear intimidating – please just give me a little space.
- I may have problems controlling the volume of my voice which can give the impression I am angry when I am not.
- I may sometimes take a while to understand what is being said to me – please give me time to think things through.
- I can sometimes find it difficult to say or do what is expected in social situations. I may find it difficult to express my emotions in my facial expressions – I may look bored or angry when I am not.
- If there are chairs with arms available, these can help make standing up easier.
- I can find it difficult to wait. If there is going to be a long delay in food being served it may help to offer something small as a stop-gap.

https://www.hda.org.uk/

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My husband has Huntington's Disease – A carers perspective

A couple of months ago, our Client Services Manager, Liz Hogan, met with Jo Sanderson to create a video. Jo shares her journey supporting her husband following his diagnosis with Huntington's Disease, and the impact HD has had.

The video is very open and honest as Jo shares her experience as both a carer and the wife of someone living with Huntington's Disease.
To listen to Jo's journey https://www.youtube.com/watch?v=aa8bj6-jtcM .

Support Groups

Support groups are about people coming together to connect, they are people who understand what you are going through with the opportunity to build friendships.

The discussions are not always about MS or HD, the groups talk about all sorts. But they are also a space to discuss challenges and help others do the same. Talking to people who understand can be hugely beneficial.

It's more than a support group—it's a place to connect, grow, and even have fun along the way! Talk with Liz or Karen about finding a group that is right for you.

HD Carers Group – Bi-monthly meeting, contact Liz or Karen (as day may change) – Turtle Lake Café, Hamilton Gardens – 10.30am

Exercise Class – Every Monday and Wednesday - Anytime Fitness, Cnr Anglesea and Clarence St – 10.30 – 11.30am, $2 for financial members or $5 for non-financial members. Contact Liz or Karen to organize an initial assessment.

MS Walking Group – Every Saturday - The Veranda Café, Hamilton Lake – 9.00am

Hamilton

MS Support Group – 1st Thursday in the month, (4th December, 5th February) - location varies, contact Liz or Karen for details – 10.30am

MS Connect - **Evening Social Group** - 2nd week of the month – location varies, contact Liz or Karen for details

MS blokes having a beer – if you're interested in a bi-monthly catch up with other men living with MS contact Liz or Karen for details.

Raglan

MS Support Group – 3rd Tuesday in the month, (16th December, 20th January, 17th February) - Orca Café - 11am

Te Awamutu

MS Support Group – Quarterly group meeting Wednesday 17th December, Churchill Café – 10.30am

Important Telephone Numbers

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

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

NOTICE BOARD

CHRISTMAS CLOSURE

The office will close on
Tuesday 23rd December
and re-open on
Monday 12th January

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 very generous 30% 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.

Subscripions & Payments

Please note 2025 subscriptions are now due.

The cost is $40 or $20 if you hold a Community Services Card. A subscription form is attached if these have not been received.

Any payments or donations can be made directly to the Trust bank account – 02 0316 0488196 000, please note for confirmation of payee our account name is MS WAIKATO TRUST.

An Eftpos machine is also available, please let staff know if you would like them to bring this with them when they visit.

Thank you for your support.

Entertainment App

MS Waikato are selling the Entertainment app (previously a book), 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.

Healthline

Healthline is a free over-the-phone health service available 24 hours a day, 7 days a week.
If you or someone in your family is unwell, you can call Healthline and speak to experienced nurses and paramedics for health advice and information about what to do next.

Phone 0800 611 116

TravelScoot

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

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

Dogs in Homes

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

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.

Thanks to our Sponsors and Supporters

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