

Issue 89 – May 2026

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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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Saturday Morning Coffee Catch Up - Walking Optional

My name is Lisa Andrew; I have been facilitating the Saturday morning walking group since March 2018. The purpose of this article is to promote the Saturday Morning Coffee Catch Up where everyone is welcome. Over the years we have been promoted as a walking group as the primary focus, and the coffee catch up afterwards as a nice way to end our walk. However, in the last couple of years the coffee catch up has become the main stay and the walking has become optional. So here we are promoting our Saturday Morning Coffee Catch Up as a great way to meet new friends, share life experiences and support each other through life's ups, downs and challenges.

Benefits of the Saturday Morning Coffee Catch Up – Walking is Optional.

- It's on a weekend, great if you work full time and can't attend things on a week day or in the evening.
- You get to spend time with amazing, awesome, supportive people.
- We talk about anything and everything, sharing life's joys and life's challenges, movies to watch and books to read.
- There are no obligations - join us once, join us sometimes or join us often.
- Walking optional at Hamilton Lake beforehand where you choose the distance that suits you on the day, a loop is 3.85 kms or you can do a shorter walk out and back.

We meet at 9.10 am outside The Verandah Café on the corner near the road. Note, we don't always walk so you would need to confirm you are coming so there is someone there to meet you.

Coffee catch up is predominately at Café Fresca, 78 Alison Street, Hamilton Lake at 10.00 am, however we occasionally change cafes if it suits everyone and there is the odd time when we don't catch up as no one is available. So, I strongly recommend that you text me on 021 382 263 to let me know you are coming and if you want to do coffee and/or walk so I can co-ordinate everyone. You can also request I add you to the text group where I send a text message to everyone on Friday night and you let me know that night or in the morning if you are coming. No problems with last minute cancellations, life happens.

Now the bit about me. My awareness of my MS journey started on Christmas Eve, 24 December 2007 at Waikato Hospital where myself and a room full of patients and visitors on the ward were told that they were 90% certain that I have MS. My first reaction was I have what Michael J Fox has, and then thought no, that is Parkinson's. I had no idea what MS was let alone how to deal with it! My mental state at the time was that I thought I had failed. I was the biggest door mat,



lacking in confidence, avoider of social situations, at work I was doing the jobs of three people for the price of one and I was unable to say I was a worthwhile person. I was broken and struggling to move forward and being diagnosed with MS was not a fix to my situation. Randomly opening a magazine in a bookstore, one sentence jumped out “illness comes from emotion”. Illness doesn’t always come from emotion but in that moment where physically I was unable to do much I thought I can work on my emotions. So, there started my journey of working on myself, letting go of baggage, dealing with my issues and clearing out a whole lot of flawed beliefs about myself and how life works for me. I did counselling, self-help books, spiritual group work, watched a lot, listened to a lot, anything and everything to move me forward.

Here are some of the things I have found to be important:

- Leaning back into my belief system and understanding how it works for me. That spirituality is a belief in something and a belief in self. It doesn’t matter what the belief in something is as long as it has a basis of love and that it is okay to pick and mix and adapt your belief system. The most important thing is a belief in self. It is not about getting over things but working through things.
- Every day is a good day if you are breathing as everything else you can deal with whether by yourself or with the help of others. My response to being asked how my day is going is often “I have achieved my first goal for the day, I am breathing, everything else is a bonus”.
- Comparison is the thief of joy takes on a whole new meaning with MS. Comparing yourself with how you used to be pre-symptoms and how you were last year, last week, yesterday. Celebrate and enjoy your moments and if today is a stay in your PJs all day and watch TV, then enjoy that, as beating yourself up is

not going to change that you are having a PJs day watching TV!

- You are your biggest medical advocate, verbalising your symptoms, what you are experiencing and the impact this is having on your life is just as important as any medical tests or scans. Don’t minimise your lived experience.
- Some days you feel like a million bucks, some days you feel like you have been hit by a bus that has backed up a few times, some days you can do an activity and feel fine and other days you can do the same activity and end up flat on your back trying to recover. Having code sentences with family and friend’s helps as I don’t have to keep explaining how I am feeling and what I am experiencing all the time when to them I look the same. One of my code sentences is “I am fragile today” which means don’t expect a lot from me today.
- Make life as easy as you can for yourself to manage energy and symptoms and use tools and resources to assist. It is just as much about prevention before you have to deal with the outcome. For example, in summer on a sunny morning you will see me walking from the car to work with an umbrella to keep the sun off me. I use clothes horses and the dryer as I can’t have my arms up in the heat hanging out washing.

I am sharing a photo of myself and Kevin (my Mum’s dog) who is a living embodiment of finding joy in every moment.

My goal for this article is to encourage you to join us on a Saturday morning for coffee where all are welcome. Hope to see you there. If you are unable to come and want to talk with someone who you can share experiences of living with MS feel free to message or phone me on 021 382 263. With much love, take care,
Lisa Andrew

Disability and Support Services

People who use flexible funding through Disability Support Services (DSS) now have more choice and control over how they use their funding.

Implemented from 1 April:

- People’s allocated budgets for flexible funding will stay the same as they are now. There will be no change.
- The purchasing rules for flexible funding will be removed.
- Flexible funding must still be used in line with people’s plans - but people will have more choice over what supports work for them, including respite options for carers.
- A small number of items will remain prohibited or require pre-approval before spending.
- There will be more support for people to plan and manage their flexible funding in line with their plan. People with Hosts can expect to hear about this support from April onwards.
- People don’t need to do anything to get ready for these changes.
- There is more information on the DSS website: : [Flexible funding changes | Disability Support Services](#)

Ocrelizumab

As many of you are aware we have changed our protocol for giving Ocrelizumab and the reason for this is that long term treatment with Ocrelizumab might lead to a weakened immune system over time, making it more difficult for you to fight infections. Receiving Ocrelizumab at an extended dose interval, in particular a gap that is longer than 6 months, might be helpful to avoid this. There is evidence extending the dose interval does not significantly affect relapse rate or disability progression, therefore the effectiveness of Ocrelizumab is not reduced.

This is how we are managing this;

- To maintain 6 monthly infusions for the first year on treatment (meaning 3 infusions: month 0, 6 and 12)
- From then on, 6 months after your last infusion you will receive a blood form to check on CD19 count. These are B cells numbers, targeted by Ocrelizumab.
- If your CD19 is between 0 to 5 = blood test every 2nd month from when your infusion is due
6 to 9 = blood test monthly
10 and greater, we will arrange an infusion

So, the following infusion would be given when the CD19 count reaches 10 (normal range between 100 and 500). This might take a few more months depending on each person. It is important that you have this blood test from month 6 after your last infusion so we can monitor for when you need your next infusion.

We recommend you let us know if you are experiencing longer or more frequent infections than before being on Ocrelizumab.

Subcutaneous Ocrelizumab

We would also like to let you know Pharmac has approved subcutaneous Ocrelizumab.

- **It is as effective as the infusion.**
- **We are looking forward to having it available from the end of May.**
- **You can decide what would be your preference in the future.**

Any questions please contact Karen Clark and Tania Bull - Email Karen.Clark@TeWhatuOra.govt.nz or phone 021 412 025.

Karen Clark - Clinical Nurse Specialist

Further information regarding extending the dose interval of Ocrelizumab can be found at

<https://www.sciencedirect.com/science/article/abs/pii/S221103482500001X>



AGM Updates

The MS Waikato AGM was held on the 26 March. For 2 of our Trustees, it was the right time for them to step away and retire from the Board. Dave Cordery had been an elected Trustee and served 4 years as our Deputy Chairperson, we would like to extend a huge thank you to Dave for his support and commitment to the organisation. We also thank Hongxia Tang as a co-opted Board member.

We are fortunate to have a strong and robust board who bring a diverse range of skills from their different backgrounds. The board continues to be led by Keith Small as Chairperson, and Rachel Webster has taken on the role of Deputy Chairperson. Our other Trustees are Euan Reeve, Amber Hammill, Bill Shaw and Brenda Johnson.

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 give and the knowledge they share.

MS Sex and Intimacy

Sex and intimacy are valuable aspects of personal well-being, relationships, and quality of life. Living with MS can create both physical and emotional challenges for sexual relationships—whether you are in a partnership or seeking new intimacy. The good news: with open communication, self-awareness, and tailored adjustments, you can enjoy a fulfilling sex life regardless of MS.

What is sexual dysfunction in MS?

Sexual dysfunction in MS refers to difficulties experienced around desire, arousal, orgasm, and physical intimacy. Problems may include:

- Reduced interest or desire for sex (libido)
- Difficulty with arousal, sensation, lubrication (women) or erection/ejaculation (men)
- Physical symptoms interfering with intimacy, such as muscle weakness, fatigue, spasticity, pain, or bladder/bowel issues
- Emotional challenges, like embarrassment, self-image concerns, mood changes, or altered confidence
- Side effects from medications or secondary effects of living with MS

Sexual challenges may arise or change over time, and can affect anyone regardless of gender, age, or relationship status.

What causes sexual and intimacy problems in MS?

There are several direct and indirect causes:

- Neurological changes from MS may disrupt nerve signals between the brain and sexual organs, leading to physical problems with arousal or orgasm.
- Emotional impacts: adjusting to an MS diagnosis, changes in roles, or worries about your future can lead to stress, low mood, or reduced desire.
- Body image: feelings of embarrassment about MS symptoms, appearance, or bodily changes can reduce sexual confidence.
- Secondary symptoms: fatigue, pain, spasticity, bladder/bowel issues, and medication side effects can all directly or indirectly reduce enjoyment or confidence with intimacy.

Sexual desire and activity naturally fluctuate across a lifetime, and can be influenced by non-MS factors like menopause, parenting, relationship dynamics, and stress.

What else can I do to manage this?

It's normal to feel awkward raising the topic, but these issues are common and treatable!

- Talk openly with your partner, or take time to clarify your feelings in writing first.
- Communicate with your GP, MS nurse, or neurologist – they are used to discussing sensitive issues and can suggest treatments or referrals.

- Raise the issue as part of your wider symptom review. “MS can affect my sex life – can we talk about it?”
- Keep a brief diary of challenges, noting timing, symptoms, and associated feelings, to help your care team find solutions.
- Consider advice from community support advisers or relationship counsellors.

If you're single or dating, it's your choice when to discuss MS with new partners – there's no right answer. Let it come naturally as you build trust and intimacy.

What else can I do to manage and enjoy sex and intimacy?

Practical tips:

- Experiment with different positions that require less muscle strength or relieve pressure on the bladder (e.g., lying on your back with pillows, side positions, or on top for more control).
- Use aids like slings, sex furniture, or pillows for comfort or support.
- Physiotherapists can design safe exercise plans and teach energy-conserving techniques.
- If you use a catheter or have bladder/bowel symptoms, time medication or choose positions that relieve pressure—check with your health team first.
- Try body mapping—gently explore which types of touch give pleasure, discomfort, or numbness, alone or with a partner.
- Use sex toys and aids—there is a wide range available, including easy-grip options and hands-free designs for accessibility.
- Masturbation can help relearn what works for you and boost confidence.
- Look after your health—exercise, eating well, relaxing, and maintaining personal care all support feeling attractive and confident.

Communication:

- Share your feelings using “I” statements rather than criticism (e.g., “I feel...” or “I would like...”).
- Set aside time for intimacy and for non-sexual physical closeness (hugs, massages, holding hands).
- Learn about sex and disability—dispelling myths and knowing your options empowers you and your partner.

For emotional challenges:

- If you or your partner experience low mood, grief, anger, or loss of interest in sex, talking openly (together or with a therapist) can help restore closeness.
- Recognise that emotional withdrawal or lack of

cont. MS Sex and Intimacy

- concentration during intimacy may relate to MS.
- Self-care and activities that boost confidence are important (haircuts, clothes, or relaxation)

How is sexual dysfunction in MS treated?

Practical tips:

- Women: A full assessment of history, exam, and sometimes pelvic examination may be needed. Issues with arousal or lubrication may be managed with over-the-counter lubricants, prescription medications, or adjustments in timing/positioning.
- Men: Issues with arousal, erection, or ejaculation are often manageable with medications or simple changes. Hormone levels, diabetes, and medication effects may be assessed and addressed.
- Medication changes: Some antidepressants and other drugs impact sexual function—discuss alternatives with your provider if you suspect a link.
- Specialist referral: If initial treatments are not effective, a sexual health expert or relationship counsellor may be able to help both partners.

- It's important for both partners to be involved in treatment planning, since relationships are affected by both people's experience.

If you are struggling to talk to your healthcare team, you can always ask to see someone else. There is no 'wrong' person to talk to—MS nurses, community advisers, GPs, neurologists, or sexual health experts can all help.

General Information

MS can impact sex and intimacy, but you do not have to go through it alone. Open conversations, support from your partner, and tips from community advisors can make a big difference.

- Liz and Karen can provide advice and help you connect with other health experts.
- MSNZ information sheets offer clear, practical and reliable information.

Source:

<https://www.msnz.org.nz/ms-symptoms/sex-and-intimacy/>

The Michael Ford Memorial Golf Tournament

Our golf tournament, held recently at Ngahinepouri golf club was another very successful day. We had a great turnout and raised a total of \$8,377.

First place and overall best Stableford was awarded to Rhondda Bruce.

Thank you to our generous sponsors and to the players. In particular, we would like to thank the Ngahinepouri golf club who donated the course to us for the day and our Platinum sponsors Midland Neurology and Stihl Shop Te Rapa. Thank you also to our wonderful volunteers – Kay Gregory, our Master of Ceremony and Sue King who ran the gambling hole.

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 services for our clients and their families.

Please remember our sponsors and support them too

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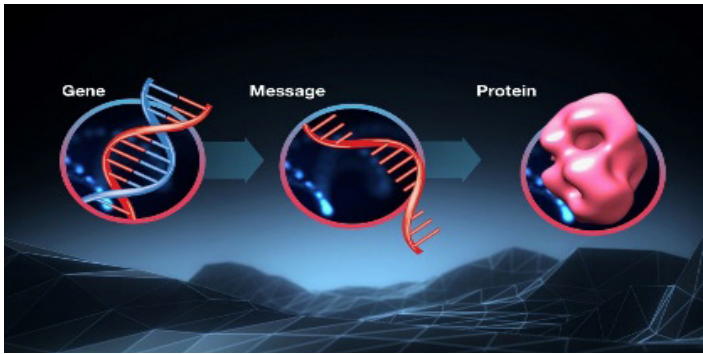
HD Research - Cutting to the Chase with CRISPR

Huntington's disease (HD) is caused by a repetition of the genetic letters C-A-G in the huntingtin gene. People who won't develop HD have 35 or fewer CAGs, whereas people who go on to develop HD have 36 or more. Because the cause of HD is so clear, scientists have long been chasing a powerful idea: *What if we could remove the mutant gene?*

A new study in *Science Advances* takes a major step in that direction. Using CRISPR gene editing, researchers were able to directly remove the mutant huntingtin gene in the brains of HD mice – leading to long-lasting improvements in brain health, movement, and lifespan.

Going upstream: targeting the source of the problem

DNA stores the cell's genetic instructions, which are copied into an RNA message that is used to make proteins, the molecules that do the actual work within cells. The extra CAGs in the huntingtin gene lead to an expanded protein that is believed to derail the inner workings of cells.



DNA stores the cell's genetic instructions, which are copied into an RNA message that is used to make proteins.

Most current therapeutic strategies for HD aim to lower levels of huntingtin RNA and protein. These include approaches like antisense oligonucleotides (ASOs) or RNA interference (RNAi), which act at the RNA level – after the gene has already been read and copied.

CRISPR works differently. Instead of reducing the message or cleaning up the protein, CRISPR aims to change the DNA itself. This makes it a particularly attractive approach for HD, where a single faulty gene drives the entire disease.

CRISPR: molecular scissors with a built-in GPS

To understand why this recently published study is exciting, let's take a closer look at how CRISPR works.

At its core, CRISPR is a way to edit DNA directly inside cells. But it's not random – it's precisely targeted. Think of it as a pair of molecular scissors guided by a GPS. DNA is incredibly long and densely packed – like a gigantic instruction manual. CRISPR needs a way to locate the exact spot to edit.

It uses a guide RNA, which acts like a search term. This

small piece of RNA is designed to match a specific DNA sequence—in this case, part of the huntingtin gene. Like using “find” in a massive document, the guide RNA scans the genome until it finds its perfect match.

Once the target is found, the guide RNA brings in a protein called Cas9 – the actual “scissors.” Cas9 cuts both strands of DNA at that precise location. This creates a break that the cell must urgently repair. When cells repair the cut, they often introduce small errors. These tiny changes can disrupt the gene, preventing it from working properly.

In this study, the researchers targeted a region just before the disease-causing CAG repeat expansion in the HTT gene. And here's the key idea: If the huntingtin gene is disrupted, it can no longer produce the RNA or protein.

A safer design: CRISPR that switches itself off

One of the biggest challenges with gene editing is safety. If CRISPR stays active too long, it could cut unintended parts of the genome. To reduce this risk, the researchers designed a self-inactivating CRISPR system.

This means that CRISPR edits the gene and then turns itself off shortly after.

Think of it like a saw with an automatic safety shut-off—it cuts what it needs to, then immediately powers down to avoid causing extra damage.

“These findings represent an important step forward, while also underscoring that more work is needed before CRISPR-based therapies can become a reality for people with HD.”

Testing CRISPR in an HD mouse model

To test this approach, the researchers used a mouse model carrying a human version of the mutant huntingtin gene with a very long repeat expansion. These HD mice typically develop problems with coordination, balance, and movement, and clumps of huntingtin protein (aggregates) build up in their brain cells.

They delivered the CRISPR system directly into the brain using a viral vector, a modified virus that can enter cells, but is engineered to be harmless. This specialized packaging allowed the researchers to target regions most affected in HD, like the striatum and cortex.

The results were striking. Mutant huntingtin levels dropped by 60–90% and aggregates were reduced by up to 90%. These aggregates are a hallmark of HD pathology, and their reduction suggests a major improvement at the cellular level.

After CRISPR treatment, gait abnormalities improved, motor coordination increased and hyperactive, repetitive movements were reduced. Beyond the brain, treated mice showed reduced weight loss and extended lifespan,

approaching that of healthy animals.

One of the most encouraging findings was that CRISPR was effective at different stages of disease. Administering the CRISPR system to the mice before symptoms began led to strong prevention of HD-like movement problems and fewer aggregates. When the mice received the viral vector as symptoms were just beginning, they showed clear improvements. But even when given after symptoms were established, there seemed to be meaningful benefits.

This suggests that even after the disease has begun, targeting the HD gene itself can still make a difference.

Looking ahead

This study shows that editing the huntingtin gene with a self-inactivating CRISPR system can reduce toxic protein, improve symptoms, and extend lifespan in HD mice – even when treatment begins after disease onset. These results highlight the potential of gene editing to target the root cause of Huntington’s disease in a long-lasting way.

However, several key challenges remain before this approach could be used in people. Ensuring safety is critical, as unintended DNA edits could have serious consequences in humans. Delivering gene-editing tools across the human brain – which is around 1,000 times larger than a mouse brain – also remains a major hurdle. In addition, most people with HD carry both a healthy and a mutant copy of the gene, so therapies need to be developed to target only the harmful version. Finally, moving from successful experiments in mice to safe and effective treatments in humans requires many additional scientific and regulatory steps.

Together, these findings represent an important step forward, while also underscoring that more work is needed before CRISPR-based therapies can become a reality for people with HD.

Summary

- Huntington’s disease is caused by a single faulty gene—making it a strong candidate for gene-editing therapies like CRISPR.
- Researchers used CRISPR “molecular scissors” to cut and disrupt the mutant huntingtin gene directly in the brain.
- The team developed a self-inactivating CRISPR system that switches itself off after editing, improving safety.
- This approach reduced toxic protein levels by up to 90% and improved movement, behaviour, and lifespan in HD mice.
- Benefits were seen even when treatment was given after symptoms had started, highlighting the potential for long-lasting therapies that target the root cause of HD.

By [Sonia Vázquez-Sánchez](#), Edited by [Dr Leora Fox](#)

<https://en.hdbuzz.net/cutting-to-the-chase-with-crispr/>

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 – 10.00am

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.

Saturday Morning MS Coffee Catch Up – Walking Optional – Every Saturday – Walking from the Veranda Café, Hamilton Lake – 9.10am, Coffee at Café Fresca at 10am. Contact Lisa on 021 382 263

Hamilton

MS Support Group – 1st Thursday in the month, (4th June, 2nd July, 6th August) - location varies, contact Liz or Karen for details – 10.30am

MS Connect - Evening Social Group - meeting monthly, day, activity and location varies, contact Liz or Karen for details

MS blokes having a beer – if you’re interested in a catch up with other men living with MS contact Liz or Karen for details

Raglan

MS Support Group – 3rd Tuesday in the month, (16th June, 21st July, 18th August) - Orca Café - 11am

NOTICE BOARD

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

Newly Diagnosed with MS?

MS Auckland and Auckland Hospital invite newly diagnosed clients and a guest for a morning of informative and inspirational talks. Guest speakers include Dr Jennifer Pereira, Neurologist.

- Date - Saturday 29th August, 9am – 1pm
- Place - Remuera Club, Auckland

Free of charge, but bookings are essential. For more information email events@msaki.org.nz or phone 09 845 5921.

Subscriptions & Payments

Please note 2026 subscriptions are now due.

The cost is \$45 or \$22.50 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.

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.

WORLD MS DAY

Saturday 30th May – A day of global solidarity, to raise awareness of MS.

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

Travelscot

We have a TravelScot available for short term loan. We ask for a donation to borrow this. For more information contact Liz or Karen.

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

COGS – Hamilton City, South Waikato, Waikato West and Hauraki - WDFW Karamu Trust - Rehabilitation Welfare Trust
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MS Waikato Trust, 20 Palmerston Street, PO Box 146, Hamilton 3240 Telephone - 07 8344740, Email – mswaikato@mswaikato.org.nz, Website – www.mswaikato.org.nz Disclaimer: "MS Waikato accepts no responsibility for accuracy of information contained within this newsletter"