

Inside:

Bounce Back from Adversity	P1
Motors 4 MS	P2
Get Ready - Advice for people with disabilities	P3 - P4
Manuscript – Your Newsletter	P5
Your Subs & why we ask for them	P5
HD Research	P6 - P7
Support Groups	P7
Noticeboard and Sponsors	P8

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:

MS Waikato
20 Palmerston Street
PO Box 146, Hamilton 3240

Ph: 07 834 4740
mswaikato@mswaikato.org.nz

Liz - 07 834 4741
Karen - 07 834 4742
Janet - 07 834 4740

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Bounce Back From Adversity

When did you last encounter adversity and how effectively did you deal with it?

The pop band R.E.M. in their song "Everybody hurts sometimes" reminds us that life at times can be difficult, no one is exempt from the ups and downs of life. Setbacks, misfortune and painful experiences are common.

Our ability to bounce back from challenging life experiences is known as resilience and refers to the ability to cope with and recover from difficulties and stresses. It is a trait that can be learned and developed through practice.

Some strategies you can use to build resilience in your life are:

1. Acknowledge that adversity does not discriminate; we all must deal with confronting times. Pay attention to your self-talk as our evolutionary inclination is to watch for negative events. Consequently, we sometimes respond to setbacks with pessimistic thinking which hinders us from noticing the good things in our life.
2. Every night before you go to bed, write down three good things that went well during the day and why you are grateful for them. Research highlights that when individuals do this consistently for a period, they feel less depressed and better about themselves. Count your blessings whether they are small or big.
3. Some of you may have seen the film "Pay it Forward" where an act of kindness is repaid by doing something good for someone

else. Random acts of kindness are small and thoughtful actions that you can do to make some else's day a little brighter. They can be done for strangers, friends and family. Studies have linked the practice of random acts of kindness to the release of dopamine in the brain which is known as the "feel-good" hormone.

4. Cultivate hope and optimism as they are powerful positive emotions associated to feelings of wellbeing. There is a line from the movie The Shawshank Redemption which states "Hope is a good thing. May be the best of things. And no good thing ever dies". Believe in yourself, a concept known as self-efficacy which is the belief that you can achieve your goals. It can enhance your motivation and performance.
5. Imagine your best self, recognise your strengths and how you can use them as levers for positive change. Identifying and employing your personal strengths can help you navigate challenging situations that require you to use your skills and talents to overcome obstacles.

These strategies seem straightforward, it takes discipline and practice to incorporate them into your daily life. The US Army concerned by the number of soldiers experiencing post-traumatic stress disorder has incorporated them into the training of their military. This training is known as "Hunting the Good Stuff". I wish you well for hunting the good stuff in your life.



The above article was written by MS Waikato Trustee, Bill Shaw. Bill is a registered social worker and psychologist, he is also a tertiary educator in psychology, counselling and social work.

Motors 4 MS

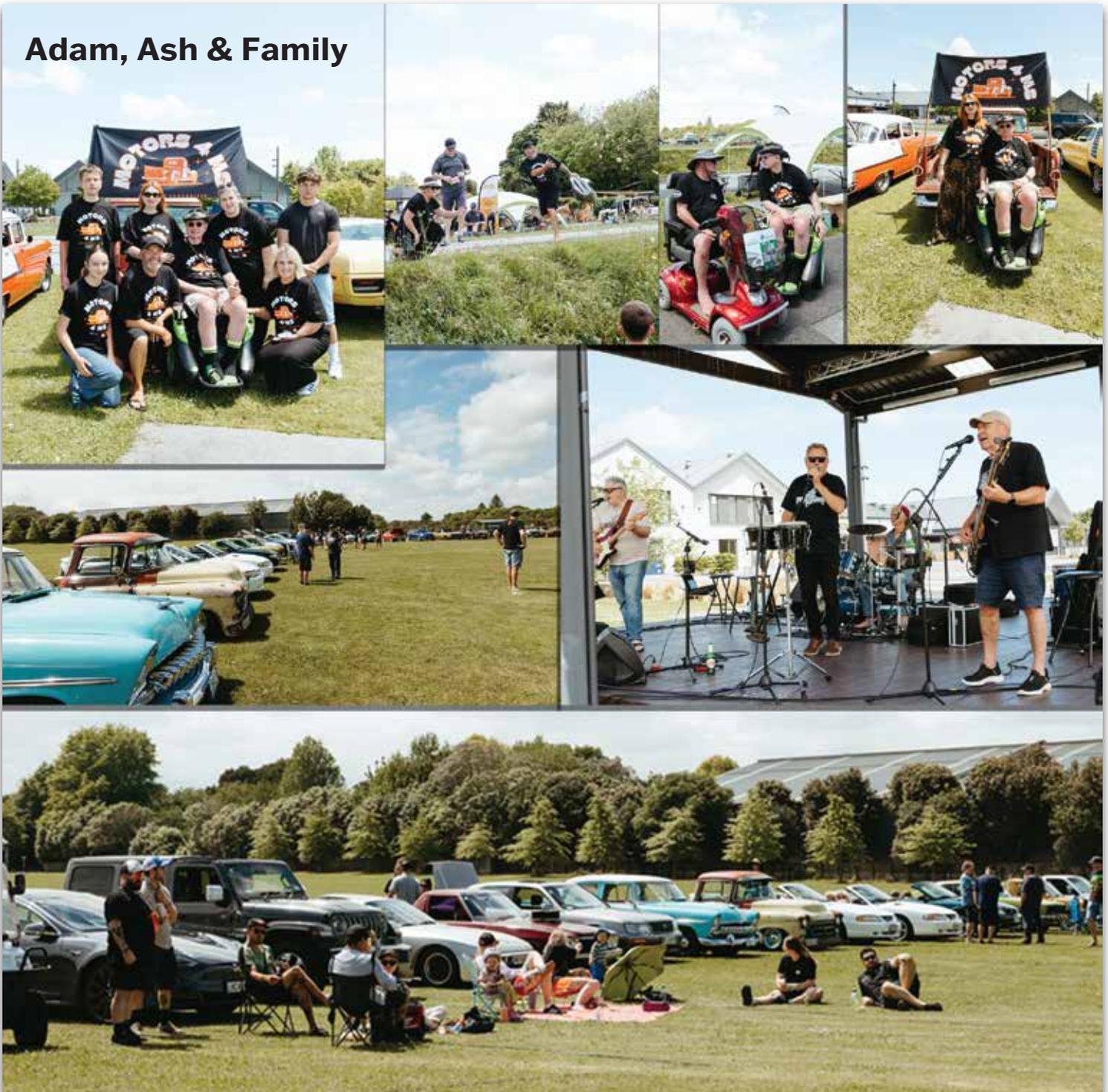
They've done it again! Adam Muir and his daughter Ash organized another fantastic fundraiser in November, supporting MS Waikato. Originally the Kawhia Cruise, this is the same event but rebranded as Motors 4 MS with a new location at Tamahere.

Despite being a hot day, it didn't deter people and there was a great turn out. There were many different styles of vehicles to admire, plenty of friendly banter, good music and huge range of items which had been donated for auction. This included a handcrafted bench seat and tailgate table by long time supporters Rex and Kerry. The children enjoyed the face painting and lolly scramble.

We have received an incredible \$3,586.24 from the event.

We would like to extend a huge thank you to both Adam and Ash, also to their extended family who helped run the day, the sponsors and supporters for their generous donations, the band Shotgun for the music and all those who came along to support and enjoy the day.

Adam, Ash & Family



Get Ready – Advice for people with disabilities

In New Zealand we have a lot of natural hazards. Earthquakes, floods, landslides, severe weather, tsunami, volcanic activity, and other hazards can happen any time and often without warning.

If you have a disability or any requirements that may put you at greater risk in an emergency, follow these steps to get ready.

Talk about how an emergency could affect you

In an emergency, civil defence and emergency services will be busy helping the people who need them most. It's up to you to get ready. That may mean having things like medical supplies or backup power systems for three days or more.

How will an emergency affect you? What if the roads and shops are closed? What if there is no power, water, phone or internet? What if you have to leave home in a hurry?

Talk with your household and your support network about:

- the types of supplies you might need
- the support you need, and
- where you will go if you can't stay at home.

Think about what you will do if:

- things have moved around or broken, or there is debris
- familiar landmarks move or are destroyed
- your service animal is hurt or too frightened to work.

Make a plan

Make a plan to get through an emergency. You should decide what you will be able to do for yourself and what help you may need before, during and after an emergency.

Make a list of your personal needs and your resources for meeting them in an emergency. An emergency can change your ability to deal with your environment. It's important you plan for your lowest level of functioning.

Make sure you're familiar with the plans for your work, school or any other places you spend a lot of time. If your work or school's current plan doesn't make arrangements for people with disabilities, make sure management knows your needs.

Build a personal support network

Build a support team of people who will help you in an emergency, before you need them. In an emergency, you may need to ask for help to do the things you usually do independently.

The first people to help in an emergency are often your neighbours, friends, caregivers and co-workers. They should be people who are often in the same area as you.

Get to know your neighbours. Share contact details so you can get in touch if an emergency happens. Tell them about your emergency plan and ask about their plans.

Do not depend on one person. That person may not be able to contact you or be available when you need them.

Your support network can help you get ready for an emergency. For example, they can help you check your home or workplace to make sure it is safe and suitable.

Build a support team at each place where you spend a large part of your day. Talk with your support team about your emergency plan. This can help your network members learn the best way to help you and give you other ideas to think about.

Practice your plan with your support network. Include how you will Drop, Cover and Hold in an earthquake and how you will evacuate if you are in a tsunami or flood zone.

Agree on how you will contact each other during an emergency. How will you contact each other if internet and phone lines are down?

Get your network to check on you immediately if you are advised to evacuate.

Make sure you have any supplies you may need

In an emergency, roads and shops could close for days. Or they may only be able to take cash.

Make sure you have supplies for at least three days. Include any medicine or special equipment you may need.

- If you need to refrigerate your medical supplies, make sure you have an alternative power supply or refrigeration system.
- Wear a medical alert tag or bracelet to identify your disability or health condition.

Get Ready – Advice for people with disabilities - Continued

- Work out what supplies you need. Have essential supplies in a grab bag in case you need to leave in a hurry.
- If you are traveling, let a hotel or motel manager know your needs in case of an emergency.
- Know where to go for help if you are dependent on life-sustaining equipment or treatment that might not work in an emergency.
- If you have dietary requirements or food allergies, make sure you have enough food for up to three days. You should also include snack food in your grab bag and make sure your meeting place is stocked with long-lasting, suitable foods.
- If you have asthma or a respiratory disorder, make sure your grab bag has dust masks (rated P2 or N95). Emergencies like volcanic eruptions and earthquakes can make it harder to breathe.

How to Drop, Cover and Hold

DROP down on your hands and knees. This protects you from falling but lets you move if you need to.

COVER your head and neck (or your entire body if possible) under a sturdy table or desk (if it is within a few steps of you). If there is no shelter nearby, cover your head and neck with your arms and hands.

HOLD on to your shelter (or your position to protect your head and neck) until the shaking stops. If the shaking shifts your shelter around, move with it.

How to Drop, Cover and Hold in different situations

If you are outside

If you are outside, Drop, Cover and Hold.

Move no more than a few steps away from buildings, trees, streetlights and power lines.

Then Drop, Cover and Hold.



If you are in an elevator

If you are in an elevator, Drop, Cover and Hold.

When the shaking stops, try and get out at the nearest floor if you can safely do so.



If you are driving

If you are driving, Pull over and Wait. Pull over to a clear location. Stop.



Wait there with your seatbelt fastened until the shaking stops.

Once the shaking stops, proceed with caution and avoid bridges or ramps as they may have been damaged.

If you are in bed

If you are in bed, Stay, Cover and Hold.

Stay in bed and pull the sheets and blankets over you. You are less likely to be injured if you stay in bed.



Cover your head and neck with your pillow.

Hold on until the shaking stops.

If you have a mobility impairment or use a cane

If you have a mobility impairment or use a cane, Drop, Cover and Hold or Sit, Cover and Hold



Drop by getting as low as you can or Sit on a chair, bed, etc.

Cover your head and neck with both hands. Keep your cane near you so you can use it when the shaking stops.

Hold on until the shaking stops.

If you use a walker or a wheelchair

If you use a walker or wheelchair, Lock, Cover and Hold.



Lock your wheels and get as low as possible.

Bend over and Cover your head and neck as best you can.

Then Hold on until the shaking stops.

Source:

www.getready.govt.nz/emergency/earthquakes/drop-cover-hold

Manuscript – Your Newsletter

Over recent years the cost to produce and mail out Manuscript has increased significantly. As a result, the decision was made just over a year ago to send this out electronically, to all those who were able to receive this via Email. We are also mindful of environmental sustainability and not producing something unnecessarily.

However, we have received feedback that for some of you, a hard (paper) copy was much more valuable and easier to read. We appreciate that a hard copy may also be easier to come back to or share with others. The newsletter is a valuable resource, and it is important to us that we get this right.

While unfortunately we don't have the funds to revert

to mailing out hard copies to everyone, if receiving a hard copy would be beneficial to you, we hope to be able to offer you this, please email Janet – janet@mswaikato.org.nz and let us know.

The cost to produce and mail out a hard copy is currently \$20 per person per year. If you wish to receive a hard copy, and are able to, you may wish to consider making a donation to cover the cost to receive it. Or even to pay it forward, making a donation to support someone else who would benefit from a hard copy but is perhaps not in the position to make a donation. The MS Waikato bank account is 02 0316 0488196 000, please include your name and Manuscript donation as a reference.

Your Subscriptions and why we ask for these

Each year MS Waikato asks for subscription fees, and we thought it might be helpful to explain why we ask for the subscription and how it is used.

As many of you will know MS Waikato is a charitable trust, we are a non-government organisation and as such don't receive any funding to employ our wonderful Client Services staff – Liz and Karen. Nor do we have any contracts to support many other expenses such as home visits or office rent. The annual cost for phone calls alone is \$3,500, and for vehicles to enable home visits or support at appointment is \$5,400.

To enable us to provide services to you and your family we are dependent on grants, fundraising, subscriptions and donations. Every grant we apply for is assessed individually and there is a lot of competition with many other not for profit organisations applying for the same grants.

MS Waikato has been serving the Waikato and Coromandel regions for 63 years. We continue to grow, regularly receiving new referrals and are providing support services to 353 clients and their whanau.

We work closely with people who are newly diagnosed, who maybe going through enormous change and grief, supporting them to understand a new diagnosis, have a comprehensive knowledge of their condition and the support that's available so they can live their best lives.

Over many years we walk alongside our people and their families impacted by MS and HD and support and help them if life becomes a challenge.

Our services are needs-driven. Staff provide home visits, regular phone support and emailing of relevant information. We host several monthly support groups, specialist education sessions, twice weekly exercise classes with professional instruction, a weekly walking group and provide quarterly newsletters. Clients are supported at neurology appointments and clinics, appointments with health providers, and other related organisations.

MS Waikato staff also offer in-service education for rest homes and community living homes, we talk at education days for allied health professionals and are available to speak to interested community groups.

As you can see even if we are not directly involved with you on a one to one at any given time, we are available to support you when you need us.

Last year we only received subs from 31% of clients. Every little bit helps and we appreciate it if you are able to pay the annual subscription of \$45, or if you have a community services card \$22.50. The cost for subs has increased slightly this year, however this is the first time in 12 years as we endeavour to keep the costs as low as we are able to. We are happy to discuss quarterly payments if that would help you or if you really feel it is too much, we would be grateful for a donation.

Payments can be deposited directly to our bank account, 02 0316 0488196 000, remembering to include your name and that payment is for subscriptions.

Thank you to those of you who have paid subscriptions this year, a subs notice is included if this payment has not been received yet.

HD Research - Better Sleep, Better Function:

New Study Links Sleep Quality to Clinical Outcomes in Huntington's Disease

Most people with HD report sleep problems, & new research suggests sleep quality is linked to many aspects of living with the disease. Wearables tracked people with HD for a year & revealed better sleep & strength training might help.

Sleep problems are nearly universal in Huntington's disease (HD) with up to 90% of people with HD reporting sleep-related issues. But new research from a Spanish team suggests these nighttime struggles might be more than just an inconvenience. A year-long study tracking people with HD using wearable devices has uncovered some surprising connections between sleep quality and aspects of living with HD that range from daily function to muscle health. The findings point toward practical interventions that might help improve quality of life for people with HD.

Catching Zzz's Is Critical

We've known for years that sleep-related issues are incredibly common in people with HD. But a new study from researchers in Spain suggests that sleep quality isn't just about feeling tired. It may be directly connected to how well people function day-to-day, how severe their symptoms are, and their overall quality of life.

Published in *Sleep Medicine*, the study followed 28 people with HD for one year, using wearable Fitbit devices to objectively measure their sleep patterns. Unlike questionnaires that rely on people remembering how they slept, these devices tracked sleep continuously and provided a clearer picture of what's really happening night-after-night.

Sleep problems are nearly universal in Huntington's disease (HD) with up to 90% of people with HD reporting sleep-related issues.

The HD-Sleep Connection

Perhaps unsurprising to anyone who has suffered a poor night's sleep, there was a link between better sleep and increased ability to function. The researchers found that people who slept better at the one-year follow-up had better functional capacity (measured by the Total Functional Capacity scale), fewer behavioral problems, better mental and physical quality of life, and less mental fatigue.

One surprising finding was that at the start of the study, younger people and those with more CAG repeats tended to sleep better. Initially, this might seem counterintuitive. Wouldn't more CAG repeats mean more severe disease and worse sleep? The researchers say, not necessarily. Everyone with HD has a unique journey, and folks could have entered the study at different disease stages. Essentially, the research suggests that sleep is more aligned with clinical status than the length of one's CAG repeat.

Muscle Strength and Sleep: A Two-Way Street?

One of the most interesting findings was the connection between muscle strength and sleep. People with lower handgrip strength, which is a key measure of sarcopenia (muscle loss), had significantly worse sleep quality. The researchers measured muscle mass and strength, and the pattern was clear: weaker muscles = worse sleep.

Why might this be? Sleep disturbances can disrupt hormones that are critical for muscle health, like growth hormone, cortisol, and insulin-like growth factor. When sleep is disrupted, these hormones get thrown off balance, potentially accelerating muscle loss. But it may work the other way too, since losing muscle strength might somehow worsen sleep quality, creating a vicious cycle. However sleep is impacted by numerous things, so the interplay between strength and sleep may be more complex, with these symptoms arising together, but not in a directly causative role.

Does Walking More Mean Better Sleep?

In this 1 year study with a small group of people, the researchers also found that people with worse sleep walked about 600 fewer steps per day on average. But surprisingly, just walking more didn't seem to improve sleep quality for these folks. This seems to contradict what we know from the general population, where aerobic exercise typically improves sleep.

Why might HD be different? The researchers suggest that HD damages the brain regions that control sleep and circadian rhythms, particularly the hypothalamus and suprachiasmatic nucleus. This damage might limit how much exercise can help sleep, at least when it comes to just walking more steps.

However, the study did suggest that strength training, not just walking, might be key. Since people with better muscle strength slept better, resistance exercises that build strength could potentially help more than just increasing step counts.

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Wearables vs. Questionnaires

When it comes to tracking sleep, wearables seem to give more accurate data than self-reported questionnaires. The Fitbit data didn't match up well with traditional sleep questionnaires, especially early in the study (though agreement improved by one year). This suggests that wearable devices might catch sleep problems that people don't notice or remember, making them potentially valuable screening tools.

The devices showed 67% sensitivity and 80% specificity, which means they're pretty good at identifying when someone has a sleep problem. If a

Fitbit flags an issue, it might be worth discussing sleep interventions or, if needed, more detailed sleep testing.

What This Means for HD Families

This small study adds to growing evidence that sleep health matters tremendously in HD, possibly even more than in the general population. Good sleep appears to be associated with maintaining independence, managing psychiatric symptoms, and preserving quality of life.

The findings also point toward actionable strategies, like strength training exercises that might help with sleep quality (and have many other benefits). Additionally, wearable devices, like a Fitbit, could help identify sleep problems before they become severe.

The Bigger Picture

It's important to note this was a relatively small study (28 participants) conducted over one year. The researchers couldn't determine cause and effect: does poor sleep cause worse function, or does worse function lead to poor sleep? Honestly, it's probably both, in a complex cycle.

The study also couldn't account for all the factors that affect sleep, like medications, stress, or other health conditions. And we don't know yet whether interventions that improve sleep, like strength training, sleep hygiene, or medications, would actually improve the clinical outcomes the researchers measured.

But the message is clear that sleep isn't just about feeling rested. In HD, it appears to be intimately connected with muscle health, daily function, mood, and quality of life. Taking sleep seriously, and working with healthcare providers to address sleep problems, might be an important step people with HD can take for their overall health.

Summary

- Spanish researchers tracked 28 people with HD for one year using Fitbit wearables to measure sleep objectively
- People with better sleep had better functional capacity, fewer behavioral problems, less fatigue, and better quality of life
- Lower muscle strength was associated with worse sleep quality
- Those with poor sleep walked ~600 fewer steps per day on average
- Wearable devices may be useful screening tools for sleep problems in HD
- Findings suggest strength training, not just increasing step count, might help improve sleep in HD

Source: Dr Sarah Hernandez -

<https://en.hdbuzz.net/better-sleep-better-function-new-study-links-sleep-quality-to-clinical-outcomes-in-huntingtons-disease/>

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, followed by coffee.

Hamilton

MS Support Group – 1st Thursday in the month, (5th March, 2nd April, 7 May) - location varies, contact Liz or Karen for details – 10.30am

MS Connect - Evening Social Group - meeting monthly, day and 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, (17th March, 21st April, 19th May) - Orca Café - 11am

NOTICE BOARD

AGM

The MS Waikato AGM is being held on Thursday 26th March at 5.15pm. This will be in the office board room – 20 Palmerston Street, Hamilton.

If you would like to attend, either in person or receive a Teams link, please register by emailing janet@mswaikato.org.nz

by Tuesday 23rd March. Financial members will be entitled to vote.

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 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.

The Michael Ford Memorial Golf Tournament

Our annual golf tournament is taking place at Ngahinepouri golf club on Friday 20th March.

We are seeking businesses or individuals who may be interested in sponsoring the tournament, and have a wide range of sponsorship options.

For more information on the event contact Janet on 07 8344740 or email janet@mswaikato.org.nz ..

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.

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

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

COGS – Hamilton City, South Waikato, Waikato West and Hauraki - WDFP Karamu Trust - Rehabilitation Welfare Trust
The Norah Howell Charitable Trust - Glenice and John Gallagher Foundation - Gallagher Charitable Trust
Anytime Fitness Hamilton Central - Ngahinepouri golf club - Ruth Mylchreest - Annex



MS Waikato Trust, 20 Palmerston Street, PO Box 146, Hamilton 3240

Telephone - 07 8344740, Email – mswaikato@mswaikato.org.nz, Website – www.mswaikato.org.nz

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